

Psychosocial adjustment to physical disability / chronic illness

Ineke Pit-ten Cate

CAMHS North Wales summer school

13 June 2006

Overview

- Paediatric Psychology
- Psychosocial adjustment in families of children with physical disabilities / chronic illness
 - Theoretical models and research findings
- Child experience of disability
 - Peer groups and friendships
 - Developmental theory
 - Findings CHADS
- Pain or Gain?
- What can we do to help?

Paediatric Psychology

- Focus: the examination of how conditions of health, illness and disability are related to children's behaviour and development.
 - Addresses the relationship between children's physical, cognitive, social, and emotional functioning and their physical well-being, including maintenance of health, promotion of positive health behaviours, and treatment of chronic or serious medical conditions.
- Paediatric psychology is the application of developmental psychopathology to the physical wellbeing of children, adolescents and families.

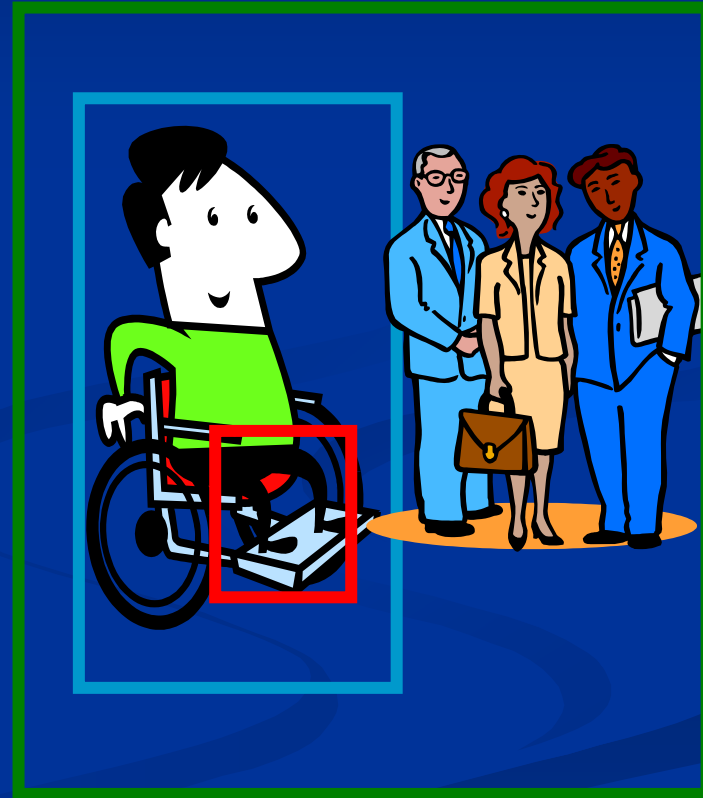


Group activity

- A core component of Paediatric psychology is the collaboration with paediatricians and health professionals.
- I would like you to think about the advantages and challenges of this specific collaboration
- Work in small groups and report feedback in 5 minutes

Medical model

- International Classification of Diseases (ICD)
- International Classification of Impairments, Disabilities and Handicaps (ICIDH)
 - Impairments – loss or deficit of a psychological, physiological or anatomical structure or function (organ level)
 - Disability – loss or decreased possibility to perform ADL activities as result of impairment (personal level)
 - Handicap – a less favourable position of a person, resulting from an inability to fulfil ‘normal’ social roles due to impairments and associated limitations (social-cultural level)



- "Definitions and classifications must not have the effect of separating people with disabilities from society or excluding them from the possible steps of rehabilitation and integration, but point to their individual problems and prospects and ways in which all people with disabilities can gain access to the assistance they need to enable them to fully participate in society."

International Classification of Functioning, Disability and Health (ICF)

- The ICF is structured around the following broad components:
- Body functions and structure
- Activities (related to tasks and actions by an individual) and participation (involvement in a life situation)
- Additional information on severity and environmental factors

Psychosocial model

- Focuses on associated problems in personal functioning rather than illness per se
 - Somatic problems
 - ADL
 - Social functioning
 - Psychological wellbeing
 - Communication

General issues in Paediatric Psychology

- Adherence

- Health promotion

“Health promotion refers to activities designed to enhance individual and family functioning” (Black, 2002)

- Prevention

- Primary, secondary and tertiary
- Universal, selective and indicative

- Child and family psychosocial adjustment

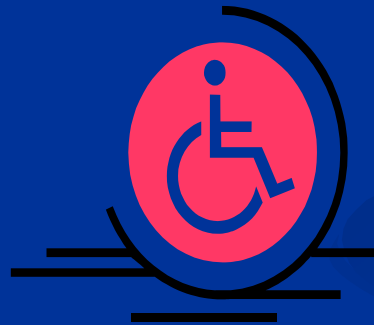
Developmental, Behavioural and emotional problems

- Failure to thrive
- Eating problems
 - Anorexia nervosa, Bulimia, Feeding problems
- Elimination disorders
 - Enuresis, Encopresis
- Somatoform disorders and factitious disorders
 - Somatoform disorders: characterised by the existence of medically unexplained physical symptoms (real though sometimes exaggerated)
 - Factitious disorders: physical symptoms intentionally falsified to meet some psychological need of the patient. Sometimes even manufactured (Munchausen's by proxy)
- Genetic chromosomal disorders
 - E.g. Turners syndrome, Klinefelter's syndrome, Fragile X syndrome
- Habit disorders and sleep disturbances
 - Tics
 - Narcolepsy (falling asleep unintentionally), Insomnia, Hypersomnia (sleeping too much)

Physical conditions (and associated neurobehavioral and psychosocial problems)

- Spina bifida and/or hydrocephalus
- Asthma
- Cerebral palsy
- Diabetes
- Cystic fibrosis
- Leukaemia and cancers
- JRA
- ...

Psychosocial adjustment in families of children with disabilities / chronic illness



- Both parent and child at increased risk of maladjustment
- Models can help to better understand the processes that influence stress and its adjustment outcome
- Coping is understood to affect the relationship between occurrence of a stressful situation and the outcome (Beresford, 1994; Lazarus & Folkman 1984)
- Theoretical models of stress applied to families of children with a disability/chronic illness

Models of stress and adjustment to disability

- An integrated model of adjustment (Pless & Pinkerton, 1975)
- The life crisis model (Moos & Schaefer, 1984)
- The disability-stress-coping model (Wallander et al 1989; Wallander & Varni 1992)
- The transactional stress and coping model of adjustment to disability (Thompson et al 1993)

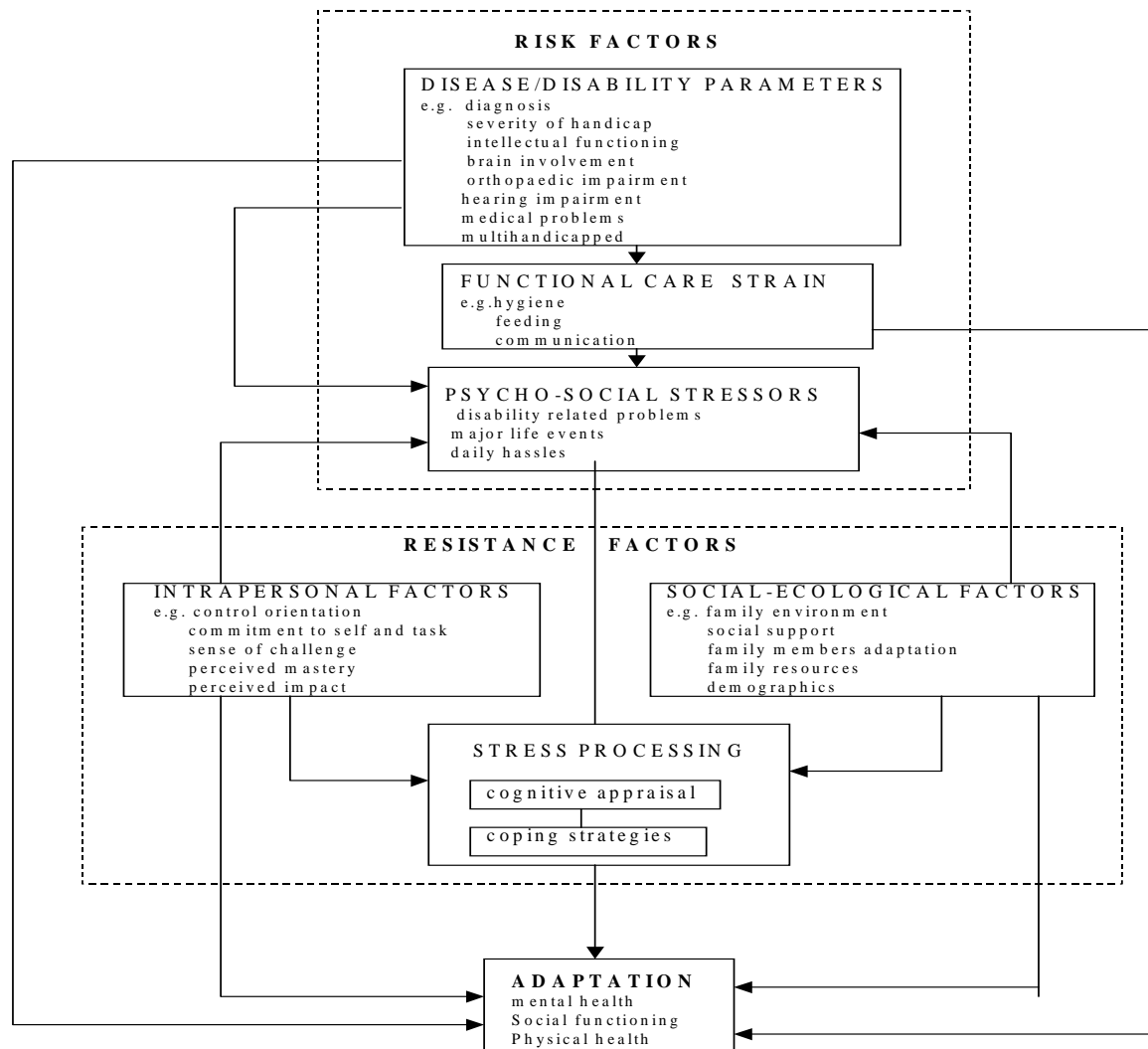
Adaptation versus Adjustment

- Adaptation = the extent to which a person can accommodate the demands of the stressful situation (e.g. find resources, change lifestyle)
- Adjustment = psychological balance or freedom from abnormality in face of pathological circumstances

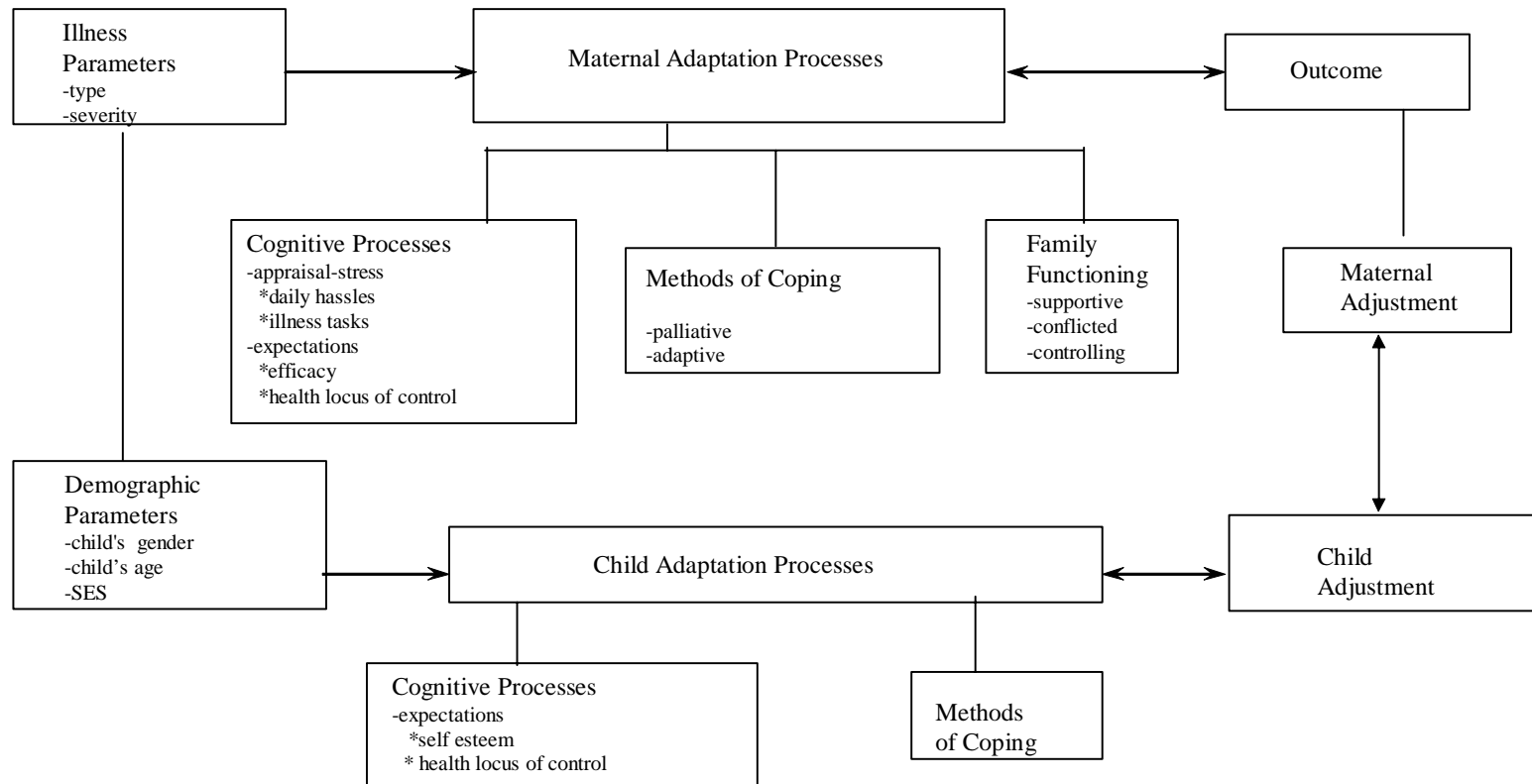
Categorical vs. non-categorical approach

- Categorical approach: focuses on disease specific characteristics
- Non-categorical approach: focuses on the commonalities between diseases
- Modified or partial categorical approach: recognizes that there are both illness specific and generic processes of importance to adjustment

Conceptual model for research on mothers of physically handicapped children (From Wallander et al., 1989)



Conceptual transactional stress and coping model for chronic childhood illness (From Thompson et al., 1994)



Family based models

- Double ABCX model (McCubbin & Patterson, 1983)
A=stressful situation; B=family resources; C=family's appraisal of the situation;
X=family response
 - B and C determine the family's response X to a stressful situation A
 - In the double ABCX model A reflects an accumulation of experiences to which the family repeatedly needs to adapt
 - Test in sample of children with mental retardation revealed linear chain following the ACBX path (Orr, Cameron & Day, 1991)
- Circumplex model of marital and family systems (Olson, Russell & Sprenkle, 1983)
- Models of stress, coping and family ecology (Crnic, Friedrich & Greenberg, 1983)

- All models have in common that they perceive the condition of the child as a *stressor* to which a family has to *adapt*. The success of the adaptation process will determine the level of *adjustment*.

Imagine.....

- You have just heard that you / your 10 year old daughter / sister with a neurodevelopmental disorder needs to undergo a serious operation. After the operation you/she will be in a full body cast for 6 weeks, which will make you/her dependent on others for quite a few things. Although the surgery aims to increase mobility, there are also risks of secondary problems, e.g. incontinence, associated with the surgery.
- Imagine you are the father, mother, sibling or the affected child in this situation. Write down for yourself what you feel, how it may affect you and your family in the short/long term, and how you are going to approach this situation (5 min)

Imagine....

- Feelings (illness related stress and appraisal)
- Effect on family (illness related stress and adjustment)
- How do you approach (adaptation processes)

Parenting

- Birth of child changes peoples lives which requires an initial time of adjustment
- Becoming a parent and raising a child can be a challenging but rewarding experience. This may be even more true for raising a child with a disability / chronic illness

Research findings-parents

- Parents of children with disabilities experience higher levels of parenting stress, i.e. stress associated with their role as a parent
- Parents report more psychosocial adjustment problems (e.g. depression)
- Illness parameters and demographic variables typically account for only a small portion of variance in maternal adjustment. The most predictive illness parameters is functional limitations
- Use of problem focused coping has been associated with better adjustment outcomes than the use of emotion focused coping

Research findings-siblings

- Siblings form a special relation
 - Developmental importance
 - Influences on relationships and experiences with others
 - Dissemination of information
- In general siblings of children with disabilities experience more adjustment problems than other sibs (e.g. anxiety, lower self esteem, depression, psychosomatic illness) but positive outcomes reported as well (e.g. altruistic behaviour)
- Mixed findings regarding gender and age
- No uniform relationship between impairment and sibling adjustment

Research findings siblings

■ Sources of stress for sibling:

- Sibling relationship: meeting affect ional needs, developing an identity
- Parent child relationship: inadequate communication, discrepant expectation, parent adjustment
- Relationship with peers and interaction larger community: informing friends, guarding against discrimination, feelings of shame, isolation of family

■ Siblings fare better:

- Larger families
- Better SES
- Parents have positive attitude towards child with disability
- Sibs are younger than affected child
- Greater age difference between sib and affected child
- Affected child is still young
- Disability is less severe

Research findings – affected child

- Children with physical disorders show increased risk for psychological adjustment problems as well as decreased levels of self esteem (Lavigne & Faier Routman, 1993; 1992)
- However findings are mixed (e.g. Boekaerts and Roder, 1999)

Research findings – affected child

- Wallander et al (1989) estimated incidence of clinical maladjustment among children with chronic illness / disabilities is at least twice that expected for children in general population
- Rutter et al (1970) found that 30% of children in their study had educational, psychiatric, family and/or social problems despite receiving adequate medical care

Research findings – affected child

- Goodman & Graham (1996) found that psychiatric problems were common in large sample of children with hemiplegia
- These problems proved not only common but also persistent (Goodman, 1998) stressing the vulnerability of these children in developing secondary problems

Conclusion

- The impact of a child's disability on the family may be best conceptualised as a risk factor, the significance of which is mediated by socio demographic features, individual and family adaptive and functional patterns, and disability characteristics.

The child's experience of disability: Peer groups and friendships

What makes a good friend?

- Which qualities make a good friend
 - Trust
 - Give and take
 - Empathy
 - Communication
 - Sharing feelings
 - Forgiveness

What are friends for.....

- Functions of friendships:
 - Social support
 - Empathy
 - Sharing feelings
- Friendship interview (Berndt et al) taps into 6 distinctive features:
 - play association
 - prosocial behaviour
 - intimacy
 - loyalty
 - attachment and self esteem enhancement
 - conflicts

How do we make friends

- Making friends is not easy
- You will need to:
 - Find them (at school, in your neighbourhood)
 - Take initiative (making the first move)
 - Share (from playing alone – next to each other - together)
 - Understand feelings of others
 - Know how to behave in social situations
 - Be able to communicate
- Children with good social skills will have more friends and experience less rejection so improving social skills may be one way to intervene

Psychosocial development: social-emotional development

- Social-emotional functioning concerns people's social behaviour, social skills and psychological wellbeing.
- Refers to the manner in which an individual experiences his/hers social environment and his/her place within it
- Refers to the way the individual interacts with his/her environment
- Self-esteem is the view one has of him/herself. Self-esteem concerns both cognitive and emotional aspects

Psychosocial development

- Adequate dealing with social world emerges from interrelationships
 - Close relationships (trust and attachment)
 - Coordinating yours and other's actions
 - Mutual regulation
 - Social referencing
 - Knowledge of oneself
 - Knowledge of the world

Basic needs

- Need for efficacy and competence, i.e. I can make things happen and am successful in my interaction with the world
- Need for acknowledgement, i.e. I am loved, respected and appreciated
- Need for autonomy, i.e. I have control over what I think, do and feel

Social emotional development 0-4 years

- Basic needs already apparent in babies and young children
- For babies it is important to experience success in the social interactions and simple effects in the direct environment
- For toddlers success in autonomous behaviours is important
- Parenting plays vital role in fulfilment of basic needs for young children
 - Responsiveness: direct and consequent
 - Response should match needs of child

Effect of disability 0-4 years

- Medical and physical needs of child may interfere with social interaction
- Parents may have difficulty to come to terms with disability and may therefore be less responsive to socio emotional needs of child
- Babies with disabilities may be more passive, less predictable and display behaviour that is not easy to interpret, making it more difficult to establish positive social communication
- Physical impairments may make it harder for toddlers to successfully play, explore and manipulate materials. It may also be harder to do things without help from others

Social-emotional development 4-12 years

- Development of self esteem
- Children learn to reflect on themselves, match perceptions of ability with actual achievement
- Differentiation in domains of competence (good in sports, not so good in maths)
- Link cause and effect (He wants to play with me because I am nice)
- Feedback from ever increasing outside world – school, peers

Effect of disability 4-12 years

- Reactions from others (pity, awkwardness, resentment)
- Also others may be inclined to take over, help when child could do things by itself – sending message that child is less competent or efficacious
- Comparisons with others (more competent in sports, but often also in regards to academic achievement and peer relationships)

Social-emotional development 12-18 years

- Adolescence is phase of cognitive development, big physical changes and new demands from environment
 - Cognitive development enables reflection of self and social roles (who am I and what do I want to do)
 - Physical changes require adaptation of self image
 - Environment demands autonomous behaviour and taking responsibility for own actions
 - Peer relationships become more important

Effect of disability 12-18 years

- Physical changes may be harder to deal with
- Feelings of autonomy may be jeopardized if individual needs lot of assistance
- Social interaction may be harder
 - Acceptance by others
 - Difficulties in getting around (e.g. public transport or access to pub)
 - Choices may be limited

In summary

- The social-emotional development of children with a disability/chronic illness can be negatively affected by limitations in:
 - age-appropriate independence from parents
 - exposure to same-age healthy peers
 - participation in childhood activities
 - development of sense of self efficacy and self definition

Specific research findings: peer relationships / friendships

- Social competence scores in general lower than in comparison groups
- Estimates of social competence problems vary from 5-54% depending on illness
- Children with illnesses affecting CNS especially at risk for social adjustment problems

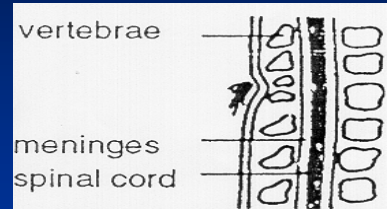
Spina Bifida

- Spina bifida is a congenital neural tube defect, arising from a failure of neurulation or canalisation of the primitive neural tube. Spina bifida is characterised by a fault in the spinal column in which one or more vertebrae fail to form properly leaving a gap or split. This defect may occur anywhere along the spinal column but is usually found in the mid-back (thoracic), in the lower back (lumbar) or at the base of the spine (sacral)

Spina bifida

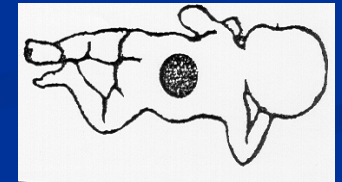
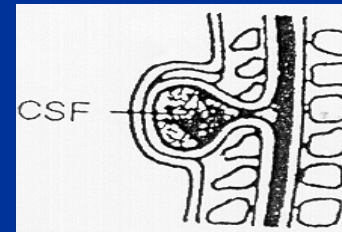
Occulta

Outer part of vertebrae not completely joined. Spinal cord and covering meninges undamaged. Hair often at sight of defect.



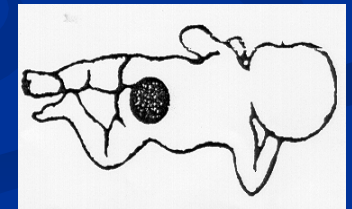
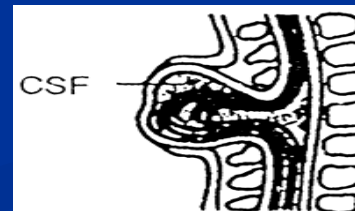
Aperta - Meningocele

Outer part of vertebrae split. Spinal cord normal. Meninges damaged and pushed out through opening.



Aperta - Myelomeningocele

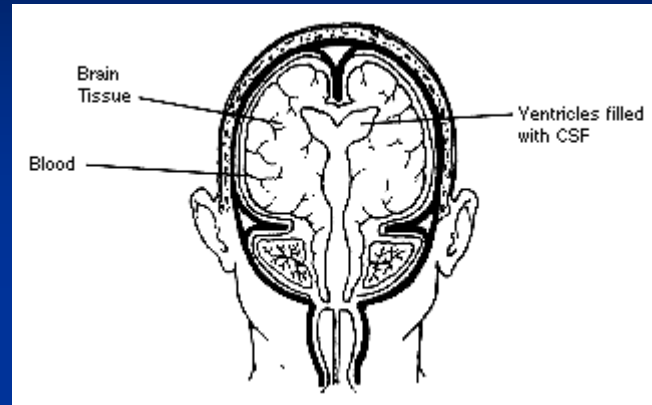
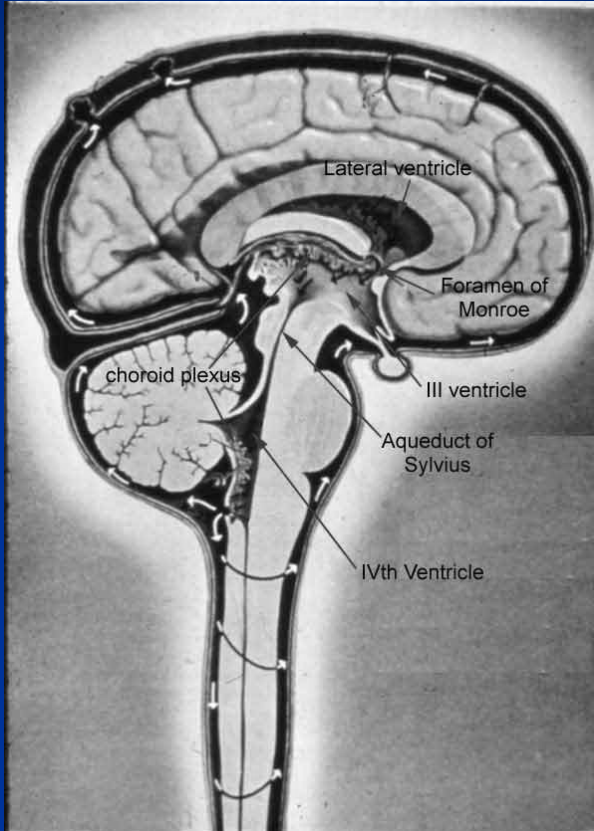
Outer part of vertebrae split. Spinal cord and meninges damaged and pushed out through opening. Possible hydrocephalus.



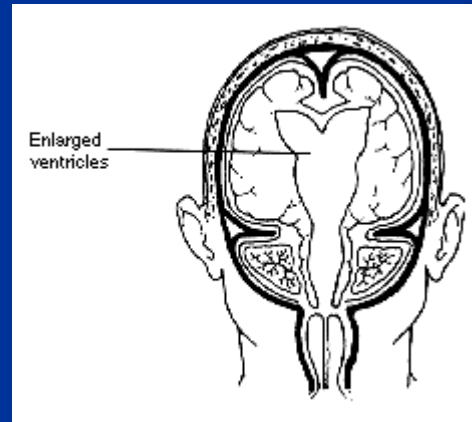
Hydrocephalus

- Hydrocephalus is a neurological condition which occurs when there is an abnormal accumulation of cerebrospinal fluid (CSF) within the ventricles and/or subarachnoid space of the brain. Hydrocephalus causes raised intracranial pressure, and can be a result from an overproduction of CSF, an obstruction of the CSF flow, or a failure of the structures of the brain to reabsorb the fluid.

hydrocephalus



Normal brain



Hydrocephalus

Associated adjustment problems

- Motor function
- Cognitive functioning
- Academic achievement
- Peer relationships
- Self esteem
- Behavioural problems
- Psychopathology in parents (e.g. stress, depression)

CHADS: Peer relationships and friendships

- Friendship interview – obtain a score indicating the extent to which there are positive features in close friendship
- Children with HC but not SB reported that their friendships were less positive than control samples
- Adolescents with SB and/or HC reported less positive friendships
- Parents also reported poorer peer relationships

Factors affecting social adjustment outcome

- Illness severity (not so much severity per se as functional limitations)
 - Lifestyle opportunities
 - Limits re: social interaction
- Gender (boys may be more at risk)
- Family variables (resources)

Pain or Gain??

Disability and positive gain

- Traditionally studies have focused on pathology
- Few studies have looked at positive outcome associated with disability.
- However from the perspective of stress theory it is plausible that families might derive some positive affects from an adverse situation.
- Susan Folkman: co-occurrence of positive and negative states throughout stressful events

Positive gain and parenting

- Positive gain may be experienced by all parents caring for a young child. However the extra challenges/stresses associated with raising a child with a disability may make some mothers even more sensitive to recollections of positive moods

Positive gain and Stress Theory

- Theoretically the ongoing process of reacting to stressors may not only lead to dysfunction and crisis (mal-adaptation), but also to a progressively upward spiral of growth (bon-adaptation) (Summers, Behr and Turnbull, 1989).
- Bon-adaptation :
 - maintenance or strengthening of family integrity
 - continued promotion of both individual family members and the family as a whole
 - maintenance of family independence and its sense of control over environmental influences (McCubbin & Patterson 1983; Summers et al 1989)

Positive gain and Thriving

- Thriving = the effective mobilization of individual and social resources in response to risk or threat, leading to positive mental or physical outcomes and/or positive social outcomes (Ickovics & Park, 1998).
- Value added model – a challenge can provide impetus for growth and greater well-being

Positive gain - positive psychology

- Personal gain can be found in suffering.
- Positive changes can include
 - Change life philosophy
 - Believe themselves to be wiser or act more altruistically in service to others and have greater sense of personal resilience and strength
 - Dedicate energies to social renewal or political activism
 - Report relationship are enhanced

- Viewpoint of positive psychology supported by data: parents typically report increased family cohesion, personal growth and development and increased awareness regarding scope and nature of disability (Darling, 1987; Summers et al, 1989)
- Similar results in sample of mothers of children with spina bifida/hydrocephalus

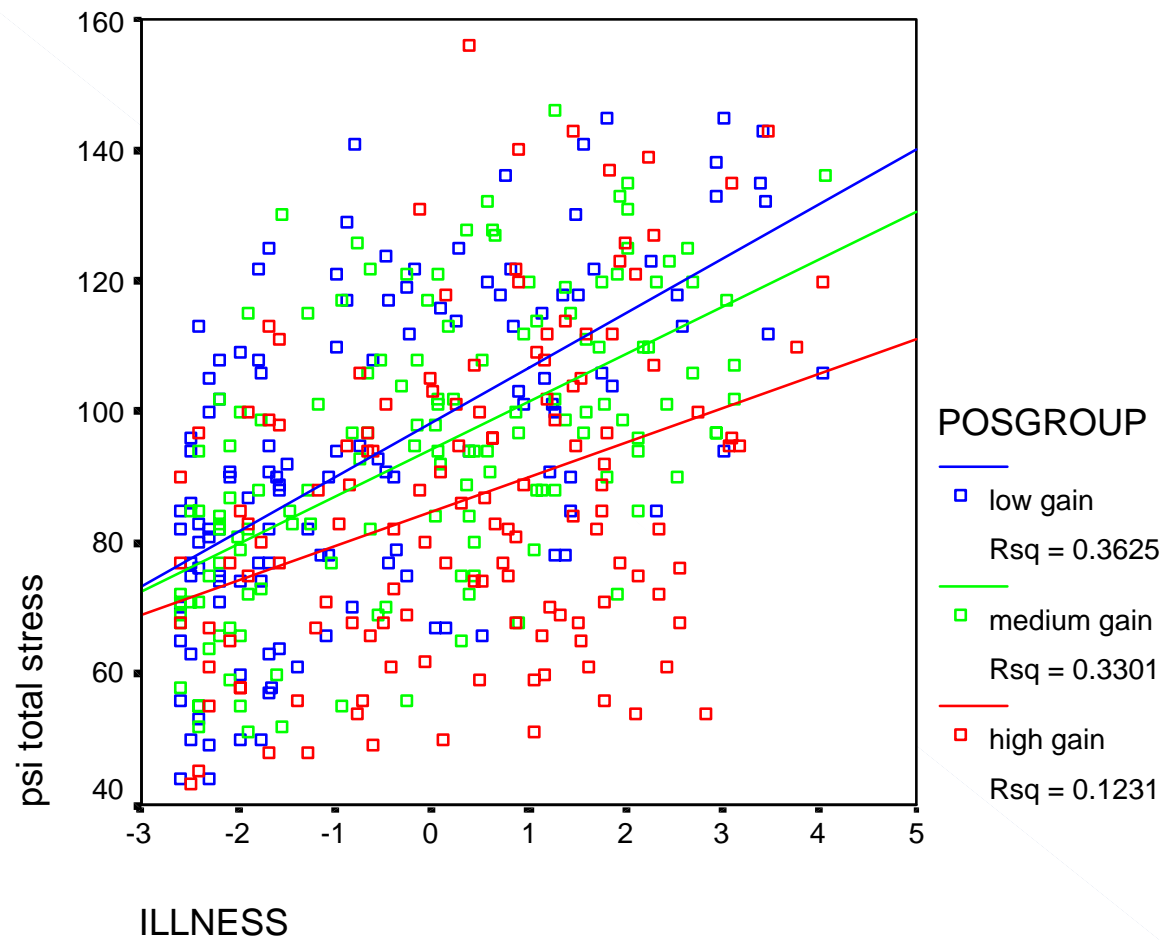
- Adaptation processes, especially coping, can alleviate the threat of stressful events and ultimately result in positive adjustment outcomes (Affleck and Tennen, 1996)
- Better understanding of the adaptation processes, specifically appraisal and coping, will be key to understanding why some families adjust well to child's disability whilst others do not (Summers et al, 1989).

Positive gain - adjustment outcome

(Pit-ten Cate, 2004)

- Results of regression analyses showed that 28 % of variance in positive gain can be explained by illness parameters and adaptation processes
- Small correlations with parenting stress

- Higher levels of positive gain related to
 - increased functional impairment
 - problems associated with child's condition
 - increased levels of problem focused coping
 - increased levels of care-giving efficacy
 - higher levels of family satisfaction
- Positive gain moderated the illness adjustment outcome relationship
 - at low levels of illness there was little effect of varying levels of positive gain.
 - Conversely, at higher levels of illness mothers with higher levels of positive gain reported less parenting stress.
 - i.e. perceived positive gain protects against the effect of illness parameters on parenting stress.



CONCLUSION

- The impact of a child's disability on the family may be best conceptualised as a risk factor, the significance of which is mediated by socio-demographic features, individual and family adaptive and functional patterns and disability characteristics.
- Research is needed to identify those families most at risk for developing adjustment problems
- Both risk and protective factors have to be identified

What can we do to help?

- Early intervention!
 - Not only focus on the disability and medical regimen but also on psycho-social development
- Do not step in too soon
- It is all about creating the right conditions
 - Provide opportunity to interact with (able bodied) peers from early age but arrange the meetings such that the child feels safe (i.e. small groups, regular meeting place, same children)

Service needs and provision

- Needs: medical versus social model
 - Medical model: need for treatment of impairment to prevent disability, intervention aimed at reducing disabling condition, prevention of secondary problems, e.g. child maladjustment
 - Social model: child is part of a social system, focuses more on disability in society (attitudes, provision) and existing support systems (instrumental and emotional)

Resources and challenges

- Material: income
 - Mothers of disabled children are less likely to be in employment possibly due to the increased care demands
- Personal: ways of coping, sense of control,
 - Problem focused coping (active approach) associated with better adjustment outcomes
 - Medical regimens quite often leave parents feel powerless as parents (have to) defer control to consultants. Assertive parents fare better.
- Social: Instrumental and social support
 - Access to services: seeking help mostly for child not for family / services tend not to reach out
 - Families of children with disabilities are more socially isolated

Unmet needs

- Substantial levels of unmet needs (Sloper et al)
- Service on Offer: service or family led?
 - Do we fit services to needs or needs to services?
 - Fragmentation of support - coordinated service provision
- Timing
 - There is only so much families can take in at one time. (e.g. psych services after head trauma)

Service models

- Main feature that make service models effective is that they give parents back a sense of control. Because of the attempt to focus on family needs, parents feel
 - Acknowledged, Respected, Cared for
 - Empowered
 - Services are problem focused
- Service models:
 - Key worker – person who coordinates services
 - Parent counselling- parent advisor who provides counselling
 - Parent partnership- parents and professionals working together
 - Coping skills – teach parents problems solving skills
 - Parent to parent
 - Respite services
 - Early intervention (e.g. White lodge center)

EVERY CHILD MATTERS!

- Policy: the **green** paper
- Sets out for consultation a framework for improving outcomes for all children and their families, to protect them, to promote their well being and to support all children to develop their full potential

THANK YOU

Ineke Pit-ten Cate
Senior Teaching Fellow / Research Tutor
University of Southampton
Clinical Doctorate Programme
ip@soton.ac.uk