VRAAG 4A: BIJ PATIËNTEN MET EINDSTADIUM NIERFALEN (ESRD OF CKD STADIUM V OF DIALYSE), LEIDT ADVANCE CARE PLANNING TOT EEN BETERE KWALITEIT VAN LEVEN, HOGERE TEVREDENHEID VAN DE FAMILIELEDEN?

VRAAG 4B: WAT ZIJN DE KENMERKEN VAN ACP IN DIE STUDIE(S) WAARIN AANGETOOND WERD DAT HET WERKT?

Systematic reviews

Study ID	Method	Patient characteristics	Intervention(s)	Results	Critical appraisal of review quality
Luckett 2014 [1]	• SR • Funding/CoI: none; none • Search date: Apr 2013 • Databases: MEDLINE, PsycINFO, Embase, AMED (Allied and Complementary Medicine Database), CINAHL (Cumulative Index to Nursing and Allied Health Literature), and Sociological Abstracts • Study designs: any design • N included studies: 52 (55 articles), of which 8 intervention studies, of which 4 RCTs	• Eligibility criteria: studies on advanced care planning for adults with chronic kidney disease • Patient characteristics: ○ Not reported on	Advanced care planning	Satisfaction with decision making process: CRITICAL OUTCOME The 2 Song studies found a significant effect on both patient-clinician communication and interaction (no quantified/meta-analysed data) Satisfaction with decision: CRITICAL OUTCOME Neither Song study found a significant effect for decisional conflict (no quantified/meta-analysed data) Quality of life: CRITICAL OUTCOME Neither study by Song s found a significant effect on well-being for either patients or surrogates (no quantified/meta-analysed data) Patient choices: IMPORTANT OUTCOME Not reported on	• Systematic review of low quality • Included RCTs: ○ Perry 2005 ○ Singer 1995 ○ Song 2009 ○ Song 2010 • Perry 2005 is another intervention (peer-mentor–facilitated ACP sessions) and is not described here • No relevant outcomes reported for Singer 1995

Abbreviations: CoI: conflicts of interest; SR: systematic review

Primaire studies

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
Song 2009 [2]	• Design: RCT • Funding/CoI: National Institutes of Health; CoI not reported on • Setting: multiple centers, United States • Sample size: N=58 dyads	• Eligibility criteria: self-identified African Americans with end-stage renal disease and their chosen surrogate decision makers, on dialysis for at least 3 months	SPIRIT (N=29) vs. Usual care (N=29) SPIRIT: The guiding theory of SPIRIT is the representational approach to patient education. The representational approach is based on Leventhal's common sense model	Satisfaction with decision making process: CRITICAL OUTCOME Quality of patient-clinician (or interventionist) communication about end-of-life care (mean ±SD, higher scores indicate better communication, range: 4-12): Patient 1 week: 11.18 ± 1.12 vs. 8.83 ± 3.55 (p=0.03) Patient 3 months: 11.30 ± 1.41 vs. 7.52 ± 3.66 (p<0.01) Surrogate 1 week: 11.68 ± 0.55 vs. 6.79 ± 3.57 (p<0.01) Surrogate 3 months: 11.58 ± 0.72 vs. 10.22 ± 2.49 (p=0.03)	Level of evidence: high risk of bias • 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

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	- Duration: Jan 2007-Jun 2008; outcomes assessed at 1 week and 3 months post-intervention	- A priori patient characteristics: intervention vs. control ○ Age, mean: 58 vs. 58 years ○ Male: 66% vs. 48% ○ Married/living with partner: 28% vs. 48%	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) 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 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	Quality of interaction with clinician (or interventionist) (mean ±SD, lower scores indicate better interaction): Patient 1 week: 5.56 ± 0.90 vs. 7.29 ± 3.42 (p<0.01) Patient 3 months: 5.68 ± 0.77 vs. 7.29 ± 2.65 (p not reported) Surrogate 1 week: 5.39 ± 0.96 vs. 7.12 ± 3.39 (p=0.08) Surrogate 3 months: 5.46 ± 0.59 vs. 6.93 ± 3.04 (p not reported) Satisfaction with decision: CRITICAL OUTCOME Patient Decisional Conflict Scale (score ≥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) Quality of life: CRITICAL OUTCOME Not reported on Psychospiritual well-being (28-item Self-Perception and Relationship Tool) (mean (SD)) 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) Patient choices: IMPORTANT OUTCOME Not reported on	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
Song 2010 [3]	- Design: RCT - Funding/CoI: University of Pittsburgh Central Research Development Fund; CoI not reported on - Setting: single centre, United States - Sample size: N=19 dyads - Duration: not reported; follow-up 1 week	- Eligibility criteria: African-American dialysis patients with a surrogate, on dialysis for at least 3 months - A priori patient characteristics (not reported per group): ○ Age: mean 53 years ○ Male: 59% ○ Single: 65%	Patient-centered advance care planning (N=11) vs. Usual care (N=8) 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	Satisfaction with decision making process: CRITICAL OUTCOME Quality of patient-clinician (or interventionist) communication about end-of-life care (mean ±SD, higher scores (range: 3-12) indicate better communication): Patient 1 week: 10.10 ±2.08 vs. 8.14 ±2.34 (p<0.05) Quality of interaction with clinician (or interventionist)(mean ±SD, lower scores (range: 5-20) indicate better interaction): Patient 1 week: 6.20 ±2.90 vs. 6.29 ±2.56 (ns) Satisfaction with decision: CRITICAL OUTCOME Patient Decisional Conflict Scale (score ≥2 indicates difficulty in making choices) (mean (SD)): 1 week: 1.92 ±0.43 vs. 1.80 ±0.43 Surrogate's decision making confidence (mean (SD): 1 week: 18.40 ±1.84 vs. 18.57 ±2.44 Quality of life: CRITICAL OUTCOME	Level of evidence: high risk of bias - 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

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			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 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	Psychospiritual well-being (28-item Self-Perception and Relationship Tool) (mean ± SD) Patient 1 week: 1.60 ±0.62 vs. 1.08 ±1.74 Surrogate 1 week: 1.56 ±0.87 vs. 1.97 ±1.07 Patient choices: IMPORTANT OUTCOME Low chance of survival: Continue all treatment: 80% (8/11) vs. 28.6% (2/8) Cardiopulmonal resuscitation: Attempt resuscitation: 90% (9/11) vs. 57% (4/8)	
Song 2015 [4]	• Design: RCT • Funding/CoI: National Institutes of Health; CoI: none • Setting: multiple centres, United States • 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	• Eligibility criteria: 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 score of 6 or higher or Charlson Comorbidity Index score of 5 and hospitalization in the last 6 months • A priori patient characteristics: intervention vs. control ○ Age 61 vs. 63 years ○ Male 40% vs. 45% ○ Married/living with partner: 51% vs. 40%	SPIRIT (N=109 dyads) vs. Usual care (N=101 dyads) SPIRIT: The interventionists had completed a 31/2-day training 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	Satisfaction with decision making process: CRITICAL OUTCOME Not reported on Satisfaction with decision: CRITICAL OUTCOME Patient Decisional Conflict Scale (range 1-5, score ≥2 indicates difficulty in making choices) (mean (SD)): Patient 2 months: 1.7 (0.5) vs. 1.7 (0.5) p=0.6 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 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 Quality of life: CRITICAL OUTCOME Not reported on Patient choices: IMPORTANT OUTCOME Not reported on	Level of evidence: unclear risk of bias • Unclear sequence generation, not reported whether blinding of patients and personnel took place

Study ID	Method	Patient characteristics	Interventions	Results	Critical appraisal of study quality
			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 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 DNR order in the record, a desire for "full code" (receiving cardiopulmonary resuscitation) was presumed		

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

Table 2 Elements and Goals of the SPIRIT Intervention [2]

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

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4. 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.