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Case report

Amenable for psychological interventions? Case report of a child with multiple developmental disabilities and challenging behaviours

Poornima V, Nithya Poornima Murugappan, Arul Jayendra Pradeep, John Vijay Sagar Kommu

Address for correspondence: Department of Clinical Psychology, NIMHANS, Bengaluru, India. Email id: nithya.s.poornima@gmail.com

Abstract

Intellectual disability (ID) with comorbid Autism Spectrum Disorder (ASD) can have complex and challenging behavioural presentations, in the context of socio-emotional issues such as attachment ruptures and bereavement. It is important to incorporate appropriate psychological interventions that also address the underlying emotional needs of the child in addition to the management of behaviours. This case report is of a 12- year- old boy with ID, ASD, and attention deficit hyperactivity disorder. The child presented with anger outbursts, self-harm and harming of others, and exacerbation of problem behaviours in the context of the recent death of his grandfather. There were also various psychosocial issues such as insecure attachment, depression in the mother, multiple caregivers, and expressed emotions. The child improved with the addition of attachment informed interventions. The report highlights the importance of going beyond pharmacotherapy and behavioural interventions to address the underlying socio-emotional needs of the child.

Keywords: Intellectual disability, Autism Spectrum Disorder, Psychological intervention, Attachment, Challenging behaviour

Introduction

While Intellectual Disability (ID) is characterized by significant limitations both in intellectual functioning and in adaptive behaviour [1], comorbid developmental disability such as Autism Spectrum Disorder (ASD) increases complexity of issues. Comprehensive management of ID involves addressing family adaptation, developmental needs of the child, transactional or interactional processes between the child and the caregivers, physical care, and behavioural management [2]. Given the impairment in communication skills, reading the child's emotional states during daily functioning, particularly when significant life events such as bereavement occur becomes an important component of a Clinical psychologist's work.

The consequences of bereavement may be more challenging for individuals with developmental disabilities due to lack of preparedness to deal with the grief, lack of assistance in handling the grief reaction, cognitive difficulties in processing the loss, lack of or altered emotional expression, change in behaviours rather than feelings, and poor response of caregivers and professionals to the expression of grief [3]. Approximately 50% of the persons with ID develop withdrawal and aggression following the death of a close one [4] and may fear the loss of other significant individuals around them [5]. According to Brickell and Munir [6], individuals with ID have a higher vulnerability to develop traumatic grief, as there is a risk of secondary loss, difficulty in verbal and emotional expression, and difficulty in meaning-making.

There has been a long-standing debate with regard to the effectiveness of psychotherapy in the case of individuals with ID [7, 8]. One of the challenges in this context could be attunement of the therapist to the perceptual, emotional and cognitive frames that individuals with ID and ASD use to perceive, understand and express their experience. However, there is a need for more rigorous research, identification of specific ingredients, especially process factors that are helpful in therapy with this population [9]. Attachment theory is key, especially in cases of

grief and separation anxiety in children with ID living in conditions of psychosocial adversities [10-12].

While caregivers might also not have the resources required to deal with the complex socio-emotional challenges of children with ASD [13], developing positive affect in the mother may serve as a protective factor [14].

Case summary

Master Y, a 12-year-old boy, first of three siblings, born of a consanguineous marriage, from lower socio-economic status, had been attending a school for children with special needs for 6 years. Y reportedly was restless and hyperactive from the age of three years and had a fluctuating course of anger outbursts and, self-harm and aggression towards others. This was observed both at home and school. He responded best to his maternal grandmother. While his siblings were fond of him, they also became fearful when he was dysregulated. He would want them around but would not initiate interactions with them. His father was reportedly punitive to him often. 18 months prior to the current consultation, these behaviours had increased following the death of his paternal grandfather. Episodes of anger outbursts, reduced need for sleep, watching television at 2 AM, incessant crying spells, increased psychomotor activity and physical aggression towards self and others were observed. These episodes had a fluctuating course, lasting for a range of five days to two weeks. During this period, he was also quite withdrawn and interacted only with his immediate family members. He was staying with his parents and used to cling to his mother constantly.

The episode that necessitated hospitalization, marked by severe behavioural dysregulation had lasted one and a half months. He had not been attending school and there was deterioration in self-care including food-intake. While he was able to indicate basic needs and perform self-help activities with assistance and prompting earlier, currently the caregivers had to take over completely.

There was history of eclampsia, neonatal seizures, a 10-day admission to Neonatal Intensive Care Unit (NICU), delayed breast-feeding and delayed attainment of developmental milestones. He was a temperamentally difficult child. He had not received formal training or intervention till six years of age. From six years of age, he was staying with his maternal grandparents and alternated between a regular school and special school. The behavioral disturbances continued through this period.

Psychosocial adversities such as low income even with both parents working, harmful pattern of alcohol use in the father and depression with several suicide attempts in the mother were present. Hence, the maternal grandparents became primary caregivers. The maternal grandmother engaged in permissive parenting while there was criticality and punitiveness from the maternal grandfather. Parents had limited contact with him. The mother's engagement with him increased only after the paternal grandfather's death.

From 6 to 10 years of age, he had received regular medication (Risperidone 4 mg per day, Trihexyphenidyl 2mg per day, and Sodium Valproate 400 mg per day) and behavioural interventions on an out-patient basis to address the behavioural dysregulation.

On mental status examination, the child was well-kempt and tidy. Rapport could not be established and he did not cooperate to sit inside the interview room. He did not maintain eye contact with the interviewer. He cried and rolled on the floor or banged his head on the floor when asked to sit down or when his mother was not giving him attention. He was also beating the mother and the grandmother. He could only speak two to three words. He had dysphoric and anxious affect.

He was diagnosed to have Bipolar Affective Disorder–mixed affective state, Attention Deficit Hyperactivity Disorder and Autism Spectrum Disorder; Expressive Speech Disorder; Intellectual Disability and no medical conditions. Multiple caregivers, inconsistent parenting,

harmful alcohol use in father, depression in mother and death of paternal grandfather were coded on associated abnormal psychosocial conditions.

Assessments revealed severe impairment in socio-adaptive functioning (Social age of 3 years 10 months, Social Quotient of 27 on Vineland Social Maturity Scale) and moderate ASD (Score of 139 on Indian Scale for Assessment of Autism).

Management and outcome

Master Y received pharmacological and psychological interventions over two months of hospitalization. Given the comorbidities, nature of developmental disabilities and, severe emotional and behavioural dysregulation, the child was initially considered not to be amenable for psychotherapy. However, considering the presence of significant psychosocial factors, psychological interventions were attempted by the clinical psychology team over 22 sessions.

The first four sessions focused on building rapport with the child and caregivers; observation of the child in the ward activities; behavioural analysis of challenging behaviours, and deriving a psychopathology formulation. During this time, the child was observed to cling to the mother and not interact with anyone else in the ward. (Figure-1)

Case Conceptualization: The case was approached using an attachment and behavioural perspective. (Figure-2)

Interventions: Sessions five to twenty focused on managing child's behavioural and emotional dysregulation, increasing child's ability to communicate needs, dealing with separation anxiety of child, working with the family to develop a routine and increase child's levels of stimulation and development of child's self-help skills.

Rapport had improved as seen by child's eye contact and non-verbal greeting. The behavioural analysis was discussed with the mother. She was helped to understand the sequence of

preempting the behaviours, soothing the child using massage or a calm tone, and distancing when the challenging behaviours occurred through demonstrations by the therapist.

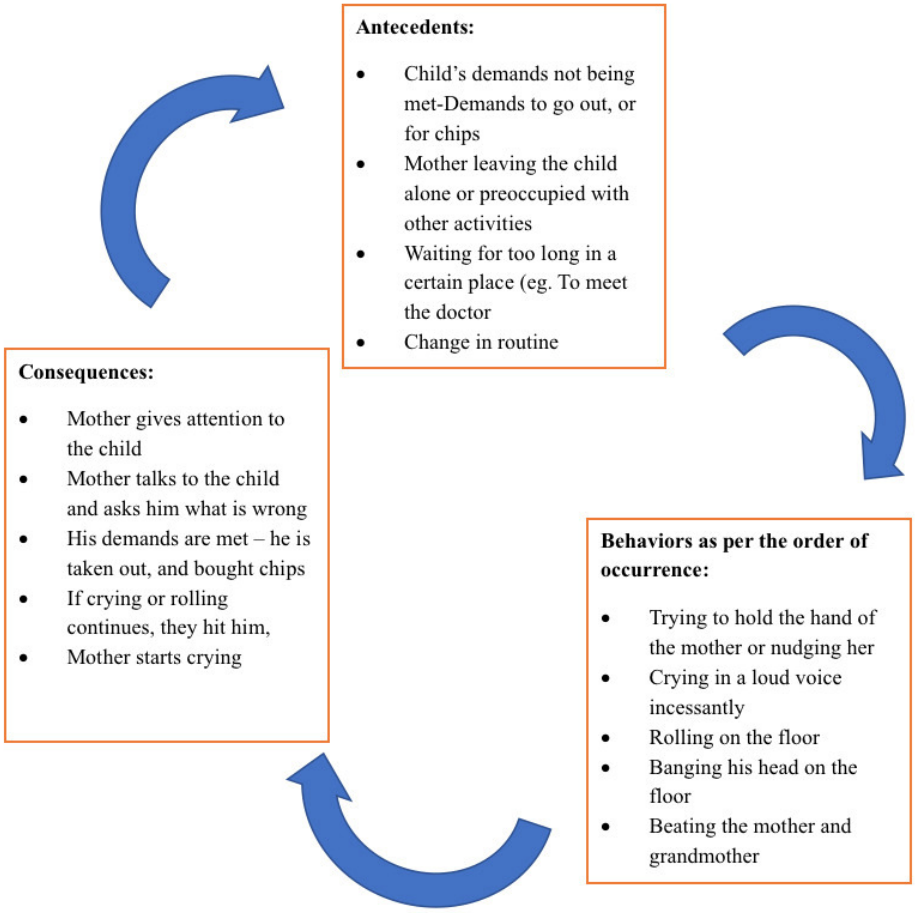

Figure-1: Behavioral analysis

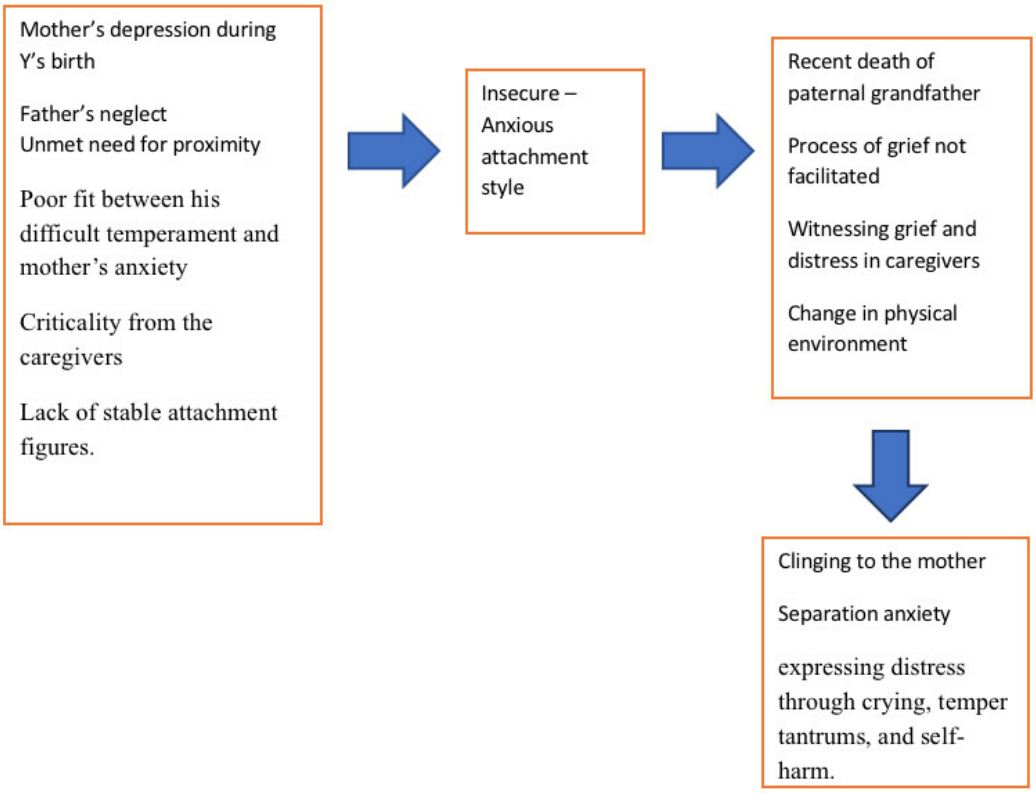

Figure-2: Case conceptualization

Y was receptive to the emotions of the caregivers and would try to comfort them when distressed by holding their hands. As Y responded to caregivers' distress by holding their hand, the potential impact of caregivers' emotions on the child was discussed. Play sessions using techniques such as praising, reflecting, imitating, describing, and using enthusiasm during play were demonstrated to the mother. After twelve sessions, his emotion regulation had improved and the frequency of challenging behaviours had decreased from 15-17/ day to 2-3/day. Differential reinforcement of alternative adaptive behaviours was encouraged. Behavioural outcomes as observed during everyday interactions were used to gauge progress, no structured assessments were used.

The child's communication skills were enhanced by developing his pointing skills, using signals, and by offering him choices to respond to. Co-regulation of emotions such as anger and fear, was facilitated by encouraging the mother to model appropriate ways of expressing them, enabling her to be an external regulator during potential moments of dysregulation. Story-narration by the mother was used to increase the repertoire of adaptive responses. Developmentally-appropriate activities were designed to address separation anxiety. Graded exposure to separation and relational permanence was concretized through activities. Either ends of a twine was tied to the wrists of the mother and the child. The distance between them was gradually increased, from a few steps, to different ends of the corridor. Gradually the mother moved out of sight. Another activity involved the mother gradually moving away, and the child running towards the mother, initially with the therapist and later alone. This helped the child understand that he can move to the mother when he needed her, even when she was not right next to him.

The mother was trained to use shaping to enhance child's self-help skills and decrease her assistance. She was encouraged to engage the child in cognitively stimulating activities such as sorting, using picture books, puzzles, and finding his direction to different places. In the last two sessions, a structured routine to be followed at home including high-interest activities for the child like music, bright colored objects and video games was developed. Interventions for psychological support to mother and to reduce maternal grandfather's criticality towards the child were carried out.

His medications were optimized to Tab Risperidone 4 mg per day, Tab Trihexyphenidyl 2mg per day, Tab Sodium Valproate 400 mg per day and Tab Clonidine 0.1 mg per day.

Challenges: Building rapport with a child with core socio-communicational deficits and conducting therapy outside the therapy room, in an open play area were initial challenges. Supporting the mother over multiple sessions to modify her responses to the child's challenging

behaviours while addressing the grandfather's criticality and grandmother's permissiveness was challenging.

Outcomes: At the time of discharge, the frequency of child's dysregulation had decreased to three to four times a day. The caregivers were better able to deconstruct the situation to understand the child's behavior and were often able to respond appropriately. He was more cheerful, smiled more often, and responded better to the caregivers. He cooperated well while the mother assisted him in self-care and was able to tolerate separation for 5-10 minutes comfortably.

Discussion

Many events and socio-emotional issues that a typically developing child can experience such as anxiety, loss and grief, and difficulties in attachment become quite complicated in a child with developmental disabilities due to deficits in processing events and expressing emotions, leading to a complex behavioural presentation. Master Y had an underlying difficult temperament; cognitive, communication and social skill deficits; challenging behaviours and multiple psychosocial adversities. The bereavement, subsequent gamut of difficult emotions and change in physical and psychosocial environment appear to have contributed to the challenging behaviours.

Significant separation anxiety in Master Y suggested the presence of underlying emotional and attachment issues. While early research and clinical interventions primarily focus on cognitive and behavioural manifestations in ID, later research emphasizes the importance of attachment theory, especially when there is bereavement and loss [11,15, 16]. A systematic review of bereavement in people with profound and multiple disabilities indicated that attachment-based perspectives provide channels to establish therapeutic relationships that may help resolve challenging behavior [16]. While children with ASD can develop secure attachment patterns,

the risk to develop insecure attachment patterns increases when there is comorbid ID. Understanding early relationships in developmental history, observation of the child with significant others and their way of seeking comfort and expressing their needs, and analyzing their response to loss of contact are important aspects of history taking and assessment [17]. In Master Y, ruptures in attachment in early childhood, observation of excessive clinging to significant others, difficulties in seeking comfort and indicating needs, and exacerbation of behavioural problems after the bereavement served as important indicators to consider attachment-informed interventions.

A secure therapeutic bond with the child, using positive interactions as a motivation for working on behavioural problems, and developing a positive relationship between the caregivers and child are essential components in any form of attachment focused therapies. This has been documented in a case series involving young people with severe multiple disabilities [12]. Facilitating coregulation of emotion by working on maternal factors is also important [18]. A thorough behavioural analysis to identify communication functions of the challenging behavior was primary. The secure therapeutic alliance; a developmentally-appropriate environment including developmentally-appropriate experiential activities to counter separation anxiety in the child; helping the child understand alternative modes of expressing anger and needs, and parent management training played an important role in decreasing the frequency of behavioural and emotional dysregulation. Supportive psychotherapy elements included addressing the distress, needs and concerns of the mother, and decreasing expressed emotions in all the caregivers. Through the facilitation of coregulation of emotions such as anger and frustration through maternal scaffolding, caregivers were assisted to respond to the needs of the child adequately which in turn facilitated the development of a healthier caregiver-child relationship.

This case highlighted the need for psychological interventions beyond behavioural management in a child with developmental disability. The initial sense of hopelessness of the trainee therapist was countered by the child demonstrating security in the therapeutic relationship in the initial sessions and by the impact of activities that carry a symbolic meaning in the later sessions. The case also highlighted the importance of maintaining long-term contact with the family, the need for multidisciplinary interventions and the role of incorporating the socio-cultural context in therapy. This case illustration suggests that therapists need to think twice before they say, "Not amenable for therapy."

Conflict of interest: None declared

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Poornima V, PhD. Scholar, Nithya Poornima Murugappan, Assistant Professor, Department of Clinical Psychology, Arul Jayendra Pradeep, Senior Resident, John Vijay Sagar Kommu, Professor and Head, Department of Child and Adolescent Psychiatry, NIMHANS, Bengaluru, India.