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EDITORIAL

Lessons from assessment of quality in palliative care

Marinela Olăroiu, MD, PhD, Editor-in-Chief of PALIAȚIA

There is no doubt: palliative care is important. It is not because recently the World Health Organisation (WHO) has confirmed the need for palliative care worldwide. It is because palliative care adds quality to human life, not only quality of life for patients, but also for their beloved ones. Also, palliative care may save health care costs. Not because patients die earlier, on the contrary, they may live longer. The cost saving is because less unnecessary expensive medical interventions are executed when proper palliative care is available.

There is no doubt: palliative care is not easy. On the contrary, it is a difficult, challenging task. It asks for expertise, skills and compassion of health care professionals and for commitment and compassion of family and volunteers. In this issue of PALIAȚIA we pay attention to the difficulties health professionals have to encounter when taking care for patients with a terminal disease. Even, this may result in ‘compassion fatigue’ as recent articles indicate, which concept is shortly explained in this issue.

Given its importance and its difficulty the question has to be raised and answered continuously: is the quality of end-of-life care adequate? The question supposes the availability of palliative care. However this care is absent for most people on need. WHO has estimated that only 14% of people in need for palliative care receive such care. Still the question remains: what is the quality of this end-of-life care, which may be answered on two levels: individually and institutionally?

At individual level this quality can be assessed by several instruments like the Quality of Dying and Death (QODD) questionnaire or The Canadian Health Care Evaluation Project (CANHELP). The QODD has been discussed in PALIATIA in 2012. In this issue, the CANHELP questionnaire is presented in a validation study from India to assess the quality of end-of-life care in patients and family members.

At institutional level, quality of palliative care could be assessed in health care institutions but also in national health care policy. Recently, the Economist Intelligence Unit (EIU) presented a worldwide study on the quality of death. For that purpose, the EIU has developed and adapted a ‘Quality of Death Index’. In this issue we present this publication as well as an analysis of the outcomes, which shows where European countries are placed concerning quality of end-of-life care.

The message to take home is: there is a lot of work to do to realize the availability and quality of palliative care.
ORIGINAL PAPERS

Does quality of palliative care improve in Europe?

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Abstract

Objective:
This paper analyses which countries in Europe did increase or decrease their quality of end-of-life care efforts in the last five years. It describes the overall ranking of 27 European countries on the 2015 Quality of Death Index and it compares the changes in ranking on the Quality of Death Index of 22 European countries between 2010 and 2015.

Method:
To assess changes in quality of palliative care the scores and ranking of the Quality of Death Index of 2010 and 2015 were compared. The comparison was made on the Quality of Death Index as well as on two of its domains: affordability of palliative care and quality of care.

Results:
The countries ranking highest on the Quality of Death Index are situated in West-North Europe, the lowest ranking ones in East-South Europe. There is a wide gap between countries ranking high and low. Efforts to improve palliative care vary over time within countries. In Austria and Hungary the ranking on the quality of death index decreased, but in Finland and Portugal the index increased significantly. Overall, the comparison of ranking shows that ‘negative’ changes in ranking between 2010 and 2015 seem more frequently in Central-/Eastern European countries as compared to Scandinavian and Southern-West European countries.

Conclusion:
The comparison of ‘quality of death’ between 22 European countries indicates that palliative care lacks to be an integral part of health care. This applies especially to Central-Eastern European countries. In half of the participating European countries the quality of death did not improve over the last five years. Almost half of the European countries provide insufficient palliative care services for their suffering citizens.

Key words: palliative care, end-of-life care, quality of death, international comparison

Introduction

In 2010 the Economic Intelligence Unit (EIU) published a study on ‘Quality of Death´ of 40 countries, including 24 European ones (1). Based on 4 domains (with 24 indicators) a ‘Quality of Death Index´ was composed. The index intended to assess the quality of end-of-life care in each country (1).

Assessment of quality of palliative care per country is important because it may show what efforts governments make to reduce suffering of citizens, i.e. patients with long-term care needs and/or terminal diseases, and how these governments concern about the quality of life for those patients as well as for their beloved ones. Assessment of quality of end-of-life care is also relevant because recent studies indicate that adequate palliative care may safe health
care costs, which costs are a major concern for many governments, especially in ageing societies (2).

A comparison between countries on the quality of their end-of-life care may contribute to improve palliative care services nationwide and internationally. Comparative studies also demonstrate the cultural differences between countries in the awareness and acceptance of death and dying (3, 4).

Recently the EIU published the 2015 ‘Quality of Death Index’ (5). In this study the number of countries as well as the number of domains are extended. Although therefore direct comparisons between the scores of 2010 and 2015 are not possible, the report concludes that ‘some countries are stepping up their effort to ensure all citizens have access to palliative care’ (5).

The question in this paper is which countries in Europe did step up or not, i.e. which European countries did increase or decrease their quality of end-of-life care efforts based on the ranking on the Quality of Death Index? The choice for Europe is based on the large number of European countries which are included in both studies of the EIU.

This paper will describe the overall ranking of the 27 European countries which participated in the 2015 Quality of Death Index. Next a comparison will be made between the 22 European countries who participated in the studies of 2010 and 2015.

Methods

As stated the method to assess the Quality of Death Index differs between the one of 2010 as compared to the one of 2015. The four domains used in the 2010 to construct the ‘Quality of Death Index’ were: basic end-of-life healthcare environment (10 indicators), availability of end-of-life care (4 indicators), cost of end-of-life care (3 indicators), and quality of end-of-life care (7 indicators) (1). The scores in the 2010 Quality of Death Index are scaled from 0 to 10.

In 2015 five domains with in total 20 indicators were used: palliative and health care environment (4 indicators), human resources (5 indicators), affordability of care (3 indicators), quality of care (6 indicators), and community engagement (2 indicators) (5). The overall ranking of the European countries involved in the 2015 Quality of Death Index is based on the total score of the index, which may vary from 0 to 100.

For a comparison between the participating European countries in 2010 and 2015 the ranking will be used because the way the actual scores are calculated differs between 2010 and 2015. The following variables will be used for comparison: the Quality of Death Index, the domain affordability of palliative care, and the domain quality of care.

As is stated in the 2015 report, the Quality of Death Index of 2010 and 2015 may be used for comparison, although they differ in the way they are composed (5). The domain affordability of palliative care of 2015 was called ‘costs of end-of-life care’ in 2010, but the same 3 indicators were used. The domains quality of end-of-life care (in 2010) and quality of care (in 2015) share 4 indicators.

The total number of European countries of which these data over both years are available is 22. For comparison the changes in ranking between 2010 and 2015 are an indication for an increase or decrease of efforts in palliative care per country. Also it may show which countries made more effort than others.

Results

The scores on the quality of death index in the 27 participating European countries varies from 93.9 for the UK (rank 1) to 25.5 for the Ukraine (rank 27) (see figure 1). It is a wide gap
in scores within Europe. It indicates it is better to die in the UK than in the Ukraine. The countries ranking highest on the Quality of Death Index are situated in West-North Europe, the lowest ranking ones in East-South Europe.

Figure 1 - Scores on Quality of Death Index in participating European countries 2015 (source 5)

However, the level of quality of death index varies over time. The differences in ranking between the assessments of 2010 and 2015 indicate which states did increased their efforts to improve the quality of death in five years and which did not. The comparison shows that in Austria and Hungary the ranking on the quality of death index evidently decreased, but in Finland and Portugal increased (see figure 2). Austria being on rank 4 in 2010 was on rank 10 in 2015 and Hungary was on rank 7 in 2010 and on rank 18 in 2015.

Figure 2 - Ranking on Quality of Death Index in between 2015 and 2010 of 22 European countries (sources 1 and 5)

The ranking of Finland, the UK, Belgium, Italy, Ireland, Spain, and Portugal on the domain ‘affordability of palliative care’ improved strongly between 2010 and 2015, indicating that more public funding was available for patients in need for palliative care in 2015 as
compared to 2010 and that criteria and procedures to receive such care were improved (see figure 3). The reverse seems the case in Norway, Hungary, France, and Austria.

Figure 3 - Ranking on affordability of palliative care of 22 European countries in 2015 and 2010 (sources 1, 5)

In the domain of ‘quality of care’ (including indicators as presence of accreditation and standards for palliative care, availability of opioid painkillers, presence of do-not-resuscitate policy, and shared decision making) the ranking in Italy, Sweden, Finland, Switzerland, and France strongly improved, while the ranking in Hungary, Czech Republic, Poland, Ireland, and Slovakia evidently decreased (see figure 4).

Figure 4 - Ranking on quality of care of 22 European countries in 2015 and 2010 (sources 1, 5)

Overall, the comparison shows that ‘negative’ changes in ranking between 2010 and 2015 seem more frequently in Central/Eastern European countries as compared to Scandinavian and Southern-West European countries. The comparison also shows that the ranking of some countries increases on one domain but decreases on another. For example, France ‘looses’ 7 ranks in the affordability domain, but ‘wins’ 7 in the quality domain. A more detailed overview of the European countries, who changed 5 or more positions on ranking (positive or negative) between 2010 and 2015 shows that the ranking on the 2 domains (affordability of palliative care and quality of care) increased strongly in Finland and Italy, but decreased strongly in Hungary and Poland (see Overview 1).
Overview 1 - Changes in five ranking positions or more on the Quality of Death Index, affordability of palliative care, and quality of care between 2010-2015 (sources 1, 5)

<table>
<thead>
<tr>
<th>Positive changes (5 &gt;) in ranking from 2010 to 2015</th>
<th>Negative changes (5 &gt;) in ranking from 2010 to 2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Death Index</td>
<td></td>
</tr>
<tr>
<td>Finland +6</td>
<td>Hungary -7</td>
</tr>
<tr>
<td>Portugal +5</td>
<td>Austria -6</td>
</tr>
<tr>
<td>Affordability of palliative care</td>
<td></td>
</tr>
<tr>
<td>Finland +16</td>
<td>Hungary -12</td>
</tr>
<tr>
<td>Belgium +9</td>
<td>Norway -10</td>
</tr>
<tr>
<td>Italy +8</td>
<td>Austria -7</td>
</tr>
<tr>
<td>Spain +7</td>
<td>France -7</td>
</tr>
<tr>
<td>Ireland +6</td>
<td>Poland -6</td>
</tr>
<tr>
<td>Quality of care</td>
<td></td>
</tr>
<tr>
<td>Italy +12</td>
<td>Hungary -17</td>
</tr>
<tr>
<td>Switzerland +12</td>
<td>Czech Republic -11</td>
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<tr>
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<tr>
<td>Finland +7</td>
<td>Poland -10</td>
</tr>
<tr>
<td>France +7</td>
<td>Slovakia -6</td>
</tr>
</tbody>
</table>

Discussion

The 2015 Quality of Death Index presents a worldwide picture on the way governments try to realise the availability and quality of palliative care. In this paper the situation in Europe is described. The worldwide picture of the Quality of Death Index is not positive. As was concluded by WHO, worldwide 86% of people in need for palliative care do not receive it (6). The situation in Europe is as compared to the 80 countries worldwide rather positive. However, within Europe some countries rank low also when compared with the worldwide situation. Of the 80 countries worldwide, Ukraine is ranked on place 69, Romania on 64, and Bulgaria on 62. Of we consider a score of 50 or higher on the 2015 Quality of Death Index as ‘sufficient’, also Greece, Slovakia, Kazakhstan, Russia, Turkey, and Hungary score ‘insufficient’. Insufficient scores in Europe concentrate in Eastern Europe.

Comparison between the 2015 and 2010 Quality of Death Index opens the opportunity to compare whether ‘some countries are stepping up their effort to ensure all citizens have access to palliative care’ as the 2015 report states (5). While comparison of scores is not possible, the interpretation of differences in ranking is not easy. Nevertheless, our analysis indicates that some countries have made real progress (for example Finland and Italy) in improving conditions for palliative care, while investments in improving palliative care of other countries (for example Hungary, Austria and Poland) may be questioned.

It seems that former investments in palliative care in Central-Eastern European countries are not continued. An explanation may be that initiatives to stimulate palliative care in Central-Eastern European countries in the beginning of this century was taken by charity funds and non-profit institutions from abroad, while commitment of national ministries and policy makers was not ensured. In the EIU reports Romania is used as an example. In 2010 Romania was qualified as a beacon for the development of palliative care: ‘from last to leader’, thanks to funding by UK charity funds. In 2015 the situation in Romania is deteriorated. The 2015 report states that ‘to cope with future demand, countries need to embrace the public health model of palliative care and to extend palliative care into a broad range of health care services’ (5; p 37). This is evidently not the case in Romania or in Hungary.

The comparison of ‘quality of death’ between 22 European countries underlines the WHO resolution that palliative care need to be an integral part of health care (7). This applies especially to Central-Eastern European countries. This means policy makers in these countries should take responsibility for the availability and quality of palliative care (i.e.}
funding and standards). Also, health care professionals should be trained in end-of-life care and the public awareness on death and dying needs to be stimulated. The 2015 Quality of Death Index report recommends a needed change in the culture of health care: ‘moving from a culture of curing illness to managing long-term conditions’ (5).

The answer on the question of this paper is: palliative care did not improve in Europe during the last 5 years. Palliative care improved in a few countries. Palliative care has a stable, high quality position in about 5-6 European countries, but even ‘top/ranked nations currently struggle to provide adequate palliative care services for every citizen’ (5; p 6). About half of the European countries provide insufficient palliative care services for their suffering citizens.

References


Conflict of interest: none
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Relevance of Canadian health care evaluation project (CANHELP) questionnaire in Assessment of Satisfaction of End of Life Care provided in patients and families receiving Home Based Palliative Care: A pilot study

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Abstract

Introduction:
Good palliative care provision should culminate in a high quality end-of-life (EOL) care. The Canadian Health Care Evaluation Project (CANHELP) questionnaire assesses the patient and family satisfaction with provided EOL care.

Aims:
To study the relevance of the CANHELP questionnaire in patients and families enrolled in home based palliative care, to identify unmet needs of end of life care, and to bridge the gaps in care provision.

Methods:
A cross-sectional study conducted in patients and their families who are enrolled for home based palliative care with the Palliative Medicine Department. The CANHELP questionnaire is a 1-5 Likert scale assessing satisfaction of EOL care provided with 38 patient centred questions and 40 family centred questions.

Results:
Both patients and their caregivers gave highest importance to illness management (patient mean 67.63 sd 2.67, caregiver mean 45.83, sd 7.56), and expressed highest satisfaction (patient mean 58.58 sd 5.61, caregiver mean 40.33 sd 5.55). Significant differences were found in importance and satisfaction regarding illness management (p<0.001), benefit of communication and decision-making (p<0.001), well-being (p<0.001), general satisfaction of care received (p<0.001) between patients and their families. There are communication gaps regarding discussions about the use of life sustaining technologies, comfortable talking with relative about his/her illness, dying, and death and discussions with relative during the past month about wishes for future care in the event he or she is unable to make those decisions which needs to be improved.

Conclusion:
The CANHELP questionnaire is relevant to patients and their families in assessing satisfaction of EOL care services provided.

Key words: home based care, palliative care, CANHELP questionnaire, end of life care, satisfaction with care

Introduction

The World Health Organization (WHO) estimates that on an average 60 percent of people who die will benefit from palliative care before death (1). India has a population of 1.22 billion and a death rate of 7.39 deaths/1,000 population (2). So each year more than 7.5 million
individuals in India could benefit from palliative care, but less than 2% of the needy population have access to it (3). Also it is widely believed that quality of end-of-life (EOL) care should be espoused as a “right” of all citizens and a responsibility of all the governments.

Unfortunately, recent studies continue to identify significant gaps in care provision and there remain ample opportunities for improvement (4-11). Historically, improving EOL care has been hampered by inadequate definitions of and a lack of validated measurement tools for quality EOL care, particularly from the perspective of the seriously ill patient and/or their family members (12,13).

The Canadian Health Care Evaluation Project (CANHELP) questionnaire was developed and validated to assess both patient and family satisfaction with EOL care provided to patients who have a variety of diagnoses across diverse settings (14). This questionnaire is more practicable for developing countries where families are available to provide the care. A study by Hwang and Ryu (15) concluded that a nurse initiated home based palliative care program is an effective measure to reduce patients’ pain and symptom experience, to improve patient quality of life (QOL) and decrease family burden. A study by Banerjee (16) demonstrated that an affordable home based palliative care services are more preferred by the society in comparison to hospice, hospital or self-contained societal medical skills as specialist care is accessed the patients at their door step (17).

The Department of Palliative Medicine is running a home based palliative care program for the last ten years with a multidisciplinary team comprising of doctors, nurses, social workers and volunteers/ counsellors. In addition to control physical symptoms, the team concentrates on psycho-social and emotional support too. In some cases, the visits have helped to change the attitude of families towards the patients, for example, allaying fear of contagion; and attitude of neighbours towards the patient and so on. In spite of problems like long distances involved and bad condition of roads, the experience of this team shows that a home care system is essential for delivery of effective Palliative care in Mumbai.

The aim of this pilot study was to learn the relevance of the CANHELP questionnaire for patients and families provided with home based palliative care. This would help us to identify unmet needs of care provided at end-of-life. Gaps in service provision can then be used as targets for service improvement.

Methods

A cross-sectional pilot study was conducted to assess patient and family satisfaction of end of life care provided through home based palliative care

Inclusion Criteria:
1. Age > 18 years;
2. Patients who are registered with the Department of Palliative Medicine and enrolled under home based palliative care program;
3. Patient and families who have agreed to be part of the study and have signed the informed consent form.

Exclusion Criteria:
1. Patients who are not registered with the Department of Palliative Medicine;
2. Patient residing beyond the geographic territory of home based palliative care;
3. ECOG > 03;
4. Physician predicted survival less than four weeks.

Study setting and intervention
Mumbai based patients and their families registered with Palliative Medicine Department accessing home based palliative care services were selected for this study. Subjects were enrolled after they have filled up the informed consent form. The questionnaire was served to 29 patients and their families from September to November 2012 after taking informed consent in their preferred language. The questionnaires were filled by patient and caregiver themselves. The investigator was present to assist them in case they face any difficulty.

Data analysis was done by using SPSS version 20 (18). The questionnaire was translated in local languages (Hindi and Marathi) for indigenous population. This questionnaire was not validated separately as the purpose of the pilot study was to evaluate the relevance of CANHELP questionnaire in assessment of satisfaction of End of Life Care.

**Tool**

The CANHELP questionnaire was designed to evaluate satisfaction of care in older patients with life threatening illnesses, and their family members. It has been subdivided into various domains by the authors (See Table 1).

<table>
<thead>
<tr>
<th>Patient Questionnaire</th>
<th>Caregiver Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Domain name</strong></td>
<td><strong>Number of questions</strong></td>
</tr>
<tr>
<td>General satisfaction with the quality of care received during the past month</td>
<td>1</td>
</tr>
<tr>
<td>Relationship with the Doctors</td>
<td>4</td>
</tr>
<tr>
<td>Illness Management</td>
<td>14</td>
</tr>
<tr>
<td>Communication</td>
<td>5</td>
</tr>
<tr>
<td>Decision Making</td>
<td>4</td>
</tr>
<tr>
<td>Role of the Family</td>
<td>6</td>
</tr>
<tr>
<td>Your Well Being</td>
<td>4</td>
</tr>
</tbody>
</table>

Before rating the domain-specific items, respondents were asked to rate their overall level of satisfaction with the care they had received in the past month. It consists of two versions, one for patients and another for family caregivers. It is a 5 point Likert scale with 1 = not at all satisfied, 2 = not very satisfied, 3 = somewhat satisfied, 4 = very satisfied and 5 = completely satisfied. CANHELP questionnaire correlates with other established measures of satisfaction with quality of care at the end of life, has good internal consistency (Cronbach α > 0.70) and can be grouped into valid subscales.


There was no availability of prior information for understanding the feasibility of these questionnaires in Indian patients. So we evaluated the importance of each question in the CANHELP questionnaire on a scale of 1 = not at all important, 2 = not very important, 3 = somewhat important, 4 = very important and 5 = completely important.

The study was conducted at 5% significance level. No formal sample size and power estimation was done as there was no prior information for feasibility of these questionnaires.
in the Indian patients. As per the observations made at the Palliative Care Clinic, at least 100 patients are seen on home care every year, so we estimated a minimum of 20 patients to achieve statistical significance, however we enrolled 29 patients for this pilot project.

Data collection and analysis

Data was collected and entered in SPSS version 20 data sheet. The summation of all patient data were done to prepare a dataset and descriptive statistics were used to describe the main study results (e.g., mean, median value with lower and upper value ranges) for individual questions as well groups previously assigned by the investigators (14). Test for normalcy was applied for each data distribution. Comparison of means were done by using T-test for independent samples and Wilcoxon rank-sum test for parametric and nonparametric data respectively. The significant differences were noted. Missing data were reported as such, rather than using any specific statistical techniques to counteract for it. We also made a note of the questions which the subjects did not answer. We assumed that those were the questions which were difficult to understand or be answered by the subjects. Schematic bar diagrams were constructed for the individual datasets.

Results

Highest importance was given to illness management (patient mean score 67.63 standard deviation (SD) 2.67, caregiver mean score 45.83, SD 7.56) by both the groups. Highest satisfaction (patient mean score 58.58 SD 5.61, caregiver mean score 40.33 SD 5.55) was reported with same.
In other words, the patients and their families feel that they can contribute more towards their own involvement and decision of care process at the end of life (see figures 1 and 2).

Significant differences were found in importance and satisfaction regarding illness management (p<0.001), benefit of communication and decision-making (p<0.001), well-being (p<0.001) and general satisfaction of care received (p<0.001) between patients and their families (see table 2)

Difficulties were encountered in the following questions.
Regarding the importance of the questions:
a. Discussions during the past month with doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis) for patients and families.
b. Ability during the past month to talk comfortably with relative about his/ her illness, dying, and death and discussions with relative during the past month about wishes for future care in the event he or she is unable to make those decisions in case of families.

Regarding satisfaction with care:
Discussions during the past month with your doctor(s) about the use of life sustaining technologies (for example: CPR or cardiopulmonary resuscitation, breathing machines, dialysis) for the patients and their families.

This signifies that there remain communication gaps regarding discussions about the use of life sustaining technologies, comfortability in talking with the relative about his/ her illness, dying, and death. Also there was insufficient discussions with relative during the past month about wishes for future care in case the patient is unable to make those decisions by themselves.
Figure 2 - Mean scores on the CANHELP patient questionnaire

Table 2 - Differences between CANHELP scores between patients and their families
### Discussion

We have conducted a cross-sectional observational study involving 29 patients and their family caregivers to find out the relevance of the CANHELP questionnaire in Indian settings.

This new instrument has various domains (illness management, communication and decision-making, relationships and well-being) which represent key areas of quality EOL care that can stand alone as significant indicators of end of life care in the subjects. We have shown that the various domains of are relevant to both patient and family members in our study population in India. QOL refers to the holistic notion of ‘well-being’. Whether QOL or quality of care measures should be the primary endpoint of EOL studies will depend on the context and the nature of the study. A major impediment to progress in EOL care research has been the failure to define the distinctions between or the boundaries of terminologies (21). A tool to assess QOL at the EOL go beyond physical, role and social functioning and provides direct attention to the more complete social, psychological, and spiritual wellbeing. Quality of care at the EOL focuses on patient and family caregiver assessment of satisfaction in key domains of care in real time when interventions targeting specific areas needing improvement can be addressed. For quality of care assessments, there is a clear link between the measurement of key processes of care and subsequent efforts to improve quality of care during the final weeks to months of life (19). A conceptual framework published by Stewart et al (20) describes various outcomes (QOL, satisfaction with care) at EOL care, as a function of patient and social variables, and structure and process of care variables.

The strengths of this study was that the rigorously tested psychometrically developed, holistic and patient/family-centred instrument focusing on EOL care in Canada (14) was also relevant to our sample population in India. A further strength of this study was that both the versions for the patient and family member were relevant which enhances the clinical utility of the questionnaires. Often, in situations where the patient is no longer capable of communicating, the caregivers provide the only perspective on the care received at the EOL. Interestingly, the patient and family version of the questionnaires are not exactly the same. They measure differing perspectives on care issues over subscales that best measure each aspect of care. Again, family ratings of satisfaction are an important outcome by themselves (22) which is independent of the patient’s assessment of outcome and is quite evident from the results.
The limitations of this study include the fact that the majority of our patients with advanced cancer were residents of Mumbai. Minority group of patients having cognitive, hearing or speech impediments, and surgical patients at the EOL are under-represented in our sample. Although this instrument was relevant in Mumbai, its applicability to other places even within India with dissimilar diaspora may be limited. In addition, we do not yet know the test–retest reliability and responsiveness of the CANHELP Questionnaire, nor do we know the validity of using the questionnaire without the assistance of research personnel (self-administered). In spite of being a pilot study, the sample size was small, so study remains underpowered to show a statistically significant effect. Future studies should be tried with bigger samples. Finally, we acknowledge that the CANHELP instruments are lengthy and might pose a challenge to the patient and caregivers who are suffering from serious illness. Future studies should evaluate the relevance of shorter versions of CANHELP questionnaire instead of this longer version.

In short, the CANHELP questionnaire is relevant to patients and their families regarding satisfaction with the end of life care services and both of them are satisfied with end of life care services provided to them. There is need for further discussions with doctor about the place of care and use of life sustaining technologies in end of life care. By enabling often disempowered, voiceless, and vulnerable patients to share their perspectives comprehensively with us at their EOL, we are in a much better position to improve the quality of EOL care in Mumbai.

References


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Utility of the portable driver syringe in palliative care

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Abstract

Driver syringe is a small instrument used for subcutaneous administration of opioids or other drugs for patients receiving palliative care. It can be set to a maximum of 24 hours. The subcutaneous route either as a bolus or by continuous infusion is necessary in clinical situations when the oral route cannot be used as follows: nausea, vomiting, severe oral lesions, mouth ulcers, severe dysphagia and difficult swallowing.

There is a table with the possible drug combinations which can be administrated with driver syringe but not all these drugs exist in Romania. It’s useful to utilise this table in your activity in order to see what drugs can be mixed in the same driver syringe.

Key words: driver syringe, subcutaneous route, drugs combinations

(Full text in Romanian)
Terminal condition - fear, challenge, professionalism in its approach

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Abstract

A terminally ill status is a very stressful and difficult condition for doctors but also for the patient and family. The main aim of the doctor is to treat the patient's suffering and tackle the main symptoms but especially to support and advise the family. Also, the doctor will provide continue care to maintain all medical interventions that do not harm the patient and will not abandon the patient, continuing to care him.

On the other hand, recognition from the physician of the terminal state is crucial because a properly management of the situation will reduce addressing patient to emergency services or to emergency rooms, and avoid therapeutic stubbornness and especially unnecessary diagnostic. “Truth” gently said is the essence of communication with the patient and his family. Information provided (and those required by the patient) during the evolution of cancer will vary and will be adjusted as the patient reaches the terminal stage of live.

Key words: terminal condition, medication, counselling, revaluation of care

(Full text in Romanian)
The 2015 Quality of Death Index. Ranking palliative care across the world
A report by the Economist Intelligence Unit (EIU).

This 2nd edition of the ‘Quality of Death Index’ evaluates 80 countries using 20 indicators in 5 domains: the palliative and healthcare environment, human resources, the affordability of care, the quality of care and the level of community engagement. By expanding the list of countries and the domains as well as changing the type of indicators, comparison with the first edition of 2010 is limited. Nevertheless, comparing the two indices it is clear that some countries have made real progress in improving palliative care, but others have not.

The conclusions of the study suggest that to less attention is given to a needed change in the culture of health care. The change should be ‘moving from a culture of curing illness to managing long-term conditions’.

The study makes seven recommendations to improve the quality of palliative care and make this available for more people worldwide. For (Central-Eastern) European countries some of these recommendations should have high policy priority:
- Make palliative care more affordable for those in need.
- Integrate palliative care training in the curricula of health care professionals.
- Stimulate home- and community based palliative care.
- Increase public awareness of palliative care.

Reading and discussing the analysis made by the EIU is strongly recommended, especially to health care policy makers.

Compassion fatigue is a syndrome known among formal and informal health care providers. It is a syndrome which may be observed in persons involved in palliative care, i.e. family members and health care professionals. Compassion fatigue describes a sense of helplessness and hopelessness that can overtake a person providing care for someone whose suffering seems never-ending. Exhaustion, frustration and hopelessness are symptoms described by people who suffer from compassion fatigue.

The American Academy of Family Physicians published a list of symptoms related to compassion fatigue. These symptoms include sleep disturbances, frequent headaches, physical or emotional exhaustion, hypertension, depressive feelings, anger, hopelessness, low self-esteem and are often accompanied by abuse of drugs, alcohol and food. Also a self-assessment test to assess risk for compassion fatigue is available.

For more information see: http://www.recovery.org/pro/articles/compassion-fatigue-is-it-happening-to-your-family/