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Factors associated with non-adherence to clinic visits among patients with severe mental illness enrolled in the SMILE study in Uganda

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Abstract

Background Non-adherence to clinic visits among patients with severe mental illness (SMI) presents challenges to patient management, treatment outcomes, and research in resource-limited settings. This study investigated the factors associated with non-adherence to clinic visits in Uganda, using appointment attendance as a proxy for clinic adherence.

Methods This cohort study took place at Butabika National Referral Mental Hospital and Masaka Regional Referral Hospital from January to March 2018. A total of 1,201 participants with confirmed diagnoses of SMI were systematically sampled from over 3,000 outpatients. Data on socio-demographic, psychosocial, psychiatric, and behavioural factors were collected, with adherence defined as attending scheduled visits at 3, 6, 9, and 12 months post-enrolment. Descriptive statistics, bivariate, and multivariate logistic regression analyses were employed to identify significant predictors of non-adherence.

Results The overall prevalence of non-adherence to clinic visits was 20% (95% CI: 17.8 – 22.3%), with males showing higher rates (22.9%) compared to females (17.6%). Factors significantly associated with increased non-adherence included younger age, being treated at Butabika National Referral Mental Hospital, and alcohol use. Conversely, higher social support was linked to improved adherence. Among psychiatric variables, patients with major depressive disorder and severe psychiatric symptoms were more likely to miss appointments.

Conclusions The study highlights the multifaceted nature of non-adherence in patients with SMI, emphasizing the need for targeted interventions addressing socio-demographic, psychosocial, and clinical factors. Enhancing social support, managing psychiatric symptoms, and reducing substance use are critical strategies for improving adherence rates, which could, in turn, lead to better health outcomes and resource optimization in mental health services.

Keywords Severe mental illness, Non-adherence, Uganda, Social support, SMILE study

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Introduction

Non-adherence to clinic visits is a global challenge affecting the treatment outcomes of individuals with severe mental illness (SMI) [1–4]. In this study, severe mental illness (SMI) was operationalized per DSM-5 criteria as a diagnosable mental, behavioral, or emotional disorder (e.g., schizophrenia, bipolar disorder, or major depressive disorder) that results in serious functional impairment (e.g., limitations in daily activities, interpersonal functioning, or self-care) and typically requires sustained psychiatric intervention [5]. This issue (Non-adherence to clinic visits) is more pronounced in low- and middle-income countries (LMICs), where healthcare systems often face significant constraints [6]. In Uganda, mental health resources are often constrained, and understanding the dynamics of patient adherence to clinic visits is crucial for optimizing the care of patients with SMI [7, 8]. According to studies in high-income and Upper Middle-Income Countries, clinic appointment non-adherence rates among patients with SMI range from 19 to 65%, with factors such as stigma, forgetfulness, and lack of insight being prominent [9–15]. However, the dynamics of non-adherence in low- and middle-income countries (LMICs), particularly in Africa, are less well understood due to limited research in these regions.

Some recent studies in LMICs have begun shedding light on the burden of non-adherence to scheduled clinic visits among patients with SMI. For example, different studies in Nigeria have reported the different rates such as 32.6% [16], 25.7% [16] and 31% [17]. A study in KwaZulu Natal, South Africa reported a higher prevalence of 46.2% [18]. On the other hand, the reasons for missed appointments include financial constraints, stigma, substance use and lack of social support [19–21]. Several other factors have been reported to be associated with non-adherence to scheduled clinic visits among patients with SMIs, including transportation barriers [21], type of psychiatric diagnosis [22], maladaptive behaviours [23–25] and cultural perceptions and beliefs [26]. The importance of scheduled clinic visits cannot be overstated since this serves as a cornerstone for the management of the mental illness [21, 27]. However, non-adherence to scheduled clinic visits remains a pervasive issue, leading to incomplete data collection, compromised study outcomes and a limited understanding of the long-term implications of mental health interventions [8, 21].; Additionally, non-adherence to scheduled clinic visits is associated with increased patient morbidity and is a significant drain on health service resources [28].

Existing Ugandan studies on non-adherence among patients with SMI have identified critical barriers such as poverty, stigma, and healthcare access [29, 30]. However, these studies often relied on small samples, focused narrowly on urban settings, or lacked robust methodologies to assess multifactorial influences. For instance, prior work seldom examined the interplay of psychosocial, clinical, and behavioral factors longitudinally. This study addresses these gaps by leveraging a large, geographically diverse cohort and advanced statistical modeling to provide comprehensive insights into adherence determinants unique to Uganda's context. The intersection of the complex factors associated with non-adherence within the Ugandan context necessitates a dedicated examination to inform targeted interventions and enhance the overall success of mental health research initiatives. This study sought to address this void by examining the prevalence of missed clinic visits, exploring the associated factors, and discussing the implications of non-adherence for patient management and treatment outcomes among individuals with SMI in Uganda.

Materials and methods

Study design and site

This study is a secondary analysis of data from the SMILE study [30], which originally investigated HIV clinical trial preparedness among patients with severe mental illness in Uganda. While the parent study examined broad adherence factors including HIV risk and risky sexual behaviour, this secondary analysis specifically focuses on clinic visit adherence patterns within the same cohort, using appointment attendance as a proxy for adherence [30, 31]. The analysis investigated the relationship between variables affecting adherence to study visits (appointment attendance) which were used as a proxy measure for non-adherence to clinic visits among 1201 individuals with severe mental illness (SMI) who were enrolled from the out-patient departments of Butabika National Referral Mental Hospital (urban central) and the Department of Psychiatry, Masaka Regional Referral Hospital (rural southwestern) Uganda, between January-March 2018. Participants were assessed at baseline, followed up at 3 months, 6 months, 9 months and 12 months.

Butabika National Referral Mental Hospital offers general and specialised mental health services both to in-patients and out-patients. It has a current psychiatric bed occupancy of 1100 in-patients and sees about 30,000 psychiatric out-patients annually [32]. Masaka Regional Referral Hospital offers all services expected of a regional referral health facility, including psychiatric services. The Psychiatric Department at Masaka Regional Referral Hospital has a 30-bed capacity, offers in-patient service and an out-patient service. In the period between July 2018 to June 2019, the psychiatric department at Masaka Regional Referral Hospital attended to 8,260 out-patients [33–35].

Eligibility criteria

Severe mental illness (SMI) was operationalized as a condition whereby someone over the age of 18 years has (or had within the past year) one or more of the following diagnosable mental disorders: schizophrenia, bipolar affective disorder and recurrent major depressive disorder that caused serious functional impairment leading to at least one admission [32]. The diagnosis was confirmed by a review of the clinical records by a psychiatrist (member of the research team). At the time of enrollment into the study, the study participant must have been in remission and attending the out-patient departments of either Butabika National Referral Mental Hospital or Masaka Regional Referral Hospital [32]. Additional eligibility criteria included speaking either English or Luganda (the local language spoken in the study areas) [32]. Exclusion criteria were concurrent enrollment in another study (to avoid confounding effects or competing interventions that might influence adherence behavior), being in need of immediate medical attention, and being unable to understand the study assessment instruments for any reason [32].

Recruitment and data collection

Participants were recruited from outpatient clinics at Butabika and Masaka hospitals during the period from January to March 2018, following eligibility criteria outlined in the SMILE study [35]; The selection process involved systematic random sampling, where every second eligible patient on a clinic day was chosen to participate.; participants were followed up at 4 time periods (3, 6, 9 and 12 months) as shown in the study flow chart [32]. The trained research assistants (Psychiatric Clinical Officers and Psychiatric Nurses) gave potential participants information about the study before obtaining informed consent and assent to enroll into the study. Research assistants collected the data using structured, standardised, and locally translated assessment instruments [36–39]. Participants with predetermined high-risk criteria or severe psychiatric symptomatology [36, 38, 29] were referred to attending clinicians in the out-patient departments of the two participating hospitals (Fig 1).

Measures

To determine the pool of variables potentially related to non-adherence to clinic visits for this study, an expert team of specialists (psychiatrists, clinical psychologists) was convened who, informed by available evidence, developed a priori hypotheses about which characteristics were associated with study appointment attendance (see attached conceptual framework- Fig. 2). The expert team of specialists derived variables that were grouped under conceptual categories by the team and included: (i) socio-demographic characteristics (age, gender, study site, education level, religion, marital status, employment status, having enough food in the last month, Socio-economic status); (ii) psychosocial environment (social support, stigma, childhood trauma, sexual abuse, physical abuse, perception about HIV risk); (iii) psychiatric illness factors (psychiatric diagnosis, severity of depressive symptoms, severity of psychiatric symptoms, severity of manic symptoms, physical comorbidities); (iv) maladaptive behaviour (use of alcohol, use of tobacco, adherence to psychiatric medication). We examined each of these characteristics separately for association with adherence, and then evaluated across characteristics for association with adherence. As illustrated in Fig. 2, Non-adherence with study visits served as our proxy measure for clinic visit adherence, defined as missing ≥ 1 scheduled visits at 3, 6, 9, or 12 months. We justified this proxy because: (1) study visits coincided with routine clinical follow-ups at the same facilities; (2) both visit types involved identical care components (medication review, symptom monitoring); and (3) this approach has been validated in similar LMIC mental health studies [21]. While we acknowledge that clinical schedules can vary across individuals, in our setting, the SMILE study was designed in close coordination with standard outpatient care to minimize redundancy and enhance participant retention.

The assessment battery comprised of a structured and standardised, locally translated psychosocial instruments [36–39]. SMIs (schizophrenia, depression and bipolar affective disorder) were established through a two-step process: (1) the MINI International Neuropsychiatric Interview (version 7.2) administered by trained research assistants to assess symptoms against DSM-5 criteria, and (2) independent psychiatrist review of clinical records to confirm diagnosis and hospitalization history. This dual approach combined research-standardized assessment with real-world clinical documentation to ensure diagnostic accuracy. The interviews were conducted by trained mental health professionals (Psychiatric Nurse/Psychiatric Clinical Officer research assistants), who received specific training to ensure consistent and accurate administration of the Mini International Neuropsychiatric Interview version 7.2. The Mini International Neuropsychiatric Interview facilitated the identification of SMIs by systematically evaluating participants' symptoms against standardized diagnostic criteria. Diagnoses were confirmed through a combination of the MINI results, review of patient clinical records and clinical evaluations by the administering professionals, ensuring a comprehensive assessment of each participant's mental health status. Severity scores for depressive, manic, and general psychiatric symptoms were analyzed separately, as they were derived from different validated modules of the MINI (V7.0.2 DSM-5) and reflect distinct clinical dimensions. Aggregating them would obscure

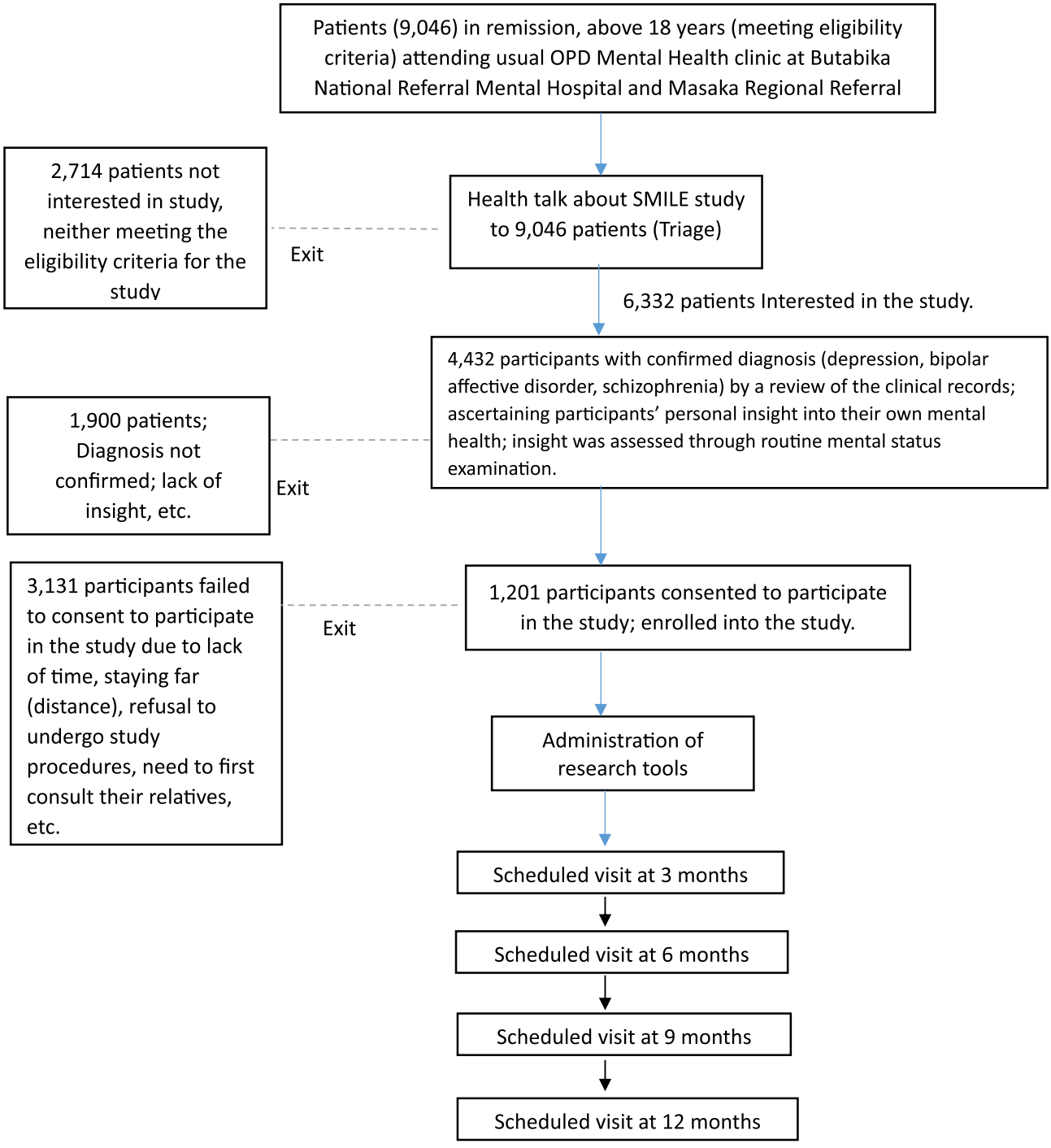

Fig. 1 Study Flow Chart showing recruitment and enrollment of participants in the SMILE study (January–March 2018)

diagnosis-specific patterns relevant to clinical interpretation. Similarly, the same trained Psychiatric Nurse/Psychiatric Clinical Officer research assistants administered other standardized measures which included; (a) The *Socio- economic index (SEI)* which was constructed from commonly available household items in a typical Ugandan households, this has previously been used in Uganda by this study group [38, 29, 40]. The SEI is a measure of socio-economic status based on household assets. It includes items commonly found in Ugandan households, such as electricity access, providing a culturally relevant assessment of economic status. (b) The *Multidimensional Scale of Perceived Social Support (MSPSS)* was used to assess for social support [41]. The MSPSS is a 12-item instrument that was designed to assess perceptions about support from family, friends and significant others. The

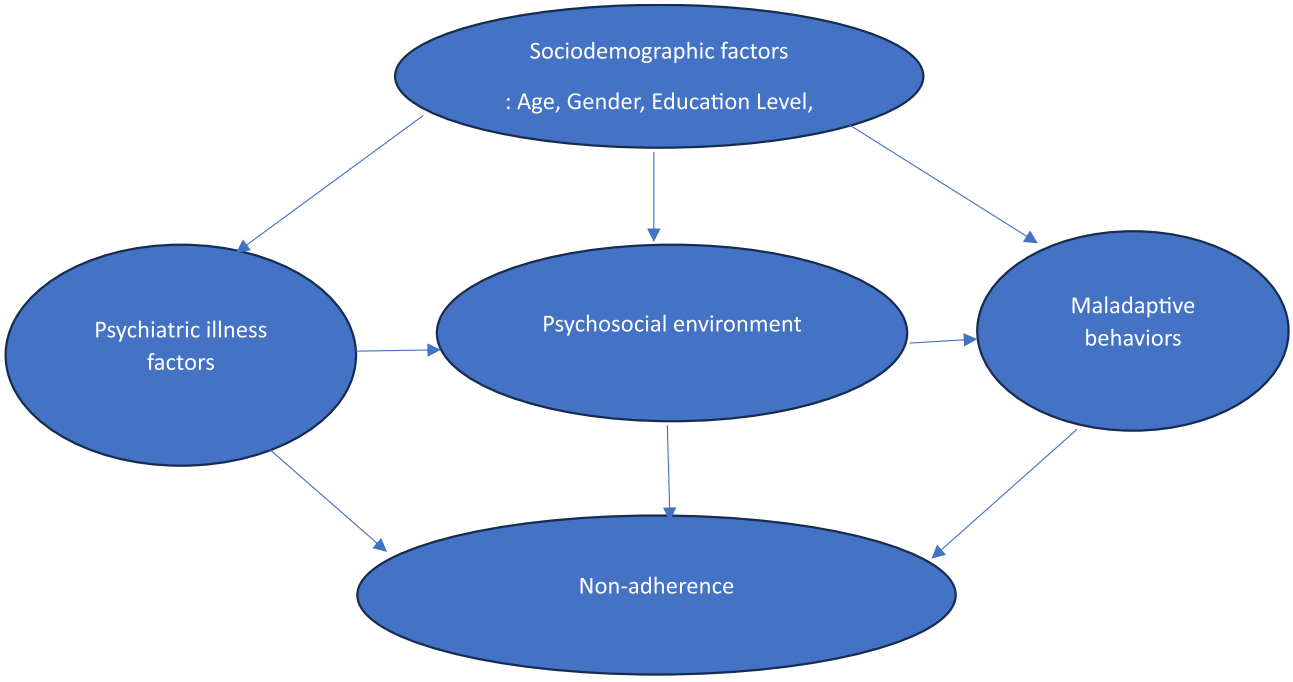

Fig. 2 Conceptual framework-Non-adherence to clinic visits

MSPSS has previously been translated into Luganda and used in local studies with good internal consistency ratios [37]. (c) The *Stigma Scale* was used to assess for mental health stigma [42]. This 28-tem questionnaire assesses for 'patient felt stigma' related to their mental illness, such as discrimination in education and social interactions. This instrument was used in the Ugandan socio-cultural context for the first time and it was therefore subjected to the translation/adaptation process, achieving a Cronbach's Alpha of 0.71, indicating good reliability. (d) The *Childhood Trauma Questionnaire-Short Form (CTQ-SF)* assessed for adverse life events in childhood [43]. This is a 28- item questionnaire that asks about negative life events (childhood trauma, including emotional, physical, and sexual abuse) experienced as a child and as an adolescent. The CTQ-SF has previously been translated into Luganda and used in local studies (It has been validated for use in Ugandan settings, making it suitable for understanding adverse childhood experiences.) with good internal consistency ratios [44]. (e) Items from the modified *Adverse life events module of the European Parasuicide Interview Schedule (EPSIS)* [36, 45] were used to assess for sexual abuse in adulthood. This tool assesses lifetime experiences of physical and sexual abuse in adulthood, providing insights into traumatic experiences that may influence adherence behaviours. The items that were used to inquire about sexual abuse assessed for previous exposure to a given trauma in the two time periods, 'later in life (from onset of adulthood, 18 years to 12 months before the study)' and 'in the last 12 months'. Similarly, the modified *Adverse life events module of the European Parasuicide Interview Schedule (EPSIS)* [36, 45] was used to assess for physical abuse in adulthood. The items that were used to inquire about physical abuse in adulthood assessed for previous exposure to a given trauma in the two time periods, 'later in life (from onset of adulthood, 18 years to 12 months before the study)' and 'in the last 12 months. (f) The *CAGE Substance Abuse Screening Tool* [46] was used to assess for alcohol use and alcohol drinking problems. The CAGE questionnaire is a 4-item tool widely used for screening alcohol abuse. It is named after key questions: Cut down, Annoyed, Guilty, and Eye-opener. A score of 2 or more indicates potential alcohol problems, and it is reliable in diverse settings. The CAGE questionnaire was developed in 1970 and remains one of the most reliable and easy screening instruments for the detection of alcoholism [46]. (g) *HIV testing* was undertaken using the HIV Determine strips for screening and the HIV Stat-pak for confirmatory test and SD Bioline as a tiebreaker based upon the algorithm recommended by the Uganda Ministry of Health [47]. (h) *Syphilis testing* was conducted using Treponema pallidum antibody tests to identify any co-occurring infections as recommended by Uganda Ministry of Health [48]. Details of all other measures and variables used in this study are attached (for details, see Additional file Table 3 attached separately).

Statistical analysis

Statistical analyses were conducted using Stata release 18 (StataCorp, TX, USA). Socio-demographic characteristics were described using frequencies and percentages and mean (standard deviation) for the continuous variables. A binary outcome variable "non-adherence to clinic visits" was generated as having missed one or more of the four clinic visits (3, 6, 9 &12 months) after enrolment. The prevalence of clinic visit non-adherence was calculated together with 95% CIs.

To investigate the association between "non-adherence to clinic visits" with socio-demographic and psychosocial, psychiatric illness factors and maladaptive behaviors, a two-step procedure was adopted. During the first step, bivariate associations between the outcome variables ("non-adherence to clinic visits") and the independent variables were assessed using simple logistic regression models. In the second step, those socio-demographic, psychosocial, psychiatric illness factors and maladaptive behavior factors that attained a level of significance of $P \leq 0.1$ (liberal cutoff point) at bivariate analyses were included in the final multivariable logistic regression model that assessed for the factors that were independently significantly associated with non-adherence to clinic visits.

Table 1 Socio-demographic characteristics

Factor	Never missed any visit (*n* = 961)	Missed at least one of 3,6,9 or 12 months (*n* = 240)
Age (mean SD)	38.1 (11.7)	35.7 (11.2)
Gender		
Male	421 (43.9%)	125 (52.1%)
Female	539 (56.1%)	115 (47.9%)
Study site		
Butabika NRMH	502(52.2%)	199(82.9%)
Masaka RRH	459(47.8%)	39(17.1%)
Education Level		
No Formal Education	29 (3.0%)	8 (3.3%)
Primary	367 (38.2%)	109 (45.4%)
Secondary	380 (39.6%)	80 (33.3%)
Tertiary	184 (19.2%)	43 (17.9%)
Religion		
Christian	791 (82.5%)	186 (77.5%)
Moslem	160 (16.7%)	52 (21.7%)
Other	8 (0.8%)	2 (0.8%)
Marital Status		
Currently married	309 (32.2%)	75 (31.3%)
Widowed	46 (4.8%)	11 (4.6%)
Separated/Divorced	231 (24.0%)	64 (26.7%)
Single	374 (39.0%)	90 (37.5%)
Employment Status		
Farmer/Fisherman	231 (24.1%)	73 (30.7%)
Professional	106 (11.0%)	33 (13.9%)
Informal	173 (18.0%)	33 (13.9%)
Unemployed	450 (46.9%)	99 (41.6%)
In the last month, did you or your family have enough food?		
Yes	816 (85.4%)	198 (83.9%)
No	140 (14.6%)	38 (16.1%)
Socio-economic status		
1–2	147 (15.3%)	42 (17.5%)
3–4	324 (33.7%)	85 (35.4%)
5–6	398 (41.4%)	88 (36.7%)
7–8	92 (9.6%)	25 (10.4%)

NRMH National Referral Mental Hospital, *RRH* Regional Referral Hospital, *SD* Standard Deviation

Ethical considerations

The study obtained ethical approvals from the Uganda Virus Research Institute's Research and Ethics Committee (GC/127/19/10/612) and the Uganda National Council of Science and Technology (HS 2337). Participants were given information about the study by trained study Psychiatric Clinical/Psychiatric Nurses and informed consent and assent sought before enrolment into the study. Participants found to have a SMI were provided healthcare and supported at the out-patient departments (OPDs) of their respective hospitals.

Results

On average, participants with 'non-adherence to clinic visits' were slightly younger (mean age 35.7, SD = 11.2) compared to those who consistently attended visits (mean age 38.1, SD = 11.7). Gender distribution varied, with a higher percentage of males among those with non-adherence to clinic visits (52.1%) compared to those who consistently attended (43.9%). Study site influenced visit attendance, with a higher proportion of participants from Masaka RRH missing visits (82.9%) compared to Butabika NRMH (52.2%). Educational attainment showed significant differences, as participants with tertiary education were less likely to miss visits (19.2%) compared to those with only primary education (45.4%) and lower tertiary education (17.9%). Participants with tertiary education were less likely to miss visits (19.2%) compared to those with only primary education (45.4%) and lower tertiary education (17.9%). Regarding religion, a higher percentage of participants with non-adherence to clinic visits were Moslem (21.7%) compared to those who consistently attended (16.7%). Marital status differences were observed, with 31.3% of those with non-adherence to clinic visits currently married, 4.6% widowed, 26.7% separated/divorced, and 37.5% single, while among those who consistently attended visits, these percentages were 32.2%, 4.8%, 24.0%, and 39.0%, respectively (Table 1).

The prevalence of non-adherence to clinic visits, defined as missing at least one visit out of 3, 6, 9, or 12 months, was observed in 20% (95% CI: 17.8–22.3%) of

the study population, with males exhibiting higher rates (22.9%) than females (17.6%) (Table 2).

Table 2 Prevalence of outcome (missing at least one visit of 3, 6, 9 & 12 months)

Prevalence	Combined (95% CI)	Males (95%CI)	Females (95%CI)
Non-adherence	***n*=240 20% (17.8; 22.3)**	***n*=125 22.9% (19.6; 26.6)**	***n*=115 17.6% (14.8; 20.7)**
Time point	Number missing at that visit		
3 months	89 (7.4%)		
6 months	118 (9.8%)		
9 months	101 (8.4%)		
12 months	98 (8.2%)		

Socio-demographic characteristics

Non-adherence patterns revealed consistent demographic disparities across multiple dimensions. Younger individuals and male participants demonstrated markedly higher rates of missed visits, with particularly pronounced disparities between the National referral hospital (Butabika) and Regional Referral Hospital/facility (Masaka) that persisted after adjustment for travel distance. While females showed consistently better adherence than males, educational attainment revealed only a non-significant gradient relationship with appointment attendance. Participants experiencing socioeconomic challenges, including food insecurity and lower asset-based wealth, were disproportionately represented among those missing visits.

(Complete statistical results, including adjusted models, are presented in Table 1 and Additional file Table 3)

Psychosocial environment

Psychosocial factors demonstrated clear differential impacts on adherence behaviors, with social support emerging as a consistent protective factor—lower perceived support was associated with higher non-adherence, underscoring the critical role of social networks in treatment engagement. Alcohol use constituted the most significant modifiable risk factor, showing strong associations with missed visits. While heightened HIV risk perception showed a tentative positive relationship with non-adherence, other trauma-related factors including stigma, childhood trauma, and physical or sexual abuse histories revealed no meaningful associations. These patterns remained robust after adjustment for clinical and demographic confounders (see Additional file Table 3 for complete statistical outputs).

Psychiatric illness factors

The analysis identified clinically significant patterns in treatment adherence, with mood disorders—particularly major depressive disorders showing the strongest association with missed visits. Patients experiencing more severe depressive symptoms or greater general psychiatric symptom burden demonstrated progressively worse adherence, highlighting symptom severity as a key determinant of disengagement. Each symptom severity domain was modeled independently to maintain diagnostic clarity and reflect specific symptom trajectories associated with clinic attendance behavior. Notably, these patterns emerged independently of manic symptom severity and physical comorbidities (including HIV/syphilis status), which showed no meaningful associations with attendance. All findings remained robust after adjustment for demographic and psychosocial confounders (see Additional file Table 4 for complete statistical outputs).

Maladaptive behavior

Alcohol use emerged as both the most significant behavioural predictor and key modifiable risk factor for missed visits, demonstrating a strong, consistent association with non-adherence. In contrast, neither tobacco use nor self-reported adherence to psychiatric medications showed any meaningful relationship with clinic attendance patterns. These findings remained robust after adjustment for relevant clinical and demographic characteristics (complete statistical results, including adjusted models, appear in Additional file Table 3).

Discussion

In this study, we determined the prevalence of non-adherence to clinic visits, explored the associated factors, and discussed the potential implications of non-adherence for patient management and treatment outcomes among individuals with SMI in Uganda. The prevalence of non-adherence in our sample was 20%. The main factors associated with non-adherence were age, gender, study site, socioeconomic status, maladaptive behaviours, environmental factors and psychiatric diagnosis. The observed non-adherence patterns have important implications for the management of SMI and treatment outcomes, as they highlight key risk factors that may disrupt continuity of care.

Prevalence of non-adherence to scheduled clinic visits

The observed prevalence of 20% non-adherence to scheduled clinic visits among patients with severe mental illness (SMI) is consistent with some international studies, such as the 19% reported by Cheng et al. (2014) in Taiwan [14]. However, it is notably lower than figures reported in high-income countries [e.g., 26.7% in Canada [49] and studies from other sub-Saharan African countries [For instance, Nigerian studies reported rates of 32.6% [19],

25.7% [16], while Ramlucken and Sibiya (2018) documented a prevalence of 46.2% in KwaZulu Natal, South Africa [18].

These variations may be attributed to differences in the operational definitions of non-adherence (e.g., missed first appointments versus follow-up visits), characteristics of the study populations, methodological approaches, and sample sizes. In our study, non-adherence was defined as missing at least one of four scheduled appointments over a 12-month period, whereas other studies used different thresholds, such as < 80% attendance. Furthermore, our sample size of 1,201 participants was relatively large compared to most referenced studies, which may have contributed to more stable estimates.

Despite geographic and cultural differences, the similarity in non-adherence rates across some settings suggests the presence of shared structural and psychosocial barriers. Factors such as stigma, cognitive impairments, and limited access to mental health services are likely universal barriers that transcend cultural and regional boundaries, influencing similar non-adherence patterns globally [50–52]. Moreover, the unique contexts of these studies likely encompassed factors mitigating non-adherence, highlighting the importance of considering diverse contextual elements when interpreting and comparing adherence rates across different populations and regions. Additionally, methodological similarities in how adherence was defined and measured in both studies could have contributed to the concordant prevalence rates. Cheng et al. (2014) and the current study employed similar criteria for measuring non-adherence, such as missing at least one clinic visit within a specified timeframe, which might have contributed to the observed alignment in prevalence rates.

However, the 20% prevalence of non-adherence observed in this study is lower than the 27–28% prevalence reported in 2019/2020 for the United States [9], 26.7% for psychiatric patients in Canada [10], 31.4% for patients with Schizophrenia in Thailand [11]. The prevalence rate (20%) from this study was also lower than the prevalence rates of the following studies; 32.6% reported by Akhigbe et al. (2014) in a study about the Prevalence and correlates of missed first appointments among outpatients at a psychiatric hospital in Nigeria [19]; 25.7% reported by Nwefoh et al. (2018) in a study about the prevalence of missed first outpatient appointment in South Eastern Nigerian [16]; 31% reported by Thomas et al. (2018) in a study of people living with schizophrenia in Benin [17]; 46.2% reported by Ramlucken and Sibiya (2018) in a study about a prevalence of missed appointments among outpatient mental health care users in uMgungundlovu District, Kwazulu Natal, South Africa [18]. Several factors account for the discrepancy between the observed prevalence of non-adherence to scheduled clinical visits and the prevalence rates reported in the foregoing studies.

Firstly, a plausible explanation for the variations in prevalence across studies lies in the differences in defining and measuring non-adherence. In the current study, non-adherence was operationalized as missing at least one clinic visit within the 3, 6, 9, or 12-month timeframe. In contrast, Ray [9] defined non-adherence as neither calling nor showing up for a clinic appointment and cancelling within 24 h of the appointment. Meanwhile, Nwefoh, Aguocha [16] and Ramlucken and Sibiya [18] characterized non-adherence as a failure of patients to attend scheduled follow-up appointments post-hospital discharge. Thanapathomsinchai et al. (2016) adopted a different approach, categorizing non-adherents as patients who attended the psychiatric clinic for less than 80% of the total appointed visits. The variation in definitions underscores the importance of standardizing non-adherence criteria for cross-study comparisons to facilitate more accurate comparisons and interpretations of prevalence rates.

The comparatively lower non-adherence rate of 20% in this study gains importance in light of the substantial sample size disparities. In contrast to the larger and more robust cohort of 1201 subjects in our study, previous investigations, such as those by Ray [9] with 49 subjects [9], Thanapathomsinchai et al. (2016) with 280 subjects [11], Akhigbe, Morakinyo [19] with 310 subjects [19], Nwefoh, Aguocha [16] with 311 subjects [16], Thomas, Olotu [17] with 275 subjects [17], and Ramlucken and Sibiya [18] with 182 subjects [18]; most studies employed notably smaller samples size than the one used in this study (1201 subjects). Probably, the smaller sample sizes in these studies may have contributed to the relatively higher reported non-adherence rates to scheduled clinical visits. Limited sample sizes can pose challenges in capturing the full spectrum of adherence behaviors, potentially leading to an overestimation of non-adherence rates. In contrast, the current study's larger sample size provides a more comprehensive understanding of adherence patterns among patients with severe mental illness, underscoring the importance of robust sampling for accurate and meaningful insights into adherence behaviors.

Additionally, the observed prevalence of non-adherence to scheduled clinic visits might be lower than what is reflected in prior studies on account of different contexts in which the studies were conducted. Variations in non-adherence prevalence may reflect differences in healthcare infrastructure, cultural attitudes, and accessibility to mental health services across regions.

Similarly, variations in prevalence rates might be attributed to the specific demographic characteristics of the studied populations. Notably, all the other referenced

studies concentrated solely on patients diagnosed with schizophrenia, while the present study encompassed a broader spectrum of severe mental illnesses (SMI). Incorporating a diverse range of severe mental illness diagnoses in this research likely contributes to variability in adherence behaviors, as different psychiatric conditions might elicit distinct treatment experiences and adherence behaviors. This underscores the importance of considering the heterogeneity within the SMI population when interpreting and comparing adherence rates across studies focused on specific psychiatric diagnoses.

Lastly, the time period in which the studies were conducted may also play a role in the reported prevalence. Temporal differences, such as Akhigbe et al.'s 2014 study compared to more recent works from 2018 to 2021, may also influence prevalence rates. Changes in mental healthcare systems, policies, and attitudes towards mental illness over time may impact the prevalence of non-adherence.

On the contrary, the observed high prevalence of non-adherence among males in this study might be influenced by cultural norms prevalent in Uganda, where societal expectations often place a significant emphasis on men as breadwinners. This cultural context may contribute to a prioritization of work responsibilities over seeking mental health treatment among men [53]. The traditional expectations of masculinity, emphasizing strength and self-reliance, may contribute to a reluctance among men to acknowledge and address mental health concerns openly. Consequently, the societal pressure for men to fulfill the role of primary providers might hinder their willingness to prioritize and adhere to scheduled mental health clinic visits. This cultural lens provides a nuanced understanding of gender-specific factors influencing non-adherence in this population, underscoring the need for culturally sensitive interventions to enhance mental health-seeking behaviors, particularly among men in Uganda.

Socio-demographic characteristics associated with non-adherence to scheduled clinic visits

The association between younger age and higher non-adherence may reflect life-stage-related factors, such as greater mobility, weaker support networks, and prioritization of work or social obligations over clinic visits. Similarly, this relationship may be explained by the likelihood that older individuals possess more stable and supportive social networks, thereby creating an environment conducive to adherence to scheduled clinic visits. It highlights the relevance of age-related social support dynamics in the specific context of adherence to scheduled psychiatric clinic visits, underscoring the importance of age-specific considerations in interventions aimed at improving adherence outcomes among persons with SMI. However, the observed decline in the odds of non-adherence with each year increase in age contrasts with prior research that did not explicitly consider age as a predictor for non-adherence. This divergence may be attributed to methodological considerations and the specific research questions guiding those studies, which may not have prioritized the examination of age as a distinct predictor for non-adherence to scheduled clinic visits.

Study Site was found to be a significant predictor of non-adherence among patients with SMI. Participants from Butabika NRMH had significantly higher odds of non-adherence compared to those from Masaka RRH. The significant difference in non-adherence between participants from Butabika National Referral Mental Hospital (NRMH) and Masaka Regional Referral Hospital (RRH) may be influenced by the varied catchment areas and geographic reach of these healthcare facilities. Butabika NRMH, serving as a national referral hospital, offers mental healthcare to patients from a broader jurisdiction, including those from distant regions. The increased prevalence of non-adherence at Butabika National Referral Mental Hospital could be associated with the greater distances patients have to travel for clinic visits, adding logistical challenges and potentially impacting adherence rates. This aligns with Ramlucken and Sibiya [18] who found travel distance to clinic appointment location was a significant predictor of non-adherence. Furthermore, factors such as the burden of work for rent, food, and sustenance in the city, along with the rigors and costs of transportation to/from the clinic, may contribute to the observed higher non-adherence rates at the national referral hospital. In contrast, the Masaka RRH, with a more regional focus, may experience relatively shorter travel distances for a significant portion of its patient population, potentially easing the logistical barriers and facilitating better adherence.

Gender was found to be a significant predictor of non-adherence to clinic visits with Females having lower odds of non-adherence compared to males. This finding is consistent with previous research [14] which also found males with SMI more likely to be non-adherent to appointed clinic visits compared to females. The gender disparity—where males were more likely to be non-adherent—may relate to sociocultural expectations that discourage help-seeking behaviors among men, especially in patriarchal settings like Uganda. These findings emphasize the need for gender- and age-sensitive approaches in mental health programming.

Interestingly, education level was not found to be a determinant of non-adherence in this study. This finding aligns with the results of the reviewed studies, which correspondingly did not identify education as a significant predictor of non-adherence to scheduled clinic visits. The consistent lack of significance regarding education across

studies suggests that, in this context, factors other than educational attainment may play a more substantial role in influencing adherence behaviors among individuals with severe mental illness.

This study highlights the need for targeted interventions to improve adherence, particularly among younger males and those with limited social support, who face compounded challenges in maintaining clinic engagement [8].

Psychosocial and environmental factors associated with non-adherence to clinic visits

Non-adherence to clinic visits in patients with severe mental illness is significantly influenced by psychosocial environmental factors. Results from this study indicate that a decrease in social support was associated with increased odds of non-adherence; findings from this study rhyme with a previous study which established that lower levels of social support are associated with higher odds of non-adherence, underscoring the importance of robust support systems in enhancing clinic visit adherence [21]. Surprisingly, this study established that stigma did not show significant associations with non-adherence to clinic visits; findings from this study contradicts with findings from a previous study which established that stigma surrounding mental health issues can deter patients from attending scheduled visits due to fear of discrimination or misunderstanding within the community [27]. Addressing these psychosocial barriers through community education and supportive interventions can potentially increase adherence rates.

Psychiatric illness factors associated with non-adherence to scheduled clinic visits

This study's findings reinforce the importance of mood disorders—particularly depressive syndromes—as risk factors for disengagement from care. Participants with bipolar affective disorder, major depressive disorder, and those reporting higher severity of depressive symptoms had significantly higher odds of non-adherence to clinic visits. These findings align with existing evidence, including prior research showing that patients with more severe symptoms, especially those with major depressive disorder, are more likely to miss scheduled appointments [11].

The association between psychiatric symptom severity and non-adherence may be explained by cognitive impairments, motivational deficits, and emotional dysregulation, which can interfere with planning and sustaining regular engagement with care. In contrast, participants with manic symptoms did not demonstrate similar patterns of non-adherence, potentially due to greater illness insight variability or differential care-seeking behavior during manic episodes.

These patterns underscore the need for tailored clinical strategies that address diagnosis-specific symptom burdens and treatment challenges in mental health care. However, the analysis did not incorporate patient, family, or cultural perspectives that could influence adherence behaviors. Understanding these contextual and explanatory models is essential for designing culturally responsive interventions.

Maladaptive behaviours associated with non-adherence to scheduled clinic visits

Maladaptive behaviors, notably substance use, are strongly linked to non-adherence. The association between alcohol use and non-adherence highlights a critical area for intervention, given the disruptive role of substance use in continuity of psychiatric care. This study established that patients engaging in alcohol use demonstrated higher odds of missing scheduled clinic visits, disrupting treatment continuity; findings from this study rhyme with a previous study which revealed that patients engaging in alcohol use have higher odds of missing clinic visits [25]. The 'alcohol use behavior' may interfere with the organization required to adhere to scheduled appointments and can exacerbate psychiatric symptoms, leading to decreased clinic attendance. Integrated mental health and substance use interventions could mitigate this barrier, thus improve adherence [54, 55].

Implications for mental health services and policy in Uganda

Our findings highlight critical opportunities to strengthen mental health systems in Uganda by addressing modifiable barriers to clinic adherence. Three priority areas emerge:

1. Service-Level Interventions

Task-shifting: Deploy Uganda's existing network of psychiatric clinical officers and community health workers to conduct targeted home visits for high-risk groups (e.g., younger males, individuals with low social support), ensuring continuity of care between appointments.

Integrated care: Combine mental health and substance use interventions at primary care clinics, with screening and brief interventions for alcohol use embedded in routine psychiatric follow-ups.

2. Policy Actions

Transport subsidies: Advocate for national policy reforms to subsidize travel costs for clinic visits, particularly for rural patients attending Butabika National Referral Hospital, where distance disproportionately affects adherence.

Anti-stigma campaigns: Partner with Uganda's Ministry of Health to scale public awareness programs addressing cultural stigma, leveraging community leaders and media to reframe mental illness as treatable.

3. Resource Allocation

Implement the decentralization policy: Extend and Improve upon the existing psychiatric services at all regional referral hospitals and extend psychiatric services to all Health Center fours (HC IV) and Health Centre threes (HC III) countrywide to reduce travel burdens, using lessons from Uganda's HIV decentralization efforts.

Technology: Pilot low-cost mHealth solutions (e.g., SMS reminders, mobile money incentives for attendance), adapting platforms successfully used in Uganda's HIV programs. For Example: A bundled intervention pairing community health worker outreach with SMS reminders could address both logistical barriers (transport) and clinical risks (alcohol use), while costing less than centralized care models.

Limitations

This study has several limitations that should be considered when interpreting the findings. First, while the use of clinical records provided a reliable source for adherence data, potential gaps in record-keeping or inaccuracies in appointment documentation could have influenced the reported prevalence of non-adherence. Second, the study was conducted in two major health facilities in Uganda, Butabika National Referral Mental Hospital and Masaka Regional Referral Hospital, which, while capturing both urban and rural settings, may not fully represent adherence behaviors in other regions of Uganda or low- and middle-income countries (LMICs) with different healthcare infrastructures and cultural contexts. Third, the study's longitudinal design allowed for a detailed analysis of adherence over time; however, unmeasured time-varying factors, such as changes in social support or access to transportation, could have influenced adherence behaviors. Fourth, while robust, standardized measures were used to assess psychosocial and clinical variables, residual confounding from unmeasured variables cannot be ruled out. Fifth, this study did not explore patient, family, or cultural explanatory models of illness and treatment. These perspectives—particularly cultural beliefs, family influences, and traditional healing practices—may shape perceptions of mental illness and contribute significantly to non-adherence, and their exclusion limits the comprehensiveness of our findings. Understanding these socio-cultural dimensions is critical for designing culturally responsive interventions and should be explored in future research. Finally, approximately two-thirds of eligible individuals declined participation. While detailed data on non-consenters were not collected, it is plausible that their characteristics differed from those who consented, potentially introducing selection bias. These individuals may have experienced more severe illness, higher levels of stigma, or greater structural barriers to accessing care—all of which could affect adherence patterns and limit the generalizability of our findings.

Conclusion

The study highlights that non-adherence to clinic visits among patients with severe mental illness is a multifaceted issue influenced by psychosocial environments, psychiatric illness factors, and maladaptive behaviors. Addressing non-adherence to clinic visits among individuals with severe mental illness requires comprehensive strategies. These should include targeted interventions for psychiatric symptoms, robust psychosocial support systems, and integrated treatment approaches for substance use disorders, aiming to enhance clinic attendance and overall health outcomes. Future studies should also explore the role of cultural, familial, and patient-specific beliefs to fully capture the complex drivers of adherence in this setting.

Abbreviations

SMI	Severe Mental Illness
LMIC	Low- and Middle-Income Countries
BMC	BioMed Central
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
SEI	Socio-Economic Index
MSPSS	Multidimensional Scale of Perceived Social Support
CTQ-SF	Childhood Trauma Questionnaire - Short Form
EPSIS	European Parasuicide Interview Schedule
CAGE	Cut down, Annoyed, Guilty, Eye opener (Substance Abuse Screening Tool)
OPD	Outpatient Department
NRMH	National Referral Mental Hospital
RRH	Regional Referral Hospital
AOR	Adjusted Odds Ratio
CI	Confidence Interval
HIV	Human Immunodeficiency Virus

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12888-025-07121-7.

Additional file 1. Table 3. Results for fitting a multivariate logistic regression model.

Additional file 2. Table 4. Measures and variables for the study.

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Clinical trial registration
Not applicable, as this study is not a clinical trial.

Authors' contributions
RSM, WS, GZR, PA, CB, AK, RR, JI, CT, KDG, VP, MN and EK have made substantial contributions to conception, design, acquisition of data, drafting the manuscript, revising it critically and gave the final approval of this version to be published. WS did the analysis and interpretation of data. Each author participated sufficiently in this work and takes public responsibility for appropriate portions of the content.

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Data availability
All data generated or analysed during this study are included in this published article [and its supplementary information files].

Declarations

Ethics approval and consent to participate
Ethical clearance was provided by the Uganda Virus Research Institute's Research and Ethics Committee (GC/127/19/10/612) and the Uganda National Council of Science and Technology (HS 2337). This study was conducted in accordance with the ethical principles outlined in the Declaration of Helsinki. Participants were given information about the study by trained study Psychiatric Nurses/Psychiatric Clinical Officers (*In Uganda, clinical officers are mid-level healthcare providers who undergo 3 years of training in general medicine, with some specializing in psychiatry through additional certification. They are licensed to diagnose, treat, and manage mental health conditions under supervision, and form the backbone of psychiatric care in many resource-limited settings*) and informed consent and assent sought before enrolment into the study. Participants found to have a SMI were provided healthcare and supported at the out-patient departments (OPDs) of their respective hospitals. Informed consent and assent were obtained from all individual participants included in the study.

Consent for publication
Consent for publication was not applicable.

Competing interests
The authors declare no competing interests.

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