Advancing Palliative Care by Learning

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IN THIS BUMPER ISSUE OF JPM there is a wealth of new learning on how to improve palliative care, across the many settings where patients experience suffering or progressive illness. I read these at a time when palliative care has been placed under great scrutiny and challenge here in Europe, as the results and conclusions of the review into the Liverpool Care Pathway for the Dying Patient, ordered by the UK government, are released.¹ The Liverpool Care Pathway, or LCP, as it is commonly known, was developed in response to the problems of poor care in hospitals. It is, after all, important to attempt to do something, rather than only to describe the problem. It was not the first attempt at a pathway. It was promoted widely by the UK End of Life Care Strategy, and its use was seen as good practice. However, although when used properly and supported by palliative care and appropriate training it worked well, cases came to light where the LCP was used badly and some relatives were unable to discuss what was happening and believed the LCP was started when a person was not dying. Equally worryingly, review of individual cases suggested that although the paperwork was completed, in some cases what actually happened on the ground was different. This was made worse by the introduction of a system of financial rewards based on hospitals achieving target proportions of patients whose death was supported by the LCP. This process measure assumed a high proportion of patients being supported by the pathway equalled good care, rather than focusing on outcomes or testing the correct use of the LCP. An independent evidence appraisal conducted by the University of Nottingham found limited comparative evidence into the potential effects (benefits or otherwise) of the LCP, even after 10 years of widespread implementation.² The review concluded that the LCP should be phased out and replaced with more-individualized care plans and with a greater emphasis on specialist palliative care, 24-hour provision, education, a focus on outcomes, and research.

One of the great challenges for palliative care is that it deals with complex people, who experience complex problems in complex circumstances. Simple solutions are attractive, but we should be wary: as the American journalist H. L. Mencken said: "For every complex problem there is an answer that is clear, simple, *and* wrong." Thus, I was impressed in this issue by the randomized trial of online training of palliative care for primary care physicians by Pelayo and colleagues. Two key strengths of this study: first, the design of a randomized trial, the best method to assess the effectiveness and controlling for biases, and second, the focus on patient and family outcomes, using in their study the palliative care outcome scale and other validated measures, as well as the intermediate measure

of physicians' self-assessed knowledge. Conducting a trial on an educational intervention is rare and to be congratulated. The trial suggests that online education results in as good, and possibly better, education participation and patient and family outcomes compared to traditional education. Of course there is more to be done on developing the theoretical models of such educational approaches and considering how to sustain education and changes in practice, but this is one important step in the right direction. Also in the vein of education, Woo and colleagues explore ways to improve education in long-term care institutions, a commonly neglected place of care. Canavan and colleagues compare staffing levels across hospices, in particular registered and nonregistered nurses, with the view that higher staffing levels give higher quality. Palliative care is a technology-low, people-high speciality, so the availability of properly trained and supported staff is certainly important, although the ultimate outcome must be patient and family experiences and outcomes.

One of the other challenges we face in palliative care is equality of access to care. A report from the United Kingdom by Calanzani and colleagues, as a collaboration between Public Health England, Marie Curie Cancer Care, and King's College London Cicely Saunders Institute, found that, similar to the white British population, black and minority ethnic groups are ageing and will represent a substantial number of people in need of palliative and end-of-life care in the future.³ Care that is currently being provided is often far from adequate for these groups. This is a global concern. In this issue of JPM Loggers and colleagues compared the rates and predictors of intensive end-of-life and hospice care among Latino and white patients with advanced cancer. Whereas some factors seem to predict intensive end-of-life care for white patients, they did not for Latino patients, something which needs further investigation.

Examining further the issue of implementing improvements into practice, from Australia, Rhee and colleagues report the results of interviews with general practitioners to understand why advance care planning decisions are not implemented. The factors reducing implementation are multifactorial, including legal factors, illness factors, prognostic certainty, family attitudes, and organizational and care setting factors.

But the difficulties of developing, robustly evaluating, implementing, and sustaining improvements in practice should not stop us from this endeavor. As Florence Nightingale said, "The main end of statistics should not be to inform the government as to how many men have died, but to enable immediate steps to be taken to prevent the extension of disease

and mortality.” So it must be for palliative care. And to help us, new guidance has emerged from project MORECARE, supported by the UK Medical Research Council and National Institutes of Health Research.^{4–7} This work, collaboration between several universities and clinical groups, and involving experts across the globe, has recently published a statement that provides 36 best practice solutions for research evaluating services and treatments in palliative and end-of-life care. This work is a start in developing the methods to robustly develop and evaluate services, and to learn from good research as the services or interventions develop. In addition to recommendations on using mixed methods (quantitative and qualitative), robust trial designs, and short, easy-to-use outcome measures, the work explains how the development and evaluation of new interventions needs to incrementally build from initial testing to robust comparative trials. Considering how to implement such complex interventions, such as new services or education, needs to be built into all stages. This includes training, workforce, and environmental aspects. This issue of JPM reports valiant work to ‘do something’ to improve palliative care. We need more of this, done robustly, supported by funding agencies, with timely publication of both positive and negative findings, and learning at all stages.

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