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Palliative Care Declarations: Mapping a New Form of Intervention



To the Editor:

It is 21 years since the *JPSM* published the Declaration of Florianópolis, drawing attention to the need for improved access to pain and palliative care services in Latin America.¹ In the intervening years, there has been a growing tendency for palliative care associations and organizations to issue formal public statements of this type. Declarations have become part of the international palliative care landscape. They appear to require significant orchestration and planning, and yet they have not been examined from a research perspective. Defined as “statement(s) of intent or summaries of the desirable situation to which participants intend to work and to which they would like to encourage others to work,”² declarations highlight matters of particular concern or call others to action in some way. They are a window on the priorities emerging in the field.

Understanding why, how, and with what effect declarations are produced has the potential to inform those who develop them and to improve their formulation and impact in the future. Our exploratory study set out to 1) map the emergence of the practice of palliative and end-of-life care declarations in the international context, 2) capture their form and characteristics, and 3) assess what is known about their purpose. To achieve this, we built a comprehensive collection and timeline of declarations that relate to palliative and end-of-life care, and are available in the public domain.

Methods

Palliative and end-of-life care declarations published in the English language were collected using a four-stage approach. Our method was systematic but inevitably had some ad hoc elements, given the undocumented terrain we were investigating. Systematic searches on the Internet using the key words: palliative care, end-of-life care, declaration, manifesto, charter, commitment, and proclamation yielded 22 declarations. Web site scrutiny, especially the advocacy pages, of palliative care associations and organizations yielded seven declarations. A social media appeal through a blog post (by H.I.) listing the examples already found and requesting details of others was made, yielding one declaration. Finally, monitoring of social media from March 2015 to February 2016 led to the identification of four more declarations.

A timeline of palliative and end-of-life care declarations was created, and content analysis was undertaken to identify the geographical scope, relevant organizations, format of the documents, and key issues addressed.

Results

Timeline

Thirty-four palliative care declarations were identified in the period 1983 to February 2016 (Table 1). The timeline suggests a progressive increase in the production of declarations with 16 declarations published in the five-year period 2011 to 2015.

Geographical Scope

The declarations were found to differ in their intended geographical reach. Seventeen were global in ambition. Nine declarations were international in focus but restricted to a particular world region or set of countries (two each for Latin America, Europe, and the developing countries and one each for Eastern Europe, Sub-Saharan Africa, and selected countries from Europe). Of the six declarations with

Table 1
 Thirty-Four Palliative Care “Declarations”: 1983 to February 2016^a

Year	Name of Declaration and Geographical Scope	Source	Recommendations and Key Content
1983	Declaration of Venice on terminal illness (Global)	Macpherson G. World Medical Association in Venice: BMA fails to reform constitution. <i>Br Med J</i> (Clin Res Ed). 1983;287:1644.	<ul style="list-style-type: none"> • The physician may relieve suffering of a terminally ill patient by withholding treatment • Withholding treatment does not free the physician from the obligation to assist the dying person and give necessary medications • The physician may refrain from using any extraordinary means that would prove of no benefit for the patient.
1994	The Declaration of Florianópolis (Latin America)	Stjernsward J, Bruera E, Joranson D, et al. Opioid availability in Latin America: the declaration of Florianopolis. <i>J Pain Symptom Manage</i> . 1995;10:233–236.	<ul style="list-style-type: none"> • The WHO should report patterns of use of opioids • Members to work with respective health ministries • Make available advice on legislation • Encourage multinational companies to bring in opioids • Encourage national companies to produce opioids at lower cost
1995	Barcelona Declaration on Palliative Care (Developing countries)	Barcelona Declaration on Palliative Care. <i>EJPC</i> 3 (1) 15.	<ul style="list-style-type: none"> • Develop clear informed policies • Implementation of specific services • Education of health professionals • Make necessary drugs available
1998	The Poznan Declaration (Eastern Europe)	The Poznan Declaration. <i>EJPC</i> 6 (2) 61–65.	<ul style="list-style-type: none"> • Promote national policies, education, and drug availability • Develop multidisciplinary palliative care services • Build wider awareness
2002	Cape Town Declaration (Sub-Saharan Africa)	Mpanga Sebuyira L, Mwangi-Powell F, Pereira J, Spence C. The Cape Town palliative care declaration: home-grown solutions for sub-Saharan Africa. <i>J Palliat Med</i> 2003;6:341–343.	<ul style="list-style-type: none"> • Palliative care is a right for everyone • Appropriate drugs should be made available • Education programmes should be established • Palliative care should be provided across all levels of care
2004	Charter for the Normalization of Death, Dying and Loss (Global)	Silverman P. The 2004 Tucson IWG (International Work Group): Charter for the Normalization of Dying, Death and Loss. <i>OMEGA-J Death Dying</i> 2005;50:331–336.	<ul style="list-style-type: none"> • Advocacy to recognize death as normal human experience • Involvement and partnerships with community • Political lobbying • Target legislative changes
2004	Palliative Care Manifesto (UK)	http://www.politicsresources.net/area/uk/ge05/man/groups/PalliativeCareManifesto.pdf	<ul style="list-style-type: none"> • Proposes additional £100 million annual investment in palliative care • Proposes introduction of monitoring care of the dying • Proposes a national training programme in palliative care
2005	Korea Declaration on Hospice and Palliative Care (Global)	http://hospicecare.com/uploads/2011/8/Korea_Declaration.pdf	<ul style="list-style-type: none"> • Include hospice and palliative care in government health policies • Access to hospice and palliative care is a human right • Integrate hospice and palliative care education and training into undergraduate and postgraduate curricula of medicine, nursing, research, and other disciplines • Make necessary drugs available, including affordable and available morphine to the poorest • Make hospice and palliative care available to all citizens
2006	WMA Resolution of Venice on Terminal Illness (Global)	http://www.wma.net/en/30publications/10policies/i2/	<ul style="list-style-type: none"> • Physicians should recognize the right of patients to develop written advance directives • Physicians should ensure psychological and spiritual resources are available • National Medical Associations should encourage governments to invest additional resources for palliative care and should advocate for a network of palliative care institutions/organisations • Medical schools' curricula should include palliative care

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