



Wish to hasten death / Desire for hastened death:

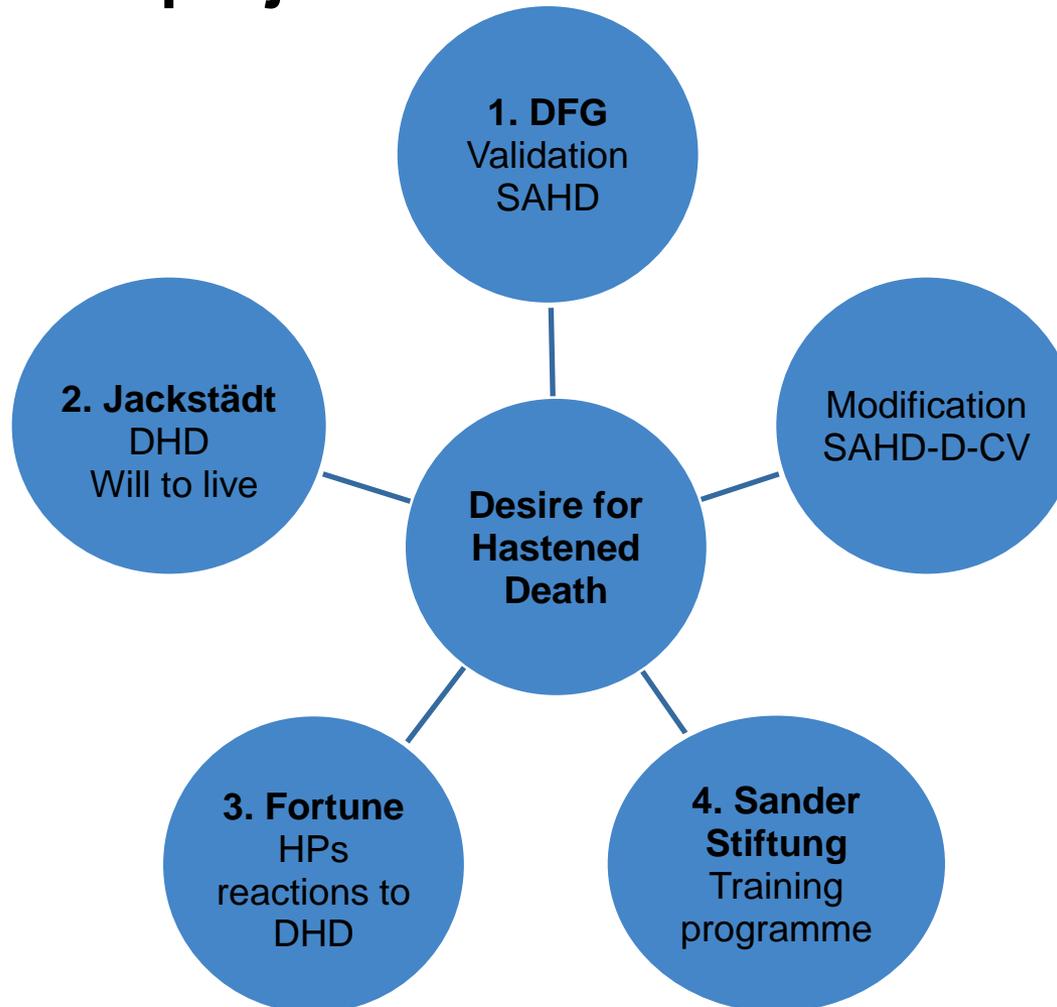
The Reaction of Professionals

Development of a Training Programme

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**Financed by:
KölnFortune/University Cologne, Sander Foundation/Munich**

Research projects on DHD



Voltz et al., 2010
Voltz et al., 2011
Galushko et al., 2012
Galushko et al., 2014
Frerich et al., 2015



How Do Professionals in Specialized Palliative Care Respond to DHD?

Background

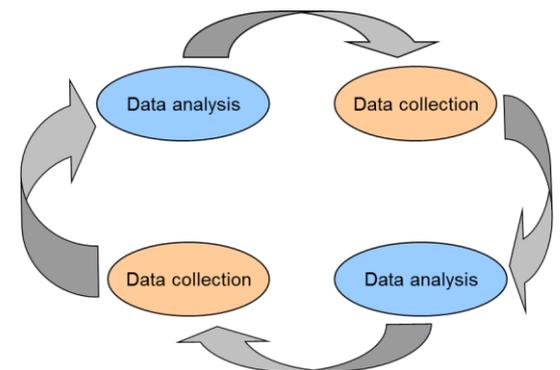
- Desire for hastened death (DHD) prevalent in terminally ill patients
- Health professionals (HP) often underprepared to respond to DHD
- Guidelines for this phenomenon exist but are lacking evidence

Aim

- To identify and analyse the responses in daily practice

Methods

- Interviews with 19 staff members, multiprofessionell
- 4 palliative care wards at German university hospitals
- Prerequisite: min. 1 year work experience
- Narrative interviews
- Analysis with documentary method to assess practical knowledge

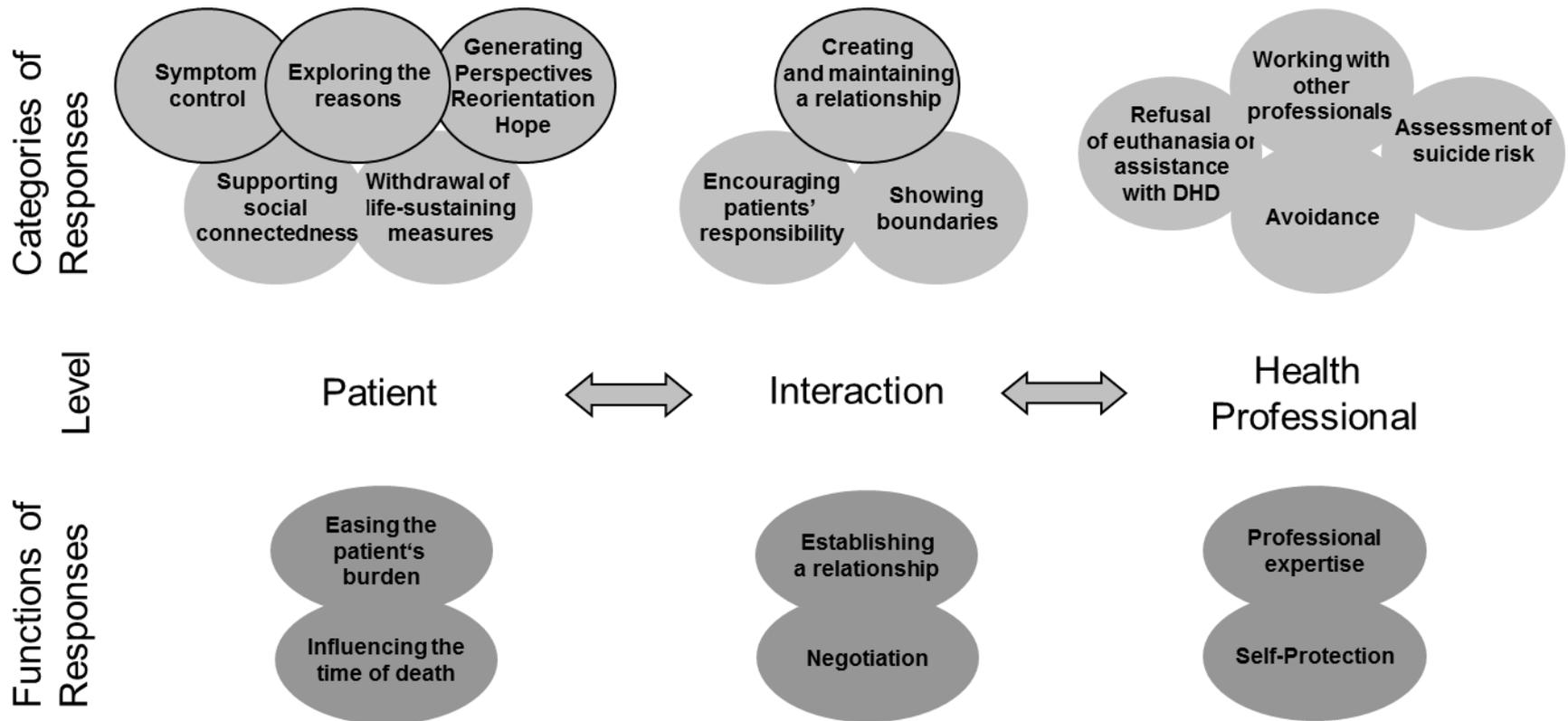


Sample

| Occupational group | N | Sex | | HPs' PC experience in years mean/ range | Age Mean/ range | Frequency of DHD during HPs experience | | | Training Programs | | | |
|------------------------------------|----|-----|----|---|-----------------|--|-------|------|-------------------|-----|------|-----|
| | | m | f | | | 1-3x | 4-10x | >10x | PC | Com | Ther | Oth |
| | | | | | | | | | | | | |
| Physicians | 8 | 3 | 5 | 5,4 (1,5-16) | 45,4 (38-56) | 1 | 1 | 6 | 7 | 2 | 2 | 1 |
| Nursing staff | 6 | 2 | 4 | 7,25 (3-17) | 39,2 (32-47) | 0 | 1 | 5 | 6 | 0 | 1 | 1 |
| Psycho-social spiritual occupation | 5 | 1 | 4 | 4,85 (1,5-13) | 38,4 (29-57) | 2 | 1 | 2 | 3 | 2 | 2 | 2 |
| All | 19 | 6 | 13 | 5,85 (1,5-17) | 41,6 (29-57) | 3 | 3 | 13 | 16 | 4 | 5 | 4 |

(Galushko M, Frerich G et al., 2015; financed by Köln Fortune)

HPs' responses to DHD



(Galushko M, Frerich G et al., 2015; financed by Köln Fortune)



„Generating Perspective, Reorientation, Hope“

“A reasonable perspective is also to say ‘Okay, you will still live for so and so long. And I promise if the symptoms are that severe, we could then sedate [...] that means also having the chance, for me, to distract from the thing which SEEMS to be so threatening and to have the chance to address other needs and feelings.’”



Stress factors and how to relieve them

Possible stress factors:

- Lacking differentiation between identifying with the patient and acting professionally
- Dilemma: Supportive role – ending the relationship
- Ambivalent DHD

How to relieve them:

- Joint goal setting with patients/ family carers
- Keeping calm instead of rushing to act
- Admitting insecurities and discussing feelings of stress
- Institutionalised algorithms
- Increasing competences in dealing with negative feelings



Interviews: Aspects for further training

- Personal development and confidence
- Professional relationship and self-care/ self-protection
- Not focusing on refusal, be empathetic
- Exploring the reasons
- Maintaining patient's feeling of autonomy
- Ethical and juridical background to DHD/suicide



Concept of the training programme – Content, teaching methods, evaluation

| Sections | Sources |
|---------------------------|---|
| Relevant content / topics | <ul style="list-style-type: none">- Own research: Interviews, focus groups- Curricula, evaluation of training sessions- Guidelines, recommendations |
| Teaching methods | <ul style="list-style-type: none">- Focus groups- Curricula, evaluation of training sessions |
| Evaluation | <ul style="list-style-type: none">- Literature |



Focus Group: Results

- Knowledge: law on euthanasia and suicide
- Knowledge: current research on DHD (types, motivations, intentions)
- Ways of responding (med.-psycho-social-spiritual)
- Establishing relationships (with patients and family carers)
- Suicide-Assessment
- Reflecting on one's own attitude towards death and DHD
- Coping with emotions
- Team aspects (finding consensus, obtain external expertise, take care of vulnerable colleagues)

→ Foster self-confidence



Literature Search: Guideline, Recommendations, Curricula

Guidelines, Recommendations:

- Hudson: responding to desire to die statements from patients with advanced disease: recommendations for HP (2006)
- Royal College of Nursing: When someone asks for your assistance to die (2011)

Curricula:

- Basic curriculum palliative care for psychosocial professions (2004), Curricula for physicians, nurses, social workers, counselors in palliative medicine (1997)
- Qualification course palliative care for counselors (2010)

Literature Search: Suicide Prevention, Training

Suicide Prevention:

- Wolfersdorf 2014: Suicide Prevention, Training
- Alliance against depression (Regensburg, Nürnberg): Suicide intervention programme

Training programmes on existential issues:

- Udo 2014: Surgical nurses' attitudes towards caring for patients dying of cancer - a pilot study of an educational intervention on existential issues
- Morita 2014: Nurse education program on meaninglessness in terminally ill cancer patients
- Strang 2013: Communication about existential issues with patients close to death
- Wasner 2005: Effects of spiritual care training for palliative care professionals



Learning Objectives

Main objective: Improved (self-) confidence in responding to patients with DHD

Sub-objectives:

Knowledge

- Current research on DHD: types, reasons, purposes
- Helpful ways of responding
- Legal background

Skills

- Building and maintaining relationships
- Communication
- Coping with emotions
- Setting boundaries, self care
- Teamwork

Attitudes

- Reflection on personal attitudes, difficulties and emotions



Teaching methods (exemplary)

- Multiprofessional exchange of experiences
- Reflection
- Self experience
- Communication training (roleplay)
- Lectures on law issues and research on DHD
- Case studies
- Plenary discussions
- Small-group work
- Individual work (reflective essays)



Training concept (work in progress)

Day 1

| Time | Content |
|---------|--|
| | Welcome & personal meeting |
| 60 min | Module 1: Exchange of practical experience <ul style="list-style-type: none">• Reflection & discussion on previous handling of DHD |
| 15 min | Break |
| 90 min | Module 2: Background Knowledge <ul style="list-style-type: none">• Current research on DHD• Possible responses• Team aspects• Law issues |
| 45 min | Break |
| 120 min | Module 3: Own norms & values <ul style="list-style-type: none">• Reflection on own norms & values on DHD and more |
| 30 min | Closing: Feedback on the first day |



Training concept (work in progress)

Day 2

| Time | Content |
|--------------------|---|
| 180 min with break | Module 4: Own norms & values – hands-on <ul style="list-style-type: none">• Key aspects of guidelines• Explanation of role play method• Role plays in small groups on responses based on self-reflection and including guideline-aspects |
| 45 min | Break |
| 45 min | Feedback-discussion on role play experience |
| 90 min | Module 5: Setting boundaries, self care <ul style="list-style-type: none">• Highlighting the importance of this topic• Reflection: Emotions, fears and difficulties in communication• Self-care strategies |
| 45 min | Feedback on the whole training programme, evaluation |



Evaluation

Outcome regarding participants' knowledge/skills/attitudes

- Main Objective : Improved (self-) confidence in responding to patients with DHD and selected sub-objectives
=> Subjective / objective measures?

Evaluation of the quality of the training programme from participants' perspective

- Content (something missing / something redundant), amount of time, teachers, teaching materials and methods, comprehensibility etc.

Evaluation- Design

Baseline:
Eg. 3 weeks
before training

Training

Follow-Up:
6 months after
training

Questionnaire 1

(Survey of main
objective and possibly
sub-objectives)

**Feedback-
Discussion and
Questionnaire 2**
(Evaluation of training –
content, methods...)

**Questionnaire 1
and open questions
about testing acquired
skills in practice**
(measuring effect)



Evaluation - Instruments

- Currently no (validated) instrument to measure improvement in responding to DHD
- Self-developed questionnaire, according to existing instruments (for evaluation of thematically and methodically similar training programmes):
 - Confidence Scale (Morita 2007, 2014)
 - FatCod - Frommelt attitudes toward care of the dying scale (Frommelt 2003)
 - Self-reported Practice Scale (Morita 2007)
 - Attitudes Toward Caring for Patients Feeling Meaninglessness Scale (Morita 2007, 2009, 2014 & Udo 2013, 2014)



Further steps

- 2nd meeting with national advisory board
- Finalisation of training concept and evaluation method Self experience
- Two pilot training courses: March and June 2016
- So far based on national experts but welcoming international cooperation



Thank you for your attention!

