

Relationship between Caregiver's Quality of Life and Childhood Tuberculosis in Bauchi State, Northeastern Nigeria

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Abstract

Background: In Nigeria, childhood tuberculosis (TB), a debilitating and deadly disease, is highly prevalent and case reporting is poor due to weak health systems. Globally, children account for at least 10 percent of the TB burden, yet they remain neglected in TB prevention and control efforts. Research studies integrating family and community-centered strategies have been recommended by stakeholders to address the paucity of current local prevention and management strategies for childhood TB. Study Design: Observational study. Methods: This quantitative cross-sectional study explored the relationship between caregivers' quality of life (QOL) and the reporting of TB in their children aged 0 - 14 years. Using the abbreviated version of World Health Organization's (WHO) QOL tool, the WHOQOL-BREF, data were collected individually in a face-to-face setting from caregivers (n = 47) whose children had been diagnosed with TB in Bauchi State, Northeastern Nigeria, over a 5-year period. Data were collected in the same manner from another set of caregivers of children without TB (n = 47) within the same period and setting. Results: Logistic regression indicated a statistically significant relationship (p < 0.001) between the caregivers' QOL and the reporting of childhood TB. Conclusion: This finding underscores the need to identify the factors that positively impact the QOL of caregivers of childhood TB cases. It also reflects the importance of integrating QOL interventions as part of TB control programs seeking to improve childhood TB reporting. This can mitigate the disease burden in vulnerable age-groups living in resource limited settings, thereby contributing to positive social change in the society.

Subject Areas

Public Health

Keywords

Tuberculosis, World Health Organization, Bauchi, Childhood TB, National TB Control Programme, Caregivers, Quality of Life, Northeastern Nigeria

1. Introduction

Children accounted for 10% of the global tuberculosis (TB) burden in 2016 (World Health Organization) [1], yet they remained neglected relative to preventive responses to control TB. In addition, it is well documented that TB research, prevention, and control worldwide have predominantly focused on adults, neglecting children 0 - 14 years old [2] [3] [4] [5] [6]. However, children can no longer be ignored in TB research, prevention and control, as they accounted for 10% of the total global burden in 2016 [1], 15% in South Africa [7], 25% in Afghanistan [8], 3.4% in India [9], 7.9% in Peru [10], 13.7% in Nigeria [1] and 6% in the United States [11].

TB is a public health burden in Nigeria, estimated at 407,000 cases in 2016, ranked seventh among the 30 highest TB burdened countries in the World and second in Africa [1]. Furthermore, this burden is further fueled by co-infection with HIV/AIDS as well as the emergence of drug resistant TB [12] [13]. Although curable and preventable, TB is a highly infectious disease caused by a bacterium known as *mycobacterium tuberculosis* which can affect any part of the body, even though the lungs remain the organs mostly affected, giving rise to pulmonary TB. Extra-pulmonary TB is that which affects any organ other than the lungs [6].

This study, however, focused on pulmonary TB in children aged 0 - 14 years. The infection is spread from person to person through the air as a result of coughing, sneezing, spitting, speaking or even singing by people with pulmonary TB [6]. A healthy person needs to inhale only a few of these bacteria to become infected. An infected person can transmit the bacteria to about 10 to 12 healthy individuals per year, although being infected with the bacteria is not synonymous with having the disease [6] [14].

Childhood TB (CTB or pediatric TB) refers to TB in children aged 0 - 14 years old [15] [16]. According to the WHO [1], children accounted for 10% of the total global burden in 2016, which translates to an estimated 1 million CTB cases and 210,000 deaths. Once infected with *mycobacterium tuberculosis*, children tend to progress more quickly with the disease than adults [16]. The presence of CTB in a community reflects recent and current transmission of the infection in that community, and the burden of the disease provides a clue to the level of TB prevention and control efforts being achieved in that particular setting [4]. Additionally, the presence of infected children in a particular community is an indication of having a reservoir of the bacteria as well as the possibility of having future cases of infections if preventive measures are not taken [5]. However, extensive literature review has shown that there is a paucity of research studies examining the relationship between CTB and caregivers' quality of life (QOL). The purpose of this study was to examine the relationship between CTB reporting and caregivers' QOL in Bauchi State, Northeastern Nigeria.

2. Methods

Bauchi state, nicknamed "Pearl of Tourism", is one of the six states in the northeastern region of the country, divided into 20 local government areas (LGAs) with a projected population of 6,056,519 million people comprising of 51% males and 49% females [17]. It occupies a total land area of 49,119 km², representing about 5.3% of the country's total land mass and is located between latitudes 9°3' and 12°3' north and longitudes 8°50' and 11° east. It is multiethnic and multilingual in nature with an estimated 55 tribal groups, with Hausa Language being the most widely spoken across all parts of the state. The economy is driven essentially by agriculture and tourism apart from few manufacturing industries in iron, steel, water, ceramics, food and beverages. The vast fertile soil and water resources available in the state makes crops production and animal husbandry the main stay of its economy, coupled with the presence of the famous Yankari Game Reserve, which is said to be the biggest game reserve in West Africa [18].

The study was a cross-sectional survey of caregivers whose children had been diagnosed with CTB in Bauchi State, Northeastern Nigeria from January 1, 2011 to December 31, 2015 as recorded in the State Ministry of Health CTB database. The QOL was measured through face-to-face interviews with a sample of caregivers, using an internationally recognized tool developed and used by the WHO, the WHOQOL-BREF questionnaire [19]. It comprises of 26 questions, 24 of which are spread in four domains: physical, psychological, social relations, and environment. These domains consisted of seven, six, three, and eight questions respectively. The questions were measured on a five-point scale ranging from 1 to 5. The domain scores were scaled in a positive direction. The overall well-being of the respondents was dichotomized into poor or good based on WHO standard procedures. The remaining two questions are general: One linked to the self-perceived QOL and the other to contentment with health. Summed scale scores for all the items within the QOL measure were created. Additionally, transformed scale scores were also created as per the scoring instructions provided on the WHO-QOL BREF questionnaire. These were the scores used in the analysis.

All respondents had signed consent forms before being interviewed. The questions ascertained information on the caregivers' QOL and excluded all personal identifiers such as names, street addresses, and telephone numbers so as to ensure that the collected data remains confidential, in accordance with the general conduct of ethical biomedical studies as defined by the WMA Declaration of Helsinki in 1964 and revised in 2013 [20]. Information on CTB was extracted and reviewed retrospectively by the researchers, from the Bauchi State CTB database for the 5-year period, taking care to avoid double reporting.

The inclusion criteria included 1) only children aged 0 - 14 years old diagnosed by a physician with CTB, 2) all cases would have to meet WHO/National Tuberculosis Programme (NTP) case definition for CTB [15] [16], 3) all cases diagnosed and treated in any of the eight selected DOTS treatment centers, and, 4) all CTB cases diagnosed and treated between January 01, 2011 to December 31, 2015. Conversely, the exclusion criteria included: a) all children outside the 0 -14 year age range, b) all cases that have not met the WHO/NTP case definition for CTB, c) all CTB cases diagnosed and treated outside the NTP and/or within facilities that are not designated as DOTS treatment centers by the NTP, and, d) all CTB cases diagnosed before January 1, 2011 or after December 31, 2015.

The sample size for the study was determined using the formula, $n = \frac{z^2 pq}{r^2}$

[21]. The formula was utilized in a similar cross-sectional study conducted by [22] in order to assess the attitude of public health workers in Calabar, Cross River State of Nigeria, towards people living with HIV/AIDS using the AIDS attitude scale. Similarly, [23] used the formula to determine the sample size in an experimental study of HIV positive patients on care and treatment in Kisumu District, Nyanza Province, Kenya.

Assuming a non-response rate of 20%, the minimum required sample size was 53, where, 6% = proportion of Nigerian children aged 0 - 14 years diagnosed with TB in 2014 [24]. Therefore, the sample size for the study was 53 caregivers of CTB cases. Bearing in mind that Bauchi State has a total population of 6,056,519 people, 3 geopolitical zones, 20 Local Government Areas (LGAs), and 196 directly observed treatment, short-course (DOTS) treatment centers, a representative sample of these 53 caregivers of CTB cases were obtained using the multi-staged sampling technique. These were proportionally contributed by each of the 8 randomly selected DOTS centers through systematic random sampling technique [25].

3. Statistical Analysis

Data generated for this study was analyzed using SPSS version 21 [26]. Demographic characteristics of the respondents such as gender, age, and marital status were analyzed. The relationships between caregivers' QOL and the reporting of CTB were determined by MLR model. The reporting of CTB was measured as a dichotomous variable where 0 = no TB and 1 = TB present. Therefore, based on the sample size calculation above, 53 caregivers of CTB cases and 53 caregivers of children without CTB (controls) were randomly selected and interviewed face to face with the help of the WHO-QOL BREF questionnaire. The assumptions for this test include the fact that the dependent variable is dichotomous, and has been coded as such; all the variables in the WHOQOL-BREF questionnaire would be included in the analyses; and the fact that an adequate sample size would be calculated. All these assumptions were met.

4. Ethical Clearance

Permission to conduct this research was sought and obtained from Bauchi State Ministry of Health's Research Ethics Committee (HREC), after providing written assurances that the study would be strictly for academic research purposes and that its outcomes would be meted with utmost confidentiality. The ministry was further assured that identifiers such as the name of CTB patients, their parents and/or caregivers, addresses were coded to safeguard against identification by people outside the research community. Secondly, each of the potential participants was adequately informed about the study to enable him/her decide whether to participate or not. For those who agreed to participate, a written consent was obtained from each one of them in line with ethical standards [20].

5. Results

Out of the 53 invited caregivers of CTB cases, a total of 47 (88.7%) agreed to participate and were interviewed by the researchers face to face in their communities of residence after signing an informed consent form. Similarly, the same number of caregivers without TB were interviewed in the same manner and setting as control population. Thus, the data obtained from the 94 interviewed caregivers was subjected to descriptive and inferential statistics using the SPSS version 21. As shown in **Table 1**, majority of the respondents in both groups were males (63.8% and 57.4%), young within the reproductive age group of 18 - 49 years (76.6% and 80.8%) and married (80.9% and 83.9%). However, respondents whose children had no TB appear to be more educated, as 34 of them (72.4%) either attended high school or college, than those whose children had TB, where less than half of them (23% or 49%) attended either high school or college.

Furthermore, the mean and standard deviation (SD) for overall QOL rating as well as for those of the other four QOL domains for the respondents (each of the two groups separately and then combined) have been determined with the help of SPSS. For instance, the overall QOL rating for respondents whose children do not have TB appears to be higher (mean 7.87 and SD 1.84) as compared with that of respondents whose children have TB (mean 6.85 and SD 1.37). This difference was statistically significant (p < 0.01) as shown in **Table 2**. Likewise, the scores for each of the four QOL domains were higher in respondents whose children do not have TB than in respondents whose children have TB and these differences were statistically significant (p < 0.01). These findings suggest that respondents whose children do not have TB have higher QOL than those whose children have TB.

Demographics		Number of Children with TB	Number of Children without TB	% Children with TB	% Children without TB	Total
Gender	Male	30	27	63.8	57.4	57
	Female	17	20	36.2	42.6	37
Age	18 - 29	15	16	31.9	34.0	31
	30 - 39	13	12	27.7	25.5	25
	40 - 49	8	10	17.0	21.3	18
	50 - 59	7	8	14.9	17.0	15
	60+	4	1	8.5	2.1	5
Marital Status	Single	4	3	8.5	6.4	7
	Married	38	39	80.9	83.0	77
	Divorced	2	2	4.3	4.3	4
	Widowed	3	3	6.4	6.4	6

Table 1. Demographic characteristics of respondents.

Table 2. WHO QOL scale table of means for children with and without TB.

	Children with TB		Children without TB		Total		n value
	Mean	Standard Deviation	Mean	Standard Deviation	Mean	Standard Deviation	p-value
Overall QOL Rating	6.85	1.367	7.87	1.837	7.36	1.690	0.003
Physical Health Scale Score (Transformed)	58.51	11.38	72.26	20.89	65.39	18.11	0.000
Psychological Health Scale Score (Transformed)	55.14	11.53	63.65	15.80	59.40	14.41	0.004
Social Relationships Score (Transformed)	57.09	15.44	67.73	14.50	62.41	15.83	0.001
Environmental Score (Transformed)	47.88	11.51	69.15	14.71	58.51	16.94	0.000

6. Discussion

The purpose of the study was met through face to face interviews with both caregivers of children with TB and caregivers of children without TB, administered using the WHOQOL-BREF questionnaire. Majority of the caregivers in both groups were males (63.8% and 57.4%). This finding contrasts with similar studies that showed a majority of the caregivers of children with chronic diseases to be females [27] [28]. Furthermore, majority of the caregivers in both groups

were young within the 18 - 49 age group (76.6% and 80.8%) and married (80.9% and 83.9%). However, caregivers of CTB cases had a lower literacy level (as only 49% of them attended either high school or college) compared with the control group, where 72.4% of them attended either high school or college. These findings were similar to those discovered in India and Egypt that also found low literacy levels among caregivers of CTB cases [29] [30].

The overall QOL for respondents whose children do not have TB appears to be higher (mean 7.87 and SD 1.84) compared with respondents whose children have TB (mean 6.85 and SD 1.37). This difference was statistically significant (p <0.01). Likewise, the scores for each of the four QOL domains were higher in respondents whose children do not have TB than in respondents whose children have TB and these differences were statistically significant (p < 0.01). These findings suggest that respondents whose children have TB have impaired QOL compared with those whose children do not have TB. This is consistent with the findings of several studies that measured the QOL of adult caregivers whose children suffered from chronic diseases such as osteogenesis imperfecta [27], sickle cell disease [31], cancer [32] [33], disabilities, Down's syndrome [34], speech and language disorders [35], COPD [28], and schizophrenia [36]. All these studies revealed that the caregivers of the diseased children had impaired QOL compared with control populations.

Thus, the QOL of women of child bearing age, parents and other caregivers should be improved, since this would have a direct relationship to the well-being of their children. This is even more expedient given the patriarchal nature of our society, where men tend to dominate over women in all aspects of life [37]. Improving the QOL of women in a patriarchal society entails giving them proper atmosphere where they can voice their opinions against inequalities and the gender-gap they are going through as well as improving their status in every aspect [37].

Moreover, improvement in the QOL of caregivers would involve multiple sectors other than health such as food security, housing, security of lives and property, provision of clean drinking water, qualitative education, and creation of jobs. Clearly, these are responsibilities of policy makers holding political offices. For the health sector, public health authorities should give priority attention to health promotion activities, preventative and curative health care services.

7. Study Limitations

Limitations of this study are those inherent in cross sectional designs such as selection and information (interviewer) biases as well as confounding [38]. The former was controlled through randomization of the study participants while the latter was controlled because the author personally interviewed all the study participants face to face using a standard valid tool, the WHOQOL-BREF questionnaire, thereby reducing differential misclassification to the barest minimum [38]. Confounding was controlled by matching the age and gender of each child with TB with another child without TB [39]. This ensured that the study participants do not differ significantly with respect to possible confounders of age and gender.

8. Conclusion

This study found a statistically significant relationship between the caregivers' QOL and reporting of TB in their children there by establishing a vital evidence for all stakeholders to put all hands on deck towards improving the QOL of caregivers, including empowering them socio-economically as a panacea for the prevention and control of TB in their children. This research study should, however, be replicated in other parts of the country in order to determine if findings would significantly differ between one region/state to the other, in view of the multiethnic and multicultural nature of Nigeria.

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Conflicts of Interest

The authors wish to declare that there is no any conflict of interest or royalty attached to this study.

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