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Exploring Knowledge of Caregivers of HIV Infected Children: A Cross-Sectional Study at A Tertiary Health Centre, Kolkata

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ABSTRACT

Introduction: HIV/AIDS is a major global threat today with huge number of HIV infected children. Caregivers of these children have a vital role to play, to meet their distinct care, support and treatment needs. They should have adequate knowledge regarding this lethal disease to successfully play their roles. This study was attempted to assess the knowledge of the caregivers of HIV infected children regarding the disease and factors associated with the above.

Methodology: This cross-sectional study was conducted at a Tertiary Health Centre, Kolkata among caregivers of HIV positive children. Relevant information was collected by interview method and from treatment cards.

Results: Majority of the caregivers were mothers (64.6%). Only 5.9%& 4% caregivers knew all the correct modes of transmission and common manifestations of the disease respectively. Overall 56.2% caregivers had poor knowledge (i.e.<=Median score) on HIV/AIDS. Illiteracy among caregivers, less than mean duration of disease of the attending child, HIV negative status of the caregivers and hospital as the most common source of knowledge of the caregivers were significantly at risk of having poor knowledge among the caregivers.

Conclusion: In spite of dedicated services at the ART centre, more than half of the caregivers had poor knowledge regarding HIV/AIDS.

Keywords: Caregivers, Children, HIV/AIDS, Knowledge

INTRODUCTION

Human Immunodeficiency Virus (HIV) infection or its advanced form Acquired Immunodeficiency Syndrome (AIDS) is making news worldwide for the last four decades. In 2017 there were 36.9 million people living with HIV/ AIDS(PLHA).[1] In 2017 alone, 1.8 million people were newly infected with HIV; among them children (<15 years of age) were estimated as 1.8 lacs.[1] The prevalence of HIV/AIDS among adult population (15-49 years) were .8% in the same year.[1]This incurable disease has a huge annual death toll (9.4 lacs in 2017); 1.1 lacs were children.[1]The disease has made its presence well felt in India. In 2015 there were 2.1 million PLHA in India; among them 6.5% were children. [2]The prevalence among adult population was .2% in 2017 with annual new infection in 88,000 population, 3700 being children.[3]The annual death toll was 69000, among them 2600 were children.[3] The number of orphans(0-17 years) due to AIDS stood at 9.3 lacs in 2017 in our country.[3]

The face of HIV/AIDS is increasingly young; the children living with HIV/AIDS pass through multiple challenges viz. rapid progression of the disease, malnutrition and other severe manifestations, poverty, orphanhood and its adverse consequences, stigma and discrimination, psycho-social distress, adhering to lifelong treatment etc.[4,5,6,7]And

care of children with HIV/AIDS is extremely demanding. Lack of awareness, diagnostic challenges, disclosure of HIV positive status, complexity of ART administration and adherence to it, accessability to health services and their utilization and quality of health care are some of the barriers to overcome.[8,9]These HIV infected children have very distinct care, support and treatment needs.[10]Caregivers of these children have a vital role to play viz. mobilising them to attend health facilities, nutritional care, helping regular intake of medicines, monitoring, care during severe illness and addressing psychological trauma, social stigma, discrimination and many other issues.[10]Thus they complement the health care team for provision of various services and play pivotal role for improved clinical outcome. [11]Caregivers should have adequate knowledge regarding this lethal disease to successfully play their roles.

Very few studies have been done on knowledge of caregivers of HIV positive children especially in India. With this context this study was proposed and carried out with the objectives to assess the knowledge of the caregivers of HIV infected children regarding different aspects of HIV/AIDS and finding out association, if any, between knowledge of the caregivers with the socio demographic, biological and other characteristics.

METHODS

This was an institution based cross-sectional study. The study was conducted at Regional Paediatric ART centre, Medical College and Hospital, Kolkata. It is the onlyART centre in Kolkata where exclusively HIV positive children are treated. This centre caters to patients mostly from districts of South-Bengal, but there is no geographic demarcation for service for this centre. Caregivers of HIV positive children of the above centre were considered for the study. Data was collected for a period of one year (1st May 2014— 30th April 2015).

Those caregivers who fell in any one or more of the following criteria were excluded from the study--- a) those caregivers who refused to give consent for the study b) those who accompanied children who have been diagnosed as HIV positive for less than two months from the day of interview and c) those caregivers who were from NGOs (Non-Governmental Organisations) or CBOs (Community Based Organisations).

The patients availed services here for six days a week. The centre was attended on any two days of a week and all the eligible caregivers who attended on those days with their wards were included in the study. Thus during the one year period the 283 caregivers were included in the study. By applying exclusion criteria, 91 caregivers were excluded from the study (30 caregivers refused to participate, 36 were from NGOs/CBOs and 25 children were diagnosed with their infectivity status for less than 2 months).Thus, finally 192 caregivers were selected for this study. Relevant information was collected by interviewing the caregivers with the help of a pre-designed pre-tested structured schedule in the local language (Bengali and Hindi).Other relevant data were obtained from Treatment cards of the children**.**

Ethical clearance: At the outset approval from Institutional Ethical Committee (IEC) of Medical College and Hospital, Kolkata were sought for this study. Before inclusion in the study, voluntary informed consent was sought from the caregivers. During this process the caregivers were explained about purpose of the study, right of the participants for adequate information, right to refuse to participate in the study and right to receive standard medical care available in spite of refusing to join the study. They were also ensured about anonymity and confidentiality of information. And there were no incentives for participating in the study.

Statistical analysis: Data was put in Excel spreadsheet and analysed using SPSS software version 20.Frequency Distribution tables and Logistic Regression (Univariate and Multivariable) were used to analyse the qualitative data.

RESULTS

Majority of the caregivers were mothers (64.6%).Rest were close relatives namely grandfather, grand-mother, uncle, aunt or 'Others' i.e. step-mother, foster-mother, commercial sex workers (CSW) etc. There was high prevalence of illiteracy among caregivers (31.3%). Very few caregivers (1% only) had higher education i.e. graduation or above**. (Table 1)**

Majority of caregivers i.e. 88.5% knew the name of the disease (HIV or AIDS) their children were suffering from. A total of 141(73.4%) caregivers knew correctly that this disease could not be cured while only 39(20.3%) caregivers knew correctly regarding the fate of this disease. (**Table 2)**

Eighty-five percent caregivers knew correctly that HIV is transmitted by sexual route and 57.8% caregivers believed that contact with infected blood may cause HIV/AIDS. Only 21.3% of the caregivers knew that the disease may be transmitted from mother to child. Again only 5.9% caregivers knew all the correct modes of transmission of the disease but 8.4% caregivers were unaware of any route of transmission of this disease. Ten (5.2%) and 6 (3.1%) caregivers wrongly opined that sharing

Table 1: Socio-Demographic and Biological Characteristics of the Study Population (n=192)

Characteristics	Frequency (%)
Categories of Caregivers	
Mother	124(64.6)
Father	36(18.8)
Close relatives	25(13)
Others	7(3.6)
Educational level	
Illiterate	60(31.3)
Primary level	71(37)
Middle level	30(15.6)
Secondary level	21(10.9)
Higher secondary level	8(4.2)
Graduate or above	2(1)
Residence	
Kolkata	43(22.4)
Other districts	149(77.6)
Religion	
Hindu	148(77.1)
Muslim	44(22.9)
PCI(Rs) Median(IQR) =625(400-1100)	
<Median	97(50.5)
>Median	95(49.5)
HIV positive status	
Yes	175(91.1)
No	17(8.9)
Duration of disease (Mean=2.98years)	
<Mean	106(55.2)
>Mean	86(44.8)
Death in family due to HIV infection	
Yes	81(42.2)
No	111(57.8)

(PCI=Per capita income,IQR=Inter quartile range)

Table 2: Response of study subjects regarding some general knowledge questions on HIV/AIDS. (n=192)

General questions	Respondent (%)
Name of the disease your child is suffering from	
Correct response(HIV/AIDS)	170(88.5)
Do not know	22(11.5)
Can a HIV infected patient be cured, if treated?	
Correct response(No)	141(73.4)
Incorrect response(Yes)	17(8.9)
Do not know	34(17.7)
Fate of this disease in spite of proper treatment?	
Correct response*	39(20.3)
Partially correct response#	90(46.8)
Incorrect response@	36(18.9)
Do not know	27(14)

*Remain healthy, but survive less than a normal person
#Remain healthy and survive as long as a normal person/Remain healthy and survive more than a normal person
@Patient will be cured

food with HIV positive person and mosquito bite may transmit HIV infection respectively. Twenty-two (11.5%) caregivers believed wrongly that caressing a baby by a HIV positive person may put the baby at risk of transmission**. (Table 3)**

Regarding knowledge on common manifestations of HIV/AIDS, fever and loose motion were cited by 71.8% and 55.2% caregivers respectively. Only 4% caregivers had knowledge about all the common manifestations of HIV/AIDS.A large number of caregivers i.e. 180 (93.8%) knew correctly that breastfeeding increases chance of transmission of HIV infection to the baby. Hundred (52.1%) caregivers knew correctly that caesarean section delivery is better than normal delivery for HIV positive pregnant mother to prevent Mother-to-child-transmission (MTCT) to the new-born. About 113 (58.9%) caregivers knew correctly that Anti-retroviral (ARV) prophylaxis to mother and/or baby is beneficial for the baby. Majority of caregivers i.e. 148 (77.1%) knew that Anti-retroviral therapy (ART) was the treatment available for HIV/AIDS; another 15(7.8%) believed wrongly that a vaccine was also available for treating these HIV/AIDS patients. **(Table 4)**

Overall 108(56.2%) caregivers had poor knowledge (i.e.<=Median attained score), the rest had adequate knowledge. On Bivariate analysis it was found that factors like caregivers other than mother, less than mean duration(2.98 years) of disease, HIV negative status of the caregivers and hospital as the most common source of knowledge of the caregivers were significantly at risk of having poor knowledge score. On Multivariate (Logistic Regression) analysis it was noted that, illiteracy among caregivers, less than mean duration of disease of the child, HIV negative status of the caregivers and hospital as the most common source of knowledge of the caregivers were significantly at risk of having poor knowledge score of the caregivers. However, in Multivariable analysis caregivers other than mothers lost its significance as risk factor for poor knowledge score of the caregivers.**(Table 5)**

DISCUSSION

In comparison to the present study where 56.2% caregivers had poor knowledge on HIV/AIDS, another study by *Nicholson O et al, USA* observed caregivers correctly answered 74% of the knowledge questions; though specific misconceptions were also noted.[11] Regarding knowledge on modes of transmission of HIV infection there was varied response from caregivers in the current study e.g. high knowledge on transmission via sexual route (85%) and exclusive breastfeeding (93.8%); moderate knowledge on transmission by unsafe injection/blood contact (57.8%) and poor knowledge on MTCT (21.3%) and all the modes of transmission (5.9%). Compared to the above findings another study by *Aderemi-Williams RI et al,Nigeria* found high knowledge on transmission via blood transfu

Table 3: Knowledge of the Caregivers regarding Different Modes of Transmission of HIV/AIDS (n=192)

Questions on Modes of transmission	Freq(%)
Causes of this disease	
Sexual exposure	163(84.9)
Blood transfusion	66(34.4)
Mother to child	41(21.3)
Unsafe injection (IDU/blood contact etc)	111(57.8)
All of the above	12(5.9)
f. Do not know	17(8.4)
Sharing food with HIV +ve transmit HIV infection	
Correct response(False)	170(88.6)
Incorrect response(True)	10(5.2)
Do not know	12(6.2)
HIV infection is transmitted by mosquito bite.	
Correct response(False)	176(91.7)
Incorrect response(True)	6(3.1)
Do not know	10(5.2)
Caressing a baby by a HIV positive person is risky	
Correct response(False)	156(81.3)
Incorrect response(True)	22(11.5)
Do not know	14(7.3)

(IDU=Injecting Drug User)*multiple response

Table 4: Knowledge of the caregivers on manifestations, prevention and treatment of HIV/AIDS (n=192)

Knowledge variables	Freq (%)
Common manifestations of this disease*	
Fever	138(71.8)
Loose motion	106(55.2)
Cough	55(28.6)
Tuberculosis	37(19.3)
Skin diseases	49(25.5)
Weight loss	24(12.5)
Weakness	44(22.9)
Others	42(21.9)
All of the above	8(4)
Prevention (of MTCT) and treatment	
Breastfeeding by HIV positive mother increases chance of infection to the baby	
Correct response(True)	180(93.8)
Incorrect response(False)	5(2.6)
Do not know	7(3.6)
Normal delivery is better option than Caesarean Section delivery of HIV positive mother	
Correct response(False)	100(52.1)
Incorrect response(True)	42(21.9)
Do not know	50(26)
Giving antiretroviral prophylaxis to mother and/ or newborn baby is beneficial for the baby	
Correct response(True)	113(58.9)
Incorrect response(False)	35(18.2)
Do not know	44(22.9)
Treatments available for HIV infection?	
Correct response(ART)	148(77.1)
Partially correct response (ART + Operation or Vaccine)	15(7.8)
Incorrect response(Operation/Vaccine)	2(1)
Do not know	27(14.1)

(MTCT=Mother-to-child-transmission, ART=Anti-retroviral therapy); *Multiple response

sion (92.2%) and breastfeeding (88.2%); average knowledge of transmission through unprotected sex (56.9), use of unsterilized needles and sharps (57.8%) and below average knowledge of transmission through circumcision (40.2%), MTCT (35.5%) and via oral sex (12.1%).[12]Another study in Burkina Faso reported that 97% caregivers had correct knowledge about MTCT and majority of them knew about prevention of MTCT by ARV prophylaxis and substituting breast milk.[13] In consistent with this study finding (i.e. 26.6%), other studies in *Ethiopia and Varanasi, India* reported that minority of caregivers believed wrongly that HIV can be cured(18.5 % and 22.9 % respectively).[14,15]The above mentioned study in *Varanasi* also found electronic media as the major source of information(40%) for caregivers compared to hospital in the present study(69.4%).[15]

In comparison to the present study, in National Family Health Survey-4(NFHS-4), in West Bengal it was found that only 18.6 % of women and 25.9 % of men had 'comprehensive knowledge' of HIV/AIDS. [16]The figures for India were 20.9 % and 32.5 % respectively.[17] This means that they knew that a healthy-looking person can have HIV/AIDS, that HIV/AIDS cannot be transmitted through mosquito bites or by sharing food,and that condom use and having only one faithful, uninfected partner can help prevent HIV/AIDS.[16]The greater proportion of the caregivers in the present study had adequate knowledge(i.e. 44%), might be due to the facts that majority had HIV positive members in the family including themselves and the experience they got from different health facilities or NGOs which were lacking in community in general surveyed by NFHS-4.

For the apparent paradox that those caregivers who mentioned hospital as the most important source of their knowledge had poorer knowledge may be explained by the fact that most of the other caregivers who scored better attended NGO or Positive Network besides hospital. Thus it can be concluded that NGOs/Positive Networks do excellent work in advocacy of correct knowledge regarding HIV/AIDS. Lack of quality counselling spanning enough time for the attending caregivers was observed at the centre. Attending a large number of patients at this tertiary centre was one reason of such practices.

Considering paucity of such studies in India on knowledge profile of caregivers of HIV positive children and factors related to it, this study surely threw some light on these issues. It should also be mentioned that another strength of the study was that data was collected from 192 subjects of ten districts of West Bengal i.e. a large geographic hinterland was included. However cross-sectional design

Table 5: Covariates of Poor Knowledge Score (<=Median): Univariate and Multivariable regression

Covariates	Total (n=192)	<=Median Score (n =108) (%)	OR (95% CI)	AOR (95% CI)	p valve
Categories of Caregivers					
Mothers	124	62(50)	1	1	0.122
Others	68	46(67.6)	1.54(1.05-2.27)	1.58(.79-3.18)	
Education of caregivers					
Literate	130	67(51.5)	1	1	0.001
Illiterate	62	41(66.1)	1.43(.97-2.11)	2.68(1.28-5.63)	
Duration of disease of the attending children					
>Mean(2.98 years)	86	37(43)	1	1	0.002
<Mean(2.98 years)	106	71(67)	1.73(1.24-2.4)	2.67(1.38-5.17)	
HIV positive status					
Yes	175	95(54.3)	1	1	0.011
No	17	13(76.5)	1.94(.81-4.65)	4.38(1.24-15.45)	
Most common source of knowledge					
Others	58	26(44.8)	1	1	0
Hospital	134	93(69.4)	1.91(1.41-2.57)	3.51(1.7-7.2)	

(OR=Odds Ratio,AOR=Adjusted Odds Ratio,CI=Confidence Interval)

*Other covariates i.e.residence (Kolkata/Others), religion(Hindu/Muslim),PCI (>Median/<Median), death due to HIV/AIDS in family(Yes/No) were not significantly at risk for poor knowledge score of the caregivers by Bivariate or Multivariate analysis.

of the study precluded us to elicit the association of level of knowledge of caregivers and different aspects of care and clinical outcome of the disease in their children. Lastly, along with knowledge, sincerity of care by the caregivers also has important role to play in care of the children. We missed on finding out that aspect of the caregivers.

CONCLUSION

In spite of sincere services at the ART centre, more than half of the caregivers had poor knowledge regarding HIV/AIDS. The factors related to the above were--illiteracy, HIV negative status, hospital as the most common source of knowledge and less than mean duration of disease of the attending child. Greater efforts by ART Centre personnel would run a long way to improve knowledge of caregivers, subsequently child care practices and clinical outcome.

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