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Perceptions of HIV positive adolescents about the disease and its manifestations: A cross sectional study in a tertiary care teaching hospital in Telangana India

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Abstract---Introduction: The lack of information on knowledge, perceptions, and behaviours regarding HIV risk and preventive behaviours among Indian adolescents is alarming. Objective: To assess the perceptions of HIV Positive adolescents about disease and its manifestations. Materials and Methods: 101 HIV positive adolescents were randomly selected into the study. study populations were given a questionnaire in Telugu and English containing questions regarding the 1) knowledge on HIV disease, 2) attitude towards life,3) perceptions and feelings about disease, 4) issues relating to treatment 5) impact of counselling, 6) attitude towards the other HIV positive people. The questions were explained to them, and they were asked to write answers. Results: More than 64% of adolescents have an idea about HIV transmission. More than 44% ,84%, 64% have an idea that HIV is a manageable disease, concept about the disease, good hope about their future respectively. More than 40% adolescents preferred HIV positive person as their partner. More than 90% of adolescents felt that many things are there to live happily. Conclusion: From the results it can be concluded that study gave a general idea about few perceptions of HIV positive adolescents about the disease and its manifestations.

Keywords---perceptions, HIV, adolescents with HIV, counselling, manifestations.

Introduction

Adolescents living with HIV have been infected with HIV through one of two pathways: through vertical transmission (from mother to child via pregnancy or breastfeeding) or through horizontal transmission (from either sexual or non-sexual methods, e.g. injecting drug use, exposure to infected blood, medical procedures). Globally, over million people are living with HIV/AIDS among them who estimated more than 3.2 million children younger than 15 years of age are living with HIV/AIDS. More than 5 million people are between the age group of 10-19 years. An enormous section of the world's population, more than 1.75 billion, is young and aged between 10 and 24 years, making every fifth person in the world an adolescent¹. Owing to the transitional nature of this age group, they are vulnerable to HIV/AIDS. India, where 95,000 adolescents are living with HIV, has been listed along with the sub-Saharan countries having the highest number of youngsters infected by the deadly virus, according to a UN report. In the age group of 10-19 years, India with 46,000 infected girls and 49,000 boys has been ranked tenth in the list of countries most affected with HIV in 2009.

Although there have been studies on the presence of human immunodeficiency virus (HIV) among the adult and even pediatric population, the adolescent population has been neglected. . In countries like India where more than 22.8% of its population is between 10 to 19 years², HIV can be a formidable threat both in terms of incidence and prevalence. Despite the prominence of young adults in the HIV epidemic, prevention research regarding adolescents has been scant. Adolescence is the second decade of life (10–19 years) and is a period of both physical as well as psychological development³. This is a phase of experimentation and risk that includes early sexual debut, sexual coercion and violence, trafficking, and substance abuse. Along with these, other factors such as the lack of knowledge about HIV/AIDS, inaccessibility to healthcare services and commodities, lack of education and life skills, and early marriage have increased their vulnerability to HIV/AIDS⁴.

Since adolescents comprise a major part of reproductive group, they are likely to play a significant role in determining the future growth pattern of India's population and economy. Adolescents constitute 22.8% of India's population⁵. Thus, it is crucial that investment in terms of finances, research, and developmental policies be done to improve their wellbeing. Since India has emerged as a major player in the global HIV epidemic, and given the importance of adolescents in the Indian epidemic, the lack of information on knowledge, perceptions, and behaviors regarding HIV risk and preventive behaviors among Indian adolescents is alarming⁶. At same time the adolescents who were positive, their needs and wellbeing also should be looked after.

Materials & Methods

This cross sectional study titled “Perceptions of HIV Positive Adolescents About the Disease and its Manifestations: A Cross Sectional Study in a Tertiary Care Teaching Hospital in Telangana India” was carried out during the period of September 2015 to November 2016. The study was conducted on 101 HIV positive adolescents who are attending YUVA clinic at Niloufer hospital, Hyderabad with an aim to evaluate the Perceptions of HIV Positive Adolescents About the Disease and its Manifestations

Inclusion criteria

- Adolescents between the age 10- 19 years who are HIV positive and on HIV medication, visiting to YUVA clinic of Niloufer hospital, Hyderabad.

Exclusion criteria

- Age group less than 10 years and more than 19 years.
- Adolescents who are negative for HIV.

Ethics

This study was approved by the Institutional Ethics Committee Osmania Medical College Hyderabad. An informed written consent was taken from all the patients involved in the study after explaining regarding the study.

Study Procedure

101 HIV positive adolescents who are attending YUVA clinic at Niloufer hospital, Hyderabad, were randomly selected into the study. In terms of psychological, physiologic and social development, adolescence is subdivided into 3 classes. Early, middle and late adolescence. In class- A early adolescents, the early stage (10–13 years), independence-dependence struggles are heralded by rapid physical changes with the onset of puberty. The class-B: mid adolescents, middle stage (14–16 years) is characterized by an increased scope of feelings, and increased importance of peer group values and more risk-taking behaviors. The class-C; late adolescents, late stage (17–19 years) represents emerging adults who have successfully transitioned into accepting responsibility for their behaviors.(SMRITI).The sample populations were given a questionnaire^{19,20} containing questions regarding the 1) knowledge about the HIV disease, 2) attitude towards life,3)perceptions and feelings about the disease , 4)issues relating to treatment 5) impact of counseling, and 6) attitude towards the other HIV positive people. The questions were explained to them, and they were asked to write answers. The questionnaire was given in Telugu and English format. The response rate of students was 100%. They were given a pre-designed proforma, which included YES or NO type questions and one word answer type questions. They were asked to fill that questionnaire at YUVA clinic of Niloufer. Care was taken to minimize consultation amongst them.

Statistical analysis

Data were entered and analysed using SPSS Version 13.0 by means of simple comparison of proportions.

Results

101 HIV positive adolescents who are attending YUVA clinic at Niloufer hospital, Among them 48 Are Females, 53 Are Males. (Fig.1)

Fig :1 Gender Wise Distribution

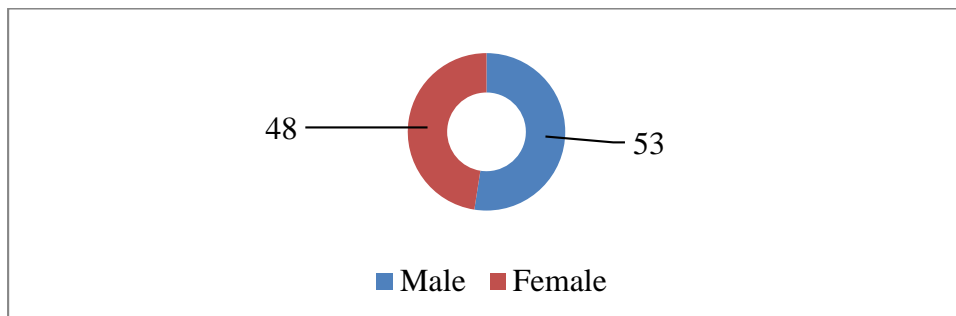
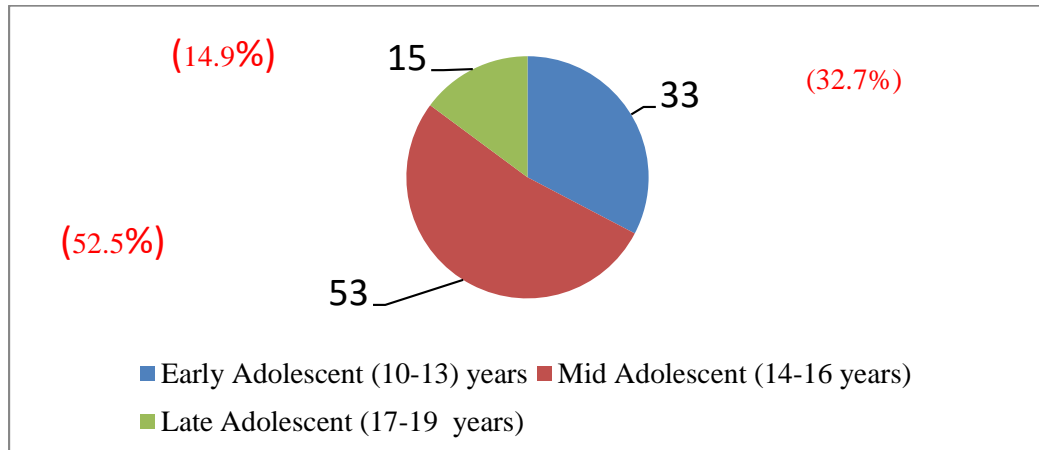
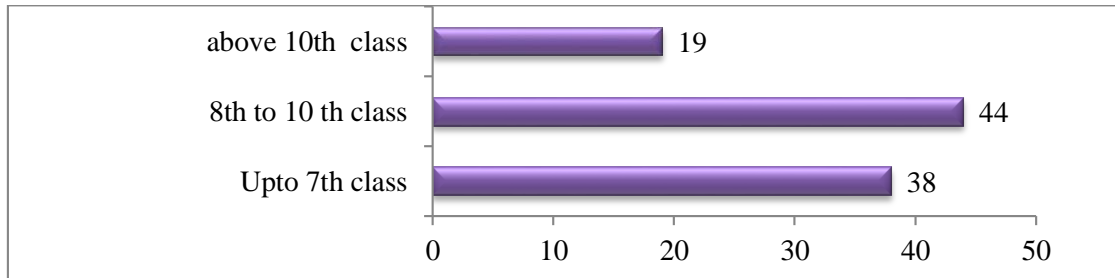


Fig :2 Age Group Wise Distribution



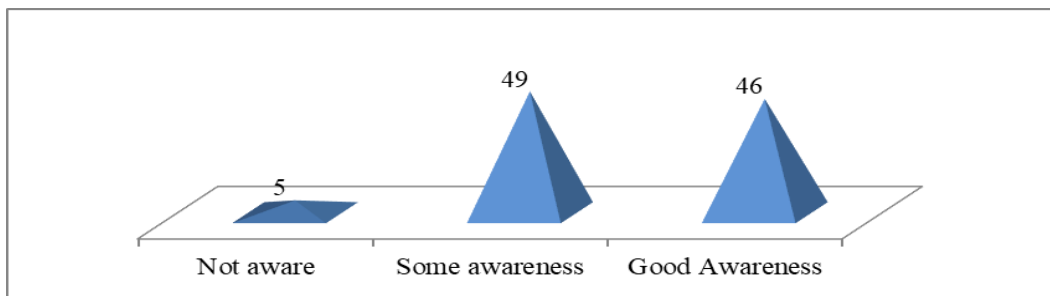
Among 101 HIV positive adolescents, 33 are in early adolescent age, 53 are in mid adolescent age, and 15 are in late adolescent age.

Fig :3 Education Wise Distribution



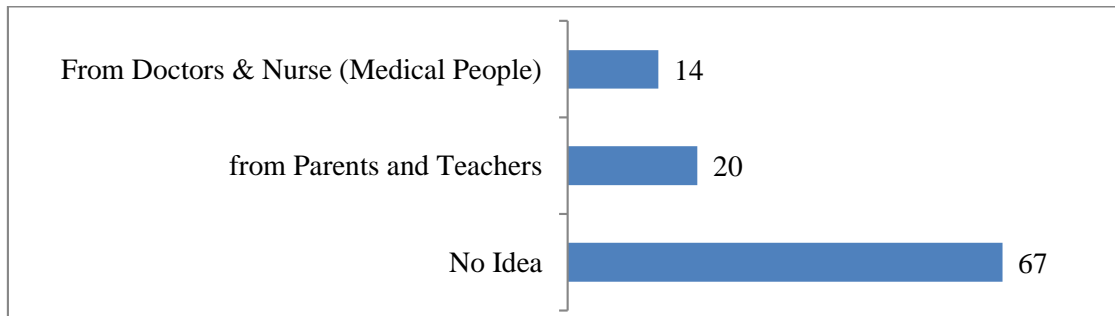
According to their education, They are divided In 3 Groups. Up To 7th Class and Less Than 7th Class Are Group1, 8th Class To 10th Class are Group2, above 10th Class are Group3. In Group 1 there are 38 adolescents; In Group 2 there are 44 adolescents and In Group3 there are 19 adolescents are Participated(Fig.3)

Fig :4 Percentages Showing Knowledge about the Disease



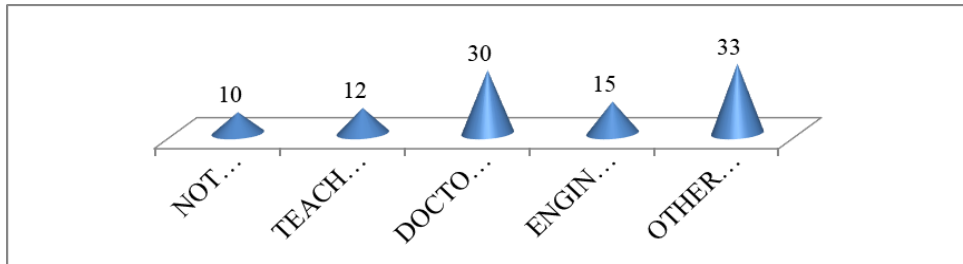
Among 101 HIV positive adolescents ,46% have good awareness about the disease.49% have some awareness,5% are not aware about the disease

Fig :5 Percentages Showing, through whom they Know about their Status



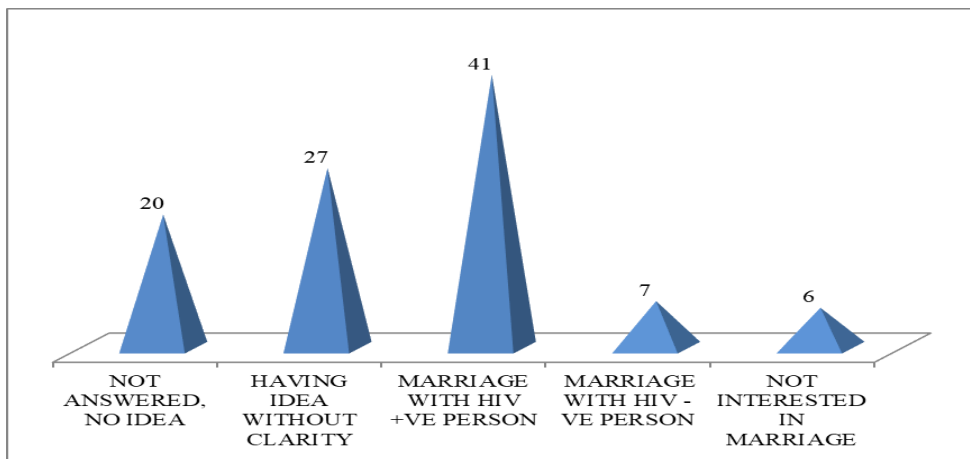
Among 101 HIV positive adolescents 20% of adolescents know about their HIV status through their parents.3 people know through teacher,warden.14% of adolescents know through medical people(Doctor, nurse) 67% have no idea through whom they came to know about their HIV Status.

Fig :6 Percentage Showing Interested Professions



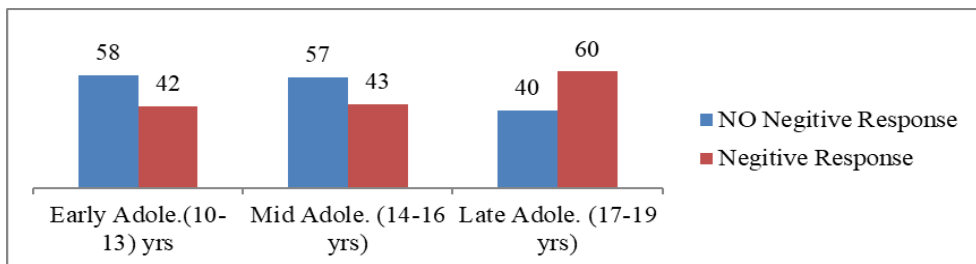
About the profession of choice 30% preferred medical profession, like doctor, nurse.12 % liked to choose teaching profession.15 % liked to choose engineering, MBA, software.33 % opted other professions like business, police, collector, social service. Etc.9.9% have no idea about their profession of choice.92.1% have good idea about their earnings

Fig :7 Percentages Showing about the Attitude towards Marriage



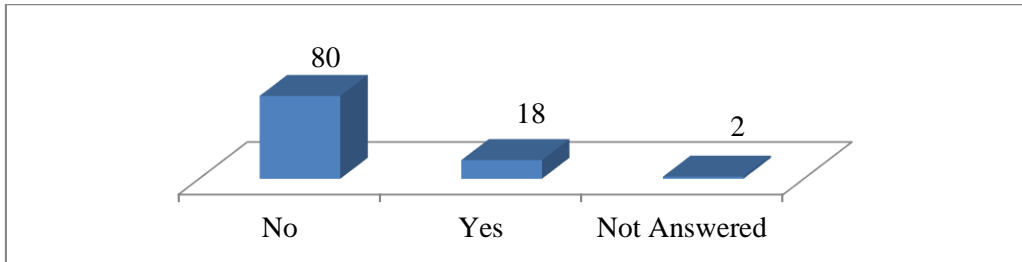
27% have no clear idea about whom they want to marry, But they are willing to get marry 41% want to marry HIV +ve persons only,7% are willing to marry HIV - ve persons.6% do not want to marry.19.8% don't have any idea about marriage.

Fig :8 Percentages Showing Others Response Towards Positive Adolescents



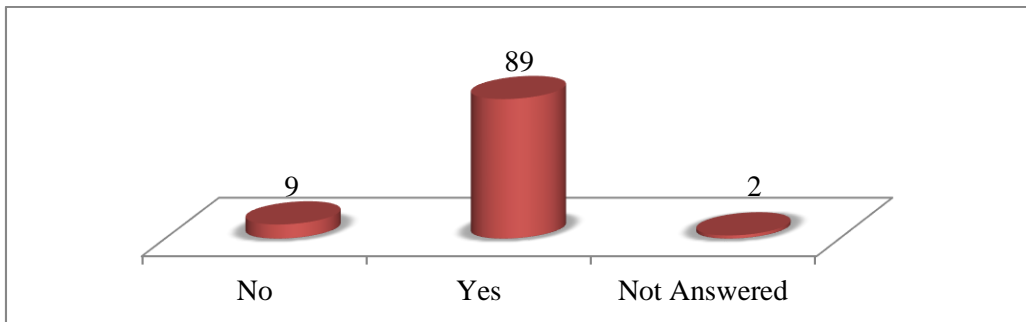
58 % early adolescents face no negative response,57 % mid adolescents face no negative response,60 % late adolescents face no negative response ,42% of early adolescents face negative response,43% of mid adolescents face negative response,60% late adolescents felt negative response from others.

Fig :9 Percentages Showing Side Effects of Drugs



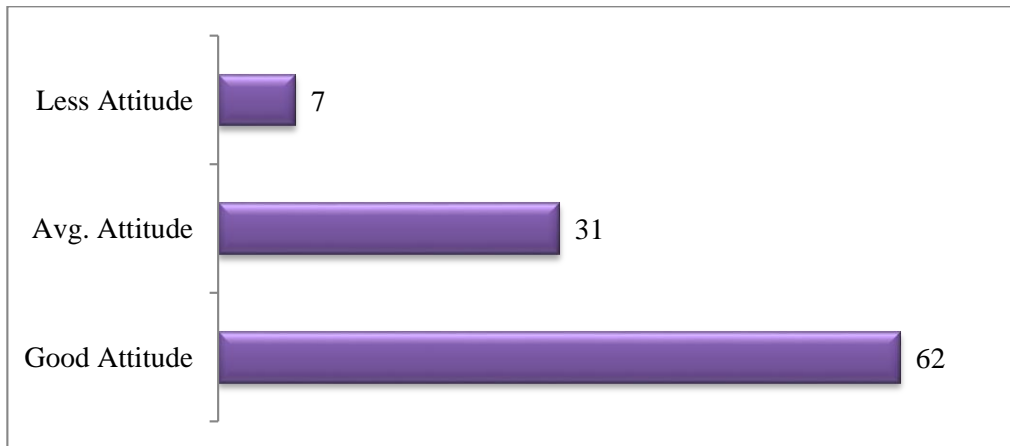
18% of all have some side effects of drugs. 80% do not have side effects.2% have not answered

Fig :10 Percentages Showing Effect of Counselling



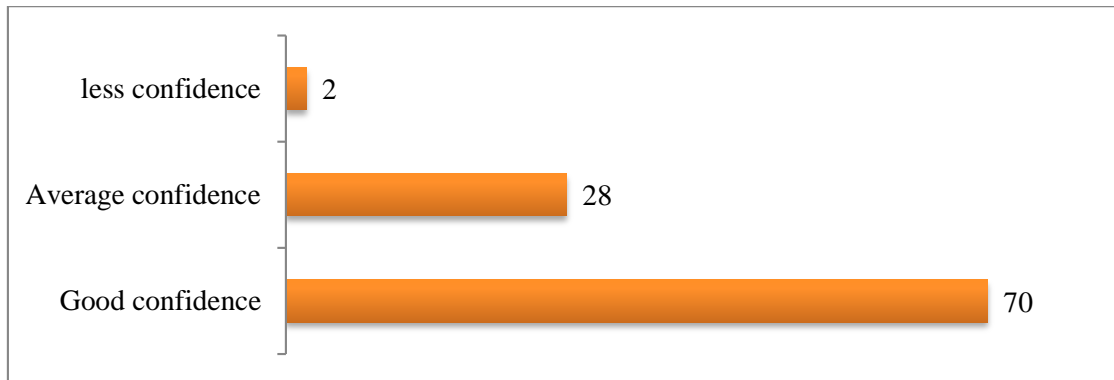
89% have gained confidence after counseling.9% are not satisfied with counseling.2% have not answered

Fig :11 Percentages Showing Attitudes Towards Other Positive People



62.2% have good attitude towards other +ve people,31% have average attitude towards +ve people,7% are not showing interest

Fig :12 Percentages showing Overall Confidence about Leading Life



70% have good confidence in leading quality of life.28% have an average level of confidence 2% are less confident and need more counselling.

Discussion

101 HIV positive adolescents who are attending YUVA clinic at Niloufer hospital, Hyderabad, were randomly selected into the study. In the present study 46.6% thought there is no cure for the disease and 43.6% felt that it is a manageable disease like diabetics and hypertension. Over all more than 84% have concept about the disease.95%have awareness of the disease. Nearly 35% of adolescents know about their status through parents, medical people and wardens. Regarding perceptions and feeling about the disease 60.4% are feeling sad about the disease 37.6% feeling guilt about the disease but majority (70%) are not blaming about the disease. Regarding the negative reactions form others:24.8% faced negative attitudes and some insults from others, 36.6% faced some restrictions in their day-to-day activities like playing. Overall, 45% faced some small or big negative response from others among them 60% are late adolescents.

Haven b battles et al.,⁷ conducted study, shows psychosocial adjustment associated with long-term survival of HIV.and concluded that social support and open communication about the diagnosis are essential.pparticularly at this age, plans for the future are the focus of adolescent development and individuation¹³. With advances in medical treatment, HIV-infected children are more likely to survive into adolescence and beyond. Accordingly, their psychosocial needs are changing to more closely resemble the needs of the chronically ill individual, rather than the terminally ill. Families of HIV-infected children should seriously consider preparation for independent living.

Jamie I. Forrest⁸:et al.,studied social stigma surrounding HIV and childbearing. High rates of infection and patterns of high fertility make adolescents a crucial demographic to qualify perceptions of HIV and fertility. They conducted two focus groups ($n = 11$ males, $n = 8$ females). They also used this concern to justify their

attitudes that HIV positive couples should adopt when faced with the desire to have children. Lastly, participants spoke of a need to revise adolescent sexual and reproductive health services to make them more youth-friendly where users could avoid stigma generated by community healthcare workers¹⁴. This study adds to the growing literature that calls for an evaluation of adolescent HIV educational programs and a healthcare worker intervention that specifically targets stigma surrounding HIV and childbearing.

Mara Kardas-Nelson⁹ et al., study showed, As the number of young people living with HIV increases internationally, new and innovative ways to talk about sex, disclosure, and health need to be developed for HIV-positive adolescents. The needs of adolescents living with HIV are much more sensitive and varied than those of adults, as they must simultaneously deal with 'adult' issues like disclosure, practicing safe sex, and adhering to treatment, while also addressing issues traditionally associated with adolescence, such as body image, first sexual experience, peer pressure and forming personal identity.

Ivana Drummond¹⁰; et al., study was regarding Knowledge and perceptions of parents and/or responsible and of their HIV infected children and adolescents. The discovery of the HIV infection by the family, their social conditions, access to prevention and treatment and their perception of the disease. Results show that a significant number of relatives interviewed ($n=28$) realized that they were also HIV-carriers when their children's health deteriorated (14 or 50.0 %); the death of the spouse occurred (6 or 21.4%) and by the symptoms of the disease in themselves (8 or 28.6%). Among the 32 children interviewed, 28 (87.5%) were not aware of their diagnosis and 18 (56.3%) were not enrolled into school. Out of the 14 different schools frequented by 14 (43.8%) children, only 7 (50%) of these institutions knew about the children's diagnosis. Since AIDS is a disease that involves the entire family, it is mandatory to reflect on its spread, its implications within the family circle and the physical and emotional effects on the children. The disease will affect their activities at home, with their siblings and friends, and also at school. Their perceptions about the illness reinforce the need for an integrated approach where the playroom can be a very important support.

Gitau, Mburu¹¹, et al., qualitative study examined the experiences of adolescents living with HIV in Zambia. In-depth interviews were conducted with adolescents aged 10–19 living with HIV ($n = 58$) and their health care providers ($n = 14$). In addition, 13 focus group sessions were conducted with adolescents living with HIV ($n = 53$), health care providers ($n = 24$) and parents ($n = 21$) results suggest that a positive self-concept, strong locus of control, are important factors that shape the perception of an HIV diagnosis at the individual level. Adolescents' experiences of living with HIV are determined by factors located *within and beyond* adolescents themselves, including factors at the family and peer level, community level and structural level^{17,18}. Creating supportive environments for adolescents are very much needed¹⁵.

G.Thupayagale¹², et al., study describe adolescents' perceptions in Botswana on the behaviours that HIV-positive adolescents use in dealing with stigmatization. Four focus group discussions were held with 18 adolescents. Adhering to AIDS therapies, seeking early treatment for common conditions and keeping silent

about their diagnosis were the major findings of the study. The findings have implications for both policy makers and health care practitioners. The above studies gave about the perceptions of positive adolescents of different countries and of different issues. Regarding the knowledge, and treatment to adherence and family issues, other's responses were studied and analyzed¹⁶. In the present study shows the following responses of HIV positive adolescences who visit YUVA clinic, regarding the knowledge of the disease more than 95% have awareness about the disease and more than 84% have a good concept about the disease.

About the attitude towards the life, nearly 91% want to go for higher education among them nearly 27% have specific idea about their study and regarding the choice of their profession, 30% like choice the medical field, 26% choice is engineering and software fields. 34% of adolescents like to choice other professions like police and business and social services etc. Majority of them have clarity about their future and about their earnings.

Regarding marriage, More than 70% are willing to marry. 41% are willing to marry HIV +ve person only. 27% willing to marry but not specified the partner HIV status. 6% are not willing to marry because of their children may get HIV. About the perceptions and feeling about the disease, more than 60% are feeling sad about their disease, more than 70% are not blaming anyone for this disease and more than 80% felt people are accepting them normally, more than 93% felt that they can change their life style as they were advised. More than 86% have someone to take care of them.

Concerns about medication, More than 90% are taking medicines regularly and following the health instructions as they were advised. Majority are coming for health checkups, 17.8% have side effects of the drugs. 93.1% are satisfied with the facilities available here. More than 85% are expecting some support from family, friends and health care providers. Regarding the impact of counseling, More than 89% gained confidence after counseling; more than 58% felt they were told necessary things. More than 42% want to now much details about their disease and its course; more than 92% felt they can fight against the disease.

About the attitude towards other positive people, more than 65% of adolescents are visiting other HIV positive friends; 90% are sharing their ideas and guiding them for the better life. Overall, 62% have good concern and attitude towards other HIV positive people. Regarding overall confidence, more than 70% are confident about leading the quality of life and 28% have some confidence.

Limitations

The sample is taken from adolescents visiting to YUVA clinic only. All of them are on ART. The socio economical background was not taken into consideration. The cultural background was not taken into consideration. The family background (orphan/non orphan) was not taken into consideration. Study results were dependent on participant's responses

Recommendations

In the present study, Majority of positive adolescents willing to know much about the disease and its course, so the health care providers should give proper information about their disease to them. For that special booklet, audio visuals should be provided and counseling clinics and ART centers should be provided. Majority of adolescents have planned for their marriage and they have some doubts and confusion about the vertical transmission (mother to child). Every adolescent should be aware of PPTCT (Prevention of Parent to Child Transmission). Majority of the individuals are feeling sad about their disease, psychologists' interventions are needed. The counselors and staff should be trained in those aspects "HIV care requires approaches that accentuate positive experiences while mitigating negative ones".

Conclusion

From the results it can be concluded that study gave a general idea about few perceptions of HIV positive adolescents about the disease and its manifestations. Dealing with the adolescents is a bit different because they behave like adults in sometimes and children in sometimes, their emotional state is very sensitive, particularly HIV +ve adolescents.

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