The end of life: unknown and unplanned?

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In an age when we can map the human genome and communicate globally across the Internet, it is amazing how little we know about the experience of people towards the end of life. For those who die, we do not know how many feel pain at the end of life, or how many receive effective symptom control, how many die in the place they want to be cared for, or what the quality of their care is. We do not know how many families feel supported during or after the illness, or to what extent this strains them and their finances. We also do not know what it costs to care for people towards the end of their lives, although there are global concerns about the inappropriate use of expensive technologies at the end of life. These issues are only just beginning to be addressed in cancer and even here knowledge is still patchy.

This lack of knowledge is especially acute now, because of the changes in the patterns of illness across the world. In most countries populations are ageing rapidly. Increasingly, more people die as a result of serious chronic disease. More people are now living with the effects of serious chronic illnesses towards the end of life. Older people in particular are more likely to suffer from multi-organ failure. The WHO Global Burden of Disease Project predicts that in 2020 the top five causes of death will be heart disease, cerebrovascular disease, chronic respiratory disease, respiratory infections and lung cancer. In Africa and many developing countries the devastating effect of HIV/AIDS, and the limited effectiveness of antiretroviral therapy when food and clean water are in short supply, means that many young people face terminal illness. This is ripping up the population of working adults and leaving their older family members to care for them and their children. The question then arises, who will look after the older people in developing countries in years to come. These are major public health challenges for us all.

The World Health Organization (WHO) has a history of taking an early stand on improving care towards the end of life. In 1986, it sought to promote better pain relief in cancer patients. The World Health Assembly adopted a Resolution on Cancer Prevention and Control calling on all Member States to develop national cancer programmes, including increased prevention measures, early detection and screening, as well as improved treatment and palliative care. The lessons learnt so far in the now world-wide field of palliative care were never meant to be confined to one group of patients and their families. Carers struggling to cope over long periods of stress are equally deserving of support and their voices are too often unheard.

In the last two years the WHO Regional Office for Europe has taken steps promoting wide awareness of the concept of comprehensive palliative care services and examining the implications for ageing populations. The information was published in two concise publications written primarily for policy makers providing an overview of the key issues and the best available evidence on the difference palliative care can make to people. Both publications have proved extremely popular judging by the demand for large numbers of copies from around Europe and the number of downloads from the WHO website. A special effort is being made to overcome language barriers and reach out to decision-makers and professionals in all parts of the Region through translation in national languages. Thanks to a grant from the Open Society Institute the Russian version of the booklets is at present being disseminated.

Palliative care is now understood as an approach to care concerned with caring for the whole person faced with a range of physical, psychological and social needs. The WHO definition in 2002 is ‘... an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.’ Unusually for health care it has from the outset taken a strongly multidisciplinary approach, seeking to integrate the expertise of doctors, nurses, social and welfare professionals, psychologists and counsellors, those providing spiritual support, and to care for both the patients and their family or close friends. It now extends beyond cancer patients to include those with serious life threatening illness, progressive chronic diseases and HIV/AIDS.

There are three pressing needs: the need for awareness and recognition of the value of palliative care; the need for political commitment to develop comprehensive palliative care services as an integral part of mainstream health and social care systems; and third the need for a better and systematic knowledge base for planning and delivering effective palliative care services.

Raising awareness about the value and evidence of palliative care and dispelling the myths is essential. We also need to understand what the public knows about palliative care, whether the belief that it is relevant only to the very end of life still persists—a misperception sometimes reinforced by payment reimbursement systems. We also need to know their views about the care they would prefer, and of that already received by relatives and close friends. Understanding and being educated about palliative care concerns the public as well as professionals and policy-makers. This was best described in the words of Cicely Saunders—founder of the modern hospice movement—"The lessons learnt so far in the now world-wide field of palliative care were never meant to be confined to one group of patients and their families. Carers struggling to cope over long periods of stress are equally deserving of support and their voices are too often unheard."

Political commitment is required, although policy could be implemented in slightly different country specific ways, the strategic entry point for developing palliative care services

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may be a national policy for cancer prevention and control or a national policy for the health of older people or other relevant policies and programmes that relate to the healthy needs of children, people with HIV/AIDS, etc. Palliative Care is in fact an issue that concerns all levels of government, national, regional and local. Very often Palliative Care services are provided locally by a host of statutory and non-statutory agencies. The emphasis must be on making appropriate Palliative Care services accessible to all those who need them irrespective of their socio-economic circumstances.

To be able to plan and deliver high-quality services national sources of data should be used more effectively. For example, death registrations should be better standardized according to multiple underlying cause of death as well as place of death, ethnicity and culture, and area of residence. Countries need to develop simple ways of monitoring need for and quality of care received. Such intelligence is critical for planning services and the workforce required to deliver them. Currently few states invest in research into palliative care. For every €10 spent on cancer research, in the UK less than 2 cents and in the USA 9 cents goes to palliative and end of life care research. Canada leads others with its nationally funded programme of research in palliative care, and a separate assessment panel. This kind of approach is critical if the specific research challenges for palliative care are to be understood.

The time has now come for action in these three areas. This will require both a social and a political impetus, entailing changes in public and professional attitudes and widespread education of all professionals involved with patients who have a life-threatening illness. It demands human commitment rather than expensive drugs and interventions, and should be a concern for all governments.

References


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