100 ACP FOR PEOPLE WITH INTELLECTUAL DISABILITIES: THE VIEWS OF FAMILY MEMBERS AND CARE STAFF

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The evidence base to support the development of ACP processes for people with intellectual disabilities and their families is limited. There is a paucity of studies that have explored the most appropriate means of engaging this population in ACP discussions. Evidence from previous research would suggest that people with intellectual disabilities are at risk of both 'under-treatment' at the end of life, for example, through sub-optimum pain management, and 'over-treatment', for example overly-interventionist care. As a result the extent to which people with intellectual disabilities and their families want to engage in ACP, and the mechanisms by which this can be achieved, remains unclear, particularly within the New Zealand (NZ) context. IDEA services has over 800 community homes supporting around 5800 people with intellectual disabilities across NZ, of whom 24% are aged over 50 years resulting in an increase in the incidence and prevalence of conditions such as dementia. In this presentation, we report the preliminary findings from a qualitative interview study conducted with individuals including care staff from IDEA services, general practitioners and family care givers regarding their views about ACP focusing on the barriers to, and facilitators of ACP. We report on the views of participants in relation to: understandings of ACP, the importance of interpersonal relations and the role of advocacy. This study suggests the need to rethink the traditional autonomy focused framework of ACP and the need for broader initiatives that incorporate the views of significant others to achieve an individuals' end of life care wishes.

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