Behind closed doors: How advanced cancer couples communicate at home

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Abstract

Objective: Describe communication between patients with advanced cancer and their spouse/partner caregivers. Design: Prospective observational study. Sample: 83 advanced cancer patient–spouse caregiver couples.

Methods: Couples completed surveys and recorded naturalistic communication for one day. Descriptive analysis was performed on self-report and observational communication data.

Findings: Both patients and caregivers self-reported high likelihood of engaging in positive interactions. The majority of observed communication was logistical or social small-talk. Cancer and relationship talk was highly skewed; many couples had no talk in these domains.

Conclusion: This study is one of the first to assess continuous naturalistic observation of communication in the homes of couples coping with advanced cancer. We found that routine aspects of daily life continue even when couples are facing important challenges.

Implications for Psychosocial Providers: There appear to be few naturalistic cues encouraging couples to discuss potentially difficult topics. More work is needed to determine appropriate levels of communication.

Keywords

advanced cancer; behavioral observation; communication; couples; self-report

Introduction

A growing body of research recognizes the impact cancer has on patients, but also on their caregivers, who are often spouses/partners. Spouse or intimate partner caregivers may provide physical and emotional support to patients and be involved in decision making and

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coordinating care.[1] In addition to involvement in activities surrounding cancer, spouse caregivers may also view cancer as a shared stressor and couples may react as a unit.[2,3] As a function of this dyadic coping approach, patients and spouse caregivers' experiences of cancer can be highly interdependent and their mental and physical health outcomes are often linked.[4–6]

Communication is a key factor to determine the success of dyadic coping strategies.[2,7] For example, constructive communication within couples, consisting of mutual self-disclosure and responsiveness, can help clarify goals and increase caregiver-patient agreement about what those goals are, leading to better collaboration and ultimately improving adjustment and quality of life.[8,9] Dyadic goal-congruence may be of particular importance in advanced cancer, where stakes may be higher. Conversely, couples who fail to communicate, even in the interest of "protecting" the other partner often have worse outcomes.[10,11] When communication does occur, but is seen as unsupportive or critical, it can disrupt individual and dyadic coping, potentially leading to distress and future communication avoidance.[12,13]

Recognizing the importance of these findings, many interventions to support couples coping with cancer include a focus on building effective communication.[14] However, existing interventions have a wide range of success.[15,16] One of the major barriers to developing a prescription for effective communication about cancer is a clear understanding of how the suggested techniques might fit within the communication that naturally occurs between couples. Some research suggests many couples avoid or withdraw from discussing difficult topics,[17,18] particularly those dealing with a stressor such as cancer,[19,20] which may make it more difficult for couples to practice or implement communication techniques in real-life discussions about these topics.

Few studies capture naturalistic communication between couples coping with cancer.[21] Although many of these couples report high levels of self-disclosure and constructive communication,[22] observational research of couples from other fields of research suggests couples may not spend much time together at home, and when together are often focused on day-to-day logistical management of home and family or are distracted and inattentive to each other.[23] Little is known about the frequency and content of daily communication in couples coping with advanced cancer, particularly as it relates to cancer or relationship topics. Infrequent communication or communication during which one or both partners are distracted may limit the opportunity for couples to practice or improve communication skills. Naturalistic research can provide the starting point for typical couples' communication patterns, highlighting specific needs and existing strengths that could be built upon. In addition to helping to focus targeted communication behaviors, knowing how often couples communicate may also inform aspects of communication intervention implementation, such as the amount of time during sessions dedicated to practicing skills.

To fill the gap in knowledge about everyday communication patterns for couples coping with advanced cancer, our goals are to (a) describe the domains of naturalistic communication in the home between patients with advanced cancer and their spouse caregivers and (b) determine the relationship between self-reported communication and observation. Understanding how much couples coping with cancer discuss cancer and their relationships

under everyday conditions can inform future interventions that more effectively direct and support these types of conversations.

Methods

Data were gathered as part of a prospective observational study of couples coping with advanced cancer. A detailed description of study methods can be found elsewhere.[24]

Recruitment

Research staff screened patient lists in thoracic and gastrointestinal clinics for eligible patient participants. Aside from prostate and breast cancer, which may introduce gender differences, lung and colorectal cancer are most common types of cancer diagnosed in the US and are responsible for the most deaths.[25] As such, the thoracic and GI clinics at our institution have relatively high census of patients with advanced disease. On the day of their scheduled appointment, patients and caregivers were approached in clinic and were told this was a study about how couples coping with cancer communicated in the home; study procedures were described. Staff invited participation and verified eligibility. Inclusion criteria for patients included a diagnosis of stage III or IV non-small cell lung or pancreatic, esophageal, gastric, gallbladder, colorectal, hepatocellular, and bile duct cancers; Karnofsky Performance Status scores of 70+; a prognosis of more than 6 months; and undergoing active treatment at Moffitt Cancer Center. Patients had to have a cohabiting spouse/partner who identified as providing some care and also agreed to participate. Both patient and caregiver were required to be over 18 years of age and English-speaking/writing. Eligibility was verified for interested couples and research sessions were scheduled, either to take place in their homes or the clinic (with participants taking research materials home for later use).

Procedure

At the research session, both the patient and caregiver provided written consent and were asked to independently complete demographic and general health questionnaires as well as the 11-item Communication Patterns Questionnaire-Short Form (CPQ),[26] which asks individuals to identify their typical communication patterns when discussing both a cancer- or a relationship-relevant everyday stressor. Items were scored on a 9-item Likert-type scale. Subscales were calculated for mutual constructive, criticize/defend, and demand-withdraw communication styles; higher scores on the subscales indicate a greater likelihood of using that style.[27] Although not explicitly linked to frequency of talk, the CPQ communication types of constructive discussion and avoidance should provide some insight as to the likelihood that couples will engage in discussion about a potentially-difficult topic.

Participants were instructed by research staff on how to use recording equipment (Sony ICD-UX533 Digital Recorder and Olympus ME-52W lavaliere microphone) before they began their naturalistic recordings. Recorded sessions occurred on a day when patient and caregiver expected to be home together and typically began between 10:30 am and noon in the home. Participants were instructed to power down equipment (if still on) when they went to bed. Both patient and caregiver had their own recordings to capture the full breadth of communication within the day and to provide a backup for the couple if one recorder failed.

Staff was available to answer participant questions throughout the day. Equipment was returned either in clinic at the next appointment or by mailer, and digital files were uploaded. Participants also completed a brief 3-item questionnaire to determine awareness and impact of the recorder and the typicality of the observed day. All procedures were conducted with the approval of the Institutional Review Board.

Coding and processing

Trained coders used Noldus Observer to review recordings and identify and timestamp communication. In addition to identifying communication participants (patient, caregiver, other, combination), coders categorized communication as pertaining to the relationship, cancer, or other topic (Table 1). Conversation related to the relationship included any talk about what one's spouse/family meant to him/her, how couples were getting along, or emotions toward the spouse (both affection and complaints). Talk related to cancer included any information exchange or positive or negative emotional expression regarding medication, symptoms, insurance, appointments, etc. All other talk was captured if there was more than one exchange (e.g. patient comment, caregiver response, patient response) or it lasted over 1 min (if one person was talking with no response—e.g. narrating activities, talking to a pet). Often these discussions consisted of small talk or household logistics. A new conversation was defined by a change in domain (e.g. talking about managing medication, then talking about cleaning the bathroom) or a lapse in communication longer than 90 s. A random sample of 10% of recordings was double-coded to calculate reliability. Percent agreement between coders was excellent, ranging from 91 to 99%.

Codes from separate patient and caregiver recordings were reconciled. In six couples, only one member of the dyad submitted a recording (three patients, three caregivers). In these cases, only the data from one individual's recording were used (which could still capture communication from the other spouse if it occurred nearby). In all other cases, codes representing patient talk were selected from patient recordings, codes representing caregiver talk were selected from caregiver recordings, and codes representing patient and caregivers talking together as well as total recording time were averaged between patient and caregiver. This corrected for potential lapses in recording, which occurred in recordings for 23 individuals (representing 17 dyads). Lapses occurred mostly by accident (e.g. participant turned off the recording lock).

Analysis

Descriptive statistics were calculated on the amount of time spent communicating within each domain by speaker (patient or caregiver), as well as the proportion of talk within domain relative to all talk and total recording time. *T*-tests were conducted to determine differences in talk between and within caregivers and patients. Generalized linear modeling was used to determine the relationship between demographics, self-reported communication, and observed communication.

Results

Of 368 eligible dyads approached, 105 agreed to participate (29%), which is in line with previous dyadic studies in advanced cancer populations.[28,29] Twenty couples dropped out or became ineligible before their home research session, mostly due to the patient's declining health. Audio recordings were collected from 83 heterosexual couples (missing audio was mostly due to equipment failure). Recordings from one couple were discarded because the recording only included talk while the research staff was present. Preliminary analysis using independent *t*-tests showed no significant differences for amount of talk or total recording length between participant dyads with and without lapses in recordings. The final sample consisted of data from 82 couples.

Summary statistics for demographic variables are presented in Table 2. Most participants were Caucasian (93% of patients and 90% of caregivers). Patients were more likely to be male (71%) and were slightly older on average than caregivers (66.8 versus 64.8 years). Couples had been together on average 35.0 years ($SD = 15.8$). The majority of participants had completed at least some college or vocational school, and most were no longer working (mostly due to retirement).

Self-reported communication

As seen in Table 3, both patients and caregivers reported being highly likely to have positive interactions ($Ms > 6.86$ out of 9) and a relatively low likelihood of demand/withdraw ($Ms < 3.28$) or criticize/defend interactions ($Ms < 2.95$) in both cancer and relationship domains. There were no significant differences between patient and caregiver assessments of positive interactions or criticize/defend interactions. Caregivers rated the likelihood of demand/withdraw significantly higher than patients in the relationship domain ($t=-2.336$, $df=79$, $p=.02$), and marginally higher in the cancer domain ($t=-1.915$, $df=78$, $p=.059$). Older patients were significantly more likely to report positive interactions related to cancer ($F=5.59$, $df=1,74$, $p=.02$) and the relationship ($F=5.58$, $df=1,74$, $p=.02$), but there were no other demographic differences ($ps>.12$).

Audio-recorded communication

Both patients and caregivers reported being somewhat aware of the recorder (median score of 3/5), but that recording did not impact their behavior much (median score 2/5). Caregivers reported the day as being somewhat typical (median score 3/5) and patients reported the day as being very typical (median score 4/5).

As seen in Table 4, the median length of recording was 9.78 h (range=1.35–16.0 h). The median total amount of all talk during that time between patient and caregiver was 88.15 min [1.47 h] (range 3.37 min–6.56 h). Talk represented a median of 22% of total recorded time (range: <1 to 80%). The median number of unique conversations between caregivers and patients was 35.75 (range=1–97), lasting a median of 7.23 min each (range=9.31 s to 56.16 min).

As expected, the majority of talk between patients and caregivers fell in the "other" category, generally including household logistics or small talk. Both caregivers and patients had

similar amounts of talk (t=0.345, df=80, p=.73). There were no significant relationships between amount of total observed communication and demographic factors (ps>.11) or self-reported communication (ps>.32).

The median total amount of time spent discussing cancer was 1.46 min (range=0–41.20 min); 18 couples had no cancer talk at all (22%). The median number of cancer discussions was 2, and the median length of a single cancer discussion was 40.16 s. Because the data were highly skewed, those who had no discussion of cancer were compared with those who had any discussion of cancer. There were no significant differences in demographics or self-reported communication.

Although the maximum total amount of relationship talk was 19.87 min across the day, the majority (54%, n=45) of couples had no relationship talk at all. The longest single discussion of relationship talk was 4.97 min. As above, couples that had any relationship talk were compared with those who had none. There were no significant differences in any demographic variables except patient age; couples with a significantly younger patient (M=64.30 versus 68.89, t=2.315, df=80, p=.023) were more likely to discuss relationship topics. For self-reported communication, caregivers of couples who discussed relationship topics had a higher average score for positive interactions in cancer (M=22.64 versus M=20.42, t=−2.217, df=79, p=.047) and relationship conversations (M=22.08 versus M=19.40, t=−2.683, df=79, p=.021). There were no significant differences in patient self-reported communication.

Discussion

This study is one of the first to capture and analyze continuous naturalistic recordings of a "day in the life" of couples coping with advanced cancer within the home. Our study demonstrates the feasibility of working with continuous observational communication data and provides insight into everyday communication in couples coping with advanced cancer. For couples coping with advanced disease, effective communication about cancer and the relationship can be important to support connection, clarify values and goals of care, and help prioritize meaningful activities as the patient approaches end-of-life.

We found that advanced cancer patients and caregivers each speak on average just under 2 h, or a little over 20%, of their recorded day. The low amount of observed talk between couples is in contrast with the self-report ratings of high likelihood to positively engage in discussion and low likelihood of avoiding discussion. Although self-report methods are useful and have important predictive value,[30] including capturing a broader sample of relationship experience and the participants' personal interpretations, they are subject to self-presentation bias and may omit aspects of couples' communication that may be seen in observation of behavior in the home.[31,32] Although participants in our study reported being moderately aware of the recorders, which may introduce self-presentation bias, the majority of participants reported the recorder did not alter their behavior, which is consistent with other research using audio- and video-recording to capture communication behavior.[33,34] Using multiple methods to triangulate behavior is ideal, but when this is not feasible, researchers

should weigh the potential value of the particular methods selected for the goals of the research.

Though couples may have felt that they *could* have meaningful discussions about cancer or their relationship, many patients and caregivers in our study did not. Although meaningful conversations are not necessarily lengthy, most cancer discussions in our study were quite short and were often limited to managing care (e.g. organizing medication, checking on an oncology appointment time). Although practical discussions are certainly important, disclosure of concerns or sharing emotions may have larger implications for self-efficacy, perceptions of intimacy, and psychological health outcomes.[9,12,20] This may be of particular value for couples coping with advanced versus early-stage cancer as treatments and their effects are often more intense, there may be more uncertainty, and the fear of patient death can be more acute. As such, there may be more need for more effective coping, which can be facilitated by communication.

Talk pertaining to the relationship was even less prevalent. Relationships are often an important source of strength for couples coping with cancer and more relationship talk has been associated with increased intimacy and mutual disclosure.[35] Although we mostly captured short expressions of affection (e.g. saying "I love you") rather than deeper discussions about the relationship itself, it is likely that the affective nature of this talk makes it more powerful than more neutral talk.[36] Although verbal disclosure of feelings for each other is important, non-verbal communication may be a uniquely powerful tool within this domain. For example, we were unable to capture facial expressions or touch (though we did often capture kissing), which can convey feelings of love and the importance of the relationship. In fact, affectionate touch may be a unique pathway within the relational domain to promote intimacy, reduce stress, and enhance well-being in couples.[37]

The vast majority of this talk was coded as outside the realm of cancer and the relationship. Our findings, taken with other limited research showing that day-to-day communication between couples is largely focused on general observation, household planning, and more superficial social chitchat,[23,38] suggest that even when couples are facing important challenges, such as an advanced cancer diagnosis, routine aspects of daily life continue. These communication topics, though seemingly unimportant, might serve as a foundation to build or demonstrate trust or caring in relationships. These small behaviors may set couples on a trajectory to discuss larger, higher-stakes issues and provide important support when those issues arise.

More research on the "right" amount of communication is needed; the low levels of cancer and relationship talk we found may be appropriate for the typical day we captured. Though we know communication is important, too much focus on stressful topics may be maladaptive. Couples may also be checking in with each other in non-verbal ways to determine when the right time might be to address topics; for example, by reading facial expressions, a caregiver can determine the patient is not in pain and avoid a discussion about pain management that otherwise might be seen as nagging. Future research can identify verbal and non-verbal communication strategies of couples who cope successfully and how they unfold over time.

Our finding that caregiver self-reported likelihood of positive communication was predictive of engaging in relationship talk was the only link between self-report and observational data. Caregivers may have more realistic perceptions of the quality of relationship functioning, have higher levels of empathic accuracy, or be responding more to patient cues than patients respond to caregivers.[39,40] More research is needed to understand the dyadic factors linking self-reported communication to observed communication and how communication impacts patient and caregiver outcomes.

Limitations

Several limitations should be noted. Despite being one of the first studies to observe continuous naturalistic couples' communication in the home, we only captured communication that occurred during one day. Many participants reported the day captured was very typical, but this was not the case for all participants. More research is needed to better identify the variability, content, and process of communication across longer periods of time to understand communication dynamics over the cancer care trajectory. Although it is important to capture everyday communication, days surrounding important decisions or changes (e.g. before/after an oncologist appointment) may show more cancer or relationship communication,[41] which may offer other unique insights. Additionally, although we captured the majority of the day's talk, couples did not usually start recording until mid or late morning and stopped recording before bedtime. For some couples, these missed periods of time might represent important times of connection.[42] Further, our sample was primarily white, older than 60 years of age, and high income, with mostly male patients, and our findings may not generalize to other couples coping with advanced cancer.

Conclusion

There is a need to better understand the social factors that impact the cancer experience.[43] Some couples may find it difficult to acknowledge cancer or relationship issues on their own because they want to maintain normalcy.[19] Further, in day-to-day life there appear to be few cues to encourage couples to initiate or sustain conversation about potentially difficult topics, which may limit the ability for couples to employ communication skills. More work is needed to determine appropriate levels of communication. For those couples who require intervention to achieve these levels, it will be important to determine the best way to encourage and cue more overall communication in key domains within everyday life to provide more context for beneficial communication processes, such as mutual self-disclosure.[44]

Communication is a key factor in both planning and meaning-making, and can have an important impact on intimacy, well-being, and adaptation to cancer or bereavement. Despite research indicating the benefits of frequent, open communication across a variety of topics, [45] few couples engage in these types of discussions in daily life. Using direct observation, we are able to present a different picture of couple's typical communication, which may inform future components of interventions for couples coping with cancer. More research is needed to determine what levels of communication is most beneficial to patient and

caregiver outcomes and how couples can best initiate communication to achieve these benefits.

Funding

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Implications for psychosocial providers or policy

- Most patients and spouse caregivers self-report high likelihood of positive communication.

- Little observed naturalistic talk between patients and caregivers in the home is related to cancer or the relationship.

- Self-reported communication from patients and caregivers was not robustly linked to observed communication in the home.

TABLE 1

Communication domains and examples.

Domain	Examples
Relationship	"I love you"
	"Why do you have to argue with me all the time?"
	"You always sound like you don't care."
	"Do you remember the first time we met?"
	"No honey, I didn't notice that. You are the only person I pay attention to."
	"I just wanted to let you know that I am so grateful for you."
Cancer	"My brain is being cooked with radiation."
	"When was the last time I took my pain medication? Oh, I can't take it for another hour."
	"I'd rather have the pain than take those pills. I can't stand being groggy"
	"You're always wiped out after a treatment day. We shouldn't plan anything."
	"I'm going to be stuck at the clinic all day tomorrow."
	"My last visit to the clinic was very excellent. They always treat me well there."
	"When my mother had cancer, she didn't have the same symptoms as you."
Other	"What do you feel like for dinner?"
	"Anything but leftovers!"
	"I thought you liked leftovers?"
	"Did you hear what happened to the neighbor's dog?"
	"No, what?"
	"It escaped out the back gate and went on an adventure…"
	"Can you help me move this table?"
	"Where do you want to move it?"
	"Just over so I can clean."

TABLE 2

Demographic characteristics of participants.

Characteristics	Patient (*n* = 82)	Caregiver (*n* = 82)
	M (SD)	M(SD)
Age	66.8 (9.2)	64.8 (9.4)
Years married	35.0 (15.8)	
Number of persons in household	2.4 (1.0)	
	n (%)	*n* (%)
Sex		
Female	24 (29.3)	58 (70.7)
Race		
American Indian/Alaska Native	1 (1.2)	2 (2.4)
Black/African American	5 (6.1)	4 (4.9)
White/Caucasian	76 (92.7)	74 (90.2)
Other	0	1 (1.2)
Ethnicity		
Hispanic or Latino	3 (3.7)	3 (3.7)
	N%	*N*%
Highest level of schooling		
7–11 years	3 (3.7)	2 (2.4)
High school graduate or equivalent	12 (14.6)	14(17.1)
Some college or vocational school	26 (31.7)	30 (36.6)
College graduate	15 (18.3)	12 (14.6)
Some graduate or professional school	6 (7.3)	5 (6.1)
Graduate or professional degree	20 (24.4)	19 (23.2)
Currently employed		
No	65 (79.3)	50 (61.0)
Part-time	2 (2.4)	11 (13.4)
Full-time	14 (17.1)	18 (22.0)
Missing/no response	1 (1.2)	3 (3.7)
Financial situation		
Not very good	9 (11.0)	8 (9.8)
Comfortable	48 (58.5)	54 (65.9)
More than Adequate	23 (28.0)	19 (23.2)
Missing/no response	2 (2.4)	1 (1.2)

TABLE 3

Self-reported communication patterns.

Communication style	Patient						Caregiver					
	Cancer			Relationship			Cancer			Relationship		
	Mean (*SD*)	Min.	Max.	Mean (*SD*)	Min.	Max.	Mean (*SD*)	Min.	Max.	Mean (*SD*)	Min.	Max.
Total demand/ withdraw	2.58 (1.65)	1.00	6.83	2.74 (1.63)	1.00	7.00	3.10 (1.86)	1.00	7.00	3.28 (1.71)	1.00	7.67
Criticize/defend	2.32 (1.67)	1.00	7.00	2.67 (1.81)	1.00	7.00	2.69 (1.98)	1.00	7.00	2.95 (1.96)	1.00	9.00
Positive interaction	7.39 (1.91)	1.00	9.00	6.96 (1.98)	1.33	9.00	7.14 (1.67)	3.00	9.00	6.86 (1.74)	2.33	9.00

TABLE 4

Observed communication.

Domain	Minutes per discussion, median (range)	Discussion frequency, N (range)	Total domain talk (minutes) Median (range)	Domain/all talk % (range)
Relationship				
Patient total	0.00 (0.00–4.97)	0.00 (0.00–26.50)	0.00 (0.00–19.87)	0.00 (0.00–0.00)
Caregiver total	0.00 (0.00–4.97)	0.00 (0.00–27.50)	0.00 (0.00–19.87)	0.00 (0.00–0.00)
Patient & caregiver together	0.00 (0.00–4.97)	1.12 (0.00–26.50)	0.00 (0.00–19.87)	0.00 (0.00–0.00)
Cancer				
Patient total	1.13 (0.00–26.12)	2.25 (0.00–34.00)	2.10 (0.00–53.18)	0.00 (0.00–0.00)
Caregiver total	1.15 (0.00–21.50)	2.25 (0.00–24.00)	1.88 (0.00–42.57)	0.00 (0.00–0.00)
Patient & caregiver together	0.67 (0.00–20.13)	2.00 (0.00–21.00)	1.46 (0.00–41.20)	0.00 (0.00–0.00)
Other				
Patient total	10.64 (0.16–73.48)	36.00 (1.00–95.00)	97.46 (3.37–355.43)	0.01 (0.00–0.02)
Caregiver total	9.92 (0.16–54.49)	37.00 (1.00–173.00)	102.67 (3.37–370.74)	0.02 (0.01–0.02)
Patient & caregiver together	6.05 (0.16–54.49)	32.25 (1.00–83.00)	87.47 (3.37–338.28)	0.01 (0.00–0.02)
Total Talk				
Patient total	12.54 (0.16–75.16)	39.75 (1.00–125.00)	103.80 (3.37–361.35)	–
Caregiver total	11.69 (0.16–56.16)	41.00 (1.00–175.50)	109.05 (3.37–376.65)	–
Patient & caregiver together	7.23 (0.16–56.16)	35.75 (1.00–97.00)	88.15 (3.37–344.20)	–
Total recording length (hours)	9.78 (1.35–16.00)			