

# Psychological Impacts of the Society on Children of PLHIVs

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**Abstract:** The Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS) have become a serious problem for developing and developed countries alike in recent years. A high level of Stigma and discrimination from the society to the children from PLHIV families, who may need to attend to the needs of their family or to attend to an ill family member, undermines children's access to social benefits. The quality of education is likewise undermined, since children's concentration is often directed towards personal problems at home rather than lessons, and fear of, or actual, community stigmatization towards the PLHIV family member in question. This Paper sought to examine knowledge of HIV/AIDS stigma and discrimination, attitudes towards the children affected by HIV/AIDS. For children affected by AIDS, one psychological challenge is whether or how to disclose their parents' HIV status to others. The findings indicated that a high proportion of children preferred not to disclose parental HIV status to others would not like to tell the truth to others in the situations of having talk about parental HIV and also had strong negative feelings about the disclosure. The study findings confirmed that keeping secrecy of parental HIV infection was associated with higher level of negative psychological outcomes (e.g., depression, loneliness, perceived stigma, and enacted stigma), and children's age was strongly associated with both their perceptions of secondary disclosure and psychological measures. This paper comprehensively reviews the psychosocial issues of the PLHIVs children and offers some of the strategies to address the issues comprehensively. Culturally and developmentally appropriate evidence-based interventions are urgently needed to promote the psychological well-being of children affected by HIV/AIDS.

**Keywords:** Human Immunodeficiency Virus (HIV), PLHIVs children.

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## 1. HIV/AIDS AFFECTED CHILDREN

WORLDWIDE there was an estimate of more than 16 million children under the age of 18 who had lost one or both parents to AIDS in 2009. Meanwhile, millions of children are living with HIV-positive parents. AIDS orphans (i.e., children who lost one or both of their parents to AIDS) and vulnerable children (i.e., children who lived with HIV-positive, alive parents) often suffer a variety of psychological reactions to parental illness and death related to HIV/AIDS, and are at great risk of mental health problems due to change of caregivers and family composition, and potential emotional deprivation in their development. One of the psychological challenges for children affected by AIDS (both AIDS orphans and vulnerable children) is to decide whether or how to disclose their parents' HIV status to others (i.e., secondary disclosure).

In consistence with the widely used definition by UNAIDS, "children affected by HIV/AIDS" is defined for the purpose of this review as children under 18 years of age who are in one of the two categories: children who have lost one or both of their parents to HIV-related illness (AIDS orphans), children living with one or both HIV infected parents (vulnerable children). By the end of 2010, roughly 17.1 million (range from 15.4 million to 19.1 million) children under the age of 18 have lost one or both parents to AIDS, and millions more are facing the potential of losing their parents to HIV/AIDS. In the past decade, plights of children affected by HIV/AIDS increasingly received attention from mass media, scholars, government, non-governmental organizations and service providers. Some of the challenges experienced by children affected by HIV/AIDS have been progressively documented. The potential stressors associated with parental HIV/AIDS include economic deprivation, disrupted schooling, multiple losses, and uncertainty of clinical course of parental HIV/AIDS, inadequate care, stigma, and social isolation.

HIV-related stressful life events, stigma, and poverty were risk factors that might aggravate the negative impact of parental HIV/AIDS on children. Individual coping skills, trusting relationship with caregivers and social support were suggested to protect children against the negative effects of parental HIV/AIDS

The exposure to a number of stressors associated with parental HIV/AIDS is likely to threaten children's psychological well-being. Psychological well-being is "a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community". Specifically, with regard to the children affected by HIV/AIDS, psychological well-being refers to the possession of emotional, behavioural and social competence appropriate to their developmental stages and the resilience in the adversity of parental illness and death. Psychological well-being is one of the important elements of children's health and development. Global literature has shown that children's psychosocial adjustment is profoundly affected by parental HIV/AIDS (Chi & Li, 2013). Children from HIV-affected families demonstrate poorer psychological and physical health than children from non-affected families in the same communities (Cluver, Orkin, Gardner, & Boyes, 2012). However, it is a challenge for health care providers to determine how best to evaluate the mental and behavioural health of school-aged children. Most previous studies examined this issue through children's self-report measures, or proxy measures from parents and family members (Cluver, et al., 2012; Du, Li, Chi, Zhao, & Zhao, 2014; Li, Barnett, et al., 2009; Sherr, Mueller, & Varrall, 2009).

## 2. MATERIALS AND METHODS

### Study design:

Qualitative research methods are particularly suited for exploring experiences of HIV related stigma in a population of HIV positive people living in Delhi. In contrast to more confirmatory qualitative approaches, such as classic content analysis, our goal was engaged in a generative process to discover key domains of Psychological impact on the children of PLHIVs as experienced in the social and cultural context of participant's lives. We use focus group of HIV affected children to explore experiences and perceptions of stigma in a diverse group of women and men living with HIV .we systematically identify the most salient domains of stigma from the narrative of our participants and explore how they are link together to build a framework to understand HIV related stigma.

### Participant recruitment:

Focus group participant were recruited from NGOs and from to government hospitals in Delhi. The inclusion criteria were as follows age more than 18 years, Diagnosis of HIV and ability to provide informed consent. Potential subjects were screened; they were invited to sign up for one of the group discussion. We intentionally recruited from site that serves primarily minority women and men. Many of whom have limited education and income.to explores the perception and experience of stigma among HIV positive persons who may also be marginalized by race/ethnicity, gender, sexual orientation. Poverty or some combination of these factors

### Data collection:

We choose focus group to discuss the potentially sensitive topic of HIV related stigma , as they offered participant a safe environments to share experience and ideas in the company of others who have a central element of their experience in common (i.e. HIV AIDS)

The goals of the focus group were to generate ideas and real life example of the perceptions and experiences of HIV related stigma, and to explore how this stigma may affect their Children Psychologically and socially. We developed a focus group script based one broad review of the literature on stigma and both qualitative and quantitative studies of stigma specific to HIV infection. Open ended questions were used to guide each discussion. If key concepts/contents areas were not generated by the group, standard probes were used to elicit further information. We focused on identifying mutable factors that define or contribute to HIV related stigma in women and men because these factors may be amenable to intervention in future studies. We conducted five groups: three comprised of HIV positive men and two HIV positive women. Each focus group consisted of 5 participants' for a total sample of 25 participants. Groups were gender specific because individuals may be more comfortable discussing sensitive topics such as stigma in same sex groups, and this stratification allows us to understand how stigma may differ by gender. Focus groups were not specific to race or ethnicity.

### 3. DATA ANALYSIS

Category	Sympathetic		Just Normal		Harsh/Hated		Indifferent	
	#	%	#	%	#	%	#	%
Teachers	8	32	4	16	1	4	9	36
Friends	1	4	15	60	1	4	3	12
Relatives	2	8	3	12	9	36	7	28
Family Members	12	48	0	0	2	8	4	16
Community Members	2	8	3	12	8	32	9	36

Teachers are really the backbone of any society. But one should not forget that they are human beings too. Fifty Two percent of the respondents were of the view that their children's teachers' behaviour was entirely changed. Teachers were having fear that children might be carrier of HIV and they might transfer to others. They remained at an arm's length from them. Thirty two percent of the respondents said that teachers were feeling pity for children and reflecting their sympathies whereas 36 percent of the respondents said that teachers were considering their kids a part of stigma

During classes, teachers tried to point out the children of patients (Malaney.2000). Children were feeling quite disgraced and humiliated.

The behaviour of the family for the children of HIV positive was not as normal as it should be. Stigmatization discrimination and social isolation, dropping out of school, moving away from friends, and bearing an increased workload in the home all increase the stress and trauma that accompanies the death of a parent (Foster et al 1997). According to the table, 8 percent of the respondents were of the views that relatives were having sympathetic behaviour towards children. They were feeling pity on the fate of their children. About 16 percent of the respondents were observing that family members (uncles of patient's children) were not allowing their kids to play and even talk to the patient's children. They might be doing this a safety measures for their own children but respondents were feeling their hateful behaviour towards their kids.46 percent of the respondents were of the opinion that dealings of family with their children were entirely different as compared to their previous behaviour. Such type of behaviour involves the children in inferiority complex and distrust atmosphere

The behaviour of relatives with the kids was as it was shown with their parents. They even did not want to see them and felt kids would be burden after the death of patients. They were having pessimistic attitude towards the victimized family. According to the table, there were 60 percent of the respondents who were complaining about the adverse behaviour of their relatives. Thirty Six percent of the respondents had the observation that their relative hated their children. Four percent of the respondents were optimistic and said that their relatives had concern with their kids, whereas 3 respondents informed that his relatives are still normal with kids due to unawareness of their HIV positive status.

Fear, worries, observing and caring for ill parents in pain, stigmatization, hospital visits, shattered hope and eventual loss are all experienced by children affected by HIV/AIDS at various times over several years. Along with all, it is observed by 56 percent of the respondents, according to table , that people from the surrounding always pointed out them along with their kids. This segment of respondents was of the view that their kids were more neglected and punished by the unethical behaviour of the general community. Thirty four percent of the respondents were of the view that there was indifferent behaviour of the community towards their children. Children were not in the position to play in the streets due to strong community rejection. Ultimately, children were quite depressed and lethargic regarding the fearful environment prevailing around them. To 12 percent of the respondents, the community people were normal at least with their children. But those people in the surrounding were not aware of the implications of HIV/AIDS. Only Two respondents were of the view that the children got sympathetic behaviour from community members.

Impacts	Yes	%	No	%	Not Applicable	%
Mental retardation	5	20	8	32	12	48
Inferiority complex	15	60	4	16	6	24
Isolation	17	68	4	16	4	16
Sense of deprivation	13	52	6	24	6	24
Insecurity/ unprotected	17	68	5	20	3	12
Fear of Disclosure Parents HIV Status	20	80	5	20	-	-

Children of PLHIVs have been facing psychological problems as they have developed sense of deprivation (52 percent) and inferiority complex. Most of the children may developed inferiority complex as they are stigmatizing and discriminated in the society. 68 percent of the children feels insecurity within the society. In many of the children fear of disclosure of their parents HIV status still severely persists. Due to all the negative psychological impacts children are feeling isolated from the society and within the families.

#### **4. DISCUSSION**

The data in the current study were consistent with the existing qualitative studies, suggesting that the majority of children affected by AIDS would not like to disclose their parental HIV status to others and they may experience strong negative feelings during the disclosure. Older children may be able to understand more about HIV infection. Therefore, they may more easily realize the HIV-related stigma and have more fears of disclosing parental HIV status to others and its negative consequences.

Parental illness or death due to AIDS is traumatic for a child, profoundly affecting the child's psychological well-being. Psychosocial problems of these children call for exploration of risk and resilience factors. Communication about the illness or death of loved ones is an important step for recovery from grief. Open communication with others can provide affected children opportunities of receiving emotional support and coping strategies, therefore, their needs and problems could be heard and addressed appropriately. Hiding within "The wall of silence" built around children affected by AIDS could not protect them from discrimination or bullying from their peers, because other children learned situations of the affected children's parents from other persons in the community.

The analyses found significant differences between the orphan hood groups on perceived social support from the family but not from friends and significant others. Concerning support from the family, children living with HIV/AIDS-infected parents and other orphans reported the least perceived social support consistent with

it is particularly interesting that children living with HIV/AIDS-infected parents reported lower perceived social support than children orphaned by AIDS. Several factors could account for this situation. First, it might be that parents-infected with HIV/AIDS are preoccupied with their own situation (HIV/AIDS infection and its attendant stress) to the extent that it compromises their ability to provide quality child care, yet other support systems have not come into play because the parents are still alive and in a care-giving role. Similarly, as infected parents progress with the HIV/AIDS in severity, they may become too ill to be available for support.

When a parent is infected with HIV/AIDS, other family members may shift the available support to the sick parent to the detriment of the child, thus further limiting the support available to the child. Third, it is also possible that most children when orphaned by AIDS are well cared for by the surviving parent, extended family or others, whereas in the case of children living with HIV/AIDS-infected parents, parental sickness more severely reduces and limits the availability and quality of support for children

Future studies should engage children of different age groups; particularly adolescents are needed to compare perceptions of children in different development stages. The study of secondary disclosure can be expanded from children's perceptions to children's practice (e.g., rate of disclosure, target of disclosure, settings of disclosure). Studies with a longitudinal design are needed to explore the causal relationship between children's disclosure and psychological adjustment. In addition, prior to an intervention integrating multiple resources, we need to examine various family, community, and culture factors that may potentially influence children's perceptions and practices of secondary disclosure, isolation and social deprivation and potentially mediate the effect of secondary disclosure on psychological well-being. Children's disclosing parental HIV status to others and its effects on children's psychological adjustment are important aspects of their coping with parental HIV-related infection and death. Further research and intervention efforts are needed to maximize the long term benefit of secondary disclosure to children affected by AIDS.

#### **5. CONCLUSIONS**

Despite these limitations, the present study shows several strengths and makes significant contributions to the evidence base about children affected by HIV/AIDS in relation to their levels of social support.

It can be concluded from the study that there is an understanding of stigma and discrimination among the target audiences. However, it is observed there is a narrow understanding of discrimination, as none of the groups were able to link discrimination to human rights. The study showed stigma and discrimination are real for the target audiences. For PLHIV, having HIV is synonymous to being stigmatized and discriminated against. Caretakers, particularly guardians and

parents, are associated with stigma and discrimination through their children. Religious leaders are stigmatized when their followers contract HIV, which is perceived as evidence of sexual immorality.

The effects of stigma and discrimination on access to and utilization of prevention, treatment, care and support services are acknowledged by all target audiences. HIV stigma and discrimination is experienced in various settings included homes, schools, workplace, health units and places of worship. All the groups acknowledge that there is inadequate awareness within the population on HIV/AIDS transmission and existing services. The major conclusion of this study is that the experiences of the target audiences on stigma and discrimination create an opportunity to form partnerships with these groups who have the potential to act as change agents in addressing stigma and discrimination at the national level.

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