



Effects of Social Stigma on Children Living with Hiv/AIDS in Pune District, India

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ABSTRACT

Studies have shown that stigma and discrimination fuel HIV transmission and hinder access to programmes and services. The greatest impact of HIV is on children and young people. An attempt to arrive at a clear picture of the effects of social stigma due to HIV/AIDS on Children Affected with HIV/AIDS (CLHA) is made in the present study. The research mainly focusses on identifying stigmatizing attitudes due to HIV/AIDS in the context of CLHA. The study was conducted in Lohiya Nagar and other pockets in the Pune city and the blocks of Indapur, Maval and Bhor Taluka of the district of Pune. With convenient sampling procedure a sample of study participants was obtained. Interview schedules, in depth interviews and case studies were done in the course of the research to gather relevant qualitative data. Results show that the problem of stigma and discrimination against PLWHAs is far from being reduced. It calls for special focus by the policy makers on the plight of children living with HIV/AIDS.

Introduction

Every disease has an organic or biological aspect and a psycho-social-cultural aspect. Often the psycho-socio-cultural aspect of disease is overlooked (Rozemberg, 2012). From an anthropological point of view, it is imperative to note that diseases are interpreted using various cultural stereotypes. Disease-related or health-related stigma is indicative of an adverse social judgment based on a sustained feature of identity due to a health problem or health-related condition (Mahendra, et al., 2007). Health-related social stigma contributes to the burden of sickness and influences the effectiveness of finding incidences and treatment, which are major interests of disease control (Weiss & Ramakrishna, 2004). It is an undeniable fact that the epidemic of HIV/AIDS has caused loss of life in apocalyptic proportions. Yet, several cultural stereotypes used to judge this disease have been identified in the context of various interventions to arrest and reverse the epidemic. One of such stereotypes is health-related stigma. The common denominator attached to HIV-AIDS is stigma AIDS has given ample possibilities to study the social construction of stigma (Castro & Farmer, 2005). The adult HIV prevalence in India is 0.27 percent, as of 2011. While this figure is small relative to other middle-income countries (UNDP 2013, "Statistics"), the large population of 1.2 billion inhabitants means there are still around 2.1 million people living with HIV in India. Overall, India's HIV epidemic is slowing down, with a 57 % decline in new infections between 2000 and 2011, and a 29 % decline

in AIDS-related deaths between 2007 and 2011 (NACO Annual Report, 2012-13). With the onset of the epidemic of HIV/AIDS women and children were identified as the most vulnerable group (Chin, 1990). (Here after in this paper Children affected by HIV/AIDS will be referred to as CLWHA -Children living with HIV/AIDS). This can be clearly illustrated by the example of children whose parents are made incapable of earning for the family due to HIV/AIDS (Foster & Williamson, 2000). Lorey & Sussman (2001) give a picture of the adverse effects of discrimination due to HIV/AIDS on children affected by it. They contend that decreased access to and quality of food and nutrition, quality of education, quality of healthcare, quality of shelter and increased psychosocial distress are among the major concerns when it comes to CLWHA. Studies on children's experiences of stigma and discrimination reveal that children affected and infected by HIV/AIDS go through material and psychosocial disadvantage due to AIDS-related stigma. Children whose parents are ill with AIDS or who have died of AID report being marginalised and isolated from other children, being teased and gossiped about, being presumed to also be HIV-positive, and not receiving care (Strode, 2001). Adult research in this area does indicate that stigma would finally result in reduced self-esteem through internalisation in AIDS-affected children (Santana & Dancy, 2000). A brief overview of the literature produced in the highlights that very few studies detailing the impact of HIV/AIDS related stigma on CLHA have been produced. Above all fewer studies have been done in India. A comprehensive research design is required to undertake such a study to produce reliable data.

Method of the study

The principal objective of this qualitative study was to complement the quantitative data from other studies on the effects of stigma on CLWHA to understand how they perceived, experienced, and responded to HIV stigma. The study was conducted in the Pune district in the state of Maharashtra, India. Maharashtra, along with Andhra Pradesh, Karnataka, Tamil Nadu, Manipur and Nagaland, is considered to be one of the high HIV prevalence states of India (Verma, et al., 2002). According to NACO Annual Report 2011-2012 state fact sheet estimates, the no. of PLHA in Maharashtra is 40,060 and CLHA (Children Living with HIV/AIDS) are believed to be 871 in number. Out of the 14 talukas the study focused (due to its limited scope) on the four talukas of Bhor, Indapur, Mawal (Talegaon) and Haveli (Pune City). Both quantitative and qualitative data collection tools were utilized, but this study is characteristic of a qualitative epistemological position that recognizes the importance of locating the research within a particular social, cultural, and historical context. Non-probability Sampling (Purposive and Snowball Sampling) were used to arrive at a sample size of 77 respondents spread out in four different locations in Pune District of Maharashtra State. Questionnaires were used to gather relevant data from the study subjects. In case of respondents belonging to age-groups below 15-18 years the details were filled by their parents/guardians. Case studies relevant to the research were produced. Ethical considerations, especially in the context of HIV/AIDS studies, as given by NACO, India have been strictly adhered to. The data obtained through qualitative measures was quantified by assigning variables and relevant values. This helped to generate statistical data from the information obtained. The Data was then statistically analysed through SPSS in order to make it presentable for further assessment.

Results of the study

Profile of the Respondents

As the study focused on the CLHA, the age-groups ranged from 6-8 years to 16-18 years. Children below the age of six were excluded from the study due to its limited scope. However, it cannot be

denied that they too face the risk of being highly vulnerable. The study shows that about 56.1% of the sample size belongs to the adolescent group. The gender-wise distributions according to the age-groups of the subjects indicate that this distinction is important as the vulnerability on account of social stigma faced by girls is much pronounced as compared to that involving the boys. The majority of the respondents belong to the age-group of 16-18 years. Adolescents altogether formed 61.1% of the population size. Out of these children 26 (33.7%) are HIV positive, and the remaining 51 (66.3%) are HIV negative. When it comes to India, according to UN statistics, it is home to the largest number of AIDS orphans in the world. India is expected to become the next epicentre of the AIDS orphan crises. In the present study out of the 77 respondents 50 (64.9%) are either maternal (2.6%), paternal (48.1%) or double (14.3%) orphans. The literacy level of the children under study has been found to be impressive, with only three of the respondents being reported as not attending school. Two of them are school dropouts having studied till the primary level and one specially abled child is not sent to school. A majority 45.5% of the sample size fall under the economically backward category of having monthly household income less than Rs. 2000.

Experience of Stigma at various levels

It has been found during the study that the level of stigma the PLWHA and the CLHA face during the Healthcare level has reduced remarkably. Out of the 21 who faced discrimination 12 pointed out that they were asked to stand in the same queue as the general public at the hospital. Since they were on ART they had to sign in the Register at the pharmacy which aroused curiosity among other patients. Often the nature of their visit (ART) would be called out loudly from the counter at the pharmacy. Another issue was that some of the healthcare providers refused to touch them because the latter were HIV infected. In the present study 63 of the 77 respondents said that their family members other than the immediate family did not know of their or their children's HIV status. The same number also said that they don't take or don't give to their children medical care in the same vicinity of their residence. They prefer to go to another locality so that their HIV status is not revealed even by chance to anyone in the area of their residence. Many of the questions in the interview guide are related to enacted Stigma. But due to non-disclosure many of the PLWHAs do not have direct experiences of being stigmatized and discriminated. But when asked of the consequences of disclosure of their HIV status either to the family or the community many reported that they were more than certain to directly experience enacted stigma. 10 out of the 14 whose status was known to their family and relatives, reported that their family members had stopped visiting them and 23 whose status was not disclosed, said that they were sure to face similar situation had their HIV status been known. Similarly 48.1% and 68.8 % said that their family members refused to touch them and placed restriction on sharing of food with others respectively. An interesting point to note here is that 25 respondents out of the 53 who experienced such discrimination were HIV negative.

At the community level discrimination was experienced on account of unnecessary inquisitiveness about their children, questions about repeated hospitalization of the CLHA, different outreach workers visiting their houses etc. Out of the 14 respondents about whom the community knows ten have been actually excluded from community events and 25 of the respondents whose status is not known to the community feel they will be excluded if their status is revealed. At the educational level, out of the 14 about whose serostatus the community knows; 11 actually suffered discrimination at educational institution and the remaining 27 expected to be discriminated once their status is revealed. Out of the 11 who faced discrimination three did not respond to the question how they were discriminated but 8 said that they/their children were not allowed to eat with other children. HIV's transition from an acute, lethal disease to a subacute, chronic disease has great implications for the neurocognitive and

psychosocial development of children and families (Brown & Lourie, 2000).

Many children continue to be adversely impacted by non-HIV factors such as poverty, inadequate medical services, and a lack of social support and these factors in turn create great psychological duress. The major issues causing anxiety the subjects, a majority of them, were concerned about being severely stigmatized at the hands of the society once their HIV status was known to them. It is also interesting to note that among the female respondents the greatest concern was about contracting a marital alliance. On the other hand, the male respondents were more worried of being stigmatized.

Conclusion & recommendations

As evidence shows and in accordance with previous studies HIV/AIDS-related stigma and discrimination aggravates the negative effects of the pandemic on children. The findings of the present study agree with those of the previous studies undertaken in this research area. The basic reason for discrimination is that HIV/AIDS is a disease that often attracts judgement and retribution, not empathy and compassion (Allen & Heald, 2004). A similar finding emerges out of the present study, yet the level of experiences of stigma (Enacted, Felt and Internalized) varies. Before a judgement is passed on the findings of the study we need to take cognizance of one pivotal point. Many of the PLWHAs are living in hiding. In other words, their association with a family in which someone is HIV/AIDS infected or their own serostatus for that matter is not disclosed to even close kin. The reasons are, of course, a deep fear of being discriminated once their serostatus is known. This aspect has influenced the present study a great deal. The incidences of enacted stigma will be considerably less as a result of non-disclosure of one's association with HIV/AIDS. But when the CLHAs and their parents/guardians were asked about the prospect of being stigmatized had their status been disclosed, the results change dramatically. In their own assessment they were sure to be stigmatized because they had seen concrete instances other PLWHAs being discriminated whose HIV status was known to the community. Apart from these, attention needs to be given to the major issues of anxiety that the CLHA themselves or their guardians face. These are challenges not just for the CLHAs but even for the policy makers. Many of the CLHAs, who are orphans will need resources for sustenance. The study shows that a majority of the study subjects fall into the critical stage of adolescence.

Bartlett and Finkbeiner (2006) reveal the emotional duress the children living with HIV/AIDS undergo by stating that the children are angry, basically over the unfairness of the situation (why me?), being handicapped by the disease and social stigma. The present study found presence of such feelings of anger in many of the adolescent respondents and the parents/guardians of the children aged between 6-12 years. Harbouring anger at this age can lead to adverse effects on the psychological health of the children. Such effects are hardly assessed by many behaviour surveillance studies by various agencies. Interventions to counter social stigma must address such issues in the context of CLWHA.

Catherine Campbell et al (2005) in their article, "I Have an Evil Child at My House": Stigma and HIV/AIDS Management in a South African Community," chart out a three-pronged approach to counter stigma related to HIV/AIDS. They speak of efforts to be made in the line of educating individuals about non-stigmatising facts, mobilise the participation of community members in anti-stigma efforts and enact anti-discriminatory laws. In the Indian context the first two approaches have been underway and are integral part of countering stigma related to HIV/AIDS. However, our country still has made no efforts to pass a legislation to protect the HIV/AIDS affected/infected against discrimination due to stigma. Responding to an invitation from the Global Commission

on HIV & Law a few of the NGOs and other organizations wrote highlighting the need for a Anti-discrimination Law to protect PLWHAs. For instance, LEpra society writes that in order to facilitate working with the children, families and communities to overcome their isolation, exclusion and impoverishment proper framework of law will be very useful (LEpra, 2011). They further state that in the absence of a Law to protect them, women and children are unable to internalize the violence against them due to HIV/AIDS stigma, and they think that they are destined to suffer. Some organizations have also demanded a Patients' Rights charter for India in order to protect the PLWHAs (Sangram, 2011). In the absence of a comprehensive statute, HIV positive people remain vulnerable to rights violations, thus weakening the response to AIDS. While hailing the interventions made so far to combat HIV/AIDS related stigma the present study strongly recommends that adequate measures be taken to combat violation of rights of people living with and affected by HIV/AIDS, especially the CLWHA. This policy formulation should be done with the greater involvement of people living with and affected by HIV/AIDS. The basic purpose of such legislation would be to ensure a holistic and integrated approach to fight HIV/AIDS related stigma and discrimination and assure social security of CLWHAs.

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