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Influence of an ACP intervention on documentation of end-of-life issues – a cluster randomized clinical trial

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Outline

- Present our project; design and aims
- Present quantitative data
- Discussion of results



Background – Norwegian context

- National guidelines on ACP do not exist.
- More than half of nursing homes respond they do ACP (Gjerberg, Lillemoen, Weaver, Pedersen, & Forde, 2017)
- However, ACP was initiated most often due to exacerbation, and less than a third did ACP as part of a process (Gjerberg, Lillemoen, Weaver, Pedersen, & Forde, 2017)

Background – Norwegian context

- Hospital physicians admitted overtreating patients admitted from nursing homes, but claimed part of the reason is a lack of information on the patient (Romoren, Pedersen, & Forde, 2017)
- A majority of nursing home physicians did not include patients in decisions regarding treatment and level of treatment (Romoren, Pedersen, & Forde, 2016)
- Most nursing home patients stated they had not had an opportunity to discuss their values and preferences for treatment and care related to end of life with the staff (Gjerberg, Lillemoen, Forde, & Pedersen, 2015)

Background – Norwegian context

- ACP – who is it for?
 - Nursing home patients and next of kin were unaware of content of the conversation
 - Patients participated in a way which was described as quiet, and with a passive, apprehensive attitude
 - The social dimension as well as psychological, existential, spiritual and emotional aspects in end-of-life communication and care are lacking

(Thoresen, Ahlzén, & Solbrække, 2016)

«End-of-life Communication in Nursing Homes – Patient Preferences and Participation»

- Part one – a systematic review
- Part two – a study of the practice of and experiences with ACP and shared decision making in Norwegian nursing homes
- **Part three – Developing, implementing and evaluating ACP through a randomized controlled study**

Design and methods

- A pair-matched cluster randomized clinical trial – total of 8 clusters
- Evaluation will use a mixed-methods approach
- This presentation concerns the quantitative data

The intervention

- A guideline for systematic ACP, which emphasizes aim of including patients with lacking decision-making capacity in conversations (Thoresen et al., 2015)
- Training, supervision, and follow-up of the project teams
- Written information to patients and relatives including project information, content of conversations, invitation to conversation and contact information.
- Information meeting about the ACP project for NH staff

Quantitative data

Registrations of documentation from patient electronic health record at baseline and after the 1-year intervention period.



Primary outcome

Number of patients with a documented conversation on end-of-life treatment during a span of 12 months



Statistical analysis

- Mixed model analysis
- General estimating equations (GEE) approach
- Power calculation:
 - Design effect 0,02 = sample size of 19
 - Design effect 0,05 = sample size of 24

Results - descriptive

- Results are not yet published, and as a consequence numbers will not be presented here
- Participants at T0 and T1 were fairly similar. Patients in both the intervention and control groups were characterized by high age, most of them were female, many had a form of cognitive impairment. Most patients were multimorbid.

Results – statistically significant

- Comparing control and intervention groups there was a significant increase in the intervention group from T0 to T1:
 - Our primary outcome – number of patients with a documented conversation on end-of-life treatment.
 - Documentation of patients' hope and/or worries for the future.
 - Patients' being positive to life-prolonging treatment + hospitalization.

Results – clinically important

- There was no difference between the groups on treatment given – that is life-prolonging treatment or hospitalization. Also, no difference found when decisions were made not to give life-prolonging treatment or hospitalization.
- There was an increase in concordance between treatment given and patients' wishes in the intervention group from T0 to T1. However, registered incidences were low and statistical analysis could not be performed due to 0 counts in some of the cells.

Not significant changes

- Increase, but not statistically significant:
 - Documentation of patient's and NOK's wishes for treatment intensity (life-prolonging treatment and hospitalization)
 - Assessment of competency to consent in relation to conversations on end-of-life treatment
 - Patient's wishes for decision-making process and involvement in the process (included wishes for information to oneself, information to NOK, if there is appointed a proxy).

Cognitive impairment (C.I.) intervention group

- Comparing patients with and without C.I. in the intervention group:
 - Conversation on end-of-life treatment: greater increase among those with C.I.
 - Greater increase among patients with C.I. also on hopes and worries for the future, patient's wishes for treatment intensity (life-prolonging treatment and hospitalization) and patient's being positive to end-of-life treatment and hospitalization.

Discussion

- ACP are complex interventions.
- Nevertheless, our intervention was relatively novel making use of resources already at the wards.
- Still, we saw an increase in ACP in the intervention group.

Discussion

- Patients with cognitive impairment were included in ACP.
- However, assessment of competency to consent remained at a low level – a potential threat to patient autonomy.
- Also, relevant information to the decision-making process did not see a substantial increase.

Discussion

- No evidence of ACP as a means to reducing life-prolonging treatment/hospitalization of patients.
- Wishes regarding life-prolonging treatment/hospitalization did not turn negative after the intervention – rather the opposite.

Discussion

Achievement of the aims:

- promoting patient participation in ACP
- promoting the possibility for conversations about the end of life with patients and relatives
- creating a better foundation for important decisions in the case of medical emergencies at the end of life

Thank you!



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All photos by Kristin Ellefsen

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