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Palliative Care and Heart Failure: can implementation science help where the evidence alone has failed?

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Recent decades have witnessed a continuous stream of health care innovations, from diagnostic tools to therapeutic approaches, all promising a better quality of life for patients. However, the promised benefits are rarely experienced by patients, due to lack of attention on how to implement novel interventions in practice. Put quite simply, too much focus is put on trying to evidence effectiveness through a linear cause and effect approach, which fails to ignore the messy, non-linear world of real-life practice. What are we left with? Frustrated researchers, disillusioned clinicians and patients with continuing unmet needs.

With the alarming reality that gaps between publication and the adoption of research into practice can take up to 17 years, with only 14% of original research ever applied for the benefit of patient care, it is imperative that we accelerate the translation of evidence into practice.

In the case of progressive/advanced heart failure (when patients have refractory symptoms despite optimal medical or device therapy, or have limited options for escalation of therapy), a palliative care approach integrated with conventional/active heart failure management has strong evidence for improved outcomes for patients in terms of QoL, symptom burden, caregiver outcomes, and reductions in health service costs. However, patients with heart failure across Europe are still marginalised when it comes to receiving palliative care. Only 7% of heart failure patients received palliative care compared to 50% of patients with cancer, and less than 1% of patients who die in a hospice setting have a primary diagnosis of heart failure. This is despite having a symptom burden equal to, and sometimes greater than that experienced by people with cancer and other chronic illnesses. This resonates with a report by the Institute of Medicine (IOM) entitled Crossing the Quality Chasm, “Between the health care we have and the care we could have lies not just a gap, but a chasm”.

A recent editorial had a clear message – it’s time for change in relation to integration of palliative care and heart failure. Despite clinical guidelines and global policy support, two decades on palliative care is still a luxury for some patients, but not available to all who could benefit. Perhaps the clue to the key barrier can be found in the observation that “we have pockets of excellence driven by enthusiasts, but with no expectation of routine implementation”.

Might implementation science, the study of how to promote the uptake of novel, evidence-based interventions into routine care, hold any answers? There is a wealth of learning to be gained from the failed implementation and sustainability of the Liverpool Care Pathway for the Dying Patient (LCP) that draws some parallels with problems around routine implementation of integrated palliative care and heart failure.

Although a Realist Evaluation of the LCP, and several implementation models highlight the importance of enthusiasm i.e. a champion for successful implementation of novel complex healthcare interventions, they also caution that
enthusiasm of one or more key stakeholders is not enough for widespread uptake and sustainability. There are a myriad of other factors that can pose additional barriers, such as lack of appropriate education and training for practitioners implementing the intervention, organisational support, and the wider policy context to name but a few. Vital resources include internal facilitators, adequate time for planning, piloting and adapting the intervention. Hence, a whole systems approach is required prior to implementation, which addresses the needs of intended users, resources and any intermediary actions and external links such as inter-organisational networks in a co-ordinated programme, to help successfully embed a sustainable change in practice.8

Realistic evaluation (RE), a theory driven approach to evaluating complex interventions offers a valuable theoretical framework for understanding why, how and in what circumstances routine implementation is likely, or just as importantly, not likely to be successful. RE suggests that it is not programmes but peoples’ reasoning and decision making in response to programmes that influence change.9 Therefore, change requires winning hearts and minds. A key feature of this process is skilled communication – something that has proved elusive within this setting.10

Those championing the integration of palliative care in advanced heart failure’ need to work together to win the hearts and minds of cardiology practitioners and use a whole systems approach to break down the barriers to routine implementation and sustainability of integrated palliative care and heart failure care. A realist approach could provide a sound theoretical understanding of how the palliative care and heart failure intervention may bring about change, while at the same time identify barriers to implementation and sustainability. As per MRC guidelines, adapting to the local context is also crucial.11 Although implementation is the final link in the MRC development and evaluation process, the evidence shows it is the most crucial link for achieving patient benefit and should be considered prior to any research endeavour.

Implications for practice
- Patients with progressive/advanced heart failure are still marginalised when it comes to receiving palliative care, hampering evidenced benefits for patients, carers, and health service utilisation
- Work to identify what influences successful implementation of integrated models of palliative care and heart failure should be a priority
- A whole systems approach, identifying and addressing the needs of intended users is required to help successfully embed a sustainable change in practice

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