Advance Care Planning

A way to improve end-of-life care?

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(Mette Asbjørn Neergaard)
November 2017

Palliative Care
Research Aarhus

Program

Background and aim

Papers I-III

Conclusions

………………………………………

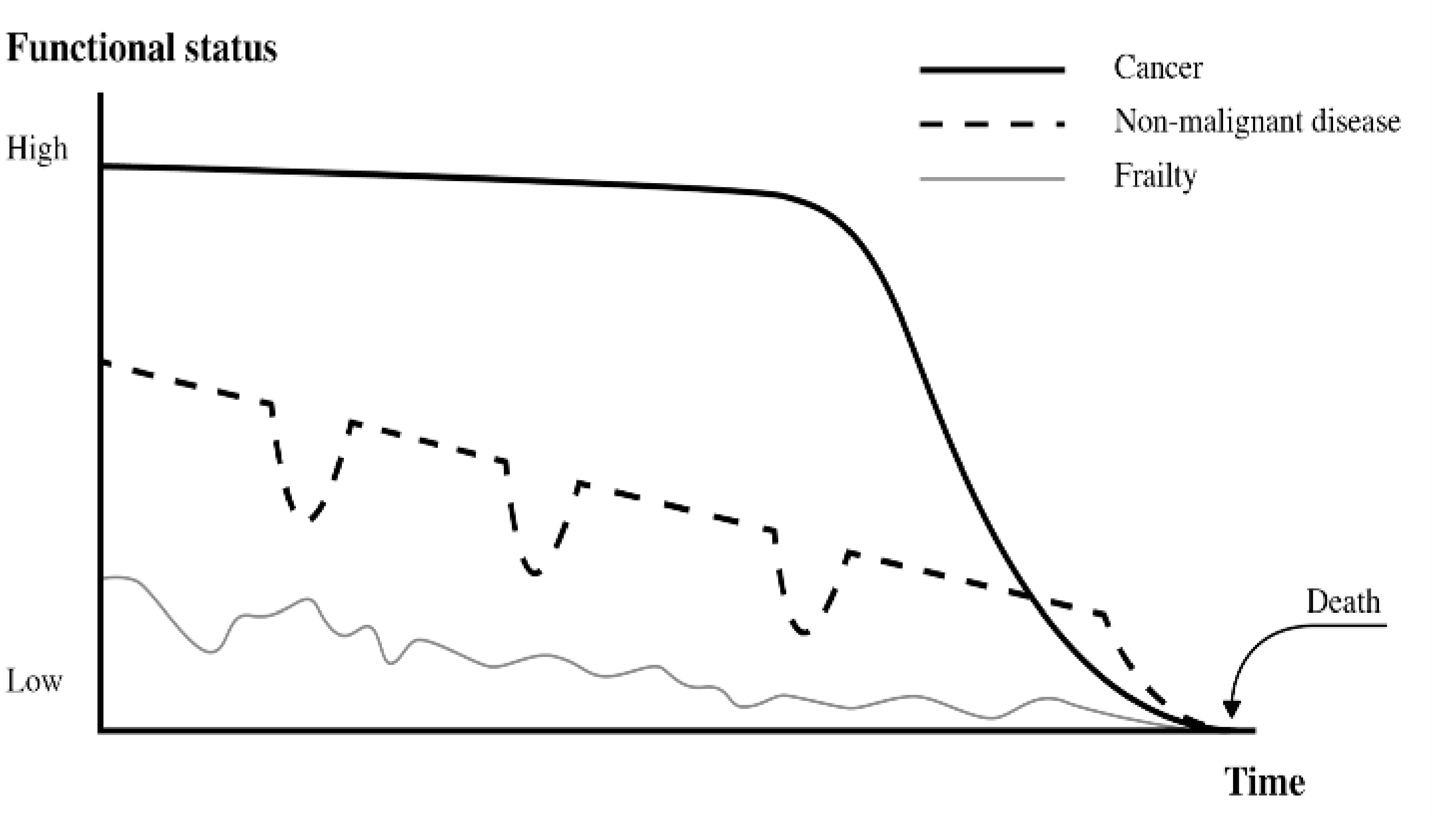
Hvad lykkedes?

Hvad lykkedes knap så godt?

Hvad ville vi have gjort anderledes?

It matters how you die

Different trajectories



Lunney, Lynn, & Hogan, 2002

Advance care planning (ACP)

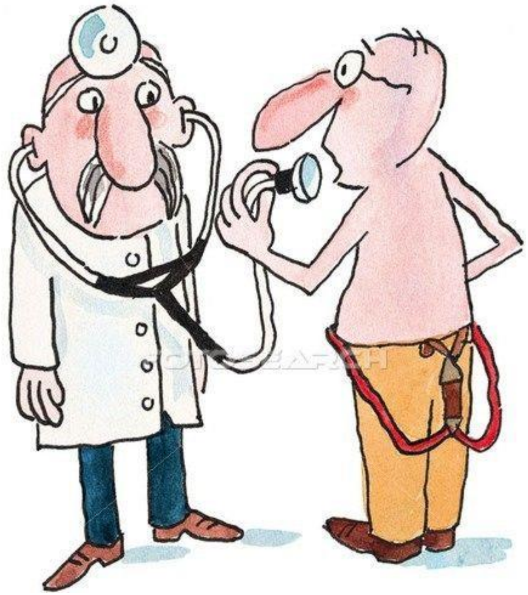
Inspiration

- Detering et al, 2010
- A randomised controlled trial in elderly patients

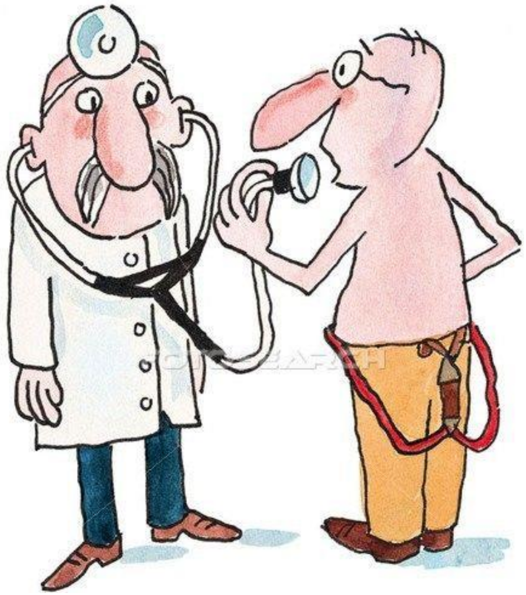
Conclusion

- Improved fulfillment of preferred place of death, satisfaction with health care and reduced stress, anxiety, and depression in bereaved relatives

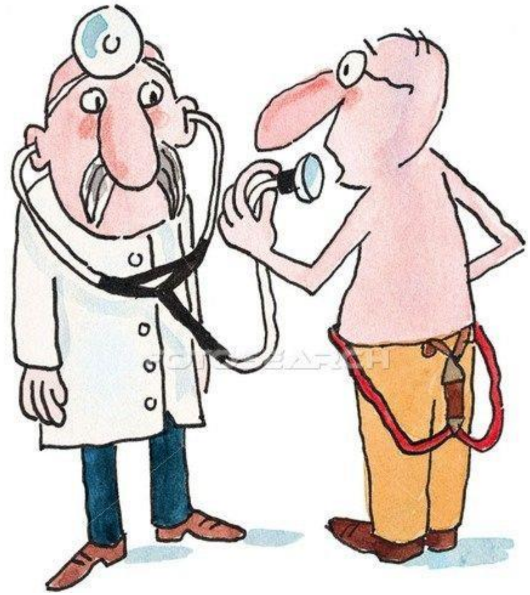
Advance care planning (ACP)



Advance~~d~~ care planning (ACP)



Advance care planning (ACP)



Systematic approach

discussion & documentation

Definitions of ACP

Singer et al. 1996

“Whereby a patient, in consultation with health care providers, family members and important others, makes decisions about his or her future health care, should he or she become incapable of participating in medical treatment decisions.”

White paper, Lancet Oncol. 2017

“… review these preferences if appropriate.”

Overall aim

Is ACP feasible, **effective and beneficial** in a Danish context in a population of terminally ill adult patients whether they have malignant or non-malignant diseases?

Outcomes:

- Fulfillment of preferred place of death
- Time spend out of hospital in EOL
- Survival

Paper III

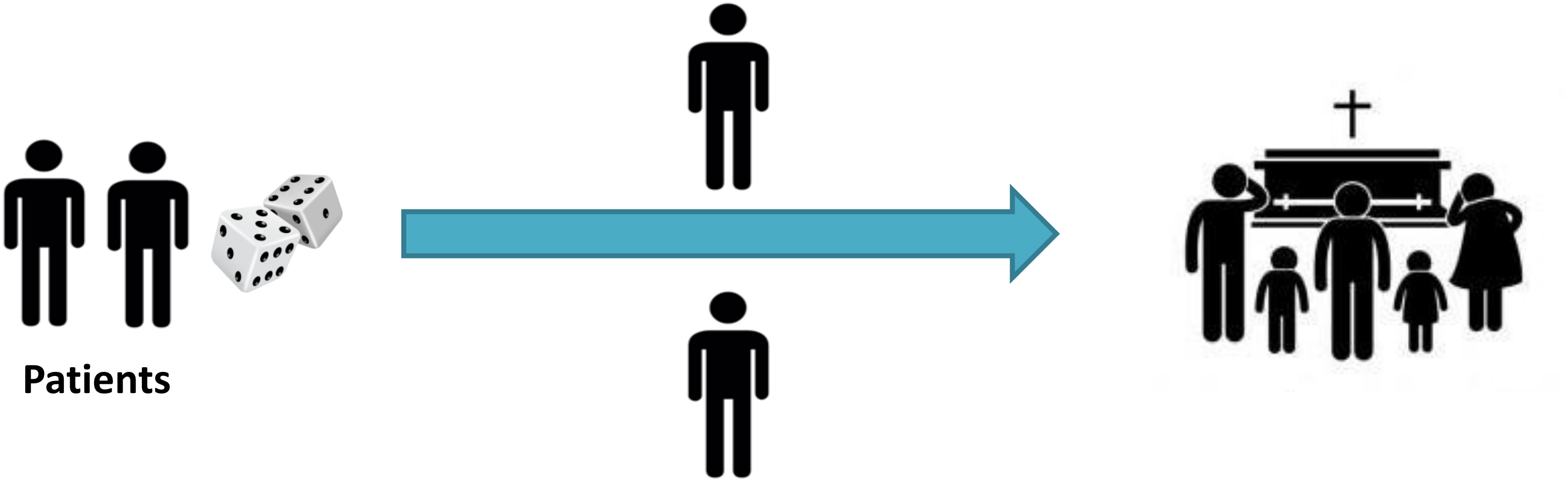
- Level of anxiety and depression
- Satisfaction with health care
- QOL and symptoms

Paper II

Do patients with various diagnoses have different end-of-life preferences and different levels of anxiety?

Paper I

Overview of study



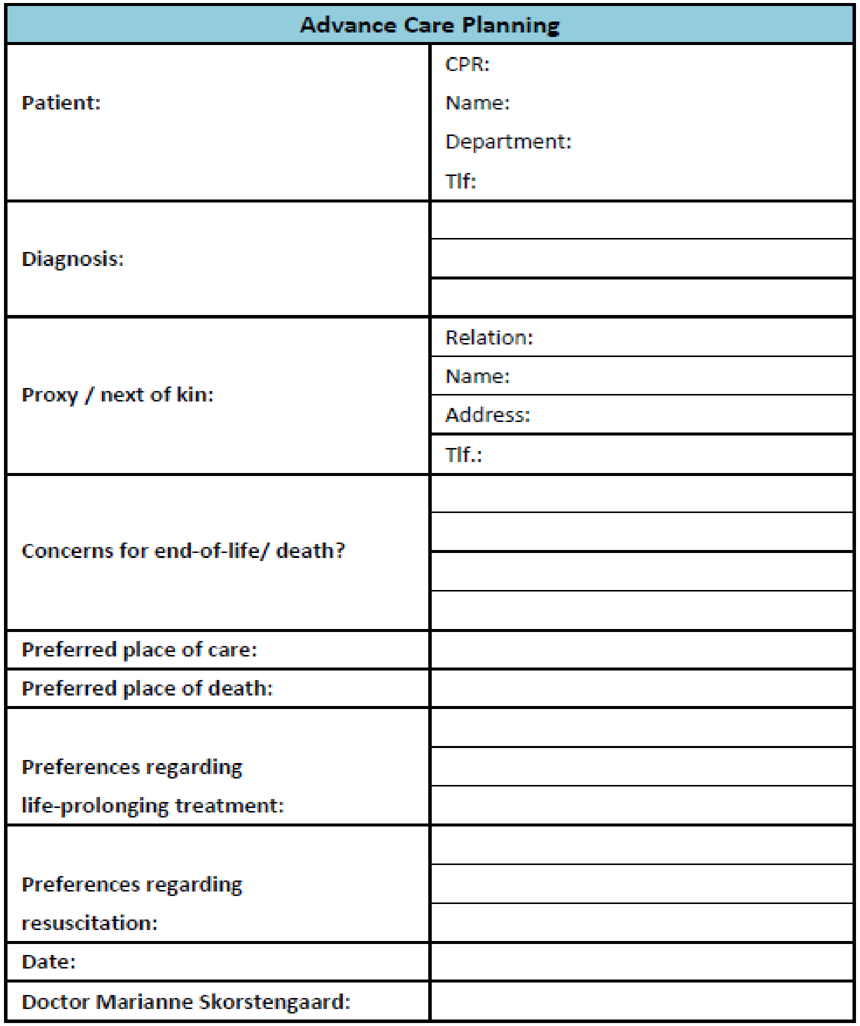
Intervention

Patients

Control

The intervention

Fictive ACP-discussion



Advance Care Planning	
Patient:	CPR: Name: Department: Tlf:
Diagnosis:	
Proxy / next of kin:	Relation:
	Name:
	Address:
	Tlf.:
Concerns for end-of-life/ death?	
Preferred place of care:	
Preferred place of death:	
Preferences regarding life-prolonging treatment:	
Preferences regarding resuscitation:	
Date:	
Doctor Marianne Skorstengaard:	

Palliative and Supportive Care, page 1 of 8, 2015.

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Talking about sensitive topics during the advance care planning discussion: A peek into the black box

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(RECEIVED October 9, 2014; ACCEPTED January 21, 2015)

ABSTRACT

Objective: Advance care planning (ACP) discussions are emphasized as a valuable way of improving communication about end-of-life care. Yet we have very little knowledge of what goes on during actual ACP discussions. The aim of our study was to explore how the sensitive topics of end-of-life decisions are addressed in concrete ACP discussions, with special focus on doctor–patient interactions.

Method: Following a discourse-analysis approach, the study uses the concept of doctor and patient "voices" to analyze 10 directly observed and audiotaped ACP discussions among patients, relatives, and a physician, carried out in connection with a pilot study conducted in

The diverse impact of advance care planning: a long-term follow-up study on patients' and relatives' experiences

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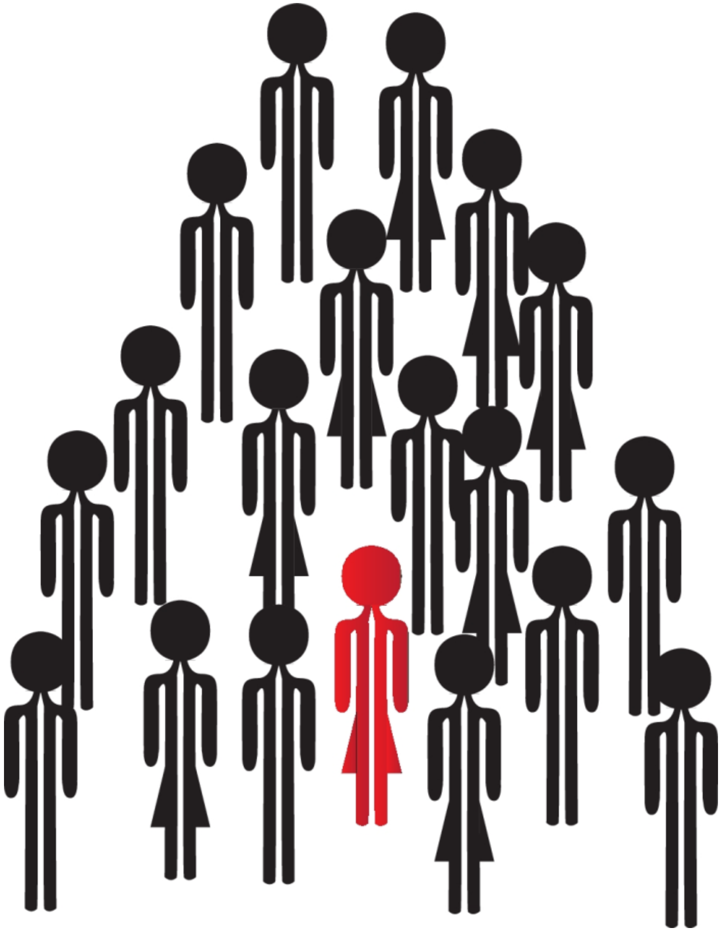
ABSTRACT

Background Advance care planning (ACP) is a process of discussing and recording patients' preferences for future care, aiming to guide healthcare decisions at the end of life (EOL).
Aim To explore nuances in the long-term impact of ACP by studying patient and relative experiences.
Design A qualitative follow-up interview study. Interviews were recorded, transcribed and analysed using thematic synthesis.
Setting/participants 3 patients with a life-limiting disease (lung or heart disease), affiliated

communication between patients, relatives and healthcare professionals, encompassing discussions about the patient's values and preferences for end-of-life (EOL) care, and documentation of, for example, treatment preferences and proxy decision-makers. ACP is recommended as best practice and is intended to ensure that medical and EOL decisions are in line with the patient's preferences, should he or she lose the capacity to express them.[1 2]

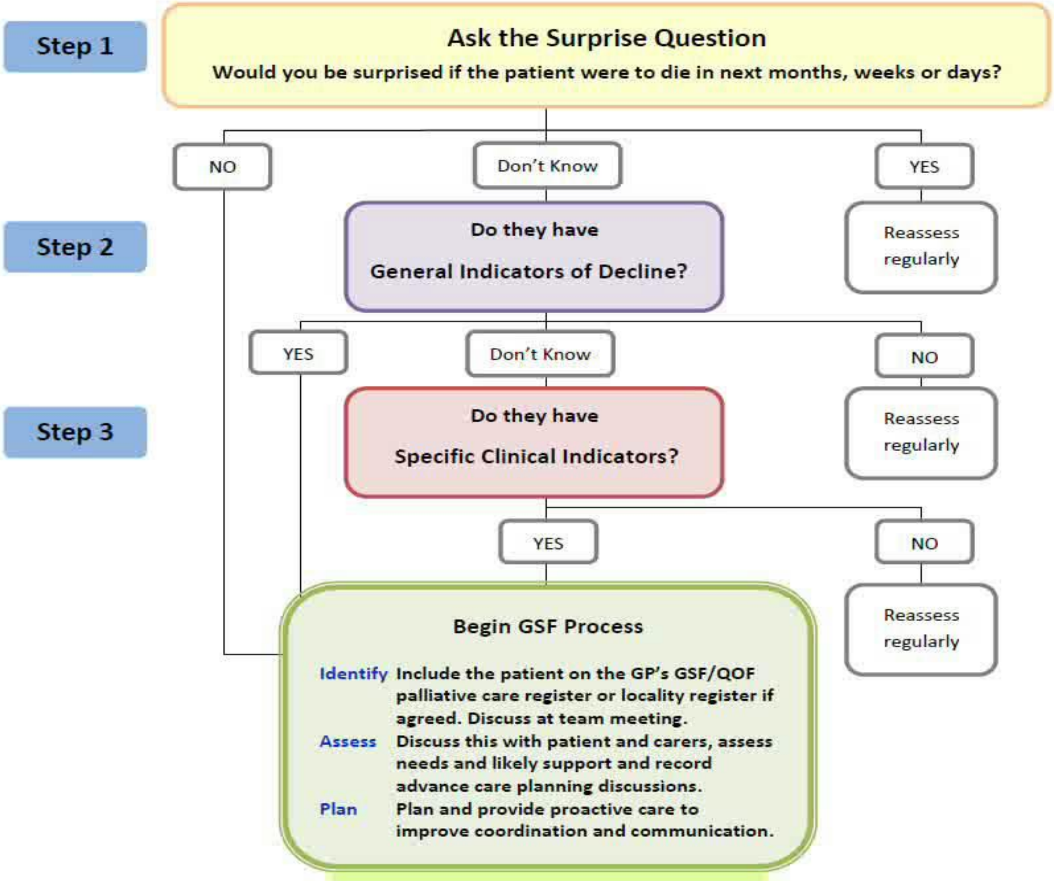
Quantitative research on ACP has

Patients



Patients

the gold standards framework®



Step 1

Ask the Surprise Question

Would you be surprised if the patient were to die in next months, weeks or days?

NO

Don't Know

YES

Reassess regularly

Step 2

Do they have General Indicators of Decline?

YES

Don't Know

NO

Reassess regularly

Step 3

Do they have Specific Clinical Indicators?

YES

NO

Reassess regularly

Begin GSF Process

Identify Include the patient on the GP's GSF/QOF palliative care register or locality register if agreed. Discuss at team meeting.

Assess Discuss this with patient and carers, assess needs and likely support and record advance care planning discussions.

Plan Plan and provide proactive care to improve coordination and communication.

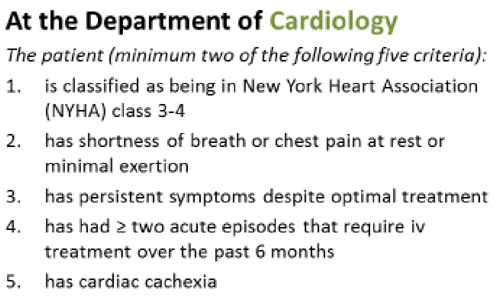
The Gold Standards Framework

General criteria

The patient (all of the five criteria)

1. is above 18 years of age
2. is able to speak and understand Danish
3. is not expected to die within 1 month
4. has relatives
5. is cognitively able to participate in the intervention

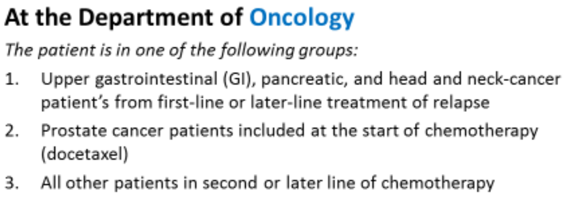
Disease-specific criteria



At the Department of Cardiology

The patient (minimum two of the following five criteria):

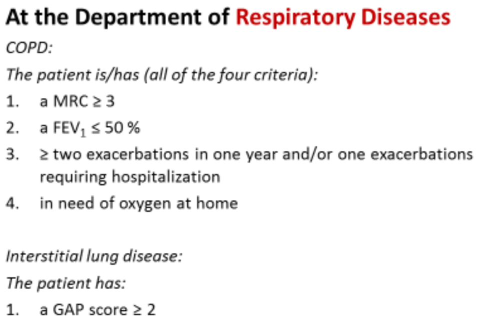
1. is classified as being in New York Heart Association (NYHA) class 3-4
2. has shortness of breath or chest pain at rest or minimal exertion
3. has persistent symptoms despite optimal treatment
4. has had ≥ two acute episodes that require iv treatment over the past 6 months
5. has cardiac cachexia



At the Department of Oncology

The patient is in one of the following groups:

1. Upper gastrointestinal (GI), pancreatic, and head and neck-cancer patient's from first-line or later-line treatment of relapse
2. Prostate cancer patients included at the start of chemotherapy (docetaxel)
3. All other patients in second or later line of chemotherapy



At the Department of Respiratory Diseases

COPD:

The patient is/has (all of the four criteria):

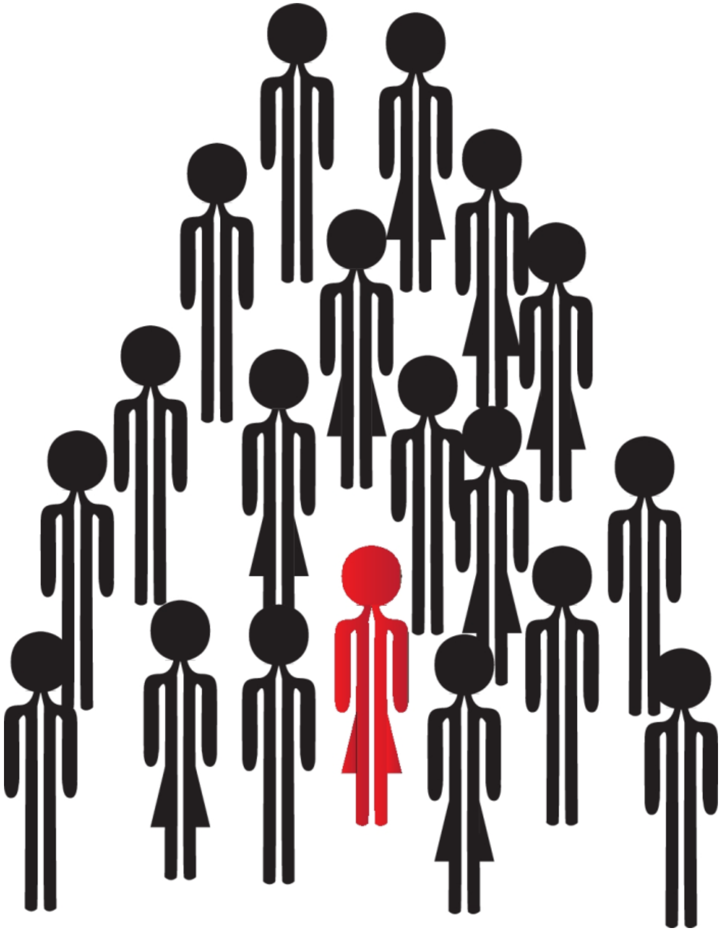
1. a MRC ≥ 3
2. a $FEV_1 \leq 50\%$
3. ≥ two exacerbations in one year and/or one exacerbations requiring hospitalization
4. in need of oxygen at home

Interstitial lung disease:

The patient has:

1. a GAP score ≥ 2

Patients



The participants

Patients (n=205)

- Cancer: 103 (50%)
- Lung: 68 (33%)
- Heart: 34 (17%)
- Mean age of 70 years

Relatives (n=205)

- Mean age of 63 years

Data collection

Data consisted of questionnaire and registry data

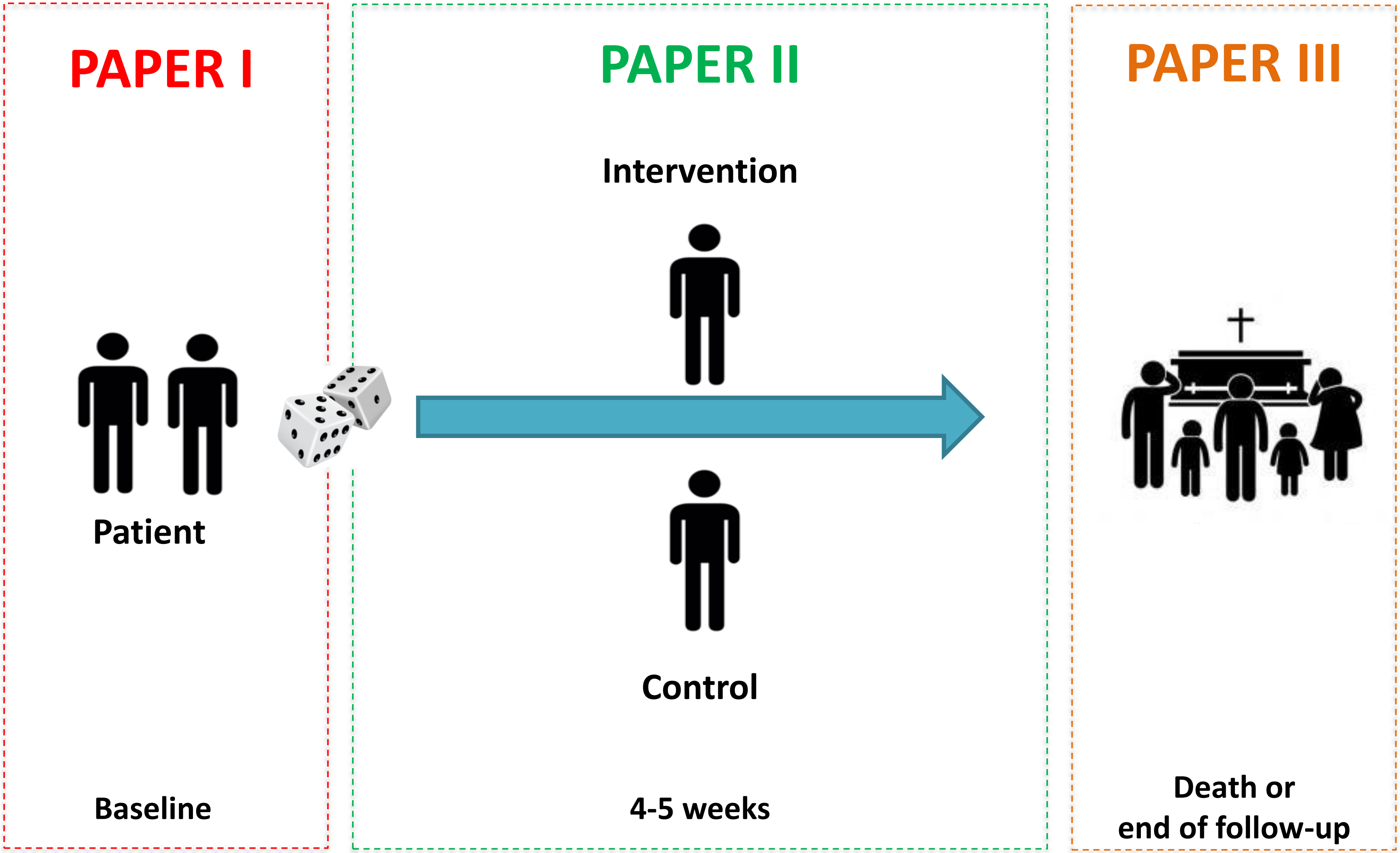
Questionnaires (4-5 weeks after randomisation)

- Anxiety and depression (SCl-92)
- Health related quality-of-life (EORTC QLQ C-15 scale)
- Satisfaction with health care (FamCare)

Registries

- The Danish National Patient Register
- The Danish Register of Causes of Death

Papers



PAPER I

Patient

Baseline

PAPER II

Intervention

Control

4-5 weeks

PAPER III

Death or
end of follow-up

Paper I

JOURNAL OF PALLIATIVE MEDICINE
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Original Article

Preferred Place of Care and Death in Terminally Ill Patients with Lung and Heart Disease Compared to Cancer Patients

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Elisabeth Bendstrup, MD, PhD,[5] Anders Løkke, MD, PhD,[5] Susanne Aagaard, MD,[6]
Henrik Wiggers, MD, PhD,[6] Per Bech, MD,[7] and Anders B. Jensen, MD[1]

Abstract

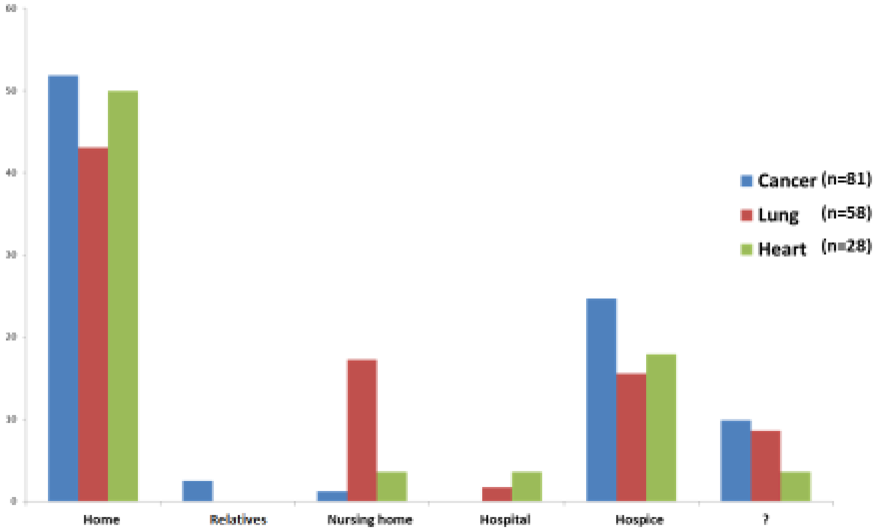
Objectives: The dual aim of this study is, first, to describe preferred place of care (PPOC) and preferred place of death (PPOD) in terminally ill patients with lung and heart diseases compared with cancer patients and second, to describe differences in level of anxiety among patients with these diagnoses.
Background: Previous research on end-of-life preferences focuses on cancer patients, most of whom identify home as their PPOC and PPOD. These preferences may, however, not mirror those of patients suffering from nonmalignant fatal diseases.
Design: The study was designed as a cross-sectional study.
Setting: Eligible patients from the recruiting departments filled in questionnaires regarding sociodemographics, PPOC and PPOD, and level of anxiety.
Results: Of the 354 eligible patients, 167 patients agreed to participate in the study. Regardless of their

Aim

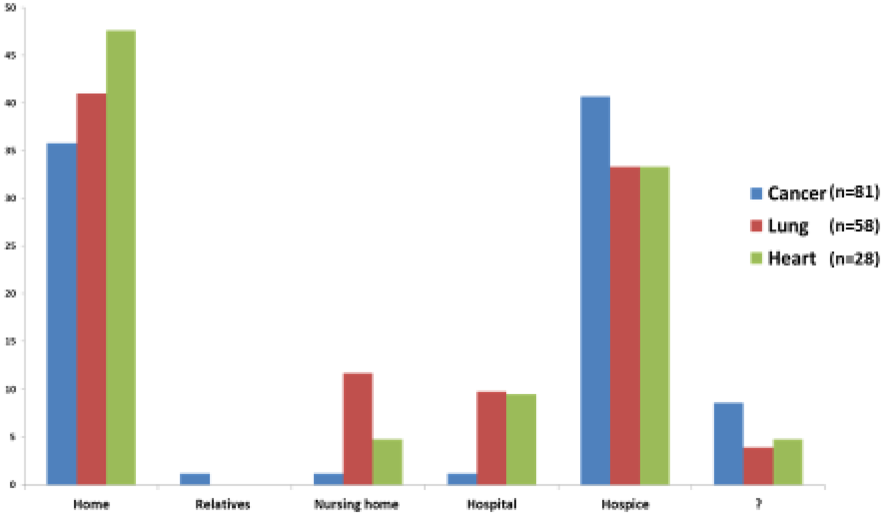
To describe preferred place of care and death in terminally ill patients with lung and heart diseases compared with cancer patients

To describe differences in level of anxiety among patients with these diagnoses

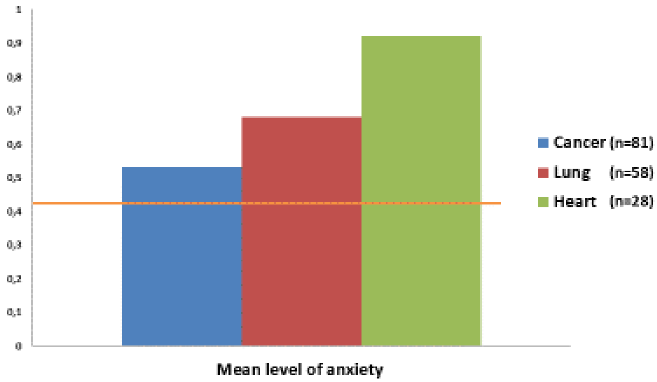
Preferred place of care



Preferred place of death



Anxiety



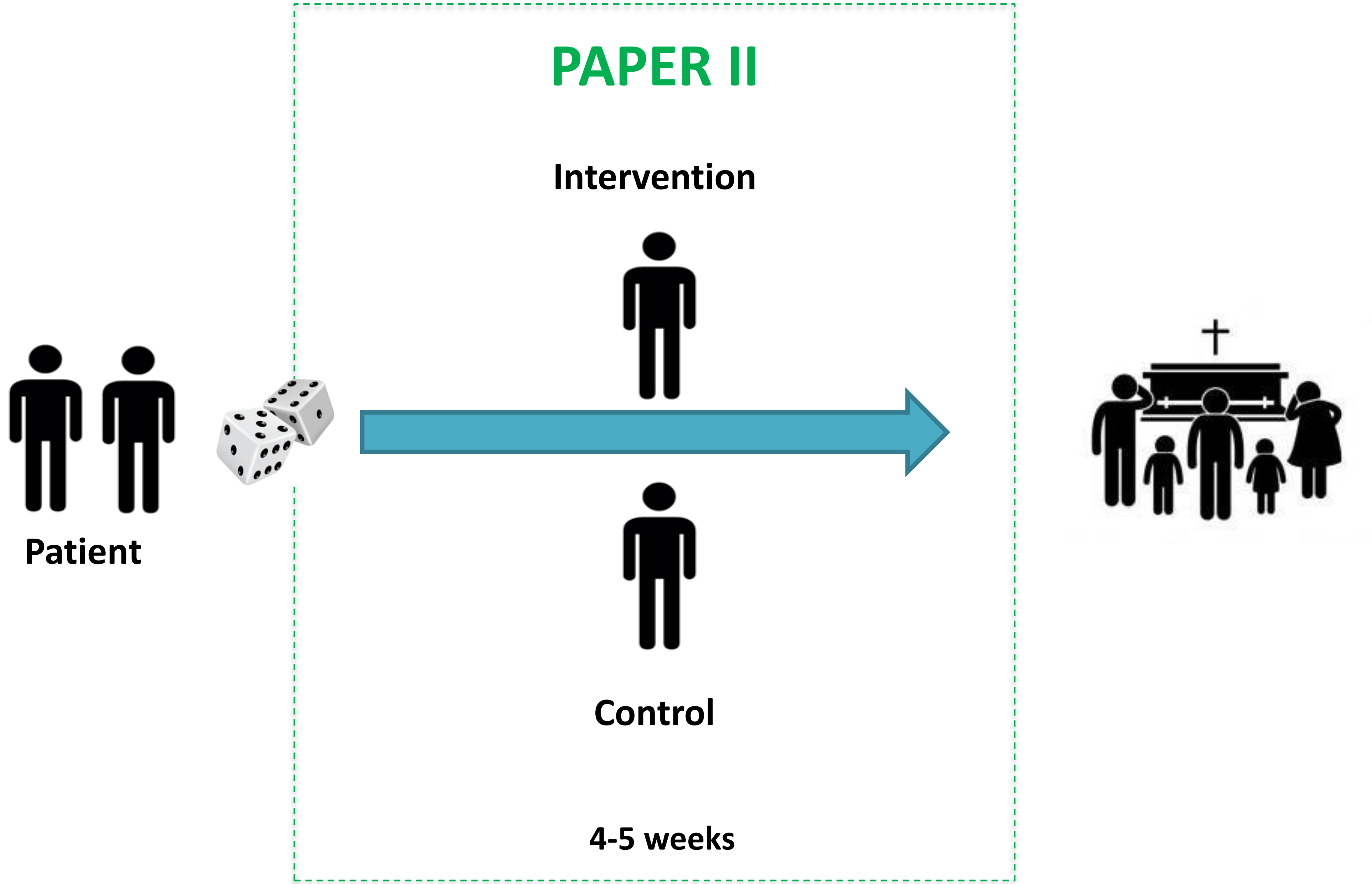
SCL-92

Conclusion

Marked differences among patients

- Preferences for place of care and death
- Differences in levels of anxiety

Papers



PAPER II

Intervention

Patient

Control

4-5 weeks

Paper II

Skorstengaard MH, Johnson AT, Jensen AB, Andreassen P, Brogaard T,
Bendstrup E, Løkke A, Aagaard S, Wiggers H, Neergaard MA.

Advance Care Planning for terminally ill lung-, heart- and cancer patients and their relatives; a randomised controlled trial measuring the effect on quality of life, anxiety, depression and satisfaction with health care

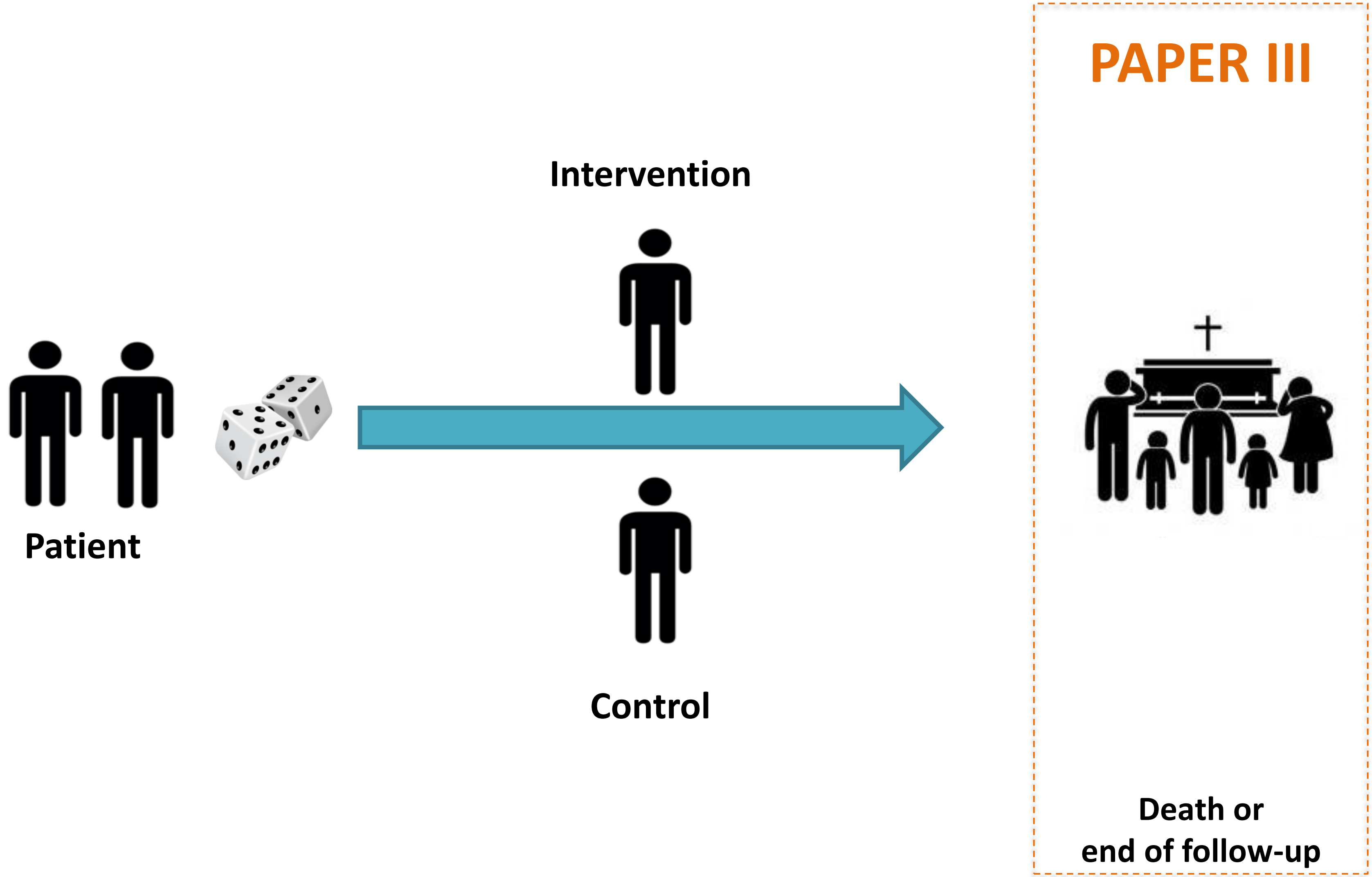
Aim

To investigate the effects of ACP among terminally ill patients with lung, heart, and cancer diseases concerning

- Health-related quality of life (patients)
- Anxiety and depression (patients and relatives)
- Healthcare satisfaction (patients and relatives)

Slides med resultater og konklusion af Paper II er fjernet, da artiklen endnu ikke er publiceret.

Papers



PAPER III

Intervention

Patient

Control

Death or
end of follow-up

Paper III

Skorstengaard MH, Neergaard MA, Andreassen P, Brogaard T, Bendstrup E, Løkke A,
Aagaard S, Wiggers H, Jensen AB.

Advance care planning improves survival in terminally ill patients with heart, lung and cancer diseases; a randomised controlled trial

Aim

To investigate the effects of ACP among terminally ill patients with lung, heart, and cancer diseases with respect to

- Fulfillment of preferred place of death (PPOD)
- Proportion of time spent in hospital
- Survival

Slides med resultater og konklusion af Paper III er fjernet, da artiklen endnu ikke er publiceret.

It matters how you die

Overall conclusion

ACP has been shown to be clinically meaningful and feasible to patients with cancer, heart and lung diseases.

No harmful outcomes were found.

The results from the RCT is yet to be published.

Patients with non-cancer diagnosis have higher levels of anxiety and different preferences for EOL than patients with cancer.

Hvad lykkedes?

- RCT blandt svært syge patienter
- ACP blandt patienter med alle tre diagnoser
- Samarbejde med de tre typer afdelinger
- 79 (+ 10) ACP samtaler udført
- Indledende kvalitativt studie
- Ikke tegn på ”bivirkninger”
- Høj deltager-procent
- Validerede sp.sk. (EORTC QLQ C15 PAL, FamCare, SCL-92)

Hvad lykkedes knapt så godt?

- Sammenlignelige grupper?
- Sampling via klinikere
- Ikke-valideres spørgeskemaer ift. sprog og patientgruppe (EORTC, FamCare, SCL 92)
- Main outcome i registre…
- Ikke påviselig effekt…
  - Virker ACP ikke iDK?
  - Større sample?
  - Mere effektful intervention?
  -

Hvad ville vi have gjort anderledes?

- Sampling:
  - Overveje kriterier nøje. Surprise question?
  - Metode til sampling uden om klinikere?
  - Flere patienter inkluderet
- Main outcome:
  - Vurdere nøje(Bestemmer sample size. Realistisk?)
  - Raffinere data på main outcome
- Involvere professionelle mere aktivt?
- Gentagne målinger i forløb?
- Gentagne ACP samtaler i forløb?

Tak for opmærksomheden!

Palliative Care
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