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“I carry her in my heart”: An exploration of the experience of bereavement for people with learning disability

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Published in:

British Journal of Learning Disabilities

DOI:

[10.1111/bld.12212](https://doi.org/10.1111/bld.12212)

Publication date:

2018

Link:

[Link to publication in PEARL](#)

Citation for published version (APA):

Thorp, N., Stedmon, J., & Lloyd, H. (2018). “I carry her in my heart”: An exploration of the experience of bereavement for people with learning disability. *British Journal of Learning Disabilities*, 0(0). <https://doi.org/10.1111/bld.12212>

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Accessible summary

- Four people with learning disability talked about what it was like when someone they cared about had died.
- They said that it was important they were included, but that it was hard.
- They said they carried on loving the person after they died and that they missed them.

Key words: learning disability, experience of bereavement, IPA, continuing bonds

Abstract

Background: Bereavement is a universal experience, and yet little research has explored the lived experience of bereavement for people with learning disability (PWLD).

Materials and methods: Four PWLD were interviewed about their experience of bereavement. Data was analysed using Interpretative Phenomenological Analysis (IPA).

Results: Four themes were identified: 'Needing to know: Being included', 'Struggling to say: Barriers to bereavement', 'Love after death: A continuing relationship' and 'Missing their presence: The wider impact of death'.

Conclusions: PWLD should have the opportunity to make informed choices about their level of involvement and to develop their emotional experience. PWLD should be supported to develop a continued bond with the deceased and the wider impact of their loss recognised.

‘I carry her in my heart’: An exploration of the experience of bereavement for people with learning disability (PWLD)

Nicki Thorp, Jacqui Stedmon and Helen Lloyd

People with learning disability (PWLD)¹ are one of our society’s most marginalised populations (DoH, 2001). When experiencing bereavement PWLD are particularly vulnerable because they are usually dependent upon others to facilitate their bereavement needs (Read & Elliott, 2003) and provide them with factually correct information (McEvoy et al, 2012). Overprotection can increase PWLD’s experience of disenfranchisement (Doka, 2002; Morgan & McEvoy, 2014) and a sense of being disregarded (Clute & Koybashi, 2012). Given the prevalence of psychiatric diagnoses in PWLD compared to general population rates (Emerson et al, 2012) it is perhaps unsurprising that LD has long been identified as a predictor of mental health problems following bereavement (Bonell-Pascual et al, 1999).

Previous research on bereavement and PWLD

Despite a common view that involvement in bereavement rituals is helpful (Hall, 2014), PWLD are often excluded (Forrester-Jones, 2013). This may be influenced by carer’s ability to cope (Handley & Hutchinson, 2013), especially if they are attempting to manage their own grief (Read & Elliott, 2003). However, exclusion increases vulnerability to disenfranchised grief, whereby loss cannot be openly acknowledged, publically mourned or socially supported (Doka, 2002).

Involving PWLD when death is predictable has been highlighted as beneficial (Ryan et al, 2010) due to the opportunity for anticipatory grief (Read & Elliott, 2003). However organisational constraints and confidentiality issues have been identified as barriers (Ryan et

¹ The terms ‘learning disability’ and ‘intellectual disability’ are both used. Despite growth in use of ‘intellectual disability’ (BILD, 2016) the author selected ‘learning disability’ following feedback from a consultancy group of PWLD.

al, 2010). Raji et al (2003) interviewed funeral directors and religious group representatives who described a lack of involvement with PWLD, yet felt unable to intervene. Funeral attendance can help PWLD accept the reality of loss (Gilrane-McGarry & Taggart, 2007), express their grief and recall positive memories of the deceased (Gray & Abendroth, 2016). Funerals have also been found to offer concrete finality, and facilitate continuing bonds with the deceased (Morgan & McEvoy, 2014; Klass et al, 1996).

Secondary losses describe the additional losses experienced following bereavement. These can be substantial (loss of the family home), or more subtle, (loss of family rituals). Secondary losses can be momentous for the individual but are often unrecognised by others, which can compound the original grief (Blackman, 2003). PWLD experience significant health inequalities and an increased risk of early death (Emerson, 2012), therefore are more likely to experience peer deaths.

The absence of PWLD's voices in bereavement research

Bereavement research in LD populations has increased (Todd et al, 2013) but has predominately focused on observation of behaviour change or mental health (Dodd et al, 2005). The need to “give voice” to PWLD continues to be highlighted (Gilrane-McGarry & Taggart, 2007; Corby et al, 2015). Difficulty recruiting PWLD in research has been well documented (Cameron & Murphy, 2007) and is further confounded by sensitive topics. Previous research has focused on carers' perceptions, citing “restricted access” (Clute and Kobayashi, 2012) or the idea that carers would be a “more reliable source” (Gray and Abendroth, 2016), which silences PWLD. Research that has recruited PWLD has acknowledged the role of “gate-keepers” (McEvoy et al. 2012; McRitchie et al, 2014) which may have biased the sample.

Corby et al (2015) conducted a systematic review of the phenomenological research that has endeavoured to “give voice” to PWLD. Of the 28 papers reviewed none related to bereavement, although two explored ageing. They concluded that to understand the experience of PWLD, “hearing their views is essential rather than depending on the views of others such as staff or therapists” (Corby et al, 2015).

PWLD have been recruited as participants to explore the concept of death (McEvoy et al, 2002), future planning (Bowey & McGlaughlin, 2005), end of life care (Bekkema et al, 2016) and bereavement intervention (Gilrane-McGarry & Taggart, 2007), but little has explored the lived experience of bereavement. The one exception is McRitchie et al (2014). Using a qualitative methodology, they interviewed thirteen PWLD, recruited from day centres in Scotland, who had been bereaved within the last three years. They concluded that all participants experienced disenfranchisement, either as lack of acknowledgement or support for their loss, or as a denial of an opportunity to express their grief. They reported that participants experienced a range of emotions and concluded that the way PWLD viewed their continuing relationship with the deceased influenced their experience of bereavement.

Despite employing a qualitative methodology, McRitchie et al (2014) did not include a clear reflexive statement, therefore the researcher wondered whether the findings may have influenced by the prevailing discourse that bereavement for PWLD is largely disenfranchised? Participation was also restricted to those who been bereaved within the last three years which excluded those with historical experiences.

Aim

The current study aimed to build upon the findings of McRitchie et al (2014) by exploring the experience of bereavement for PWLD within an English context.

Method

Design

A qualitative research design utilising a phenomenological approach was selected to allow the detailed investigation of how individuals described and made sense of their experience (Hennick, Hutter & Bailey, 2010). Data collected from semi-structured interviews completed with PWLD was analysed using Interpretative Phenomenological Analysis (IPA). IPA employs a double hermeneutic whereby the researcher attempts to make sense of how the participant tries to make sense of their subjective experience, whilst considering the impact of their own perspective on the analysis (Smith & Osborne, 2008).

Participants

Participants were recruited through a day centre for adults with LD. Sampling was purposive to ensure participants had personal experience of bereavement. Inclusion and exclusion criteria are presented in Table 1.

Table 1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Confirmed LD	Significantly impaired expressive/receptive language
18 years or older	Discussing bereavement caused too much distress
Could remember a significant bereavement	Unable to give informed consent
Gave informed consent to participate	

Eleven people expressed interest: two could not provide informed consent and three made an informed decision to withdraw prior to data collection. The researcher met with participants over three sessions to build rapport and answer any questions to increase capacity whilst avoiding coercion (Cameron & Murphy, 2007).

Six people consented to participate. During interview one participant was solely preoccupied with maintenance work required on his parent's graves and another only gave single word responses. The researcher concluded that these participants had not fully understood the research and their data were excluded from the analysis.

A final sample of four PWLD participated in the research. One person was supported by his mother during the interview. All participants had mild/moderate LD, lived in a rural location and could communicate verbally. Demographic information is presented in Table 2.

Table 2: Participant demographics

Name* (*pseudonym)	Gender	Age	Ethnicity	Relationship to the deceased	Included in final sample
Rachel	Female	33	White British	Grandfather	Yes
Michelle	Female	32	White British	Grandmother, school friend	Yes
David	Male	40	White British	Grandparents, girlfriend, brother's dog	Yes
Edward	Male	35	Afro Caribbean	Grandfather, step-father	Yes
James	Male	49	White British	Father	Consented but excluded
Colin	Male	61	White British	Parents	Consented but excluded
Michael	Male	48	White British	Mother	Unable to give informed consent
Sandra	Female	45	White British	Brother	Unable to give informed consent
Fiona	Female	47	White British	Father	Withdrew before data collection
Helen	Female	59	White British	Brother	Withdrew before data collection

Clare	Female	44	White British	Brother	Withdrew before data collection
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Materials

EasyRead information sheets, consent forms and interview schedule consisting of descriptive and narrative questions were developed collaboratively with a consultancy group comprised of PWLD.

Procedure

All meetings and interviews were conducted in a comfortable, private room at the day centre. Participants had the option to have someone with them and were encouraged to bring photos/mementoes of the deceased to facilitate the interview. The aim of semi-structured interviewing is to encourage the participant to talk about the topic with as little prompting as possible (Smith & Osborn, 2008). However some prompts and probes were prepared and additional lines of questioning pursued to ensure that the participant was the 'experiential expert' (Smith & Osborn, 2008). None of the participants needed to take a break or stop the interview. Interviews lasted between 20 and 40 minutes.

Participants were thanked for taking part and provided with contact details for the researcher and a local bereavement service. Day centre staff offered support to participants post interview.

Interviews were audio recorded using a digital recorder, and then transferred to a secure folder on a password protected computer. The interviews were transcribed verbatim, pseudonyms applied and any identifying information removed.

Method of analysis

The interview transcripts were analysed using the stages of IPA described by Smith & Osborn (2008). An in-depth analysis of each transcript was completed in turn. The first transcript was read several times and annotated with comments, reflections and emerging themes identified. Themes were clustered according to analytical or theoretical links and super-ordinate themes identified. The transcript was checked to ensure the verbatim data supported the themes. Subsequent transcripts were analysed following the same process, guided by the themes identified from the first transcript. Earlier transcripts were reviewed in light of themes that emerged from subsequent transcripts. The final themes were translated into a narrative account and interpretation of the participant's experiences.

Quality assurance

In qualitative research rigour must be applied to analysis to ensure that interpretation is not unduly influenced by the researcher's preconceptions (Corby et al, 2015). A number of quality assurance strategies were incorporated into the design (Elliott et al, 1999). The researcher attended a research analysis group. Participant validation checks were made to ensure the themes were an accurate representation and the findings were shared with day centre staff and service users to check they resonated with the wider client group.

Although not specifically a feature of IPA, qualitative researchers attempt to 'bracket' their pre-understandings of the phenomenon under study (Corby et al, 2015). The researcher kept a reflexive research journal, had regular supervision with an experienced IPA researcher

and participated in bracketing interviews (Rolls & Relf, 2006) to help uncover unconscious assumptions.

Ethical considerations

The study was granted ethical approval from the university ethics committee and local authority research governance panel.

The researcher considered the potential vulnerability of PWLD to acquiesce alongside taking steps to increase participant's capacity to make an informed choice; including EasyRead materials and facilitating a space to discuss the topic separate to the research. The researcher was clear that participation was about sharing personal experience of bereavement for research purposes and not any form of 'therapy'.

Reflexive positioning

The researcher is a white British female with five years experience of working in community LD services in a rural location. The researcher acknowledges that her research interest has been influenced by her clinical experience of PWLD being included and excluded from bereavement. The research was undertaken as a requirement of the researcher's doctorate training in clinical psychology.

Results

The aim of this research was to explore the experience of bereavement for PWLD. The analysis resulted in four super-ordinate themes: 'Needing to know: Being included', 'Struggling to say: Barriers to bereavement', 'Love after death: A continuing relationship' and 'Missing their presence: The wider impact of death'. A narrative account of the themes, illustrated with participant quotes is reported.

Theme 1: 'Needing to know: Being included'.

Participants described varying levels of involvement. The extent to which participants were included before death, the amount of information shared and involvement in bereavement rituals varied depending on the nature of their relationship and family communication.

Rachel described visiting her granddad in hospital: 'I see my granddad, yeah. I hold his hand'. The opportunity for them to spend time together before he died appeared to reflect the quality of their relationship: 'It's important for me, it's important for me because, he's, he is a good guy to me' (Rachel). Other participants demonstrated awareness of ill health preceding death: 'think so, been poorly' (Michelle), 'he was poorly' (David). For Edward the news of his grandfather's death came as a shock: 'I found out that he passed away' 'I was, well it was you know, I was quite shocked' (Edward).

Awareness of the circumstances of death varied between participants. Some described specific details: 'erm, nanny slipped on the bathroom floor, passed away' (Michelle). Some knew vague details, and looking for confirmation was observed: 'erm, I think he passed away peacefully I think' (Edward). Despite the lack of detail it felt important for participant's to demonstrate their knowledge. Being included appeared to be most important: 'I need to know. I want to know what happened' (Rachel).

The level of involvement in bereavement rituals varied between participants. The choice about attending appeared explicitly important: 'I didn't want, yes I know why because I don't want more crying' (David). Some described others helping them decide: 'yeah, I don't like the funeral, too tearful, mum tell me to stay at home and don't go, tearful' (Michelle). For some there appeared to be a sense of pride in attending: 'There was a funeral. I was in the church' (Rachel). Again it appeared that being informed was the most important

factor: 'Yeah I mean it didn't bother me. It didn't bother me that I didn't go to the funeral but I was glad that I was told to be honest' (Edward).

The collective experience of rituals appeared to increase inclusion: 'I got a family in the church' (Rachel). Even for those who did not attend the funeral, collective rituals appeared important to commemorate the deceased and say goodbye: 'Get a drink, say take care and cheers' (Michelle).

Theme 2: 'Struggling to say: Barriers to bereavement'

The combination of the painful emotional experience of bereavement and difficulties articulating their experience was indicated by what participant's said and their observed presentation during interview. The role the researcher played in co-constructing the interview to elicit this is also highlighted.

Rachel described an accumulation of emotions. The researcher used probing questions to help develop her narrative and make sense of her emotional experience:

Researcher: 'You told me that you felt a bit, you felt quite sad, and that you miss him.'

Rachel: 'Yeah. I was, I got a bit worried.'

Researcher: 'You were worried?'

Rachel: 'I worried about him.'

Researcher: 'You worried about your granddad?'

Rachel: 'Yeah.'

Researcher: 'Do you know what you were worried about?'

Rachel: 'I'm a bit worried because I thought he's gone.'

Researcher: 'You were worried that he was gone?'

Rachel: 'Yeah.'

Researcher: 'And what was is about, what was it about that that made you worry?'

Rachel: 'It make me worry, it make me worried that I get, I get upset.'

Other participants gave vivid descriptions of other's emotional responses: 'I felt like sad, [mum] cry her eyes out' (Michelle). The physical experience of emotion was also described: 'I was tearful, I stayed at home. I had a funny belly' (Michelle), 'I feel very very sick when my granddad died' (Rachel). Some participants appeared to minimise their emotional experience which could be indicative of a wider strategy of avoidance: 'erm, I don't mind really. I was sad, but I'm ok' (David). However an acceptance of emotions: 'can't help being sad' (Michelle) and healing role was also identified:

'and erm, I did get slightly upset. I did cry in my step-mum's arms, and er, and then, and er, and then erm, and and and I was quite fine to be honest, I've coped with it I mean because, I don't know why but for some reason I just, I just knew it was ok' (Edward).

Despite Edward's apparent acceptance, an attempt to minimise his emotional experience and use defended processes to counter his distressing emotions is also indicated.

All participants had experienced multiple bereavements. David described how the emotional experience was different: 'Well it has meant the most about [brother's dog] and [girlfriend]' (David). The impact of losing his brother's dog and girlfriend, whom he both loved and felt loved by, was of greater significance compared to the loss of his grandparents, which was: 'not really hard you see' (David).

Difficulty articulating was observed during interview with Edward, as he appeared to struggle to find his words:

Researcher: 'Tell me a bit more what you mean about that, so you have to be careful

about what you say?'

Edward: 'Yeah, well I mean, er what was I saying, erm, oh I, oh I can't remember now'.

Researcher: 'It's ok'.

Edward: 'Well I know what I mean but I lost, I lost what I was trying to explain'.

Edward's frustration at not being able to verbalise his thoughts are poignant and reflective of the wider experience for PWLD, but may also be further indication of an avoidance of the emotion. Michelle also expressed a limitation in her ability to vocalise her experience, but for her it indicated an avoidance of something that was hard to say: 'not nice, tearful, I'm not going to say it. I don't want to say it anyway' (Michelle).

David appeared to look to his mother, whom he had asked to support him during the interview, to help him express his views: 'I'm not sure. I know you know mum' (David). Although likely to have influenced David's responses, his mother's presence did appear to enable David to identify his emotion:

Researcher: 'Do you remember how you felt when grandma died?'

David: 'Hmmm, can't think.'

Mother: 'Can you think of a word to say how you felt?'

Researcher: 'It's hard. I know, it's hard.'

David: 'Erm, I don't mind really. I was sad'

Mother: 'That's right.'

Theme 3: 'Love after death: A continuing relationship'

Participants demonstrated strength and resilience facilitated by an on-going relationship with the deceased, afterlife beliefs and specific coping strategies.

All participants spoke warmly about the deceased and described a continuing bond. Some participants used the present tense: 'He is, he is a very nice man' (Rachel). This could be interpreted as a denial of his death, or attributable to Rachel's less sophisticated language use. However the emotion seemed more to suggest that her grandfather continues to be experienced as 'a very nice man' in her life. On-going love for the deceased: 'oh yes, I still love her you know' (David) and the idea of love continuing in the physical absence of the person: 'I carry her in my heart' (David) was described.

The experience appeared to be bittersweet as participants described a longing for more time together: 'he loved me a lot, and (pause) I'd love a bit more of a time with my granddad' (Rachel): 'I still like her. I miss her though' (Michelle).

For Edward, the strength of the relationship seemed to help with acceptance of death:

'I mean it didn't, ah well it did upset me at the time but it doesn't now, I just thought you know, I mean I just thought he was a loving grandfather and I can't, I dunno, I just think it was the best. He was, he meant a lot to me in my life to be honest, so (laughs), yeah so I dunno' (Edward).

Many of the participants talked about an afterlife, notably with religious connotations. This appeared to offer comfort by physically placing the deceased: 'up, like a, like a heaven' (Rachel) and a sense of being cared for after death: 'I remember, god looks after them, in the sky, god' (Michelle). Edward described his religious beliefs as a central part of his identity and fundamental in making sense of his bereavement: 'erm, well it's being part of like, its part of being a Christian has really helped me to understand to be honest' (Edward).

'I mean the average person sees death as an awful thing because they don't, to me they don't understand the meaning of death, then that they, with a faith in God they

can carry onto heaven, into the next life and there won't be, there would be no worries in heaven' (Edward).

David was the only participant who did not make reference to any religious beliefs.

However, similar to locating the deceased in heaven, David described a permanent location in which he placed those he cared about: 'I carry [girlfriend] and [brother's dog] in my heart' (David).

Participants described coping strategies they used to feel better following bereavement. These included remembering happy memories: 'Well yes, I can think about the old days' (David), practical activities: 'I feel better when, I usually go outside and get some, get some fresh air' (Rachel) and talking to others about the deceased: 'I talk to [mum] sometimes' (Michelle). The use of mementoes was also described: 'I look at the photos' (Rachel).

Theme 4: 'Missing their presence: the wider impact of death'

All the participants described the impact of bereavement going far beyond the loss of the deceased. Highly significant personal losses were described. The effect of bereavement on others was also described.

The implication of loss was suggested by the description of memories of the deceased. They included the loss of treats: 'yes, I can remember we are going, fish and chips shop' (David), loss of support: 'he's helped me, he help me with everything' (Rachel) and the loss of feeling special: 'I could make her laugh' (David). The loss of a relationship that could have been was also described: 'erm, I suppose I would have wanted to have known more about him, and I don't get to know that really' (Edward). The totality of loss experienced was poignantly described by Michelle:

Researcher: 'What do you miss about nanny?'

Michelle: 'Everything'.

Participants described an acute awareness of the impact bereavement had upon others. A sense of wanting to protect others from the pain of being exposed to loss was described: 'that's why mum, I don't want you going in my meeting, I know you'll be upset because you lost your mum and your dad' (David). A wish that more help had been available for others was also described: 'well it does hurt me, when he's gone. It would help, it help, for mum and dad as well' (Rachel). Participants also described the role they played in supporting others: 'really sad, tearful, mum, I gave mum cuddle' (Michelle).

Discussion

The aim of this research was to explore the experience of bereavement for PWLD. Four key themes were identified: 'Needing to know: Being included', 'Struggling to say: Barriers to bereavement', 'Love after death: A continuing relationship' and 'Missing their presence: The wider impact of death'.

Links to previous research

Similar to the findings of McRitchie et al (2014) participants reported varied involvement. The opportunity to make an informed choice about participation before death and attendance at bereavement rituals was identified as important. This supports previous findings which has concluded that the needs of the individual (Dodd et al, 2008) should be considered. Participants involved in the preparation for death may have experienced anticipatory grief (Read & Elliott, 2003) which has been highlighted as beneficial (Ryan et al, 2010). Participants who experienced sudden bereavement with no opportunity to be involved still highlighted the importance of being informed.

Communication difficulties and limited emotional expression were identified as barriers to bereavement. In contrast to McRitchie et al (2014) participants expressed a much narrower range of emotions, and there was some evidence of defensive strategies to move away from experiencing grief. Previous research has concluded that limited verbal communication and emotional expression make it difficult for PWLD to express their needs and emotions in a socially acceptable way, which can exclude them from attending funerals (Read & Elliott, 2003). For participants in the current study, difficulties with communication or their emotional experience presented as barriers to bereavement regardless of whether or not they attended the funeral. Therefore the findings suggest that funeral attendance alone may not be sufficient to protect PWLD from the experience of disenfranchised grief (Doka, 2002).

Participants found strength through a continued relationship with the deceased, religious afterlife beliefs and practical coping strategies. The development of a continued bond with the deceased recognises that death ends a life, but not necessarily a relationship (Klass et al, 1996). All participants seemed to understand death as final and irreversible (McEvoy et al, 2002), which is necessary for the development of more psychologically and attachment based continuing bonds. The continued relationship described by participants was concrete in nature, most commonly developed by re-locating the deceased in heaven or within themselves. Similar to the findings of McRitchie et al (2014) participants spoke warmly about the deceased and identified valued characteristics, and some described a continuing sense of loss. However the sense of feeling obliged to continue to please the deceased person was not replicated. Participants reported using mementoes, such as photos of the deceased, as helpful which supports previous findings from a carer's perspective that personal mementoes allowed PWLD to feel connected to the deceased (Gray & Abendroth, 2016).

The loss experienced by participants was far greater than the death of a loved one. Similar to the findings of Morgan & McEvoy (2014) secondary losses following bereavement were common. However the experience of loss reported related to intimate memories linked to their relationship with the deceased, rather than more noticeable life changes that have commonly been reported (Dodd et al, 2005). The personal nature of the losses may increase the risk of them going unrecognised, which has previously been linked with complicated grief (Brickell & Munir, 2008).

Clinical implications

McRitchie et al (2014) suggested open communication, facilitation of informed choice and a culture of inclusion could improve the bereavement experience for PWLD, and this is supported by the current study. PWLD should be supported to make an informed decision about the level of involvement they want. Rather than prioritising bereavement interventions (Gilrane-McGarry & Taggart, 2007), emphasis should be placed on promoting PWLD to actively engage in all aspects of life, including death and bereavement. PWLD should be supported to develop skills to deal with adversity in life, thus reducing the need for specialist intervention. Targeted bereavement support services should be preserved for the most complex situations.

The experience of emotions for PWLD is likely to be as overwhelming as it can be for the general population, however with limited emotional expression and communication the intensity is likely to be heightened. The opportunity to explore emotional states in situations outside of bereavement may provide PWLD with additional resources to cope with emotionally challenging experiences, such as bereavement, when they do occur.

All participants described a continuing relationship with the deceased as a positive experience. Rather than avoiding talking about the deceased PWLD should be supported to

nurture this relationship according to their personal needs. Looking at photos and encouraging open conversation about the deceased is likely to be helpful. Acknowledging why the deceased was important and therefore why their death matters should help PWLD to make sense of, and process, the emotions following bereavement. Practical activities such as visiting the grave may help PWLD feel connected to a lost loved one. This may also facilitate a shared experience with new carers or bereaved others which may enhance new relationships. There may be a role for carers to help PWLD develop more abstract ideas such as a sense of continuing identity with the deceased (Klass et al, 1996).

The personal nature of secondary losses described by participants increases the risk of them going unrecognised. Parents, carers and professionals need to be mindful of the wider impact of bereavement. The experience will be unique for each individual, for every bereavement experience. PWLD need to be supported to identify changes following bereavement, and their emotional response validated.

Limitations of the current study

The researcher initially aimed to recruit between six and eight participants. Preliminary recruitment indicated there would be an adequate pool of potential participants and eleven PWLD initially expressed interest. The researcher was rigorous about the consent process (Cameron & Murphy, 2006), resulting in a final sample of four. This smaller sample size allowed an in-depth individual analysis (Smith & Osborn, 2008).

Stroebe (2003) highlighted that the most traumatised people may avoid participation in bereavement research, therefore the findings may be biased towards those with more emotional resilience. In addition the exclusion of people with limited verbal communication skills limits will have skewed sampling (Cambridge & Forrester-Jones 2003). Although it

was not the aim of the current study to generalise the findings it is important to acknowledge this limitation.

The role the researcher had in co-constructing the interviews must be acknowledged. Although this was necessary due to the specific needs of the participants, it will inevitably have influenced the direction and subsequent findings.

Future research

The current study identified four key areas relevant to the bereavement experience for PWLD. Further research to explore these areas in more detail would be helpful. Of particular interest to the researcher would be further exploration of the personal secondary losses following bereavement.

Collaborative participatory research approaches may provide a useful framework for further exploration of the experience of bereavement for PWLD. Although a consultancy group comprised of PWLD were involved in the development of materials and planning of the current study, the collection and analysis of data was completed predominately by the researcher. Further involvement of PWLD may offer insight into the salient issues experienced following bereavement and encourage more PWLD to become involved in research.

Flexible, creative methods are needed to include those with more profound LD and who are non-verbal. Collaborative research with speech therapists may help develop accessible methods of exploring and reporting the experience. In addition to opening up research to those often excluded (Cambridge & Forrester-Jones 2003), more accessible methods may facilitate those already involved in research to present more of their experience.

In the current study the use of photos and mementoes was observed to facilitate emotive discussion and recall of memories; other less verbally-dependant methods may further enhance this. This may also address some of the frustration PWLD experience feeling unable to express what they want to say.

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