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QUALITY OF LIFE IN CHILDREN LIVING WITH HIV INFECTION

Paediatrics

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ABSTRACT

Aim: To study the quality of life in HIV infected children .Also to study the clinical spectrum of HIV infection in children. Materials and Methods: This is a cross sectional study that enrolled children aged 2-12 years with established HIV infection presenting to the ART centre at Lok Nayak Hospital, New Delhi . The Paediatric Quality of Life (PedsQL) Inventory(version 4.0) was used to measure the quality of life in children living with HIV infection. The CD4 counts, complete haemogram, liver function tests, renal function tests and WHO Staging were also done. Analysis was done using Statistical Package for Social Sciences (SPSS) latest version. A p value of <0.05 was considered statistically significant. Results: A total of 80 HIV infected children were included in the study. Eighty age and sex matched healthy controls were also included. The mean age of HIV infected children was 8.54 ± 3.2 years. There was male predominance with 54 (67.5%) males and 26 (32.5%) females. The health related quality of life mean scores in all the 4 domains were significantly less in the cases as compared to the controls (p<0.001).Children with advanced disease stage had significantly low scores in all domains as compared to the controls. The mean scores of Ped QL in the all 4 domains were lower in those with CD4 counts <500 cells/ml as compared to those with CD4 counts >500 cells/ml. Conclusion: Children in advanced clinical stages and lower CD4 counts had lower quality of life scores as compared to those in less advanced disease. Thus early diagnosis and ART initiation is essential to preserve the quality of life in these children affected by a chronic debilitating illness like HIV.

KEYWORDS

INTRODUCTION

Infection with HIV is one of the greatest challenges to global health faced by the medical profession. Globally, there were 1.8million children living with HIV, 110,000 AIDS-related deaths, and 150,000 new infections among children in 2015. The total number of People Living with HIV (PLHIV) in India was estimated to be 21.17 lakhs in 2015 compared with 22.26 lakhs in 2007 1. Children (< 15 years) accounted for 6.54%. This decline was consistent with the rapid expansion of access to ART in the country. HIV infection in children is a chronic illness with effects on physical, emotional and social well-being. The PedsQL (Paediatric Quality of Life Inventory) is a modular instrument for measuring health related quality of life(HRQOL) in children and adolescents ages 2 to 18 years 2. It is designed to measure physical, emotional and social dimensions which are the core domains delineated by WHO3. This model also includes school dimension. With the advent of highly active antiretroviral therapy the life span of HIV infected children has increased but studies on Quality of life of these children are still few. Also, there is paucity of information on assessment of quality of life among HIV infected Indian children.

MATERIALS AND METHODS

The study was conducted in the department of pediatrics and ART center of Lok Nayak hospital, New Delhi from Feb 2016to Feb 2017. The study population comprised of all children aged 2-12 years with established HIV infection presenting to ART center at Lok Nayak hospital.

Total 80 HIV infected children were included in the study. Eighty age and sex matched healthy controls were also included.

The Paediatric Quality of Life (PedsQL) Inventory(version 4.0) was used in the present study to measure the the quality of life in children living with HIV infection. There are 23 items in the paediatric quality of life generic core scale which are designed to measure the core dimensions of health delineated by WHO. The four (4) multidimensional scales.are; physical functioning (8 items), emotional functioning (5 items), social functioning (5 items) and school functioning (5items). This tool consists of child self report and parental/ care taker report. Hence both child's

perception and parental/caretaker's perception on the quality of life can be assessed. The pediatric quality of life inventory is divided according to the age of the patient namely 2-4 years,

5-7 years and 8-12 years. Higher scores in the inventory indicate better health related quality of life .Baseline demographic factors including age, gender and Kuppuswamy's socioeconomic status of the family were collected. Staging of HIV infection as per World Health Organization guidelines was also recorded[4].

The Mean QOL scores were compared among the cases and controls and also among various demographic and clinical variables. Quantitative variables were compared using Unpaired t-test/ Paired t-test while qualitative variable were compared using Chi-Square test /Fisher's exact test. A p value of <0.05 was considered statistically significant at 95% confidence level.

RESULTS

The maximum number of cases enrolled was in the age group 8-12 years accounting for 57.5% of the total number of cases. The mean age of HIV infected children was 8.54 ± 3.2 years. There was a male predominance with 54 (67.5%) males and 26 (32.5%) females. Using the modified Kuppuswami scale, it was found that 53 out of 80 (66.25%) cases belonged to lower class.76 out of 80 (95%) cases had acquired the HIV infection from their parents.

Out of 80 children, 21 (26.25%) had lost either of their parents. Five had lost both parents because of HIV. Out of 15 children less than 5 years moderate or severe malnutrition was seen in 10 (66.66%). In children more than 5 years 44.6% were under weight and 38.4 % were stunted. The common clinical features at presentation were fever (42%), loose stools (40%) and cough (33.7%). Tuberculosis was seen in 11 out of 80 cases (13.7%).Out of 80 cases, 29 were in advanced clinical stage (stage III and stage IV).

The Paediatric Quality of Life (PedsQL) Inventory(version 4.0) was used in the present study to measure the the quality of life in children living with HIV infection .The mean scores in all the 4 domains namely physical functioning, social functioning, emotional functioning and school functioning were significantly less in the cases as compare to the controls.

Table 1: Health Related Quality of Life Mean Scores of the Respondents on PedsQL Scales

Scale	CASES (n=80)		CONTROL(n=80)		p value
	Mean	SD	Mean	SD	
Physical Functioning	78.2	8.92	82.7	3.91	<0.001
Emotional Functioning	80.0	8.79	84.5	3.23	<0.001
Social Functioning	81.2	8.71	84.9	3.55	<0.005
School Functioning	74.9	8.75	78.12	4.25	<0.005
Total Functioning	78.6	8.10	82.5	1.88	<0.001

In the children with the age group2-4 years, only physical functioning was significantly low as compare to the controls ($p<0.05$). In older children 8-12 years, mean score in the all 4 domains namely physical, social, emotional and schooling were significantly low as compared to age matched controls. Mean score of Peds QL in the various clinical stages namely stage I, stage II, stage III and stage IV were significantly different in between the groups. Children with advanced disease stage III and stage IV had significantly low scores in all domains as compared to the controls. The mean scores of Ped QL in the all 4 domains were lower in those with CD4 count <500 cells/ ml as compared to those with CD4 counts > 500 cells/ ml. The mean scores of the children not on ART were higher than those not on ART. The children who were not on ART were in less advanced stage of disease and had CD4 counts >500 cells/ µl since presentation.

DISCUSSION

Advances in the management of HIV have resulted in significant improvement in the mortality and morbidity of children living with this infection. So, the ongoing management of HIV should aim to improve the health-related quality of life (HRQoL). Hence, in this study we have explored the clinical features of HIV infection in children and have assessed the quality of life in them and have also compared it with age and sex matched healthy controls.

Using PedQL(version 4.0) quality of life was assessed in 80 HIV infected children and compared with 80 ages and sex matched controls. In this study we compared the HIV infected children with the healthy controls and found quality of life in all domains to be less than the controls. ($p<0.05$).With advancement of the age in children in the age group8-12 years, scores in the physical functioning ($p <0.05$), emotional functioning ($p <0.001$), social functioning ($p<0.05$), schooling ($p<0.05$) were all statistically lower than the controls. With the advancement of the age these children had multiple morbidities like opportunistic infections, emotional and social problems and frequent school absenteeism. All this thus reflected in the poor quality of life in all domains compared to controls. Poor quality of life in these children has also been reported by Bunupuradah et al 4 and Lang et al 5. The quality of the scores of the children who had lost either parent or both parents were not significantly different from those whose both parents were alive. The joint family system, social
support groups, effective counseling and presence of the alternate care givers perhaps did not impair the quality of life in the orphaned children.

The scores in the all 4 domains in stage I, stage II, stage III and stage IV of illness were significantly different ($p<0.001$) when compared between the groups. Children with stage III and IV illness had all scores in all domains significantly lower than the controls ($p<0.001$). Thus with advanced clinical stage, quality of life of HIV infected children is poor as compared to the controls.

Next the quality of life scores in the children with CD4 counts less than 500 cells/µl were compared those with >500 cells/ µl . The mean score in the all 4 domains were significantly lower ($p<0.001$) in those with CD4 counts less than 500 cells/µl. The lower CD4
counts are associated with clinical symptoms and ill heath leading to poor physical functioning,

emotional and social problems and school absenteeism.Also,it was seen that the mean score of the children with the CD4 counts >500 cells/ µl were better than those in controls. This finding could be attributed to the fact that these children were clinically well, had better access to the financial support from NACO and social support from the health care providers in HIV clinic. There were also significant differences in the mean scores of the children on anti retroviral therapy (ART) with respect to those not on ART . The mean scores of the children not on ART were higher than those not on ART .This could be attributed to the fact that children who were not on ART were in less advanced stage of disease and also had CD 4counts >500 cells/ µl at presentation ,the reason for which ART was not initiated in them. Also there were only limited number of cases who were not on ART available for comparison in this study.

CONCLUSIONS

To conclude, with the advent of ART ,HIV infection in children has become a chronic illness with effects on quality of life. It was seen in this study that the older children had inferior quality of life as compared to younger ones. This could be attributed to a longer duration of illness with its morbidity affecting the quality of life in these children. Children in advanced clinical stages and lower CD4 counts had lower quality of life scores as compared to those in less advanced disease. Thus early diagnosis and ART initiation is essential to preserve the quality of life in these children affected by a chronic debilitating illness like HIV.

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