



Blog of the Month

AMPJ Blog of the Month: December 2022 Edition

Dr Jenny Terry is an Internal Medicine Trainee from the Peninsula region. For this month's APMJ blog post, she shares with us a recent piece submitted for her PG Cert in Palliative Care on the future of the speciality. Her interests include Palliative Medicine, Medical Education and Medical Humanities. Thank you, Dr Terry!

Interested in submitting something yourself, have any comments or questions on this piece? Email submissions.apmj@gmail.com or tweet us @APMJuniors

‘What Is Palliative Care?’: The Evolving Specialty

Introduction

- The speciality of Palliative Care is a remarkably recent addition to modern medicine, having been established in the UK in 1987 and recognised as a fundamental responsibility of health systems at the 2014 World Health Assembly.¹
- Since its creation, its aims and scope have evolved - and are likely to continue to do so.
- In this article we compare the 1990 and 2002 World Health Organisation (WHO) definitions of palliative care and explore how these might be further refined.

WHO Definitions



Palliative care is the active, total care of patients with progressive, far advanced disease and limited life expectancy whose disease is not responsive to curative treatment. It refers to the control of pain and of other symptoms as well as the treatment of social, psychological, and spiritual problems.² **(WHO 1990)**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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).³ **(WHO 2002)**

Search

- Simple searches were performed on Google Scholar and Ovid database for 1) “definition of palliative care”; 2) “‘definition’ AND ‘palliative care’”.

Discussion: Definition Strengths & Weaknesses

WHO’s 1990 definition expresses the essence of palliative care as it is practised today, raising the idea of ‘total care’ with physical, psychological, social and spiritual needs being addressed.

A comparative strength of this early definition is its clarity: the ‘active total care’ of a discrete subset of patients is easily conceptualised. The switch to the more passive term ‘approach’, plus the broadening of scope to include both patients and families facing any life-threatening illness, makes the later definition less distinct.

A notable weakness of the 1990 definition is its narrower scope. Including only patients with ‘far advanced disease... not responsive to curative treatment’ lies at odds with the current recognition that early palliative care involvement is desirable, improving symptom burden and quality of life and reducing unnecessary hospital admissions.^{4,5,6}

In the 2002 definition, WHO shifts the focus from 'advanced' to 'life-threatening' illness, and specifically acknowledges the importance of 'early identification' and management of problems. However, including early identification as a defining characteristic of palliative care is problematic; while this is a laudable goal, late presentation and identification may be unavoidable in practice, and treatment of late-presenting problems should still be referred to as palliative care.

While broadening the scope is important, in excess it has the potential to leave palliative care so nebulous as to be confusing for providers, policy makers and funders, as well as patients and families.⁷ Having clear boundaries can help ensure that palliative care providers' skills and expertise are utilised effectively in the areas of most need, and not stretched too thin.

Family members' needs are acknowledged in the later definition. This is an important addition - palliative care improves quality of life for families too⁶ - but is not without criticism. Randall discusses the 'distortion' of original palliative care values, asserting that there is now 'a doctrine that relatives are as much objects of palliative care concern as the actual patients'.⁸ The prioritisation of individual vs family needs is likely to vary between cultural settings.^{4,8}

Lastly, we must note the controversial use of the word 'impeccable' in the 2002 definition. Asserting this unattainably high standard as an essential tenet of palliative care opens the door to disappointment and criticism from palliative care providers and family members alike.

Discussion: Further Refinement

To refine the 2002 definition we propose removing the word 'impeccable' (or amending this to the more achievable 'high-quality'). The phrase 'early identification' could also be removed, as although this is desirable it is not a universal element of palliative care.

The International Association for Hospice and Palliative Care (IAHPC) developed a consensus-based definition of palliative care in 2019, involving >450 palliative care workers worldwide.⁷ Participants had significantly different perceptions, ranging from those who felt palliative care describes the relief of all suffering to those who believed it is limited to the care of individuals with a very limited remaining life span.⁷ This will likely remain a complicating factor in defining palliative care.

Palliative care is the active holistic care of individuals across all ages with serious health-related suffering due to severe illness and especially of those near the end of life. It aims to improve the quality of life of patients, their families and their caregivers.⁷ (IAHPC 2019)



Conclusions

Compared to its predecessor, WHO's 2002 definition includes a broader view of what palliative care encompasses, and promotes early palliative care input and consideration of family members' needs

Its flaws include lack of clarity and a requirement for 'early identification' and 'impeccable' assessment and treatment of problems

There is significant scope for further refining the WHO definition of palliative care

IAHPC has developed a consensus-based definition of palliative care which addresses many of the flaws identified in the 2002 definition

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