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Pilot Study of a Communication Coaching Telephone Intervention for Lung Cancer Caregivers

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Abstract

Background—Family caregivers are a key communication source for nurses and there is a need to provide communication skills building for caregivers.

Objectives—A pilot study was conducted to determine feasibility and utility of a communication coaching telephone intervention aimed at improving caregiver confidence in communication and reducing psychological distress.

Methods—A printed communication guide for caregivers and a one-time communication coaching call delivered by a research nurse was provided to caregivers. Recruitment and attrition, implementation and content of coaching calls, caregiver outcomes, and satisfaction with intervention were analyzed.

Results—Twenty caregivers were recruited across four cohorts: diagnosis, treatment, survivorship, and end of life, with recruitment above 70%. Caregiver calls averaged 37 minutes and the majority of caregivers reported communication challenges with family members. Caregiver action plans revealed a need to develop communication skills to ask for help and share information. Caregivers reported satisfaction with the print guide and 90% of caregivers followed through with their action plan, with 80% reporting that the action plan worked. Caregiver confidence in communication with healthcare providers was improved, except for caregivers of cancer survivors.

Conclusions—Recruitment and attrition rates demonstrate feasibility of the intervention. Caregivers reported that the communication coaching telephone intervention was considered valuable and they were able to implement a communication action plan with others.

Implications for Practice—Lessons were learned about intervention content, namely that nurses can help caregivers learn communication strategies for asking for help, sharing cancer information, and initiating self-care.

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Keywords

cancer; communication; family caregiver; coaching; lung cancer

Currently, interventions for family caregivers do not specifically target communication skill building to support the caregiver's communication role and improve caregiver confidence in communication with patient, family, and healthcare providers. However, interventions with communication skills training have shown to be an option with good results. A recent study found that a family-oriented communication skills training program for older adults reduced depression, anxiety, and stress.¹ Developing the confidence of caregivers to communicate with others about cancer is a key caregiving skill² and interventions to develop caregiver communication skills are needed.

While telephone coaching is not novel in cancer intervention research, most interventions have been based on problems identified by researchers rather than tailored to the unique needs of patients.³ Additionally, coaching interventions have been primarily offered to cancer patients and survivors and have not included family caregivers. There is a vital need for lung cancer caregivers, in particular, to develop confidence in communication as they report feeling responsible for the psychological well-being of the patient⁴ and attempt to protect the patient and maintain hope by avoiding discussions about the diagnosis and illness trajectory.⁵ The desire to protect each other results in topic avoidance between caregiver and patient, impacting communication with other family members and healthcare providers. In the absence of open communication, caregiver depression results from low quality relationships among family members, a lack of emotion from the patient, and greater conflict.⁶ Communication constraints can be a barrier to quality care⁷ and potentially influence caregiver distress. This study explored the feasibility and utility of a nurse-delivered communication coaching telephone intervention specifically designed to improve caregiver confidence in communication and reduce psychological distress by supporting caregivers in their communication about cancer with others.

Theoretical Framework

The Cancer Family Caregiver Experience⁸ framework outlines context, primary stressors, appraisal of caregiving, and secondary stressors as antecedents of caregivers' and patients' health and well-being. The framework depicts that family caregivers manage caregiving within a family system, which influences secondary stressors (family communication patterns about illness that reveal role changes, changes in family structure, lifestyle changes as a result of illness) and shapes their cognitive/behavioral responses (communication apprehension), ultimately impacting both caregiver and patient health and well-being. Prior research on caregiver stress and coping has determined that communication is a central part of the stress process model as communication is one way caregivers manage interpersonal challenges, especially in communicating emotions.⁹

Using this framework, we designed a nurse-delivered communication coaching telephone intervention to provide knowledge and skills building to help caregivers develop positive appraisals of caregiver through preparedness and to strengthen the coping process by

improving communication with patient, family, and healthcare providers. The caregiver's communication skills may be an intervening variable that explains the relationship between two variables of the stress process leading to better outcomes.

Methods

The pilot study was conducted at a comprehensive cancer center in the Western United States. The study was approved by the cancer center's institutional review board (IRB #15359) and written consent was obtained.

Intervention

The intervention consisted of a print copy of *A Communication Guide for Caregivers*¹⁰ and a nurse-delivered communication coaching telephone call. The guide has four sections for caregiver communication with the patient, local family, family who are far away, and healthcare providers. Each section identifies communication challenges, example language, questions for reflection, questions to ask providers, and ways to share information with others. Development of the guide has been described elsewhere¹¹ and table 1 shows the table of contents. The guide is written at the sixth grade level and meets health literacy standards. Caregivers have previously reported that content is relatable, useful, and easy to read. Healthcare providers have also rated the material as easy for patient/family members of diverse backgrounds and varying levels of literacy to understand and use.

Although coaching interventions are typically conducted longitudinally, a one-time call was initially tested in this pilot to confirm caregiver acceptance of communication skill building and because telephone-based coaching is an effective format for caregiver interventions that ensures flexibility and adaptability.¹² Table 2 shows an overview of the content of the intervention coaching call. The research nurse attended a two-day communication training course to develop communication coaching skills, which included instruction on family caregiver communication characteristics, active listening skills, and how the nurse can use open-ended questions to meet the caregiver's communication style. The PI of the study also met with the research nurse weekly to discuss study protocol, provide feedback on coaching calls, and review data.

Participants

Eligibility criteria included age 18 years of age or older, English-speaking, and primary family caregiver as identified by the lung cancer patient. Five caregivers were recruited in each cohort based on the cancer care continuum: cohort 1 - diagnosis (patient diagnosis received within last 45 days but had not yet started treatment); cohort 2 - treatment (patient started initial treatment within last 30 days with prognosis of more than one year); cohort 3 - survivorship (patient had completed treatment and clinically disease free at time of caregiver enrollment); and cohort 4 - end of life (patient estimated to have 6 months or less to live).

Intervention Implementation

Patients receiving outpatient care were screened by the oncologist and research nurse to identify potential caregivers in each cohort. Cohort eligibility was confirmed via medical

records and oncologist consultation. Eligible caregivers were approached in the clinic and written consent was obtained. Caregivers who received the intervention were given a copy of the guide upon consent and participated in a communication coaching call scheduled one week from study consent. Communication coaching calls were audio-recorded and transcribed.

Caregiver Outcomes

All caregivers completed baseline and follow-up measures of psychological distress and caregiver confidence in communication by phone one month after the coaching call. The psychological distress thermometer is an efficient tool to evaluate caregiver distress over the past week, based on a scale of 0 to 10, and is included in the National Comprehensive Cancer Network Psychological Distress guidelines.¹³ A score of 5 or above indicates a need for intervention¹⁴ and appropriate support referrals are made, such as social work services, pastoral counseling, and psychological treatment.¹⁵ The distress thermometer has a sensitivity of $\alpha = 0.87$ and specificity of $\alpha = 0.72$ for detecting clinical levels of distress.^{14,16}

The caregiver confidence in communication survey was developed by the research team for this study to measure caregivers' confidence communicating with patient, family members, and healthcare providers across four specific topic areas (cancer diagnosis, cancer treatment and goal of treatment, symptom management including managing pain and side effects, and broader life topics such as spirituality and stress from caregiving). Caregivers rated their communication confidence using a likert scale rating from 0 (not confident) – 10 (very confident).

Finally, the research nurse conducted a brief phone interview with the caregiver regarding intervention satisfaction at one month. Caregivers were asked to report how satisfied they were with the printed guide, how prepared they felt to carry out their action plan, whether or not they carried out the action plan, and if the action plan worked.

Data Analysis

Transcripts from the coaching calls and satisfaction interviews were analyzed using content analysis and demographic data were summarized. The Wilcoxon rank sum test was used to compare baseline and post-intervention metrics for each cohort.

Results

Recruitment and Attrition

Thirty-two caregivers were approached and 72% of eligible caregivers consented (n=23). Six caregivers declined study participation due to lack of interest, two reported that they were too busy, and one declined due to health reasons. Three caregivers were lost to attrition across cohorts due to lack of interest (cohort 4 - end of life), non-response (cohort 3 - survivorship), and declining patient health (cohort 1 - diagnosis). The mean age of caregivers was 56.1 years. Most caregivers were Caucasian (80%), female (70%), and college-level educated (75%). The majority of caregivers were spouse/partner (65%).

Implementing Coaching Calls

Communication coaching calls averaged 37 minutes (range, 11 minutes – 85 minutes). Although all consenting caregiver completed the communication coaching call, there was difficulty scheduling the calls due to caregiver availability. Overall, eight caregivers completed the communication coaching within one week from consent. On average, calls took place within two weeks. One caregiver from cohort 4 (end-of-life) did not complete the communication coaching until 54 days post consent.

Only half of caregivers participated in role-play during the call. Caregivers were reluctant to try role-playing their communication challenge with the research nurse. In many cases, caregivers just wanted to talk in general about communication approaches rather than try a new communication strategy. Caregivers politely avoided role-play with the nurse by explaining that there were other people available for support, talking in general about how to use the communication strategy, or focusing on how their self-care needs were being met. Below are some examples:

- In one instance, a caregiver focused on ways to be present with the patient and initiated a discussion about nonverbal communication and ways she could communicate respect to the patient.
- When the nurse attempted to role-play ways to share information with a child, the caregiver responded by talking in general about the many topics to cover in the conversation.
- After identifying the need for self-care, including a physical exam, the caregiver deflected an attempt to role-play by explaining that her husband, sister and brother-in-law support all of her caregiving efforts.

Reported Challenges During Calls

Nine caregivers (45%) reported that family was the most challenging to talk to about cancer, followed by the patient (30%) and healthcare providers (15%). Two caregivers reported no communication problems. Family communication challenges were embedded in prior family experiences, reflecting fears of loss, fear of causing stress to others, and not knowing how to initiate conversations or what questions to ask. A caregiver from cohort 4 (end-of-life) explains that communication with her siblings is difficult:

“Sometimes they refuse to hear or see above my mom’s illness or they don’t bother to ask. I have to take the initiative and make the conversation ... and I have to do it one at a time. I’m not going to talk with all of my brothers at the same time.”

Although most caregivers did not initially identify communication challenges with healthcare providers, coaching calls often detailed the caregiver’s self-described inability to communicate with providers caused by nervousness, a desire to avoid certain conversations, daunting medical jargon, fast-paced conversations, language barriers, and not knowing what questions to ask. When asked who was most difficult to talk with, one caregiver responded: “I would say probably the healthcare provider just because ... It’s not her, it’s me. The inability to communicate. I’ve always had a hard time.”

Patient communication challenges were less frequent in coaching call discussions and focused almost exclusively on fear of discussing the future and frustration with cognitive decline. A caregiver from cohort 1 (newly diagnosed) shared that her number one communication challenge was “the nervousness and communicating about the disease and my mother and then not wanting to go in certain directions with the conversations.”

Caregiver Action Plans

During the coaching call, caregivers worked with the research nurse to develop a personal action plan based on a self-identified communication challenge. Based on the caregiver’s unique circumstances, the research nurse identified strategies in the communication guide to assist the caregiver in developing an action plan for communicating with others. Caregiver action plans varied and there were four main challenges present across all caregiver action plans: asking others for help or to do something specific, sharing information about cancer with family members, being present for the patient, and initiating self-care. Table 3 provides a summary of caregiver action plans by themes.

Caregiver Outcomes

A comparison of mean scores showed improvement in caregiver confidence in communication across caregivers in each cohort except for the survivorship cohort (table 4). Combined results from all four cohorts showed statistically significant improvement in confidence with healthcare providers ($p=.01$). The average decline in stress was .09 on the distress thermometer, however caregivers in cohort 4 (end of life) had increased stress from baseline (mean 4.2 out of 10) to one-month follow-up (mean 4.8).

Caregiver Satisfaction with Intervention

Caregivers reported that they were very satisfied (60%) and somewhat satisfied (25%) with the print guide, however one caregiver described the guide as a painful reminder that his wife was sick and two caregivers shared that the guide was not useful for them. “It was not very helpful. It’s been six years since my wife’s diagnosis and I have done most of the things suggested in the guide,” explained one caregiver in cohort 3 (survivorship). On the other hand, caregivers in cohort 4 (end-of-life) found the guide “informative, enlightening, and very helpful”. One caregiver explained, “It helped me understand and accept the challenges ahead of me.” Several caregivers commented that the guide was easy to read, yet they found it “too simplistic” and “too generalized”, desiring more information specific to their family situation. Table 5 outlines caregiver satisfaction with the intervention by cohort. Caregivers from all cohorts reported feeling generally prepared and 90% of caregivers followed through with their action plan, with 80% reporting that the action plan worked. “I have better tools in my toolbox... I feel confident,” shared one caregiver.

Discussion

This is the first study to evaluate the feasibility of a communication coaching telephone intervention developed for family caregivers of lung cancer patients using a tailored approach that allows caregivers to identify communication challenges. Recruitment in an outpatient cancer care clinic was successful and the enrolled-to-consent rate of caregivers

was similar to other nurse-led intervention research,¹⁷ averaging more than 70%. Recruitment with the support of the oncologist was effective and needs to be considered for a larger trial.

There are several implications for intervention delivery in a future randomized controlled trial. For example, caregivers were reluctant to participate in role-play during the call. Caregiver discomfort with role-playing a scenario with the nurse indicates that intervention content may need revision, such as focusing more on reviewing communication skills in the print guide. Although role-play activities have been shown to be an effective teaching tool for communication skill building in healthcare provider training,^{18–20} this study suggests that role-play may not be an appropriate communication skill building activity for caregivers. A future trial would need to consider ways to discuss what the caregiver might say rather than attempting a formal role-play with the nurse. Scheduling coaching calls with caregivers also proved to be challenging, with a one-week expected time frame from consent to scheduled call difficult for caregivers to achieve. This pilot study demonstrates that two weeks is more appropriate. Providing availability of the guide in digital format may also increase the flexibility of the intervention study design. In line with lung cancer patient and caregiver preferences for intervention delivery, the telephone intervention was acceptable.²¹ As more and more supportive care is being delivered to caregivers by phone, and caregivers also desire more support by phone, there is a need for both clinicians and research personnel to develop better phone skills to improve interactions with caregivers.

Similar to other lung cancer caregiving research,^{4,22} this pilot study found that common communication challenges experienced by caregivers occur with family members. Caregivers predominantly identified family as the most challenging to talk to about cancer and their action plans centered on communication skills with family members. Overall there was less importance placed on caregiver-patient communication during coaching calls and within action plans, suggesting that future communication interventions should concentrate on caregiver skills with providers and/or family members.

This study highlights four key areas for communication skill development for lung cancer caregivers. First, caregivers need to learn effective ways to ask for help from others in a manner that makes them feel comfortable. Information and healthcare services remain among the top unmet supportive care needs of lung cancer caregivers and healthcare service needs are associated with caregivers' fatigue.²³ Second, caregivers need tools for how to share information about the patient's cancer with others. The ability and willingness to sharing information about cancer has been shown to improve the patient's quality of life²⁴ and may have a similar effect on caregivers. Future research should explore the impact of information sharing on caregivers, as recent research has found that complicated grief symptoms are higher among families with family members who had difficulty accepting the illness.⁷ For example, the use of communication facilitators (trained nurses and social workers) to support communication between clinicians and families in the intensive care unit has been shown reduce family distress.²⁵ Third, caregivers need to learn how to be present for the patient by recognizing specific nonverbal behaviors that can indicate poor psychological well-being. Fourth, caregivers need encouragement to recognize and initiate self-care. Action plans developed by caregivers in this study demonstrated that talking about

caregiving prompted thinking about self-care needs. More research on caregiver communication skill and ability and impact on quality of life are warranted.

A recent qualitative study with lung cancer patients and caregivers revealed a desire for educational interventions that focus on adverse effects and the provision of various coping skills.²¹ Similarly, in a palliative care intervention study for lung cancer caregivers, which had a significantly positive impact on caregiver quality of life, symptom management strategies were a top priority across the four educational sessions of the quality of life intervention.²⁶ Findings in this pilot study suggest that caregiver education should include attention to communication skills in order to combine both knowledge needs for symptom management as well as communication skills to aid in coping with symptom management responsibilities. It has previously been surmised that coaching builds confidence by reinforcing the participants' efficacy expectation and confidence in communication can therefore be improved by creating an awareness of one's own communication approach and style.²⁷ This may account for the disparity between the content of the action plans developed by caregivers, which centered on family communication, and outcome results showing improved caregiver confidence with healthcare providers about the patient's treatment and side effects. The tailored intervention approach, which allowed caregivers to self-identify a communication challenge for the coaching call, suggests that these skills are applicable to others. Further research is required to formally evaluate the impact of caregiver communication coaching on communication in clinical visits with providers and patient outcomes.

Recruitment strategies developed for future work should target caregivers of patients who are newly diagnosed, undergoing treatment, or at the end of life. While there is a need to improve patient-centered communication between healthcare providers and cancer survivors,²⁸ this intervention did not result in improved caregiver confidence in communication for caregivers of cancer survivors. Still, the one-time communication skills development session with a research nurse resulted in a communication action plan that could be carried out by the caregiver. Furthermore, distress may be the wrong outcome variable to assess study effectiveness.

This study was limited by the use of a small and select sample, thus observed differences among the cohorts may not be meaningful. While natural improvements to caregiver outcomes may occur over time irrespective of the intervention, statistically significant improvements are not common in small sample sizes. Notably, caregivers in the study were primarily Caucasian and college-educated and the study is thus limited by a lack of cultural diversity. Further research is needed to explore how communication difficulties vary among other races and with lower education levels. Given that the guide is written at a low literacy level, and most caregivers in this sample were college-educated, there is a need to evaluate the intervention with caregivers with low education and non-English speaking backgrounds. Finally, although caregivers were able to carry out their action plan, results of the action plans remain unknown and communication barriers may be culturally linked.

As family caregivers increasingly become clinician partners in oncology care, nurses are challenged to prepare family caregivers for their role. This study has captured the important

role of family caregivers in cancer care and illustrates the need to provide support as caregivers face communication difficulties related to caregiving tasks and decision-making. Key implications for nursing practice include the need to assess for communication between family caregivers, patients, and other members of the family. Identifying caregivers who may benefit from communication coaching is vital to ensure caregiver involvement in cancer care. This study demonstrates that a one-time telephone coaching intervention can help caregivers with communication challenges. Including communication skills building as part of caregiver support is important as caregiver concerns vary over time. The nurse's ability to support caregivers is essential to quality cancer care, including teaching caregivers how to ask for help, how to share information with others, how to recognizing patient nonverbal behavior, and how to convey the need for self-care.

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Table 1Overview of Contents for A Communication Guide for Caregivers[©]

Table of Contents
Section 1 • Communication with the Patient
How do I take care of someone with cancer?
What should I care with the patient/family member?
What if we don't agree?
Section 2 • Communication with Other Family Member
Who is family?
How do I talk about cancer with my family?
Why is talking about cancer difficult?
How can my family help me?
Section 3 • Communication with Family Members who are Far Away
What is it like to be a family member far away?
What does the cancer journey look like?
Section 4 • Communication with Health Care Providers?
What do health care providers need from me?
What can I ask a health care provider?
What if I can't do what is asked?

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Table 2

Communication Coaching Telephone Intervention

Question
Who is the most challenging to talk to about cancer? Probe: Patient, Family members, or Healthcare Providers
What is most challenging for you to talk about? Probe: What barriers keep you from communicating better? Probe: What is happening that makes communication difficult?
When you think about having to talk about cancer, and you know it will be challenging, how does this impact you? Probe: Physically? Psychologically? Socially? Spiritually?
Let's review the guide and select a strategy that may work in this situation or select an exercise.
Let's develop a personal action plan for you to improve the communication you have described as challenging.
Let's role-play the potential solution to the communication challenge we have been talking about.
Finally, I'd like to briefly identify other pages in the guide that may be useful to you.

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Table 3

Examples of Caregiver Action Plans

<i>Asking others</i>	
•	When Uncle offers to watch her child, caregiver will ask him to watch patient so she can spend time with her child. She plans to communicate that sitting with the patient while she ran errands with her daughter would be more helpful.
•	Asking son and daughter to stay with the patient so caregiver can attend a three-day conference
•	Ask the patient to have family game night on Fridays again to stimulate family conversation and communication
•	Ask doctor to slow down when communicating
•	Ask husband for help with children so she can better attend to patient's needs
•	Ask father's sister to help by coming on Sundays to visit with mother (patient) so caregiver can spend quality time with her husband
<i>Sharing information</i>	
•	Caregiver will share her need for help and support with daughter
•	Strategies for sharing information with step-father regarding patient's chemotherapy treatment
•	Caregiver will tell in-laws that he believes holistic modalities are not realistic for patient
•	Caregiver will tell sister-in-law that her brother was diagnosed with cancer
<i>Being Present</i>	
•	When patient isolates herself by sitting away from family, caregiver will engage in nonverbal communication strategies to "be present" with patient.
•	Recognizing when something is different with the patient
<i>Initiating and Reinforcing Self-Care</i>	
•	Continue to improve and maintain her self-care needs
•	Schedule a doctor's appointment for routine exam
•	Realization that yearly physical exam has not been done
•	Caregiver realizes during call that she has been crying alone and needs to talk about stress of caregiving

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Summary of Mean Scores By Cancer Care Continuum

Table 4

	Diagnosis		Treatment		Survivorship		End of Life	
	Base	FU	Base	FU	Base	FU	Base	FU
Caregiver Confidence Communicating with ^a :								
Patient	7.7	8.6	7.7	8.6	9.3	9.2	8.1	7.2
Family	7.8	8.9	7.2	8.0	8.7	8.6	7.6	7.9
Healthcare Provider	7.1	9.5	8.3	9.2	9.0	8.0	7.8	8.8
Psychological Distress ^b	5.6	2.8	4.2	3.6	2.4	1.6	4.2	4.8

Abbreviations: Base, Baseline; FU, Follow-Up.

^aScale of 0 (not confident) – 10 (very confident).

^bScale of 0–10, with 5 or more indicating a need for intervention.

Table 5

Caregiver Satisfaction with Intervention

	Cohort 1 Diagnosis (n=5)	Cohort 2 Treatment (n=5)	Cohort 3 Survivorship (n=5)	Cohort 4 End-of-Life (n=5)
Satisfaction with printed guide, N (%)				
Very Satisfied	4 (80%)	4 (80%)	1 (20%)	3 (60%)
Somewhat Satisfied	1 (20%)	0	3 (60%)	1 (20%)
Neutral	0	0	1 (20%)	1 (20%)
Somewhat Dissatisfied	0	1 (20%)	0	0
How Prepared, N (%)				
Very Prepared	3 (60%)	3 (60%)	4 (80%)	4 (80%)
Somewhat Prepared	2 (40%)	1 (20%)	1 (20%)	1 (20%)
Neutral	0	1 (20%)	0	0
Follow-Through with action plan, N (%)				
Yes	5 (100%)	5 (100%)	4 (80%)	4 (80%)
No			1 (20%)	1 (20%)
Did action plan work, N (%)				
Yes	5 (100%)	3 (60%)	4 (80%)	4 (80%)
No	0	0	1 (20%)	1 (20%)