

# **RESEARCH ARTICLE**

#### A CROSS SECTIONAL STUDY OF CHALLENGES AND BARRIERS OF PSYCHO SOCIAL ADJUSTMENT TO HIV POSITIVE STATUS FACED BY HIV POSITIVE ADOLESCENTS IN JAMNAGAR DISTRICT

### Dr. Nilesh Prajapati<sup>1</sup>, Dr. Tejal Khokhar<sup>2</sup> and Dr. Hardik Yagnik<sup>3</sup>

- 1. Assistant Professor, Department of Community Medicine Swaminarayan Institute of Medical Sciences & Research, Kalol, Ghandhinagar, Gujarat.
- 2. Assistant Professor, Department of PrasutiTantra&StreeRoga (PTSR) Ananya College of Ayurveda, Kalol, Ghandhinagar, Gujarat.
- 3. Assistant Professor, Department of Community Medicine Ananyacollege of Medicine & Research, Kalol, Ghandhinagar, Gujarat.

#### ..... Manuscript Info

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Manuscript History Received: 27 June 2023 Final Accepted: 31 July 2023 Published: August 2023

#### Key words:-

Adolescents, HumanImmunodeficiencv Virus, Anti RetroviralTherapy, Stigma, Discrimination

#### Abstract

..... Background: Adolescents constitute 22% of India's population. There are total 5.8 million people living with HIV in India, 2018. Over 35% of all reported AIDS cases in India occur among young people in the age group of 15-24 years.

Aim & Objectives: To document the factors affecting the psychosocial adjustment to HIV Positive status among HIV Positive adolescents.

Material & Method: It was a hospital based cross sectional study (quantitative component). There were 108 HIV positive adolescents registered upto February, 2020 at ART Centre, Jamnagar (Tertiary care institute), Gujarat. Out of 108 HIV positive adolescents, I approached 84 adolescents during their regular monthly follow up visit for treatment and counselling at ART center. 24 subjects from ART register were not included in this study because either lost to follow up at ART center or death. Out of 84 subjects only 77 were disclosed their HIV status and consented to be enrolled and interviewed under the study. Pretested semi-structured questionnaire provided to participants which containing socio-demographic information, issues during transition for adjustment within the family and society and status disclosure were filled up for quantitative data. Study was approved by Institutional Ethical Committee, shrim.p.shahgovt medical college, Jamnagar, gujarat and also approved by Gujarat state AIDS Control Society, Ahmedabad.

**Results:**Mean age of participants was 14.88 years (SD± 2.52). Most of them were boys (55.80%) and Hindu by cast (92.20%). Majority of the participants belonged to Nuclear type of family (87.01%) and living with biological parent/parents (87.01%). Majority participants had their mother positive (80.51%) followed by father (66.23%). Majority of the participants were disclosed about their status by first degree relative (mostly mother or father) (75.32%). Only 1(1.31%) participants, reported problem in consuming medicine after transition to adult clinic.

**Conclusion:** Stigma and Discrimination plays a pivotal role in the psychological health of HIV adolescents and loss of parents was found to have a significant impact on the psycho-social adjustment among these adolescents. The knowledge regarding the spread of HIV & its various routes of transmission was found to be low in some study participants.

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#### **Introduction:-**

In 2018, there are 110000 adolescents (10-14) living with HIV, the vast majority of whom acquired HIV through vertical transmission. Unfortunately, many young people aged 10-14 remain unaware of their HIV status<sup>1</sup> between 2005 and 2012, the number of aids related deaths among adolescents increased by 50%, while the overall number of aids related deaths fell by 30%.<sup>2</sup> the government of India, in the national youth policy, defines adolescent's age group as 10-19 years<sup>3</sup>Adolescents constitute 22% of India's population. There are total 5.8 million people living with HIV in India, 2018. Over 35% of all reported AIDS cases in India occur among young people in the age group of 15-24 years.<sup>4,6</sup> The government of India, in the national youth policy, defines adolescent's age group as 10-19 years.<sup>5</sup>Stigma directed towards HIV positive people may perpetuate to the epidemic in several way. First, fear of being stigmatized leads some to avoid HIV testing. Lack of knowledge about once sero-status may in turn lead to inadvertent transmission of virus and delays in the initiation of treatment. Second, among those who have been tested and are HIV positive, stigma constitute a chronic stressor that may contribute to coping difficulties, inadequate self-care, and difficulties with safer sex negotiations and condomuse.<sup>7</sup>

#### Materials and Methods:-

It was a hospital based cross sectional study. There were 108 HIV positive adolescents registered upto February, 2020 at ART Centre, Jamnagar (Tertiary care institute), Gujarat. Out of 108 HIV positive adolescents, I approached 84 adolescents during their regular monthly follow up visit for treatment and counselling at ART center. 24 subjects from ART register were not included in this study because either lost to follow up at ART center or death. Out of 84 subjects only 77 were disclosed their HIV status and consented to be enrolled and interviewed under the study. Pretested semi-structured questionnaire provided to participants which containing socio-demographic information, issues during transition for adjustment within the family and society and status disclosure were filled up for quantitative data. Study was approved by Institutional Ethical Committee, shrim.p.shahgovt medical college, Jamnagar, gujarat and also approved by Gujarat state AIDS Control Society, Ahmedabad.

#### **Results:-**

Mean age of participants was 14.88 years (SD $\pm$  2.52). Majority of the participants were boys (55.80%) followed by girls (44.10%). The religion respected by majority of the participants was Hindu (92.20%) followed by Muslim (7.70%). Most of the participants belonged to Gujarat (93.50%) and the other are migrants from other states (6.49%). The study reported that 16.80% of the participants have dropped school while 83.10% have continued their education. Majority of the participants belonged to Socio-economic class IV (51.94%) and class III (27.27%) followed by Class V (19.48%), class II (1.29%). Majority of the participants belonged to Nuclear type of family (87.01%) followed by joint family (12.98%). Majority were living with biological parent/parents (87.01%) followed by siblings (79.22%), relatives (31.16%), and grandparents (28.57%). Using multiple response analysis, family members of participants who were seropositive were calculated. Majority participants had their mother positive (80.51%) followed by father (66.23%), sister (15.58%) and brother (14.28%). 9.09% Participants reported that nobody in their family is seropositive. 22.07% participants had lost their father, and 15.58% had lost their mother. 5.19% Participants had lost both their parents. About 71.42% of the participants were aware about all the 4 modes of transmission while 10 (12.98%) were not aware of any mode of transmission of HIV. 76 (98.70%) of the participants were transferred from pediatric clinic. Out of 76 participants who were transferred, none reported difficulty in the transition to adult clinic. Only 1 out of 76 participants, reported problem in consuming medicine after transition to adult clinic. Out of 76 participants, 31 had to be hospitalized after change in the medicine to adult dose and major reason for the hospitalization was found to be infection(83.87%) [Table 1].Almost 93.50% of the participants reported rarely feeling blamed by others for their illness. Almost 87.01% of the total participants reported rarely feeling ashamed of their illness. Out of total participants, 77.92% reported rarely thinking their illness as a punishment for the past. 51.94% of the participants always felt fear that they might be expelled from their school if

the school came to know about their illness. Around 59.74% of the participants rarely felt compelled to change their residence because of their illness. Around 62.33% of the participants reported often avoiding getting treatment due to fear that someone might find out about their illness. Around 32.46% of the participants felt some or the other time that someone might hurt their family if they learnt about their illness. Around 44.15% of the participants reported rarely feeling people are uncomfortable with them. Around 42.85% of the participants rarely felt avoid by people. Out of total participants, 38.96% always felt that they will lose their friends if they came to know about their illness. About 55.84% of the participants reported rarely feeling that they would not get good health care if people knew about theirillness[Table 2].when asked about change in diet to improve their health, 97.4% reported positively. When asked about inability to cheer oneself, 98.7% reported negatively. On asking about problems in planning ahead, nearly 92.2% reported negatively. When asked about whether the positive health will improve their health, majority (96.1%) reported positively. When asked about their belief to get better, 83.11% reported positively. Out of total participants 58.44% of the participants reported that they have left it all to doctors. 54.54% of the participants reported negatively to feeling that life is hopeless. 61.03% of the participants reported that they exercise to improve health. Almost 85.71% of the participants admitted that they have put their life in the hands of God.Out of total participants, 64.93% admitted having plans for the future. Out of total participants, nearly 68.83% felt inability to help themselves. Majority of the participants (72.72%) reported to trying to carrying on with their lives as usual. Majority of the participants (63.63%) reported making contacts with others. Outof total participants, 80.51% reported feeling great deal of anxiety about the HIV-positive status. Nearly 68.83% of the participants reported taking oneday at a time. Nearly 80.51% of the participants reported feeling like giving up. Out of total participants, 92.2% admitted trying to keep a sense of humor about the HIV-Positive status. Nearly 98.7% of the participants reported that other people worry about them. Nearly 90.9% of the participants reported that they tried to keep busy to not think about their status. Around 94.8% of the participants reported that they avoid finding out more about their status [Table 3]

### **Discussion:-**

Present study revealed that mean age of participants was14.88 years (SD  $\pm 2.52$ ). Majority of the participants were boys (55.80%) followed by girls (44.10%). Kajuro B. et al reported 52% boys and 48% girls in their study among HIV-infected children (5-17 years). In present study, the religion respected by majority of the participants was Hindu (92.20%) followed by Muslim (7.70%). Most of the participants were from Gujarat (93.50%) and only 6.50% were Migrants in the present study. Surat city has reported 58% migrants.<sup>13</sup>Various studies have reported higher prevalence of HIV among migrants in Surat<sup>12-13</sup> and other cities of India, and so NACO has initiated Targeted Intervention (TI) among migrants.<sup>14</sup>In present study, almost one-fifth of the participants (22.07%) had lost their father, and 15.58% had lost their mother. Participants who had lost both their parents were 5.19%. Study conducted by Marfatia YS et al. at Vadodara, India reported 8 orphans out of 21 HIV- positive adolescents.<sup>8</sup>Nostlinger C. et al. reported 39% orphans in the study conducted among adolescents living with HIV.<sup>15</sup>

In the present study, relatives with which participants are currently residing were calculated by multiple response analysis. Majority were living with biological parent/parents (87.01%) followed by siblings (79.22%), other relatives (31.16%) and grandparents (28.57%).Kajura B. et al. reported that 31% of HIV Positive adolescents were living with their parents and 57% were living other relatives.<sup>9</sup> Using multiple response analysis, it was observed that majority participants had their mother positive (80.51%) followed by father (66.23%), sister (15.58%), brother (14.28%),both father and mother (5.19%), whole family positive (2.59%). Kallem S. et al. reported that 80% of the total HIV positive adolescents had their mother's positive and 50% had their father's positive.<sup>10</sup> Most of the participants (71.42%) were aware about all the 4 modes of transmission while 10 (12.98%) were not aware of any mode of transmission of HIV. Out of 77 participants, 12(15.58%) knew about sexual route of transmission and mother to child transmission as a mode of transmission of HIV. Kenu E et al. reported that 66.7% of all HIV-positive adolescents knew that HIV was transmitted through sex and 63.6% knew about mother to child transmission.<sup>16</sup>

Out of 77 participants, 76 were transferred from pediatric clinic to ART center of Medicine Department of tertiary care hospitals, none reported difficulty in the transition to adult clinic because in ART centre, they feel family atmosphere, everyone behave nicely, respond warm fully. They always feel safe with their status disclosure to anyone. Pharmacist explained everything about drugs (when & how & how many time take) & related problems to them nicely. The present study setting caters to all the HIV related services including ART, PPTCT, ICTC and others on the same floor of the building. The pediatric ART services are provided once a week at the adult ART

clinic itself by the pediatric department.So the adolescents did not report any difficulty in the transition process from pediatric to adult care. Though it is difficult to transition from pediatric to adult care, in our study there were not found any difficulty in transition process. Transition to an adult care setting is a challenge for most HIV- infected adolescent patients because of the loss of the stable and Long-term nature of their relationships with their pediatric or adolescent healthcare team.<sup>18</sup>

Many studies conducted in other countries have reported contradictory findings to the present study as the hospital setup changes entirely in transition from pediatric to adult clinic. Common barriers have been identified in the literature regarding transition of adolescents with chronic diseases into adult care.<sup>19-20</sup> Out of 77 participants, 18 (23.37%) had suffered from any form of opportunistic infection (OI). Out of these 18 participants, almost half (8 (10.38%)) suffered from tuberculosis. Study conducted by Ferrand et al. in 2010 reported 44% of the HIV Positive adolescents had suffered from tuberculosis.<sup>11</sup>Mitiku et al. reported the overall of prevalence of OIs among HIV/AIDS infected adolescents on ART to be 48%. In the present study, out of 77 participants, 31 (40.78%) participants were hospitalized for indoor treatment. The main reason for hospitalization was infection (83.87%) due to any reason. Other reasons for inpatient care were psychiatric ailment (9.67%), pneumonia (6.45%) Ferrand et al. reported 29% hospitalization among HIV-Positive adolescents in 2010 mainly due to infection which is similar to the present study findings<sup>11</sup>. In present study, Majority of the participants were disclosed about their status by first degree relative (mostly mother or father) (75.32%) followed counsellor (19.48%) and doctor (5.19%).Bhattacharya et al. reported that disclosure was most frequently done by parents [51/60 (85%)] at a mean age of  $9.1\pm1.4$  years.<sup>17</sup>Nostlinger C et al. in 2015 in Eastern Africa reported that 19.9% of HIV Positive adolescents had disclosed their status to peers, friends and girl-or-boyfriends<sup>15</sup> which is higher than the present studyfindings.

# **Conclusion:-**

The current study reported no difficulty in transition from pediatric to adult care among HIV positive adolescents. As ART is provided for one month & school going participants facing problem regarding visiting hospital during exams in the current study. Stigma and Discrimination plays a pivotal role in the psychological health of these adolescents according to the present study finding. From the current study finding, loss of parents was found to have a significant impact on the psycho-social adjustment among these adolescents. The knowledge regarding the spread of HIV & its various routes of transmission was found to be low in some study participants.

| Variable                |           | Categories                            | Frequency  |
|-------------------------|-----------|---------------------------------------|------------|
|                         |           |                                       | (%)        |
| Transferred from $n=77$ |           | Pediatric clinic                      | 76 (98.70) |
|                         |           | Other Centre/ Registered at later age | 1 (1.29)   |
| Transitionprocessn=76   |           | Easy Difficult                        | 76 (98.70) |
|                         |           |                                       | 0          |
| Problem in consuming    | medicines | Yes No                                | 1 (1.31)   |
|                         | after     |                                       | 75 (98.68) |
| transition n= 76        |           |                                       |            |
| Hospitalization         | after     | Yes No                                | 31(40.78)  |
| change in medicinen=76  |           |                                       | 45(59.21)  |
| Reason                  | for       | Infection/Opportunistic Infection     | 26 (83.87) |
| hospitalization n= 31   |           | Trauma / Injury Others                |            |
|                         |           |                                       | 2(6.45)    |
|                         |           |                                       | 3(9.67)    |

Table 1:- Distribution of participants according to their transition process to Adult Care.

# **Table 2:-** Frequency distribution of Responses to Items on Modified HIV Stigma Scale (n= 77).

| Item                     | Not at | Rarely  | Sometimes | Often | Always |
|--------------------------|--------|---------|-----------|-------|--------|
|                          | all    |         |           |       |        |
| 1. Do you feel blamed by | 5      | 72      | 0         | 0     | 0      |
| others for your          | (6.49) | (93.50) |           |       |        |
| illness?                 |        |         |           |       |        |
| 2. Do you feel           | 7      | 67      | 3         | 0     | 0      |

| ashamed of your illness?   | (9.09)        | (87.01)       | (3.89)        |               |               |
|--|---------------|---------------|---------------|---------------|---------------|
| 3. Do you think your illness<br>was a punishment for<br>things you have donein<br>the past?                    | 16<br>(20.77) | 60<br>(77.92) | 1<br>(1.29)   | 0             | 0             |
| 4. Do you fear that you might<br>be expelled from your<br>school if someone found<br>out aboutyour<br>illness? | 10<br>(12.98) | 17<br>(22.07) | 9 (11.68)     | 1<br>(1.29)   | 40<br>(51.94) |
| 5. Do you feel<br>compelled to<br>change your residence<br>because of your illness?                            | 11<br>(14.28) | 46<br>(59.74) | 16<br>(20.77) | 4 (5.19)      | 0             |
| 6. Do you avoid<br>getting treatment<br>because someone might<br>find out aboutyour<br>illness?                | 6<br>(7.79)   | 16<br>(20.77) | 48<br>(62.33) | 7<br>(9.09)   | 0             |
| 7. Do you fear that people<br>would hurt your family<br>if they learnt about your<br>illness?                  | 20<br>(25.97) | 12<br>(15.58) | 25<br>(32.46) | 20<br>(25.97) | 0             |
| 8. Do you think<br>other people are<br>uncomfortable being<br>withyou?   | 6<br>(7.79)   | 34<br>(44.15) | 10<br>(12.98) | 25<br>(32.46) | 2<br>(2.59)   |
| 9. Do you feel people avoid<br>you because ofyour<br>illness?  | 2<br>(2.59)   | 33<br>(42.85) | 7<br>(9.09)   | 32<br>(41.55) | 3<br>(3.89)   |
| 10. Do you fear you would<br>lose your friends if they<br>learnt about yourillness?                            | 0             | 6<br>(7.79)   | 4<br>(5.19)   | 37<br>(48.05) | 30<br>(38.96) |
| 11. Do you feel you wouldn't<br>get as good health care if<br>people knew About<br>yourillness?                | 6<br>(7.79)   | 43<br>(55.84) | 23<br>(29.87) | 4 (5.19)      | 1<br>(1.29)   |

# Table 3:- Frequency distribution of Responses to Items on Mental Adjustment to HIV Scale (MAHIV) n= 77.

| Items   | Does not apply to | Applies to me |
|---|-------------------|---------------|
|   | me                |               |
| 1. I have changed my diet to                        | 2 (2.59)          | 75 (97.4)     |
| improve my health                                   |                   |               |
| 2. I can't do anything to cheer                     | 76 (98.7)         | 1 (1.29)      |
| myself up   |                   |               |
| 3. Problems with my health prevent me               |                   |               |
| fromplanning  | 71 (92.2)         | 6 (7.79)      |
| ahead.  |                   |               |
| 4. I believe that my positive attitude will improve |                   |               |
| myhealth.   | 3 (3.89)          | 74 (96.1)     |
| 5. I firmly believe Iwillgetbetter.                 | 13 (16.88)        | 64 (83.11)    |
| 6. I have left it all to my                         | 32 (41.55)        | 45 (58.44)    |
| doctors.  |                   |               |
| 7. I feel that life is hopeless.                    | 42 (54.54)        | 35 (45.45)    |

| 8. I have been exercising to                        | 30 (38.96) | 47 (61.03) |
|---|------------|------------|
| improve my health.                                  |            |            |
| 9. I have put myself in the                         | 11 (14.28) | 66 (85.71) |
| hands of gods.                                      |            |            |
| 10.I have plans for the future.                     | 27 (35.06) | 50 (64.93) |
| 11. I feel that there is nothing I                  | 24 (31.16) | 53 (68.83) |
| can do to help myself.                              |            |            |
| 12. I try to carry on withmy                        | 21 (27.27) | 56 (72.72) |
| life as I have always done.                         |            |            |
| 13. I make contact with others.                     | 28 (36.36) | 49 (63.63) |
| 14.I suffer a great deal of anxiety                 |            |            |
| about my HIV  | 15 (19.48) | 62 (80.51) |
| positive status.                                    |            |            |
| 15. I take one day at a time.                       | 24 (31.16) | 53 (68.83) |
| 16. I feel like giving up.                          | 15 (19.48) | 62 (80.51) |
| 17. I try to keep a sense of humor about my         |            |            |
| HIV-positive status.                                | 6 (7.79)   | 71 (92.2)  |
| -   |            |            |
| 18. Other people worryabout                         | 1 (1.29)   | 76 (98.7)  |
| my HIV positive status.                             |            |            |
|   |            |            |
| 19. I keep busy so that I don't have to think about |            |            |
| mvHIV   | 7 (9.09)   | 70 (90.9)  |
| positive status                                     | . (,       |            |
| F   |            |            |
| 20. I avoid finding out more                        |            |            |
| about my HIV positive status.                       | 4 (5.19)   | 73 (94.8)  |
|   |            |            |
|   |            |            |

**Source(s) of support**: Nil.

**Conflicting Interest:** 

Nil.

# Acknowledgement:-

we are very thankful to the professor and head, community medicine department and institutional ethical committee, shrim.p.shah govt. medical college, Jamnagar, Gujarat and also thankful to the Gujarat state AIDS control society, Ahmedabad. And finally thanks to my wife, Dr. TejalKhokhar for helping me during data collection.

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