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'I Know Death': Perceptions and Attitudes Towards Death Among Middle-Aged Adults With Intellectual Disabilities in South Korea

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ABSTRACT

Background: For adults with intellectual disabilities, their understanding of and preparation for death present unique challenges. This study explored how middle-aged adults with intellectual disabilities perceive death.

Method: Using purposive sampling, 21 middle-aged adults with intellectual disabilities who had experienced parental bereavement were recruited for interviews.

Results: Participants conveyed diverse interpretations and understandings of death. The reflective process deepened their emotional engagement with the concept and fostered acceptance of their mortality. They integrated the reflections into their life, striving to live with purpose and seek a fulfilling life.

Conclusions: Study findings emphasise how death perceptions, both cognitive and emotional, shaped participants' attitudes towards mortality and influenced their approach to daily life. The resulting insights can inform the development of culturally tailored interventions that promote communication about death and dying while encouraging acceptance of mortality in later life.

1 | Introduction

Questions of existence, life, and death have long occupied central places in philosophical, religious, and psychological inquiry, as they often invite profound reflection and evoke complex emotional response. Across cultures and throughout history, existential concerns have captivated philosophers, theologians, and scientists, highlighting humanity's enduring quest to understand and find meaning in mortality (e.g., Ariès 1981; Becker 1975; Heidegger 1962; Riley 1983). The concept of death holds particular significance, encompassing cultural, spiritual, and existential dimensions that continue to shape human thought and discourse (Walter 1994, 2008).

For adults with intellectual disabilities, the universal theme of death intersects uniquely with their life experiences, presenting

an underexplored area of inquiry. A common assumption is that individuals with intellectual disabilities have a limited understanding of death due to their cognitive constraints (McEvoy et al. 2002; Wiese et al. 2014). This view, however, overlooks how personal experiences, societal values, and caregiving dynamics shape their awareness of mortality. Recent studies highlight that comprehension of death is not inherently limited but is significantly influenced by the presence of appropriate supports and caregivers' willingness to engage in open discussions (Hedayioglu et al. 2022). Challenging common assumptions can deepen our understanding of how individuals with intellectual disabilities engage with mortality and loss.

Research has shown that adults with intellectual disabilities have varied understandings of death, from partial to full comprehension, often accompanied by heightened fear and anxiety

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Summary

- Middle-aged adults with intellectual disabilities interpreted death cognitively and emotionally.
- Personal experiences of parental bereavement influenced perceptions and attitudes towards death among middle-aged adults with intellectual disabilities.
- Death perceptions shaped attitudes towards mortality and influenced daily life.
- Culturally tailored interventions should be developed to promote communication about death and dying while encouraging acceptance of mortality in later life.

(Chow et al. 2017; McEvoy et al. 2012, 2017; Stancliffe et al. 2016; Tuffrey-Wijne et al. 2020). Although cognitive challenges can shape perceptions of death (McEvoy et al. 2017), emotions are central to how grief and loss are experienced (Young et al. 2017). Bereaved individuals often demonstrate strong communication skills and substantial understanding of death (Tuffrey-Wijne et al. 2020). When provided with appropriate support, they are capable of engaging in informed discussions about life-limiting conditions and end-of-life care (Cithambaram et al. 2020; Stancliffe et al. 2021). Even when comprehension is limited, people often express grief through emotional and behavioural responses such as sadness, anxiety, or distress (Brickell and Munir 2008).

Adults with intellectual disabilities often lack agency in end-of-life planning, frequently relying on caregivers or family members to make decisions (Stancliffe et al. 2016; Tuffrey-Wijne et al. 2020). Individuals are at times denied information about their illness or impending death, despite expressing a desire for information and support in planning (Reilly et al. 2020; Tuffrey-Wijne et al. 2020). Such lack of self-determination is exacerbated by discomfort that caregivers and support staff members often experience when discussing death and dying (Foo et al. 2021; Lord et al. 2017).

People with intellectual disabilities often define independence through their lived experiences and strive towards it, yet are rarely provided with adequate support to realise these goals (Parchomiuk et al. 2025). Adding to this challenge, difficulty initiating conversations about death and dying among caregivers and support staff members may leave individuals unprepared for their mortality and the loss of loved ones (Hedayioglu et al. 2022; McMaugh et al. 2017; Tuffrey-Wijne et al. 2020; Wiese et al. 2015).

Middle-aged and older adults with intellectual disabilities face unique challenges at the intersection of ageing, intellectual disabilities, and bereavement. They often recognise and interpret ageing in personal and relational ways, shaped by family context and life experience, which influences their understanding of life's progression and mortality (Trip et al. 2020). People with disabilities experience significantly higher rates of loneliness and social isolation compared to their peers without disabilities (Emerson et al. 2021). Especially those experiencing intellectual disability often feel socially excluded and lonely (Robinson and

Idle 2023). Loneliness and social isolation often intensify with age, as the emotional and social complexities of later life intersect with declining health, reduced independence, and shrinking social networks (Strnadová 2019). Such shifts are frequently associated with increased reliance on caregivers and family members, who play a central role in sustaining social and emotional support.

Research has suggested that the loss of family members can be a significant motivator for individuals with intellectual disabilities to develop a deeper understanding of death and their mortality (Wiese et al. 2013). Parental loss serves as a particularly pivotal moment for middle-aged and older adults with intellectual disabilities, because parents often play crucial roles as caregivers, advocates, and emotional anchors throughout their life (Dodd et al. 2021). The death of a parent disrupts the foundational relationships, forcing individuals to navigate profound shifts in their living and caregiving arrangements (Brickell and Munir 2008). Ageing can intensify these vulnerabilities and grief.

Middle-aged and older adults with intellectual disabilities may experience repeated losses in their social networks, such as the deaths of peers, family members or caregivers (Strnadová 2019; Wee et al. 2013; Wiese et al. 2013). Such losses can lead to diminished support and growing anxiety about the future (Clute 2017; Holmgren and Ahlström 2024a; Strnadová 2019). Recent evidence indicates an elevated risk of complicated grief that can be associated with significant functional challenges, compared with the general population (O'Riordan et al. 2022; Shear et al. 2014). Grief can be shaped by direct exposure to illness or death, deepening individuals' awareness and understanding of mortality (Dusart 2008). Without adequate emotional support or cognitively accessible explanations, repeated losses may heighten feelings of confusion, fear, and psychological distress (Gascón et al. 2022; Morgan and McEvoy 2014). Despite the importance of enhancing well-being and informing caregivers, healthcare providers, and policymakers about systems that uphold autonomy, dignity, and emotional needs, middle-aged and older adults with intellectual disabilities continue to be marginalised in research on grief, loss, and ageing (Kim, Yi, et al. 2021; Holmgren and Ahlström 2024a).

In cultural contexts such as South Korea, these challenges are further compounded by societal taboos surrounding death. Confucianism, a deep influence in South Korean culture, prioritises the continuity of life and legacy, emphasising the duties of the living to honour their ancestors and ensure the family line continues. Cultural emphases on familial and societal roles tend to redirect attention away from individual mortality towards obligations during life (Yun et al. 2022), with discussions about death often regarded as unnecessary and therefore avoided (Shin et al. 2016). South Korean cultural norms often discourage open discussions about mortality, leading to limited attention to end-of-life issues (Kwak and Salmon 2007). Adults with intellectual disabilities in South Korea tend to focus on achieving independence or assume that they will reside in care facilities as they age, rather than preparing for their mortality (Shin and Kim 2018). Additionally, individuals with intellectual disabilities and their families rarely plan for end-of-life care, exacerbating the challenges they face in addressing their emotional and practical needs (Kim, Lee, and Kim 2021).

The present study explored the following research question: ‘How do parentally bereaved middle-aged adults with intellectual disabilities in South Korea conceptualise and perceive death?’ South Korea’s population includes approximately 2,631,356 individuals with disabilities, representing 5.1% of the total population. Approximately 233,322 individuals have intellectual disabilities, representing 8.9% of all registered people with disabilities in the country (Ministry of Health and Welfare of South Korea 2025a, 2025b). Of this group, 77,738 individuals are between ages 40 and 64, accounting for 33.3% of people with intellectual disabilities (Ministry of Health and Welfare of South Korea 2025a, 2025b). With advancing age, attention to perceptions of death and bereavement among this population becomes increasingly important, not only for addressing emotional and practical needs but also for guiding culturally sensitive practises and policies that respect dignity and self-determination.

2 | Methods

2.1 | Participants

Inclusion criteria required participants to be adults with intellectual disabilities aged 40 or older who had experienced the bereavement of one or both parents. To mitigate potential psychological distress, individuals were excluded if their bereavement had occurred in the past 6 months. Additionally, those living in large-scale residential facilities were excluded, because their experiences of parental bereavement might differ from those in smaller or familial settings.

As shown in Table 1, the sample featured 21 bereaved adults with intellectual disabilities (13 female and eight male). All participants were born and currently resided in South Korea. Their mean age was 50.4 years (standard deviation = 6.0), ranging from 40 to 60. Seventeen participants were not married and four were married. Based on the conceptual framework defined by the American Association on Intellectual and Developmental Disabilities model (Schalock et al. 2021), participants exhibited varying levels of support needs. Ten participants had minimal support needs, eight had regular support needs, and three had extensive support needs. Sixteen participants lived with their families, although three lived alone and two resided in a group home. Twelve participants had lost their father, four had lost their mother, and five had lost both parents. The time since their primary bereavement ranged from 1 to 30 years with a mean of 9.6 years (standard deviation = 8.2). Fifteen participants had experienced their loss more than 5 years prior, whereas six had experienced it in the past 5 years.

2.2 | Procedures

This study was approved by the Institutional Review Board of the University with which the principal investigator is affiliated. The analysis drew on data from a qualitative inquiry aimed at enhancing the understanding of bereavement and perceptions of death among middle-aged individuals with intellectual disabilities. While a prior publication using this dataset examined their overall parental bereavement experiences (Kim et al. 2023), the

present study focused on their perceptions and understanding of death.

The participant selection process adhered to inclusion and exclusion criteria to ensure the collection of relevant and meaningful data. Using purposive sampling, the research team recruited potential participants by distributing an announcement that outlined the study’s objectives, participant inclusion criteria, and researcher contact information to relevant organisations, such as welfare and daycare centres for individuals with disabilities. The study was further promoted through a bulletin posted on the website of the Parents of the Disabled Association. Purposive sampling was used due to the difficulty of accessing adults with intellectual disabilities who have experienced parental bereavement. Transitions to long-term care facilities in later adulthood are common within this population, creating practical challenges for sustained access and engagement. Recruitment through disability-related organisations and support networks facilitated access to potential participants and leveraged trust in these communities. Interested individuals were asked to verify their eligibility by contacting the research team via telephone. Twenty-three participants from South Korea, including areas such as Seoul, Incheon, and Gyeonggi-do, volunteered to participate in the study. Two participants later withdrew during the study, resulting in a final sample of 21 participants.

In-depth interviews ranging from 30 min to 1 h and 20 min were conducted in 2022. The choice of interview locations sought to balance privacy, accessibility, and participant comfort—key factors known to influence the quality of qualitative data collection. Fifteen interviews were held in meeting rooms at community centres that participants regularly used, providing a familiar and accessible environment that enhanced their sense of comfort and trust. Five interviews took place in study rooms or quiet cafes in participants’ local neighbourhoods, selected for their convenience and to foster a more informal, less clinical atmosphere that could encourage open sharing. One interview occurred at the participant’s home at their request, offering a highly familiar and comfortable setting that may have facilitated more candid and in-depth responses.

The principal investigator and three graduate students, all of whom had prior research or clinical experience with individuals with intellectual disabilities, facilitated the interviews. Before conducting interviews, each interviewer completed targeted training focused on qualitative interviewing techniques with people with intellectual disabilities. This training included discussions of effective communication strategies, rapport building, the use of plain language, and techniques for checking comprehension and consent. Additionally, training sessions emphasised the importance of being attuned to participants’ verbal and nonverbal cues to ensure that their perspectives were accurately captured.

To address potential interviewer bias, the interviewers engaged in continuous reflexive practise throughout the data collection process, consistent with approaches to reflexivity commonly used in qualitative research (Berger 2015). Immediately following each interview, interviewers wrote detailed field notes capturing initial impressions, contextual factors, and any perceived influence of their perspectives on interaction. Regular debriefing

TABLE 1 | Sample characteristics ($n = 21$).

Pseudonym	Age	Gender	Marital status	Support needs	Living circumstances	Parental loss	Time elapsed since loss
Jin	47	Male	Not married	Minimal support	Living in a group home	Father	10 years
Kyungsoo	42	Male	Not married	Regular support	Living with families	Father	10 months
Somi	53	Female	Not married	Minimal support	Living with families	Mother	5 years
Eunha	56	Female	Not married	Regular support	Living alone	Both	9 years
Wongi	44	Male	Not married	Extensive support	Living with families	Father	20 years
Boram	55	Female	Married	Minimal support	Living with families	Father	8 months
Yuna	44	Female	Not married	Minimal support	Living with families	Father	5 years
Jihwan	60	Male	Not married	Minimal support	Living in a group home	Both	7 years
Kimin	44	Male	Not married	Regular support	Living alone	Both	1 years
Woojin	54	Male	Not married	Regular support	Living with families	Mother	16 years
Youngji	52	Female	Not married	Minimal support	Living with families	Mother	15 years
Momi	50	Female	Not married	Extensive support	Living with families	Father	3 years
Nami	48	Female	Not married	Minimal support	Living alone	Mother	13 years
Hoon	59	Male	Not married	Regular support	Living with families	Father	30 years
Hyori	43	Female	Not married	Minimal support	Living with families	Both	7 years
Yuri	40	Female	Not married	Regular support	Living with families	Father	6 years
Minjun	54	Male	Not married	Extensive support	Living with families	Father	6 months
Jiwoo	50	Female	Married	Regular support	Living with families	Father	11 years
Yerin	59	Female	Married	Minimal support	Living with families	Both	6 months
Daeun	53	Female	Married	Minimal support	Living with families	Father	20 years
Sunjoon	51	Female	Not married	Regular support	Living with families	Father	20 years

sessions occurred among interviewers throughout the data collection process to discuss challenges, share reflections, and identify potential biases that could affect data interpretation. These discussions helped refine interviewing approaches and

fostered critical awareness of how the researchers' knowledge backgrounds, assumptions, and beliefs—including cultural or religious perspectives on bereavement and the afterlife—might influence the interviews. For example, interviewers made a

conscious effort to incorporate participants' spiritual or religious frameworks (such as Christian concepts of heaven or angels or Buddhist ideas of reincarnation) into the discussions to ensure a more participant-centred and culturally sensitive approach.

The researchers sought to establish rapport with participants by engaging in simple, conversational exchanges, aiming to foster a comfortable environment conducive to open discussion. Participants were encouraged to share their thoughts and perceptions about death, guided by the main question: 'How do you understand death?' To help participants understand the interview questions better, the researchers used prompts designed to elicit thoughtful responses. These included questions such as, 'How do you feel when you think of death?' and 'What comes to your mind when you think of death?' The prompts were designed to encourage reflection and ensure that participants' responses were clear and meaningful. To promote full comprehension of participants with intellectual disabilities during the interviews, the interviewers used simplified language and provided sufficient explanations. In addition, photos and visual aids from the internet were used to explain difficult terms, such as graveyards and columbaria.

Ethics specific to qualitative research involving sensitive topics such as death, especially among participants with intellectual disabilities, were considered. First, the informed consent process ensured full comprehension using both written and verbal consent with simplified language, and the study team provided detailed information on the potential harm or risk and benefits of the research. Participants had sufficient time to review this material.

Second, interview time and duration was thoughtfully determined, considering the participants' condition. Five participants requested their personal assistant to be present to increase the clarity of the interview questions or clarify the participants' answers.

Third, interviewers were trained to recognise signs of distress and provide immediate emotional support if needed, such as offering comforting words, acknowledging participants' emotions, and reminding them that they could withdraw at any time without penalty. Additionally, break time was allocated and interviewers continuously checked in with participants' comfort and emotional state during the interviews. Four participants reported difficulties in concentration and psychological stress when participating in the interviews, prompting the interviewers to stop the discussion and arrange an additional interview either another day or after taking a break. When necessary, participants received information on local mental health resources and support services that could be contacted after the interview to ensure ongoing emotional well-being.

2.3 | Analysis

The research team brings together varied experiences with disability. Team members include individuals with long-standing clinical experience in disability services as well as those newer to the field. One member recently acquired a disability through a back injury and another through a movement disorder, offering

fresh personal perspectives alongside academic expertise. There is a wide range of belief and religious systems in the team, and none have lived experience with intellectual disabilities. Ongoing discussions were held to reflect on how their assumptions, backgrounds, and experiences might shape data interpretation, fostering critical reflexivity. When disagreements between coders emerged, they adopted a consensus approach, whereby all coders discussed their differing interpretations in detail, shared their perspectives, and reached a mutual agreement on the most appropriate coding and subtheme categorisation. This method ensured that all voices were heard and that thematic decisions reflected a balanced and inclusive interpretation of the data. Subthemes were reorganised as many times as necessary to achieve consensus.

The interviews were audio recorded with participants' permission and subsequently transcribed verbatim. Using ATLAS.ti software, two researchers conducted thematic analysis following the guidance by Braun and Clarke (2006). Open codes were generated independently, then shared among the team members. The research team reviewed the open codes and categorised them into subthemes. This collaborative process occurred multiple times to ensure that the open codes and subthemes were accurate and appropriately aligned. For example, several open codes (e.g., 'Thinking about the fact that a person can die one day,' 'Realizing that as I grow older, I too will die, just like my parents,' and 'Feeling that I must accept this, even though death is scary') were combined into the subtheme 'Approaching my death with calm acceptance'.

Member checking and peer debriefing strategies were used to enhance credibility and trustworthiness. One participant had the opportunity to review and validate the themes derived from their interview. Additionally, findings were shared and discussed with independent researchers with expertise in this domain who were not part of the research team to minimise any researcher bias.

3 | Findings

3.1 | Cognitive Understanding of Death

3.1.1 | Understanding the Reality of Death

Although four participants did not recall the precise timing of their parents' deaths, other participants exhibited a clear awareness of these events. They provided detailed accounts, such as their age at the time, presence of family members, and general circumstances surrounding the loss. Details included specific information such as the year, date, and time of death. Their narratives often included extensive knowledge of their parents' illnesses.

My dad died when my younger one was a baby. (It's been) 20 years (since he died). Liver cancer. He drank a lot. (He) didn't eat meals, just drank. No food, just drinking. Then, later, (we found out) he had liver cancer. He had surgery, but they said no hope (Daeun, 53 years old, minimal support).

Four participants were present during their parents' final moments, witnessing medical emergencies or their transportation to the hospital by ambulance. The urgency of these moments, such as seeing their parents collapse or vomit blood, had a lasting and profound impact. Eunha, who lived with her mother, described the traumatic experience of returning home after attending a community centre programme to find her mother lying on the floor and bleeding. In a state of panic, she reached out for help from others, including the community centre staff, a church pastor, her older sister, and teachers. Accounts of the sudden death of a parent frequently involved expressions of intense fear and distress. Their vivid recollections and emotional responses underscored how such events shaped their understanding of death and influenced their coping.

At 6:15 p.m., I called a church pastor. I called my sister. I called the homeroom teacher at the community centre. My teacher helped with everything. My teacher called 119 (South Korean emergency number) and all that. But (Mom) passed away. Mom was (acting) weird at home. (She collapsed) like this, suddenly. There's a big bed. And more blood came out (of her). I was alone. (I told her to) come quickly. I'm scared alone. So, I called everyone and told them to come fast (Eunha, 56 years old, regular support).

3.1.2 | Perceiving Death as a Transition to the Afterlife

Death was understood as 'going to the afterlife'. The deceased parent was described as now being in heaven or another afterlife realm. This belief was often rooted in religious views, though participants who were not religious shared a common belief in life after death. Participants used expressions such as 'the place where God is' or 'going up holding hands with angels and Jesus' to describe where they believed their deceased parents had gone.

Heaven is where God is. A happy place. When you die, you go to heaven. Everyone goes (to heaven) when they die (Jihwan, 60 years old, minimal support).

The terms 'afterlife' and 'heaven/sky' in this context do not necessarily correspond to a single religious doctrine. In traditional South Korean culture, after death, souls are believed to journey to a spiritual realm where they continue to exist and can influence the lives of the living. Participants described death using both religiously influenced notions of an afterlife and culturally rooted beliefs that emphasise ongoing spiritual connection and ancestral ties to deceased parents. They expressed a desire to join their deceased parents 'soon' in a place perceived as comforting and desirable. Somi expressed a longing to be reunited with her mother and reflected on the afterlife, whereas Jin focused more on understanding death.

I'm really curious (about death). I want to go to heaven quickly. (I want to) go there quickly and see my mom' (Somi, 53 years old, minimal support).

I'm curious (about what happens after death). I miss my dad, but I cannot see him. Because he went to heaven (the afterlife) recently (Jin, 47 years old, minimal support).

3.1.3 | Embracing the Inevitability of Death

Participants acknowledged death as an inevitable, inescapable part of life, often associated with illness or ageing, or simply a universal experience everyone will face at some point. This recognition reflects their understanding of the finite nature of life.

When you get really old, you die. ... I (thought about it) a lot. When I get really old (I will die). Once, you would (die). We all would go (to die) (Wongi, 44 years old, extensive support).

Awareness and acceptance of death were shaped not by books or formal education, but by personal experience—particularly the loss of parents and witnessing the process of death firsthand. Daeun, for instance, described death as a transition to another realm, cessation of bodily functions, and loss of sensory perception, including sight. Although they found death frightening, they also recognised its inevitability and the need for acceptance. This understanding included the realisation that not only would their older siblings face mortality, but so would they.

Why wouldn't (death) be scary? It is scary. People say, 'I'm not scared (of dying)'. But when death actually comes (anyone would be scared). When you die, you can't see anything. You don't hear anything from earth. Because your body disappears. It is death (Daeun, 53 years old, minimal support).

3.2 | Emotional Response and Process of Acceptance

3.2.1 | Experiencing Death as a Source of Fear and Sadness

Although they had experienced the loss of at least one parent, participants reported never being taught about death or having it explained to them. The death of a parent often served as the first significant encounter with mortality. Participants described death as a barrier to seeing loved ones again and connected it to feelings of sadness, fear, emptiness, and loneliness, particularly when it occurred through illness or disease. Their narratives consistently framed the experience of loss with deeply negative emotions.

I think death isn't good. It feels empty now without Dad (Kyungsoo, 42 years old, regular support).

Respondents described death not only as a sad event but also as something inherently negative and unsettling. They strongly expressed aversion to the idea of dying. Minjun, for instance, described the belief that after death, one is confined to a coffin,

an idea he found both distressing and frustrating, especially due to his experience of feeling constricted when being bedridden because of an illness. This perception highlighted his negative association with death. Similarly, Sunjoo expressed a strong determination to avoid death altogether, stating firmly that she would not die. Yerin's fear of death increased after witnessing various forms of mortality. Exposure to deaths caused by societal or natural disasters such as the spread of infectious diseases such as COVID-19 and floods heightened their perception of life's fragility. Moreover, the loss of a younger sibling emphasised the unpredictable and uncontrollable nature of death.

Participants also grappled with their mortality, reflecting on their fear of death and the uncertainty surrounding when and how they might die. Anxiety emerged regarding the timing and circumstances of dying, including fears of illness or unexpected accidents. Jin, who moved to a group home after losing his parents, shared discomfort about the possibility of having no one to care for him at the end of life. Boram feared dying from illness, whereas Yerin expressed a particular fear of dying unexpectedly in an accident. These sentiments underscored their complex emotions and concerns regarding mortality.

I could die from being very sick. I think I only know when it happens. (When I think about dying), I feel strange' (Hyori, 43 years old, minimal support).

Sometimes people die because of pain. Sometimes it's because they are sick. It's sad. It's scary (Yerin, 59 years old, minimal support).

Fears related to the afterlife also emerged, shaped in part by religious beliefs. One participant was particularly concerned about the possibility of going to hell, something they linked to irregular church attendance. In contrast, Hyori described a belief in reincarnation and feared that failing to live a virtuous life could lead to being reborn as a nonhuman creature. She expressed anxiety about her past actions, uncertain if she had lived in accordance with her beliefs.

(I do) think I can be reborn after I die. I believe in Buddha. (In Buddhism, they say) if you live badly and die, you can be reborn as an animal. I wonder if I did something wrong. It's a bit scary. If I'm reborn, I wonder if I can be reborn nicely, beautifully. But I feel like I'll be reborn as an animal (Hyori, 43 years old, minimal support).

3.2.2 | Approaching My Death With Calm Acceptance

Although fear of death was commonly expressed, other accounts were grounded in a sense of peace, particularly through belief in an afterlife such as heaven or a similar realm. In these narratives, participants described their deceased parents who had suffered from illness and pain as now being liberated and at peace. This belief helped ease participants' apprehensions about death. Additionally, the idea of being reunited with loved ones in heaven transformed death into something less intimidating and even something to

anticipate. For instance, Nami shared that her lack of fear towards death stemmed from the belief that God was watching over her deceased mother in heaven, which provided comfort and a sense of reassurance about death. These findings underscore how participants' spiritual perspectives and beliefs in an afterlife helped them cope with the fear and uncertainty surrounding death, offering them a hopeful outlook and emotional solace.

(My father's last moments were) peaceful. He was always in pain and noisy. ... (When I die), I think I'll be at peace. No thoughts. Dying seems better. I'm not scared (of death) at all (Yuna, 44 years old, minimal support).

In contrast, Daeun, who did not follow a specific religion, expressed a more secular view of death as part of the natural course of life. She described a desire to accept death peacefully when it comes, without the belief in a defined afterlife or religious framework.

Of course, we all (die) once. People don't know what will happen tomorrow. We don't know when we'll die. We could die in our sleep. When a person dies, we must accept it calmly (Daeun, 53 years old, minimal support).

The wish for a prolonged and healthy life was not shared uniformly among participants. Participants expressed readiness to accept death calmly when it arrives—perspectives shaped by life histories marked by caregiving burdens, financial difficulties, and other forms of hardship. For instance, Yuna, who raised a child with a disability on her own, shared feelings of exhaustion and a lack of desire to continue living now that her child had grown. Similarly, Somi expressed hopes for a swift passing, indicating a sense of readiness for life's end. These perspectives highlight the diversity of attitudes towards life and death among participants, shaped by personal experiences, caregiving duties, and challenges encountered throughout their life.

I really want to go (to heaven). I almost died three times but came back. At that time, my baby was young, so (God) let me live. But now, my baby has all grown up. I'm so tired of living. Those who have raised a disabled child would understand. It's the hardest. And I'm the only one enduring it. ... Other people all have their own houses. But I have a house from the country (social housing). I want a house, even if it's not mine, just a slightly better one. I don't feel like living much (Yuna, 44 years old, minimal support).

3.2.3 | Feeling Comfort and Connection Thinking About My Dead Parents

Participants described a comforting belief that their deceased parents were now watching over them from a serene and peaceful realm, often conceptualised as heaven or the afterlife, in line with their religious beliefs and personal convictions. Participants imagined their parents, who had endured significant illness during their lives, now experiencing liberation from

pain and suffering. They envisioned their parents engaging in joyful activities, such as playing cards, smiling brightly, and contentedly observing their family from the afterlife. This belief provided solace by allowing participants to envision their loved ones liberated from suffering and finding comfort and happiness in the afterlife.

I think (my father who passed away) is in heaven. In heaven, he's probably drinking and playing cards. I feel like (I can) hear him (talking to me). Like he said goodbye from heaven and told me to see him later. It feels nice (Kyungsoo, 42 years old, regular support).

Furthermore, participants said that their deceased parents continued to wish for their well-being and success. This conviction offered comfort and reassurance, particularly for those grappling with profound parental loss. Knowing that their parents wanted them to live well provided participants with a sense of enduring support. They found peace in the belief that their parents were protecting and watching over them, even if they were no longer physically present. Such belief helped foster a sense of connection beyond physical realm and emotional strength.

If (he is) in heaven, he would be watching over us well. My father is protecting us. (So), it feels good (Sunjoo, 51 years old, regular support).

3.3 | Living With Purpose

3.3.1 | Desiring to Live Forever Without Facing Mortality

A wish for longevity emerged across participant accounts, suggesting a tendency to engage with the idea of mortality indirectly. The age of 100 was framed as a marker of an energetic and meaningful life. Jin, for example, articulated a desire to continue working into old age, emphasising the significance of maintaining a daily routine. Similarly, Jihwan, who said he was still in his prime at age 60, credited advancements in medical technology for enhancing life expectancy. Participants expressed confidence about ageing and embraced a positive outlook on longevity, articulating hopes for an active and prolonged life while emphasising the importance of preserving independence and maintaining familiar routines into later years.

(I'm still a) young man. I'm not an old man. At 100 years old, (I'll be) an old man. (I want to live) to be 100 years old. Life expectancy has increased now, so if I don't get cancer, I think I can live (that long) (Jihwan, 60 years old, minimal support).

Kyungsoo expressed a particularly poignant desire to live a long life alongside his mother, after the loss of his father. He envisioned a future dedicated to supporting and caring for his mother while maintaining his own health. This aspiration underscores the participant's strong familial bonds and view of longevity to sustain and nurture his role in the family.

I want to live forever. I want to help my mom. I want to work with my mom. My mom's knees and back hurt (Kyungsoo, 42 years old, regular support).

3.3.2 | Striving for Health and Vitality in Later Years

Participants demonstrated a proactive approach to longevity by emphasising healthy lifestyle choices. They engaged in regular physical activity, maintained a balanced diet, and refrained from alcohol and tobacco use as part of their strategy to promote well-being. Somi, for example, highlighted a holistic approach to living a long life that combined prayer, regular exercise, a nutritious diet, and leisure activities such as watching films and travelling. Participants envisioned their old age as a time enriched by meaningful connections and experiences. This commitment reflects participants' desire to lead an active, healthy life and enjoy their later years to the fullest.

I must exercise and be healthy. Set the timer for 30 min and walk. To get healthy. Not eating salty food (Boram, 55 years old, minimal support).

(To live long), you must eat good food. Get dentures. (You) must make an effort. Exercise hard. Do stretches hard. (I want to live long so I) eat good food, watch movies, and go on trips (Somi, 53 years old, minimal support).

4 | Discussion

This study explored the diverse perceptions of death among South Korean middle-aged adults with intellectual disabilities. The findings highlight how both cognitive and emotional interpretations of death shaped their attitudes towards mortality and influenced their daily life.

A key finding of this study is that personal experiences of bereavement shaped emotional responses to death. Perceptions of death are dynamic, influenced by personal experiences, past losses, and support available during the grieving process (Brickell and Munir 2008; Chow et al. 2017). Despite the common assumption that discussing death with individuals with intellectual disabilities may be distressing or harmful (Ryan et al. 2011), such conversations can be safe and beneficial when approached with sensitivity and appropriate support (Stancliffe et al. 2021). Providing structured opportunities for individuals with intellectual disabilities to explore thoughts on mortality and loss can reduce anxiety and aid in processing grief. Thus, tailored support to help them navigate their evolving perceptions of death should be provided.

The process of bereavement in this study appeared to encourage participants to reflect on their mortality and develop a sense of acceptance. Notably, reflections on deceased parents as a source of security appeared across participant narratives, suggesting that grief can play a central role in reshaping perspectives on mortality. This finding contrasts with previous

findings that adults with intellectual disabilities struggled to define ageing, avoided related discussions, or viewed it negatively (Burke et al. 2014; Holmgren and Ahlström 2024b). These differences may be attributed to the impact of bereavement, which forces individuals to confront the reality of mortality, potentially leading to a more integrated understanding of ageing and death.

However, not all participants viewed mortality with apprehension. Those who had endured lifelong challenges such as caregiving burdens, economic hardship, and personal struggles, expressed a sense of readiness to embrace death peacefully when it arrives. For these individuals, they viewed death as a natural or even welcome end to prolonged hardship. However, this sense of readiness should be interpreted with caution, as it may reflect underlying vulnerability or emotional fatigue rather than genuine acceptance. Further research and careful assessment are needed to distinguish between adaptive acceptance and forms of distress that may require additional support. Although participants demonstrated varying degrees of acceptance of mortality, the emotional toll of bereavement warrants careful consideration. The same life experiences that foster a sense of readiness for death can also contribute to heightened distress. Significant life events, including major life transitions, interpersonal conflicts, and the loss of a parent, have been associated with heightened psychological vulnerability among individuals with intellectual disabilities (Dodd et al. 2016; Persechino et al. 2025). Emerging evidence further suggests that distress in this population may be under-recognised due to social isolation, communication barriers, and challenges in meaning-making related to life and death (Chan and Bhandarkar 2025). Future research should explore how expressions of mortality acceptance relate to social and emotional support needs, with the aim of informing interventions that promote resilience while mitigating distress in the context of bereavement.

Beyond cognitive and emotional processing of death, this study also revealed that participants expressed a sense of purpose in life. Many participants expressed a strong desire to live a long life, framing continued existence as meaningful through engagement in health-promoting behaviours and long-term goal setting. Confronting death can be a motivating factor to prioritise well-being and proactively shape their future. These orientations towards well-being and future planning reflect how participants understood and responded to mortality, suggesting that awareness of death informed their motivation to sustain health, routines, and valued social roles (Bevan et al. 2014; Spitzenstätter and Schnell 2022).

Emphasis on longevity may also reflect a desire for stability and control in the face of uncertainty, particularly considering the structural and social challenges that individuals with intellectual disabilities often face. Future research should further examine how reflections on death influence not only emotional well-being but also health behaviours and lifestyle choices. Understanding these motivations can inform interventions that support both emotional processing and the promotion of long-term well-being, ensuring that discussions of mortality contribute to a sense of empowerment rather than distress.

Cultural attitudes towards discussing death often function as barriers to end-of-life care planning for individuals with intellectual disabilities (Bruun et al. 2025). In South Korea, Confucian cultural values—particularly those emphasising family harmony, filial piety, and the continuation of an ancestral lineage—deeply shape societal views on death and dying. Death is often treated as taboo, with open discussions perceived as disruptive to family unity and even an omen that may bring misfortune (Ha et al. 2023; Lee et al. 2024; Yun et al. 2022). Such avoidance is further intensified for individuals with intellectual disabilities, whose cognitive and communicative differences are often misunderstood as an inability to engage with abstract or emotionally charged topics like death. Traditional family structures, which emphasise hierarchical authority and parental responsibility, often lead families to managing care unilaterally without involving the individual with intellectual disabilities. As a result, many families lack concrete future care plans and report significant anxiety about their capacity to provide ongoing support, contributing to vague or absent planning and a reluctance to include individuals with intellectual disabilities in conversations about death (Kim, Lee, and Kim 2021; Lee and Kim 2021). Limited access to death-related education among individuals with intellectual disabilities can result in reduced preparation for bereavement and barriers to accessing services that support end-of-life planning.

Cultural avoidance of death occurs across societies, but it takes distinct forms depending on cultural context. In South Korea, Confucian-influenced norms emphasising intergenerational obligation and social harmony shape how death is discussed, creating conditions in which individuals with intellectual disabilities may experience compounded marginalisation through both disability-related stigma and cultural silence surrounding mortality. In contrast, research from western contexts—where individual autonomy and rights-based disability services are more prominent—has documented more intentional efforts to include individuals with intellectual disabilities in end-of-life planning and death-related education. Nevertheless, even in these settings, challenges persist in providing appropriate communication and emotional support (Bruun et al. 2025). Attending to these cultural dynamics is therefore critical for developing support systems that enable individuals with intellectual disabilities to engage with questions of mortality in ways that align with their cognitive and emotional capacities. In South Korea, the Act on Welfare of Individuals with Disabilities stipulates that residential facilities for people with disabilities should consider their needs regarding end-of-life care and death (Ministry of Health and Welfare of South Korea 2025a, 2025b). Additionally, a manual has been developed to guide caregivers during the ageing and death of older adults with intellectual disabilities (Ministry of Health and Welfare of South Korea 2017). However, education or training for people with intellectual disabilities to prepare for their own death remains inadequate. In cultural contexts where discussing one's own death is considered taboo, tailored education is needed to help people with intellectual disabilities better understand ageing and death and to prepare for end-of-life care in ways that are both accessible and culturally sensitive. Intervention programmes have demonstrated effectiveness in improving death awareness and coping mechanisms. Fernández-Ávalos et al. (2023) found that a structured intervention programme improved individuals' understanding of the

inevitability and universality of death, along with their grief processes and attitudes towards mortality.

Emotional responses to death may not always be expressed in conventional ways. Grief among individuals with intellectual disabilities may be communicated through diverse verbal and behavioural expressions. Although the participants in this study were able to articulate their emotions, those who do not express grief verbally are not necessarily unaffected by their mortality. Recognising nonverbal expressions of distress as equally valid is essential for ensuring that bereavement support is accessible and appropriate for diverse communication styles. Individuals with intellectual disabilities should have opportunities to explore their thoughts and emotions in ways that feel natural to them. Having accessible ways to engage with the topic could help them process grief and develop a better understanding of mortality. Creative outlets such as drawing, storytelling, or music can be used to support emotional expression without relying solely on verbal communication. As visual media are often used when interviewing participants with intellectual disabilities in research on death and dying (Diaz et al. 2024), memory boxes or picture albums may offer comfort by serving as tangible reminders of the deceased, reinforcing positive memories and solidifying the concept of loss. Honouring the deceased through simple activities like lighting a candle, planting a tree, or participating in memorial events may foster a sense of connection and continuity. Introducing discussions about death in a gradual and supportive manner—such as through conversations about life cycles or the use of stories—may be especially helpful when a parent or caregiver is ageing or terminally ill, as this can lessen the emotional shock of loss when it occurs. Reassurance, patience, and environmental stability are crucial in supporting individuals to grieve in their own way. Future research should explore how different sociocultural contexts influence death perceptions among individuals with intellectual disabilities, including the role of spirituality, caregiving structures, and community support systems. Longitudinal studies could also examine how perceptions of mortality evolve over time and how various support mechanisms contribute to emotional adaptation and well-being.

Culturally appropriate and rights-based interventions are essential to support South Korean middle-aged adults with intellectual disabilities in navigating bereavement and understanding mortality. Structured death education programmes should use accessible materials, such as pictures, simplified language, and visual stories, that reflect cognitive capacity and cultural context. These programmes can address topics such as the lifecycle, what happens when someone dies, and rituals associated with honouring ancestors. Integration of familiar cultural elements, such as memorial ceremonies or ancestral rites, could reduce discomfort while fostering understanding. Creative expression methods, including drawing, storytelling, and memory boxes, should be offered as nonverbal avenues for grief expression. Such approaches not only respect communication differences but also reinforce emotional processing through tangible, symbolic acts. Integrating such practises into community centres, group homes, or day programmes would promote consistent, contextually appropriate engagement with death and bereavement. These interventions should affirm the autonomy of individuals with intellectual disabilities by supporting their right to be fully informed, to express preferences, and to participate meaningfully

in end-of-life planning and grieving processes. Recognising accessible death education as a fundamental human right underscores the need for individualised approaches that accommodate diverse cognitive, emotional, and cultural needs.

Caregiver and professional training programmes are needed to equip families, social workers, and disability support staff members with the skills to engage in compassionate and culturally sensitive conversations about death. Workshops for caregivers should focus on understanding how grief may be expressed differently, recognising nonverbal signs of distress, and reducing fears related to involving individuals with intellectual disabilities in end-of-life planning. The development of visual or simplified tools for advance care planning can foster autonomy and participation. These efforts should engage individuals with intellectual disabilities not only as recipients of support but also as codesigners of educational materials and services—ensuring their voices inform practise, policy, and advocacy. Policy-level changes are also necessary, including revisions to national care guidelines and practise frameworks to explicitly incorporate education on ageing, death, and grief. A rights-based approach must recognise intersectional factors—such as gender, socioeconomic status, or type of living arrangement—that influence access to support. Finally, safeguarding measures are essential to prevent exploitation, emotional harm, or paternalistic exclusion during sensitive discussions about death. Inclusive, culturally grounded, and ethically sound practises can empower individuals with intellectual disabilities to engage with mortality with dignity, agency, and support.

4.1 | Limitations

The findings of this study should be interpreted in light of several limitations. First, some participants' perceptions were shaped by their religious beliefs, which may have significantly influenced their emotional responses to death and views of the afterlife. While not all participants identified as religious, these beliefs may have affected the overall findings. Future research should further examine the role of religious beliefs in shaping perceptions of death. Second, the study did not consider participants' level of communication with family or support staff members, nor did it account for their prior educational experiences related to death and dying. The participants' level of intellectual disabilities and socioemotional development may have shaped their narratives yet were not systematically analysed in this study. Researchers should investigate how these factors affect perceptions of death and attitudes towards mortality. Third, elapsed time since participants' parental bereavement varied widely, which might have affected their recollections and narratives. Future studies could explore how narratives differ according to elapsed time since parental bereavement.

Fourth, although the interviewers made efforts to create supportive relationships, interview dynamics may have influenced the participants' narratives. Given the historical marginalisation of individuals with intellectual disabilities and the hierarchical nature of researcher–participant interactions, participants may have shaped their responses based on perceived expectations or a desire to please the interviewer. This dynamic could have influenced the depth or authenticity of the narratives, especially when discussing emotionally sensitive topics such as death and

bereavement. Future research should explore alternative or participatory methods that minimise hierarchical dynamics and empower individuals with intellectual disabilities as collaborative researchers or narrators of their stories.

Fifth, our purposive recruitment strategy could have introduced biases that warrant reflection. By relying on organisations and networks that support individuals with disabilities, the sampling process may have overrepresented those already engaged with formal support systems, thereby potentially underrepresenting individuals who are isolated or disconnected from such services. The use of organisational announcements and websites as recruitment tools may have inadvertently excluded individuals with limited internet access or those not engaged with disability advocacy groups. This may have limited the diversity of experiences represented in the study and affected the transferability of the findings. Additionally, participants' willingness to engage with the research team may reflect a self-selection bias; those with more motivation or comfort regarding discussing bereavement might have been more likely to volunteer. Despite these limitations, purposive sampling was deemed appropriate given the study's exploratory aim of capturing nuanced, in-depth experiences from this specific, hard-to-reach population. Future studies might consider integrating additional recruitment methods—such as outreach through healthcare providers, community outreach workers, or snowball sampling—to enhance sample diversity and mitigate potential biases introduced by organisational recruitment.

Finally, our study only focused on people with intellectual disabilities in the South Korean cultural context. Study findings should not be interpreted as representative of a unified or homogeneous cultural framework. When considering their relevance beyond the study setting, careful attention should be given to specific sociohistorical and cultural contexts, territorial differences, and the enduring impacts of colonialism (Abay and Soldatic 2024). Given these contextual variations, the transferability of the findings is limited, underscoring the need for comparative research across diverse cultural settings and disability groups.

5 | Conclusion

Although discussions of death are often constrained by cultural taboos in South Korean society, individuals with intellectual disabilities have the right and capacity to understand mortality. Breaking this silence and incorporating comprehensive death education into learning and support systems is essential. By deepening our understanding of death perceptions among middle-aged adults with intellectual disabilities, we can better inform policies and interventions that foster resilience, emotional well-being, and a sense of purpose in later life. Study findings emphasise the importance of incorporating culturally appropriate approaches in bereavement support for individuals with intellectual disabilities, prioritising understanding, acceptance, and empowerment rather than fear or avoidance.

Author Contributions

Jaehye Yi: study conception and design, analysis and interpretation of results, draft manuscript preparation, review and editing; **Min Ah**

Kim: study conception and design, data collection, analysis and interpretation of results, draft manuscript preparation, review and editing; **Seong Young Lee:** analysis and interpretation of results, draft manuscript preparation, review and editing; **Shinyeong Hwang:** data collection, analysis and interpretation of results; **Chaerim Park:** data collection, analysis and interpretation of results. All authors reviewed the results and approved the final version of the manuscript.

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Ethics Statement

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Ethical approval was obtained from the institutional review board of the Sungkyunkwan University (SKKU 2022-05-018).

Consent

The research was undertaken with the understanding and written consent of each participant.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data are not publicly available due to privacy.

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