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Development of a Symptom Management Intervention: Qualitative Feedback from Advanced
Lung Cancer Patients and their Family Caregivers

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Abstract

Background: Little is known about cancer patient and family caregiver preferences for the content and format of non-pharmacologic interventions. Revising interventions based on patient and caregiver feedback before implementation may improve intervention feasibility and acceptability, especially in the context of advanced cancer.

Objectives: To obtain feedback from advanced, symptomatic lung cancer patients and their family caregivers on the content and format of a non-pharmacologic symptom management intervention under development. The intervention blended evidence-based cognitive-behavioral and emotion-focused strategies to reduce physical and psychological symptoms.

Methods: Semi-structured qualitative interviews were conducted with 21 advanced, symptomatic lung cancer patients and caregivers. Participants reviewed handouts regarding intervention components and provided feedback.

Results: Patients and caregivers desired intervention components that addressed the patient's high symptom burden such as education regarding treatment side-effects and the provision of various coping tools. Offering interventions with a brief or flexible length and delivering them via telephone were other suggestions for enhancing intervention acceptability. Participants also preferred an equal focus on patient and caregiver concerns and a more positive intervention framework.

Conclusions: Intervention preferences of advanced lung cancer patients and caregivers underscore the severity of the disease and treatment process and the need to adapt interventions to patients with high symptom burden. These preferences may be incorporated into future intervention trials to improve participant recruitment and retention.

Implications for Practice: Nurses can modify interventions to meet the needs of advanced, symptomatic lung cancer patients and caregivers. For example, flexibility regarding intervention content and length may accommodate those with significant symptoms.

Keywords: lung neoplasms; family caregivers; intervention; symptoms; coping; qualitative research; preferences

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Lung cancer is one of the most common cancers diagnosed in men and women.¹ Most lung cancer patients (85%) have regional or distant stage disease at diagnosis,¹ which contributes to their high rate (80%) of multiple physical and psychological symptoms.²⁻⁴ Lung cancer patients have a higher prevalence of anxiety and depressive symptoms and report more unmet psychological needs than other cancer patients.⁵⁻⁷ Research has found that as many as 52% of lung cancer patients experience clinically meaningful levels of anxiety and depressive symptoms.⁸⁻¹⁰ Psychological distress in lung cancer patients has been associated with increased frequency and severity of physical symptoms.^{3, 11, 12} The most prevalent physical symptoms in lung cancer patients include pain, fatigue, and breathlessness.^{2, 13}

The high physical and psychological symptom burden makes lung cancer especially distressing for family caregivers.¹⁴⁻¹⁶ Studies have found that one-third of spousal caregivers of lung cancer patients report clinically elevated anxiety or depressive symptoms.^{9, 17} Another study of primarily spousal and adult child caregivers of lung cancer patients during the initial months of cancer care found that 50% of caregivers met clinical criteria for significant anxiety or depressive symptoms.¹⁸ Moreover, distress and subjective caregiving burden have been found to increase over time among lung cancer patients' caregivers.¹⁹

Although lung cancer patients and their caregivers have reported high rates of unmet needs for symptom management and psychosocial support,^{20, 21} few interventions have been tested to alleviate significant problems of this population.^{22, 23} A Cochrane review of non-pharmacologic interventions for lung cancer patients found preliminary evidence that nurse-delivered counseling and training in breathing and relaxation techniques are efficacious.²³ However, most trials have excluded advanced lung cancer patients and have not concentrated on cancer patients with moderate to severe symptoms.^{23, 24} In addition, caregivers have rarely been

included in intervention trials for patients with advanced cancer or lung cancer.²⁵⁻²⁸ Even when caregivers are included, the patient is typically the primary focus, and these trials have often failed to yield improvement in caregiver mental health outcomes.^{29,30} One exception is a recent pilot trial of a telephone-based dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers.³¹ The intervention reduced patient and caregiver anxiety and depressive symptoms and caregiver burden relative to usual care.

Best practices in intervention design recommend obtaining feedback from the target population throughout the research process.³² This approach is consistent with models of patient-centered care.³³ In general, patient-centered interventions are responsive to patients' and family members' needs, goals, beliefs, and preferences.³³ Conducting patient-centered intervention research involves modifying the intervention's format or content in collaboration with participants.³³ Little research has obtained feedback from cancer patients and their caregivers on the format and content of non-pharmacologic interventions prior to testing the interventions. One qualitative study found that lung cancer patients and caregivers were more receptive to non-pharmacologic interventions that addressed current problems and were delivered at a convenient time and place.³⁴ Developing interventions with input from lung cancer patients and caregivers may help enhance the feasibility of future trials. To date, researchers have faced significant challenges in study recruitment and retention of lung cancer patients due to their poor functional status and high symptom burden.³⁵

To enhance acceptability and uptake of future interventions, the present study sought to elicit feedback from advanced, symptomatic lung cancer patients and their family caregivers on a novel symptom management intervention under development. Patients and caregivers did not participate in the intervention; instead, they reviewed handouts detailing intervention

components during in-depth, qualitative interviews. We elicited feedback on a telephone intervention with the patient and caregiver concurrently participating. In contrast to most interventions with cancer patients and caregivers that primarily focus on patient concerns,^{22, 29, 36} the current intervention had a dual focus on patient and caregiver symptom management concerns identified in the literature.^{20, 21} The intervention was an innovative blend of evidence-based cognitive-behavioral and emotion-focused strategies to reduce patients' pain, fatigue, and breathlessness and patients' and caregivers' anxiety and depressive symptoms.³⁶⁻³⁹ The intervention was developed by the first author based on Social Cognitive theory,⁴⁰ prior intervention research,^{35, 37-39} and consultation with clinicians. According to Social Cognitive theory, increasing self-efficacy (i.e., one's confidence in performing a particular behavior) is a key factor underlying behavior change associated with symptom reduction.⁴⁰ The intervention was designed to enhance self-efficacy by encouraging appropriate goal setting and practice of new symptom management skills, emphasizing the benefits of practicing the skills, and changing maladaptive thoughts. The goal of the present study was to obtain patient and caregiver thoughts about the topics, length, and format of the intervention. Patient and caregiver feedback informed subsequent tailoring of the intervention to their needs and preferences prior to its formal testing in a randomized trial.

Methods

Recruitment

Advanced lung cancer patients were recruited from a university outpatient oncology clinic in the Midwestern United States. Study procedures were approved by the university's institutional review board. Purposive sampling was used to ensure diversity regarding patient gender and age. Eligible patients were English speakers who were at least 3 weeks post-

diagnosis of advanced (stage III or IV) non-small cell lung cancer. Patients receiving hospice care were ineligible because this study was designed to inform intervention development for patients who had not yet enrolled in hospice. Review of medical records and consultation with oncologists confirmed these eligibility criteria. During a clinic visit, a research assistant described the study and administered a 13-item screening questionnaire of symptom severity with the patient's verbal consent. Eligible patients had at least one physical or psychological symptom of moderate severity, defined by validated cutoffs for depressive symptoms (Patient Health Questionnaire-2 score ≥ 3 on this 0 to 6 scale);⁴¹ anxiety (GAD-2 score ≥ 3 on this 0 to 6 scale);⁴² pain (PEG score ≥ 5 on this 0 to 10 scale);⁴³ fatigue (SF Vitality score ≤ 45 on this 0-100 scale);⁴⁴ or breathlessness (Memorial Symptom Assessment Scale shortness-of-breath severity score ≥ 2 on this 0 to 4 scale).⁴⁵ During the written informed consent process, interested patients identified and permitted the study team to contact their primary family caregiver (i.e., the person who performed the majority of their unpaid, informal care).

The research assistant then approached family caregivers in clinic or via telephone to assess them for eligibility (i.e., English fluency and age ≥ 18 years) and obtain informed consent. At the time of study entry, all participants received brochures with a description of mental health services and phone numbers for these services. Staff were trained to recognize significant symptoms and make appropriate referrals. Each person received \$25 for study participation.

Data Collection

Semi-structured telephone interviews were performed by a female master's level research nurse with extensive experience conducting qualitative interviews with medically ill patients and their family caregivers. Participants did not have a prior relationship with the interviewer and were told that the research team was interested in their feedback on a new support program for

lung cancer patients and family caregivers. Participants were asked to complete the telephone interview in a private location so that patients and caregivers would be interviewed separately. Interviews were digitally recorded and were 45 to 60 minutes in length. During the interview, participants reviewed handouts on a new telephone symptom management program for lung cancer patients and their family caregivers (see Table 1). This program involved an innovative blend of non-pharmacologic strategies for reducing patient pain, fatigue, and breathlessness as well as patient and caregiver anxiety and depressive symptoms.

The interviewer first gave a general description of the telephone program and then described the first intervention component while referring to a handout. Participants answered the following questions regarding the intervention component outlined on the handout: (1) Tell me what you like. Why? (2) Tell me what you don't like. Why? (3) In your experience, how accurate is this? (4) How helpful would this be to you? To your [refers to relationship to patient or caregiver]? (5) Tell me any changes you would make. (6) Tell me anything we left out. Follow-up questions asked participants to explain their answers. This interview structure was repeated for each of the 5 handouts detailing intervention components. For handouts 2-5, participants answered questions about their experience with the intervention component prior to providing feedback on the handout (e.g., "Have you ever tried pursed lip breathing or other relaxation exercises? What was your experience?"). After discussing handout 3 which outlines pursed lip breathing, the interviewer asked participants for their "thoughts about providing a relaxation exercise that involves imagining yourself in a nice place, such as a beach or garden." Finally, participants answered general questions about the telephone program (e.g., "Would you add anything to the program? Would you leave anything out of the program?") and stated their preferences regarding the intervention modality (i.e., phone vs. in-person) and number of

sessions. Throughout the interview, the research nurse asked follow-up questions to obtain a detailed narrative. The nurse also took field notes after the interview which described the participant's demeanor and concepts that emerged from the interview. Patients' medical information was retrieved from medical records.

Analysis

Interview transcripts were imported into Atlas.ti software for qualitative analysis. Grounded theory methodology was used to inductively develop an understanding of patient and caregiver preferences with respect to the topics, length, and format of the intervention.⁴⁶ A research nurse with expertise in qualitative methods and a clinical psychologist with expertise in psycho-oncology entered this analysis within a framework of patient-centered care that incorporates patients' and caregivers' needs, goals, beliefs, and preferences.³³ The researchers reviewed the transcripts and field notes and engaged in open coding and memo-writing. Then a constant comparative analysis was conducted across participants and target groups (patients vs. caregivers).⁴⁶ The researchers independently coded the transcripts in Atlas.ti and met regularly (i.e., after the first two interviews and then after every five interviews) to review the codes and resolve differences until complete agreement was reached. During each meeting, the researchers jointly decided whether saturation had been achieved. Saturation is the point at which no new codes are identified in the data analysis, and further interviews are not expected to significantly change the codes. Once the transcripts were coded, 12 codes that were most relevant to the aim of the research were identified (see Table 2). Finally, the researchers sorted the codes into broader themes and checked to ensure that data within themes were consistent, and that the themes were distinct from one another. Themes were compared between patients and caregivers and within patient-caregiver dyads. Participants did not receive copies of the transcripts or

provide feedback on study findings. This study adheres to the consolidated criteria for reporting qualitative research (COREQ).

Results

Most lung cancer patients (38/42) who were approached regarding this study were eligible for the screening assessment. Reasons for ineligibility included cognitive impairment, the inability to speak or read, and disease status. Of the 38 patients who were eligible to complete the symptom screening questionnaire to assess their eligibility status, 87% (33/38) agreed to complete screening and 13% (5/38) declined to participate. Primary reasons for declining participation were illness and lack of interest in the study. Seventy percent of patients (23/33) showed clinically meaningful levels of pain, fatigue, breathlessness, anxiety, and/or depressive symptoms based on established cutoffs on standardized questionnaires. A significant proportion of the eligible sample reported each symptom (range = 32% for anxiety to 73% for breathlessness). Ninety-six percent of eligible patients (22/23) consented to participate in the study and allowed the research assistant to contact their primary family caregiver. One consenting patient did not complete the study interview due to hospice enrollment. Ninety-five percent of caregivers (21/22) consented to participate in this study and completed the study interview, and one caregiver could not be reached via phone. Following analysis of data from 21 patients and 21 caregivers, the researchers agreed that saturation had been reached.

Demographic and medical characteristics of the sample appear in Table 3.

Our analysis identified three types of symptom management intervention preferences among advanced lung cancer patients and their family caregivers within a framework of patient-centered care.³³ First, participants reported intervention preferences related to the patient's high symptom burden. Specifically, patients and caregivers preferred the following: (1) education

regarding treatment side effects; (2) a range of tools for coping with symptoms; (3) flexible pacing of the patient's activities that accommodates symptom fluctuations; (4) a shorter or more flexible intervention length; and (5) telephone delivery of the intervention. Second, participants wanted the intervention to have an equal focus on patient and caregiver concerns. Third, some patients and caregivers desired a more positive framework for the intervention, including the omission of materials on negative changes since the diagnosis, changing negative thoughts, and communicating thoughts and feelings. Approximately equal numbers of patients and caregivers reported each type of intervention preference, except that caregivers were more likely to desire a range of tools for coping with symptoms and an equal focus on patient and caregiver concerns. In addition, patients were more likely than caregivers to describe a preference for flexible pacing of activities. Furthermore, intervention preferences were often dissimilar within patient-caregiver dyads, with the exception of preferences for education about treatment side effects, telephone delivery, and a positive framework for the intervention. These three preferences were consistent between dyad members in about half of cases. Each set of intervention preferences is described below, and quotes regarding each preference are provided in Table 4.

Intervention Preferences to Address High Symptom Burden

Patients and caregivers reported a range of preferences to enhance the intervention's feasibility and acceptability for individuals with high symptom burden. First, education regarding treatment side effects, including possible symptoms, functional limitations, and emotional responses, was a common preference among patients and caregivers. Participants wanted written and verbal reassurance from clinicians that their symptoms were a normative aspect of treatment. Second, many patients and caregivers desired a range of tools for coping with physical and psychological symptoms and noted that their needs may change over time. For

example, when reviewing a handout on pursed lip breathing, some participants stated that a menu of options for relaxation should be presented to patients and caregivers. These options included yoga, massage, music, aromatherapy, imagery, progressive muscle relaxation, and the use of a focal point for relaxation. A few participants wanted their faith-based coping strategies to be integrated into the intervention, such as reading devotional books and discussing existential issues.

Another intervention preference to address the patient's high symptom burden was the desire for flexible pacing of activities. This pacing would take into account fluctuations in fatigue and other symptoms. Rather than setting specific time limits for activities and rest periods, participants suggested providing general advice to stop activities and rest when experiencing symptoms, such as fatigue, a racing heartbeat, or breathlessness.

Other preferences to accommodate high symptom burden included having a shorter or more flexible intervention length and providing the intervention via telephone. The interviewer asked participants for their thoughts about holding four, 45-minute telephone sessions with the patient and family caregiver participating together. Many patients and caregivers desired greater flexibility regarding the number, timing, and length of sessions, as participant needs, schedules, and symptom severity change over time. In addition, some participants preferred 30-minute sessions or fewer sessions. A few participants stated that four, 45-minute sessions were adequate, and only one participant desired more sessions. When asked to provide their thoughts about delivering the intervention via telephone, the majority of patients and caregivers preferred the phone modality and noted its convenience, especially for those with physical limitations. In addition, some participants said that they would disclose their thoughts and feelings more readily via the telephone and feel a greater sense of "freedom and control" relative to a face-to-face

session. The minority of participants who preferred one or more in-person sessions cited the impersonal nature of phone interactions.

Equal Focus on Patient and Caregiver Concerns

Some participants, almost all of whom were caregivers, stated that the intervention materials on changes since the diagnosis, helpful thoughts, and pursed lip breathing pertained more to the patient than the caregiver. For example, some materials listed physical symptoms (e.g., pain, coughing) that only applied to patients. Some caregivers suggested that intervention materials should equally focus on patient and caregiver concerns and noted their own fatigue and significant caregiving responsibilities.

More Positive Framework

Some patients and caregivers desired a more positive framework for the intervention. First, some participants thought that the handout on changes since the diagnosis, such as increased symptoms and activity restriction, should be omitted. Although most participants could identify with these changes, they noted their acceptance of the illness and characterized further illness-related discussions as “depressing.” Second, some participants stated that the exercise of challenging negative thinking would only increase their negative thoughts. Other participants wanted to replace this exercise with faith-based strategies for avoiding negative thoughts, including prayer and Bible reading. Finally, a few participants stated that reviewing tips for communicating thoughts and feelings would lead to criticism and negative emotional exchanges with family members.

Discussion

In this study, advanced, symptomatic lung cancer patients and their family caregivers provided feedback on a novel symptom management intervention for patient-caregiver dyads.

Obtaining such feedback is consistent with models of patient-centered care that incorporate patients' and caregivers' needs, goals, beliefs, and preferences.³³ The current telephone-delivered intervention included cognitive-behavioral and emotion-focused strategies for managing patient physical symptoms and patient and caregiver anxiety and depressive symptoms.³⁶⁻³⁹ Following a review of intervention materials, patients and caregivers reported intervention preferences related to the patient's high symptom burden such as education regarding treatment side effects and the provision of a range of coping tools. Some participants also desired an equal focus on patient and caregiver concerns throughout the intervention and a more positive framework for the intervention (e.g., omitting discussion of negative changes since the diagnosis). All of these preferences underscore the severity of the disease and treatment process for advanced lung cancer patients and caregivers and the need to adapt interventions to highly symptomatic patients with life-limiting illness.

A number of intervention preferences pointed to the need to accommodate and reduce the patient's high symptom burden. First, patients and caregivers desired education regarding potential physical symptoms, functional limitations, and emotional responses prior to cancer treatment. This preference is consistent with literature suggesting that providing practical details regarding cancer treatment and psychoeducation reduces patient and caregiver psychological distress.^{22, 24} In addition, interventions to alter expectations regarding treatment side effects may lead to reductions in patient physical symptoms.⁴⁷ Further research is needed to assess the impact of patient and caregiver preparation for treatment side effects on health outcomes.

Another common intervention preference in our study was the desire for a range of coping tools. This preference was more prevalent among caregivers than patients, reflecting their need for diverse resources in assisting the patient. For example, participants suggested

providing options for relaxation such as yoga, massage, music, and imagery. Similarly, another qualitative study of lung cancer patients and caregivers found wide variation in the components that they desired in a non-pharmacologic intervention for symptom management.³⁴ Overall, research suggests that this population may be most receptive to a menu-based service that takes into account their changing needs and preferences.

Another intervention preference, primarily expressed by patients, was flexible activity pacing. Rather than setting specific time limits for activities and rest periods, participants preferred general advice to pace activities based on their level of fatigue and other symptoms. Researchers have recognized the need to modify activity pacing for advanced cancer patients. Specifically, Greer and colleagues⁴⁸ have suggested creating several activity schedules that vary according to the patient's symptom level.

The preferred format of the intervention in the current study also accommodated the patients' high symptom burden. Specifically, when asked for their thoughts about having four, 45-minute telephone sessions jointly delivered to the patient and caregiver, many participants wanted a shorter or more flexible session length. In addition, the majority of participants preferred the telephone modality as compared to in-person sessions and cited the convenience and greater openness during conversation when receiving professional support via telephone. Testing technology-based interventions is an important future direction for cancer symptom management research.⁴⁹

In addition to modifying the intervention to accommodate patient symptoms, some participants, almost all of whom were caregivers, desired an equal focus on patient and caregiver concerns throughout the intervention. For example, it was suggested that study materials include an equal number of changes since the diagnosis that apply to patients and caregivers. The desire

to shift from a patient-focused intervention to a dyad-focused intervention points to the shared psychosocial burden of lung cancer as well as caregivers' critical role in patient care.

Another suggestion, expressed by a minority of patients and caregivers, was the omission of negative content from the intervention, such as discussion of changes since the diagnosis. By omitting negative content, participants sought to avoid conflicts with family members and negative emotions related to the illness. However, avoidance coping strategies such as denial and thought suppression have generally been associated with greater distress over time in cancer patients.⁵⁰ Further research is needed to determine for whom and under what conditions expression of negative thoughts and feelings is adaptive. In addition, some participants wanted to replace negative intervention content with faith-based strategies (e.g., prayer). Thus, religious participants may be receptive to challenging negative thoughts with faith-based beliefs and incorporating their religious practices into interventions.

Limitations of this study should be noted. The sample primarily consisted of Caucasian individuals from the Midwestern U.S. with the range of cultural and religious beliefs typical of the region; however, we had adequate saturation, and findings should be transferrable to similar populations. In addition, this study provides a cross-sectional analysis of advanced lung cancer patient and caregiver intervention preferences, which may change over time. Future longitudinal research should document intervention preferences at different phases of the illness (e.g., diagnosis, active treatment).

Implications

Findings have implications for future symptom management intervention trials with advanced lung cancer patients and caregivers. First, we made a number of revisions to our intervention, including the use of more coping tools, flexible activity pacing that accommodates

symptom fluctuations, and materials that equally focus on patient and caregiver concerns. This revised intervention is being tested in an efficacy trial. Although efficacy trials with this population are an important initial step, standardization of interventions in these trials conflicts with participants' desire for flexibility in intervention content and length. Thus, once intervention efficacy is determined, effectiveness research is needed to document intervention uptake and outcomes as its content and format are adapted to real-world settings. Greater attention to advanced lung cancer patient and caregiver intervention needs and preferences in future studies should result in greater intervention adoption, implementation, and maintenance and more patient-centered care.

Findings also suggest that oncology nursing efforts are needed to prepare advanced lung cancer patients and caregivers for the disease and treatment process. Given that patients and caregivers desired education regarding treatment side effects, a joint conversation with both dyad members prior to treatment may be beneficial. In addition, caregivers were more likely than patients to desire a range of tools for managing symptoms; thus, directing caregivers to resources for symptom management may lead to better health outcomes for both patients and caregivers. Finally, flexibility with respect to the length, timing, and modality of intervention delivery may enhance their feasibility for highly symptomatic patients.

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Table 1. Summary of Print Materials for a Symptom Management Intervention Reviewed by Advanced Lung Cancer Patients and Their Family Caregivers

Topic	Examples of Handout Content
An overview of intervention sessions 1-4 is provided.	<p data-bbox="602 464 1044 499">Handout 1: Overview of Sessions:</p> <ul data-bbox="654 541 1401 947" style="list-style-type: none"> <li data-bbox="654 541 979 577">• Session 1: Relaxation <li data-bbox="654 619 1360 720">• Session 2: Coping with thoughts and feelings about cancer <li data-bbox="654 762 1328 798">• Session 3: Communicating thoughts and feelings <li data-bbox="654 840 1401 947">• Session 4: Maintaining focus: Finding time for what is important to you
Changes since the lung cancer diagnosis are discussed.	<p data-bbox="602 989 1114 1024">Handout 2: Changes with Lung Cancer:</p> <ul data-bbox="654 1066 1422 1398" style="list-style-type: none"> <li data-bbox="654 1066 1369 1102">• Bodily responses (e.g., fatigue, breathlessness, pain) <li data-bbox="654 1144 1422 1180">• Activity level (e.g., cutting back on activities you enjoy) <li data-bbox="654 1222 1146 1257">• Feelings (e.g., sad, anxious, angry) <li data-bbox="654 1299 1369 1398">• Thoughts (e.g., thoughts about symptoms, treatment concerns)
Steps of pursed lip breathing are provided.	<p data-bbox="602 1440 1036 1476">Handout 3: Pursed Lip Breathing:</p> <ul data-bbox="654 1518 1433 1850" style="list-style-type: none"> <li data-bbox="654 1518 1073 1554">• Sit in a comfortable position. <li data-bbox="654 1596 1360 1696">• Take an easy breath through your nose. Slowly and gently squeeze your air out through pursed lips. <li data-bbox="654 1738 1433 1850">• Remember to relax and to not put much pressure on your chest.

<p>Replacing negative thoughts with more helpful thoughts is discussed.</p>	<p>Handout 4: Helpful Thoughts:</p> <ul style="list-style-type: none">• Several examples of replacing negative thoughts with more helpful thoughts are provided (e.g., changing thoughts related to symptoms and limitations in activities).
<p>Tips for communicating thoughts and feelings are reviewed.</p>	<p>Handout 5: Tips for Communicating Thoughts and Feelings:</p> <ul style="list-style-type: none">• Practice saying your thoughts out loud.• Look directly at a person when speaking to them and have an open rather than a closed posture.• Think of a time and place that is convenient for both people.
<p>A method of activity pacing is discussed.</p>	<p>Handout 6: Pacing Activities:</p> <ul style="list-style-type: none">• Identify an activity that you tend to overdo.• Set a time limit for this activity and a subsequent rest period.• Keep track of the number of times that you stop yourself from overdoing this activity.

Table 2. Coding Scheme for Patient and Caregiver Feedback on Symptom Management**Intervention**

Theme	Codes
Intervention preferences to address high symptom burden	<ul style="list-style-type: none"> • Education about treatment side effects • Preference for more coping tools • Flexible activity pacing • Intervention is too lengthy • More flexible timing of intervention • Preference for phone sessions
Equal focus on patient and caregiver concerns	<ul style="list-style-type: none"> • Materials are too patient-focused • Equal focus on patient and caregiver concerns
More positive framework	<ul style="list-style-type: none"> • General comment: more positive framework for intervention • Omit discussion of changes since diagnosis • Omit discussion of negative thoughts • Omit discussion of communication tips

Table 3. Patient and Caregiver Characteristics (N = 21 Lung Cancer Patient-Family Caregiver Dyads)

Variable	n (%)	M (SD)	Range
Caregiver's relationship to the patient			
Spouse/partner	12 (57)		
Adult child	4 (19)		
Sibling	5 (24)		
Caregiver lives with the patient	14 (70)		
Patient gender—female	11 (52)		
Caregiver gender—female	15 (71)		
Patient race/ethnicity			
Non-Hispanic White	18 (86)		
African American/Black	3 (14)		
Caregiver race/ethnicity			
Non-Hispanic White	18 (86)		
African American/Black	3 (14)		
Patient marital status			
Married or marriage equivalent	15 (71)		
Single, divorced, or widowed	6 (29)		
Caregiver marital status			
Married or marriage equivalent	17 (81)		
Single or divorced	4 (19)		
Patient age (years)		63 (12)	39-80
Caregiver age (years)		58 (12)	38-78
Patient education (years)		13 (2)	8-18
Caregiver education (years)		14 (3)	10-21
Patient annual household income (median)		>\$50,000	<\$21,000 - >\$100,000
Caregiver annual household income (median)		>\$50,000	<\$21,000 - >\$100,000
Months since the patient's lung cancer diagnosis		15 (15)	1-52

Non-small cell lung cancer stage	
Stage III	5 (24)
Stage IV	16 (76)
Lung cancer treatment type	
Surgery	7 (33)
Chemotherapy	16 (76)
Radiation	6 (29)
Chemoradiation	4 (19)

Abbreviations: M, Mean; SD, standard deviation.

Table 4. Patient and Caregiver Feedback on Symptom Management Intervention

Key Finding	Examples of Patient or Caregiver Quotations
Intervention preferences to address high symptom burden	
<ul style="list-style-type: none"> • Education about treatment side effects 	<p>I definitely wish somebody would have given me a handout in the beginning just telling me what to expect because my doctor sure didn't. Honestly, I guess in the beginning maybe I didn't want to know all the terrible side effects and things that were going to happen (39-year-old female patient).</p> <p>. . . you get a lot of symptoms you don't know are normal or not and you just want somebody to talk to, to let you know that this is normal and everything is okay (52-year-old female patient).</p>
<ul style="list-style-type: none"> • Provision of a range of coping tools 	<p>. . . you could give more relaxation techniques . . . maybe soft music . . . maybe some aromatherapy. Just baby and treat yourself well. . . . I would massage [the patient's] legs (70-year-old wife of the patient).</p> <p>. . . this exercise here [pursed lip breathing] was good, but it wouldn't work in an emergency situation. . . . Different things work for different people and</p>

	<p>they work for different people at different times and situations. [The clinician could say] here's a menu of things you can try (45-year-old daughter of the patient).</p> <p>. . . he [my husband] needs to cope with the fact that he might die--well that he's going to die from this. I don't think that he's really truly accepted it because . . . he's told me before "I don't want to die" (42-year-old wife of the patient).</p>
<ul style="list-style-type: none"> • Flexible pacing of daily activities 	<p>I really can't set a time limit [for an activity] . . . because it just depends on what it is, the temperature outside, how I feel that day. . . [patients] need . . . to recognize when they need to rest rather than set a specific time limit (65-year-old male patient).</p> <p>I think your time limit [for an activity] . . . is going to be different at different times. . . . depending upon how fatigued they are to begin with, or whether they've slept well that night (70-year-old wife of the patient).</p>
<ul style="list-style-type: none"> • Shorter or more flexible intervention length 	<p>. . . a lot of times [the session length] may depend on how that person feels that day. Because some days if you call, I may not feel like a session 45</p>

	<p>minutes long (68-year-old female patient).</p> <p>It's pretty lengthy. I might suggest it be cut down a little bit on time to maybe 30 minutes or so. I don't know if you could get through all of the material (64-year-old sister of the patient).</p>
<ul style="list-style-type: none"> • Phone modality 	<p>I myself would probably be more apt to speak a little more freely about my feelings over the phone. And I think [the patient] might also instead of being . . . face to face with someone. I think he would be more open (64-year-old sister of the patient).</p> <p>In a lot of ways [providing the sessions over the phone] may even be less stressful. There's no appointments that you had to make . . . [the patient] didn't have to get dressed or go out anywhere to do anything. And in some ways I think it would give you a little bit more freedom and control not to be face to face in front of each other (47-year-old sister of the patient).</p>
<p>Equal focus on patient and caregiver concerns</p>	<p>[Referring to handout on changes since the diagnosis] I'm sad. I'm anxious. I'm angry. Yes. I'm very much that way because nobody wants to lose a loved one. But he's the one that's overloaded with responsibilities. He's the</p>

	<p>one that feels like he's a burden. . . . I don't know if [the intervention] really pertains to me . . . as much as it does to him (64-year-old sister of the patient).</p> <p>[Referring to handout on changes since the diagnosis] it's absolutely geared to the patient, which is fine, but it would be helpful to have an advocate [the caregiver] or to think about that in this process (72-year-old male patient).</p>
<p>More positive framework</p>	
<ul style="list-style-type: none"> • Omit handout on negative changes since the diagnosis 	<p>. . . if you look at all of the things [on the handout], it's all depressing-- fatigue, breathlessness, pain, cutting back on his activities, having to changes his plans, we're sad, angry, overwhelmed. There's nothing really to like about that (38-year-old male partner of the patient).</p> <p>I've talked about it [the cancer]. I'm dealing with it. And going back and stirring up these things [by reviewing the handout] . . . it's like dealing with it again. I don't. It's there. It's done, you know. And get on with it. That's the way I feel about it. (69-year-old female patient).</p>
<ul style="list-style-type: none"> • Omit handout on replacing negative thoughts 	<p>It [the handout] wouldn't be helpful Because I go to my Bible and read</p>

<p>with more positive thoughts</p>	<p>the Psalms and then I'm good to go. And if I start feeling a little down . . . or too tired, I read some more Bible (74-year-old female patient).</p> <p>. . . for me to even think about sitting on the phone with a counselor, thinking about my negative thoughts, I'd probably be getting negative thoughts, and I'd want to get off the phone (59-year-old wife of the patient).</p>
<ul style="list-style-type: none"> • Omit handout with tips for communicating thoughts and feelings 	<p>You know my family is just so positive . . . when I say anything negative or [I am] not feeling well all I get is oh get out of your pity party So I don't feel like I could talk to my family about these things cause they . . . think I should be brave and I shouldn't have a pity party (52-year-old female patient).</p> <p>. . . obviously I don't tell [the patient] how I'm feeling right now because it would probably hurt her feelings. And it probably wouldn't help me</p> <p>My frustration is she doesn't always do what the doctors tell her she can flare at me if I correct her (54-year-old sister of the patient).</p>