

Dyadic Perceptions of the Decision Process in Families Living With Lung Cancer

Lyndsey M. Miller, PhD, RN, Donald R. Sullivan, MD, MA, and Karen S. Lyons, PhD

Miller is a postdoctoral fellow in the College of Nursing at the University of Utah in Salt Lake City; and Sullivan is an assistant professor in the Department of Medicine and Division of Pulmonary and Critical Care Medicine and Lyons is an associate professor in the School of Nursing and the Department of Psychiatry, both at Oregon Health and Science University (OHSU) in Portland.

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Miller can be reached at lyndsey.miller@nurs.utah.edu, with copy to editor at ONFEditor@ons.org.

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Purpose/Objectives: To use dyadic analyses to identify determinants of patients' and family members' perceptions of the positive and negative aspects of the decision-making process in families living with lung cancer.

Design: Cross-sectional study.

Setting: Community setting in Greater Portland, Oregon.

Sample: 109 family care dyads (patient and family member) recruited from a statewide cancer registry.

Methods: Surveys were completed in-person, separately, and privately by each member of the family care dyad. Secondary analysis was completed using multilevel modeling.

Main Research Variables: Negative and positive aspects of the decision process.

Findings: Level 1 data revealed significant variability across care dyads' positive or negative perceptions of the decision-making process. Level 2 results for negative perceptions of decision making indicated that patient and family member perceptions were significantly associated with their own depressive symptoms and feelings of not being listened to by others. Level 2 results for positive perceptions of decision making indicated that patient and family member perceptions were significantly inversely associated with their own feelings of not being listened to and being in nonspousal relationships. In addition, family members' perceptions were more positive when the patients were older.

Conclusions: This study highlighted the complexity of the decision-making process in families with lung cancer, and underscored the importance of the care dyad feeling listened to by family members in the context of life-threatening illnesses.

Implications for Nursing: Nurses assisting families with decisions about lung cancer should be aware of the dynamics of the care dyad and how the decision process is perceived by patients and their family members.

A cancer diagnosis affects both patients and family members, and gives rise to many decisions that families often work through and process together. However, the life-changing nature of cancer diagnoses do not necessarily bring about greater communication or agreement among families (Siminoff, Dorflinger, Agyemang, Baker, & Wilson-Genderson, 2012; Siminoff, Rose, Zhang, & Zyzanski, 2006; Venetis, Greene, Checton, & Magsamen-Conrad, 2015; Zhang, Zyzanski, & Siminoff, 2010). Indeed, family communication often breaks down in the context of cancer (Badr & Taylor, 2006; Zhang & Siminoff, 2003a). This may be especially true in families affected by lung cancer—the leading cause of cancer-related mortality in the United States (Howlander et al., 2013)—because of the potential for blame associated with smoking and family conflict surrounding smoking cessation (Badr & Taylor, 2006; Lobchuk, Murdoch, McClement, & McPherson, 2008; Siminoff, Wilson-Genderson,

& Baker, 2010; Stone, Mikucki-Enyart, Middleton, Caughlin, & Brown, 2012; Zhang & Siminoff, 2003b). Despite these challenges, the majority of patients with cancer and their family members want to participate in the decision-making process together (Shin et al., 2010, 2013). Researchers have called for intervention approaches to help promote better family decision making (Kramer, Kavanaugh, Trentham-Dietz, Walsh, & Yonker, 2009). However, the development of interventions is impeded by a lack of understanding regarding the complexity of the decision process and perceptions of this process within the care dyad. The goal of this study was to understand the care dyad's perception of the decision-making process in families living with lung cancer.

Lung cancer is an aggressive disease involving what many patients perceive as an onslaught of difficult treatment and care-planning decisions. The rapid disease course intensifies patients' and family members' negative perceptions (e.g., conflict, disagreement, avoidance) of family communication and decision making (Siminoff, Zyzanski, Rose, & Zhang, 2008; Zhang & Siminoff, 2003b; Zhang et al., 2010). In contrast, positive perceptions of communication about cancer in families (e.g., family cooperation, respectful communication) may be beneficial to care dyads and lead to greater agreement in decision making (Manne et al., 2004; Shin et al., 2010, 2013). A few studies have revealed that a variety of factors, such as declining mental and physical health and the quality of the family care dyad's relationship, influence how communication and decision making are perceived by cancer and noncancer dyads (Hagedoorn et al., 2000; Menne, Tucke, Whitlatch, & Feinberg, 2008). Depressive symptoms are high in lung cancer dyads in general (Siminoff et al., 2010; Sullivan et al., 2014) and are also related to negative perceptions of the decision process (Siminoff et al., 2008; Stone et al., 2012; Zhang & Siminoff, 2003b; Zhang et al., 2010). Finally, the family's responsiveness or ability to listen may be important to dyads' perceptions of the decision-making process (Manne et al., 2004; Rose, Radziewicz, Bowmans, & O'Toole, 2008).

Previous studies have demonstrated significant discordance between the perceptions of patients with lung cancer and their family members regarding the decision process, making it essential to analyze the perceptions of both members of the care dyad (Shin et al., 2013; Siminoff et al., 2006, 2012; Zhang et al., 2010). In addition, research involving families living with other cancer types points to an interdependent emotional system at work in the family care dyad (Badr & Taylor, 2006; Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Stone et al., 2012). Therefore, each dyad member's perception of the decision process is important to the dyad and could

be determined by factors in dyad members' own lives or in each other's lives (i.e., cross-partner effects) (Berg & Upchurch, 2007; Stone et al., 2012). Using an analytic method that takes into account the interrelatedness of the patients and family members is crucial to understanding dyads' perceptions of the family decision-making process related to lung cancer and the determinants of each member's perceptions. Other studies of lung cancer dyads have examined aspects of communication and the decision process from one person's perspective (Stone et al., 2012) or used methods that do not take into account the interrelatedness of the dyadic data, such as group-level correlation analyses (Siminoff et al., 2008). The purpose of this study was to use dyadic analyses to identify determinants of patients' and family members' perceptions of the positive and negative aspects of the decision-making process in families living with lung cancer.

Methods

Participants

This study is a secondary analysis of baseline data from a longitudinal study of families living with lung cancer. The original study is described in detail elsewhere (Lyons et al., 2014). A statewide cancer registry was used to recruit eligible participants, including patients diagnosed with a primary invasive non-small cell lung cancer within the past six months and patients who nominated a family member who was involved in his or her care and was also willing and eligible to participate in the study. Patients and family members were required to have access to a telephone, speak English, live within 50 miles of the metropolitan area of Portland, Oregon, and be at least 18 years old. Staff from the cancer registry initially contacted patients by letter with a description of the study. Interested participants mailed back a reply form to the study project director, who then determined their eligibility over the telephone using the contact information provided. Patients and family members provided informed consent separately, in person with the project director, and then participated in a baseline interview (approximately 45–60 minutes). The study was approved by the Institutional Review Board at Oregon Health and Science University.

Measures

Patients' and family members' perceptions of the negative aspects of the decision process for families living with lung cancer were measured using the negative aspects subscale of the decision process scale (Noelker, Townsend, & Deimling, 1984). In this measure, items are either not endorsed (score of 0) or

TABLE 1. Sample Characteristics (N = 109 dyads)

Characteristic	Patients		Family Members	
	\bar{X}	SD	\bar{X}	SD
Age (years)	68.68	11.75	60.9	13.6
Characteristic	n		n	
Gender				
Female	51		81	
Male	58		28	
Race/ethnicity^a				
Caucasian	101		99	
African American	3		2	
Native American/ Pacific Islander	1		2	
Asian	1		4	
Hispanic/Latino	2		3	
Other	1		-	
Relationship to patient				
Spouse	-		76	
Adult child	-		26	
Neighbor or friend	-		3	
Other family member	-		4	
Stage IV lung cancer (distant metastasis)	37		-	

^a One family member identified as both Asian and Latino.

endorsed (score of 1) on a scale of 0–11 on the negative aspects subscale. An example item on the scale is: “When decisions concerning your family member are discussed does anyone become overly tense or upset?” In this study, the negative aspects subscale demonstrated good internal consistency (patient alpha = 0.87; family member alpha = 0.84).

Patients’ and family members’ perceptions of the positive aspects (5 items) of the decision process of families living with lung cancer were measured using the positive aspects subscale of the decision-process measure (Noelker et al., 1984). In this measure, items are either not endorsed (0) or endorsed (1) on a scale range of 0–5. An example item on the positive aspects subscale is: “When decisions concerning your family member are discussed does everyone cooperate to make a decision?” In this study, the subscale demonstrated good internal consistency (patient alpha = 0.79; family member alpha = 0.82).

Patients’ ratings of relationship quality in the dyad was measured using the Mutuality Scale (Archbold, Stewart, Greenlick, & Harvath, 1990). Although data were collected from patients and family members, the authors included only one perception to conserve the ratio of variables to sample size, and they chose the patients’ perceptions according to previous literature, indicating that it may be the more salient perspective (Lyons et al., 2015). Patients responded to 15 items about their relationship with family members using

a Likert-type scale from 0 (not at all) to 4 (a great deal). High scores indicated high levels of relationship quality. The scale demonstrated strong internal consistency in this study (patient alpha = 0.89).

The physical health of family members was measured by the physical component summary (PCS) of the SF-36® (Ware, Kosinski, & Dewey, 2005). The PCS includes scales of physical functioning, role-physical, pain, and general health. Scores were transformed to norm-based scoring (i.e., mean of 50 and standard deviation of 10) (Ware et al., 2005) and range from 0–100, with higher scores indicating better physical health status. Internal consistency of the PCS in this sample was excellent (alpha = 0.89).

The Center for Epidemiological Studies–Depression (CES-D) scale (Radloff, 1977) was used to measure depressive symptoms in patients and family members. Each of the 20 items are rated on a Likert-type scale ranging from 0 (rarely/none of the time) to 3 (most/all of the time). Scores are summed for a possible range of 0–60, and higher scores signal greater depressive symptoms. In the current study, the reliability of the CES-D was good (patient alpha = 0.83; family member alpha = 0.86).

The degree to which patients and family members did not feel that they were being listened to by other family members was reported using a single-item measure: “How much difficulty do you have getting your family to listen to your opinion?” (Noelker et al., 1984). The item is rated on a three-point scale ranging from 0 (none) to 2 (a great deal).

Statistical Analyses

Analysis of the family dyad data was conducted using multilevel modeling (MLM) and the software program Hierarchical Linear Modeling, version 7. MLM accounts for nonindependence of dyadic data by estimating and controlling the degree of shared variance (Barnett, Marshall, Raudenbush, & Brennan, 1993; Sayer & Klute, 2005). In MLM, level 1 analyzes the unconditional (i.e., no covariates included) model of the decision process and generates estimates of the average values for the two equivalent decision-process measures (one for the patient, one for the family member) of each outcome variable (negative aspects, positive aspects). In addition, level 1 estimates the amount of variability around the averages. At level 2, covariates are included to explain this variability. In this study, separate models were run for perceptions of the negative and positive aspects of the family decision process.

Specifically, the level 1 (within-dyads) model represents the decision-process scores (Y) for each of patient and family members as the sum of a latent true score (β_1 for the patient and β_2 for the family member)

plus a residual term *r* that captures measurement error and was specified as:

$$Y_{ij} = \beta_{1j} (\text{PATIENT}_{ij}) + \beta_{2j} (\text{FAMILY}_{ij}) + r_{ij}$$

Y_{ij} represents the decision-process score *i* in dyad *j*. PATIENT is an indicator variable taking on the value of 1 if the response was obtained from a patient and 0 if the response was obtained from a family member. FAMILY is an indicator variable taking on the value of 1 if the response was obtained from a family member and 0 if the response was obtained from a patient. Therefore, each of the two decision-process models (positive and negative aspects) resulted in two scores—*β_{1j}* and *β_{2j}*—that represent the patient’s and family member’s latent decision-process scores, respectively.

The level 2 (between-dyads) models include predictors to explain the variability across dyads. Based on hypothesized explanatory variables and preliminary correlational analysis, independent variables were included in level 2 models where the parameters for latent true decision-process scores of patients (*β_{1j}*) and family members (*β_{2j}*) became the outcome variables and were specified as:

$$\beta_{1j} = \gamma_{10} + [\gamma_{11} \text{Predictor}_1 + \gamma_{1n} \text{Predictor}_n] + u_{1j}$$

$$\beta_{2j} = \gamma_{20} + [\gamma_{21} \text{Predictor}_1 + \gamma_{2n} \text{Predictor}_n] + u_{2j}$$

γ₁₀ and *γ₂₀* are the level 2 intercepts, representing average values of the decision process for the patient and family member, respectively, adjusted for the effects of the predictors in each equation. Therefore, the authors examined two models at level 2 (negative and positive aspects), each with two outcomes: (a1) the patients’ perceptions of the negative aspects of the decision process, (a2) the family members’ perceptions of the negative aspects of the decision process, (b1) the patients’ perceptions of the positive aspects of the decision process, and (b2) the family members’ perceptions of the positive aspects of the decision process.

Results

This study included data from 109 patient-family caregiver dyads who had complete information on baseline measures (96% of the original study sample). Sample characteristics and measurement results are shown in Tables 1 and 2.

Level 1 results for the negative aspects of the decision process revealed that patients’ perceptions were similar, on average, to family members’ perceptions (*X̄* = 1.11, *p* = 0.29). In addition, significant variability existed in how negatively the decision process was perceived by patients (*X̄* = 724.57, *p* < 0.001) and family members (*X̄* = 694.45, *p* < 0.001). Level 2 results for the negative perceptions of the decision process indicated that patient and family member perceptions were significantly associated with their own depressive symptoms and feelings of not being listened to by others. All models controlled for relationship quality, physical health of the family member, and stage of lung cancer. Together these independent variables accounted for 29% of the variance in the patients’ perceptions and 33% of the variance in the family members’ perceptions of the negative aspects of the decision process.

Level 1 results for the positive aspects of the decision process revealed that patients’ perceptions were similar, on average, to family members’ perceptions (*X̄* = 0.1, *p* = 0.5). In addition, significant variability existed in how positively the decision process was perceived by the patients (*X̄* = 511.89, *p* < 0.001) and the family members (*X̄* = 602.53, *p* < 0.001) (see Table 3). Level 2 results for the positive aspects of the decision process indicated that patient and family member perceptions were significantly inversely associated with their own feelings of not being listened to and with being in a nonspousal relationship. In addition, the perceptions of family members were more positive when the patients were older (see Table 4). All models controlled for relationship quality, physical health of the family member, and stage of lung cancer. Together these independent variables accounted for 38% of the variance in the

TABLE 2. Measurement Scales Results (N = 109 Dyads)

Variable	Measure	Patients		Family Members	
		<i>X̄</i>	SD	<i>X̄</i>	SD
Physical health	SF-36® PCS	–	–	49.52	10.46
Depressive symptoms	CES-D	12.03	10.16	11.72	8.48
Relationship quality	Mutuality Scale	3.55	0.41	–	–
Feelings of not being listened to	Single-item measure	0.39	0.53	0.34	0.47

CES-D—Center for Epidemiological Studies–Depression; PCS—physical component summary

Note. The PCS score ranged from 1–100, with higher scores (after transformed to norm-based scoring) indicating better physical health status. Scores for the CES-D had a possible range of 0–60, with higher scores indicating greater depressive symptoms. The score for the Mutuality Scale ranged from 0–4, with higher scores indicating higher levels of relationship quality. The score for the single-item measure ranged from 0–2, with higher scores indicating more difficulty in getting family members to listen.

patients' perceptions and 39% of the variance in the family members' perceptions of the positive aspects of the decision process.

Discussion

The current study was an examination of the decision process of families living with lung cancer. Specifically, the purpose was to identify the determinants of patients' and family members' negative and positive perceptions of the family decision process using MLM. Findings revealed that, although patients' and family members' perceptions of the decision process were similar, on average, significant variability existed among patients' and family members' perceptions of the decision process. Significant determinants of negative perceptions of the decision process for both patients and family members included patients' and family members' own depressive symptoms and feelings of not being listened to by others. Significant determinants of the positive perceptions of the decision process included patients' and family members' own feelings of not being listened to by family members and being in nonspousal family care dyad relationships (e.g., parent–adult child relationship). In addition, positive perceptions of family members were higher when the patients were older.

The most striking finding in this study was the significance of not feeling listened to as a determinant of dyads' perceptions of the decision process. A consistent finding across both models was that the individuals' (patient or family member) own rating of the difficulty they had in getting the other family member to listen to their opinion influenced both the negative and positive perceptions of the decision process. When patients and family members had more difficulty getting their family to listen to their opinions, they had more negative perceptions of the decision pro-

cess and fewer positive perceptions. These findings suggest the simple yet crucial importance of feeling listened to in stressful situations like life-threatening illness. This measure can also be interpreted as proxy for another concept, such as the feeling of solidarity or cohesion in a family relationship, which has been found to be related to more positive cancer-related decision making and communication (Siminoff et al., 2008; Zhang & Siminoff, 2003b). However, the analysis controlled for the patient's perception of the quality of his or her relationship with the family member, which is a similar concept and was not a significant determinant in the results.

Depressive symptoms were another determinant of the patients' and family members' negative perceptions of the decision process. The association between depressive symptoms and negative perceptions of the decision process (e.g., perceptions of conflict, disagreement, becoming overly tense, avoidance) is consistent with previous studies on cancer-related decision making and communication (Siminoff et al., 2008; Zhang et al., 2010). Depressive symptoms were not significantly associated with perceptions of the positive aspects of the decision process in this study, which may indicate that the positive aspects (e.g., showing affection, respect) are more enduring and less susceptible to negative appraisals, which can be exacerbated by depressive symptoms. Investigating this phenomenon with a qualitative approach would likely yield more in-depth understanding. In the current study, depressive symptoms were conceptualized as a contextual factor influencing individuals' perceptions of the decision process. However, the lack of longitudinal data in this and previous studies makes it impossible to establish the direction of influence between depressive symptoms and the decision process of families living with lung cancer. Most likely, a recursive

TABLE 3. Positive and Negative DPSs: Level 1 (N = 109 Dyads)

Fixed Effects (With Robust SE)	Positive DPS			Negative DPS		
	β	SE	t	β	SE	t
Patient Intercept	4.24	0.12	34.16*	2.17	0.26	8.36*
Family member Intercept	4.18	0.13	31.05*	2.49	0.27	9.31*
Random Effects	Variance Component	X̄		Variance Component	X̄	
Patient	1.31	511.89*		6.21	724.57*	
Family member	1.61	602.53*		6.56	694.45*	

*p < 0.001

DPS—Decision Process Scale; SE—standard error

TABLE 4. Positive and Negative DPSs: Level 2 (N = 109 Dyads)

	Positive DPS			Negative DPS		
Fixed Effects (With Robust SE)	β	SE	t	β	SE	t
Patient						
Intercept	3.64	0.81	4.47***	3.97	1.74	2.28*
Patient age	–	0.01	0.04	–0.02	0.02	–0.84
Spousal/nonspousal relationship	0.85	0.28	3.07**	–0.78	0.58	–1.34
Family member physical health	–	0.01	–0.3	–	0.02	–0.16
Patient stage of lung cancer	–0.03	0.22	–0.14	–0.01	0.47	–0.01
Patient depressive symptoms	–	0.01	0.45	0.07	0.03	2.71**
Family member depressive symptoms	–0.01	0.01	–0.94	0.01	0.04	0.13
Patient rating of relationship quality	0.23	0.25	0.92	–0.04	0.51	–0.07
Patient not feeling listened to	–0.91	0.24	–3.81***	1.22	0.52	2.36*
Family not feeling listened to	–0.31	0.2	–1.52	0.74	0.44	1.68
Family member						
Intercept	1.79	0.93	1.93*	3.98	1.83	2.17*
Patient age	0.02	0.01	2.17*	–0.01	0.02	–0.59
Spousal/nonspousal relationship	0.81	0.31	2.62**	–0.61	0.6	–1.01
Family member physical health	–	0.01	0.41	0.02	0.02	0.89
Patient stage of lung cancer	0.48	0.25	1.89	–0.33	0.5	–0.66
Patient depressive symptoms	0.02	0.01	1.46	0.01	0.03	0.23
Family member depressive symptoms	–0.02	0.02	–1.42	0.1	0.03	3.07**
Patient rating of relationship quality	0.28	0.28	0.99	0.26	0.63	0.41
Patient not feeling listened to	–0.28	0.27	–1.04	0.73	0.56	1.32
Family not feeling listened to	–0.77	0.27	–2.84**	1.34	0.61	2.21*
Random Effects	Variance Component		̄X	Variance Component		̄X
Patient	0.8		354.16***	4.25		525.43***
Family member	1		401.76***	4.33		491.4***
*p < 0.05; **p < 0.01; ***p < 0.001						
DPS—Decision Process Scale; SE—standard error						

*p < 0.05; **p < 0.01; ***p < 0.001

DPS—Decision Process Scale; SE—standard error

relationship exists between contextual factors and perceptions (Berg & Upchurch, 2007)—depressive symptoms could influence the family care dyad's perceptions of the decision process and be colored by negative perceptions of the decision process, which often is ongoing in lung cancer.

Age and type of kin relationship of the dyad also influenced the family members' positive perceptions of the decision process. The older the patients, the more positively the family members perceived the decision process. The models controlled for actor effects, and age was not a significant determinant of the patients' perceptions. Age is an important developmental aspect that contributes to dyadic perception and coping with an illness like lung cancer (Berg & Upchurch, 2007). Consistent with previous research, the impact of cancer is not as great on family members when patients are older versus when they are diagnosed at a younger age or earlier developmental stage, such as in families that are raising young children or pursuing midcareer goals (Carter, Lyons, Stewart, Archbold, & Scobee, 2010; Harden, 2005). In addition, when dyads were com-

prised of spouses rather than adult children, family members had significantly more positive perceptions of the decision process. This finding is similar to that of another study of lung cancer dyads, in which spouses agreed about treatment decisions significantly more than adult children dyads (Shin et al., 2013).

Limitations

The generalizability of this study is limited by the homogeneity (race, age) of the sample and the cross-sectional nature of the data, which makes it difficult to determine whether the conceptualization of independent variables as predictors of dyads' perceptions of the family decision process is supported. Longitudinal research on the family decision process in lung cancer is needed to determine if the relationships between outcomes and predictors are supported or are, in fact, reversed. This distinction will be important to intervention research aimed at the more modifiable factors that influence dyads' perceptions of the family decision process. Modifiable factors in the current study included depressive

Knowledge Translation

- Feeling listened to is important to patients with cancer and their family members and helps to minimize negative perceptions and maximize positive perceptions of the decision process.
- Dyads exhibiting depressive symptoms are significantly more likely to have negative perceptions of the decision-making process.
- Spousal dyads and family members of older patients with cancer perceived the decision process more positively.

symptoms and feelings of not being listened to by others. In addition, although the goal of the current study was to examine dyadic perceptions of the family's decision process, determining which family relationships (e.g., spouses, adult children, parents) were the source of the negative and positive perceptions was not possible. A more specific investigation of the influence of particular kin relationships in the decision process is necessary to gain this insight. However, this study addressed a needed area of research and contributed a dyadic perspective of the positive and negative aspects of the family decision process in a life-threatening context.

Implications for Nursing

Nurses assisting families with lung cancer decisions should be aware of the importance of the dynamics of the care dyad and how the decision process is perceived by patients and family members. Feeling listened to is important to patients with cancer and their family members and helps to minimize negative perceptions and maximize positive perceptions of the decision process. Dyads exhibiting depressive symptoms are more likely to have negative perceptions of the decision process. Finally, nurses should be aware that dyads comprised of an adult child caring for a parent with lung cancer may not benefit as much from the positive aspects of the decision process, such as affection and respect, as spousal dyads do.

Conclusion

This study highlighted the complexity of the decision process in families with lung cancer and underscored the importance of the care dyad feeling listened to by family members in the context of life-threatening illness. To improve the difficult decision-making experience of families living with lung cancer, research and translation studies must acknowledge the importance

of both patients' and family members' perceptions of the decision process.

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