

Original Article

Knowledge and perceptions of traditional birth attendants treating patients with HIV/AIDS and its related stigma and discrimination in District Multan, Pakistan.

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Abstract

Background: In Pakistan, only 20% of births are attended by a competent health expert, while traditional birth attendants (TBAs) deliver 90% of births. Therefore, in Pakistan, TBAs play a dynamic role in providing maternal health. This study assessed the Knowledge and Perceptions of TBAs treating patients with HIV/AIDS and its related stigma and discrimination in district Multan, Pakistan.

Methodology: A descriptive study design is used to conduct in-depth interviews and focus group discussions using a self-structured questionnaire with TBAs (FGDs = 4; n = 18) who were permanent residents. In addition, in-depth interviews (IDIs = 6) were conducted with women who had more than five years of experience and are still in practice. Participants were sampled through convenience sampling resulting in 100.

Results: The results of the study indicated that TBAs have heard about HIV/AIDS, but 53.5% did not have a clear understanding of the signs and symptoms of HIV/AIDS. The knowledge of this deadly virus and disease was perceived rather vaguely by the TBAs. Most (82%) of the respondents presented a discriminatory attitude towards the people living with HIV.

Conclusion: This study inferred that the targeted group was poorly informed about the actual concerns of HIV/AIDS and how to overcome stigma and discrimination. So, if we ought to cope with the hideous challenge of the pandemic and meet the 2030 goal of removing this pandemic, we are supposed to reposition and train our health care providers, especially TBAs, to meet up with the best global practices.

Keywords

TBA, HIV, AIDS, PLHIV, Pandemic, Gender stereotype, Stigma, Discrimination.



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Introduction

TBAs play a vital role in the provision of maternal health. In Pakistan, unsurprisingly, only 20% of births are attended by a competent health expert. On the other hand, in most rural regions, which are home to almost 70% of the population, 90% of the births are delivered by TBAs¹. That is why, after being acquainted with the significance of their work, the Family Health Project (FHP) of the Department of Health, Sindh, financed by the World Bank, attempted to boost the expertise and abilities of TBAs through comprehensive training courses. This project granted training to 650 TBAs in 10 districts. The training was delivered by the department of community health sciences of Aga Khan University, who acted as a technical consultant to the project².

Generally, TBAs act as an affected person's first and frequently preferred line of treatment. In rural regions, TBAs are more readily available to patients and are believed as a substitute for insufficient allopathic services³. An extensive range of tasks such as outreach and case finding, medical appointments, domestic visits, health education, patient education, and care management are carried out by TBAs⁴. The positive association between maternity care and TBAs training has been indicated through varying degrees of evidence. A significant increase in attributes was linked with TBAs training, such as knowledge, attitude, behavior, and guidance for pregnancy outcomes and prenatal care. It is estimated that in most emerging countries of South Asia, fewer pregnant women obtain proficient medical aid during their delivery. Surprisingly, this number still covers a larger primary dissimilarity between urban and rural areas where most of the population inhabits. In emerging countries, rural mothers are 40% less likely to be focused by experienced health workers compared to their urban colleagues⁵. On the other hand, some demanding situations confronted by TBAs are inspiring females to go to health care centers for preventive amenities. As a change agent, TBA has a significant part to show in certifying that mother-to-child transmission of HIV is condensed to the negligible stage. This role is sequenced with the significant

tactics for preventing mother-to-child transmission, which includes primary prevention of pregnancy among women with HIV; preventing transmission from HIV-infected mothers and infant⁶. Authentic and proficient presentation of this role by TBAs is based on their sufficient information, assertiveness, and practices. Evidence has shown that reliable information about disease progression and its preventive measures demonstrates the enriched practice of preventive measures. Similarly, people with an extra positive attitude towards preventive measures are persuaded by enhanced knowledge to take defensive measures against the infection⁷.

In Pakistan, the stigma is extremely considerable to fight against HIV/AIDS since it could impact patients' attendance at healthcare centers to obtain anti-retroviral prescriptions and consistent medical check-ups⁸. Stigmatization generates an unwanted culture of privacy and silence based on unawareness and fear of oppression. The stigma and discrimination related to HIV refer to adverse attitudes, intolerance, and mistreatment. In 35% of countries with accessible data, over 50% of individuals report discriminatory attitudes towards people living with HIV and AIDS (PLHIV). Moreover, stigma and discrimination make people liable for HIV. Those at high risk of HIV face stigma and discrimination based on their real or apparent health status, race, socioeconomic status, sex, age, sexual orientation or gender identity, or other grounds⁹.

Stigma and discrimination are noticeable in numerous ways. Discrimination and other human rights violations might also arise in health care sites excluding people from accessing health services or appreciating quality health care. Their own family and friends forbid some PLHIV, most at-risk populations, and the wider community. In contrast, others face pitiable behavior in academic and work settings, loss of their rights, and mental damage. All these factors limit access to HIV testing, treatment, and other HIV services¹⁰. In Pakistan, mostly HIV-positive has to go through repetitive screening for visa processing or renewals. According to National AIDS Control Program¹¹,

Pakistan is facing a rigorous epidemic among ID users in numerous main cities in Pakistan. Stigma, disgrace, doubt, discrimination, and lack of concern have been associated with AIDS dominance.

On the other hand, trust, sincerity, exchange of ideas between persons and groups, domestic support, harmony, and diligence to find new ways and resolutions have been accredited to defeat AIDS¹². The ability of individuals, families, and societies to defend themselves and offer support and comfort to the ones affected has been destabilized by the distress of the epidemic, stigmatization, and discrimination. This hampers the efforts to curtail the epidemic, which in turn obscures choices about testing, an acquaintance of current status, and the capability to negotiate prevention behaviors, including usage of family planning services¹³.

Gender inequalities, including GBV, increase women and girls' physiological susceptibility to HIV and block their approach to HIV services¹⁴. It points out that scarcity counts for the women and girls' lower social and financial status. Violations of their basic human rights are also one of the additional challenges in addressing receptiveness to HIV infection¹⁵. The current study shows the knowledge and perceptions of TBAs treating patients with HIV/AIDS and its related stigma and discrimination in district Multan, which has not been discussed in any previous studies conducted in Pakistan. It also determines the comfort level and attitude of TBAs while rendering services to HIV and AIDS patients and the associated stigma and discrimination.

This study aims to determine how at risk TBAs are of contracting HIV/AIDS and its related stigma and discrimination. It is assumed that the risk of contracting HIV/AIDS and its related stigma will depend on their knowledge and the quality of services they provide. The current study tries to explain TBA's knowledge and perceived risk of contracting HIV/AIDS along with the stigma and discrimination attached to it while rendering their services.

Methodology

A cross-sectional qualitative and quantitative survey was conducted from October 2017 to March 2018. The study area was limited to district Multan consisting of six main towns (Shershah town, Bosan town, Musa Pak Shaheen town, Shujaabad town, and Jalalpur Pirwala town.). It is a descriptive study describing the knowledge and perception of TBAs treating patients with HIV/AIDS and its related stigma and discrimination in the district Multan.

Qualitative Analysis

In qualitative analysis, in order to gain a better view to determine the knowledge and perceptions of TBAs treating HIV/AIDS patients and its related stigma and discrimination, observation, in-depth interviews, and focus group discussions were conducted with 100 female participants. FGDs were conducted with TBAs; two FGDs involved 4 TBAs, and two FGDs involved 5 TBAs. They were selected through convenience sampling. And only those participants were selected in FGDs who were permanent residents of the targeted areas and willing to participate in open discussion. The discussions during FGDs lasted about half an hour to one hour for each group. They were asked questions, and their responses were recorded and noted. TBAs were also interviewed to recognize their knowledge, working experience, and challenges they faced while rendering their services.

The surveys were used to select participants who belonged to the target group (21-49 years old). Interviews were conducted, which lasted approximately 15-20 minutes each. Answers were noted by note-taking with consent. The interviews were transcribed, and a thematic analysis was conducted. The criteria for in-depth interviews were to include TBAs with more than five years of experience while rendering their services in targeted areas and are still in practice. All the members were recognized through convenient sampling with the help of the EQUIP Research & Development Survey Team because participants' selection was based on their availability and willingness to participate in the study.

Quantitative Analysis

In quantitative analysis, a self-structured questionnaire was designed and used to generate numerical data, comprising 35 closed-ended and open-ended questions regarding the demographical characteristics of respondents, items, and questions. It was very difficult to motivate the participants to fill out the questionnaire. 20 out of 138 simply denied being a part of the study as they were Government employees. 5 were reluctant to give appropriate answers as they were cautious about their job privacy. 10 of them didn't have ample time to complete the questionnaire. Finally, out of 138, only 100 survey results were involved in the analysis, and 15-20 minutes were assigned to fill out the questionnaire.

Data management and analysis

The sample size was calculated through <http://www.raosoft.com/samplesize.html> by keeping a 5% margin of error and 95% confidence interval. Data analysis is conducted by eliminating invalid data (which didn't underpin the appropriate answer according to the research question) by organizing and giving meaning to the data. Prior to analysis, missing data were rechecked. Data was entered through an excel spreadsheet and then analyzed through IBM SPSS 26.0. Qualitative data was also coded and described. While conducting

FGDs and interviews, notes were taken during and immediately after each FGD and interview. Data were transcribed and translated from Seraiki and Urdu to English and were analyzed manually. Qualitative content analysis was conducted to understand the apparent content (what the transcript states) and latent content (understanding of the meaning of the transcript). Transcriptions were prepared from all the recorded data. The text was divided into meaningful units, condensed, and labeled with a code without losing the study context. Codes were then analyzed and accumulated into categories based on questions and compared to search for connotations, configurations, and identification of themes to capture the apparent meaning. In the final step, themes and subthemes were recognized. Study precision was ensured by triangulation of data sources (TBAs) and data collection methods (FGDs and IDs). Upon data entry, errors for the uncertainty of responses to associated questions within a questionnaire were checked again for further reassurance of the data quality, and bias was eradicated through discretion and privacy of the respondents and the principle of impartial treatment and justice. No personal information accompanied these records.

Results

Table 1: Demographic and socioeconomic section (DSES).

Variables	Percentage	
The age group of respondents	21-30	25
	31-40	54
	Above-40	21
Duration of continuous stay in Multan	less than 1 year	4.0
	1-5 years	22.8
	6-10 years	37.6
	more than 10 years	34.7
Ethnic group	Punjabi	33.7
	Seraiki	58.4
	Baloch	6.9
Most spoken language	Urdu	43.6
	Punjabi	10.9
	Seraiki	43.6

	Balochi	1.0
Marital status	single	6.9
	married	63.4
	divorced	17.8
	separated	5.0
	widowed	5.9
Qualification of respondents	matriculation	75.2
	F.A/F.Sc/I.COM	20.8
	B.A/B.Sc/B.COM	3.0
	other(specify)	0.0
Monthly income of respondents	10-20 thousand	41.6
	21-30 thousand	33.7
	31-40 thousand	19.8
	41-50 thousand	4.0
Working Type of Medical Facility	public hospital	8.9
	private hospital	52.5
	Private practice	37.6
Location of medical facility	urban	5.0
	semi-urban	38.6
	rural	55.4

Table 2: Perceptions of TBAs regarding HIV and AIDS (n=100).

Variables	Percentage	
Meaning of HIV	yes	24.8
	no	8.9
	don't know	65.3
Meaning of AIDS	yes	18.8
	no	17.8
	don't know	62.4
Source of hearing about HIV & AIDS	television	12.9
	newspaper	16.8
	doctor or nurses	35.6
	friends	9.9
	social media	23.8
	other(specify)	0.0
Modes of transmission of HIV & AIDS	sexual intercourse	80.2
	blood transfusion	11.9
	breast feeding	6.9
How HIV & AIDS cannot be transmitted	casual kissing or hugging	13.9
	swimming pool	21.8
	sharing toilets	14.9
	shaking hands	14.9
	insect/mosquito bites	9.9
	none	23.8
	Signs are symptoms of HIV & AIDS	
enlarged lymph glands	16.8	
fever for more than a month	15.8	

	severe weight loss of 10% of body weight	12.9
	none	53.5
Preventive measures of HIV & AIDS	avoid sexual activities	79.2
	screen blood products	13.9
	use disposable syringes	5.9
Ways to be protected from HIV & AIDS	abstain from sex	59.4
	use contraceptives	8.9
	avoid sex with commercial sex workers	10.9
	avoid sex with injecting drug users	6.9
	avoid unscreened blood	7.9
	avoid unsterilized needles and syringes	5.0
Potential cause of HIV	injecting drug users	15.8
	commercial sex workers	83.2

Table 3: Effects of HIV and AIDS-related stigma and discrimination (n=100).

Variables	Agree (%)	Disagree (%)
Avoid touching belongings of suspected or HIV patients	81.2	17.8
Avoid assistance/being assisted by an HIV-positive colleague	28.7	70.3
HIV-positive family member	85	15
Spread of HIV in the community: Promiscuous Men	30.7	68.3
Commercial sex workers	82	18
Injecting drug users	58.4	41.6
Being an HIV patient	85	15
Fear of people getting infected	82	18
Medicine practice by HIV-positive physicians and nurses	74	26

Qualitative Results

Out of 100 participants, 6 TBAs with more than 5 years of experience and are still in practice participated in in-depth interviews. The following main areas were covered: "Basic knowledge of HIV/AIDS,;" "working experience,;" "stigma and discrimination."

a) Basic knowledge of HIV/AIDS

All those TBAs who participated in FGDs and IDIs were surprised by collecting information through discussions and interviews. However, few of them were even reluctant to talk openly about this deadly virus and disease and had a lot of misconceptions.

Interviewer: Do you ever heard about HIV and AIDS?

"Yes, I have heard about it. It is a bad disease and people do not like to talk about it" (TBA-FGDs).

"It is a curse on bad people who are engaged in bad activities. It is a dangerous" (TBA-IDI).

"I am unable to answer your question because my husband does not want me to take part in any activity otherwise he will physically abuse me." (TBA- IDI).

Interviewer: Do you have any idea about its mode of transmission?

"The women who are engaged in sexual activities especially those who are commercial sex workers" (TBAs- FGD).

"I heard you can get it through unsafe sex, blood transfusion, piercing objects and even using clothes of infected person. If you borrow clothes from someone who is HIV positive and if that person sweats a lot then you can get it" (TBA in FGD).

"I and my husband both are positive HIV patients but because of anti-retroviral therapy, we made it possible that it may not be transferred to our baby" (TBA 4- IDI).

"Many TBAs like me are also herbalists or you can say traditional healers. HIV/AIDS is also an infection. We give herbs to eradicate infection from woman's body and uterus. Furthermore, we recommend them to conceive quickly so that they could liberate themselves from such type of infections. Some of us are somehow not united with the proper health care system but still assists the community and accompany women to health facilities for proper care" (TBA- FGDs). The participants had their perceptions regarding HIV/AIDS. Their knowledge showed that they had little knowledge about the virus and disease.

b) Working Experience

When TBAs were asked about the type of medical facility in which they spend most of their time and why they do so. They were on the following views. "We prefer to work privately as we are not answerable to any authority. Because of our experience, people of our community prefer us to examine their wives" (TBA- FGD).

"High charge of treatment, extreme distance to medical facility, absence of conveyance and necessity of an attendant from the family or village to visit a health facility are significant aspects for people living in rural areas that is why they do not

seek care from health care providers outside their localities and prefer us to their daughters, wives and daughter-in-laws" (TBAs- FGDs).

c) Stigma and discrimination

The participants were concerned about the stigma and discrimination associated with HIV/AIDS. Generally, they believed that women are hit harder by the disease because they are in an unfavorable position in society where they have barely any means of financial freedom and no control over their bodies in their sexual relationships. So some of the penalties of HIV/AIDS stigma contain; minor approval of maternity health services by women, fear of health workers getting infected, and less endowment of health care workers' services because they consider the HIV status of the patient. Few of them were even afraid to talk about it openly.

"If you could come tomorrow during 09:00 am – 12:00 pm, it would be easy for me to give you details as I am positive (HIV patient) but my family does not allow me to talk about it openly" (TBA 2- IDI.) "My husband considers me responsible for spreading this deadly virus as I am more likely to line up with the health system but I am totally unaware that how I interacted with the virus" (TBA in FGD).

"I am 25 years old and a positive AIDS patient, my family does not want me to share this reality with anyone because of loss of marriage and child-bearing options" (TBA 3- IDI). "Yes, because everybody would think that I have done something wrong. It will surely be a shame for my family" (TBA-IDI) and me.

"People say that someone who is HIV positive is not a noble person as the person is engaged in very bad activities like sleeping around with more than one partner. So, if someone is HIV positive, many people will say that he is disloyal and treacherous" (TBA in FGD).

This study provided an exclusive chance to understand perceptions and experiences of the TBAs while treating HIV/AIDS patients and their

Discussion

attitudes in district Multan, Pakistan. TBAs have been working for a long time and have established trust and reliance in the communities. Contrary to the previous studies,¹⁶ most of them were not trained in HIV prevention. During the survey, it was observed that the information is conveyed to TBAs to some extent, and they lack basic knowledge regarding HIV and AIDS. It is contrary to the previous study, which reported that though they were aware of HIV, their awareness of PMTCT, practices of HIV counseling, and referring of patients for HIV testing was specifically low.¹⁷

Similar to the previous studies, this study reported that sexually active women are HIV carriers, especially commercial sex workers. They hide their HIV status and are unwilling to take ARVs for PMTCT because of stigma and confidentiality.¹⁸⁻¹⁹ Contrary to the previous studies, which reported that blood transfusion and then sex with stable partners are the blameless routes of HIV transmission²⁰, this study's respondents (80.2%) reported that sexual intercourse is the main route of transferring HIV. A similar study shows that the knowledge of modes of transmission of HIV was less than adequate and included a lack of knowledge of the existence of HIV/AIDS amongst practitioners like TBAs²¹. This study also shows that it is quite evident from their statements that all have heard about HIV/AIDS, but very few know the exact meaning of HIV/AIDS. The study found that knowledge of modes of transmission of HIV was less than satisfactory and included a lack of knowledge of the presence of HIV/AIDS. IDIs and FGDs exposed that women recurrently used the terms 'bad' or 'dangerous' when discussing HIV/AIDS. According to their perception, being HIV positive means that the person is associated with infidelity, wicked behavior, or even criminal activity and prostitution.

A previous study shows that lack of exposure, opportunities, and education are the major culprits and reasons that most respondents did not obtain any training regarding the prevention of transmission of HIV from mother to child, which can be either through gestation, labor, or prolonged breastfeeding including exclusive

breastfeeding²²⁻²³. This study inferred that many interviewees believed that the major transmission mode of HIV/AIDS is through unsafe sex, and very few respondents said that blood and blood products. Even the contradiction is also present among them that how HIV/AIDS cannot be transmitted and the ideas about signs and symptoms are vaguely observed among them. Even most of the respondents had ambiguity about whether HIV/AIDS has a treatment or even if it is curable or not. In line with the previous studies²⁴⁻²⁵, this study also stated that people living with HIV and AIDS face constant psychological difficulties, ignorance, marginalization, etc., due to a lack of awareness. In this study, the stigma problem became quite evident as 85% of the respondents reported that they would be ashamed if they or someone else in their family was suspected of having HIV and AIDS.

A large number of TBAs revealed that they would not feel protected if their other patients and colleagues identified that they were involved in handling or providing care to HIV-positive patients, as 82% of the targeted group are afraid to come in contact because of fear of getting HIV. Similarly, a previous study shows that TBAs agreed to participate in most activities except performing a blood test²⁶. In concordance with the previous study, our study reported that 70.3% TBAs have disagreed with assisting or being assisted by HIV-positive colleagues²⁷ as discriminatory attitudes of the TBAs toward people living with HIV were also linked with social and economic factors of communal and domestic intolerance and lack of remunerations as working with HIV-positive people is adversely observed by the people and society. It is quite clear from the respondents that those who are positive have a fear of being stigmatized and discriminated which ultimately prompts us about the significance of acquainting with suitable intervention programs to decrease stigma or other marginalization within social groups and a need to assess their situation and help them to make decisions²⁸⁻²⁹.

After conducting this study, we figured out that there is a need for balancing prevention and

reduction of discrimination, proper certification, and timely training workshops as mentioned in the education and training series of the World Health Organization (WHO) that good training and ongoing professional development are vital as health workforce considered an essential component in providing safer primary care.³⁰ In this regard, intervention programs are essential from the grass root level to train and educate our health care workers, especially TBAs. Intervention programs should also be supported by those attempting to reduce stigma or other marginalization within social groups. People with HIV/AIDS should not be highlighted as a risk group; instead, they should be portrayed as patients with persistent diseases who may still contribute to society.

Conclusion

In this study, it has been demonstrated through observations, IDIs, FGDs, and self-structured questionnaires that the TBAs who are infected with HIV or dealing with HIV/AIDS patients are facing multiple issues like social, medical, psychological, and cultural challenges. It also demonstrates that TBAs didn't have the appropriate information on how to solve practical issues of transmission of HIV from mother to child. The result of this study also reveals some gaps in the knowledge of TBAs about HIV/AIDS, and they are, therefore, unable to play a dynamic role in the prevention of HIV. It also shows that discriminatory attitude is common across Pakistan, especially in our region towards people living with HIV and our targeted group TBAs.

Conflicts of Interest

None.

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