

A study of complicated grief symptoms in people with intellectual disabilities

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Abstract

Introduction Previous studies have shown a significant association between familial bereavement and the onset of challenging behaviours and psychopathology in people with intellectual disabilities (ID). However, little work has been done to accurately describe the specific symptoms of grief, in particular symptoms of complicated grief in this population. Consensus criteria for the diagnosis of complicated grief have been drawn up and tested for validity in the general population.

Aims To examine the occurrence of symptoms of complicated grief, and to explore the relationships between complicated grief and bereavement experience.

Method A bereavement history questionnaire and a newly developed measure examining for symptoms of complicated grief were administered to a group of carers of people with mild or moderate ID, who had experienced a parental bereavement within the previous 2 years. The questionnaires were also administered to a matched comparison group, who had not been bereaved.

Results/Conclusions This carer-based comparison study has revealed that bereaved individuals with ID experience complicated grief symptoms follow-

ing the death of a parent, with one-third of the bereaved group experiencing 10 or more clinically apparent symptoms. In addition, complicated grief symptoms were more likely to occur with higher rates of bereavement ritual involvement. These findings have both clinical and research implications.

Keywords bereavement, complicated grief, intellectual disabilities

Introduction

Although grief in response to bereavement is a normal, inevitable part of life, it is now well accepted that grief may, in certain instances, be acutely distressing, persistent and functionally impairing (Kristjanson *et al.* 2006). Complicated grief involves the experience of certain grief-related symptoms at a time beyond which is considered adaptive. These symptoms include separation distress-type symptoms, such as longing and searching for the deceased, loneliness, preoccupation with thoughts of the deceased, in addition to symptoms of traumatic distress, such as feelings of disbelief, mistrust, anger, shock, detachment from others and experiencing somatic symptoms of the deceased.

Recently, much attention has been given to improving our understanding of the characteristics of complicated grief symptoms. Diagnostic criteria for complicated grief have been drawn up using grief symptoms taken from existing psychopathology and

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grief symptom inventories (Frank *et al.* 1997). Symptoms were divided into symptoms of 'separation distress' and 'traumatic distress', coupled with evidence of poor social and occupational performance. It is generally agreed that that symptoms of separation distress are at the core of complicated grief, relating to the idea that complicated grief is a form of an attachment difficulty resulting from separation, as originally described by Bowlby (1980). Traumatic distress symptoms represent bereavement-specific manifestations of being traumatised by the death. The proposed traumatic distress symptoms included efforts to avoid reminders of the deceased, feelings of purposelessness about the future, a sense of numbness, feeling shocked and stunned, difficulty acknowledging the death, feeling that life is empty without the deceased, an altered sense of trust and security, in addition to anger over the death. Much work has been carried out to refine the diagnostic criteria, and there is strong argument for the inclusion of complicated grief as a distinct diagnostic entity in Diagnostic and Statistical Manual of Mental Disorder-V (Prigerson *et al.* 1997, 2008). Furthermore, complicated grief has been shown to have major adverse health effects, with increased risks of cancer, hypertension, cardiac events and suicidal ideation (Prigerson *et al.* 1999).

People with intellectual disabilities (ID) experience feelings of grief and sadness following a bereavement (Dowling *et al.* 2003), and their behaviour and mental health can deteriorate (Hollins & Esterhuyzen 1997; Dodd *et al.* 2005). However, there is a lack of understanding of the types and characteristics of grief symptoms experienced by people with ID and whether these symptoms and changes in behaviour represent so-called 'normal' grief symptoms, or more serious 'complicated grief' symptoms (Hollins & Esterhuyzen 1997; Dodd *et al.* 2005; Kristjanson *et al.* 2006).

The symptoms of complicated have not been examined in this population to date. In addition, there is a lack of consensus on the optimal level of bereavement ritual involvement for people with ID, following the death of a close relative. Although best practice would suggest that a high level of ritual involvement seems most appropriate and best illustrates the finality of death for the individual, it may be that rituals need to be contextualised for the individual prior to full-scale involvement. Thus,

experience of funeral ceremonies and the like, alongside appropriate death education, would seem to be the best psychological preparation for the individual, though there is little evidence in the literature to support this approach.

Aims of the present study

The aim of this study was to assess the specific symptoms of complicated grief among a population of individuals with ID, who had experienced parental bereavement within the previous 2 years. This population was compared with an age-matched comparison population who had not been bereaved, in order to best illustrate the effects of the bereavement. In addition, bereavement history and the experience of bereavement rituals were examined. Any possible relationships between the experience of bereavement rituals and the possible occurrence of complicated grief symptoms were examined.

Method

Study design

In order to examine the occurrence of complicated grief symptoms among individuals with ID, a matched-sample independent group design was applied. There is a lack of agreement regarding the length of a so-called 'normal' grief reaction, though it is generally accepted that for most individuals significant symptoms of grief have resolved within 1–2 years of the bereavement (Dodd *et al.* 2005). The study sample consisted of individuals with ID who had experienced the death of a parent within the previous 2 years (the bereaved group), and a matched group who had not been bereaved during the same period (the comparison group). The two groups were matched for demographic characteristics including level of disability, gender and approximate age (within 5 years). As this was the first study of complicated grief symptoms in people with ID, a carer-based assessment study was deemed the most appropriate mode of investigation.

Sampling and participant characteristics

Seventy-six individuals with an ID took part in the study. Half ($n = 38$) of the sample had experienced

Demographics	Group	Bereaved	Comparison
Gender	Male	58.3% (21)	58.3% (21)
	Female	41.7% (17)	41.7% (17)
Age	Mean	40.39	38.29
	SD	9.264	7.139
Service user attends a day service		97.4% (37)	94.7% (36)
Service user is in residential care		65.8% (25)	55.3% (21)

Table 1 Sample characteristics

a parent bereavement with the previous 2 years while the other half ($n = 38$) had not. The characteristics of the two groups are reported in Table 1.

The sample was recruited from two large voluntary agencies providing residential and day services to people with ID in Dublin. Bereaved cases were identified using electronic databases, which detail parent deaths among other information. In order to identify any cases not included on the database, senior staff in each centre were also contacted. At each centre, bereaved cases and comparison cases were identified and the key workers (carers who worked most closely with the individual and their family, for at least 1 year) for each case were contacted and recruited. Finally, as low adaptive and/or cognitive functioning or reduced social interaction may impact on carers' ability to interpret symptoms, individuals with autistic spectrum disorders and those with low levels of adaptive functioning [as assessed using the Index of Competence (McConkey & Walsh 1982)] were excluded from the study.

Assessment tools

Complicated Grief Questionnaire for People with Intellectual Disabilities

The Complicated Grief Questionnaire for People with Intellectual Disabilities (CGQ-ID) is a modified version of the Inventory of Complicated Grief (Prigerson 1999), which has been adapted for use with this study population. This questionnaire includes all of the possible symptoms covering the broad diagnostic criteria for complicated grief (see Table 2).

While the original Prigerson questionnaire was designed to assist with a diagnosis of complicated grief, the modified version used in the present study

was designed to identify the occurrence of the symptoms of complicated grief in adults with ID. The psychometric properties of this scale, when used with an ID population, have been previously reported by Dodd (2007). Dodd's (2007) analysis identified an overall complicated grief scale (CGQ-ID) as well as sub-scales of traumatic grief (CQG-TG) and separation distress (CGQ-SD). All scales and sub-scales (see Table 3) were shown to have good discriminant validity, good internal consistency and good inter-rater reliability. Average scores on the scales are calculated based on the number of questions answered.

The CGQ-ID was further modified for use with a comparison group. Respondents in this group were asked about symptoms included in the questionnaire in the context of a short-term separation from a family member/key worker, such as might be experienced during a respite care break.

Bereavement History Questionnaire (Adapted)

This was adapted for the purposes of this study from the Bereavement History Questionnaire developed by Hollins & Esterhuyzen (1997). This instrument covers areas relating to the level of contact with the deceased parent prior to the death, the circumstances of the breaking of the news of the death to the bereaved individual, the level of support that the subject received both before and after the bereavement, and the level of participation in bereavement rituals. Content and face validity of this questionnaire were established by its previous use (Hollins & Esterhuyzen 1997) and the familiarity of the authors with issues related to bereavement and this population. The internal reliability of sub-scales within the questionnaire is considered in the results as part of the analysis of the data. A short

Table 2 Items included in the original Inventory of Complicated Grief for Children (Prigerson 1999)

<p>Traumatic grief</p> <ul style="list-style-type: none"> 3. Thinks the deceased will come through the door 7. Feels guilty if they are having a good time 8. Feels angry about the deceased's death 9. Believes the deceased is not dead 10. Finds it hard to trust people since the death 11. Finds it hard to feel close to people since the death 12. Avoids things that remind them of the deceased 13. Reports hearing the deceased's voice 14. Describes the feeling of seeing the deceased 15. Finds it difficult to feel anything 16. Thinks its unfair that he/she is alive 17. Feels envious of others who have not been bereaved 19. Feels insecure since the death 21. Feels the deceased death was their fault 23. Avoids talking about the deceased because it is painful 	<p>Separation distress</p> <ul style="list-style-type: none"> 2. Gets upset when thinking about the deceased 4. Misses the deceased so much – cannot tolerate it 5. Wishes the deceased were here to look after them 6. Wants to revisit places they used to go to with deceased 18. Feels lonely since the death 22. Thinks about the deceased when wanting to think about other things <p>Social/occupational disturbance</p> <ul style="list-style-type: none"> 1. Finds it hard to do normal activities 20. Grief/sadness gets in the way of activities
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Table 3 CGQ-ID symptoms and sub-scales used in the current study (See Dodd 2007)

<p>Separation distress</p> <ul style="list-style-type: none"> 2. Gets upset thinking about the deceased 4. Misses the deceased so much – cannot tolerate it 5. Wishes the deceased were here to look after them 6. Wants to revisit places they used to go to with deceased 18. Feels lonely since the death 22. Thinks about the deceased when wanting to think about other things <p>Other items</p> <ul style="list-style-type: none"> 1. Finds it hard to do normal activities 20. Grief/sadness gets in the way of activities 	<p>Traumatic grief</p> <ul style="list-style-type: none"> 7. Feels guilty if they are having a good time 10. Finds it hard to trust people since the death 11. Finds it hard to feel close to people since the death 15. Finds it difficult to feel anything 19. Feels insecure since the death <ul style="list-style-type: none"> 12. Avoids reminders of the deceased 23. Avoids talking about the deceased because it is painful
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CGQ-ID, Complicated Grief Questionnaire for People with Intellectual Disabilities.

modified version was administered to the comparison group, to document that the participants in this group had not experienced parental bereavement within the previous 2 years.

Index of Social Competence

The Index of Social Competence (McConkey & Walsh 1982) was used to ensure that all participants had an appropriate level of functioning and to ensure the comparability of the bereaved and comparison groups. This index covers 15 adaptive behaviour domains and four sub-scales of overall competence: additional handicaps, communication

skills, self-care, community skills. McEvoy & Dagnan (1993) report this scale to be internally consistent and to discriminate well between people on levels of ability.

Description of data collection

All data were collected by the key investigator (PD), who began by outlining the purpose of the study as well as the format for carer interviews and selection procedures for inclusion in the study. The CGQ-ID was explained to the carers and they were referred to the information note at the beginning of the

questionnaire. Following this guidance, the carers completed the questionnaire independently. The investigator was available for questions, but carers were encouraged to answer the questions based on their own observations of the individuals, and without recourse to notes/files. The Index of Social Competence and the Bereavement History Questionnaire were completed by the investigator with individual carers as informants.

Results

Comparability of bereaved and comparison groups

Demographic variables and levels of functioning were examined to demonstrate the comparability of the index and comparison groups. There were no significant differences between the groups with regard to gender, age or pattern of service use. It should be noted that 16 of the control group had experienced a bereavement; however, these deaths had occurred between 4 and 20 years previously (Mean = 8.68 years, SD = 4.33). All individuals in the study were identified as 'high ability' and no significant difference was found on levels of overall functioning as measured by the Index of Social Competence.

Occurrence of complicated grief symptoms in bereaved and comparison groups

One of the main aims of the study was to identify the frequency of symptoms of complicated grief among adults who had been bereaved. Table 4 below summarises the frequency of response for each symptom between both groups.

In addition, the number of symptoms on which each individual scored within the clinical range (i.e. 'sometimes-always') was calculated. The number of symptoms among the bereaved group ranged between 0 and 17 (out of a possible total of 23), and 13 participants (34.2%) within the clinical range were reported as presenting with 10 or more of the symptoms. The number of symptoms among the comparison group ranged from 0 to 2, with 86.8% ($n = 33$) reporting no symptoms.

Comparison of bereaved and comparison groups on Complicated Grief Questionnaire and sub-scales

Total CGQ-ID scale scores, and CGQ-SD and CGQ-TG sub-scale scores were calculated for each participant and bereaved and comparison groups compared on these scales. Table 5 below reports the findings of this analysis. As illustrated below,

Table 4 Occurrence of symptoms among bereaved and comparison groups

Symptom	Bereaved group		Comparison group	
	Never – rarely	Sometimes – always	Never – rarely	Sometimes – always
Finds it hard to do normal activities	58.3% (21)	39.5% (15)	100% (38)	–
Gets upset when thinking about the deceased	36.8% (14)	63.2% (24)	97.4% (37)	2.6% (1)
Misses the deceased so much – cannot tolerate it	76.3% (29)	13.7% (9)	100% (38)	–
Wishes the deceased were here to look after them	36.8% (14)	63.2% (24)	94.4% (36)	5.6% (2)
Wants to revisit places previously visited with deceased	54.1% (20)	39.5% (15)	100% (38)	–
Feels guilty if they are having a good time	77.8% (28)	18.4% (7)	100% (38)	–
Finds it hard to trust people since the death	63.1% (24)	36.9% (14)	100% (38)	–
Finds it hard to feel close to people since the death	68.4% (26)	28.9% (11)	100% (38)	–
Avoids reminders of the deceased	78.9% (30)	21.1% (8)	97.4% (37)	2.6% (1)
Finds it difficult to feel anything	65.8% (25)	23.7% (9)	100% (38)	–
Feels lonely since the death	26.3% (10)	73.7% (28)	100% (38)	–
Feels insecure since the death	50.0% (19)	50.0% (19)	100% (38)	–
Grief/sadness gets in the way of activities	60.5% (23)	39.5% (15)	100% (38)	–
Thinks about the deceased when wanting to think about other things	68.4% (26)	31.4% (12)	100% (38)	–
Avoids talking about the deceased because it is painful	68.4% (26)	31.4% (12)	100% (38)	–

Table 5 Group comparisons on the scales of the CGQ-ID

Sub-scale	Group	Mean	SD	Range	t_{obs}	d.f.	Sig.
Overall CGQ-ID	Bereaved	1.410	0.859	0–3.00	9.052	40.67*	<0.01
	Comparison	0.114	0.191	0–1.00			
CGQ-SD	Bereaved	1.930	1.032	0–3.83	9.847	44.67*	<0.01
	Comparison	0.191	0.334	0–1.67			
CGQ-TG	Bereaved	0.967	0.927	0–3.00	6.102	38.83*	<0.01
	Comparison	0.037	0.146	0–0.80			

* No homogeneity of variance reported, therefore d.f. adjusted.

CGQ-ID, Complicated Grief Questionnaire for People with Intellectual Disabilities; CGQ-SD, Complicated Grief Questionnaire for People with Separation Distress; CGQ-TG, Complicated Grief Questionnaire for People with Traumatic Grief.

significant differences were identified between the groups on all three scale scores, with the bereaved group scoring higher, particularly for the separation distress sub-scale.

Bereavement history

The bereavement history of the bereaved group was also explored as part of the study. All of the service users in bereaved group had lost a parent, with 42.1% (16) losing a father and 57.9% (22) losing a mother. In addition, 44.7% ($n = 17$) had experienced a previous bereavement in the family, with 13.2% ($n = 5$) having lost a member of their immediate family. Looking at the most recent parental bereavement, in almost two-thirds of the cases (68.4%, $n = 26$), the parent had passed away in hospital, and the service user was aware of the parent's illness in a similar number of cases (71.1%, $n = 27$). In addition, although only three (7.9%) service users were involved in caring for their deceased parent, in almost two-thirds of the cases (68.4% $n = 26$) the service user had visited the parent in hospital and in 22 of these cases (84.6%) the service user had visited their parent at least weekly.

Service users were reported to have discussed the impending parental death in 55.3% ($n = 21$) of cases. Participants in these discussions were generally staff or staff and family members together. Table 6 below illustrates the high frequency with which service users were involved in various aspects of bereavement rituals. Finally, staff members reported that very few of the service users had

Table 6 Involvement of service users in funeral rituals

Activity	Yes ($n = 35$)
Involved in saying goodbye	76.3% (29)
Involved in visiting the body	73.7% (28)
Involved in preparing for the funeral	73.7% (28)
Involved in talking about the deceased	89.5% (34)
Involved in attending the funeral	94.7% (36)
Involved in attending the 'wake'	71.1% (27)
Involved in looking at photographs	89.5% (34)
Involved in attending the months mind	68.4% (26)

received bereavement counselling following the death ($n = 4$, 10.5%).

The relationship between bereavement history and scores on Complicated Grief Questionnaire for People with Intellectual Disabilities

In order to examine the relationship between bereavement experience and scores on the CQG-ID for the bereaved group, it was necessary to create an index of service user involvement in, and experience of, the parental bereavement. Twelve items (see Table 7 below) were initially identified as possible items in a 'Bereavement Involvement Index' (BII). The internal reliability of this scale was found to be high (Cronbach's Alpha = 0.8600), with no problematic items highlighted. Further examination of the scale suggested that this scale included both events that preceded the death (e.g. visiting the person while ill) and events that followed the event (e.g. attending the funeral). Therefore, a factor

Table 7 Factor structure of the Bereavement Involvement Index

Bereavement involvement items	Factor 1	Factor 2
Involved in attending the 'months mind'	0.823	
Involved in preparing for the funeral	0.763	
Involved in attending the 'wake'	0.725	
Involved in talking about the deceased	0.732	
Involved in looking at photographs	0.732	
Involved in 'saying goodbye'	0.515	
Involved in visiting the body	0.521	
Involved in attending the funeral	0.333	
Visited the person whilst in hospital		0.957
Aware of the person's illness		0.939
Person's imminent death was discussed		0.817
Involved in caring for the person during their illness	–	–

analysis was conducted. The resulting model was found to explain 57% of the variance in the data and yielded a two-factor structure. (The two-factor structure is outlined in Table 7.) The final location for items that loaded in both factors was decided based on a qualitative consideration of the item and its suitability. Only one item was excluded, which related to 'caring for the individual'.

Overall, Factor 1 (BII-Post; involvement following the death) was found to have an internal reliability score of 0.8465, while Factor 2 (BII-Pre; involvement prior to the death) had an internal reliability of 0.9213. As with previous scales, average scores were calculated to take into account the number of valid answers in the scale.

Spearman's rho correlations (as the BII could not be assumed to be normally distributed) and linear regression were conducted to examine the relationship between bereavement involvement and CGQ-ID. Six sub-scales were used in this analysis. The first was the overall BII, along with the two sub-scales of post-death involvement (BII-Post), and pre-death involvement (BII-Pre). For all three scales, higher scores were indicative of more involvement. The other scales were the overall complicated grief score (CGQ-ID), along with the two sub-scales of separation distress (CGQ-SD) and traumatic grief (CGQ-TG). For these scales, higher

scores are indicative of greater difficulty in post-bereavement adjustment. Table 8 below presents the outcomes of the correlation analysis.

Using Spearman's rho correlations, a significant positive correlation was found between CGQ-SD and BII. However, the correlation coefficient ($r = 0.278$) represents a low-moderate relationship. Significant correlations were not found for BII and CGQ-ID or CGQ-TG. The next scale to be considered was BII-Pre, but no significant correlations were identified with any of the CGQ scales. Finally, significant correlations were identified between BII-Post and overall CGQ-ID, CGQ-SD and CGQ-TG, all of which could be classed as moderate correlations.

Linear regression analysis was conducted to examine whether these significant relationships were predictive, i.e. that bereavement involvement was a predictor of complicated grief. The results are presented in Table 8. Overall BII-Post was a significant predictor of CGQ-ID, suggesting that greater involvement in bereavement rituals following the death was predictive of higher scores on over-complicated grief symptoms. However, the adjusted r -square value, which represents the percentage variance CGQ-ID scores accounted for by involvement, was 0.16, suggesting that less than 20% of the variance in complicated grief scores is accounted for by BII = post scores. This indicates that other factors are involved in the level of overall post-bereavement difficulty.

Correlations were also found between CGQ-SD and both BII and BII-Post; therefore, both were included as possible predictors. However, only BII-Post was included in the prediction model, which was both significant, and accounted for just over 25% of the variance in the data (adjusted r -squared value = 0.26). Again, this suggests that other factors are involved in predicting separation distress. Finally, no significant predictors were identified for the CGQ-TG sub-scale.

Relationship between Complicated Grief Questionnaire scores and other aspects of bereavement history

In addition to correlation and regression analyses, a number of specific variables were identified for use as independent variables in an examination of

Table 8 Correlations between CGQ-ID scales and BII scales

	CGQ-ID	CGQ-SD	CGQ-TG
BII	($r = 0.204, P = 0.110$)	($r = 0.278, P = 0.046$)*	($r = 0.126, P = 0.226$)
BII-pre	($r = -0.121, P = 0.235$)	($r = -0.025, P = 0.440$)	($r = 0.091, P = 0.294$)
BII-post	($r = 0.411, P = 0.005$)*	($r = 0.441, P = 0.003$)*	($r = 0.301, P = 0.033$)*
Regression	($F = 6.84, d.f. = 1.36; P = 0.013$)	($F = 12.672, d.f. = 1.36; P = 0.001$)	No significant predictors

* Significant correlations, included in regression analyses.

BII, Bereavement Involvement Index; CGQ-ID, Complicated Grief Questionnaire for People with Intellectual Disabilities; CGQ-SD, Complicated Grief Questionnaire for People with Separation Distress; CGQ-TG, Complicated Grief Questionnaire for People with Traumatic Grief.

Table 9 Impact of bereavement history on CGQ-ID scales

Bereavement history	CGQ-ID	CGQ-SD	CGQ-TR
Was death discussed in advance?	$t = -0.112; d.f. = 26; P > 0.05$	$t = 0.464; d.f. = 28; P > 0.05$	$t = -0.394; d.f. = 31; P > 0.05$
Previous bereavement	$t = -1.586; d.f. = 36; P > 0.05$	$t = -1.532; d.f. = 36; P > 0.05$	$t = -1.609; d.f. = 36; P > 0.05$
Type of bereavement	$t = 0.270; d.f. = 36; P > 0.05$	$t = 0.215; d.f. = 36; P > 0.05$	$t = 0.528; d.f. = 36; P > 0.05$

CGQ-ID, Complicated Grief Questionnaire for People with Intellectual Disabilities; CGQ-SD, Complicated Grief Questionnaire for People with Separation Distress; CGQ-TG, Complicated Grief Questionnaire for People with Traumatic Grief.

Table 10 Analysis of Variance outcomes for quality of relationship analysis

Group	% (n)	CGQ-ID	CGQ-SD	CGQ-TG
Poor/minimal relationship	23.7 (9)	$F = 0.021;$	$F = 0.054;$	$F = 0.153;$
Good relationship	36.8 (14)	$d.f. = 2.35;$	$d.f. = 2.35;$	$d.f. = 2.35;$
Very good relationship	39.5 (15)	$P > 0.05$	$P > 0.05$	$P > 0.05$

CGQ-ID, Complicated Grief Questionnaire for People with Intellectual Disabilities; CGQ-SD, Complicated Grief Questionnaire for People with Separation Distress; CGQ-TG, Complicated Grief Questionnaire for People with Traumatic Grief.

CGQ-ID scores. The results of these group comparisons are presented in Tables 9 and 10.

The first variable examined was whether there had been an opportunity to discuss the death prior to the event, and thus perhaps prepare the individual for the event. As reported above, this had occurred in just over half of the cases (55.3%, $n = 21$). However, no significant differences were found between these two groups on scores of overall complicated grief, separation distress or traumatic grief. Also considered was whether the individual had experienced a previous bereavement, which occurred for 44.7% ($n = 17$) individuals.

Again, no significant differences were found between those who had experienced a previous bereavement, compared with those who had not, on the three scales. Moreover, no significant differences were found between these two groups on scores of overall complicated grief, separation distress or traumatic grief for differences in the type of parent bereavement (mother or father).

Finally, ratings of the quality of the relationship with the deceased were assessed as a possible influencing factor. Key workers indicated the quality of the relationship (subjectively, from their perspective) and their responses categorised as poor/

minimal, good and very good. Table 10 below reports the frequencies for each group. A three one-way non-repeated Analysis of Variance was conducted and no significant differences were found.

Discussion

Summary of results

As far as we are aware, this is the first study of complicated grief symptoms in people with ID. This carer-based comparison study has shown that complicated grief symptoms were recognised in bereaved individuals with ID following the death of a parent, with one-third of the bereaved group experiencing 10 or more clinically apparent symptoms. These symptoms occur more often in the bereaved group than in a non-bereaved comparison group, and the bereaved group score consistently higher on the three scales used. It is interesting to note that the highest scores for the bereaved group were in the separation distress sub-scale. In developing the CGQ-ID, Dodd (2007) reported that a number of symptoms originally associated with traumatic grief were excluded as they failed to distinguish between the bereaved and comparison groups. Therefore, there is good evidence to suggest that symptoms of separation distress are experienced more consistently in this population when compared with the traumatic grief symptoms. This is in keeping with the proposition developed by Bowlby (1980) that grief is an extension of a general response to separation where an attachment has been broken. This innate response best explains the ability of people with ID to grieve more than one would expect based on narrow considerations such as cognitive ability. However, it is clear that the present study needs to be replicated and complicated grief symptoms explored in other bereaved individuals in order to improve validity and further measure rates of occurrence in the wider intellectually disabled population.

This study has also gathered information on bereavement-related experiences of individuals both before and after their loss. There was a high level of awareness of the approaching death, and in most cases, a high level of bereavement ritual involvement after the death. Previous research suggests that those of higher ability tend to have better

developed concepts of death (McEvoy 1989; McEvoy *et al.* 2002) and therefore possibly a better understanding of the implications of a bereavement.

An effort was made to ascertain if bereavement-related experiences predicted whether an individual went on to develop complicated grief symptoms. A positive correlation was found between those individuals who were very involved in bereavement rituals after the death (seeing the body, attending the funeral, etc) and the development of complicated grief symptoms, and this involvement was found to predict scores on overall complicated grief and particularly 'separation distress'. On the surface, this would seem to be at odds with the commonly understood practice of maximising involvement in bereavement rituals to help the individual understand the finality of death, etc. (Dodd *et al.* 2005). However, remembering that the post-bereavement ritual involvement accounted for only a quarter of the variance in separation distress symptoms and less in the case of overall complicated grief; clearly other factors are involved in predicting this unexpected finding. This is particularly important as factors such as the type of bereavement (maternal vs. paternal), experience of a previous bereavement and the quality of the relationship with the deceased did not appear to impact on the scores. The important point here may be the context of the ritual involvement: if the bereaved individual was very involved in rituals for the first time in their life, then it is possible that this involvement may prove to strengthen the separation distress type symptoms. The analysis does not indicate that these individuals will necessarily go on to experience significant complicated grief problems; all that can be said is that those individuals who were involved in an increased number of post-death bereavement rituals experienced a higher level of separation distress and complicated grief symptoms. This finding may have implications for the way in which we support bereaved individuals. While involvement in bereavement rituals is important, previous exposure to, and the development of an understanding of these rituals is clearly important. It may well be that, before recommending a bereaved individual be involved in all of the bereavement rituals, a bereavement ritual history may need to be conducted; those with little previous ritual involvement may be less distressed by

being involved in rituals commonly regarded as less traumatic (e.g. avoiding seeing the dead body or seeing the coffin lowered into the ground). Of course, decisions regarding the level and type of involvement can only be made on an individualised basis.

Methodological issues

Given that this is the first study to look at complicated grief symptoms among this group, it is important to consider the possible impact of methodological issues. An important strength of the study lies in the fact that it incorporates a well-matched comparison group allowing stronger conclusions to be drawn regarding the occurrence of symptoms. However, it still remains a carer-based study. All of the information gathered was based on the observations of carers. In addition, the study was retrospective, relying on the observation skills and memory of the individual's key worker. However, only staff that knew the individual well were chosen, and the level of agreement between the key worker and the other carers was high.

Another strength is the use of an adapted questionnaire specifically for use with an intellectually disabled population. The psychometric properties of this adapted scale have been reported elsewhere; however, it is acknowledged that the scale will need to be used more widely in order to further test its validity. As there is currently no diagnostic gold standard for complicated grief in the general population, the issue of diagnostic validity with an ID population could not be pursued.

A final issue, which may be classed as a limitation, relates to the generalizability of the findings. This study only examined the experiences of high-ability adults with ID, and as such it does little to advance our understanding of the experiences of people with more severe ID following a bereavement. However, the participants were selected from two service providers and from both day and residential services which adds to the generalizability of the findings to other high-functioning adults.

Suggested future research

Sufficient information has been collected in this study to suggest that a study involving direct inter-

views with bereaved people with ID is warranted. A replication of this study, with all of the initially proposed symptoms of complicated grief, would be of benefit in terms of both further exploration of symptoms and examining the psychometric properties of the CGQ-ID questionnaire itself. In addition, more detailed information could be collected about previous bereavement history and in particular the quality of bereavement ritual involvement, which would allow for this important issue to be examined further. Following this, a prospective study of complicated grief symptoms could be conducted with symptom assessments at 3- or 6-month intervals. This may help to indicate the time following a bereavement, when an individual with ID is most vulnerable. The prospective study could be linked with a randomised control trial of a bereavement education package for both individuals and carers prior to any significant bereavement; this may show the positive mental health benefits of bereavement education for this population.

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