



Parents of Indian Children with Down Syndrome: Stigma and Health Related Quality of Life

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To the Editor: One day in our clinical genetics OPD a mother of a child with Down syndrome (DS) while giving history of her child broke in tears saying “*I feel guilty to have given birth to such a child*”. It made us ponder over the issue of psychosocial health of parents of children with intellectual disabilities (ID). We wish to share salient findings of our study aimed to assess the psychosocial health of parents of children with DS.

There were 50 parents in the study, 25 mother-father dyads, with mean age of 33.1 y for mothers, 37.7 y for fathers and 5.9 y for children. We found that study participants experience severe stigma, with an overall mean weighted score of 2.28 (SD 0.40) on the Caregivers of People with Mental Illness (CPMI) Stigma Scale, which is consistent with previous research findings [1].

Coping Health Inventory for Parents (CHIP) scale was used to assess coping strategies. In consistent with prior research our results revealed that maintaining relationships (36.04±5.15) was the most frequently used coping strategy, followed closely by preserving family integration (32.34±4.82) [2]. Understanding healthcare settings was the least effective coping method (14.74±3.72), implying that parents may feel unsupported by the health services they access.

Health-related quality of life (HRQoL) was assessed by WHOQoL; in line with a previous study we found that parents were more satisfied with social relationships (14.00±3.31) then orderly physical, psychological and least with their environmental conditions (12.82±2.78) [3].

The study emphasizes the importance of interventions that eliminate stigma and increase health care support services for parents of children with Down syndrome in India. Raising public awareness about such conditions would reduce caregivers stigma and strengthen their social support networks. There is a need towards larger and more comprehensive studies on this subject from India.

Declarations

Conflict of Interest None.

References

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