Recommendations to Address Barriers to Patient Portal Use Among Persons with Diabetes Seeking Care at Community Health Centers: A Qualitative Study

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Abstract

Background: Community Health Centers (CHCs) are safety-net healthcare facilities in the US that provide care for a substantial number of low-income, non-English speaking adults with type 2 diabetes (T2D). Whereas patient portals have been shown to be associated with significant improvements in diabetes self-management and outcomes, they remain underutilized in CHCs. Additionally, little is known about the specific barriers and facilitators to patient portal use in CHCs as well as strategies to address the barriers.

Objective: The objective of this qualitative study was to explore the barriers and facilitators of the use of patient portals for managing diabetes in two CHCs from the perspective of adults with T2D and clinicians (community health workers, nurses, nurse practitioners, and physicians) and to make recommendations on strategies to enhance usage

Methods: A qualitative description design was used. Twenty-one participants (13 clinicians and 8 adults with T2D) were purposively and conveniently selected from two CHCs. Adults with T2D were included if they were an established patient of one of the partner CHCs, ?18 years old, diagnosed with T2D ? 6 months, and able to read English or Spanish. Clinicians at our partner CHCs who provided care/services for adults with T2D were eligible for this study. Semi-structured interviews were conducted in either Spanish or English based on participant preference. Interviews were audio-recorded and transcribed. Spanish interviews were translated into English by a bilingual research assistant. Data were analyzed using a rapid content analysis method. Standards of rigor were implemented.

Results: Themes generated from interviews included perceived usefulness and challenges of the patient portal, strategies to improve patient portal use, and challenges in diabetes self-management. Participants were enthusiastic about the potential of the portal to improve access to health information and patient-provider communication. However, challenges of health/technology literacy, maintaining engagement, and clinician burden were identified. Standardized implementation strategies were recommended to raise awareness of patient portal benefits, provide simplified training and technology support, change clinic workflow to triage messages, customize portal notification messages, minimize clinician burden, and enhance the ease with which blood glucose data can be uploaded into the portal.

Conclusions: Adults with T2D and providers at CHCs continue to report pervasive challenges to patient portal use in CHCs. Providing training and technical support on patient portal use for patients with low literacy and implementing standardized patient portal use strategies to address the unique needs of patients receiving care at CHCs have potential to improve health equity and health outcomes associated with patient portal use.

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Abstract

The aims of this study were to determine if HIV symptoms among sexual minority men (SMM) formed clusters and to examine the sociodemographic and clinical characteristics that are associated with these clusters. We analyzed cross-sectional data from Ghanaian SMM (*N* = 225*)* living with HIV. We employed both principal component analysis and multivariable linear regression. Our findings indicate that sadness (64.0%) and headache (62.7%) were the most prevalent symptoms among our sample. Seven symptom clusters were identified: *neurological symptoms*, *psychological symptoms*, *gastrointestinal symptoms*, *dermatological symptoms*, *self-concept/self-esteem*, *weight/diet-related symptoms*, and *sleep quality and potential disturbances*. Late HIV diagnosis was significantly associated with higher distress scores for all symptom clusters except for the *self-concept/self-esteem* and *gastrointestinal symptoms* clusters. The findings emphasize the importance of early HIV symptom identification.

Keywords: Africa, Ghana, HIV, sexual minority men, symptom cluster

HIV symptom clusters among Sexual Minority Men in Ghana, West Africa: A cross-sectional study

Globally, men whose sexual histories include contact with other men have 26 times greater risk of HIV infection compared with the general population (World Health Organization, 2020). In Western and Central Africa, nearly 7 out of 10 new HIV infections are concentrated among men with same-gender sexual histories (Dah et al., 2021; Joint United Nations Program on HIV, 2020). In Ghana, there also exists a disparity among persons living with HIV, with the SMM population estimated to be at least eight times more likely to be living with HIV compared with the general population (Ali et al., 2019; Ghana AIDS Commission, 2012). HIV produces a wide range of symptoms that often co-occur in clusters. Symptom clusters are defined as two or more symptoms that are related to each other, usually co-occur and may or may not share a common etiology (Miaskowski & Meek, 2009). The clinical utility of understanding symptom clusters has been well established. Knowledge of symptom clusters can prompt clinicians to assess associated symptoms when one symptom belonging to a cluster is detected in a patient. Symptoms presenting in clusters can be early indications of HIV disease progression or of other underlying psychoneuroimmunological dysregulation that may warrant further medical evaluation and intervention. Clinicians' knowledge of symptom clusters may also enhance symptom management because the treatment of a symptom in one cluster may produce alleviation in a related symptom in the same cluster (Moens et al., 2015).

While symptom clusters have been well studied in other chronic conditions such as cancers (Dong et al., 2014), it remains an emerging field of inquiry in HIV. Earlier studies on HIV symptoms have focused on describing individual symptoms in isolation while not addressing the fact that in real life, persons with HIV experience multiple symptoms that, taken together, have detrimental effects on their quality of life and other health outcomes (Barger et al., 2023; Zhu et al., 2019). In a recent systematic review, researchers identified 13 studies that examined HIV symptom clusters using principal component analysis, exploratory and confirmatory factor analysis, network analysis, structural equation modeling, or hierarchical cluster analysis (Zhu et al., 2019). The common

symptom clusters that were reported across studies included “1) sad/depressed/loss of interest and nervous/anxious/worrying; 2) difficulty sleeping, problems with sex, and fatigue/loss of energy; 3) fever/chills/sweat, nausea/vomiting, and loss of appetite; 4) numbness, muscle aches, and joint pain; and 5) dizziness and headache” (Zhu et al., 2019, p. 126)zthat were not psychometrically validated (Zhu et al., 2019). Thus, there is the need for more standardized methods to effectively understand and address the complex symptomatology in HIV infection.

Despite the growing understanding of HIV symptom clusters, some major gaps still exist in the current literature. First, there is limited HIV symptom cluster research emanating from within Africa. This is a striking gap, given that in 2018 the continent of Africa accounted for almost two-thirds of all new HIV diagnoses worldwide (World Health Organization, 2019). To the best of our knowledge, only two HIV symptom cluster studies (via hierarchical cluster analysis) have been conducted in Africa—Uganda and South Africa (Moens et al., 2015; Namisango et al., 2015). In Uganda, using the Memorial Symptom Assessment Schedule (MSAS), five clusters were identified including *gastrointestinal symptoms*, *social/image symptoms*, *dermatological symptoms*, *persistently present symptoms*, and *anxiety* (Namisango et al., 2015). Another study conducted in both Uganda and South Africa similarly identified five clusters including: Cluster 1 (*participants with both sensory discomfort and eating difficulties symptoms*), Cluster 2 (*participants with psychological and gastrointestinal symptoms*), Cluster 3 (*participants with high pain and sensory disturbance symptoms*), Cluster 4 (*participants with high general HIV/AIDS symptoms*), and Cluster 5 (*those with low frequency of mood and cognitive symptoms*) (Moens et al., 2015). Second, previous HIV symptom cluster studies have either not focused on or included men with same-gender sexual histories (we henceforth refer to as sexual minority men [SMM]). This gap is especially important because given the additional stressors SMM experience (Gu et al., 2021), it is plausible that symptoms presentation among this population may differ in form and/or severity from what is observed in the general population of people living with HIV (PLWH). In most African countries,

same-gender sexualities are criminalized, which has been shown to be a barrier to HIV treatment engagement (Gu et al., 2021). Inadequate HIV treatment can influence both the emergence and exacerbation of HIV symptoms. Moreover, SMM in Africa also experience intersectional stigma (HIV, sexual, and gender non-conforming stigmas) that can increase their psychological distress (Kushwaha et al., 2017) and hence may exhibit different patterns of mental health-related HIV symptoms that have not been investigated. Despite progress in examining HIV symptom clusters among sexually diverse samples in African communities, there is a lack of empirical research focused on Ghanaian SMM.

To fill this gap, we conducted a secondary analysis to identify whether HIV symptoms formed clusters in a sample of Ghanaian SMM. We also examined the sociodemographic and clinical characteristics that are associated with HIV symptom cluster distress scores. The identification of symptom clusters and their correlates can allow clinicians to identify and target interventions for SMM living with HIV who are at a higher risk for poor HIV outcomes.

Methods

Study Design and Sample Selection

The present study was a secondary analysis of a cross-sectional study conducted from January 2017 to August 2017 among Ghanaian SMM living with HIV. Although data were collected about 7 years ago, the insight from the data remains germane in the Ghanaian context as recent studies have shown that barriers to care such as gender non-conforming stigma in the healthcare settings and criminalization of same sex activity persist (Abu-Ba’are et al., 2024; Saalim et al., 2023). For the purpose of the present analysis, data were accessed in August 2023. Details of participant recruitment, eligibility criteria, and sampling techniques have been described elsewhere (Gu et al., 2021). The study included 225 adult (≥ 18 years) cisgender men, with confirmed HIV diagnosis, who had no severe mental health conditions. Participants were recruited across four major cities in Ghana (Takoradi, Kumasi, Accra, and Koforidua) through referrals from peers as well as

HIV clinic staff, and Priorities on Rights & Sexual Health (PORSH)—a non-governmental organization specializing in health and human rights for sexual and gender minority Ghanaians.

Measures

HIV symptoms were measured by the HIV Symptom Distress Scale (SDS) (Marc et al., 2012). The SDS has 20 items rated on a 5-point Likert scale ranging from 1 to 5 (1 = *I do not have the symptom*, 2 = *I have the symptom, does not bother me*, 3 = *I have the symptom, bothers me a little*, 4 = *I have the symptom, bothers me sometimes*, and 5 = *I have the symptom, bothers me a lot*). The sixth item on the symptom scale was split into two separate items, one for nausea and the other for vomiting, resulting in a total of 21 items for the SDS scale in this study. The total score is determined by computing the mean score of all items. Higher scores reflect symptom distress. The scale has a Cronbach's alpha of 0.92 and a strong negative correlation with quality of life indicating adequate internal consistency and predictive validity, respectively (Harris et al., 2023; Marc et al., 2012).

HIV viral load is a measure of how well the individual's immune system can suppress the replication of HIV virus. Viral load was assessed by measuring the volume of HIV in serum using reverse transcriptase polymerase chain reaction.

Social isolation was measured by six items adapted from the Social Isolation Scale developed in a previous study (Zavaleta et al., 2014). Two items related to the construct of *external isolation*; the remaining four items measured *internal isolation*. External isolation items were rated on a 4-point Likert scale ranging from 1 – *Everyday* to 4 – *Never*. Example items on the scale includes, *How often in the previous two weeks have you spent time together with family?* Internal isolation items, on the other hand, were rated on a 5-point Likert scale ranging from *Very satisfied* to *Don't know*. An example internal isolation item includes, *How often in the previous two weeks have*

you spent time together with family? On both scales, higher scores are indicative of greater external or internal social isolation. For this study, the Cronbach's $\alpha\alpha$ for internal and external social isolation scales were .76 and .69, respectively.

Sociodemographic variables included age, monthly income, highest level of education completed, city of closest residence, marital status, sexual attraction, and church attendance.

Clinical variables included late HIV diagnosis and receipt of treatment for HIV infection. Late diagnosis was defined as experiencing HIV-related symptoms before a formal diagnosis of HIV disease is made and was assessed with a yes or no response option (Antinori et al., 2011). Receipt of treatment for HIV infection was assessed by responding *yes* or *no* to the question: "Are you taking any medications to treat your HIV?"

Ethics Statement

Ethical clearance for this study was obtained from the University of Rochester's Research Subjects Review Board (Approval No. 60120) and the Kwame Nkrumah University of Science & Technology Committee on Human Research, Publication, and Ethics (Approval No. CHRPE/AP/523/16). Written informed consent was obtained from eligible participants prior to data collection.

Procedure and Data Collection

Following recruitment, HIV diagnosis was confirmed by a rapid HIV antibody/antigen test. Study questionnaires were then administered to participants via Research Electronic Data Capture. To assess viral load, an authorized laboratory technician performed venipuncture to collect whole blood (5mL) in each of two 7mL ethylenediaminetetraacetic acid tubes. The tubes were labeled with participants identification code and held onsite in a locked refrigerator until its retrieval for transport

to a lab at Komfo Anokye Teaching Hospital within 16 hours for processing. An authorized lab technician used the participant identification code to record HIV viral load results in Research Electronic Data Capture. Specimen disposal followed standard biohazard protocols used by the Teaching Hospital lab.

Data Analysis

Statistical analyses were conducted using R 4.2.1. Descriptive analyses were performed for study covariates with frequencies and percentages calculated for categorical variables and means and standard deviations calculated for continuous variables. To understand symptom clusters among the 21 HIV-related symptoms, we summarized their prevalence and average symptom scores, and then performed principal component analysis (Mardia et al., 1989) based on the distress scores of symptoms. The number of factors was determined based on the factor loadings in orthogonal transformation through the varimax rotation and Kaiser normalization (Venables & Ripley, 1999) as well as expert clinical opinion. The cut off for the eigenvalue was 0.85, which is reasonable given the relatively small sample size. Symptoms with factor loadings greater than 0.47 were included in clusters. We used Cronbach's $\alpha\alpha$ coefficient to assess the internal consistency and reliability within each of the seven formulated clusters. We considered $\alpha > 0.6\alpha > 0.6$ as sufficient in our study context (i.e., sample size, previous results in HIV symptom clustering).

We further performed multivariable regression analyses to assess the association between demographic, clinical, and social characteristics, and the distress score of each symptom cluster. The outcomes in this set of analyses were averages of symptom scores within each cluster (with higher average scores indicating greater symptom distress). Linear regression coefficients and *p*-values based on two-sided *t*-tests were obtained for all analyses. For categorical variables with more than 2 levels, we also provided a joint *p*-value. Coefficients with $p < 0.05$ were considered statistically

significant. Our regression models were exploratory analyses, and we were not concerned about the type I error rate. The missing indicator method was used to address a small portion of missing or failed tests in the viral load, income, and internal social isolation variables in the regression models.

Results

Characteristics of Study Sample

The analyses included N = 225 SMM aged 18 years and above and living with HIV. Their characteristics are shown in Table 1. The majority (88.8%) of participants were aged 18–34 years, had completed high school education (70.2%), earned between 201 and 500 Ghanaian Cedis (46.5%), and were living in Greater Accra (60.4%). Ninety-four percent (94.2%) of participants were single, four-fifths reported church attendance regularly (79.2%), and about half were sexually attracted to men only (51.1%). Approximately one-third had late HIV diagnosis. More than half of the participants had HIV viral load above 200 (59.1%) and were receiving antiretroviral treatment (58.2%).

Prevalence of HIV Symptoms

The prevalence and average symptom distress scores are presented in Table 2. Two out of the 21 symptoms (i.e., *felt sad, down or depressed* and *headache*) were reported among more than 60% of participants. These two symptoms also had the highest distress scores (2.6 or above). Seventeen symptoms had a prevalence between 30%–60%. Two symptoms (i.e., *vomiting* and *hair loss and the changes in the way your hair looks*) had less than 30% prevalence. These two symptoms also had the lowest distress score, on average (1.51 or below).

HIV Symptom Clusters

Seven symptom clusters were identified. They included *neurological symptoms*,

psychological symptoms, *gastrointestinal symptoms*, *dermatological symptoms*, *self-concept/self-esteem symptoms*, *weight/diet-related symptoms*, and *sleep quality and potential disturbances*. The specific symptoms, factor loadings, and the internal consistency within each cluster as assessed by Cronbach's $\alpha\alpha$ are shown in Table 3. *Neurological symptoms* included headache, dizziness, fever, chills or sweat, and muscle pains. *Psychological symptoms* comprised sadness, anxiousness, trouble remembering, loss of energy, and pain. *Gastrointestinal symptoms* included nausea, vomiting, bloating, and diarrhea. *Dermatological symptoms* included hair loss and skin problems. The *self-concept/self-esteem* cluster had only two symptoms which were changes in body appearance and problems with having sex. The *diet/weight-related symptoms* included loss of appetite and weight loss.

Sociodemographic and Clinical Correlates of Symptom Clusters.

All symptom clusters had Cronbach's $\alpha\alpha$ > 0.6. The supplementary file contains the results of the bivariate associations between sociodemographic and clinical variables and symptom clusters. In the bivariate analysis, we found significant associations between city of residence and *gastrointestinal symptoms* (p = 0.04). Additionally, whereas external social support was significantly associated with *psychological symptoms* (p = 0.01) and *sleep quality* (p = 0.024), internal social support was associated with *neurological symptoms* (p = 0.013), *psychological symptoms* (p = 0.028), *diet-weight-related symptoms* (p = 0.022), and *sleep quality symptoms* (p = 0.030).

The results of the multivariable regression analyses are shown in Supplementary Tables S1 and S2. Late diagnosis was positively associated with *neurological symptoms*, *psychological symptoms*, *weight/diet-related symptoms*, *sleep quality and potential disturbances*, and *dermatological symptoms* with $\beta = \beta =$ 0.38 to 0.51. High viral load (200 or above) was only found to be positively and significantly associated with *dermatological symptoms* and *sleep quality and potential disturbances*, with $\beta = \beta =$ 0.38 and 0.68, respectively. A significant regional difference

was identified for *dermatological symptoms* (i.e., highest symptom distress in Kumasi). The city of Takoradi had the highest distress score in the symptom cluster of *self-concept/self-esteem*. In addition, internal social isolation was associated with greater distress score for *neurological symptoms* and *sleep quality and potential disturbances* ($\beta = 0.26$), while external social isolation related positively with *psychological symptoms*.

Overall, late diagnosis was significantly associated with the distress score in 5 out of 7 symptom clusters, whereas high viral load was only associated with 2 out of 7 symptom clusters. Lastly, age, education, income, sexual attraction, marital status, HIV treatment status, and external social isolation were not found to be significantly associated with the distress score of any symptom clusters.

Discussion

Our study highlights the occurrence of symptom clusters among SMM in Ghana, providing insight into how they affect a marginalized population of men that is understudied in extant literature. Clusters included *neurological symptoms, psychological symptoms, gastrointestinal symptoms, self-concept/self-esteem*, *dermatological symptoms*, *weight/diet-related symptoms*, and *sleep quality and potential disturbances*. We identified that late diagnosis was positively associated with five of the symptom clusters: *neurological symptoms*, *psychological symptoms*, *dermatological symptoms*, *weight/diet-related symptoms*, and *sleep quality*. This finding confirms the negative impact of late HIV diagnosis on management of symptoms and quality of life for people living with HIV (Getaneh et al., 2023), which highlights the need for availing routine testing services to SMM in Ghana to facilitate early diagnosis or use the testing opportunity to review prevention measures (Chone et al., 2022). Our study is especially important given that SMM is adversely affected by HIV in Ghana, with rates eight times greater than the general population (Ali et al., 2019; Ghana AIDS Commission, 2012). Additionally, this study, to our knowledge, is the first to examine symptom clusters among Ghanaian SMM.

Further, the study's identification of symptom clusters underscores the interconnected nature of these symptoms, with certain clusters often co-occurring. The clusters identified in our study align with findings from previous studies in Uganda and South Africa among non-Key population individuals with HIV in which *gastrointestinal symptoms, self-concept/self-esteem, dermatological symptoms, persistently present symptoms, and anxiety clusters* were identified (Namisango et al., 2015). Our study revealed that 17 out of 21 symptoms had a prevalence of 30%–60% among participants, suggesting that addressing these symptoms as clusters, rather than in isolation, may be more effective in improving the well-being of individuals living with HIV. Our findings warrant that interventions/therapy should focus on managing multiple symptoms at a time in order to improve the quality of life for people living with HIV. Since clusters occur together with or without the same cause, or are sometimes interrelated, clinicians should focus on managing them as clusters to improve the quality of life for persons living with HIV (Wilson et al., 2016). Such areas include pain management, sleep quality, anxiety, and depression (Wilson et al., 2016).

Our data demonstrated that symptoms related to psychological distress were highly prevalent. Two symptoms (*felt sad, down, or depressed* and *headache*) were reported more than 60% among participants and had the highest distress score. These findings highlight the need to address adverse psychological symptoms impacting people living with HIV. Ghanaian SMM are further impacted by same-sex intercourse stigma, criminalization of same sex activity, gender conformity stigma, societal attitudes toward SMM, and social isolation (Kushwaha et al., 2017; Nelson et al., 2021), which may additionally affect rates of depression and other mental health outcomes.

Previous research has shown that experiencing HIV stigma and identifying as a sexual minority negatively affects a person's mental health and worsens their health outcomes (Turan et al., 2017). Stigma against sexual minorities has been found to result in higher rates of negative mental health conditions (Fingerhut et al., 2010). It has been documented that societal and same-sex stigmas can result in low testing rates for HIV among Ghanaian SMM (Kushwaha et al., 2017). It has also

been found that depression affects ART adherence and HIV care in Sub-Saharan Africa, yet not much is known about how depression influences HIV treatment outcomes in Ghana (Nutor et al., 2023).

Addressing these psychological symptoms requires a multifaceted approach that targets both the symptoms themselves and the broader structural and societal factors contributing to stigma, which may also contribute to depression and other mental health conditions. This is especially imperative given minimal mental health service provision geared towards Ghanaian SMM.

Our study revealed significant regional disparities in the distress scores of distinct symptom clusters among SMM living with HIV in Ghana. Notably, Kumasi exhibited the highest distress score for *dermatological symptoms*, whereas Takoradi reported the most severe *self-concept/self-esteem* issues. The findings of regional disparities were not surprising as evidence from the second wave of the Ghana Men Study demonstrated regional differences in HIV prevalence, discriminatory experiences at the healthcare facilities, and risky sexual behaviors among SMM in Ghana (Ghana AIDS Commission [GAC] et al., 2017). These regional variations underscore the importance of recognizing the unique healthcare challenges faced by different geographic areas within Ghana. Understanding and addressing regional disparities are paramount for crafting effective, targeted interventions that cater to the specific needs of each locality. Health authorities and policymakers should heed these disparities when allocating healthcare resources and designing interventions aimed at improving the well-being of SMM living with HIV. Tailored strategies, responsive to the distinct symptom profiles and challenges in each region, should be developed and implemented to ensure equitable access to healthcare services and the promotion of holistic care. Acknowledging and proactively addressing these regional disparities can advance the goal of providing comprehensive, region-specific healthcare, SMM responsive, and non-stigmatizing support to SMM living with HIV across Ghana, ultimately enhancing the overall quality of life for this vulnerable population.

Strengths and Limitations

One of the strengths of our study lies in its focus on a specific and understudied population—

SMM living with HIV in Ghana. By examining symptom clusters and their correlates, we contribute valuable knowledge to the field of HIV care in a region where such research is limited. Additionally, our study's use of regression analysis allowed us to identify key associations between late diagnosis, symptom distress, and symptom clusters, providing actionable insights for healthcare providers and policymakers. Despite its contributions, our study is not without limitations. First, the data were collected through self-report, which may be subject to recall bias and social desirability bias. Additionally, the study sample primarily consisted of individuals residing in urban areas, potentially limiting the generalizability of our findings to other areas in Ghana. Furthermore, the cross-sectional nature of the study restricts our ability to establish causality between late diagnosis and symptom distress. Longitudinal studies are needed to explore the temporal relationships between these variables. Finally, as with any study, there may be unmeasured confounding factors that influence the observed associations.

Conclusion

Our study on SMM living with HIV in Ghana highlights the complex landscape of HIV symptomatology in a marginalized population. The findings emphasize the importance of early diagnosis, holistic symptom management, and considering regional disparities in healthcare interventions. The existence of symptom clusters means that HIV symptoms are interconnected and require comprehensive and multidisciplinary approaches to address them. It is important to implement community- and clinic-based approaches to better identify persons with significant symptom burden and institute supportive systems to link and retain them in HIV care. Furthermore, although not tested in this study, the widespread SMM stigma in Ghana may account for the high prevalence of psychological symptoms reported in this study. Future studies should examine this empirically.

Key Considerations

- Integrated Symptom Management: The identification of seven symptom clusters highlights the need for integrated symptom management approaches. Clinicians should consider treating symptoms within clusters holistically and collectively, as alleviating one symptom may

reduce the severity of associated symptoms.

- Impact of Late HIV Diagnosis: Late HIV diagnosis is associated with higher distress scores in multiple symptom clusters. Clinicians should emphasize the importance of early HIV testing and diagnosis to reduce the burden of symptom distress and improve quality of life for patients.

- Psychosocial Support: The high prevalence of psychological symptoms such as sadness among Ghanaian SMM living with HIV underscores the need for robust psychosocial support services. Addressing the intersectional stigma and societal attitudes towards SMM is crucial in mitigating psychological distress and improving mental health outcomes.

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