A better understanding of the concept “a good death”:

How do patients, close relatives and healthcare providers define a good death and which affecting factors are important?

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Abstract

Title: To a better understanding of the concept of “a good death”: How do patients, close relatives and healthcare providers define a good death and which affecting factors are important?

Introduction: The goal of palliative care is to improve the quality of life when recovery isn’t possible anymore. The objective is to widen our vision of potential (unspoken) needs at the end of life with patients, close relatives, nurses and general practitioners. This is to aim at a more versatile, but personal care at the end of life. The research question is: “How important do patients, close relatives and healthcare providers consider the 11 core themes in defining a good death as described in the article of Meier ‘Defining a Good Death’ in 2016?”

Method: Specific questionnaires for general practitioners, nurses, patients and family members were distributed in the working area of the Palliative Care Network in the region Aalst-Dendermonde-Ninove with the cooperation of 5 Local Quality Groups (LOK’s), 2 nursing homes and 2 groups of homecare nurses. The data was analyzed with Microsoft Excel 2016 and the statistical program SAS.

Results: The questionnaire was completed by 67 nurses, 57 general practitioners, 16 patients and 8 family members. Although, the 34 subthemes were generally considered important to be able to speak of a good death, there were still significant differences determined with healthcare providers, between general practitioners and nurses, men and women, and depending on their age. Nurses found the following themes significantly more important than general practitioners: dying during sleep, the patient isn’t a burden to their close relatives, life well lived, faith, all available treatments were used, the patient’s last phase of life can be lived in a usual and meaningful manner, he/she can talk to their healthcare provider about spiritual beliefs or fears in relation to dying, the presence of pets and the cost of healthcare. All groups considered unanimously that a pain-free death was the most important. General practitioners, nurses, patients and close relatives found the following themes as important: support of family, respect for the patient as an individual, being able to say goodbye and euthanasia in case of unbearable suffering.

Discussion and conclusion: In agreement with the patient, medical care should focus on a pain-free situation during the last phase of life and not on the exhaustion of possible treatments which prolongs life unnecessarily. Appropriate care at the end of life can be broader and all 34 subtheme’s can be important in early healthcare planning.
Significant differences between general practitioners and nurses deserve attention, because patients and family members expect that healthcare providers will work together as a team.

Introduction

Dying is inextricably tied to life, yet we still notice a reluctance to speak about death. However, a good death is an important goal in palliative care. We know that this can go further than “being pain-free”. One of the pioneers, Cicely Saunders, spoke in the 50’s already of “Total pain concept”. We can find this in the definition of palliative care, prepared by the WHO in 2002 (1). The general practitioner should prevent and relieve suffering on a physical, psychological, emotional, social and spiritual level. Open communication is important for a successful guidance/care of terminally ill patients and their close relatives. According to the definition of the American Institution of Medicine, a good death is free from avoidable distress and suffering for patients, family members and healthcare providers; in general accord with the patients and family members wishes; and reasonably consistent with clinical, cultural and ethical standards (2). Meier and her co-authors researched in 2015 which themes were previously addressed in the literature in order to know what was really important. Eleven core themes were identified to be able to define a good death, specifically: preferences related to the dying process, a pain-free situation, emotional well-being, family, dignity, completion of life, religiosity-spirituality, preferences in regards to treatments, quality of life, relationship with healthcare providers and others; each with 2 to 4 subthemes (3). There is a consensus between patients, family members and healthcare providers about the importance of the themes in order to talk of a good death. There are still differences, depending who is asking. From the perspective of family members the following themes are mentioned more frequently in the literature: “life completion”, “quality of life”, “dignity” and “presence of family”. On the other hand, from the perspective of patients, “religiosity and spirituality” are mentioned more often as a theme, as part of a good death. Other research highlights how important we find “control” in the West: control over time and place of dying (often with preference for home environment), control over unwanted symptoms, planning and preparing on different levels (4). We can frequently read or hear editorials about dying, in which the euthanasia debate in Belgium has acquired a very important role. We live in one of the few countries where euthanasia is regulated by law and often this is considered obvious by patients. Is this about having control as mentioned above? Other factors are also discussed why euthanasia plays an important role, such as the denial of the natural dying process by existential uncertainty or the increased medicalization of the terminal phase of life (4, 5). Patients affix more to the integration of spiritual care as the end of life approaches (6). General practitioners also view the importance of spiritual well-being of their patients, but applying this in practice seems to be more difficult for various reasons, such as lack of time and uncertainty or lack of vocabulary to engage in these conversations. References to other professionals can be necessary when spiritual needs are identified and the general practitioner feels uncomfortable to take this role upon themself. Therefore, it is important in palliative care for interdisciplinary cooperation (7). The goal is to broaden our view of the possible (unspoken) needs at the end of life with patients, close relatives, nurses and general practitioners. On one hand this is to strive for versatile, but personal care at the end of life. On the other hand, this is to integrate this information in discussions about early care planning. We want to know howimportant the eleven core themes are to define a good death to patients, close relatives and healthcare providers as described in the article of Meier “Defining a Good Death” in 2016?

Method

The 11 core themes and 34 subthemes in Meiers’ paper were translated and poured into a query for the four groups: patients, close relatives, nurses and general practitioners. Each participant scored their answer on a symmetric Likert scale of 0-10, depicted as a visual analogue scale:

- “How important do you find the below themes to speak of “a good death” (for your family member/close relative) (for your patient)?”

The questionnaires were distributed over the scope of the Palliative Care Network in the region Aalst-Dendermonde-Ninove (Flanders, Belgium) after a pilot study with each target group. To do so, there was a collaboration with the Palliative Care Network itself, five local quality groups of GPs (LOK), two nursing homesand two groups of home care nurses. The general practitioners were included through the LOK’s and they were also asked to include legally capable patients older than 18 registered in their practice as patient or close relative. Nurses were included through the nursing home , the Palliative Network and home nursing groups.
The data was analyzed with Microsoft Excel 2016 and the statistical software program SAS. The GLM procedure was applied to the latter. Independent variables include the group (general practitioner/nurse), gender and age. The dependent variables are the 34 subthemes identified by Meier et al (3). The scores from 0 to 10 are continuously divided.

Ethics Committee

The study was approved by the programme-specific Ethics Advisory Committee of “Masters in Family Medicine” education (Leuven and others) on 3/30/2017.

Results

A total of 67 nurses, 57 general practitioners, 16 patients and 8 family members took part in the study. The main characteristics of the participants are summarized in table 1. The percentages specify the share in relation to the total group.

Table 1: Characteristics of the participants

	General Practitioners n=57 (%)	Nurses n=67 (%)	Patients n=16 (%)	Close Relatives n=8 (%)
Gender				
M	37 (65%)	6 (9%)	6 (38%)	0 (0%)
F	20 (35%)	61 (91%)	10 (62%)	8 (100%)
Age				
<25	0 (0%)	3 (5%)	2 (13%)	1 (13%)
25-34	7 (12%)	14 (21%)	2 (13%)	0 (0%)
35-44	4 (7%)	31 (46%)	0 (0%)	1 (13%)
45-54	15 (26%)	11 (16%)	3 (19%)	2 (25%)
55-64	24 (42%)	5 (8%)	4 (25%)	2 (25%)
≥65	5 (9%)	0 (0%)	5 (31%)	2 (25%)
Reflection on a good death?				
Yes	51 (89%)	63 (94%)	14 (88%)	7 (88%)
No	6 (11%)	3 (5%)	2 (12%)	1 (12%)
Terminal care frequency				
Occasional	17 (30%)	9 (13%)		
Monthly	22 (39%)	23 (34%)		
Weekly	14 (25%)	14 (21%)		
Daily	3 (5%)	20 (30%)		
In practice				
Solo	26 (46%)			
Duo	7 (12%)			
Group	23 (40%)			
Home care nurse		46 (69%)		
Palliative Network		5 (7%)		
Nursing Home		16 (28%)		
Education				
Basic			0 (0%)	0 (0%)
Secondary			8 (50%)	1 (13%)
Higher			5 (31%)	4 (50%)
Academic			3 (19%)	3 (37%)

Remark: Percentages are rounded to the nearest integer. Invalid answers are not displayed.

Results Healthcare Providers

Significant differences between general practitioners and nurses can be found in table 2. The highest scores in both groups are given on the core theme, a pain-free situation (no suffering, and pain- and symptom management).

*Table 2: Results compared between general practitioners and nurses. (Significant values are indicated with *)*

	General Practitioner Average ± SD	**Nurse** Average ± SD	Not completed	P-value
Preferences for dying process				
Death scene (where, how, …)	8,44 ± 1,52	8,76 ± 1,21	2	0,4900
Dying during sleep	6,52 ± 2,05	7,79 ± 1,87	2	0,0184*
Preparations for death (Last Will and Testament,…)	7,71 ± 1,78	8,23 ± 1,57	2	0,3615
A pain-free status				
Pain- and symptom management	9,48 ± 0,70	9,53 ± 0,83	2	0,1050
Not suffering	9,26 ± 0,85	9,63 ± 0,73	2	0,6009
Emotional well-being				
Emotional support	8,58 ± 1,49	9,03 ± 1,21	2	0,3407
Psychological comfort	8,56 ± 1,34	9,08 ± 1,04	2	0,6047
Chance to discuss the meaning of death	7,61 ± 1,73	8,22 ± 1,46	2	0,9618
Family/close relatives				
Family support	8,70 ± 0,99	8,94 ± 1,17	2	0,5734
Family acceptance of death	8,01 ± 1,48	8,43 ± 1,54	3	0,4965
Family is prepared for death	8,16 ± 1,32	8,81 ± 1,15	2	0,7521
Not being a burden to close relatives	5,37 ± 2,25	7, 51 ± 2,04	2	0,0007*
Dignity				
Respect for patient as a unique individual	8,69 ± 1,47	8,94 ± 1,03	2	0,4489
Patient independency	6,95 ± 2,11	7,38 ± 1,94	3	0,2729
Completion in life				
Saying goodbye	8,54 ± 1,36	9,12 ± 1,07	2	0,6530
Life well lived	5,57 ± 2,43	7,37 ± 2,00	2	0,0022*
Acceptance of death	7,66 ± 1,55	8,10 ± 1,58	2	0,6839
Religiosity and spirituality				
Religious or spiritual comfort	6,93 ± 1,82	7,30 ± 2,00	2	0,9706
Faith	6,15 ± 2,15	7,52 ± 2,10	2	0,0049*
Spiritual or layman consultant	6,49 ± 2,14	7,27 ± 2,06	2	0,0907
Preferences in terms of treatments				
Not prolonging life (unnecessarily)	8,99 ± 1,15	8,75 ± 1,44	2	0,5247
All available treatments	5,74 ± 2,33	7,60 ± 2,49	2	0,0025*
Control over treatment	8,25 ± 1,66	8,90 ± 1,17	2	0,5051
Euthanasia in case of unbearable suffering	8,96 ± 1,33	9,09 ± 1,18	2	0,5344
Quality of life				
Living as usual	7,02 ± 1,87	8,22 ± 1,36	3	0,0025*
Maintaining hope, pleasure and gratitude	8,23 ± 1,44	8,74 ± 1,15	3	0,2116
Life is worth living	7,04 ± 2,01	8,40 ± 1,34	2	0,0122*
Relationship with healthcare providers				
Support from healthcare provider	8,87 ± 1,08	9,03 ± 1,06	2	0,5561
Experience with terminal care	8,45 ± 1,34	8,90 ± 1,20	2	0,6122
Discuss spiritual beliefs with healthcare provider	7,75 ± 1,80	8,46 ± 1,28	2	0,0350*
Other				
Recognition of cultural background	7,32 ± 2,01	7,94 ± 1,51	2	0,3311
Physical touch when dying	7,12 ± 2,05	8,04 ± 1,64	2	0,0826
Being with pets	6,02 ± 2,94	8,27 ± 1,66	3	<0,0001*
Healthcare costs	5,05 ± 2,45	7,35 ± 2,38	2	0,0001*

SD: standard deviation
*P<0,05

The differences between male and female healthcare providers (general practitioners and nurses) are displayed in table 3. The male healthcare providers do not find any themes significantly more important than the female healthcare providers to speak of a good death.

*Table 3: Results compared between male and female healthcare providers. (Significant values are displayed with *)*

	Male Average ± SD	**Female** Average ± SD	Not competed	P-value
Preferences for dying process				
Death scene (where, how,…)	8,09 ± 1,49	8,89 ± 1,22	2	0,0065*
Dying during sleep	6,55 ± 2,13	7,56 ± 1,93	2	0.2194
Preparations for death	7,65 ± 1,96	8,17 ± 1,50	2	0,4491
A pain-free situation				
Pain- and symptom management	9,24 ± 0,80	9,65 ± 0,72	2	0,0084*
Not suffering	8,95 ± 0,94	9,73 ± 0,57	2	<0,0001*
Emotional well-being				
Emotional support	8,14 ± 1,55	9,19 ± 1,09	2	0,0012*
Psychological well-being	8,16 ± 1,36	9,20 ± 0,95	2	0,0002*
Chance to discus the meaning of death	7,21 ± 1,73	8,33 ± 1,41	2	0,0096*
Family/close relatives				
Support from family	8,70 ± 0,93	8,90 ± 1,17	2	0,5735
Family can accept death	7,61 ± 2,10	8,57 ± 1,26	3	0,0045*
Family is prepared for death	7,86 ± 1,41	8,85 ± 1,04	2	0,0039*
Not being a burden to close relatives	5,37 ± 2,48	7,14 ± 2,10	2	0,0696
Dignity				
Respect for patient as a unique individual	8,43 ± 1,54	9,04 ± 1,02	2	0,0670
Patient independency	7,02 ± 2,35	7,27 ± 1,97	3	0,9319
Completion in life				
Saying goodbye	8,30 ± 1,42	9,15 ± 1,03	2	0,0183*
Life well lived	5,78 ± 2,55	6,95 ± 2,18	2	0,7905
Acceptance of death	7,27 ± 1,76	8,23 ± 1,36	2	0,0315*
Religiosity and spirituality				
Religious and spiritual comfort	6,63 ± 1,94	7,40 ± 1,87	2	0,0318*
Faith	6,22 ± 2,33	7,25 ± 2,09	2	0,1893
Spiritual or layman consultant	6,53 ± 2,34	7,11 ± 1,99	2	0,2388
Preferences in terms of treatments				
Not prolonging life (unnecessarily)	8,90 ± 1,23	8,84 ± 1,36	2	0,5380
All available treatments	5,90 ± 2,21	7,19 ± 2,66	2	0,5198
Control over treatment	8,07 ± 1,74	8,88 ± 1,77	2	0,3267
Euthanasia in case of unbearable suffering	8,81 ± 1,42	9,14 ± 1,14	2	0,5666
Quality of life				
Living as usual	7,12 ± 1,80	7,96 ± 1,76	3	0,9822
Maintaining hope, pleasure and gratitude	8,21 ± 1,78	8,66 ± 1,30	3	0,4467
Life is worth living	6,97 ± 2,02	8,20 ± 1,53	2	0,1740
Relationship with healthcare providers				
Support from healthcare provider	8,62 ± 1,14	9,14 ± 0,99	2	0,1706
Experience with terminal care	8,23 ± 1,36	8,93 ± 1,17	2	0,0234*
Discuss spiritual beliefs with healthcare provider	7,81 ± 1,67	8,30 ± 1,50	2	0,4836
Other				
Recognition of cultural background	7,23 ± 2,02	7,88 ± 1,60	2	0,2399
Physical touch when dying	7,02 ± 1,93	7,93 ± 1,80	2	0,1144
Being with pets	6,36 ± 2,77	7,70 ± 2,44	3	0,9246
Healthcare costs	5,37 ± 2,53	6,78 ± 2,61	2	0,8971

SD: standard deviation
*P<0,05

Based on non-normal distribution, there was no statistically significant difference in scoring in the degree of importance of the themes to speak of a good death for their patient in function of age.

Results Patients and Close Relatives

No significant differences can be calculated due to the limited scale of these groups and only Excel was used for further analysis.

Figure 1: Scores by patients

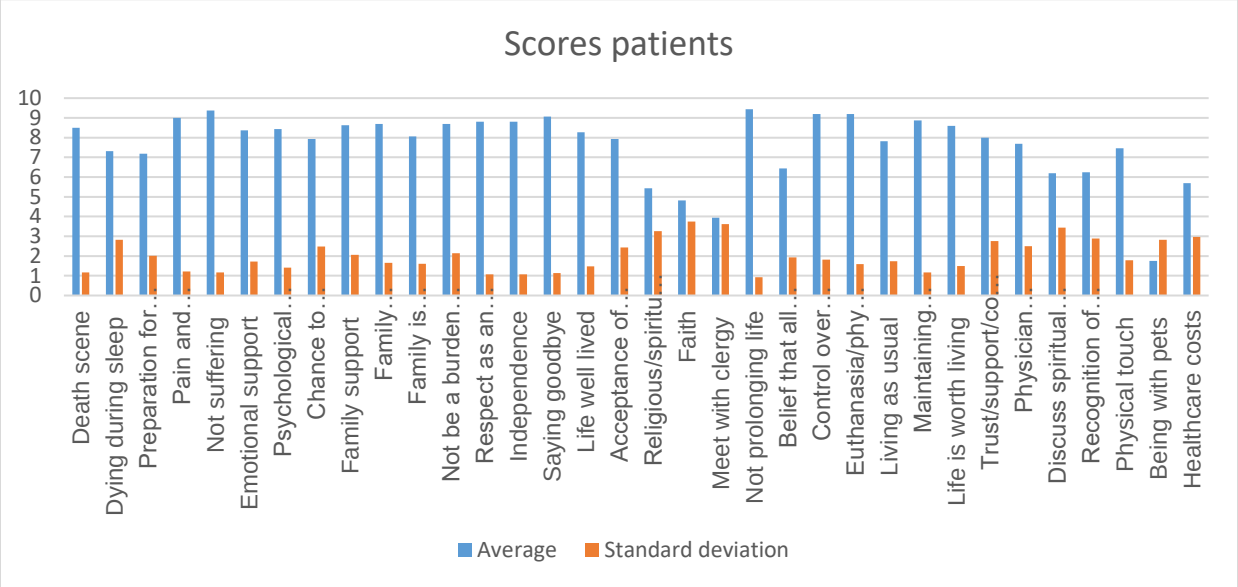
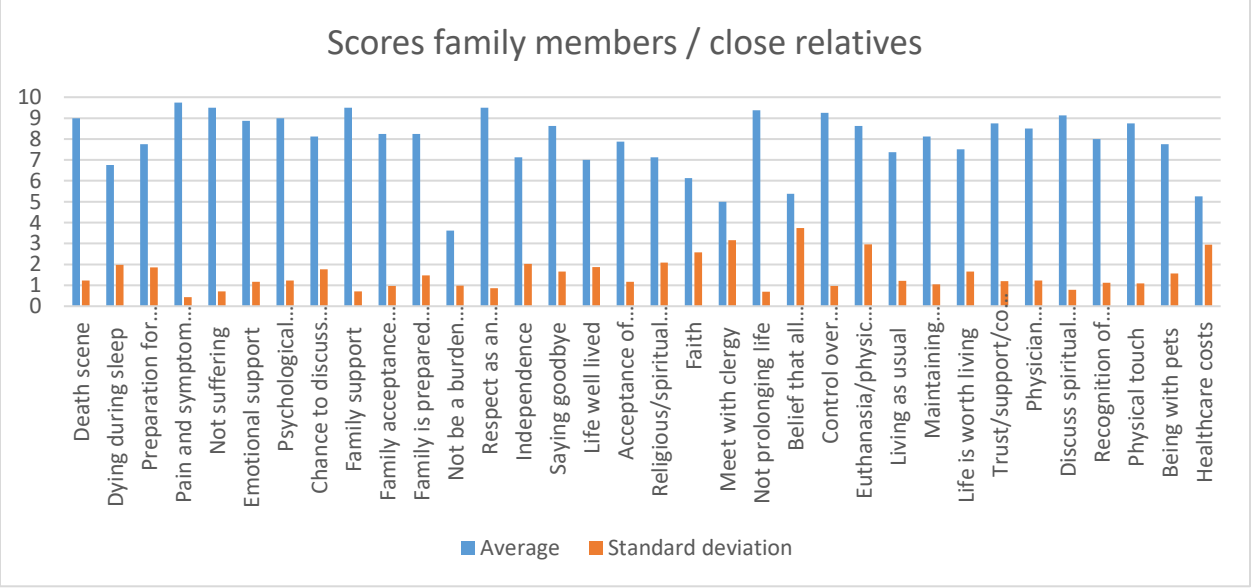


Figure 2: Scores by family members



The main differences are seen in the following themes: being with pets, patient is not being a burden to their close relatives in their final phase of life, spiritual beliefs can be discussed with

their healthcare provider, recognition of cultural background, religious or spiritual comfort and patient independency.

Discussion

Patients as well as close relatives and healthcare providers generally gave a high score to the 34 covered subthemes. This indicates that all themes can play an important role in appropriate care in the last phase of life. A “pain-free situation” was unanimously presented by all groups as the most important core theme that is in line with the article of Meier et al, which supported this research (3). Results show that medical treatments should focus on a pain-free final stage of life and not on exhausting all possible treatments that (needlessly) prolong life, in which the patient keeps control of his own treatment. In addition, general practitioners, nurses, patients and close relatives also considered the following themes very important: support by family, respect for patient as an individual, being able to say goodbye and euthanasia in case of unbearable suffering. Since the law regarding euthanasia has been promulgated on May 28, 2002, euthanasia seems more and more accepted based on these results. However, there is a big difference between finding the possibility of euthanasia when there is unbearable suffering important, and to request or perform euthanasia.

Experience with terminal care by general practitioners and nurses was considered important by the healthcare providers themselves and the family members. A healthcare provider whom is well aware of what palliative care can mean, will see the needs more rapidly and will provide the necessary additional care at the end of life. This is also important to keep in mind for a good education in family medicine.

Religiosity and spirituality were considered less important by all parties compared to other themes. This was scored low by patients and family members. After reading the literature this was rather surprising. A possible explanation for this could be that the participants didn’t have much understanding of the concept of spirituality. Furthermore, we see a large distribution in all groups, which means that religion and spirituality are being experienced individually, for one irrelevant and for the other necessary to speak of a good death.

Professionals as well as patients and close relatives gave the lowest scores to health care expenses. Does this indicate that it is difficult for those directly involved to integrate a general concern such as healthcare costs in the individual care of the patient at the end of life?

Nurses gave the themes for a good death in general a higher score in importance than general practitioners. A possible reason could be that these healthcare providers often have a much closer and intimate relationship with their patient (and their close relatives). Significant differences were also found. Nurses considered it more important than general practitioners that all available treatments were used. This is important to reflect on in practice, because patients can receive conflicting messages about whether or not to undergo, for example, an additional (invasive) examination or a third-line chemotherapy. Another explanation could be that general practitioners have a more comprehensive picture of possible treatments in comparison to nurses in home care and nursing home. Moreover, it is possible that the question “all available treatments” leaves too much space for interpretation. Another important difference is that the general practitioners consider the healthcare costs for a good terminal care less important than nurses. Could this difference of opinion have an influence on the predetermined care by the concerning healthcare

provider? The importance that the patient won't be a burden to their close relatives at the end of life is another significant difference between general practitioners and nurses. Presumably the nurse who takes care of the patient and their environment daily in the nursing home or at home finds this more important, because he/she is confronted daily with the consequences of an increasing need of care in all areas (physical, psychological, spiritual,…). It is also very striking that the participating family members found it less important that their close relative would become a burden to them in their last phase of life. However, patients themselves found it important not to be a burden to their relatives to be able to speak of a good death. This is reflected in the theme of independence, which was scored high by patients and rather low by family members. A possible explanation is that family members perceive the care of their terminal close relative less as a burden than the patient themself. Although this care can be tough, it gives to some purpose and meaning which in turn gives them strength. Misunderstandings and tensions can be avoided with open communication. This is particularly important, because healthcare providers, unanimously, consider support from family members very important.

It is striking that the female healthcare provider often gave higher scores than their male colleagues. They found both the emotional as spiritual or religious comfort of the patient significantly more important. This could mean that less attention will be paid to a patient who happens to have a male nurse and general practitioner.

88% or more of all participants said they had once thought about a good death. Nevertheless, it is clear from literature that it is more difficult to discuss impending death for patients as well as close relatives and caregivers. Being able to have this conversation can be a great relief for patients and their close relatives and it is very important for healthcare providers to offer customized care for the patient.

The Federal Resource Center for Healthcare in Belgium published in december 2017 an important report about appropriate care at the end of life. Nine aspects are hereby mentioned in the definition of appropriate care at the end of life. (8)

Table 1: KCE report 296: Appropriate care at the end of life (8)

Appropriate care at the end of life	1	relieves the patient's physical pain and insures their well-being and comfort
	2	corresponds with the patient their vision, wishes and choices
	3	is a personalized and complete care, adapted to the patient their situation and needs
	4	supports both patients and their close relatives
	5	is given by trained and experienced healthcare providers
	6	is given by healthcare providers with empathetic and respectful attitude
	7	is given by healthcare providers who take their time to listen to the patient and their family
	8	is given by healthcare providers who work together in a multidisciplinary team
	9	Is given by healthcare providers who openly communicate with all those involved, including the patient and their family

Even though this study was conducted in a very different way (along with the use of open questions), a comparison is interesting. All these 9 aspects are implicitly or explicitly addressed in the 34 surveyed subthemes. The first aspect corresponds with the high scores of the core themes, a pain-free situation and emotional well-being. The second and third criterion could be compared with the core themes preferences related to the dying process and preferences related

to treatments. The fourth condition shows the importance of family and close relatives. This emerges in the research of the core theme of family (support by family, family can accept the death, family is prepared for the death and patient is no burden to their close relatives). The last fiveconditions are about the healthcare providers or caregivers, which is defined more extensively in the core theme of relationship with healthcare providers. In the subthemes we see that experience and spiritual beliefs can be discussed with healthcare providers (in which an empathetic attitude is necessary) and support by healthcare providers is mentioned. Taking time to openly communicate with all involved parties is not literally questioned in the research, but is a necessary condition if you want to discuss all 34 subthemes. The KCE report assigns the cooperation in a multidisciplinary team, which is missing in the themes of Meier et al.

Conclusion

Patients, family members, nurses and general practitioners generally gave high scores to the 34 subthemes regarding a good death, which indicates that all of these themes can play an important role in the appropriate care at the end of life and thus addressed in a discussion about early care planning. Medical treatments should focus on a pain-free last phase of life and not on the exhaustion of possible treatments which prolongs life unnecessarily, this should always be in agreement with the patient. Significant differences between general practitioners and nurses deserve attention in the clinical practice, because patients and family members expect that healthcare providers work as a team.

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