End-of-life care: practices from around the world

- Understanding Global End-of-Life Care Practices: IHF 2014 Research Project
- Introduction of an Advance Care Planning Clinic in a Regional Care Coordination Service
- Overcoming the Obstacles in Promoting Hospice Palliative Care - Sharing Experiences of the Taiwan Changhua Christian Hospital
- Palliative Care and legislation around dying
- Establishing Palliative Care across the AKDN Health Services: Opportunities and Challenges
- End of life care in Acute Geriatric Units: making decisions about sedation
- Evolution of palliative care in the French Cancer Centers - Unicancer

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The Role of Hospitals for end of life care

Eric de Roosenbeke
Chief Executive Officer
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End of life care has been a function of hospitals through the ages but over the last decades there has been a strong shift in the role of healthcare services. On one hand there has been a move toward home based end of life care, as it is better to end life close to the family and in a familiar environment. On the other hand, the complexity of treatments and the nature of care in these clinical situations have increased end of life care in hospitals.

If there is no question on the importance of palliative care and the need to promote recognized treatments alleviating pain, there are many questions on how much healthcare should be provided for end of life and where it is best for patients and families to receive it.

For this reason the IHF University hospital Special Interest Group has undertaken, with the support of the University Hospital Consortium from USA, a survey to assess the role of university hospitals for end of life care. The results of this survey are presented in this issue as well as approaches from various parts of the world.

End of life care is both an ethical and an economical question considering the cost of the last 15 days of life, especially in intensive care units. The majority of adults in need of end-stage care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Many other conditions may require palliative care, including kidney failure, chronic liver disease, multiple sclerosis, Parkinson’s disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

Chronic diseases that requiring palliative and end-stage care are no longer diseases of rich nations. According to WHO, each year, an estimated 40 million people are in need of palliative care, 78% of them live in low- and middle-income countries. Worldwide, only about 14% of people who need palliative and end-stage care currently receive it. Among children, 98% of those needing palliative care live in low- and middle-income countries with almost half of them living in Africa.

Public health policies focused on healthier lifestyles and environmental policies focused on addressing health related causes of pollution are the most significant and effective action to reduce both the incidence and prevalence, conditions that require palliative and end-stage care.

Changing population behavior and addressing the main causes of environmental pollution should, should therefore be a major priority in preventing the need for palliative and end-stage care. In 2011 the adoption of the UN Political Declaration on NCDs has set the path for the adoption by the 66th World health assembly of a global target to reduce NCD mortality by 25% by 2025.

All these actions are needed but will take decades if not longer before they have an impact. So the conditions that need palliative and end-stage care are here to stay in the near future even if growth in the incidence and prevalence can be stemmed through collective global action.

After the initial diagnosis of an end-stage condition has been made, the hospital remains an important part of the health system in diagnosing the specific cause, treatment, chronic care and palliative care.

As discussed by the contributing authors, increasingly the trend is towards specialized hospital departments and self-standing palliative care units with strong primary health care and community/home-based care.

The International Hospital Federation is fully committed to supporting the first ever global resolution on palliative care adopted in 2014 by the World Health Assembly (resolution WHA67.19). It called on WHO and Member States to improve access to palliative care as a core component of health systems, which recognized the importance of hospitals, while emphasizing the central role of primary health care and community/home-based care.

In addition, the International Hospital Federation, in support to the Australian Healthcare and Hospitals Association, is calling on all health leaders to ensure that modern health services provide appropriate care for people who are nearing the end of their lives. Do not hesitate to further disseminate the statement on end of life care, and to provide your support by signing it.
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.

OCCUPATIONAL 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

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

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


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.
**FIGURE 4. STAFF DEDICATED TO EOL CARE AT ORGANIZATIONS WITH CENTRALIZED TEAMS/SPECIALIZED STAFF**

![Bar chart showing percentage of staff dedicated to end-of-life care](https://www.uhc.edu/docs/5555-22-16417_EndOfLifeCareStudyKT_2.pdf)


EOL = end of life.

**FIGURE 5. CHALLENGES THAT IMPEDE PROVISION OF EFFECTIVE EOL CARE AT 99 UNIVERSITY HOSPITALS AND CANCER CENTERS**

![Bar chart showing challenges that impede end-of-life care](https://www.uhc.edu/docs/5555-22-16417_EndOfLifeCareStudyKT_2.pdf)


*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>


* For respondents with centralized teams/specially trained staff.

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

EOL = end of life.

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

<table>
<thead>
<tr>
<th>Weighted Total Self-Assessment Score*</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>


* The weighted total score is the sum of response scores—i.e., strongly agree = 1.00, agree = 0.50, neutral = 0.00, disagree = -0.50, strongly disagree = -1.00, excluding responses of “not applicable”—divided by the total number of responses to self-assessment items per organization. The maximum possible score was 1.00.

### Table 3. Level of Agreement With Self-Assessment Statements*

<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>
Self-Assessment Statement | Percentage of “Agree” and “Strongly Agree” Responses | All University Hospitals (n = 84) | All Cancer Centers (n = 15)
--- | --- | --- | ---
EOL services are adequately funded by the existing payment system. | 21 | 27
Robust processes are in place to evaluate the impact of EOL care on the overall costs of care. | 17 | 7
It is an organizational priority to control/reduce the use of aggressive therapies near EOL. | 45 | 26


*a A total of 15 “ideal” statements served as the basis for the self-assessment scores shown in Table 2; not all are shown here.

EOL = end of life.

| Self-Assessment Statement | Percentage of “Agree” and “Strongly Agree” Responses | All University Hospitals* (n = 84) | Americas (n = 47) | Europe (n = 19) | Western Pacific (n = 15) | Cancer Centers, US (n = 7) | Cancer Centers, France (n = 6) |
--- | --- | --- | --- | --- | --- | --- | ---
Staff are offered ongoing education about discussing EOL issues with terminally ill patients and their families | 80 | 79 | 84 | 80 | 67 | 100 |
Challenges/barriers to effective EOL care include “communication issues between clinicians and patients and families” | 62 | 60 | 68 | 60 | 67 | 100 |
Required physician training includes essential EOL skills | 57 | 53 | 58 | 67 | 33 | 83 |
Most physicians can competently provide EOL counseling services | 11 | 9 | 11 | 13 | 11 | 34 |


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

EOL = end of life.
Experience the power of collaboration by joining the IHF’s University Hospital Special Interest Group (UH-SIG).

Advancing international knowledge exchange, performance improvement, and collaboration among university hospitals around the world, UH-SIG members participate in benchmarking projects, innovative studies, online collaborations, and international meetings.

The University HealthSystem Consortium (UHC), which serves as Secretariat of the UH-SIG, has supported university hospitals for more than 30 years, acting as a catalyzing force for performance improvement.

The UH-SIG is open to IHF members’ university hospital leaders. For more information, contact the UH-SIG Secretariat:

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End-of-life care: practices from around the world

Introduction of an Advance Care Planning Clinic in a Regional Care Coordination Service

**ABSTRACT:** Advance Care Planning is an increasingly important consideration in health care service provision. Barriers to Advance Care Planning including lower prioritization than clinical care, and the complex logistics of completing the documentation have been identified in the literature and clinical practice. The Chronic Care Program within Canberra Hospital and Health Services introduced mobile and outpatient Advance Care Planning Clinics for care coordinated patients with chronic diseases, to address some of these barriers and facilitate end-of-life care discussion amongst this patient group. The implementation of the clinics was evaluated, looking at the practicality of running these clinics within existing resources and patient acceptability. The number of Statement of Choices completed was used as a marker of whether the clinics led to an increase in Advance Care Planning amongst this patient group. The introduction of the clinics received positive feedback from patients and was able to be implemented without requiring additional external resources. Following introduction of the Advance Care Planning clinics, an increase in the proportion of patients with a completed a Statement of Choices was seen.

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**Introduction.** With an increasing ageing population and the number of deaths in Australia projected to double over the next 25 years (1), end-of-life care is becoming an increasingly important consideration for health care planning in Australia (2). Advance Care Planning (ACP) allows a person, in consultation with their relatives and health professionals, to make plans and decisions about their preferences for medical care, including end of life care (3). ACP can help avoid unnecessary interventions and hospital admissions, and most importantly facilitate people dying in accordance with their wishes (4-6).

Information contained within an Advance Care Plan is only used in the circumstances where the individual no longer has capacity to make their own decisions regarding treatment (7). In the Australian Capital Territory (ACT), preferences about end of life care decisions can be made in three ways; by completion of a Health Direction; writing a Statement of Choices (SoC) or appointing an Enduring Power of Attorney (EPoA) (8). Both the Health Direction and EPoA are legal documents that only come into effect if the person is unable to participate in the decision-making process. The Health Direction documents a person’s preferences related to withdrawal or withholding of specific treatments (9), where as an EPoA appoints a nominated attorney with the power to make decisions on behalf of the individual (10). To help guide care if the individual is unable to participate in the decision-making the SoC documents a person’s wishes regarding the kind of care, degree of intervention they would want to receive or their preferences related to specific treatments and place of treatment. Within ACT Health, the Advance Care Plan is used to record a SoC and to document whether a person has an EPoA or Medical Directive in place.

Several barriers to completion of Advance Care Plans have been identified in the literature including a lack of knowledge and understanding of ACP amongst the community, inaccessibility and difficulty in the logistics of completing and signing forms which require two witnesses (at least one person authorized as per the Statutory Declarations Act 1959 and one other person who is not the nominated attorney), avoidance of having conversations
about death, and clinical pressures such as time constraints, lack of privacy in the ward setting, lack of practitioner knowledge, lack of systems in hospitals for addressing ACP, and failure of clinicians to initiate the discussion (7, 11, 12).

In order to improve ACP, clinics called Respecting Patient Choices TM (RPC) were introduced in Australia in 2002 as a pilot at the Austin Hospital in Melbourne, based on the program developed by Guubderson Lutheran Medical Foundation in La Crosse Wisconsin (13). Following the success of the RPC clinics at the Austin the program received further Federal funding and has been adopted in several other hospitals within Victoria and other states (14). The RPC program was established within the Canberra Hospital and Health Services (CHHS) in 2006. Care Coordinators working within the ACT Health Chronic Care Program (CCP) also offer assistance with ACP as part of their role and run an RPC clinic specifically for patients who are part of the CCP. The CCP provides clinical support, education and care co-ordination for frequent users of Canberra’s acute health sector who have Chronic Heart Failure, Chronic Obstructive Pulmonary Disease or Parkinson’s Disease. Care coordination is offered to patients with more complex care needs. Care Coordinators are trained RPC consultants, many of whom are authorised under the Statutory Declarations Act 1959 to witness completion of an Advance Care Plan, including a SoC or witnessing an EPoA, but not Medical Directive. Care Coordinators visit patients in their home and liaise with inpatient and community areas to facilitate a smooth transition from hospital back into the community. Despite introduction of the RPC clinic, many patients with chronic conditions accessing the CCP were noted to not have Advance Care Plan in place, and many of the issues surrounding ACP were still barriers.

The aim of this project was to trial the introduction of ACP clinics targeting care coordinated patients within the CCP to help address some of the identified barriers for completing an Advance Care Plan. The proportion of SoC completion amongst care coordinated patients in CCP before and after introduction of the clinics was used as a marker to assess the effect the clinics. Informal feedback from patients was collected to assess acceptability.

Method

In August 2011 the Care Coordinators established a fortnightly home-based mobile APC clinic where staff members visited patients at home to discuss and complete Advance Care Plans. All CCP patients were offered visits, with care coordinated patients initially targeted due to the complexity of their issues. At these visits two trained and authorised CCP Care Coordinators facilitate and witness patient’s completion of their Advance Care Plan comprising of a SoC and/or EPoA documents. Patients are reassured that their documents can be modified if their wishes alter over time. Partners and carers were also offered the opportunity to complete their own ACP at this time if they wished.

Following implementation of the mobile ACP clinic, several ongoing barriers to increasing the completion of SoC were still noted including extensive travel time required by staff, availability of staff to conduct home visits and waiting times to book into clinics. In order to address these issues a fortnightly outpatient ACP clinic was commenced in late August 2012 at The Canberra Hospital. A suitable outpatient consulting room was found in the Canberra Hospital for use every fortnight as the Respecting Patient Choices Outpatient Service. Patients were allocated an hour long appointment to allow for an information/education session in relation to Advance Care Planning and completion of the documents. Further appointments were made if discussions and documentation are unable to be fully completed within the hour. To encourage participation packs of blank Advance Care Planning documents including EPoA and SoC information and forms were distributed to all patients in the CCP who had no current Advance Care Plan in place and staff initiated discussion about the clinic. Patients then had the choice to be booked into either the mobile or outpatient clinic. Patients who were fairly mobile and had available transport were encouraged to attend the hospital based clinic, allowing for more mobile clinic appointments to be made available for patients who were less mobile or did not have available transport. Both clinics were run within the existing resources of the CCP.

The number of completed SoC was recorded for care coordinated patients within CCP. The proportion of care coordinated patients who had completed a SoC was measured before introduction of the ACP clinics and at three time points after the introduction of the mobile clinic (20, 24 and 26 months) and outpatient clinic (4, 8 and 10 months). We also measured patient self-reported satisfaction with the clinic.

Results

In March 2011, prior to introduction of the mobile ACP clinic, the proportion of care coordinated patients who had completed an SoC was 35 percent. By December 2012, 20 months after the start of the mobile clinic, and 4 months after the introduction of the outpatient clinic, the proportion of care coordinated patients with a completed SoC was 39 percent. In April 2013 48 percent of care coordinated patients had completed a SoC, and in June 2013 the proportion had increased to 56 percent. The increase in proportion of SoC completion amongst care coordinated patients in CCP at these different time points is presented in Table 1 and Graph 1.

Informal feedback from patients was positive, with frequent responses from patients stating that the clinics made discussing ACP more accessible, increased understanding and decision making capacity and assisted people in completing a SoC who otherwise would not have done so.

Table 1: Number and percentage of care co-ordination patients with completed SoC between March 2011 and June 2013.

<table>
<thead>
<tr>
<th>Date</th>
<th>Months post introduction of outpatient ACP clinic</th>
<th>Number of care co-ordination patients</th>
<th>Number (%) of care coordination patients with SoC</th>
</tr>
</thead>
<tbody>
<tr>
<td>March 2011 (prior to clinics)</td>
<td>N/A</td>
<td>54</td>
<td>19 (35%)</td>
</tr>
<tr>
<td>December 2012</td>
<td>4</td>
<td>89</td>
<td>35 (39%)</td>
</tr>
<tr>
<td>April 2013</td>
<td>8</td>
<td>95</td>
<td>48 (51%)</td>
</tr>
<tr>
<td>June 2013</td>
<td>10</td>
<td>102</td>
<td>57 (56%)</td>
</tr>
</tbody>
</table>
Discussion

The great majority of deaths in Australia are in elderly people with chronic diseases (1). Chronic diseases accounted for 90% of deaths in Australia in 2011 (15). The often long interval between diagnosis of a chronic condition and death provides the opportunity for end-of-life discussion; however, studies suggest the number of Australians with an Advance Care Plan is low (16-18). The trajectory of illness in chronic conditions is often unpredictable (19) emphasising the importance of discussing ACP early so that in the case of sudden deterioration a person’s end-of-life care wishes are known.

Targeting care coordinated patients within the CCP and increasing access to clinics to discuss ACP an effective method of addressing some of the barriers of ACP. Mobile and outpatient ACP clinics increased access for patients who may not have otherwise been able to attend, facilitated increased discussions about ACP by initiating the conversation in patients with diagnosed chronic illnesses, and allowed patients the opportunity to have dedicated time to discuss their concerns and explore their options. Following implementation of the mobile ACP clinic and initially after the introduction of the outpatient clinic there was only a small increase in the proportion of care coordinated patients with a completed SoC, from 35 percent in March 2011 to 39 percent in December 2012. The small increase following introduction of the mobile may have been due to some of the identified issues surrounding constraints on staffing availability to conduct home visits and travel times required for home visits on top of other work duties. By April 2013, 24 months after the introduction of the mobile clinic and 8 months after the introduction of the outpatient clinic, there was a notable increase in the percentage of care coordinated patients who had completed a SoC from 39 percent in December 2012 to 51 percent in April 2013 (Table 1, Graph 1). Comparison of the proportion of care coordinated patients with a completed SoC in March 2011 and June 2013 showed a 21% increase in proportion of patients with a SoC. Following the success of the ACP clinics, they were extended to all patients within the Chronic Care Program in addition to continuing the program for care coordinated patients. The establishment of the ACP clinics helped facilitate patient completion of a SoC, and ACP, in general, beyond the scope of care coordinated patients to the overall CCP patient group. It also created the opportunity for the patient’s partners to complete an Advance Care Plan as well.

Whilst measuring completion of SoC has been used to measure the impact of introducing ACP clinics, it does not measure the other important outcome, which is increased discussion about end of life care and raising awareness and introducing the topic to patients with chronic conditions. Despite the success of the project, there are still several ongoing challenges including the time taken for staff to enable patients to feel unhurried in discussion and completion of ACP, increased administrative load in addition to clinical caseload responsibilities, patient reluctance to discuss end of life care, and beliefs that ACP has no impact on care. During the project it was noted that a number of patients had completed an EPoA prior to being enrolled on to the CCP but had either not considered completion of a SoC or found the process too confronting. For those patients who had not completed either document it was noted that most patients were comfortable to complete an EPoA but needed additional support and education around the value of completing a SoC. One of the reasons some patients reported for not wanting to complete a SoC was the belief that a SoC had no impact on care (or could even be detrimental to care), due to anecdotal stories about end of life care, despite having documented their clearly defined wishes.

The fear and mistrust about end of life care planning supports the findings of other studies identifying these issues as ongoing challenges in ACP (11, 20). Whilst several studies have supported that documentation of ACP improves compliance with patients end of life wishes (4-6), other studies such as the American SUPPORT study indicate that ACP does not necessarily correlate with increased compliance with patient wishes (21).

The patient population in our case study is relatively small,
However, an increase in the proportion of patients who completed a SoC following the introduction of ACP clinics was seen. This reflects the positive impact the ACP clinics had on increasing access to ACP and completion of a SoC amongst this patient group. Despite the small study population, this case study provides strong support for the implementation of ACP clinics to address some of the identified barriers to completing SoC, which can be generalized to other components of an Advance Care Plan. This will be clinically significant as the proportion of people with chronic diseases increases in future. Another limitation of this study was the use of administrative data to measure the number of patients with a SoC, where for research purposes it would have been beneficial to have more frequent and standardized time points to monitor this along with retention of atomic data to facilitate post-hoc statistical analysis. Despite this, the positive outcome from this study highlights the benefits of using administrative data and existing resources for the improvement and development of clinical services.

Future considerations

Further studies regarding compliance with documented Advance Care Plans, including SoC, in the Australian setting are needed to either identify factors contributing to poor compliance with Advance Care Plans that need to be addressed; or to provide information to allay these fears and improve patient confidence in the process if these concerns are shown to be unfounded.

Further work needs to be done to integrate ACP into routine clinical care and facilitate discussions around end of life care. Implementation of ACP group education sessions could be one method of increasing awareness and knowledge about ACP. These could be held within the hospital as well as in the community and be targeted to both patients and health professionals. A small pilot study is planned to assess the feasibility and success of this type of program in the Canberra Hospital.

Following the success of implementing the ACP clinics within the CCP, other departments within the hospital are implementing ACP clinics using this model.

The ACT Health Respecting Patient Choices program in conjunction with the local Primary Health Network have developed a public media campaign called BeMyVoice to raise awareness, improve knowledge and normalize ACP discussions (22). Improving knowledge of ACP amongst practitioners should embed ACP into health professional training so it becomes a normal part of routine practice. In line with this, involvement of General Practitioners is vital to address some of the barriers to ACP. Future work should focus on opportunities to support ACP become a routine part of a GP management plans.

Conclusion

The establishment of ACP clinics has been a practical way within existing resources to help overcome multiple barriers for patients preparing their Advance Care Plans, by providing increased access and support for timely completion. ACP is now embedded into CCP core business. This approach enabled staff to improve SoC completion rates whilst simultaneously managing a substantial caseload increase. This case study provides good evidence to support the introduction of ACP Clinics as part of the evolution toward a better chronic care model by regional health services.

BIOGRAPHIES

Belinda Jones has an MBBS from the Australian National University and completed her Master of Public Health through The University of Sydney in 2014. She is currently working in Chronic Disease Management as an Advanced Trainee in Public Health.

Wendy Appleton has a Bachelor of Social Work from the Australian Catholic University in the ACT and has worked extensively in government and non-government organisations in the UK and Australia. She has been working at The Canberra Hospital since 2002; initially in ward social work in the areas of Gastroenterology, Respiratory and Oncology prior to commencing as a in 2010 providing biopsychosocial support to people with Heart Failure, Respiratory disease and Parkinson’s disease. She is passionate about advance care planning and patient well-being both in hospital and the community and assisted with the setting up of the Chronic Care Program advance care planning clinics and is also involved with the hospital advance care planning committee.

Toni Heazlewood has a degree in Social Work and is currently working as a Clinical Care Coordinator with the Chronic Care Program at the Canberra Hospital. She has worked in Health for well over 11 years. Her experience includes Cardiology, Medical/Surgical, Medical Assessment and Planning Unit, Renal Unit, Respiratory and Clinical Care Coordination. The latter specializes in working with people who have end stage Heart Failure, Chronic Obstructive Pulmonary Disease and Parkinson’s. The role includes ensuring care needs are met through coordinating services in the primary health and community areas and by facilitating clients to complete Advance Care Plans.

Jan Ironside was the Clinical Manager of the Chronic Care Program, Canberra Hospital from 2009-2015. During this time Jan was involved in several service redesign projects including one on Advance Care Planning and the re-alignment of the care coordination service. The program comprised of 6 staff in 2009 and grew to 12 staff by the end of 2013. The program also won team of the year in 2012 for it’s outstanding service. Jan was nominated for ACT Nurse of the Year in 2014. Prior to this role Jan was the GP Liaison Officer for ACT Health and has also held numerous other roles in the community and hospital settings. Jan is passionate about the provision of high quality, safe patient-centred care without compromise and that empowers patients to be the decision drivers in their health care journey. Jan took an early retirement in 2015 to pursue a quieter pace of life in NSW’s Southern Highlands.

Paul Dugdale is an academic in public health and also the Director of the Centre for Health Stewardship at the Australian National University and Chair of the Australian Healthcare and Hospitals Association.
References

The International Hospitals Federation and the Australian Healthcare and Hospitals Association summary statement on End-of-Life Care

Sydney, Australia 2 November 2015

The Australian Healthcare and Hospitals Association sponsored a seminar, *International Perspectives and Australian Experiences on End-of-Life Care* featuring Eric de Roodenbeke, Director General of the International Hospitals Federation and Australian researchers and clinicians.

**Preamble**

This summary statement about End-of-Life Care was inspired by the speakers and participants of this seminar. It is intended to influence Hospital Chief Executives, Health Executives, Directors of Medicine, Directors of Nursing, Hospital and Health Service Boards.

**Aim**

We call on all health leaders to ensure that modern health services provide appropriate care for people who are nearing the end of their lives.

**Background**

There is growing evidence in Australia and internationally that people prefer to spend the last part of their lives at home, but most spend their last days in a health setting. The health system is set up to provide increasingly aggressive therapies for the frail elderly and that by stopping some people from dying, it is creating harm. We have been slow to adapt from acute care to chronic and aged care in our hospitals, with medicine that is designed around diagnosis and interventions, not normal ageing and the inevitability of death. Hospitals can be both inappropriate and expensive places to die, yet we do not have enough palliative care and End-of-Life (EoL) services to offer as alternatives.

**Principles**

End-of-Life care should:

- Relieve suffering and preserve dignity
- Include person centred informed choice
- Provide care in a culturally and spiritually appropriate manner
- Ensure communication with individuals and family about the available options for EoL care are transparent and respectful
- Ensure palliative care or EoL care services are accessible to those who choose these paths
- Enable individuals to die in a place of their choice
- Support health care professionals to provide appropriate, high quality individualised EoL care to individuals and their family
**Barriers**

There are no universal definitions for end-of-life care, futile care, palliative care, active and passive euthanasia.

Lack of funding for non-health setting EoL care, or inappropriate funding types.

No agreed metrics or data to benchmark EoL care.

There are limitations in understanding cultural differences about EoL values.

From an economic perspective there are no systematic data about costs of EoL care.

Slow adaptation from acute care to chronic and aged care in our hospital systems.

Medicine is designed around diagnosis and treatment rather than discussing options about normal ageing and dying.

**Markers of success** for hospitals with an international best practice approach

Ongoing education about discussion about End-of-Life wishes with chronic and terminally ill individuals and their families.

Regulations to support palliative or EoL care.

Patient centred choices.

Standardised and organisation wide approaches to EoL care.

Agreed metrics that measure changes in outcomes.

Identification of normal dying processes with appropriate responses.

Palliative care nurses that are available at all times.

Health professionals that can: assess urgency; discuss care options with individuals and relatives; inform available health care teams about desired goals; design programs with empowered liaison support—e.g. community and home care.

**What we need to do next**

Conduct public discussions about the limitations of the current system.

Provide education about End-of-Life care options for doctors, nurses and allied health.

Increase the utilization of EoL services by selected populations.

Offer legal counselling and non-medical therapies as routine services.

Reduce the use of aggressive therapies (critical care) as an automatic response to deterioration.

Develop agreed definitions and methods to measure changes in outcomes.
Overcoming the Obstacles in Promoting Hospice Palliative Care - Sharing Experiences of the Taiwan Changhua Christian Hospital

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ABSTRACT: Hospice palliative care for terminal patients is necessary, yet challenges are on the way worldwide. This study demonstrated that hospice palliative care has been quickly developed in Taiwan due to the support of the National Health Insurance system, the promotion by civil societies and religious groups, patient’s legal right for DNR, easier access to pain killers through medical prescription, and well-planned hospice staff training programs. This paper introduces how hospice consultation is provided by a comprehensive hospice palliative team at Changhua Christian Hospital to establish trust and cooperation with the medical team, and to improve hospice- palliative care referral and utilization rates.

Introduction

Many researches have shown that hospice palliative care is able to improve the quality of life and medical satisfaction of terminal ill patients, and reduce the burden of personal and national medical cost. The dominant three palliative care delivery models in the world are hospital palliative care, community palliative care, and hospice. Yet obstacles are encountered worldwide because of national health policies, legal regulations, limited access to pain killers, attitudes towards death and dying, caring ability of medical professionals, and public understanding.

Also, hospice palliative care is not well conducted in in-patient, consultation, and referral systems. The barriers of in-patient hospice palliative referral are doctors, the general public, and referral system procedures. The Doctor is the key person to decide if consultation or referral is necessary. Thus, a referral physician is considered as one of the primary stakeholders of hospice and palliative care. The referral and utilization rates of hospice palliative care are low because the physician 1) is unfamiliar or does not believe in the benefits that hospice could provide, 2) is afraid to lose patients, 3) fears to be considered a medical failure, 4) is worried that the families of patients will be disappointed and depressed.

To solve the above obstacles, hospice policy makers and palliative care providers have to work together to develop policies and strategies to overcome them. Thus, hospice palliative care would be understood and accepted, and terminal ill patients have the opportunity to receive holistic care.

Exposition

Taiwan is located in East Asia with a population of twenty-three million people. Life expectancy of Taiwan residents reaches 79.8 years. The per-capita GDP of Taiwan in 2014 is 22,635 US dollars. The top three leading causes of death are cancer, heart diseases, and cerebrovascular diseases. Hospice palliative care was developed in Taiwan 25 years ago. Later compared with the West, yet it rapidly developed. According to research by the Economist Intelligence Unit (the quality of death index) on death quality published in Oct. 2015, Taiwan ranks as the 6th country with excellent hospice care quality compared with 80 countries in 5 categories: Palliative and healthcare environment, Human resources, Affordability of care, Quality of care and Community engagement. Taiwan also provides the best hospice care in Asian countries.

MacKay Memorial Hospital, a Christian hospital in Taiwan, constructed the first hospice ward in 1990. Taiwan then became the 18th country to provide hospice palliative care around the world. The attention of the government, hospitals and the general public was engaged due to the promotion of hospice palliative care by civil societies and religious groups. The National health Insurance (NHI) Administration, Ministry of Health and Welfare reimbursed the cost to health providers or organizations with hospice care.
home-service, inpatient care and hospice shared care, a service for patients in non-hospice wards. Patients admitted are those with cancer, motor-neuron diseases, and other life-threatening diseases including: 1. dementia, 2. severe brain damage, 3. heart failure, 4. chronic obstructive pulmonary disease and other lung disease (such as cystic fibrosis lung), 5. liver cirrhosis, and 6. renal failure. No extra medical fee is required for terminal patients who receive hospice palliative care.

In addition, the legislation of the “Hospice Palliative Care Act” was approved in 2000, and Taiwan became the first country in Asia to approve “Natural Death Act.” Patients over 20 with terminal diseases have the right to express in writing their desire for “DNR - Do Not Resuscitate” and to withdraw/withhold life-sustaining treatment. The general public are encouraged to sign their consent to receive hospice palliative care in NHI IC cards. The approval of the Act demonstrated how Taiwan people emphasize patients’ right. Medical professionals respect terminal patients’ decision not only based on professional/ethical judgment, but legal basis.

Besides official subsidies to civil organizations, the government provides funding for training healthcare professionals, including social workers and spiritual care workers for hospice services. They are required to receive basic and advanced training programs. Issues are proposed on hospice palliative care, the public is educated on life issues and death with dignity in order to understand the rights and resources of terminal patients. The general public are encouraged to discuss hospice caring models. Religious groups support hospice palliative care for it neither hastens nor prolongs death, values life and accepts death as a natural process. To provide spiritual care, Lotus Hospice Care Foundation, for example, greatly promotes life education and trains clinical Buddhist Chaplains to work with medical teams. Christian and Missionary Alliance focuses on recruiting and training to care cancer patients volunteers, cultivating spiritual care workers, and promoting licensing to spiritual care workers. “Spiritual care worker” is a new profession in Taiwan and the government attributes great importance to it. During hospital accreditation, a bonus is given to the hospital if spiritual care workers who received hospital palliative care are included in the hospital team. Thus, the hospital is encouraged to hire spiritual care workers for hospice service.

The availability and use of opioids in Taiwan is legitimate. Taiwan adopted a “Statute for the Control of Controlled Drugs,” easing restrictions on morphine and other opioids, increasing the manufacture, sale and distribution of new opioid analgesics, and making it easier for hospitals to obtain the narcotic.

According to the statistics of Taiwan National Health Department, only 7.42% of terminally ill patients received hospice care within the last year of life in 2000. The hospice palliative coverage rate increased to 51% by 2012. The hospice palliative care awareness rate increases from 40% (2004) to 80% (2012) among cancer patients / families.

Changhua Christian Hospital (CCH) is a medical center with 1,600 beds in central Taiwan. Over 2,700 people are newly diagnosed as cancer patients every year in CCH. There are 3 full-time well trained to reach mature staffing level palliative medicine physicians, nurses, home care nurses, psychologists, social workers, spiritual care workers and volunteers to provide hospice service, including inpatient consultation service, palliative shared care, inpatient palliative care, outpatient palliative clinic, and hospice home service.

In the inpatient setting, hospice palliative consultation is given when the referring physician consents for the hospice palliative team to approach the patient with cancer. Then, hospice palliative physicians evaluate the patient and arrange further hospice palliative services. Therefore, an early palliative care consultation is very important for terminal cancer patients to receive hospice palliative care. CCH cancer patients are hospitalized in different wards based on their cancer diagnosis. On the first day that the patient is hospitalized the doctor has to document whether the cancer patient is in terminal stage. Hospice consultation will be recommended if the answer is positive in the assessment item. If judgment is not easy at the beginning, the doctor is able to arrange hospice consultation after the development of the cancer patient’s disease is more obvious. A computerized palliative trigger tool is to facilitate screening of the potential cancer patients for palliative care. This hospice palliative alarm system helps cancer care physicians to determine the best time for hospice consultation, complete consultation procedure in a short time, improve consultation convenience, and enhance the doctor’s willingness to arrange hospice consultation. However, the hospice-palliative coverage rate for cancer patients of the CCH in 2013 was 47% (47% in 2012), which was lower than the 60% target goal set by the Health Promotion Administration, that means hospice resources were not fully used for cancer patients in the CCH.

The major reason is that the doctor perceives hospice palliative care as “end of life” care, and equals death. Hospice consultation is arranged when the patients’ vital signs are unstable. They appear not to be familiar with the essence and service items provided by hospice palliative care, and they are unsure if the hospice team will help patients. They doubt if patients will become angry and upset if hospice consultation is arranged, and patients will think that physicians do not want to care for them. In addition, the patients’ family members have unreasonable expectations related to disease prognosis, and they refuse hospice consultation. All these lead to the lack of familiarity with the availability and suitability of a hospice.

There used to be 4 hospice training physicians taking turns for hospice consultation on a daily basis in the CCH. Since 2014, this model was modified. The hospital wards are divided into 3 areas. Three hospice doctors with higher staffing levels, shared care nurses, social workers and spiritual care workers are responsible for consultation
to understand the ideas and needs of the doctors with regards to hospice palliative care. They clarify their doubts, demonstrate how to use pain killers correctly, instruct medical professionals how to discuss advanced care planning with patients, and illustrate different management and caring models in terms of illness trajectories, such as psychological support, ease of side-effect, turning and positioning of patients with absolute bed-rest, and preparation for peaceful death. As to the unreasonable expectation of disease prognosis, the hospice team guides patients and their family members in the progression of the illness, and to reset the treatment goals and options. It helps to reduce the pressure of the original medical team.

The results of assessment, goals and suggestions are written in medical records for the caring team. The caring team and hospice team members are able to interact smoothly and work in partnership. By doing so, the caring team members understand how the hospice team helps to relieve patients’ symptom, provide comfortable care, make medical decision, and facilitate communication between medical team and patients/families. The remarkable result is that the doctor’s consultation workload increased from 120 in 2013 to 168 in 2014 persons per month on average. (figure 1.) The hospice-palliative coverage rate of cancer patients increased to 56% in 2014 and 68% during January-August 2015 (figure 2.), indicating that this mechanism is helpful to greater palliative care integration in CCH.

**Conclusion**

Hospice palliative care, a holistic service, is provided in the event of chronic illness, patients in disease progression and their families. Key elements in promoting hospice palliative care include 1. hospice palliative care to be covered by the national health policy, 2. life education to be promoted to the general public, 3. training programs to be provided to health care-givers, and 4. medicinal product management policy to be developed for terminal patients to obtain pain killers effectively. The attitude of frontline medical professionals toward the hospice is an essential factor if patients are to receive hospice palliative service. Doctors are aware of the importance of hospice palliative care, and hospice service meets their needs. CCH sets a ward-specific hospice team in every ward to provide better service for terminal patients to achieve high quality hospice palliative care.

**BIOGRAPHY**

**Pei-Yu Tsai**, Chief of Department of Palliative Care, Changhua Christian Hospital, Taiwan. ROC

Dr. Tsai is a specialist of Hospice-palliative Medicine, Geriatric Medicine and Family Medicine, and has been devoted to hospice palliative care for 15 years. Besides hospice home care, in-patient care and consultation, Dr. Tsai also promotes hospice in the community, and educates local medical staff to provide hospice in place.

**References**


End-of-life care: practices from around the world

Palliative Care and legislation around dying

ABSTRACT: Around the world forty million people a year need palliative care yet more than four in five of these have no access to basic analgesia with morphine. 6% of those dying with no pain relief are children. Those left behind carry with them the memory of the death and it can colour their future lives, making good palliative care an urgent public health issue around the world. Everyone providing healthcare needs core training in palliative care, including the fundamentals of pain and symptom relief. Governments must urgently address barriers to morphine availability and educators of health care professionals must eliminate myths and phobias, and teach good end of life care.

Background. Cicely Saunders, founder of the modern hospice movement, said “How people die remains in the memory of those who live on.”

Most bereaved children worldwide are bereaved through disease. In the west at any one time about 0.75% of the adult population will have palliative care needs; (Murtagh, et al., 2014) (Marie Curie, 2012) in other words, they will be in their last illness. They are mainly affected by the chronic diseases of more affluent societies: heart disease, stroke, cancers, degenerative disorders including neurological disorders, lung disease, kidney and liver failure, advanced diabetes, and now increasingly from end stage dementia. They are also affected by more prevalent infections including HIV and anti-microbial resistant infections, such as tuberculosis.

Death is the only certainty we all have; whether that death is relatively slow or relatively fast in coming, the vast majority of people will have conditions to which the principles of palliative care apply, even if only for days or hours. These principles are of comfort care, particularly pain relief, of being listened to and of being respected and valued as a human being when dying. Again, to quote Cicely Saunders: we should all say: “You matter because you are you, and you matter to the last moment of your life. We will do all we can, not only to help you die peacefully, but also live until you die.”

Global concerns

The World Health Organisation’s Global Atlas of Palliative Care has shown how far we are from ensuring that the basic human right of having this care is actually achieved. Across the world, each year approximately 40 million patients need palliative care, 80% of these people lack analgesic access and 80% of the need is in low/middle-income countries. Alarming, 6% of the need for good end of life care is in children, who are dying from congenital disorders, neonatal conditions, and conditions such as malignancy and fulminant infections. (Worldwide Palliative Care Alliance, World Health Organisation, 2014)

Morphine phobia in governments and amongst many health care professionals remains widespread. There is no evidence that opioids, including morphine, when given for pain relief to terminally ill patients, shortens their lives – they may actually prolong active life and enhance survival, because patients no longer die of exhaustion through unrelieved pain. Patients with good pain control are also better able to prepare those around them for their death, to put their affairs in order and to gain pleasure from whatever time they have left. Morphine in such patients is not addictive, patients do not develop tolerance and, given orally, it is a cheap and effective analgesic. Many governments have policies that are so restrictive that it is impossible for patients to get the right dose, at the right time, by the right route (which is orally for repeated administration) thereby preventing patients from remaining out of hospital, functioning in their own home.

The barriers to good analgesia in much of the world are a combination of lack of access to essential medicines; lack of education in palliative care; lack of government policies that include palliative care in the healthcare system; and a lack of palliative care resources, particularly at the patient’s home.

The physical component of the vast majority of pains in terminal illness will respond to morphine and similar analgesics but the patient’s experience will be made far worse if their emotional social and spiritual concerns - questions such as “what will happen to my children”, financial stringencies and depression - are not also addressed.

The aim of all palliative care is to decrease the deficit in quality of life that is brought about by disease (the deficit is the ‘gap’ between reality and how a person would like to feel), by improving patients’ reality through good symptom control and support, as well as helping them adjust their expectations and aspirations to the reality of their situation. This model is
Children as relatives

The only way a clinician can know what a patient is experiencing is by listening to the patient describing the problems they are experiencing. Careful, attentive listening with undivided attention is a skill increasingly lost in medicine; pressures to give information and undertake tests and treatments have supplanted the core skill of a thorough history taking, which requires attentive listening.

The skills of listening, of addressing distress and meticulous attention to symptom control are the embodiment of good palliative care. For many patients such an approach is applicable relatively early in a disease, or sometimes at the time of diagnosis if it is clear that the illness is terminal. Palliative care skills therefore need to be included in every clinical training curriculum and to be recognised as a core attribute of the duty every health care professional, because dying patients are ubiquitous. Specialist palliative care has an important place for helping to care for very complex clinical scenarios, for teaching others and for research.

As crises arise during an illness, palliative interventions, such as good analgesia and urgent attention to distress in the patient and their family, are often needed in conjunction with disease-targeted treatments. For example a patient with malignant spinal cord compression may need urgent radiotherapy, but also pain relief, as well as support to adjust to the changed reality of reduced mobility and a worsening prognosis. Thus in parts of the world where palliative care works alongside other disciplines such as cardiology, neurology and oncology, patient outcomes are improved. (Temel, Greer, & Muzikansky, 2010)

Specialist palliative care has beneficial effects in terms of patient outcomes and thereby in cost saving. 56% of cancer patients showed a significant improvement in their anxiety/depression after just one supportive/palliative care consultation. (Worldwide Palliative Care Alliance, World Health Organisation, 2014) Cancer patients receiving palliative care are 50% less likely to attend the emergency department in the last month of life compared to those not receiving palliative care. (Henson, et al., 2015) and a quarter of all emergency department visits by cancer patients (including those receiving and not receiving palliative care) may be avoided if several areas of palliative care were improved. (Delgado-Guay, et al., 2015)

Hospital costs are by far the largest cost element of end-of-life care – care in the final three months of life averaged over £4,500 per person, with most of this cost being due to emergency hospital admissions. (Georghiou & Bardsley, 2014) To reduce these costs requires adequate support outside hospital, in the community. Such support can include hospice beds, hospice home care teams and other types of community help. But to be effective such help and support must be available every day of the week, as must access to medication. General clinical staff who need to ask for help or advice must be able to access support at all times of the day and night.

In Wales, to meet this need, we have established a single open access website (http://wales.pallcare.info/). This site hosts guidelines on all aspects of palliative care, supported by reference to the evidence base behind each recommendation. It also includes an opioid dose converter, to help avoid medication errors when there are changes to the type of analgesic or the route of administration. In addition there are links to other useful web resources and to other documents that have been developed for Wales, but may be useful in informing thinking far further afield.

When it comes to providing care as death approaches, families often ask “How long?”, expecting the doctor to be able to predict the time of death will occur. There is no evidence that an accurate prognosis can be given. ‘Uncertainty in dying’ is an important explicit concept that must be recognised, so that clinical decision makers recognise the potential for recovery and can balance it against the need to avoid futile interventions. (Kennedy, Brooks-Young, & Gray, 2014)

Difficult decisions

Difficult decisions arise when there is a decision to withhold or withdraw a treatment: occasionally this process is wrongly confused with euthanasia. But these are fundamentally different decisions both in intent and in planned outcome. When treatment is not predicted to be of benefit it is unethical to start or, if it is proving to be failing, to continue it. When such an intervention is stopped the intention is to avoid harm, by decreasing the risks and burdens to the patient of a futile intervention. The patient may die rapidly, such as when ventilation is stopped in a patient with advanced motor neurone disease, and during the time of dying the doctor is under a duty of care to provide comfort

**Figure 1: Schematic graph showing the effect of good palliative care on the quality of life (Calman, 1984).**

Narrowing the quality of life ‘gap’ through good palliative care

- **Hopes and aspirations**
- **Reality**
- **Gap**

Quality of life

Time
measures, usually as anxiolytic doses of medication and often small doses of morphine to avoid distressing dyspnoea. But sometimes patients get dramatically better when treatment stops, such as when all involved realise that chemotherapy was even more toxic for the individual than had been thought. Some of these patients have gone on to live active productive lives for months or years after the decision to stop treatment.

But these decisions are fundamentally different to euthanasia where a lethal dose of drugs is given to deliberately bring about death as rapidly as possible, irrespective of how much longer the patient might have lived dying from their disease.

Children as relatives

Children are often the most affected and their needs the most ignored when a family member dies. In many societies the “stable family unit” is a thing of the past, and a grandparent may represent the most stable part of a child’s life. When the grandparent dies, the child is devastated, feels abandoned and may have many unanswered questions. Health care professionals are not good at always asking: is there a child affected by this death? What has the child been told? What does the child understand is happening?

And, importantly, those adults providing the child’s care need to be helped to understand that children grieve differently from adults. In many parts of the world the figures are much higher, with almost one third of them that is the loss of a parent or sibling. In many Western world have suffered a serious bereavement and that for many it has been estimated that 10% of schoolchildren aged 5-16 in the UK may be bereaved, as happens if a classmate or teacher dies. It is likely that a whole school class then suddenly misbehave or become distressed as the reality of their loss impinges on their mind. Sometimes a whole school class may be bereaved, as happens if a classmate or teacher dies. It has been estimated that 10% of schoolchildren aged 5-16 in the Western world have suffered a serious bereavement and that for one third of them that is the loss of a parent or sibling. In many parts of the world the figures are much higher, with almost all children having experienced a serious bereavement.

Today we see children, orphaned through the recent calamities of Ebola and other conflicts, who struggle to find a way to survive, let alone to make sense of what has happened to them. Care of the child before and after a death is a public health issue. The outcomes for children who are grieving are far worse if they are not supported. Children who are unsupported are more likely to develop depression, suicidal ideation, get caught up in criminal behaviours or form inappropriate relationships resulting in teenage pregnancy and disordered emotional attachments. All this stresses the importance of that little question: “is there a child affected by this death?”

Political debates

In some parts of the world, legislation for physician assisted suicide and/or euthanasia has been passed. The House of Commons of the UK Parliament has recently voted overwhelmingly against such proposals for England and Wales, principally because of the dangers; the MPs criticised the proposed so called “safeguards” as inadequate, highlighting that it is impossible to state accurately who is terminally ill, the inaccuracies around prognosis, the problems of diagnostic errors and that the dangers of coercive pressures on an individual, which are almost impossible to detect. Parliament was clear in its message that such actions do not have a place in clinical care.

BIographies

Professor the Baroness Finlay of Llandaff, is a Honorary Professor of Palliative Medicine, Cardiff University and Lead Palliative Care Clinician (Wales), Chairs The National Mental Capacity Forum on behalf of the Ministry of Justice and Department of Health; Chairs the National Council for Palliative Care. She is immediate past President of British Medical Association (2014-15) and member of BMA ethics committee.

Harriet Lancaster, is currently working as a Parliamentary researcher for Baroness Finlay in the House of Lords, dealing primarily with Medical and Health Policy, End of Life Care, and Medical Ethics. She is lead author on an academic paper looking at the provision of Palliative Care in England. She has a BSc in Biological Sciences, with Neuroscience Hons from the University of Edinburgh, where she researched the effects of illegal drug use on developmental biology and cognitive function.

References


Establishing Palliative Care across the AKDN Health Services: Opportunities and Challenges

Preamble. The Aga Khan Development Network (AKDN) is a group of development agencies with mandates that include the environment, health, education, architecture, culture, microfinance, rural development, disaster reduction, promotion of private-sector enterprise and the revitalization of historic cities. [1] Aga Khan Health Services (AKHS), an agency of AKDN, is one of the most comprehensive private not-for-profit health care systems in the developing world. [2] Aga Khan University (AKU) is the intellectual turning-plate of the AKDN, with academic programs in eight countries and a University Health Services enterprise that includes Aga Khan University Hospitals (AKUH) in Karachi and Nairobi in addition to affiliated teaching hospitals and an outreach services network in five countries. These two entities make up the AKDN Health Services which includes thirteen state of the art urban academic tertiary care centers and service hospitals. More than 300 community based primary care centers comprise the outreach network and extend from the most urban to the remotest areas of Central and South Asia and East Africa. Figure 1

Defining the Scope of the Issue and Establishing the Approach

Our analysis showed that only twenty countries (8%) have palliative care well integrated into their healthcare systems and 80% of the need for palliative care is in low and middle-income countries, yet most is provided in high-income countries. [3] This clearly highlights a significant unmet need for palliative care in the developing world. The World Health Organization (WHO) made the resolution to ‘Strengthen palliative care as a component of comprehensive care throughout the life course’ at the sixty-seventh world health assembly in 2014. [4] The following year, the WHO included ‘universal health coverage’, defined as Promotion – Prevention – Treatment – Rehabilitation – Palliation; as one of the sustainable developmental goals for health at the sixty-eighth world assembly. [5] In light of this escalating global urgency for palliative care, the AKDN decided to undertake a major focus where (a) AKHS would integrate cost-effective palliative care
across its significant international footprint, and (b) AKU would integrate palliative services and establish academic offerings in its programs. To achieve this goal, AKDN commissioned a baseline study to determine the issues, needs, challenges, resources and capacity in palliative care within its member healthcare entities. [6] Entity participants were individuals dealing with patients identified as terminally ill or at the end of life stage within the cultural and geographical context of AKDN health entities. Key perceptions of health care staff and patients regarding aspects of palliative care that were revealed and will inform program development, include the following:

“We also find it difficult to talk about death because we think death as failure of our abilities to treat our patients…death is supposed to depress everybody…we are just trying to avoid this elephant in the room.” (P3, FGD, Pakistan)

“…either the medications are not available or if available too expensive…” (P1, FGD, Tajikistan)

“So you know, when you talk about palliative care, I mean forget the skills, you just don’t even have the numbers of people to take care.” (P6, FGD, Tanzania)

“Within the hospital, right now, the vast majority is sort of biased towards oncology and patients with cancer that is probably got to do with education and I don’t know by default or by design, see all of us [referring to the FGD participants themselves] are attached to the cancer program…” (P3, FGD, Kenya)

“Here it is family members and the doctor, and the patient is at the discretion of the family…We have to negotiate with caregivers that you know we need to have the same discussion with your patient.” (KII, India)

Based on the evidence and having decided that palliative care needed to be made widely available within its health network, AKDN decided on an Initiation Strategy that invited all key stakeholders to a Palliative Care Conference in Dar-es-Salaam, Tanzania in June 2015 with the following objectives:

I Share findings from the baseline assessment of palliative care in the AKDN health entities and the countries within which they are located;

II Discuss a collective understanding of palliative care and understanding the possible models of provision;

III Develop some tangible action points for each cluster in palliative care provision; and

IV Agree on a collective way forward for building palliative care capacity across the AKDN health entities.

A multi-country conference participation strategy was developed to include Pakistan, Kenya, Tanzania, India, Afghanistan and Tajikistan. The conference design included international leaders in palliative care to lead the sessions. Another design element was to review successful experiences and models of palliative care to enlighten and guide participants to work on proposals to (a) develop contextual palliative care models in their respective entities; and (b) provide an assessment of existing services and future plans for developing palliative care with regional collaboration.

Implementation across the Network – A Regional Approach

Implementing the AKDN vision of palliative services across different regions, cultures and health systems offers a complexity of issues. The approach we undertook, therefore, was to structure implementation by Region.

South Asia Region

Countries of focus included Pakistan, India and Afghanistan. Karachi is the hub of the AKDN health services in Pakistan and offers a significant platform to implement the palliative care strategy. The Aga Khan University Hospital, Karachi (AKUH) is an academic medical center and the teaching hospital of AKU. With a network of four secondary hospitals covering primary care and a range of specialties, it serves patients from all socio-economic groups. Within Karachi, hospital based clinics extend into the community through the Integrated Medical Services (IMS) centers which provide family health facilities, phlebotomy and pharmacy services in varying combinations. This urban platform is supported by Aga Khan Health Services, Pakistan (AKHS, P) through its network of primary care centers which extends into all the provinces and remote regions of the country. Palliative care is not an integral part of the AKHS, P centers yet, but as part of the regional implementation plan, will now be developed to add to the current services in place. This collective platform will then serve as the delivery mechanism for implementation of palliative services.

Academic Hospital as the Strategy to Develop Capacity and Extend Services

Having an academic element in the offering of palliative care is now a core design element. The academic service strategy within the AKUH, K was initiated through formation of a hospital and university wide committee two years ago and was mandated to implement palliative care services in response to the emerging need for palliative care globally. The department of oncology established three years ago as a Center of Excellence, provides palliative care through its section of palliative medicine through palliative care clinics and in-patient consults. Although the maximum referrals to this service are from the department of oncology, patients are increasingly being referred from other departments. The extension of services into the homes of patients is a key strategy being implemented through home health care services (HHCS), composed of trained physician and nursing teams. [7, 8] Physician support is provided through senior family medicine residents. Palliative medicine clinical attachments and home health care visits are a mandatory part of the 4 year training period.

East Africa Region

The East African region is much more integrated with an open border flow, and here the design principle was to structure one integrated approach in two countries. Therefore in Kenya and Tanzania, the East Africa Steering Committee on Palliative Care (SC), has been established to oversee the development and implementation of a functionally integrated, palliative care service across both countries. The Aga Khan University Hospital Nairobi (AKUH-N) is the main tertiary care hospital in Kenya. In addition, there are two secondary hospitals in Mombasa and Kisumu. In Tanzania, the main hospital, The Aga Khan Hospital Dar-es-Salaam (AKH-D) is linked to five primary medical centers in Dodoma, Iringa, Mbeya, Morogoro and Mwanza. Both hospitals have an extensive network of outreach clinics spread across both countries. Palliative care services are a part of the oncology program, as is the norm with inception of palliative care services in hospital settings. Protocols related to assessment, reassessment and evaluation of end of life patients are in place and staff have received palliative care training.
in the preliminary phase. This three-tiered structure will provide the foundation on which the envisioned palliative care services are expected to grow in both countries. With defined pathways and cohesive systems, a palliative care multidisciplinary team will provide both in-patient and out-patient services across the network. Home-based care is available in both sites for oncology patients and will be expanded. Figure 1

Taking an Integrated Approach into the Future - Local yet Global

A key strategy is to ensure that each region, through its committees and systems, will provide strategic direction for an integrated approach to the Palliative Care Programs in the AKDN regions. Although geographically distinct and separate, they will continue to collaborate and draw upon each other’s resources. Both regions have a comprehensive structure spanning the full spectrum of primary, secondary and tertiary care services that provide contextual templates for integration of palliative care. The dearth of hospices in both regions is an impetus to the addition of in-patient palliative care. With robust administrative and management direction, supported by trained medical staff, the integration of both in-patient and out-patient palliative care is designed to be implemented in parallel with capacity building across the AKDN network. To provide accessible, seamless service to the remotest AKDN centers, systematic linkages will be developed between specialist palliative services of tertiary care centers, secondary care hospitals and designated out-patient palliative care service centers of each region. Given the demographic distribution of both regions, the addition of a pediatric service is seen to be an imperative, and is being developed. Figures 1 and 2

To ensure high standards of palliative care practice, standardization of hospital and community-based systems is in process and will be implemented to monitor and evaluate quality and outcomes across all AKDN health institutions.

Taking Accessible and Cost effective Services into the Community

Making services accessible and affordable in the community is a key goal. The outreach clinics and AKHS centers will therefore serve as the springboard for the extension of home-based palliative care services into the community and will be staffed by trained physicians and nurse teams. Ancillary services, including nutrition, specialist pharmacist, psychologist and social care will reach the homes of patients through this pathway. This model will draw upon and encompass relevant AKUH departments in fulfillment of the multidisciplinary nature of palliative care services. [9]

Public private partnerships and community led collaborations will serve as a way to overcome financial and resource constraints and make the service widely available to all those in need. [10] Successful models have been implemented in India. [11]

Ensuring an Academic Palliative Program that has Reach

To ensure an appropriate academic grounding in palliative care, a contextual, patient-centered, blended learning course on ‘end of life care’ for physicians was developed at AKUH-K as a faculty development program in 2014. Endorsed by two international leaders in palliative care education, it is being offered regularly to develop in-country capacity. Pediatrics and nursing components are being integrated and will be offered from 2016 onwards. Education in palliative care is presently an integral part of undergraduate medical and nursing education of the Aga Khan Medical College and School of Nursing and Midwifery (SONAM). The long-term goal is to develop academic programs with a Fellowship in Palliative Medicine recognized by the national regulatory body.

The philosophy of the AKDN system of inter-agency partnership and collaboration in the areas of service, education, training and research should enable AKHS and AKU to benefit from each other’s expertise and strengths to expand their reach. Blended learning courses will be offered to all AKHS regions and adapted as required. As a first step, all physicians in the palliative care service network will be trained as the program develops.

Palliative medicine is not a part of the medical syllabus in Pakistan, Afghanistan or Tajikistan and is present in varying degrees in the national medical curricula of India, Kenya, Uganda and Tanzania. AKDN will, where appropriate, assist to shape future policy and strategy at national levels for the development of comprehensive palliative care programs in the countries that it serves.

Public education, awareness and dissemination will be done through public communication initiatives and palliative care marketing in all regions.

Conclusion and Key Challenges

Program evaluation and research are important elements of quality assurance and continuous monitoring will be in place to ensure the highest quality with patient and family satisfaction as defining objectives. Cost of care in developing countries can be a major barrier to the development of a self-sustaining, cost effective, palliative care service. Confronting these challenges with the support of thoughtful research, community partnership and a commitment to serve is expected to assure an effective implementation process.

BIOGRAPIES

Salim Hasham is Vice President Health Services for Aga Khan University (AKU) overseeing the health services enterprise of AKU globally. Prior to this, he served as Senior Vice President - Global Services for Johns Hopkins Medicine International. Mr Hasham has also served as President and CEO of a two hospital system in Hawaii and has a 30 year history in international health care work. He has a MHA from University of Ottawa, Canada; a Summa Cum Laude MSyEng from Clemson University, USA; and an B.Sc Honours in Mathematics from University of Nairobi.

Sameena Shah FCPS, Ad. Dip.Med.Edu. AKU, MRCGP [INT]. Dr. Shah is an Assistant Professor in the Department of Family Medicine at the Aga Khan University Hospital, Karachi (AKUH,K), where she leads the palliative care program and heads the palliative medicine section of the department of Oncology. In this capacity Dr. Shah conducts palliative medicine clinics and in-patient consults. She developed the blended learning End-of-Life Care program for physicians.

Laila Khymani has served at Aga Khan Health Services, Pakistan as a Clinical Nursing Lead and at the French Medical Institute for Children in Kabul as Administrator, Nursing and Quality Assurance. Building on her diverse experience, she has recently assumed the responsibility of strengthening the Home Based Palliative Care Program at Aga Khan University Hospital, Karachi as per the broad vision of the Aga Khan Development Network.
End-of-life care: practices from around the world

David Makumi is the Regional Manager – Cancer Program for the Aga Khan University Hospital, Nairobi. David has a Post Graduate Diploma in Palliative Care from Dundee University Scotland and is a Registered Nurse with professional interests in end of life care. He was the 2011 recipient of the Oncology Nursing Society (ONS-USA) International Award for contribution to cancer care.

Zeenat Sulaiman Khan has held leadership positions for 25 years, with the last 15 years at an executive nursing level in Asia and Africa. She has well-developed leadership skills with a strong understanding of both strategic and operational aspects of healthcare management. She has been involved in developing strategic and operational plans for programs such as Cardiology, Oncology and is now involved in strengthening the Palliative Care Program in the East Africa region.

References
8. Palliative Care: The World Health Organization’s Global Perspective
End of life care in Acute Geriatric Units: making decisions about sedation

INTRODUCTION. The model for end-of-life care (EOLC) applies to the last months of illness and, in accordance with geriatric care, includes patients with chronic illnesses with less predictable developments (which are also more dependent on intercurrent processes (1, 2).

There are numerous documents published by various scientific bodies on the subject of Geriatric Medicine and Palliative Medicine which express concerns, analyse unmet needs, and attempt to establish quality criteria for medical care at the end of life. All of these documents share three main priorities: the requirement for adequate symptomatic control, the importance of respecting the opinion of the patient, and the need for an appropriate clinical and ethical framework when making decisions (3, 5).

With an in-hospital mortality rate of around 10% in acute geriatric units (AGU) and uncertain prognoses, end-of-life care places the clinic in a process of reflection, where the most appropriate therapeutic approach is based on the concept of proportionality.

By proportionate, we mean maintaining the most appropriate balance between effectiveness (based on the medical criteria for diagnostic correction and the scientific basis of the different therapeutic approaches), benefits, and disadvantages derived from the decision or from the treatment (according to the perspective of both the doctor and the patient and family), all in accordance with the objective sought in each clinical decision we analyse.

In order to make such decisions, the professionals involved must have acquired scientific knowledge through appropriate specialist medical training for approaching clinical conditions based on advanced illness of organs in geriatric patients.

Due to its complexity, each decision will require a high level of reflection, as well as agility, due to the rapid changes possible in conditions, and flexibility, in order to consider the three main factors involved: aspects relating to the base illness (severity, developments that have already occurred, complications etc.), a detailed analysis of the current event (severity and prognosis, therapeutic options, adequacy of symptomatic control), and the opinion of the patient and the family (6, 7).

Therapeutic sedation is a part of the medical actions of EOLC and is one of the medical decisions which require the greatest care. While it may be legally permitted and ethically accepted if it is within good medical praxis, it is not without controversy. The decision-making process must ensure an appropriate clinical framework (with correct indications and processes) and a rigorous ethical framework for implementation (2, 4).

METHODOLOGY AND RESULTS

Clinical guides and performance protocols for sedation in EOLC help clinics to make more rigorous decisions, although there is great variability in medical opinions regarding concept definition and procedure guidelines (4, 8, 9).

In 2005, the Spanish Society of Geriatrics and Gerontology published the Clinical Protocol for Terminal Sedation from that produced at the Geriatric Service of the Hospital Central Cruz Roja in Madrid and approved by our hospital in 2008 (10).

In addition to establishing an ethical framework for the use of sedation in accordance with the four fundamental principles of bioethics proposed by Beauchamp and Childress (11), they also established a series of requirements for clinical and ethical correctness (BOX 1).

Below we show the results of the analysis carried out by
Box 1. Requirements for clinical and ethical correctness of the Clinical Protocol of Terminal Sedation at the geriatric service Hospital Central Cruz Roja de Madrid.

**Requirements for clinical correctness**

1. Indication
2. Symptomatic rating
3. Drugs and most recommended routes of administration
4. Monitoring response
5. Information and coordination with the healthcare team
6. Family involvement in monitoring the process

**Requirements for ethical correction**

1. Diagnostic accuracy and detailed forecast analysis: requirement of a solid training in geriatrics, obtaining a second opinion, detailed record and clear and proven indication
2. Existence of a refractory symptom and identification of potentially reversible factors
3. Objective of sedation: systematic documented and explicit record in the medical record of intention of sedation in patient’s clinical context, the process developed for making decisions, the proposed and followed procedure and monitoring the patient’s response measurement parameters
4. Process of explicit, implicit or delegate informed consent

internal audit by the Mortality Commission of the Hospital Central de la Cruz Roja (HCCR) in Madrid. This audit assessed the quality achieved in fulfilling the Clinical Protocol for Terminal Sedation, as applied to the patients who died in our hospital’s AGU over the course of one year and who required sedation as a therapeutic measure in their final days.

During 2012, care quality data was collected retrospectively for the medical assistance process which occurred during the final days of all patients who died during 2011 in the AGU of the HCCR, which is equipped with 50 beds. The data was collected by trained assessors who were not involved in the care of the patients studied. During this evaluation, patients who received drugs with the intention to produce sedation under the terms defined in the protocol were identified and a third trained evaluator who was outside the care of said patients was assigned to carry out the analysis. Once the report and statistical analysis were complete, the data was reviewed by the authors of the protocol for interpretation and discussion.

The authors of the protocol were part of the Geriatric Service during 2011 and 2012 and were not involved in medical assistance in the AGU.

The cases were identified anonymously; the clinical records of 146 patients who had died were reviewed and the following variables were collected: the irreversible clinical process which necessitated end of life care and the written record of the quality parameters in the patient’s clinical history which were used in the application of the protocol, and measured against a record of ethical safeguards in the terminal sedation process written by the authors of the protocol and approved by the hospital’s mortality commission.

In 2011, 1303 patients were admitted to the AGU for acute medical pathology (65.5 % women). The average age was 87 (ST = 6.2yrs), with frequent comorbidity and a high prevalence of functional dependence or cognitive deterioration prior to the incident which led to admittance. The most frequent reasons for admittance (which includes 63% of the sample studied) overlap with the reasons for admission to other Internal and Geriatric Medicine services in the country (12). The average length of stay was 10.2 days (Standard deviation = SD = 9.09) with an overall mortality of 11.2% (146 deaths). 75% of the patients were initially admitted by Emergency Services (table 1).

### Table 1: Characteristics of patients admitted to the acute geriatric unit at Hospital Central de la Cruz Roja Madrid in 2011

<table>
<thead>
<tr>
<th>Patients</th>
<th>1303</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>65.5%</td>
</tr>
<tr>
<td>Average age</td>
<td>87 (DE=6.2 years)</td>
</tr>
<tr>
<td>Charlson I</td>
<td>2.79 (DE 2.51)</td>
</tr>
</tbody>
</table>

**Main causes of admission of patients in the Acute Geriatric Unit**

- Heart failure | 22%
- Pneumonia | 18%
- Non pneumonic respiratory infection | 9%
- Acute stroke | 3%
- Reno-urinary disorder | 8%
- Others | 57%

**MODERATE functional dependence prior to admission**

- CRF>2 | 52%
- Barthel I <60 | 50%

**Early cognitive dependence**

- CRM>2 | 49.9%

CRF: Scale of Physical Red Cross; CRM: Scale of Mental Red Cross (18); Barthel I : Barthel index (19); Charlson Comorbidity Index (20).

Out of the 146 patients who died in the AGU (57% women), 100% received treatment to control symptoms and care to provide comfort in their final days and 35 (23.9%) patients were sedated during this process.
In 100% of the patients, their imminent death and the irreversible failure of therapeutic processes with curative intent were identified. For 30 (85.7%) of the patients, the clinical processes which led to their need for end of life care were non-oncological and for 5 (14.3%) of the patients, the processes were oncological (table 2).

Table 2: Quality control sheet for the therapeutic process of palliative sedation Geriatrics Service at the Central Hospital of the Red Cross.

<table>
<thead>
<tr>
<th>IDENTIFICATION OF MAIN REVERSIBLE CLINICAL PROCESS</th>
<th>100% (n 35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumonia and respiratory infections</td>
<td>48.6% (n 17)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>14.3% (n 5)</td>
</tr>
<tr>
<td>Sepsis of non-respiratory origin</td>
<td>22.8% (n 8)</td>
</tr>
<tr>
<td>Oncological processes</td>
<td>14.3% (n 5)</td>
</tr>
<tr>
<td>REFRACTORY SYMPTOMS</td>
<td>100% (n 35)</td>
</tr>
<tr>
<td>ESTIMATED NEAR DEATH</td>
<td>100% (n 35)</td>
</tr>
<tr>
<td>PROFESSIONAL SECOND OPINION</td>
<td>51.4% (n 18)</td>
</tr>
<tr>
<td>CONSENT</td>
<td></td>
</tr>
<tr>
<td>Explicit of a patient</td>
<td>8.6% (n 3)</td>
</tr>
<tr>
<td>Implicit of a patient</td>
<td>14% (n 5)</td>
</tr>
<tr>
<td>Delegated</td>
<td>71% (n 27)</td>
</tr>
<tr>
<td>INFORMED TEAM</td>
<td>100% (n 35)</td>
</tr>
<tr>
<td>USED DRUGS</td>
<td></td>
</tr>
<tr>
<td>Benzodiazepines</td>
<td>100% (n 3)</td>
</tr>
<tr>
<td>Neuroleptics</td>
<td>11.4% (n 54)</td>
</tr>
<tr>
<td>REGULAR MONITORING OF THE EFFECT</td>
<td>100% (n 35)</td>
</tr>
</tbody>
</table>

The symptoms which were considered refractory and therefore justified the use of the sedation process were principally, in order of importance: dyspnoea, distress, delirium and pain. In 4 patients, combinations of 3 or more refractory symptoms were seen, which required sedation as a last resort for symptom control. In all of the cases, the pharmacological resources and non-pharmacological resources used to attempt to control the refractory symptom before proceeding to sedation were recorded in the history.

In order to make the decision to begin sedation, the protocol required that a second opinion be sought from another professional who could provide an additional point of view regarding the clinical case, with regards to the refractory nature of the symptoms with other therapeutic methods. This requirement was recorded in the clinical history in 18 cases (51.4%).

In 100% of the cases, the communication to the rest of the team (assistant and resident doctors, nursing staff) regarding the decision and the procedure for the sedation process was recorded in writing, in such a way as to ensure the intended treatment and support for the patient’s end of life was coordinated and coherent in terms of provision of comfort and family support.

There was a written record of the explanation of the sedation process, described in a comprehensible manner for the patient-family unit for 31 patients (88.6%). Consent was obtained in 100% of the cases; for 27 patients (77.1%) this was delegated consent, for 5 patients (14.3%) consent was implicit and for 3 patients consent was explicit (8.6%). In all cases, benzodiazepines were used during the sedation process. 4 patients (11.4%) required combinations of benzodiazepines and neuroleptics (these 4 patients demonstrated delirium as a refractory symptom).

In all cases, the monitoring process for the clinical effects of the drugs used in the sedation process was recorded in writing.

CONCLUSION

The percentage of sedation as a therapeutic approach in end-of-life care varies greatly between different countries, and there has been an increase in its employment in recent years (from 8 to 20% in different European studies). Although it is difficult to compare the data due to the differences in the populations studied and the different methodologies used in the published works, cultural, social, legal, organisational and educational factors play an important role in this diversity (13, 14).

The majority of studies showed a higher percentage of sedation in non-geriatric patients treated in hospital, and with oncological illnesses. In our case, the percentage of sedation among patients who died in hospital was almost 24%. Despite the small size of our sample group, this may reflect an increase in the number and severity of refractory symptoms in the elderly population, given that patients with pluripathology and those presenting greater symptomatology in their final days, are those who most frequently die in hospital, as shown in other studies (13, 15).

In order to make decisions regarding sedation, it is essential that professionals receive training regarding the clinical behaviour of illnesses in their advanced stages, prognostic aspects, and correct clinical evaluation which allow for the identification of the patients’ approaching death as a preliminary step (15, 16).

The refractory symptoms which motivated the decision to sedate our patients were similar to those described by other authors, and the most common choice of drug was benzodiazepines (13, 18).

While it is considered highly recommended to share the decision with another professional in order to contrast opinions and reduce the influence of the moral and personal perspective of the doctor making the decision, in our study a second opinion was turned to in only 51.4% of cases, although once the decision was made, the plan of action was shared in all cases with the rest of the medical team (4).

Recording the process of information, communication, reflection, and discussion with the patient’s family in the clinical history must also be a requirement (19). Obtaining consent presents its difficulties, with variable percentages in different studies. Our protocol considers obtaining consent that is explicit, implicit (in the values and desires normally demonstrated by the patient and the family or the team) or delegated (by representative), and does not require that a specific document be used, nor that signed permission be obtained. The percentage of explicit consent was very low, which may have been influenced by the high prevalence of cognitive deterioration in the sample...
group and by the frequency of delirium as a refractory symptom. Adequate monitoring of the effects of the process employed for sedation must always be recorded, given that the suitability of the dosage according to the response of the symptoms being treated is an essential requirement as a quality parameter (20).

The development of protocols and clinical pathways for decision-making, as well as carrying out internal audits has shown itself to be an important strategy for improving the quality of end-of-life care, as with other systematic records for clinical processes which are as ethically complex as sedation (4, 9, 16, 17). In our case, the systematic analysis of quality criteria for the care of patients who died in the geriatric ward was extremely enriching and useful as a professional development tool and as a teaching tool for training specialists in the geriatric specialism.

References


End-of-life care: practices from around the world

BIOGRAPHIES

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Ainhoa Esteve Arrien finished her fellowship in Geriatric Medicine at the Hospital Central de la Cruz Roja and has worked as a consultant, both in the same hospital and in several other centres. From 2012 onwards, she has been working at the Hospital Infanta Leonor as a consultant in Geriatric Medicine for other departments and outpatients. Her fields of interest are mainly end-of-life care, geriatric assessment, dementia, stroke and chronic cardiac failure.
ABSTRACT: The French Cancer Centers (FCC) have a threefold mission, care research and education. Their specificity is multidisciplinary and comprehensive patient support at all stages of cancer. Innovation and research are at the heart of FCC action, but the care of patients in the palliative phase is a major and long-time concern. In each center there is an autonomous or integrated structure of palliative care in a service or Interdisciplinary Department of Support Care for the Patient in Oncology. These include, besides the hospice activity, chronic pain, psycho-oncology, social support, nutrition, functional rehabilitation, etc. Furthermore, the FCC have, in accordance with a secondary regulatory text to National Plans for palliative care, identified beds of palliative care (IBPC) in oncology day hospitals and in palliative care. In 2006 a Unicancer-FCC group was established. One of the group’s goals is to promote “early palliative care” together with other FCC teams. A common research dynamic has been implemented, ensuring the development of organizations and palliative culture.
activity, that of chronic pain, psycho-oncology, social support, nutrition and functional rehabilitation. Alongside the abovementioned palliative care organizations (palliative care unit, mobile palliative care teams, day hospital), most of the FCC have identified, in accordance with a secondary regulatory text to National Plans for palliative care, identified beds for palliative care (IBPC) in the various services (3). These are intended to provide additional ways to optimize the management of certain seriously ill patients in services, in relation to the palliative care structure at the FCC.

Given the diversity of these organizations, an annual meeting of the different professionals in palliative care at the FCC was held in 2006 at the initiative of the Institute Bergonié (Bordeaux). A Federal Palliative Care group at the FCC was formed. These meetings, place of multi-professional exchange on the specific practices for palliative care in the FCC, allowed to compare the different methods of organization, to harmonize practices while respecting local specificities and provide initiatives for developing new proposals in these areas. Thus a few years ago, palliative care day hospitals were established that helped to develop an alternative to hospitalization while promoting home support for patients who so wished.

The Palliative Care Day Hospital is a place for evaluating and treating symptoms associated with psycho-social support for the patient and his family.

Its concept is to provide the earliest multidisciplinary consultation possible (on the model of the “early palliative care” of the Anglo-Saxons) for the patient’s overall care, in his presence, in connection with the oncology team, sometimes associated with ethical questions, and complemented by a city-hospital work coordination.

Alongside these organizational ideas on palliative care, a common research process was put in place with, for example, the CEOLE (6), carried out by the FCC Angers (West Cancer Institute) or PREPA 10 (7) backed by the FCC Lyon (Centre Léon Bérard).

These meetings have led teams to foster the knowledge and the implementation of laws relating to the patients’ rights and end of life in the FCCs, including the Act of 2005 on said law Leonetti (4).

With the approach of a new law in France creating new rights in favor of patients and people at the end of life, palliative support for patients within the FCC represents a triple challenge, in light of our major mission:

- Scientific issue, with the accumulation of tangible evidence of an increase in the quality of life but also the survival of metastatic patients receiving early joint support by the oncology team and the palliative care team (Temel) (5);
- Human issue for persons in care, their relatives and staff accompanying them, all subject to medical-economic constraints and current performance;
- Social issue, when it comes to saying when we can book the next appointment to someone whose life will end soon.

These challenges require collective reflection within the FCC on the necessary means and their financing in order to bring a proposal of excellence in care for patients at the end of life into their territory.

The palliative care group remains attentive to the evolution of these organizations and to the dissemination of palliative culture. It wants to be increasingly watchful in this area and a force of proposals, in its peculiarities in oncology from participation in therapeutic choices up to accompaniment at the end of life.

UNICANCER unites all of the Cancer Centers in France: these private non-profit health institutions are exclusively devoted to healthcare, research and education and training in oncology. The leading edge in cancerology in France, and key players internationally, French Cancer Centers participate in public hospital service and provide care for the patient in accordance with conventional tariffs, without any overrunning of fees.

Research represents one of the fundamental missions of the French Cancer Centers. It enables patients to benefit from diagnostic and therapeutic innovations by calling on all of the disciplines involved in caring for cancer.

In each Centre, multidisciplinary teams associate the care with the research units in order to develop integrated research on cancer, based on the clinical, fundamental and translational research continuum.

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(5) TMEL NEJM 2010 Zimmerman, Lancet 2014
(6) CEOLE: étude de qualité de vie en soins palliatifs
(7) PREPA 10: Prévalence Pallia 10 : étude de prévalence des patients relevant de soins palliatifs hospitalisés dans les CRLCC un jour donné
UNICANCER brings together all of the Cancer Centres in France. The Centres provide a triple mission: care, research and education, without any overrunning on fees.

As major stakeholders in the funding of research in cancerology, the Cancer Centres are private non-profit health institutions, authorised to receive donations and bequests.
Comprendre les pratiques des soins de fin de vie dans le monde : Projet de recherche IHF 2014

La première enquête en son genre de pratiques mondiales de fin de vie a démontré les principales différences sur comment les soins de fin de vie sont définis, effectués et mesurés. Selon les personnes interrogées d’hôpitaux universitaires et de centres contre le cancer dans 17 pays, les principaux défis pour fournir des soins de fin de vie efficaces sont la communication entre les médecins et les patients et leurs familles, les croyances culturelles à propos de la morte, les croyances renforcées du personnel à propos du prolongement de la vie, et le manque de financement. Cependant, de nombreuses organisations sont en train de mettre en place des améliorations dans les services de fin de vie qui prennent en charge l’identification dans tout l’hôpital des patients pour lesquels de tels services sont appropriés, de dépister pour éviter des thérapies agressives inutiles, en améliorant la formation du personnel et des moyens pour évaluer la qualité de vie des patients en phase terminale.

Introduction d’une planification clinique préalable des soins dans un service de coordination régional des soins

Une planification préalable des soins est un facteur de plus en plus important dans la prestation de services de soins de santé. Les obstacles à la planification préalable des soins, y compris la hiérarchisation inférieure plutôt que les soins cliniques, et la logistique complexe de remplir les documents ont été identifiés dans la littérature et la pratique clinique. Le Programme de soins chroniques dans les services hospitaliers et de santé de Canberra introduit les soins cliniques de planification des soins avancées de consultation externe et mobile pour les soins coordonnés des patients atteints de maladies chroniques, de répondre à certains de ces obstacles et de faciliter la discussion de soins de fin de vie au sein de ce groupe de patients. La mise en œuvre des cliniques a été évaluée, en regardant la pratique de la gestion de ces cliniques selon les ressources existantes et l’acceptabilité du patient. Le nombre de déclaration de choix rempli a été utilisé comme un marqueur pour savoir si les cliniques ont conduit à une augmentation de la planification préalable des soins au sein de ce groupe de patients. L’introduction des soins cliniques a reçu des commentaires positifs de la part de patients et a pu être mise en œuvre sans nécessiter de ressources extérieures supplémentaires. Après l’introduction de la planification préalable des soins dans les cliniques, une augmentation de la proportion de patients avec une déclaration de choix complétée a été remarquée.

Surmonter les obstacles de la promotion des soins palliatifs - Partager son expérience du Taiwan Changhua Christian Hospital

Les soins palliatifs pour les patients en phase terminale sont nécessaires, mais les défis sont au niveau mondial. Cette étude a démontré que les soins palliatifs a été rapidement développé à Taiwan grâce à l’appui du système national d’assurance maladie, la promotion de la société civile et les groupes religieux, le droit du patient pour les NPR, l’accès facilité à des analgésiques sur ordonnance médicale ainsi que des programmes de formation du personnel de soins palliatifs bien planifiés. Cet article présente la manière dont la consultation de soins palliatifs est assurée par une équipe de soins palliatifs polyvalente du Changhua Christian Hospital pour établir la confiance et la coopération avec l’équipe médicale, et améliorer les soins palliatifs de référence et les taux d’utilisation.

Soins palliatifs et législation relatifs à la mort

Partout dans le monde, quarante millions de personnes par an ont besoin de soins palliatifs, pourtant plus de quatre sur cinq d’entre eux n’ont pas accès à l’analgésie de base avec la morphine. 6 % des personnes qui meurent sans soulagement de la douleur sont des enfants. Ceux qui restent portent avec eux la mémoire de la mort en faussant leurs vies futures et en faisant des bons soins palliatifs un problème urgent de santé publique dans le monde. Toutes les personnes prodiguant des soins de santé ont besoin d’une formation de base en soins palliatifs, comprenant les principes fondamentaux de la douleur et le soulagement des symptômes. Les gouvernements doivent traiter d’urgence les obstacles à la disponibilité de la morphine et des éducateurs de professionnels de soins de santé doivent éliminer les mythes et les phobies, et enseigner les bons soins de fin de vie.

Établir des soins palliatifs à travers les services de santé de l’AKDN : Opportunités et défis

AKDN possède l’un des systèmes de soins de santé privée à but non lucratif le plus complet du monde en développement. Il définit la perfection des centres urbains de soins tertiaires universitaires, des services des hôpitaux et des centres de soins primaires communautaires répartis dans les zones les plus reculées des régions de l’Afrique
centrale et orientale et de l’Asie du Sud. En réponse à une initiative mondiale visant à rendre les soins palliatifs largement disponibles, ce système de soins de santé est le fer de lance de l’intégration des soins palliatifs à travers son réseau de santé international. Le champ d’application comprend les services de soins palliatifs spécialisés dans les centres urbains de soins tertiaires ainsi que les programmes secondaires et de sensibilisation jusqu’aux services de soins palliatifs à domicile. Le but ultime est de développer une structure complète de services de soins palliatifs qui, en plus de la réalisation de la vision de la qualité, répond également aux besoins des collectivités qu’elle dessert. Cet article décrit cette entreprise internationale ; ses défis et ses clés contextuelles dessinent les principes de la mise en œuvre.

Soins de fin de vie dans les unités gériatriques de soins aigus: prise de décisions concernant la sédation

Dans la pratique de soins en fin de vie dans les unités gériatriques de soins aigus, et avec un taux de mortalité de 10%, les décisions concernant la sédation nécessitent une approche extrêmement rigoureuse concernant la correction de tous les aspects cliniques et éthiques.

Le développement d’un protocole de sédation qui comprend une série de garanties éthiques et cliniques dans l’application de cette mesure thérapeutique est utile pour améliorer le processus de prise de décision et encourager la réflexion des professionnels impliqués. Nous analysons la correction mise en œuvre du protocole établi dans notre hôpital pour la sédation terminale chez les patients qui sont morts au cours d’une année dans notre unité dans laquelle la sédation est indiquée dans ses derniers jours.

Évolution des soins palliatifs au sein des Centres de lutte contre le cancer

Les Centres Régionaux de Lutte contre le Cancer (CRLCC) ont une triple mission de soins de recherche et d’enseignement. Leur spécificité est la pluridisciplinarité et la prise en charge globale du patient, à tous les stades du cancer. L’innovation et la recherche sont au cœur de l’action des CRLCC, mais la prise en charge des patients en phase palliative est une préoccupation majeure et ancienne. Dans chaque Centre il existe une structure de soins palliatifs autonome ou intégrée dans un service ou un Département Interdisciplinaire de Soins de Support pour le Patient en Oncologie. Ces derniers regroupent, outre l’activité de soins palliatifs, celle de douleur chronique, psycho-oncologie, accompagnement social, nutrition, réadaptation fonctionnelle, etc. Les CRLCC ont aussi identifié, conformément aux Plans Nationaux de soins palliatifs, des lits identifiés de soins palliatifs (LISP) dans les services d’oncologie et des hôpitaux de jour en soins palliatifs. Il a été créé en 2006 un groupe Fédéral des CRLCC. Un des objectifs du groupe est de favoriser l’« early palliative care » en lien avec les autres équipes CRLCC. Une dynamique de recherche commune a été mise en place et veille à l’évolution des organisations et de la culture palliative.
Comprender las prácticas de cuidados al final de la vida a nivel mundial - proyecto de investigación de IHF 2014

Esta encuesta, primera en su clase, de prácticas al final de la vida (EOL) dejó al descubierto diferencias importantes sobre cómo se define la atención de la EOL, cómo se suministra y cómo se mide. Según los encuestados de hospitales universitarios y centros de cáncer en 17 países, los desafíos principales para proporcionar una atención eficaz de EOL son la comunicación entre los médicos y los pacientes y/o sus familiares, las creencias culturales sobre la muerte, las creencias arraigadas del personal sobre prolongar la vida y la falta de financiación. Sin embargo, muchas organizaciones están implementando mejoras en los servicios EOL que permiten una identificación por todo el hospital de pacientes para los cuales estos servicios son apropiados, de detección para evitar terapias agresivas innecesarias, mejorando la educación de los proveedores y las formas de evaluar la calidad de vida de los pacientes con enfermedades terminales.

Introducción de una clínica de planificación anticipada de la atención en un Servicio Regional de Coordinación de Servicios

La planificación anticipada de la atención es un factor cada vez más importante en la prestación de servicios de atención médica. Las barreras a la planificación anticipada de la atención, incluyendo la priorización más baja antes que la atención clínica y la compleja logística de completar la documentación se han identificado en la literatura y en la práctica clínica. El Programa de Cuidados Crónicos dentro de los Servicios hospitalarios y de salud de Canberra introdujo la planificación clínica anticipada de la atención en consulta externa y móvil para los pacientes coordinados de atención con enfermedades crónicas, para abordar algunas de estas barreras y facilitar la discusión sobre los cuidados al final de la vida útil entre este grupo de pacientes. Se evaluó la aplicación de las clínicas, mirando a la viabilidad de la ejecución de estas clínicas dentro de los recursos existentes y la aceptabilidad del paciente. El número de la declaración completa de opciones se utilizó como marcador para saber si las clínicas llevaron a un aumento en la planificación anticipada de la atención dentro de este grupo de pacientes. La introducción de las clínicas recibió comentarios positivos de los pacientes y fue capaz de aplicarse sin necesidad de recursos externos adicionales. Tras la introducción de las clínicas de planificación anticipada de la atención, se observó un aumento en la proporción de pacientes con una declaración completa de opciones.

Superar los obstáculos en la promoción de cuidados paliativos - Compartir las experiencias del Taiwán Changhua Christian Hospital

Los cuidados paliativos para pacientes terminales son necesarios, sin embargo, los desafíos están presentes en todo el mundo. Este estudio demostró que los cuidados paliativos se han desarrollado rápidamente en Taiwán gracias al apoyo del sistema de seguro nacional de salud, la promoción de la sociedad civil y los grupos religiosos, el derecho legal del paciente al DNR, la facilidad del acceso a los analgésicos por prescripción médica y los programas de capacitación de personal del hospital bien planificados. Este artículo presenta cómo se proporciona la consulta en cuidados paliativos en el Changhua Christian Hospital por un equipo polivalente para establecer la confianza y la cooperación con el equipo médico y para mejorar los cuidados paliativos de referencia y las tasas de referencia.

Los cuidados paliativos y la legislación en torno a la muerte

En todo el mundo cuarenta millones de personas al año necesitan cuidados paliativos sin embargo más de cuatro de cada cinco de ellos no tienen acceso a la analgesia básica con morfina. 6% de los que mueren sin aliviar el dolor son niños. Los que quedan llevan con ellos el recuerdo de la muerte y quedan marcados para siempre haciendo que una buena atención paliativa sea un problema urgente de salud pública en todo el mundo. Todos aquellos que proporcionan atención médica necesitan una formación básica en cuidados paliativos, incluyendo los principios fundamentales del dolor y el alivio de los síntomas. Los gobiernos deben abordar con urgencia las barreras a la disponibilidad de la morfina y los educadores de los profesionales de la salud deben eliminar los mitos y las fobias y enseñar los buenos cuidados al final de la vida.

El establecimiento de cuidados paliativos a través de los servicios de salud AKDN: Oportunidades y desafíos

AKDN tiene uno de los sistemas más completos de atención médica sin fines de lucro en los países en desarrollo. Tiene modernos centros académicos de atención terciaria, hospitales de servicios y centros de atención de base comunitaria distribuidos en las zonas más remotas de las regiones del este de África Central y el sur de Asia. En respuesta a una iniciativa mundial para hacer que los cuidados paliativos sean ampliamente disponibles,
este sistema de atención de salud está a la cabeza de la integración de los cuidados paliativos a través de su red de salud internacional. Su alcance incluye servicios de cuidados paliativos especializados en centros de atención terciaria urbanas en los programas de secundaria y la divulgación de los servicios de cuidados paliativos a domicilio. El objetivo final es el desarrollo de una estructura integral de servicios de cuidados paliativos que, además de cumplir con la visión de calidad, también satisface las necesidades de las comunidades que sirve. En este artículo se describe esta empresa internacional; sus retos y sus claves contextuales diseñan los principios de la aplicación.

**Cuidados al final de la vida en Unidades Geriátricas de Agudos: toma de decisiones respecto a la sedación**

En la práctica de los cuidados al final de la vida en las Unidades Geriátricas Hospitalarias de Agudos, y con una mortalidad del 10%, las decisiones respecto a la sedación requieren un abordaje extremadamente riguroso en cuanto a la corrección de todos sus aspectos clínicos y éticos.

El desarrollo de un protocolo de sedación que contemple una serie de garantías éticas y clínicas en la aplicación de ésta medida terapéutica resulta útil para mejorar el proceso de la toma de decisiones y favorece la reflexión de los profesionales implicados. Analizamos la corrección en la aplicación del protocolo establecido en nuestro Hospital para la sedación terminal en aquellos pacientes que fallecieron a lo largo de un año en nuestra Unidad en los que se indicó sedación en sus últimos días.

**Evolución de los cuidados paliativos en los centros de lucha contra el cáncer**

Los Centros Regionales de Lucha contra el Cáncer (CRLC) tienen una triple misión: la investigación, la atención y la educación. Su especificidad es la multidisciplinariedad y la atención integral del paciente en todas las etapas del cáncer. La innovación y la investigación son el centro de la acción de los CRLC pero la atención a los pacientes en la fase paliativa es una antigua e importante preocupación. En cada centro hay una estructura de cuidados paliativos independiente o integrada en un servicio o departamento interdisciplinario de cuidados de soporte para el paciente en oncología. Estos últimos incluyen, además de la actividad de cuidados paliativos, la del dolor crónico, la psico-oncología, el apoyo social, la nutrición, la rehabilitación funcional, etc. Los CRLC también han identificado, de acuerdo con los Planes Nacionales de cuidados paliativos, camas identificadas de cuidados paliativos (LISP) en los servicios de oncología de los hospitales de día en cuidados paliativos. También se creó en el año 2006 un grupo Federal de los CRLC. Uno de los objetivos del grupo es promover el “cuidado paliativo temprano” en conexión con otros equipos CRLC. Una dinámica de investigación común se ha establecido y garantiza el desarrollo de las organizaciones y de la cultura paliativa.
了解全球临终关怀工作：UHC 2014调研项目

本全球性临终（EOL）工作调研尚属首次，其目的在于提出EOL定义、开展和度量上的主要差异。来自于17个国家的高校医院和癌症中心的受访者表示，在提供有效EOL关怀方面，最主要的问题在于医务人员与患者/家属的沟通，关于死亡的文化信仰、关于工作人员在延长生命上的根本正确性、以及资金不足。但目前有多个组织机构正着手于提高EOL服务质量，从而让医院上下能确定哪些患者适合接受这些服务，进行筛查以避免不必要的激进治疗，提高服务人员的素质，并找到评价病危患者生命价值的方法。

区域性的护理协调服务机构的预立医疗计划诊所介绍

虽然预立医疗计划（Advance Care Planning）已经成为健康护理服务机构越来越重视的一个方面。它的难点包括：优先级次于临床护理、资料和临床方面发现要完成文献记录所需的组织工作相当复杂等等。堪培拉医院及健康服务处的慢性病护理计划（Chronic Care Program）中，针对享受护理的慢性病患者提供预立医疗计划诊所，以期解决上述难题，为这些患者群体讨论对于临终护理的意见提供便利。根据这些诊所评估的实施情况，选择声明（Statement of Choices）的数量，作为诊所是否提高相应患者小组内采用预立医疗计划的一个指标。诊所的开设收到了患者的积极反馈，无需额外的外部资源就可实施。引入预立医疗计划诊所后，完成选择声明的患者比例上升。

如何消除安宁疗护推广中遇到的障碍 - 台湾彰化基督教医院的经验分享

临终病人的安宁疗护非常必要，但全球范围内这一领域还有很多问题尚待解决。本研究指出，在台湾，由于全民健康保险的支持、民间团体和宗教组织的大力倡导、患者的DNR法定权益、通过医疗处方开止痛药规定的放宽、以及各种规划良好的临终关怀医护人员培训项目，安宁疗护得以快速发展。本论文介绍了彰化基督教医院的综合性安宁疗护团队如何提供临终关怀咨询、让医疗团队取得信任、合作，同时也提高了安宁疗护和推荐率和利用率。

与临终相关的缓和疗护和立法

全球每年有四千万人需要接受缓和疗护。而这些人中，每五个人就有四个没有条件获得吗啡进行基本的镇痛。在临终时无法得到止痛的中，6%是儿童。继续活下去的人们带着死亡的记忆前行。在医院中，这样的记忆将被成为他们今后生活的一种力量，将缓和疗护放在一个全世界亟待解决的保健事宜的位置。提供保健服务的人员需要接受关于缓和疗护的重要培训，包括缓解疼痛和症状的基本知识；政府必须尽快着手消除获得吗啡的障碍；缓和疗护专业教育者们则需要努力打消人们在这方面的虚构成和恐惧心理，传授关于善终和生命关怀的理念。

构建阿迦汗发展网（AKDN）保健服务的缓和疗护：机会与挑战

AKDN（阿迦汗发展网）拥有发展中国家最大的综合性非盈利性保健系统。它的艺术小镇艺术三重式护理中心、服务区域和社区护理中心遍布中亚、南亚和东方最偏远的地区。作为对倡导广泛开展缓和疗护的全球活动的支持，该保健系统现在正率先行动，将缓和疗护整合到它的整个国际保健网络中。实施的涵盖范围，从二和外展服务活动的城镇三级式护理中
**IHF events calendar**

### 2016

**IHF**

<table>
<thead>
<tr>
<th>Event</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>40th World Hospital Congress</strong></td>
<td>30 October – 3 November 2016, Durban, South Africa</td>
</tr>
<tr>
<td></td>
<td>Visit <a href="https://www.ihf-fiih.org/ihfcongress">https://www.ihf-fiih.org/ihfcongress</a></td>
</tr>
<tr>
<td><strong>2017 IHF 41st World Hospital Congress</strong></td>
<td>7-9 November, Taipei, Taiwan</td>
</tr>
<tr>
<td></td>
<td>For more information, contact <a href="mailto:sheila.anazonwu@ihf-fiih.org">sheila.anazonwu@ihf-fiih.org</a></td>
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For further details contact the: IHF Partnerships and Project, International Hospital Federation, 151 Route de Loëx, 1233 Berne, Switzerland; E-Mail: sheila.anazonwu@ihf-fiih.org or visit the IHF website: [http://www.ihf-fiih.org](http://www.ihf-fiih.org)
Durban, South Africa Warmly Welcomes Delegates to the

40th World Hospital Congress

“Addressing the Challenge of Patient-centred Care and Safety”

Durban ICC

Durban, 30 October - 3 November 2016

For more information go to: www.worldhospitalcongress.org

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