Support Care Cancer (2014) 22:1391–1399
DOI 10.1007/s00520-013-2099-6

ORIGINAL ARTICLE

Experience of meaning in life in bereaved informal caregivers of palliative care patients

Monika Brandstätter · Monika Kögler · Urs Baumann · Veronika Fensterer · Helmut Küchenhoff · Gian Domenico Borasio · Martin Johannes Fegg

Received: 20 April 2013 / Accepted: 5 December 2013 / Published online: 3 January 2014

Abstract

Purpose Providing care for terminally ill family members places an enormous burden on informal caregivers. Meaning in life (MiL) may be a protective factor, but is jeopardised in caregiving and bereavement. This study evaluates the following questions: To what extent do bereaved informal caregivers of palliative care (PC) patients experience meaning in their lives? What differences emerge in carers compared to the general German population? How does MiL relate to well-being in former caregivers?

Methods Eighty-four bereaved PC caregivers completed the Schedule for Meaning in Life Evaluation, the Brief Symptom Inventory, the WHOQOL-BREF, a single-item numerical rating scale of quality of life, and the Satisfaction with Life Scale. The experience of MiL of bereaved caregivers was compared to a representative population sample ($n=977$).

Results The overall MiL fulfillment of bereaved caregivers (69 % female, age 55.5±12.9 years) was significantly lower than in the general population (68.5±19.2 vs. 83.3±14, $p<.001$), as was the overall importance ascribed to their meaning framework (76.6±13.6 vs. 85.6±12.3, $p<.001$). PC caregivers are far more likely to list friends, leisure, nature/animals, and altruism. Higher MiL was correlated with better life satisfaction and quality of life.

Conclusion Coping with the loss of a loved one is associated with changes in MiL framework and considerably impairs a carer's experience of MiL fulfillment. Individual MiL is associated with well-being in PC caregivers during early bereavement. Specific interventions for carers targeted at meaning reconstruction during palliative care and bereavement are needed to help individuals regain a sense of meaning and purpose.

Keywords Meaning in life · Idiographic outcome measure · SMiLE · Palliative care · Informal caregivers · Bereavement

Introduction

Informal caregivers provide an enormous amount of care to ill family members, often at a considerable cost to their own well-being [1–3]. The point prevalence of clinically relevant psychological distress in individuals providing care to family members at the end of life is about 30 %; most frequent are depression and anxiety [4]. Informal caregivers of palliative care (PC) patients often report equivalent or even higher levels of burden than the patients themselves [3]. The burden of caregivers in the final phase of their relative's life and in early bereavement is comparable [5]. In palliative care, family caregivers are also care recipients—they are an integral part of the unit of care [6]. While there is abundant research about the needs and burden of caregivers, there is a dearth of information about conceptual models for preventive approaches and effective interventions [2, 3, 7, 8]. Reviews about existing interventions criticise the lack of stringent designs and many interventions show only small or no effects [9–11].

In the treatment of palliative patients, clinicians and researchers have recognised that existential concerns are just as

M. Brandstätter (✉) · M. Kögler · M. J. Fegg
Department of Palliative Medicine, Ludwig-Maximilians-University, Marchioninistrasse 15, 81377 Munich, Germany
e-mail: monika_brandstaetter@hotmail.com

U. Baumann
Department of Psychology, University of Salzburg, Salzburg, Austria

V. Fensterer · H. Küchenhoff
Statistical Consulting Unit, Department of Statistics, Ludwig-Maximilians-University, Munich, Germany

G. D. Borasio
Centre Hospitalier Universitaire Vaudois, Service de Soins Palliatifs, University of Lausanne, Lausanne, Switzerland

important to address as well-known clinical syndromes such as depression or anxiety [12, 13]. Newer interventions in end-of-life care have been aimed at increasing the feeling of dignity [14] and meaning in patients' lives [15–17]; however, they have mostly neglected promotion of meaning in life (MiL) in relatives and caregivers so far.

MiL is related to well-being in the general population [18, 19], as well as in samples of caregivers [20, 21], and the bereaved [22, 23]. MiL has been defined as "the cognizance of order, coherence, and purpose in one's existence, the pursuit and attainment of worthwhile goals, and an accompanying sense of fulfillment" ([24], p. 41); thus, it comprises a cognitive and a motivational component (providing a *framework* for meaning), and an emotional component (*fulfillment*). A large number of questionnaires have been developed to assess the various aspects of MiL [25]. Idiographic MiL measures assess the subjective meaning a person experiences by allowing them to list applicable meaning areas [25].

Meaning making [26, 27] and finding meaning through caregiving [28–30] reflect coping strategies used when faced with adverse events [31, 32] and must be differentiated from general MiL. The latter can be conceptualised as "meanings-made" [31]; thus, MiL can reflect an outcome of the aforementioned coping strategies. Several studies have examined general MiL in the context of caregiving and bereavement. The experience of MiL may be a buffering mechanism against negative outcomes in caregiving [21] and in bereavement [23, 33]. Higher MiL was associated with better health in spousal caregivers of patients with advanced cancer [21]. Widows were shown to have higher MiL than psychiatric patients, but lower MiL than a mixed sample of healthy adults and non-psychiatric patients [34]. In grieving parents, higher MiL was related to less grief [33]. In newer studies, perceiving one's life as worth living was associated with lower burden in caregivers of disabled elderly [35]. MiL significantly predicted psychological well-being in older adults after spousal loss, even after controlling for social support and physical health [22]. These studies were restricted to investigate the relationship between MiL *fulfillment* and caregiver well-being. However, no studies have reported on how the *framework* for MiL in bereaved family carers differs from other populations.

The objective of this study is to explore MiL in bereaved caregivers and compare it to a representative population sample [36]. Using the individual assessment afforded by the Schedule for Meaning in Life Evaluation (SMiLE; [37]), we explore the extent to which bereaved caregivers experience *fulfillment* of MiL, as well as look at how they construct their MiL *framework* (number and type of listed MiL sources; ascribed importance). Additionally, we investigate how MiL fulfillment relates to quality of life and psychological distress in bereaved carers.

Methods

Study design

Participants were informal carers of PC patients who agreed to take part in a randomised supportive group intervention trial [38]. They were recruited from two palliative care wards and a radiooncology department in Munich, and completed a battery of self-report questionnaires including the ones used in this study. Questionnaires were either mailed or handed out in person and were completed by respondents on their own. To preclude intervention influences, respondents completed self-report questionnaires before the intervention started. At this point, 70 % of the randomised controlled trial participants were bereaved. To achieve reasonable sample homogeneity, only data from the bereaved subgroup are reported. This group's MiL is compared to MiL data from a German nationwide representative sample, gathered via computer-assisted telephone interviews [36]. The study has been approved by the Research Ethics Committee of the University Hospital Munich, Germany (project no. 120-06).

Measures

MiL was assessed with the SMiLE [37]. Respondents list up to seven areas relevant for their MiL, and rate their current level of satisfaction (−3 to +3) and importance of each area (0–7). From the importance ratings, an overall index of weighting is calculated (IoW, 0–100), the satisfaction ratings yield a total index of satisfaction (IoS, 0–100) and a combination of the importance and satisfaction ratings yields the overall index of weighted satisfaction (IoWS, 0–100). In contrast to previous publications [36, 39, 40], an 8-point Likert scale was introduced for the importance ratings to avoid ceiling effects (previously 5-point) [39]. Importance ratings of the previously assessed representative sample were transformed using proportional transformations [41]. Furthermore, to control for individual differences in response scale use, we calculated relative importance ratings following an established method from personal values research [42]. MiL areas were subsumed under 13 categories found in earlier studies [36, 37]. Satisfaction ratings (overall and by content category) indicate the extent of MiL *fulfillment* an individual experiences, while the content of listed MiL areas, the overall index of weighting and the relative importance ratings reflect a person's individual construction of MiL *framework*. The SMiLE has shown satisfactory psychometric properties (retest reliability, convergent and discriminant validity) [37].

Psychological distress was assessed with the Global Severity Index of the 53-item Brief Symptom Inventory [43]. Raw scores were converted into gender-adjusted *T* values (mean=50, SD=10). Quality of life was assessed with the 26-item WHOQOL-BREF [44], which comprises four dimensions:

physical, psychological, social and environmental quality of life. An overall score (0–100) was used in this study. Additionally, overall quality of life was assessed using a single item numerical rating scale (NRS, 0–10; "How do you rate your quality of life at the moment"). Life satisfaction was assessed using the five-item Satisfaction with Life Scale (SWLS, 1–7) [45].

Statistical analysis

Separate linear regression model analyses were used to test for group differences in MiL between PC caregivers and the representative sample. All analyses were controlled for gender and age (categorical, up to 19, 20–29, 30–39, etc.). Loglinear quasi-Poisson regression analyses were applied to test for differences in the number of listed MiL areas. Binary logistic regression analyses were performed to identify differences in the likelihood of listing a specific MiL area. In these, the number of remaining MiL areas listed by each participant was entered as an additional covariate. The same analyses were used in the preliminary analyses to examine the effects of relationship with the patient and time since loss. For all analyses, Bonferroni corrections were employed, and differences were considered to be statistically significant at the adjusted level for $p<.05$ for multiple comparisons. Results significant at $p<.05$ without alpha-error adjustments are reported for exploratory purposes. To evaluate the relationship between MiL (IoWS), psychological distress and well-being in the bereaved PC caregiver sample, partial age- and gender-adjusted Pearson-correlation coefficients were calculated. Statistical tests were performed with the Statistical Package for Social Sciences (SPSS), version 19.

Results

Preliminary analyses

Of the participants, 69.0 % were partners of the patient, 23.8 % adult children, 3.6 % parents and 3.6 % had other relationships. Time since death of patient was 68.0±47.0 days (range, 4–183 days). To examine whether our sample of bereaved PC caregivers is homogenous with regard to their experience of MiL, we performed preliminary analyses to test for effects of relationship to the patient and bereavement length of time within the sample of caregivers. The inclusion of the variable time since loss (in days) in all analyses revealed only one effect at $p<.05$: The relative importance of friends increased with time (days) since loss. The inclusion of a variable coding the effect of being the partner of the patient versus having a different relationship revealed no effect on the SMiLE indices or number of provided areas. However, partners of patients were more likely to include the areas partner and spirituality as meaning providing areas, they ascribed more importance to partner, and were more satisfied with family, while meaning areas concerning their house/garden were less important and yielded less satisfaction (all $p<.05$, except lower satisfaction with house/garden: $p<.01$). Since none of these effects reached significance after Bonferroni correction, data from all bereaved caregivers were analysed as a single group.

Respondents' characteristics

Table 1 provides the respondents' characteristics for the bereaved PC caregivers as well as the representative sample.

Mean age of PC caregivers was 55.5±12.9 years, 81.0 % were caregivers of cancer patients. Other diagnoses included neurological disorders (13.0 %), chronic obstructive pulmonary disease (3.6 %) and other (2.4 %).

With regard to sociodemographic characteristics, significant group differences emerge with regard to age [$\chi^2(6)=52.78, p<.001$], gender [$\chi^2(1)=4.38, p<.05$] and marital status [$\chi^2(3)=214.37$, $p<.001$], but not with regard to education [$\chi^2(2)=0.48$, n.s.]. We included age and gender as covariates; marital status was not included because it is confounded with group membership for the 69.0 % of PC caregivers who had just experienced the loss of their spouse at the time of assessment.

Overall MiL

Table 2 shows descriptive statistics of the overall SMiLE indices and the number of listed MiL areas for the two groups.

Table 3 shows linear regression results examining group differences in these indices. PC caregivers had lower overall satisfaction (IoS), overall importance (IoW) and weighted satisfaction (IoWS) than the representative sample (all $p<.001$). With a B ranging from −9.57 to −15.52 points, effect sizes are medium for the SMiLE indices (possible range from 0 to 100). As an interpretation example, a B of −15.52 for the IoWS indicates that when comparing a respondent of the PC caregiver group to a person with the same age and gender in the representative sample, the former's overall SMiLE index is 15.52 points lower. On the other hand, PC caregivers listed on average more MiL areas than the representative sample [$\exp(B)=1.32$, SE=0.05; CI, 1.22–1.42, $p<.001$]. The $\exp(B)$ of 1.32 indicates that a person in the PC caregiver group would list 1.32 times more MIL areas than a person of similar age and gender in the representative sample (multiplicative effect).

Frequency of specific MiL areas

PC caregivers listed overall 424 MiL areas. These listings were assigned to 13 categories derived from the representative analyses [36].

Table 1 Respondents' characteristics of bereaved PC caregivers ($n=84$) and a German representative sample ($n=977$)

		Bereaved PC caregivers (%)	Representative sample (%)
Age	16–19 years	0.0	7.0
	20–29 years	1.2	18.7
	30–39 years	10.7	22.0
	40–49 years	20.2	20.2
	50–59 years	29.8	13.4
	60–69 years	25.0	11.8
	>70 years	13.1	7.0
Gender	Male	31.0	42.7
	Female	69.0	57.3
Marital status	Single	6.0	35.5
	Married	36.9	48.3
	Divorced/separated	3.6	10.3
	Widowed	53.6	5.6
Education	Elementary/lower secondary	21.4	24.2
	Middle secondary	35.7	36.3
	Higher secondary/ university	42.9	39.5
	Missing	0.0	6.1

Table 4 presents percentages of participants who named MiL areas in the respective category along with descriptive statistics of satisfaction (s) and relative importance (w_{rel}) ratings for PC caregivers and the representative sample. Kendall's rank correlation coefficient was used to compare the order of MiL areas ($N=13$) in the two groups. The groups showed similar rank orders with regard to frequency of MiL types ($r=.59$, $p=.006$), but only a trend towards a similar rank order with regard to satisfaction ($r=.37$, $p=.09$) and relative importance scores of MiL areas ($r=.40$, $p=.07$) emerged.

Table 2 Descriptive statistics of overall MiL indices by group

SMiLE indices	Bereaved PC caregivers ($n=84$)		Representative sample ($n=977$)	
	$M\pm$SD	Range	$M\pm$SD	Range
IoW	76.6±13.6[a]	28.6–100	85.6±12.3	20.0–100
IoS	68.3±19.1[a]	4.2–100	82.8±14.7	16.7–100
IoWS	68.5±19.2[a]	4.8–100	83.3±14.8	13.9–100
Number of areas	5.0±1.6[b]	1–7	3.8±1.4	1–7

IoW index of weighting (importance), *IoS* index of satisfaction, *IoWS* index of weighted satisfaction

[a] Significant group difference compared to representative sample (see Table 3)

[b] Significant group difference compared to representative sample (see "Results")

Table 3 Linear regression model testing for group differences between bereaved PC caregivers and the German representative sample in overall MiL indicators (controlled for age and gender, $N=1061$)

SMiLE indices	Adj. R^2	B	CI low	CI high	p value	Partial r^2
IoW	*0.05*	*−9.57*	*−12.39*	*−6.75*	*<.001*	*0.04*
IoS	*0.07*	*−15.32*	*−18.76*	*−11.89*	*<.001*	*0.07*
IoWS	*0.07*	*−15.52*	*−19.00*	*−12.04*	*<.001*	*0.07*

Italics indicate significant after Bonferroni correction ($p<.017$)

IoW index of weighting (importance), *IoS* index of satisfaction, *IoWS* index of weighted satisfaction, *Adj. R^2* adjusted total explained variance, *B* unstandardised regression coefficient, *CI* confidence interval for *B*, *Partial r^2* squared partial correlation coefficient (amount of uniquely explained variance as indicator of effect size)

Results of the binary logistic regression analyses testing for significant group differences in the likelihood to list specific MiL areas are provided in Fig. 1.

Compared to the representative population sample, PC caregivers are more likely to list MiL areas falling within the categories friends, leisure, nature/animals and altruism ($p<.004$, see Fig. 1). In addition, PC caregivers tend to list spirituality more often and health and finances less often ($p<.05$). The largest effects are observed with respect to friends (OR, 5.26), altruism (OR, 3.94) and nature/animals (OR, 2.91).

Satisfaction with MiL areas

Compared to the representative sample, bereaved PC caregivers showed significantly lower satisfaction in the MiL areas of family, friends, leisure, nature/animals, partner, and altruism ($p<.004$, see Table 5). Effect sizes are medium to large (B ranges from −0.81 to −1.70, response scale range −3 to +3). Additionally, there is a trend towards lower satisfaction in the area of work, spirituality, home/garden and well-being ($p<.05$).

Relative importance of MiL areas

Compared to the representative sample (see Table 5), PC caregivers ascribed higher relative importance to family ($p<.004$) with a small to medium effect size and showed trends towards higher ratings for partner and health and lower ratings for pleasure ($p<.05$).

Relationship between MiL and well-being in PC caregivers

Only small correlations were observed between MiL (IoWS, $M=68.33$, SD=19.12) and overall symptom severity ($M=65.14$, SD=11.42, $r=-.26$, $p<.02$) and quality of life (NRS; $M=4.12$, SD=1.96, $r=.23$, $p<.05$). However, moderate correlations were found between MiL and life satisfaction (SWLS, $M=3.79$, SD=1.15, $r=.45$, $p<.001$) and quality of life

Table 4 Descriptive statistics by MiL area: frequencies of listing, satisfaction and importance ratings by group

	Bereaved PC caregivers (N=84)			Representative sample (N=977)		
	Percent	s M±SD	w_{rel} M±SD	Percent	s M±SD	w_{rel} M±SD
Family	82.1	1.4±1.6	0.8±1.0	83.3	2.3±1.0	0.4±0.6
Friends	67.9	1.4±1.4	0.0±0.9	40.4	2.2±0.9	0.1±0.6
Leisure	53.6	0.8±1.5	−0.5±1.0	36.2	1.7±1.2	−0.5±0.7
Work	48.8	0.9±1.7	−0.3±1.4	56.0	1.4±1.6	−0.3±0.7
Nature/animals	26.2	1.4±1.8	−0.1±1.0	8.3	2.4±0.9	−0.1±0.6
Partner	21.4	0.7±2.1	0.8±1.2	26.9	2.3±1.1	0.4±0.5
Spirituality	19.0	1.8±1.1	−0.1±1.3	7.2	2.4±0.8	0.2±0.8
Altruism	16.7	0.5±1.8	0.8±1.0	3.8	2.0±1.0	−0.3±0.6
Health	14.3	1.3±1.7	0.7±0.8	30.0	1.8±1.5	0.4±0.5
Home/Garden	14.3	0.8±1.6	−0.3±1.1	7.2	2.0±1.2	−0.5±0.8
Well-being	3.6	−0.3±2.1	0.4±0.4	4.1	1.7±1.3	−0.1±0.7
Pleasure	2.4	0.0±0.0	−1.8±1.9	3.8	1.8±1.4	−0.2±0.7
Finances	1.2	1.0±0.0	0.4±0.0	13.4	0.9±1.8	−0.6±0.8

Percentage of respondents listing each category, means (M) and standard deviations (SD) of the satisfaction ratings (s, range −3 to +3), and relative importance ratings (w_{rel}, centered on each respondents mean importance rating)

assessed with the WHOQOL-BREF (M=63.78, SD=10.50, r=.41, p<.001).

Discussion

This study evaluates the experience of individual MiL and its relationship to well-being in bereaved informal caregivers.

Overall MiL in caregivers

Bereaved caregivers had lower overall importance (IoW), satisfaction (IoS) and weighted satisfaction (IoWS) with regard to MiL than a representative sample of the German population. This result concurs with Levinson's findings of lower MiL in widows compared to a mixed adult (non-psychiatric patient) sample [34]. In studies comparing palliative patients to the representative sample [39, 46], PC patients also had lower satisfaction and weighted satisfaction scores (*fulfillment*), but did not differ from the general population in terms of the overall importance they ascribed to their meaning-providing areas (*framework*). This finding underscores the importance of support for informal carers during palliative care [1–3, 9–11] and into bereavement [47, 48], and confirms the notion that they experience often as much or even higher psychological maladjustment than the patients [3].

Differences in MiL fulfillment

Bereaved PC caregivers' overall experience of satisfaction in MiL is considerably lower than in the representative sample [36]. It is worth noting that caregivers have the absolute lowest IoS and IoWS observed in any of the samples so far, their average indices being between 6 and 10 points lower than in samples of patients with amyotrophic lateral sclerosis (ALS) [46], cancer patients [40] and students [37]. The preliminary analyses indicate that these effects similarly affect partners and non-partners, and are homogenous throughout the first 6 months of bereavement.

All areas that 15 % or more of PC caregivers list as meaning providing are impaired: Their satisfaction is significantly (family, friends, leisure, nature/animals, partner and altruism) or by trend lower (work and spirituality) than in the representative sample. Among the affected are all areas that caregivers are more likely to list. These consistently lower satisfaction ratings indicate a pervasive impact of the caregiving role and the recent loss of a loved one on the experience of MiL. While PC patients [39] succeeded in keeping their satisfaction unimpaired for at least some MiL areas (family, partner and spirituality), caregivers do not seem to have such protected areas. Furthermore, comparing descriptive statistics shows that caregivers seem to be less satisfied with family than patients [39]. This may reflect conflict potential and unfulfilled expectations with regard to support from one's family [48, 49]. Preliminary analyses indicate that caregivers who are partners of the patient are somewhat more satisfied with family than non-partner caregivers. Possibly, when one's partner is affected, immediate and extended family may rally together more to support the surviving partner, than when the patient is not a partner. Attention should be paid to whether non-partner carers receive sufficient informal social support during caregiving and bereavement. The lower satisfaction

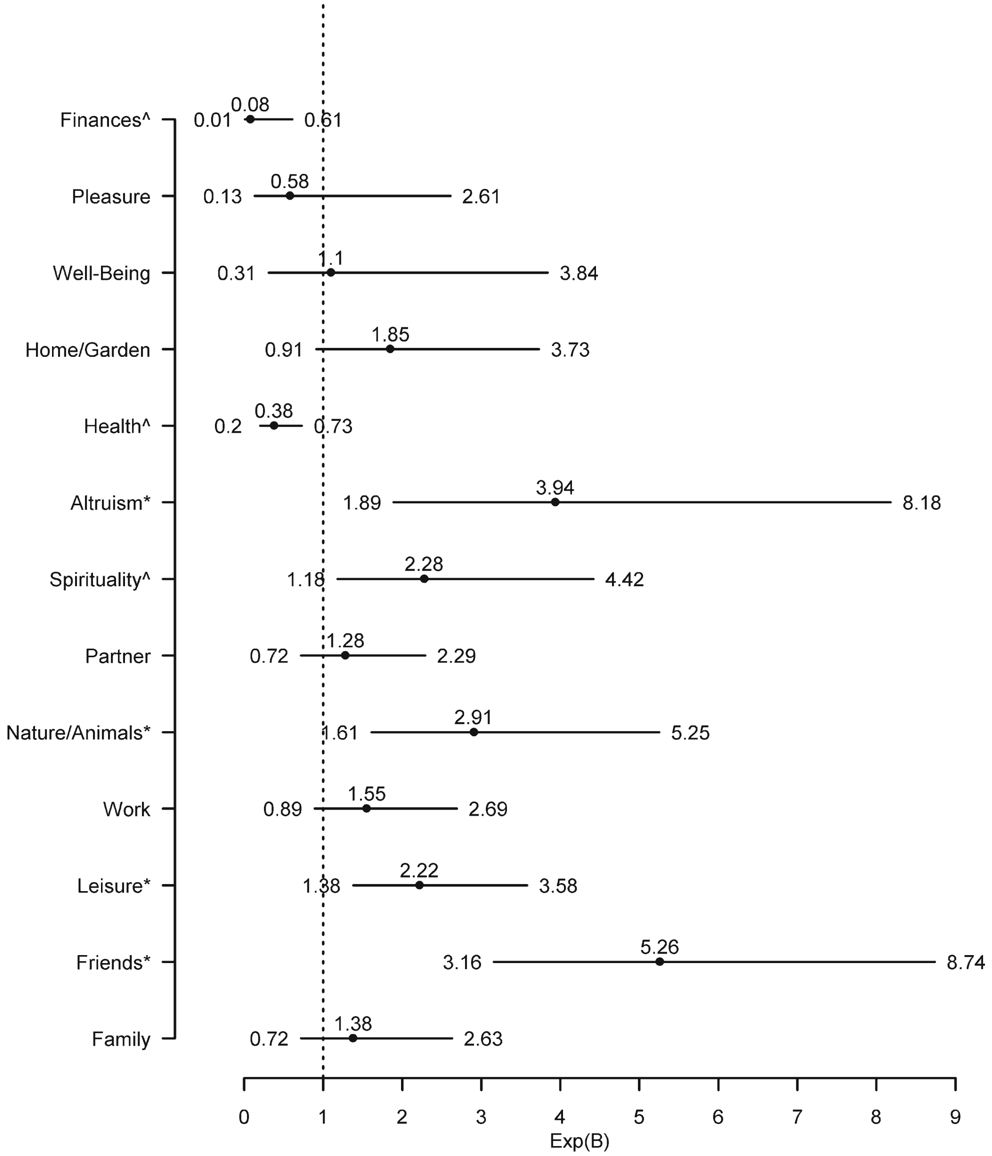

Fig. 1 Odds ratios [Exp(*B*)] with low and high confidence intervals for comparison of frequencies of MiL areas between bereaved PC caregivers and the German representative sample (controlled for age, gender, and remaining number of listed MiL areas). *Numbers below 1* indicate a lower, *numbers above 1* a higher likelihood in PC caregivers to list a specific MiL area. * $p<.004$ (significant), ^$p<.05$ (trend)

expressed by partners with house/garden when compared to non-partners could arise from the fact that the surroundings they have shared with their partner before the death are filled with permanent reminders of their loss and the necessity to adapt to the new situation.

Differences in MiL framework

The unique MiL framework of caregivers is expressed (1) by the specific MiL areas mentioned, as well as (2) by the importance ratings associated with them.

First, the categories mentioned most often by bereaved PC caregivers (in descending order) were family, friends, leisure, work, nature/animals and partner. Caregivers are equally likely to list family or work as relevant for MiL as the representative sample. However, they list friends, leisure, nature/animals and altruism much more frequently. Leisure and nature/animals were also listed more often by PC patients [39]. These areas may be important for both patients and caregivers as ways to counteract the respective burden experienced in their illness or caregiving role. Friends may be listed more often either as part of a social support network in relation to caregiving, or as a niche where carers are able to occasionally escape from the illness or loss of their relative. Altruism was listed by 16 % of the caregivers; this is about four times more often than in the representative sample. This may reflect that caregivers experience meaning in their role as caregiver of a terminally ill patient [3, 29]. The trend (p=.004) that caregivers list health less often parallels findings from ALS patients [46], and may be explained by a possible response shift [50]. Experiencing the terminal illness of a loved one and the helplessness associated with it may lead to perceiving health as something brittle that is mostly outside one's control. Thus, building one's MiL around other areas may be

Table 5 Linear regression model testing for group differences between bereaved PC caregivers and the German representative sample in satisfaction and relative importance ratings by MiL area (controlled for age and gender)

MiL category	Satisfaction							Relative Importance						
	N	Adj. R^2	*B*	CI low	CI high	*p* value	Partial r^2	*N*	Adj. R^2	*B*	CI low	CI high	*p* value	Partial r^2
Family	**883**	**0.06**	**−1.00**	**−1.26**	**−0.74**	**.000**	**0.06**	**883**	**0.02**	**0.40**	**0.23**	**0.56**	**.000**	**0.03**
Friends	**452**	**0.07**	**−0.81**	**−1.11**	**−0.51**	**.000**	**0.06**	451	0.10	0.17	−0.02	0.36	.077	0.01
Leisure	**399**	**0.04**	**−0.94**	**−1.36**	**−0.53**	**.000**	**0.05**	399	0.01	0.02	−0.21	0.25	.850	0.00
Work	*588*	*0.01*	*−0.54*	*−1.06*	*−0.02*	*.043*	*0.01*	590	0.02	−0.04	−0.29	0.21	.735	0.00
Nature/Animals	**103**	**0.16**	**−1.12**	**−1.68**	**−0.56**	**.000**	**0.14**	103	0.00	−0.10	−0.45	0.25	.560	0.00
Partner	**281**	**0.09**	**−1.66**	**−2.27**	**−1.04**	**.000**	**0.09**	*281*	*0.02*	*0.36*	*0.06*	*0.66*	*.020*	*0.02*
Spirituality	*85*	*0.05*	*−0.63*	*−1.15*	*−0.12*	*.017*	*0.07*	86	−0.08	−0.22	−0.75	0.32	.420	0.01
Altruism	**51**	**0.13**	**−1.70**	**−2.65**	**−0.76**	**.001**	**0.24**	50	−0.11	−0.11	−0.65	0.43	.682	0.00
Health	305	0.00	−0.30	−1.17	0.58	.501	0.00	*304*	*0.04*	*0.37*	*0.06*	*0.68*	*.021*	*0.02*
Home/Garden	*82*	*0.14*	*−1.12*	*−1.91*	*−0.34*	*.006*	*0.10*	80	−0.03	0.26	−0.31	0.83	.372	0.01
Well-being	*43*	*0.08*	*−2.23*	*−4.22*	*−0.24*	*.029*	*0.13*	43	0.01	0.02	−0.96	1.01	.960	0.00
Pleasure	39	0.02	−1.54	−3.86	0.78	.186	0.06	*39*	*0.12*	*−1.38*	*−2.73*	*−0.03*	*.045*	*0.13*
Finances	132	0.05	0.13	−3.40	3.66	.942	0.00	132	0.08	0.89	−0.64	2.42	.253	0.01

Bold: significant after Bonferroni correction ($p<.004$). Italics: trend ($p<.05$)

Adj. R^2 adjusted total explained variance, *B* unstandardised regression coefficient, *CI* confidence interval for B, *Partial r^2* squared partial correlation coefficient (amount of uniquely explained variance as indicator of effect size)

an adaptive response to the experience of caregiving [32]. Relatives who had lost their partner were more likely to name the areas partner and spirituality as MiL providing, possibly indicating that the loss of one's partner leads more often to questions concerning the transcendent.

Second, only one significant difference in importance of specific MiL areas was observed: Family was rated as more important in caregivers; combined with the fact that this area is relevant for most caregivers (82.3 %) and that they experience distinctly lower satisfaction in it, this is a prominent target for intervention, such as family focused grief therapy [49] or counselling targeted at improving family relationships [48]. The lower overall index of weighting may reflect a general insecurity or even "shattering" of assumptive worlds [31] in the bereaved with regard to their MiL framework. Referring to Park's meaning-making model [31], it seems that bereaved caregivers are in a transition phase. They have experienced loss of MiL and have started to change their framework of how to experience MiL (as evidenced by the different types of MiL areas and the overall lower certainty about what is important to them), but have not yet achieved satisfactory fulfillment within their new framework [51].

Relationship of MiL to other constructs

In line with Fry [22], MiL in bereaved PC caregivers was moderately related to well-being in the expected direction. Thus, MiL appears to be a relevant construct for psycho-oncology and end-of-life research, and may mediate the relationship between caregiver burden and well-being [18, 35]. Within the current cross-sectional design, it is not possible to discern a plausible causal direction of these relationships. Longitudinal studies are needed to investigate what mechanisms underlie these associations.

Limitations of the study

One limitation is the mixed sample of bereaved caregivers: They had various relationships to the deceased family member, and time since loss varied from a few days to 6 months. However, preliminary analyses indicated that these subgroups are sufficiently similar with regard to their experience of MiL. The cross-sectional design of the study does not allow assessment of changes within respondents over time. Differences between samples could have existed prior to the beginning of caregiving. Only caregivers who decided to participate in an intervention study and had lost their ill relative prior to the pre-treatment assessment were included. It is likely that participating caregivers differ from those who declined with regard to the degree of burden and other variables (e.g. time constraints) that play a role in the uptake of such offers [1, 52]. We have introduced a new response-scale format to prevent ceiling effects [39], which may have led to slight distortions in the IoW and IoWS comparisons [41].

Conclusion

In conclusion, both the framework and the fulfillment of MiL appear to be substantially impaired in PC caregivers. The observed differences in framework point to a response shift [50]. The loss of MiL fulfillment, comparable in extent or even higher than the loss observed in ALS [46] and PC [39] patients, underscore the need for specific interventions for informal caregivers in PC. Such interventions should not only provide practical support but also focus on promoting emotional well-being [1, 53]. As MiL was related to well-being, promoting the reconstruction of caregivers' MiL may be a promising focus for caregiver interventions. Existential behavioural therapy, for example, was shown to improve quality of life and reduce distress of caregivers immediately after treatment and at a 1-year follow-up [38]. To our knowledge, this is the first empirical investigation of the specific areas of MiL important to bereaved caregivers. Further research is needed to examine whether these differences represent a general phenomenon in caregivers.

Acknowledgements This research was supported by the Deutsche Krebshilfe e.V. (reference no. 107433).

Author disclosure statement The authors declare that there is no conflict of interest. The funding source was not involved in study design, or data collection, analysis, interpretation or presentation of study results. The authors have full control of all primary data and agree to allow the journal to review their data if requested.

References

1. Aoun SM, Kristjanson LJ, Currow DC, Hudson PL (2005) Caregiving for the terminally ill: at what cost? Palliat Med 19(7): 551–555. doi:10.1191/0269216305pm1053oa
2. Grande G, Stajduhar K, Aoun S, Toye C, Funk L, Addington-Hall J, Payne S, Todd C (2009) Supporting lay carers in end of life care: current gaps and future priorities. Palliat Med 23:339–344. doi:10.1177/0269216309104875
3. Payne S (2010) EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 1. Eur J Palliat Care 17(5):238–245
4. Pitceathly C, Maguire P (2003) The psychological impact of cancer on patients' partners and other key relatives: a review. Eur J Cancer 39(11):1517–1524. doi:10.1016/S0959-8049(03)00309-5
5. Chentsova-Dutton Y, Shucter S, Hutchin S, Strause L, Burns K, Dunn L, Miller M, Zisook S (2002) Depression and grief reactions in hospice caregivers: from pre-death to 1 year afterwards. J Affect Disord 69(1–3):53–60. doi:10.1016/S0165-0327(00)00368-2
6. World Health Organization (2002) National cancer control programmes: policies and managerial guidelines. WHO, Geneva
7. Funk L, Stajduhar K, Toye C, Aoun S, Grande G, Todd C (2010) Part 2: Home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008). Palliat Med 24:594–607. doi:10.1177/0269216310371411
8. Stajduhar K, Funk L, Toye C, Grande G, Aoun S, Todd C (2010) Part 1: Home-based family caregiving at the end of life: a comprehensive review of published quantitative research (1998–2008). Palliat Med 24:573–593. doi:10.1177/0269216310371412
9. Candy B, Jones L, Drake R, Leurent B, King M (2011) Interventions for supporting informal caregivers of patients in the terminal phase of a disease. Cochrane Database Syst Rev (6):CD007617. doi:10.1002/14651858.CD007617.pub2.
10. Harding R, Higginson I (2003) What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. Palliat Med 17:63–74. doi:10.1191/0269216303pm667oa
11. Hudson PL, Remedios C, Thomas K (2010) A systematic review of psychosocial interventions for family carers of palliative care patients. BMC Palliat Care 9:17. doi:10.1186/1472-684X-9-17
12. Kelly B, McClement S, Chochinov H (2006) Measurement of psychological distress in palliative care. Palliat Med 20:779–789. doi:10.1177/0269216306072347
13. Lin H, Bauer-Wu SM (2003) Psycho-spiritual well-being in patients with advanced cancer: an integrative review of the literature. J Adv Nurs 44:69–80. doi:10.1046/j.1365-2648.2003.02768.x
14. Chochinov HM, Kristjanson LJ, Breitbart W, McClement S, Hack TF, Hassard T, Harlos M (2011) Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: a randomised controlled trial. Lancet Oncol 12:753–762. doi:10.1016/S1470-2045(11)70153-X
15. Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, Tomarken A, Timm AK, Berg A, Jacobson C, Sorger B, Abbey J, Olden M (2010) Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. Psychooncology 19:21–28. doi:10.1002/pon.1556
16. Lee V, Cohen SR, Edgar L, Laizner AM, Gagnon AJ (2006) Meaning-making and psychological adjustment to cancer: development of an intervention and pilot results. Oncol Nurs Forum 33:291–302. doi:10.1188/06.ONF.291-302
17. Morita T, Murata H, Hirai K, Tamura K, Kataoka J, Ohnishi H, Akizuki N, Kurihara Y, Akechi T, Uchitomi Y (2007) Meaninglessness in terminally ill cancer patients: a validation study and nurse education intervention trial. J Pain Symptom Manag 34: 160–170. doi:10.1016/j.jpainsymman.2006.10.021
18. McKnight PE, Kashdan TB (2009) Purpose in life as a system that creates and sustains health and well-being: an integrative, testable theory. Rev Gen Psychol 13(3):242–251. doi:10.1037/a0017152
19. Scheier MF, Wrosch C, Baum A, Cohen S, Martire LM, Matthews KA, Schulz R, Zdaniuk B (2006) The life engagement test: assessing purpose in life. J Behav Med 29(3):291–298. doi:10.1007/s10865-005-9044-1
20. Konstam V, Holmes W, Wilczenski F, Baliga S, Lester J, Priest R (2003) Meaning in the lives of caregivers of individuals with Parkinson's disease. J Clin Psychol Med Settings 10(1):17–26. doi:10.1023/a:1022849628975
21. Stetz KM (1989) The relationship among background characteristics, purpose in life, and caregiving demands on perceived health of spouse caregivers. Sch Inq Nurs Pract 3(2):133–153
22. Fry P (2001) The unique contribution of key existential factors to the prediction of psychological well-being of older adults following spousal loss. The Gerontologist 41(1):69–81. doi:10.1093/geront/41.1.69
23. Ulmer A, Range LM, Smith PC (1991) Purpose in life: a moderator of recovery from bereavement. Omega J Death Dying 23(4):279–289. doi:10.2190/33VU-BANW-C54V-W7VF
24. Reker GT (2000) Theoretical perspective, dimensions, and measurement of existential meaning. In: Reker GT, Chamberlain K (eds) Exploring existential meaning: optimizing human development across the life span. Sage, Thousand Oaks, pp 39–55
25. Brandstätter M, Baumann U, Borasio GD, Fegg M (2012) Systematic review of meaning in life assessment instruments. Psychooncology 21:1034–1052. doi:10.1002/pon.2113
26. Keesee NJ, Currier JM, Neimeyer RA (2008) Predictors of grief following the death of one's child: the contribution of finding meaning. J Clin Psychol 64(10):1145–1163. doi:10.1002/jclp.20502
27. Kim Y, Schulz R, Carver CS (2007) Benefit finding in the cancer caregiving experience. Psychosom Med 69:283–291. doi:10.1097/PSY.0b013e3180417cf4

28. Noonan AE, Tennstedt SL (1997) Meaning in caregiving and its contribution to caregiver well-being. The Gerontologist 37(6):785–794. doi:10.1093/geront/37.6.785
29. Sanjo M, Morita T, Miyashita M, Shiozaki M, Sato K, Hirai K, Shima Y, Uchitomi Y (2009) Caregiving Consequences Inventory: A measure for evaluating caregiving consequences from the bereaved family member's perspective. Psychooncology 18(6):657–666. doi:10.1002/pon.1447
30. Farran CJ, Miller BH, Kaufman JE, Donner E, Fogg L (1999) Finding meaning through caregiving: development of an instrument for family caregivers of persons with Alzheimer's disease. J Clin Psychol 55(9):1107–1125. doi:10.1002/(sici)1097-4679(199909)55:9<1107::aid-jclp8>3.0.co;2-v
31. Park CL (2010) Making sense of the meaning literature: an integrative review of meaning making and its effects on adjustment to stressful life events. Psychol Bull 136(2):257–301. doi:10.1037/a0018301
32. Folkman S, Greer S (2000) Promoting psychological well-being in the face of serious illness: when theory, research and practice inform each other. Psychooncology 9(1):11–19. doi:10.1002/(SICI)1099-1611(200001/02)9:1<11::AID-PON424>3.0.CO;2-Z
33. Wheeler I (1993) The role of meaning and purpose in life in bereaved parents associated with a self-help group: compassionate friends. Omega J Death Dying 28(4):261–271. doi:10.2190/T531-78GF-8NQ3-7E7E
34. Levinson JI (1989) Existential vacuum in grieving widows. Int Forum Logotherapy 12(2):101–109
35. Okamoto K, Momose Y, Fujino A, Osawa Y (2009) Life worth living for caregiving and caregiver burden among Japanese caregivers of the disabled elderly in Japan. Arch Gerontol Geriatr 48(1):10–13. doi:10.1016/j.archger.2007.09.003
36. Fegg M, Kramer M, Bausewein C, Borasio G (2007) Meaning in life in the Federal Republic of Germany: results of a representative survey with the Schedule for Meaning in Life Evaluation (SMiLE). Health Qual Life Outcomes 5:59. doi:10.1186/1477-7525-5-59
37. Fegg M, Kramer M, L'hoste S, Borasio G (2008) The Schedule for Meaning in Life Evaluation (SMiLE): validation of a new instrument for meaning-in-life research. J Pain Symptom Manag 35(4):356–364. doi:10.1016/j.jpainsymman.2007.05.007
38. Fegg M, Brandstätter M, Kögler M, Hauke G, Rechenberg-Winter P, Fensterer V, Küchenhoff H, Hentrich M, Belka C, Borasio G (2013) Existential behavioural therapy for informal caregivers of palliative patients: a randomised controlled trial. Psychooncology 22:2079–2086. doi:10.1002/pon.3260
39. Fegg M, Brandstätter M, Kramer M, Kögler M, Haarmann-Doetkotte S, Borasio G (2010) Meaning in life in palliative care patients. J Pain Symptom Manag 40(4):502–509. doi:10.1016/j.jpainsymman.2010.02.010
40. Stiefel F, Krenz S, Zdrojewski K, Stagno D, Fernandez M, Bauer J, Fucina N, Lüthi F, Leyvraz S, Borasio G, Fegg M (2008) Meaning in life of cancer patients assessed with the "Schedule for Meaning in Life Evaluation" (SMiLE). Support Care Cancer 16:1151–1155. doi:10.1007/s00520-007-0394-9
41. Colman AM, Norris CE, Preston CC (1997) Comparing rating scales of different lengths: equivalence of scores from 5-point and 7-point scales. Psychol Rep 80(2):355–362. doi:10.2466/pr0.1997.80.2.355
42. Schwartz S (1992) Universals in the content and structure of values: theoretical advances and empirical tests in 20 countries. In: Zanna M (ed) Advances in experimental social psychology, vol 25. Academic, New York, pp 1–65
43. Derogatis LR, Melisaratos N (1983) The Brief Symptom Inventory: an introductory report. Psychol Med 13:595–605. doi:10.1017/S0033291700048017
44. Angermeyer MC, Kilian R, Matschinger H (2000) WHOQOL-100 und WHOQOL-BREF. Handbuch für die deutschsprachige Version der WHO Instrumente zur Erfassung von Lebensqualität. Hogrefe, Göttingen
45. Diener E, Emmons RA, Larsen RJ, Griffin S (1985) The satisfaction with life scale. J Pers Assess 49(1):71–75. doi:10.1207/s15327752jpa4901_13
46. Fegg M, Kögler M, Brandstätter M, Jox R, Anneser J, Haarmann-Doetkotte S, Wasner M, Borasio G (2010) Meaning in life in patients with amyotrophic lateral sclerosis. Amyotroph Lateral Scler 11(5):469–474. doi:10.3109/17482961003692604
47. Grbich C, Parker D, Maddocks I (2001) The emotions and coping strategies of caregivers of family members with a terminal cancer. J Palliat Care 17(1):30–36
48. Zaider T, Kissane D (2009) The assessment and management of family distress during palliative care. Curr Opin Support Palliat Care 3(1):67–71. doi:10.1097/SPC.0b013e328325a5ab
49. Kissane DW, McKenzie M, Bloch S, Moskowitz C, McKenzie DP, O'Neill I (2006) Family focused grief therapy: a randomized, controlled trial in palliative care and bereavement. Am J Psychiatry 163(7):1208–1218. doi: 10.1176/appi.ajp.163.7.1208
50. Richards TA, Folkman S (2000) Response shift: a coping perspective. In: Schwartz CE, Sprangers MAG (eds) Adaptation to changing health: response shift in quality-of-life research. American Psychological Association, Washington, pp 25–36. doi:10.1037/10382-002
51. Gillies J, Neimeyer RA (2006) Loss, grief, and the search for significance: toward a model of meaning reconstruction in bereavement. J Constr Psychol 19(1):31–65. doi:10.1080/10720530500311182
52. Payne S (2010) EAPC Task Force on Family Carers White Paper on improving support for family carers in palliative care: part 2. Eur J Palliat Care 17(6):286–290
53. Hebert RS, Schulz R (2006) Caregiving at the end of life. J Palliat Med 9(5):1174–1187. doi:10.1089/jpm.2006.9.1174