



LINDENHOFGRUPPE

Kantonsspital
Baselland

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Ethical Tensions in a Patient-Oriented Research Project: Advance Care Planning (ACP) in Chronic Obstructive Pulmonary Disease (COPD)

SGBE-Seminar Bigorio

Background

- The future healthcare system should be partnership-based, interprofessional, and sustainable (according to SAMS).
- The project examines a patient-oriented approach to health planning according to ACP.
- Inclusion of (caring, supportive) close persons is central in chronic diseases (persons authorized to represent).
- COPD is the third leading cause of death worldwide.
- Due to the complexity of the symptoms and the unpredictable course, advance care planning (= ACP) is urgent.

Short Description of the ACP Process

- Within the research project, COPD patients undergo specific advance planning (ACP) approach with two trained counselors.
- The aim of this advance planning process is to talk with patients and their close caregivers/persons (legal surrogates) about their **personal values, wishes and ideas, about life, the disease and also about dying**.
- In a second step, based on these wishes, **therapy goals** for different situations of incapacity are determined.
- At the end of the counseling conversations, the persons affected by COPD can - if they wish - set up a living will.

Project Hypotheses

- ACP counseling conversations are very challenging for affected persons and their relatives/closely related persons.
- Trigger emotions due to...
 - ... confrontation with progression of the disease, fear of death/suffocation
 - ... reminding and awareness of (possibly increasing) limitations due to progress of disease
 - ... mourning processes
- ACP counseling conversations are complex in content and relatively long in duration
- Cognitively demanding

Research Goals

Evaluation of ACP counseling conversations in terms of

- 1) The way of conducting the conversions by the counselors and
- 2) Content, duration, and framework of the conversations -> Interviews with COPD patients and legal representatives.
- 3) Self assessment concerning "preparedness" for the situation of decisional incapacity.

Objective: To improve and adapt the ACP counseling process to patients affected by COPD.

Research Questions

- How do persons affected by COPD experience the ACP counselling conversations?
- How do the relatives / close persons (healthcare proxies) experience these conversations?
- Is the instrument of the ACP-COPD advance directive with the associated offer for conversations suitable for advance care planning for COPD affected persons (and their surrogates)?
- Do these conversations have an influence on being prepared for, and confident about situations of incapacity in which medical decisions have to be made?

Research Project – More Information

- 3 test interviews
- 10 ACP conversations with patients and surrogates at Lindenhofspital in Berne and Kantonsspital Baselland (sites: Liestal, Bruderholz)
- Mixed-method study
- Thematic analysis

- Research project developed with a Dr. Sarah Ziegler (psychologist from the Epidemiology, Biostatistics, and Prevention Institute, UZH)
- Involved evaluation process: Dr. med. Eva Maria Tinner (research group of University Department of Internal Medicine, KSBL)

Advance Care Planning: Concept

Part 1: Standortbestimmung

Wie wichtig ist es Ihnen, noch lange zu leben?

Was ist in Ihrem Leben bedeutend?
Wie gerne leben Sie?

Gibt es Situationen, in denen Sie nicht mehr lebensverlängernd behandelt werden möchten?

Wenn Sie ans Sterben denken, was kommt Ihnen in den Sinn?
Haben Sie Erfahrungen gemacht mit Menschen, die gestorben sind, die Sie geprägt haben?



Advance care planning: Concept

PART 2: THERAPEUTIC GOALS

Therapieziel A: Lebensverlängerung

A0 ●●●●●

Therapieziel B: Lebensverlängerung mit Einschränkungen der medizinischen Massnahmen

B0 ●●●●●

B1 ●●●●●

B2 ●●●●●

B3 ●●●●●

Therapieziel C: Leidenslinderung/Lebensqualitätsverbesserung

C0 ●●●●●

Role of the facilitator / Aim of ACP

*The aim of Advance Care Planning is,
"that you are treated in the way you want in the future - even if you are no longer
able to express yourself."*

(ACP Deutschland, Vereinigung der ACP-Gesprächsbegleiter*innen in Deutschland)

Role of the facilitator:

- Non-directive / personal-centered approach (Carl Rogers)
- Shared decision making (Glyn Elwyn)
- Empowerment
- Self-reflection



Quotes from the Conversations – Patient-Oriented

"I've already talked to my partner about finitude and what I want. It's important to me to discuss that with you and then put it in writing so the doctors understand it and know what I want."

"Actually, we haven't talked that much about the future. I realize the disease is progressing and it's not getting better. It's not easy to talk about it, it can be scary too. But it would be good, if my wife had something in hand."

Nudge

Blumenthal-Barby/Burroughs (2012)

Categories of Nudges:

- Incentives
- Defaults
- Salience and affect
- Norms and messenger
- Priming
- Commitments and ego

→ Recruitment by pneumologist (physician-patient relationship)

→ Informed consent form → sort of «Commitment» after the first conversation (opting-out)

→ Relationship to the facilitator

Ethical reflection

Contents of the ACP discussions:

- «Depth» of conversations
- Addressing emotional issues
- Facilitators get a special status (intimacy): Do participants respond differently (biais)?

Role “design” of the facilitator after the conversations:

- A reflection process is initiated with ACP. For consultants, the whole process is completed after two sessions.
- Responsibility/role of the facilitator in the further process?
- "Therapeutic effect" of ACP -> Thematization of biographical aspects that are needed for the formulation of therapy goals, but which then remain in the room and on which further work could/should be done (does not belong to the role of the facilitator)?

Ethical reflection

Personal issues during ACP-discussion:
Who is the privileged ACP-facilitator:

- The home care nurse ?
- The family physician?
- The pneumologist?

Which information is needed before starting ACP, for giving an «informed consent» for our research project participation?

Dealing with loneliness / social isolation of the participants during the communication process?

Questions for the discussion

- Are these kind of nudges ethically justified?
- Which information should be given to the participants before the study intervention concerning the emotional aspects / contents of the ACP-discussions?
- How much information would be «too much»?
- Which role for the ACP facilitator ?
- ACP is not supposed to be «therapeutical»:
- How deal with the wish to keep in contact & to continue this kind of talk ?

