

Therapeutic support to an Adolescent with Aids dementia : Case Study

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Abstract— The major neurological complications associated with HIV infection include cognitive, behavioral, and motor disturbances, which may range in severity from subtle, mild cognitive deficits to the clinical syndrome referred to as HIV-associated dementia or AIDS dementia complex (ADC).(Rebecca .A. Meehan, PhD et;al, 2001). In this paper, I would like to highlight how the problem behaviors interrupt with the compliance and make socially isolated followed by delay in treatment, thus made difficult to prevent further progression of disease. The aim of the present study is to examine the application of integrative approach to enhance the quality of life in patients with Aids Dementia. A single case pre -and post-design intervention study was adopted. Adolescent suffering from Aids Dementia with presenting problem behaviors was given 8 sessions of comprising Cognitive Retraining, Behavior modification, few techniques from Cognitive therapy(Mistakes in thinking – learning to recognize them). The sessions were conducted once in alternate day for a period of 45 minutes - 1 hour. Child was assessed on CBCL in Pre - Post condition. The resulted psychological profile of the patient was qualitatively analyzed. The pre-assessment showed score of 55 which appeared to be severe level of problem behaviors .The post intervention assessment results indicated the improved quality of life with reduced problem behaviors in turn distress in personal and social life. The results of this study are encouraging and suggest that the therapeutic intervention, would be helpful in improving the patient compliance to the treatment and in turn prevention of disease progressiveness.

Key words: AIDS Dementia, Behavioral problems, Compliance, quality of life

INTRODUCTION

Progress in HIV/AIDS prevention and treatment over the last twenty years has been remarkable. With access to antiretroviral drugs, AIDS has become a chronic condition, even in poorly resourced, hyper-endemic areas (UNAIDS, 2012). AIDS and its associated symptoms, throwing a challenge to the professionals during the treatment process. The HIV/AIDS pandemic has severely impacted the mental health of children and families worldwide. According to the (WHO 2011) , 34 million people were living with AIDS by the end of 2010, Reported to be most of them were women and children. According to UNAIDS - 36.7 million [34.0 million–39.8 million] people globally were living with HIV (end 2015).AIDS is a Biopsychosocial disease whose impact is far beyond of physical symptoms, it's not the diagnosis creating chaos it's the thoughts associated with the diagnosis like negligence, negative expressions, fear of rejection, isolation, stigma, lack of awareness about the disease and resources available.

HIV and Neurocognition :

The primary targets for HIV infection of the central nervous system are the microglia and microphages.

HIV neurotoxicity has the ability of inflammatory factors that cause neuronal cell damage and death. Two types of encephalopathy has been characterized in adolescents with HIV and CNS involvement. (Benton TD et;al, 2013) Progressive HIV -1 encephalopathy characterized by the classic triad of a) acquired microcephaly b) delay or loss of developmental milestones (motor, cognitive and language) c) Pyramidal tract motor deficits. Child with encephalopathy would be presenting with average overall intellectual functioning , but with learning difficulties like facing problem in acquainting new skills, which makes them day to day dependent on others and in turn builds under lying low self esteem. Evidence further suggests that higher viral loads are associated with more severe cerebral atrophy (Brouwers et al, 2000). Untreated HIV infection in children has been associated with cognitive, motor, language, and psychological developmental deficits (Smith et al, 2006).

Behavioral psychopathology :

The pattern of behaviors exhibited is depending on the developmental stage of the brain when the infection get progresses. During the developmental stages the brain is immature which when gets effected leads to passive in learning and adapting the skills. Slowly the viral load gets active then it suppresses the plasticity of the brain and due

to the neuronal cell death some of the previous learned behaviors might get impaired and reacting instead of responding starts to visible like externalizing behaviors. As the child transforms into an adolescent, in a normal case self identity would be prominence and like to explore new things, wants to prove themselves as an individualistic personality, which develops in to an entity from past experiences and memories. Adolescent tries to be independent in taking decisions during the crisis, but when the infection progresses the flavor of the adolescence features gets fogged being dependent on others for his needs. His ambitions becomes unrealistic and difficult to achievable. To reach immediate goals like self care e.t.c also becomes big deal. The disparity between before and after the infection about himself results in despair.

Neuro-pathogenesis:

The pattern of the disease depends on the stage of brain development when HIV infection occurs. As highlighted already, neurocognitive developmental delays may be due to the direct effect of HIV, antiretroviral toxicity, or psychological and socioeconomic factors (Willen, 2006). A difference between adult and child (especially children under 1 year of age) is that CNS disease from HIV in children occurs more often before there is significant immunosuppression. As a result of improved treatment, children are surviving into adolescence and neurocognitive deficits are now being noted. Adolescence is a critical period for brain development, nerve myelination and synaptic pruning—neural processes crucial for higher order functions (e.g., efficient information processing, decision making). The HIV virus affects subcortical white matter and frontostriatal systems that are important for the regulation of emotions and behavior, increasing the risk in adolescence of impaired decision making, poor impulse control, risky sexual behavior, and aggression. Among adolescents who acquire HIV disease through risky behaviors or transfusions, antiretrovirals have prolonged survival. However, adolescents living longer with HIV are more likely to experience CNS sequela including attention, memory and cognitive processing deficits. Similar to adults, adolescents who develop AIDS show late neurocognitive changes with progressive bradykinesia, spasticity, and hallucinations (Watkins et al, 2000).

Although the HIV-associated dementia found in adults has not been well described in adolescents, recent case studies describing dementia in adolescents suggest that this syndrome may be observed more frequently in the future (Scharko et al, 2006).

Global Factors : Social

Neurocognitive developmental delays may be due to multiple factors such as the direct effect of HIV, antiretroviral drugs toxicity, or psychological and socioeconomic factors (Willen, 2006). Many infected children may have no medical symptoms and their developmental progress may be more influenced by poverty and a lack of resources than the infection itself. For those presenting with behavioral and developmental symptoms, the specific etiology of these symptoms is often unclear. The determination of whether a child's neuro-behavioral deficit is related to HIV—as opposed to other environmental, social or medical reasons—is critical because of its implications for treatment.

Globally, the social context of many HIV positive children includes poverty, low socioeconomic status, lack of resources, and family losses interacting with environmental stressors and neglect. Low levels of maternal literacy, poor quality of interaction between caregivers and child, low birth weight and anemia are often more frequent in HIV-positive children (Brown et al, 2000)

For adolescents, prevention of CNS disease requires adherence to antiretroviral therapy, which can be challenging for them. Poor adherence to anti-retroviral's, which can require multiple doses daily, can lead to resistance, higher viral loads, and increased susceptibility to CNS infection.

Method

Participants information

Child named 'S' aged about 14 years, male, Muslim, diagnosed Z+ve, hails from Middle socio economic strata, urban back ground brought by NGO with the **Presenting complaints** of severe pain in Lower limbs, Bladder and bowel incontinence (since 1 year), memory impairment, Behavioral problems(since 4months) with insidious onset course continuous and progress deteriorating. Child was under ART(Anti Retroviral therapy) with irregular compliance.

Child was admitted with the above complaints in the hospital. He came in wheel chair, not able to walk, unable to unfold the legs and screamed at people when tried to make him rest on the bed, when asked child complained about the severe pain in the knees of lower limbs, so not

allowing others to touch them. Refluxes were present . Child was on diaper due to not able to control in passing urine and motion.

Child was observed to be not paying attention to what others said and asked to do . Speech is Incoherent and reaction time is fast. Child found to be talking to everyone with poor social inhibition and if they won't respond properly he abuses them badly. The people who responds , he asks them saying "naam kya hai, haath milao" and kisses them on their hands repeatedly,(even if we sit for longer time) it reported to be with women frequently. He repeatedly asks the names or the instructions what others said even in immediate situations. Because of this behavior and abusing others people got scared to go near by him. Even the care takers used to be away from him.

During the admission child was observed to be talking to himself and sometimes muttering behavior. The same was inquired with the NGO and they replied " we are seeing it from last couple of days".

Child sleep pattern was normal but sometimes used to say about vivid dreams in which he can see his mother and father talking to him. Childs appetite is normal and likes to eat " ghosh " everyday.

When inquired about the parents he showed the photo frame in which 3 of them were present. He forgot about the death of his father and mother.

Child was not able to say where he stayed , NGO name , care takers names but he could recognize them.

According to the NGO people mother got diagnosed Z+ ve during her delivery but did not use the medication. No information about complete birth history due to lack of primary care givers. When parents got diagnosed, relatives from both the sides abandoned them completely.

Child was reported to be normal in growth and development and studied up to 5th grade. Father died at the age of 7- 8 years of child age with the progression of disease. After some years mother condition got deteriorated so with the help of community people child at the age of 12 years was adopted by the NGO and started (Anti retroviral therapy)ART treatment (6-8

months? irregular compliance) .Mother died after some period and child was taken to the rituals , but at present he could not remember. Child continued the medication with irregular compliance . Slowly he started developing pain in lower limbs , bowel and bladder incontinence since 1 year i.e 2016 became dependent on others for self care. Since 4 months child started forgetting names of the people , food he takes ,

place he lived and so on ..with the abnormal behavior of kissing and abusing. Since couple of days he started talking to himself and muttering behavior. With the above complaints people from NGO admitted the child for supportive care.

There is no history suggestive of seizures, high grade fever, head injury, spinal cord injury , tumours.

Child's CT FLAIR and T2- weighted images demonstrate ill- defined symmetric white matter abnormalities consistent with HIV associated Dementia. Child is under medical treatment and started Physiotherapy with simple exercises in Hospital. Child's Family history suggestive of father and mother used to live in joint family before his birth but when they got diagnosed during pregnancy All the relatives from both the sides abandoned them . Father and mother died with Z +ve. Care takers were arranged by the NGO according to them his maternal grandmother is in Goa and the paternal side relatives were not bothered .Birth and

development history were not known exactly, family history of both the parents died with Z+ve and now the caregivers were people from NGO.

on **MSE** (mental status examination) rapport was easily established ,Speech was incoherent, reaction time was fast, productivity was high and Psychomotor activity was Observed fidgeting with his hands. On Mood and Affect ,Objectively – labile, In cognition orientation to place person time were absent . Attention was aroused but could not sustained. Recent , Remote and delayed memory were impaired. General information was impaired ,conceptual understanding was impaired. Understanding the clinical history and MSE and CT reports, provisional diagnosis was **Aids Dementia with behavioral problems** with poor prognosis. Cognitive retraining , Behavioral therapy, Cognitive therapy techniques were planned to target the behavioral problems and also to enhance the medical compliance.

Measures :

CBCL : The CBCL is a paper and pencil instrument with excellent psychometric properties. Good convergence between structured interview-derived diagnostic categories and syndrome-congruent CBCL scales has been well documented . The CBCL contains broad-band Internalizing and Externalizing scales that largely correspond to mood and anxiety disorders and disruptive behavior disorders, respectively, they can be particularly suitable for the investigation of whether they can predict divergent patterns of risk from early childhood to adolescent years in

children at risk. That is, broad behavioral conditions in early childhood may be predictors of later, more specific psychopathology. If effective in predicting psychopathological outcomes, the CBCL would be an inexpensive method for identifying at-risk children in need of preventative or early intervention strategies. The cutoff scores for girls and boys were given separately. (Carter R. Petty, M.A. et; al, J Anxiety Disord. 2008) Table - A : Cutoff scores

Age	Girls	Boys
4-5	42	42
6-11	37	40
12-16	37	38

Design:

A single case experimental design with pre- and post-assessment was used, to evaluate the changes in the patient in response to the intervention.

Procedure :

Data were collected at two points, The first was the baseline assessment , conducted during the admission with the help of caregiver from NGO. Person was explained about the need of conducting the assessment and was asked to give answers 0- not at all , 1- sometimes , 2 - frequently to each question. . Sessions were planned for a period of 45 minutes every day, along with the physiotherapy and other recreational activities, After the 8 sessions again the same scale was conducted to check the symptoms which were rated 2 in the pre assessment

RESULTS

The psychological profile obtained from the base line assessment revealed increased levels of behavioral problems i.e score obtained was 55 which is above the cut off score. The post- assessment results, post the completion of intervention revealed marked improvement on the same assessments i.e insignificant levels on the reported problem behavior, was reported the score of 27 which is below the cut off scores according to the age of the child.

Content of the intervention : Evidence based intervention
 Therapy was intended to improve his quality of life by building trust and facilitating to explore Table - B

Short term goals	Long term goals
<ul style="list-style-type: none"> • Building relationships • Improve sustained attention • Modifying his behaviors • Improving medical compliance 	To become independent

Therapeutic techniques Cognitive retraining Attention enhancement :

- Beads and thread
- Sorting of beads
- Disc board
- Segregating tokens
- Finger dexterity board with Tweezers

Memory retraining :

- Familiarization
- Simplification and symbolization

Behavioral therapy

- Play therapy

Cognitive therapy (Mistakes in thinking -learning to recognize them)

- Good and Bad
- Positive and Negative

Therapeutic session - 1

Behavior modification – Applied behavior analysis

ABA is an approach to learning that focuses on the acquisition of skills to enhance attention, communication, imitation, play, activities of daily living, and socialization.

Functional analysis –

Child was observed for 1 hour during admission through indirect contact

- Restlessness
- Aggression – getting irritated if it is against to him
- Stubborn - not listening to others, does according to him
- Abusive words – if no one responding to him
- Abnormal behaviors – kissing on hands – 6- 7 times for

same person (2)

- Affect – labile , laughs for no reason and enacts as feeling sad by bending his head ...

Table - C - ABC approach

Antecedent	Behavior	Consequences
When people were not responding	Abusive words	No acceptance from others – its repeating
If responding	Not leaving hand and kissing	seeking nurturance and showing love in his way

Therapeutic session - 2 & 3

- Touch therapy – showing I have concern, building trust

Negative reinforcement (mutual contract) – kissing behavior = No one will come

- Scheduled time – to meet and talk (during beginning 2- 3 days he was repeatedly explained)

Cognitive retraining :

Attention enhancement -

- a)Beads were given to segregate – 1 color from 50 beads
- b)Disc board – Discs were asked to place in right side rod of the stand with right hand repeat same with the left hand. Now in opposite direction.

Memory retraining : Familiarization :

Associated with some names of his choice to the people.

Behavior therapy

- Play therapy- reduce externalizing behaviors and increase child's social skills and cooperation To understand his feelings To reduce his impulsive behaviors
- Hand puppets (family)- Therapist narrated about her family. he took the puppets and was interested in mother puppet. But didn't say anything.

Therapeutic session - 4&5

Cognitive retraining

- a) Attention enhancement : Beads were given to segregate – 1 color from 75 beads
- b) Disc board – same as previous day
- c) Finger dexterity exercises using board with pins and Tweezers - asked to set pins of 30 using tweezers with both the hands using alternatively.

Memory retraining

- Familiarization : Continued to do the same with 4 people
- Cuing – visual 2

Behavior therapy

Play therapy – puppets were given to explore.

Therapist – yeh tho mother doll haina

Child - he replied with low voice “ ammi mujhe bahuth pyar karthi hain ”

Therapist -aur aap

Child- “ Main bhi vunse bhahuth pyar kartha hoon ”

Therapist - What about this father doll dekho aapko dekh raha hain

Child-“gaaliya detha hain mere ammi ko, aur maartha bhi hain tho meri ammi bahar bhagthi hain”

Therapeutic session - 6

Cognitive retraining

- a) Attention enhancement : Beads were given to segregate – 1 color from 100 beads
- b) Tokens – Different colors of tokens were asked to give to different people who were there with him
- c) Finger dexterity exercises using board with pins and Tweezers - asked to set pins of 50 using tweezers with both the hands using alternatively. Asked to take out the pins from the board using Tweezers.

Memory retraining

- Familiarization : He started calling me and inquiring about me with others (name of his choice)
- Cuing – visual 3

Cognitive therapy

During the session he started abusing opposite patient I did not interrupt and asked

Therapist – What are those words

Child – gaaliyan ... laugh

Therapist - What is gaaliyan .. I don't know can you please tell me ?

Child – Laughed at me and said yeh bhi patha nahi hain – gussa aaya tho aise karthe hain

Therapist – Who said that

Child – Mere abba – ammi ko aise hi datthe hain

Therapist – Aapko acha lagtha hain abba aise karthe hain tho ?

Child – Nahi ...

Therapist – Kyun .. Kyan lagtha hain

Child – Bhura lagtha hain

Therapist - Aur

Child – Ammi bhauth rothi hain tho vunhe dekh ke rona aatha hain

Therapist – Ammi rothi hain kyunki vunhe acha nahi lagtha... haina

Child – Haan

Therapist – Abhi aap vunhe daat rahe the tho vusko kya lagtha hoga na

Child – woh aisi dekhthi rahthi hain .. Bath nahi karthi

Therapist – Vusko tho bhura laga na .. Dekho kaise dekh rahi hain .. Poocho abhi kyun bath nahi kar rahi aapse
(he asked that lady and she replied I don't know Hindi)

Therapist – Ab samjhe tho sorry bhool dheerjiye

Child – He said sorry

After this session under observation slowly he stopped abusing others

Therapeutic session - 7

Cognitive retraining

- Attention enhancement : Beads were given to segregate – 2 colors from 75 beads
- Tokens – repeated the same
- Finger dexterity exercises using board with pins and Tweezers - asked to set pins of 60 using tweezers with both the hands using alternatively. Asked to take out the pins from the board using Tweezers.

Memory retraining

- Familiarization : Familiarity with unfamiliar people
- Cuing - visual – 4

Behavior therapy -

- Play therapy- asked him to enact something ... he did as he was eating ghosh – leg pieces and biryani We asked other than ghosh what do you like to have ..he said Tea and biscuit – provided the same and he felt very happy

Therapeutic session - 8

Cognitive therapy

Therapist – showing opposite patient - Now you both became best friends

Child – Everyone is good

Therapist – What made you to feel that ?

Child – sab log ache bath kar rahe hain

Therapist – Aapko acha lag raha hain

Child - haan

Therapist - Aap bhi sabse acha bath kar rahe ho ..hum ko bhi acha lag raha hain

Therapist – main aap se ek bath pooch na chahthi hoon ? Shadi kya hain

Child – Shadi Ladka ladki karthe haina .. Cinema mein dikhathe hain (laugh)

Therapist – Kab karna hain

Child – Bade hokar

Therapist – Kithna bada .. Aapke hisaab se aap kab kar sakhthe hain (he showed height)

Therapist – Abhi aap ko time hain kya

Child – abhi time hain ...abhi tho ithna hi hoon na (showed his height)

Therapist – aap phir bhar bhar sisters se kyu pooch rahe hain ... wah sahi baath hain kya

Child - Silence

Therapist – Aap pehle teek hojav aur bade hojav thab sochenge ..teek

haina ... mein kuch galath bholi

Child – nahi sahi bath hain ... sisters ko sorry

Cognitive retraining

- Attention enhancement : Beads were given to segregate – 2 colors from 100 beads
- Disc board – Discs were asked to place in right side rod of the stand with right hand repeat same with the left hand. Now in opposite direction. (in a time of 5 minutes - he could complete it in 4minutes 51seconds)
- Finger dexterity exercises using board with

pins and Tweezers - asked to set pins of 80 using tweezers with both the hands using alternatively. Asked to take out the pins from the board using Tweezers.

Memory retraining

He could recognize 5 people with names (of his choice)

Cuing – he could recall 5 things names

DISCUSSION :

Child was observed to be inattentive during the beginning days in the aspects of listening to the instructions, when asked to take medicines e.t.c It was really challenging to the professionals to make him compliance to the treatment. Calls everyone and if anyone responds used to catch hold of them by asking to give shake hand and would not leave them by engaging in some conversation. This behavior was observed to be with the of intention seeking for nurturance which he could not experience it completely during his developmental stages.Early relationships are dyadic i.e, Every child experience a range of caring relationships which will become the experience to care for others (Vygotsky - relational model). The early internalized relationship patterns are then enacted again and again, throughout one's life time with both others , and with oneself. The child learns how to elicit "caring" responses , in order to feel "cared for" in turn. But when the child internalized harsh and punitive relationship patterns which will affect the way the child relates to both others and himself. Participant of this study who was reportedly does well up to 5th grade with average performance but the deterioration started slowly as the social issues like poverty , death of a care givers, social isolation , poor nutrition which became the mediators to progress his disease. Experiences from poor parenting like abused father resulted in "familiar" and "automatic" Reciprocal roles. If we get back to the presenting complaints duration i.e since 4 months child has the difficulty with memory and appropriate behavior which could be the progression of disease and also kind of learned behavior . During the period when he became completely dependent on others the behavior might be enacted again and again to meet his needs . Understanding the intention or the resultant of the behavioral responses and using techniques according to the child, was the key feature to succeed in the intervention which helped the child to improve compliance to the treatment.

Conclusion

Therapy was effective in providing the child to follow the medications which in turn helped to prevent the progression of disease .Child also tried to modify his

behaviors in understanding what helps to meet his intention .Child was able to recognize 5 people with names , 5 things with cuing , learned to improve his social skills, problematic behaviors were subsided, improved medical compliance , following oral commands . This therapy made him to experience the acceptance and affection by Positively relating to others.

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