

Poster

Title: Health care consumption in infants with CHARGE syndrome - a case-study

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Main focus: Mainly research/Congenital deafblindness

Abstract: Purpose: To describe health care consumption during the first year, in a Swedish sample having CHARGE syndrome.

Background: CHARGE syndrome is characterized by impaired vision and hearing, as well as physical malformations. In Sweden, approximately 1 per 10,000 newborns is diagnosed with CHARGE syndrome. Previous studies have reported etiology and various malformations related to CHARGE syndrome and the treatment (hearing and vision aids, medication) provided. However, no study focusing on the healthcare consumption related to the identified malformations has been identified.

Methods: Through the medical records of four males and one female, born in Sweden between 1978 and 2005, the health care consumption was calculated in terms of number of hospitalizations, diagnostic procedures, pharmacological treatments and multi-disciplinary contacts.

Results: The median age of the suspicion of a hearing impairment was 6 weeks. It was confirmed between the age of 6 weeks and 10.5 months (md= 5 months). The age at which the coloboma(s) were diagnosed varied. However, in all but one case it was identified within the first 4 weeks. The infants were hospitalized 26-230 days (md = 113), subjected to 10-34 (md = 20) different diagnostic procedures and prescribed 10-28 (md = 14) different medications during their first year. In addition to the primary pediatrician 8 to 11 (md = 9) medical specialties were involved in care. The findings highlight CHARGE syndrome as a highly complex medical condition, leading to a significant consumption of health care during the first year in life.

Conclusion and clinical suggestions: A cooperation of the infant and her/his parents is essential for successful healthcare interventions. From a parental perspective integration and coordination of care between specialists could improve daily life for these families. From a child perspective it is important to individually support the infants with CHARGE syndrome in their health care contacts, as their dual sensory loss makes it difficult for them to understand the world around them. Tactile stimuli such as the use of a pacifier, swaddling, rocking or skin-to-skin contact with a parent could be encouraged for the infant in order to decrease discomfort and pain during procedures. Likewise a small amount of oral sucrose could be worth trying for infants not affected by severe swallowing problems.