Advance Care Planning: lessons learned from research with vulnerable patients

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Background

- **Advance Care Planning** (ACP) is an evidence-based gold standard

- **Key to success**: context-sensitive and standardized process

- **Specific challenges in dementia**: (1) long trajectory, (2) short window of opportunity, (3) crucial role of the family, (4) specific decisions (conflict ACP vs. current behavior)
**ADIA Study**  
*Alzheimer’s Disease-specific Intervention of Advance care planning*

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Method</th>
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<tbody>
<tr>
<td><strong>Develop</strong> a dementia-specific ACP intervention</td>
<td><strong>Pilot</strong> one-arm clinical trial</td>
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<tr>
<td><strong>Identify</strong> the ideal moment for initiating it</td>
<td><strong>Sample:</strong> patients after diagnosis of dementia and close relatives (20-30 dyads)</td>
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<td><strong>Explore</strong> the feasibility and acceptability of the intervention and suitable outcome criteria for a later trial</td>
<td><strong>Intervention</strong> adapted from Zurich ACP model</td>
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<td><strong>Multi-method evaluation</strong></td>
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Challenges I

- Failed collaboration with a US partner due to a for-profit ACP model and strict licensing rules

- ACP is a cognitively demanding process → challenge to adapt to cognitively impaired persons

- Recruitment difficult: 108 screened, 44 exclusions by gatekeepers

- Explained by the institutional and professional culture: (1) Taboos around dying, (2) Skepticism and ignorance of palliative care, (3) Dementia not seen as terminal disorder, (4) Competing for research participants, (5) Lacking interprofessional team culture
Challenges II

- **Research ethics committee**: required psychiatrist as co-investigator, consent by primary care physicians, emergency response plan

- Additional problems in the clinical requirements: (1) physicians unsure and overly protective in assessing decision-making capacity, (2) problems diagnosing dementia and lack of disclosure

- High rates of refusal: 18 among 34 eligible patients/families refused: (1) low knowledge (34%) and use (7%) of advance directives in Western CH, (2) unfamiliar with shared decision making, (3) belief that advance directive is sufficient
Conclusions

- Design trials in knowledge of local restrictions (multiple recruitment sites, wide inclusion criteria)
- Carefully select collaboration and recruitment partners
- Raise awareness about ACP and advance directives in the general population and among health care professionals
- Reduce taboos and misconceptions about end of life
- Transform the medical culture to a more patient-centered practice
Same Same but different:
Experiences from Advance Care Planning trials at the University Hospital Zurich
• MAPS Study 2012-2017, NFP 67
• ACP and SDM in TAVI, starting 01/2019, SAMW Palliative Care (see lessons learnt, Poster)
Success stories ....
Advance care planning for the severely ill in the hospital: a randomized trial

Tanja Krones,1 Ana Budilivschii,2 Isabelle Karzig,3 Theodore Otto,4 Fabio Valeri,2 Nikola Biller-Andorno,7 Christine Mitchell,7 Barbara Loupapatatzis8

ABSTRACT
Objectives To investigate the impact of advance care planning (ACP) including decision aids for severely ill medical inpatients.
Methods Single-centre randomised controlled trial at a Swiss university hospital. Patients were randomly assigned (1:1) to receive an extra consultation with the hospital social service or a consultation with in-house facilitators trained according to an internationally established ACP programme. Trial participants with the exception of the observers were fully blinded. 115 competent severely ill adults, their surrogates and their attending physicians were enrolled and followed for 6 months after discharge or 3 months after death. The patient's wishes

INTRODUCTION
Advance care planning (ACP) has attracted growing attention since the 1990s. ACP describes a structured interactive process involving patients, their loved ones and their care providers to plan future treatments that respect patients' wishes and goals.1,2 Over the past 20 years the focus has shifted from completion of advance directives to effective professional communication promoting patient-centred goals-of-care discussions for future care. Several systematic reviews on the effectiveness of ACP strategies1-4 indicate that ACP interventions increase the number of advance directives (ADs) and do not attempt to aggregate evidence.
And Backstage
Die Bedeutung der Konkurrenz im Gebiete des Geistigen

The meaning of competition in the area of the intellectual

[Sammelwerksbeitrag]
1) The ACP Pill
2) ACP and Palliative Care
3) Dilemmas in evaluating complex interventions
4) Tensions in Implementation of ACP
**ACP-Training mit Schauspielpatientin**

**Goals of care approach VIDEOS and Skilltraining**

**Documentation**

**Shared decision making/DECISION AIDS**

Entscheidungshilfe zum Thema

Insgesamt sind also im Durchschnitt von den Patienten mit COPD ein Jahr nach einer schweren respiratorischen Krise mit der Notwendigkeit einer stationären Behandlung auf einer Intensivstation 60% dieser Patienten am Leben.

Die Patienten sind entweder direkt im Spital oder nach Entlassung innerhalb des darauf folgenden Jahres verstorben.

Darum Unterschrift / vorliegende Person

Darum Unterschrift / verantwortungsbewusste Person

Darum Unterschrift / Anze des Verlassers
1) What, how, how much to teach and do by whom?

2) The problem of «application» of communication skills trainings

3) Hidden ingredients, hidden agendas
« Just a Trial on ACP »

Physicians / CEOs / Institutions / health care systems embracing

- Shared decision-making instead of minimum informed consent only
- Interprofessional team approaches
- Patient centred goals of care instead of intervention focused medicine
- Openness to life long communication skills trainings

- Researchers in epidemiology, qualitative methods, implementation science
- Communication skill teachers knowledgable of ACP including risk communication and shared decision making
- Physicians / nurses / social workers open to new skills
- Institutional support to do research tackling the core of medical procedures incl. discussion of emergency plans, goals of care (…)

« wool-milk pigs laying eggs »
ACP facilitation training DAY 1

Timetable: 9 am – 4:30 pm

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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</thead>
<tbody>
<tr>
<td>9.00 – 9.05</td>
<td>Welcome</td>
</tr>
<tr>
<td>9.05 – 9.25</td>
<td>Introduction of the participants including their expectations</td>
</tr>
<tr>
<td>9.25 – 9.30</td>
<td>Aims of the training program</td>
</tr>
<tr>
<td>9.30 – 9.45</td>
<td>Introduction of the ACP concept</td>
</tr>
<tr>
<td>9.45 – 10.00</td>
<td>Exchange of experience with the AD the participants had to fill in: What was easy? What kind of support would be useful</td>
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ACP facilitation training DAY 2

Timetable: 9am – 4pm

<table>
<thead>
<tr>
<th>Time</th>
<th>Session</th>
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</thead>
<tbody>
<tr>
<td>9.00 – 9.05</td>
<td>Welcome</td>
</tr>
<tr>
<td>9.05 – 9.55</td>
<td>Questions concerning the study plan</td>
</tr>
<tr>
<td>10.00 – 10.30</td>
<td>Experiences with homework</td>
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<tr>
<td>10.30 – 10.45</td>
<td>Break</td>
</tr>
<tr>
<td>10.45 – 11.30</td>
<td>Interaction between General Goals of care and Decision Aids</td>
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<td>Medical background for goals of care, examples</td>
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<td></td>
<td>Logic of the AD including emergency forms</td>
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Follow-up: Individual coaching support of facilitators by the MAPS study team ACP trainers up to 10 hours; ACP facilitation meetings every two months to exchange experiences
Basiskurs Botschafterinnen und Botschafter Advance Care Planning (ACP)

Dauer
2 Tage, 8.30 Uhr - 17.30 Uhr

Theoriekurs Beraterinnen und Berater Advance Care Planning (ACP)

Dauer
4 Tage, 8.30 Uhr - 17.00 Uhr
Recruitment problems

and respected) and smaller effect (30% wishes known and respected) for the MAPS study. To achieve 90% power with a certainty of 95% for the primary outcome measure of wishes of resuscitation being known and respected, we calculated a sample size of 89 patients in each study arm, for a total of 178 patients undertook by blinded study team members on an intention-to-treat basis. In total, 115 patients were recruited between July 30, 2013 and December 18, 2014 to ensure a maximum follow-up of 9 months. Follow-up was completed in August 2015. Many patients were treated or died outside of the study hospital requiring further data collection, which was completed by September 2016.

Advance care planning for the severely ill in the hospital: a randomized trial.

And records were reviewed 6 months after discharge/intervention. Due to limited study resources, observers were not fully blinded since they screened patients for inclusion and interviewed patients after the interventions. Data monitoring and analysis were
AGEK
Arbeitsgemeinschaft der Schweizerischen Forschungs-Ethikkommissionen für klinische Versuche
Communauté de travail des Commissions d’éthique de la recherche en Suisse
CT CER

Schriftliche Einverständniserklärung des Patienten zur Teilnahme an einer klinischen Studie

- Bitte lesen Sie dieses Formular sorgfältig durch.
- Bitte fragen Sie, wenn Sie etwas nicht verstehen oder wissen möchten.

Nummer der Studie: MAPS
Titel der Studie: „Multiprofessional Advance Care Planning and shared decision making for end of life care (MAPS trial)“

Patientinnen-/Patienteninformation

Studie „MAPS-Studie (Multiprofessionelle Vorausplanung und gemeinsame Entscheidungsfindung) zu Behandlungen am Lebensende“

Sponsor der Studie: Klinische Ethik Universitätsspital und Universität Zürich
Gefördert vom Schweizerischen Nationalfond

Selbst gemachte Patientin
Selbst gemachter Patient

1. Auswahl der Studienteilnehmer

The Power of Palliative Care
The power and pain of (male) surrogates of younger female patients

<table>
<thead>
<tr>
<th></th>
<th>Included patients</th>
<th>Non-participants</th>
<th>Excluded patients</th>
<th>P values</th>
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<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
<td>n (%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Gender (male)</td>
<td>88 (77)</td>
<td>47 (53)</td>
<td>726 (58)</td>
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</tbody>
</table>

Table 3: Baseline characteristics of all screened patients
The Surprise Question

91 old patient with left ventricular output failure,

urinary tract infection

82 old patient with COPD Gold III

65 old patient on dialysis with pAVK

« doctor evaluates patient negative the 12 months surprize question »

Less clinically stable patients, patients too sick, mostly oncologic patients
The dilemma of complex interventions

Blinding
Placebo Intervention
Concealment of Allocation
Avoidance of «contamination»

Do not be too transparent

Best effect of the intervention
Shared process

Be open and transparent
What I would have done differently during the trial ...

No surprise question, no mentioning of end of life in the informed consent form (if the IRB had let us...) but focus on wishes of severely ill patients

Much more time and (wo)man power for training and ACP facilitation

Include patients in the ambulatory setting of the hospital right away

Include implementation scientists in the team

more ACP campaigns/less blinding during the trial

Maybe screen by study team not by physicians

Maybe include patients without surrogate consent