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Investigating illness and bereavement in young people with autistic spectrum disorder

**By
Helen Phelps**

A thesis submitted in partial fulfilment of the requirements for
the degree of Doctor in Clinical Psychology.

**Coventry University, School of Health and Social Sciences
and University of Warwick, Department of Psychology**

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Summary

Alexithymia is a personality trait that has been linked with a variety of health problems, especially with somatic complaints. It is characterised by a number of difficulties including identifying and describing feelings (Loas et al, 2001). Studies looking at the link between alexithymia and illness have mainly focused on adults however research exploring children's levels of alexithymia have recently commenced due to the design a couple of assessment tools made specifically for children.

Research suggests (Hobson, 1996), that children with autistic spectrum disorder (ASD) have difficulties with emotional skill. No studies however could be found that looked at the relationship between alexithymia and this group of children. The literature review sought to explore the possibility that alexithymia and ASD might be linked and discusses the implications for children with ASD regarding their health if this is found to be the case.

The main paper goes on to explore children with ASD's understanding and experience of illness, taking a parents' perspective. Themes emerged covering the 3 broad domains of understanding illness, differences in expression of illness / pain and awareness that their child was unwell. This links in with the alexithymia literature, as children with ASD sometimes found it difficult to identify when they are unwell and had difficulty expressing themselves also some parents felt that their child expressed their distress through ill health.

Further to this study parents of children with ASD were asked about their child's understanding and experience of bereavement as this was also thought to be a complex concept for children who have difficulties with emotional skill. This was found to be the case, with children appearing to understand bereavement on an intellectual level but finding it more difficult to understand emotionally.

This study has a number of implications concerning health care and bereavement support for children with ASD.

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Chapter I

A Review of Alexithymia and Health: Relationship with Autistic Spectrum Disorder

Purpose. To critically review the literature on alexithymia and health and to relate this literature to a group of children who typically have difficulties with emotional skill, namely autistic spectrum disorder.

Methods. The papers used in this literature review were identified by literature searches for the years 1980-2002 and a hand search. Searches were conducted on Psychinfo and Medline databases and also a paper search was done with the papers found. Key words looked for included alexithymia, emotional skill, health, illness, young people, children, adolescents, theory of mind, autism and Aspergers Syndrome. Only papers written in English were used.

***"I am what I do and think instead of what I feel"* Temple Grandin (1999)**

1.1. Introduction

This paper reviews the literature on alexithymia and health, initially in the general population and then more specifically in children. It then relates this literature to a group of children who typically have difficulties with emotional skill, young people with autistic spectrum disorder (ASD). There are many studies that document the association between alexithymia and health in the adult population, however there are few studies that look specifically at children. Young people

with ASD have difficulties with emotional skill and the literature on alexithymia would therefore suggest that this might have implications on their health status. No studies were found that linked alexithymia with ASD.

1.2. Alexithymia

The relationship between health and emotion has been suggested for many years, as far back as James (1842-1910) and Freud (1856-1939). In the recent literature a number of terms have been used to describe difficulties with emotional skill one of these difficulties is alexithymia. Alexithymia literally means '**no words for feelings'** and is a term that Sifneos (1973) used to describe a group of patients with 'classical' psychosomatic illnesses. Alexithymia has since been linked to and thought to be a risk factor in physical and mental illness (Loas et al, 2001, Lumley, Strettner et al, 1996, Taylor et al, 1997). For example studies have found associations between alexithymia and diverse medical and psychiatric disorders such as myocardial infarction (Kojima et al, 2001), pain (Nyklicek, Vingerhoets, 2000), eating disorders (Corcos et al, 2000), anxiety (Devine et al, 1999) and depression (Saarjavi et al, 2001).

1.2.1. Measurement

Alexithymia is a multidimensional personality construct, which is characterised by a difficulty in identifying and describing feelings, difficulty distinguishing feelings from bodily sensations and a cognitive style that is concrete and externally orientated and lacking in fantasy (Loas et al, 2001).

A number of measures have been developed to assess alexithymia. The Toronto Alexithymia Scale (TAS-20) and its predecessors are the most widely cited and have been used in research and clinical practice (Bagby, Parker, et al 1994 & Bagby, Taylor, et al, 1994). A number of difficulties had been identified with the psychometric properties of the original TAS. Two revised versions were therefore developed to improve on it, the TAS-revised (TAS-R) (Taylor et al, 1992) and the 20-item Toronto Alexithymia Scale, TAS-20 (Bagby, Parker et al, 1994, Bagby, Taylor, et al, (1994). The TAS-20 has been shown to have good internal consistency and good test-re-test reliability even with samples from different countries (Bagby et al, 1994, Bressi et al, 1996 & Dion, 1996).

The TAS-20 is a self-report questionnaire, which contains 20 questions, e.g. "***I am often confused about what emotion I am feeling***", "***It is difficult for me to find the right words for my feelings***". A five-point Likert scale is provided to rate the extent that the responder agrees or disagrees with the statements. Three factors were identified by the developers of the scale, difficulty identifying feelings (DIF), difficulty describing feelings (DDF), and externally oriented thinking (EOT).

The TAS-20 has been criticised by several authors. Loas et al (2001) for example argue that although the TAS-20 improved the internal consistency of the previous scales, its cross-cultural validity decreased. It has also been argued according to Loas et al (2001) that the TAS-20 does not cover the full range of the

alexithymia construct, items assessing day dreaming and imaginable activity were dropped from the original TAS because of low corrected item-total correlations (Taylor et al, 1997). Other authors have suggested that alexithymia might be difficult to measure by means of a self-report, because if you are unaware of your feelings you might not be aware of a deficit in your emotions, (Kirmayer, Robins et al, 1994). Fava et al (1995), state that a self-rating scale cannot gain important information about emotions as this can only be obtained through interviews.

1.2.2. Prevalence of Alexithymia

A large scale prevalence study was carried out in the general population of Finland (Salminen et al, 1999). A random sample of 2000 people of working age from five social insurance districts all over Finland were asked to take part in the study. A total of 66% of the sample returned the questionnaires, a slightly higher percentage of them were women. Salminen and colleagues (1999) found alexithymia as measured by the TAS-20 to be normally distributed in the population in both genders, suggesting that alexithymia is a personality trait. The study found a significant gender difference in the mean scores of the TAS-20 where almost twice as many men, 17%, were alexithymic as compared to 10% of women.

The above study also found alexithymia to be associated with advanced age, low educational level and low socio-economic status. Salimen et al (1999) proposed

that alexithymia might be a link in a chain, leading to poor health status via socio-economic deprivation in some segments of the population.

1.2.3. Social and emotional understanding in alexithymia

The alexithymia construct is purported to examine difficulties in identifying and describing emotion however the definition does not include 'difficulty recognising the emotions of others'. A number of studies have been carried out to examine more closely difficulties that people with alexithymia might have recognising and expressing their own and others' emotions.

A preliminary study conducted by McDonald & Prkachin (1990), looked at the relationship between alexithymia and the recognition and expression of emotions. Results found that although students with alexithymia were comparable to controls in their ability to recognise and label posed expressions of emotion, they had difficulty spontaneously showing negative emotions. They were also less able to show the emotions of happiness and anger. This study utilised the Schalling-Sifneos Personality Scale (Apfel & Sifneos, 1979) to assess for alexithymia which, according to Taylor, Bagby & Parker, (1997) lacks internal validity and internal reliability and is therefore not to be recommended for clinical or research purposes.

Twenty-four males participated in a study conducted in India by Pandey & Mandal (1997). Twelve were alexithymic and twelve were non-alexithymic,

based on the Hindi version of the TAS-20. They were shown photographs depicting facial expressions of emotions. Participants were asked to match, label and verbally describe the facial emotions. Alexithymics were found to match and label as well as non-alexithymics but alexithymics had significantly more difficulty verbally describing emotional expressions than non-alexithymics. Their findings suggest that alexithymics are not able to use emotional words in their appropriate context. This study needs to be taken with caution however due to the low numbers of participants.

Other studies have found that people with alexithymia have difficulty accurately identifying the emotional expressions of others. In a study carried out by Parker, Taylor & Bagby (1993), students were categorised into groups of high, moderate and low alexithymia. They were asked to identify posed facial expressions of emotion in photographs. They found that students in the high alexithymia group were less able to recognise the correct emotional expression than students in the low alexithymia group.

These studies demonstrate that people with alexithymia appear to have some difficulty accurately describing others' emotions and a limited capacity to express emotions themselves. At this stage however it is unclear whether people with alexithymia are able to identify emotions of others as these studies are conflicting and further research is necessary. The authors of these studies put forward the suggestion that people with alexithymia might lack empathy or the ability to

understand or experience others' emotions, and this might also impact on social awareness.

Alexithymia is a construct closely related to emotional intelligence. Emotional intelligence however is a broader concept than alexithymia and includes both interpersonal and intrapersonal awareness along with other emotional coping skills (Bar-On, 1997). The Bar-On Emotional Quotient Inventory (EQ-I; Bar-On, 1977) is a tool that was designed to rate emotional intelligence. It is a 133-item inventory with 13 subscales that go into four second-order factors: intrapersonal (emotional self-awareness, assertiveness, self-regard, self-actualisation, independence), interpersonal (empathy, relationship skills, social responsibility), adaptability (problem solving, reality testing, flexibility), and stress management (stress tolerance, impulse control). There are also two subscales that assess general mood (happiness and optimism).

Parker et al (2001) carried out an empirical study looking at the relationship between emotional intelligence and alexithymia. They compared the three factors of the TAS-20 with the total score of the EQ-I and its four factors. The scales correlated significantly with high levels of alexithymia being associated with lower levels of emotional intelligence. They then tested that the constructs were independent by carrying out a series of two-factor models and found that although the constructs strongly inversely correlated, they were independent of each other.

The close relationship between the two constructs is interesting because alexithymia by definition only refers to intrapersonal skill. It suggests that people who have difficulty with intrapersonal skill also have difficulty with interpersonal skill. Interpersonal skill, including difficulty with empathy, might therefore also be a difficulty for people with alexithymia.

Some studies have attempted to provide an insight into the social functioning of people with alexithymia. Lumley, Ovies et al (1996) carried out three studies in order to see if there was a relationship between alexithymia, social support and health problems. Both healthy young adults and patients participated in the various studies. The first two studies found alexithymia to be related to global perceptions of reduced support. The third study sought to extend these findings and used a more objective measure to rate social support networks. They attempted to see if social skills mediated the relationship between alexithymia and social networks and whether social network mediated the relationship between physical symptoms and health. Two hundred and twenty five healthy college students were asked to rate their social network, their social competence, physical symptoms, depression and alexithymia.

Alexithymia, in particular the 'difficulty communicating feelings' factor, was found to be related to having a small social network, this was independent of mood. Alexithymia was also related to poorer social skills. Social skill appeared to mediate fully the relationship between alexithymia and social network size.

Alexithymia might therefore reduce the capacity of people to form close relationships that require interpersonal skill and emotional awareness to maintain.

The alexithymia construct includes as part of its definition difficulty with imaginal thinking. Studies have looked closer at this difficulty in alexithymics. A study conducted by Campos et al (2000), found that students who were classed as alexithymic from their score on the TAS-20 showed lower imaging capacity than non-alexithymic students. Imaging capacity was evaluated on the basis of a self-report questionnaire, the Vividness of Visual Imagery Questionnaire (VVIQ) (Marks, 1973). There is a need for further research in this area as their results only show that alexithymic subjects report less vivid images than non-alexithymics rather than that they have a weaker imaging capacity, Campos, Chiva et al (2000). It might be that people who are alexithymic are not as skilled in verbally reporting as non-alexithymics. The authors of this study suggest that a non-subjective measure should be used in future in place of the VVIQ.

According to Taylor, Bagby & Parker (1997), a consequence of having difficulty with identifying and expressing own emotions and lacking the ability to imagine what it is like to be in other people's shoes, is lack of empathy. In their book 'Disorders of Affect Regulation' they suggest that group therapy is useful for people with alexithymia, as gaining feedback in a supportive manner helps people with alexithymia learn about their lack of empathy.

1.2.4. Neurobiology of alexithymia

Taylor et al (1997) suggest that there are differences in the organisation of the brains of people with the alexithymia trait. At present it is not known what these differences are, but Taylor et al (1997) predict that future research will find deficiencies in how the two cerebral hemispheres coordinate their operations.

1.3. Alexithymia and relationship with health status in the general population

Alexithymia, although originally thought to influence somatic illness, has also been found to be associated with patients with a wide variety of physical and psychiatric illnesses and pain. As a vast amount of studies have been carried out in this field only a few recent examples of its relationship with health status will be presented. These studies have been chosen to demonstrate the range of research in the area and will concentrate here on the physical illnesses associated with alexithymia.

Kojima et al (2001), found that alexithymia as measured by the TAS-20, increased following a myocardial infarction. They suggested that alexithymia in myocardial infarction patients was a dynamic state, which was influenced by prior experience of myocardial infarction or from living alone. This finding is contrary to those of Salminen, Saarijarvi, et al (1999), who claimed that alexithymia was a psychological trait. Kojima et al (2001), also found a relationship between depression and alexithymia with patients who were post myocardial infarction.

Valkomo et al (2001) conducted a study looking at alexithymia in patients with coronary heart disease (CHD). They found 21% of CHD patients had alexithymia according to the TAS-20. This is a higher percentage than Salminen et al (1999) found in the general population of Finland. They were unable to say however, due to the design of the study, whether alexithymia was a permanent personality characteristic or whether it was secondary to CHD. They argued that their study showed that CHD patients with alexithymia needed greater support and attention than non-alexithymic patients as alexithymia was related to self rated depression and decreased life satisfaction. Alexithymics were also more often rated as incapable of work than other CHD patients.

Alexithymia has been demonstrated to have associations with both chronic and acute pain. The authors of a recent review of pain and emotion reported on studies that demonstrated that chronic pain patients had higher levels of alexithymia than healthy controls and that alexithymia might actually contribute to chronic pain (Keefe, et al, 2001). They report that this is because alexithymic patients are unable to differentiate between physiological arousal from tissue damage, and emotional arousal. They also suggest that alexithymia might limit patients' ability to use cognitive strategies which are often found helpful for patients who experience chronic pain.

Nyklicek & Vingerhoets (2000) studied the association between experimentally induced pain and alexithymia in students. The Dutch translation of the TAS-20 was used to assess for alexithymia. Only six of the thirty-nine participants were considered alexithymic based on the cut off score. A laboratory study was used where participants controlled the level of electric current and hence pain that they administered to themselves. Participants had to indicate when they first felt something, their sensory threshold, when the stimulus first became painful, their pain threshold, and the level at which the stimulation became too uncomfortable and they had to stop, their pain tolerance. Participants scoring highly on the TAS-20 were found to have higher pain sensitivity than low alexithymic scorers. Alexithymia was related most strongly to pain tolerance. The authors of this study suggest that people with alexithymia have a hypersensitivity to unpleasant physical stimuli. They do however point out that further studies need to be carried out with other painful stimuli to see if it does generalise.

Many studies have found associations between alexithymia and somatic illness Taylor, Bagby et al, (1997). Lumley, Ovies, et al (1996) in their studies discussed previously, found alexithymia to be related to both somatic symptoms and depression. Lack of social support was not found to account for the association. Jyvasjarvi, Joukamaa et al (2001), found that alexithymia was associated with somatisation in people who frequently attended primary health care. However neither psychological distress nor alexithymia were able to explain the frequent attendances of somatisers to primary health care.

A number of criticisms however have been made as to whether there really is a link between alexithymia and somatic complaints. Lundh & Simonsson-Sanecki (2001) argue that there is no strong evidence of an association when emotional distress is controlled for. They found low correlations between alexithymia and somatic complaints in their study, and these were completely eliminated when negative affect was taken into account. They argue that their results suggest that either alexithymia and somatisation are not related, or that the TAS-20 was unable to pick up the association, and is therefore not a valid measure of alexithymia.

1.3.1. How alexithymia and illness are linked

The above studies on the whole suggest that there is a relationship between physical illness and alexithymia, however little research has been conducted into finding out how they are related. Lumley, Stettner et al (1996) carried out a review examining the pathways that could potentially link alexithymia with illness. Details of their findings will not be repeated here, however it is interesting to note some of their main tentative conclusions. They separated out physical illness into organic disease and illness behaviour. Illness behaviour is the subjective report of physical symptoms, how the illness is expressed and the likelihood of seeking medical assistance, whereas organic disease is the actual physical aetiology of an illness. Some evidence was found to suggest that physiological and behavioural pathways affect organic disease. They concluded however that

this was more likely to be due to unhealthy behaviours, which have been related to alexithymia rather than from physiological changes caused by alexithymia.

A recent study (Helmers & Mente, 1999) found further evidence to suggest that alexithymia was associated with some unhealthy behaviour. They conducted a study examining the health behaviours of healthy young males in America. They found that alexithymia was associated with poor nutritional consumption and the different subscales of the TAS being associated with other maladaptive behaviour. The subscale 'identifying feelings', was associated with alcohol and drug use. The 'difficulty communicating feelings' scale was associated with a sedentary lifestyle. Helmers & Mente (1999) suggested that children and adolescents who have alexithymia might develop unhealthy behaviours that are risk factors for premature death. They proposed that maladaptive health behaviours might be a possible pathway for the increased risk of mortality in middle-aged men who had a high alexithymia score on the TAS (Kauhanen, et al, 1996).

Lumley, Stettner et al (1996) also found considerable evidence to suggest that alexithymia was linked to and might affect illness behaviour through cognitive pathways, where people with alexithymia might misinterpret emotional arousal as symptoms of physical illness. Lumley, Stettner et al (1996) however, found conflicting findings on whether alexithymia caused increased or decreased awareness of physical symptoms. They proposed that for chronic symptoms the

person with alexithymia might focus inwardly causing amplified sensations, which are experienced as biological rather than psychological or benign causes. If illness was novel however, they proposed that people with alexithymia might not be aware of their symptoms because of their biased external focus of attention.

Although there is a mass of research that suggests there is an association between alexithymia and illness, little has been done in looking at how they are connected. Further research into the different pathways that link alexithymia to illness needs to be carried out (Lumley, Stettner et al, 1996).

1.4. Alexithymia and children

Garralda (1996) reported on the paucity of research on alexithymia and somatisation that has been conducted with children. To date few studies were found that looked at alexithymia and health status. The majority of studies investigating alexithymia in children were looking at associations with eating disorders and addictive behaviours, e.g. Leonie, et al (1998). Only studies looking at children and health status will be discussed below.

1.4.1. Alexithymia, children and health status

Fukunishi, et al, (1998) in Japan, wanted to study the development or aetiology of alexithymia. There were no specifically designed measures to rate alexithymia in children and so they developed 'The Alexithymia Scale for Children-Teacher Form.' This form instead of being self-rated like the TAS-20 is rated by teachers.

In their preliminary study of the scale, 286 elementary school children with a mean age of 9 participated. Participants were each rated by two teachers one of whom had observed the child at school for at least six months, however only the scores of the teacher who knew the child best were used in the analysis. The scale consisted of 23 items which were related to the constructs of alexithymia as measured by the TAS-26, difficulty describing and identifying feelings, difficulty communicating feelings to others, poor fantasy life and externally orientated thinking. The results of a Factor analysis revealed two factors for alexithymia, difficulty describing feelings and difficulty relating to others. It did not identify the other factors that are not so easy to observe by others, such as externally orientated thinking and lack of fantasy and daydreaming. The measure was validated against the Japanese version of the Yatabe-Guildford Personality Test and high correlations were found. The scale demonstrated internal consistency (Cronbach alpha of .84), and reliability. Teachers were asked to complete the scale again after two months and satisfactory re-test correlations were also found.

Further research is required on this scale before it is used as a research or clinical tool. At present it is not known if it can be used cross-culturally and in translated versions. It would have been interesting to see if teachers' scores were correlated with those of children and parents using the same scale. The two factors found on 'The Alexithymia Scale for Children-Teacher Form' were those that could be made by observations, this might miss a large part of the

alexithymia construct that looks at internal processing of emotion. A great deal of knowledge about a child and time would be required for teachers to rate a child on the scale. Teachers themselves require a certain amount of ability to identify and describe feelings if they are to rate them in others.

Meade, Lumley & Casey (2001) conducted a study looking at stress, emotional skill and illness in children. They found that their results mirrored those of the adult literature, finding that children with greater emotional skill reported better health. Interestingly this was only true when the children reported their health status. The authors had also asked parents to report on their children's health. They found that the relationship was the inverse and that children with better emotional skill had poorer health status when reported by a parent. Health status was indexed by a questionnaire that counted the number of somatic symptoms over the last three months and frequency of days off school and visits to the doctor.

Meade, Lumley & Casey (2001) proposed possible interpretations for the difference in reported health status by parents and children. First, that parents' ability to recognise when their child is ill relies in part on their child communicating its internal state to parents. If the child was unable to communicate how it was feeling, parents might remain unaware of the emotional and physical problems of that child. The second explanation that they put forward was that parents' and children's emotional skills could have been

positively related. This relationship has also been suggested by Fukunishi & Paris (2001), who carried out a study looking at intergenerational transmission of alexithymia. Their findings suggest that the alexithymia trait is passed on from mother to children. Children with poor emotional skill therefore might have parents who are less aware or sensitive to their distress.

A shortened and simplified version of the TAS-20, the 12-item TAS-Child, was used in Meade et al's (2001) study. The externally orientated thinking factor was dropped from their total score as they found poor item-total correlations (ranging from $r=-1$ to $r= .33$) and yielded poor internal reliability (Cronbach's alpha=-.16). They found good reliability however in the other two factors, difficulty identifying and difficulty describing feelings (Cronbach's alpha=.83). The two factors of the TAS-Child might not accurately represent the complete construct of alexithymia. Children might have difficulty reporting their ability to identify and describe feelings. It would be interesting to see if the TAS-Child and 'The Alexithymia Scale for Children-Teacher Form' correlated and it might be useful for research purposes to use both a self-report scale and teacher report scale as both have disadvantages and advantages, particularly when assessing children.

Fukunishi, et al, (2001), used the Alexithymia Scale for Children for a study that examined the frequency and severity of post traumatic stress symptoms in children with refractory haematological diseases, e.g. myoblastic leukaemia. The study also explored the association of alexithymic characteristics on the

development of post traumatic symptoms following medical treatment. The study compared children who had medical treatment following haematological diseases with children who had been in a severe flood disaster and with healthy children. They found more severe and frequent post traumatic symptoms in the children who had treatment for haematological diseases. Children with haematological diseases were more likely than controls to exhibit alexithymic characteristics. The authors suggest that secondary alexithymia developed in children due to the stressful conditions of the medical treatment.

This was a preliminary study and has drawbacks including the small sample size, the cross sectional investigation rather than longitudinal and the use of parents' reports of post traumatic stress symptoms and alexithymia.

Now that two scales have been developed to look at alexithymia in children, it is hoped that these will be used to study the relationship between alexithymia and health status in children within the normal developmental range.

1.5. Autistic spectrum disorder

To date the research conducted in the area of alexithymia and health has been with people who have normal developmental patterns. A number of children have difficulties with certain aspects of development. Of particular interest in this paper are children with a diagnosis of Autistic Spectrum Disorder (ASD) who are more likely to have difficulties with emotional skill. A core difficulty for children

with ASD is deficit in theory of mind (see Baron-Cohen, 1995) where children have difficulties understanding the beliefs, thoughts and feelings of others.

To the author's knowledge, no research has been carried out with people who have theory of mind deficits to test for the presence of alexithymia. This paper will now go on to look at emotional skill in children with ASD and then discuss the implications of a relationship between ASD and alexithymia.

1.5.1. Autistic spectrum disorder and alexithymia

The prevalence of ASD in the UK is presently unknown, however Scott (2000) reported that 1 in 175 children in Cambridgeshire had autistic spectrum disorder. Autism is at one end of the autistic spectrum and Asperger Syndrome (AS) at the other end. AS is a subgroup of the autistic spectrum and has its own diagnostic criteria (Attwood, 1998).

Children with ASD often have difficulties with emotional skill and this is reflected in some of the definitions. ICD-10 (World Health Organisation, 1993) incorporates 'the triad of impairments' (Wing & Gould, 1979) into their diagnosis. This includes difficulties with social interaction, social communication and imagination. In the diagnostic criteria for AS, Szatmari, Bremner & Nagy (1989) refer to impaired social interactions due to difficulties in sensing the feelings of others and impaired non-verbal communication because of limited facial expression. Attwood (1998) uses tests that examine abilities of emotional

labelling and expression of emotion as part of his diagnostic assessment for AS. Children are asked to name an emotion shown in photographs or to demonstrate on their own face a range of emotions. Children with AS often have difficulties with these tasks and can be seen trying to manipulate their faces with their hands in order to show a particular emotion.

According to Attwood (1998), people who have Asperger's Syndrome "find 'the land of emotions' to be uncharted territory" and have a number of difficulties with understanding emotions: 1) They have difficulties understanding the emotional expression of others and expressing their own feelings. 2) They might not show the range and depth of facial expression and lack precision and subtlety in their expression of emotion. Their body language also can be easily misinterpreted. 3) They have difficulty talking about inner feelings. Attwood, (1998) reports that people with Asperger's Syndrome might be upset but not have the words to explain why and that some people with ASD have to cognitively learn how to identify feelings.

Temple Grandin (1999), an adult with ASD, writes about her intellectual discovery of how emotions are communicated. Before reading Mind-blindness by Baron-Cohen (1995), she had not known that people could communicate their feelings through eye contact. She writes about when she was young and how she did not recognise the emotional friction in their house when her parents were

going through a divorce. To Grandin, knowledge is more important than emotion and she is able to separate fact from emotion.

Studies examining emotional skill in children with ASD are controversial as complex methodological issues make definitive findings difficult (Hobson, 1991). There is not space to discuss the various issues or studies that have been conducted in this area and the reader is referred to Hobson (1993). A more recent study (Hobson, 1996) looked at children with autism's appraisal of emotion. Thirteen children with autism were matched with non-autistic children with learning disabilities. The aim of the study was to see if children with autism were impaired at choosing drawn gestures of emotion to correspond with vocalisations and to see if they could match the gestures with videotaped facial expressions. Children with autism were found to be significantly more impaired than non-autistic children at these tasks. This suggests that relative to non-autistic children of the same non-verbal intelligence, children with autism have difficulty with a number of facets of emotional understanding, including recognition and matching emotionally expressive faces, gestures and vocalisations.

There is a substantial body of research that demonstrates that autistic children differ in the ways they express, perceive and understand emotion (Hobson, 1993). Jones et al (2001) argue that the majority of this research is carried out in the third person and does not gain an understanding from the people

themselves. To try and gain an understanding of the emotional knowledge of people with ASD he carried out an interesting analysis of first hand accounts posted on the Internet. Thematic analysis was used to code five personal accounts for their emotional content. Four themes were identified in the analysis, a sense of alienation, a sense of frustration, depression and fear. His results suggest that emotions are relevant to people with ASD and are often negative. There are issues of the generalisation of these findings, particularly as those who wrote the first hand accounts are likely to be those who have the greatest abilities.

The research suggests that people with ASD have difficulties with emotion and with imaginal thinking and this implies that people with ASD are alexithymic. No research could be found that assessed people with ASD on either the TAS-20, or any of its predecessors, or the EQ-I, (Bar-On, 1977).

A higher percentage of males have ASD, reflecting the findings of Salminen et al's (1999) prevalence study, where a higher percentage of men were found to be alexithymic than women in the general population in Finland. Salminen et al's (1999) study did not exclude people with ASD, or to the author's knowledge find out if anyone in this group had a diagnosis. The study's findings might therefore be more a reflection of the gender difference in ASD than of alexithymia in Finland.

Alexithymia and ASD appear to have many commonalities. They both have difficulties with concrete and imaginal thinking. The research also tends to suggest that people with ASD and people who are alexithymic have difficulties identifying and expressing emotions. The alexithymic construct by definition states there is a deficit in intrapersonal emotion, however the research also suggests that there are difficulties with interpersonal understanding. The central emotional deficit of ASD is more about interpersonal emotion for example the understanding how others are feeling because of a deficit in theory of mind. There also appears however, to be intrapersonal emotional difficulties in children with ASD. This would suggest that alexithymia and ASD are somehow related. It might be that alexithymia is at the mild end of the autistic spectrum or that ASD is a subgroup of alexithymia. It would be interesting to investigate this relationship further.

1.5.2. Implications

If it is found that ASD is related in some way to alexithymia, then there are implications for the health status of children with ASD. Children with ASD might not be aware of their symptoms of ill health and might confuse psychological distress for something physical, resulting in somatic complaints. Parents might not be aware that their child with ASD is unwell because the child would be less likely to report ill health to their parents. Research is needed to look at somatisation in children with ASD and to consider implications of health status.

Programmes have been set up to help children with ASD recognise emotion and learn to distinguish between the expressions of others (Attwood, 1998). This clinical work could be used with children who are alexithymic. If these techniques help reduce alexithymia this might lower the risk of alexithymia leading to illness.

1.6. Conclusion and future research

This paper suggests there might be a relationship between alexithymia and ASD, however research is necessary to examine what form this relationship might take. The TAS could be administered to children with ASD to see if they obtain high scores for alexithymia. If there were elevated scores on all three of the subscales it would suggest that there was a conceptual overlap between ASD and alexithymia. It might be predicted that children with ASD only score highly on certain subscales of the TAS particularly the scale 'difficulty describing emotions' and they might not score so highly on the scale 'recognising emotions'. It would be interesting to take each dimension of the alexithymia construct in turn, as in the study carried out by Devine, et al (1999) that assessed the relationship between anxiety sensitivity and alexithymia in a non-clinical sample.

It would also be interesting to carry out a similar study to that of Meade & Lumley (2001) with children with ASD to see if similar results are obtained. It is important to note however that people with ASD often find it difficult to keep track of time (Howlin, 1997) so the study should be prospective where a daily diary is completed of somatic complaints.

To conclude, a vast amount of research has been carried out in the last thirty years researching the links between alexithymia and health (Salminen, 1995). Very few studies though investigated the link in children and no studies were found with children who have ASD. It appears that alexithymia and ASD are related, however further research is necessary to find the nature of this relationship and its implications.

1.7. References

- Apfel, R.J. & Sifneos, P.E., (1979). Alexithymia: concept and measurement. *Psychotherapy and Psychosomatics*. 32, 180-190
- Attwood, T. (1998). *Asperger's Syndrome. A guide for parents and professionals*. Jessica Kingsley Publishers, London and Philadelphia.
- Bagby. R.M., Parker, J.D.A. & Taylor, G.J. (1994). The twenty-item Toronto Alexithymia Scale: 1. Item selection and cross validation of the factor structure. *Journal of Psychosomatic Research*. 38, 23-32
- Bagby. R.M., Taylor, G.J. & Parker, J.D.A. (1994). The twenty-item Toronto Alexithymia Scale: 2. Convergent, discriminant, and concurrent validity.. *Journal of Psychosomatic Research*. 38, 33-40
- Bar-On, R. (1997). *BarOn emotional quotient inventory*. Toronto: Multi-Health Systems Technical manual.
- Baron-Cohen, S. (1995) *Mindblindness. An essay on autism and theory of mind*. Cambridge, Massachusetts. The MIT Press.
- Bressi, C., Taylor, G., Parker, J., Bressi, S., Brambilla, V., Aguglia, E., Allegranti, I., Bongiorno, A., Giberti, F., Bucca, M., Todarello, O., Calegari, C., Vender, S.,

Gala, C. & Invernizzi, G., (1996) Cross validation of the factor structure of the 20-item Toronto Alexithymia Scale: an Italian multicenter study. *Journal of Psychosomatic Research*. 41, 551-559

Campos, A., Chiva, M. & Moreau, M. (2000), Alexithymia and mental imagery. *Personality and individual differences*, 29, 787-791.

Corcos, M., Guilbaud, O., Spenanza, S., Loas, G., Stephan. P. & Jeammet, P. (2000). Alexithymia and depression in eating disorders. *Psychiatry research*. 93,263-266

Devine, H., Stewart, S.H. & Watt, M.C. (1999). Relations between anxiety sensitivity and dimension of alexithymia in a young adult sample. *Journal of Psychosomatic Research*, 47, 145-158.

Dion, K. (1996) Ethnolinguistic correlates of alexithymia: Toward a cultural perspective. *Journal of Psychosomatic Research*. 41, 531-539

Fava, G.A., Fryberger, H.J., Bech, P., Christodoulou, G., Sensky, T., Theorell, T. & Wise, T.N. (1995), Diagnostic criteria for use in psychosomatic research. *Psychotherapy and Psychosomatics*, 63, 1-8.

Freud, S. (1961). *Introductory lectures in psychoanalysis* (J Strachey, trans.). New York: W.W. Norton& Co. Original work published.

Fukunishi,I. & Paris, W. Intergenerational association of alexithymic characteristics for college students and their mothers. *Psychological Reports*. 89, 77-84

Fukunishi,I., Tsuruta, T., Hirabayashi, N. & Asukai, N. (2001). Association of alexithymic characteristics and posttraumatic stress responses following mediacial treatment for children with refractory haematological diseases. *Psychological reports*, 89, 527-534.

Fukunishi,I., Yoshida, H. & Wogan, J. (1998). Development of the alexithymia scale for children: A preliminary study. *Psychological reports*. 82, 43-49.

Grandin, T. (1999). Social problems: understanding emotions and Developing Talents. <http://www.nas.org.uk>

Garralda, M. E. (1996). Somatisation in Children. *Journal of Child Psychology and Psychiatry*. 37, 13-33

Helmers, K.F. & Mente, A. (1999). Alexithymia and health Behaviours in healthy male volunteers. *Journal of Psychosomatic Research*. 47, 635-645

Hobson, R. P. (1991). Methodological issues for experiments on autistic individuals' perception and understanding of emotion. *Journal of Clinical Psychology*. 32, 1135-1158.

Hobson, R. P. (1993). *Autism and the development of mind*. Lawrence Erlbaum Associates.

Hobson, R. P. (1996). The autistic child's appraisal of expressions of emotion: A further study. *Journal of Clinical Psychology*. 27, 671-680.

Howlin, P. (1997) *Autism, preparing for adulthood*. Routledge.

James, W. (1890). *Principles of psychology*. New York: Holt.

Jones, R.S. P., Zahl, A. & Huwa, J.C. (2001). First-hand accounts of emotional experiments in autism: a qualitative analysis. *Disability & Society*, 16, 393-401

Jyvasjarvi, S., Joukamaa, M., Vaisanen, E., Larivaara, P., Kivela, S. & Keinanen-Kiukaanniemi, S. (2001). Somatizing frequent attenders in primary care. *Journal of Psychosomatic Research*, 50, 185-192.

Kauhanen, J., Kaplan, G.A., Cohen, R.D., Julkunen, J. & Salonen, J. (1996). Alexithymia and risk of death in middle aged men. *Journal of Psychosomatic Research*. 41, 541-549

Keefe, F. J., Lumley, M., Anderson, T., Lynch, T., Studts, J. L. & Carson, K. L. (2001). Pain and emotion: New research directions. *Journal of Clinical Psychology*. 57, 587-607

Kirmayer, L. J., Robins, J.M. & Paris, J. (1994). Somatoform disorders: personality and the social matrix of somatic distress. *Journal of Abnormal Psychology*. 103, 125-136.

Kojima, M., Frasure-Smith, N. & Lesperance, F. (2001). Alexithymia following myocardial infarction. Psychometric properties and correlates of the Toronto Alexithymia Scale. *Journal of Psychosomatic Research*, 51, 487-495.

Leonie, L., Monique, B., Bernard, P., Philippe, S. & Olivier, H. (1998). Is alexithymia a typical characteristic of addictive behaviours in adolescents and young adults? *Swiss Journal of Psychology*. 57, 145-152.

Loas, G., Corcos, M., Stephan, P., Pellet, Bizouard, P., Venisse, J., Perez-Diaz, F., Guelfi, J.D., Flament, M. & Jeammet, P. (2001). Factorial structure of the 20-

item Toronto Alexithymia Scale Confirmatory factorial analyses in nonclinical and clinical samples. *Journal of Psychosomatic Research* 50, 255-261

Lumley, M.A. Ovies, T., Strettner, L., Wehmer, F. & Lakey, B. (1996). Alexithymia, social support and health problems. *Journal of Psychosomatic Research*. 41, 519-530

Lumley, M.A., Strettner, L. & Wehmer, F. (1996). How are Alexithymia and physical illness linked? A review and critique of pathways. *Journal of Psychosomatic Research*. 41, 505-518

Lundh, L. & Simonsson-Sarnecki, M. (2001) Alexithymia, Emotion and Somatic Complaints. *Journal of Personality*, 69:3, 484-509

Marks, D. F. (1973). Visual imagery differences in the recall of pictures. *British Journal of Psychology*. 64, 17-24.

McDonald, P. W. & Prkachin, K. M. (1990). The expression and perception of facial emotion in alexithymia: A pilot study. *Psychosomatic Medicine*, 52, 199-210

Meade, J.L., Lumley, M.A. & Casey, R.J. (2001) Stress, Emotional Skill, and Illness in Children: The importance of Distinguishing between Children's and

Parent's reports of illness. *Journal of Child Psychology and Psychiatry*. 42, 405-412

Nyklicek, I. & Vingerhoets,A. J. J. M. (2000). Alexithymia is associated with low tolerance to experimental painful stimulation. *Pain*. 85, 471-475.

Pandey, R. & Mandal, M.K. (1997). Processing of facial expressions of emotion and alexithymia. *British Journal of Clinical Psychology*. 36, 631-633.

Parker, J.D.A., Taylor, G.J. & Bagby, R.M. (1993). Alexithymia and the recognition of facial expressions of emotion. *Psychotherapy and Psychosomatics*. 59, 197-202

Parker, J.D.A., Taylor, G.J. & Bagby, R.M. (2001) The relationship between emotional intelligence and alexithymia. *Personality and Individual Differences*, 30, 107-115

Saarjavi, S., Salminen, J.K. & Toikka, T.B. (2001). Alexithymia and depression. A 1-year follow up study in outpatients with major depression. *Journal of Psychosomatic Research*. 51, 729-733

Salminen, J.K., Saarijarvi, S. & Aarela, E. (1995), Editorial. Two decades of alexithymia. *Journal of Psychosomatic Research*, 39, 803-807

Salminen, J.K., Saarijarvi, S., Aarela, E., Toikka, T. & Kauhanen, J. (1999). Prevalence of alexithymia and its association with sociodemographic variables in the general population of Finland. *Journal of Psychosomatic Research*. 46, 75-82

Scott, F. (15th May 2000). At the public launch of the new All Party Parliamentary Group on Autism of the Autism Research Centre at Cambridge University NAS website. <http://www.nas.org.uk>

Sifneos, P.E. (1973). The prevalence of 'alexithymic' characteristics in psychosomatic patients. *Psychotherapy and Psychosomatics* 22, 255-262

Szatmari, P., Bremner, R. & Nagy, J. (1989). 'Asperger's syndrome: A review of clinical features.' *Canadian Journal of Psychiatry*. 34, 554-560. In Attwood, T. (1998). *Asperger's Syndrome. A guide for parents and professionals*. Jessica Kingsley Publishers, London and Philadelphia.

Taylor, G.J., Bagby, R.M. & Parker, J.D.A. (1992). The revised Toronto Alexithymia Scale: some reliability, validity and normative data. *Psychotherapy and Psychosomatics*. 57, 34-41.

Taylor, G.J., Bagby, R.M. & Parker, J.D.A. (1997) Disorders of affect regulation: alexithymia in medical and psychiatric illness. Cambridge, UK: Cambridge University Press.

Valkamo, M., Hintikka, J., Honkalampi, K., Niskanan, L., Koivumaa-Honkanen, H. & Viinamaki, H. (2001). Alexithymia in coronary heart disease. *Journal of Psychosomatic Research*. 50, 125-130.

WHO (1989) *Tenth Revision of the International Classification of Disease*. Geneva: World health Organisation.

Wing, L. & Gould, J. (1979). 'Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification.' *Journal of Autism and Developmental Disorders*. 9, 11-29.

Chapter II

Physical illness in young people with ASD – A parent's perspective

2.1. Abstract.

Objectives. Research suggests that people with autistic spectrum disorder (ASD) may have difficulties in identifying, expressing and understanding illness and appear to have a decreased sensitivity to pain. This study aims to give parents perspectives on how young people with ASD understand ill health and pain.

Design. Interpretative phenomenological analysis was employed to study parents' views of their children's experience and understanding of illness and pain.

Method. Semi-structured interviews were carried out with 13 mothers of adolescents who have a diagnosis of ASD. The verbatim transcripts were used as the data for an interpretive phenomenological analysis.

Results. Eight main themes were identified and these are described under the 3 broad domains of understanding illness, differences in expression of illness / pain and the awareness of parents that their child is unwell.

Conclusions. Parents noticed many differences in how their children who had ASD understood and expressed pain and illness compared with siblings and other children without the disorder. These differences are explained in terms of the literature on autism.

2.2. Introduction

This paper begins by discussing some of the general literature about people's personal knowledge of health and illness and why it is a valuable area to investigate. Most literature in this area has focused on children and in particular on children who are chronically ill. The literature relating to the experience of health and illness in people who have autistic spectrum disorder (ASD) is scarce. The literature that exists suggests that there may be differences between ASD and a non-ASD population in understanding, recognition and expression of illness and also differences in pain threshold. This present study goes on to outline the nature of ASD and investigates parents' perceptions of their child's understanding of illness.

2.2.1. The concept of health and illness

A number of studies have been carried out to try to understand how children conceptualise health and illness (e.g. Bibace & Walsh, 1980, Eiser 1989, Hergenrather & Rabinowitz, 1991). Recent studies have shown that children are able to understand more about illness than previously thought (Rushforth, 1999). In understanding children's concepts of health and illness, improvements can be made in their provision of care and more effective communication can be achieved. According to Eiser & Kopel (1997) the study of the development of concepts of health and illness are justified because it has practical implications such as providing age-appropriate health education, reducing anxiety and fears

of treatment and helps to include children in health care decisions and service development.

Bibace and Walsh (1980) proposed a stage theory of how children understand illness based on Piaget's stages of cognitive development (Piaget & Inhelder 1969). They suggest that by the age of 11 children should have achieved the highest level of explanations for conceiving illness. This stage is the formal operational stage where there is greatest differentiation between self and other. Rushforth (1999) who carried out a review of research pertaining to children's understanding of health and illness suggests that Vygotsky's developmental theory (1962) may be a more appropriate way to understand how children learn to conceptualise health and illness. This suggests that children might have a certain level of understanding but that this level can be increased within what Vygotsky (1962) describes as the "zone of proximal development" and that this can be done through instruction and teaching.

Kister and Patterson (1980) studied children's understanding about the causes of illness. They found that as age increased there was greater understanding about the actual cause of illness, that many children used "immanent justice" explanations to explain illness and that these explanations were inversely related to their understanding of contagion. This means that an increase in children's understanding of the physical causes of illness is associated with children becoming less afraid or feeling less guilty about illness.

However, whilst this research is useful, it only tells us about normally developing children. How children with developmental difficulties understand the concepts of health and illness have not been explored.

2.2.2. High Functioning People who have ASD

ASD covers a whole range of ability and disability, however high functioning individuals with autism still have a range of difficulties that arise from the same basic impairments.

One of the core deficits experienced by people who have ASD is difficulty with "theory of mind". According to Myles and Southwick, (1999) this is what sets high functioning individuals with ASD (sometimes known as Aspergers Syndrome) apart from people who do not have ASD. Theory of mind is a limitation in understanding other people's mental state (Baron-Cohen, 1989). People who have deficits in theory of mind may have a variety of difficulties including understanding their own and others' emotions and difficulty in explaining their own behaviour (Myles and Southwick, 1999).

2.2.3. ASD and the concept of health and illness

Given the difficulties experienced by children with ASD it would seem important to look at this group's understanding of health and illness. There is a dearth of literature on ASD and concepts of health and illness. A number of books about ASD briefly mention individual's expression, identification and understanding of

illness and pain. Lacamera and Lacamera (1997) state that people with ASD do not always seem to identify if they have been hurt and it is not uncommon for a child or adult with ASD to fracture a bone and for this to go undetected. They report that young men who have ASD are often unaware of lumps or masses in their genitalia.

Howlin (1997) reports that people with ASD have become seriously ill without being able to communicate that they were in pain. She says that this is particularly marked with people who also have severe learning disabilities and that undiagnosed physical illness or infections may be a cause of behavioural change.

Taylor (1990) advises that people with ASD should have regular health check ups and that even though individuals may have good use of language and have gained a degree of independence, she argues that it does not follow that they will be able to recognise or explain symptoms of ill health. A major problem for people with ASD is their lack of ability to talk about and fully understand abstract concepts such as feelings, emotions and pain (Howlin, 1997).

People with ASD have difficulty in understanding facial expressions and difficulty in matching their own expressions with how they are feeling. Just as they are unable to share pleasurable experiences, many people with ASD are unable to share pain and distress in the normal way (Howlin, 1997) and this may hamper

their learning about illness. It may also hamper others, in particular the ability of parents to notice subtle signs of ill health in their children.

Traue and Pennebaker (1993) refer to the growing number of research studies that have found links between emotional expression and mental and physical health. They state that it is not a new discovery to suggest that inhibition of emotions can lead to health and psychological problems, it was noted as far back as 1890 by William James and by Sigmund Freud (e.g. 1917). If health and illness were inter-related with emotion and its expression, it would suggest that people who could not express emotion might suffer with health consequences.

Recently there have been a number of first person accounts written by people who have ASD and their carers. A number of these mention experiences of illness and pain such as Kenneth Hall (2001) a 10 year old boy who took his GCSE's 6 years early. He believes people with Aspergers Syndrome feel things differently and that they can be very sensitive. He reports being immune to certain types of pains and not noticing till the morning that he had been sick in the night, whilst at other times he felt things intensely. Schnieder (1999) in "Discovering my autism" writes about two symptoms of his autism that had a significant role in his life, namely his high pain threshold and his blasé reaction to physical danger. Clare Sainsbury (2000) gives an insightful testament of her experience at school as a child with Aspergers Syndrome. She reports about tactile defensiveness where physical contact and even proximity were

overwhelming and intolerable. She reports that a slight brush by someone when walking past may result in a child with Aspergers Syndrome reacting angrily and consequently being told that they are over reacting.

2.2.4. Conclusion

There may be a number of reasons why people with ASD may not have the same understanding of illness and pain or do not seek help when they are sick or ill in the same way as clinically normal individuals. This study attempts to explore some of these issues by investigating concepts of illness in adolescents functioning within the high range of the autistic spectrum.

Initially a parent's perspective was chosen because of the language and expressive difficulties of children with autism and predicted difficulties in gaining informed consent from young people with ASD to participate in the study. An interpretative phenomenological approach (IPA) (Moustakis, 1994; Smith, Jarman and Osborne, 1999) was utilized. This approach attempts to allow the researcher to enter the world of parents and their experiences of parenting a child who has ASD. The IPA approach also acknowledges that it is the author's interpretation of the data that is being presented.

2.3. Aims

The aim of this study was to explore parents' perceptions of their child's understanding about illness using an IPA approach among those with an autistic spectrum disorder.

2.4. Method

2.4.1. Process

Semi-structured interviews were carried out with thirteen mothers who had children with a diagnosis of an autistic spectrum disorder. The interviews as a whole lasted between twenty minutes and one hour and also formed part of another study (Phelps et al, 2002). The interviews were taped and parents' verbal content transcribed and analysed using an interpretative phenomenological approach as described below. The participants' names, along with any identifying information have been changed for reasons of confidentiality. A fictitious child's name has been put alongside the quotes to help the reader know whether the quote refers to a male or female.

2.4.2. Participants

Ethics approval was obtained from two local Child and Adolescent Mental Health Service NHS Trusts (appendix A & B).

Fifty-six parents of children aged between 12 and 16 with a diagnosis of ASD were invited to take part in the study via a letter. All children had at some point

attended mainstream school, however three were now attending special schools for people with autism. Thirteen parents returned participation slips indicating they were willing to be interviewed. Further demographic details can be found in table 1.

Table 1. Demographic details of Participants

| | |
|--------------|---|
| Parents | 13 mothers (however two fathers were around for part of the interviews but only one spoke on the tape). |
| Age of child | 12-15. Mean age 13 |
| Gender | 3 female, 10 male |
| Siblings | All had at least one sibling or half brother / sister |

2.4.3. Interviews

The interviews followed a semi-structured format as described by Smith (1995) in that the interviews were guided by the schedule rather than dictated by it. See appendix C. for the interview schedule. Any new themes brought up were incorporated into the questioning in subsequent interviews; this flexibility enabled richness to be brought to the data. The aim of the interview was to elicit the parents' story of their perceptions of their children's experience of illness and pain. The interview was prior-research driven (Boyatzis 1998) in that it was devised on the basis of prior data in the area. The areas thought to be of interest to investigate were young people's understanding, recognition and expression of ill health and pain. In order to gain greater insight into any differences that may

be due to ASD, parents were asked about any differences to do with health and illness that they had noticed between their children.

2.4.4. Interpretative phenomenological approach

An interpretative phenomenological approach was employed to analyse the data (see Moustakis, 1994; Smith, Jarman and Osborne, 1999). The aim of this approach is to explore the views of the participants about the topic under investigation. It was felt this approach was valuable, as it is not attempting to produce an objective statement of how young people with ASD understand and experience illness but to explore the parents' perception. Although this approach tries to get as close as possible to the participants' perspective of events (Conrad 1987), it recognises that the researcher also brings their own interpretations. The evolving guidelines for the publication of qualitative research suggested by Elliot, Fischer & Rennie, (1999) have been followed.

2.4.5. Analysis Process

Table 2 summarizes the analysis process. It was an iterative procedure throughout in that the data informed the themes, and new themes that emerged were tested against the data from previous interviews. To verify the internal validity and reliability of the analysis a number of checks were carried out as suggested by Elliott, Fischer & Rennie, (1999). The second author checked the emergent analytic account at each stage of the process in order to ensure that the arguments presented in the study were internally consistent and justified by

the data. This was not intended as an inter-rater reliability check. As an additional validity check a parent who had not taken part in the study but whose child fitted the criteria for participation, was asked to read through the results section. They were asked to comment on whether the results made sense to them and whether they could identify what had been written.

Table 2. Analysis Process

| | |
|---------------|---|
| Step 1 | The first interview transcript was read and re-read a number of times. Preliminary notes were then made, keeping as close as possible to the data. |
| Step 2 | The transcript was re-read and emerging themes and titles were identified. |
| Step 3 | Where there were connections between emerging themes these were clustered together. Checks were made to ensure that the clusters of themes fitted in with the original data from the transcripts. |
| Step 4 | A master list of themes and sub-themes was identified and instances where each occurred in the script were noted. |
| Step 5 | The above process was carried out with all the interviews. Summaries were written for some of the interviews to help with the analysis. A qualitative research collective met and analysed two of the interviews independently. The collective discussed the interviews and emergent themes were agreed upon. |
| Step 6 | By consolidating the themes from all the interviews a master list of themes was produced. These were reviewed and worked upon with one of the collaborators until 8 main themes were identified. After discussion these themes were grouped together into 3 domains. |

2.5. Results

This section presents the eight main themes that were constructed from the analysis. These themes were organised together into three general domains, see table 3. The domains and themes are illustrated below with quotes in order to provide further transparency. According to Smith (1995), the presentation of evidence is required so the reader can check the author's interpretation of the data.

A prominent theme that developed was differences in the perceptions that parents had of their child with ASD and their siblings with regard to all the themes. It was felt that rather than include these differences as a separate theme they would be better discussed in relation to each theme in turn.

Table 3. Domains and themes that emerged from analysis

| | Domains and themes | Number of respondents with themes. |
|----------------|--|---|
| | Difficulties understanding illness | |
| Theme 1 | Understanding the concept of illness | 11 |
| Theme 2 | Recognition of illness | 8 |
| Theme 3 | Understanding others' illness | 10 |
| | Differences in expression of illness / pain | |
| Theme 4 | Subdued reaction | 6 |
| Theme 5 | Extreme reaction | 7 |
| | Parental awareness of their child's health | |
| Theme 6 | Communication | 6 |
| Theme 7 | Distress and illness | 8 |
| Theme 8 | How parents find out if their child is unwell | 8 |

2.5.1. Domain 1 – Difficulties understanding illness

This domain covers parents' perceptions of their children's understanding of the concept of illness. It also looks at the young persons' ability to recognise that they and others are unwell.

Theme 1 - Understanding the concept of illness

Eleven parents described some difficulties in their child's understanding of the concept of illness, however there appeared to be quite a range of knowledge. Only two parents felt there were no difficulties in their children's understanding.

This theme will be highlighted below.

Melanie's mother felt that her daughter had difficulties understanding illness on a number of levels.

***"I am aware that Melanie's understanding of illness and pain is not the same as ours, on lots of different levels"* Melanie's mother**

Other parents felt that their children's understanding of illness was limited like David who did not appear to understand about contagion.

***"He would not associate the fact that if he had a room full of people all with colds, measles or chicken pox that he runs the risk of getting it himself. It's almost as if it has been purely manifested for him."* David's mother**

Stuart's mother was very concerned about her son's understanding of illness, as he had generalised the concept of contagion to all illnesses.

"And if he thinks he has got something he thinks he has caught it off somebody else. He wouldn't accept that it just happens. People get these things. He said he would not sit next to a cancer patient in case he caught it." Stuart's mother

Patrick's mother believed that even though her son understood the concept of contagion intellectually and was quite obsessed about it, it did not stop him putting what he understood about germs, in to practice, like washing his hands.

"He knows that that is how you pick up germs and that is what causes an upset tummy but it does not stop him from doing it. So although he knows that it does, it does not affect what he does."

Patrick's mother

Other difficulties children had in understanding illness was with taking medical terms literally; this had caused a lot of anxiety in one particular case.

"A doctor came and looked at it and she said I think we should get it x-rayed, it could be something floating in there. And that was it he just freaked out because all of a sudden there is something that has invaded his body. Something is floating in his body. He had taken it literally, that was it. What is going to happen? This thing is floating inside me." David's mother

Parents felt that concrete information was required to help their child to understand. Grant's mother had talked about her embarrassment when her son returned from school where they had been taught about periods and asked to see her period.

"Yes, and to see it is to believe it, it's alright to talk about it but he needed to see it and that personal thing didn't exist with him."

Grant's mother

Theme 2 - Recognition of illness

This theme is about young people's skill in recognising that they are ill. In eight cases difficulties in this area emerged.

Parents often felt that their child was not able to recognise the early stages of illness. Grant's mother had been very concerned that he would not recognise that something was seriously wrong until it was too late. Her nephew had had his appendix out recently and she didn't know if Grant would be aware in time if he had something similar wrong with him.

"Some people say I'm not feeling too good and it's like as though that bit he misses and it's not until he's really unwell till the end symptoms like actually getting sick and you know.... I often wondered if there was anything like that would we know or would he tolerate it for too long."

Grant's mother

However his mother felt that as he was getting older he was able to identify earlier when he was becoming unwell.

"It's still along the line you know, if you had 0, it would be nearing towards the 10 before we'd realise."

Grant's mother

Some parents felt that their child had trouble distinguishing between feeling unwell and something external.

"I think he does have trouble knowing when he actually feels ill or whether it is something from outside that is affecting him." Patrick's mother

Theme 3 - Understanding others' illness

This theme relates to young people's understanding of other people's illnesses. It covers difficulties in recognising and responding appropriately to others when they are unwell or in pain. This theme emerged in ten of the interviews and some quotes are cited below to illustrate the theme.

Parents mentioned that their children had difficulties in recognising that other people were unwell. For example Adam had difficulty recognising the body language of someone who was unwell.

"He'd be sympathetic if you told him but I don't think he'd recognise if you sat there holding your head." Adam's mother

In a number of the interviews it emerged that young people did not make concessions when others were unwell, they expected them to carry on the same.

"Whilst I was in hospital I was ill but once I got home you're alright. He just thought I could get up and do everything, it's like only sick people are in hospital but when you're at home, they put you right and that is how it goes." Grant's mother

"It was as if she knew I was ill but it did not actually make any differences as to how I should be. She could not appreciate the fact that I felt ill, meant I may not want to do the things I normally do."
Melanie's mother

David expected his mother to drive him somewhere even though she had had a cartilage operation on her knee.

"Well why can't you? You have this colossal knee, crutches, and he would still expect you to do everything you would normally do."

David's mother

2.5.2. Domain 2 - Differences in expression of illness / pain

This domain is about parents' perceptions of the way young people react to pain and illness. Two contrasting themes emerged, namely subdued and extreme reactions. Reactions appeared to be disproportionate to the injury / illness where some of the young people were unresponsive to large amounts of pain / illness or reacted in an extreme way to small amounts. In eleven of the thirteen interviews differences between children with ASD and siblings or other children of a similar age emerged regarding expression to pain and illness.

Theme 4 - Subdued reaction

In six of the interviews parents described their children's reactions to pain and illness as subdued, withdrawn and with limited fuss made. In some cases reaction appeared disproportionate to the injury or illness like Keith's reaction to injury.

"I mean it might turn out to be more bruised than ... but he does not seem to turn around and show on the outside a lot of pain." Keith's mother

Parents seemed to notice differences in this area from an early age, often before the diagnosis of autism was made. Some parents reported being surprised by

their child's lack of response to injury. For example when Stuart broke his leg, he did not react much to the pain but was more annoyed that he hadn't received many 'get well soon' cards.

"He did not make a big issue about his leg at all, which I found quite strange." Stuart's mother

Even Grant's doctor was very surprised at how much pain Grant had put up with for three days without anyone knowing, his injury only came to light because his mother noticed when it became inflamed.

"You must be one on your own to be able to pull your toe nail off."
Grant's mother referring to what the doctor had said to Grant

Some parents described their child as being good and appeared to be proud that they were resilient to pain and illness. For example Miles' mother described her son as being good because he did not cry or anything when he fell off his bike and was pouring with blood. Grant's mother thought her son made a perfect patient.

"He was the perfect patient in respect that when he felt ill he was happy to just lie there in bed on his own and didn't want anyone there." Grant's mother

Three parents, including Veronica's mother actually reported that they felt their child had a high pain threshold.

"She has a strong pain threshold, that saying when she was a baby she would, I know it sounds cruel, walk and bump into the table and she would just get up." Veronica's mother

Theme 5 - Extreme reaction

This theme is about extreme reactions to pain / illness that are often excessive to the injury / illness. In some instances parents reported that they felt their children had a low pain threshold where slight injuries caused the child to react as if they were severe. Quotes below demonstrate the examples from four interviews.

"If he bangs a toe he screams, if he slips on the stairs you would think he has broken a limb and even now he really doesn't like pain"
John's mother

"He finds it very difficult to express himself so if he does have a pain he tends to blow it out of proportion, like if it was a headache for example, he will be screaming around in pain but it may not be so severe as he is actually letting on, and you would think it was a tumour."
Stuart's mother

"If Melanie falls over and hurts herself, it is very difficult to tell how badly hurt she is because she can react in exactly the same way. She can fall over and just bang her knee and she can scream and yell and it will be terrible."
Melanie's mother

"You would think he had been hit by a bus if he had fallen over and bumped his knee. It is always a very, very excessive reaction whereas others would come in crying but David would not be crying, but he would be carrying on, complaining and being cross."
David's mother

In some cases parents did not appear to believe that their child was ill or in pain, they put the extreme reaction down to their child wanting attention.

"Everything just stops for him; he wants time off from school to go to the doctor. I usually don't take him seriously. Once he shouted so much that the neighbours called the police because he had a sore throat." Jeremy's mother

2.5.3. Domain 3 – Parental awareness of their child's health

This domain is about difficulties that parents have in knowing that their child is genuinely ill, and how parents find out if there is something wrong. In twelve of the interviews parents referred to difficulties in knowing whether their child was genuinely ill or in pain and to what extent. Reasons why these difficulties may occur include poor communication, not knowing if there is something else wrong, disproportionate reactions to pain and illness, difficulties understanding the concept of illness and difficulties in recognising that they are unwell. Some of these have already been described above and so this section will concentrate on the first two, as they have not previously been discussed.

Theme 6 - Communication

Six parents reported that their child was not good at communicating that they were unwell. For some parents they felt that this was due to their children's difficulties in expression.

"It is very hard to know if he is actually in a lot of pain because he can't express himself" Stuart's mother

In some instances illness was identified by changes in behaviour.

"He doesn't actually tell me that he is ill, it is just in the way he behaves differently, he goes quiet or he won't get out of bed."

Patrick's mother

Other parents appeared quite confused as to whether their child was ill or there was something else wrong because of their child's communication difficulties. Six months ago Patrick was bullied at school, at the time his mother did not know what was wrong.

"And I did wonder at the time whether there was something happening or whether he was not very well, he was a bit confused.... He just does not know how to explain things." *Patrick's mother*

Theme 7 - Distress and illness

This theme is related to the manifestation of distress through illness and the use of illness to communicate distress. This theme emerged on eight occasions, with a selection printed below.

Adam would regularly have stomach ache on Thursday mornings. His mother thought it was because he hated geography and he was either using it as an excuse or the stress was actually making him ill.

"He could have just been using it as an excuse or he could have been working himself up into it that he physically felt ill." *Adam's mother*

Other emotions also appeared to bring on illness, for example Stuart's mother felt that the excitement leading up to his birthday had caused him to be ill.

In some situations parents felt that illness was used to communicate distress, the following extracts demonstrate this. John would tell his mother he was ill but she thought that it was stress. She did not think his siblings would have done this.

"The only way he could articulate he wasn't happy, he didn't want to go to school, was by saying I am not well." John's mother

"We also think that maybe if she is feeling unhappy or a bit confused or she is miserable, we suspect she expresses that by saying she has got a headache.... I often feel she will say she has a headache or pain when she is feeling unhappy because she cannot express emotions very well. I think she uses pain as a descriptor for unhappiness or sadness." Melanie's mother

For about a year prior to Keith's diagnosis with ASD he complained to his mother about a pain he had in his elbow but she did not think that there was anything wrong, as he still used it in the same way as he had previously done. However when he got his diagnosis this complaint ceased and his mother feels that it was his way of communicating that something was wrong but could not express what the problem really was.

"He was trying to say there is something wrong, I realise that now, he was trying to tell me there is something wrong" Keith's mother

Theme 8 - How parents find out if their child is unwell

This theme emerged in eight of the interviews. Parents discussed ways that they used to find out if their child was genuinely ill or in pain. Parents described doing detective work, observing their child's behaviour, mood and physical changes.

They asked their child regularly about their health and took them to the doctors to check that they were well.

"She might start behaving badly. So you are constantly watching to see the signs. Not obsessed with illness but if she is being silly you are looking to see if she is ill." Melanie's mother

"Trial and error finding out whether he is ill or something has happened at school, you just have to go through all the questions."

Patrick's mother

2.6. Discussion

The analysis of the interviews revealed many examples of how parents perceived their child's understanding of health and illness. It needs to be taken into account that this is how parents perceive their child and may not be an accurate representation of their level of understanding. Each domain in turn will now be discussed in terms of the literature in the area on autism and health.

2.6.1. Domain 1 - Difficulties understanding illness

In general parents perceived that their child who had ASD had difficulties with understanding illness, however their degree of understanding appeared quite varied. Possible reasons why children with ASD may have difficulties in this area are suggested below, however whilst they will be discussed in turn, they are not mutually exclusive and all potentially impact on each other.

According to Bibace and Walsh's theory (1980) the children in this study should have reached the formal logical stage of understanding illness, where illness is understood in terms of a breakdown of body parts (Eiser & Twamley, 1999). Most of the young people in this study clearly understood illness at a lower developmental level based on Bibace and Walsh's (1980) stage theory. David for example blamed his mother for making him ill. This would suggest that his understanding was at a pre-operational stage, where children cannot separate between cause and effect. According to Myles & Simpson, (1998) people with Asperger Syndrome, do not sequentially proceed through various stages of development and might have gaps in their knowledge.

Other parents felt their children understood illness at the concrete operational level, in relation to contagion and contamination. As suggested by the name, this level is a more tangible way of understanding illness. Melanie's mother for example, felt her daughter had a very concrete way of understanding how illness was caused.

"I think she thinks germs are like little peas that live in your stomach and they make you feel ill." Melanie's mother

Children with ASD often have difficulties understanding abstract concepts (Howlin, 1998) and may therefore have difficulties with concepts like illness that are not concrete.

Hergenrather and Rabinowitz (1991) found that a greater proportion of 6-7 year olds compared with 13-14 year olds, believed all illnesses were contagious. Some of the young people with ASD appeared to generalise contagion as the only cause of illness. Stuart for example, according to his mother, thought that all illnesses could be caught off other people. The information gained from the interviews suggests that the children in this study had a lower developmental understanding of illness concepts than would be expected for their age.

In some cases the young people with ASD used consequences of behaviour rather than symptoms to identify that they were ill. Grant, according to his mother, appeared to identify that he was unwell by whether or not he could eat; he would carry on eating until he was sick and would only then go to bed. Hergenrather and Rabinowitz (1991) found that all the children in their study to some degree relied on behavioural cues such as being sent to bed to determine when they were ill. This decreased with knowledge about illness and age, only 35% of 13-14 year olds in their study relied to some extent on behavioural cues compared with 62% of 6-7 year olds.

First person accounts have described sensory abnormalities in people with ASD, one account written by an 8 year old boy and his carer refer to difficulties that people with ASD have recognising body signals (Matthew & Williams, 2000). This difficulty along with a lower level of understanding about illness may impact on how people with ASD recognise when they are ill. Melanie's mother felt that

"not feeling too well" was an abstract feeling and felt that this was why Melanie had difficulty recognising when she was unwell.

Vygotsky (1962) suggested that children might reach a certain level of understanding but that this level can be increased through instruction. Many of the parents had been trying to teach their child about illness, like Keith's mother who had been teaching him about testicular cancer. This may have been above his level of understanding but it appeared that he was able to learn.

Semantic pragmatic language problems are often present in people with ASD (Howlin, 1998). These problems may have been influential in the confusion that David experienced understanding his doctor. David literally interpreted his doctor's diagnosis, believing that something was actually floating in his leg and he therefore refused to walk.

According to Howlin (1999) almost all children with ASD show problems in the area of obsessions and rituals. Some of the parents felt that their child had become quite obsessive about germs. Stuart for example, refused to eat off plates in his school canteen because he was obsessed about catching germs.

For people who have ASD, routines and structure bring security to their lives. Changes in these routines can cause strong negative reactions (Myles & Simpson, 1998). Illness, whether it be their own or others, can cause disruption

to normal routines and consequently may result in behaviour difficulties. David for example disliked being ill because he had to stay in and his mother felt that he became quite inconsolable when he was ill.

A number of the young people had difficulties in understanding other people's pain and illness. The young people often missed non-verbal signs of illness. These difficulties may be explained by deficits in theory of mind, which can result in difficulties understanding the perspectives of others and predicting their emotional state (Myles & Southwick 1999). In some cases young people used hospital as a concrete signal that someone was ill. Once that person was at home recovering however some children had difficulties understanding why they could not do what they usually did.

2.6.2. Domain 2 – Differences in expression of illness / pain

In this study the expression of young people with ASD to illness / pain appeared to be at two opposing ends, either extreme or subdued.

Parents who took part in the study were often surprised by the differences between their children who had ASD and those who did not. Some of the parents described their child as showing little reaction to illness and injury. The literature suggests that people who have ASD have a decreased sensitivity to pain (Peeters and Gillberg 1999) and are less likely to locate and express the source of discomfort than their peers (Aarons and Gittens, 1999). Pain is a

highly subjective experience and was assumed in the past to be difficult for children to identify and locate. Parents' reports however have been found to be inaccurate and influenced by anxiety (Eiser & Twamley, 1999). Perceptions of parents to their children's lack of emotional expression varied. Some parents perceived their child's ability to withstand large amounts of pain and illness 'without a fuss', as 'good' and 'stoical'. For other parents this lack of expression was a concern, they were worried that they would not identify illness early enough if their child needed medical intervention.

On the other hand some of the parents felt that their child reacted extremely to minor illness or injury, in some cases as if they were dying. Some parents perceived this disproportionate way of expressing illness or injury as their child's way to get attention.

According to Trevarthen, Aitken, Papoudi & Robarts (1998), people with ASD can have abnormal sensory responses, being very sensitive to certain stimuli, even a light touch causing pain. This may be another explanation for the extreme reaction of children with ASD to pain and illness. Parents were often frustrated by their children's extreme reaction to illness and pain. One parent who had six other children said that she would rather all of them be ill for a week instead of her son with ASD being unwell for one day.

2.6.3. Domain 3 - Parental awareness of their child's health

In this study, parents reported finding it difficult to know whether their child was unwell. Parents used a variety of methods to try to find out if their child was unwell or whether there was another problem. On the whole parents felt that their child did not communicate that they were ill or that they were distressed. In a number of cases, parents thought their child's distress had been expressed through illness.

People who have deficits in their theory of mind according to Myles & Southwick (1999) may have difficulties in understanding their own emotions and may not have the ability to express emotions adequately. According to Lloyd (1986) difficulties in the ability to verbalise distress is the underlining factor in somatisation. Somatisation is the manifestation of psychological distress through somatic symptoms (Gerralda, 1996). Emotional distress in the young people with ASD may have been manifested in somatic symptoms. Distress may also be expressed through behaviour difficulties. Children with ASD, according to Howlin (1998), experience an inevitable pressure at school that if too excessive will be communicated through behaviour.

A study by Meade, Lumley & Casey, (2001) found that children's emotional skill was correlated with better health when children were asked about the state of their health. This, according to Meade, Lumley & Casey, (2001), echoes the adult literature demonstrating that the ability to identify and describe feelings is

associated with fewer health problems. Their study also found however that when parents reported on their children's health status, children's emotional skill was correlated with worse health. One hypothesis that they put forward was that children who were more emotionally skilled were more able to report their internal state to their parents, whereas those who were less emotionally skilled were unable to do so. Parents of the less emotionally skilled child might therefore be unaware of their child's ill health. Generally it emerged that the children in this study had difficulties expressing their emotions. This research suggests that these parents may not always be identifying when their child is unwell. In most cases however, parents were aware that their child had more difficulty expressing themselves and used other methods to find out if their child was unwell. In some of the interviews parents reported that their child was hardly ever ill and in one case a mother reported that her child had 100% attendance at school. This response was particularly common when children were reported as having little expression to pain and injury. It may be that parents are actually not aware that their child was unwell and this may have serious implications.

2.7. General conclusions

Although this study is based from a parent's perspective it is hoped that the findings will be beneficial in the exploration of how young people with ASD understand and experience illness. The parents interviewed tended to suggest that there were differences in understanding among young people with ASD compared with young people in the normal population. Whilst people with ASD

appeared to understand illness on a concrete level the abstract concepts and emotional side of illness appeared to have been more difficult for some young people to understand. Further research needs to be conducted in this area to gain a greater understanding of differences. A subsequent study questioning the children with ASD about how they understand illness could be carried out.

This study goes some way in exploring parents' experiences of illness in children with ASD however it has limitations. As qualitative studies utilise small samples, the results cannot be considered to be representative of the wider population (Eiser and Twamey, 1999). IPA is looking at parents' experiences and the researchers' interpretations of them, it is not intended to be generalised to all parents who have a child with ASD. This study does not discover the views of the children who may have a greater knowledge than parents attribute to them. Due to the limitations of using an IPA approach further research needs to be conducted to complement this work.

2.7.1. Clinical implications

This study has some important implications for health care professionals. For instance it highlights some of the difficulties experienced communicating about illness and injury with someone with ASD. These difficulties may arise due to the young person making literal interpretations of information. Difficulties may arise because young people with ASD might have a greater difficulty understanding

the abstract concept of illness or in recognising and expressing that they are unwell.

Howlin, (1998) recommends that people with ASD have regular visits from their doctor so that both parties can get to know each other. Medical professionals according to Howlin (1998) might have little knowledge about ASD and need time to become accustomed to their patient.

This study found that a number of the diagnoses of ASD were pre-empted by health professionals because they noticed unusual reactions by the young person to illness / pain. Increasing health professionals' knowledge about ASD might help earlier diagnoses being made.

Greater information needs to be given to medical professionals to help them care and communicate effectively with children with ASD.

2.8. References

- Aarons, M. & Gittens, T. (1999.) *The Handbook of Autism, A guide for parents and professionals, 2nd edition.* Routledge.
- Baron-Cohen, S. (1989)'The Autistic child's theory of mind: a case of specific developmental delay', *Journal of Child Psychology and Psychiatry.* 30: 285-297.
- Bibace, R. & Walsh, M.E. (1980). 'Development of children's concepts of illness", *Pediatrics,* 66: 912-917.
- Bibace, R. Lothar, R. Schmidt & Walsh, M.E. (1994). 'Children's perceptions of illness.', Cited in G.N. Penny, P. Bennett, M. Herbert. (Eds.) *Health psychology. A lifespan perspective.* Harwood Academic Publishers.
- Boyatzis, R.E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development.* Sage Publications.
- Conrad, P. (1987) 'The experience of illness: Recent and new directions', *Research in the Sociology of Health Care,* 6: 1-31.
- Eiser,C. (1989). 'Children's concepts of illness: Towards an alternative to the stage approach', *Psychology and Health,* 3: 93-101.

Eiser, C. & Kopel, S.J. (1997). 'Children's perceptions of health and illness', in J.A. Weinman & K.J. Petrie (eds.) *Perceptions of Health and Illness*. Harwood academic publishers.

Eiser, C. & Twamley, S. (1999). 'Talking to Children about Health and Illness', in M. Murrey and K. Chamberlain (eds.) *Qualitative Health Psychology Theories and Methods*. London: Sage Publications Ltd.

Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). 'Evolving guidelines for publication of qualitative research studies in psychology and related fields', *British Journal of Clinical Psychology*. 38: 215-229.

Freud, S. (1917/1966). 'Introductory lectures on psychoanalysis', New York: Norton, in H.C. Traue & J.W. Penneebaker, (1993) (eds.) *Emotion, inhibition and Health*. Hogrefe & Huber Publishers.

Garralda, M.E. (1996). 'Somatisation in Children', *Journal of Child Psychology and Psychiatry*. 37: 13-33.

Hall, K. (2001). *Asperger Syndrome, the Universe and Everything*. Athenaeum Press.

Hergenrather, J.R. & Rabinowitz, M. (1991). 'Age-Related Differences in the Organization of Children's Knowledge of Illness', *Developmental Psychology*, 27, 6: 952-959.

Howlin, P. (1997). *Autism, preparing for adulthood*. Routledge

Howlin, P. (1998). *Children with Autism and Asperger Syndrome, A guide for Practitioners and Carers*. John Wiley and Sons.

James, W. (1890). 'The Principles of Psychology (vol.2)', New York: Holt, in H.C Traue & J.W. Pennebaker, (1993) (eds.) *Emotion, Inhibition and Health*. Hogrefe & Huber Publishers.

Kister, M.C. & Patterson, C.J. (1980). 'Children's conceptions of the causes of illness: Understanding of contagion and use of immanent justice', *Child Development*. 51: 839-846.

Lacamera, R. & Lacamera, A.C. (1997) 'Routine Health Care', in D. J. Cohen, & F.R. Volkmar, (eds.) *Handbook of Autism and Developmental Disorders, Second Edition*. John Wiley and Sons, Inc.

Matthews, J. & Williams, J. (2000). *The self-help guide for special kids and their parents*. Jessica Kingsley Publishers, London and Philadelphia.

Myles, B. S. & Southwick, J. (1999). *Asperger Syndrome and Difficult moments: Practical Solutions for Tantrums, Rage, and Meltdowns*. Autism Asperger Publishing Co.

Myles, B.S. & Simpson, R.L. (1998). *Aspergers Syndrome. A Guide for Educators and Parents*. Pro-ed, Inc.

Meade, J. A., Lumley, M.A. & Casey, R.J. (2001). 'Stress, Emotional Skill, and Illness in Children: The Importance of Distinguishing between Children's and Parents' Reports of Illness'. *Journal of Child Psychology and Psychiatry*. 42: 405-412.

Moustakis, C. (1994). *Phenomenological Research Methods*. London: Sage Publications.

Peeters ,T. & Gillberg, C. (1999) *Autism, Medical and Educational Aspects, Second edition*. Whurr Publishers, London.

Piaget, J. & Inhelder, B. (1969). *The Psychology of the Child*. London; Routledge & Kegan Paul.

Phelps, H.A., Elliott, J. Knight, E.S. & Knibbs, J.A., (2002). 'Investigating the Concept of Death in Adolescents Functioning at the High End of the Autistic Spectrum'. *To be submitted to Death Studies.*

Rushforth, H. (1999). 'Practitioner Review: Communicating with Hospitalised Children: Review and Application of Research Pertaining to children's Understanding of Health and Illness', *Journal of Child Psychology and Psychiatry*. 40, 5: 683-691.

Sainsbury, C. (2000) *Martian in the Playground*. Lucky Duck Pubs.

Schneider, E. (1999) *Discovering my Autism*. Kingsley.

Smith, J.A. (1995). 'Semi-structured interviewing and qualitative analysis', in Smith, J.A., Harre, R. & L. Van Langenhove, (eds.) *Rethinking Methods in Psychology*. London: Sage.

Smith, J.A., Jarman, M. & Osborn, M. (1999) 'Doing Interpretative Phenomenological Analysis', in M. Murrey & K. Chamberlain (eds.) *Qualitative Health Psychology Theories and Methods*. London: Sage Publications Ltd.

Taylor, G. (1990). 'Adolescence and Early Childhood (1): The needs of the more able young adult', in. K. Ellis. (ed.) *Autism, Professional perspectives and*

practice, *Therapy in practice series*. Published in association with the National Autistic Society. Chapman and Hall.

Traue, H.C., & Pennebaker, J.W. (eds.) (1993) *Emotion, Inhibition and Health*. Hogrefe & Huber Publishers

Trevarthen,C., Aitken,K., Papoudi, D. & Robarts, J. (1998). *Children with Autism. Diagnosis and Interventions to Meet Their Needs, 2nd edition*. Jessica Kingsley Publishers, London and Philadelphia.

Vygotsky, L. (1962). 'Thought and Language'. Cambridge, MA:MIT Press. Cited in H. Rushforth, (1999) Practitioner Review: Communicating with Hospitalised Children: Review and Application of Research Pertaining to children's Understanding of Health and Illness. *Journal of Child Psychology and Psychiatry*. 40, 5: 683-691.

Chapter III

**Investigating the concept of death in adolescents
functioning at the high end of the autistic
spectrum**

3.1. Abstract

This two-part study aims to investigate the concept of death in adolescents functioning at the high end of the autistic spectrum.

The first part involved interviewing young people who had an autistic spectrum disorder (ASD) using a structured interview based on Speece and Brent (1992).

The second part took the form of a semi-structured interview based on the same structured interview but with parents regarding their perception of their children's understanding and experience of bereavement.

The results suggest that although the young people with ASD technically understood the concept of death their emotional understanding and expression were not as well developed.

3.2. Introduction

3.2.1. Background

Studies conducted into children's understanding of the concept of death suggest that it is made up of a number of distinct components. The most widely studied of these are universality, irreversibility and non-functionality and all are required for someone to be considered as having a mature concept of death (Speece and Brent, 1992).

1. Universality: an understanding that all living things die.
2. Irreversibility: an understanding that once dead a living body cannot come back to life.
3. Non-functionality: an understanding that when a living thing dies, life defining functions such as hearing, seeing, and breathing cease.

(Speece and Brent, 1992).

Speece and Brent (1992) found that most children did not achieve a mature understanding of death until the age of 10 years. They also found that the different components of the concept were acquired at different time periods. Universality is considered easier to understand and therefore tending to be acquired earlier and with irreversibility and non-functionality occurring concurrently.

Most research into our understanding of the concept of death has been carried out with children in the normal population. Little research has looked at specific

populations of children with a diagnosis. McEvoy (1989) looked at how adults with learning disabilities understand the concept of death using a structured interview schedule. He found that 55 percent of the adults questioned did not think that they would die. Adults who were aware of their own mortality tended to have a more mature concept of death. Fifty five percent of the adults said that illness and disease were a possible cause of death; however 18 percent said they did not know what caused death. Experience of bereavement did not seem to influence their overall understanding of death.

3.2.2. ASD and the concepts of death

Individuals who have ASD have deficits in their ability to understand the thoughts, feelings and beliefs of others, otherwise known as "theory of mind" (Baron-Cohen, 1989). People who have ASD often have difficulty in understanding concepts about self and others and abstract concepts; they may therefore have difficulty in understanding the abstract concept of death. It is interesting to note that McEvoy (1989) found in his research that the adults who had higher abilities in communication, self-care and community skills had a greater understanding that death was irreversible and that when someone died they are unable to function. People who have ASD often have difficulties with communication and self care (Howlin, 1998). It could therefore be hypothesised that people who have ASD would have greater difficulty in understanding these two concepts (irreversibility and non-functionality).

In a personal account about growing up with a brother who had ASD, Konidaris (1997) discussed the loss of their father and her brother's reaction to it. She describes her brother saying goodbye to their dead father as if he were leaving the house for an afternoon shopping trip. She felt that her brother did not understand the concept and finality of death. She tried to explain to him that their father had gone to heaven but felt that he did not understand and could only conceive it as being a place like California where their father frequently visited.

Apart from case histories, there is an absence of research investigating the understanding that people with ASD have about death. Information gathered from research in this area may be helpful for families and professionals to help them to communicate better about death and bereavement and to help understand unusual reactions to death.

3.3. Design and method

3.3.1. Aim

The purpose of this study was to investigate the concept of death in adolescents functioning at the high end of the autistic spectrum, to see if they had developed a mature understanding of the main three components of the concept of death as would be expected for their age.

3.3.2. Participants

Clinicians from two local NHS Trusts identified potential participants. Fifty-six parents of children aged between 12 and 16 with a diagnosis of ASD and were functioning at the high range were written to inviting their children to take part in the study. Six participants agreed to take part in the study. One participant was female and five were male. This age group was decided upon because the concept of death should be mature at this age in the normal population.

Owens & Payne (1999), assert that qualitative approaches can bring an added strength to research in the area of death and dying and that they complement quantitative approaches. Parents were also invited to take part in the research in order to bring a subjective angle and enhance the quantitative data. Thirteen parents whose children all fulfilled the above criteria were interviewed in total; this included the parents of the six young people participating in the study. The other parents either did not want their child interviewed or the young people did

not want to take part. The participants' names along with any identifying information have been changed to protect confidentiality.

3.3.3. Procedure

A letter was sent to fifty-six parents stating the aims of the research. Those parents interested in taking part returned the reply slip. Parents were contacted by phone and appointments arranged at a place of their convenience, this was normally in participants' own homes. At the appointment the nature of the study was explained to parents and children and consent forms were completed (see appendix D & E). The parents' interviews were audio recorded and later transcribed.

Given the sensitive nature of the study the interviews were approached in a supportive manner. Opportunity was given at the end of the interviews to debrief and discuss any issues that were raised with the interviewer. Further appointments could have been arranged if either the researcher or participants felt it necessary, however these were not required.

3.3.4. The interview schedule

The young people taking part in the study were asked questions based on Speece and Brent's (1992) structured interview, which examined the concept of death (see appendix F). Questions were added to supplement the information (previous experience of death, causes of death and perceptions about what

happens after death). The interview schedule was amended for parents in order to gain information about parents' perceptions of their child's understanding of the concept of death (see appendix G). This interview followed a semi-structured style and was conducted as part of a larger study (Phelps, Knight, Knibbs, Elliott, 2002)

3.3.5. Analysis

Young persons' interview

One point was received for each correct answer to the questions regarding the three components of the concept of death. If the participants scored 5 in any of the components they were said to have achieved a mature understanding for that component, if they achieved correct answers on all three of the components then they were said to have achieved a mature understanding of the concept of death. Data from the other parts of the interview did not form part of a concept of death score and were examined using descriptive statistics.

Parents' interview

The data from the three components of the concept of death were analysed quantitatively. The rest of the interview material was analysed using an interpretative phenomenological approach (See Moustakis, 1994; Smith, Jarman and Osborne, 1999). Table 1 summarizes the analysis process. Throughout the analysis process the data informed the themes and any new themes that emerged were tested against the data from previous interviews. To verify the

internal validity and reliability of the analysis a number of checks were carried out as suggested by Elliott, Fischer, and Rennie (1996). One of the collaborators checked the emergent analytic account at each stage of the process in order to ensure that the arguments presented in the study were internally consistent and justified by the data. This was not intended as an inter-rater reliability check. As an additional validity check a parent who had not taken part in the study but whose child fitted the criteria for participation, was asked to read through the results section. They were asked to comment on whether the results made sense to them and whether they could identify what had been written.

Table 1. Analysis Process

| | |
|--------|--|
| Step 1 | The first interview transcript was read and re-read a number of times. A summary was written of the transcript in order to re-enter into the world of the interview and begin the processing of the data, as suggested by Boyatzis (1998). |
| Step 2 | The summary was re-read and emerging themes and titles were identified. |
| Step 3 | Where there were connections between emerging themes these were clustered together. Checks were made to ensure that the clusters of themes fitted in with the original data from the transcripts. |
| Step 4 | A master list of themes and sub-themes was identified and instances where it occurred in the script were noted. |
| Step 5 | The above process was carried out with all the interviews. A qualitative research collective met and analysed two of the interviews independently. The collective discussed the interviews and emergent themes were agreed upon. |
| Step 6 | By consolidating the themes from all the interviews a master list of themes was produced. These were reviewed and worked upon with one of the collaborators until 5 main themes were identified and after discussion these were grouped together into 3 domains. |

3.4. Results

3.4.1. Young people's interviews

Understanding the terms 'alive and dead' (section 1)

The first section of the interview schedule was designed by Speece and Brent (1992) to determine whether the young person understood that alive and dead were mutually exclusive states. All the young people understood what alive and dead were and that something could not be both alive and dead at the same time. Jeremy replied that television could be both alive and dead as "***people on television were alive but the machine was dead". Jeremy***

Components of the concept of death (sections 2,3,4)

Table 2 Results of young people's interviews

| Participant | Universality | Irreversibility | Non-functionality | Mature concept |
|-------------|--------------|-----------------|-------------------|----------------|
| Veronica | 5 | 5 | 0 | 10 |
| Jeremy | 5 | 5 | 5 | 15 |
| Keith | 5 | 5 | 5 | 15 |
| Grant | 5 | 5 | 5 | 15 |
| Patrick | 5 | 5 | 5 | 15 |
| Miles | 5 | 5 | 5 | 15 |

Table 2 shows that only one of the young people in the study did not achieve a mature understanding of the concept of death, she was the only female participant.

Previous experience of bereavement (section 5)

All the young people reported knowing people who had died.

Causes of death (section 6)

Four of the young people were able to identify possible causes of death. The most frequently cited cause was cancer, which was cited by four participants; heart attack, disease, tuberculosis and strokes followed this.

Perceptions about what happens after death (section 7)

When asked about what happened after death three of the participants said that people go to heaven, two replied hell. Heaven was described as “*a really nice place*” by Veronica and “*peaceful*” by Keith. Hell on the other hand was described as “*horrible*”. Jeremy said that when you die, “*you are put in a freezer, then coffin, you are buried and then you rot*”. Patrick answered, “*we are reborn like a life cycle, there's a few minutes of blackness then you are reborn. This keeps going till eventually the earth suddenly disappears.*” He also said that people are cremated. Grant did not know what happened when someone died.

3.4.2. Parents' interviews

Parents' interviews were then analysed to find out parents' perceptions of their children's understanding of the concept of death.

Components of the concept of death (sections 2,3,4)

Table 3. Parents' perceptions of their children's understanding of the concept of death.

| | Understood | Did not understand | Don't know |
|-------------------|------------|--------------------|------------|
| Universality | 8 | 2 | 3 |
| Irreversibility | 11 | 1 | 1 |
| Non-functionality | 7 | 1 | 5 |

Table 3 shows the results of parents' perceptions of their children's understanding of the concept of death. The majority of parents felt that their child understood the three components of the concept and in particular that children understood that if someone died they could not come back to life. Parents found it harder to know if their child understood that when someone died they would not be able to function any more.

Melanie's mother did not think that her daughter would understand any of the components of the concept of death; Melanie was female, no longer went to mainstream school and had not experienced the death of someone she knew. Melanie's mother felt that understanding would come with experience. At

present she felt that Melanie's understanding of heaven was very concrete. When Melanie is angry she will say that she wants her mother to die and go and live with Jesus and her Grandfather.

***"Its more like going on a trip to Birmingham, you'll come back one day."* Melanie's mother**

Interestingly, contrary to what was expected, Veronica's mother believed that her daughter would achieve a mature understanding of the concept of death however Veronica was the only young person who did not obtain full marks in each of the three components.

Jeremy's mother was unsure about her son's understanding of the concept of death. She thought he understood about animals but was not sure if he related this to humans. Jeremy had been confused about actors dying on television and appearing again in other programs. Patrick also had difficulty with this until he was 8 or 9 years old. Stuart's mother was unsure if her son understood the difference between fact and fiction. She found some of her son's behaviour disturbing; "***as he talks a lot about quite violent death,***" she thinks he believes that heaven is rubbish and that all people go to hell.

3.4.3. Qualitative results

| | Domain and themes | Number of respondents with themes |
|-----------------|--------------------------------|-----------------------------------|
| Domain 1 | Emotional expression | |
| Theme 1 | Lack of emotion | 8 |
| Theme 2 | Inappropriate emotion | 8 |
| Domain 2 | Understanding Emotions | |
| Theme 3 | Understanding others' emotions | 6 |
| Theme 4 | Understanding own emotions | 1 |
| Domain 3 | Interest in process | |
| Theme 5 | Interest in process | 7 |

Domain 1 - Emotional expression

This major domain concerned parents' perceptions of how their child expressed their emotions following bereavement. Parents felt their child either seemed to show little emotion or that the way they expressed emotion was inappropriate to the situation.

Theme 1 - Lack of emotion

This theme emerged 8 times, it occurred when children were described as showing limited expression when a person or animal died. Some parents did not feel that their child was affected by the bereavement because they appeared

unconcerned, and responded in an almost clinical way. Patrick's mother was surprised by his detached response when his Nan died just before Christmas.

"It did not have any affect on him at all ...it was not the reaction I was expecting from him at all...He was actually quite interested in the whole process, quite clinical attitude to it I would say...It was almost like he was going to a party" Patrick's mother

Some parents put the lack of emotion shown by their children down to the difficulty their children had expressing themselves. Stuart's cousin died young when he was 10. His mother felt that Stuart was 'brilliant' at the funeral as he did not show any emotion and did not cry.

"I think it hit him a bit, but he wasn't able to express it. He never really talked about her death." Stuart 's mother

In a few cases parents reported differences in their child's response to death compared with others of a similar age. In one case it was the unemotional response to bereavement and consequent behaviour problems that resulted in help being sought for Spencer and ASD being diagnosed.

"I think he took it in his stride and bottled it up and from that point on we noticed something different about him." Spencer's mother

A number of parents reported their children's responses to the terrorist attacks in America on September 11th. Stuart's mother had to cancel their holiday to New York following the events. Stuart blamed it on the Palestinians, and when his mother reminded him of all the people dead he replied

"So what, I don't care about them, I'm not going to New York' and that was all he cared about them." Stuart's mother

Stuart's mother felt that if there were a car crash and Stuart didn't know the person who had died he would respond in the same way, he wouldn't care.

John's mother was angry with her son when he told her that the little girl who had been in the news because she had been abducted and murdered, deserved to die. His mother had tried to make sense of her son's blasé response by him not knowing the girl personally.

"Which is how he probably views most deaths on the news and in films, it's very matter of fact." John's mother

Theme 2 - Inappropriate expression of emotion

In eight of the interviews the theme of inappropriate expression of emotion emerged. This was where parents felt their children's expression of emotions were not appropriate to the situation. For example at a recent funeral of Veronica's best friend's mother, Veronica had started smiling.

"I don't know why she started smiling and she was quite shocked to see people crying." Veronica's mother

John's mother felt that John got pleasure burying his hamsters in the garden.

"He didn't give a damn, he got more pleasure burying it in the garden." John's mother

Stuart's mother felt that at the time of the events on September 11th he was quite affected however she was quite upset when Stuart laughed when somebody jumped out of the building to their death.

Other parents explained that their children reacted to bereavement through their behaviour, either being difficult and throwing things around like Kerry or being irate and agitated like David when his grandfather died.

Domain 2 - Understanding emotions

This domain is concerning how parents perceived their children's understanding of their own and others' emotions.

Theme 3- Understanding others' emotions

This theme is about parents' perceptions of difficulties young people had in understanding the emotions of others it emerged in 6 of the interviews.

Patrick's mother felt that Patrick couldn't understand why the rest of the family were upset following the death of their cat. She thinks that Patrick thought that you could easily replace the cat with another and his mother wondered whether he thought the same about people. She was worried at the recent funeral of his Nan that he would upset people.

"He does not realise a lot of times that he has hurt someone, he does not have much feeling for other people's emotions." Patrick's mother

In some of the interviews parents described times when their child did not understand why people were upset. When Grant's Grandmother died Grant could not understand why people were crying, he was 10 at the time.

"When we were at the crematorium his cousins who were about his age were stood crying and he actually came over to me and said why are they crying." Grant's mother

A few days after the funeral of Grant's aunt, his mother cried. Grant could not understand why she was crying.

"You cried the other day, you don't have to cry now...he couldn't understand my emotion." Grant's mother

Theme 4 - Understanding own emotions

This theme is about young people's understanding of their own emotions. It only occurred in one of the interviews but it was a dominant theme in the interview. It revealed the concerns that Grant's mother had about her son's future. She had not taken him to see his aunt in the coffin as she did not know how he would react not only because of his age but because he had Aspergers Syndrome. Grant's mother explained that she tried to protect Grant from his emotions because he found them difficult to understand. She hoped that in the future his emotions would develop enough to be able to cope with bereavement, she felt that if they did not there would be difficulties ahead.

"If I was being honest I think a lot of me is trying to not let him have to deal with feelings and emotions too much at the moment.... Because I know it's an area he finds difficult to understand." Grant's mother

Domain 3 - Interest in process

This domain relates to young people's interest in the process and rituals of dying.

Theme 5 - Interest in process

Another theme that emerged was young people's apparent fascination about death, its process and rituals rather than the emotional experience. This theme emerged in 7 interviews. For example when Miles' uncle died, there were no tears.

"But Miles wanted to go to the funeral because he wants to know what does go on." Miles' mother

In some interviews, parents felt that death had become quite an obsession for their children. Stuart's mother felt that he was obsessed with death, he wanted to talk in depth about it and was worried about being alive when he was either cremated or put in a coffin.

"We do talk about death a lot, he is obsessed by death and quite violent death as well...He wants to go into these things deeply, you have to go through every detail." Stuart's mother

3.5. Discussion

3.5.1. Concept of death

The results of the interviews with the young people suggest that children and adolescents on the high functioning end of the autistic spectrum have a mature understanding of the concept of death. There could have been extraneous factors that have not been adjusted for which have influenced the results. For the one young person who failed to achieve a mature understanding, factors such as IQ, level of autism and gender difference may have had a part to play. The child may also have misunderstood the questions. Unfortunately there were a limited number of participants and so conclusions are tentative.

The majority of parents perceived that their child had a mature understanding of the concept of death, as would be expected for their age. There was only one parent who did not think that their child had a 'mature' understanding of this concept. Other factors as cited above may have influenced this. The one young person whose mother did not think she would understand the concept of death appeared to have a very literal understanding on the concept, believing heaven to be like a box or a house. The concept of death is an abstract concept and her mother felt that if she had had a more concrete experience this would help her understand as "***seeing is believing***". One of the difficulties that children who have ASD experience is in the literal interpretation of language and in difficulties with abstract or metaphorical concepts (Howlin, 1998).

Parents reported that a couple of the young people had experienced difficulties in distinguishing between fact and fiction and had been confused between actors dying in one programme only to reappear in the next one. Identifying fact from fiction is one of the problems that people with ASD sometimes have, and this is thought to be because of deficits in theory of mind (Myles and Southwick, 1999). Generalising one concept to another is an additional difficulty people on the autistic spectrum sometimes have, this may be the case with the child whose parent did not know if he had related what he had learned about animals to humans.

3.5.2. Thematic analysis

Five themes emerged in the analysis which are thought to reflect as accurately as possible parents' interviews and in doing so parents' perceptions of their child's understanding of the concept of death. An interpretative phenomenological approach was used which explicitly acknowledges that the account of the interviews is an interpretation made by the author. The quotes illustrated allow for readers to make their own judgements.

The interviews revealed that parents felt their children had difficulty expressing emotions appropriately when bereaved. Parents described a number of difficulties in their child's ability to express emotion, sometimes there being a lack of emotion and sometimes emotion being shown inappropriately. Parents also felt their child had difficulties understanding their own and others' emotions. One

of the core deficits that people who have ASD experience is with "theory of mind". This, according to Myles and Southwick (1999) can lead to a number of difficulties including; difficulty understanding and expressing their own and others' emotions, difficulty predicting the behaviour or emotional state of others and problems understanding the perspectives of others. Attwood (1998) discusses how mild distress is sometimes expressed as giggling in children with Aspergers Syndrome. He argues that this expression of incongruent emotions is because of "an expressive system that lacks subtlety and precision." (Attwood, 1998)

Interest in process was another theme that emerged. If people are having difficulty in understanding the emotional content of a situation like a funeral, their interest might be directed towards the process of the occasion instead. People with ASD sometimes develop special interests in particular topics and these sometimes develop into obsessions (Myles & Simpson, 1998). They may also collect facts rather than objects (Howlin, 1998).

There are strong clinical implications from the results of this study that can be used to help parents and professionals understand reactions to bereavement in young people who have ASD. Even though the child may theoretically understand the concept of death they may have difficulties in expressing and understanding the emotional content; this may result in a more clinical interest in the process of death emerging. Knowing that these difficulties may occur can

help parents and professionals develop ways of communicating about this abstract concept in a helpful way.

It is hoped that this research helps parents who have a child with ASD to gain a greater insight into their child's reaction to bereavement. How parents understood their child's reactions to bereavement varied greatly in this study. Some parents were surprised by their child's lack of emotion; some had tried to make sense of unusual comments, emotions and behavioural changes. For some parents their child's remarks and emotional expression had angered or upset them. For one parent there was an overriding concern about her son's ability to cope with future experiences of bereavement because of his difficulties in understanding emotion.

3.6. Conclusions

This study represents a preliminary exploration about what young people with ASD understand about the concept of death. Methodological issues need to be recognised in light of the findings. A limited sample of young people with ASD participated in the study. There may have been a sampling bias influencing participation in the study, young people who were more likely to understand the concept of death being more likely to agree to take part and parents being more willing for them to do so.

Clinically this study suggests that young people functioning at the high end of the autistic spectrum appear to understand technically the concept of death however they may have difficulties with the emotional content of bereavement. This has implications on how death is explained to young people who have ASD. It also has implications on parents' understanding of their children's reactions to bereavement.

The use of the two methodological approaches in this study has provided a broad insight into this area. The use of IPA enabled the subtle differences that were not detected in the questionnaire to come to light.

3.7. References

- Attwood, T. (1998) *Asperger's Syndrome. A Guide for parents and Professionals.* Jessica Kingsley Publishers, London and Philadelphia.
- Baron-Cohen, S. (1989). 'The autistic child's theory of mind: a case of specific developmental delay.' *Journal of Child Psychology and Psychiatry.* 30, 285-297.
- Boyatzis, R.E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development.* Sage publications.
- Elliott, R., Fischer, C.T., Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology.* 38, 215-229.
- Howlin, P. (1998). *Children with Autism and Asperger Syndrome, A guide for Practitioners and Carers.* John Wiley and Sons.
- Konidaris, J.B. (1997). Personal Perspectives: A Sibling's Perspective of Autism. D.J. Cohen and F.R. Volkmar, (eds) *Handbook of Autism and Pervasive Developmental Disorders.*

Owens, R.G., Payne, S. (1999) Qualitative Research in the Field of Death and Dying. In M. Murray and K. C. Chamberlain (eds). *Qualitative Psychology, Theories and Methods*. London: Sage Publications Ltd.

McEvoy, J. (1989). Investigating the concepts of death in adults who are mentally handicapped. *British Journal of Mental Subnormality*. 35,2 ,69, 115-121

Moustakis, C. (1994). *Phenomenological Research Methods*. London: Sage Publications.

Myles, B.S., Simpson, R.L. (1998). *Aspergers Syndrome. A Guide for Educators and Parents*. Pro-ed, Inc.

Myles, B. S., Southwick, J. (1999). *Asperger Syndrome and Difficult moments: Practical Solutions for Tantrums, Rage, and Meltdowns*. Autism, Asperger Publishing Co.

Phelps, H.A., Knight, E.S., Knibbs, J.A., Elliott, J. (2002). Physical Illness In Young People With ASD – A Parent's Perspective. *To be submitted to Autism*.

Smith, J.A., Jarman, M. and Osborn, M. (1999) Doing Interpretative Phenomenological Analysis. In M. Murrey and K. Chamberlain (eds) *Qualitative Health Psychology Theories and Methods*. London: Sage Publications Ltd.

Speece, M. W., Brent, S.B. (1992). The Acquisition of a Mature Understanding of Three Components of the Concept of Death. *Death Studies*. 16, 3, 211-229

Chapter IV

Reflections

4. Introduction

This paper aims to provide an overview of the research process and highlight some of the significant issues that have arisen carrying out this thesis. These can be broadly described under the three headings of methodological issues, ethical and clinical implications and finally my research story. Throughout this paper I have reflected on my experiences of carrying out the research and how it has enabled me to develop personally and professionally.

4.1. Methodological issues

4.1.1 Qualitative approach

This thesis has used mainly a qualitative methodology, which has enabled a subjective understanding of how children with ASD experience illness and death. Previously there has been little research in these areas. Chapter 3 demonstrates how using both qualitative and quantitative approaches can enhance the understanding that using only a single methodology could not have accomplished. I liked the idea of gaining a parent's perspective alongside the child's, as it highlighted the subtle difficulties that people with ASD have understanding a concept intellectually but perhaps not to the same degree emotionally.

This was the first time that I had explicitly used a qualitative approach in research and there was a very quick learning curve. Apart from my panic when I was supposed to be reducing the data and it seemed to be expanding, I settled well

into the approach and felt that it enabled research to be carried out sensitively. I would definitely use this approach again as it felt much more relevant and close to my clinical work than quantitative methodologies and can bring such rich insights into under researched areas.

4.1.2. Interpretative Phenomenological Analysis

The aim of these studies was to gain a parent's perspective of their child's understanding and experience of illness and bereavement. This was felt to be important, as it is often parents who make decisions about their child's health status and talk to their child about the death of a loved one. It was thought that an interpretative phenomenological analysis (IPA) would be a useful way to achieve this as it aims to get as close as possible to the personal world of the participant (Smith, Jarman and Osborne, 1999).

4.1.3. Methodological concerns

Elliott, Fischer & Rennie's (1999) evolving guidelines for good practice in conducting qualitative research were extremely helpful for someone new to the methodology. Having the criteria, I believe helps to demonstrate the rigorousness of the approach and acts as a reassurance. Validity however still needs to be considered carefully and any threats to it acknowledged. For instance I had previously worked with children with ASD at both ends of the spectrum and this prior knowledge might have coloured my approach to the two studies. In order to check that the data was credible, a credibility check was

carried out. The results section was shown to a mother of a 15-year-old boy who had a diagnosis of ASD. This mother related to many of the themes in the results section however she acknowledged that her son's behaviour varied and he would react differently at different times when ill or in pain.

The results of qualitative methodologies are not intended to be generalised like those of quantitative approaches. Emphasis instead is placed on the ability of the approach to enrich understanding in the area. It needs to be acknowledged that ASD covers a wide spectrum and the children whose parents participated in the study might have varied considerably in their abilities. Clinicians however had been asked to put forward only the names of adolescents functioning at the high end of the autistic spectrum and attending mainstream school. A couple of the adolescents however no longer attended mainstream school when interviews were carried out with parents.

Jones, Zahl & Huwa, (2001) report that research into the emotions of young people with ASD has been mainly through third hand accounts and has found that children with ASD lack emotion. They argue that the voice of the individual with ASD should be heard and that children with ASD do experience emotions and that these are often quite negative. Children with ASD should be heard and it is hoped that this research initiates further studies to look at children's understanding of illness and bereavement from their perspective. I feel however, that it is also valuable to find out parents' perspectives on how they understand

their child's emotions. For example in paper 3 one of the themes that emerged was lack of emotion shown by children with ASD and that parents reacted quite differently to this, some putting it down to difficulties with emotion, others being angered or upset by it.

4.1.4. Reflexivity

Qualitative research explicitly includes the reflexive nature of the research process, where the researcher is central at every step, from the questions asked to the way the interviews are conducted and the decision on which quotes to include in the results section (Smith, Jarman & Osborne, 1999). IPA acknowledges this and was one reason why I liked it as a methodology.

There is obviously considerable emotional strain researching topics such as death and dying (Owens & Payne, 1999). It requires a great deal of sensitivity and needs to be introduced carefully. In this study it was often the parents of the mother who was being interviewed, who had passed away. On a couple of occasions mothers became upset because they felt that their children did not care when somebody close had died. I found this difficult but the parents reported that they were pleased to have been able to talk about it.

Carrying out research into death and dying can bring you in touch with personal experiences and this needs to be seriously considered before being taken on.

At the ethics committee meeting that I attended, one member of the board was sensitive to this and checked that I had adequate support.

When I was 15, I was bereaved. Carrying out this research brought back memories of this time and how difficult I found it communicating and sharing my feelings of loss. I considered how my parents perceived and understood my reactions and expression at that difficult time in my life. As a consequence of the research, I discussed this period with my parents and feel that this has been an important part of my personal development. It also made me question how people who have difficulty understanding and communicating their feelings normally, make sense and cope with such experiences.

4.1.5. Interviews

During my clinical training I have always shied away from recording clinical sessions. Carrying out the research interviews threw me into the deep end. The process of transcribing and listening to myself (many times) conducting interviews was initially a highly uncomfortable experience, however it was a valuable opportunity for me to develop my clinical skills. I now feel much happier listening to my clinical sessions and had not realised how soon you forget that you are being recorded. The interviews also helped me develop my skill at phrasing a question in a slightly different way to achieve a fuller response. I also now feel more comfortable talking with people about death and dying and illness.

I had not anticipated the practical difficulties that were to be encountered conducting interviews in people's own homes. In one of the interviews I found it very difficult to concentrate and even harder to transcribe as a parrot was making noises in the room and a road sweeper kept going up and down the road outside. The most difficult interview with a parent was when two of her children kept coming over and talking to their mother and to me and were singing down the tape recorder. I tried to rearrange this interview for another time in a more private venue but the parent insisted that it was fine to carry on. If this occurred again I would be more assertive as it did not feel right discussing the young person with his siblings present.

Thankfully I had read Smith's (1995) chapter on semi-structured interviewing, and taken his advice on the need for thorough preparation so I had prepared prompts and open-ended questions. However there were still difficulties and I had to re-assess how I asked certain questions and the question order. A number of the parents appeared quite reticent at the beginning of the interviews and did not understand why questions were being asked about their child's understanding of illness. The semi-structured nature of the interviews facilitated rapport and interestingly it was the questions about how their children expressed themselves when ill that often stimulated the parents' interest in the interviews. These questions were therefore moved to earlier in the interview schedule in order to build rapport. The nature of the interviews was obviously sensitive and plenty of time had to be allowed for them. Some parents had been extremely

keen to take part in the research and were more than happy to talk about their child.

4.1.6. Analysis

The interviews could have been analysed on many different levels such as the family, attachment issues, cultural issues etc. However due to limitations of space, papers 2 and 3 focused mainly on the parents' view of the child's experience.

4.1.7. Research with young people with ASD

Carrying out research with high functioning adolescents who have ASD was new to me. I had to consider carefully how to carry out the interviews. According to Myles & Simpson, (1998) it is best to use a single modality, either visual or auditory, so as not to overload the young person. Myles & Simpson, (1998) report that many students with Asperger Syndrome have difficulty with auditory input and require a longer processing time than their peers. Therefore plenty of time was assigned to the interviews.

According to Myles & Simpson (1998), children with Asperger Syndrome might not be motivated to do tasks that are of no interest or relevance to them. This might in part explain the low uptake of young people wishing to take part.

4.2. Ethical and clinical implications

There were many ethical issues to consider in this thesis, some of which have already been raised. I think the biggest dilemma for me was whether it was ethical to ask young people with ASD about their experiences of death. Similar research has been carried out with developmentally normal children, however children with ASD have difficulties in areas such as understanding emotion. Four of the 13 parents interviewed did not want their child to take part in the study for various reasons. For one parent it was the concern that her child might become obsessed by death and that this might become the next topic of conversation and she did not feel that it was a happy topic to be talking about. Another parent spoke about trying to protect her child from difficult emotional experiences and this might be true for most parents. However it is probably more poignant if your child has ASD.

In qualitative research the raw data is in the participants' own words and so identification could be more easily achieved, a number of considerations therefore had to be made. According to Boyatzis (1998), qualitative analysis requires a high degree of sensitivity and thought regarding informed consent and confidentiality.

A number of the parents were very enthusiastic about the research and were very keen to participate. One mother thought that it might help doctors understand the experiences of parents who have a child with ASD. She felt that

doctors often thought she was wasting their time when she made appointments for her son. She did this to check that there was not anything wrong with him as he did not ever make a fuss when he was ill or in pain. Another mother, whose child would react in a disproportionate way when injured or ill, would prefer to go to her own doctor rather than A & E as she knew him well and knew he would take her seriously.

Paper 2 also has implications about the health of children with ASD. It suggests that some children with ASD find it difficult to notice the early signs of ill health and express that they are unwell. It emerged that parents often tried many ways to discover whether their child was well or not. Doing this type of detective work could be suggested to the parents of newly diagnosed individuals.

Regular check-ups are suggested for children with ASD as this might help children feel more comfortable about going to the doctors. This was a problem with a few of the children whose parents were interviewed. It might also help doctors become more accustomed to communicating with the child (Howlin, 1998).

In a number of cases it was the medical professionals, doctors and dentists who noticed that the child's reaction to pain or illness was unusual and recommended a diagnosis being sought. Educating medical professionals to look out for

unusual reactions might accelerate diagnoses being made and help being provided.

4.3. My research story

As I have included the narratives of my participants in my research I felt it only fitting to conclude by sharing some personal narratives from my research story in which there were many high and low points. One of the low points came when consent had been obtained from one of the Trusts and I had only managed to recruit a handful of participants after months of work.

I can't believe that I have gone through months of waiting, photocopying and sending letters, only to find that 3 people have said they would take part.

The following is an excerpt from my research diary having just returned from an appointment where I had arranged to interview a young person. I had already been feeling desperate about not having enough young people to interview, as the two previous young people I had visited had not wanted to participate.

I feel terrible. I arrived at the allotted time at the house, apprehensive, as the parent interview had been really difficult due to lack of privacy (kids coming up talking and singing). I had purposefully arranged the time so that his two younger siblings

would be out. When I arrived however, mum, dad and three children were sat finishing their dinner in the lounge. I was ushered into the dining room that led into the lounge (no privacy). I tried to protest and say I would come back but both parents insisted I stayed. John ran through the tiny dining room into the kitchen protesting that he would not take part in the research. Mum and dad started issuing threats about not being allowed pudding if he didn't take part. I tried protesting but to no avail. John made himself some pudding and then his parents started trying to bribe him to take part with the incentive of playing on the play station all week. I was feeling extremely awkward. Of course I would have liked him to say "okay then" but the last thing I wanted was for him to be pressured into it. I was in their home and it was so difficult as I did not want to undermine the parents and so had to be so careful about what I said. The bribes had gone so far now that John was not going to be allowed to use the play station all week (because of me!) and to make it even worse his two younger siblings were by now joining in.

Eventually I managed to calm down the situation. I explained to mum that other young people had also not wanted to take part and that it had to be his decision etc. I was able to explain to John and his parents that it was John's decision and that I wouldn't be upset if he didn't want to take part. Mum was happy after this but still

insisted that I phoned up at the end of the week to see if he had changed his mind.

Other times there were highs, particularly after speaking with parents who had been so helpful and given their time and appeared really grateful to me for listening to them. This is what I wrote after seeing a parent after work, who lived a long way away.

I'm shattered but it is worth it, that was fascinating.

A really enjoyable time was when I was immersing myself in the data. Although it was not always easy and was very time consuming, it was extremely interesting. I also enjoyed discussing the narratives and process with my colleagues in the research collective. It was great to share thoughts and ideas with people who were going through a similar process.

4.4. Concluding remarks

Using mainly a qualitative approach in this thesis has allowed me to gain rich insights into the understanding and experiences of illness and bereavement of children with ASD. Taking a parents' perspective enabled me to gain information that asking the children would not have achieved. This thesis has many implications for the health care and bereavement support of children with ASD. Finally it has enabled me to learn about a new approach to research, one that I hope to utilise again in the future.

4.5. References

Boyatzis, R.E. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Sage publications.

Elliott, R., Fischer, C.T. & Rennie, D.L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

Howlin, P. (1998). Children with Autism and Asperger Syndrome, A Guide for Practitioners and Carers. *John Wiley and Sons*.

Jones, R.S. P., Zahl, A. & Huwa, J.C. (2001). First-hand accounts of emotional experiments in autism: a qualitative analysis. *Disability & Society*, 16, 393-401

Myles, B.S. & Simpson, R.L. (1998). *Aspergers Syndrome. A Guide for Educators and Parents*. Pro-ed, Inc.

Owens, G. & Payne, S. (1999) Qualitative Research in the Field of death and Dying in Qualitative Health Psychology, Theories and Methods. In M. Murrey and K. Chamberlain (eds) *Qualitative Health Psychology Theories and Methods*. London: Sage Publications Ltd.

Smith, J.A. (1995). Semi-structured interviewing and qualitative analysis. In Smith, J.A., Harre, R. & L. Van Langenhove, (Eds.) *Rethinking Methods in Psychology*. London: Sage.

Smith, J.A., Jarman, M. & Osborn, M. (1999) Doing Interpretative Phenomenological Analysis. In M. Murrey & K. Chamberlain (eds). *Qualitative Health Psychology Theories and Methods*. London: Sage Publications Ltd.

Appendix A

Ethical approval from Warwickshire Research Committee

PAH

5th July 2001

Westgate House
Market Street
Warwick

Tel:
Fax:

WARWICKSHIRE RESEARCH ETHICS COMMITTEE

The following LREC trial protocol has been examined from an ethical viewpoint and the decision of the Committee is as follows:

**Documentation Reviewed
as itemised in ICH guidelines**

1. * Approved

Protocol
Patient Information Form/
Consent Form

2. Approved subject to amendments listed below

Indemnity (signed)
CTX
Protocol Amendments

3. Rejected for reasons listed below

4. Approved by Chairman's Action

Ethical Committee Minute Number 541/01 Dated 27th June 2001

Protocol Title and Reference Number

RE 486 Investigating the concepts of health and illness and life and death in high functioning adolescents who have autism
(Helen Phelps)

Signed.....Committee Chairman

Dated.....7/8/01.....

This approval is subject to the following standard conditions :

1. the study must begin within one year;
2. the researcher must seek the Committee's approval in advance of any Proposed deviations from the original protocol;
3. any unusual or unexpected results which raise questions about the safety of the study must be reported to the Committee.
4. progress reports must be submitted to the Committee annually; and
5. a summary of the study's findings must be submitted to the Committee upon its Completion.

Appendix B.

Ethical approval from Coventry Research Committee

Ljsc/ht

Coventry Health Authority
Christchurch House
Greyfriars Lane
Coventry

Ms Helen Phelps

Telephone:
Facsimile:

29 August 2001

Please note address for correspondence:

Administrative office, Coventry Research Ethics Committee, (Former School of Nursing), University Hospital Coventry & Warwickshire NHS Trust, Clifford Bridge Road, Walsgrave, Coventry

Tel/Voice Mail:

Fax:

NB: Coventry Health Authority is still responsible for Coventry Research Ethics Committee.

Dear Ms Phelps

**CREC 021/09/01 (Please quote this number on all correspondence).
Investigating Concepts of Health and Illness and Life and Death in Adolescents Functioning at the High End of the Autistic Spectrum. Research Protocol not dated.**

Thank you for your letter dated *22 August 2001, in response to my letter of 1 August 2001, *enclosed Research protocol, Appendix 1 (Illness recognition Stimuli), Appendix 2 (Conceptions of Illness - Bibace and Walsh Revised protocol 1993), Appendix 3 (Your Symptoms C.S.I. – Child Report), Appendix 4 (Interview for young people regarding their understanding of health and illness), Appendix 5 (Your Child's Symptoms C.S.I. – Parent Report), Appendix 6 (Interview for Parents/Guardians Regarding their Children's Understanding of Health and Illness), Appendix 7 (TAS-Child), Appendix 8 (Life and Death Questions), Appendix 9 (Interview for Parents/Guardians of High Functioning Autistic Adolescents Regarding Concepts of Death), Appendix 10 (Consent Form for Parents/Guardians), Appendix 11 (Information Sheet and Consent Form for Young People), Appendix 12 (Information Sheet (Parent/Guardian), Appendix 13 (Consent Form to Audio Recording), your Curriculum Vitae not signed and undated, and Coventry University School Research Ethics Committee Approval Form.

I confirm that you have now met the requirements, as requested, by Chairman's action, and I am pleased to inform you that your study, as amended, is now approved under the procedures for Chairman's review.

I am bound to add that confirmation of approval will be considered by the Committee in full session at its meeting on 18 September 2001 and, should any variation be agreed, I shall inform you accordingly.

It must be clearly understood that, prior to the commencement of the study, it is your responsibility to obtain management approval from the Research & Development Committee, and/or the Chief Executive, Coventry Healthcare NHS Trust, to undertake this study.

All protocol amendments, or unexpected events, must be notified.

The Committee must be informed of any new authoritative guidance or persuasive scientific evidence that may cause the Committee to reconsider approval or rejection of a protocol.

We look forward to receiving progress reports as appropriate and in due course an end of study summary.

The Committee proposes that in future, unless we hear to the contrary, the title of all research trials approved by the Committee will be made available to bona fide interested parties.

The study must be started within 12 months of the date on which LREC approval is given. If for any reason you do not meet this timescale, you must re-submit your study to the Committee.

We thank you for your co-operation in these matters.

Yours sincerely

**L J SANT CASSIA
CHAIRMAN
COVENTRY RESEARCH ETHICS COMMITTEE**

Appendix C.

Interview format

1. Can you tell me about your experience of your son /daughter being ill?
2. Can you tell me about a time when your son / daughter was recently ill.

How did you know they were ill?

Did they communicate that they were unwell?

How did they react to being unwell?

Were they aware that they were ill?

3. What do you think they understand about illness?

Do you think they know about what causes illness?

Do you think they feel they have any control over their health?

4. Can you tell me about their experience of pain?

5. Are there any differences in your children's experience of illness and pain?

Appendix D.

Information Sheet For Parents / Guardians.

About this project

This research is looking at concepts of health, illness, life and death in young people who have complex social learning needs. It has implications for:

- ***Parents and professionals understanding of reactions to illness and death.***
- ***Action in the area of prevention of illness and the content of health education programmes.***
- ***Communication with this group of young people concerning their treatment if they become ill.***
- ***Better communication and bereavement support for this group of young people.***

What the project will involve

The project would involve me asking questions to yourself and your child. The questions would initially be about your child's understanding of health and illness, asking questions about their views and understanding of illness and how they communicate that they are ill. There would then be questions regarding your child's understanding of and reaction to death, if you felt it was appropriate.

Confidentiality

Information that you provide will be confidential to the research. Details of your responses to the questions will be given an anonymous identification and kept in a confidential place.

Consent to participate

It is entirely your decision whether or not you and your child take part in the research. If you prefer not to, or you choose not to answer all the questions or you withdraw your consent at any point in the interview this will not affect your child's health care provision in any way. I will go through the questions that I will be asking your child with you so you can inform me if any of the questions may not be suitable for me to ask them.

Audio recording

I would like you to agree for the interviews to be audio recorded in order to help with my note taking. These tapes will be kept in a confidential place and be destroyed when the research has been completed.

Appendix D

Consent form for parents / guardians

Investigating concepts of health, illness, life and death in young people

Please initial box

- 1. I confirm that I have read and understood the information sheet for the above study.**
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without my health care or my child's being affected in any way.**
- 3. I agree to take part in the study described above.**

Name of participant

Signature

Date

- 4. I agree to my child taking part in the study as described above.**

Name of child

Signature of parent/guardian

Date

- 5. I agree to allow the interviews to be audio recorded.**

Name of participant

Signature

Date

Helen Phelps

Researcher

Signature

Date

Appendix E

Information sheet and consent form for young people

My name is Helen Phelps. I am a Trainee Clinical Psychologist. I am doing some research to look at young people's understanding of health and illness and death. This research may help parents and professionals understand young people's reactions to health, illness and death and this may help them communicate better.

This project will involve me asking questions to you and your parent / guardian. These questions will be about your understanding of health, illness and life and death.

What you tell me will be kept safe to people involved in the research.

It is up to you if you participate or not. If you don't want to then no one will mind and your health care will not be affected.

I would like you to agree to the interview being audio recorded to help me with my note taking.

Consent

Name of participant_____

I agree to take part in the study.

Signature_____

Date_____

I agree to the interview being audio recorded.

Signature_____

Date_____

Researcher Helen Phelps Signature_____ Date_____

Appendix F

Understanding of Death Interview For High Functioning Autistic Adolescents

Section 1- Life and death questions

What does alive mean?

Can you name something that is alive?

What does dead mean?

Can you name something that is dead?

Can an object be both alive and dead?

Section 2 - Universality

Will everybody die someday?

Will I (the experimenter) die someday?

Will (best friend's name) die someday?

Will your mother die someday?

Will you die someday?

Section 3 - Irreversibility

Can a dead person become alive again?

If I gave a dead person a drink of water, could he become alive again?

If I gave a dead person some food to eat, could he become alive again?

If I gave some medicine to a dead person, could he become alive again?

If I said some magic words to a dead person, could he become alive again?

Section 4 - Non-functionality

Can a dead person still do the things that he did when he was alive?

Can a dead person still move?

Can a dead person still speak?

Can a dead person still hear?

Can a dead person be sad?

Section 5 - An understanding of participants' previous experience of death.

Do you know anyone who has died?

Have you had any pets that have died?

Do you know anyone or anything on television or in a book that has died?

Section 6 - Perceptions about possible causes of death.

Can you suggest two possible causes of death?

Section 7 - Perceptions about what happens after death

What do you think happens to people when they die?

If reply is heaven ask - What do you think heaven might be like?

Appendix G

Understanding the concept of Death

Interview For parents of children who have ASD

Section 1- Life and death questions

Do you know if **** understands what alive means?

Do you know if **** understands what dead means?

Section 2 - Universality

Do you know if **** knows that everybody will die?

Section 3 - Irreversibility

Do you think that **** would think that a dead person can become alive again?

Section 4 - Non-functionality

Do you think that **** would think that a dead person can do the things that he did when he was alive?

Section 5 - Previous experience of death

Has anyone that **** knew died?

What was ****'s reaction to this death?

Has **** had any pets that have died?

What was ****'s reaction to this death?

What experiences to death has **** had from television / books?

What was ****'s reaction to this death?

Section 6 - Perceptions about causes of death

Do you think that **** understands what causes people to die?

Section 7 - Other

What do you think **** understands happens after death?

Prompt: If heaven, have they said what it might be like?

Appendix H.

Letter of introduction to parents.

Dear

I am writing on behalf of Helen Phelps a Trainee Clinical Psychologist in her final year of training at the Universities of Coventry and Warwick. She is currently carrying out some research to look at concepts of health and illness and life and death in young people who have complex social learning needs. This research has implications for:

- **Parents and professionals understanding of reactions to illness and death.**
- **Action in the area of prevention of illness and the content of health education programmes.**
- **Communication with this group of young people concerning their treatment if they become ill.**
- **Better communication and bereavement support for this group of young people.**

The project would involve Helen asking questions to yourself and your child either at your home, at or at a convenient venue to suit you. The questions would initially be to yourself about your child's views and understanding of health and illness. There would then be questions regarding your child's understanding of the concepts of life and death and their reaction to loss. This would be followed by a similar set of questions being asked to your child if you felt it was appropriate.

It is entirely your decision whether or not you and your child take part in the research. If you prefer not to, this will not affect your child's health care provision in any way.

Helen hopes to have the research published; it will be confidential and no names or means of identification will be included.

Please would you complete the reply slip below and return it in the pre-paid envelope. Thank you very much for your time.

.....
Consultant Clinical Psychologist

Reply slip

Name.....

I would be happy to take part in the research and for Helen Phelps to be given my name in order for her to contact me to arrange an appointment.

I do not want to take part in the research and I am aware that this will not affect my child's health care provision in any way.

Please delete as appropriate

Appendix I

Consent form to audio recording

We have now come to the end of the interview, thank you very much for your help. As you know I have been recording the interview to help with note taking. At this point however you may wish to delete some or all of the tape, if you would like to do this please let the interviewer know and this will be arranged.

If you still consent to the audio recording of this interview being used in this research project please will you sign the consent form below.

Signature of participant

Printed name

Date

Signature of researcher

Printed name

Date

Appendix J

Autism

Instructions to authors

NOTES FOR CONTRIBUTORS

1. The aim of the journal is to publish original research or original contributions to the existing literature on autism. Papers should not previously have been published nor be under consideration elsewhere.
 2. Each paper submitted will be refereed by at least two anonymous referees.
 3. Length of papers. Brief reports (up to 3000 words) and more substantial reports (between 5–8000 words) will be considered for the journal. There is scope for longer papers to be published on an occasional basis but please consult with the Editors before submission.
 4. When submitting papers for consideration, please supply four paper copies. If the paper is accepted for publication, then a copy of the final version will be required on disk. The author is responsible for guaranteeing that the final hard copy and diskette versions of the manuscript are identical.
 5. Unsolicited manuscripts will not be returned to authors if rejected.
 6. Blind peer review. Authors should provide two title pages, one containing names, affiliations, full mailing address plus telephone, fax, email address, and one containing the title only.
 7. Please number all pages except the title pages, in the following order: abstract (100–150 words), keywords (up to five), acknowledgements and address for correspondence; main text; tables; figures; figure captions; notes; references; appendices. Each of the above sections should start on a fresh page.
 8. Articles submitted for publication must be typed (or word processed) in double spacing throughout (especially all notes and references), on one side only of white A4 or US standard paper, with generous left- and right-hand margins but without justification. Pages should not be stapled. Titles and section headings should be clear and brief with a maximum of three orders of heading.
 9. Quotations. Lengthy quotations (exceeding 40 words) should be displayed and indented in the text.
 10. American or UK spelling may be used, to the author's preference. Indicate italics by underlining and use single quotation marks. Dates should be in the form '9 May 1995'. Delete points from 'USA' and other such abbreviations.
 11. Tables and figures should have short, descriptive titles, and be clearly numbered. All footnotes to tables and their source(s) should be typed below the tables. Column headings should clearly define the data presented. Camera-ready artwork must be supplied for all figures. The location of tables and figures in the text should be given by a note 'Table/Figure X about here' on a separate line in the text.
 12. References in the text should be presented in the Harvard system, i.e. the author's name and year of publication in brackets, together with the page number, e.g. 'As Hobson (1989: 22–3) has observed...', or, in a more general reference: 'Scott (1985) appears to be saying...'.
13. Reference list. The references should be listed alphabetically in full at the end of the paper, typed double-spaced for ease of editing, in the following style:
- Happé, F. (1995) *Autism: An Introduction to Psychological Theory*. Cambridge, MA: Harvard University Press.
- Hobson, R.P. (1989) 'Beyond Cognition: A Theory of Autism', in G. Dawson (ed.) *Autism: Nature, Diagnosis and Treatment*, pp. 22–8. New York: Guilford.
- Sigman, M.D., Kasari, C., Kwon, J. & Yirmiya, N. (1992) 'Responses to the Negative Emotions of Others by Autistic, Mentally Retarded and Normal Children', *Child Development* 63(3): 796–807.
- In multi-authored articles, the names of all authors should be given in the reference list. In the text, if there are more than two names, please give the first name and et al.
- NB: (eds) as a contraction but (ed.) as an abbreviation.
14. Language and terminology. Jargon or unnecessary technical language should be avoided as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. autist, normals or retardates). Wherever possible use phrases such as 'children with autism' rather than 'autistic children'. Language that might be deemed sexist or racist should be avoided.
 15. Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Abbreviations that are common enough to be in the dictionary, e.g. IQ and USA, are acceptable, but AS (for Asperger syndrome) and SPS (for Semantic Pragmatic syndrome) are not. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviation in brackets) the first time they are mentioned in the text.
 16. Authors will receive proofs of their papers and 25 offprints of the published version, plus one copy of the printed journal.
 17. Copyright. On acceptance of their paper, authors will be asked to assign copyright to Sage Publications Ltd and The National Autistic Society, subject to retaining their right to reuse the material in other publications written or edited by themselves, and due to be published preferably at least one year after initial publication in the journal. Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere.
 18. Typescripts: Authors should retain one copy of their typescript and send four copies, each fully numbered and legible, together with all figures and tables and a covering letter to: Submissions Editor, *Autism: The International Journal of Research and Practice*, The National Autistic Society, 393 City Road, London, EC1V 1NE, UK. Fax: +44 [0]171 833 9666; email: autism@dial.pipex.com
 19. Reviews. Books and suggestions should be sent to the Reviews Editor: Tony Charman, University College London, Sub Department of Clinical Health Psychology, Gower Street, London WC1E 6BT; email: t.charman@ucl.ac.uk

Appendix K

Death Studies

Instructions to authors



Journals Listings

Journal Resources

Information

[Click here to check your article status](#)

*****Note to Authors:** please make sure your contact address information is clearly visible on the **outside of all packages** you are sending to Editors.***

Submission of Manuscripts

Original and four copies of the manuscript should be submitted to the Editor, Robert A. Neimeyer, Department of Psychology, University of Memphis, Memphis, TN 38152.

In addition to these four paper copies, authors are strongly encouraged to submit manuscripts on disk. The disk should be prepared using MS Word or WordPerfect and should be clearly labeled with the authors' names, file name and software program. Each manuscript must be accompanied by a statement that it has not been published elsewhere and that it has not been submitted simultaneously for publication elsewhere. Authors are responsible for obtaining permission to reproduce copyrighted material from other sources and are required to sign an agreement for the transfer of copyright to the publisher. All accepted manuscripts, artwork, and photographs become the property of the publisher.

All parts of the manuscript should be typewritten, double-spaced, with margins of at least one inch on all sides. Number manuscript pages consecutively throughout the paper. Authors should also supply a shortened version of the title suitable for the running head, not exceeding 50 character spaces. Each article should be summarized in an abstract of no more than 100 words. Avoid abbreviations, diagrams, and reference to the text.

Manuscripts, including tables, figures, and references, should be prepared in accordance with the Publication Manual of the American Psychological Association (Fourth Edition, 1994). Copies of the manual can be obtained from the Publication Department, American Psychological Association, 750 First Street NE, Washington, DC 20002-4242; phone (202) 336-5500.

A Microsoft Word author template file, which also includes more detailed instructions in its "Read Me" file, can be downloaded from this page.

[Download Template](#)

Illustrations

Illustrations submitted (line drawings, halftones, photos, photomicrographs, etc.) should be clean originals or digital files. Digital files are recommended for highest quality reproduction and should follow these guidelines:

- 300 dpi or higher
- sized to fit on journal page
- EPS, TIFF, or PSD format only
- submitted as separate files, not embedded in text files

Tables and Figures

Tables and figures should not be embedded in the text, but should be included as separate sheets or files. A short descriptive title should appear above each table with a clear legend and any footnotes suitably identified below. All units must be included. Figures should be completely labeled, taking into account necessary size reduction. Captions should be typed, double-spaced, on a separate sheet. All original figures should be clearly marked in pencil on the reverse side with the number, author's name, and top edge indicated.

Proofs

One set of page proofs is sent to the designated author. Proofs should be checked and returned within 48 hours.

Article Title

Author's Name
Author's Affiliation

Author's Name
Author's Affiliation

Author's Name
Author's Affiliation

Address Correspondence to:

Interview with Grant's mother

Can you tell me about your experience of your son being ill?

Can I just say something in general first we noticed that before as well, long before he was actually diagnosed with aspergers, when he was younger, he's done well recently, he used to get a lot of these tummy bugs and we used to notice that he could keep going and keep going, you know when some people start to feel off they go and they'll go off their food but even though eventually he went off his food he would struggle to eat rather than leave it. Yes, and then he'd be sick and then he goes to bed. I mean he was a perfect patient in respect that when he felt ill he was quite happy to just lie in bed on his own he didn't want anyone there, he just wanted to lie there and if you said to him how long have you been feeling like this he'd say oh well a few days. But initially he wouldn't tell you until he got to the stage when he was so ill and then he used to look dreadful and then he couldn't eat. But one of the funny things and we were only talking about it the other day was when he was ill like that he always used to think of food and he'd say when I'm better can I have such and such, he doesn't seem to recognise early symptoms in something as general as that he'd actually get very sick and starting to you know and then he'd go off his food totally he was ever so funny but when he's ill he's the perfect patient.

So initially he won't recognise symptoms it is only later on ..

When they are quite severe really you know some people say I'm not feeling too good and its like as though that bit he misses and its until he's really unwell till the end symptoms, like actually getting sick and you know. He had a bad throat, was it before or after xmas and he also suffers an awful lot with mouth ulcers, now when he gets a mouth ulcer he'll put up with it for days. Now mouth ulcers are very painful anyway and he sometimes won't even say that he's got one, it's how he talks and his speech just goes, doesn't go whatever way he speaks and I can tell that something's wrong and I can say have you got a mouth ulcer, and he'll say yes. Now they aren't little tiny ones I mean we've got this paste from the doctor. and they're like craters and he may have three or four sometimes but I will say to him is your mouth soar and then occasionally he'll have had them for days and he'll say I've got an ulcer. He's now at the age of 14 whereas before he would let them go till they were really bad but even when you've got a soar throat or anything its not the minute its soar its not you know you start thinking I think I'm getting a soar throat his gets to the extent whenever you have to take him to the doctor's, what we have noticed is he doesn't notice the early signs, yes, it's usually when things have developed.

Yes. When was the last time that he wasn't feeling very well?

He had a soar throat maybe no more than a few months ago it could have been a bit earlier. We ended up going to the doctor's for antibiotics and things like that.

How did you first find out then that he wasn't feeling well?

Uhh, how did he show it? Umm, I'm not sure did he actually go off his food a bit? Yes I think he was eating and he said I'm having trouble swallowing. Yes. It's hurting me to swallow. Which meant that it had to have been sore for a while for it to have got to that stage. So then when he said that and I get a torch and a spoon, sometimes his tonsils do sort of look, I mean sometimes in the past he has actually had white spots on his tonsils before he's actually said.

You are aware before he tells you that he's ill?

Sometimes yes, as he's getting older now I think he's recognising just a bit earlier but again the initial symptoms aren't there he doesn't pick up on them. You know it's more, um and I don't know the initial ones because I think the initial ones are when

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you are actually not feeling too well yourself, its understanding how you are feeling isn't it?

Yes

And I think it's not until the pain gets to a degree that he can feel it. What we have said is that he has a great pain threshold. You know when he was young he fell down and he'd pick himself up and rub his knee things like that never bothered him. But when he is in pain he has very, very bad pain.

Yes

If I could just mention that when he was 6 he had to have a circumcision yes but prior to that he had been at the doctors it must have been a couple of years before he had this, we waited nearly a year, so it must have been a couple of years before he had this. Um and we had him down the doctors, he must have been ... and we noticed he kept pulling at himself so we took him to the doctors' and he said he's just discovered what he's got down there and we left at that we then went back 2 or 3 times. Finally the doctor decided that he had an infection and he needed to see a specialist. So we went to see the specialist and he recommended a circumcision. When it finally came round we took him into the hospital at the day surgery, he had it done and we brought hem home. They said he'll be fine within 3-4 days, and there were a number of other people who's son had had it done. He was off school for 3 weeks his was so severe we had a nurse coming in for 2 weeks we had to cut up a laundry basket like a cage so that the covers didn't touch him. We had to give him painkillers every four hours. The reason I'm saying this is that he literally cried out in pain. I mean this was before he was diagnosed. He tolerated how soar that was occasionally he might say something. His must have been more severe because the lady down the road her son was back at school within 2/ 3 days. He couldn't put clothes on; he couldn't have the bedclothes near him. We were giving him salt baths twice a day.

So sometimes he doesn't notice pain but other times when it gets bad he can really suffer?

He has a high pain threshold but when it gets to there its like as though it's major. That was one of the worse times to see him in pain. We didn't know what to do and we were getting through paracetemal and stuff like that.

How did he express himself?

He literally just cried out at 2 am I mean sometimes he came in and said give me something for the pain. He was about 6 years old then and even though he hadn't been diagnosed then but looking back seeing how severe he was I hadn't heard of any other children needing three weeks off school after a minor operation. I mean everyone is sore after an operation but his was bad. We had to take him back to the doctors a few times.

Is that the same with pain now days?

I do feel that he can tolerate a good deal of pain. We were at the doctors just before Christmas. He has a terrible habit of picking his toenails, both of them won't let you cut them he picks them. He had one of his toes get very large as a baby they said it was like a birth mark and that toe is slightly larger on the bottom, if I didn't tell you wouldn't notice but he actually whatever way he picks his toe nails he actually pulled the whole toe nail off. And we went to the doctors, the reason that I took him down, he'd done this for days before he'd said this to me and it began to look very angry and I thought it was infected before he said this to me, and it was starting to look very angry and I thought it was infected. We showed it to the doctor and he said that's certainly one, you must be one on your own to be able to pull your toenail off. He had done it days before and it was only because he said it was starting to hurt that I thought it was infected. It's actually grown back now. That's the sort of pain he

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can stand and I wouldn't even dream of picking my toenails but to literally pull your whole toenail off.

He didn't express any pain at the time?

No, I mean if that can give you an idea of how he.. I mean I've heard of some children who have no response to pain at all. Grant can respond to pain but I think it has to be at the higher level, it really has to be on the extreme, I mean some people scratch themselves and they're moaning about it. That doesn't bother him, you get to a different level and you know you pull your toenail off.

How does he express it when it gets to that level?

When the toe was bad, he said oh yeah it came off the other day, he was very matter of fact that it happened but obviously the soreness, it was beginning to hurt when his shoes were on. Once the doctor gave him some medication he was fine. Whether if you give him something to relieve the pain, even if it doesn't take it all away, he was able to cope with it. If it had been anyone else they'd have been there with their foot up. I do wonder sometimes if he really had a serious problem with something like his appendix and needed to have it out, would it be at such a level that it would be quite dangerous cause, I have a nephew that had to have it out, they weren't sure at first you know there's a level, I often wondered if there was anything like that would we know or would he tolerate it for too long. Before he got to that level. It's a case of really, I have to keep asking him, I mean when he comes in from school we often have a few minutes before his brother comes in and I'll say to him have you had a good day, how are you are there any problems, if you've got any pain, its sort of like just now and again you have to say it just to jog his memory if there's anything there. If there is sometimes I might take him to the doctors and he's fine. But it's a case of not knowing, it's a case of has he got this pain or has he got something wrong and its so mild there really isn't anything wrong at all, or is it mild to him but more severe in the degree that ...

Now he is getting older, we don't seem to be have that great long bit where he's so poorly, he is starting to say I'm not feeling too good, I'm feeling a bit off. It's still along the line you know, if you had 0, it would be nearing towards the 10 before we'd realise.

Is that the same with his brother?

His brother is younger and if he hurt himself you'd know straight away. If he's got this little cut or little whatever, looking at the 2 of them they are so individual and maybe that was part of what started us looking at Grant. If he fell over and hurt himself he'd get up and pick himself up whereas L. would sit down and cry his eyes out. I'm not saying that was the only thing there were a number of things that made us think something wasn't quite right, but that was one of the things Grant's tolerance of pain.

Are there any differences in illness?

Um, I'd say in the last 2 years they've both been pretty well. If Grant were to get ill it would pull him right down he would stop eating and drinking, he used to look really poorly, you could tell by his eyes. His eyes would start sinking into his head. But when he started getting better, we noticed that he'd say when I'm better can I have this to eat. That was a good sign we were over the hill.

Whereas L, he wouldn't get as severe but whether he would tell us earlier that he wasn't ill and Grant had got to the extreme before we could treat him

What is the connection between his food and getting better?

It's funny really he likes his sandwiches from M & S, there been occasions when he's been lying here sipping water and you'll be saying don't gulp it or you'll be sick. When I'm better can I have a big milkshake and a sandwich from M & S and we used

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to laugh and there was one occasion when he was on the road to recovery and we were in the car and I nipped onto town for something and I'd picked him up this sandwich, S. had said don't eat it in the car, or you'll make a mess and he must have been longing for this sandwich and he said can I open it just to smell it. We laughed, he couldn't even eat it all, it was something he'd visualised when he wasn't well. Something like that he doesn't forget, 'you said when I'm well I can have such and such'. And you have to get it for him. He does talk about food when I'm better....

Has he ever had any particular interest in illness?

No, he does like watching casualty and ER and on school holidays he likes watching City Hospital, he doesn't have an obsession about it. My way of looking about it is its good for learning about what's going on. I had to have a hysterectomy a couple of years ago, we never told the boys till a few days before I was going in to hospital. I put it very simply as I had the two of them together we just said that I had a lump in my tummy and immediately I said that, Grant said you've got cancer and I said no I haven't. So then when I got him on his own I explained in more detail to him, he was 12 years old but L. was only 7 or 8 he wouldn't have understood. It did amaze me that he just jumped. Whether its just there's a lot on TV about cancer, I had to give him more detail. What I gave him initially just made him think. If the 2 of them had been older it would have been easier, but it wasn't enough for Grant. I had to give him that in depth information and he understood, I wouldn't have told him if I didn't think he would but because he's been doing sex education at school and the body he had a rough idea. It's funny, when he was at the primary school and doing sex education I was worried whether he'd understand it, they said they do it a very low level and children take in board what they want. We were heading up to CAMHS and I asked him how he was getting on in the sex education, is there anything that's bothering you wanted to talk about? What are you doing, he said we were talking about ladies and their periods. He said do you still get periods? So I said yes.

Then he said next time you have one can I have a look, so I said no. He was curious and although I was trying to be as open as I could with him I just felt that was too far. I don't think any other kid would be that naive as to ask can I have a look. I very gently tried to say know but he'd occasionally ask have you had that period yet? I'd say look Grant that's a personal thing you can't do that. But when I had the hysterectomy I was able to say I don't have any periods now. Which put a lid on that side of it. I'd have to give him a bit more information.

H?.....

Yes, and to see it is to believe it, it's all right to talk about it but I need to see it and that personal private thing didn't exist with him. Laugh.

Would Grant understand when other people are ill?

Yes sometimes, um when I came out of the hospital after the hysterectomy and I was home for a few days. Whilst I was in the hospital I was ill but once I got home your alright, he just thought I could get up and do everything, it's like only sick people are at hospital but when your at home, they put you right and that is how it goes. He kept asking why aren't you doing this? Grant I can't do that I have to be careful, but you're not in the hospital anymore. If you genuinely say to him, I had problems with my back a little while ago and he would say after a while how are you. I'd say I'm not feeling well my back is hurting. I think it took a while to sink in but to say your not well once isn't enough you have to say where your pain is or where your not feeling well.

If someone had broken their arm or something visible would he be the same?

Again it's the seeing bit, both myself and L. are diabetics, he'd had his diagnosis of aspergers, he was 10 when he was diagnosed and all the way along when we were gong through it, we were doing this for a reason he was having problems we were

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hoping to get help if this thing was there. So when he had the diagnosis, because he was older, he's reasonably intelligent. He was diagnosed in September and the following summer we on our way home and he was going to a football party. He was sat very quietly in the car and said mum is my aspergers like L.'s diabetes that it won't go away and you have to learn to live with it? He'd heard me saying to L. you have to live with it it wont go away. Grant knew about the diabetes as he could see him having the injection but Grant wasn't having any medication he had this thing that unless you understood how you were feeling no one else would know. Yes you have to live with the things you can and cant do. And he was happy.

About diagnosis.....group...etc.....

How does he understand his brother's diabetes?

He's quite good at that he realises that we have to have his injections and checking his blood. L. has to have 3 injections a day. The last one at night, I'll ask 7 to ask L. to come down. L. can be very oppositional. He's like sergeant major and say s" L. get down here and do that blood and injection now. He knows it's got to be done. Before L. could read properly he would say you can have this drink but not that one and if he's going low he'll say L. needs some sugar.

He has a good understanding then?

Yes but not the other way around L. thinks Grant just gets away with things, he can't see anything wrong with him.

Is there anything else about his understanding of illness?

Do you think he knows he can do things to stay well?

I think so, he does a lot at school and there's a lot on the TV about healthy eating and exercise and fitness and that. I'm afraid he doesn't really go out after school. He used to go swimming, but I stopped taking them because of rivalry between the two...

I want to move on now to ask about Grant's understanding of life and death, do you know if he understands what the difference between alive and dead is?

Um, I think he does, because you are posing that question to me its making me think, I've never actually asked him. Going back to when his grandmother died, she was buried the day after he got his diagnosis and she had been ill for some time, he'd been to the hospital to see her um, when we were at the crematorium his cousins who were about his age were stood there crying and he actually came over to me and said why are they crying? Bearing in mind he was actually 10, now it's a different matter. I said its because your Nan has died and we often have gone up to the grave but he doesn't talk about her, she's not here, in fact I don't remember him talking about her. I had an aunt who died last august, I was very close to her

Yes

She used to come here a lot and had a lot to do with the boys, now when she died, she died suddenly he did initially, I don't think he cried but he looked sad and said he felt sad.

Yes

But when the days went on after she died, I got really upset and at the funeral and that and remember we came out of the church and he said to me you didn't need to cry when we were in the church, you cried the other day, you don't have to cry now.

He couldn't understand why you were upset?

He couldn't understand my emotion, and I said to him auntie has died and I miss her terribly. And he said yes but you cried you don't have to cry now and we went up to the graveside and it was the first time he'd been to a funeral, his other cousins were there, they watched the coffin go down. A couple of days later we went up to the grave to look at the flowers, but since august he's said to me do you think we ought

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to go and visit auntie..’s grave but he’s never said that about his Nan, whether or not it’s because he saw the coffin being lowered into the ground, his Nan was cremated and her ashes were scattered and we weren’t there when they were scattered. So as far as Grant knows, he knows we go up to where they were scattered but he actually saw the coffin going into the ground, but it amazed me when he said we need to go and see auntie..’s grave.

Well whether the whole concept of what’s going on down there, that it’s all going to rot etc. or whether it’s because he visually saw her and he know that’s where she is.

He can conceptualise it?

Yes, He knows that’s where she is. When I say I’ve been up to see auntie he says oh why didn’t you take me and I say well I was feeling a bit sad today so I thought I’d go for a chat. ‘Well can I come next time?’ Now L. has never mentioned that but L. is at the age that Grant was when his grandmother died, you know. So is it because he’s a little older and he’s also a lot closer to my aunt he’s done a lot with them. They only saw his Nan once a week and she interact well with him. But my aunt would baby-sit and look after them if I wasn’t well.

What do you think Grant thinks happens after someone dies?

Um, he is a catholic and goes to a catholic school, so within the catholic school they say when people die they go to heaven and he’s go that understanding but whether he just going along with it or he has any other thoughts at all. There was a girl in his class at primary school and she actually died, she had a brain tumour. When my aunt was being buried last year, it happened to be near where ... had been buried.

Yes

He said ... is buried over here, he knew she’d died and he could relate that she was there.

Yes.

So he’s never said or had a conversation, they say at school about heaven and that, whether that concept will always stay with him or whether hell have a view of his own as he gets older I don’t know

.....?

May be if I’d asked him before, but I haven’t really talked about it before.

My dads nearly 70 and he’s not got good health, I’ve often wondered if anything happens to him if he dies that it will really, really hit Grant as they are very close. I do worry that there will be a huge void if anything happens to him and how he will cope. And whether he will be able to cope enough to understand that that’s going to happen to all of us, I don’t know. I hope, as he gets older he may understand or will it be such a tragedy to him that it may affect him adversely. You hear of people who can’t get over death. But they are so close they have a bond. If he got ill and you had time to prepare Grant that something was going to happen whether that would be advisable, again it’s just thoughts that have gone through my mind.

How does he react when someone on TV dies?

He just watches that. But do you remember the Israeli president, Iksat Rabin, he got shot a few years ago. He wanted to watch it on the TV. He kept saying why was he shot. Whether he was old enough to understand that there was trouble going on. But it amazed me how he was talking about why he got shot. Whether the TV showed you the pictures, and he was actually watching the news or whether he was just starting to take notice of what was on the news. He used to ask is there anything about that Rabin on the news

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Initially when it happened he was very interested, he would ask about it and read about it in the newspaper. At school he’s been covering JFK, he’s really interested in

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history, he's been doing all this research on JFK, is he just taking it like that because it's a piece of work he's doing at school and it's somebody else and he isn't close to home.

Yes

I think all of us deal with death differently don't we. He's looked at death regarding people who've died but is he actually beginning to understand some of these feelings, emotions.

Before he didn't?

No, I'm hoping that it develops enough for him to cope with it, if it doesn't we may have problems.

Does he understand, that it's not reversible, that they can't move

I should think he does, from watching TV and the people he knows who have died, yes. You mean that no one can say to them get up and walk and again with my aunt actually seeing her lowered into the ground, there was no way that if she's down there she can't come back. He knows if they are buried or cremated they don't come back.

Do you think he understands that when someone's dead that they can't do the things they did when alive?

Yes I think he does understand that, he knows when you're dead that's it, I think he accepts that you can't do it when you're dead but what he couldn't understand when I wasn't well was that because I was out of the hospital I should have been able to do things for him and that understanding wasn't there. And initially when my aunt died he wanted to go and see her. But I felt that was too much for him to take on board. I explained that it might upset him, as people look different when they are dead and its best to remember her laughing and joking. We spoke about it a few times, and then he accepted it. I just felt it was too much. And maybe if he'd seen her in that coffin would he have thought that if you'd given her an injection, because she looked like she was asleep, she can just get up now, or you know, those things went through my mind and I was trying to protect him. Maybe when he's older, he might be able to cope with it and think differently, with his age and the fact he has aspergers it wasn't wise.

Do you think he knows what causes people to die?

Yes, I think he understands that if you have a severe illness because he's heard a lot about cancer and he knows his friend from school had cancer.

Yes

And I'm sure he knows that old age, because his cousin her grandfather died a few years ago and he was well into his 70's even though Grant didn't see him, I remember him and his cousin talking about it. She said but my grandfather was old, I think he does have that concept that you don't live forever.

Yes

But we haven't gone into great detail. Maybe I'm just trying to wait until things happen, like when my aunt died we did talk about it. But I don't know whether his emotions would I don't know. If I was being honest I think a lot of me is trying to not let him have to deal with feelings and emotions too much at the moment,

Yes

Because I know its an area he finds difficult to understand, again he will have to deal with them but I'm hoping as he gets older he will have matured just enough to do that, does that make sense?

Yes

End of tape....