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Neurodevelopmental Disorders in Children

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Abstract

Parenting a child with neurodevelopmental impairment is linked to a lower quality of life, a higher risk of anxiety and depression and greater stress (NDD). Although there is research that suggests it may be challenging to raise NDD children in LMIC, little is known about the psychological hardship these parents go through, especially in rural areas. The goal of the study was to look at the psychological distress those rural Nepalese caregivers of NDD children go through. A team of skilled mental health professionals went and spoke with 63 carers in their homes. In this study, the General Health Questionnaire was utilised to evaluate psychological distress, perceived caregiver load, disability severity and demographic information.

Keywords: Neurodevelopmental disorders • Williams Syndrome • Down syndrome • Children's voices • Education and Health and care

Introduction

Parenting a child who has a neurodevelopmental disorder could be challenging. This issue could be exacerbated in some regions of the world by poverty and a dearth of social assistance. Cerebral palsy, genetic abnormalities, intellectual disability and other ailments that impair cognition, motor function, vision, hearing, speech and behaviour are just a few of the issues that impact the developing brain that are referred to as "NDD." Although there is a dearth of epidemiological data on the prevalence of NDD in low- and middle-income countries, it is estimated that 93 to 150 million children globally have some sort of disability, with the majority of them living in low-income countries [1-5].

Description

The fact that children with disabilities are usually underestimated in official statistics contributes to their continued "invisibility" in politics and society. Because of the increasing occurrence of established risk factors such insufficient prenatal and postnatal care for mothers and children, nutritional inadequacies and infant infections, NDD issues are projected to be more common in low- and middle-income nations. Due to its high incidence, lifetime duration, considerable social, emotional and financial consequences, as well as their impact on post-secondary education and employment prospects, NDD pose a public health concern for LMIC. Treatment, prevention and management of these ailments are commonly overlooked in healthcare plans despite the fact that they have a large financial impact on healthcare systems.

Caregiving experiences may differ based on the environment due to the various additional challenges brought on by raising a kid with NDD in an LMIC. Social isolation and psychological suffering might get worse due to stigma, rejection and unfair legislation. According to reports, lower levels of social support, dysfunctional families, a greater negative impact of the child's situation on the family, poorer child behavior, unfavorable parenting approaches, poorer child psychosocial functioning and even a negative effect on siblings and marriage are all associated with caregivers who are experiencing psychiatric distress. The mother's depression has been shown to have an influence on the child's psychological, intellectual and emotional development. It has also been hypothesized that this may increase the chance of malnutrition and physical and mental illness in the child.

Cultural variations in information, attitudes and ideas about mental health and disabilities have an impact on how individuals manage stress and seek out help, which can lead to ineffective treatment. Clarke and colleagues found that Nepali mothers' judgments of psychological distress typically included gender and family-related difficulties. A fatalistic worldview regularly affected how people responded to suffering and discomfort commonly developed in situations where women were expected to take care of the family and had limited autonomy. In Nepal, there is a widespread conviction that sins from a past life, fate and God's will are to blame for one's infirmity. According to Human Rights Watch, stigmatization affects relatives of people with disabilities.

This study is the first to look at the representation of the voices of children with severe genetic neurodevelopmental diseases, including WS and DS, in their statutory papers in England. The study's findings showed that, when using the first person, only 7.7% of EHC plans directly expressed the viewpoints of the children. When it came to issues involving their education, health and care, the majority of statutory papers for both WS and DS children only included the voices of the parents and professionals, not those of the kids. More significantly, 41.4% of EHC plans that featured a narrative written in the first person, as if the child or young person were speaking for themselves, failed to indicate how their voice was acquired. These findings show that the voices of children themselves may not have been adequately represented, despite the fact that parental perspectives can frequently improve the health, care and educational decision-making for children with complex neurodevelopmental disorders and should be included in statutory documents.

First-person narratives required by law do not always mean that the youngster has stated such opinions. Does an adult have the right to assume what a child or young person would have said or thought given the frequent lack of information about how children expressed themselves when the first person is used? Ethical concerns about the design of these statutory documents and the degree of genuine child/young person representation are undoubtedly raised. If so, the adult shouldn't be vague about how the child's voice was used to permit the usage of the first-person narrative? We contend that the underrepresentation of children's voices and the lack of transparency around how the children's voices were obtained are worrisome. This discovery necessitates more investigation into how different categories of children with complex needs are represented in relevant legislative texts.

The study does have certain flaws. Statistical interpretation should be used with caution given the small sample size. Nepal is a fairly ethnically and culturally diverse country; therefore even though the sample was taken from a

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variety of areas, the findings could not accurately reflect what NDD caregivers in rural Nepal actually experience. Due to the absence of a public register for kids with NDD, information on possible NDD cases in the region was gathered from locals, youth organizations, local governments and other organisations; nonetheless, some cases may have been missed. However, other families might not have wanted to disclose that their child had a handicap. Because such children were not included in the research, this might be biassed.

Conclusion

The study found that caregivers of children with NDD had considerable levels of psychological distress and general poverty in four regions of Nepal. Receiving help from medical specialists and having a close friend to confide in were both associated with decreased psychological suffering, but it appeared that the perceived burden of being a caretaker was associated with increased psychological suffering. It is important to recognize and treat the role that the cultural and socioeconomic setting in which the families reside plays in the psychological anguish experienced by NDD caregivers.

Acknowledgement

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Conflict of Interest

The author shows no conflict of interest towards this manuscript.

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