

IAHPC List of  
Essential Practices  
in Palliative Care  
Project Description

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## FOREWORD

Evidence from around the world confirms that millions of patients with life-threatening conditions suffer severe pain and have many other physical, psychosocial and spiritual problems. Much of this suffering is unnecessary. Many are not given medications appropriate for their symptoms or given them in the wrong dose or by the wrong route. The suffering of their families, though different from that of the patient, also deserves but is not always offered, skilled investigation and care.

This document, describes a consensus based process of palliative care workers, other clinical specialists, primary care workers and general practitioners to identify those practices needed to identify, evaluate and treat the suffering still endured by so many. It is hoped that teachers and tutors - doctors, nurses, clinical psychologists – will in the light of this information and guidance, review their own skills and practice, their teaching and their priorities in this realm of palliative care in the primary care setting

The IAHPC List of Essential Practices in Palliative Care is the result of a 3-year process which consisted of several phases including three rounds of Delphi and two surveys. In total, 410 individuals from around the world and 49 representatives of pain and palliative care organizations participated in the project.

Points to note about this process:

- A patient whose symptoms can be investigated and treatment initiated at home might still have to go to hospital for a variety of reasons. That does not reflect primary care failure.
- The complexity or relative rarity of some symptoms illustrates the benefit of specialists who may have much more experience than should be expected of a generalist primary care clinician.
- Much thought was given to the crucially important issue of Communication, recognizing that it embraces communications about diagnosis, prognosis, treatment, end-of-life issues, place of care, spiritual needs, the multi-faceted needs of relatives, and bereavement.
- Some might be surprised that such confidence was displayed that primary care clinicians could provide such skilled, comprehensive care. The authors are confident.

What is the way forward? It is assumed that all who read this document want to see primary care clinicians able and eager to provide palliative care of the highest quality. This will need:

- Each clinician to look at his/her practice, assessing its strengths and its weaknesses with regard to palliative care.
- Each clinician to update knowledge and skills as a matter of urgency
- Each teacher of primary care to review curricula, teaching methods, and continuing professional development programs.
- Each specialist in palliative care, whether medical or nursing, to review the quality of assistance offered to primary care, the availability of 24 hour advice, every aspect of collaboration.

**Derek Doyle, MD**

Founding member and Lifetime Board Member, IAHPC

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## INTRODUCTION

The World Health Organization (WHO) advocates that palliative care should be incorporated as a component of care in health care policies and programs [1], yet data indicate that the vast majority of the world's population does not have access to palliative care [2,3]. This results in unnecessary suffering, particularly among the poor and underprivileged. In many countries, palliative care is still unrecognized, and there are insufficient resources for end of life care and for patients with life limiting conditions [4].

Care provided in the primary care settings improves the efficiency and effectiveness of resources applied to health care interventions [5,6,7,8] and several authors have called for the need to incorporate palliative care in primary care [9,10,11]. Data also suggest that most people with advanced illnesses prefer to be cared for at home or near their home [12,13]. Yet, most people die in institutions or if at home, without the appropriate level of care needed to meet their basic needs [14, 15].

Some of the challenges to the provision of palliative care in primary care include lack of education of health professionals; limited resources; limited access to medications - especially opioids for pain treatment- and the lack of appropriate policies to ensure availability and access to palliative care within the health care system [16,17,18]. In addition, time limitations in primary care have resulted in a decrease in the amount of time available for the consultation [19,20], requiring physicians to adopt strategies to meet the most pressing needs of the patients more effectively and efficiently.

These limitations call for the identification of priorities in the delivery of primary palliative care, so that health care providers are able to meet the most pressing needs of the patients and their families at the community level. Several regional and national palliative care organizations [21, 22, 23, 24, 25] and some governments [26] have developed norms and standards for the delivery and provision of palliative care focusing on the quality of structural and process indicators, including those related to service provision. These documents provide useful frameworks but are not specific to the essential practices in palliative care. After reviewing the published literature we identified the essential components of palliative care [27] and a selection of performance indicators in primary care [28], but were not able to find a list of essential practices in palliative care.

In 2007, the International Association for Hospice and Palliative Care (IAHPC) decided to use the concept of the WHO Model List of Essential Medicines [29] and applied it to palliative care. As a result, the IAHPC developed, in collaboration with palliative care workers and organizations from around the world and based on consensus, a list of essential medicines for palliative care [30]. This List has been used as a reference to the development of medicine lists for palliative care services throughout the world. Several board members of the IAHPC raised the strategic importance and usefulness to identify other “essential” components in the provision of palliative care.

The objective of this project was to identify, through a consensus process, the essential practices in palliative care which could be provided by physicians, nurses and nurse aides working at the primary care level and could be applicable in all socioeconomic settings.

## METHOD

A three phase descriptive study was designed and conducted by several Directors of the IAHPC and external advisers over a 2-year period. The study was designed utilizing the checklist for cross-sectional studies of the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement [31]. An ethics review board from the *Federacion Medica de la Provincia de Buenos Aires* (Federation of Physicians of the Province of Buenos Aires - FEMEBA) [32] in Argentina approved the study. The phases and steps in each are summarized in Figure 1 and outlined below.



## Phase 1

**1. Development of the Working Group (WG):** In September 2008, two co-authors (RW and LDL) drafted the project proposal and identified IAHPC board members and external experts who had previously expressed interest in working in special projects with the organization and who had significant experience and contribution to clinical, academic and policy aspects of palliative care. Discussions took place over email, phone conversations and meetings via Skype™ [33].

**2. Literature review:** A scientific literature review in peer-reviewed journals was performed in November 2008 using Medline® and CINAHL™. Criteria for selection included: i) Research studies related to symptoms/problems of palliative care patients; ii) Multinational research palliative care studies, iii) Palliative care research studies in primary care level and iv) Studies published between 2000 and 2008. Terms used for the search included: Palliative Care, Palliative Medicine, Hospice, End of Life care; Symptom Control, Symptom Prevalence, and Primary palliative care.

Criteria for exclusion included non-research articles, articles not related to palliative care and articles published in non-scientific peer reviewed journals.

**3. Development of initial list of practices in palliative care:** Using the definitions below, the Gold Standards Framework [34] seven dimensions (also known as 7Cs: Communication, Coordination, Control of symptoms, Continuity of care, Continued learning, Caregiver support and Care in the dying phase) and the evidence from the literature review, members of the WG developed a baseline list of practices which they considered essential in palliative care. The following definitions were applied in the development of the baseline list:

- a. Essential referred to *“Belonging to the very nature of a thing and therefore being incapable of removal without destroying the thing itself or its character”*; and *“Important in the highest degree; indispensable to the attainment of an object; indispensably necessary”* [35]
- b. Primary palliative care provider was defined as a *“Medical, nursing or allied health professional who provides primary care with a palliative approach to patients with a life-limiting illness”* [36]

When there were differences in perception of the meaning of a term (i.e. suffering), members of the WG reviewed various published definitions, until a definition was identified that everybody agreed upon. Based on this step, a Glossary of terms was developed and applied for the project.

**4. Levels of intervention:** Based on a staged care approach, three different levels of intervention (*Identification/Evaluation; Diagnosis; and Treatment/Solution measures*) were identified and assigned to the practices whenever applicable.

## Phase 2 – Delphi survey

**1. Sample selection:** Palliative care focuses on multidisciplinary approach to patient care, taking into account the physical, social, spiritual and psychological aspects of the patient and those of his/her family [37]. On the other hand, primary care tends to be provided by family practitioners, generalists, physician assistants, nurses and nurse assistants [38]. Based on this, the WG decided on the following inclusion criteria: individuals who were physicians, nurses, health clinicians and nurse aides actively working at the time of the survey, fully dedicated to palliative care or who occasionally see patients with palliative care needs in the course of their work (i.e. oncology, geriatrics, family practitioners, etc).

Exclusion criteria included those individuals who did not fit any of the categories and those who reported were not working at the time the survey was conducted.

Assuming a  $\pm 5$  margin of error,  $p=0.05$ , and 95% confidence interval, the sample size was determined to be 400 [39].

The list of potential participants was developed applying the following steps:

- a. An initial list of 951 individuals was developed using the IAHPHC's database and by asking members of the WG and the rest of the IAHPHC Directors to recommend health care workers in their countries/regions. Information collected included the names, emails and countries of individuals.
- b. 631 individuals met the criteria.
- c. Based on their countries, the potential participants were divided into their corresponding WHO region [40]: Africa, Americas, South East Asia, Europe, Eastern Mediterranean and Western Pacific.
- d. In order to ensure the representation of individuals in countries with different socio economic levels, the corresponding countries in each Region were then classified as High, Upper Middle, Lower Middle and Low, based on the World Bank income classification categories [41].
- e. The 631 potential participants were listed by name in a matrix in their corresponding region/category cell. The total number of region/category cells was 20.
- f. Using List Randomizer [42], one name was randomly selected from each region/category and this process was repeated several times. Whenever the number in a given category was insufficient, additional individual(s) were selected from the following category until a list of 425 potential participants was achieved. All were contacted by e-mail and invited to participate.

**2. Delphi surveys:** A Delphi method [43] was used to determine consensus. The Delphi rounds and surveys were developed using Lime Survey™ [44] and custom-made software. A description of the study and instructions to accessing the survey was sent to the participants who accepted the invitation between February and March 2010. Two e-mail reminders were sent at 2-week intervals after initial contact for each round. A signed informed consent for voluntary participation and agreement to confidential data sharing of their responses was submitted by the participants before completing each survey. Participants were provided with the estimated amount of time needed to respond the Delphi survey rounds (between 30 and 45 minutes). Participants confidentially accessed the online web-based survey system through the IAHPHC website.

The survey included the baseline list of practices developed by the WG. In the first round, the participants:

- Were asked to rate each practice as Essential (YES) or non Essential (NO). Participants who selected NO were asked to provide comments explaining their selection. Participants were informed that their comments would be shared confidentially with the participants in the second round.
- Who were unsure or did not know, could select DON'T KNOW/NOT SURE option.

In the second round, the participants:

- Were able to learn the percentage of respondents who selected each of the three options and read their comments.
- Were asked to select between YES or NO.
- Were able to change their selection from the first round if they wished to do so.
- Who had selected DON'T KNOW/NOT SURE in the first round, had to select between YES or NO.

In order to recommend a practice as essential and select the appropriate level of intervention, participants were instructed that it should meet the definitions above, plus the following criteria:

- a. *Can be provided in primary care settings (but may not be available in the current setting of the responder)*
- b. *Can be implemented/started during a brief physician/nurse/nurse aide/clinician visit*
- c. *Easy to implement/apply (if local condition allows appropriate utilization not requiring sophisticated technology)*

In a third and final Delphi round, participants were asked to select the appropriate level of intervention(s) for each practice.

### Phase 3 – Ranking of practices

**1. Sample selection:** A list of all the international, regional and national palliative care organizations, institutions and associations registered in the IAHPC database was developed. An invitation was sent to 54 directors, presidents or executive directors and invited to participate in the survey. The link to the selection panels was sent to those who accepted the invitation.

**2. Selection and Ranking:** A signed informed consent and consent on data sharing was submitted by the participants before completing the survey. Participants were presented with the list of practices resulting from Phase 2 of the project and were asked to select and rank in order of importance the 10 practices they considered to be essential in palliative care and were provided with the same definitions and criteria used in the Delphi rounds. The system was set so that participants could only select and rank 10 practices with no possible repetitions. Each practice received a score (1-10) depending on how it was ranked: the first choice was given 10 points; the second choice was given 9 points; and so on, until the 10<sup>th</sup> choice was given 1 point. Quantitative data were collected and analyzed using simple descriptive statistics.

### Final Step – Development of the List of Essential Practices

Using the results from Phase 3 and based on the definition of primary care from the Institute of Medicine in the USA [45] which calls for integrated health services that are comprehensive, coordinated and continuous, the WG divided the resulting practices in four categories: 1) Care Planning and Coordination, 2) Communication, 3) Physical care needs, and 4) Psychological /Emotional /Spiritual care needs. The practices were then clustered in groups whenever applicable (i.e. Gastrointestinal problems). The practices were listed in a table in the above categories and clusters, as well as from highest to lowest scores and linked each to its corresponding line in the ranking table. The resulting list is the IAHPC List of Essential Practices in Palliative Care.

## RESULTS

### Phase 1

**1-2. Development of the WG and Literature review:** The WG included the co-authors of this paper. During the consultation process and the Delphi rounds, additional IAHPC board members who provided suggestions to the project proposal and methodology are listed as collaborators in this study. Thirteen publications were selected for the literature review by the WG [46,47,48,49,50,51,52,53,54,55,56]

**3-4. Development of baseline list:** Whenever applicable, three levels of intervention were identified: *Identification/Evaluation*; *Diagnosis*; and *Treatment/Solution measures*. Based on a staged care approach, the levels of intervention were combined in the following options:

- Identification /Evaluation
- Or:
- Identification /Evaluation and Diagnosis
- Or:
- Identification /evaluation; Diagnosis; and Treatment/Solution measures

Based on the literature review and the identified levels of practice, an initial baseline list of 140 practices in palliative care was developed by the WG.

## Phase 2

**1. Selection of study sample:** A list of 425 potential participants was achieved. All were contacted by e-mail and invited to participate.

**2. Delphi process:** Four hundred and ten individuals responded to the first Delphi round (96.5% RR), 313 responded to the 2nd round (73.6% RR) and 305 responded to the 3rd round (71.3% RR). Participants were from 64 different countries. The majority (58.8%) were based in three regions: Latin America (63/305), Western Europe (62/305), and Asia Pacific (54/305). Participants included *palliative care specialist physicians dedicated full time to palliative care practice* (67/305); *primary care practice physicians dedicated full time to palliative care* (61/305) and *specialist physicians in a field different than palliative care* (54/305). Table 1 includes the different categories of participants and the level where they work in. Table 2 represents the number of participants who were working full time in palliative care (194/305) at the time the survey was conducted.

A cut off point of  $\geq 80\%$  consensus for the Delphi rounds was set empirically. Data from the first two Delphi rounds were sorted, resulting in 113 practices and 27 being eliminated. Of the initial 140 practices, *Nausea* (identification/evaluation) and *Vomiting* (identification/evaluation) were rated as essential (YES) by all (100%). *Skin rash* (treatment/solution measures) had the highest NO response rate with 19.5%. Of the resulting 113, thirty-one practices had more than one possible combination of levels of intervention. The third and final Delphi round to select the appropriate level(s) of intervention resulted in 62 practices.

## Phase 3

**1. Sample selection:** Forty five palliative care organizations accepted the invitation and all participated in the survey (100% RR).

**2. Ranking of Practices:** Of the 62 practices from Phase 2, forty nine were selected. *Pain Identification /evaluation; Diagnosis; and Treatment/Solution measures* received the highest score (352) followed by *Patient's psychological distress* and *Development of a plan of care based on the resources available* (233 and 141 points respectively). Thirteen practices did not receive any scores. Some of these include the evaluation, diagnosis and treatment of *Bronchial secretions*, *Hiccups*, *Itching*, *Tingling in hands and feet*, and *Myoclonus*. Table 3 includes the six practices with the highest scores. Of these, one received >300 points, one between 200-299 and four <100. All the rest (n=43) received less than 100 points.

Table 4 lists the categories and their corresponding scores. The majority of the practices (23/49) fell under Physical care needs category, with a broad range (350 points) between the lowest and highest

scores. Care planning and Coordination had the highest median (45) followed by Communication (38.5). Overall median and average for all practices were 32 and 49.3 respectively.

## Final List

The final list of essential practices is represented in Table 5 and it includes practices which cover the evaluation, diagnosis and whenever possible, treatment and solution measures of physical, psychological, emotional and spiritual needs, as well as issues related to care planning and coordination, and communication.

## DISCUSSION

The process to identify the essential practices was challenging and required several phases. The large number of participants and the high response rates demonstrate an interest in the topic and a perceived need for such a list.

We identified the appropriate levels of intervention in primary care level for the different practices based on the consensus of participants. These should be taken as guidance with the actual level of intervention defined by the resources available in the local system, the accessibility to these resources and the skills and knowledge of the health care worker.

The large number of practices identified as essential (n=113) after the three Delphi surveys indicate that when forced to choose, the participants preferred to identify a practice as Essential. This may reflect the fact that 194/305 of the participants were fully dedicated to palliative care, and that their perception of what essential is, may be influenced by their daily work.

Identifying and dealing with pain, dyspnoea, psychological distress and making a care plan were considered the most important components of primary palliative care. There was good consensus among the respondents of the ranking survey (Phase 3) with respect to the most important practices (Table 4): *Pain identification, diagnosis and treatment* was considered top priority, indicating that comprehensive pain management was considered the most important practice in palliative care in the community, which is consistent with results published by authors in the field [57,58,59,60]. Among the top six practices, two fell under Physical care needs; two under Care Planning and Coordination; and two under Psychological /Emotional /Spiritual care needs, while none under Communication. The practice under the Communication category with the highest score was *Providing information to Patients and Caregivers* (64 points at 13<sup>th</sup> place). Given the enormous need at the level of physical care and the pressing needs for planning and coordination, other issues such as communication, may be considered to deserve less emphasis.

*Psychological distress or suffering* and *Caregiver's distress or suffering* were second and sixth respectively and may reflect the approach to whole person care of the palliative care field as well as regarding the patient/family/caregiver as the unit of care. *End of life care/death management* also ranked among the highest (109 points at 5<sup>th</sup> place) probably reflecting the perception that palliative care focuses on end of life and on the care of patients in terminal stages.

The category with the highest number of practices was Physical care needs (n=23), followed by Care Planning and Coordination (n=14). This may reflect the constraints in time, resources, structure and personnel in primary health care, which may force health care workers to focus on what they consider to



be the priorities. When the most pressing physical needs are addressed and the structures and processes needed to deliver comprehensive palliative care are available, the relief of psychosocial, emotional and spiritual issues can be addressed.

Further research may be useful to determine the differences in responses among the geographical regions and socioeconomic categories and their level of significance.

### Study limitations:

This study has several limitations: It relies on the consensus of physicians, nurses and nurse aides. In this initial process the authors recognize that the vast majority of palliative care in developing countries is delivered almost exclusively by teams of physicians, nurses and nurse aides. The authors are aware that this approach may have resulted in some issues not being included and recognize the importance of interdisciplinary teams in the delivery of comprehensive palliative care. Further research with representatives of other fields of care, such as psychology, social work, chaplaincy and others should be the focus of study of organizations which are better fitted to represent those professionals and would be useful.

## CONCLUSION

The identification of essential practices for patient care is critical in order to improve palliative care in primary care and it may be relevant and applicable in other levels (secondary and tertiary). Whenever treatment is required but not possible at the primary care level, referral is recommended. The level of complexity in each setting, the amount of resources available, and the level of knowledge and skills of the care provider will determine how providers may use the Essential List and build upon it if needed and possible.

The practices can inform the development of learning outcomes in training manuals for community based doctors and nurses to promote a comprehensive approach to palliative care in the community. Primary care practitioners could potentially address most of the unmet palliative care needs of patients with life threatening conditions and their families and could also become competent to identify patients in need of specialized consultation, referral and/or support from the secondary, tertiary and quaternary levels. The list of essential practices may guide development of clinical programs, educational systems, and national policies.

Additional research and work needs to be developed to evaluate how these practices are to be implemented and their impact in the quality of care delivered to palliative care patients at the primary care levels. The organization hopes to collaborate with others in these future projects.



Figure 1 - Steps

**Phase 1**

1. Development of WG
  2. Literature Review: Identify most common symptoms and needs in palliative care based on scientific evidence.
  3. Development of initial List
  4. Identification of levels of intervention for each practice (when applicable)
    - Identification/Evaluation
    - Identification/Evaluation and Diagnosis
    - Identification/Evaluation; Diagnosis and Treatment
- } → Baseline list of practices

**Phase 2**

1. Sample selection: Physicians (specialists and GPs); Nurses (specialists and certified); Physician/Nurse aides
  2. Delphi Process
    - 1<sup>st</sup> round Delphi → Participants asked to rate each practice:
      - Yes
      - No
      - Don't know / Not sure
    - 2<sup>nd</sup> round Delphi → Participants asked to rate each practice:
      - Yes
      - No

{ Learned the % of responses for each question in the first round. Able to change their selection from first round.
    - 3<sup>rd</sup> round Delphi → Participants asked to select the appropriate level of intervention for each practice
- The IAHPC List of Essential Practices in Palliative Care

**Phase 3**

1. Sample selection: Palliative Care Organizations (Global and Regional)
2. Selection and Ranking of Practices: Representatives of Palliative Care organizations asked to select and rank the 10 essential practices resulting from the Delphi rounds
3. Final selection and organization of practices in categories by members of the WG.

**Table 1 – Participants in the 3 Delphi surveys (N=305)**

Categories	Working in primary care level		Working in other levels		TOTAL	
	N	%	N	%	N	%
Physician - General practitioner. Dedicated full time to palliative care.*	51	17	10	3	61	20
Physician - General practitioner. Dedicated to a field different than palliative care. Occasionally sees patients with palliative care needs in the course of work.	15	5	4	1	19	6
Physician - Specialized. Dedicated full time to palliative care.*	12	0	55	18	67	22
Physician - Specialized. Dedicated to a field different than palliative care. Occasionally sees patients with palliative care needs in the course of work.	8	3	46	15	54	18
Nurse - Registered. Dedicated full time to palliative care.*	7	2	16	5	23	8
Nurse - Registered. Occasionally sees patients with palliative care needs in the course of work.	4	1	0	0	4	1
Nurse - Advanced degree. Dedicated full time to palliative care.*	6	2	37	12	43	14
Nurse - Advanced degree. Dedicated to a field different than palliative care. Occasionally sees patients with palliative care needs in the course of work.	4	1	14	5	18	6
Other (Nurse aid/health clinician) Occasionally sees patients with palliative care needs in the course of work.	16	5	0	0	16	5
<b>TOTAL</b>	<b>123</b>	<b>40</b>	<b>182</b>	<b>60</b>	<b>305</b>	<b>100</b>

\*Full-time palliative care workers

**Table 2 – Participants in Delphi surveys working full time in Palliative Care**

<b>Level</b>	<b>N</b>	<b>%</b>
In primary care	76	25
In other levels	118	39
<b>Total</b>	<b>194</b>	<b>64</b>

**Table 3 – Practices with highest scores**

Practice	Levels of Intervention	Score*	Category
Pain (all types)	Identification /Evaluation Diagnosis Treatment/Solution Measures	352	Physical care needs
Psychological distress or suffering	Identification /Evaluation Diagnosis Treatment/Solution Measures	233	Psychological / Emotional / Spiritual care needs
Developing a plan of care based on the resources available (caregivers capabilities and skills, community support, etc.)	NA	141	Care Planning and Coordination
Dyspnoea	Identification /Evaluation Diagnosis Treatment/Solution Measures	140	Physical care needs
End of life care (last days or weeks) / death management	Identification /Evaluation Diagnosis Treatment/Solution Measures	109	Care Planning and Coordination
Caregivers distress or suffering	Identification /Evaluation Diagnosis Treatment/Solution Measures	107	Psychological / Emotional / Spiritual care needs

**NA:** Not Applicable

\* Each of the representatives of the 45 organizations selected and ranked the 10 practices in order of importance. The highest possible score was 450.

**Table 4 – Distribution of Practices by Categories and Scores**

<b>Category</b>	<b>Number of Practices</b>	<b>Range (Ranking Scores)</b>	<b>Average</b>	<b>Median</b>
Physical care needs	23	2 - 352	53.5	24
Care Planning and Coordination	14	7 - 141	54.8	45
Psychological /Emotional /Spiritual care needs	6	16 - 107	38	27
Communication	6	2 - 64	34.5	38.5

**Table 5 – IAHPC List of Essential Practices in Palliative Care©**

<b>Identify, evaluate, diagnose, treat and apply treatment and solution measures for:</b>
<b>Physical care needs:</b>
Pain (all types)
Respiratory problems (dyspnea, cough)
Gastro intestinal problems (constipation, nausea, vomiting, dry mouth, mucositis, diarrhoea)
Delirium
Wounds, ulcers, skin rash and skin lesions
Insomnia
<b>Psychological / Emotional / Spiritual care needs:</b>
Psychological distress
Suffering of the relative and/or caregiver
Anxiety
<b>Identify and evaluate - provide support and when possible, refer for diagnosis, treatment and solution measures for:</b>
<b>Physical care needs:</b>
Fatigue
Anorexia
Anaemia
Drowsiness or sedation
Sweating
<b>Psychological / Emotional / Spiritual care needs:</b>
Spiritual needs and existential distress
Depression
Family / caregivers grief and bereavement issues
<b>Other:</b>
<b>Care Planning and Coordination issues:</b>
Identify the resources and support available and develop and implement a plan of care based on the patient's needs.
Provide care in the last days/weeks of life
Identify, evaluate and implement solutions to facilitate the availability and access to medications (with emphasis on opioids)
Identify the psychosocial / spiritual needs of self and other professionals involved in the care
<b>Communication issues:</b>
Communicate with patient, family and caregivers about diagnosis, prognosis*, condition, treatment, symptoms and their management, and last days/weeks care issues.
Identify and set priorities with patient and caregivers.
Provide information and guidance to patients and caregivers according to available resources. Sensitize other health care professionals and workers about palliative care.

\***Note:** The determination of prognosis and safe delivery of this information requires appropriate training and knowledge.



## REFERENCES

1. Stjernsward J, Foley K, Ferris F. The public health strategy for palliative care. *Journal of Pain and Symptom Management*. 2007; 33(5):486-493.
2. Wright M, Wood J, Thomas Lynch T, David Clark D. Mapping Levels of Palliative Care Development: A Global View. *Journal of Pain and Symptom Management*. 2008; 35(5):469-485.
3. Worldwide Palliative Care Alliance (2011) Mapping levels of palliative care development: A global update 2011. WPCA, London. Available in <http://www.thewpca.org/latest-news/mapping-report-2011/>
4. Stjernsward J, Pampallona S. Palliative Medicine – A global perspective. In: *Palliative Medicine* (2<sup>nd</sup> ed) Doyle, Hanks, MacDonald (editors). OUP: Great Britain 2003.
5. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. *Milbank Q* 2005;83:457-502.
6. Safran, D. G., Kosinski, M. A., Tarlov, A. R., Rogers, W. H., Taira, D. A., Lieberman, N., Ware, J. E. "The Primary Care Assessment Survey: Tests of Data Quality and Measurement Performance". *Medical Care*, 1998;36(5):728-739.
7. Safran, D. G., Taira D. A., Rogers, W. H., Kosinski, M., Ware, J. E., "Linking Primary Care Performance to Outcomes of Care", *Journal of Family Practice*, 1998; 47(3): 213-20.
8. Palliative Care Australia. Palliative and end of life care glossary of terms. Internet. Accessed July 10, 2011. Available at <http://www.palliativecare.org.au/Default.aspx?tabid=2028>
9. Charlton R. (2002) Primary palliative care. Oxford: Radcliffe Medical Press.
10. Murray SA, Boyd K, Thomas K, Higginson IJ. Developing primary palliative care People with terminal conditions should be able to die at home with dignity. *BMJ*. 2004; 329(7474): 1056–1057.
11. Murray SA, Kok JY. Internationally, it is Time to Bridge the Gap between Primary and Secondary Healthcare Services for the Dying. *Annals Academy Medicine, Singapore* 2008;37:142-144.
12. Tang, ST. When Death Is Imminent: Where Terminally Ill Patients With Cancer Prefer to Die and Why. *Cancer Nursing*. 2003;26(3), 245-251.
13. Gomes B, Higginson IJ. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ* 332: 515 doi: 10.1136/bmj.38740.614954.55 (Published 8 February 2006)
14. Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ* 327: 192 doi: 10.1136/bmj.327.7408.192 (Published 24 July 2003).
15. Docherty A, Owens A, Asadi-Lari M, Petchey R, Williams J, Carter YH. Knowledge and information needs of informal caregivers in palliative care: a qualitative systematic review. *Palliative Medicine*. 2008; 22(2):153-171.
16. De Lima L, Hamzah E. Socioeconomic, Political and Cultural Issues in Palliative Care. In: *Palliative Care in the Developing World: Principles and Practice*. Eduardo Bruera, Liliana De Lima, Roberto Wenk and William Farr W (eds). Houston: IAHPC Press, 2004; pp 23-37.
17. Rajagopal MR, Mazza D, Lipman AG (eds). *Pain and Palliative Care in the Developing World and Marginalized Populations: A Global Challenge*. Haworth Press, 2003.
18. De Lima L, Sweeney C, Palmer JL, Bruera E. Potent Analgesics are more expensive for Patients in Developing Countries: A Comparative Study. *Journal of Pain and Palliative Care Pharmacotherapy*. 2004;18(1):59-70.
19. Bindman AB, Forrest CB, Britt H, Crampton P, Majeed A,. Diagnostic scope of an exposure to primary care physicians in Australia, New Zealand and the United States: cross sectional analysis of results from three national surveys. *BMJ* 2007; doi:10.1136/bmj.39203.658970.55 (published 15 May 2007)

20. Mechanic D, McAlpine DD, Rosenthal M. Are patients' office visits with physicians getting shorter? *New England Journal of Medicine*. 2001; 344:198-204.
21. Lukas Radbruch, Sheila Payne and the Board of Directors of the European Association for Palliative Care (2009). *Standards and Norms for Hospice and Palliative Care in Europe: The EAPC White Paper (Monograph)*. Available in: [http://www.eapcnet.eu/LinkClick.aspx?fileticket=uW\\_JGKKvpZI%3D&tabid=167](http://www.eapcnet.eu/LinkClick.aspx?fileticket=uW_JGKKvpZI%3D&tabid=167)
22. African Palliative Care Association (2010). *APCA Standards for Providing Quality Palliative Care Across Africa (monograph)*. Available in the internet at [http://www.hospicecare.com/standards/APCA\\_Standards\\_AW.pdf](http://www.hospicecare.com/standards/APCA_Standards_AW.pdf)
23. Norwegian Association for Palliative Medicine (2004). *Standard for Palliative Care (monograph)*. Available in the internet in [http://www.palliativmed.org/asset/32504/1/32504\\_1.pdf](http://www.palliativmed.org/asset/32504/1/32504_1.pdf)
24. National Consensus Project for Quality Palliative Care (2009). *Clinical Practice Guidelines for Quality Palliative Care (2<sup>nd</sup> ed)*. Pittsburg: National Consensus Project for Quality Palliative Care. Available in <http://www.nationalconsensusproject.org/Guideline.pdf>
25. Canadian Hospice Palliative Care Association. (2006) *The Pan-Canadian Gold Standard for Palliative Home Care: Towards Equitable. Access to High Quality Hospice Palliative and End-of-Life Care at Home*. Ottawa, ON: Canadian Hospice Palliative Care Association. Available in: [http://www.chpca.net/uploads/files/english/resource\\_doc\\_library/pan-cdn\\_gold\\_standards/Gold\\_Standards\\_Palliative\\_Home\\_Care.pdf](http://www.chpca.net/uploads/files/english/resource_doc_library/pan-cdn_gold_standards/Gold_Standards_Palliative_Home_Care.pdf)
26. Ministerio de Sanidad y Política Social de España (2009). *Unidades de Cuidados Paliativos: Estándares y Recomendaciones*. Madrid: MSPS. Available in: <http://www.msc.es/organizacion/sns/planCalidadSNS/docs/cuidadospaliativos.pdf>
27. O'Neill B, Fallon M. ABC of palliative care: Principles of palliative care and pain control. *BMJ*; 1997; Vol. 315 (7111): 801.
28. Barnsley J, Berta W, Cockerill R, MacPhail J, Vayda E. Identifying performance indicators for family practice: Assessing levels of consensus. *Can Fam Physician*. 2005; 10; 51(5): 701-709.
29. World Health Organization. *Essential Medicines: Definition and Concept*. Last retrieved from the WWW, November 24<sup>th</sup>, 2009 from [http://www.who.int/medicines/services/essmedicines\\_def/en/index.html](http://www.who.int/medicines/services/essmedicines_def/en/index.html)
30. De Lima L, Krakauer E, Lorenz K, Praill D, MacDonald N, Doyle D. Ensuring Palliative Medicine Availability: The Development of the IAHPCC List of Essential Medicines for Palliative Care. *Journal of Pain and Symptom Management*. 2007;33(5):521-6.
31. STROBE Statement. Checklist for cross-sectional studies. Available in: <http://www.strobe-statement.org/index.php?id=available-checklists>
32. Federacion Medica de Buenos Aires (FEMEBA) <http://www.femeba.org.ar/index.php>
33. Skype™ Limited. Available from <http://www.skype.com/>
34. NHS End of Life Care. *The Gold Standards Framework in Primary Care*. GSF Primary Care briefing paper. Available online in <http://www.goldstandardsframework.org.uk/Resources/Gold%20Standards%20Framework/PDF%20Documents/FINAL%20GSF-BRO%20single%20page.pdf> (accessed November 2009)
35. Merriam-Webster Online Dictionary. From <http://www.merriam-webster.com/dictionary/essential> Accessed November 23rd, 2008.
36. Palliative Care Australia. (2005). *Palliative Care Service Development: A population based approach*. Deakin West ACT: PCA. Available in: <http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf> Retrieved July 11, 2011.

37. World Health Organization (2002). National Cancer Control Programs: Policies and Managerial Guidelines, 2<sup>nd</sup> Ed. Geneva: WHO.
38. World Health Organization (2008). The World Health Report. Primary Health Care: Now More Than Ever. Geneva: WHO. Available in [http://www.who.int/whr/2008/media\\_centre/table1.pdf](http://www.who.int/whr/2008/media_centre/table1.pdf)
39. Krejcie, R.V., & Morgan, D.W. Determining sample size for research activities. *Educational and Psychological Measurement*; 1970; 30: pp 607-610.
40. World Health Organization Regional Offices. Available in About WHO in: <http://www.who.int/about/regions/en/index.html> Accessed January 2009.
41. World Bank. Country and lending groups. Available in: <http://data.worldbank.org/about/country-classifications/country-and-lending-groups>
42. Haahr M. List Randomizer. Dublin: Distributed Systems Group –Trinity College. Available in <http://www.random.org/lists/>
43. Harold A. Linstone, Murray Turoff (1975). *The Delphi Method: Techniques and Applications*, Reading, Mass.: Addison-Wesley.
44. The Lime Survey Project Team. Lime Survey software. Available in [www.limesurvey.org](http://www.limesurvey.org)
45. Institute of Medicine, Division of Health Care Services (1994). Molla Donaldson, Karl Yordy and Neal Vanselow (eds.) *Defining Primary Care: An interim report*. Washington DC: National Academy Press. pp16.
46. Solano JP, Gomes B, Higginson IJ. A Comparison of Symptom Prevalence in Far Advanced Cancer, AIDS, Heart Disease, Chronic Obstructive Pulmonary Disease and Renal Disease: Systematic Review. *Journal of Pain and Symptom Management*. 2006; 31(1) pp.58-69.
47. Teunissen SCCM, Wesker W, Kruitwagen C, de Haes HCJM, Voest EE, de Graeff A. Symptom Prevalence in Patients with Incurable Cancer: A Systematic Review. *Journal of Pain and Symptom Management*. 2007;34(1), 94-104.
48. Murtagh FEM, Addington-Hall J, Higginson IJ. The Prevalence of Symptoms in End-Stage Renal Disease: A Systematic Review. *Advances in Chronic Kidney Disease*. 2007, 14(1): 82-99.
49. Meuser T, Pietruck C, Radbruch L, Stute P, Lehmann KA, Grond S. Symptoms during cancer pain treatment following WHO-guidelines: a longitudinal follow-up study of symptom prevalence, severity and etiology. *Pain*. 2001; 93(3): 247-257.
50. Bruera E. Clinical research in palliative care: Patient populations, symptoms, interventions and endpoints. *Palliative Medicine*. 2001;15(2): 163-168.
51. Exley C, Field D, Jones L, Stokes T. Palliative care in the community for cancer and end-stage cardiorespiratory disease: the views of patients, lay-carers and health care professionals. *Palliative Medicine*; January 2005;19(1): 76-83.
52. Walshe C, Caress A, Chew-Graham C, Todd C. Implementation and impact of the Gold Standards Framework in community palliative care: a qualitative study of three primary care trusts. *Palliative Medicine*; 2008; 22(6): 736-743.
53. Fainsinger RL, Brenneis C, Fassbender K. Edmonton, Canada: A Regional Model of Palliative Care Development. *Journal of Pain and Symptom Management*. 2007;33 (5): 634-639.
54. Finlay IG, Higginson IJ, Goodwin DM, Cook AM, Edwards AGK, Hood K, Douglas HR, Normand CE. Palliative care in hospital, hospice, at home: results from a systematic review. *Annals of Oncology*; 2002. 13;(suppl 4): 257-264.
55. Kumar SK. Kerala, India: A Regional Community-Based Palliative Care Model. *Journal of Pain and Symptom Management*. 2007;33(5): 623-627.

56. Harding R, Higginson IJ. Palliative care in sub-Saharan Africa. *The Lancet*. 2005; 365(9475;4-10): 1971-1977.
57. Auret K, Pickstock S. Pain management in palliative care - An update. *Australian Family Physician*. 2006; Vol 35, (10) 753 – 832.
58. van Oorschot B, Schuler M, Simon A, Schleicher U, Geinitz H. Patterns of care and course of symptoms in palliative radiotherapy: a multicenter pilot study analysis. *Strahlenther Onkol*. 2011;187(8):461-6.
59. Wilson KG, Chochinov HM, Allard P, Chary S, Gagnon PR, Macmillan K, De Luca M, O'Shea F, Kuhl D, Fainsinger RL. Prevalence and correlates of pain in the Canadian National Palliative Care Survey. *Pain Res Manag*. 2009;14(5):365-70.
60. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, Mashao T, Mmoledi K, Sebuyira LM, Ikin B, Higginson IJ. The prevalence and burden of symptoms amongst cancer patients attending palliative care in two African countries. *Eur J Cancer*. 2011;47(1):51-6.

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