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Europe-wide survey reveals priorities for end-of-life care

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A survey of over 9,000 people in seven different countries across Europe has shown that the majority would want to improve the quality of life in the time they had left, rather than extend it. The survey reveals attitudes across Europe for dealing with serious illnesses such as cancer, and issues raised when caring for a close friend of relative in the last few months of life. The research was carried out as part of an EU-funded project led by researchers from King's College London.

The telephone survey of 9,339 people was carried out to explore attitudes to end of life care in seven European countries: Germany, England, the Netherlands, Belgium (Flanders), Portugal, Spain and Italy. The survey showed that 71% of people said they would want to improve quality of life for the time they had left; 4% would like to extend life; and 25% said both quality and extending life was equally important. Across all countries in the survey, 'being in pain' was the symptom or problem that was of most concern, followed by 'being a burden to others'

The results of the survey will be discussed by policy makers, research funders and experts in palliative care on Thursday in Brussels at a symposium held by PRISMA – a consortium of experts from nine European and African countries, led by King's College London. The PRISMA group says greater attention must be paid to quality of life alongside potentially life-prolonging treatments, as the survey shows quality of life is important to people, often more so than extending it.

A group of leading researchers and clinicians, led by Professor Irene

Higginson OBE at King's College London, will call for delivery of end-of-life care across Europe to be reviewed in the light of the results, and investment in research increased, in order to meet people's needs more effectively at the end of their lives.

Professor Irene Higginson OBE, scientific lead of PRISMA and Professor of Palliative Care and Policy at King's College London, said: 'There needs to be a fundamental shift in the approach to delivering end-of-life care across Europe. Although individuals' priorities and needs will differ, it is absolutely clear that people value highly the quality of the time they have left.

'What we need to see is a step-change in the way policy-makers and clinicians across Europe look at end-of-life care, and ensure that people's priorities and needs inform planning and delivery of these services. Together with an increased investment in scientific research into end-of-life care, this will really make a difference to the quality of people's lives as they face their last weeks and days.'

The PRISMA group is calling for a change in the way all health care professionals working with patients with advanced diseases measure things which are important to patients and their families. Currently, the focus is on physical tests such as x-rays, scans and monitoring bloods. But PRISMA warns that, although important, these routine tests may miss the effects of the illness on the person and their family. A move towards assessment of symptoms, psychological, social and spiritual needs is urgently required in order to ensure an adequate response to patient and family priorities.

PRISMA compared the survey results with the views of nearly 800 clinicians working in end-of-life care and recommended a five-pronged approach to tackle: symptom control; emotional well-being; family support; choice for where to be cared for; and information needs.

Professor Stein Kaasa, a member of PRISMA, Professor of Palliative Medicine and an oncologist at the Norwegian University of Science and Technology said: 'It is now the responsibility of all clinicians working with patients with life-threatening diseases such as advanced cancer, to measure and lead others to measure the outcomes of their work against what matters to patients, so they know they are on the right track to providing quality care.'

Provided by King's College London

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