

# THE PSYCHOSOCIAL IMPACT OF LIVING WITH HI

Leela Morrow, PsyD

Pediatric Psychologist  
Division of Endocrinology and Diabetes

Co-Chair of Diversity and Inclusion Committee  
Department of Child and Adolescent Psychiatry and Behavioral Sciences

Assistant Professor of Psychiatry  
Perelman School of Medicine  
University of Pennsylvania

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# HOW I GOT HERE...



Psychology Fellowship in  
Pediatric Oncology



Inpatient Consults  
and Eating Disorders



Parental and Family Coping  
Adjustment to New Diagnosis  
Coping with Medical Condition  
Psychoeducation  
Infants, Toddlers, Children, Adolescents, Adults

# HEALTH-RELATED QUALITY OF LIFE OF CHILDREN AND ADOLESCENTS WITH CONGENITAL HYPERINSULINISM – A SCOPING REVIEW

# QUALITY OF LIFE

- Very limited research when looking at CHI.
- At an early age, neurons (brain cells) are developing and the metabolic changes that occur with HI can impact neurodevelopmental outcomes.
- Children with CHI can have rates of abnormal developmental outcomes– studies range between 26-44%.
- Tendency towards motor and language delays. Also reported feeding problems.

# QUALITY OF LIFE

- When CHI is diagnosed early and treatment begins quickly, most children develop a typical range of cognitive, emotional and social abilities.



# FAMILY CONSEQUENCES OF POTENTIALLY TRAUMATIC PEDIATRIC MEDICAL EVENTS: IMPLICATIONS FOR TRAUMA-INFORMED CARE

# BACKGROUND

- To examine the aftereffects of potentially traumatic pediatric medical events for families in order to inform the practice of *family-centered, trauma informed* pediatric health care.



# SYMPTOMS OF PEDIATRIC MEDICAL TRAUMATIC STRESS (PTMS)

- Reexperiencing
  - Intrusive thoughts, nightmares
- Avoidance
  - Avoiding people, places, and things that are reminders of the medical event
- Arousal
  - Heightened startle reactions, irritability and trouble sleeping



# PARTICIPANTS AND MEASURES

- Total of 28 families participated across medical divisions, including Endocrinology
- 44 caregivers
- 24 patients
- 14 siblings
- Focus groups were conducted

# THEMES IDENTIFIED

Family members experience strong emotional reactions and distressing thoughts

Family members experience trauma-related reactions and behaviors

Family patterns and routines change

Family conflict arises

Family members feel different from their peers and strive for normalcy

Family members construct positive narratives about these events and positive consequences and emotions.

# TYPES AND EXAMPLES OF POTENTIALLY TRAUMATIC EVENTS

- Procedures: IV access/shots/insulin administration
- Diagnosis: Knowing something is wrong; seeking, waiting for diagnosis
- Being at the hospital: Attending clinic outpatient appts; witnessing procedures, tests; seeing other patients in crisis
- Experiencing medical emergencies: Ambulance rides; sudden unexpected changes

# TYPES AND EXAMPLES OF POTENTIALLY TRAUMATIC EVENTS CONTINUED

- Integrating treatment into home life: changes to routine and activities to accommodate patient; new medication and treatment routines
- Provider communication: Overwhelming amounts of information
- Physical symptoms, physical changes in patient: changes in physical appearance

# DISCUSSION

- Family members reported constructing positive narratives about pediatric medical events
  - Resilience or posttraumatic growth may include increased feelings of personal strength, meaning in life, and spirituality; a greater appreciation of life; and improved interpersonal relationships
  - All family members identified the joy in giving back and providing support to other families in need

# SO HOW DO I DEAL WITH ALL OF THIS AS A PARENT?

## New Diagnosis

Should my child have surgery?

Am I feeling guilty about this diagnosis?

Who do we share this with, if anyone?

Who needs to know?



# SO HOW DO I DEAL WITH ALL OF THIS AS A PARENT?

## New Diagnosis

Preparing myself and my child for:

Attending doctor's visits

Getting blood drawn



# PARENT PERSPECTIVES- MY CLINICAL EXPERIENCE

- Difficulty sleeping
- Difficulty eating
- Re-experiencing
- Avoidance
- Hypervigilance
- Depression
- Anxiety



# TRANSITION FROM HOSPITAL TO HOME

# SO HOW DO I DEAL WITH ALL OF THIS AS A PARENT?

How do I tell my child what she/he/they have?

Disclosure

Age/Developmentally Appropriate



# COPING WITH HI AS A CHILD

- Early Intervention
- 504 Plan for School
- Neuropsychological evaluations, psychoeducation evaluations
- Disclosure to others about HI
- Potential bullying due to side effects of medication
- Social integration despite caring for oneself

# HAVING AN ADOLESCENT WITH HI

- Blood sugar checks
- Medical appointments
- Dating relationships/Sexual relationships
- Disclosure to others
- Social Media
- Transition from adolescence to early adulthood → independent living



# BODY IMAGE/APPEARANCE

- Include body positivity language
- Nutrition
- Exercise
- Weight, shape, and social media
- Importance of social support



# EMOTIONAL CONCERNS

- Depression
- Anxiety
- Suicidal thoughts
- Social support as a buffer for mental health related concerns



# COPING WITH HI AS AN ADULT

- Managing your medications
- Discussing your healthcare with others- family, friends, partner
- Partner with your medical team
- Make a healthy investment in yourself
- Be aware of depression and anxiety
- Reach out to your support!



Adapted from <https://www.health.harvard.edu/staying-healthy/10-steps-for-coping-with-a-chronic-condition>

# REFERENCES

- Kristensen, K., Quitmann, J. & Witt, S. (2021). Health- related quality of life of children and adolescents with congenital hyperinsulinism- A scoping review, *Frontiers in Endocrinology*, 12, DOI=10.3389/fendo.2021.784932
- Christofferson, J., Okonak K., Kazak A., Pierce J, Kelly, C., Schifano, E., Sciolla, J., Deatrck J., Alderfer, M. (2020). Family consequences of potentially traumatic pediatric medical events: Implications for trauma-informed care. *Journal of Family Psychology*, 34(2):237-246. doi: 10.1037/fam0000597. Epub 2019 Oct 24. PMID: 31647256.



# THANK YOU!

- Questions? Comments?
- To keep the conversation going, feel free to email me at [morrowl1@chop.edu](mailto:morrowl1@chop.edu)

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