Psychosocial Care and Support Services for Children Infected with AIDS

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Abstract

Children living with AIDS experience a great deal of social stigma and discrimination. This results in children being marginalised from essential services such as education and health. The present study assessed the socio-demographic variables and the identified the psychosocial needs of HIV infected children and the services for children infected with AIDS in public and private sectors. A total of 180 children infected with AIDS, and 180 service providers were included as sample. Random and purposive sampling techniques were used. A structured interview schedule consisting of needs and services of HIV infected children was given to caretakers and service providers. The study areas were Visakhapatnam, Chittoor and Khammam districts. The data collected was subjected to relevant statistical analysis. The psychological care and support needs of CIAs identified by caretakers in three study areas were compared, it was found that there was difference between the sample in Khammam and Chittoor as odds ratio was 3.038 (>1) and p-value 0.01 (p<0.05).

Paediatric AIDS results in death more quickly in developing countries, where there is wide spread poverty, poor nutrition, low health awareness and other contributing factors that call for augmented efforts to provide free and compulsory treatment to children and HIV positive mothers (Bhatia, 2009).

Every minute that passes a child under 15 years dies of an HIV-related illness and four young people aged 15-24 years become infected with HIV. The world must act now, urgently and decisively, to ensure that the next generation of children is AIDS-free. According to the AIDS epidemic update 2009, released by UNAIDS, there were 33.4 million PLHIV including 2.1 million CHLIV globally by the end of 2008. Moreover, one-third of the HIV positive children die before the age of 1.5 years while half of them die by 2 years of age (UNAIDS, 2012).

Children have specific needs for growth and development, and of early diagnosis of infection; besides they need a strong family support. Orphaned and vulnerable children, both infected and uninfected require special care in terms of vulnerability, social security, livelihood, poverty etc. (NACO, 2006). Roughly five million HIV infected people are there and probably thousands need anti-retroviral therapy. Some of the states with good health indicator have high HIV prevalence (Tripati, 2014).

Hong & Lix (2010) examined the relationship between perceived social support and psychosocial wellbeing among children with AIDS. The study underscores the importance of providing social support and mental health services for children in China.

So far non-governmental and faith-based organisations, as well as community groups, have mainly pioneered assistance in counselling and psychological support. Dandona (2010) carried out a study on cost effectiveness of HIV prevention in Andhra Pradesh state of India. This is useful contributor to take decisions on the best use of resources to prevent HIV.

Children affected by HIV/AIDS include a relatively small number of children who are positive and for large number who are not infected but whose parents are living with, or have died of AIDS. There is a need for a simple yet comprehensive policy covering a broader agenda. It should cover both the medical and socio-economic dimensions of the epidemic as it affects children (NACO, 2007).

Angami and Reddy (2004) studied on prevalence of HIV infection and AIDS symptomatology in malnourished children. The prevalence rate was 21.7 percent children aged between 1.5-3 years had the highest seroprevalence (47.4%) and male to female ratio was 1.5:1. Underweight children showed the highest seroprevalnce (47.4%).

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Table 1: Demographical variables of children infected with AIDS

S. No.	Independent variables	Classification	Percentage of Children in Study Area		
			Khammam	Chittoor	Visakhapatnam
1	Age	1-5 Years	28.30	36.70	31.70
		6-10 Years	31.70	26.70	40.00
		11-15 Years	40.00	36.70	28.30
2	Gender	Male	61.70	48.30	46.70
		Female	38.30	51.70	53.30
3	Annual family income	‹ Rs. 12000	65.00	56.70	65.00
		Rs. 12001-36000	25.00	28.30	20.00
		Rs.36001-60,000	8.30	13.30	8.30
		› Rs.60001	1.70	1.70	6.70
4	Education of mother	Illiterate	65.00	41.70	61.70
		Primary School Education	26.70	28.30	36.70
		High School Education	6.70	30.00	1.70
		College / Technical Education	1.70	Nil	Nil
5	Education of father	Illiterate	58.30	48.30	58.30
		Primary School Education	33.30	30.00	25.00
		High School Education	8.30	21.70	15.00
		College / Technical Education	Nil	Nil	Nil
6	Occupation of mother	Daily Wage	55.00	45.00	58.30
		Business / Self employed	16.70	18.30	11.70
		Employed	1.70	16.70	3.30
		Any Other	26.70	20.00	26.70
7	Occupation of father	Daily Wage	61.70	50.00	60.00
		Business/ Self employed	26.70	25.00	26.70
		Employed	5.00	13.30	5.00
		Any Other	6.70	11.70	8.30
Total			100.00	100.00	100.00

The public health system has been able to reach to the entire country up to some extent through NRHM, however, private sector including nongovernmental organisation (NGO) involvement in many hard to reach areas is minimal. With this background an effort was made to study the psychosocial needs of HIV infected children and the service provided by the Government, private and partnership.

Objectives

The present study was undertaken to (i) study the personal and family profile of HIV infected children; (ii) identify the psychological needs of HIV infected children; and (iii) assess the psychosocial support services to HIV infected children.

Materials and Methods

The study was conducted in three districts, Chittoor, Khammam and Visakhapatnam. From each district Government hospitals and other care and support agencies were selected randomly. The sample size was 180 service providers and 180 care takers of HIV-infected children. Purposive sampling technique was used. The independent variables are age, gender, education, occupation, and annual income, type of family and size of family. Dependent variables were psychosocial needs of HIV-infected children and the support services provided by public and private sector service providers.

Tools used:

PART-A: Demographic data from service providers and care takers. PART-B: Care and support need identification scale. PART-C: Care and support services identification scale.

Description of Tool

The structured interview schedule used to collect demographic data of beneficiaries and service providers. Five-point Likert scale was developed and used to identify the psychosocial needs of HIV-infected children.

CIAs care and support need identification scale: Psychosocial care and support need identification scale was developed. The investigator collected information on care and support needs of children infected with AIDS from available literature, beneficiaries, service providers and expert conversation with the topic. The needs thus identified are presented in the form of statements (80) on a five-point scale to a panel of experts consisting of subject experts (10 number). Service providers (10 members) and beneficiaries themselves (10 members). The scale was finalised and tested for its reliability using test-retest method in the pilot study conducted earlier. The correlation computed between the first and second set of scores and the reliability coefficient of 0.90 was obtained which shows that there is highest correlation.

Results & Discussion

Table 1 shows that the children aged between 11-15 years are more (40%) in Khammam when compared to Chittoor (36.7%) and Vishakapatnam (28.3%) related to gender the children infected with AIDS(61.7%) in Khammam, 48.3% in Chittoor and 46.7% in

Table-2: Logistic Regression – Psychosocial needs of HIV-infected children

S.No.	Sample	Areas	Odds Ratio	p-value
1	Beneficiaries	KMT-CTR	3.038	0.01
		KMT-VSKP	0.408	0.04
		CTR-VSKP	0.134	0.00
2	Service providers	KMT-CTR	0.245	0.00
		KMT-VSKP	0.646	0.24
		CTR-VSKP	2.638	0.01

Visakhapatnam are male, remaining percentage are female in these areas. The majority of children in three study areas belonged to families with an annual income of less than Rs. 12,000. Regarding education of parents the majority in all the three areas had no education or very low level of education. The occupation of parent level shows that majority were daily wage earners.

The psychosocial care and support needs of CIAs identified by care takers in three study areas were compared (Table 2). It was found that there was difference between the sample in Khammam and Chittoor as odd ratio wass 3.038 (>1) and p-value was 0.01 ($p<0.05$), which indicates that care takers of CIAs in Khammam gave less importance to psychosocial needs when compared to the sample in Chittoor. The sample Khammam and Visakhapatnam did not differ as the odd ratio was 0.408 and p-value 0.04. Similarly the sample in Chittoor and Visakhapatnam did not differ in identification of psychosocial care and support needs of CIAs as odds ratio was 0.134 and p-value 0.00. Needs identification by service providers in three study areas were compared. Thus there was difference between the sample in Chittoor and Visakhapatnam as odds ratio was 2.638 (>1) and p-value 0.01 ($p<0.05$).

Table 3 shows that the care takers identified the services needed to HIV-infected children in psychosocial aspects. Majority of the service providers rated psychosocial services as very important to HIV-infected children. This shows that there was a difference between service providers and care takers of CIAs in identification of existing care and support services.

Discussion: The global prevalence of HIV was gradually increased from 29.8 million in 2001 to 36.9 million in 2014. According to the United Nations Programme on HIV and AIDS (UNAIDS, 2014), about 2 million new HIV infections were documented in the year 2014. Stigma and social ostracism, intra- and inter-personal relationships affect the quality of life of children infected with AIDS.

Among all three areas, Chittoor, Khammam and Visakhapatnam, majority of the sample rated psychosocial needs as very good. In Khammam, a notable percent of sample (68.34%) rated psychological services as very good. In Chittoor, 46 percent of the sample rated psychosocial services as very good. In Visakhapatnam, 44 percent of the sample rated psychosocial services as very good. The beneficiaries did not vary significantly in their identification of children infected with HIV psychosocial needs among the three regions and also within the groups. There was variation in needs of children of three age groups (1-5 years, 6-10 years and 11-15 years). The psychosocial care and support services provided to children infected with AIDS were assessed by beneficiaries and service providers in three regions. It was found that they differed in their assessment of psychosocial care and support services provided by government private and public and private partnership agencies in the three regions of Andhra Pradesh.

After three decades of intensive research on the Human Immunodeficiency Virus, it remains as an important public health challenge worldwide with significant social and economic implications (Murray et al, 2014).

Implications: The study provided a state level data base on psychosocial care and support service needs of children infected with AIDS identified by the beneficiaries and also service providers of government, private and PPP agencies which is very much necessary to address the needs of CIAS through relevant programmes.

The study assessed the psychosocial care and support services provided by government, private and PPP. This mapping was done by both the beneficiaries and the service providers this data helps in identifying the gaps and to take necessary measures to strengthen the services.

Table-3: Psychosocial care and support services for HIV infected children (KMT-CTR-VSKP)

S No	Sample	Percentage of Services															
		Less important			Somewhat important			Important			Very important			Very very important		
		KMT	CTR	VSKP	KMT	CTR	VSKP	KMT	CTR	VSKP	KMT	CTR	VSKP	KMT	CTR	VSKP
1	Care takers	0.00	0.00	0.00	13.3	15.0	0.00	28.3	75.0	0.00	51.6	9.9	65.0	6.66	0.00	3.5
2	Service providers	3.33	1.68	3.33	13.3	17.6	3.33	24.9	26.3	41.6	54.9	35.0	46.6	3.33	23.3	5.0

Recommendations

The public and pri-

vate partnership in psychosocial care and support services delivery system may be developed to overcome bureaucratic procedures which are long and affect the utilisation of services by children infected with AIDS. The PPP initiatives needs both political and community support PPP is not a substitute to public sector but supplements and complements public sector.

Conclusion

Caretakers in the three regions of Andhra Pradesh differed in their identification psychosocial care and support needs. The psychosocial care and support services differed in three areas, provided by the Government, private and PPP agencies in the three regions of Andhra Pradesh. The right approach to care and support programmes need to be adopted to provide rightful needs to the children. This study made an effort to assess the psychosocial needs of children which are inter linked and are provided through a coordinated effort among the service delivery agencies.

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