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Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

by

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Abstract

The literature examining the development of theoretical models of Chronic Sorrow and Parenting Stress is reviewed. A critique of these models is presented in the context of parents of children with disabilities, in the form of Down syndrome (a congenital disorder), autism (a pervasive developmental disorder) and acquired brain injuries (through trauma, infection or ischaemic event). These three diagnostic categories represent time specific onsets with Down syndrome recognised in utero or at birth, autism typically manifesting at two to three years and brain injuries being acquired at any point in a child's development. This study examined how the temporal aspects of onset of disability may be significant in the development of Chronic Sorrow and consequential Parenting Stress. Measures of stress, sorrow and adaptive behaviour were administered to parents of children in all three diagnostic categories. Results indicate significant effects on stress and sorrow of the age of the child when parents first suspected a problem, parental education and occupation, the gender of both parent and child and satisfaction with informal support levels. A strong relationship between stress and sorrow even when controlling for adaptive behaviour was found, thereby identifying areas for future research into the implications of these findings for clinical practice.

Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

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Finally, I would like to thank my friends and family for their support and encouragement, particularly my brother Rob and nephew Robbie for giving me the idea in the first place.

Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

Contents Page

Literature Review – Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress.

Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

Contents Page

Empirical Paper – Parents of Children with Down syndrome, Autism and Acquired Neurological Difficulties: Chronic Sorrow and Parenting Stress.

Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

Tables and Figures

Literature Review

Empirical Paper

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Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress. A literature review

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Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

Abstract

There is an established literature relating to grief, however there is a less robust literature that examines non-finite loss, particularly when addressing disability as a loss experienced by significant others. The concept of parental loss or Chronic Sorrow in childhood disability and the associated stress has a comparatively weak evidence base. Traditional theoretical linear models of grief are considered alongside cyclical models, which appear to provide a more relevant interpretation of parental grief in the non-finite loss situation of childhood disability. Attachment, particularly the attachment of a pregnant mother to her unborn child (maternal-foetal attachment) and the development of maternal representations of the child and the self as a parent are discussed as are the implications of having a child that is incongruent to the one imagined. The Chronic Sorrow and Parenting Stress felt by parents of children with various disabilities are discussed, particularly Down syndrome (a congenital disorder detectable in utero or at birth), autism (a pervasive developmental disorder, usually manifesting at two to three years) and acquired brain injuries (whether through trauma, infection or ischaemic event, which may occur at any age). Future research is required that examines parental loss and sorrow as it relates to disability and specific onset periods from neonatal across the developmental range.

Keywords: Chronic Sorrow, Parenting Stress, Down syndrome, autism, acquired brain injury.

Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

Olshansky (1962) first used the term "Chronic Sorrow" to describe a cyclical grief process that is experienced by parents of children with a learning disability. Since then, many authors have gone on to examine this process and research has shown that it differs from the traditional linear grief that is experienced by people who have been bereaved, that is widely held to end with acceptance (e.g. Wikler, Wasow & Hatfield, 1981). It is therefore important that health professionals understand the differences between cyclical and linear grief and the factors that contribute to its onset and maintenance, in order to provide the most effective service for families in this situation. The term "Chronic Sorrow" is therefore used to describe a cyclical grief process, that does not end in acceptance, which is characterised by periodic cycles of grief in the face of a non-death loss such as that faced by parents of a child with a disability, spouses of people with dementia and other such non-death losses that invoke a grief response.

The concept of maternal-foetal attachment is an important contributing factor to be explored, as are the maternal representations developed by a mother whilst her child is in the womb. Discrepancy between the "fantasy baby" and the "reality baby" can lead to a need to mourn for the loss of the perfect child that the parents had envisaged (Condon & Dunn, 1988). Such a discrepancy can arise when the child is born with a genetic condition such as Down syndrome, or when a normally developing child changes, through a pervasive developmental disorder or through an acquired condition, such as a brain injury.

Chronic Sorrow and the cyclical nature of this grief will then be compared to traditional, linear models of grief such as that proposed by Bowlby (1980) and the reasons why these models may not be applicable will be explored.

Parenting stress is also an important area to cover and the research on levels of stress felt by parents of children with disabilities is reviewed, along with possible moderating factors. Research such as that by Baker and McCal (1995) has shown similar patterns in the levels of stress and Chronic Sorrow felt by parents of children with various disabilities, but no studies have explored the possibility of a relationship between the two concepts. Parenting stress is defined as the stress felt by parents in terms of three domains, namely stress associated to the characteristics of the child, the parent themselves and the situation in which they interact, that may be associated with dysfunctional parenting (Abidin, 1995).

The implications for health professionals, both of Chronic Sorrow and parenting stress are explored and recommendations are made as to how professionals can facilitate the adaptive coping of parents. Finally, suggestions are made about the best way to do this, through the use of support groups (e.g. Shultz et al, 1993) or individual therapy (e.g. Roos, 2001).

Normal Maternal/Foetal attachment (MFA)

Maternal/foetal attachment is a phrase used by researchers to describe the feelings of attachment felt by mothers, whilst their child is still in the womb. The development of normal MFA may have changed in recent years with the declining maternal mortality rate and medical advances (Salisbury, Law, LaGasse & Lester, 2003). The authors suggest that, compared to 100 years ago, expectant mothers now have far fewer concerns for their own well being during pregnancy and may therefore have more time to develop representations of their baby and start to form an attachment to it. High-resolution scans may also contribute to this, as the mother is able to see her baby clearly from a very early stage of development. Scales have been developed which try to quantify maternal/foetal attachment, such as those by Condon (1993), Cranley (1981) and Muller (1993). Whilst these measures can be useful in trying to understand how MFA affects the mother's subsequent relationship with the child, studies using these measures should be treated with care, due to the lack of a formal, operationalised definition of MFA. Siddiqui and Haeggloef (2000) used the Prenatal Attachment Inventory (Muller, 1993) to examine whether pre-natal attachment could predict postnatal interaction between mother and baby. They found that there was a strong positive relationship between the two factors, indicating that reinforcement of positive attachment to the foetus could assist in the post natal bonding of mother and baby.

Maternal Representations

During pregnancy, an internal representation of the baby develops, with the process accelerating once the mother can both see and feel that she is pregnant through her expanding waistline and the movement of the baby (Matarazzo, 1992). Ammaniti et al, (1992) suggest that because the baby is growing within the mother, her representation of it will encompass various aspects of her own experiences, especially her relationships with her partner and her parents. As well as developing a representation of the baby, the woman must also foster a representation of herself as a mother that is separate from her view of herself as a woman. From the moment of birth, the mother will be involved in an ongoing process of either confirming or disconfirming those aspects of herself she has placed within her representation of her baby and her view of herself as a mother.

Condon and Dunn (1988) hypothesised that a mother's reaction to her newborn baby would be predictable from her attitude to the unborn child and the degree of congruence between the "fantasy baby" and the "reality baby". This congruence was seen as necessary to facilitate a smooth transference of feeling from the foetus to the newborn. Their study showed support for these hypotheses, although they did not rule out other factors that may contribute, such as traumatic delivery. In the case of a child being diagnosed with a genetic condition at birth, such as Down syndrome, it can be seen that this might produce a high level of incongruence between the fantasy and the reality and therefore affect the smooth transition of feelings from the foetus to the baby.

Larney, Cousens and Nunn (1997) conducted interviews with women experiencing their first pregnancy to assess their maternal representations during pregnancy and again at four months after the birth. They recruited 82 first time mothers, all of whom were experiencing normal pregnancies and none of whom were suffering any mental health difficulties. They found that mothers' representations of their babies, themselves and their own maternal characteristics were all relatively stable and all became more positive after the birth of the baby, regardless of birth experience, maternal age or socio-economic status. The authors suggest that their results do not support the idea of the transference of feelings from the fantasy baby to the real one, as the maternal representations were stable. However, all the mothers included within the study had healthy babies, which may have been very congruent to the fantasy of the child and were from middle or upper level socio-economic groups, possibly providing them with more financial and practical support after birth. The authors make salient points about the clinical implications of their findings. If maternal representations are stable by the third trimester and can be predictive of representations after birth, then clinicians should be involved in helping the mother to develop positive representations of her baby, herself as a woman and herself as a mother at an early stage in the pregnancy in order to help facilitate a positive experience with their newborn and provide the optimum conditions for secure attachment.

The Development of Internal Representations

The processes of attachment begin in early childhood, when a child begins to develop working models of inner certainty and outer predictability (Bowlby, 1988). If a child does not develop schemas of a safe world, for instance if they grow up in an abusive situation, then maladaptive or dysfunctional schemas may be created (Beck, 1967). Dysfunctional schemas such as "the world is not safe" can lead to emotional difficulties, such as anxiety disorders (e.g. Clarke & Wells, 1995). It is not within the scope of this research to examine the development of dysfunctional schemas. Instead, it shall examine how normal schemas are developed and how these can affect a grief response.

Adaptive knowledge structures allow a person to feel safe within their world and to feel a sense of their own role (Marris, 1986). These mental templates, or cognitive schemas, are constantly being shaped and elaborated upon over time, but the individual is likely to try to shape new information to fit their existing schemas and they will act as a filter to knowledge that is incongruent, thereby influencing a person's memory of an event (Bartlett, 1932). Kelly (1955) proposed the development over time of a picture of "the world that should be". This assumptive world will also be projected in to the future, in the form of plans and goals (Neugarten, 1976). In the case of a parent of a disabled child, the world should be many things at varying intervals, depending on their frame of reference. Berger and Luckmann (1966) refer to this frame of reference as a correct life sequence, resulting from primary socialisation. In other words, a mother will develop the sequence that, as other children do, their child should walk at around one year, talk at around two, be at school by five and eventually develop independence and form adult relationships as others do and as their parents did. Recurring reminders that the world is "not as it should be" are what triggers a non-finite grief process, or Chronic Sorrow. The inflexibility of schematic norms that have been developed over many years, through observing other families and their children developing, means that parents may cling to their forward plans in the form of unrealistic hopes and wishes. To have these wishes unmet contributes to feelings of grief at every anticipated milestone (Bruce & Schultz, 2001). There are no right and wrongs, but expectations of physical, educational and environmental milestones will have been developed through personal experience and the society that people live within. Marris (1986) even goes so far as to say that hopes and dreams about what we will become in the future are sometimes more meaningful than our present.

People also develop internal representations about disability. Our attitudes towards certain disabilities will depend upon our experience of people suffering from that particular condition and our attributions as to how they are caused (Flavell, Miller & Miller, 1993). Marks (1997) described people's reluctance to be around disabilities as a primitive fear of somehow being "contaminated". If a parent has developed a negative view of a certain disability throughout their life, then how do they go about reorganising their view when they have a child with that disability, whom they are expected (by society) to love unconditionally? Bruce and Shears (2000) suggest that some parents are traumatised by their child's disability, possibly due to their internal representation of "Autism" or "Down syndrome" and may feel that they will not be able to cope with the demands of the child or their own fear of being different. Pre-conceived ideas of disability may not always be negative though. For instance, the publication of the novel "The Curious Incident of the Dog in the Night-Time" by Mark Haddon (2004) might have introduced some people to the world of autistic spectrum disorders in a positive way, helping them to understand what life is like for these children and therefore empathise a little more – however, this is conjecture as it could be hypothesised that the people who chose to read this book were people who had some interest in, or connection with autism already.

It is therefore important to examine what happens to both the mother's internal representations and MFA when the baby that is born is not the one that is expected. Zimerman (2003) found that women who were pregnant having already given birth to a child with Down syndrome (DS), showed different levels of prenatal attachment to their unborn child than other second time mothers, as measured by the Prenatal Attachment Inventory (Muller, 1993). This suggests that their experience of having a child who was born with a disability may have affected their internal representations of motherhood and pregnancy in some way. The results of this study did not reach statistical significance and used small samples but the qualitative data supported the hypothesis that prenatal attachment was different for those mothers who already had a child with a disability. Zimerman and Doan (2003) reported results with a larger sample of mothers who were pregnant, subsequent to having a child with DS and were able to find significant differences in various areas. Mothers of a child with DS were less joyful at the announcement of pregnancy, spent less time engaged in attachment behaviours (e.g. stroking their stomach) and were less likely to have planned the pregnancy.

Robb (2003) writes of her personal experience of having a granddaughter born with a cleft palate. A psychotherapist herself, Robb watched with concern as her daughter's grief and distress for her baby appeared to get in the way of them forming a secure attachment immediately after birth. This deficit is described as lessening, as the family learn more about the prognosis for the baby and accept her condition. Robb describes the particularly helpful intervention of a specialist baby nurse, who was able to normalise events for the mother and help her to realise that the cleft palate was a temporary, fixable condition, which did not reflect on her relationship with her baby. But what happens when the condition is neither temporary, nor fixable? Bendell, (1984) describes the processes that parents of children with a disability must go through immediately after birth, compared to parents of a healthy baby. Questions and anxiety regarding the future, long separations from the infant for any medical procedures and even disengagement in anticipation of the child's death may occur. All of these factors may result in disrupted attachment during the early part of the child's life as the parent's responses of shock, denial or anger take precedence

Research has also been conducted into attachment with children with various different diagnoses, rather than the broad categories of disabled/not disabled. Hall and Marteau (2003) found that the attributions that mothers had as to the cause of their child's Down syndrome had a direct effect on their subsequent adjustment. Those mothers who blamed someone (e.g. medical staff, husband) had significantly higher levels of anger, depression, parenting stress and more negative attitudes towards their baby than those mothers who accepted DS as a random chromosomal abnormality that was not due to any outside influences. This research shows the importance of educating parents as to the nature of their child's disability and the reasons for it, if any. Quinn (1991) also examined the attachment between mothers and their babies with DS. This research showed that those mothers who perceived greater social support around them were able to attach to their disabled babies more quickly than those who felt unsupported. Both these studies used large groups of participants and robust scales, thereby producing statistically significant results.

Hoppes and Harris (1990) conducted a study to compare attachment in mothers of children with autism, to mothers of children with Down syndrome. They found that mothers of children with autism described their relationship with their child as significantly less attached than mothers of children with DS. The authors found that these statistical differences could be explained by the qualitative reports of the mothers, that their children were less emotionally expressive or intimately close to them, than those of children with DS. Their secondary hypothesis, that mothers of children with autism would receive less maternal gratification, was also statistically supported. It should be noted however, that this study used a relatively small sample size and all the data was based on the mother's reports, rather than clinical observation. Nonetheless, the cited research produces some evidence that the birth of a child with a disability can cause disruption to the mother's attachment to the child. It can also be hypothesised that these mothers have to change their internal representation of their baby that had been developed whilst in utero. In the same way, their representation of themselves as a mother will need to be revised.

However, not all disabilities are detectable at birth. Developmental disorders such as autism may not manifest themselves until later in the child's life. Also, acquired disabilities as a result of a head injury, medical event (e.g. restriction of blood flow to the brain) or infection may also require the parents to reorganise their view of their child and themselves, but at a later date. It could be hypothesised that the parents need to relinquish their attachment to the original child and re-attach to the child with a disability. This process of reorganisation could also therefore create a grief reaction in the parents, or Chronic Sorrow. Rather than incongruence between the fantasy baby and the reality baby, this situation would be incongruence between the way the child used to be and the way they are now. There are also the same issues of looking into the future and wondering what might have been. So it can be seen that Chronic Sorrow occurs in many different situations. But how does it differ from grief that occurs as a result of a death?

Traditional Models of Grief versus Non-finite Loss

As in the seminal work of Kubler-Ross (1969) on the stage model of grief, most traditional models of the grief process have followed the same structure of a linear process, during which a person passes through a number of stages finally leading to acceptance. But how do these compare to the non-finite loss situation of having a child with a learning disability?

Freud (1917) described grief as a linear process, during which a gradual "letting go" of the person who has died defends the mourner against the implications of the loss. The mourner has the cognitive tasks of reviewing their own inner world and detaching their memories and hopes for the future from the lost person. This process may result in a loss of interest in the outside world and a preoccupation with the lost person. Freud suggested that resolution comes about by the mourner taking on some characteristics of the lost person so that their best qualities will live on.

In a non-finite loss situation the source of the grief remains and so the mourner cannot detach himself from the lost person, nor can they develop new expectations about a future that is unpredictable. The mourner also has to grieve for what they themselves may have become had the loss not occurred (Bruce & Shultz, 2001).

Bowlby (1980) described grief as a relinquishment of attachments. He suggested that there were four phases that a person needed to pass through before this would be successfully achieved and acceptance reached.

1) Numbing
2) Yearning and searching for the lost person
3) Disorganisation and despair when the irreversibility is realised
4) Reorganisation

As the person learns that their repeated attempts to recover the lost person are futile, the urge to do so becomes extinct. The individual will process the loss information in reference to their pre-existing models of the world, which can be a painful task. They may idealise what has been lost and have to redefine both themselves and their situation.

In a non-finite loss situation, the urge to recover what has been lost may be more difficult to extinguish, as the person is still physically present. It could be hypothesised that this could lead to constant battles for a "cure" or a futile hope that the situation will reverse itself over time.

Marris (1986) entitled his model "The Restoration of Meaning". This approach places less importance on the loss of the loved person, but more on the associated collapse of the structure of meaning that was dependent on the lost person. Marris hypothesised that as meaning develops with a child's first attachment, then innate predispositions to attach interact with the experience from childhood, to form habits of feeling, behaviour and perceptions. Any change that contradicts these habits (such as the death of a loved one) disrupts the mourner's ability to organise their experiences in a meaningful way. Therefore, grief is an expression of the conflict between the despair of giving up the lost person and the impulse to avoid all reminders. As in Freud's model, Marris suggests that the mourner will take on some characteristic of the lost person, or some ideal of the lost relationship in order to extract meaning and purpose from the loss.

In a non-finite situation, as before, reminders cannot be avoided. In addition, the relationship has been changed, rather than lost, so there is a rather different reconstruction of meaning to be undertaken that still includes the person but in a different capacity. Also, because it is possible that the mourner is grieving for an ideal, such as a perfectly healthy child, there are no definite characteristics that can be taken on. As described in the research on internal representations, the relationship could have been an imagined and longed for one, rather than a reality.

Parkes (1988) classified bereavement reactions as the mourner relinquishing their internal view of the world and grief as the discrepancy between the reality of the world and the way it should be (the assumptive world). Parkes advocated the use of Bowlby's four-stage model and described the behavioural and emotional manifestations of grief as part of the process of realigning the internal world with reality. Because this is a painful process, it may be that the mourner will avoid reminders of the lost person until they feel they have the emotional strength to deal with the difficult feeling. Parkes recognises that events can occur at a later date, which bring to mind the lost person and can return the person to the stage of yearning and searching for the lost loved one. This highlights one of the problems with a linear structure for a model of grief. If someone can move backwards through the stages is it correct to call the model linear?

In a non-finite situation, it is impossible to avoid reminders of the loss, as the person is still physically present and requires care. Therefore, the mourner is expected to confront the process of realignment immediately, without a gradual acceptance period (Bruce & Schultz, 2001). The model does allow for the recognition that grief may recur at significant times and is not simply a process that, once completed, will never be revisited.

Horowitz (1990) paid rather more attention to unconscious processes. He suggests that the mourner subconsciously initiates emotions, memories and triggers. The only way to revise their inner model of the world and those in it is by constant repetition of thoughts and unconscious defence against pain. This model had five phases:

1) Outcry
2) Denial
3) Intrusion
4) Working through

5) Completion

Each phase is characterised by the balance between intrusive experiences and avoidance. Self-schemata are matched against working models of reality and eventually become resolved. Again, this model does not really explain a non-finite loss situation, such as a diagnosis of a learning disability, as it is impossible for a parent to avoid reminders of their child's disability when they have to care for that child.

All of the above models have a linear structure and were originally developed to describe the grieving process in the event of the death of a loved one. They all include some mention of avoidance of reminders of the loss, in order to gradually face painful memories. Most of the models make some mention of the mourner having to re-evaluate their view of the world and their position in it, now that their loved one is no longer present. Shifts in roles may have to come about, for example, the shift from married woman to widow. But none of the models appear to adequately explain the phenomena of Chronic Sorrow, or non-finite grief.

Non-finite Grief and Chronic Sorrow

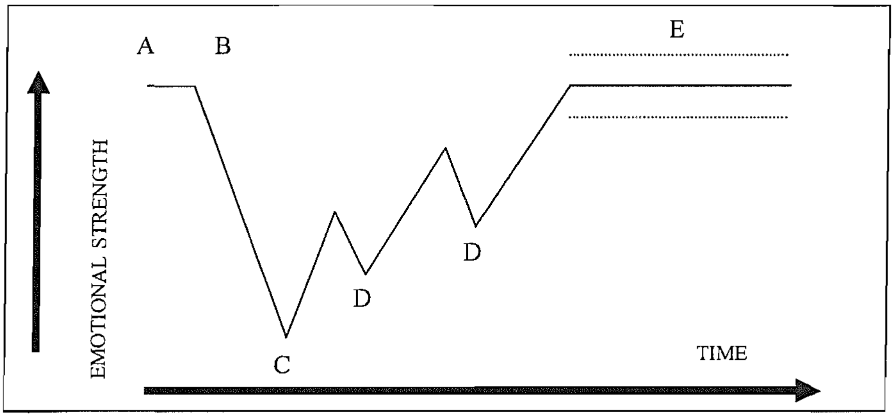
Drotar (1981) proposed a stage model to explain the reaction of parents to the diagnosis of disability in their child. His five-stage model suggests that parents move through phases that are similar to those of someone who has been bereaved.

1) Shock
2) Denial
3) Sadness, anger and anxiety

4) Adaptation
5) Re-organisation

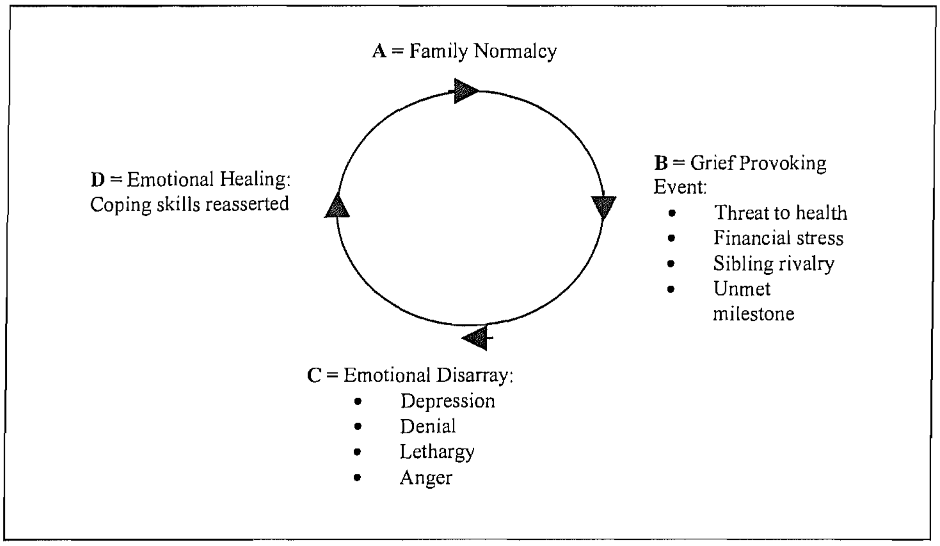
Other authors, such as Wikler, Wasow and Hatfield (1981) have criticised this model as being too linear to explain the more complicated non-finite loss situation that occurs in this case. They also question the idea that there is a right or wrong way for parents to react and that this will differ greatly depending on the situation. Some parents may have fought for a diagnosis for some time and may therefore feel a sense of relief at finally having an answer to their concerns and a way to access appropriate services. They propose a more cyclical model of grief that affects parents of children with a diagnosis of a disability over time. The idea of a cyclical grief experience is reiterated by Worthington (1994). See Figure 1 for a model of accepted linear grief, such as those already described and Figure 2 for a model of cyclical grief, proposed by Worthington (1994).

Figure 1: A Model of Linear Grief – Worthington (1994)



The model shows progression from point A (emotional normalcy) to point B (grief event, such as the death of a loved one) to point C (emotional low point) to point D (reminder of event B) to point E (grief resolution). Point E may be a new level of emotional normalcy, as the person may have been permanently affected by their loss.

Figure 2: A Model of Cyclical Grief – Worthington (1994)



This cyclical model assumes that parents undergo a series of recurring stresses that can sometimes be predictable (e.g. when the child does not meet a developmental milestone). These events force the family into a state of continual adjustment, therefore never attaining a state of true acceptance of the situation and resolution of feelings of grief. The length of time that the family stays in emotional disarray (Point C, Figure 2) will depend on factors such as the strength of the family to start with, social resources and the perceived severity of the event. Worthington (1994) proposes that health professionals should be able to pick up on symptoms that may signal the onset of a period of emotional disarray, such as non-attendance at appointments by a usually punctual family, or strengthening denial in a family that is usually realistic. During the healing process (Point D) health professionals can help the family to manage the crisis and provide appropriate coping strategies and support to enable a return to Point A, family normalcy, as soon as possible.

Olshansky first used the term "Chronic Sorrow" in reference to the reaction of mothers to their "mentally retarded" children in 1962. Over time, the concept of Chronic Sorrow has not just been applied to the scenario of having a disabled child, but has been researched in other areas, notably that of caring for a person with dementia. Despite the physical presence of the loved one they are no longer the same person and the carer will mourn for the loss of their parent, spouse or whomever they are caring for (e.g. Meyer, 2001). Similarly, parents of young people suffering from mental illness (schizophrenia and bipolar disorders) are at risk of suffering from Chronic Sorrow (Eakes, 1995). Mercer (1974) described the Chronic Sorrow reaction of parents as one of long-term mourning for the longed for, perfect child. Although Chronic Sorrow is unresolved grief, it differs from pathological unresolved grief in many ways. An individual who is suffering from pathological grief (displaying excessive and prolonged grief after a sudden or traumatic death) may display continual feelings of guilt, anger and sadness, whereas an individual who is suffering from Chronic Sorrow will typically be focussed and functional in the face of their ongoing loss (Burke, Hainsworth, Eakes & Lindgren, 1992). It is also distinguishable from a depressive disorder, that may be physiologically based and lacking a known precipitating event. Table 1 shows a comparison of the features of Chronic Sorrow, pathological grief and depressive disorder, which illustrates the differences between the three situations that clinicians should be aware of in order to recognise those families most in need of support and recognition.

Table 1: A comparison of Chronic Sorrow, pathological grief and depressive disorder.

From Burke, Hainsworth, Eakes & Lindgren, 1992, page 234

Distinguishing characteristics	**Pathological Grief**	**Depression**	**Chronic Sorrow**
Classification	Abnormal reaction	Mental disorder	Normal reaction
Trigger Event	Unexpected death/loss	Often not discernible	Ongoing loss of normality
Treatment	Counselling/medication	Psychotropic medication and therapy	Recognition/support
Attitude	Avoids reality testing	Sees loss as punishment	Ambivalent but willing to deal with the loss
Preoccupation	Constant: focus on lost person	Constant: focus on self	Periodic: focus on loss of normality
Anger	Not usually discernible	Not directed externally	Directed externally
Responsiveness	Limited, detached	Unresponsive	Responds to warmth and support
Coping method	Intellectual or emotional without integration	Self punitive/restrictive	Integration of intellectual emotional & physical
Coping ability	Dysfunctional	Dysfunctional	Functional

The birth of a child with a disability has a multi-faceted impact on the family as a whole. The practical and financial aspects have been described as a source of ongoing stress, as well as the emotional experience (Collins Moore, 1984). Phillips (1991) also examined the impact of practical changes on mothers' emotional reactions. This was a qualitative study that only examined three case studies of families with a chronically ill child as opposed to one with a disability, but the results highlighted issues such as the presence of nursing care in the home and a significantly changed lifestyle as contributing factors to mothers' Chronic Sorrow.

Partington (2002) conducted a focus group with six mothers of children with learning disabilities (LDs), two of whom had received post-natal diagnoses of non-specific LD in their child and four of whom had received foetal diagnoses of Down syndrome. He found four main themes that impacted the development of a grief response, using qualitative data analysis: a) diagnosis, b) reactions being similar to bereavement, c) factors regarding causation and d) examples of poor communication from medical professionals. Those women who had received a foetal diagnosis felt that they were under pressure to terminate the pregnancy by health professionals. This meant that the appraisal that they were left with was a very negative one, possibly interfering with maternal-foetal attachment. All the participants felt that the initial grief feelings had returned intermittently as their children had got older. Partington makes a good argument for the presentation of information to mothers to be non-judgemental, non-directive and clear. Obviously, hearing that your foetus has a genetic syndrome will produce many emotions and mothers should not feel pressured into making any decisions regarding the future, but simply provided with the necessary information and support to allow them to make informed choices.

The recurring nature of Chronic Sorrow has now been accepted by a number of authors as an alternative to the traditional linear model of grief (Worthington, 1989) and often the stages of recurrence can be predictable if a health care provider is familiar with the particular family and the issues that are poignant to them (Wright & Leahey, 1987). For example, if a family was particularly fixated on their child's education then the age at which they would have been going into secondary education may be an important milestone for them. If the child does not achieve this, then a cycle of grief could be triggered at this point. Cameron, Snowdon and Orr (1992) conducted a large study examining the Chronic Sorrow reactions of mothers of children with developmental disabilities. Their results support the hypothesis that mothers experience a grief reaction, but that this was not predictable and did not follow any coherent sequence. Some emotions such as sadness, guilt and anger frequently re-emerged throughout the child's life. The authors therefore support the concept of Chronic Sorrow in these cases, rather than a time-bound grieving, which culminates in acceptance. Roos (2001) places Chronic Sorrow within the Gestalt therapy theory of "unfinished business". The premise behind this theory is that unfinished business from the past will interfere with present functioning until it is resolved, leading to misinterpretation and distortions of present events. She refers to the unfinished business in the case of Chronic Sorrow as the loss of parts of the self, significant others, fantasies and anticipated reality.

Visible disabilities have been described as having a greater initial impact on the parents, but with a more rapid dissipation as resources and social support are gathered around the family (MacGregor, Abel, Byrt, Lauer & Weissmann, 1953). If this is the case, then it could be hypothesised that a disability such as Down syndrome, with its characteristic physical presentation may produce more of a grief response than an invisible condition such as autism, but with a faster resolution. This could be due to people's acceptance of differing behaviour in a child if they can see a reason, rather than just assuming that the child is being "naughty". Bradbury and Hewison (1994) found that a facial disfigurement such as a cleft lip and palate led to more emotional distress and a longer period of adjustment for parents than a hand anomaly. However, their results showed a significant effect of social support in the speed of adjustment and subsequent attachment to the child.

There can also be differences in adjustment between mothers and fathers of children with disabilities. Damrosch and Perry (1989) conducted a qualitative study with 18 fathers and 22 mothers of children with Down syndrome. Whilst the fathers reported a steady, gradual recovery from their initial feelings of grief and anxiety for the family, mothers were much more likely to describe a cyclical Chronic Sorrow, with periods of crisis. The authors found that these crises were likely to be associated with cognitions of self-blame and the expression of negative affect in mothers. One short fall of this study is that the authors did not take into account the amount of time spent with the child as primary caregiver. It could be hypothesised that it is more likely that fathers would be out at work, amongst a supportive network and away from the family, whilst mothers were at home and providing more of the personal care required by the child. Bruce, Shultz, Smyrnios and Shultz (1994) also found that fathers showed a less intense grief reaction to the diagnosis of a developmental disability in their child, regardless of the age of the parents. However, this study utilised the Impact of Events Scale (Horowitz, Wilner & Alverez, 1979), which is not necessarily a measurement of grief reactions and could be seen as measuring the parent's stress level rather than grief. If this was the case and the scale lacks ecological validity in this situation, then the results should be treated with the utmost care. It could be that, as previously pointed out, mothers spend more time at home, possibly having made more sacrifices as a result of the child's diagnosis. A study by the same authors a year previously (Bruce, Shultz, Smyrnios & Shultz, 1993) had produced results that indicated, when compared to parents of children without a disability, those whose children had a disability were a) perceiving a greater discrepancy between their child and their ideal child, b) experiencing more limitations on their family, c) reporting more frequent disappointments in their child's development, d) reporting greater numbers of parental concerns and e) experiencing greater impairment of psychological and physical well-being. One interesting point was that the two groups of parents did not present significant differences in their experience of happiness in parenting their child. This puts a rather more positive light on the concept of Chronic Sorrow and suggests that, even though parents may be experiencing significant difficulties, their overall happiness in relation to parenting does not have to be compromised. Cunningham and Davis (1985) also point this out, remarking that "it is not uncommon for parents to say that they love the child, but resent the handicap" (p.59). A further study by Bruce, Shultz and Smyrnios (1996) followed families over a three-year period. Their results showed that the patterns of grief and the intensity of feelings stayed constant over the three-year period, suggesting that the grief reaction did not resolve into a state of acceptance. The significant difference between the intensity of feelings of mothers and fathers also persisted over the longitudinal study. However, the problems with the initial research remain, in that the Impact of Events Scale (Horowitz, Wilner & Alverez, 1979) may not be the most appropriate measure of Chronic Sorrow. Measures have been developed that may provide a more focussed measure of the feelings associated with Chronic Sorrow. Reliable and valid measures are needed for us to understand the construct further, but good definitions of the construct are needed for the measures to be even more meaningful.

The first of these is the Chronic Sorrow Questionnaire, developed by The Nursing Consortium for Research on Chronic Sorrow and first validated by Burke (1989) in a study of mothers of children with spina bifida. Essentially, the Chronic Sorrow Questionnaire is a qualitative instrument, providing a semi-structured interview, which aims to get at specific symptoms of Chronic Sorrow. It does allow for the quantification of demographic data. Since this original validation, further studies have gone on to use the Chronic Sorrow Questionnaire and provide more evidence of its validity in measuring the intensity of cyclical grief feelings in parents of children with a range of disabilities (e.g. Burke, Hainsworth, Eakes & Lindgren, 1992).

The second measure that attempts to capture the symptoms of Chronic Sorrow is the Grief Experience Inventory – Non-death version (Sanders, Mauger & Strong, 1985). This measure was developed from an inventory that examined bereavement. The items referring to a specific death were removed and the non-death version was then validated using samples of divorcees, adult children who had placed a parent in residential care and parents of developmentally handicapped children.

Zinner, Ball, Stutts and Philput (1997) used the Grief Experience Inventory when assessing the grief reactions of mothers of adolescents who had suffered a traumatic brain injury. The authors hypothesised that the grief reactions would be affected by the length of time since the event, the severity of the injury (as measured by length of coma), and the child's present level of functioning. They therefore included a measure of adaptive behaviour, the Neurobehavioural Rating Scale (Levin et al, 1987). They found that the length of time since injury only affected the mother's level of guilt, shown to be particularly intense in the initial period. The severity of the injury was unrelated to the grief response, but the functioning of the child did significantly influence grief reactions, the lower the level of functioning the higher the grief reaction. Using the theory of congruency between the child now and the "fantasy child" this could be due to the greater disparity between how the child was before the event and how they are now. Those children who were still functioning at a relatively high level may still be able to attain some of the mother's expected milestones. The authors include a quote from a mother, which illustrates this point. "The closer you get to seeing what they won't get back, the worse the grief, until you bury the old person and start getting to know the new one" (p 445).

Stress Associated with Parenting a Child with a Disability

Belsky (1984) proposed a process model of parenting with multiple determinants of parental functioning. These determinants arise from three sources of stress and support: within the individual parent, within the individual child, and within the social context in which the parent-child relationship occurs. Stressors from each source can directly or indirectly influence children's development. Consequently, each area should be examined by professionals when trying to reduce parental stress.

Abidin (1992) acknowledged the vital role that appraisal plays in parent's perception of stress and combined it with the influence of child characteristics and the context of interaction on the parent's perception. Abidin (1992) developed a parenting stress model, which presented components of dysfunctional parenting identical to those of Belsky's parenting model. Abidin (1992) proposed that the total stress experienced by a parent is a compilation of specific child temperament characteristics, parental characteristics, and family situational variables, which are all directly related to the role of being a parent. He stated that the ability to identify potential high-risk situations through the measurement of parental stress at the earliest possible time would allow for more efficient and effective interventions for dysfunctional parenting.

Research has shown that parents of children with learning disabilities show levels of parenting stress that are higher than those of the general population and that the patterns of stress reported can be similar to those of Chronic Sorrow (e.g. Baker & McCal, 1995, Faerstein, 1981), but to date, no research has looked for any relationship between these two concepts. Some studies have shown this higher stress level to be a result of the behaviour problems of a child with a learning disability, as opposed to the cognitive delay itself. Using Abidin's (1992) model, this would be increasing the stressful nature of the child characteristics. For example, Baker, Blacher, Crnic and Edelbrock (2002), conducted regression analyses on their data from 225 families, which supported the hypothesis that the behaviour difficulties of the child were significantly stronger contributors to parenting stress than cognitive delay. There have been many studies that have examined this hypothesis and there is a growing body of evidence that this is the case, however, care must be taken not to infer a causal relationship. It could also be hypothesised that higher levels of stress in the parents may lead to more behaviour problems in the child, or that highly stressed parents may appraise their child as having more behaviour difficulties. Baker and McCal (1995) compared levels of stress in parents of children with a learning disability (LD), but few behaviour problems, to parents of children with attention-deficit hyperactivity disorder (ADHD) who were displaying a large number of behaviour problems but little developmental delay. They found that the parents of children with ADHD had the highest level of parenting stress, followed by the parents of children with a LD and finally, a control group of non-referred families showed the lowest stress levels. This research used well-validated measures and examined an important distinction, however the sample sizes were relatively small and so it is difficult to translate these results to a general population. Fuller and Rankin (1994) also examined three groups of parents, those of children with a learning disability (LD), those with emotional impairments (EI) and a control group. Their results were similar, showing that the parents of those children with EI displayed the highest level of parental stress, followed by the LD group, and finally the control group. The authors go on to suggest that the parents of children with EI may have some disruption in their attachment to their child, as they report the child to be less bright, pleasant and attractive than they would have wished. This hypothesis fits with the research on parental attachment that has been discussed previously. It also touches on the idea that the parent has not been able to change their representation of their child and is therefore still comparing them to their ideal representation or "fantasy" child, suggesting the stress is coming from the parent's appraisal of the child, as in Abidin's model (1992). The suggestions made by Fuller and Rankin (1994) are that schools can play a part in facilitating the parent-child interaction and helping the parent to come to terms with their child's condition. Whilst this study lends more evidence to the field, it also has some methodological weaknesses. As before, the sample sizes examined were too small to allow the findings to be generalised to the population. Secondly, the authors do not specify their definition of either learning disabled, or emotionally impaired, but rely simply on the classification made by schools. It could be that there is a large variation between what one school would classify as emotionally impaired and another's criteria. The age range of the children was also very large, considering the small sample sizes. Dyson (1991 & 1993) conducted a longitudinal study with families of children with disabilities. She found that those families who had a child with a disability had a significantly higher level of stress than controls and this stress level was stable over time when re-tested four years later. She took care to match the samples for socio-economic status and marital status of the parents. However, the study did not define the category of disability succinctly and included children with sensory difficulties, physical handicaps, learning disabilities and speech disorders. It would have been interesting to separate out these different types of disability and examine any differences in the level of parental stress associated with the type of disability.

There have been studies that have separated out distinct diagnostic categories for examination of parenting stress. This has become increasingly recognised as important due to the growth in research conducted on behavioural phenotypes. Specific genetic disorders can be associated with specific behavioural problems, or other characteristics such as speech difficulties (Udwin & Dennis, 1995). These behavioural phenotypes could influence the behaviour of those around the child – not just the parents but also the general public, as they will have their own internal representations of what a child with that particular syndrome will be like. The following sections provide an overview of the research in this area and how this advances our understanding of parent's stress and grief processes.

Down syndrome:

Research into the stress faced by parents of children with Down syndrome has described parental reactions to the birth in terms of anger, anxiety, sorrow and guilt (Szymanski & Crocker, 1985). Whilst it is acknowledged that not all parents will feel these emotions (Byrne & Cunningham, 1985) it can be seen that these emotional reactions may affect the stress levels of parents, with the sorrow and grief response contributing to the onset of stress. Atkinson et al (1995) recruited fifty-six mothers of children with Down syndrome, who were followed over a period of two years. The results showed that those mothers who were more vigilant towards their child and more sensitive to the child's needs showed the lowest levels of stress. Those mothers who employed a coping strategy of avoidance of their child's needs showed the lowest level of sensitivity and therefore high levels of stress. The authors recognise that there may be difficulties in interpreting what a child with Down syndrome needs at any particular time, due to difficulties with communication and that interventions such as the use of sign language may be beneficial in allowing the mother to be more responsive.

Spagenberg and Theron (2001) attempted to investigate the relationship between stress and the coping strategies employed by parents of children with Down syndrome. Sixty parents took part in the study and, as in the Atkinson et al (1995) study, stress was shown to be associated with avoidant coping strategy scores. The authors therefore conclude that interventions are required that train parents in the use of effective coping strategies. Whilst this study examines an important area and had a relatively large sample of participants, they used the Beck Depression and Anxiety Inventories (Beck & Steer, 1987, 1990), which are not necessarily indicative of stress and did not use a comparison group. Therefore, the positive relationship described was between depression and anxiety scores and avoidant coping. It could be hypothesised that parents who are depressed and anxious might be more likely to use an avoidant coping style or be more withdrawn, rather than the coping style being the root of the problem, as suggested by Spangenberg and Theron. If this were the case, it would be more appropriate to treat the anxiety or depression than provide training in coping strategies. Further research is required here in order to find a causal effect, possibly through the use of longitudinal research, which follows families from the birth of the child onwards. This would be able to inform us as to which way round the interaction is occurring and what possible protective factors may be influencing the interaction.

Hodapp, Ricci, Ly and Fidler (2003) also interviewed mothers of children with Down syndrome and compared them with a group of mothers of children with unspecified disabilities (including Prada-Willi syndrome, Williams syndrome and autism). The authors firstly acknowledge the "stereotype" of a child with Down syndrome, as a happy, friendly and affectionate child. Whilst it is dangerous to assume this and the authors are quick to point out that children with DS can also be defiant and stubborn, there have been many studies that have found that parents reinforce the typical view when asked about their children's characters (e.g. Dykens & Kasari, 1997). Their results showed that mothers of children with Down syndrome showed lower stress than those of the comparison group. On further examination of the results, the authors found that the variance between the two groups was accounted for by the Child Domain on the Parenting Stress Index (Abidin, 1995) and not the Parent Domain. In other words, the mothers of children with Down syndrome were less stressed because they scored lower on items such as "my child does not like to be touched" or "my child rarely does things to make me feel good". They concluded that parental stress could be predicted in this sample by the child's behavioural difficulties and their degree of communicative impairment, but items such as whether the child does things to make the parent feel good can also rely on the parent's appraisal. They also found that, within the Down syndrome group, parents rated their children less favourably as they got older. This is an important point and one that would benefit from further study. Why this should be has not been examined in this study, although the authors speculate that it is possible that children with Down syndrome become more withdrawn as they reach adolescence, or that their developmental rate slows down, frustrating the parents. One further shortcoming of this study is that Down syndrome is a much better known disorder and it is therefore possible that parents are better supported both by friends and family and by formal services such as support groups. The authors did not include a measure of social or formal support in their analysis, however this study goes a long way towards a focussed approach, which would enable professionals to tailor their interventions depending on the type of disability the child is suffering from. It also has implications in terms of helping to inform good practice guidelines that enable professionals to be conscious of the meaning of a particular disability to parents.

Holroyd and McArthur (1976) examined the differences between Down syndrome and autism. They found that the mothers of autistic children reported the most problems in terms of the effect of their child's disability on the family. Mothers of children with Down syndrome reported less than the autistic group and mothers of children attending a psychiatric outpatient clinic. The inference here is that the behavioural problems of the psychiatric group contributed more stress than a child with Down syndrome. Whilst this study used large, well-matched groups, with 100 families in each category, this is only a snapshot of one point in time. It could be hypothesised that once the psychiatric disorders of the third group of children had been treated, that the levels of stress in the parents decreased again, whilst those associated with a lifelong disability will remain. Research that explores differences between acute and Chronic stress may be helpful in describing this further.

Autism:

Autistic spectrum disorders are pervasive developmental disorders that tend to manifest themselves in the early years of a child's life. They are characterised by a triad of impairments, in communication, social interaction and imagination. Specifically, autism can become apparent when a language delay is noted, usually at around two years of age, but may have shown signs earlier in a lack of eye contact or social behaviour (Carr, 1999). Autism is a life long disorder and has no obvious visible features, unlike Down syndrome, where the child is likely to have the characteristic eye folds and therefore be identified as having a disability by members of the public (Harper, 1999).

Liwag (1989) interviewed mothers and fathers of children with autism, using a sentence completion measure to elicit emotional reactions. A content analysis of the data showed that it was aspects of the disorder itself that elicited the most stress in parents, specifically the language deficit and tantrum behaviour. A secondary source of stress was found to be the permanence of the condition and the perception that the child will never be “normal”. This exploratory study used a very small sample, but is useful in that it highlights some of the difficulties associated with raising an autistic child. Midence and O’Neill (1999) found that it was the parent’s difficulty in understanding their child’s behaviour that produced the biggest stress reaction. They discovered that receiving an official diagnosis of autism went some way towards relieving this stress, as parents were more able to adapt and receive appropriate support.

Parents of children with autism not only show elevated levels of stress, but also increased levels of anxiety and depression when compared to the normal population (Sharpley, Bitsika & Efremidis, 1997). More than 80% of the participants in this study reported being stretched beyond their limits at times, when dealing with their child’s behavioural problems. This raises serious concerns for the well-being of not only the parents, but the children themselves if parents are not coping. Kasari and Sigman (1997) specifically identified the lack of social interaction as the behaviour most likely to cause stress in parents of children with autism. Linking with the theory of maternal perceptions and cognitive appraisal, research has also indicated that those mothers who perceive their child as showing threatening behaviour have higher levels of stress than those who appraise behaviours as non-threatening (Fong, 1991). These results were given further support by a longitudinal study conducted by Gray (2001). Families were followed over a ten-year period and in general, stress levels appeared to fall as parents gained efficacy in dealing with difficult behaviours. However, those families whose children were displaying aggressive behaviour did not see a significant reduction in stress over time, indicating a need for further professional support in these cases.

Acquired Neurological Deficits:

Unsurprisingly, similar results have been found for the parents of children with an acquired neurological deficit or brain injury, as have for those of children with Down syndrome or autism. An acquired brain injury (ABI) can lead to significant interpersonal, financial and emotional problems within families (Wade et al, 2004). Using the theories explored in this review, it can be hypothesised that the "overnight" nature of the onset of difficulties associated with an ABI could cause a huge discrepancy between the child parents had and the one they now have, leading to incongruence between the fantasy future and the reality. The stress of physically caring for a child who may have been independent prior to the event must not be underestimated (Wallander, Pitt & Mellins, 1990), let alone the emotional stress of coming to terms with the consequences. As with autism, high levels of parenting stress are associated with high levels of depression in mothers of children with an ABI (Manamaker & Glenwick, 1998). Another parallel result to that of parents of children with autism is that parents of children with an ABI showed higher levels of stress when their children were displaying aggressive behaviours (Sokol et al, 1996). Parental stress may also affect the level of recovery in the child, following an ABI (Taylor et al, 2002). Studies have indicated that the educational and behavioural recovery of the child can be significantly better in families with low stress levels. However, a causal relationship has not been shown in any studies, so it could be that the poor recovery of the child leads to higher parental stress. One element of support for this hypothesis is that Taylor et al (2002) found that children from those families who had a lower socio-economic status before the ABI showed a poorer recovery and whilst it cannot be assumed that low socio-economic status automatically means a higher family stress level it could be that financial pressures will add to this stress.

Resilience and Mediating Factors for Parenting Stress

Not all families who have a child with a disability suffer from high stress levels. It is important for clinicians to understand the mediating factors of parenting stress so that they can enhance these as much as possible. Costigan, Floyd, Harter and McClintock (1997) found that some families of children with learning disabilities display resilience to stress that is born out in the family problem-solving interactions. Those families who utilised an active problem solving strategy, with inclusion of all family members but overall direction from parents, showed the lowest levels of stress. Single parents of children with a learning disability displayed the highest level of parenting stress and the most directive problem solving styles. Therefore, helping parents to develop effective problem solving skills could act as a protective factor against stress.

Adequate social support has often been cited as a "buffer" to stress (e.g. Cohen & Wills, 1985). However, most of the studies that have supported the buffer model have examined particular numbers of life events, rather than the Chronic stress associated with parenting a child with a disability (Quittner, Glueckauf & Jackson, 1990). Although social support may be useful at times of acute stress, Quittner, Glueckauf and Jackson (1990) suggest that an influx of support in the context of a Chronic stressor can sometimes be seen as intrusive or taken as a suggestion of incompetence on the part of the parents. The authors hypothesise that in this case parents may require more emotional support from health professionals, rather than from their social network.

Kinsella, Ong, Murtagh, Prior and Sawyer (1999) highlight the moderating effects of a supportive spouse. Single parents reported significantly more stress than intact families and those mothers who reported their husbands to be emotionally supportive showed the least amount of parenting stress. It can therefore be seen that health professionals have a role, both in providing additional support to single parents and in encouraging spouses to be emotionally supportive of each other.

Clinical Implications and Treatment

Olshansky (1962) offers the following suggestions to professionals to help parents move through the grief reaction.

1) Abandon the simplistic and static concept of parental acceptance.
2) Accept that Chronic Sorrow is a natural reaction, rather than a neurotic reaction.

3) Provide information and supportive counselling throughout the entire time period.

Kratochvil and Devereux (1988) describe a group called Tots and Parents, which runs in Canada. This group specifically uses grief models to discuss feelings and experiences of parents and appears to be of significant benefit to those parents who participate. Counselling for grief is not only available at diagnosis, but at any point during the child's development, should the parents feel the need for further support. The authors report anecdotal evidence from parents who have used the counselling services and found them to be beneficial, some for many years. They therefore recommend the provision of ongoing support for parents, that they can access as and when they feel appropriate.

Bruce and Shultz (2001) describe three main goals of therapy for Chronic Sorrow: to preserve the individuals identity (as a parent and as a woman/man), to restore their control and to facilitate adaptive reality testing and grieving. The psychological principles that underlie these goals are given as:

1) The expression of grief commensurate with the perception of the magnitude of the loss, through the establishment of a good therapeutic relationship that defers to the loss and affirms the grief.
2) The preservation of identity, by creating connections with the past, present and future contexts.
3) The reinstatement of control, through education and coping strategies.
4) Reduce the potency of recurring ideals, through the reworking of expectations.

5) Reduce the potency of dreaded events, through reality testing
6) The need to attach meaning to the emerging reality, by establishing a feeling of hopefulness.

(Bruce & Shultz, 2001, p189)

An evaluation study of their programme, Caring for Parent Caregivers, found that the psychoeducational support provided significantly reduced emotional distress in parents at a 12 month follow-up (Shultz et al, 1993). This study used both qualitative and quantitative methods and made use of a control group. Those parent dyads who attended the group showed positive emotional, behavioural and attitudinal outcomes.

Roos (2001) uses Gestalt therapy to "downsize" the fantasy that the parent was holding and allow them to come to terms with the reality of their child. She expresses the vital role that the therapeutic relationship plays during therapy and the importance of empathy and unconditional positive regard. Some of the feelings that parents may express may feel shameful to them so it is imperative that they feel able to be honest and open, without feeling judged. The anecdotal evidence that Roos provides for this approach seems to support the method. However, further, empirical research into this type of therapy is needed before it can be advocated fully.

Future Directions

There are currently no studies that examine any relationship between parenting stress and Chronic Sorrow. The cited research shows that both are present in parents of children with various disabilities, including Down syndrome, Pervasive Developmental Disorders and Acquired Neurological Deficits, but does not examine any relationship between the two phenomena.

The protective factor of social support has been examined, but only the study by Quittner et al (1990) makes any suggestion of the benefit of professional support in decreasing parenting stress. The protective factor of professional support could therefore be examined further in order to understand the effect this has at various points in time. It could be hypothesised that the most important time for professional involvement is at the time of diagnosis, making sure that the family are provided with information about the disorder, prognosis and access to support services as appropriate. Helping parents to develop a positive appraisal of the disorder could contribute to their ability to accept the situation. Chronic Sorrow is a normal reaction to a difficult situation and professionals could play an important role in validating parent's feelings and helping them to understand that it is normal to feel grief and to mourn the loss of the "fantasy" child.

Parental factors that contribute to stress and Chronic Sorrow have been touched upon, but the socio-economic status of the family has only been shown to have an influence on a child's recovery, rather than the parent's well being (Taylor et al, 2000). This could be an important area to examine in order to identify risk factors that professionals can identify and therefore tailor interventions to those families most at risk of having adverse reactions to their child's disability. Another parental factor that is touched upon, but not examined fully, is how the attribution of the cause of the child's problems can affect the parents (Hall & Marteau, 2003). No studies have asked whether a parent blames themselves for their child's condition (e.g. due to allowing them to have an MMR vaccine, or smoking during pregnancy) and it could be hypothesised that this would contribute to the onset of grief.

Finally, the main child factor that has been researched is that of behaviour difficulties, especially aggression (e.g. Zinner et al, 1997). No studies have used this factor as a confounding variable when examining stress or sorrow. Would it affect the levels of grief if behaviour problems were controlled for? The age of the child has been mentioned by Hodapp et al (2003) as affecting levels of stress, but this is another area that could help professionals to provide services to families at particular points in time and could therefore bear further study. No research has mentioned any effect of the gender of the child on the parent's appraisals.

All of the factors mentioned require further study in order to assist professionals in providing the best possible support to families at the most opportune time, in order to reduce stress and attempt to alleviate Chronic Sorrow.

Conclusions

This review has followed the development of parents' (particularly mothers') representations of their children, from foetus onwards. The construction of internal representations as we go through life has also been examined. This is an important area to consider as it is essential to understand how expectations are developed, in order to understand what happens when these are not attained. This is exactly what happens in the case of a child who is born with a genetic condition, such as Down syndrome, who develops a disorder in childhood, such as an autistic spectrum disorder, or is permanently changed by an event such as an acquired brain injury. As the research has shown, the discrepancy between the fantasy child and the reality can trigger a grief reaction in parents. Chronic Sorrow seems to be different from normal grief in that it follows a cyclical process rather than a linear progression to acceptance and can be triggered at various points in time. Parenting stress is also higher in all of the groups mentioned, possibly due to the increased behavioural problems of the child, or possibly due to the increased practical pressures on the family. However, it could be hypothesised that those parents who are suffering from Chronic Sorrow would also report the most stress, due to the added pressure of the emotional difficulty and negative appraisals of the child that does not match the "fantasy". There are some protective factors, such as spousal support, which may reduce the level of stress faced by parents of children with a learning disability, but there is little research on whether this also reduces Chronic Sorrow reactions. Finally, the implications for health care professionals and some suggestions for treatment methods have been outlined. It would appear that the most important factor is for professionals to be aware of the cyclical nature of Chronic Sorrow and to provide support for parents when they request it, rather than just at diagnosis or follow-up. Ideas for future research to help professionals provide a better service have been examined. Further investigation of all the factors mentioned could help professionals such as clinical psychologists to be more aware of the issues involved and how best to predict and alleviate feelings of stress and sorrow in parents of children with disabilities.

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UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE, HEALTH AND LIFE SCIENCES

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Parents of Children with Down syndrome, Autism and Acquired Neurological Difficulties: Chronic Sorrow and Parenting Stress

by

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Parents of Children with Disabilities: Chronic Sorrow and Parenting Stress

Abstract

Background: The aim of the present study was to investigate the relationship between Chronic Sorrow and Parenting Stress and the factors affecting their onset. **Method**: A quasi-experimental mixed design was used, consisting of three groups of participants: parents of children with Down syndrome (N=10), parents of children with autism (N=34) and parents of children with an acquired brain injury (N=9). Standardised measures of Chronic Sorrow, Parenting Stress and Adaptive Behaviour were employed, along with supplementary questions designed to elicit data regarding temporal aspects of onset, levels of support and attributions as to the cause of the disability. Correlational analysis was conducted on the within groups factors and analysis of variance (ANOVA) on the between groups factors. **Results**: Results show a strong relationship between Chronic Sorrow and Parenting Stress, even when controlling for adaptive behaviour. The age of the child when the parent first suspected a problem, the gender of both parent and child, parental education level and occupation and satisfaction with informal support were all found to have significant effects on stress and sorrow. **Conclusions**: The limitations due to sample size and restrictions associated with data collection at one point in time are considered. Findings indicate a starting point for applied clinical research, from which further evidence may be collected regarding Chronic Sorrow, Parenting Stress and childhood disability, which may be used to shape future clinical practice.

Keywords: Chronic Sorrow, Parenting Stress, Down syndrome, autism, acquired brain injury.

Parents of Children with Down syndrome, Autism and Acquired Neurological Difficulties: Chronic Sorrow and Parenting Stress

Parenting any child can be a demanding process, but parenting one with a learning disability brings its own unique sources of stress and emotion. These are often higher in parents of children with disabilities than in the general population (e.g. Baker & McCal, 1995). Some studies have suggested that these differences may be due to the level of emotional feedback that the parent receives from the child (Hodapp, Ricci, Ly & Fidler, 2003) although it could be hypothesised that the additional stress felt is due to the adaptive behaviour level of the child.

A further explanation could be that the parents are suffering from cyclical grief, or Chronic Sorrow, a term first used by Olshansky (1962) in reference to mothers of "mentally retarded" children. This concept has gained support over time, with authors describing a feeling of grief in parents that does not follow a linear route to acceptance, but instead recurs at intervals when the parents are reminded that their child is not the "perfect baby" they were hoping for (Mercer, 1974; Wikler, Wasow & Hatfield, 1981; Worthington, 1994; Partington, 2002). There are many factors that need to be taken into account when trying to understand the development of Chronic Sorrow in parents. Firstly, the mother's attachment to the foetus will impact (e.g. Salisbury, Law, LaGasse & Lester, 2003), as will their mental representations of their baby and themselves (e.g. Condon & Dunn, 1988). Everyone within the family will have internal representations of what the baby will look like or be like, as well as having internal knowledge structures about the meaning of various disabilities (Marks, 1997). It is therefore important to examine what happens when the baby that is born does not fit the parent's representation, or when something happens to a child that causes it to change, thereby becoming someone other than the child that has been pictured. There are currently no studies that explore any relationship between parenting stress and Chronic Sorrow. Research shows both are present in parents of children with various disabilities, but does not examine any relationship between the two phenomena.

Parenting Stress

Theoretical models of parenting stress, such as that by Abidin (1992), propose that stress is the result of a combination of factors within the parent, the child and the social context in which the relationship exists, or in other words, the family culture. This model suggests it is not just the behaviour of the child that causes stress, but the appraisal the parent places upon that behaviour will play a vital role. The coping mechanisms of the parent and the level of support available in a social context will all have an effect on the level of stress felt. The model suggests early identification of stress and all its components can help to inform professionals and to make interventions more effective. For example, if the child is displaying difficult behaviours that the parent is appraising very negatively, it may be appropriate to help the parent to re-appraise the situation as well as trying to change the behaviour of the child. Studies have shown the highest levels of parenting stress tend to be displayed by parents of children with behavioural problems compared to parents of children with a cognitive delay (e.g. Fuller and Rankin, 1994). This model would suggest that, whilst the behaviour of the child does have an impact it is also the parent's appraisal of the behaviour as "bad" or "naughty" that impacts on stress.

It could be hypothesised that parents of children with a cognitive delay may be less inclined to label behaviour as "bad" and perhaps less likely to think the child is deliberately behaving inappropriately.

Research has also studied the differences between stress levels in parents of children with different specific diagnoses. For example, Hodapp, Ricci, Ly and Fidler (2003) found that mothers of children with Down syndrome scored lower on measures of stress than mothers of children with other disorders (e.g. Prada-Willi syndrome). The authors hypothesise that this difference could be due to the stereotype of children with Down syndrome as happy and affectionate. Whilst they do not advocate these assumptions of characteristics on the basis of a genetic disorder, there have been many studies that have found that parents tend to reinforce this typical view when asked about their children. It is therefore possible that the positive appraisal of the children leads to lower levels of stress, despite their adaptive behaviour level. It is also possible the social context is easier for mothers of children with Down syndrome as it is more widely recognised and other people may also adhere to the stereotype.

Chronic Sorrow

Traditional models of grief describe a linear process, with a number of stages through which the mourner must pass before they reach a state of acceptance of their loss (e.g. Freud, 1917; Horowitz, 1990). Many of these models describe a need for the mourner not only to relinquish their attachment to the lost person, but also to reorganise their own internal world and their view of themselves without the person who has died. One example of this could be a reorganisation of the self from “wife” to “widow”. Drotar (1981) proposed a similar linear model to explain the grief reactions of parents of children with a chronic condition or disability. This model has been criticised as being too structured however and subsequent authors have suggested that a cyclical model is more appropriate in this situation (e.g. Worthington, 1994; Wikler, Wasow & Hatfield, 1981). Cyclical grief or Chronic Sorrow has been accepted as a more realistic representation of parent’s reactions as they are forced to undergo a series of recurring stressors as their child grows. Developmental milestones are missed and the parents have to accept that events they may have predicted would occur (e.g. their child would get married or give them grandchildren) may not. The family is therefore in a constant state of adjustment and can find feelings of grief and sorrow recur at various intervals. There are many factors that could affect these recurring periods of grief, but among the most important are attachment and the parent’s internal representations of their child and themselves. As with mourning a death, the parent will have to reorganise their internal world to fit the new situation. From the moment they find out they are expecting a baby parents will start to form an internal representation of the child (Matarazzo, 1992). The development of maternal/foetal attachment may have changed in recent years, as high resolution scans mean that a mother can see her baby from a very early stage, as well as feel it moving. Modern medicine in western culture has also meant that the mortality rate of both mothers and babies has fallen dramatically in recent years, thereby making it “safer” for a mother to form an attachment to her baby from a early stage (Salisbury, Law, LaGasse & Lester, 2003). Parents’ reactions to their newborn baby have been suggested to be predictable from their attitude towards the unborn baby and the level of congruence between the imagined child (or "fantasy baby") and the real baby (Condon & Dunn, 1988). Therefore, if their baby is born with a genetic condition such as Down syndrome, or suffers from a lack of oxygen at birth and has neurological damage, the real child will be incongruent to the baby the parents have spent months picturing in their minds. Not only will parents have developed an internal representation of their child, but they will also have developed a projected view of how the future should be, in terms of plans and goals (Neugarten, 1976). It is normal for people to develop a representation of how they believe life will be in the future, or a correct life sequence. This sequence of events will depend upon their frame of reference that develops as a result of the societal norms of their situation (Berger & Luckman, 1966). For example, a mother may predict that her child will walk at one year, talk at two and go to school at five. This sequence will have come about through her observation of other children. Therefore, any disturbance of the correct sequence, for example as a result of a learning disability, will act as a reminder that their world is not "as it should be" and could potentially trigger a grief cycle as she struggles to come to terms with the loss of the "normal" child she had envisaged all over again. People also develop internal representations of disability, again as a result of the society in which they are living. Our attitudes towards certain disabilities and the stereotypes that we develop will depend upon our experience of people with that condition and our attributions as to its cause (Flavell, Miller & Miller, 1997). Parents themselves may have developed an internal representation of, for example, "autism". If this is a negative view, then how do they go about resolving this when their own child is diagnosed with an autistic spectrum disorder? Research has examined this area and studies such as that by Hoppes and Harris (1990) have found mothers of children with autism can be significantly less attached to their child than mothers of children with Down syndrome. The authors found that significant factors affecting attachment were the level of emotional feedback received from the child and their feelings of maternal gratification. However, it could be hypothesised that mothers of children with Down syndrome have longer to come to terms with their child's condition, as it would probably have been apparent from birth and possibly even diagnosed in utero. Therefore, their internal representations of their "fantasy" (Condon & Dunn, 1988) child may not have been as fixed as mothers of children with autism, who may have had a normally developing child for some time after they were born and have had to reorganise a well-developed view of their child, the future and themselves as a mother. It would have been informative to ask the mothers what their view was of autism or Down syndrome, before they knew that their child had the condition. Taking into account the research on internal representations of disability it is possible that the stereotype of children with Down syndrome as happy and affectionate may have meant it was easier for those mothers to adapt.

The protective factor of social support against stress and Chronic Sorrow reactions has been examined, but only Quittner, Glueckauf and Jackson (1990) make any suggestion of the benefit of professional support in decreasing parenting stress. Whilst social support was shown to be associated with reduced stress, too much social support was actually related to increased stress, possibly if the influx was taken by the parents as a criticism of their ability to cope. As the authors point out, much of the research into social support and stress has focused on life events, rather then the chronic ongoing stress associated with raising a child with a disability. It could also be hypothesised those families who show the highest level of stress received increased levels of support, therefore a causal relationship cannot be inferred from this study. The protective factor of professional support should therefore be examined further in order to understand the effect this has at various points in time. Some families show resilience to stress, which research has suggested could be due to the way in which the family solves problems. Active problem solving methods, using all family members may help to increase resilience to stress (Costigan, Floyd, Harter & McClintock, 1997). Professional support could therefore be useful in helping families to develop effective problem solving skills.

Parental factors that contribute to stress and Chronic Sorrow have been touched upon in the literature. In particular, mothers have been shown to report higher levels of both stress and Chronic Sorrow than fathers (e.g. Damrosch & Perry, 1989). The research has failed to examine the reasons behind this and it could be hypothesised that mothers typically spend more time involved in the active care of the child and may possibly have made more sacrifices (e.g. career, social life) than fathers. Education level and income do not appear to have been examined as parental factors that may affect the level of stress or sorrow felt. The socio-economic status of the family has been shown to have an influence on a child's recovery after an acquired brain injury, but it was not explored in terms of the parent's well being (Taylor et al, 2000). This could be an important area to examine in order to identify risk factors that professionals can be aware of and therefore tailor interventions to those families most at risk of having adverse reactions to their child's disability. Another parental factor that is touched upon, but not examined fully, is how the attribution of the cause of the child's problems can affect the parents (Hall & Marteau, 2003). This research showed that mothers of children with Down syndrome had poorer outcomes when they blamed an external influence (e.g. medical investigation) for their child's condition, than if they accepted it as a random chromosomal abnormality. No studies have asked whether a parent blames themselves for their child's condition and it could be hypothesised that this would contribute to the onset of grief. In terms of the recent debate about the MMR vaccine and the alleged link between this and the onset of autism, would this be considered as an external influence (the injecting of the vaccine) or may parents blame themselves for deciding to go ahead with the inoculation? In addition, as Down syndrome is linked to increased maternal age, then a mother may feel more self blame due to her age being a risk factor. Obviously, the parental attributions in these cases could make a difference to the appraisal of the event and possibly to the grief reaction.

Finally, the main child factor that has been researched is that of behaviour difficulties, especially aggression (e.g. Zinner et al, 1997). No studies have used this factor as a confounding variable when examining stress or sorrow. Would grief and stress be affected if behaviour problems were controlled for? The age of the child has been mentioned by Hodapp et al (2003), with stress increasing as the child gets older, possibly due to increased problems with behaviour, but this is another area that could help professionals to provide services to families at particular points in time and could therefore bear further study. No research has mentioned any effect of the gender of the child on the parent's appraisals.

All of the factors mentioned require further study in order to assist professionals in providing the best possible support to families at the most opportune time, in order to reduce stress and attempt to alleviate Chronic Sorrow. It is also important to investigate any relationship between these two concepts. If there is a relationship, then it could be possible that one is maintaining the other and this obviously has implications for treatment. If a family is presenting with high stress levels, it may be more appropriate to validate and treat their feelings of sorrow or vice versa.

The current study was therefore designed to examine some of the factors that are missing in the literature, in order to better inform health professionals about the best way to support families who have a child with a genetic disorder, a pervasive developmental disorder or an acquired neurological deficit and to tailor interventions depending on the status of that family and the diagnosis of the child.

As studies of both Chronic Sorrow and parenting stress have found differences in the levels felt by parents of children with different diagnoses and therefore different ages of onset, it was decided that the relationship between the two should be examined, along with the parental and child factors that may affect levels of Chronic Sorrow and stress.

Hypotheses:

1) That Chronic Sorrow, as measured by the Grief Experience Inventory – Loss version, (Sanders, Mauger & Strong, 1985), occurs in parents of children in all

three groups (genetic, PDD and acquired), but that it will increase as the age of onset of the disability increases.

2) That various parental and child factors (e.g. gender, age, socio-economic status) will affect the level of Chronic Sorrow and stress felt.

Research Question:

Does Chronic Sorrow (as measured by the Grief Experience Inventory – Loss version, Sanders, Mauger & Strong, 1985) correlate with parenting stress (as measured by the Parenting Stress Index, Short Form, Abidin, 1995), even when the level of adaptive functioning of the child (as measured by the Vineland Adaptive Behaviour Scale, Sparrow, Balla and Cicchetti, 1984) is controlled for in the analysis?

Method

Design

The study was conducted using a quasi-experimental mixed design. Participants were assigned to groups depending upon whether their child had a genetic disorder (Down syndrome), a pervasive developmental disorder (Autism/Asperger's syndrome) or an acquired neurological deficit, whether through traumatic injury, infection or an ischaemic event. The quasi-independent variable is therefore the diagnostic category of the child. Correlational analyses were conducted on the within subjects factors and analyses of variance on the between subjects factors.

Participants

Participants were parents of children with Down syndrome, an autistic spectrum disorder or an acquired neurological deficit. Participants were recruited through advertisements in:

1) Communication magazine - The National Autistic Society quarterly newsletter
2) The National Autistic Society website
3) The Down syndrome Association website
4) Down syndrome UK email forum (DS-UK@listserv.downsyndrome.net)
5) Hemihelp Magazine – The Hemiplegia Society Quarterly Magazine
6) The Child Brain Injury Trust annual conference
7) Contact a Family website (www.cafamily.org.uk)

Those parents who were interested in taking part contacted the researcher via telephone, post or email. This lead to a self-selecting sample, which may have caused some bias in the results, but it would be contrary to ethical guidelines to attempt to coerce other families to participate.

A total of 66 questionnaire packs were sent out to interested participants, of whom 7 were fathers and 59 mothers (see Materials section for contents of pack). 58 completed packs were returned, a response rate of 87.9%. Of the returned packs, 5 could not be included due to either a high level of incomplete data or an inability to contact for the telephone interview. Of the remaining 53 participants, 10 were parents of a child with Down syndrome, 34 of a child with an autistic spectrum disorder and 9 of a child with an acquired neurological deficit.

Materials

A covering letter was included in the pack, which explained the basic procedure for completing the questionnaires (Appendix 1). This letter also explained the use of the word "loss" in the Grief Experience Inventory, in reference to having a child with a disability and apologised for the negative wording of the questionnaires. It went on to explain that it was not the view of the researcher that to have a disabled child was necessarily a "loss" but that the questionnaires were measures of emotion and that it was hoped that participants could complete them as accurately as possible without taking offence at the wording in some cases.

An information sheet for participants was sent with the questionnaire pack, to inform participants of issues such as confidentiality before they decided whether or not to take part (Appendix 2).

A consent form was also included, which required participants to write their initials by statements regarding the study and then sign the overall form to indicate that they understood the process and their right to withdraw at any time and also that they understood they would be contacted by telephone for a further interview (Appendix 3).

A demographics questionnaire was included to provide information about the participant and index child such as age, education level and occupation (Appendix 4).

The Parenting Stress Index – Short Form (Abidin, 1995)

This 36 item, self-administered form takes approximately ten minutes to complete. The index has three sub-scales: Parental Distress, Parent-Child Dysfunctional Interaction and Difficult Child. These three sub-scales combine to produce a score for Total Stress. The scale consists of 36 statements about aspects of parenting and participants are asked to indicate whether they agree with the statement by circling a response on the answer sheet (SD = strongly disagree, D = disagree, NS = not sure, A = agree, SA = strongly agree). The scale also has a sub scale of Defensive Responding. This measures whether the participant might be giving a biased view of their parenting and is not included in the calculation of total stress. If a score of 10 or less is recorded on this sub-scale then the entire scale is invalid as the parent is reporting levels of stress below that of normal parenting and is possibly not responding accurately. None of the participants in this study scored 10 or less on this sub-scale. The PSI-SF has a test-retest reliability coefficient of .84 and an internal reliability level of .91. The short form correlates with the original, longer version with a value of .95. This very high correlation with the original version means it is acceptable to assume that the short form shares the good validity of the original form.

The Grief Experience Inventory – Loss Version (Sanders, Mauger & Strong, 1985)

This scale consists of 135 statements, frequently associated with bereavement. In the death version of the scale, the statements occur with the word "death" in them (e.g. "I showed little emotion after the death"). In the loss version, the word death has been replaced with the word “loss” (e.g. “Upon first learning of the loss I had a dazed feeling”). Participants are asked to simply respond with True or False to each statement. The scale produces two validity scales, Denial and Atypical Response, which are used to determine participants who may be responding inaccurately. The bereavement scale includes Despair (GEIDES), Anger/Hostility (GEIAH), Social Isolation (GEISI), Loss of Control (GEILC), Somatisation (GEISOM) and Death Anxiety (GEIDA). These sub-scales are particularly useful in determining a grief reaction. There are also six research scales, but the authors admit that these are in need of further development and do not contain enough items to be used in statistical analysis. The test-retest reliability of the Bereavement sub-scales ranges from .61 to .84. The internal consistency ranges from .52 to .84. The validity of the scale has been assessed by comparison with other measures and also by administration to various groups of bereaved and non-bereaved participants. It has been validated for the non-death situations of divorce, the institutionalisation of adult parents by their children and the grief experienced by parents of children with various disabilities.

The Vineland Adaptive Behaviour Scale (Sparrow, Balla & Cicchetti, 1984). This scale is a revision of the Vineland Social Maturity Scale (Doll, 1965). It has been designed to be administered to a respondent who is familiar with the behaviour of the individual in question. It measures four domains of adaptive behaviour: Communication, Daily Living Skills, Socialisation and Motor Skills. There is also a Maladaptive Behaviour sub-scale that can be administered for children over the age of five, but this is optional. The measure can be used with both disabled and non-disabled children and adults and produces a score for each of the domains and a total Adaptive Behaviour Composite score. Each domain consists of a number of statements of ability (e.g. "Uses sentences of four or more words" – Communication domain). When the respondent has answered "No" to seven consecutive statements it is considered that a ceiling has been reached and the interviewer moves to the next domain. The scale was standardised on a US population, with a representative sample of three thousand people over twenty-four states. The split-half reliability coefficient of the Adaptive Behaviour Composite was .94, with those of the domains ranging between .83 and .90. The test-retest reliability scores for the domains ranged between .80 and .95. The validity of the scale has been shown through administration to supplementary norm groups (such as the emotionally disturbed, or sensorially impaired) and also by comparison with existing measures of adaptive behaviour. As the authors note, the correlation between this scale and those already in existence was moderate, but a scale that correlated too highly with others would be simply measuring the same things and therefore redundant (Sparrow, Balla & Cicchetti, 1984, p46).

Procedure

The study received approval from the University of Southampton School of Psychology Ethics Committee (see Appendix 5 for approval letter). Parents who contacted the researcher expressing an interest were sent a questionnaire pack. Once the completed packs were returned, participants were contacted to arrange a convenient time for the telephone interview. This interview consisted of the Vineland Adaptive Behaviour Scale as well as allowing participants a chance to tell their story. The majority of the telephone interviews were carried out in a private office at Southampton University. Those that were not were conducted from a landline in a closed room, to avoid being overheard. The VABS was conducted first and then participants were asked to give a brief history of their child's development, from the moment the parent first suspected there may have been something wrong, through diagnosis, to the present day. Obviously, for some parents, such as those of children with Down syndrome, there was no delay between first suspicion and diagnosis, whereas for others this could be a number of years.

If participants were not available to arrange the telephone interview, a message was left. They were contacted a total of twice to arrange a time and if there was still no response, or if they were not available at the agreed time on two separate occasions, this was taken as a withdrawal from the study and no further contact was made to avoid the risk of coercing participants and making them feel under pressure to take part.

After the telephone interviews, the participants were thanked for their participation and were asked if they had any questions for the researcher about the study. They were then assured that they could contact the researcher at any time, should they have questions in the future. If they had requested a summary of the results then they were assured that this would be sent to them during August 2005.

Results – (All results used a significance level of $p<.05$)

The sample sizes were uneven, but the Levene test of homogeneity of variance was conducted on the data concerned. Since none of the components showed significance homogeneity of variance can be assumed. It was therefore acceptable to conduct ANOVA's on the samples, provided that the post hoc Sheffé test was used, as this gives a conservative analysis of statistical significance. All data was checked to ensure it conformed to assumptions of normality.

Table 1. Descriptive Statistics for Parenting Stress Index Total Stress, Grief Experience Inventory Components and Vineland Adaptive Behaviour Component – Whole Sample.

Measure	**Minimum**	**Maximum**	**Mean**	**Stand. Dev.**
PSI Total Stress	63	151	109.8	23.4
CS Despair	35	67	49.1	9.6
CS Anger & Hostility	32	66	51.6	10.1
CS Loss of Control	23	67	51.7	9.0
CS Social Isolation	36	74	54.4	10.5
CS Somatisation	36	74	51.5	10.7
CS Death Anxiety	34	72	51.7	9.3
Vineland	19	110	44.2	15.2

Factors affecting Parenting Stress and Chronic Sorrow

Diagnostic Factors:

In order to address the hypothesis that levels of Chronic Sorrow components and Parenting Stress would be different in the different diagnostic categories, a one-way ANOVA was conducted (diagnostic category, 3 levels: genetic, PDD and ABI). There was a significant difference in the mean level of stress (PSITS) felt by parents in the different groups, $F(2,49) = 4.24, p=.02$. Post hoc Sheffé analysis showed the significant difference to be between the genetic (Down syndrome) group (*M* = 94.1, *SD* = 16.6) and the PDD (Autism) group (*M* = 116.2, *SD* = 24.9), with parents of children with Down syndrome showing a significantly lower level of Parenting Stress than parents of children with Autism, (*p*=.031). There were no significant differences in the levels of any Chronic Sorrow components felt by parents in the three groups. See Figure 1 for a graphical presentation of the mean scores.

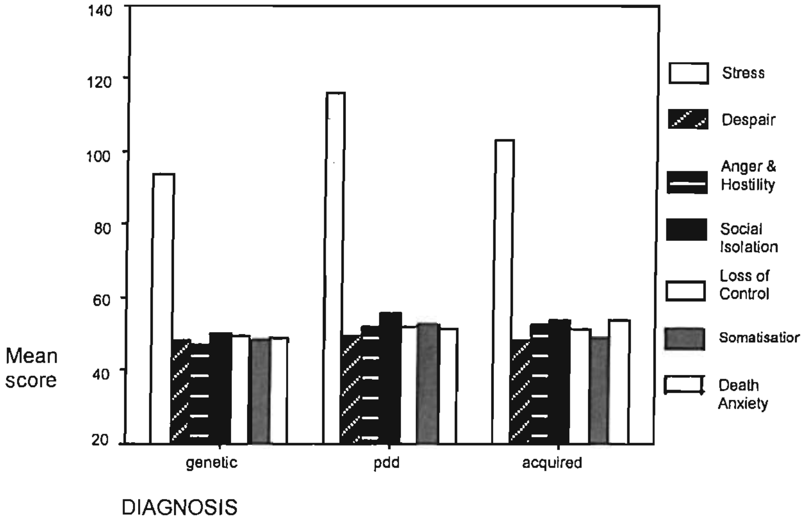

Figure 1. Graph to show mean scores on stress and Chronic Sorrow components, by diagnosis

There was a significant overall effect of the age of the child at which the parent first suspected a problem (8 levels: in utero, birth, 0-1, 1-2, 2-3, 3-4, 4-5, and 5-6) on Parenting Stress, *F*(7,44) = 2.5, *p*=.03, and the Chronic Sorrow components of Social Isolation, *F*(7,44) = 2.26, *p*=.047 and Loss of Control, *F*(7,44) = 2.52, *p*=.029. Post hoc analyses could not be carried out in this case as some of the levels of the variable contained less than two cases. See Figures 2-4 for graphs of the significant components.

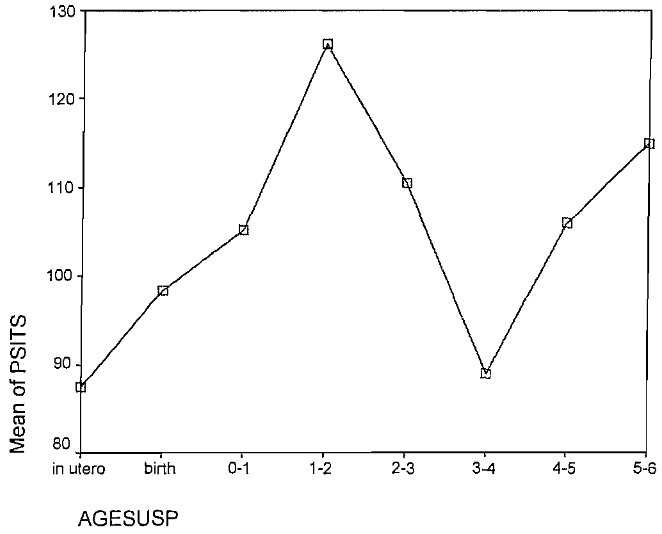

Figure 2. Graph to show the effect of age of first suspicion (AGESUSP) on parenting stress (PSITS)

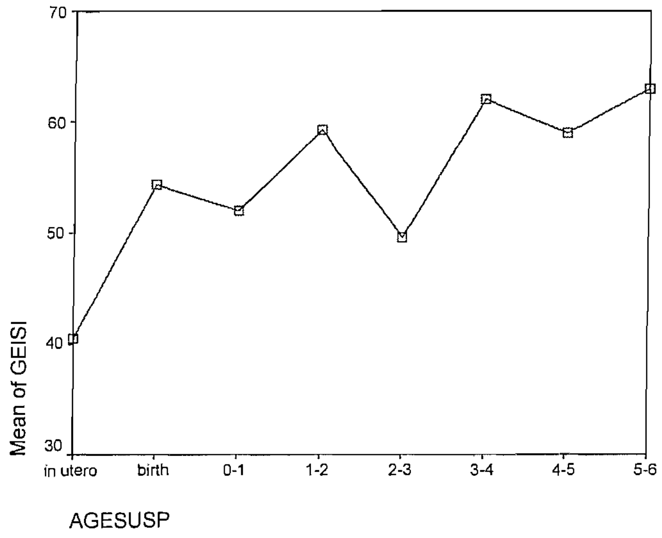

Figure 3. Graph to show the effect of age of first suspicion (AGESUSP) on the Chronic Sorrow component of Social Isolation (GEISI)

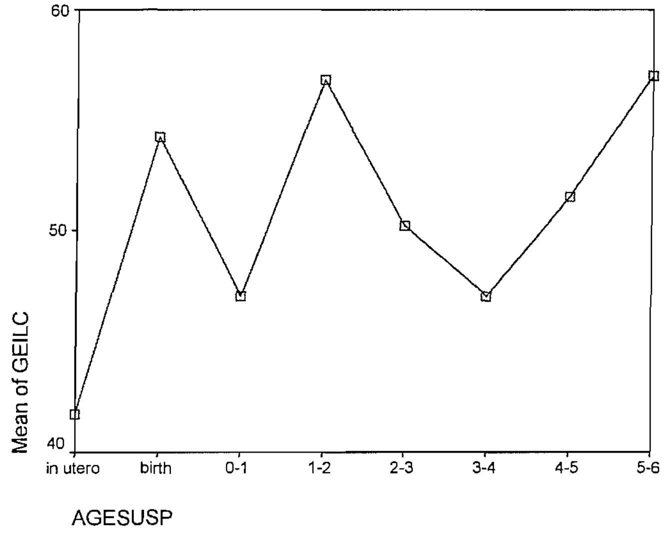

Figure 4. Graph to show the effect of age of first suspicion (AGESUSP) on the Chronic Sorrow component of Loss of Control (GEILC)

There was no significant effect of age of the child at diagnosis.

Parental Factors:

There was a significant effect of the level of education of the parent (5 levels: secondary, college (e.g. HND), undergraduate, masters, PhD) on all of the Chronic Sorrow components except Somatisation, with levels of Chronic Sorrow decreasing with higher levels of education of the parent.

- Despair, $F(4,49) = 4.37, p=.004$
- Anger and Hostility, $F(4,49) = 4.64, p=.003$
- Social Isolation, $F(4,49) = 2.94, p=.03$
- Loss of Control, $F(4,49) = 2.83, p=.03$

- Death Anxiety, *F*(4,49) = 3.98, *p*=.007

There was no significant effect of level of education on Parenting Stress.

In a related category, there was a significant effect of parent's occupation (4 levels: homemaker, unskilled, skilled, professional) on the Chronic Sorrow component of Anger and Hostility, *F*(3,50) = 3.1, *p*=.035. Homemakers showed the highest levels of this component and professionals the lowest levels.

The gender of the parent had a significant effect on the Chronic Sorrow components of Anger and Hostility, *F*(1,52) = 8.22, *p*=.006 and Loss of Control, *F*(1,52) = 8.97, *p*=.004, with mothers showing significantly higher levels than fathers.

Child Factors:

There was a significant effect of the gender of the child on the Chronic Sorrow component of Somatisation, *F*(1,50) = 6.03, *p*=.018, with male children producing a higher level of Somatisation in parents.

Correlational Analysis

Partial correlations were undertaken, in order to examine the relationship between Parenting Stress and all the Chronic Sorrow components whilst controlling for the adaptive behaviour level of the child, both in the group as a whole and within each diagnostic group separately.

Whole sample:

There was no significant difference between the levels of adaptive behaviour of the child reported by parents in the three groups.

Parenting Stress correlated significantly with all Chronic Sorrow components, when controlling for the adaptive behaviour level of the child (see Table 2).

Table 2. Correlation between Parenting Stress and Chronic Sorrow components when adaptive behaviour is controlled for – Whole Sample.

Chronic Sorrow Component	Correlation with Parenting Stress (*pr*)
Despair	.605**
Anger and Hostility	.468**
Social Isolation	.597**
Loss of Control	.369**
Somatisation	.564**
Death Anxiety	.479**

**Note: $p<.01$

Within Down syndrome group:

Parenting Stress did not significantly correlate with any Chronic Sorrow components when controlling for the adaptive behaviour level of the child. (See Table 3)

Table 3. Correlation between Parenting Stress and Chronic Sorrow components when adaptive behaviour is controlled for – Down syndrome group only.

Chronic Sorrow Component	Correlation with Parenting Stress (*pr*)
Despair	.190
Anger and Hostility	-.019
Social Isolation	.522
Loss of Control	-.290
Somatisation	-.029
Death Anxiety	.483

**Note: *p*<.01

Within Autism group:

Parenting Stress significantly correlated with all components of Chronic Sorrow when controlling for the adaptive behaviour level of the child (see Table 4).

Table 4. Correlation between Parenting Stress and Chronic Sorrow components, when adaptive behaviour is controlled for - Autism group only.

Chronic Sorrow Component	Correlation with Parenting Stress
Despair	.698**
Anger and Hostility	.477**
Social Isolation	.625**
Loss of Control	.476**
Somatisation	.617**
Death Anxiety	.558**

**Note: $p<.01$

Acquired Neurological Deficit Group:

Parenting Stress did not significantly correlate with any Chronic Sorrow components apart from Death Anxiety when controlling for the adaptive behaviour of the child. (See Table 5)

Table 5. Correlation between Parenting Stress and Chronic Sorrow components when adaptive behaviour is controlled for – Acquired Neurological Deficit group only.

Chronic Sorrow Component	Correlation with Parenting Stress (*pr*)
Despair	.622
Anger and Hostility	.669
Social Isolation	.279
Loss of Control	.698
Somatisation	.083
Death Anxiety	.807*

*Note: $p<.05$

Discussion

The current literature on parenting stress suggests that parents of children with disabilities suffer higher levels of stress than parents of non-disabled children (e.g. Baker & McCal, 1995). There have also been studies that have shown the presence of Chronic Sorrow, or cyclical grief patterns, in parents of children with disabilities (e.g. Damrosh & Perry, 1989), but to date none have examined any relationship between these two components. This study aimed to highlight any existing relationship between stress and sorrow in three different diagnostic categories. Studies that have compared diagnostic groups in the fields of stress and sorrow have found that different diagnoses can affect the levels reported by parents (e.g. Holroyd & McArthur, 1976). Attachment theory is particularly relevant to these results, with maternal/foetal attachment being a salient issue. Research in this field has shown that parents attach to their child over time, beginning in the womb. Any discrepancy between the "real" child and the one the parent had originally attached to (even if this was a "fantasy" child in the womb) can cause difficult emotions for the parent (Matarazzo, 1992). It could therefore be hypothesised that the later the onset of the disability, the higher the levels of stress and sorrow in the parents as their attachment to the pre-disabled child (real or fantasy) will be more established. This study aimed to examine this by recruiting participants from three different diagnostic categories, namely Down syndrome (genetic), autism (pervasive developmental disorder) and acquired neurological deficit, which would produce a wide range of ages of onset.

The aim of this research was to examine the relationship between parenting stress and Chronic Sorrow in parents of children with various diagnoses, with differing ages of onset. Three groups of parents took part, a total of 53 participants. Of these, 10 had children with Down syndrome, 34 had children with autism and 9 had children with an acquired neurological deficit. Along with parenting stress and Chronic Sorrow, the adaptive behaviour level of the child was also examined, in order to exclude this from the analysis of any relationship. If this had not been taken into account, it could have been hypothesised that parent's levels of stress and sorrow increased with the level of disability of their child.

Analysis of the data showed that there was a significant difference between the groups in the level of stress reported but not in levels of Chronic Sorrow. Parents of children with autism showed the highest levels of stress, followed by the acquired neurological deficit group and then the Down syndrome group. This could be due to the fact that some of the children in the acquired group actually had lower ages of onset than the autism group. It was therefore necessary to examine the sample as a whole, to see if there was any significant effect of the age of the child at which the parent first suspected a problem. There was a significant result for stress and the two Chronic Sorrow components of Social Isolation and Loss of Control. Post hoc analyses could not be conducted on this factor as some of the age groups contained less than two sets of data, but examination of the graphical data shows an increase in the levels of the Chronic Sorrow components as the age of suspicion of a problem increases (see Figures 2-4).

The mean levels of stress in all groups showed that the participants were experiencing clinical levels of stress. Abidin (1995) states that a score of 90 or above on the Parenting Stress Index indicates a clinical level of stress. The mean score was 109.8, showing that the majority of participants were experiencing clinical levels of stress. Sanders, Mauger and Strong (1985) do not report clinical levels for the Grief Experience Inventory as the measure was validated with a clinical population (all participants had experienced a loss).

However, they report the mean score for a clinical population as 50 on the component scores, so it can be seen that these participants were reflecting that finding, with mean scores on the components ranging from 49.1 to 54.4.

Various parental factors have been examined in the literature and some have been found to have a relationship with the levels of stress and sorrow felt by parents. It was therefore important to explore some of these factors in this study. The level of education of the parent had significant effects on all the Chronic Sorrow components, apart from Somatisation. The higher the level of education of the parent, the lower the level of Chronic Sorrow. This is important, as it may help health professionals to be aware of those families that are most at risk of suffering a grief reaction and the financial pressures of raising a child with a disability should not be ignored. It is possible that the higher educated parents are more able to access information and determine sources of support and so it should be ensured that all families have equal access to this information. The significant effect of parental occupation may be related to the results for education, as it could be hypothesised that those parents with a higher level of education may be more likely to be employed in professional or skilled jobs, though this should not be assumed. Gender has been found to have a significant effect on stress and sorrow in separate studies (e.g. Damrosch & Perry, 1989), with fathers showing significantly lower levels of parenting stress and Chronic Sorrow. This study found a significant effect of gender of the parent on two Chronic Sorrow components, Anger and Hostility and Loss of Control. It could be hypothesised that mothers spend more time at home with the child and provide more of the care, which may account for these differences, but this was not specifically examined. In future studies it may be useful to examine the levels of care provided by each parent before making assumptions about this. It could be suggested that mothers may have had to give up a career or other aspects of their life to care for the child and may feel a loss of control of their own lives, or levels of anger and resentment as a result of these sacrifices, but further investigation is required.

The gender of the child was the only child factor that had any significant effect on the parent's reaction, with male children being related to higher levels of Somatisation in the parents. It is not possible to state why this might be but there are several explanations that would require additional study before they can be fully understood. The first of these is that autistic spectrum disorders are much more common in boys than girls, with a ratio of 3-4:1 (Carr, 1999) and studies have shown that parents of children with autism may be less attached to their child than parents of children with Down syndrome (e.g. Hoppes & Harris, 1990). Research has also highlighted that parents of children with autism may report higher levels of stress than parents of children with genetic or psychiatric disorders (e.g. Holroyd & McArthur, 1976) and higher levels of anxiety and depression (Sharpley, Bitsika & Efremidis, 1997). This study also showed that the levels of Chronic Sorrow reported by parents increased as the age of onset of the child's difficulties increased. It could be hypothesised that the gender difference arises because autism presents later in a child's life than Down syndrome and certain acquired neurological problems. These differences may provide some explanation for the higher levels of Somatisation in this study, due to the large number of boys in the PDD group, but more research is warranted in this area.

When the whole sample was analysed, parenting stress significantly correlated with all components of Chronic Sorrow, even when the adaptive behaviour level of the child was controlled for. However, when the groups were examined separately, only the PDD group showed significant results for all the components and the acquired group only achieved significance in the component of Death Anxiety. The Down syndrome group did not achieve a significant correlation on any of components. Therefore, the highly significant results in the PDD group may have overshadowed the non-significant results in the other two diagnostic categories when the sample was examined as a whole. It is possible that the higher numbers of participants in the PDD group contribute to this and it is therefore important to recognise that significance may have been achieved for the Down syndrome and acquired neurological disorders groups, had there been higher numbers of participants in each of these categories. The correlation coefficients in the Down syndrome and acquired groups were actually higher than those in the autism group in some cases, indicating that it was the small sample sizes that prevented the results reaching statistical significance. Whilst the sample sizes were uneven, statistical tests were performed to ensure that the groups could be compared, despite the discrepancy in numbers of participants. It is a point of interest that parents of children with autism responded to the advertisement for participants in such high numbers and speculation about why this may be is unsubstantiated without further research. However, it could be that issues such as greater involvement in support agencies (such as the National Autistic Society) may have contributed, as more parents would have seen the advertisement. It may also be possible that parents of children with autism are more interested in contributing to research, due to the ongoing speculation as to possible contributing factors to the onset of the disorder.

Whilst three specific diagnostic categories were examined in this study, the results regarding parental and child factors may be applicable across a number of situations, including parents of children with severe and enduring mental illness, or physical disability. All of the reported results have clinical implications for health professionals and should be taken into account, along with the established literature base, when providing services for parents of children with a variety of difficulties.

The specific clinical implications that are highlighted by this study relate to the identification of those families that may be in greatest need of support and possibly professional help to deal with their feelings of cyclical grief. All three diagnostic groups showed symptoms of Chronic Sorrow and parenting stress. Obviously, these feelings will impact on the family's ability to function effectively as well as the obvious implications of dealing with difficult emotions.

Olshansky (1962) offered three suggestions to professionals working with families, to help them to facilitate the resolution of Chronic Sorrow. The first of these was to abandon the standard view that parents will reach a state of acceptance of their loss. As described, Chronic Sorrow has been widely accepted as a cyclical grief process and not a linear one that will automatically resolve to acceptance. The second suggestion is to explain to families that this is a natural reaction and not a neurotic one. This validation of the parent's reaction may help them to overcome feelings of guilt or shame at their feelings of bereavement, despite the fact that their child is still alive. The final suggestion made is to provide information and supportive counselling, throughout the time period that parents are requesting help. This implies that support should not just be available at diagnosis and should not be time limited. Support of the family has been discussed in the literature as a mediating factor for stress (e.g. Cohen & Wills, 1985). However, it has also been suggested that an influx of too much social support in a time of crisis may lead the parents to feel disempowered and can be taken as a suggestion of incompetence, thereby actually increasing stress (Quittner, Glueckauf & Jackson, 1990). Longitudinal research would be required in this area to examine the timeline of events before any judgements about decreasing support were made as it could be hypothesised that families who are displaying the highest stress levels receive the most support and so a causal relationship cannot be inferred.

More recently, Bruce and Shultz (2001) have described the goals of therapy for Chronic Sorrow, making use of theories of internal representations and schemas as well as a model of cyclical grief. They suggest that professionals should help parents to preserve their own identity as people as well as facilitating grieving and adaptive reality testing. These goals can be achieved through allowing parents to express their grief and normalising their reaction as well as helping the parent to make connections between themselves now, in the past and a new projected view of self, using schema based work. This work can also help to produce new expectations for themselves and for their child, through education and the development of new coping strategies. Finally, the authors emphasise the need for fostering a feeling of hopefulness for the parents, by allowing them to attach meaning to their newly emerging reality. The outcomes of this approach have shown good results, in that at 12 month follow-up, parents felt positive emotional, behavioural and attitudinal outcomes (Shultz et al, 1993). The type of support system described here would seem to fit with all the theoretical data that has been described, on internal representations, attachment theory and the cyclical nature of Chronic Sorrow. Langridge (2002) suggests that children's community nurses could play a role in helping families to resolve feelings of grief. They have regular contact with families and may be best placed to provide empathetic support, validation of feelings and accurate information about the child's condition. As they are engaged with families over time, they may also be well placed to identify when a period of crisis could be imminent and a grief cycle triggered and be on hand to provide additional support at the most opportune times.

There was a significant difference in the levels of parenting stress felt by the three different diagnostic groups. This may help professionals to provide targeted stress management where it is needed most, namely for parents of children with autism. This is not to say that the other groups of parents would not benefit from stress management and practical support in reducing the sources of their stress, whether this is through behaviour management strategies, or helping them to develop a more positive appraisal of their child's behaviour. There was no significant difference between the levels of Chronic Sorrow felt by the three groups, but Chronic Sorrow was shown to significantly correlate with stress scores. As discussed earlier, this could be due to the highly significant correlations in the largest group (PDD) overshadowing the other groups, but this result still needs to be examined in terms of it's implications. This study did not have the scope to explore any causal relationship between stress and sorrow, but it is the only study ever to have examined any relationship between them. Longitudinal work is required here to discover which comes first, stress or sorrow. It could be hypothesised that feelings of grief are contributing to stress levels. If this is the case, then simply providing stress management in the form of behavioural strategies and relaxation may not be the most helpful approach. Future research could explore whether stress reduces as parents receive therapy for their feelings of sorrow, thereby resolving an underlying source of stress, as opposed to simply providing coping strategies.

Because the current study shows a relationship between stress and sorrow, but not a causal effect it could be hypothesised that the Parenting Stress Inventory (Abidin, 1995) and the Grief Experience Inventory (Sanders, Mauger & Strong, 1985) are simply measuring the same construct. However, when the data are examined further, it can be seen that if this were the case then we would expect the differences to be uniform across the groups. This is not the case and the fact that there are significant differences in stress levels across the groups but not Chronic Sorrow indicate that they can be discussed as separate and distinct constructs. Future research would need to make use of larger sample sizes in order to examine this further and it may be beneficial to make use of qualitative data to explore the differences.

The current literature base does not adequately explore issues of cultural differences in parenting stress or Chronic Sorrow. Fatimilehin and Nadirshaw (1994) conducted structured interviews with Asian and White British families to explore the differences in attitudes towards their children with learning disabilities. They found that service utilisation and attitudes to the child were affected by cultural and religious differences, rather than characteristics of the parents or children. The Asian families also showed a lack of knowledge about the possible causes of their child's difficulties and the services that were available to them. This small-scale study highlights an important issue that has been neglected by current research. It would appear that cultural and religious beliefs may affect parental appraisals of their children and therefore could possibly be affecting attachment due to negative internal representations of disability. Health professionals should be aware of this and should explore parental representations and attitudes in order to provide the most appropriate support, in terms of helping parents to create more positive appraisals of their child and themselves.

This research does have some limitations, as in any research that is examining real-life phenomena. The study was a quasi-experiment, in other words, participants were allocated into groups due to existing criteria (diagnosis of the child) and not randomly assigned by the researcher. Quasi-experiments are therefore at risk of being confounded by subject variables and this would lead to serious restrictions on the validity of inferring a causal effect. In this case, the research design tried to take some of these factors into account by controlling for the adaptive behaviour level of the child, but issues such as perceived emotional feedback (Hodapp et al, 2003) were not controlled for and may have confounded the results. The issue of whether stress and sorrow are similar constructs, rather than two distinct constructs that have a relationship is mentioned earlier in this discussion. In fact, due to the differences between the groups on stress levels and not on sorrow levels, it can be assumed that the two are distinct and separate. Another factor that threatens internal validity is the variance in age of onset between participants within each group (Heiman, 1995). This leads to a reduction in the apparent effect of diagnostic category on Chronic Sorrow and stress scores, but was overcome to some extent by examining the age of onset in the sample as a whole, as well as by diagnostic category. The small numbers of participants in the Down syndrome and acquired injury groups meant that statistical significance was not achieved for the correlation analysis, despite the high correlation coefficients in some cases. Ideally, more participants would have been recruited in these two groups but this was not possible given the time frame of the study. As mentioned previously, the participants were a self-selecting sample, as they were answering an advertisement for participants. This may have caused some bias in the results, particularly when the large numbers of parents of children with autism is taken into account. However, this is an issue that all research of this kind faces. It would not be ethical to approach families and attempt to coerce them into taking part and therefore researchers must accept the limitations of self-selecting samples in studies of this kind. The parents who took part did so despite being under a lot of pressure and often discussed difficult emotions with the researcher, providing a rich data source for the study and also helping the researcher to gain insight into the difficulties and emotions that these families live with every day. A qualitative analysis of the interviews may have highlighted important issues for additional study, but this was outside the scope of the current study. As each family would have different representations and therefore experience a grief cycle at different points and for different reasons, qualitative analysis would be a good way of examining any commonality between families and therefore aid prediction of the onset of a grief cycle (Bruce & Schultz, 2001). This research was also only examining a single point in time for these parents. The nature of Chronic Sorrow is that it fluctuates over time due to the cyclical nature and these fluctuations will occur at different times for different families, depending on their individual representations. This study is therefore providing a limited view of Chronic Sorrow and its relationship to stress. Longitudinal research may be better able to chart the fluctuations and cycles of grief as well as any changes in the stress levels of parents, either to trigger the grief cycle or in response to it. Dyson (1993) examined stress levels of parents of children with disabilities over time and found that this too was a fluid concept, with families experiencing different stress levels at different time points and displaying different rates of adjustment after a four-year interval. Further longitudinal research could examine possible variables that may have contributed to family adjustment or the lack of it.

In conclusion, the main findings of this research would appear to support the development of services that help parents to normalise feelings of grief and develop positive appraisals of the diagnosis, their child and themselves as parents. The results go some way to identifying particular risk factors that may indicate those parents most in need of support. Mothers of children with autism would appear to be at particularly high risk of Chronic Sorrow and stress. It is also possible that the later in a child's life a diagnosis is received, the more difficulty parents will have in attaching to the "new" child and relinquishing their hopes and dreams that were projected into the future for the "fantasy" child. Areas that require additional study have also been highlighted, in particular, longitudinal studies may help to provide more data on any causal relationship between stress and Chronic Sorrow, thereby providing information on the most appropriate focus for support. Our society is changing, becoming increasingly multi-cultural and the traditional model of the nuclear family seems to be less influential. Grandparents may live some way from their children and may be less able to provide support, whereas in the past it may have been more likely that families stayed in the same area. Pressures of careers and spiralling house prices may have contributed to this. It should also be taken into consideration that many children with learning disabilities, autistic spectrum disorders or brain injuries would have, in the past, been taken to live in institutions. Children now tend to live within the family, but little or no training is given to parents to cope with these often challenging children. Parents face many difficulties, both in terms of daily stressors and long-term emotional upheaval. Health professionals such as psychologists are well placed to provide support and this study has gone some way into exploring how this may be achieved in the best interests of the families in question.

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List of Appendices

APPENDIX 1

COVERING LETTER TO PARTICIPANTS

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Tel +44 (0)23 8059 5321
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Email

September 2004

Dear Participant

Thank-you for agreeing to take part in this research into the stress and emotions faced by parents of children with various learning disabilities. I am happy to enclose the paper questionnaires, which should take you around 30-40 minutes to complete. Once these are done, I would be very grateful if you could return the three questionnaires and the signed consent form in the freepost envelope provided. There is no need for a stamp. Please do not put any identifying information on anything except the consent form. Once I receive your completed questionnaires I will be in touch to arrange a time for the phone interview that is convenient.

The questionnaires themselves are fairly self-explanatory:

1) The 36 item parenting stress index just requires you to circle the appropriate response as to whether you agree with the statements or not. (SA = strongly agree, A = agree, NS = not sure, D = disagree, SD = strongly disagree.)
2) The 135 item Grief Experience Inventory requires you to blacken the appropriate answer on the response sheet – either true or false.
3) The demographics questionnaire is just to ensure that we are comparing fairly.

The questionnaires are both rather negatively worded and, in particular, the Grief Experience Inventory refers to having a disabled child as a loss. This is not necessarily the view of health professionals and the measure is simply being used to try to understand the emotions that go with a diagnosis/realisation that your child has a learning disability. I fully appreciate that many of you would not regard this as a loss and hope you will not be offended by the terminology, but will be able to complete the form as accurately as possible.

If you have any questions, please do not hesitate to contact me on 07971 518975 or email ksmj102@soton.ac.uk. I look forward to hearing from you soon.

Best wishes

Kate (Jenkins)

APPENDIX 2

PARTICIPANT INFORMATION SHEET

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PARTICIPANT INFORMATION SHEET
Chronic Sorrow and Parenting Stress in parents of children with learning disabilities, with varying age of onset and diagnostic criteria.

You are being asked to take part in a research study. Before you do, it is important that you understand why the research is being done and what it will involve. I understand that your time is at a premium, but please read the following information carefully and feel free to discuss it with others if you wish. If you have any questions or concerns you are welcome to contact me by any of the methods below. Thank-you for your time.

What is the purpose of this study?

This study is trying to find out about levels of stress in parents with children with various disabilities. It includes an examination of Chronic Sorrow, which is a concept that describes feelings of grief in parents whose children may have difficulties. It is hoped that research such as this will enable health professionals to better support parents who may be experiencing difficulties as a result of their child's disability.

Why have I been asked to participate?

Parents of children with various difficulties have been invited to take part, in order to gain a wide variety of responses. In this way, it is hoped that the research will be relevant to the real life difficulties that parents face.

Do I have to take part?

It is entirely your decision whether you would like to participate. If you decide to say no, this will in no way affect the services you receive.

What will happen if I do take part?

You will complete the enclosed questionnaires. These will take around half an hour to fill in and once you have finished you can return them in the pre-paid envelope provided, along with your signed consent form.
Completion and return of the questionnaires will be seen as informed consent to be included as a participant in this study and for your data to be used for the purposes of research.
You will then be contacted by telephone by the researcher to complete one further interview, taking approximately forty minutes.

Will my participation be confidential?

Yes, all information will be strictly confidential and any identifying information, such as your name and address will be removed from the results.

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What will happen to the results of the study?
The report will be written up in the form of a doctoral thesis. You may have a summary of the results if you wish. Please tick the box on the consent form if you would like to request a summary in advance.

Who is organising the research?
I am a second year Trainee Clinical Psychologist at the University of Southampton, Doctoral Programme in Clinical Psychology. The research is being conducted as part of my training and is being supervised by Dr Tony Brown, Chartered Clinical Psychologist.

Who has reviewed the study?
The School of Psychology Research Ethics Committee, University of Southampton has reviewed the study and approved it.
If you have any questions about your rights as a participant in this research or if you feel you have been placed at risk then you may contact the Chair of the Ethics Committee, School of Psychology, University of Southampton, Southampton, SO17 1BJ. Tel: 02380 593995

Contact Details:
If you have any queries regarding the research please contact me:
Kate Jenkins, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ
Tel: 07971 518975, Email: ksmj102@soton.ac.uk

APPENDIX 3

CONSENT FORM

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CONSENT FORM

Chronic Sorrow and Parenting Stress in parents of children with learning disabilities, with varying age of onset and diagnostic criteria.

Please initial boxes:

I confirm that I have read and understood the information sheet dated 10/01/04, version 1, for the above study. ☐

I understand that my participation is voluntary and that I may withdraw consent at any time without affecting my medical care or legal rights in any way. ☐

I understand that the study will be totally confidential and that all identifying information will be removed. ☐

I agree to take part in the above study and include my completed questionnaires with this form. ☐

I understand that I will be contacted by telephone to complete one further interview, lasting approximately forty minutes and agree to this. ☐

Name:.. Date:.............

Telephone Number...

Most convenient time to be contacted (please circle): AM / PM / evening

Signature:...

Please tick this box if you would like to request a summary of the results: ☐

Version 1 10/01/04

APPENDIX 4

DEMOGRAPHICS QUESTIONNAIRE

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DEMOGRAPHICS QUESTIONNAIRE

THIS QUESTIONNAIRE WILL REMAIN TOTALLY CONFIDENTIAL. ANY IDENTIFYING INFORMATION WILL BE REMOVED.

Please write you answers in the space provided or delete options as appropriate.

Age...

Occupation...

Education Level (last educational establishment, e.g. secondary, undergraduate)

....

Relationship to child...

Gender of child: M / F

Age of child.......................................

Number of other children...

Position of child in family (e.g. oldest, youngest)..

If you have any questions or concerns, please feel free to contact me.
Kate Jenkins, Trainee Clinical Psychologist, School of Psychology, University of Southampton, Highfield, Southampton, SO17 1BJ
Tel: 07971 518975, email: ksmj102@soton.ac.uk

CODE:

APPENDIX 5

ETHICAL APPROVAL LETTER

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22 June 2004

Kate Jenkins
Department of Clinical Psychology
University of Southampton
Highfield
Southampton SO17 1BJ

Dear Kate,

Re: Chronic sorrow and parenting stress in parents of children with learning disabilities with varying age of onset and diagnostic criteria

I am writing to confirm that the above titled ethics application was approved by the School of Psychology Ethical Committee on 22 June 2004.

Should you require any further information, please do not hesitate in contacting me on 023 8059 3995.

Please quote approval reference number CLIN/03/43.

Yours sincerely,

KMLucas

Kathryn Lucas
Secretary to the Ethics Committee

APPENDIX 6

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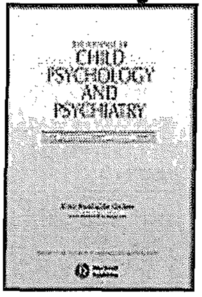

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Top