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Needs, strengths and challenges in the international congenital hyperinsulinism center of Denmark: A nursing perspective

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Background: Congenital Hyper Insulinism (CHI) is a complex, heterogeneous disease with often very severe, persistent hypoglycemia from birth and a high risk of brain damage. In highly specialized, multidisciplinary centers, 18F-DOPA PET/CT-pancreatic surgery result in a dramatic cure in the focal type of CHI. In diffuse and atypical forms, management involves complex medication and sometimes partial pancreatectomy. The International Hyperinsulinism Center in Odense, Denmark, receives international patients from many countries, including Sweden, Russia, Latvia, Belarus, Ukraine, Kazakhstan, Georgia, Armenia and Singapore.

Methods: Descriptive analysis of needs, challenges and strengths in the ward, based on semi-structured interviews with staff nurses.

Results: Our multidisciplinary center needs to include experts in pediatric nursing of CHI-patients, pediatric endocrinology, neurology and cardiology, clinical genetics, nuclear medicine and radiology, neurophysiology, ophthalmology, pediatric abdominal surgery and pancreatic surgery, pathology, anesthesiology/intensive care, diet, physiotherapy, professional interpreters and administration. On top of this, the team has supportive persons allocated, who are mainly bi-lingual volunteers, for help with private funding for the parents, to arrange travel and hospitalization and spread of information on the social media. Parents arrive with hope and fear from an often very different cultural background, which needs to be understood. Strengths include a dedicated and experienced team, ambulance ground transportation with specialized CHI-team from airport to hospital if needed, excellent single-patient-room facilities with family beds and bathroom, free internet facilities including Google translate, written pamphlets about CHI in e.g. Russian thanks to collaboration with The Endocrine Center of Moscow, collection of all center facilities under the same hospital roof, low costs for the families thanks to a non-profit policy of our governmental hospital and collaboration with the charity/family organization Congenital Hyperinsulinism International.

Conclusion: Nursing in an international referral center for a rare, severe and difficult disease as CHI involves multiple challenges, even though strengths meet needs in most aspects. Even in case of cure of hypoglycemia, neurodevelopmental impairment may persist, which call for a worldwide improvement in early recognition and prompt and adequate treatment of persistent hypoglycemia in neonates and infants.

Biography

Helle Mazanti is a staff-nurse at The Oncology Ward at Odense University Hospital, Denmark. She is a certified therapist for grief, losses and trauma treatment. Currently working as a staff-nurse at HC Andersen Children Hospital, Odense University Hospital, Denmark.

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