White Paper for Global Palliative Care Advocacy

PAL-LIFE experts advisory group of the Pontifical Academy for Life, Vatican City

Presented by
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What is it the PAL-LIFE group?

- An advisory group of the Pontifical Academy for Life (PAV)
- Mission: to inform, offer guidance and advice in promoting and advancing Palliative Care globally

  - According with the mission of the PAV to promote care for human life, recognizing the dignity in all persons regardless of their condition, diagnosis or prognosis
Members of PAL-LIFE group

13 palliative care experts and advocates, all regions, backgrounds, and religious or spiritual beliefs

- Al-Sirafy, Samy
- Bruera, Eduardo
- Centeno, Carlos
- De Lima, Liliana
- Luyirika, Emmanuel
- Mosoiu, Daniela
- Pettus, Katherine
- Puchalski, Christina
- Rajagopal, MR
- Sitte, Thomas
- Yong, Jin-Sun
- Callaway, Mary V.
- Foley, Kathleen M.
When did it all started?

1st meeting
Rome, April 2017

1. A basic PC strategy for the PAV
2. The writing of a *White Paper* for Global PC Advocacy
3. A big event in the Vatican was also proposed
Letter to the Editor

“PAL-LIFE Project: International Advisory Working Group on Diffusion and Development of Palliative Care in the World” — First Meeting Report

Nunziata Comoretto, MD, PhD

The Pontifical Academy for Life (Vatican City) has recently launched a new Project on the care for the dying, called “PAL-LIFE: International Advisory Working Group on the Diffusion and Development of Palliative health systems, is considered an important step on to urge member states to develop PC policies (M. Rajagopal).

The biggest obstacle to the development of PC programs globally is the lack of awareness of their existence and spec-
The White Paper represents a position statement of the Pontifical Academy of Life and aims at presenting the most important recommendations for the diverse stakeholders groups involved in global PC development.
How was the White Paper developed?

- Decision on methods
- Stakeholders identification
- Proposal of recommendations
- Consensus process
- Ranking main recommendations
- WHITE PAPER versions

Working mainly by e-mail and using ATLANTES Research Group, University of Navarra as the Research central office.
Results

- 13 stakeholder groups were identified
- 43 recommendations were formulated
- The ad hoc group considered all of them of the highest importance
- The highest recommendation (per each stakeholder) was selected as MAIN REC. for the brief version
**Results**

**PALLIATIVE CARE: EVERYWHERE & BY EVERYONE**

Palliative Care in every region.
Palliative Care in every religion or belief

Rome February 28th - March 1st 2018

**WORKSHOP PROGRAM**

**PAL-LIFE Advocacy Group**

**Palliative Care around the World**

**The global situation**

It is estimated that over 40 million people currently require palliative care every year, and this is expected to grow due to population ageing. The global prevalence of non-communicable diseases, and the persistence of other chronic and infectious diseases worldwide.

**PAL-LIFE project**

The Pontifical Academy for Life (PAL) has identified the Palliative Care movement as the most humane response to the needs of seriously ill and dying children, adults, and fragile elders, to ensure that they are cared for until the end. In 2017, it launched an international project called "PAL-LIFE: International Advocacy Working Group on Palliative Care in the World".

**Selected Recommendations for the Stakeholders**

**POLICYMAKERS**

Policymakers must recognize this societal and ethical value of PC and modify the existing structures, policies and outcome measures of healthcare to allow universal access to PC for all patients with progressive chronic diseases before death.

**UNIVERSITIES (ACADEMIA)**

All universities engaged in formation of healthcare workers (doctors, nurses, pharmacists, social workers, chaplains, etc.) should include basic level PC training in mandatory undergraduate coursework.

**PHARMACISTS**

Pharmacists should work to provide efficient mechanisms for the temporal availability of non-standard dosage forms, and find ways to make them available and accessible for the patient, especially when there are no generic/cheaper formulations available in the country.

**PROFESSIONAL ASSOCIATIONS & SOCIETIES**

Professional associations and societies should also advocate for the role of PC and the domestication of regional and global policy frameworks and declarations such as the 2014 WHO PC Resolution, Universal Health Coverage, the Sustainable Development Goals, and the Non-Communicable Diseases declaration.

**PHARMACEUTICAL AUTHORITIES**

Morphine is the preferred medicine for moderate/severe cancer pain control and should be made available, especially the immediate-release and oral. Other opioids are helpful, but should not replace morphine.

**MEDIA**

Mass media should be involved in creating a culture of understanding around advanced illness and the role of PC throughout the illness.

**INTERNATIONAL ORGANIZATIONS**

WHO Member States should develop policies and procedures to implement WHO Resolution WHA67.14 as an integral part of their strategies to implement the G7 Agenda for Sustainable Development, paying specific attention to the needs of children and older persons.

**RELIGIOUS INSTITUTIONS, SPIRITUAL GROUPS**

Religious leaders and organizations should advocate for the inclusion of spiritual care in PC on the local, state and country levels. They should ensure developing of professional spiritual care providers or chaplains and ensure their sustainability in all health settings.

**HOSPITALS AND HEALTH CENTRES**

Every Hospital and Healthcare Centre should ensure affordable access to basic PC medicines, particularly to opioid medicines like morphine which is in the essential medicines list of WHO.

**PATIENTS & PATIENTS’ GROUPS**

PC patients need a health literacy campaign to integrate PC for all serious or life limiting diseases.

**HEALTH CARE WORKERS**

All healthcare workers engaging in PC should receive certification appropriate for one’s profession and degree of involvement in palliative care, while actively participating in ongoing education to develop competencies required for certification.

**PHILANTHROPIC ORGANIZATIONS & CHARITIES**

PC individuals and organizations must engage, educate and advocate for philanthropic organizations and charities to support PC development and implementation. Recommended areas of funding should include PC education and training of all health care professionals, ensuring government health policy to include PC, making pain-relieving medications available, raising public awareness about the need for PC, model service delivery at home, in hospital and hospices.

**PROF. ASS. & SOCIETIES OTHER THAN PC**

To encourage human rights organizations to take forceful action and declarations and to implement strategies whose aim is advancing PC development worldwide within the Human Rights framework.
Main Results

Selected Recommendations for the Stakeholders

POLICYMAKERS
Policymakers must recognize the societal and ethical value of PC and modify the existing structures, policies and outcome measures of healthcare to allow universal access to PC for all patients with progressive chronic diseases before death.

UNIVERSITIES (ACADEMIA)
All universities engaged in formation of healthcare workers (doctors, nurses, pharmacists, social workers, chaplains, etc.) should include basic level PC training as mandatory undergraduate coursework.

PHARMACISTS
Pharmacists should work to provide efficient mechanisms for dispensing, compounding of nonstandard dosage forms, and should find ways to make these available and accessible for the patient, especially when there are no generic/cheaper formulations available in the country.

PROFESSIONAL ASSOCIATIONS & SOCIETIES
Professional associations and societies should also support the advocacy role and the domestication of regional and global policy frameworks and declarations such as the 2010 WHA PC Resolution, Universal Health Coverage, the Sustainable Development Goals and the Non-Communicable Diseases declaration.

PHARMACEUTICAL AUTHORITIES
Morphine is the preferred medicine for moderate/severe cancer pain control and should be made available, especially the immediate-release oral and suppository formulations. Other opioids are helpful, but should not replace morphine.

MASS MEDIA
Mass media should be involved in creating a culture of understanding around advanced illness and the role of PC throughout the illness.

INTERNATIONAL ORGANIZATIONS
WHO Member states should develop policies and procedures to implement WHA Resolution 67/9 as an integral part of their strategies to implement Agenda 2030 for Sustainable Development, paying specific attention to the needs of children and older persons.

RELIGIOUS INSTITUTIONS, SPIRITUAL GROUPS
Religious leaders and organizations should advocate for the inclusion of spiritual care in PC on the local, state and country levels. They should ensure the development of professional spiritual care providers or chaplains and ensure their sustainability in all health settings.

HOSPITALS AND HEALTH CARE CENTRES
Every Hospital and Healthcare Centre should ensure affordable access to basic PC medicines, particularly to opioid medicines like morphine which is in the essential medicines list of WHO.

PATIENTS & PATIENTS' GROUPS
PC patients need a health literacy campaign to integrate PC for all serious or life-limiting diseases.

HEALTHCARE WORKERS
All healthcare workers engaging in PC should receive certification appropriate for one’s profession and degree of involvement in palliative care, while actively participating in ongoing education to develop competencies required for certification.

PHILANTHROPIC ORGANIZATIONS & CHARITIES
PC individuals and organizations must engage, educate and advocate for philanthropic organizations and charities to support PC development and implementation. Recommended areas of funding should include PC education and training of all health care professionals, refining government health policy to include PC, making pain-relieving medicines available, raising public awareness about the need for PC, model service delivery at home, in hospitals and hospices.

PROF. ASS. & SOCIETIES OTHER THAN PC
To encourage human rights organizations to take into account existing declarations and to implement strategies whose aim is advancing PC development worldwide within the Human Rights Framework.
Policymakers

Recognize the societal and ethical value of Palliative Care and modify the existing health care structures, policies and outcome measures to ensure access to universal access to PC for all patients in need.
Universities (Academia)

All universities offering degrees in healthcare related fields, should include mandatory palliative care courses as part of the undergraduate curricula.
Pharmacists

Pharmacists should be able to prepare compounded opioid formulations, and find ways to make them available and accessible for the patient, especially for children, the elderly and when there are no generic/cheaper formulations in the country.
Recommendations to stakeholders

Professional Associations & Societies

Become effective advocates and work with their governments in the process of implementing international policy framework, including Conventions, Resolutions and Declarations in their countries.

Examples:

WHA PC Resolution (2014), Universal Health Coverage, the Sustainable Development Goals and the WHO Roadmap on Non-Communicable Diseases
International Organizations

International organizations should encourage WHO Member states to develop policies and procedures to implement WHA Resolution 67/19 as an integral part of their strategies to implement Agenda 2030 for Sustainable Development, paying specific attention to the needs of children and older persons.
Religious Institutions and Spiritual Groups

Advocate for the inclusion of spiritual care in PC on the local, state and country levels.

Ensure development of professional spiritual care providers or chaplains and their employment stability in health settings.
Hospitals and Health Care Centres

Every hospital and healthcare center should ensure affordable access to palliative care medicines included in the WHO Model List of Essential Medicines, particularly to opioid analgesics such as morphine.
Patients and Patients’ Groups

There needs to be a health literacy campaign to increase the understanding of PC and their role in the decision making process for all patients with palliative care needs and their families.
Healthcare Workers

Healthcare professionals working in PC should receive appropriate certification while actively participating in continuing education to maintain the adequate competency levels.
Philanthropic Organizations & Charities

Philanthropic organizations and charities should support PC development and implementation.

Recommended areas of funding include:

• Increase in PC education and training of all healthcare professionals,
• Adequate policies revising government health policy to include PC,
• Improving availability and access to opioid analgesics
• Raising public awareness about the need for PC, and service delivery at home, in hospital and hospices.
Recommendations to stakeholders

Other Non-Palliative Care Professional Associations & Societies

To encourage human rights organizations to take into account existing declarations, and implement strategies whose aim is advancing PC development worldwide within the Human Rights framework.
THANK YOU!