



# Knowing, planning for and fearing death: Do adults with intellectual disability and disability staff differ?



Roger J. Stancliffe<sup>a,\*</sup>, Michele Y. Wiese<sup>a</sup>, Sue Read<sup>b</sup>, Gail Jeltres<sup>c</sup>, Josephine M. Clayton<sup>d,e</sup>

<sup>a</sup> The University of Sydney, Centre for Disability Research and Policy, Australia

<sup>b</sup> School of Nursing and Midwifery, Keele University, UK

<sup>c</sup> Sunshine, Sydney, Australia

<sup>d</sup> HammondCare Palliative and Supportive Care Service, Greenwich Hospital, Sydney, Australia

<sup>e</sup> The University of Sydney, Northern Clinical School, Sydney, Australia

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## ABSTRACT

**Background:** Adults with intellectual disability (ID) are thought to understand less about death than the general population but there is no available research demonstrating this. Further, the detail of any possible differences in understanding is unknown.

**Methods:** We compared the responses of 39 adults with mild or moderate ID and 40 disability staff (representing the general population) on (a) understanding the concept of death, (b) knowledge of and self-determination about end-of-life planning, and (c) fear-of-death.

**Results:** We found that adults with ID had a significantly poorer understanding of the concept of death, knew much less about and were less self-determined about end-of-life planning, but reported greater fear-of-death.

**Conclusions:** We demonstrated, for the first time, the feasibility of assessing end-of-life planning and fear-of-death among adults with ID. The poorer understanding and lower levels of self-determination we found suggest that future research should develop and evaluate interventions to increase understanding and self-determination.

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## What this paper adds

Our paper reported the first comparisons between adults with and without intellectual disability (ID) of (a) understanding the concept of death, (b) knowledge of and self-determination about end-of-life planning, and (c) fear-of-death. In addition, we demonstrated for the first time, the feasibility of assessing end-of-life planning and fear-of-death. The results reveal that, relative to disability staff, adults with ID had a significantly poorer understanding of the concept of death, knew much less about and were less self-determined about end-of-life planning, but reported greater fear-of-death. These findings indicated that there is a need to develop and evaluate interventions to increase understanding and self-determination about these issues among adults with ID.

\* Corresponding author. Tel.: +61 2 93519984.

E-mail addresses: [roger.stancliffe@sydney.edu.au](mailto:roger.stancliffe@sydney.edu.au) (R.J. Stancliffe), [michele.wiese@sydney.edu.au](mailto:michele.wiese@sydney.edu.au) (M.Y. Wiese), [s.c.read@keele.ac.uk](mailto:s.c.read@keele.ac.uk) (S. Read), [gailjeltres@sunshineidg.org.au](mailto:gailjeltres@sunshineidg.org.au) (G. Jeltres), [josephine.clayton@sydney.edu.au](mailto:josephine.clayton@sydney.edu.au) (J.M. Clayton).

## 1. Introduction

Individuals with intellectual disability (ID) are at risk of unnecessary personal distress and confusion about death and dying (Read & Elliott, 2007; Todd, Bernal, & Forrester-Jones, 2013). Adults with ID deserve information and support about these topics to help them understand and plan. A common concern is that people with ID could not cope and would be overcome with fear and distress (Tuffrey-Wijne & McEnhill, 2008; Wiese, Dew, Stancliffe, Howarth, & Balandin, 2013a), yet very little is known about the fear-of-death experienced by adults with ID.

Knowing about death and end-of-life planning is important for several reasons. People with ID have the right to know about these issues and to exercise self-determination about this aspect of life. Not understanding means that people with ID may not know what is happening when they are dying, and so have no opportunity to plan, make informed treatment decisions, farewell loved ones, or pass on valued possessions. Moreover, when others die, people with ID who do not fully understand are at risk of developing complicated grief, a prolonged and intense sadness arising from an ambiguous loss (Boss & Yeats, 2014). Likewise, well-intentioned exclusion of people with ID from mourning and bereavement rituals can increase the risk of disenfranchised grief, wherein the individual cannot participate in socially sanctioned grief rituals (Doka, 2010). Both complicated grief and disenfranchised grief increase the likelihood of mental health problems and personal distress (Dodd & Blackman, 2014; Read & Bowler, 2007). Lastly, understanding the fear of death experience by people with ID can help guide practice about informing people with ID about end of life, decisions that are currently made without data.

This paper reports on three key issues related to people with ID and dying and death: (a) understanding the concept of death, (b) knowledge of and self-determination about end-of-life planning, and (c) fear-of-death (see Wiese, Stancliffe, Read, Jeltres, & Clayton, 2015). We compared the responses of adults with ID to those of disability staff. The disability staff sample was intended as a proxy for the general population, allowing comparison between those with and without ID.

### 1.1. Understanding of death

McEvoy, MacHale, and Tierney (2012) interviewed Irish adults with mild or moderate ID about their understanding of the basic biological components of death: *Causality* (the biological or external causes of death), *Finality* (the dead cannot come back to life), *Non-functionality* (all life functions stop after death), *Universality* (all living things die), and *Inevitability* (one's own death is inevitable) (McEvoy et al., 2012; Slaughter & Griffiths, 2007). Understanding varied between individuals and across death-related topics. Overall, 24% had a full understanding of all five components of death, 70% displayed an incomplete understanding, while 6% had quite limited knowledge. Across topics, 85% were able to provide accurate information on one or more causes of death, whereas only 42% demonstrated a full understanding of the inevitability of their own death. These results confirmed earlier research showing that many, but not all, adults with ID have an incomplete understanding of death (McEvoy, Reid, & Guerin, 2002). Based on such findings, it has been assumed that adults with ID understand less about death than adults without ID, but no direct comparison has been reported.

### 1.2. End-of-life planning

End-of-life planning includes will-making and bequeathing possessions, advance care planning, choices about where and from whom to receive end-of-life care, funeral planning, and organ donation (Wiese, 2014; Wiese, Stancliffe, Dew, Balandin, & Howarth, 2013b). Research in the general community shows that documenting and upholding the person's end-of-life preferences improves outcomes for the dying person and for surviving relatives. The person experiences enhanced quality of care and feelings of self-control, while relatives report improved satisfaction, and reduction in stress, anxiety, and depression (Detering, Hancock, Reade, & Silvester, 2010; Singer, Martin, & Kelner, 1999).

Research is silent about what people with ID know about end-of-life planning. People with ID have few opportunities to learn about or plan for dying (Ryan, Guerin, Dodd, & McEvoy, 2011; Wiese et al., 2013a,b, 2015). Planning requires having appropriate information, but people with ID have limited understanding of dying and death, which in turn may restrict their ability to plan.

In addition, people with ID are typically less self-determined than members of the broader community (Sheppard-Jones, Prout, & Kleinert, 2005), so they may be less aware that they can exercise any control over the end stage of their life. Consequently, they may see it as someone else's role to make decisions about their end-of-life, or may defer to others' views.

No suitable end-of-life planning scale appropriate for adults with ID was available. To address this measurement gap in the literature, we developed the End-of-Life Planning Scale (EOLPS) (Wiese, Stancliffe, Clayton, Read, & Jeltres, 2014), an instrument we specifically designed for people with ID. The development and testing of the EOLPS is described in a companion paper (Stancliffe, Wiese, Clayton, Read, & Jeltres, 2015).

### 1.3. Fear-of-death

Children and adults with ID can self-report about fear (Duff et al., 1981; Gullone, Cummins, & King, 1996). Studies of fear in general have shown reasonably consistently that people with ID are more fearful than people without ID (Duff et al., 1981; Gullone et al., 1996), but no research has specifically looked at fear-of-death.

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