

The Social Consequences of Assisted Dying: A Case Study

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Introduction

The End-of-Life Choice Bill has now passed its third reading in the New Zealand Parliament, which takes the final decision on this legislation to a referendum on the End of Life Choice Act. The overriding discourse in countries where assisted dying (AD) is legal or under consideration concerns individual emancipation from the perspective of human suffering. Although the use of AD legislation may liberate individuals from suffering, it is also necessary to consider the impact embracing a new means of dying may have on families, healthcare practitioners and the wider community.

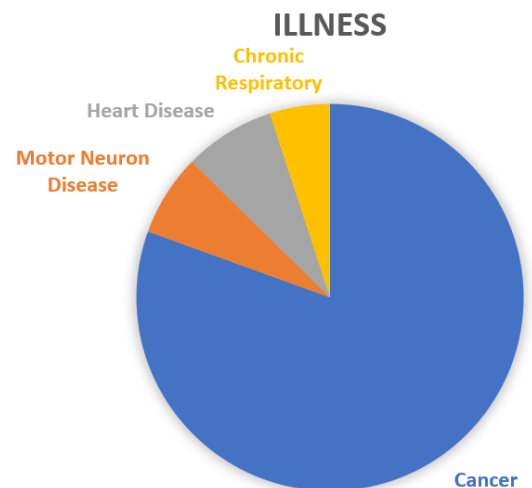
Background

The process of dying has become taboo for contemporary Western societies – death remains invisible until frail, older, disabled or unwell people become a physical, social and financial burden on their communities. The next cohort to die includes the baby-boomer generation. It has been suggested that this will change the landscape of how death will occur, as this generation has experienced life through the lens of individualism and perceived freedom of choice and may therefore expect death to be similar. Despite the prevalence of right-to-die narratives that support those concerned about loss of dignity and quality of life, there is concern that the right-to-die produces a 'slippery slope' effect, whereby some patients may feel obligated to terminate their lives prematurely to fit with social expectations that caring for our dying is burdensome.

Another emerging issue is the real possibility of stigma, both for family members and clinicians, where they fear the reactions and judgements of others. There is ongoing concern about a potential contagion effect as well, particularly if legislative boundaries slip, thereby erasing restrictions around eligibility. Clear boundaries and limits that reflect the underlying justifications for assisted dying are crucial. Robust safeguards are vital to ensure compliance. The provision of positive role-modelling of AD practices may normalise or even promote this means of death unless assisted deaths are protected by rigorous legislation that supports those involved.

Case Study

This case study uses an in-depth interview with a participant who self-identified as having first-hand experience of assisted dying from a relative's perspective (in a country where this is legal). The interview took place 12 months after the death occurred. The narrative depicted a situation where the individual concerned had a chronic and progressive illness, which had a mental health component. He was a highly educated scientist in his mid-70s who was still relatively active. Thematic analysis was used to identify themes and trends from the interview transcript.



Source: [Oregon Public Health Data 2015](#)

Currently legal in:

- Belgium, Canada, Colombia, Luxembourg, The Netherlands, Sweden, Switzerland
- Parts of the United States (California, Colorado, Hawai'i, Maine, New Jersey, Oregon, Vermont, Washington, Washington DC)
- Parts of Australia (Victoria, Western Australia)

Results

Three key themes emerged from the interview:

1. Life Value and Expectation to Use AD

In considering the burden and expectations with regard to AD legislation, there appeared to be a shift in terms of where the burden sits. Life value was questioned, with the notion of being burdensome transferring to those still living, in that AD may become a future expectation for them.

2. Stigma

Stigma can occur on both sides of AD legislation, with doctors and nurses being stigmatised whichever decision they make regarding service provision - even when the legislation is legal. Despite a growing number of individuals using AD, they often fail to inform wider family and friend networks that they intend to use, or have used, this legislation. The current NZ legislation does not require an applicant to discuss this decision with family or whanau. Furthermore, there are strict regulations on the disclosure of individuals who use the legislation, and for the purposes of insurance, insurance companies will not be advised that AD has been used.

3. AD as Contagion

The participant hinted that there may be a contagion effect at play, as he had known three extended family members use the legislation over a short period of time.

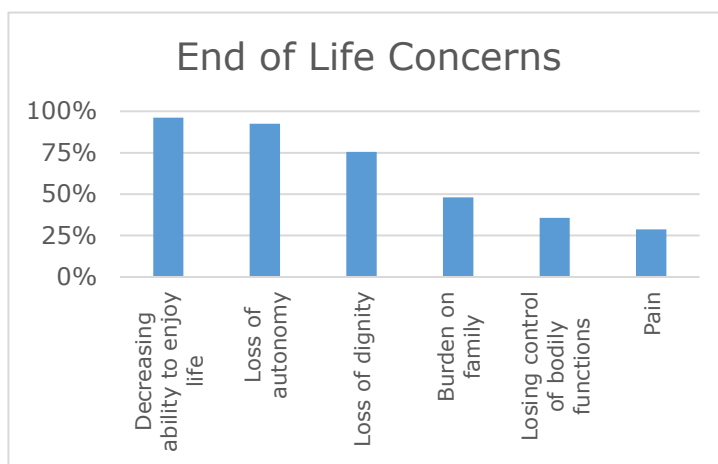
The case study also highlighted problems with the AD process:

- the process of accessing and using AD legislation
- the time frame from decision to death, with a stand down period of only 10 days. (The current legislation in NZ has no official stand down period, but allows 48 hours to obtain prescriptions)
- secrecy around information unless you were the individual seeking assistance
- family members were unable to access support
- time constraints around the administration of medication, with a set number of minutes allocated to asking if the person still wished to die, to say goodbye and is a very formal and rigid framework.

It was anticipated that the social consequences of AD legislation would be present in terms of the 'slippery-slope' discourse. However, it was unexpected to obtain data that painted a distinct picture of how the slippery-slope effect was unfolding in a country where AD was legal. While the right of individuals to choose assisted dying in some instances may be appropriate, evidence from this study must be factored into the New Zealand debate before the referendum on the End of Life Choice Act in 2020.

Conclusion

Experiencing AD through a relative's lens (partial engagement) can impact broader family and friend networks. AD remains contentious, irrespective of legality. The introduction of AD legislation into New Zealand culture provides a hotspot for family, community and social discord that may not be easily remedied. Globally, there remains ongoing debate with regard to the slippery slope effect. Further study is needed to investigate how we, as a society, negotiate a conflicted pathway complicated by prejudice, judgement and stigma for those who actively seek solace from indignity and suffering.



Key Policy Recommendations:

- Implement an official cooling off period of at least 10 days to process decisions being made
- Consultation with Māori and Pacific populations around AD legislation, particularly around lack of need of discussion with family and whanau
- Transparency in reporting of AD use, including on death certificates
- Support for family and whānau left to cope with the decision to avoid fracturing our communities
- Strong legislative boundaries

To find out more about this research, please visit: [New Zealand Medical Journal](#) June 2020
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Adapted with assistance from Sarah Hendrica Bickerton and Suzanne Woodward, PPI