

## Advance Care Planning and End-of-Life Decision Making in Dialysis: A Randomized Controlled Trial Targeting Patients and Their Surrogates

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**Background:** Few trials have examined long-term outcomes of advance care planning (ACP) interventions. We examined the efficacy of an ACP intervention on preparation for end-of-life decision making for dialysis patients and surrogates and for surrogates' bereavement outcomes.

**Study Design:** A randomized trial compared an ACP intervention (Sharing Patient's Illness Representations to Increase Trust [SPIRIT]) to usual care alone, with blinded outcome assessments.

**Setting & Participants:** 420 participants (210 dyads of prevalent dialysis patients and their surrogates) from 20 dialysis centers.

**Intervention:** Every dyad received usual care. Those randomly assigned to SPIRIT had an in-depth ACP discussion at the center and a follow-up session at home 2 weeks later.

**Outcomes & Measurements:** Primary outcomes: preparation for end-of-life decision making, assessed for 12 months, included dyad congruence on goals of care at end of life, patient decisional conflict, surrogate decision-making confidence, and a composite of congruence and surrogate decision-making confidence. Secondary outcomes: bereavement outcomes, assessed for 6 months, included anxiety, depression, and posttraumatic distress symptoms completed by surrogates after patient death.

**Results:** Primary outcomes: adjusting for time and baseline values, dyad congruence (OR, 1.89; 95% CI, 1.1-3.3), surrogate decision-making confidence ( $\beta = 0.13$ ; 95% CI, 0.01-0.24), and the composite (OR, 1.82; 95% CI, 1.0-3.2) were better in SPIRIT than controls, but patient decisional conflict did not differ between groups ( $\beta = -0.01$ ; 95% CI,  $-0.12$  to  $0.10$ ). Secondary outcomes: 45 patients died during the study. Surrogates in SPIRIT had less anxiety ( $\beta = -1.13$ ; 95% CI,  $-2.23$  to  $-0.03$ ), depression ( $\beta = -2.54$ ; 95% CI,  $-4.34$  to  $-0.74$ ), and posttraumatic distress ( $\beta = -5.75$ ; 95% CI,  $-10.9$  to  $-0.64$ ) than controls.

**Limitations:** Study was conducted in a single US region.

**Conclusions:** SPIRIT was associated with improvements in dyad preparation for end-of-life decision making and surrogate bereavement outcomes.

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**INDEX WORDS:** Advance care planning (ACP); end-of-life decision making; surrogate decision maker; medical decision; patient-surrogate dyad; dyad congruence; treatment options; life-sustaining treatment; bereavement; death; emotional distress; hemodialysis; end-stage renal disease (ESRD); advanced kidney disease; randomized controlled trial (RCT); patient education intervention.

Advance care planning (ACP) is a process in which patients and family members or surrogate decision makers anticipate and discuss future health states and treatment options.<sup>1,2</sup> It has the potential to improve end-of-life care and reduce costs associated with unwanted or nonbeneficial aggressive treatment near the end of life.<sup>3-6</sup> Initial ACP efforts focused on documenting patients' decisions about end-of-life care.<sup>7</sup> However, given evidence that advance directives do not adequately improve end-of-life care,

ACP for patients with serious chronic illness has evolved to focus on preparing patients and surrogates for treatment decision making at the end of life.<sup>8-12</sup>

The importance of surrogates also has been recognized because they are frequently involved in key medical decisions at the end of life.<sup>2,13,14</sup> However, rarely have trials examined the long-term impact of ACP, including surrogate outcomes.

For patients with end-stage renal disease (ESRD), with mortality exceeding that for most types of

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cancer,<sup>15,16</sup> dialysis may extend life but it might not improve the quality of survival time. Experts suggest that clinicians initiate timely discussions with patients with ESRD and surrogates to help them express desires about end-of-life care.<sup>17</sup> However, these discussions often focus narrowly on advance directives and are delayed until near death.<sup>18,19</sup> Further, no trials have examined whether ACP helps both patients with ESRD and their surrogates prepare for end-of-life decision making, the beneficial impact of ACP sustains over time, or ACP improves surrogates' bereavement outcomes.<sup>18</sup>

Our ACP intervention, Sharing Patient's Illness Representations to Increase Trust (SPIRIT), was based on the Representational Approach to Patient Education<sup>20,21</sup> reflecting theories of illness cognition and conceptual change. In the representational approach, the interventionist first obtains a clear understanding of the patient's perspective on their illness, symptoms, or prognosis before providing information to correct misunderstandings. SPIRIT sessions establish comprehension of the cognitive, emotional, and spiritual facets of the patients' representation (understandings) of their illness, laying the groundwork for the interventionist to provide individualized information such as the effectiveness of mechanical supports at the end of life and to aid patients in examining their own values about such supports.

In a pilot study, SPIRIT had beneficial effects on patient and surrogate preparation for end-of-life decision making.<sup>14</sup> The present trial tested the long-term effects of SPIRIT on preparation for end-of-life decision making (preparedness outcomes) for patients with ESRD and their surrogates and bereavement outcomes for surrogates.

## METHODS

### Design

We conducted a 2-group randomized trial with measures of patient and surrogate preparedness at baseline and 2, 6, and 12 months later and measures of surrogate bereavement outcomes at baseline, 2 weeks, and 3 and 6 months after the patient's death. Before the first dyad reached the 12-month follow-up, the protocol was modified to ask dyads to extend their participation until study end in order to maximize the number of surrogates with bereavement outcomes. The University of North Carolina at Chapel Hill Institutional Review Board approved the study.

### Setting and Participants

Patients were recruited from March 2010 through December 2012 from 20 outpatient dialysis centers in 8 counties in North Carolina. Inclusion criteria were 18 years or older, self-identified African American or white (acceptability of SPIRIT had not been tested with other groups), on dialysis therapy for at least 6 months, Charlson Comorbidity Index<sup>22,23</sup> score of 6 or higher or Charlson Comorbidity Index score of 5 and hospitalization in the last 6 months (criteria associated with 1-patient-year mortality of 30%<sup>24</sup>), English-speaking, no hearing impairment, fewer than 3

errors on the Short Portable Mental Status Questionnaire,<sup>25</sup> and an English-speaking surrogate older than 18 years who could participate.

A short battery of questions<sup>26</sup> was used to help patients identify and confirm a previously designated surrogate. Patients and surrogates provided written consent and received compensation for completing measures (\$15 at baseline, \$20 at 2 months, \$25 at 6 months, and \$30 at 12 months). Each dyad received \$15 at baseline for transportation to the dialysis center. Surrogates who completed bereavement measures received \$20 at 2 weeks, \$25 at 3 months, and \$30 at 6 months.

### Randomization and Interventions

Group assignments were generated prior to enrollment and concealed in sequentially numbered opaque envelopes opened after participants completed baseline measures. Patient-surrogate dyads were randomly assigned (1:1 ratio) to usual care plus SPIRIT or usual care only (control) using permuted blocks (size of 4) stratified by race (African American vs white), dialysis center type (university affiliated vs nonaffiliated), and dialysis modality (hemodialysis vs peritoneal dialysis).

### Usual Care

As required by the Centers for Medicare & Medicaid Services (CMS),<sup>27</sup> written information for advance directives was provided to every patient on the first day of dialysis, and a social worker encouraged patients to complete an advance directive and addressed questions about life-sustaining treatments. A nephrologist, physician assistant, or nurse practitioner reviewed resuscitation statements with the patient to determine whether the patient wanted a do-not-resuscitate (DNR) order in the center. If there was no DNR order in the record, a desire for "full code" (receiving cardiopulmonary resuscitation) was presumed.

### Intervention

Dyads randomly assigned to intervention received usual care plus SPIRIT, conducted by 1 of 3 nurse interventionists using a structured intervention guide. The interventionists had at least 2 years of clinical experience and completed a 3½-day training program designed for competency in communication skills and knowledge in ESRD and end-of-life care.

SPIRIT is a psychoeducational intervention designed to assist patients to clarify their end-of-life preferences, help surrogates increase their understanding of the patient's wishes, and prepare surrogates for the role and responsibilities of being a surrogate. The SPIRIT intervention included 2 sessions, and all sessions included both patient and surrogate. During the first session in a private room at the dialysis center, the interventionist assessed cognitive, emotional, and spiritual/religious aspects of the dyad's representations of the patient's illness, prognosis, and end-of-life care. This allowed the interventionist to provide individualized information about topics such as the effectiveness of life-sustaining treatment for people with end-organ failure and assisted the patient in examining his or her values about life-sustaining treatment at the end of life. The interventionist aimed to help the surrogate prepare for being a decision maker and for the emotional burden of end-of-life decision making by actively involving the surrogate in the discussion. A goals-of-care document was completed at the end of the session to indicate the patient's preferences.

In a brief second session delivered 2 weeks later at the patient's home (to reduce travel burden), the goals-of-care document and resuscitation preferences were reviewed. If the surrogate was someone out of the order of the hierarchical compensatory model<sup>28</sup> (eg, a sibling was chosen when the patient had a spouse), the interventionist explored potential family conflicts and encouraged

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