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**The impact of staff training on the knowledge of support staff
in relation to bereavement and people with a learning
disability**

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Accessible summary

- It can be hard for everyone if someone they care for dies
- People with a learning disability may need extra support when someone they know dies
- Care staff may not always know what to do to help
- This study found that one day of training helped care staff to know more about how people might feel and how to support them
- We don't know how long this training was helpful to staff for.

Summary

This study aimed to investigate whether a one day training course improved support staff knowledge about bereavement and grief in people with a learning disability. A questionnaire based, mixed design was used. Forty eight participants were randomly assigned to one of two equal groups. A staggered design allowed for group 2 to act both as a control group and to receive training. Within and between group comparisons were made. Training significantly improved staff knowledge in all the areas measured. An analysis of staff knowledge at one month after training was not possible due to a low response rate. A short training course was successful in significantly increasing the knowledge of paid carers about issues relating to bereavement for people with a learning disability. The clinical and ethical implications of the study are discussed along with limitations and suggestions for further research.

Key words: Bereavement, training, staff knowledge

Introduction

Bereavement results from a loss that triggers the expression of grief and intense emotional distress (Stroebe *et al.*, 1993) while mourning describes the behaviours and actions associated with the expression of grief (Schuchter & Zisook, 1993). These vary from individual to individual but commonly include the following components: cognitive (e.g., confusion and helplessness); emotional/affective (e.g., anger, sadness); behavioural (e.g., social withdrawal) and physiological (e.g. sleep disturbance, loss of appetite) (Hansson & Stroebe, 2006; Stroebe *et al.*, 2007).

Models of grief generally propose that that bereavement leads to an initial period of shock characterised by numbness, disbelief and denial, leading to yearning, disorganisation and despair before resolution, adjustment and acceptance of the loss can occur (e.g. Parkes, 1996). Worden (2003) proposed the concept of the ‘tasks of grieving’ to account for the fact that grieving is a dynamic process: acknowledging and accepting the person is dead and will not return; experiencing the pain of grief; adjusting to an environment without the deceased and finding a place for the deceased in ones emotional life in a way that enables the person to move on and complete the grieving process.

Despite a growing understanding of bereavement and mourning in the general population, the needs of individuals with a learning disability who are bereaved have often been neglected and misunderstood (Oswin, 1991). Individuals may be excluded from bereavement, whether due to disregard of their feelings or as a means of protecting them from the painful experience of death (Read & Elliott, 2003). Likewise, symptoms of

distress may be attributed to the person's learning disability rather than as a common response to loss (Read & Elliott, 2003), despite there being no evidence that the presence of a learning disability precludes a reaction to death (Palazon, 1991).

Research has clearly demonstrated that individuals with a learning disability suffer bereavements (Service *et al.*, 1999), are capable of grieving (Dodd *et al.*, 2005), appear to pass through the same stages or phases of grief (Carder, 1987) and often respond to death in a manner similar to the general population (Harper & Wadsworth, 1993). Within this group of individuals, however, there will be differences in level of ability and previous experiences, which may impact on reactions to bereavement (James, 1995).

Grief has been shown to be a major contributing factor to a wide range of behavioural and mental health problems in individuals with a learning disability including increased irritability, lethargy, hyperactivity, depression, anxiety and adjustment disorders (Dodd *et al.*, 2005, Hollins & Esterhuyzen, 1997). Cathcart (1994) also identified a number of common non verbal expressions of grief in people with a learning disability, including clinginess, uncharacteristic incontinence, self injurious behaviour, restlessness, clumsiness and reluctance to go out. It is, however, difficult to differentiate between bereavement reactions and reactions that occur as a consequence of additional losses faced by the bereaved individual, such as having to move to new accommodation (Bonell-Pascual *et al.*, 1999).

Individuals with a learning disability can also experience complicated grief, although the research in this area is limited (Dodd *et al.*, 2008). Having a learning disability can increase the risk of additional difficulties following bereavement. Communication difficulties may impede the process of grieving, by reducing the ability of the individual to express grief and verbalise feelings (Cochrane, 1995). Restricted support networks and relationships with others characterised by strong attachments and high levels of dependency may mean that the loss of a significant relationship can have a greater impact (Stylianios & Vachon, 1993), particularly if the deceased was the main provider of instrumental and emotional support (Delorme, 1999). Individuals with a learning disability may also experience a profound degree of disruption in their lives following bereavement, including loss of their home, possessions, security, routine and familiarity, possibly all within a short space of time (Bonell-Pascual *et al.*, 1999; Cochrane, 1995).

Lack of preparation for bereavement can also increase the trauma when death occurs (Wright, 1992) as well as further increasing the likelihood of multiple losses (Bowey & McGlaughlin, 2005). There has been a tendency for death to be concealed, for information about an impending death to be withheld and for people with a learning disability to be denied the opportunity to participate in mourning rituals in order to shield them from the emotional pain and sadness this can create (Hollins & Esterhuyzen, 1997). There are mixed findings about the impact of such rituals on the bereaved. Some authors suggest participation improves adjustment after a death (Palazon, 1991) and reduces repetitive questions about the location of the deceased and the presentation of problematic behaviours (Sheldon, 1998). By contrast, others have found a link with a

greater number of complicated grief symptoms (Dodd *et al.*, 2008). Despite this, it has been suggested that withholding information about a death or denying an individual the opportunity to participate in bereavement rituals may impede the acceptance and expression of grief, which could in turn contribute to the development of complicated grief (Read & Elliott, 2003).

Preparation for bereavement is considered to be an important element of support (Crick, 1988) and people with a learning disability are thought to benefit from receiving education about death, dying and loss, as well as offering encouragement to participate in rituals surrounding the death (Cathcart, 1991, 1994). Carers should also attempt to minimise any additional significant changes in the individual's life following bereavement (Oswin, 1991) and facilitate access to existing support systems (Blackman, 2003).

It is important to recognise the factors that may hinder the grieving process and which indicate the need for individuals with a learning disability to seek specialist help. These include individuals with high levels of anger, with limited or absent support networks, those exhibiting profound distress and yearning for the deceased and those who are failing to cope with the bereavement (Elliott, 1995). A number of approaches have been identified which can facilitate the grieving process for people with a learning disability, including tolerating repetition from clients to help them make sense of the loss, allowing sufficient time for the individual to grieve, normalising the reaction, identifying verbal and non verbal clues to feelings, respecting privacy and listening and offering the

individual opportunities to talk about their feelings (e.g., Cochrane, 1995; Crick, 1988; Oswin, 1991; Read, 2003).

Offering support at a time of bereavement can, however, be both difficult and challenging. Carers often receive little education or training to prepare them for dealing with bereavement in the individuals they support (Read & Elliott, 2003) and they may fail to provide appropriate support for their clients at a time of bereavement (Murray *et al.*, 2000). One contributing factor is a lack of knowledge and understanding about bereavement in this group (Cochrane, 1995), although some researchers have found such knowledge to be relatively good in support staff and health professionals (Dodd *et al.*, 2005; Murray *et al.*, 2000; Reynolds *et al.*, 2008). Unfortunately, there is still a tendency for carers, staff, family members and professionals to presume that individuals with a learning disability are unable to comprehend the concept of death and grieve in a similar manner as the general population, which can impact on the support offered (McEvoy & Smith, 2005).

There are, however, very few training programmes specifically for staff working with individuals with learning disabilities. A small study by Bennett (2003) investigated the impact of loss and bereavement education on the knowledge and understanding of carers for adults with a learning disability and found it resulted in increased personal insight and greater ability to identify necessary changes to the care provision. Similarly, Reynolds *et al.* (2008) demonstrated that a two day training programme on bereavement and loss significantly increased the confidence of thirty three support staff about offering support

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to individuals with a learning disability at a time of bereavement. A follow-up was, however, not conducted to assess the longer term impact of the training and determine if confidence levels were maintained.

The aim of the present study was to add to the small existing literature and investigate the impact of a one day training course on the knowledge of care staff about supporting an individual with a learning disability who has experienced bereavement.

It was hypothesised that:

1. There will be a significant increase in knowledge in relation to bereavement and grief following training.
2. This knowledge increase will be sustained over time as evidenced by the one month follow-up.

Method

Design

A mixed design was used, incorporating both between and within participant comparisons. The study had a staggered design, with all participants receiving training, but with the time lag for group 2 participants allowing them to act as a control group for group 1. This allowed for comparisons in knowledge about bereavement between those who had and had not received training as well as comparisons before and after training. The study had twenty four participants in each group (total $n = 48$).

Participants

The participants (39 females and 9 males) were from local support provider organization and the number of years working within the service ranged from 1 to 30 (Mean = 7.46, SD = 7.77). Twenty four participants were randomly allocated to each group. The age of the participants within the study ranged from 22 to 61 (Mean = 38.96, SD = 11.19). None had received training specifically on bereavement and individuals with a learning disability, although 5 (10.4%) participants had received prior training on bereavement (e.g. general bereavement training, preparing for bereavement). Thirty two (66.7%) participants had access to bereavement guidelines in their organisation and 29 (60.4%) had previous experience of offering support to a bereaved individual with a learning disability.

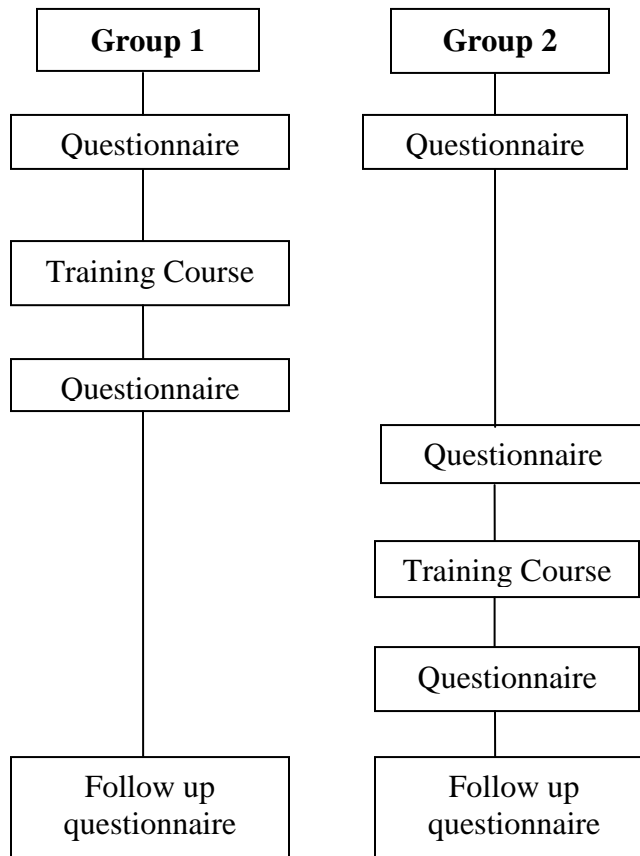
Recruitment

Once ethical clearance was gained from the local ethics committee, a letter was sent to the managers of 24 support provider organisations within the first author's health board area. This letter provided details of the research and asked if staff within the organisation would consider participating in the study. Responses were received from fourteen organisations who indicated an interest in participating in the study, reflecting a response rate of 58% and of these eight participated.

Procedure

Participants were randomly allocated to group one or two and completed the questionnaires as illustrated in figure 1. Group 1 completed the questionnaire immediately before and immediately after training and at one month follow-up. Group 2 completed the questionnaire on four occasions: at the same time as group 1 completed the pre-training questionnaire; one week later to allow for a measure of test-retest reliability; immediately before and after training and at one month follow up. Forty eight questionnaires were sent out one month after training and fifteen were returned, giving a 31.3% response rate.

Figure 1: Study design



Training Course

The training lasted 6 hours, including breaks. A training course was specifically designed for the study by the first author, following a literature review of the evidence base focusing on bereavement and grief. The contents were:

1. Bereavement and Grief: What is bereavement and why do we grieve; theories and models of grief; tasks of grieving; grief responses; risk factors in bereavement outcome; complicated grief
2. Bereavement and learning disability: what can make bereavement more difficult for individuals with a learning disability; grief reactions and responses in individuals with a learning disability; factors increasing vulnerability of developing complicated grief reactions
3. Supporting an individual with a learning disability through bereavement: preparation for bereavement; practical support after bereavement; facilitating the grieving process; identifying difficulties; looking after yourself; available resources

Measure

The questionnaire used was designed for the purposes of the study. It asked for basic demographic information including age, gender and job title and experience of working with a bereaved individual with a learning disability. A total of ten questions were

developed utilising an open ended approach (Niedomysl & Malmberg, 2008). The questionnaire had 3 sections: knowledge about the process of grieving in the general population, knowledge about the grieving process in people with a learning disability and knowledge of supporting an individual with a learning disability through bereavement. The questionnaire was piloted individually with five staff who worked with people with a learning disability. All staff fed back to the first author that the questionnaire had face, social and content validity.

Scoring Criteria

For each question, a list of predetermined response categories, based on a literature review of the evidence base for the grief process and supporting people with a learning disability through bereavement, were identified with detailed examples included for each category. Copies of the questionnaire and details of the scoring criteria can be obtained from the first author. An example of scoring criteria is shown in relation to some of the responses in Table 1.

Table 1: An example of the scoring criteria applied to staff responses

Question: Please describe some of the grieving responses often associated with 'normal grieving'		
Response category	Description	Examples
Emotional	An accurate example of emotional responses associated with normal grieving	Sadness, anger, guilt, shock, loneliness, yearning, relief, anxiety
Behavioural	An accurate example of behavioural responses associated with normal grieving	Social withdrawal, searching for the deceased, restlessness/over activity, crying
Physiological	An accurate example of physical responses associated with normal grieving	Hollow feeling in stomach, lack of energy, breathlessness, loss of appetite, sleep disturbance
Cognitive	An accurate example of thoughts associated with normal grieving	Disbelief, confusion, preoccupation with the deceased, rumination, helplessness

Results

All variables used in the analysis were normally distributed. Due to the small number of questionnaires received at the one month follow-up, it was not possible to include this factor in the analyses.

Inter-Rater Reliability

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Twenty five (18.5%) of the 135 questionnaires completed throughout all stages of the study were analysed by two raters to assess inter-rater reliability. All questions had ‘excellent’ levels of inter-rater reliability, with Kappa values between 0.94 and 1.00.

Test-Retest Reliability

The 24 participants in group two completed the questionnaire a week before they attended the training course and again one week later. All sections had significant ($p < 0.001$) and strong correlations (with r values ranging from 0.82 to 0.98), indicating good test-retest reliability.

Hypothesis 1

There will be a significant difference in overall knowledge between group one (after receiving training) and group two (prior to receiving the training).

The mean scores and standard deviations for both groups, pre and post training are shown in Table 2.

Table 2: Mean scores and Standard Deviations for Overall Scores of Group 1 and Group 2 Pre and Post Training

Group	Time Point	Number	Mean	SD
Group 1	Pre-training	24	7.79	4.12
	Post-training	24	16.08	4.87
Group 2	Pre-training	24	8.50	3.35
	Post-training	24	17.54	5.62

A 2 x 2 (group by time) mixed ANOVA was used to compare the mean overall scores of group one and group two both before and after training, to examine the main effects of

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group and time and any interaction of the two variables. Analysis showed that the main effect for group was not significant ($F = 1.18$, $df = 1$, $p = 0.284$), indicating that the effect of training was not dependent on group. Results also showed a significant main effect for time ($F = 101.25$, $df = 1$, $p = <0.001$), indicating that training had a significant impact on mean overall scores in both groups of participants, as predicted. The results also showed that there was no significant interaction between the variables of group and time ($F = 0.19$, $df = 1$, $p = 0.665$).

The results show that there was a significant difference in the scores obtained by participants in both groups before and after training; that there was a significant difference between the scores obtained by participants in group 2 (post training) and the scores obtained by participants in group 1 (pre-training). The effect of training was not dependant on group and there was no significant interaction between group and scores obtained at the two time points.

Due to the lack of significant differences between the two groups, the groups were combined and all further analyses were conducted using within participant comparisons

Impact of training on staff knowledge of the components covered on the training course

A series of related t-tests found significant increases in participants' knowledge, after training in all of the areas measured. Table 3 illustrates the mean scores, standard

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deviations, *t* values and significance levels for each component taught in the training course, pre and post training.

*Table 3: Means scores, standard deviations, *t* values and significance levels for each component taught in the training course pre and post training*

Area covered	Pre training		Post training		<i>t</i>	<i>df</i>	<i>p</i>
	Mean	SD	Mean	SD			
Knowledge about bereavement and grief in individuals with an intellectual disability	2.19	1.10	4.40	1.87	-8.87	47	0.001
Knowledge about supporting an individual with an intellectual disability through bereavement	1.92	1.33	4.33	1.67	-9.86	47	0.001
Knowledge about the process of grieving in the general population	3.21	1.92	7.85	2.68	-13.99	47	0.001

Discussion

There is a substantial body of research that highlights both the need for, and benefits of, staff training about the process of bereavement for individuals with a learning disability (e.g., Hollins & Sinason, 2000; McEvoy & Smith, 2005). The proposed benefits of staff training include improving staff knowledge and increasing understanding (e.g., Bennett,

2003; Reynolds *et al.*, 2008), with the overall aim of enhancing the support that is offered to the bereaved individual. In turn, it is hoped that this may reduce the likelihood of the person developing associated behavioural problems or mental health difficulties (Dodd *et al.*, 2005, Hollins & Esterhuyzen, 1997). This is important because carers have been found to overestimate the understanding of those they support about the concept of death and there are also indications that they underestimate the likelihood of behavioural difficulties as a reaction to grief (MacHale *et al.*, 2009)

There is, however, only limited training provision on this topic for staff supporting individuals with a learning disability and limited research examining the impact of this (Bennett, 2003, Reynolds *et al.*, 2008). The results of the present study suggest that the short staff training intervention was effective at increasing staff knowledge overall and in relation to each component covered on the one day course. Both the present study and previous research has found that very few carers have received training specifically relating to the bereavement process in people with a learning disability (MacHale *et al.*, 2009) and there is the suggestion that staff may lack confidence in providing support after a bereavement because they perceive this to be a specialist area (MacHale *et al.*, 2009) It could be argued that the provision of short training courses such as that outlined in the present study may go some way to addressing both of these issues.

It should, however, be acknowledged that, in isolation, training may not be sufficient to change the working practices of staff in the longer term (Cullen, 2000). It could, therefore, be argued that while staff knowledge was found to have increased after training

in the present study, this may not necessarily have impacted on staff practice when supporting a bereaved individual.

The study also had additional limitations. A relatively small sample size drawn from one geographical location calls into question the extent to which the results of the study can be generalised. The former factor may also have contributed to the poor response rate at follow up, which meant that the aim of the study to assess whether increases in staff knowledge were maintained one month after training could not be achieved. This may also be partly attributable to the fact that, in order to establish the test- retest reliability of the measure developed for use in the study, participants were asked to complete the questionnaire on a number of occasions. While the questionnaire was found to have good face, content and social validity and high inter-rater and test-retest reliability scores, the number of times that participants were asked to complete them may have made them reluctant to do so for a final time at the follow up stage. It is, therefore, unclear to what extent the staff knowledge gains were maintained over time

Despite these limitations, the provision of staff training is consistent with the systemic model of providing support to bereaved people with a learning disability, outlined by Read (2005) and developed by Read & Elliot (2007). This model recognises that support can be facilitated at different levels from the micro e.g. where the focus is the individual, to the macro, reflected by national policies and directives. Read & Elliot (2007) see education as underpinning the support and intervention for individuals with a learning disability and all those who support them. The present study focused on paid carers,

however, approximately sixty per cent of individuals with a learning disability live at home and are cared for by their families (Department of Health, 2001). Input has There is, therefore, a need to further develop input in relation to bereavement related issues for family carers. Indeed it has been suggested that training on bereavement should be mandatory for all individuals in professional and caring roles (Wass, 2004) as well as being available for families, friends and carers, to ensure they are adequately informed about grief and sufficiently prepared for such situations (e.g. Bennett, 2003).

Previous research has also highlighted that individuals with a learning disability can benefit from being provided with information about death and dying (Luchterhand & Murphy, 1998; Stoddart *et al.*, 2002). In order to adopt a more proactive approach it may, therefore, be useful to consider the role of education groups specifically designed for individuals with a learning disability to discuss issues of death and grief, such as that reported by Boyden *et al.* (2009), as well as the provision of training for paid and family carers.

In conclusion, the aim of study was to investigate the impact that a one day training course had on staff knowledge about bereavement and grief. The results demonstrated significant improvement in knowledge after training, suggesting that staff training may offer one means of increasing the ability of carers to offer appropriate support to people with a learning disability following a bereavement.

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