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### Should palliative care be rebranded?

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# EDITORIALS

## Should palliative care be rebranded?

Changing perceptions is more important than changing names

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Nearly 30 years after the World Health Organization first defined “palliative care,” we are no closer to agreeing what the term means.

Palliative care has driven major improvements in the care of people with life limiting illnesses and fostered more open public discourse about death and dying. National and international policies advocate better access to palliative care for everyone who needs it. The Lancet Commission goes further, describing it as a basic human right in the face of unrelieved suffering affecting millions worldwide.<sup>1</sup> The 2018 Astana Declaration endorses palliative care as an essential component of primary healthcare worldwide: “Promotive, preventive, curative, rehabilitative services, and palliative care must be accessible to all.”<sup>2</sup> Yet, stigmatisation of the term among patients, professionals, and the public continues to counter positive messages about its benefits.<sup>3</sup>

By 2002, WHO had a new definition, which is still in use: “Palliative care is for people with life threatening illness; prevents and relieves suffering through holistic care; and is applicable from early in the illness.”<sup>4</sup> The central tenet has always been its focus on what matters to the person and those close to them, captured by the term “quality of life.” The emphasis is on personal, values based care instead of disease centred concepts of illness and treatment. The lived experiences of health related suffering are afforded greater significance.<sup>5</sup>

UK guidance uses the term “palliative and end-of-life care” more specifically for people in the last year of life, even though prognostic judgments are problematic.<sup>6</sup> The intention is to show that palliative care is relevant well before the final weeks of life. Paradoxically, however, combining these terms links palliative care inextricably with imminent death and dying in the minds of professionals and the public. Studies report negative views about receiving palliative care among patients and families, particularly those with no direct experience of these services.<sup>7,8</sup> The Royal College of Physicians emphasises the

importance of talking about dying to help tackle professional discomfort about introducing palliative care.<sup>3,9</sup>

Could a change of name change these negative perceptions? One paradigm refers to “early” or “integrated” palliative care to emphasise that it can begin at diagnosis. Palliative care is even being rebranded to make it appear more socially acceptable. “Enhanced supportive care,” for example, delivers specialist palliative care from within oncology services. It is not clear, however, if this is helpful or confusing for patients and families.<sup>10</sup> “Best supportive care” is another euphemism that can have adverse consequences unless that care is well coordinated, and includes teams from both primary and secondary care who have easy access to palliative care specialists if needed.<sup>11</sup>

Use of language matters, and getting it right or wrong can promote or prevent an ethos of shared endeavour across multidisciplinary teams. Negative language in the context of palliative care has the potential to cause distress and harm to patients—talk of “treatment withdrawal” or “futile treatment,” for example, can make people feel abandoned or devalued. Terms such as “ceiling of treatment” or “ceiling of care” are still used by professionals and in good practice documents to indicate that patients who are not expected to recover fully will not benefit from intensive treatment. This language can give the impression, however, that a person is being denied potentially helpful interventions.<sup>12</sup>

Consistent, positive language is better for everyone—in team working, shared decision making, and when offering palliative care. Positive communication means finding out what matters to patients and families, before discussing the benefits, realities, and limitations of all the available options, framed in a way that maintains hope.<sup>13,14</sup>

Good palliative care should be available from early in the course of a final illness, whatever its underlying cause, and many clinicians are acquiring greater expertise. Training opportunities

and required curricular competencies go a long way, but it is equally important that healthcare professionals value and invest time in this important aspect of good clinical practice.<sup>15</sup> Palliative care specialists play a key role in providing expertise, education, and support for other teams. They should be introduced to patients and families in a positive way—as an opportunity for specialist advice on managing pain and other symptoms, for help with complex decision making, and in preparing for the future.

As the recent Astana declaration makes clear, palliative care is integral to the goal of universal health coverage. Instead of changing its name, we should work to change professional and public attitudes from at times negative to universally positive. In this way we can help ensure that vital services, expertise, and the principles of good palliative care are available to everyone.

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