

Dying In The Margins: Understanding the needs and  
capacities of a lower socioeconomic population for end of  
life care

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Thesis submitted in fulfilment of the degree of  
Doctor of Philosophy

University of Technology Sydney

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## Certificate of Original Authorship

I certify that the work in this thesis has not previously been submitted for a degree nor has it been submitted as part of requirements for a degree except as fully acknowledged in the text.

I also certify that the thesis has been written by me. Any help I have received in my research work and the preparation of the thesis itself has been acknowledged. In addition I certify that all information sources and literature used are indicated in the thesis.

Signature of student

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# Anthology of Publications Associated with Thesis

**Lewis J**, Davidson PM, DiGiacomo M, Lockett T, Currow D. A social capital framework for palliative care: Supporting health and wellbeing for people with life limiting illness and their carers through social relations and networks. *Journal of Pain and Symptom Management*, 2013, 45(1):92-103. [IF 2.5]; DOI:10.1016/j.jpainsymman.2011.12.283

**Lewis J**, DiGiacomo M, Currow D, Davidson PM. Dying in the margins: understanding palliative care and socioeconomic deprivation in the developed world, *Journal of Pain and Symptom Management*, 2011, 42(1),105-118, I:10.1016/j.jpainsymman.2010.10.265. [IF 2.5]

Currow D, Allingham S, Bird S, Yates P, **Lewis J**, Dawber J, Eagar K. Referral patterns and proximity to palliative care inpatient services by level of socio-economic disadvantage. A national study using spatial analysis, *BMC Health Services Research* 2012, 12:424 doi:10.1186/1472-6963-12-424

**Lewis J**, DiGiacomo M, Newton P, Currow D, Davidson PM. Socioeconomic status as a marker of specialist palliative care service access, submitted to *BMC Health Services Research*, 15 January 2013.

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## Abstract

Increased disease burden and unmet health care needs are defining features of lower socioeconomic groups, both in Australia and internationally. In Australia, there is limited understanding of the needs of lower socioeconomic groups for end of life care. At the end-of-life, health disparities are often more pronounced for both patients and their caregivers. Globally, there has been scant attention on the needs of individuals from socially and economically disadvantaged groups at the end-of-life. As gaps between the rich and poor widen and the emphasis on community-based care increases, this research area is of growing significance.

The research objectives of this study were to (i) provide a snapshot of the impact of socioeconomic status on place of death and after-hours crisis service utilisation by comparing outcomes of areas of high and low disadvantage; (ii) explore and describe the socioeconomic demographics, needs, capacities and experiences of patients and/or carers from a disadvantaged area focussing on (ii a) the social, economic and care outcomes and capacities at individual, community and government levels, (ii b) the nature and impact of social capital outcomes, (ii c) the experience of access for a specialist palliative care service; and (iii) describe the appropriateness, acceptability, and feasibility of self-report tools for capturing wellbeing, consumption, health literacy, social capital and palliative care needs and capacities in this population.

This study used a concurrent embedded mixed method design with a qualitative emphasis and explicit use of social determinants of health framework and social capital concepts. The conceptual framework determined selection of self-report tools which additionally structured interviews. Integration of the quantitative and qualitative data was achieved through the study design, data collection and discussion. Four years of administrative data from a single palliative care service, located in a socioeconomically disadvantaged area was collected and analysed. Place of death and after-hours crisis service data were compared for a most and a least disadvantaged area compared over a twelve month period. Semi-structured interviews were conducted with 14 patients and/or carers from a lower socioeconomic area and five key informants who provided formal care for this group. Demographic data and outcomes of self-report tools were collected from patient and carer participants during interviews. Semi-structured interview responses to self-report tools were evaluated for appropriateness, acceptability and feasibility of these measures.

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The findings demonstrate that a lower socioeconomic group experienced end of life care within margins of social and economic resources and care networks. *Social margins* were shaped by limited community trust, engagement and deficiencies in social policy (public housing). *Economic margins* reflected income loss, healthcare spending on co-payments and economic disparity in aged care facility access. *Care network margins* were defined by limited informal and formal care support. Patients from the disadvantaged area had fewer home deaths and greater home care needs warranting facility admission. Capacities within the end of life care experience were demonstrated by trust and engagement with government organisations, potential for community club, neighbourhood and friendship support, access to financial support programs and benefits, and examples of supported home care networks. Recommendations for research, clinical practice and policy to address these issues are discussed.

This thesis has provided a unique and novel contribution to the literature. Specifically, it has demonstrated the needs and capacities for a lower socioeconomic group not previously described in the Australian literature, and in particular, it has advanced conceptual and theoretical issues in investigating social and economic issues in end-of-life care.

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## List of Abbreviations

<b>ABS</b>	Australian Bureau of Statistics
<b>ASCAT</b>	Adapted Social Capital Assessment tool
<b>CNC</b>	Clinical Nurse Consultant
<b>CNS</b>	Clinical Nurse Specialist
<b>COAG</b>	Coalition of Australian Governments
<b>CSDH</b>	Commission for Social Determinants of Health
<b>HILDA</b>	Household Income and Labour Dynamics in Australia
<b>IRSD</b>	Index of Socioeconomic Disadvantage
<b>NHMRC</b>	National Health and Medical Research Council
<b>OECD</b>	Organisation of Economic Co-operations and Development
<b>OOP</b>	Out of Pocket
<b>PCA</b>	Palliative Care Australia
<b>PCOC</b>	Palliative Care Outcomes Collaborative
<b>SDH</b>	Social Determinants of Health
<b>SEIFA</b>	Socioeconomic Indexes for Areas
<b>SOCAT</b>	Social Capital Assessment Tool

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## Glossary of Terms

**Advanced care directive:** Documents containing instructions that consent or decline specific medical treatments and/or specify care and lifestyle preferences in anticipating future situations or circumstances. These directives are activated in situations where the person is no longer able to make decisions. As legal documents, advanced care directives are distinct for legislative requirements in each State and Territory in Australia.

**Bulk Billing:** The process by which a practitioner sends the bill for services directly to Medicare, so that the patient receiving the service pays nothing.

**Consumption survey:** A self-completion 21-item survey which identifies approximate weekly, monthly, and yearly household expenditure and additional items for costs of medications and medical consumables and equipment hire /purchase costs.

**End of life care:** Combines the broad set of health and community services that care for the population at the end of their life. Inclusive of networks between specialist palliative care providers, primary generalist providers, primary specialists and support care providers and the community.

**Home care services:** The Home and Community Care (HACC) Program is a joint Australian Government, State and Territory initiative to provide community care services to frail aged people, younger people with a disability and their carers.

**Index of relative Socioeconomic Disadvantage (IRSD):** The Index of Relative Disadvantage uses indicators of low socio-economic wellbeing as a general measure of disadvantage. Its use is appropriate for users interested in the relative disadvantage of people in an area (lower deciles), and the relative lack of disadvantage of people in an area generally (upper deciles).

**Medicare:** Australia's government-funded health care system that subsidises the costs of personal medical services for all Australian Medicare card holders and aims to support affordability of medical care.

**Needs assessment tool: Progressive disease Cancer(NAT:PD-C):** A sixteen-item, multiple section assessment tool administered by health professionals to assess levels of need in patients and carers in specialist and generalist health care settings and match these needs to specialist palliative care services as necessary.

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**Personal Wellbeing Index(PWI):** An 8 item, 11 point self-report end-defined response scale, which assesses a person’s subjective quality of life across eight domains (‘standard of living’, ‘health’, ‘achieving in life’, ‘personal relationships’, ‘safety’, ‘feeling part of the community’, ‘future security’ and ‘spirituality or religion’).

**Pharmaceutical Benefit Scheme (PBS):** A publicly funded insurance scheme in Australia aimed at providing universal affordable access to prescription medicines.

**Primary care providers:** In the context of end of life care, a primary care provider is the first contact medical, nursing or allied health professional who undertakes an ongoing role in the care of a patient and their family or carer.

**Rapid Estimate of Adult Literacy Medicine-Revised (REALM-R):** An eight item instrument designed to rapidly screen adult primary care patients for low health literacy.

**Social Capital Questionnaire (SCQ):** The questionnaire is a researcher-designed tool to measure the quality and quantity of individual, community and societal relations and networks for the patient or their carer. The questionnaire has 16 questions with multiple item responses to 5 questions.

**Socioeconomic Index for Areas (SEIFA):** A measure of socioeconomic status in Australia used to define levels of disadvantage within and across areas. SEIFA scores are indicators of socioeconomic status and are the most widely used measure of socioeconomic status (SES) in Australia. They are based on international research and information collected in the census reflected in the Australian Bureau of Statistics (ABS) data.

**Specialist palliative care services:** Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care, homes and hospices and palliative care units.