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Do persons with intellectual disabilities understand death?

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Background: With the longer lifespan of the persons with Intellectual Disabilities (PWID), they have a higher chance of outliving their parents. The loss of parents among PWID is intricate because of the exceptionally intimate parent-child relationship. Yet, PWID are often considered as incapable to understand the concept of death, thus do not have the ability to grieve.

Aim: The study is to explore PWID's level of understanding of death.

Methodology: Persons with mild to moderate level of ID, who are service users of the Rehabilitation services of Tung Wah Group Hospitals, are the participants in this study. A stratified random sampling approach is adopted. Data were collected through an in-depth interview, guided by a standardized protocol. In particular, one of three vignettes describing death-related incidents was used to assess the understanding of five dimensions of death: causality, inevitability, finality, non-functionality, and universality. Self-care ability, bereavement experience and demographics were measured as well.

Findings: 104 participants joined the study, with 60 having had bereavement experiences. More than half of the participants showed a full understanding towards the irreversibility and non-functionality dimensions respectively. Around a third showed a full understanding towards the universality and causality dimensions respectively. 31.7% of participants showed a full understanding to the inevitability dimension. Gender and self-care ability seems to have minimal effect in understanding the different dimension of conceptualization of death. Bereavement experiences were found to be correlated significantly with nearly all the dimensions (r^2 ranged from 4.48 to 6.03, $p < 0.05$), except for irreversibility.

Conclusions: Though not all PWID can understand the concept of death, a significant group of participants, even assessed to be with moderate grade of intellectual disability, showed a full understanding towards different dimensions of death conceptualization. It definitely refutes the hypothesis of persons with ID not understanding death.