

A systematic review of HIV/ AIDS related stigma among children and youth living with HIV

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HIV/AIDS-related stigma is one of the significant obstacles to HIV prevention attempts in the world. Children and Youth infected with HIV/AIDS are particularly more prone to stigma and discrimination because of lack of knowledge about the disease and their rights. The objective of the present review article is to explore the researches and studies related to HIV/AIDS related stigma among children and youth living with HIV/AIDS and highlighting major findings. A detailed review and critical evaluation of published empirical studies from various databases such as PubMed, PsycINFO and online published data of several organizations were accessed for through survey, internet searches, and online journals related to HIV/AIDS related Stigma have been accessed till date to present the current state of research and development in this area. The outcome of database search resulted in 74 potentially relevant articles related to HIV/AIDS stigma. Among these, only eight articles were found applicable and met the inclusion criteria of assessing the HIV/AIDS related stigma of HIV/ AIDS children and youth. These studies concluded that HIV/AIDS related stigma is negatively associated with (a) medical adherence, (b) disclosure of HIV status, (c) health care satisfaction, (d) coping strategies and (e) social support and positively correlated with depressive symptoms among children and youth living with HIV/AIDS. The stigma associated with HIV/AIDS is a major risk for the prevention and intervention efforts for enhancing the psychological health and well-being of HIV/AIDS children and Youth.

Keywords: HIV/AIDS, HIV/AIDS related stigma, HIV infected children and youth, systematic review

HIV/AIDS

HIV/AIDS has rapidly established itself throughout the world with 34 million people presently suffering from it (UNAIDS, 2012) and 25 million people lost their lives because of it over the past thirty years. Worldwide, 590,000 adolescents of 15-24 were recently infected with HIV of whom 250,000 were adolescents of 15-19 years age group (UNICEF 2017). Reports present that 35 % of AIDS patients in India belong to 15-24 years age group. The youth is one of the most susceptible groups as far as the threat of HIV/AIDS is concerned (NACO, 2013).

HIV/AIDS related stigma

Stigma and Discrimination related to the HIV disease are some of the major challenges for the people living with HIV/AIDS in present scenario globally. In this context HIV/AIDS related stigma has been defined as prejudice, negative attitudes and insulting against people perceived to have HIV (Rueda et al., 2016). Stigma and discrimination affect people in the healthcare setting by limiting them from accessing, primary and secondary HIV/AIDS services voluntary testing and counselling, also barring them to avail to care and treatments and support programmes (Holzemer & Uys, 2004; UNAIDS, 2007). Stigma and discrimination have been considered as a fundamental principle in phase three of India's National programme to prevent and control HIV (National AIDS Control

Organization-NACO, 2006). It is important to choose a human rights approach to HIV / AIDS in favour of public health it will become the crucial solution to eliminate stigma and discrimination. In India research on this significant subject is picking up however yet the areas such scopes and intervention are largely unaddressed (Bharat, 2011). Nevertheless, all chronic diseases have potential to confine the practical status efficiency and quality of life of the people suffering with them, but HIV/AIDS and cancer are exceptional among them as both arouse extreme fear and are encompassed by extensive stigma and discrimination (Pandey & Shukla, 2016).

HIV/AIDS related stigma is multidimensional and is of three broad types namely:

- Self-stigma, related to self-blame and self-deprecation of individuals living with HIV/AIDS (Sweat & Levin, 1995; Apinundecha et al., 2007; Zhou, 2007).
- Perceived stigma, associated with the fear of disclosure of their HIV-Positive status, that if the status is revealed they might get stigmatized.
- Enacted stigma transpires when PLHIV are exactly discriminated based on their HIV status: Real or perceived (Thomas, 2006; Bond et al., 2002; Van Landingham et al., 2005; Steward et al., 2008).

Verbal abuse, gossip, distancing attitudes, degradation, rejection and abandonment towards people living with HIV/AIDS manifest HIV/AIDS stigma (Thomas, 2006; Bond et al., 2002; & Deng et al., 2007). It can be subtle or extreme action. Stigma is an important life concern which needs to be addressed for the children infected and affected by HIV/AIDS (Brackins et al., 2003).

HIV/AIDS children and youth

A child and youth infected with HIV/AIDS below the age of 25 are known as HIV/AIDS children and Youth (UNICEF, UNAIDS,

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USAID, 2004). In contrast to adults, children and adolescents infected by HIV/AIDS are disproportionately affected by the HIV/AIDS epidemic and they are at increased vulnerability to stigma and discrimination since they are frequently not responsible for their condition and are less aware to ask for their rights. Stigma can have an influence on children in various ways when it advances towards active discrimination like denied entry to schools, separation from school friends, making them orphans, intimidating their leaving and survival and it worsens their material and psychological problems. Since research and studies have been conducted regarding HIV/AIDS related stigma on adults, However, their findings cannot be applied to children and youth surviving with HIV/AIDS.

Method

Search strategy

A detailed search strategy was developed and executed for standard review methodology using the search terms 'HIV/AIDS related stigma'. In addition, literature search was specified by using precise search terms like 'HIV/AIDS related stigma and children and youth living with HIV/AIDS'. Electronic databases PubMed, PsycINFO,

Web searches (Google, Google Scholar, & Yahoo) and the websites of UNAIDS, UNESCO, UNICEF, and WHO were explored till date for all published articles explicitly associated to HIV/AIDS related stigma of HIV/AIDS children and youth (625 years), All 74 articles were critically examined for consideration eventually, only eight articles out of 74 met the set inclusion criteria. In particular only articles with HIV/AIDS related stigma of HIV/AIDS children and youth, On the basis of qualitative and quantitative methods published in the English language were incorporated. Articles on HIV/AIDS related stigma of non-HIV/AIDS children and youth, HIV/AIDS-affected children and youth, and children suffering from other chronic illnesses (except HIV/AIDS) were excluded. The review selection process and inclusion and exclusion criteria are stated in Figure 1. All eight studies of HIV/AIDS related stigma are cross-sectional in nature out of which six are quantitative study, and two are quantitative and qualitative research. A summary table of eight reviewed article including methods, sample and key finding of HIV/AIDS related stigma among children and youth living with HIV/AIDS are also explained in Table 1.

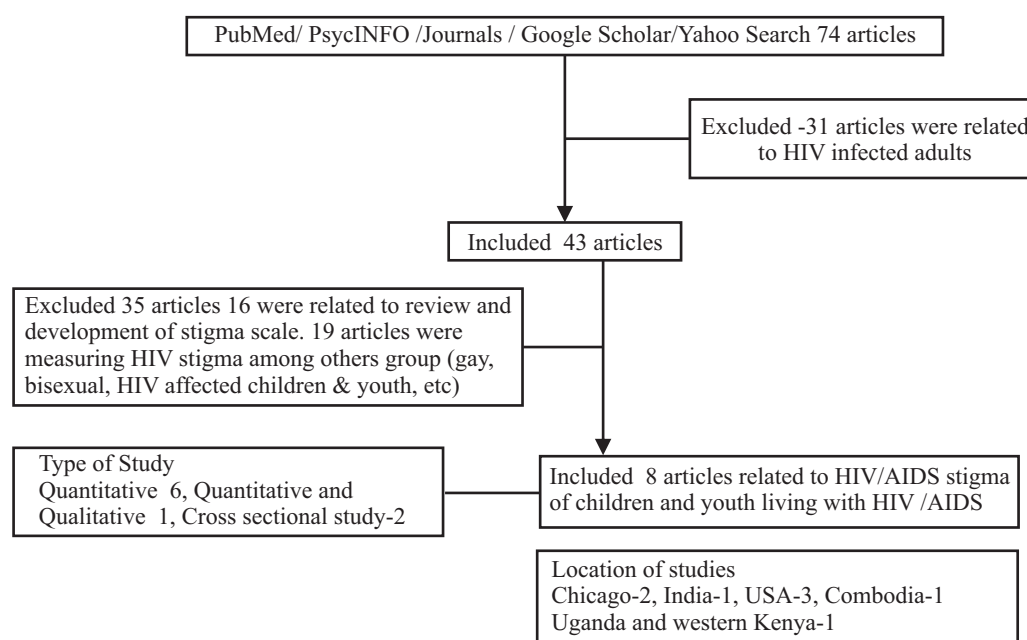


Figure 1: Review/selection process and distribution of selected articles.

Table 1: Summary of Studies Investigating studies of HIV/AIDS related Stigma among children and youth living with HIV/AIDS

Author/year/ country	Types of Research Design	Study Sample	Measures	Main findings
1. Martinez et al. (2012), Chicago, Illinois.	Quantitative research, Longitudinal Design	178 HIV positive young girls of 1524 yrs.	Self-report of medication adherence with ACASI-12 items, Berger Stigma scale-40 items, Social provision scale-24 items, CES-D scale, CSS-11 items, A-COPE 54 items scale	HIV-infected young women encounter HIV stigma and poor adherence. healthcare satisfaction and Coping factors/reduces impact of stigma' on medication adherence.

2. Gupta et al. (2015) Delhi India.	Cross-sectional study, Single-group design.	100 HIV infected children of 10-18yrs age enrolled in tertiary care hospital	Structured interview schedule on a pre-tested questionnaire which includes child personal history, knowledge of HIV, psychological concern, HIV stigma and behavioural problems.	Among 100 HIV infected children only 65% respondents knew about their HIV status, 23 had an anger feeling, 19 children showed isolation tendencies, 15 were fearful, 29 children had a feeling of stigma towards HIV, and 10 felt discriminated by classmates and community. Majority of respondents 91% wanted to be a grown up and fight the disease bravely.
3. Barennes et al. (2014). Cambodia.	Quantitative Research, Correlational design	183 HIV infected children of 07-15 yrs.	Pre-tested standardized questionnaire of 47 items, Perceived Stigma questionnaire adapted from Jacoby scale of Perceived Stigma.	Study findings suggest that among 183 HIV positive children 79 (43.2%) encounter perceived stigma, including refusal by different peoples (26.8%), no welcome to social functions (18.6%) followed by exclusion from recreational activities (14.2%). A sum of 43 children were frightful of their disease whereas knowledge of own HIV status was reported by 61 (53.9%) of 113 children older than 6 yrs. Among 136 children above five years and entitled for education, 7 (3.8%) could not go to school due to perceived stigma. Imperfect adherence to ART was accounted for 17 (9.2%) children. multivariate analysis results reveals that, attending school and income of less than one dollar for each individual everyday were related with perceived stigma. Alternatively, getting social support was related with decreased risk of perceived stigma
4. Tanny et al. (2013) USA.	Quantitative and Multisite study.	186 HIV infected youth of 18-30yrs	CRAFFT-6 items, Berger shortened Stigma scale-10 items and BIS for Depression and CAPI	Stigma, Behavioral disease, elderliness, more problem behaviours added to the prognosticator of higher depression scores in youth living with HIV/AIDS.
5. Nöstlinger et al. (2015). Uganda, Kampala and western Kenya.	Quantitative analysis Cross-sectional study	ALHIV-582 of 13 to 17 yrs.	Self-constructed scale to assess self-efficacy to disclose HIV, Rosenberg's self-esteem scale, Short HIV stigma scale-10 items, HQOL and KIDSCREEN for social support.	Research outcomes suggest that fifty percent ALHIV had not informed anyone (except health-care providers) about their HIV status, and about 18% had revealed to either one of their peer, classmate, or a boy- or girlfriend. Detailed levels of self-perceived stigma were in the medium range, with the elevated scores for personalized stigma, which measures part of interacting with friends and responses to HIV got by others. Regression models explained that disclosing HIV status to peers was significantly associated with several factors such as being elderly, being a paternal orphan, /adding to family salary, systematically attending HIV clinic, and higher social help through friends while perceived stigma associated variables were altogether significantly associated with social self-disclosure in the bivariate analysis however not in the final regression model.
6. Swendeman et al. (2006) USA.	Quantitative Research, Pre-Post	147 Substance using Young living with HIV/AIDS (YPLH)	Sowell and colleagues (1997) Stigma Scale for enacted and perceived stigma. Self-reported	Findings reveal that approximately 89 % HIV positive youth reported perceived stigma and 31% report enacted experiences

	Design	of 16 to 29 years.	measure of HIV risk behaviour, Serostatus awareness an HIV/AIDS	in the previous three months; 64% reported stigma/encounter in their life. Enacted stigma was found to be associated with gay/bisexual identity, symptomatic HIV or AIDS, and bartering sex. Perceived stigma score of youth was significantly correlated with female, symptomatic HIV or AIDS, sex trading, lower injection drug use, and lesser friends and family knowing serostatus. Gay, bisexual AIDS diagnosed youth was experienced more HIV-stigma in comparison to their heterosexual friend.
7. Clum et al. (2009) the USA	Quantitative and Qualitative Research. Single group and Correlational design	147 HIV-infected girls and young adults of 1324 years.	NIMH Multisite Cooperative Agreement sexual risk behaviour assessment, Interview scheduled for Drug use, Berger HIV stigma scale-40 items, SPS-24 items, NIMH Diagnostic Interview Schedule for Children for the Major depressive disorder.	This study investigated that HIV stigma significantly predicted Major Depressive Disorder (MDD) ($\beta = 0.056$, $p < 0.05$) among female adolescents suffering from HIV/AIDS. The relation between HIV stigma and engagement in risk behaviour of female adolescence was partially mediated by MDD, thus MDD reported as a significant mediator between stigma and risk behaviour class.
8. Rao et al. (2007) Chicago, Illinois.	A qualitative study, Single-group design	25 HIV positive patients (52% male and 48% female) between the age group of 17 and 25.	Focus group interview to access Substance use, HIV Stigma, HIV status disclosure, lifestyle factors and psychological factors of HIV participants.	Findings reveal that half of the participants signify that they skipped doses since they were scared that (perceived stigma) family or peers would come to know their status. HIV stigma impacts treatment for youth on multiple levels, from the precision of correspondence with medical providers to medication adherence, following health outcomes, and the occurrence of treatment-resistant strains.

Notes: Full form of all scales: Audio computer assisted self-interviewing (ACASI), Center for Epidemiological Studies Depression Scale for Children (CES-DC) (Fendrich, Weissman, & Warner, 1990); Client Satisfaction survey (CSS) (Martinez et al. 2012), Adolescent Coping Orientation for Problem Experiences Scale (A-COPE) (Patterson and Hamilton 1995), Car, Relax, Alone, Forget, Friends, Trouble (CRAFTT) (John R Knight 1999), Brief Symptoms Inventory (BSI) (Derogatis & Spencer, 1982), computer assisted personal interviewing (CAPI), Health related quality of life (HQOL)(Ravens-Sieberer et al., 2008, 2010), National Institute of Mental Health (NIMH), Social Provision Scale (SPS) (Russell & Cutrona, 1984,

Results

As the result of an extensive database search, 74 articles were found potentially relevant to HIV/AIDS stigma of people sustaining with HIV/AIDS. Among these, only eight articles were found applicable and met the inclusion criteria of assessing the HIV/AIDS related stigma of HIV/AIDS children and youth. The study and analysis of the article can be conceptualized as follows.

HIV related stigma assessment among children and youth living with HIV/AIDS

In the study Martinez et al. (2012) it is revealed that HIV-infected young women encounter HIV stigma and poor adherence. HIV stigma self-experienced by adolescents women was with a mean score of 57.60 (SD of 11.83); scores range: the low score was 25, the high score was 86. Gupta et al. (2015) assessed that 29 out of 100 HIV infected children had developed a feeling of stigma towards HIV, and 10 felt discriminated by schoolmates and society. Barennes et al. (2014) reported that among 183 HIV positive children 79(43.2%)

experienced perceived stigma including refusal by different people (26.8%), no welcome to social functions (18.6%) followed by rejection from recreation activities (14.2%). In a related study by Nöstlinger et al. (2015) it is examined that among 147 substance using HIV infected youth 89 YPLH

Reported perceived stigma and 31% reported enacted experiences in the previous three months. In an investigation by Rao et al. (2007) on 25 HIV infected children half of the of the participants encountered perceived stigma. Participants report similar oppressed behaviour by their relatives.

The positive association between HIV related stigma and depressive symptoms

In the study by Tanny et al. (2013) researchers found the association between depression and stigma in a multi-site sample of youth living with HIV (YLH). This study also reports depression as a significant mediator between HIV-related stigma and risk behaviour.

Clum et al. (2009) examined that HIV stigma significantly predicted Major Depressive Disorder (MDD) ($\beta = 0.056$, $p < 0.05$)

among female adolescents suffering from HIV/AIDS. The relation between HIV stigma and engagement in risk behaviour of female adolescence was partially mediated by MDD, thus MDD reported as a significant driving factor between stigma and risk behaviour class.

The negative association between HIV/AIDS related stigma and medical adherence

Rao et al. (2007) analyzed the association between HIV/AIDS stigma and Medical adherence on 25 HIV infected children and the research concludes that HIV stigma impact treatment for youth on multiple levels. Additionally, Martinez et al. (2012) inspected the connection between HIV/AIDS related Stigma and Medical Adherence on a sample of 178 HIV-infected adolescent women and results propose that women experience HIV stigma and poor association to their antiretroviral drugs which demonstrated that there is strong negative correlation between stigma and medication adherence among HIV infected young women. Barennes et al. (2014) observed the moderating effect of Social support on HIV/AIDS related stigma and medical adherence of ALHIV in his study. Research results reveal that among 183 HIV positive children 79 (43.2%) experienced perceived stigma; imperfect adherence to ART was accounted for 17 (9.2%) children.

Moderating effect of perceived social support on HIV stigma and medical adherence

Martinez et al. (2012) examined the moderating effect of Perceived social support (PSS) on the effect of stigma on medication adherence among HIV positive young women. No significant moderating effect was observed for the social support measure exhibiting that this category of young women revealed great perceived social support; therefore, social support would not moderate the stigma-adherence relationship.

Barennes et al. (2014) studied the association amongst PSS and Stigma among 183 HIV infected children. In the study, multivariate regression analysis presents social support as an independent factor related to a decreased risk of Perceived stigma. Receiving support was negatively related to perceived stigma if the father or mother was dead. The investigation additionally concluded that the absence of social support is one of the significant risk factor associated with perceived stigma.

The intervening impact of social support on HIV related stigma and disgrace and engagement in risk behaviour among young females was studied by Clum et al. (2009) research revealed that HIV stigma significantly anticipated social support among young females living with HIV/AIDS. Thus, offering social support to children and youth living with HIV helps them to confront with perceived stigma.

Moderating effect of healthcare satisfaction on stigma and medical adherence

Martinez et al. (2012) analyzed the moderating effect of health care satisfaction on the relationship between stigma and medication adherence. The initial moderator analysis, revealed the significant ($B = -0.020$, $SE = 0.010$, $p < 0.05$) interaction between healthcare satisfaction and stigma Post hoc analyses revealed that at low degree of health care satisfaction, stigma was adversely associated with medication adherence on contrary high degrees of health care satisfaction showed no relation associated with, stigma and medication adherence. Accordingly, at a low level of satisfaction with health care, increasing levels of stigma will be related to lower

levels of adherence. Trustful association and optimistic working relationships with primary care providers it might become an effective tool for HIV positive youth to adhere to their treatment and to battle with HIV stigma and disgrace.

Moderating effect of coping strategies on stigma and medical adherence

Martinez et al. (2012) examined the significance of people involved in active strategies for coping that can subside the association between stigma and treatment adherence. Research findings recommend that proactive coping strategies and spiritual coping strategies were found to be the moderating factor of the relationship between stigma and medication adherence. This study suggests that proactive coping and spiritual coping help young women with HIV, to adhere to medications despite stigma.

The negative association between HIV/AIDS stigma and HIV status disclosure concern

Swendeman et al. (2006) examined the relation between Perceived stigma and disclosure concern. Research findings suggested that Perceived stigma was related to lesser friends and family knowing serostatus. Youth ($M = 23$ years) with increased levels of perceived stigma, frequently maintained a strategic distance from social contacts. Perceived HIV-stigma very likely impacts YPLH to restrain others' awareness of their HIV serostatus, as well as decreased disclosure. This may result in both self-defensive (e.g., limiting chances for stigmatizing & discriminating events and responses), and negative results (e.g., restricting social support & receipt of suitable care and services, increased risk of HIV transmission, etc. In a follow-up study, Rao et al. (2007) found the negative association between stigma and disclosure. Thus, it is crucial to develop and assimilate safe condition in regular HIV care and in the family through which ALHIV can build a trustful relationship with their friends, family and practice disclosure skills and abilities.

Nöstlinger et al. (2015) investigated the factor impacting social self-disclosure among HIV infected adolescents. Research outcomes suggest that fifty percent ALHIV had not informed anyone (except health-care providers) about their HIV status, and about 18% had revealed to either one of their peer's classmates or a boy- or girlfriend. Furthermore, Logistic regression models explained that disclosing HIV status to peers was significantly associated to several factors such as being elderly, being a paternal orphan, contributing to family income, regular visits to the HIV clinic, and greater social help through peers while perceived stigma-related factors were altogether significantly associated with social self-disclosure in the bivariate analysis however not in the final regression model.

A socio-demographic factor associated with perceived stigma

Swendeman et al. (2006) studied the relationship between socio-demographic factors (gender, sexual orientation, ethnicity, monetary status) and HIV stigma among youth living with HIV. The Perceived Stigma score of youth was significantly correlated with the females, symptomatic HIV/AIDS, sex trading, lower injection drug use, and lesser friends and family aware of serostatus. However, youth from black ethnicity reported a higher level of perceived social discrimination than whites. The HIV-stigma was

observed more in bisexual YPLH who were also HIV symptomatic or AIDS diagnosed in comparison to their heterosexual peers.

Discussion and conclusion

HIV infected youth and children widely report experience of HIV/AIDS stigma. They avoid socializing, enjoying recreational activities, are ignored and discriminated at school and society. It is important to provide counselling, education, training and interventions to diminish the adverse behavioural and psychological impact of perceived HIV/AIDS stigma.

HIV/AIDS stigma was found to be positively correlated with depression among youth and children infected with HIV. Maximum adolescents scored at or above clinical cut off limit for depression Tanny et al. (2013) which suggests that these circumstances make them prone to loneliness, detachment from society, loss of interest, self blame, fear and psychological trauma. Depressive symptoms lead to lack of medical adherence and inclination towards suicidal ideation. They feel like they are going through a bad time and avoid taking care of themselves. The mental well-being of these children is in danger and the endeavours are missing for enhancing their psychological well-being.

HIV/AIDS stigma was reviewed to be negatively associated with medical adherence. HIV-infected children and youth report HIV-related stigma and show poor response to their antiretroviral medications and treatment. Antiretroviral therapy is very much necessary for individual infected with HIV/AIDS and proper ART adherence can help in managing fatal and chronic illness. But due to the perceived stigma associated with the disease children and youth confine them and they avoid going to ART centers because of shame and disgrace. They have fear taking medicine in public which lead to skipping doses and avoiding medical adherence. Children fear from health care provider as authoritative persons and do not want to discuss about their poor adherence because they think that they will be criticized for that. Thus for improving medical adherence among these children it is important to make them aware about realities of living with HIV and providing sense of acceptance so that they can continue their treatment without hesitation.

Moderating effect of Perceived social support on the relationship of HIV/AIDS stigma and medical adherence was also observed from this review. The receipt of social support was directly related to the lesser risk of perceived stigma whereas the absence of social support was seen as one of the serious threat associated with perceived stigma (Barennes et al., 2014). Family and friends can provide social support to HIV infected children and youth in form of emotional support like showing love and empathy towards them. Health care provider can provide them informational support like suggestion, advice and awareness related with medication and tangible support like offering them services and aid related with the disease. Thus social support in the form of help in giving tablets, talking about their problems, devoting time, sharing things with them, avoiding discrimination and providing them counseling and positivity towards life can help them to confront HIV stigma and help in improving their medical adherence

Health care satisfaction and coping strategies moderate the relationship between HIV stigma and medical adherence. It is observed from this review that perceived health care satisfaction effect the medical adherence. Trustful, positive and constructive relationship of a patient with primary care providers like doctor, nurses or social workers can perform a vital role in enhancing

medical adherence among HIV/AIDS children. If health care providers shows positive attitude towards these children it will increase their health care satisfaction and feel comfortable talking about the disease and which in turn will diminish HIV/AIDS stigma and hence enhance medical adherence among them. A collaborative doctor-patients relationship, which provides children and youth a sense of mutual sympathy and acceptance, will promote them to talk about their disease and adherence with health care providers. They can provide education to the children about the proactive coping strategies and spiritual coping strategies which would also help them to manage their stress and anxiety related with the HIV/AIDS.

Disclosure concern was observed to be negatively associated with HIV/AIDS-related stigma. Stigma moreover brings a urge not to know their own HIV status, which further delays testing and getting to treatment. Negative attitude associated with HIV/AIDS for example shame and disgrace, perceived discrimination, fear of rejection, alienation from society raises the reason for non-disclosure of HIV status among HIV positive youth and which leads to spread of the epidemic.

Implications of the study

India is a country, where cultural beliefs and values, social conviction, and misguided judgment prevail; these all factors adversely affect children with HIV/AIDS. The most horrifying among them is gender discrimination towards girls with HIV and most frustrating is the misinterpretation that they are more prone to HIV transmission. Bringing HIV and AIDS related issues to the mainstream can ensure its importance as an essential part of the education sector and plan formulation. This incorporates consideration regarding HIV in education frameworks such as curriculum development, teacher training and observation and assessment of overall outcomes and impact of programs.

It is suggested to execute constructive policy and intervention program that would help to reduce stigma among youngsters resulting in increased therapeutic adherence and furthermore others factor like education, awareness regarding disease is important to implement to reduce stigma among them. It is required from society and, community not to further stigmatize them. This positive approach will enable them in combating trauma and psychosocial distress. Thus, there is a requirement of an evolved comprehensive medical care which is developmentally appropriate and attends to psychosocial concern including the effect of HIV stigma on medical treatment. The review suggests its very important that the process of stigmatization be addressed as a substantial hindrance to fighting HIV and AIDS and a thorough research should be organized with the well-framed goal so that the programs and policymakers endeavouring to work for their well-being and prosperity may find supportive and relevant data to design practical and evidence-based interventions. Beside this, there is also an urge to drive programs to reduce stigma and discrimination in health care centres. Inventive community education and training schemes should also be investigated, experimented and executed through the fundamental organization.

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