Health Related Quality of Life of Children Infected with HIV in Agra Region, India

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Authors' contributions

This work was carried out in collaboration among all authors. Author AK designed the study, performed the statistical analysis, wrote the protocol and wrote the first draft of the manuscript. Author DA edited the manuscript and provided valuable inputs and author NCP conceptualized the study, gave valuable inputs and edited the manuscript. All authors read and approved the final manuscript.

Original Research Article

ABSTRACT

Objective and Methods: HIV specific health related quality of life (HRQOL) instrument based on PedQL™ 4.0 generic scale was prepared and named HIV-QOL. It was validated and used to evaluate HRQOL in HIV infected children in an observational, crossectional study conducted in the Department of Pediatrics, Sarojini Naidu Medical College, Agra, India.
Results: Cronbach's alpha score > 0.7, supported acceptable internal consistency of the instrument.The correlation coefficient of more than 0.8 indicated that the instrument was valid for application. Study included 40 HIV infected children between age 8 to 18 years.Their mean scores were calculated in all four domains (viz physical, social, emotional and school functioning) and comparison of HRQOL scores was done with respect to various social and demographic parameters. CD4 counts, clinical stage of the disease and living status of the parents and anti retroviral therapy (ART) had significant influence on the HRQOL scores.

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Conclusion: HIV QOL is a valid instrument to assess the health related quality of life of HIV infected children in India. It can help in assessing their health status, as well as in evaluating the impact of various medical and social programmes aimed at improving their quality of life.

1. INTRODUCTION

HIV/AIDS is now considered to be a chronic condition due to access to more effective clinical interventions. Thus traditionally used outcome measures, such as viral loads and CD4 percentages are not adequate to monitor effectiveness of treatments. Hence, an additional health measure, Health related Quality of Life (HRQOL), has been suggested to evaluate the outcome for HIV infected children [1-3]. An exploration of factors affecting their HRQOL and well-being provides a glimpse into the world experienced by these children, children who are especially sensitive to the impact of both illness and treatment. The result from these analysis can assist in determining whether there are any modifiable factors affecting their quality of life.The large and growing number of affected children and adolescents makes it essential that we learn about their needs so that effective intervention can be provided.

Research into HRQOL and HIV has focused more on the adult population. Garvie et al. [4] studied nineteen QOL/HRQOL measures in HIV, but none of them included pediatric or adolescent populations in their development. Cleary et al. [5] studied HRQOL in adults with HIV and found that fatigue, functional status,and average severity of all symptoms were the best predictors of overall perceived health status in adults with HIV. Only few studies have focussed on HRQOL in children with HIV and most of them have used generic scales for HRQOL evaluation [6,7]. There is paucity of HRQOL instruments specifically designed for children with HIV [8-10].

The purpose of the present study was to prepare HIV specific instrument applicable in Indian context. Our instrument was based on Peds QL™ 4.0 generic scale [11,12], which is a brief, standardised and validated generic assessment instrument that systematically assesses patients' and parents' perceptions of HRQOL in paediatric patients with chronic health conditions .We modified the Peds QL 4.0 generic scale to generate HIV specific instrument suitable in Indian context and evaluated its reliability and validity. and further applied it to study HRQOL in HIV infected children and its relations to various sociodemographic variables, clinical stage and immunological status of the disease.

2. MATERIALS AND METHODS

Study design: This cross sectional study was conducted in the Department of Pediatrics, Sarojini Naidu Medical College, Agra (India), during the study period from January 2011 to October 2012.

Inclusion criteria: All HIV infected children between 8-18 years of age attending the OPD or admitted at dept. of Pediatrics, Sarojini Naidu Medical College, Agra,India during the study period were enrolled for the study.

Exclusion criteria: Children suffering from any cognitive or communicative disabilities or psychotic disorders.

Methods: Disease specific HRQOL Questionnaire was developed based on PedsQL™ 4.0, after obtaining permission from Dr James W.Varni, who owns its copyrights .The instrument was modified to suit the Indian cultural setting. The new instrument generated was named HIV-QOL. It comprised of 22 questions (18 out of the 23 questions contained in the Peds QL core scale) plus 4 new questions. These questions were subgrouped in four different domains viz physical functioning (6 items), emotional functioning (5 items), social functioning (5 items) and school functioning (6 items).The HIV-QOL questionnaire from PedsQL 4.0 was translated to Hindi and retranslated to English independently.

Administration of HIV-QOL: A detailed profile of the child pertaining to age, sex, socioeconomic status (by modified Kuppuswamy's socioeconomic scale [13], disease profile (CD4 count, clinical stage, etc) at the time of enrollment in the study was obtained and recorded on a predesigned proforma. Most of the children were aware of their disease status, however full confidentiality was maintained to not disclose

the diagnosis to other children at any stage of the study. HIV-QOL was administered to children by either proxy method or self administered.

Scoring system: Using five point likert scale from 0 (never) to 4 (almost always). Items were reverse scored on a 0-100 scale as follows: 0-100; 1- 75 ; 2- 50; 3-25; 4-0. Total score- sum of all the items over the no of items answered on all the scales.A child with higher score will have a better HRQOL.

2.1 Statistical Analysis

The reliability of the instrument was assessed using cronbach's alpha for internal consistency [14,15]. For structural validity, we calculated the correlation coefficients between individual domains score and total HIV-QOL score. For the analysis of correlates of quality of life, various factors were evaluated as independent variables like age, gender, parents alive or not, education of caregiver, occupation and socioeconomic status of caregiver [13], variables related to disease progression like CD4 count, clinical stage, on ART therapy or not. Independent variables were reported as numbers and percentages, facet and domain scores were reported as mean and standard deviation. Student t test was used to compare the means. Data analysis was performed using Med-calc software, http/www.medcalc.org.

3. RESULTS

Mean cronbach's alpha in all four domains as well as for all 22 items were more than 0.7. Pearson's correlation coefficient for association between all four domains and overall HRQOL scores were more than 0.8. Table 1.

Out of Forty HIV infected patients enrolled for the study, 30 (75%) were males with a skewed sex ratio of 3:1. Mean age was 11.38 ± 2.99 years. 62.5% of children were either asymptomatic or mildly symptomatic ,WHO clinical stage I and II [16]. 26 (65%) children were on Anti Retroviral Therapy (ART). Table 2.

HIV-HRQOL Scores: Mean scores were highest in the domain of physical functioning (73.83 ± 17.73), followed by emotional (72.11 ± 14.15), social (71.25 ± 20.02) and school functioning (70.08 ± 9.4). 10% of children had total score below 50.

Impact of different parameters on HIV-HRQOL scores: (Table 3) Age, gender, socioeconomic status and educational status of caregiver did not have significant impact on HIV-QOL scores. Children living with both parents alive had better total scores when compared with children living with single parent alive. Significant difference was observed in physical (*P=.0009*), social (*P=.0072)* and school functioning (*P=.0058*) domains. There was a significant fall in all four domain scores with lower CD4 counts (*P=.0126*, for CD4 <200). Similarly significant difference was found between total scores with WHO clinical staging. In Stage I and II mean score was 75.7 ± 11.35 and in stage III and IV mean score was 62.625 ± 12.49 (*P =.001*).Children on ART had better scores in Emotional and School performance, but showed no difference in Physical and Social domains.

4. DISCUSSION

We studied health related quality of life in children infected with HIV using disease specific HRQOL instrument . Cronbach's α scores were more than 0.7 , supporting an acceptable internal consistency of instrument. The correlation coefficient of more than 0.8, indicating that the instrument was valid for application.

Overall, HIV infection was associated with lower scores in physical, school and emotional functioning in children between 13 to 18 years of age, although the difference was not statistically significant. One explanation for this can be the pscychological reactance in adolescent age group, because of which children in the stage of adolescency are less likely to communicate with their caregivers about their problems, especially psychological and emotional problems. Children from HIV/AIDS affected families are less likely to communicate with their caregivers than those from the ordinary families . The mean scores in our study were comparable to previous studies [17,18].

There was no difference in domain scores between males and females in our study, similar finding was reported by Gupta et al in children infected with HIV [19].However contrary to these reports, better scores for women have been found in a study in adults age group [20]. Other socio demographic parameters did not have influence over the HRQOL scores. Children living with both parents alive had significantly better scores when compared with children living with single parent or without parents.

Table 1. Cronbach's alpha and pearson's correlation coefficient of HIV-QOL

Domain	Mean score	Standard deviation	Cronbach's α	Correlation with overall HRQOL score
I. Physical functioning	**73.83**	**17.73**	**0.8682**	**0.8285***
1 Running	63.75	28.84	0.9281	
2 Participating in sports activity or exercise	66.87	26.79	0.9288	
3 Taking a bath or shower by him or herself	93.12	12.64	0.9332	
4 Doing Chores around the house	85.62	18.68	0.9312	
5 Low energy level	63.12	18.77	0.9327	
6 Having hurts or aches on lifting something heavy	73.12	21.47	0.9300	
II. Emotional Functioning	**72.11**	**14.15**	**0.8518**	**0.8321***
1 Feeling afraid or scared	72.50	16.79	0.9333	
2 Feeling sad or blue	70	22.07	0.9288	
3 Feeling angry	57.5	18.08	0.9320	
4 Trouble sleeping	89.37	13.74	0.9328	
5 Worrying about what will happen to him or her.	74.37	20.79	0.9314	
III. Social functioning	**71.25**	**20.02**	**0.8531**	**0.8553***
1 Getting along with other children	69.37	23.67	0.9287	
2 Other kids not wanting to be his or her friend.	70.62	24.60	0.9311	
3 Getting teased by other children	80.62	24.34	0.9319	
4 Sharing things with other children	58.12	22.92	0.9311	
5 Attending social gatherings like other children	74.37	20.79	0.9286	
IV. School functioning	**70.08**	**9.4**	**0.8197**	**0.9003***
1 Paying attention in class	73.61	13.29	0.9371	
2 Forgetting things	67.36	18.73	0.9327	
3 Keeping up with school work	78.47	14.82	0.9328	
4 Missing school because of not feeling well	59.03	18.08	0.9328	
5 Missing school to go to the doctor or hospital	56.25	15.09	0.9341	
6 Being discriminated by teachers and school staff.	86.11	15.17	0.9283	

Table 2. Socio-demographic and disease related characteristics of study subjects

Variable		Frequency (%)
Sex	Male	30 (75)
	Female	10 (25)
Age	8-<13	26 (65)
	13-18	14 (35)
Parents alive or not	Both alive	12 (30)
	Either parent dead	28 (70)
Occupation of parents	farmer	15 (37.5)
	labourer	11 (27.5)
	service	4 (10)
	Self employed	10 (25)
Socioeconomic status	lower	10 (25)
	Upper lower	13 (32.5)
	Lower middle	15 (37.5)
	Upper middle	2 (5)
Level Of education of caregiver	illiterate	8 (20)
	Educated(>8class)	32 (80)
Opportunistic infection	yes	26 (65)
	no	14 (35)
ART	yes	26 (65)
	no	14 (35)
CD4	≤200	14 (35)
	>200	26 (65)
WHO Clinical stage	I and II	25 (62.5)
	III and IV	15 (37.5)

Table 3. Mean scores of HRQOL according to demographic and disease related variables

Variables		Physical	Emotional	Social	School	Total
Sex	Male	71.78(±19.3)	72.98(±15.08)	72.33(±22.4)	71.8(±10.5)	70.88(±15.0)
	Female	79.97(±9.78)	69.5(±11.16)	68.0(±9.7)	65.79(±3.81)	70.55(±6.25)
	*P value**	*.2080*	*.5076*	*.5593*	*.0842*	*.9468*
Age	8<13	75.73(±17.36)	73.82(±15.21)	70.19(±20.99)	71.32(±10.29)	71.72(±14.7)
	13-18	70.28(±18.52)	68.92(±11.29)	73.21(±18.66)	67.38(±6.93)	69.17(±10.4)
	P value	*.3606*	*.3022*	*.654*	*.208*	*.5695*
Parents Alive/dead	Alive	87.54(±9.5)	74.16(±15.3)	81.25(±10.47)	75.66(±9.19)	79.15(±9.92)
	Dead	67.95(±17.25)	71.22(±13.81)	66.96(±21.7)	67.17(±8.36)	67.22(±13.05)
	P value	*.0007*	*.5536*	*.0369*	*.0069*	*.0074*
Socioeconomic status	Lower	70.08(±18.42)	70.19(±15.9)	70.21(±20.09)	71.04(±9.41)	68.9(±15.22)
	Middle	78.90(±15.89)	74.7(±11.24)	72.64(±13.24)	69.07(±9.66)	73.30(±9.99)
	P value	*.1213*	*.3245*	*.7095*	*.524*	*.3065*
Education of caregiver	Illiterate	68.075(±15.69)	71.8(±16.76)	72.5(±19.27)	70.81(±9.50)	68.56(±12.6)
	Educated	75.27(±18.15)	72.18(±13.73)	70.93(±20.49)	69.93(±9.59)	71.36(±13.5)
	P value	*.3196*	*.9425*	*.8457*	*.8174*	*.5983*
Opportunistic infections	Present	68.69(±19.3)	68.72(±13.9)	67.91(±18.58)	67.95(±7.60)	67.16(±12.8)
	Absent	81.54(±11.79)	77.18(±13.28)	76.25(±21.64)	72.62(±10.97)	76.25(±12.4)
	P value	*.0225*	*.0625*	*.2007*	*.1194*	*.0367*
ART	Yes	72.88(±16.69)	68.05(±12.19)	67.88(±20.44)	67.72(±8.53)	68.29(±11.93)
	No	75.58(±20.06)	79.64(±14.8)	77.5(±18.26)	74.61(±9.80)	75.46(±14.82)
	P value	*.6519*	*.0114*	*.1495*	*.0262*	*.1042*
CD4	≤ 200	61.21(±16.39)	66.02(±11.17)	65.7((±20.64)	64.97(±4.88)	63.8(±10.59)
	> 200	80.62(±14.62)	75.38(±14.6)	74.23(±19.4)	69.36(±10.1)	74.56(±13.2)
	P value	*.0005*	*.0445*	*.0572*	*.1355*	*.0126*
Clinical stage	III and IV	61.308(±19.96)	64.29(±11.66)	64.33(±21.11)	64.56(±4.90)	62.62(±12.4)
	I and II	81.346(±11.04)	76.8(±13.60)	75.8(±18.53)	72.29(±9.98)	75.70(±11.3)
	P value	*.0002*	*.0052*	*.0531*	*.0081*	*.001*

*P value <0.05 was taken as significant

Clinical and immunological status of the disease had significant effect on HIV-QOL scores. Overall lower scores were seen in physical and social domains in children with lower CD4 counts. This is contrary to the finding in a previous study in which no such relationship was found [21]. The most likely reason being, use of disease specific tool instead of generic tool in our study which is more sensitive to detect effect of immunosuppression on HRQOL .This fact is further substantiated by the findings of Oberdorfer et al. [22], who also found significant difference in HRQOL scores when comparison was done using HIV specific module .We also observed that children with advanced disease had lower scores in Physical,Emotional,and School domain .This is probably because children in worse clinical stage are burdened with physical symptoms of disease which in turn impairs HRQOL as observed in some other studies [20].

Children receiving antiretroviral therapy showed significant improvement in Emotional and School performance. Conflicting reports have been reported in previous studies regarding impact of ART on Improvement in HRQOL scores.In a cross sectional study from U.S, HIV infected children who were receiving ART had higher QOL scores than children who were not receiving ART [1]. Contrary to these findings Bunupuradah et al. [23] did not find significant difference in QOL scores between ART naïve and ART treated HIV infected children at baseline and at followup at week 144.

However total HRQOL score and Physical and Social domain scores in our study did not show any significant difference between the two groups (ART vs ART naive). This may be because the mean duration of ART in our study was 17 months,which was much less than in other studies eg 8.9 years in a study from Thailand [18] and hence most of the children were clinically asymptomatic at the time of study regardless of the initial clinical staging.

Our findings should be interpreted with some limitations. Being a crossectional study, it could not evaluate how QOL changed over time.Small samle size could be another limiting factor. Moreover, parents and caregivers might not have given accurate assessments of the QOL.

5. CONCLUSION

HIV-QOL is a validated instrument and can be used for assessing the quality of life in

children with HIV in Indian context. Living status of the parents,clinical stage of disease,CD4 counts and anti retro viral therapy causes significant effect on their QOL. The information gathered on the quality of life of children with HIV/AIDS would be of benefit to all the health team members, and family, involved in the treatment of young children with HIV/AIDS. The information would assist in determining the resource allocation that is necessary in terms of social, emotional and school support that would optimise the quality of life of the children with HIV/AIDS. In addition, the specific domains assessed using the HIV-QOL may highlight specific aspects of quality of life that are consistently affected by the disease process that need specific intervention and considerations when treating a child with HIV/AIDS holistically. We suggest follow up studies designed to monitor changes in HRQOL with disease course to gain further insights into the problems faced by this age group.

CONSENT

After obtaining informed, written consent from the parent/guardian, child was enrolled for the study

ETHICAL APPROVAL

This study was performed as a part of post graduate thesis programme at S.N. Medical college, Agra,India. Necessary approval was taken from institutional ethical committee at the beginning of the study. Approval No.- Thes/pg/peds/2010/02

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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