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RESEARCH ARTICLE

PSYCHOSOCIAL IMPACT IN CHILDREN WITH HIV INFECTION

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ABSTRACT

Objective: The objective of the present study was to assess the psychological impact of children living with HIV/AIDS in India

Materials and Method: A group of 23 children ranging from 11 to 15 years with confirmed diagnosis of HIV were part of the study. Children were divided into 2 groups with 11 in group 1 and 12 children in group 2. A structured in-depth interview and focused group discussion (FGD) were used to assess the psycho-social impact in children. Group 1 underwent in-depth interview and group 2 underwent FGD.

Results: The mean age of participants was 13.6 ±1.6 years; most of the children completed primary education. All children belonged to the lower socio economic status, 87.5% of the children hailed from rural area while 9.1 % of them were urban background, 3 % of the children had mixed exposure. 72.7% were male 27.3% were female. The major psychosocial impacts expressed by children were emotional, behavioural and cognitive. Other than psychological, majority also expressed their physical restrictions.

Conclusion: The psychosocial impacts and physical restrictions by the infected children were specific to the socio cultural back ground. The results of the present study emphasis on the specific assessment protocol, rather than a generalised assessment tool for better intervention

INTRODUCTION

Children and families infected with HIV/AIDS have continued to be a significant public health Challenge. (Punpanich, Detels, Gorbach, & Leowsrisook, 2008). Though the disease was thought to be fatal, availability and accessibility of anti-retroviral therapy made HIV disease, as a chronic disease course than an imminently fatal (Ainsworth, Beyrer, & Soucat, 2003; Chandeying, 2005; Punpanich, Ungchusak, & Detels, 2004). The effectiveness of the medical intervention such as antiretroviral therapy extends the lifespan up to 30 - 50 years post infection which was not a case a decade ago(Collaboration, 2008). The intervention is effectively aiding individuals survive into adolescence in significant numbers, with better clinical and nutritional status(Sutcliffe, van Dijk, Bolton, Persaud, & Moss, 2008). Although treatment programs have not been able to eradicate the virus and cure the disease, the increased course of chronic illness, children are at increased risk of developing social, physical, and psychological challenges as well (Capaldini, 1999; Huurre & Aro, 2002; Tate *et al*., 2003).In addition to the health and treatment related challenges, adolescents born with HIV/AIDS have to learn to cope with the effect of HIV on normal developmental Challenges, including pubertal delays (Buchacz *et al*., 2003), neurodevelopmental and cognitive problems (Brackis-Cott, Kang, Dolezal, Abrams, & Mellins, 2009; Nozyce *et al*. 2006), and a tendency for greater social and emotional immaturity as compared to peers (Donenberg, 2005). Apart from the developmental challenges, epidemiology of paediatric HIV diseases places the children at risk for psychosocial and behavioural problems. On the other hand HIV-infected persons, as other as patients with chronic medical disorders, are at increased risk for specific psychiatric and psychosocial problems (Capaldini, 1999; Lichtenstein, Laska, & Clair, 2002; Tate *et al*. 2003; Wachsler-Felder & Golden, 2002). Lower self-esteem, poorer body-image and psychological well-being, behaviour and social adjustment problem are the impact on the children with chronic illnesses (Huurre & Aro, 2002). The number of children living with HIV infection and AIDS are on the rise with the availability of medical intervention.

Psychosocial impacts in individuals with HIV infection have been extensively reported in the literature. Emotional and behavioural problems have been the primary psychological impact. Most of the available literature reporting the psychological issues has predominantly reported the environmental influence on psychological wellbeing. The environmental changes and the treatment protocol will be

significantly influencing the outcome results. Hence it is very important to understand the specific demands or psychological support for the individuals. In this context understanding the psychosocial needs of children in Indian context is vital. The present study will focus on identifying the psychosocial need of children/adolescent in Indian context.

MATERIALS AND METHODS

Participants

This study aimed at assessing the psychosocial impact of children with vertical HIV infection. The participants were recruited from Karnataka positive network (KNP+), Karnataka. These children were recruited based on the registry maintained by the organization which has been maintained from the year of 2005. 109 children were listed in the registry. Convenience sampling was adopted for this study. Among 20 children 11 children were consented to take part in interview. Interview was conducted with 11 children and each interview lasted for 45 minutes to an hour.

Procedure

The medium of interview was in Kannada or Tamil language depending on the preference of the individual. Approximately 2 -3 children were interviewed in a day. In some of the interviews children were accompanied by a parent and at times field worker or programme coordinator of the organization. Interview was held at the organization itself with following inclusion criteria (1) having a diagnosis of HIV-infection made at Integrated Counselling and Testing Centre (2) those who have been availing services for minimum of one year at the NGO (3) who were on ART (4) Both genders (5) Age group of 11 – 15 years (6) parent consent (7) verbal assent from children (8) Kannada and Tamil speakers. Terminally ill, children with developmental disability, Children living with both parents and children from the same family were excluded from the study. The purpose of the study was explained to children and their parents and strict confidentiality was assured. All participants completed a questionnaire on sociodemographic characteristics. Participants were reimbursed for their transportation. This study approved by the ethics committee of National Institute of mental health and Neuro Sciences, Bangalore, India.

The appropriate psychosocial intervention was given for the disturbed children in the process of interview. The focus group discussion conducted to validate the information obtained from the in - depth interviews and confirm the saturation of the information. Participants were from the same organization, who met the above mentioned inclusion and exclusion criteria. The appropriate psychosocial intervention was given for the disturbed children in the process of FGD. 12 children participated in the FGD it was audio taped. The response of the individual form in-depth interview was validated in FGD. Development of a semi-structured interview guide involved the process of literature review on psychosocial impact of HIV among infected children and input from the mental health professionals working in the field of HIV/AIDS. Interview guide were prepared for in-depth interview. Which consist of 10 questions for the target audience. Which was face validated with the experts and the mental health professionals. These questions were to identify the psychosocial impact of HIV infection. Minor changes were made in the interview guide during the pilot study on 3 children who were not included in the main study. Face to face interviews were conducted and responses were audio recorded and transcribed.

Analysis

The accuracy of all the transcripts was ensured by validating the recordings by the second author. Field notes taken after the interview and data-set transcripts were considered as the final material for analysis. Thematic analysis approach was adopted and data was manually analysed. This approach involves getting familiarized with the data through an iterative process of reading the data-set transcripts, generating initial codes, arranging codes into larger categories, drawing connections between codes and categories until generation of a saturated thematic map of the analysis (Braun & Clarke, 2006). Initially the transcripts were coded and emerging themes relevant to the research question were identified. In the first phase, discrepancies in coding were discussed and resolved by consensus of the first and the second expert. The codes and categories were revised and refined through the discussion with an expert panel in the second phase. Quotes from the participants were provided in support of the identified themes for easy reading which were slightly edited. Maximum efforts were made not to substantially alter the contents of the quotes.

RESULTS

Socio-demographic profile

All participants (100%) were currently on ARV treatment and regular follow up, vertically infected and having single parent. The mean age of participants was 13.64 ±1.62 years; most of the children completed primary education (8th standard). All children belonged to the lower socio economic status with mean annual family income of 19,090 INR. 72.7% were male 27.3% female. 90.9 % of them were from rural 9.1 % of them were urban background. All participants are living with their mother.

Impact of HIV Infection

In the process of narrating the impact of HIV infection, physical and psychological impact was expounded by the children.

Emotional Impact

Emotional difficulties of the infected children had high impact on day to day affairs, especially the school going children, who did not disclose their HIV status outside their home.They feared discrimination and isolation from their peers if disclosed. These children restricted themselves in socialization with their peers.

Narration of a 14 year old girlon her emotional impact,

"I frequently thought about my HIV infection which made me feel unhappy, hopeless and fear full that others may come to know about my HIV status. It takes 2-3 days to become normal if get disturbed and I am not happy like others. My friends speak with others happily and able laugh crack jokes whereas I could not do that"

Narration of a 12 year old boy on his emotional impact,

A 12 year boy said that "most of the time feeling lonely, not worthy like others though I feel I have some potentials" other child narrated that "we are in the need of constant emotional support and very often feeling like to cry and I have lot of

apprehension about future which constantly create a fear in us""

Narration of a 13 year old boy on his emotional impact

"I have unresolved anger on the society because of no fault I am discriminated. My inabilities to participate in certain activities make me feel angry towards myself and sometime feeling guilty because I am burden for my family. I need somebody to share my feeling and my mother is the only person who is genuinely listening my concern, I feel sometimes my teacher is sympathetic and discriminating me" another girl expressed.

Behavioral Impact

Parents of these vertically infected children were not trained in handling the problems of children, which made them to feel sometime that they need someone to address their problem. Frequent disturbances in the behaviours of children affected the treatment; daily routine. Not interacting with others was a predominant behavioural manifestation of HIV infected children.

Narration of a child

"*I do not take medicines that is the only way I can show my anger towards myself and I know that it is wrong and has significant negative impact on my health*" *"I don't feel like to take food and do not interact with anyone if I am disturbed, almost all daily routines are disturbed frequently" another 12 year old child reported. "More often I am stuck, non-responsive to any of the stimulus"*

Cognitive Impact

There was negative cognition building up in the children when they face stigma or perceive stigma.
12 year girl said that
"I may die, Should not have born with this illness "
15 year old girl said.
"I frequently thought about HIV infection and was pre - occupied with this thought which was disturbing me in scholastic activities and my daily routine"
12 year old girl said
"I keep forgetting things and think about my future, I ask myself that why am I infected"
13 year old girl said

"I wish that nobody suffer with same illness .I dislike others anticipating fear of getting teased about the infection"

Physical

Their inability to participate in sports, even in normal activity like other students was influencing their psycho social wellbeing.

When a child speak about his physical activity he said that
"I am not able to play in school like others; always I am slow but other students run and go out of the class when the bell rings"

Other child spelled out that "I can't function like others and I should get rid of this virus"

"I wanted to perform well academically as well as in extracurricular activities but my body is not cooperating"

FGD Responses

The themes emerged from key informant interview were validated through focused group discussion. FGD was conducted with12 children who were demographically matched; these children were different from the in-depth interview. In the process of FGD the emotional and behavioural issues, cognitive difficulties frequently raised by the participants which were concurred by the majority of children by the group were validated. The details of the subsects of the emotional, behavioural, cognitive and behavioural impact are illustrated.

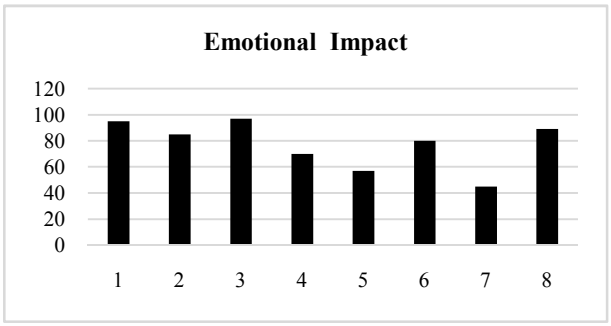

Figure 1 Emotional impact of infected children. X-axis refers the problems encountered by the respondent while Y-axis refers the percentage of agreed responses

X axis parameters: 1. It takes 2-3 days to become normal if get disturbed 2. Not happy like others, hopeless 3. Constant emotional support needed 4. Feeling to cry a lot 5. Fear about future 6. Feeling sad, Hopeless, loneliness 7. Feel disturbed when some of the activities are not able to perform 8. Get angry towards my self

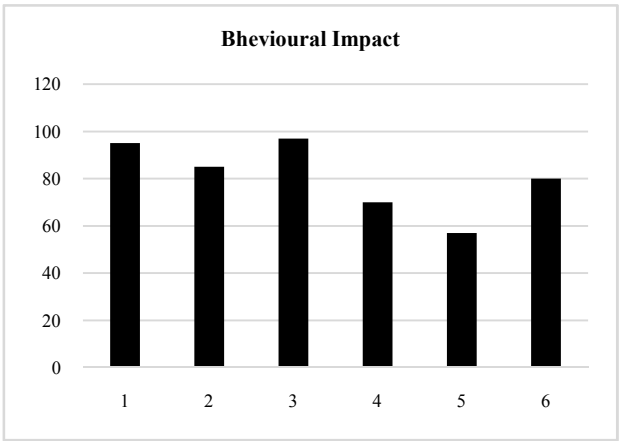

Figure 2 Behavioural impact of infected children. X-axis refers the problems encountered by the respondent while Y-axis refers the percentage of agreed responses

X axis parameters: 1. do not take medicines, food, do not interact with anyone if I am disturbed 2.Sick role played by the children 3. Not able to interact with others, not interested to go toschool4. Prefer to be alone at extreme emotional difficulties 5. Daily routines are disturbed Frequently 6. Not responding at times due to preoccupation

X axis parameters: 1. I may die 2. Shouldn't have born 3. Frequently thought about HIV infection 4. Preoccupation 5. Others should not suffer like this 6. Others may tease me 7. Don't like others 8. Keep forgetting things 9. I think a lot 10. Why did I get infected?

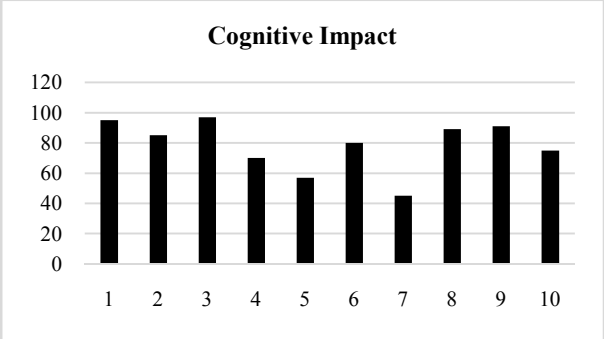

Figure 3 Cognitive impact of infected children. X-axis refers the problems encountered by the respondent while Y-axis refers the percentage of agreed responses

X axis parameters: 1. I may die 2. Shouldn't have born 3. Frequently thought about HIV infection 4. Preoccupation 5. Others should not suffer like this 6. Others may tease me 7. Don't like others 8. Keep forgetting things 9. I think a lot 10. Why did I get infected?

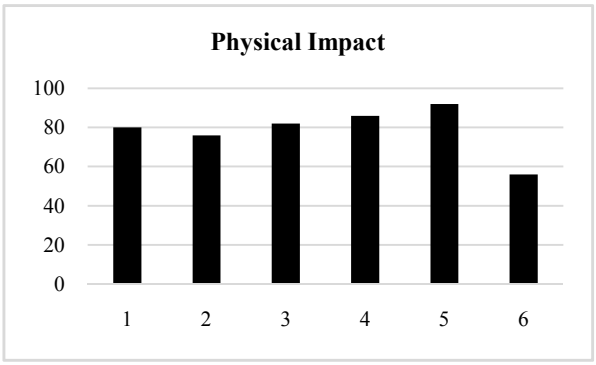

Figure 4 Cognitive impact of infected children. X-axis refers the problems encountered by the respondent while Y-axis refers the percentage of agreed responses

X axis parameters: 1. not able to participate in sports and games 2. Slow in doing things 3. Physical activities are less 4. Not able to function like others 5. Physically not active 6. Not able to get up early to read

DISCUSSION

There are few studies that have adapted qualitative approach in India to understand the psychosocial issues of HIV infected children. The socio demographic profile of the Children shows that the majority of the respondents are from rural area. Reason for the rural people being majority was the NGO's operating location. The male respondents are vast majority because the parents could not bring female child as they are engaged in the house hold activities.

Psychological impact could be due to the unfavourable family atmosphere such as parental distress of HIV infected children (Wiener, Vasquez, and Battles, 2000), aging parent and their HIV illness(Solomon, O'Brien, Wilkins, & Gervais, 2014), possibility of death of the parents, increased burden of adult caregivingare significantly affecting the normal growth of the children(Murphy, Roberts, & Herbeck, 2013).On the whole familial and environmental conditions, negatively affect their quality of life, thereby contributing to increased risk for behavioural problems (Bomba *et al*., 2010).

Perceived stigma plays a vital role in the psychological wellbeing. Most of the children did not disclose their HIV status outside the family, though they fear of discrimination which made them prevent from interaction with their peers this findings collaborated with the study done by Subramanian, Gupte, Dorairaj, Periannan, & Mathai, (2009). They also established that perceived stigma is more compared to the actual stigma.

Studies also demonstrated that children with HIV are more likely to experience maladjustment with respect to their emotional and activity spheres (Thomaidis, 2010). The children expressed the negative cognition which clearly indicates the depressive symptoms. Most of the children fall under the sub clinical population if at all they meet the diagnostic criteria. Various studies have linked HIV/AIDS with depressive symptoms (Capaldini, 1999; Lichtenstein, Laska & Clair, 2002; Tate *et al*., 2003; Wachsler-Felder & Golden, 2002).

The physical impact significantly contribute to the psychological impact in the current study children expressed the reason for that they have demotivation to participate in the extracurricular activities due to the physical restrictions. It could be concluded that the physical impact was directly proportional to the psychological impact. The immediate family members could be trained to handle the adverse psychological effect of HIV infected children.

CONCLUSION

The results of the present study signify the specific psycho social impacts on children with HIV. The broad spectrum of emotional, behavioural, physical and cognitive impacts of the western literature was not applicable for Indian context. The environmental under which the children are had a significant influence on their psycho social wellbeing. Some of the important issues reported by the children were fear of physical weakness, negative cognition, perceived stigma, poor social support and anticipation of isolation. The results of the present study should be carefully considered in developing a intervention plan for infected individuals in Indian context. Some of the issues addressed in western literature are not applicable.

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