
# Advance Care Planning: lessons learned from research with vulnerable patients

Prof. Ralf J. Jox
Lausanne University Hospital
Prof. Tanja Krones
Zurich University Hospital

# 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*

## Objectives

- **Develop** a dementia-specific ACP intervention
- **Identify** the ideal moment for initiating it
- **Explore** the feasibility and acceptability of the intervention and suitable outcome criteria for a later trial

## Method

- **Pilot** one-arm clinical trial
- **Sample:** patients after diagnosis of dementia and close relatives (20-30 dyads)
- **Intervention** adapted from Zurich ACP model
- Multi-method **evaluation**

# 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

USZ Universitäts Spital Zürich

# Same Same but different:

# Experiences from Advance Care Planning trials at the University Hospital Zurich

Tanja K

- 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 Budilivschi,[2] Isabelle Karzig,[3] Theodore Otto,[4] Fabio Valeri,[5] Nikola Biller-Andorno,[6] Christine Mitchell,[7] Barbara Loupatatzis[8]

► Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/bmjspcare-2017-001489).

For numbered affiliations see end of article.

**Correspondence to**
Tanja Krones, Clinical Ethics, University Hospital Zürich/ Institute of Biomedical Ethics and History of Medicine University of Zürich, Zürich CH-8006, Switzerland;
tanja.krones@usz.ch

Received 27 December 2017
Revised 25 June 2018
Accepted 25 July 2018

## ABSTRACT

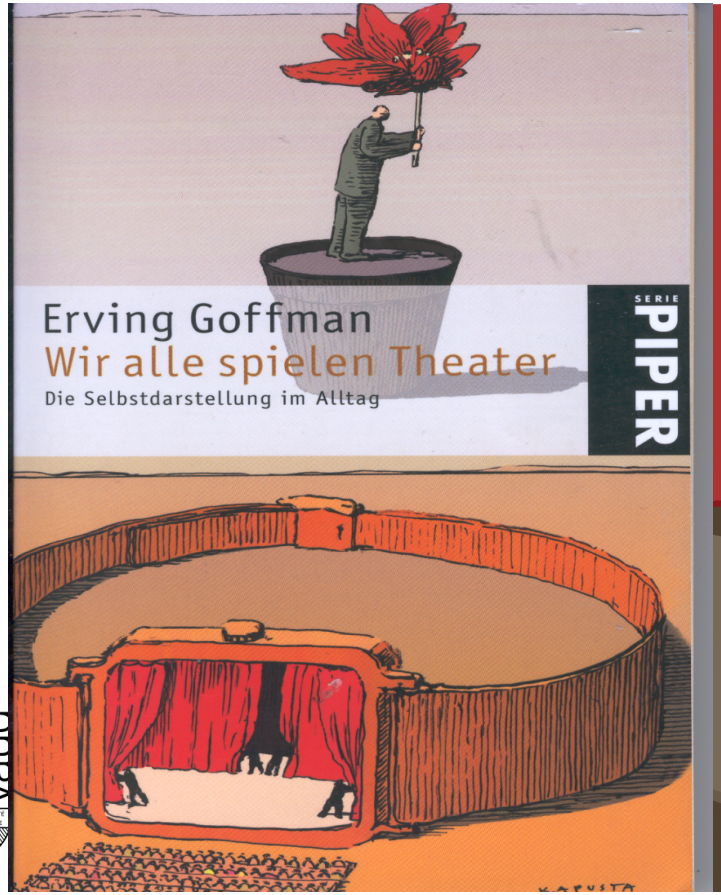
**Objectives** To investigate the impact of advance care planning (ACP) including decision aids for severely ill medical inpatients.

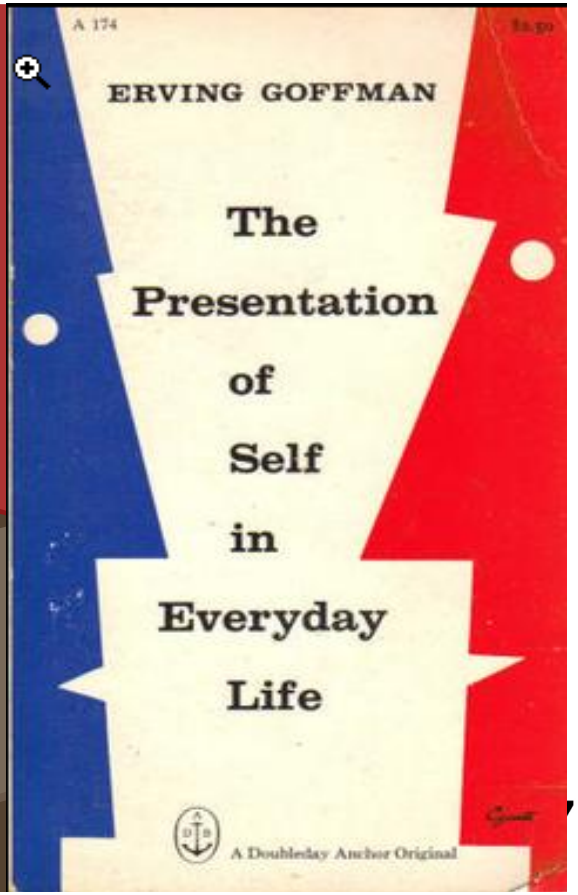
**Methods** Single-centre randomised controlled trial at a Swiss university hospital. Patients were randomly assigned (1:1) to receive an extra consultation with the hospital social service or a consultation with in-house facilitators trained according to an internationally established ACP programme. 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 strategies[3–5] indicate that ACP interventions increase the number of advance directives (ADs) and do-not-attempt-to-resuscitate orders

# And Backstage




SSOAR Social Science Open Access Repository

SSOAR ▼ | Browsen und suchen | Dokument hinzufügen | OAI-PMH-Schnittstelle

Volltext herunterladen
(3.703 MB)

# 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


I'm Vitamin
Love vitamin
I'm Vitamin
Happ vitami
I'm Vitamin
Health vitamin
I'm Vitamin
lucky vitamin

Documentation»

Goals of care approach
VIDEOS and Skillstraining

Shared decision making/
DECISION AIDS

Ärztliche Notfallanordnung (ÄNO) / Aktuell

Notfalltherapie

B1 Keine Herz- / Lungenwiederbelebung und keine invasive (Tubus) Beatmung, ansonsten uneingeschränkte Notfalltherapie

B2 Keine Herz- / Lungenwiederbelebung, keine invasive (Tubus) Beatmung und keine Behandlung auf einer Intensivstation, ansonsten uneingeschränkte Notfalltherapie

B3 Keine Herz- / Lungenwiederbelebung, keine invasive (Tubus) Beatmung, keine Behandlung auf einer Intensivstation und keine Mitnahme ins Spital, ansonsten uneingeschränkte ambulante Notfallbehandlung

Lebensqualität in jedem Fall

C0 Uneingeschränkte lindernde/ palliative Therapie auch stationär

C1 Uneingeschränkte lindernde/ palliative Therapie nur ambulant

Datum Unterschrift / verfügende Person

Datum Unterschrift / vertretungsberechtigte Person

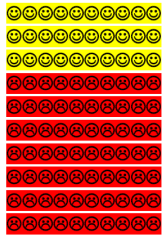
Datum Unterschrift / Arzt des Vertrauens


Video «Goals »

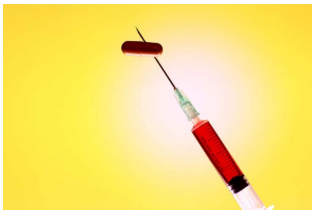
ACP-Training mit
Schauspielpatientin

Entscheidungshilfe zum Thema

n dies bei 70
solchen Krise
n noch vor der
esichter) die
sen,
rote Gesichter) sterben auf der Intensivstation.



Insgesamt sind also im Durchschnitt von den Patienten mit COPD ein Jahr nach einer schweren gesundheitlichen Krise mit der Notwendigkeit einer starken Beatmung auf einer Intensivstation 30 (gelbe Gesichter) Patienten am Leben.
70 (rote Gesichter)sind entweder direkt im Spital oder nach Entlassung innerhalb des darauf folgenden Jahres verstorben.



1) What, how, how much to teach and do by whom?

2) The p ation» of comm ainings

3) Hidden en 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

«wool-milk pigs laying eggs»

-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 (…)

## Supplementary data

[bmjspcare-2017-001489-supp1.pdf]

ACP facilitation training DAY 1

Timetable: 9 am – 4:30 pm

| | |
|---|---|
| 9.00 – 9.05 | **Welcome** |
| 9.05 – 9.25 | **Introduction of the participants including their expectations** |
| 9.25 – 9.30 | **Aims of the training program** |
| 9.30 – 9.45 | **Introduction of the ACP concept** |
| 9.45 – 10.00 | **Exchange of experience with the AD the participants had to fill in:** What was easy? What kind of support would be useful |

ACP facilitation training DAY2

Timetable: 9am – 4pm

| | |
|---|---|
| 9.00 – 9.05 | **Welcome** |
| 9.05 – 9.55 | **Questions concerning the study plan** |
| 10.00 – 10.30 | **Experiences with homework** |
| 10.30 – 10 .45 | **Break** |
| 10.45 – 11.30 | **Interaction between General Goals of care and Decision Aids**<br>Medical background for goals of care, examples<br>Logic of the AD including emergency forms |

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)

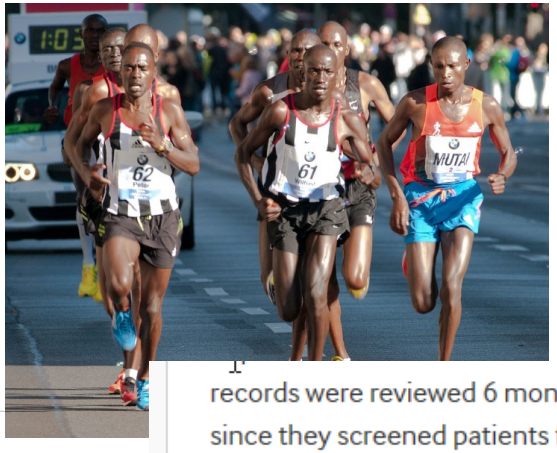
**Dauer**

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.

undertaken 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.




BMJ Support Palliat Care. 2019 Jan 21. pii: bmjspcare-2017-001489. doi: 10.1136/bmjspcare-2017-001489. [Epub ahead of print]

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

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

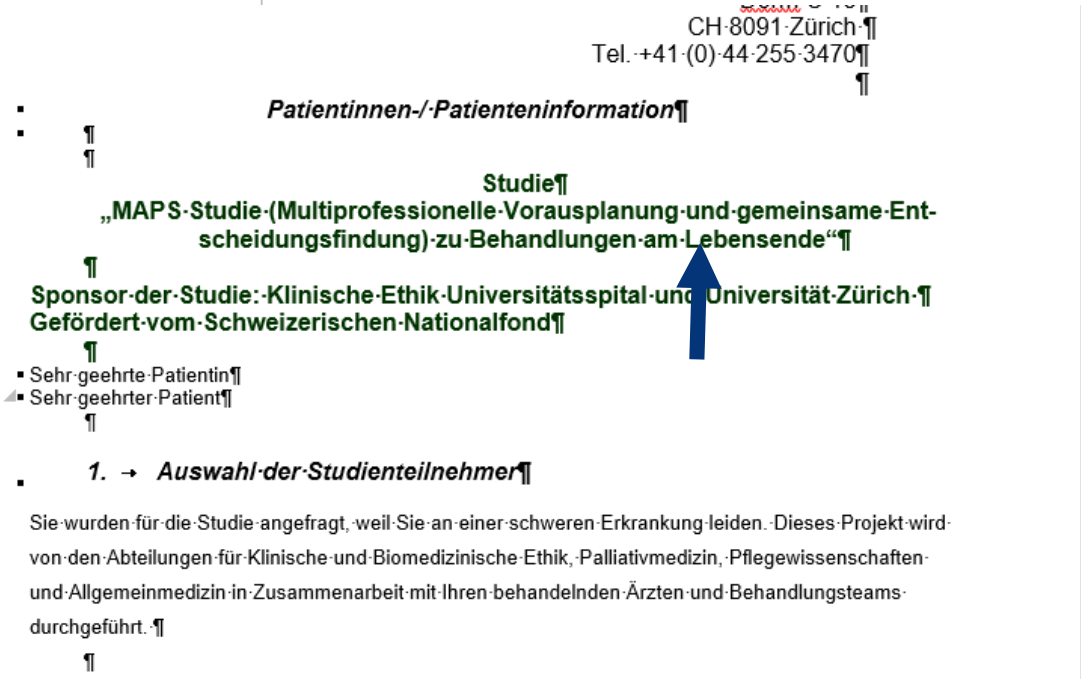
Arbeitsgemeinschaft der Schweizerischen Forschungs-Ethikkommissionen für klinische Versuche
Communauté de travail des Commissions d'éthique de la recherche en Suisse

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)" |



CH·8091·Zürich·¶
Tel.·+41·(0)·44·255·3470¶
¶

***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¶**

¶
Sehr·geehrte·Patientin¶
Sehr·geehrter·Patient¶

¶

***1. → Auswahl·der·Studienteilnehmer¶***

Sie·wurden·für·die·Studie·angefragt,·weil·Sie·an·einer·schweren·Erkrankung·leiden.·Dieses·Projekt·wird·von·den·Abteilungen·für·Klinische·und·Biomedizinische·Ethik,·Palliativmedizin,·Pflegewissenschaften·und·Allgemeinmedizin·in·Zusammenarbeit·mit·Ihren·behandelnden·Ärzten·und·Behandlungsteams·durchgeführt.·¶

¶

# The Power of Palliative Care

g 5 | The grim reaper

# The power and pain of (male) surrogates of younger female patients

**Table 3**
**Baseline characteristics of all screened patients**

| | Included patients n (%) (n=115) | Non-participants n (%) (n=88) | Excluded patients n (%) (n=1261) | P values |
|---|---|---|---|---|
| Gender (male) | 88 (77) | 47 (53) | 726 (58) | <0.001 |

canton de vaud

# The Surprise Question

# 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 surprize 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