

Perceived Burden and Family Functioning among Informal Caregivers of Individuals  
Living with Schizophrenia in Tanzania: A Cross-Sectional Study

by

Rosarito María José Clari Yaluff

Duke Global Health Institute  
Duke University

Date: \_\_\_\_\_

Approved:

\_\_\_\_\_  
Joy Noel Baumgartner, Advisor

\_\_\_\_\_  
Joseph Egger

\_\_\_\_\_  
Lauren Franz

Thesis submitted in partial fulfillment of  
the requirements for the degree of  
Master of Science in the Duke Global Health Institute  
in the Graduate School of Duke University

2021

ABSTRACT

Perceived Burden and Family Functioning among Informal Caregivers of Individuals  
Living with Schizophrenia in Tanzania: A Cross-Sectional Study

by

Rosarito María José Clari Yaluff

Duke Global Health Institute  
Duke University

Date: \_\_\_\_\_

Approved:

\_\_\_\_\_  
Joy Noel Baumgartner, Advisor

\_\_\_\_\_  
Joseph Egger

\_\_\_\_\_  
Lauren Franz

An abstract of a thesis submitted in partial  
fulfillment of the requirements for the degree  
of Master of Science in the Duke Global Health Institute  
in the Graduate School of Duke University

2021

Copyright by  
Rosarito María José Clari Yaluff  
2021

## **Abstract**

*Background:* Deinstitutionalization of persons with schizophrenia has led to families providing the majority of care and carrying the bulk of burden. There is a need to identify factors that influence caregiver burden in order to properly address the needs of caregivers. This is particularly important in low-resource settings, where psychiatric services are scarce and interventions for schizophrenia could be most effective if targeted to the affected individual and their caregiver. This study seeks to examine the association between family functioning and perceived burden in informal caregivers of individuals with schizophrenia in Tanzania and identify socio-demographic and illness-related factors that may be associated with caregiver burden in the study population.

*Methods:* This study analyzed cross-sectional data from 65 dyads of individuals with schizophrenia and their informal caregivers in Dar es Salaam and Mbeya, Tanzania. Caregiver burden was measured using the Burden Assessment Scale (BAS). Univariable and multivariable regression analyses were performed to determine the relationship between perceived caregiver burden and family functioning and explore correlates of burden among caregivers.

*Results:* Sixty-three percent of caregivers in our study reported experiencing high burden as a result of caring for a relative with schizophrenia. Multivariable regression analyses revealed that poor family functioning was a significant correlate of

high caregiver burden (OR = 4.79; 95% CI = 1.19, 19.32). Additionally, caregiver having worked in the past 3 months was associated with high caregiver burden (OR = 4.80; 95% CI = 1.14, 20.23), while higher levels of hope in the caregiver were associated with low caregiver burden (OR = 0.82; 95% CI = 0.70, 0.95). Although not included in the multivariable regression model, another factor that was linked to high caregiver burden was caring for a woman with schizophrenia (OR = 3.91; 95% CI = 1.13, 13.50).

*Conclusions:* We found that poor family functioning, caregiver having worked in the past 3 months, lower levels of hope in the caregiver, and caring for a woman with schizophrenia were correlates of high caregiver burden. Future interventions aiming to reduce caregiver burden may benefit from improving family functioning and nurturing hope among caregivers of individuals living with schizophrenia. We must pay special attention to the needs of caregivers that work in addition to providing care for a relative with schizophrenia in order to better support them.

## **Dedication**

I dedicate this thesis—the fruit of hard work, passion for scientific inquiry, and the desire to help others—to my parents. They have instilled in me the virtues of compassion and perseverance and relentlessly encouraged me to strive for excellence.

# Contents

Abstract .....	iv
List of Tables.....	ix
List of Figures.....	x
Acknowledgements.....	xi
1. Introduction.....	1
1.1 Study Aims.....	5
2. Methods.....	6
2.1 Setting .....	7
2.2 Participants.....	8
2.3 Procedures.....	10
2.3.1 Ethical Approvals & Informed Consent .....	11
2.3.2 Data Collection .....	12
2.4 Measures.....	12
2.4.1 Measures for Informal Caregivers.....	13
Socio-demographic Characteristics.....	13
Caregiver Burden.....	13
Family Functioning .....	14
Hope .....	14
Religiosity .....	15
2.4.2 Measures for Individuals Living with Schizophrenia .....	16

Socio-demographic and Clinical Characteristics .....	16
Symptom Severity .....	16
Disability/Functioning .....	17
Self-Efficacy .....	17
Internalized Stigma .....	18
Instrumental Support.....	18
2.5 Analysis .....	18
3. Results .....	20
3.1 Participant Characteristics .....	20
3.2 Correlates of Caregiver Burden .....	24
4. Discussion.....	30
4.3 Limitations .....	32
4.2 Implications for further research .....	34
4.3 Implications for policy and practice.....	35
5. Conclusion .....	37
Appendix A .....	38
References .....	39



## List of Tables

Table 1. Characteristics of Individuals Living with Schizophrenia Stratified by Sex.....	20
Table 2. Characteristics of Informal Caregivers Stratified by Sex .....	22
Table 3. Univariable Regression Models for Caregiver Burden Using Characteristics of Individuals with Schizophrenia and Informal Caregivers .....	26
Table 4. Multivariable Regression Model for Caregiver Burden Using Caregiver Characteristics .....	28

## List of Figures

Figure 1: Family Functioning Distribution by Caregiver Burden Level.....	24
Figure 2: Logistic Predicted Probability of Caregiver Burden by Family Functioning .....	25
Figure 3: Results from Multivariable Logistic Model Predicting Caregiver Burden .....	29

## **Acknowledgements**

I am extremely thankful to Dr. Joy Noel Baumgartner for her support and guidance throughout the thesis process, from its conception to completion. She has been an extraordinary mentor—honest, understanding, and invested in my well-being as much as my academic success. I am grateful to Dr. Joseph Egger for his incredible patience and statistical advice. Thanks to Dr. Lauren Franz for being on my thesis committee and providing me with valuable feedback. I was very fortunate to be part of the KUPAA team, an amazing group of Tanzanian and American researchers committed to conducting high-quality research and helping individuals living with psychotic disorders. I also want to acknowledge my favorite psychology professors and dear friends, Drs. Paul Dennis and Catherine Lemley, for always believing in me. Finally, I want to thank Nick Viscardi for being my constant source of strength and encouragement.

# 1. Introduction

Schizophrenia is a psychiatric disorder characterized by a combination of positive (e.g., delusions, hallucinations), negative (e.g., blunted affect, avolition), and cognitive symptoms (e.g., deficits in attention and memory).<sup>1</sup> The course of the illness is typically chronic and, if left untreated, can impact all major domains of an individual's life. It is estimated that 20 million people are affected by schizophrenia worldwide, many of them living in low-resource settings.<sup>2</sup> In the past 50 years, there has been a major global transition in psychiatric care from inpatient hospital-based care to community-based, outpatient care.<sup>3</sup> This shift has resulted in families providing the majority of care and support and thus often carrying the bulk of burden. In low- and middle-income countries, community-based health services are extremely limited, mainly due to a shortage of mental health professionals. Family involvement in psychiatric care thus plays an even bigger role in the recovery of individuals living with schizophrenia in these settings.<sup>4</sup>

Caregiver burden refers to the strain endured by a person who cares for a chronically ill individual. Although there has been much debate in the literature regarding the dimensions and attributions of the construct, a distinction has been made between objective and subjective burden.<sup>5</sup> Objective burden includes concrete costs to the caregiver, such as time and finances devoted to care. Subjective burden, in contrast, refers to the extent to which the caregiver feels the burden of care.<sup>6</sup> It is important to

draw attention to the negative connotation of the concept of burden, which obscures any positive experiences related to care. In fact, there is evidence suggesting that caregivers become more sensitive to persons with disabilities, gain insight into their life priorities, and experience a deeper sense of inner strength as a result of caring for an individual with schizophrenia.<sup>7</sup> We should therefore clarify that the present study is concerned with the negative effects of caregiving.

There is extensive evidence from high-income countries indicating that informal caregiving for an individual with schizophrenia is associated with poor mental, physical, social, and financial outcomes for the caregiver.<sup>8-12</sup> More recently, studies conducted in Sub-Saharan Africa have shown comparably high levels of caregiver burden, impacting similar domains. For example, a study in Ibadan, Nigeria found that caregivers of individuals with schizophrenia are at risk for mental disorders themselves.<sup>13</sup> Moreover, a systematic review of studies done in multiple African countries, including Ghana, Ethiopia, and South Africa, reported moderate to severe caregiver burden characterized by financial constraint, productivity loss, and lost employment.<sup>14</sup> In addition to severe psychological and financial burden, qualitative interviews conducted with caregivers of individuals with schizophrenia in Harare, Zimbabwe revealed physical and social burden associated with caregiving.<sup>15</sup>

There are certain socio-demographic and illness-related factors that can render caregivers of individuals with schizophrenia more vulnerable to experiencing burden.

Likewise, there are factors that can be protective against the consequences of the illness's impact on the caregiver. Studies on factors associated with burden among families or caregivers of a person living with schizophrenia in Africa are few and sparse. The literature suggests that caregivers who are female, older, with lower education levels are more likely to experience burden and that illness-related risk factors (i.e., greater illness severity, longer duration of illness) can exacerbate the experience of burden.<sup>13,16-19</sup> When it comes to potential protective factors, higher levels of income and social support have been linked to the caregiver's well-being.<sup>17,20</sup>

An important goal in the field of global mental health is to develop evidence-based interventions for individuals with schizophrenia that target not only the affected person but the family as a unit.<sup>4</sup> Given the significant involvement of family members in the psychiatric care of individuals with schizophrenia, it is imperative to address the needs of caregivers in conjunction with those of the affected persons. In order to develop such family-focused interventions, however, it is crucial to gain a deeper knowledge of the factors that are associated with perceived caregiver burden.

In Tanzania, to the best of our knowledge, there has been no research on this particular area. Considerable work is needed to elucidate specific factors that influence the extent of caregiver burden to recommend culturally-appropriate areas for supportive interventions. Studies conducted in Dar es Salaam, Tanzania, found that poor family and social support are significant determinants for relapse in schizophrenia.<sup>21,22</sup> A better

understanding of these factors can have important implications for the caregiver's well-being as well as for the affected individual's recovery and overall quality of life.

Among the factors that could impact perceived burden of caring for someone living with schizophrenia is family functioning.<sup>9,23</sup> Family functioning, broadly speaking, refers to the ways in which relationships operate in the family. Family functioning is believed to be central to the welfare of all family members; dysfunctional family processes can lead to psychological problems or conversely, positive and supportive family processes can facilitate therapeutic change.<sup>24</sup> Nevertheless, family functioning has often been overlooked in the literature, particularly in low-resource settings. Two of the studies that evaluated family functioning in relation to caregiver burden were conducted in China and Spain, respectively. Yu et al. (2017) demonstrated that higher family functioning, among other factors, was an important correlate of decreased family burden. In Spain, Ribé et al. (2018) showed that caregivers of individuals with schizophrenia with low levels of caregiver burden and high levels of family functioning tended to report better quality of life than their counterparts. The present study aims to address this gap in the literature by examining caregiver burden and family functioning in a Sub-Saharan African country.

The purpose of this study is to understand the levels of perceived burden among caregivers of individuals with schizophrenia and its relationship to family functioning in two different regions of Tanzania. Our hypothesis is that higher family functioning is

associated with lower perceived caregiver burden. In addition, we aim to identify other socio-demographic and illness-related factors that may affect perceived caregiver burden in this population. This research study represents an important first step towards understanding perceived caregiver burden and thus tailoring interventions to improve outcomes for individuals with schizophrenia and their relatives.

### **1.1 Study Aims**

This study has two aims. The primary aim is to evaluate the association between family functioning and perceived caregiver burden of individuals with schizophrenia in Dar es Salaam and Mbeya regions in Tanzania. The secondary aim is exploratory in nature and entails the identification of factors that are associated with perceived caregiver burden among the study population.



## 2. Methods

The data for this study come from the parent project entitled: “Family Psychoeducation for Adults with Psychotic Disorders in Tanzania,” a pilot randomized clinical trial (Clinicaltrials.gov # NCT04013932) which is funded by the National Institute of Mental Health (NIMH) [R34MH106663, PI: Baumgartner, JN]. This pilot study will inform a future fully powered R01 to test the effectiveness of a culturally-tailored Family Psychoeducation intervention for individuals with psychotic disorders and their relatives. Family Psychoeducation is an evidence-based practice for high-income settings that has been shown to reduce relapse and re-hospitalization compared to standard services and improve functional aspects of recovery, such as employment and social functioning.<sup>25,26</sup> This study and the culturally tailored version of Family Psychoeducation for use in Tanzania are called KUPAA, which means ‘to soar’ in Kiswahili [Kuwezeshana Kupata Uzima—supporting one another in wholeness]. The KUPAA intervention retains the core components of Family Psychoeducation with the additional elements of incorporating biomedical and traditional perspectives on mental illness—as long as those beliefs support engagement with recovery-oriented care—and involving experienced caregivers as co-facilitators alongside health providers for this group-based intervention.

The KUPAA project was carried out through a partnership between Duke University, Columbia University, and Muhimbili University of Health and Allied

Sciences (MUHAS) in two sites located in the regions of Dar es Salaam and Mbeya, Tanzania. Utilizing a randomized controlled trial design and a mixed-methods approach, the KUPAA project aims to assess the feasibility and acceptability of an adapted Family Psychoeducation intervention delivered over 16 weeks and explore its impact on patient relapse, quality of life, and disability.

In support of the KUPAA project, I worked closely with the research team, assisting them with study logistics (e.g., data cleaning and quality assurance procedures) as well as with the preparation of manuscripts. Whereas the original plan was to spend the summer of 2020 as an elective student at MUHAS in Dar es Salaam to gain valuable on-site experience, the coronavirus (COVID-19) pandemic halted this endeavor. Nevertheless, I had the opportunity to continue collaborating with the Tanzanian team throughout the summer via weekly calls and email correspondence until the completion of all data collection.

## **2.1 Setting**

As previously mentioned, this study was conducted in Dar es Salaam and Mbeya regions in Tanzania. With a population of 6,701,650, Dar es Salaam is Tanzania's largest city and a major commercial port on the country's Indian Ocean coast.<sup>27</sup> The first study site was Muhimbili National Hospital (MNH)—the national referral hospital—in Dar es Salaam, which serves local area residents as well as referrals from across the country. The Department of Psychiatry at MNH provides inpatient and outpatient care and its

staff includes psychiatrists, psychiatric nurses, social workers, and psychologists.

Although general mental health education classes are offered at MNH for outpatients and their families, outpatient psychiatric services largely focus on medication management.

The second study site was Mbeya Zonal Referral Hospital (MZRH), which is located in Mbeya city, 900 km from Dar es Salaam and 100 km from the Tanzania-Zambia border. MZRH is the only referral facility in the southern part of the country with a total population of approximately 2 million. The Psychiatry and Mental Health Unit is comprised of one psychiatrist, general practitioners, psychiatric nurses, and social workers. Similar to MNH, MZRH may offer ad hoc mental health education and family counseling sessions but does not offer any structured and evidence-based routine psychosocial services for adults with psychotic disorders.

## **2.2 Participants**

All participants in this study were recruited from the aforementioned KUPAA project. Brochures containing information about the KUPAA project were distributed around the psychiatry departments and pharmacies at both study sites. Additionally, research assistants gave general announcements about the study in outpatient waiting areas on a daily basis during the recruitment period. Recruitment of individuals with schizophrenia was conducted systematically by reviewing all monthly outpatient visits to identify potentially eligible participants for targeted recruitment in combination with

encouraging individuals who saw the brochures and announcements to self-identify as interested.

A total of 66 dyads of individuals with schizophrenia and their respective caregivers were included in the study, which aligned with our target sample size.

Eligibility criteria are noted below.

For individuals with schizophrenia, inclusion criteria were:

- Attending outpatient psychiatric services at MNH or MZRH.
- International Classification of Disease (ICD-10) diagnosis of a non-organic psychiatric disorder (confirmed by study psychiatrists): F20-Schizophrenia, F21-Schizotypal disorder, F22-Delusional disorders, or F25-Schizoaffective disorders.
- Comorbid diagnoses were acceptable for inclusion, such as F12.15-Cannabis abuse with psychotic disorder, as long as they had a primary diagnosis of one of the aforementioned disorders.
- Age 18-50 at the time of informed consent.
- Hospitalization or non-hospitalized relapse (confirmed by attending psychiatrist or medical officer) within the past year.

For individuals with schizophrenia, exclusion criteria were:

- Any of the following ICD-10 diagnoses: F23- Brief psychotic disorder, F28- Other psychotic disorder not due to a substance or known physiological condition, and F29- Unspecified psychosis not due to a substance or known physiological condition.
- Epileptic psychoses.
- Bipolar disorder or mania.
- Comorbid developmental disorder or other severe cognitive deficit that renders individuals unable to provide informed consent.

Eligibility criteria for matched caregivers/relatives were:

- Age 18 or older at the time of informed consent.
- Individual with schizophrenia agreed to be partnered with this person for the KUPAA project.

Although the caregiver was usually a relative as these individuals usually accompany outpatients to the clinic, a non-relative caregiver (e.g., guardian, close friend) was also acceptable for the study.

### **2.3 Procedures**

Data collection for the present study, corresponding to the baseline for the KUPAA project, took place at both study sites in September and October of 2019.

Interviews and questionnaires were administered to 67 outpatients and 66 matched

caregivers—1 outpatient was enrolled without a matched caregiver and later dropped from the study.

### **2.3.1 Ethical Approvals & Informed Consent**

All study procedures were approved by the ethical review boards at Duke University Medical Center, MUHAS, MZRH, and the National Institute of Medical Research (NIMR) in Tanzania. Individuals with schizophrenia who attended outpatient services at MNH or MZRH and expressed an interest in the study were screened for eligibility. Every outpatient then identified a caregiver, usually a relative, who could participate in the study. If both were eligible, the pair provided informed consent after being given thorough information about the study and having all of their questions answered. Although the pair could be together when learning about the study, all participants were given individual time to ask questions and sign consent without their respective outpatient and/or caregiver present in order to avoid undue influence from the other. Importantly, all participants with psychotic disorders had to be stable at the time of the informed consent process as well as later during the baseline interview. The study psychiatrists were responsible for determining whether the participant was stable and had the competence and capacity to consent to research participation. All participants were paid 7,500 Tsh (~US \$3.50), established per NIMR guidelines, for travel and subsistence costs related to their study attendance.

### **2.3.2 Data Collection**

Study visits were carried out at office facilities within MNH or MZRH. Research assistants administered all outpatient assessments in one session of no more than 2 hours, except for the clinician-rated measure (i.e., PANSS), which was typically done the same week by one of the three study psychiatrists or one clinical psychologist who received training on its use. The matched caregiver interviews were conducted separately to guarantee the confidentiality of the information. All assessments were done in Kiswahili, the official language in Tanzania, unless the participant preferred to do it in English. Data were collected electronically on encrypted tablets through the online REDCap server. The study psychiatrists used outpatient medical records to extract clinical information, which was then entered on REDCap.

### **2.4 Measures**

Data for the present study utilized measures from both informal caregivers and individuals living with schizophrenia. All scales used in the study underwent the World Health Organization's four-step process for translation and cultural validation, namely, forward-translation, back-translation, pre-testing, and finalization with expert consensus.<sup>28</sup>

## **2.4.1 Measures for Informal Caregivers**

### **Socio-demographic Characteristics**

Self-report questionnaires were used to gather socio-demographic characteristics of informal caregivers. These included age, sex, education, relationship status, and employment situation. Information regarding the relationship of the informal caregiver to the individual with schizophrenia, including whether they were living together, was also collected.

### **Caregiver Burden**

For the main dependent variable, the Burden Assessment Scale (BAS) was completed by the matched caregiver as a measure of perceived burden.<sup>29</sup> The scale consists of 19 items assessing perceptions of burden associated with providing support to a relative with mental illness. Items 1-10 measure objective consequences, such as financial difficulties, limitations on personal activity, and household disruptions. Items 11-19 assess subjective consequences, including shame, stigma, and resentment. Each item is rated on a 4-point Likert scale (1 = *not at all*; 4 = *a lot*). A sum score was computed ranging from 19-76, where higher scores indicated greater levels of caregiver burden. The frequency distribution of the variable was inspected visually and showed a natural break in the data at 40, which was used to dichotomize the variable (see Appendix A). The cut-off points for the BAS were 19-39 for low burden and 40-76 for high burden. In



this study, Cronbach's alpha for the BAS was 0.95, indicating high internal consistency or reliability.

### **Family Functioning**

The main independent variable was family functioning as rated by the matched caregiver. The 15-item version of the Systemic Clinical Outcome and Routine Evaluation (SCORE-15) was used to measure this construct.<sup>30</sup> The SCORE-15 is a questionnaire for completion by family members of individuals engaged in systemic therapy to evaluate family functioning. It has a three-factor structure, which assesses family strengths, difficulties, and communication, respectively. Statements about family life are rated on a 5-point Likert scale from 1 (*describes us: very well*) to 5 (*describes us: not at all*). The total score for the SCORE-15 ranges from 15 to 75, with a lower score indicating better family functioning. The SCORE-15 has been widely used in various studies with satisfactory psychometric properties reported.<sup>31</sup> The Cronbach's alpha of the SCORE-15 was 0.80 in this study, indicating good reliability.

### **Hope**

The Hearth Hope Index (HHI) was used to assess hope in caregivers. The HHI contains 12 items and evaluates three factors of hope: temporality and future, positive readiness and expectancy, and interconnectedness.<sup>32</sup> Scoring of the HHI consists of summing the items for the subscales and for the total scale. The HHI scores range from

12 to 48, the higher the score the higher the level of hope. The internal consistency of the HHI was high in this study (Cronbach's alpha = 0.92).

### **Religiosity**

The Duke University Religion Index (DUREL) is a 5-item scale that was used to measure religiosity in caregivers.<sup>33</sup> The DUREL scale assesses 3 major dimensions of religiosity: organizational religious activity (ORA), nonorganizational religious activity (NORA), and intrinsic religiosity (IR). The ORA dimension focuses on the frequency of participation in religious activity and the NORA dimension involves the frequency of private engagement in religious activities. Both ORA and NORA dimensions are measured by 1 item each and rated on a 6-point scale. The IR dimension contains 3 items that evaluate the degree of personal religious commitment or motivation on a 5-point scale, from 1 (*definitely not true*) to 5 (*definitely true of me*). The IR dimension is considered a form of religiosity in which pursuing religion is an end in itself, as opposed to being used to achieve, for example, social or financial status. Each dimension is a distinct subscale meant to be analyzed separately. In this study, we exclusively focused on the IR subscale for analyses. The score range of the IR subscale is 3 to 15, with higher scores indicating higher religious involvement. The Cronbach's alpha of the DUREL's IR subscale was 0.61, indicating acceptable reliability.

## **2.4.2 Measures for Individuals Living with Schizophrenia**

### **Socio-demographic and Clinical Characteristics**

Self-report questionnaires were used to gather socio-demographic characteristics of individuals living with schizophrenia. These included age, sex, education, relationship status, employment situation, and financial contribution to the household. Clinical characteristics were obtained from the outpatients' medical charts and included the year of illness onset, which was used to calculate the length of illness.

### **Symptom Severity**

The severity of symptoms was measured using the Positive and Negative Syndrome Scale (PANSS).<sup>34</sup> The PANSS includes a structured interview to assess individuals with schizophrenia on 30 items covering positive and negative symptoms as well as general psychopathology. Of the thirty items included in the PANSS, seven constitute a positive scale, seven a negative scale, and the remaining sixteen a general psychopathology scale. Items are rated on a 1 (*absent*) to 7 (*extreme*) scale of increasing levels of psychopathology. The scores for each of the three scales are arrived at by summation of ratings across component items. Therefore, the potential ranges are 7 to 49 for the positive and negative scales, and 16 to 112 for the general psychopathology scale. The PANSS has been previously used in studies conducted in other African countries.<sup>35,36</sup> The Cronbach's alpha of the PANSS was 0.91 in this study, indicating high internal consistency.

## **Disability/Functioning**

Functioning of the individual with schizophrenia was measured using the World Health Organization Disability Assessment Schedule-Second Version (WHODAS 2.0).<sup>37</sup> This self-report assessment measures the difficulty the individual has had with performing particular daily activities over the past 30 days. It consists of 36 Likert-formatted questions, divided into six domains: understanding and communicating, getting around, self-care, getting along with others, life activities, and participation in society. The complex scoring method was used to determine a total score, ranging from 0 (no disability) to 100 (full disability). The WHODAS has proven to be a useful measure of functioning in people with severe mental disorders in an African context.<sup>38</sup> The Cronbach's alpha of the WHODAS 2.0 was 0.96 in this study, indicating high reliability.

## **Self-Efficacy**

The General Self-Efficacy Scale (GSE) was used to assess the affected individual's belief in their ability to manage stressful situations.<sup>39</sup> Respondents indicate their level of agreement with 10 items (e.g., "I can solve most problems if I invest the necessary effort") on a Likert-type scale ranging from 1 (*not true at all*) to 4 (*exactly true*). The total score is calculated by summing all items and ranges between 10 and 40, with higher scores indicating more self-efficacy. The Swahili version of the GSE has been shown to possess sound psychometric properties.<sup>40</sup> The Cronbach's alpha of the GSE was 0.89 in this study.

### **Internalized Stigma**

The Internalized Stigma of Mental Illness (ISMI) scale was utilized to measure the affected individual's subjective experience of stigma.<sup>41</sup> The ISMI contains 29 items with a 4-point Likert scale and evaluates five areas (i.e., subscales) of self-stigma: alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance. Both the subscale and total scores are calculated by adding the item scores together and then dividing by the total number of answered items. In this study, the internal consistency of the scale was high (Cronbach's alpha = 0.92).

### **Instrumental Support**

Instrumental support was assessed using a measure from PROMIS v2.0 (Patient-Reported Outcomes Measurement Information System). All PROMIS measures were developed and validated by a National Institutes of Health (NIH) working group.<sup>42</sup> The Instrumental Support scale is comprised by 11 items asking whether respondents have someone who could assist with various daily tasks. The internal consistency of the scale was very high (Cronbach's alpha = 0.96).

## **2.5 Analysis**

Due to incomplete data for one caregiver, the analysis sample included 65 individuals with schizophrenia and 65 matched caregivers, excluding the pair with missing data. Data were examined for the presence of missing values, influential values, and outliers. Missing values in the SCORE-15 and WHODAS were handled using mean

imputation—the imputed value being the average of all observed responses within the same domain for that participant—as per the recommendation of the developers of the scales.<sup>37,43</sup> Cronbach’s alpha was estimated for each psychometric instrument to assess the validity of the scale to measure the underlying latent construct.

Continuous variables were summarized by their mean and standard deviation and categorical variables as counts and percentages. Due to convergence problems when fitting log-risk models, univariable and multivariable models used a logistic function to (1) examine the association between family functioning and caregiver burden on the multiplicative scale and (2) explore potential correlates of caregiver burden.

The method used to select variables for the multivariable regression is data-driven but also consistent with a priori theory. Given the small sample size and a lack of a strong understanding of the relationship between variables, the final model included variables that were significantly associated with caregiver burden as well as family functioning in univariable regression analyses. Although sex of the individual with schizophrenia was significantly associated with caregiver burden, it was not associated with family functioning and therefore not included in the final model. This is consistent with previous research indicating no relationship between family functioning and sex of the individual with schizophrenia.<sup>44,45</sup> A p-value of <0.05 was used for testing our hypothesis and as a threshold value for determining covariates in the multivariable model. STATA 16.0 statistical software was used to perform all analyses.<sup>46</sup>

### 3. Results

#### 3.1 Participant Characteristics

The socio-demographic and clinical characteristics of individuals living with schizophrenia stratified by sex are presented in Table 1. The average age of individuals living with schizophrenia was 33 years old (SD = 8.2). A large majority reported being single (66.7%)—more males than females—and completing secondary education or obtaining a higher degree (62.1%). Whereas 57.6% of individuals with schizophrenia indicated having worked in the past 3 months, only 34.9% reported having contributed financially to their household. The average length of illness was nine years, with a minimum of less than a year and a maximum of 29 years. The average disability score in the WHODAS was 74.8 (SD = 24.7). The mean score of the severity of the symptoms was 11.0 (SD = 4.3) for positive PANSS scale score, 11.1 (SD = 4.7) for negative PANSS scale score, 23.8 (SD = 7.7) for general PANSS scale score, and 45.9 (SD = 14.5) for total PANSS score.

**Table 1. Characteristics of Individuals Living with Schizophrenia Stratified by Sex**

	<b>Total</b> (N = 66)	<b>Males</b> (N = 44)	<b>Females</b> (N = 22)
<b>Age Categorized</b>			
<= 24	10 (15.2%)	7 (15.9%)	3 (13.6%)
25-34	27 (40.9%)	20 (45.5%)	7 (31.8%)
35-50	29 (43.9%)	17 (38.6%)	12 (54.6%)
<b>Age, in years</b>			

Mean (SD)	33.0 (8.2)	32.6 (8.2)	33.9 (8.4)
Min, Max	18, 50	18, 49	21, 50
<b>Relationship Status</b>			
Partnered, living together	10 (15.2%)	7 (15.9%)	3 (13.6%)
Partnered, not living together	12 (18.2%)	4 (9.1%)	8 (36.4%)
Single, not partnered	44 (66.7%)	33 (75.0%)	11 (50.0%)
<b>Educational Level</b>			
Primary or less	25 (37.9%)	15 (34.1%)	10 (45.5%)
Secondary or higher	41 (62.1%)	29 (65.9%)	12 (54.6%)
<b>Worked in the Past 3 Months</b>			
No	28 (42.4%)	16 (36.4%)	12 (54.6%)
Yes	38 (57.6%)	28 (63.6%)	10 (45.5%)
<b>Financial Contribution to Household</b>			
No	43 (65.2%)	26 (59.1%)	17 (77.3%)
Yes	23 (34.9%)	18 (40.9%)	5 (22.7%)
<b>Length of illness, in years</b>			
Mean (SD)	9.1 (8.1)	9 (7.5)	9.4 (9.3)
Min, Max	0, 29	0, 29	0, 26
<b>Disability (WHODAS)</b>			
Mean (SD)	74.8 (24.7)	74.6 (24.5)	75.3 (25.7)
Min, Max	32, 136	32, 128	36, 136
<b>Positive PANSS Scale Score</b>			
Mean (SD)	11.0 (4.3)	11.9 (4.8)	9.2 (2.2)
Min, Max	7, 26	7, 26	7, 15
<b>Negative PANSS Scale Score</b>			
Mean (SD)	11.1 (4.7)	11.6 (5.2)	9.9 (3.3)
Min, Max	7, 30	7, 30	7, 20
<b>General PANSS Scale Score</b>			
Mean (SD)	23.8 (7.7)	24.5 (8.7)	22.6 (5.3)
Min, Max	16, 60	16, 60	16, 35
<b>Total PANSS Score</b>			
Mean (SD)	45.9 (14.5)	48.0 (16.4)	41.7 (8.9)
Min, Max	30, 103	30, 103	30, 67

WHODAS, World Health Organization Disability Assessment Schedule; PANSS, Positive and Negative Syndrome Scale



Table 2 shows socio-demographic and other characteristics of informal caregivers stratified by sex. The average age of caregivers was 48.8 years (SD = 13.1). More than half of the caregivers (51.5%) reported currently being in a relationship and living with their partner. Most caregivers (63.6%) indicated that the highest level of education attained was primary school. Fifty-three percent of caregivers reported having worked in the past 3 months and a large majority (74.2%) had financially contributed to their household. Informal caregivers were mostly parents of the affected individual (48.5%) and lived in the same household (84.9%). The average religiosity score from DUREL's IR subscale was 14.2 (SD = 1.1) and the average hope score in the HHI was 38.7 (SD = 6.8) for caregivers. The main independent variable, family functioning, had a mean of 2.4 (SD = 0.6) in the SCORE-15. Lastly, the average caregiver burden reported in the BAS was 45.8 (SD = 15.7), with most caregivers (63.1%) falling into the high burden category.

**Table 2. Characteristics of Informal Caregivers Stratified by Sex**

	<b>Total</b> (N = 66)	<b>Males</b> (N = 23)	<b>Females</b> (N = 43)
<b>Age Categorized</b>			
<= 24	1 (1.5%)	1 (4.4%)	0 (0.0%)
25-49	32 (48.5%)	13 (56.5%)	19 (44.2%)
50-74	33 (50.0%)	9 (39.1%)	24 (55.8%)
<b>Age, in years</b>			
Mean (SD)	48.8 (13.1)	47.0 (15.3)	49.7 (11.9)
Min, Max	21, 72	21, 72	25, 70
<b>Relationship Status</b>			
Partnered, living together	34 (51.5%)	14 (60.9%)	20 (46.5%)

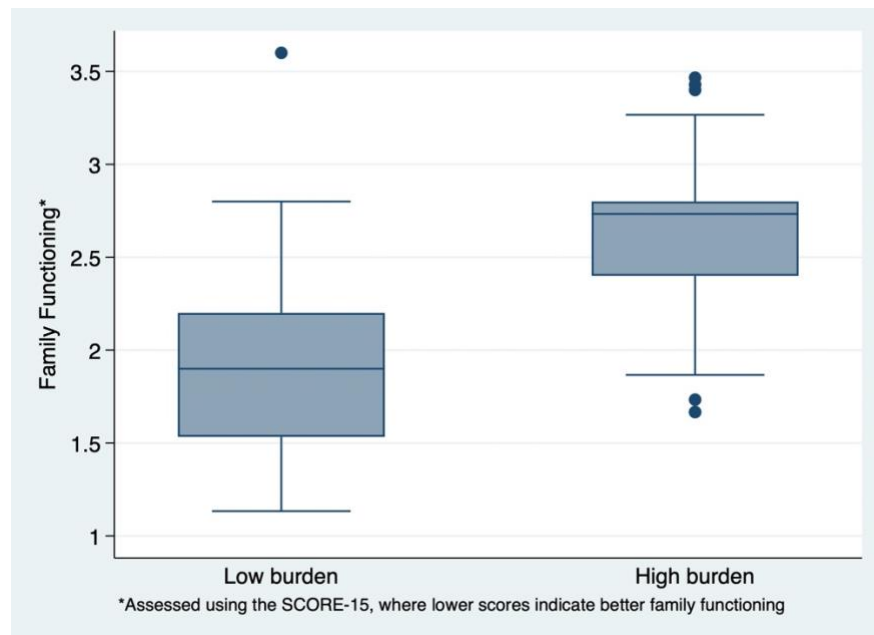
Partnered, not living together	9 (13.6%)	4 (17.4%)	5 (11.6%)
Single, not partnered	23 (34.9%)	5 (21.7%)	18 (41.9%)
<b>Educational Level</b>			
Primary or less	42 (63.6%)	14 (60.9%)	28 (65.1%)
Secondary or higher	24 (36.4%)	9 (39.1%)	15 (34.9%)
<b>Worked in the Past 3 Months</b>			
No	31 (47.0%)	11 (47.8%)	20 (46.5%)
Yes	35 (53.0%)	12 (52.2%)	23 (53.5%)
<b>Financial Contribution to Household</b>			
No	17 (25.8%)	3 (13.0%)	14 (32.6%)
Yes	49 (74.2%)	20 (87.0%)	29 (67.4%)
<b>Relationship to Individual with Schizophrenia</b>			
Partner	7 (10.6%)	2 (8.7%)	5 (11.6%)
Child	2 (3.0%)	1 (4.4%)	1 (2.3%)
Parent	32 (48.5%)	7 (30.4%)	25 (58.1%)
Sibling	9 (13.6%)	4 (17.4%)	5 (11.6%)
Other relatives	15 (22.7%)	8 (34.8%)	7 (16.3%)
Friend	1 (1.5%)	1 (4.4%)	0 (0.0%)
<b>Living Together</b>			
No	10 (15.2%)	4 (17.4%)	6 (14.0%)
Yes	56 (84.9%)	19 (82.6%)	37 (86.1%)
<b>Religiosity (DUREL)</b>			
Mean (SD)	14.2 (1.1)	14.3 (1.1)	14.2 (1.2)
Min, Max	10, 15	11, 15	10, 15
<b>Hope (HHI), Continuous †</b>			
Mean (SD)	38.7 (6.8)	39.0 (6.6)	38.5 (7.0)
Min, Max	11, 48	25, 48	11, 48
<b>Family Functioning (SCORE-15) †</b>			
Mean (SD)	2.4 (0.6)	2.3 (0.6)	2.5 (0.6)
Min, Max	1.1, 3.6	1.3, 3.5	1.1, 3.6
<b>Caregiver Burden (BAS), Continuous †</b>			
Mean (SD)	45.8 (15.7)	43.2 (17.4)	47.1 (14.8)
Min, Max	19, 75	19, 75	22, 73
<b>Caregiver Burden (BAS), Categorical †</b>			
Low Burden	24 (36.9%)	10 (45.5%)	14 (32.6%)

High Burden	41 (63.1%)	12 (54.6%)	29 (67.4%)
DUREL, Duke University Religion Index; SCORE-15, Systemic Clinical Outcome and Routine Evaluation; BAS, Burden Assessment Scale; HHI, Herth Hope Index			

† N = 65 (Males = 22, Females = 43)

### 3.2 Correlates of Caregiver Burden

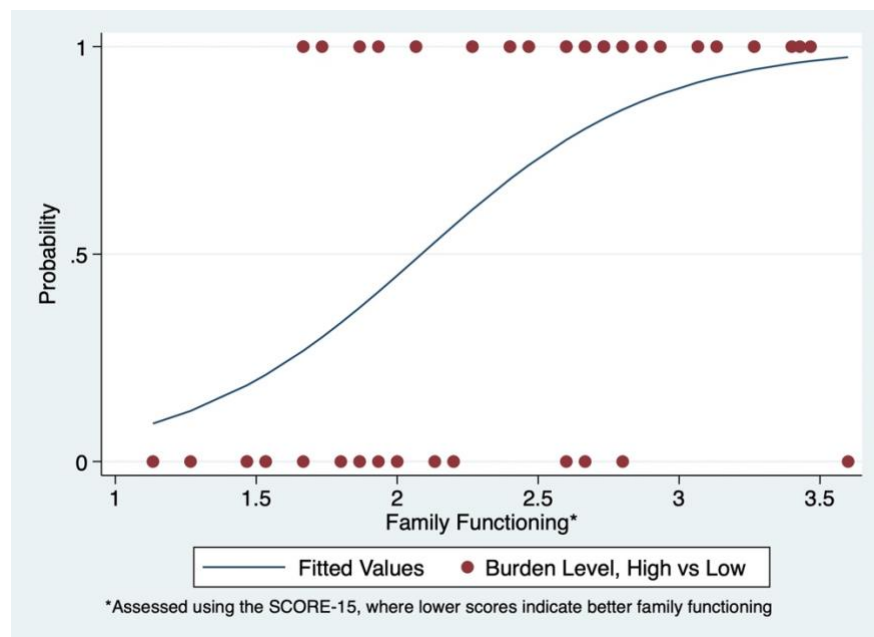
Figure 1 shows the distribution of family functioning by each burden level. The median for high burden was 2.7 (IQR = 0.4) compared to 1.9 (IQR = 0.7) for low burden.



**Figure 1: Family Functioning Distribution by Caregiver Burden Level**

The results of univariable logistic regressions of the relationship between caregiver burden and demographic, clinical, and other characteristics, respectively, are presented in Table 3. Regarding the main independent variable, the logistic regression

model indicated that lower levels of family functioning, that is higher scores in the SCORE-15, were significantly associated with high caregiver burden (OR = 11.13; 95% CI = 3.22, 38.41). In Figure 2, the predicted probability of caregiver burden given family functioning score is displayed.



**Figure 2: Logistic Predicted Probability of Caregiver Burden by Family Functioning**

In addition to family functioning, factors that were significantly associated with caregiver burden in univariable analysis were sex of the individual with schizophrenia (OR = 3.91; 95% CI = 1.13, 13.50), caregiver work (OR = 4.68; 95% CI = 1.57, 13.95), and caregiver hope (OR = 0.79; 95% CI = 0.72, 0.88). Individual with schizophrenia being female and caregiver having worked in the past 3 months were associated with high

caregiver burden, while higher levels of hope in the caregiver were associated with low caregiver burden.

**Table 3. Univariable Regression Models for Caregiver Burden Using Characteristics of Individuals with Schizophrenia and Informal Caregivers**

<i>Characteristics of Individuals with Schizophrenia</i>	N	Univariable Model	
		Crude OR (95% CI)	p-value
<b>Sex</b>			
Male	43	REF	
Female	22	3.91 (1.13; 13.50)	0.031
<b>Relationship Status</b>			
Partnered, living together	10	REF	
Partnered, not living together	11	4.50 (0.63; 32.29)	0.135
Single, not partnered	44	1.59 (0.40; 6.31)	0.511
<b>Educational Level</b>			
Primary or less	24	REF	
Secondary or higher	41	0.43 (0.14; 1.29)	0.132
<b>Worked in the Past 3 Months</b>			
No	28	REF	
Yes	37	0.39 (0.13; 1.15)	0.087
<b>Financial Contribution to Household</b>			
No	43	REF	
Yes	22	0.58 (0.20; 1.66)	0.310
<b>Age</b>	65	0.96 (0.90; 1.02)	0.164
<b>Length of illness</b>	65	0.97 (0.91; 1.04)	0.398
<b>Disability (WHODAS)</b>	65	1.00 (0.97; 1.02)	0.939
<b>Self-Efficacy (GSE)</b>	65	1.03 (0.95; 1.12)	0.528
<b>Instrumental Support (PROMIS)</b>	65	1.01 (0.97; 1.06)	0.511
<b>Internalized Stigma (ISSMI)</b>	65	1.44 (0.51; 4.03)	0.491
<b>PANSS Positive</b>	65	0.93 (0.83; 1.05)	0.239
<b>PANSS Negative</b>	65	0.92 (0.82; 1.03)	0.139
<b>PANSS General</b>	65	0.96 (0.90; 1.03)	0.253
<b>PANSS Total</b>	65	0.97 (0.94; 1.01)	0.153

<i>Characteristics of Informal Caregivers</i>	N	Crude OR (95% CI)	p-value
<b>Sex</b>			
Male	22	REF	
Female	43	1.73 (0.60; 4.95)	0.310
<b>Educational Level</b>			
Primary or less	41	REF	
Secondary or higher	24	0.96 (0.34; 2.73)	0.941
<b>Worked in the Past 3 Months</b>			
No	31	REF	
Yes	34	4.68 (1.57; 13.95)	0.006
<b>Living with Patient</b>			
No	10	REF	
Yes	55	0.69 (0.16; 2.98)	0.623
<b>Age</b>	65	0.98 (0.94; 1.02)	0.377
<b>Family Functioning (SCORE-15)</b>	65	11.13 (3.22; 38.41)	<0.001
<b>Hope (HHI)</b>	65	0.79 (0.72; 0.88)	<0.001
<b>Religiosity (DUREL)</b>	65	0.61 (0.35; 1.08)	0.091

OR = odds ratio; CI = confidence interval.

WHODAS, World Health Organization Disability Assessment Schedule; GSE, General Self-Efficacy scale; PROMIS, Patient-Reported Outcomes Measurement Information System; ISMI, Internalized Stigma of Mental Illness scale; PANSS, Positive and Negative Syndrome Scale; SCORE-15, Systemic Clinical Outcome and Routine Evaluation; HHI, Herth Hope Index; DUREL; Duke University Religion Index

All variables that had a significant association with caregiver burden, as well as with family functioning, were included in the multivariable logistic regression — thus excluding sex of the individual with schizophrenia. Family functioning, caregiver work, and caregiver hope, respectively, remained significant after controlling for all other factors (see Table 4). On adjustment, the effect of family functioning on caregiver burden was significantly attenuated. For every one-point increase on the family functioning

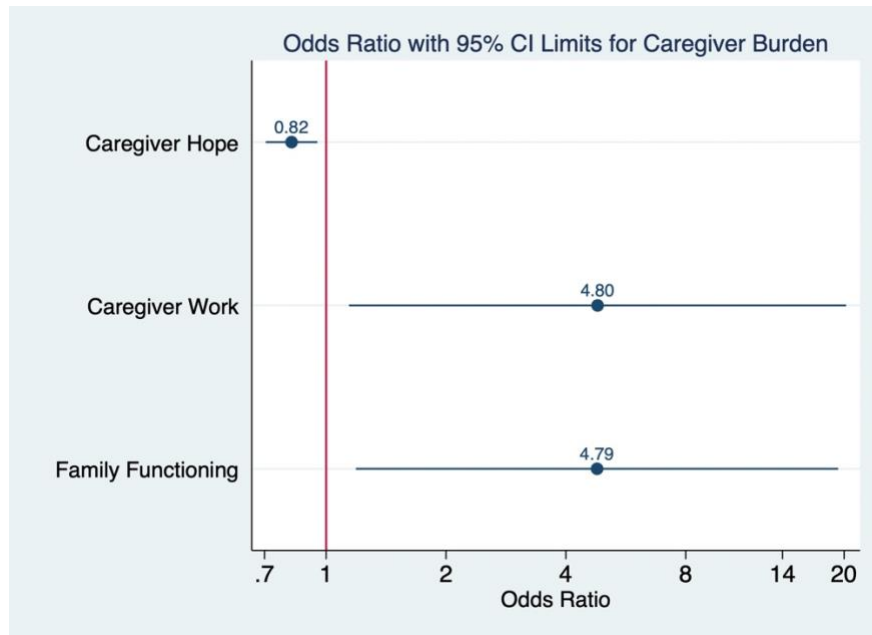
measure (i.e., lower family functioning), the odds of experiencing high caregiver burden will increase approximately fivefold, holding all other variables constant. The effects of caregiver hope and caregiver work on caregiver burden did not change considerably when adjusting for the other variables. With every one-point decrease in the levels of hope of the caregiver, we will see an 18% increase in the odds of experiencing high caregiver burden, while holding all other variables constant. Caregivers that worked in the past 3 months are almost five times more likely to experience high burden than their counterparts. It is important to note that the predicted estimates for family functioning and caregiver work were not very precise (see 95% CI levels in Table 4 and Figure 3).

**Table 4. Multivariable Regression Model for Caregiver Burden Using Caregiver Characteristics**

<i>Characteristics of Informal Caregivers</i>	N	Multivariable Model	
		Adjusted OR (95% CI)	p-value
<b>Worked in the Past 3 Months</b>			
No	31	REF	
Yes	34	4.80 (1.14; 20.23)	0.032
<b>Family Functioning (SCORE-15)</b>	65	4.79 (1.19; 19.32)	0.028
<b>Hope (HHI)</b>	65	0.82 (0.70; 0.95)	0.009

OR = odds ratio; CI = confidence interval.

SCORE-15, Systemic Clinical Outcome and Routine Evaluation; HHI, Herth Hope Index



**Figure 3: Results from Multivariable Logistic Model Predicting Caregiver Burden**



## 4. Discussion

The majority of our study sample (63%) reported experiencing high burden as a result of caring for a relative living with schizophrenia. Although this is consistent with previous reports of significant burden in informal caregivers, the rates were higher in our study than those reported in other parts of sub-Saharan Africa, including Ghana and Nigeria.<sup>19,47,48</sup> The reason for this may simply be the variation in psychometric tools for the assessment of caregiver burden across studies rather than a meaningful difference in the way informal caregivers perceive their caregiving responsibilities.

As hypothesized and established in former research, we found that family functioning was an important correlate of caregiver burden.<sup>23</sup> More specifically, lower levels of family functioning were associated with high caregiver burden. While our analyses do not allow us to claim a causal relationship between these variables, we could theorize that unhealthy family dynamics, such as poor communication and hostile interactions, exacerbate the burden perceived by the caregiver. However, it could also be that the experience of burden as a consequence of caring for an individual with schizophrenia leads to a worse family environment. In this regard, other studies have shown that dissatisfaction with family support is linked to caregiver burden and relapse in people with schizophrenia.<sup>18,21,22</sup> The present study adds to the growing literature about family functioning as a potential target for treatment that aims to improve schizophrenia outcomes and reduce caregiver burden.

Whereas our study focused on family functioning from the informal caregiver perspective, recent evidence has emerged indicating that there is concordance between reports of poor family functioning by family caregivers and individuals with schizophrenia.<sup>44</sup> This highlights a need for evidence-based family interventions for schizophrenia that improve family functioning by—for example—facilitating communication and helping the family learn new ways of relating to each other.

Another factor that was related to caregiver burden was caregiver hope. We found that lower levels of hope were associated with high burden. This finding is congruous with previous observations in other populations, such as in informal caregivers of individuals with advanced cancer and multiple sclerosis, respectively.<sup>49-51</sup> In the context of schizophrenia, hopefulness has been shown to mediate the relationship between caregiver burden and positive aspects of caregiving.<sup>52</sup> Positive caregiving experiences, in turn, can also impact the caregiver's level of hope.<sup>53</sup> Fostering positive caregiving experiences and nurturing hope among caregivers will be helpful in promoting better outcomes in families of individuals living with schizophrenia.

Whereas previous studies have looked at income level as a predictor of caregiver burden, our study focused on caregiver work as it relates to perceived burden.<sup>14,17</sup> We found that caregivers that held a job in the past 3 months were more likely to report high burden than those that were not working. This increased level of burden could be explained by distress stemming from having to juggle responsibilities at work and at

home. We must pay particular attention to the needs of caregivers that work in addition to providing care for a relative with schizophrenia in order to better support them.

Finally, sex of the individual with schizophrenia was linked to caregiver burden in univariable regression analysis. In our study, informal caregivers of women with schizophrenia were more likely to report high caregiver burden than their counterparts. There is extensive evidence indicating that female caregivers experience higher burden than male caregivers but, to our knowledge, no studies have established a relationship between sex of the affected individual and caregiver burden.<sup>16,17,23</sup> That being said, there was a noticeable difference in relationship status between men and women in our sample—more women indicated being in a romantic relationship than men. We could speculate that caring for a woman with schizophrenia is associated with greater perceived burden in the caregiver since the family as a whole may be more dependent on her. Further research is warranted to examine this association more thoroughly, including cultural attitudes that may provide an explanation for it.

### **4.3 Limitations**

This study had several limitations. The first limitation is the data-driven approach used to dichotomize caregiver burden for statistical purposes. Previous studies have not identified cut-off points for burden levels using this scale, which made it difficult for us to make a decision based on theory. That said, our cut-off choice was data-driven in that it aligned with a natural break seen in the data. Additionally,

although the BAS includes items assessing objective and subjective burden, it may still be too simplistic and therefore inadequate to accurately measure caregiver burden.

Further research is needed in this context to explore caregiver burden acknowledging the multidimensionality (e.g., financial, psychological, physical, social burden) and complexity of the construct.

Given that all participants were solely recruited from outpatient clinics, the sample may not be representative of the larger population of individuals who live with psychotic disorders. Many affected individuals in Tanzania likely have either accessed inpatient services or no services at all. This is perhaps also suggested by the higher levels of education of individuals with schizophrenia as compared to their caregivers. Although improved access to education of the younger generation is one reason for this, it could also indicate that individuals with higher education have greater access to mental health services. Moreover, the sample is mainly made up of clinically stable individuals with psychotic disorders since most of the participants had to demonstrate capacity to consent to research participation at the time of recruitment. Therefore, the burden measured in our study may be underestimated.

Another limitation is the cross-sectional design of the study, which does not allow for causal inferences regarding the relationship between family functioning and caregiver burden. As a preliminary analysis of this relationship, we are not certain that the variables included in the multivariable model are only confounders — they may also

be mediators. Consequently, the possibility that the reported odds ratios are simply direct effects, as opposed to total effects, cannot be ruled out.

An important caveat for interpreting our results is that the effect of family functioning on caregiver burden was not robust to other factors. The estimate changed considerably as other variables were added to the final model. It is possible that any unmeasured confounder could reduce the estimate even further. Lastly, the confidence intervals were wide due to the small sample size, particularly for family functioning and caregiver work, indicating a lack of precision in the estimates.

## ***4.2 Implications for further research***

Our study represents an initial but limited assessment of perceived burden in caregivers of individuals with schizophrenia in two regions of Tanzania. In order to gain a better understanding of the extent of the burden experienced by caregivers, future studies should use multiple or more comprehensive scales evaluating caregiver burden in all its complexity. Additionally, qualitative studies are warranted to obtain a nuanced account of the unique experiences of caregivers that will better inform interventions.

Considering that all participants in the current study were attending outpatient psychiatric services at the time of recruitment, further research looking at caregiver burden and family functioning should include individuals living with schizophrenia that have not had access to clinical services. It would be reasonable to expect greater perceived burden in the caregivers of those people living with schizophrenia who have

never had psychological support nor taken antipsychotic medication. Therefore, we must pay special attention to those caregivers in research as they may be the most vulnerable.

### ***4.3 Implications for policy and practice***

In Tanzania, there is legislation in place to protect and promote the rights of individuals with mental disorders. The Persons with Disabilities Act of 2010 covers a wide range of provisions for those with mental illness and/or other disabilities.<sup>54</sup> Of particular importance in the context of this study is that under the Persons with Disabilities Act of 2010, relatives of a person with a disability are obliged—although not currently enforced—to provide social support to such person. Nevertheless, there is no social safety net for people with schizophrenia and their families. Our study offers evidence of high levels of perceived burden in informal caregivers in Tanzania and calls for immediate action at the policy level to address the needs of families of individuals with schizophrenia and provide support for them.

Additionally, the present study shows the relevance of family functioning to perceptions of burden in informal caregivers of people with schizophrenia. This has significant implications for clinical practice, as it suggests family functioning could be an important target for treatment aiming to improve outcomes in persons with schizophrenia and decrease caregiver burden. Our results also make a compelling argument for fostering hope in family caregivers, especially in those that have both

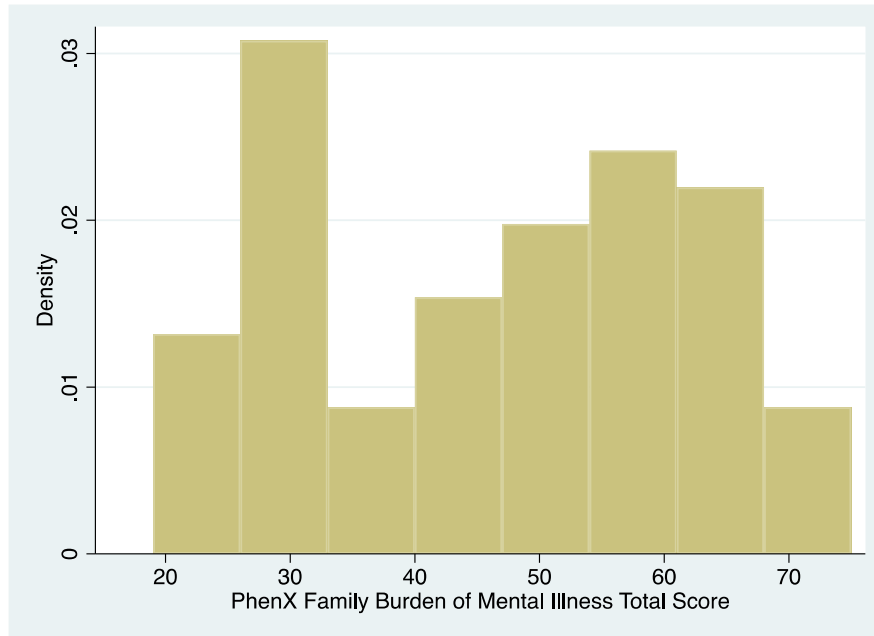
work and caregiving duties, as it can be protective against caregiver burden. Lastly, our study underscores the urgent need for evidence-based interventions that are appropriate for cultural contexts where resources are limited and families are fundamental for treatment.

## 5. Conclusion

This was the first study to examine levels of perceived burden among caregivers of individuals with schizophrenia and its relationship to family functioning in Tanzania. Caregiver burden in the present study was comparably high to other parts of Sub-Saharan Africa. We found that family functioning was a significant correlate of caregiver burden, confirming the importance and need to foster healthy family dynamics in families afflicted by schizophrenia. Moreover, factors that were shown to be related to high caregiver burden were lower levels of hope in the caregiver, caregiver having worked in the past 3 months, and the affected individual being female. Future interventions aiming to reduce caregiver burden may benefit from improving family functioning and nurturing hope among caregivers of individuals living with schizophrenia. We must pay special attention to the needs of caregivers that work in addition to providing care for a relative with schizophrenia in order to better support them.



## Appendix A



**Supplementary Figure 1: Caregiver Burden Distribution**

## References

1. Kahn, R. S. *et al.* Schizophrenia. *Nature Reviews Disease Primers* **1**, 1–23 (2015).
2. World Health Organization. *Schizophrenia* <https://www.who.int/news-room/fact-sheets/detail/schizophrenia> (2019).
3. Thornicroft, G. & Bebbington, P. Deinstitutionalisation--from hospital closure to service development. *Br J Psychiatry* **155**, 739–753 (1989).
4. Kohrt, B. A. *et al.* The Role of Communities in Mental Health Care in Low- and Middle-Income Countries: A Meta-Review of Components and Competencies. *Int J Environ Res Public Health* **15**, (2018).
5. Tamizi, Z. *et al.* Defining the concept of family caregiver burden in patients with schizophrenia: a systematic review protocol. *Systematic Reviews* **8**, 289 (2019).
6. Maurin, J. T. & Boyd, C. B. Burden of mental illness on the family: A critical review. *Archives of Psychiatric Nursing* **4**, 99–107 (1990).
7. Kulhara, P., Kate, N., Grover, S. & Nehra, R. Positive aspects of caregiving in schizophrenia: A review. *World J Psychiatry* **2**, 43–48 (2012).
8. Flyckt, L., Löthman, A., Jörgensen, L., Rylander, A. & Koernig, T. Burden of informal care giving to patients with psychoses: A descriptive and methodological study. *Int J Soc Psychiatry* **59**, 137–146 (2013).

9. Ribé, J. M. *et al.* Quality of life in family caregivers of schizophrenia patients in Spain: caregiver characteristics, caregiving burden, family functioning, and social and professional support. *Int J Psychiatry Clin Pract* **22**, 25–33 (2018).
10. Wan, K.-F. & Wong, M. M. C. Stress and burden faced by family caregivers of people with schizophrenia and early psychosis in Hong Kong. *Internal Medicine Journal* **49**, 9–15 (2019).
11. Caqueo-Urizar, A., Gutiérrez-Maldonado, J. & Miranda-Castillo, C. Quality of life in caregivers of patients with schizophrenia: A literature review. *Health Qual Life Outcomes* **7**, 84 (2009).
12. Gupta, S., Isherwood, G., Jones, K. & Impe, K. V. Assessing health status in informal schizophrenia caregivers compared with health status in non-caregivers and caregivers of other conditions. *BMC Psychiatry* **15**, (2015).
13. Lasebikan, V. O. & Ayinde, O. O. Family Burden in Caregivers of Schizophrenia Patients: Prevalence and Socio-demographic Correlates. *Indian J Psychol Med* **35**, 60–66 (2013).
14. Addo, R., Agyemang, S. A., Tozan, Y. & Nonvignon, J. Economic burden of caregiving for persons with severe mental illness in sub-Saharan Africa: A systematic review. *PLoS One* **13**, (2018).

15. Marimbe, B. D., Cowan, F., Kajawu, L., Muchirahondo, F. & Lund, C. Perceived burden of care and reported coping strategies and needs for family caregivers of people with mental disorders in Zimbabwe. *Afr J Disabil* **5**, (2016).
16. Adeosun, I. I. Correlates of Caregiver Burden among Family Members of Patients with Schizophrenia in Lagos, Nigeria. *Schizophrenia Research and Treatment* <https://www.hindawi.com/journals/schizort/2013/353809/> (2013)  
doi:10.1155/2013/353809.
17. Ayalew, M., Workicho, A., Tesfaye, E., Hailesilassie, H. & Abera, M. Burden among caregivers of people with mental illness at Jimma University Medical Center, Southwest Ethiopia: a cross-sectional study. *Ann Gen Psychiatry* **18**, (2019).
18. Hidru, T. H., Osman, M. H., Lolokote, S. & Li, X. Extent and pattern of burden of care and its associated factors among Eritrean families of persons living with schizophrenia: a cross-sectional study. *BMJ Open* **6**, (2016).
19. Inogbo, C. F., Olotu, S. O., James, B. O. & Nna, E. O. Burden of care amongst caregivers who are first degree relatives of patients with schizophrenia. *Pan Afr Med J* **28**, (2017).
20. Ohaeri, J. U. Caregiver burden and psychotic patients' perception of social support in a Nigerian setting. *Soc Psychiatry Psychiatr Epidemiol* **36**, 86–93 (2001).

21. Sariah, A. E., Outwater, A. H. & Malima, K. I. Risk and protective factors for relapse among Individuals with Schizophrenia: A Qualitative Study in Dar es Salaam, Tanzania. *BMC Psychiatry* **14**, 240 (2014).
22. Iseselo, M. K. & Ambikile, J. S. Promoting Recovery in Mental Illness: The Perspectives of Patients, Caregivers, and Community Members in Dar es Salaam, Tanzania. *Psychiatry J* **2020**, 3607414 (2020).
23. Yu, Y. *et al.* Reported family burden of schizophrenia patients in rural China. *PLoS ONE* **12**, e0179425 (2017).
24. Stratton, P. *et al.* Detecting therapeutic improvement early in therapy: validation of the SCORE-15 index of family functioning and change. *Journal of Family Therapy* **36**, 3–19 (2014).
25. Dixon, L. B. & Lehman, A. F. Family interventions for schizophrenia. *Schizophr Bull* **21**, 631–643 (1995).
26. Xia, J., Merinder, L. B. & Belgamwar, M. R. Psychoeducation for schizophrenia. *Cochrane Database Syst Rev* CD002831 (2011) doi:10.1002/14651858.CD002831.pub2.
27. World Population Review. *Dar Es Salaam Population 2020*  
<https://worldpopulationreview.com/world-cities/dar-es-salaam-population> (2020).
28. World Health Organization. *Process of translation and adaptation of instruments*.  
[https://www.who.int/substance\\_abuse/research\\_tools/translation/en/](https://www.who.int/substance_abuse/research_tools/translation/en/) (2020).

29. Reinhard, S. C., Gubman, G. D., Horwitz, A. V. & Minsky, S. Burden assessment scale for families of the seriously mentally ill. *Evaluation and Program Planning* **17**, 261–269 (1994).
30. Stratton, P., Bland, J., Janes, E. & Lask, J. Developing an indicator of family function and a practicable outcome measure for systemic family and couple therapy: the SCORE. *Journal of Family Therapy* **32**, 232–258 (2010).
31. O'Hanrahan K. *et al.* Validation of 28 and 15 item versions of the SCORE family assessment questionnaire with adult mental health service users. *Journal of Family Therapy* **39**, 4–20 (2017).
32. Herth, K. Abbreviated instrument to measure hope: development and psychometric evaluation. *J Adv Nurs* **17**, 1251–1259 (1992).
33. Triveni, D., Grover, S. & Chakrabarti, S. Religiosity among patients with schizophrenia: An exploratory study. *Indian J Psychiatry* **59**, 420–428 (2017).
34. Kay, S. R., Fiszbein, A. & Opler, L. A. The positive and negative syndrome scale (PANSS) for schizophrenia. *Schizophr Bull* **13**, 261–276 (1987).
35. Akinsulore, A. *et al.* Disability assessment as an outcome measure: a comparative study of Nigerian outpatients with schizophrenia and healthy control. *Ann Gen Psychiatry* **14**, (2015).
36. Phahladira, L. *et al.* Changes in insight over the first 24 months of treatment in schizophrenia spectrum disorders. *Schizophrenia Research* **206**, 394–399 (2019).

37. WHO | Developing the World Health Organization Disability Assessment Schedule 2.0. WHO <https://www.who.int/bulletin/volumes/88/11/09-067231/en/>.
38. Habtamu, K. *et al.* Validation of the World Health Organization Disability Assessment Schedule in people with severe mental disorders in rural Ethiopia. *Health and Quality of Life Outcomes* **15**, 64 (2017).
39. Schwarzer, R., Bäßler, J., Kwiatek, P., Schröder, K. & Zhang, J. X. The assessment of optimistic self-beliefs: Comparison of the German, Spanish, and Chinese versions of the General Self-efficacy Scale. *Applied Psychology: An International Review* **46**, 69–88 (1997).
40. Johnson, L. R., Johnson-Pynn, J. S., Drescher, C., Sackey, E. & Assenga, S. Predicting Civic Competencies Among East African Youth and Emerging Adults: Report on the Swahili General Self-Efficacy Scale. *Emerging Adulthood* **7**, 309–314 (2019).
41. Ritsher, J., Otilingam, P. G. & Grajales, M. Internalized stigma of mental illness: psychometric properties of a new measure. *Psychiatry Research* **121**, 31–49 (2003).
42. Ader, D. N. Developing the Patient-Reported Outcomes Measurement Information System (PROMIS). *Medical Care* **45**, S1 (2007).
43. Zetterqvist, M., Hånell, H. E., Wadsby, M., Cocozza, M. & Gustafsson, P. A. Validation of the Systemic Clinical Outcome and Routine Evaluation (SCORE-15) self-report questionnaire: index of family functioning and change in Swedish families. *Journal of Family Therapy* **42**, 129–148 (2020).

44. Hsiao, C.-Y., Lu, H.-L. & Tsai, Y.-F. Factors associated with family functioning among people with a diagnosis of schizophrenia and primary family caregivers. *Journal of Psychiatric and Mental Health Nursing* **27**, 572–583 (2020).
45. Koutra, K., Triliva, S., Roumeliotaki, T., Lionis, C. & Vgontzas, A. N. Identifying the socio-demographic and clinical determinants of family functioning in Greek patients with psychosis. *Int J Soc Psychiatry* **61**, 251–264 (2015).
46. StatCorp. *Stata Statistical Software*. (StataCorp LLC, 2019).
47. Adewuya, A. O., Owoeye, O. A. & Erinfolami, A. R. Psychopathology and subjective burden amongst primary caregivers of people with mental illness in South-Western Nigeria. *Soc Psychiatry Psychiatr Epidemiol* **46**, 1251–1256 (2011).
48. Opoku-Boateng, Y. N. *et al.* Economic cost and quality of life of family caregivers of schizophrenic patients attending psychiatric hospitals in Ghana. *BMC Health Services Research* **17**, 697 (2017).
49. Lohne, V., Miaskowski, C. & Rustøen, T. The relationship between hope and caregiver strain in family caregivers of patients with advanced cancer. *Cancer Nurs* **35**, 99–105 (2012).
50. Madan, S. & Pakenham, K. I. The stress-buffering effects of hope on changes in adjustment to caregiving in multiple sclerosis. *J Health Psychol* **20**, 1207–1221 (2015).



51. Utne, I., Miaskowski, C., Paul, S. M. & Rustøen, T. Association between hope and burden reported by family caregivers of patients with advanced cancer. *Support Care Cancer* **21**, 2527–2535 (2013).
52. Wang, T.-T., Beckstead, J. W. & Yang, C.-Y. Social interaction skills and depressive symptoms in people diagnosed with schizophrenia: The mediating role of auditory hallucinations. *Int J Ment Health Nurs* (2019) doi:10.1111/inm.12643.
53. Marshall, T. & Solomon, P. Professionals' responsibilities in releasing information to families of adults with mental illness. *Psychiatr Serv* **54**, 1622–1628 (2003).
54. Tanzania: Persons with Disabilities Act, 2010: Key Issues. (2010).