

# Meaning in life of terminally ill parents with minor children compared to palliative care patients – a quantitative analysis using SMiLE

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## Abstract

**Background:** Caring for terminally ill patients with minor children can be very stressful. The perceived quality of life is significantly influenced by the Meaning in Life (MiL). No studies were found that focus on the prioritized special needs of this patient group.

**Objectives:** The aim is to compare and contrast terminally ill parents with minor children and palliative care patients in Germany, in order to provide appropriate support beyond medical, nursing or therapeutic interventions.

**Methods:** Terminally ill parents diagnosed were surveyed using a validated instrument 'Schedule for Meaning in Life Evaluation (SMiLE)'. The study listed various areas that contribute to the MiL, followed by an evaluation of their importance and satisfaction levels. The researchers then compared these findings with data collected from palliative care patients.

**Results:** In Germany, 54 patients, mostly female and with a mean age of 43, were included in this study between February 2017 and September 2020. The median age of the 96 children during the survey phase was 7 years. The comparison group consists of 100 palliative care patients in Germany; mostly aged 50 years and older. For terminally ill patients most important areas were in decreasing order family (100%), social relations (80%), leisure time (61%), nature/animals (39%) and home/garden (30%). Although the overall indices are close between both groups, there are significant and highly correlated differences between them. Parents felt limited by their illness in being a mother or father, as they wanted to be.

**Conclusion:** The involvement with SMiLE led patients to consider their coping resources. The areas relevant to terminally ill parents differed from those relevant to palliative care patients. All participants identified family as the most important factor for MiL. The results suggest that evaluating MiL can serve as a coping strategy and help terminally ill parents with minor children.

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## Plain language summary

### A comparison of answers to the meaning in life from seriously ill parents with young children with the answers of other seriously ill patients

Background: Caring for seriously ill patients with young children can be very stressful. The quality of life depends on meaning in life. No studies were found that focus on the needs of this patients. Objectives: The aim was to explore similarities and differences between seriously ill parents with young children and palliative care patients in Germany to find the best way to support them. Methods: The Meaning in Life questions were used to find this out. Two researchers asked seriously ill parents about different things that make their lives meaningful. The researchers then compared the results with data from other seriously ill patients in need of palliative care. In Germany, 54 seriously ill parents

with young children were interviewed between February 2017 and September 2020. The children were usually seven years old. The compared group consisted of 100 palliative care patients and was mostly older than 49 years. For seriously ill patients most important were family, social relations, leisure time, nature/animals, and home/garden. The values seemed similar, but there are clear differences between the groups. Parents felt their illness limited them in being a mother or a father. Conclusion: The questions helped patients helped to remember meaning in life and set goals. The things that mattered to seriously ill parents were different from those that mattered to palliative care patients. All participants said that family was the most important thing for meaning in life. The results show that thinking about meaning in life can help.

**Keywords:** biography, meaning in life, palliative care, quality of life, reminiscence, terminally ill parent with minor children

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## Background

According to Müller *et al.* accompanying patients with young children is described as very stressful.<sup>1</sup> In a previous study Cuhls *et al.* showed that a biographical intervention can help patients with young children.<sup>2</sup>

Overall biographical work as a non-therapeutical intervention shows positive effects on depression, well-being and quality of life.<sup>3-5</sup> The Meaning Making Model, proposed by Park,<sup>6</sup> distinguishes between meaning-making and meanings-made. Meaning-making is defined as the understanding of a stressor as appraised meaning and its incorporation into a global meaning system. Meaning-made was defined as growth, life meaningfulness and reduced inconsistency of just-world beliefs. They assess the presence of and search for meaning, ask for meaning in crisis, or sources of meaning-making, and meaningful activities.<sup>6</sup> Based on this approach, several research results indicate an impact on psychological distress. In addition, findings among others led to an evaluation of meaning-making intervention with aspects of life priorities and aim to foster coping and mastery of illness.<sup>7-10</sup> Many assessment instruments take these categories into account. Fegg *et al.*<sup>11</sup> have developed a validated questionnaire called the Schedule for Meaning in Life Evaluation (SMiLE) to assess the areas that provide meaning to life. SMiLE also measures the importance of and satisfaction with the meaning and quality of life.

In gerontology, geriatrics and palliative medicine, healthcare staff are presented with patients' life stories in the context of care.<sup>12</sup> During an

advanced serious illness, individuals may re-evaluate their priorities in response to the situation. This includes to questions about the meaning and satisfaction of one's own life.<sup>13</sup> The fact that young children are left behind can be emotionally challenging for some healthcare professionals, making it difficult to accompany them. The study by Müller *et al.* demonstrated that providing support to terminally ill parents with young children and the demand for such support are perceived as highly stressful.<sup>1</sup> Identifying meaningful domains in life can assist in identifying the specific areas in which support is required. Once these patient-oriented needs have been identified, the care teams can then initiate and support the provision of resources in line with the identified needs. This approach has the potential to relieve the care teams, as they are aware of the necessary actions to be taken, and to enhance the health-related quality of life of terminally ill patients with young.

To provide a research-based intervention for vulnerable terminally ill young patients with minor children, it was necessary to identify a suitable instrument for determining Meaning in Life (MiL). Especially, since there is no available data on this group in Germany, we have selected the instrument by Fegg *et al.* as a non-therapeutic intervention based on the literature review by Hesse.<sup>11,12,14</sup> The instrument was selected because of its sensitivity to the vulnerable situation of these patients and their children, as well as the opportunity for comparison with other terminally ill patients.<sup>14</sup> This article compares the responses of terminally ill young parent with minor children regarding the MiL with those of a previous cohort

of patients with palliative care needs. As both populations are diagnosed with a serious life-threatening disease, the comparison will provide insights into similarities and differences in the MiL for patients with the same health condition.

## Methods

### *Study population and recruitment process*

Study inclusion criteria were (1) patients diagnosed with life-limiting disease, (2) fluent in the German language, (3) 18 years of age or older and (4) having at least one child younger than 18 years. Exclusion criterion was psychiatric impairment such as dementia, psychosis, severe depression or diagnosed personality disorder.

In 2017, the patient recruitment began at a clinic in Bonn, Germany. Initially, participants who meet the study inclusion criteria were recruited by a social worker, a nurse or a psycho-oncologist with research training. As the main aim of the project is to create an audiobook for bereaved children, it quickly attracted considerable media attention, leading to patients in North Rhine-Westphalia approaching the project group and asking to be involved. Consequently, the sampling is non-representative and purposive, with a high degree of self-selection bias. Inclusion criteria were checked by two researchers. Patients were enrolled after giving written informed consent and were asked signing a self-disclosure form about their medical history.

### *Data collection methods and research design*

All participants were asked about their state of health to determine whether the interview could take place before the question about the MiL was asked. In this pilot study, SMiLE was assessed twice per respondent: before and after the audiobook recording. Although it is a longitudinal study, only the data from the first SMiLE assessment (pre-intervention) is analysed and compared in this study, as the first responses as well as the intervention may influence the response behaviour in the second SMiLE assessment. Additionally, the first survey corresponds to an uninfluenced response behaviour in palliative patients, as it was elicited by Fegg *et al.* in their cross-sectional study.<sup>14</sup> Participants were interviewed by an experienced biographical researcher and a physician specialist in palliative care (one

physician and one psycho-oncologist). All data were collected in a standardized way administering the accuracy of the study protocol. We followed the standardized test instructions given by the authors of the SMiLE.<sup>11,15</sup> The form of assessment changed during the project from face-to-face interviews to telephone contact due to Covid-19 restrictions.

For all patients and researchers, psychological counselling was offered to address issues of emotional distress, fear, anger or other emotions. None of the interviewed patients was treated by members of the recruitment or interviewer team.

### *Measure*

The SMiLE was used as a paper-pencil test. In SMiLE, the participants indicate areas that provide meaning to their lives in their current situation. The participants nominate individual items from three to seven areas ( $n$  = number of areas), but this is only a suggestion (participants are free to name more areas). In a second step (level of satisfaction), participants rate the current level of satisfaction with each area ( $s_1$ . . .  $s_n$ ) on a scale ranging from ‘-3 very unsatisfied’ to ‘+3 very satisfied’. Finally, the importance of each area ( $w_1$ . . .  $w_n$ ) is rated with an eight-point adjective scale, ranging from ‘0 = not important’ to ‘7 = extremely important’ with ‘3 = important’ and ‘6 = very important’. So, We used the three questions from a protocol on the website of Fegg<sup>15</sup> and discussed upcoming questions by email:

1. ‘Please nominate 3–7 areas that give meaning to your life, regardless of how satisfied or unsatisfied you are with these areas at the moment. The order of your answers is not important’.
2. ‘Please rate how satisfied or unsatisfied you are with each nominated area. That is, how much – positively or negatively – the area affects your total meaning in life’.
3. ‘Please rate how important each area is for your total meaning in life. Try to distinguish between the areas as best possible by considering all numbers’.<sup>15</sup>

In line with Feggs’ definitions of terms, open-ended responses were classified into their respective categories.<sup>16</sup> Several parents used family and children as synonymous. Following the advice of Fegg, we put both items in the category family.

### Analysis

First, two researchers assigned the items provided by the participants according to Fegg *et al.*'s coding scheme. In case of disagreement, the assignment was discussed in detail until agreement was reached.<sup>2</sup>

“Secondly, the Index of Satisfaction (IoS) indicates the mean satisfaction or dissatisfaction with the individual MiL areas (range 0-100, with higher scores reflecting higher satisfaction). To obtain a clear index varying from 0-100 the satisfaction ratings are recalculated ( $s'_i$ ). ‘Very satisfied’ ( $s_i = -3$ ) is set to  $s'_i = 0$  and ‘very satisfied’ ( $s_i = +3$ ) is set to  $s'_i = 100$ .”<sup>11,15</sup>

$$\text{IoS} = \frac{\sum_{i=1}^n s'_i}{n}$$

Third, “the Index of Weighting (IoW) indicates the mean weighting of MiL areas (range 0-100, with higher scores reflecting higher weights).”

$$\text{IoW} = \frac{\sum_{i=1}^n w_i}{n} \cdot 100$$

Finally, “in the total SMiLE index (Index of Weighted Satisfaction; IoWS), the ratings for importance and satisfaction are combined (range 0-100, with higher scores reflecting higher MiL).”

$$\text{IoWS} = \sum_{i=1}^n \left( \frac{w_i}{w_{ges}} \cdot s'_i \right)$$

Levels and weight assigned to particular areas are independent and can change independently. A person may be satisfied in a particular area but assign little importance to it. Other areas may be described at a high level of both importance and satisfaction. An area that is going worse but of little importance will have less implication for the individual MiL. A very important area that is going badly has a higher impact on the person. This impact is reflected in the IoWS.<sup>11,15</sup>

Considering the findings of Tomás-Sábado *et al.*<sup>17</sup> regarding country-specific group differences between Spanish, German and Swiss palliative care patients, we compare our data with that of patients in the same condition collected by Fegg *et al.* Both populations are diagnosed with a serious life-threatening disease and are surveyed in Germany.<sup>14</sup> One of the aims was to examine how the groups differ in the priorities they set and the meaning they give to life. Therefore, distributions

were presented and discussed. For the strength of a significant association for two categorical variables, we calculated Phi as a coefficient in a  $2 \times 2$  contingency table. The data were organized and analysed using SPSS version 26, a statistical analysis program. Additionally, unpaired *T* tests with a significance level of 0.05 were calculated for IoW, IoS and IoWS indices to identify differences and similarities between the groups.

### Results

Our survey was carried out between February 2017 and September 2020. Fifty-eight patients signed an informed consent and four patients dropped out due to death. The remaining respondents were not representative as they were largely self-selected. Finally, 54 terminally ill parent with minor children completed the SMiLE questionnaire at least once, 13 men and 41 women. The average age was 43. Most of them were married ( $n=45$ ), seven divorced and two single. Apart from four, all other participants were diagnosed with cancer (see Table 1).

One hundred patients in palliative care were surveyed between 2005 and 2007 in the study by Fegg *et al.* Most patients were at least 50 years old ( $n=86$ ) and had been diagnosed with cancer ( $n=83$ ). Half of the patients were male and 69 were married or lived in a partnership (see Table 1).

#### SMiLE – Descriptive comparison between groups

Figure 1 illustrates that family is highly important for all terminally ill parent and 80% of palliative care patients. Partner or partnership is mentioned separately by 30% of terminally ill parent and 50% of palliative care patients. There are also large differences in the proportions for social relationships, with 80% of terminally ill parent and 43% of palliative care patients, as well as minor differences in the importance of leisure time, which is mentioned by 61% of terminally ill parent compared to 55% of palliative care patients. Further differences between these groups exist in the areas of religion/spirituality (11% of terminally ill parent and respectively 28% of palliative care patients), finances (0% and 6%, respectively), home/gardening (30% and 14%, respectively). Health as meaningful in life is mentioned by 4% of terminally ill parent and 31% of palliative care patients. There were no differences

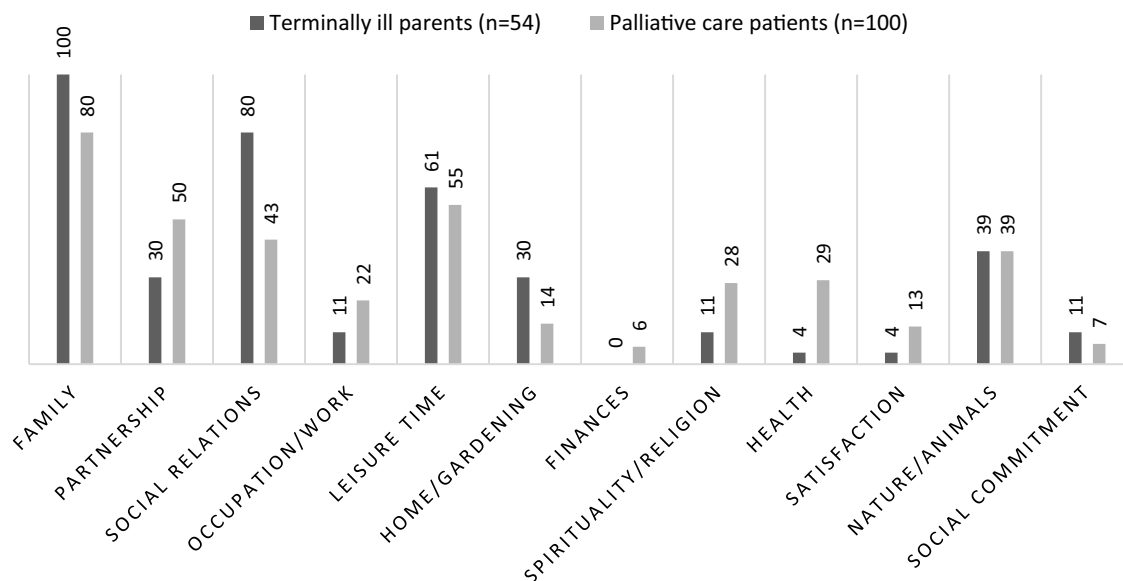
**Table 1.** Sociodemographic characteristics of terminally ill parents with minor children.

Sociodemographic characteristics	Terminally ill patients with minor children (2017–2020) <sup>a</sup>	Palliative care patients (Fegg <i>et al.</i> 2005–2007) <sup>b</sup>
Disease		
Cancer	50	83
Non-cancer	4	16
Gender		
Men (mean age ± standard deviation)	13 (44 years ± 7 years)	49 (not available)
Woman (mean age ± standard deviation)	42 (42 years ± 6 years)	51 (not available)
Age groups		
49 years and younger	51	14
At least 50 years	3	86
Marital status		
Married/living with a partner	45	69
Divorced	7	12
Single parent	2	13
Widowed		6
Total number of children (median age)	96 (7 years) One outlier: 27-year-old with disability	NA
<i>n</i>	54	100
<sup>a</sup> Terminally ill parents with minor children, own data, <i>n</i> = 54. <sup>b</sup> Palliative care patients, data from Fegg <i>et al.</i> Survey, <i>n</i> = 100. <sup>14</sup> NA, not available.		

between the two (39% each) in the nature/animals category.

The differences between the participant groups are significant and very strongly correlated with family ( $\Phi = -0.333$ ;  $p = 0.000$ ), social relationship ( $\Phi = -0.380$ ;  $p = 0.000$ ) or health ( $\Phi = 0.337$ ;  $p = 0.000$ ). For partnership ( $\Phi = 0.204$ ;  $p = 0.004$ ), occupation/work ( $\Phi = 0.148$ ;  $p = 0.036$ ), home/gardening ( $\Phi = -0.193$ ;  $p = 0.006$ ), finances ( $\Phi = 0.176$ ;  $p = 0.013$ ), spirituality/religion ( $\Phi = 0.215$ ;  $p = 0.002$ ) or satisfaction ( $\Phi = 0.161$ ;  $p = 0.022$ ), the differences between these groups are also significant and strongly correlated. These differences are not readily obvious from the following total scores of IoW, IoS and IoWS (Table 1).

A comparison of SMiLE scores shows similarities between groups (Table 2). Even though the SMiLE scores for the group in need of palliative care are very close to each other, there are also differences in the frequencies of individual listed MiL categories (Figure 1). Overall, we see satisfaction scores are smaller in parents with young children and palliative care patients than in representative samples. The satisfaction category is smaller in parents with young children (3.7%) compared to palliative care parents (5.3%). This might be due to concentration on the children and deny of selfish needs. The results of the independent *T* test analysis indicate that the differences were not significant for IoW [ $t(152) = 1.6128$ ,  $p = 0.1089$ ], IoS [ $t(152) = 0.3550$ ,  $p = 0.7231$ ] and IoWS [ $t(152) = 0.1179$ ,  $p = 0.9063$ ] between



**Figure 1.** Comparison between terminally ill with parents with minor children and palliative care patients (%). Black bars=terminally ill parents with minor children, own data,  $n = 54$ ; grey bars=palliative care patients, data from Fegg et al. Survey,  $n = 100$ .<sup>14</sup>

**Table 2.** Comparison of means  $\pm$  standard deviations ( $m \pm SD$ ) of SMiLE scores.

	IoW	IoS	IoWS
Terminally ill parent with minor children <sup>a</sup> ( $m \pm SD$ )	81.5 $\pm$ 12.2	71.4 $\pm$ 20.6	72.4 $\pm$ 21.3
Palliative care patients <sup>b</sup> ( $m \pm SD$ )	84.7 $\pm$ 11.5	70.2 $\pm$ 19.7	72 $\pm$ 19.4

To facilitate comparison, all indices were standardised and range from 0 to 100. (0=low to 100=high). IoW= Index of Weighting (IoW) indicates the mean weighting of Meaning in Life domains; IoS= Index of Satisfaction (IoS) mean satisfaction or dissatisfaction with the individual MiL indicates; IoWS= Index of Weighted Satisfaction.


<sup>a</sup>Terminally ill parents with minor children, own data,  $n = 54$ .

<sup>b</sup>Palliative care patients, data from Fegg et al. Survey,  $n = 100$ .

terminally ill patients with minor children and palliative care patients.

Having a proactive conversation about the MiL led terminally ill parents to reflect and make spontaneous statements, which were recorded in writing. The analysis of field notes taken during

the evaluation of the SMiLE showed a new awareness of resources as well as high level of satisfaction with their role as father or mother. A majority of parents found MiL in spending quality time (social relations; leisure time; home/garden; nature/animals) with their children. The present-ing quotes give a little insight:



*'It brought to my mind that I used to have a lot of creativity and now I have a number of projects and ideas'. (R77-PS)*

*'I hang around all day not able to play or cavort with my child'. (S27-00)*

*'Cars are my passion and I will not be able to teach and share this with my son'. (L31-JG)*

Source: Field notes, own data,  $n = 54$ .

## Discussion

Biographical interventions have been studied as an initial therapy for seriously ill patients.<sup>4-6,12,13</sup> The 'Schedule of Meaning in Life' by Fegg *et al.* is a validated questionnaire that uses case-based domains to initiate conversations about the different areas of MiL. This questionnaire can also be used to calculate statistical models and make comparisons between groups, such as our study population, terminally ill parents with minor children and the palliative care patients surveyed by Fegg *et al.* Both groups share the experience of being confronted with an incurable disease at an advanced stage of illness.

By examining specific areas related to different groups, patient-centred needs can be better addressed. This is particularly important as terminally ill parents of young children show significant differences from palliative care patients in terms of MiL. The paramount role of parenting seems to shift priorities to social and family life, spending time at home and in nature. The focus is on the young children and therefore partnership may not be mentioned as often as in palliative care or seen to be mentioned with the field family.

In their conclusions, Bernard *et al.* emphasize the clinical significance of incorporating the concept of MiL and the impact of MiL loss. The SMiLE scores of the inquired palliative care patients in Switzerland differ from those of the palliative care patients in Germany in terms of IoS and IoWS.<sup>10</sup> In a study comparing Spanish, German and Swiss palliative care patients, Tomás-Sábado *et al.*<sup>17</sup> used the SMiLE to elicit aspects of MiL. that similar levels of SMiLE scores did not necessarily correspond to patients' perceived areas of nor satisfaction with the aforementioned areas in their lives. Consequently, they also differ from our scores among terminally ill parents with minor children. However, these differences must be interpreted with caution, as they may be affected by a number of factors, including the composition of the sample, the size of the sample and/or other factors specific to origin, social as well as the individual.

Sprangers and Schwartz<sup>13</sup> described a change in values, a recalibration and a reconceptualization of the trajectory as a 'response shift'. Therefore, an interview guide can provide valuable insights into the domains of MiL, which can be used to develop comprehensive individual care plans.

The inclusion of MIL, which Bernard *et al.* considered a part of spirituality, is associated with a number of significant outcomes in the context of palliative care. These include a positive impact on quality of life, relief of anxiety and depression, suicidal ideation, a desire for hastened death or various physical symptoms. An assessment of the MIL can also assist in the identification of appropriate (short-term) intervention options.<sup>10</sup> From the field notes taken during the administration of SMiLE, we found evidence for this theory. In particular, the questions raised awareness of the gap between parents' self-expectations and the actual situation. Others were able to recall resources from earlier times and reactivate them.

In the context of care, SMiLE appears to be a good elicitation instrument for sorting and ranking patients' end-of-life priorities in clinical practice. Its use can save time, give a voice to the less talkative, be easily embedded in subsequent treatment plans and set processes in motion in a targeted way.

In our project, we gave terminally ill parents the opportunity to record their personal life stories in the form of an audiobook as a legacy for their children. In this way, they provide a self-authored reminiscence to be remembered as they wish beyond their own death. Guiding and actively developing interventions together as a measure of coping strategies helps patients, carers and health-care staff to perceive the situation of terminally ill parents with young children as less stressful.<sup>12</sup>

## Study limitations

Our sample was small and not representative. Small sample sizes effect confidence intervals and statistical power analysis. As awareness increased, the sample size could have been increased, which would have increased the statistical power, but our practical constraints, such as no funding, scarce staff resources and self-selection bias, did not allow this as voluntary enquiries predominated over time. In addition, the pilot study focused on the sensitive and time-consuming process of creating the audio book for the bereaved child(ren). Thus, the resource of time and the associated ethical responsibility to each individual participant outweighed the objective large sample size or large number of participants. Assignment to categories leaves room for interpretation though we discussed every single item in depth. It should also be noted that the comparison data is

with an earlier cohort in 2005–2007, as no new data is known to be available in Germany.

In addition to the limitations to the survey instrument listed by Fegg *et al.*<sup>11,14</sup> telephone interviews pose another challenge for this group.<sup>14</sup> The pandemic situation led to a change in study performance from face-to-face interviews to telephone calls and this might have influenced participants' answers. Interviews by telephone might have been exhausting for the participants with reduced performance status.

### Conclusion

The MiL domains relevant to terminally ill parents with minor children differed in the assessments given by patients receiving palliative care. The results suggest that assessing MiL is a coping strategy and helps to guide appropriate interventions for terminally ill parents with young children. The most important domain for MiL was family, which was mentioned most frequently by both groups.

### Declarations

#### Author's note

All methods were carried out following relevant guidelines and regulations such as COREQ (supplemental material),<sup>18</sup> GCP and the Declaration of Helsinki.

#### Ethics approval and consent to participate

The research ethics committee of the University Hospital Bonn reviewed and approved the study (no. 389/16). All participants have given written informed consent. For all patients and researchers psychological counselling was offered to address issues of emotional distress, fear, anger or other emotions.

#### Consent for publication

Not applicable.

#### Author contributions

**Henning Cuhls:** Conceptualization; Formal analysis; Investigation; Methodology; Project administration; Resources; Software; Supervision; Visualization; Writing – original draft; Writing – review & editing.

**Michaela Hesse:** Conceptualization; Formal analysis; Investigation; Methodology; Project

administration; Resources; Software; Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing.

**Gregory Heuser:** Formal analysis; Software; Writing – review & editing.

**Lukas Radbruch:** Conceptualization; Data curation; Methodology; Resources; Supervision; Writing – original draft; Writing – review & editing.

**Gülay Ateş:** Conceptualization; Formal analysis; Methodology; Software; Validation; Visualization; Writing – original draft; Writing – review & editing.

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#### Competing interests

The authors declare that there is no conflict of interest.

#### Availability of data and materials

The recorded datasets, transcripts and audiobooks are sensitive information and underlie the personality rights of the patients. We have written consent to use the material for this study, but we are not allowed to share this not blinded material publicly. Further Information can be obtained from the corresponding author on reasonable request.

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#### Supplemental material

Supplemental material for this article is available online.

#### References

1. Müller M, Pfister D and Markett S. Wie viel Tod verträgt das Team? *Der Schmerz* 2009; 23: 600–608.
2. Cuhls H, Hesse M, Ates G, *et al.* Audiobooks from terminally ill parent for their children: a qualitative evaluation. *BMC Palliat Care* 2021; 20: 172.



3. Stagg EK and Lazenby M. Best practices for the nonpharmacological treatment of depression at the end of life. *Am J Hosp Palliat Med* 2012; 29: 183–194.
4. Breitbart W, Rosenfeld B, Pessin H, *et al.* Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA* 2000; 284: 2907–2911.
5. Nelson CJ, Rosenfeld B, Breitbart W, *et al.* Spirituality, religion, and depression in the terminally ill. *Psychosomatics* 2002; 43: 213–220.
6. Park CL. Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events. *Psychol Bull* 2010; 136: 257–301.
7. Henry M, Cohen SR, Lee V, *et al.* The Meaning-Making intervention (MMi) appears to increase meaning in life in advanced ovarian cancer: a randomized controlled pilot study. *Psychooncology* 2010; 19: 1340–1347.
8. Lee V, Robin Cohen S, Edgar L, *et al.* Meaning-making intervention during breast or colorectal cancer treatment improves self-esteem, optimism, and self-efficacy. *Soc Sci Med* 2006; 62: 3133–3145.
9. Menn L, Corsten S, Lauer N, *et al.* The effectiveness of biographical approaches in long-term care: a systematic review. *Gerontologist* 2019; 60: e309–e328.
10. Bernard M, Berchtold A, Strasser F, *et al.* Meaning in life and quality of life: palliative care patients versus the general population. *BMJ Support Palliat Care* 2020; 0: 1–9. DOI: 10.1136/bmjspcare-2020-002211.
11. Fegg MJ, Kramer M, L’Hoste S, *et al.* The Schedule for Meaning in Life Evaluation (SMiLE): validation of a new instrument for meaning-in-life research. *J Pain Symptom Manage* 2008; 35: 356–364.
12. Hesse M, Forstmeier S, Mochamat M, *et al.* A review of biographical work in palliative care. *Indian J Palliat Care* 2019; 25: 445–454.
13. Sprangers MAG and Schwartz CE. Integrating response shift into health-related quality of life research: a theoretical model. *Soc Sci Med* 1999; 48: 1507–1515.
14. Fegg MJ, Brandstatter M, Kramer M, *et al.* Meaning in life in palliative care patients. *J Pain Symptom Manage* 2010; 40: 502–509.
15. Fegg MJ. Testmanual SMiLE (englisch), <https://www.psychotherapie-muenchen.de/forschung/lebessinn-smile/> (2024, accessed July 17).
16. Fegg M, Lehner M, Simon ST, *et al.* [What influences end-of-life decisions? Results of a representative German survey]. *Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz* 2015; 58: 1118–1123.
17. Tomás-Sábado J, Villavicencio-Chávez C, Monforte-Royo C, *et al.* What gives meaning in life to patients with advanced cancer? A comparison between Spanish, German, and Swiss patients. *J Pain Symptom Manage* 2015; 50: 861–866.
18. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007; 19: 349–357.

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