



## Lay Summary

### ***Meaning in life, personal values, and spirituality at the end of life***

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## 1. Background

Palliative care is defined by the World Health Organization as “an approach that improves the quality of life of individuals and their families facing problems associated with a life limiting illness, through prevention and relief of suffering by means of identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. Quality of life is defined as a multidimensional construct which encompasses physical, cognitive, psychological, social, and also spiritual-existential aspects that contribute to a patient’s total well-being. This concept therefore became an important outcome measure in palliative care research. Some authors highlighted that the existential domain was at least as important as any other domain in predicting the overall perceived quality of life for palliative patients. Numerous studies have shown that quality of life at the end of life is closely linked to non-physical determinants. Recent data show that spiritual/existential well-being is one of the most often cited domains that contribute to quality of life.

The concept of meaning in life became a central one in recent years in the palliative care domain. From a clinical point of view, this construct was first introduced by the Austrian psychiatrist Viktor Frankl, who defined meaning as the manifestation of values which are based on (i) creativity (e.g. work, actions, dedications to causes), (ii) experience (e.g. nature, love), and (iii) attitude (one’s attitude toward suffering and existential problems). Individuals are naturally and strongly disposed to search and find meaning and to feel that their life is therefore worthwhile. meaning in life is one of the most severely affected domains in patients with terminal illness and has been included as an indicator of well-being in several studies in palliative care.

Little is known about the relationship between meaning in life, personal values, and spirituality as well as their significance in the context of wishes for hastened death and their interplay with depression and anxiety at the end of life. Recently, there has been a growing interest in understanding the wish to hasten death in the area of palliative care. Studies suggest a multi-factorial basis for the wish to hasten death that includes pain, physical suffering, existential distress, and psychiatric disorders. Available data indicate that physical suffering does not play a key role in wishes for hastened death. Rather, more general existential (e.g., loss of meaning and hopelessness), psychological (depression) and social (feeling like a burden) aspects are the most prevalent factors underlying this type of wish.

## 2. Goals of the project

Our research questions were the following:

- 1) What is the perception of meaning in life in palliative patients in Switzerland?
  - Which are the relevant areas for meaning in life?
  - What is the level of importance assigned to the relevant areas, the perceived satisfaction regarding those areas and their relation to the meaning in life total score?
  - Is there any notable difference with regard to the patients’ linguistic origins and the different meaning in life parameters?
- 2) What is the relation between personal values, the concept of meaning in life, spirituality, and the wish toward hastened death for palliative patients? What is the nature of

the relation between these concepts and the symptoms of depression and anxiety?  
Are there differences between the three linguistic regions of Switzerland?

- 3) In which measure these non-physical determinants can be regarded as significant predictors of perceived quality of life?

### 3. Methods

We performed face-to-face interviews in three culturally, geographically, and linguistically diverse regions of Switzerland: Lausanne/Vaud, St-Gallen, Bellinzona/Ticino. **The inclusion criteria** for eligible patients were (i) 18 years or older, (ii) treated by one of the palliative care teams involved either in a hospital palliative care unit or in a palliative care home setting, and (iii) <6 months life expectancy according to the treating physician. **The exclusions criteria** were (i) evidence of psychiatric disease impacting the capacity for discernment, (ii) evidence of significant cognitive impairment, and (iii) insufficient knowledge of the local language.

**The standardised questionnaires** were:

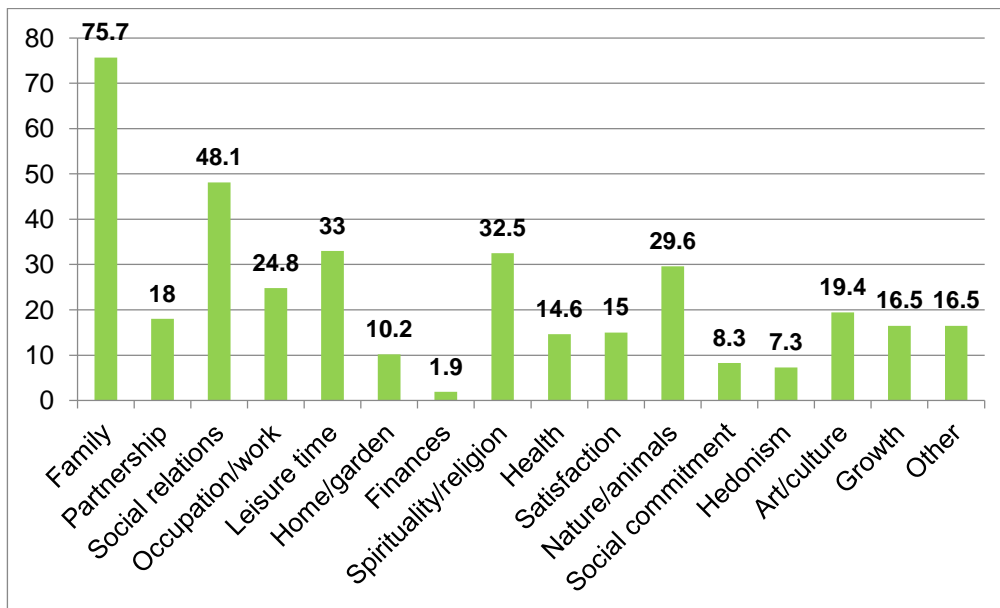
- *The Scheduled for meaning in life evaluation (SMILE)*: this questionnaire focuses on the sources of meaning in life. It allows the identification of life areas providing meaning in life and the levels of importance and satisfaction associated with those areas.
- *The Scheduled of Attitudes towards Hastened Death*: the questionnaire aims to evaluate the wish for hastened death among terminally ill patients, from general ideas about hastened death to concrete requests for euthanasia and physician-assisted suicide.
- *The Idler Index of Religiosity* measures formal and Informal (private) religiosity.
- *The Single-Item quality of life scale*: global quality of life is measured with a rating scale from 0 (worst imaginable quality of life) to 10 (best imaginable quality of life).
- *The Portrait Values Questionnaire* measures the importance of ten values: universalism, benevolence, achievement, power, conformity, tradition, security, self-direction, stimulation, and hedonism.
- *The Spiritual subscale of the Functional Assessment of Chronic Illness Therapy*: This spiritual well-being scale comprises three subscales: meaning, sense of peace, faith.
- *The Hospital Anxiety and Depression Scale*.

### 4. Results

#### 4.1 Recruitment characteristics and descriptive results

- 206 participants were recruited (91 in the German, 77 in the French, 40 in the Italian part). They all came from inpatient palliative care units or home palliative care services.
- Most patients had cancer (96%), particularly digestive, pulmonary and urological cancer. The mean age of the patients was 67.5 years.
- The most mentioned life areas contributing to meaning in life were “family” (76%), “social relation” (48%), leisure time (33%), and “spirituality/religion” (33%), see figure 1 below.

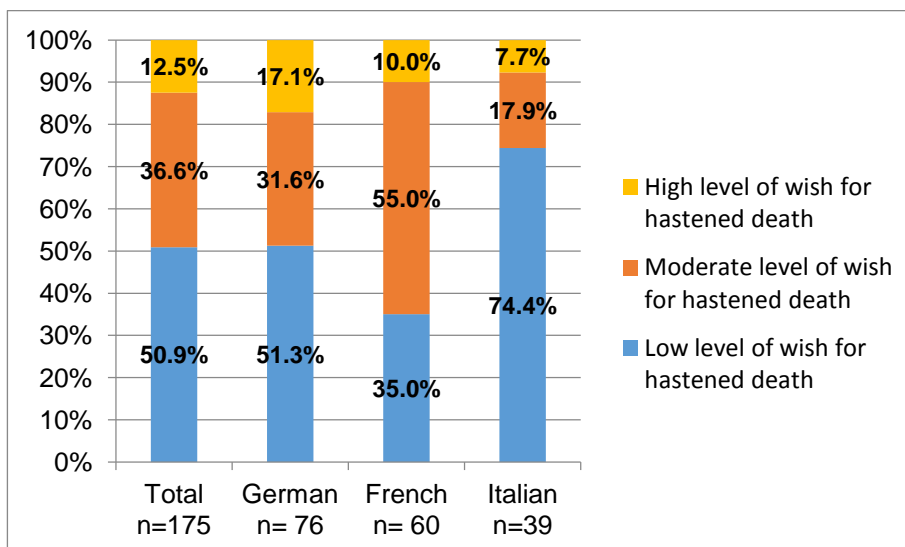
**Figure 1.** Life areas contributing to meaning in life (%)



The category “partnership” was more often mentioned by the German than the French and Italian participants (G=31.5%; F=10.4%; I=2.5%). The category “occupation/work” was more often mentioned by Italian participants (I=50%; G=27%; F=9.1%). The category “spirituality/religion” was more often cited by the German participants (G=50.6%; F=24.7%; I=7.5%).

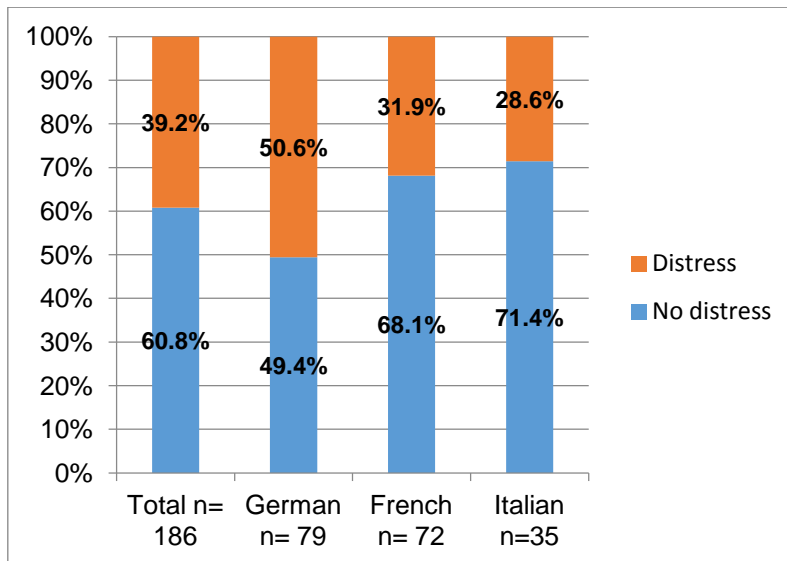
- There was a generally “low to moderate” level of wish for hastened death in the total sample. French and German participants had a higher level than the Italians.

**Figure 2.** “High” vs “moderate” vs “low” wish for hastened death



- 39% of the total sample showed significant psychological distress, which was higher for the German than the French and the Italian patients.

**Figure 3.** “Psychological distress” vs “no distress”



#### 4.2 Predictors of the wish for hastened death and psychological distress

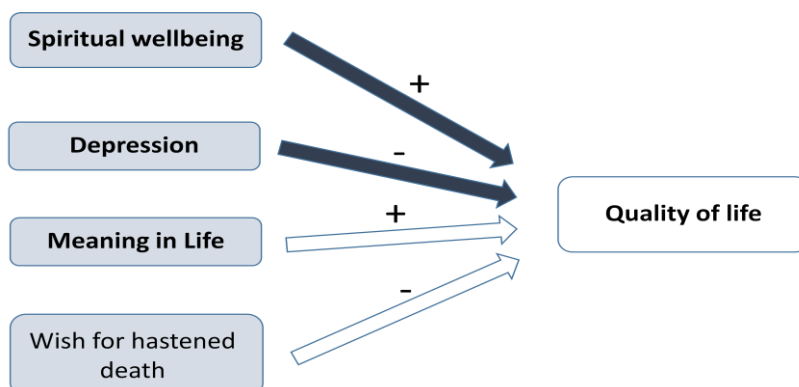
The main results are as follows:

1. There is a negative relationship between spiritual well-being (particularly its meaning dimension) and the wish for hastened death.
2. There is a negative relationship between psychological distress and spiritual well-being.
3. There is a negative relationship between psychological distress and meaning in life.

#### 4.3 Predictors of perceived quality of life

From all the variables considered in this study, the best predictors of the patients’ quality of life are spiritual wellbeing, depression and the wish for hastened death. Considered all together, these variables explain 37.4% of the perceived quality of life (see figure 4 below). Among these variables, spiritual wellbeing (positive) and depression (negative) are the strongest predictors of quality of life.

**Figure 4.** Variables influencing the quality of life



#### 4.4 Personal values in palliative patients: “benevolence” and “universalism”

The results indicate

- a negative relationship between psychological distress and benevolence.
- a negative relationship between depression and benevolence.
- a positive relationship between spiritual wellbeing and benevolence.
- a positive relationship between meaning in life and benevolence.
- a positive relationship between meaning in life and universalism.

### 5. Significance of the results for science and practice

- 1) The most important results of this study are:
  - a. The “**family**” and “**social relationships**” categories are the most cited life areas contributing to meaning in life.
  - b. **Spiritual wellbeing is a protective factor** against wish for hastened death, anxiety and depression in palliative patients.
  - c. **Non-physical determinants** contribute to a large extent to the quality of life of palliative care patients.
  - d. Among the non-physical determinants, spiritual well-being and depressive symptoms are the best predictors of quality of life in palliative care patients.
  - e. **Benevolence**, as an altruistic value, correlates negatively with depression and positively with spiritual wellbeing.
  - f. Our results were relatively homogeneous between the three linguistic regions.
- 2) In order to implement these results into clinical practice, the following points need to be taken into account:
  - a. There is an urgent need to clarify and determine the **criteria used for identifying depression** in the palliative care setting.
  - b. There is a necessity to determine a valid instrument in order to **assess existential suffering** in the palliative care setting.
  - c. Some study limitations need to be considered, including the great fragility of the palliative care patients and the fact that functional and physical indicators were not considered for this study.
- 3) Possible interventional or clinical developments for the future include:
  - a. The development of a **specific psychotherapeutic intervention** aimed at stabilizing or restoring spiritual well-being and meaning in life in palliative care patients, taking into account the specificity of the palliative care setting and the fragility of the patients.
  - b. The use of **questionnaires such as the SMILE as door-openers** to communicate with patients about non-physical determinants of quality of life may represent a starting point for an intervention.

- c. The implementation of **specific communication skills trainings** dedicated to end of life issues may help health care professionals to detect and respond to existential/spiritual needs expressed by palliative patients.
- 4) The following recommendations can be issued to PNR stakeholders as a result of this project:
  - a. The role and the necessity of developing **interprofessional collaboration** (including psychologists, social workers, and chaplains) in the palliative care setting is clearly supported by our results, since the patients' quality of life is largely explained by non-physical determinants. This has implications for resource allocations, consistently with the definition of palliative care given by the World Health Organization.
  - b. Special attention and consideration need to be given to the **family and significant others**. It is clear from our data that they represent a crucial aspect for terminally ill patients, through the altruistic values shown by the patients and as a major area contributing to meaning in life.
  - c. Research funds should be allocated to the **development of interventions specifically aimed at non-physical determinants of quality of life** (meaning in life, spiritual wellbeing), given their crucial role for quality of life at the end of life.