



Desire to Die in Palliative Care — Optimization of Management (DEDIPOM)

Background and subject

Regardless of the legal possibility to use (physician) assisted suicide, palliative patients frequently express a desire to die or be dead. Health professionals confronted with such a desire often report uncertainty about the appropriate therapeutic response.

One can assume that this uncertainty will increase with a changing legal landscape (e.g. the repeal of §217 National Criminal Code) and pending new regulations of physician assisted suicide.

References and list of images

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Desire to die in patients receiving palliative care – how to talk about it?

Background

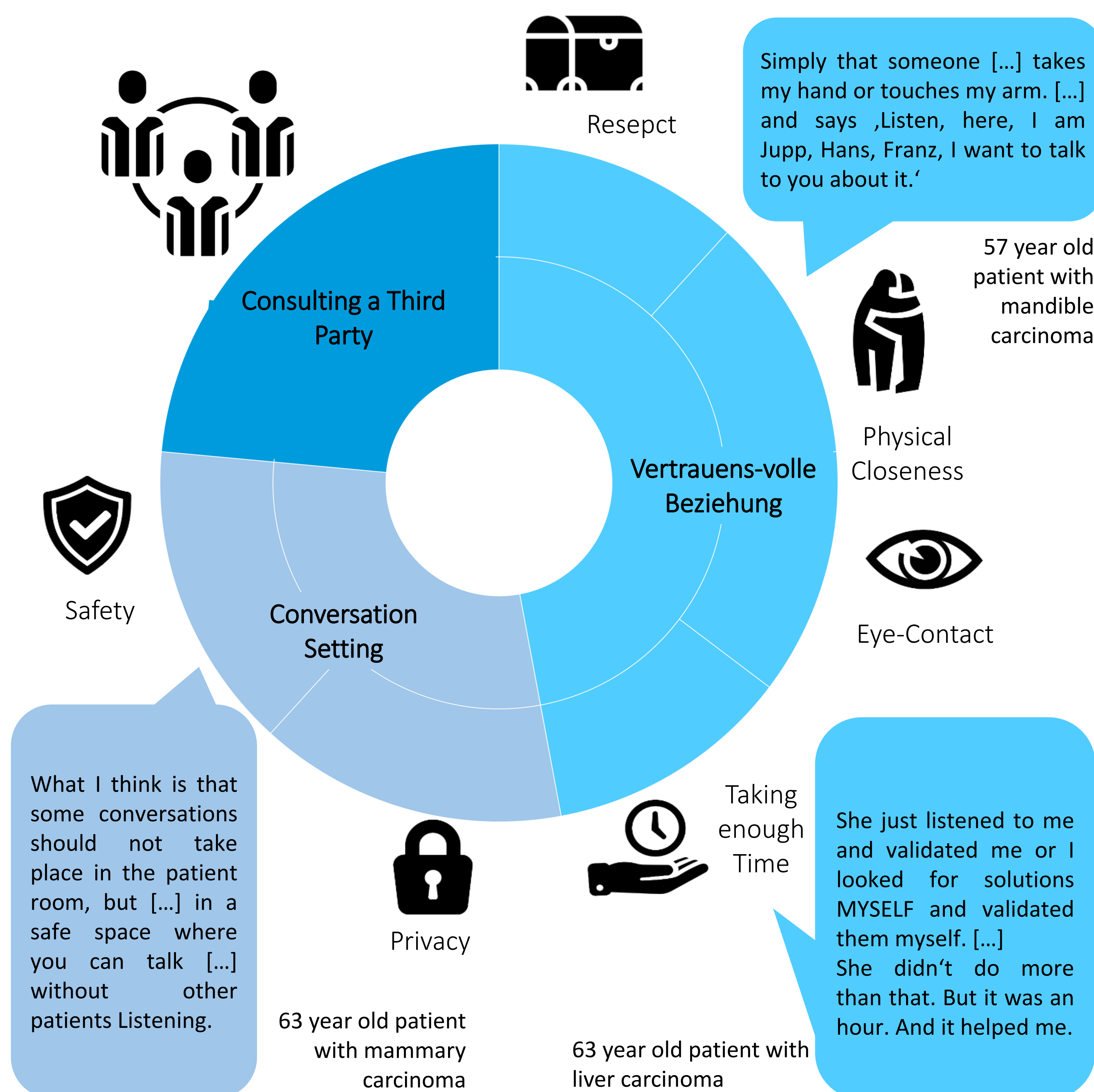
Even though staff working in palliative care is frequently confronted with patients’ Desire to Die (DD) statements, uncertainty remains concerning the appropriate therapeutic response. To address this issue, a training program for dealing with DD was developed, piloted and evaluated. As part of this process, a first draft of the semi-structured clinical interview schedule with prompts (CISP) was designed; meant to support health practitioners’ (HPs) reactions to patients’ DD.

The CISP allows for routinely addressing topics such as death and dying in order to actively assess potential DD. The aim of this study was to revise and consent the CISP for use in everyday clinical practice.

Results

In-person Interviews

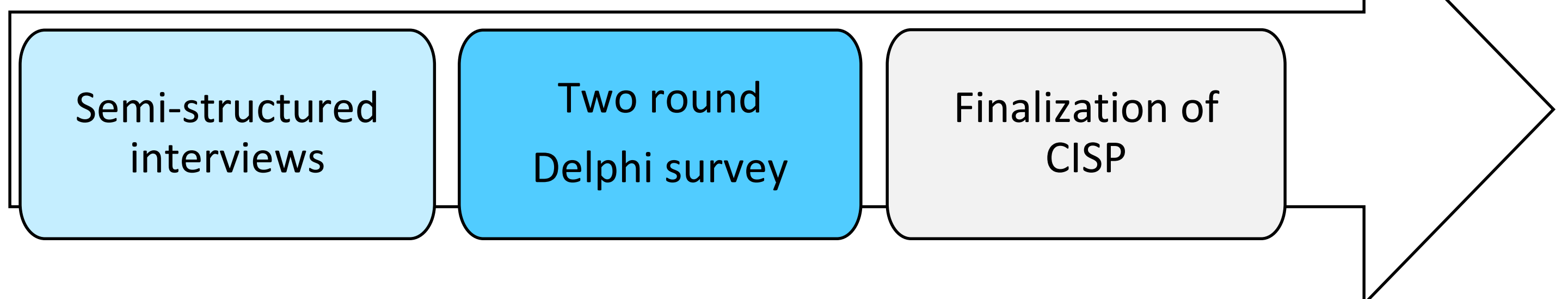
7 men and 4 women (51 - 88 years, $\phi = 71$) from different care settings participated in individual in-person interviews. Reasons for declining participation were (acute) deterioration of (either) bodily and / or psychological health. A trustful relationship between HP and patient was identified as the central concern. This relationship is based on respectful interaction, operationalized as taking enough time, but also conscious eye contact and appropriate physical closeness. Other than that, the conversation setting needs to provide privacy and safety. If deemed necessary and appropriate, consulting a third party, e.g. pastoral care, was considered helpful.



Methode

16 palliative patients were invited by HPs that were personally acquainted with the research team („gatekeepers“) to take part in semi-structured interviews.

Data was analysed using structural qualitative content analysis. Subsequently, 377 (inter-) national experts, patient representatives and relatives were invited to a two round online Delphi survey (a priori consensus criterion: $\geq 80\%$ agreement).



Two Round Delphi Survey (01/2018 bis 03/2018)

Opinions of $n = 149$ experts (39,5%) were analyzed. The sample showed the following characteristics:



	Mean (Standard Deviation)			Consent		
	Round 1	Round 2	p	Round 1	Round 2	Increase
A – Usage notes						
1. Usage notes	-	4,32 (0.91) ⁵	-	-	92,6 %	-
B – Conversation Aspects						
2. Actively Building the Relationship	4,64 (0.85)	-	-	92,6 %	-	-
3. Proactively Addressing DD	4,01 (0.94)	4,16 (0.92)	< 0,05	74,5 %	83,2 %	8,7 %
4. Closure of Discussion	4,62 (0.74)	-	-	92,6 %	-	-
5. Nach dem Gespräch	4,64 (0.65)	-	-	94,0 %	-	-
C – Classification, Meaning and Functions						
6. Classification of DD	4,26 (1.0)	4,37 (0.80)	0,10	85,2 %	90,6 %	5,4 %
7. Background and Meaning of DD	4,81 (0.50)	-	-	97,3 %	-	-
8. Functions of DD	4,31 (1.07)	4,64 (0.73)	< 0,01	83,9 %	95,3 %	11,4 %
D – Self-Reflection						
9. Conscious engagement with own attitudes and emotions	4,77 (0.53)	-	-	97,3 %	-	-
10. Self-Protection	4,74 (0.53)	-	-	96,0 %	-	-
E – Further recommended action						
11. Further recommended action	4,53 (0.85)	4,68 (0.56)	0,07	87,9 %	95,3 %	7,4 %

In total, 92,4 % of respondents rated the CISP as helpful or very helpful for everyday clinical practice. Commentary in free texts mostly related to proactively addressing DD, physician-assisted suicide and active euthanasia.

Discussion

The developed and consented CISP can support health professionals with identifying DD in palliative patients, proactively addressing their DD and generating an appropriate therapeutic response. This evidence-based approach stems from the perspectives of experts, health professionals and patients. Statements and comments from the interviews with patients, experts and relatives, as well as data from the Delphi survey, all represent central topics in the discussion of DD in patients at the end of life.

Take Home Message A semi-structured clinical approach for (proactively) addressing desire to die can help to improve multiprofessional competences in dealing with desire to die of patients at the end of life.

Insecure health professionals – how should a training program look like?

Background

Even though health professionals in palliative care are frequently confronted by their patients desire to die, they often report uncertainty towards the appropriate way of dealing with it. To increase their self-confidence, a training program as well as a semi-structured clinical approach were developed in a previous project.^{1,2} Within a three-phase mixed-methods study this clinical approach was developed further and consented (Phase 1).³ Subsequently, health professionals were trained in dealing with desire to die utilizing the clinical approach (Phase 2).

Question *How do health professionals evaluate the clinical approach and their own self-confidence in dealing with desire to die after participation in the training program?*

Method

Within a sequential mixed-methods study, five multiprofessional two-day trainings were planned for dealing with desire to die and utilizing the clinical approach.

Health professionals evaluated their self-confidence in dealing with desire to die by questionnaire right before (t0), directly after (t1) and one year after training participation (t2). In addition to general self-confidence, the questionnaire contained items concerning skills in dealing with, knowledge about and attitudes towards desire to die. At t2, the option to answer open questions regarding the use of the clinical approach was given. After training participation, health professionals were asked to apply what they learned in desire to die conversations with their patients and reflect these conversations in writing.

Results

Sample Between 03/2018 – 01/2020, due to high demand, 103 health professionals participated in twelve trainings.

Self-Confidence

Health professionals' self-confidence in dealing with desire to die significantly increased through training participation ($p = .000$, Effect size $d = .074$). This effect remained stable after one year ($p = .000$, $d = .072$). Please refer to *Image 1*.

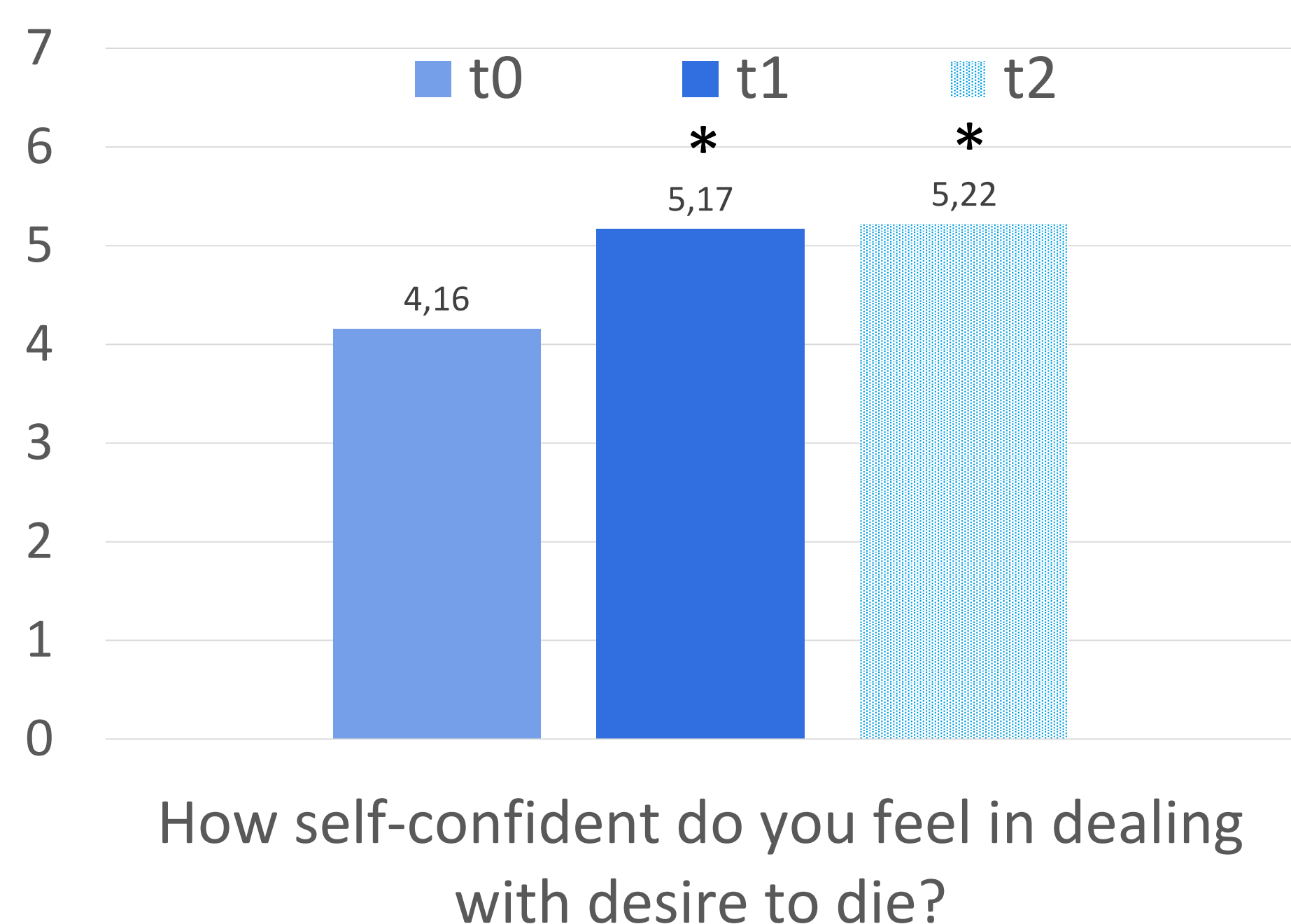


Image 1. Self-Confidence in dealing with desire to die.
Preliminary $N (=45)$ at t2 due to ongoing evaluation.
* = significant difference compared to t0 with $\alpha=0.05$.

Application of training content in real life conversations with their patients was deemed especially enriching on a personal level:

Reflection of these conversations and thusly derived changes in personal perception and attitudes was also considered to be beneficial:

Ø 48 years (+/- 11)

75% women

Ø 12 years (+/- 9) professional experience

46% Nursing

20% Medical Care

34% Psycho-social Care

50% reported more than 10 confrontations with desire to die



Except for one item („Due to time constraints, it is not possible for me to have desire to die conversations.“) all items of the three subscales skills, knowledge and attitudes showed a significant increase at both t1 and t2.

Evaluation of the Clinical Approach

At t2, 60% of health professionals considered the clinical approach to be helpful or very helpful:

Reminding myself that there is this clinical approach inspires me to have a look at it once in a while. It helps to sensitize yourself again and again.

48 year old female palliative care physician

These conversations were mostly very intensive and the patients were grateful for the openness and space that this topic received. The conversations enrich my work and bring me closer to my patients.

53 year old female senior physician

Yes, through the training I have learned not to have fear/anxiety towards my patients and towards addressing the subject of death. On the contrary, to be the one who addresses the "big pink elephant" in the room.

34 year old female general physician

Discussion

The high demand (five planned vs. twelve completed training sessions) and the long-term increase in self-confidence in dealing with desire to die confirms both the need for the training and its effectiveness. A limiting factor for the interpretation of the results is the pending validation of the questionnaire used. Phase 3 of the study will evaluate the effect of desire to die conversations of trained health professionals on palliative patients.

Take Home Message *There is a great need for training programs on dealing with desire to die in palliative care. A training concept including a semi-structured clinical approach can meet this need effectively and in the long term.*

Stressful or relieving – What effect do conversations about desire to die have on patients receiving palliative care?

Background



Although health professionals are frequently confronted with desire to die of palliative patients, they often report uncertainty in dealing with them. To increase their self-confidence, a training concept and a semi-structured clinical approach were developed in a previous project.¹

Within a three-phase study, the clinical approach was further developed and consented (phase 1),^{2,3} health professionals were trained in dealing with desire to die using the clinical approach (phase 2) and then asked to have conversations with their patients about possible desire to die (phase 3).

Method

Within a sequential mixed-methods study a standardized survey of patients in palliative settings was conducted. Validated questionnaires were used to evaluate depression, desire to die, death and dying distress, health professional-patient-relationship and hopelessness.

After researchers conducted the baseline survey (t0), trained health professionals had an open conversation about possible desire to die utilizing the developed clinical approach. Two (t1) and six weeks later (t2) the questionnaire survey was repeated. Subsequently, semi-structured interviews were conducted with some of the patients.

Question

What effects do conversations about desire to die have on patients receiving palliative care?

Results

Between 4/2018 and 3/2020, 43 trained health professionals screened 172 patients for study participation; 85 could be included for the quantitative baseline survey at t0. Data collection was completed (t0, conversation about desire to die, t1, t2) with 49 patients. Of those, 13 participated in qualitative interviews in which they were asked to talk about their experience of the desire to die conversation.

Sample

Patients were 57% female, were 69 years on average and had heterogeneous underlying diseases (59% oncologic, 13% neurologic, 28% other).

Quantitative Results: Standardized Survey



Patients reported moderate depressiveness. Death and dying distress, desire to die and hopelessness were reported to be mild. Satisfaction with the health professional-patient-relationship was described as consistently high which was also reported about the will to live (see table 1).

Differences in means were tested for significance through a two-sided Wilcoxon-Test. Depressiveness significantly decreased from t0 to t1 ($p = .002$; effect size $d = .43$). This difference did no longer reach significance at t2.

There was no worsening in any of the outcomes, however, positive trends in other outcomes were merely marginal:

Outcome	N t0	t0	N t1	t1	N t2	t2
Depressiveness (Patient Health Questionnaire-9)	79	0,6 (+/- 5,8)	64	8,2 (+/- 5,4)	49	8 (+/- 5,7)
Death and Dying Distress (Death and Dying Distress Scale)	77	13,6 (+/- 7,6)	58	14,1 (+/- 8,3)	44	10,8 (+/- 7,5)
Desire to Die (Schedule of Attitudes Towards Hastened Death)	79	5,9 (+/- 4,8)	64	5,3 (+/- 4,2)	48	5 (+/- 4,4)
Versorgendenbeziehung (Patient-Doctor-Relationship-Questionnaire-9)	71	31,1 (+/- 6)	58	32,3 (+/- 4,7)	42	32,1 (+/- 4,5)
Hopelessness (Beck Hopelessness Scale)	79	8,4 (+/- 4,5)	61	8,4 (+/- 5)	48	7,8 (+/- 4,9)
Will to Live (Visuelle Analog Skala)	82	7,5 (+/- 2,9)	63	7,8 (+/- 2,6)	49	7,9 (+/- 2,7)

Mittelwerte (und Standardabweichung) aller Outcomes zu den drei Erhebungszeitpunkten.

Qualitative Results: Sem-structured Interviews



Interviews were analyzed thematically building inductive categories. Although all 13 participating patients had had a conversation about desire to die with their health professionals, 8 were not able to explicitly recall such a conversation upon inquiry. These patients seemed to experience desire to die conversations as part of a (communicative) process and not as a specific intervention:

Did you talk about these topics with your doctor?

Actually- NO, not really. She only asked me once, because she had noticed that there was a living will (...), how I would like it when the end was approaching acutely, whether they should put me in the hospital or not. (...) I said, yes, if I have to suffocate because I lack air I would do it. That was the only occasion, otherwise we did not talk about it.

40 year old female patient with multiple sclerosis

Patients who did recall a conversation about desire to die with their health professional experienced them as helpful:

How do you feel during these conversations?

Fine. Like, on to new shores (...). This urge, it came from these conversations, this, well, yes, urge to get moving.

66 year old female patient with mammary carcinoma

Diskussion

In a heterogeneous sample of patients receiving palliative care, conversations about desire to die did not have a negative effect on any of the outcomes. Moreover, there was a temporary improvement in depressiveness. These results are in line with previous studies on proactively assessing desire to die of oncological patients.⁴ Our results contribute to the evidence that supports the recommendation for proactively addressing desire to die within the current *German National Guideline on Palliative Care for Patients with a Incurable Cancer*⁵ and may help to reduce uncertainty in health professionals.

Take Home Message

An open conversation about desire to die between trained health professionals and patients receiving palliative care does not lead to an increased burden on patients, but has the potential to relieve them.