

THE UNIVERSITY OF HULL

The Experience of Bereavement for  
People with Intellectual Disabilities

being a Thesis submitted for the Degree of  
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by

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## Overview

This portfolio thesis consists of two journal articles relating to bereavement in adults with Intellectual Disabilities (ID). The first article documents a systematic literature review on interventions relating to bereavement and ID. The second article provides a report on an empirical study exploring the experience of carers in supporting people with ID through the process of bereavement.

The systematic literature review identifies and critically evaluates existing research into the effectiveness of interventions relating to bereavement in people with ID. Interventions were aimed at either people with ID or their carers. The article outlines the procedures used within the review including details of search strategies and the inclusion criteria used. A critical review of existing research is provided and the findings are synthesised to provide information on both the quality of existing research and the apparent effectiveness of bereavement interventions. The article includes a discussion of the clinical implications of the systematic review and identifies areas requiring further research.

The empirical paper documents a study which used qualitative methodologies to explore the experiences of carers in supporting people with ID through bereavement. The introduction summarises findings of previous research and outlines difficulties that are sometimes faced by people with ID in relation to bereavement. It also outlines the important role played by carers in relation to the bereavement experiences of people with ID and provides a rationale for exploring the perspectives of carers. The study involved semi-structured interviews with both family caregivers and residential care staff, which

were analysed using Interpretative Phenomenological Analysis. The emerging themes are discussed at length and linked to previous research to identify theoretical implications. The clinical implications and methodological limitations are also discussed and areas requiring future research are identified.

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Systematic Literature Review

The Effectiveness of Interventions relating to Bereavement and Intellectual Disability

– A Systematic Literature Review

The Effectiveness of Interventions relating to Bereavement and Intellectual Disability  
– A Systematic Literature Review

Abstract

*Purpose*

To review the existing evidence on the effectiveness of interventions relating to bereavement and Intellectual Disability.

*Method*

Electronic database and hand searches were conducted to identify studies investigating the impact of interventions relating to bereavement in adults with ID. Studies eligible for inclusion were subjected to critical review, to determine the effectiveness of interventions and assess the quality of existing research.

*Results*

A total of six studies were eligible for inclusion, namely one qualitative study, four quantitative studies and one study using a mixed design. Interventions were aimed at either adults with ID or carers. A number of methodological limitations were apparent in the studies and the potential for comparability was limited due to the differences in interventions and methods of outcome evaluation. Overall, interventions were associated with positive outcomes such as increased confidence, knowledge and insight amongst carers and decreased levels of mental distress amongst adults with ID, as well as increased knowledge surrounding death and emotions.



### *Conclusions*

Interventions relating to bereavement and Intellectual Disability appear to result in positive outcomes for both carers and people with ID. However, inconsistencies and methodological limitations in the small body of existing research make it difficult to identify which interventions are most effective and for whom. There is clearly a need for further, higher quality research in this area to establish a more comprehensive evidence base.

## Introduction

The purpose of this systematic literature review is to evaluate existing evidence on interventions relating to bereavement in people with ID. Historically, there were widely held misconceptions that people with ID do not understand the concept of death and are not affected by bereavement (Kitching, 1987; Oswin, 1991). However, an increasing body of evidence has emerged demonstrating that people with ID do understand the concept of death, in many cases, (Bihm & Elliot, 1982; Sternlicht, 1980; Yanok & Beifus, 1993) and do grieve in response to bereavement (Bonnell-Pascual et al., 1999; Brelstaff, 1983; Hollins & Esterhuyzen, 1997). It also appears that cognitive understanding of death is not a necessary precursor to experiencing an emotional reaction to bereavement (Ray, 1978).

When people in the general population experience bereavement, they typically access the support they need from within their social network, with only some people requiring additional support from outside agencies. Although it might be assumed that a similar culture should exist for people with ID, there is evidence to suggest that it does not and the emotional needs of people with ID are not always met when faced with bereavement (Oswin, 1991).

Many people with ID experience numerous, varied relationships within both the family and the wider community, often developing strong attachments and high levels of dependency (Dodd et al., 2005). It is therefore likely that they will be affected by experiences of bereavement (Hollins & Esterhuyzen, 1997).

For people with ID, bereavement is sometimes associated with multiple losses, particularly when the deceased was a primary caregiver. Where people have to move home as a result of bereavement, they can potentially lose their home, possessions, friends and pets as well as the deceased. According to Oswin (1991), the enormity of such losses is not always recognised.

Elliott (1996) describes a tendency for carers to want to protect people with ID from the pain of grief. This can result in inadequate preparation for bereavement, as the possibility of death is not always discussed and people are sometimes prevented from visiting loved ones during their illness (Hollins & Esterhuyzen, 1997). It is not uncommon for individuals with ID to be excluded from important mourning rituals such as attending funerals or visiting graves (McLoughlin, 1986; Raji, Hollins & Drinnan, 2003; Wadsworth & Harper, 1991).

A study involving health and social care staff, conducted by Murray, McKenzie and Quigley (2000) found that, despite having positive attitudes and accurate knowledge of issues relating to bereavement and Intellectual Disability, some staff lack confidence surrounding their ability to support people through bereavement. Furthermore, carers sometimes attribute signs of grief to the individual or Intellectual Disability rather than to bereavement, despite knowing that bereavement has occurred (Dowling, Hubert, White & Hollins, 2006; Hollins & Esterhuyzen, 1997).

Murry-Parkes (1996) includes low self-esteem, previous psychiatric disorder, a dependent relationship with the deceased, absent or unhelpful family, multiple losses and unexpected deaths amongst factors that potentially increase a person's vulnerability to experiencing complicated grief. These are often pertinent issues for people with ID, therefore it is vital that appropriate bereavement support is available. For this to be feasible, some carers or adults with ID may require interventions relating to bereavement.

The aims of this systematic review were to review existing evidence on the provision of interventions relating to bereavement and Intellectual Disability and the extent to which they are effective. It is hoped that the findings will contribute towards the identification of potential areas of service development as well as identifying areas requiring further research.

## Method

### *Search Strategy*

Preparatory searches were conducted to identify appropriate search terms for the review. Combinations that yielded key studies amongst the search results were considered to offer the most validity. The resulting search terms included various expressions for Intellectual Disability combined with words relating to bereavement and types of intervention (see Appendix A).

The search terms were applied to four electronic databases, namely Psychinfo, Medline, Cinahl and Embase. This ensured that a broad range of sources were accessed including

Biomedical, Psychological, Pharmacological, Nursing and Allied Health information. The electronic search covered the period between the start of the databases and week 3 of April 2008. Key journals were searched by hand, between January 2000 and April 2008 (see Appendix B), and reference lists from all included studies were searched.

### *Inclusion Criteria*

To be eligible for inclusion, studies had to evaluate an intervention relating to bereavement in adults with ID over the age of eighteen. Qualitative or quantitative outcome evaluation was required and literature reviews were excluded. Interventions could be delivered to either individuals with ID or their carers and could be provided in preparation for an anticipated bereavement, in response to a past bereavement or more generally for those yet to face bereavement. For the purpose of this review, 'bereavement' was considered to involve loss through death rather than issues related to more general losses, transition or awareness of personal mortality.

### *Data Extraction*

Data was extracted from studies using a proforma designed for the purpose of this review. Information relating to the design, methodology, sample, intervention and outcome of the studies was collected.

### *Quality Control*

The quality of included studies was assessed using checklists recommended in the National Institute for Health and Clinical Excellence Guidelines Manual (NICE, 2007). Checklists

were allocated to studies using the NICE ‘algorithm for classifying study design’ (NICE, 2007) and the quality of studies was assessed based on factors such as the selection of participants, the internal validity, the approach to outcome evaluation and management of potential confounding variables. An additional checklist was developed for the purpose of this review, as a checklist for ‘before-after’ studies has yet to be developed. The resulting checklist comprised of the relevant aspects from existing checklists recommended by NICE (2007). Each study was assigned a quality rating of either ‘+’, ‘++’ or ‘-’.

## Results

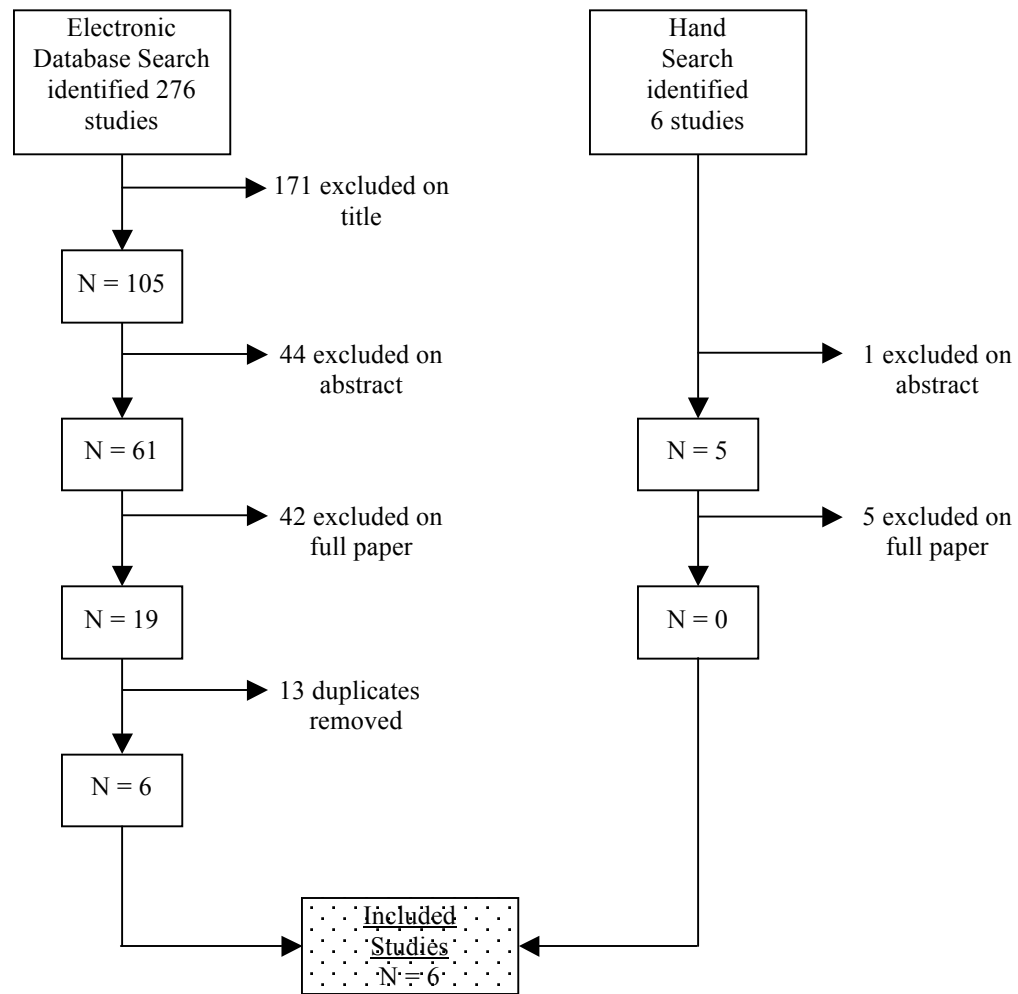
### *Search Results*

The electronic search yielded a total of 276 studies, 171 of which were excluded based on title alone. The remaining abstracts were examined, resulting in 44 exclusions and a further 42 were excluded on the basis of full paper articles. A total of 19 studies met the inclusion criteria; however 13 were duplicates and were therefore excluded.

The hand search of reference lists identified five studies, one of which was excluded upon examination of the abstract and the remaining four following examination of the full paper article. The hand search of key journals identified one study, which was excluded following examination of the full paper article.

Figure 1 illustrates the selection process for the search.

Figure 1. A summary of the selection process for the search.



A total of six studies met the inclusion criteria and these are summarised in Table 1.

Common reasons for exclusion involved the inclusion of participants who had experienced losses other than bereavement, studies involving children and articles discussing interventions but not evaluating their impact on a specific sample. A number of highly relevant studies were excluded due to the absence of a qualitative or quantitative approach to outcome evaluation. Table 2 provides a summary of such studies.

Table 1. Studies eligible for inclusion in the review.

Author/ Date	Sample	Intervention	Design/ Methodology	Outcome Evaluation	Findings
Bennett (2003)	<b>Carers</b> (residential.) N=12	<b>Bereavement Education</b> Preparing for anticipated bereavement Duration: 1 session Delivered by: palliative care nurse	Qualitative Ethnographic	Structured Questionnaire Post intervention	Carers identified potential areas for change due to increased knowledge & insight.
Reynolds et al. (2008)	<b>Carers</b> (day & residential.) N=17 Experience: 1-24 yrs	<b>Bereavement Training</b> Not related to specific bereavements Duration: 2 days Delivered by: OT	Quantitative Repeated Measures Control Group (N=16)	Confidence Questionnaire Pre & Post intervention	Significant increase: training group confidence No significant change: control group confidence
Dowling et al. (2006)	<b>Adults with ID</b> N=56 Age: <30-60+ yrs ID: mild, moderate & severe	<b>Counselling</b> (N=32) <b>Carer Support</b> (N=24) Response to specific bereavements Delivered by: Bereavement Counsellors & Carers (family, day & residential)	Mixed Repeated Measures Comparison Group	Aberrant Behaviour Checklist HONOS – LD Semi-structured Interviews Pre & Post intervention	Significant decrease: counselling group No significant change: carer support group (delivery proved unfeasible)

Note. ID = Intellectual Disability



Table 1. continued

Author/ Date	Sample	Intervention	Design/ Methodology	Outcome Evaluation	Findings
Mappin and Hanlon (2005)	<b>Adults with ID</b> N=6 Age: 29-42 yrs ID: severe & significant	<b>Bereavement Group</b> Not related to specific bereavements Duration: 10 sessions Delivered by: Clinical Psychologists	Quantitative Repeated Measures No Control Group	3 x questionnaires - Death Concept - Knowledge about Death - Understanding Emotions Pre & Post intervention	Significant increase: Knowledge about Death Understanding Emotions No significant change: Death Concept.
Stoddart et al. (2002)	<b>Adults with ID</b> N=21 Age: mean 39 yrs ID: borderline, mild, moderate & severe	<b>Bereavement Group</b> Response to specific Bereavements Duration: 8 Sessions	Quantitative Repeated Measures No Control Group	Children's Depression Inventory Hopkins Symptom Checklist Knowledge of Death & Bereavement Questionnaire Pre & Post intervention	Significant decrease: depression No significant change: anxiety knowledge.
Yanok and Beifus (1993)	<b>Adults with ID</b> N=25 Age: 22-63 yrs ID: IQ 18-73	<b>Bereavement Group</b> Not related to specific bereavements Duration: 8 sessions	Quantitative Randomised Control Trial Control Group (N=25)	Oral Examination Post intervention	Intervention group scores significantly higher than control group

Note. ID = Intellectual Disability

Table 2. Studies excluded due to a lack of formal outcome evaluation.

Author/ Date	Sample	Intervention	Reported Findings
McDaniel (1989)	<b>Adults with ID</b> N=8 Age: 40-65 years ID: IQ 55-70	<b>Bereavement Group</b> Response to specific bereavements Duration: 10 sessions Delivered by: Social Work intern	Participants engaged well and both the group facilitator and carers considered the intervention to have been beneficial.
Allan and Harling (1996)	<b>Adults with ID</b> N= $\leq$ 5	<b>Bereavement Group</b> Delivered by: Community ID Nurse	Both family members and professionals perceived a decrease in emotional pain and behavioural needs.
Persuad and Persuad (2003)	<b>Adults with ID</b> N=8 ID: Verbal communication or ability to read&write	<b>Bereavement Workshops</b> Duration: 10 workshops Delivered by: Community ID Nurse & Clinical Trainer	Outcome evaluated through interviews but study excluded as there was no qualitative or quantitative analysis of the data. Participants made positive comments, relating to feeling better and communicating more about bereavement.
French and Kuczaj (1992)	<b>Adults with ID</b> N=7 <b>Key Workers</b> N=7	<b>Bereavement Workshops</b> Response to specific bereavements Duration: 2 days Delivered by: OT & Art Therapist	Participants appeared to find it beneficial as they asked for more workshops and support in the future.
Summers and Witts (2003)	<b>Adult with ID</b> N=1 Age: Mid-forties ID: Moderate to Severe	<b>Individual Psychotherapy</b> (Psychoeducation & Psychodynamic) & work with carers 12 sessions (individual therapy)	Staff reported a decrease in participant's distress, indicated by reduced psychological and behavioural manifestations of grief.
Kennedy (1989)	<b>Adult with ID</b> N=1 Age: 24 yrs	<b>Bereavement Counselling</b> Delivered by: Community ID Nurse	Care staff observed decrease in the participant's aggressive behaviour and an improved demeanour.

Note. ID = Intellectual Disability

Table 2. continued

Author/ Date	Sample	Intervention	Reported Findings
Read and Bowler (2007)	<b>Adult with ID</b> N=1 Age: 40 yrs	<b>Life Story Work</b> Delivered by: Community ID Nurse	Nurse reported that the process was cathartic and that the Life Story Book would facilitate communication between the participant and others.
Elliott and Dale (2007)	<b>Adults with ID</b> N=2 Age: 30 yrs & 34 yrs	<b>Support from Community ID Nurse (Case 1)</b> Preparation for anticipated bereavement <b>Bereavement Counselling (Case 2)</b> Response to specific bereavement (fortnightly sessions for 5 months)	Case 1) Nurse reported that the residential placement was maintained Case 2) Counsellor reported that participant's behaviour and mental health remained stable and confidence towards future bereavements increased.
O'Nians (1993)	<b>Adult with ID</b> N=1 ID: Limited Communication	<b>Support from Community ID Nurse</b> Preparing for anticipated bereavement	The nurse observed the participant moving through the stages of grief and reported an increase in independence and trust in others.
Clarke and Read (1998)	<b>Adult with ID</b> N=1 ID: Good Verbal Skills	<b>Collaborative support from Community ID Nurse and residential carers</b> Response to specific bereavement	Facilitators report that people with ID are able to grieve, given the appropriate support.

Note. ID = Intellectual Disability

Four of the included studies evaluated interventions aimed at carers, whilst two studies evaluated interventions aimed at adults with ID. For ease of comprehension, the findings of studies relating to each target population are presented separately.

### *Studies Evaluating Interventions Aimed at Carers*

#### *Quality Control & Critical Appraisal*

The study conducted by Reynolds et al. (2008) received a ‘+’ rating when assessed using a quality checklist (NICE, 2007). Factors preventing it from receiving a ‘++’ rating included the use of non-standardised measures to evaluate outcome and the lack of evidence that confounding variables were controlled for. Although the benefits of longer term follow-ups were acknowledged, limited conclusions can be drawn because results obtained after one month and three months were combined, due to a lack of apparent differences.

The study conducted by Bennett (2003) received a ‘-’ rating. This was due to a number of factors including a lack of information on the approach to data analysis and the absence of any discussions relating to ethical issues, the role of the researcher and study limitations, which should be afforded high priority in qualitative studies. Despite receiving a ‘-’ quality rating, this study was not excluded from the review, as the National Institute for Health and Clinical Excellence (NICE, 2007) advocates for the inclusion of ‘-’ rated studies when the findings of such studies are consistent with the remaining, albeit weak, body of evidence.

### *Design and Methodology*

Bennett (2003) used a qualitative design and ethnographic methodologies. Reynolds et al. (2008) conducted a cohort study, which included a control group of participants receiving no interventions.

### *Participants and Settings*

Bennett (2003) included twelve carers working within the same residential setting, who had between one and twenty-four years experience of working with people with ID; their gender was not reported. Reynolds et al. (2008) compared two groups of carers from a range of residential and day service settings. One group included seventeen carers whilst the other included eighteen. There was only one male carer within the study and carers' experience levels were not reported.

### *Nature of Interventions*

Bennett (2003) evaluated a one-off training session for carers, provided as preparation for an anticipated bereavement. This was delivered by a Nurse with a background in palliative care. Reynolds et al. (2008) evaluated a two day training programme delivered by an Occupational Therapist, which was not provided in relation to any specific bereavements.

### *Methods used to Evaluate Outcome of Interventions*

Approaches to outcome evaluation varied across the studies. Bennett (2003) carried out structured interviews with carers following bereavement training, which were analysed

using qualitative methodologies. Reynolds et al. (2008) developed a self-report questionnaire to measure changes in carers' confidence following bereavement training.

### *Main Findings of the Included Studies*

Both studies evaluating the effectiveness of interventions aimed at carers reported positive findings (see Table 1). However, it is important to acknowledge that methodological limitations were apparent within both studies.

Reynolds et al. (2008) reported a statistically significant increase in carers' confidence following bereavement training, which was not observed in the control group. However, the study used a small sample and non-standardised measure, it is not known whether carers applied the principals from the training to their role and there was no long-term follow up. Bennett (2003) identified increased knowledge and insight amongst carers following bereavement training, as well as an increased ability to identify potential areas for change in service provision. However, this study was assigned a '–' quality rating for the reasons outlined previously.

### *Studies Evaluating Interventions Aimed at Adults with ID*

#### *Quality Control & Critical Appraisal*

The four studies evaluating interventions aimed at adults with ID received '+' ratings when assessed using quality checklists (NICE, 2007). Factors preventing them from receiving '++' ratings included the use of non-standardised measures, the lack of evidence that confounding variables were controlled for and the lack of any long term follow ups.

### *Design and Methodology*

The studies used a range of different designs, namely one randomised control trial (Yanok & Beifus, 1993), two before-after studies (Mappin & Hanlon, 2005; Stoddart et al., 2002) and one mixed design, combining qualitative methodologies with a randomised control trial (Dowling et al., 2006).

Yanok and Beifus (1993) used a control group of participants receiving no interventions, whilst Dowling et al. (2006) used two groups to compare two different interventions. The remaining two studies did not include a control group (Mappin & Hanlon, 2005; Stoddart et al., 2002).

### *Participants and Settings*

The studies evaluating interventions for adults with ID included participants whose disabilities varied across the range of mild, moderate and severe classifications. One exception was a study which only involved participants with disabilities described as “significant” and severe” (Mappin & Hanlon, 2005). Sample sizes varied, with one study including six participants (Mappin & Hanlon, 2005), one including twenty-one (Stoddart et al., 2002), one including two groups of twenty-five (Yanok & Beifus, 1993) and one including a group of thirty-two and a group of twenty-four (Dowling et al., 2006).

Yanok and Beifus (1993) did not report gender but the average ages of each of the two groups were 42.8 years and 35.1 years. Dowling et al. (2006) did not report age or gender,

whilst the remaining two studies (Mappin & Hanlon, 2005; Stoddart et al., 2002) included a fairly equal balance of male and female participants, with average ages in the late thirties.

### *Nature of Interventions*

The interventions aimed at adults with ID included bereavement groups, bereavement counselling and integrated bereavement support provided by carers.

Three studies evaluated bereavement groups for adults with ID (Mappin & Hanlon, 2005; Stoddart et al., 2002; Yankok & Beifus, 1993). Stoddart et al. (2002) evaluated a group provided for adults who had experienced a bereavement within the past ten years. It lasted ten sessions and involved participants sharing their experience of loss with the group, reflecting on their responses to the loss and working through the grief process. The facilitator's professional background was not reported. The other two bereavement groups were more educational than experiential and focused on the universality and irreversibility of death. They were not provided in response to specific bereavements. Mappin and Hanlon (2005) evaluated a group lasting ten sessions and delivered by Clinical Psychologists, whereas the group delivered by Yanok and Beifus (1993) lasted eight sessions and their professional background was not reported.

Dowling et al. (2006) compared bereavement counselling for adults with ID to integrated support from carers. These interventions were provided to adults with ID who had experienced bereavements within the past thirty years. Voluntary bereavement counsellors from mainstream services delivered the counselling intervention whilst the integrated



support was provided by carers from residential and day services. The integrated support was not actually delivered in the majority of cases, which was attributed to a range of practical and emotional factors.

### *Methods used to Evaluate Outcome of Interventions*

The studies evaluating the effectiveness of bereavement groups evaluated outcome using questionnaires developed specifically for the purpose of the studies. Mappin and Hanlon (2005) developed the 'Death Concept', 'Knowledge about Death' and 'Understanding Emotions' questionnaires, whilst Yanok and Beifus (1993) developed the 'Knowledge and Attitudes about Death' oral examination. Stoddart et al. (2002) developed the 'Knowledge about Death and Bereavement' questionnaire, which was used in combination with pre-existing measures of symptomatology, namely the Children's Depression Inventory – Short Form (CDF-SF; Meins, 1993) and the Hopkins Symptom Checklist (HSC-25; Hesbacher, Rickels, Morris, Newman & Rosenfeld, 1980).

It is important to acknowledge that questionnaires developed specifically for the purpose of studies the were not standardised, therefore the reliability and validity of the findings is unknown. In addition, the Hopkins Symptom Checklist (HSC-25; Hesbacher et al., 1980) has not been validated for use with adults with ID.

Dowling et al. (2006) conducted semi-structured interviews with carers, when comparing bereavement counselling for adults with ID to integrated support from carers. The interview data was analysed using qualitative methodologies. Dowling et al. (2006) also

measured changes in symptomatology using the Aberrant Behaviour Checklist – Community (ABC-C; Aman, Burrow & Wolford, 1995) and the Health of the Nation Outcome Scales for people with Learning Disabilities (HONOS-LD; Ashok, Matthews, Clifford, Fowler & Martin, 2002).

### *Main Findings of the Included Studies*

The four studies evaluating interventions aimed at people with ID each reported positive findings (see Table 1). However, methodological limitations were apparent within each study.

Mappin and Hanlon (2005) observed statistically significant increases on the ‘Knowledge about Death’ and ‘Understanding Emotions’ questionnaires amongst adults with ID, following participation in an educative bereavement group. However, no significant changes were apparent on the ‘Death Concept’ questionnaire. Yanok and Beifus (1993) observed statistically significant increases on the ‘Knowledge and Attitudes about Death’ oral examination, following a similar intervention.

Stoddart et al. (2002) identified significant decreases in levels of depression amongst adults with ID following participation in an experiential bereavement group but no significant changes in anxiety or ‘Knowledge of Bereavement and Death’. However, anxiety levels were mild and knowledge was high prior to intervention, which may account for the lack of changes.

All three studies evaluating the effectiveness of bereavement groups used small samples and predominantly used non-standardised measures. The reliability and validity of the findings of these studies is therefore unknown. The three studies did not involve long term follow-ups therefore it is not known whether the benefits derived from the bereavement groups are maintained over time. Each bereavement group was facilitated by the authors who were also responsible for evaluating outcome, which introduces a potential for bias. This also prevented the use of blinding or concealment for the study using a control group (Yanok & Beifus, 1993).

Dowling et al. (2006) observed significant decreases on the Aberrant Behaviour Checklist – Community (ABC-C; Aman et al., 1995) and the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD; Ashok et al., 2002) following bereavement counselling for adults with ID, which was supported by the qualitative data. No changes were apparent for participants receiving integrated support from carers, although given that the intervention was not delivered in most cases, this is perhaps not unexpected. This study involved a small sample and high drop-out rates, therefore the findings are somewhat limited. The quality of the qualitative data is unknown as minimal information was provided on the data analysis.

It can be seen that only six studies met the criteria for inclusion in this review. The studies employed different designs and evaluated a range of different interventions relating to bereavement and ID, which limited the potential for comparability across studies. There is

a clear need for further research in this field, not only due to the paucity of existing research but also because of methodological limitations apparent in previous studies.

## Discussion

This review suggests that interventions relating to bereavement and ID can be beneficial to both carers and people with ID.

Beneficial interventions include bereavement groups and bereavement counselling for adults with ID and bereavement training for carers. Despite these encouraging findings, there is clearly a paucity of research in this field and existing studies involve a number of methodological limitations.

The quantitative studies used small sample sizes and relied predominantly on non-standardised outcome measures. It is therefore difficult to be certain about the reliability and validity of reported findings. Studies did not involve long term follow-ups therefore the extent to which benefits are maintained over times is unknown. Only two studies included a control group (Reynolds et al., 2008; Yanok & Beifus, 1993) and neither blinding or concealment were used to control against bias. The qualitative study (Bennett, 2003) provided minimal information on data analysis and there was no discussion of ethical issues or the potential impact of the researcher. Responsibility for outcome evaluation was held by the authors of all six studies who also delivered the interventions. This clearly introduces the potential for bias.

Comparability across studies is limited due to variations in the designs and differences in samples, interventions and approaches to outcome evaluation.

Further research is clearly needed before definitive recommendations can be made surrounding the provision of interventions relating to bereavement and ID. Despite methodological limitations and limited comparability across studies, this review has important implications as it synthesises existing research and identifies areas requiring further research.

The benefits of interventions vary somewhat across the studies. Bereavement training for carers can lead to increased confidence (Reynolds et al., 2008) knowledge and insight into bereavement and ID and the ability to identify potential areas for change in service provision (Bennett, 2003). Previous research identified misconceptions (Elliot, 1996; Hollins & Esterhuyzen, 1997; McLoughlin, 1986; Oswin, 1991) and a lack of confidence (Murray et al., 2000) as difficulties experienced by carers in relation to bereavement and ID. Carers often play an important role in the experience of people with ID as they often contribute to decisions surrounding their inclusion in mourning rituals (McLoughlin, 1986; Raji et al., 2003; Wadsworth & Harper, 1991) and preparation for anticipated bereavements (Hollins & Esterhuyzen, 1997). Therefore, if carers apply principles from bereavement training to their role as carers, it could potentially impact positively on bereavement experiences for people with ID.

Bereavement groups for people with ID can result in decreased levels of depression (Stoddart et al., 2002), increased knowledge about death (Mappin & Hanlon, 2005; Stoddart et al., 2002); Yanok & Beifus, 1993) and increased understanding of emotions (Mappin & Hanlon, 2005). Positive outcomes are apparent following groups provided in anticipation of bereavement (Stoddart et al., 2002) or more generally to people who have not necessarily been bereaved (Mappin & Hanlon, 2005; Yanok & Beifus, 1993).

Bereavement counselling for adults with ID can lead to improved mental health and behaviour (Dowling et al., 2006). These outcomes support findings of other research which demonstrates that people with ID understand the concept of death (Bihm & Elliot, 1982; Sternlicht, 1980) and are affected by bereavement (Bonnell-Pascual et al., 1999; Brelstaff, 1983; Hollins & Esterhuyzen, 1997).

Dowling et al. (2006) found that integrated support from carers was unfeasible and appeared to place unrealistic demands on carers. This was attributed to various difficulties including time constraints, lack of experience, carers' personal experiences of loss and concerns regarding the wellbeing of people with ID. This highlights the need for bereavement training for carers and for interventions to be available to people with ID. This would indeed be similar to the approach of the general population, who primarily access support within their social network but sometimes go to outside agencies for additional support.

Although only six studies were eligible for inclusion in this review, Table 2 illustrates that further literature has been published on interventions relating to bereavement and ID. The

absence of formal outcome evaluation in these studies highlights the need for a more empirical approach towards research in this field. Despite the lack of formal evaluation, the excluded studies in Table 2 all reported positive feedback following the interventions. Interventions included bereavement groups, bereavement counselling or psychotherapy, life story work and bereavement support from Community Intellectual Disability Nurses.

### *Clinical Implications*

This review yielded only a limited number of studies which involved a number of methodological limitations. There were significant variations in designs, intervention and outcome evaluation, which limits comparability of findings. Consequently, there is not yet a sufficiently comprehensive evidence base upon which to make clear recommendations regarding the provision of interventions relating to bereavement and ID. It is difficult to know which interventions would be most effective and for whom.

Despite limitations in the findings of this review, bereavement interventions do appear to result in positive outcomes for people with ID and their carers and this is evident for general interventions and those provided in anticipation of, or in response to specific bereavements. Given that bereavement is clearly a universal phenomenon and that people with ID do not always receive adequate support when facing bereavement, it is vital that interventions should be available to people with ID and their carers.

Interventions in the included studies were delivered by a range of professionals including Occupational Therapists, Nurses and Clinical Psychologists from ID services and voluntary

bereavement Counsellors from mainstream services. Previous research identified that Health Care staff sometimes lack confidence in supporting people with ID through bereavement (Murray et al., 2000). It is therefore possible that health care staff may need additional training and support to encourage them to provide bereavement interventions. Bereavement interventions delivered by a range of professionals appear to have a positive impact, therefore the findings of this review have important implications for staff from all disciplines within both ID and mainstream services.

Bereavement interventions should not be provided to support discourses suggesting that people with ID should be sheltered from pain and distress. Rather they should be seen as a means of facilitating people with ID to work through the normal grief process. It is not suggested that all adults with ID and their carers will need bereavement interventions but that they should be routinely available and not delivered solely to people experiencing complicated grief. It is vital that service providers understand issues relating to bereavement and ID, as some carers attribute distress to factors other than bereavement (Hollins & Esterhuyzen, 1997) and do not always acknowledge the enormity of multiple losses (Oswin, 1991). If services are not aware of these issues, people with the highest bereavement related needs may not access the support they need.

### *Future Research*

A clear limitation of this review was the wide inclusion criteria, which limited comparability across studies. However, given that only six studies were eligible for inclusion, comparability would not have increased by using more stringent inclusion



criteria, as even fewer studies would have been included. This, combined with the methodological limitations of the included studies, highlights the need for further research using robust, higher quality research methodology.

There is a clear need for further well-controlled quantitative research using larger samples and standardised outcome measures. Outcome should also be evaluated by objective individuals who are not involved in the delivery of intervention and for whom group allocation is concealed.

There is also a need for higher quality qualitative research, to gain insight into the value and meaning associated with bereavement interventions for people with ID and their carers. Through increased understanding of the lived experience of bereavement for carers and people with ID and the issues they face in relation to bereavement, interventions can be developed to best meet the needs of those receiving them. The intervention delivered by Bennett (2003) was based upon a qualitative assessment of needs, which resulted in a positive outcome, according to qualitative and quantitative data.

Studies involving interventions for adults with ID provided limited information of the degree of Intellectual Disability, past experiences of bereavement, levels of involvement in the bereavement process or the timing of interventions. Future research should evaluate the impact of these factors, as their potential confounding influence has not been acknowledged in previous studies.

Future research investigating bereavement training for carers should evaluate the extent to which carers apply principals from training to their role as carers and the impact this has on the people they support. This should provide information on the impact of indirect interventions for people with ID.

In summary, there is a need for extensive further research into interventions relating to bereavement and ID, using both quantitative and qualitative methodologies. Only then will a robust evidence base be established, upon which to base service recommendations. Staff from all disciplines working within both ID and mainstream services have a responsibility to offer interventions relating to bereavement and ID. It is vital that these interventions are evaluated using good quality research methodologies and the findings disseminated.

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Empirical Paper

The Experience of Carers in Supporting People with Intellectual Disabilities through the  
Process of Bereavement: An Interpretative Phenomenological Analysis

The Experience of Carers in Supporting People with Intellectual Disabilities through the  
Process of Bereavement: An Interpretative Phenomenological Analysis

Abstract

*Background*

Previous research investigating the bereavement experiences of people with Intellectual Disabilities found that carers do not always prepare people for deaths or include them in mourning rituals. It has also been found that some carers lack confidence in providing bereavement support to people with Intellectual Disabilities. This study explored the personal experiences of family caregivers and residential care staff in supporting adults with Intellectual Disabilities through the process of bereavement.

*Method*

A semi-structured interview was used to interview eleven carers on their experience of supporting adults with Intellectual Disabilities through the process of bereavement. The transcripts were analysed using Interpretative Phenomenological Analysis (IPA).

*Results*

A total of five super-ordinate themes were identified: (i) Factors making the experience difficult for carers (ii) Factors that helped carers (iii) Carers' perspectives on the responses of people with Intellectual Disabilities (iv) Approaches to supporting people with Intellectual Disabilities (v) Carers' perspectives on support.



### *Conclusions*

The identified themes are discussed in relation to existing literature on bereavement and Intellectual Disability. Clinical implications of the findings are outlined and methodological limitations and areas for future research are discussed.

## Introduction

Bereavement is a universal human experience, which inevitably affects everybody at some point in their lives, including people with Intellectual Disabilities (ID) (Thomas & Woods 2003). Historically, it was assumed that people with ID were not affected by bereavement (see Ray 1978); however there has been increased acknowledgement that such assumptions were unfounded. People with ID typically experience varied relationships and often develop strong attachments and high levels of dependency (Dodd *et al.* 2005). It is therefore likely that they too will be affected by bereavement (Hollins & Esterhuyzen 1997). It has been shown that many people with ID understand the concept of death (Bihm & Elliott 1982; Sternlicht 1980; Yanok & Beifus 1993) and indeed, emotional reactions can occur even when the concept of death does not appear to be understood (Ray 1978).

An increasing body of evidence has demonstrated that people with ID experience grief following bereavement. Throughout the seventies and eighties, a number of anecdotal articles were published in which professionals described the emotional and behavioural responses of people with ID following bereavement. Responses included crying, social withdrawal, anger, confusion and difficulty accepting the loss (e.g. Kitching 1987; Thurm 1989). In 1977, Emerson reported that 50% of individuals referred for behavioural management had experienced a bereavement prior to the onset of the difficulties.

There also exists empirical research demonstrating that people with ID grieve following bereavement. Hollins and Esterhuyzen (1997) found higher levels of distress amongst bereaved individuals with ID compared to those who had not been bereaved in the

preceding two years. Distress was evident through higher levels of irritability, lethargy, hyperactivity, inappropriate speech, depression, anxiety and adjustment difficulties. A follow-up study after five years identified similar levels of distress, indicating that grief had not resolved six to eight years after bereavements (Bonell-Pascual *et al.* 1999).

Literature refers frequently to people with ID being unprepared for deaths and excluded from mourning rituals. Indeed, Hollins and Esterhuyzen (1997) found that only 17% of bereaved participants had regular contact with their ill relative, only 16% were known to have had the possibility of death discussed with them, 54% were known to have attended the funeral and only 16% visited the grave. More recent studies have shown higher rates of preparation and inclusion of people with ID (Dodd *et al.* 2005; Dodd *et al.* 2008; Gilrane-McGarry & Taggart 2007) however they were conducted in Ireland therefore cultural differences may be apparent.

There is a paucity of empirical research investigating the impact of preparation and inclusion on people with ID following bereavement. However, preparation is generally viewed as important as unexpected deaths are sometimes associated with complicated grief (Murray-Parkes 1996). Attendance at funerals is believed to facilitate acceptance of loss and resolution of grief (Worden 2003) and this is generally assumed to apply to people with ID (Oswin 1991; Raji *et al.* 2003; Read & Elliott 2007). Indeed, people with ID have themselves described involvement in mourning rituals as positive (Gilrane-McGarry & Taggart 2007). However, despite this evidence, a recent study found a positive correlation between involvement in mourning rituals and symptoms of complicated grief (Dodd *et al.*

2008). Although involvement in rituals did not account for all the variance in complicated grief symptoms, it was concluded that people with ID need to understand mourning rituals prior to participation.

The potential link between mourning rituals and complicated grief has prompted a recommendation that decisions relating to involvement of people with ID in mourning rituals should be made on an individualized basis (Dodd *et al.* 2008) It is therefore vital that carers understand issues relating to bereavement and ID so that informed decisions can be made in the best interests of each individual. Anecdotal hypotheses in the literature suggest that a number of unhelpful factors may influence decisions made by carers in relation to bereavement. Indeed, Hollins and Esterhuyzen (1997) suggest that logistical difficulties may prevent people with ID from visiting ill relatives or the significance of such contact may not be recognised. Alternatively, visiting ill relatives may be considered too distressing for the person with ID or indeed their carer (Hollins & Esterhuyzen 1997). Factors associated with exclusion from mourning rituals include failure to recognise grief in people with ID (Dowling *et al.* 2006), a desire to protect them from distress (Elliott 1996) and the 'double taboo' surrounding death and ID (Kloepell & Hollins 1989). Supporting people with ID through bereavement could also serve as a painful reminder of carers' personal experiences of loss (Oswin 1991; Worden 2003). It has also been suggested that carers have limited time and space to provide bereavement support (French & Kuczaj 1992) and they may even lack the necessary knowledge and skills to do so (Moddia & Chung 1995).

Carers play a vital role in the lives of people with ID (Department of Health 2001), particularly when facing bereavement (Dodd *et al.* 2005; Murray *et al.* 2000). However, despite the plethora of hypotheses attempting to explain carers' decisions surrounding bereavement, there is a paucity of empirical research investigating the perspective of carers. One study found that, despite good knowledge of the grieving process, health and social care staff lack confidence in their ability to support adults with ID through bereavement or teach them about death (Murray *et al.* 2000). Further research is clearly needed, as confidence was assessed using a non-standardised measure and there was no information on why carers lacked confidence. Despite limitations, this study demonstrates that a supposed lack of knowledge or skill (Moddia & Chung 1995), is not an adequate explanation of the issues effecting carers' decisions surrounding bereavement. Indeed, Dodd *et al.* (2005) also identified a comprehensive understanding of bereavement and ID amongst carers in Ireland.

Hamlin (2003) used Interpretative Phenomenological Analysis to explore the bereavement experiences of adults with ID. Internal bereavement experiences were found to be the same as the general population, whilst external experiences were different, as participants were not always involved in decisions or mourning rituals or supported to make informed decisions. These differences were attributed to the impact of societal beliefs about ID rather than to the disability itself. The number of people involved in participants' care was found to be disproportionate to the level of bereavement support they felt they received, which was attributed to a sense of diffused responsibility amongst carers. Another qualitative study explored the perspective of people with ID on their experience of bereavement

support (Gilrane-McGarry & Taggart 2007). Practical support, such as involvement in mourning rituals, was viewed positively whilst emotional support was perceived to be lacking. Some participants described feeling that some carers “didn’t seem to care” and most participants did not ask questions relating to bereavement, which one lady linked to not wanting to “bother” carers.

Carers clearly play an important role in the bereavement experiences of people with ID, through providing emotional support and making decisions surrounding involvement in mourning rituals. It can be seen that further understanding of the perspective of carers is needed along with increased insight into the issues carers face and the factors influencing their decisions. Such insight would inform services on how best to meet the needs of carers, to enable them to make informed decisions and provide adequate support to people with ID facing bereavement.

The aims of this study were to explore the experience of carers supporting people with ID through bereavement and gain insight into the sense they made of their experiences.

## Method

### *Design*

A qualitative design involving semi-structured interviews and an Interpretative Phenomenological Analysis (IPA) was used, which involved an exploration of the sense participants make of their experiences and the meaning experiences hold for them (Smith

& Eatough 2007). This was considered appropriate as the research sought to explore the lived experience of carers supporting people with ID through bereavement.

Qualitative research does not typically involve a search for a definitive truth or ‘correct’ interpretation of data. Indeed, IPA explores participants’ perspectives whilst simultaneously acknowledging the influence of researchers on the research process. Smith and Osborn (2003) describe this as a “double hermeneutic”, as it involves researchers making sense of the way participants make sense of their experiences.

#### *Recruitment*

A purposive sampling approach was used, which uses the judgment of researchers (Robson 2002) to select participants for whom the research question is relevant (Smith & Osborn 2003).

Ethical approval was sought and obtained from the Local Research Ethics Committee and information was then distributed to family caregivers by staff from NHS Community Intellectual Disability Teams and local authority day services. Potential participants were given information sheets and consent forms and asked to contact the researchers if interested in participating. Meetings were then arranged with participants.

Residential care homes were sent information sheets and contacted by telephone to discuss the research. Meetings were arranged with residential care staff interested in participating.

On meeting participants, the researcher went through the information sheet, answered questions and obtained written consent.

Four of the 10 residential homes contacted agreed to participate and six of the eleven family caregivers.

### *Participants*

Eleven participants took part, namely seven family caregivers and four members of residential care staff. Ten interviews were conducted as one involved a joint interview with both a husband and wife. The mean age of carers was 59 years (range 47–79) and there was only one male. Participants included five parents, one aunt, one sibling and four residential carers. The mean experience of caring for people with ID was 21 years (range 1–44).

Family caregivers had known the people they supported throughout their whole lives, whereas residential carers had known them for a shorter, though not insignificant, duration (range 1.5–17 years).

Participants had supported at least one adult with an ID through at least one bereavement, occurring between eight months and five years previously. Some carers had only supported one individual through one or more bereavements, whilst others had supported several individuals through several bereavements. The adults supported were males and females aged between 21 and 81 years with disabilities described as mild, moderate, severe or profound.



The losses experienced by those supported by family caregivers included the death of one mother, four fathers, one brother and one grandmother. Residential care staff supported individuals through bereavements relating to the death of three mothers, two fathers, one niece and three fellow residents. The family caregivers experienced simultaneous bereavement themselves because losses related to the deaths of their own family members. Residential carers experienced simultaneous bereavement when losses related to the deaths of residents but not when losses related to the deaths of residents' family members.

IPA involves detailed analysis of interview data, prioritising insight into the meaning experiences hold for individuals over a need to generalise findings to larger populations (Smith & Osborn 2003). The use of small samples in IPA studies is therefore recommended (Turpin *et al.* 1997).

#### *Data Collection*

Data collection was carried out by the first author. A brief questionnaire was used to gather demographic information on carers and the adults they supported (see Appendix C). An interview schedule was then used to guide a semi-structured interview (see Appendix D), which allowed the researcher to explore interesting avenues which emerged and enables participants to provide a detailed picture of their experiences (Smith 1995). The questions related to events surrounding bereavements, the involvement of adults with ID in the events and carers' perceptions of the responses of adults with ID to bereavement. Carers' experiences of supporting adults with ID through bereavement were also explored, as were their perception of the role of services.

Interviews ranged between 25 and 79 minutes in duration, lasting until participants had nothing more to say and the areas of enquiry guided by the interview schedule were all covered. Interviews were recorded digitally and transcribed verbatim.

### *Data Analysis*

Data analysis occurred following the completion of all ten interviews. The interview transcripts were subjected to IPA, using the recommendations outlined by Smith and Osborn (2003). An idiographic approach was used in which the first author conducted an in-depth analysis of one transcript before analysing the remaining transcripts in turn.

The first transcript was read and reread and the left hand margin was used to note responses and identify passages of particular interest. The right hand margin was then used to record potential themes, which were then clustered according to analytical or theoretical links. Each cluster included a number of sub-ordinate themes and was labelled using a super-ordinate theme. The transcripts and emerging themes were discussed in supervision and within an IPA group attended by qualitative researchers. The author then returned to the text to ensure verbatim data supported the themes.

The above process was repeated for each transcript and previous transcripts were searched to identify data supporting themes emerging from subsequent transcripts. The final themes offered an interpretation of the experiences of all participants.

An example of data analysis using an extract from one transcript is provided in Appendix E.

### *Validation*

Despite acknowledgement that a single ‘correct’ interpretation can not be reached, credibility checks are used within IPA to investigate the validity of findings and various checks were therefore applied to this study.

The first author used an iterative approach in which all transcripts were searched for verbatim evidence supporting the emerging themes. The second author conducted a mini-audit (see Smith 2003), by reading a selection of annotated transcripts to ensure clear links were apparent between the first author’s interpretations and the original text.

A reflective diary was used throughout the research process to increase insight into the potential impact of the researcher at different stages. Pertinent reflections were discussed with the second author to further this insight.

Extracts from two transcripts were analysed by eight independent qualitative researchers. Interpretations and themes discussed within the group were compared to those of the first author and feedback was incorporated into the data analysis.

## Results

Participants described their experience of supporting adults with ID through bereavement. Whilst accounts differed on some levels, certain elements were shared across participants. A total of five superordinate themes were identified, each encompassing subordinate themes. A summary of the themes is provided in Table 1.

*Table 1.* Summary of superordinate and subordinate themes

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Summary of superordinate and subordinate themes
1. Factors making the experience difficult for carers
1.1 Multiple Conflicting demands on carers – “you’re split, absolutely split”
1.2 Carers’ personal grief – “did she think I’m going to bring my timesheet? I’ve come to tell people so and so’s died!”
1.3 Uncertainty surrounding how to support the person – “you’re thinking ‘oh my God’, you know, ‘how do I explain this?’”
2. Factors that helped carers
2.1 Having to carry on – “they gave me a reason to get up in the morning”
2.2 Feeling supported by the person with Intellectual Disabilities – “she helped me more than I could help her really”
3. Carers’ perspectives on the responses of people with Intellectual Disabilities
3.1 Trying to understand the responses – “you just don’t know what’s going on in their minds
3.2 Comparing people with Intellectual Disabilities to the general population – “if I chopped off her arm she’d feel it!”
3.3 Recognising the enormity of the loss – “he just said ‘I’m on my own now’”
4. Approaches to supporting people with Intellectual Disabilities
4.1 Providing information – “honesty and trust” vs. withholding information – “I thought it would sort of upset him”
4.2 Inclusion – “they had a right to say goodbye” vs. exclusion – “they thought it was better if he didn’t”
4.3 The importance of belief systems – “he’s going to heaven”
4.4 Remembering the deceased – “she won’t want to forget ‘em”
5. Carers’ perspectives on support
5.1 Seeing a need for support – “you do need a bit of a back up”
5.2 Negative expectations of outside help – “I don’t think it would have been any use”
5.3 Wanting information and advice – “to have known some of the issues might have helped”

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Themes will now be described in more detail.

## 1. Factors making the experience difficult for carers

A number of factors appeared to make experiences difficult for carers when supporting people with ID through bereavement.

### *1.1 Multiple Conflicting demands on carers – “you’re split, absolutely split” (Participant 8, line 536)*

Participants described having a multitude of demands placed on them which were, at times, very difficult to manage. Caring for an ill person placed significant additional demands on carers and left them feeling

“split because I knew I should be at home with [name of person with Intellectual Disabilities] but I wanted to be with [name of ill person] (Participant 8, lines 666-667).

Most carers talked about the ongoing care needs of the person with ID and some carers acquired additional responsibilities by inheriting roles previously held by the deceased

“I mean obviously there was always somebody to help me with [name of person with Intellectual Disabilities] whereas I’ve got to do it on my own now” (Participant 7, lines 383-385).

The demands on carers appeared to have a significant impact on carers’ lives with one explaining

“I was doing a lot less at work and my business suffered for that. Erm and your home life suffers for that because, if your business suffers you worry about finances and, so it had a sort of spiralling effect really” (Participant 5, lines 586-589).

*1.2 Carers' personal grief – “did she think I'm going to bring my timesheet? I've come to tell people so and so's died!” (Participant 6, lines 552-553)*

It was not uncommon for family caregivers to experience grief surrounding bereavement as well as having to support somebody with ID. One family carer explained that

“it's different to counsel and console someone whose bereaved when you're also bereaved” (Participant 5, lines 894-895).

Residential care staff were reminded of previous experiences of bereavement when supporting others as

“you've got that experience [cries] to sort of maybe understand what he might be thinking” (Participant 10, lines 348-349).

Experiences for family caregivers and residential care staff were clearly emotionally laden, with one residential carer explaining

“it was the empty chairs, you know, that was difficult” (Participant 11, lines 597-598)

following the death of a resident and she latter added

“it’s not like working in a shop or a factory or a, you know, when you’re actually involved with people’s lives and their day to day lifestyle, you know, it’s really, it was really really hard” (Participant 11, lines 661-663).

Despite the inevitably emotional nature of their experiences, carers attempted to hide their feelings from the people they supported, as though

“you can’t bring her down really. You’ve got to still be up although you’re hurting inside yourself” (Participant 8, lines 580-581).

*1.3 Uncertainty surrounding how to support the person – “you’re thinking ‘oh my God’, you know, ‘how do I explain this?’” (Participant 3, lines 697-698)*

Carers gave the impression they lacked confidence and that

“you do your best, you do what you thinks is right, I don’t know if it is” (Participant 5, lines 869-870).

One carer admitted that she

“certainly didn’t know what I was going to say until I said it” (Participant 6, lines 508-509)

whilst another remembered thinking

“oh my God, what do I say here?” (Participant 3, line 877).

## 2. Factors that helped carers

There were also a number of factors which carers experienced as helpful.

*2.1 Having to carry on – “they gave me a reason to get up in the morning” (Participant 9, line 460)*

Having a role in supporting individuals with ID appeared to help carers to carry on following bereavement. One carer mentioned that

“I think it probably helps because you’ve got somebody else that you, you know, take your mind off things and therefore you’ve got to carry on and erm do the things for them” (Participant 7, lines 456-458).

There was a sense that supporting people helped carers cope with their own grief. For example, one family caregiver explained that



“to do something after the event is the only thing you can do. You know, so, so yeah I do think it helped me” (Participant 4, lines 462-463)

whilst a residential carer said

“you have to move on for the sake of the new ones that are coming in (Participant 11, lines 664-665).

*2.2 Feeling supported by the person with Intellectual Disabilities – “she helped me more than I could help her really” (Participant 8, lines 499-450)*

Most carers recalled being supported by the person with ID and saw it as a

“mutually beneficial arrangement” (Participant 9, lines 452-453).

One carer explained that

“we helped each other through the grieving process really” (Participant 5, lines 139-140).

It seemed as though the presence of the person with ID had a positive impact on the grief process for carers. One carer recalled that

“[name of person with Intellectual Disabilities] got a bit mixed up with presents on Christmas morning [laughter]. It meant that made fun of it, it broke the horrible feeling of Christmas morning” (Participant 4, lines 559-565).

### 3. Carers’ perspectives on the responses of people with Intellectual Disabilities

Carers spoke at length about their perceptions of the responses of the people they supported following bereavement.

*3.1 Trying to understand the responses – “you just don’t know what’s going on in their minds” (Participant 8, line 486)*

Carers seemed to find it easier to understand the responses of people with ID when they were consistent with their expectations surrounding grief. For example, one carer explained that the individual she supported was

“still grieving for her father, you know, she is, she still weeps for him, she’s still sad for him and sometimes very low because of it” (Participant 5, lines 639-641)

whilst another said

“he was upset wasn’t he? He did cry didn’t he?” (Participant 4, line 222).

Carers seemed to find it harder to understand responses when reactions they expected were not apparent. This was evident in the attributions carers made surrounding their observations.

One carer explained that the person she supported had

“cleaned the house from top to bottom, kept taking all his clothes out and washing them so he was keeping himself constantly busy” (Participant 1, lines 266-268)

and described him as

“a totally different person to how he was when Mum and Dad were alive” (Participant 1, lines 788-789).

However she did not associate these observations with the bereavement as she also mentioned that she

“would have expected him to have kind of shown some emotion and been upset” (Participant 1, lines 362-363)

but in fact she

“never really saw any reaction” (Participant 1, line 116).

Talking appeared to help carers understand the responses of people with ID and difficulties were apparent when individuals could not or would not talk to carers. One carer explained that she

“just tried to talk to him and just see what was going on in his mind but he just...just wouldn’t really say anything” (Participant 1, lines 383-384)

and another said

“he can’t tell us and he can’t, the only way you can tell is through facial expressions and body language” (Participant 10, lines 469-471).

*3.2 Comparing people with Intellectual Disabilities to the general population – “if I chopped off her arm she’d feel it!” (Participant 9, lines 306-307).*

Carers generally spoke of similarities in grief amongst people with ID and the general population. Indeed one carer remarked that

“I don’t think he’s been any different to anybody else really has he?” (Participant 4, line 577).

Carers felt that individual differences are apparent in all grief reactions, which is the same for people with ID. One example of this is a carer who passionately warned that one should “never ever confuse a certain lack of mental acumen with a lack of emotion because it’s not true. Some people are more emotional than others but that’s true of me and you and the world and his wife” (Participant 9, lines 636-638).

Some carers spoke of discrete differences between grief for people with ID and the general population, such as them allowing

“the natural welling up whereas we might sit here and repress it which is very bad for you. I think they’re probably a little bit more earthy and will let things out a bit more” (Participant 6, lines 323-326).

A few carers felt that bereavement could potentially be more distressing for people with ID, for example

“in some circumstances I think they feel it more acutely than we do” (Participant 9, lines 43-44)

*3.3 Recognising the enormity of the loss – “he just said ‘I’m on my own now’” (Participant 1, line 105)*

Carers were keen to communicate recognition of the enormity of the loss for the people they supported. Indeed, one carer explained

“I think she was concerned about ‘what happens to me now?’” (Participant 5, lines 162-163)

whilst another mentioned that she

“did recognise there’d be a big hole and a big loss in [name of person with Intellectual Disabilities]’s life” (Participant 3, lines 95-96).

#### 4. Approaches to supporting the person with Intellectual Disabilities

Carers provided insight into the approaches they took to supporting people with ID through bereavement and the factors underpinning their choice of approach.

*4.1 Providing information – “honesty and trust” (Participant 3, lines 857-858) vs.*

*withholding information – “I thought it would sort of upset him” (Participant 1, line 738)*

Some carers considered it important to provide information to people with ID and to tailor communication to individual needs. Indeed, one carer talked about

“honesty and trust because they’ve got to trust you. If you lie to them they’re never going to trust you. If you say how it is in words that they can understand, they trust you”

(Participant 3, lines 857-860).

Carers cited various reasons for providing information, such as wanting to prepare people for deaths. For example

“we kept the residents informed of how [name of ill person] was and, you know, that she wasn’t very well so, so they knew that she, she hadn’t been well so probably it wasn’t quite as big a shock” (Participant 11, lines 410-414).

Providing information was also linked to an increased understanding of the finality of death

“so she’s not under any false pretences that he’s going to walk through the door”

(Participant 9, lines 67-68).

Conversely, some carers withheld information from people with ID through a fear of potential repercussions and a desire not to upset them. For example, one carer said

“I don’t think I even kind of thought about mentioning it to him because I thought it would sort of upset him to know exactly what was in the urn” (Participant 1, lines 737-739)

and described a fear that, if she had told him,

“it might have come back at me later down the line” (Participant 1, lines 769-770).

Providing information was not easy for carers, with one describing it as

“one of the very hardest things I’ve had to do” (Participant 6, line 106)

and another saying

“I think you’ve got to get your own head round it before you can talk to anyone else about it” (Participant 4, lines 63-64).

*4.2 Inclusion – “they had a right to say goodbye” (Participant 6, line 187) vs. exclusion – “they thought it was better if he didn’t” (Participant 1, lines 127-128)*

Some people with ID were supported to visit the ill person and were involved in mourning rituals whereas others were not involved in such events. Carers cited various reasons for inclusion, such as people with ID having

“a right to, you know, show her last respects and to say goodbye and be involved with other members of the family” (Participant 3, lines 138-140).



However, some carers cited reasons for excluding people from events, such as a desire to protect them or to protect the ill person. One carer said

“I think it probably would have upset [name of ill person]” (Participant 5, line 116)

and later added

“I don’t know if [name of person with Intellectual Disabilities] could have coped with seeing [name of ill person] (Participant 5, lines 120-121).

There was also a sense that carers’ own needs influenced decisions surrounding inclusion, for example one carer admitted

“I don’t know whether I could have coped with [name of person with Intellectual Disabilities]” (Participant 8, lines 874-875)

and explained this was because

“you are really broken yourself” (Participant 8, line 879).

Decisions regarding inclusion were sometimes complicated by the extent to which people in the system had shared or conflicting perspectives, with carers finding it much easier to make informed decisions when everyone was

“singing from the same hymn sheet” (Participant 3, lines 315-316)

Conversely, decision making was increasingly complicated when people had conflicting perspectives, with one carer explaining that

“you don’t want parents alienating er and feeling that I was against their views”

(Participant 6, lines 185-186)

and another felt in

“a really awkward position because I felt I couldn’t really go against a family’s wishes”

(Participant 3, lines 449-450).

#### *4.3 The importance of belief systems – “he’s going to heaven” (Participant 9, line 62)*

Most carers talked about belief systems within the process of bereavement. In some instances, beliefs were held only by the person with ID but in others they were shared by the carer. Sometimes carers felt confused by the beliefs of people they supported, for example

“he still goes on about ‘are they ghosts?’, he’s got this thing about ghosts” (Participant 1, lines 749-750)

whilst another carer admitted

“we just said [name of deceased] has gone to heaven or he’s going to heaven and he’s going to take [name of a deceased family pet] for a walk. I mean that’s not my religious beliefs either and it wasn’t [name of deceased]’s so they’re [name of person with Intellectual Disabilities]’s so you respect what they believe” (Participant 9, lines 62-66).

One carer appeared to have a shared belief system with her daughter as they both found comfort in believing the deceased had become a star. The carer explained that

“she’d pull my hand and we’d go outside and we stood for hours in our nighties and everything but I think that really helped her” (Participant 8, lines 213-219)

One carer implied that she relied on belief systems to lessen the impact of bereavement, which she considered inadequate, stating

“there’s the ‘gone to be an angel’ tripe or, whether you believe it or not it’s immaterial. I mean that’s just a sugar coating isn’t it? (Participant 6, lines 510, 511)

and she later remarked

“I think you probably do use that sort of sad euphemism ‘gone to heaven’. Which I mean I, not that I disbelieve that but, you know, it’s just that, you know, it’s a bit of a cop out really isn’t it?” (Participant 6, lines 520-522).

#### *4.4 Remembering the deceased – “she won’t want to forget ‘em” (Participant 3, line 280)*

A huge emphasis was placed on a need to support people to remember the deceased, which carers appeared to consider helpful to both themselves and the people they supported. This often involved photographs, for example one carer explained

“we had a photograph done of my Mum and, um, I think that helps because every night now she says ‘night night Nanny’ to the picture. Even now, yeah well I do, I do exactly the same” (Participant 8, lines 243-248).

Carers also talked about sharing happy memories of the deceased, for example

“I’ll say ‘do you remember when we used to put [name of deceased] to bed, she’d never want to go did she?’ So we try and leave it a happy, you know, dwell on the happy times rather than the sad times (Participant 11, lines 496-499).

#### 5. Carers’ perspectives on support

Carers spoke at length about their perspectives of support for themselves in relation to supporting people with ID through bereavement.

*5.1 Seeing a need for support – “you do need a bit of a back up” (Participant 8, line 150)*

Carers spoke of a need for support themselves and one carer explained

“you can’t do it on your own” (Participant 5, line 424).

Carers seemed to have mixed perspectives on the availability of support. For example, one carer described herself as

“quite lucky really because there’s family and friends around me, you know, that would, you know, I could talk to them and they were there for me” (Participant 1, lines 852-854).

Conversely, carers appeared to find it difficult when people were not available to support them, with one carer explaining

“my sister wasn’t well enough to look after her, my brother couldn’t, I had nobody else to back up” (Participant 8, lines 72-73).

Family carers spoke highly of respite care, as it not only enabled them to spend time with the ill person, it also served as an additional source of support. One carer explained that respite care

“meant that I could just go without having to worry about what I was going to do with [name of person with Intellectual Disabilities]” (Participant 8, lines 158-159)

and later added that respite had

“been really helpful with me, you know, and they even bothered about me as well as [name of person with Intellectual Disabilities] which was nice” (Participant 8, lines 708-709).

Some carers spoke of having negative experiences of accessing support, for example one family caregiver admitted that

“it’s frustrating when you have to keep pushing to get basic things done” (Participant 5, lines 752-753) (Participant 5, lines 752-753).

*5.2 Negative expectations of outside help – “I don’t think it would have been any use” (Participant 10, line 412)*

On the whole, carers appeared to have negative expectations of support from outside agencies. For example, one carer said

“I don’t think anybody could have done any different with [name of person with Intellectual Disabilities] if they’d actually come to help us” (Participant 1, lines 831-832)

and another remarked that

“I don’t think outside influences would have helped or hindered her” (Participant 9, lines 505-506).

There was a sense amongst some carers that they should manage without support, with one carer saying

“it’s very much a family affair” (Participant 4, line 980)

and another remarking

“I think you’ve got to cope with it on your own” (Participant 7, line 694).

*5.3 Wanting information and advice – “to have known some of the issues might have helped” (Participant 1, Line 885)*

There was a sense that carers would have liked additional information or advice to help them support people with ID through bereavement. Indeed, one carer admitted

“it would have been nice to have somebody to say, you know, ‘these are some hints and tips’” (Participant 5, lines 891-892).

Carers also mentioned that training could be beneficial, with one residential carer remarking that

“staff training is probably the most important thing” (Participant 3, line 1060)

and a family caregiver felt

“I would have liked to have that training myself because I would like to know some of the things to say to her that will make it better” (Participant 5, lines 883-884).

## Discussion

### *Summary of Main Findings*

A total of five superordinate themes emerged from this study, providing one interpretation of the experience of a group of carers supporting people with ID through bereavement. Themes related to factors that helped carers through their experiences, factors that made experiences difficult and carers’ perceptions of responses to bereavement. Themes also related to carers’ approaches to providing support and their perceptions of their own experiences of support.

### *Relating Themes to Existing Literature*

Carers within this study talked about the multitude of demands faced in addition to their role in supporting people with ID through bereavement. This supports the notion that carers sometimes lack the necessary time and space to provide bereavement support (French &



Kuczaj 1992). Carers gave the impression that meeting these multiple demands can be extremely difficult and they inevitably experienced a sense of failure and inadequacy as a result. Although a plethora of literature provides insight into the experience of carers supporting people with dementia (e.g. Papastavrou *et al.* 2007), there is comparably little literature relating to the experience of carers supporting adults with ID. However, there has been an increased acknowledgement that this role includes both rewarding and difficult aspects (Smith 1996) and that some carers consider it a struggle to meet the role's demands (Shearn & Todd 1997). It is therefore difficult to ascertain whether difficulties faced by carers in this study were unique to experiences of bereavement or an integral part of their role as carers.

Personal grief was a pertinent issue for all carers in this study, either as a result of simultaneous bereavement or through memories of past losses. This supports previous suggestions that personal grief may impact on carers' experiences of supporting people with ID through bereavement (Oswin 1991; Worden, 2003). The grief process has been defined in terms of stages (Kubler-Ross, 1969), phases (Murray-Parkes, 1996) and tasks (Worden, 1991) and carers experiencing personal grief are faced with the task of negotiating this process themselves, whilst simultaneously supporting others through it. Although carers in this study did not appear to experience complicated grief reactions (see Worden, 1991), it is interesting to consider the potential impact of this scenario on supporting adults with ID through bereavements.

Previous research shows that carers are more likely to offer sympathy and help to adults with ID when their behaviour is attributed externally, to a situation rather than internally, to the individual or ID (Dagnan & Cairns, 2005). There has been increased acknowledgement in recent years, of the impact of bereavement on people with ID. This may have increased the propensity of carers to attribute behavioural changes and psychological distress to bereavements, whereas historically they tended to be attributed to the ID (see Hollins & Esterhuyzen, 1997).

Carers within this study clearly acknowledged the enormity of losses for people with ID, despite experiencing difficulties making sense of their reactions. This was particularly apparent when responses were not consistent with carers' expectations and this resulted in feelings of frustration. Carers communicated a need for training on how to best support people with ID through bereavement and seemed to lack confidence in their existing skills. This is consistent with findings of previous research (Murray *et al.* 2000).

All carers within this study spoke of a need to feel supported themselves and those who felt inadequately supported found their experiences particularly difficult. However, carers also tended to have negative expectations of support from services, which provides further evidence to suggest that services for carers are perceived as insufficient, inadequate and inflexible (Todd & Shearn, 1996b).

Some carers considered it important to provide information to the people they supported, whereas others withheld it through a fear of potential consequences. It was apparent that

decisions surrounding the provision of information were emotionally laden and experiences of providing information were particularly distressing. Decisions surrounding the inclusion of people with ID in mourning rituals were also complicated, as it was necessary to consider the needs and wishes of the deceased, the family and the carer as well as the person with ID. It can be seen that decision making processes are particularly complex and distressing for carers, a notion which has not been acknowledged in previous literature.

Hamlin (2003) concluded that bereavement experiences for people with ID only differ to those of the general population due to societal beliefs about ID and decisions made by carers regarding their level of inclusion in events surrounding bereavement. This study provides increased insight into the complex nature of carers' decisions, the difficult emotions they experience and the inevitable dilemmas associated with attempts to meet the needs of everybody within the system.

### *Clinical Implications*

Carers may need support from services to help them cope with the multiple conflicting demands and personal grief associated with supporting people with ID through bereavement. Acknowledging the needs of carers would appear to be a vital factor within endeavours to improve bereavement experiences for people with ID. Services must adopt a flexible, needs-led approach to ensure they are perceived as a useful resource. Information and training should be available routinely, as carers often lack time and emotional resources once bereavements have occurred.

Services could play an important role in facilitating carers to provide information to people with ID and to involve them in decisions regarding inclusion in bereavement related events. Practical support at such events could be invaluable when carers are struggling to meet the needs of everybody within the system. Indeed, it could increase the likelihood that the needs of people with ID will be adequately met.

### *Methodological Limitations*

The sample used within this study lacked homogeneity, as it included both family caregivers and residential care staff. It is apparent that the duration of relationships between family caregivers and the adults they supported was greater than for residential carers. Furthermore, residential carers tended to have wider experiences of working with adults with ID. However, the nature and meaning of these and other differences was not explored, as data analysis was conducted across the whole sample. The emerging themes aimed to represent the experiences of all participants. However, a richer and more in-depth understanding may have emerged if the accounts of family caregivers and residential care staff were analysed separately.

The sample also lacked homogeneity for the following four reasons: differences in the degree of ID experienced by those supported, the nature of their relationship with the deceased, the nature of relationships between carers and the deceased and how recently the bereavements occurred. Interpretative Phenomenological Analysis (IPA) aims to provide an in-depth exploration of the experiences of participants rather than endeavouring to discover a definitive truth or generalise findings to a wider population. However, the

heterogeneous nature of the sample could be seen to have encouraged premature generalisations, to the detriment of in-depth exploration of individual experience.

The study was retrospective in nature and the time since the deaths varied between eight months and five years. It is possible that these delays influenced the ways in which carers made sense of their experiences.

IPA acknowledges that the perspectives of researchers will inevitably influence the interpretation of data (Smith 1996) and play an important role in the construction of meaning (Horn *et al.* 2007). The authors of this study work systemically with adults with ID and their families, which will have influenced their interpretations. The authors endeavoured to limit the influence of their perspectives through reflection on personal biases and discussion of transcripts and themes with a group of independent qualitative researchers. Verbatim data supporting each theme was also identified.

#### *Areas for Future Research*

Attribution theory could provide increased insight into the ways in which carers make sense of grief reactions amongst people with ID. Models of mourning could potentially provide a framework within which to understand carers' experiences of supporting people with ID through bereavement. Research into the application of attribution models and models of mourning could therefore contribute positively to this field.

The demand for interventions aimed at people with ID could potentially be affected if carers received adequate support. Research into the impact of support for carers on the bereavement experiences of people with ID would therefore seem an appropriate direction for future research.

Future research should also investigate the capacity of people with ID to contribute to informed decisions surrounding bereavement experiences. This could facilitate carers and services in choosing appropriate approaches to making difficult decisions.

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## Appendixes

## Appendix A – Search Terms

(“mental deficiency” or “mental\* handicap\*” or “mental\* retard\*” or “mental\* impair\*”  
or “mental\* disab\*” or “mental\* subnormal\*” or “learning disab\*” or “learning difficult\*”  
or “intellectual difficult\*” or “intellectual disab\*”)

AND

(bereavement or grief or grieve or grieving or bereaved or “mourn\*”)

AND

(intervention or treatment or education or support or group or therapy or counselling)

## Appendix B – Key Journals Searched by Hand

British Journal of Learning Disabilities

Journal of Intellectual Disability Research

Learning Disabilities Research and Practice

Journal of Applied Research in Intellectual Disabilities

Journal of Intellectual Disabilities

Participant ID Number: 

<b>Questionnaire</b>
----------------------

Information relating to the individual with a learning disability

1) Age: \_\_\_\_\_

2) Gender:  Male  Female

3) Are you aware which of the following categories the individual falls within in terms of his or her level of learning disability? (Please Tick)

Mild  
Moderate  
Severe  
Profound  
Don't Know  

4) Are you aware if the individual has any of the following syndromes? (Please Tick)

Downs Syndrome	<input type="checkbox"/>
Prader Willi	<input type="checkbox"/>
Fragile X	<input type="checkbox"/>
Phenylketonuria (PKU)	<input type="checkbox"/>

Sturge Weber	<input type="checkbox"/>
Neurofibromatosis	<input type="checkbox"/>
Tuberous Sclerosis	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>

5) When did the bereavement experienced by this individual occur?

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6) What was the individual's relationship to the deceased?

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7) Where did the individual live prior to the death of their loved one? (e.g. family home, residential accommodation etc.)

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8) Where did the individual live after the death of their loved one? Did they move house as a result of the death?

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9) How often does the individual have contact with the following people? (Please Tick)

	Yourself	Parents	Siblings	Other Family	Other Paid Carers
Daily or more	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Several times a week	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Several times a month	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Occasionally	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No contact	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

*Questionnaire Version 1 (19.03.07)*

10) Does the individual with a learning disability have any of the following physical health difficulties? (Please Tick)

Eyesight problems		Diabetes	
Ear/Hearing problems		Bone/Joint problems	
Continence/Excretory problems		Mobility problems	
Circulatory/Respiratory problems		Digestive system problems	
Skin/Foot care problems		Epilepsy	
Eating/Swallowing/Dental problems		Psychological problems	
Thyroid problems		Behavioural problems	
Other			

11) Is the individual involved in any of the following activities?

Further Education		Local Community Groups	
Day Services		Hobbies/Activities outside home?	
Religious Activities		Other	

12) Do you have responsibility for caring for, or monitoring any of the problems listed in question ten? (Please describe below)

---



---

Information relating to the carer participating in the research

13) Age: \_\_\_\_\_

14) Gender:  Male

Female

15) What is your relationship to the person with a learning disability?

---



---

16) If you are a paid carer, how long have you been working with people with a learning disability?

---



---

17) How long had you known the individual with a learning disability before the death occurred?

---



---

*Thank you for taking the time to complete this questionnaire*

*Questionnaire Version 1 (19.03.07)*



**Interview Schedule**

**(A) Events surrounding the death**

*Could you start by telling me a bit about the events surrounding \_\_\_\_\_'s death?*

1) Was \_\_\_\_\_ involved in any **events leading up to** the death?

Prompt: Did they visit the person in hospital?

Prompt: Were they aware the person was going to die?

Prompt: How did they know? Who told them? What was it like?

2) Was \_\_\_\_\_ involved in any **events after** the death?

Prompt: Were they aware the person had died?

Prompt: Who told them? What was it like?

Prompt: Did they see the body?

Prompt: Did they go to the funeral?

Prompt: (Is there a grave/memorial?) Have they visited it? When?

3) What were the **reasons for \_\_\_\_\_'s level of involvement** in events before and after the death?

Prompt: Who was responsible for making these decisions?

Prompt: Was \_\_\_\_\_ involved in these decisions?

Prompt: Did everyone agree with the decisions?

Prompt: What were the benefits of this level of involvement?

Prompt: What were the drawbacks of this level of involvement?

**(B) Reaction to the death**

4) How did \_\_\_\_\_ **react to the death**?

Prompt: What was their initial reaction?

Prompt: What did they say/do?

Prompt: Did they show any emotions? What emotions?

Prompt: Did their behaviour change?

Prompt: Have you noticed any long-term changes since the death?

5) Was \_\_\_\_\_'s reaction consistent with **what you had expected**?

Prompt: What was the same as your expectations?

Prompt: What was different to your expectations?

**(C) Supporting the individual through the bereavement**

6) **What was it like supporting** \_\_\_\_\_ through the process of bereavement?

7) Was there anything that helped you to support \_\_\_\_\_?

8) Was there anything that made it difficult for you to support \_\_\_\_\_?

9) Did your personal experiences of bereavement impact on your experience of supporting \_\_\_\_\_?

**(D) Role of Services**

10) Is there anything you think of that **would have helped** you support \_\_\_\_\_ through the process of bereavement?

Prompt: Is there anything you would like to have been told?

Prompt: Is there anything you would like to have been done for you?

Prompt: Is there anything services could provide to make it easier?

**(E) Has anything been missed?**

11) Is there anything else about supporting \_\_\_\_\_ through a bereavement that you would like to tell me about?

Prompt: Anything you expected to talk about today that we haven't mentioned?

Prompt: How have you found the interview? (compared to your expectations)

## Appendix E – Example of Data Analysis

<p><i>Not preparing people is considered to intensify grief</i></p>	<p>50 It just compounds the grief almost. Instead of making it better, instead of 51 allowing them to speak about it and allowing them to rant and rave if they 52 want to about it, about how they feel about how they miss them. That is one 53 of the things that [name], even four years on, will say to me “I miss my dad” 54 55 <b>Right, so she still says that to you?</b> 56 57 Yeah, and she’ll still say – one way we got to describe it to her there was – 58 we had a dog called [name] which initially came to us, as often happens with 59 animals, they are a comfort, if you like. She obviously found it very – a 60 very new experience, coming to live in a new family and everything so [name] 61 went to bed with her, [name] got told everything, she talked to [name] and 62 when [name] died she was very very upset and we just said that [name] has 63 gone to heaven or he’s going to heaven and he’s going to take [name] for a 64 walk. 65</p>	<p><i>Including person in rituals (and the reasons for it)</i></p>
<p><i>Linking death to past deaths to ↑ understanding</i></p>	<p>66 I mean, that’s not my religious beliefs either and it wasn’t [name]’s so they’re 67 [name] so you respect what they believe and you explain in a manner that 68 she understands so she’s not under any false pretences that he’s going to 69 walk through the door again. She knew [name] had gone, she knew [name] had 70 gone or was going to go and that was it. She didn’t like it but it allowed her 71 to express herself, to express her grief, to express her loss. I find it difficult to 72 put into words but, erm, you see what I mean? 73 74 <b>Yeah.</b> 75 76 She could – she could then express her feelings... 77 78 <b>I see.</b> 79 80 ...more easily. 81 82 <b>Than she would have been able to.</b> 83</p>	<p><i>Role of person’s personal belief system</i></p> <p><i>Role of person’s personal belief system</i></p> <p><i>Providing information (and the reasons for it)</i></p>
<p><i>Respecting her religious beliefs</i></p>	<p>84 Than she would have been able to if she wasn’t allowed – you can’t not 85 allow people to talk about how they feel otherwise you’re just going to 86 compound damage to them. 87 88 <b>It sounds like you felt that quite strongly when your husband was</b> 89 <b>poorly.</b> 90</p>	<p><i>Providing information (and the reasons for it)</i></p>
<p><i>Helping person to understand by using appropriate communication</i></p>	<p>91 Yes, we did. I mean, she used to come and see him in hospital with me... 92 93 <b>Right.</b> 94 95 ...and she used to – he actually died at home but she saw him just before he 96 died. 97 98 <b>I see.</b></p>	<p><i>Including person in events (and the reasons for it)</i></p> <p><i>Including person in events (and the reasons for it)</i></p>
<p><i>Carer considers it important that the person expresses her grief</i></p>		
<p><i>A sense that not telling the person &amp; not talking about it is worse</i></p>		
<p><i>Carer involved the person in events leading up to the death</i></p>		

## Appendix F – Reflective Statement

The process of conducting a large-scale research project often involves a steep learning curve. Indeed, this was certainly my experience when conducting the research documented within this portfolio thesis. The purpose of this reflective statement is to provide insight into what I have learnt from the approach I took to the research. In addition I will reflect upon the difficulties which arose throughout the course of the research and how I overcame them, as well as discussing the factors which particularly furthered research progress.

Before embarking upon my own research, I endeavoured to gain a comprehensive understanding of existing literature relating to bereavement and Intellectual Disability (ID). I believe that this facilitated the identification of clear gaps in the literature, which enabled me to conduct research underpinned by a clear rationale. As a result I feel that both articles within this portfolio provide valuable contributions to our understanding of bereavement and ID and both theoretical and clinical implications are apparent.

One area in which I experienced a particular setback was in the process of participant recruitment for the empirical study. I have come to realise that I was somewhat naïve when assessing the feasibility of the study and allowed myself to be overly influenced by the enthusiasm of senior colleagues within local ID services. Indeed, my colleagues hypothesised that recruitment would be straightforward and appropriate participants would be readily available. As a result, I perhaps allowed myself to become overly confident regarding the recruitment process. This resulted in an underestimation of both the time that recruitment would take and the extent to which staff would be able to contribute to

recruitment. I was thankfully able to overcome this error of judgement and ultimately recruited sufficient participants, albeit at a later stage than anticipated. I believe that my enthusiastic commitment to the promotion of my research during this crisis was invaluable and contributed to the positive outcome. I have subsequently realised that more time should be allocated to the recruitment process, allowing for potential difficulties and delays.

I endeavoured to maintain a conscious awareness and assessment of ethical issues throughout the course of the research. One area requiring particular consideration was the distress that was apparent in carers during interviews for the empirical study. Indeed, the majority of participants cried when talking about their experiences. Ethical approval was gained from the Local Research Ethics Committee on the grounds that I would show sensitivity to distress and provide information on sources of further support to carers who seemed unduly distressed. Of course I obliged with these requirements but I also went to additional lengths to maintain an ethical approach throughout the course of the research. Indeed, I ensured that ample time was allocated to meeting with each participant to ensure that I would not have to leave with any degree of urgency. I also spent time after each interview discussing carers' experiences of participation and using my clinical judgement to assess the impact of participation on their emotional well-being. Although no carers accepted the offer of help in accessing additional support, they all appeared to value the time for an emotional debrief prior to ending our meeting. I certainly learnt a lot about the potential emotional impact of the in-depth exploration achieved using qualitative methodologies and will utilise a similarly sensitive and patient approach when conducting research in the future.

Upon reflection, I believe that an unnecessarily large sample was used within the empirical study. I chose to interview eleven participants, which is more than is typical for studies using Interpretative Phenomenological Analysis. When designing the study, I was aware of a tension between the values of qualitative researchers and the dominant discourses within academic settings, which sometimes privilege quantitative over qualitative methodologies. I now realise that I allowed myself to be unduly influenced by anxieties relating to conducting research for the purpose of an academic qualification and the research could have benefited from a smaller sample. Although the experiences of all participants contributed valuable meaning and insight to the research, I feel that interpretation could have been enhanced if there was a smaller amount of data.

I learnt a lot about the process of research through reflecting on my approach to data analysis for the empirical paper. Indeed, I became aware after two days of analysis that I was following an unrealistic timetable and was subsequently jeopardising my interpretations. I realised that a perceived pressure to complete the analysis had caused me to place a greater emphasis on the frequency of ideas within transcripts rather than a search for meaning via reflective interpretation. Having identified this error, I adapted my timetable and adopted a more interpretative approach to the data analysis. In future research endeavours I shall prioritise the development of a better planned timetable using more realistic goals, to prevent such difficulties arising.

Despite working incredibly hard throughout the course of the research process, I have learnt about my weaknesses in terms of time management. The two articles contained within this portfolio represent two quite different streams of research activity. Hindsight has shown me that a protocol for the systematic literature review should have been developed earlier as, to an extent, I underestimated the stages involved in the review. Although this did not cause me any obvious catastrophes, I now realise that a comprehensive research timetable encompassing a realistic overview of the research tasks would have enhanced my experience of the research process. At times I found myself working on one study to the detriment of the other, which could perhaps have been prevented by following a comprehensive plan.

I believe that the empirical study provides valuable insight into the experiences of carers in supporting people with ID through bereavement. I decided to write the article for the Journal of Applied Research in Intellectual Disabilities. This is an international peer-reviewed journal which aims to enhance the lives of people with ID, through the dissemination of applied research. A multi-disciplinary journal seemed appropriate as the further the understanding of issues faced by carers is disseminated, the greater the chance that people with ID and their carers will receive adequate support in relation to bereavement.

The systematic literature review was written for the British Journal of Clinical Psychology. Although the findings may be relevant to a range of disciplines, a number of factors contributed to the decision to target Clinical Psychologists. First of all, bereavement

interventions may be provided within both mainstream and ID services. Given that Clinical Psychology training covers multiple specialties, Clinical Psychologists may be well equipped to impart information relating to ID within mainstream services. This could be seen as particularly pertinent for universal experiences such as bereavement. In addition, it is apparent that healthcare staff sometimes lack confidence in supporting people with ID through bereavement. Clinical Psychologists could therefore play an important role in the provision of supervision and consultation to facilitate colleagues in the delivery of bereavement interventions. Finally, there is a clear paucity of existing research which has used robust methodologies to evaluate the effectiveness of interventions relating to bereavement and ID. Clinical Psychologists are well equipped with the necessary skills to contribute to the evidence base through the application of their research skills.

## Appendix G – Portfolio Thesis Word Count

### *Systematic Literature Review*

Word Count: 4423 (excluding abstract, tables, figure, references & appendixes)

Maximum: 5000

### *Empirical Paper*

Word Count: 6893 (excluding abstract, table, references & appendixes)

Maximum: 7000

### *Portfolio Thesis*

Word Count: 15632 (excluding references, appendix E & appendix H)



## **Notes for Contributors**

The *British Journal of Clinical Psychology* publishes original contributions to scientific knowledge in clinical psychology. This includes descriptive comparisons, as well as studies of the assessment, aetiology and treatment of people with a wide range of psychological problems in all age groups and settings. The level of analysis of studies ranges from biological influences on individual behaviour through to studies of psychological interventions and treatments on individuals, dyads, families and groups, to investigations of the relationships between explicitly social and psychological levels of analysis.

The following types of paper are invited:

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- Theoretical papers, provided that these are sufficiently related to the empirical data
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- Brief reports and comments

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The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

### **2. Length**

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

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The journal operates a policy of anonymous peer review. Papers will normally be scrutinised and commented on by at least two independent expert referees (in addition to the Editor) although the Editor may process a paper at his or her discretion. The referees will not be aware of the identity of the author. All information about authorship (including personal acknowledgements and institutional affiliations) should be confined to the title page (and the text should be free of such clues as identifiable self-citations, e.g. 'In our earlier work...').

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- Tables, figures, captions placed at the end of the article or attached as separate files

*Empirical Paper: Journal of Applied Research in Intellectual Disabilities*

### **1. GENERAL**

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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**Running Title:** A short title of not more than fifty characters, including spaces, should be provided.

**Keywords:** Up to six key words to aid indexing should also be provided.

**Main Text:** All papers should be divided into a structured summary (150 words) and the main text with appropriate sub headings. A structured summary should be given at the beginning of each article, incorporating the following headings: Background, Materials and Methods, Results, Conclusions. These should outline the questions investigated, the design, essential findings and main conclusions of the study. The text should proceed through sections of Abstract, Introduction, Materials and Methods, Results and Discussion, and finally Tables. Figures should be submitted as a separate file.

**Style:** Manuscripts should be formatted with a wide margin and double spaced. Include all parts of the text of the paper in a single file, but do not embed figures. Please note the following points which will help us to process your manuscript successfully:

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- Do not use the carriage return (enter) at the end of lines within a paragraph.
- Turn the hyphenation option off.
- In the cover email, specify any special characters used to represent non-keyboard

characters.

-Take care not to use l (ell) for 1 (one), O (capital o) for 0 (zero) or ß (German esszett) for (beta).

-Use a tab, not spaces, to separate data points in tables.

-If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

Spelling should conform to *The Concise Oxford Dictionary of Current English* and units of measurements, symbols and abbreviations with those in *Units, Symbols and Abbreviations* (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of S.I. units.

### 5.3 References

The reference list should be in alphabetic order thus:

-Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.

-McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.

-Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

Journal titles should be in full. References in text with more than two authors should be abbreviated to (Brown *et al.* 1977). Authors are responsible for the accuracy of their references.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

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### 5.4 Tables, Figures and Figure Legends

Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1, and given a short caption.

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