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How do Adults with an Intellectual Disability Experience

Bereavement and Grief? A Qualitative Exploration.

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Abstract

This qualitative study explored the lived experiences of bereavement and grief in 13 adults with an intellectual disability (ID). Four themes which mediated individuals' experience of bereavement and grief were identified: (1) Intra- and inter-personal experiences, (2) Core beliefs about life and death, (3) Level of inclusion, and (4) Continuing relationship with the deceased. The findings suggest that the participants experienced bereavement and grief in a manner similar to that of the general population, and endorse the role of clear and open communication, the facilitation of informed choice, and a culture of inclusion.

Keywords: Intellectual disability; bereavement; grief; coping

Introduction

Limited research exists about the experiences of bereavement and grief in people with an intellectual disability (PWID), perhaps reflecting a tendency to shield this group from the realities of death (Clements, Focht-New, & Faulkner 2004). Models of grief developed in relation to the general population have moved from stage models, consisting of various predictable phases associated with tasks of grieving (e.g. Marris, 1992; Parkes, 1988; Worden, 1983) to those which take greater account of dynamic psychological processes, individual differences, and the systemic impact of bereavement (Dent, 2005; Kissane & Bloch, 1994). These models situate grief as a normal response to loss (Clegg & Lansdall-Welfare, 2003), however, PWID have in the past, been considered unable to experience feelings of grief following bereavement (Hollins & Kloeppel, 1989). This was influenced by early beliefs that they may be incapable of forming attachment relationships (Burlingham & Freud, 1942) or understanding the concept of death (Hughes & Noppe, 1985).

Research indicates that PWID can and do develop attachments, making them open to experiencing grief (e.g. Clegg & Lansdall-Welfare, 1995) and that while some aspects of grief, such as finality and non-functionality (McEvoy, 1989) and more abstract causes of death (Mayreddi & Narayan, 1993) are better understood by those with greater cognitive abilities, factors other than level of cognitive functioning have been found to influence level of understanding of death. This includes chronological age (Seltzer, 1989) and environmental factors (Kastenbaum & Costa, 1977), such as exposure to death.

It has also been suggested that PWID may process death in the same way as children, based on assumptions about similarities in developmental levels (Bihm & Elliott, 1982), despite a number of differences between the two: PWID tend to see death as an externally influenced process, while children, from as young as seven years of age, develop the understanding that death can be an inevitable internal biological process (McEvoy, 1989).

Harper and Wadsworth (1993) argue that level of conceptual understanding in no way predicts the ability of an individual to feel the emotional impact of bereavement or display emotional behaviour. As such, there is growing acknowledgement that PWID are not exempt from the experience of grief and that they exhibit behaviours that can be interpreted as manifestations of grief (e.g. Bonnell-Pascual et al., 1999; Hollins & Esterhuyzen, 1997). Dodd, Dowling, and Hollins (2005) conducted a systematic review and concluded that PWID, like others, may show emotional reactions to grief such as sadness, anxiety, and distress; behavioural manifestations such as increased crying, hyperactivity, inappropriate speech and challenging behaviour and mental health problems such as depression, mania and psychosis.

While PWID are not homogeneous, this research suggests that many grieve in a manner similar to the general population (Harper & Wadsworth, 1993; Oswin, 1991) and that cognitive impairment does not, in itself, prevent the experience of grief (Brelstaff, 1984). There is, however, also evidence that PWID are more likely to experience complications during the grieving period than the general population, due to factors such as secondary losses, communication problems, difficulties with tasks of grieving, and issues around inclusion.

Significant secondary losses for PWID include the loss of their primary carer and the related loss of their home (Hollins & Esterhuyzen, 1997; MacHale & Carey, 2002), as well as fewer visitors and daytime activities; changes in roommate and employment status and less money (Harper & Wadsworth, 1993).

A second complicating factor can be the reluctance to communicate with PWID about death and grief (Murray, McKenzie, & Quigley, 2000; Oswin, 1991) and some individuals may never be informed of a death (Oswin, 1991). Carers have reported feeling they lack the skills required for tackling the subject of grief or, having had appropriate training, feeling a lack of confidence in their ability to put such training into practice (Dodd, McEvoy, et al., 2005; Dowling, Hubert, White, & Hollins, 2006; Murray et al., 2000; Watters, McKenzie, & Wright,

2011). They have also reported believing that if they broach the subject of grief the individual will require a level of support that exceeds that which they feel able to provide (MacHale, McEvoy, & Tierney, 2009). All of these factors may lead to PWID experiencing disenfranchised grief. This refers to situations where individuals do not receive acknowledgement or support for their loss or are denied the opportunity to publicly mourn (Doka, 2002).

Related to this is the reluctance to include PWID in the rituals of death, such as attending a funeral (Harper & Wadsworth, 1993; Hollins & Esterhuyzen, 1997; Oswin, 1991), despite evidence that this can be helpful in aiding understanding of death (Raji, Hollins, & Drinnan, 2003) and normalising the emotional experience of grief through observing the mourning of others (De Ranieri, Clements, & Henry, 2002). PWID also report that they find inclusion in rituals helpful (Gilrane-McGarry & Taggart, 2007) and supported involvement has been shown to reduce both repetitive questions about the whereabouts of the deceased, and the frequency and intensity of challenging behaviour (Sheldon, 1998). Others have found that, if managed poorly, ritual involvement can result in more problematic grief, thought to be due to insufficient preparation beforehand or explanation and communication following (Dodd et al., 2008). This is reiterated by Clegg and Lansdall-Welfare (2003) who stress that involvement alone is not sufficient and that, for participation to be beneficial, a generalised culture of emotional support is required.

In summary, research suggests that PWID can and do experience bereavement and grief, and that many have grief reactions which are consistent with those of the general population. However they may experience additional challenges associated with grief due to factors such as secondary losses, lack of communication about death by others and limited inclusion in the rituals surrounding death. Despite the growing body of research in this area, much of it has been indirect, based on family or carer reports rather than on the experiences of

PWID (Booth & Booth, 1994). Consistent with the focus on the inclusion of PWID in all aspects of society, the present study aims to explore the lived experience of bereavement and grief for a group of individuals with ID.

Method

Procedure

Design: The study adopted a qualitative methodology, using interpretative phenomenological analysis (IPA) of direct semi-structured interviews. IPA is concerned with investigating how people make sense of major life experiences (Smith & Osborn, 2008) and has previously been used effectively to access the views of PWID (e.g. Cookson & Dickson, 2010).

Ethical issues and approval: Ethical approval was granted by the educational establishment of the second author and the local National Health Service (NHS) Research and Development Department. Given the potential vulnerability of PWID, a number of ethical issues were considered. To reduce potential acquiescence, the participants only met the researcher once they had already expressed their interest in participating via a key worker. To ensure informed consent, all participants received an accessible information sheet describing the full implications of being involved in the research, including that the topic could be upsetting. Informed consent was obtained anew for each interview session. The emotive and possibly distressing nature of the subject matter covered in the interviews was considered in the context of the need to be inclusive and give PWID the opportunity to express their perspective. In this context and following McCarthy (1998), it was concluded that the willingness of the PWID to participate and share their experience transcended any presumed negative effects. In addition, it was made clear that if participants became

distressed, the first author would stop the interview and offer support. To ensure

confidentiality, at the point of transcription all identifying data was removed from the

digitally recorded interviews and a pseudonym was allocated to each participant. Following

transcription, the original recordings were destroyed.

A purposive sampling approach was used. Participants were included if they were

aged over 18, able to give informed consent, had the cognitive and communication abilities to

participate and had experience of the death of a close relative, friend or staff member within

the last 3 years. Participants were excluded if participation was deemed to be detrimental, for

example if the person was very recently bereaved or showed extreme emotional distress.

Participants were recruited through day service providers in Scotland. Service managers and

key-workers were provided with information about the study and asked to identify possible

participants and to send them an accessible invitation letter inviting them, if interested in

participating, to meet with the first author to allow her to discuss the study, answer questions

and obtain informed consent. A further interview was then arranged to conduct the research, at

a time and location of the participant's choice. A semi-structured interview format was chosen

as studies have shown that PWID can benefit from some level of structure when being

interviewed (Gilbert, 2004). Interviews were recorded using a digital voice recorder and

subsequently transcribed, removing all identifiable data.

The first author read each transcript a number of times to familiarise herself with the

data. In line with IPA recommendations (e.g. Smith & Eatough, 2007), she took initial notes

which informed the transcript coding process. She used the NVivo9 software to code transcripts

according to identified units of meaning. These were categorised as emergent themes which

were then considered as a whole and organised into interconnected hierarchies. Each interview

was analysed individually, before comparative analysis was carried out between interviews,

allowing an overall group analysis, while still maintaining the value and importance of each individual participant's experience.

The data analysis process was assessed using the quality criteria proposed by Yardley (2008): sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance.

Sensitivity to the theoretical and socio-cultural context was addressed by the first author carrying out a review of relevant literature and reflecting on the power dynamics within the research relationship and how it might impact the study's findings. The literature review confirmed the potential impact and importance of the topic and provided a strong argument for the need for inclusive research which could contribute to the knowledge base and help inform practice. While the previous research informed the study design and area of interest, the authors did not adopt a specific theoretical position based on it when conducting data analysis.

In order to evidence commitment and rigour, purposive sampling was used to ensure the sample was appropriate, suitable and homogenous. Triangulation of data was used to compare and refine interpretation of individual participant accounts.

Transparency and coherence were addressed by the first author ensuring clear and unambiguous documentation at all stages of the research process, including a written reflection on any internal or external influences, which may have affected either the collection or interpretation of data. Independent colleagues regularly reviewed the research process and sample interview transcripts and agreed the themes and subthemes.

Participants

Of 23 potential participants identified by care staff, 10 opted out or did not meet the inclusion criteria. Of the remaining thirteen, eight were men and five women. They were aged between 20 and 72 years. All participants had a mild intellectual disability. Eight lived in a group home, two in a shared tenancy, two in their own tenancy, and one in a nursing home.

Eight had experienced the death of one or both parents, one of a grandparent, one of her partner, two of friends and one of a flatmate.

Results

Four main themes were identified; 'inter- and intra-personal experiences' incorporated the participants' descriptions of their experience of bereavement and grief both from the standpoint of their own inner experiences, and those between themselves and others. 'Core beliefs about life and death' reflected the participants' internal models of the world and how these related to the concepts of life and death. 'Level of inclusion' encompassed the level to which each participant was included in the entire bereavement process. 'Continuing relationship with the deceased' provided insight into how, and to what extent, participants went on to incorporate their relationship with the deceased into their on-going lives.

Intra- and inter-personal experiences

This theme included several experiential features of each participant's bereavement 'journey'. Intra-personal experiences included emotional response, losses, and helplessness. Inter-personal experiences encompassed exclusion, support, and changes in roles and responsibilities.

Emotional response: Participants described experiencing a wide range of feelings during their initial grief, including sadness, worry, upset, loneliness, denial, helplessness and avoidance: '*Didn't feel like coming out… Tired. And I feel a bit lost… I just feel I'm in a corner, left out… Just sad. (Beth)*' and challenging behaviour: 'I got a little bit upset because *I was at school…I got mental. I hit people. I hit staff.*' Emotions oscillated, particularly in the

later stages of their grief: '*... it comes and goes away. (Jeremy)'*. Some participants struggled

with the permanence of the situation:*' I even think now he's still alive… I just think I still*

even now don't think it's real. (Louise).' On the other hand many described a sense of healing

over time, and a reduction in the negative emotions they felt during the initial stages of the

bereavement: *'Sometimes I feel it within me for a while and then it comes alright again.*

(Jack).' Such accounts were consistently worded in the past tense. This may suggest the value

of time and hindsight in the grieving process.

Losses: Participants described a wide range of losses that resulted from their

bereavement. This included the most immediate social loss of the deceased and the role they

played such as carer, companion, housemate, or confidante: 'Yeah other people listen. But not

the same as mum. (Jane).' Participants also described material losses such as the loss of their

home, community, and job: '*I had to move out. I was told "Just move out right away." (Jack)',*

and more complex losses, such as the inability of Jeremy to reminisce about his mother with

staff, as a result of staff turnover.

Helplessness: This often manifested as feeling unable to make their loved ones better

and prevent their death: 'Oh, but she was old and there's nothing I could do about it. (Kevin).

Helplessness was also described as being denied the opportunity to have their individual

preferences respected and not having the power to do anything about it: 'No I didn't go [to

the funeral]. I wish I had. (Beth).' 'It's up to the staff at [day centre] what they do with me…

probably they decided what to do [with Mum's ashes]. (Jeremy).'

Support: This was seen as crucial. One participant, when asked what is helpful after

experiencing a bereavement, replied "Well, as well as being there for each other you mean?"

Others described the relief that sharing their grief with others provided: 'If you share it with

somebody it makes it a whole lot lighter than trying to deal with it yourself. (Bill).' At times

support was not available, usually due to time pressures: '*I haven't had the chance… Just carers been busy. (Beth),' o*r was perceived as unhelpful: 'Some *...just tell you "Come on. Come on, you'll be alright."...* [That makes me] just more a bit sad. *(Jack)'*

Changes in roles and responsibilities: Many experienced a change in their roles and the roles of those around them, which resulted in greater responsibility for them: 'When mum was ill in bed I had to do all the washing because I was the oldest. *(Mary).'* Participants also observed the way in which the bereavement changed those around them: 'I organised the, *erm, funeral… Dad didn't want anything to do with it'. (Jane).'* Here there is a reversal in roles where the previously responsible father is now in need of care and support from his daughter.

Core beliefs about life and death

This theme presents the participants' views of life as a cycle, and death as a natural part of that cycle. This is reflected in the sub-themes: predictability, causes of death, fairness of death, life goes on, and afterlife beliefs.

Predictability: Participants' expectations of death varied dependent upon the information available and how they interpreted it. Many described being unaware of any underlying health problems and described the death as unexpected: 'It was very sudden and totally unexpected.*'. (Louise). Others were aware of their loved one's ill-health but did not realise the potential for this to be life-threatening:' I knew he was bothered with his asthma. *But I didn't know that he was in his last days*. (Mary)*'.* Several participants described being 'fore-warned' of the impending death: 'You know the night before he went away and left me he *told me this would be his last. (Mary).'*

Causes of death: Awareness of the cause of death varied: some participants provided medical explanations: 'She had *cancer… (Jeremy)',* while others were less clear: *'She died*

because… She had stones that didn't work. (Matthew).' Accounts may reflect information given directly, information pieced together from indirect, overheard accounts; or a participant's own theory as to their loved one's cause of death.

Fairness of death: In many cases it was the participant's understanding of the manner of death that influenced their opinion of whether a death was fair and a natural part of life, or unfair and untimely. Variables impacting this opinion included the deceased's wealth of life experience, age at point of death, and level of suffering while still alive: 'She was a good age. *(Jack)' '...we knew that it wasn't his time. (Bill).'* This suggests that contextual information, such as whether the death was expected and viewed as fair impacts on how well it is accepted by others.

Afterlife beliefs: Afterlife beliefs (religious or otherwise) also influenced participants' acceptance of death. Many revolved around the existence of a 'heaven' and captured the sense of someone being at peace or at rest: '*She must be in heaven… (Beth).'* *'I'll see mum again when I'm dead. (Jane).'* In addition to, and perhaps because of these beliefs, many of the participants felt that they still had a connection of some kind with their loved one: *'I think he's kind of upstairs looking over on us… I still think he's around. (Louise).'* Afterlife beliefs were a source of comfort to those who held them, providing a conduit through which participants could maintain some level of relationship with the deceased.

Life goes on: One method participants used to deal with grief was to move on with life and, to some extent force themselves to forget about the grief: 'I need to get on with my own *life. So I can't stay sad… (Katie).'* Others tried to move beyond their grief by their actions: "I *still go. Even though my mother isn't there. (Jack)."* Participants generally described this as a positive process: *'I think dad would just like me to carry on. Just what I'm doing* - coming here

to [day centre]. *(Louise).'* It appears that there is a sense of comfort in learning that life continues in a familiar manner, even in the absence of their loved one.

Level of inclusion

Participants reported varying levels of involvement in the different aspects of the bereavement process. Level of inclusion was influenced, not only by the extent to which participants were supported and/or permitted by others to be involved, but also by the extent of their own understanding of what had occurred. This was reflected in the sub themes of communication, predictors of impending death, and ritual involvement.

Communication: Participants were kept informed of their loved one's circumstances to varying degrees. Nearly all knew how long ago their bereavement occurred, with some stating the exact date: 'She died on the 3rd *of MONTH… She's been dead for 2 years. (Jane).'* Information such as duration of illness, type of illness and treatment options were less likely to be understood and/or remembered, with participants typically reporting not having had the relevant information at the time, or having been unaware of circumstances: '*We didn't find this* [nature of illness] *out until after the funeral. (Bill)'*. Participants who had been kept well informed conveyed a sense of pride at having been included: 'I was *the first to be told. (Keith).'*

Predictors of impending death: Commonly reported indicators of impending death were the gradual loss of the loved one's skills or their hospitalisation: *'He had been ill for a while. And he had been in hospital for a couple of weeks. (Bill).'* Witnessing this decline was a negative process for all participants who experienced it: '*She didn't look like my mum. She was breathing heavily. And she kept on not… erm… remembering. That's how you knew. (Jane).'* For some, awareness of the death occurred after the event in an impersonal way: 'I *read it in the paper… Yes, her death in the paper… (Beth).'*

Ritual involvement: Participants' understanding of the function of traditions surrounding death varied. One was aware that decisions could be made on the basis of a will,

while another was aware of cremation. Participants also varied in their level of involvement in traditional rituals. Many had viewed the body or been present when their loved one died: '*Well I went to see my mum's body. I was very upset…but she was just lovely lying there. (Keith)'*. The accounts portrayed a 'bittersweet' experience; the participants found viewing the body of their loved one as an unpleasant experience, but they also conveyed a sense that they would not wish to forego it: '*Well I would've felt it worse if I hadn't seen him… Because he was away. (Mary).'* Other participants did not view the body, mainly because they were not offered the opportunity, despite wanting to: 'I sa*id I wanted to see her body but they wouldn't let me. (Jane).'*

All had attended a funeral in the past and the majority described it as a positive and worthwhile event, despite the difficult emotions that it elicited: '*It's definitely a good thing to* go to *the actual service at the funeral and to go and speak to the family. (Alan).'* The funeral offered the opportunity to receive support from others, reminisce and see how much others thought of the loved one: 'It shows how much he was thought about and cared *about. (Louise).'* Two participants had not attended the funeral of their most recently deceased loved one, against their wishes: '*No I didn't go. I wish I had. To say goodbye… No they didn't ask me. I wish they had. (Beth).'* Both conveyed a sense of being prevented from expressing an aspect of their grief, and of being denied an opportunity that they believed to be rightfully theirs.

In contrast, some male participants had an active role in the funeral: '*I carried my dad's* coffin and I had a rope to hold *at my uncle's funeral. (Jack).'* Participants described fulfilling such responsibilities with a sense of pride and duty. It also allowed participants to be seen by others as centrally involved in proceedings, thus acknowledging their right to grieve. Others experienced ambivalence; having assisted in lowering his father's coffin into the grave, one participant (Jack) felt as though he "was helping to get rid of him because I helped put him down there." He also felt "proud" when carrying the coffin.

Many had visited their loved one's grave and viewed the experience positively. Of those who had not, all but one expressed the wish to do so because it would "most likely be scary (Beth)". Most had mementos of the deceased, predominantly photographs. Looking at these was also experienced as bittersweet: '*I've got one photo. It's good to have… It's just upsetting looking at it…(Keith).*' This reflects the range of confusing emotions experienced after bereavement and suggests a need to tailor participation in rituals to suit the individual's needs.

Continuing relationship with the deceased

Another factor which served to mediate the experience participants had of bereavement and grief was the way in which they viewed their continuing relationship with the deceased although he/she was no longer physically present. Three sub-themes were discerned: lingering pride, obligation, and yearning.

Lingering pride: Many participants took pride in their deceased loved ones, suggesting that their valued characteristics still held meaning: *'Just how funny he was and witty, and he could do excellent accents. (Louise).'* This pride was also evident in the way participants reminisced about happy times: '...my mum always used to make toffee, chocolate *cake… And she would scratch my* head like this [Tickles own head]*! (Matthew).'*

Obligation: Participants described feeling obligated to continue to please the deceased person, whether by grieving in a particular way, maintaining their memory to a 'good enough' standard, or in living life as they would have liked: 'Well if they were here *they would still want you to carry on your life and do your own things. (Jack).'* 'You have to *go if somebody died. I didn't want to go but I HAD to. That was my DAD. (Katie).'*

Yearning: Participants described how the death left a void in their life, and the continuing strong sense of loss, often long after the person's death: 'The day after I phoned

his work – I just wanted to hear his voice one more time. On his answering machine at work.

(Louise).' 'I know he's not there now, so… I just miss him…. (Mary).'

Discussion

The study aimed to explore the experiences of PWID of bereavement and grief. Overall, the results indicated that: the participants can acknowledge bereavement and experience grief, and they do so in ways that are consistent with those of the general population; have bereavement-related intra-and inter-personal experiences; are sensitive to a wide range of oscillating emotions; are subject to the same (if not more) losses; and hold similar values when it comes to maintaining their relationship with the deceased. This suggests a need to focus on how PWID can be effectively supported when experiencing life events such as bereavement.

In terms of the emotional impact of bereavement, participants described an 'oscillation' between emotional states, consistent with Stroebe and Schut's (1999) suggested Dual Process Model of grief, where the opposing roles of intrusion and avoidance serve as a regulatory mechanism within which grief is managed. This oscillation continues until a point of habituation, and therefore adaptation to loss is reached (Greene, 2002). The emotional reactions of many of the present participants some time after their bereavement, suggested that they had not yet accepted their loss.

All participants held beliefs that helped them made sense of death and dying. Their conceptualisations seemed to be influenced by the way the process of death had been communicated and the extent to which they felt included in it. Those who had factual information appeared to feel more control over the experience. Participants preferred to be informed about their loved one's health, the manner of their death, and the arrangements afterwards. Those who were not, communicated a sense of additional loss, and felt they had

missed out on key parts of mourning rituals, undermining the view that involvement in such rituals is beyond the abilities of PWID (Hollins & Esterhuyzen, 1997).

Participants expressed comfort in the idea that their loved one was still present in some form communicated the importance of sustaining their past relationship with the deceased by means of reminiscence and keeping mementos. This is consistent with the stage of grieving suggested by Marris (1992) and Worden (2009) where there is a role for extraction of the important aspects of a lost relationship which then continue to play an important part in the bereaved's new reality. It has, however, been suggested that 'fixating' on a continuing bond rather than adapting to the new reality can be detrimental (Field, Gal-Oz, & Bonanno, 2003). This need for balance was reflected by the current participants who stressed the importance of both sustaining a bond with the deceased and of moving on with their lives (Shaver & Tancredy, 2001).

Similarly, participants were able to describe the balance between recognising the usefulness of a grieving activity, despite its intrinsic capacity to cause them emotional upset, such as attending a funeral. This is consistent with the concept of 'finding benefit' in bereavement (Davis, Nolen-Hoeksema, & Larson, 1998). Despite the importance of such grieving rituals, a number of participants were prevented by others from grieving as they wished. Many were neither included in grieving rituals, nor were their wishes in relation to these rituals always respected by those supporting them. This is consistent with the concept of disenfranchised grief (Doka, 2002) whereby the loss of a person and their subsequent grieving is not publicly supported or acknowledged. Disenfranchised grief has been found to be a relatively common occurrence for PWID (Lavin, 2002) and this lack of supported inclusion appears to be the most significant way that PWID differ from the general population and may contribute to their increased risk of developing complicated grief reactions (Sheldon, 1998).

Overall, the current study supports suggestions for a systemic approach in order to facilitate an optimal grief experience for PWID (e.g. Read & Elliott, 2007). This includes the need for education about, and participation in, the death culture and facilitation of the grief process with therapeutic intervention as required. There is also a need for a culture of openness about the realities of death and dying in a form that is accessible to PWID. A number of resources are now available to help with this (e.g. Hollins, Sireling, & Webb, 2004; Read et al., 1999; Summers & Witts, 2003) and there is some evidence that prior education about the concept of death can improve the knowledge and attitudes of PWID about this topic (Yanok & Beifus, 1993).

Any approach needs to be underpinned by the inclusion of PWID. Providing accessible, accurate and timely information is likely to be valuable in helping them to generate and express an informed choice about how they wish to deal with their loss and resulting grief. While the relationship between choice and better quality of life has been well-documented (e.g. Neely-Barnes, Marcenko, & Weber, 2008) it is of little value if an individual's expressed choices are then ignored, which was a relatively common experience for the participants in the present study.

The participants also highlighted the need for support to take account of individual differences and be maintained throughout the grieving process. Many were supported in the early stages of bereavement, however, regular acknowledgement of their loss by means of rituals such as visiting the grave site, or recognising annual memorials was less common, despite appearing straightforward things to facilitate. The participants' expressions of their support needs following bereavement were also straightforward: simply having an opportunity to express their feelings in an unpressured, unbiased manner. Despite the existence of a range of therapeutic interventions for grief (e.g. Persaud & Persaud, 1997; Summers & Witts, 2003) participants' primary need was not for formal intervention, but rather to be given the

opportunity to be heard. It may be, however, that carers are reluctant to take on this role (Dowling et al., 2006).

Limitations

While the study successfully accessed the lived experiences of the participants, it did have a number of limitations. While, the participants identified issues thought to be associated with complicated grief e.g. non-participation in rituals and secondary losses, the exclusion criteria meant those who were experiencing complicated grief would not be included and so limited conclusions could be drawn from the present study about this important area. In addition, while it was not the aim of the study to look at the influence of cognitive ability on grief, the fact that all participants had a mild intellectual disability, limits the extent to which the results can be generalised to those with lower cognitive skills. Future research with people with differing levels of intellectual disability and which includes those who have experienced complicated grief, would, therefore, be valuable in order to further understand the support needs of bereaved PWID.

<div align="center">Conclusion</div>

The study indicated that the participants' lived experiences of death and grief were mediated by their intra- and inter-personal bereavement experiences, their core beliefs about life and death, their level of inclusion, and the way in which they maintained a continuing relationship with the deceased. Participants showed an ability to evaluate their lived experience in terms of having been helpful or otherwise. The findings suggest that the participants experienced bereavement and grief in a manner similar to the general population. This highlights the need for a system of support around PWID who have experienced bereavement, consisting of a culture of openness regarding, and basic education about, death and dying, the

opportunity for inclusion in all aspects of bereavement, the facilitation of informed choice, and

support and structured intervention where required.

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