

## **Charlene Somers**

## What Constitutes a 'Good Death'? Perspectives from The Public and Generalised and Specialised Professionals in Palliative Care

End of life care (EOLC) raises critical issues, most importantly for individuals approaching death, but also for their family/caregiver(s) and professionals (Cipolletta & Oprandi, 2014). A fundamental line of inquiry is, what constitutes adequate EOLC and where can possible improvements be made? This research therefore centres upon the concept of a 'good death'(GD) (Meier et al, 2016; Smith 2000, p. 20, cited in, Cipolletta & Oprandi, 2014). International research has examined opinions of a GD from the view of the terminally ill, the bereaved, caregivers and various EOLC professionals (Tenzek & Depner, 2017). Yet, public views on this topic is scant throughout national/international literature despite studies showing the public believes preferences in EOLC should be ascertained before a terminal diagnosis or medical crisis when they are healthy and capable (Carr et al., Death Matters, 2011). Few international studies and none to date in Ireland have explored the concept of a GD from both public and professional viewpoints comparatively (Loughlin, 2017; Meier et al, 2016; McQuinlan et al., 2013; The Office of the Ombudsman, 2014). Therefore, it is unknown if current EOLC service delivery reflects public expectation. Recent legislative developments in Ireland has further prioritised the need to promote, support and understand individuals' decision-making processes in EOLC. This research, therefore, is a timely investigation into both public and professional perceptions of what it means to have a GD. Given the nature of the topic a qualitative approach was fostered. In total twenty-four interviews were conducted. The research findings showed fifty-four perceived characteristics of a GD, some of which reflected previous national/international literature. While numerous components considered important in achieving a GD were shared by all participant groups significant differences were also apparent. Most notably the public revealed maintaining independence and dying without fear as fundamental components of a GD. Generalised professionals spoke of love and not dying alone. Whereas specialised professionals prioritised family and professional supports and effective multidisciplinary team involvement. Findings also revealed various challenges in current EOLC service delivery as perceived by all groups. Expectantly professionals provided greater insight in this regard, yet common themes across all key stakeholders were outlined namely time constraints, resource and environmental issues, societal barriers and lack of public awareness. A recurring issue recounted by professionals is a lack of support structures for professionals.

Supported by current literature this research concludes what it means to have a GD may be impossible to concretely answer. Yet, ascertaining perceived characteristics of a GD is an invaluable line of inquiry to highlight existing gaps in service delivery and enhance a holistic approach in EOLC care for both the terminally ill and their family/caregivers. It may also

assist professionals in anticipating present and possible future care needs of these groups in EOLC service delivery. Given the current and projected future need for EOLC the finding relating to a perceived lack of support for professionals warrants further investigation. A similar study on the concept of a GD on a larger scale is also recommended to gain further insight on this worthy topic. Enhanced public awareness campaigns on palliative, hospice and EOLC is also needed to defuse public misconceptions and diminish societal barriers on death and dying discourse.