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## Psychometric Evaluation and Design of Patient-Centered Communication Measures for Cancer Care Settings

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## Abstract

### Objective

To evaluate the psychometric properties of questions that assess patient perceptions of patient-provider communication and design measures of patient-centered communication (PCC).

### Methods

Participants (adults with colon or rectal cancer living in North Carolina) completed a survey at 2 to 3 months post-diagnosis. The survey included 87 questions in six PCC Functions: Exchanging Information, Fostering Health Relationships, Making Decisions, Responding to Emotions, Enabling Patient Self-Management, and Managing Uncertainty. For each Function we conducted factor analyses, item response theory modeling, and tests for differential item functioning, and assessed reliability and construct validity.

### Results

Participants included 501 respondents; 46% had a high school education or less. Reliability within each Function ranged from 0.90 to 0.96. The PCC-Ca-36 (36-question survey; reliability=0.94) and PCC-Ca-6 (6-question survey; reliability=0.92) measures differentiated between individuals with poor and good health (i.e., known-groups validity) and were highly correlated with the HINTS communication scale (i.e., convergent validity).

## Conclusion

This study provides theory-grounded PCC measures found to be reliable and valid in colorectal cancer patients in North Carolina. Future work should evaluate measure validity over time and in other cancer populations.

## Practice implications

The PCC-Ca-36 and PCC-Ca-6 measures may be used for surveillance, intervention research, and quality improvement initiatives.

## Keywords

Patient-centered communication, Patient-centered care, Psychometrics, Questionnaire development

## 1. Introduction

*Crossing the Quality Chasm*, the Institute of Medicine's (IOM) landmark 2001 report, called for improvement in six areas of health care. The report included the recommendation that medical care should be patient-centered, which is defined as "care that is respectful of and responsive to individual patient preferences, needs, and values, and ensures that patient values guide all clinical decisions"<sup>1</sup>. Patient-centered care is grounded in strong communication between patients and healthcare providers, which entails two-way sharing of information and supports patients' active involvement in their care (to the extent that they wish to be actively involved)<sup>2</sup>. Arguably, patient-centered communication (PCC) is the primary mechanism through which patient-centered care is achieved.

Research about the relationship between patient-provider communication and patient outcomes has often focused on patient satisfaction and adherence to medical treatment, health habits, and self-care<sup>3,4</sup>. However, studies also show that PCC contributes both directly and indirectly to other important patient outcomes<sup>4,5,6,7</sup>, including patient self-efficacy, empowerment, and enablement<sup>8</sup>, reduced anxiety and better psychological adjustment<sup>9,10,11,12,13</sup>, high-quality clinical decisions informed by clinical evidence and concordant with patient values and preferences<sup>1,14</sup>, and health-related quality of life (HRQOL)<sup>15,16</sup>. Effective PCC is also integral to informed decision making, based on the patient's understanding of the medical evidence and consideration of personal values and preferences<sup>17,18,19</sup>. PCC likely contributes to patient outcomes through several "pathways," such as improving access to care, raising patient knowledge and shared understanding, enhancing therapeutic alliances, and enhancing patient self-efficacy<sup>7</sup>.

Evidence is limited regarding the mechanisms through which specific elements of PCC affect HRQOL and other health outcomes in the context of cancer care<sup>3,7</sup>. Consequently, reliable and valid measures are needed to examine these relationships. While several measures of patient-centered care and PCC exist, no single PCC measure captures the complex types of

communication that are experienced in cancer care settings, nor is designed with psychometric rigor for reliable assessment of PCC <sup>20</sup>.

When faced with a cancer diagnosis, patients often experience significant emotional distress and feelings of uncertainty about their future <sup>21</sup>. They must process complex information and make difficult and often life-altering treatment decisions. Patients look to their healthcare providers throughout their cancer experience to meet their needs for information and support <sup>4</sup>. Care usually involves multiple specialists, such as surgeons and medical and radiation oncologists. This requires patients to communicate with each provider and potentially to face issues that may arise because of lack of coordination or communication among clinicians.

Recognizing the importance of PCC in cancer care, the National Cancer Institute (NCI) launched an initiative in 2007 to strengthen research in this area, beginning with the monograph *Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering*<sup>3</sup>. This seminal document lays the theoretical foundation for the six core PCC Functions: (1) Fostering Healing Relationships, (2) Exchanging Information, (3) Responding to Emotions, (4) Managing Uncertainty, (5) Making Decisions, and (6) Enabling Patient Self-Management. Setting forth a future research agenda, this monograph called for advancing methods to measure and monitor PCC in cancer care.

In response, our team explored designing and validating PCC measures that are grounded in this theoretical foundation and used in a variety of research and healthcare settings. Subsequently, we developed a questionnaire to measure the six PCC Functions noted above <sup>17</sup> and refined the questionnaire using cognitive interviewing with a diverse group of cancer patients <sup>22</sup>. The PCC questionnaire was then administered to adults with colorectal cancer (CRC).

Patients with CRC face exceptionally difficult decisions across the care continuum, including deciding about and coping with surgeries that might lead to permanent ostomies and deciding whether to continue with therapy that may offer little gain in survival at the cost of decreased quality of life. CRC care is also complex, often requiring multimodality therapy that might include surgery, radiotherapy, and chemotherapy. Effective PCC is critical to addressing CRC patients' needs and improving their outcomes. Consequently, this cancer population serves as a relevant platform to evaluate the PCC measures. This study evaluates the psychometric properties of the PCC items and scales among CRC patients and documents the selection of items to create a long form and short form of PCC measures.

## 2. Methods

### 2.1. Participants

Adults 21 years or older with a diagnosis of colon or rectal cancer and receiving care in North Carolina were eligible to participate in this study. We used North Carolina's Rapid Case Ascertainment (RCA) system, which contacts hospital registrars directly, to identify patients from across all 100 counties in North Carolina. CRC patients were contacted within 2 to 3 months of their diagnosis. Prior to patient contact, the patient's physician was given the

opportunity (via mail) to opt out their patients from the study. We mailed the survey to patients at their home address, with the option to complete it by mail or online, and used follow-up mailings to improve response rates. Data from paper-based and online-based assessments were combined for analyses based on multiple studies showing equivalence of data across modes, as summarized in a literature review by Rutherford et al.<sup>23</sup>. This study received approval from the RTI International Institutional Review Board.

## 2.2. Measures

The following variables were included on the survey: sociodemographic and clinical characteristics, PCC, and the Health Information National Trends Survey (HINTS) PCC Scale.

Participants provided demographic and clinical information, including cancer type, treatments received, age, gender, race, ethnicity, level of education, marital status, health insurance, income, and general health status. Stage of cancer was derived from pathology reports.

The pilot survey included the following number of items for each PCC Function: Exchanging Information (13 items), Fostering Health Relationships (13 items), Making Decisions (15 items), Responding to Emotions (7 items), Enabling Patient Self-Management (9 items), Managing Uncertainty (19 items), and cross-cutting items (11 items). Cross-cutting items assess general communication skills (e.g., listening). Different response option formats were used to assess different aspects of PCC, including frequency (never, rarely, sometimes, often, always), amount (not at all, not very much, somewhat, a lot, a great deal), quality (poorly, not very well, fairly well, very well, outstanding), and presence (no, yes). When appropriate, a “does not apply” option was included. Many items were included in the survey to evaluate different ways to ask the questions with the purpose to select a subset of the questions that performed well psychometrically while retaining content validity. Prior to fielding the survey, items were evaluated qualitatively using two rounds of cognitive interviewing with a diverse group of individuals with CRC<sup>22, 24</sup>. Based on the results of the cognitive interviews, CRC patient participants preferred referring to their care providers as “doctor or other healthcare professionals.”

Seven items on patient-provider communication from the Health Information National Trends Survey (HINTS) were included on the survey for use in assessing convergent validity of the PCC measures<sup>25, 26</sup>.

## 2.3. Analyses

Within each PCC Function, the goal was to select a set of items that assessed a single construct, was highly discriminating, and contained no locally dependent item pairs or items exhibiting differential item functioning (DIF). This selection process involved an iterative set of analyses. We used descriptive statistics to examine overutilized or underutilized response categories and item-level missingness. Confirmatory factor analysis (CFA), using the lavaan software (an R package)<sup>27</sup>, was used to test the fit of a single factor model for the items within each Function, to select items that loaded highly on the Function, and to permit use of unidimensional item response theory (IRT) models. Unidimensional model fit was assessed by

the root mean squared error of approximation (RMSEA; ideally <0.08), confirmatory fit index (CFI; ideally >0.95), and the Tucker-Lewis Index (TLI; ideally >0.95). IRT modeling, using IRTPRO software<sup>28</sup>, was used to identify and remove local dependence among items and to find highly discriminating items. Local dependence occurs when a pair of questions has a significant association between the items even after controlling for the covariation due to the PCC Function being measured. Locally dependent items can reduce the validity of the measured Function, so items are removed until no local dependence remains.

DIF was evaluated to confirm that individuals from different groups (males versus females; individuals aged less than 70 years versus aged 70 years or older) did not respond differently to an item after controlling for differences on the measured Function between the groups. Items exhibiting DIF reduce the validity of a measure for group comparisons or for combining data across the groups. Measures without DIF allow for unbiased estimates of scores within and across these groups. Sample sizes did not permit evaluation of DIF in other subgroups in this study. The split at 70 years yielded sufficient sample size to test for DIF by age. Wald tests implemented in IRTPRO were used to test for DIF.

Across the six PCC Functions, the goal was to evaluate the relationship among the Functions and the meaningfulness of an overall global PCC score. Using lavaan software, we fit a six-factor CFA model and evaluated the correlation among factors. We also fit a bifactor model to examine how the items loaded on an overall PCC factor, adjusting for the specific Functions. Only items that performed well in previous steps were included in these analyses.

An expert panel comprising PCC content experts, psychometricians, oncology clinicians, and patient advocates from Fight Colorectal Cancer (<http://fightcolorectalcancer.org/>) participated in the design and evaluation of the measures<sup>21</sup>. Final selection of items for the Patient-Centered Communications in Cancer Care (PCC-Ca) measures was based on their psychometric performance and content relevance. We designed a 36-item PCC measure, the PCC-Ca-36, to provide reliable measurement of each of the six PCC Functions and an overall PCC score. We also created a six-item short-form PCC measure, the PCC-Ca-6, which contains one item from each PCC Function to reliably measure an overall PCC score. The selected question performed well psychometrically (reliability) and the question's content was deemed by the authors to capture the overall concept intended to be measured by the Function. Cronbach's alpha was used to estimate internal consistency reliability, with recommended thresholds of 0.70 or greater for group level assessment and 0.90 or greater for individual-level assessment<sup>29, 30, 31</sup>.

We evaluated construct validity of the PCC-Ca measures by examining known-groups validity and convergent validity. For known-groups validity of the PCC measures, the most consistent factor associated with patients' rating of the quality of communication was health status. In the published literature, worse health status has been associated with poorer ratings of communication both in CRC<sup>32, 33</sup> and in other cancers<sup>25, 26, 34</sup>. Patients with worse health status are more challenging to treat, often have multiple chronic conditions, see multiple providers, and likely suffer more physically and mentally. For health status, we compared individuals who rated their "overall health" or "overall quality of life" as poor or fair versus individuals who reported their health or quality of life as good, very good, or excellent.



Convergent validity for the PCC-Ca measures was assessed by examining the correlation of the new PCC-Ca measures with the HINTS communication measure and a global satisfaction of quality of care item.

### 3. Results

#### 3.1. Participants

We sampled a total of 1,333 patients for the study. Of those sampled, physicians refused for 33 patients to be contacted about the study. Of those who were contacted, 707 patients did not respond, 39 were deceased, 35 refused, 11 were incapacitated, and 8 were ineligible. Altogether, 501 patients responded; 80% with colon cancer, 17% with rectal cancer, and 3% with multiple primaries, as shown in Table 1. Forty-six percent of participants had a high school education or less and 20% had an income less than \$20,000. Eighty-one percent reported undergoing surgery, and 47% had chemotherapy. Most of the surveys (91%) were completed by mail.

Table 1. Demographic and clinical characteristics for individuals with colorectal cancer (N = 501).

<b>Characteristic</b>	<b>N (%*)</b>
Age (mean, SD)	66.7, 13.1
Gender	
Female	257 (51%)
Male	244 (49%)
Hispanic ethnicity	10 (2%)
Race	
White	399 (80%)
Black	64 (13%)
Asian	6 (1%)
Other	11 (2%)
Education	
Less than High School	81 (16%)
High School graduate (or GED)	150 (30%)
Some college	125 (25%)
College degree or higher	53 (11%)
Marital Status	
Married (or living as married)	304 (61%)
Divorced/Separated/Widowed	142 (28%)
Single	36 (7%)

Characteristic	N (%*)
Insurance Status	
Private Insurance	210 (42%)
Medicare/Medi-gap	183 (37%)
Medicaid	21 (4%)
Other Insurance	31 (6%)
No Coverage	21 (4%)
Income	
<\$20,000	101 (20%)
\$20,000 to <\$40,000	104 (21%)
≥\$40,000	146 (29%)
Cancer type	
Colon	403 (80%)
Rectal	83 (17%)
Multiple synchronous primaries	15 (3%)
Treatment	
Had surgery? – yes	404 (81%)
Had chemotherapy? – yes	236 (47%)
Had radiation treatment? – yes	68 (14%)

*Note:* \*Percentages may not add up to 100% as missing is included in the calculation.

The response rate was 38%, which is not an uncommon percentage in the current survey research environment. We performed a nonresponse analysis on key demographic variables to examine differences between respondents and nonrespondents. We found no differences between respondents and nonrespondents by age ( $p=0.30$ ), ethnicity ( $p=0.85$ ), or gender ( $p=0.98$ ). However, we did find differences by race ( $p < 0.01$ ), with fewer blacks among respondents (15%) than nonrespondents (24%).

### 3.2. Item selection

Items were set aside because of poor discrimination (relative to items selected), local dependence, and/or high missing rates. Content experts and the patient advocates helped to select the items, especially in cases of local dependence and one item had to be removed. Table 2 provides a list of the selected questions for each of the PCC Functions, including item statistics (i.e., mean, SD, item-total correlation, and factor loading) and scale statistics (coefficient alpha, unidimensional model fit statistics). No DIF by age group or gender was detected for the selected items. Supplemental Table 1 shows the 87 items evaluated in the survey ordered by PCC Function and, if removed, reasons for removal.

Table 2. Statistics for items retained for the Patient-Centered Communication (PCC) Measures.

Item Wording by PCC Function	Mean (SD)	Item-total r	Factor loading (se)
<b>Exchanging Information</b>			
How often do your doctors and other health professionals talk with you about your concerns and questions?	4.37 (.79)	0.80	0.89 (.01)
How often do your doctors and other health professionals give you helpful information, even when you don't ask for it?	4.10 (.95)	0.81	0.90 (.01)
How often do your doctors and other health professionals make sure you have the information you need?	4.39 (.84)	0.88	0.96 (.01)
How often do your doctors and other health professionals help you understand the information you need to know?	4.32 (.91)	0.86	0.94 (.01)
How often do your doctors and other health professionals make sure your questions are answered?	4.52 (.78)	0.85	0.95 (.01)
How much do your doctors and other health professionals make you feel comfortable asking questions?*	4.38 (.82)	0.74	0.83 (.02)
Reliability=0.94; RMSEA=0.03; CFI = 1.00; TLI = 1.00			
<b>Fostering Healing Relationships</b>			
How much can you depend on your doctors and other health professionals to give you the care you need?	4.56 (.72)	0.72	0.78 (.03)
How often do your doctors and other health professionals show they care about you?	4.33 (.88)	0.81	0.92 (.02)
How often do your doctors and other health professionals remember details about you between visits?	4.19 (.90)	0.78	0.89 (.01)
How often do your doctors and other health professionals have open and honest communication with you?*	4.43 (.86)	0.81	0.91 (.01)
How much do your doctors and other health professionals seem well-informed about your type of cancer?	4.65 (.66)	0.69	0.81 (.03)
Different doctors and health professionals are often involved in a patient's care. How well do your doctors and other health professionals explain what they each do?	4.13 (.86)	0.73	0.81 (.02)
How often do your doctors and other health professionals listen carefully to what you have to say?	4.51 (.74)	0.78	0.86 (.02)
Reliability=0.92; RMSEA=0.05; CFI = 1.00; TLI = 1.00			
<b>Making Decisions</b>			

<b>Item Wording by PCC Function</b>	<b>Mean (SD)</b>	<b>Item-total r</b>	<b>Factor loading (se)</b>
How often do your doctors and other health professionals involve you in making decisions about your care?	4.57 (.78)	0.64	0.74 (.03)
How well do your doctors and other health professionals explain the different choices you have?	4.18 (.84)	0.81	0.94 (.01)
How well do your doctors and other health professionals explain what they recommend?	4.32 (.79)	0.76	0.92 (.02)
How much do your doctors and other health professionals show interest in what you say about the decisions?	4.33 (.84)	0.79	0.89 (.02)
How much do your doctors and other health professionals give you information and resources to help you make decisions?*	4.11 (1.04)	0.78	0.91 (.01)
Reliability=0.90; RMSEA=0.07; CFI = 1.00; TLI = 1.00			
<b>Responding to Emotions</b>			
How often do your doctors and other health professionals give you the attention you need to your feelings and emotions?	4.33 (.89)	0.79	0.86 (.02)
How much do your doctors and other health professionals pay attention to how you are doing emotionally?	4.07 (.99)	0.91	0.98 (.00)
How much do your doctors and other health professionals show concern for your feelings, not just your illness?	4.05 (1.01)	0.91	0.97 (.01)
How much do your doctors and other health professionals show concern for how your family is doing emotionally?	3.75 (1.21)	0.88	0.94 (.01)
How much do your doctors and other health professionals make you feel comfortable to talk about your fears, stress, and other feelings?	3.99 (1.05)	0.89	0.94 (.01)
How well do your doctors and other health professionals talk with you about how to cope with any fears, stress, and other feelings?*	3.81 (1.04)	0.84	0.91 (.01)
Reliability=0.96; RMSEA=0.08; CFI = 1.00; TLI = 1.00			
<b>Enabling Patient Self-Management</b>			
How well do your doctors and other health professionals help you understand ways you can take care of your health?	3.93 (.88)	0.71	0.78 (.03)
How much do your doctors and other health professionals talk with you about how cancer is affecting your everyday life?	3.65 (1.21)	0.85	0.90 (.01)
How much do your doctors and other health professionals talk with you about ways you can manage any side effects or symptoms?	3.92 (1.13)	0.84	0.90 (.01)
How much do your doctors and other health professionals talk with you about how your family can help care for you?	3.66 (1.25)	0.86	0.95 (.01)

Item Wording by PCC Function	Mean (SD)	Item-total r	Factor loading (se)
How much do your doctors and other health professionals talk with you about any concerns you have about taking care of yourself?	3.81 (1.15)	0.87	0.93 (.01)
How often do your doctors and other health professionals... Make sure you understand the steps in your care?*	4.28 (.92)	0.75	0.83 (.01)

Reliability=0.94; RMSEA=0.05; CFI = 1.00; TLI = 1.00

### Managing Uncertainty

Cancer patients often face uncertainties about their cancer. For example, patients may not know what will happen, how treatment is working, and how to make sense of different information and opinions. How well do your doctors and other health professionals help you deal with the uncertainties about your cancer?*	3.96 (1.03)	0.83	0.86 (.01)
How much do your doctors and other health professionals help you understand if you are getting better or worse?	3.92 (1.13)	0.82	0.91 (.01)
How much do your doctors and other health professionals help you understand the goal of your care?	4.09 (1.06)	0.84	0.89 (.01)
How much do your doctors and other health professionals help you understand what is likely to happen with your cancer?	3.79 (1.21)	0.84	0.92 (.01)
How much do your doctors and other health professionals help you understand how your symptoms may change?	3.90 (1.18)	0.83	0.89 (.01)
Patients often get information from different places. How well do your doctors and other health professionals help you understand what information is most important?	3.85 (1.02)	0.80	0.85 (.02)

Reliability=0.94; RMSEA=0.04; CFI = 1.00; TLI = 1.00

Note: Items with an asterisk (\*) were selected for the PCC-Ca-6 measure. Reliability estimated from Cronbach's Coefficient Alpha. SD = standard deviation, SE = standard error, RMSEA = root mean squared error of approximation, CFI = confirmatory fit index, TLI = Tucker-Lewis index.

### 3.3. Model fit and reliability

For the items retained in each PCC Function, there was good model fit to the unidimensional model and high scale reliability ranging from 0.90 to 0.96. The estimated correlations among the latent variables measured by the Functions ranged from 0.79 (between Exchanging Information and Managing Uncertainty) and 0.91 (between Making Decisions and Fostering Healing Relationships). In the bifactor model, items loaded higher on the general PCC factor (ranging from 0.76 to 0.90) than on the Function-specific factors (ranging from 0.05 to 0.56). Together, the high inter-Function correlations and the high loadings on the general PCC factor support use of an overall PCC score from the selected items from each Function. For the PCC-

Ca-36 measure with the overall score computed as the average of the Function scores, coefficient alpha reliability is 0.94. For the PCC-Ca-6 measure, coefficient alpha reliability is 0.92.

### 3.4. Construct validity

For known-groups validity analysis, Table 3 presents means (SDs) for the PCC-Ca-36 for each PCC Function and overall PCC scores and for the PCC-Ca-6 overall PCC scores, both by health status and quality of life. All groups were statistically different from each other on all PCC outcomes ( $p < 0.01$ ). For convergent validity, the PCC-Ca-36 and PCC-Ca-6 overall PCC scores were highly correlated with the HINTS communication scale ( $r=0.79$  and  $0.76$ , respectively) and with the patients' satisfaction with quality of cancer care ( $r=0.67$  and  $0.67$ , respectively).

Table 3. Known-groups evaluation of the PCC-Ca-36 and PCCCa-6 measures by overall health and quality of life.

		Overall Health			Overall Quality of Life		
		Poor, Fair	Good, Very Good, Excellent	p-value	Poor, Fair	Good, Very Good, Excellent	p-value
		Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
PCC- Ca-36	Exchanging Information	3.97 (.94)	4.42 (.70)	<0.0001	3.89 (.96)	4.41 (.70)	<0.0001
	Fostering Healing Relationships	4.10 (.79)	4.45 (.61)	0.0001	3.97 (.86)	4.45 (.59)	<0.0001
	Making Decisions	3.85 (1.03)	4.26 (.74)	0.0011	3.72 (1.04)	4.26 (.75)	0.0002
	Responding to Emotions	3.58 (1.12)	4.05 (.92)	0.0003	3.42 (1.17)	4.05 (.91)	<0.0001
	Enabling Patient Self-Management	3.49 (1.07)	3.95 (.91)	0.0003	3.37 (1.05)	3.95 (.91)	<0.0001
	Managing Uncertainty	3.53 (1.07)	4.01 (.90)	0.0002	3.41 (1.12)	4.01 (.90)	<0.0001
	Overall Communication	3.76 (.90)	4.19 (.70)	<0.0001	3.64 (.94)	4.19 (.70)	<0.0001
	PCC- Ca-6	Overall Communication	3.80 (.96)	4.23 (.75)	0.0001	3.64 (.99)	4.23 (.75)

## 4. Discussion and conclusion

### 4.1. Discussion

Based on a conceptual model<sup>3</sup>, we designed two measures of PCC in cancer care, the PCC-Ca-36 and the PC-Ca-6. The longer version (PCCCa-36) provides scores for each of the six PCC Functions and overall PCC, and the shorter version (PCC-Ca-6) provides a score for overall PCC only. Items were developed using a comprehensive, evidenced-based process that included qualitative and quantitative research methods<sup>22, 24</sup>.

Using a large sample of CRC patients and modern psychometric methods, we selected a final set of items that was highly discriminating, contained no DIF (by gender or age), and was relevant for the PCC Function they measure. The measures had strong reliability above 0.90 on subscale and overall PCC scores. For construct validity, the PCC-Ca measures differentiated between those with better and worse health and quality of life, and were strongly associated with another measure of communication used in the HINTS study and with patients' ratings of quality of care.

The PCCCa-36 measure is designed for use in surveillance activities, intervention research, and for quality improvement initiatives. It can be used to evaluate the extent of patient-provider communication within each Function (and overall PCC) and how it may vary across the cancer care continuum. For example, Information Exchange and Decision Making may be critical functions in the early phases of cancer care. Enabling Patient Self-Management may be critical to manage the symptoms associated with treatment and long-term effects in survivorship phases of care. Additionally, the PCC-Ca-36 measure allows end-users to select items to measure only one Function (e.g., Exchanging Information) or as many Functions as are of interest; however, all Functions need to be administered to calculate the overall PCC score. The idea is that some patient-centered outcomes studies may design interventions to affect only a subset of PCC Functions. The PCC-Ca-6 measure is designed for use in population surveillance in which space on surveys is limited, or for when there is only interest in assessing PCC overall.

This study has several limitations. First, the overall goal of the study was to design PCC measures for use across a broad range of cancer settings; however, the study was limited to English-speaking individuals with CRC in North Carolina. To address the generalizability of results, future studies will need to be conducted in other cancers, settings, and patient populations. However, we intentionally selected CRC because of the routine incorporation of multimodality therapy as standard of care, including surgery, radiotherapy, and chemotherapy, suggesting the PCC-Ca is likely to be applicable to other similarly complex cancers such as breast, lung, bladder, and pancreatic cancers. The PCC-Ca measures will also need to be translated to other languages and evaluated for measurement equivalence. Second, this study only examined the performance of the measures at a single time point. A follow-up paper is planned to examine changes in PCC in the CRC sample over time. Third, these measures only capture communication from the patient's perspective and not from the provider's perspective. Lastly, the PCC-Ca measures were evaluated using paper surveys or web-surveys, further evaluation is needed for other modes of administration.

## 4.2. Conclusion

This study provided theory-grounded, valid, and reliable PCC measures that numerous organizations—including health systems, public-sector programs and agencies, insurers, health professional organizations, medical educators, accreditation organizations, and other entities invested in improving quality of care can use for comprehensive assessment of PCC. Future work is planned to evaluate the measures longitudinally and to test them in other cancer populations.

## 4.3. Practice implications

Recent initiatives and policy reforms have focused renewed attention on PCC and patient-provider communication specifically, moving this aspect of quality health care to center stage<sup>2, 35, 36</sup>. The 2010 Patient Protection and Affordable Care Act (ACA) aims to “facilitate collaborative processes between patients, caregivers or authorized representatives, and clinicians that engage the patient, caregiver or authorized representative in decision making; provides patients, caregivers or authorized representatives with information about trade-offs among treatment options; and facilitates the incorporation of patient preferences and values into the medical plan”<sup>37</sup>. The ACA also calls for quality measures related to shared decision making, patient-centeredness, patient experience, and satisfaction; and provides momentum and support for improving PCC and developing ways to assess this critical aspect of care. The 2006 Center for Medicare & Medicaid Services mandate to establish patient-centered medical homes to improve care for patients with chronic illnesses also emphasizes the patient-clinician relationship and communication<sup>38</sup>. The rules for meaningful use of electronic health records emphasize patient-clinician communication, including fostering patient engagement and patient education<sup>39</sup>. The Institute of Medicine also emphasized the importance of measuring patient perceptions of clinician behavior and identified the patient experience as the paramount source for evaluating quality of care<sup>1, 40</sup>.

Recognition also is growing in the medical field that clinician education and training should emphasize enhancing communication skills<sup>36, 41, 42</sup>. For example, the Medicare Payment Advisory Commission recommended that Medicare payments for graduate medical education be linked to development of such skills<sup>43</sup>. Additionally, the National Board of Medical Examiners, the Association of American Medical Colleges, and several medical associations have called for strengthening communication skills training<sup>36, 41</sup>.

With investment in PCC and improved patient-provider communication being undertaken on a large scale, valid and reliable PCC measures such as the PCC-Ca-36 and the PCC-Ca-6 meet an important need to evaluate whether these reforms and initiatives meet their goals. By quantifying PCC, healthcare providers and systems that demonstrate success in improving patient-provider communication can be recognized and rewarded.

Health systems could assess patients' PCC experiences via Web-based patient portals or paper surveys at key points in their care. This approach could combine PCC assessment with measures of other patient-reported experiences such as symptom burden or self-efficacy for disease management. The PCC-Ca can also be used for population surveillance to track the



quality of patient-clinician communication at the population level and to establish benchmarks for improvement. We also expect that the measures will provide further evidence about the association between PCC and satisfaction with healthcare or HRQOL. Researchers and practitioners will be able to explore the overall importance of PCC and the relative importance of specific PCC Functions at different phases of cancer care relative to changes in HRQOL. This type of evidence is essential to inform the development of interventions to improve communication in cancer care and patient outcomes<sup>3, 4</sup>.

## Conflict of interest

The authors have no conflicts of interest to report.

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## Appendix B. Supplementary data

The following are Supplementary data to this article:

[Download Acrobat PDF file \(81KB\)](#)[Help with pdf files](#)

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