Palliative care as a human right: what has the Prague Charter achieved?

The Prague Charter was launched in 2013 to urge governments worldwide to put more efforts into developing or improving palliative care, including widening patient access to pain medication. Esther Schmidlin and David Oliver explain how the Charter has been used so far, and how it will continue to serve as a powerful advocacy tool.

Since the early days of 1967, when Dame Cicely Saunders opened St Christopher’s Hospice in London – the first modern hospice, committed to patient care, education and research – palliative care has become increasingly available across the world. However, the development of hospice and palliative care has varied greatly from country to country.

The WHO defines palliative care as ‘an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’. That type of care has been shown to allow people with various end-stage diseases to live and die with the least possible pain and distress, and their families and carers to receive the right support. That type of care is far from being available everywhere. However, the United Nations (UN) have recently acknowledged that access to palliative care is a legal obligation on the part of governments and health services, when the first WHO resolution dedicated to palliative care was passed at the 67th World Health Assembly in Geneva in May 2014.

Highlighting inequalities

In the last 20 years, some countries have developed a palliative care system that is fully integrated with the national healthcare system while, in other countries, service provision relies on small, local charity-based organisations. These inequalities have become increasingly visible. Significant barriers to the access to palliative care have been identified, including the lack of adequate health policies, non-existent or limited research and training, and limited access to opioid-based analgesics. A recent study, conducted in 234 countries, areas or territories, found that palliative care was well integrated in less than 12% of them, while there was no delivery system for palliative care services in 42%, and service delivery only reached a small percentage of the population in 32%.

It is estimated that 80% of the world’s population lack adequate access to palliative care medication. While the levels of opioid consumption have risen in several regions in the last few years, the bulk of the increase has occurred in a limited number of countries mostly located in Europe, North America and Oceania (including Australia). In some countries or regions, particularly in Africa, Asia and South America, opioid consumption levels have stagnated or even decreased.

In 2012, the WHO estimated that, every year,
5.5 million patients with late-stage cancer and 1 million patients with end-stage HIV/AIDS experience moderate-to-severe pain but have no access to adequate pain treatment. The absence of palliative care, which leads to people facing severe pain and distress, can be seen as constituting cruel, inhuman or degrading treatment, according to a report by the UN Special Rapporteur on torture, and it certainly does not allow people access to the highest attainable standard of physical and mental health, which is a right enshrined in the UN International Covenant on Economic, Social and Cultural Rights.

Instances of avoidable pain and distress have been highlighted. The EAPC online collection of ‘true stories from around the world’ features personal accounts from patients and carers: some where good palliative care has had a positive impact on patients’ and families’ experience of incurable illness, death and dying, and, at the other end of the spectrum, some where the lack of palliative care has caused unnecessary suffering. The ‘worst case scenario’ stories show the human aspect of the consequences of a lack of access to essential medication.

What is the Prague Charter about?

In 2012, it was felt that there was an increasing need to advocate palliative care as a human right. The EAPC, the International Association for Hospice and Palliative Care, the Worldwide Hospice Palliative Care Alliance, Human Rights Watch and the Union for International Cancer Control collaborated to launch the Prague Charter, urging governments to relieve suffering and ensure people’s right to palliative care. The Charter was officially launched at the World Congress of the EAPC in Prague in May 2013. The Prague Charter calls on governments to:

- Develop comprehensive health policies that address the needs of people with life-limiting or terminal illness and provide support for families
- Ensure access to essential medicines, including opioid analgesics, for all who need them
- Ensure healthcare workers receive adequate training on palliative care and pain management at undergraduate and postgraduate levels
- Ensure the integration of palliative care into healthcare systems at all levels.

The full text of the Prague Charter can be found on the EAPC website.

Collecting signatures

From the start, people were encouraged to get involved – whether they were individuals or members of international and local organisations – and sign and support the Charter.

By signing and showing their support, signatories were urging governments to ensure that patients and families could make use of their right to palliative care; to integrate palliative care into health systems; and to ensure equal access to palliative care. Signatories were also inviting palliative care associations, nationally and regionally, to spread the palliative care philosophy; and academic institutions and teaching hospitals to train and motivate professionals to integrate palliative care into their services.

Since December 2012, when the online petition was published on the Avaaz.org community petitions website, over 7,500 people have signed it. This expression of solidarity with the aims and objectives of the Charter does show that there is a groundswell of support for the establishment of palliative care as a human right.

Use of the Charter across the world

The Charter has been used across the world by many organisations. The International Alliance of Patients’ Organizations, the International Council of Nurses, the European Society for Medical Oncology and a variety of WHO Collaborating Centers have officially endorsed it. Some national associations have launched specific actions to raise awareness of the need to recognise palliative care as a human right; for example, the Irish Association for Palliative Care promoted the Prague Charter through a national bike event.

A useful tool at different levels

In September 2014, all organisations associated with the EAPC and its Prague Charter partners received a short questionnaire about their experience with the Charter. In all, 223 organisations or healthcare providers from 66 countries replied; 84% had heard of the Prague Charter; 69% had informed their members about the petition via a newsletter, direct mailing, their website or their professional journal. Many respondents
explained that they had presented and discussed the Charter in educational settings; for example, with master students and doctors in subspecialty courses, or during continuing medical education and other workplace meetings. Some respondents also reported talking about it at their national conference or promoting it through social media.

Twenty-two per cent of respondents had informed the public about the Charter, via the media or their own publications. And 21% had used the Prague Charter as a tool in advocacy for palliative care; for example, in negotiations with government or insurance health authorities, in plans to set up or extend services, or in explaining palliative care in national or local documents.

Moreover, 37% of the organisations felt that they may use the Charter in future advocacy work. One respondent expressed that the Prague Charter can help ‘to make the case for the development of palliative care in “developing” or low/middle income countries where the healthcare infrastructure is 20–40 years behind where it needs to be’, adding that ‘palliative care should be built into the infrastructure now, rather than added on […] once the rest of the infrastructure is in place’.

Another comment showed an example of how the Charter may be used: ‘In my country, Brazil, palliative care is growing and the Prague Charter, an instrument made by high-impact institutions, is a strong tool to help show the importance of palliative care to our authorities; for me it is important to convince my superiors and directors of my hospital to support our palliative care team, which is still small and fragile.’

Overall, it was felt that the Charter had been useful: on a ten-point scale (0 being ‘not at all useful’ and 10 being ‘very useful’), 52% of respondents gave it a mean score of 4.7 and 31% gave a mean score of 7 or more.

In future
What will happen next? The prominence of the Prague Charter is now diminishing and the number of signatures is reducing. But its effects will live on, as organisations involved in palliative care across the world continue to use its principles in pressing for the development of services for people with advanced disease. The themes publicised in the Charter can be used by anyone involved in developing palliative care who wants to obtain equity of access and appropriate care and medication to all who need them. In some countries, important changes have already taken place. One of many examples is that of Albania, where, on 16 October 2014, the national parliament has passed a palliative care law, which includes plans to implement appropriate policies, consider palliative care as an integral component of the health system, and put in place adequate education. The law also recognises patients’ need for essential medicines and plans to overcome legislative barriers to them accessing opioids.14

So even when the petition on Avaaz.org is closed after the Copenhagen Congress at the end of May, the Prague Charter will continue to serve as an advocacy tool. The EAPC will unceasingly advocate for palliative care and the Charter will remain a crucial means of doing so, until we have achieved our goal: equal access to palliative care for every person who needs it – because it is a human right!

Declaration of interest
The authors declare that there is no conflict of interest.

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