Stress and coping in fathers with severely disabled institutionalised children

by

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A thesis submitted in partial fulfilment of the requirements of the degree of

Philosopheia Doctor in Child Psychology and Related Fields

in the Faculty of Humanities of the University of the Free State.

November 2003

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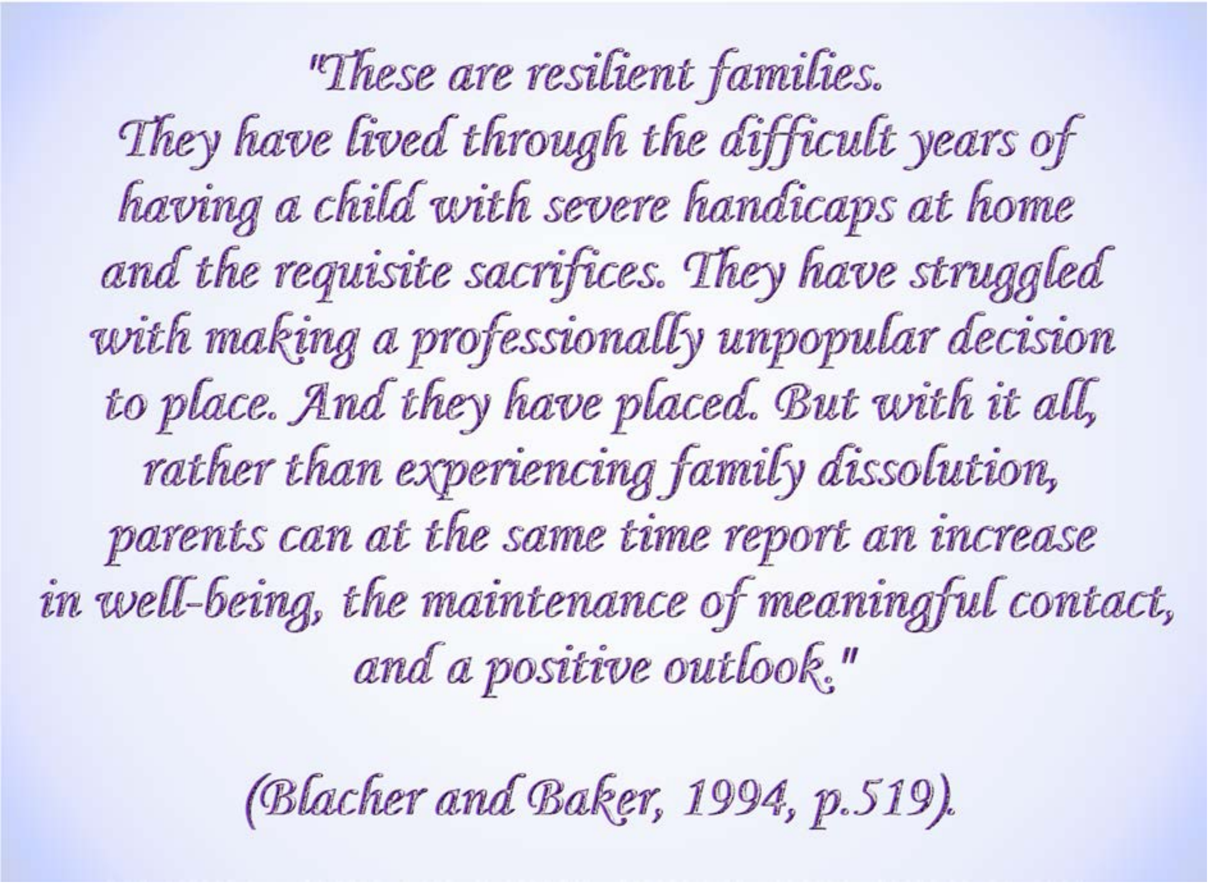
Acknowledgements

The author wishes to express his sincere appreciation to:

- Prof Malan Heyns, UFS, for his competent guidance and patience;
- Prof D Luiz, UPE, who gave of her precious time during the planning stage of this study;
- Prof TB Pretorius, UWC, for his willingness to review the research proposal and for the provision of helpful reading material;
- Mrs Pauline van der Merwe for her valuable assistance with the development of the research proposal;
- Prof C Carver, University of Miami, USA, for his assistance in obtaining the COPE Questionnaire;
- Prof J Holroyd, UCLA, USA, for her help in obtaining the QRS;
- Dr Karel Esterhuyse, UFS, for his help in processing the data;
- Ms Estie Pretorius, Mrs Annamarie du Preez and their co-workers at the Sasol Library, UFS, for their effective sourcing and delivery of reference material;
- The NRF (National Research Foundation) for financial assistance;

- The parents of all the severely handicapped children who participated in this study;
- The care facilities, Woodside Johannesburg, Woodside, Rondebosch-East, Our Nest, John Peattie House and Little Eden for their co-operation;
- Mrs Estelle Kitshoff, his Personal Assistant, for her hard work and support;
- Mrs Helene Steffens for capturing the data;
- Mrs Sumari Silva and Mrs Magda Scholtz, who filled in at his practice while he was on study leave;
- Mrs Toitjie Vorster, for her technical and linguistic input in the finishing of this publication;
- His wife, Ronél, and children for their support and encouragement;
- His parents who, through their sacrifice, have given him the opportunity to qualify and work as a psychologist; and
- God, the Creator of all, without whose support and guidance this study would not have been possible.



"These are resilient families.
They have lived through the difficult years of
having a child with severe handicaps at home
and the requisite sacrifices. They have struggled
with making a professionally unpopular decision
to place. And they have placed. But with it all,
rather than experiencing family dissolution,
parents can at the same time report an increase
in well-being, the maintenance of meaningful contact,
and a positive outlook."

(Blacher and Baker, 1994, p.519).

Dedication

This study is dedicated to my son,

Philip (1995-05-06 to 1997-01-02),

a severely handicapped little boy diagnosed with

Amnion Band Syndrome,

and to the

staff of the Woodside Sanctuary, Rondebosch,

who loved him and cared for him

in a way we could not.

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Summary

This study deals with the stress and coping of parents with severely handicapped, institutionalised children, with specific emphasis on the experience of the father. Little research has been directed at these parents. In this study their stress and coping is considered according to their material, psychological and social resources and their coping strategies. The aim was to reveal how the fathers differ from the mothers in terms of their perceived stress, resources and coping strategies and to provide guidelines to professional helpers who assist parents.

Parents of handicapped children experience ongoing and complex grief and recurrent distress-generating crises. These processes impact on the parents' informal and formal support systems. The extent to which parents are able to find meaning in their loss and manage the tension generated by their various crises may have predictive value in terms of their adjustment.

This study is aligned with the tenets of Positive Psychology and stress is approached from a transactional point of view. In particular, the importance of psychological health (Salutogenesis) and strength (Fortigenesis) is emphasised and the role of cognitive and emotional appraisal of the stressor and the stress-reducing function of mediators, such as resources (internal and external) and coping (strategies and behaviours) is seen as central to the outcome of the tension management process.

A review of the relevant literature shows that certain child characteristics, such as age, severity of the handicap, gender, behavioural difficulties, care-giving demands, the presence of another handicapped child and cultural factors affect parental stress. Indications are that care-giving demands are the greatest child-related source of parental stress. Certain parental characteristics, such as age, health and income also act as mediators of stress. Previous studies identify internal resources, such as Sense of Coherence, personality characteristics, positive beliefs, religion, history of pre-crisis management, perceived stress and the perceived burden of care as mediators of stress in parents of handicapped children. As far as external resources are concerned, informal support systems such as the spousal relationship, siblings, close family and friends, extended family and neighbours, other parents of handicapped children and respite care are identified as possible mediators of stress. Of these, the spousal support and the support from close friends and family seems to have the greatest stress-reducing effect. Formal support systems, such as support services, associations, organisations, professionals and care facilities are not seen by parents as primary sources of support. Coping behaviours and strategies also function as mediators of stress. Effectively coping parents maintain a relatively normal lifestyle, engage in warm, secure and open spousal and family relationships. They seek further personal development, stay involved with their children, utilise their support systems and follow a planned, practical and problem-focused strategy.

In this study 77 parents of severely handicapped, placed children, including 12 couples, were examined by means of the Questionnaire for Resources and Stress, The Perceived Stress Scale, The Sense of Coherence Scale, the Fortitude Questionnaire and the COPE Inventory.

Results show that (a) the parents with high levels of perceived stress will be more prone to make negative appraisals of their severely handicapped child, their internal stress-reducing ability and of their available social support systems, (b) the father may be more vulnerable than the mother due to his dependence on the mother as his main source of social support and (c) the father with high levels of perceived stress may be more vulnerable than the mother with high levels of perceived stress. Findings highlight the need for intervention of psychologists in order to assist both parents to fulfil demanding and mutually supportive roles.

Die stres en aanpassing van vaders met erggestremde geïnstitusionaliseerde kinders

deur

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Opsomming

Hierdie ondersoek handel oor die stres en aanpassing van ouers met erggestremde geïnstitusionaliseerde kinders. Daar word veral aandag gegee aan die belewenis van die vader. Min navorsing is nog hieroor gedoen. Bogenoemde onderwerp word bestudeer aan die hand van ouers se materiële, psigologiese en sosiale hulpbronne asook hul aanpassingsvaardighede. Dit was een van die hoofoogmerke van hierdie ondersoek om die verskille tussen ouers ten opsigte van hul waargenome stres, hulpbronne en aanpassingsvaardighede bloot te lê en om, aan die hand daarvan, riglyne aan professionele helpers te verskaf.

Ouers van gestremde kinders ervaar ‘n herhalende en komplekse rouproses en die opeenvolging van streswekkende krisisse. Hierdie prosesse het ‘n impak op hul informele en formele ondersteuningstelsels. Die mate waarin die ouers hul verlies sinvol kan verwerk en hul krisisverwante stres beheers, mag hul uiteindelike aanpassing voorspel.

In hierdie studie word die uitgangspunte van Positiewe Sielkunde onderskryf. Stres word benader vanuit ‘n transaksionele oogpunt. Die belang van sielkundige gesondheid (Salutogenese) en sterkte (Fortigenese) word beklemtoon. Daar veral aandag gegee aan die sentrale rol van die kognitiewe en emosionele interpretasie van die stressor en die stresverminderende funksie van mediators (intern en ekstern) en aanpassing (strategieë en meganismes) in die streshanteringsproses.

Verskeie kenmerke van die gestremde kind, soos ouderdom, graad van gestremdheid, geslag, gedragsprobleme, versorgingsvereistes, nog ‘n gestremde kind in die gesin en kulturele faktore ‘n impak het op ouerlike stres. Veral die versorgingsvereistes hou verband met ouerlike stres. Seker ouerlike kenmerke, soos ouderdom, gesondheid en inkomste speel ook ‘n rol as mediators van stres.

Vorige ondersoeke identifiseer verskeie interne hulpbronne, soos koherensiesin, persoonlikheidstrekke, positiewe opvattings, godsdiens, geskiedenis van vorige aanpassing, waargenome stres en waargenome versorgingsvereistes as mediators van stres. Met betrekking tot eksterne hulpbronne, word informele ondersteuningstelsels soos die egpaarverhouding, kinders, naby-familie en vriende, veraf-familie en bure, ander ouers met gestremde kinders en kinderversorgers vermeld. Van hierdie sisteme speel die egpaar en naby-familie die belangrikste stresverminderende rol. Formele ondersteuningstelsels, soos ondersteuningsdienste, verenigings, organisasies, professionele helpers en versorgingsoorde word nie as primêre stresverminderende hulpbronne genoem nie.

Aanpassingstrategieë en meganismes dien ook as mediators van stres. Goedaangepaste ouers poog om ‘n relatief normale leefwyse te handhaaf en streef na oop, veilige en warm gesinsverhoudings. Hierdie ouers is steeds ingestel op hul eie ontwikkeling, hul betrokkenheid by hul kinders en hul handhaaf ‘n beplande, praktiese en probleem-oplossende benadering.

In hierdie ondersoek is 77 ouers van erggestremde kinders, insluitend 12 egpare, betrek. Daar is gebruik gemaak van die *Questionnaire for Resources and Stress*, die *Perceived Stress Scale*, die *Sense of Coherence Scale*, die *Fortitude Questionnaire* en die *COPE Inventory*. Die hoofbevindinge is dat (a) ouers met hoë vlakke van waargenome stres meer geneig is tot ‘n negatiewe evaluering van hul gestremde kind, hul eie innerlike streshanteringsvermoë en hul sosiale hulpbronne, (b) die vader meer kwesbaar is as die moeder weens sy aanwending van haar as sy hoof sosiale ondersteuningsbron en (c) die vader met hoë vlakke van waargenome stres meer kwesbaar is as die moeder met hoë vlakke van waargenome stres. Hierdie bevindinge benadruk die noodsaaklikheid van sielkundige intervensie wat ouers in staat sal stel om hul veeleisende en wedersydse ondersteunende rolle te vervul.

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The story of my son…

Our pregnancy with Philip was very different. From the outset we had a sense that everything was not OK. He was very restless, moving constantly, excessively and awkwardly, and seldom slept. Ultimately this made Ronél very tired and sore.

Given our sense of disquiet, we found ourselves insisting on further blood tests and an amniocentesis and harboured fears he may be situated in Ronél's fallopian tubes. Following the reassurance of our Gynaecologist and three further scans; we decided to abandon the idea of an amniocentesis and any further tests. Still, our sense of apprehension remained…

It's as if a parent knows…

For me, Philip was a very significant child. At the age of 35, I was ready to acknowledge the contribution of my father. Hence, Ronél and I decided that we would name our son Philip Constantine Costandius – the family name. For my father and I this was an emotional event, which, for me, signified a sense of forgiveness and release.

Philip would be our first attempt at a normal birth. After two pretty botched-up lumbar epidurals and painful episiotomies we felt that we were more than ready for the real thing.

On the afternoon of 5 May 1995, from within his mother who, at that time was shopping in Pick & Pay, Philip started sending signals that he wanted out… This was three weeks before due date

Within an hour or so, we found our way to Panorama Medi-Clinic. Following some hours of labour, Philip appeared. I recall looking down across the green sheeting that covered Ronél's legs. In an instant I saw a huge rounded forehead, a face that looked sort-of squashed…Ronél also caught a glimpse of his leg and started asking whether his leg was OK or whether he had a clubfoot. In what must have been a reflex action, the maternity nurse turned him away from us. All of this must have taken only a few seconds, because the next moment they had him swaddled in one of the green sheets and rushed him out of the room.

This was the hardest part: the waiting, the uncertainty, not knowing what to expect, feeling helpless, out of control. We wait an indeterminable wait, with Ronél babbling on about how she would be Ok with a "special child".

We wait…

Finally the Gynaecologist returns, "Your child is severely handicapped". He then explains how they have had to intubate him so that he could breath and goes on to list a myriad of problems: arms, legs, nose, feet …

I lose it. Overwhelmed with anger, I demand that they remove the tube. I don't want him to live – it just seems so crazy. The gynaecologist starts to explain that they are compelled to assist him - he talks of reconstructive surgery, neurological testing, brain scans, second opinions – all of this just makes me feel more angry, frustrated, powerless and overwhelmed…

I become aware that Ronél is also acting oddly. Still aglow from the delivery, she seems hazy, sore and tired. Her primary need is for Milo and rusks! Amidst the chaos, the medical personnel forget to remove the Placenta ..

We wait…

After another eternity the Gynaecologist returns. "It seems as if the brain stem has not developed, this means that …we have decided to remove the breathing tube, but the child is now breathing independently (!)"

On the inside I explode…"What the hell now? How long will the child live? What am I going to tell my parents, my children?" I just feel more overwhelmed. My life grinds to a halt.

At that stage I am aware of one certainty: I don't want the child to survive, I don't want him the way he is. Little did I know that, from that point on, it would take me more than a year to really accept him for who he was.

At two or three on the morning of 6 May 1995 I go home. Arrangements are made for us to view the child at 09:00.

I return to Panorama, filled with anxiety and apprehension. I find Ronél, dressed in Jeans, and Sister Joey Francis from the neonatal ICU. Sr Francis tries to comfort us, hugs us, says a prayer…

Walking down the long passage to the ICU, I realise that I'm stuck, there's no way around this but to confront my worst fears. For me this is a defining moment in my life for which I remain continually thankful to Philip..

The neonatal ICU is brightly lit… Rows and rows of neon tubes shining down on babies that look like gutted fish… It is an overpowering array of monitors, pipes, funny-looking machines, and wires, people with sad eyes.

Sr Francis guides us to a screen. There we find an incubator tagged with a blue cardboard sign reading "minimal handling please" and a professional-looking paediatrician.

Very quietly he breaks the news, "Your child has Amnion Band Syndrome" – Tiny fibres, due to a rupture in the amnion Sac, tore through Philip from early in his gestation, inhibited his growth and finally cut him into pieces – now I understand his restlessness.

One feels too scared even to touch him. I am aware of a shattered dream, of horror and of love – all mixed into one. This moment of diagnosis is truly the "event that changes the future" and confronts me with a double grief – for my real and profoundly damaged child and for the child I will never have – the beautiful, flawless child of my fantasies and dreams…

Once the sense of shock has dissipated, I find myself in another mode. I grieve, I go back to work, I make enquiries, I phone colleagues, I cope (somehow)…

Ronél, still in hospital, opts for the task of phoning our parents. They are shattered.

She recalls with indignation and anger how one nurse wrote in her file "the patient is very calm, accepts the situation". How dare they assume that, simply because she is not hysterical and acting out, that she is in any way OK?

The next day Ronél, bereft of milk by a particularly painful injection, comes home. There is no feeding routine, no visits to the baby room, no trolleys that bring baby for feeds and quiet time on mom's tummy, no dozing off in the comfort of a pampered hospital bead, no salt baths, no tea time. Just home, to a waiting, but very empty baby room.

Everyday is a *schlep*. Commuting to Panorama and back. Enduring the endless and frivolous Strauss waltzes that parody from the lift loudspeakers. Nothing makes sense.

We don't have a clue what to tell the children. We start off by saying "your brother is very ill, you will not be able to see him for a while…" My daughter, Angela, is beside herself with anger.

Both Ronél and I have a sense that we don't want anybody near us. We don't want our parents, people from the church, nobody – we just want space…

In the following week we are confronted with a seesaw ride of prognoses… precarious blood-oxygen levels, possible amputations, oedema - maybe he will last a few days, maybe he'll get a lung infection, maybe, maybe, maybe..

I am fed-up. A second opinion brings no hope, and I start to doubt the competency of the doctor. I also take the results of a brain scan to my friend, Piet the Psychiatrist – I need him to translate the report - in a nutshell: profound brain damage.

Days become a week during which we sway between life and death, hope and despair, to the point that, at day 4, we actively consider Euthanasia. Initially Philip could not breath effectively when placed on his back. So, finally, we convince the paediatrician to allow us to take him into a private ward, turn him on his back, and allow him to smother … the very next day, Philip can breath independently. This broken little boy is determined to live!

Back to work again.

In a way I cope well, make calls to resource centres and colleagues. At the bottom of all of this frenetic activity is the realisation that in no way will we be able to care for Philip within our home.

The next day we have an appointment at Woodside Sanctuary, a care facility for severely handicapped children. Officially they have no place for him – the waiting list is endless. We reassure them that it will only be for a short while and they relent. Well, a week became a month, a month became three months and three months became almost two years. Only at the age of 20 months did Philip decide that he had fulfilled his life task.

Woodside has a smell of its own. A mix between urine, sanitary soap, bleach, cooked soya and pumpkin, Jelly and custard. In its own way it is overwhelming and I wonder to myself "Should I leave my child here?"

We are received by Matron Bosson – a tall, reserved, matter-of-fact woman – we discuss finances, the unavailability of state subsidies, the fee of R900 per month, with extras for our account – things like Annique's rash cream, baby powder, soap, and clothes clearly marked…

Like Panorama Hospital, Woodside has tremendously long passages. Passages filled with the wrecks of Meningitis, near-drownings, assaults, profound cerebral palsy, micro-cephaly, extreme autism. In a way, I sense that my child will be at home here.

The following day we take the plunge and discharge Philip from Panorama and head for Woodside. The trip in the car is difficult. Philip's enlarged head is very unstable on his thin little neck and he has continual breathing difficulties. With a small blanket we try to hide him from the view of other motorists.

It is really hard to give up your parental responsibilities and lay it in the hand of foreigners. Having left Philip in a small Pinewood cot we drive back home, both in tears, angry and devastated. Again we return home with no child, no sense of achievement, no hope.

Very soon Angela, then 5, demanded to see her brother. Initially we are unwilling to allow this, but ultimately decide that openness is the best course of action. Angela was beside herself – she DOESN'T WANT THIS BROTHER, WE MUST GIVE HIM BACK! It would take several months of gradual exposure before she and her brother settled down and acclimatised to Philip and developed a relationship with him.

Giving up motherhood was particularly difficult for Ronél. For the first few months she tried so desperately to work, care for our children, do domestic tasks and still find the time to see Philip on a daily basis. Ronél has no clear recollection of the first six months following Philip's birth…

From the outset, I was very clear about the assistance Philip should receive. Accordingly I had to write the following letter:

> ***<u>INSTRUCTIONS REGARDING THE MEDICAL MANAGEMENT OF MY SON, PHILIP</u>***
>
> ***I hereby instruct you that my son may, under no circumstances be prescribed any antibiotics or other medication, apart from pain killers to alleviate his suffering. Nor may he be actively resuscitated should his condition deteriorate. Our only wish is that he be made as comfortable as possible.***

I suppose this is what Dads have to do, give instructions like this, and register births and deaths…

Initially we still tried to include Philip in our family life. On three occasions we attempted to bring him home – with disastrous results. Following the third visit, I decide NO MORE! I cannot deal with the frustration of Ronel's desperate and tearful attempts, lasting for two to three hours at a time, to get 50ml of milk down Philip's throat.

At the age of three months we take Philip to Red Cross Children's Hospital. In the midst of the Cape winter, with hundreds of day patients sheltering in passages against the onslaught of the rain, we find our way to wooden benches in the waiting area of Paediatric Neurology. Here we are confronted with the open curiosity of children and the sidelong glances of adults who can't quite believe what they see.

We meet the Prof and his assistant – they talk in muted tones. After the initial assessment, we make our way to the CT Scan. There Ronél sits with Philip – holding his head still. While I see her crying at his side, I also see for myself the immense dams of fluid in Philip's head. The Prof's response is simple and final, "Give him love and keep him warm".

Hope is lost. In a way this is very liberating, to give up all hope and expectations and to face life as it is.

Gradually Woodside brought its own pleasures:

Amidst recurring apnoea attacks, semi-comatose states and deteriorations, Philips started responding to music, singing along with gusto to the Halleluja chorus and Reggae music.

Saturdays became family days. In the inner courtyard of Woodside, amidst the falling leaves of Autumn we found a new sense of family and were able to re-establish our family cohesion.

Ultimately Philip occupied a unique position in Woodside. He became a favourite of many of the staff and was often spoilt with a treat or with chocolate

It took me 17 months to consent to a baptism. By consenting I finally give him permission to live and, by implication, to die. I don't recall much of the sermon, but remember vividly that the Reverend's attention and eye contact was directed exclusively at Ronél. This was on of many experiences where I perceived that people tended to respond to Ronél's emotions, but would disregard mine.

Philip passed away on 2 January 1997 and on the next day, our wedding anniversary we held a funeral service. I wait in the chapel until everyone has left, take a last look at the little white coffin and then purposefully walk out of the double doors and into the Cape sunlight.

Since then life has regained a sense of normality. Philip has left us enriched, saddened, scarred, and victorious. In short, he has had a profound impact on our lives and therefore, to this day, he rests in a place of honour, his ashes neatly encased in a little box placed within the fragrance of his mother's cupboard.

⁂

1 Introduction

This is the story of a very small proportion of the population: the parents of severely handicapped children in care facilities. Following many losses and crises, these parents have placed their fragile and profoundly handicapped children in the hands of professional caregivers and have reconstructed their lives whilst maintaining a relationship with the placed child (Bristor, 1984; Edelson, 1992; Irving, Kennell & Klaus, 1976).

Relatively little research has been directed at the stress and coping of families with severely handicapped, placed children.
Mothers have been the main focus of most studies, with much less attention being directed at examining the effects upon fathers (Byrne & Cunningham, 1985; Gallagher, Cross & Scharfman, 1981; Krauss, 1989).

S. Thomas Cummings (1976a), one of the pioneers in this field of research, points out that research on fathers of handicapped children is vital. He contends that it could assist service providers so that they are better able to:

(1) Mobilise family strengths and counter the effects of long-term family stress;
(2) Empower smaller modern families where both parents have almost exclusive caretaking responsibility for their children;
(3) Bolster modern fathers against the stressful effects of greater participation in the care of their handicapped children; and
(4) Adjust helping strategies according to the changing needs of parents as they move through their life cycle.

Although this study examines the stress and coping of both parents, there will be an attempt to add to the body of knowledge surrounding the father's stress and coping. This knowledge may be helpful in developing interventions that benefit not only the father, but could also contribute to the psychological well-being of the mother and the rest of the family. The above considerations emphasise the need for this study.

Early research (pre-mid-1970's) was characterised by a theoretical and 'pathological' approach which assumed that families caring for handicapped children were homogeneous and subject to high levels of debilitating stress. Researchers frequently disregarded major theoretical and methodological developments in closely related fields and their studies exhibited various methodological shortcomings. Recent research (post-mid-1970's) adopted a complex, multivariate and theory-driven approach that rejected the simplistic cause-effect relationship between stress and psychological impairment and emphasised the essential 'normality' of families (Beresford, 1994; Byrne & Cunningham, 1985; Beresford, 1994; Crnic, Friedrich & Greenberg, 1983; Du Toit, 1999; Holroyd & McArthur, 1976; Kazak, 1986).

Three distinct groups of researchers have contributed to recent research on families with handicapped children (Byrne & Cunningham, 1985).

- Group 1: This group sought to discover which families and family members are most vulnerable to the stress of having a handicapped child. Their main conclusion was that pathological stress does not necessarily occur in these families; instead, a combination of factors appears to predict family adjustment.

- Group 2: The second group suggests that unmet service needs cause family stress. Although limited by its a theoretical nature and methodological shortcomings, this group's research clearly illustrates that services are not regular, reliable and relevant; and

- Group 3: The third, most recent, approach recognises the fact that many families cope well and seeks to discover how they do so. This approach focuses on the family's material, psychological and social resources and their coping strategies.

This study on the stress and coping of parents with severely handicapped, placed children adheres to the approach of the third group.

The following chapters offer, firstly, a review of the relevant literature, secondly, a discussion of methodological issues and, thirdly, an empirical study of the stress and coping of parents of severely handicapped, placed children, which aims to:

- Assess the perceived stress, resources and coping strategies of parents who have placed their severely handicapped child in a care facility;

- Reveal how the fathers included in this study differ from the mothers in terms of their perceived stress, resources and coping strategies; and

- Provide guidelines to professional helpers who assist parents and, specifically fathers, of severely handicapped, placed children.

2 Literature review

Can parents possibly make sense of the birth and/or diagnosis of a severely handicapped child? How do they bear the stress of caring for such a child? Do fathers and mothers ultimately have a different experience of living through the life events that pertain to their severely handicapped child? Why do they hand the child over to professional care givers? Can they live a fulfilling life following the placement of their child? How can professionals help?

This chapter offers some insights into these questions by focussing on the following:

- A depiction of the presence of the severely handicapped child in the family as a systemically disruptive event which introduces complex and ongoing grief and continuing distress-generating crises into the parents' emotional landscape;
- A brief review of theoretical paradigms that refer to stress and coping; and
- The sources, mediators and outcomes of stress as they manifest in the parents.

2.1 The impact on the parents of the birth/diagnosis of the severely handicapped child

Figure 2.1 depicts the complete model of the grief and tension management of parents of severely handicapped, placed children.

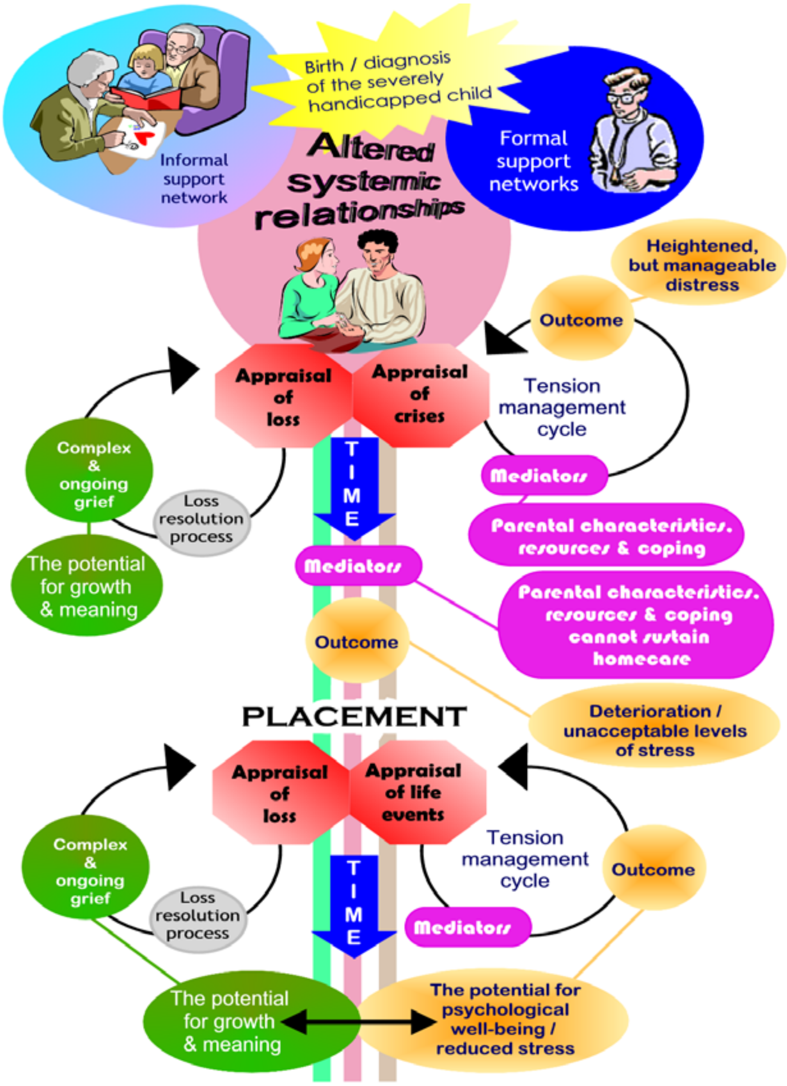


Figure 2.1: The grief and tension management of the parent of the severely handicapped, placed child

2.1.1 Grief – the response to loss

The birth- /- diagnosis of a severely handicapped child signifies the commencement of (2.1.1) a complex and ongoing grief process and (2.1.2) recurrent distress-generating crises (Arnstein, 1972; Farber, 1972; Goodnough & Lee, 1996; King, 1968; Roos, 1985).

Figure 2.2 represents the loss resolution process of the parent with a handicapped child.

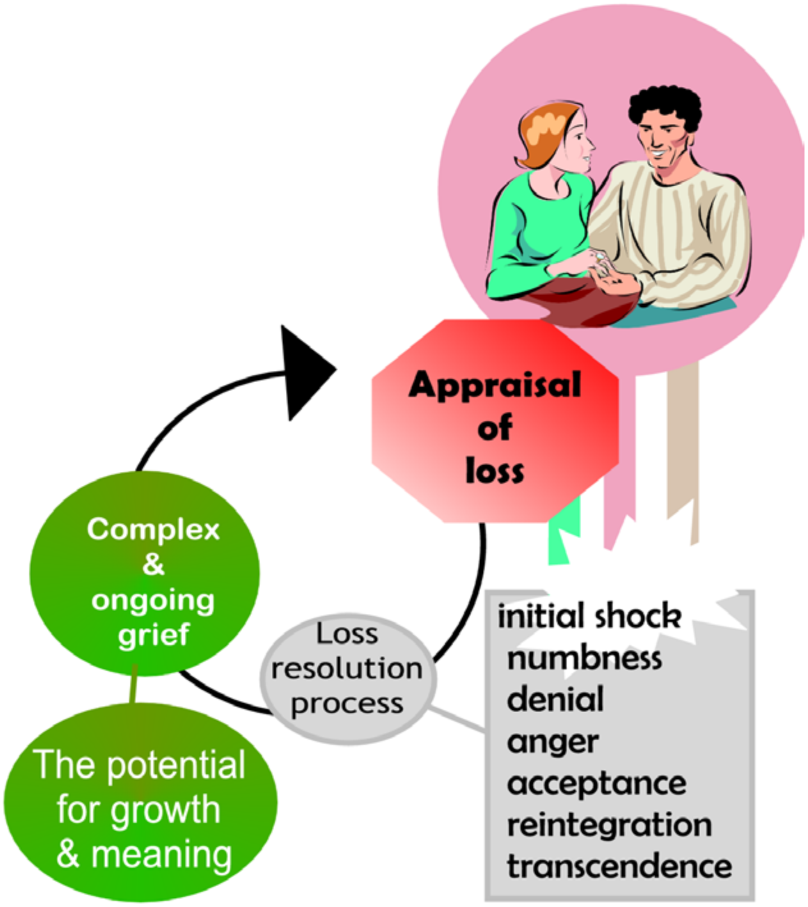


Figure 2.2: The loss resolution process

2.1.1.1 Theoretical considerations

2.1.1.1.1 The function of loss: adaptation and accepting new roles

Although normal pregnancy brings joy to the family, it also holds the potential for loss of existing roles. The grief that results from this loss enables the parents to disengage from former roles and accept new ones. The birth and/or diagnosis of a severely handicapped child can signify the start of a grief process during which parents may struggle to adapt to their situation and the new roles they are required to assume (Bristor, 1984; Elkins & Brown, 1986; Ellis, 1989; Gardner & Merenstein, 1986b; Lemons & Weaver, 1986; Olshansky, 1962; Roehner, 1976; Solnit & Stark, 1961; Wikler, Wasow & Hatfield, 1981).

2.1.1.1.2 Stages of grief

Many researchers in the field of handicapped children have developed stage theories to explain the sequence of parental responses to the birth- /diagnosis of a handicapped child. Most of these theories describe the parental grief process in terms of stages that move from initial shock and numbness through denial and anger to the final stages of acceptance and reintegration and eventual transcendence.

Stage theories have inherent difficulties when applied to the grief process of the parent with a handicapped child. Whereas they mostly presume a "*time-limited 'natural' progress through the stages*" (Davis, 1987, p.352), parents of a handicapped child experience ongoing grief.

Stage models may, therefore, distort and limit insight into this complex mourning process (Bradbury & Hewison, 1994; Bristor, 1984; Bullock, 1981; Drotar, Baskiewicz, Irvin, Kennell & Klaus, 1975; Elkins & Brown, 1986; Fortier & Wanlass, 1984; Jayashankarappa & Puri, 1984; Solnit & Stark, 1961; Stewart & Pollack, 1991).

2.1.1.2 The nature of parental grief

2.1.1.2.1 Anticipatory grief

A prenatal diagnosis of severe handicap may forewarn the parent about a potential loss situation. This anticipatory grief prepares the parents for and protects them against the psychological pain of impending loss and the further sorrow associated with participation in a doomed relationship. In extreme cases, anticipatory grief may render the parent unable to reattach should the neonate survive (Davis, 1987; Gardner & Merenstein, 1986b; Mölsä & Ikonen-Mölsä, 1985).

2.1.1.2.2 Grieving for the "perfect child"

The parent not only grieves for the real child, who is not as anticipated, but also for the fantasy child, the "*perfect child*", which was envisaged before the birth or diagnosis. The possibility of fulfilling these fantasies and entering into a fulfilling relationship with the child disappears with the birth- /- diagnosis of a severely handicapped child. By grieving, parents can separate from a significant lost dream (Bristor, 1984; Elkins & Brown, 1986; Gardner & Merenstein, 1986b; Pueschel, 1986; Solnit & Stark, 1961, p.524).

2.1.1.2.3 Grieving for the loss of a valued object

The unborn / or pre-diagnosed child also represents a valued object, which has already received the investment of parental love, care, hopes and dreams. Accordingly, the loss will result in grief that is comparable to the grief reaction when an infant dies (Gardner & Merenstein, 1986b).

2.1.1.2.4 Contradiction and ambivalence

The parent's grief is fraught with contradiction and ambivalence. As their child does not die, their grief experience cannot be resolved and they cannot reach a stage of emotional detachment. In addition, they do not receive the temporary respite normally granted to bereaved persons, but are required to assume a multitude of new roles and strenuous tasks.

Lack of validation, insensitive social attitudes, previously unresolved grief and cultural scripting could form barriers in the resolution of the grief process. This ambivalent and contradictory stress encounter can rapidly affect the parent's psychological and physical well-being. As a result, parents may desperately seek relief by accepting simple and immediate answers of well-meaning professionals to problems that mostly have only long-term and complex solutions (Bowlby, 1979; Davis, 1987; Elkins & Brown, 1986; Garland 1986; Goldberg, Morris, Simmons, Fowler & Levinson, 1989; Moses, 1983; Trout, 1983).

2.1.1.2.5 Chronic sorrow

As the child fails to meet the milestones of non-handicapped children, the parent may experience an ongoing and cyclic grief process, termed by Olshansky (1962, p.190) as a "*chronic sorrow*".

Chronic sorrow presents in most, if not all parents of severely handicapped children, irrespective of whether the child is in care or not. Many factors such as a parent's personality, ethnic group, religion and social class influence the intensity of this sorrow (Davis, 1987; Olshansky, 1962; Pueschel, 1986; Trout, 1983).

Wikler *et al* (1981; 1983, p.313), whilst reaffirming the concept of chronic sorrow as a normal, non-pathological reaction to the birth of a handicapped child, noted that, for some parents, "*being the parent of a retarded child had been a strengthening rather than a debilitating experience*".

Society, discounting chronic sorrow, may exacerbate parental stress by expecting parents to cease grieving once the initial crisis is over and encouraging them to assume a heroic and dedicated caretaker role. Professionals may reinforce the belief that extended grief is unacceptable by initially encouraging crying, but then prescribing sedatives to suppress further grieving behaviour (Kennedy, 1970; Voysey, 1975).

2.1.1.2.6 The grief-relief phenomenon

Parents may on the one hand grieve for the child, but at the same time they may also wish to be released from this suffering. When the child does die there may be a rapid movement to the relief stage. This is the grief-relief phenomenon (Bullock, 1981).

2.1.1.3 The potential for growth and meaning

2.1.1.3.1 Resolution of grieving tasks

The parents of handicapped children are confronted with new psychological conflicts, the resolution of which may contribute to their psychological well-being. Roos (1985) depicts these as follows:

- **Disillusionment vs Hope:** For them to stay positive, parents need to reassess and possibly redefine their values, establish new priorities, engage in constructive problem-solving and strive to maintain equilibrium.
- **Aloneness vs Intimacy:** Parents cannot fulfil their need for complete "intimacy" with the handicapped child and may feel isolated as a result. Once they learn that their feelings of isolation and loneliness do not reflect anything about them, but are more indicative of other people's inability to cope with their child's handicap, these feelings are resolved.
- **Fear of Vulnerability vs. Acceptance of Vulnerability:** Parents experience a sense of helplessness and vulnerability - an all-encompassing loss. They now need to accept their vulnerability so they can assess problem areas and make major decisions without fear.
- **Fear of Inequity vs. Acceptance of Inequity:** To some parents the birth of a handicapped child may represent retribution for a past deed. Feelings of blame, guilt and worthlessness assault the parents' perceptions of their basic moral, ethical and religious beliefs. Once parents learn not to view the event of the child's handicap as catastrophic and accept the inequities of life, they can develop a positive attitude about the child.

- **Insignificance vs. Purpose:** The birth/diagnosis prompts parents to reassess their own significance and that of the child. They question the meaning of life, battle to appreciate a seemingly senseless birth and have to accept that not everything in life is fair or explicable.
- **Past Orientation vs. Optimistic Present and Future Orientation:** These parents frequently fear the future. Realistic preparation could help relieve some of these fears.
- **Loss of Immortality vs. Growth in Awareness of Life:** The parents are simultaneously confronted with the finiteness of life as well as a loss of identity. Resolution lies in the discovery of the significance of life.

2.1.1.3.2 Making sense of the loss

Ultimately, parents need to find some meaning in the life and death of their severely handicapped child.

One such father writes:

> “*Life goes on, and yet somehow it will never be the same. I have certainly learnt a great deal about the brevity of all human endeavours. Although the pain associated with my daughter's death still returns,*
> *I am glad that she died in a peaceful way among caring people.*
>
> *Laura Lin taught me a great deal about the meaning of love. She demanded so much of us, and yet gave so much in return. My only wish is I could tell her just one more time how much I love her…*

> *Perhaps my pain and openness will help others see the love which we all ultimately share, as part of the human family. Life itself goes on, and in its ongoingness there is much beauty. Indeed, I know I do not understand, but I am just beginning to appreciate life in all its infinitely varied forms. Laura Lin, I love you. Peace.” (Marburg, 1985, p.12)*

2.1.1.4 Parental grief within the socio-ecological context

2.1.1.4.1 Altered systemic relationships

The impact of the grief process on the socio-ecological system is illustrated in Figure 2.3

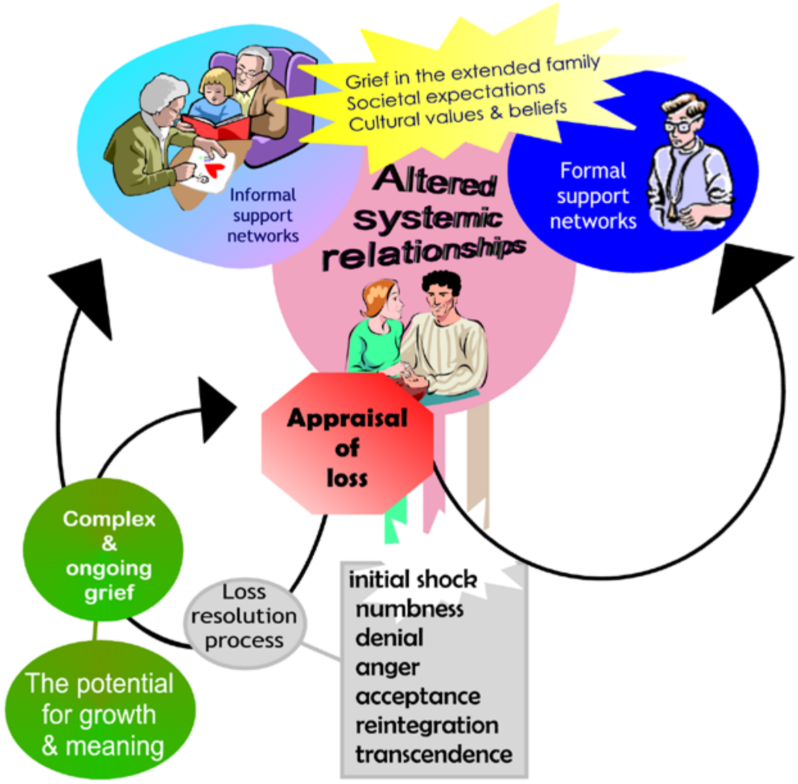


Figure 2.3: Altered systemic relationships

The arrival of the severely handicapped child touches the immediate and extended family and affects the relevant helping professionals and service providers, the staff of the care facility and - in a broader context - the policy- makers of care-giving institutions and the government (Bronfenbrenner, 1979).

2.1.1.4.2 Parental isolation

After the birth of a severely handicapped child, the parents may feel isolated. They may withdraw from others in the belief that no one else has ever experienced their overwhelming loss and disappointment, thus intensifying their loneliness and isolation. These negative responses increase the parents' pessimism about the situation and the child (Gardner & Merenstein, 1986b).

2.1.1.4.3 Grief in the extended family

Sometimes a pregnancy has a special significance for the extended family. When a severely handicapped child is born or diagnosed, the family too has to deal with the immediate shock and pain and with the loss of the idealized normal child (Gericke, Op't Hof, Torrington, Graham, Edwards & Van der Vyver, 1983).

2.1.1.4.4 Societal expectations

The societal expectations and management of parental grief differ according to the gender of the parent. Fathers, more so than mothers, are expected by society to "*bear up splendidly under tragic circumstances*" (DeFrain, Taylor & Ernst, 1982, p.25). As the father attempts to be this tower of strength, the mother may view his seeming lack of feelings and emotions as an indication that he does not care. This adds tension to the spousal relationship.

Society's lack of validation for paternal grief may partly rest in the fact that women more easily express grief-related symptoms than men tend to do. This may lead society to believe that the father is coping with the loss and needs less support. The above-mentioned societal expectations and pressures, together with the lack of validation could complicate an already complex grief process, putting the father at greater risk for inner conflict and feelings of defectiveness, inferiority or inadequacy (Gardner & Merenstein, 1986a; Garland, 1986; Stearns, 1984).

2.1.1.4.5 Cultural values and beliefs

Existing cultural values of physical beauty, intelligence and success may further exacerbate the parents' grief for the 'perfect child'. This may drive parents to frantically search for a cause. Lack of a clear diagnosis and aetiology could foster the development of irrational beliefs regarding the cause and course of the handicap. This, in turn, may lead to increased self-blame and spousal conflict (Gardner & Merenstein, 1986b; Trout, 1983).

Across cultures there are some commonalities and contrasts in how severely handicapped children are viewed. In a review of a Greek, South African-Zulu, Mexican-American and Chinese-American studies there were three common tendencies:

- firstly the parents experience a similar grief processes;
- secondly they seek recourse to traditional beliefs, cures and practices and;
- thirdly they hold religion-based attributions.

Mexican-American and South African-Zulu parents also held other views of socio-cultural causation, namely, premonitions, prior attitudes and past transgressions. Greek and Chinese-American parents were especially concerned with planning for the future and coping with financial burdens. Dissimilar to non-Asian parents, Chinese-American parents did not recognise their child's handicap as early as preferable (Kotsopoulos & Matathia, 1980; Mabaso & Uys, 1990; Mardiros, 1989; Ryan & Smith, 1989).

The profound trauma of a significant loss can trigger a resurgence of the traditional values that inhibit grief (Garland, 1986).

2.1.2 Recurrent distress-generating crises: Theoretical considerations

The tension management cycle is depicted in Figure 2.4.

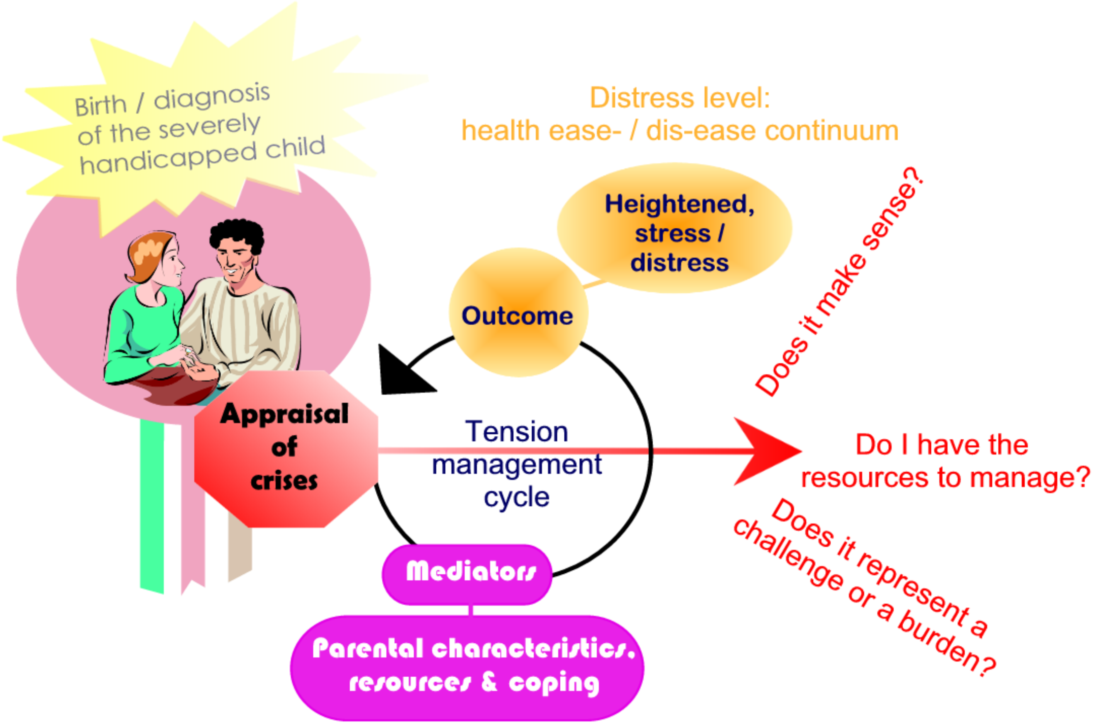


Figure 2.4: The tension management cycle

2.1.2.1 The definition of distress

The birth and/or diagnosis of a severely handicapped child represent a major life event, a crisis point, beyond which parents may appraise their present norms and customary problem-solving techniques as ineffective and completely lacking. This event and the resultant crises occur within a socio-ecological context with its own unique cultural qualities that prescribe parental responses and denote possible imbalance, harm, threat or challenge.

This distress and stress in general can thus be defined as a particular transactional relationship between the person and the environment. Ongoing distress elicits recurrent crisis resolution behaviour (Antonovsky, 1987; Folkman, 1984; Folkman & Lazarus, 1985, Folkman *et al*, 1986; Lazarus, 1974; Slavin, Rainer, McCleary & Gowda., 1991).

2.1.2.2 Two opposing paradigms in stress theory

Two opposing paradigms in stress theory, namely pathogenic and positive psychology, shed light on the parents' response to the ongoing situation of the severely handicapped child.

2.1.2.2.1 The pathogenic paradigm

The term pathogenic refers to a paradigm that sees stress as a negative influence that creates disease, requires diagnosis and demands intervention. Pathogenic models, such as the Process Model of Lazarus (1974), have been the dominant paradigm in psychology for many years. Although the pathogenic paradigm has been valuable in the description of mental illness and generation of various interventions, this study departs from a positive point of view.

Researchers have shown that parents of severely handicapped, placed children can remain resilient (Antonovsky, 1979, 1987; Blacher & Baker, 1994; Seligman & Csikszentmihalyi, 2000; Selye, 1974; Widerstrom & Dudley-Marling, 1986; Wikler *et al*, 1983).

2.1.2.2.2 Positive psychology

Positive psychology developed out of the strong belief that

> "*Psychology is not just the study of pathology, weakness and damage; it is also the study of strength and virtue. Treatment is not just fixing what is broken; it is nurturing what is best.*" (Seligman & Csikszentmihalyi, 2000, p.7).

This paradigm encompasses models of stress and coping that emphasise the nature, maintenance and development of psychological health, strength and subjective well-being.

A number of developments within psychology and related fields have led to articulation of this approach, namely,

1. The greater emphasis on primary intervention;
2. The development of Health Psychology;
3. The growth of humanistic trends in psychology;
4. The movement towards in eclecticism in psychology;
5. The increasing demand for accountability and relevance in psychology; and
6. The economic reality that prevention is cheaper than cure (Antonovsky, 1979, 1987; Diener, 2000; Pretorius, 1998; Strümpfer, 1990, 1995; Van Eeden, 1996).

2.1.2.2.2.1 Salutogenesis

Aaron Antonovsky (1979, 1987) asked the fundamental question of what people do to remain psychologically healthy despite adversity. He named this field of study Salutogenesis and subsequently developed the concept of a Sense of Coherence (SOC), a disposition defined as:

> "*A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, explicable; the resources are available to one to meet the demands posed by these stimuli; and these demands are challenges, worthy of investment and engagement.* " (Antonovsky, 1987, p.19).

The SOC constitutes three core concepts (Antonovsky, 1987, p.18):

- **Comprehensibility:** The extent to which one perceives internal and external stimuli as

  > *"clear, ordered, structured and consistent information and on the basis of which he or she can expect that these stimuli will in future also be orderable, explicable and even predicable. It means that the perceptions make cognitive sense."*

- **Manageability:** The degree "*to which one perceives that resources are at one's disposal which are adequate to meet the demands posed by the stimuli that bombard one*"; and

- **Meaningfulness:** The extent to which the person feels that life makes sense emotionally, rather than cognitively. At least some of life’s problems and demands are felt to be welcome challenges rather than burdens, motivating one to invest energy.

The stronger a person’s Sense of Coherence (SOC) the lesser the general tendency to respond to stressors with anxiety and the greater the individual’s ability to remain healthy and maintain his or her position on the health ease/dis-ease continuum. The SOC seems to have a greater ameliorating effect in ego-threatening situations than in situations where a whole community experiences threat. Given that having a severely handicapped child may be more of an ego-threatening nature, the SOC may in fact buffer the parent against excessive anxiety (Antonovsky, 1987; Antonovsky & Sagy, 1986; Gottlieb, 1998; Strümpfer, 1990).

People that have a strong SOC view their entire world as comprehensible, manageable and meaningful. They set boundaries outside which events do not trouble them.

Four spheres need however be included if parents are to maintain a strong SOC, namely, their own feelings, immediate interpersonal relations, the major sphere of activity and existential issues such as death, inevitable failures, shortcomings, conflict and isolation. The degree of individual/personal flexibility about the life areas that need to be included within these boundaries may be one of the most effective ways of maintaining a coherent view of one's world (Antonovsky, 1987).

2.1.2.2.2.2 Fortigenesis

Strümpfer (1990) analysed Salutogenesis and other related concepts, such as hardiness and learned resourcefulness. He found that they all point to the underlying construct of strength ie that which makes people psychologically strong to ward off stress and to remain resilient. Subsequently he developed the concepts of Fortigenesis: a study of the origins of psychological strength- and fortitude, a descriptive term for psychological strength. Furthermore, he contended that Fortigenesis was a more descriptive term than Salutogenesis. Individuals with fortitude,

i.e those who cope well with stress and exhibit low levels of depression, have positive appraisals of the self, the family and the support of others and, consequently, are more able to cope with life stress (Antonovsky, 1979, 1987, 1991; Kobasa, 1979, 1981; Pretorius, 1997, 1998; Rosenbaum, 1990; Strümpfer, 1995).

Further analysis of Salutogenesis and Fortigenesis led Van Eeden and Wissing (1994), to develop the term psychofortology. This construct refers to psychological well-being that derives from intra-psychic aspects, such as self-concept and certain cognitive and affective qualities, interpersonal factors, as well as broader social and contextual factors and values.

2.1.2.2.2.3 From struggling against adversity to finding happiness in everyday life

Both Salutogenesis and Fortigenesis refer to dispositional characteristics that keep people psychologically healthy and strong in times of adversity and stress.

To a lesser degree these fields of study reflect concerns with the questions of (1) what keeps normal people happy and content under normal circumstances and (2) "*what makes life worth living*" (Seligman & Csikszentmihalyi, 2000, p.5). These issues are, however, central to the focus of Positive Psychology.

Seligman and Csikszentmihalyi (2000, p.5) define the nature of Positive Psychology very eloquently.

They state:

> *"The field of positive psychology at the subjective level is about valued subjective experiences: well-being, contentment and satisfaction (in the past); hope and optimism (for the future); and flow and happiness (in the present). At the individual level, it is about positive individual traits: the capacity for love and vocation, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future-mindedness, spirituality, high talent, and wisdom. At the group level, it is about civic virtues and the institutions that move individuals toward better citizenship: responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic."*

It could certainly be the ideal of any intervention to foster the above in the parent of the severely handicapped, placed child.

2.1.2.3 Three conceptual domains in stress theory

Most models of the stress process include three conceptual domains, namely, the sources, mediators and the outcomes of stress and emphasise the appraisal process as it relates to these domains.

These factors are fundamental in crisis resolution and operate in a feedback system and will in this study be referred to as the **tension management cycle** (See Figure 4, p.18) (Aguilera, 1990; Antonovsky, 1979, 1987; Folkman, Lazarus, Gruen & DeLongis, 1986; Patterson, 1988; Pearlin, Lieberman, Menaghan & Mullan, 1981; Pearlin & Schooler, 1978).

2.1.2.3.1 The source of stress

According to transactional models of stress, of which Salutogenesis (Antonovsky, 1979, 1987) is an example, stress arises from the appraisal process. This is depicted in Figure 2.5.

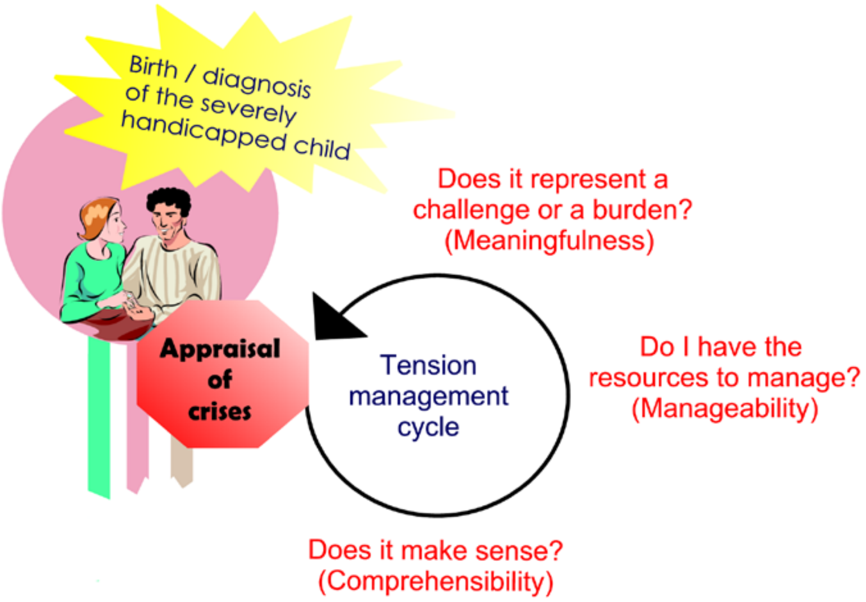


Figure 2.5: The sources of stress

Stress arises from the cognitive and emotional appraisal of three interlinked sources, namely,

- Stimuli that are appraised as introducing imbalance or "*entropy into a system – that is, a life experience characterised by inconsistency, under- or overload, and exclusion from participation in decision making*" (Antonovsky, 1987, p.28);
- The appraisal of the extent to which internal and external resources provide opportunities for gratification, potential for frustration or harm and are adequate to meet the demands posed by the stress-generating stimuli (see Figure 5); and
- The extent to which the demands are felt to be welcome challenges (see Figure 5) rather than burdens, motivating one to invest energy (Antonovsky, 1987; Pretorius, 1998).

Within the context of Salutogenesis and Fortigenesis, appraisal determines the emotional responses and coping activities of parents with severely handicapped children by mediating in the transaction between parents and their internal and external environments. These responses and activities may differ between mothers and fathers, are not necessarily dysfunctional and do not inevitably lead to family maladjustment (Antonovsky, 1987; Fong, 1991; Gardner & Merenstein, 1986b; Klaus & Kennel, 1976; Parke & Beitel, 1988; Price-Bonham & Addison, 1978; Strümpfer, 1990; Widerstrom & Dudley-Marling, 1986).

Parents of severely handicapped children actively seek for meaning on a cognitive and emotional level. Unfortunately, for most of these parents there are no ready answers compounding their sense of guilt and increasing the likelihood of parental conflict.
In their pursuit of a precise diagnosis many parents fail to adapt to the needs of the present and future. Often professionals further confuse parents by making countless referrals to other experts in order to obtain a precise diagnosis. For some parents the search for meaning has been helpful: An explanation for the handicap brings relief (Bradbury & Hewison, 1994; Bradbury & Hewison, 1994; Russel, 1981; Waskowitz, 1959).

In order to accept a handicapped child, parents need to appraise this event in a way that buffers against stress. Within their own cultural and idiosyncratic family context, they also have to re-appraise their ideas about life, their coping options, available social resources and stress outcomes so that they can master the difficult task of accommodating the handicapped child within their family structure and future planning (Leyser, Heinze & Kapperman, 1996; McCubbin, Thompson, Thompson, Thompson, Elver & McCubbin, 1998; Minde, Hackett, Killou & Silver, 1972; Slavin *et al*, 1991; Viljoen, 1975).

2.1.2.3.2 The mediators of stress

The position of the mediators of stress in the tension management cycle is illustrated in Figure 2.6.

2.1.2.3.2.1 Systemic characteristics and resources

Research into the interaction between the handicapped child and family reveals a complex exchange between the individual members and a series of subsystems. Each of these, especially the child, the parent and the support structures, have inherent characteristics and offer resources that can contribute to or buffer against the parent’s stress.

Antonovsky (1979, p.99) defines these characteristics, named generalized resistance resources (GRRs), as “*any characteristic of the person, the group, or the environment that can facilitate effective tension management*”.

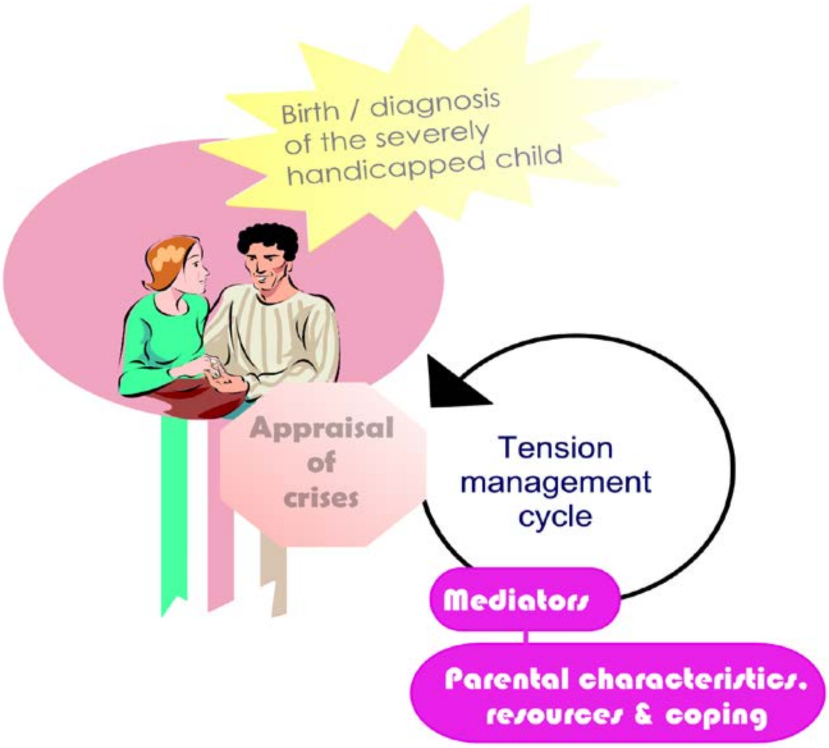


Figure 2.6: The mediators of stress

The parent utilises GRRs to interpret stressors and to effectively manage tension in any situation of demand. By repeated utilisation of GRRs, the parent develops, over time, a strong sense of coherence (Antonovsky, 1979, 1987; Bronfenbrenner, 1979; Kazak, 1986; Sloper, Knussen, Turner & Cunningham, 1991; Yura, 1987).

Parents of handicapped children, although similar to parents of non-handicapped children in many respects, may be more reliant on available resources and the efficacy of informal and formal support systems. They will also make more innovative use of available internal and external resources in their life-long adjustment to caring for a severely handicapped child.

Limited access to these resources may increase the parents' vulnerability to stress which, in turn can deplete resources, again increasing vulnerability. The parent's cognitive appraisal of the resource will ultimately determine its function and the consequent coping strategy.

Most research has focused on the external resources of parents as they are relatively easy to measure. Personal resources are often more elusive and subtle and have been research to a lesser degree until recently (Antonovsky, 1979, 1987; Barakat & Linney, 1995; Beresford, 1994; Fortier & Wanlass, 1984; Frey, Greenberg & Fewell, 1989; Jenkins, 1979; Kobasa, 1979; Kobasa, Maddi & Courington, 1981; Levitz, 1992; Pueschel, 1986; Shapiro, 1983; Sloper & Turner, 1993; Strümpfer, 1990, 1995; Waisbren, 1980).

2.1.2.3.2.2 Coping strategies and behaviours

2.1.2.3.2.2.1 The definition of coping

Antonovsky (1979, p.112) defines a coping strategy as "*an overall plan of action to overcome stressors*". He distinguishes between the terms coping strategy, which indicates an overall plan, as opposed to the specific coping behaviours that may be part of a tension management plan. According to this formulation, a coping response is an action, thought, verbalisation or feeling brought forth by a particular stressor. This implies that people are actively responsive to forces that affect their lives (Pearlin *et al*, 1981; Pearlin & Schooler, 1978).

2.1.2.3.2.2.2 The role of appraisal

In order to galvanise their resources, coping strategies and behaviours, parents employ an appraisal process. In terms of the SOC, this refers to appraisal inherent in the aspect of manageability (Antonovsky, 1979).

2.1.2.3.2.2.3 The functions of coping

Coping has two major functions: (1) dealing with the problem that is causing the distress (problem-focused coping), and (2) regulating emotion (emotion-focused coping).

People use **problem-focused coping** more frequently in encounters that they appraise as changeable. **Emotion-focused coping** prevails when people feel that the stressor is something that must be endured. This form of coping, which occurs when direct action is either too costly to undertake or when the person cannot manage the environmental transaction, focuses on ways of reducing the affective, visceral or motor distress.

By controlling the distress, the person can improve the prospects for coping with the basic problem. Depending on the context, one coping strategy can fulfil a problem-focused and emotion-focused function (Beresford, 1994; Carver, Scheier & Weintraub, 1989; Folkman, 1984; Folkman & Lazarus, 1985; Folkman *et al*, 1986; Lazarus, 1974; Pearlin & Schooler, 1978; Petrosky & Birkimer, 1991).

Problem-focused and emotion-focused coping is by no means a simplistic distinction and can entail various and divergent coping behaviours. Problem-focused coping can potentially include several distinct activities: planning, taking direct action, seeking assistance, screening out other activities and even forcing oneself to wait before acting.

Emotion-focused responses can involve denial, positive reinterpretation of events and the eliciting of social support. These responses are very different from each other, and they may have very different implications for a person's success in coping (Beresford, 1994; Carver *et al*, 1989).

2.1.2.3.2.2.4 Coping efficacy

In determining coping efficacy, both coping behaviours and the context within which the behaviour occurs should be considered. Not all contexts offer similar coping mechanisms and resources and different persons and groups have unequal success in dealing with the same set of stressors (Pearlin & Schooler, 1978).

Effective copers possess three skills, namely, **rationality** (the ability to accurately perceive their situation), **flexibility** (the willingness to generate new or consider available alternative coping strategies) and **farsightedness** (the ability to anticipate the long-term consequences of each coping strategy). They also have **more social support**, which in turn facilitates coping (Antonovsky, 1979; Sloper *et al*, 1991).

Achieved status as well as higher levels of education and occupation predicts better coping. Less educated, poorer parents of handicapped children have more hardships and fewer resources with which to cope (Pearlin & Schooler, 1978; Mabaso & Uys, 1990).

There are contradictory findings with regard to the predictive value of dispositions considering coping efficacy. Coping behaviours may be most effective within the close interpersonal context of marriage and parenting, whereas dispositional factors, such as personality traits could be more efficient in dealing with economic and occupational problems.

Other findings suggest that personality traits are not likely to be useful as predictors of coping. With the development of Positive Psychology it became clearer that dispositional factors such as the Sense of Coherence and Fortitude could predict the nature of coping (Antonovsky, 1979, 1987; Carver *et al*, 1989; Folkman & Lazarus, 1980; Pearlin & Schooler, 1978; Pretorius, 1997, 1998; Strümpfer, 1995).

2.1.2.3.2.2.4.1 Effective coping strategies

Effective coping strategies alleviate the problem and reduce emotional distress. It leads to better personal adjustment and suggest family strengths. If used to manage emotions that hinder problem solving emotion-focused coping- can facilitate effective and active problem-focused coping such as planning, direct problem-solving, information seeking, cognitive restructuring and self-praise (Beresford, 1994; Judge, 1998; Miller, Gordon, Daniele & Diller, 1992; Pearlin & Schooler, 1978; Sloper *et al*, 1991).

Educated and affluent persons, especially males, generally make more use of effective coping mechanisms. Individuals' coping interventions are most effective when dealing with problems within the close interpersonal role areas of marriage and child rearing. In the area of parenthood and marriage, self-reliant and involved parents, who (1) believe they can exert a potent influence over their child’s life, (2) adhere to reflective and probing problem-solving strategies, (3) are able to manipulate their goals and values and (4) are able to gather support from others without having to ask for it, will cope better (Pearlin & Schooler, 1978).

2.1.2.3.2.2.4.2 Ineffective coping strategies

Coping is least effective in “*areas of life, such as a job, that are impersonally organised and in which the forces affecting people are beyond the personal coping controls*” (Pearlin & Schooler, 1978, p.10).

2.1.2.3.2.2.5 Coping research

The method of research may determine the identification, description and measurement of coping strategies: Qualitative techniques often reveal a range of coping strategies, whereas strictly quantitative multi-variate studies utilising coping questionnaires only provide a predetermined list of coping strategies and behaviours.

Much data regarding the coping of couples may be invalid as fathers and mothers have been expected to complete similar, mother-orientated questionnaires. Often measures of coping strategies fail to evaluate resource maintenance coping strategies (Beresford, 1994).

2.1.2.3.3 The outcomes of stress

The position of the outcomes of stress in the tension management cycle is illustrated in Figure 2.7.

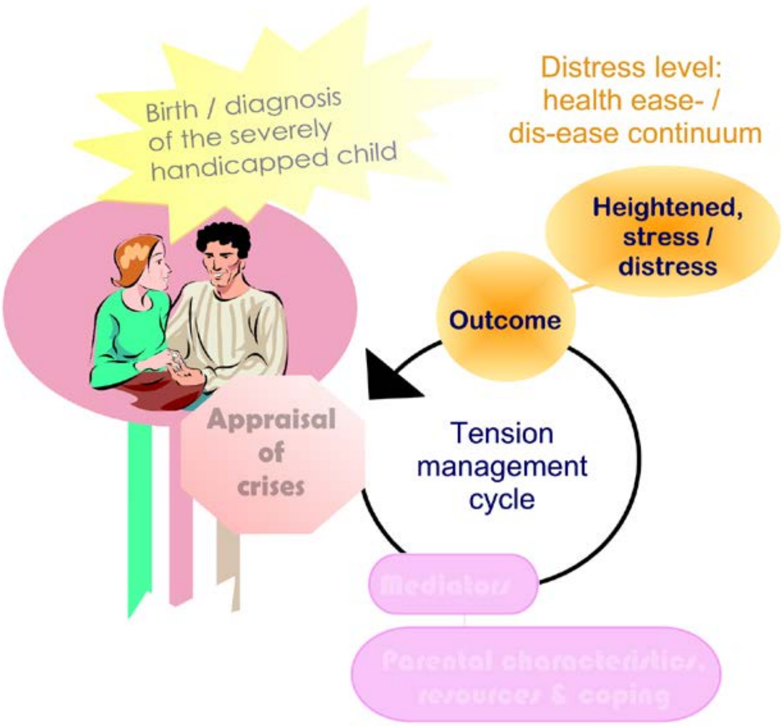


Figure 2.7: The outcomes of stress

In terms of the Salutogenic Model of Antonovsky (1979, 1987), a positive outcome would be related to the parents' ability to maintain or improve their position on the health ease/disease continuum.

These would be parents who, through their ability to

(1) Appraise the stress generated by the birth and/or diagnosis of a severely handicapped child as something that can be resisted, avoid threat or life-endangering activities and engage in behaviours that promote health;

(2) Perceive their stressors as manageable, consequently selecting and utilising appropriate resources instead of responding with helplessness; and

(3) Approaching this major life event as a challenge worthy of engagement and the investment of energy instead of as a paralysing threat that leads to negative behaviour, have secured and reinforced their position on the health ease/disease continuum.

The Fortigenic Model predicts that those parents who have been able to stay positive in their appraisals of themselves, their families and their support systems, have succeeded in coping with the stress of having a severely handicapped child (Pretorius, 1998). The presence of high levels of fortitude can enable the father and mother to stay psychologically strong and healthy despite the adversity of having to deal with the ongoing crisis of having and caring for a severely handicapped child.

Outcome may change with time. A coping strategy, which relieves immediate distress, may also be the cause of later difficulties (Beresford, 1994).

2.2 Research findings on the mediators and outcomes of parental stress

The stress and coping process will be examined within the systemic context of the family and its subsystems, the child, the couple, the mother and the father. Lastly the stress and coping of the single parent will be considered.

2.2.1 Child-related characteristics

Various researchers have investigated the impact on parents of the specific alterable and unalterable characteristics of handicapped children. These are represented in Figure 2.8.

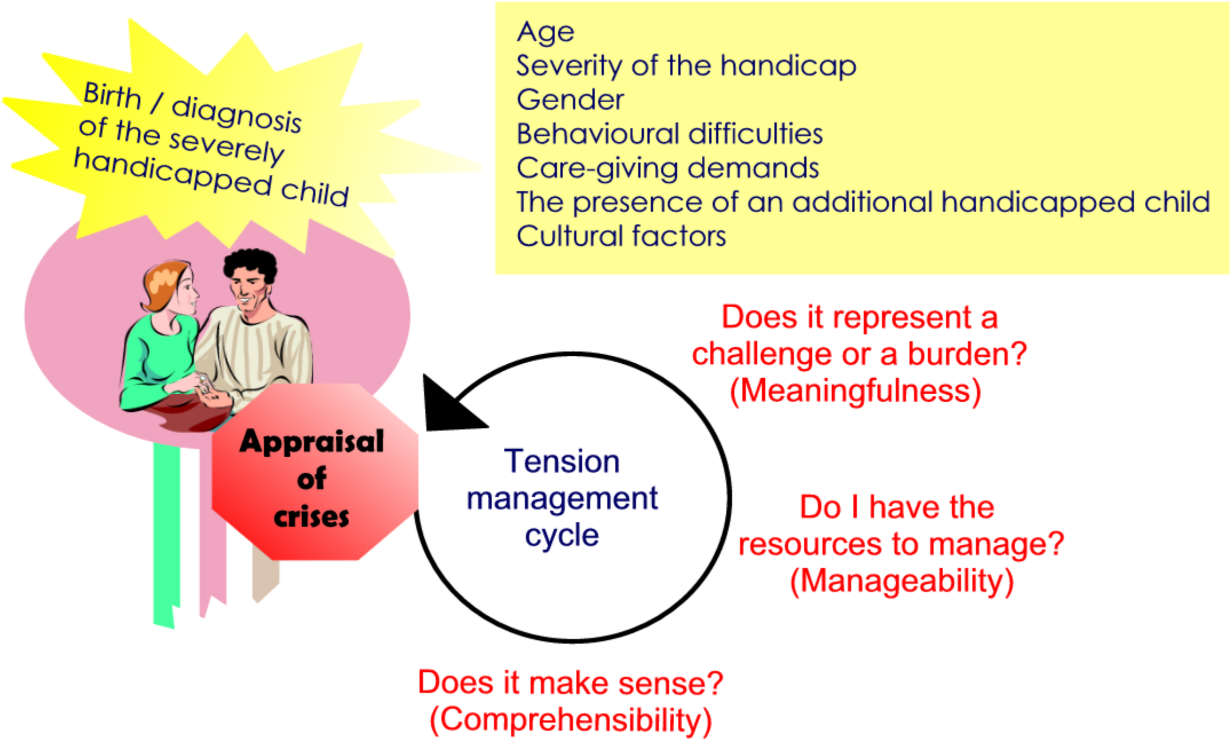


Figure 2.8: Child-related characteristics

The majority of these studies focussed on the responses of the mother and found that factors such as the age, severity and nature of the handicap, gender of the child, behavioural difficulties and care-giving demands impact on the stress of the parents.

Severely handicapped child may have many of the researched characteristics. Given this, it puts the parents at great risk for very high levels of stress, especially if they are not prepared for the birth of a handicapped child and if the child is both severely handicapped and chronically ill. However this does not mean that they will be unable to cope with or establish meaningful relationships with the handicapped child.

The greater prevalence of child-related stressors may urge parents to consider placement at an earlier stage of the handicapped child's development (Barakat & Linney, 1992; Beckman, 1983; Beckman-Bell, 1981; Benson, Gross, Messer, Kellum & Passmore, 1991; Bouma & Schweitzer, 1990; Bromley & Blacher, 1991; Bradbury & Hewison, 1994; Cole & Meyer, 1989; Cummings, 1976a; Eyman, O'Connor, Tarjan & Justice, 1972; Farber, 1972; Fong, 1991; Frey, Fewell & Vadasy, 1989; Frey, Greenberg & Fewell, 1989; Gallagher, Beckman & Cross, 1983; German & Maisto, 1982; Goldberg *et al*, 1989; Hanson & Hanline, 1990; Holroyd & McArthur, 1976; Karraker, Vogel & Lake, 1995; McLinden, 1990; Mölsä & Ikonen-Mölsä, 1985; Parke & Beitel, 1988; Seltzer & Krauss, 1984; Slobody & Scanlan, 1959; Sloper *et al*, 1991; Tausig, 1985; Waisbren, 1983; Widerstrom & Dudley-Marling, 1986; Wishart, Bidder, & Gray, 1980).

2.2.1.1 Age

Older children are more difficult to manage and therefore more demanding. Parents' motivation to place may increase as the child ages. Fathers seem to be less stressed by their older children (Cummings, 1976a; Farber, 1972; Gallagher, Beckman & Cross, 1983).

2.2.1.2 Severity of the handicap

The severity of the handicap does not necessarily affect the nature of the parental response (Mölsä & Ikonen- Mölsä, 1985), but where children present with visible congenital disfigurement, a low level of competence, chronic psychological disorder, a slow rate of development, a lack of social responsiveness, poor or non-existent communication skills and a particular collection of temperament characteristics, parents are more likely to experience a disruption of parent-child relationship.

These parents are less likely to (1) feel parental warmth and acceptance towards the child and (2) perceive adequate and satisfying family and social support. Fathers, especially, are more sensitive to the lack of communication skills, particularly if the child is a boy. Parents of more severely children handicapped prefer full time care. Children with an IQ below 53 who are more demanding in daily management and more physically disabled are more likely to be placed (Beckman-Bell, 1981; Benson *et al*, 1991; Bouma & Schweitzer, 1990; Bradbury & Hewison, 1994; Daniels & Berg, 1966; Gallagher, Beckman & Cross, 1983; Holroyd & Guthrie, 1979; Holroyd & McArthur, 1976; Wishart *et al*,1981).

2.2.1.3 Gender

Parents of handicapped boys may experience more stress in their marital relationship. As handicapped boys age, they become more difficult to manage than girls. Fathers experience more stress if the child is male and non-communicative. There is no significant difference between the number of boys and girls that are placed (Farber, 1972).

2.2.1.4 Behavioural difficulties

Parents of aggressive, self-injurious handicapped children, who present with stereotyped behaviour patterns and tantrums, are more likely to experience high levels of stress. Although high levels of behaviour problems correlate with the high stress in the parent, low levels of behaviour problems do not necessarily represent a positive factor. The presence of more extreme behaviour difficulties would however strongly predispose a family to place a child in a care facility (Beckman, 1983; Bristol & Schopler, 1983; Sloper *et al*, 1991).

2.2.1.5 Care-giving demands

The greater and more unusual the care-giving demands of the handicapped child, the higher the parental stress. Care-giving demands is the variable most highly related to the presence of parental stress. Fathers seem to be less affected by the caretaking demands of the child.

As severely handicapped children grow, parents may have increasing difficulty to meet their needs and may ultimately decide to place the child in full time care. The medical needs of severely handicapped children may play a central role in determining placement. The family may battle to keep up a schedule of visits to therapists, whereas care facilities are better positioned to provide these services with minimal strain on and disruption to the family (Beckman, 1983; Beckman-Bell, 1981; Gallagher, Beckman & Cross, 1983; Quittner, DiGirolamo, Michel & Eigen, 1992).

2.2.1.6 The presence of an additional handicapped child

Mothers who have more than one handicapped child are more inclined to place the handicapped child in a care facility (German & Maisto, 1982).

2.2.1.7 Cultural factors

Children in American care facilities are more likely to be of Anglo background (Farber, 1972).

2.2.2 The couple

Much of the literature concerned with spousal support deals with the father's support of the mother with very little attention to the support that mothers provide to fathers. In addition most family counselling services and group activities are mother-oriented and female dominated, creating an intimidating environment for fathers searching for a way to participate (Beresford, 1994; Gallagher, Beckman & Cross, 1983).

Perceived spousal support is an important resource to mothers. Glendinning (1983) found that it was the mothers' perceptions of the fathers' willingness to help that affected their well-being rather than the actual amount of tasks carried out by the father.

Families who have successfully adjusted to the presence of a handicapped child seem to resemble effective families of other non-handicapped children in many ways. They manage to balance the needs of the handicapped child with other needs of the family.

Small, two-parent families, which contain a healthy parental subsystem and make effective use of their family and friendship resources, seem to have the best chance of remaining strong. Although, parents of handicapped children are more stressed and display greater levels of depression, these levels of depression are seldom of clinical concern (Gallagher et al, 1981; Trute, 1995; Trute & Hauch, 1988a).

2.2.2.1 Mediators of stress

2.2.2.1.1 Parental Characteristics

The parental characters that act as mediators of stress are depicted in Figure 2.9.

2.2.2.1.1.1 Age

Mölsä and Ikonen-Mölsä (1985) identified a tendency amongst older parents to adapt more quickly than younger ones.

This phenomenon could be explained in the light of the development of dispositional factors such as the Sense of Coherence which Antonovsky (1998) asserts is only fully developed by the age of 30. Accordingly, younger people may be more vulnerable.

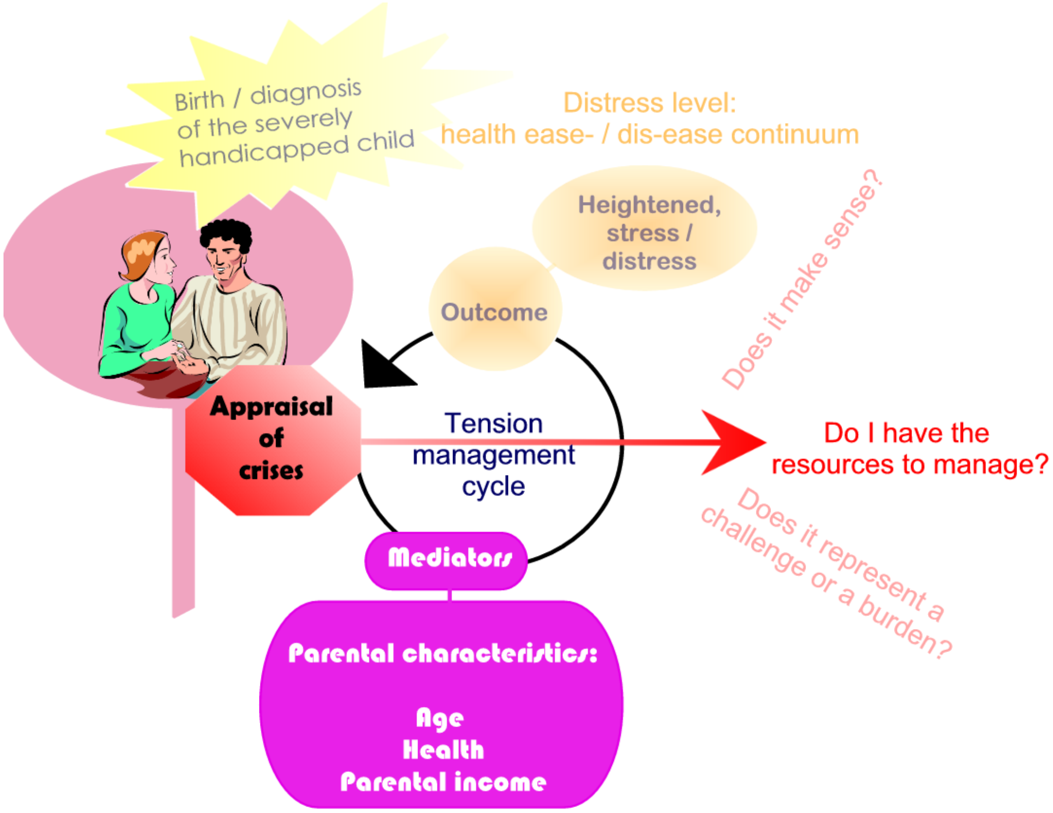


Figure 2.9: The couple: parental characteristics

2.2.2.1.1.2 Health

There are conflicting findings regarding the mediating role of parental health in parental stress.

Some researchers found physically healthy mothers to be less willing to place their handicapped child. A decline in the mental health of individual family members increases the probability of a placement (Cole & Meyer, 1989; Ellis, Bostick, Moore & Taylor, 1981; Levinson, 1976).

In contrast, Farber (1972) established that treatment of the mother for nervous conditions did not increase the likelihood of a placement.

2.2.2.1.1.3 Parental income

Conflicting findings exist with regard to the role of family income in the placement of handicapped children (Cole & Meyer, 1989; Eyman *et al*, 1972).

2.2.2.1.2 Internal resources

The internal resources of the couple that act as mediators of stress are illustrated in Figure 2.10.

2.2.2.1.2.1 Sense of coherence

Having a handicapped child may be one of those situations that "*induce anxiety no matter what coping mechanisms may be at the person's disposal or to what extent he or she has a disposition to respond to anxiety*" (Antonovsky & Sagy, 1986, p. 216).

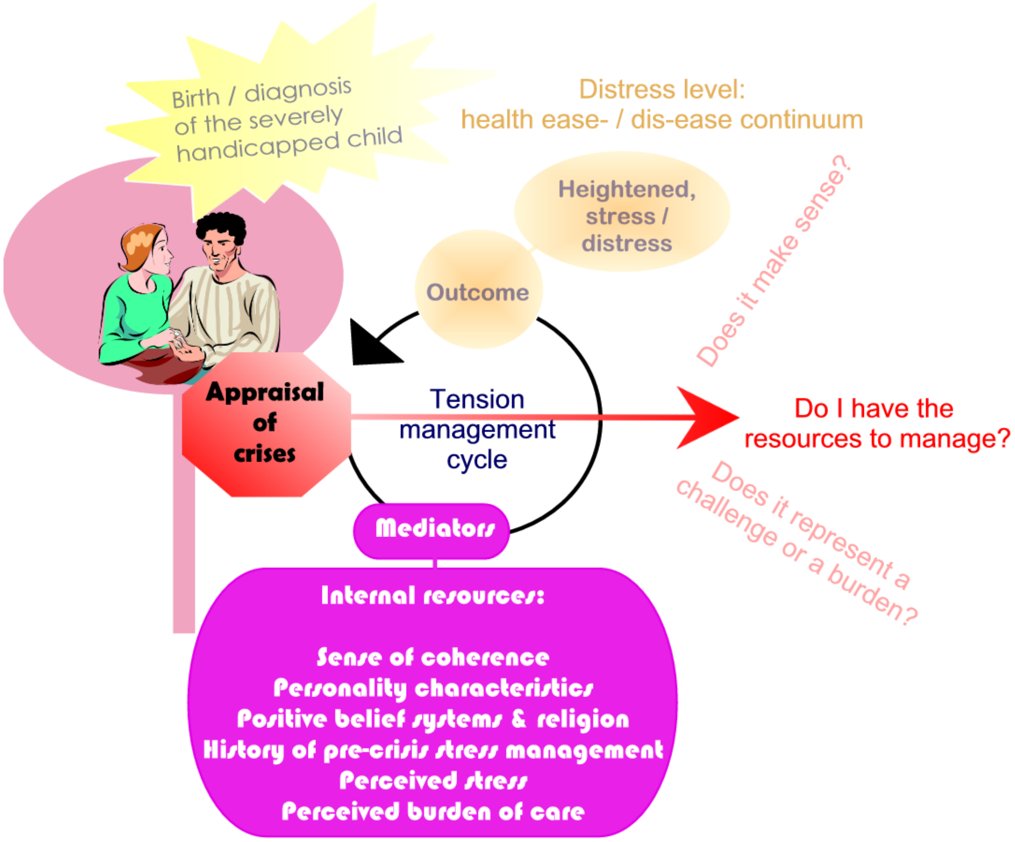


Figure 2.10: The couple: internal resources

Accordingly, these parents have great difficulty maintaining their position on the health-ease/disease continuum and show greater discrepancies in their sense of coherence than parents of non-handicapped children. This may reflect (1) these parents' lowered ability to remain mutually supportive whilst raising a handicapped child and (2) the child's negative effect on the parents (Margalit & Leyser, 1991; Margalit, Raviv & Ankonina, 1992).

On the other hand, above discrepancies could suggest an

> "*adaptive emphasis on alternative modes of functioning and on varying parental definitions of their roles… through lower cohesiveness and greater individuation, these parents may develop unique roles and definitions in the family, increasing the probability that at least one parent will be able to adjust to and cope with the family's increased needs*" (Margalit & Leyser, 1991, p.433).

Parents with a high sense of coherence were disposed to caring for their children at home. Lower levels of sense of coherence were positively associated with decisions to apply for out-of-home placements (Raif & Rimmerman, 1993).

2.2.2.1.2.2 Personality characteristics

Certain personality characteristics of parents, such as beliefs, commitments, low levels of neuroticism, higher levels of optimism and self-esteem, extraversion, humour and internal locus of control, may predispose the parent to more effective stress management (Affleck, Allen, Tennen, McGrade & Ratzan, 1985; Barakat & Linney, 1995; Carver *et al*, 1989; Folkman *et al*, 1986; Folkman, 1984; McKinney & Peterson, 1987; Mechanic, 1991; Sloper *et al*, 1991; Sloper & Turner, 1993; Trute, 1995).

2.2.2.1.2.3 Positive belief systems and religion

Positive beliefs about inner locus control over life events and positive appraisals of coping skills and social support predict lower parental stress, better family adjustment, and less psychological distress for the parents of handicapped children (Barbarin, Hughes & Chesler, 1985; Beresford, 1994; Bristol & Schopler, 1984; Byrne & Cunningham 1985; Copeland, 1980; Frey, Greenberg & Fewell, 1989; German & Maisto, 1982; Pearlin & Schooler, 1978; Petrosky & Birkimer, 1991; Rimmerman, 1991; Rimmerman & Portowicz, 1987; Waisbren, 1980).

Greater parental pessimism and a negative perspective of familial problems increase the parent's potential for experiencing future distress. The successful use of beliefs as coping resources depends not only on the effective utilisation of existing philosophies, but also on the degree to which the parent can modify previously held beliefs to adapt to a dramatic change of circumstances. A positive attitude towards the child does not however cancel out the stressful effects of the handicapped child's behaviour problems.

Research on the buffering effect of religious/spiritual beliefs is sparse and findings are contradictory.

2.2.2.1.2.4 History of pre-crisis stress management

There is little research on the mediating effects of prior coping experiences. Parents who have previous experience and a better understanding of handicaps and who hold positive perceptions of their coping efficacy seem to experience less stress (Beresford, 1994; Fortier & Wanlass, 1984; Frey, Fewell & Vadasy, 1989).

2.2.2.1.2.5 Perceived stress

The majority of parental decisions to place a child in care coincide with high levels of perceived stress (Bromley & Blacher, 1991).

2.2.2.1.2.6 Perceived burden of care

Parents of handicapped children older than 21, indicated that the perceived burden of future care was an important factor in their decision to place (Tausig, 1985).

2.2.2.1.3 Informal external resources

The informal external resources of the couple that act as mediators of stress are shown in Figure 2.11.

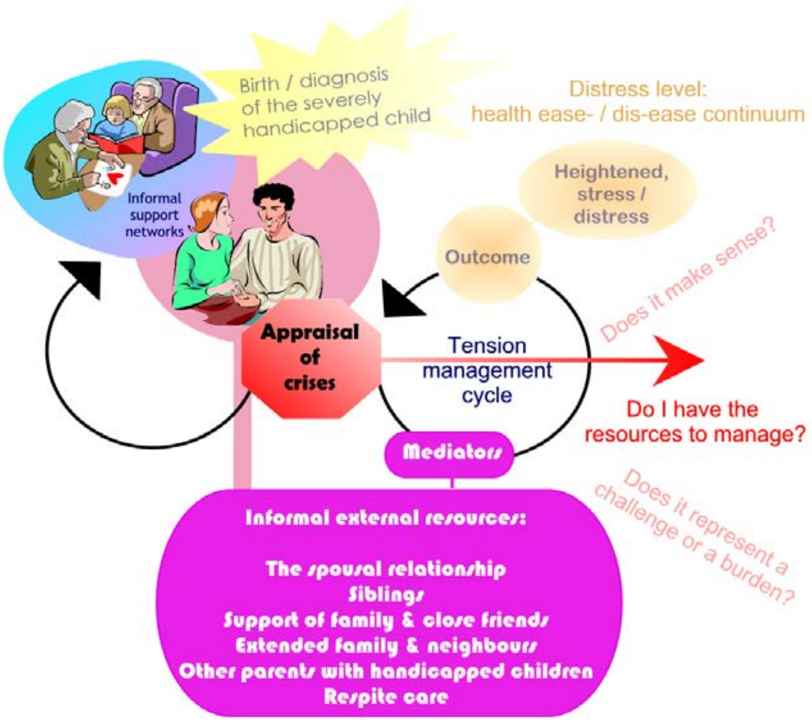


Figure 2.11: The couple: informal external resources

2.2.2.1.3.1 The spousal relationship

A pre-crisis supportive spousal relationship with a strong foundation can diminish the negative impact of having a handicapped child (Bradbury & Hewison, 1994; Farber, 1962; Friedrich, 1979; Gallagher *et al*, 1981; Gath, 1977; Parke & Beitel, 1988; Pueschel, 1986; Quine & Paul, 1991; Sloper *et al*, 1991).

Relative to other external resources an intimate, supportive spousal relationship and marital satisfaction are the most significant predictors of coping behaviour. Feeling secure in the marital relationship increases a mother's feelings of parental competence and the father's satisfaction with life (Friedrich, 1979; Holroyd, 1974; Sloper *et al*, 1991).

The marital relationship is especially vulnerable to the stress of having a handicapped child. These parents may experience less marital satisfaction, psychological well-being, social support and religiosity and more isolation. In order to maintain positive feelings toward the handicapped child, parents may internalise some of the strain, experience physical symptoms and could tend to displace their negative feelings onto a spouse, leading to greater marital strain.

Marital discord heightens the probability of a placement. Negative marital interaction is an important predictor of aversive parent-child interaction.

When parents differ in their appraisal of the child's problem and urge for opposing decisions regarding the care and management, marital stress may increase (Bradbury & Hewison, 1994; Cooke & Lawton, 1984; Ellis *et al*, 1981; Farber, 1962; 1972; Floyd & Zmich, 1991; Friedrich & Friedrich, 1981; Gallagher, Beckman, & Cross, 1983; Kazak & Marvin, 1984; McLinden, 1990; Pedersen, 1976; Pueschel, 1986; Tallman, 1965; Trout, 1983; Waisbren, 1980).

The presence of handicap could well lead to the strengthening of the relationship and couples can overcome the adversity of caring for a handicapped child (Barbarin *et al*, 1985; Burden, 1980; Byrne & Cunningham, 1985; Kazak & Marvin, 1984; Martin, 1975; McLinden, 1990; Waisbren, 1980 Widerstrom & Dudley-Marling; 1986).

2.2.2.1.3.2 Siblings

Researchers have rarely sought the needs and views of siblings of handicapped children. Parents who over-utilise their non-handicapped children by placing high demands on them to assist and expecting them to overcompensate for the disappointment of a handicapped child may cause these siblings to miss important emotional and social milestones and may also increase their tendency to develop psychological problems.

Of all the siblings, it seems that the older sister, who may have to act as a parent-substitute and the youngest male child are most at risk.

Not all siblings are negatively affected by participation in the care of the handicapped child. Sharing problems may lead to a greater sense of purpose and cohesiveness in the family (Byrne & Cunningham, 1985; Gath, 1972; Farber, 1972; Lobato, 1983; Slade, 1988; Wikler *et al*, 1983; Wilks & Wilks, 1974).

2.2.2.1.3.3 Support of family and close friends

If skilfully utilised support from grandparents, family and close friends is a critical resource to parents of handicapped children. Members of this support group offer temporary relief from the burden of caring for the handicapped child, freeing parents to invest in their marital relationship. High levels of family cohesion and family expression are positively associated with good stress outcomes.

n contrast, previous and existing familial problems, absence of family support, a high degree of family conflict and a lack of family flexibility, predicts a higher level of stress, less perceived life satisfaction and more physical and mental health difficulties in both parents. Parents of handicapped children may have difficulty retaining their level of social support, as it existed prior to the arrival of the handicapped child. This could lead to them viewing their family climate as less supportive and as providing less opportunities for intellectual and leisure activities.

The presence of higher and more extensive family stress, fewer family resources and a lack of support systems is predictive of a decision to place a child in a care facility (Beresford, 1994; Bradbury & Hewison, 1994; Farber, 1972; German & Maisto, 1982; Holroyd, Brown, Wikler & Simmons, 1975; Holroyd & McArthur, 1976; Margalit & Leyser, 1991; Margalit *et al*, 1992; McCubbin & Patterson, 1983; Raif & Rimmerman, 1993; Rimmerman & Portowicz, 1987; Seltzer & Krauss, 1984; Sloper *et al*, 1991; Tausig, 1985; Trute & Hauch, 1988a; 1988b; Urbani, 1980; Waisbren, 1980).

2.2.2.1.3.4 Extended family and neighbours

Relatives, friends and neighbours, whose participation will be shaped by cultural factors, do not generally assist on a day-to-day basis. Mostly they help out only during times of crisis. As a result, parents may report a lack of extended family or neighbourly support (Cooke & Lawton, 1984; Groce & Zola, 1993; Russel, 1981).

2.2.2.1.3.5 Other parents with handicapped children

Parents of handicapped children generally welcome visits from other parents in similar circumstances (Murdoch, 1983).

2.2.2.1.3.6 Respite care

Respite workers and respite centres can be of great help to parents. Respite services offer support in abstract and real terms. Families who utilise respite services perceive greater social support and report lower levels of stress and higher morale. The lack of appropriate alternative care-giving arrangements limits the time that the family have to spend together away from the handicapped child. The greater and more severe the child’s handicap, the less the parent is willing to leave the child in respite care and the more difficult it becomes to source a suitable respite worker or centre. The less respite care is available to parents who provide home-care, the higher the probability of a placement (Beresford, 1994; Bose, 1991; Burden, 1980; Cooke & Lawton, 1984; McLinden, 1990; Wilks & Wilks, 1974; Wishart *et al*, 1980).

2.2.2.1.4 Formal external resources

Figure 2.12 illustrates the formal external resources of the couple.

2.2.2.1.4.1 Support services

Parents of handicapped children do not identify formal support systems as primary providers of emotional or tangible support and generally see their needs as unmet by these services.

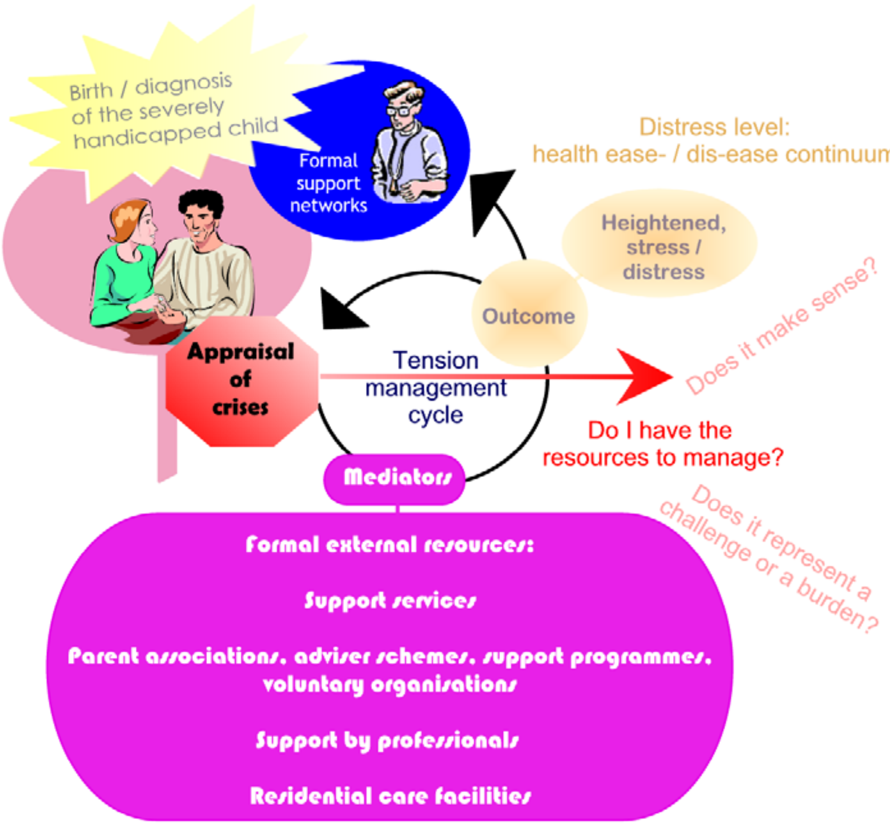


Figure 2.12: The couple: formal external resources

Parental need for professional support increases when they have to decide about the child's future care. Ultimately, parents of handicapped children need formal services to cope but only make use of them in times of crisis (Ayers, 1984; Beresford, 1994; Florian & Krulik, 1991; Herbert & Carpenter, 1994; Sloper & Turner, 1992; Urbani, 1980; Waisbren, 1980).

Formal support programs can contribute to parental stress. Services are often impersonal, slow, cumbersome, insensitive, irregular, unreliable and inappropriate. The evaluation of many support programs has been neglected.

Some programs focus on the needs of the child, with minimal attention to the needs and role of parents and to socio-cultural factors that can interfere with the successful implementation of intervention programs (Adkins & Young, 1976; Ayers, 1984; Davis, 1985; Florian & Krulik, 1991; Gallagher & Gallagher, 1985; Kazak, 1986; Leyser *et al*, 1996).

In South Africa formal specialised and support services are very limited. Available services include (1) single care grants, (2) hospitals, (3) clinics, (4) day care centres and (5) residential institutions. Each of these resources has inherent difficulties (Luiz, Lombard & O'Brien, 1997; Mabaso & Uys, 1990; Roper, 1992).

Bromley and Blacher (1991) found that the lack of support services was only slightly significant in the placement decision of the parents polled in their study. In contrast, Cole and Meyer (1989) concluded that families who made greater use of external resources were more inclined to report plans to keep their child at home until age 21.

2.2.2.1.4.2 Parent associations, adviser schemes, support programs and voluntary organizations

Support in the form of parent associations Parent Advisers (skilled counsellors trained by helping professionals), parental training and support programs as well as voluntary movements can be beneficial.

Parents value these organisations most for their emotional support and practical advice, less so for their role in service provision. Only a small proportion of parents belong to voluntary movements, but those who do find them helpful. Membership declines as the child ages.

Appropriate psycho-educational programs can alleviate the stress of parents, possibly prolonging the decision to do a long-term placement. Professionals should not pressurise parents into joining associations, support programs or voluntary movements (Buchan, Clemerson & Davis, 1988; Bruce, 1991; Burden, 1980; Cole & Meyer, 1989; Cooke & Lawton, 1984; Davis, 1985; Ellis *et al*, 1981; McBride, 1991; Morgan, 1979; Pisterman, Firestone, McGrath, Goodman, Webster, Mallory & Goffin, 1992; Russell, 1981; Straton, 1979; Tynan, Serper & Emory, 1985; Vadasy, Meyer, Fewell & Greenberg, 1985).

2.2.2.1.4.3 Support by professionals

Professionals, although not rated by parents as a primary resource, often have to initiate the parent into the stressful, painful and life-altering process of dealing with a handicapped child. They are in a unique position to relay the diagnosis in a way that furthers the parents' adjustment, to deal with the parents' worries and to reassure them that the child, though handicapped, is a worthy human being with inherent rights. The way in which the medical professional handles the whole issue of diagnosis sets the tone for years to come.

Professionals should be aware of the possible negative implications of their own model of intervention, give accurate information, empower parents whilst alleviating their anxiety and develop a team approach inclusive of the parent in order to reduce frustration and conflict with parents. They should avoid:

1. Ignoring socio-cultural factors;
2. Overloading the parent;
3. Minimising or overemphasising the parents' emotional process;
4. Pathologising the parent;
5. Attempting to find something positive in situation;
6. Patronising or offering platitudes; and
7. Refusing to discuss the loss (Amick, 1984; Adkins & Young, 1976; Bernheim, 1990; Davis, 1985; Gallagher, Beckman & Cross, 1983; Gallagher *et al*, 1981; Garland, 1986; Levinson, 1976; McClure & Lindsey, 1984; Pueschel, 1986; Russel, 1981; Roy & Huguet-Pech, 1987; Stone, 1989; Waisbren, 1980; Waskowitz, 1959; Wikler *et al*, 1983).

The professional in the Neonatal Intensive Care Unit (NICU) may play multiple roles, providing information and cognitive guidance, material resources, emotional support and practical help to assist parents to master emotional distress. The way that these roles are fulfilled may reduce or increase parental stress.

Parents' experience in the NICU may reinforce a sense of failure and feelings of loneliness and ambivalence. With the available advanced technology, critically ill and severely handicapped children can be kept alive indefinitely. Although this may be ethically correct, parents have to endure the futility of medical interventions and the continued suffering of their child who may not otherwise have survived. In addition, parents may have limited access to the child, which inhibits the bonding process.

NICU staff rarely assigns a central coordinator to manage referrals to support services such as social workers, psychiatrists or psychologists (Elkins & Brown, 1986; Diaz, 1993; Flynn & Collum, 1989; Murdoch, 1983; Pueschel, 1986; Rothstein, 1980; Strain, 1983).

Support by professionally-run family groups, led by physicians, psychiatrists or social workers can provide a coping resource. These groups are mostly non-directive, emphasise group discussion and the disclosure of feelings. They rarely stem from an empirical or theoretical base. Given that these groups are rarely systematically evaluated, there is no clarity as to how these programmes contribute to family adjustment. It is important to point out that even though such groups would be available in rich first-world countries they may be non-existent in developing and third-world countries (Valman, 1981; Walton, 1993).

Available literature makes very little mention of how psychologists can assist in the support of parents of severely handicapped children. This may be because psychologists do not generally form part of a multi-disciplinary team at a hospital or care facility. Given that these parents are at such high risk for complex grief and extreme stress, psychologists certainly have the expertise to make a significant contribution and ways should be for including them in the helping process.

Ultimately physicians and other professional helpers may battle to control their own emotions when confronted with a severely handicapped child. Hence, they may conclude that the parent’s burden is too great to bear and may hastily and inappropriately recommend placement, accordingly losing their position as mediators and confusing their role with that of the parent (McClure & Lindsey, 1984; Roy & Huguet-Pech, 1987; Slobody & Scanlan, 1959; Waskowitz, 1959).

2.2.2.1.4.4 Residential care facilities

Residential care facilities can alleviate the stress of parents who have to provide care to severely handicapped children (Blacher & Baker, 1994; Blacher, Hanneman & Rousey, 1992; German & Maisto, 1982; Mabaso & Uys, 1990; Taylor, Lakin & Hill, 1989).

Parents could also experience residential care facilities as a source of stress. This occurs when staff members feel ambivalent towards parents. Staff members who support the "normalisation" principle may judge negatively those parents who place their children. Ambivalence could also arise out of the staff's unique care-giving role – they come to see the child as their child and resist intrusion by the biological parents (Blacher & Baker, 1992; Bernheim, 1990).

2.2.2.1.5 Coping strategies and behaviours

The coping strategies and behaviours that act as mediators of stress for the couple are shown in Figure 2.13.

Coping strategies and behaviours are a very important resource for the family. Parents may have preferred coping styles which can be congruent (both or neither use a coping strategy) or complementary (one partner uses a strategy a lot, the other does not) (Barbarin *et al*, 1985; McCubbin, 1979; Patterson,1988).

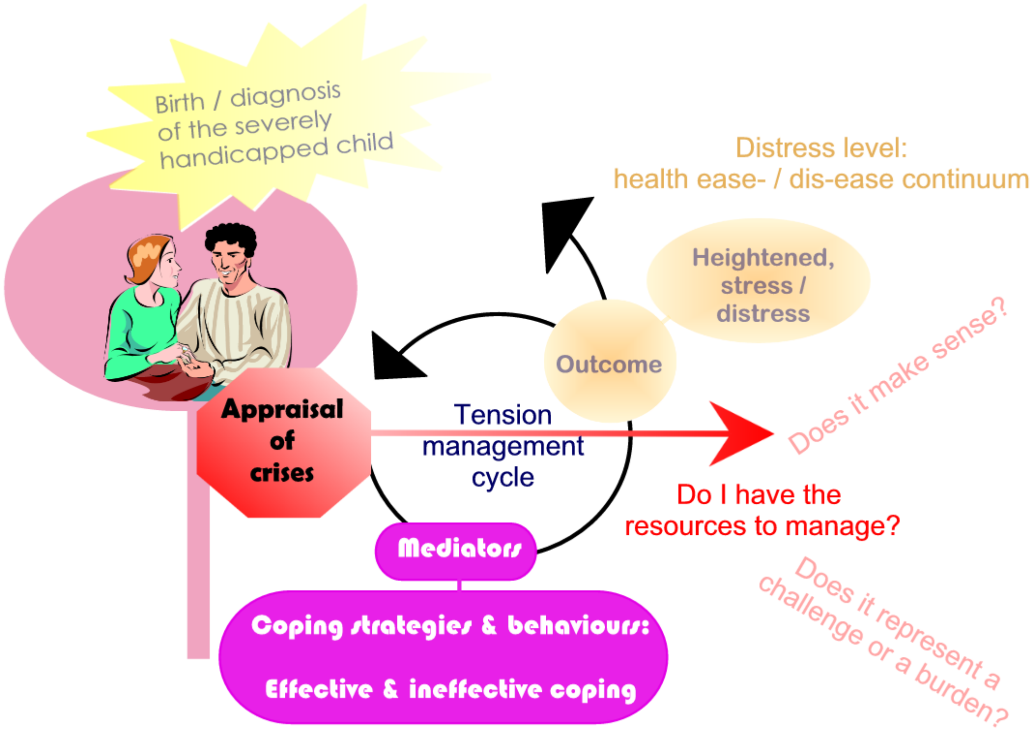


Figure 2.13: *The couple: coping strategies & behaviours*

2.2.2.1.5.1 Effective coping strategies

Parents of the handicapped child that cope effectively have distinguishing internal resources and foster particular relationships with their informal and formal support systems.

Parents that cope effectively perceive themselves as having good coping skills and utilise cognitive restructuring. Congruent use of optimism and complementary use of problem-solving predicts better marital functioning and spouse support. Some effectively coping parents believe in God. With regard to their handicapped child, these parents develop acceptance and understanding of the handicap and focus on the positive aspects of the child. They encourage self-sufficiency in the child, whilst learning to better assist and structure their child.

Effectively coping parents aim to maintain a lifestyle that is as normal as possible. They maintain warm, secure and open spousal and family relationships, further personal development and stay involved with their children. Furthermore, they utilise their support systems especially close family and grandparents.

These parents follow a planned, practical and problem-focused strategy that they appraise as effective in the situation. They are able to adopt a flexible, day-to-day approach, managing and reducing the risks of daily crises and focusing on the present rather than plan for a future that seems uncertain at best.

Parents who cope effectively maintain and develop coping resources. They show initiative and stamina in the area of therapy and rehabilitation, develop trusting relationships with helping professionals, believe in the benefit of intervention programs and realise the importance of effective seeking information and help (Barbarin *et al*, 1985; Bregman, 1980; Bristol & Schopler, 1984; Daniels & Berg, 1966; Darling, 1979; Deaton, 1985; Frey*,* Greenberg & Fewell, 1989; Judge, 1998; Miller *et al*, 1992; Quine & Pahl, 1991; Shapiro, 1983; Sloper *et al*, 1991; Sloper & Turner, 1993).

2.2.2.1.5.2 Ineffective coping strategies

Parents, who present with lower levels of education and a lower sense of coherence and have a handicapped child with more severe behavioural difficulties, make greater use of avoidance (Margalit *et al*, 1992).

Whereas the expression of emotions may contribute to adjustment and the resolution of grief, suppression or over-expression of emotions over an extended period of time may be maladaptive (Beresford, 1994; Beavers, Hampson, Hulgus & Beavers, 1986; Judge, 1988; Quine & Paul, 1991).

Emotion-focused strategies, such as behavioural disengagement, may reduce the parents' effort to deal with the stressor and may lead to helplessness. Parents may tend to disengage if there is poor hope of a positive outcome, thus reducing the emotional impact of the situation. Disengagement can also occur on a mental level. It distracts the parent from thinking about the behavioural goal with which the stressor is interfering (Carver *et al*, 1989; Frey*,* Fewell & Vadasy, 1989; Frey*,* Greenberg & Fewell, 1989; Miller *et al*, 1992).

Parents may assume a sick role in order to cope with their failure to adjust to the demand of the handicapped child. In this they may be supported by professionals who legitimise and prioritise their illness as opposed to dealing with the underlying issue of failure (Shuval, Antonovsky & Davies, 1973).

2.2.2.1.6 Placement as an adaptive coping response

Placement, as illustrated in Figure 2.14, can be an adaptive coping response to the demands of the severely handicapped child.

It is the purpose of this section to (1) provide a contextual and theoretical framework within which helping professionals can interpret the placement decision of parents, (2) discover the reasons why they make this sometimes unpopular decision, and (3) describe the process of post-placement parental adjustment.

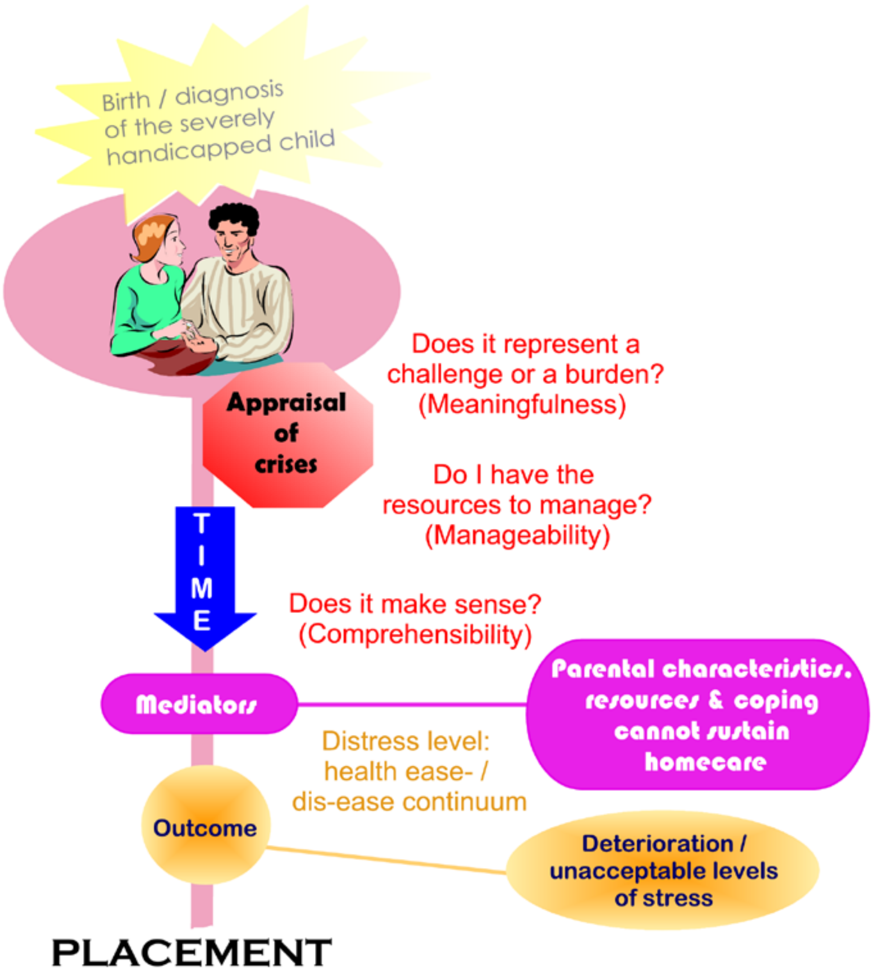


Figure 2.14: ***The couple:*** **placement as an adaptive coping option**

2.2.2.1.6.1 The impact of de-institutionalisation

Since the 1950's there has been a movement towards de-institutionalisation which assumed that (1) community care was preferable to institutional care, (2) communities were capable and prepared to take on the responsibility for the care of the mentally ill, (3) community-based facilities were better at providing care than state hospitals and (4) community-based services may be cheaper to maintain. This placed a massive burden on families of severely handicapped children.

De-institutionalisation could also infringe on the family's rights to personal freedom and growth opportunities and place the parent of the severely handicapped child in the role of primary caregiver, without them having the infrastructure or support system to do so. As such, the pressure to provide home-care at all costs can be construed as a discriminatory act that saps the family's financial, physical, emotional and time resources.

In response some families, especially those that are highly stressed, have to face the reality that they cannot continue to care for their severely handicapped child in a home setting and accordingly seek placement for their child (Bruns, Burchard & Yoe, 1995; Cole, 1986; Harris, 1987; Holroyd *et al*, 1975; Kane, 1984; Levinson, 1976; Pueschel, 1985; Slobody & Scanlan, 1959; Zimmerman, 1984).

2.2.2.1.6.2 A parental decision

Placement remains a parental decision. Parents, who, after careful consideration of the factors involved, have decided to place their child, deserve the support of the professionals (Pueschel, 1986).

2.2.2.1.6.3 Detachment vs. involvement

Given that such a placement is often a permanent step, agencies and care facilities need to empower families to stay involved. Family members can be important sources of physical and financial assistance and advocacy as they are often the only figures that are constantly present in the child's life.

Moreover, ongoing contact with the natural family can contribute to the placed child’s overall quality of life (Bernheim, 1990; Blacher & Baker, 1992; Levinson, 1976; Taylor *et al*, 1989).

The family's continuing role in the life of a placed child and the family’s post-placement adjustment has not been well researched. Pre-1990 studies show a tendency towards parental detachment. These results may not be very reliable due to flaws in the methodology.

Later studies suggest that placement can benefit the family and the child. These families can disengage from pre-placement stress, resume daily activities, pursue personal interests and seek personal and occupational growth opportunities that may not have been accessible with the child in the home.

These improvements enable families to maintain a high level of involvement with the child. Highly involved parents live closer to the care facility; have children with higher IQ’s and a lower incidence of physical anomalies; and report stronger marriages, higher levels of education and income. Families may tend to become uninvolved when they believe that their placed child has no potential for further development (Blacher & Baker, 1992; Blacher & Newfelt, 1989; Harris, 1987).

2.2.2.1.6.4 The decision to place, as illustrated by the Salutogenic Model

Parents will most probably perceive the unexpected arrival or the final diagnosis of and the ongoing and taxing demands of providing home-care for a severely handicapped child as major life events.

This introduces inconsistency, unpredictability, overload and possible exclusion from decision-making and participation into the parents' system. Parents' existing expectations and schemas fall away, they are overwhelmed, not only with the care-taking needs of the child, but the intensity of their own grief and stress. They may find themselves lacking in existing and automatic stress-reducing mechanisms.

Parents who have lower levels of Sense of Coherence (SOC) may be more inclined to apply for out-of-home placements, i.e. their SOC is not strong enough to mediate the stress generated by the presence of the severely handicapped child. They may experience their situation as unstructured, unpredictable and inexplicable and may find themselves lacking in the necessary resources. In addition, they may not see the presence of such a child as a challenge, but a burden (Raif & Rimmerman, 1993).

Parents with a strong SOC may also opt for a placement decision. Firstly, having a severely handicapped child directly attacks all four spheres within the individual's boundaries of awareness that are required to maintain a strong Sense of Coherence. This could lead to an erosion of the SOC and the development of greater dis-ease, to the point where the parents see placement as the only way to arrest their decline into dis-ease. Secondly, parents may accurately perceive their situation as one with which they are not equipped to deal (rationality) and are willing to generate new or consider available alternative coping strategies (flexibility), in this case placement in a care facility. The parent may also have the ability to anticipate the long-term consequences of home-care and the benefits of placement (farsightedness). By addressing their situation in this way, the parents would be identified as effective copers. (Antonovsky, 1987)

2.2.2.1.7 The process of post-placement parental adjustment

The success of the placement would be reflected in the post-placement functioning of the parents. Blacher and Newfelt (1989) offer a sequential theoretical model of post-placement parental adjustment.

The stages are:

- Acknowledging the reality of the need to place;
- Placement itself;
- Disengaging from pre-placement stress and conflict and the resumption of daily activities;
- Experiencing loss of the placed child;
- Resurgence of attachment upon visitation;
- Resolving guilt;
- Resolution of loss and accepting the permanency of placement; and
- Achieving realistic hopes for the child and family.

This model embodies the hopes for the post-placement resumption of normal family functioning and the maintenance of meaningful relationships with the placed child. It suggests that parents are able to overcome the guilt and grief and re-establish close relationships. This implies that placement can benefit the family and assist it in finding a new and meaningful balance that includes the placed child.

The couple's post-placement adjustement is illustrated in Figure 2.15.

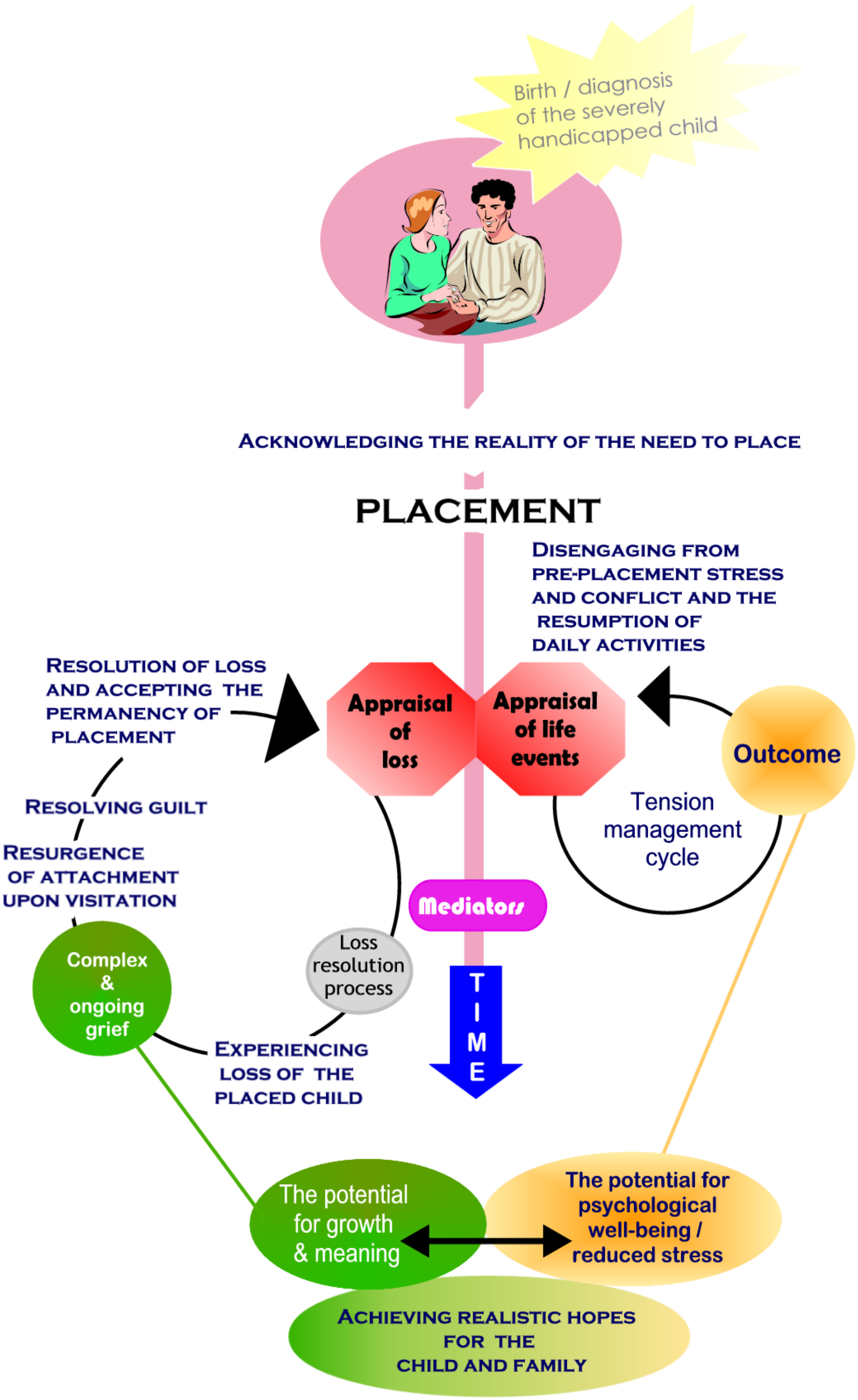


Figure 2.15: The couple : post-placement parental adjustment

2.2.2.2 The outcomes of stress

The outcomes of stress for the couple are depicted in Figure 2.16.

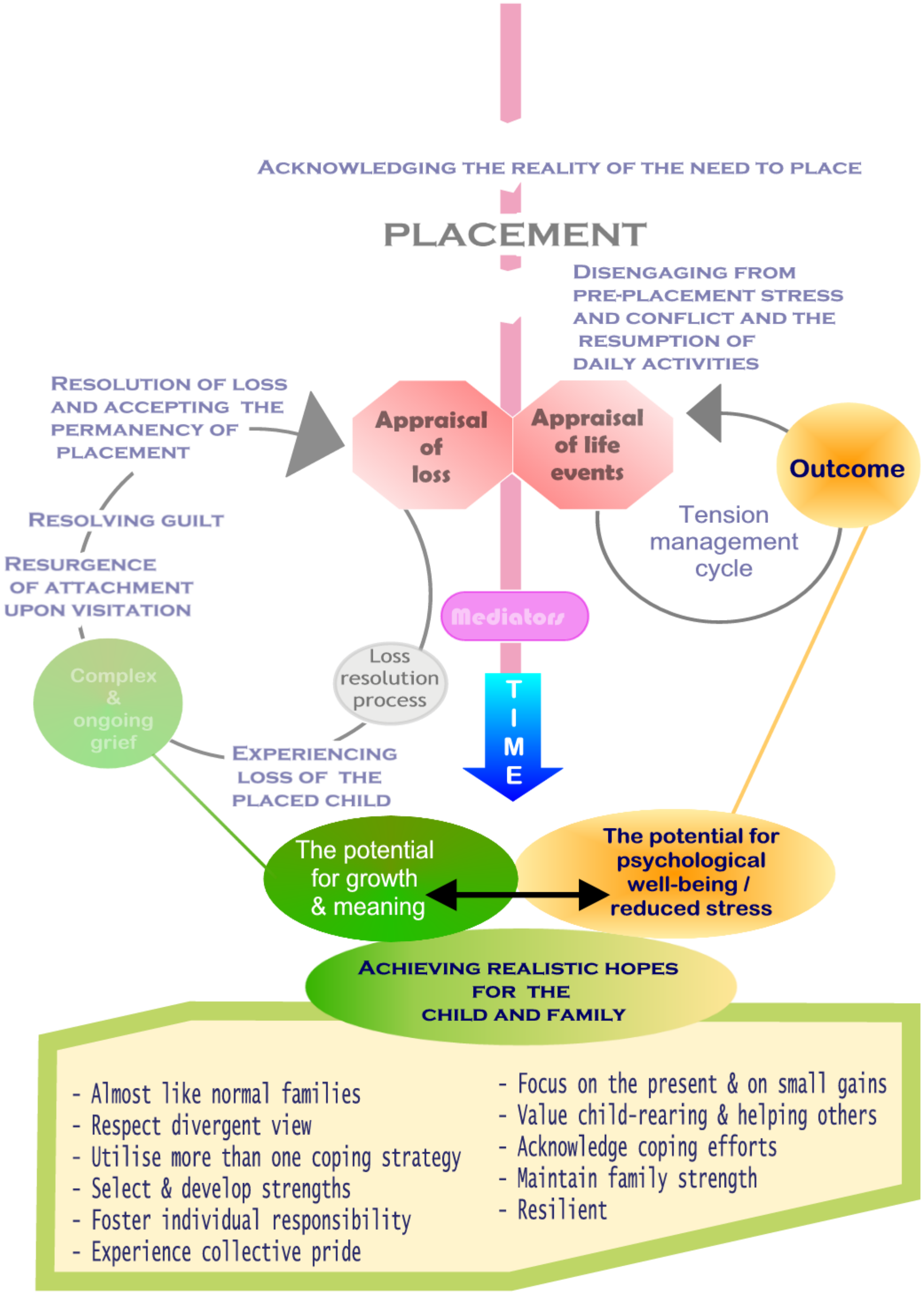


Figure 2.16: The couple: the outcomes of stress

2.2.2.2.1 Characteristics of the successfully adjusted family

Although they appeared to have high degrees of stress, the families of severely handicapped children differ only minimally from other families in their family functioning. Better functioning families of handicapped children respect divergent views and use more than one coping approach. They are able to select and develop areas of strength and can capitalise on the individual responsibility of family members and experience collective pride in being a good family for the handicapped child.

These families tend to focus on small gains and on the present rather than the future. They also articulate values such as the importance of child rearing, helping the less fortunate, acknowledging the importance and significance of their coping efforts and maintaining family strength (Beavers *et al*, 1986; Dyson, 1991; Kazak, 1987; Kazak & Marvin, 1984).

Ultimately, families of severely handicapped, placed children "*are resilient families. They have lived through the difficult years of having a child with severe handicaps at home and the requisite sacrifices. They have struggled with making a professionally unpopular decision to place. And they have placed. But with it all, rather than experiencing family dissolution, parents can at the same time report an increase in well-being, the maintenance of meaningful contact, and a positive outlook*." (Blacher & Baker, 1994, p.519.)

Although studies on the stress outcomes of placement are extremely rare, those that are available suggest that families of severely handicapped children report feelings of relief once they have placed the child and have a favourable impression of the way that their children are cared for by the care facility.

Quality of care may be higher in small, privately funded care facilities. This suggests that parents who have to rely on meagrely funded state facilities may not have the same peace of mind (Blacher & Baker, 1992; Ellis *et al*, 1981; Price-Bonham & Addison, 1978).

2.2.2.2.2 Detachment vs involvement

Earlier studies of the family's post-placement involvement suggest that families become detached in the course of time. Later studies show a different trend. They demonstrate that families disengage from pre-placement stress, resume daily activities and maintain high levels of involvement with the handicapped child. Where detachment does occur, it can be attributed to the familial belief that the placed child has no potential for further development. Families with high involvement (1) live closer to the care facility; (2) have children with higher IQ's and a lower incidence of physical anomalies; and (3) contain a healthy spousal relationship with better educated and higher-income parents (Blacher & Baker, 1994; Blacher *et al*, 1992; Blacher & Newfelt, 1989; Bromley & Blacher, 1991; Fisher & Tessler, 1986).

Blacher and Baker (1992) emphasise that meaningful family involvement must be part of programme planning for community residential services. These programmes should foster the development of opportunities of parents to remain involved and address the attitudes and possible ambivalence of care facility staff members towards parents.

Promoting family involvement benefits parent and handicapped child. Ongoing contact with the natural family has been noted as a contributor to placed child's overall quality of life (Bernheim, 1990; Taylor *et al*, 1989).

2.2.2.2.3 Short- and medium-term placement programmes

Parents may not initially intend long-term placement, but opt for short- to medium-term placement as a way to relieve stress in the family. Ellis *et al*, (1981) find that short to medium-term placement (six to twelve months) of the child, accompanied by a self-help skills training program for the child, would alleviate family stress, make the child more acceptable for the home environment and would postpone long-term placement. Those parents who ultimately opt for their children’s re-admission are more likely to do so if they are still highly stressed, their initial intention was long-term placement and the child (1) is male; (2) does not show benefits from the training program; (3) functions less independently or deteriorates during the period following the first discharge; and (4) shows deteriorating language skills following the initial discharge.

2.2.3 The mother

2.2.3.1 Mediators of stress

2.2.3.1.1 Maternal characteristics

The maternal characteristics that act as mediators of stress are shown in Figure 2.17.

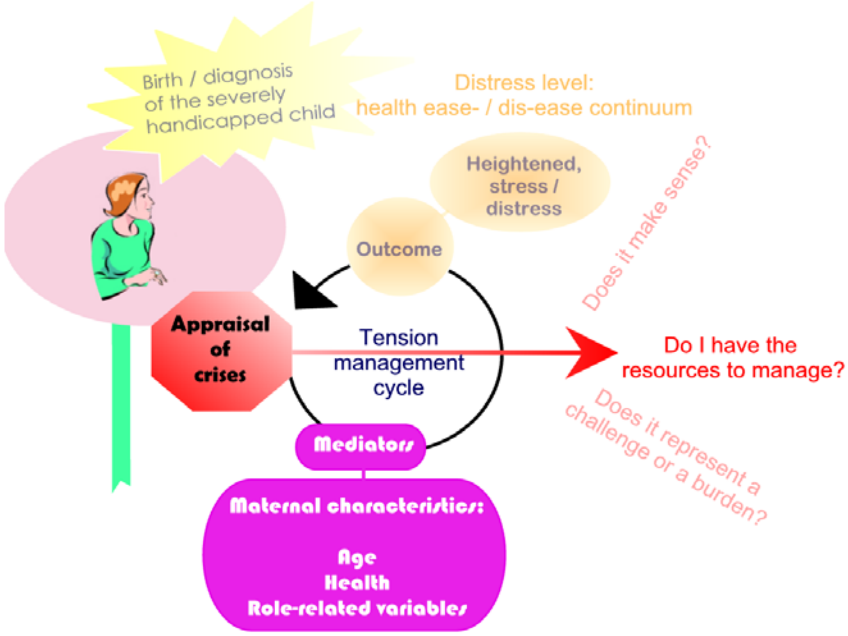


Figure 2.17: Maternal characteristics

2.2.3.1.1.1 Age

Older mothers may be more at risk for having handicapped children and seem more vulnerable to stress, especially if the child presents with odd characteristics and a greater degree of physical disability (Beckman, 1983; Rimmerman & Portowicz, 1987; Urbani, 1980).

2.2.3.1.1.2 Health

Health is an important maternal coping resource. Should the mother's health decline, she may become more vulnerable to the stress of providing long-term care and more likely to experience lower marital integration, perceive the handicapped child more demanding and to consider placement. Decreased health can offer a way in which mothers can cope with their failure to adjust to the handicapped child (Beresford, 1994; Farber, 1972; Shuval *et al*, 1973; Waisbren, 1980).

2.2.3.1.1.3 Role-related variables

Generally, women are more sensitive to the needs of others and show greater skill in caring for others than men. They may differ from fathers in their view of the nature of and responsibility for the handicapped child's needs and in their utilisation of coping resources and use of coping behaviours. Mothers seem to be more concerned with the nurturing and practical caretaking aspects of parenting (Schilling, Schinke & Krikham, 1985; Sloper *et al*, 1991).

Especially mothers of young handicapped children are more at risk for developing depression as they have (1) more problems and involvement with the handicapped child; (2) more concerns regarding the behaviour of the child, especially boys; (3) extra demands on their time, energy and health; (4) a more tense home atmosphere; (5) a greater degree of special family problems; (6) lowered personal and family ambition; (7) a strong tendency to feel greater pressure to take proper care of the child; and (8) greater sensitivity to how the child fits into the community.

This depression is infrequently of such a magnitude that it requires clinical intervention (Burden, 1980; Ferguson & Watt, 1980; Holroyd, 1974; Tavormina, Boll, Dunn, Luscomb & Taylor, 1981; Trute, 1995).

Research results also show that generally mothers of handicapped children have more caretaking responsibilities and suffer greater distress than fathers. This may be due to the use of mother-related indices, such as caretaking demands, and exclusive maternal reports in research studies (Carey, 1982: 269; Goldberg *et al*, 1989: 356; Holroyd, 1974; Krauss, 1989; Trute, 1995).

Some mothers' unwillingness to complain about the child could create the perception that fathers have more difficulties than mothers do. Whereas fathers seem more open in reporting their child-related difficulties and frustrations, mothers may view this as "*non-maternal*" and may be more willing to speak about their personal adjustment problems (Goldberg *et al*, 1989, p.356).

Mothers may show greater benefits than fathers from dealing with their handicapped child. They show higher levels of understanding, acceptance and trust of the child, higher levels of open personal communication and view their families as more sociable (Tavormina *et al*, 1981).

2.2.3.1.2 Internal resources

The maternal internal resources that act as mediators of stress are shown in Figure 2.18.

2.2.3.1.2.1 Positive belief systems and religion

Mothers with an inner locus of control and positive attitudes towards their handicapped children are less likely to project negative feelings onto the father and more likely to value their handicapped children despite any behaviour problems. They do not make child-related problems a central issue in their relationship with the child.

Low level internal beliefs may predispose mothers to attribute any progress in their child's development to luck or external factors and not to their own teaching or parenting abilities. As a result, they may be less inclined to teach the child.

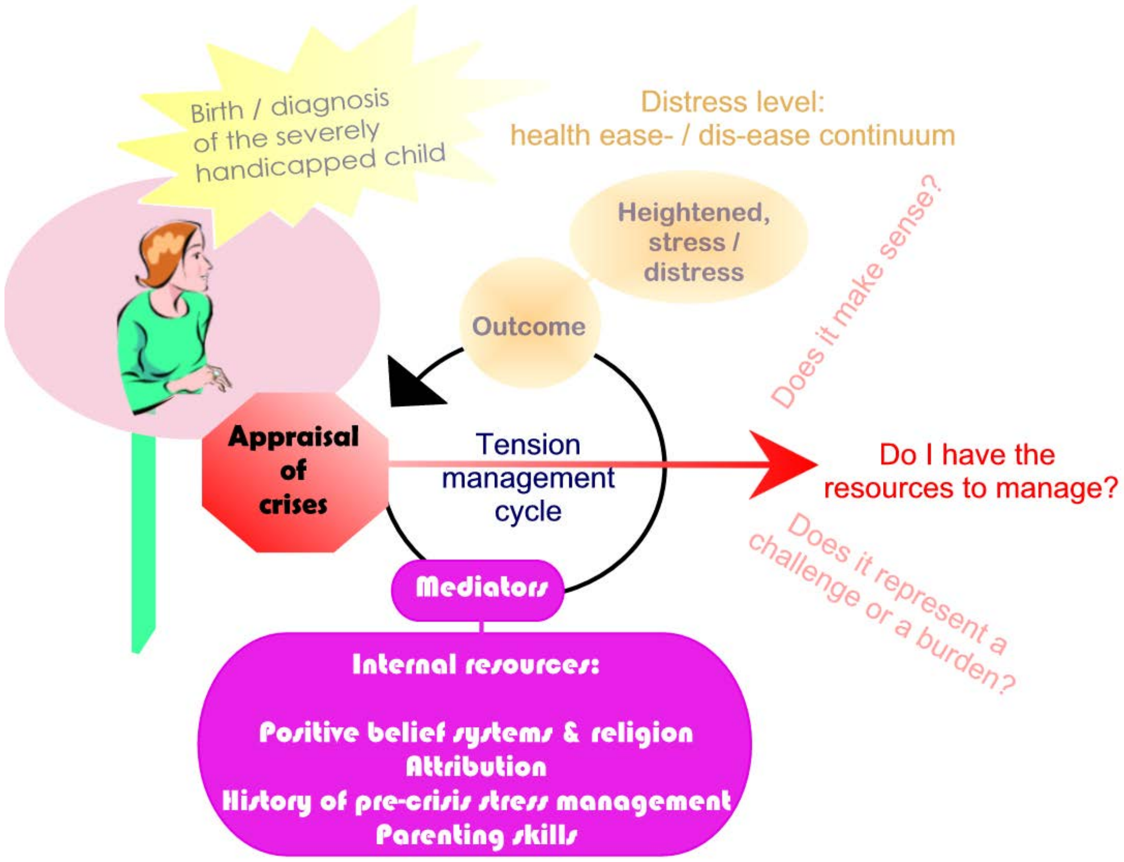


Figure 2.18: Maternal internal resources

Jewish mothers were more reluctant than their husbands to place the handicapped child in a care facility. This did not apply Protestant and Catholic mothers (Brantley & Clifford, 1980; Farber, 1972; Maisto & German, 1981; Sloper *et al*, 1991).

2.2.3.1.2.2 Attribution

Mothers who view their child's condition as manageable and attribute the handicap to environmental causes may adapt more successfully than mothers who rate their children's symptoms as more severe and who attribute the illness to their own behaviour (Affleck *et al*, 1985).

2.2.3.1.2.3 History of pre-crisis stress management

A history of psychiatric problems and poorer marital relations before the diagnosis of the handicapped child predisposes the mother to experience such a diagnosis as more stressful and perceive the handicapped child as making greater demands upon her (Farber, 1972).

2.2.3.1.2.4 Parenting skills

Mothers who are dissatisfied with their parenting competency and levels of social support may experience more stress (Gallagher *et al*, 1981; Hanson & Hanline, 1990; Holroyd, 1974; Krauss, 1989; 1993).

2.2.3.1.3 Informal external resources

A number of informal external resources act as mediators of maternal stress. These are shown in Figure 2.19.

2.2.3.1.3.1 The spousal support system

Mothers benefit from their spouse’s practical, emotional and perceived support. During the initial stages of diagnosis, the father often fulfils the tasks of liaising with professionals and acting as a conduit to the outside world. The way in which the father fulfils these tasks could bring a sense of calm to the situation.

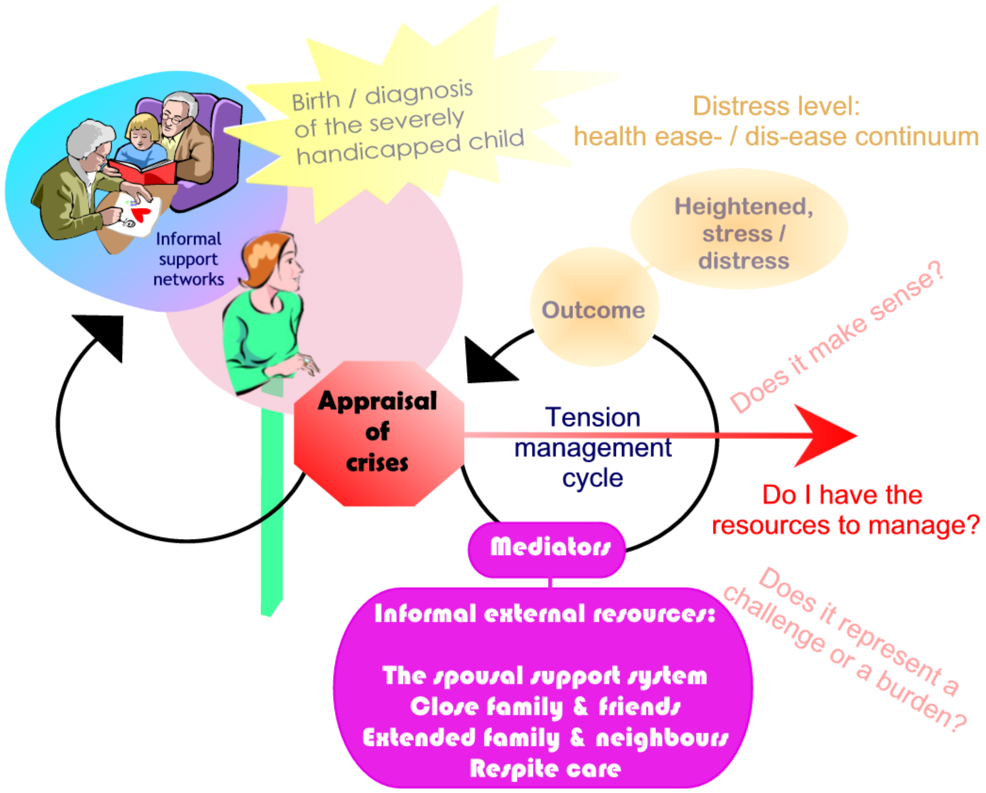


Figure 2.19: Maternal informal external resources

Wives whose husbands actively participate in caring for the handicapped child and seek information about the child's condition perceive them as being highly supportive. Mothers who are married to professional men; have little domestic assistance; and have severely handicapped daughters may receive less support as their husbands are less likely to assist with housework as well as when the child is a severely handicapped girl. Fathers prefer to help with child minding (as opposed to caretaking) and are more willing to do so if the child is a boy (Barbarin, Hughes & Chesler, 1985; Bradbury & Hewison, 1994; Cooke & Lawton, 1984; Parke & Beitel, 1988; Tallman, 1965).

German and Maisto (1982) determined that mothers who were married were less likely to place the child in care. In the case of low-social-status families, the mother was somewhat more disposed to place the child in care (Farber, 1972).

2.2.3.1.3.2 Close family and friends

Highly supportive in-laws and a very supportive social network incline mothers to have more positive feelings about their child and to consult fewer doctors. Conversely, mothers with unfulfilled family and social support needs, stand a lesser chance of dealing with the stress of having a severely handicapped child. Mothers experience more support and draw more strength from their relationship with their own mother. In contrast, mothers of handicapped children, who experienced a negative response from the paternal grandmother, experienced more stress (Bradbury & Hewison, 1994; Farber, 1972; Frey, Fewell & Vadasy, 1989; Gallagher, Beckman & Cross, 1983; Mölsä & Ikonen-Mölsä, 1985; Waisbren, 1980).

German and Maisto (1982) found that mothers who opted for residential placement perceived less support from their parents and family members.

2.2.3.1.3.3 Extended family and neighbours

High levels of neighbourly involvement may be indicative of poor adjustment. Farber (1972) found that mothers with a high degree of neighbourliness tended to have a lower marital integration score than wives who were relatively isolated from their neighbours.

In addition, husbands in poorly adjusted families with high levels of involvement in formal organisations reported marital distress.

2.2.3.1.3.4 Respite care

Day care during school holidays and weekends, baby-sitting and assistance with transport can alleviate the stress of the mother. Mothers who opted for residential placement had less access to sitters. Eyman *et al* (1972) reported that mothers benefited from the availability of physical assistance and the presence of alternative child supervisors. Moreover the availability of medical and dental professionals capable of working with severely handicapped children; in-home medical assistance with such techniques as catheterisation and aspiration; and coverage of medical and dental expenses enabled parents to continue with home care (Burden, 1980; Cole & Meyer, 1989; German & Maisto, 1982; Wilks & Wilks, 1974).

2.2.3.1.4 Formal external resources: Support services

The formal external resources that act as mediators of stress for the mother as depicted in Figure 2.20.

Often formal services are mother-orientated and their content determined by professionals. Furthermore the programs mostly reflect the concerns of mothers. Mothers who care for their severely handicapped child in the home are not always aware of the services available to them (Ayers, 1984; Parke & Beitel, 1988).

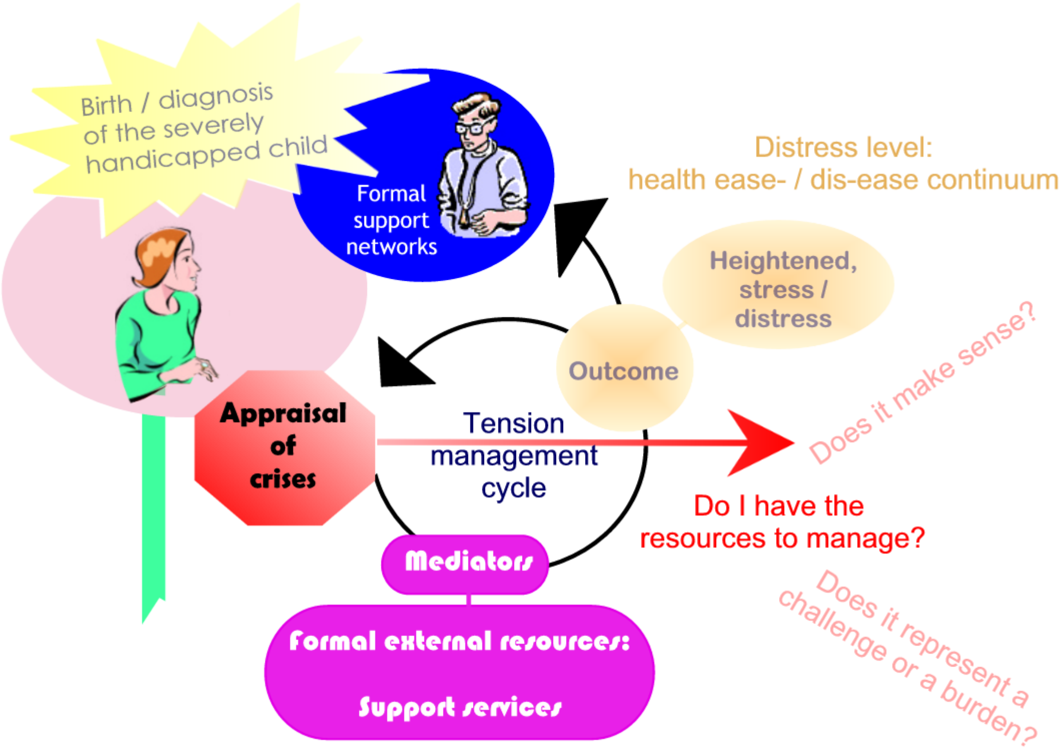


Figure 2.20: Maternal formal external resources

2.2.3.1.5 Coping strategies and behaviours

The maternal coping strategies and behaviours that act as mediators of stress are shown in Figure 2.21.

Sloper *et al* (1991) clearly demonstrated that coping strategies have an effect on the reactions of mothers of handicapped children to potential stressors. The mothers of handicapped children who are most likely to cope with child behaviour problems without risk to their health are those who have good adjustment to the child; have suffered few stressful life events in the preceding year; are employed and from non-manual social classes.

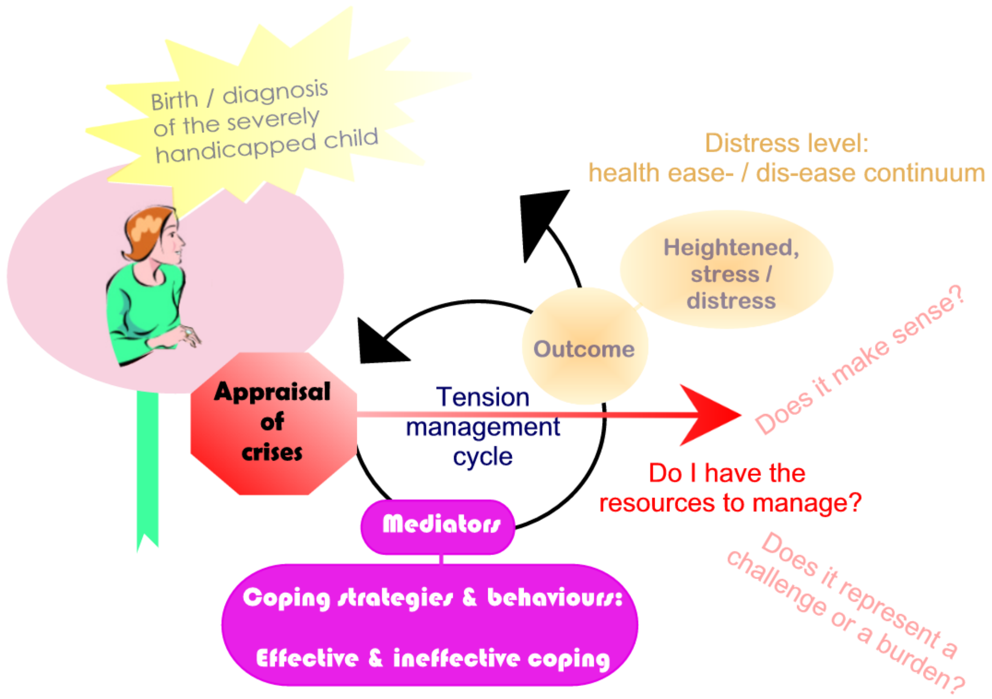


Figure 2.21: Maternal coping strategies and behaviours

2.2.3.1.5.1 Effective coping strategies

Beresford (1994) suggests that coping may be a more significant determinant of maternal well-being than the severity of the stressor being experienced.

2.2.3.1.5.2 Ineffective coping strategies

Generally emotion-focussed coping (for example, avoidance, self-blame, passive acceptance and wishful thinking) is related to increased psychological distress in mothers of handicapped children.

Although greater use of emotion-focused coping may contribute to more depressive symptoms in mothers of developmentally delayed children, the child's behaviour was a stronger predictor of depressive symptoms than the use of emotion-focused coping (Barakat & Linney, 1995; Judge, 1998, Seltzer, Greenberg & Krauss, 1995; Sloper *et al*, 1991; Sloper & Turner, 1993).

2.2.3.2 The outcomes of stress

The outcomes of maternal stress are shown in Figure 2.22.

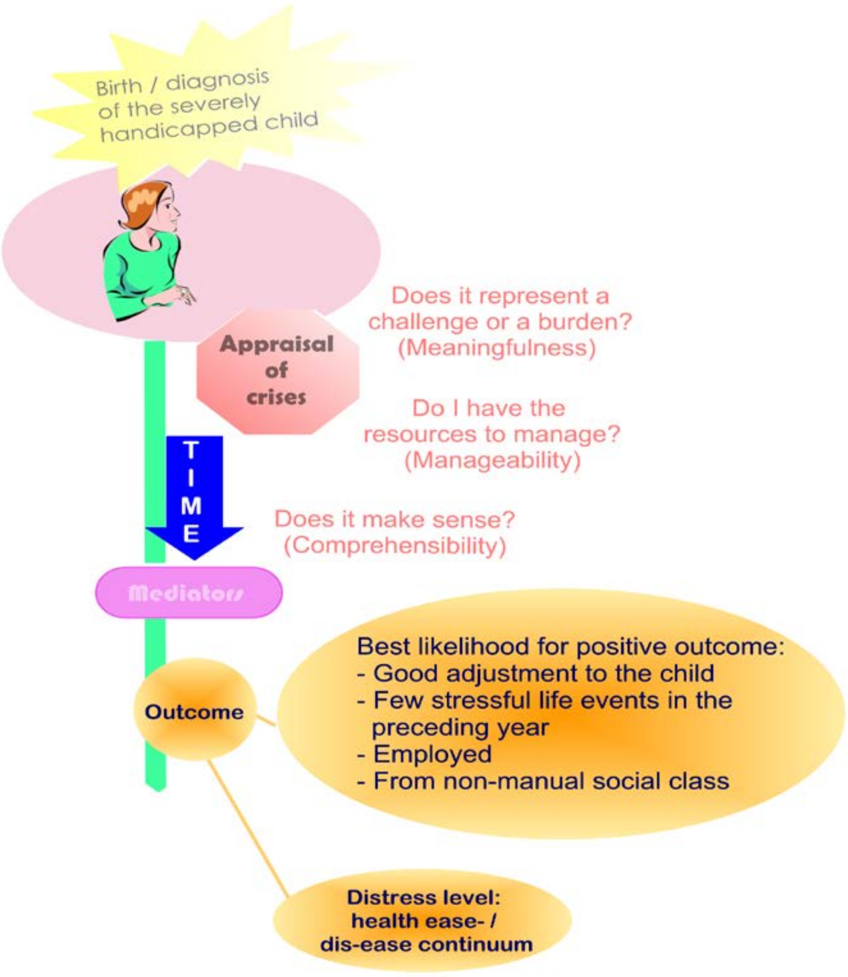


Figure 2.22: The outcome of maternal stress

2.2.4 The father

2.2.4.1 The vulnerable father

The above event confronts the father with overwhelming demands. Consequently he may experience confusion, futility and frustration in his efforts to play the role of a modern, nurturing father. This distress is exacerbated by the loss of his fantasies and plans, the presence of complex grief, the disruption of his normal paternal developmental tasks, as well as societal labelling, stereotyping and isolation. At times, he may fear that this child reflects on his own masculinity, consequently decreasing his own self-esteem.

Life events as they have unfolded since the arrival of the severely handicapped child may have left the father vulnerable to stress. The father who (1) is poorly prepared for a severely handicapped child; (2) has limited support from family and work; and (3) experiences role friction is at even greater risk for heightened distress and may require the intervention of the helping professional (Byrne & Cunningham, 1985; Ellis, 1989; Farber, 1972; Fein, 1976; Gallagher, Beckman & Cross, 1983; Goodnough & Lee, 1996; Hall, 1994; Lemons & Weaver, 1986; Obrzut & Obrzut, 1976; Olshansky, 1962; Opirhory & Peters, 1982; Pruett, 1993; Pueschel, 1986; Riesch, Kuester, Brost & McCarthy, 1996; Roehner, 1976; Trout, 1983; Wikler *et al*, 1981).

2.2.4.2 Socio-ecological impact

The father has faced many challenges in his dealings with the above socio-ecological systems, the context of which define the nature of fatherhood.

He has had to (1) deal with a potentially overtaxed wife; (2) console disappointed siblings and deeply saddened grandparents; (3) live with fears of job loss as child-related demands cut into his workday; (4) attempt to interact with medical and associated helping professionals; and (5) endure frustrating limitations of service providers and government agencies.

The nature of the interaction with and feedback from these systems alters through time and contributes to the father's evolving perception of his efforts at mastering a highly specialised form of fatherhood. Assisting the father starts with understanding his socio-ecological context and providing interventions and support systems that empower him to stay mentally healthy and strong (Garbarino, 1993; Jaffe-Ruiz, 1984; McBride & Black, 1984).

2.2.4.3 Mediators of stress

2.2.4.3.1 Paternal characteristics

The paternal characteristics that act as mediators of stress are shown in Figure 2.23.

2.2.4.3.1.1 Role-related variables

The results from studies of families with handicapped children, which have concentrated mostly on the mother cannot easily be applied and generalised with regard to fathers.

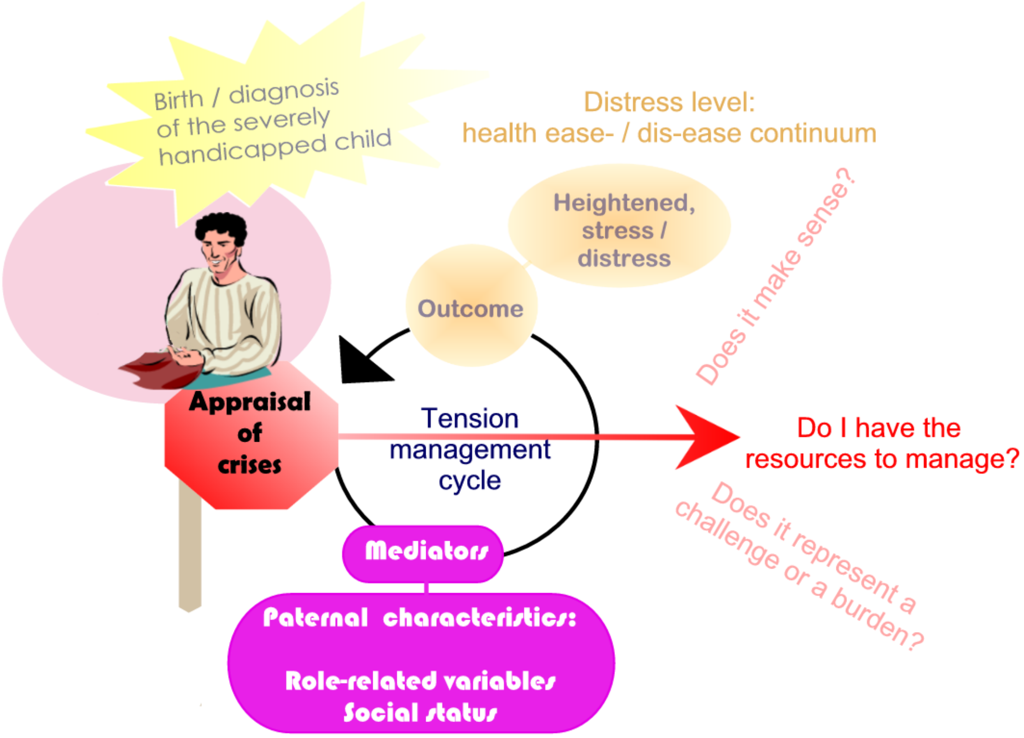


Figure 2.23: Paternal characteristics

Fathers, although less concerned with the nurturing and practical caretaking aspects of parenting than the mother, may have more worries about external issues, such as social and economic dependence, legal and educational concerns and instrumental matters. These gender-related concerns might be complementary to those of the mother or give rise to conflict (Gallagher et al, 1981; Meyer, Vadasy, Fewell & Schell, 1982; Parke & Beitel, 1988; Schilling et al, 1985; Sloper et al, 1991; Wilks & Wilks, 1974).

The father's role may predispose him to higher stress levels. The added responsibility to provide may entail longer working hours and greater avoidance of child-related tasks and problems. This form of lesser involvement does not mean that the father is less stressed or that the mother feels unsupported by the father.

Being less available the father has limited opportunity to (1) alleviate his stress through sharing his experiences with other fathers that are in a similar situation; (2) offer the direct help that could provide concrete evidence of his love, caring, and concern; (3) compensate for and process his sense of loss, frustration, anger and grief; and (4) accept a child, especially a son, with severe impairment and inability to communicate. As a result these fathers are more at risk for developing depression and maintaining a more distant relationship with their handicapped child (Carey, 1982; Cooke & Lawton, 1984; Cummings, 1976a; Frey, Greenberg & Fewell, 1989; Gallagher et al, 1981; Goldberg et al, 1989; Holroyd, 1974; Kazak, 1986; Krauss, 1989, 1993; Tavormina et al, 1981; Trute, 1995).

Fathers respond to having a handicapped child in different ways: (1) withdrawal from the handicapped child; (2) joining his spouse in rejecting the child, followed by placement; (3) over-involvement with the handicapped child at the expense of the rest of the family; and (4) joining the mother in mutual support of the child and of each other, while maintaining a sense of their own identity and resemblance of normal family life.

In well-adjusted families of handicapped children, there is greater consensus about family roles. In these families predominant male roles were provider, protector, outside home maintenance and maintenance of equipment (Gallagher et al, 1981; Tavormina et al, 1981; Trout, 1983).

Although some fathers may tend to be more negative towards their handicapped child, they do not necessarily have (1) more stress than the mother or (2) experience greater difficulty accepting their handicapped child (Cummings, 1976a; Goldberg, Marcovitch, MacGregor & Lojkasek, 1986; Mölsä & Ikonen-Mölsä, 1985; Widerstrom & Dudley-Marling, 1986).

2.2.4.3.1.2 Social status

Farber (1972) found that the higher the social status of the parents, the greater was the willingness of the father - compared with the mother - to place the handicapped child in a care facility. He also determined that the lower the marital integration, the more willing fathers in low status families were to place the handicapped child. In high-status families, however, the influence of marital integration on the father's willingness to place the child was small. This difference in the decisions of high and low status fathers could possibly be attributed to the traditional, provider role of the father. High status fathers may occupy positions and occupations that are more visible in society and may be more concerned about society's view of them. Accordingly, these fathers may wish to hide the child from view in order to maintain the status of the family.

2.2.4.3.2 Internal resources

The internal resources that act as mediators of stress in the father are shown in Figure 2.24.

2.2.4.3.2.1 Sense of coherence

Although less involved with daily interaction with the handicapped child, some fathers of handicapped children, in comparison with fathers of non-handicapped children, exhibit a lower sense of coherence, derive less satisfaction from family life and view their families as less encouraging of personal growth amongst family members.

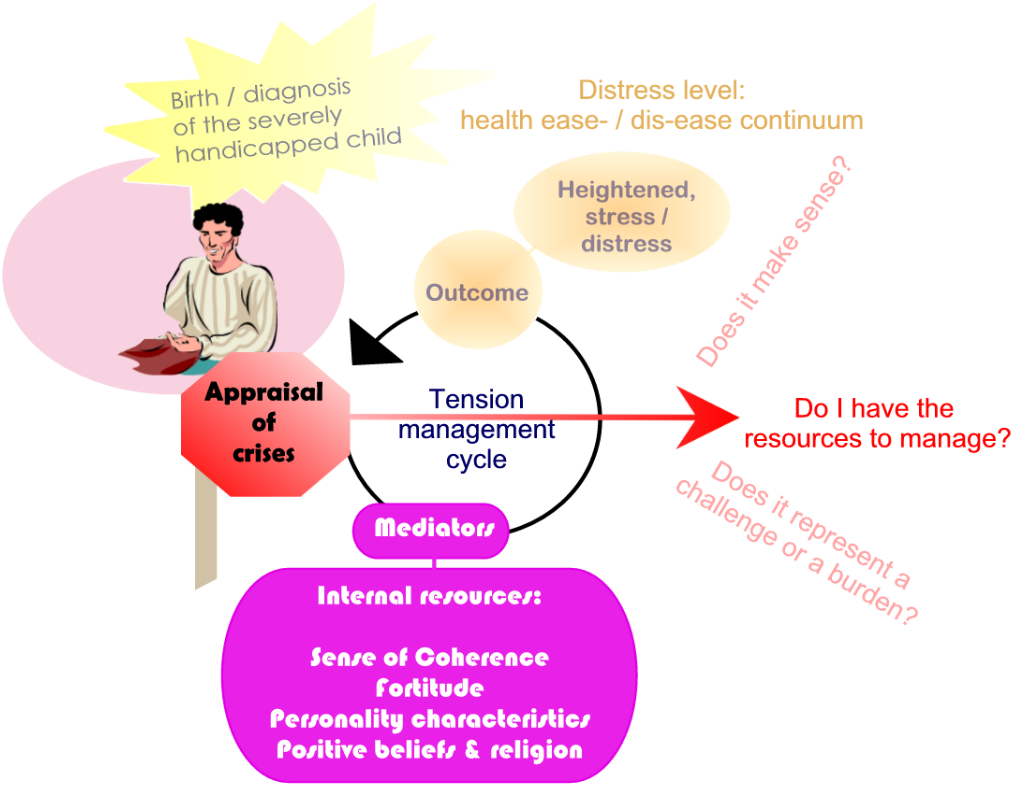


Figure 2.24: Paternal internal resources

Fathers affected in this way may experience a lowered quality of life and a greater degree of stress (Kazak & Marvin, 1984; Margalit, Leyser & Yakov, 1989).

2.2.4.3.2.2 Fortitude

At this time there are no studies to confirm the expectation that a high level of fortitude could enable the father to stay psychologically strong despite the demands of having and caring for a severely handicapped child.

2.2.4.3.2.3 Personality characteristics

Cummings (1976a, p.254) concluded that fathers of handicapped children differ from fathers of non-handicapped children in that they undergo long-term personality changes. Unfortunately, Cummings' psycho-analytically and pathogenically orientated concept of "*a pattern of neurotic-like constriction*" has not been experimentally verified and does not fit within the framework of Positive Psychology.

2.2.4.3.2.4 Positive belief systems and religion

Protestant fathers in families with low marital integration were more willing than those in more highly integrated families to place their handicapped child. Jewish fathers regardless of marital integration or degree of emotional impact were very unwilling to place the child in care. Catholic fathers exhibited only a very slightly greater tendency to place the handicapped child when marital integration was low than when marital integration was high.

2.2.4.3.3 Informal external resources

The informal external resources of the father are shown in Figure 2.25.

2.2.4.3.3.1 The spousal support system

There are very few studies on how the mother's support buffers the stress of the father. There are indications that marital satisfaction contributes positively to the father's satisfaction with life (Sloper *et al*, 1991).

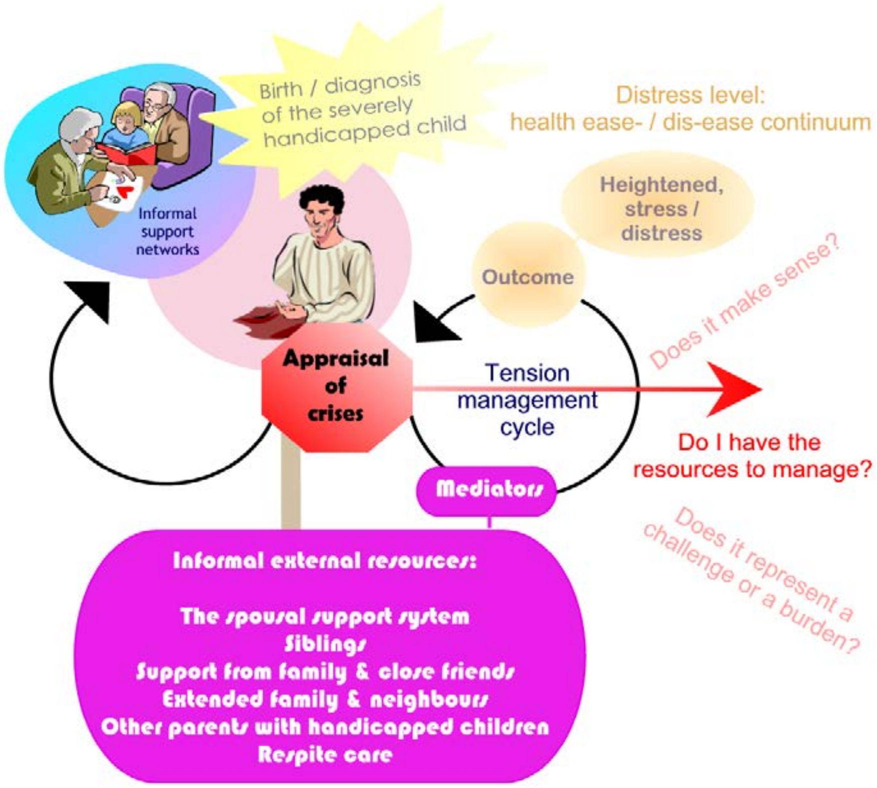


Figure 2.25: Paternal informal external resources

2.2.4.3.3.2 Siblings

Low marital integration together with the father's rejection of his normal daughter's behaviour, was especially predictive in the decision to place the severely handicapped child in a care facility. The higher the social status of the family and the greater the number of other children in the family, the more likely the father would be to place the child (Farber, 1972).

2.2.4.3.3.3 Support of family and close friends

Fathers are not as reliant on social support. Those who come from highly critical families may experience higher levels of stress.

Grandparents, especially paternal grandparents, play an important supportive role.

Fathers of handicapped children who perceived their own parents as highly supportive, were (1) more willing to interact with their child; (2) had more positive feelings about the child; (3) felt they themselves had changed for the better; and (4) were more willing to plan for the future. With the exception of the spousal relationship, this was the most important source of social support for fathers (Bradbury & Hewison, 1994; Farber, 1972; Frey, Greenberg & Fewell, 1989; Waisbren, 1980).

2.2.4.3.3.4 Extended family and neighbours

Fathers in poorly adjusted families and with high levels of involvement in formal organisations, report more marital distress (Farber, 1972).

2.2.4.3.3.5 Other parents with handicapped children

There is no data on how fathers benefit from visits by other parents of handicapped children.

2.2.4.3.3.6 Respite care

Respite care can be a valuable resource to fathers. The unavailability of these services or the mother’s unwillingness to make use of them limits his access to a vital support system, namely his spouse.

As the mother's unwilling to leave the child in respite care may increase with the severity of the handicap, fathers of severely handicapped children may have even less opportunity to invest in and benefit from their spousal relationship (Beresford, 1994; Bose, 1991; Burden, 1980; Cooke & Lawton, 1984; McLinden, 1990; Wilks & Wilks, 1974).

2.2.4.3.4 Formal external resources

The formal external resources that act as mediators of stress for the father are shown in Figure 2.26.

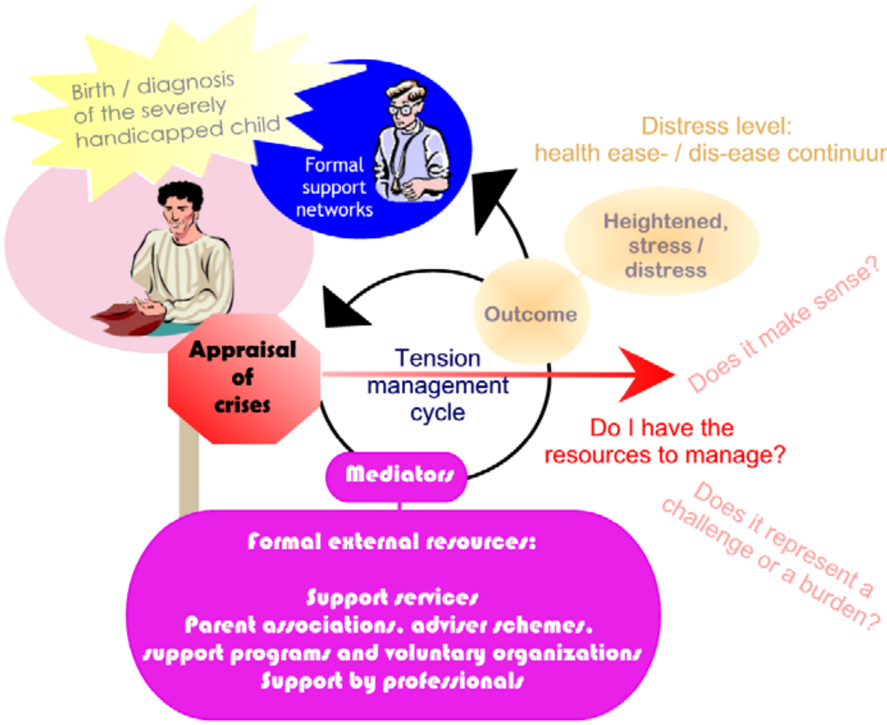


Figure 2.26: Paternal formal external resources

2.2.4.3.4.1 Support services

Over and above the fact that support services and programmes cater mostly for mothers, they disregard the needs, value and availability of the father. Consequently fathers rarely participate in and are less content with these programmes (Ayers, 1984; Cummings, 1976a; Meyer *et al*, 1982; Parke & Beitel, 1988; Price-Bonham & Addison, 1978; Wishart *et al*, 1980).

2.2.4.3.4.2 Parent associations, adviser schemes, support programs and voluntary organizations

McBride (1991) illustrates the efficacy and stress-reducing qualities of such a programme for fathers of handicapped children. These programmes allow fathers the opportunity to interact with men who value fatherhood and to learn about different issues in parenting. They can within a supportive environment share their frustrations, fears, and anger associated with being a parent of a handicapped child. Since the 1980's there has been a growing awareness of the needs of the father and certain programmes have been developed to address these needs. These programmes have benefited both the father and the mother of the handicapped child (Gammon & Rose, 1991; Meyer *et al*, 1982; Vadasy *et al*, 1984).

2.2.4.3.4.3 Support by professionals

Professionals may perceive and treat fathers differently. Professionals, not necessarily equipped to address the specific needs of fathers, may focus exclusively on the child's handicap and the needs of the mother.

This predicts that the father may be more at risk for receiving inadequate or inappropriate support from professionals. The increased demands on the provider role of the father, which may make him less available to professionals, could hinder his acceptance of and adjustment to his situation. The less available father is not necessarily disinterested or apathetic (Herbert & Carpenter, 1994; Kazak, 1986; Price-Bonham & Addison, 1978; Roy & Huguet-Pech, 1987; Russel, 1981).

NICU staff may overlook the implications of the father's provider role and impact of the NICU on him. The father may require more support in his efforts to fund the intervention. Fathers too may have more initial contact with the handicapped, critically ill child. Often he must relay the bad news to the hospitalised and distressed mother. In all of this, the father is often expected to remain strong and not given sufficient opportunity to express his own grief. Some of these fathers have voiced the view that hospital staff were not trained to deal effectively with them. Post-discharge support for fathers may still be lacking (Gardner & Merenstein, 1986a; Herbert & Carpenter, 1994; Obrzut & Obrzut; 1976).

2.2.4.3.5 Coping strategies and behaviours

The coping strategies and behaviours that act as mediators of stress for the father are shown in Figure 2.27.

There are findings that suggest that, in general, men are better able to deal with stress (Pearlin & Schooler, 1978). Little predictive data is available with regard to fathers of handicapped children.

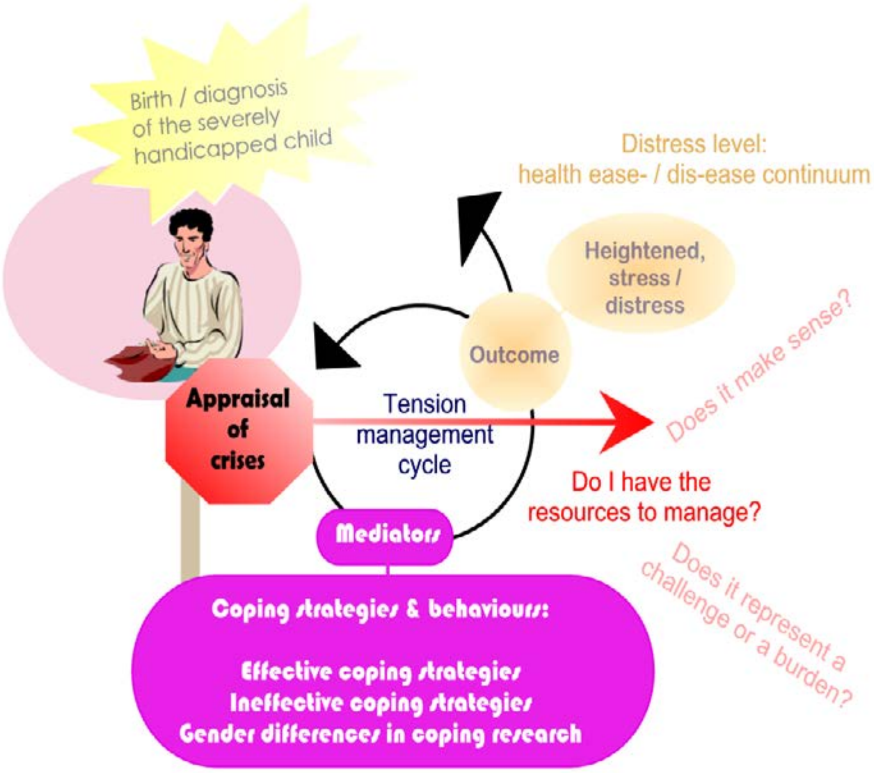


Figure 2.27: Paternal coping strategies & behaviours

2.2.4.3.5.1 Effective coping strategies

Fathers of handicapped children who make greater use of cognitive coping mechanisms such as problem-solving skills and who help develop more effective solutions to their child-related problems exhibit better personal adjustment and experience less negative ideation (Frey, Fewell & Vadasy, 1989; Sloper *et al*, 1991).

2.2.4.3.5.2 Ineffective coping strategies

With the exception of passive acceptance no coping strategies have been found that significantly predict poor adjustment in fathers (Sloper *et al*, 1991; Sloper & Turner (1993).

2.2.4.3.5.3 Gender differences in coping research

Multi-variate studies suggest that fathers show a less pronounced relationship between the use of certain coping strategies and adjustment. This may be because mothers and fathers have different roles and respond to different aspects of having and caring for a handicapped child (Cummings, 1976a, 1976b).

2.2.4.4 The outcomes of stress

The outcomes of stress for the father are illustrated in Figure 2.28.

Little predictive data is available with regard to fathers. Fathers in successfully adjusted families believe they should share more in family activities involving the handicapped child and the mothers generally agree that they participate to help fulfil such a need.

Despite their willingness to help, the fathers have some difficulty defining the way in which they should demonstrate this (Gallagher *et al*, 1981; Sloper *et al*, 1991).

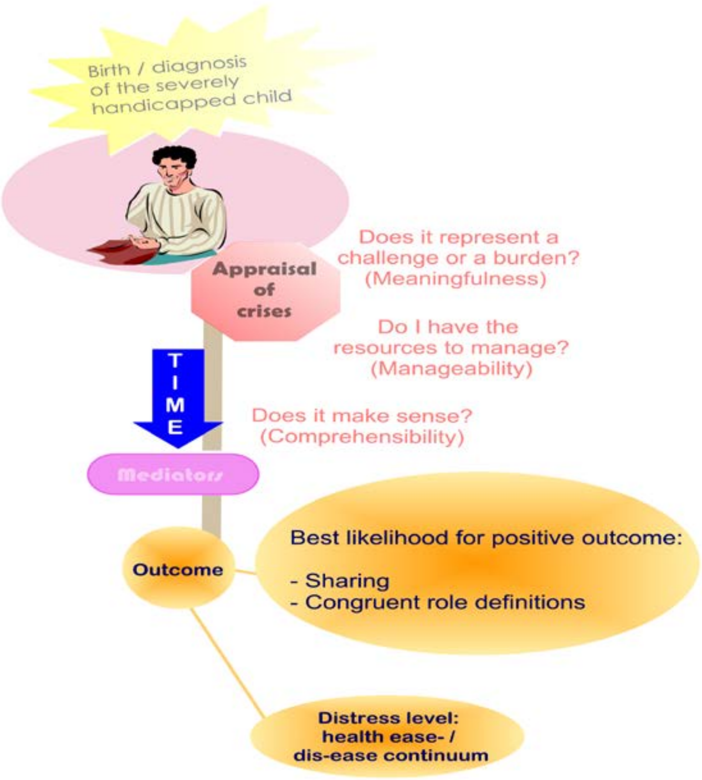


Figure 2.28: Outcomes of paternal stress

2.2.5 The single parent

The issues relating to single parents are shown in Figure 2.29.

Figure 2.29: Single parents

Studies that have focussed directly on single mothers (or fathers for that matter) with handicapped children are rare (Gottlieb, 1998).

2.2.5.1 Separation and divorce

Single parent families are not more common amongst families containing handicapped children. Handicapped children may be only one of many reasons why parents decide to end a marriage and this finding suggests that the presence of a handicapped child is not a greater contributor to marital breakdown than any of a number of other stressors.

These children are, however, more likely than non-handicapped children to experience at least one spell of separation as their parents may possibly split at least once in their first 10 years of marriage. The more severe the child’s handicap, the longer the parental separation and the more improbable the possibility of family reconstitution.

Fathers rarely leave the marriage shortly after the birth of the handicapped child. Departure tends to follow a long stretch with no clear developmental progress in the child, the addition of yet another diagnosis, a medical pronouncement that the child would either die soon or would live, but remain sick or handicapped. Research on the presence of a handicapped child in a family and divorce is inconclusive. In the case of divorce, fathers are more likely to remarry, whereas mothers who have retained custody of the child do not (Beckman, 1983; Garland, 1986; Cooke, Bradshaw, Lawton & Brewer, 1986; Gath, 1977; Martin, 1975; Tew, Lawrence, Payne & Rawnsley, 1977; Sabbeth & Leventhal, 1984; Trout, 1983; Widerstrom & Dudley-Marling, 1986).

2.2.5.2 A heavier load

The single parent has more stress. An absent or unsupportive father can lead to deterioration in the mother-child relationship and in the mother's ability to maintain family integration, cooperation, and optimism about future stressful situations. Single mothers may also experience more demands on their time, more financial problems and less social support (Beckman, 1983; Gallagher, Beckman & Cross, 1983; Hanson & Hanline, 1990; Holroyd, 1974; Pederson, 1976; Quine & Paul, 1985).

2.2.5.3 Flexibility and adaptability

Although single mothers are more stressed, they are also more adaptable and flexible with regard to family rules, power structure, and role relationships (McCubbin, 1989; Salisbury, 1987).

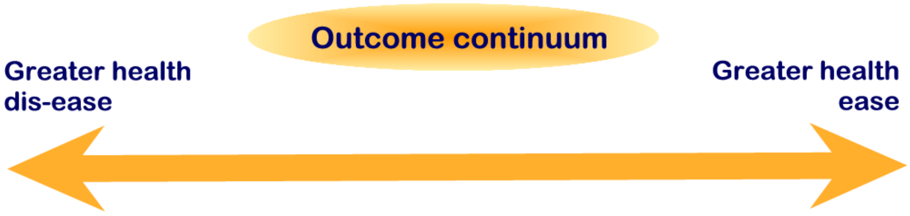
2.2.5.4 Sense of coherence

Single mothers with a strong SOC are less likely to have a handicapped child with behavioural difficulties and it is more probable that these mothers will have a more stable family life and the ability to make more frequent and effective use of a greater variety of coping strategies. Generally a strong SOC suggests a positive outcome in single mothers with handicapped children (Gottlieb, 1998).

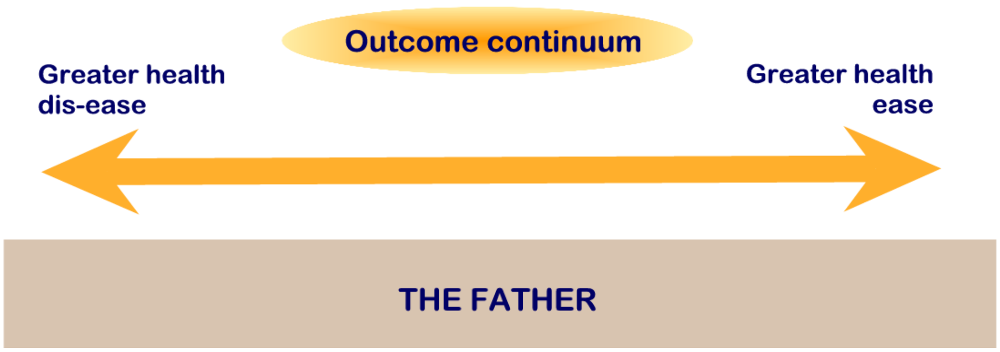
2.3 The big picture

2.3.1 Child-related characteristics

A summary of the child-related characteristics that act as mediators of stress for parents of handicapped children is provided in Figure 2.30. The summary depicts how each characteristic relates to the outcome of parental stress.



	THE COUPLE	
Older	**Age**	Younger
More	**Severity**	Less
Boy	**Gender**	Girl
More problems	**Behaviour**	Less problems
More	**Care-giving demands**	Less
One or more	**Handicapped sibling**	None
Anglo	**Culture**	Other
	THE MOTHER	
More	**Caretaking needs**	Less



More	**Communication delay**	Less
Boy	**Gender**	Girl

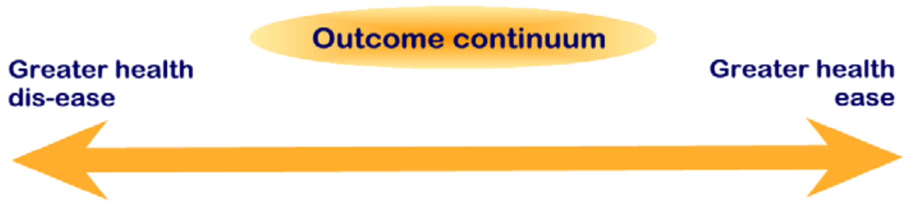
Figure 2.30: Mediators of stress: Child-related characteristics

Severely handicapped children have many of the characteristics that put parents at risk for very high levels of stress. **Care-taking demands** especially have a greater impact on the mother whereas a **lack of communicative ability and gender** (if the child is a boy) has a greater impact on the father.

2.3.2 The parent

2.3.2.1 Parental characteristics

A summary of the parental characteristics that act as mediators of stress for parents of handicapped children is provided in Figure 2.31. The summary depicts how each characteristic relates to the outcome of parental stress.



Parental characteristics

THE COUPLE

Younger	**Age**	Older
Worse	**Physical health**	Better
Worse	**Mental health**	Better
Low	**Income**	High
Single	**Marital status**	Unmarried

THE MOTHER

Many odd child features & greater physical disability	**Vulnerability of older mother**	Few odd child features & less physical disability

THE FATHER

Role-related variables

More	**Worries about external issues**	Less
Conflicting	**Fulfilment of gender-related roles**	Complementary

More	**Provider demands**	Less
Less	**Availability to family**	More
High status = placement	**Status**	Low status = homecare
Low status + marital problems = placement	**Status & marital problems**	Low status without marital problems = homecare

Figure 2.31: *Mediators of stress: Parental characteristics*

When **older parents** have a severely handicapped child they are more likely to present with better adjustment. Younger parents may be more vulnerable from the outset and have greater adjustment difficulties. These may be the parents who due to high distress and greater demands on their resources are more likely to place the child. They may have the greatest need of professional intervention.

A **decline in maternal physical and mental health** places strain on the spousal relationship and inclines parents towards residential care.

Both parents fulfil **unique roles**. Mothers mostly undertake nurturing and caretaking, whereas fathers are more involved in fulfilling a provider, child-minding and recreational role. Parents cope best when these roles are complementary and consensual.

Social status affects the placement decisions of fathers. High status fathers may choose to place the child in order to maintain the status of the family. Social status plays no significant role in the placement decisions of mothers.

2.3.2.2 Internal resources

A summary of the parental internal resources that act as mediators of stress for parents of handicapped children is provided in Figure 2.32. The summary depicts how each resource relates to the outcome of parental stress.

Internal resources

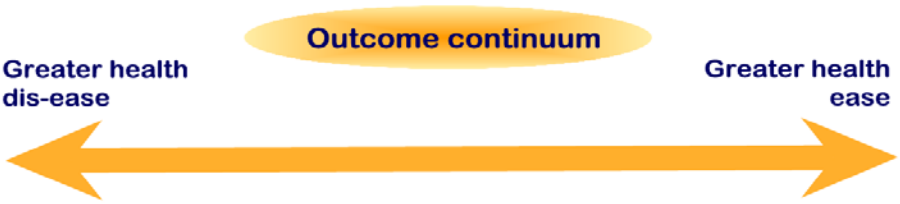
THE COUPLE

Dispositional factors

Low	**Pre-crisis SOC**	High
Very weakened	**Current SOC**	Slightly weakened

Personality factors

Weak	**Beliefs**	Strong
Weak	**Commitments**	Strong
High	**Neuroticism**	Low
Low	**Optimism**	High



Low	**Self-esteem**	High
Introversion	**Personality Orientation**	Extraversion
Absent	**Humour**	Present
External	**Locus of control**	Internal

Positive belief systems and religion

Negative	**Beliefs about locus of control**	Positive
Negative	**Appraisals of coping skills**	Positive
High	**Pessimism**	Low
Negative	**Appraisals of social support**	Positive
Negative	**Perspective on family problems**	Positive
Unsuccessful	**Use of beliefs as coping resources**	Successful
Ineffective	**Utilisation of existing philosophies**	Effective

Ineffective	**Modification of existing philosophies**	Effective
?	**Religion**	?

History of pre-crisis stress management

Poor	**Prior experience & understanding**	Good

Perceived stress

High stress = placement	**Perceived stress level**	Low stress = homecare

Perceived burden of care

High care = placement	**Perceived burden**	Low care = homecare

THE MOTHER

SOC in single mothers

Low = more child behaviour difficulties + use of fewer coping strategies	**SOC level**	High = less child behaviour difficulties + use of more coping strategies

Attribution

Unmanageable	**Child’s condition**	Manageable

Self-inflicted	**Attributed cause of handicap**	Environmental
Parenting skills		
Low	**Satisfaction with competency**	High

Figure 2.32: Mediators of stress: Parental internal resources

Effective **pre-crisis tension management**, previous exposure to handicaps, positive perceptions of coping efficacy and the absence of pre-crisis psychiatric problems increases the likelihood of better maternal adjustment to the birth/diagnosis of the severely handicapped child. In general, a history of effective pre-crisis tension management seems beneficial to both parents.

There is little doubt that the presence of a severely handicapped child buffets the parents' **Sense of Coherence** and results in a negative shift on the health ease-/dis-ease continuum. Lowered SOC does not necessarily signal deterioration in the spousal relationship, but could suggest positive parental adjustment.

Whereas there are no findings on unique ways in which the married mother's SOC responds to the handicapped child, generally a strong SOC suggests a positive outcome in the tension management process of the single mother and in the behaviour outcome for her child.

Indications are that fathers of handicapped children exhibit a lower sense of coherence, which suggests a higher dis-ease level.

Although there is a finding to the effect that fathers of handicapped children are not more stressed than fathers of non-handicapped children it is thought to be highly improbable that he will remain unaffected given the combination of the nature of both the stress process and of severe child handicap as well as he extend to which he is embedded in his socio-ecological environment. It is considered to be very likely and appropriate that he may have significantly higher levels of stress and a lower SOC than fathers of non-handicapped children.

In the end it is not about whether the parents shift to a lower position on the health ease-/dis-ease continuum. They will shift. The issue is to what point they will shift; to what degree the strength of their pre-existing SOC can buffer against too great a decline in health-ease; and to what extent their SOC can assist them in developing appropriate and effective tension management and coping strategies in order to find new stability.

Certain **personality characteristics** (beliefs, commitments, low levels of neuroticism, higher levels of optimism and self-esteem, extraversion, humour, internal locus of control) may predispose the parent to more effective stress management.

Both parents' ability to maintain an **inner locus of control** over life events, **utilise existing and develop new beliefs** in order to adjust and to have **positive appraisals of social support and coping skills**, predicts positive adjustment for the parents of handicapped children. The presence of these aspects in the mother not only assists her in maintaining a stronger spousal relationship, but facilitates positive engagement with her handicapped child. In contrast, mothers who are dissatisfied with their **parenting competency** and **levels of social support** may experience more stress.

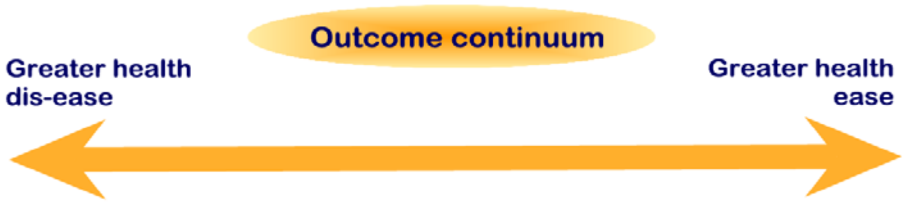
Attribution can influence mothers' stress levels. Those who view their child's condition as manageable and attribute the handicap to environmental causes may adapt more successfully than mothers who rate their child's symptoms as more severe and who attribute the illness to their own behaviour.

Perceived stress and **perceived burden of future care** is an important factor in parents' decision to place.

For some people the presence of **religious beliefs** may buffer or aggravate their stress and influence their placement decisions. The findings are equivocal.

2.3.2.3 Informal external resources

A summary of the parental external resources that act as mediators of stress for parents of handicapped children is provided in Figure 2.33. The summary depicts how each resource relates to the outcome of parental stress.



Informal external resources

THE COUPLE

Weak	**Pre-crisis spousal relationship**	Strong
Weak	**Current spousal relationship**	Strong

Inappropriate	**Utilisation of siblings**	Appropriate
Low support	**Family & close friends**	High support
Non-availability during crisis	**Extended family and neighbours**	Availability during crisis
No visits	**Other parents with handicapped children**	Visits
Not available	**Respite care**	Available

THE MOTHER

The spousal relationship

Low	**participation**	High
Seldom	**Information seeking**	Often
Professional	**Occupational status**	Non-professional
Less	**Child-minding assistance**	More

Close family and friends

Low support	**In-laws**	High support

Low support	**Own mother**	High support

Extended family and neighbours

At all times	**Involvement with neighbours**	Only during crisis

THE FATHER

The spousal relationship

Poor	**Marital satisfaction**	Good

Siblings

Poor	**Relationship with siblings-**	Good
More	**Number of siblings**	Less

Support of family and close friends

More	**Family criticism**	Less
Less	**Support from paternal grandparents**	More

Figure 2.33: Mediators of stress: Parental informal external resources

The **spousal relationship** is the most important predictor of parental tension management. It bears the brunt of the stress introduced by the presence of the severely handicapped child. Marital discord heightens the probability of a placement.

There is ample evidence that some marriages can weather the stressful onslaughts brought about by the presence of the severely handicapped child. Divorced or single-parent families are no more prevalent amongst parents of severely handicapped children. Divorced mothers of severely handicapped children may be at risk as they carry a heavier load and tend not to remarry and, consequently have to cope without a vital support system.

The parental relationship with, attitude towards and utilisation of the **siblings** seems to predict the adjustment to the non-handicapped children in the family. Over-utilisation and parent-child conflict predicts poor adjustment and higher levels of distress for both parent and child.

Mothers are most reliant on their close, informal support network. Hence support from **grandparents**, **family** and **close friends** is a critical resource to them. The presence of higher and more extensive family stress, fewer family resources and a lack of support systems is predictive of a decision to place a child in a care facility. Although fathers are not as reliant on social support, they are sensitive to family criticism. Paternal grandparents can play an important supportive role for the father.

Relatives, **friends** and **neighbours** mostly assist during times of crisis. They are not a primary support system. Maternal over-dependence on neighbours suggests poorer adjustment.

Other parents of handicapped children offer a special sort of support as they have first-hand experience of what it means to have such a child. They may however also add to parental stress if they make excessive demands on the parents they are attempting to support.

Both parents, individually and jointly, can glean tension-relieving benefits from **respite care** or **respite workers**. It seems, however, that parents of severely handicapped children have less access to these resources as appropriate facilities and people are scarce.

2.3.2.4 Formal external resources

A summary of the parental external resources that act as mediators of stress for parents of handicapped children is provided in Figure 2.34. The summary depicts how each resource relates to the outcome of parental stress.

Formal External Resources

	THE COUPLE	
Non-availability during crisis	**Support services**	Availability during crisis
Non-availability for future planning	**Support services**	Availability for future planning
Inappropriate	**Support programmes**	Appropriate

Unavailable	**Organisations**	Available
Inappropriate support	**Professionals**	Appropriate support
?	**Psychologists**	?
Unavailable	**Residential facilities**	Available
	THE MOTHER	
Poor	**Knowledge of available services**	Good
	THE FATHER	
Services		
Less	**Father-orientated**	More
Support programs		
Less	**Father-orientated**	More
Professionals		
Less	**Father-orientated**	More

Figure 2.34: Parental formal external resources

Formal **support services**, which are mostly mother-orientated and disregard the needs, value and availability of the father do not seem to play a very important role in the tension management process of the parent of the severely handicapped child. They are only called on in times of crisis or when parents need to involve them in future planning for the child. In South Africa, services and facilities for parents of severely handicapped children are lacking.

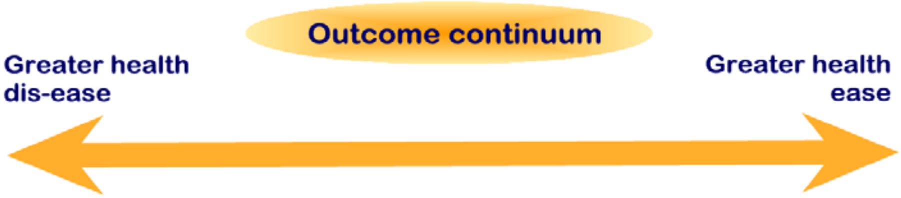
Parent associations, **Parent Advisers**, **parental training** and **support programs** as well as **voluntary movements** can be beneficial to parents. Since the 1980's some programme developers have recognised the unique needs of the father. High levels of paternal involvement in formal organisations coupled with poor family adjustment can compound marital distress.

Professionals although not rated by parents as a primary resource can set the tone for the parents' future adjustment and tension management. At this time it seems that psychologists have a very limited role in supporting parents through their various crises. Most probably psychologists only become involved following referrals from medical professionals and social workers.

Especially in the case of parents of severely handicapped children facing a long-term involvement with the child the psychologist could play a much more significant role in optimising the parent's psychological health and strength. There is a need to address the training of professionals in order to equip them to deal effectively with both parents.

2.3.2.5 Coping strategies and behaviours

A summary of the parental coping strategies and behaviours that act as mediators of stress for parents of handicapped children is provided in Figure 2.35. The summary depicts how each resource relates to the outcome of parental stress.

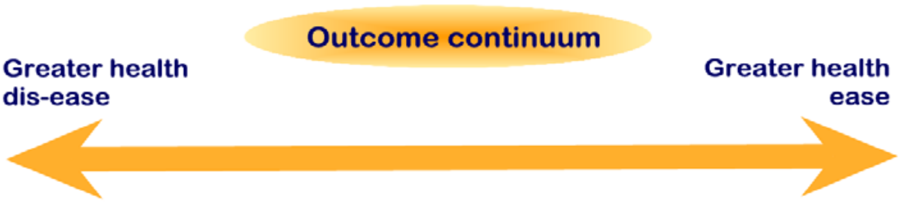


Coping strategies and behaviours

THE COUPLE

Poor	**Acceptance & understanding of child's handicap**	Good
Discourage	**Self-sufficiency in child**	Encourage
Negative	**Focus on child**	Positive
Seldom	**Problem-focused coping**	Often
Seldom	**Emotion-focused coping that facilitates problem-focused coping**	Often
Low	**Parental belief that he/she can have a potent influence**	High

Seldom	**Use of cognitive restructuring**	Frequent
Incongruent	**Use of optimism**	Congruent
Low	**Rationality**	High
Low	**Flexibility**	High
Low	**Far-sightedness**	High
Seldom	**Day-to-day approach (with awareness of long-term consequences)**	Often
Low	**Utilisation of informal & close support system**	High
Direct	**Demand for social support**	Indirect
Seldom	**Maintenance & development of resources**	Often
Negative	**Appraisal of coping skills**	Positive
Non-complementary	**Use of problem-solving**	Complementary



Disrupted	**Lifestyle**	As normal as possible

THE MOTHER

Poor	**Adjustment to child**	Good
Many	**Previous stressful events**	Few
Unemployed	**Occupational status**	Employed
Manual	**Social class**	Non-manual
High	**Avoidance**	Low
More	**Suppression of emotion**	Less
More	**Over-expression of emotion**	Less
High	**Behavioural disengagement**	Low
High	**Mental disengagement**	Low
Often	**Assumption of sick role**	None

Poor	**Involvement with intervention**	Good
Poor	**Relationships with helping professionals**	Good

THE FATHER

Less effective	**Child-related problem-solving**	More effective
Less use	**Cognitive coping mechanisms**	More use
Worse	**Personal adjustment**	Better
Negative	**Ideation**	Positive
More	**Passive acceptance**	Less

Figure 2.35: Mediators of stress: Parental coping strategies and behaviours

Coping strategies and behaviours represent a very important resource for the family.

The tension management cycle based on the components of the SOC facilitates coping. **Problem-focused coping** strategies as well as **emotion-focused coping** that facilitate problem-focused coping strategies can lead to positive adjustment in the parent of the severely handicapped child. Both problem- and emotion-focused coping strategies entail a **variety of coping behaviours**. Parents may have **preferred coping styles**.

In order to determine **coping efficacy**, both **coping behaviours** and the **context** within these behaviour occur should be considered.

2.3.2.5.1 Effective strategies

Where parents:

- Develop **acceptance and understanding** of the handicap;
- Develop **self-sufficiency** in the child**;**
- Focus on the **positive aspects** of the child;
- Have **higher educational, occupation and status levels**;
- Adhere to **reflective, probing, planned, practical** and **present-orientated problem-solving strategies**;
- Exhibit the belief that they can exert a **potent influence** over their child’s life;
- Utilise **cognitive restructuring**;
- Make **congruent use of optimism** and **complementary use of problem-solving**;
- Exhibit the coping skills of **rationality**, **flexibility** and **farsightedness**;

- Are able to **manipulate their goals and values**;
- Follow a **day-to-day approach** with awareness of long-term consequences;
- Utilise **informal and close support** systems;
- Are able to galvanise their **social support systems** without directly eliciting too much support;
- **Maintain**, **develop** and **engage effectively** with **coping resources**; and
- **Perceive** themselves as having **good coping skills**; and
- Attempt to maintain a **lifestyle that is as normal as possible** they stand a better chance of coping effectively.

Employed mothers from non-manual social classes, with good adjustment to the child and a history relatively free of previous stressful life events, are most likely to cope with child behaviour problems without risk to their health.

Fathers of handicapped children who make greater use of cognitive coping mechanisms such as problem-solving skills and develop more effective solutions to their child-related problems, exhibit better personal adjustment and experience less negative ideation.

2.3.2.5.2 Ineffective coping strategies

The birth/diagnosis or mere presence of a severely handicapped child introduces demands that may be **beyond the personal coping controls** of the parent.

Thus, this parent may be more at risk for ineffective coping. Especially **less educated**, **poorer** parents who have (1) a **lower sense of coherence;** (2) **less available resources;** and (3) a handicapped child with **more severe behavioural difficulties** may make greater use of ineffective emotion-focused coping strategies.

Generally **emotion-focussed coping** is related to increased psychological distress in mothers of handicapped children. With the exception of **passive acceptance** no coping strategies have been found that significantly predict poor adjustment in fathers.

2.3.2.5.3 Coping research

Coping research needs to take into account the unique role-related aspects of both parents. Much research has been biased against the father due to the omission of this consideration.

2.4 The focus of this study

A well-managed tension management process (realistic appraisal, effective utilisation and development of resources and effective coping) may enhance the psychological health and strength of the parents of handicapped children. To what extent this is so in the case of parents of severely handicapped, placed children is less clear.

It is the purpose of this study to provide further clarity with regard to

(1) the nature of (a) stressors, perceived stress, sense of coherence, fortitude and coping; (b) the relationship between perceived stress and personal-, family- and child-related stressors and; (c) the relationship between perceived stress and the psycho-fortigenic factors of sense of coherence, fortitude and coping as experienced and reported by the parents as a whole and by fathers and mothers separately;

(2) The extent to which fathers and mothers differ with regard to (a) stressors, perceived stress, sense of coherence, fortitude and coping; (b) the relationship between perceived stress and personal-, family- and child-related stressors and; (c) the relationship between perceived stress and the psycho-fortigenic factors of sense of coherence, fortitude and coping; and

(3) The degree to which psycho-fortilogical characteristics (sense of coherence, fortitude and coping) of the one parent influence the perceived stress of the other.

3 Methodological considerations

3.1 Introduction

Some parents of severely handicapped children have to choose an out-of-home setting - this entails further losses and makes new demands on the family. It has been clear in the Literature Review that placement of a severely handicapped child in a care facility can represent an adaptive response to which there can be a positive outcome. Given that the spousal support system is pivotal to the stress management of both parents, it follows that the mother's perceived stress and coping efficacy could be moderated by the father's ability to remain supportive and psychologically strong. A moderator variable is represented statistically by an interaction with the independent variable; on a conceptual level, it specifies the conditions under which the variable exerts its effects (Quittner, Glueckhauf & Jackson, 1990). A stressed and psychological unwell father may have difficulty to remain supportive.

Within the context of the stress theories presented in the previous chapter, the father's ability to stay psychologically well could be determined by (1) his appraisal of the stressor and his stress; (2) his appraisal and utilisation of coping resources; and (3) application of effective coping strategies. It follows that the amount of perceived stress, availability and use of coping resources and coping strategies could serve the purpose of determining the psychological wellness of the father.

Most related research refers to the mother, child and family, with limited reference to the father. Research on fathers of severely disabled, institutionalised children is rare. This study can contribute the sketchy body of knowledge that is available about fathers who have severely handicapped and in so doing provide guidelines for appropriate interventions by professional helpers.

3.2 Purpose of the study

The purpose of this study is two-fold: Firstly, to investigate how factors such as the sources of stress, perceived stress, stress-resistance resources (sense of coherence and fortitude), coping resources and coping strategies contribute to the psychological wellness of fathers with severely handicapped, placed children and secondly, to examine the moderating effects of the father's sense of coherence, fortitude, coping resources and coping strategies on the perceived stress and coping of the mother.

This research project consists of a **quantitative study**, encompassing the completion of five questionnaires by a sample of parents who have severely handicapped children in care facilities.

3.3 Research goals

The goals of the study are fourfold, namely:

- To determine whether fathers and mothers differ significantly with regard to levels and sources of stress, perceived stress, sense of coherence, fortitude and coping dispositions and responses. The nature of the relationship between those variables that are found to differentiate between the fathers and the mothers will also be examined;
- To determine the relationship between the perceived stress and the different stressors that the parent is actually confronted with;
- To examine the extent to which parents' sense of coherence, fortitude, coping dispositions and coping responses serve as a stress-reducing function for themselves;

- To examine the nature of the relationship between certain qualities (coping dispositions, fortitude and sense of coherence) of fathers and perceived stress of mothers and vice versa; and
- To provide guidelines to professional helpers.

3.4 Instruments of measurement

In the introduction to this study (See page 2) it was stated that this study on the stress and coping of fathers with severely handicapped children in care facilities adheres to the research approach that "*recognises the fact that many families cope well and seeks to discover how they do so. This approach focuses on the family's material, psychological, social resources and the coping strategies*".

Stress itself is seen within a multi-variate and socio-ecological context and both pathogenic and positive models of stress have been offered.

In order to compile a comprehensive picture of perceived stress, stressors, coping resources and coping strategies five questionnaires were utilised, namely the Questionnaire on Resources and Stress (Holroyd, 1974, 1982), The Perceived Stress Scale (Cohen, Kamarck & Mermelstein, 1983), The Sense of Coherence Scale (Antonovsky, 1987, 1993), The Fortitude Questionnaire (Pretorius, 1998) and the COPE Inventory (Carver *et al*, 1989).

In addition to the above questionnaires, respondents were provided with a brief biographical questionnaire.

3.4.1 Instruments of measurement that assess the origins and amount of stress

3.4.1.1 The Questionnaire on Resources and Stress (QRS)

In 1974 Prof Jean Holroyd (Holroyd, 1974), a widely acknowledged researcher within the field of handicapped and terminally ill children, developed the (QRS).

The QRS examines the stressful impact of disability on three areas relevant to the world of the handicapped child, namely, the problems of the parent, the family and the handicapped child. It is a multi-dimensional, objective, self-report questionnaire consisting of 285 true/false self administered items divided into 15 scales.

The QRS provides useful information about the way in which the respondents appraise their various stressors related to themselves, their family and their child. This information can be utilised by clinicians to optimise intervention and to monitor treatment effects (Jansen, 1995: 82).

The QRS scales have been validated primarily on families of children and adolescents with various mental or physical illnesses or developmental disabilities (Holroyd, 1974; Holroyd *et al*, 1975; Holroyd & Guthrie, 1979; Holroyd & McArthur, 1976). Validity data has been obtained in various settings and across different cultures. This suggests that the QRS is applicable in a cross-cultural setting (Jansen, 1995).

Although a short form of the QRS is available, Holroyd (1982) suggests the use of the full scale for clinical differentiations and research.

3.4.1.1.1 Development of the QRS

Both deductive and inductive approaches were used to develop the 15 QRS scales (Holroyd, 1974).

As a first step a team of experts all of whom had experience with handicapped populations consisting of a psychologist, psychiatrist, social worker, parent and two teachers compiled a pool of 556 items. Next, 12 psychologists, social workers and public health nurses were asked to rate the items and reduced the number to 251. In the next round 29 additional items were included because of their theoretical importance. In the fourth and final round another 15 items focussing on care for a dependent family member (Holroyd, 1982) were added, bringing the total number of items to 285.

Once selected the items were formulated in such a way that, if answered by respondents in a supposedly healthy, adjusted and well-coping environment, 50% would be answered true and 50% false. In addition, the items were amended so that they (1) would suit any age or gender and (2) were readable at a Grade 6 level. Language and syntax was simplified to benefit poorly educated populations (Holroyd, 1982).

Following the selection of the 285 items, a social worker conducted in-depth interviews with six parents who had completed the QRS. Four items, which the parents identified as confusing or unacceptable, were re-formulated.

Fifteen scales were developed from the pool of 285 items. This was done by means of inter-correlations using 43 unmatched parents. A factor analysis of the 285 items yielded 11 factors, five for personal, three for family and three for index case problems (Holroyd, 1982).

3.4.1.1.2 Description of each scale (Holroyd, 1982)

3.4.1.1.2.1 Personal problems scales

Scale 1: Poor Health/Mood (PHM), is an 11-item scale that reveal sadness, depression, tension, fatigue, poor health and a feeling of pressure from taking care of the identified patient. Sadness measured on this scale is not only associated with the emotional impact of caring for a handicapped family member, but also reflects the respondent's dissatisfaction with his/her role within the family (Jansen, 1995). The scale also differentiates between mothers and fathers and has a rather high internal consistency (Kuder-Richardson $\underline{r}$ = 0.79).

Scale 2 Excess time demands (ETM), contains 14 items that are associated with the demands on the primary caregiver of the handicapped family member. High scores reveal both the ensuing isolation and the increased time demands experienced by the primary caregiver, most often the mother. The scale includes items pertaining to having outside activities including a job, visiting friends, and having time for oneself. This scale differentiates between mothers and fathers and its internal consistency is moderate ($\underline{r}$ = 0.73).

Scale 3: Negative attitude toward index case (NA), may have a misleading title. Validation studies show that it measures oversensitivity to illness and disability more than critical attitudes towards the patient (Jansen, 1995: 86). The 23 items of this scale indicate: (1) anxiety about how much to expect from the handicapped person; (2) social sensitivity in terms of what others may think of the handicapped child and the respondent; and (3) sensitivity to the level of cognitive impairment of the handicapped child. The scale has a high internal consistency (***r***= .81).

Scale 4: Overprotection/Dependency (OPD), . has 13 items that reflect the opinion that the patient is too dependent on assistance, perhaps overprotected. The Overprotection/Dependency Scale was originally included as a Parent Problem scale in the belief that it would measure respondent characteristics (the tendency to overprotect and create dependency in a handicapped family member). However, strong relationships with child-related characteristics such as motor impairment (Friedrich & Friedrich, 1981; Holroyd & Guthrie, 1979) and autism (Holroyd & McArthur, 1976) indicate that the scale is truly inter-active with high scores that can partly be attributed to child-related problems and in part be the result of the parents' attitudes or behaviours. Mental handicap is clearly associated with this type of dependency or perceived dependency (Holroyd, 1974) and the Dependency score may be higher for institutionalised handicapped children than for those not institutionalised (Holroyd *et al*, 1975). Scores do not relate to the amount of involvement with the family member but rather to the perceived severity of the disability (Jansen, 1995: 87). The scale only has a moderate internal consistency (***r*** = 0.67).

Scale 5: Lack of Social Support (LSS), is a scale that consists of 10 items reflecting (1) a shortage of community and medical resources; (2) a lack of family involvement with whatever resources might be available; (3) a lack of supportive friendships; (4) family isolation from friends and community; and (5) family disagreement over the caretaking tasks. Overall the scale may reflect the inadequacy of community services rather than the severity of the disease or mental handicap. The manual does not record this scale's internal consistency.

Scale 6: Over-commitment/Martyrdom (OC), merely lists seven items. It shows the degree to which the respondent (1) is over-involved with the handicapped child and (2) believes that only he or she can take care of the child. The score does not seem to relate to the actual amount of responsibility for care. Some items pertain to a sense of worth derived from caring for the handicapped and other items suggest worry about what will happen to the handicapped child when the respondent can no longer provide care. Scale 6 has a very low internal consistency (r = 0.28).

Scale 7: Pessimism (P), lists 13 items on this scale that show the respondent's expectation that the handicapped child's condition will deteriorate and that the family will have to shoulder a greater burden in the future. It also indicates that placement in a care facility may be a pertinent option. High scores suggest that the respondent knows that the child's condition is getting worse and that the prognosis is poor. Higher scores also show that the degree of impairment is not anticipated, but already significant. As such high scores reflect both a realistic hopelessness and a resultant high level of stress. The internal consistency of this scale is moderate (r = 0.65).

3.4.1.1.2.2 Family problems scales

Scale 8: Lack of family integration (LFI), Is a 23 item scale that reflects general family stress (emotional problems amongst family members, disharmony in the family, exclusion of the handicapped member in family activities and feelings of rejection towards the handicapped member) and could also indicate the respondent's unhappiness with the parenting situation or household role. The scale is partly independent of the severity of the handicap and internal consistency is moderately high ($\underline{r}$ = 0.78).

Scale 9: Limits on family opportunity (LFO), Is a scale concerned with family members' lack of opportunities for personal growth, work, social activities and education. It consists of nine items that measure the respondent's and family's dissatisfaction with household and caretaking responsibilities, as well as the level of income. As with Scale 8, this scale probably is more a function of a respondent's family role and the difficulty the family has in meeting the needs of its caretaking members than it is a function of severity of the handicap.

This scale indicates less family pathology than Scale 8, while also showing that family members' needs for personal growth and development are not being met. High scores can occur even when the child's disability is not severe and scores seem to be rather independent of a child's handicapping condition. The scale has a moderate internal consistency ($\underline{r}$ = 0.69).

Scale 10: Financial problems (FP), lists 17 items on this scale. These items measure inadequate family income as well as the high costs of providing care for the handicapped child.

Physical handicaps relate more strongly to financial hardship than other handicapping conditions. Internal consistency is moderately high (***r*** = 0.74).

3.4.1.1.2.3 Problems of index case scales

Scale 11: Physical incapacitation (PI), lists 14 items on its scale pertaining to the handicapped child's (1) health; (2) his or her ability to take care of physical needs like feeding, toileting, and ambulation; (3) use of special aides like medicine or bedpan; and (4) capability for normal sports or outings. Internal consistency is moderate (***r*** = 0.74)**.**

There is a significant negative correlation with age across most clinical groups; hence, Holroyd (1982) warns that care should be taken not to over-interpret high scores obtained by parents of young children who developmentally could be expected to be less capable physically and less capable of self-care.

Scale 12: Lack of activities for index case (LA) is a scale, which focuses on the handicapped child not having enough things with which to keep busy and entertained. The scale consists of six highly focused items and has a moderate internal reliability (***r*** = 0.63). Endorsing any more than one of the six items is associated with significant impairment, either physical or mental, being present in the child. The scale may be culturally sensitive (Jansen, 1995: 90). Scores on this scale do not decrease if the child is placed in an out-of-home setting such as a care facility.

Scale 13: Occupational limitations for index case (OL), is a scale, which consists of seven items and has a moderate internal consistency (***r*** = 0.41). The scale is concerned with insufficient education or training opportunities that may limit the handicapped member's potential for employment. It also reflects, to a lesser degree, the family's concerns about the handicapped member's future career opportunities: The older the handicapped member, the greater the concern about present and future occupation opportunities (Jansen, 1995: 91).

Scale 14 Social obtrusiveness (SO), is a scale has extremely low internal consistency (***r*** = 0.24) and consists of seven items. The low internal consistency means that the scale may measure different characteristics or variables. Items relate to the patient's inappropriate behaviour and unusual appearance as well as to the respondent's sensitivity to community opinion. Mothers score higher than fathers do on this scale, which is one of only three QRS scales that differentiate mothers from fathers.

Scale 15: Difficult personality characteristics (DP), is the longest and one of the most internally consistent (***r*** = 0.88) scales in the QRS. It consists of 32 items that reveal behavioural and personality problems as well as organic cognitive deficits in the handicapped child. High scores may indicate a lack of social support and parental isolation. This scale is also an indicator of the general level of family stress.

3.4.1.1.3 Psychometric properties of the QRS

In addition to the manual (Holroyd, 1982), Jansen (1995: 82-106) presents an extensive review of the QRS, its properties and its use in South African circumstances.

3.4.1.1.3.1 Administration and scoring

The manual (Holroyd, 1982) provides a detailed description of the administration, scoring and computer data analysis instructions.

3.4.1.1.3.2 Normative data (Holroyd, 1982)

Norms are based on parents of **107 children** from California, Georgia and New Zealand. These children were matched with handicapped children on the basis of age, sex and socio-economic status. Given that no indication is given as to what criteria were used to select the normal control group, it cannot be assumed that the normality of the group was rigidly established. Separate norms apply for children under the age of five and children of school-going age.

The QRS has been independently **correlated with age** for each major classification and for non-handicapped subjects. In non-handicapped populations age correlates negatively with QRS scores, i.e. the older the child, the less the stress. In contrast, age correlates positively with the QRS scores of severely handicapped populations, i.e. the older the child, the more the stress on the family.

The QRS is a **very reliable instrument**. The entire questionnaire has an **internal consistency** (Kuder-Richardson-20 coefficient = 0.96). Test-retest reliability coefficients are not presently available. Twelve experts established **content validity** during the initial phases of questionnaire development. The QRS also fulfils the criteria for **criterion validity** and **construct validity**.

The QRS has established itself as a **culture-fair questionnaire** with applications in a variety of settings (Jansen, 1995). It has also been utilised for a number of South African studies, for example, Luiz *et al* (1997), Jansen (1995), Turk (1991), Van Rooyen (1989), Wiehann (1991) and Zimmerman (1993). Jansen (1995) points out that none of the South African studies have been replicated and that the studies thus far have not been representative of the general South African population. All studies did, however, contain control groups and utilised quasi-experimental designs to ensure "*stringent methodological rigour*".

3.4.1.1.3.3 Use of the QRS

Glidden (1993) points out that, despite three core problems namely definitional difficulties, the existence of multiple measures of the same construct that do not converge and the failure to replicate studies, no better measure than the QRS has been developed and an extensive research base has been developed for the QRS. Despite its shortcomings, it remains a highly useful and popular research instrument in assessing the stress and coping of various populations (Byrne & Cunningham, 1985; Holroyd, 1974; Holroyd & Guthrie, 1979; Holroyd & McArthur, 1976).

3.4.1.2 The Perceived Stress Scale (PSS)

The PSS was developed by Cohen *et al* (1983). It measures the extent to which people appraise their lives as unpredictable, unmanageable and overloaded. It is a global instrument of measurement that gauges perceived stress levels as a function of stressful life events, coping mechanisms and personality factors.

The PSS consists of 14 items that evaluate a specific thought or feeling. Respondents are required to indicate the frequency of these thoughts of feelings within the space of the past month.

3.4.1.2.1 Psychometric properties of the PSS

In addition to the article of the developers of this scale (Cohen *et al*, 1983), Van der Merwe (1998) presents a brief discussion of the PSS, its properties and its use in South African circumstances.

3.4.1.2.2 Administration and scoring

Cohen *et al* (1983) provides a description of the administration, scoring and computer data analysis instructions.

3.4.1.2.3 Normative data

Cohen *et al* (1983) utilised two samples, consisting of 332 and 114 college students respectively. Both samples had to complete five questionnaires and their visits to student medical centres were recorded in periods preceding and following the test date.

The PSS has adequate **internal and test-retest reliability** and is appropriately correlated with a range of self-report and behavioural criteria set by the authors (Cohen *et al*, 1983).

The **internal reliability coefficient** (alpha) lies between 0.84 and 0.86 and a moderate level of **criterion validity** (0.52 – 0.76) has been established.

The PSS has been utilised successfully in South African studies (Van der Merwe, 1998).

3.4.2 Fortigenic instruments of measurement

3.4.2.1 The Sense of Coherence Scale (SOC-29)

Following his formulation of the Sense of Coherence concept in 1979, Antonovsky (1987) developed a 29-item Sense of Coherence scale, of which thirteen items constitute a short form (SOC-13). The SOC-29, which was developed by means of a facet-theoretical design, assesses the strength of the person's Sense of Coherence, namely the extent to which life events are comprehensible, manageable and meaningful.

3.4.2.1.1 Psychometric properties of the SOC-29

In addition to the description of the SOC-29 (Antonovsky, 1987), Antonovsky (1993) provides additional normative and reliability data for several Israeli, American Canadian and Nordic samples. Antonovsky (1993, p.726) states "*to my knowledge, at the present count, there are 113 persons or teams in 20 countries who have used or who are using the SOC as a more or less central concept in their research*".

3.4.2.1.2 Administration and scoring

Antonovsky (1987) provides information on the application, scoring and analysis of the SOC-29 Scale.

3.4.2.1.3 Normative data (Antonovsky, 1993)

The SOC-29 has been applied and evaluated over a very broad base. It has been translated into 14 languages and almost 10 000 people have completed the SOC-29.

The **internal consistency** of the SOC (Cronbach alpha) as determined by the comparison of various studies varies between 0.78 and 0.91. Consistently high internal consistency has been found in a number of populations. There are still relatively few test-retest reports available, but indications from available data are that the SOC-29 has high test-retest reliability (above 0.75).

Content, construct and criterion validity has been well established.

Although Antonovsky (1993) offers ample evidence of reliability and validity, Strümpfer (1990, p.269) commented that the psychometric properties of the scale "*require further exploration*". He adds that the wording and structure of some items may also require a high level of verbal comprehension, which could inhibit the use of the scale with less educated persons.

3.4.2.2 The Fortitude Questionnaire (Pretorius, 1998)

Pretorius (1998) developed the Fortitude Questionnaire (FORQ), as based on the concept of *fortitude* (Strümpfer, 1990, 1995). Pretorius (1997) illustrated that fortitude develops from a positive appraisal of self, family and social support. The FORQ is intended to assess the appraisal of these dimensions.

The FORQ consists of 20 items, representing the above three domains (self-appraisals: 7 items; family-appraisals: 7 items; and support appraisals: 6 items). Respondents had to rate each item according to a four-point scale.

3.4.2.2.1 Psychometric properties of the FORQ

Pretorius (1998) developed and validated the FORQ in South African circumstances.

3.4.2.2.2 Administration and scoring

The manual of the FORQ (Pretorius, 1998) contains an explanation of the administration, scoring and computer data analysis instructions.

3.4.2.2.3 Normative data

The FORQ was field-tested using 484 undergraduate psychology students at the University of the Western Cape, South Africa. The sample was predominantly female, full-time students, single, from an urban background and with an average age of 26.18 years.

The **reliability** of the sub-scales ranged between 0.74 and 0.82 and for the full fortitude scale the alpha coefficient was 0.85. Internal consistency for the sample used in this study (See Table 3.2) was established at 0.91 (Cronbach's α-coefficient).

Content validity, factor validity, predictive validity and concurrent validity of the domains (self, family, social support) were established.

As stated above, the FORQ was developed and validated in South Africa, which makes it an extremely suitable instrument of measurement.

3.4.2.3 The COPE inventory

The COPE, a multidimensional coping inventory based on the Process Model of Lazarus and a self-regulatory behavioural model reflects both coping dispositions and different situation-specific coping tendencies. It was developed by Carver *et al* (1989) during the course of three studies that focused on item selection and scale construction, associations with personality dimensions and coping with a specific event.

The COPE consists of 53 items, categorized into 13 scales. Five scales measure aspects of problem-focused coping (active coping, planning, suppression of competing activities, restraint coping and seeking of instrumental social support); five scales measure emotion-focused coping (seeking of emotional social support, positive reinterpretation, acceptance, denial, turning to religion); and three scales that measure less effective coping responses, namely, focus on and venting of emotions, as well as behavioural and mental disengagement. Respondents had to rate each item according to a four-point scale. A high score on the subscales indicates the individual makes frequent use of the coping skill, whereas a low score would reflect the contrary.

3.4.2.3.1 Psychometric properties of the COPE

The COPE, although developed in the USA, has been successfully utilised in South African circumstances (Du Toit, 1999).

3.4.2.3.2 Administration and scoring

The article published by Carver *et al* (1989) details the application and scoring of the COPE.

3.4.2.3.3 Normative data

The COPE was validated using a sample of 978 undergraduate students at the University of Miami.

Carver *et al* (1989) report satisfactory reliability and validity data (Chronbach alpha ranges from 0.45 to 0.92). The individual scales also show good reliability. Test-retest reliability varies between 0.46 to 0.86 and 0.42 to 0.89 following retests of 6 and 8 weeks respectively. Good validity indexes were also found.

The COPE has been successfully used in South African studies (Du Toit, 1999).

3.4.3 Biographical Questionnaire

The biographical questionnaire consists of six multi-choice questions and six open-ended questions.

The multi-choice questions deal with (a) the respondent's
(1) relationship to the handicapped child, (2) age, (3) current marital status and (4) relationship to the other biological parent of the handicapped child, and (b) the handicapped child's (1) birth order and (2) sex.

The open-ended questions deal with (a) the handicapped child's
(1) date of birth, (2) current age, (3) age of placement and
(4) residential facility and (b) the parent's (1) reasons for placing the child, and
(2) future plans regarding continued placement.

3.5 The sample

In the planning of the study it was envisaged that at least 100 fathers and 100 mothers of severely handicapped placed children, the most of which who would be couples, would be included in the study. Following contact with various provincial and national mental health authorities and organisations, 83 care facilities were identified and approached by means of a letter explaining the research project. Of these, 9 facilities, namely, Woodside Johannesburg, Woodside Cape Town, A.M. Moolla Special School (Phoenix, KwaZulu Natal), John Peattie House (Pietermaritzburg, KwaZulu Natal), Talje Home (Warmbaths, Mpumalanga), Little Eden (Edenvale, Gauteng), Tower Hospital (Fort Beaufort, Eastern Cape), Algoa Centre (Newton Park, Port Elizabeth) and Our Nest (Springs, Gauteng) responded positively.

Following the provision of name lists by these facilities, **275 test booklets** were forwarded to the parents, together with an explanatory letter.

Following a high percentage of non-returns and incorrectly addressed booklets (RTS) and the exclusion of incomplete questionnaires, **77 subjects** from Woodside Johannesburg, Woodside Rondebosch, Our Nest, John Peattie House and Little Eden were available for the study. Of these, **12 couples** completed the questionnaire. The other **53** persons consisted of either single parents or families where only one parent had opted to complete the questionnaire. Overall, **50 mothers**, **2 stepmothers** and **25 fathers** completed the test booklet consisting of the above questionnaires.

3.5.1 Parent-related data

The frequency distribution of the sample with regard to the biographical variables of the parents is reported in Table 3.1. Parents reasons for opting for full-time placement is reported in Table 3.2.

Table 3.1: Frequency distribution of the sample with regard to the biographical variables of the parents

Biographical variable	f	%
Age of parents		
21 – 30	1	1,3
31 – 40	13	16,9
41 – 50	22	28,6
51 – 60	24	31,2
60 and above	17	22,1
TOTAL	77	100,0
Marital status of parent		
Married	61	79,2
Divorced	5	6,5
Never married	3	3,9
Widowed	8	10,4
TOTAL	77	100,0
Still married to father/mother of your handicapped child		
Yes	54	70,1
No	12	15,6
Never been	3	3,9
Widowed	8	10,4
TOTAL	77	100,0

Table 3.1 illustrates that approximately a third of the parents included in the sample are between 51 to 60 years old and the majority of parents (59.8%) are between 41 to 60 years old. The majority of the parents included in the sample (79.2%) are still married and approximately 70% still have the same spouse.

Table 3.2: Frequency distribution of the sample with regard to the reasons for placing children and for the parents' intention to keep the children in care

Biographical variable	f	%
Reason for placing child in full-time care		
Needs special care	12	15,6
Care taking needs	27	35,1
Lack – social support	3	3,9
Parental inability to cope	18	23,4
Behavioural difficulties	5	6,5
Professional pressure	2	2,6
Financial constraints	1	1,3
Disintegration of family life	7	9,1
No reason provided	2	2,6
TOTAL	77	100,0
Intend moving child from full-time care into home care		
No	69	89,6
Yes	7	9,1
No response	1	1,3
TOTAL	77	100,0

According to the data reported in Table 3.2, there were three major reasons why parents opted for full-time placement, namely, caretaking needs of the child (35,1%), parental inability to cope (23,4%) and the need for specialised care (15,6%).

The first two considerations may be very closely related. The above data is very consistent with existing research findings that the greater the caretaking and specialised care needs, the greater the likelihood of placement (Beckman, 1983; Beckman-Bell, 1981; Gallagher *et al*, 1983; Quittner *et al*, 1992).

Family disintegration only accounted for approximately 10% of the placement decisions, whilst a lack of social support only featured in 3,9% of the decision to place the child in care. This suggests that for the parents in this sample placement was not primarily the outcome of increased family pathology or heightened social isolation.

Only 10,4% of the parents indicated that they would consider removing the child from the care facility.

3.5.2 Child-related data

The biographical details of the severely handicapped children are reported in Tables 3.3 and 3.4.

In most cases (75%), the severely handicapped child was either the first-born (40,3%) or second-born 35,1%) child (See Table 3.3). The majority of the children included in this study were male (57,1%). The average current age of the children in the sample (see table 3.4) was 24,17 years, with the youngest child being 6 and the eldest 53. The average age of placement was 8,31 years, with the youngest child being placed at birth and the oldest at 49 (see table 3.5).

The majority of the children in the sample (See Table 3.3), 32,5% and 27,3% respectively, are housed in the two Woodside Sanctuaries (Cape Town & Johannesburg). Little Eden and John Peattie House both house 16,9% of the children.

Table 3.3: Frequency distribution of the sample with regard to the biographical variables (residential care facility, birth order, gender) of the handicapped children

Biographical variable	f	%
Child's residential care facility		
Our Nest	2	2,6
Little Eden	13	16,9
John Peattie House	13	16,9
Woodside Cape	25	32,5
Woodside Johannesburg	21	27,3
Home Talje	1	1,3
AM Moolla	2	2,6
TOTAL	77	100,0
Birth order of handicapped child		
First	31	40,3
Second	27	35,1
Third	15	19,5
Fourth	4	5,2
TOTAL	77	100,0
Gender of handicapped child		
Male	44	57,1
Female	33	42,9
TOTAL	77	100,0

Table 3.4: Average current age of children in the sample and their average age at the time of placement

Biographical variable	Years
Child's current age	
Average age of children in sample	24,17
Standard deviation	10,49
Youngest child in sample	6
Oldest child in sample	53
Child's age at the time of placement	
Average age of children in sample	8,31
Standard deviation	10,49
Youngest child in sample	Birth
Oldest child in sample	49

3.6 Formulation of hypotheses

The research goals, as discussed in section 3.1.3, gave rise to three research hypotheses.

3.6.1 Research hypothesis 1

There is a significant difference between the average stressor, perceived stress, sense of coherence, fortological and coping scores of fathers and mothers of severely handicapped children in care facilities.

3.6.2 Research hypothesis 2

There is a significant positive relationship between the perceived levels of stress of these parents and the stressors with which they are confronted.

3.6.3 Research hypothesis 3

There is a significant negative relationship between (1) the perceived levels of stress and the various psycho-fortigenic aspects (Sense of coherence, fortitude and coping) and (2) parental stressors and the abovementioned psycho-fortigenic factors.

3.6.4 Further investigation

During the testing of research hypotheses 2 and 3, the relationships as they occur for fathers and mothers respectively, will be examined to determine whether significant differences exist between them.

In addition, the relationship between the perceived stress of the father and the psycho-fortigenic characteristics of the mother and vice versa will be investigated to determine the extent to which the psycho-fortigenic characteristics of one parent interact with the perceived stress of the other.

Specific statistical hypotheses will be formulated at a later stage.

3.7 Statistical procedures

Extensive efforts were made to secure a large sample (See par 3.1.3.2). Unfortunately of the 275 questionnaires forwarded to parents only 77 were finally included. This sample provided measurements on a wide variety of dependent variables.

The relative small size of the sample could bring the assumption of the normality of the scores into question and, accordingly, it is not possible to test the formulated statistical hypotheses by means of parametric statistical techniques. Rather, it was decided to utilise non-parametric tests.

The first research hypothesis entails the comparison of the averages of various dependent variables for the two groups (fathers and mothers). All the dependent variables have been measured on an interval scale. This, according to Howell (2002), suggests the use of the Mann-Whitney-U-test, a non-parametric test that can be utilised to compare the central tendency of two independent groups.

Research hypotheses 2 and 3 will be examined by means of Pearson's product moment correlation. In order to determine the significance of difference between mothers and fathers, Fisher's *r* – to *z*- transformation will be employed. In this case, the nil-hypothesis states that the difference between two population groups is equal to 0 and that the nil-hypothesis can be examined by using the following statistical test (Howell, 2002):

$$Z = \frac{r'_1 - r'_2}{\sqrt{\frac{1}{N_1 - 3} + \frac{1}{N_2 - 3}}}$$

Where r'_1 and r'_2 are the z-values of the respective correlations r_1 and r_2, the original correlation coefficients are transformed by means of Fisher's r- to z prior to computing the test statistical value.

In order to determine the practical importance of statistically significant results, which are investigated by means of the co-relational study (See research hypotheses 2 and 3), the practical significance of results will have to be considered. In order to determine practical significance, effect size will be computed. Given that this study entails the investigation of linear relationships between variables, Cohen (In Steyn, 1999) suggests that the correlation coefficient, namely p, be utilised as effect size. He provides the following criteria:

$p = 0,1$: small effect
$p = 0,3$: medium effect
$p = 0,5$: big effect

The practical value of statistical significance will be determined by considering effect size.

The raw scores of the variables have been employed in the various computations. The significance level of 1% will be maintained.

3.8 Closing comment

This is a quantitative study that utilises non-parametric statistical methods in order to highlight the stress and coping processes of 77 parents of severely handicapped, placed children. A special effort will be made to discover any significant differences between the fathers and mothers of these children. In the following chapter, the results of the study will be reported.

4 Results

4.1 Reliability of questionnaires and scales, as determined for this study

The **SPSS** computer statistical software package (SPSS Incorporated, 1983) was used to determine the internal consistency of each instrument of measurement in this study. This was done by computing Cronbach's α-coefficient for the scales of each questionnaire. The coefficients for the stressor and stress-related questionnaires are reported in Table 4.1, whilst those that relate to the parent's fortological functioning are listed in Table 4.1.

The computed α-coefficients vary from relatively low (0,40) to quite high (0,91) measures of internal consistency.

4.1.1 Reliability of the instruments of measurement that assess the origins and amount of stress as determined for the sample in this study

4.1.1.1 Reliability of the QRS as determined for the sample in this study

Cronbach's α-coefficient for each of the scales of the QRS is reported in Table 4.1.

Table 4.1: Cronbach's α-coefficients for the stressor and stress-related questionnaires (QRS & PSS)

Questionnaire / Scale	α- coefficients
Questionnaire on Resources and Stress (QRS)	
Scale 1: Poor health/mood (PHM)	0,77
Scale 2: Excess time demands (ETM)	0,69
Scale 3: Negative attitude toward index case (NA)	0,72
Scale 4: Overprotection/dependency (OPD)	0,51
Scale 5: Lack of social support (LSS)	0,48
Scale 6: Over-commitment/martyrdom (OC)	0,55
Scale 7: Pessimism (P)	0,56
Scale 8: Lack of family integration (LFI)	0,52
Scale 9: Limits on family opportunity (LFO)	0,74
Scale 10: Financial problems (FP)	0,75
Scale 11: Physical incapacitation (PI)	0,46
Scale 12: Lack of activity for index case (LA)	0,69
Scale 13: Occupational limitations for index (OL)	0,40
Scale 14: Social obtrusiveness (SO)	0,47
Scale 15: Difficult personality characteristics (DP)	0,59

4.1.1.1.1 Personal problem scales

Scale 1: Poor Health/Mood (PHM) Internal consistency for the sample used in this study (see Table 4.1) was established at 0,77 (Cronbach's α-coefficient). This corresponds well to the internal consistency of 0.79 reported by Holroyd (1982). The scale has a relatively high internal consistency for this study and the results obtained are deemed meaningful.

Scale 2 Excess Time Demands (ETM) Internal consistency for the sample used in this study (see Table 4.1) was established at 0,69 (Cronbach's α-coefficient). This is very close to the ***r*** of 0.73 reported by Holroyd (1982) and shows that this scale also has moderate internal consistency for the sample in this study.

Scale 3 Negative Attitude toward Index Case (NA): Internal consistency for the sample (see Table 4.1) used in this study was established at 0,72 (Cronbach's α-coefficient). This is somewhat lower than the ***r*** of 0.81 reported by Holroyd (1982), but still represents moderate reliability.

Scale 4: Overprotection/Dependency (OPD): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,51 (Cronbach's α-coefficient). In contrast to the moderate ***r*** of 0.67 reported by Holroyd (1982), this scale exhibits a lower internal consistency for this study. Accordingly, **interpretation of the results obtained for this scale should be done tentatively**.

Scale 5: Lack of Social Support (LSS): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,48 (Cronbach's α-coefficient). This is reflects low levels of internal consistency, accordingly, **the results obtained for this scale should be interpreted tentatively**.

Scale 6: Over-commitment/Martyrdom (OC): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,55 (Cronbach's α-coefficient). This is somewhat higher than the low ***r*** of 0.28 reported by Holroyd (1982). This suggests that, for this sample, this scale may have moderate reliability.

Scale 7: Pessimism (P): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,56 (Cronbach's α-coefficient). This is 0.09 lower than the ***r*** of 0.65 reported by Holroyd (1982). This scale is considered to have moderate to low internal consistency for use in the sample of this study. Accordingly, **some care should be taken in the interpretation** of the results obtained with this scale.

4.1.1.1.2 Family problem scales

Scale 8: Lack of Family Integration (LFI): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,52 (Cronbach's α-coefficient). This is 0.26 lower than the ***r*** of 0.78 reported by Holroyd (1982) and suggests that, for this sample, this scale only has moderate to low internal consistency

Scale 9: Limits on Family Opportunity (LFO): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,74 (Cronbach's α-coefficient). This is 0.05 higher than the ***r*** reported by Holroyd (1982) and suggests that, for use in this sample, this scale has moderately high reliability.

Scale 10: Financial Problems (FP): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,75 (Cronbach's α-coefficient). This is very similar to the reliability (***r*** = 0.74) reported by Holroyd (1982) and suggests that, for use in this study, reliability can be considered to be moderately high.

4.1.1.1.3 Problems of Index Case Scales

Scale 11: Physical Incapacitation (PI): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,46 (Cronbach's α-coefficient). This is 0.20 lower than the ***r*** of 0.61 reported by Holroyd (1982). This indicates that, for use in this study, **this scale has low internal consistency and results obtained by means of its use should be tentatively interpreted**.

Scale 12: Lack of Activities for Index Case (LA): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,69 (Cronbach's α-coefficient). This is very similar to the ***r*** of 0.63 obtained by Holroyd (1982). Accordingly the internal consistency of this scale, when utilised in this study, can be considered to be moderate.

Scale 13: Occupational Limitations for Index Case (OL): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,40 (Cronbach's α-coefficient). This suggests l**ow reliability and the results obtained from this scale for the parents involved in this study should be tentatively interpreted**.

Scale 14: Social Obtrusiveness (SO): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,47 (Cronbach's α-coefficient). Although 0.23 higher than the ***r*** reported by Holroyd (1982), it still reflects **low reliability and therefore the results obtained for this study by means of this scale should be tentatively interpreted**.

Scale 15: Difficult Personality Characteristics (DP): Internal consistency for the sample used in this study (see Table 4.1) was established at 0,59 (Cronbach's α-coefficient). This is 0.29 lower than the coefficient reported by Holroyd (1982). Accordingly this suggests that, for use in this study, the scale has only moderate reliability.

4.1.1.2 Reliability of the PSS as determined for the sample in this study

Cronbach's α-coefficient for PSS is reported in Table 4.2.

Table 4.2 Cronbach's α-coefficient for PSS

Questionnaire / Scale	**α-coefficients**
Perceived Stress Scale (PSS)	
Cronbach's α-coefficient for the entire scale	0,84

Internal consistency for the sample used in this study (see Table 4.2) was established at 0,84 (Cronbach's α-coefficient). This coincides with the high internal reliability coefficient reported by Cohen *et al.* (1983) and suggests that the results obtained for this study by means of the PSS can be considered reliable.

4.1.2 Reliability of the fortigenic scales (SOC, FORQ & COPE)

4.1.2.1 SOC

Cronbach's α-coefficient for the SOC is reported in Table 4.3.

Table 4.3: Cronbach's α-coefficients for the SOC

Questionnaire / Scale	**α-coefficients**
Sense of Coherence (SOC)	
Cronbach's α-coefficient for the entire scale	0,90

Internal consistency for the sample used in this study (see Table 4.3) was established at 0,90 (Cronbach's α-coefficient). This is comparable to the highest reliability coefficients reported by Antonovsky (1993). This suggests that the results obtained from the SOC for this study are highly reliability.

4.1.2.2 FORQ

Cronbach's α-coefficient for the FORQ is reported in Table 4.4.

Table 4.4: Cronbach's α-coefficients for the FORQ

Questionnaire / Scale	**α-coefficients**
Fortitude Questionnaire (FORQ)	
Cronbach's α-coefficient for the entire scale	0,91

Cronbach's α-coefficient obtained for the FORQ in this study exceeds the ***r*** of 0.85 reported by Pretorius (1998). It follows that the results obtained for the FORQ in this study can be considered to be highly reliable.

4.1.2.3 COPE

Cronbach's α-coefficient for the COPE is reported in Table 4.5.

Table 4.5: Cronbach's α-coefficients for the COPE

Questionnaire / Scale	**α-coefficients**
Cope Inventory (COPE)	
Scale 1: Active coping	0,59
Scale 2: Planning	0,66
Scale 3: Suppression of competing activities	0,50
Scale 4: Restraint coping	0,45
Scale 5: Seeking social support for instrumental reasons	0,79
Scale 6: Seeking social support for emotional reasons	0,79
Scale 7: Positive reinterpretation & growth	0,62
Scale 8: Acceptance	0,68
Scale 9: Turning to religion	0,90
Scale 10: Focus on & venting of emotions	0,66
Scale 11: Denial	0,60
Scale 12: Behavioural disengagement	0,59
Scale 13: Mental disengagement	0,61

Internal consistency for the sample used in this study was established for each subscale (see Table 4.5). Cronbach's α-coefficient varies from 0,45 to 0,90. Results obtained via Scale 4 should be interpreted with care as it shows only low reliability for use in this study. Scale 3 shows moderate to low reliability, whereas scales 1, 2, 7, 8, 10, 11, 12 and 13 exhibit moderate reliability for use in this study. Scales 5 and 6 have moderately high reliability and scale 9 seems very reliable.

4.2 Descriptive statistics for this sample

The descriptive statistics (means and averages) with regard to all the variables for this sample were computed prior to the testing of the research hypotheses. The means and averages for the stressor and stress-related variables appear in Tables 4.6 and 4.7, and the means and averages for the fortigenic variables are reported in Table 4.8 and 4.10. Comparative statistics are provided where available.

The mean scores (QRS, SOC & FORQ) of this research sample were compared to that of the various reference groups by performing *t*-tests for two independent groups. Given that the sizes of the groups differed, it was decided to make use of the pooled variance estimate. According to Howell (2002), this procedure is preferable when sample sizes differ.

The effect sizes of the differences between the two sets of averages were calculated by means of determining Cohen's *d* (Cohen, in Steyn, 1999). This procedure expresses the difference between the two means in terms of the size of the standard deviation. In other words, the difference has been standardised. This means that in, for example, scale 15 of the QRS (see Table 4.1), the sample of the current study differed from Holroyd's group by $^{6}/_{10}{}^{\text{ths}}$ of a standard deviation. This is considered to be quite a substantial difference.

Cohen (in Steyn, 1999) laid out very general guidelines for what he considered to be small, medium and large effect sizes. He characterized ***d* = 0,20** as a small, but probably meaningful effect size, ***d* = 0,50** as a medium effect (half a standard deviation difference) and an effect size of ***d* = 0,80** as large.

4.2.1 Descriptive statistics with regard to stressor and stress-related variables

4.2.1.1 QRS

The means and standard deviations of this sample were compared to those reported by Holroyd (1982) in manual of the QRS (see Table 4.6). The scores of developmentally disabled clinical reference group were selected as its composition has the best correspondence with severely handicapped, placed children.

Table 4.6 illustrates that significant statistical differences exist for 8 of the scales. For four of the scales, namely scales 5, 7, 11 and 15 the scales are significant on the 1% level. Scales 7, 11 and 15 reflect higher averages than that of the reference group (Holroyd, 1982), whereas in the case of scale 5, the reverse applies.

The results with regard to scales 7 and 11 reflect large and practically meaningful effect sizes. This suggests that the sample obtained for this study may include children of greater physical incapacitation and that the parents may be significantly more pessimistic about the child’s chances for recovery or improvement, more aware of their future burden of care and more realistically hopeless (Holroyd, 1982).

This situation would be consistent with the indications from literature that the more profound the handicap, the greater the chance of placement in a care facility and the greater the parent’s awareness of the irreversibility of the situation.

Table 4.6: Means and standard deviations for the stressor and stress-related variables (QRS) of the entire sample (n=76 / 77)

Questionnaire on Resources and Stress (QRS)	**This study**			**Developmental disability reference group (Holroyd, 1982)**			***t-value***	**Cohen's d**
	N	**ξ**	**s**	**N**	**ξ**	**s**		
Scale 1: Poor health/mood (PHM)	76	5,11	2,96	145	4,99	3,02	0,28	0,04
Scale 2: Excess time demands (ETM)	76	6,59	2,73	145	5,63	2,82	2,46*	0,34
Scale 3: Negative attitude toward index case (NA)	76	12,08	4,04	145	11,08	4,56	1,61	0,23
Scale 4: Overprotection/ dependency (OPD)	76	6,45	2,03	145	6,23	2,61	0,63	0,09
Scale 5: Lack of social support (LSS)	76	3,43	1,78	145	4,52	1,49	-4,95**	0,68
Scale 6: Over-commitment/ martyrdom (OC)	76	3,92	1,29	145	3,50	1,33	2,47*	0,32
Scale 7: Pessimism (P)	76	7,49	2,00	145	3,63	2,70	3,51**	1,57***
Scale 8: Lack of family integration (LFI)	76	6,08	4,05	145	5,34	3,82	1,35	0,19
Scale 9: Limits on family opportunity (LFO)	76	2,46	2,14	145	1,79	2,08	2,23*	0,32
Scale 10: Financial problems (FP)	76	5,68	3,83	145	5,52	3,32	0,33	0,05

Table 4.6 (cont): Means and standard deviations for the stressor and stress-related variables (QRS) of the entire sample (n=76 / 77)

Questionnaire on Resources and Stress (QRS)	**This study**			**Developmental disability reference group (Holroyd, 1982)**			***t-value***	**Cohen's d**
	N	**ξ**	**s**	**N**	**ξ**	**s**		
Scale 11: Physical incapacitation (PI)	76	8,08	2,68	145	2,83	2,07	15,91**	2,28***
Scale 12: Lack of activity for index case (LA)	77	3,01	1,63	145	2,42	1,88	2,46*	0,33
Scale 13: Occupational limitations for index (OL)	77	3,35	1,33	145	3,39	1,27	-0,24	0,03
Scale 14: Social obtrusiveness (SO)	76	2,64	1,27	145	2,42	1,39	1,29	0,16
Scale 15: Difficult personality characteristics (DP)	76	18,75	5,31	145	15,37	5,47	4,39**	0,62

* p ≤ 0,05 (two-sided *t* > 1,96) ** p ≤ 0,01 (two-sided *t* > 2,58)

*** Large and practically significant effect size

4.2.1.2 Perceived Stress Scale

The means and standard deviations for the stressor and stress-related variables (PSS) of the entire sample are reported in Table 4.7.

Table 4.7: Means and standard deviations for the stressor and stress-related variables (PSS) of the entire sample (*n*=76)

Perceived Stress Scale (PSS)	**This sample**			**Student sample** (Cohen *et al*., 1983)			***t*-value**	**Cohen's *d***
	N	**ξ**	**s**	**N**	**ξ**	**s**		
Measurement for full scale	76	23,87	8,12	332	23,18	7,31	0,77	0,09

The mean obtained for the current research sample is 23,87 with a standard deviation of 8,12 (see Table 4.7). This corresponds very well to the measures of the student sample (mean = 23,18; standard deviation = 7,31) reported by Cohen *et al* (1983) as there is no significant difference between the two sets of scores. No comparable sample of parents of severely handicapped, placed children was available.

4.2.2 Descriptive statistics with regard to fortigenic variables

4.2.2.1 Sense of Coherence (SOC)

The means and standard deviations of the research sample as a whole and of the fathers and mothers respectively were compared to the scores of two populations (see Table 4.8), that of Kibbutz fathers and Kibbutz mothers with handicapped children (Antonovsky, 1993).

Table 4.8: Means and standard deviations for the fortigenic variables (SOC) of the entire sample (*n*=75)

Sense of Coherence	**This sample**			**Kibbutz fathers, disabled children** (Antonovsky, 1993)			**Kibbutz mothers, disabled children** (Antonovsky, 1993)		
	N	**ξ**	**s**	**N**	**ξ**	**s**	**N**	**ξ**	**s**
Measurement for the full scale	75	138,25	25,64	67	146,3	19,4	67	140,1	22,6
	Fathers			***t*-value (fathers)**			**Cohen's *d* (fathers)**		
	75	139,00	23,30	-1,52			0,36		
	Mothers			***t*-value (mothers)**			**Cohen's *d* *(mothers)***		
	75	137,88	26,95	-0,48			0,09		

There is no significant difference, not even on the 5% level, between the respective scores of the groups, suggesting that the research sample is also comparable to other samples of parents of handicapped children.

4.2.2.2 Fortitude Questionnaire (FORQ)

The mean and standard deviation obtained from the research sample (58,96; 10,79), as reported in Table 4.9, is very similar to the statistics reported by Pretorius (1998). As such, the research sample demonstrates some similarity to the general population.

There is no significant difference, not even on the 5% level, between the respective scores of the groups.

Table 4.9: *Means and standard deviations for the fortigenic variables (FORQ) of the entire sample (n=75)*

Fortitude Questionnaire	**This sample**			**Student sample (Pretorius, 1998)**			***t*-value**	**Cohen's *d***
	N	**ξ**	**s**	**N**	**ξ**	**s**		
Measurement for the full scale	75	58,96	10,79	483	57,79	9,43	0,98	0,12

4.2.2.3 COPE Inventory

Table 4.10 reports the means and averages of the research sample and those of two other samples, namely, one which examined the general coping disposition of students and another which assessed the coping of students following exposure to situational stress (Carver et al., 1989). Unfortunately no comparable sample of parents of severely handicapped children was available for scrutiny.

The means and standard deviations obtained from the research sample compares very favourable with that of other parents of handicapped children. The only exception is the trend in the research sample to experience greater (and appropriate) pessimism and to have a greater awareness of the severely handicapped, placed child's physical incapacitation.

In the following section, the research hypotheses, as set out in Chapter 3, will be statistically investigated and further investigation will be done into the effect of the one parent's fortigenic characteristics on the perceived stress of the other.

Table 4.10: *Means and standard deviations for the fortigenic variables (COPE) of the entire sample (n=77)*

Cope Inventory (COPE)	**This sample**			**Dispositional COPE scales (Carver, *et al.*, 1989)**			**Situational COPE scales (Carver, *et al.*, 1989)**		
	N	ξ	**s**	**N**	ξ	**s**	**N**	ξ	**s**
Scale 1: Active coping (ac)	77	12,17	2,49	1030	11,89	2,26	117	10,69	3,18
Scale 2: Planning (pl)	77	12,86	2,42	1030	12,58	2,66	117	11,86	3,08
Scale 3: Suppression of competing activities (sp)	77	11,06	2,51	1030	9,92	2,42	117	9,31	3,38
Scale 4: Restraint coping (re)	77	10,66	2,32	1030	10,28	2,53	117	9,38	3,43
Scale 5: Seeking social support for instrumental reasons (ir)	77	9,58	3,34	1030	11,50	2,88	117	6,69	3,39
Scale 6: Seeking social support for emotional reasons (er)	77	9,37	3,26	1030	11,01	3,46	117	11,08	3,60
Scale 7: Positive reinterpretation & growth (po)	77	12,30	2,65	1030	12,40	2,42	117	11,35	2,85
Scale 8: Acceptance (ap)	77	13,25	2,56	1030	11,84	2,56	117	11,49	2,81
Scale 9: Turning to religion (tu)	77	12,32	3,77	1030	8,82	4,10	117	7,56	4,24
Scale 10: Focus on & venting of emotions (fo)	77	8,82	3,00	1030	10,17	3,08	117	10,37	3,50
Scale 11: Denial (de)	77	5,99	2,36	1030	6,07	2,37	117	5,57	2,28
Scale 12: Behavioural disengagement (bd)	77	7,12	2,35	1030	6,11	2,07	117	6,03	2,22
Scale 13: Mental disengagement (md)	77	8,43	2,77	1030	9,66	2,46	117	8,07	2,86

4.3 Statistical investigation of the research hypotheses

4.3.1 Research hypothesis 1

There is a significant difference between the average stressor, perceived stress, sense of coherence, fortological and coping scores of fathers and mothers of severely handicapped children in care facilities.

Research hypothesis 1 deals with the question of whether statistically significant differences exist between the average stressor, perceived stress, sense of coherence, fortitude and coping scores of fathers and mothers of severely handicapped, placed children.

This suggests the formulation of the following statistical hypotheses:

$$\mathbf{H_0 : \mu_1 = \mu_2}$$

$$\mathbf{H_1 : \mu_1 \neq \mu_2}$$

(Everitt, 1996)

Where μ_1 = the average stress (QRS and PSS) and psycho-fortological (coping, SOC and fortitude) scores for the **fathers** of severely handicapped, placed children and μ_2 = the average stress (QRS and PSS) and psycho-fortological (coping, SOC and fortitude) scores for the **mothers** of severely handicapped, placed children.

Huysamen (1983) indicates that, in cases where the sample exceeds 20 persons (as is the case in this study), the sample distribution of ***U*** will be normal and that it will have the statistical value of

$$Z_U = \frac{U - \mu_U}{\sigma_U}$$

Which suggests the research sample can be considered to be a standard normal distribution.

Research hypothesis 1 was investigated by means of the computation and comparison of the respective average scores of the two groups (fathers and mothers) on the various scales of the stress and psycho-fortigenic questionnaires and scales. Given the small number of couples (12), it was decided that analyses would include the complete sample of 77 persons.

The averages for the complete sample were determined with assistance of the SAS software package.

The results of the Mann-Whitney-U-test for the **stressor and stress-related scales** are reported in Tables 4.11 and 4.12.

Tables 4.11 and 4.12 clearly illustrate that there is no significant difference between the respective scores on the various scales for the two groups. The null-hypothesis applies in every case and has to be retained.

The results of the Mann-Whitney-U-test for comparison between the two groups' averages on the **fortigenic scales** are reported in Table 4.13 and 4.14.

Table 4.11 The difference between the scores of fathers and mothers with severely handicapped children on the QRS

Dependent variable	**Fathers**		**Mothers**		**z-value**	**p-value**
QRS	**ξ**	**s**	**ξ**	**s**		
Scale 1: (PHM)	4,81	3,20	5,26	2,91	-0,67	0,5020
Scale 2: (ETM)	6,08	2,77	6,86	2,69	-1,32	0,1861
Scale 3: (NA)	11,96	4,24	12,14	3,98	-0,17	0,8647
Scale 4: (OPD)	6,54	2,42	6,40	1,82	0,34	0,7341
Scale 5: (LSS)	3,58	1,86	3,36	1,76	0,52	0,6043
Scale 6: (OC)	3,88	1,21	3,94	1,34	-0,28	0,7804
Scale 7: (P)	7,65	1,89	7,40	2,07	0,52	0,6035
Scale 8: (LFI)	6,96	4,57	5,62	3,71	1,06	0,2884
Scale 9: (LFO)	2,54	2,02	2,42	2,21	0,39	0,6936
Scale 10: (FP)	5,58	4,02	5,74	3,77	-0,32	0,7456
Scale 11: (PI)	8,00	2,86	8,12	2,61	-0,13	0,8946
Scale 12: (LA)	3,19	1,81	2,92	1,53	0,70	0,4839
Scale 13: (OL)	3,58	1,24	3,23	1,37	0,72	0,4724
Scale 14: (SO)	2,54	1,24	2,70	1,29	-0,26	0,7935
Scale 15: (DP)	19,54	5,64	18,34	5,15	1,40	0,1612
Scale 11: (PI)	8,00	2,86	8,12	2,61	-0,13	0,8946

Table 4.12 The difference between the scores of fathers and mothers with severely handicapped children on the PSS.

Dependent variable	Fathers		Mothers		z-value	p-value
	ξ	s	ξ	S		
PSS	21,32	7,61	25,12	8,15	-1,80	0,0720

Table 4.13 The difference between the scores of fathers and mothers with severely handicapped children on the SOC and FORQ.

Dependent variable	**Fathers**		**Mothers**		**z-value**	**p-value**
Sense of Coherence	ξ	**s**	ξ	**s**		
	139,00	23,30	137,88	26,95	0,34	0,7316
Fortitude Questionnaire	ξ	**s**	ξ	**s**	**z-value**	**p-value**
	58,60	10,07	59,14	11,22	-0,52	0,5992

Table 4.13 does not indicate any significant differences between fathers and mothers with regard to SOC and fortitude and the null hypotheses cannot be rejected for these scales.

Table 4.14 reflects only one significant difference ($p \leq 0{,}01$), namely on Scale 9 (turning to religion). In this case the null hypothesis can be rejected. The average scores of mothers on this scale are significantly higher than those of fathers, suggesting that, in comparison with fathers, **mothers are more inclined to turn to religion in an effort to cope with their situation**.

Table 4.14 The difference between the scores of fathers and mothers with severely handicapped children on the COPE.

Dependent variable ***Cope Inventory (COPE)***	**Fathers**		**Mothers**		**z-value**	**p-value**
	ξ	**s**	ξ	**s**		
Scale 1: **(ac)**	12,27	2,24	12,12	2,63	0,22	0,8281
Scale 2: **(pl)**	12,88	2,92	12,84	2,16	0,72	0,4724
Scale 3: **(sp)**	10,58	2,64	11,31	2,43	-1,04	0,2994
Scale 4: **(re)**	10,15	2,41	10,92	2,25	-1,35	0,1777
Scale 5: **(ir)**	8,58	3,05	10,10	3,39	-1,98	0,0476
Scale 6: **(er)**	8,50	3,19	9,82	3,24	-1,64	0,1000
Scale 7: **(po)**	11,69	2,48	12,61	2,70	-1,49	0,1375
Scale 8: **(ap)**	13,19	2,19	13,27	2,74	-0,47	0,6377
Scale 9: **(tu)**	10,42	3,87	13,30	3,36	-3,21	0,0014*
Scale 10: **(fo)**	7,92	2,54	9,27	3,13	-1,65	0,0987
Scale 11: **(de)**	5,65	1,76	6,16	2,61	-0,48	0,6282
Scale 12: **(bd)**	6,38	2,21	7,49	2,35	-2,16	0,0312
Scale 13: **(md)**	8,23	2,98	8,53	2,69	-0,76	0,4476

* p ≤ 0,01

4.3.2 Research hypothesis 2

> There is a significant positive relationship between the perceived levels of stress of these parents and the stressors with which they are confronted.

This research hypothesis addresses the question of whether there exists a significantly positive relationship between perceived stress levels and the various stressors, as identified by the fathers and mothers. The possibility of significant differences between the relationships found for fathers and mothers will also be investigated.

In order to determine the presence of a positive relationship between the abovementioned variables, the following statistical formula was employed:

$\mathbf{H_0 : \rho = 0}$

$\mathbf{H_1 : \rho > 0}$

Where ρ = the correlation between perceived stress and stressors for the population of parents with severely handicapped, placed children.

The alternative hypothesis (H_1) is directionally formulated. The expectation is that the higher the levels of perceived stress, the greater the tendency of parents to experience stressors.

In order to determine whether a statistically significant **difference** exists between the above-mentioned relationships for mothers and fathers, the following statistical hypothesis can be formulated:

$\mathbf{H_0 : \rho_1 = \rho_2}$

$\mathbf{H_1 : \rho_1 \neq \rho_2}$

Where $\boldsymbol{\rho_1}$ = correlation between perceived stress and stressors for the population for fathers and $\boldsymbol{\rho_2}$ = correlation between perceived stress and stressors for the population for of mothers.

The alternative hypothesis (H_1) is non-directionally formulated, as it is not clear if the relationships are higher for one group than for the other.

In order to determine whether positive relationships exist between the parents' stressors and perceived stress, the SAS software package (SAS Institute, 1985) was employed to compute Pearson's product moment correlation coefficient (***r***). The software automatically does a *t*-test to check whether the computed coefficients differ significantly from null.

The results for the whole research sample, as well as for the fathers and mothers respectively are reported in Table 4.15.

Table 4.15 clearly illustrates that, in the **total group**, eight of the stressors, namely, **Personal Problem Scales** (Scale 1: Poor health/mood, Scale 2: Excess time demands, Scale 3: Negative attitude towards index case, Scale 5: Lack of social support and Scale 6: Over-commitment / Martyrdom) and **Family Problem Scales** (Scale 8: Lack of family integration, Scale 9: Limits on family opportunity and Scale 10: Financial problems) correlate positively with perceived stress on a significance level of 1%.

This positive correlation suggests that the more parents see their life as unpredictable, unmanageable and overloaded (according to the PSS), the greater their stress will be on the above scales.

In the case of **fathers** (See Table 4.15), five of the stressors, namely **Personal Problem Scales** (Scale 1: Poor health/mood and Scale 5: Lack of social support) and **Family Problem Scales** (Scale 8: Lack of family integration, Scale 9: Limits on family opportunity and Scale 10: Financial problems) correlate positively with perceived stress on a significance level of 1%.

Table 4.15: Correlation coefficients as computed between the QRS-Scales and the PSS for the whole research sample (n=77) and for the fathers (n-25) and mothers (n=52)

	Perceived stress				
QRS Scales	**Total group**		**Fathers**	**Mothers**	***z+***
	r		***r***	***r***	
Personal problems					
Scale 1: (PHM)	0,59*		0,66*	0,55*	0,692
Scale 2: (ETM)	0,41*		0,49	0,34	0,719
Scale 3: (NA)	0,32*		0,49	0,23	1,194
Scale 4: (OPD)	0,20		0,34	0,13	0,881
Scale 5: (LSS)	0,45*		0,61*	0,40*	1,126
Scale 6: (OC)	0,32*		0,25	0,36*	-0,482
Scale 7: (P)	0,16		0,37	0,09	1,178
Family problems					
Scale 8: (LFI)	0,35*		0,53*	0,35	0,889
Scale 9: (LFO)	0,48*		0,69*	0,41*	1,628
Scale 10: (FP)	0,43*		0,50*	0,42*	0,399

Table 4.15 (continued): Correlation coefficients as computed between the QRS-Scales and the PSS for the whole research sample (n=77) and for the fathers (n-25) and mothers (n=52)

	Perceived stress				
QRS Scales	**Total group**		**Fathers**	**Mothers**	***z+***
	r		***r***	***r***	
Child problems					
Scale 11: (PI)	0,16		0,47	0,01	1,976
Scale 12: (LA)	0,18		0,28	0,15	0,542
Scale 13: (OL)	0,01		0,23	0,06	0,688
Scale 14: (SO)	0,29		0,45	0,22	1,032
Scale 15: (DP)	0,22		0,42	0,17	1,091

* p ≤ 0,01 + p ≤ 0,01 (critical *z* for two-sided test: ±2,33)

Mothers also present with five of the stressors (See Table 4.15) that correlate significantly with perceived stress (p ≤ 0,01). The stressors are **Personal Problem Scales** (Scale 1: Poor health-/mood, Scale 5: Lack of social support and Scale 6: Over-commitment-/Martyrdom) and **Family Problem Scales** (Scale 9: Limits on family opportunity and Scale 10: Financial problems).

Table 4.15 does not reflect any significant differences in the correlations between the QRS and Perceived Stress scores of the fathers and the mothers. It is also important to note that neither fathers nor mothers identify child-related stressors that correlate significantly with perceived stress.

4.3.3 Research hypothesis 3

> There is a significant negative relationship between (1) the perceived levels of stress and the various psycho-fortological aspects (Sense of coherence, fortitude and coping) and (2) parental stressors and the abovementioned psycho-fortological factors.

Research hypothesis 3 investigates the question of whether a significant relationship exists between (1) the stressors and the psycho-fortological factors (sense of coherence, fortitude and coping) and (2) between the perceived stress and the psycho-fortological factors as they occur in fathers and mothers.

Three psycho-fortological factors, namely sense of coherence, fortitude and coping were utilised in this study. In order to provide a more structured presentation of the results, the correlation of each of these factors with the stress scales were computed.

4.3.3.1 Sense of coherence and the stress scales

The following statistical hypothesis applies:

$$\mathbf{H_0 : \rho = 0}$$

$$\mathbf{H_1 : \rho < 0}$$

Where ρ = the correlation between perceived stress/stressors and sense of coherence for the population of parents with severely handicapped, placed children.

An alternative hypothesis (H_1) was directionally formulated. It was expected that the higher the levels of perceived stress, the lower the sense of coherence experienced by parents of severely handicapped, placed children. The respective relationships that exist for fathers and mothers will be investigated in order to determine whether significant differences exist between them.

In order to determine whether negative relationships exist between the parents' perceived stress/stressors and sense of coherence, Pearson's product correlation coefficient (***r***) was computed with the assistance of the SAS software package (SAS Institute, 1985). The results for the total group and the fathers and mothers respectively are reported in Tables 4.16 and 4.17).

It is clear that the, for the **total group**, seven of the stressors, namely **Personal Problem Scales** (Scale 1: Poor health/mood, Scale 2: Excess time demands, Scale 3: Negative attitude towards index case and Scale 5: Lack of social support) and **Family Problem Scales** (Scale 8: Lack of family integration, Scale 9: Limits on family opportunity and Scale 10: Financial problems) and the Perceived Stress Scale show a significantly negative correlation on the 1%-level with sense of coherence.

The negative correlation suggests that the less the parents find their life to be unpredictable, unmanageable and overloaded (according to the PSS) and the less they experience the stressors, as identified by the QRS, the higher their sense of coherence.

Table 4.16 and 4.17 illustrates that, for **fathers**, seven of the stressors - **Personal Problem Scales** (Scale 1: Poor health/mood, Scale 2: Excess time demands, Scale 3: Negative attitude towards index case, Scale 4: Overprotection/ dependency and Scale 5: Lack of social support) and **Family Problem Scales** (Scale 9: Limits on family opportunity and Scale 10: Financial problems) – as well as perceived stress (PSS) correlates negatively on the 1% level with the sense of coherence.

For mothers, three of the stressors – **Personal Problem Scales** (Scale 1: Poor health/mood and Scale 5: Lack of social support) and **Family Problem Scales** (Scale 8: Lack of family integration) – as well as perceived stress (PSS) correlate negatively on the 1% level with the sense of coherence.

Finally, Table 4.16 reflects a significant difference ($p \leq 0{,}01$) with regard to the relationship between the sense of coherence and Scale 9 (Limits on Family Opportunity) of the QRS for fathers and mothers. It seems that the negative relationship between these two variables is stronger for fathers (-0,73) than for mothers (-0,27), i.e. the greater the sense of loss of family opportunities for growth, the lower the sense of coherence.

4.3.3.2 Fortitude and the stress scales

The following statistical hypothesis applies:

$$\mathbf{H_0 : \rho = 0}$$

$$\mathbf{H_1 : \rho < 0}$$

Where ρ = the correlation between perceived stress/stressors and fortitude for the population of parents with severely handicapped, placed children.

An alternative hypothesis (H_1) was directionally formulated. It was expected that the higher the levels of perceived stress, the lower the fortitude experienced by parents of severely handicapped, placed children. The respective relationships that exist for fathers and mothers will be investigated in order to determine whether significant differences exist between them.

Table 4.16: Correlation coefficients between the QRS and SOC scale for the total group (n=77) and the fathers (n=25) and mothers (n=52)

	Sense of Coherence			
Scales	**Total group**	**Fathers**	**Mothers**	***Z+***
QRS-scales	***R***	***r***	***r***	
Personal problems				
Scale 1: (PHM)	-0,55*	-0,70*	-0,48*	-1,359
Scale 2: (ETM)	-0,38*	-0,56*	-0,31	-1,233
Scale 3: (NA)	-0,34*	-0,62*	-0,21	-2,024
Scale 4: (OPD)	-0,27	-0,52*	-0,14	-1,719
Scale 5: (LSS)	-0,46*	-0,68*	-0,36*	-1,787
Scale 6: (OC)	-0,24	-0,41	-0,17	-1,043
Scale 7: (P)	-0,02	-0,45	-0,14	-1,359
Family problems				
Scale 8: (LFI)	-0,37*	-0,40	-0,38*	-0,095
Scale 9: (LFO)	-0,40*	-0,73*	-0,27	-2,577*
Scale 10: (FP)	-0,37*	-0,52*	-0,30	-1,051
Child problems				
Scale 11: (PI)	-0,05	-0,42	-0,13	-1,253
Scale 12: (LA)	-0,03	-0,24	-0,07	-0,692
Scale 13: (OL)	-0,02	-0,34	-0,09	-1,043
Scale 14: (SO)	-0,23	-0,34	-0,19	-0,640
Scale 15: (DP)	-0,20	-0,30	-0,16	-0,589

* p ≤ 0,01 + p ≤ 0,01 (critical *z* vir one-sided test: ±2,33)

Table 4.17: Correlation coefficients between the PSS and SOC scale for the total group and the fathers and mothers respectively

	SOC				
Scales	**Total group**		**Fathers**	**Mothers**	***Z*+**
PSS	*r*		*r*	*r*	
	-0,66*		-0,72*	-0,66*	-0,455

In order to determine whether negative relationships exist between the parents' perceived stress/stressors and fortitude, Pearson's product correlation coefficient (***r***) was computed with the assistance of the SAS software package (SAS Institute, 1985). The results for the total group and the fathers and mothers respectively are reported in Table 4.18.

According to the results for the **total group** (See Table 4.18), four of the stressors, namely **Personal Problem Scales** (Scale 1: Poor health-/mood and Scale 5: Lack of social support) and **Family Problem Scales** (Scale 8: Lack of family integration and Scale 9: Limits on family opportunity) and the Perceived Stress Scale show a significantly negative correlation on the 1%-level with fortitude. This means that, the less the parents perceive their life as unpredictable, unmanageable and overloaded (according to the PSS) and the less they experience stress with regard to the abovementioned stressors, the higher their level of fortitude.

For **fathers** there exists a negative correlation between five of the stressors – **Personal Problem Scales** (Scale 1: Poor health/mood, Negative attitude towards index case and Scale 5: Lack of social support) and **Family Problem Scales** (Scale 9: Limits on family opportunity and Scale 10: Financial problems) and the Perceived Stress Scale show a significantly negative correlation on the 1%-level with fortitude.

Mothers show a negative correlation (significant on the 1% level) with only one stressor, namely (Scale 8: Lack of family integration).

Finally, Table 4.18 illustrates that fathers and mothers differ significantly ($p \leq 0{,}01$) with regard to the relationship between fortitude and Scale 9 (Limits on family opportunity). It seems as if the negative correlation between the two variables is stronger for fathers (-0,76) than for mothers (-0,24).

4.3.3.3 Coping and the stress scales

The following statistical hypothesis was investigated, namely:

$$\mathbf{H_0 : \rho = 0}$$

$$\mathbf{H_1 : \rho \neq 0}$$

Where: ρ = correlation between perceived stress / stressors and the coping scales for the population of parents with severely handicapped, placed children.

Table 4.18: Correlation coefficients as determined between the stress scales (QRS and PSS) and the FORQ for the total group and for fathers and mothers

Scales	Fortitude			
	Total group	**Fathers**	**Mothers**	*z*+
QRS-scales	*r*	*r*	*r*	
Personal problems				
Scale 1: (PHM)	-0,40*	-0,51*	-0,35	-0,783
Scale 2: (ETM)	-0,27	-0,34	-0,25	-0,391
Scale 3: (NA)	-0,27	-0,51*	-0,16	-1,589
Scale 4: (OPD)	-0,04	-0,31	-0,12	-0,791
Scale 5: (LSS)	-0,38*	-0,65*	-0,26	-2,012
Scale 6: (OC)	-0,13	-0,19	-0,11	-0,324
Scale 7: (P)	-0,08	-0,45	-0,08	-1,601
Family problems				
Scale 8: (LFI)	-0,43*	-0,48	-0,42*	-0,296
Scale 9: (LFO)	-0,39*	-0,76*	-0,24	-2,967*
Scale 10: (FP)	-0,25	-0,51*	-0,12	-1,747
Child problems				
Scale 11: (PI)	-0,06	-0,41	-0,12	-1,245
Scale 12: (LA)	0,11	-0,30	-0,31	0,043
Scale 13: (OL)	0,03	-0,14	-0,09	-0,202
Scale 14: (SO)	-0,23	-0,31	-0,19	-0,509
Scale 15: (DP)	-0,09	-0,23	-0,02	-0,846
Perceived stress	-0,41*	-0,70*	-0,32	-2,115

*** p ≤ 0,01** **+ p ≤ 0,01 (critical *z* vir one-sided test: ±2,33)**

Given that high scores on some coping scales indicate ineffective coping and high scores on others suggest effective coping, the alternative hypothesis (H1) was non-directionally formulated. As the COPE consists of 13 coping scales, it was decided to compute only the relationships for the total sample, and not for the fathers and mothers respectively. This was done by means of calculating Pearson's product moment correlation coefficient (***r***) with the aid of the SAS-software package. The results are reported in Table 4.19.

The results in Table 4.19 show that a positive correlation exists between perceived stress and five of the coping scales ($p \leq 0,01$). This suggests that, the more parents use **suppression of competing activities**, **focus on and venting of emotions, denial, behavioural disengagement** and **mental disengagement** as coping strategies, the more they will tend to experience higher levels of perceived stress, that is the more they will tend to experience life as unpredictable, unmanageable and overloaded.

Table 4.19 illustrates that:

- The coping strategy ***"suppression of coping activities"*** correlates positively ($p \leq 0,01$) with **six** scales of the QRS – **Personal Problem Scales** (Scale 1: Poor health/mood, Scale 2: Excess time demands and Scale 3: Negative attitude towards index case), **Family Problem Scales** (Scale 9: Limits on family opportunity and Scale 10: Financial problems) and **Child Problems** (Scale 11: Physical incapacitation).

Table 4.19 Correlation coefficients as determined between the stress scales (QRS and PSS) and the COPE scales for the total group

Stress scales	**Cope scales**												
QRS	**ac**	**pl**	**sp**	**re**	**ir**	**er**	**po**	**ap**	**tu**	**fo**	**de**	**bd**	**md**
Personal problems													
Scale 1: (PHM)	07	-01	39*	07	09	-01	13	-11	03	24	21	25	18
Scale 2: (ETM)	05	01	41*	09	19	23	-02	-25	19	38*	33*	38*	17
Scale 3: (NA)	02	02	32*	-02	18	23	-11	-14	16	26	08	22	14
Scale 4: (OPD)	06	-09	26	01	16	26	05	-06	-09	30*	19	32*	09
Scale 5: (LSS)	01	-02	25	04	12	11	-09	-16	-09	28	16	31*	08
Scale 6: (OC)	-01	04	15	19	11	12	-05	-08	09	19	19	23	14
Scale 7: (P)	-11	01	-13	-26	-21	-08	01	18	02	10	-08	-05	08
Family problems													
Scale 8: (LFI)	02	09	28	05	03	-04	-17	-14	-10	09	07	-05	11
Scale 9: (LFO)	-04	-06	34*	01	19	25	-16	-30*	04	36*	27	30*	19
Scale 10: (FP)	07	03	42*	18	10	15	-02	-21	24	29	38*	49*	27
Child problems													
Scale 11: (PI)	23	26	34*	10	11	09	05	01	05	13	02	07	20
Scale 12: (LA)	13	08	21	08	04	06	06	06	17	18	01	11	-01
Scale 13: (OL)	17	13	11	-03	09	03	05	11	03	04	-21	-03	04
Scale 14: (SO)	-13	-02	21	-15	19	25	-12	-27	18	28	15	25	09
Scale 15: (DP)	01	09	20	07	06	06	15	05	09	13	07	21	12
Perceived Stress	-14	-15	32*	10	14	11	-06	-25	05	33*	40*	44*	34*

Please note: The decimal sign has been omitted.

Note: [ac=active coping; pl=planning; sp=suppression of competing activities; re=restraint coping; ir=seeking social support for instrumental reasons; er=seeking social support for emotional reasons; po=positive reinterpretation and growth; ap=acceptance; tu=turning to religion; fo=focus on and venting of emotions; de=denial; bd=behavioral disengagement; md=mental disengagement]

- The coping strategy ***"behavioural disengagement"*** correlates positively ($p \leq 0{,}01$) with **five** scales of the QRS – **Personal Problem Scales** (Scale 2: Excess time demands, Scale 4: Overprotection/Dependency and Scale 5: Lack of social support) and **Family Problem Scales** (Scale 9: Limits on family opportunity and Scale 10: Financial problems).

- The coping strategy ***"focus on and venting of emotions"*** correlates positively ($p \leq 0{,}01$) with **three** scales of the QRS – **Personal Problem Scales** (Scale 2: Excess time demands and Scale 4: Overprotection/Dependency) and **Family Problem Scales** (Scale 9: Limits on family opportunity).

- The coping strategy ***"denial"*** correlates positively ($p \leq 0{,}01$) with **two** scales of the QRS – **Personal Problem Scales** (Scale 2: Excess time demands) and **Family Problem Scales** (Scale 10: Financial problems).

- The coping strategy ***"acceptance"*** positively ($p \leq 0{,}01$) with **one** of the scales of the QRS – **Family Problem Scales** (Scale 9: Limits on family opportunity).

The above relationships suggest that the more the parent ascribes stress to the particular stressors of the QRS, as mentioned above, the more they will be inclined to use the specific coping mechanism.

4.3.4 Further investigation

Assessing the nature of the relationship between the psycho-fortigenic characteristics of fathers and perceived stress of mothers and vice versa.

A relationship exists between the psycho-fortigenic characteristics of fathers and the perceived stress of mothers as well as between the psycho-fortigenic characteristics of mothers and the perceived stress of fathers. Accordingly, the following statistical hypothesis was investigated, namely:

$$H_0 : \rho = 0$$

$$H_1 : \rho \neq 0$$

Where, in the case of the relationship between the father's perceived stress and the stressors and psycho-fortigenic characteristics of the mother, ρ = correlation between the father's perceived stress and the psycho-fortigenic characteristics of the mother for the population of parents with severely handicapped, placed children and, in the case of the relationship between the mother's perceived stress and the stressors and psycho-fortigenic characteristics of the father, ρ = correlation between the mother's perceived stress and the psycho-fortigenic characteristics of the father for the population of parents with severely handicapped, placed children.

The above calculations were done by means of calculating Pearson's product moment correlation coefficient (***r***) with the aid of the SAS-software package. The results are reported in Table 4.20.

The relationships between the psycho-fortigenic characteristics (sense of coherence, fortitude and coping) of the mother and the perceived stress of the father (and vice versa) were investigated **for the 12 couples in the sample**. This was done as the sizes of the group of mothers and fathers in the study were considered to be too unequal (52 mothers vs. 25 fathers). Given the size of the sample included for the statistical calculations (12 couples), it was difficult to determine statistically significant differences. Consequently, **practically significant differences** will be indicated.

Table 4.20 illustrates the following tendencies:

- The higher the mother's *suppression of competing activities*, the **higher** the father's perceived stress;
- The higher the mother's *focus on and venting of emotions*, the **higher** the father's perceived stress;
- The higher the mother's *acceptance*, the **lower** the father's perceived stress;
- The higher the mother's *sense of coherence*, the **lower** the father's perceived stress; and
- The higher the mother's fortitude, the lower the father's perceived stress.

When considering the converse, namely the relationships between the psycho-fortigenic characteristics (sense of coherence, fortitude and coping) of the father and the perceived stress of the mother (see Table 4.20), the tendencies are that:

- The higher the father's seeking of social support for emotional reasons, the higher the mother's perceived stress;
- The higher the father's *turning to religion*, the **higher** the mother's perceived stress;
- The higher the father's *focus on and venting of emotions*, the **higher** the mother's perceived stress;
- The higher the father's *denial*, the **higher** the mother's perceived stress;
- The higher the father's *behavioral disengagement*, the **higher** the mother's perceived stress;
- The higher the father's *mental disengagement*, the **higher** the mother's perceived stress;

Table 4.20: Correlation coefficients as determined between perceived stress (PSS) of fathers (n=12) and the psycho-fortigenic characteristics (SOC, Fortitude, Coping) of mothers (n=12) from the same couple and vice versa

Correlation coefficients		Correlation coefficients	
Mother's psycho-fortigenic factors	**Father's perceived stress**	**Father's psycho-fortigenic factors**	**Mother's perceived stress**
Ac	-0,05	Ac	-0,36
Pl	0,04	Pl	-0,34
Sp	0,64*	Sp	-0,13
Re	0,16	Re	-0,40*
Ir	0,37	Ir	0,03
Er	0,20	Er	0,50*
Po	-0,18	Po	0,39
Ap	-0,58*	ap	-0,05
Tu	-0,18	tu	0,41*
Fo	0,69*	fo	0,55*
De	0,33	de	0,66*
Bd	0,20	bd	0,59*
Md	0,11	md	0,60*
Sense of coherence	-0,76*	Sense of coherence	-0,50*
Fortitude	-0,70*	Fortitude	-0,43*

Nota: [ac=active coping; pl=planning; sp=suppression of competing activities; re=restraint coping; ir=seeking social support for instrumental reasons; er=seeking social support for emotional reasons; po=positive reinterpretation and growth; ap=acceptance; tu=turning to religion; fo=focus on and venting of emotions; de=denial; bd=behavioral disengagement; md=mental disengagement]

(Refers to high practical significance)

- The higher the father's *restraint coping*, the **lower** the mother's perceived stress;
- The higher the father's *sense of coherence*, the **lower** the mother's perceived stress; and

- The higher the father's *fortitude*, the **lower** the mother's perceived stress.

4.3.5 Effect sizes

All correlation coefficients that indicate significant statistical differences also represent medium to large effect size, which suggests that the findings of this study may have average to strong practical value.

4.4 Closing comment

The descriptive statistics obtained for this study show that this sample of parents is comparable to a number of other populations.

For the sample as a whole, and for fathers and mothers respectively, correlations between (1) stressors and perceived stress and (2) stressors/perceived stress and the psycho-fortigenic factors of sense of coherence and fortitude have been calculated. Correlations between the stressor-related stress/perceived stress of the whole sample and a variety of coping skills has been investigated.

Lastly, the perceived stress of one parent in a couple was compared with the psycho-fortigenic characteristics of the other. A number of significant relationships and differences have been found.

The meaning and implications of these results will be discussed in the next chapter.

5 Discussion

5.1 Introduction

The preceding chapters offer a review of the relevant literature, a discussion of methodological issues and an empirical study of the stress and coping of parents of severely handicapped, placed children.

In this chapter the emphasis will fall on:

- A discussion of the themes that come to the fore in the results of the study and relating them to research findings where appropriate;
- A review of the shortfalls of existing research and suggesting possible directions for future research; and
- The offering of guidelines for intervention by professional helpers.

From the outset it is important to emphasise that the sample of this study consisted of parents who were able to afford placing their children in private care facilities. Given that placement in South Africa is not state funded or subsidised, this implies that these are parents with some financial means, which may also indicate a higher socio-economic level, higher levels of education and higher social status.

5.2 Four emergent themes

Four research goals (see par. 3.3) were formulated and investigated (see Chapter 4). The results of this study, which are mostly consistent with existing research findings, illuminate four important themes, namely,

- The close interaction of perceived stress of parents of severely handicapped children with their personal and family-related stressors and their psycho-fortigenic functioning;
- That the interaction between the father's sense of coherence and fortitude on the one hand, and his personal and family-related stressors on the other may be greater than such an interaction in the mother;
- The differential role of "*turning to religion*" as a distinguishing coping mechanism between fathers and mothers of severely handicapped, placed children; and
- That the interaction of the father's psycho-fortigenic characteristics with the perceived stress of the mother may be greater than the interaction between the mother's psycho-fortigenic characteristics and the perceived stress of the father.

Each of these themes will now be discussed in detail.

5.2.1 The close interaction of perceived stress of parents of severely handicapped children with their personal and family-related stressors and their psycho-fortigenic functioning

From the outset, this study has been allied to a transactional understanding of stress. Hence the role of appraisal has been emphasised as a core component in the experience and meaning of and response to stress. As such, the concept of perceived stress relates very closely to the appraisal process, as it reflects the degree to which parents perceive or appraise their world as unpredictable, unmanageable and overloaded. Given the expectation that perceived stress would affect other areas of parents' life experience, it was also predicted in the formulation of certain of the research hypotheses that higher levels of perceived stress would correlate positively with stressors, lowered SOC and less fortitude. Given technical considerations no prediction was made with regard to coping skills. As yet, no studies could be identified that correlate perceived stress in parents with severely handicapped, placed children with stressors (as identified by the QRS), SOC, fortitude and coping. Hence very limited reference can be made to available literature.

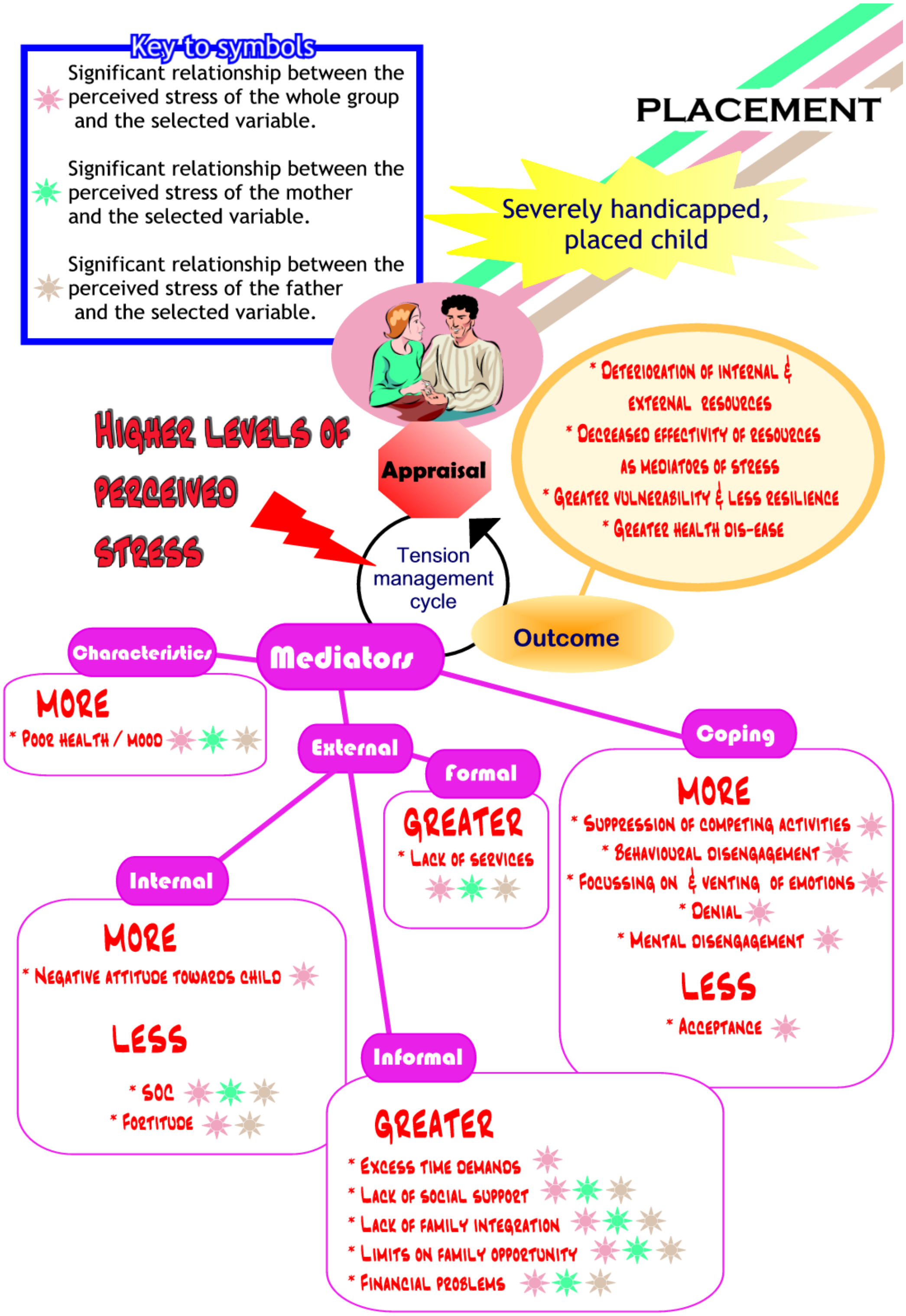
The results of this study suggest clearly that the presence of high levels of perceived stress in the parents of severely handicapped, placed children coincides with wide-ranging negative effects in their physical and psychological environments, tension management mechanisms and external socio-ecological support systems.

Fig 5.1 illustrates the interaction of perceived stress with the stressors and the psycho-fortigenic functioning of the parents of severely handicapped, placed children.

The introduction of higher levels of perceived stress affects most of the mediators of stress as identified in the literature study (see Chapter 2), i.e. parental characteristics, internal (dispositions and beliefs) and external mediators (informal and formal social support systems). Accordingly it can be expected that this effect will reduce the effectiveness of the tension management cycle and may limit parents' ability to effectively manage future stress. This, in turn, may gradually lead to increased vulnerability, deterioration of internal and external stress-reducing resources, reduced effectiveness of these resources in the tension management process and greater health dis-ease.

In the following paragraphs of this section (5.2.1), the difference between fathers and mothers will not be the main focus. Rather, the general trends obtained by combining the outcomes of research hypotheses 2 and 3 will be emphasised.

Figure 5.1: The interaction of perceived stress with the stressors and the psycho-fortigenic functioning of the parents of severely handicapped, placed children



In order to better understand the interaction of perceived stress with parental stressors and psycho-fortigenic characteristics, the discussion will be organised according to the same categorisation of mediators of stress as used in the literature study (see Chapter 2, paragraphs 2.1.2.1.3.2 and 2.2.2.1.1). The nature and the impact of the stressors will be interpreted according to the manual of the QRS (Holroyd, 1982).

5.2.1.1 Parental characteristics

The results of this study suggest that the parent with higher levels of perceived stress exhibits more stress with regard to **health/mood**. This suggests that these parents may experience more stress with regard to the following specific issues:

5.2.1.1.1 The risk of detachment

Although these children are in full-time care, the parents with high levels of perceived stress may still experience involvement (or the thought of involvement), which includes travelling and other disruptions, as an overwhelming hassle. This suggests that such parents, as indicated by previous researchers (Blacher & Baker, 1992; Blacher & Newfelt, 1989; Harris, 1987; Holroyd, 1982) may be more inclined to **detach** from the child or that they may have greater difficulty than less stressed parents to maintain a meaningful relationship with the child and the caretaking staff. Such detachment may create negative perceptions of the parent with care facility staff, as a result of which they may not be as welcoming when the parent does attempt to see the child.

5.2.1.1.2 The emotional burden of providing ongoing care

Although most parents of severely handicapped children, placed or not, experience ongoing grief (Davis, 1987; Olshansky, 1962; Pueschel, 1986; Trout, 1983), the results of this study suggests that parents with high levels of perceived stress may more acutely and intensely feel **the emotional impact of caring for the child and experience chronic sorrow on a more profound level** than less stressed parents. Consequently they may have greater difficulty attempting and completing the various grieving tasks (Roos, 1985) in order to find meaning in their loss and may find themselves "stuck" in the grief process. For these parents, having and caring for a severely handicapped, placed child may indeed become debilitating (Wikler et al, 1981, 1983).

5.2.1.1.3 Role satisfaction

The results of this study suggests that parents with higher levels of perceived stress, more so than parents with lower levels of perceived stress, experience **dissatisfaction with role definition and fulfilment**. This may make it more difficult for them to be mutually supportive in the resolution of their grief process and in their efforts to adjust to their situation.

The above corresponds well to previous research findings that show that the complex grief process, initiated by the birth-/diagnosis of the child and maintained by the chronic nature of the child's situation, introduces the loss of old and the assumption of new and difficult roles and **that effective role fulfilment predicts better parental adjustment and less marital strain** (Barbarin *et al.,* 1985, Bristor, 1984; Elkins & Brown, 1986; Ellis, 1989; Fein, 1976; Gardner & Merenstein, 1986b; Lemons & Weaver, 1986; Olshansky, 1962; Roehner, 1976; Solnit & Stark, 1961; Wikler *et al*, 1981).

5.2.1.2 Internal mediators of stress

In this study it is clear that **higher perceived stress** coincides with **lowered SOC** (things are less explicable, manageable and meaningful), **less fortitude** (the self, family and others are more negatively assessed) and **a more negative attitude with regard to the child**. This suggests that, in parents with higher levels of perceived stress, the stress-reducing function of SOC and fortitude will be impaired, putting them at greater risk for increased health dis-ease. These parents may also experience greater negativity in their attitudes and appraisals, which predicts a poorer outcome in terms of their physical and psychological well-being.

Previous researchers have shown that both the Sense of Coherence (SOC) and fortitude fulfil a stress-reducing function, but that parents with handicapped children have greater difficulty maintaining their position on the health-ease/dis-ease continuum and show greater discrepancies in their sense of coherence than parents of non-handicapped children. This suggests that, as lowered SOC and less fortitude seems inevitable in the parent of the severely handicapped child, it may the degree to which these psycho-fortigenic characteristics are lowered and to which they can stabilise that may predict the level of perceived stress and the efficacy of adjustment (Antonovsky, 1979, 1987; Affleck, Allen, Tennen, McGrade & Ratzan, 1985; Barakat & Linney, 1995; Carver *et al*, 1989; Pretorius, 1997, 1998; Sloper *et al*, 1991; Sloper & Turner, 1993; Trute, 1995).

There is abundant evidence from previous studies that positive attitudes and appraisals predict a better outcome (Folkman *et al*, 1986; Folkman, 1984; McKinney & Peterson, 1987; Mechanic, 1991). Accordingly, a negative attitude towards the child would predict a poorer stress outcome for the parents of severely handicapped, placed children and may give rise to the following parental concerns:

5.2.1.2.1 The child's survival and degree of handicap

The results of this study suggest that parents with higher levels of perceived stress may show greater concern about certain child-related concerns than parents with lower levels of perceived stress. They may be more worried about the **child's potential for illness** and the **extent of his/her disability**, feel more anxiety about **what to expect** from the child and are more sensitive to the child's **level of cognitive impairment** (Holroyd, 1982).

Many other researchers have demonstrated that child characteristics, such as the severity of the handicap, are mediators of parental stress. Where these handicaps are profound (as is often the case with severely handicapped, placed children), the parents are at greater risk than parents with less severely handicapped children for feeling less parental warmth and acceptance and to perceive family and social support as inadequate and dissatisfactory (Beckman-Bell, 1981; Benson *et al*, 1991; Bouma & Schweitzer, 1990; Bradbury & Hewison, 1994; Daniels & Berg, 1966; Gallagher, Beckman & Cross, 1983; Holroyd & Guthrie, 1979; Holroyd & McArthur, 1976; Wishart *et al*,1981).

5.2.1.2.2 The risk of detachment

High levels of perceived stress in parents of severely handicapped, placed children, as measured in this study, together with the above mentioned concerns, could lead to **disengagement**. A greater tendency to disengage may reflect on the parent's **grief process** and could suggest that the parent still has greater difficulty in accepting the child's condition and situation.

Researchers (Blacher & Baker, 1992; Blacher & Newfelt, 1989; Harris, 1987; Holroyd, 1982) have demonstrated that highly stressed parents may tend to become uninvolved when they believe that their placed child has no potential for further development.

Carver *et al* (1989) states that the use of denial, of which detachment is an expression, suggests that the parent with higher levels of perceived stress may (1) be more vulnerable to the stress and (2) have greater difficulty resolving the grief associated with having and caring for a severely handicapped, placed child. The use of denial, as a coping mechanism, will compound stress and make the ultimate coping process more difficult.

5.2.1.3 Informal support system

It is in the area of informal social support that the interaction between perceived stress and stressors is the most evident.

This study illustrates that **high levels of perceived stress** could leave parents of severely handicapped, placed children with a **more negative appraisal of their informal support systems**. More specifically, parents with high levels of perceived stress are more likely than parents with low levels of perceived stress to experience stress with regard to **time demands**, **lack of social support**, **lack of family integration**, **limits on family opportunity** and **financial problems**.

There is ample evidence that social support and positive appraisals of social support mediates stress and facilitates effective coping (Antonovsky, 1979; Barbarin, Hughes & Chesler, 1985; Beresford, 1994; Bristol & Schopler, 1984; Byrne & Cunningham 1985; Copeland, 1980; Frey *et al*, 1989; German & Maisto, 1982; Pearlin & Schooler, 1978; Petrosky & Birkimer, 1991; Rimmerman, 1991; Rimmerman & Portowicz, 1987; Sloper *et al*, 1991; Waisbren, 1980).

Given the above results, it can be expected that the parents with high levels of perceived stress may experience more stress with regard to the following stressors associated by Holroyd (1982) with a lack of informal social support.

5.2.1.3.1 Personal and social isolation

The results of this study suggests that strain in the area of excess time demands may lead the parent with a high level of perceived stress to experience a **stronger sense of personal and social isolation.**

Most researchers associate time demands with the stress of the primary caregiver, traditionally the mother (Beckman, 1983; Beckman-Bell, 1981; Gallagher *et al*, 1983). This may be different in the case of the severely handicapped placed child as the father may accompany the mother on visits, has to assist the mother in reaching the care facility, or has to deal with home demands while the mother is absent. Given that both parents may perceive the time demands as stressful, this may be more so in the case where parents present with high levels of perceived stress. This, in turn, may lead these parents to detach from the child as a way of avoiding the stress of frequent visits.

5.2.1.3.2 Social sensitivity and perceived societal bias

High levels of perceived stress in the parents included in this study increases the likelihood that they will experience **greater social sensitivity** in terms of what others may think of the child and themselves and that they may have a **more negative appraisal of themselves and of society's attitude towards them and their severely handicapped child**. These parents' perception of society's attitude may be a projection of their own fears and biases or could reflect their fear for rejection by society. This highlights a parental perception that, by having a severely handicapped child, they themselves have become abnormal.

There are previous research findings that show that a lack of validation and insensitive social attitudes could hinder the resolution of the grief process and that some parents will adopt a handicapped identity (Garland, 1986, Stewart & Pollack, 1991).

Although it is very possible that all parents of severely handicapped children are sensitive to society's response and also experience some societal negativity, the previous research findings, together with the indications from the current study, suggests that parents with high levels of perceived stress may be more vulnerable to the above-mentioned social stressors than parents with low levels of perceived stress. This heightened vulnerability may hinder or halt the grief resolution process and contribute to increased social isolation.

5.2.1.3.3 Individual and family role definition

The results of this study show that, where parents, in general, and fathers, specifically, have high levels of perceived stress, they will be more inclined to experience unhappiness with the **parenting situation or household role**. As indicated in par. 5.2.1.1.3, difficulties surrounding the issue of role definition may hinder the grief resolution process and hamper the positive adjustment of parents of severely handicapped, placed children. Given that the mother with high levels of perceived stress may be more inclined towards a **martyr role** this may have an adverse effect on the father, as it would limit his access to his primary support system, his spouse. In this case, the mother's primary focus may be the well-being of the handicapped child and not the well-being of her spouse, which may leave the **spouse feeling isolated and dissatisfied** with the way that the mother has formulated her parenting role. Furthermore, it may put a **greater demand on the father** as he attempts to compensate for the absence (emotional or physical) of the mother as she attends to the needs of the severely handicapped child. This situation may lead to greater strain in and a breakdown of the marital relationship.

Previous studies show that high levels of perceived stress may lead to **maternal feelings of parental incompetence** (Friedrich, 1979; Holroyd, 1974; Sloper *et al*, 1991). This may either motivate the mother in the assumption of a martyr role as she accordingly tries harder to effectively fulfil her perceived role, or it may cause her to withdraw from involvement with the severely handicapped, placed child, but also from the other siblings. As a result, the father may experience a **heavier load within the family**, which could lead to deterioration of his emotional well-being, his ability to provide continued support and to fulfil multiple roles (Holroyd, 1982).

5.2.1.3.4 General family stress

In this study, high levels of perceived stress in parents (and fathers in particular) accompany more general family stress. This may take the form of (1) strain and potential disintegration in the spousal relationship, (2) inappropriate utilisation of and disturbed relationships with siblings of the handicapped child and (3) troubled relationships with close family, such as grandparents and close friends.

All of the above, as illustrated also in various previous studies, can be very detrimental to the parental relationship with the severely handicapped, placed child (Beresford, 1994; Bradbury & Hewison, 1994; Byrne & Cunningham, 1985; Cooke & Lawton, 1984; Ellis *et al*, 1981; Farber, 1962; 1972; Floyd & Zmich, 1991; Friedrich & Friedrich, 1981; Gath, 1972; German & Maisto, 1982; Gallagher, Beckman, & Cross, 1983; Holroyd *et al*, 1975; Holroyd & McArthur, 1976; Kazak & Marvin, 1984; Lobato, 1983; Margalit & Leyser, 1991; Margalit *et al*, 1992; McCubbin & Patterson, 1983; McLinden, 1990; Pedersen, 1976; Pueschel, 1986; Raif & Rimmerman, 1993; Rimmerman & Portowicz, 1987; Seltzer & Krauss, 1984; Slade, 1988; Sloper *et al*, 1991; Tallman, 1965; Tausig, 1985; Trout, 1983; Trute & Hauch, 1988a; 1988b; Urbani, 1980; Waisbren, 1980; Wikler *et al*, 1983; Wilks & Wilks, 1974).

Conversely, the results from the current study suggests that, as found in previous studies, **mothers with less perceived stress may feel more secure in the marital relationship and that fathers may experience more satisfaction with life** (Friedrich, 1979; Holroyd, 1974; Sloper *et al*, 1991).

In considering fathers of severely handicapped, placed children separately, it is possible that the **fathers in this study may be more sensitive to general family problems than mothers** (see Table 4.9). This can best be explained by the gender-based difference in the utilisation of social support. Previous studies show that, whereas mothers are more reliant on informal support systems, i.e. their social support has a broader base (Bradbury & Hewison, 1994; Farber, 1972; Frey *et al*, 1989; Gallagher, Beckman & Cross, 1983; Mölsä & Ikonen-Mölsä, 1985; Waisbren, 1980), fathers may be more reliant on the support of intimate family members, particularly his spouse and his parents (Bradbury & Hewison, 1994; Farber, 1972; Frey *et al*, 1989; Waisbren, 1980). It is therefore very probable that, if their primary support system is not able to act effectively as mediator in their tension reduction efforts, fathers with high levels of perceived stress will experience greater strain in their intimate family relationships than fathers with low levels of perceived stress.

5.2.1.3.5 Limits on family opportunity

In this study, high levels of perceived stress and stress about time demands suggests a greater awareness amongst parents of **limited opportunities** (1) for outside activities, visiting friends and having time for oneself and (2) to build social ties and nurture self-development through work and other outside opportunities.

As suggested by the discussion in par. 5.2.1.3.1, parents with high levels of perceived stress may experience **greater social isolation** and may **engage less in societal interaction**. The above isolation and withdrawal may impede **personal growth** and **development opportunities**, such as work, social activities and education. Given that the fulfilment of personal and family growth opportunities contributes to the psychological well-being and life satisfaction, it is very possible that parents of severely handicapped, placed children, who present with high levels of perceived stress may feel unfulfilled, psychologically unwell and dissatisfied with their quality of life. As such they may be limited in their ability to contribute to the well-being of their spouse and family, which not only puts more strain on the spouse and family, but due to the increased stress load that the spouse and family have to carry, this could also further limit the growth opportunities of the family as a whole.

The above coincides with the findings of Margalit *et al* (1989) that fathers of handicapped children may view their families as less encouraging of personal growth amongst family members. Whereas it can be expected that the presence of a severely handicapped child may inhibit growth opportunities to some extent, the above suggests that high levels of perceived stress reduces to a greater extent parents' ability to achieve a satisfactory level of psychological well-being and personal growth. Such limitations could easily lead to the build-up of resentment and frustration in the parents that, in turn, could impact negatively on the marital integration of the couple.

5.2.1.3.6 Financial problems

The results of this study suggests that, where parents of severely handicapped, placed children experience high levels of perceived stress, they will be more inclined to have concerns about the **adequacy of their income** as well as the **high costs of providing care**.

Previous studies (Holroyd, 1982; Kane, 1984; Levinson, 1976; Pueschel, 1985; Slobody & Scanlan, 1959; Zimmerman, 1984) show that financial concerns may be more prevalent in cases where the children are physically more incapacitated. This would apply directly to the type of child catered for in care facilities. For severely handicapped children placement is, in the most cases, a long-term coping option, therefore it is understandable that the parent will have to make long-term financial arrangements. In the case of the parent with high levels of perceived stress, financial concerns may however become overwhelming to the point where the parent loses effectiveness as a provider.

5.2.1.4 Formal social support

Jointly and separately, fathers and mothers in this study who present with high levels of perceived stress will experience more stress with regard to a **lack of social support**, leading to a more acute awareness of (1) **insufficient community and medical resources** and services and (2) **poor family involvement** with those resources.

Previous studies show that parents of handicapped children are more reliant on resources and that cognitive appraisal determines the use of the resources (Antonovsky, 1979; Barbarin *et al*, 1985, Bregman, 1980; Bristol & Schopler, 1984; Darling, 1979; Deaton, 1985; Frey *et al*, 1989; Judge, 1998; Miller *et al*, 1992; Quine & Pahl, 1991; Shapiro, 1983; Sloper *et al*, 1991; Sloper & Turner, 1993). Accordingly, the presence of high levels of perceived stress may coincide with a parental tendency to:

1. Utilise resources less effectively and creatively;

2. Invest less effort into developing and maintain resources;

3. Be less involved in therapy and rehabilitation;

4. Be less able to develop trusting relationships with helping professionals;

5. Not believe in the benefit of treatment;
6. Disregard the importance of seeking information; and
7. Feel more vulnerable.

In short, high levels of perceived stress can have a very adverse effect on the parents' utilisation of and relationship with resources, which could have a very negative effect on the parents' adjustment.

In South Africa the paucity of services and resources for parents with severely handicapped, placed children is a reality (Mabaso & Uys, 1990). Given that the parent with low levels of perceived stress may be better at harnessing existing resources, this means that, not only may the parent with high levels of perceived stress have greater difficulty accessing and utilising resources, but that these resources may already be occupied by those parents that are coping better.

5.2.1.5 Coping

In this study, high levels of perceived stress in parents of severely handicapped, placed children correspond with the greater use of less effective and the lesser use of effective coping strategies. The results suggest that parents with high levels of perceived stress will **make greater use** of:

- **Suppression of competing activities:** This is a problem-focused coping strategy which entails "*putting other projects aside, trying to avoid becoming distracted by other events, even letting other things slide, if necessary, in order to deal with stressor*" (Carver *et al,* 1989, p 269);

- **Focussing on and venting of emotions:** ie *“the tendency to focus on whatever distress or upset one is experiencing and to ventilate those feelings*” (Carver *et al,* 1989, p 269). Although this emotion-focused coping strategy may be functional over the short-term, Carver *et al,* (1989) suggests that utilising this strategy over an extended period of time may impede adjustment;

- **Denial:** ie “*refusal to believe that the stressor exists or trying to act as though the stressor is not real*” (Carver *et al*, 1989, p 270). Carver *et al*, (1989, p 270) also suggests that although denial may be a useful strategy in the initial phases of crisis management, extended use of this strategy may “*cause the event to become more serious, thereby making more difficult the coping that eventually must occur*”;

- **Behavioural disengagement:** ie “*reducing one’s efforts to deal with the stressor, even giving up the attempt to attain goals with which the stressor is interfering”* (Carver *et al*, 1989, p 269). Sometimes behavioural disengagement is expressed in the form of helplessness. This strategy is most likely to occur when people expect poor coping outcomes; and

- **Mental disengagement:** This strategy occurs when behavioural disengagement is not a possible response. It is expressed via a number of “*activities that serve to distract the person from about the behavioural dimension or goal with which the stressor is interfering”* (Carver *et al*, 1989, p 269). Ultimately disengagement impedes adaptive coping.

In addition, parents with higher levels of perceived stress will make **less use of acceptance**. This coping skill, which is considered to be a functional coping response, entails that the parent will accept the reality of the stressful situation. Carver *et al*, (1989, p 270) points out that the use of acceptance is “*particularly important in situations in which the stressor is something that must be accommodated to, as opposed to circumstances where the stressor can easily be changed*’.

The co-occurrence in this study of high levels of perceived stress in parents with the greater and lesser use of the above coping strategies suggests that **these parents have remained "stuck" in their grief process and their adjustment efforts**. In most cases the short-term use of the first five strategies mentioned above could actually suggest positive outcomes, but at this stage, where the child has already been placed these strategies are no longer appropriate as they impede adjustment and create imbalance.

On the one hand the ongoing use of these strategies highlights the profound and often permanent impact of the presence of a severely handicapped, placed child within a family, but on the other Carver *et al*, (1989) points out that the ongoing use of (1) **suppression of competing activities** may lead to over involvement in the stressor to the detriment of other important activities and relationships, (2) **focussing on and venting of emotions** may impede adjustment as the parent remains upset and emotionally unbalanced by the stressor, (3) **denial** increases the intensity of the stressor and ultimately demands more intense and emotionally exhausting coping strategies and (4) **behavioural and mental disengagement** both impede adaptive coping and suggest that the parents expect themselves to cope badly. A negative appraisal of coping ability will ultimately lead to greater emotional discomfort. Furthermore, **acceptance seems crucial for good adjustment** when a parent is confronted with a long-term stressor such as the presence of a severely handicapped, placed child.

The results of this study clearly illustrates that high levels of perceived stress and the accompanying prevalence/lack of the above coping strategies will be very detrimental to both parents, may hinder them in dealing with their grief and could hamper their ability to be mutually supportive, leading to a breakdown in communication and a consequent deterioration in the spousal relationship.

In the relevant literature there is the suggestion that **problem-focused coping** is more frequently used in encounters that are appraised as changeable and that **emotion-focused coping** prevails when the stressor is appraised that something that must be endured (Beresford, 1994; Carver *et al*, 1989; Folkman & Lazarus, 1985; Folkman *et al*, 1986; Lazarus, 1974; Pearlin & Schooler, 1978; Petrosky & Birkimer, 1991). Given the relatively permanent situation of the severely handicapped, placed child, one would expect a degree of emotion-focused coping to occur amongst all these parents, especially as this form of coping, if used to effectively manage emotions that hinder problem solving, can facilitate effective and active problem-focused coping, such as planning, direct problem-solving, information seeking, cognitive restructuring and self-praise. These coping skills, in addition with the skilful management of informal social resources, are associated with good adjustment. Their presence in the coping repertoire of parents of severely handicapped, placed children may predict a better stress outcome and may assist parents in maintaining a lifestyle that is a normal as possible (Beresford, 1994; Judge, 1998; Miller, Gordon, Daniele & Diller, 1992; Pearlin & Schooler, 1978; Sloper et al, 1991). Should the parent however present with high levels of perceived stress, the results of this study suggest that this parent might be less able to utilise emotion-focused way in a way that aids problem-focused coping, with the result that the parent's psychological well-being may decline.

Previous studies confirm that the use of coping strategies such as avoidance, disengagement (behavioural and mental) and suppression or over-expression of emotions over an extended period of time coincides with poorer adjustment and lowered SOC. These findings support the results of this study (Beresford, 1994; Beavers, Hampson, Hulgus & Beavers, 1986; Carver et al, 1989; Judge, 1988; Margalit et al, 1992; Miller et al, 1992; Quine & Paul, 1991).

5.2.1.6 The outcome of stress: the impact of high levels of perceived stress on the resources of parents of severely handicapped, placed children.

Parents with high levels of perceived stress are at great risk. These parents will be more prone to negative appraisals of the severely handicapped child, their internal stress-reducing ability and of their available social support systems. Consequently their tension management ability, which relies on the positive appraisal and effective functioning of internal and external stress-reducing mediators, will be weakened. This may lead to increased vulnerable, reduced ability to utilise and develop their resources effectively, a significant decline on the health-ease/dis-ease continuum, greater difficulty in dealing with the ongoing grief process and, ultimately, poorer adjustment.

It seems as if the integrity of informal social support systems may be the most afflicted by the presence of high levels of perceived stress. For the mother with high levels of perceived stress this predicts greater isolation from close family and greater dependence on the husband, who is not accustomed to being the sole source of social support. Pressure on the father to become the mother's only social resource may inhibit his opportunities for personal growth and development and could deplete his psychological health and strength to the point where the demands become too great and he may decide to separate from the mother for the sake of ensuring his own psychological survival.

High levels of perceived stress in the father predict alienation from his spouse and increased efforts to elicit social support from close family and friends. Both of these systems are not skilled in providing social support for fathers. Hence the father may not only find his interaction with his spouse strained, could experience his interaction with his close family and friends as unsatisfactory. Accordingly the father may also opt for isolation from social contact and greater emotional disengagement, whilst finding other areas of focus and growth, such as over involvement in his work.

5.2.2 The interaction between parents' Sense of Coherence and fortitude on the one hand, and their personal and family-related stressors on the other

5.2.2.1 The role of appraisal in perceived stress, SOC and fortitude

In par 5.2.1, as well as in Chapter 2, the role of appraisal in the stress process is emphasised. Perceived stress, SOC and fortitude arise from an appraisal process. In the case of perceived stress it is an appraisal of the degree to which parents perceive or appraise their world as unpredictable, unmanageable and overloaded (Cohen *et al*, 1983). SOC reflects the appraisal of the degree to which life events are explicable, manageable and meaningful (Antonovsky, 1979, 1987), whereas fortitude reflects the positive appraisal of self, family and others (Pretorius, 1997, 1998). It is to be expected that a more negative appraisal of perceived stress would entail a lowered SOC and less fortitude.

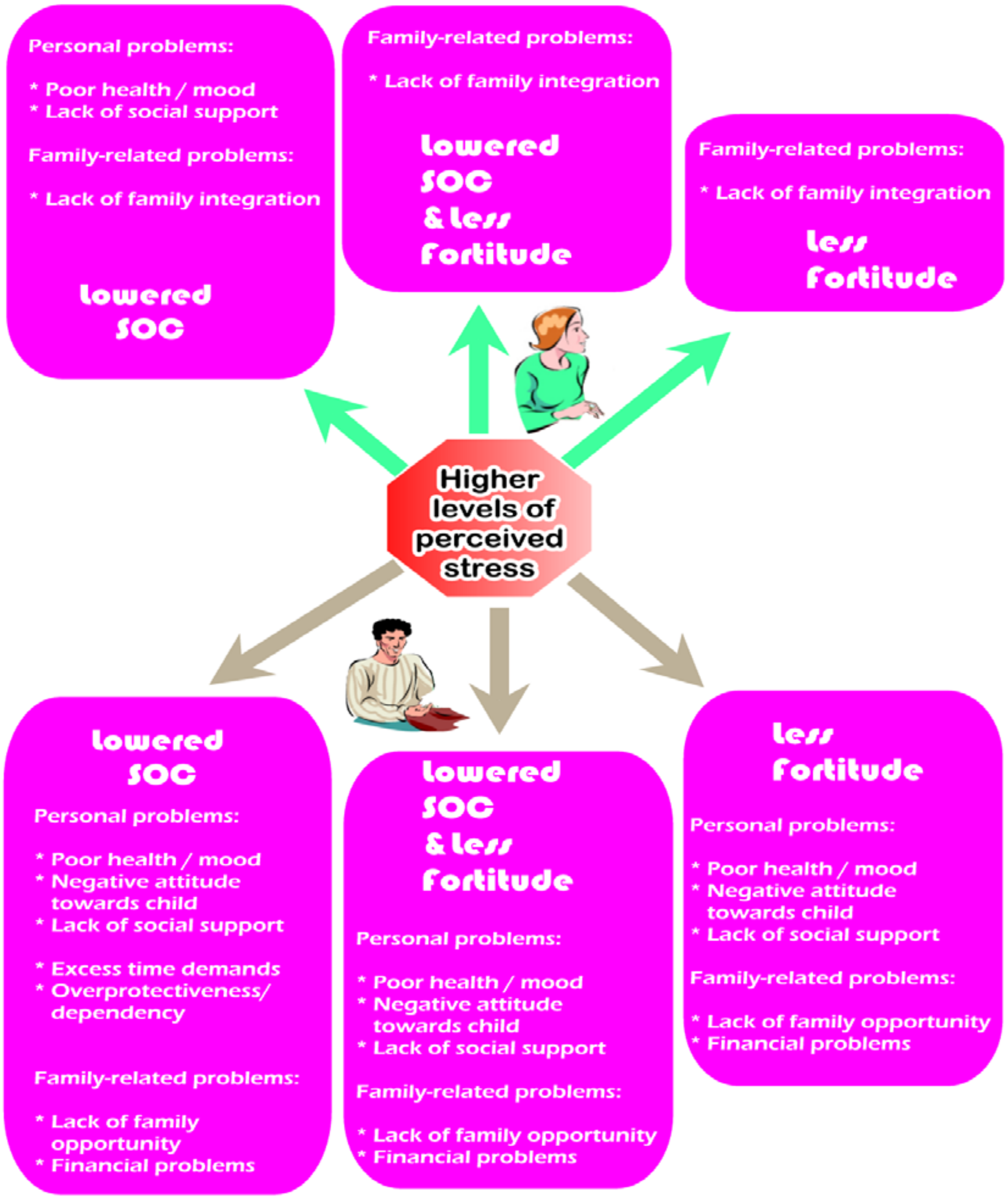
As is the case of in the previous section, the meaning and the impact of the stressors are interpreted according to the descriptions provided by Holroyd (1982).

What is very striking in this study is that the results obtained by means of investigating research hypothesis 3 that high levels of perceived stress, together with lowered SOC and less fortitude seems to have a greater interaction with the stressors, as experienced by the father, than that experienced by the mother (see Tables 4.16 to 4.18).

Figure 5.2 clearly illustrates that when fathers with high levels of perceived stress experience both **lowered SOC and less fortitude**, they will experience five common stressors, namely poor health / mood, negative attitude towards the child, lack of social support, lack of family opportunity and financial problems.

Mothers with levels of perceived stress, who present with **lowered SOC and less fortitude** have, as common stressor, stress with regard to lack of family integration.

Figure 5.2: The interaction between the parents' Sense of Coherence and fortitude on the one hand, and their personal and family-related stressors on the other



5.2.2.2 The difference between mothers and fathers

5.2.2.2.1 The mother with higher levels of perceived stress, lowered SOC & less fortitude

The results of this study shows that mothers with high levels of perceived stress, lowered SOC and less fortitude experience more stress in the areas of **poor health/mood**, **lack of social support** and, especially, **lack of family integration**.

Antonovsky's formulation suggests that a lowering of SOC would lead to the appraisal that life events are indeed a greater burden, rather than a challenge (Antonovsky, 1987). High levels of fortitude imply a positive appraisal of self, immediate family and others (Pretorius, 1997, 1998). It is therefore understandable that a mother with high levels of perceived stress will find her **involvement with the child to be less meaningful**, that she may experience, to a greater degree, **the emotional burden of having and caring for the severely handicapped child** and, given that she will have a **more negative appraisal of herself and her social resources**, of which the informal support system is the most important (Friedrich, 1979; Holroyd, 1974; Sloper *et al*, 1991), she may, according to Holroyd (1982), tend to

1. Feel **more dissatisfied with her role** within the family and **more aware of family conflict** with regard to the division of caretaking tasks and responsibilities as it relates to the severely handicapped, placed child;
2. Be more aware of (a) **general family stress**, i.e. family conflict and disharmony, (b) a **lack of family involveme**nt, (c) a **lack of supportive friendships** and (d) **family isolation** from friends and community;
3. Exclude to a greater degree, the severely handicapped child from family activities, which implies a **greater risk of detachment;** and
4. Lastly, this mother may have a much greater awareness of **lacking community and medical services**.

What is very evident from the above is that when the mother of the severely handicapped, placed experiences high levels of perceived stress, lowered SOC and less fortitude, she experiences stress regarding **a lack of family integration**, ie she has a **more negative appraisal of her primary resources**, ie her **informal social support system** (marriage, immediate family and close friends). Accordingly, her utilisation and management of and investment in these resources may decrease, leading to a deterioration of her relationship with these resources, limiting their stress-reducing function. **The mother's decreased ability to effectively reduce her own stress not only has very negative implications for her, but also may have dire consequences for her spouse, as she is his primary mediator of stress**.

5.2.2.2.2 The father with higher levels of perceived stress, lowered SOC & less fortitude

The results of this study illustrates that high levels of perceived stress, low SOC and less fortitude in the father coincides with greater paternal stress regarding **excess time demands**, **over-protectiveness-/dependency** and, especially, **poor health/mood**, **negative attitude towards the child**, **lack of social support**, **lack of family opportunity** and **financial problems**.

The father with high levels of perceived stress may be more concerned about the **time demands** that coincide with the presence of the severely handicapped child. Although the primary caregiver is most often the mother, her **over-involvement** in the handicapped child would have negative implications for the father with high levels of perceived stress (as expressed by the stressor: over-protectiveness / dependency) as it **limits his access to his primary support system**. Such over-involvement by the mother, which may lead to her social isolation and places limits on her ability to grow in herself and in her relationships, may clearly **limit growth and socialising opportunities for the father**.

Given that the mother remains the father's primary support system, deterioration in her functioning with the consequent worsening of her relationship with her primary support system (spouse, family, close friends) would place greater demands on him to play a supportive role. It follows that this will make it much more difficult for him to pursue such opportunities, hence his stress regarding over-protectiveness / dependency.

The presence of greater limitations on the father with high levels of perceived stress may cause him to harbour a **more negative attitude towards the child**, as he is more aware that any change or deterioration in the child's condition places greater demands on the mother. This adds to his concerns about **over-protection-/dependency**, as he sees the severity and possible deterioration of the child's condition as the source for his spouse's increased and narrowed focus on the child.

Stress regarding poor health/mood suggests that the father with high levels of perceived stress, lowered SOC and less fortitude will have a greater awareness of the **emotional burden of providing care** and may be more dissatisfied with **his role within the family** (Holroyd, 1982)**.**

The **spousal relationship and the paternal grandparents** play a pivotal stress-reducing role for the father (Bradbury & Hewison, 1994; Farber, 1972; Frey *et al*, 1989; Waisbren, 1980: 350). It follows, as suggested by the results of this study, that should the father experience high levels of perceived stress, lowered SOC and less fortitude, it can be safely assumed that **these primary mediators are not working well**. Consequently, as suggested by Holroyd (1982), he will experience greater stress with regard to a **lack of family involvement**, **isolation from friends and community**, **disagreement about caretaking tasks** (as he may feel that the mother is over-involved and over-committed to the child, whilst not recognising his needs for stress relief) and he may have a more **negative appraisal of the availability of formal resources**.

The father's need for the availability of resources may not be so much because they can directly benefit him, but because he sees these resources as possible avenues along which the mother can reduce her own stress so that she may fulfil her stress-reducing role in his life. Should she not be able to do so, he may harbour resentment not only at the child, but also at the professional community for debilitating his spouse and, consequently damaging his own quality of life.

The above suggests that the father with high levels of perceived stress, lowered SOC and less fortitude may have greater difficulty fulfilling a provider role as **his higher stress levels may impact negatively on his ability to hold down a demanding job as well as generating an extra income to cover the costs of care**. It is therefore to be expected that this father **will have greater financial stress**.

5.2.2.2.3 Impact on the spousal system

Within a socio-ecological perspective it is very probable that higher levels of perceived stress, lowered SOC and less fortitude in one partner may coincide with the same state of affairs in the other. The above discussion highlights the interaction of high levels of perceived stress, lowered SOC and less fortitude with maternal and paternal stressors.

It is clear that fathers with high levels of perceived stress, lowered SOC and less fortitude are sensitive to a greater number of stressors, whereas these mothers are mostly sensitive to a lack of family integration.

When the mother, as the father's primary support system, takes greater strain it is to be expected that the father may perceive himself as suffering more extensively than his spouse as he has few alternative support systems to mediate his stress.

This may disrupt his functioning in the family, leading to the mother's greater stress about family integration as she experiences concern at her spouse's deterioration and the decline of his ability to function as part of her support system and frustration at her own inability to arrest the situation.

In par 5.2.4 the interaction between high levels of perceived stress of the one marital partner on the psycho-fortigenic functioning of the other will be discussed.

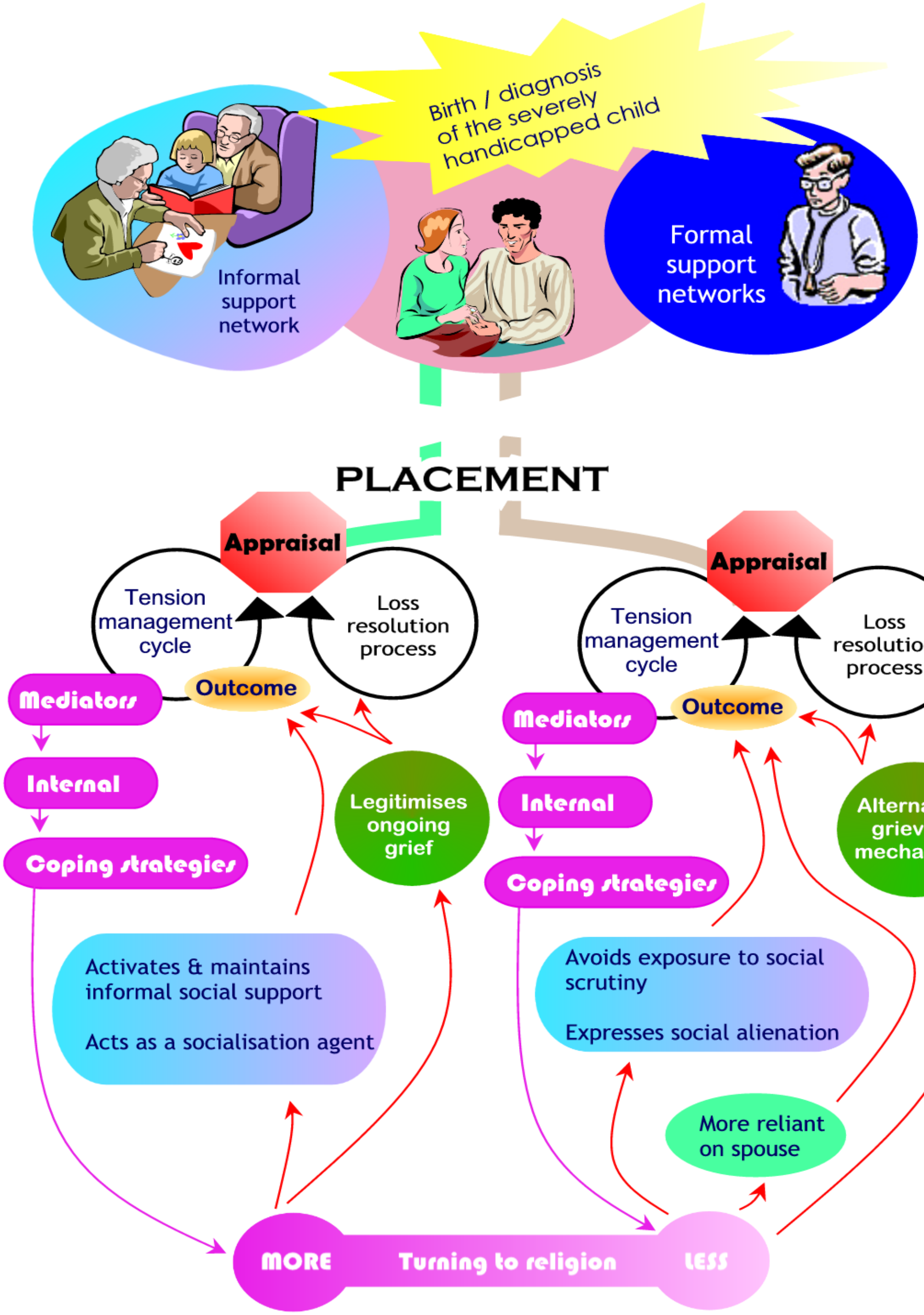
5.2.3 The differential role of religion in mothers and fathers of severely handicapped, placed children

Figure 5.3 illustrates the differential use of religion and highlights the reasons, to be discussed below, for that difference.

Without considering any relationships between the various stressors, stress-related and psycho-fortigenic factors, the results obtained from the processing of research hypothesis 1 (see 3.6.1) indicates that the fathers and mothers in this study differ in only one aspect, namely, with regard to the coping strategy, **"turning to religion"**.

The finding that mothers make greater use of religion as a coping mechanism replicates that of Barbarin et al (1985), namely, that the mothers of children with terminal cancer employed the use of religion more frequently than fathers. They add that parents, who had received the diagnosis within three years of their research interview, gave greater weight to the use of religion than parents who had received the diagnosis more than three years prior to the interview. This would suggest that, in the research by Barbarin et al (1985), use of religion might have been coupled with hope for recovery, which would fade as the child's terminal status was confirmed.

Figure 5.3: The role of religion in the adjustment of fathers and mothers of severely handicapped children



Parents of severely handicapped, placed children probably harbour little hope for the recovery of their children as their handicaps and abnormalities are of a permanent nature. Often their only certainty is the realisation that the child's condition may deteriorate over time and that, at some point, the child will die. It is therefore clear that, for the parents in this study, especially, the mother, religion has a different function than for the parents of terminally ill children.

In Chapter 2 it was pointed out that research findings on role of religious beliefs as a mediator of stress are contradictory (Farber,1972; Friedrich, 1979; German & Maisto, 1982; Kazak, 1986; Olshansky,1962; Waisbren, 1982).

Carver *et al* (1989, p. 270) point out that a person may "*turn to religion when under stress for widely varying reasons: religion might serve as a source of emotional support, as a vehicle for positive reinterpretation and growth, or as a tactic of active coping with a stressor."* The scale included in the COPE questionnaire reflects religion, as utilised in times of stress, but does not identify its particular function.

In this study, the use of religion may signify at least four functions in the adjustment of the mother.

- Turning to religion could be **a way to legitimise continued mourning**. Although some religions prohibit mourning, Davis (1987), points out that, apart from psychotherapy which is essentially time-limited, religion may be the only way to express grief over an extended period of time as other societal systems do not encourage ongoing grief – something which is a fundamental aspect of the parent of the severely handicapped, placed child's life (Olshansky, 1962; Wikler *et al*, 1981, 1983);

- Religion can be an **agent in the socialisation process** that specifically prepares the mother for the role of mother-of-a-severely-handicapped -placed-child. Meadow and Meadow (1971, p.21) point out that "*the socialization to the role of parent of a handicapped child is a transition to an unwanted and distasteful status for most if not all who find themselves in this position*". They suggest that religion may have an effect on the socialisation process.

In the case of the mothers in this study, they have already had long-term exposure to the situation of the child, which means that they have passed through initial transitions. Depending on the religious definition of motherhood-of-the-handicapped-child, religion could play either a negative or positive role in the ongoing socialisation process. One the one hand, it could **reinforce the perception for maternal martyrdom**, whilst, on the other hand, **strengthening the mother** emotionally/spiritually in her efforts to remain involved in the child's life whilst maintaining her family/work responsibilities.

- Turning to religion, as expressed in involvement with the church or church groups, could be a way in which the mothers included in this study express their **utilisation of informal social support** and demonstrates that they are not solely reliant on their husbands. It has been pointed out that sole reliance on the husband may, in actual fact, suggest poor adjustment (see par. 5.2.1.6). Therefore the greater use of religion may suggest that the group of parents in this study are reasonably well adjusted. The mother's greater usage of religion as social support also correlates with previous research findings that **mothers are reliant on informal social support networks** (Bradbury & Hewison, 1994; Farber, 1972; Frey *et al*, 1989; Gallagher, Beckman & Cross, 1983; Mölsä & Ikonen-Mölsä, 1985; Waisbren, 1980).

- A further possibility is that mothers may turn to religion in cases where they **do not feel adequately supported** by their spouses and/or close family support system. This explanation may be less likely as indications are that deterioration in one subsystem of the informal support system may lead to increased social isolation (see par. 5.2.1.3.1, 5.2.1.3.2 and 5.2.1.4).

The nagging question is: ***why do fathers not turn to religion to the same degree?*** There are a number of possibilities:

- Fathers may use **other mechanisms** to express chronic sorrow.
- Given that this study focussed on parents who have their children in privately funded care facilities, it suggests that the fathers would have a higher earning potential that enables them to pay monthly fees. Hence, they would probably have positions that are more visible in society and may be more sensitive to social evaluation. As a result they may want to avoid societal institutions, such as churches, which could represent, for the father, **greater exposure to social scrutiny**. Previous research findings suggest that fathers are **more sensitive to social status** (Farber, 1972).
- There may be, amongst certain fathers, **a greater scepticism, loss of hope and social alienation** with regard to the issues relating to the child. This could find its expression through lesser participation in the church. No research findings on fathers of severely handicapped children were available to confirm such a possibility; and
- As stated in the above paragraphs dealing with the mother's usage of religion, turning to religion can be seen as providing emotional support to the mother. Fathers have shown themselves to be less reliant on social support in general, but **more reliant on their spouse** (Bradbury & Hewison, 1994; Farber, 1972; Frey *et al*, 1989; Waisbren, 1980: 350). ***If the mother is strengthened through religion, she may able to offer greater support to her husband, hence his lesser tendency to seek out religion/religious activities as a form of social support***. Accordingly, should the father seek out religion as a resource it may be indicative of poor adjustment in the mother. Given the picture surrounding the role of social support that has gradually emerged throughout the foregoing discussions, this may the most likely explanation.

5.2.4 The interaction of the psycho-fortigenic characteristics of one parent with the perceived stress of the other

Figure 5.4 shows the effect of the perceived stress of one spouse on the psycho-fortigenic functioning of the other.

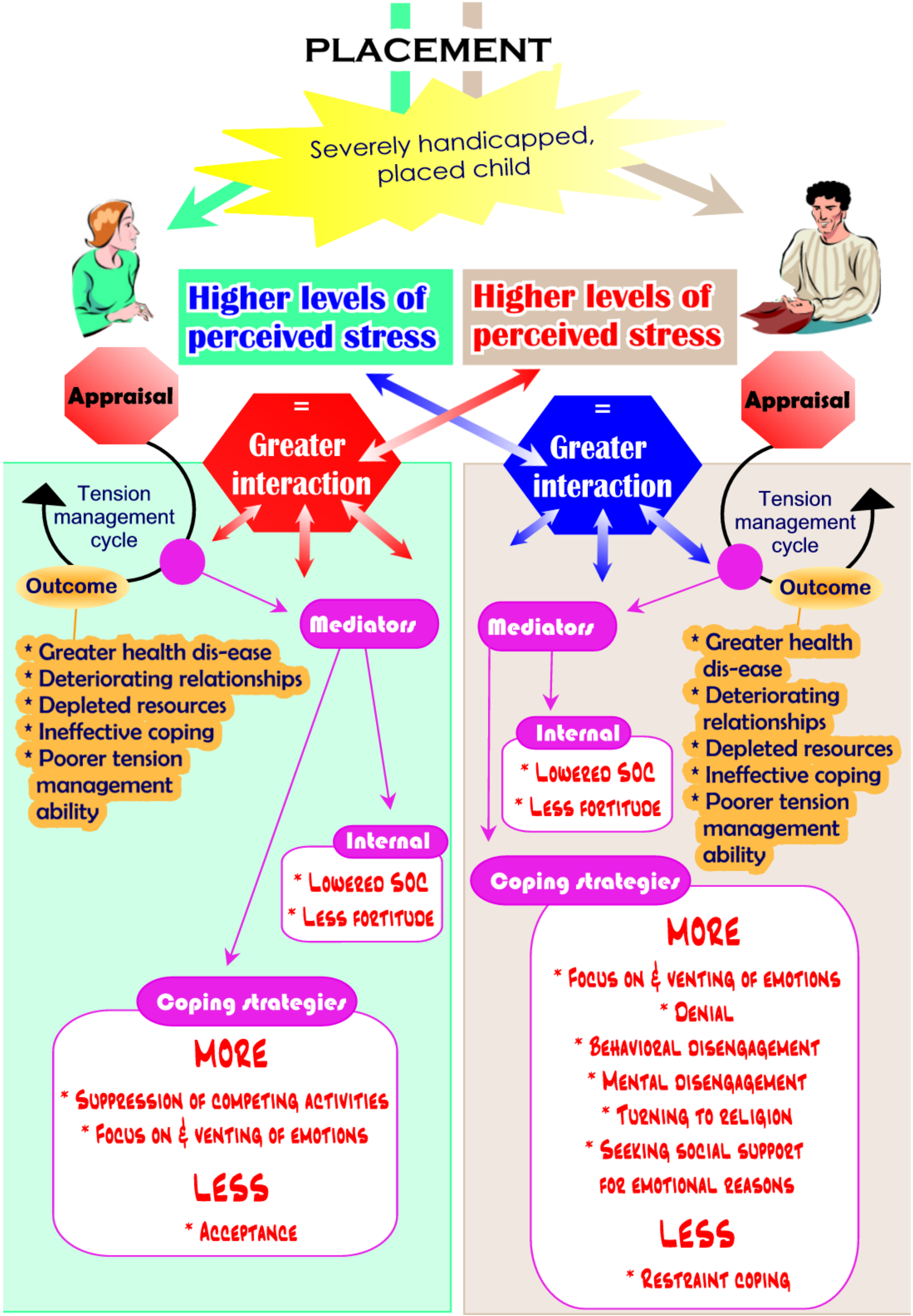
From the outset, the parents of severely handicapped, placed children have been discussed from a socio-ecological perspective. Within this perspective it follows that the well-being of the one must interact with and should influence the well-being of the other. The comparison of the fathers and mothers in the twelve couples included in this study abundantly illustrate this principle.

The results of the further investigation proposed in par 3.6.4 suggest that the father’s coping seems more adversely affected by the mother’s perceived stress than vice versa.

5.2.4.1 The vulnerable father

The results suggest that where one spouse presents with higher levels of perceived stress, the other will show both lowered SOC and less fortitude and will exhibit a coping style that predicts poor adjustment. Although the above is true for both marital partners, it also seems that, as in the case of the father’s greater sensitivity to stressors, in conjunction with his own higher perceived stress, lowered SOC and less fortitude (see par. 5.2), **higher levels of maternal perceived stress** will coincide, in the father, with **lowered SOC**, **less fortitude** and the **greater use of ineffective coping strategies**. This tendency confirms very much a strong and recurrent emerging theme, namely that the mother remains the primary stress-reducing mediator for the father and any deterioration in her ability to fulfil this role, puts the father at great risk, especially as he has few other social supports.

Figure 5.4: The interaction of perceived stress of one parent with the psycho-fortigenic functioning of the other



Accordingly the results suggest that, once the mother is no longer able to fulfil the primary stress-reducing role, the father will be more inclined to **seek other social support for emotional reasons** and **turn to religion**, as a form of informal social support, in order to alleviate his stress. It was pointed in par. 5.2.3 that turning to religion in the father may be an expression of the mother's poor adjustment.

Furthermore, the father whose coping is affected by his wife's high levels of perceived stress may tend to **disengage behaviourally and mentally** from the problem, i.e. the child, as he sees the severely handicapped, placed child as the source of his troubles. His disengagement may also take the extreme form of **denial** – a strategy that, at this stage, may greatly compound the impact of the stressor and put greater demands on the adjustment process.

With the mother less able to fulfil a stress-reducing function, it also follows that the father may indeed be more inclined to **focus on and vent emotions** and exhibit **less restraint coping**, ie less waiting until an appropriate opportunity presents itself, less holding back and a greater tendency to exhibit premature actions (Carver *et al,* 1989). This may lead, on the father's part to impulsive and drastic actions that could put the well-being of his spouse and the integrity of his family at great risk.

No research studies could be found that compare the perceived stress of one partner with the SOC, fortitude and coping of the other.

5.2.4.2 The fate of the mother…

Higher levels of perceived stress in the father, coincides with lowered SOC, less fortitude and the greater use of the coping skills **suppression of competing activities** and **focus on and venting of emotions** and the **lesser use of acceptance**. Suppression of competing activities may lead to the **greater isolation of the mother** within the spousal relationship and within the informal support system. This, in turn, isolates the mother from one of her primary stress-reducing mediators, which would lead to her to have more prevalent and intense negative emotions. The result is that her grief process I stunted by her limited acceptance of the child's situation.

5.2.5 The big picture

The birth/diagnosis of a severely handicapped child is traumatic for any parent. It introduces an ongoing and cyclic grief process that confronts the parent with the resolution of complex grieving tasks. Such grief is compounded by the necessity to place the child in care in order to assure the psychological health of the family. Once placed, having such a child still puts ongoing demands on both parents and challenges them to accommodate this trauma in their lives whilst maintaining personal growth as well as effective spousal and family relationships.

Parents with acceptable levels of perceived stress, sufficiently strong SOC and higher levels of fortitude seem to have the best chance of utilising their resources effectively and coping well with their situation.

In contrast, higher levels of perceived stress, lowered SOC, less fortitude, ineffective coping - all of these - put the parents of severely handicapped children at risk and make them more acutely aware of the personal and family-related stressors that confront them. These parents specifically show greater stress with regard to the severity of the handicap, the risk of detachment, the emotional burden of care-giving, individual and family role definition and fulfilment, personal and social isolation, social sensitivity and perceived societal bias, general family stress, limits on growth opportunities, financial problems and the lack of formal support systems.

Both fathers and mothers with high levels of perceived stress, lowered SOC, less fortitude show **great stress with regard to their informal support systems**, suggesting that (1) the parents would benefit from **a positive appraisal of this system** and (2) that **these systems need to function well** in order to assure the father and mother’s well-being.

The mother’s role and well-being in the adjustment of the family seems pivotal. Throughout the preceding discussion it has been made abundantly clear that the mother’s effective utilisation of her support systems benefits the father as it enables her to continue in her role as primary stress-reducing mediator for the father. When she is able to do so, the father is able to continue with his supportive role and he has a better chance of experiencing a better quality of life. This, in turn, would benefit the mother. Where the mother cannot maintain her role as primary stress-reducing mediator for the father, the couple and their family are at great risk.

5.3 The shortfalls of previous research

A review of the applicable literature still leaves many questions unanswered.

The impact on the father, with the resultant effect on his own emotional health and the well-being of his spouse and family has been neglected by researchers and professional helpers alike and, sadly, studies on the coping of single fathers with severely handicapped children are either very rare or non-existent, as no such studies could be traced. Even for married fathers, very little data is available with regard to the tension reducing effects of mediators such as paternal characteristics and internal psychological mechanisms, such as the SOC, fortitude and beliefs.

Previous research findings on the impact of caretaking demands of the handicapped child on the father may be misleading. Although the father is less directly affected by the physical caretaking demands, he must surely experience its impact on his spouse's ability to maintain the marital relationship. Accordingly he may be very sensitive to the emotional impact, especially if excessive, on his spouse that results from the caretaking demands of the child.

It is clear from the literature review that the father is primarily reliant on spousal support (Bradbury & Hewison, 1994; Farber, 1972; Frey *et al*, 1989; Waisbren, 1980). Researchers have given very limited attention to the strong possibility that the lack of systemic resources for the mother may lead to stress in the father and have under-emphasised the need to keep the mother psychologically strong so that she may fulfil her role as primary mediator of stress for the father.

There are very few cross-cultural and longitudinal studies that explore mediators of stress, such as the way in support by the mother and grandparents help to alleviate the stress of fathers and there is no data available on how fathers benefit from visits by other parents of handicapped children.

Researchers need to determine the nature of the environmental support system that would further all-round father-participation.   Overall, there is a great need for development of father-related services and the introduction for appropriate training content for helping professionals.

Available studies on fathers with handicapped children seem to over-emphasise cognitive coping skills, whereas few studies have examined the ways in which emotion-focused coping or the utilisation of affective mechanisms can benefit fathers. The results of this study suggest that the coping of parents of severely handicapped, placed children the effective use of emotion-focused coping ensures the successful use of problem-focused coping. Generally, more father-related studies on coping are essential.

The father's role in the placement decision still requires further illumination. It is unclear as to how often this is a joint decision. It may be that this decision may mostly rest with the father, who has to override the mother's inherent tendency to provide care at all costs. There is no clarity as to how post-placement involvement of fathers and mothers may differ.

5.4 Shortcomings of this study

This study has a number of shortcomings, most of which have to do with the composition of the sample.

The most pertinent of these shortcomings is the small sample (n=77) and the very small number of couples (12) that was included. In the planning stages of this study extensive efforts were made to assure a representative population. Contributing factors, which resulted in the poor return, (77 out of 275 questionnaires) may be that many of these parents were (1) too stressed to set aside the time and energy to complete quite a bulky questionnaire, (2) found the 18 pages of the questionnaire too bulky, (3) found the QRS (285 items) too frustrating to complete or (4) chose not to revisit the intense emotions that would inevitably accompany the completion of the questionnaire.

Another shortcoming is the big difference between the number of fathers and mothers that responded (25 vs. 52). Although this is a trend common to previous studies, ways of obtaining a more representative paternal response should be sought by future researchers.

Whereas this study points out that high levels of perceived stress debilitates parents' ability to effectively manage their tension and many correlations were found between negative factors such as high levels of perceived stress, lowered SOC, less fortitude and ineffective coping, little came to the fore in terms of the relationships between low levels of perceived stress, high SOC, strong fortitude and effective coping. As yet we know what to avoid, but not what exactly to encourage.

5.5 Intervention

5.5.1 A personal note

The reader is aware that I am the father of a now-deceased, severely handicapped child. I had the opportunity to share 20 months of my life with my son, Philip, and the staff of Woodside Sanctuary, Rondebosch. In this time I was able to share intimately the effects of this traumatic event with my wife, other children, the grandparents, friends, clerics and professionals. Through this process I became acutely aware that many of these people would treat me differently to my wife and that they would respond more openly to her emotional process. This often left me feeling emotionally isolated, as I could not share with them and found it hard to burden my wife with my sorrow.

Ultimately the process left me with the realisation that something needs to be done to ease the emotional adjustment of fathers of severely handicapped, placed children. In the service-related literature there is a clear message that more father-orientated services are required and that steps need to be taken to include fathers in various ways and, accordingly, my initial thoughts centred on providing programmes and therapeutic interventions tailored to meet the need of fathers. The outcome of this study impresses on me, however, **the importance of the mother's pivotal stress-reducing role for the father**. This may indicate that it is not so much father-orientated services and therapies that may be required, but rather services and interventions that enable:

(1) The mother to remain psychologically strong and resilient so that she may deal with the stressors associated with the child, attend to her other work and family responsibilities, cultivate and utilise her informal support system and act as primary mediator for the father's stress; and

(2) The father to invest in such a way in the spousal relationship and informal systems to ensure the mother's ability to perceive and utilise her informal support system in a positive way.

It is my view that fathers certainly need more direction and structure in order to optimise their involvement with their severely handicapped, placed child.

5.5.2 A positive approach

Throughout the literature review (see Chapter 2) there has been the acknowledgement that parents of severely handicapped children are highly stressed. Within the tenets of positive psychology intervention should be focused at achieving not only triumph over the adversity of having and caring for a severely handicapped, placed child, but also at generating a degree of everyday happiness and fulfilment that will empower parents to:

(a) Foster "valued subjective experiences: well-being, contentment and satisfaction (in the past); hope and optimism (for the future); and flow and happiness (in the present)";

(b) Empower individual parents of handicapped children to grow in their "capacity for love and vocation, courage, interpersonal skill, aesthetic sensibility, perseverance, forgiveness, originality, future mindedness, spirituality, high talent, and wisdom"; and

(c) Assist these parents, as part of their group, to develop the "civic virtues" of "responsibility, nurturance, altruism, civility, moderation, tolerance, and work ethic" (Seligman & Csikszentmihalyi, 2000, p 5).

Many researchers (Bailey, Simeonsson, Winton, Huntington, Comfort, Isbell, O'Donnell, & Helm, 1986; Bromley & Blacher, 1991; Caro & Deverensky, 1991; Dyson, 1991; Jayashankarappa & Puri, 1984; Olshansky, 1962; Stone, 1989; Lemons & Weaver, 1986; Olsen, 1970; Opirhory & Peters, 1982; Urbani, 1980; Wikler, et al, 1980) have offered suggestions with regard to effective intervention. These researchers suggest that:

1. Assistance to families should be moulded to the whole family's needs and experiences.
2. Skilled, respectful and sensitive handling should be provided by informed and familiar professionals who are aware of their own stress, moral values and the nature of their role;

3. Professionals review, within a multi-disciplinary approach, diagnostic information, the positive aspects and strengths of the child, guidelines and resources. The professional should not promote home care or push for residential placement of the child. Rather, parents should be provided with the necessary information so that they can make a choice in keeping with their family values. By reducing daily stress and reducing the child's behaviour difficulties, professionals may empower the family to maintain the child in the home environment;
4. Professionals provide continued treatment that gives handicapped children the opportunity to develop their potential;
5. Professionals introduce stress-related and community-based interventions that mobilise family strengths, recognise the grief process, maintain hope, develop appropriate parenting skills, promote future planning, further family reintegration and foster involvement by grandparents and siblings;
6. Parents of handicapped children are assisted in networking with other successfully coping parents and staying socially involved;
7. Government regularly reviews policy; and
8. Constant scrutiny of training programmes for professionals and professional helpers is done to ensure that these people (1) are adequately skilled, (2) understand the complexities of parental grief, (3) know how to facilitate effective tension management and the maintenance of family strength and (4) are appropriately employed.

To this I would add the following suggestions:

1. An emphasis should be placed on research studies that include a representative group of parents. In South Africa, there is a dire need for research across different population groups and into the identification and development of care facilities and associated career opportunities. Future researchers should explore the nature, maintenance and strengthening of family resilience to the task of raising a child with handicaps;

2. Professionals should:

    a. Focus on early intervention to re-establish the parents sense of control and empower them to actively and constructively manage their stress;

    b. Identify and assess the parents' existing body of cultural beliefs, values, strengths, coping skills and resources, linking them to aspects of the demand where they can engage positively;

    c. Assist parents in understanding and managing the complexity of their grief process;

    d. Assess the extent to which the parents see having and caring for a severely handicapped child as comprehensible, manageable and meaningful;

    e. Introduce interventions that strengthen SOC, bolster fortitude and encourage the use of effective coping mechanisms;

    f. Harness this knowledge to mobilise these resources and enhance coping efforts, and, in doing so, assisting the parents to maintain a positive outlook on themselves, their family and support system;

    g. Provide information and support in a skilled, respectful and sensitive way;

h. Provide continued treatment/care for the child without creating false hope or protracting the child’s suffering;

i. Empower the father to invest effectively in the life of the mother and the informal support system so that the mother may be better able to continue her multiplicity of demanding roles, whilst still acting as primary stress-reducing mediator for the father;

j. Provide stress-related and community-based interventions that mobilise family strengths, recognise the grief process, maintain hope, develop appropriate parenting skills, promote future planning, further family reintegration and foster involvement by grandparents and siblings;

5.6 Closing comments

There is little doubt that the birth/diagnosis and continued presence of severely handicapped child, even when placed, is a significance source of grief and distress for the parent. Accordingly, the efficacy of the loss resolution and tension management processes are vital in that they can protect the parent against excessive distress, bolster the parents’ psychological health and strength, foster the development and maintenance of resources and facilitate the development of a meaningful and fulfilling relationship with the child.

It is clear that professionals, especially psychologists, still have a long way to go in bringing their knowledge and skills to bear on these processes.

Ultimately, one hopes that, for every parent of a severely handicapped child, there is the possibility of transcending the ongoing struggle of providing and caring for such a child so that, at least some of the time, they may experience everyday happiness.

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Addendum A: The initial letter to care facilities

Addendum B: The questionnaire booklet

Addendum C: The story of my son

Kinder- en Gesinseenheid
Pro med
Child & Family Unit

Anthony J. Costandius
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2000-11-24

The Manager

Dear Sir or Madam:

RESEARCH PROJECT: STRESS AND COPING IN PARENTS OF SEVERELY HANDICAPPED, INSTITUTIONALISED CHILDREN

I am a Counselling Psychologist currently in private practice. At the moment I am in the process of completing a Ph. D. in Psychology under the supervision of Prof Malan Heyns, University of the Orange Free State. In part fulfilment of this degree I have to complete a research project.

As a parent of a now deceased severely handicapped, institutionalised child, I became acutely aware of the needs of such parents and have accordingly decided to focus my research on this area.

In order to complete the research I urgently require the input of both parents of severely handicapped, institutionalised children, hence my approach to your facility. The criteria for participation are that:

1. The child should be living in the institution full time and requires full time care. This does not disqualify children that are still able to go on home visits, but the child must spend the majority of his / her time in care.
2. The child should be mentally handicapped to the degree that he / she will not benefit from input at a training centre.
3. The child does not necessarily have to be physically handicapped.
4. The parents must have a reasonable command of English or have access to a translator / interpreter.

I would appreciate it if you would approach your management body and determine which of the parents of the children cared for at your facility would be prepared to participate in a research project. Once you have established this, I would appreciate it if you would provide me with their names, addresses and telephone numbers so that I may forward the relevant questionnaires to them.

I estimate that the completion of the questionnaire would require 90 minutes of their time. Envelopes and postage will be provided to ease the return of the questionnaires.

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It is my hope that you will be willing to assist in the completion of this project as there is very little South African data available on this topic and this research could make a positive contribution to the knowledge and understanding that professionals have of this particular population.

Kindly contact me as soon as possible.

Yours truly,

Anthony J Costandius