

THE PSYCHOLOGICAL BURDEN OF CONGENITAL HYPERINSULINISM

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Acknowledgments

- **Dr Sarah Mann**

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- **Parents** who have kindly shared their stories

Role of Clinical Nurse Specialist

- ❑ We are not Psychologists – but as CNS's we build up long term therapeutic relationships with patients and families. We are in very privileged position to join individual journeys
- ❑ We have expertise in HI management and its complications.
- ❑ Best placed to provide education/support to parents who need to learn new skills.
- ❑ On HI journey - smooth communication, working collaboratively and co-ordinating care.
- ❑ Support parents regimes of care to keep the infants/children well at home, preventing repeated hospital admissions.
- ❑ Empower families.
- ❑ Liaison with local services.
- ❑ Point of contact when at home.

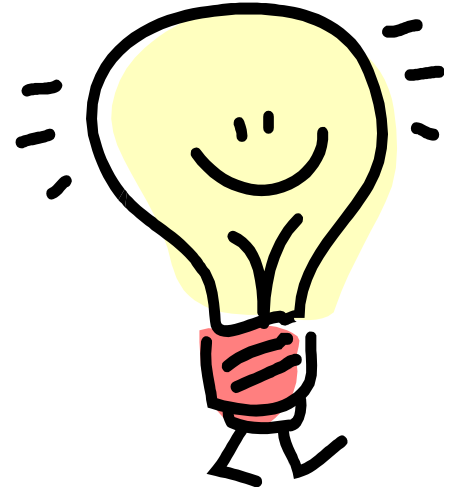
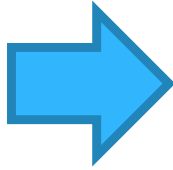
Signs and Symptoms of Hypoglycaemia

Are these familiar symptoms of stress and anxiety?

- Feeling tired / sleepy
- Feeling wobbly /shaky
- Feeling dizzy / hungry
- Having a fast heart rate
- Feeling grumpy / angry
- Having a headache
- Look pale
- Clammy-cold sweat
- Poor concentration
- Being nervous/ upset



AS PARENTS.....



Impact of Diagnosis of a chronic life long condition

(Nuutila and Salanter 2006, Popp et al 2014, Morawska et al 2015)

- Fear of unknown/loss of normality
- Child's illness dominates the lives of the whole family
- Future expectations on health/development
- Psychological/Social/financial difficulties
- Conflict / isolation
- Emotional adjustment
- Parental/extended family relationships
- Burden of care / skills required for adaptation
- Increased rates of depression/anxiety/low self esteem in parents



Feelings about Diagnosis

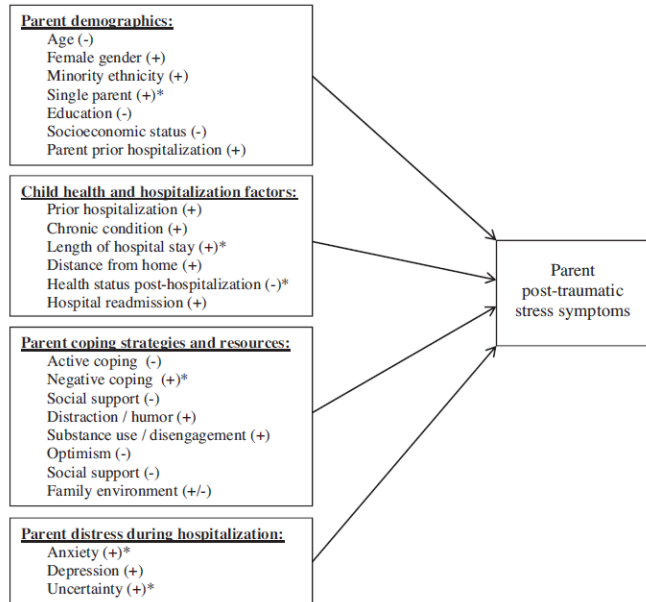
- Emotional responses - likened to Kubler Ross (1969) seminal work on the five stages loss.
- Denial (shock)
- Anger (Anxiety / Frustration)
- Depression (Overwhelmed)
- Bargaining (Struggling to find meaning)
- Acceptance (Moving on)
- (can move backwards and forwards between any of these stages)
- It is suggested that individuals experiencing change face a variety of psychological states. One response that is common is that of feeling threatened.
- It has been suggested that it is human nature to respond to change in an emotional way when the status quo is altered - with the response not always be rationale (don't feel guilty).
- Staff need to use human qualities such as empathy, social skills and motivation to support and help parents on this journey.

Parental needs

- The literature suggests that the adaption to illness following diagnosis seems to be related to individual and family characteristics rather than to illness characteristics (Frank et al., 1998)
- (Nuutila and Salanter 2006) suggest information provided to parents about their child's illness plays a pivotal role in starting the process of parental coping.
- A permanent relationship between families and health care personnel is required to achieve this (Nuutila and Salanter 2006)



Family Centred Care-reducing anxiety



- Role change for parent with critically ill child
- 38% parents of children hospitalised for 3 or more days scored in clinical range for anxiety
 - Screening those at risk beneficial (Wray et al, 2011)
- High Parental stress –barrier to care of child
 - (Franck et al, 2015)

(Franck et al, 2014)

Family Stories

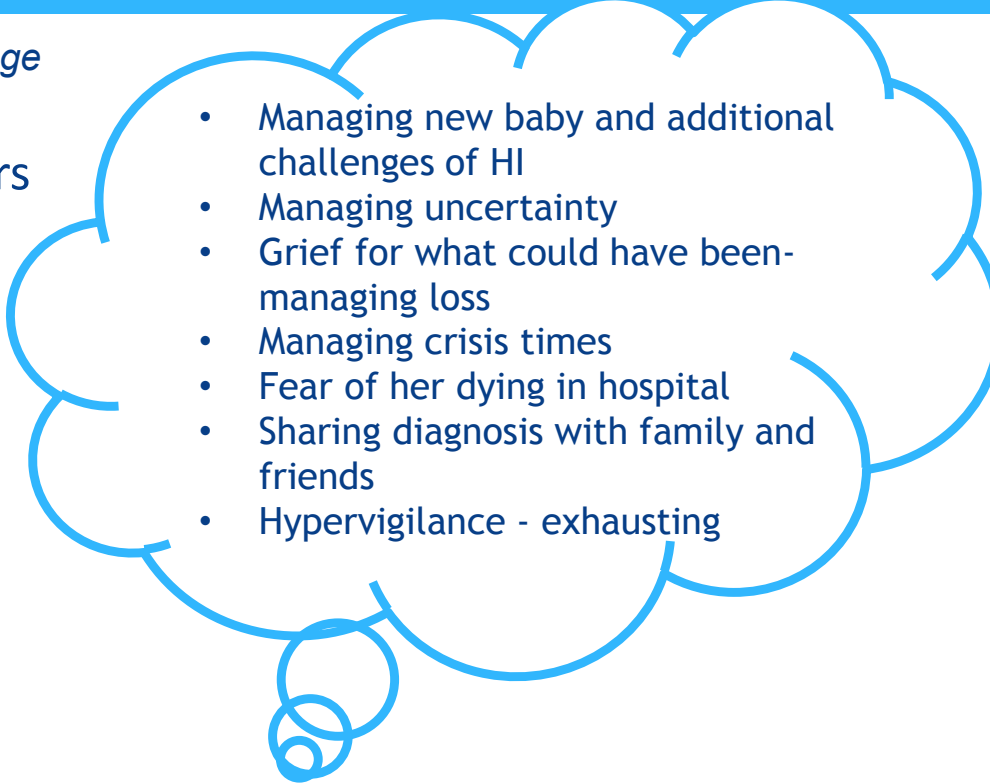
- **Family 1**-Complex syndromic presentation
- **Family 2**-Patient not referred to specialist centre
- **Family 3**-Illiterate in own language and refugees

Caring for HI across the lifespan.

The new born and early years... Family 1

The best way we can support a child at this age is by supporting the parent.

- ❑ Syndrome diagnosed- Mosaic Turners
- ❑ Complex long admission
- ❑ Pulmonary Hypertension- worsened by Diazoxide
- ❑ Cardiac Surgery
- ❑ Continuous Feed
- ❑ Lanreotide Injections
- ❑ Close relationship with local team

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- Managing new baby and additional challenges of HI
 - Managing uncertainty
 - Grief for what could have been- managing loss
 - Managing crisis times
 - Fear of her dying in hospital
 - Sharing diagnosis with family and friends
 - Hypervigilance - exhausting

Caring for HI across the lifespan living with medical needs...Family 2

Biology

- Normal pregnancy, normal birth
- Cardiac arrest
- Cerebral palsy and Liver Failure
- Diazoxide responsive HI

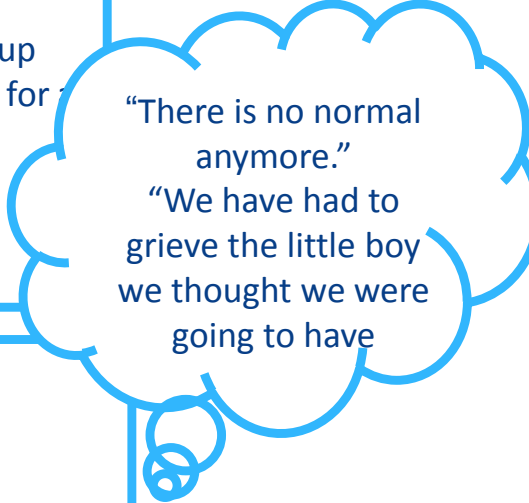
Life

- Extended family in denial at CP diagnosis-believe he will catch up
- Sibling lived with grandparents for 7 months
- Financial burden
- Mum now classed as a carer



Psychological Needs

- Grief and loss for expected life
- Illness journey so far
- Managing uncertainty about the future- decision making
- Identity in context of illness
- Loss of previous social contacts



“There is no normal anymore.”
“We have had to grieve the little boy we thought we were going to have”

Parents quotes

- “We live everyday like it is our last, when I have a tough day coming up I look back at how far we have come and know we will breeze through, nothing can be as bad as that moment”
- “I check on him through the night because I am so scared he may not survive the night. He still feeds generally twice per night”
- “We have had to learn to adapt our thoughts and be as proactive as possible and push for everything we can get for him”

Family 3

BIOLOGY


- No antenatal concerns, born at term , normal delivery Bw=4.1kg
- Day 1 of life- poor feeding, lethargic, jittery, low grade temperature -NICU- treated for ? Sepsis
- Hypoglycaemia identified- difficult to manage - transferred
- Initial Hyposcreen confirmed HI
- Complex medical journey –Discharged on -Continuous feeds, Octreotide injections, Lanreotide injections, Sirolimus, poor feeding
- Near total pancreatectomy

LIFE!

- Culture – large refugee family – x1 previous infant death
- Family relationships / Social support
- Mother – illiterate, Father poor English skills
- Increased stress and anxiety due to language barriers
- Coping strategies - Picture aids used to teach patient care.
- Needed to involve MDT
- Financial / housing concerns

PSYCHOLOGICAL NEEDS

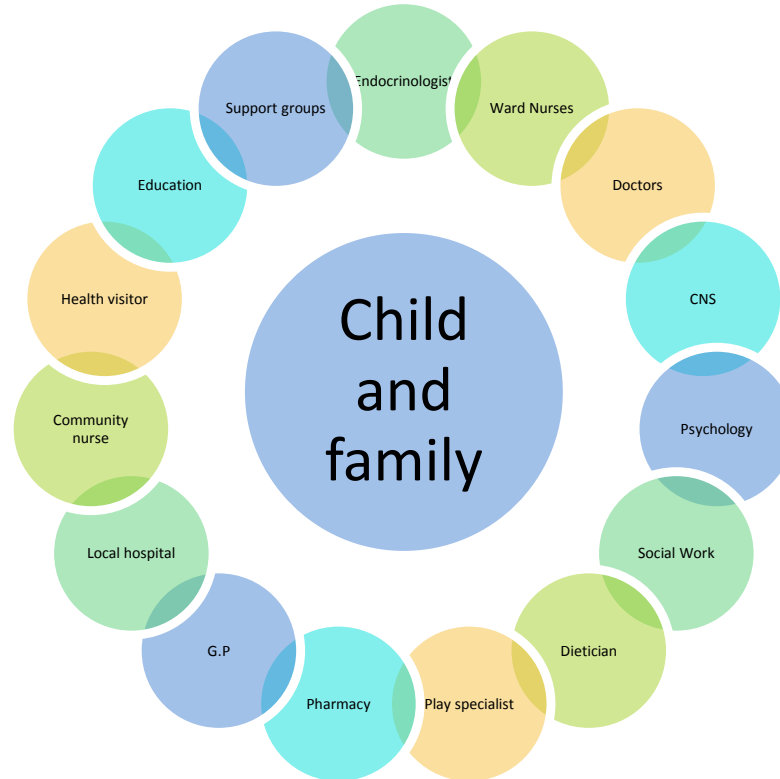
- Adjustments of whole family
- Coping with day to day care
- Understanding of medical needs
- Mother - initially isolated /depression /Low self esteem
- Making decisions about treatment and next steps



Learnt all new skills
Became experts
Managed and adapted to new normal
Developed a strong working relationship with all teams

MULTIDISCIPLINARY APPROACH

Working Together for the individual



Feedback

“ I want to thank you for all the care that you have given Polly since we have come home.

When we first came home it was a struggle and I just didn't know where to turn at time's but every time I spoke to you always calm me down by taking matters into your hands and solving the situations.

Thank you so much for being here for Polly and I.

You have always been very supportive and you go above and beyond to do what you can do to help.

I can never thank you enough you guys are truly amazing you really are. **THANK YOU!**”

SUPPORT Across the lifespan

It is also important to remember that changes in one part of life (e.g. when starting school) can affect how a child and parents cope

When the child starts school

Parents face handing of trust & responsibility for the child's care

Challenges of ensuring the right support is in place for the child (never heard of HI)

Anxiety for parent and child about this new stage

At this age a child may have ideas about 'fairness' e.g. it is unfair I have to take medication

Managing a 'difference' that is not always visible to other people can be challenging at school

As the child progresses through school

They may be increasingly curious about their medical needs – might ask more questions, want to learn more information

At this age they will increasingly be comparing themselves with their friends

They may experience more "Why Me?" thoughts and feelings

Children are establishing identity, in the context of their medical needs

At secondary school

Young people are often thinking more about disclosure of medical needs to any new friends

The young person will be increasing independence around own cares, learning this and managing it and child and parent go through this handover

The young person is managing the challenges of adolescent life in addition to their medical needs

Transitioning to adult services

Coincides with the end of school, so there can be a lot of change to manage

The young person will be thinking more about the future, relationships, work and family ; and their medical needs in relation to these topics



- ❑ Early preparation and organisation is key
- ❑ Anxiety triggers -Training blood glucose monitoring, administration of medication/ feeds, emergency hypo treatment/ can't give injections of octreotide in school
- ❑ Funding: EHCP /Care plans
- ❑ Pros and cons of one-to-one care
- ❑ School's concern regarding risk / requesting collection of child



Parents - "They really DO need to have lunch and snacks
Young person - "I worry about what will happen to me at school"

Referrals to Psychologist

- Some children with HI do present with Attention Problems
 - ▣ Sustained attention and memory
 - ▣ Divided attention

- Ensure teacher is aware of child's cognitive strengths and weaknesses



Why Psychology support?

- Children and their families living with a health condition have an increased chance of experiencing Psychological difficulties
- This is not true for all children and families and does not mean everyone will experience these challenges!
- But it is important to notice and acknowledge when some more support may be helpful

Supporting a child to Talk about feelings

- Young children need prompts to talk about feelings
- May find it hard to articulate or answer open questions.



- Older children can begin to relate to metaphors for feelings and why it isn't good to bottle things up
- E.g Carrying about worries about HI is like carrying around a backpack with heavy books. If you share them out you will feel lighter.



- Teenagers may have more complex feelings/ emotions they need support with.
- E.g feelings of guilt/ anger/ denial about their HI

Living well with CHI

- It is absolutely possible to live well with HI at all times!
- Psychology input can help a child or young person think about the non medical elements of their identity
- HI is a part of you but what else are you good at /what do you enjoy?

Summary

- HI is not a familiar condition to general population
- Aim is always to keep children with HI well and out of hospital
- Task is to empower and equip parents and later the young person with knowledge and skills to manage own health needs
- Parents/young person become the real experts
- Parents support groups – supporting each other



Questions



Contact Details

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