Concept Of Death In Adults With Learning Disabilities

Emma Foster

Submitted in partial fulfilment of the
Doctorate in Clinical Psychology,
University College London,
May, 1998.

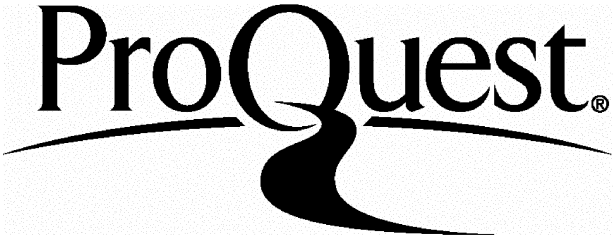


TABLE OF CONTENTS

TABLE OF TABLES

TABLE OF FIGURES

ABSTRACT

Seventy four adults with learning disabilities were interviewed using Piagetian tasks, the British Picture Vocabulary Scale (BPVS) and an adapted version of Smilansky's (1987) concept of death questionnaire. Demographic information and details of any death-related experience were gained from carers or relatives.

Analyses indicated that cognitive ability (as measured by the BPVS), awareness of personal mortality and certain death-related experiences (i.e. seeing a dead animal and having attended a funeral) all influenced participants' understanding of the concept of death. There was no evidence of a significant link between age, sex, Piagetian level or other death-related experiences and comprehension of death.

The sequence of acquisition of the sub-components of the death concept was investigated. Variation was found according to object of reference (human or animal). However in both human and animal death, the sub-components of causality and finality were significantly more difficult to understand than irreversibility, old age and inevitability. This finding supports the observational-hypothetical principle suggested in the child literature (i.e. mastery of death's sub-components form a continuum with those which are observable being more readily understood than those which are more abstract or hypothetical). This principle was also present within the sub-component of finality. Comparison with developmental sequences previously reported in the child literature indicates that adults with learning disabilities develop an understanding of the concept of death in a similar manner to children without learning disabilities. The clinical and research implications of these findings are discussed.

ACKNOWLEDGEMENTS

My sincere thanks go to all the individuals and organisations who gave me their valuable time to discuss this study and especially the participants and staff members who participated. Their enthusiasm, co-operation and genuine interest made this study possible and the participants' openness and willingness to discuss personal experiences during our interviews made the whole experience very memorable and often moving.

I would like to thank Nancy Pistrang, my research supervisor, for agreeing to supervise this study despite her limited experience with adults with learning disabilities. Her enthusiasm, constructive criticism and statistical advice have been invaluable. I also wish to acknowledge the contribution of Roman Rackza, my clinical supervisor, in helping me to explore the practical implications of implementing this study and in being an excellent source of contacts, support and encouragement. In addition I would like to acknowledge the contributions of several local psychologists, including Sandra Baum, Asha Desai, Sarah Stern and John Newland, who helped me to formulate my initial ideas into a coherent structure and also facilitated access to potential participants. Finally I want to thank Paul Osler for his continual support and patience.

CHAPTER ONE: INTRODUCTION

This study aims to investigate how adults with learning disabilities understand the concept of death. The area of death and bereavement within the field of learning disabilities is a much neglected one. As McEvoy (1989, p115) states:

> *" a possible reason for the dearth of interest in such a topic, may be the fact that, both death and mental handicap are conceived of as taboo subjects".*

In recent years there has been increasing interest in the area of bereavement, indicating that people with learning disabilities experience grief and loss in a similar way to non-learning disabled adults. Research into the concept of death within this population however has been scarce.

In order to understand how the concept of death may develop in adults with learning disabilities, it is important to think about how this concept may develop normally in non-learning disabled children. This study makes no assumptions that adults with learning disabilities are a homogenous group or are identical to children: after all how could the experiences and perceptions of middle aged adults be identical to those of young children. However, the Mental Health Act (HMSO, 1983) defines learning disability (termed "mental impairment") as

> *"a state of arrested or incomplete development of mind which includes significant impairment of intelligence and social functioning"* (p2).

Therefore, the possibility that any findings from the child literature might enhance our understanding of how adults with learning disabilities understand the concept of death is worthy of investigation.

This chapter is therefore divided into five main sections. Firstly, the main findings from the child literature will be summarised in Section 1.1. Research into how the adult and learning disabled populations understand the concept of death will then be presented in Sections 1.2 and 1.3. Finally the rationale for the present study and the research questions will be described in Sections 1.4 and 1.5.

1.1 CONCEPT OF DEATH IN CHILDHOOD

1.1.1 Early Research

Despite the fact that early research in this area was fraught with methodological problems which greatly limited its generalisability, it has provided the foundation of more recent, and arguably more useful, research into the understanding of the concept of death in children. The first research in this field consisted of qualitative studies of children's responses to general questions about death and dying, such as asking children to report everything they knew about death.

Nagy (1948), probably the most widely cited researcher in this area, interviewed 378 children (three - ten years old) in Budapest at the end of World War 2. Their understanding of death was assessed by means of drawing, essay writing and discussion. Nagy subsequently described three stages in children's learning about death. Firstly, children between three and five years attributed life and consciousness

to the dead; tending to view death as meaning the same as living on under changed circumstances. Death was seen as a departure or like being asleep and is also believed to be temporary or gradual (i.e. life and death can be simultaneous and are interchangeable). This stage therefore is marked by the child's inability to accept death as a regular and final process. Nagy described how in early infancy (under five), a child's desires guide it even at the price of modifying reality:

> *"Opposition to death is so strong that the child denies death, as emotionally it cannot accept it"* (p13).

The second stage (between five and nine years) involves the child personifying death. Either death is imagined as a separate person, such as a death-man or skeleton, or death is identified with the dead. Therefore, death is perceived as being outside the child and is not universal. Nagy reported how these children believed that they could outrun or outsmart death and therefore be exempt. She reported a strong desire to keep death at a distance during this second stage. More recent research has failed to replicate Nagy's finding that children of this age personify death. This discrepancy may be explained by either the widespread use of folklore in Hungarian culture during the 1940s or the reality of 'death-men' who were responsible for the death of many during the second world war.

The final stage (from age nine onwards) involves the realisation that death is the cessation of corporal life. According to Nagy, these children were also able to

recognise that death is a process operating within us and therefore recognise that it is universal and final.

Another key researcher, Anthony (1940) assessed children in England in the late 1930s. She found that at age three children are ignorant of the word 'dead' but the child is aware of the word 'death' and knows its meaning by the age of five or six. Like Nagy, she found that prior to the age of five, death as a process is egocentrically denied as being a different kind of life and only temporary. Life is equated with death. By five, death is distanced and not deemed universal but is perceived to exist in a personal, artificial form. By approximately seven, children understand death by focusing on associated phenomena (e.g. the ability to move). By nine or ten, a biological and logical explanation can be provided for the word 'dead'.

While these early studies provide a useful framework for viewing children's developing conception of death, they do not elucidate the mediating variables in concept acquisition. One apparent factor affecting the development of a conception of death is the child's level of cognitive ability and several researchers have attempted to explain death concept development in terms of Piaget's theory of cognitive development (Kane, 1979; Koocher, 1973).

1.1.2 Piagetian theory and concept of death

Koocher (1973) applied Piaget's theoretical framework for conceptualising cognitive development in analysing attitudes to death. He believed that Piaget's (1960) three levels of cognitive functioning (pre-operational, concrete-operational and formal-operational) provided a good basis for supporting Nagy's three identified stages in

the understanding of death. He divided 75 children (aged six - fifteen) into their Piagetian level of development according to their ability on three tests of conservation and a hypothesis testing task. Each child was asked four questions about death and their responses were rated as either egocentric, concrete or abstract by a pair of raters. His results showed that only pre-operational children believed that dead things can be brought back to life and also gave significantly less abstract responses than those functioning at a concrete- or formal-operational level. He concluded that children's understanding of the causes of death are clearly related to their level of cognitive development. Whilst children at the higher levels of cognitive functioning produced higher order answers, pre-operational subjects tended to give more concrete or egocentric responses to the questions. Koocher believed these responses highlighted the importance of the reciprocity skills that come with the onset of concrete-operations. Until reciprocity is learned, the child cannot use the observed experiences of others in thinking about death. Therefore he argued that at the pre-operational stage, the child is unable to share the experiences of others to a significant degree and is not fully able to distinguish between animate and inanimate objects. Since he has had no personal experience of death (i.e. he himself has never died), the child at this level might not be expected to regard death as permanent.

Tallmer, Formanek and Tallmer (1974) supported Koocher's findings about the applicability of Piagetian theory and the development of the concept of death. They also found no relationship between the child's understanding and their experiences with death but did report that lower class children were significantly more aware of the concept of death than middle class children. This finding has not been replicated in other studies.

More evidence for Piagetian stages in development of death concept was provided by White, Elsom and Prawat (1978) who divided children into conservers and non-conservers depending upon their ability to pass two out of three Piagetian conservation tasks. They found that universality (i.e. all living things die) was understood significantly more by conservers than non-conservers, whilst irreversibility (i.e. death is not reversible) and cessation (i.e. all bodily functions stop at death) were equally understood by the two groups. These results were interpreted in the light of Vygotsky's (1962) distinction between "spontaneous " and "scientific" concepts: the former are based on everyday experience while the latter are acquired through tuition. Their contention that universality is a spontaneous concept is supported by Piaget's research into moral judgement (1948). Piaget found a relationship between concrete-operational thinking in children and the belief that rules are absolute and universal, a belief that resembles the concept of universality in death. White et al suggest that as the belief about the universal nature of rules appears to develop naturally so might the belief in the universality of death.

Much research has studied the relationship between Piaget's stages of cognitive development and the comprehension of death (summarised in Ginsburg & Opper, 1988) and there has been some support for the hypothesis that a level of concrete operational functioning is a necessary condition for a mature understanding of death. Pre-operational thinking has been related to the view that death is reversible by various means (e.g. magic or intervention of others). During the concrete operational stage, death is understood as being irreversible, due to the cessation of bodily functions and universal. Formal operational thinking has been related to the

development of religious and philosophical thought concerning the nature of death and life after death.

Certain cognitive abilities have been suggested which may facilitate the acquisition of a concept of death. Koocher (1973) maintained that reciprocity skills (i.e. recognition of correspondence between individual and other's perceptions of the same event) allow the child to draw on the experience of others in developing a conception of death. White et al. (1978) conclude that children who use concrete modes of thought have a higher frequency of believing in personal mortality than pre-operational children. Based upon these findings it would appear that there is a relationship between concrete-operational thought and awareness of personal mortality.

Kastenbaum and Aisenberg (1972) provide the rationale for the relationship between the death concept and maturation of cognition. Understanding the highly abstract and complex concept of death requires an ability to distinguish between animate and inanimate, to grasp the meaning of object constancy, to differentiate self from non-self objects and to understand the concept of time and its one way flow from past to present to future. Thus theoretically it is reasonable to assume that a child's ability to understand death will be related to their ability for abstract thought.

1.1.3 Sub-components of concept of death

The idea that the death concept can be more or less complete, i.e. that it has several components has been discussed by many researchers. Most of the research to date has sought to delineate both the ages and stages at which children acquire key

components. The conceptual underpinning has most frequently been Piagetian. The underlying assumption is that a complete or mature concept of death consists of understanding fully each of the sub-components of the concept of death.

Barbara Kane's very influential paper (1979) was the first attempt to refine the criteria for a mature concept of death by identifying its sub-components. During interviews with 122 children (aged between three and twelve) she identified these ten sub-components of the concept of death: realisation (awareness that death can happen to someone and can make the living die); separation (location of the dead); immobility (dead are inactive); irrevocability (death is permanent and irreversible); causality (what brought about the state of death); dysfunctionality (death stops bodily functions); universality (everybody dies); insensitivity (cessation of mental and sensory functions); appearance (whether dead person appears physically the same as when alive); and personification (death as concrete person or thing).

She found that the development of a full understanding of these sub-components varied as a function of age maturity. According to Kane, children acquired realisation by age three; they understood separation and immobility by age five; irrevocability, causality, dysfunctionality and universality were acquired by age six; insensitivity by age eight; and appearance by age twelve. Other interesting findings were that a) experiences with death accelerated death concept development in six year olds and below and b) children realise that external, non-cognitive aspects of functioning (such as moving and talking) cease at death before they understand that other cognitive aspects of functioning (such as thinking and feeling) also cease at death.

She concludes that children's concepts of death developed in three stages clearly related to the pre-operational, concrete-operations and formal-operations stages suggested by Piaget. In stage one, children showed pre-operational thought; their thinking was egocentric and magical and death was viewed in terms of structure and the here and now. By stage two, (concrete operational stage) children were able to view death as specific and concrete but were unable to interrelate the different sub-components they had acquired. Stage three children were able to think about death in the abstract and understood that death was a state of internally caused dysfunction. This showed evidence of formal operational thinking according to Kane. This three stage model also provided some support for Nagy's assertions. Differences between the two theories include the fact that Kane found no evidence of personification of death within her sample and she reported a younger age of understanding inevitability (age six) than Nagy (age nine).

More recent research has tended to focus on a sub-group of these ten sub-components. In 1984, Speece and Brent reviewed all past research (35 studies) on the three most widely investigated sub-components of the death concept: irreversibility, non-functionality and universality. Participants were primarily white, urban, middle class children of average or above average intelligence. Despite several methodological difficulties in comparing the data from differing studies, they conclude that all three components have a mean and modal age of acquisition of seven years, considerably earlier than previous research suggests. Their findings suggest that all three components are acquired simultaneously and at around the expected time of transition from pre-operational to concrete-operational thought (Piaget, 1976).

Twelve (of the total 35) studies examined suggested a relationship between cognitive development and the understanding of death. All used a Piagetian framework. Results were very varied with some studies indicating that pre-operational thought alone may be sufficient for understanding irreversibility, non-functionality and universality, while others suggest that concrete-operational thought by itself is not sufficient for understanding these three components. These studies provided vastly contradictory data and used very different methodologies making between-study comparison particularly difficult. Unfortunately this means that no firm conclusions can be drawn from these findings. Inconsistencies in the literature may be due to using measurement instruments which vary greatly in validity and reliability. Alternatively, they may reflect the influence of important social and cultural experiences that differentially affect the children sampled to produce between-sample differences in the concept of death. At present this remains unclear.

There is much disagreement between researchers about the exact ages of acquisition of the different sub-components, with more recent research indicating earlier ages of acquisition. For example, in Lansdown and Benjamin's (1985) study, most three year olds were able to use the word dead and apply it correctly (e.g. by distinguishing between pictures of a dead and a live rabbit), approximately 60% of five year olds had a complete or almost complete concept of death, whilst almost all eight or nine year olds had fully developed notions (as defined by Kane, 1979). This suggests that verbally competent four or five year olds may be able to discuss death and have a good grasp of the meaning of the word death. However, it could be argued that the

trend towards understanding at an earlier age is more a reflection of increased sophistication in techniques of enquiry than of valid cognitive change.

Stambrook and Parker (1987) point out that there is considerable dispute about the age of acquisition of the sub-component of irreversibility. Many researchers (Kane, 1979; Koocher, 1973) indicate that children of nine or older perceive death to be final and irreversible, whilst certain others have found absence of this sub-component in large proportions of their nine and ten year old subjects (for example, White et al. [1978], found that one half of their sample failed to acknowledge that death is final and absolute). Differences in research design, measurement tools and between-subject differences might help to explain these discrepancies. Unfortunately these contradictory findings limit the generalisability of these age-related findings.

1.1.4 Implications of an incomplete or immature concept of death

By defining a complete or mature concept of death, the literature indicates that achieving this level of understanding of death is important and potentially useful for individuals. This in turn suggests that absence of a full understanding of the sub-components is potentially detrimental to a child's ability to assimilate and accommodate a personal bereavement. Research into children's reactions and adaptations to loss supports this. Table 1 gives details of the most commonly accepted sub-components of the concept of death, their definition, how an incomplete understanding might be manifested and what implications this might have for a bereaved child. (Adapted from Schonfeld & Kappelman, 1990).

Table 1: Commonly accepted sub-components of the concept of death, their definition and examples and implications of their incomplete understanding.

Sub-component	Definition	Example of incomplete understanding	Implications of incomplete understanding
Irreversibility	Death is a permanent phenomenon from which there is no recovery or return	The child expects the deceased to return, as if from a trip	Failure to understand irreversibility prevents the child from detaching personal ties to the deceased, a necessary step in successful mourning
Finality (non-functionality)	Death is a state in which all life functions cease completely	The child worries about a buried relative being cold, hungry or in pain	May lead to preoccupation with the physical suffering of the deceased and impair readjustment
Inevitability (universality)	Death is a natural phenomenon that no living being can escape indefinitely	The child views significant individuals (i.e. self, parents) as immortal	If death is not deemed inevitable, child is more likely to view death as punishment (either for actions or thoughts of the deceased or child) leading to excessive guilt or shame
Causality	The child develops a realistic understanding of the causes of death	The child who relies on magical thinking may assume responsibility for the death of a loved one by assuming that bad thoughts or unrelated actions were causative	Tends to lead to excessive guilt that is difficult for the child to resolve

According to Worden (1991) there are four "tasks of mourning". In adulthood these are: to accept the reality of the loss; to experience the pain of grief; to adjust to an environment in which the deceased is missing; and to withdraw emotional energy and reinvest it in another relationship. In childhood these are identical apart from Task four which is to relocate the dead person within one's life and find ways to memorialise the person (Worden, 1996). Inability to work through these tasks can result in complicated grief (i.e. chronic, exaggerated, delayed or masked grief reactions).

As Table 1 illustrates, an incomplete understanding of any of the sub-components of the concept of death might result in difficulties completing these tasks of mourning. For example, if an individual does not understand that death is irreversible, it will be more difficult for them to accept the reality of their loss and they may expect the dead person to return and visit them. The use of magical thinking may lead to the individual believing that they caused the death and therefore result in unnecessary guilt. In addition, the less developed coping skills in younger children or people with learning disabilities may result in difficulties adjusting to an environment where the deceased is missing. Certain funeral rituals (e.g. cremation) could be very distressing for an individual who does not understand that bodily functions stop at death: they may be concerned and distressed about the welfare of their loved one after death, which could also impair the process of mourning.

Evidence for the influence of an incomplete understanding of death on the mourning process is provided by Worden's (1996) Child Bereavement study. He interviewed

125 children who had recently lost a parent and found that understanding of death is an important mediator that influences the course and outcome of adaptation to loss.

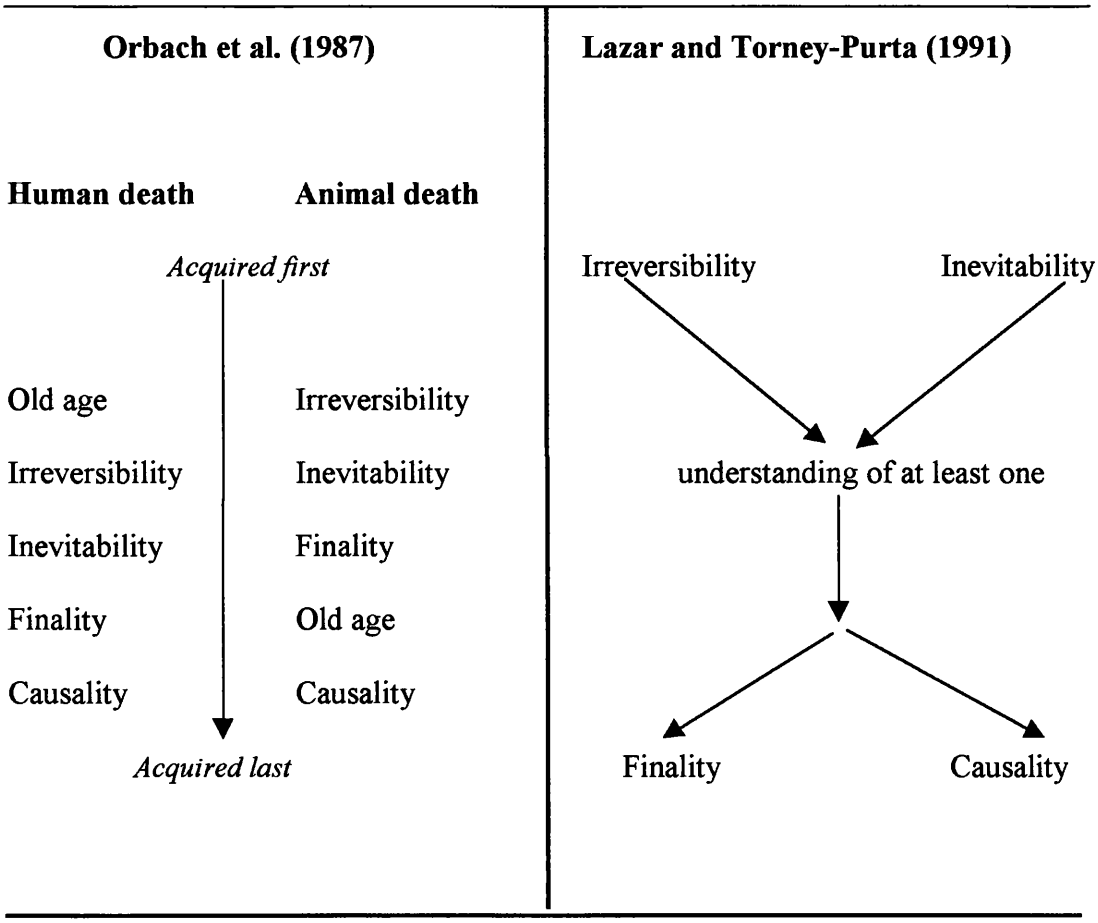
1.1.5 Acquisition of sub-components

More recent research has attempted to identify the order in which the sub-components of death are acquired. Evidence for sequential development of the sub-components is variable, depending upon the sub-components studied, their definition and the tool of measurement used in differing studies (Hoffman & Strauss, 1985; Speece & Brent, 1992). Two studies using Smilansky's Death Concept Questionnaire (1987), which is the measurement tool used in the present study, will be discussed in some detail. Figure 1 provides a summary of the acquisition patterns found in these two studies.

Orbach, Talmon, Kedem and Har-Even (1987) used Smilansky's questionnaire to investigate the sequential acquisition of five sub-components in human and animal death from two independent studies (197 children in total). They found that the order of acquisition of these sub-components seemed to form a continuum that starts with observable phenomena and ends with the more hypothetical phenomena. This continuum was present in both high and low cognitive ability groups.

In human death, Orbach et al.'s sequence of acquisition started with old age (the easiest sub-component to comprehend), followed by irreversibility, inevitability, finality and eventually causality (the most difficult sub-component). They explain this continuum in the following way. Old age in humans is observable and definable

Figure 1: Order of Acquisition of sub-components of concept of death as suggested by 2 different studies.



and children are likely to learn at an early age that old people are the ones who die. Old age (the easiest sub-component) is therefore readily related to death in children. Next children learn, mainly by experience, that death is irreversible (i.e. people or animals who die never come back). Then gradually children learn that death is inevitable and universal. This sub-component is more difficult to learn because it is not immediately experienced or visible. Its acquisition therefore is probably based on accumulated experiences and requires a good ability for inference.

Finality, the next acquired sub-component, is more difficult to understand. Understanding of finality requires the comprehension that all life activities cease at death. This idea in turn requires an understanding of the nature of death itself, i.e. the cessation of all life activities, both observable and non-observable. Certain aspects of finality (e.g. immobility) are observable and therefore are more easily grasped than other aspects of finality (e.g. lack of awareness or feeling) which were unobservable even when the human was alive. Orbach et al. argue that it is difficult to relate the absence or cessation of these higher functions in the dead. This point is well demonstrated by other researchers (such as Kane, 1979).

Causality of human death is the most difficult sub-component to comprehend because it requires both knowledge of biology and an ability for abstract thinking, which does not develop until later childhood or adolescence. Causality requires inference about internal bodily functions and life processes, even when the causes of death can be observed. White et al. (1978, referring to the work of Vygotsky [1962]) suggested that such components are more difficult to comprehend because they are

"scientific" concepts and are acquired through intuition rather than "spontaneous" concepts, which emerge through experience.

Animal death forms a similar continuum, with irreversibility being the most easily comprehended sub-component, followed by inevitability, finality, old age and causality in order of increasing difficulty. Old age is therefore considered to be more difficult to comprehend in animals than in humans. This finding is explained in terms of the observable-hypothetical principle. That is, old age in animals (unlike humans) is almost unobservable. There are few signs that distinguish old and young animals. Therefore distinguishing old animals demands an extensive body of knowledge and information not readily available or observable by direct experience; therefore this is a more difficult sub-component in animals than humans.

The fact that human and animal death concepts are organised differently, suggests that the general meaning of death is learned and applied to each form of life separately. Within each form of life, learning is gradual and accumulative.

Findings of other studies about understanding of human death are consistent with Orbach et al.'s findings. For example, finality was also found to be less easily comprehended than irreversibility and inevitability by Speece and Brent (1992). Hoffman and Strauss (1985) report that within the sub-component of finality the cessation of external bodily functions (such as moving, speaking and hearing) were more readily understood than the cessation of internal bodily functions (thinking and dreaming).

The importance of studying the sub-components of the death concept both separately and in relation to one another was emphasised by Lazar and Torney-Purta (1991). They examined the development of four of Smilansky's sub-components in an extremely rare longitudinal study of 99 six- and seven-year olds. Children were questioned at two time points (seven months apart) using Smilansky's death concept questionnaire. Most scores were found to have improved significantly between Time 1 and 2. A probabilistic model was used to identify a possible underlying structure to the development of the sub-components of death. They found that children first understand irreversibility and inevitability, and that their development does not seem to be conditional on one another. However at least one of these sub-components needs to be understood before the child understands the sub-components of finality and causality. This pattern of acquisition is identical to that reported by Orbach et al. (1987).

Despite slightly different findings, which may be due to variations in methodology, all these acquisition studies indicate differences in the complexity of the sub-components and emphasise the importance of examining sub-components separately and in relation to each other. A common finding in all of these studies is the fact that inevitability is amongst the first of the sub-components to be developed and finality is usually amongst the last.

1.1.6 Cultural and environmental factors

Research suggests that environmental and cultural factors may play a role in the understanding of the concept of death. For example, Candy-Gibbs, Sharp and Petrun (1985) looked at the effect of age and religious background on children's

conceptions of death. Age was found to be a contributing factor in relation to understanding of inevitability, universality and the belief that death could be a personal event; it was not found to be related to children's understanding of irreversibility. Irreversibility was related to religious background of the children participating (either Baptist or Unitarian).

This data is supported by a study of Muslim, Christian and Jewish children which found that different cultural (ethnic and religious) contexts foster different rates of death concept development as defined by western scientific death conception (Florian & Kravetz, 1985). This suggests that environmental factors also play an important role in the development of a mature death concept.

Additional evidence for the role of cultural and environmental factors in the development of the concept of death is provided by Schonfeld and Smilansky (1989) and Brent, Speece, Lin, Dong and Yang (1996). The first study compared death concept development in Israeli and American children, and found higher overall death concept scores across all ages (four - seven years) in their Israeli children. Brent et al.'s study compared US and Chinese children (aged three – seventeen years) and found a greater percentage of Chinese children gave the presumed adult response to questions about inevitability, irreversibility and finality than US children. This difference was interpreted as a reflection of their different educational systems.

The efficacy of school based education in increasing understanding of death in four to eight year old children has been demonstrated by Schonfeld and Kappelman (1990). Their randomised trial compared pre- and post-intervention scores on

Smilansky's questionnaire for a control and experimental group. Intervention consisted of six thirty-minute presentations (audio-visual and books) on death. Significant mean gains were noted for the experimental group as compared to controls in total death concept score, total score for human and animal death, as well as the sub-components of causality, inevitability and old age. The gain in total death concept score as a result of the three week intervention was equivalent to the amount of conceptual development that is seen in one year in the absence of intervention. This supports Speece and Brent's conclusion (1984) that experience and what children are told about death are crucial factors in the promotion of their understanding of death.

1.1.7 Death related experience

Evidence of the impact of death related experience on the child's developing concept of death is mixed. Several researchers (Derry,1979; Kane, 1979; Reilly, Hasazi & Bond, 1983) have found evidence of more advanced death concepts amongst younger children who have experienced a number of aspects of death (from discussing death in the classroom to death of a pet or family member) when compared to peers who have no death related experience. Some researchers have found less well developed concepts of death in those who have recently suffered a bereavement (Worden, 1996) or in those who have received euphemistic religious explanations of death (Randy-Cotton & Range, 1990). Other researchers (Jenkins & Cavanaugh, 1985; Mahon, 1993; Tallmer et al., 1974) have failed to find such a relationship. However, this may be attributable to their subject's lack of experience involving the death of a parent or sibling and rather global definitions of death

experience (e.g. "concrete death experience") making it difficult to evaluate the quality of experiences present in their samples.

In Reilly, Hasazi and Bond's (1983) study, the majority of six year olds possessed some understanding of personal mortality and all eight year olds expressed a belief in personal mortality (consistent with the research of Kane). Understanding of personal mortality was related to both level of cognitive development and to death related experience. This provided support for earlier research (e.g. White et al., 1978) that linked awareness of personal mortality to the ability to use concrete operational thinking whilst also suggesting those who have experienced the death of a significant other are more aware of their personal mortality than those who have not. This indicates that death experiences play a contributory (and catalytic) role in the child's developing knowledge of death especially for five and six year olds. The only exception to the catalytic role of death-related experience is the finding that children who have recently lost a parent have less developed concepts of death than those who have not had this experience (Worden, 1996). It could be argued that this apparent deficit in comprehension of death is related to the process of grieving and a reluctance to acknowledge the finality of death whilst struggling with the tasks of mourning (Worden, 1991).

1.1.8 Emotional factors

In contrast to the findings of the cognitive development studies, some researchers believe that anxiety is a key component in a child's understanding of death. Existential theorists and therapists (i.e. Rochlin, 1967; Yalom, 1980) argued that anxiety and fear can interfere with children's comprehension of death through

various defence mechanisms, such as denying the inevitability and irreversibility of death. Children deny their helpless feelings about death by altering inner reality; believing in personal invulnerability and omnipotence. Yalom also argues that feelings of hopelessness might be indicative of a failure to deny inner reality and therefore of accurate death concepts. Yalom (1980) concludes that children as young as four or five can comprehend the meaning of death and any misunderstandings demonstrated by under twelve's are due to their defensive manoeuvres against the anxiety aroused by this topic.

Orbach, Gross, Glaubman and Berman (1985) examined the relationship between anxiety and concept of death scores (as measured by Smilansky's questionnaire) in six - eleven year olds. As expected, they found that age and cognitive ability influence concept of death scores. More interestingly however, they divided children into high and low anxiety groups based on their performance on the General Anxiety Scale for Children (Sarason, Davidson, Waile & Ruebush, 1960) and found that children in the lower anxiety group achieved significantly higher scores than those in the high anxiety group. They also found that anxiety has a stronger impact on cognitively high subjects than on cognitively low subjects. Orbach et al. conclude that the acquisition of the meaning of death requires a certain cognitive maturation, but when this maturation is reached, comprehension of death can be interfered with by a high level of anxiety (i.e. meaning of death can be distorted if it is perceived to be anxiety-provoking). In the low cognitive levels, anxiety has almost no influence on concept of death scores. Possibly this is because lack of a full understanding of death means that it is less anxiety-provoking in an equally anxious but less cognitively developed child.

Further evidence for the influence of emotional factors in understanding of death is reported by Orbach, Weiner, Har-Even and Eshel (1994). Whilst hypothesising that understanding of death would vary as a function of interpersonal closeness to the dead person, they interviewed children (aged six - eleven), using Smilansky's questionnaire, about the hypothetical death of a stranger, a cousin and a brother. They found that children of all ages had less accurate understanding about the death of the brother, the most interpersonally close individual; whilst younger children had less accurate understanding about both a cousin and a brother. They suggested that the death of an emotionally close person is appraised as being more dangerous to the child than the death of a distant person and therefore evokes more anxiety. This anxiety interferes with the conceptualisation of death by prompting more defensive distortion.

Fear of death was also related to development of death concepts in Randy-Cotton & Range's (1990) study. However, there was no evidence of a link between hopelessness and concept of death scores in this study. This finding is consistent with the existential argument that fear can interfere with the child's development of an understanding of death. This theory has obvious implications for an individual's belief about their personal mortality (presumably a highly threatening possibility). Indeed Worden (1996) reports increased levels of anxiety in those children who demonstrated personal death awareness, in comparison to their peers who did not demonstrate this awareness.

1.1.9 Methodological issues

Measurement issues

A variety of methods have been utilised to measure children's concept of death. These are reviewed by Prichard and Epting (1992) and include structured interview formats (standardised and non-standardised), paper and pencil formats and qualitative methodology. However, the bulk of research has utilised the Development of Death Concept Questionnaire (Smilansky, 1987), a standardised questionnaire about death in humans and animals, which has been well tested for reliability and validity within this population. Several researchers have consistently found that cognitive ability and age affect performance on this measure (Schonfeld & Kappelman, 1990). Also there is a strong case for a better understanding of human than animal death in children of all ages, suggesting that the comprehension of animal death is acquired chronologically later than that of death in humans (Orbach et al., 1985; Orbach et al., 1987; Smilansky, 1981). The only slight exception to this finding was the fact that finality was better understood in animals than humans in Lazar & Torney-Purta's (1991) study. This is explained in terms of the fact that children probably have more actual visual experience of dead animals than dead humans and therefore are more easily able to learn that dead animals do not move.

Design Issues

Studies in this field have largely consisted of cross-sectional research in examining age differences in children's understanding of death. Obviously this is not entirely satisfactory as cross sectional data is confounded by the effects of experience unique to individuals born in a certain place at a certain time. For example, comparing a

seven year old from 1940s Hungary (Nagy, 1948) with a seven year old from 1980s New York poses a number of difficulties. Cohort and age effects therefore pose inherent difficulties in inferring longitudinal processes from cross sectional data. This problem is magnified because inconsistent results often occur in studies differing in subject characteristics, measurement instruments, sub-components of the death concept and the cultural-historical effects associated with the year of measurement, all at the same time. Longitudinal or cross sectional-sequential research would be important to firmly establish the developmental formation of the concept of death in childhood. However, despite the large numbers of studies of death concepts in children, only one has attempted a longitudinal design and this was only over a period of seven months (Lazar & Torney-Purta, 1991).

1.1.10 Summary of concept of death research in children

Several studies investigating children's notions of death have suggested stage-based conceptualisations emerging from the qualitative analyses of children's responses to questions about death and dying (Anthony, 1940; Kane, 1979; Koocher, 1973; Nagy, 1948). In general there is correspondence in the conclusions drawn from these studies (as summarised by Stambrook & Parker, 1987). At very young ages (three – five years) the child has little information about death and dying. This conceptual paucity may range from total ignorance to limited notions of the meaning of death. The pre-schooler may view death as a reversible process and describe several ways one can avoid death. During middle childhood (five - eight years) the child possesses more knowledge about death including some awareness of its finality and cause, yet death is still considered a remote possibility. During pre-adolescence (eight – eleven

years) the child acquires a mature conception of death which can be considered adult like; i.e. he understands the finality, universality and non-functionality of death.

Experimental and clinical investigations of children's views of death have suggested evidence of sequential development of the sub-components of the death concept. This sequence has been related to general cognitive development, to the critical stages of psychosexual or psychosocial development and to the impact of death experiences, religious affiliation, life circumstances, social class and emotional development. Disagreement about the precise nature of the developmental trend and the exact age or stage at which children develop a full understanding of the various sub-components makes specific predictions based on chronological age alone very risky. However, generally children have been depicted as moving through a sequence ranging from denial of death as final, inevitable or personal to an acceptance of death as final, inevitable and personal.

Two theories attempt to explain the development of the death concept. Mitchell (1967) believes that the child develops an understanding of death by observing nature. The child has more opportunities for observing death in animals and through generalisation he transfers this knowledge to death in humans and eventually to death in oneself. In contrast, Anthony (1971) suggests that the child understands the meaning of death through his own experiences which are related to death (i.e. separation). Via generalisation, these experiences are then related to the death of living objects in general. The finding that children more readily understand human than animal death provides some limited support for Anthony's theory of death concept development. However it is important to consider the possibility that

children may erect more defences against death in animals, to which they may be more emotionally related and about which they may have had more experience than human death (Orbach et al., 1985).

1.2 CONCEPT OF DEATH IN ADULTHOOD

The concept of death has rarely been studied beyond the childhood years, possibly due to the implicit and largely untested assumption that our concept of death develops until adolescence and then remains fairly unchanged throughout life (Kastenbaum & Costa, 1977). The result is that little is known about how adults conceptualise death.

The mature adult's understanding of death needs to be clarified. All investigations of the development of the concept of death in children have used a presumed mature comprehension of death as the developmental endpoint against which the children's understandings were compared. Assumptions of a mature concept have a number of problems (Kastenbaum, 1992). Firstly, maturity may be a culturally biased concept. Secondly, the preservation and application of mature death concepts throughout adulthood has not been systematically established. Finally, the possibility that additional types of death constructs may develop during adulthood has not been systematically investigated.

Minimal research suggests that the mature adult concept of death is more complex than is suggested by the simple definitions of each sub-component. For example, Brent and Speece (1993) compared scores of 165 undergraduates (mean age = 25 years) with those obtained by children (five - ten years) on five irreversibility

questions. Their results showed that adults as a group conformed less well to the presumed adult standard than did the children. However, the adults' explanations indicated that their:

> *"lower conformation to the presumed adult concept was not the result of some anomalous regression but was a by-product of their more sophisticated understanding of the complexity of irreversibility"* (p203).

This complexity results as an individual attempts to integrate his or her belief in the general irreversibility of bodily death with a possible belief about spiritual continuation and with the awareness of a flexible boundary between life and death (i.e. the knowledge of medical instances in which an individual presumed to be dead was subsequently revived by successful resuscitation). Awareness of this complexity is obviously important when questioning adults about the sub-component of irreversibility.

Brent and Speece's study appears to imply that the conventional form of the death concept, which the child achieves at about age ten, subsequently:

> *"comes to serve as merely the core of a connotational sphere which the child continues to enrich and elaborate throughout the remainder of life by the addition of all kinds of exceptions, conditions, questions and doubts"* (p223).

Their later finding that older children (ten -seventeen years) are increasingly likely to deviate from the presumed adult standard as they get older confirms this

hypothesis (Brent et al., 1996). Research of this nature supports the view of certain researchers (e.g. Carey, 1985) that concept development in general may be a more complex process, may extend over a longer period of the life-span and may result in more varied and individualised outcomes than those described or implied by a Piagetian-grounded approach.

1.3 CONCEPT OF DEATH IN THE LEARNING DISABLED POPULATION

To date there have been five studies which have focused on the concept of death in this client group. One looked at children's understanding of death, the other four focused on adults' concept of death. One additional study has also made reference to adults' understanding of death, though this was not the main focus of their study. These studies will be described chronologically in some detail before the rationale for the present study is explained.

1.3.1 Studies which have investigated concept of death in the learning disabled population

In the earliest study, Sternlicht (1980) examined the concept of death in pre-operational children (as defined by their failure to pass one or more of three Piagetian conservation tasks of mass, number and volume). In a replication of Koocher's (1973) study, 14 children with learning disabilities, eight males and six females, aged 10 to 19 years, were asked four open-ended questions about death: "What makes things die?", "How can you make dead things come back to life?", "When will you die?" and "What will happen then?". Their responses were

categorised as either egocentric, concrete / specific or abstract / generalised by two raters. She found that 70% of all responses were rated as egocentric, a characteristic of pre-operational thought. The majority of her subjects neither had an understanding of the irreversibility and permanence of death nor when they would die. She concluded that the pre-operational learning disabled child cannot give a naturalistic picture of death but do have a specific or concrete idea of how death occurs. She related the lack of a naturalistic explanation to the fact that they have had no first hand experience of death.

The next study, by Bihm and Elliott (1982), also used Piagetian tasks to discriminate between 79 adults with mild learning disabilities (mean age = 19 years) who were functioning at a pre-operational or concrete-operational level. These adults were categorised according to their ability to pass three conservation tasks and a hypothesis testing task. Eight questions (both open-ended and fixed-response) were asked to determine their understanding of death and these responses were rated as either egocentric, concrete or abstract by independent raters. Questions included; "How can you tell when someone is dead?", "Why is it that people die. How does it happen?", "Do you know anyone who died?", "Can a dead person feel anything like hot or cold outside?", "Can he talk?", "Do you think that everyone will die?" and "Do you think you will die?". No subject showed undue upset at being questioned in this manner.

Bihm and Elliott found no significant relationship between participants' age and their conception of death. However, cognitive level, as determined by Piagetian tasks, was related to understanding of death: i.e. concrete-operational participants (32% of the

sample) had a more realistic comprehension of death than pre-operational participants (68% of the sample). These findings support previous work done with intellectually average children and suggest that cognitive level is probably a much better predictor of an understanding of death than is chronological age. They did not examine the relationship between experience of death and level of response to the questions, despite stating that *"many of the subjects knew of someone who had died"* (p209).

The third study with this population involved Lipe-Goodson and Goebel (1983) examining the perception of death in a sample of 65 adults with learning disabilities, who were all living in a residential facility. Their participants were 27 women and 38 men, aged between 17 and 62 years, with IQs between 19 and 80. This sample therefore represented a wider range of ages and abilities than Bihm & Elliott's sample. The participants' IQ, age and percentage of life institutionalised were compared to their understanding of the universality, inevitability and irreversibility of death, as measured by three fixed-choice (Yes/No) questions. Participants were divided along the median for age, IQ and percentage of life institutionalised. Their results showed that older participants and participants with higher IQs demonstrated more adequate concepts of death than younger participants and participants with lower IQs; indicating a significant effect of both age and level of intellectual functioning on the understanding of death. They conclude that their results

> *"suggest the developmental process involved in .... concept of death is similar in nonmentally retarded children and mentally retarded adults"* (p68).

However they also emphasise that some adults with learning disabilities will never have a fully developed concept of death.

Lipe-Goodson and Goebel's finding that older individuals have a clearer understanding than younger participants suggests that life experience enhances understanding of death. Chronological age may thus serve as an index of experience in persons with learning disabilities, which permits them to conceptualise death in a manner similar to more cognitively advanced persons. Opportunities to participate in rituals of death and dying therefore may compensate to some extent for cognitive limitations.

Next, McEvoy (1989) investigated the concept of death in adults with learning disabilities who attended day services in south Dublin. He interviewed 38 participants; 68% of whom were male. Participants were aged between 20 and 50. However two thirds of this sample were below 25 years of age. The Index of Social Competence (McConkey and Walsh, 1981) was used as a measure of functioning and participants were divided into two groups depending upon their ability in the areas of communication, self-care and community skills. His interview consisted of nine open-ended questions which focused on the irreversibility, non-functionality and universality of death as well as the causes of death and the participant's death experience. Responses were classified and rated as either showing a good level of understanding, some understanding or little or no understanding.

McEvoy found no significant relationship between age, sex or reported experience and the concept of death. Details of how the relationship between reported

experience and understanding of death was investigated are not given. However, those participants who had higher abilities (on the Index of Social Competence) had a significantly better developed understanding of irreversibility and non-functionality (i.e. that body functions stopped at death). He also found a relationship between awareness of personal mortality and a more mature concept of death; suggesting that for these adults, a greater awareness of one's own mortality contributes to a more mature understanding of what is involved in death and dying.

The concept of universality was not well developed within McEvoy's sample: 71% of participants believed that everybody will die but only 42% believed that they will die. This contradicts the findings in the child literature which suggest that universality (inevitability) is one of the first sub-components of the death concept to develop and is more easily understood than the sub-component of non-functionality (finality). McEvoy suggests that confusion over personal mortality must either reflect poor understanding of the ageing process and the normal life cycle or be due to the fact that questions regarding time or future events may create difficulties for adults with learning disabilities. However, he makes no comment on the potential impact of anxiety or cognitive distortion on the perception of personal mortality, which has been shown to be an important variable in children's understanding of death.

Illness was the most commonly cited cause of death (55% of all responses) and was suggested more frequently by younger adults than by their older peers, who often cited natural causes as a reason. This indicates that McEvoy's participants, and especially the younger ones, had a poor understanding of the ageing process and did not see death as an internal biological process that operates according to natural laws.

He concludes that comparisons can be drawn between these findings and reports in the literature on the development of the concept of illness in young children. Between the ages of seven and eleven, children move from believing that illness is externally caused to believing that illness is the result of internal physiological dysfunction. Also older children are more likely to realise that the effects of illness are due to internal malfunctioning (Bibace & Walsh, 1981). The frequent citing of illness as a cause of death indicates that these adults might not have understood the biological inevitability of death. Cathcart (1995) believes that this apparent lack of understanding of ageing as a natural part of the life cycle reflects the fact that some people with learning disabilities *"continue to be treated as children and are not encouraged to act, speak or dress in age-appropriate ways"* (p168).

The most recent study on this topic was published by Myreddi and Narayan in 1993. They investigated the concept of death in 70 young adults (aged 16-20 years) in India. The majority of their subjects were Hindu (77%), male, and with mild learning disabilities (59%). Interviews focused on the areas of what happens to the dead, causes of death, what is done to the body and what do people do when someone dies.

Myreddi and Narayan provide no explanation of their scoring criteria, scoring procedure or statistical analysis of their data. However, they report that their results indicated a clear relationship between level of learning disability and appreciation of the concept of death, with finality and irreversibility being more readily comprehended by persons with higher cognitive ability. They suggest that an individual's experience of death influences their concept of death but they do not define the nature or extent of this relationship.

Views about the causes of death also varied according to level of learning disability, with mildly learning disabled participants giving more abstract explanations (e.g. old age and heart attack) and those with moderate learning disabilities giving more concrete explanations of why people die (e.g. accidents or murder). In comparison to McEvoy's sample, participants were significantly more likely to highlight accidents as a primary cause of death; 35% reported accidents as a cause of death compared to 3% of McEvoy's sample. This finding is related to the fact that data collection was in progress at the time of Mr Rajiv Gandhi's assassination, which received widespread media coverage. The authors argue that those participants with a moderate learning disability showed a more concrete reliance on media coverage of death.

Additional findings from Myreddi and Narayan were that a) the visible aspects of death are more easily understood and reported than invisible or implied aspects of death and b) individuals with learning disabilities comprehend and retain concrete aspects of death more readily than they do those of an abstract nature. In addition, they found that all participants, irrespective of level of ability, demonstrated a good understanding of the *"fact of mourning"* (p329) and specific religious practices with regard to disposal of the body. Their conclusions are that individuals with mild impairments acquire a conception of death which corresponds roughly to Nagy's (1948) third stage of development whilst persons with moderate learning disabilities may not proceed beyond the first stage.

One additional study within the learning disabled population provides information about understanding of the concept of death, although this was not the main focus of

this study. In 1993, Harper and Wadsworth conducted structured interviews with 43 adults with moderate to severe learning disabilities to investigate their experiences of grief and loss. This study included nine fixed-response (yes/no) questions about the finality and inevitability of death as well as individual's experience of death. They found that a large proportion of their sample (78%), including individuals with significant learning disabilities, were able to verbalise a literal and reasonably accurate understanding of the finality of death. They conclude that adult's understanding of death reflects a combination of varying conceptual knowledge as well as experiential opportunities and religious ritual participation.

1.4 RATIONALE FOR THE PRESENT STUDY

Information about the development of the concept of death may be useful in addressing some profoundly human issues, such as bereavement, terminal illness and suicide. Increased insight into what people with learning disabilities can and do comprehend about death could be useful for those who work in situations where people with learning disabilities confront death and for those who are questioned about death by this group.

Several studies have suggested that the concept of death in adults with learning disabilities resembles the development of the concept of death in children (Bihm & Elliott, 1982; Lipe-Goodson & Goebel, 1983). The child's concept of death has been related to level of cognitive development based on the stages proposed by Piaget. The findings within the learning disabled literature also support the relationship between cognitive development and a mature understanding of death. Extensive

research on children's death concept provides a clear framework against which to compare the development of the concept of death in people with learning disabilities.

Limitations of previous studies which have investigated the concept of death in the learning disabled population provide a strong case for further investigating this topic. These limitations include: small sample sizes (especially Sternlicht's study of 14 children); a focus on young adults; and biased samples (e.g. young, mainly male Hindus with mild learning disabilities in India) which limit the generalisability of the findings. Past research has relied on evaluation of the concept of death based on only a small number of questions and there has been evidence of an uneven spread of questions between sub-components, which might have resulted in an inadequate reflection of adults' perceptions. Finally there has been no previous attempt either to use or create standardised questionnaires or scales for this population or to make use of standardised scales from the child literature in an attempt to integrate the two fields of research.

The usefulness of a structured interview format for interviewing people with learning disabilities has been demonstrated by other researchers (McEvoy, 1989), as well as the ability of these individuals to express their opinions on this sensitive, important but much neglected topic. This study involves the use of a structured interview format to elicit the views of participants.

To date, measures used to assess concept of death in people with learning disabilities have varied between studies. No research has utilised standardised measures which have been constructed for use with children. The present study adapts a well

evaluated measure from the child literature (Smilansky's [1987] Death Concept Questionnaire). The concept of death is investigated in relation to a number of variables, including age and cognitive development as measured by both Piagetian tasks and a measure of receptive language ability (British Picture Vocabulary Scale). The aim of using these measures is both to attempt to replicate previous findings (i.e. that concept of death understanding is related to Piagetian developmental level) and to expand on these findings by investigating an additional, previously unused, measure of intellectual functioning.

Little attention has been paid to the importance of personal experience of death and the development of this concept in people with learning disabilities: despite the child literature which suggests that death experience may enhance an understanding of the concept of death in young children. This study therefore addresses the impact of experience of death on the development of the concept of death in adults with learning disabilities.

The impact of cultural and religious beliefs has also been neglected in previous research. The majority of studies on death concept have focused on white western cultures. Whilst some researchers (e.g. Derry, 1979) have found no relationship between religious denomination and death concept development, others suggest that beliefs about death and understanding of death can be heavily influenced by religious beliefs (Anthony & Bhana, 1988). It would therefore be useful to investigate if different religions and cultures account for any differences in the development of a mature death concept in this population.

1.5 RESEARCH QUESTIONS

This study will attempt to answer three questions. These are:

Research question one: What variables account for differences in the development of the concept of death in learning disabled adults?. This question will focus on cognitive ability, experience of death and demographic factors (e.g. age, sex, religion and ethnicity).

Research question two: What is the sequence of acquisition of the sub-components of a mature concept of death in learning disabled adults? Does this resemble the pattern found in the child literature?

Research question three: Within the sub-component of finality, is finality of external, non-cognitive functioning more readily understood than finality of internal, cognitive functioning?

CHAPTER TWO: METHOD

OVERVIEW

The present study examined how factors such as cognitive ability, experience of death and demographic characteristics influenced how 74 adults with learning disabilities understood the concept of death. All participants were interviewed and their understanding of the concept of death was assessed using a standardised questionnaire from the child literature (Smilansky, 1987). Their cognitive ability was measured by use of Piagetian tasks and the British Picture Vocabulary scale. Demographic information (e.g. sex, age, ethnicity and religion) and information about participant's experience of death was gained from carers or relatives.

This chapter has three main sections. Section 2.1 describes the participants and their recruitment. Section 2.2 describes the measures which were used. Finally section 2.3 describes the procedure employed and how the data was subsequently analysed.

2.1 PARTICIPANTS

2.1.1 Recruitment

Participants were adults with learning disabilities from three London Health Trusts. Inclusion criteria specified that participants must be: a) verbal; b) able to be interviewed for approximately one hour; c) willing to participate in the research; and d) not have experienced a recent bereavement or become easily distressed when

discussing the topic of death. Participants from Fulham, Chelsea, Westminster, Hammersmith, Ealing and Hounslow were interviewed.

Participants were recruited via liaison with staff members working in services for people with learning disabilities. A variety of residential homes, day centres and out-reach projects were approached by the researcher and details given of the proposed study. Potential participants were then approached by their carer or staff member. The study was discussed with them and verbal consent was gained to participate. Details of these individuals were then passed on to the researcher who organised individual interviews. No individual was approached directly by the interviewer.

Although carers were asked to recruit any individual meeting the inclusion criteria regardless of their experience of death, carers appeared more likely to approach those who had experienced a bereavement and/or had experienced difficulties in adapting to a bereavement than to approach individuals without this experience of death. Unfortunately, this sampling bias was unavoidable, as the method of recruitment was specified by the ethics committees as being the most appropriate. Concerns were raised by the ethics committees about the possibly coercive nature of any direct approaches to potential participants by the researcher and it was deemed more appropriate for participants to be initially approached by a familiar individual.

2.1.2 Description of participants

Seventy nine individuals were interviewed by the researcher. Five of these interviews were terminated before completion either by the participant or by the interviewer because the participant appeared to be distressed. The focus of the interview had

been explained to all participants prior to their agreeing to take part. However, these five individuals became distressed or asked to stop as soon as the topic of death was mentioned; indicating an inability or reluctance to discuss this topic. All participants were given the opportunity to discuss their concerns after the interview was terminated. Information about these individuals did not indicate any significant differences from the other seventy four participants who completed the interview.

Seventy four participants were therefore included in this study; 45 (61%) were female and 29 (39%) male. Age ranged from 19- to 90-years old (mean = 44.56 years, SD = 15.10). Participants were from a range of ethnic backgrounds: 53 (72%) described themselves as white British, 6 (8%) as Irish, 1 (1.4%) white European, 1 Pakistani, 1 Chinese, 3 (4%) black African, 4 black Caribbean (5.4%) and 4 as other (i.e. of mixed race). This range of ethnicity appears to provide a realistic reflection of the ethnic characteristics within the three recruitment areas.

Information on the participants' religious affiliation was gained from carers or the individual themselves. Information was not available for all participants. Within the sample, the majority of participants were described as Christian: either Catholic (24%), Protestant (7%), Church of England (43%) or Baptist (1.4%). Only one participant was Muslim. Two individuals described themselves as atheist (2.7%) and the remainder (19%) reported having no religion. The majority of the sample attended their place of worship never (50%) or once a year (15%). However, 27% of participants did report attending their place of worship once a week or more frequently.

The majority of those interviewed lived in a group home (58%). Twelve percent lived in the family home and 12% lived in a convent for people with a learning disability. The remainder (18%) lived more independently in their own home. Day provision varied within the sample, with the majority of participants attending either day centre (33%), college (20%), work centre (5%) or Mencap training centre (6%). Sixteen percent of participants were currently in sheltered employment and the remaining 20% received no day services at the time of interview.

2.1.2 Ethical considerations

Ethical approval was gained from Riverside Research Ethics Committee, Ealing Hospital Research Ethics Committee and the Hounslow District Research Ethics Committee. Copies of approval letters are contained in Appendix 1.

Verbal agreement to participate was gained from all participants prior to being approached by the researcher. Information sheets (Appendix 2) detailing the procedure and purpose of the study were distributed to potential participants and their families. A written reply (Appendix 3) was requested from each participant's primary carer or guardian. This reply signified that the carer was unaware of any expression by the potential participant that they did not wish to take part in the study. In addition to this, the study was explained and verbal consent obtained from all participants at the beginning of the interview. It was made explicit to participants that they could withdraw from the study at any time and without giving a reason. All participants were informed that results of the study would be available to them in due course and that they were welcome to contact the researcher at any time if they had any questions or concerns.

2.2 MEASURES

2.2.1 Carer's questionnaire

A questionnaire was completed by the participant's relative or carer. This asked for information about the participant's age, sex, ethnicity, religion and their experience of death. A copy of this questionnaire is included in Appendix 4.

2.2.2 Interview measures

A variety of measures were used during the individual interview with each participant. These included the British Picture Vocabulary Scale, Piagetian tasks, a concept of death questionnaire and a mood gauge.

British Picture Vocabulary Scale (BPVS)

The BPVS (Dunn, Dunn & Whetton, 1982) is a British version of the Peabody Picture Vocabulary Test – Revised (Dunn & Dunn, 1981). It is a widely used and well standardised measure of a subject's receptive vocabulary with good reliability (split-half reliability of 0.80; Dunn et al., 1982) and validity. It measures vocabulary and provides an estimate of the level of current intellectual functioning of an individual.

It has been used with both children and adults with learning disabilities (e.g. Hobson & Lee, 1989; Hobson, Ouston & Lee, 1989) and is a very useful measure of verbal development in people with a learning disability because it does not require reading or writing skills and responses to test items can be gestural.

The BPVS has a long and short form. Both forms were standardised on a large British national sample (N= 3334) and a cross-section of all strata was used during standardisation (Dunn, Dunn & Whetton, 1982). The short form was used in this study. It consists of 32 test item plates preceded by 6 training plates. Each plate contains four pictures of different objects or actions. (Appendix 5 contains a copy of two test plates of varying difficulty). A word was read out and the participant was asked to point to the picture which represents that word. Prior to testing, the participant was given the opportunity to practice responding with the training plates. All participants were given as many opportunities to practice as necessary and the test only proceeded if it was clear that the participant fully understood the task. The test was terminated after 4 errors in 6 consecutive responses.

Once completed, the results of the BPVS gave an age equivalent for each participant. Age equivalents are developmental norms and were derived from a growth curve fitted to the median performance of successive age groups in the standardisation sample. Therefore each participant's score was compared to the scores of the standardisation sample and based on this comparison, an estimated age of functioning was calculated.

Piagetian Tasks

These tasks were based on Piaget's theory of cognitive development and were designed to assess the participant's level of cognitive functioning.

According to Piaget, participants would be functioning at one of 3 levels:

- Pre-operational (comparable with children aged approximately 2-7 years)
- Concrete-operational (comparable with children aged approximately 7-11 years)
- Formal operational (comparable with adolescents aged approximately over 11 years).

The procedure for these tasks was taken from Phillips (1969) and Ginsburg & Opper (1988). All participants undertook four tasks to assess their ability to conserve length, number, volume and substance amount. Those participants who passed all 4 conservation tasks also undertook a hypothesis testing task. (Appendix 6 contains details of all tasks assessed). Correctly answering the 4 conservation tasks differentiated between pre-operational and concrete operational functioning, whilst correctly answering the hypothesis testing task differentiated between concrete operational and formal operational functioning. Use of Piagetian tasks as a measure of cognitive functioning allowed comparison with previous studies which had utilised this measure (Bihm & Elliott, 1982; Sternlicht, 1980).

Concept of death questionnaire

This questionnaire was originally developed in Hebrew by Smilansky and Weissman (1978) but was translated into English by Smilansky in 1987. It has good psychometric properties (test-retest reliability of 0.84, internal consistency of α = 0.77 and good construct and criterion related validity; Smilansky, 1981) and has been widely used with children of all ages, thus ensuring that the wording is relatively simple. Appendix 7 contains a copy of the concept of death questionnaire.

It consists of two parts, 15 questions about human death and 15 identical questions about animal death. The questions in each part refer to five different aspects of the definition of death:

- Finality – i.e. that once dead, the living body ceases to function (e.g. "Can a dead person feel?"),
- Irreversibility – i.e. that once dead, the living body does not come back to life (e.g. "Can a dead person become alive again?"),
- Causality – i.e. an understanding of the range of causes of death (e.g. "Of what do people die?"),
- Inevitability – i.e. an understanding that all living things eventually die (e.g. "Does everyone die?")
- Old age – i.e. an understanding that all living things get old and that death is a natural part of the life-cycle (e.g. "Who gets old?").

Responses to the questionnaire yield scores of between 0 and 3 for the ten sub-components of irreversibility, inevitability, finality, causality and old age in animals and humans. These scores can be summarised to give total scores for the concept of animal death (maximum score of 15), concept of human death (maximum score 15) and an overall total concept of death score (maximum score of 30). The scores for this questionnaire are determined by pre-defined criteria (described by Smilansky, 1987). Maximum scores indicate a complete understanding of that sub-component or concept. In order to gain maximum scores, individuals must answer both the yes/no questions correctly and also provide acceptable explanations for their answers.

All questionnaires were coded by the researcher and a random sample of 20 questionnaires (27% of the total sample) were also coded by a second rater, a male Clinical Psychologist in Training. Inter-correlations of the two raters' scores indicated high levels of inter-rater reliability for each of the 5 sub-components: irreversibility (0.99); causality (1.00); finality (0.94); inevitability (0.85) and old age (0.89). Correlations were also high for total animal death scores (0.90), total human death scores (0.97) and overall concept of death scores (0.96). These correlations were all significant at the $p < 0.001$ level.

The animal death sub-scale (i.e. all 5 animal sub-components taken together) was found to have good internal consistency (α=0.76). The human death sub-scale (i.e. all 5 human sub-components taken together) was also found to have good internal consistency (α=0.74). In addition, internal consistency for the total scale (i.e. all 10 sub-components) was also high (α=0.86) indicating that use of the total overall score for concept of death was justified. Despite the high internal consistency for the total scale, the sub-scales for animal and human death were also included in the analysis of this data. Their inclusion was justified on the grounds of allowing comparison with previous studies which had examined animal and human death separately and also on the basis that conceptually these aspects of death might differ.

In addition to Smilansky's questionnaire, participants were also asked several other questions about human death. These were adapted from Speece and Brent's (1992) study into children's understanding of inevitability, irreversibility and finality. They were included firstly to provide additional information about understanding of certain aspects of human death, such as personal mortality, and to allow more precise

exploration of the understanding of the finality of internal and external functioning in human death. Secondly, Flynn (1986) argues that the use of both open-ended and fixed-response questions may increase the validity of the responses given by the learning disabled population. All additional questions were fixed-response and participants were either correct or incorrect depending on their yes/no response. No explanations were necessary to gain full marks for these questions and these questions were included to provide a comparison to Smilansky's questionnaire which requires correct responses to both open-ended and fixed-response questions. These additional questions are specified in Appendix 7.

Mood rating

Participants were asked to rate their mood at the beginning and end of the interview. The rating scale (Appendix 8) was a five-picture scale ranging from "very happy" to "very sad / upset". Participants were asked to point to the picture which best described how they were feeling at that time. This measure was included to allow the researcher to assess if the questions had had a significant negative impact on the participant's mood.

2.3 PROCEDURE

Participants were initially approached by a carer or staff member who gained verbal agreement to take part in the study. Reply forms and carers' questionnaires were then returned to the researcher, giving background information about potential participants. Individual interviews were then arranged.

All participants were interviewed individually at their home or day service provision. Carers were also present during interviews when participants expressed their wish to have support, but were encouraged not to assist participants with their answers. Interviews lasted between 30 minutes and 60 minutes depending upon the amount of information participants wished to discuss. A copy of the full interview protocol is contained in Appendix 9.

All interviews followed the following format:

- Introduction of the researcher
- Explanation of the study
- Gaining verbal agreement to participate
- Initial mood rating
- BPVS
- Piagetian Tasks
- Concept of death questionnaire
- Final mood rating
- Opportunity to de-brief

2.3.1 Data analysis

Once interviews were completed all quantitative data was coded by the researcher and analysed using SPSS for Windows 95 (Statistical Package for Social Sciences) version 7.01.

CHAPTER THREE: RESULTS

This chapter has five main sections. Section 3.1 presents descriptive data about the participants and their responses during the interview. Sections 3.2, 3.3 and 3.4 will address the three research questions which were the focus of the present study. Each question will be addressed in turn and details given in each section of the statistical analyses performed and their findings. Finally, interesting additional findings will be discussed in section 3.5.

The term carer will be used throughout this section for ease. It should be noted that information about participants in some cases was gained from family and staff members in both residential and day service settings.

3.1 DESCRIPTIVE DATA

3.1.1 Experience of Death

Participants' experience of death and death-related phenomena was measured by asking either carers or the participants themselves to give details of their experience. As certain carers admitted to not knowing the participants' history in great detail, the information obtained may not be totally accurate.

The total number of deaths experienced ranged from 0 to 14 (mean = 3.93, SD = 2.59). Twenty one percent reported having known six or more friends or family who had died, 34% reported knowing between three and five people who had died and

40% reported knowing one or two people who had died. One participant reported having no experience of family or friend's death, one reported having only experienced the death of a less familiar person and one reported having experienced no deaths.

Fifty nine percent of the sample had experienced the death of an immediate family member and 83% of participants had experienced the death of either an immediate or an extended family member. The remaining 17% had experienced the death of non-family members, such as fellow residents and staff members.

Fifty two participants (70.3%) had attended a funeral ritual. The number of funerals attended varied with most participants (44%) only having attended one funeral. However, a substantial proportion of this sample had attended two or three funerals (26% and 18% respectively) and 12% had attended four or more funerals. Forty three percent were reported to have seen a dead human body and 47% had not. Fifty eight percent of participants had seen a dead animal, whilst 40% reported that they had not.

Sixty seven percent of carers had discussed the topic of death with the participant. Forty two percent had also attempted to explain a death to the participant. Only 20 carers (27%) responded to the question asking how they had explained the death. These responses fell into five categories: 13 had described "going to heaven", three had explained how the dead person was now "at rest or peace following a long illness". Two explained that the dead person had "gone to a better world" whilst one

described how the individual had "gone from the tangible world but was still around in a spiritual sense". Finally one carer had described death as "like being asleep".

Carers were also asked to indicate on a five point scale how good they believed the participant's understanding of death to be. Understanding was judged to be non-existent in one case, "limited" in 26% of the sample, "fairly good" in 32%, "good" in 30% and "complete" in 9% of participants. Correlations of these estimates and participants actual scores on the concept of death questionnaire indicate a relatively low but significant relationship between carers judgements and total human death scores (0.32, $p < .01$), total animal death scores (0.26, $p < .05$) and overall concept of death scores (0.30, $p < .01$).

3.1.2 Mood rating

Participants were asked to rate their mood on a five point pictorial scale at the beginning and end of the interview. Table 2 shows the number of participants who rated their mood in each of the five categories. Eighty five percent of participants rated their mood as very happy, fairly happy or neutral prior to the interview. This increased to 86.5% at the end of interview. Within subjects analysis showed that 55% of participants showed no change in mood, 18% rated themselves as being more happy and 27% rated their mood as being more sad by the end of interview. Of those who rated themselves as more sad, 11 (55%) had moved only one category down the scale (e.g. from neutral to fairly sad), whilst six participants (30%) and three participants (15%) had moved two and three categories down the scale respectively.

Table 2: Distribution of mood ratings pre- and post-interview.

Mood rating categories	Mood rating at beginning of interview	Mood rating at end of interview
Very happy	40 (54.1%)	34 (45.9%)
Fairly happy	14 (18.9%)	16 (21.6%)
Neutral – neither happy nor sad	9 (12.2%)	14 (18.9%)
Fairly sad / upset	8 (10.8%)	8 (10.8%)
Very sad / upset	3 (4.1%)	2 (2.7%)

3.1.3 Verbal ability

The BPVS provides an age equivalent score of verbal ability in years. Possible scores range from 1.35 to 19 years. BPVS age equivalent scores obtained by participants ranged from 2.16 years to the maximum19 years (mean = 7.05, SD = 3.44), indicating a broad distribution of verbal ability within this sample.

3.1.4 Piagetian Tasks

Piagetian level of cognitive development was measured by ability to correctly answer four tasks of conservation and a hypothesis testing task. Performance on these tasks indicated that 10 participants (13.5%) were at the concrete-operational stage of cognitive development, whilst the remainder (86.5%) were pre-operational. No participant showed evidence of formal-operational thinking. Within the pre-operational group there was evidence of differences in cognitive ability with 18% failing on all tasks, 31% answering one correctly, 30% answering two correctly and 8% and 13% correctly answering 3 and 4 tasks respectively.

Performance on the four tasks of conservation reflect their varying difficulty. Results indicate that the conservation of number was most readily understood (69% of participants answered correctly), followed by the conservation of length (39% correct), conservation of volume (35% correct) and finally the conservation of substance amount (26% correct).

3.1.5 Concept of Death

Scores were obtained for the five sub-components in animal and human death, total animal death scores, total human death scores and an overall concept of death score. Table 3 depicts the means and range of scores obtained for each of the sub-components as well as the total scores obtained. These results clearly indicate that different sub-components vary in the proportion of participants showing a complete understanding. This suggests that the sub-components differ in their difficulty, with some being more readily understood than others. This finding will be discussed in more detail in section 3.3 when research question two is considered.

Table 3 indicates that mean scores for sub-components of animal and human death vary. The significance of these differences was analysed via. paired-sample t-tests. The results are in Table 4. Despite the finding that causality, finality and inevitability mean scores were higher for animal than human death, whilst mean scores for old age and irreversibility were higher for human death, most of these differences did not reach significance. The only exception was inevitability, with significantly higher scores for animal than human inevitability, suggesting that level of understanding of this sub-component is not identical for human and animal death. There was no significant difference between total animal death mean scores and total human death mean scores ($t = 1.46$, d.f. 73, $p = .15$, ns).

Table 3: Scores for sub-components and total scores for concept of death questionnaire

	Mean score	**Standard deviation**	**Number of participants with complete understanding**
Animal			
Irreversibility	2.04	1.16	38 (51.4%)
Inevitability	2.34	1.09	51 (68.9%)
Old age	2.01	1.10	40 (54.1%)
Causality	1.42	1.12	21 (28.4%)
Finality	1.03	1.11	11 (14.9%)
Human			
Irreversibility	2.12	1.18	42 (56.8%)
Inevitability	1.81	1.07	22 (29.7%)
Old age	2.30	1.07	50 (67.6%)
Causality	1.22	0.96	14 (18.9%)
Finality	0.93	1.08	9 (12.2%)
Total score for concept of animal death	8.83	4.01	6 (8.1%)
Total score for concept of human death	8.38	3.76	5 (6.8%)
Overall concept of death score	17.22	7.29	1 (1.4%)

Table 4: Paired sample t-tests comparing mean scores for animal and human death on five sub-components.

Sub-component	Mean animal death score	Mean human death score	T value	Level of significance
Irreversibility	2.04	2.12	-0.64	0.53
Inevitability	2.34	1.81	3.65	0.00***
Old age	2.01	2.30	-1.90	0.06
Causality	1.42	1.22	1.71	0.09
Finality	1.03	0.93	0.94	0.35

*** = $p < 0.001$

3.2 RESEARCH QUESTION ONE: WHAT VARIABLES ACCOUNT FOR DIFFERENCES IN THE DEVELOPMENT OF THE CONCEPT OF DEATH IN LEARNING DISABLED ADULTS?

The relationship between all hypothesised variables and participants' total human, total animal and overall concept of death scores was analysed firstly by the use of univariate statistics (t-tests and correlations) and then by the use of multiple regression. Table 5 presents the results of Pearson's correlations whilst Table 6 presents all independent sample t-tests performed. Due to an uneven distribution and small variation in participants' ethnic groups and religions, these variables were excluded from the analyses.

These results indicate that BPVS scores, awareness of personal mortality and having seen a dead animal are all important factors in developing a complete understanding of the concept of death. The significant correlation between BPVS age equivalent scores and concept of death scores indicates that more verbally able participants have a significantly better understanding of animal death, human death and higher overall concept of death scores than less verbally able participants. This finding was supported when participants were divided along the median BPVS score into high and low cognitive ability groups, with high ability participants having significantly higher overall concept of death scores than low ability participants ($t = -3.26$, d.f. 72, $p = 0.002$). Comparison of concrete-operational and pre-operational participants showed higher mean scores for human, animal and overall death concept scores in concrete-operational participants. However, this difference in mean scores was not

statistically significant. Therefore, there was no evidence of a link between cognitive ability, as measured by Piagetian tasks, and concept of death development.

Participants who were aware of personal mortality (i.e. that they would die one day) had significantly higher concept of death scores than participants who did not demonstrate this awareness. Those who reported having seen a dead animal also had significantly higher concept of death scores than those who had not seen a dead animal. There was no evidence for a link between other forms of death experience (such as attending a funeral, having lost a family member or experiencing a high number of bereavements) and overall concept of death scores. Those who had attended a funeral or experienced the death of either an immediate or an extended family death had higher mean scores than those who had not. However, the experience of immediate family death and viewing a dead human body was associated with lower mean concept of death scores than not viewing a body or no experience of an immediate family member's death. These differences were not statistically significant.

Table 5: Pearson correlations for concept of death scores for age, BPVS score, number of Piagetian tasks correct and total number of deaths experienced

Independent variable	Concept of animal death	Concept of human death	Overall concept of death score
Age	-0.14	-0.12	-0.14
BPVS score	0.61***	0.58***	0.63***
Number of Piagetian tasks correct	0.12	0.15	0.14
Total number of deaths experienced	0.01	0.08	0.04

*** = $p < 0.001$

Table 6: Independent sample t-tests comparing concept of death scores with sex, Piagetian level and a number of death-related experiences

Independent variable	Concept of animal death		Concept of human death		Overall concept of death	
	Mean score	T value	Mean score	T value	Mean score	T value
Sex						
Male	9.04		8.59		17.62	
Female	8.71	-0.32	8.24	-0.38	16.96	-0.36
Funeral						
Attended	9.27		8.87		18.14	
Not attended	8.10	-1.15	7.29	-1.64	15.38	-1.48
Dead human body						
Seen	8.75		8.28		17.03	
Not seen	9.50	0.76	8.77	0.51	18.27	0.68
Personal mortality						
Aware	10.29		9.59		19.88	
Not aware	6.00	-4.82***	5.65	-4.67***	11.65	-5.13***
Piagetian level						
Pre-operational	8.61		8.16		16.77	
Concrete-operational	10.30	-1.25	9.80	-1.29	20.10	-1.35
Immediate family death						
Experience	8.58		8.07		16.65	
No experience	9.23	0.68	9.03	1.09	18.27	0.93
Immediate or extended family death						
Experience	9.12		8.74		17.85	
No experience	7.50	-1.27	7.08	-1.42	14.58	-1.43
Dead animal						
Seen	10.02		9.14		19.16	
Not seen	7.14	-3.25**	7.17	-2.24*	14.31	-2.95**

* = $p < 0.05$ ** = $p < 0.01$ *** = $p < 0.001$

Note: Scoring criteria meant animal and human death rated between 0-15, overall concept of death rated from 0-30. Higher scores indicate more complete understanding. Degrees of freedom ranged from 64 to 72, due to missing data.

In order to further examine the relationship between participants' scores on the concept of death questionnaire and the variables of age, sex, cognitive ability and experience of death, multiple stepwise regression analyses were performed. The results are presented in Table 7. It is clear that concept of animal death scores and overall concept of death scores can be significantly predicted by BPVS scores, awareness of personal mortality and having seen a dead animal. Concept of human death scores can be significantly predicted by BPVS scores and awareness of personal mortality only. Performance on the BPVS is the single most powerful predictor of understanding of concept of death: accounting for 37%, 35% and 41% of variance in scores for animal death, human death and overall concept of death respectively.

With one exception, multiple regressions on each of the 10 sub-components produced similar results (i.e. BPVS scores, awareness of personal mortality and having seen a dead animal were significantly predictive of scores for nine of the sub-components). However, multiple regression on participants' scores for human inevitability (i.e. the fact that everyone will eventually die) indicated that awareness of personal mortality and having attended a funeral were more predictive of scores for this sub-component. Details of this multiple regression are presented in Table 8. Personal mortality awareness therefore accounted for 23% of the variance in human inevitability scores, whilst awareness of personal mortality and having attended a funeral accounted for 58% of the variance. This indicates that attending a funeral has a strong influence on understanding of the fact that everyone dies.

Table 7: Multiple regression analyses of independent variables (age, sex, cognitive development and experience of death) on concept of death scores

Predictor variable	R^2	F for increase in R^2	Overall F
Concept of animal death:			
BPVS score	0.37	41.90^{***}	41.90^{***}
Personal mortality	0.43	6.74^{*}	26.01^{***}
Seen a dead animal	0.48	6.28^{*}	20.59^{***}
Concept of human death:			
BPVS score	0.35	38.20^{***}	38.20^{***}
Personal mortality	0.47	15.78^{**}	30.88^{***}
Overall concept of death:			
BPVS score	0.41	48.86^{***}	48.86^{***}
Personal mortality	0.50	13.13^{**}	35.16^{***}
Seen a dead animal	0.54	5.81^{*}	26.85^{***}

$^{*} = p < 0.05$ $^{**} = p < 0.01$ $^{***} = p < 0.001$

Table 8: Multiple regression analyses of independent variables (age, sex, cognitive development and experience of death) on human inevitability scores

Predictor variable	R^2	F for increase in R^2	Overall F
Sub-component of human inevitability:			
Personal mortality	0.24	21.84^{***}	21.84^{***}
Attendance at a funeral	0.58	57.00^{***}	17.53^{***}
Seen dead animal	0.63	9.46^{***}	14.95^{***}
BPVS score	0.66	6.86^{*}	13.13^{***}

* = $p < 0.05$ *** = $p < 0.001$

Specific differences according to cognitive ability (as measured by the BPVS) were also found within the sub-component of causality. Participants were asked two questions about the causes of death: one focused on what people die of and the other asked what animals die of. Causes of death were classified into 4 broad categories: illness, accident, old age and human intention (e.g. neglect, murder or suicide). Participants were divided along the median BPVS age equivalent score (6.25 years) into low and high cognitive ability groups and their explanations of causes of death were compared. Variations were found based on both cognitive ability and the object of reference (animal or human).

Mean number of causes given for animal and human death were 1.45 and 1.53 respectively. Correlation between number of causes of death given and BPVS scores indicated a highly significant relationship for both animal and human death (0.56 and 0.62 respectively, $p< 0.001$). When divided along the median BPVS score into high and low cognitive functioning groups, differences in the mean number of causes of death between the two groups were evident: with mean causes of animal death as 1.11 and 1.78 and mean causes of human death as 1.14 and 1.92 for the high and low cognitive groups respectively. These differences were highly significant for both animal (Mann-Whitney $U = 436.50$, $p < .01$) and human death (Mann-Whitney $U = 401.50$, $p < .001$). This indicates that, despite encouragement from the interviewer, participants from the low cognitive ability group were more likely to give single causes of death for both animal and human death than those from the high cognitive ability group. Conversely, those from the high cognitive ability group were more likely to give multiple causes of death for both animal and human death than those from the low cognitive ability group.

High ability participants were significantly more likely to report accident or human intention as a cause of death than low ability participants (Binomial exact test, $p < .05$ in both cases). However, there were no significant differences between cognitive ability and frequency of reporting illness and old age as causes of death. In addition, low ability participants were significantly more likely to give incorrect or don't know answers when questioned about causes of animal and human death than participants with high cognitive ability. Twelve participants from the low ability group gave don't know or incorrect responses as causes of animal death, in comparison to four participants from the high ability group (Chi-square [χ^2] = 5.10, d.f. = 1, $p < .05$): whilst 10 low ability and three high ability participants gave don't know or incorrect responses as causes of human death ($\chi^2 = 4.57$, d.f. = 1, $p < .05$). These findings support the view that cognitive ability is an important factor in comprehension of the causes of death.

Irrespective of cognitive ability, illness was the most frequently reported cause of death, followed by accident, old age and human intention which was reported least frequently. Illness was significantly more frequently reported as a cause of animal death than old age (Binomial exact test, $p < .05$), accident (Binomial exact test, $p < .01$) or human intention (Binomial exact test, $p < .001$). Illness was also significantly more frequently reported as a cause of human death than old age (Binomial exact test, $p < .001$), accident (Binomial exact test, $p < .001$) or human intention (Binomial exact test, $p < .001$). Illness was more frequently reported as an explanation of human than animal death by all participants, (59 and 45 replies respectively). Conversely, old age was reported less when the participant was asked about human

death (14 times) than animal death (25 times). However, these differences failed to reach significance.

Awareness of personal mortality was also related to cognitive ability. A significant relationship was found between BPVS scores and awareness of personal mortality ($t = -4.44$, d.f. 70, $p < .001$), indicating that participants who were aware of personal mortality had significantly higher BPVS scores than those who did not demonstrate this awareness. There was no evidence of a link between Piagetian level and awareness of personal mortality ($\chi^2 = 0.98$, df1, $p = .27$, ns). The only aspect of death experience which influenced development of personal mortality was having seen a dead human body (χ^2_m [1, N= 66] = 4.45, $p < .05$). Personal mortality awareness did not differ depending upon attendance at a funeral (χ^2_m [1, N= 73] = 0.14, $p = .71$, ns), having experienced an immediate family death (χ^2_m [1, N= 73] = 0.43, $p = .51$, ns), having experienced an extended family death (χ^2_m [1, N= 73] = 1.24, $p = .27$, ns) or having seen a dead animal (χ^2_m [1, N= 72] = 0.52, $p = .47$, ns).

3.3 RESEARCH QUESTION TWO: WHAT IS THE SEQUENCE OF ACQUISITION OF THE SUB-COMPONENTS OF A MATURE CONCEPT OF DEATH IN LEARNING DISABLED ADULTS? DOES THIS RESEMBLE THE PATTERN FOUND IN THE CHILD LITERATURE?

The sequence of acquisition of the sub-components was analysed in a variety of ways, based on previous analyses of the sub-components of the concept of death in the child literature (Lazar & Torney-Purta, 1991; Orbach et al., 1987; Speece & Brent, 1992). Firstly, the sequence of acquisition was investigated by means of a Guttman scalogram analysis (Guttman, 1944; Green, 1956). Secondly, Cochran's Q-test (Cochran, 1950) and McNemar's test for correlated proportions (McNemar, 1955) were performed. Lastly, Lazar and Torney-Purta's finding (1991) that the acquisition of finality and causality are dependent on having first understood inevitability or irreversibility was investigated. This research question will therefore be answered in 3 sections and the rationale for choosing each statistical test will be presented in each section.

3.3.1 Investigating whether the sub-components form a meaningful scale.

A method of scalogram analysis using summary statistics was used based on Guttman's scalogram analysis. Orbach et al. (1987) argue that this is the most appropriate method for determining the sequentiality of the sub-components of death. This analysis is based on the number of participants showing the same sequence of acquisition versus the number of participants who deviated from this sequence.

Scores for the sub-components were recoded dichotomously (i.e. complete vs. incomplete understanding of the sub-component). The sequence of acquisition was based on the frequency of participants' complete understanding of the sub-components, rather than on the mean scores gained for each sub-component. The sequence and means of the five sub-components for both animal and human death are presented in Table 9. The table also presents the reproducibility score and the scalability score for each sequence. It should be noted that a reproducibility score of 0.85 and above and a scalability score of 0.50 and above are considered a valid indication of scalability (Green, 1956).

The high scores for reproducibility and scalability indicate that the observed sequences for human and animal death form a statistically significant scale (i.e. significantly more participants adhere to this sequence than deviate from it). The sequence of acquisition differs slightly depending upon object of reference. The sequence for human death is: old age, irreversibility, inevitability, causality and finality. Whilst the sequence for animal death is: inevitability, old age, irreversibility, causality and finality. These sequences differ from those found by Orbach et al. (1987) with a sample of children aged six – eleven years. (These differences will be discussed in more detail in Chapter 4).

Table 9: Sequence, reproducibility, scalability scores and mean scores for the sub-components of human and animal death.

Human death			Animal death		
Sub-component	**Frequency of participants with complete understanding**	**Mean**	**Sub-component**	**Frequency of participants with complete understanding**	**Mean**
Old age	50	2.29	**Inevitability**	51	2.34
Irreversibility	42	2.12	**Old age**	40	2.01
Inevitability	22	1.81	**Irreversibility**	38	2.04
Causality	14	1.22	**Causality**	21	1.42
Finality	9	0.93	**Finality**	11	1.03
Reproducibility	0.96		**Reproducibility**	0.96	
Scalability	0.59		**Scalability**	0.57	

Note: A score of 0-3 was obtainable for each sub-component

3.3.2 Order of acquisition of the sub-components

In order to investigate whether the sub-components were acquired sequentially or concurrently, further statistical tests were performed. Drawing on Speece and Brent's analysis of sequentiality (1992), the logical basis for inferring the order of acquisition was derived from the four-fold classification of participants according to their understanding of each pair of sub-components as shown in Figure 2. A and B represent the pair of sub-components whose pattern of acquisition is of interest. At any given time, an individual can only be in one of four mutually exclusive and exhaustive states: the participant may understand 1) neither A nor B (NEITHER); 2) A but not B (A-ONLY); 3) B but not A (B-ONLY); or 4) both A and B (BOTH).

Figure 2: The four classifications of understanding two sub-components

		Sub-component A	
		-	+
Sub-component B	-	NEITHER	A-ONLY
	+	B-ONLY	BOTH

A concurrent acquisition pattern may be inferred when both the A-ONLY and B-ONLY cell frequencies are 0 and the NEITHER and BOTH frequencies are greater than 0. This pattern implies that understanding changes from no understanding (NEITHER) to an understanding of both concepts (BOTH) without passing through an intermediate state in which only one or the other is understood.

A sequential acquisition pattern may be inferred when either the A-ONLY or B-ONLY cell frequency is 0 and the other is greater than 0. This pattern implies that understanding changes from no understanding (NEITHER), to understanding one concept (e.g. A-ONLY), to a final phase in which both are understood (BOTH).

Frequency of understanding for each sub-component was analysed using the binomial distribution. Cochran's Q-test and McNemar's test for correlated proportions were performed; these use the chi-square distribution to approximate the exact binomial probability of the hypothesis that p(A-ONLY) = p(B-ONLY). Both tests compare the difficulty of dichotomously scored items; Cochran's Q compares more than two items while McNemar compares two items. In both cases, a significant finding (i.e. rejection of the null hypothesis) implies that the items differ in difficulty.

Cochran's Q was calculated for all five sub-components for both animal and human death firstly. However, this does not give information about pair-wise differences so significant Qs were followed with pair-wise McNemar's in order to determine specific acquisition patterns.

Animal Death

Cochran's Q indicated a significant difference in difficulty between the five sub-components of the concept of animal death, Q (4 d.f., N=74) = 72.028, $p < 0.001$. Figure 3 shows the separate McNemar comparisons used to examine the pair-wise differences between sub-components. The frequencies of the four possible

relationships between each pair of sub-components are contained within each cell. A diagonal line within each cell indicates the crucial frequencies compared in the McNemar test for that cell (i.e. A-ONLY and B-ONLY).

In animal death, old age was easier to understand than causality (χ^2_m [1, N=74] =11.17, p< .001) and finality (χ^2_m [1, N=74] =25.29, p< .001). But was less easily understood than inevitability (Binomial exact test, p< .05) and did not differ significantly from irreversibility (χ^2_m [1, N=74] = 0.03, ns). Irreversibility differed significantly from causality (Binomial exact test, p< .001) and finality (χ^2_m [1, N=74] = 25.04, p< .001) but was significantly less understood than inevitability (χ^2_m [1, N=74] = 4.97, p< .05). Inevitability was significantly better understood than causality (χ^2_m [1, N=74] = 23.36, p< .001) and finality (χ^2_m [1, N=74] = 34.57, p< .001). Finally, causality was significantly better understood than finality (Binomial exact test, p< .05).

In summary, these data suggest that the acquisition of the sub-components of animal death is partially sequential and partially concurrent. Firstly, an understanding of inevitability develops, followed by old age and irreversibility which are acquired concurrently followed by the sequential acquisition of causality and then finality. (If a conservative alpha level of p< .01 is adopted, old age, inevitability and irreversibility appear to be concurrently acquired followed by the concurrent acquisition of causality and finality).

Human death

Cochran's Q indicated a significant difference in difficulty between the five sub-components of the concept of human death, Q (4 d.f., N=74) = 88.89, $p < 0.001$. Figure 4 shows the separate McNemar comparisons used to examine the pair-wise differences between sub-components.

In human death, old age was easier to understand than inevitability (χ^2_m [1, N=74] = 20.25, $p < .001$), causality (χ^2_m [1, N=74] = 32.24, $p < .001$) and finality (χ^2_m [1, N=74] = 35.56, $p < .001$) but did not differ significantly from irreversibility (χ^2_m [1, N=74] = 1.53, ns). Irreversibility was significantly more easily understood than inevitability (χ^2_m [1, N=74] = 12.89, $p < .001$), causality (χ^2_m [1, N=74] = 21.44, $p < .001$) and finality (χ^2_m [1, N=74] = 31.03, $p < .001$). Inevitability was significantly more easily understood than finality (Binomial exact test, $p < .001$) and was also more easily understood than causality but this difference failed to reach significance (Binomial exact test, $p = .07$, ns). Causality and finality in contrast did not differ significantly from each other (Binomial exact test, $p = .23$, ns).

In summary, these data suggest that the acquisition of the sub-components of human death is also partially sequential and partially concurrent. Firstly, an understanding of old age and irreversibility develops concurrently, followed by the sequential acquisition of inevitability, followed by the concurrent acquisition of causality and finality. This pattern is similar to that found in the acquisition of animal death, with one exception that inevitability appears to develop separately at a later stage in human death, in comparison to its earlier concurrent acquisition in animal death. Figure 5 summarises these acquisition sequences.

Figure 3: Pair-wise comparisons of sub-components of animal death

	Old age		**Finality**		**Inevitability**		**Irreversibility**	
	-	+	-	+	-	+	-	+
Causality -	29	24	51	2	20	33	33	20
	***		*		***		***	
Causality +	5	16	12	9	3	18	3	18
Irreversibility -	19	17	36	0	15	21		
	ns		***		*			
Irreversibility +	15	23	27	11	8	30		
Inevitability -	19	4	21	2				
	*		***					
Inevitability +	15	36	42	9				
Finality -	33	30						
	***							
Finality +	1	10						

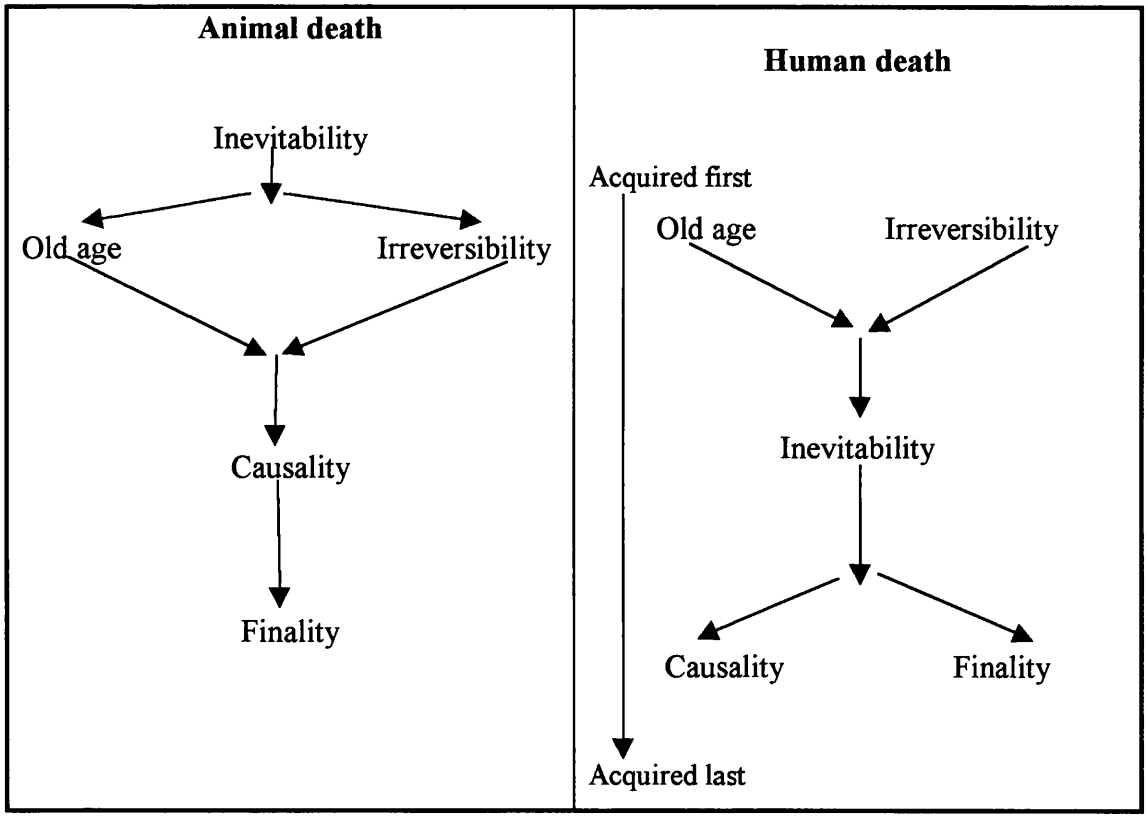
ns = not significant * = $p < 0.05$ *** = $p < 0.001$

Figure 4: Pair-wise comparisons of sub-components of human death

	Old age		**Finality**		**Inevitability**		**Irreversibility**	
	-	+	-	+	-	+	-	+
Causality -	23	37	57	3	48	12	29	31
	***		ns		ns		***	
Causality +	1	13	8	6	4	10	3	11
Irreversibility -	12	20	32	0	28	4		
	ns		***		***			
Irreversibility +	12	30	33	9	24	18		
Inevitability -	20	32	52	0				
	***		***					
Inevitability +	4	18	13	9				
Finality -	22	43						
	***							
Finality +	2	7						

ns = not significant *** = $p < 0.001$

Figure 5: Pattern of acquisition of animal and human death.



Note: If a conservative alpha level ($p < .01$) is adopted, inevitability is acquired concurrently to old age and irreversibility, whilst causality and finality are acquired concurrently in animal death.

3.3.3 Development of finality and causality in relation to inevitability and irreversibility

Lazar and Torney-Purta (1991) suggest that understanding of finality and causality is dependent on understanding of irreversibility and / or inevitability. Figure 6 illustrates the number of participants demonstrating a full understanding of causality according to whether they had mastered inevitability and / or irreversibility. Figure 7 presents a similar frequency table regarding mastery of the sub-component of finality. Diagonal lines indicate the relationship tested by the McNemar test.

Both figures strongly support the hypothesis that an understanding of either inevitability or irreversibility is necessary in order to fully understand causality and finality of animal and human death. In the case of causality, only two participants showed mastery of this sub-component without mastery of either irreversibility or inevitability. The McNemar test was highly significant for both animal (χ^2_m [1, N=74] = 36.03, $p < .001$) and human death (χ^2_m [1, N=74] = 26.69, $p < .001$). In finality, no participant showed mastery of this sub-component without also mastering either irreversibility and / or inevitability, which was also highly significant for both animal (χ^2_m [1, N=74] = 46.02, $p < .001$) and human death (χ^2_m [1, N=74] = 35.03, $p < .001$). These findings support the hypothesis that finality and causality are only acquired after the sub-components of inevitability and / or irreversibility are mastered.

Figure 6: Frequencies of participants demonstrating mastery of causality, according to whether they had mastered inevitability and / or irreversibility.

		Animal causality		**Human causality**	
		-	+	-	+
Inevitability and / or irreversibility	-	15	0	26	2
		***		***	
	+	38	21	34	12

*** = $p < 0.001$

Figure 7: Frequencies of participants demonstrating mastery of finality, according to whether they had mastered inevitability and / or irreversibility.

		Animal finality		**Human finality**	
		-	+	-	+
Inevitability and / or irreversibility	-	15	0	28	0
		***		***	
	+	48	11	37	9

*** = $p < 0.001$

3.4 RESEARCH QUESTION THREE: WITHIN THE SUB-COMPONENT OF FINALITY, IS FINALITY OF EXTERNAL, NON-COGNITIVE FUNCTIONING MORE READILY UNDERSTOOD THAN FINALITY OF INTERNAL, COGNITIVE FUNCTIONING?

Within the sub-component of finality certain researchers (e.g. Hoffman & Strauss, 1985; Orbach et al, 1987) have found that some aspects are more easily understood than others: i.e. that understanding of the finality of external, non-cognitive functions is more readily understood than the finality of internal, cognitive functions.

In the present study, five questions assessed participants' understanding of the finality of non-cognitive external functioning in human death. These questioned whether a dead person could see, hear, move, speak and do the things they did when alive. Three questions assessed participants' understanding of the finality of internal, cognitive aspects of functioning in human death; questioning whether a dead person could know, feel or be sad. Understanding of finality of animal functioning was assessed by two questions about internal, cognitive functions (i.e. knowing and feeling) and three questions about external, non-cognitive functions (i.e. seeing, hearing and moving).

Table 10 depicts the number of participants who correctly answered each of the questions on finality as well as showing how many participants answered more than one question correctly. This table suggests that finality of external functions is more readily understood than finality of internal functions: with 83.8% and 74.3% of

participants understanding at least one question about the finality of external functions in humans and animals respectively, in comparison to 66.2% and 58.1% of participants understanding the finality of internal functions in human and animal death respectively. The statistical significance of this relationship was analysed via McNemar tests.

Figure 8 illustrates the number of participants who correctly answered at least one question about finality of external functions in comparison to those who answered at least one question about finality of internal functions correctly.

The results of the McNemar tests indicate that understanding of the finality of external functions in humans is significantly easier than understanding of finality of internal functions in either human (Binomial Exact test, $p < .001$) or animal death (Binomial Exact test, $p < .001$). Whilst considerably more participants demonstrated understanding of the finality of external functions in animals than demonstrated understanding of finality of internal functions in either human or animal death, comparison of this difference was not significant in the case of finality of human internal functions (Binomial Exact test, $p = .26$, ns) and was only significant at the .05 level in the case of finality of animal internal functions (Binomial Exact test, $p < .05$). There was no significant difference between understanding of finality of external functions in animal and human death (Binomial exact test, $p = 0.07$, ns), nor in understanding of finality of internal functioning in animal and human death (Binomial exact test, $p = 0.24$, ns).

Table 10: Frequency of participants correctly answering questions about finality of internal and external functions in human and animal death

Question	Number of participants answering correctly
Human death	
External functions	
See	25 (33.8%)
Hear	37 (50%)
Move	35 (47.3%)
Do things did when alive	54 (73%)
Speak	56(75.7%)
Understanding finality of at least one external function	62 (83.8%)
Internal functions	
Know	22 (29.7%)
Feel	28 (37.8%)
Be sad	37 (50%)
Understanding finality of at least one internal function	49 (66.2%)
Animal Death	
External functions	
See	33 (44.6%)
Hear	39 (52.7%)
Move	47 (63.5%)
Understanding finality of at least one external function	55 (74.3%)
Internal functions	
Know	22 (29.7%)
Feel	37 (50%)
Understanding finality of at least one internal function	43 (58.1%)

Figure 8: Frequencies of participants demonstrating mastery of at least one question of finality of internal and external functions in human and animal death.

		Understanding of at least one human external finality question		**Understanding of at least one animal external finality question**	
		-	+	-	+
Understanding of at least one human internal finality question	-	12	13	12	13
		***		ns	
	+	0	49	7	42
Understanding of at least one animal internal finality question	-	11	20	15	16
		***		*	
	+	1	42	4	39

ns = not significant * = $p < 0.05$ *** = $p < 0.001$

In summary, these results provide strong evidence for the hypothesis that the finality of external, non-cognitive functioning is more readily understood and sequentially precedes understanding of the finality of internal, cognitive functioning in human death. This pattern is also present in animal death but statistical evidence for this is less conclusive.

3.5 ADDITIONAL FINDINGS

In addition to the main research questions, this study also analysed the relationship between participants' scores on Smilansky's questionnaire and their responses to several fixed-response questions (as presented in Appendix 7). This analysis was two-fold. Firstly, responses to a question about the mutually exclusive nature of 'alive' and 'dead' were compared to scores gained on Smilansky's questionnaire. Secondly, scores for three sub-components of death (as measured by Smilansky's questionnaire) were compared to participants' answers to fixed-response questions addressing the same sub-components.

3.5.1 Awareness of mutually exclusive states of 'dead' and 'alive'.

Participants' awareness of the mutually exclusive states of being dead or alive was assessed by the question, "Can something be dead and alive at the same time?". Forty nine participants (66.2%) answered this question correctly, 20 participants (27%) answered incorrectly and 5 (6.8%) answered that they did not know. Independent sample t-tests showed a significant relationship between awareness of dead and alive as incompatible states and concept of death scores. Participants who showed this awareness had significantly higher total animal death scores ($t = 2.54$,

d.f. 72, $p < .01$), total human death scores ($t = 3.39$, d.f. 72, $p < .001$) and overall concept of death scores ($t = 3.16$, d.f. 72, $p < .01$) than participants who did not show this awareness. Awareness of these states as mutually exclusive was also related to cognitive ability, as measured by the BPVS; with participants who answered correctly having significantly higher BPVS scores than those who answered incorrectly ($t = 2.53$, d.f. 72, $p < .05$). These results indicate that a participant's response to this question provided an indication of their cognitive ability and their understanding of the concept of death.

3.5.2 Comparison of fixed-response and open-ended questions on three sub-components.

Scores for the inevitability, irreversibility and finality sub-components were correlated with the additional questions (adapted from Speece & Brent, 1992) asked on each of these topics. The results are presented in Table 11 and show significant correlations between participants' scores gained on Smilansky's questionnaire and scores gained on the additional, fixed-response questions. This indicates that scores gained via open-ended questions are significantly related to scores gained via fixed-response questions tapping the same sub-components; suggesting that participants' scores on Smilansky's questionnaire are truly representative of their level of understanding.

Table 11: Correlations of scores gained on Smilansky's questionnaire and scores gained on additional, fixed-response questions

Smilansky's scores	Scores for additional questions		
	Inevitability	**Irreversibility**	**Finality**
Sub-component of inevitability	0.58***		
Sub-component of irreversibility		0.69***	
Sub-component of finality			0.51***
Total score for animal death	0.48***	0.46***	0.49***
Total score for human death	0.48***	0.53***	0.55***
Overall concept of death score	0.51***	0.53***	0.56***

*** = $p < .001$

CHAPTER FOUR: DISCUSSION

OVERVIEW

This study examined the relationship between a variety of factors (i.e. cognitive ability, experience of death and demographic characteristics) and understanding of the concept of death in 74 adults with learning disabilities. Information about participants' experience of death and demographic information (such as age, sex and ethnicity) was gained via a questionnaire completed by participants' carers. All participants were interviewed and their performance on a concept of death questionnaire, Piagetian tasks and the British Picture Vocabulary scale was assessed. This provided information about their understanding of death and their cognitive ability. Data was subsequently analysed to examine how the concept of death developed within this population.

This chapter consists of four main sections. Section 4.1 will summarise the main research findings which addressed each research question and section 4.2 will discuss how these findings can be interpreted in light of previous research, both within the learning disabled population and with children. Methodological issues will be addressed in section 4.3 and finally the implications of the findings will be discussed in section 4.4.

4.1 MAIN FINDINGS

4.1.1 Research question one: What variables account for differences in the development of the concept of death in learning disabled adults?.

Cognitive ability, awareness of personal mortality and having seen a dead animal were all important factors in developing a complete understanding of the concept of death. There were no significant differences between participants on the basis of age or sex.

Cognitive ability

More cognitively able participants (as measured by the BPVS) had significantly higher concept of death scores than less able participants. Despite concrete-operational participants having more complete understanding of concept of death than pre-operational participants, the link between Piagetian level and concept of death scores was not statistically significant. Cognitive ability (as measured by the BPVS) was the single most powerful predictive factor in understanding of the concept of animal and human death.

Cognitive ability was also an important factor in comprehension of the causes of death. Participants with lower cognitive ability were significantly more likely to give don't know, incorrect responses or single causes of death in response to questions about animal and human death than more cognitively able participants. Conversely, high ability participants were significantly more likely to report accident or human intention as a cause of death and were more likely to give multiple causes of death for both humans and animals than less cognitively able participants.

Personal mortality

Participants who were aware of personal mortality (i.e. that they would die one day) had a significantly more complete concept of death than participants who were not aware of personal mortality. Awareness of personal mortality was a highly significant predictor of comprehension of both animal and human death. Personal mortality was related to cognitive ability and having seen a dead human: those who were aware of personal mortality were significantly more able and more likely to have seen a dead human than those who were not aware. Other aspects of death-related experience did not influence understanding of personal mortality.

Death-related experience

There was limited evidence of a link between death-related experience and understanding of the concept of death. Participants who reported having seen a dead animal had significantly better understanding of the concept of death than those who had not seen a dead animal. Experience of seeing a dead animal was also a significant predictor of knowledge of animal death and overall concept of death. Within the sub-component of inevitability of human death, having attended a funeral was a significant predictor of understanding. In combination with awareness of personal mortality, it accounted for 58% of the variance in scores on this sub-component: indicating that attending a funeral has a strong influence on awareness of the fact that everyone dies.

However, there was no evidence of other death-related experiences (such as seeing a dead human body, having lost a family member or experiencing a high number of bereavements) influencing comprehension of the concept of death to a significant extent.

4.1.2 Research question two: What is the sequence of acquisition of the sub-components of a mature concept of death in learning disabled adults? Does this resemble the pattern found in the child literature?

Findings of this study indicate that the sequence of acquisition of the five sub-components differs according to object of reference (i.e. human or animal death). The sequence of acquisition found in the present study was inevitability, old age, irreversibility, causality and finality in animal death, whilst for human death the sequence was old age, irreversibility, inevitability, causality and finality. A series of analyses indicated that significantly more participants followed these sequences of acquisition than deviated from them. These sequences differ from those found by Orbach et al., 1987 with a sample of children aged six-eleven years (as presented in Figure 1, Chapter One). In the present study, sequence of animal death acquisition differs greatly to the pattern found by Orbach et al, whilst sequence of human death acquisition differs only in the order of finality and causality. Possible explanations for these differences will be discussed in more detail below.

Further analyses of the sub-components indicated that acquisition of both animal and human death is partially sequential and partially concurrent. In animal death, inevitability is acquired first, followed by the concurrent acquisition of old age and irreversibility and then the sequential acquisition of causality and finality.

In human death, an understanding of old age and irreversibility is acquired concurrently, followed by the sequential acquisition of inevitability, and finally the concurrent acquisition of causality and finality.

The mastery of either inevitability and / or irreversibility was found to sequentially precede the acquisition of both finality and causality. This indicates that full comprehension of either inevitability and / or irreversibility is necessary in order to fully understand the sub-components of finality and causality. This finding is identical to that reported by Lazar and Torney-Purta (1991) in their longitudinal study of six and seven year old children.

4.1.3 Research question three: Is finality of external functioning more readily understood than finality of internal functioning?

This study indicates that the finality of external, non-cognitive functioning is more readily understood by adults with learning disabilities and sequentially precedes understanding of the finality of internal, cognitive functioning in human and animal death.

4.1.4 Additional findings

The addition of fixed-response (yes / no) questions adapted from Speece and Brent (1992) provided useful information about certain aspects of participants' knowledge of death. For example, awareness of 'dead' and 'alive' being mutually exclusive states was strongly related to understanding of concept of death and was also related

to cognitive ability, with participants who answered correctly having significantly higher cognitive ability and better understanding of death than those who answered incorrectly.

Comparison of scores gained for open-ended questions (Smilansky's questionnaire) and fixed-response questions (from Speece & Brent, 1992) on finality, inevitability and irreversibility indicated that both forms of questioning produce similar profiles. This provides evidence for the usefulness of Smilansky's questionnaire with learning disabled adults.

4.2 INTERPRETATION OF FINDINGS

4.2.1 Cognitive ability

The importance of cognitive ability in the comprehension of death is not a surprising finding. Previous studies, both with learning disabled individuals and non-learning disabled children, have consistently found a relationship between cognitive ability, measured in a variety of ways, and understanding of death (Bihm & Elliott, 1982; Speece & Brent, 1984; Sternlicht, 1980). The finding in the present study that cognitive ability, as measured by BPVS, is highly correlated with understanding of the concept of death in adults with learning disabilities therefore confirms that these participants' comprehension of death is directly related to their intellectual ability: i.e. adults who were more able had a better grasp of death and its meaning. This replicates the findings of all previous studies into concept of death in this population (Bihm & Elliott, 1982; Lipe-Goodson & Goebel, 1983; McEvoy, 1989; Myreddi & Narayan, 1993). In addition, it supports Kastenbaum and Aisenberg's (1972)

assertion that understanding of the highly abstract and complex nature of death requires an ability for abstract thought, which is associated with higher levels of intellectual functioning.

However, the failure of this study to replicate previous studies which have found a significant relationship between Piagetian level and knowledge of death is unusual. For example, Bihm and Elliott (1982) found that concrete-operational adults with learning disabilities had a more accurate perception of death than pre-operational adults with learning disabilities. Whilst participants functioning at a concrete-operational level in this study did gain higher scores than pre-operational participants, this difference failed to reach significance. This may have been a consequence of only a small part of this sample (13.5%) passing all four conservation tasks and being classified as concrete-operational. Previous studies tended to have larger proportions of their sample functioning at this level (e.g. 32% of Bihm & Elliott's sample were classified as concrete-operational). Alternatively, lack of a clear differentiation between the abilities of these two groups might be due to the nature of the Piagetian tasks chosen and their limited ability to differentiate individuals according to cognitive ability. Methodological issues arising from the administration of the Piagetian tasks will be discussed in more detail in section 4.3.

4.2.2 Age

No significant relationship between chronological age and comprehension of death was found in the present study. Previous findings on the role of age have been mixed. Certain researchers (Bihm & Elliott, 1982; McEvoy, 1989) have reported no evidence of a link between age and comprehension of death in adults with learning

disabilities, whilst others (Lipe-Goodson & Goebel, 1983) have found a significant effect of age on the understanding of death, with older participants demonstrating more complete understanding than younger participants. The present study refutes the relationship between age and concept of death. In fact, although not statistically significant, when participants were divided along the median for age, younger participants demonstrated a better understanding of death than the older participants. This finding therefore contradicts Lipe-Goodson and Goebel's discovery that life experiences acquired as a consequence of ageing enhance understanding of death. However it does support Bihm and Elliott's assertion that cognitive level is a much better indicator of an understanding of death in learning disabled adults than is chronological age.

Age has been consistently related to understanding of death in the child population, with older children demonstrating better knowledge of death than younger children. In non-learning disabled children, both mental age and experience tend to increase proportionally with chronological age whereas in the learning disabled population these relationships do not hold (Lipe-Goodson & Goebel, 1983). This might explain why age is a less significant factor in the development of the concept of death among the learning disabled than is cognitive functioning level.

4.2.3 Causes of death

Cognitive ability also played an important role in comprehension of the causes of death, with high ability participants (when divided along the median BPVS score) more likely to give multiple causes of death, more likely to report accident or human intention as a cause of death and significantly less likely to give don't know or

incorrect answers than lower ability participants. This partially supports Myreddi and Narayan's (1992) findings. They found that more able individuals demonstrated better understanding of the range of causes of death, gave more abstract explanations of death and were significantly less likely to give don't know responses than less able participants. This has been replicated in the present study.

However, Myreddi and Narayan also reported that less able participants cited accident and human intention as causes of death more frequently than higher ability participants. They related this to the assassination of Mr. Rajiv Gandhi during their data collection, which received widespread media coverage and argued that the increased citing of accident and human intention by less able individuals was a reflection of their more concrete reliance on media coverage of death. This is contrary to the present study which found significantly more reports of accident and human intention in participants with higher cognitive ability than in those with lower ability.

Data collection for the present study began shortly after the accidental death of Princess Diana, another high media coverage event. Comparison of the frequency of accidents being reported as a cause of death in the present study and Myreddi and Narayan's study (19% and 35% respectively) reveal a significantly increased rate of reporting in both studies in comparison to McEvoy's (1989) study (3% of reports cited accident as a cause of death). Whilst this does indicate a higher rate of reporting which could reflect the influence of media coverage, the significantly larger proportion of high ability individuals citing accident as a cause of death contradicts

Myreddi and Narayan's hypothesis that less able participants showed a more concrete reliance on media coverage of death.

Illness was the most frequently reported cause of death both in this study and in McEvoy's (1989) research (with illness being cited as a cause of death in 48% and 55% of all responses in the two studies respectively). McEvoy argued that this reflected a poor understanding of the ageing process and the biological inevitability of death. In the present study, significant differences in participants' comprehension of the sub-components of old age (i.e. awareness that everyone gets old) and causality (which required citing of old age as a cause of death in order to gain full marks) indicate that whilst many adults with learning disabilities acknowledge that everyone gets old, they are less likely to comprehend that old age is an important cause of death. This supports McEvoy's hypothesis that this population have a limited understanding of the fact that death is an internal biological process that operates according to natural laws.

4.2.4 Personal mortality

Awareness of personal mortality and concept of death development has been examined in several previous studies and has been linked to a better comprehension of death in people with learning disabilities (McEvoy, 1989); a finding which was replicated in the present study. It has also been related to both level of cognitive development and to death related experience. Previous research indicates that concrete-operational participants and those who had experienced the death of a significant other were significantly more likely to be aware of personal mortality

than pre-operational participants or those who had not experienced a significant bereavement (Bihm & Elliott,1982; Reilly et al., 1983; White et al., 1978).

The present study has also found a clear relationship between personal mortality, cognitive ability and death-related experience, with participants who demonstrated awareness of personal mortality being significantly more cognitively able and more likely to have seen a dead human than those who did not demonstrate this awareness. It failed to find a link between personal mortality and either Piagetian level of development or experience of family bereavement. However, this may have been due either to the small number of participants who were classified as concrete-operational or a consequence of gathering data about death-related experiences from carers. This issue will be discussed in more detail in section 4.3.

4.2.5 Death-related experience

In the present study, evidence of a relationship between death-related experience and understanding of death was present but limited. Past research in the child literature on this topic has produced mixed results, with several researchers arguing that death experience does influence development of the concept of death (Derry, 1979; Kane, 1979; Reilly et al., 1983), whilst others argue that it does not (Jenkins & Cavanaugh, 1985; Mahon, 1993; Tallmer et al., 1974). Unfortunately studies within the learning disabled population have provided minimal information on this subject. Only two studies have examined the impact of death-related experience in adults with learning disabilities; neither discuss how the relationship was analysed and they report contradictory findings (McEvoy, 1989; Myreddi & Narayan, 1993).

This study found that certain death-related experiences did influence participants' knowledge about death (i.e. having seen a dead animal and having attended a funeral were significant predictors of a more mature understanding of animal death and the inevitability of human death). This suggests that having seen a dead animal or attended a funeral were important factors in influencing participants' understanding of death: a finding which supports the link between experience of death and its understanding. No other death-related experiences were found to influence comprehension of death to a significant extent. It is unclear whether this is a true reflection of their limited impact on participants' understanding or whether collecting data on death experience from carers was an unreliable method of obtaining this information. It is probable that data on whether participants had seen a dead animal or attended a funeral was more accurate as this was collected from participants during interviews either in response to a specific question or if discussed spontaneously by the participant.

4.2.6 Acquisition of the sub-components

Several researchers have examined the order in which the sub-components of the concept of death are acquired in children but no study has yet looked at this sequence in adults with learning disabilities. Findings of the present study can therefore only be compared with studies involving children.

This study looked at three aspects of the acquisition sequence of the sub-components of death. Firstly, the order of acquisition found was tested for scalability and was found to be significant. This indicated that the observed sequence formed a meaningful scale, with more participants adhering to this sequence than deviating

from it. Secondly the exact inter-relationship between sub-components was investigated and patterns of sequential and concurrent acquisition were found; indicating that mastery of the sub-components follows a specific developmental pattern. Finally, the sub-component of finality was examined in more detail and it was found that finality of external, non-cognitive aspects of functioning was understood more readily than finality of internal, cognitive aspects of functioning in this population.

These findings were presented in Figure 5 (Chapter Three) and can be summarised as follows. For animal death, inevitability is understood most readily, followed by the concurrent acquisition of old age and irreversibility, finally the sub-components of causality and finality are acquired sequentially. For human death, old age and irreversibility are concurrently acquired and most easily understood, followed by the sequential acquisition of inevitability and lastly the concurrent acquisition of causality and finality. For both animal and human death, the finality of external functioning is more readily understood than the finality of internal functioning.

The pattern of acquisition found in this study is similar to that found in previous research with children in a number of ways. Firstly, in human death, the sequence of acquisition is identical to that found by Orbach et al. (1987; presented in Figure 1) with the exception of finality and causality which are in the reverse order. Secondly, in all previous studies which analysed the order of acquisition, inevitability and irreversibility preceded the development of causality and finality (Hoffman & Strauss, 1985; Lazar & Torney-Purta, 1991; Orbach et al., 1987; Speece & Brent, 1992). This is also true of the present study. Thirdly, the present study has replicated

Lazar and Torney-Purta's (1991) finding that full comprehension of either inevitability and / or irreversibility is necessary in order to fully understand the sub-components of finality and causality. Finally, research suggests that in children, finality of external aspects of functioning is more readily understood than finality of internal aspects of functioning (Hoffman & Strauss, 1985; Kane, 1979; Orbach et al., 1987). This pattern was also present within this learning disabled population.

Comparison of the present study and previous findings in the child literature reveal two minor differences. Firstly, the pattern of acquisition of the sub-components of animal death did differ from those found by Orbach et al. (1987). Some of this difference might be explained by the fact that, unlike Orbach et al.'s study, the present study did not control for order effects when administering the questions. As a result, questions about animal death were always preceded by questions about human death. Considering the repetitive nature of the questions it is possible that participants were becoming tired by the end of the interview and therefore may not have answered the questions about animal death as accurately as those about human death. This could account for the variation between Orbach's finding and the results of the present study.

Secondly, certain studies have found a better understanding of human than animal death in children of all ages on Smilansky's questionnaire (Orbach et al., 1985; Smilansky, 1981). Whilst others have failed to find a difference between children's understanding of animal and human death (Hoffman & Strauss, 1985). In the present study, irreversibility and old age gained higher mean scores for human than animal death, whilst inevitability, causality and finality gained higher mean scores for

animal than human death. However, this difference was only significant for inevitability. This could be explained either by the fact that adults with learning disabilities probably have had more experience of animal than human death and therefore are more easily able to learn that all animals eventually die (Lazar & Torney-Purta, 1991). Alternatively, acknowledging the inevitability of animal death may be less anxiety-provoking than acknowledging the inevitability of human death and therefore is less likely to be distorted (Orbach et al., 1994; Yalom, 1980). Finally the potential effects of practice might account for differences between animal and human scores. This study provides no evidence for the hypothesis that within the learning disabled population understanding of animal death is developed chronologically later than human death.

The developmental sequence for animal and human death found in the present study adheres to Orbach et al.'s (1987) finding that the sub-components form a continuum with observable phenomena being more readily understood than hypothetical phenomena. In human death, this sequence of acquisition starts with old age and irreversibility which are understood concurrently, followed by the understanding of inevitability and then the concurrent acquisition of causality and finality of external functions and lastly the understanding of the finality of internal functions.

It could be argued that old age (especially in humans) is observable and therefore easily understood even by adults with limited cognitive ability. Irreversibility is also fairly easy to understand because through experience, individuals learn that when someone dies they do not come back, however much the individual might want them to. An understanding of inevitability is more difficult (especially in human death

because of the anxiety provoked) as it is not readily observable. Experience (such as attending a funeral) or the ability to make inferences may be necessary to help individuals understand this sub-component. This might explain why a higher level of cognitive ability is necessary to understand inevitability than old age and irreversibility which are more observable.

Causality and finality of external functioning are the next sub-components to be acquired. Mastery of the sub-component of causality requires an understanding of biology and an ability to make inferences about internal bodily functions and life processes. This is obviously more difficult for the individual to comprehend and therefore requires a higher level of cognitive ability than the previous sub-components. Mastery of the sub-component of finality requires an understanding of the nature of death itself (i.e. that all life activities [both observable and unobservable] cease at death). The cessation of aspects of functioning which are observable (e.g. immobility) are more easily understood than those aspects of functioning which are unobservable (e.g. lack of awareness or feeling). Orbach et al. (1987) argue that it is difficult to relate the absence or cessation of these higher functions in the dead, as they were unobservable even when the person was alive. The mastery of finality of internal functioning is therefore the last and most difficult aspect of human death to understand.

Animal death forms a similar continuum with inevitability being understood first and then old age and irreversibility concurrently, followed sequentially by causality, finality of external functions and finality of internal functions. There are two major differences between acquisition of animal and human death. Firstly, understanding of

inevitability is acquired at an earlier stage in animal than human death. This may be explained by Yalom's (1980) theory that inevitability of animal death is less anxiety-provoking than human death and acknowledgement is therefore less likely to be distorted. Alternatively it could be a consequence of the order effects of animal questions always being asked after the questions about human death.

Secondly, old age is less well understood in animal than human death. This finding can be explained in terms of the observable-hypothetical principle (Orbach et al, 1987), in that signs of old age in many animals are less observable than signs of old age in humans. Few signs distinguish old and young animals and understanding that animals grow old requires more information and cognitive ability than understanding that humans grow old. The sub-component of old age in animals is therefore more difficult to understand than old age in humans.

To summarise, the findings of the present study strongly support the hypothesis that the order of acquisition of the sub-components of the concept of death is similar in children and learning disabled adults. As with children, this developmental sequence appears to form a continuum that starts with observable phenomena and ends with more hypothetical phenomena (Orbach et al., 1987). In addition, a complete understanding of either inevitability and / or irreversibility is necessary before individuals can master the sub-components of finality and causality.

4.3 METHODOLOGICAL ISSUES

Several factors must be borne in mind when considering the findings of the present study. These include the difficulties inherent in interviewing this population, the measurement tools utilised, the interview procedure and issues arising from recruitment and data collection. Each of these factors will be considered in turn.

4.3.1 Difficulties present in interviewing learning disabled population

Research suggests that it can not be assumed that what learning disabled persons say in response to questions is necessarily valid. Literature on survey research suggests that obtaining valid information from anyone is troublesome. Gaining valid information from learning disabled adults, who almost by definition have difficulty with receptive and expressive communication is likely to be even more problematic. Both the ability to answer interview questions and the ability to convey information accurately through one's answers are a function of intelligence. The literature suggests that there are several common obstacles to response validity when people with learning disabilities are interviewed (Lenski & Leggett, 1960; Wells, 1963; Rosen, Floor & Zisfein, 1974; Sigelman, Budd, Sphanel & Schoenrock, 1981a).

The seminal work of Sigelman and her colleagues (1980, 1981a, 1981b and 1982) underlines some of the difficulties associated with interviewing adults who are learning disabled. They compared different methods of interviewing this population in terms of responsiveness, agreement with informants and freedom from systematic response bias and found that the ability to respond to questions is influenced by the type of questioning. They report that open-ended questions, although preferable on the grounds of validity, were unanswerable by many persons. Yes/no questions

enhanced responsiveness but introduced serious acquiescence bias (i.e. the tendency to respond affirmatively regardless of a question's content), especially in individuals with lower IQs and therefore often yield invalid answers. Verbal either/or questions are slightly more difficult to answer but yield more valid responses. The major limitation of verbal either / or responses appears to be their tendency to generate a small bias towards the last option named. The addition of pictorial either / or questions eliminates this small last-option bias and were easier to answer. Such questions can be answered non-verbally and possibly reduce the need to rely on short-term memory to retain both of the response options in mind. Multiple choice questions, particularly with pictures, yielded valid answers from a high proportion of interviewees.

Sigelman et al. (1982) conclude that the validity of answers given by the learning disabled population can never be assumed. They suggest that information must be asked for in different ways to determine whether answers are consistent with each other and what, if any, systematic biases are operating. Where possible, answers from this population might be compared with independently obtained information from informants, files or observations.

An awareness of the methodological problems of interviewing people with learning disabilities is important when considering the findings of this study. In the present study, a variety of types of questioning were used. Any methodological considerations arising from the use of these questioning techniques will be discussed more fully in Section 4.3.2 when each measure is summarised.

Flynn's (1986) study identifies the need to see people in their own environments and for the collection of data to be performed in a manner which is as relaxed, informal and least threatening as possible. Card (1983) found that adults interviewed in the presence of their families offered contrasting views when interviewed privately. This highlights the importance of conducting interviews in private. The present study involved the private interview of individuals in their home, day centre or work place. Thus the individual was given every opportunity to feel more comfortable and therefore responses should have been more accurate than if the participants were interviewed in an unfamiliar place with others present.

4.3.2 Measures used

Concept of death

Smilansky's death concept questionnaire was the primary method of measuring participants' concept of death. Whilst this is a well standardised questionnaire and has been frequently used with children of all ages, it should be treated with some caution. A weakness of this questionnaire is that the number of questions used to assess each sub-component is quite variable: causality, inevitability and old age are all assessed by a participants' response to one question, whilst irreversibility is assessed by two items and finality by five items. In order to achieve full marks for the finality sub-component, participants had to provide five correct answers and five correct explanations. The present study found that only a small proportion of participants demonstrated mastery of finality and it could be argued that the scoring criteria might have influenced the proportion of participants who scored full marks on this sub-component. Whilst this might have influenced participants' scores for

finality, it is important to note that previous studies (including those which employed different measures of death concept) have all found that finality is one of the most difficult sub-components to understand. This finding is therefore consistent with what has been reported in previous research; indicating that finality has been measured accurately, despite the relatively high number of questions asked about this sub-component.

Despite variability in the number of items assessing each sub-component, two additional factors suggest good reliability and validity of the measure. Firstly, the scoring of the Smilansky Death Concept questionnaire is predominantly based on conceptual sophistication of explanation; merely answering questions right or wrong does not yield credit. This meant that participants who correctly answered the fixed-response part of a question but failed to provide an adequate explanation for their response did not demonstrate a full understanding and their score reflected this. Participants who guessed the correct response would therefore be penalised for failing to provide a correct explanation for their response, which reduced the likelihood of correct answers gained by chance which could have resulted in unrealistically high scores for participants. The use of yes / no questions and open-ended questions in combination is a strength of Smilansky's questionnaire as this allows many participants to answer the questions while also reducing the possibility of acquiescence present in the use of only yes / no questions (Sigelman et al., 1982). A high inter-rater reliability also indicates that Smilansky's scoring criteria are clear and scores are easily replicated by independent raters.

Secondly, significant correlations were found between Smilansky's scores for the sub-components of irreversibility, inevitability and finality and participants' answers to fixed-response questions on these topics. This indicates that scores gained on Smilansky's questionnaire, which required both fixed-response and open-ended answers, were significantly related to the number of correct answers given to fixed-response questions on the same topic. This provides support for the validity of scores obtained from Smilansky's questionnaire.

Another potential criticism of death concept questionnaires is that the use of total death concept scores might be seen to be misleading since the sub-components can be seen to have different weights. Not to be fully conversant with the appearance of a corpse, for example, is perhaps less important in every day terms than not comprehending the inevitability of death. In order to address this criticism, in the present study participants' awareness of death was examined both as a consequence of their understanding of the sub-components and also as an overall concept of death score. This enabled both general comments to be made as well as more specific examination of how understanding of the sub-components was inter-related.

Piagetian Tasks

Piagetian tasks were included as a measure of cognitive ability in order to allow comparison with previous studies which have employed these tasks. As Mahon (1993) pointed out, when using a Piagetian model to assess a child's cognitive level, scoring is usually at the nominal level of pre-operational, concrete-operational or formal-operational categories. This was true of the present study. However, it has been suggested that this scoring does not reflect true developmental progression

(Vaidya & Chansky, 1980). For example it is universally recognised that an accurate understanding of death is acquired gradually rather than as a single step from not understanding to accurate understanding. Therefore, performance on the Piagetian tasks was also scored as interval level data (i.e. the number of tasks answered correctly which therefore manifested concrete-operational thought). Previous research strongly indicates a relationship between understanding of death and both Piagetian level and number of Piagetian tasks completed. Unfortunately, the present study failed to replicate this finding. This suggests that the use of Piagetian tasks was a less useful measure of cognitive ability than the BPVS which was also administered.

Possible reasons for the absence of any relationship between cognitive ability as measured by Piagetian tasks and concept of death include the small number of participants who were classified as concrete-operational. In addition to this, the Piagetian tasks were administered as suggested by previous literature (Ginsburg & Opper, 1988; Phillips,1969). This meant that tasks were presented as a choice of two possible responses, with the incorrect response always presented after the correct response. It is difficult to estimate how many participants might have been influenced by the sequence in which these options were presented but Sigelman et al. (1981b) report a bias in verbal either / or questions towards choosing the last option regardless of its content. In addition to this, research suggests that the performance of cognitively limited children on Piagetian tasks can be dramatically affected by question wording (Estes, 1979; Rothenberg, 1969). Future research might benefit from alternating the order in which responses are presented or from the use of alternative questioning techniques such as multiple choice questions or the

introduction of pictorial either / or questions which eliminates the last-option response bias present in verbal either / or questions (Sigelman et al., 1981b).

British Picture Vocabulary Scale (BPVS)

The BPVS appears to be a useful measure of verbal ability in adults with learning disabilities. Its format consisted of pictorial multiple choice response to a verbally presented word. Methodologically this is an accurate method of collecting data from people with learning disabilities as it employs the use of both multiple choice presentation and pictorial cues, thereby reducing the participants' reliance on short-term memory (Sigelman et al., 1982). This indicates that it provides a useful method of gathering information about the verbal ability of people with learning disabilities.

In this study, the BPVS provided strong evidence of a link between cognitive ability and understanding of concept of death. However, as Lansdown and Benjamin (1985) point out, it could be argued that there is some circularity arising from the observed association in studies between vocabulary and death concept score since the method of eliciting the concept was verbal, and verbally able individuals revealed a fuller understanding. They are therefore suggesting that any relationship between cognitive ability and concept of death understanding is an artefact of using measures which both rely on verbal ability.

Whilst this is obviously one possible explanation for these findings, the literature consistently reports a positive correlation between knowledge of the concept of death and cognitive ability as measured by a variety of methods other than vocabulary tests (Lipe-Goodson & Goebel, 1983; McEvoy, 1989). This therefore suggests that any

relationship is real and not just an artefact of the measures used. In order to disprove this alternative explanation completely, non-verbal measures of the concept of death and / or cognitive ability would need to be employed within the same study. No study has employed this methodology to date.

4.3.3 Generalisability of findings

The method of recruitment might have implications for how representative this sample was of the learning disabled population. Ethical considerations meant that the researcher was not permitted to approach individuals directly to discuss whether they wished to participate in this study. Instead, carers and staff at residential homes and day centres were approached initially and asked to discuss the study with any individuals who might be willing to participate. In effect, the carers initially chose which individuals to approach, thus directly influencing the sample. Participants were often approached by carers because they had experienced a bereavement and / or had difficulties in adapting to a bereavement. This meant that participants who had little or no experience of death were under-represented in this sample. This has obvious implications for the generalisability of these findings to the wider learning disabled population. Any technique which reduced this bias in sampling would obviously be beneficial in future research.

This method of recruitment also had implications for comparing comprehension of death in adults from different ethnic groups and with different religions. As participants were not recruited directly by the researcher it was difficult to recruit sufficient numbers of participants from differing ethnic groups and with varying religious affiliations. This meant no meaningful analysis of these variables was

possible. Due to the potential impact of these variables on comprehension of death, future research which aimed to recruit and compare an equal number of individuals from certain specific ethnic groups or religions would be useful.

4.3.4 Method of data collection

Data for this study was gathered by means of an interview with the individual and a questionnaire completed by the carer. There are a number of implications about these methods of data gathering.

Firstly, relying on carers to provide information about participants' experience of death may not be the most reliable method of data gathering. Some carers specified that they had minimal knowledge about the participant and information gathered from carers was also contradicted during interviews with the participants themselves. This suggests that death-related experience data may have been inaccurate.

Increasing the accuracy of this information might have revealed more detailed information about the relationship between death-related experience and understanding of the concept of death. Unfortunately, within many learning disability settings, high staff turn-over and poor long term record-keeping pose inherent difficulties in collecting this type of information. Time constraints on the present study restricted the collection of this information from other sources. However, information gathered from a wider variety of sources (including family, written records and more than one carer or staff member) might increase the reliability of this information in future studies.

Secondly, the method of acquiring information about understanding of death required the participant to be able to respond verbally to questions. This therefore restricts the pool of potential participants to those with milder learning disabilities and without additional physical and / or sensory impairments. This obviously limits the generalisability of these findings to individuals with more severe learning disabilities who are not verbal. The ability for people in the severe and profound range of learning disability to respond to simple verbal questions is suspect (Sigelman et al.,1980). This finding points to the need for alternative behavioural and non-verbal data collection techniques. Alternative methods of collecting this data (e.g. the use of visual aids or pictures) might enable future researchers to examine if differences exist between these more severely impaired individuals and those in the present study.

Thirdly, within each interview the procedure was identical for each participant. That is, each participant was assessed on the BPVS firstly, followed by the Piagetian tasks and finally the concept of death questionnaire (human and animal death questions respectively). Cognitive ability tests were designated to precede the concept of death questionnaire to allow the participant to feel more at ease, to 'break the ice' and to allow the researcher to gauge the participant's mood and develop a rapport before questioning them about death. To have begun the interview with questions about death could have been more anxiety-provoking for participants and the researcher felt that this might have resulted in more participants failing to complete the interview. The concept of death questionnaire was administered as specified by Smilansky (i.e. human death questions preceding animal death questions). However, other researchers have alternated these questions to counteract any practice or

sequence effects (Orbach et al., 1987). In light of apparent differences between understanding of animal and human death in the present study, ensuring that half of the sample answered questions about animal death first, whilst the other half answered about human death first, might have allowed order effects to be ruled out.

4 .4 IMPLICATIONS OF FINDINGS

4.4.1 Research implications

This study has several implications for future research into how adults with learning disabilities understand the concept of death. Firstly, it has provided good evidence that adults with learning disabilities are both able and willing to discuss this neglected topic. Secondly, it indicates that Smilansky's questionnaire provides a reliable and useful measurement tool for use with this population. Finally it challenges the belief that a Piagetian approach is the most useful manner of conceptualising the development of knowledge about death in adults with learning disabilities. These implications will all be discussed in more detail below.

Impact of research into death in learning disabled population

It has been suggested that some people with learning disabilities use magical thinking and are reluctant to talk about the dead for fear of bringing them back or causing them distress (Turner & Graffam, 1987). It would appear that not all individuals fear this. Bihm & Elliott (1982) reported that none of the people they interviewed were upset by the topic. The authors commented that this may be due to the structured nature of the interview which assessed comprehension of death only and did not address emotional concerns directly. French & Kuczaj (1992) found

during a two day workshop for clients who had recently suffered a major change or loss that they were very keen to talk in depth about death and what this meant to them.

Evidence from this present study supports Cathcart's assertion (1995) that people with learning disabilities find talking about death no less, but no more, difficult than other people. All 74 participants who completed the interview willingly answered the questions and many openly discussed their own experiences of death. Examination of changes in mood rating during the course of the interview indicate that 73% of participants rated their mood as the same or more happy by the end of the interview. This is consistent with the majority of participants reporting having enjoyed participating and appreciating the opportunity to discuss their own experiences of bereavement. It would appear therefore that most participants experienced some benefit and no significant detriment as a consequence of answering these questions. This suggests that future research into this topic would be of benefit to both the individuals involved and to the minimal body of death-related research within the learning disabled population.

Utility of Smilansky's death concept questionnaire

The present study has also demonstrated the potential efficacy of using Smilansky's death concept questionnaire as a measurement tool with learning disabled adults. The questions were simply-worded and responded to appropriately by the majority of participants. Similarities between the development of the concept of death in children and adults with learning disabilities also justifies the use of a measure from the child literature which will allow further comparisons with previous studies with children.

This questionnaire might also benefit from some additional fixed-response questions (e.g. questions assessing awareness of personal mortality and the mutually exclusive nature of alive and dead) as these have been of particular significance in the present study.

Smilansky's questionnaire may only be of use with those individuals who are relatively able and also verbal. Within this group, there was still some evidence of questions being misunderstood. For example, some of the questions elicited totally incorrect or irrelevant answers from certain participants which highlighted the difficulties inherent in this type of research. One major difficulty relates to the language and comprehension ability of the learning disabled population. This study (as well as previous studies with this population, such as McEvoy, 1989) has demonstrated the efficacy of open-ended questions when interviewing, but the danger of inadequate and irrelevant answers remains. The development and introduction of additional data gathering techniques, e.g. the use of pictures and multiple choice questions, might benefit future research into this subject. This would mean that data from a number of sources could be used to build up a picture of adults' perceptions (Flynn, 1986).

In addition to comparisons with the child population, future research could also examine the responses of non-learning disabled adults to Smilansky's questionnaire, thus allowing comparison between the learning disabled and non-learning disabled adult populations. This is important in light of Brent and Speece's (1993) finding that adults as a group perform less well to the presumed adult standard than did a group of children. An adult comprehension of death is therefore complex and more

thorough research into this population would be necessary before making firm comparisons or conclusions about differences between non-learning disabled and learning disabled adults.

Piagetian framework for comprehension of death

The present study failed to find a significant link between cognitive ability, as indicated by Piagetian level, and comprehension of death. This replicates previous studies which have questioned the usefulness of a Piagetian framework when explaining how adults with learning disabilities conceptualise death. For example, some of the anecdotal information about death and its consequences verbalised by very cognitively limited adults in Harper and Wadsworth's (1993) study raised fundamental questions about whether the models of cognitive development based upon a Piagetian framework provide the best explanation of what these older adults actually know and use to cope with their losses.

Harper and Wadsworth found that several adults with "very low tested IQs" (low moderate to severe learning disability) seemed to be able to accurately understand and express conceptual issues (death finality and inevitability) despite operating at a pre-operational level. The present study also supported this finding, with many pre-operational participants exhibiting a relatively mature comprehension of death.

According to Gampel (1990), there are two major theories of cognitive development; the developmental position which asserts that persons with and without learning disabilities of similar mental age show similar cognitive patterns and the difference hypothesis which indicates that there is a difference in these patterns. These theories

have generally been tested using Piagetian tasks because these are viewed as a direct measure of cognitive abilities and Hore & Tryon (1989) report that the preponderance of evidence supports the developmental position.

However the use of Piagetian tasks is based on two assumptions (Gampel, 1990). Firstly, that developmental tasks follow an invariant sequence based on actual physical change in mental structures that is genetically determined and therefore unaffected by training or environment. Secondly, that there must be a specific time for transition among individuals without learning disabilities. Gampel argues that these assumptions are not necessarily true of persons with learning disabilities. He is supported by research which indicates that training and environmental factors can influence the development of cognitive structures (Barratt, 1975; Bruner, Oliver & Greenfield, 1966) and findings that large numbers of individuals do not achieve the stage of development expected based solely on their mental or chronological age (Renner et al, 1976; Gelman & Baillargeon, 1983; Weithorn & Campbell, 1982). This research provides more support for the assertion that the use of Piagetian tasks and a Piagetian framework might not be the most useful approach to understanding the cognitive development of persons with learning disabilities.

Several other developmental psychologists have challenged the Piagetian tradition (Eiser,1989; Nelson & Gurendel, 1986) and have proposed alternative models for cognitive development. These alternative models suggest that children and adults structure information similarly where degree of experience is equivalent. This newer theory of cognitive development might have implications for individuals with a learning disability. For example, adults who have had experience with death and

funerals may accumulate knowledge "scripts" (Nelson & Gurendel, 1986) beyond what older cognitive theories would suggest. As Harper and Wadsworth point out, this possibility remains speculative but intriguing.

The present study would provide some support for the view that certain death-related experiences (such as seeing a dead animal and attending a funeral) do influence an individual's understanding of certain aspects of death. If the theory of knowledge "scripts" is applicable, individuals with learning disabilities may acquire a better understanding of certain sub-components than one would assume based solely on cognitive ability. These scripts therefore may be tapped to enable us to assist those with learning disabilities more than we would traditionally expect. Future research which more clearly delineates the impact of death-related experience on comprehension of death could provide more information about how knowledge scripts may influence understanding of death. For example, comparison of equal groups of adults with learning disabilities who had and had not experienced a number of death-related events would be a useful starting point.

4.4.2 Clinical implications

This study has implications for both direct work with adults with learning disabilities and for indirect work with staff members and organisations. These implications will be discussed separately below.

Implications for direct work

This study has implications for working directly with adults with learning disabilities, either individually or in groups. It has demonstrated the efficacy of using Smilansky's questionnaire as a measure of comprehension of death. As Cathcart (1995) comments there is no report in the literature of a therapist using the client's understanding of the sub-components of the concept of death in a clinical setting. Assessing a client's understanding of these could provide useful information when planning a treatment intervention (Cathcart, 1994). Therefore, if a client presented with difficulties adapting to a bereavement, knowledge of what they understood about death could be useful for pinpointing incorrect or unhelpful beliefs. If deficits in their understanding were identified, the therapist could adopt a more educational approach and discuss these issues with the client.

Previous studies indicate that an incomplete understanding of death might adversely influence the grieving process. McLoughlin (1986) suggested that in adults with a learning disability, depending upon degree of ability, there is a varying impairment in the ability to formulate abstract concepts and it therefore seems likely that the ability to understand the concept of death will affect the grieving process. He argues that work carried out with children provides evidence for a relationship between conceptual ability and the ability to work through a normal mourning process. Research carried out with non-learning disabled children where there is an impending death in the family suggests that the group most vulnerable to anxiety and maladaptive reactions is the pre-adolescent (10-12 years), to a lesser degree younger children (6-9 years) and least adolescents (15-16 years) (Rosenheim & Reicher, 1985). McLoughlin relates this finding to the child's level of comprehension of

death. The pre-adolescent conceives the full meaning of death but is not equipped with the ego strength to cope with it emotionally. Younger children's incomplete understanding of death and its finality afforded them some protection whilst adolescents demonstrated the ability to go through a mature mourning reaction. He related this model to adults with learning disabilities and argued that those with a more sophisticated concept of death may be better equipped to work through the normal grieving process, while those with a vague concept may be more vulnerable and less able to resolve their grief. This supports the view that an incomplete understanding of death can adversely affect the process of mourning in the learning disabled population.

The actual implications of an incomplete understanding of death on the grieving process were highlighted in Table 1 (Chapter one). An example might be that a client does not understand the irreversibility of death and therefore expects the deceased to return. This can cause difficulties as it may prevent the client from detaching personal ties to the deceased and therefore prevents them from reinvesting their emotional energy in another relationship. Worden (1991) argues that this is an important task of mourning. An intervention which focused on the irreversibility of death for all forms of life might enable the client to accept that the deceased would not return and so aid the mourning process.

Awareness of how a client understands death is therefore potentially useful in identifying clients who might benefit from a more educational intervention. Information about death could then be discussed either on an individual or group basis. This study has also found that development of the concept of death is similar

in children and learning disabled adults. This indicates that resources which are beneficial with children might be adapted for use with the learning disabled population.

The child literature provides evidence for the efficacy of formal death education in enhancing an individual's understanding of the concept of death. For example, Schonfeld and Kappelman (1990) report significant gains in comprehension of death as a result of six thirty-minute presentations (audio-visual and books) on death. As this study indicates that development of death concept is similar in children and the learning disabled population, it could be hypothesised that individuals with learning disabilities might also benefit from specific education on death.

In fact some research indicates that people with learning disabilities can benefit from death education. Working with older adults with learning disabilities, Hedger and Smith (1993) used the life cycles of plants and animals to address four issues: that all persons and things change with age; everything in life is part of a continuous cycle; all living things and persons die; and after death the life cycle begins again. As Erikson (1980) points out the primary developmental task of all ageing persons is to confront and accept the irreversibility of the death experience. Hedger and Smith report that their education enabled individuals to understand the changes that occur in their environment as a result of the death of friends, relatives or caregivers. They argue that this understanding improves an individual's quality of life by allowing them to express their loss personally.

Kloeppel and Hollins (1989) also found that death education using human, plant and animal life cycles was effective for people with limited cognitive skills. These studies therefore provide evidence for the usefulness of informal death education with persons with learning disabilities and comparisons with the child literature also indicates the role of more formal, structured death education. This education could be on either an individual or group basis and could make use of teaching resources designed for adults with learning disabilities (such as "When Dad Died", Hollins & Sireling, 1991). If used pro-actively this intervention might enable individuals to understand more about death, thus reducing the likelihood of future bereavement difficulties.

Implications for indirect work in learning disability settings

The current findings have a number of implications for working indirectly with adults with learning disabilities.

The present study's finding that certain death-related experiences can enhance an individual's understanding of death has obvious implications for clinical practice. Dissemination of this knowledge to other professionals who work with people with learning disabilities (via consultation or staff training) is important in order to influence their day-to-day practice. There are a number of ways of increasing an individual's experience of death-related phenomena. These include facilitating their involvement in funeral rituals, encouraging open discussion of death and dying in other settings and ensuring that when death is discussed the terminology used is simple, concrete and unambiguous.

Worden's (1991 & 1996) framework for the four tasks of mourning provides a rationale for the importance of attending a funeral ritual. He argues that this is a good place to begin accepting the reality of losing the deceased (i.e. Task one of the mourning process). Several researchers have discussed the importance of involving individuals with learning disabilities in the mourning and funeral rituals of the deceased. Carder (1987) provides good anecdotal evidence of how attending a funeral and being involved in funeral arrangements was beneficial to a variety of clients she worked with. Silverman and Worden (1992) outline the potential benefits of attending a funeral during childhood. They report that attendance had helped children acknowledge the death, provided an occasion for honouring the deceased and made it possible for them to receive support and comfort. This in turn facilitated these children in completing their tasks of mourning. Due to the similarities between how the child and learning disabled populations develop an understanding of death, it could be argued that adults with learning disabilities might benefit in similar ways from being involved in the funeral of relatives or friends. In fact the present study indicates that attendance at a funeral was an important factor in developing an understanding of the inevitability of human death.

Likewise there is evidence which indicates the importance of allowing adults with learning disabilities to view the body of their deceased friend or relative if they wish. Research suggests that while few people regret viewing the body, many of those who do not view eventually regret the missed opportunity (Finlay & Dallimore, 1991; Singh & Raphael, 1981). This is obviously another important aspect of death-related experience which might enable the individual to acknowledge the reality of the death

and provide the opportunity for them to ask questions and discuss death with significant others, such as staff members.

Research from the child literature does emphasise the importance of preparing an individual for the experience of attending a funeral, especially if they have not previously attended one. Worden (1996) found that children who were not prepared were more likely to show disturbed behaviour, low self-esteem and low self-efficacy two years after their parent's death and to have more difficulty talking about the deceased than those who were prepared for the funeral. This indicates that individuals with learning disabilities should be allowed to make an informed decision about attending a funeral. If they have not previously attended a funeral they need to be given explicit information about what will be seen and experienced (e.g. adults crying, the body being in a coffin which is put into the ground).

Opportunities to discuss aspects of life and death are available on a regular basis to staff working in learning disability settings, for example, news or nature programmes on the television, seasonal changes in plant life, as well as experiences of personal bereavement. Facilitating staff (via supervision or training) to enable them to make use of these opportunities and discuss aspects of death and dying is important.

Although the relationship between the carers' estimate of participants' understanding of death and their actual understanding was significant in this study, the correlations were small and should therefore be treated with caution. It is therefore possible that carers might have a tendency to misjudge how much individuals comprehend about death. This finding would be consistent with findings in the child literature that

children's understanding of death is better developed than either parents or paediatricians suspect (Vianello & Lucamante, 1988; Vianello & Marin, 1985). Unfortunately, the child literature also indicates that adults who believe that children have only a superficial and poorly developed concept of death also perceive them as only slightly interested or incapable of asking questions about it (Vianello & Lucamante, 1988). If this is true of the learning disabled population, there might be a reluctance on the part of carers, relatives or professionals to discuss death with those who they judge to have a limited understanding. The role of staff training and consultation to correct this misperception might prove important.

The present study also indicates that the method of communicating about death should be appropriate to the individual's level of cognitive ability and understanding of death in order to reduce confusion.

Koocher (1973) reported that the best explanations for children, especially those under age seven or eight, were those that are simple, direct and draw as much as possible from the child's own experiences. In this way the relative concreteness of the younger child will produce the least possible distortion. Providing euphemistic explanations for death may not be helpful to those who have experienced a bereavement. Children can see the distress that death causes in others and this can conflict with the euphemistic idea that death is a positive event (Randy-Cotton & Range, 1990).

Worden (1996) describes the importance of giving children clear information to reduce the likelihood of them "making up a story to fill in the gaps" (p140). He

reports that lack of information can make a child feel less important or anxious; worst of all they may feel responsible for the person's death. He believes it is helpful for the child to have information about the causes of death because without this they can develop unrealistic fears about death and disease, especially if their understanding of the causality of death is under developed. Children also need to know they are not to blame, which might include reassurance that negative feelings towards the deceased did not contribute to or cause their death.

The relationship between understanding of death and cognitive ability level suggests that death should be discussed in a similar manner with adults with mild-moderate learning disabilities. Language should be clear, simple and unambiguous. The use of euphemisms and metaphors (e.g. comparing dying to going to sleep) should be avoided as these can cause confusion for individuals who do not understand the irreversibility and finality of death. Information about the death should be openly discussed if the individual shows interest or asks questions. This is especially important as one way to facilitate the grief process is to talk about the deceased and the circumstances of the death (Worden, 1991).

The importance of clear communication to aid understanding of death-related experiences has been highlighted by Cathcart (1995). Several studies (including the present one) have found that experience of bereavement in itself does not result in a better developed concept of death. Some studies (Oswin, 1981, 1985, 1991) have reported that clients are often given misleading or confusing information when they are bereaved. Cathcart suggests that support and information differ for different individuals depending upon their cultural and religious backgrounds. Conflictual

messages may arise when a client, relatives, keyworker and other professionals hold different views about the meaning of death and the 'right' way to show feelings and express respect for the dead. She concludes that being bereaved may not help someone understand death if the situation is not explained or if the person is excluded from the events surrounding the death. Possibly it is not the death but the meaning that is attributed to the experiences at that time which is important.

The findings and implications of the present study are consistent with Cathcart's conclusions. This study indicates that experience of death can influence an individual's understanding if they are involved in the process and if it is consistently explained to them in clear, unambiguous terminology which is readily understood and which is appropriate to their cultural and religious beliefs. This emphasises the importance of clear communication and consistent support for individuals with learning disabilities who experience a bereavement. Effective communication links between different professionals, contexts and agencies are also important in order to ensure that the bereaved individual is given a consistent and clear message about their loss.

Interaction about death with the learning disabled population should therefore be appropriate to their cognitive ability as well as their level of understanding about the concept of death. By ensuring that communication is readily understood there is an increased likelihood that an individual can make sense of their death-related experiences and potentially gain a better comprehension of death and thus improve their ability to adapt to bereavement.

REFERENCES

Anthony, S. (1940). The Child's Discovery Of Death. New York: Harcourt, Brace.

Anthony, S. (1971) The Discovery of Death In Childhood and After. Basic Books: New York.

Anthony, Z & Bhana, K. (1988). An exploratory study of Muslim girls' understanding of death. Omega, 19, 215-227.

Barratt, B. (1975). Training and transfer in combinatorial problem-solving: The development of formal reasoning during early adolescence. Developmental Psychology, 11, 700-704.

Bibace, R. & Walsh, M. (Eds.). (1981). Children's conceptions of illness. In R. Bibace and M. Walsh (Eds.), Children's Conceptions of Health, Illness and Bodily Functions. San Francisco: Jossey-Bass.

Bihm, E. & Elliott, I. (1982). Conception of death in mentally retarded persons. Journal of Psychology, 3, 205-210.

Brent, S. & Speece, M. (1993). "Adult" conceptualisation of irreversibility: Implications for the development of the concept of death. Death Studies, 17, 203-224.

Brent, S., Speece, W., Lin, C., Dong, Q. & Yang, C. (1996). The development of the concept of death among Chinese and US children 3-17 years of age: From binary to "fuzzy" concepts?. Omega, 33, 67-83.

Bruner, J., Oliver, R. & Greenfield, P. (1966). Studies in Cognitive Growth. New York: Wiley.

Candy-Gibbs, S., Colby Sharp, K. & Petrun, C. (1985). The effects of age, object, and cultural/religious background on children's concepts of death. Omega, 15, 329-346.

Card, H. (1983). "What will happen when we've gone?". Community Care, 28, 20-21.

Carder, M. (1987). Journey into understanding mentally retarded people's experiences around death. Journal of Pastoral Care, 41, (1), 18-31.

Carey, S. (1985). Conceptual Change in Childhood. Cambridge, MA: MIT Press.

Cathcart, F. (1994). Understanding Death and Dying. A series of three booklets for the client, relative and professional carer. British Institute of Learning Disabilities: Wolverhampton.

Cathcart, F. (1995). Death and people with learning disabilities: Interventions to support clients and carers. British Journal of Clinical Psychology, 34, 165-175.

Cochran, W. (1950). The comparison of percentages of matched samples. Biometrika, 37, 256-266.

Derry, S. (1979). An Empirical Investigation Of the Concept of Death in Children. Unpublished doctoral dissertation. University of Ottowa: Ottowa, Canada.

Dunn, L. & Dunn, L. (1981). Peabody Picture Vocabulary Test – revised: Form M. Circle Pines, MN: American Guidance Service.

Dunn, L., Dunn, L. & Whetton, C. (1982). British Picture Vocabulary Scale. Nfer Nelson: Windsor.

Eiser, C. (1989). Children's concepts of illness: Towards an alternative to the "stage" approach. Psychology and Health, 3, 93-101.

Erikson, E. (1980). Identity and the Life Cycle. New York: W.W. Norton.

Estes, K. (1979). The role of preference in children's responses to more and less. Genetic Psychology Monographs, 100, 233-256.

Finlay, I. & Dallimore, D. (1991). Your child is dead. British Medical Journal, 302, 1524-1525.

Florian, V. & Kravetz, S. (1985). Children's concepts of death : A cross-cultural comparison among Muslims, Druze, Christians and Jews in Israel. Journal of Cross-Cultural Psychology, 16, 174-189.

Flynn, M. (1986). Adults who are mentally handicapped as consumers: Issues and guidelines for interviewing. Journal of Mental Deficiency Research, 30, 369-377.

French, J. & Kuczaj, E. (1992). Working through loss and change with people with learning difficulties. Mental Handicap, 20, 108-111.

Gampel, E. (1990). Comment on Hore and Tryon's study of similar structure hypothesis. American Journal of Mental Retardation, 95 (2), 236-238.

Gelman, R. & Baillargeon, P. (1983). A review of some Piagetian concepts. In P. Mussen (Ed.), Handbook of Child Psychology (vol. 3). New York: Wiley.

Ginsburg, H & Opper, S. (1988). Piaget's Theory of Intellectual Development. (3rd Edition). Prentice Hall: Englewood Cliffs, New Jersey.

Green, B. (1956). A method of scalogram analysis using summary statistics. Psychometrika, 21, 79-88.

Guttman, L. (1944). A basis for scaling qualitative data. American Sociological Review, 9, 139-150.

Harper, D. & Wadsworth, J. (1993). Grief in adults with mental retardation: Preliminary findings. Research in Developmental Disabilities, 14, 313-330.

Hedger, C. & Smith, M. (1993). Death education for older adults with developmental disabilities: A life cycle therapeutic recreation approach. Activities, Adaptation & Ageing, 18 (1), 29-36.

HMSO: Her Majesty's Stationery Office. (1983). Mental Health Act 1983. London: HMSO.

Hobson, R. & Lee, A. (1989). Emotion-related and abstract concepts in autistic people: Evidence from the British Picture Vocabulary scale. Journal of Autism and Developmental Disorders,19 (4), 601-623.

Hobson, R., Ouston, J. & Lee, A. (1989). Naming emotion in faces and voices: Abilities and disabilities in autism and mental retardation. British Journal of Developmental Psychology, 7, 237-250.

Hoffman, S. & Strauss, S. (1985). The development of children's concepts of death. Death Studies, 9, 469-482.

Hollins, S. (1987). How do people with mental retardation cope with loss? Paper presented at the ICPS conference. Sidney Sussex college, Cambridge, 23-27th March, 1987.

Hollins, S. & Sireling, L. (1991). When Dad Died. Nfer Nelson: Windsor.

Hore, A. & Tryon, W. (1989). Study of the similar structure hypothesis with mentally retarded adults and nonretarded children of comparable mental age. American Journal of Mental Retardation, 94, 182-188.

Jenkins, R. & Cavanaugh, J. (1985). Examining the relationship between the development of the concept of death and overall cognitive development. Omega, 16, 193-199.

Kane, B. (1979). Children's concepts of death. Journal of Genetic Psychology, 134, 141-153.

Kastenbaum, R. (1992). The Psychology of Death (2nd Edition). New York: Springer Publishing Company.

Kastenbaum, R. & Aisenberg, R. (1972). The Psychology of Death. New York: Springer Publishing Company.

Kastenbaum, R. & Costa, P. (1977). Psychological perspectives on death. Annual Review of Psychology, 28, 225-249.

Kloeppel, D. & Hollins, S. (1989). Double handicap: Mental retardation and death in the family. Death Studies, 13, 31-38.

Koocher, G. (1973). Childhood, death and cognitive development. Developmental Psychology, 9, 369-375.

Lansdown, R. & Benjamin, G. (1985). The development of the concept of death in children aged 5-9 years. Child: Care, Health Education, 11, 13-20.

Lazar, A. & Torney-Purta, J. (1991). The development of the subconcepts of death in young children: A short-term longitudinal study. Child Development, 62, 1321-1333.

Lenski, G. & Leggett, J. (1960). Caste, class and deference in the research interview. American Journal of Sociology, 65, 463-467.

Lipe-Goodson, P. & Goebel, B. (1983). Perception of age and death in mentally retarded adults. Mental Retardation, 21, 68-75.

Mahon, M. (1993). Children's concept of death and sibling death from trauma. Journal of Paediatric Nursing, 8, 335-344.

McConkey, R. & Walsh, J. (1981). An index of social competence for use in determining the service needs of mentally handicapped adults. Journal of Mental Deficiency Research, 26, 47-61.

McEvoy, J. (1989). Investigating the concept of death in adults who are mentally handicapped. The British Journal of Mental Subnormality, 40, 115-121.

McLoughlin, I. (1986). Bereavement in the mentally handicapped. British Journal of Hospital Medicine, October, 256-260.

McNemar, Q. (1955). Psychological Statistics (2nd ed.). New York: Wiley.

Mitchell, N. (1967). The Child's Attitude To Death. New York: Schocken Books.

Myreddi, V & Narayan, J. (1993) The concept of death among people with mental handicap. International Journal of Rehabilitation Research, 16, 328-330.

Nagy, M. (1948) The child's view of death. Journal of Genetic Psychology, 73, 3-27.

Nelson, K. & Gurendel, J. (1986). Children's scripts. In K. Nelson (Ed.) Event Knowledge: Structure and Function in Development. New Jersey: Lawrence Erlbaum.

Orbach, I., Gross, Y., Glaubman H. & Berman, D. (1985). Children's perceptions of death in humans and animals as a function of age, anxiety and cognitive ability. Journal of Child Psychology and Psychiatry, 26, 453-463.

Orbach, I., Talmon, O., Kedem, P. & Har-Even, D. (1987). Sequential patterns of five subconcepts of human and animal death in children. Journal of the American Academy of Child and Adolescent Psychiatry, 26, 578-582.

Orbach, I., Weiner, M., Har-Even, D. & Eshel, Y. (1994). Children's perception of death and interpersonal closeness to the dead person. Omega, 30, 1-12.

Oswin, M. (1981). Bereavement and Mentally Handicapped People. London: King's Fund Document, December.

Oswin, M. (1985). Bereavement. In A. Craft, J. Bicknell & S. Hollins (Eds.), A Multi-disciplinary Approach to Mental Handicap. London: Balliere Tindall.

Oswin, M. (1991). Am I Allowed to Cry?. London: Souvenir Press.

Phillips, J. (1969). The Origins of Intellect: Piaget's Theory. Freeman & Co.: San Francisco.

Piaget, J. (1948). The Moral Judgement of the Child. Glencoe, Illinois: Free Press.

Piaget, J. (1960). The Child's Conception of the World. Paterson, NJ: Littlefield, Adams & Co.

Piaget, J. (1976). The Psychology of Intelligence. New Jersey: Littlefield, Adams & Co.

Prichard, S & Epting, F. (1992). Children and death: New horizons in theory and measurement. Omega, 24, 271-287.

Randy-Cotton, C. & Range, L. (1990). Children's death concepts: Relationship to cognitive functioning, age, experience with death, fear of death and hopelessness. Journal of Clinical Child Psychology, 19 (2), 123-127.

Reilly, T., Hasazi, J. & Bond, L. (1983). Children's conceptions of death and personal mortality. Journal of Paediatric Psychology, 8, 21-31.

Renner, J., Stafford, D., Lawson, A., McKinnon, J., Friot, F. & Kellogg, D. (1976). Research Teaching and Learning with the Piaget Model. Norman: University of Oklahoma Press.

Rochlin, G. (1967). How younger children view death and themselves. In E. Grollman (Ed.), Explaining Death to Children. (p51-88). Boston: Beacon.

Rosen, M., Floor, L. & Zisfein, L. (1974). Investigating the phenomenon of acquiescence in the mentally handicapped. I. Theoretical model, test development and normative data. British Journal of Mental Subnormality, 20, 58-68.

Rosenheim, E. & Reicher, R. (1985). Informing children about a parent's terminal illness. Journal of Child Psychology and Psychiatry, 26, 995-998.

Rothenberg, B. (1969). Conservation of number among four and five year old children: Some methodological considerations. Child Development, 40, 382-406.

Sarason, S., Davidson, K., Waile, R. & Ruebush, B. (1960). Anxiety in Elementary School Children. New York: Wiley.

Schonfeld, D. & Kappelman, M. (1990). The impact of school based education on the young child's understanding of death. Developmental and Behavioural Paediatrics, 11 (5), 247-252.

Schonfeld, D. & Smilansky, S. (1989). A cross-cultural comparison of Israeli and American children's death concepts. Death Studies, 13, 589-600.

Sigelman, C., Budd, E., Winer, J., Schoenrock, C. & Martin, P. (1982). Evaluating alternative techniques of questioning mentally retarded persons. American Journal of Mental Deficiency, 86, (5), 511-518.

Sigelman, C., Budd, E., Sphanel, C. & Schoenrock, C. (1981a). When in doubt, say yes: Acquiescence in interviews with mentally retarded persons. Mental Retardation, 19, 53-58.

Sigelman, C., Budd, E., Sphanel, C. & Schoenrock, C. (1981b). Asking questions of retarded persons: A comparison of yes-no and either-or formats. Applied Research in Mental Retardation, 1981, 347-357.

Sigelman, C., Schoenrock, C., Sphanel, C., Hromas, S., Winer, J., Budd, E. & Martin, P. (1980). Surveying mentally retarded persons: Responsiveness and response validity in three samples. American Journal of Mental Deficiency, 84 (5), 479-486.

Silverman, P. & Worden, J. W. (1992). Children's understanding of funeral ritual. Omega, 25, 319-331.

Singh, B. & Raphael, B. (1981). Post-disaster morbidity of the bereaved: A possible role for preventative psychiatry. Journal of Nervous and Mental Disease, 169, 203-212.

Smilansky, S. (1981). Children's Perception of Death. Haifa: Ach Company.

Smilansky, S. (1987). On Death: Helping Children Understand and Cope. Peter Lang Publishing, New York.

Smilansky, S. & Weissman, T. (1978). A Guide for Rehabilitation Workers with Orphans of War Casualties and Their Mothers. Jerusalem: Henrietta Szold Institute.

Speece, M & Brent, S. (1984). Children's understanding of death: A review of three components of a death concept. Child Development, 55, 1671-1686.

Speece, M & Brent, S. (1992). The acquisition of a mature understanding of three components of the concept of death. Death Studies, 16, 211-229.

Stambrook, M. & Parker, K. (1987). The development of the concept of death in childhood: A review of the literature. Merrill-Palmer Quarterly, 33 (2), 133-156.

Sternlicht, M. (1980). The concept of death in pre-operational retarded children. The Journal of Genetic Psychology, 137, 157-164.

Tallmer, M., Formanek, R. & Tallmer, J. (1974). Factors influencing children's concepts of death. Journal of Clinical Child Psychology, 3, 17-19.

Turner, J. & Graffam, J. (1987). Deceased loved ones in the dreams of mentally retarded adults. American Journal of Mental Deficiency, 92, 282-289.

Vaidya, S. & Chansky, N. (1980). Cognitive development and cognitive style as factors in mathematics achievements. Educational Psychology, 72, 326-330.

Vianello, R. & Lucamante, M. (1988). Children's understanding of death according to parents and paediatricians. Journal of Genetic Psychology, 149 (3), 305-316.

Vianello, R. & Marin, M. (1985). Children's Understanding of Death. Firenze, Italy: Giunti.

Vygotsky, L. (1962). Thought and Language. New York: MIT Press.

Weithorn, L. & Campbell, S. (1982). The competency of children and adolescents to make informed treatment decisions. Child Development, 53, 1589-1598.

Wells, W. (1963). How chronic over-claimers distort survey findings. Journal of Advertising Research, 3, 8-18.

White, E., Elsom, B. & Prawat, R. (1978). Children's conceptions of death. Child Development, 49, 307-310.

Worden, J. W. (1991). Grief Counselling and Grief Therapy. New York: Springer Publishing Company.

Worden, J. W. (1996). Children and Grief: When a Parent Dies. Guilford Press: London.

Yalom, I. (1980). Existential Psychotherapy. New York: Basic Books.

TABLE OF APPENDICES

Appendix 1 – Ethical Consent From Hounslow, Riverside And Ealing Ethics Committees.

Our Ref. JMB/LL
Tel:0181-565 5118

WEST MIDDLESEX
UNIVERSITY HOSPITAL
NHS TRUST

29th July 1997

Dear Ms Foster,

Re: 97/376/Foster Investigation into how adults with learning disabilities understand the concept of death.

Thank you for your letter of the 1st of July. I apologise for the delay in responding to it. I am pleased to be able to say that your amended information and proposed recruitment strategy now meets with the requirements of the Committee and I am accordingly giving permission for your study to commence.

Please note that approval is subject to the following conditions:

a) to your notifying the Committee should a change of researcher take place during the study,
b) to your allowing a member of the Committee access to your records for audit purposes if required,
c) to your submitting a short report on completion of the study or at 12 monthly intervals from the acceptance date for work in progress. **Please use the local reference number in any future correspondence with us.**

Yours sincerely,

Laila Lockett (secretary)

Dr JANET BALDWIN
Chairman, Hounslow District Research Ethics Committee

West Middlesex University Hospital NHS Trust • Twickenham Road • Isleworth • Middlesex • TW7 6AF
Telephone (switchboard) 0181 560 2121 • Facsimile (central) 0181 565 2535

Telephone (direct line)

Chairman • Jane Kelly Chief Executive • John de Braux

RIVERSIDE RESEARCH ETHICS COMMITTEE
CHELSEA & WESTMINSTER HOSPITAL
Lower Ground Floor Pharmacy Offices
369 Fulham Road London SW10 9NH
Tel: 0181 846 6855 Fax: 0181 846 6860

Miss Emma Foster (Clinical Psychologist in Training, University College London)

29th 1997

Dear Miss Foster

RREC 1461 - Investigation into how adults with learning disabilities understand the concept of death.

I am writing to inform you that the above study has been considered and now approved by Chairman's action.

Please note the following conditions which form part of this approval:

[1] This approval is for one year only. For projects with an expected duration of more than one year, a letter from the principal investigator will be required in order to further extend consent. This will enable the Committee to maintain a full record of research.

[2] Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee's approval.

[3] The Committee should be notified immediately of any serious adverse events or if the entire study is terminated prematurely.

[4] You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, e.g., extra work for laboratories. Approval by the Committee for your project does not remove your responsibility to negotiate such factors with your colleagues.

Cont/2...

Cont/2...**RREC 1461 - Investigation into how adults with learning disabilities understand the concept of death.**

[5] You must ensure that nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

[6] Pharmacy must be told about any drugs and all drug trials, and must be given the responsibility of receiving and dispensing any trial drug.

[7] The Committee must be advised when a project is concluded and should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

May I take this opportunity to wish you well in your research. However, if any doubts or problems of an unexpected nature arise, please feel free to contact me at any time.

Yours sincerely

J Nigel Harcourt-Webster MD FRCPath
Chairman - RREC

Seen and Approved	
Submission 12-06-97 and letter of 27-07-97	Signed Initials: J.N.H.W.
Protocol	Signed Initials: J.N.H.W.
Information Sheet Appendix 5 - amended	Signed Initials: J.N.H.W.
Consent Form Appendix 6 - amended	Signed Initials: J.N.H.W.
Questionnaires	Signed Initials: J.N.H.W.
Letter of Indemnity	Signed Initials: —
CTX/DDX/Licence	Signed Initials: —

LOCAL RESEARCH ETHICS COMMITTEE

Ealing Hospital NHS Trust

Level Eight, Uxbridge Road, Southall, Middlesex, UB1 3HW

Tel: 0181 354 5441/5458 Fax: 0181 354 5447

WAL/sjb

October 15, 1997

Dear Ms Foster,

Re: Investigation into how adults with learning disabilities understand the concept of death

Thank you for forwarding the above protocol to the Ealing Hospital Local Research Ethics Committee. Having reviewed the protocol and the questionnaires in conjunction with the approval of the Hounslow Ethical Committee, I am happy to take Chairman's Action to approve this study forthwith.

Yours sincerely,

Dr. William Lynn
Chairman - LREC

Appendix 2: Information sheet distributed to carers and potential participants

You and your relative/person you care for are being asked to participate in a research project. The statement below explains exactly what you are both being asked to do and what we hope to learn as a result of your taking part.

PLEASE READ THE FOLLOWING

Title of Study: Investigation into how Adults with Learning Disabilities Understand the Concept of Death.

Explanation.
This study is supervised by a Consultant Clinical Psychologist and aims to explore how adults with learning disabilities understand death. Understanding and coming to terms with the death of a friend or relative can be a distressing and upsetting process for any individual. However, it may be more difficult for people with a learning disability if their understanding is less developed. This study aims to find out more about how adults with a learning disability understand the concept of death. By learning more, we hope to be able to respond more effectively and appropriately to individuals who have been bereaved and those people who care for and work with them.

The study consists of two stages. Firstly, keyworkers will approach individuals and ask if they wish to participate in this study. If they give their initial agreement, you will be asked to complete a brief questionnaire giving details of your relative's/person you care for's age, ethnic group and experiences of death. We then ask you to return this questionnaire to us in a stamped addressed envelope along with a completed reply form which indicates that you are unaware of any reason why your relative/friend would not wish to take part in this study.

Secondly, your relative/friend will be interviewed. The interview will be carried out by a Clinical Psychologist in Training and should last approximately one hour. It will involve your relative/friend being asked a number of questions about their understanding of death and also being asked to complete two brief tests of general ability. Your relative's/ friend's mood will be monitored during the interview and they will be offered the opportunity to discuss any concerns at the end of the interview.

You and your relative/friend should only take part in the study if you are both willing to do so. If you decide not to, your future medical care will not be affected in any way. If you decide to take part, you are both free to withdraw at any time without affecting your future care.

All information given on the questionnaire and during the interview will be strictly confidential: it will not be traced back to your relative's/ friend's medical notes or be available to anyone who is not directly involved in the study.

Thank-you for your help.

Appendix 3: Reply form requested from potential participant's carers

Title of Study: Investigation into How Adults with Learning Disabilities Understand the Concept of Death.

Participant's Name:

Please read the following statements. If you agree with them and are willing for you and your relative/person you care for to take part in this study, please sign below.

I have been fully informed of what the study involves for my relative/friend who is named above. This has been explained to me by: (please write name)

I have received, read and understand the information sheet and any questions I had relating to the study have been answered to my satisfaction.

I understand that my relative's/friend's participation is voluntary and that she/he is free to withdraw at any time, without reason and without prejudice to their further treatment. I believe that the above participant is willing to participate in such a study. My relative/friend has not expressed any objections to taking part. I also agree to participate in this study by completing a questionnaire about my relative/friend.

I understand that personal information about my relative/friend will be treated as strictly confidential and that data from the study may be presented anonymously for publication in medical journals and at clinical/scientific meetings.

Name of relative/carer/guardian (block letters):

Signature of relative/carer/guardian:

Relationship to participant:

Date:

Appendix 4: Questionnaire completed by carer

In order to gain a fuller understanding of the participants in this study, it is necessary to ask certain questions about their lifestyle and experiences. Please complete this questionnaire as fully and honestly as possible on behalf of your relative/friend. All information will be treated as strictly confidential and is for the sole use of this study. Once completed, the identity of your relative/friend will be changed to maintain anonymity.

Participant's Name:..... **Date of Birth**:..... **Sex**: Male / Female

Ethnic Group. Please tick the category which best describes the ethnic group to which your relative/friend belongs.

- White English/Welsh/Scottish
- Irish
- White European
- White Other. Please specify.....
- Indian
- Pakistani
- Bangladeshi
- Chinese
- Asian Other. Please specify.....
- Black African
- Black Caribbean
- Black Other. Please Specify...
- Other. Please specify.....

Religion. Please tick the category which best describes the religion of your relative/friend.

- Roman Catholic
- Protestant
- Church of England
- Baptist
- Muslim
- Sikh
- Hindu
- Buddhist
- Jewish
- Atheist
- No religion
- Other. Please specify.....

Please indicate below (by ticking the most appropriate category) **how often your friend/relative visits their place of worship**

- ☐ Never
- ☐ Once or twice a year
- ☐ Once every two months
- ☐ Once a month
- ☐ Twice a month
- ☐ Once a week
- ☐ More than once a week
- ☐ Don't Know
- ☐ Other. Please specify.....

Q1. Where does your relative/friend currently live? (please tick)

- ☐ Family Home
- ☐ Own flat/house
- ☐ Group Home
- ☐ Other. Please specify.....

Q2. Does your relative/friend currently attend. (please tick)

- ❑ Day centre
- ❑ Sheltered employment post
- ❑ College
- ❑ None of the above
- ❑ Other. Please specify...............

Personal Experience of Death. Please tick **any of the following** which apply to your relative/friend.

Q3. Has your relative/friend

- ❑ known **6 or more** close friends or relatives who have died
- ❑ known **between 3 and 5** friends or relatives who have died
- ❑ known **between 1 and 3** close friends or relatives who have died
- ❑ known **no** close friends or relatives who have died
- ❑ experienced the death of a **less familiar person**
- ❑ experienced the death of a **pet**
- ❑ had **no experience** of the death of a relative/friend/less familiar person or pet ?

If your relative/friend has had **any personal experience of death**, please give details of **each experience** below:

Relationship to the deceased....................Any other relevant details........................
Cause of death....................................... ....
Approximate date of death...................... ....

Was your relative/friend invited to attend the burial/cremation/funeral ritual? Yes/No
Did your relative/friend attend the burial/cremation/funeral ritual? Yes / No

Relationship to the deceased....................Any other relevant details........................
Cause of death....................................... ....
Approximate date of death...................... ....

Was your relative/friend invited to attend the burial/cremation/funeral ritual? Yes/No
Did your relative/friend attend the burial/cremation/funeral ritual? Yes / No

Relationship to the deceased....................Any other relevant details........................
Cause of death....................................... ....
Approximate date of death...................... ....

Was your relative/friend invited to attend the burial/cremation/funeral ritual? Yes/No
Did your relative/friend attend the burial/cremation/funeral ritual? Yes / No

Relationship to the deceased....................Any other relevant details........................
Cause of death....................................... ....
Approximate date of death...................... ....

Was your relative/friend invited to attend the burial/cremation/funeral ritual? Yes/No
Did your relative/friend attend the burial/cremation/funeral ritual? Yes / No

Relationship to the deceased.....Any other relevant details.....
Cause of death..... .....
Approximate date of death..... .....
Was your relative/friend invited to attend the burial/cremation/funeral ritual? Yes/No
Did your relative/friend attend the burial/cremation/funeral ritual? Yes / No

Relationship to the deceased.....Any other relevant details.....
Cause of death..... .....
Approximate date of death..... .....
Was your relative/friend invited to attend the burial/cremation/funeral ritual? Yes/No
Did your relative/friend attend the burial/cremation/funeral ritual? Yes / No

To the best of your knowledge,
Q4. Has your relative/friend ever attended a funeral ritual? Yes / No

Q5. Has your relative/friend ever seen a dead body? Yes / No

Q6. Have you ever discussed the topic of death with your relative/friend? Yes / No

Q7. Have you ever tried to explain a death to your relative/friend? Yes / No. If Yes, please give brief details of how you explained it to them (for example, going to heaven, being reincarnated in a different form etc.).....
.....
.....

Q8. On the following five point scale, please indicate (by circling the appropriate number) how good you judge your relative's/friend's understanding of death to be.

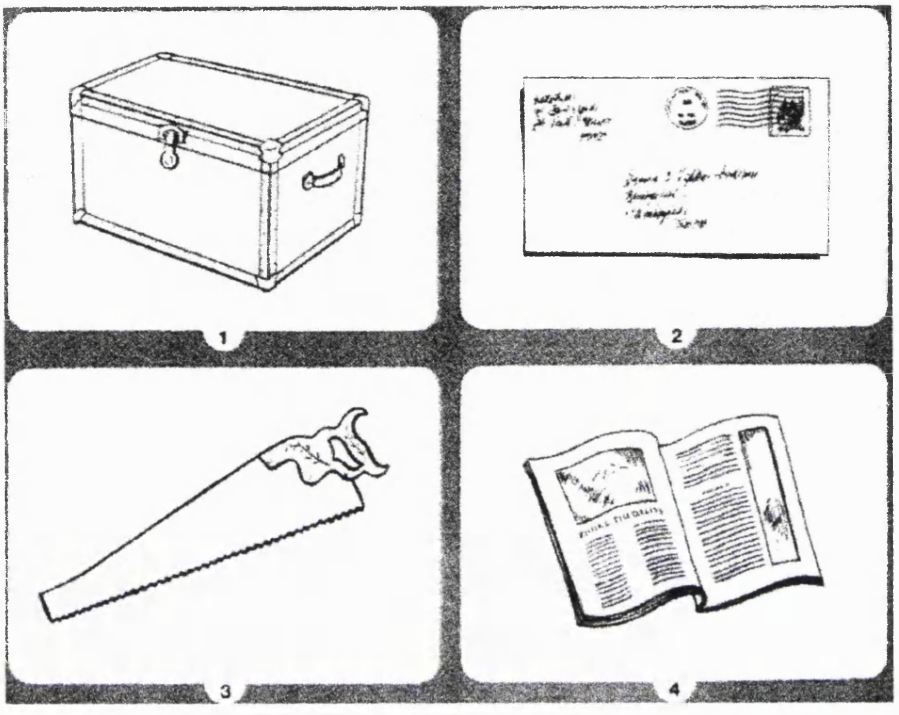
1	2	3	4	5
Has no understanding of death	Has limited understanding of death	Has fairly good understanding of death	Has good understanding of death	Has complete understanding of death

Any additional comments.....
.....
.....
.....
Date questionnaire was completed .....

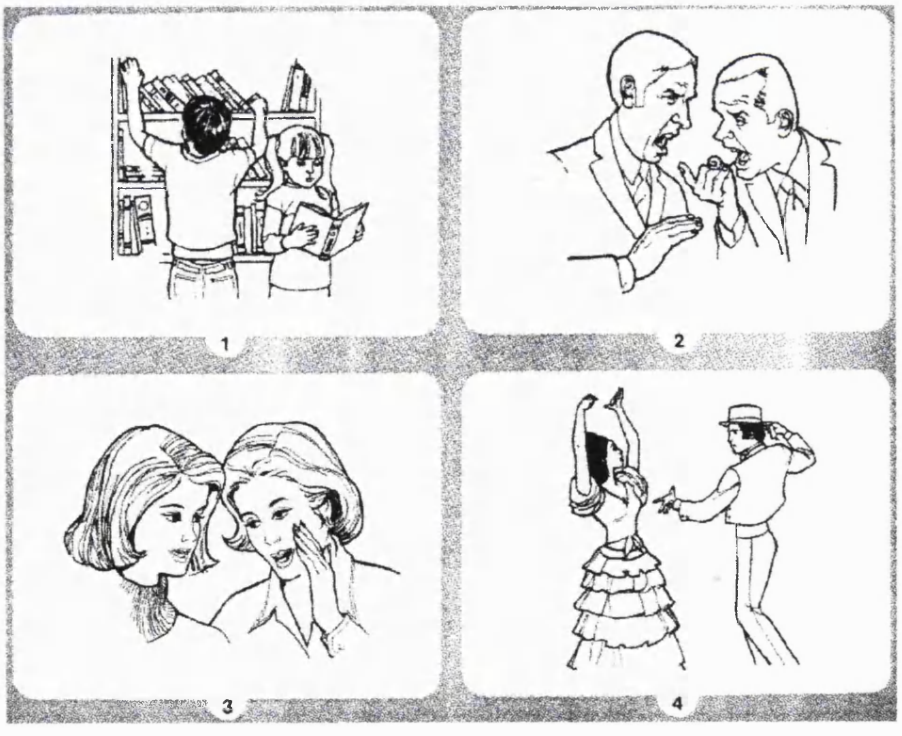
Many thanks for your co-operation in completing this questionnaire and for agreeing to take part in this study. Please return your completed questionnaire and reply form (indicating that you believe your relative/friend to be willing to participate in this study) to me in the enclosed stamped addressed envelope.

Appendix 5: Two test plates from the British Picture Vocabulary Scale

Test Plate 6: Envelope



Test Plate 25: Confiding



Appendix 6: Protocol for Piagetian Tasks

Piagetian Tasks. (Adapted from Phillips, 1969 and Ginsburg & Opper, 1988).

All participants will undertake tasks 1 to 4. If they pass all four of these, they will undertake task 5. Tasks 1-4 differentiate between pre-operational and concrete operational functioning, whilst task 5 differentiates between concrete operational and formal operational functioning.

Procedure.

Task 1 - Conservation of Length.

Participant is presented with two sticks of equal length which are placed one above the other and is asked: "Are they the same length or is one longer than the other?".

One stick is then moved (so they are no longer symmetrical) and participant is asked the same question again.

Task 2 - Conservation of Substance Amount.

Two identical plasticene balls are prepared. Participant is asked: "Are they the same size or does one have more plasticene in it than the other?".

One of the balls is rolled into a sausage shape and the question is repeated.

Task 3 - Conservation of Number.

Equal numbers of round and square blocks are placed in two lines directly above each other. Participant is asked: "Are there the same number of squares and triangles or is there more of one of them?".

The row of square blocks are compressed so that they no longer have a one-to-one correspondence with the triangular blocks and the question is repeated.

Task 4 - Conservation of Volume.

Two identical balls of plasticene are placed in two identical glasses which contain an equal amount of water. Participant is asked: "Do both pieces of plasticene displace the same amount of water?".

One of the plasticene balls is re-shaped into the shape of a sausage and the question is repeated.

Task 5 - Hypothesis testing task - Pendulum Oscillation.

Participant is presented with a set of weights and a piece of string and shown:
1) how to make a pendulum
2) how to vary the length of the string
3) how to change the weight of the suspended object
4) how to release the pendulum from different heights
5) how to push it with different degrees of force.

The participant is then asked to find out what makes the pendulum swing faster and slower.

Appendix 7: Concept of Death questionnaire

Questions Related to Human Death.

1. What does "to die" mean? What is death?
2. Can something be dead and live at the same time? *
3. Of what do people die? Of what other reasons can people die? *C*
4. Who gets old? Does everyone get old? *OA*
5. What happens to a person who dies? What do we do with him?
6. Does a dead person know that he is dead? Does he know what is happening to him? Why? *F*
7. Is a dead person able to feel? Does he feel pain? Why? *F*
8. If a person dies and has been in his grave for some time, can he return to become a living person? Why? *IR*
9. If a person dies and has not yet been buried, can he return to become a living person? Why? *IR*
10. Can a dead person see? Why? *F*
11. Can a dead person hear? Why? *F*
12. Can a dead person move? Why? *F*
13. Can a dead person come out of his grave? Why?
14. Does everyone die? Why? *IN*
15. Will I (the researcher) die someday? * *IN*
16. Will you die someday? * *IN*
17. Can a dead person become alive again? * *IR*
18. If I gave a dead person a drink of water, could he become alive again? * *IR*
19. If I gave a dead person some food to eat, could he become alive again? * *IR*
20. If I gave some medicine to a dead person, could he become alive again? * *IR*
21. If I said some magic words to a dead person, could he become alive again? * *IR*

Questions Related To Animal Death.

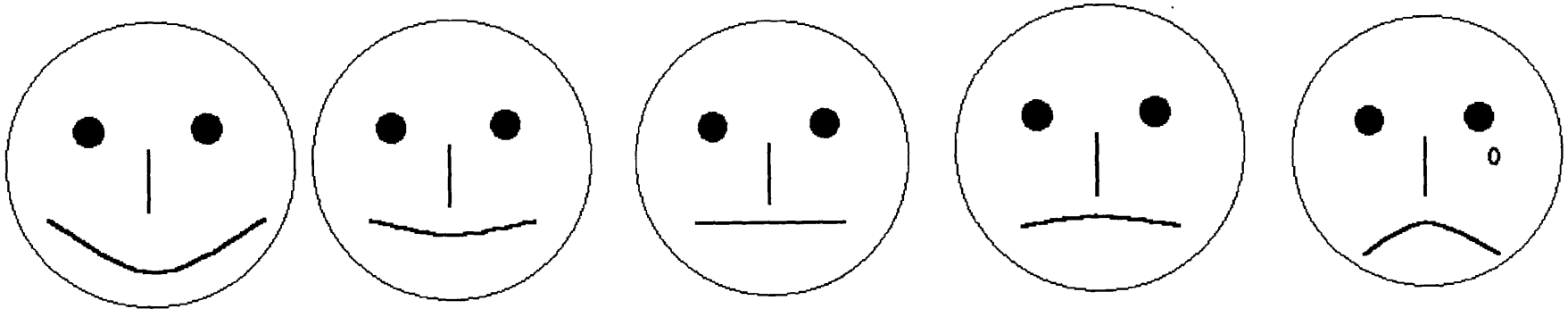
22. Have you ever seen a dead cat or dog?
23. Of what do cats and dogs die? Of what other reasons can dogs die? *C*
24. Does a dog get old? Do all dogs get old?. Why? Do cats get old? *OA*
25. What do we do with dead dogs and cats?
26. Does a dead dog know that he is dead? Why? *F*
27. Can a dead dog or a dead cat feel anything? Can he feel pain? Why? *F*
28. If a dog dies and is put in the ground, can he become a live dog again? Why? *IR*
29. If a dog dies and is put into the rubbish bin, can he become a live dog again? Why? *IR*
30. .Can a dead dog see? Why? *F*
31. Can a dead dog hear? Why? *F*
32. Can a dead dog move? Why? *F*
33. Can a dead dog get out of wherever he is put? Why?
34. Do all dogs die? *IN*

Note: 1) All questions taken from Smilansky's (1987) questionnaire, except those marked with an asterisk which were taken from Speece and Brent (1992).

2) Sub-components being assessed are indicated: *F* = finality, *C* = causality, *IR* = irreversibility, *IN* = inevitability and *OA* = Old Age.

Appendix 8: Mood Rating

Which face best describes how you feel now?



Very Happy **Fairly Happy** **Neutral - Neither Happy nor Sad** **Fairly Sad / Upset** **Very Sad / Upset**

Appendix 9: Interview Protocol

Description of study for participants at the beginning of the interview.

Hello. My name is Emma Foster and I'm a Clinical Psychologist in Training. I understand that you know why we are meeting today but I want to just check that you are clear about what I am asking you to do.

I am looking at the way in which people understand the topic of death. This interview should last about one hour and I will be asking you a number of questions. Firstly, I will read out some words and ask you to point to some pictures which represent these words. Next I will show you different objects and ask a couple of questions about these objects. Finally I will ask several questions about humans and animals in order to find out how you understand death. There will be a chance for us to talk more about the questions or anything else you wish to discuss at the end of the interview and I shall also ask you to let me know how you are feeling at the beginning and end.

Your answers will be confidential - i.e. I won't tell anyone else the answers you give to me. If you tell me something which I think we should tell someone else, we will discuss it first. If you do not want to take part in this study, that is fine and if you want to stop at any time just let me know and we can stop.

Do you understand what I am asking you to do? Can you tell me what we are going to do? Are you happy to answer these questions? Do you have any questions before we start?

.....

Procedure for Interview.

1. Mood rating
2. BPVS
3. Piagetian Tasks
4. Concept of death questionnaire
5. Mood rating
6. Opportunity to de-brief.