Case Report

The Need for Psychiatric Care among Visually Impaired Children with Traumatic Life Events: a case report from rural India

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ABSTRACT

Children with visual impairment face the incredible challenge of learning to cope and manage their disability in order to function daily. For those living in rural India where resources are limited and stigma in seeking psychiatric care is high, rehabilitation is vital for furthering their education and livelihood. Comorbid mental health issues are known to impact a child's functioning. Children with visual impairments along with mental health concerns face multiple challenges that could potentially impact their rehabilitation goals into adulthood. This case report illustrates a child faced with psychological trauma while navigating her visual impairment. The case demonstrates that it is vital to screen this particularly vulnerable population in rural India for mental health concerns by integrating psychiatric care with their ophthalmologic care.

Key Words Mental Health, India, Vision Impairment, Blind, Rural, Stigma

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INTRODUCTION

This case report demonstrates a visually impaired youth living in rural India presenting with mental health concerns in the context of traumatic life-events and limited access to psychiatric services. Of the 26.8 million disabled people living in India, 18.8% are found to be visually impaired [1]. Epidemiological studies show a prevalence of mental illness in India ranging from 9.5 to 370 per 1,000 [2]. With 75% of the population living in rural areas and only about 4 psychiatrists per million, this means that much of the country's population has limited access to mental health services [2]. Multiple risk factors identified in this case report highlight the importance of integrating mental health services in the rehabilitation of visually impaired children with mental health concerns in a community where mental health is heavily stigmatized.

CASE REPORT

The patient was a 19-year-old South Asian female from rural India residing at a residential school in the 8th grade with a history of visual impairment and hemiparesis secondary to an ependymoma[1] status post resection/radiation therapy with a history of significant psychological trauma impacting her rehabilitation and activities of daily living. This patient was first encountered at 17 years old for an in-person psychiatric consultation at her home due to school refusal. Written consent was obtained from the patient and her family, and the project was approved by the ethics committee. The consultation was conducted by the first author, a US-based psychiatrist, in partnership with Tejas Eye Hospital run by Divyajyoti Trust in rural part of Gujarat, India. A virtual two-part follow up occurred when she was 19 years old due to the emergence of

[1] A type of tumor forming in the brain or spinal cord that most often occurs in young children for which primary treatment is surgery. *Retrieved from https://www.mayoclinic.org/diseases-conditions/ependymoma/cdc-20350144*

passive suicidal thoughts. Additional psychometrics were administered during these interviews, which were conducted in the presence of people familiar to the patient including the community rehabilitation supervisor, teacher, and paediatric ophthalmologist for collateral information, translation, and patient's comfort. At the time of the first evaluation at 17-years-old, she was refusing to participate in the local school and the hospital's supplemental hostel program for blind children. She reported that her mood was "happy." While her appetite and sleep were reportedly fine, she refused to leave her house and exhibited a lack of interest in socializing with adolescents her age. She did not provide any reason for her refusal to return to school or hostel program, expressed wanting to go back, yet continued to refuse when attempts were made. She was able to tend to basic activities of daily living but otherwise depended on her family.

Past Psychiatric and School History

Her history was obtained through the community rehabilitation supervisor and review of all available medical records. She started attending the village school at the age of 5 years old and was then admitted to Tejas Eye Hospital's hostel program for blind children for educational support. She maintained good attendance until 9 years old when she started refusing to attend. When she was 16 years old, her mother died by suicide by hanging herself. The community outreach team comprised of the village leader, peer support, and community rehabilitation supervisor offered support and counselling to the family. They also attempted to transition the patient to a residential school for the blind. After three days, she returned home reporting her physical limitations at the residential school and refused the hospital's offer to instead return to the hostel program in the interim. The patient did not offer nor relate to any further details regarding her school refusal. While psychiatric services were indicated due to concerns for anxiety and trauma, no local services were available. Therefore, the plan was for the community rehabilitation team to continue with home visitations in attempts to reengage her back into the program. She denied any suicide attempts, self-injurious behaviours, or violent behaviours towards others.

Trauma History

There had been domestic violence between her parents witnessed by the patient. Her father had developed an alcohol use disorder and was physically abusive towards her mother.

Birth/Developmental History

The patient was born in a tribal community within a rural village in Gujarat. Her mother had a full-term, normal delivery at home without complications during the pregnancy or birth. As per the family, the patient's developmental milestones were normal.

Medical History

At 3 years old, the patient developed high fevers, weakness, and visual impairment and was first symptomatically treated by a local healer with minimal relief. She gradually became weaker and eventually lost her vision. She was not seen by a physician until she was 8 years-old during a community outreach camp conducted by Tejas Eye Hospital and was referred to a general hospital in a neighbouring city for further workup showing a 5.1x4.1x3.8 cm lesion pressing against the 4th ventricle on MRI. The tumour was determined to be a grade II ependymoma. Even after 30 treatments of radiation followed by surgical resection, her visual impairment remained permanent. Due to the size, there were complications from the surgery which resulted in left sided facial hemiparesis and left sided upper and lower extremity muscle weakness. She also developed bilateral descending optic atrophy, left sided esotropia, and nystagmus.

Family/Social History

Her father was a farmer, and her mother was a homemaker. The family fell below the poverty line, qualifying for government aid. The patient also received an additional stipend for her disability. Following the death of her parents, her household was split between her maternal grandmother and her brother, sister-in-law, and young nephew. The patient denies any use of alcohol, smoking, or other illicit substances. Her father likely suffered from alcohol use disorder and both parents died by suicide.

Interval History and Treatment Course

Shortly after the initial interview, the community rehabilitation team was unable to work with the patient and her family for about one year due to the COVID-19 pandemic. During this time, her father's alcohol use worsened. He died by suicide by ingesting pesticide. He also tried to convince the patient to ingest pesticide, but this was interrupted by her grandmother. The community rehabilitation team reconnected with the family to offer support and arranged for the patient to return to the hospital's hostel program, to which she finally agreed. Though typically only for children under 12 years old, the team made an exception with the intention to transition her to an appropriate residential school for the blind. At this time, her teacher raised concern after the patient made a passing statement wishing she died from ingesting the pesticide so that she would not have to continue living in pain.

This prompted another psychiatric consultation which was completed virtually when she was 19 years old. She was more withdrawn compared to two years prior. Her responses were often met with monosyllable 'yes/no' answers or silence. She became distraught several times during the interview with any mention of her past trauma resulting in a two-part interview to give her a break. When asked directly about her complaints, she mostly focused on back pain and weakness resulting in difficulty walking. Though she completed her activities of daily living and took pleasure in singing and listening to music, she admitted to feelings of anxiety pertaining to her physical limitations and sadness when thinking about her parents. She admitted to flashbacks of witnessing domestic violence and of the day her father died. She denied experiencing any nightmares but exhibited avoidance surrounding the mention of her parents. She admitted to feelings of anger when asked about her life experiences. She had a close relationship with her brother, sister-in-law, nephew, and grandmother but attributed her struggles to her family's financial problems. When asked about her passive suicidal remark a few months prior, she denied any previous attempts, plan, or intent but rather wished for her physical pain and blindness to end. In fact, she expressed hopes of becoming a Hindi teacher. With the ongoing support from Tejas Eye Hospital, she eventually agreed to join a smaller residential school for the blind but refused the recommendation for a larger city school which could have provided psychiatric services.

Patient Health Questionnaire-9 (PHQ-9) [3] revealed a score of 9 which indicated moderate depression. The Screen for Child Anxiety Related Disorder (SCARED) [4] revealed an overall score of 79 with high scores in subcategories for generalized anxiety disorder, panic/somatic, separation anxiety, social anxiety, and school avoidance. PTSD Checklist for DSM-5 (PCL-5) [5] was attempted multiple times with the patient, however she would become too distraught to complete the assessment.

Mental Status (most recent)

The patient was a petite, south Asian female who appeared younger than her stated age with left sided facial hemiparesis. She was well-groomed and dressed appropriately. She was unable to make eye contact secondary to her visual impairment. Her gait was slow and unsteady, requiring assistance in ambulation. She spoke fluent Gujarati, her mother tongue, at a low volume but appropriate rate and rhythm. However, her responses were given in short answers or complete silence. She presented to be withdrawn, anxious, guarded, regressed, and intermittently tearful. She reported her mood as "sad" and appeared blunted, constricted, and limited in her range of affect. Her thought process was linear, logical, goal-directed, and future oriented. She denied any suicidal or homicidal ideations. No delusions or paranoia were elicited. She denied auditory or visual hallucinations. She was oriented to person, place, and time. Her cognition and abstraction appeared grossly intact, however not formally assessed with psychometric tests. Her insight seemed limited as evidenced by her lack of understanding of her past experiences affecting her current emotional state. However, her judgment appeared poor due to her unwillingness to attend the larger residential school which could have offered her mental health resources.

Diagnosis

The patient was diagnosed with major depressive disorder, moderate, recurrent episode without psychotic features and unspecified anxiety disorder. She also likely had posttraumatic stress disorder.

DISCUSSION

There are multiple factors to be taken into consideration when discussing this case. This patient's psychiatric symptoms began in early childhood starting with school refusal. Children aged 0 to 14 years old make up 37.77% of the India's population [2]. While education is a right, the literacy percentage of India is 77.7% with only 71.5% in women [6]. This number is likely lower in rural areas and does not consider literacy rates for those with visual impairment. Therefore, education is crucial for this patient who already falls under high-risk statistics. Her ability to partake in her education/rehabilitation was impacted by mental health issues, possibly due to her trauma. In a study measuring the anxiety level of 150 visually impaired adolescent students in India, there was a statistically significant relationship between their anxiety level and its impact on their social and personal adjustment. This study also revealed that participants of the female gender had a higher prevalence of anxiety than their male counterparts [1]. Another study surveying 515 visually impaired children in across 7 schools for the blind in Northern India revealed that 56.52% had anxiety/stress based on the Depression Anxiety Stress Scales and 85.52% had a reduction in quality of life [7]. Investigators surveying adults with blindness in Mangalore, India, found that 68% were depressed based on the Beck Depression Inventory with rates being highest in the 7th decade [8]. Two-thirds of these participants reported lack of motivation, family dependence, and stigma as reasons for low change-readiness scores for psychiatric care. Thus, our patient may be at continued risk for depression and anxiety into later adulthood and may not seek or receive much needed mental health services further impacting her daily functioning. She was already predisposed to mental illness given her family history of suicide of both parents as well as alcohol abuse in her father. In a study of 68 attempted suicide cases within a rural agrarian community in India, 85% of the attempts involved pesticide ingestion, and at least 60% involved depression [9] which suggests her parents may have suffered from depression as well. In fact, in a study of 522 individuals in Rampur, India, who were the primary caregivers of family members with visual impairment suggested a correlation of depression in the caregivers, which ranged from 16% to 48%, to the severity of blindness [10]. Despite these risk factors, the significance of family and values of collectivism in Indian society can be viewed as a protective factor. After losing her parents, other family members stepped in to assume that responsibility along with members of her tribal community and the Eye Hospital's rehabilitation team. Her psychiatric assessment revealed significant depression, anxiety, and trauma for which psychiatric services including psychotherapy and pharmacotherapy would classically have been the treatments of choice but were not available to her. In addition, seeking mental health treatment holds a large stigma in this society. Therefore, the first recommendation was to strengthen her relationship with the community rehabilitation team to engage her back into school and hostel program. Though she did not receive psychiatric services, she was supervised 24/7 by staff who became an extension of her family which likely helped mitigate some risks related to her mental health issues. The goal was to send her to a specialized school for the blind with access to psychiatric services and rehabilitation programs that might address her chronic symptoms related to depression and possibly PTSD. However, she chose to attend a school in a smaller town, thereby limiting her access to such care. While this school and the Eye Hospital continue to provide her with further education and social support, she will likely continue to be at risk for mental health issues into later adulthood.

CONCLUSION

This case report demonstrates the need to pay attention to the mental health needs of visually impaired children with traumatic life-events in rural India. While there are limited studies within this specific population, there is some evidence suggesting strong relationships between visual impairment, mental health, and daily functioning. Unfortunately, along with being heavily stigmatized, most rural areas in India severely lack mental health services to supplement rehabilitation programs to support visually impaired children and young adults with psychological trauma. Screening visually impaired children for risk factors at these specialized eyecare centres for comorbid mental health conditions could identify vulnerable patients who may have a more difficult time participating in rehabilitation/educational opportunities. One aspect to consider as part of rehabilitation would be allocating funds to integrate in person psychiatric services into rehabilitation services. This would provide high risk, visually impaired youth with culturally sensitive mental

health services, thereby potentially improving their participation and engagement in rehabilitation, school, and family/social life.

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Conflict of Interest – Dr. Suhal Shah is the niece of Tejas Eye Hospital Vice President, Dr. Uday Gajiwala. Dr. Uma Shroff is the daughter of Tejas Eye Hospital Vice President, Dr. Uday Gajiwala and employed under Tejas Eye Hospital.

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