The challenges of evidence-based palliative care research

Applying an evidence-based approach to clinical care requires the clinician to understand the associations between research design and strength of evidence, assess and evaluate the relevance of the evidence and decide on its applicability to a patient’s context and wishes. In the palliative care setting, the ‘gold standard’ randomized controlled trial may be more difficult to achieve. Small sample sizes and higher attrition rates, coupled with a heterogeneous patient cohort and the need for a person-centred approach to management, can be a challenge for evidence-based palliative care research.

The WHO defines palliative care as ‘an approach that improves the quality of life of patients and their families facing the problem 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’. The National Institute for Healthcare Excellence provides a set of guidelines for an integrated approach to the provision of services to people approaching the end of life and their families and carers. The guidelines highlight the importance of a coordinated approach to the delivery of high-quality care to this group of people. The difficulty that arises when multiple providers are involved in the care of the patient is that there may be a lack of clarity around the benefits of some of the interventions proposed.

In the area of palliative care, there is no ‘one size fits all’ approach due to the severity of the disease prognosis of managing palliative care patients. Patients will have various journeys depending on the severity of their conditions and their health needs. Sawatzky et al. has highlighted the importance of an integrated approach for the successful delivery of palliative care to patients. The authors found that embedding a palliative approach into existing care delivery systems is crucial for successful collaboration of multidisciplinary teams. Elements of successful teams include effective communication within and across the multidisciplinary team, including the nonprofessional healthcare workers, and clinical approaches within the organizations need to be both comprehensive and compassionate.

Recent articles examining the challenges associated with palliative care research found that only a small percentage of the literature published clinical trials in the palliative care area. Moreover, most of the Cochrane reviews published in the palliative care area do not provide robust evidence to guide clinical practice because of the small number of studies in the field or the heterogeneous nature of the studies and in some cases their low quality.

Furthermore, many palliative care trials are observational in nature and observational studies lack the robustness of randomized controlled trials. Therefore, most published retrospective studies are unlikely to produce robust results due to their study design and the small number of participants included. However, this problem could be overcome by a collaborative research approach to recruit a sufficiently large number of participants to produce a high-quality observational study. This approach has been used by a number of studies conducted in the United States of America and Europe. This approach enables researchers to use a randomized controlled design in various sites of the study due to the possibility of recruiting a high number of participants. For example, the work by Spathis et al., which investigated the efficacy of modafinil for the treatment of fatigue in lung cancer patients was able to achieve a sufficiently high number of participants to undertake the study.

Another consideration in palliative care research is the indirect link between the evidence and practice. An example of this issue is the use of anticholinergic treatments for the management of excessive secretions at the end of life. A Cochrane systematic review of four randomized prospective studies found that there was no evidence to support the efficacy of this intervention. Despite the evidence and the limitations of the review (the small number of studies and the small sample size), this treatment is currently being administered to palliative care patients. Furthermore, qualitative studies with nurses in palliative care services found that family members are generally distressed by the sound from the respiratory secretions produced by these patients and nurses felt that they were obliged to administer these medications despite the lack of evidence.

The challenges in palliative care research raised in this article provide a small account of how difficult it can be to apply evidence-based medicine in palliative care.
research. The patient population, the individualized aims of the treatment and the trajectory of the incurable nature of the patients’ disease require a shift in thinking towards how to design and implement robust and rigorous research into palliative care that is person centred and also adds to the evidence base for palliative care practice.

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Conflicts of interest
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