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# Randomized trial of an uncertainty self-management telephone intervention for patients awaiting liver transplant

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### ABSTRACT

**Objective:** We tested an uncertainty self-management telephone intervention (SMI) with patients awaiting liver transplant and their caregivers.

**Methods:** Participants were recruited from four transplant centers and completed questionnaires at baseline, 10, and 12 weeks from baseline (generally two and four weeks after intervention delivery, respectively). Dyads were randomized to either SMI (n = 56) or liver disease education (LDE; n = 59), both of which involved six weekly telephone sessions. SMI participants were taught coping skills and uncertainty management strategies while LDE participants learned about liver function and how to stay healthy. Outcomes included illness uncertainty, uncertainty management, depression, anxiety, self-efficacy, and quality of life. General linear models were used to test for group differences.

**Results:** No differences were found between the SMI and LDE groups for study outcomes.

**Conclusion:** This trial offers insight regarding design for future interventions that may allow greater flexibility in length of delivery beyond our study's 12-week timeframe.

**Practice implications:** Our study was designed for the time constraints of today's clinical practice setting. This trial is a beginning point to address the unmet needs of these patients and their caregivers as they wait for transplants that could save their lives.

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## 1. Introduction

Patients awaiting liver transplants live with significant uncertainty while suffering substantial morbidity and mortality [1–4]. Agonizing uncertainty [5,6] exacerbates chronic illness symptoms, including fatigue, muscle weakness, nausea, and weight loss, and in cases of advanced disease, encephalopathy and diminished cognitive ability [7,8]. Uncertainty includes wondering about transplant wait time, whether physical function will deteriorate before transplantation, and whether deterioration will increase dependence on caregivers. The experience of waiting may exacerbate depressive symptoms and worsen quality of life. Currently, more than 15,000 Americans await liver transplants [9] and up to 17% will die before the surgery can take place [10]. Despite this enormous impact, little attention has been paid to the experience of waiting, and few interventions address the patient's emotional needs [11,12].

One randomized controlled trial has been conducted outside of the United States for patients awaiting liver transplants and caretakers [13]. Psycho-educational interventions were delivered to patients in three face-to-face sessions for each patient and a family member. Patients and their caregivers also participated in a 90-min group session. While results were promising, the session lengths are not realistic in the current U.S. healthcare environment.

To address patients' needs and provide a more timely delivery of services, we designed a telephone intervention comprised of cognitive behavior-based coping skills training and symptom management strategies informed by Uncertainty in Illness Theory [14]. Mishel has proposed that over time, chronic illness causes uncertainty to spread from symptom and disease state concerns to uncertainty about broader life issues [14]. The theory has informed interventions aimed at helping patients and their family members manage uncertainty and disease symptoms associated with a variety of illnesses [15,16]. In a previous study, we evaluated the benefits of an uncertainty intervention delivered by telephone for men who chose "watchful waiting" after a prostate cancer diagnosis, and found that experimental group participants experienced less confusion and improved quality of life [14,17].

Our aim was to see if we could reproduce those positive results in a randomized controlled trial (RCT) for the efficacy of a telephone-delivered uncertainty self-management intervention designed to teach patients and their caregivers (1) cognitive-behavioral coping skills and (2) symptom management strategies. Caregivers served as coaches for their family members in between intervention sessions. This study, one of three projects in the Center for Self-Management in Life-Limiting Illness, a P01 Center funded by the National Institute of Nursing Research [18], compared this self-management intervention to an education control condition on outcomes of patient and caregiver psychological well-being (illness uncertainty, depression, anxiety), self-efficacy, symptom control, uncertainty management, and quality of life.

## 2. Methods

We collected data from patients awaiting liver transplant and their caregivers at baseline, 10 weeks and 12. Patients and caregivers participated in six weekly phone calls over a period of eight weeks; we allowed an additional two weeks for participants unavailable for their scheduled calls. After the intervention period, staff conducted follow-up surveys. Patients received \$20 per survey; caregivers received \$10 per survey.

We enrolled patients and caregivers from four liver transplant centers: Duke University Medical Center, University of North Carolina at Chapel Hill, University of Pittsburgh Medical Center, and University of Nebraska Medical Center. Eligible patients were:

on a liver transplant list, 18 years or older, able to read and speak English, had not received a prior transplant (any organ), and had a caregiver willing to participate. Caregivers were: the individual who accompanied the patient to pre-transplant clinic visits, 18 years or older, and able to read and speak English. Eligible patients and caregivers had no significant cognitive impairment.

### 2.1. Recruitment and randomization

A letter describing the study was mailed to eligible patients with upcoming appointments. The letter was followed with a face-to-face clinic visit or telephone contact. A member of the study team obtained written consent. Dyads were randomly assigned to either the treatment or comparison condition via a computer-generated block randomization sequence stratified by Duke/non-Duke study site. The interventionist disclosed the randomization status to the dyad; study team members conducting follow-up surveys were blinded to randomization arm. Institutional Review Boards at all four sites approved the protocol.

### 2.2. Setting and intervention

This study builds upon our prior work by adding cognitive-behavioral coping skills training and symptom self-management based on Uncertainty in Illness Theory [14,19] for patients awaiting liver transplant. The benefits of coping skills training, used to help patients reframe how they view their symptoms, are well known [20,21]. They are beneficial in reducing pain, fatigue and psychological distress. Symptom self-management refers to the patient's ability to manage treatment, symptoms, and psychosocial challenges [21].

#### 2.2.1. Self-Management Intervention (SMI)

The standardized intervention was delivered to dyads by a trained interventionist, either a registered nurse or social worker, in six 30-min phone calls. Intervention components included: (a) coping skills training, based on cognitive-behavioral principles, to help patients change illness-related thoughts, emotions and behaviors; and (b) symptom management strategies, based on Uncertainty in Illness Theory, designed to provide information about symptoms and strategies to decrease their frequency and intensity.

The first session introduced the intervention and role of coping skills. Caregivers participated as coaches by learning and practicing new skills with the patients, and helping them apply the skills on a daily basis. Caregivers were also encouraged to use what they learned to manage their own stress. This portion of the intervention included progressive muscle relaxation, brief relaxation (mini-practices), pleasant imagery, activity pacing (activity-rest cycling), and cognitive restructuring. Traditionally cognitive restructuring focuses on modifying irrational thoughts, however our approach was to help the patient identify overly negative thoughts that contribute to distress (such as "I can't do the things I used to do") and replace them with more positive, realistic coping thoughts (e.g., "I can't do all of the things I would like to do, but there are still things I *can* do"). This approach is recommended for patients with chronic illness [22] and is similar to that used in our prior study of patients with lung cancer [23]. The interventionist taught each skill by providing a description and rationale for its use, then led the patient and caregiver through practice with feedback. Subsequent sessions began with a review of the previous sessions' content and how the new skills were being used. Sessions ended with homework assignments. In the final session, the interventionist reviewed learned skills and helped the dyad develop a sustainable plan. Participants received handouts

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