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So what is so special about specialist palliative care?

Abstract

Introduction. Palliative care is primarily concerned with improving the quality of life of patients with life-limiting diseases. End of life care represents the care of patients approaching the very end of life and has traditionally been and will likely remain a focus of specialist palliative care, there is a shift towards helping patients live to their fullest until they die.

Discussion. As a result, there is an ever-increasing number of early referrals from colleagues working in other specialities allowing specialist palliative care to offer interventions that can positively impact the quality of their lives. Multiprofessional specialist palliative care training has been key to developing the human resource in the speciality. There is a dearth of specialist palliative care human resources across the globe and as referrals increase, we will need more palliative care specialists to keep up with the increasing workload. Moving forwards all health care professionals will have an increasing role to play in the provision of palliative care.

Conclusions. There has been an increasing body of research in palliative medicine that has informed the practice of palliative care. Given the paucity of the evidence base in the speciality, we need to invest more time and resources into this area as well.

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Key words: palliative care, enhanced supportive care, research, quality of life

Introduction

Palliative care is primarily concerned with improving the quality of life of patients with life-limiting diseases. Whilst most of the palliative care is delivered by non-specialists such as general practitioners, there is an increasing number of palliative medicine specialists and hospice care providers for end-of-life care. Figures from the Hospice UK show that more than 225,000 individuals with advanced life-limiting diseases are supported by hospices in the UK [1]. In keeping with this change, palliative care has had to move on from simply dealing with "terminal or end of life care" to managing fairly complex medical and psychosocial issues of patients with an advanced incurable disease at an earlier stage. Even though for the terminally ill, end of life care will always be within the domain of specialist palliative care, there is an increasing focus on helping patients to live well until they die. Putting it in another way, palliative care is increasingly about enabling and supporting patients to live to their fullest before they die. So what is so special about specialist palliative care and how has this role been shaped over time?

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Discussion

Even though there is no evidence-based definition of specialist palliative care, a study involving clinicians in Australia was able to gain consensus on certain items that defined specialist palliative care. Specialist palliative care physicians were deemed to have advanced knowledge of dying and the skill to manage complex symptoms. In addition, palliative care specialists were also involved in specific tasks such as managing families holistically including bereavement support and had advanced communication skills training [2].

Over the years there has been increased recognition of specialist palliative care by other medical specialities and commissioners of services. This has led to an ever-increasing number of referrals to specialist palliative care from other specialities in hospitals and general practitioners. Patients with cancer are being referred at an earlier stage allowing specialist palliative care to offer interventions that can positively impact the quality of their lives. So, for example, working concurrently with oncology is now seen more commonly in cancer centres than perhaps a couple of decades ago when patients were usually referred only when they were terminally ill. This model has been referred to as non-hospice palliative care [3] or enhanced supportive care [4]. The landmark paper published in the New England Journal of Medicine in 2010 highlighted the benefits of early palliative care intervention in metastatic non-small cell cancer patients. In this non-blinded, randomised study the authors were able to show a demonstrable increase in the quality of life, an improvement in mood and survival of patients, in the arm that received both the standard oncology treatment and palliative care intervention [5].

Palliative care specialists are now an integral part of oncology multidisciplinary team meetings such as lung cancer, upper gastrointestinal cancers and carcinoma of unknown primary since patients with these cancers often have a relatively short life expectancy and a high symptom burden [6]. Even though people with cancer still represent most referrals to specialist palliative care, there has been a gradual increase in non-cancer referrals to the speciality as well [7, 8]. Hence conditions like dementia, motor neurone disease, multiple sclerosis, Parkinson's disease, end-stage renal disease, heart disease or chronic obstructive pulmonary disease are now on the caseload of virtually every specialist palliative care service. An evidence review by the National Institute for Health and Care Excellence in the UK showed that patients who were referred early to palliative care were more likely to have their choices met in terms of preferred place of care and death which is an important outcome measure of their quality of life [9]. At the national level in the UK, clinical standards for the provision of specialist palliative care have been spelt out for both the providers and commissioners of services [8].

The formal development of curricula and training in various disciplines has been key to developing the multi-professional human resource in the speciality. The multi-professional teams include palliative medicine consultants, specialist nurses, social workers, and psychologists who have specialist palliative care training in their areas of expertise. This has come about as the speciality has evolved [10]. In the UK the specialist training period for doctors, for example, is 4 years leading to an award of completion of the certificate of training (CCT) in palliative medicine which allows them to work as consultants in the speciality and provide leadership for their teams.

Finally, all specialities draw on education and research which informs their practice. Anecdotal medicine has been superseded largely by evidence-based medicine which is based on robust research methodologies such as randomised controlled trials and systematic reviews. Research in palliative medicine, however, poses several challenges due to the complexity and diversity of the patient population, limitations in research methodology, inadequate sample size and high attrition rates [11]. However, despite these limitations, there has been an increasing body of research in palliative medicine over the years. The Oxford textbook of palliative medicine is a testament to the scholarly work of numerous researchers over the years. There is in addition a plethora of conferences, educational material and palliative care networks in all continents and regions of the world available to generalists and specialists alike [12].

The bulk of palliative care is and always will, be provided by general practitioners. Specialist palliative care input should be for the few that are complex i.e., the metaphorical tip of the pyramid. Defining complexity has been a challenge and is a major determinant of the decision to refer to specialist palliative care. In some cases, such as recurrent hospital admissions and exhaustion of treatment options for heart failure and progressive renal impairment have signalled a change in the direction of treatment and has been a prompt for referral to palliative care. Similarly, in patients with dementia, the onset of progressive dysphagia is usually considered an indication for referral to palliative care. However, it is not always so clear and clinicians often have differing views on when to refer to specialist palliative care. Given that studies have demonstrated a benefit in the quality of life of patients who were referred early to palliative

care, perhaps its integration with other specialities is the way forwards [13]. There remain many patients that are missing out on the benefits of early palliative interventions. This is true for patients with a diagnosis of both cancer and non-cancer [14].

The changing landscape with cancer and its treatment means that patients are living longer. Consequently, there is an increasing number of patients who require palliative interventions to enable them to live as fully as possible. Early intervention by palliative medicine, also referred to as enhanced supportive care, has already demonstrated an improvement in quality of life of patients, improved communication and a reduction in health care costs and should be the logical way forwards for specialist palliative care in both the inpatient and ambulatory care settings [15]. Given the ever-increasing number of patients requiring palliative interventions, all health care professionals will have an increasing role to play in the provision of palliative care.

Conclusions

Each speciality will need to incorporate the basic understanding and principles of palliative care provision, within their training curricula. Specialist palliative care should therefore invest more in the education of other specialities to enable them to better meet the needs of their patients. There is a dearth of specialist palliative care human resources across the globe and as referrals increase, we will need more palliative care specialists to keep up with the increasing workload [16]. The COVID-19 pandemic has fast-forwarded the use of technology in health care settings and this has enabled us to better share information and to deliver care to patients via video consultations. Specialist palliative care should embrace and ramp up the use of such technologies which will make it possible for us to reach out across the globe and provide education, training and clinical services to patients. This is particularly true for areas with limited or non-existent specialist palliative care provision. Finally, given the relative paucity of the evidence base in the speciality, we need to invest more time and resources into this area. There is an increasing acceptance of a variety of epistemological frameworks used in palliative care research and these should be seen as enriching and enhancing our understanding of end-of-life care [17]. The use of a mixture of quantitative and qualitative research methodologies, for example, can provide us with results that are clinically meaningful in a palliative care population. Collaboration in education and research across continents and cultures will be key to success.

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