

Hopefulness Among Individuals Living with Schizophrenia and their Caregivers in  
Tanzania: An Actor-Partner Interdependence Model

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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

2022

ABSTRACT

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## **Abstract**

Background: Hopefulness is a positive orientation or state of mind that can aid in the recovery and treatment for mental illness, as it can have significant impacts on clinical and psychosocial outcomes. As resource-constrained settings work to implement recovery-oriented care, there is a need to better understand hopefulness among people living with schizophrenia (PLWS) and caregivers in their extended family networks. This study seeks to examine the dyadic relationship of hopefulness and its associated correlates among PLWS and their caregivers in Tanzania.

Methods: This study utilized longitudinal data collected as part of a randomized controlled trial testing a culturally-tailored model of Family Psychoeducation in Tanzania. The Herth Hope Index was used to measure hopefulness among PLWS and their caregivers at baseline and three months post-intervention. Univariable and multivariable regression models were conducted to determine correlates of hopefulness at baseline, while the Actor-Partner Interdependence Model (APIM) was employed to examine the longitudinal, dyadic relationship of hopefulness among PLWS and their caregivers. APIM can help determine how an individual's level of hope at time 0 impacts his or her own level of hope at time 1 and their partner's level of hope at time 1.

Results: For PLWS and their caregivers, actor effects were less than one (PLWS,  $\beta = 0.261$ ; caregivers,  $\beta = 0.318$ ), indicating stability in hopefulness over time. Regarding partner effects, caregivers baseline hopefulness had a positive effect on PLWS

hopefulness at follow-up ( $\beta = 0.100$ ). This indicates that higher caregiver hope at time 0 is associated with higher levels of hope in PLWS at time 1. Baseline hopefulness levels for PLWS had a negative effect on caregiver hopefulness at follow-up ( $\beta = -0.106$ ). This suggests that higher PLWS hope at time 0 is associated with lower levels of hope in caregivers at time 1.

Conclusions: Hopefulness seems to be interesting to consider because caregiver hopefulness can influence improvements in patient hopefulness over time. Future studies should further explore the dyadic relationship of hopefulness in this population, as hope is a non-pharmacological mechanism of change that is underutilized globally.

## **Dedication**

I dedicate this thesis to Dr. Marjorie L. Carlstein, a wonderful psychiatrist who changed my life and inspired me to pursue a career in global mental health.

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# 1. Introduction

Schizophrenia is a severe psychiatric disorder that affects 21 million people worldwide.<sup>1</sup> It can cause significant distress for both the individual living with the disorder and their family members. Schizophrenia is characterized by positive symptoms (e.g., hallucinations, delusions), negative symptoms (e.g., flat emotions, reduced speaking), and cognitive symptoms (e.g., attention deficits), and is often chronic in nature with a considerable level of disability.<sup>2</sup> That said, the disorder is treatable, and long-term symptom management and recovery are possible.<sup>2,3</sup>

In both low- and middle-income countries like Tanzania, and high-income countries like the United States, there are high rates of relapse and rehospitalizations for schizophrenia, highlighting the need for accessible, recovery-oriented care globally.<sup>4</sup> Optional treatment of schizophrenia includes both pharmacological and psychosocial treatment.<sup>5</sup> While psychosocial interventions in combination with medication are more readily available in high-income settings, more resource-limited clinical settings may lack formal treatment options entirely or only offer medication management, which is more often the case for Tanzania.<sup>2,6,7</sup> Besides limited resources (providers, hospital beds, etc.), there is no financial security net in Tanzania for individuals living with severe psychiatric disorders.<sup>8,9</sup> Tanzanian law obliges family members to be the informal caregivers for those with significant psychiatric disabilities, and puts the onus for financial support on the families if assistance is needed.<sup>8</sup> In fact, historically, family

members often fulfill roles for those with more severe psychiatric conditions.<sup>10</sup>

Therefore, treatment and recovery may largely depend upon the capabilities of the family caregivers, thus highlighting the importance of better understanding family-involved interventions for schizophrenia.

Existing evidence indicates that families are important for influencing clinical and social outcomes of their relatives living with schizophrenia.<sup>11</sup> For family members to best perform their roles as caregivers and partners in the recovery process, it is important that they too receive support to deal with the associated difficulties and challenges of caregiving.<sup>10,12</sup> Family interventions that include both caregivers and individuals living with the illness have been found to prevent relapse more effectively than standard care alone.<sup>11</sup> Family interventions, including the evidence-based counseling intervention Family Psychoeducation, have also been found to improve symptoms, and to increase functioning for people living with schizophrenia (PLWS). Family members who participate in these interventions gain problem-solving and communication skills that may ultimately support their relative's road to recovery.<sup>11,13</sup>

<sup>3</sup> Hope may be an important construct in recovery-oriented care of schizophrenia because it facilitates agency, self-efficacy, and pathways to healthier lives.<sup>3,14,15</sup> A loss of hope is a common experience among individuals living with chronic diseases, including mental health challenges, which negatively impacts the recovery process.<sup>3</sup> An individual's sense of hope is critical to the personal, social, and clinical recovery

processes for severe mental illness as it is often necessary for positive change to occur related to one's illness. This could have positive implications in low-resource settings where familial care is essential and rehospitalizations are common. While the association between hope and recovery for schizophrenia has been identified, not enough is understood about its mechanisms of action within psychosocial interventions.<sup>16</sup>

Hope goes beyond optimism and has been defined several ways across different disciplines.<sup>17,18</sup> C.R. Snyder, a psychologist known for his work in positive psychology, defines hope as "the perceived capability to derive pathways to desired goals and motivate oneself via agency thinking to use those pathways."<sup>14</sup> Kaye Herth, a registered nurse and creator of the Herth Hope Index instrument, interprets hope as "a multi-dimensional dynamic life force characterized by confident yet uncertain expectation of achieving good, which to the hoping person, is realistically possible and personally significant."<sup>19</sup> Herth's definition differs from Snyder's in that it recognizes one's interconnectedness as an important component influencing hope. Hope is shaped largely by cultural context, making for different experiences and meanings across the globe.<sup>17</sup>

Hope can have positive impacts on both patient and caregiver populations. Hopefulness positively influences clinical and psychosocial outcomes, as made evident in several studies with varying chronic indications.<sup>17,18,20,21</sup> Hope specifically enhances

coping, particularly for those living with chronic illnesses and their caregivers. A recent study in Dar es Salaam, Tanzania found that hope motivated positive health-seeking behaviors among people living with HIV.<sup>20</sup> A study among older adults in the United States found higher levels of hopefulness to be associated with a reduced risk of all-cause mortality, lower risk of cancer, increased life satisfaction, lower psychological distress, and better social well-being.<sup>22</sup> Studies have additionally identified positive impacts of hope on outcomes related to various mental illnesses like depression, although the research is limited.<sup>21,23,24</sup>

There is limited literature available on the role of hopefulness in improving the mental health of PLWS and their caregivers. Most of the existing literature is set in high-income countries and focuses solely on the individuals living with schizophrenia.<sup>25–28</sup> For example, Oles et al. conducted a study on the relationship between hope and patient activation among PLWS in the United States.<sup>26</sup> One qualitative study, also set in the U.S., focused on hope in Latino populations with schizophrenia and their caregivers found supportive family interactions were “critical for the development and maintenance of hope.”<sup>28</sup> Additionally, not much is known about hopefulness among this population in Tanzania. Most of the available evidence on hope in Tanzania is related to HIV/AIDS or cancer, although a recent schizophrenia study did identify the association between high levels of hope and low caregiver burden.<sup>12,17,20</sup> HIV researchers in Tanzania have called for a better understanding of the role of hopefulness in the

treatment and recovery of chronic illnesses."<sup>17</sup> Therefore, there is a need to understand the extent to which hopefulness may be related to recovery in PLWS and their caregivers in Tanzania. Addressing and increasing hope among PLWS and their caregivers has the clear potential to improve treatment models.

Mental illness does not occur in a vacuum and is instead experienced within the context of one's family, which may be even more critical to consider in more collectivist cultures.<sup>13</sup> For family-focused interventions such as Family Psychoeducation, which requires participation of both PLWS and their relatives, examining hopefulness within a dyadic relationship could be particularly illuminating about the role of hope in recovery. The Actor-Partner Interdependence Model (APIM) was developed from the field of psychology and is a widely used analytical model of dyadic relationships.<sup>29,30</sup> The model accounts for the interdependence within interpersonal relationships, where dyad members may influence each other's outcomes. Due to the high potential for interdependence of the family caregivers and PLWS in Family Psychoeducation, the APIM model is a strong fit to examine hopefulness within the caregiving relationship.<sup>31</sup>

The purpose of this study is to explore hopefulness among PLWS and their caregivers in the Dar es Salaam and Mbeya regions of Tanzania. There was no strong hypothesis, as the study was exploratory.



## **1.1 Study Aims**

The primary aim of this study is to examine the dyadic relationship of hopefulness among individuals living with schizophrenia and their caregivers in Tanzania. The secondary aim of this study is to identify sociodemographic and illness-related factors that may be associated with hopefulness separately for PLWS and their caregivers.

## 2. Methods

All data used in this study were collected as part of the pilot randomized clinical trial titled: “Family Psychoeducation for Adults with Psychotic Disorders in Tanzania” (clinicaltrials.gov #NCT04013932) funded by the National Institute of Mental Health (NIMH) [R34MH106663, PI: Baumgartner]. Family Psychoeducation is an evidence-based treatment approach used in high-income settings that helps both PLWS and their caregivers to cope with the illness.<sup>32,33</sup> The version of Family Psychoeducation used in the parent study, KUPAA, which means ‘to soar’ in Kiswahili, was culturally-tailored to be appropriate for populations that may hold biomedical and traditional beliefs about mental illness and which involved family caregivers as co-facilitators of the group session part of the intervention.

The parent project was conducted in collaboration with Duke University, Columbia University, and Muhimbili University of Health and Allied Sciences (MUHAS). The KUPAA intervention was piloted at two sites in Tanzania using a two-arm, parallel randomized controlled design and included both quantitative and qualitative methods. The main objectives of the pilot study were to assess the intervention’s feasibility and acceptability, as well as to explore its impacts on patient relapse, disability, and quality of life.

## **2.1 Setting**

The KUPAA pilot study was conducted in Dar es Salaam and Mbeya, located in the East African country of Tanzania. The first study site was Muhimbili National Hospital (MNH), which is located in the major urban city of Dar es Salaam. MNH is the national referral hospital with a catchment area of about 4 million people. The Department of Psychiatry and Mental Health has both inpatient and outpatient care, with 70 beds in total, usually fully occupied. Psychiatrists, psychiatric nurses, social workers, psychologists, and occupational therapists work together to provide care at this facility.

The study also took place at the Mbeya Zonal Referral Hospital (MZRH), located in the southern highlands zone. MZRH is the only referral facility in the southern part of Tanzania with 8 districts and it also acts as a referral facility for neighboring regions. The Psychiatry and Mental Health Unit has 24 beds in total, which are also typically fully occupied. One psychiatrist, along with general practitioners, psychiatric nurses, and social workers provide care at MZRH.

## **2.2 Participants**

A total of 66 dyads of individuals living with schizophrenia and their matched caregivers were included in the study. The study was powered for the parent project with the primary aim of assessing intervention efficacy and not for the APIM analysis. All treatment-engaged participants had an ICD-10 (International Classification of

Disease) diagnosis of either Schizophrenia (F20, n=56) or Schizoaffective disorder (F25, n=10), were age 18-50 years at the time of consent, attending outpatient services at either study site, and had relapsed within the past year. Caregiver participants were identified by individuals living with the psychotic disorder and were at least 18 years old.

Caregivers could have been a family member, spouse, friend, etc. of the PLWS.

### **2.3 Procedures**

This study utilizes longitudinal data collected at baseline and 3-months post-intervention as part of the KUPAA clinical trial. Baseline data collection took place in September and October of 2019, while follow-up data collection occurred in May and June of 2020.

Written informed consent was obtained from all participants after being screened for study eligibility. Individuals living with schizophrenia were required to be stable at the time of consent, which was determined by the study psychiatrists. To ensure that these individuals were able to give adequate informed consent, the research team revisited the consent form with them prior to the follow-up interview. All participants were compensated 7,500 Tsh (~ \$3.50 USD) for costs related to study attendance.

Study visits and data collection occurred in office facilities within MNH and MZRH. Self-report questionnaires were completed by participants to gather sociodemographic information. Research assistants administered all patient assessments, including sociodemographic information, except for the clinician-rated

measure (PANSS) in a single session lasting around 2 hours. The PANSS was administered in a separate interview by a study psychiatrist or clinical psychologist. Caregiver interviews were brief and administered separately to ensure confidentiality. Interviews were carried out in Kiswahili, the official language in Tanzania. Data were collected electronically on tablets using the REDCap online server, which were password-protected and locked away when not in use to protect sensitive participant information.

All study procedures were approved by the ethical review boards at Duke University Medical Center (Protocol No. Pro00094163), MUHAS (Ref No. DA.282/298/0 I.C), MZRH (Ref No. SZEC-2./39/R.E IV 11-13), and the Tanzanian National Institute of Medical Research (Ref No. NIMRJHQ/R.8a/Vol. IX/3156).

## **2.4 Measures**

This study includes measures for PLWS and their matched caregivers. The World Health Organization's four-step translation and cultural validation process, namely, forward-translation, back-translation, pre-testing, and finalization with expert consensus, was implemented for all scales in the study.<sup>34</sup>

### **2.4.1 Sociodemographic Characteristics**

All participants self-reported sociodemographic information including age, sex, relationship status, education, and employment status. Length since illness onset was captured for PLWS. Additional characteristics were also noted for caregivers, including

the type of relationship to the individual living with schizophrenia (e.g., partner, sibling, friend, etc.).

## **2.4.2 Psychometric Instruments**

### **Herth Hope Index**

Hopefulness was measured using the Herth Hope Index (HHI).<sup>19</sup> This was completed by all PLWS and their matched caregivers. The HHI was administered at baseline (pre-intervention) and 3 months post-intervention which allowed for an estimation of changes in hope over time. The HHI includes and contains three factors including temporality and future, positive readiness and expectancy, and interconnectedness.<sup>19</sup> Factor 1 attempts to measure the perception that a positive outcome is possible in the future, while factor 2 attempts to measure the feeling of confidence to initiate action plans. Factor 3 assesses the recognition of interdependence between self and others.<sup>19</sup> Scores range from 12-48, with a higher HHI total indicating a higher level of hopefulness. Questions are scored using a four-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). Scoring entails an unweighted summing of item points for subscales and the total scale. The internal consistency of the scale was very good in this study (Cronbach's alpha = 0.91).

### **Hellen Siril Hope Scale**

The Hellen Siril Hope Scale (HS) was used to measure hopefulness in PLWS only. The HS is a 13-item scale that assesses three domains of hope including planning

and future optimism, affective/positive emotions, and cognitive positive results of care.<sup>17</sup>

The HS was initially developed and validated among people living with HIV in Dar es Salaam, Tanzania in order to create a local, culturally-appropriate measure of hope.

Total scores range from 0-39, with higher scores indicating higher levels of hope. The Cronbach's alpha in this study was 0.91, indicating high reliability.

### **Religiosity**

Religiosity was measured for all participants using the Duke University Religion Index (DUREL).<sup>35</sup> DUREL is a 5-item scale that measures religious involvement. The scale assesses three major dimensions of religiosity including organizational religious activity (ORA), non-organizational religious activity (NORA), and intrinsic religiosity (IR). The DUREL instrument is designed so that each dimension is to be measured and analyzed separately. This study utilized the IR subscale for analysis, which refers to one's degree of personal religious commitment. DUREL-IR scores range from 3 to 15, with higher scores indicating higher levels of religious commitment. The Cronbach's alpha for the IR subscale was 0.76 in this study, indicating acceptable reliability.

### **Internalized Stigma**

The Internalized Stigma of Mental Illness (ISMI) scale was employed to assess experiences with stigma in participants living with schizophrenia.<sup>36</sup> The scale consists of 29 items scored on a 4-point Likert scale. The instrument includes statements such as "I feel out of place in the world because I have mental illness." The ISMI measures five

subscales of stigma including alienation, stereotype endorsement, discrimination experience, social withdrawal, and stigma resistance. Higher scores reflect higher levels of internalized stigma. Internal consistency of the scale was good in this study with a Cronbach's alpha of 0.92.

### **Symptom Severity**

The severity of symptoms experienced by PLWS was measured using the Positive and Negative Syndrome Scale (PANSS).<sup>37</sup> The PANSS is a 30-item structured interview comprised of 7 positive and 7 negative symptom items, in addition to 16 general psychopathology items. Items are ranked on a 7-point Likert scale, with symptom subscale scores ranging from 7 to 49 and general psychopathology scores ranging from 16 to 112. Higher scores indicate a higher level of symptom severity. The Cronbach's alpha was 0.91, indicating high internal consistency.

### **Family Functioning**

Family functioning was assessed for all participants using the 15-item version of the Systemic Clinical Outcome and Routine Evaluation (SCORE-15).<sup>38,39</sup> The SCORE-15 is a questionnaire that can be used to measure therapeutic changes in functioning for those engaged in family or couples therapy. The instrument consists of three dimensions including strengths and adaptability, overwhelmed by difficulties, and disrupted communication. Items are rated on a 5-point Likert scale and total scores



range from 15 to 75, with lower scores indicating better family functioning. The Cronbach's alpha was 0.83, indicating good reliability.

## **Disability**

The level of disability in PLWS was assessed using the World Health Organization Disability Assessment Schedule-Second Version (WHODAS 2.0).<sup>40</sup> The WHODAS 2.0 is constructed of 36-items in a Likert format that are divided into the domains of understanding and communicating, getting around, self-care, getting along with people, life activities, and participation in society. The complex scoring approach was used, with total scores ranging from 0 (no disability) to 100 (full disability). The Cronbach's alpha was 0.96, indicating high reliability.

## **Caregiver Burden**

Burden experienced by caregiver participants was measured utilizing the Burden Assessment Scale (BAS).<sup>41</sup> The BAS consists of 19-items measuring objective and subjective consequences of providing care to a relative with mental illness. Items are rated on a 4-point Likert scale and total scores range from 19 to 76, with higher scores indicating higher levels of caregiver burden. The BAS had very high internal consistency in this study (Cronbach's alpha= 0.95).

## **2.5 Analysis**

Descriptive statistics were summarized for all members of the study population. Continuous variables were summarized by their mean and standard deviation (SD),

while categorical variables were summarized as counts and percentages. Internal consistency of the psychometric instruments was measured by calculating the unstandardized Cronbach's alpha using baseline data for caregivers and PLWS as appropriate. No hypothesis testing was performed, and p-values were not used due to the exploratory nature of the study.

Univariable and multivariable linear regression modeling was performed to identify potential correlates of hopefulness (HHI total) separately in individuals living with schizophrenia and their caregivers using baseline data. The regression analysis for PLWS included the full sample (n=66) and a nearly full sample (n=65) for caregivers, as one caregiver had incomplete data. Mean imputations were performed to handle missing values for the HHI, WHODAS, and SCORE-15 instruments. Model fit of continuous variables was assessed using  $R^2$ , adjusted  $R^2$ , F-statistics, and scatter plots. Linear and non-linear associations between dependent and independent variables were considered. All psychometric measures were fit as continuous variables. Bivariate associations were summarized by their mean difference and 95% confidence interval. Variables for the multivariable regression analyses were selected by *a priori* theory. Due to the small sample size and lack of a strong *a priori* understanding of the relationships, we chose to do a minimally adjusted model for both participant groups. For PLWS, models were adjusted for sex, length of illness, and symptom severity. For caregivers, models were adjusted for sex and age.

The Actor-Partner Interdependence Model (APIM) was employed to account for the non-independence of the caregiver and PLWS dyads. Complete dyad data for 65 pairs and partial dyad data for 1 pair was used in the APIM analysis. **Figure 1** portrays the repeated measures APIM framework of a caregiver-patient dyad in which there is one variable at two different timepoints from each dyad member: hopefulness at baseline and 3 month follow-up.<sup>42</sup> The model estimates individual-level effects of a predictor, otherwise known as actor effects (e.g., how a PLWS's level of hope at time 0 affects his or her own level of hope at time 1). APIM also simultaneously estimates partner effects (e.g., how a caregiver's level of hope at time 0 impacts the PLWS's level of hope at time 1), which are the effects of a predictor from the dyad partner on the paired individual's outcome.<sup>29,30</sup> More specifically, the model estimates the mean HHI total as a function of actor and partner effects. In this study, the dyads were treated as distinguishable based off of the theoretical distinction between roles (caregiver vs. PLWS). The two-intercept approach in multilevel modeling was used to obtain the actor-partner effects per level of the distinguishing variable (e.g., dyadic role). The original KUPAA dataset was restructured into a pairwise organization with each dyad participant occupying a separate record. Two dummy variables for the distinguishing variable were coded and included in the model separately and as interaction terms (caregiver = 1 if caregiver, 0 if patient and patient = 1 if patient, 0 if caregiver). Four variables were then created using the dummy variables and included in the model:

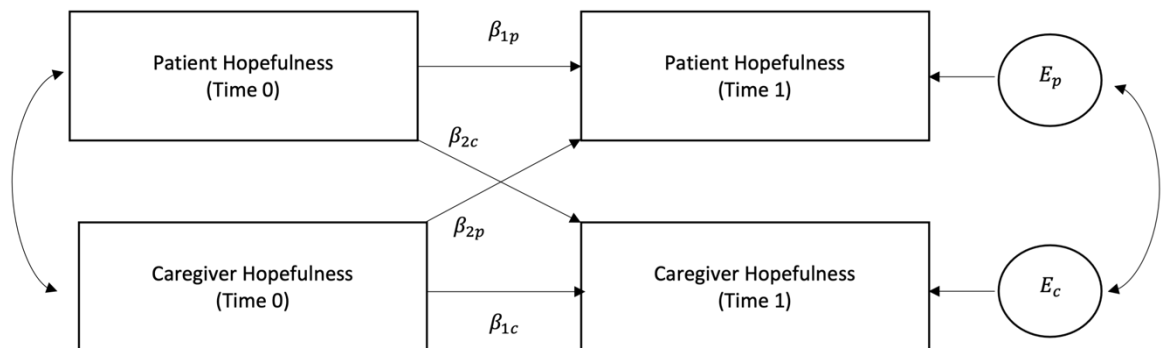
$\beta_{1p}$  = actor effect among patients

$\beta_{1c}$  = actor effect among caregivers

$\beta_{2c}$  = partner effect among caregivers

$\beta_{2p}$  = partner effect among patients

The residual errors on hopefulness for caregivers and patients are represented by  $E_c$  and  $E_p$  in Figure 1. Beta coefficients were estimated with a linear mixed model using baseline HHI totals for each dyad member as appropriate. STATA 17.0 software was used to perform all statistical analyses.<sup>43</sup>



**Figure 1: Actor-Partner Interdependence Model of Hopefulness**

## 3. Results

### 3.1 Participant Characteristics

Table 1 shows the sociodemographic and clinical characteristics of the PLWS stratified by sex. The average age of PLWS was 33 years (SD = 8.2) and the majority were men (66.7%). Most PLWS reported being single (66.6%) and having worked in the last three months (57.6%). The majority completed secondary school or obtained a higher education (62.1%). The average length of illness was 9 years. The mean hopefulness score (HHI) was 35.1 (SD = 6.6) in men and 31.7 (SD = 7.3) in women. The mean symptom severity score (PANSS total) was 45.9 (SD = 14.5) and the mean disability score (WHODAS 2.0) was 37.5 (SD = 20.6).

**Table 1: Characteristics of Individuals Living with Schizophrenia at Baseline, Stratified by Sex**

	<b>Total</b> (N=66)	<b>Males</b> (N=44)	<b>Females</b> (N=22)
<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>Age Categorized Count (%)</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>Relationship Status Count (%)</b>			
Partnered, living together	10 (15.1%)	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 (54.5%)
<b>Worked in the Past 3 Months</b>			
No	28 (42.4%)	16 (36.4%)	12 (54.5%)
Yes	38 (57.6%)	28 (63.6%)	10 (45.5%)
<b>Religion</b>			
Muslim	18 (27.3%)	13 (29.5%)	5 (22.7%)
Catholic	9 (13.6%)	5 (11.4%)	4 (18.2%)
Christian/Protestant	38 (57.6%)	25 (56.8%)	13 (59.1%)
Other	1 (1.5%)	1 (2.3%)	0 (0.0%)
<b>Length of illness, in years</b>			
Mean (SD)	9.1 (8.1)	9.0 (7.5)	9.4 (9.3)
Min, Max	0, 29	0, 29	0, 26
<b>Hope (HHI)</b>			
Mean (SD)	34.0 (7.0)	35.1 (6.6)	31.7 (7.3)
Min, Max	20, 48	24, 48	20, 46
<b>Hope (HS)</b>			
Mean (SD)	24.8 (6.9)	25.6 (7.0)	23.4 (6.8)
Min, Max	7, 39	11, 39	7, 34
<b>Symptom Severity (PANSS Total)</b>			
Mean (SD)	45.9 (14.5)	48.0 (16.4)	41.7 (8.9)
Min, Max	30, 103	30, 103	30, 67
<b>Disability (WHODAS 2.0, Complex)</b>			
Mean (SD)	37.5 (20.6)	37.2 (20.5)	38.1 (21.3)
Min, Max	0, 83.7	0, 82.6	4.3, 83.7

HHI, Herth Hope Index; HS, Helen Siril Hope Scale; PANSS, Positive and Negative Syndrome Scale; WHODAS, World Health Organization Disability Assessment Schedule; Variables are reported as count (%) unless otherwise noted.

**Table 2** shows the sociodemographic characteristics of caregivers stratified by sex. The average age of caregivers was 48.8 years (SD = 13.2) and the majority were women (65.2%). Most caregivers reported being partnered and living together (51.5%). More than half of the caregivers had worked in the past three months (53.0%) and the majority had completed primary education (63.6%). Nearly all caregivers reported living with the affected individual (84.8%). Most caregivers were parents to the affected individual (48.5%). The mean hopefulness score (HHI) was 38.7 (SD = 6.7). The average burden score (BAS) was 43.2 (SD = 17.4) for men and 47.1 (SD = 14.8) for women.

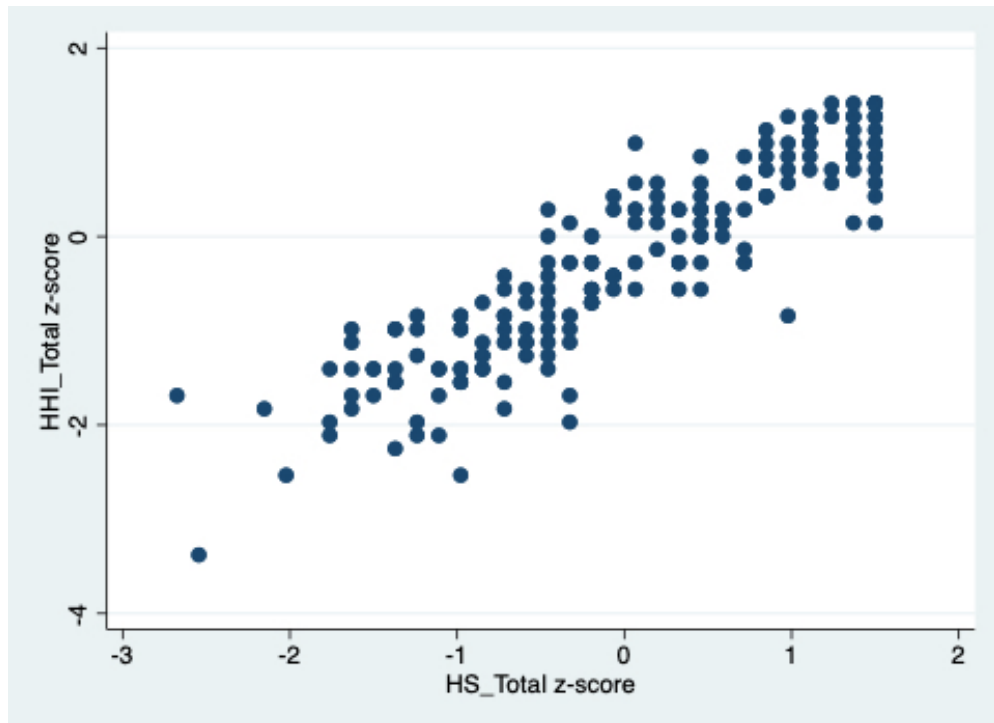
**Table 2: Characteristics of Caregivers Stratified by Sex**

	<b>Total (N=66)</b>	<b>Males (N=23)</b>	<b>Females (N=43)</b>
<b>Age, in years</b>			
Mean (SD)	48.8 (13.2)	47.0 (15.3)	49.7 (11.9)
Min, Max	21, 72	21, 72	25, 70
<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>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>Religion</b>			
Muslim	15 (23.1%)	4 (18.2%)	11 (25.6%)
Catholic	11 (16.9%)	2 (9.1%)	9 (20.9%)
Christian/Protestant	38 (58.5%)	16 (72.7%)	22 (51.2%)
Other	1 (1.5%)	0 (0.0%)	1 (2.3%)
<b>Living Together</b>			
No	10 (15.2%)	4 (17.4%)	6 (14.0%)
Yes	56 (84.8%)	19 (82.6%)	37 (86.0%)
<b>Relationship to Individual with Schizophrenia</b>			
Partner	7 (10.6%)	2 (8.7%)	5 (11.6%)
Child	2 (3.0%)	1 (4.3%)	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>Hope (HHI)</b>			
Mean (SD)	38.7 (6.7)	39.1 (6.6)	38.6 (6.8)
Min, Max	14, 48	25, 48	14, 48
<b>Caregiver Burden (BAS)</b>			
Mean (SD)	45.8 (15.7)	43.2 (17.4)	47.1 (14.8)
Min, Max	19, 75	19, 75	22, 73

HHI, Herth Hope Index; HS, Helen Siril Hope Scale; BAS, Burden Assessment Scale; Variables are reported as count (%) unless otherwise noted.



The Hellen Siril Hope Scale and Herth Hope Index were very highly correlated ( $r=0.901$ ) in this study as seen in **Figure 2**. This suggests good reliability of the HHI instrument in the Tanzanian context.



**Figure 2: Correlation of Hope Instruments**

### ***3.2 Correlates of Hopefulness***

**Table 3** shows crude and adjusted results of the linear regression analysis estimating the associations between HHI total and characteristics of PLWS. HHI total was approximately linearly associated with the psychometric measures. Higher (better) HHI totals were associated with lower levels of stigma (ISMI), better family functioning (SCORE-15), and less disability (WHODAS 2.0). Little difference in crude and adjusted

models were observed on adjustment for sex, length of illness, and symptom severity (PANSS).

**Table 3: Univariable & Multivariable Linear Regression Models of Hopefulness for PLWS**

<i>Independent Variable</i>	<i>N</i>	<i>Crude Model</i>		<i>Adjusted Model</i>	
		<i>Mean HHI</i>	<i>(95% CI)</i>	<i>Mean HHI</i>	<i>(95% CI)</i>
<b>Internalized Stigma (ISMI)</b>	66	-9.96	(-12.47, -7.45)	-8.86	(-11.37, -6.36)
<b>Symptom Severity (PANSS)</b>	66	-0.15	(-0.26, -0.04)	-0.17	(-0.29, -0.06)
<b>Family Functioning (SCORE-15)</b>	66	-6.30	(-8.85, -3.76)	-5.39	(-7.94, -2.84)
<b>Disability (WHODAS 2.0)</b>	66	-0.23	(-0.30, -0.17)	-0.24	(-0.31, -0.16)

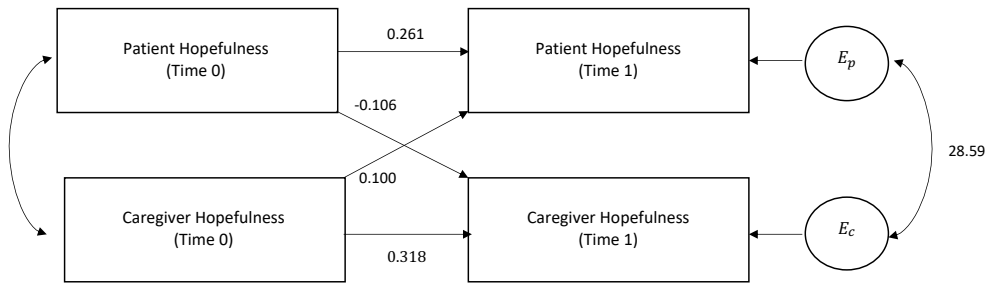
**Table 4** shows the crude and adjusted results of the linear regression analysis estimating the associations between caregiver HHI total and caregiver characteristics. Caregivers living in the same household as their matched partner living with schizophrenia had a higher average hope total than those who were not cohabitating (mean diff: 2.15; 95% CI: -2.43, 6.74). Mean HHI totals were approximately linearly associated with the psychometric measures. Higher (better) caregiver HHI totals were associated with lower levels of caregiver burden (BAS) and better family functioning (SCORE-15). On adjustment for age and sex, little differences from the crude models were observed.

**Table 4: Univariable & Multivariable Linear Regression Models of Hopefulness for Caregivers**

<i>Independent Variable</i>	<i>N</i>	<i>Crude Model</i>		<i>Adjusted Model</i>	
		<i>Mean HHI</i>	<i>(95% CI)</i>	<i>Mean HHI</i>	<i>(95% CI)</i>
<b>Living with Patient</b>					
No (REF)	10	36.90	(32.68, 41.12)	36.25	(32.11, 40.39)
Yes	55	39.05	(37.26, 40.85)	39.17	(37.42, 40.92)
<i>Difference</i>	65	2.15	(-2.43, 6.74)	2.92	(-1.59, 7.43)
<b>Family Functioning (SCORE-15)</b>	65	-4.39	(-7.00, -1.78)	-4.91	(-7.44, -2.37)
<b>Caregiver Burden (BAS)</b>	65	-0.27	(-0.35, -0.19)	-0.27	(-0.35, -0.19)

### **3.3 APIM Analysis**

The results of the APIM analysis are depicted in **Figure 3**. For both people living with schizophrenia and their caregivers, positive actor effects less than one were observed, indicating stability. (for PLWS,  $\beta = 0.261$  (95% CI: 0.043, 0.479); for caregivers,  $\beta = 0.318$  (95% CI: 0.089, 0.548)). With regard to partner effects, caregivers' baseline hopefulness had a positive effect on PLWS' hopefulness at follow-up ( $\beta = 0.100$ ; 95% CI: -0.133, 0.332). Baseline hopefulness levels for people living with schizophrenia had a negative effect on caregiver hopefulness at follow-up ( $\beta = -0.106$ ; 95% CI: -0.322, 0.111).



**Figure 3: Results of APIM Analysis**

The joint effect for PLWS is 0.361 ( $0.261+0.100$ ) if baseline values in both dyad partners are above the mean, indicating that PLWS hopefulness at follow-up is 0.361 units above the mean. However, if caregiver hopefulness at baseline is below the mean, the joint effect for PLWS is 0.161 ( $0.261-0.100$ ) indicating a quicker return to the mean for the PLWS. The joint effect for caregivers is 0.212 ( $0.318 + (-0.106)$ ) if baseline values in both dyad partners are above the mean, indicating a rapid return to the mean for the caregiver. If PLWS hopefulness at baseline is below the mean, the joint effect for caregivers is 0.424 ( $0.318 - (-1.06)$ ), indicating that caregiver hopefulness at follow-up would be 0.424 units above the mean.

**Table 5: Mean Hopefulness by Time in PLWS & Caregivers**

	<i>PLWS</i>	<i>Caregivers</i>
Timepoint	Mean HHI Total (SD)	
<b>Baseline</b>	33.98 (6.98)	38.72 (6.67)
<b>Follow-Up</b>	37.30 (6.73)	41.00 (5.97)

## 4. Discussion

The current study examined the independent and dyadic processes of hopefulness within the PLWS-caregiver relationship. Hopefulness in our study population exhibits interdependence, in which dyad partners influence one another's level of hope over time. To the best of our knowledge, there is currently no existing literature on the interdependence of hopefulness among PLWS and their caregivers for comparison.

Family functioning was found to be an important correlate of hopefulness among both participant groups. Better family functioning was associated with higher levels of hopefulness, suggesting that the maintenance of a healthy relationship with one's dyadic partner is essential. This finding speaks to the interdependent nature of hopefulness among this population and suggests that facilitating healthy relationship dynamics could promote positive outcomes in both PLWS and caregivers.

Among PLWS, we found various psychosocial and clinical factors to be important correlates of hopefulness. Precisely, lower levels of internalized stigma, symptom severity, and disability were associated with higher levels of hopefulness. This aligns with findings from the limited studies that have explored correlates of hopefulness among PLWS.<sup>44-46</sup> These findings are correlations and do not indicate causation. Therefore, hope may also be contributing to reduced stigma, symptom severity, and disability.

Expected positive actor effects of hopefulness in both PLWS and caregivers were found, indicating stability in hopefulness over time. A positive partner effect was identified among PLWS. This indicates that higher caregiver hopefulness is associated with higher patient hopefulness at follow-up. Therefore, caregivers may play a significant role in influencing hopefulness levels among PLWS. Facilitating hopefulness in caregivers may ultimately be important for improving psychosocial and clinical outcomes in PLWS. A negative partner effect among caregivers was identified, indicating that higher patient hopefulness is associated with lower caregiver hopefulness at follow-up. This finding is only somewhat unexpected. There is literature to indicate that PLWS who have low insight (illness awareness) have more difficulties in the recovery process which could include goal setting alignment with clinicians and caregivers who are more or less hopeful about what is possible given symptomology and functioning.<sup>47,48</sup> Therefore, if PLWS have misguided hopefulness, caregivers could become less hopeful over time. Future studies should seek to confirm these findings given the exploratory nature of the study.

#### ***4.1 Study strengths and limitations***

This study has several limitations. A critical limitation to note is the small sample size of dyads (n=66). As the present study was a secondary analysis of data captured in the KUPAA RCT, it was not powered for the APIM analysis. The p-values were not considered for this reason and the results were interpreted in an exploratory manner.

Future studies with larger samples should investigate the dyadic relationship of hopefulness in order to make stronger conclusions.

Second, hopefulness is a latent construct that is subject to measurement error. The Herth Hope Index instrument has not been validated in Tanzania and may not have accurately captured the experience of hopefulness in our study population despite instrument translation and adaptation. It is important to note that the HHI in our study was highly correlated with the Hellen Siril, a local measure of hopefulness, indicating reliability. Future research is needed to validate the HHI tool more thoroughly among this population in Tanzania.

Lastly, the study sample may be not representative of the larger population of PLWS and their caregivers in Tanzania. Participants were eligible to participate if they were receiving outpatient services at either of the study sites. This criterion likely excluded several affected individuals due to the logistical and financial challenges associated with accessing care in Tanzania. Additionally, symptoms of PLWS had to be stable at the time of informed consent which likely led to the exclusion of affected individuals who were experiencing an acute episode of their illness at the time of study recruitment. As many of the PLWS in our study are reliant on their relatives for organizing their treatment and appointments, our study may exclude less involved caregivers. Consequently, hopefulness levels may be higher in the present study than in the general population of PLWS in the areas studied.

## ***4.2 Implications for policy and practice***

The present study highlights the positive influence that caregivers can have on hopefulness levels in their paired partner living with schizophrenia. This has significant implications for both policy and clinical practice, as it suggests that targeting hopefulness in PLWS-caregiver dyads is important for promoting better psychosocial and clinical outcomes.

Tanzania's Disabilities Act of 2010, which legally requires informal family caregivers to take financial and social responsibility of the affected individual, could be improved upon with a government-backed statutory financial safety net. While caregivers are need for a range of psychosocial supports, removing the additional financial burden could help them better carry out their roles effectively while remaining hopeful. Additionally, caregivers should be included in clinic and community-based interventions targeted at fostering hopefulness alongside patients. Similar to the intervention implemented by Chan et al. in persons recovering from cancer, a clinic-based hope intervention may consist of therapy on topics including goal setting, identification of pathways to achieve goals, and positive self-talk.<sup>49</sup> Healthcare providers may also be trained to facilitate hopefulness in both dyadic members throughout routine care.



### ***4.3 Implications for further research***

To the best of our knowledge, this study is the first to examine the longitudinal, dyadic relationship of hopefulness among PLWS and their caregivers in Tanzania. In order to gain a wider understanding of the issue at hand, future research should be more inclusive of participants' illness severity and accessibility of mental health services so as to have a more comprehensive study population. Future studies should also conduct APIM analyses on larger sample populations. It may be important to include other predictors of hopefulness using the APIM model.

Qualitative research may be particularly beneficial to conduct on this topic, as hopefulness is a multifaceted construct that is influenced by culture. Qualitative research should be conducted among both PLWS and their caregivers in order to further reveal the complexities of hopefulness as experienced in the family context.

## **5. Conclusion**

The results of our exploratory analysis suggest hopefulness may be important to consider as caregiver hopefulness is associated with improvements in PLWS hopefulness over time. Dyads of this nature are complex, and members are continuously influencing each other's outcomes. Neither schizophrenia nor hopefulness are experienced in a vacuum. Therefore, caregiver mental health and well-being are absolutely critical to consider when working to promote recovery in individuals living with schizophrenia. Future studies should further explore the dyadic relationship of hopefulness in this population, as hope is a powerful non-pharmacological tool that is underutilized in both high-resource and resource-constrained settings.

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