

End-of-life care should focus on quality of life, not prolonging it

February 20 2019, by Lachlan Gilbert



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Terminally ill, older adults would prefer to receive higher quality supportive care rather than aggressive end-of-life treatments to prolong their lives, a UNSW Sydney study has found.

In an article published recently in the journal Health Expectations, the

authors interviewed 24 [older adults](#) in NSW who were either terminally ill or cared for a person faced with advanced or irreversible disease, to determine whether their end-of-life (EOL) care needs were being met. The researchers were then able to identify a list of common themes that patients or their caregivers expressed about their health care experience.

The seven themes were identified as follows: quality as a priority; a desire for a sense of control; living a life on hold; the need for health system support; a preference for being at home; talking about death; and dealing with competent and caring health professionals. An underpinning priority throughout the seven themes was knowing and adhering to patient's wishes.

To date, much of the research concerning consumer preferences around [end-of-life care](#) has been undertaken in the oncology setting. But according to lead author of the study, UNSW School of Public Health and Community Medicine's Ebony Lewis, the latest findings look at older terminal patients with a range of chronic conditions beyond cancer, as well as including caregivers.

Ms Lewis says the study found that older terminally ill health care consumers and caregivers have a strong community-based preference for less aggressive EOL treatments and higher quality supportive care in line with their personal values. But despite this, many older Australians are still spending their last weeks of life in hospital.

"While the government recognises the importance of providing high-quality and safe end-of-life care, and has developed guiding principles for its provision, our consultation found that 'real life' alternative options for end-of-life care outside the acute hospital may not be available," Ms Lewis says.

"Urgent strategies are needed to support terminal care outside the acute

hospital as well as tools to give health care professionals the ability to deliver more skilled end-of-life communication that incorporates the patients' personal values."

Ms Lewis says such action would address this gap in services as well as the unmet care needs of older adults and relatives caring for dying patients, which ultimately affects everyone in society.

"The general community is also affected by the traumatic experiences of their elders whose suffering and dying processes are prolonged without gains in quality end-of-life. This can leave families with great regret and can cause dissatisfaction with health services."

Ageing population

The fact that the proportion of those over 65 in the Australian population is expected to double in the next 30 years is also a pressing concern for Ms Lewis.

"Our growing ageing population will have an impact on the efficiency and workload of emergency services and hospitals. Our health system needs to start getting ready to face this challenge." Ms Lewis says.

"An increase in demand for services will end up contributing to the escalating cost of non-beneficial intensive care or surgical treatments. Doing everything that is technically available for [older people](#) dying of natural causes is not necessarily appropriate and leads to inequities of access available to the rest of the general population."

Rather than persisting with care guidelines that have evolved out of top-down delegation of health policy and practice, Ms Lewis and her co-authors call for a community-based approach for terminal care services.

This would require better communication between [medical staff](#) and patients and between patients and their families to ensure expectations are met in palliative and supportive care.

"Much work remains in the area of increasing public awareness of the need to hold the conversations with their family and GP about what people consider unacceptable and what they are prepared to go through in the event of a health crisis when they cannot speak for themselves," says Ms Lewis.

The research authors also call for the development of planning tools for medical staff enabling them to identify earlier those people who are near the end of life and whose [end-of-life](#) care needs have not been articulated.

"We're working on improving shared decision-making to facilitate advance care planning," Ms Lewis says. "We hope that using these in routine clinical care may offer a valuable strategy to reduce both unnecessary hospitalisations and low-value care."

Provided by University of New South Wales

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