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# Factors impacting on the lives of terminally ill older people, and requests for euthanasia, PhD thesis, University of Queensland

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## ABSTRACT

**Background:** Over the past decade, while the use of new technology and improved life support systems meant that many people were continuing to live who would otherwise have died, there has been increasing international debate about the quality of the lives that have been extended. Advocacy for the rights of dying patients not to use the new technologies (Leenen, 2001) led to increasing community support for patients to be given more control over medical treatment at the end of life (Ashby et al, 1995).

The majority of Australians believe that active voluntary euthanasia (AVE) and physician-assisted suicide (PAS) should be legally available for terminally ill people (Cartwright et al, 2002; Walsh, 1996). However, there is strong resistance to this, particularly from Churches and the medical profession (Gill, 1998; Somerville, 2003). Before the *Rights of the Terminally Ill Act* (1995) was overturned by the Commonwealth government, the NT was the only jurisdiction in the world to legally allow both of these options. However, we have little insight into the factors which predict attitudes to AVE and/or PAS, and comparatively few studies have investigated the lived experience of terminally ill people in relation to requests for AVE. There was therefore both a need and an opportunity for the present study to add some evidence to this issue.

### Study Hypotheses

The hypotheses underpinning this study are, that: attitudes to end-of-life issues are the result of socio-demographic factors, religious beliefs and life experiences; such attitudes will be modified by experience of illness, death and dying, exposure to palliative care and the availability of formal and informal supports; that attitudes of older people will be different to those of younger people; and factors can be identified which will predict which terminally ill older people are likely to request assistance to end their lives.

### Aims of the Study

This study aimed to: examine attitudes to end-of-life issues among older and younger community members and health professionals in Queensland, including support for legislative change to allow AVE and/or PAS; identify factors that predict which older people are likely to want AVE and/or PAS for themselves; investigate the experiences of the last months of life of a group of terminally ill older patients and their carers, from the perspectives of the primary carers and community nurses, in order to understand

what factors positively or negatively impacted on the quality of their lives; determine whether any of those patients had requested assistance to end their lives; and, if so, to identify what factors may have influenced such requests.

### **Significance of the Study**

Identification of factors that lead to requests for AVE may enable some to be ameliorated, and contribute to guidelines for health professionals dealing with such requests. In addition, a comprehensive study of the last stage of the lives of terminally ill older people living in the community may provide a deeper understanding of these issues and indicate ways in which this experience can be enhanced for all those involved. Finally, findings of this study should contribute to the debate on policy and legislative changes related to end-of-life community care, and help to clarify our understanding of some of the reasons older people request assistance to end their lives.

**Methodology:** Two empirical studies were undertaken, the first of which examined attitudes and perspectives of Queensland community members and health professionals to a range of end-of-life issues. This study sought to identify variables associated with and/or predictive of community members wanting AVE or PAS to be available both for others and for themselves, if they were terminally ill, and to compare community and health professional attitudes. The second study focussed on the lived experiences of the last stage of life of terminally ill older patients who had died in the 12-18 months prior to the study interviews, as perceived by their primary carers and Blue Nurses.

**Results:** Study 1 found that predictive factors of wanting AVE/PAS for self or others included lack of religious affiliation or belief, living in a rural location, concern about autonomy and loss of control, and fear of pain and protracted dying. Six of the 43 patients in Study 2 asked for assistance to end their lives. All six experienced many distressing symptoms and other factors which caused them distress included not being able to do their usual work or activities, loss of control or loss of independence. All were somewhat or very depressed and none were Catholic. However, 11 other patients who did not ask for assistance to die had the same characteristics.

**Conclusion:** Some requests for AVE may be associated with identifiable factors which potentially can be addressed but other requests appear to be idiosyncratic.