


Essay/Personal Reflection

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Author for correspondence:

Ravi Prasad Varma, Achutha Menon Centre for Health Science Studies, Thiruvananthapuram, India.
E-mail: rpvarma@sctimst.ac.in, dr.rpvarma@gmail.com

Sreedevi Warriar, M.Sc.^{1,2} and Ravi Prasad Varma, M.D.³ 

¹Pallium India, Thiruvananthapuram, India; ²Cardiff School of Medicine, Cardiff, UK and ³Achutha Menon Centre for Health Science Studies, Sree Chitra Tirunal Institute for Medical Sciences and Technology, Thiruvananthapuram, India

“It is not really health ...” is a recurring trope about palliative care in medical and public health circles in Kerala, India, and possibly in other parts of the world. As it happens, Kerala finds mention in one of the first global documents on palliative care — the World Health Organization Technical Report Series on cancer pain relief and palliative care, 1990 (WHO, 1990). Today, Kerala is also one of the few regions in the world that can boast of a “model” of palliative care (Kumar, 2007). In these circumstances, we wish to reflect on the occasional statement of lack of acceptance of palliative care and the plausibility of an epistemic schism in the acknowledgement of the discipline within medicine and public health.

Palliative care and the clinical medicine paradigm

Both approaches cater to sick persons who solicit care. However, there are several important differences that may be considered as reasons for the reluctance in accepting palliative care as medical or health related.

Unaccustomed spaces and team members around care

Interactions in palliative care often happen at patients’ homes, outside conventional institutional spaces of medical or health care. The palliative care approach does not shy away from the juxtaposition of social, spiritual, or religious considerations alongside physical and psychological issues. Decision-making processes aim for co-equality of the doctor with the patient and significant others. The interactions are, therefore, permissive to and often incorporates persons and systems with non-medical/non-health attributes like religious persons, friends, or neighbors. Communication thus becomes central to the palliative care process.

Unorthodox nature of the care discourse

Palliative care consultations are much more recursive than usual medical consultations. Both provider and patient shape the interaction on near-equal terms. The story of a recent consultation with Patient A (named so for the sake of anonymity) illustrates this point: “Ration rice (State-provided free rice) is not good for us to eat ... we don’t eat it. We use it for making chicken feed, doctor. You need to mix one-part ration rice with ...” reeled off Patient A from the wheelchair. The palliative care doctor came off enlightened on preparation of chicken feed and the need to house different species of poultry in different pens. One could easily abrogate such engagements as not strictly within the realm of medicine or health. However, the above said exchange happened during a consultation for worsening neuropathic pain in progressive spinal muscular dystrophy along with diabetic peripheral neuropathy. The interaction extended to assessment of nature of the pain, dermatomal distribution, and medication history. Patient A’s palliative care record does bear the Greek, Latin, and alphabet monikers (e.g., allodynia, TCA) characteristic of biomedical expression. Palliative care continues in the approach of medical manipulation of the body, but tries to take into consideration the whole person. But the story of Patient A, a parable on being empathetic, would evoke a different imagery than that arising from a conventional physician–patient interaction.

Limited conformity to disease-specific theory

Palliative care practice is less contingent on disease-specific theory that usual medical practice. Consider a patient with intestinal obstruction. Conventional management would imply laboratory evaluation and imaging followed by conservative management with electrolyte correction, antibiotics, bowel rest, or surgical management as indicated (Jackson and Cruz, 2018). However, a palliative care approach would be adopted when the classical approach is likely to be futile as in the case of advanced malignancies. The focus, then, would be on the symptoms — vomiting, pain, and constipation. Clinical assessment would be around pain, nature of

vomiting, and clinically suggestive type of obstruction. Investigations would be minimal and depending on accessibility and affordability, and often limited to an X-ray abdomen in erect pose. Treatment approaches like dexamethasone are central but do not find a place in usual medical discussions on the topic (Feuer et al., 1999). This is not to say that palliative care is theory-free and approaches to entities like whole body pain and complex regional pain syndromes, and interventions aimed at pain relief are increasingly becoming theory-informed (Denk et al., 2014).

Different position of values

The ontological prior of palliative care remains clinical medicine but the values often differ. Death for conventional medicine is an event to be prevented at all cost. When all curative options fail patients are often allowed to go home, but the medical records may have phrases like “discharge against medical advice” as reported by Gursahani (2016), or at times it is “referred to <name of a tertiary hospital>.” This suggests that medical professionals may be unsure of how to handle worsening of disease and anticipation of death. Palliative care professional, however, embrace the reality of death and dying. Care is through relational processes that help the patient and the family to come to terms with the realities they face, often alongside other approaches the patient and family endorse, like religious practices. This often conflicts with the meaning and values of curative medicine that is characterized by proactive interventionism applied to clearly delineated physical or physiological compartments with an instrumental rationality.

Public health and the care of incurable conditions

It is somewhat easier to reckon the divergence of palliative care from public health than from clinical medicine. Winslow in 1920 defined the public health approach as one aimed at preventing disease, prolonging life and promoting physical health and efficiency (Winslow, 1920). Palliative care conceptualizations begin with irremediable problems and clearly state that there is no attempt to prolong life. Death for a public health practitioner would probably imply “verbal autopsy into cause of death,” while a palliative care practitioner would contemplate “bereavement support.” However, the preceding century has witnessed marked demographic and epidemiological transition and chronic medical conditions have emerged as important public health issues. Consequently, even if we consider these two paradigms to be mutually exclusive, several parallels can be drawn between the two.

In public health, understanding a disease independent of the social, economic, and political setting is often denounced and the palliative care approach resonates with this remarkably. The “Chinese boxes” of the eco-epidemiological approach promulgated by Susser and Susser (1996) and the “circles” of palliative care of Abel et al. (2013) differ in their core functions, but both move outward from individual to structural layers or circles of factors that underpin the central outcomes they aim for. The community centred approach for health and wellness proposed by Public Health England, an executive agency of the Department of Health and Social Care in the United Kingdom, makes a strong case for person and community centred ways in public health (South, 2015). The report mentions capacity building, peer roles, partnerships, and community resources, and the neighborhood network for palliative care in Kerala is an approach on par with this (Sallnow et al., 2010).

Moreover, the discourse on welfare and development has included disability and suffering, recognizing the setback that these render to the development agenda. Powell et al. (2015) have described the increasing coherence of palliative care and global health. This continues with the recent evidence on chronic pain syndromes from the Global Burden of Disease evidence (Jordan et al., 2019), and the lancet commission on serious health-related suffering (Sleeman et al., 2019).

Discussion and conclusion

Balfour Mount introduced the term “palliative care” in 1973 and considered palliative medicine as a rich combination of clinical pharmacology, rehabilitation medicine, and internal medicine (Hamilton, 1995). In November 1987, this field had become a medical speciality in UK called “palliative medicine” and Ventafridda in 1991 declared that “a new medicine has been born” (Ventafridda, 1991; Pastrana et al., 2008). The palliative care discourse is textured across different perspectives, medical, social, and spiritual. But doctors are not very comfortable beyond the language of structure and function (Cassel, 1982). This may be the reason for the remonstrance mentioned at the start of this essay. This brings to mind the statement that “medical dogma can be slow to change.” — attributed to the Nobel Laureate in Medicine, Jean Dausset (Ameisen, 2009). The increasing inception of Palliative Medicine into the medical curriculum should result in a circumspect endorsement of palliative care by the medical faculty.

With respect to public health, the palliative care approach may never become fully prototypical of this discipline like maternal health did. Yet, a co-existence of palliative care in the post-modern approach to health effectively exists at least at some level. Concepts like compassionate cities and dementia-friendly communities are increasingly being developed and implemented. It may be prudent to recall that Winslow, along with stating a definition for public health, had called for closer correlation between clinical medicine and public health across the “artificial boundary line.”

Implicit dismissals of the discipline within medical and public health circles may result in sub-optimal development of the discipline. We, nevertheless, conclude with the recollection that resistance to change is part of the normal human nature. Palliative care professionals must continue to work toward demonstrating how humanizing the complexities of the biomedical and health paradigm may be beneficial to individuals and communities.

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