A STUDY ON ASSESSING THE INTERNALIZATION OF STIGMA AND DISCRIMINATION AND ITS IMPLICATIONS AMONG CHILDREN LIVING WITH HIV/AIDS

M. Mudiappan[1] R. Mangaleswaran[2] and V. Arockia Hensilin[3]

Asst. Professor & Ph.D.Research Scholar, P.G. Department of social work, Sree Saraswathi Thyagaraja College, Pollachi, mudiappan68@gmail.com

Asst. Professor, P. G. Department of social work, Bharathidasan University, Tiruchirappalli, *Eeswaran2010@gmail.com*

Teaching Assistant, SBOA Matriculation Higher Secondary School, Coimbatore

hensilinnavis@gmail.com

Abstract **--AIDS is redefining the very meaning of childhood for millions, depriving children of many of their human rights- of the care, love and affection of their parents; of their teachers and other role models; of education and options for the future; of protection against exploitation and abuse. (UNICEF, 2000). AIDS stigmas and discrimination create significant barriers to HIV prevention, testing, and care and can become internalized by people living with HIV/AIDS (UNAIDS, AIDS Epidemic Update, December 2003).There is evidences that internalized AIDS stigmas adversely affect health and mental health. The present study was conducted in Namakkal town and find out the internalization of stigma among children with HIV/AIDS. The main aim of the study is to find out the internalization of the stigma and its effects on the health and well-being of the children with HIV/AIDS. The researcher used convenient sampling and selected 60 respondents. The researcher used self prepared questionnaire based on the Internalized AIDS Related Stigma Scale (IA-RSS).and used interview schedule to collect the data from the respondents. The findings showed that majority of the respondents were affected by the internalized stigma and discrimination. The findings of the research will be discussed in the full paper.**

Keywords: **Internalized AIDS stigma, Discrimination, Children living with AIDS and coping with HIV/AIDS**

I. INTRODUCTION

AIDS is redefining the very meaning of childhood for millions, depriving children of many of their human rights- of the care, love and affection of their parents; of their teachers and other role models; of education and options for the future; of protection against exploitation and abuse. The world must act now urgently and decisively to ensure that the next generation of children is AIDS-free (UNICEF, 2000)

HIV/AIDS greatly impacts the social fabric of Indian society, especially through the escalating AIDS related stigma such as the unprecedented number of children being left with little or no care and protection. Stigma has been described as a dynamic process of devaluation that 'significantly discredits' an individual in the eyes of others (Goffman, E. (1963). HIV related stigma is multi-layered, tending to build upon and reinforce negative connotations through the association of AIDS with already marginalized behaviours. The stigma associated with AIDS has silenced open discussion, both of its causes and of appropriate responses. Visibility and openness about AIDS are prerequisites for the successful mobilization of government, communities and individuals to respond to the epidemic. Concealment encourages denial that there is a problem and delays urgent action. It causes people living with HIV to be seen as a problem rather than as a solution to containing and managing the epidemic.

Stigmatization associated with AIDS is underpinned by many factors, including lack of understanding of the illness, misconception about how HIV is transmitted, lack of access to treatment, irresponsible media reporting on the epidemic, the incurability of AIDS and prejudice and fear relating to a number of socially sensitive issues including sexuality, disease, mental health and general well-being, drug use, alcoholism, and death. Stigma is deeply rooted and

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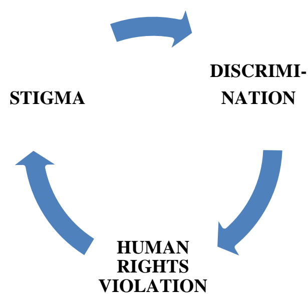
operating within the values of everyday's life. Although images associated with AIDS vary, they are patterned so as to ensure that HIV related stigma plays into, and reinforces, social inequalities.(Parker,R. and Aggleton,2003). These inequalities particularly include those linked to gender, race, ethnicity and sexuality. Discrimination consists of actions or omission that are derived from stigma and directed towards poor self image and less involvement in any activities. Discrimination is defined by UNAIDS (2000) in the Protocol for Identification of Discrimination against People Living with HIV, refers to any form of arbitrary distinction, exclusion or restriction affecting a person severally. AIDS related discrimination may occur at various levels (Malcolm, A. et al., 1998). Discrimination is a violation of human rights. The principle of non-discrimination, base on recognition of the equality of all people, is enshrined in the Universal Declaration of Human Rights and other human rights instruments.

Stigmatizing and discriminatory actions violate the fundamental human right to freedom from discrimination. In addition to being a violation of human rights in itself, discrimination directed at people living with HIV or those believed to be HIV-infected, leads to the violation of other human rights, such as the rights to health, dignity, privacy, equality before the law, and freedom from inhuman, degrading treatment or punishment.

The United Nation Convention on the Right of the Child (CRC) stresses that the children are 'entitled to special care and assistance' and this care and assistance should enable 'full and harmonious development' (Amon, 2002, 143). The HIV pandemic poses major threats to the socio-economic and psychological welfare of HIV infected and affected children. Researches show that stigma and discrimination can exaggerate the material and psychological problems children already faced in the context of HIV/AIDS (Clay et al 2003, Gernholtz and Ritchter, 2004)



Stigmatization can also occur on another level. People living with HIV and AIDS may themselves internalized the negative responses and reactions of others- a process that can result in what some people called 'self or internalized stigmatization' self stigmatization has links to what some people described as felt as opposed to enacted stigma in that it primarily affects an individuals or affected community's sense of pride and unworthy. It leads to poor self image and less self-esteem and pay ways to poor mental health and general well-being This will be manifested in feeling of shame, self blame, and worthlessness which are combined with the feelings of being isolated from the society and can lead to depression, self imposed withdrawal and even suicidal feelings (Mangaleswaran, R. and Mudiappan, M., 2010). Religious doctrines can have a strong influence on how AIDS is viewed and, in some regions; have fueled stigma and discrimination by portraying AIDS as a punishment for sin. When stigma and discrimination are strong, they can easily be internalized by children with HIV/AIDS, causing severe pain and suffering and leading to self-induced isolation from society. The internalization of stigma poses a serious problems in the treatment process as well as in the access of social support from the Government and non-governmental organization. The present study focused on this dimension of the children with HIV/AIDS.

II. MATERIALS AND METHODS

The main aim of the study is to study the level of internalization of stigma and discrimination among children with HIV/AIDS the objectives are: To study the socio – economic background of the respondents, to study the family and social discrimination and various health services provided to the children with HIV, to study the influence of socio economic background on internalization of stigma and discrimination and to study the psycho-social needs of the respondents. The research hypotheses are: There is a significant relationship between gender and internalization of stigma and discrimination of the respondents. - There is a significant difference between the years of sickness of the respondents and the internalization of stigma and discrimination among children with HIV/AIDS.

The researcher is interested in studying the internalization of stigma and discrimination among the children with HIV^+ in Namakkal town and tried to portray the various characteristics of study population and hence, the study is considered to be descriptive in nature. The children receiving services received in the month of November and December 2010 in HUNS (HIV Ullor Nala Sangam) in Namakkal. The researcher used convenient sampling and selected 60 respondents. The researcher used self prepared questionnaire based on the Internalized AIDS Related Stigma Scale (IA-RSS).and used interview schedule to collect the data from the respondents. To analyze the data the statistical tools namely, mean, median, standard deviation, were used. Statistical analysis of non-parametric tests such as Mann Whitney't'

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test, chi-square and Karl Pearson's correlation analysis were also conducted for the purpose of the statistical analysis.

III. RESULTS AND DISCUSSION

A. Socio-Demographic Findings

There were 26.7 per cent of the respondents were at the age group of 11-13 and there were 61.9 per cent of the respondents were male and the rest of the respondents were female. There were 44.8 per cent of the respondents were having 1-2 and 3-4 as birth order. There were 43.8 per cent of the respondents were belonging to the nuclear family and 67.6 per cent of the respondents were living in the concrete house, 17.2 per cent of the respondents were living in hut and 67.6 per cent of the respondents were from town. There were 56.2 per cent of the respondents were living in the rented house and 43.8 per cent of the respondents were living in their own house. Nearly half of the respondents (47.6%) were studying 11 and 12 and 27.6 per cent of the respondents were studying 9 and 10th standard and 24.8 per cent were studying in the primary school. There were 49. 5 per cent of the respondents' mothers were doing coolie work and two third of the respondents (68.6 per cent) were suffering more than 6 years of AIDS. There were 45.3 per cent of the respondents living with AIDS for more than 5 years.

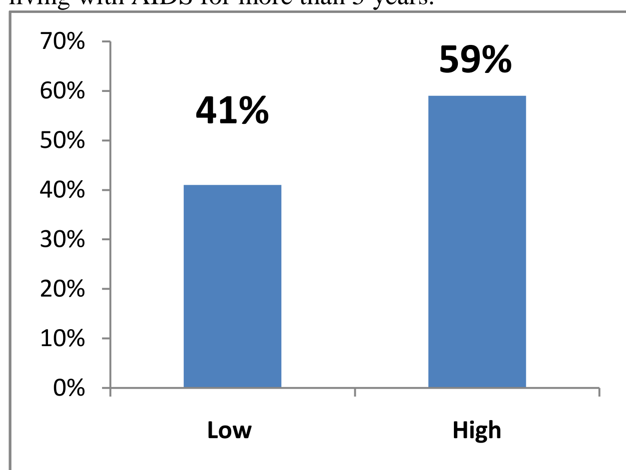

Fig. 1: Distribution of level of internalization of stigma and discrimination of the respondents

The figure 1 indicates that there were 59 per cent of the respondents were having high level of internalization of stigma and discrimination while 41 per cent of the respondents were having low level of internalization of stigma and discrimination. The study by Ravi K. Verma (2002) on HIV/AIDS and Children in the Sangli District of Maharashtra point out experience of stigmatization and discriminations and send their children away to distant relatives, and withdraw children from school. Discrimination in accessing health care is a major form of social exclusion faced by people infected or affected, including orphans. About two-thirds of children born to HIV-positive mothers do not contract the infection and grow up to be as healthy as any other child in the community (UNAIDS, 2005) The children with AIDS also expressed that stigma and secrecy surrounding AIDS causes social isolation, bullying, shame, and lack of opportunity to openly discuss their loss. Poor levels of AIDS-related knowledge and communication can lead to children being ignorant of the cause of death, or fearing that they will also be infected (Cluver, and Gardner, 2006). All of the families recounted experiences with stigma, including 100% of mothers, 88% of fathers, 82% of children, and 79% of adult children. About 97% of families described discrimination fears, 74%of families' experienced actual discrimination. Inter personal discrimination seemed to stem from fears of contagion. Findings indicate a need for interventions to reduce HIV stigma in the general public and to help families cope with stigma (Laura, et al., 2007).

Table 1

:'t' Test between the Genders of the Respondents with Regard to Level of Internalization of Stigma and Discrimination

S. No	Gender	$\overline{X}$	S.D.	Statistical Inference
1	Male	26.176	8.269	t =1.986 $P < 0.05$ Significant
2	Female	29.476	8.061	

The table 1 demonstrates that there were the significant difference between gender of the respondents with regards to their level of internalization of stigma and discrimination. It was inferred that gender plays a decisive role in the process of internalization of stigma and discrimination. The earlier study done by Becky L. Genberg et al., (2007) clearly explains that emotional problems are quiet high among the male and female children and Systematic and significant differences in stigmatizing attitudes were found across countries, with little age or gender differences noted. This short, comprehensive and standardized measure can be easily incorporated into questionnaires in international research settings.

Table 2:

Association between duration of illness of the respondents and their level of internalization of stigma and discrimination

Duration of the illness	Internalization of stigma		Statistical Inference
	Low (n=24)	High (n=36)	

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Less than 1 year	7	9	$X^2 = 8.199$
1-2 years	5	12	df = 3
3-5 years	6	7	$P < 0.05$
Above 5 years	6	8	Significant

The table 2 explained that there were significant association between the uration of sickness and the internalization of stigma and discrimination. It is inferred that the duration of illness of the respondents were influencing the process of internalization of stigma and discrimination and led to isolation from social functioning. Main findings of the study by Joison et. al.(2002), on "The perception of parents and the problems of children infected /affected by HIV / AIDS in Chennai" shows 65per cent of the respondents were not attending schools due to the stigma internalization and negativism. This led to isolation and low self esteem (Mudiappan et al 2010). The previous study one by Sharma, Permalatha (1981) on Study of factors related to Academic under achievement of Girls of secondary schools located in Rural Areas of Haryana pointed out that higher the educational standard higher the study involvement of the students. Shanty M. Jacob (2005) made "A Study on the Academic Profile of students in Thanjavur to find the level of the students' level of study habits and study involvement. The study indicated that there is a significant association between the study habits and study involvement on the basis of various dimensions such as age, educational standard, parent's education etc.

B. Social Work Intervention

- ❖ Sensitizing the community for reducing stigma and discrimination and building up a positive towards people with AIDS Creating awareness and helping in clarifying misconceptions for prevention strategies of this disease. In addition, On-going counselling must address denial, guilt, and anger and internalization of children with HIV/AIDS.
- ❖ Combining counselling and information based approaches that break the 'culture of silence' and promote the culture of openness and support and Doing the catalytic effort-starting a chain of actions that reduces stigma and discrimination
- ❖ Counselling the children with AIDS and strengthening the ego of the children and Prevention of further spread of HIV/AIDS by encouraging the proper and regular testing of the pregnant women.
- ❖ Conducting social work research and propose suitable measures develop the new modal for stopping the process of internalization of stigma and discrimination.
- ❖ The social work professionals, NGO organizations and the Government should take effort and appeal to policy makers for enacting appropriate programmes and policies to reduce stigma and discrimination and promotion of equality and general well-being.

C. Suggestions

- ❖ The Indian government should enact and enforce national legislation prohibiting discrimination against people living with HIV/AIDS and their families in health facilities, schools, places of employment, and other institutions.
- ❖ The National AIDS Control Organization (NACO) should provide greater leadership to states on preventing and addressing discrimination against people living with and affected by HIV/AIDS and, for children especially, in the areas of education, health, and care.
- ❖ State health departments should prohibit government hospitals from discriminating against people living with HIV/AIDS, set guidelines for maintaining the confidentiality of HIV statuses of persons using health services, and explore ways of better regulating the private sector.
- ❖ In cooperation with professional associations and HIV/AIDS experts, the Indian government should vastly expand training programs on HIV/AIDS for teachers, health workers, lawyers, social workers, other government officials, others caring for children, and students of these professions.
- ❖ It is the right time to develop social Parenting in the community

Conclusion

Discrimination, stigma, poverty and such other problems lead to vulnerability and oppression for the women/children infected with HIV/AIDS. Stigmatization and discriminations and send their children away to distant relatives, and withdraw children from school. Discrimination in accessing health care is a major form of social exclusion faced by people infected or affected, including orphans. About two-thirds of children born to HIV-positive mothers do not contract the infection and grow up to be as healthy as any other child in the community (UNAIDS, 2005). The fear, discrimination, ignorance and social stigma associated with AIDS leave these children completely isolated and thus their basic psychosocial needs such belongingness, self esteem, security and acceptance are unfulfilled (Shekar and

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