

Research Article

Living with HIV/AIDS: A Qualitative Study to Assess the Quality of Life of Adolescents (13-19 Years) attending ART Centre of Selected Hospital in New Delhi

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A B S T R A C T

Introduction: Adolescents are the vulnerable group likely to have multiple interacting factors affecting their quality of life especially in Indian setting which has a large population of HIV positive children. Therefore, in order to understand the lived experiences and challenges faced by adolescents a Qualitative study was conducted to assess the QOL (Quality of Life) of Adolescents living with HIV/AIDS (ALWHA) under 3 domains: Psychological, Social & Spiritual. The research questions assessed were: What are the psychological experiences of ALWHA, What are the social experiences of ALWHA? How has the diagnosis of the illness affected the day to day life of ALWHA? What challenges do the adolescents face in their day to day life as a person living with HIV/AIDS?

Methods: A Qualitative approach with phenomenological design was implemented. Participants were selected through purposive sampling technique and data was collected using semi-structured interview schedule.

Result & Conclusion: Data was analyzed using thematic analysis and subsequent themes, sub-themes and categories emerged, which were: Reluctance to disclosure of HIV status, Experiences with Disclosure, Social Support, Spiritual well being, Difference in living with the disease before and after disclosure, Positive Living and Sexuality and Shame. The participants in this study had several resources at hand, including the treatment facilities and social support, which contributed to the acceptance of the disease condition and a positive living. Thus, it showed that ALWHA had an overall good QOL.

Keywords: Adolescents Living with HIV/AIDS, Quality of Life, Anti-Retro Viral Treatment

Introduction

HIV/AIDS emerged as one of the most important public health issues of late 20th century and is one of the leading causes of global mortality and morbidity.¹ The first Pediatric case was reported in 1982 in the Centre for Disease Control in USA. However, its epidemic is no longer limited to the medical field, but has crossed boundaries and thrown up issues which have social, legal and economic connotations². HIV destroys the immune system, resulting in increased susceptibility to a wide range of infections, cancers and other diseases that people with healthy immune system can fight off. The most advanced stage of HIV infection is Acquired Immunodeficiency Syndrome (AIDS).³

HIV epidemic matures with a growing population of adolescents; in recent years, this particular vulnerable group has seen a 50% increase in AIDS-related mortality compared with a decrease of 30% globally.⁴ Adolescence is a period of great physical, mental and emotional turmoil, and adolescents, in search of their identity, very often start experimenting with intravenous drugs or sex, both making them vulnerable to contract HIV.⁵

Adolescents are defined as individuals in 10-19 years age group. It is an age for sexual identity, exploration and experimentation.⁴ In 2016, about 2.1 million adolescents between the ages of 10 and 19 were living with HIV worldwide.⁶ The children (<15 years) account for 6.54% living with HIV in India in 2015 according to NACO.⁷ India estimated to have around 86000 new HIV infection in 2015, children (<15) account for 12% while remaining new infections were among adults (>15 years).⁸

The risk of HIV in Indian adolescents is further compounded by their inadequate knowledge about it. In addition, the conservative Indian culture with its social restrictions and norms prevents free and open discussion about HIV/AIDS within family and denies the children and adolescents even the basic information about it.⁹

Adolescents are the vulnerable group likely to have multiple interacting factors affecting their quality of life especially in Indian setting which has a large population of HIV positive children.¹⁰ Along with the prospect of lifelong treatment, the adolescents tend to navigate the usual challenges of their developing maturity-emotionally, psychologically, physically and sexually. Thus, adolescents suffer with stress due to their disease condition which in turn affects their Quality of Life.¹¹

The existence of stigma of HIV/AIDS in Indian society affects the life of Adolescents living with HIV irrespective of the awareness of their status. Any kind of deterioration during the adolescent stage may affect their future. Therefore, in this study the lived experiences and challenges faced by the adolescents were explored so that the health team members can focus on strengthening the services and help

them to accept their status, achieve a good Quality of Life and have a productive and meaningful future.

The Quality of Life was assessed under 3 domains: Psychological, Social and Spiritual with the help of research questions which were addressed as: What are the psychological experiences of adolescents living with HIV/AIDS (ALWHA)? What are the social experiences of ALWHA? How has the diagnosis of the illness affected the day to day life of ALWHA? What challenges do the adolescents face in their day to day life as a person living with HIV/AIDS?

Materials and Methods

Study Design

This Qualitative, phenomenological study was conducted at Anti-Retroviral Treatment centre of Safdarjung Hospital, New Delhi from 19th Dec 2017 till 15th Jan 2018 and was approved by the Institutional Ethical Committee. The samples were the adolescents aged between 13-19 years attending ART centre.

In this study, both schools of phenomenology were addressed. Descriptive phenomenology was addressed by studying and then describing the experiences of participants. The researcher made an attempt to take a peek into the lives of the ALWHA to unleash their emotions related to their psychological and social experiences. The researcher observed the verbal as well as non-verbal cues of the ALWHA. Then the experiences were interpreted by converting statements into codes and identifying themes thereby addressing the interpretative phenomenology. The participants were selected through purposive sampling technique as all the participants must have experienced the phenomenon and their participation in the study was on voluntary basis. A written informed consent was taken from the participants and their parents. The sample size was determined based on the data saturation, which was achieved with responses of nine participants because participants were the good informants as they were able to reflect on their experiences and communicate effectively; therefore the data saturation was achieved with a small sample number of participants.

Study Participants

Inclusion Criteria: ALWHA (Adolescents living with HIV/AIDS) with age between 13-19 years attending the centre, willing to participate in the study & available during the data collection period, physiologically stable (CD4 count \geq 500 and with no recent Opportunistic Infections), were diagnosed and disclosed with HIV for \geq 2 years.

Exclusion Criteria: The ALWHA who were critically ill and orphans were excluded from the study.

Data was collected using a Semi-structured Interview schedule validated by eleven experts, which was developed under two sections: i) Subject data sheet which included 11

items to assess the demographic profile of participants and history related to HIV/AIDS which comprises of Age, Gender, Education, Awareness of HIV status, Mode of transmission of illness, source and duration of disclosure of HIV status, HIV status of parents, Duration of ART, Counseling session attended and Attending support groups.

ii) Interview Schedule which was divided into four broad questions:

- What are your psychological experiences as living with HIV/AIDS?
- What are your social experiences as a person living with HIV/AIDS?
- How has the diagnosis of illness affected your life?
- What challenges do you face in your day to day life?

The interviews were recorded in an audio-recorder and transcribed and then translated from Hindi to English with the help of a language expert. Interviews were conducted in Hindi; each interview was approximately of 30-40 minutes each. There were no financial benefits provided to the participants associated with the study and there were no reported risks. Data collected was analyzed using thematic analysis and subsequent themes, subthemes and category emerged.

Result

The study results were based on the data collected through participants which were nine in number achieved through data saturation. The analyzed data was organized in terms of the research questions and presented under the following sections as phenomenon emerged.

Section I: Demographic Characteristics and History related to HIV/AIDS

Out of the nine participants 6 were males of 17-18 years and 3 were females between the age group of 15-16 years. Out of them four was school going, three were not attending school and three had completed their senior secondary education. HIV status of parents of six participants was positive. Six of them acquired HIV through their parents, two of them through blood transfusion and one was unknown. Out of the nine, seven participants were disclosed to their illness by their parents and two of them by health professionals. All participants were aware of their status. Six of them were attending support groups.

Table I. Themes emerged in the study

S. No.	Themes
1.	What are the psychological experiences of adolescents living with HIV/AIDS?
	1.1: Reluctance to Disclosure of HIV status to others
	1.2: Experiences with Disclosure

2.	What are the social experiences of adolescents living with HIV/AIDS?
	2.1: Social support
3.	How has the diagnosis of illness affected the day to day life of adolescents living with HIV/AIDS?
	3.1: Spiritual well being
	3.2: Difference in living with the disease before and after disclosure
	3.3 Positive Living
4.	What challenges do the adolescents face in their day to day life as a person living with HIV/AIDS?
	4.1: Sexuality and shame

Section II: Themes and Sub themes Emerged

In the present study, the major themes emerged helped to describe the phenomenon of the quality of life of ALWHA through the experiences and problems faced by the adolescents.

Theme 1. I: Reluctance to Disclosure of HIV Status to Others

Sub-theme 1.1.1: Fear of Stigmatization

The researcher revealed that the participants did not disclose their disease to their friends, relatives and neighbors due to the fear of discrimination and social stigma of the disease.

Code 8: *"It is obvious that If I will tell about my disease then people will think wrong about me. This disease is considered wrong, people will ask me multiple questions, that how did I got this? But I feel that my friends would probably not think wrong, they are sensible, they know how this disease spreads, in school we were told about HIV, in books as well it is written. But mummy papa has asked me to keep quiet so, I do not tell anybody".*

Sub-theme 1.1.2: Fear of Rejection and Social Isolation

Through these findings it was revealed that the adolescents are afraid of disclosing their identity of being HIV positive to their friends, neighbors and other relatives, they have a fear of getting neglected by the society and fear of getting socially isolated.

Code 1: *"I don't want to tell about my illness, if anyone gets to know this, they may not talk to me, my friends may leave me."*

Sub-theme 1.1.3: Instructed by parents to hide HIV status

The stigma of HIV/ AIDS doesn't allow anyone to reveal their identity to their family, friends and society. The parents of the participants instructed them to keep their HIV status a secret and not to share their condition with anyone.

This shows that parents have internalized stigma towards HIV/ AIDS.

Code 4: *“Neither my friends nor my neighbors are aware of my disease. My mother told me that this disease is bad, it occurs due to wrong relations and I should not tell about this to anybody.”*

Sub-theme 1.1.4: Hiding status from friends, family and school

The non disclosure of HIV status is central to how people manage themselves after the diagnosis.

The adolescent also reported that they got discriminated and rejected by their friends which were the reason for non disclosure of their status to anyone except their close ones.

1. Category 1.1.4.1: Issue of Trustworthiness

The trust and confidentiality are the key factors which enables the adolescents to disclose their illness to others. Many adolescents fear that if they tell one person of their status then rumors may spread and then the entire school, neighbors and the community will know about them.

Code 4: *“If I will tell about my disease to my relatives, then everyone in the area will get to know about my disease, everyone will make rumors about me that I might have done something wrong due to which I have acquired this disease.”*

Theme 1.2: Experience with Disclosure

Sub-theme 1.2.1: Depressive reactions

It was revealed that adolescents had different feelings and reactions after they learnt about their status. Most of the participants felt strange after disclosure of their HIV status, it was a shock and unexpected thing which has happened to them.

Code 1: *“That day I cried, I felt like everything has just stopped, my life has stopped and I can’t move on with my life. It was not my fault, why only me”?*

Sub-theme 1.2.2: Acceptance of HIV status

The adolescents revealed that along with the support of family members, the importance of taking medicine and its routine for the good quality of life helped them to accept themselves as HIV-positive person and live their life to the fullest. The participants expressed the desire to live as others do.

Code 4: *“Sometimes it seems that if I did not have this disease, my health would have been good, but now I don’t think of that, when I see so many people coming here for their treatment suffering with the same disease, if they can live a normal life then I also can”.*

Theme 2.1: Social Support

Sub-theme 2.1.1: Family as a positive resource

Family was reported as an important support system by

the ALWHA. The researcher revealed that majority of adolescents felt supported by their family members.

Code 3: *“My family supports me completely, I never feel alone, Mummy and papa take care of my medicine, both my brothers’ love me very much, and they always help me in everything”.*

Sub-theme 2.1.2: Support group as a positive resource

Three of the participants are attending a support group for people living with HIV. The researcher reveals the findings that the adolescents enjoyed being part of the support group where they are able to share information with their fellow HIV positive adolescents. The participants reveal that being with the support groups helps them to share their ideas on how to solve their problems and ‘move on in life.’

Code 5: *“I used to go to an NGO, 3-4 children of my age and adults living with HIV come there for the guidance and support, we share our experiences and are being informed about HIV, I feel good when I share my feelings with them”.*

Sub-theme 2.1.3: Health care provider and ongoing counseling sessions as a positive resource

The participants depicted that Counseling provided to them in the ART centre helped them to overcome the feeling of depression, anger and fear and they felt motivated after attending the sessions.

Code 7: *“I share all my secrets and my feelings with counselor, she always helps me deciding what to do and what not to do. Since then I have not made sexual relations with any person as I don’t want to harm others because of me. I like taking advice from them”.*

Theme 3.1: Spiritual Well Being

Sub theme 3.1.1: Praying as a positive resource

Participants reported that praying helped them to change a state of mind in positive ways. They linked their praying to have more hope, feeling stronger, being more positive about themselves and their lives. One of the participants expressed that praying to God help her to fight with her daily life struggles and challenges and gives her strength.

Code 2: *“Initially I used to complain to God, that why only me? Why I got this disease? But now I am fine, I have no complaints to God, I am happy now.”*

Code 6: *“I have complete faith in God, I always pray to him, sometimes I ask God to make me free of this disease. I hope that God does not forbid that anyone else has this disease.”*

Theme 3.2: Difference in living with disease before & after disclosure

Sub-theme 3.2.1: Seeking Knowledge about HIV

Most of the adolescents were not aware of HIV/ AIDS before they got disclosed to their positive status. The participants

revealed that they are now aware of the disease and thus they have become careful for their health.

Code 3: *"HIV is a virus, which spreads through injections, blood products, and from parents to children."*

Code 4: *"I have been taking medicines since 5 years, at that time I was not aware of HIV, since 2 years I have been disclosed to my illness, I got to know about HIV in the centre, where I was told that it is a virus which spreads in our blood and weakens the immune system and spreads through injections, blood, making sexual relations and by parents to children"*

Sub-theme 3.2.2: Improved general health care practices

Most of the adolescents revealed that they consume healthy diet, perform regular exercises and prevent themselves from any kind of infection.

Code 2: *"After I got diagnosed to my illness, I have seen changes in my body, I did not feel hungry, even my weight was reduced, but now everything is fine, I take care of my health, I don't take stress as doing so makes the CD4 count decrease in our blood"*

Code3: *"I sometimes face health problems, but I take care of myself, I eat fruits and vegetables."*

Code 5: *"I eat healthy food and try to prevent myself from infection, in school also I take care of myself and take medication on time."*

1. Category 3.2.2.1: Acceptance of disease and adapting healthy lifestyle

Sub-theme 3.2.3: Understanding the importance and maintaining adherence with ART

The health professionals and parents emerged as a source of encouragement for the adolescents to adhere to the ART. Most of the adolescents, who have knowledge about HIV, show increase adherence to ART which indeed leads to a better quality of life.

Code 7: *"Once I got scared as my father asked me to get milk from a dairy, a man there asked me that do I know about HIV. So, I got scared and had a thought that is he aware of my disease? Then, I replied that I don't know, then he told me that a soldier in his village had HIV, he never took any medicine for that and he used to live like this and he died. After hearing this incidence, I realized that it is necessary to take medicines, so, I don't miss even a single dose, I was told in the centre that medicines have to be taken on time and it should not be missed."*

Code 8: *"I was told by the doctor that in this disease taking daily medicine is very important; medicine makes our life longer and better. Mother told me that medicine has to be taken for the lifetime and by this way only I can have a healthy life"*

Code 9: *"In this disease, the only way to be healthy and safe is to take medicines on time"*

Theme 3.3: Positive Living

Positive Living means taking care of one's health and body when one has HIV. An individual with HIV can live a healthy, normal and productive life when they practice Positive Living. The study participants revealed their positive approach towards life, their hope for the cure to come for HIV and the hope for a good future showed the signs of positive living which may ultimately lead to a good quality of life.

Sub-theme 3.3.1: Hope for complete cure of the disease in future

The potential sources for fostering hope are receiving support, engaging in life experiences, receiving treatment and maintaining QOL. While some of the participants concentrated on the present moment, others focused on hopes of what the future might be like. For an instance few of them hoped for a cure.

Code 5: *"I heard that by 2018 something will happen that will end HIV. I wish this disease should have a complete cure."*

Code 7: *"Now for the future I wish that some cure would come for the disease, no matter if I have to pay 20-25 Lakh rupees, the cure should come"*

Code 8: *"I hope someday this disease will be cured, I will be free of this."*

Sub-theme 3.3.2: Envisioning the future

The adolescents studying in school had higher aspirations for their future while the adolescents who discontinued their education had regretted for not completing their schooling and they had desired to complete their studies and wanted to have a good future for themselves.

Code 5: *"I want to become an Air hostess, although earlier I thought of becoming a doctor but now I get scared when I see blood, so I dropped this idea. If I could become a doctor I would have made a drug to cure HIV."*

Code 6: *"I wonder if I would have completed my school, then I could have become a doctor. I discontinued my studies due to my family's condition, but now I have decided to get admission in 10th class and complete my education."*

Code 7: *"I look after my father's business, I have left my studies in between, and I don't want to study. I am interested in business and I have thought of doing that only."*

Theme 4.1: Sexuality and Shame

Sub-theme 4.1.1: Denial for Marriage

The participants reported that they don't want to get married as they wanted to focus on their career and also

due to the fear of non- acceptance by their future partner or family.

Code 8: "I don't even want to get married; I wonder what kind of family I may get? They might think wrong about me, everyone do not have a good mentality about this disease, it depends on those people. So, I decided that I will not get married ever in my life."

Code 6: "I want to have a family in future but due to my illness I don't want to spoil the life of a person so, I decided that will not get married. Till I have no plans for that, firstly, I want to complete my schooling."

Sub-theme 4.1.2: Abstinence from sexual relationships

One of the participants reported being very strongly discouraged from having girlfriends by his parents. Therefore, the adolescent also decided to never get married to someone in his life due to the fear of spreading disease to anyone.

Code 2: "Mother told me not to have any relation with girls (don't make a girlfriend) because of my illness, even mother has denied for my marriage and I also agreed to never get married in my life."

Code 5: "I have never had a relationship with a guy. I have

not thought about it. I don't think I will be in a relationship one day".

Sub-theme 4.1.3: Depicting moral values and social responsibility

It was found that most of the participants didn't want their HIV status to be kept hidden in future if they plan to get married. They wanted to make other person aware of their disease condition.

Code 6: "I have decided that If ever I would thought of getting married, then I will inform my partner about my disease, I won't marry without telling her, if I would do so, my relationship would get in danger and I would not have a happy married life."

On the other hand one of the participants cancelled his marriage after getting aware of his illness.

Code 7: "I refused my in laws to marry their daughter; I told them that I drink alcohol and I am not a good guy and asked them to get their daughter married to someone else."

Conceptual Framework was developed by employing Wilson and Cleary Health Related Quality of Life Model by Ferrans et al (2005) based on the themes and subthemes emerged in the study.

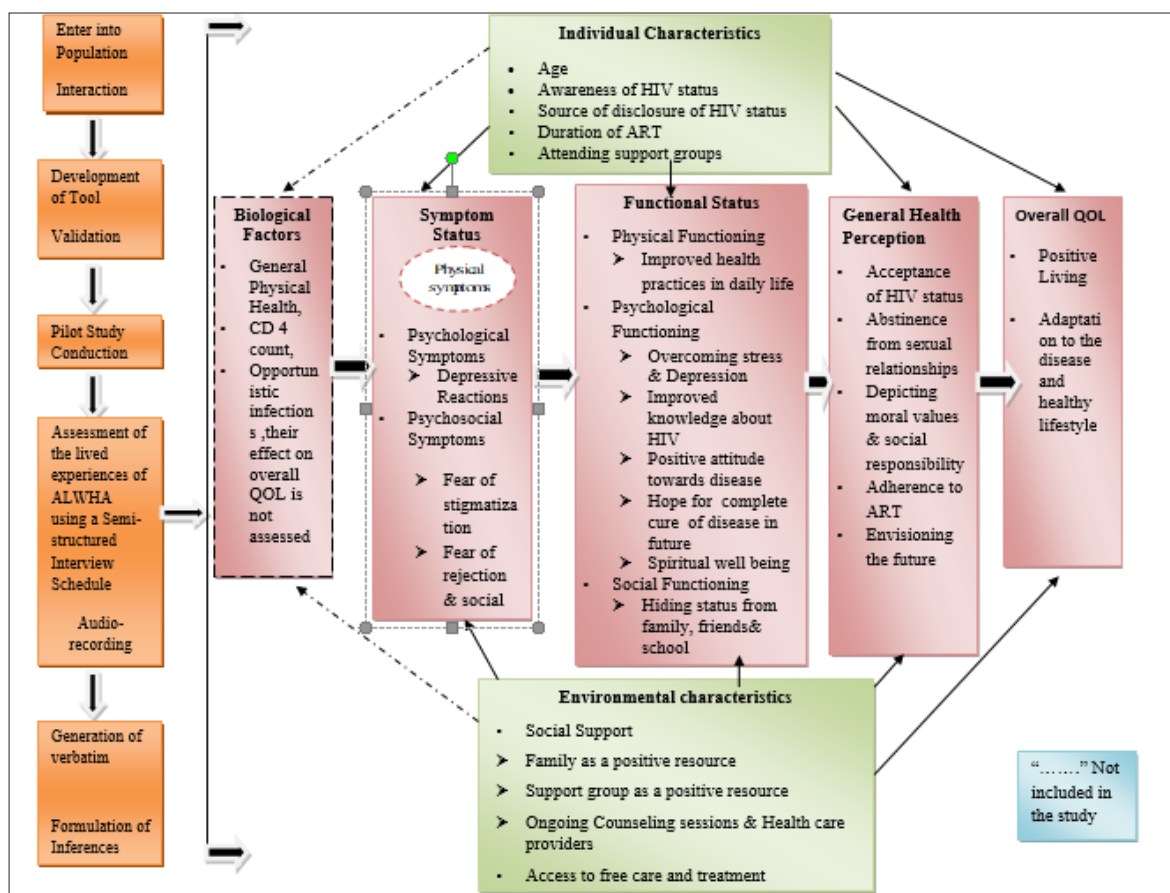


Figure 1. Revised Wilson & Cleary model of QOL by Ferrans et al. (2005)

Discussion

The findings of the present study were in conformity with the findings of a qualitative study conducted by Hogwood J, Campbell T, Butler S.¹² revealed a number of societal factors which were found to be important barriers inhibiting disclosure to others. Although stigma and discrimination are considered to be among the most important barriers preventing disclosure among youth.¹³ Another theme which emerged was the social support system, the present research findings were consistent with the findings of a study conducted by Riberio CA.¹⁴ reported that family participates in the adolescents life and its presence in the surrounding world of care with the adolescents helped in promoting the wellbeing of the adolescent having HIV/AIDS.

Spirituality played a major role in assisting participants to live a healthy life. An exploratory qualitative study conducted by Spurr S, Shelley, Berry L and Walker K.¹⁵ focused on the meanings older adolescents aged 16-19 attached to spirituality. The findings suggested that the majority of participants agreed that spirituality significantly affected their sense of wellness.

Another factor which contributed to a good quality of life was adherence to treatment regimen. Contrary to the present study findings a cross sectional study conducted by Veinot TC, Flicker SE, Skinner HA, McClelland A, Saulnier P, Read SE et al.¹⁶ In Canada among adolescents reported that participants did not understand or believe in, antiretroviral treatment. Difficulties in taking medications, problems with social routine disruption, feeling "different" and side effects were the factors contributing to non adherence to treatment.

The study limitations: Mode of transmission was not given importance in exploring the experiences of ALWHA. The generalizability of the study findings is difficult to make out due to the small sample size and only one study setting. The physical health and socio-economic status were not explored to assess the QOL of ALWHA.

Conclusion

The ALWHA had varied experiences as a person living with HIV/ AIDS; participants were disclosed to their illness by their parents and health professionals. They had different reactions when they got to know about their Sero-positive status. The optimistic attitude of the adolescents, social support provided by family, support groups, health care providers and on-going counseling sessions and their spiritual beliefs helped the participants to adapt to their life situation. Although the participants faced a few challenges in their life like dilemma of sexuality and making of heterosexual relationships. At the same time the complete abstinence from sexual relationships showed that the participants had a sense of social responsibility and

moral values as they decided not to hide their status from their partner if in future they consider for getting married. The findings from the analysis of the verbatim of ALWHA revealed that various factors contribute to QOL.

Conflict of Interest: None

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