EMOTION RECOGNITION AND CONCEPT OF DEATH IN PEOPLE WITH LEARNING DISABILITIES

John McEvoy, Yael Reid and Suzanne Guerin

Introduction

Several studies suggest that the concept of death in adults with learning disabilities is related to cognitive ability (Bihm and Elliot, 1982, Lipe-Goodson and Goebel, 1983). However, discussion of an understanding of the concept of death purely from the point of view of cognitive ability is limiting. Grief responses are manifest across physical, behavioural, psychological and emotional domains (Worden, 1991) and as Kronick (1985) suggests a certain level of emotional development may be necessary to fully understand death. Within the learning disabled population, equating the ability to conceptualise death with the ability to feel or display grief is far too simplistic (Wadsworth and Harper, 1991). Although some individuals may have difficulty in understanding concepts of loss and death (McEvoy, 1989) they still miss people and express the full range of emotions (Harper and Wadsworth, 1993). Thus, an important element in coping with and understanding death is an appreciation of the expression of sadness and grief associated with death (Stoddart and McDonnell, 1999).

Reed and Clements (1989) suggest that emotional awareness is an important precursor of the ability to report accurately on one’s own emotional state and is related to language comprehension. Unfortunately, people with learning difficulties do not do well on a range of emotion recognition tasks (Rojahn et al.,

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1995). Furthermore, poor ability in recognising emotions is predictive of behavioural and psychiatric difficulties in people with learning disabilities (Matson and Sevin, 1994). Because of difficulties in expressing and understanding the emotional aspects of death (Wadsworth and Harper, 1991), people with learning disabilities are at increased risk for emotional and behavioural problems following bereavement (Day, 1985; Emerson, 1977; McLoughlin, 1986; Hollins and Esterhuysen, 1997).

The aim of the present study was to establish the relationship between ability to recognise emotions and understanding the concept of death. The study focused on a) whether those adults with a more developed level of language comprehension would also demonstrate a more developed concept of death, b) whether those adults who were more emotionally aware would have a more mature concept of death and c) does emotional awareness generalise to the bereavement context?

**Method**

**Participants**

The study was conducted in a day service for people with intellectual disabilities within the West Midlands, UK. Care staff were invited to identify participants most likely to respond well on interview. A letter of invitation, outlining the interview schedule was sent to each prospective participant and their families. Forty-one adults, 25 (61%) males and 16 (39%) females with a learning disability agreed to take part in the study. Ages ranged from 20 to 62 years with a mean age of 36.8 years (SD, 10.8). Twenty people (49%) lived at home with their family, 21 (51%) in hostels or community residential homes. Sixteen (39%) participants were diagnosed with Down’s syndrome.

**Materials**

i) *The British Picture Vocabulary Scale*

Receptive language ability was assessed using the shortened version of the British Picture Vocabulary Scale (BPVS: Dunn *et al.*, 1982). Participants were presented with a series of plates from which they were invited to choose one of four pictures in response to a stimulus word spoken by the interviewer.

ii) *Concept of death*

Three components of the concept of death were examined using a short story with pictures describing the relationship between a boy and his grandfather, the grandfather’s death, and the responses of the various characters to events in the story. Questions based on McEvoy, (1989) focused on a) Irreversibility; that once a living thing dies it can not be made alive again, b) Non-functionality; that all life-defining functions cease at death; and c) Universality; that all living things die. Scores ranged from 0 to 11. In addition questions concerning the causes of death and what might happen after death were also asked.

iii) *Assessment of emotional awareness*

Emotional awareness was assessed using the procedure described by Reed and Clements (1989). Six simple scenarios were described to participants who indicated verbally or by pointing to either a happy or sad face how they would feel in each of the situations. Correct
identification of the emotion associated with each scenario was required to pass the test. Scores ranged from 0 to 11.

iv) Recognition of emotion following bereavement.

Participants were asked to describe a pictorial representation of a funeral scene and to describe how James and members of his family might feel following the death of the grandfather.

Procedure

Interviews, twenty to thirty minutes long, took place in a quiet room attached to the day centre. Prior to the interviews the second author had spent considerable time (three weeks) at the centre getting to know potential participants. The BPVS was administered first, followed by the assessment of emotional awareness (Reed and Clements, 1989) and the assessment of ‘Concept of death’.

Results

BPVS raw scores ranged from 1 – 25 with a mean of 13.7 (SD = 5.91). Seventeen participants (41%) passed the Reed and Clements, (1989) understanding of emotional states assessment. Total Concept of Death Scores ranged from 0 to 11 with a mean of 6.7 (SD 3.93). Performance on the BPVS was correlated significantly with concept of death (Pearson’s r = 0.67, p < 0.001) and the Reed and Clement’s assessment (Pearson’s r = 0.54, p < 0.001). Using Mann-Whitney tests because of unequal group sizes, significant differences were found in BPVS language ability (Z = -3.05, p < 0.005) and concept of death assessment (Z = -3.75, p < 0.001) between those people passing or failing the Reed and Clement’s assessment. Comparisons involving age and gender across all measures were not significant.

Concept of death

Achievement levels for the concept of death assessment are outlined in TABLE I. Nine (22%) participants had a full concept of death, 26 (63%) a partially developed concept and 6 (15%) had no concept of death. Participants performed least well on non-functionality with only 14 (34%) of participants describing bodily functions as ceasing after death. Of those participants with an incomplete understanding, 10 (24%) reported that grandfather could

<table>
<thead>
<tr>
<th>Concepts of Death</th>
<th>Complete Concept</th>
<th>Incomplete Concept</th>
<th>No Understanding</th>
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</thead>
<tbody>
<tr>
<td>Irreversibility¹</td>
<td>21 (51%)</td>
<td>8 (20%)</td>
<td>12 (29%)</td>
</tr>
<tr>
<td>Non-functionality²</td>
<td>14 (34%)</td>
<td>18 (44%)</td>
<td>9 (22%)</td>
</tr>
<tr>
<td>Universality³</td>
<td>18 (44%)</td>
<td>14 (34%)</td>
<td>9 (22%)</td>
</tr>
<tr>
<td>Causes of Death</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness/Disease</td>
<td>46%</td>
<td></td>
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<tr>
<td>Natural Causes</td>
<td>32%</td>
<td></td>
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</tr>
<tr>
<td>Accidents</td>
<td>9%</td>
<td></td>
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</tr>
<tr>
<td>Other</td>
<td>13%</td>
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</tr>
</tbody>
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¹ ‘the physical body cannot be made alive again’
² ‘all life-defining functions cease after death’
³ ‘all living things die’
breathe, fifteen (36%) that he could hear and seventeen (41%) that he could still see after his death. Fourteen (34%) participants had an incomplete understanding that animate objects (e.g. mother, dog) die and inanimate objects (e.g. ball, table) do not die.

Causes of death

TABLE I also shows the possible causes of death suggested by participants. Nine participants mentioned heart attack and eight cancer as the most common causes of death from illness and disease. Other causes of death (13%) included suggestions such as “… to make room for more babies”, “… because he had worked too hard”, “… he had been taking drugs” and “… he had something wrong with his brain”. Of the 11 (27%) unable to make a suggestion as to possible cause of death all except one had concept of death scores below 5.

What happens after death?

When asked, “What happens after death?” 20 (48%) people gave funeral associated responses and 12 (30%) replied “… they go to heaven”. Of those participants making funeral related responses, fourteen mentioned ‘burial’, four ‘a funeral’ and two participants mentioned cremation. Thirty-four (83%) participants recognised the funeral scene in the picture, however, only one person described funeral onlookers as being sad. The seven participants (17%) who failed to recognise the funeral scene had a total concept of death score of 0.

Recognition of emotion following bereavement

When discussing the funeral following the death of the grandfather, participants were asked “How might James feel?” and why might he feel that way?” Thirty-one (76%) described appropriate emotional responses. Of these, 16 (52%) had passed and 15 (48%) had failed the Reed and Clement (1989) assessment. Though only one participant passing the Reed and Clement (1989) assessment failed to assign an appropriate emotional response to the bereavement scene, twenty-two (54%) participants, who had a partially developed concept of death, were able to do so. Typical responses included “… bound to feel terrible”, “… he will be tearful”, “… he will cry”.

Emotional Awareness and the Concept of Death

With concept of death scores as the dependent variable and BPVS, and the Reed and Clements assessment scores as the independent variables, regression analysis was found to be significant with $F = 25.7$, $p < 0.001$. Both receptive language ability and emotional understanding were found to be important predictors of understanding the concept of death with $\beta = 0.43$, $t = 3.5$, $p < 0.001$, for the BPVS and $\beta = 0.43$, $t = 3.4$, $p < 0.001$ for the Reed and Clement test. The regression model suggests that receptive language ability combined with an understanding of emotional states accounted for 55% of the variance.
Discussion

In the present study adults with a learning disability were able to respond to questions concerning aspects of death and bereavement, were able to understand the finality of death and were able to link loss and sadness to a bereavement situation. These results extend the findings of McEvoy (1989) and Harper and Wadsworth (1993).

Overall, these findings are similar to McEvoy (1989), though the percentage of those failing to understand non-functionality is higher in the present sample demonstrating that the components of the concept of death will be understood at different levels before full understanding is achieved (Kane, 1979).

A significant positive correlation was found between receptive language ability, emotional awareness and total scores for an understanding of the concept of death. Adults with a learning disability assessed as achieving higher language comprehension (BPVS scores) had a more complete understanding of each of the components of the concept of death and were more likely to ‘pass’ the Reed and Clements (1989) test of emotional awareness. Only one participant scoring below the BPVS median (14) achieved a full concept of death score. In addition, regression analysis indicated that language ability and emotional understanding were both significant predictors of understanding of death thus providing further evidence of the relationship between cognitive and emotional awareness skills. However, in the context of understanding the concept of death, this relationship should be interpreted with caution.

First, although this study suggests that linguistic performance may constrain performance in understanding the concept of death, it can be argued that there is some degree of circularity in the observed relationships between receptive language, understanding of emotion and concept of death as verbal explanations and responses were involved in the methodology.

Second, one cannot simply equate an inability to verbalise with a lack of knowledge about death (Spinetta, 1974). Results from the present study suggest that although people with a learning disability may possess an incomplete concept of death they can attribute appropriate emotions to the context of bereavement. For example, nearly three-quarters of participants not achieving a full death concept were able to assign an appropriate emotional response to the post bereavement scene.

Half of the present sample had a reasonably clear idea of events (e.g. burial, etc.) after death. However, their understanding was at times incomplete with some individuals aware of the rituals and the emotions associated with bereavement but failing to report that bodily functions cease for all living things. Such confusion and factually incorrect thoughts may be a potential source of post – bereavement distress. It would be helpful to determine whether such cognitive distortions are the result of ‘magical’ thinking (Koocher, 1973) or result from a lack of mental reciprocity skills and cognitive delay or stem from a lack of insufficient information and experience of death.

There are a number of methodological weaknesses in the present study. Understanding of the concept of death was investigated using a simple story with pictures. The use of pictures may not necessarily have aided responsiveness (Cardone, 1999). Also, one must be cautious in extrapolating from a hypothetical story to ‘real life’. The story has only face validity and there is the danger of misin-
interpretation by participants. The same format for the presentation of assessment measures and questions was used throughout, therefore order or task effects can not be discounted.

The measurement of emotional understanding in people with a learning disability may require a more complex approach than that adopted here. And while the majority of participants were able to describe an appropriate emotional response in the context of a bereavement of these half had failed the Reed and Clement’s test. Use of a simple measure of ability to recognise emotions in the context of grief work may be inadequate or misleading, nor do such measures provide any indication of the ability to monitor or label internal states.

Helping people with a learning disability to recognise and link emotions to beliefs about death is important in supporting them through the grieving process. Findings from the present study suggest that although understanding of the death concept and emotional awareness are cognitively linked, individualised qualitative assessment of emotional recognition from a variety of perspectives is advisable. Moreover, support involving the direct teaching of the components of death and ‘facts’ around death should be accompanied by the labelling and contextual exploration of emotions.

**Summary**

The relationship between receptive language ability, understanding of emotions and the concept of death is explored. Forty-one people with learning disabilities were assessed using a variety of measures, including a picture story describing death and bereavement. Less than a quarter of participants had a fully developed concept of death, two thirds had a partially developed concept of death. While language ability, understanding of emotion and concept of death were positively correlated, the relationship is complicated. For example, nearly three-quarters of participants not achieving a full concept of death score and fifty percent of those failing an assessment of emotion recognition task were able to assign an appropriate emotional response to a bereavement scene. It is suggested that therapeutic interventions and assistance with bereavement issues should incorporate individual assessment, particularly of emotional understanding, and include the teaching of emotional labels in conjunction with the basic components of the death concept. In the light of these results how conceptual ability relates to grieving and emotions might be better pursued via a qualitative research framework.

**References**


