

# Meaning in Life of Terminally Ill Parent with Young Children – A Quantitative Evaluation with SMiLE

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## Research Article

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# Abstract

## Background

Increasing the quality of life is one of the objectives of palliative care. Meaning in life has a significant influence on the perceived quality of life. We found no studies focusing on patients with young children.

## Methods

Young parents diagnosed with life-limiting disease could participate and create an audiobook. Patients were assessed using Schedule for Meaning in Life Evaluation (SMiLE) pre and post intervention. The SMiLE is a validated instrument to assess meaning in life. Patients list their individual items that provide meaning in life. In a second step they are requested to rate their current level of satisfaction and in a last step they are asked to rank the importance of each item. Overall indices of weighting, satisfaction and importance are calculated. In addition, participants were interviewed twice over the course regarding expectations, concerns, motivation, and experiences.

## Results

The data were collected from February 2017 till September 2020. Fifty-four patients with ninety-six children at a mean age of seven years could be included. The involvement with the SMiLE made patients think about their resources. Most important items were in decreasing order family (100%), social relations (79.6%), leisure time (61.1%), nature/animals (38.9%), and home/garden (29.6%). Index of weighting (IOW) was 81.5, index of satisfaction (IOS) was 71.4, and a total SMiLE Index (IOWS) was 72.4. Parent felt limited by their illness in being a mother or father, as they wanted to be.

## Conclusion

Items relevant for young parent showed differences to evaluations of cancer patients and palliative care patients. Most important item for meaning in life is the family numerated by all participants. The results indicate that evaluation of meaning in life is a coping strategy and helps young parent with young children.

## Background

Increasing the quality of life is one of the objectives of palliative care. Studies could confirm that quality of life is mainly influenced by patients' sense of meaning and purpose in life (1, 2). Thus meaning in life has a high impact on psychological distress and we find a great body of research dealing with meaning. Studies found a correlation between psychological adjustment to stressful events such as life-limiting disease and the role of meaning. This was described as meaningmaking model by Park et al. (3). These findings among others led to an evaluation of meaningmaking intervention with aspects of life priorities and aim to foster coping and mastery of illness (4, 5). Park et al. (3) distinguished between meaningmaking and meaning made. Meaningmaking was defined as understanding of a stressor as

appraised meaning and incorporation of this understanding in a global meaning system. Meaning made was defined as growth, life meaningfulness and reduced inconsistency of just-world beliefs (6). These categories found consideration in a great number of assessment instruments. They assess the presence of and search for meaning, ask for meaning in crisis, or sources of meaning-making, and meaningful activities (7). We decided to use the Schedule for Meaning in Life Evaluation (SMiLE). It was developed as a respondent-generated instrument for the assessment of individual meaning (8). This instrument provides an individualized measure because items that give meaning are generated by the patient him or herself.

The aim of this study was to evaluate 1. the meaning of life areas in parent with young children in provision of palliative care, and 2. to examine differences to general PC patients or other samples tested with regard to meaning in life with SMiLE.

## Methods

Young parents diagnosed with a life-limiting disease could participate and create an audiobook for their young children. The audiobook itself was recorded over several days and edited by qualified radio journalists. After providing informed consent participants were interviewed twice over the course of the intervention regarding expectations, concerns, motivation, and experiences. Interviews and notes were transcribed verbatim and were analyzed using content analysis. This part of the evaluation is already published (9). In addition, participating patients were assessed twice with questionnaires before and after the audiobook recording. We conducted the SMiLE and analysed the results with SPSS version 26.

## Setting/participants

Participants were recruited by a social worker, a nurse, or a psycho-oncologist with research training or asked for participation themselves. Due to high media attention to the project, most of the patients asked for participation themselves. Patients had to sign a self-disclosure form about their case history. Inclusion criteria were checked and patients were included following written informed consent. None of the interviewed patients was treated by members of the recruitment or interviewer team. The research ethics committee of the University Hospital Bonn reviewed and approved the study (no.389/16). Inclusion criteria for this study 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.

## Provider

Participants were interviewed by an experienced biographical researcher and a physician specialist in palliative care (HC physician and MH psycho-oncologist). Both researchers were not part of patient's care

network. All data were collected in a standardized way administering accuracy of study protocol. In addition, we followed the standardized test instructions given by the authors of the SMiLE (10, 11).

The Schedule for Meaning in Life Evaluation (SMiLE) was used as a paper-pencil test.

For all patients and researchers, psychological counselling was offered to address issues of emotional distress, fear, anger, or other emotions.

## Data collection

Assessment of SMiLE was conducted at two-time points. In addition, HC and MH conducted semi-structured interviews pre and post the creation of the audiobook as described in Cuhls et al. (9). The form of the assessment changed in the run of the project from face to face to telephonic contacts due to restrictions from Covid-19.

## Analysis

Items given by participants were assigned into categories as defined by Fegg (11) by HC and MH. In case of differences, assignment was discussed in depth until consent was reached. Quantitative data was organized and analysed with SPSS version 26.

## Procedures

In the 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 ( $s_1 \dots s_n$ ) on a scale ranging from “-3 very unsatisfied” to “+3 very satisfied”.

Finally, the importance of each area ( $w_1 \dots w_n$ ) is rated with an eight-point adjective scale, ranging from “0= not important” to “7= extremely important” with “3 =important” and “6= very important”.

We followed the protocol given on the website of Professor Fegg (11) and discussed upcoming questions by email. Consistent with Feggs' definitions of terms, open-ended responses were classified into their respective categories (12). Several parents used family and children as synonymous. On the advice of Professor Fegg, we put both items in the category family.

Comparability might not be given with all studies in all dimensions due to a different number of categories. The categories art/culture and growth are missing in older studies (8, 12, 13).

# Analysis

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  $s'_i = 100$ .

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

The index of Weighting (IoW) indicates the mean weighting of the MiL areas (range, 0-100, with higher scores reflecting higher weights).

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

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).

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

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.

## Results

The data were collected from February 2017 till September 2020. Fifty-eight patients could be included. Four patients dropped out due to a declining performance status after their inclusion. Finally, 54 people were able to participate in the study; 13 men and 41 women. The average age was 43. Most of them were married ( $n=45$ ), 7 divorced and 2 single. All but four had cancer (see Table 1).

Table 1  
Sociodemographic characteristics

<b>Gender</b>	
Men	n = 13, mean age 43.9 (SD 33-57)
Women	n = 41, mean age 41.7 (SD 35-57)
<b>Marital status</b>	
Married/living with a partner	n = 45
Divorced	n = 7
Single	n = 2
Cancer	n = 50 [gynecologic (n=23), gastrointestinal (n=13), brain (n=5), lung (n=2), other (n= 7)]
Non-cancer	n = 4 (1xCOPD Stage IV, 2x Amyotrophic lateral sclerosis, 1x Huntington's disease)
Children	n= 96, mean age 7.25 (SD 0.4-18) discordant value: 1 handicapped child 27 years old

## SMiLE – descriptive comparison between groups

As expected, the individual items of SMiLE show large differences between the representative study with the general population and our study with dying parents with young children (Figure 1).

This is also evident from the total scores of IoW, IoS and IoWS (Table 2). Comparison of SMiLE scores shows similarities in the representative population samples and in the samples with persons in need of palliative care (Figure 1). The largest differences are between the groups of the representative population sample and the group with palliative care needs. 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 individual items present (Figure 2). Furthermore, all samples show almost identical median ages of the respondents, namely up to 49 years of age (8, 13, 14).

Table 2  
Comparison of the SMiLE Scores

	loW	loS	loWS
Swiss Representative Sample Bernard 2015 (13)	82.9 ± 11.3	85.9 ± 13.1	86.5 ± 13.6
German Representative Sample Fegg 2007 (15)	85.6 ± 12.3	82.8 ± 14.7	83.3 ± 14.8
German Palliative Care Patients Fegg 2010 (8)	84.7 ± 11.5	70.2 ± 19.7	72 ± 19.4
Terminally ill Parent with young children (9)	81.5 ± 12.2	71.4 ± 20.6	72.4 ± 21.3

Unsurprisingly the category mentioned by all participants was family (TP 100%, PC 76%). In decreasing order followed by social relations (TP 80%, PC 39%), leisure time (TP 61%, PC 44%), and nature/animals (TP 39%, PC 31%). Surprisingly partnership was only enumerated by 30% (PC 45%). Spirituality/religion are only mentioned by 11% of parents (PC 23%). Finances were not mentioned at all (PC 8%). Health was only mentioned by 4% of participants (PC 31%). Unexpectedly we found 30% indicating home/garden (PC 12%).

Dying parents who want to leave a digital legacy to their children therefore also indicate a high value of the family or children. At the same time, satisfaction decreases because there is limited time left with their children. In the face of an incurable, advanced disease, the importance of health decreases, too.

## Additional Comments

Conducting of SMiLE let parents think about their life. Here we present often mentioned examples for illustration:

The analysis of notes taken during the evaluation of the SMiLE showed a new awareness of resources.

*„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)*

Rating the level of satisfaction let patients assess their role as father or mother.

*„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)*

## Discussion

There are numerous publications investigating the quality of life with SMiLE in different entities (8, 10, 14–20). In the following section, we compare our sample (terminally ill parent with young children; TP) with a sample of palliative care (PC) patients to show distinctions in the ranking (8).

Hence young parents with little children show different categories of meaning than palliative care patients in general. The outstanding role of parenting seems to shift priorities to social and family life spending time at home and in nature. Primary focus lays on the young children and therefore partnership might not be mentioned as often as by palliative care patients. In the face of an incurable, advanced disease with a limited lifetime might influence the importance of health. This might also be a reason for little regard for health. Due to the same number of categories, we compared our findings with a study of Bernard et al. with a representative sample in Switzerland and found significant differences in ranking (see figure1). The extent of accordances seems to depend on the sample. Indices such as IoS, IoW, IoWS are comparable and show accordances in similar samples (see Table 2). However, we still see differences in cancer patients, palliative care patients, and parents with little children. Overall we see satisfaction scores are smaller in parents with young children and palliative care patients than in representative samples. The category of satisfaction is the smallest item in parents (3.7%) in comparison with all other samples (cancer 8%, PC 5.3%). This might be due to concentration on the children and deny of selfish needs.

In research of quality of life, we find different constructs describing a change of attitudes in the trajectory of disease (21–23). Calman et al. describe a gap between expectations and reality leading to a reduction of expectations to alleviate the gap (21). Sprangers et al. see a change of values, a recalibration, and a reconceptualization in trajectory called ‘response shift’ (22). Regarding the field notes taken in administering the SMiLE, we find hints for this theory. The survey of the questions evoked awareness of the gap especially between the self-expectation as a parent and the actual situation. Others were able to remember resources of former times and were able to reactivate them. Comparing our findings in the evaluation of the SMiLE with our qualitative analysis of interviews with the patients shows the impact of both interventions on coping with life-limitation (9, 24). A majority of parents found meaning in life in spending quality time (social relations; leisure time; home/garden; nature/animals) with their children. They found consolation in recording their history of life for their children and leaving them with their oath of love.

In the context of palliative care, SMiLE seems to be a good elicitation tool to sort and rank patients’ end-of-life priorities. The use of the instrument can save time, give less talkative a voice, easily embedded in further treatment plans and set processes in motion in a focused way.

For terminally ill parents, audiobooks are an opportunity to leave their personal life stories. In this way, they submit reminiscence and might have a lasting effect on the family system beyond their own death. Further research is now necessary to survey the effects of the audiobook on bereaved children. This would fill another scientific gap and answer the impact of digital inheritance on the bereaved.

## **Study limitations**

Our sample was small and not representative. With increasing awareness and scarce human resources, self-selection bias also increases, as voluntary requests predominate over time. In addition to the

limitations to the survey instrument listed by Bernard (13), telephone interviews pose another challenge for this group. The pandemic situation led to a change in study performance from face-to-face to telephone and might have influenced participants' answers. Interviews by telephone might have been exhausting for this sample in reduced health status. Assignment to categories leaves room for interpretation though we discussed every single item in depth.

## **Conclusion**

Items relevant for young parent showed differences in evaluations of cancer patients and palliative care patients. The most important item for meaning in life is the family enumerated by all participants. The results indicate that evaluation of meaning in life is a coping strategy and helps young parent with young children.

## **Declarations**

All methods were carried out following relevant guidelines and regulations such as COREQ (25), 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

### **Availability of data and materials**

The recorded datasets, transcripts and audiobooks are sensitive information and underly 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.

### **Competing interests**

The authors declare that they have no competing interests.

### **Funding**

Not applicable

## Authors' contributions

MH and HC performed the study. MH and HC wrote and revised the article and both read and approved the final manuscript. GA revised the article and checked the results. Assignment to categories was run by HC and MH. Data entry and analysis with SPSS were performed by GH and HC. GA and LR provided helpful suggestions in the discussion and revised the article. All authors reviewed the manuscript.

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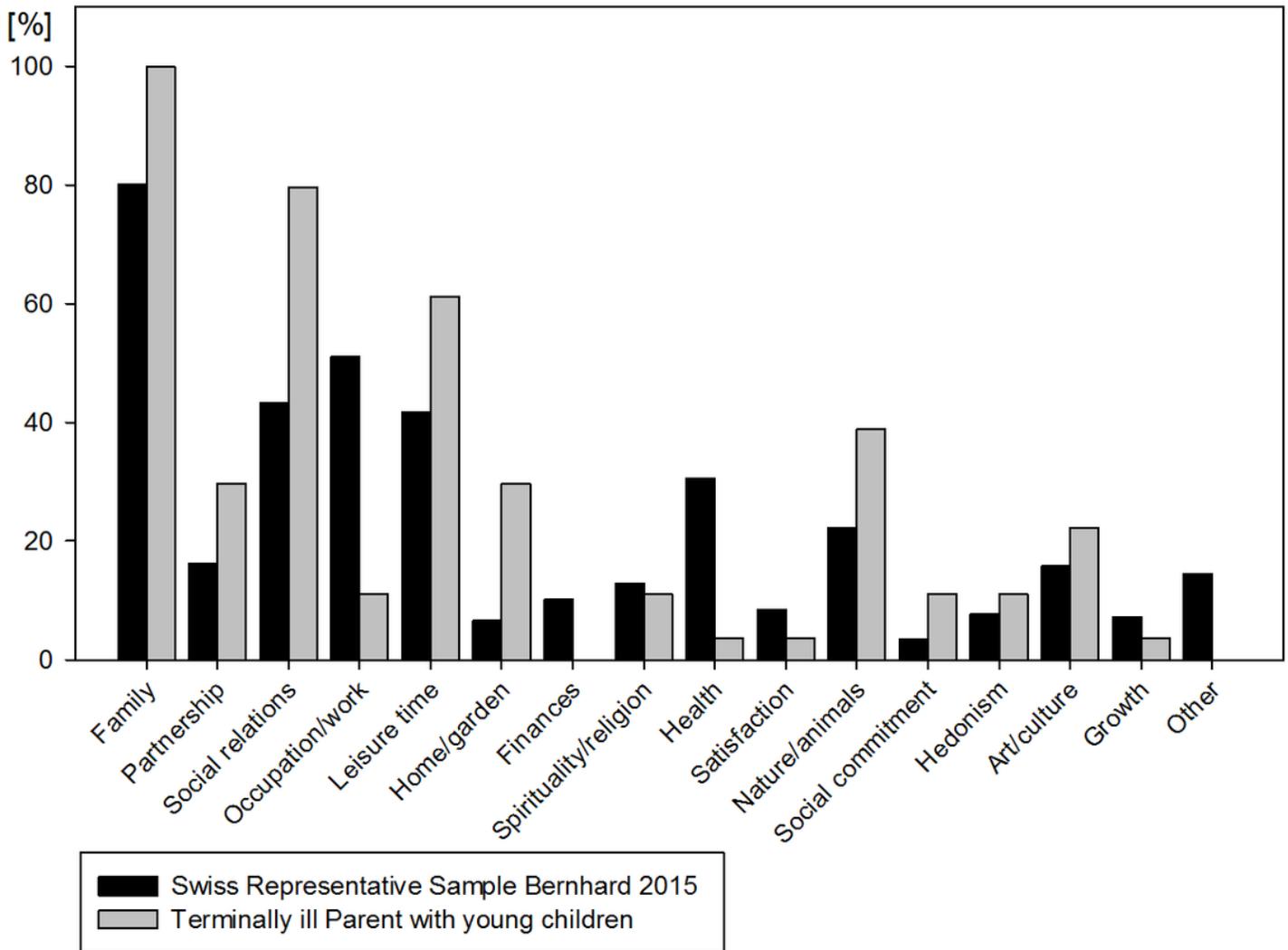
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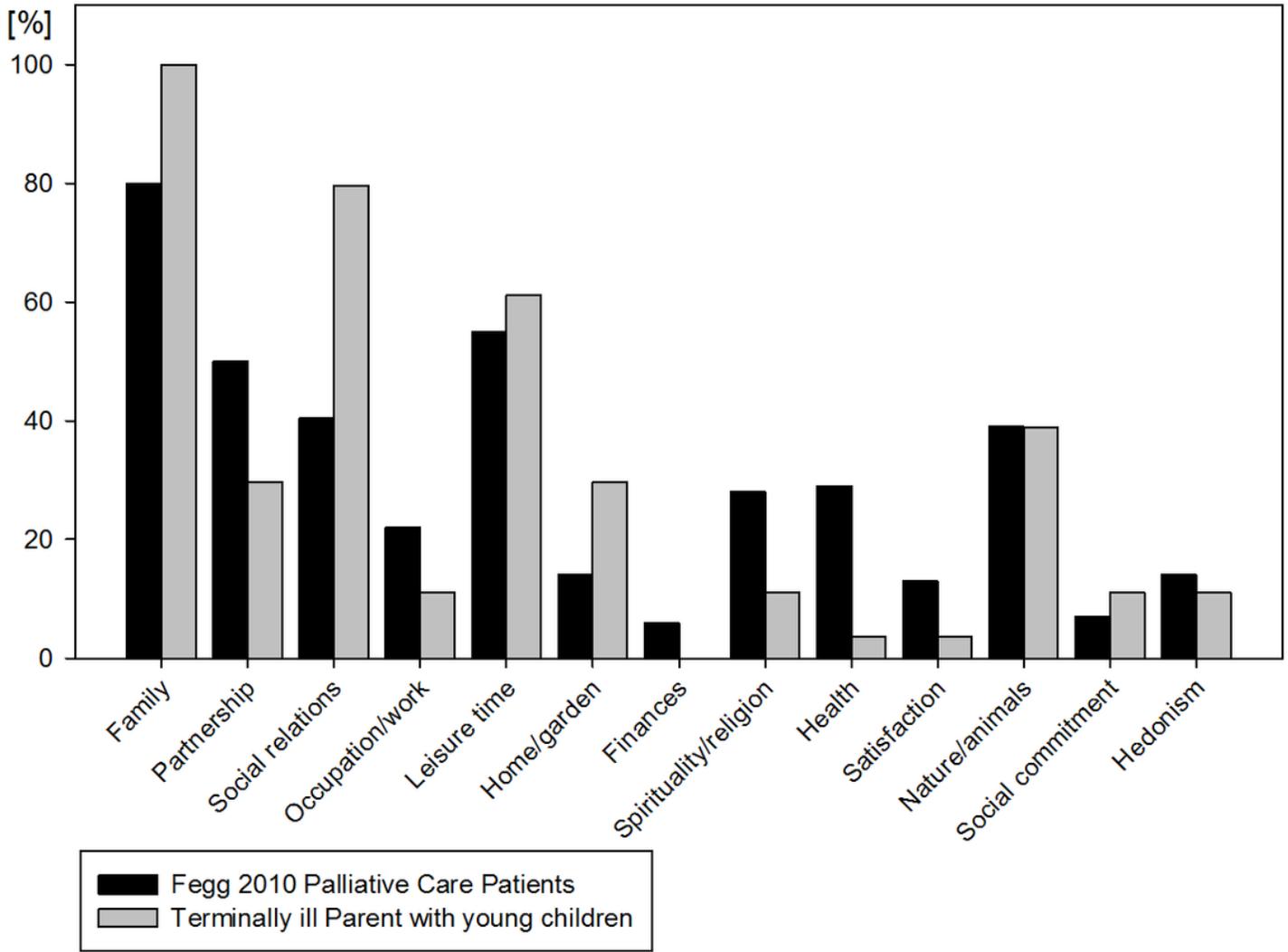
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## Figures



**Figure 1**

Areas of MiL: Categories mentioned by the Swiss representative sample compared terminally ill parent with young children



**Figure 2**

Comparison Palliative Care Patients (PC) with Terminally ill with young children (TP)