

To make informed choices for / together with people with dementia - Development and evaluation of an education programme for *Betreuer**

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Background: In Germany approximately 1.3 million people are represented by *Betreuer*. Everybody has an ethical and legal right to informed decisions. In case of dementia, people are often not able anymore to exercise their rights. In these cases *Betreuer* represent them in the process of informed decision-making, and have to support their autonomy. They have to represent their needs and preferences and have to take into account the medical evidence. In contrast, only exceptionally *Betreuer* have a qualification in the field of health care. Until now, there are no authorization criteria or standardized training courses for *Betreuer*.

How to improve the current situation? The ability to pass through an informed and shared decision making process should be a basic competence of *Betreuer*. Therefore there must be widespread dissemination of appropriate education offers.

Certain methodological and content-related conditions are required:

1. The training content represents typical situations in health care.
2. The training content is based on the current scientific evidence.
3. The training has been scientifically developed and evaluated.

Our example: An education programme for volunteers and professional *Betreuer** – exemplary decisions in health care for people with dementia: „Physical Restraints (PR), „Percutaneous Endoscopic Gastrostomy (PEG)“ and „Antipsychotic drugs (AP)“.

Phase I – Development (finished [1])

- Semi-standardised interviews with *Betreuern* and senior citizens on the subject of decision-making processes
- Preparatory work, research about the evidence for :
1. decision-making process; 2. PR; 3. PEG; 4. Antipsychotics

- ➔ Evaluation of an 8-hour education programme in four modules (Tab.1)
- ➔ Evaluation of evidence based information and detailed training materials (Fig. 2-5)

Phase II – Piloting (finished [1])

- Performance of 8 training courses with totaly 47 *Betreuer*
- Standardised telephone interviews after 7 days and 6-12 months after training course, to evaluate usability, comprehensibility and acceptance as well as the influence on current decisions

- ➔ Identification of barriers and optimization strategies (Tab.2)
- ➔ High acceptance and comprehensibility
- ➔ Feasibility into practice seems to be possible

Training goal

Improved decision-making processes, taking into account:

- Weighing of benefits and harms
- Decision-making approaches
- Role perception of participants in the decision-making process

Tab. 1: Content of the training

Module A	Decision-Making Process & Methods
Module B	Percutaneous Endoscopic Gastrostomy (PEG)
Module C	Physical Restraints (PR)
Module D	Antipsychotic drugs (AP)
(Module E)	good practice examples

Methods and Material

- Presentation of evidence based information
- Reflection, exchanges of experiences, case discussions
- interactive (group) work, discussion (Fig.1)
- Textual work (studies, decision aid, guideline)
- training material (Fig. 3-5)

Fig. 1: Group work „study designs“



Fig. 3: Extract of the training materials – evidence based information about PEG

Mortality
Subjects with dementia and with a feeding tube (nasal or percutaneous) and subjects with dementia and without any feeding tube, living in nursing homes, were investigated. There was no difference in mortality. This means, that this studies did not show any association between using a feeding tube and time of survival (2,4,6)

It could NOT be shown a correlation between people with dementia having a feeding tube and time of survival.

Two large American cohort studies investigated this issue. Between 1999 and 2007 more than 36.000...

Fig. 2: Decision-making approaches

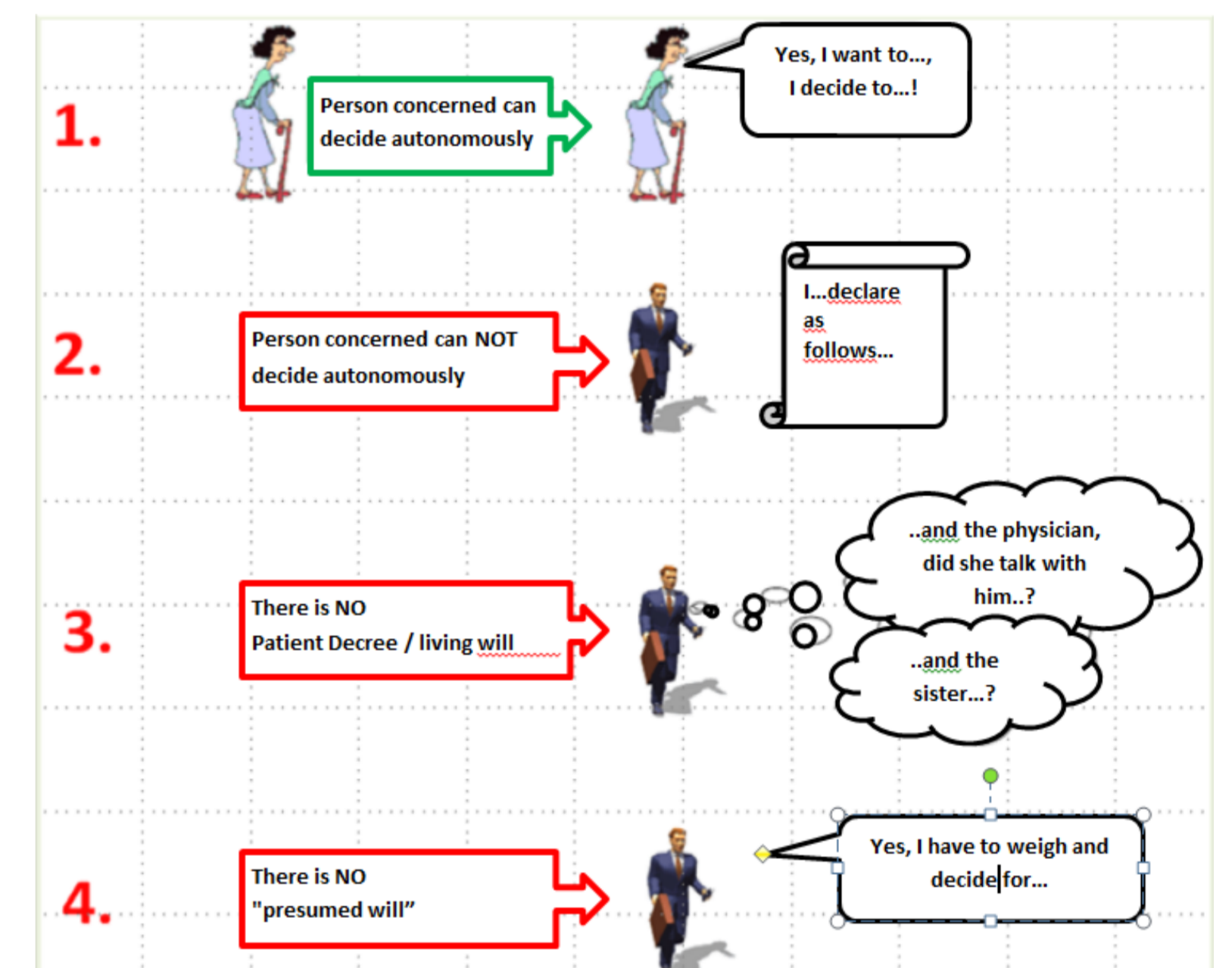


Fig. 4: Extract of the training materials – Presentation slide about benefit and harm of PR

Risk of falling

It has been shown that the abandonment of Physical Restraint as part of a structured training program does not lead to an increased number of falls.

Results of a randomized controlled study:
The number of PR was reduced by 6,5% within 6 months. The number of falls was not significantly different between intervention and control group. (Köpke 2012)

It has been shown an association between using PR and physical impairment, which increases the risk of falling.

Results of a cohort study:
It is unclear, if physical impairment is a result of PR or if it is the other way around, physical impairment leads to an use of PR. (Evans 2002)

Fig. 5: Extract of the training materials – guideline recommendations for AP in dementia

Guideline recommendation for other atypical antipsychotics:
E 64: "There is NO EVIDENCE for a therapeutic effect in the treatment of psychotic symptoms in dementia for other atypical antipsychotics [than Risperidon and Aripripzol]. Therefore the use is NOT recommended."
<http://www.dgppn.de/publikationen/leitlinien/leitlinien10.html>

Tab.2: Results of the piloting

Barriers

- ↳ Uncertainty of *Betreuer* over one's own role
- ↳ Lots of content, too little time for discussion / to deepen understanding of particular themes
- ↳ limited (time) resources

Optimization strategies

- ↳ More time to deepen particular themes
- ↳ More role playing, case discussions
- ↳ Flexible offer of single modules

Phase III – Evaluation (under preparation)

- Development and piloting of assessment instruments to verify the effectiveness of the education programme
- Randomized controlled effectiveness study (RCT)
- Cluster randomized controlled implementation study (cRCT)

- ➔ Degree of understanding decision making processes and realistic expectations in benefit and harm of PR, PEG and AP
- ➔ Frequency of PR, PEG and AP in people with dementia who are supported by a *Betreuer*
- ➔ Cooperation with established training providers
- ➔ Development of an implementation strategy, e.g. e-learning modules