STEPS TO SUCCESSFUL PALLIATIVE CARE
Changing attitudes to palliative care for older people

Professors Lieve Van den Block and Bregje Onwuteaka-Philipsen, and Mrs Anne-Sophie Parent form part of a consortium that seeks to address the challenges associated with palliative care across Europe. Below, they describe the background to the consortium, the challenges with palliative care up to this point and why it remains a taboo subject.

Can you explain why palliative care up to this point has had negative connotations? Why is it vital to change attitudes towards palliative care programmes?

BOP: Palliative care has negative connotations for many people because they associate it with death and dying. Acknowledging that the end of life is near for somebody and that care is no longer possible is difficult – both for individuals and in conversations between people. When talking about life-threatening disease this is often done in terms of not giving up and fighting. There can be a hesitance of care providers to discuss palliative care options with patients and their relatives because of the association with death and dying.

Palliative care programmes can only be successful if people are willing to openly and proactively think about how the time left can be spent with as much quality of life as possible. So, a shift in attitude among healthcare providers, patients and family – and more broadly society – to think about and discuss at a timely point the last phase of life (in terms of weeks, months and even years) is essential for the success of palliative care programmes.

Why has palliative care in the past been mainly offered to cancer patients?

UBVP: Palliative care grew out of the hospice tradition, which began as terminal care for cancer patients, particularly in the UK. The main reason for this is because the need of these patients was clearly high. Many suffered from severe symptoms, not only physical, but also psychosocial and spiritual. From these needs, hospice and other palliative care services grew. However, the way these specialist services operate does not fit the disease trajectories of older people. The latter often have multiple problems and conditions, over longer periods of time, and needs that fluctuate considerably across the disease trajectory. Hence, providing palliative care to these groups of people at the right time will involve more than a culture change; it will also involve systemic and service changes which might take a long time – and we need evidence to be able to show how it might work.

Steps to successful palliative care

PACE – Comparing the effectiveness of palliative care for older people in nursing and care homes in Europe is a consortium intent on informing and assisting policy and decision-makers at national and European levels. The team hopes to develop specific tools and products to help policy makers to make evidence-based decisions on optimal palliative care delivery in long-term care facilities.

The World Health Organization (WHO) defines palliative care as being an approach to improving the quality of life of patients and their families who face the problems associated with life-threatening illnesses. There are many ways in which palliative care manifests, but a key focal point is preventing and relieving suffering, often by means of early identification and the effective assessment of treatment of pain and other problems. Through the provision of palliative care, individuals and their families can experience physical, psychosocial and spiritual benefits. However, there is huge variability between countries in the development of palliative care. These differences have an obvious bearing on the outcomes for people dying in care or nursing homes, and it is therefore essential that a consensus on best practice be established. Such a consensus should naturally be evidence-based or evidence-informed to encourage the forming of it more rapidly. In addition, the fact societies across Europe are ageing, necessitates an improvement in the quality of life and the quality of dying for patients.
ASSESSING THE EFFECTS OF PALLIATIVE CARE

With these points in mind, a consortium from across Europe has been developed to tackle many of the challenges associated with palliative care. Entitled PACE, the consortium is composed of eight research institutes across six European countries. A total of four European organisations are responsible for the impact and dissemination of the findings. Together, they will perform three separate studies.

The three studies are, firstly, mapping palliative care systems in care and nursing homes across Europe. Secondly, the consortium will perform a large-scale representative study to examine quality of dying and palliative care in care and nursing homes in six European countries. Finally, PACE will study the impact of an innovative trial called ‘PACE Steps to Success’, which aims to improve the integration of palliative care in mainstream nursing home care.

Professor Dr Lieve Van den Block is coordinating the PACE project. ‘One study investigates deceased residents in a representative sample of care and nursing homes in six countries,’ explains Van den Block. ‘In this, we compare countries with different healthcare systems, and with – or without – formal palliative care structures in terms of resident outcomes, quality of end-of-life care, and staff knowledge and attitudes.’ From this, the team hopes to gain an understanding of which countries, systems and practices might be related to higher quality of dying. It is as much about changing the culture of care homes, as it is the attitudes of individuals within them. Thus, a crucial element of successful implementation of the findings is to ensure the management and leading decision-makers of care homes are also enthusiastic; the changes PACE hopes to bring about must be supported from the top down. In light of this, the team plans to conduct extensive process evaluations that will enable them to measure the level of implementation, and give them ideas for improved implementation in other long-term care facilities.

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CHANGING THE CULTURE OF LONG-TERM CARE FACILITIES

While the ultimate goal of PACE is to have an impact on patients in long-term care facilities, the interventions that PACE are developing are specifically aimed at changing the attitudes, knowledge and skills of the staff that care for these patients. Although the study has not yet been completed, there has been encouragement in terms of the enthusiasm of the care staff the team have spoken with. There is, however, some potential difficulty in the staff finding the time to use the tools developed by PACE, as well as the many personnel changes that make sustainable implementation difficult.

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