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Differential Patient-Caregiver Opinions of Treatment and Care For Advanced Lung Cancer Patients

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Abstract

This study examined the differences of opinion between cancer patients and caregivers with regard to treatment and care decisions. 184 advanced lung cancer patients and 171 primary caregivers were recruited as a convenience sample from clinics in Cleveland, Ohio. A telephone interview was conducted to collect data using a semi-structured questionnaire. Nonparametric tests and regression analysis were performed. The findings showed that patients and caregivers reported significant disagreement on three main issues: trade-off between treatment side effects and benefits; reporting treatment side effects to physicians, and hospice care. Caregivers were more concerned about patient's quality of life and more willing to discuss hospice issues than were patients. Perceived family disagreement is associated with depression in both patients and caregivers. The study provided empirical evidence for patient-caregiver disagreement about treatment and care decisions and its significant adverse impact on both patients and caregivers.

Keywords

family disagreement; lung cancer; depression; decision making; caregiving; USA; treatment

A cancer diagnosis can be devastating to the individual and his or her family. The decision-making process concerning treatment and patient care is replete with uncertainty and anxiety (Temel et al., 2008). Lung cancer is associated with a high mortality rate and a multitude of treatment options (ACS, 2008a). In addition to these characteristics, a lung cancer patient's average age at diagnosis is 71 years (ACS, 2008b). This can add complexity to already difficult choices as older patients often take a more passive approach to decision-making (Siminoff, Ravdin, Colabianchi, & Sturm, 2000) and increasingly rely on family members for support. However, their spouses are sometimes also in poor health and adult children may not live at or near the patient's home, resulting in limited insight into the physical and social needs of the patient (Lederberg, 1989).

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Making decisions about treatment and care is particularly challenging for patients with aggressive and advanced cancer. Advanced lung cancer patients have an average survival time of 18 months (Marino, Pampallona, Preatoi, Cantoni, & Invernizzi, 1994). In the late stages, numerous treatment decisions need to be made within a short period of time. Despite increasing options for treating lung cancer, treatment efficacy is as yet limited (Group N-sCLCC, 1995) and treatment side effects are pronounced. Weighing limited survival advantage against worsened quality of life is difficult. It is widely reported that despite limited benefits, a substantial portion of lung cancer patients prefer aggressive treatment (Brundage, Feldman-Stewart, Cosby, Gregg, Dixon, & Youssef et al., 2001; Week, Cook, O'Day, Peterson, Wenger, & Reding et al., 1998) and most have an unrealistic expectation of treatment outcomes (Yardley, Davis, & Sheldon, 2001).

Finally, no matter what treatment or care option is chosen, the responsibility for handling its outcome falls squarely on the shoulders of family caregivers. Disagreement among family members about treatment and care can provoke emotional stress (Zhang & Siminoff, 2003a), which may worsen patient health and impair family adjustment and function in the long term (Badr & Taylor, 2008). The magnitude of these adverse effects needs to be better understood in order to be prevented or minimized.

Previous research has primarily focused on communication and treatment decisions by patients and their physicians. Research of patient-caregiver communication and decision making for advanced cancer is limited. Our pilot study (Zhang & Siminoff, 2003b) provided preliminary, qualitative evidence for the presence of patient-caregiver disagreement about lung cancer treatment, but the finding requires scientific substantiation. To help address this knowledge gap, we recently conducted a larger study of decision making and communication among lung cancer patients and caregivers. In this study, we sought to answer two questions: (1) what are the major differences of opinion regarding treatment and care decisions between patients and caregivers; (2) how do differences of opinion regarding treatment and care decisions in the family affect the psychological well-being, specifically the level of depression, of patients and caregivers?

Methods

This study was conducted between 2001 and 2004 at the Case Comprehensive Cancer Center, the Cleveland Clinic and the MetroHealth Medical Center in Cleveland and was approved by all relevant Institutional Review Boards. Patients with a diagnosis of advanced stage non-small cell lung cancer and at least one family caregiver were eligible for participation. Trained research staff reviewed medical charts to identify potentially eligible patients. With the physician's permission, an introductory letter with the principal investigator's signature that informed the study basics and the physician's permission, along with the IRB approved consent, was mailed to the identified patients. Research staff contacted all the identified patients by telephone to introduce the study and obtain consent. About 8% of consented patients had been initially diagnosed at stage II and later advanced and the rest were diagnosed at stage III or IV. The primary caregiver on whom the patient relied most of time for making a treatment or care decision was identified and contacted to seek consent. The total patient plus caregiver recruitment rate was 76%.

A semi-structured questionnaire was used to collect contextual information (appended here). Both structured and open-ended questions were constructed based on information that was collected from a previous focus group study (Zhang & Siminoff, 2003b) and used to probe family disagreements in three main areas: routine health care decisions such as where, when and how to receive treatment; decisions on trade-off treatment benefits and side effects; and decisions about hospice care. The original protocol called for in-person interviews. However,

we found this too difficult to implement during a pilot study and switched to telephone interviews, because patients could not predict when they might be feeling well enough for an interview and frequently needed to cancel it due to sickness. Patients and caregivers completed the semi-structured questionnaire in approximately 30 minutes. All interviews were audiotaped and transcribed. Patients and caregivers also completed the Center on Epidemiologic Study of Depression (CES-D) and received a \$30 honorarium.

Three interviewers were trained together to ensure that the interview was conducted uniformly. The project coordinator listened to every tenth interview to safeguard against interviewer drift. The study's Principal Investigator (LAS) developed a codebook to classify responses to open-ended questions. All three interviewers followed the codebook to conduct coding and discussed problematic coding at the weekly meeting. They doubled coded 25% of the interviews to ensure coding accuracy.

Nonparametric tests (Chi-square, Fisher's exact and Mann-Whitney U tests) were performed to compare patient and caregiver responses on categorical and ordered variables abstracted from the semi-structured questionnaire. Hierarchical linear regression analysis was performed to examine how both patient and caregiver variables indicating patient-caregiver disagreements predicted the level of depression as measured by the CES-D scale (Hofmann, 1997). STATA software was used to calculate robust standard error, using the Huber-White sandwich estimator. This calculation produces more accurate predictions of depression because it accounts for the interdependency of depression between a patient and a caregiver in a family unit. The intraclass correlation of depression was also estimated because it provides an estimate of the extent to which the level of depression covaries within a patient-caregiver dyad.

Results

Two hundred and thirty-five lung cancer patients and 196 primary caregivers provided consented and completed the semi-structured interview. Seventy-six participants did not respond to the CES-D, the dependent variable of the regression analysis, and were therefore excluded. The remaining 355 participants constituted the study sample that included 184 patients and 171 primary caregivers. Nineteen patients and six caregivers that did not have a counterpart (caregiver or patient) due to missing data on CES-D were retained. Our analysis showed that inclusion or exclusion of these patients and caregivers made no difference to the study outcomes for all statistic tests performed.

The average age of patients was 65 years and the mean age of caregivers was 56 years. The sample included slightly more male than female patients (54% vs. 46%), whereas the caregiver's gender was predominantly female (75%). This gender split is concordant with a growing trend of more lung cancer diagnosis in women as opposed to a male dominant lung cancer diagnosis in the past. The proportion of African Americans is higher in the patient than caregiver sample (24% vs. 12%), indicating a possibility that African American patients had fewer caregivers at home. Significantly more caregivers than patients were married (85% vs. 65%) and had higher incomes and education. The majority of primary caregivers were patient spouses (58%) while 42% identified themselves as the patient's children, parents or significant others. Most patient participants had received surgery and/or radiation and at least one course of chemotherapy. The mean CES-D score of depression was 14 (S.D.=9.2) for patients and 11.4 (S.D.=9.6) for caregivers.

We observed significant disagreements between patients and caregivers about treatment and care decisions (see Table 1). More caregivers (31%) than patients (20%) reported disagreements about issues other than a specific decision that they chose to discuss ($p=0.02$). Caregivers more often reported (90% vs. 60%, $p\leq.001$) that they had expressed opinions during

the decision-making process. Caregivers also reported a significantly higher degree of involvement with decision-making ($p \leq .01$). There was no significant difference between patients and caregivers in rating the frequency of their disagreements about treatment ($p = .09$) or doctor recommendations for an unwanted treatment ($p = .87$). Nonetheless, caregivers reported a significantly higher frequency of patient-caregiver disagreement about care decisions ($p \leq .01$).

In response to questions about routine treatment and care decisions, one-third of the participants disagreed about whether the patient had reported treatment side effects to physicians immediately. Among these disagreeing participants, significantly more caregivers reported that a reason for not reporting a side effect was that the patient did not want to worry or upset others (27% vs. 10%; $p = .04$). Also, a significantly higher proportion of caregivers said that patients eventually reported side effects only when caregivers asked them to (26% vs. 6%; $p = .02$) or directly confronted the patients about the matter (40% vs. 13%; $p \leq .01$).

When probed about how to weigh treatment side effects against benefits, patients and caregivers agreed that the following circumstances could justify treatment termination: a doctor recommendation to terminate treatment ($p = .58$), worsened treatment prognosis ($p = .13$) and no further treatment options ($p = .09$). However, they disagreed elsewhere. Patients were more willing to stop treatment if it was no longer effective (45% vs. 26%; $p \leq .01$) and caregivers were more likely to stop treatment if the side effects adversely affected patient quality of life (83% vs. 60%; $p \leq .001$). While patients and caregivers agreed on a number of reasons for continuing treatment, significantly more patients would continue treatment if “the patient wants to keep trying” (51% vs. 18%; $p \leq .001$) or “would die without treatment” (24% vs. 9%; $p \leq .01$), whereas significantly more caregivers would do so because family members “want to keep trying” (34% vs. 0%; $p \leq .001$), “want a remission” (5% vs. 0%; $p \leq .01$) or “respect patient’s personal choice” (21% vs. 1%; $p \leq .001$).

Patients and caregivers also held different views about hospice care. After being provided with a formal definition of hospice, they were asked about their opinions concerning hospice care. Caregivers, as compared to patients, exhibited more understanding of hospice care as palliative care for managing symptoms ($p \leq .001$); had a greater willingness to discuss hospice ($p \leq .01$); reported that they had talked about hospice with each other ($p = .04$); and stated a greater preference for the patient receiving hospice care in the home ($p = .04$).

Finally we examined predictors of depression in patients and caregivers and whether disagreement about treatment and care decisions was significantly associated with depression as measured by the CES-D (see Table 2). Hierarchical regression analysis indicates that higher depression scores in both patients and caregivers were significantly associated with fewer family members being informed about treatment and care decisions ($p \leq .001$), exclusion of any family member from decision-making ($p = .03$), doctor’s recommending a treatment that was unwanted by either patient or caregiver ($p = .04$), caregiver’s preference to stop a treatment ($p = .02$), and less willingness to discuss hospice care at home ($p \leq .01$). Variables of age, gender, race, marital status, household income and a proxy variable of family size (number of people living in household), which together explained 8% of variance, were controlled in the model. The final model explained a total of 16% of the variance, with 8% of the variance explained by the five variables of family disagreement alone. This R^2 value of 8% suggests a small to medium effect size of the impact of family disagreements (Cohen, 1988). Based on our computed estimate, the coefficient of intraclass correlation between patient and caregiver depression in a family was 0.26. This is considered a large intraclass correlation and could have biased the estimation of participant’s depression if standard regression analysis were used without correcting the patient-caregiver interdependency within the family (Hofmann, 1997).

The analyses conducted here specifically controlled for this interdependency in the units of analysis.

Discussion

The study findings demonstrated significant disagreements between advanced lung cancer patients and caregivers about treatment and care decisions. The results suggest that caregivers perceived significantly more family disagreement than did patients and that patient-caregiver differences of opinions were more pronounced with regard to care than treatment decisions. This discrepancy in the patients' and caregivers' report may be explained by the possibility that some disagreements have occurred among caregivers without the patient's knowledge, namely "conspiracies of silence" that existed between the patient and the caregiver for protecting the patient (Fallowfield, Jenkins, & Beveridge, 2002); this speculation is consistent with the assertions of caregivers that they had provided their opinions about treatment. It is also likely that caregivers were more aware of disagreements about care because they bear the caregiving burden (Thomas, Morris, & Harman, 2002).

The substance of family disagreements indicates that family disagreement may be due to patient's and caregiver's different perspectives of the patient's health (McPherson, Wilson, Lobchuk, & Brajtman, 2008). Lung cancer patients seemed to be more concerned about taking treatment to stay alive, whereas caregivers stressed patient's quality of life. This tension in the family is best reflected on the contention over reporting treatment side effects. Lung cancer patients were less willing to discuss hospice care and this may be related to their perception of hospice as a place to die rather than for symptom relief and palliative care (Ford, Nietert, Zapka, Zoller, & Silvestri, 2008). They were also more likely to prefer hospice care outside of their home. This finding is consistent with previous reports (Zhang & Siminoff, 2003b; Thomas, 2005) that indicate patients' concerns about being a burden to caregivers at home.

Nevertheless, patient and caregiver opinions of treatment and care converged on most issues. In each of the three identified major decision-making areas patients and caregivers provided seemingly unanimous answers. It was only when probed with more specific questions, such as reasons for their answer to a global question that we began to see the differing perspectives. This indicates that family disagreement about treatment and care decisions is highly situationally-specific as observed by others (Lobchuk & Degner, 2002). Future researchers should bear this in mind as they design interview questions.

Despite the overall agreement on most issues, family disagreements on even a few specific issues had a significant impact on the stress levels of patients and caregivers. Regression analysis in this study demonstrated that a modest but significant component of depression was explained solely by family disagreement regarding treatment, doctors' recommendations for treatment, hospice care and communication. In view of a wide range of stressors associated with having life-threatening cancer (Rodin, Mikulincer, Donner, Gagliese, & Zimmermann, 2009), the finding suggests that family disagreement can be a significant source of stress as patients approach end of life. We found that when discussions about treatment or care were restricted to a few members, when individuals were reluctant to discuss hospice care, when there were disagreements between the physician and either patient or caregiver about treatment, and when caregiver requested that the patient stop a treatment, depression was more likely. The intraclass correlation for depression of 0.26 suggests that depression, experienced by either party, affected the other considerably (Hofmann, 1997). It is imperative to identify at-risk patients and caregivers and provide timely psychosocial interventions.

A limitation of this study is that it only included advanced lung cancer patients and primary caregivers, most of whom were spouses. A study with a larger and diverse sample would help

to clarify the role that the relationship between patients and caregivers played in the reported differences. A potential sample bias is that we interviewed community dwelling individuals and not those in nursing homes or hospice who may face a different set of family issues. In addition, studies of patients with other types of cancers might not produce the same results. Nonetheless, this study highlights the important influence that patients and caregivers have on each other's mental health well-being and the importance of communication to this process.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Patient and Caregiver Disagreement about Treatment and Care

Variable	N*	Patient N (%)/ Mean (S.D)	N* Caregiver N (%)/ Mean (S.D)	p
General patient-caregiver disagreement				
Do patient and caregiver disagree about any other treatment issues? <i>Yes</i>	184	37 (20)	170 53 (31)	.02 ^a
Does caregiver express opinion of patient treatment? <i>Yes</i>	160	107 (67)	146 131 (90)	.01 ^a
Degree of caregiver' involvement in making the decision (<i>5pt</i>)	184	3.5 (1)	170 3.8 (1)	.01 ^b
How frequently patient and caregiver disagree on treatment decision (<i>7pt</i>)	184	1.4 (1)	171 1.5 (1)	.09 ^b
How frequently patient and caregiver disagree on care decision (<i>7pt</i>)	184	1.5 (1)	170 1.9 (2)	.01 ^b
Doctor wanted a treatment that was unwanted by patient or caregiver: <i>Yes</i>	184	22 (12)	171 22 (13)	.87 ^a
Patient-caregiver disagreement about reporting treatment side effects				
Patient keeps side effects to his/herself: <i>Yes</i>	182	49 (27)	171 58 (34)	.17 ^a
Reason of not reporting - Do not want to worry or upset others: <i>Yes</i>	49	5 (10)	56 15 (27)	.04 ^a
Reason of reporting - Family is concerned and asked patient to report: <i>Yes</i>	48	3 (6)	55 14 (26)	.02 ^a
Reason of reporting - Family confronted patient about side effect: <i>Yes</i>	48	6 (13)	55 22 (40)	.01 ^a
Patient-caregiver disagreement about stopping a treatment				
Any situation would let or have let you to decide to stop a treatment? <i>Yes</i>	184	76 (41)	170 88 (52)	.06 ^a
Reason to stop - Side effect is too bad, affects patient quality of life: <i>Yes</i>	84	50 (60)	91 75 (82)	.01 ^a
Reason to stop - Treatment is no longer effective: <i>Yes</i>	84	38 (45)	91 24 (26)	.01 ^a
Reason of not to stop - Patient wants to keep trying treatment: <i>Yes</i>	111	57 (51)	83 15 (18)	.01 ^a
Reason of not to stop - Patient would die without treatment: <i>Yes</i>	105	25 (24)	77 7 (9)	.01 ^a
Reason of not to stop - Family wants to keep trying treatment: <i>Yes</i>	111	0	83 28 (34)	.01 ^a
Reason of not to stop - Family wants the patient to reach remission: <i>Yes</i>	111	0	83 5 (6)	.01 ^a
Reason of not to stop - It is a personal decision for patient to decide: <i>Yes</i>	111	1 (1)	83 17 (21)	.01 ^a
Patient-caregiver disagreement about hospice care				
Understanding of Hospice Care (<i>7pt</i>)	184	3.3 (2)	171 4.0 (2)	.01 ^b

Variable	N*	Patient N (%)/ Mean (S.D)	Caregiver N (%)/ Mean (S.D)	p
Observer rating of willingness to discuss hospice care (7 pt)	184	4.1 (2)	4.6 (1)	.01 ^b
Patient and caregiver talked about hospice: Yes	178	42 (24)	58 (35)	.02 ^a
Where to have hospice care	162		156	
Hospice at home		96 (59)	113 (72)	.04 ^c
Hospice outside home		16 (10)	9 (6)	
Unsure of location		24 (15)	11 (7)	
Depends on circumstance		26 (16)	23 (15)	

^a Fisher's exact test

^b Mann-Whitney U test

^c Chi-square test

* N=355 but the sample size varied due to a skip pattern or missing data

Table 2**Multilevel Analysis of Predictors of Depression in Patients and Caregivers**

Variable	b	Robust s.e.	t	p
Age	-.09	-.05	-1.77	.08
Gender (1=female, 0=male)	.47	.97	.48	.63
Race (1=white, 0=others)	2.49	1.55	1.61	.11
Married (1=married, 0=others)	-.61	1.47	-.41	.68
Household income	-1.91	.53	-3.58	.01
Number of people living in household	-.74	.53	-1.40	.16
Total number of family members that were informed about a specific treatment	-.58	.17	-3.50	.01
Anyone in family was not told about a specific treatment (1=yes, 0=no)	2.53	1.18	2.15	.03
Doctor recommended a treatment that patient or family did not want to take (1=yes, 0=no)	3.34	1.58	-2.11	.04
A family member asked patient to stop treatment (1=yes, 0=no)	6.45	2.72	2.37	.02
Willingness to discuss hospice care (scale of 1-7)	-.84	.34	-2.48	.01

F=5.14; df=11, 185; p=.0001

R²=0.16

Intra-class Correlation=0.26