

VRAAG 3:

3A: LEIDT HET GEBRUIK VAN CONFLICT-/COMMUNICATIE-TECHNIEKEN BIJ PATIËNTEN MET EINDSTADIUM NIERFALEN TOT EEN BETERE KWALITEIT VAN LEVEN OF MEER VOLDOENING IN DE BESLUITVORMING/HET BESLISPROCES OVER HET WEL OF NIET DOORGAAN OF HET WEL OF NIET STARTEN MET DIALYSE BEHANDELING?

3B: WELKE COMMUNICATIE- EN CONFLICTTECHNIEKEN (CONFLICT MANAGEMENT) WORDEN DAN BESCHREVEN IN DE GEVONDEN STUDIES?

Primaire studies

| Study ID | Method | Patient characteristics | Interventions | Results | Critical appraisal of study quality |
|---------------|--|---|---|--|--|
| Song 2009 [1] | <ul style="list-style-type: none"> Design: RCT Funding/Col: National Institutes of Health; Col not reported on Setting: multiple centers, United States Sample size: N=58 dyads Duration: Jan 2007-Jun 2008; outcomes assessed at 1 week and 3 months post-intervention | <ul style="list-style-type: none"> Eligibility criteria: self-identified African Americans with end-stage renal disease and their chosen surrogate decision makers, on dialysis for at least 3 months A priori patient characteristics: intervention vs. control <ul style="list-style-type: none"> Age, mean: 58 vs. 58 years Male: 66% vs. 48% Married/living with partner: 28% vs. 48% | <p>SPiRiT (N=29) vs. Usual care (N=29)</p> <p>SPiRiT: The guiding theory of SPiRiT is the representational approach to patient education. The representational approach is based on Leventhal's common sense model and the conceptual change model. These representations serve as a cognitive framework in which new information is processed. The conceptual change model proposes that the likelihood of learning increases when an opportunity is given to reflect and comment on current ideas and their consequences, when the individual is dissatisfied with current ideas or recognizes the limitations of the ideas, and when alternative information is seen as beneficial. 1-hour, single session, interview with a patient-surrogate dyad, delivered by a trained nurse interventionist who had completed 3.5 days of training. The elements and goals of SPiRiT are described in Table 1 (below)</p> <p>Usual care: A social worker at each dialysis clinic provided written information on advance directives and the patient's right to have an advance directive to every patient on the first day of dialysis treatment. The social worker encouraged patients to complete an advance directive and</p> | <p>Satisfaction with decision making process: CRITICAL OUTCOME</p> <p>Quality of patient-clinician (or interventionist) communication about end-of-life care (mean \pmSD, higher scores indicate better communication, range: 4-12): Patient 1 week: 11.18 \pm 1.12 vs. 8.83 \pm 3.55 (p=0.03) Patient 3 months: 11.30 \pm 1.41 vs. 7.52 \pm 3.66 (p<0.01) Surrogate 1 week: 11.68 \pm 0.55 vs. 6.79 \pm 3.57 (p<0.01) Surrogate 3 months: 11.58 \pm 0.72 vs. 10.22 \pm 2.49 (p=0.03)</p> <p>Quality of interaction with clinician (or interventionist) (mean \pmSD, lower scores indicate better interaction): Patient 1 week: 5.56 \pm 0.90 vs. 7.29 \pm 3.42 (p<0.01) Patient 3 months: 5.68 \pm 0.77 vs. 7.29 \pm 2.65 (p not reported) Surrogate 1 week: 5.39 \pm 0.96 vs. 7.12 \pm 3.39 (p=0.08) Surrogate 3 months: 5.46 \pm 0.59 vs. 6.93 \pm 3.04 (p not reported)</p> <p>Satisfaction with decision: CRITICAL OUTCOME</p> <p>Patient Decisional Conflict Scale (score \geq 2 indicates difficulty in making choices) (mean (SD)): 1 week: 2.12 (0.31) vs. 2.05 (0.44) 3 months: 1.88 (0.37) vs. 1.94 (0.55)</p> <p>Quality of life: CRITICAL OUTCOME</p> <p>Not reported on Psychospiritual well-being (28-item Self-Perception and Relationship Tool) (mean (SD))</p> | <p>Level of evidence: high risk of bias</p> <ul style="list-style-type: none"> High risk of selective reporting At 3 months 2 vs. 2 surrogates dropped out (2 for marital reasons, 1 died, 1 not reported) and 0 vs. 2 patients dropped out (died) leaving 27 vs. 25 dyads Completers analyses Selective reporting: p-values not reported for all comparisons; QoL data not reported |

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| Song 2010 [2] | <ul style="list-style-type: none"> Design: RCT Funding/Col: University of Pittsburgh Central Research Development Fund; Col not reported on Setting: single centre, United States Sample size: N=19 dyads Duration: not reported; follow-up 1 week | <ul style="list-style-type: none"> Eligibility criteria: dialysis patients with a surrogate, on dialysis for at least 3 months A priori patient characteristics (not reported per group): <ul style="list-style-type: none"> Age: mean 53 years Male: 59% Single: 65% | <p>addressed their individual questions about life-sustaining treatment options. If completed, the advance directive was placed in the medical record. Questions about their medical condition and related end-of-life treatment options were referred to their physicians. Typically, this usual care is a one-time service provided on admission to the dialysis clinic unless the patient expresses his or her desire for a Do-Not-Resuscitate order</p> <p>Patient-centered advance care planning (N=11)</p> <p>vs.</p> <p>Usual care (N=8)</p> <p>Patient-centered advance care planning: The guiding theory is the representational approach to patient education. The representational approach is based on Leventhal's common sense model and the conceptual change model. An in-depth interview with the patient-surrogate dyad, delivered by a trained nurse interventionist who had completed 2.5 days of training. The intervention took place over approximately 1 hour in a face-to-face session. During that session, the interventionist addressed the five elements of the representational approach: (a) representational assessment of participants' beliefs about their illness condition along the five dimensions of illness representation; (b) exploration of gaps or misunderstandings regarding chronic kidney disease and its progression and life-sustaining treatment, including dialysis; (c) creation of conditions for conceptual change; (d) introduction of replacement information; and (e) summarization of the discussion</p> <p>Usual care: Written information on advance directives was provided to every patient by a nurse or social worker who encouraged patients to complete an advance directive and addressed their questions about life-sustaining treatment options. Completed advance directives were placed in the medical record</p> | <p>Patient 1 week: 1.71 (0.76) vs. 1.67 (0.79) Patient 3 months: 1.68 (1.03) vs. 1.95 (0.81) Surrogate 1 week: 1.51 (0.90) vs. 1.79 (0.97) Surrogate 3 months: 1.65 (0.99) vs. 1.84 (0.98)</p> <p><u>Satisfaction with decision making process: CRITICAL OUTCOME</u> Quality of patient-clinician (or interventionist) communication about end-of-life care (mean \pmSD, higher scores (range: 3-12) indicate better communication): Patient 1 week: 10.10 \pm2.08 vs. 8.14 \pm2.34 (p<0.05) Quality of interaction with clinician (or interventionist)(mean \pmSD, lower scores (range: 5-20) indicate better interaction): Patient 1 week: 6.20 \pm2.90 vs. 6.29 \pm2.56 (ns)</p> <p><u>Satisfaction with decision: CRITICAL OUTCOME</u> Patient Decisional Conflict Scale (score \geq2 indicates difficulty in making choices) (mean (SD)): 1 week: 1.92 \pm0.43 vs. 1.80 \pm0.43</p> <p>Surrogate's decision making confidence (mean (SD)): 1 week: 18.40 \pm1.84 vs. 18.57 \pm2.44</p> <p><u>Quality of life: CRITICAL OUTCOME</u> Psychospiritual well-being (28-item Self-Perception and Relationship Tool) (mean \pm SD) Patient 1 week: 1.60 \pm0.62 vs. 1.08 \pm1.74 Surrogate 1 week: 1.56 \pm0.87 vs. 1.97 \pm1.07</p> | <p>Level of evidence: high risk of bias</p> <ul style="list-style-type: none"> 1 dyad who did not receive allocated intervention (patient-centered advanced care planning) excluded from analysis 1 patient from control group lost to follow-up |
| Song 2015 [3] | <ul style="list-style-type: none"> Design: RCT Funding/Col: National Institutes of Health, Col: none Setting: multiple centres, United States | <ul style="list-style-type: none"> Eligibility criteria: 18 years or older, self-identified African American or white (acceptability of SPIRIT had not been tested with | <p>vs.</p> <p>Usual care (N=101 dyads)</p> <p>SPIRIT: The interventionists had completed a 31/2-day training</p> | <p><u>Satisfaction with decision making process: CRITICAL OUTCOME</u> Not reported on</p> <p><u>Satisfaction with decision: CRITICAL OUTCOME</u> Patient Decisional Conflict Scale (score \geq2 indicates difficulty in making choices) (mean (SD)): Patient 2 months: 1.7 (0.5) vs. 1.7 (0.5) p=0.6</p> | <p>Level of evidence: unclear risk of bias</p> <ul style="list-style-type: none"> Unclear sequence generation, not reported whether blinding of patients and personnel took |

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| | <ul style="list-style-type: none"> Sample size: N=210 dyads Duration: Mar 2010-Dec 2012; follow-up 12 months, or 6 months after the patient's death for the dyads | <p>other groups), on dialysis therapy for at least 6 months. Charlson Comorbidity Index score of 6 or higher or Charlson Comorbidity Index score of 5 and hospitalization in the last 6 months</p> <ul style="list-style-type: none"> A priori patient characteristics: intervention vs. control <ul style="list-style-type: none"> Age 61 vs. 63 years Male 40% vs. 45% Married/living with partner: 51% vs. 40% | <p>program. 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 (e.g., a sibling was chosen when the patient had a spouse), the interventionist explored potential family conflicts and encouraged the dyad to talk with other family members and complete a health care power of attorney. The interventionist then summarized the patient's end-of-life preferences, listed the surrogate's name and relationship to the patient, and indicated whether the patient desired a do-not-resuscitate order or assistance in completing an advance directive. The interventionist communicated this information to dialysis staff (the social worker and nurse manager or the medical director), and the document was placed in the medical record</p> <p>Usual care: 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</p> | <p>Patient 6 months: 1.6 (0.5) vs. 1.8 (0.4) p=0.007 Patient 12 months: 1.6 (0.4) vs. 1.8 (0.5) p<0.001</p> <p>Surrogate's decision making confidence (range 1-4, higher indicating better) (mean (SD): Surrogate 2 months: 3.7 (0.4) vs. 3.6 (0.5) p=0.05 Surrogate 6 months: 3.7 (0.4) vs. 3.6 (0.5) p=0.1 Surrogate 12 months: 3.7 (0.4) vs. 3.7 (0.5) p=0.7</p> <p><u>Quality of life: CRITICAL OUTCOME</u> Not reported on</p> | <p>place</p> |

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| | | | DNR order in the record, a desire for "full code" (receiving cardiopulmonary resuscitation) was presumed | | |

Abbreviations: Col: conflict of interest; ns: not significant; QoL: quality of life; RCT: randomised controlled trial; SD: standard deviation

Table 1 Elements and Goals of the SPIRIT Intervention [1]

| Element | Goal |
|--|---|
| 1. Representational assessment | Both patient and surrogate describe illness representations along with the following dimensions: identity, timeline, consequences, controllability, and spiritual and emotional representations. The goal for all parties is to achieve a deeper understanding of patient's illness experience and the surrogate's experience with his/her loved one's illness. |
| 2. Identifying and exploring gaps and concerns | The interventionist identifies and explores gaps and concerns the dyad may have regarding illness progression, life-sustaining treatment and decision making. The goal for each member of the dyad is to exchange own values and concerns about life-sustaining treatment at the end-of-life. |
| 3. Creating conditions for conceptual change | The interventionist encourages the dyad to share their views and ideas about death and dying and end-of-life care. She assists the patient to identify his/her threshold for unacceptable outcomes of life-sustaining treatment. The goal is to gain a good understanding of the dyad's values of treatment outcomes and concerns. |
| 4. Introducing replacement information | The interventionist presents end-of-life scenarios and encourages the patient to clarify goals of care and express concerns. The interventionist assists the surrogate to examine her/his willingness to take the responsibility to act on them and to appreciate surrogate roles. |
| 5. Summary | The interventionist summarizes the value of the discussion and the need for future discussions. She also assesses any additional support they need such as consultation with social worker at the clinic and spiritual advisor. |

References

1. Song, M.K., et al., *Randomized controlled trial of SPIRIT: an effective approach to preparing African-American dialysis patients and families for end of life*. Res Nurs Health, 2009. **32**(3): p. 260-73.
2. Song, M.K., et al., *Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease*. Appl Nurs Res, 2010. **23**(2): p. 65-72.
3. Song, M.K., et al., *Advance Care Planning and End-of-Life Decision Making in Dialysis: A Randomized Controlled Trial Targeting Patients and Their Surrogates*. Am J Kidney Dis, 2015.