Parenting Children with Epilepsy: A Case Report from India

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Abstract: Epilepsy is a common neurological disorder of childhood which has complex ramifications and epilepsy related seizures can differ widely in terms of severity and in parts of the brain affected. A boy aged 14 years, presented to a tertiary hospital with complaints of jerky movements during sleep. Lack of sleep and stressful home environment acted as precipitating factors for his seizures. Psycho-social interventions was done focusing on psycho-education about epilepsy and by developing an emotionally coherent narrative which aimed at helping child to improve his relationship with his mother.

Key Words: Parenting, adolescence, Epilepsy, Stress, Psycho-education, Parent Reconnection Interventions.

Introduction:
Epilepsy is a common neurological disorder of childhood which has complex ramifications and epilepsy related seizures can differ widely in terms of severity and in parts of the brain affected. Population based studies report a prevalence rate of Epilepsy among children to be 3.6 to 4.2 per 1000 in developed countries[17] and around double these rates in developing countries[3-17-19]. In India, recent studies report a differential distribution of epilepsy among various socio-demographic and economic groups with higher rates reported for the male gender, rural population, and low socioeconomic status[5].

Becoming parent of a child with epilepsy was not a job anyone has prepared for. Sense of helplessness that surrounded the epileptic condition led some parents to exert control in non-health related areas of their child's life longer than what was reasonable or appropriate especially mothers of children with epilepsy who were described as being permissive or overprotective or excessively restrictive towards their child.[4]

Case Report:

“I was told that I get seizures. I've just been put on tablets and no-one has discussed anything with me”, says Master K.

Master K was an engaging and spirited fourteen year old child who was looking angrily at his mother from the bench outside the consultation room. His mother was quiet distressed and has burst out in tears. He has come along with his mother to the hospital. From the urban background of West Bengal, this was the first contact of child with the hospital. The child was diagnosed with generalized seizures few months back. He gets myoclonic jerks during sleep about which he was not aware but his mother has noticed it and immediately consulted doctors in Kolkata and that doctor further referred him to tertiary care hospital to get an expert opinion.

Sessions:
Master K and his mother were seen at a frequency of 5 times in a week over a period of one month. Each session was of 45 minutes to one hour.

Number of Session:
- Individual Session with Mother: 8
- Individual Session with Child: 8
- Co-joint sessions: 4

Assessment:
Birth and developmental history of Child: There was no pre-natal or peri-natal complication like maternal infection during pregnancy, low birth weight, maternal hemorrhage, assisted vaginal delivery or post-term delivery. Master K’s was full term normal delivery. He was quiet healthy as a child and never had any physical illness for which he has to be admitted in the hospital during childhood. The developmental course was normal and he attained all his developmental milestone on time.
School History: Child started going to school at the age of 3 yrs. He was studying in class VIII in a private medium. As reported by child’s mother school teachers has always described child as all-rounder i.e. being good in studies, participating in group activities, sports, organizing any events etc.

Family Assessment: The background study of the child’s family revealed that there was no history of seizure disorder in the family. The diagnosis of seizure disorder was a precipitating factor for escalation of crisis in the family that was already going through difficulties. K’s father was of very little help as because of marital discord parents got separated when child was a toddler.

Child’s mother reveals, “His father has never been bothered to know what was going on in his son’s life. He was an alcoholic and used to beat me badly. So I left him and came to stay with my mother and brothers. My son hates me for leaving his father... He tells me that I am fat, ugly and worthless that’s why his father treated me like that. He blames me for everything going wrong in my marital life though he hardly knows anything about it.... He tries to please me whenever he wants me to fulfill his demands. I don’t fulfill all his demand for which he fights with me.”

K’s mother was working as a receptionist in a private company and was staying with her family of origin. She was getting paid around Rs 8000 which was not enough to meet all their needs and day to day expenses. The child’s father worked as a village quack and was staying in far off village. Father was alcohol dependent and spend all his salary in procuring alcohol. Father never visited the family. Over the period of time, the child has adjusted to the fact as he revealed,

“I understand it’s better for my parents to be separated because I know that otherwise they would fight again all the time. If I ask my mom anything to buy she would outright say no without even completely listening to me. I think she is not doing enough for me…”

He further adds, “I can’t study as my uncles’ keeps fighting among themselves on property issue. When they sleep I get some peace of mind and I can read for some time. I want to come out of that miserable pit I am staying in.

It’s not home…. It’s battleground... When my mom is not around my uncles would keep telling me that I should be thankful to them that they have allowed me and my mom to stay in the house so accept whatever was given to us without complaining.”

The boy become quiet tearful and says, “I love to stay at school because my teachers adores me. My classmates give importance to me as I am class representative and good in studies so they will come to me to clarify their doubts. If possible even on Sunday I would love to go to school.”

Child had some concern about disclosure of seizures to his school teacher or classmates as he did not want to reveal about seizures to anyone fearing being treated differently or people being nervous around him just like one of his classmate who has revealed to everyone at school about his seizures and because of restrictions imposed on him after that he was not able to participate in sports activities and do many other group activities which other children use to enjoy doing. On the other hand, child’s mother wanted to reveal this information to school authority especially to sports teacher as child was part of football team at his school.

Following tools were used for objective assessment

With Mother:
1. The Child Rearing Practice Inventory [18]
2. Seizure Severity (SS) scale - Parent [6]
3. Childhood-Illness related Parenting Stress Inventory [7]

With Child:

Assessment revealed:

1) Child-rearing Practices:
   - It consists of seven dimensions-overprotection, disciplinarian, esteem building, normal, harsh and ridicule to rejection. The child’s mother used high rejection in her child-rearing practices and has become excessively restrictive or overprotective towards the child since the onset of seizures not allowing him play football or do cycling which were his favorite hobbies often it led to quarrel between mother-son. Master K mother used low esteem building as she was more
restrictive and controlling towards the child because of poor knowledge about seizures.

- She was less sensitive towards the child’s emotional needs as a result on many occasions ridiculed him or being harsh to him if the child questioned decisions taken by her. If she was not able to control his behavior she would try to discipline the child by saying rude words to him or ignoring him.

2) Child’s Seizure Severity:

- Child had repeated jerky movements, muscle pain during his sleep but no tongue bite and urine incontinence. He resumed normal activity when he woke up from his sleep.
- Whenever he use to get seizures it was quiet noticeable that was the reason mother was able to identify it and took the child to doctor immediately after the first episode as a result it terms of severity it has not much affected child’s day to day functioning.

3) Mother’s Stress:

- Child’s mother felt quiet confuse about the information provided by health care team because of medical jargon used by them, speaking with child and other family members about seizures were some of the other difficult areas identified.
- She had more general stress rather than child’s illness-related stress. Being a single parent and a working mother was a challenge for her.
- Her family of origin was emotionally supportive especially child’s maternal grandmother but financially she was struggling to manage household expenses, child’s school fees, medicines and treatment cost.
- The emotional bonding between mother and son has never been strong and putting restriction on child’s day to day life made their relationship worse.

4) Child’s Experience:

- In terms of good event had topped in his class and got award for that. His mother has recently taken him for shopping to get him some new clothes.
- In terms of bad event his uncles would fight among themselves on property issue and child had broken off with his girlfriend. There has been lot of restriction on the child since the onset of seizures like he was not allowed to pursue his hobby like cycling or playing football.

Goal Setting:

Goal setting was done on weekly basis.

Individual session with Mother would focus on:

- The first week was planned for assessing for her knowledge about epilepsy. If poor then psycho-education about epilepsy, what can trigger a seizure, how to respond to a seizure and common side-effects of anti-epileptic medicines.
- Focusing on improving her relationship with the child.
- Managing her stress.

Individual session with Child would focus on:

- Coach him to express his negative emotions in a more constructive way.
- Improving mother-child interaction.
- Psycho-educate about seizures.

Co-joint session with Mother and Child would focus on:

- Discussed the risks and benefits of telling others (friends, relatives, etc.).
- Provided examples of when it is necessary to reveal this information (e.g., sports tryouts, when child take medications during school).

Discussion:

Through Ecological Systems Theory Bronfenbrenner tried to explain how different aspects of child environment like microsystem, mesosystem, exosystem and macrosystem affects child’s physical, cognitive, emotional and social development. In this case microsystem was individual factors such as separation of parents, the interaction of child with his mother or extended family members, the need for the child to control one aspect of his life by excelling in his studies and it seems to be one of the ways child has learned to cope up with the stressful life situations. The mesosystem like child’s home atmosphere being quiet tense because of interpersonal issues between extended family members. The child had good relationship with his teacher and classmates who has gratified child’s need for being valued and respected. The exosystem affecting child as mother not being able to spend quality time with the child as she does over time to get extra pay for managing household and other expenses. In terms of
macrosystem child not letting his mother revealed to school authority about his seizures as he feared of being treated differently by his teachers and classmates. Ryan (2001) was of the opinion that if these subsystems are not conducive for child’s growth and development then child may have anti-social problems later on in life.

From attachment theory perspective, there was insecure avoidant type of attachment style where child was emotionally independent of his mother as mother has not been emotionally available to for the child whenever he needed her. Child was struggling to individuate as during this adolescence he has started defining himself as a young man and expected mother to give him more independence and wanted to have open communication with her. It was important for the mother to allow the child to individuate from her in order to develop healthy identity and formation of healthy relationship with others. There are studies which has proved that troubled family dynamics often contribute to unsuccessful individuation process.[13]

As per Baumrind[14] style of parenting, there was authoritarian style of parenting in this case. Child cannot control stressful home environment so he use to display his anger and frustration by verbalizing his negative feelings and emotions which was a way he has learned to cope up with stressful home atmosphere. Mother would try to control the child’s emotional reactivity and behavior by being more critical towards him and putting more restrictions on him.

From social learning theory perspective, Master K has learned the way to cope up with his negative emotions like anger and frustration by externalizing it towards his mother. He has learned this through vicarious learning i.e. by observing the reaction of his uncles and other family members react to stressful situations. Also mother has reinforced the child’s behavior by giving him more attention or fulfilling his demand if he has been too rude with her. Barthassa[15] in his study has pointed out that consequences of family-centered conflicts has effects on biological, cognitive, social and emotional development and the child learns to react to stressful situation by observing the reactions of family members.

The onset of seizures has made mother put more restrictions towards the child. There are studies which has highlighted that diagnosis of epilepsy in childhood has a consequences for the parents as they become fearful about child’s safety and the ‘loss of a perfect normal child’ and realization that the child may not be normal like other children makes parents over-protective, restrictive or indulgent with their child with epilepsy.[10,11]

Interventions:

Master K had lot to vent about situation back home which was quiet distressing and difficult to cope. So, initial few sessions focused on encouraging him to express his negative emotions like anger and frustration openly and validating it without becoming judgmental. Sessions with child also focused on facilitating discussions about anger and coach him on how to express his angry feelings in a constructive way through artwork as he was fond of sketching or maintaining a diary.

In exploring the child’s relationship with his mother, core relational themes of neglect and disappointment were discussed so he was helped to process strong feelings of disappointment and frustration. In one poignant exchange, he tearfully shared his disappointment with the lack of trustworthiness shown by the people in his life (especially his mother and maternal relatives). As the therapist continued to gently probe, he expressed how much his mother’s attitude towards him bothered him. The therapist instilled hope by stating that they would focus on this together in therapy and that she would help him relay his feelings to his mother. The discussion about his relationship with his mother seemed to elicit a loving response from the child. He may have been angry with his mother, and justifiably so, but he concluded that he wanted and needed her in his life.

“I was told that I get seizures. I’ve just been put on tablets and no-one has discussed anything with me. My mom keeps me at home more often than usual. I love playing football and cycling. She wouldn’t say you’re not going out but she won’t let me go anywhere on my own”, says Master K.

So next phase of intervention was focused on addressing the child’s concerns about taking medicines and various restrictions imposed on him because of having seizures. Therapist encouraged the child to ask questions and clarify his doubts. Then educated him about the need for taking medicines regularly, need for adequate sleep and lifestyle modification which he needed to make after the onset of seizures.

The initial phase of the intervention with the mother, focused on normalizing and validating her
feelings about being a single parent which was quiet stressful for her. Although she had always been aware of the failure of her marital life, until she was in therapy, she has not been able to link her anger and frustration, which had been free – floating, with memories of her husband’s treatment towards her.

By developing an emotionally coherent narrative of her marital experience and gaining compassion for her own motherhood experience, she was able to become the mother she wished to be.

After entering into therapy, K’s mother was able to grieve that she never had a good relationship with her husband. During the therapy, she realized that her husband, not herself has been the problem. During the initial evaluation parenting strengths and weaknesses was also assessed. According to mother, K disobeyed her rules and he exhibited emotional and at times violent outbursts. Despite her son’s disconnection, K mother’s attitudes about her son was generally positive (“He’s got a good heart, he is caring...he’s a good child”). And this serve as a protective factor and an important foundation to use in building relationships and creating change. However, K mother’s authoritarian parenting style and lack of emotional connectivity diminished any positive parenting outcomes. The therapist explored ways for the child’s mother to improve existing parenting skills and adapt new parenting behavior. New parental skill acquisition was accomplished via the use of Parent Reconnection Interventions(PRI)[12], which helped in reducing the emotional distance between mother and child. The following PRIs were used by the therapist in this case: (1) Enhancing feelings of commitment and love by the mother,

(2) Validating mother’s past efforts,
(3) Acknowledging mother’s stress and burden,
(4) Generating hope via the therapist as an ally
(5) By helping mother understand that her influence was important for child’s growth and development

Mother was also oriented about how mood, thoughts, behavior and health are related and discussed physical and emotional aspect of being in stress. Need to have a healthy diet as it affects mood and health, good sleep hygiene and its purpose in relation to health, importance of time-off from work for her as excessive work related pressure can lead to burnout in her which would have direct effect on her relationship with the child.

The last phase of intervention with mother focused on discussing with mother physical, psychological and emotional changes a child go through during adolescent and frequent mood changes which could be a way to react to stressful situations. Giving them more freedom and independence but not giving in to his unreasonable demands rather than having positive and negative consequences for it. Discussed with mother how to negotiate with the child to reach a compromise. One of the effective way to do that could be sign a written contract that the compromise which makes both mother-child accountable to effectively implement it. Emphasize on the need for the mother to find time to connect privately with the child to enhance her bonding with the child.

During session with mother also discussed how child’s mental health was being affected by the conflict between family members. The therapist has acknowledge that no relationship was entirely free from conflict and disagreements but when family members become physically aggressive towards each other during arguments, raise their voices and involve in verbally insult each other it may take emotional toll on children even though they are not directly experiencing it. Child’s mother readily agreed to talk about it with her siblings.

The sessions also focused on educating mother about nature of seizures child had, triggers for seizures, need for long-term medication, some of the common side-effects of anti-epileptic medicines as well as safety and injury prevention during the time of seizures.

In co-joint session with mother and son, provided examples when it was necessary to disclose about child having seizures (e.g. going on a school trip, participating in sports activities and taking medication during school). Discuss the risks and benefits of disclosing about seizures. Through case vignette and role play showed what to tell, how to tell and whom to tell about child having epilepsy.

One of the limitation was child and mother were focused of intervention though there were many other environmental factors which was affecting child’s relationship with his extended family members.

**Outcome of the Intervention:**

At the end of therapy, K’s mother understood need to become more emphatic in recognizing and responding to her son’s need for affection and comfort from her and, in the process maintain a nurturing and authoritative parental role. The child was much more positive about his mother and more supportive about giving her more “emotional space”. Both mother and son expressed...
their happiness and satisfaction as with the intervention they got to know the fact of the illness, it can be controlled by proper medication adherence and lifestyle modification which needed to be made since the onset of seizures.

Conclusion:

Parents played the most important role in helping the child with epilepsy to adapt to his/her condition. In practical terms their functions included seeking treatment, ensuring the child’s compliance with treatment, facilitating the child’s functioning in and outside the home, and regulating the impact of other people’s attitudes on the child which requires collaborative relationship of mutual trust between the treating team, the parents and the child. Any intervention focusing children with epilepsy and their parents should keep in mind social ecological model i.e. there was reciprocal relationship between children with epilepsy and systems surrounding them so intervention should integrate psychosocial needs of both parents and children.

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