Clinical Characteristics, Socio-demographic Profile, and Quality of Life Among Children with Thalassemia Major: A Hospital-Based Cross-Sectional Study

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Abstract

Background: Thalassemia major imposes a multi-dimensional burden on the health-related quality of life (HRQoL) of affected children. The Paediatric Quality of Life Inventory (PedsQL) provides a validated, multidimensional assessment of functioning in physical, social, emotional and school domains. Region-specific data from North India on children's QoL and its clinical correlates remain limited. **Material & Methods:** A hospital-based cross-sectional study was conducted among 100 children with thalassemia major (eligibility 2-18 years; all enrolled children were 5-18 years) attending the Blood Transfusion Centre of a public (government) tertiary care facility in Haryana. Participants were enrolled by purposive sampling. Socio-demographic and clinical data were recorded on a pre-tested, semi-structured proforma. HRQoL was assessed using the Hindi version of the PedsQL 4.0 Generic Core Scales, on which higher transformed scores denote better HRQoL. Independent samples t-test, Kruskal-Wallis test and multivariable linear regression were applied ($p < 0.05$). **Results:** The mean total PedsQL score was 84.47 ± 8.16. School functioning (78.30 ± 9.33) and physical functioning (80.47 ± 18.71) were the most affected domains. Female children had significantly lower mean QoL scores than males (81.32 ± 9.85 vs 86.84 ± 5.61, $p < 0.001$). Children requiring high-frequency transfusions had significantly lower mean QoL scores than those with low-frequency transfusions (83.00 ± 8.63 vs 88.24 ± 5.26; $p = 0.003$). On multivariable linear regression, female sex (adjusted $\beta = -6.49$, 95% CI -9.51 to -3.48; $p < 0.001$) and high annual transfusion frequency (adjusted $\beta = -5.84$, 95% CI -9.77 to -1.91; $p = 0.004$) remained independently associated with lower total scores; the model explained 25.9% of the variance (adjusted $R^2 = 0.220$). Religion, residence and educational status of the child were not significantly associated with QoL. **Conclusion:** HRQoL in children with thalassemia major was most compromised in the school and physical functioning domains. Female sex and higher annual transfusion frequency were independently associated with poorer HRQoL after adjustment for age, residence and education. Gender-sensitive psychosocial support and strategies to reduce transfusion burden are critical components of holistic paediatric thalassemia care.

Keywords: Thalassemia, Paediatric quality of life, PedsQL, Transfusion frequency, HRQoL

Introduction

The most critical type of thalassemia, beta-thalassemia major, is marked by severe chronic anaemia that necessitates iron chelation therapy and frequent lifelong red blood cell transfusions.[1] With 10,000-15,000 babies born with this morbidity each year, India accounts for around 25% of the world's beta-thalassemia burden.[2] The focus of clinical and public health research has gradually shifted from mere survival to health-related quality of life (HRQoL), which includes the emotional, physical, social and functional aspects of well-being, as survival rates have significantly improved with modern transfusion and chelation protocols.[3] Beyond the immediate biological effects, chronic sickness in children has far-reaching effects that interfere with education, peer relationships, emotional development and social engagement.[4] Thalassemia is especially likely to impair several quality of life (QoL) dimensions at once due to its cyclical transfusion schedule, frequent hospital visits, persistent exhaustion and treatment-related disruptions.[5]

Indian evidence on paediatric thalassemia HRQoL, though growing, remains limited and geographically uneven. Dhirar et al., in 241 children aged 2-18 years attending a thalassemia day-care centre in Delhi, reported a mean total PedsQL score of 82.0 ± 14.4 and identified the current age of the child and the presence of comorbidity as significant correlates; total scores were higher among boys, but the difference did not reach

statistical significance.[6] Sharma et al., comparing 75 children with beta-thalassemia major and 80 healthy controls in Navi Mumbai, demonstrated a substantial HRQoL deficit relative to healthy peers, but the study was designed as a case-control comparison and was not powered to examine clinical correlates within the thalassemia group.[7] Saha et al., among 365 admitted children in West Bengal, reported duration since splenectomy, last pre-transfusion haemoglobin level, family history of thalassemia and frequency of blood transfusion to be predictors of the total summary score.[8] Chordiya et al. in Jodhpur found higher PedsQL scores among children transfused once a month than among those transfused more frequently, but restricted enrolment to children aged 8-18 years.[9] A recent scoping review of Indian thalassemia QoL literature observed that the available studies originate predominantly from western, eastern and southern India, are largely single-centre, and infrequently report adjusted estimates capable of separating the contribution of sex from that of disease burden.[3] To the best of our knowledge, no published study from Haryana or the adjoining north-Indian plains has assessed HRQoL in this population using the PedsQL 4.0 Generic Core Scales.[10] The present study was therefore undertaken to address this regional and analytical gap.

Therefore, the current study was conducted in order to: (i) describe the clinical and socio-demographic profile of children with thalassemia major who attend a blood transfusion centre in Ambala, Haryana; (ii) measure HRQoL using the PedsQL 4.0 Generic Core Scales; (iii) investigate associations between QoL and socio-demographic characteristics; (iv) assess the association between transfusion frequency and QoL; and (v) identify variables independently associated with the total PedsQL score on multivariable analysis.

Materials and methods

Over the course of a year, from September 2024 to September 2025, a hospital-based cross-sectional study was conducted at the Blood Transfusion Centre of a public (government) tertiary care facility in Ambala, Haryana. Before the study started, the Institutional Ethics Committee gave its approval (Ref. IEC 3264), and caregivers provided written informed consent and children's assent. Using purposive sampling, 100 children aged 2-18 years with diagnosed thalassemia major who were registered for transfusion at the Centre were included. The study excluded children with co-occurring haematological conditions other than thalassemia. In practice, no child in the eligible age band of 2-4 years was registered at the Centre during the study period, and the age of the enrolled children therefore ranged from 5 to 18 years.

Sample size was calculated using the formula for estimating a single mean with absolute precision, $n = Z^2_{1-\alpha/2} \times \sigma^2 / d^2$. Taking the standard deviation of the total PedsQL 4.0 score among Indian children with thalassemia major as 14.4, as reported by Dhirar et al. in 241 children,6 with 95% confidence (Z = 1.96) and an absolute precision of 3 points on the 0-100 scale, the minimum required sample size was 89. Allowing approximately 10% for incomplete or unusable responses, the sample size was rounded to 100.

Data were collected on a pre-tested, semi-structured proforma through face-to-face interview and review of the case record. Socio-demographic variables comprised the child's age (completed years at interview), sex, religion, place of residence, number of siblings, and the educational status. Clinical variables were abstracted from the hospital record and comprised age at diagnosis, duration of illness, duration of transfusion therapy, annual transfusion frequency (the number of packed red cell transfusions received in the 12 months preceding the interview, categorised as low, 6-12 per year, and high, 13-22 per year, following Hossain et al.),[11] history of splenectomy, presence of any documented comorbidity, receipt of iron chelation therapy, and transfusion-transmitted infection (defined as reactive serology for hepatitis B surface antigen, anti-hepatitis C virus antibody or HIV recorded at any time since registration). Compliance with iron chelation therapy was classified as good when the child had collected the prescribed chelator from the Centre on every scheduled occasion during the preceding six months and the caregiver reported no missed doses on more than two days in the preceding month, and as poor otherwise.

All interviews were conducted in Hindi, the language spoken by all participants, by a single trained investigator, which minimised inter-interviewer variability. HRQoL was assessed using the PedsQL™ 4.0 Generic Core Scales ("Hindi-for-India" version), which is available for non-funded academic research through the developer's distribution platform.[10-12] The scale evaluates four primary domains: physical functioning (8 items), social functioning (5 items), emotional functioning (5 items) and school functioning (5 items). The questionnaire consists of 23 items scored on a 5-point Likert scale. This ranges from 0 ("never") to 4 ("almost always"), reflecting how frequently the child experienced difficulties during the previous month.

Items are reverse-scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, 4 = 0), such that higher transformed scores denote better HRQoL. Each scale score is computed as the mean of the transformed scores of the items answered within that scale. The Physical Health Summary Score is identical to the Physical Functioning scale score. The Psychosocial Health Summary Score is the mean of the 15 transformed items comprising the Emotional, Social and School Functioning scales. The Total Scale Score is the mean of all 23 transformed items.[10,13]

The data were entered into Microsoft Excel and then analysed using IBM Statistical Package for the Social Sciences (SPSS) version 28.0 and Jamovi. Categorical variables were reported as frequencies and percentages, whereas continuous

variables were expressed as mean ± standard deviation (SD). Normality of the total and domain scores was assessed using the Shapiro-Wilk test together with inspection of histograms and Q-Q plots prior to the application of parametric tests. The independent samples t-test was utilised to compare mean QoL scores between two groups, such as gender, residence and transfusion frequency. The Kruskal-Wallis test was used for variables with more than two categories, such as religion and educational status, in which subgroup sizes were small and unequal. To identify variables independently associated with the total PedsQL score and to account for potential confounding, univariable linear regression was first performed for each variable, and all variables were then entered simultaneously into a multivariable linear regression model. Unadjusted and adjusted regression coefficients (β) with 95% confidence intervals are presented. A p-value of < 0.05 was considered statistically significant.

Results

Table 1 displays the socio-demographic details of the 100 children that were enrolled. With a mean age of 12.46 ± 3.66 years, the age group with the highest percentage (46%) was 10-14 years; no child aged 2-4 years was registered at the Centre during the study period. Most children (57%) were male; 69% practised Hinduism; 52% lived in urban areas; 92% had studied up to high school or above; and 94% had fewer than four siblings.

Table 1 Socio-demographic Profile of Children with Thalassemia Major (n = 100)

Variable	Frequency (n)	Percentage (%)
Age (years)		
5-9	22	22.0
10-14	46	46.0
15-18	32	32.0
Mean age (years ± SD)	12.46 ± 3.66	
Gender		
Male	57	57.0
Female	43	43.0
Religion		
Hindu	69	69.0
Muslim	29	29.0
Sikh	02	2.0
Residence		
Rular	48	480
Urban	52	520
Education		
Illiterate	02	20
Primary School	06	6.0
High School above	96	92.0
Number of Siblings		
< 4 siblings	94	94.0
≥ 4 siblings	06	6.0

Table 2 presents the clinical profile of the 100 children. Transfusion frequency was defined as low (6-12/year) and high (13-22/year) as per Hossain et al.[11] The majority (72%) needed high-frequency blood transfusions (13-22 times/year), while 28% needed low-frequency transfusions (6-12 times/year). All 100 children (100%) were on iron chelation therapy and were classified as compliant by the pre-defined criteria; none had undergone splenectomy, and none had any documented comorbidity; 4% had contracted a transfusion-transmitted infection (TTI). Because splenectomy, comorbidity, receipt of chelation therapy and compliance showed no variation within this cohort, these variables are reported descriptively only and could not be examined analytically.

Table 2 Clinical Profile of Children with Thalassemia Major (n = 100)

Clinical Variable	Frequency (n)	Percentage (%)
Age at diagnosis (years, mean ± SD)	2.46 ± 1.14	
Age at First Transfusion	2.96 ± 1.43	
Duration of illness (years, mean ± SD)	10.00 ± 3.75	
Duration of transfusion therapy (years, mean ± SD)		
Transfusion Frequency	28	28
Low (6–12 times/year)	72	72
High (13–22 times/year)		
Transfusion in Last 3 Months		
Yes	100	100
No	0	0
Splenectomy		
Yes	0	0
No	100	100
Comorbidity		
Yes	0	0
No	100	100
Iron Chelation Therapy		
Yes	100	100
No	0	0
Compliance with Chelation Therapy		
Good	100	100
Poor	0	0
Transfusion-Transmitted Infection (TTI)		
Yes	4	4
No	96	96

TTI = transfusion-transmitted infection; Compliance was classified as good when the prescribed chelator had been collected from the Centre on every scheduled occasion during the preceding six months and the caregiver reported no missed doses on more than two days in the preceding month. Splenectomy, comorbidity, receipt of chelation therapy and compliance showed no variation in this cohort and were therefore not entered into any analytical model.

The distribution of PedsQL scores is shown in Table 3, where the mean total PedsQL score was 84.47 ± 8.16. The physical functioning score was 80.47 ± 18.71 while the emotional functioning score was 84.20 ± 13.63. The average social functioning and school functioning scores were 97.30 ± 4.89 and 78.30 ± 9.33 respectively. The mean psychosocial health score was 86.60 ± 5.37. School functioning and physical functioning were therefore the most affected domains, and social functioning the least affected.

Table 3 Quality of Life Scores Among Children with Thalassemia Major - PedsQL 4.0 (n = 100)

Variable	Mean	Standard deviation
Total PedsQL score	84.47	8.16
Physical functioning score	80.47	18.71
Emotional functioning score	84.2	13.63
Social functioning score	97.30	4.89
Social functioning score	78.30	9.33
Psychosocial Health score	86.60	5.37

PedsQL = Pediatric Quality of Life Inventory.

Table 4 shows associations between mean QoL scores and socio-demographic variables. A statistically significant association was observed between the gender of the child and the mean quality of life score ($p < 0.001$). Male children presented with a higher mean quality of life score (86.84 ± 5.61) compared to female children (81.32 ± 9.85). In contrast, no statistically significant association was found between quality-of-life scores and other socio-demographic variables, including religion ($p = 0.14$), residence ($p = 0.31$) and educational status of the child ($p = 0.60$). The association between the age of the child and the total PedsQL score was examined in the regression analysis presented in Table 6.

Table 4 Association Between Quality of Life and Socio-demographic Characteristics of Children with Thalassemia Major (n = 100)

Variable	Total PedsQL Score (Mean ± SD)	Standard deviation
Gender		< 0.001
Male (n = 57)	86.84 ± 5.61	
Female (n = 43)	81.32 ± 9.85	13.63
Religion		
Hindu (n = 69)	83.82 ± 9.39	0.14
Muslim (n = 29)	86.43 ± 3.62	
Sikh (n = 2)	83.68 ± 9.49	
Residence		
Rural (n = 48)	85.33 ± 6.40	0.31
Urban (n = 52)	83.68 ± 9.49	
Education		
Illiterate (n = 2)	86.96 ± 0.00	0.6
Primary School (n = 6)	86.96 ± 3.57	
High School and above (n = 92)	86.96 ± 3.57	

*$p < 0.05$ considered statistically significant; Higher mean score indicates better health-related quality of life.

Independent samples t-test for Gender ($t(98) = -3.54$, $p < 0.001$) Kruskal–Wallis test for Religion ($\chi^2 = 3.89$, $p = 0.14$) Independent samples t-test for Residence ($t(98) = 1.01$, $p = 0.31$) Kruskal–Wallis test for Education ($\chi^2 = 1.01$, $p = 0.60$)

Table 5 shows the association between transfusion frequency and quality of life among the children. A statistically significant association was observed ($p = 0.003$), with children requiring a high transfusion frequency demonstrating a lower mean QoL score (83.00 ± 8.63) compared to those requiring a low transfusion frequency (88.24 ± 5.26).

Table 5: Association Between Transfusion Frequency and Quality of Life Among Children with Thalassemia Major (n = 100)

Transfusion frequency	Total PedsQL Score (Mean ± SD)	p-value*
Low (n = 28)	88.24 ± 5.26	0.003
High (n = 72)	83.00 ± 8.63	

*$p < 0.05$ considered statistically significant; SD = standard deviation. Independent samples t-test. Higher mean score indicates better health-related quality of life.

Table 6 presents the unadjusted and adjusted associations between socio-demographic and clinical variables and the total PedsQL score. On univariable analysis, age, gender and transfusion frequency were each significantly associated with the total score, whereas residence and educational status of the child. The multivariable model containing all five variables was statistically significant and explained 25.9% of the variance in the total PedsQL score ($R^2 = 0.259$, adjusted $R^2 = 0.220$, $F(5, 94) = 6.584$, $p < 0.001$).

After simultaneous adjustment, female gender (adjusted $\beta = -6.49$, 95% CI −9.51 to −3.48, $p < 0.001$) and high annual transfusion frequency (adjusted $\beta = -5.84$, 95% CI −9.77 to −1.91, $p = 0.004$) remained independently associated with lower total PedsQL scores. Female children scored, on average, 6.49 points lower than male children, and children in the high-frequency transfusion group 5.84 points lower than those in the low-

frequency group, after accounting for the remaining variables. Both adjusted coefficients were larger in magnitude than their unadjusted counterparts, indicating that these associations were not attributable to confounding by the other measured variables. In contrast, the negative association between age and total score observed on univariable analysis ($\beta = -0.56$, 95% CI -1.00 to -0.13, $p = 0.011$) was attenuated by approximately half and was no longer statistically significant after adjustment (adjusted β = -0.27, 95% CI -0.74 to 0.20, p = 0.25). Place of residence and educational status of the child showed no independent association with the total PedsQL score in either the univariable or the multivariable analysis.

Table 6 Unadjusted and Adjusted Associations between Socio-demographic and Clinical Variables and Total PedsQL 4.0 Score (n = 100)

Variable (reference category)	Unadjusted β (95% CI)	p-value*	Adjusted β (95% CI)	p-value*
Age, per completed year	−0.56 (−1.00 to −0.13)	0.011	−0.27 (−0.74 to 0.20)	0.25
Gender: Female (Male)	−5.52 (−8.62 to −2.43)	< 0.001	−6.49 (−9.51 to −3.48)	< 0.001
Residence: Urban (Rural)	−1.65 (−4.89 to 1.59)	0.31	1.03 (−2.24 to 4.30)	0.53
Transfusion frequency: High (Low)	−5.24 (−8.70 to −1.77)	0.003	−5.84 (−9.77 to −1.91)	0.004
Education High school and above (up to primary school, including illiterate)	−2.71 (−8.68 to 3.27)	0.37	−2.65 (−8.27 to 2.97)	0.35

β = unstandardised regression coefficient; CI = confidence interval. Dependent variable: total PedsQL 4.0 score (0-100), on which a higher score indicates better health-related quality of life; a negative β therefore denotes poorer HRQoL. Unadjusted estimates were derived from separate univariable linear regression models. Adjusted estimates were derived from a single multivariable linear regression model containing all five variables entered simultaneously: $R = 0.509$, $R^2 = 0.259$, adjusted $R^2 = 0.220$, $F(5, 94) = 6.584$, $p < 0.001$.

Discussion

The mean total PedsQL score in the present cohort was 84.47 ± 8.16. Among the domains, school functioning (78.30 ± 9.33) and physical functioning (80.47 ± 18.71) were the most affected, while social functioning was the least affected (97.30 ± 4.89); the mean psychosocial health score was 86.60 ± 5.37. This overall level is closely comparable with Indian estimates obtained with the same instrument. Dhirar et al. reported a mean total score of 82.0 ± 14.4 among 241 children attending a thalassemia day-care centre in Delhi,[6] and Sharma et al. reported a mean child self-reported total score of 83.7 ± 10.8 among 75 children with beta-thalassemia major in Navi Mumbai, which was significantly lower than that of healthy controls (97.6 ± 3.3).[7] Saha et al., in 365 Bengali children, identified duration since splenectomy, last pre-transfusion haemoglobin level, family history of thalassemia and frequency of blood transfusion as predictors of the total summary score.[8] Jajhara et al. reported similar moderate QoL scores among thalassemic children in Rajasthan,[14] and Nadgir et al., using the parent-proxy version among 40 children aged 8-12 years in Bengaluru, found that HRQoL was compromised across all domains.[15] A scoping review of Indian thalassemia QoL studies[3] and the systematic review by Greco and Marino[16] both concluded that children with beta-thalassemia consistently report reduced physical, emotional and social functioning in comparison with their healthy peers.

The noteworthy discovery that female children had a lower quality of life (81.32 ± 9.85 vs 86.84 ± 5.61; p < 0.001) persisted after simultaneous adjustment for age, residence, education and transfusion frequency (adjusted β = -6.49; p < 0.001), indicating that it was not explained by the other measured variables. A similar direction of effect has been reported from within India: Dhirar et al. found higher total scores among boys, although the difference was not statistically significant in that cohort,[6] and Nadgir et al. reported significantly higher overall scores among male children.[16] Mansoor et al. found that adolescent females with thalassemia in the Maldives had considerably poorer HRQoL.[17] Explanations advanced in the literature include greater internalisation of illness-related stigma by girls, differential allocation of psychosocial support within the family, and familial anxiety regarding future marriage prospects. It should be emphasised that stigma, intra-familial resource allocation and psychosocial support were not measured in the present study; these mechanisms are therefore hypotheses generated by, rather than demonstrated in, this analysis. They nevertheless underline the need for gender-sensitive psychological support within paediatric thalassemia services.

Children in the high-frequency transfusion group scored significantly lower than those in the low-frequency group (83.00 ± 8.63 vs 88.24 ± 5.26; p = 0.003), and this association also remained after adjustment (adjusted β = -5.84; p = 0.004). The finding is consistent with Indian data: Chordiya et al. in Jodhpur reported higher PedsQL scores among children transfused once a month than among those transfused more often,[9] and Saha et al. found frequency of blood transfusion to contribute to the total summary score in West Bengal.[8] In the BELIEVE study, Cappellini et al. showed that a therapy which lowered transfusion frequency produced significant improvements in physical QoL, supporting the mechanistic connection between transfusion burden and QoL impairment.[18] A qualitative study by Drahos et al. among patients with transfusion-dependent β-thalassemia in the USA and the UK described a cyclical pattern of severe fatigue and psychological distress in the days preceding each

transfusion, followed by temporary post-transfusion recovery.[19] The present study collected cross-sectional data at a single time point and did not assess within-cycle variation; this pattern is therefore cited only as one mechanism proposed in the literature that could plausibly underlie the association observed here, and not as a finding of the present study. School functioning was the second-most affected domain in this cohort, which is consistent with the expectation that repeated day-time hospital attendance interrupts learning continuity and peer contact, although school absenteeism itself was not recorded.

No significant association was found between the total PedsQL score and religion, place of residence, or educational status of child, either on bivariable or on multivariable analysis. Socio-economic status, household income and parental occupation were not recorded in the present study, and the absence of an association with the socio-demographic variables that were measured should therefore not be interpreted as evidence that social circumstances are unimportant. Where such variables have been measured, they have been shown to matter: Alshamsi et al., in transfusion-dependent children in Dubai, found that lower monthly household income independently predicted lower total and psychosocial HRQoL,[20] and Saha et al. identified family history of thalassemia as an important predictor in West Bengal.[8] The inclusion of a validated socio-economic status scale is recommended for future work in this population.

The strengths of this study include the use of the PedsQL 4.0, a widely validated tool for assessing paediatric HRQoL, administration of the Hindi version by a single trained investigator, which minimised inter-interviewer variability, and the simultaneous collection of clinical and socio-demographic data with multivariable adjustment.

Several limitations should be acknowledged. First, the cross-sectional design permits the identification of associations only and not of causal relationships. Second, participants were recruited by purposive sampling from a single centre, and children who attend a government transfusion centre regularly may differ from those who do not; the findings may therefore not be generalisable to all children with thalassemia major in the region. Third, although the title refers to clinical characteristics, annual transfusion frequency was the only clinical variable with sufficient variation in this cohort to permit analysis; markers of disease severity such as serum ferritin, pre-transfusion haemoglobin concentration and growth parameters were not available and could not be examined, while splenectomy, comorbidity, receipt of chelation therapy and compliance showed no variation and therefore contributed no analytical information. Fourth, compliance with chelation therapy was classified from pharmacy collection records and caregiver report; the resulting figure of 100% good compliance is likely to be an over-estimate influenced by social-desirability bias, and an objective marker such as the serum ferritin trend would have been preferable. Fifth, the very high social functioning score (97.30 ± 4.89) may in part reflect social-desirability and interviewer effects inherent in face-to-face administration, since the questionnaire was not self-completed. Sixth, responses for younger children were obtained with caregiver assistance, and proxy report may not correspond fully with the child's own perception. Finally, Indian normative PedsQL values for healthy children are not available and no healthy comparison group was recruited, so the magnitude of impairment relative to the general paediatric population could not be quantified.

Conclusion

In this cohort of children with thalassemia major attending the blood transfusion centre of a public tertiary care facility in Haryana, HRQoL was most affected in the school and physical functioning domains. Female sex and high annual transfusion frequency were independently associated with poorer HRQoL after adjustment for age, place of residence and education. These findings support the routine incorporation of HRQoL assessment into paediatric thalassemia care alongside haematological monitoring, with particular attention to gender-sensitive psychosocial counselling for female children and to service-level measures that reduce the burden of frequent transfusion visits, such as flexible scheduling and day-care arrangements that minimise school absenteeism. Prospective, multicentre studies that incorporate markers of disease severity and socio-economic status are needed to confirm and extend these associations.

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