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# Family Caregiver Communication Tool: a new measure for tailoring communication with cancer caregivers

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# 1 | INTRODUCTION

Clinical assessment tools that guide a tailored communication approach can inform providers of families in need of immediate intervention.<sup>1</sup> The Family Caregiver Communication Tool (FCCT) is a measure of communication patterns dependent upon 2 dimensions: conversation and conformity. Family conversation includes the frequency and range of topics discussed. Conformity includes congruence in family member attitudes, values, beliefs, and roles. High and low dimensions of conversation and conformity produce 4 different caregiver communication types: manager, partner, lone, and carrier caregivers.<sup>2</sup> Figure 1 provides an overview of the typology. The goal of the FCCT is to determine a specific caregiver type so that clinicians can tailor their communication with caregivers.

Data were collated from 2 separate randomized controlled trials (R01NR015341-018NINR; and RSG-13-370-01, American Cancer Society). Both studies were approved by the institutional review board. Family caregivers (n = 115) were primarily female (71%), white and not Hispanic/Latino (75%), and spouses (63%), with a median age of 59 years (range 30-83 y). Family caregivers cared for a stage II, III, or IV cancer patient and completed the FCCT, the Cultural Justification of Caregiving Scale (CJCS), and 2 subscales (open communication and adaptability) from the Family Climate Scale (FCS). Item generation and content and face validity of FCCT items and preliminary testing are described elsewhere.<sup>2</sup> The CJCS assesses caregivers' cultural reasons and expectations for providing care.<sup>3</sup> The FCS is a self-report of family cultures and process.<sup>4</sup>

Cronbach's  $\alpha$  values for the conversation and conformity subscales were 0.80 and 0.67, respectively, attesting to the internal consistency of the measured scales. A principal components factor analysis of the FCCT explained 82% of the variance (49% factor 1 and 33% factor 2). With the varimax rotation, all items in the conversation factor had loadings over 0.6, and all items in the conformity factor had loadings of 0.37 or above, with no items having a cross-load of 0.3 or higher. A Likert scale from 0 (never) to 4 (frequently) is used for each item and the tool can be done by the caregiver independently. The factor loading matrix is presented in Table 1. The FCCT conversation subscale was highly correlated with the FCS instrument ( $\rho = 0.430$ , P < .01), while the FCCT conformity scale had significant correlation with the CJCS instrument ( $\rho = 0.295$ , P < .05).

The FCCT provides a brief tool guiding tailored communication in cancer care (Figure 1). Score interpretation is based on high and low cutoff points on each subscale (conformity and conversation), using 0–11 as low and 12–20 as high, producing a specific caregiver type. The FCCT offers a tool for future research on caregiving, including patient, family, cultural, relational, and decision factors influencing family involvement.<sup>5</sup> Research findings on patient and caregiver characteristics and family involvement suggest future directions for the FCCT. Younger patients are more likely to experience problematic family communication,<sup>6</sup> and well-educated patients are less likely to have family involved in their care.<sup>5</sup> Caregiver characteristics, such as less educated caregivers and adult-parent child dyads, are associated with family communication problems.<sup>6</sup> These trends may be associated with family caregiver types.

In recent years, cancer caregiving has changed. Family caregivers now take a more active role in the patient's decision making and care. Despite this role change, caregiver assessment has continued to focus on measuring the impact of cancer caregiving, including lifestyle disruption, well-being, caregiver health, management of the situation, and relationships.<sup>7</sup> Family caregiver assessment should include characteristics that impact family involvement and ways to improve family caregiver participation. Currently, family interventions offer a "one size fits all" approach, yet every family caregiver has different needs and preferences. Whether or not there are other families involved in the patient's care, the FCCT identifies a caregiver type for the primary caregiver, thus informing clinicians how to tailor their communication Family Caregiver Communication Types and Recommended Communication Approaches

Family Caregiver Type	Communication Pattern		Communication Characteristics	Tailored Communication Approach	
	Conversation	Conformity			
Manager	High	High	<ul> <li>Demonstrates credibility with use of medical words</li> <li>Makes decisions swiftly and independently</li> <li>Minimizes illness trajectory by focusing on treatment</li> <li>Acts as family decision-maker</li> </ul>	<ul> <li>Use medical terminology to compliment caregiver's use of medical terms</li> <li>Conduct one-on-one meetings with other family members</li> <li>Ask: "What are you worried about?"</li> </ul>	
Carrier	Low	High	<ul> <li>Avoids talking about death or alternatives other than cure</li> <li>Over-performs caregiving tasks</li> <li>Avoids discussing caregiving with family; may discuss with others</li> <li>Relies on patient's making care decisions</li> </ul>	<ul> <li>Explain and advocate for support resources to relieve caregiver stress</li> <li>Address caregiver burden in team meeting and with caregiver</li> <li>Ask: "What have you done for yourself today?"</li> </ul>	
Partner	High	Low	<ul> <li>Initiates death and dying, spirituality, quality of life discussions</li> <li>Accepts caregiving assistance from other family members</li> <li>Shares, discusses caregiving burden with patient and family</li> <li>Includes family members in problem-solving</li> </ul>	<ul> <li>Focus on education, use medical words, teach back approach</li> <li>Facilitate large family meetings</li> <li>Ask: "What do you need from the team?"</li> </ul>	
Lone	Low	Low	Focuses on one aspect of care, typically physical     Cannot consider all aspects of holistic care     Focuses on treatment and avoids quality of life topics     Performs caregiving without family support in tangible care or conversation	<ul> <li>Use plain language and pictures to address health literacy</li> <li>Avoid large team meeting format</li> <li>Ask: "What gives you hope?"</li> </ul>	

**FIGURE 1** Family caregiver communication types and recommended communication approaches

**TABLE 1** Resultant pattern matrix using principal axis factoring with varimax rotation and Kaiser normalization (n = 115) for factor loadings of 10item Family Caregiver Communication Tool

	Factor	
Item	Conversation	Conformity
My family talks about what might happen if treatment doesn't work.	0.7260	
I talk with my family, which can include online and text messages, about my loved one's illness.	0.6943	
After a medical appointment, I contact family members to share details of the visit.	0.6891	
Family members ask me about my loved one's illness.	0.6562	
My family talks about death and dying with our ill loved one.	0.6489	
My family lets me know that they expect me to take care of my loved one and that I am to do most of the caregiving.		0.6957
My ill loved one lets me know that he/she expects me to provide care and do most of the caregiving.		0.6408
My family hides their opinion about the quality of my caregiving.		0.6126
My family tries to act as though my loved one is not ill.		0.4448
When I am stressed from caregiving, I prefer to hide this from my family members.		0.3754

to reduce caregiver stress. Future work will explore sociodemographic variables (eg, gender) and coping styles, in addition to caregiver outcomes. Diverse samples are needed to further inform and develop the conformity construct of the FCCT as it is heavily based on cultures emphasizing collectivism.

While a family caregiver type can be found from FCCT, it does not mean that all family members aspire to or report the same caregiver type. Their role is likely different, and more research is needed to explore multiple caregivers from a single family. Our prior work on collective caregiving has found that these caregivers experience more distress and are in higher need of clinician involvement.<sup>8</sup> Future work should examine caregiver communication across the caregiving trajectory to see what communication interventions are needed based on caregiver type at different points in the cancer trajectory. Although grounded and tested in a cancer caregiver population, there is potential for FCCT to be applicable to caregivers of other diseases.

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## DISCLOSURES

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