

Research

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A Study of Psychological Impact of Diagnosis of HIV in Children and Adolescents in Indian Population

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Objectives: To identify psychosocial impact in children and adolescents infected with HIV with a view to improve counselling and minimize impact of HIV and improve their quality of life.

Material and Methods: This was a cross-sectional study, conducted at a tertiary care hospital among 100 consecutively enrolled HIV infected children between 10 and 18 years of age. A detailed interview on a pretested questionnaire was conducted, which include child's personal history, knowledge of HIV, psychological concern, behavioral problems on an observation scale. Misconceptions and ignorance about the HIV/AIDS were clarified to the respondents, using this session as an educational tool also.

Result: Mean age of study population was 13.8 years with male: female ratio of 0.8:1. Only 65% respondents knew about their HIV status and only 14% had knowledge about mode of spread and prevention. 33 children complained of frequent sicknesses, 23 had feeling of anger, 19 isolation tendencies, 15 were fearful, 12 lost their confidence and 14 children were unable to concentrate on study. 29 children had a feeling of stigma towards HIV, 10 felt discriminated by classmates and community. History of sexual exploitation was given by 6 and bedwetting by 3 children. Thirteen children looked unhappy, 5 felt guilty, 3 were nervous and 1 stared blankly. Majority of respondents (91%) wanted to be a grown up and fight the disease bravely.

Conclusion: 65% respondents knew about their HIV status and 14% had knowledge about HIV. The disclosure of HIV was told to only 65% adolescents and most of them by the doctors. There was a significant psychological impact in form of anger, isolation tendencies, fearfulness, loss of confidence, and suicidal tendencies. We need to provide appropriate counseling, education and creative ways to decrease the psychological impact of HIV/AIDS with a view to improve their quality of life.

KEYWORDS: HIV disclosure; Psycho-social impact; Adolescent counselling.

INTRODUCTION

Children are an ever-growing part of the HIV/AIDS pandemic. As per WHO and UNAIDS 2011 epidemiological update, globally at the end of 2010, an estimated 34 million people were living with HIV.¹ In India, as per National AIDS Control Organization (NACO), an estimated 2.39 million Indians were infected with HIV in 2009, of which, 4.4% were children.²

With the universal availability of Highly Active Antiretroviral Therapy (HAART), HIV is increasingly been recognized as a chronic manageable disease, rather than terminal illness. This transition has led to various psychological, social and behavioural maladjustments, especially in children. Stigma and discrimination, often associated with HIV can lead to exclusion and isolation, deprives children of education, feeling of discrimination by friends, classmates or community and thus affects quality of life. Various psycho-social implications on children include anger, fear, anxiety, depression, grief, guilt and shame, lack of interest in surrounding, loss of confidence, complaining that no one loves, feeling worthless or inferior to others suicidal tendencies, lower cognitive abilities and other behavioural problems.^{3,4} This study was conducted to evaluate psychosocial impact and behavioural changes in children infected with HIV with a view to counsel them appropriately and minimize adverse impact of HIV and improve their quality of life.

MATERIAL AND METHODS

This was a cross-sectional study, conducted at pediatric HIV centre of a tertiary care hospital, among 100 consecutively enrolled HIV infected children between 10 and 18 years of age. The ethical clearance was obtained from the institutional ethical committee. The instrument used was a structured interview schedule in the form of a pretested questionnaire. It was read out to the respondents in the language, they understand and responses were recorded. Prior to beginning the study, a pilot study was carried out to validate the questionnaire. The interview was preceded by an informed consent, obtained from the participants or their attendants. The data were compiled and analyzed. Miscon-

ceptions and ignorance about the HIV/AIDS were clarified to the respondents at the end of the interview, using this session as an educational tool also.

RESULTS

Mean age in the study population was 13.8 years with male: female ratio of 0.8:1. The commonest mode of transmission was vertical from parent-to-child seen in 92% children. 16 children did not attend school, reasons being frequent illnesses of self or family members. Forty seven children were orphans and staying with NGOs and 61 children were on HAART.

a) Respondents' knowledge about HIV: Only 65% children knew their HIV status, of which 36 (55%) children were disclosed by the doctors, 13 (20%) by their parents, 10 by others and 6 of them learned it by themselves. 26 children (40%), who knew their HIV status, felt sad after they were disclosed about the disease. Only 14 children knew about the HIV disease, however details about the nature of the disease and how it spreads was not known to them. 20 children knew the duration of therapy and only 12% knew how to prevent this disease. The knowledge about HIV among the respondents is shown in figure 1.

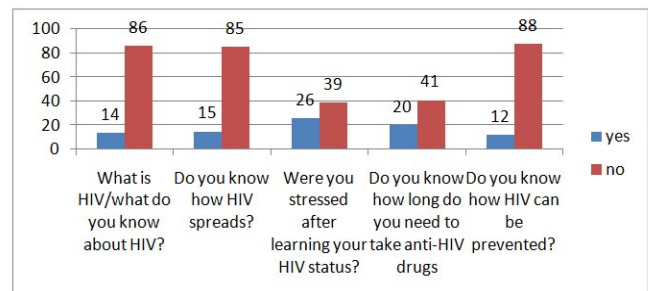


Figure 1: Distribution of respondents' knowledge about HIV.

b) Psychological concern among respondents: Thirty three children often complained of frequent sicknesses, 23 had feeling of anger, 15 were fearful and 14 were unable to concentrate on studies due to self or family sicknesses. Five of the respondents were having suicidal tendencies. (Figure 2)

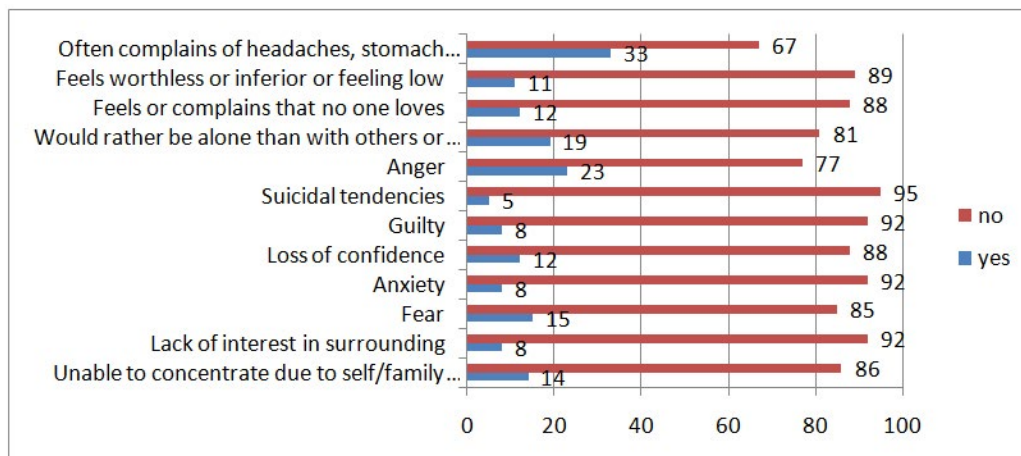


Figure 2: Showing the respondents' psychological concern.

c) Social acceptance of respondents: 29 children have a feeling of stigma towards HIV and the response is shown in table 1.

d) Behavioural problems among respondents: Behavioural problems were not very common in our study. History of involving in sexual activities were given by 6 children, bedwetting by 3 and alcohol and drug consumption in one each.

e) Psychosocial assessment: Most of the respondents had good interaction with the researcher. They were well dressed up and personal hygiene was good. Only 8 children were shy to talk to the researcher, 13 looked unhappy, 5 felt guilty, 3 nervous and 1 stared blankly and the details are shown in table 2.

Self-perception, values and risk factors: Majority of respondents (91%) wanted to be a grown up and fight with the disease bravely and also look after other persons suffering from the disease as shown in table 3.

DISCUSSION

HIV/AIDS is not only threatening the physical health and survival of millions of children, it also destroying their families and depriving them of parental love, care and protection. It has a great negative psychological impact on those infected with the disease in a number of ways. Because of the strong stigma associated with this disease, “stigmatized persons lose their social status, feel discounted and discredited, spoiled and tainted” which affect their social lives, their employment, emotional well-being, and self-perception. These children involve in commercial sex, trafficking, violence, arms conflict, sexual abuse, alcohol and drug consumption, stealing, smoking etc, all of which may be precipitated by economic need, peer pressure, exploitation and lack of supervision. Some studies of street children show that vulnerable children do little to protect themselves from HIV infection because, the pressures for basic survival such as finding food far outweighs the future orientation required to

S. No	Respondents' social acceptance	Yes	No	Total
1	Do you feel HIV as stigma?	29	71	100
2	Do you feel discriminated by family members?	5	95	100
3	Do you feel discriminated by friends during play?	0	100	100
4	Do you feel discriminated by classmates?	2	98	100
5	Do you feel avoided by community/ others?	3	97	100
6	Do you get along with other kids?	97	3	100
7	Do you share readily with other children?	90	10	100
8	How was your interaction with other children in clinic?	89	11	100

Table 1: Showing the respondents' social acceptance.

S. No	Statement	Present	Absent	Total
1	Interaction with examiner	100	0	100
2	Too shy or timid	8	92	100
3	Unhappy or sad, tearful/ cries a lot	13	87	100
4	Nervous, high strung or tense	3	97	100
5	Feels too guilty	5	95	100
6	Poorly coordinated or clumsy	1	99	100
7	Self-conscious	1	99	100
8	Stares blankly	1	99	100
9	Clothes and dressing up	99	1	100
10	Personal cleanliness or hygiene	100	0	100

Table 2: Showing respondents' psycho-social assessment.

S. No	Statement	(a)	(b)	(c)	(d)	(e)	Total
1	I want to become a grown up	4	5	0	47	44	100
2	I can complete tasks	0	2	0	65	33	100
3	I have hope for my future	2	1	2	64	31	100
4	I can influence my future	2	1	2	65	30	100
5	I take care of other people	1	6	2	62	29	100
6	I share feelings with others	13	14	1	65	7	100
7	I am angry with my situation	15	74	0	10	1	100
8	I feel lost because i do not have parents	8	51	0	15	1	100
9	I am afraid that i will be removed from my house/ school/society	18	73	0	7	2	100
10	I want to become doctor	21	26	17	14	22	100

The Scale used for the assessment was as strongly disagree-no as a quick response – (a), Disagree-no as delayed response – (b), Neutral-no response/don't know – (c), Agree- yes as delayed response – (d) and strongly agree-yes as a quick response – (e).

Table 3: showing the assessment of self-perception, values and risk factors.

avoid infection.^{5,6} Being shunned from society can lead to low self esteem, isolation, self-loathing and self deprecation. Children whose families are affected by HIV/AIDS experience severe emotional and psychological distress.² With proper support from their health care providers and community, the challenges of living with childhood HIV/AIDS will be easier to surmount.⁷ These psychological challenges comprises of three general areas: emotional, cognitive and behavioural. Emotionally, the family must accept the child's diagnosis.⁸ Doing so includes grieving the loss of the idea of their once-healthy child, as well as guilt, sadness, and anger. If the child acquired HIV through mother-to-child transmission, the mother may feel enormous guilt and may be blamed by other family members for the child's infection. The cognitive challenge is to educate the child's family about HIV/AIDS.^{9,10}

Disclosure of HIV infection status to children and adolescents should take into consideration their age, psychosocial maturity and complexity of family dynamics.^{11,12} As some family members have been reluctant to discuss the nature of the illness with their infected child, and reasons include concerns about the impact that disclosure¹³ may have on a child's emotional health and fear by the parents that the knowledge will negatively affect a child's will to live, a sense of guilt about having transmitted infection to the child, anger from the child related to knowledge of perinatal transmission, and fear of inadvertent disclosure by the child.¹⁴ Children also may inadvertently learn the nature of their illness in a manner that is not supportive. Studies suggest that children who knew their HIV status have higher self-esteem than children who are unaware of their status.⁶

The disclosure of HIV status in our study was poor and only 65% of the children know their HIV status and the knowledge about the nature of disease was rather much poorer. Studies from the United States in 1999 show that between 25% and 90%

of HIV-infected school-age children have not been told about their infection.¹⁵

In our study the psychological concern was observed in 33 children in form of frequent sicknesses, 19 felt isolated, 15 were fearful and 23% of the children showed feeling of anger, while in similar studies among AIDS orphan just over half of the children (55.5%) say that they are angry about their situation.¹⁶ In our study 9% were afraid of being removed from house/school/society, while in a similar study 45.8% of children are afraid that they will be removed from their home. Behavioural problems in form of substance use, alcohol, and sexual exploitation were common in these children; however in our study these problems were rare.¹¹

Most of the respondents had good interaction with the researcher. They were well dressed up and personal hygiene was good. Regarding self-perception, values and risk factors, majority of respondents (91%) in our study wanted to be a grown up and fight with the disease bravely and also look after other persons suffering from the disease. In a similar study 76.2% children say they take care of themselves, two-thirds (62.8%) say that they take care of others.^{16,17} Results from the present investigation should be interpreted in the context of some possible limitations, due to geographical area of urban population and consequently to the hospital setting.

CONCLUSION

In our study, the disclosure of HIV was known to only 65% adolescents and most of them were disclosed by the doctors. Knowledge about the nature of the disease was not known to most of them. There was a significant psychological impact in form of frequent sicknesses, anger, isolation, fearfulness, loss of confidence, and suicidal tendencies. We need to provide appro-

ropriate counseling, education and creative ways to decrease the psychological impact of HIV/AIDS. Education and support are the most effective tools that help children and adolescents infected with HIV to survive into psychologically healthy adulthood. They can also extend this education to others and help reduce the stigma within their larger communities. Through these changes and the support of family, friends, communities, and health care professionals, these affected children will grow in to tomorrow's happy and healthy adults.

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RG, SS & KS conceived the study. SS & VM involved in data collection, interpretation and VG helped in analysis, and drafting the article. RG & KS supervised the study and revised the manuscript.

ETHICAL CLEARANCE

Obtained from the institutional ethical committee.

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COMPETING INTERESTS: None stated

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