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ONCOLOGISTS' ASSESSMENTS OF LUNG CANCER PATIENT AND FAMILY DISAGREEMENTS REGARDING TREATMENT DECISION MAKING

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Summary

Background—Disagreements between cancer patients and their caregivers about treatment and care can affect the patient's physical and mental well-being. Therefore it is important to understand if oncologists can accurately identify the presence of patient-caregiver decisional conflict. This study examined assessments made by lung cancer patients, their caregivers, and their oncologists regarding patient-caregiver disagreements concerning treatment and care decisions.

Participants and methods—We assessed the extent to which the patient, caregiver, and oncologist reported disagreement between the patient and the family member regarding treatment decisions in 134 patient-caregiver-oncologist triads. Descriptive statistics were used to explore rates of concordance amongst all possible combinations of raters. Loglinear models were tested for 3-way agreement.

Results—Most patient-caregiver pairs, 82.1% (n=110), reported agreement concerning presence or absence of decisional conflict. Oncologists were more successful in detecting absence of conflict than the presence of conflict. When the *caregiver* and the oncologist agreed, it was regarding the absence of conflict (64.9%), rather than the presence of conflict. In 10.6 % (n = 15) of cases, oncologists reported that conflictual relationships negatively impacted their ability to provide patient care.

Conclusions—Recent models of cancer patient care promote including the caregiver fully in the process while respecting the primacy of the patient's perspective. However, these models assume that the oncologist will recognize when disagreements exist and be able to assist in conflict resolution. The degree to which the oncologist identified that conflict exists and implications for their ability to provide patient care when familial disagreements existed are discussed.

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Keywords

lung cancer; family caregivers; treatment; decision making; conflict; patient care

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Introduction

Disagreements between cancer patients and their caregivers about treatment and care can affect all aspects of the patient's physical and mental well-being. The American College of Physicians (ACP) acknowledged the increasingly important role of family caregivers in patient care in a 2009 position paper outlining ethical guidelines to optimize relationships and communication among patients, physicians, and family caregivers.[1] These guidelines provide physicians with a means to align their clinical practice with current models of patient care that include the caregiver in patient care while respecting the autonomy of the patient. Guidelines include assessing the patient's wishes regarding caregiver participation, validating the family caregiver's role and perspective on caregiving, and being alert to signs of distress in the caregiver and suggesting referrals if necessary.[1] Implicit in these guidelines is that the clinician is able to accurately determine the presence of decisional conflict in the patient-caregiver dyad. Of concern is that the ability of the physician to rate patient preferences for prognostic and decision-making preferences has been examined and has been found to be suboptimal.[2–5] The importance of the caregiver in the provision of optimal treatment cannot be underestimated, therefore it is critical that oncologists be able to recognize difficulties as they arise.

Caregiving for patients with cancer is a physically and emotionally demanding role and both patients and caregivers may feel that they do not receive enough support from others, including their physician.[6–9] Patients and caregivers may experience difficulties regarding communication about diagnosis and decision-making.[7] Research suggests that lung cancer patients and their spouses are at increased risk for spousal conflict, which can exacerbate each individual's distress and coping difficulties.[8, 10] One survey of family members of deceased lung cancer patients reported that more than one-third of families reported some sort of family conflict, including disagreements or arguments among family members, resentments among family members, and anger and/or yelling among family members.[11]

Physicians can play an important role in supporting the patient-caregiver relationship that in turn can improve quality of life and enhance informed decision-making. Nonetheless, the literature suggests that physicians avoid initiating discussions about possible family conflict or other psychosocial problems[12, 13] and may make incorrect assumptions about patient-family relationships, patient needs, and emotional functioning. They may inaccurately assess patients' psychosocial needs[14, 15] and erroneously assume that patients and families are adjusting to the cancer diagnosis and treatment when they are struggling.[12, 14–16] Furthermore, cancer patients generally report that they would like physician assistance in negotiating their relationships with family members, including when initiating difficult conversations with family members.[17] In fact, a recent review identified psychosocial support, which often encompasses facilitation of patient-family communication, as one of cancer patients' most frequently reported unmet needs.[18] Recognizing the central role that health significant others or family caregivers play in the care of cancer patients, Kahana and Kahana[19] proposed a health care partnership communication model that conceptualizes cancer care communication as occurring within a triad involving the patient, physician, and health significant other. Physician communication is hypothesized to directly influence health significant other communication and patient outcomes.[19]

This study examined whether oncologists can accurately identify the presence of decisional conflict between lung cancer patients and family caregivers. We discuss the implications of these findings for the delivery of patient care.

Participants and methods

Study design

This cross-sectional study was part of a larger study designed to develop and validate the Cancer Communication Assessment Tool for Patients and Families (CCAT-PF). The measure was developed to assess congruence in patient-family caregiver communication. The results of this study have been published elsewhere. [20, 21] All data were obtained from semi-structured individual interviews that were audiotaped and transcribed. Patients and caregivers were interviewed separately in the patient's home. Most patients and all caregivers were interviewed individually with measures presented in the same order to all respondents. Interviews lasted approximately 45–60 minutes and included questions about treatment preferences, decision-making regarding treatment, and demographics. There was ample opportunity for the patient and caregiver to discuss information and feelings that were outside the limits of the semi-structured questionnaires.

Eligibility, recruitment and consent

The sample consisted of 134 lung cancer patients, their primary caregivers, and the treating oncologist. Patients were identified through review of electronic medical records from the previous six-months at a comprehensive cancer center and its community affiliates in the Midwest. Patient consent was not required for the record review because a HIPAA waiver was granted for case finding. Patients were contacted by letter after obtaining their physicians' permission. Ninety-one percent of the patients were smokers. Caregivers (identified by patients) were individuals (non-healthcare providers) patients primarily relied on for help with care, treatment, and decision-making. Inclusion criteria stipulated that patients all had advanced-stage (III and IV) non-small cell lung cancer; stage of disease was confirmed through chart review. Study eligibility required that a patient and at least one caregiver agreed to participate in the study. Prior to participation, written informed consent was obtained from the patient and the caregiver as approved by the Institutional Review Board (IRB). All physicians treating study relevant patients agreed to participate in the study. Overall, 76% of patient-caregiver pairs consented to be part of the study. Although some patients also had a secondary caregiver, this report examined data from only the primary caregiver.

Patient and caregiver questionnaire

Sociodemographic information was collected from patients and caregivers. Patients and caregivers completed questionnaires assessing their perceptions of differences in opinion between patient and family regarding treatment decisions. "Treatment decisions" include decision-making about specific types of treatment such as chemotherapy and radiation, palliative care options such as hospice, and additional testing. It also includes care issues such as transportation, diet and exercise. The first section of the interview asked each to discuss a recent decision, how the decision was made and whether any conflicts arose between patient and family about that decision. Each subject was asked to provide global ratings about the degree of decisional conflict they had experienced, in general, about treatment decisions on a Likert scale of 1 (no differences of opinion) to 7 (almost always differences of opinion).

Physician questionnaire

The consulting oncologist was asked to participate in a brief questionnaire regarding the patient's and family's treatment-related decision-making. Based on their history with the patient and caregiver, oncologists rated their global perceptions of how strongly patients and families disagreed about treatment decisions on the same Likert scale of 1 to 7 used by patients and caregivers; how uncomfortable the patient was with disagreements with his/her family about treatment decisions; and to endorse or refute whether differences of opinion or family disagreements affected their ability to provide care for the patient. In other words, did family-patient conflict interfere with patient acceptance of treatment or adherence?

Statistical analysis

Descriptive statistics (means and frequencies) for sample participant characteristics were computed. Descriptive statistics for oncologists' ratings of the presence and impact of conflict are reported. Before analysis, the distributions of the variables were inspected for skewness, kurtosis, and outliers. Ratings for the presence of conflict were highly skewed and kurtotic for the patient (skew = 4.5, kurtosis = 21.9), the caregiver (skew = 3.5, kurtosis = 13.0) and the physician (skew = 2.1, kurtosis = 8.7). Due to the distributional properties of the original variables, the responses from all participants regarding the existence of differences of opinion regarding treatment decisions were dichotomized representing no differences of opinion (= 0 when respondent endorsed that there was never conflict) and differences of opinion exist (= 1 if the respondent indicated there was ever conflict).

We computed the frequencies for the concordance between patient and caregiver, physician and caregiver, physician and patient and amongst all three raters for the whole sample. We report the McNemar statistic, a non-parametric test assessing agreement when 2 raters rate the same target using a dichotomous response (presence or absence of conflict). We also examined the physicians' rates of agreement for just those patient-caregiver dyads in which some conflict was reported. Log linear models were created to examine the relationships amongst the 3 participants' responses regarding the presence of conflict between the patient and the family members. The log-linear approach is appropriate when there is no clear distinction between response and explanatory variables. The main emphasis of these models is to assess inter-observer agreement for dichotomous variables when there are more than 2 raters. Dummy variables were created as needed for use as possible covariates. For example, we coded caregiver type as spousal and non-spousal caregivers. As is the convention, we initially tested the fully saturated loglinear model (all 2 and 3 way interactions included). We then examined the reduced model in which all main effects were maintained but all non-significant interaction terms were dropped.

Results

Patient and caregiver characteristics

Descriptive statistics are presented in Table 1. Half of the patients were diagnosed with stage III and half with stage IV lung cancer. Sixty-seven percent of the patients were in treatment or in the planning phase for the next round of treatment. Most of those who reported not being in treatment had just finished initial treatment (n = 28). The majority of the caregivers were patients' spouses (59%), 27% patients' adult children (most of whom were daughters), and the remainder had some other familial relationship.

Patient and caregiver reported rates of agreement about decisional conflict

In the 134 patient-caregiver pairs, 82.1% (n=110) reported agreement concerning the presence or absence of decisional conflict. A majority of patient-caregiver pairs (70.9%) agreed that conflict was absent and 11.2% agreed on the presence of conflict. The caregiver

reported conflict more than twice as often when the patient did not (12.3% vs. 5.2%). The McNemar statistic assessing agreement was 4.2 ($df = 1$), $p = .041$ indicating that the caregiver was more likely to report conflict even when the patient did not.

Physician and caregiver agreement

Oncologists were more successful in detecting the absence of conflict rather than the presence of conflict. When the *caregiver* and the oncologist agreed, it was regarding the absence of conflict (64.9%), rather than the presence of conflict. Of the 47 cases in which the caregiver, oncologist, or both reported conflict, they agreed on the presence of conflict in 14.9% of cases; the oncologist alone reported conflict in 31.9% of cases, and the caregiver alone reported conflict in 53.2% of cases. Thus the oncologist was unaware of conflict in more than half the cases in which conflict existed for the caregiver. The McNemar statistic assessing agreement was 2.02 ($df = 1$), $p = .15$ indicating no statistically significant difference for discrepant conflict reports.

Physician and patient agreement

When the *patient* and the oncologist agreed, it was regarding the absence of conflict (70.2%) rather than the presence of conflict (3.0%). Of the 40 cases in which the patient, oncologist, or both reported conflict, they agreed on the presence of conflict in 10% of cases. Both the oncologist alone and patient alone reported conflict in 18% of cases indicating that the patient and oncologist were equally likely to report the presence of conflict when the other did not. The McNemar statistic was invalid in this case as the number of discrepant conflict reports was the same for patient and physician.

Physician, patient and caregiver agreement

In triads consisting of patient-caregiver-oncologists, 82 of 134 (61.2%) all concurred that there was no conflict between the patient and the caregiver regarding treatment decisions. However, only 2 triads (1.5%) had complete agreement when conflict was present. This yields a total concordance of 62.4%. The remainder of the time there was a general lack of concordance regarding whether conflict exists: 22% of the time the physician reported no conflict when one or both of the other 2 did; and 15% of the time the physician reported conflict when one or both of the others did not (see Table 2).

Loglinear models

The saturated loglinear model revealed that the only significant interaction was between the caregiver and patient ratings. The rest of the interactions were not significant; these terms were dropped and the model was re-estimated. The reduced loglinear model (see Table 3) revealed that the main effect for patient, caregiver, and oncologist ratings was significant, suggesting that each individual's ratings influenced the distribution of the 3-way agreement. The analysis also revealed that the interaction between the patient and caregiver was significant, suggesting that the joint responses of these 2 raters influenced the distribution of responses. Patient and caregiver concordance was therefore associated with the overall rates of agreement amongst the three raters. It also suggests that rates of concordance with oncologists were too low to influence the overall distribution (see Table 3). There were no detectable associations between patient and oncologist concordance attributable to patient gender, age, cancer stage, or current treatment status. Likewise there were no detectable associations between caregiver and oncologist concordance attributable to patient gender or age (data not shown).

Physician characterization of conflict

Physicians mostly viewed these conflicts as minor with just 7 rating disagreement as strong or slightly strong and only 6 reporting that the nature of the disagreement was unpleasant or slightly unpleasant. We examined whether the existence of oncologist-reported disagreements between the patient and the family had an impact on his/her ability to care for the patient. In 10.6 % (n = 15) of cases, oncologists reported that conflictual relationships negatively impacted their ability to care for the patient.

Discussion

The results of this study demonstrate that in most lung cancer patient-family caregiver dyads (70.9%), neither the patient nor the caregiver reported the presence of decisional conflict, and in 61.2% of cases, the patient, caregiver, and oncologist all agreed about the absence of conflict. While the majority of patients and caregivers reported an ability to make care and treatment decisions without discord, an appreciable minority did have difficulty.

This study indicates that oncologists had difficulty detecting conflict between patients and caregivers. When only one member of the dyad reported conflict, the oncologist was aware of conflict less than one-third of the time, and when both members of the dyad reported conflict, the oncologist was aware in about 13% of cases. Overall, the oncologist report less decisional conflict (16.4% of cases) than patients (29.1%). Further, in most (59.1%) of the cases in which the oncologist perceived conflict, neither the patient nor caregiver reported conflict. Thus, not only did oncologists perceive decisional conflict within the dyad less often than the members of the dyad report, but it also appears that the oncologist was frequently inaccurate when s/he reported the presence of conflict. These findings are in line with previous studies that have shown that oncologists are often not on the same page with patients and their family members when it comes to treatment goals, care preferences, and patients' well-being [22–24]. One caveat is that during the interview process patients and families had detailed discussions about a specific decision and were then asked to provide a global rating about conflict whereas the physicians only provided global ratings. This methodology may have prompted a more in-depth thought process concerning disagreements by patients and families whereas the physician did not go through this kind of 'review' process.

The guidelines outlined by the ACP regarding physician communication with patients and caregivers emphasize the importance of validating the roles and perspectives of both patient and caregiver, and being alert to possible signs of distress in both members of the dyad. [1] Past research has shown that although cancer patients express a desire to discuss spousal/family relationships with their physicians, [12, 13] physicians are hesitant to discuss family conflict and other psychosocial outcomes. [13, 15] The current study suggests that there is an additional barrier to physicians discussing issues of conflict with the patient and caregiver – the physician's inability to accurately identify the presence of decisional conflict. Specifically, we found that oncologists were more successful in detecting absence of conflict than the presence of conflict, which augments other study findings that physicians and other healthcare staff have more difficulty recognizing when patient distress is present than when it is absent. [25] If oncologists are unaware of the presence of conflict and are also hesitant to discuss these issues, they may be less effective in addressing and assisting patients in managing patient-caregiver conflict, thus decreasing the opportunity to reach harmonious treatment decisions. This can lead to continued disagreements and resentment among family members during an already stressful time.

To provide the best care possible to a vulnerable cancer patient population, oncologists must assess both patient and caregiver well-being and concerns to ensure that all interactants are

clear about each person's values and goals. The oncologist, using her position of authority and trust is in an optimal position to elicit both patient and caregiver opinions and feelings about treatment options and to foster open and honest discussions about treatment decisions. The results of the current study suggest that, in most cases, oncologists are unaware when one or both members of the patient-caregiver dyad are experiencing conflict about treatment and care. We believe that awareness of conflicts between patients and caregivers can help physicians understand problems they encounter delivering treatment to certain patients and, in more extreme cases, guide the physician to make appropriate referrals to psychologists and social workers. These findings are especially salient in light of evidence that undetected and neglected, distress among cancer patients and their families can diminish quality of life for both patients and their relatives. [26] Checking in with patients and caregivers more explicitly is recommended to optimize decision-making and increase both patient and caregiver quality of life.

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Table I

Sociodemographic Characteristics of Patients and Caregivers

	Patient	Caregiver
	Mean (SD)	Mean (SD)
Age	66.1(10.0)	57.0 (13.1)
	N (%)	N (%)
Sex (male)	74 (55)	21 (16)
Married	95 (71)	114 (85)
Race (African American)	15 (11)	13 (10)
Education		
Less than High school	21 (16)	11 (8)
High school	47 (35)	44 (33)
Some college	30 (22)	43 (32)
College	24 (18)	23 (17)
Beyond college	12 (9)	13 (10)

Table II

Distribution of agreement regarding the presence of decisional conflict between the patient and caregiver and oncologist assessment (N=134 triads)

Patient Reports Conflict	Caregiver Reports Conflict	Oncologist Conflict Assessment	Total
			N (%)
Y	Y	Y	2 (1.5)
Y	Y	N	13 (9.7)
Y	N	N	5 (3.7)
Y	N	Y	2 (1.5)
N	Y	Y	5 (3.7)
N	Y	N	12 (9.0)
N	N	Y	13 (9.7)
N	N	N	82 (61.2)

Note: 'Conflict' refers to endorsing (or denying) the presence of disagreement between the patient and the family caregiver.

Table III
Loglinear Models of Patient, Caregiver and Oncologist Rating of Conflict between the Patient and Caregiver

	Saturated Model			Reduced Model		
	Chi sq (df)	Parm	se	Chi sq (df)	Parm	se
Patient rating of conflict	18.38 (1) **	0.6882	0.1605	26.79 (1) **	-0.6833	0.132
MD rating of conflict	18.38 (1) **	0.6882	0.1605	48.7 (1) **	0.8137	0.1166
Caregiver rating of conflict	2.24 (1)	-0.2402	0.1605	3.29 (1) **	-0.2396	0.132
Caregiver rating * MD rating	0 (1)	-0.00135	0.1605			
Patient rating * MD rating	0 (1)	0.00886	0.1605			
Patient rating * Caregiver rating	8.91 (1) *	0.4791	0.1605	22.1 (1) **	0.6207	0.132
Patient rating * Caregiver rating * MD rating	2.24 (1)	0.2402	0.1605			
Log Likelihood (df)	(0)			3.07 (2)		

* p<.01

** p<.00