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Title: Knowing, planning for and fearing death: Findings from adults with intellectual disabilities and disability staff

R. Stancliffe, M. Weise, S.Read, G.Jeltes & J. Clayton.

Aim: Adults with intellectual disabilities (ID) are thought to understand less about death, but no comparisons are available to adults without ID. Research involving people with ID is silent on end-of-life planning and fear of death. Method: We compared the response of 39 adults with mild or moderate ID and 40 disabled staff on experiences of death, understanding of the concept of death, knowledge of and self-determination about end of life planning, and fear of death. Results: Adults with ID (95%) and disability staff (100) reported that they had experienced the death of other people. 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: 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 about end of life.