



‘Desire to Die’ in palliative care patients—legal framework and recommendations of the national evidence-based guideline on palliative care in Germany

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Background: Desire to die, understood as a broad phenomenon, is common in patients receiving palliative care. Euthanasia (“termination of life on request”, §216 German Criminal Code) is currently forbidden in Germany, the legal restrictions with regard to assisted suicide (“assistance of suicide with intent of repeated conduct”, §217 German Criminal Code) has recently been repealed by the national Federal Constitutional Court. This dynamically changing legal situation adds to health professionals reported uncertainty in dealing appropriately with a desire to die.

Methods: As part of the new extended version of the *German Palliative Care Guideline for Patients with Incurable Cancer*, evidence and consensus-based statements and recommendations on desire to die were developed by an interdisciplinary and multi-professional working group. The best available evidence was identified through systematic literature searches and by asking experts for further known quantitative as well as qualitative literature. Included publications were assessed as recommended by the Scottish Intercollegiate Guidelines Network (SIGN). Due to the limited availability of high-quality empirical publications related to desire to die, close attention was paid to national clinical expertise to develop recommendations. Consensus for these recommendations was reached at a conference of the guideline group consisting of elected representatives from 61 professional societies and patient associations. Each recommendation was approved by at least 75% of those present.

Results: The expert panel developed and agreed on 21 statements and recommendations on desire to die and related phenomena. A descriptive definition was agreed upon of desire to die as a complex phenomenon with individual causes, manifestations, and consequences. The potential background of desire to die, its meanings, functions and possible interventions are described. The guideline recommends proactively addressing and exploring a potential desire to die as the intervention that should be considered before all others, because evidence from studies on suicidality found no negative effect when asking study participants about suicidality.

Conclusions: The guideline informs health professionals working within the German statutory framework, how to care for and communicate with patients who are receiving palliative care and who express a desire to die.

Keywords: Germany; guideline; palliative care; suicide; euthanasia

Submitted Feb 19, 2020. Accepted for publication Sep 09, 2020.

doi: 10.21037/apm-20-381

View this article at: <http://dx.doi.org/10.21037/apm-20-381>

Introduction

Desire to die has been an object of increasing research interest in recent years (1). Studies show a considerable prevalence of desire to die among patients receiving palliative care. Chochinov *et al.* found in 1995, that of 200 patients living with advanced cancer, 45% experienced an occasional desire to die and almost 10% reported a strong and persistent desire (2). In a more recent study with 377 patients living with cancer, 18% reported an occasional and 12% a serious desire to die (3). However, this phenomenon is not limited to patients with cancer. According to Strupp *et al.*, 22.1% of 573 patients with multiple sclerosis have suicidal thoughts (4). Patients with multiple sclerosis or other neurological conditions (for example motor neuron disease) are the largest sub-group of those seeking support to end their life prematurely (5,6), and are at high risk of attempting and completing suicide (7-9). However, a comparison between studies and different patient populations is difficult because there is no common definition of desire to die.

Although health professionals are often faced with a patient's desire to die (10), it is not routinely assessed in palliative care. In Germany, uncertainty exists for health professionals about how to approach desire to die in clinical practice (11). This is mainly caused by a lack of preparation on how to deal with this complex and sensitive topic, as well as the legal restrictions with regard to euthanasia ["termination of life on request", §216 German Criminal Code (StGB)] and assisted suicide ["assistance of suicide with the intent of repeated conduct" (§217 StGB)], the latter having been repealed in February 2020 (12). After a public debate, the Federal Constitutional Court declared suicide and the use of assistance from third parties to aid in suicide a personal right (12). A new regulation is currently pending. In this context of clinical uncertainty and rapidly evolving legislation (13), health professionals might avoid the topic, even if patients themselves raise the issue (11).

The German Ethics Council issued an official statement calling for suicide prevention rather than assistance

in suicide (14). In 2017, the German Parliament also passed a resolution across parties, which aims at further strengthening of suicide prevention (15). The German Hospice and Palliative Law (Hospiz- und Palliativgesetz, HPG) provides the necessary basis for this requirement, as it improves care for seriously ill and dying patients (16). Paying attention to a patient's possible desire to die is an integral part of care at the end of life (17). To provide orientation and assurance in responding to a desire to die appropriately within the German statutory framework, the extended 2019 version of the *German Palliative Care Guideline for Patients with Incurable Cancer* includes a chapter on desire to die (1).

The guideline was developed and funded within the *German Guideline Program in Oncology* (GGPO) and therefore focuses on patients with cancer from the diagnosis of an incurable disease. However, the recommendations may also be applicable to other patient groups with advanced diseases. The aim of the guideline is to enable optimum quality of life until death for patients suffering from severe symptoms. By providing systematically developed treatment recommendations based on current evidence and on the clinical experience of a large representative panel of experts, the guideline supports decision-making in practice. We present the following article in accordance with the AGREE reporting checklist (available at <http://dx.doi.org/10.21037/apm-20-381>).

Methods

The evidence and consensus-based *German Palliative Care Guideline for Patients with incurable Cancer* (1) was developed between 2011 and 2019 under the leadership of the *German Association for Palliative Medicine* using the methodological framework of the GGPO. This program fosters the development and implementation of evidence-based clinical practice guidelines in oncology and created by the *Association of the Scientific Medical Societies in Germany* (AWMF), the *German Cancer Society* (DKG) and the *German Cancer Aid* (DKH). The first part of the guideline was published in 2015 on seven aspects of

palliative medicine, namely breathlessness, cancer pain, constipation, depression, communication, dying phase, and organization of palliative care (18). From 2016 to 2019, these seven topics were updated and the guideline was extended on eight further aspects, namely fatigue, sleep disturbance, nausea, and vomiting (not induced by tumor-specific therapies), malignant bowel obstruction, anxiety, malignant wounds, establishment of goals of care, and desire to die.

Preparation

A representative panel of experts elected from 61 professional societies, institutions and patient representatives agreed on key questions to be answered on desire to die during a Structured Consensus Conference, an acknowledged formal consensus development method (19). According to an *a priori* defined criterion, consensus was achieved with the agreement of $\geq 75\%$ of participants. It stipulated, which key questions could be answered through a systematic literature review and for which expert consensus should be sought.

Subsequently, a multi-professional and interdisciplinary working group was formed to develop the guideline chapter on desire to die. Ten elected representatives from professional societies and institutions—from the fields of psychiatry, suicidology, palliative care, psychooncology and ethics—and 20 experts on desire to die from the fields of nursing, law, and research were involved in the working group to reach the required expertise. Two of its members (RL, RV) led the working group.

Literature search, selection, and appraisal

To compile the existing evidence for answering the key questions, the guideline coordination office followed the AWMF Guidance for Guideline Development (20) in three steps:

- (I) Search for guidelines: we first searched for existing guidelines in the databases *Guidelines International Network* (G-I-N), *National Guideline Clearinghouse* (NGC), AWMF and Medline (via PubMed) in January and February 2016. The search revealed no evidence-based guideline suitable for adaptation;
- (II) Search for systematic reviews: we consecutively conducted a systematic literature search for systematic reviews, by searching the database

Medline (via Ovid) from January 2008 until September 2018 (20). A broad and sensitive search strategy (see [Appendix 1](#)) was developed, as overall few publications on the topic were expected;

- (III) Search for randomized controlled trials (RCTs): for the key question (III) on caring for patients with a desire to die, only a systematic review of qualitative studies could be identified. In order to supplement these findings, we conducted a systematic search for RCTs in the databases Medline (via Ovid), PsycINFO and Cochrane Central Register of Controlled Trials (CENTRAL) from inception until October 2018, according to the recommendations of the PRISMA Statement (21) (for search strategies see [Appendix 1](#)). We limited our research to RCTs as we aimed to investigate the effectiveness of interventions.

We complemented all the electronic searches by handsearching reference lists and citation tracking. Two authors (AP, STS) screened titles and abstracts of the identified records for potentially relevant studies. Trial eligibility was then assessed independently by the same two authors based on the full text according to pre-specified inclusion criteria (see [Appendix 1](#)) and discussed in case of divergence. Regarding publication type, we decided to include systematic reviews not only of quantitative but also of qualitative studies, as they are best suited to describe the phenomenon of desire to die. Indeed, desire to die is a new and complex research field and the literature of recent years is mostly qualitative, reflecting the attempt to investigate, to conceptualize and to better understand the background of desire to die.

All included studies were assessed on their level of evidence (LoE) by the SIGN assessment system that evaluates studies according to their design, internal validity, and overall quality (18). Qualitative studies were assigned a SIGN LoE 3 as descriptive evidence (20).

Finally, the working group was asked for further known qualitative and quantitative literature. This broad consultation of experts was necessary because of the difficulty in developing a sensitive search strategy on desire to die. Indeed, there is no uniform definition yet of desire to die in the literature and the electronic searches may therefore not have identified all relevant publications. The literature yielded by the expert consultation was used as background literature for drafting the guideline, but was not systematically appraised with SIGN.

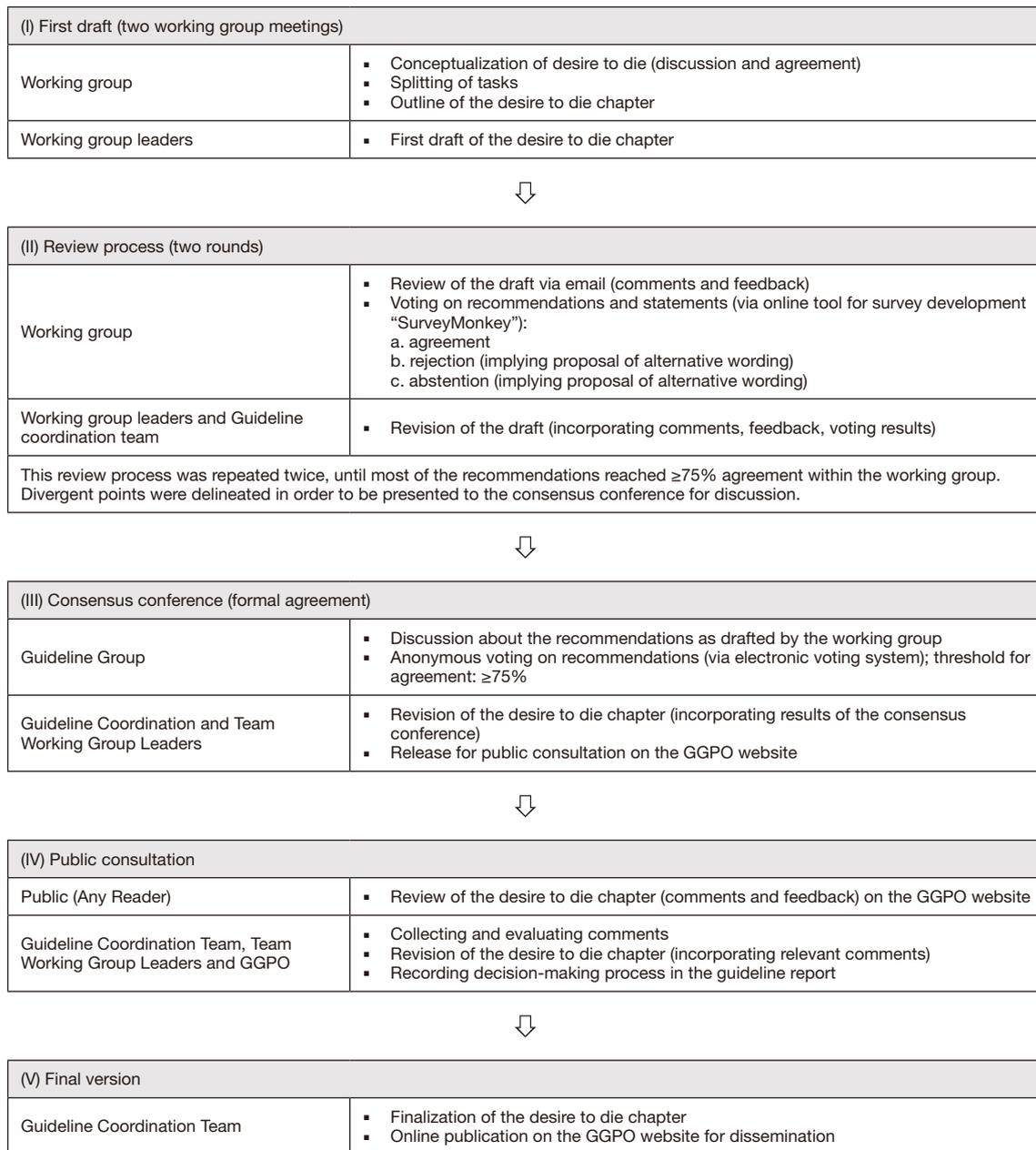


Figure 1 Development of the Desire to Die Chapter of the *German Palliative Care Guideline for Patients with Incurable Cancer* (1).

Elaboration of the guideline draft and structured consensus on recommendations

We followed a structured procedure to elaborate the guideline, as visualized in *Figure 1*. Working group members wrote a first draft of the recommendations, the statements, and the corresponding background texts, based on their clinical expertise and, where available, on the

identified evidence. Afterward, the working group reviewed the draft and voted on the recommendations via an informal consensus procedure consisting of a two-round online survey. The revised draft was submitted for discussion to the guideline group consisting of representatives of 61 professional societies and patient organizations. All recommendations and statements went through formal agreement via a Structured Consensus Conference (14–15

October 2018). Consensus was achieved with the agreement of $\geq 75\%$ of representatives. Finally, the guideline was published after a public consultation.

The Consensus Conference agreed on the formulation, content, and grade of the recommendations. Following the AWMF policy, three grades of recommendation (GoR) are stipulated for evidence-based recommendations: A (strong recommendation, “shall”), B (recommendation, “should”) and 0 (open recommendation, “can”) (20). The GoR is assigned according to the level of evidence, consistency of results, clinical relevance, risk-benefit ratio, ethical considerations, patient’s preferences, and feasibility (20). When recommendations were not based on empirical evidence but on formal expert agreement, they were marked with “EC” (expert consensus). In this way, high-relevant clinical topics could be covered by the guideline, even though they were not evidence-based. Beneath recommendations, the guideline also contains explanatory statements (ST). A statement is an assertion of fact. It can be evidence-based and assigned a level of evidence, or judged to be consensus-based.

Ethical statement

As the reported guideline development process did not include medical research involving humans, the study needed no approval by an institutional ethics committee.

Results

The *German Palliative Care Guideline for Patients with Incurable Cancer* includes 18 recommendations, three statements, explanatory background texts and a first definition of desire to die (1). Besides recommendations based on literature reviews, the guideline group also formulated recommendations on the basis of expert consensus. About one third of the recommendations were evidence-based. With the integration of recommendations based on expert knowledge, the guideline group aimed to provide the best possible information to health professionals working within the German statutory framework about how to care for and communicate with patients receiving palliative care and expressing a desire to die. Subsequently, we report our results structured in terms of content, following the identified key questions. Results from literature review (evidence-based recommendations and statements), are marked by their GoR and/or LoE; results based on expert knowledge are marked by Expert

Consensus (EC).

The key questions agreed by the guideline group at the beginning of the development process addressed the following topics: (I) the phenomenon of desire to die: definition, forms, causes, significance and functions; (II) screening and assessment of desire to die; (III) caring for patients with a desire to die; and (IV) supporting family members and the health care team. The electronic search for systematic reviews yielded 134 references, of which two met the inclusion criteria. With additional records from hand searching, a total of four systematic reviews were included (for PRISMA chart see [Appendix 1](#)). One review of qualitative studies answered question 1) on the desire to die phenomenon and partly question 3) on caring for patients with a desire to die (22). Three reviews helped answering question 2) on screening, assessment, and proactive addressing of desire to die (23-25). The search for RCTs identified 766 electronic references, out of them four RCTs were included (26-29). One additional RCT was identified through hand searching (for PRISMA chart see [Appendix 1](#)) (30). Results of the systematic search are reported in the following sections of this paper (*Tables 1,2*)—together with the findings based on expert knowledge. *Table 3* lists all recommendations and statements on the key questions related to desire to die.

Definition of “desire to die”

Using the term “desire to die”, the *German Palliative Care Guideline* applies a broad definition to describe a phenomenon that focusses on people living with a life-limiting progressive disease. This definition was developed by consensus within the working group drawing together expertise primarily from palliative care and suicidology. Therein, desire to die is described as a continuum ranging from the acceptance of death (“satiety of life”) to acute (consciously planned) suicidality. Between these two poles, the pressure to enact the desire increases, hoping to die soon or wishing to accelerate the dying phase. This definition of desire to die takes into account the multi-faceted nature of the phenomenon (10,31-37).

Forms of desire to die

The literature search for systematic reviews identified a publication, which provides the evidence base for a statement describing desire to die as a complex phenomenon with individually different causes, manifestations, and

Table 1 Systematic reviews included for evidence-based statements and recommendations

Reference	Related key question	Inclusion criteria	Main results	SIGN LoE
Rodriguez-Prat <i>et al.</i> 2017 (systematic review; meta-ethnography)	Phenomenon desire to die	Population: adult patients with advanced disease who express a wish to hasten death (WTHD) Content: analysing WTHD Study design: primary qualitative studies	Study number: 14 studies (n=255) Population: cancer patients in 9 studies; other terminally ill Analysis: WTHD is a reaction to physical, psychological, social, and existential suffering, impacting the patient's sense of self, dignity and meaning in life. WTHD has individually meanings.	3 (1++ to 4)
Bellido-Pérez <i>et al.</i> 2018 (systematic review)	Assessment of desire to die	Population: adult patients with advanced disease and/or who were being cared for in any palliative care setting Measurement tools: any instrument used to assess the WTHD Study design: no restrictions; language: English, French, Spanish	Study number: 50 studies Population: cancer patients (39 studies); others, i.e., HIV/AIDS or MND Measurement tools: 7 tools (scales, questionnaires, or VAS), item number between 1 and 20: • SAHD (Schedule of Attitudes toward Hastened Death): most widely used in research; • DDRS (Desire for Death Rating Scale) or modified DDRS: designed for clinician administration; • Other instruments developed ad hoc for study purpose	3 (1++ to 4)
Blades <i>et al.</i> 2018 (systematic review; meta-analysis)	Assessment of desire to die/ Risk of suicide assessment	Population: study participants (children and adults, healthy or sick) being asked about suicide or exposed to suicide-related content in the context of research studies Intervention: suicide assessment or screening, or exposition to suicide-related content Design: original, empirical articles; language: English	Study number: 18 studies (12 with control group; no further details on study design) Population: healthy volunteers (incl. children/adolescents), psychiatric patients Outcomes (meta-analysis): (I) Distress: • Pre-post within-group comparison (8 studies, n=5,562): non-sign.; • Between-group comparison, immediate effects (6 studies, n=3,430): non-sign.; • Between-group comparison, delayed effects 2 days later (2 studies, n=2,319): non-sign. (II) Suicidal ideation: • Pre-post within-group comparison (4 studies, n=3,699): small sign. reduction, Hedges' g=-0.13, 95% CI: -0.16, -0.10, P<0.001; I ² =0.00; • Post between-group comparison (6 studies, n=7,398): non-sign. (III) Suicide attempt: • Post between-group comparison (4 studies, n=5,261): sign. reduction, OR =0.714, 95% CI: 0.56, 0.91, P<0.05; I ² =0.00	1- (1++ to 4)
DeCou <i>et al.</i> 2018 (systematic review; meta-analysis)	Assessment of desire to die/ Risk of suicide assessment	Population: not stated Intervention: suicide assessment Design: RCTs, experimental or single sample longitudinal design	Study number: 13 studies, n=4,406 (out of them 4 RCTs) Population: healthy volunteers (incl. children/adolescents), psychiatric patients Outcomes (meta-analysis): (I) Suicidal Ideation: • Within 2 days of assessment (4 studies): non-sign.; • 2 to 4 weeks post-assessment (3 studies): non-sign.; • 2 months to 2 years post-assessment (3 studies): non-sign.; • Among high-risk/vulnerable patients (7 studies): non-sign.; (II) Psychological distress: • Overall (8 studies): non-sign.; • Among high-risk/vulnerable patients (6 studies): non-sign. Suicidal behavior (3 studies): no MA; no higher suicidal behavior in 1 study; could not be stated in the other 2 studies	1- (1++ to 4)

Table 2 RCTs included for evidence-based recommendations on the key question “Dealing with patients’ desire to die”

Reference	Patients characteristics	Intervention (I)/Control (C)	Main results	SIGN LoE
Breitbart <i>et al.</i> 2010 (Pilot RCT) USA	Adult patients with diagnosed stage III or IV solid tumor or non-Hodgkin’s lymphoma: n=90 (I: n=49; C: n=41) Drop outs (T1): n=35 (I: n=14; C: n=21), 38.8%	I: Meaning Centered Group Psychotherapy (MCGP); 8-week duration C: supportive psychotherapy intervention (SGP); 8-week duration Measurement: Baseline (T0), 8 (T1) and 16 weeks (T2)	Desire for death (SAHD): • Between-group comparison: non-sign.; • Pre-post MCGP group: sign.; - T0–T1: d=0.29; P=0.09 - T1–T2: d=0.63, P=0.04 • Pre-post SGP group: non-sign.	1– (1++ to 4)
Breitbart <i>et al.</i> 2015 (RCT) USA	Adult patients with diagnosed stage IV cancers (or III if poor-prognosis disease): n=253 (I: n=132; C: n=121) Drop outs (T1): n=126 (I: n=63; C: n=63), 49.8%	I: Meaning Centered Group Psychotherapy (MCGP); 8-week duration C: supportive psychotherapy intervention (SGP); 8-week duration Measurement: Baseline (T0), 8 (T1) and 16 weeks (T2)	Desire for death (SAHD): • Per protocol analysis: - Between-group comparison: non-sign. - Group x time: sign. reduction: B = –0.22 (95% CI: –0.39 to –0.05), P<0.05 • ITT: Group x time: sign. reduction, although effect was smaller	1+ (1++ to 4)
Breitbart <i>et al.</i> 2018 (RCT) USA	Adult patients with stage IV solid tumor cancer, and at least moderate distress: n=321 (I: n=132; C1: n=108; C2: n=104) Drop outs (T1): n=114, 35.5%	I: IMCP (individual meaning-centered psycho-therapy) C1: SP (supportive psychotherapy): widely used in oncology settings C2: EUC (enhanced usual care) Measurement: Baseline, 4, 8 and 16 weeks	Desire for hastened death (SAHD): • Analysis of patients achieving 3 or more sessions (n=264): - Group x treatment interaction: non-sign., but trend: F (2,589) =2.55; P=0.08) - Between-group IMCP vs. EUC: sign. greater improvement, d=0.17, p<.05 - Between-group IMPC vs. SP: non-sign. • ITT: - Group x treatment interaction: non-sign. - Time x treatment arm effects: o IMPC vs. EUC: sign. greater improvement (–0.9; 95% CI: –0.17 to –0.01), P<0.05 o SP vs. EUC, IMCP vs. SP: non-sign.	1+ (1++ to 4)
Chochinov <i>et al.</i> 2011 (RCT) Canada	Adult patients with a terminal prognosis (life expectancy ≤6 months) who were receiving palliative care in a hospital or community setting n=441 (I: n=165; C1: n=140; C2: n=136) Drop outs (T1): n=115 (I: n=57; C1: 29; C2: 29), 26.0%	I: dignity therapy (DT) C1: client-centred care (CCC) C2: standard palliative care (SPC) Duration: 7 to 10 days	Desire for Death (Structured Interview for Symptoms and Concerns): non-sign.	1+ (1++ to 4)
Juliao <i>et al.</i> 2017 (Phase II RCT) Portugal	Adult patients having a life-threatening disease with a prognosis of 6 months or less (inpatients on palliative care unit): n=80 (I: n=41; C: n=39) Drop-outs: n=12 at day 4 (I: n=8; C: n=4)	I: Dignity Therapy (DT) C: Standard Palliative Care (SPC) Measurement: Baseline (T0) and day 4 post-DT (T1)	Desire for death prevalence (DDRS ≥ 4): • T0: 20% (no sign. difference between groups) • T1: sign. decrease in DT group (P=0.054) - DT: 0%; - SPC: 14.3%	1– (1++ to 4)

Table 3 All recommendations and statements regarding desire to die in patients with incurable cancer (1)

	Recommendations (1 to18) and statements (A to C)	GoR/EC	LoE	Key question answered	Based on
A	The desire to die of patients with incurable cancer should be considered a complex phenomenon with individually different causes, manifestations, and consequences	ST	3 (1++ to 4)	Phenomenon desire to die	Systematic literature search
B	Patients with incurable cancer and a desire to die may also have a desire for life within them. Over time and in terms of intensity, the desire to die and the will to live can change.	ST	3 (1++ to 4)	Phenomenon desire to die	Systematic Literature Search
1	Patients with incurable cancer should be actively asked about the presence of desire to die during the course of the disease.	B	4 (1++ to 4)	Assessment of desire to die	Systematic literature search
C	There is no evidence that addressing the subject of suicidal thoughts results in their development or increase.	ST	1– (1++ to 4)	Assessment of desire to die	Systematic literature search
2	When a desire to die is expressed by patients with incurable cancer, questions shall be asked about the course, severity, and subjective causes, as well as possible suicidal thoughts, intentions, and plans.	EC	–	Assessment of desire to die	EC
3	Validated instruments can be used to record the desire to die of patients with incurable cancer as an accompaniment to the discussion.	0	3 (1++ to 4)	Assessment of desire to die	Systematic literature search
4	The discussion about desire to die shall be conducted with a basic attitude of openness, interest and respect for the patient's thoughts, experiences, and actions. The attitude of respect does not necessarily imply agreement with the active termination of life.	EC	–	Caring for patients having a desire to die	EC
5	When patients with incurable cancer express a desire to die, the presence of helplessness, hopelessness, pointlessness, futility, demoralisation and loss of faith, as well as depressiveness and suicidality, shall be recorded and treated or support shall be offered.	A	3 (1++ to 4)	Caring for patients having a desire to die	Systematic literature search
6	Two-question screening can be used to detect depression in patients with incurable cancer: (I) Have you often felt depressed, sad or hopeless in the last month? (II) In the last month, have you experienced significantly less joy and pleasure in things that you otherwise like to do?	0	4 (1++ to 4)	Caring for patients having a desire to die	Adaptation of existing guidelines
7	If a patient with incurable cancer has a desire to die, coping strategies should be developed with him/her on how to deal with the situation.	B	3* (1++ to 4)	Caring for patients having a desire to die	Systematic literature search
8	In the event of a desire to die combined with the experience of (impending) loss of control, possibilities should be worked out with a patient with incurable cancer as to how they can (again) experience or regain control over their situation.	EC	–	Caring for patients having a desire to die	EC
9	In the event of a desire to die combined with the experience of (impending) loss of control, possibilities should be developed with a patient with incurable cancer as to how they can (again) experience or regain control over their situation.	EC	–	Caring for patients having a desire to die	EC
10	In the case of a patient with incurable cancer and a persistent desire to die, the professionals should tolerate this wish and give the patient advice and support in an empathetic manner.	EC	–	Caring for patients having a desire to die	EC
11	In the discussions with the patient about desire to die, the therapeutic goal and the resulting decisions about the beginning, continuation and termination of life-sustaining medical measures shall be addressed.	EC	–	Caring for patients having a desire to die	EC
12	Particularly in patients with incurable cancer and a desire to die, inadequately controlled symptoms such as pain, respiratory distress, nausea, vomiting, anxiety, depression, etc. shall be treated as best as possible.	A	3 (1++ to 4)	Caring for patients having a desire to die	Systematic literature search
13	A psychiatric/psychotherapeutic expert shall be consulted in the following cases: • Uncertainty in the diagnosis of a psychiatric disorder and the planning of its treatment; • In the case of a (per)acute suicidal tendency; • If there is a wish for advice by professionals, e.g., in difficult conversations about dealing with the desire to die.	EC	–	Caring for patients having a desire to die	EC
14	In the case of peracute suicidal tendencies, i.e., when the suicidal action is imminent and cannot be avoided by other measures, the indication for committal to a psychiatric and psychotherapeutic clinic shall be examined, with critical consideration of the benefits and harm.	EC	–	Caring for patients having a desire to die	EC
15	Palliative sedation can be offered for symptom control in patients with incurable cancer and insufficiently manageable symptoms resulting in the desire to die.	EC	–	Caring for patients having a desire to die	EC
16	Those involved in the treatment of a patient with incurable cancer shall be further trained with regard to desire to die, the (occupational) legal framework conditions and the relevant concepts.	EC	–	Supporting health care teams and family members	EC
17	In the event of a desire to die, the family members should be included in the discussion about this with the patient.	EC	–	Supporting health care teams and family members	EC
18	Suitable opportunities for reflection, such as case discussions, pastoral care, and supervision (e.g., for interactional problems with the patient), as well as ethical advice (e.g., in the case of ethical questions) and further training shall be offered for teams accompanying patients with a desire to die.	EC	–	Supporting health care teams and family members	EC

*, The guideline group downgraded the LoE of the recommendation [3], as the identified RCTs do not cover the whole spectrum of coping strategies.

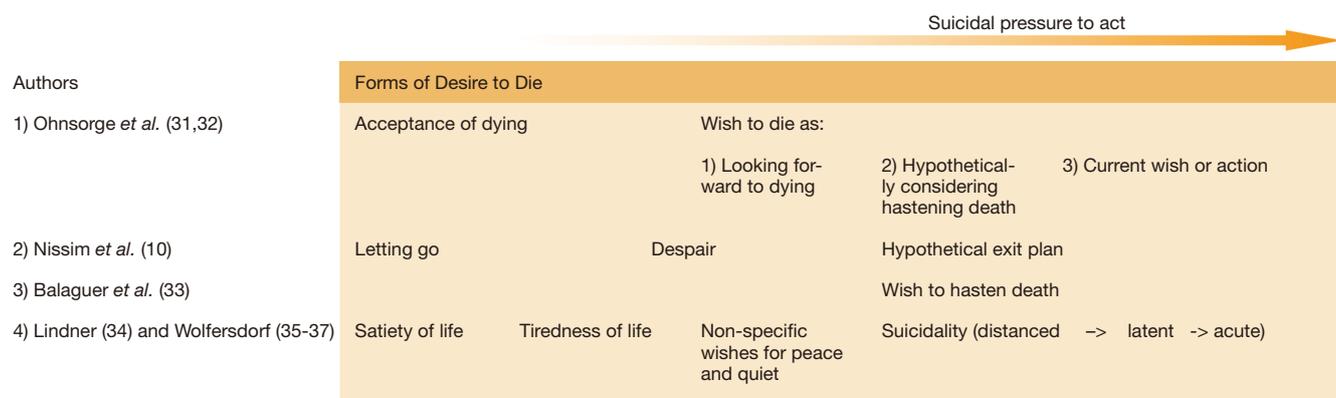


Figure 2 Forms of desire to die arranged along a continuum of increasing suicidal pressure (1,10,31-37).

consequences (LoE 3) (22). This is relevant for health care providers, as a desire to die requires a differentiated approach in clinical practice. The systematic review and meta-ethnography included 14 primarily qualitative studies that explored the phenomenon of desire to die in a total sample size of 225 patients receiving palliative care, mostly living with cancer (22).

In order to give credit to the complexity of the phenomenon and to illustrate the different forms that the desire to die can take, the *German Palliative Care Guideline* compiled some concepts of desire to die and suicidality by different authors (10,31-37) based on studies identified through the expert consultation. These concepts from psychiatric and palliative care perspective complement each other. They can best be visualized along a continuum ranging from satiety of life and acceptance of dying to acute suicidality (*Figure 2*).

As *Figure 2* illustrates, suicidality is not equivalent to desire to die, but only one extreme form of it. Desire to die can express satisfaction with the foreseeable end of one's own suffering of simply a tiredness of life and acceptance of its end without the pressure to actively hasten death, while suicidality is defined by a pressure to act. It is often difficult for health professionals to distinguish between a desire to die without a suicidal component and a desire to die with it. In those cases of uncertainty, the guideline recommends drawing upon external expertise of mental health professionals (EC).

Desire to die can vary both over time and in terms of its intensity (22). Additionally, even though it may seem counter intuitive, patients who harbor a desire to die might simultaneously have a desire for life (LoE 3) (22). This might result in patients expressing their desire to die and opting for curative therapies at the same time. Keeping

in mind this common phenomenon might also help differentiating a desire to die with or without suicidality.

Causes, significance, and functions of desire to die

Desire to die in patients with incurable cancer may be caused and influenced by numerous factors (24,34,38,39), also described within the guideline:

- (I) Existing or anticipated physical symptoms (pain, fatigue, physical weakness, nausea, or loss of appetite);
- (II) Mental health symptoms (depression, anxiety, hopelessness);
- (III) Social problems (isolation/being alone);
- (IV) Personality (desire for autonomy and control, loss of identity);
- (V) Quality of the patient's relationships with people who are important to them;
- (VI) Not wanting to be a burden;
- (VII) Existential or spiritual issues.

Within a longitudinal analysis, a model identified hopelessness as the strongest influencing factor on the development of desire to die (40). The second strongest factor was depression, strongly influenced by physical symptom burden. However, those results must be interpreted with caution as statistical differences were significant, but small.

A desire to die can have different meanings and functions. Meanings of desire to die refer here to subjective meanings that the patient ascribes to his own desire to die (22). Functions of desire to die are to be distinguished from meanings: Ohnsorge *et al.* define them by how the patients' social environment is affected

by their desire to die (22). It is not possible to strictly separate meanings and functions from each other, yet they are not congruent. For example, meanings can include the following aspects (32):

- (I) Accepting death as a natural occurrence;
- (II) Ending suffering that can no longer be endured by bringing about death;
- (III) Pondering the situation and concluding that unnecessary suffering should be ended—with death as the endpoint;
- (IV) Not wanting to wait until death comes;
- (V) Rather maintaining control than giving it up in dying.

Functions would be understood as follows (41):

- (I) Manifestation of the desire to live;
- (II) Preferring a faster death in the dying phase;
- (III) The intolerability of the situation demands action without fail;
- (IV) Way to escape from an intolerable situation;
- (V) Manifesting final control;
- (VI) Drawing attention to one's own individuality;
- (VII) Gesture of altruism;
- (VIII) Attempt to manipulate the family;
- (IX) Exclamation of despair, which is intended to illustrate the current distress.

Screening and assessment

The thorough assessment of a patient's desire to die—including a screening for possible suicidality or underlying depression—is strongly recommended for understanding a desire to die and providing the best possible care and support. This issue (key question 2) is addressed in four recommendations. Two of them focus on the proactive addressing of possible desires to die (*Table 3*). Patients with incurable cancer should be actively asked about a potential desire to die during the course of the disease (GoR B/LoE 4) (41,42). Concerns about possible adverse effects of addressing desire to die are defused by an evidence-based statement, whereupon addressing suicidal thoughts doesn't lead to their emergence or increase (LoE 1-) (24,25). DeCou *et al.* (in 2018) investigated the iatrogenic risk of suicidality assessment in healthy volunteers as well as psychiatric patients (25). They did not find any significantly increased iatrogenic risk as measured by the outcomes suicidal ideation, suicidal behavior, or emotional/psychological distress. Blades *et al.* (in 2018) conducted a similar review and came to comparable conclusions (24). The guideline

group considered this indirect evidence applicable to patients receiving palliative care with a potential desire to die.

Once patients express a desire to die, the health care professionals shall assess the course, severity, and subjective causes of this desire, as well as possible suicidal thoughts, intentions, and plans (EC). In some cases, a patient-centered, respectful, and open conversation can be accompanied by the use of validated instruments (GoR 0/LoE 3) (23). To report and rate the psychometric properties of available assessment instruments for desire to die, Bellido-Pérez *et al.* (in 2017) conducted a systematic review of 50 studies that yielded seven tools (23). Among those, the Schedule of Attitudes Towards Hastened Death (SAHD) mainly used for research purposes, and the Desire for Death Rating Scale (DDRS) for clinicians, are the most widely used. Included studies were limited by low participation of eligible patients and some of the included validation studies lacked data, therefore the guideline does not recommend any specific tool for clinical use.

Caring for patients having a desire to die

As desire to die is a complex phenomenon with various possible meanings and many underlying factors, the question arises about which goals should be pursued in caring for patients who express a desire to die. The *German Palliative Care Guideline* describes a four-level plan (*Figure 3*) (1).

When caring for patients with desire to die receiving palliative care (key question 3), the guideline differentiates between professional attitudes, strategies and techniques. Professional attitudes are defined as comprising all affects, feelings, thoughts, and behaviors of the health care professionals with regard to the patient that become apparent in the treatment situation and have an influence on the treatment process (39). With regard to such attitudes, the guideline recommends that discussions about desire to die shall take place in an atmosphere of openness, interest and respect (EC). It is stressed that respect does not imply agreement with the patients' wish to end their life. Professional techniques are theory-based (verbal or non-verbal) activities in various, mostly critical situations of treatment. The guideline formulates a number of recommendations on various strategies and techniques as listed in *Table 3*. Most of them are based on clinical expertise and consensus, since the systematic literature search yielded little evidence. Five RCTs were identified that examine the

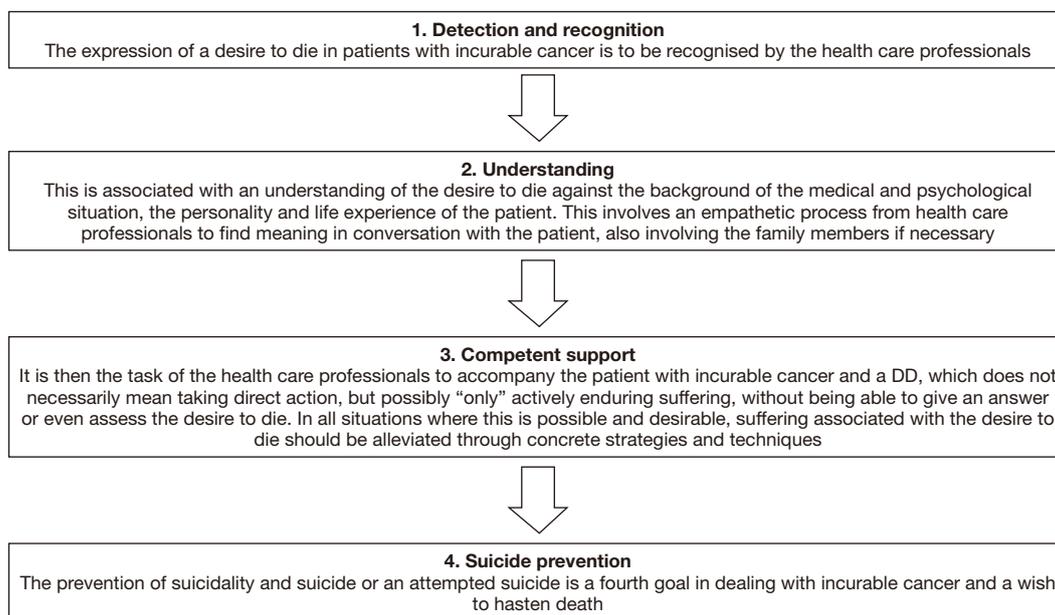


Figure 3 Goals in dealing with desire to die in palliative care (1).

effectiveness of specific coping strategies for patients with a desire to die. They investigated two psychotherapeutic interventions, a meaning centered psychotherapy (24,25,28) and a dignity centered therapy (26,27). Most of them showed a significant reduction of desire to die in patients receiving palliative care (26,27,29,30). However, the guideline group decided not only to focus on these two psychotherapeutic interventions, but to make a wide recommendation on coping strategies in general (GoR B/LoE 3). Indeed, there are numerous therapeutic options that have not yet been sufficiently investigated on their effectiveness in RCTs, but which are used in clinical practice. Furthermore, the systematic review of qualitative studies supports a recommendation on treating inadequately controlled symptoms, as these may also influence a desire to die (GoR A/LoE 3) (22).

Special measures

In some cases, an expressed desire to die might be without consequences for the patient's treatment plan. Other cases might necessitate considering special measures to prevent further harm or suffering to the patient. These measures often involve thorough ethical reflections within the palliative care team but also taking into account the patient's relatives.

In general, all health professionals involved in the treatment of patients with incurable cancer should be

trained in dealing with desire to die and the related legal framework (EC). Further recommendations on strategies for dealing with acute suicidality and the use of palliative sedation have to be applied against this background. If a patient presents with peracute suicidal ideation and suicidal actions cannot be avoided with other measures, it is recommended to consider admitting the patient to a psychiatric clinic (EC). Benefits and harms must be critically considered beforehand. Sometimes, patients express desire to die when they experience their symptoms as unbearable. In cases of insufficiently manageable symptoms, palliative sedation can be offered to those patients (EC). It shall only be provided by physicians and nursing staff skilled in palliative medicine (EC).

Family members

Talking about patients' desire to die is not easy for their relatives either (43), be it in conversation with the patient or with a third party. To answer key question 4, the guideline recommends involving relatives in conversations, if the patient has provided consent (EC). Such a conversation between health professionals and relatives might improve, clear up or deepen the relationship with the relative. Therefore, the guideline chapter on desire to die offers more advice on conversations with relatives on a patients' desire to die. The current relationship between patient and

relative as well as the relatives' burden has to be taken into account. Patients' and relatives' wish about hastened death or prolonged life are not always in synchrony. Especially if relatives consider assisting the patient with suicide, a conversational offer is advised, as a non-judgmental conversation might help in showing alternatives (43). If relatives express the wish to end the patients' life by themselves, the guideline advises to react sensitively. Often enough, such thoughts hint at the relatives' intense suffering and need for support that should first and foremost be interpreted as a conversational offer.

Health care team

Like patients and relatives, the professional care team is also affected by patients' desire to die. Talking about desire to die can both be an enriching and intimate experience, as well as a potential trigger for one's own unresolved issues (44). Key question 4 addresses this issue.

Confronted with conflicting situations, supervision, spiritual care, and case conferences can help health care professionals in providing new perspectives and are explicitly recommended by expert consensus of the guideline (EC). This recommendation is furthermore complemented by advice about the stabilizing impact of psychotherapeutic, psychiatric, or psychosomatic counselling on health professionals (45). Health professionals need to establish sensitivity for their own limits and possible (emotional) overload. They have to be clear about their own norms and values regarding desire to die.

Legal framework conditions at the end of life

Dealing with desire to die in patients receiving palliative care is necessarily confined by the legal framework conditions at the end of life. Therefore, the *German Palliative Care Guideline* pays special attention to the presentation of possible actions and the current legal situation (1,12,46-49) (Table 4).

Discussion

According to the *German Association for Palliative Medicine* (DGP), the life-affirming approach of palliative care attempts to offer help while dying, but not to help to die (50). As such, ending life prematurely—including assisted suicide and euthanasia—is seen as being incompatible with the fundamental principles of palliative care. Nevertheless,

desire to die is a common phenomenon in patients with advanced disease. The *German Palliative Care Guideline for Patients with Incurable Cancer* presents best practice recommendations for dealing with desire to die in palliative care within the national legal framework and general standards of palliative care (51,52). The recommendations are evidence and consensus-based and were developed according to strict methodical criteria (20).

The *German Palliative Care Guideline* explicitly refers to the treatment of patients living with cancer, however the recommendations, statements, and background texts on desire to die aim at offering reliable advice for dealing with desire to die in patients that suffer from non-malignant, for example neurological conditions as well. We assume the recommendations presented in the guideline with regard to desire to die, to still hold for different advanced diseases with diverse trajectories (53).

A specific feature of our guideline is the broad concept of desire to die. Compared to the narrower understanding of (suicidal) death wishes at the end of life that is discussed as the wish to hasten death (33), desire to die covers a wider range of related phenomena and must not necessarily be associated with suicidality (10). This broad definition allows for a continuum of desire to die manifestations that are changeable over time and encompass the possibility of a simultaneous will to live. It also makes health professionals aware that some patients may need therapeutic measures to deal with their desire to die and others not, or that such measures have to be adapted during the course of the disease according to the dynamic of the desire to die in the same patient.

German legislation prohibits euthanasia, and assisted suicide was also legally restricted until February 2020. As a result, German patients with a desire to end their lives may have travelled to neighbor countries where such regulations are not in place (5). Between 2008 and 2012, nearly half (44%) of all so called "suicide tourists" in Switzerland came from Germany (5). Still, 74% of German health professionals participating in a DGP survey German health professionals participating in a DGP survey state they have been asked by their patients to provide assisted suicide (13). A majority of these health professionals agreed that assisted suicide is not a part of palliative care (60%) and approved the legal prohibition (56%) (13). How this attitude will develop with a new legislation remains to be seen. However, almost all physicians (98%) valued talking to their patients about possible desire to die, as those conversations alone can offer psychological relief (13).

Table 4 Legal framework at the end of life: terminal care and assisted dying within the German statutory framework (1)

Action	German legal situation
Euthanasia	Voluntary euthanasia (killing on request, <i>Tötung auf Verlangen</i>) is prohibited by law within the German statutory framework according to §216 StGB (national criminal code). The Federal Constitutional Court sentences killing on request with 6 months to 5 years of imprisonment. Examples include delivering an injection towards the goal of killing the patient on their explicit demand. In cases such as this physical control is not with the patient but with the person delivering the injection. As such, the person delivering the injection is held legally accountable (47)
Physician-assisted suicide	According to the Federal Constitutional Court, the general right of personality includes a right to self-determined death—including a right to take one's own life and to seek help for this purpose (ruling of 26.02.2020) (12). This ruling declared §217 of the German Criminal Code (StGB), which has been in force since 2015, unconstitutional. According to §217 StGB, assistance of suicide with intent of repeated conduct was prohibited. A new regulation on suicide assistance is still pending. Depending on the circumstances of the individual case, anyone who aids a suicide that is not freely responsible can be charged with failure to provide assistance (§323c StGB), killing by omission (§§212, 13 StGB), and possibly also with negligent or intentional killing (§222 or §212 StGB). In addition, the provisions of professional law have been applicable to doctors up to now: talking to the patient about desire to die and suicidal intent is part of the doctor's duties, but not helping the patient to commit suicide. In accordance with the model professional code of conduct for doctors, some state medical associations have also decided on a separate prohibition of medical suicide assistance under professional law
Therapies at the end of life	Formerly sometimes called "indirect euthanasia" (<i>indirekte Sterbehilfe</i>), therapies at the end of life include all (palliative) medicinal measures aimed at alleviating suffering at the end of life. They are permitted if indicated, if patients have consented with their implementation and if they are delivered properly (as confirmed by experts). Potential life-shortening effects have to be accepted and measures for alleviating suffering can under certain circumstances even be required ethically or by law (48)
Letting die	"Letting die" (<i>Sterben zulassen</i>), formerly sometimes called "passive euthanasia" (<i>passive Sterbehilfe</i>), designates the decision not to implement or to discontinue life-prolonging measures. As soon as life-prolonging measures are no longer indicated or no longer desired by the patient this is permitted and can under certain circumstances even be required ethically or by law (49)
Palliative sedation	Palliative sedation is permitted if indicated, if the patient provided an according advance health care directive (<i>Patientenverfügung</i>) and if it is delivered properly (as confirmed by experts). Palliative sedation is predominantly meant to provide an ethically acceptable measure for alleviating symptom burden in palliative patients in a therapy-refractory situation. In order to alleviate symptom burden, the health care professionals actively induce the reduction or suspension of consciousness (50)

The recommendations of the *German Palliative Care Guideline* continue to apply despite the shift in the legal framework due to the repeal of §217 and a still pending new regulation of assisted suicide, which currently is under intensive discussion.

Conclusions

The guideline recommends health professionals to proactively address a patient's possible desire to die. Those conversations can strengthen the relationship between health professional and patient, even in case of a permanent and long-lasting desire to die. The guideline stresses that enduring such desire to die with the patient does not equal approval of a premature termination of life or the willingness to comply with any such request. It can,

however, offer support during the whole disease trajectory and provide room to discuss alternatives. Desire to die can also have a stabilizing function for the patient as an exit strategy for unbearable times. Dealing with desire to die early in an open, respectful, and interested way can help health professionals in clarifying possible backgrounds and functions for each individual.

This article has strengths and limitations. Desire to die is a new research field. Its definition and conceptualization vary greatly in the literature and most of the current studies on desire to die are qualitative, reflecting the attempt to better understand the concept and background of desire to die. Therefore, the working group on desire to die first delineated a definition of desire to die. Thanks to the contribution of experts from psychiatry, suicidology and palliative care, it was possible to integrate both concepts

of desire to die at the end of life on the one hand and suicidality on the other, which used to be considered separately in the literature. A research gap with a lack of quantitative studies on desire to die was detected. Because of the lack of studies, it was challenging for the guideline group to draw up evidence-based recommendations. Most of the recommendations are based on consensus of experts. Nevertheless, the recommendations found a broad agreement among numerous national experts and should be considered as an important contribution for dealing with desire to die in clinical practice as well as an innovative conceptualization of desire to die, which can trigger more research in this field.

Acknowledgments

The authors thank all elected representatives and experts of the Working Group on Desire to Die and of the Guideline Group for their energetic help in drawing up the guideline. Particular thanks are due to Dr. Markus Follmann, Prof. Ina Kopp, Dr. Monika Nothacker, Thomas Langer, and Dr. Simone Wesselmann of the German Guideline Program in Oncology for their advice on methods and their unwavering support.

Funding: We are very thankful to the three bodies that created the German Guideline Program in Oncology and provided financial support: the Association of the Scientific Medical Societies in Germany, the German Cancer Society, and the German Cancer Aid.

Footnote

Provenance and Peer Review: This article was commissioned by the Guest Editors (Nancy Preston, Sheri Mila Gerson) for the series “Hastened Death” published in *Annals of Palliative Medicine*. The article has undergone external peer review.

Reporting Checklist: The authors have completed the AGREE reporting checklist. Available at <http://dx.doi.org/10.21037/apm-20-381>

Peer Review File: Available at <http://dx.doi.org/10.21037/apm-20-381>

Conflicts of Interest: All authors have completed the ICMJE uniform disclosure form (available at <http://dx.doi.org/10.21037/apm-20-381>). The series “Hastened Death”

was commissioned by the editorial office without any funding or sponsorship. RV reports grants from Federal Ministry of Education and Research, during the conduct of the study; grants from Federal Joint Committee (G-BA) Germany, Innovation Fund, grants from Federal Ministry of Education and Research, grants from EU - Horizon 2020, grants from Robert Bosch Foundation, grants from Robert Bosch Foundation/Trägerwerk Soziale Dienste in Sachsen GmbH/Association Endlich. Palliativ & Hospiz e. V., grants from Ministry of Labor, Health and Social Affairs of North Rhine-Westphalia, grants from Innovation Fond, grants from German Cancer Society, Association of the Scientific Medical Societies, German Cancer Aid, grants from Ministry of Culture and Science of North Rhine-Westphalia, personal fees from AOK Health insurance, personal fees from German Cancer Society/National Health Academy (NGA), personal fees from MSD Sharp & Dome, grants from Federal Ministry of Education and Research, grants from Hertie Foundation, outside the submitted work. The authors have no other conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. As the reported guideline development process did not include medical research involving human, the study needed no approval by an institutional ethics committee.

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Cite this article as: Kremeike K, Pralong A, Boström K, Bausewein C, Simon ST, Lindner R, Voltz R; On behalf of the Working Group on Desire to Die of the German Palliative Care Guideline. 'Desire to Die' in palliative care patients—legal framework and recommendations of the national evidence-based guideline on palliative care in Germany. *Ann Palliat Med* 2021;10(3):3594-3610. doi: 10.21037/apm-20-381

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Date	September 03, 2018
Hits	134
Search strategy	<ol style="list-style-type: none"> exp Attitude to Death/or exp Right to Die/or exp Suicide, Assisted/or exp Euthanasia/or exp Euthanasia, Active/ ("hasten* death" or "hasten* dying" or ((desire or wish) adj2 (die or death or dying))).mp. 1 or 2 exp Suicide, Attempted/or exp Suicidal Ideation/or exp Suicide/ suicid*.mp. 4 or 5 exp Terminal Care/ exp Hospices/ exp Palliative Care/ exp Terminally Ill/ (palliati* or hospice\$ or "terminal care" or "terminally ill" or dying or "end of life" or "end-of-life").mp. or/7-11 exp neoplasms/ (cancer* or malignan* or carcino* or neoplasm* or tumor* or tumour* or oncolog*).mp. 13 or 14 6 and 12 and 15 3 or 16 Meta-Analysis as Topic/ meta analy\$.tw. metaanaly\$.tw. Meta-Analysis/ (systematic adj (review\$1 or overview\$1)).tw. exp Review Literature as Topic/ or/18-23 cochrane.ab. embase.ab. (psychlit or psychlit).ab. (psychinfo or psychinfo).ab. (cinahl or cinhal).ab. science citation index.ab. bids.ab. cancerlit.ab. or/25-32 reference list\$.ab. bibliograph\$.ab. hand-search\$.ab. relevant journals.ab. manual search\$.ab. or/34-38 selection criteria.ab. data extraction.ab. 40 or 41 Review/ 42 and 43 24 or 33 or 39 or 44 exp animals/not humans.sh. 45 not 46 exp child/not adult.sh. 47 not 48 50. (erratum or editorial).pt. 49 not 50 17 and 51 exp animals/not humans.sh. 52 not 53 exp child/not adult.sh. 54 not 55 57. (erratum or editorial).pt. 56 not 57 59. Limit 58 to yr="2008-current"
Handsearch	Blades <i>et al.</i> 2018, DeCou <i>et al.</i> 201
Sentinel papers	Bellido-Perez <i>et al.</i> 2017, Rodriguez-Prat <i>et al.</i> 2017

Systematic search for primary studies: dealing with patients' desire to die

Database	Medline (via Ovid)	PsycINFO (via Ovid)	Cochrane Library
Date	October 08, 2018	October 08, 2018	October 08, 2018
Hits	568	69	129
Search strategy	<ol style="list-style-type: none"> exp Attitude to Death/or exp Right to Die/ or exp Suicide, Assisted/or exp Euthanasia/ or exp Euthanasia, Active/ ("hasten* death" or "hasten* dying" or ((desire or wish) adj2 (die or death or dying))).mp. 1 or 2 exp Suicide, Attempted/or exp Suicidal Ideation/or exp Suicide/ suicid*. mp. 4 or 5 exp Terminal Care/ exp Hospices/ exp Palliative Care/ 10. exp Terminally Ill/ (palliati* or hospice\$ or "terminal care" or "terminally ill" or dying or "end of life" or "end-of-life").mp. or/7-11 exp neoplasms/ 14. (cancer* or malignan* or carcino* or neoplasm* or tumor* or tumour* or oncolog*).mp. 13 or 14 6 and 12 and 15 17. 3 or 16 Randomized Controlled Trials as Topic/ Randomized controlled trial/ Random Allocation/21. Double Blind Method/ Single Blind Method/ clinical trial/ clinical trial, phase i.pt. clinical trial, phase ii.pt. clinical trial, phase iii.pt. clinical trial, phase iv.pt. controlled clinical trial.pt. randomized controlled trial.pt. multicenter study.pt. clinical trial.pt. exp Clinical Trials as topic/ (clinical adj trial\$).tw. ((singl\$ or doubl\$ or treb\$ or tripl\$) adj (blind\$ or mask\$3)).tw. placebos/ placebo\$.tw. randomly allocated.tw. (allocated adj2 random\$).tw. or/18-38 case report.tw. historical article/42. or/40-41 39 not 42 17 and 43 	<ol style="list-style-type: none"> exp "DEATH AND DYING"/or exp DEATH ATTITUDES/ ("hasten* death" or "hasten* dying" or ((desire or wish) adj2 (die or death or dying))).mp. 1 or 2 exp ATTEMPTED SUICIDE/or exp ASSISTED SUICIDE/or exp SUICIDE PREVENTION/or exp SUICIDE/ suicid*.mp. 4 or 5 exp Terminally Ill Patients/or exp PALLIATIVE CARE/or exp "Death and Dying"/or exp Hospice/ ("hasten* death" or "hasten* dying" or ((desire or wish) adj2 (die or death or dying))).mp. 7 or 8 exp Neoplasms/ 11. (cancer* or malignan* or carcino* or neoplasm* or tumor* or tumour* or oncolog*). mp. 10 or 11 6 and 9 and 12 3 or 13 limit 14 to "0300 clinical trial" 	<ol style="list-style-type: none"> MeSH descriptor: [Attitude to Death] explode all trees MeSH descriptor: [Right to Die] explode all trees MeSH descriptor: [Euthanasia] explode all trees ("hasten* death" or "hasten* dying" or ((desire or wish) near/2 (die or death or dying)):ti,ab,kw #1 or #2 #3 or #4 MeSH descriptor: [Suicide] explode all trees suicid*:ti,ab,kw #6 or #7 MeSH descriptor: [Terminal Care] explode all trees MeSH descriptor: [Palliative Care] explode all trees MeSH descriptor: [Hospices] explode all trees MeSH descriptor: [Terminally Ill] explode all trees (palliati* or hospice* or "terminal care" or "terminally ill" or dying or "end of life" or "end-of-life"):ti,ab,kw #9 or #10 or #11 or #12 or #13 MeSH descriptor: [Neoplasms] explode all trees (cancer* or malignan* or carcino* or neoplasm* or tumor* or tumour* or oncolog*):ti,ab,kw #15 or #16 #8 and #14 and #17 In: Trials
Handsearch	Breitbart <i>et al.</i> 2018		
Sentinel papers	Breitbart <i>et al.</i> 2015		

Inclusion and exclusion criteria for systematic searches

Systematic search for systematic reviews

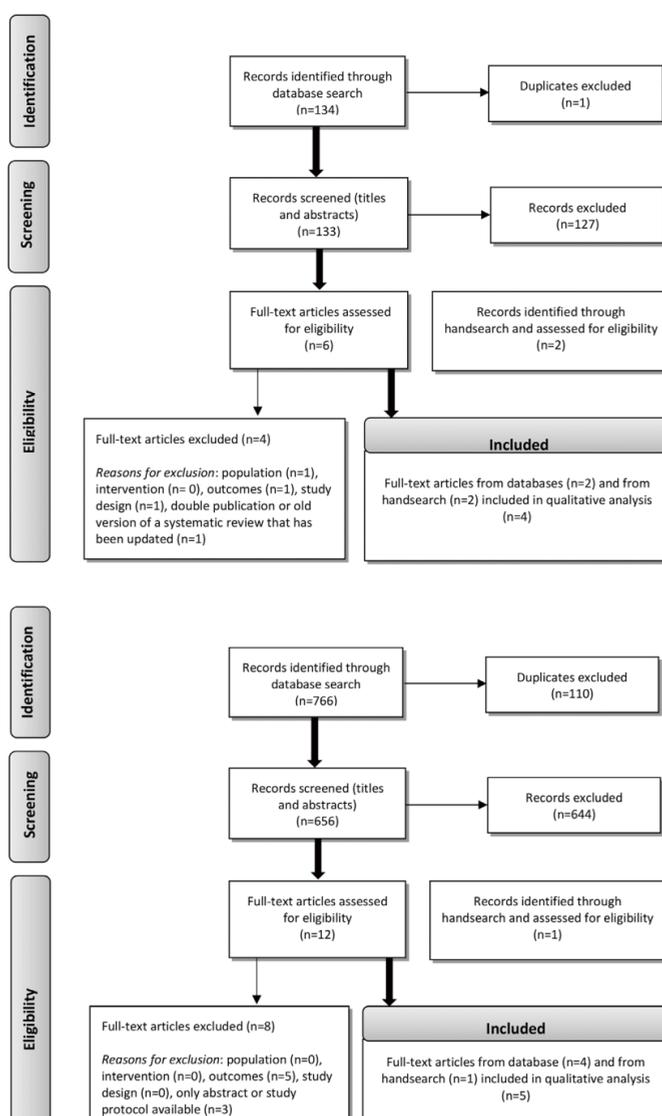
Inclusion criteria	<ol style="list-style-type: none"> Population: adult patients with a desire to die or suicidality and an incurable cancer Intervention: <ul style="list-style-type: none"> Assessment of desire to die Dealing with desire to die Qualitative description of desire to die Outcome: <ul style="list-style-type: none"> For assessment: validity/reliability, sensitivity/specificity of assessment instruments For dealin with desire to die: Increase, decrease or other change in suicidality/desire to die Qualitative description of desire to die Study type: systematic review
Exclusion criteria	<ol style="list-style-type: none"> Only abstract available Double publication or old version of an updated systematic review

Systematic search for primary studies: dealing with patients' desire to die

Inclusion criteria	<ol style="list-style-type: none"> Population: adult patients with potential suicidality or a potential desire to die Intervention: any type of pharmaceutical or non-pharmaceutical procedure teste das an RCT Outcome: decrease of desire to die/suicidality related burden Study type: RCTs, CCTs
Exclusion criteria	Only abstract or study protocol available

PRISMA charts

PRISMA flow diagram for the inclusion of systematic reviews



PRISMA Flow diagram for the inclusion of primary studies: dealing with patients' desire to die