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Current Perspective

Investment of palliative medicine in bridging the gap with academia: A call to action

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ABSTRACT

Palliative care and palliative medicine define a relatively new medical discipline that has arisen in response to the need for better approaches to caring for people with advanced life-limiting illnesses. For professional, managerial, and cultural reasons, it has evolved largely outside of academic structures. As the discipline has matured, its needs for education, training, intellectual discourse, evidence development, and new science have become more apparent. Traditional academia remains skeptical about the role of palliative medicine, and bastions of palliative medicine expertise in universities have been slow to develop. Yet the engagement of the academic sector in palliative medicine has distinct benefits: (1) promoting the exploration of the culture, humanities, and science of the discipline; (2) generating evidence to support practice; (3) creating a legion of educators to train a palliative medicine workforce and to inform clinical colleagues of the role of palliative medicine; and (4) providing order and direction to the discipline's development. A roadmap leading to better engagement between palliative medicine and academia is needed. Examples of developments that could help bridge the two domains include: standardisation of terminology and clarification of boundaries of influence; focus on high-quality research that will generate robust evidence to support clinical decision-making; and clear definition of outcomes, with measures that are understandable across medical disciplines.

1. Introduction

In recent years, palliative care and palliative medicine have substantially grown, developed, and changed.[1–3] The growth of this field has been in response to the unmet humanistic and social need for providing support to individuals with incurable illnesses and who are suffering. Understanding the issues that are encountered in the end-of-life setting, such as accumulating symptoms, debility, and existential suffering that patients, families, and caregivers face, is becoming a primary topic in societies in which civil rights must be fully guaranteed.

Despite the widespread consensus concerning the significance of the issue, academia is not sufficiently involved. Palliative care has developed in an ad hoc style, frequently through grass roots efforts that are predominantly focused

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on day-to-day health care tasks, rather than through thoughtful, sequential progressions in response to intellectual exploration, new discoveries, and scientific implementation. The tension and distinction between 'palliative care,' which is the provision of health care for people with advanced life-limiting illnesses, and 'palliative medicine,' which is a formalised medical discipline with explicit principles, educational systems, and advancing science, directly results from the disorganised growth of the discipline.

In this social and cultural setting, academia seems to fail in its primary functions as the 'place for debate,' the arena of social questions, and the setting for the application of the scientific method to resolve problems; academia has failed to embrace its role of providing a forum to establish the 'fabric of culture' and explore it freely. Consequently, there are insufficient numbers of homogeneous and effective teaching programs and a non-representative number of figures with academic professional training.

What are the possible causes of this insufficient training and academic attention? Palliative medicine is poorly defined, and, instead, its humanistic components are its defining force, which have been predominantly developed through cultural, economic, and religious domains rather than through academic exploration and science.[4] In other words, palliative medicine cannot simply be inserted into the academic ranks as a discipline based on a clear, categorised, and uniform picture.

After exploring the key features of palliative medicine that have led to its disconnect from academia, we put forth a call to action to encourage a renaissance of academic investment and exploration into this field of human care.

2. The evolution of palliative medicine in 'leading countries'

The United Kingdom (UK), the United States (US), and Canada have pioneered the development of modern day palliative care and palliative medicine. In particular, the UK may be considered the cradle of the palliative care movement. The actions of these countries have been driven by a common moral question: 'What should be the standard level of services and competencies for the care of people with advanced life-limiting illnesses?'

Accordingly, many efforts to reach a high-level of service have been accomplished in these countries. In the UK, palliative care has become 'a cultural movement.'[5–7] In Canada, 'home care' palliative models first developed due to the wide geographic area.[7–9] In the US, single hospice care services have directed the development of a 'board of hospices.'[5] Although these methods are different, the final goal is common: the creation of standard professional levels of care for people with life-limiting illnesses by clinicians and professional caregivers.[10–14]

Unfortunately, even when referring to 'leading countries,' we must acknowledge that the development of a culture in palliative medicine has received a belated contribution from academia. In fact, the development of teaching and training programs has undergone a slow growth, and, moreover, these programs were not established until at least 20 years after the birth of the movement despite their importance in ensuring a systematic education in core principles, providing students with exposure to new science and the role of evidence to inform clinical practice, and granting 'academic dignity' to the discipline. In the UK, the palliative medicine specialty was created in 1987, although St. Christopher Hospice was founded in 1967.[5,7] In the US, sub-specialty recognition and a clear path for post-graduate education was established in 2006 by the American Board of Medical Specialties and the Accreditation Council for Graduate Medical Education, although the first hospice care service was started in 1974.[5,15]

Similarly, palliative medicine education has been historically lacking from the curricula of general healthcare education for physicians, nurses, social workers, and others. Therein, lectures and clinical exposure have only recently been added and are usually brief and unsystematic despite the fact that death is a universal part of healthcare.[16,17] The most developed example is Canada, where, in response to requests from the Association of Canadian Medical Colleges and of the Canadian Hospice Palliative Care Association, the public health system has provided the financial support of 1.25 million Canadian dollars over 5 years to organise and guarantee training programs in palliative care. These programs have been primarily directed toward medical students[18] and were previously provided in 17 faculties of medicine throughout the country.[8] A major challenge to the provision of more systematic palliative medicine education is the lack of a large cohort of trained academicians that are available to teach the discipline.

3. The evolution of palliative medicine in 'non-leading countries': an example from Italy

In Italy, the birth of palliative care involved a local event that was created outside of the university framework. Following the example of the home care program that was created in Milan in the 1980s, the so-called 'Floriani Model,'[e] palliative care organisations were developed in other areas of the country.[5,7] The movements were sustained by philanthropic organisations and by individual initiatives, and they were partially supported by the public health system.[7] In 2000, the Italian government launched the 'Hospices Program.'[19,20] The introduction of this process increased the disorder in a yet-immature context. Consequently, the country required assistance to create additional and different models and services. Meanwhile, academic input into this development was absent, yet universities were tasked with responding to the dilemma regarding 'What type of palliative care professionals should be trained and by whom?' Because they were unable to provide a proper answer and clear precedent from external models in 'leading countries' was lacking, the universities responded with heterogeneous courses and teaching programs. At present, there is a disarray of training proposals

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[e] The program resulted from a collaboration between several Italian organizations, such as the Unit on Pain Control of the National Cancer Institute, the 'Floriani' Foundation in Milan, and the Italian League against Cancer.

with disparate technical, clinical, and holistic approaches.[f] The outcome is a large number of professionals with different educational backgrounds and perhaps limited common competencies and comprehension levels. This kaleidoscopic situation does not allow for the development of a proper Italian culture of palliative care, palliative medicine, and action.

4. Additional factors that have increased the divide between palliative medicine and academia

The divide between the recognition and acceptance of palliative medicine within academia has been exacerbated by several additional factors. First, palliative care was generated outside of the 'fabric of academic medicine.' From an orthodox perspective, this might be considered by the 'ivory towers of academia' to be an unacceptable event. Consequently, part of the academic world still considers palliative medicine to be an extraneous work that was born outside of the university structures that is unsystematic, uncultured, and lacks a definite profile.

Second, this core prejudice is aggravated because palliative medicine represents an antithesis of the classical bio-theoretical model of medicine, which has a clear goal of cure, healing, and health. Palliative medicine primarily addresses how to care in a clinical situation that involves the consciousness that cure for the disease is impossible.[3]

Third, palliative medicine considers the whole of the social and human dimensions of a disease, and the actions are above the simple dimension of the illness as a biological event. Palliative medicine is 'bedside medicine' with an imprecise science and an intangible mission to avoid useless suffering. Accordingly, it represents a multidisciplinary clinical and humanistic area without a tailored dimension.[4]

Fourth, the core principles of palliative medicine, such as listening to narratives, life review, and 'being there,' cannot be easily tied to quantitative outcomes. This concept is considered to be distant from the vision of academic medicine, which is principally based on the mainstream idea of 'to do.'

Fifth, palliative medicine is positioned in a medical sphere in which efficacy is not measurable using standard quantitative parameters. Quantitative outcomes for palliative medicine are still under development, and the indistinct characterisations of impact through 'quality of dying' and measures of family satisfaction are poor approximations.

Sixth, palliative medicine has not historically demanded science to substantiate practice. Evidence supporting common clinical interventions is just emerging (e.g. the impact of palliative oxygen on breathlessness[21]). Basic science exploration of the mechanisms that underpin effective interventions is rare.[22]

Seventh, the language of palliative medicine is imprecise. Even from within the discipline, few agree on the meaning of various terms. The multiple definitions of palliative care indicate different care models across services and different groups of individuals who qualify for access to palliative care.[23] Words that are chosen by palliative specialists may be exclusionary to other areas of academic medicine and specialties outside of the field, and a lack of research standardisation reporting contributes to the disorganised understanding of palliative medicine and its scientific rationale.[22]

Eighth, there is significant diversity in professional 'palliative care operators' (e.g. physicians, nurses, psychologists, chaplains, social workers, and anesthesiologists). Moreover, palliative care professionals require a broad, 'creative' component, and this artistic feature opposes the high-tech model that is fostered by modern medicine and taught at universities; hence, it becomes difficult to identify an appropriate academic home for palliative medicine. Is it within medicine, nursing, social work, divinity, or across them all?

Ninth, the relationship between palliative care providers and other disciplines within the routine care of patients can be tense. Resistance to palliative care practices can be exacerbated when new palliative care teams try too hard and too fast to make changes in the patient treatment by limiting involvement of the primary care team. Negative interactions with subspecialists over the appropriateness of curative treatment at the end of life may disengage these important colleagues. Tension between palliative care providers and other medical disciplines that are already fully ensconced in the academic fabric of the university widens the divide between palliative medicine and traditional academia.

In this context, skepticism from academics may be understandable or at least understood. To further increase the diffidence of academia, some palliative care professionals and organisations have a propensity toward an excess of self-confidence and autonomy. Broadly speaking, this attitude can limit the diffusion of knowledge in the field by delaying cultural and social changes.

5. Bridging the divide between palliative medicine and academia

At present, the fast growth of palliative medicine services is occurring without a thoughtful plan and with a heterogeneous answer from the universities. Palliative medicine must thoughtfully consider whether there is a benefit to better alignment with academia. On the one hand, the avoidance of 'ivory tower medicine,' wherein pontification by academics is wholly disconnected from the reality of day-to-day practice is prudent; on the other hand, the engagement of the academic sector in palliative medicine has the following distinct benefits: (1) promoting the exploration of the culture, humanities, and science of our discipline; (2) generating evidence to support our practice; (3) creating a legion of educators to train our workforce and inform our clinical colleagues of the role of palliative medicine; and (4) providing order to the chaotic state of our discipline. A roadmap to better engagement between palliative medicine and academia is needed.

In this process, academia must acknowledge its role of 'moral authority' in defining the professional figures and competencies that are committed to social needs. With respect to the aforementioned attempts that have been implemented by leading countries, the history of the commitment of universities to palliative medicine might be considered to be a

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[f] Biasco G. Formazione universitaria in cure palliative. SICP annual meeting, Lecce, October 2009. Data not published.

dynamic process that is based on three stages: *absence*, *latency*, and *recovery*. In the *absence* period, academia is unable to identify the professional figure that is involved in palliative care or the role that he/she plays. During the *latency* phase, academia recognises palliative care as a model while analysing changes, so as to assist practices in different social and cultural contexts. At this stage, the university gives credit to a new type of professional. Finally, during the *recovery* phase, the university matures to the need for homogeneous training models with high-level standards. Legislators are also involved in this step.

Leading countries have spanned the gap between *latency* and *recovery* by raising the moral query of how to rigorously define the individual who is fully involved in palliative medicine. This definition is necessary to generate training and research programs, which are useful for the establishment of palliative care services that have homogeneous, high-quality standards. In this context, Michel Focault wrote in ‘The Birth of the Clinic’ that language education is greatly important.[24] Several universities in North America stress the requirement of communication skills in students[17]; this is an excellent place for a broader exposure to palliative medicine to start.

While on the forefront, leading countries still have a long way to go in moving palliative medicine closer to academia. To date, education and the development of service delivery models have been emphasised, which are fundamentally important but only initial steps in the right direction. To maintain progress, attention to the known factors that generate the divide is prudent. For example, as a profession, we must better emphasise the standardisation of terminology and clarify boundaries of influence. We must continue to push for better research and expect high-quality evidence to support our decision-making. We must define outcomes clearly and make sure that the measures are understandable across medical disciplines.

Non-leading countries like Italy should follow a similar path to bridge the chasm between palliative medicine and academia. This process starts with overcoming denial and influencing the educational process. Bruera have outlined that the ‘denial’ of palliative medicine as a medical discipline is the first obstacle in the diffusion process of palliative care culture.[25] In the ‘denial’ stage, individuals and organisations are not aware of the need for palliative programs or palliative medicine training in our universities and post-graduate schools for health professionals. To move past denial, palliative medicine providers must meaningfully contribute to currently available courses and voraciously advocate for enlarging their presence in the curriculum. Post-graduate programs should be organised by universities to reflect the cultural, economic, and social characteristics of a given country. It is extremely important that the established training programs refer to a common academic base and that the trained professionals therein are capable of playing specific roles in a multidisciplinary team. The coordinator of academic courses should be an individual with a competent but broad vision of the problem.[4] This critical investment will generate the required palliative care workforce and increase awareness of the discipline within universities. Without this basic investment, we cannot expect to reverse the denial, because palliative care predominantly increases its presence in academia via education and teaching, university officials should be encouraged to provide adequate political credibility within the university structures.[26,27] As non-leading countries observe a greater presence of palliative medicine teaching and education within universities, progress toward increasing research, improving discourse, and providing bridges among colleagues across various medical disciplines should follow in a similar fashion to that being undertaken in leading countries today.

6. Conclusions

Palliative care and palliative medicine have evolved in response to the need for better approaches to care for people with advanced life-limiting illnesses, which has resulted in a new medical discipline that is distinctly outside of typical academic structures. As the discipline has matured, the needs for education, training, intellectual discourse, evidence development, and new science have become more apparent. However, traditional academia is skeptical about the role of palliative medicine, and bastions of palliative medicine expertise in universities have been slow to develop. The development of a cultural process that bridges palliative medicine to academia requires time and deliberate investment, but the establishment of an effective and coherent approach is an urgent matter that is worth the associated effort. Leading countries that have already initiated coordinated education programs within university settings are trailblazers, and they can continue to bring palliative medicine and academia closer together through thoughtful investment and coordinated steps. Less-developed counties should follow suit, first focusing on integrated efforts to increase education, teaching, and visibility of the discipline within the universities.

Conflict of interest statement

None declared.

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