



Public Health Palliative Care Unit

Public Health Palliative Care (PHPC)
Quality End of Life (QEL)
Indicators Project

*Developing indicators for the public health factors contributing to the
Quality of End of Life (QEL)*

PHPC QEL Indicators Project

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Preamble

Public Health Palliative Care (PHPC) initiatives represent a new and fast developing field of end-of-life care in Australia. The field is transitioning from the conceptual and piloting stage to the roll-out of programs and services. The La Trobe University Public Health Palliative Care Unit (the Unit), implements a National Public Health Palliative Care (PHPC) Framework in a range of projects that build end-of-life capacity within systems, sectors, organisations, services and communities across Australia. Learning from these projects has informed strategic frameworks that the Unit uses and now offers to those wishing to implement a public health approach to palliative and end-of-life care. The growing level of interest and funded activities in this field provides an unprecedented opportunity to research and evaluate the impact of Public Health Palliative Care initiatives, including the impact on palliative care policies and practice, bearing in mind that public health strategies include, but are not limited to, health service provision. Research and evaluation are incorporated into each of the Unit's PHPC initiatives to improve our understanding of Public Health Palliative Care approaches in an Australian context. The Healthy End of Life Project (Grindrod and Rumbold, 2018) provides one of our frameworks to guide both PHPC interventions and evaluation.

Introduction

Traditionally, attitudes towards individuals with life-limiting illness assume that most aspects of dying will be taken care of by health professionals and institutions. However, a public health approach to palliative care has seen a move to develop end-of-life initiatives that also incorporate broader societal and local community resources in order to meet the needs of individuals at the end of life. Inherently included into a public health approach is the 'social determinants of health' (WHO, ref). The social determinants of health (SDH) 'are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life'. SDH examples include our early childhood experiences, gender, biogenetics, level of income and education, social support networks, culture and race. Inextricably linked to socio-economic, the social determinants of health might also be viewed as the 'social determinants of death' – that is to say, the circumstances of our dying often reflect the circumstances of our living. Bringing to bear the relationship of these social factors on population-based (end-of-life outcomes, coupled with the inherent principles of public health approaches as set out by the WHO), a strengthened public health approach to palliative and end-of-life care has the potential to elucidate; a) the direct relationship between our determined social circumstances and the quality of our end of life, b) the implications of structural inequity in our society upon choice, and c) the subsequent approaches required to achieve accessible and equitable palliative and end-of-life care for all.

Public Health Palliative Care (PHPC) attempts to improve the identification of people who may benefit from palliative and end-of-life care, including disadvantaged citizens, while recognising the wider sources of support within society and communities and the need for collaborative and integrated service provision. Essentially, PHPC incorporates a broad perspective to care that recognizes the importance of social and community factors that contribute to the quality of end of life. This represents a challenge to traditional approaches to quantitative research and monitoring of the circumstances of the end of life.

At present the datasets and key indicators in this field of research are narrowly focused on the medical and service delivery aspects of end-of-life care and death. In order to measure the quality and effectiveness of public health palliative care, a new broader approach to the strategic measurement and monitoring of end-of-life care, including the social context of death will be required.

Rationale

Currently, there is no program of systematic data collection and reporting that has been established to inform, monitor and measure new public health initiatives that focus on the social and community context, including disadvantage and low socio-economic states, of end-of-life experience. In addition, there is no routine way of linking up datasets from the health, social and community context that could assist in our understanding of the broader circumstances of end-of-life care. A major initiative will be required to augment the narrow existing range of end-of-life care and death datasets in order to develop a data analysis and reporting system that supports the planning and evaluation of the public health initiatives in this field.

Existing data sets and analysis relating to the measurement of the quality of end of life in Australia and overseas focus on measures of health care service delivery, cost, service resources provided, access to pain relief etc. These are too narrow to be relevant to public health palliative care initiatives. An example includes the 2015 EU Quality of Death Index - 20 quantitative and qualitative indicators across five categories: the palliative and healthcare environment, human resources, the affordability of care, the quality of care and the 'level of community engagement'. This final category in the context of PHPC is also too narrow, usually referring to a limited and simplistic understanding of community, failing to take into account complexity of community in all its societal variations, including vulnerable citizens.

In summary, the rationale for the development of Public Health Palliative Care (PHPC) Quality End of Life (QEL) Indicators that respond to gaps in the current methods of data collection include:

- There are currently no national data analysis and reporting programs that are directed towards examining and monitoring the social and civic dimensions of end-of-life experience and dying, including the social determinants of death.
- Existing databases, tools and indicators of end-of-life service provision and care are narrowly focused, such as on medical circumstances and disease progression, mortality endpoints and health practice delivery and episodes of care. These need to be broadened to include datasets relating to social circumstances and civic participation at the end of life to the gap in current data collection strategies.
- Current service providers, including palliative care, are being encouraged and resourced to broaden their scope to address the social environment of end-of-life care but there are currently no reporting systems to monitor this. We need to support palliative and health care with the datasets and measurement tools.
- There are currently no comprehensive datasets, indicators or measurement tools on the social context of quality of end of life to complement and inform the implementation of public health palliative care initiatives in Australia
- There is currently no method for measuring impact or outcomes of public health palliative care initiatives
- There is currently no method for using datasets to inform the setting of priorities for policy development, service deliverables, funding allocation and research. For example, which groups in the community currently have poorest outcomes in terms of social environment of death, including people living with disability, people experiencing homelessness, refugees, first Australians, Culturally and Linguistically Diverse populations etc.
- End of life health promotion practitioners are developing goals and objectives relating to the quality of the end-of-life experience that encompasses public health approaches. There is a need to translate these objectives into relevant data reporting measures and indicators.

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Expanding the current death and end-of-life data analysis and reporting systems in this manner will be a substantial undertaking that will require considerable preparation, consultation and collaboration across a number of organizations and stakeholders.

Aims and Objectives

The overall aim of the project is to expand and augment the existing narrowly focused data collection and reporting systems to incorporate key measures of the social circumstances and determinants of end of life.

Objectives of the PHPC QEL indicators project include:

- To develop national data analysis and reporting programs that are directed towards examining and monitoring the social and civic dimensions of end-of-life experience and dying, including the social determinants of death.
- Broadened existing data sets and develop new data sets to include the social circumstances and civic participation at the end of life to fill the gap in current data collection strategies.
- To support palliative and health care with datasets and measurement tools monitor and report on their broadened scope to include the social environment in the delivery of their care.
- To develop comprehensive datasets, indicators or measurement tools on the social context of quality of end of life to complement and inform the implementation of public health palliative care initiatives in Australia
- To develop methods for measuring impact and outcomes of public health palliative care initiatives
- To develop methods for using datasets to inform the setting of priorities for policy development, service deliverables, funding allocation and research, including and specifically for citizens who have the poorest outcomes on the social determinants of death.
- To support the emerging field of public health palliative care practitioners to measure the outcomes and impacts of their programs by translating the objectives of their initiatives into relevant data reporting measures and indicators.

Project Information

This project is currently in development. For project enquiries please contact Andrea Grindrod | a.grindrod@latrobe.edu.au

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