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Health related quality of life and associated factors among children living in previous leprosarium and nonleprosarium areas of Eastern Ethiopia

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Children and their families living in leprosarium areas may have a lower quality of life than the general population. However, there is limited evidence on health-related quality of life and its associated factors among children living in previous leprosarium settlement areas. Hence, this study aimed to compare the health-related quality of life among children living in previous leprosarium and non-leprosarium settlement areas in eastern Ethiopia. A community-based comparative cross-sectional study was conducted among 515 randomly selected children aged 8 to 18 years living in the Amir Nur and Babile districts from January to February 30, 2024. Data were collected through interviews with children and parents using the Pediatric Quality of Life Inventory Version 4. The data were analyzed using STATA version 14. Simple and multiple linear regression was employed to identify associations between independent and outcome variables. The overall mean health-related quality of life scores were 73.98 ± 18.47 and 77.67 ± 14.72 in the child self-reports ($P = 0.01$) and 55.78 ± 12.03 and 55.61 ± 8.50 ($P = 0.85$) in the parent proxy reports in the previous leprosarium and nonleprosarium settlement areas, respectively. In multiple linear regression, child education ($\beta = 14.69$; 95% CI: 8.69, 20.69), the absence of neglected and tropical diseases ($\beta = 4.02$; 95% CI: 0.66, 7.37), and child face washing habits ($\beta = 5.54$, 95% CI: 2.14, 8.95) increase health-related quality of life. However, a previous history of neglected and tropical diseases ($\beta = -8.54$; 95% CI: -12.93, -4.15) and the absence of hand washing facilities ($\beta = -8.57$; 95% CI, -15.22, -1.92) decrease the mean health-related quality of life. Based on child self-reports, one in four children from previous leprosarium areas had poor health-related quality of life compared to children living in none leprosarium areas. Children's educational status, their daily habits of washing their face, not having neglected, and tropical diseases had improved health-related quality of life. To improve health-related quality of life, stakeholders should pay attention to and work on the early detection and treatment of neglected and tropical diseases, child education, and proper sanitation practices in the leprosarium community.

Abbreviations
ANCOVA   Analysis of covariance
ANOVA   Analysis of variance
CESD   Center for epidemiological studies-depression scale

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FMOH	Federal Mistry of Health
HRQoL	Health-related quality of life
NTDs	Neglected tropical diseases
PedsQL4.0	Pediatric Quality of Life Inventory 4.0 Generic Core Scale
STATA	Statistical software for data science
WHO	World Health Organization

Background

The World Health Organization Quality of Life Group defines quality of life as an individual's assessment of their status in life concerning expectations, patterns, and concerns within their cultural and value system[1]. It refers to the physical, psychological, and social aspects of health that are impacted by an individual's experiences, beliefs, expectations, and perceptions[2,3]. Leprosy is an infectious neglected tropical disease (NTD) that can impaired health-related quality of life (HRQoL)[4,5]. Approximately one million people currently suffering from irreversible disability related to leprosy infection[4]. Leprosy remains a public health challenge for some low- and middle-income countries[6–8]. An estimated 4.5 per million children with leprosy infection worldwide were diagnosed in 2021. Approximately 143 countries, 37 of which are African are affected by this disease[3]. Ethiopia is one of priority country among 23 World Health Organization (WHO) focus areas, that has the second-highest leprosy incidence in sub-Saharan Africa[9]. For example, in 2019 a total of 3426 cases of leprosy were reported in Ethiopian national program, 96.2% of which were newly diagnosed and 15% of which were in children and adolescents under 15 years of age[10]. Moreover, 65.9% of leprosy patients in Ethiopia have grade I or II disability, indicating that community-acquired transmission still occurs[9,11]. In East Hararghe, 13.2% of newly diagnosed cases in 2020 were under the age of 15, and 14.1% of affected children had Grade II disability[12]. The presence of highly endemic areas and the high prevalence of 9.3 per 10,000 people suggest that the road to the eradication of leprosy in Ethiopia remains challenging[13].

Living in previous leprosarium settlement areas has a significant impact on the HRQoL of the community, particularly in children. Evidence indicates that treated and cured leprosy patients have a lower HRQoL than the general population[5]. The disease causes physical, psychological, and social disabilities and social exclusion[9]. Children living in areas with previous leprosy settlements also face challenges accessing education and health care, reduced academic success, reduced HRQoL, social support, mental health, ability to work, and suffering from the stigma associated with the disease and disability[4,14]. To address the impact of leprosy on HRQoL among people living in previously endemic areas, especially children, the Global Leprosy Strategy 2021–2030 has set a target of a 90% reduction in the rate per million of new cases with grade 2 disability and a 90% reduction in the rate of new child cases with leprosy[3].

The Ethiopian leprosy elimination strategy, 2016–2020 aimed to reduce the burden of leprosy and improve the HRQoL of children by taking the following measures: providing early diagnosis and treatment to prevent complications and disability; providing free multidrug therapy for all leprosy patients; strengthening patient and community awareness of leprosy to reduce stigma and discrimination; and supporting research and innovation to find new ways to prevent, diagnose, and treat leprosy[15]. However, its implementation is not successful or sustainable because of the fragile healthcare system in some low-income countries[16]. Therefore, the identification of factors that influence HRQoL in children provides important information to policymakers and contributes to the development and implementation of context-effective prevention programs for children, which can promote long-term mental and physical health and wellness[1,17]. It also increases governmental awareness and provides insight to health professionals on the HRQoL of children living in these settings and strengthens the implementation of preventive measures to improve HRQoL. However, the demands associated with reducing stigma and improving HRQoL among affected people have emerged and been neglected[4]. Moreover, data on HRQoL and its associated factors among children living in previous leprosarium and nonleprosarium settlement areas are scarce. Some available evidence is focused on the prevalence of leprosy among adult patients, and there are no findings indicating the HRQoL of children living in previous leprosy settlements in Ethiopia. Therefore, this study aimed to compare the HRQoL and associated factors among children living in previous leprosarium and nonleprosarium settlement areas in Eastern Ethiopia.

Methods and materials

Study setting and design

This was a community-based comparative cross-sectional study conducted in previous leprosarium and nonleprosarium settlement areas in selected districts in the Harari regional state (Amir Nur district and Oromia regional state, Babile district) from January to February 30, 2024.

In Ethiopia, the formation of the previous leprosarium settlement areas started with mass treatment of the leprosarium in the 1950s and 1960s in the following areas: Bisidimo in the Hararghe Region, Borumeda in the Wollo Region, Gambo in the Arsi Region, and Gendeberet in the Shoa Region. In 1964, Tibela (Addis Hiwot) started as an Agricultural Training Centre to provide skills training to 800 patients. This study was conducted in previous leprosarium (01 Kebeles, Ganda Fero, and Bisidimo Kebele) and nonleprosarium settlement areas (Kebele 02 and Ifadin Kebele) in the Harari and Oromia regional states, respectively. A total of 31,740 people live in the selected districts in both settlements.

Population

All children aged 8 to 18 years old and their parents who were living in the Amir Nur and Bisidimo districts during data collection period were the source population, and sampled children living in selected kebeles of

these districts were the study population. Children aged 8 to 18 years and their parents who were living in previous leprosarium settlement villages in selected Kebeles for at least six months were included in this study. However, children aged 8 to 18 years whose parents or caregivers were seriously ill and children with other conditions, such as congenital malformations and physical disability not associated with leprosy, were excluded from this study.

Sample size and sampling procedure

The double population proportion formula was used to calculate the sample size using Statcalc Epi-Info version 7.2.5.0, with the following assumptions: confidence level = 95%, power = 80%, and the ratio of unexposed to exposed almost equivalent to 1[18]. By adding the 10% nonresponse rate, the final sample size was 515. The previous leprosarium settlement areas Amir Nur district 01 Kebele and Babile district Bisidimo Kebele were selected. Then, two comparative nonleprosarium settlements (Kebele 02 and Ifadin Kebele) were selected randomly. Households with children aged 8 to 18 years from each district were selected using systematic random sampling (K^{th} =5), the first household was selected using lottery method 3, and every fifth household was included. When the selected household had no children aged 8 to 18 years, the next household was replaced. When there was more than one eligible child, we selected one participant using the lottery method.

Data collection and procedure

The questionnaires collected information on the sociodemographic characteristics of the parent and children; the health and activity of the child; psychosocial and clinical factors; and WASH-related factors. To measure HRQoL, the Pediatric Quality of Life Inventory 4.0 Generic Core Scale (PedsQL4.0) from Mapi-Trust was used[19]. Two age-appropriate instruments for children aged 8 to 12 and 13 to 18 years were used in this study. It has a 23-item, multidimensional quality-of-life instrument. The items in every 4 subscales were physical functioning (8 items), functioning, social functioning, and school functioning (5 items for each). It was reported to both the child self and parents or a proxy report. The child and the parent were asked to rate the problem on 5 Likert scales from 0 to 4. (0 = never a problem; 1 = almost never a problem; 2 = sometimes a problem; 3 = often a problem, and 4 = almost always a problem) in the last month. Then, each item was reversely scored and linearly transformed to a 0-100 scale (0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0) so that higher scores indicated better HrQoL. Scale scores were computed as the sum of the items divided by the number of items answered. If > 50% of the items in the scale were missing, the scale score was not computed.

The instrument was translated into Amharic and Afan Oromo. The data were collected through interviews administered at home-to-home visits. The child and present were interviewed separately on the same date. It was translated back to English by an independent translator to maintain the consistency of the tool. The data were collected by six trained BSc professionals: Pediatric and Child Health Nursing, Public health, and laboratory technician and supervised by an MSc Medical Parasitology professional.

Measurements

Health-related quality of life (HRQoL): is a multidimensional concept that includes domains related to physical, mental, emotional, and social functioning and is measured using the Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0) questionnaire, which was specifically designed to measure quality of life in children[20].

Poor HRQoL: Respondents who had a mean score of more than 1 standard deviation (1SD) below the sample mean of the total HRQoL score of the self-report in each subscale.

Good HRQoL: Respondents who had a mean score above 1 standard deviation (1SD) of the sample mean of the total HRQoL score of the self-report in each subscale.

Previous leprosarium settlement areas were villages from which leprosy patients evolved during the 1950s to establish a village in the vicinity of the leprosarium, which soon became a destination for the sufferers who flocked from all over the country into these villages (Ganda Qore and Ganda Feron) in search of medical treatment and better socioeconomic advantages[21].

Children: Every human being between 8 and 18 years old.

Data quality assurance

Data quality was ensured during collection, coding, entry, and analysis. We used a standard tool to measure HRQoL, and pretested questionnaires were applied for other related variables. Two days of training were given to the data collectors and supervisors. Regular supervision was performed by the investigators. The data were collected using ODK software.

Data processing and analysis

The data were validated before being imported and analyzed with STATA version 14. The data are summarized using means and standard deviations and are presented in tables and statements. A paired t-test was performed to compare the children's self-reports and parent proxy reports. One-sample independent t-tests and one-way ANOVA were used to compare the mean PedsQL™ 4.0 scores of the children according to sociodemographic and clinical variables. Simple and multiple linear regression analyses were adjusted to identify associated factors. Finally, both the mean difference in the PedsQL™ 4.0 score and the statistically significant factors were considered at $P < 0.05$.

Variables	Categories	Settlement areas	
		Previous leprosarium n (%)	Non leprosarium n (%)
Place of residence	Urban	125 (48.83)	131 (51.17)
	Rural	111 (43.48)	142 (56.52)
Mother education	Cannot read and write	122 (40.94)	176 (59.06)
	Read & write	57 (60.00)	38 (40.00)
	Primary school	20 (43.48)	26 (56.52)
	Secondary school	14 (70.00)	6 (30.00)
	College and above	23 (44.00)	27 (56.00)
Marital status	Married	218 (47.07)	243 (52.93)
	Separated/ divorced	8 (30.77)	18 (69.23)
	Widowed	10 (45.45)	12 (54.55)
Occupation	Farmer	62 (42.47)	84 (57.53)
	Merchant	52 (53.61)	45 (46.39)
	Employed	48 (51.06)	46 (48.94)
	Jobless	41 (59.70)	26 (40.30)
	Other	33 (31.43)	72 (68.57)
Child number	Less than 4	135 (54.69)	111 (45.31)
	Greater than or equal to 4	101 (38.26)	162 (61.74)
	Total	236 (46.17)	273 (53.83)

Table 1. Sociodemographic characteristics of the caregivers/mothers of children living in previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [$n = 509$].

Results

Sociodemographic characteristics of the caregiver/mother

A total of 509 caregiver/mother and child pairs were included in this study, yielding a 98.8% response rate. One hundred twenty-five (48.83%) and 131 (51.17%) participants who lived in a previous leprosarium and nonleprosarium settlement, respectively, were urban residents. The mean age and standard deviation (SD) of the caregivers/mothers were 34.1 ± 7 years. Regarding educational status, 122 (40.94%) and 176 (59.06%) participants could not read and write respectively, among participants in previous leprosarium and nonleprosarium settlement areas. Sixty-two (42.47%) and 84 (57.53%) participants from previous leprosarium and nonleprosarium settlement areas were farmers respectively. The mean monthly family incomes were 4217.596 ± 1802.449 and 4537.825 ± 1995.072 ETB in the previous leprosarium and nonleprosarium settlement areas, respectively (Table 1).

Sociodemographic characteristics of the children

A total of 509 children aged 8 to 18 years participated in this study. The mean age and SD were 10.73 ± 2.52 years. Two hundred thirty-six children (46.17%) and 273 (53.83%) were from previous leprosarium and nonleprosarium settlement areas, respectively. A total of 71 (52.59%) and 63 (47.41%) children aged 13 to 18 years were from previous leprosarium and nonleprosarium settlement areas, respectively. Among 243 male children, 116 (47.95%) were from previous leprosarium settlements, and 127 (52.05%) were from nonleprosarium settlement areas. Concerning the educational status of the children, 458 were in primary school, 207 (45.30%) were in previous leprosarium settlements, and 251 (54.70%) were in nonleprosarium settlement areas. Of the total participants, 446 had no history of NTD disease, and 63 (12.4%) had a previous history of NTD disease, 37 (58.73%) of whom were from previous leprosarium settlement areas (Table 2).

Health-related quality of life of children

The mean HRQoL of children was measured by using one-way ANOVA among children living in previous leprosarium and nonleprosarium settlement areas for child self-reports and parent proxy reports. The overall mean HRQoL scores were 73.98 ± 18.47 and 77.67 ± 14.72 (F = 6.20, $P = 0.013$) for children living in previous leprosarium and nonleprosarium settlement areas, respectively. According to the child self-report component domains, children had a mean HRQoL for physical functioning of 74.05 ± 20.26 vs. 78.30 ± 15.26 (F = 7.16, $P = 0.008$), emotional functioning of 74.85 ± 19.40 vs. 77.51 ± 15.96 (F = 2.44, $p = 0.009$), social functioning of 74.78 ± 20.85 vs. 78.49 ± 16.880 (F = 4.87, $p = 0.028$), and school functioning of 72.18 ± 21.04 vs. 75.99 ± 18.14 (F = 4.78, $p = 0.029$). According to the parent proxy report, the overall mean HRQoL scores were 55.78 ± 12.03 and 55.61 ± 8.50 for the children living in the previous leprosarium and nonleprosarium settlement areas, respectively. This difference was statistically significant within the physical functioning domain (F = 9.10, $P = 0.003$) and the emotional functioning domain (F = 10.52, $P = 0.001$) (Table 3).

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Variables	Categories	Settlement areas	
		Previous leprosarium n (%)	Nonleprosarium n (%)
Child age in years	8_12	165 (43.85)	210 (56.15)
	13_18	71 (52.59)	63 (47.41)
	Total	236 (46.17)	273 (53.83)
Sex of the child	Male	116 (47.95)	127 (52.05)
	Female	120 (44.53)	146 (55.47)
	Total	236 (46.17)	273 (53.83)
Educational status of the child	Primary school	207 (45.30)	251 (54.70)
	Secondary school	17 (65.38)	9 (34.62)
	Not in school	12 (48.00)	13 (52.00)
	Total	236 (46.17)	273 (53.83)
Previous history of NTDs	No	199 (44.62)	247 (55.38)
	Yes	37 (58.73)	26 (41.27)
	Total	236 (46.17	273 (53.83

Table 2. Sociodemographic characteristics of participant children living in previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [$n=509$].

Comparison of the child-self and parent proxy reporting of pedsql™ 4.0

For children living in areas with previous leprosarium settlements, the mean HRQoL was compared between child self-reports and parent proxy reports using paired t-tests, which revealed that there was a statistically significant difference in all PedsQL™ 4.0 subscales or domains, such as physical functioning (74.05 ± 20.26 vs. 42.63 ± 16.94, t = 17.19, $p \leq 0.001$), emotional functioning (74.85 ± 19.40 vs. 70.62 ± 21.30, t = 4.37, $p \leq 0.001$), social functioning (74.78 ± 20.85 vs. 62.83 ± 18.41, t = 10.13, $p \leq 0.001$), and school functioning (72.18 ± 21.04 vs. 54.91 ± 15.22, t = 13.08, $p \leq 0.001$). Moreover, for children living in nonleprosarium settlement areas, paired t-tests were performed to compare the mean HRQoL using child self-reports and parent proxy reports, and the results revealed that there was a statistically significant difference in all the pedsQL™ 4.0 subscales or domains (Table 4).

The overall mean HRQoL of children was compared for all children living in both villages in all 4 subscales or domains of the PedsQL4.0 between the child self-reports and parent reports using paired t-tests, and the results revealed that there was a statistically significant difference between the child self-reports and parent proxy reports. The mean HRQoL score reported by the child self-reports was 75.94 ± 16.63, compared to 55.65 ± 10.32 for the parent proxy reports (t = 31.59, $p \leq 0.001$) (Table 5).

Poor HRQoL: according to this study of 236 children living in previous leprosarium settlement areas, 61 (26%) and 131 (44.7%) children had poor mean HRQoL according to child reports and family reports, respectively, while 273 children living in nonleprosarium settlement areas 53 (22.3%) and 167 (62%) of the children had poor mean HRQoL according to child reports and family reports, respectively. Of the total 509 children living

Settlement areas						
Child self-report	Previous leprosarium ($n=236$)		Nonleprosarium ($n=273$)			
Scale	Mean	SD	Mean	SD	F	P value
Physical functioning	74.05	20.26	78.30	15.26	7.16	0.008
Emotional functioning	74.85	19.40	77.51	15.96	2.44	0.009
Social functioning	74.78	20.85	78.49	16.88	4.87	0.028
School functioning	72.18	21.04	75.99	18.14	4.78	0.030
Total score	73.98	18.47	77.67	14.72	6.20	0.013
Parent proxy report	Leprosarium ($n=236$)		Nonleprosarium ($n=273$)			
Scale	Mean	SD	Mean	SD	F	P value
Physical functioning	42.63	16.94	38.42	14.36	9.10	0.003
Emotional functioning	70.62	21.30	76.25	17.58	10.52	0.001
Social functioning	62.83	18.41	62.47	15.46	0.06	0.812
School functioning	54.92	15.22	55.63	12.39	0.34	0.560
Total score	55.78	12.03	55.61	8.50	0.03	0.858

Table 3. Comparison of the mean HRQoL of children using child reports and parent proxy reports between previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [$n=509$]. *A higher mean score indicates better health-related quality of life.

Previous leprosarium settlements

Scale	Child report N = 236)			Parent report (N = 236)			t	P value
	Mean	SD	95% CI	Mean	SD	95% CI		
Physical functioning	74.05	20.26	71.44–76.66	42.63	16.94	40.45–44.81	17.19	0.000
Emotional functioning	74.85	19.40	72.35–77.35	70.62	21.29	67.88–73.36	4.37	0.000
Social functioning	74.78	20.85	72.10-77.47	62.83	18.41	60.46–65.20	10.13	0.000
School functioning	72.18	21.04	69.47–74.89	54.91	15.21	52.95–56.87	13.08	0.000

Previous non-leprosarium settlements

Scale	Child report (N = 273)			Parent report (N = 273)			t	P value
	Mean	SD	95% CI	Mean	SD	95% CI		
Physical functioning	78.30	15.26	76.47–80.13	38.42	14.36	36.69–40.14	27.74	0.000
Emotional Functioning	77.51	15.96	75.59–79.43	76.25	17.58	74.14–78.36	1.873	0.031
Social Functioning	78.49	16.88	76.47–80.52	62.47	15.48	60.62–64.33	13.67	0.000
School Functioning	75.99	18.14	73.81–78.16	55.63	12.39	54.14–57.12	17.93	0.000

Table 4. Comparisons of the mean HRQoL on 4 subscales of the PedsQL4.0 between child self-reports and parent reports in previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [n = 509]. *A higher mean score indicates a better HRQoL.

Scale	Child report (N = 509)			Parent report (N = 509)			t	P value
	Mean	SD	95% CI	Mean	SD	95% CI		
Physical functioning	76.32	17.85	74.76–77.88	40.41	15.75	39.04–41.79	30.82	0.000
Emotional functioning	76.26	17.66	74.71–77.81	73.51	19.74	71.78–75.24	4.672	0.000
Social functioning	76.75	18.89	75.10-78.41	62.54	16.99	61.06–64.03	16.93	0.000
School functioning	74.21	19.60	72.49–75.92	55.25	13.80	54.04–56.45	21.92	0.000
Total	75.94	16.64	74.49–77.40	55.65	10.32	54.74–56.55	31.59	0.000

Table 5. Overall comparisons of the mean HRQoL of children in 4 subscales of the PedsQL4.0 between child self-reports and parent reports in previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [n = 509]. A higher mean score indicates a better HRQoL.

in both areas, 123 (24.1%) children from the child reports and 226 (44.35%) from the family reports reported poor HRQoL.

Good HRQoL: according to this study of 236 children living in previous leprosarium settlement areas, 175 (74%) and 142 (55.3%) children reported good mean HRQoL according to child reports and family reports, respectively, while 273 children from nonleprosarium settlement areas (77.7%) and 106 (38%) children reported good mean HRQoL according to child reports and family reports, respectively. Of the total 509 children living in both areas, 386 (75.9%) children from the child self-reports and 283 (55.65%) children from the family reports reported good HRQoL.

Factors associated with the health-related quality of life of children

To identify factors associated with HRQoL in children living in previous leprosarium and nonleprosarium settlement areas, simple and multiple linear regression analyses were conducted. In simple linear regression analysis, sociodemographic characteristics of the caregiver/mother (maternal or caregiver education and occupation, marital status, maternal age, child education, child sex, weight, family size, settlement sites), hygienic aspects of the child (face washing), clinical aspects of the disease (pruritus, current NTDs, and previous history of NTDs), and water, sanitation and hygiene-related factors (water shortage, latrine use, and hand washing facility) were included in the final model. The final model was fitted for the following assumptions: linearity and multicollinearity were checked using the variance inflation factor (VIF) (2.90), and the normality of the standardized residuals was tested using a normal Q–Q plot or statistical tests for normality (Figs. 1 and 2). Overall, the results showed that the utility of the predictive model was significant (F $(29, 479) = 6.08$, R2 = 0.27, $p < 0.001$). All of the predictors explained a large amount of the variance between the variables (67.82%).

Multiple linear regression analysis revealed that the HRQoL of children in primary and secondary schools was significantly different. The coefficient of HRQoL of children in primary school was ($β = 14.69$; 95% CI: 8.69, 20.69) times greater than children not in school. Children who were learning in secondary school had an increased total HRQoL score ($β = 10.88$; 95% CI: 2.01, 19.76) compared to children not in school. Moreover, the number of times children wash their face increases the HRQoL of children positively, and children who wash their face two times ($β = 5.54$, 95% CI: 2.14, 8.95), three times ($β = 4.02$, 95% CI: 0.087, 7.96), or four times ($β = 6.33$, 95% CI, 1.00 to 11.66) per day increase the HRQoL compared to children who wash their face once a day. Furthermore, children who had a previous history of any NTD (skin, trachoma, or STH) ($β = -8.54$; 95% CI
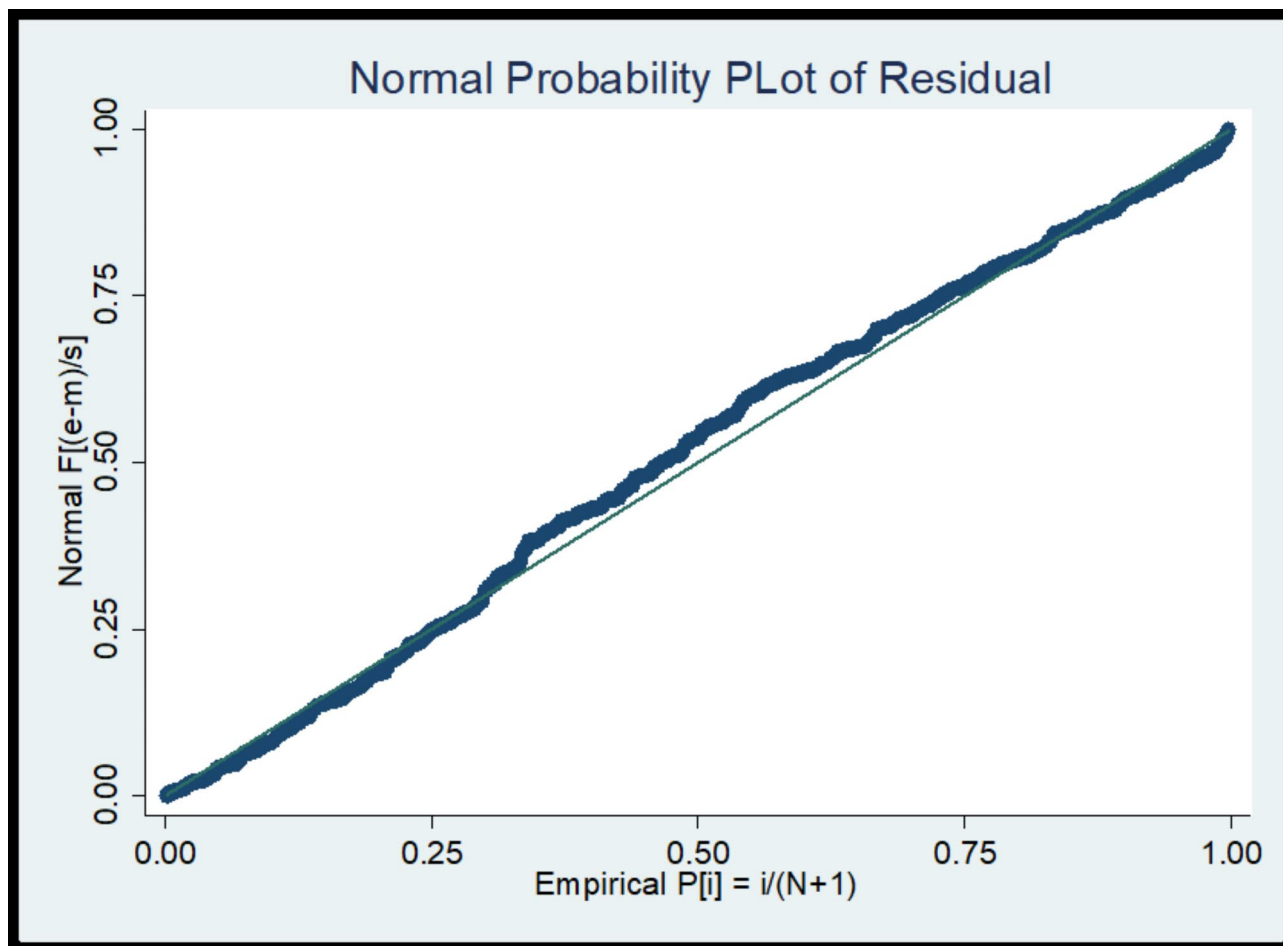
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Fig.1. Graph of the normal probability plot of the residuals (errors) of the mean HRQoL assessed for children living in previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [$n = 509$].

-12.93, -4.15) had significantly lower HRQoL than did their counterparts ($p = 0.003$). The HRQoL of children who had no current NTDs was ($\beta = 4.02$; 95% CI: 0.66, 7.37) times greater than that of children who had been diagnosed with NTDs such as skin, trachoma, and STHs. In addition, the HRQoL of children whose families did not have hand-washing facilities ($\beta = -8.57$; 95% CI: -15.22, -1.92) was lower than that of their counterparts (Table 6).

Discussion

This is the first evaluation of HRQoL among children aged 8 to 18 years who were living in previous leprosarium and nonleprosarium settlement areas in eastern Ethiopia. We estimated and compared the HRQoL of children using the well-validated Pediatric Quality of Life Inventory 4.0 (PedsQL4.0), which was used to measure and explore the relationships between 4 subscales of the PedsQL4.0 and HRQoL. The results provide important insights into the HRQoL of children living in previous leprosarium and nonleprosarium settlement areas.

The overall mean HRQoL scores were 75.94 ± 16.64 and 55.65 ± 10.32 for both settlement areas according to the child reports and parent proxy reports, respectively. The number of child reports is comparable, and the number of parent reports is lower than that in studies conducted in Slovenia[22]. The most prevalent problems were lower physical functioning (42.63 ± 16.94) than in 81.9 ± 19.6 studies performed in Addis Ababa, Ethiopia[23]. Moreover, we found that children living in previous leprosarium settlement areas reported significantly lower physical, emotional, social, and school functioning than children living in previous non leprosarium settlement areas. The overall mean HRQoL score of children living in previous leprosarium settlement areas was 73.98 ± 18.46, which was greater than that reported in a study conducted in northwest Ethiopia (61.93 ± 17.1)[18]. The lowest mean HRQoL score in the present study was from the family report, and it was the physical functioning domain in previous nonleprosarium settlement villages (38.418 ± 14.363; $F = 9.10$, $P = 0.0027$). This value is much lower than that reported in a study by Addis Ababa, which reported a value of 63.6 ± 10[23]. On the other scales, the mean HRQoL score was lower in previous leprosarium settlement villages and higher in social functioning and school functioning, which were not statistically significant according to family reports. The overall mean HRQoL
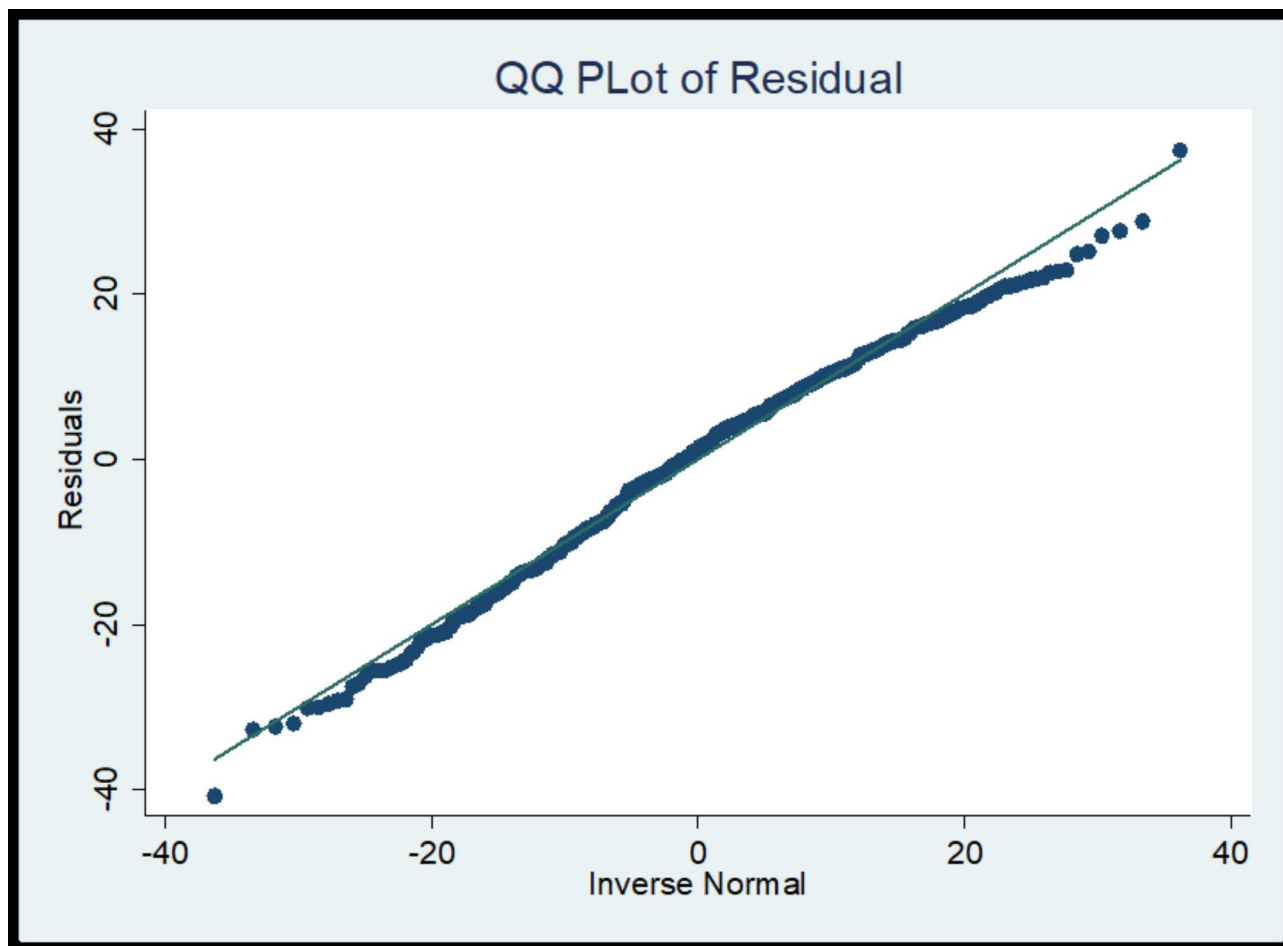
Fig.2. Normal Q-Q plot or statistical normality tests of mean HRQoL assessed for children living in previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [$n = 509$].

of children according to family reports was similar at 55.78 ± 12.028 and 55.61 ± 8.50, respectively, which was much lower than that reported in a study performed in India (90.10 ± 9.50)[24].

In the previous leprosarium settlement village, the mean HRQoL on 4 subscales of the PedsQL4.0 was compared between the child report and parent report, and the lowest mean HRQoL was 42.628 ± 16.944 according to the parent report compared to 74.052 ± 20.256 according to the child self-report, which is much lower than that reported in studies performed in India (87.50 ± 11.10 child reports and 90.10 ± 9.50 parent proxy reports)[24]. The mean HRQoL in the previous leprosarium settlement area was lower in parent reports than in child self-reports, which is similar to the findings of a study in Nepal[25]. Additionally, in the nonleprosarium settlement village, the mean HRQoL was compared between the child reports and parent reports and the results showed that the mean HRQoL according to the child reports was significantly greater for all 4 subscales of the PedsQL4 than for the family reports, and all the associations were statistically significant. Overall, there was no trend toward better HRQoL scores in these areas, indicating that children who lived in previous non leprosarium settlement villages had better HRQoL than those who lived in previous leprosarium settlement villages.

The overall comparisons of the mean HRQoL of children in the 4 subscales of the PedsQ L4.0 between child reports and parent reports in both previous leprosarium and nonleprosarium settlement villages showed that child reports had better mean HRQoL scores than did parent reports, which is comparable to the findings of a study performed in Addis Ababa (t = 31.59, $p < 0.001$)[23]. This comparison between child reports and family reports in both previous leprosarium and nonleprosarium settlement areas shows that children have more information and understanding concerning their health and the factors affecting their health than their caregivers/mothers.

This study identified several important factors that influence the mean HRQoL of children. Both univariate analysis and multiple analysis were conducted to study the associations between different variables and the HRQoL of the children. Multiple linear regression analysis revealed that the child's educational status, presence of a previous history of NTD, presence or absence of NTD in the last week, number of times the child washed his/her face per day, and absence of a hand-washing facility in the house were highly significantly associated with the mean HRQoL of the child ($p < 0.05$).

Mean HRQoL of child	Variables	Simple linear regression		Multiple linear regression	
		β Coef [95% CI]	P value	β Coef [95% CI]	P value
Sociodemographic					
Caregiver/mother's educational status	Cannot read and write	0		0	
	Read & write	-5.41 (-9.19, -1.62)	0.005	-2.95 (-6.83, 0.91)	0.133
	Primary school	2.72 (-2.36, 7.81)	0.293	2.00 (-2.95, 6.96)	0.428
	Secondary school	2.47 (-4.94, 9.89)	0.513	1.93 (-5.04, 8.91)	0.587
	College and above	-1.17 (-6.08, 3.73)	0.638	0.679 (-4.90, 6.26)	0.811
Child educational status	Primary school	15.41 (8.93, 21.89)	0.000	14.69 (8.69, 20.69)	**0.000**
	Secondary school	6.40 (-2.43, 15.24)	0.155	10.88 (2.01, 19.76)	**0.016**
	Not in school	0		0	
Marital status	Married	0		0	
	Separated/divorced	-1.78 (-8.32, 4.74)	0.591	0.26 (-5.94, 6.47)	0.934
	Widowed	-1.07 (-8.14, 6.00)	0.767	−0.11 (-7.02, 6.79)	0.974
Residency	Urban	0		0	
	Rural	4.71 (1.87, 7.55)	0.001	2.03 (-2.53, 6.59)	0.382
Child sex	Male	0		0	
	Female	−0.48 (-3.35, 2.38)	0.740	-2.48 (-5.07, 0.10)	0.060
Number of Child in the house	less 4	0		0	
	Greater or equal to 4	(-1.99, 3.74)	0.551	-1.45 (-4.99, 2.09)	0.421
Settlements	Previous leprosarium	0		0	
	Nonleprosarium	3.40 (0.57, 6.26)	0.020	2.41 (-0.43, 5.25)	0.096
Child pruritus or itch	No	0		0	
	Yes	-5.43 (-9.50, -1.37)	0.009	-3.43 (-7.42, 0.56)	0.092
Previous history of NTDs	No	0		0	
	Yes	-12.66 (-16.87, -8.44)	0.000	-8.54 (-12.93, -4.15)	**0.000**
Current diagnosis of NTDs	Yes	0		0	
	No	6.91 (3.45, 10.37)	0.000	4.02 (0.66, 7.37)	**0.019**
Child number of face washing per day	1	0		0	
	2	6.03 (2.59, 9.45)	0.001	5.54 (2.14, 8.95)	**0.001**
	3	3.92 (0.11, 7.73)	0.044	4.02 (0.08, 7.96)	**0.045**
	4	3.24 (-2.14, 8.62)	0.238	6.33 (1.00, 11.66)	**0.020**
Water shortage	No	0		0	
	Yes	-4.67 (-7.65, -1.68)	0.002	-2.44 (-5.43, 0.55)	0.110
Latrine in use	No			0	
	Yes			2.70 (-0.48, 5.89)	0.096
Hand washing facility	Yes	0		0	
	No	-6.96 (-13.99, 0.06)	0.052	-8.57 (-15.22, -1.92)	**0.012**

Table 6. Univariate and multivariate linear regression analysis: standardized beta coefficients of the mean HRQoL of children living in previous leprosarium and nonleprosarium settlement areas at Amir Nur and Babbile Districts, Eastern Ethiopia, 2024 [$n = 509$].

This finding is supported by studies in Spain, Brazil, and Kenya that concluded that the educational status of the child is strongly associated with HRQoL[20,26,27]. This is because educated children have more information and understanding concerning their health and the factors affecting their health than do their nonschooling children. Moreover, previous history and current diagnosis of NTDs have a strong relationship with HRQoL. This is supported by a review by Hannah Kuper in 2019[28]. This is because children with NTDs may have difficulties carrying out activities with their peers, and this may also be due to stigma and mental health consequences. Furthermore, poor access to water, poor sanitation, and poor housing were associated with a simple linear regression analysis but lost this association when confounders were controlled for. This finding that hand-washing practices decreased HRQoL is supported by findings in Kenya[27]. This may be due to poor hygiene and a lack of sanitation, which can propagate NTD transmission and subsequently affect the health and well-being of children[27].

Strengths and limitations

Several strengths of this study should be mentioned even if it has fewer limitations. The study was conducted in previous leprosarium settlement and non leprosarium settlement areas in rural and urban areas of eastern Ethiopia, which represent different sociodemographic characteristics; therefore, it should be noted that the estimated HRQoL of both children living in a previous leprosarium and non- leprosarium settlement areas

may better represent that of these children living in eastern Ethiopia and of the whole country. Since this was a cross-sectional comparative study, we identified and focused on understanding associations between specific sociodemographic factors and HRQoL.

Conclusion

Based on child self-reports, one in four children from previous leprosarium areas had poor HRQoL. Children's educational status, their daily habits of washing their face, not having neglected and tropical diseases had improved HRQoL. Overall mean HRQoL among the 4 subscales of the PedsQL4. 0 was 73.98 ± 18.47 and 77.67 ± 14.71 for child self-reports and 55.77 ± 12.03 and 55.61 ± 8.49 for proxy reports in leprosarium and nonleprosarium settlement areas, respectively. To improve HRQoL, stakeholders should pay attention to and work on the early detection and treatment of neglected and tropical diseases, child education, and proper sanitation practices in the community. Increasing the capacity of health extension workers through training in the provision of community health education, screening for early detection, and treatment of NTDs is essential.

Data availability

The data will be available upon request from the corresponding author.

References

1. Silva, P. A. B., Soares, S. M., Santos, J. F. G. & Silva, L. B. Ponto De corte para o WHOQOL-bref como preditor de qualidade de vida de idosos. *Rev. Saúde Pública*. **48**, 390–397 (2014).
2. Gebremedhin, T., Workicho, A. & Angaw, D. A. Health-related quality of life and its associated factors among adult patients with type II diabetes attending Mizan Tepi University Teaching Hospital, Southwest Ethiopia. *BMJ Open. Diabetes Res. Care*. **7** (1), e000577 (2019).
3. WHO. Global leprosy (Hansen disease) update, 2019: Time to step up prevention initiatives. (2020).
4. Lustosa, A. A., Nogueira, L. T., Pedrosa, J. I., Teles, J. B. & Campelo, V. The impact of leprosy on health-related quality of life. *Rev. Soc. Bras. Med. Trop.* **44** (5), 621–626 (2011).
5. Xu, L. et al. (eds) *Self-Care Ability and Life Quality of Cured Leprosy Patients: The Mediating Effects of Social Support* (MDPI, 2023).
6. Bhukhan, A., Dunn, C. & Nathoo, R. Case report of leprosy in Central Florida, USA, 2022. *Emerg. Infect. Dis.* **29** (8), 1698 (2023).
7. Hambridge, T., Nanjan Chandran, S. L., Geluk, A., Saunderson, P. & Richardus, J. H. Mycobacterium leprae transmission characteristics during the declining stages of leprosy incidence: A systematic review. *PLoS Negl. Trop. Dis.* **15** (5), e0009436 (2021).
8. Otto, C. et al. Risk and protective factors of health-related quality of life in children and adolescents: Results of the longitudinal BELLA study. *PloS One*. **12** (12), e0190363 (2017).
9. WHO. Global leprosy (Hansen disease) update, 2021: Moving towards interruption of transmission. Weekly epidemiological record; 09/20222022. 429 – 52.
10. Letta, T. *Challenges in Implementation of the Current Strategies* (editor. National TBL Program, 2020). MOH.
11. Shumet, T., Demissie, M. & Bekele, Y. Prevalence of disability and associated factors among registered leprosy patients in all Africa tb and leprosy rehabilitation and training center (ALERT), Addis Ababa, Ethiopia. *Ethiop. J. Health Sci.* **25** (4), 313–320 (2015).
12. Ephrem Mamoa, K. B. et al. *Anne Schoenmakerse,f, Robin Van Wijke,f, Christa Kasang, Liesbeth Mieras & Jan Hendrik Richardus. Epidemiological Trends of Leprosy and case Detection Delay in East Hararghe Zone* (A baseline survey, 2022).
13. Urgesa, K. et al. Evidence for hidden leprosy in a high leprosy-endemic setting, Eastern Ethiopia: The application of active case-finding and contact screening. *PLoS Negl. Trop. Dis.* **15** (9), e0009640 (2021).
14. Yamaguchi, N., Poudel, K. & Jimba, M. Health-related quality of life, depression, and self-esteem in adolescents with leprosy-affected parents: Results of a cross-sectional study in Nepal. *Nihon Hansenbyo Gakkai Zasshi Jpn. J. Lepr. Off. Organ. Jpn. Lepr. Assoc.* **85**(2), 65–68 (2016).
15. FMOH E. National leprosy strategy. Final leprosy elimination strategy for Ethiopia From. -20202017. 24 p. (2016).
16. Remme, J. H. et al. Tropical diseases targeted for elimination: Chagas Disease, Lymphatic Filariasis, Onchocerciasis, and Leprosy. *Int. J. Biomedical Health Sci.* **9**(4). (2021).
17. Thacker, S. B., Sencer, D. J. & Jaffe, H. W. *Centers Disease Control Int. Encyclopedia Public. Health* 448 (2017).
18. Abebaw, A., Atnafu, A., Worku, N. & Hagos, A. Health-related quality of life and associated factors among adult podoconiosis patients in Debre Elias district Northwest, Ethiopia. *PLoS Negl. Trop. Dis.* **16** (9), e0010673 (2022).
19. Chen, C. et al. Understanding adolescents' need support, need satisfaction, and health-related outcomes: A self-determination health behavior perspective. *Int. J. Environ. Res. Public. Health.* **17** (1), 104 (2020).
20. Gil-Lacruz, M., Gil-Lacruz, A. I. & Gracia-Pérez, M. L. Health-related quality of life in young people: the importance of education. *Health Qual. Life Outcomes*. **18** (1), 187 (2020).
21. Kebede, M. T. in *Leprosy, Leprosaria and Society in Ethiopia: A Historicalstudy of Selected Sites* 1901–2001. 276 (Addis Ababa, 2005).
22. Petek, T., Hertiš, T. & Marčun Varda, N. Health-related quality of life in pediatric arterial hypertension: A cross-sectional study. *BMC Pediatr.* **18**, 1–9 (2018).
23. Girma, D. et al. Health-related quality of life and its associated factors in children and adolescents with Type1 diabetes, Addis Ababa, Ethiopia. *Global Pediatr. Health*. **8**, 2333794X110308 (2021).
24. Raj, M. et al. Health-related quality of life in Indian children: A community-based cross-sectional survey. *Indian J. Med. Res.* **145** (4), 521–529 (2017).
25. Yamaguchi, N. & KCPaMJ. Health-related quality of life, depression, and self-esteem in adolescents with leprosy-affected parents: Results of a cross-sectional study in Nepal. *BMC Public. Health* (2013).
26. Neder, L. et al. Decrease health-related quality of life in pediatric leprosy patients with musculoskeletal manifestations. *Pediatr. Rheumatol.* **12** (1), P38 (2014).
27. Ochola, E. A., Karanja, D. M. & Elliott, S. J. The impact of neglected tropical diseases (NTDs) on health and well-being in sub-saharan Africa (SSA): A case study of Kenya. *PLoS Negl. Trop. Dis.* **15** (2), e0009131 (2021).
28. Kuper, H. Neglected tropical diseases and disability—What is the link? *Trans. R. Soc. Trop. Med. Hyg.* **113** (12), 839–844 (2019).

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Author contributions

All authors made a significant contribution to the conception, study design, execution, and acquisition of data, analysis, and interpretation; took part in drafting, revising, or critically for important intellectual content; gave final approval of the version to be published; agreed on the journal to which the article has been submitted; and agreed to be accountable for all aspects of the work.

Declarations

Competing interests

The authors declare no competing interests.

Ethical approval

This study was conducted in accordance with the guidelines and regulations of the Declaration of Helsinki. The study protocol was approved by Haramaya University, College of Health and Medical Sciences Institution Health Research Ethical Review Committee. (Ref. No. IHRERC/025/2024. An official cooperation letter was sent to Amir Nur and Babile districts Health Bureau and other concerned bodies. A written letter of permission was granted by the Districts' concerned bodies to conduct the study in Ganda Fero and Bisidimo kebeles. To participate in the study, every parent or guardian of a child under eighteen years was informed of its objectives and significance before their child's participation. Children aged 12 to 18 were asked to give their verbal consent. Parents who agreed to participate in the study were informed and allowed to give their informed, written, and signed consent before data collection began. Confidentiality was maintained at all levels of the study by excluding names and identifiers in the questionnaire, and the data were used only for this purpose.

Consent for publication

Not applicable.

Additional information

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