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ORIGINAL RESEARCH

Level of Family Support and Associated Factors Among Pulmonary Tuberculosis Patients in Eastern Uganda. A Baseline Cross-Sectional Study

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Background: The long treatment period for tuberculosis (TB) is associated with multiple challenges, some of which can be resolved through involving the patients' families in TB management. In Uganda, there is limited evidence on the extent to which family caregivers are supporting TB patients to achieve better outcomes. This study's aim was to determine the level of family support and associated factors among pulmonary tuberculosis (pTB) patients.

Methods: This was a cross-sectional baseline survey conducted at 5 TB treatment centers in Jinja, Eastern Uganda. We recruited 147 pTB patients on the first line of treatment. Data was collected on socio-demographics and clinical characteristics, as well as perceived and actual family support using semi-structured questionnaires. Data analysis involved both descriptive and inferential statistics, with p-values, odds ratios, and corresponding confidence intervals, as well as the β-coefficient computed. Variables with p-value ≤0.05 were significantly associated with family support.

Results: About two in three (68.7%) of patients perceived a high level of support from their family members. Actual family support was received by 78.9% while 21.1% did not receive any form of support from their family members. The common forms of actual support received were medication reminders (65.3%), material support (55.8%), encouragement to take TB drugs (48.3%), emotional support (21.8%), and help with prescription refills (21.8%). The regression model explained two-thirds (63.9%) of the variance observed within the scores of perceived support [R^2 = 0.639, p-value <0.0001]. Family size was significantly associated with both perceived and actual family support.

Conclusion: Family caregivers play a vital role in assisting patients during the prolonged TB treatment period to overcome TB and treatment-related challenges. Healthcare providers should routinely assess the level of different forms of patient support and integrate routine family counseling sessions into TB care to improve support availability among TB patients.

Keywords: pulmonary tuberculosis, family support, family members, tuberculosis treatment, family-centered, family engagement

Background

Tuberculosis (TB) is a disease of global and public health concern, accounting for over 10 million new infections annually and 1.25 million deaths in 2023.[1,2] The highest infection rates and slowest progress in TB elimination have been registered in Sub-Saharan Africa, and despite national efforts, Uganda is experiencing an approximate notification rate of 200 in every 100,000 of the population, making the country one of the 30 highly affected countries contributing to 87% of the global disease burden.[2,3] Data from eight districts in Central Uganda indicate a treatment success rate of 72.5%,[4] which is below the national and global targets. In Jinja, Eastern Uganda, a high case notification rate ranging from 225 to 419 per 100,000 population, coupled with a low TB treatment success rate (<70%), has resulted in increased suffering and mortality.[5] Human Immuno-deficiency Virus (HIV) has been one of the key drivers of the TB epidemic, contributing to high levels of TB-associated deaths, and in Uganda, varying levels of mortality have been demonstrated, with patients diagnosed with drug-resistant TB/HIV having a mortality rate of up to 33.2%.[6,7]

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Following the diagnosis of TB, psychological and mental distress are common among patients[8] and could challenge the patient's ability and strength to initiate and maintain treatment. More so, some patients become physically debilitated, some are dismissed from their jobs, and others subsequently deteriorate, experiencing poor quality of life,[9] an indicator that TB can have a multi-dimensional effect on an individual's well-being.[10–12] The management of tuberculosis (TB) is characterized by patients undergoing several months of treatment[13] requiring several visits to healthcare facilities for clinical evaluation and medication refills. Throughout the treatment program, patients face several challenges, and in Uganda, it has been demonstrated that financial losses, social stigmatization, lack of social support services, sub-optimal TB treatment and referral services, as well as limited access to community TB support services,[14–16] have greatly affected the continuity of TB care.

Discontinuation of care and poor adherence[17] to TB treatment have hindered the appropriate management and control of TB disease, resulting in treatment failure and increased mortality.[4,18–20] Regardless of highly efficacious TB drugs, low screening rates, loss to follow-up, poor treatment adherence, treatment failure, and the emergence of drug-resistant TB have greatly affected the success of the TB programs in Uganda.[4,6,21,22] Moreover, there is limited availability of dedicated human resources to effectively implement treatment programs such as community-based, directly observed therapy[23] and family integration into TB care, and as such, Uganda is grappling with treatment failure and an increase in TB drug resistance.[5,22,24] This may therefore require the re-designing of the approach through which TB care is being provided for optimization of therapeutic outcomes.

Patients initiated into the TB treatment program require optimal support to overcome the challenges faced for better adherence rates and access to care without disruption. The patients' family members play a vital role in caring for TB patients, serving as a support system at every stage of patient care.[25] A family-centered strategy, therefore, involves integrating family members into the care process while providing them with the resources required to assist patients in optimizing their access to TB care. Evidence indicates that patients living in homes with other people are more likely to follow instructions as advised by the care provider.[26–28] Furthermore, a review conducted among High-Income Countries with low TB incidence indicates that homeless individuals with no immediate family support are more likely to have poor treatment adherence.[29]

The challenges within the TB treatment programs are typical of any chronic illness where self-management, control, and the use of social and health system support services are vital in maintaining the demands of lengthy care needs to improve patient outcomes.[30,31] The WHO notes that to control the TB epidemic, it is vital to deliver high-quality, acceptable, people-centered care with well-planned task shifting to ensure community engagement and continuity of care.[32] It is, however, of great concern that although family caregivers are involved in processes such as directly observed therapy (DOT),[33,34] they are not fully trained and supported by the healthcare system to take on such patient support roles.[35,36] This has hindered community-based patient follow-up, resulting in poor coordination of TB care and abandonment of the treatment regimen by some patients,[15] indicating a high need for consolidated efforts from the healthcare system toward promoting family and community-based TB engagement programs.

Family members can serve as a support system, providing emotional and psychosocial support and motivating patients.[37] More evidence from other studies indicates that family support to TB patients can be highly variable, ranging from nutritional, emotional, and spiritual support, to material and infection control support.[38–41] However, due to resource limitations, the healthcare system in Uganda has primarily focused on utilizing family caregivers as medication supervisors,[27,42,43] which further limits the understanding and optimal utilization of other dimensions of family support in improving TB care.

It is the role of the healthcare providers, in collaboration with the patient, to communicate clearly the treatment plan to the family. Failure to do so can result in sub-optimal support from the family members. Poor cooperation between the patient and his/her family members can result in strained roles and relationships with poor outcomes. For instance, in Ethiopia, it was found that when patients fail to communicate with their families about their TB diagnosis status, there is limited family involvement, and the likelihood of poor adherence is high.[44] Moreover, with inadequate engagement, family members can become a source of negative energy that could lead to patient stigmatization and subsequent adoption of non-adherence behaviors.[45] As such, variations in the level of family

support received by patients have been associated with various factors. For instance, patients living in larger families and those with high social status have been found to receive better support.[46] Poor support has been elaborated among patients with low levels of education and those in younger age groups.[47]

To improve TB treatment outcomes in Uganda, optimal engagement and support of family members is paramount. It provides a multi-faceted, readily available support network capable of resolving the social, physical, financial, psychological, and emotional challenges of the TB treatment program. In the Ugandan setting, evidence of family involvement and integration into TB care has largely focused on medication supervision,[35,36] with a limited view of family other support roles, and yet support can take on different forms.[48] This, coupled with the paucity of literature on factors associated with family support during tuberculosis treatment in Uganda, limits the design and integration of family-centered TB care approaches towards improving treatment outcomes. This study, therefore, aimed at establishing the level of family support and the associated factors among pulmonary tuberculosis patients receiving TB care in Eastern Uganda.

Methods

Study Design, Study Period, and Setting

This was a cross-sectional baseline survey conducted among tuberculosis patients receiving care at five TB treatment centers in Jinja, Southeastern Uganda. The study took place from January 2024 to March 2024 to provide baseline data for the design and implementation of a family-based support intervention for TB patients. The health facilities included Jinja Regional Referral Hospital (JRRH), Bugembe, Walukuba, and Mpumudde Health Center Fours (HCIV), all operating in the Jinja City area, and then Buwenge General Hospital (BGH) located in the Jinja District local government. These treatment centers were purposively selected due to serving high volumes of TB patients. Jinja is one of the areas with a high TB notification rate in Uganda, ranging between 200 and 400 for every 100,000 people.[5] Jinja Regional Referral Hospital is a tertiary referral Center for the Southeastern sub-region of Uganda, known as the Busoga sub-region, receiving patients from all primary healthcare facilities in this area. Being a tertiary referral hospital, it serves a catchment population of about four million people.

Study Population, Sample Size, and Sampling Procedure

The study population included patients diagnosed with pulmonary tuberculosis (pTB) and initiated on the first line of TB treatment, which includes Rifampicin, Isoniazid, Pyrazinamide, and Ethambutol (RHZE). The study included patients aged 18 years and above, and patients were enrolled at ≥2 weeks of treatment initiation. Individuals with extra-pulmonary TB, those initiated on drug-resistant TB treatment, those admitted at the time of the study, or re-initiated on treatment due to previous treatment failure were excluded from the study. The sample size was initially determined for an interventional study targeting to utilize a family-based support intervention to improve TB treatment adherence. However, given that family support was a key research focus in this study, the same sample size was used to explore its relationship with relevant factors. The total number of participants was estimated using a two-proportion-difference hypothesis (2-sided test), considering the first treatment adherence proportion (p1) as 65% and the second treatment adherence proportion (p2) as 85%. The sample was calculated to attain a power of 80% and a two-sided probability of type one error of 5% using the formula $n = \frac{(Z\alpha/2xZ\beta)^2 \times \{p1(1-p1)+p2(1-p2)\}}{(p1-p2)^2}$.

Where n = sample size needed for each group, p = estimated adherence proportions, and Z = 1.96, which is the value from the standard normal distribution at a 95% confidence level. Consecutive sampling was used to enroll participants in the study until the desired sample size (140) was obtained. All patients who visited the health facilities within the study period to refill their TB drugs and met the eligibility criteria were recruited.

Study Variables

The independent variables included socio-demographic features, treatment-related factors, and the patient's clinical characteristics. The outcome variable was family support, which was divided into two forms, perceived family support (PFS) and actual family support (AFS).

Conceptual Definitions

In this study, the term family support was categorized into two forms: perceived family support and actual family support. Perceived family support was defined as the patient's subjective appraisal of and belief in the availability of assistance from family members. Actual family support was defined as observable actions of family members aimed at assisting patients. These included emotional support, material support, encouragement, helping with prescription refills, and providing medication reminders.

Data Collection Tool and Procedures

Information was obtained from participants through interviewer-administered semi-structured questionnaires by face-to-face interviews. The questionnaire was structured to capture socio-demographic features, treatment-related characteristics, clinical characteristics, and family support. Patient responses were entered directly into a mobile data collection application known as KoboCollect. Perceived family support was assessed using eight items (Supplementary Table 1), adapted from the Multidimensional Scale of Perceived Social Support (MSPSS).[49,50] Each scale item was graded on a 1-4-point Likert scale, with the support score ranging from 8 points to 32 points. Lower scores on the scale indicated a lower perceived family support, and higher scores indicated a higher perceived family support. The different types of actual family support were assessed based on the common forms found in the literature.[51] Data was collected by asking patients to identify any ways in which their family members are supporting them during their TB treatment period.

Validity and Reliability

The questionnaire was reviewed by the research supervisors and TB treatment experts to ensure that the content and constructs included were valid in assessing family support. A pretest on 10 TB patients was conducted at a different treatment center to determine and enhance face validity. The data from the pretest was not included in the final analysis. The pre-test data also allowed the team to identify areas of potential interviewer bias and then research assistants were trained on the data collection process to minimize bias during the interviews. The MSPSS scale is a reliable tool in assessing perceived family and social support with a Cronbach's alpha of 0.91, with the subscale of perceived family support scoring 0.85.[52] In our study, the PFS scale had a strong level of internal consistency, as indicated by Cronbach's alpha coefficient of 0.93.

Data Management and Analysis Procedures

The analysis process was performed using SPSS version 25. Descriptive statistics included median for all continuous variables, as well as frequencies and percentages for all categorical variables. Patients were categorized as having a high perceived level of family support if they scored 22 to 32 points on the support scale. Patients with a score ranging from 8 to 21 points were classified as having a low level of perceived family support. The data was visually presented via bar charts and frequency distribution tables. The different forms of family support received were quantified as dichotomous proportions and presented in a bar chart. We used the Shapiro–Wilk and the Kolmogorov–Smirnov tests to check for the distribution of the perceived support scores. We found that the data violated normality ($p<0.0001$) and therefore the Mann–Whitney *U*-test was used to compare the scores on the support scale with the different socio-demographic and clinical characteristics. To determine the variables associated with perceived family support, stepwise linear regression was performed considering the R^2, β-coefficients, and p-values (≤ 0.05). We checked for multi-collinearity and obtained a variance inflation factor (VIF) of <5 and a tolerance of >0.1 for all the independent variables. To determine the variables associated with the availability of actual family support, binary logistic regression analysis was performed, considering p-values (≤ 0.05), odds ratios, and the corresponding confidence intervals. The Hosmer-Lemeshow test of

goodness of fit was conducted for all the types of family support and their corresponding independent variables, and p-values >0.05 were obtained.

Ethical Considerations

The study was reviewed and approved by the Mbale Regional Referral Hospital Research and Ethics Committee (reference number MRRH-2023-358) and the Mount Kenya University (MKU) Institutional Ethics and Research Committee (permit number 2394). Further approval was obtained from the Uganda National Council of Science and Technology (registration number HS3583ES). The researchers further obtained administrative authorization from the Jinja District Local Government, the Jinja City Council, and all the TB treatment centers involved. Patients were given comprehensive information regarding the study to enable them to make an informed decision regarding their participation in the study, and every participant who took part in the study provided written informed consent. The electronic case report forms used in data collection were assigned unique participant identifiers and therefore did not capture patient-identifying information. Paper documents containing patient information were kept under lock and key, only accessible to the study team. All study procedures were conducted following good clinical practices, and the researchers were guided by the fundamental ethical principles of the Declaration of Helsinki.

Results

Comparison of Participants' Characteristics and Perceived Family Support

A total of 147 patients diagnosed with pulmonary tuberculosis and initiated on the first line of TB treatment were enrolled in this study. Regarding socio-demographic characteristics, only family size resulted in significantly different scores on the support scale. Patients residing in homes with 1–3 people had a median score of 21 points, and patients in homes with 4 or more people had a median score of 27 ($p<0.0001$). For clinical characteristics, patients with clinically diagnosed pulmonary TB ($p=0.030$), patients who did not miss any medication refill appointments ($p=0.005$), and those who were using other medicines in addition to TB drugs at the moment ($p=0.032$) obtained significantly higher median scores on the support scale than their counterparts as indicated in Table 1.

Table 1 Comparison of Perceived Family Support with Socio-Demographic and Patient Clinical Characteristics

Variables	Frequencies	Percentages (%)	Median Scores (Total 26)	U statistic	Z-score	p-value
Socio-demographic characteristics						
Residence						
Jinja	94	63.9	26.0	2223.000	−1.084	0.278
Elsewhere	53	36.1	24.0			
Age in years						
Young adults (18–35)	72	49.0	26.0	2662.000	−0.148	0.883
Middle aged & older adults (>35)	75	51.0	26.0			
Gender						
Male	82	55.8	25.5	2448.000	−0.849	0.396
Female	65	44.2	26.0			
Marital status						
Married	65	44.2	25.0	2432.000	−0.911	0.362
Single	82	55.8	26.5			

(*Continued*)

Table 1 (Continued).

Variables	Frequencies	Percentages (%)	Median Scores (Total 26)	U statistic	Z-score	p-value
Level of education						
≤ Primary	80	54.4	26.0	1817.000	−0.878	0.380
≥ Secondary	67	45.6	24.5			
Source of income						
Yes	30	20.4	25.0	1490.000	−1.277	0.201
No	117	79.6	27.0			
Family size						
1–3 people	48	32.7	21.0	1346.000	−4.267	<0.0001
≥ 4 people	99	67.3	27.0			
Clinical characteristics						
HIV status						
Positive	93	63.3	26.0	2311.000	−0.806	0.420
Negative	54	36.7	26.0			
TB disease categorization						
Bacteriologically Confirmed TB	119	81.0	25.0	1226.000	−2.174	0.030
Clinically Diagnosed TB	28	19.0	28.0			
Missed medication refills						
Yes	54	36.7	21.0	1810.000	−2.825	0.005
No	93	63.3	27.0			
Having other diseases						
Yes	71	48.3	25.0	2488.000	−0.814	0.415
No	76	51.7	26.0			
Taking other medications						
Yes	108	73.5	28.0	1617.500	−0.2149	0.032
No	39	26.5	25.5			

Level of Family Support Received by TB Patients

For perceived family support, about two in three (68.7%) of the patients perceived a high level of family support (Figure 1). The median score on the support scale was 26.0 (Interquartile range = 9.0), with a minimum of 8.0 points and a maximum of 32.0 points. Highest total scores were obtained in the statements "being able to get the help needed from someone in the family" followed by "having a special person who cares about the patient's feelings" and lowest total scores were observed under the statement; "there has been someone in my family willing to help me make decisions" as indicated in Table 2.

Regarding the level of actual family support received by patients, the study revealed that family members assist in reminding patients to take their medications, offering tangible material assistance, promoting medication adherence through encouragement and emotional support, and aiding patients in refilling their medications as per the clinic schedules. The commonly available form of assistance received by patients was medication reminders (65.3%), followed by material support (55.8%). About one in five (21.1%) of the patients reported that they did not receive any kind of support from their family members, as indicated in Figure 2. Receiving any form of support from family members was associated with significantly higher scores in perceived support, as illustrated in Table 3.

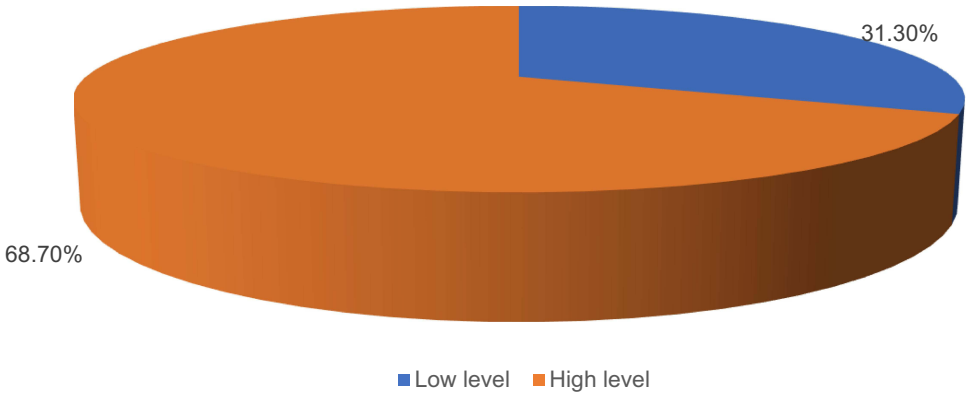

Figure 1 Proportion of TB patients with high and low perceived family support.

Factors Associated with Family Support

Linear regression analysis established family size, prescription refill appointments, availability of any form of actual family support, and use of multiple drugs during the TB treatment period as independent predictors of perceived family support. Patients who did not receive any form of actual support from their family members experienced, on average, a decrease of 6.203 points on the perceived support scale. The regression model explained two-thirds (63.9%) of the variance observed within the scores of perceived family support, [R^2 = 0.639, p-value <0.0001] (Table 4).

Different independent variables were found to be associated with the five major forms of actual family support, as illustrated in Table 5. Across these dimensions of support, family size, attendance of medication refill appointments, and the nature of the family caregiver available were common predictors of actual family support. The significantly associated factors included; family size, missing refill appointments, spouse and parent as family caregivers for

Table 2 Patient Responses and Distribution of Scores on the Perceived Family Support Scale

Family Support Statements	Patient Responses, n (%)			
	Strongly agree =4	Agree = 3	Disagree = 2	Strongly Disagree = 1
In the past 2 weeks, there has been a special person who is around when I am in need.	46(31.3)	64(43.5)	25(17.0)	12(8.2)
In the past 2 weeks, there has been a special person with whom I can share my sorrows	59(40.1)	43(29.3)	37(25.2)	08(5.4)
In the past 2 weeks, my family has really tried to help me	62(42.2)	44(29.9)	35(23.8)	06(4.1)
In the past 2 weeks, I have got the help I needed from someone in my family	55(37.5)	63(42.9)	24(16.2)	05(3.4)
In the past 2 weeks, I have had a special person who is a real source of comfort to me	57(38.8)	54(36.7)	27(18.4)	09(6.1)
In the past 2 weeks, I have been able to talk about my problems with someone in my family	57(38.8)	54(36.7)	26(17.7)	10(6.8)
There is a special person in my life who cares about my feelings	60(40.8)	57(38.8)	22(15.0)	08(5.4)
In the past 2 weeks, there has been someone in my family willing to help me make decisions	56(38.1)	43(29.2)	31(21.1)	17(11.6)

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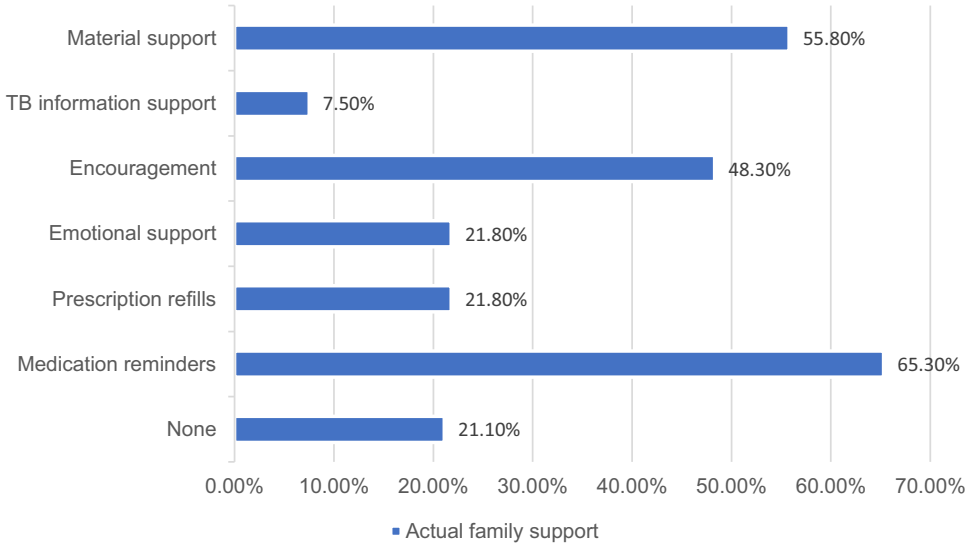

Figure 2 Proportion of TB patients receiving the various types of actual family support.

medication reminders; family size, missing of refill appointments, residence and age for assistance with refilling medications; parents as the family caregiver for encouragement, family size for emotional support, as well as parents and siblings as family caregivers for material support (Table 5). For both perceived and actual family support, family size was an important factor.

Table 3 Patients Receiving Any Form of Tangible Family Support Are Experiencing High Levels of Perceived Family Support

Actual Family Support Parameters	Frequency (%)	Median	U statistic	Z-score	p-value
Receipt of any form of family support					
Yes	116(78.9)	24.0	178.000	−7.715	<0.0001
No	31(21.1)	29.0			
Material support					
Yes	82(55.8)	28.0	1291.000	−5.374	<0.0001
No	65(44.2)	20.0			
Encouragement					
Yes	71(44.3)	29.0	865.500	−7.112	<0.0001
No	76(51.7)	21.0			
Emotional support					
Yes	40(27.2)	29.0	925.000	−5.304	<0.0001
No	107(72.8)	23.0			
Helped with prescription refills					
Yes	32(21.8)	29.0	895.000	−4.449	<0.0001
No	115(78.2)	24.0			
Received medication reminders					
Yes	96(65.3)	28.0	830.500	−6.601	<0.0001
No	51(34.7)	19.0			

Table 4 Stepwise Linear Regression Model Indicating the Independent Predictors for Perceived Family Support

Variables	β Coefficients	p-value	95% CI
Increase in family size	1.714	0.001	0.722–2.705
Missing prescription refill appointments	2.330	0.002	0.834–3.825
Failure to receive any form of family support	−6.208	<0.0001	−8.021—4.394
Receiving encouragement	3.378	<0.0001	2.011–4.744
Use of other medications	−1.646	0.018	−3.002—0.290

Table 5 Logistic Regression Analysis Indicating Factors Associated with Actual Family Support

Support Parameters /Independent Variables	COR (95% CI)	P-value	AOR (95% CI)	P-value
Received reminders for medication intake				
Family size 1–3 people 4 or more people	0.286(0.138–0.591)	0.001	0.254(0.109–0.592)	0.001*
Missing refill appointments Yes No	4.085(1.973–8.458)	0.000	3.934(1.724–8.978)	0.001*
Age Young adults Older adults	1.610(0.815–3.218)	0.169	0.805(0.314–2.061)	0.651
Spouse as a family caregiver Yes No	0.603(0.288–1.264)	0.181	0.339(0.131–0.879)	0.026*
Child/children as a family caregiver Yes No	1.892(0.836–4.280)	0.126	1.275(0.411–3.952)	0.674
Parent(s) as family caregiver(s) Yes No	0.223(0.091–0.545)	0.001	0.181(0.057–0.57)	0.004*
Helped with medication refills				
Family size 1–3 people 4 or more people	0.310(0.111–0.865)	0.025	0.279(0.088–0.886)	0.030*
Missing refill appointments Yes No	3.78(1.35–10.56)	0.011	7.954(2.193–28.850)	0.002*
Siblings as next of kin Yes No	0.455(0.17–0.126)	0.130	0.316(0.072–1.378)	0.125

(*Continued*)

https://doi.org/10.2147/JMDH.S511615

Table 5 (Continued).

Support Parameters /Independent Variables	COR (95% CI)	P-value	AOR (95% CI)	P-value
Friends as next of kin				
Yes				
No	4.650(0.59–36.63)	0.144	8.295(0.802–85.832)	0.076
TB disease category				
PBC				
PCD	0.506(0.203–1.262)	0.144	2.263(0.718–7.133)	0.163
Residence				
Jinja				
Elsewhere	2.108(0.951–4.672)	0.066	2.740(1.001–7.504)	0.050*
Age				
Young adults (18–35)	0.323(0.138–0.758)	0.009	0.137(0.045–0.413)	0.000*
Older adults (>35)				
Received encouragement				
Parents as Next of kin				
Yes				
No	0.260(0.124–0.547)	0.000	0.316(0.142–0.705)	0.005*
HIV status				
Positive				
Negative	1.827(0.924–3.615)	0.083	1.704(0.772–3.759)	0.187
Disease category				
PBC				
PCD	2.720(1.137–6.505)	0.024	2.194(0.827–5.819)	0.115
Education level				
No formal schooling	1.619(0.841–3.116)	0.149	1.783(0.824–3.862)	0.142
Attained formal education				
Occupation				
Employed				
Unemployed	1.811(0.801–4.097)	0.154	1.667(0.778–3.572)	0.189
Family size				
1–3 people	0.457(0.224–0.931)	0.031	1.403(0.559–3.522)	0.470
3 or more people				
Missed refills				
Yes				
No	2.528(1.253–5.123)	0.010	0.483(0.219–1.068)	0.072
Received emotional support				
Siblings as next of kin				
Yes				
No	0.505(0.190–1.347)	0.172	0.380(0.118–1.226)	0.105
Parent as next of kin				
Yes				
No	0.527(0.248–1.122)	0.097	0.655(0.267–1.607)	0.355

(*Continued*)

Table 5 (Continued).

Support Parameters /Independent Variables	COR (95% CI)	P-value	AOR (95% CI)	P-value
Experiencing pain as a side effect Yes No	2.128(1.010–4.483)	0.047	1.683(0.674–4.199)	0.265
Marital status Married Single	1.691(0.797–3.589)	0.171	1.322(0.547–3.194)	0.535
Family Size 1–3 people 4 or more people	0.213(0.077–0.586)	0.003	0.215(0.074–0.622)	0.005
Number of side effects 0–2 3 or more	1.892(0.906–3.953)	0.090	1.380(0.556–3.430)	0.488
Missed refills Yes No	1.979(0.875–4.479)	0.101	2.068(0.823–5.197)	0.122
Received material support				
Family size 1–3 people 4 or more people	0.707(0.354–1.413)	0.326	0.849(0.393–1.833)	0.676
Missing refill appointments Yes No	1.665(0.842–3.291)	0.143	1.578(0.746–3.339)	0.233
Gender Male Female	1.524(0.787–2.952)	0.212	1.525(0.738–3.151)	0.254
Residence Jinja Elsewhere	1.715(0.859–3.426)	0.127	1.548(0.732–3.273)	0.253
TB Disease category PBC PCD	1.877(0.785–4.483)	0.157	1.739(0.687–4.400)	0.243
Nausea and vomiting Yes No	1.611(0.810–3.204)	0.171	1.592(0.746–3.399)	0.229
Parent as a family Caregiver Yes No	0.408(0.195–0.853)	0.017	0.451(0.205–0.991)	0.047*
Sibling(s) as caregiver Yes No	0.270(0.086–0.854)	0.026	0.248(0.071–0.862)	0.028*

Note: *Factors significantly associated with actual family support.

Discussion

Tuberculosis is an infectious disease capable of traversing socio-economically constructed boundaries while causing individual and family suffering due to physical, emotional, financial, social, and psychological challenges associated with the disease.[9,53,54] The family is an indispensable source of support to TB patients, ensuring that the disease is adequately controlled while protecting and supporting the patient to overcome the associated challenges for a better quality of life.[55,56] Although TB can cause social disruption, oftentimes the care provided is not family-oriented, with a high need to establish the extent to which the patients' family members are involved in supporting the TB care processes.[57] This study's objective was therefore to determine the level of both perceived and actual family support and the associated factors to provide essential evidence for guiding the design and implementation of family-centered patient support initiatives towards improving TB care in Jinja, Eastern Uganda.

In this study, we found that two in three of our patients perceived a high level of support from their family members. This means that for every three patients, one patient felt neglected by close relatives, leaving such a group unprotected from various challenges arising from TB. Perception of support is very important given that it can influence an individual's decision to take on self-management measures or discontinue the treatment plan. The perceived support level in our study is higher than that reported in other settings, such as India (49.7%).[47] The variation may be attributed to differences in the scale scoring system used in the two studies, but could also be explained by disparities in the specific needs of each patient and their distinct social-cultural organization. Ugandan societies hold family dear, and given that people live in extended family set-ups, there are several family members who could serve as a source of support as perceived by the patient.

Actual family support can be expressed in various objective forms, as our patients indicated that they received assistance in the form of medication reminders, encouragement, emotional support, help with drug refills, and material support. In other settings, these have been highlighted among the forms of assistance desired by TB patients during their treatment period[39] and they are critical, especially in promoting motivation toward achieving optimal adherence to TB treatment.[58] The diverse range of support provided suggests that family caregivers in our study possess a comprehensive grasp of the various patient needs, enabling them to coordinate the resolution of the challenges faced. Additional research has shown comparable findings, including the use of medication reminders, emotional support, and motivation, material resources,[59,60] and assisting patients in refilling their medication at the tuberculosis clinics.[61] Theofilou[62] also asserts that patients can receive assistance from their families in various tangible and subjective ways, highlighting the family's multifaceted role as a source of support, especially for patients with chronic diseases such as tuberculosis.

For the patient to be adherent to the treatment program, they have to feel capable, well-empowered, and confident to achieve self-management, and it has been found that patients' efficacy can be improved, especially through family support initiatives such as information-sharing, reminders, and encouragement.[63] It is therefore worrying that in our study, the most widely available form of support (medication reminders) was received by only 65.3% of the patients, and yet the levels of the different forms of actual support were highly variable, indicating divergence. Support may therefore not be readily available to some patients, as elaborated by one in five of the patients reporting failure to receive any form of tangible support from their families. Such a support deficiency relates to a high vulnerability to threats of demotivation, social isolation, stigmatization, lack of essential resources, risk of dropout from the treatment program, and potential for treatment failure. Similar to our findings, a study by Kilima et al[64] demonstrated that regardless of how vital family support can be in TB care, some patients may fail to access it.

Actual patient support levels in our study were lower than those observed in previous research studies. For instance, a study conducted by Nursasi et al found that 72% of individuals in Indonesia reported receiving satisfactory emotional support, while 68% reported receiving adequate material aid.[65] Elsewhere, emotional (79.2%) and informational support (56.8%) in Indonesia,[66] as well as receiving reminders (79.5%) in India[67] were found to be higher than in our study, further illustrating a potential for detrimental treatment outcomes among patients in our study due to limited tangible support levels. The observed differences could be due to variations in family sizes and differences in engagement and support strategies by healthcare providers, which affect the effectiveness with which the family in our setting can provide actual help to patients.

Family support is the main sub-category of social support, and the number of people living in a home categorized as family size defines the primary social network with which the patient interacts. In our study, family size was significantly associated with both perceived and actual family support available to TB patients. The bigger the family, the better the availability of actual support and the higher the level of perceived family support. This is an expected finding given that support takes up multiple dimensions, which can easily be performed well and therefore perceived by the patient if the family caregivers can complement each other's efforts, and this can only be achieved with many family caregivers. A larger family size translates into increased engagement in patient support activities such as helping patients refill their prescriptions, among others. Similar results were found in Pakistan and China, where patients from larger families were found to perceive higher support levels.[46,68] It is therefore of great concern that in our study, one in three (32.7%) of the patients resided in homes with <4 members, and yet this parameter is not only associated with perceived family support but also the availability of medication reminders, helping with refills and the presence of emotional support. Patients from small-sized households should undergo targeted interventions to enhance their accessibility to support and therefore perceive more help available to them and utilize the support to achieve self-management and better TB treatment outcomes.

The patient's clinical state can play a critical role in the availability of family and perception of family support. In the current study, we found that patients receiving other drugs in addition to TB treatment were more likely to perceive high levels of support. More so, clinically diagnosed TB patients who are more likely to be severely debilitated, weak,[69] and on multiple medicines obtained higher scores on the perceived support scale. This is key given that polypharmacy is common among the elderly[70] and the pill burden can result in increased side effects, thus becoming weaker and unable to attend to activities such as refilling their medication. It is therefore a vital finding that patients aged 35 years and above were more likely to be helped regarding prescription refills, as this could otherwise deter them from optimal adherence. Similar to this phenomenon were the findings in Meghalaya, where the elderly were more likely to perceive a higher level of support than their younger counterparts.[47] Therefore, the healthcare system should engage younger patients to ensure that they are optimally supported during their TB treatment regimen.

Families are comprised of different family members ranging from parents, spouses, children, siblings, and other distant relatives. In recent times, family caregivers have changed to reflect family composition, involving various stakeholders including men, women, and children.[38,40,71] The various caregiver groups can contribute differently toward the support of TB patients. Patients who had their parents as family caregivers were more likely to receive material resources, encouragement for the use of TB medication, and being reminded of the use of TB drugs. Additionally, siblings and spouses contributed significantly to the availability of material resources and TB medication reminders, respectively, and this underscores the importance of having a composite family in patient care. The socio-cultural context in Uganda may therefore influence the nature of family support available and the extent to which the support influences the treatment program. For instance, in Ugandan communities, extended family networks and communal living are common,[72] with many people sharing responsibilities and support roles. This cultural dynamic may therefore enhance support availability and influence the types of tangible support provided in ways that differ from other individualistic societies.

Our research study is one of the few that have explored the concept of family support among TB patients in Uganda and provides great insights that can serve as a starting point in designing family-centered TB care models to promote family engagement in helping patients towards appropriate management of TB treatment. The study, however, has some limitations, which include: the assessment of family support was conducted in a hospital setting, which could have prevented the patients from expressing their actual perceptions as experienced in the home environment. More so, we utilized self-reported information; therefore, patients may have presented themselves in a favorable light, leading to socially desirable responses. These were mitigated by using a standard tool for family support assessment and assuring the patients that the information provided was confidential to promote honesty. Future studies should consider performing such assessments in environments relatively similar to the home settings. The researchers' cultural prejudices could have introduced cultural biases. All members of the research team were educated on the cultural diversity of Jinja and the need to maintain a neutral cultural perspective while collecting data. The recruitment of patients who visited the clinic as per their schedule could have introduced selection bias by excluding patients who did not come back to refill their drugs.

This was minimized by calling patients and reminding them of their refill appointments. Lastly, our study excluded patients with extrapulmonary TB and those on multi-drug-resistant TB treatment, due to these groups undergoing an intensive specialized treatment approach, characterized by a longer treatment duration, potential for several complications, and having diverse and complex support needs. The results may therefore not be a representation of support levels among these special groups of patients, indicating a need for more research focusing on these patients.

Implications for Practice, Research and Policy

In Jinja, family members have taken up multiple TB patient support roles, but the level of support needs progressive improvement. There is a need for healthcare providers to provide orientation and training for individuals partaking in such patient support roles to promote a multi-dimensional approach to patient support and address the multiple challenges faced by TB patients. These family engagement sessions should be made routine to ensure the identification and resolution of any challenges faced by both the patient and their attendants. Additionally, there is a need for high-level evidence to demonstrate the impact of healthcare provider-guided integration of family members in TB care on outcomes such as treatment adherence and quality of life. In resource-constrained settings like Uganda, policies should prioritize interventions that engage family members in providing comprehensive support to ensure that they are competent enough to promote support availability among TB patients beyond the limits of the healthcare system. Recognizing that family size and composition significantly impact support mechanisms, interventions must be adaptable to diverse family structures. For instance, although larger families may be more supportive of TB patients, the sustainability of the support may be limited by resource constraints, necessitating policies that provide additional financial or material assistance to ensure adequate support for patients from such family settings.

Conclusions

The support of TB patients by family members is a vital aspect of TB care. The family plays a significant role in assisting patients during the prolonged TB treatment period, and in Jinja, the support is multi-dimensional, which makes it an essential approach to handling the multiple challenges associated with TB disease and its treatment. Given that patients receiving poor support from their families are at risk of experiencing barriers towards optimal adherence to the treatment program, the healthcare system should routinely assess the availability of different forms of TB support and provide targeted interventions for improving the support levels. Routine counseling of family members regarding TB disease and its treatment should be integrated into the care pathway to improve the family's understanding for optimal patient support. Assessment of barriers to patient support should also be integrated into care to guide the interventions for promoting support availability. Patients residing in households with fewer members, and those living in homes without parents, spouses, or siblings, are at a greater risk of lower support levels, indicating the need for proactive counseling sessions for both patients and their attendants. Healthcare leaders should design a policy framework and procedures to guide the implementation of family engagement strategies into TB care, with more emphasis put on promoting routine support of patient attendants by the healthcare providers for effective family integration into the care process while ensuring sustainable involvement.

Data Sharing Statement

The data used to support the findings of this study are available from the corresponding author upon request.

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Author Contributions

All authors made substantial contributions to the conception, design, acquisition of data, analysis, and interpretation of data, took part in the drafting and revising of the manuscript, agreed to submit to the current journal, gave final approval of the version to be published, and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

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