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Conceptualizing How Couples Talk about Cancer

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### **ABSTRACT**

Scholarship on couple communication about cancer employs variable conceptualizations of communication and common measurement strategies make questionable assumptions about communication. This study provides a descriptive foundation for a multi-topic, multi-dimensional approach to studying couple talk about cancer. Based on interviews with persons treated for cancer in the last five years and partners, we identified 16 topics and 5 dimensions of talk. "Talk about cancer" covers a broad range of issues. The frequency, openness, difficulty, and focus of talk vary considerably for different topics and can change over time or differ between partners. Disagreements were rare but highly salient and satisfaction with talk tended to be high. These findings suggest we move away from abstract, general measures of couple communication and that we develop descriptive advice for couples, rather than simply prescribing "be open."

Keywords: cancer, marital communication, open communication, self-disclosure

## Conceptualizing How Couples Talk about Cancer

Cancer affects not only a patient but also his or her family. Communication plays a key role in how families learn of a diagnosis, make decisions, and go through all of the practical and symbolic accommodations that cancer entails (Blanchard, Ruckdeschel, & Albrecht, 1996). Health communication scholars who study cancer information campaigns (e.g., Kreps & Sivaram, 2008) and patient-centered cancer care (e.g., Arora, Street, Epstein, & Butow, 2009) have emphasized the important role families play in processing health information, making decisions about care, and interacting with health care providers.

Although it is widely recognized that families talk about cancer, and that this talk matters, relatively few studies have described communicative activities (Beach, 2009). Research has focused on showing how open communication predicts outcomes such as distress, adjustment, and relational satisfaction, but the specific contours of communication are seldom specified (Goldsmith, Miller, & Caughlin, 2008). In this study, we map these contours, describing how couples report talking about one person's cancer. Based on qualitative analysis of in-depth interviews with patients and partners, we propose that openness, frequency, difficulty, topical focus, and argument are meaningful and conceptually distinct dimensions of couple talk. We also show why we should assess these dimensions for particular cancer-related topics rather than generalizing about "cancer-related" communication.

This descriptive, conceptual work has both practical and theoretical significance. Kreps and Rutten (2011) defined the goal of cancer communication research as "conveying relevant health information to targeted audiences who confront cancer," including cancer patients/survivors and their supporters (p. 315). If we wish to advise couples to talk, we need to know what they should talk about and how. Descriptive conceptual work also contributes to

sound measurement and is essential to developing theories that explain how and why couple communication facilitates coping with cancer.

# Concepts and Measures in Previous Research

We surveyed how couple communication has been conceptualized and operationalized in previous research by searching Communication and Mass Media Complete, PsycINFO, Medline, and Cumulative Index to Nursing and Allied Health Literature data bases through July 2011 using various combinations of the search terms cancer, communication, social support, marital, spouse, and partner. We located 46 studies on the effects of open cancer communication between partners. Few of these studies discussed how communication was conceptualized or specified why particular facets should be linked with particular outcomes. Communication was usually seen as a way for partners to engage in social support and sense-making (cf. Manne & Badr, 2008) or to adjust to a terminal diagnosis. However, most studies assumed a general measure of communication would encompass whatever processes might be responsible for good outcomes (e.g., if they are talking frequently, then sense-making must be happening). Although researchers gave similar rationales for studying communication (i.e., support and sense-making), they varied considerably in what they measured and seldom justified why a particular measure was a good conceptual choice. We identified six different ways of measuring communication between partners. A complete list of studies and measures is available from the first author.<sup>1</sup>

One type of measure tapped a global, abstract perception that couple communication was open. Many of these studies used subscales or items from well-known, validated scales (e.g., the Family Environment Scale, COPE inventory). Items asked for general impressions of communication, such as, "Have you been able to talk about your feelings and problems with

<sup>&</sup>lt;sup>1</sup> https://college.lclark.edu/faculty/members/daena\_goldsmith/selected\_publications.php.

your spouse or partner in the last 2 weeks?" "We say anything we want to around home," and "I take time to express my emotions." These measures were not specific to talk about cancer.

A second type of measure asked for abstract perceptions of communication about cancer, such as "I frequently discuss my illness with my spouse," or "My spouse wants to know the truth about my illness." Conversely, a third category of measures focused on a global sense of constraint, difficulty, or avoidance in discussing cancer, using items such as "My partner doesn't like me to talk about my problems," and "My wife and I had difficulty talking about the cancer and what might happen."

A fourth approach examined communication as part of relational coping, as conceptualized by Coyne, Ellard, and Smith (1990). Active engagement referred to coping with the illness and with one's own and one's partner's distress by engaging in problem-solving; measures included statements about understanding and not feeling alone, as well as items that tapped communication, such as "My partner tries to discuss it with me openly." Protective buffering involved coping by hiding concerns and worries, concealing negative information, giving in to avoid argument, and trying to keep the other from thinking about the illness (items included statements that "my partner just waves my worries aside," or "my partner tries to hide his or her worries about me").

The fifth measurement strategy coded openness from the observed frequency of self-disclosure in a laboratory conversation between partners. Self-disclosure entailed statements about one's own thoughts, feelings, experiences, wishes, or beliefs. Coding categories focused on how frequently patients and partners engaged in self-disclosure or confronted the illness.

The final sort of study solicited self-reports of how frequently or easily couples talked about specific topics. In some studies, an interviewer asked whether a couple had discussed a

patient's recurrence or terminal prognosis and the interviewer or a coder rated the degree to which that topic had been disclosed openly. Other studies used questionnaire items on the perceived difficulty, frequency, disclosure, or avoidance of talk about specific topics such as death, health care, or sexuality.

There are several problems with the lack of explicit attention to conceptualizing communication and with the variability in how it is measured. First, measures that ask general, abstract questions about communication are likely to be tapping into relational and cultural schemas rather than actual patterns of communication. For research participants whose culture values communication (as has been documented for the US by Afifi, Caughlin, & Afif, 2007; Katriel & Philipsen, 1981), this cultural preference provides a readily available heuristic. If culturally ideal relationships entail communication, and the respondent is satisfied in his or her relationship, then he or she may conclude "we can talk about anything" or "there's nothing we cannot discuss." What appears to be a measure of communication might actually reflect relational satisfaction. General, abstract questions about one's relationship tap into these heuristics more readily than questions that focus attention on particulars (Huston & Robins, 1982). In fact, there is empirical evidence that respondents who say they are open in response to global or evaluative questions will go on to reveal withholding or communicating with caution when asked about particular cancer-related topics (Caughlin, Mikcuki-Enyart, Middleton, Stone, & Brown, 2011; Goldsmith & Domann-Scholz, in press; Hinton, 1998).

Second, even measures that are specific to cancer communication fail to draw potentially important distinctions. For example, asking if one *could* talk about cancer does not necessarily show that talk *does* occur. The degree of agreement with a statement such as, "My partner tries to discuss it with me openly" provides different information than response options that measure

frequency (e.g., never, once, a few times, etc.). "Talking about cancer" may be distinct from talking about one's *feelings* about cancer. Different measures emphasize different facets of communication and some combine items that reflect multiple dimensions.

Third, we question whether it is reasonable to ask respondents to generalize about all cancer-related topics. Some topics, such as death or sexual side effects of treatment, are especially difficult to discuss (Goldsmith et al., 2008). When asked whether or how frequently they talk about cancer, should a participant interpret this to mean just medically-oriented issues such as treatment and prognosis or should he or she generalize across medical, personal, relational, and existential facets of the experience? If a respondent has talked openly about treatment but has not addressed other issues, how should he or she aggregate experience in response to a question about openness or constraint regarding "cancer-related topics"?

Our review of previous research revealed a need for better description of what couples discuss when they talk about cancer, how couples talk about cancer, and whether they talk in similar ways about different topics. These three questions framed our investigation:

RQ1: What topics do patients and partners consider part of "talking about cancer"?

The following topics have been included in previous research: treatment decision-making; side effects and symptoms; uncertainty; changes in everyday life and activities; financial or employment difficulties; coming to terms with cancer; feeling like a different person; changes in marriage/relationship; caregiving burdens or inequalities; physical attractiveness, and sex/expressing intimacy. We examined whether additional topics emerged when participants had an opportunity to describe their conversations in response to open-ended questions.

RQ2: What dimensions describe meaningful variation in how couples talk?

If we move away from abstract, general concepts and measures, what might be useful alternative

ways of characterizing conversations? Previous research suggested some dimensions, including how often couples talk, how difficult it is to talk, whether talk is constrained or information withheld, and whether feelings are discussed. We probed these issues to see whether our participants saw them as meaningful and to see what other facets of talk were important to them.

RQ3: Do participants talk in similar ways about different topics?

Five of the six types of measurement we identified generalize across cancer-related topics. If the topics we uncover in RQ1 vary along the dimensions we discover in RQ2, this points to a need for measures that differentiate among topics rather than asking participants to report about how they "talk about cancer" or presuming that a single observed conversation represents all topics.

#### Method

Couple communication entails not only behavior (e.g., self-disclosing thoughts, feelings, or experiences) but also a participants' judgment about whether he or she withheld important thoughts, feelings, or experiences. For example, observing a patient saying, "I'm frustrated that we can't get test results sooner" reveals a personal feeling, but unless we ask, we cannot know if it also conceals the speaker's feeling of panic about possible metastasis or deflects talk from the speaker's doubts about choosing the right treatment. We conducted interviews because they can yield insight into what individuals do not wish to disclose to their partner. It also allowed us to ask about a wide range of topics rather than presuming that a single laboratory conversation on one topic represents all of a couple's interactions (Noller & Feeney, 2004). Questionnaires might have facilitated a larger sample, but interviews allowed us to probe individuals' interpretations of and reasons for communication and even to gently challenge assertions that might reflect global heuristics rather than conversational patterns.

We employed maximum variation sampling (Lindlof & Taylor, 2002; Patton, 2002) to

obtain participants with varying gender, age, occupation, relational length, and type and stage of cancer (see Table 1). All had been treated for cancer in the past 5 years or were in a committed partnership with someone who had. Participants lived in or near a mid-sized Midwestern university community with a major regional cancer treatment center where flyers describing the study were posted and given to all newly diagnosed patients. We also advertised in a newsletter for university employees. Our sample is not without limitations. It is racially homogeneous and fairly well educated. Most patients had early stage cancer but we did have variation in stage and type of cancer. This enabled us to capture a range of treatments, decisions, and partner roles; yet different forms and stages may pose distinct challenges that we could not explore systematically.

We conducted 60-90 minute semi-structured interviews in a location of the participant's choosing, either a private university office or the participant's home. Interviews were tape recorded. When both members of a couple participated, interviews were conducted separately with different interviewers. The interviews began by asking about topics that were relatively easy to discuss, difficult to talk about, and sources of conflict. For each topic they identified, we followed up with probing question about the nature and meaning of their communication. After soliciting topics in an open-ended fashion, we showed participants the list of twelve topics we derived from previous research and asked if there were any additional topics from that list that they wished to discuss with us. Following the interview, they completed standardized measures of relational perceptions and well-being. We transcribed interviews verbatim and checked transcripts to ensure accuracy, assign pseudonyms, and obscure identifying information.

University and hospital Institutional Review Boards approved our procedures.

We used a concurrent mixed method design (Cresswell, 2003) that combined qualitative and quantitative analysis. We used qualitative methods to discern if topics and features from

previous research were relevant, how they were manifested in this particular context, and what new categories emerged (Patton, 2002). We began by segmenting transcripts into the various topics a participant discussed, utilizing topics from previous research and adding new categories as needed. We selected six transcripts that represented varying types of participants and identified topics and features of communication that were salient to respondents and resonant with previous findings and theory. For each topic a participant discussed, we developed narrative memos (Strauss & Corbin, 1998) about communication. Next, we identified preliminary concepts and categories from our memos (e.g., variation in frequency of talk about a topic was a concept that could be described using categories such as "occasionally when an episode arises," or "frequently until resolved"). These concepts and categories were tested against additional transcripts until no new concepts or categories emerged.

We then engaged in data transformation (Cresswell, 2003). Using our qualitatively derived concepts and categories, we developed a profile for each participant. We reached initial profiles independently, noting the line numbers and rationale for each categorization. We met daily to compare interpretations and arrive at a categorization of each feature for each topic mentioned by each participant (e.g., for treatment-decision making, this participant communicated with ease; talked frequently, until a decision or resolution was reached; focused on facts more than feelings, etc). We assigned numerical values to categorizations for the sole purpose of detecting patterns across participants and topics; for example, by ascribing a "1" to talk that was easy and a "2" to talk that was hard, we could calculate a mean and standard deviation across topics for a participant or across participants for various topics. Our consensual coding procedure (Brusilovskiy, Mitstifer, & Salzer, 2009; Russell, 2000) is consistent with our goal of developing a contextualized profile of communication about a topic, rather than a

decontextualized application of objective codes; consequently, appropriate standards for evaluating the rigor of our method are dependability and confirmability (Baxter & Babbie, 2004). We achieved dependability by using systematic procedures and documenting our decisions in daily meetings. We ensured confirmability by linking each attribute we categorized to specific passages of the interview and by triangulating our interpretations.

Finally, we returned to analysis of each participants' entire interview for interpretations and illustrations of the numerical patterns we had detected (Stewart & Cole, 2007).

### Results

Topics of Talk

In response to RQ1, we identified 16 cancer-related topics that appeared in more than one interview (see Table 2). To the twelve topics from previous research, we added four: coping and communication, diagnosis, how to communicate with others outside the primary relationship, and feelings. On average, participants described 6.43 topics (SD = 2.19, range = 2 to 12 topics). *Dimensions of Talk* 

RQ2 asked what dimensions of talk were meaningful to participants. We identified five dimensions (Table 3) and for each, developed subcategories to capture variability. We assigned numerical values to these subcategories so that we could detect patterns across topics, across participants, and amongst features.

Openness did matter to participants. Our index of openness was based on what participants told us about their conversations, rather than on abstract, general statements that may have more to do with what a person valued or with a desire to give a positive self-presentation (Goldsmith & Domann-Scholz, in press). We asked couples to tell us about topics they did discuss as well as those they didn't and why. We also probed whether participants ever felt they

were holding back when they talked. Participants who said they had not talked about a topic included those who felt talk was unnecessary because they knew how the other person felt as well as those who noticed or thought about an issue but consciously chose not to talk. Another form of not talking occurred when both partners had a concern but each waited for the other to bring it up, so it had not been discussed. Topics that we characterized as discussed freely also took a range of forms. Many participants described how having a physician describe treatments and give a deadline for a decision created an urgency to explore all possible options, consequences, and scenarios. Sometimes participants acknowledged that a topic was difficult to discuss but said they had talked anyway. They characterized their talk using terms such as direct, outright, blunt, honest, matter of fact, or straightforward. We also found many forms of restrained talk that fell between absence and free discussion. Participants might speak indirectly or they might be careful about what they said, how they said it, and when they brought it up, a feeling one described as "like I'm always treading on thin ice." Participants tried not to bring a topic up too often or in too much depth. They talked "to an extent," telling some of what they knew or felt but not all, or they said only as much as was needed or known at that time. Some couples had tried to discuss a topic, but explicitly decided not to bring it up again.

**Difficulty** was a second feature of talk. We asked couples to tell us what topics were **easy** for them to discuss and what topics were **hard** to discuss and we probed for what made topics more or less difficult. Some topics that were discussed freely also came easily. For example, many couples said that having to make a decision about treatment compelled discussion of the options. Likewise, the day-to-day process of going through treatment frequently brought up talk about logistics or coping with side effects. In contrast, many participants said it was so hard to talk about what would happen to their children if the cancer proved terminal that they did not

discuss it for fear of upsetting one another. However, difficult topics were not always avoided.

Although the two categories are admittedly crude, we noted which topics participants said were easy and which they said were hard.

For each topic participants mentioned, we asked about the **frequency** of talk. Their answers revealed a variety of ways that talk might unfold over time. For instance, many couples said treatment options dominated their conversations during the period when they were making a decision. Other topics were discussed occasionally, as an episode arose. For example, Judith and her husband discussed side effects of her treatment "just kind of on an as needed basis. You know, he would notice a lot of hair in the waste basket." In contrast to topics that came up when prompted by some episode, coming to terms with cancer or feeling like a different person were recurring topics that continued to come up even after treatment ended. Among the topics that were discussed least often were diagnosis, death, coping and communication, and telling other people. In some cases, participants felt that one conversation was sufficient to reach a resolution. Other issues were discussed infrequently because they were emotionally intense.

On any topic, a wide range of issues could be discussed; **topical focus** captured the emphasis in a conversation. Previous research suggested the significance of talking about **facts** as well as feelings and we added three additional distinctions: **medical/personal, concrete details/big picture,** and **now/future**. Many participants said focusing on medical issues provided a respite from contemplating what cancer meant for them personally. Likewise, focusing on concrete details of treatment or caregiving gave participants an ability to feel in control and to support one another when the big picture was uncertain or overwhelming. A final distinction concerned sticking to what is happening now versus contemplating the future. Participants sometimes postponed talking about prognosis until they received bad news.

Alternatively, conversation might focus on positive events in the future or resuming valued activities rather than present discomfort. We categorized participants according to whether talk on a topic emphasized one or the other end of each of these continua or included aspects of both.

We asked participants if any cancer-related topics were a source of conflict.

**Disagreement** was particularly challenging and verbally expressing it in an argument was rare. Some partners reported feeling caught in a bind when they disagreed with the patient's preferred treatment option yet wished to honor the patient's right to choose what to do with his or her own body. Another type of disagreement emerged when patients wished to maintain or resume work activities and protective partners feared they might overdo. Couples could also have different interpretations of prognostic information.

We explored whether the features of communication we profiled contributed unique information about a conversation or whether they were highly correlated. We aggregated each participant's score across topics to create an overall average for openness, frequency, difficulty, topical focus, and disagreement. In addition to exploring correlations among these attributes, we also examined their association with a measure of marital satisfaction completed prior to the interview (the Marital Opinion Questionnaire, MOQ, Huston, McHale, & Crouter, 1986) and a five-point question about satisfaction with communication administered orally for each topic in the interview and averaged across all topics. We ran correlations separately for patients and partners because they may have different experiences and also because some, but not all, of the patients and partners in our sample were couples. Pearson *r* correlations are shown in Table 4.

With a few exceptions, openness, difficulty, frequency, topical focus, and disagreement were not so strongly correlated as to suggest that they are part of some single, overarching construct (i.e., openness). For example, openness, frequency, and difficulty are not strongly

related, nor are they significantly correlated with many of the focus variables. This is desirable insofar as the different dimensions appear to tap distinct features of communication rather than providing redundant information. Whereas previous abstract, global measures of openness might be proxies for feeling satisfied with one's partner, our five dimensions appear to be relatively independent of marital satisfaction and communication satisfaction. The one exception was that for partners, difficulty of communication was significantly correlated with marital satisfaction.

An exception to the pattern of low intercorrelations occurs among the topical focus measures. For patients, talking about feelings, personal issues, the big picture, and the future are sufficiently intercorrelated to treat as an index with reasonable reliability (alpha = .71). However, for partners, only two ratings (talking about feelings and personal matters) are strongly intercorrelated (alpha = .75). Moreover, patient and partner reports of talking about the big picture have a different pattern of correlation with argument, communication satisfaction and relational satisfaction. There are also patient-partner differences in the intercorrelations between marital satisfaction and various dimensions of communication, suggesting that patients and partners may have different experiences of talking about cancer-related topics.

Variation in Talk about Different Topics

RQ3 explored the plausibility of asking individuals to give a generalized report of how they talk about "cancer related topics." The **average across participants for each topic** tells us if some topics tend to be discussed more freely, more often, more easily, and so on. Examining **values across topics for each participant** tells us, for example, if the same individual is equally restrained about all sorts of topics or he or she tends to speak freely about some topics, carefully about other topics, and not at all about some topics.

Patterns by Topic Across Participant. We calculated the mean or mode for each

dimension averaged across participants for each topic. A table with this data is available from the first author.<sup>2</sup> This enabled us to observe the following patterns.

Some topics tended to be discussed easily and openly. Treatment decision-making was the topic discussed most openly and frequently; however, these conversations focused primarily on facts, medical aspects, and concrete details. Other topics that were discussed openly and easily included coping and communication, appearance, diagnosis, and telling others. In contrast to treatment talk, these topics tended to be discussed just once (usually because that was all it took to reach a conclusion) and talk was more likely to include both facts and feelings, medical and personal aspects. Talking about living life fully tended to be easy and open, with far ranging discussion that included facts, feelings, medical, personal, concrete, big picture, now and future aspects. These conversations happened occasionally, as some episode raised the issue.

Sex and death were the most challenging topics. Death was the most difficult topic to discuss and was usually addressed just once. Talk about death was moderately open; spanned facts, feelings, medical, and personal aspects; and was oriented toward the future and the big picture. Although it was also difficult to talk about sex, these conversations were fairly open and occurred occasionally as some episode made it relevant. Talk about sex tended to focus on feelings and on concrete and personal issues. It also focused on the future: for example, couples might look forward to resuming their sex life after treatment. For prostate cancer patients, sex talk included how they would handle impotence as a possible side effect of surgery. "Feelings" as a distinct topic (e.g., depression or suicidal thoughts, rather than one's feelings about some other issue) was the topic discussed least openly, but too few participants reported this topic and gave too little detail for us to systematically rate openness or frequency.

<sup>&</sup>lt;sup>2</sup> https://college.lclark.edu/faculty/members/daena\_goldsmith/selected\_publications.php.

Work and finances, side effects and symptoms, changes to everyday life and activities, changes in identity, uncertainty, and burdens and inequalities were topics that came up occasionally as an episode arose and inspired moderately open talk that was also moderately difficult. Participants tended to have concrete, present-focused discussions about these topics and incorporated personal aspects and feelings. Some of these topics (burdens and inequalities, changes in identity, changes in everyday life and activities) were sources of disagreement and this might account for why they were perceived as difficult and discussed with caution.

Few topics consistently generated disagreement: the modal category for all but one topic was "does not appear to be any disagreement to express." Only for the telling others topic was the modal response "disagree and express it, but do not argue." When it did occur, disagreement was usually about coping or ongoing changes—to everyday life, to identity, and to burdens and inequalities. However, even when they disagreed, couples tended to avoid arguing. Couples least often experienced disagreement about diagnosis or the desire to live life fully.

Despite variability in how they approached different topics, participants tended to be very satisfied with their communication. The overall average across all topics is 4.27 on a 5-point scale and for nearly half of the topics, mean satisfaction was greater than 4. Only feelings and burdens and inequalities had means that corresponded to less than satisfied.

Patterns by Participant Across Topics. Rarely did an individual speak the same way about all topics. For openness, 16 respondents (45.7%) described conversations in all three categories (i.e., on some topics they talked freely, on some they talked cautiously, and on some they did not talk) and fifteen (42.9%) described conversations in two categories. Only four (11.4%) reported conversations that consistently fell in only one category. Twenty-two participants (61.1%) reported three or more different frequencies of talk; the most common pattern was one in which

some topics were discussed once or a few times, some were discussed occasionally as an episode arose, and some were recurring topics. Nearly all of our respondents reported that some topics were easy to discuss whereas others were difficult; only two (5.7%) classified all of the topics they reported as being easy to discuss. Only one respondent's conversations were always factual and focused on medical aspects of cancer and one other respondent had conversations that were always future focused. For the rest of our participants, focus was different for different topics. Five participants (14.3%) had no apparent disagreement about cancer related topics; all other participants had a range of degrees of disagreement for different topics.

Participant Reports of Change Over Time and Difference Between Partners. We noticed that participants sometimes remarked how their talk had changed over time or how one person in the relationship communicated differently from the other. For each topic participants described to us, we made a judgment as to whether their communication had changed over time and whether patient and partner adopted different ways of communicating about the topic (e.g., one person did most of the talking or one person was more emotional than the other).

The way participants talked about a particular topic could change over time. This was most likely to happen for the topics coping and communication (45.45 percent said their talk had changed), death (44.44 percent), identity (40 percent), and uncertainty (38.46 percent). Talk about coping changed as stresses changed. Likewise, couples' level of uncertainty or fears about death might change, with corresponding changes in talk. Several couples reported waiting to discuss fears until after a crisis had passed. In contrast to concerns that dissipated over time, some concerns only became apparent over time, either because it became clear that cancer would be terminal or because long-term ramifications of treatment were only evident after it was over.

Nearly a third (30.91 percent) of participants perceived differences between how they

talked and how their partner talked. All participants who described talk about work and finances perceived that there were differences. For example, some partners refrained from telling a patient about their stresses at work. Half of the participants who described talk about treatment decision making perceived differences in how they talked compared to how their partner talked. Even partners who were very involved in seeking information expressed a concern that the final decision belonged to the patient (Goldsmith & Moriarty, 2008) and this could result in communication differences. Patient-partner differences also came up around the topic of sex. *Interpreting Patterns through Participant Accounts* 

A strength of a concurrent mixed method design is the ability to return to our transcripts for a deeper understanding of quantitative patterns. The following cases illustrate how and why a multi-topic, multi-dimensional approach to couple talk captures important differences among individuals and across topics that would otherwise be glossed over by measures that ask respondents to report a general perception of open communication across cancer-related topics.

Kathy and Joe. When Kathy was first diagnosed with lymphoma, she and Joe talked frequently, easily, and without restraint about her options for treatment. She had an unusual form of lymphoma and it was challenging for them to find information. Each spent time searching on the internet and talking to others. Joe said, it "was very easy to talk to because we were kind of like a team...she would look at times for things and then I would look at times for things and then we would compare notes." During that period of time, he estimated that they talked "probably hourly...at least daily or more often than that early on." Kathy explained, "For about a month solid, that was what our life was. Every day it was on your mind." Each reported, "we're pretty open with each other" (Joe) and "we pretty much talk about everything" (Kathy).

Now that Kathy's treatment is complete, she goes back periodically for CAT scans to

determine if cancer has recurred. An upcoming appointment will prompt conversation about her cancer, including whether her decision to forego radiation was a good one and whether her cancer has returned. Joe described these conversations:

I'll say, "You're worried about the test aren't you?" "Yes, I'm worried about that." "So, you know, we can't do anything until they find it and they think that they got it all." "Yes, but I'm still worrying." "I understand."

He says these conversations "are not really in-depth" and that following a brief exchange, he "may do something to get her mind off of it" even though he knows she'll continue to worry: "It'll always be there." He struggles because:

I don't have any words to say to make that fear subside...What do I say? What can I say? I'm wrestling trying to find a word or something that may be profound enough to make a difference and I can't find it, it's not there.

He feels that, "all I can do is just be there and hold her hand once in a while or give her a hug or give her a kiss. It's hard." He also wishes to avoid feeling upset until or unless they receive bad news. "[W]e don't necessarily want to talk about that a lot...it's like you're tempting fate if you talk about it a lot." They do still talk but in less depth. The focus has shifted from medical facts in the present to personal feelings about the future, the frequency is episodic, and the conversations are difficult. Their talk shows how couples can have quite different patterns of communication on different topics and at different times.

Mike and Judith also perceived their communication was open. Mike concluded, "overall we've had very good open conversation," and Judith said they had talked openly about "all of it. We had an understanding early on that we would be honest with one another." Yet their careful recurring conversations about treatment differed from the teamwork described by Joe and Kathy.

Eleven years after Judith was treated for breast cancer, she returned to her primary care physician complaining of shoulder pain. Mike, a radiologist at the hospital where Judith was treated, accompanied her. As soon as the doctor showed them Judith's x-ray, Mike said he knew:

Oh my God, you know, this is not good. I did not say, "What's the likelihood of recovering from this or any kind of long-term?" And mainly I was probably going through the thought, "Oh my God, you've only got a very short time." You know, did I share that? No. Right away? No. No, it was a long time before we were able to discuss the probability of a shortened life.

The next day, another radiologist confirmed a diagnosis of bone cancer and Mike came home to deliver the news to Judith. She recalled:

...he just said, you know, "Dr. So and So has read films and the news is not good." And I said, "What?" And he said, "It's cancer." And at that point I stood up and walked out of the room, but I had fractures and a thin breastbone and it hurt to cry and that is all I could say. He came up behind me and put his arms around me and that was all I could say is, "It hurts to cry." There was nothing else.

In contrast to Joe and Kathy's extensive discussions about treatment options, Mike had already made arrangements with Judith's primary care physician for stronger pain relief medication and an appointment with oncology for the next day. He described their conversation as follows:

So immediately...here's the facts and then it became very emotional and then it's a body language. It's a presence of saying, "Hey, I'm here with you to fight it." . . . And it was probably like for that for a couple days. There wasn't a lot of discussion, other than, "Okay, when's your med onc appointment?" It was the very next day. "When was your rad onc?" Very next day. We didn't want to waste any time. We are not going to sit and

brood over this for a couple of days. We've got to do what we've got to do.

For Judith and Mike, it was difficult to disconnect talk about treatment from fears for her future.

Both were aware that this time, treatment was unlikely to accomplish more than just buying time.

Treatment talk was brief and instrumental, focused on present concrete details. Talk about any cancer-related topic raised the specter of death, and neither Mike nor Judith saw much point in dwelling on that. When talk did venture to personal feelings or the future, Judith reported several constraints on their conversation. They could talk about anything but she said "timing was critical...I had to pick my moment." Mike also found it extremely difficult to interact if she

Sandra and Mary spoke to us in the midst of Mary's treatment for early stage ovarian cancer. Several years earlier, Sandra had been treated for breast cancer. Mary said that, as a result, "I don't know that there is anything that's not terribly easy to talk about!" She also felt that "we communicate well to start with and you know we just we're able to bring those good skills to this." Sandra agreed that "we're both pretty communicative," though she added, "feelings (pause) I'm not so sure." They were one of the few couples who argued—about upholding high standards for housework when Mary was exhausted by chemotherapy—yet Sandra also reported other disagreements that she had expressed cautiously or withheld.

started crying and Judith said that if she started to cry, "he would ask me to try not to do that."

From the moment Mary returned from the doctor with news of probable ovarian cancer, the two had a different take on things. In those first few days, Sandra reported saying to their friends, "Mary's been diagnosed with ovarian cancer," and having Mary correct her: "Well we don't know for sure." Sandra said, "It felt like everything was just gonna be suspended until we knew" and Mary discouraged talking about the big picture, saying "let's just not go there" until they knew the results. Together they gathered information about treatment options. According to

Sandra, Mary wanted to receive treatment near home and scheduled surgery to occur in a few days but Sandra's research stressed the survival advantage of seeing a gynecological oncologist (which meant travel to a larger city three hours away). When Sandra raised this with Mary, "she responded to my pressure by saying, 'just don't bug me about it." Sandra found a book at a local bookstore and it also recommended seeing a gynecological oncologist:

[I]t had just the right balance of expert advice and interviews with people...I got the book and I left it in the living room and I said something like, "I got this book for me because I don't know much about ovarian cancer but if you want to read it, you can."

Mary did read the book, decided to cancel her local surgery, and sought a referral to a specialist instead. Said Sandra, "then it didn't feel like tension, it felt like we were both on the same side. Now when we're talking she'll say, 'WE got this book'...I say nothing." The urgency Sandra felt about changing Mary's mind came from her greatest fear—losing Mary—yet she also respected Mary's right to make her own decision. Sandra concealed her fears and the tension she felt by her indirect strategy of getting into Mary's hands a book she felt sure would persuade her.

In contrast, Mary recalled teamwork in discussing and deciding on treatment:

The gynecologist scheduled me for surgery the following Friday. And then we went home sort of shell shocked having signed the consent forms ... and I started to do some research on the Internet, Sandra went to a book store and came home with the definitive five hundred page book on self help guide for ovarian cancer and as we both were trying to take in as much information as we could from various sources. That's when we saw that everything said, every reputable source we could find said that the one factor that made a difference in the survival rate outcome of ovarian cancer was whether or not you

saw a gynecologic oncologist for your treatment. ... So then in fairly short order, we put the brakes on having the operation done Friday here.

Mary agreed that talking about treatment decisions had been difficult but she attributed that to the pressure of having to decide in a short time rather than to disagreement. She recognized that Sandra was instrumental in deciding to seek treatment elsewhere, but she framed this not as an agonizing tension but simply as a difference in temperament that served them well:

I'm the kind of person who, I want to make my decision and it's made and just move forward...[Sandra]'s going to keep gathering information, keep rearranging the pieces...that could drive a couple crazy, but we've sort of learned to see that as a strength...[she] gave me the courage to keep changing my mind.

Seeking treatment elsewhere had created another source of ongoing tension. Traveling together every three weeks for Mary's chemotherapy was creating difficulties for Sandra at work, yet she felt constrained from saying much. "I don't really see that there's been any choice about it," she says, so that although "there's a certain amount of tension there...it doesn't feel like there's that much to say." Despite Sandra's perception that she had held back from expressing her stress, Mary was well aware of it. When they did talk about traveling, Sandra characterized it as "pretty instrumental": the logistics of making hotel reservations, which route to take to the hospital, where to eat, and where to park.

Sandra and Mary illustrate several nuances of open communication. Each found it stressful to talk about treatment options, though for different reasons. Mary's perception of a team effort under time pressure was sustained by Sandra's indirect means of resolving disagreement. Even so, Mary recognized their different orientations to decision-making. The daily challenges of housework and travel for treatment also created tension—one, they argued

about, the other went unspoken, even though both were well aware of the difficulties.

Anita and James said there was nothing related to James' prostate cancer that they could not discuss. James said they had "pretty straightforward and fairly efficient conversation—neither one of us are emotional talkers and neither one of us are talkers for talking's sake." This translated into a fairly rapid decision about treatment and a postponing of talk about possible side effects until it became necessary to address them.

James and Anita heard the news of his diagnosis together in the doctor's office, where the doctor reviewed three treatment options, then recommended surgery. James reported "I took the kind of immediate emotional approach and said, 'let's cut it out, let's get rid of it,'" whereas Anita "took the more analytical approach." After they left the doctor's office, she talked to friends who had gone through this and read a book they recommended. She said James "didn't really want to read any of the books...he kinda wanted to know as things were happening, and so I would read the books and say, 'you wanna know about the side effects?' 'well, no not really.'" She ended up agreeing that surgery was the best option and they met with a surgeon. James observed that the surgeon, "gave us our agenda for the things that we really needed to think about and talk about...that made it easier, because we didn't have to create the agenda for the conversation." Anita agreed that "the mechanical stuff is very easy to discuss" and that doctors model communication when they "go into mechanical mode": "You make certain decisions.

Will I have an operation, yes or no? What did they say were the pros and cons? What did he say were the possible side effects? What does the little book say?"

Both James and Anita were concerned about whether he would experience incontinence and impotence after surgery. Anita said that although these were "real central" concerns, she did not discuss them with James:

I thought about this, you know, a lot of identity is tied up in that self image...so it's difficult because of what it could mean and what one would need to deal with, and not simply in terms of like plumbing, but in terms of self image. . . that would be the difficult part, I think, of trying to figure out how to best talk about that without adding insult to injury.

James did have identity concerns but he perceived that Anita "was much more worried about my health than what it might mean to our sex life or the fact that she may have a husband who pees in his pants all the time." Nonverbal communication was their primary way of communicating concern and support. What talk occurred involved brief comments in response to some event. For example, James reported that before surgery, "we'd be in bed and it would be something like, 'well, let's hope we can continue to do this after the surgery" or "we'd see a Viagra commercial on TV and she would say something like, 'You know, you won't have to do that!" He acknowledged, "in all honesty, I don't know if Anita had uncertainty at that point or not…she was very supportive of the decision that I made." For her part, Anita said:

There's things that I knew were possible side effects that I didn't talk about with him in part because I don't think he wanted to dwell on them...I knew what the possibilities were, but I also knew that it might not happen and therefore it might not be something to talk about ahead of time.

Their uncertainties were resolved six weeks after surgery when James emerged from the shower and announced, "I had an erection in the shower" to which Anita replied, "Yeah! This is great!"

James and Anita perceived their communication was open based on the efficient and straightforward way they talked through "mechanical" issues and because they felt comfortable with different orientations to information seeking and decision-making. When it came to issues

that went beyond "plumbing," however, their communication occurred through occasional, brief verbal references and plenty of nonverbal affection and support. They felt sure they would be able to talk if James were incontinent or impotent, but since he did not experience those side effects, this was never tested.

# **Conclusions and Implications**

Simply asking people how they talk about cancer may obscure more than it reveals. "Topics related to your cancer" covers a broad array of issues, ranging from negotiating changes in everyday life to making sense of cancer and how to live life fully. It encompasses instrumental talk about diagnosis and treatment decision-making as well as personal questions about one's self image and concerns about relational equity and sexual intimacy. It includes deciding right away who to tell about cancer (and how) as well as longer term matters related to death. Individuals seldom talked the same way across topics and some participants reported that their talk changed over time or differed between partners.

Open communication *was* a salient issue for our participants but it took varied forms. For example, Kathy, Joe, Mike, Judith, Sandra, Mary, Anita, and James each asserted that they were "open" in language that bore a striking resemblance to the general, abstract measures that have been used in previous research. Yet focusing only on global "openness" told us little about *how* these couples talked. Some open discussions occurred because it was easy to talk; others happened despite considerable reluctance or difficulty. Treatment decision-making might be discussed frequently and openly for a time whereas death might only be discussed once and even then, discussed with some care and constraint. Some topics came up just once not because they were difficult but because the issue was resolved in a single conversation. Sense-making and identity came up over and over, but tended to be handled with care when they did come up. Even

discussions about treatment were quite different, depending on whether a couple emphasized medical facts and present concrete details or the personal feelings, big picture meanings, and implications for the future. For any topic, it mattered whether or not there was disagreement and if it was expressed in the form of arguing. Most previous research on "openness" has not differentiated among these dimensions, nor considered the possibility that talk varies by topic. Listening to our participants' accounts made clear that different configurations of these topics and dimensions created qualitatively different experiences of communication.

Based on our findings, we question the validity of measures that ask general, abstract questions about how openly couples communicate about cancer-related topics. With so much variability from one topic to the next, general questions require of our research participants some unknown mental calculations. Does one call to mind all topics and derive some average rating? Does one zero in on the most recent, or most salient, or most negative conversation and give a rating based on that? We suspect the complexity of the task and the generality of the question lead respondents to use cultural and cognitive heuristics rather than recalling and aggregating information about specific conversations. Our findings also raise questions about generalizing how couples communicate from observation of a single laboratory conversation about a single topic. There are likely other topics that are not discussed and topics that are handled in a different way; an open discussion in the lab about treatment does not guarantee an equally open discussion at home about death and a careful conversation about uncertainty today does not mean the couple cannot speak freely on another occasion about living life fully.

Our findings point to needed revisions in dominant measurement approaches. Openness, frequency, difficulty, topical focus, and disagreement are conceptually distinct facets of how couples talk. Measures must include explicit instructions as to whether respondents should focus

on the present or some other time period and should either instruct the respondent to focus on his or her own communication or give the opportunity to report separately on perceptions of own and partner styles. If a general measure of communication about all cancer-related topics is desired, the researcher should aggregate scores obtained for ratings of specific topics (see, for example, Donovan-Kicken, 2008; Manne, Badr, Zaider, Nelson & Kissane, 2010).

Is such an approach feasible? To measure all facets of talk for each topic taken singly from the past and present, own and partner's perspective would be a lengthy instrument indeed! We think there is even more than feasibility at stake in this realization. Is it theoretically reasonable to presume that couples' ways of talking about cancer are the same from topic to topic over time and between partners? Our findings suggest this is implausible and that we need to re-think how communication about cancer happens and through what processes it can enhance sense-making, support, or relational satisfaction. Do easy conversations prompted by the task of treatment decision-making have a different relational significance than difficult talk about sex or death? Do the salutary effects of openness diminish if individuals express uncontrollable loss, temporary uncertainty, or disagreement rather than controllable actions they can take to claim a hopeful prognosis? Can support and sense-making happen in a single conversation or do these functions need to unfold and recur in multiple interactions? Are couples who say they are open, but talk only infrequently and with great difficulty, candidates for professional support? Or do couples need to encounter hard truths in their own way and time, such that pushing disclosure prematurely would be counterproductive? Our sample and method do not afford firm answers to such questions but they provide a descriptive foundation for exploring this more nuanced view of how and why and when communication works.

Finally, our findings have implications for those who wish to advise couples about how

to communicate. Clinical advice frequently tells couples to communicate openly. For example, the American Cancer Society (2011) admonishes patients and their spouses or partners to "be direct with others and express your needs and feelings openly. It is usually more stressful to hide emotions than to express them. Sharing can be helpful both to you and those close to you." The website for Susan G. Komen for the Cure (2011) recommends: "Do not be afraid to talk about your feelings. You will find that if either of you hold your thoughts, worries and fears inside, they can create a wall between you and actually cause you to grow apart."

Few of our participants identified "feelings" as a relevant topic of talk *on its own*; those who did typically referred to thoughts of suicide or depression and said they were either careful about discussing this or avoided talking about it. This topic had the lowest satisfaction ratings of any topic. In contrast, how people *felt about* other topics happened more often, though some participants preferred to emphasize facts instead. Advice simply to "talk about your feelings" should give further guidance as to what that means and how to do that effectively, including how to incorporate feelings into discussions of other issues.

Our findings also point to some topics that may be particularly challenging for many people. For example, talking about burdens and inequalities emerged as a topic that was more difficult to discuss, less likely to be discussed freely, more likely to create argument, and less likely to be discussed satisfactorily. We can help couples by validating that cancer does impose burdens and inequalities, reassuring them that others also struggle with this topic, and then suggesting constructive ways to raise this specific issue. Acknowledging that some topics are difficult to discuss and presenting a range of ways couples may respond would be more useful than overly general prescriptions to "talk openly."

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Table 1.

Characteristics of Participants

Characteristic	Occurrence in our sample				
Sex	16 men (7 patients, 9 partners)				
	19 women (12 patients, 7 partners)				
Age	Range = $25 - 78$ years; M = $50.9$ years; SD = $10.8$ years				
Relationship type	29 opposite sex married				
	4 same sex committed partners				
	2 surviving spouses of patients who died recently				
Relationship length	Range = $1.3 - 50$ years; M = 25 years; SD = $11.55$ years				
Parental status	29 parents (11 of these had children under 18 living with them)				
Race	32 White				
	2 Hispanic				
	1 Asian				
Education	10 high school graduates				
(highest degree	7 college graduates				
earned)	18 held graduate degrees				
Occupations included	professionals, university faculty and staff, human resource professionals, engineers, sales people, homemakers, factory and blue collar workers, clerical staff, service industry managers, retirees				
Types of cancer included	breast, prostate, gynecological, colorectal, liver, skin, brain, bone marrow, leukemia, lymphoma				
Stages of cancer	16 early stage $(0-2)$				
	4 late stage (3-4)				
	15 did not give a stage				
Treatments	27 surgery				
received	13 radiation				
	18 chemotherapy				
	13 other medication				
	13 were undergoing treatment at the time of the interview				

Table 2.

Cancer-related Topics Participants Reported Discussing with Their Partners

Topic	Definition	Number	
		reporting	
Treatment decision-making	After diagnosis, deciding on what treatments to pursue. Can recur as treatment unfolds, new options arise, or cancer recurs.	33	
Sex	Includes sexual identity, desiring sex, having sex, not feeling sexy or attractive, and/or expressing intimacy in other ways.	21	
Death	Talk about prognosis and likelihood of death as well as talk about final arrangements or life without the person.	21	
Work & financial issues	Includes difficulties doing one's job, paying for treatment, insurance company hassles, quitting work.	19	
Side-effects & symptoms	Symptoms are results of cancer and may be discussed before or after diagnosis. Side effects are results of treatment, including those that occur during treatment as well as lasting side effects.	16	
Changes to everyday life & activities	Includes temporary changes during treatment (e.g., one person having to do more of the housework or child care) as well as longer term changes arising from side effects or poor prognosis.	16	
Uncertainty	The experience of not knowing what will happen and having to accept a degree of ambiguity.	14	
Coping & communication	How one or both persons cope with cancer, including how they communicate with one another about cancer-related issues.	12	
Appearance & body image	Feelings about one's body that are not sexual. Often related to treatment side effects such as hair loss, weight gain, or surgery.	10	
Diagnosis	Talk about diagnosis as distinct from treatment, including searching for cause of symptoms, determining if patient does have cancer, waiting for test results.	9	
Burdens or inequalities	How one person has to do more or make sacrifices because of the other's cancer.	8	
Telling others	How and how much to tell children, others in social network; when to tell, who to tell	7	
Changes to identity	Changes to who one is such as strong identification as a "cancer survivor," changing your personality or self-presentation, or feeling like a different person.	6	
Living life fully	Doing things one has always wanted to do or changing one's attitude toward life.	6	
Feelings	Feelings other than uncertainty such as depression or suicidal thoughts	5	
Making sense of cancer	Figuring out what it means to have cancer, as well as asking, "why me?"	4	

Table 3.

Dimensions of Talk about Cancer-related Topics

Dimension	Definition	Subcategories  Had not talked Restrained talk Discussed freely			
Openness	Degree to which couples spoke freely about topics perceived as important; feeling that one did not hold back				
Difficulty	How upsetting or challenging it was to initiate and sustain talk; how effortful it was; how much reluctance had to be overcome	Easy Hard			
Frequency	How often talk occurred and in what pattern over time	Once or just a few times Occasionally when an episode arose Some of the time Recurring Came up over and over Frequently until a resolution or decision was reached All the time			
Topical focus	The degree to which talk tended to emphasize or foreground one aspect of a topic and leave the other unspoken or presumed; talk could fall toward one end of a continua or could include both elements	Facts versus feelings Medical versus personal Concrete details versus big picture Now versus future			
Disagreement	Intensity and expression of disagreement	No disagreement to express Disagreed but not expressed to avoid arguing Disagreed and expresssed it but did not argue Argued about disagreement			

Table 4.

Correlations Among Dimensions of Communication and Satisfaction for Patients and Partners

						Patient					
		1	2	3	4	5	6	7	8	9	10
Partner	1		.28	.21	.36	.30	08	.20	12	.33	.14
	2	.15		.26	.25	26	.31	.42	10	13	.04
	3	.08	.22		.39	.27	.22	.35	19	.09	19
	4	.29	.09	.09		.63**	.27	.58**	10	25	26
	5	24	23	.18	.60*		.22	.22	18	19	29
	6	.24	.32	.17	.27	.11		.38	.28	24	19
	7	16	27	.06	26	.01	.30		.14	.05	.10
	8	51*	03	.30	.19	.53*	36	06		.09	17
	9	.39	19	15	06	19	.19	07	62*		.55*
	10	.35	07	45	23	36	.35	.28	81**	.66**	

Notes: 1 = Openness, 2 = Frequency, 3 = Difficulty, 4 = Focus on feelings v. facts, 5 = Focus on personal v. medical, 6 = Focus on big picture v. concrete details, 7 = Focus on future v. now, 8 = Disagreement, 9 = Satisfaction with Communication, 10 = Relational Satisfacton

<sup>\*</sup> p < .05, \*\* p < .01