Understanding Global End-of-Life Care Practices: IHF 2014 Research Project

ABSTRACT: This first-of-its kind survey of global end-of-life (EOL) practices uncovered major differences in how EOL care is defined, delivered, and measured. According to respondents from university hospitals and cancer centers in 17 countries, the primary challenges to providing effective EOL care are communication between clinicians and patients/families, cultural beliefs about death, entrenched staff beliefs about prolonging life, and lack of funding. However, many organizations are implementing improvements in EOL services that support hospital-wide identification of patients for whom such services are appropriate, screening to avoid needless aggressive therapies, enhanced provider education, and ways to assess quality of life for terminally ill patients.

INTRODUCTION. The purpose of the research was to promote knowledge exchange among university hospital members of the International Hospital Federation (IHF) about the current delivery and management of EOL care, and to identify areas for improvement.

The study was conducted by UHC as the secretariat for IHF’s University Hospital Special Interest Group, which was formed in 2013 as a unique platform for peer-to-peer knowledge sharing among university hospitals on global health challenges. The group has attracted leaders from university hospitals around the world who are interested in sharing information across national borders. The EOL study is the first global initiative completed by the group in pursuit of its objectives: advancing international knowledge and collaboration, enhancing organizational performance through improved effectiveness and efficiency, identifying opportunities for research and education, and influencing the health and well-being of people across the globe. (UHC’s secretariat position and its conduct of the study should not be construed as an endorsement of its topics or findings.)

The study’s primary objective was to collect baseline information about the current state of EOL care delivery among university hospitals and cancer centers. A secondary objective was to test the feasibility of a global online study of EOL care practices among the same group of respondents.

METHODOLOGY

A 16-question electronic survey was sent to IHF members to be forwarded to their university hospital and cancer center affiliates in July 2014. One response per organization was accepted. Survey questions focused on current practices in EOL care, including EOL delivery models, facilities, services, and funding. Performance measures, self-assessment, challenges encountered, and specific innovations and improvements were also captured. Standardized definitions were used to ensure consistency among responses (Box 1).

FINDINGS

A total of 84 university hospitals from 17 countries participated in the online survey, with the heaviest participation from the Americas (47), followed by Europe (19) and the Western Pacific region (15). The African and Eastern Mediterranean regions, with 3 respondents, were combined because of the small sample size. There were no responses from the Southeast Asia region. Fifteen cancer centers from the United States and France also responded, for a total of 99 participating organizations.

More than half (55%) of the respondents from the 84 university hospital respondents work in public hospitals; the remainder are in private facilities. Their organizations have a median of 606 occupied adult beds and nearly one-third (30%) have inpatient EOL or hospice units. Among the 15 cancer center respondents, 22% of the US and 50% of the French cancer centers have inpatient EOL or hospice units.

Models of EOL Care

When asked to select a single model that most closely described their EOL care delivery process, more than half (58%) of university hospital respondents reported that a centralized team of specially trained staff provides the majority of EOL services (Figure 1). This centralized model is predominant in the Americas (62%), Europe (58%), and the Western Pacific...
region (53%), but only 1 of the 3 hospitals in the Africa/Eastern Mediterranean region reported using that model. One-fifth (20%) of respondents reported significant variation in the provision of EOL services, suggesting that terminally ill patients may have inconsistent experiences with EOL care.

Most (78%) of the US cancer centers have a centralized team of specially trained staff to provide EOL services. Two-thirds (67%) of the French cancer centers have specially trained staff, but without centralized teams. None of the cancer centers reported significant variation in their EOL models of care.

Referral Patterns
Physicians and nurses are the most common sources of referrals for EOL care across all regions and organizations; attending physicians are the most frequent source of referrals for both university hospitals and cancer centers (Figure 2).

Self-referrals are more common among cancer center patients, but are still only a small fraction of referrals, as are those from family members, social workers, pharmacists, and religious/spiritual counselors. Clinical indications of eligibility for EOL services are rarely used as triggers for referral.

Terminally ill inpatients at university hospitals are most likely to die in non-EOL units and critical care units or CCUs (Figure 3). Notably, patients in the Americas are twice as likely to die in CCUs (77%) than are patients in Europe (37%). Cancer center patients are most likely to die in the hospital’s CCU, but other likely locations are the EOL care unit and at home.

Service Mix, Team Composition, and Funding
Approximately 90% of responding organizations offer symptom and pain management, family meetings, and nutritional counseling to EOL patients. Some services were more common at cancer centers than university hospitals, including psychosocial assessment (available at 100% of cancer centers vs. 86% of university hospitals), nonmedical therapies such as massage (80% vs. 44%), and legal counseling (80% vs. 32%).

Among those that have centralized teams or specially trained staff, significant variation in the composition of the core EOL teams was reported; attending physicians and EOL nurses were the most common members (Table 1). Many teams include social workers, but the inclusion of psychiatrists and psychologists, spiritual or religious counselors, pain specialists, and physical or occupational therapists on the team varied widely by region. Except in US cancer centers, pharmacists are not often included. The percentage of dedicated EOL staff was low—2% overall for university hospitals, adjusted for volume of adult occupied beds (Figure 4). Cancer centers’ EOL staffing was 7%, reflecting their different patient population, which has more intense EOL needs.

When asked about funding sources, respondents reported that government funding is most common in Europe (84%) and the Western Pacific region (62%). Funding sources vary in the United States, but one-third (37%) of EOL services delivered by university hospitals are funded privately or by insurance.

Evaluation Measures
Respondents reported a variety of measures used for evaluating EOL care, including documentation of advance directives and care goals, timely provision of care, trends in the usage of aggressive therapies such as chemotherapy near EOL, referrals to palliative and hospice care in the last 6 months of life, percentage of patients who die with or without palliative care services, percentage of nontrauma deaths in CCUs, utilization of comfort care order sets, length of stay, readmission near EOL, and patient, family, and staff satisfaction with EOL care.

Self-Assessment: Ideal vs. Actual Performance
Respondents were asked to score their organizations’ performance based on 15 “ideal” statements related to the provision of EOL services—for example, “Most leaders in this hospital recognize the value of EOL care.” Each organization was assigned a customized total weighted score based on its level of agreement with each statement. The resulting scores were low, with an overall mean of 0.08 (maximum score was 1.0), but the range of scores was broad in all respondent groups (Table 2).

A closer look at the individual statements revealed perceived gaps in EOL practices (Table 3). Respondents were critical of their organizations’ performance in offering EOL services in a timely and consistent manner, assessing patient and family satisfaction, and providing adequate funding, to name a few. University hospitals reported better performance than cancer centers with regard to minority patients’ likelihood of using EOL services and controlled use of aggressive therapies, but many self-assessment scores were low. Hospitals’ ability to evaluate the impact of EOL care on overall costs received the lowest score from all respondents, indicating difficulties with collecting and interpreting financial data.

Challenges That Impede EOL Care
Poor communication between clinicians and patients/families, cultural and medical staff beliefs, and lack of funding are the most frequently reported challenges to providing effective EOL services (Figure 5). Lack of EOL staff, poor communication among clinical staff, and inadequate information systems were factors of lesser importance.

Discrepancies in Reported and Actual Practices
Responses sometimes conflicted between actual performance and desired states. For example, 80% of the university hospital respondents reported that their staff members offer ongoing education and discussion about EOL issues to terminally ill patients and their families, yet 60% or more reported that this area is a barrier to providing effective EOL care (Table 4). More than half of participating university hospitals require physician training in EOL skills, yet only 1 in 10 respondents agreed that their physicians can competently provide EOL counseling services.
PERFORMANCE IMPROVEMENTS AND INNOVATIONS

Respondents reported a variety of initiatives they have implemented to improve EOL care, including the following examples.

Staffing and Education

Liverpool Hospital in Liverpool, NSW, Australia, has established hospital-wide “care plans for dying patients” and appointed an EOL coordinator to deliver education and support to hospital staff. Centre Hospitalier Universitaire de Liège in Liège, Belgium, provides practical training to prepare medical students to handle EOL care situations. The Ottawa Hospital in Ottawa, Ontario, Canada, participates in a regional program that promotes greater access to EOL care through education and adherence to standards of care.

Screening and Order Sets

Cedars-Sinai Medical Center in Los Angeles, California, uses the Eastern Cooperative Oncology Group score to screen for appropriateness before administering chemotherapy. Queen Mary Hospital in Hong Kong uses enhanced psychosocial care screening to promote timely referrals of high-risk patients to social workers and clinical psychologists. The Institut de cancérologie de l’Ouest, which has facilities in Angers and Nantes in France, studied criteria for stopping anticancer treatments and validated a questionnaire for assessing the quality of life of terminally ill patients. Moffitt Cancer Center and Research Institute in Tampa, Florida, uses electronic order sets to prompt consultations with chaplains and social workers when palliative care specialist consults are ordered.

STUDY LIMITATIONS

The IHF study confirmed that a global online study of EOL care practices among providers is feasible. However, the research was limited to the care of adult patients near EOL who were not receiving curative therapies. Responses reflect opinions from a small, nonrandom sample. Patients and family members were not represented and cultural differences could not be fully explored using the online survey.

OPPORTUNITIES FOR IMPROVEMENT AND FUTURE RESEARCH

The study uncovered inconsistencies in how EOL care is defined, delivered, and measured. Constructing a standardized approach to EOL terminology, measures, and practices could help institutions share ideas and compare performance across regions.

Significant variation in models for providing EOL services was reported, suggesting that terminally ill patients may have inconsistent EOL care experiences that could be standardized and improved. Currently, clinical triggers indicating eligibility for EOL services are rarely used as a basis for referral. Use of such triggers, however, could help to ensure that patients receive appropriate services in a timely fashion. Nonmedical therapies, legal counseling, and other nonclinical services should be evaluated for inclusion in standardized EOL care bundles.

The study revealed that the major challenges to providing effective EOL care are communication between clinicians and patients/families, patient/family cultural beliefs about death, entrenched beliefs among medical staff in the need to prolong life at all costs, and lack of funding. Better education for physicians and nurses could improve communication and help providers serve as effective gateways to EOL services. Avenues for improving EOL care for appropriate patients and underserved populations such as minorities and trauma patients must be explored. Increased use of EOL services could reduce the use of inappropriately aggressive and costly therapies such as critical care, surgery, and chemotherapy for terminally ill patients.

BIOGRAPHIES

Kathleen Vermoch, MPH, imperative leader, Patient Experience, at UHC, directed the international EOL care study. She has served in quality improvement roles at UHC since 2000 and has designed and led multiple benchmarking studies, collaborative projects, and educational programs on improving health care quality, safety, and efficiency.

Barbara Anason, MBA, senior vice president, Academic Medical Center Networks and Strategy, at UHC (now part of Vizient, Inc.), has served in various leadership roles for nearly 25 years. Ms. Anason leads networks focused on knowledge exchange, discovery, and collaboration among academic medical centers, as well as internal planning processes. She serves as the lead for the University Hospital Special Interest Group Secretariat for the International Hospital Federation.

BOX 1. DEFINITIONS

To counter widespread variation in terms, the survey used the following definitions:

- **EOL care**: The care of terminally ill patients with a life expectancy of 3 months or less who are not receiving curative therapies.
- **EOL services**: Include but are not limited to comfort care, counseling, care planning, pain management, palliative care, hospice care, spiritual care, and bereavement counseling.
- **Patients**: Adult recipients of EOL care.
- **Family**: Individuals closely related to the patient.
- **EOL team**: Professionals who provide EOL services.

Where appropriate, open-ended “other” responses were used to provide information about euthanasia, physician-assisted suicide, and EOL services available outside of the university hospital.
FIGURES

FIGURE 1. MODELS FOR THE PROVISION OF EOL CARE AT 84 UNIVERSITY HOSPITALS

- A centralized team of specially trained staff provide the majority of EOL services (58%)
- No centralized team, but specially trained staff provide the majority of EOL services (20%)
- No centralized/specialized EOL team; all/most staff provide EOL services (12%)
- There is significant variation in the provision of EOL services (10%)


EOL = end of life.

FIGURE 2. REFERRAL SOURCES* FOR EOL SERVICES AT 99 UNIVERSITY HOSPITALS AND CANCER CENTERS


* Respondents selected the top 3 referral sources.

EOL = end of life.

FIGURE 3. LOCATIONS* WHERE TERMINALLY ILL PATIENTS ARE MOST LIKELY TO DIE AT 99 UNIVERSITY HOSPITALS AND CANCER CENTERS


* Respondents selected the 3 most common locations.

EOL = end of life.
End-of-life care: practices from around the world

**Figure 4. Staff Dedicated to EOL Care at Organizations with Centralized Teams/Specialized Staff**

![Graph showing percentage of EOL staffing and dedicated services](source)


EOL = end of life.

**Figure 5. Challenges* That Impede Provision of Effective EOL Care at 99 University Hospitals and Cancer Centers**

![Bar chart showing various challenges](source)


*Respondents selected their top 3 challenges.

EOL = end of life.
### Table 1. Composition of the Core EOL Team, by Region

<table>
<thead>
<tr>
<th>Team Member</th>
<th>All University Hospitals (n = 57)</th>
<th>Americas (n = 33)</th>
<th>Europe (n = 12)</th>
<th>Western Pacific (n = 11)</th>
<th>Cancer Centers, US (n = 7)</th>
<th>Cancer Centers, France (n = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attending physician</td>
<td>88</td>
<td>94</td>
<td>75</td>
<td>82</td>
<td>100</td>
<td>67</td>
</tr>
<tr>
<td>Resident physician</td>
<td>47</td>
<td>42</td>
<td>50</td>
<td>64</td>
<td>71</td>
<td>67</td>
</tr>
<tr>
<td>EOL care nurse</td>
<td>81</td>
<td>73</td>
<td>100</td>
<td>82</td>
<td>71</td>
<td>100</td>
</tr>
<tr>
<td>Other nurse</td>
<td>32</td>
<td>18</td>
<td>58</td>
<td>45</td>
<td>43</td>
<td>33</td>
</tr>
<tr>
<td>Social worker</td>
<td>75</td>
<td>85</td>
<td>67</td>
<td>55</td>
<td>86</td>
<td>83</td>
</tr>
<tr>
<td>Psychiatrist/psychologist</td>
<td>6</td>
<td>83</td>
<td>55</td>
<td>43</td>
<td>100</td>
<td>100</td>
</tr>
<tr>
<td>Spiritual/religious advisor</td>
<td>79</td>
<td>50</td>
<td>27</td>
<td>86</td>
<td>50</td>
<td>50</td>
</tr>
<tr>
<td>Care manager</td>
<td>12</td>
<td>15</td>
<td>17</td>
<td>0</td>
<td>29</td>
<td>50</td>
</tr>
<tr>
<td>Pharmacist</td>
<td>27</td>
<td>25</td>
<td>45</td>
<td>71</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Pain specialist</td>
<td>39</td>
<td>30</td>
<td>75</td>
<td>27</td>
<td>29</td>
<td>83</td>
</tr>
<tr>
<td>Physical/occupational therapist</td>
<td>23</td>
<td>6</td>
<td>50</td>
<td>45</td>
<td>14</td>
<td>0</td>
</tr>
</tbody>
</table>


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### Table 2. Self-Assessment Scores, by Region

<table>
<thead>
<tr>
<th>Weighted Total Self-Assessment Scorea</th>
<th>Africa/Eastern Mediterranean (n = 3)</th>
<th>Americas (n = 47)</th>
<th>Europe (n = 19)</th>
<th>Western Pacific (n = 15)</th>
<th>Cancer Centers, US (n = 7)</th>
<th>Cancer Centers, France (n = 6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean</td>
<td>0.08</td>
<td>0.04</td>
<td>0.12</td>
<td>0.18</td>
<td>-0.14</td>
<td>0.22</td>
</tr>
<tr>
<td>Range</td>
<td>-0.57 to 0.64</td>
<td>-0.54 to 1.00</td>
<td>-0.36 to 0.54</td>
<td>-0.61 to 0.75</td>
<td>-0.57 to 0.72</td>
<td>-0.04 to 0.73</td>
</tr>
</tbody>
</table>


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### Table 3. Level of Agreement With Self-Assessment Statementsa

<table>
<thead>
<tr>
<th>Self-Assessment Statement</th>
<th>Percentage of “Agree” and “Strongly Agree” Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All University Hospitals (n = 84)</td>
</tr>
<tr>
<td>EOL services are offered to all/most patients in a timely manner.</td>
<td>37</td>
</tr>
<tr>
<td>EOL services do not vary significantly by patient population (e.g., trauma vs. cancer).</td>
<td>26</td>
</tr>
<tr>
<td>Minority ethnicities are as likely to use EOL services as majority ethnicities.</td>
<td>52</td>
</tr>
<tr>
<td>Robust processes are in place to assess patient and family satisfaction with EOL services.</td>
<td>33</td>
</tr>
</tbody>
</table>


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* a For respondents with centralized teams/specialty trained staff

* Responses from the Africa/Eastern Mediterranean region are included in *all hospitals* but is not shown separately.

EOL = end of life.
### Table 4. Performance in EOL Practices

<table>
<thead>
<tr>
<th>Self-Assessment Statement</th>
<th>Percentage of “Agree” and “Strongly Agree” Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All University Hospitals (n = 84)</td>
</tr>
<tr>
<td>EOL services are adequately funded by the existing payment system.</td>
<td>21</td>
</tr>
<tr>
<td>Robust processes are in place to evaluate the impact of EOL care on the overall costs of care.</td>
<td>17</td>
</tr>
<tr>
<td>It is an organizational priority to control/reduce the use of aggressive therapies near EOL.</td>
<td>45</td>
</tr>
<tr>
<td>Staff are offered ongoing education about discussing EOL issues with terminally ill patients and their families</td>
<td>80</td>
</tr>
<tr>
<td>Challenges/barriers to effective EOL care include “communication issues between clinicians and patients and families”</td>
<td>62</td>
</tr>
<tr>
<td>Required physician training includes essential EOL skills</td>
<td>57</td>
</tr>
<tr>
<td>Most physicians can competently provide EOL counseling services</td>
<td>11</td>
</tr>
</tbody>
</table>


*a The responses from the Africa/Eastern Mediterranean region are included in “all hospitals” but are not shown separately.

EOL = end of life.