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ORIGINAL ARTICLE



Anxiety, depression, and quality of life in parents of children with congenital hyperinsulinism

Marcia Roeper¹ · Henrike Hoermann¹ · Roschan Salimi Dafsari¹ · Felix Koestner¹ · Ertan Mayatepek¹ · Sebastian Kummer¹ · Christina Reinauer¹ · Thomas Meissner¹ 

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¹Department of General Pediatrics, Neonatology and Pediatric Cardiology, Medical Faculty, University Hospital Düsseldorf, Heinrich-Heine-University, Düsseldorf, Germany

Background

- Congenital Hyperinsulinism (CHI) is a rare disorder but the leading cause of persistent hypoglycemia in children
 - Hypoglycemic brain injury occurs in up to 50 % of affected children
 - Disease management is often time-consuming, emotionally challenging, and demands a great amount of personal commitment
 - Given the rarity of the disease, parents are often the only “experts” around
 - Psychosocial strains and reduced quality of life are common in parents of chronically ill children
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Aim of the Study

Aim of the study was to:

- Assess the prevalence of **depression** and **anxiety** symptoms, **family burden**, and **quality of life** in parents caring for child with CHI
 - Identify predictors of adverse outcome that may be addressed
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Study Design

- Anonymous **online survey** of parents caring for a child with CHI with a disease duration of at least 6 months
 - June 2019 - March 2020
 - Families were recruited in **Germany** at the University Children's Hospital Düsseldorf and via the newsletter of the German CHI group "Kongenitaler Hyperinsulinismus e.V."
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Measures

- **Anxiety** Generalized Anxiety Disorder Scale-7 (GAD-7)
 - **Depression** Patient Health Questionnaire (PHQ-8)
 - **Quality of Life** Ulm Quality of Life Inventory for Parents of Chronically Ill Children (ULQIE)
 - **Family burden** Family Burden Questionnaire (FaBeL)

 - **Sociodemographic and CHI-disease related data**
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Results

- 48 participants (75 % mothers)
 - Mean age 41.5 years
 - 85.5 % were married or in a stable relationship
 - Median number of children was 2
 - Mean weekly working hours were 25.5 for mothers and 43.9 for father
 - 33 % currently or previously received psychological care
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Results

- **PHQ-8:** 29.8 % ($n = 14$) had major depressive symptoms
 - **GAD-7:** 38.3 % ($n = 18$) had a probable general anxiety disorder
 - **ULQIE:** Scores for Quality of Life (QoL) were average
 - Highest QoL was reported for *“satisfaction with family”* and lowest for *“self-development”*
 - **FaBeL:** Family burden was moderate
 - Lowest burden was reported for *“impact on siblings”* and highest for *“personal strains”*
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Results

- Predictors for worse outcome:
 - Having fewer caretakers for the child (*anxiety + depression + QoL + family burden*)
 - Less weekly working hours (*anxiety + depression + QoL*)
 - Current or prior psychological care (*anxiety + depression + QoL*)
 - Neurological impairment in the affected child (*anxiety + depression + QoL*)
 - Sleep disturbance (*depression + QoL + family burden*)
 - Mothers (*anxiety + QoL*)
 - Comorbidities in the affected child (*QoL*)
 - Higher family burden (*depression*)

No association with any other sociodemographic, or child- and disease-specific data

Conclusion

- Rates of anxiety and depressive symptoms are high in parents of children with CHI
- The study identified some predictors of adverse outcomes that may be addressed
- Disease-related data had no impact on the outcome, e.g., frequency of hypoglycemia, use of CGM, daily blood glucose measurements, prior severe hypoglycemia with seizures or loss of consciousness

CHI centers should implement standardized mental health screenings for families to identify signs of mental distress early and refer parents and/or patients to counseling when needed

What does this mean for CHI families?

- Don't hesitate to talk to your doctors about psychological support
 - Establish a reliable support network and train others to take care of your children to share the burden of care and allow more time for personal needs and possibly a professional career
 - Apply for special care for your children at school or kindergarten
 - Consider using a CGM if it helps you sleep better
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Thank you for your attention!



*University Hospital Düsseldorf
Department of General Pediatrics, Neonatology and Pediatric
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