

A mother's experience in identifying and helping a child with ctnnb1 syndrome

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Abstract

The research examines the experience of a mother whose child received a diagnosis of CTNNB1 syndrome. CTNNB1 syndrome is a very rare genetic disease, usually associated with intellectual and developmental delay, muscle abnormalities, and speech and vision problems. Purpose: The mother's experience of recognizing and helping a child with CTNNB1 syndrome in the process of early treatment is researched. Methodology: The research approach was based on qualitative research of a singular case study. A structured interview containing open-ended questions was used. Results: The first signs of CTNNB1 syndrome appeared already when the subject was a baby. The mother noticed poor head posture, muscle tone disorders, uncoordinated movements, strabismus, and the child's absence. After the diagnosis was made, the medical staff faced mostly the challenge of a lack of information about the syndrome and insufficient possibilities of predicting the child's progress. The family received assistance at the Early Treatment Center where the child was treated by a multidisciplinary team. Conclusion: Even though the signs of CTNNB1 syndrome appear soon after birth, the process of identifying and helping the child is complex. The child and the family must receive multidisciplinary assistance as soon as possible because the course of development and its possibilities for progress are unpredictable. Keywords: CTNNB1 syndrome, early signs, family assistance, early treatment, mother's experience.

Izkušnja mame ob prepoznavanju in pomoči otroku s ctnnb1 sindromom

Povzetek

Raziskava proučuje izkušnjo mame, katere otrok je prejel diagnozo CTNNB1 sindroma. CTNNB1 sindrom je zelo redka genska bolezen, običajno povezana z intelektualnim in razvojnim zaostankom, nenormalnostmi mišičja ter težavami na področjih govora in vida. Namen: raziskana je izkušnja mame ob prepoznavanju in pomoči otroku s CTNNB1 sindromom v procesu zgodnje obravnave. Metodologija: raziskovalni pristop je temeljil na kvalitativni raziskavi singularne študije primera. Uporabljen je bil strukturiran intervju, ki je vseboval vprašanja odprtega tipa. Rezultati: Prvi znaki CTNNB1 sindroma so se kazali že pri dojenčku. Mama je opazila pomanjkljivo držanje glave, motnje mišičnega tonusa, nekoordiniranost gibov, strabizem in otrokova odsotnost. Po postavljeni diagnozi se je zdravstveno osebje srečevalo predvsem z izzivom primanjkovanja informacij o sindromu in pomanjkljivimi možnostmi napovedovanja otrokovega napredka. Družina je bila deležna pomoči v Centru za zgodnjo obravnavo, kjer je otroka obravnaval multidisciplinaren tim. Zaključek: Kljub temu, da se znaki CTNNB1 sindroma kažejo že kmalu po rojstvu, je postopek identifikacije in pomoči otroku kompleksen. Pomembno je, da so otrok in družina deležni multidisciplinarne pomoči čim prej, saj sta potek razvoja in njegove možnosti za napredek nepredvidljivi. Ključne besede: CTNNB1 sindrom, zgodnji znaki, pomoč družini, zgodnja obravnavo, izkušnja mame

INTRODUCTION

CTNNB1 syndrome or CTNNB1 neurodevelopmental disorder (CTNNB1-NDD) is an exceptionally rare genetic syndrome caused by a mutation in the CTNNB1 gene. The latter encodes the protein β -catenin, which is crucial for the normal functioning and development of the brain (Verhoeven et al., 2020; Xing et al., 2008). CTNNB1 syndrome was first discovered by De Light et al. (2012). Its prevalence is estimated at 0.003% (Grieco and Chung, 2023).

Early signs of CTNNB1 syndrome usually start to appear soon after birth. Different authors (Grieco and Chung, 2023; Kharbanda et al., 2017; Kuechler et al., 2015) note that CTNNB1 syndrome in children is mainly manifested by muscle abnormalities (hypotonia), motor retardation, microcephaly, vision problems (strabismus), problems with coordination of movements, attention, delay or absence of speech, and intellectual retardation. Verhoeven et al. (2020) note that abnormalities of the nervous system in elderly subjects with CTNNB1 syndrome manifest as intellectual deficit, global developmental delay, neurological speech impairment, and hypoplasia of the corpus callosum. Microcephaly, facial anomalies, eye abnormalities (exudative vitreoretinopathy, hypermetropia, optic atrophy, and strabismus), and musculature abnormalities (generalized hypotonia, spastic diplegia, and ataxia) are also present. Many authors (Kharbanda et al., 2017; Kuechler et al., 2015; Light et al., 2012; Verhoeven et al., 2020) also note problems in the field of social-behavioral problems (sensitivity to sound, hypo/hyperactivity, outbursts of anger, lack of empathy, and difficulties in adapting to change). Recent research (Jin et al., 2020; Kayumi et al., 2022; Moreno-De-Luca et al., 2021) suggests that CTNNB1 syndrome is a common case of misdiagnosed cerebral palsy.

Diagnosing rare diseases is complex because the identification process is lengthy and costly. Sometimes the cause is not even found (Boycott et al., 2017). Professionals involved in the early treatment of a child often have little information for parents due to the complexity and abundance of rare genetic syndromes (Ramalle-Gómara et al., 2020). Parents of children with rare diagnoses often experience high levels of stress and burden (Bruns and Foerster, 2011; Carpenter et al., 2018). The amount of information provided by professionals plays an important role here (Gundersen, 2011; Picci et al., 2015; Ramalle-Gómara et al., 2020).

The process of helping children with a rare genetic disease is often more complex than with more common diagnoses. Some genetic diseases are so rare that there is no single effective therapy or treatment for them (Simone-Baldovino et al., 2016). The child's developmental peculiarities can also be manifested in less mature forms of motor development or movements in general. Therefore, it is important to pay attention to them (Scharf et al., 2016; Žgur and Ferlinc, 2019). Very intensive brain development takes place in early childhood, which is one of the reasons that the first years of age are of extreme importance for the development and progress of infants with developmental deficits (Cunningham, 1999). Early treatment is extremely important to improve a child's development (Odžić, 2022). The former includes carefully planned and individually oriented learning of specific developmental functions. The learning begins as soon as a child's developmental deficit is detected (Vuković et al., 2011). The learning should be oriented in an interdisciplinary manner and adjusted according to the type, intensity, and sustainability of the child's special needs. The assistance should also be offered to the child's entire family, not just the child (Žgur, 2017). The goal of early treatment is to enable the child to use his or her potential as much as possible and gain the experiences necessary for his or her integral development (Odžić, 2022; Vuković et al., 2011). For the best possible results, professionals must provide appropriate medical, psychological, social, and special educational support to parents. In the process, it is important for the professionals to be flexible and to adapt to the family (Seligman and Darling, 1997; Shields, 2001).

PURPOSE

In the research, we wanted to ascertain how the mother coped with CTNNB1 syndrome and how the medical staff supported her in the process. We were mainly interested in what were the first symptoms that alerted the mother and the professionals to the CTNNB1 syndrome, how the diagnosis was received, and what were the methods of assistance that the mother and child received. The field of diagnosing and helping people with CTNNB1 syndrome is insufficiently researched in Slovenia.

Therefore, we identified this as the main research problem. Utilizing the research, we wanted to draw attention to the early signs' characteristic of CTNNB1 syndrome and to present possible forms of support for the child and family that can be of assistance to health professionals who are faced with this diagnosis.

METHODOLOGY

A causal non-experimental method was used. The research approach was based on qualitative research of a singular case study. The sample was non-randomized and included a mother of a child with CTNNB1 syndrome. For the research, we designed a structured interview based on the research problem. The interview contained open-ended questions.

RQ1: What were the first signs of CTNNB1 syndrome and when did they start to appear?

RQ2: How did the diagnosis and obtaining information about the syndrome take place?

RQ3: What forms of assistance were offered to the child and the family?

RESULTS

We ascertained that the mother started to notice the first signs of problems immediately after birth. She saw that the child was absent and sleepy. He was not making eye contact and squinted occasionally. At three months of age, the child was not yet able to hold its head. An extension pattern and dystonia were also observed. The mother attributed the child's problems to the slower course of normal development and consoled herself with the similar experiences of her friends. The pediatrician was the first to warn the mother about the problems. The child did not respond to the examination appropriately. He was writhing and had many unorganized, dystonic movements. Due to the mentioned problems, the boy was immediately treated at the Early Treatment Center.

A multidisciplinary professional team which included a pediatrician, a neurologist, a neurophysiotherapist, a social pedagogue, an occupational therapist, a speech therapist, a psychologist, and a social worker participated in the assistance process.

The child received the most intensive help in the field of neurophysiotherapy because, from the beginning, motor problems were primarily in the foreground. The child was treated by two neurophysiotherapists – one in the clinic and one at home (the service was self-pay). The therapist at the home worked mainly on stretching the muscles and maintaining the mobility of the joints. In the outpatient clinic, they worked with him on the acquisition of developmental functions and advised the parents on the use of aids and the implementation of exercises adapted for him. The exercises would contribute to better progress.

The diagnostic process lasted for nine months. First, they performed an ultrasound and magnetic resonance of the head, as well as blood tests, which showed nothing. Therefore, they also did genetic tests. The diagnosis was given to the mother over the phone by the pediatrician who did not have much information for her. She told her that very few cases had been described. Consequently, it was difficult to predict what his progress would be. Upon receiving the diagnosis, the mother first felt relief because she finally received an explanation for her child's problems. She soon realized that there was not much information about the syndrome online. The existing research only presented cases with a more severe course of development. Therefore, she became worried. The health workers reassured her that, based on the progress made so far, they expected that the child would not have major developmental problems. In the process of getting to know the diagnosis, the professionals received additional training utilizing research articles. The neurologist also attended a conference on CTNNB1 syndrome.

In the period after receiving the diagnosis, a special pedagogue and an occupational therapist were also included in the treatment. They worked with the child individually and in a pair. They also performed some treatments at his home. The special pedagogue familiarized the child and the family with the methods of communication, the use of gestures, and, later, PECS substitute communication. Within the context of the early treatment, the occupational therapist focused mainly on the appropriate use of toys and the proper feeding technique. The child also received developmental treatment at the University Rehabilitation Institute of the Republic of Slovenia – Soča and the Hospital for the Treatment and Rehabilitation of Chronically Ill Children Šentvid pri Stični.

The child made good progress from the beginning. Between the 1st and the 2nd year, however, his development suddenly stopped. The psychologist was the first to warn the mother that the child had extensive problems in all areas of cognitive functioning and that his problems were greater than initially expected. At first, the mother did not want to believe the results of the psychological testing. She wanted to change the psychologist and repeat the testing. Nevertheless, she later realized that the psychologist was right in many respects. She felt broken and hurt having thought of her child having special needs.

Over time, greater and greater differences began to appear in the development. The child often made strange noises, was bumping into glass and walls, and bit his body. His very stereotypical behaviors slowly let his mother know that their life was not going to be what she expected. At the same time, she worries about her child's future and mourns for everything he would be able to do but will not be able to do because of CTNNB1 syndrome. At the same time, she is grateful for all the support she received from her husband, family, support group, and medical professionals.

DISCUSSION

The research showed that the signs of CTNNB1 syndrome in the child began to be expressed shortly after birth. The most obvious were disorders of muscle tone, lack of muscle control, strabismus, incoordination of movements, and absence. All the mentioned symptoms are characteristic of children with CTNNB1 syndrome (Grieco and Chung, 2023; Kharbanda et al., 2017; Kuechler et al., 2015; Verhoeven et al., 2020). Nevertheless, the mentioned signs are not sufficient to make a diagnosis. The disease is also not shown on MRI or in the blood. Therefore, additional tests are needed.

Professional staff have faced the challenge of a lack of information about the syndrome because it is such a rare condition that not many cases have been described. It is a common problem that is also described by other authors (Donghi et al., 2009; Picci et al., 2015; Ramalle-Gómara et al., 2020). Nevertheless, professionals who treated the child tried their best to obtain as much information as possible for the parents. The professionals were educated utilizing expert articles and a conference on CTNNB1 syndrome and offered different forms of help to parents. Informed parents of children with rare diagnoses cope with the diagnosis more easily, more constructively, and with a lower level of stress (Dodič, 2016; Gundersen, 2011; Picci et al., 2015).

Based on the child's progress, the mother and the medical professionals believed that he would not have major developmental problems. Unfortunately, it later turned out that his development had stopped. Diagnosing and treating rare diseases can be time-consuming and unpredictable (Biesecker and Green, 2014). Therefore, it is even more important that professionals use appropriate verbal and non-verbal communication (Hedderly et al., 2003; Restoux, 2010; Seligman and Darling, 1997).

A team of experts helped the child. Other authors also write about the role of a multidisciplinary team (Globačnik, 2012; Guralnick, 2001). During the first period of assistance, the two physiotherapists worked intensively with the child. They were performing both stretching exercises and exercises to help with the assimilation of developmental functions. The experts cooperated. They were also visiting the child at home. The mother received several tips from health professionals related to appropriate positions, handling, feeding, use of toys, and encouraging communication. The multidisciplinary team offered help for the child and the family in the social, conceptual, and practical areas where the child's strong areas were also encouraged. Numerous authors (Cunningham, 1999; Žgur, 2017) mention the importance of support for the entire family by health professionals. They see the advantages mainly in easier coping of the family, a lower level of stress for the parents, and, as a result, a higher quality of treatment of the child.

In the research, we ascertained that the mother encountered many emotions in the process of getting to know and facing the diagnosis. The most expressed emotions were concern, fear, denial, and sadness. Many other authors (Dodič, 2016; Hedderly et al., 2003; Kandel and Merrick, 2007) define the mentioned emotions as normal and necessary in the process of dealing with a child's diagnosis. For the parents, accepting the child's diagnosis means accepting the title of a family with a child with special needs and the associated adaptation to a new way of life that they did not plan.

CONCLUSIONS

The process of diagnosing CTNNB1 syndrome and helping the child is complex because it is a rare diagnosis that is difficult to recognize. The first signs of CTNNB1 syndrome appear mainly in the motor area and can be seen already in babies. With the research, we wanted to draw attention to how important it is for professionals to recognize problems in time and to include the child in the process of early treatment which is very important for the child's further development. The process of helping children with rare diagnoses can be very challenging because the course of development and the child's chances for progress are unpredictable. We are aware of the limitations of the research because the latter included only one mother of a child with CTNNB1 syndrome which is currently the only case in Slovenia. In future research, it would make sense to include the perspective of other professionals who worked with the child. The research could also be expanded internationally because thus we would obtain a larger number of participants. Nevertheless, we believe that the present research contributes important insight into the process of early recognition of an extremely rare diagnosis and assistance to the child and his family.

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