

Chronic disease management along the continuum of care:
The role of the health system in supporting people with end
stage chronic illness

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Abstract

Australia faces increasing numbers of people with life limiting chronic disease as individuals live longer and advances in medical treatment help to prolong their lives. However, there is little acknowledgment that the continuum of chronic disease care must include attention to care needs at the end of life. Current policies and strategies assume that referral to palliative care services for people with advanced chronic diseases will be straightforward, despite uncertain disease trajectories and the need for complex and disease-specific interventions.

This thesis examines the health care system as it operates for people with chronic disease as they approach the end of their lives. I explored this topic from a range of perspectives, using a systems thinking framework to map the complexity of end of life care provision. I began with a national/state policy audit which identified how policies related to chronic disease and palliative care interact to facilitate end of life service provision. Using a 360⁰ review built through qualitative interviews with nine patients, six carers and ten key service providers, I examined health system functioning and access to care. I also interviewed twelve service managers and policy makers to explore their perceptions of system functioning and the changes required to make the system function more effectively. Once a picture of how the system functions was developed, I brought the results together using a complexity theory framework to understand why it functions in this way, and to determine the most appropriate places to intervene to bring about change.

The findings from these studies demonstrated that Australian policy makers have not developed effective policies to support appropriate end of life care models for people with chronic disease and there are few intersections between chronic disease and palliative care policies. Current funding mechanisms reflect this disjunction, leading to significant barriers to end of life care for people with advanced chronic disease. Advance care planning remains uncommon in chronic disease care and many health professionals remain uncomfortable about initiating conversations in this area. Despite over a decade of health system advocacy for integrated care, care silos remain entrenched and there is minimal integration between primary, secondary and community care.

This thesis demonstrates that people with advanced chronic disease require ongoing, systematic chronic disease care for symptom control and quality of life which should be combined with a palliative approach incorporating practical support with activities of daily living, ongoing advance care planning conversations; psychosocial and spiritual support and the ability to be cared for at home in the context of family and friends. To support such care, a whole of system approach and a multidisciplinary, integrated, primary care based model of care, with ongoing support from palliative care and hospice services is required. This is not currently available for most Australians.

In order to drive the changes required to provide such end of life care, culture and attitudes around end of life care need to change at both a community level and in health care organisations. Such changes can be facilitated by national programs, but also require system changes such as taking a public health approach to end of life care and making primary care the locus of end of life care for chronic disease. This will require reform of the structure and funding of primary care and the provision of incentives for quality end of life care. Above all, a shared vision of what end of life care in chronic disease should look like must be developed and the primary care sector, including general practice, specialist palliative care, community health providers and NGOs, should play a significant leadership role in driving the development and implementation of this vision and the system changes required.

Manuscripts contributing to this thesis

Burgess, T; Braunack Mayer, A; Crawford, G & Beilby J. 2013 Meeting end-of-life care needs for people with chronic disease: Palliative care is not enough. *Medical Journal of Australia*. 198(4): 186-187.

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Conference presentations arising from this thesis

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Presentation: *Understanding the Complexity of End-of Life Care in Advanced Chronic Disease.*

Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. 12th Australian Palliative Care Conference. 3-6 September 2013. Canberra, Australia.

Presentation: *Everybody's business? End of life care for chronic disease in Australia today.*

Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. The 4th International Society of Advance Care Planning and End of Life Care Conference. May 9 – 11, 2013. Melbourne, Australia

Presentation: *How well does the Australian health care system support quality end-of-life care for people with chronic disease?*

Burgess T & Crawford GB. Hospice New Zealand 20th Palliative Care Conference September 14 – 16, 2012. Auckland, New Zealand.

Workshop/Presentation: *Meeting the end of life care needs of people with advanced chronic disease.*

Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. 7th Health Services Research and Policy Conference. December 5 – 7, 2011. Adelaide, Australia.

Presentation: *Are current health policies failing people with chronic disease as they approach the end of their life?*

Burgess T; Braunack-Mayer A; Crawford GB & Beilby J. Public Health Association of Australia (SA Branch) 2011 State Population Health Conference. October 29, 2011. Adelaide, Australia.

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Thesis declaration

I certify that this work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text. In addition, I certify that no part of this work will, in the future, be used in a submission for any other degree or diploma in any university or other tertiary institution without the prior approval of the University of Adelaide and where applicable, any partner institution responsible for the joint-award of this degree.

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