



Research Article

## Prevalence of alexithymia among a cohort of well controlled HIV-infected adolescents and non-HIV-infected adolescents

M. Monica Gurupriya, Kiran Iyer, P. D. Madan Kumar

Department of Public Health Dentistry, Ragas Dental College and Hospital, Chennai, Tamil Nadu, India.



**\*Corresponding author:**

M. Monica Gurupriya,  
Department of Public Health  
Dentistry, Ragas Dental  
College, Chennai - 600 119,  
Tamil Nadu, India.

[gurupriya.monica@gmail.com](mailto:gurupriya.monica@gmail.com)

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### ABSTRACT

**Background:** With the introduction of highly active antiretroviral therapy (HAART) in 1996, the quality of life of people living with HIV has improved. Although people diagnosed and living with HIV are overwhelmed by emotions, we found that various emotional manifestations are understudied within this group of patients. One such aspect is alexithymia which is seen at exorbitantly high rates among patients with depression, causing a major public health concern. In our study, we hypothesized that clinically significant changes with HAART would be associated with changes in depression, anxiety, and alexithymia.

**Materials and Methods:** A cross-sectional study was conducted with a convenient sample of 44 HIV-seropositive children and 30 healthy school children of age 12–15 years. We obtained permission from participants to access their medical records to obtain data regarding their CD4 cell counts and viral loads over the entire study period. The enrolled participants were administered a validated 20-item Toronto alexithymia scale (TAS-20) to assess their alexithymic levels.

**Results:** Mean alexithymia score of healthy children was  $0.67 \pm 1.26$  and mean of children living with HIV was  $4.48 \pm 7.80$ . When comparing the TAS-20 scores of children living with HIV and healthy children, children living with HIV revealed scores slightly higher than healthy children, but none showed scores equal to 40. There was statistically significant difference between both groups ( $P = 0.003$ ).

**Conclusion:** Our study revealed that there was a significant difference between the TAS scores of HIV-seropositive children on HAART and healthy children, none of their scores indicated alexithymic condition. In the health sector, alexithymia has been emphasized as barriers to patient-practitioner communication. Clinicians should be aware of the decrease in alexithymic traits among HIV subjects who are under HAART. This study highlights the benefits of the HAART era, namely the chronicity of the infection and the possibility of disease management, thus improving the mental status of such population.

**Keywords:** Cross-sectional study, Depression, Highly active antiretroviral therapy, Mental health, Personality disorders, Self-reports

### INTRODUCTION

The history of HIV infection has two distinct periods: The pre-highly active antiretroviral therapy (Pre-HAART) era, when the disease was potentially fatal, and the HAART era, marked by the introduction of the combined antiretroviral therapy. In these two eras, the disease has been perceived differently.<sup>[1]</sup> Advances in antiretroviral therapies for HIV infection have given rise to

new hope for the long-term survival of people living with HIV.<sup>[2]</sup> In the HAART era, the quality of life has improved to a long-term stability<sup>[3]</sup> and so the depression symptoms which seems to be a predictor of changes in health-related quality of life<sup>[4]</sup> have also improved. Alexithymia is related to depression severity and patients with depression exhibit high rate of alexithymia, representing a major public health concern.<sup>[5]</sup> Sifneos (1973) introduced the construct of alexithymia: Literally, a lack of words for feelings (a-lexithymia). It is regarded a stable personality trait and emerged as a paradigm linking emotion with health.<sup>[6]</sup> Alexithymia is an inability to identify and communicate one's own emotional experiences. Primary alexithymia refers to a personality disorder, but secondary alexithymia emerges as a reaction to severe and prolonged stress, as in the case of a medical illness.<sup>[7]</sup> Alexithymia has only recently been examined within the context of chronic immune suppression; its prevalence is estimated to be 3–5 times higher, i.e., 25–40% in HIV-infected individuals.<sup>[8]</sup> Even though the concept has been widely studied among adults, alexithymia in children has scarcely been investigated, even though it is assumed to be present in childhood.<sup>[9]</sup>

Earlier studies have shown that subjects who experienced increase in viral load, as indexed by medical chart abstraction, reported modest increases in depression,<sup>[2]</sup> whereas subjects who experienced substantive decreases in viral load to undetectable levels demonstrated meaningful reductions in depression, after statistically controlling for years living with HIV, HIV symptoms, and age.<sup>[2]</sup> Until recently, there were few available treatments for HIV infection, and people living with HIV could do little to alter the course of their illness. In 1996, the medical management of HIV infection changed dramatically with the availability of the combinations of antiretroviral agents and technologies for monitoring HIV replication activity. Improved health and physical functioning of people living with HIV may have positive effects on their mental health and emotional well-being. However, modest declines in emotional distress occurred among HIV-positive subjects during the years that the potent class of new antiretrovirals, protease inhibitors, was first introduced. Few other studies have investigated corollary changes in mental health and emotional well-being over the course of HIV infection. Clinical observations suggest that persons who respond positively to combination antiretroviral medications experience parallel improvements in their mental health and emotional well-being. The success of antiretroviral therapies in suppressing HIV replication is monitored by periodic testing for HIV genetic material in peripheral blood (viral load). Determining that HIV viral load is at lower than detectable levels in peripheral blood reflects suppressed viral activity, and changes in viral load of 1 log or more in either direction are considered clinically significant. Improvements and setbacks in clinical health status of persons with HIV

may have corollary improvements and setbacks in emotional well-being.<sup>[2]</sup> We hypothesized that clinically significant changes with ART would be associated with parallel changes in depression, anxiety, and finally alexithymia.

Literature highlights the benefits of the HAART era, namely the chronicity of the infection and the possibility of disease management; it (a) shows the positive effects of new treatments in reducing complexity and simplifying the lives of these individuals; (b) emphasizes the standardized daily life of “normal” people who only have a chronic health condition; and (c) legitimizes abilities and skills, setting up a canvas of reality composed of capable and competent individuals integrated in their communities, while fulfilling the expected social roles, which, to some extent, is the truth.<sup>[1]</sup> The current study assessed the prevalence of alexithymia that may occur in a cohort of HIV-infected children (on ART since birth) and compare the same with a matched cohort of non-HIV-infected children.

## MATERIALS AND METHODS

### Study design

This was a cross-sectional study.

### Ethical clearance

The study was conducted following approval by the Ethical Committee, Ragas Dental College and Hospital, Chennai. The general guidelines to ensure the rights of participants were followed. Before the investigation, parental/guardian consent was obtained, and the study information was reaffirmed orally.

This study was done to assess the prevalence of alexithymia among a cohort of well-controlled HIV-infected children and healthy children between 12 and 15 years of age.

### Participants

The sample size was calculated according to previously reported data, suggesting an overall alexithymia prevalence rate of about 10% in the Indian general population<sup>[10]</sup> and of about 25–40% among HIV-infected subjects.<sup>[8]</sup> It was estimated that at least 60 patients (30 HIV and 30 healthy) would be required to detect a statistically significant difference between the HIV and the healthy group at an 80% power level and with a type-1 error of 0.05 (5%).

A convenient sampling was used to include 44 HIV-positive children (mean age 13.45 ± 1.86 years) from an institutionalized setup, at Chennai. 30 healthy children (mean age of 13.73 ± 0.69 years) were enrolled from Government Higher Secondary School, Kovalam. Both the groups were age matched. The sample was diverse in nature pertaining to

gender, ethnicity, sexual orientation, socioeconomic status, and education.

### Inclusion and exclusion criteria

To be included in the study, participants had to be aged from 12 to 15 years, who are diagnosed with HIV having CD4 count more than 200, never had a clinical AIDS-defining symptom and were under ART since birth with vertical transmission as the route of infection. HIV-positive children with any other form of physical disability such as hearing or speech disability were excluded from the study.

### Materials

#### *Alexithymia questionnaire for children*

The Toronto alexithymic scale (TAS) was a validated tool in Indian population<sup>[7]</sup> to assess alexithymic traits. First introduced in 1985 (as TAS-26, with 26 items), then revised in 1992 (with a reduction to 20 items), it is currently the most commonly used and best-validated measure of alexithymia.<sup>[11]</sup> Consistent with the original adult questionnaire for alexithymia (TAS-20) given by Bagby *et al.*, in 1994, the alexithymia questionnaire for children consisted of 20 items, representing three factors: Difficulty identifying feelings (7 items), difficulty describing feelings (5 items), and externally oriented thinking (EOT, 8 items). The 20 items are rated on a 3-point Likert scale ranging between 0=false, 1=true to some extent, and 2=true.<sup>[7]</sup> Total scores range from 0 to 40. Items 4, 5, 10, 18, and 19 are negatively keyed. Scoring was reversed for five items, which were formulated positively.<sup>[9]</sup>

To translate the questionnaire into Tamil, we followed the procedure that was first introduced by Brislin, in 1986.<sup>[7]</sup> The translation of the alexithymia questionnaire into Tamil was done by a native Tamil speaker. Another native Tamil speaker, who was also fluent in English, back-translated the Tamil version into English. This version was then compared with the original questionnaire by a native English speaker.

Data collection was done in two phases for HIV-infected children. In the first phase, participants' HIV status was verified (e.g., HIV clinic card or HIV medication prescription), the demographic data and CD4 level of each participant for the past 6 months were collected retrospectively from their respective medical records which served as the secondary data. In the second phase, the same participants who were physically present at the field setting; their alexithymia trait was measured by the TAS-20 questionnaire, which served as the primary data. For children without HIV, the demographic data and alexithymic trait measurement were done in Government Higher Secondary School, Kovalam.

### Method

The questionnaire was interviewer administered, and the children were instructed to score each item on a three-point response scale, to simplify the response scale for children and provide clear verbal labels with each answer category.<sup>[9]</sup> The procedure took about 10–15 min for each participant. The difficulties faced by the children in understanding and responding to the questions were solved with the help of their parents/guardian for HIV-infected children, and school teachers extended their help for schoolchildren.

### Statistical Analysis

Data collection and management were conducted using the Microsoft Office Excel package in association with the SPSS 20.0 software package (SPSS Inc.) for the statistical analyses.

### RESULTS

A total of 44 children, aged 12–15 years of age diagnosed with HIV, were screened for participation: Male  $n = 24$  (54.5%) and female  $n = 20$  (45.5%) with a mean age of  $13.45 \pm 1.86$  years. These demographic parameters served for the selection of age-matched healthy children of 30 subjects with male  $n = 12$  (40%) and female  $n = 18$  (60%) with the mean age of  $13.73 \pm 0.69$  years.

When comparing the TAS-20 scores of children living with HIV and healthy children, children living with HIV revealed scores slightly higher than healthy children, but none showed scores equal to 40. Mean alexithymia score of healthy children was  $0.67 \pm 1.26$  and mean of children living with HIV was  $4.48 \pm 7.80$ . Unpaired sample *t*-test was performed for the mean TAS scores of both groups. There was statistically significant difference between both groups ( $P = 0.003$ ). In healthy children, mean alexithymia score of males ( $1.25 \pm 1.65$ ) was higher than females ( $0.28 \pm 0.75$ ). In children living with HIV, males ( $4.71 \pm 9.04$ ) had similar alexithymia score compared to females ( $4.20 \pm 6.22$ ).

Table 1 represents gender distribution and mean age and mean alexithymia score of all participants.

The overall mean TAS-20 scores showed that none of the participants were alexithymic. However, the children living with HIV had a slightly higher score than healthy children.

Table 2 represents the frequency distribution of questions among both healthy and seropositive children.

### DISCUSSION

The current study assessed the prevalence of alexithymia that may cooccur in a cohort of HIV-infected children (on HAART since birth) and compared the same with a matched cohort of non-HIV-infected children.

Alexithymia represents a stable personality trait with a prevalence rate of about 10% among general population,<sup>[10]</sup> even if an association with HIV population has been reported with a prevalence rate as high as 25–40% among HIV population.<sup>[8]</sup> Empirical evidence indicates that alexithymia is associated with depression, anxiety, and problems in social relationship as well as dental fear. Alexithymia is considered to be a developmental deficit in emotional regulation.<sup>[12]</sup> According to Kalichman *et al.*, increase in depression among persons with increased viral load was, therefore, statistically significant but clinically modest. Subjects who experienced clinically significant increase in viral load showed significant increase in emotional distress. Literature review shows modest association between markers of HIV disease progression

and emotional distress. This depression finally can lead to alexithymia.

Earlier studies indicate that alexithymia can be identified in children; it is a factor that points out individual differences in children's emotional competence and contributes substantially to the prediction of their self-reported somatic complaints.<sup>[9]</sup>

In this study, TAS-20 questionnaire was adopted as a measure of alexithymia. According to Haviland and Reise (1996), alexithymia does involve more features than those measured by TAS-20. Other aspects of alexithymia might be regarded in future research and added to the operationalization of the concept. Nevertheless, difficulties in identifying and describing feelings are shown to be associated with self-reported health problems and mood states in children.<sup>[9]</sup>

In the present study, the children living with HIV had a mean TAS-20 score, which is slightly higher than the score of healthy children. However, the individual scores showed that none of the participants were alexithymic. Comparing the scores of male and female subjects, it is seen that males reported marginally higher score compared to females in both groups, similar to the findings of Taylor, 2000; Honkalampi *et al.*, 2001; and Franz *et al.*, 2008. This may be attributed to their strongly masculine norms which devalue emotional expression; many men fail to develop an adequate emotional vocabulary or awareness, resulting in difficulties understanding and labeling emotions.<sup>[13]</sup>

**Table 1:** Gender distribution and mean age and mean alexithymia score of all participants.

	Healthy	Seropositive
Number of participants	30	44
Male	40%	54.5%
Female	60%	45.5%
Mean (±SD)	13.73±0.69	13.45±1.86
Age	0.67±1.26	4.48±7.80
Alexithymia score		
Male	1.25±1.65	4.71±9.04
Female	0.28±0.75	4.20±6.22

SD: Standard deviation

**Table 2:** The frequency distribution of questions among both healthy and seropositive children.

Factors	TAS-20	Frequency of response			
		Healthy n (%)		Seropositive n (%)	
		Negative	Positive	Negative	Positive
Factor 1 difficulty identifying feeling	Q1	30 (100)	0	37 (84.09)	7 (15.9)
	Q3	30 (100)	0	35 (79.54)	9 (20.45)
	Q6	30 (100)	0	42 (95.45)	2 (4.54%)
	Q7	30 (100)	0	35 (79.54)	9 (20.45)
	Q9	30 (100)	0	37 (84.09)	7 (15.90)
	Q13	30 (100)	0	39 (88.63)	5 (11.36)
	Q14	30 (100)	0	40 (90.90)	4 (9.09)
Factor 2 difficulty describing feelings	Q2	25 (83.33)	5 (16.66)	28 (63.63)	16 (36.36)
	Q4	28 (93.33)	2 (6.66)	39 (88.63)	5 (11.36)
	Q11	29 (96.66)	1 (3.33)	41 (93.18)	3 (6.81)
	Q12	29 (96.66)	1 (3.33)	36 (81.81)	8 (18.18)
	Q17	24 (80)	6 (20)	34 (77.27)	10 (22.72)
Factor 3 externally oriented thinking	Q5	29 (96.66)	1 (3.33)	35 (79.54)	9 (20.45)
	Q8	30 (100)	0	38 (86.36)	6 (13.63)
	Q10	29 (96.66)	1 (3.33)	39 (88.63)	5 (11.36)
	Q15	30 (100)	0	41 (93.18)	3 (6.81)
	Q16	29 (96.66)	1 (3.33)	39 (88.63)	5 (11.36)
	Q18	30 (100)	0	39 (88.63)	5 (11.36)
	Q19	30 (100)	0	39 (88.63)	5 (11.36)
	Q20	30 (100)	0	43 (97.72)	1 (2.27)

## Limitation

There has been some criticism of the TAS-20 concerning its three-factor structure and its association with negative affectivity. It has also been noted that there are differences between the TAS-20 subfactors, with EOT factor repeatedly being the most problematic. Moreover, LANE *et al.* questioned the ability of the TAS-20 to detect the most severe cases of alexithymia. However, the TAS-20 is the most widely used measure of alexithymia.<sup>[12]</sup>

Another limitation of the current study is that the self-report measures entail the risk of a reporting bias and also there may be patients' denial of symptoms or even unawareness of illness and symptoms.<sup>[14]</sup> It may be less accurate than structured interview or electronic monitoring.<sup>[8]</sup> It does not always reflect actual behavior. However, alexithymia is mainly intrapsychological. This includes ideas about oneself and about one's behavioral tendencies, which are thought to be more influential in this respect than one's actual observable behavioral tendencies.<sup>[9]</sup> Several studies have indeed confirmed that it is most appropriate to ask the child itself, which is especially true for internalizing problems. This view is further supported by the fact that the internal consistency of the self-report questionnaire in our study was high.<sup>[7]</sup> Nevertheless, the fact that we only used self-report questionnaires does make this study vulnerable to response tendencies and it is important to address this issue in future studies. Other indices might be valuable in this respect, such as diagnostic interviews.<sup>[9]</sup> Future studies should consider gathering data from multiple sources such as from the participants' friends and making use of objective measures of alexithymia. Extensions of this work will need to incorporate longitudinal design to better assess AL-dependent change in psychosocial function and HIV disease progression. Future examination of the extent to which AL interacts with HIV-associated depression would also build on this and extent HIV literature.<sup>[8]</sup>

## CONCLUSION

It is, therefore, understood that people who experience clinically significant decrease in viral load and increase in CD4 count after being subjected to HAART have shown a decrease in depression or alexithymia. Thus, the introduction of HAART has resulted in significant positive impact on the emotional status of people living with HIV.

The findings of this study add to the growing body of literature demonstrating positive psychosocial and health outcomes associated with children living with HIV who are under HAART since birth. We hope that by examining this topic we have created more awareness about alexithymia in childhood HIV patients under HAART and that these findings will help design additional research. In this way, we can further

improve our understanding on this topic and implement better counseling trajectories for these children in the future on the importance of HAART. Declines in emotional distress that accompany improved health should be welcomed.<sup>[7]</sup> As advances in HIV treatments continue and the health outlook for people living with HIV improves, additional research is needed to further explain the complex relationships between HIV disease progression and emotional health. Thus, alexithymia should also be considered in developing oral health policies for HIV-infected population.

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## Conflicts of interest

There are no conflicts of interest.

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