

Original Article

Meaning in Life in Palliative Care Patients

Martin Johannes Fegg, PhD, Monika Brandstätter, MA, Mechtild Kramer, MD,
Monika Kögler, MA, Sigrid Haarmann-Doetkotte, MA,
and Gian Domenico Borasio, MD

Interdisciplinary Center for Palliative Medicine, Ludwig-Maximilians-University, Munich, Germany

Abstract

Context. The construct “meaning in life” (MiL) has recently raised the interest of clinicians working in psycho-oncology and end-of-life care and has become a topic of scientific investigation.

Objectives. The aim of this study was to compare MiL in palliative care (PC) patients with a representative sample of the German population.

Methods. In this cross-sectional study, all PC patients treated in the PC inpatient unit and through the PC consult service at Ludwig-Maximilians-University Hospital, Munich, from May 2005 to July 2007 were eligible to participate. Patients were interviewed by a doctoral student, psychologist, or physician, all previously trained to administer the Schedule for Meaning in Life Evaluation (SMiLE) in a standardized way. In the SMiLE, respondents first list individual areas that provide meaning to their life before rating their current level of importance and satisfaction with each area. Overall indices of weighting (IoW, range 20–100), satisfaction (IoS, range 0–100), and weighted satisfaction (IoWS, range 0–100) are calculated.

Results. One hundred PC patients completed the SMiLE: the IoS was 70.2 ± 19.7 , the IoW was 84.7 ± 11.5 , and the IoWS was 72.0 ± 19.4 . The representative sample ($n = 977$) scored significantly higher in the IoS (82.8 ± 14.7) and IoWS (83.3 ± 14.8) but not in the IoW (85.6 ± 12.3). Compared with healthy individuals, PC patients are more likely to list partner, friends, leisure, spirituality, well-being, nature/animals, and pleasure as meaningful areas. Examining the satisfaction ratings, it is noteworthy that PC patients' satisfaction scores are fairly high (and not lower than their healthy counterparts') in a number of domains: family, partner, home/garden, spirituality, and finances. On the other hand, they score significantly lower in nature/animals, leisure, friends, well-being, altruism, work, pleasure, and health.

Conclusion. These findings underscore the potential of the SMiLE for identifying areas that are particularly important to individuals, and that can be targeted by the PC team to improve overall life satisfaction at the end of life. *J Pain Symptom Manage* 2010;40:502–509. © 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Address correspondence to: Martin Johannes Fegg, PhD, Interdisciplinary Center for Palliative Medicine, Ludwig-Maximilians-University, Marchioninistrasse

15, 81371 Munich, Germany. E-mail: martin@fegg.de

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Key Words

Meaning in life, Schedule for Meaning in Life Evaluation, SMiLE, palliative care, representative sample

Introduction

The main goal in palliative care (PC) is to assure the highest possible quality of life for patients with advanced diseases, where consequences of the illness often include considerable psychological, social, and spiritual suffering over and above the deteriorating physical health. Kelly et al.¹ differentiate between clinical syndromes such as depression, anxiety, and delirium, as well as broader psychological dimensions of suffering such as existential concerns, spirituality, hope, and demoralization. In a recent review, Chochinov² presents empirical data, therapeutic approaches to, and an examination of the conceptual correlates of spiritual or existential suffering. These include hopelessness, burden to others, loss of sense of dignity, and desire for death or loss of will to live. Such threats to psychological, social, and spiritual well-being have been linked to desire for hastened death.^{3,4} Therefore, interventions in end-of-life care have been aimed at increasing the feeling of dignity^{5,6} and meaning in patients' lives.⁷ The concept of "meaning in life" (MiL) especially has stimulated the interest of clinicians and researchers working in psycho-oncology and end-of-life care. Moadel et al.⁸ reported that 40% of surveyed cancer patients indicated a need for help in discovering meaning in their life. Despite the surge of recent research in MiL, the concept is not yet defined sufficiently. The Austrian psychiatrist Victor Frankl⁹ defined "meaning" as the manifestation of values, which are based on 1) creativity (e.g., work, actions, and dedication to causes), 2) experience (e.g., art, nature, humor, love, relationships, and roles), and 3) attitude (one's attitude toward suffering and existential problems). His logotherapy draws on one of his well-known statements that humans are able to cope with any suffering if they are able to find meaning in it.

Meraviglia¹⁰ classifies MiL as an outcome of spirituality. Jim et al.¹¹ differentiate overall MiL from "behaviors and circumstances that are frequently sources of meaning, such as personal

success, social relationships, and contributions to society." They also refer to Park and Folkman's¹² differentiation between global and situational meaning. Global meaning encompasses beliefs about the order of life or the universe as well as personal life goals and purpose, whereas situational meaning is said to refer to the interaction of a person's global beliefs and goals and the immediate circumstances of a particular person-environment transaction. In line with Frankl's⁹ and Meraviglia's¹⁰ views, university students stated that MiL was related to spirituality and self-transcendence for them, whereas quality of life reflected their current status of subjective well-being.¹³ This also corresponds to Ryan and Deci's¹⁴ conceptualization of two traditions in the study of well-being: the hedonistic view (i.e., happiness and pleasure) and the eudaimonic view (i.e., expression of virtue). A similar distinction is drawn by Keyes et al.,¹⁵ who equate these views to subjective vs. psychological well-being.

A great number of questionnaires have been developed to capture MiL. For the most part, however, they measure the intensity of meaning, but tend to neglect the content of the reported meanings, which can be expected to vary from person to person and from situation to situation.^{16,17} In the 1980s, DeVogler and Ebersole^{18,19} started to investigate, using a one-page essay, the most important source providing meaning to college students. Later, they asked adults to describe their three most important sources of meaning. Debats²⁰ additionally asked respondents to indicate the extent to which they are committed to their previously reported sources of MiL. The Schedule for Meaning in Life Evaluation (SMiLE) was specifically developed as an extension to this individualized procedure and asks respondents to indicate the satisfaction and importance of self-selected individual sources of MiL.¹³

Objectives

After validating the SMiLE with a student population both in Germany and Ireland,¹³

as well as evaluating MiL in a representative sample of the German population,²¹ the aim of this study was to investigate MiL in PC patients and compare it with representative data of the German population. More specifically, the study aimed 1) to evaluate and categorize individually important MiL areas in PC patients and 2) to examine differences between PC patients and a representative sample of the German population with regard to the extent of MiL experienced, as well as with regard to the categories of areas important for MiL.

Methods

Study Design

This study had a cross-sectional design. All PC patients treated in the PC inpatient unit and in the PC consult service at Ludwig-Maximilians-University Hospital, Munich, from May 2005 to July 2007 were eligible to participate. Because of personal resources, recruitment was interrupted from November 2005 to March 2006. The interviews were conducted by a doctoral student, two psychologists, and a physician previously trained to administer the SMiLE in a standardized manner. The nationwide representative sample of the German population was interviewed in July 2005 by the German Social Research Institute using computer-assisted telephone interviews as previously described.²¹

Participants

Patients were eligible if they were aged 18 years or older, showed no evidence of psychiatric disease or significant cognitive impairment, and had sufficient knowledge of the German language. Patients whose physical condition was judged by the PC physician as too poor were not included. The study was approved by the Research Ethic Committee of the University Hospital Munich, Germany, and only patients who provided informed consent were included.

The SMiLE

The SMiLE was developed to provide a validated assessment instrument for MiL in PC. The method is similar to the Schedule

for the Evaluation of Individual Quality of Life—Direct Weighting (SEIQoL-DW), an established instrument in quality-of-life research.²² However, compared with the SEIQoL-DW, the importance-rating procedure has been simplified, thus allowing for a varying number of meaning-providing areas. The SMiLE is an individualized measure of MiL developed in accordance with the recommendations of the Scientific Advisory Committee of the Medical Outcomes Trust.²³ Respondents are asked to list areas important for their MiL before rating the current level of importance of and satisfaction with each area. The importance of each area is rated on a 5-point scale, ranging from 1 “somewhat important” to 5 “extremely important.” The level of satisfaction with each area is rated on a 7-point Likert scale, ranging from –3 “very unsatisfied” to +3 “very satisfied.”

The index of weighting (IoW) indicates the mean weighting of the MiL areas (range 20–100). The index of satisfaction (IoS) indicates the mean satisfaction with the individual MiL areas (range 0–100). In the overall SMiLE index (index of weighted satisfaction, IoWS), the ratings for importance and satisfaction are combined (range 0–100) to yield a weighted satisfaction score. Calculation of indices is reported in detail elsewhere.²¹ An English version of the SMiLE questionnaire and the corresponding Statistical Package for Social Sciences (SPSS) data matrix and syntax can be requested from the first author.

The psychometric properties of the SMiLE were evaluated previously with university students, PC patients, and cancer patients, showing good convergent and discriminant validity as well as test-retest reliability. Patient acceptance was very high.^{13,24} In the representative sample of the German population, the areas of MiL listed were subsumed under 13 categories established by binary cluster analyses.²¹

Statistical Analysis

Student's *t*-test was used to compare the number of MiL areas listed in each group. Linear model regression analyses were performed to test for differences in satisfaction and importance ratings of each MiL area as well as in the outcome scores (IoS, IoW, and IoWS) between PC patients and the representative German sample. To identify differences in

the likelihood of listing a specific MiL area, binary logistic regression analyses were performed. For both analyses, sociodemographic characteristics (age, gender, marital status, and education) were entered into the model as potentially confounding variables. For the analyses of differences in the likelihood to name a specific MiL area, the number of remaining areas named by each participant was entered into each regression as an additional covariate to control for differences in the number of listed areas. Thus, it was possible to evaluate whether group membership (PC patient vs. representative population) explained variance over and above these other parameters. For all regression analyses, the unstandardized regression coefficient (B) for the group variable and its respective P -value are presented. Additionally, for the linear regressions, the total explained variance (R^2) is given. For the binary logistic regression analyses, the odds ratio for the group variable $\text{Exp}(B)$ along with its confidence interval is presented.

For all analyses, Bonferroni corrections were used. Differences were considered to be statistically significant at $P < 0.05$ for single comparisons and on the respective adjusted level for the multiple comparisons. Statistical tests were performed with SPSS version 15.0.1 (SPSS Inc., Chicago, IL).

Results

Participation in the Study

From May to October 2005, a total of 91 patients were treated in the PC ward, of which 28 were included in the study (inclusion rate, 31%). An additional 22 patients were recruited via convenience sampling through the PC consult service. From April 2006 to July 2007, a total of 301 patients were treated on the PC ward; 50.5% of these patients were deemed unable to participate because of physical weakness, 8.6% because of cognitive disability, and 9.3% could not be approached because of language barriers or hearing/speaking problems. Of the remaining 95 patients, 50 agreed to participate (response rate, 53%).

Respondents' Characteristics

Table 1 provides an overview of the respondents' characteristics both in the PC group and in the representative comparison sample of the

Table 1
Respondents' Characteristics of PC Patients ($n = 100$) and the Representative Sample of the German Population ($n = 977$)

Demographics	PC Patients, %	Representative Sample, %
Age, years		
16–19	—	7.0
20–29	1	18.7
30–39	3	22.0
40–49	10	20.2
50–59	27	13.4
60–69	33	11.8
>70	26	7.0
Gender		
Male	49	42.7
Female	51	57.3
Marital status		
Single	13	35.5
Married	69	48.3
Divorced/separated	12	10.3
Widowed	6	5.6
Education		
Elementary school	38	24.2
Secondary school	33	36.3
High school/university	29	39.5

German population. The PC patients suffered from gastrointestinal cancer (35%), cancer of the genitourinary tract (15%), breast cancer (12%), brain/neurological tumors (11%), cancer of the respiratory system (10%), amyotrophic lateral sclerosis (3%), and other neoplastic disorders (14%).

MiL in PC Patients Compared with a Representative Sample

Table 2 shows descriptive statistics of the SMiLE indices and the linear regression results examining differences in these indices when controlling for sociodemographic variables. In the PC sample, 5.3 ± 1.6 areas of MiL were listed. In the representative sample, 3.8 ± 1.4 areas of MiL were listed ($t = -8.3$; $P < 0.001$).

Categories of MiL

Respondents in the PC sample listed a total of 525 statements regarding the MiL areas important to them. These listings were assigned to 13 categories derived from the representative analyses.²¹ Table 3 presents percentages of participants in both samples who named MiL areas in the respective category, along with the means and standard deviations of satisfaction and importance ratings. It also gives an overview of significant differences in the

Table 2
Linear Regression Model Predicting IoW, IoS, and IoWS

SMiLE Indices	PC Patients (<i>n</i> = 100), M ± SD	Representative Sample (<i>n</i> = 977), M ± SD	Total <i>R</i> ²	<i>B</i>	<i>P</i>
IoW	84.7 ± 11.5	85.6 ± 12.3	0.04	−1.5	0.27
IoS	70.2 ± 19.7	82.8 ± 14.7	0.07	−13.3	<0.001
IoWS	72.0 ± 19.4	83.3 ± 14.8	0.06	−12.0	<0.001

Linear regression model predicting IoW, IoS, and IoWS from group membership (PC patients vs. representative sample) controlled for sociodemographic variables (age, gender, marital status, and education). Bonferroni correction: *P* < 0.017 is significant. M = mean; SD = standard deviation.

frequency of the MiL areas listed. Compared with the representative sample of the German population, PC patients more often listed partner, friends, leisure, spirituality, well-being (comprising balance, harmony, happiness, and satisfaction), nature, and pleasure (comprising enjoying live, having fun, enjoyment, hedonism, and vitality).

Satisfaction with MiL Areas

Compared with a representative sample of the German population, PC patients showed lower satisfaction in friends, work, leisure, health, nature, pleasure, well-being, and altruism (see Table 4).

Importance of MiL Areas

Importance ratings of PC patients in MiL areas did not differ from ratings of the representative sample of the German population (see Table 4).

Discussion

This study is a comprehensive evaluation of MiL in PC patients with a previously developed respondent-generated instrument, the SMiLE.¹³ It comprises a comparison of MiL experienced by PC patients in end-of-life care with data from a nationwide survey.²¹

The categories mentioned most often by PC patients (in descending order) were family (80%), leisure (55%), partner (50%), friends (43%), and nature (39%). Patients were most satisfied with family, partner, spirituality, friends, and home/garden and least satisfied with health, pleasure, and work. Overall, the importance ratings of the listed MiL areas were high; most important were family, partner, health, and spirituality.

Compared with a study with cancer patients, the frequencies are similar. The satisfaction ratings of PC patients, however, showed a

Table 3
Areas of MiL

Areas of MiL	PC Patients (<i>n</i> = 100)		Representative Sample (<i>n</i> = 977)			Binary-Logistic Regression (<i>n</i> = 1017)					
	%	M ± SD	W	%	M ± SD	W	Confidence Interval Exp(<i>B</i>)				
							Exp(<i>B</i>)	Low	High	<i>B</i>	<i>P</i>
Family	80	2.6 ± .9	4.8 ± .5	83.3	2.3 ± 1.0	4.8 ± .7	1.25	0.67	2.32	0.22	0.48
Leisure	55	0.2 ± 1.9	3.7 ± .8	36.2	1.7 ± 1.2	3.5 ± 1.0	2.17	1.34	3.50	0.77	0.002
Partner	50	2.1 ± 1.5	4.7 ± .9	26.9	2.3 ± 1.1	4.7 ± .6	5.13	3.09	8.50	1.63	0.000
Friends	43	1.6 ± 1.6	3.8 ± 1.0	40.4	2.2 ± .9	4.3 ± .8	2.23	1.37	3.65	0.80	0.001
Nature/ animals	39	0.9 ± 2.0	4.1 ± 1.0	8.3	2.4 ± .9	4.2 ± .8	7.0	3.90	12.52	1.95	0.000
Health	29	−1.4 ± 2.1	4.7 ± .5	30.0	1.8 ± 1.5	4.8 ± .6	1.03	0.60	1.75	0.03	0.92
Spirituality	28	1.8 ± 1.7	4.4 ± .9	7.2	2.4 ± .8	4.4 ± .9	3.28	1.77	6.09	1.19	0.000
Work	22	−0.3 ± 2.1	3.9 ± .8	56.2	1.4 ± 1.6	3.9 ± .9	0.57	0.32	1.03	−0.57	0.06
Home/garden	14	1.4 ± 1.8	3.9 ± 1.1	6.9	2.0 ± 1.2	3.6 ± 1.0	1.66	0.79	3.49	0.51	0.18
Pleasure	14	−0.9 ± 1.5	4.0 ± .6	3.8	1.8 ± 1.4	4.1 ± .9	4.16	1.82	9.49	1.43	0.001
Well-being	13	0.8 ± 2.0	4.3 ± .8	4.1	1.7 ± 1.3	4.3 ± .9	5.38	2.27	12.76	1.68	0.000
Altruism	7	−0.04 ± 1.4	3.5 ± 1.2	3.8	2.0 ± 1.0	3.8 ± .8	1.38	0.53	3.58	0.32	0.51
Finances	6	1.0 ± 2.1	3.9 ± .9	13.4	0.9 ± 1.8	3.6 ± 1.0	0.53	0.21	1.32	−0.64	0.17

Percentage of respondents listing each category, means (M) and standard deviations (SD) of the satisfaction (S, range −3 to +3), and importance ratings (W, range 1–5).

The last five columns show results of the binary logistic regression model predicting listing of specific MiL areas from group membership (PC patients vs. representative sample) controlled for sociodemographic variables (age, gender, marital status, and education) and number of remaining MiL areas. Bonferroni correction: *P* < 0.004 is significant.

Table 4
Linear Regression Model Predicting Satisfaction and Importance Ratings

MiL Category	Satisfaction			Importance		
	Total R^2	B	P	Total R^2	B	P
Family	0.06	0.13	0.27	0.02	0.02	0.82
Leisure	0.15	-1.40	0.000	0.03	0.10	0.52
Partner	-0.32	0.04	0.15	0.02	-0.01	0.92
Friends	0.03	-0.59	0.002	0.09	-0.28	0.04
Nature/animals	0.23	-1.35	0.000	0.18	0.05	0.79
Health	0.29	-3.20	0.000	0.07	-0.10	0.36
Spirituality	0.10	-0.61	0.04	0.05	-0.17	0.45
Work	0.06	-1.56	0.000	0.03	-0.14	0.50
Home/garden	0.08	-0.77	0.06	0.08	0.06	0.87
Pleasure	0.50	-2.99	0.000	0.10	-0.10	0.76
Well-being	0.28	-1.68	0.003	0.25	-0.30	0.32
Altruism	0.43	-1.72	0.001	0.24	-0.48	0.20
Finances	0.13	-0.02	0.99	0.02	0.17	0.69

Linear regression model predicting satisfaction and importance ratings from group membership (PC patients vs. representative sample) controlled for sociodemographic variables (age, gender, marital status, and education) ($n = 1017$). Bonferroni correction: $P < 0.004$ is significant.

wider range. This range also included negative values, indicating dissatisfaction.²⁴

Compared with the general population, PC patients are more likely to list partner, spirituality, nature/animals, friends, leisure, well-being, and pleasure. These findings were controlled for sociodemographic variables (age, gender, marital status, and education) because a nationwide study has shown that sociodemographic variables significantly influence the respondents' MiL.²¹

Compared with the representative sample, PC patients listed significantly more MiL-relevant areas. This could be because of meaning-based coping processes after the diagnosis of an incurable disease.^{12,25} Additionally, it also could be biased because of different interview strategies (face-to-face with PC patients, telephone with the nationwide sample). Therefore, the remaining numbers of listed MiL areas were controlled for in the regression model.

Examining the satisfaction ratings of specific areas, it is noteworthy that PC patients' satisfaction scores are fairly high (and no lower than their healthy counterparts') in a number of domains: these are family, partner, home, spirituality, and finances. On the other hand, PC patients score significantly lower in the areas of nature/animals, leisure, friends, well-being, altruism, work, pleasure, and health. In these last four areas, the PC patients' score averages in the negative. Some patients reported that they had problems maintaining friendships during the progress of their disease. The decreasing health status and the

inability to work and pursue their leisure activities as well as being in nature/with animals may explain the decreased satisfaction in these areas. The dissatisfaction with pleasure calls for psychosocial interventions to improve overall quality of life at the end of life.

With regard to the overall indices, PC patients scored lower in the IoS and IoWS, although their means remain quite high. This result could be explained by a "response shift" occurring when adapting to severe illness. Response shift is defined as a change in the meaning of one's self-evaluation of a target construct as a result of one of three reasons: 1) a change in the respondent's internal standards of measurement (termed "scale recalibration"), 2) a change in the respondent's values (i.e., the importance of component domains constituting the target construct), and 3) a redefinition of the target construct (i.e., reconceptualization).²⁶ With regard to the importance ratings, no significant differences were found. This might be influenced by the respondent-generated nature of the SMiLE: respondents tend to list areas of MiL that per se are important for them. However, this could also be because of a ceiling effect in the importance scale. A broader range (e.g., from 0 to 7) could help patients to differentiate more between the importances of the listed areas.^{27,28}

MiL assessed with the SMiLE reflects different components of MiL: the areas listed by a patient provide the framework of where an individual finds meaning (reflected in the importance ratings). This seems to be an aspect

of MiL that is sustained in the PC situation. Where PC patients encounter problems, however, is the fulfillment aspect of MiL. This aspect, reflected in the diminished satisfaction ratings in certain domains, is where patients suffer from loss of meaning, and interventions are needed. These two aspects of meaning assessed by the SMiLE are consistent with Wong and Fry's model of MiL,²⁹ which consists of both a cognitive/motivational (framework) and an affective (fulfillment) component.

This study has several limitations. The respondent-generated listings were assigned to a priori categories. It is possible that not all listings were identified correctly. For further understanding, it will be helpful to obtain in-depth descriptions of what is meant by the cue labels, for example, using qualitative research designs.¹⁶ In addition, interrater training and reliability testing should be included as a standard in future studies with the SMiLE.

To sum up the findings of potential clinical interest, close relationships (partner and friends) are named 2.2–5.1 times more often as meaning-relevant areas by PC patients. Furthermore, leisure activities (2.2 times), pleasure (4.2 times), and well-being (5.4 times) are mentioned much more frequently as meaningful areas in the PC patient group. About one-third of the patients name spirituality and nature experience/animals as especially meaningful areas. The likelihood of these areas being important with respect to MiL is 3.3 (spirituality) and 7.0 (nature experience/animals) times higher for PC patients than for the representative sample. This draws attention to professional spiritual care as a necessary component of end-of-life care. For patients with nature/animals as a meaning-relevant area, assisted drives in the garden or balcony of a PC ward might be offered.

Psychological and meaning-enhancing interventions have been shown to be helpful to improve PC patients' well-being at the end of life and to prevent wishes for euthanasia.^{3,4,7} The SMiLE might be a useful tool for such interventions, not only as an outcome measure but also as a clinical screening tool. The SMiLE might assist in identifying areas that are important for patients but where they lack satisfaction. As such, it could help targeting resources at the problematic areas of MiL and thus assist in tailoring the care offered

by the PC team to the needs of each individual patient.

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