

# Information and support: implications for developing palliative care programs

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Throughout the world there is an unprecedented growth in clinical palliative care services which offers the potential to improve the quality of life and reduce the burden and distress of advanced disease (1). In many countries, these services are closely linked to oncology departments, where they form part of an integrated program of care for patients with cancer. It has been strongly argued that improving the integration of palliative care services within oncology enhances the experiences of patients and their families, and moreover, these types of services are cost-effective for health care systems (2). This is especially important in resource-poor regions where the majority of cancer patients have advanced disease at diagnosis and therefore interventions with curative intent have less to offer (3). There is even some evidence that providing patients with palliative care in addition to cancer treatment reduces symptom related distress and has a small survival advantage (4). However, there is relatively little research that charts the growth of hospital based palliative care services.

The history of palliative care needs to be understood in relation to the social context, culture and health-care system in which it is situated. Clark has argued that in a British context, hospice and palliative care services can be seen as a response to an apparent neglect of the chronically ill and dying patient in mid twentieth century hospitals where medical attention was directed more strongly towards those patients who had potentially curable diseases (5,6). In comparison he argues that different drivers have led to the development of palliative care in other countries such as the United States of America (USA); namely the imperative to treat, even when the benefits appear to be marginal and the burden of treatment onerous for patients, and financially demanding upon their families.

This 'imperative to treat' has given rise to the notion of 'medical futility' which is acknowledged to be a problematic and contentious concept (7). In this context, palliative care is seen as offering better symptom management, psychosocial support and attention to existential concerns than conventional approaches. Moreover, in the USA, there is a distinction between admission to hospice programs which require relinquishment of curative treatment and a prognosis of less than 6 months to obtain financial reimbursement; and palliative care which may be provided concurrently with anti-cancer treatments.

It was therefore with considerable interest that I read the paper by Dev and colleagues (8) which documents the first decade of an academic palliative medicine program based in a large cancer facility in Houston, USA. This paper provides a number of helpful insights into the staffing and resource required to establish hospital based specialist palliative care, and it charts the up-take of services by patients and the referral patterns of oncologists. The authors show that initially referrals and 'clinical encounters' were modest and only rose sharply after year 3 with a small annual increase thereafter, until a further larger increase in Year 10. This indicates a number of factors relating to new service implementation; namely that it takes a number of years to introduce a novel service into a hospital; to raise awareness amongst medical and other health care staff, to over-come barriers and misconceptions about the role and function of palliative care, and to gain patient and family acceptance of these referrals.

## What's in a name?

It is well known that terminology in palliative care is

problematic and there is a lack of consensus on definitions of key terms, which means it is difficult to make international comparisons (9). There have been some attempts to achieve consensus on norms and standards across European countries by the European Association for Palliative Care, for example (10,11). Dev and colleagues (8) attribute increases in referrals to a change of name in Year 7 from palliative care to supportive care. They argue that the name 'supportive care' is more acceptable to referring oncologists and to allied health professionals who closely associate palliative care with end-of-life or terminal care, and provide some survey evidence to support their claim. It could be suggested that 'supportive care' is a euphemism. This raises a number of challenging dilemmas about the extent to which the use of euphemisms should be encouraged. In many cultures and languages, there are many euphemisms for topics that are regarded as anxiety provoking and threatening. For example, there is a rich repertoire of euphemisms for death and dying, in English and Chinese. Indeed, arguably 'palliative care' is also a euphemism, developed in a Canadian context where the terms 'hospice' or 'terminal care' were seen as inappropriate. The term 'supportive care' has a comforting and comfortable feel, perhaps well suited to a death-denying society, and colludes with physicians and patients desires to temper the reality of their situation. This appears to be in rather stark contrast to evidence that open disclosure of diagnosis and prognosis is preferred by most cancer patients and has become standard communication practice in most 'westernized countries' (12). It may be that our patients and families are rather more resilient and able to confront the future than we give them credit for, and they collude with the use of euphemisms to 'protect' health professionals and to appear grateful (13).

Finally, these limitations do not reduce the organisational or clinical relevance of the presented results. The sharing of evidence about the opportunities and barriers to the development of palliative care services should be promoted. It is also helpful to present these evaluation data against the socio-economic and geo-political contexts in which the services arise. For example, it cannot be assumed that service development always follows an upward trajectory of growth and more information it needed from services that are no longer sustainable or require major reconfiguration to remain viable. This information may also help to reduce health-care costs by better targeting of resources, and foster the design of more feasible service development plans.

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