

Is there a silver lining in this cloud? Future expectations of adolescents with human immunodeficiency virus

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ABSTRACT

Background and Objective: The life span of the children living with Hiv/AIDS has increased with the invention of Retroviral drugs. As they are entering in to late adolescents and early adulthood, it becomes necessary to understand their expectations. The study aimed to explore the future expectations among the adolescents with HIV/AIDS. **Materials and Methods:** An exploratory study design was adopted for the study. Semi structured interviews were undertaken with adolescents and interpretative phenomenological analysis was used to analyze the results. The universe of the study were HIV infected adolescents who are registered in the Pediatric ART Centre and are coming for follow up in Indira Gandhi Institute of Child Health Hospital, Bengaluru. **Results:** Emergent themes demonstrated that, the adolescent with HIV/AIDS are concerned regarding their future. The themes emerged from the study was knowledge about the illness, physical health, future expectations about career and relationship and social support. **Conclusion:** Lives of the children adolescents being infected by HIV/AIDS, unlike those of their counterparts are complicated with stigma, adjustment problems, and many other psychosocial issues. While studies done in India bring to light the adjustment problems of these children, they fail to look at their future expectations and their dreams for them.

Key words: Adolescents living with human immunodeficiency virus/AIDS, adolescents, future expectation, human immunodeficiency virus/AIDS


INTRODUCTION

Over the years, Governmental programs have sought to ensure access to antiretroviral therapy (ART) for children living with human immunodeficiency virus (HIV)/AIDS as it allows

and increases the life expectancy of these children. These children do have a variety of psychosocial needs, which need to be understood so that the biopsychosocial interventions can enhance their quality of life. From the biological aspect, adolescence is universal, but it modifies according to the culture and each society's values.^[1] Most of the children, who reached adolescence with the illness, would have lost their parents, which end up in bereavement, disruption of affective bonds, and family rearrangements.^[2] Adolescents would have

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experienced parenting from different sources such as biological parents (when they are alive), extended relatives (maternal and paternal grandparents), and parenting in institutional care.

During adolescence, one develops a sense of the future orientation. Broadly, it is one's perspective toward the future. However, there is no standard way of measuring this construct.^[3] The future expectation is defined as the extent to which one expects an event to actually occur, influence goal setting, and planning, thereby guiding behavior and development.^[4,5] It is, particularly important for the ones who have significant stressors posed by the HIV. They are worried about their life, education, aim, performance, financial instability, and independence. Because of which they also lose the privacy and control over their life and their confidence is shaken. It also affects the future regarding bonding and relationship with loved one.^[6] The psychological vulnerability and mortality remove the blanket of the hidden HIV status. The activity level and productivity are affected by the illness and results in social isolation. The loss of family member also changes the entire system. As a result, it becomes difficult for the children to concentrate and ability to take decision also gets effected.^[7] Death is something which can bring extreme burden for anyone. One actually surrenders before the situation. It may result in a change in physiological and psychological processes in the body which has a negative impact on the health. This burden actually results in disruptions of relationship in the environment.^[8] There is a very little literature available on the future expectations and measurement of the future expectations among adolescents, with the information offered being widely inconsistent. Some of these children, are aware of their HIV status, some pretend to be not aware; even though, they have been taking treatment for long. The repercussion of their HIV/AIDS status on their lives has not been studied and this study makes an attempt to understand the future expectation of these children.

METHODOLOGY

Karnataka State Aids Prevention Society consolidated ART report pointed out that in Karnataka State, there are 49 ART centers. There total numbers of registered pediatric cases are 16,432 and 210,469 are of adults living with HIV/AIDS, as on August 2012. Among all the centers, Belgaum, Bagalkot, Bijapur, and Indira Gandhi Institution of Child Health Bangalore have more than 1000 registered pediatric cases. The population of this study comprised six adolescents who were receiving ART treatment Indira Gandhi Institute of Child Health Hospital, Bangalore. The study aims to assess the future expectation among the adolescents born with the HIV. The exclusion criteria were the adolescents who were residing with both the parents. The study was carried out from January 2016 to February 2016. The study was approved by the Institute Ethics Board and followed the ethical guidelines. Written consent was obtained from the caregivers, respondents, or legal guardian.

1. Sociodemographic data sheet prepared by the researcher, which includes age, sex, domicile, and education
2. Interview guide included questions regarding the future expectation, which was face validated by six professionals from the Departments of Psychiatric Social Work, Clinical Psychology, and Psychiatry.

Data analysis

Quantitative data were coded and analyzed with the help of Statistical package for social sciences software Version 22.00 Department of Biostatistics, National Institute of mental Health and Neuro Science, Bengaluru. The qualitative data were audio taped and was transcribed and coded as subthemes. The analysis was performed using interpretative phenomenological analysis. The emergent subthemes were then listed and attempts were made to look for and make sense of connections between them, creating theme into main themes. After analyzing all the themes, subthemes were clustered together, and a master list of theme was made.

RESULTS

The study sample consisted of three girls and three boys with a mean age of 16 years. Table 1, represents the sociodemographic details of the respondents. Of six children, three children are receiving institutional care and three children are residing with their extended families. The analysis of the content from the interview resulted in the development of the major themes and subthemes, which has been described below.

Themes

Future expectations

The future expectation is one of the main themes which revolve around the expectation of the respondents that what they want to do in the future or where they see themselves after 10 years. This has been categorized into subthemes as professional careers, clarity, and uncertainty about the future. A professional career can be defined as the position or opportunity when an individual chooses a job, which gives higher pay, recognition, and success. Ms. A, who is a 17-year-old female, resides with her mother and maternal uncle, says that "I desired to be an airhostess but since medical checkup is required for the profession I can't apply. That is one of the reason I changed my aim but I am a

Table 1: Socio demographic profile of the respondents

Case number	Age	Gender	Living arrangement	Family details
1	17	Female	Home (mother)	Single orphan
2	14	Female	Home (maternal grandmother)	Double orphan
3	17	Male	Home (mother)	Single orphan
4	17	Male	Institute	Double orphan
5	17	Male	Institute	Double orphan
6	15	Female	Institute	Double orphan

professional dancer and actor, so I see myself as a model in the future.”

Master S, do not have professional job, and has comorbid injury in the knee. He says that “I want to be independent in life, was thinking to open a tea stall. Once I recover from the wound, I will initiate. Most often I do get doubt and confused that my HIV illness may hinder my future and plans. Master R, who has lost both the parents, says that “I am so confused and worried when I think about restrictions in my life, due to the HIV illness, makes me sad when I think about my future. Sometime I think I should be in the hostel forever, as it protects us, and I feel scared to dream of independent life. I want to enjoy and be happy, consciously I would say to ‘myself do not think about the future’ only enjoy life as it comes.” Another boy Master J said that “My health is very bad and I am getting repetitive thoughts that I may not recover, it is time for me to prepare.... Uncertainty, about the future is one of subtheme. Illness associated with HIV status, would determine their well-being, it would shatter their dreams and hopes, making them depressed, and fearful. Some have clarity about their future, some are confused, but most of them are worried about their HIV status coming in the way for their future life. Almost all the children said that they want to be happy and enjoy life. Most children even though have made plans, at the same time aware of the limitations of their HIV status, would govern their lives.

Relationships in their life

The expectation regarding the relationship is unique for all the respondents. All students had different notions about the relationship, some felt “good” to have relationship, some expressed it as “sin” to have any relationship, and some expressed that they are too young to think about it. Romantic relationship and marriage are the two areas explored in a relationship, and respondents voices been grouped in these two themes. Ms. A, studying in coeducation school has some uncertainty and confusion about the marriage “Till now I did not like anyone, but my mother has told me that even if I like someone I can’t marry him. I should marry a person who also has HIV/AIDS. But I want to marry a normal person since it is not possible, I would remain unmarried.” Ms. F who is a double orphan and stays with maternal grandmother has no idea about marriage, “I never thought about marriage romantic relationship.” Some students say that they desire to get married, but are worried, who would marry them once they know their HIV status. Mr. D says I like a girl, but she does not know about my illness. If she comes to know she might stop talking to me. Mr. J shows no interest and says, I am not interested in love, I want to be alone. I feel I am not grown enough to think about love, I like to be single, in my life “sister” (supervisor) and other friends are there, it is enough for me. I do not think I need more people in my life. Mr. R has still not planned for the marriage and says I do not think about relationship/marriage. If my warden asks me to

marry, I will or else I will continue to stay in the hostel. Ms. N who resides in the institute has reported that they do like to talk to boys ‘I do not know why, but I am scared to talk to boys. Even if I try I can’t talk with them openly. Hence, once I grow up I will think about marriage and relationship.

Social support

The support system has been found as one of the main themes. It describes the availability of people who let an individual know who they care and love about. Size, perception, availability, and frequency of social support also play a major role. It has been found the one has social support at three levels, primary that is family, secondary that is neighborhood and friends circle, and tertiary that is institute or organization. Hence, the same has been emerged as subthemes as follows: friend, family, others, spirituality, and loss. Friendship has been emerged as one of the strongest social supports. The presence of friends, have a positive impact on the lives of people in difficult circumstances. The respondents have different voices regarding the same. Ms. A says that “I have a close friend; I will share everything with her other than my illness. According to Mr. F I have my best friend with whom I share all of my worries.” It is found that even though they are scared of the stigma attached to the illness, but another feeling and need for the support for friendship is high. Respondent also has a belief that the other person understands them well.

The family is the primary social support. The assistance and support available from the family are unique in nature. It provides emotional, social, and financial support. Here, Ms. A described how her mother has always supported her: My mother has always supported me emotionally. When I failed in exams, my mom spoke to the principle and because of which they were passing me until IX standard which I came to know recently. I failed in PUC I year, that time my mom supported me a lot. She used to say there are so many ways to become independent and I can choose some other career option.

Ms. F was supported by her grandmother. She says that my grandmother supports me very much. Mr. J has been residing in institute other than that he does not have any social support. He has narrated no one is there for me, my sister is married and stays in Bangalore only but she does not talk to me. One of our relatives has told something to my sister after that left home and started staying at my uncle and aunt; she stopped talking with me and my mother.

Not only family members but also significant others have been a source of social support. It is mostly seen in the institutions, how the caretaker or other members provide comfort Mr. J narrated the circumstance where her biological sister did not come, but the care taker took care of him. When I was very serious, the sister working in the organization took

care of me. She is very good and is always there for me. She advises me and helps me whenever needed. Ms. N also says that my warden looks after me. If I have any problem he will take care (Case 6). Caretaker and warden play a significant role in the life of the adolescents residing in the institute. That gives a feel of belongingness to the adolescents. Most of the respondents have lost their family members because of the illness. Bereavement because of loss is experienced by most of the adolescents with HIV. Mr. says that her father died because of HIV/AIDS illness and he died because of that I lost my father because of the illness. Ms. F says I have seen my father and mother suffering from the same illness. My mother died when I was in the 2nd standard, My father died in 7th standard. Losing a family member because of HIV itself is a trauma. After that institutionalization is again a trauma. Hence, the respondents have undergone that also, it shows the mental health status of the respondent. Spirituality has also emerged as one of the theme as follows: where support comfort, hope, and meaning are the results of spirituality. It is also considered as a source of strength. Mr. D explains about his support when am upset I fight with God, that why he has given me such an illness. Mr. R has been using different spiritual methods as support. If am feeling bad, I use to talk with God, pray, read the bible, and then I will be fine. The respondents have different experience and beliefs about spirituality. To one it is sharing, and to the other, it's more of questioning. However, both things provide comfort to them.

DISCUSSION

This research helped to understand the future expectation and life stories in the context of living with HIV/AIDS. Talking regarding the future expectation, the clarity and uncertainty about the future and about the romantic relationship are two different aspects. The respondents experienced unique challenges to engage in relationships where even they had fear initiating it. HIV status was considered as a secret and was associated with rejection when revealed to the romantic partner because of poor knowledge about the illness where it was told that its dark and dirty and no one is going to love you.^[9] Some of them delay dating more than they would if they did not have HIV and some delay initiation of sexual relationship due to concerns regarding disclosure.^[9] In romantic relationship, there is a strong concern about the transmission of infection to the partner, even among those who have not had romantic experiences.

There is discomfort in the treatment aspect which is medication schedule that imposes restriction to trips with friends and other social interactions.^[2] The perception regarding the future is also influenced by peer relationship.^[10] The focus of most of the adolescent is on outcome related to occupation and education.^[10] Even in the current study, respondents see themselves securing a professional job as a requirement for their future. The expectation from the

relationship also is centered on the stigma, since, after disclosing the fact that they are having illness, whether their romantic partner would understand them or would they break the relationship is a big concern for them, this has led them in to confusion of whether they need to disclose their HIV status or need to hide their status. The negative connotations associated with HIV/AIDS were described more fully and expressed as part of the unrelenting issue of stigma. The respondents actually have feared that what others will think about them and what others will react for the same.^[6]

Social support is defined as the availability of people who care about us. Most of the studies done with the adolescents have focused on the size of social support and the frequency of contacts with their social networks and their perception of social support from their networks. Most of the female adolescents with HIV perceived experiencing negative social support.^[11] Findings suggest that families were women's primary social support in the long run for HIV-positive and negative. Sisters and staff, considered as sister like figures were providing emotional support for the adolescents.^[12] Adolescents also have a perception that, others may perceive negative about them of being responsible for their sexual behaviors questioning their morality, so they do not want to start a relationship or even if they wanted, they do not want to reveal it.^[13]

Young people also had dilemma about disclosure with reference to romantic/sexual relationship, marriage as well as future jobs. They stated its inevitable referring it to getting older and expecting understanding among the peers.^[13] The association with sexual promiscuity was hard for the adolescents as they did not acquire HIV through sexual activity. It is also stage of negotiating sexual/romantic relationships and belief about sex inhibit their confidence around the relationship^[13] and this also goes with the finding of the present study.

Limitation and implication

Sample size is small, so the results cannot be generalized. The findings from the present study clearly, underpin the importance of uncertainty regarding the future and stigma associated with the illness. It also implies the importance for need of a system which can add social support to these adolescents. Further research can focus on a longitudinal approach with more focused research questions.

CONCLUSION

Lives of the children/adolescents being infected by HIV/AIDS, unlike those of their counterparts are complicated with stigma, adjustment problems, and many other psychosocial issues. While studies conducted in India bring to light adjustment problems of these children, they fail to look at their future expectations and their dreams for them. They have within themselves, an inane ability to fight for survival

which till date no study has explored. Fighting against odds and dreaming big are adult tasks but these adolescents start at an early age. The current study gives attention to the fact that there is difference in the future expectation due to the illness. This paper raises the important facet of psychological and social needs of adolescent living with HIV and support they need to fight against the stigma.

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Conflicts of interest

There are no conflicts of interest.

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