

## INVESTIGATING THE CONCEPT OF DEATH IN ADULTS WHO ARE MENTALLY HANDICAPPED

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### INTRODUCTION

The concept of death has rarely been studied beyond the childhood years, perhaps due to the assumption that such concepts become fixed by the time of early adolescence and remain stable throughout life (Kastenbaum and Costa, 1977). As a result, little is known about the concepts of death which adults may hold. Even less is known however, about the understanding of death and bereavement in adults with a mental handicap. What do people with a mental handicap know about death? Do they possess such a concept?

Recent research has indicated that adults with a mental handicap dream about deceased relatives and that often these dreams are much more rich and diverse, than was previously thought to be the case (Turner and Graffam, 1987). Research also indicates a further difficulty, in that many people with a mental handicap are reluctant to talk about the death of a relative, apparently believing that discussion on the topic may disturb the dead and cause them to return and haunt them. Such studies are very much in a minority and a review of the literature reveals very little in the way of useful information on the concept of death in adults with a mental handicap.

A possible reason for the dearth of interest in such a topic, may be the fact that, both death and mental handicap are often conceived of as taboo subjects (Hollins, 1987). A further obstacle, inherent in investigating the concept of death in adults with a mental handicap, is the possible existence of pre-conceived ideas or judgements about how people with a mental handicap view death and bereavement. Therefore, the gathering of information on adults' attitudes to death, their understanding of the possible causes and their anticipations of what happens to people following death, can only further our understanding of the adult mentally handicapped population.

### PROCEDURE

The present study was designed to actively seek out the views of persons with a mental handicap. One method of achieving this, is through interviews involving specific problems or topics (Lovett and Harris, 1987). Indeed, the view that people with a mental handicap be allowed to speak for themselves on issues, rather than relying only on information gathered from other sources has been strongly advocated (Edgerton and Bercovici, 1976). Despite the difficulties

inherent in interviewing persons with a mental handicap (Flynn, 1986; Lovett and Harris, 1987), such an approach may yield valuable information about their perceptions and attitudes to death.

The study adopted a cognitive-developmental approach, similar to that undertaken in studies of the concept of death in childhood populations (Kane, 1979). Evidence on the understanding of the concept of death, in a group of adults with mental handicap, was obtained by focusing on the most widely accepted components of a 'mature' concept of death discussed in the developmental literature (Speece and Brent, 1984). Three elements were identified; 1) irreversibility, which refers to the understanding that once a living thing dies, its physical body cannot be made alive again; 2) nonfunctionality, which refers to the understanding that all life-defining functions cease after death and 3) universality, which refers to the understanding that all living things die (Kane, 1979). The study was designed to determine whether adults could respond to questions dealing with these elements. Further, the quality of adult responses may give some indication of their understanding of death and dying.

### The Adults

The 38 adults (68% male) who participated in the study attended day services on the South-side of Dublin city. All the adults interviewed were selected because of their ability to answer questions verbally. In addition, they were socially approachable and had very few behaviour problems. Ages ranged from 20 to 50 years, with 68% of interviewees below the age of 25 years (see Table I). 66% lived at home with their family, 32% with either their father, mother, or a sibling, 2% lived in a training hostel. Other characteristics of the group, gathered from the results of assessments using the Index of social competence (McConkey and Walsh, 1981), are illustrated in Table II.

**TABLE I**  
**Age Ranges (N = 38)**

Age	%
< 20 years	2.6
20-25 yrs.	65.8
26-30 yrs.	10.5
31-40 yrs.	13.2
41-50 yrs.	7.9

**TABLE II**  
**Index of Social Competence (N = 38; CA 20 - 50 ys)**

	Low ability	High ability
Communication	29%	71%
Self-Care	16%	84%
Community Skills	55%	45%

In summary, 34% were in the high ability groupings for communications, self-care and community skills.

## The Interviews

Adults were interviewed individually and presented with a short series of nine open-ended questions concerning death and dying. A structured interview technique was employed. The interview began with a short introduction and questions dealing with basic demographic information aimed at establishing rapport between the interviewer and respondent. There then followed that section of the interview, which concentrated on respondents' views on various aspects of death. Adults were interviewed in private and the questions repeated a number of times along with probes, so as to elicit satisfactory and consistent responses. These responses were later classified and rated according to the following criteria. 1 = good level of understanding; 2 = some understanding; 3 = little or no understanding. Since no suitable interview format or assessment measures are available for use with the adult mentally handicapped population, a series of questions, focussing on the following five areas of interest were investigated.

- a) Possible causes of death
- b) Irreversibility; which implies that once a living thing dies, its physical body cannot be made alive again.
- c) Nonfunctionality; which implies that all life-defining functions cease after death.
- d) Universality; which implies that all living things die.
- e) Experience; Adults were also questioned as to whether they had known or had experience of anybody who had died.

The rating scores, awarded to adults for the quality of their answer to the various component questions, contributed to the calculation of a total concept score. Total concept scores were calculated for each individual.

## Adult's Perceptions

- a) Causes: Statements, such as "They get terrible old", "They might die from smoking, drinking, heart attacks", "Cause God wanted them", were typical of adults' responses, when asked about possible causes of death. Responses were categorised and Table III illustrates the distribution of causes chosen by the adults.

**Table III**  
**Possible Causes of Death**

Category	First suggestion	Second suggestion
Illness/Disease	55%	32%
Natural Causes	24%	8%
Accident	3%	5%
Don't Know	18%	(No response 53%)

Illness or disease was the most popular choice among the adults as a possible cause of death (55%) followed by death from natural causes (24%). Also, younger adults were more likely to suggest illness or disease as a possible cause of death than their older peers ( $\chi^2 = 6.8, df2, p > 0.05$ ).

- b) Irreversibility: When asked "Can you come back to life" 58% of adults answered "no"; 26% answered "yes" and 11% of adults said they were unsure. These results are outlined more fully in Table IV.

**TABLE IV**  
**Responses to Interview Questions**

Concept	Yes	No	Unsure	*Inc/Irel
<b>Irreversibility</b>				
Can you make dead people come back to life?	26%	58%	11%	5%
<b>Universality</b>				
Do things die?	50%	16%	11%	23%
Does everybody die?	71%	11%	18%	—
Do you think you will die?	42%	55%	3%	—
<b>Non-functionality</b>				
When someone dies can they still breathe, hear, see?	26%	61%	8%	5%
<b>What happens after;</b>				
	<b>People die?</b>		<b>You died</b>	
Go to Heaven	34%		26%	
Funeral Associated	29%		11%	
Reincarnation	5%		5%	
Emotional Associated	8%		—	
Just Die	8%		—	
Asleep	—		5%	
Don't Know	16%		53%	
* Answer Incorrect or Irrelevant				

c) **Universality:** Only 16% agreed that things (inanimate objects) do not die. However, 71% believed that everybody will die and 42% said that they themselves would die.

d) **Non-functionality:** 26% of the adults interviewed believed that it was possible to still see, hear and breathe after death; 8% were unsure. As can be seen from Table IV the most frequently cited happening after death was that 'people went to heaven' (34%), followed by funeral associated events, typified by statements such as "They get buried in a graveyard", "Stay in the coffin wearing a cloak" (29%).

e) **Experience:** 79% of the adults claimed to have known somebody who had died and gave a specific example, although this experience did not seem to influence their overall understanding of death (Chi-square tests).

A total score for each of the three components contributing to a 'mature' concept of death was calculated. No significant differences for age, sex or reported experience with death emerged for these components (Chi-square tests). However, those adults who were found to be in the high ability groupings for *communication, self-care and community skills*, as assessed by the *Index of social competence*, were more likely to achieve higher scores on the *Irreversibility* ( $x^2 = 5.4$ ,  $df,1$ ,  $p>0.05$ ) and *Non-functionality* components ( $x^2 = 4.2$ ,  $df,1$ ,  $p>0.05$ ). Also, those adults who were more aware that they themselves would die, tended to achieve higher overall concept scores. ( $x^2 = 11.5$ ,  $df,2$ ,  $p>0.005$ ).

## DISCUSSION

Training and education in death and bereavement for staff and for people with a mental handicap remains largely uncharted territory. Therefore, any information that can be gathered concerning the concept of death in adults with a mental handicap, may be useful in a staff training or counselling context. The results from the present study are encouraging in that they demonstrate the possibility of using a structured interview technique, based on elements of a mature death concept, to elicit views on death from members of the adult mentally handicapped population.

The results from the present study failed to indicate any relationship between sex, or reported experience of death and adults' understanding of the concept of death. However, those adults who were rated as having higher abilities in communication, self-care and community skills, held better developed notions of irreversibility and non-functionality. In addition, adults who accepted that they themselves would someday die, tended to have a more mature concept of death. This would seem to suggest that, for the adults, in this sample at least, a greater awareness of one's own mortality contributes to a more mature understanding of what is involved in death and dying.

Although the adults who were interviewed, seemed to have a fair understanding of the concepts of irreversibility and non-functionality, their understanding of universality — that all living things die — was not well developed. This is contrary to the research findings for older children. For example, Childers and Wimmer (1971) and White et al (1978) found that the majority of 9 and 10 year olds accepted the universality of death. However, one half of the children failed to acknowledge that death is final and absolute.

Many of the adults in the present study, particularly the younger group, did not see death as an internal biological process that operates according to natural laws. This is suggested by the finding that illness and disease were frequently given as reasons for or causes of death. Comparisons can be drawn between these findings and reports in the literature on the development of illness in young children. Between the ages of 7-11, children move from believing that illness is externally caused to believing that illness is the result of internal physiological dysfunction. Also, older children, although they may cite external causes for death and illness, realize that the resultant effects are due to internal malfunctioning (Bibace and Walsh, 1980). The frequent citing of illness as a cause of death suggests that spontaneous appreciation of the biological inevitability of death by the adults in the present study must be questioned. Indeed, future research might address the relationship between Mental Age of persons with a mental handicap and their understanding of the causes of death.

The finding that over half of the adults did not know whether they would die and had no idea what would happen to them following death, should be noted. An obvious explanation is that adults were simply reflecting the commonly held belief that "it may happen to others but it won't happen to me". However, given the finding that those who understood they were to die, achieved significantly higher concept scores, a more cognitive based explanation may be more relevant. Possible confusion over whether they themselves would die, must in some way reflect adults' poor understanding of the ageing process and the normal life cycle. On the other hand, it may be, that questions regarding time or future events may create difficulties for adults who are mentally handicapped.

Considerable caution is urged in interpreting the results of the present investigation. First, there is the uneven spread of questions between the component conceptual elements. This may have resulted in an inadequate reflection of adults' perceptions. Furthermore, calculation of the overall concept score is biased towards questions dealing with universality and non-functionality.

Second, some of the questions elicited totally incorrect or irrelevant answers, thus highlighting the methodological difficulties inherent in this type of research. The major methodological difficulty relates to the language and comprehension ability of persons with a mental handicap. Although the present study has demonstrated the efficacy of open-ended questions when interviewing adults with a mental handicap, the danger of inadequate and irrelevant responses remains. The development and introduction of additional data gathering procedures, such as the use of pictures and multiple choice questions, should be considered in future research studies. Thus, data from a number of sources can be used to build up a picture of adults' perceptions (Flynn, 1986). Moreover, comparison with other adults' groups of similar age would be advisable before making firm conclusions on the basis of such studies as the present one.

Finally, findings from the study must be interpreted in light of the limited sample size and the fact that the subjects were all from the same geographical area. Nevertheless, the adoption of an interview format, such as that employed in the present study, offers considerable scope for future work in both applied and research settings. In addition, a number of interesting discussion points have emerged from this study. Not least the demonstration that many adults with a mental handicap are capable of expressing their opinions on this sensitive, important, though much neglected topic.

## SUMMARY

This paper describes a pilot project, designed to elucidate the perceptions and opinions about death and dying among a group of adults with a mental handicap. A structured interview format, based on three components, accepted as contributing to a mature concept of death was used. The study found that although adults possessed a fair appreciation of the implications of death, many had a poor understanding of the ageing process and the normal life-cycle, particularly as it related to themselves.

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