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Design and Preliminary Testing of the Caregiver-Centered Communication Questionnaire (CCCQ)

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Abstract

The study objective was to develop and test a new survey instrument that measures caregiver-centered communication. We developed a questionnaire inspired by the National Cancer Institute framework on patient-centered communication, focusing on family caregiver communication for this tool. The questionnaire includes 5 subscales: exchange of information, relationship with team, emotions, managing care, and decision-making. The initial questionnaire was reviewed by domain experts for face validity and edited further to include 30 items. We administered the modified questionnaire to 115 family caregivers of patients with serious illness in various settings. Cronbach α for the entire scale was 0.97 and ranged from 0.82 to 0.93 for the 5 subscales. Participants found that the survey addressed important concepts and that items were in most cases easy to understand. This instrument provides a structured way to assess caregiver-centered communication, addressing a pressing need for tools that measure the extent to which communication is responsive to the needs and preferences of family caregivers. Further testing and refinement are needed to improve the ease of use and examine the reliability and validity of this measure.

Keywords

Caregiver; communication; questionnaire; shared decision making; survey

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Declaration of Conflicting Interests

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Introduction

In 2001, the Institute of Medicine (IOM) called for necessary improvements in health-care delivery, including the need for health care to be patient-centered.¹ More specifically, the IOM called for care that was responsive to individual patient preferences and needs, ensuring that patient values inform clinical decisions.¹ Despite a broad spectrum of definitions of patient-centered care,^{2–5} most definitions share the following critical elements: addressing the patient's perspective; understanding the patients' psychosocial context; involving patients in their care to the extent they desire; reaching a shared understanding of the problem and agreeing on the treatment plan; and making decisions that are consistent with patient values.⁶

Epstein and Street⁶ under the auspices of the National Cancer Institute (NCI), developed a framework for patient-centered communication. The framework consists of 6 core functions that overlap and interact, leading to improved outcomes. The first function is fostering relationships. This includes building rapport and trust between the health-care provider (HCP) and the patient and family. The second function is exchanging information. The next function is responding to emotions whereby HCPs recognize the emotional state of patients and their families and respond with expressions of understanding, empathy, and support. The remaining functions are managing uncertainty, making decisions, and enabling self-management.

While the initial framework was developed for patient-centered communication, it can be applied to family members as well, as the concept of patient-centered care has been expanded to include family members, or family-centered care. In many instances, the patient is relying on a family member or other informal caregiver (friend or other) to jointly navigate the health-care system and cope with the ramifications of serious illness; thus, the patient-caregiver dyad becomes the unit of care. In 2015, approximately 43.5 million adults in the United States were family caregivers and had provided unpaid care to a relative or other individual who was ill, disabled or aged in the prior 12 months.⁷ The caregiving role becomes crucial in cases where patients are facing a condition that limits their cognitive and functional abilities and caregivers are called to act as proxy decision makers for significant treatment and symptom management decisions. Caregivers often report that they feel isolated and overwhelmed and in some cases experience significant barriers in communicating with HCPs.^{8,9}

It is important that HCPs communicate in a way that acknowledges and addresses caregivers' preferences, needs, and perspectives. Caregiver-centered communication can facilitate a more effective adaptation throughout the illness course with better adherence to recommended treatment plans and greater satisfaction with care for both patients and families, as well as a more comprehensive response to their psychosocial needs.¹⁰ While health-care organizations often aim to increase caregiver engagement and involvement in care processes, there is a lack of tools or strategies not only to more actively engage caregivers but also to assess how ongoing approaches perform in terms of facilitating meaningful and inclusive communication.¹¹ In recent years, various scales have been developed to assess the family caregiver perspective. The CaTCoN (Cancer Caregiving

Tasks, Consequences and Needs Questionnaire),¹² for example, measures caregivers' experiences focusing mostly on the tasks and responsibilities that caregivers assume and carry out. The Family Assessment of Treatment at the End-of-Life Questionnaire¹³ assesses caregiver satisfaction with end-of-life care. Others include the Family Resilience Questionnaire¹⁴ assessing family dynamics and resources in the context of cancer care, and the Canadian Health Care Evaluation Project which has patient and family versions of a questionnaire¹⁵ that mostly assesses satisfaction with end-of-life care. These instruments provide insight into the caregiver experience but focus solely on one setting of care or condition (eg, cancer, end of life) and do not specifically target caregiver engagement in care and quality of communication. We aimed to develop and test a new tool that measures caregiver centered communication in a broad range of settings and clinical conditions. Such an instrument is meant to assess the extent to which caregivers feel their perspectives, needs, desires, and concerns are appropriately addressed by the health-care team, and to identify any communication barriers they may experience. The purpose of this paper is to describe the initial development and refinement of the Caregiver Centered Communication Questionnaire (CCCQ), a survey instrument assessing caregivers' perceptions of the extent to which communication with health-care teams is caregiver centered. Additionally, we aimed to conduct preliminary testing of this new instrument.

Methods

Survey Development

We developed an instrument to assess the extent to which informal/family caregivers believe their communication with HCPs or teams is addressing their needs and expectations. The questionnaire was based on the NCI framework of patient-centered communication that covered several topics: fostering healing relationships, information exchange, responding to emotions, managing uncertainty, making decisions and enabling self-management. Items were developed based on the NCI framework themes and subthemes, to address these categories based on the caregiver's perspective (eg, My health-care team cares about me). A first draft of the instrument with 32 items was created with 5 subscales: exchange of information, fostering health relationships with team/provider, recognizing and responding to emotions, managing care, and decision-making. All answer choices for all items were adapted to a 5-Likert scale, with 1 meaning "strongly disagree" and 5 meaning "strongly agree."

Design and Setting

Preliminary testing of the instrument was conducted in 3 phases. In the first phase, we assessed face validity of the CCCQ in its initial form (with 32 items). The instrument was reviewed by 6 domain experts (academic and clinical experts covering the domains of caregiving, palliative care, health communication and survey development) to address face validity. Experts provided feedback about the clarity of the items, potential redundancies, and suggestions for most effective phrasing. We modified the instrument based on this feedback. The next 2 phases involved a cross-sectional descriptive survey design that involved family caregivers recruited in an urban setting in a metropolitan area in the Pacific Northwest and in a rural area in the Midwest (phase 2) as well as a national sample

identified through an online platform (ResearchMatch; phase 3). ResearchMatch is a national health volunteer registry established by various academic institutions with the support of the US National Institutes of Health.¹⁶ This registry contains a large population of volunteers willing to be contacted about health-related research studies. During phase 2, we audio-recorded a subset of sessions where the survey was administered verbally to family caregivers by a member of the research team to assess their initial reactions to the survey items, their clarity and any need for clarification. After phase 2, the survey was further revised prior to its testing in phase 3. Review and approval for this study and all procedures was obtained from the University of Washington Institutional Review Board.

Participants and Data Collection

Study participants were family caregivers who were at least 18 years old who cared for adult patients. A family caregiver was defined as any person (family member, spouse, friend, or other) who provides any type of physical, psychological, emotional care (in most cases unpaid) for a patient. Caregivers were excluded if they were not able to speak and read English. For phase 2, we recruited family caregivers of patients in home hospice who were already enrolled in 2 large randomized clinical trials (in the Pacific Northwest and in the Midwest). We administered the survey at baseline prior to any exposure to study procedures or interventions. For phase 3 we recruited adult caregivers caring for adult patients broadly, and we posted a brief description of the study with a list of inclusion/exclusion criteria on the ResearchMatch website. Individuals interested in participating contacted a research assistant who screened for eligibility and, for those eligible and willing to participate, we e-mailed a demographic questionnaire and an online link to the CCCQ. A total of 115 eligible family caregivers were recruited to test the final version of CCCQ (in phase 2 a total of 72 participants including 32 from an urban site in the Pacific Northwest and 40 in a rural site in the Midwest, and in phase 3 43 participants via ResearchMatch). Interviews with 10 participants in phase 2 were also audio-recorded to assess the respondents' initial reaction to the purpose and clarity of the instrument items.

Statistical Analysis

Cronbach α was examined to address reliability by determining the internal consistency of the instrument. We also calculated values of "item-test correlations." Item-test correlation is the Pearson correlation coefficient calculated for pairs of scores (between each item and total test score). A value of 0.7 or higher was considered to indicate good internal consistency of the items analyzed.¹⁷ Analysis was performed in STATA statistics software (version 10.1; StataCorp LP, College Station, Texas).

Results

Characteristics of Study Participants

A total of 115 family caregivers completed the final version of the CCCQ instrument (that includes 30 items). Respondents could choose not to answer questions whether the survey was administered in person, over the phone or online. Completion rate was 91% for the 115 surveys. Participants' demographics and experiences of caregiving are described in Table 1. The majority of participants were women and Caucasian, and family caregivers for patients

with cancer in home hospice. Approximately half of the participants were adult children or spouses/partners of a patient in hospice.

Face Validity

Expert feedback.—The initial instrument developed in the first phase included 32 items. The 6 content experts generally found the questionnaire to be inclusive and clear but recommended minor edits and clarifications that led to modifying the wording for some of the items and eliminating one item. The revised instrument used in phase 2 included 31 items and based on these findings we further reduced the instrument to 30 items for phase 3 (but did not further modify the wording of the remaining items).

Caregiver feedback.—Ten participants who were interviewed in phase 2 overall felt that the survey questions were clear and addressed important aspects of the caregiving experience. As one participant stated, “*These questions are very important. They show that I matter, or that I should matter.*” In many instances participants provided examples to showcase how the HCP team had included or excluded them from the decision-making process. Another participant emphasized “*I could talk for hours about these [survey topics]. It is so important to have the professionals on your side and know they hear you, and that’s not always the case, you know.*”

In terms of specific items, 8 (25%) respondents commented that item 3 (My team helps me use sources of medical information) and item 4 (My team helps me learn and understand medical information) were somewhat redundant; to a lesser extent (3 respondents) a similar observation was made for items 2 (My team shares sources of medical information) and 3 (My team helps me use sources of medical information). Finally, item 25 (my team helps me get through the health-care system) caused 4 participants to ask for clarification as to what “get through” meant. Based both on the properties of items 3 and 4 (item 3 had the lowest α) and the qualitative feedback provided by respondents about potential overlap, we decided to merge the 2 items to one (My team helps me use and understand medical information). Additionally, we rephrased item 25 (My team helps me navigate the complex health-care system).

Readability

After eliminating one item in phase 1, and merging 2 items into one during phase 2, the resulting instrument had 30 items (Table 2). The instrument is designed to allow for the term “HCPs” (or a specific provider title, such as “my doctor,” “my nurse”) to also be used if we are assessing caregiver-centered communication between a dyad (provider and caregiver) rather than between a care team and a caregiver. The instrument has a Flesch Reading Ease of 70.8 and a Flesch Kincaid Grade level of 5.9. The readability statistics show a document of approximately sixth grade level and relative reading ease (although this parameter has room for improvement).

Reliability

We assessed the reliability of the final version of CCCQ with 30 items. Cronbach α reliability for the entire scale was 0.97. Item 2 “My health-care team shares sources of

medical information” was the least relating question to the 30 items (item-test correlation, $r = 0.56$). Item 28 “I feel like I am building a partnership with my health-care team” was the most relating question to 30 items (item-test correlation, $r = 0.84$; data not shown). Table 3 shows the item analysis findings by the 5 subscales. When examining reliability within each of the subscales, overall the internal consistencies of 5 subscales were high, ranging from 0.82 to 0.93. The strongest item correlation within the subscales was found in “Fostering health relationships” (Cronbach $\alpha = 0.93$), and the lowest was found in “Managing care” (Cronbach $\alpha = 0.82$). The least relating subscale to the 5 subscales was “Fostering health relationships” with item-test correlation, $r = 0.78$; and the most relating subscale was “Decision-making” with item-test correlation, $r = 0.84$.

Table 4 presents the inter-item correlations matrix among the 5 subscales. The “Exchanging information” subscale was the most discernable with moderate correlations with the remaining 4 subscales (ranging from $r = 0.65$ to $r = 0.75$). The strongest correlations were found between the “Managing care” and “Health relationships” subscales ($r = 0.88$, $P < .0001$).

Evaluation of Communication Quality

We evaluated communication quality between HCPs and caregivers with a final version of 30-item CCCQ in 115 participants. The item with the lowest average score (3.0) was item 15 (“My health-care team tries to determine whether I am anxious, depressed, or stressed”). The item with the highest average score (4.3) was item 4 (“I feel comfortable sharing information with my health-care team”). The subscale “fostering health relationships” received the highest mean score (4.0 ± 0.8) and the subscale “recognizing and responding to emotions” received the lowest mean score (mean 3.5 ± 0.9).

Discussion

The CCCQ instrument is designed as a tool to assess caregivers’ perceptions of the extent to which communication with the health-care team is caregiver centered. The instrument is meant to be applicable to a broad spectrum of health-care settings and contexts where family caregivers play a critical role in the care delivery process and not solely the hospice domain that was the setting of phase 2 of this study (more broadly, palliative care and home care may be other areas that rely heavily on the presence of informal caregivers). The proposed instrument covers a series of underlying significant constructs and can inform educational interventions for HCPs to train them in effective and respectful communication that addresses caregivers’ needs and preferences. As caregivers in many instances are called upon to act as proxy decision makers, it is important for health-care teams to provide access to information and a platform for discussion of questions and options in order to facilitate support and shared decision-making.⁶ When administered to a large group of caregivers it can provide a snapshot of the communication practices and overall culture of a health-care team recognizing that improved communication may take a longer period of time as it may require for many practitioners a paradigm shift from a paternalistic approach where the provider collects data and reaches a decision to a more empowering approach where patients and caregivers participate in this process actively ensuring their needs and values are

reflected in all health-care-related decisions.⁵ Improved communication with caregivers can lead to reduced caregiver anxiety and burden,¹⁸ improved quality of life for caregivers,¹⁹ and better coping during a stressful time.²⁰

The CCCQ survey and its 5 subscales were developed based on an expansion of the conceptual framework of patient-centered communication, thus, each subscale is meant to be conceptually distinct. However, we found moderate to high item correlations among 5 subscales. This suggests that each subscale is not strongly discernable component of the CCCQ. Although full instruments could have greater conceptual comprehensiveness, it may be worth exploring a short-form version of the instrument. In its current form the survey includes 30 items and may be more practical in use if it had a reduced set of items. Further reliability and validity testing is required, including a factor analysis with a larger sample size and examination of potential score correlation with caregiver outcomes.

There are several limitations to this study. Our population was mostly Caucasian women in home hospice settings in the United States. This may not generalize to other races/ethnicities and different cultures. Caregivers' roles and responsibilities may vary across populations; caregivers may not necessarily be the designated surrogate decision makers depending on surrogacy laws and context specific regulatory requirements. To conduct an instrument evaluation, a sample size of at least 50 participants is adequate to represent and evaluate the psychometric properties of measures.²¹ However, our small sample size limits us in conducting a full-scale psychometric testing such as content validity or a factor analysis (where a rule of thumb suggests a sample of at least 10 times the number of survey items).²² Given a shortage of instruments assessing caregiver centered communication with HCPs or teams, we did not assess concurrent validity by comparing scores between the CCCQ and some other instrument that would assess caregiver-centered communications. Future research is suggested to conduct a full-scale validation of the CCCQ with a large sample size. The instrument should also be tested further with various caregiver groups selected to represent a broad spectrum of health literacy.

Conclusion

As family caregivers are increasingly recognized as essential to the effective delivery of health-care services to people with chronic conditions, or advanced illness, emphasis is being placed on family-centered care and interventions that recognize the needs, values, and preferences of family caregivers. As we explore new paradigms of inclusive care and shared decision-making, we need instruments that help us guide the implementation of such efforts. The proposed instrument aims to address this gap. Preliminary testing indicates its potential in assessing caregivers' engagement and quality of communication with the health team but further testing and validation are required.

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Table 1.Characteristics of Caregivers.^a

Caregivers Characteristics	No. (%)
Women	71 (60.0)
Age, mean (SD)	34.2 (14.7)
Race/ethnicity	
White, non-Hispanic	89 (77.4)
Asian	11 (9.6)
Black, not Hispanic	2 (1.7)
Hispanic or Latino	2 (1.7)
Unknown	11 (9.6)
Relationship to patients	
Adult child	59 (50.4)
Spouse or partner	53 (45.3)
Other	3 (2.6)
Primary diagnosis of patients	
Cancer	99 (86.1)
Dementia or related illness	4 (3.5)
Cardiovascular disease	8 (4.9)
Unknown	4 (3.5)
Durations of providing care for patients	
Less than 1 year	43 (36.1)
1 year or more	72 (63.9)

^aN = 115.

Table 2.

Final Version of Caregiver-Centered Communication Questionnaire (CCCQ) Response Options: 1-strongly disagree; 2-disagree; 3-neutral; 4-agree; 5-strongly agree.

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1. My health-care team tries to explore my beliefs, needs and preferences as a caregiver.
 2. My health-care team shares sources of medical information.
 3. My health-care team helps me use and understand medical information.
 4. I feel comfortable sharing information with my health-care team.
 5. My health-care team knows how to deliver news whether good or bad.
 6. My health-care team is honest and open in disclosing information.
 7. I trust my health-care team's skills and knowledge.
 8. My health-care team shows that he/she is committed to my loved one's care.
 9. My health-care team cares about me.
 10. I feel that I have a connection with my health-care team.
 11. My health-care team helps me understand my loved one's illness.
 12. My health-care team lets me be actively involved in my loved one's care if I want to.
 13. My health-care team helps me deal emotionally with the uncertainty of my loved one's illness.
 14. My health-care team helps me manage and solve problems that I face as a caregiver.
 15. My health-care team tries to determine whether I am anxious, depressed or stressed.
 16. My health-care team makes me feel that it is ok to feel the way I do.
 17. My health-care team reassures me and sympathizes with me.
 18. My health-care team helps me deal with my emotions.
 19. My health-care team supports me when making decisions about my loved one's care.
 20. My health-care team helps me make choices and carry out a plan.
 21. My health-care team helps me evaluate my decisions.
 22. My health-care team discusses my choices with me.
 23. My health-care team helps me set my priorities.
 24. My health-care team helps me navigate the complex health-care system.
 25. My health-care team helps me arrange the next step in my loved one's care.
 26. My health-care team discusses with me when and where we will talk.
 27. My health-care team discusses with me the roles of the team.
 28. I feel like I am building a partnership with my health-care team.
 29. My health-care team respects my background and culture.
 30. My health-care team discusses different possible options for care.
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Table 3.**Reliability of 5 Subscales.**

	Item-Test Correlation (r)	Cronbach α
Exchange of information subscale		
1. My health-care team tries to explore my beliefs, needs and preferences as a caregiver.	0.76	0.83
2. My health-care team shares sources of medical information.	0.82	0.79
3. My health-care team helps me use and understand medical information.	0.86	0.78
4. I feel comfortable sharing information with my health-care team.	0.72	0.84
11. My health-care team helps me understand my loved one's illness.	0.77	0.83
Subtotal	0.79	0.84
Fostering health relationships with health-care team subscale		
5. My health-care team knows how to deliver news whether good or bad.	0.75	0.92
6. My health-care team is honest and open in disclosing information.	0.84	0.92
7. I trust my health-care team's skills and knowledge.	0.78	0.92
8. My health-care team shows that he/she is committed to my loved one's care.	0.83	0.92
9. My health-care team cares about me.	0.76	0.92
10. I feel that I have a connection with my health-care team.	0.80	0.92
26. My health-care team discusses with me when and where we will talk.	0.69	0.93
27. My health-care team discusses with me the roles of the team.	0.74	0.92
28. I feel like I am building a partnership with my health-care team.	0.86	0.92
29. My health-care team respects my background and culture.	0.74	0.92
Subtotal	0.78	0.93
Recognizing and responding to emotions subscale		
13. My health-care team helps me deal emotionally with the uncertainty of my loved one's illness.	0.82	0.89
15. My health-care team tries to determine whether I am anxious, depressed or stressed.	0.83	0.90
16. My health-care team makes me feel that it is ok to feel the way I do.	0.81	0.88
17. My health-care team reassures me and sympathizes with me.	0.82	0.87
18. My health-care team helps me deal with my emotions.	0.80	0.87
Subtotal	0.82	0.91
Managing care subscale		
12. My health-care team lets me be actively involved in my loved one's care if I want to.	0.80	0.78
14. My health-care team helps me manage and solve problems that I face as a caregiver.	0.84	0.75
24. My health-care team helps me navigate the complex health-care system.	0.79	0.78
25. My health-care team helps me arrange the next step in my loved one's care.	0.80	0.77
Subtotal	0.81	0.82
Decision making subscale		
19. My health-care team supports me when making decisions about my loved one's care.	0.87	0.87
20. My health-care team helps me make choices and carry out a plan.	0.89	0.87
21. My health-care team helps me evaluate my decisions.	0.83	0.89
22. My health-care team discusses my choices with me.	0.82	0.89
23. My health-care team helps me set my priorities.	0.81	0.89
30. My health-care team discusses different possible options for care.	0.81	0.89

	Item-Test Correlation (r)	Cronbach α
Subtotal	0.84	0.90

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Table 4.Item Correlations among 5 Subscales.^a

	Exchanging Information	Health Relationships	Responding to Emotions	Managing Care	Decision-Making
Exchanging Information	1.000	-	-	-	-
Health Relationships	0.752	1.000	-	-	-
Responding to Emotions	0.679	0.788	1.000	-	-
Managing Care	0.710	0.877	0.819	1.000	-
Decision-making	0.652	0.815	0.824	0.843	1.000

^aAll item correlations, r , were statistically significant (P -values < .0001).