

Online supplement

A cluster-randomized trial of a nurse-led advance care planning session in patients with COPD and their loved ones

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METHODS

Intervention

Eight respiratory nurse specialists received a two-day training, starting with theoretical background of the importance and benefits of ACP for patients with COPD and their loved ones. End-of-life care communication skills and the structured ACP-session during the study were taught and practiced. Finally, the nurses were asked to perform an ACP-session in which a specific case was simulated. Investigators used a 21-item checklist to confirm adherence to the standardized protocol for ACP. Only nurses with 17 or more adequately performed items on the checklist were certified. The training was pilot-tested with a group of eight nurses from a center not recruiting patients for the study and optimized. The training was delivered by an elderly care physician / palliative care physician and medical psychologist. All participating nurses achieved a score above the threshold and were certified.

Questionnaires

Quality of communication (QOC) questionnaire

The QOC questionnaire consists of 13 items that form two domains: general communication and communication about end-of-life care. Patients were asked to rate the communications skills of their chest physician. The subscale end-of-life care communication comprises seven items and the subscale general communication comprises six items. Each item is rated on a scale of 0 (“the very worst”) to 10 (“the very best”). In addition, patients were offered two additional response options: “My doctor didn’t do this” and “Don’t know”. The domain scores were calculated from the average from all endorsed items. This score ranges from 0 (“worst”) to 10 (“best”). The answer “My doctor didn’t do this” was replaced by a score of 0 and “Don’t know” was replaced by the median domain score of the valid items for the individual, as suggested by the QOC questionnaire developers.¹² For 26 items (2.2% of all items from all participants) from the domain end-of-life care communication on both baseline and follow-up the value of “don’t know” was replaced by the median domain score of

the valid items for the individual. The QOC questionnaire is a validated instrument and meets the standards of scale measurement, including good construct validity and internal consistency (Cronbach's $\alpha \geq 0.79$).¹ A priori, we defined a 1 point change in QOC end-of-life care domain score as clinically relevant.

Hospital Anxiety and Depression Scale (HADS)

The Hospital Anxiety and Depression Scale (HADS)³ is divided into an anxiety and a depression subscale, respectively. Total scores for each subscale can range from 0 (=optimal) to 21 (=worst) points. A score equal to or greater than 10 for anxiety and/or depression has been defined as indicative for the presence of clinically relevant symptoms of anxiety and/or depression.³ A priori, we defined a 1.5 point change in HADS-A or HADS-D score as clinically relevant.⁴

Quality of death and dying (QODD) questionnaire

The QODD⁵ consists of 17 items, which each have two parts. In the report-part the frequency of an experience/event is provided. In the rating-part the loved one evaluates the quality of the experience/event on an 11-point scale, ranging from 0 (terrible) to 10 (almost perfect). The total QODD score is calculated by summing up the scores of all items from the rating-part, divided by the number of items answered, and recalibrated to range 0 to 100, with a higher score indicating higher quality of death and dying. The QODD is a validated instrument and meets the standards of scale measurement, including cross-sectional and construct validity and excellent internal consistency ((Cronbach's $\alpha \geq 0.89$).⁶ To our knowledge a well-defined minimal clinically important difference of the QODD total score is currently unknown.⁷

RESULTS

Quality of communication

We have repeated our analysis by using a multilevel regression analysis to compare the QOC end-of-life care communication domain score between the intervention and control group at 6-months follow-up. The nesting of patients within chest physicians was taken into account and the following variables were included as possible confounders: age, prior ACP-discussions and quality of end-of-life care communication at baseline. The results were similar to the results of our analysis reported in the manuscript (Table E4).

Prevalence of ACP-discussions

From the patients in the ACP-intervention group who reported an ACP discussion with a healthcare professional at follow-up, 26 patients (68.4%) described that this discussion was in the last six months. Of these patients, 16 patients (61.5%) reported an ACP-discussion with the chest physician, three patients with the GP (11.5%), four patients (15.4%) with both the chest physician and the GP, two patients (7.7%) with the respiratory nurse specialist and one patient (3.8%) with the chest physician and the respiratory nurse specialist.

From the patients in the control group who reported an ACP discussion with a healthcare professional at follow-up, 11 patients (57.9 %) described that this discussion was in the last six months. Of these patients, 5 patients (45.4%) reported an ACP-discussion with the chest physician, one patient with the GP (9.1%), one patient (9.1%) with the respiratory nurse specialist, two patients (18.2%) with both the chest physician and respiratory nurse specialist, and two patients (18.2%) with the chest physician and the social worker.

References

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Table E1. Elements of structured advance care planning (ACP) intervention

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| 1. Reflection on patient's goals, values, and beliefs. |
| 2. Understanding the current and future medical situation, possible treatments and outcomes. |
| 3. Understanding life-sustaining treatments. |
| 4. Determining wishes regarding current and future care. |
| 5. Encouraging discussions concerning ACP with healthcare providers and loved ones. |
| 6. Appointment of a surrogate decision maker. |

Table E2. Quality of communication

| | | Baseline | 6-months follow-up |
|--------------------------------------|--------------------|---------------|--------------------|
| General communication | Intervention group | 8.2 (7.7-9.0) | 8.3 (7.7-9.0) |
| | Control group | 8.0 (7.5-8.8) | 8.0 (7.7-9.0) |
| Communication about end-of-life care | Intervention group | 0.0 (0.0-1.1) | 2.4 (0.0-5.6) |
| | Control group | 0.0 (0.0-1.1) | 0.0 (0.0-2.4) |

Data presented as median (interquartile range (IQR)).

Table E3. Report-items Quality of Death and Dying (QODD)

| | Never | | Rarely | | Sometimes | | Often | | Mostly | | Always | | Don't know | |
|---|---------------|------------|---------------|------------|---------------|------------|---------------|------------|---------------|------------|---------------|--------------|---------------|------------|
| | Inter-vention | Control | Inter-vention | Control | Inter-vention | Control | Inter-vention | Control | Inter-vention | Control | Inter-vention | Control | Inter-vention | Control |
| Had control of pain | 0 (0.0) | 1 (4.2) | 1 (8.3) | 0 (0.0) | 2 (16.7) | 2 (8.3) | 3 (25.0) | 2 (8.3) | 2 (16.7) | 7 (29.2) | 4 (33.3) | 12 (50.0) | 0 (0.0) | 0 (0.0) |
| Had control over what was going on around him/her | 2 (16.7) | 7 (29.2) | 1 (8.3) | 2 (8.3) | 3 (25.0) | 1 (4.2) | 1 (8.3) | 3 (12.5) | 3 (25.0) | 6 (25.0) | 2 (16.7) | 5 (20.8) | 0 (0.0) | 0 (0.0) |
| Had control over bladder or bowels | 2 (16.7) | 7 (29.2) | 0 (0.0) | 2 (8.3) | 1 (8.3) | 2 (8.3) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 4 (16.7) | 8 (66.7) | 9 (37.5) | 1 (8.3) | 0 (0.0) |
| Breathing comfortably | 0 (0.0) | 5 (20.8) | 1 (8.3) | 4 (16.7) | 5 (41.7) | 7 (29.2) | 3 (25.0) | 2 (8.3) | 1 (8.3) | 5 (20.8) | 1 (8.3) | 1 (4.2) | 1 (8.3) | 0 (0.0) |
| Felt at peace with dying | 0 (0.0) | 3 (12.5) | 1 (8.3) | 0 (0.0) | 1 (8.3) | 2 (8.3) | 0 (0.0) | 2 (8.3) | 2 (16.7) | 4 (16.7) | 4 (33.3) | 6 (25.0) | 4 (33.3) | 7 (29.2) |
| Was unafraid of dying | 2 (16.7) | 3 (12.5) | 0 (0.0) | 3 (12.5) | 2 (16.7) | 1 (4.2) | 3 (25.0) | 1 (4.2) | 0 (0.0) | 3 (12.5) | 3 (25.0) | 9 (37.5) | 2 (16.7) | 4 (16.7) |
| Laughed and smiled | 1 (8.3) | 4 (16.7) | 0 (0.0) | 3 (12.5) | 5 (41.7) | 5 (20.8) | 2 (16.7) | 5 (20.8) | 2 (16.7) | 1 (4.2) | 2 (16.7) | 6 (25.0) | 0 (0.0) | 0 (0.0) |
| Had worries about strain on loved ones | 2 (16.7) | 2 (8.3) | 0 (0.0) | 3 (12.5) | 3 (25.0) | 4 (16.7) | 4 (33.3) | 2 (8.3) | 0 (0.0) | 1 (4.2) | 2 (16.7) | 6 (25.0) | 0 (0.0) | 6 (25.0) |
| Died with dignity | 0 (0.0) | 0 (0.0) | 1 (8.3) | 3 (12.5) | 1 (8.3) | 0 (0.0) | 1 (8.3) | 1 (4.2) | 4 (33.3) | 7 (29.2) | 3 (25.0) | 10 (41.7) | 2 (16.7) | 3 (12.5) |
| Spent time with family and friends | 1 (8.3) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (16.7) | 4 (16.7) | 1 (8.3) | 3 (12.5) | 2 (16.7) | 7 (29.2) | 6 (50.0) | 10 (41.7) | 0 (0.0) | 0 (0.0) |
| | | | | | | | Yes | | No | | | | Don't know | |
| | | | | | | | I* | C† | I* | C† | I* | C† | I* | C† |
| Was touched and hugged by loved ones | | | | | | | 11 (91.7) | 23 (95.8) | 1 (8.3) | 1 (4.2) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Taken care of healthcare costs | | | | | | | 11 (91.7) | 22 (91.7) | 0 (0.0) | 1 (4.2) | 1 (8.3) | 1 (4.2) | 1 (8.3) | 1 (4.2) |
| Previous financial problems | | | | | | | 1 (8.3) | 1 (4.2) | 11 (91.7) | 23 (95.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Said goodbye to loved ones | | | | | | | 8 (66.7) | 13 (54.2) | 3 (25.0) | 11 (45.8) | 1 (8.3) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Had a visit from a religious or spiritual advisor | | | | | | | 4 (33.3) | 8 (33.3) | 8 (66.7) | 16 (66.7) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Experience of mechanical ventilator or dialysis as an aspect of dying | | | | | | | 3 (25.0) | 3 (12.5) | 9 (75.0) | 21 (87.5) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| Had the means to end life if needed to | | | | | | | 7 (58.3) | 10 (41.7) | 3 (25.0) | 8 (33.3) | 2 (16.7) | 6 (25.0) | 2 (16.7) | 6 (25.0) |
| Had funeral arrangement in order | | | | | | | 7 (58.3) | 7 (29.2) | 5 (41.7) | 17 (70.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 0 (0.0) |

Data presented as number of patients (%). Abbreviations: * n=12; † n=24.

Table E4. Supplementary analysis quality of communication

| | B | 95% CI | p-value |
|-----------------------------|------|--------------|-------------------|
| QOC end-of-life care domain | 1.94 | 0.93 – 2.96 | .001 [*] |
| QOC general domain | 0.03 | -0.72 – 0.78 | 0.92 [†] |

^{*}Multilevel linear regression analysis clustered for physician (28 clusters) and adjusted for quality of end-of-life care communication at baseline, hospital, age, and prior ACP. [†]Multilevel linear regression analysis clustered for physician (28 clusters) and adjusted for quality of general communication at baseline, hospital, age, and prior ACP.