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Exploring Community-Based Organizations' Approaches in Compliance with Treatment of HIV/AIDs in Larkana District

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ABSTRACT

Objective: To analyze the factors affecting adherence to ART and the role of Community-based organizations in providing for individuals facing stigma and accessibility challenges.
Study Design: Qualitative, phenomenological study.
Place and Duration of Study: Taluka Hospital, Larkana District, Sindh, Pakistan, from May to July 2024.
Methodology: Interviews and structured conversations were conducted with individuals affected by HIV/AIDS and members of Community-Based Organizations (CBOs) to gather qualitative data on adherence challenges.
Results: Stigma emerges as a major obstacle, leading to social isolation, stress, and treatment dropout. Geographical and infrastructural barriers, especially in remote areas like the tehsil of Ratodero and Dokri, obstruct access to healthcare. Community organizations have provided psychosocial support and counseling to combat stigma, introduced mobile health devices, and held community awareness sessions. Yet, cultural resistance and traditional beliefs remain challenges. The financial strain of HIV/AIDS care worsens adherence problems, with many survivors unable to afford follow-up care despite donor assistance.
Conclusion: Community-based organizations are vital in connecting formal healthcare systems with marginalized communities. The study concludes that integrated medical, psychological, and community-led approaches are crucial for enhancing treatment adherence and reducing health disparities faced by human immunodeficiency virus-positive populations in Pakistan.

Keywords: Antiretroviral Therapy, Community Health Services, Healthcare Disparities, HIV, Medication Adherence, Pakistan, Social Stigma.

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INTRODUCTION

HIV/AIDS remains a significant global challenge, affecting approximately 38 million people and continuing to claim millions of lives annually despite effective treatment. Its severe impact, especially in low- and middle-income countries, requires management strategies that address broader public health issues beyond viral suppression to prevent AIDS and enhance quality of life.[1,2]

CBOs worked to raise human immunodeficiency virus awareness, combating the stigma that blocks access to care in misinformed, culturally sensitive communities.

In Larkana, stigma impeded HIV care, a challenge CBOs address by building trust through private counseling and peer support.[3,4] CBOs improve clinical outcomes and curb treatment costs in resource-limited settings by ensuring effective treatment adherence through essential counseling.[5]

Community-Based Organizations (CBOs) play a crucial role in HIV care in Larkana but face significant challenges due to geographic, financial, and cultural barriers. Social stigma, driven by cultural beliefs, leads to secrecy and isolation, undermining treatment adherence despite CBO efforts.[6] The rural-urban divide exacerbates this issue, as limited transportation and facilities hinder access to medication and appointments. While CBOs are working to improve access through mobile clinics and outreach, logistical and financial hurdles persist.[7]

This analysis underscores the need for context-specific HIV care strategies. With CBOs providing essential services to address distinct urban and rural challenges,[8,9] By addressing both clinical and sociocultural challenges through a tailored framework, the findings highlight CBOs as a crucial partner in ensuring treatment adherence.[10]

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METHODOLOGY

This qualitative, phenomenological study was conducted in the urban and rural locations of Ratodero and Dokri sub-districts in Larkana district, Sindh Pakistan from May to July 2024 after obtaining ethical approval from the Institutional Review Board (IRB) at the Health Services Academy Islamabad, Pakistan (Vide letter no.13632/50).

Inclusion Criteria: This study includes both male and female People Living with HIV/AIDS (PLWHA) aged 18 to 50 years who have been on antiretroviral therapy (ART) for at least six months, as well as representatives from key Community-Based Organizations (CBOs) actively involved in HIV/AIDS support programs in the Larkana district.

Exclusion Criteria: Those who were not diagnosed with HIV/AIDS, PLWHA who had been on ART for less than six months, and CBO representatives not directly working in the field of HIV/AIDS were excluded.

A total of 15 participants were recruited, comprising 10 PLWHA and 5 CBO representatives from both urban and rural settings. The study participants were a diverse group representing different healthcare landscapes. Purposive sampling was done to ensure participants had relevant experiences and insights into HIV treatment devotion.

The research was carried out in two stages. Throughout the first phase, data were collected through semi-structured interviews and focus group discussions (FGDs), each lasting 40-60 minutes. The interviews used open-ended questions about the participants' experiences with HIV treatment, challenges with adherence, and the supportive roles of CBOs. Detailed field notes were taken to capture non-verbal cues and contextual nuances.

In the additional phase, the audio-recorded data were transcribed, translated, and anonymized. The qualitative data were analyzed using a Systematic Qualitative Data Analysis (QDA) approach, grounded in Braun and Clarke's thematic analysis framework with an iterative process. Thematic analysis was done to identify recurring themes and patterns in the participants' responses. Next, codes were generated by reading and re-reading the transcripts and grouping these codes into broader categories. The themes that emerged reflected the participants' perspectives on treatment challenges, community support, and the role of CBOs in promoting adherence.

All participants provided informed consent, ensuring their confidentiality and the right to withdraw at any time without repercussion.

RESULTS

This qualitative study examined HIV/AIDS

Table-I: Summary of Key Interview Findings (n=7)

Interview	Age	Gender	Location	Adherence Level	Challenges	Support from CBOs
1	28	Female	Tehsil Ratodero (Rural)	High	Stigma at initial diagnosis	Counseling sessions from Humraz Organization
2	42	Male	Tehsil Dokri (Rural)	Low	Lack of awareness about HIV/AIDS	Awareness programs by Bridge Consultancy
3	34	Female	Larkana City (Urban)	Medium	Depression due to social isolation	Mental health support from Legal Aid Society.
4	45	Male	Tehsil Bahrani (Rural)	Medium	Financial issues and distrust in healthcare.	Financial aid and trust-building efforts by SPO
5	37	Male	Larkana City (Urban)	High	Managing side effects of ART	Medical advice and support by Humraz Organization.
6	50	Female	Tehsil Ratodero (Rural)	Low	Family opposition and limited healthcare access	Family engagement and mobile health services by SPO
7	40	Male	Tehsil Dokri (Rural)	Medium	Confusion about the ART regimen and reliance on traditional practices	Educational materials and collaboration with local healers by Bridge Consultancy

Table- II: Community-Based Organization (CBO) Representatives Interviews (n=4)

Interview	CBO name	Location	Focus Area	Key Activities	Challenges Faced	Perceived Effectiveness
1	Legal Aid Society	Larkana City (Urban)	HIV/AIDS treatment adherence	Counseling services.	Funding limitations.	High
2	Humraz Organization	Tehsil Ratodero (Rural)	HIV/AIDS awareness	Awareness programs and peer support groups.	Reaching remote populations.	Medium
3	Bridge Consultancy	Tehsil Dokri (Rural)	HIV/AIDS treatment and education	Mobile health services and educational workshops.	Cultural resistance to modern treatment.	Medium
4	Strengthening Participatory Organization (SPO)	Tehsil Bakrani (Rural)	HIV/AIDS community support	Financial support for ART and home visits by health workers.	Financial constraints and distrust in modern medicine.	Medium

treatment compliance in Larkana District, Sindh, addressing the complexities of disease severity and patient management in the region. Through patient interviews, discussions with Community-Based Organization (CBO) representatives, and focus group dialogues, we identify the key obstacles and facilitators affecting treatment adherence. This research highlights the main findings and contextualizes them within the broader landscape of HIV/AIDS care for patients on antiretroviral therapy in low-income areas. Qualitative approach was adopted, emphasizing in-depth insights from interviews and observations. This method allowed for a thorough examination of participants' experiences, ensuring that findings are contextually meaningful by integrating rich qualitative data. The analysis addresses research questions from multiple perspectives, yielding nuanced and reliable results. Table--I: Summary of Key Interview Findings from patients.

Interviews Table- II, with CBO representatives in Larkana District, reveal diverse approaches to improving ART adherence among PLHA. The Legal Aid Society focuses on urban issues like workplace discrimination, emphasizing the need for sustainable funding. In contrast, the Humraz Organization promotes HIV awareness through peer support in rural areas, facing challenges in reaching dispersed populations. Bridge Consultancy provides holistic treatment and mobile health services to combat cultural resistance in rural settings, while the Strengthening Participatory Organization addresses economic barriers with financial support for ART. Focus group discussions highlight the varying challenges and strategies between urban and rural CBOs Table-IV, emphasizing the need for tailored solutions and increased funding Table--III.

Table-III: Focus Group Discussions (FGDs) with CBO Representatives (n=2)

FGD	Participants	Key Discussion Points
1	5 representatives from urban CBOs	Challenges in urban areas (stigma, side effects management).
		Strategies for improving adherence (workplace programs, peer support).
		Suggestions for policy improvements to support CBOs.
2	5 representatives from rural CBOs	Unique challenges in rural areas (cultural resistance, geographic isolation).
		Importance of mobile clinics and transportation support.
		Need for increased funding and government support.

Patient Perspectives

Interviews with individuals living with HIV in the Larkana district reveal diverse experiences and barriers to care. Despite a limited sample, it captures a range of demographics, highlighting the complexity of treatment adherence across urban and rural settings.

Stigma remains a significant barrier, as illustrated by a 28-year-old woman who maintained high adherence despite initial stigma. The Hamraz organization's counselling supports patients in overcoming these hurdles, and knowledge gaps, especially in rural areas, were also noted; a 24-year-old man cited lack of awareness as a barrier. Underscoring the need for educational programs from CBOs like Bridge Accountancy.

Metal health issues affect adherence. As seen in a 34-year-old woman experiencing depression. Economic constraints were highlighted by a 45-year-old man, with financial aid from the strengthening participatory organization(SPO) showing promise in addressing these barriers. Ongoing support for ART side effects is crucial, with grassroots CBOs providing Valuable counseling.

Gender and gaps-specific challenges, like family pressure faced by a 50-year-old woman, emphasize the need for tailored interventions. Lastly, a 40-year-old man's confusion about treatment due to cultural beliefs highlights the importance of integrating traditional practices with modern medicine, a focus of the bridge consultancy.

The thematic analysis (Table- IV). Highlights critical insights on adherence in Larkana district, emphasizing the impact of stigma, geographical isolation, the integration of traditional practices, the need for comprehensive support, and the importance of economic empowerment.

Table- IV: Factors Affecting HIV Treatment Adherence: Stigma, Isolation, Culture, Support and Economics (n=5)

Themes	Key points
Stigma	A pervasive barrier mitigated through counseling and peer support highlights the need for community strategies.
Geographical isolation	Necessitates mobile clinics and home-based care; resource limitations can hinder sustainability.
Integration of Traditional Practices	Vital for improving adherence, effective communication, and culturally sensitive messaging are crucial.
Comprehensive Support	Emotional, educational, and logistical assistance from CBOs is essential for enhancing treatment adherence.
Economic Empowerment	Short-term financial aid is helpful; long-term solutions for economic stability are crucial for sustained adherence.

DISCUSSION

This study emphasizes the problems encountered by people with HIV (PLWH) in keeping adherence to antiretroviral therapy (ART) in Pakistan, specifically during some point of the COVID-19 pandemic. Identified key boundaries encompass stigma, economic limitations, and forgetfulness which correspond with the consequences from previous studies which highlighted the effect of stigma on ART retention and adherence in people residing with HIV.[11,13] The tension surrounding the revelation of one`s HIV status often consequences in social seclusion, exacerbating the demanding situations of acquiring care.[14,15]

Additionally, economic barriers substantially hinder adherence, as several PLWH reported difficulties in securing transportation to healthcare centers, mirroring findings from earlier studies that discovered that financial uncertainty often exacerbates health inequalities in resource-constrained environments. The dependence on casual help networks, like own circle of relatives and friends, surfaced as an extensive detail affecting adherence, emphasizing the need for network-based interventions that make use of social help (UNAIDS, 2020).[16,17]

Notably, even though several contributors skilled terrible results from ART, in addition they also discovered improvements in their physical fitness, reflecting the consequences, suggesting that the perceived benefits of ART may also inspire adherence. The use of virtual equipment like SMS reminders and telehealth offerings has confirmed capability in enhancing ART adherence, specifically at some point of the pandemic, as highlighted with the aid of using current systematic reviews.[18,19]

In total, tackling those barriers necessitates a various method that entails strengthening network help, providing economic aid, and incorporating era into HIV treatment to improve ART adherence and health outcomes for PLWH in Pakistan.[20,22]

LIMITATION OF STUDY

A limitation of this study is the reliance on self-reported adherence data. This may be subject to bias and inaccuracies due to stigma and social desirability concerns among participants.

CONCLUSION

This study underscores the vital role of Community-Based Organizations (CBOs) in supporting HIV/AIDS treatment adherence in District Larkana, an area facing significant healthcare challenges. CBOs are crucial social and cultural navigators, helping patients overcome deep-seated barriers like stigma and financial instability that formal healthcare systems often neglect.

By offering services such as home-based outreach and psychosocial counseling, CBOs directly address the complex issues affecting consistent ART adherence. However, the study also notes the precarious nature of these organizations, often hindered by limited funding and a lack of formal recognition. The findings serve as a strong call to action, advocating for the integration and support of CBOs within national health strategies to ensure the continuity of their essential work on the ground.

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Discolure:

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Authors' Contribution

Following authors have made substantial contributions to the manuscript as under:

HAC & SEK: Data acquisition, data analysis, critical review, approval of the final version to be published.

ZK & ASL: Study design, data interpretation, drafting the manuscript, critical review, approval of the final version to be published.

JK & RK: Conception, data acquisition, drafting the manuscript, approval of the final version to be published.

Authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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