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This is a copy of an article published in the *Journal of Palliative Medicine*, and is available online at:

<http://online.liebertpub.com/doi/full/10.1089/jpm.2011.0162>

Please cite this as: Lobb, E.A., Swetenham, K., Agar, M.R. and Currow, D.C., 2011. A collateral benefit of research in palliative care. *Journal of Palliative Medicine*, 14(9), 986-987.

DOI: <http://dx.doi.org/10.1089/jpm.2011.0162>

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A Collateral Benefit of Research in Palliative Care

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Dear Editor:

A collateral benefit of being in a research-active clinical unit is that there is evidence that better care is delivered. The most dramatic data to date demonstrate that in cardiology, research-active cardiology departments in community and university hospitals deliver better survival than those units that do not enroll people in clinical trials.¹

In hospice and palliative care, Phase III studies are crucial to improving the quality of evidence for day-to-day practice, yet acceptance of their role is still limited to a relatively small number of clinical units. Barriers continue to include beliefs by clinicians that “we already know what works” and the concern that patients should not be burdened with participation in studies at the end of life when they have other things about which to worry. To answer the first concern, an evidence base derived from case series shows a range of benefit from a 90% underestimate of effect to a 150% overestimate when non-randomized studies are compared with subsequent randomized clinical trials.² To answer the second concern, people want to participate in studies that will improve the quality of care, and potential participation is higher in palliative care than many other clinical disciplines.³

In Australia, since 2006 a national clinical trials collaborative funded by the Department of Health and Ageing has been running 8 adequately powered, rigorously designed, double-blind, randomized controlled Phase III studies across 12 participating sites. The first of these studies has been completed, whereas the others continue to recruit.⁴ The primary aim of the Palliative Care Clinical Studies Collaborative (PaCCSC) is to generate research data of a quality that would support the listing of study medicines on the Australian Register of Therapeutic Goods and subsequent subsidy applications were the studies to be positive. Additional aims include building clinical research capacity and developing further the evidence base for practice and policy related to hospice and palliative care.

Direct benefits of this collaborative for participating sites include stronger working links with other palliative care units, and mentoring of clinical researchers. Detailed Standard Operating Procedures developed by PaCCSC underpin every aspect of trial conduct to ensure consistent approaches to research across all sites. Both Standard Operating Proce-

dures and the clinical trials protocols have the potential to impact positively on day-to-day clinical care. Research opportunities have created new foci on patient and family care.

The Australian Council of Healthcare Standards (ACHS) is the organization that accredits health care facilities and services in Australia on a 4-year cycle of quality improvement to ensure safe and effective health care is consistently available. ACHS surveyors conduct onsite visits every 2 years to provide an independent assessment of each facility’s performance against the national standards.

One objective collateral benefit of active participation in PaCCSC for 3 units recently accredited was the response by the accreditation team. All sites had other significant clinical services on campus ranging from rehabilitation to elective orthopedic surgery. Palliative care, and specifically palliative care research, was singled out for its excellence at all 3 sites at the summary meetings with 3 domains highlighted: Clinical (e.g., care planning and delivery, medications, infection control), Support (e.g., risk management, incident management, quality framework, human resources, information technology, research), and Corporate (e.g., safe practice and environment). Excellence in these 3 areas was attributed to participation in PaCCSC and was seen to have direct benefits for day-to-day patient care across the whole clinical unit, not just for people participating in studies.

For units preparing for accreditation, participation in PaCCSC provided excellent evidence of quality processes and the “virtuous cycle” of quality improvement in action. Comments from the surveyors for accreditation focused specifically on the results from research and the way in which research outcomes are informing clinical practice and service development. Potential improvements in routine clinical practice include better screening of symptoms, more consistent evaluation of outcomes after changes in clinical interventions, and more uniformity in the clinical interventions provided.

The view from surveyors for accreditation, who see a wide range of services in many health facilities, supports the importance of seeking better evidence for the routine management of key palliative care symptoms through well-designed clinical trials. Their comments on how well clinical research was embedded into routine practice reinforces that such studies are feasible, and good research can only improve

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clinical practice and teaching. In the words of the surveyors for accreditation:

This "organization is recognized...for its contribution to advancing clinical change and in expanding the body of industry knowledge related to palliative care."

"The surveyors were impressed with the...use of research relevant to care planning and delivery."

"Research is well integrated into the palliative care unit...and... directly related to the model of care and patient outcomes."

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1. Brian H. Le, Mark A. Rosenthal. 2012. Redefining the Specialist Palliative Approach: Clinical Trials, a First Year Experience. *Journal of Palliative Medicine* 15:8, 846-846. [[Citation](#)] [[Full Text HTML](#)] [[Full Text PDF](#)] [[Full Text PDF with Links](#)]