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HIV/AIDS-related Stigma is not a Myth in Kerala, India

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Abstract

The stigma associated with HIV is the foremost barrier to HIV prevention, treatment, care and support (UNAIDS, 2014). It prevents people from seeking information and services related to HIV/AIDS. The stigma hinders the efforts to prevent new HIV infections, inhibits treatment adherence and access to care and support programmes. AIDS stigma results in economic and social marginalisation and the withholding of treatment or denial of services amounting to a violation of the human rights of people with HIV (UNAIDS, 2000). The state of Kerala has been recognised internationally since the 1970s for its achievements in the developments in the health sector. In many aspects, Kerala's health status is on a par with that of developed countries. Alhough the state has a higher literacy status, the stigma and discrimination associated with HIV/AIDS is widespread in Kerala. The present paper describes the extent of stigma and discrimination faced by the women living with HIV/AIDS (WLWHAs) in Kerala. This paper is based on a study conducted among 372 women living with HIV/AIDS to explore the extent of HIV-related stigma in the form of enacted, vicarious, felt normative and internalised stigma experiences and to envisage the associated problems faced by them. The tool used to measure the same was 'the HIV-related stigma scale' and the study found that HIV/AIDS-related stigma is still prevalent in Kerala, even among the health care workers. The study finds that the respondents experienced the enacted stigma and were asked to move out of their houses because of their HIV status. The vicarious stigma is also prevalent in Kerala and many of the

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respondents frequently heard about the incidents of HIV stigma and discrimination in terms of mistreatment by hospital workers, untouchability, denial of treatment, revealing the HIV status by a health worker, refusal of care by the family members when they were sick, disclosing HIV status by themarking on records, avoidance of family members and ostracisation by the community or the village. The study also finds that the respondents had an experience with internalised stigma.

Keywords
HIV/AIDS, stigma, women, Kerala

Introduction

HIV/AIDS may be the most devastating health disaster in human history. The disease continues to ravage families throughout the world, irrespective of the religion, caste, race, status and geographical area. Stigma and discrimination associated with HIV are the foremost barriers to HIV prevention, treatment, care and support (UNAIDS, 2014). It prevents people from seeking information and services related to HIV/AIDS. It continues to hinder efforts to prevent new infections, inhibit treatment adherence and care and support programmes. AIDS stigma often results in social and economic marginalisation and the withholding of treatment or denial of services amounting to a violation of the human rights of people with HIV (UNAIDS, 2000).

According to Goffman (cited in Pryor, 2014), the term stigma dates back to the Greeks who cut or burned marks into the skin of criminals, slaves and traitors in order to identify them as tainted or immoral people that should be avoided. The stigma is not just a physical mark, but an attribute that results in widespread social disapproval. Goffman (1963) defined stigma as a discrediting social difference that yields devaluation or a 'spoiled social identity.'

Stigma refers to a negatively perceived characteristic and it is an attribute used to set the affected persons or groups apart from the normalised social order, and this separation implies a devaluation (Gilmore, 1994). The HIV-related stigma is the negative characteristics associated with the disease which includes avoidance, rejection, isolation, social ostracism, blaming, violence, denial, indifference, and awkward social interaction. It affects HIV prevention and treatment of people living with HIV in a number of ways and across a broad range of settings. Stigma can occur in one's primary,

secondary or tertiary social settings and it includes family, community, work settings and so on (Grossman, 2013).

People living with HIV/AIDS can feel the HIV-related stigma either directly or indirectly. The stigma is indirect when, for example, they hear others talk negatively about HIV. The stigma is in its direct form when they were denied a treatment only because of their HIV status. It prevents people from seeking information and services related to HIV/AIDS. It is a complex concept and it is multidimensional. The issues may vary from individual to individual because of the different perspectives about the disease throughout the communities. People living with HIV/AIDS are not different in this aspect. Stigma makes people feel different and disgraced. It denies an individual's dignity, respect and right to fully participate in their community. It can place limits on education, work, housing and health care, restrict travel, prevent participation in religious or social functions, and leads to physical violence, isolation or ostracism. It may also affect personal and family life, including the opportunity to marry and to bear and raise children. Thus people living with HIV (PLH) face problems in their daily life in many forms and it makes their life miserable.

In India, the reduced literacy and lack of scientific temper influences the stigma associated with the disease and hampers the smooth functioning ofthe PLH's life. The increased misconceptions and myths about the disease affect the lives of PLHAs to a great extent. The stigma and discrimination on account of AIDS are particularly severe in India and often at times, due to actual or even perceived fear of stigma and discrimination, individuals infected with HIV do not reveal their HIV status and deny themselves healthcare services. This indeed makes the situation all the more precarious. The lower treatment adherence results in the increase in new infections and AIDS related deaths. Most of PLHs are not in a position to access the health care service centres due to their damaged physical, social, economic and psychological conditions. The situation will be worst when it comes to the women, the less privileged citizen of a patriarchal society. Many women living with HIV in need of medical attention have to travel a long way to the health care centres and the lack of empowerment in terms of the above-mentioned dimensions will prevent them from accessing these services.

People living with HIV (PLWH) not only manage living with a chronic condition but also grapple with stigma. Although knowledge of HIV has

increased, HIV stigma still persists even after 30 years (Catona, 2016). As we enter the fourth decade of the HIV epidemic, the focus is increasingly being placed on the social context of HIV communities. An important issue in this context, and one that contributes significantly to the hidden burden of HIV, is the stigma.

The state of Kerala has been recognised internationally since the 1970s for its achievements in the development of the health sector. In many aspects, Kerala's health status is on a par with that of developed countries. Although the state has a higher literacy status, the stigma and discrimination associated with HIV/AIDS is widespread in Kerala. A decade back, women living with HIV were forced to lead a campaign aimed at battling people's illiteracy, suspicions and misconceptions about HIV/AIDS through the campaign named 'Thejaswini.' But still the issues associated with HIV-related stigma prevail in the state and the present paper intends to describe the extent of the problems faced by the Women Living with HIV/AIDS (WLWHAs) in Kerala.

Historically, Kerala is a patriarchal society where men exercise control over women's sexuality and their access to services. Men tend to be the main decision-makers within the family, and the social norms and responsibilities allow men to control women's behaviour. As a result of gender inequality and social structure, women living with HIV/AIDS are more at risk of experiencing stigma.

In the present scenario, a woman living with HIV/AIDS in Kerala faces many challenges as a patient and as a woman. The lack of awareness about HIV/AIDS among the public makes the life of HIV-infected women miserable and challenging. The challenges include social, economic, and physical ones. They are facing dual challenges of being a medical patient and a woman. In most cases, these women are the caretakers of their children and other members of the family. Most women living with HIV/AIDS are working to earn their daily bread. They have to look after their children and other relatives and at the same time work for hours to make a living. Most of these women will die at an early age, orphaning their children. During their illness, the women confront the challenges of being both patient and family caregiver. In many instances, women, the prime caregivers, are also infected with HIV, thus their health needs are regarded as secondary. Providing long term care to HIV-infected family members with scarce economic resources and ignoring the needs of their own ailing

body, exhaust these women. It becomes all the more shattering when they have to face stigmatisation, blame and abandonment from their own relatives and community members.

As per the Kerala State AIDS Control Society, the estimated number of people infected with HIV in Kerala in August 2017 is 12,116. The state of Kerala is not exempt from this kind of discrimination against women. There were many reported cases of stigma and discrimination against women living with HIV in Kerala. It is observed in Kerala that men living with HIV/AIDS experience a lesser level of stigma and discrimination and the reported number of such cases are fewer in number. This may be due to the patriarchal mindset of the people of Kerala. There are not many studies conducted of this gender aspect of HIV/AIDS in Kerala.

Methodology

This paper is based on a descriptive research study conducted by the first author, aimed at obtaining relevant information about the challenges of women living with HIV/AIDS (WLHAs) between 2014 and 2017 in the state of Kerala, India. Samples were collected from 372 WLHs using the convenient (accidental) sampling method. The inclusion criteria were being 18 years of age or older, being an HIV-positive woman and without any cognitive or communicative disabilities or psychotic disorders such as schizophrenia. Kerala was divided into three zones viz. north, centre and south and the samples (n = 372) were recruited with the help of voluntary agencies working with HIV-positive individuals, especially Network of People Living with HIV/AIDS.

Assessment of perceived stigma India HIV-related Stigma Scales developed by the Centre for AIDS Prevention Studies (CAPS) were used to measure the various forms of stigma viz., enacted stigma, vicarious stigma, felt normative stigma and internalised stigma. By assessing the enacted stigma, the researchers tried to assess whether participants have experienced specific discriminatory acts due to their HIV infection, such as being asked not to share utensils or plates with other family members. Ten items in this scale measured enacted stigma using a yes/no format. Vicarious stigma measured whether participants had heard stories about other people living with HIV/AIDS being mistreated because of their infection. Heard incidences or witnessed events that provide evidence of how HIV has been treated were assessed using this tool. Felt Stigma, a 10-item scale measures

perceived levels of stigma in one's community, such as the attitudes that people living with HIV/AIDS deserve their infections or have brought shame on their families. Internalised stigma includes the personal endorsements of stigmatising beliefs and for the people living with HIV/AIDS, it is a form of self-judgement/stigmatisation. This 10-item scale assesses the extent to which respondents believe that, as HIV-infected people, they deserved to be stigmatised. A reliability analysis was carried out on the perceived task values scale comprising 40 items. The Cronbach's alpha showed the tool used was highly reliable with the Cronbach a score of 0.926.

The original forms of standardised tools used were in the English language and hence the researchers sought the support of a professional translator to translate the tool to the Malayalam language and used another translator to re-translate the Malayalam tool to the English language to check the accuracy of the tool. For the present study, a tool in the Malayalam language was used. The researchers followed the guidelines of NASW regarding the code of ethics during the research process. Informed consents were obtained from all the respondents and confidentiality was ensured. The contact details of the researchers and the expert persons who can address the psycho-social issues which may evolve due to the study were furnished to all the respondents.

Analysis of the data was conducted using the SPSS 21 software. Student t-tests and Correlation analysis using Pearson's correlation coefficient (r) were used where appropriate. In-between group differences were calculated for groups A and B. A $p<0.05$ was considered significant for all statistical analyses.

In order to examine the relative importance of each of the four domains of HIV-related stigma, total scores were calculated for each sub-scale of the HIV Stigma Scale by summing the scores obtained for each item in the sub-scale. The total scores for each sub-scale were then tested for normality.

Analysis and Interpretation

Demographics

Table 1 shows the characteristics of women included in the analyses with their responses to key socio-demographic variables. The study sample (n=372) had a mean age of 34.37 ± 7.07and about half of the respondents are youthful, i.e., aged below 36 years (n = 185) and the rest belonged to

the age group 36–55 (n = 187). Most of the respondents were married (n = 185) and about a half are widows (n = 177). The majority of the respondents are Hindus (n = 218), about one-third are Muslims (n = 126) and only a few were Christians (n = 28). The data show that about half of the respondents belong to the general community (n= 198) and around one-third belong to the other backward communities (n = 129). Only a few respondents are included in the category Scheduled Castes (n = 39) and Scheduled Tribes (n = 6). Most of them are educated up to higher secondary level (n = 266), unemployed (n = 220) and have a family monthly income less than Rs. 5,000 (n = 280). A major number of the respondents are living above the poverty line (n = 325), and in their own houses (n = 235). Most of the respondents are living in nuclear families (n = 280) and a half of them have family member size ranges of 4-6 (n = 187).

Table 1. Socio-demographic profile of women living with HIV/AIDS

No.	*Variable*	*Categories*	*Frequency*	*Per cent*	*Mean*	*Mode*	*Minimum*	*Maximum*	*Std. Deviation*
1.	Age	18–35	185	49.7	34.37	41	21	45	7.07
		36–60	187	50.3					
2.	Marital Status	Married	185	49.7	2.51	1	1	5	1.52
		Divorced/ Separated	4	1.1					
		Widowed	177	47.6					
		Cohabitation	6	1.6					
3.	Religion	Hindu	218	58.6	1.49	1	1	3	0.633
		Muslim	126	33.9					
		Christian	28	7.5					
4.	Community	General	198	53.2	2.18	1	1	4	0.07
		SC	39	10.5					
		ST	6	1.6					
		OBC	129	34.7					
5.	Education	Primary	5	1.3	2.95	3	1	4	0.57
		Secondary	55	14.8					
		Higher Secondary	266	71.5					
		Graduation	46	12.4					

6.	Employment Status	Private	113	30.4	3.88	5	2	5	0.07
		Self employed	39	10.5					
		Unemployed	220	59.1					
7.	Economic status	BPL	47	12.6	1.87	2	1	2	0.33
		APL	325	87.4					
8.	Housing	Owned	235	63.2	1.42	1	1	3	0.59
		Rented	117	31.5					
		Relatives House	20	5.4					
9.	Housing type	Individual House	365	98.1	1.04	1	1	3	0.27
		Slum	7	1.9					
10.	Family's Monthly Income	Below Rs.5000	280	75.3	1.37	1	1	3	0.69
		5000–10000	46	12.4					
		Above 10000	46	12.4					
11.	Type of Family	Nuclear	280	75.3	1.25	1	1	2	0.43
		Joint	92	24.7					
12.	Number of Family Members	Below 3	139	37.4		2	1	3	0.66
		4–6	187	50.3	1.75				
		Above 6	46	12.4					
13.	No. of HIV +ve members in the family	1	92	24.7		2	1	3	0.60
		2	233	62.6	1.88				
		Above 2	47	12.6					

Enacted Stigma

As Table 2 shows, half of the respondents (n = 187) had not experienced enacted stigma related to HIV in any manner. But another half (n = 185) shared their experiences with enacted stigma. Around one-third of the respondents (n = 121) faced enacted stigma in a single manner, but some respondents (n = 64) experienced the enacted stigma in more than one manner. A majority of the respondents (n = 334) was not mistreated by a hospital worker, but a few respondents (n = 38) shared their experiences of mistreatment by a hospital worker. While most of the respondents (326) had not experienced any kind of discrimination, some respondents (46) shared their experiences of enacted stigma in the form of discrimination because of their HIV status. Some

respondents also shared their bitter experiences of enacted stigma in the form of avoidance in sharing food or utensils with family (n = 46) and of touching or caring for children (60) in their family because of their HIV status. While a majority (n = 326) was not denied any hospital services, a few (46) were denied such services only because of their HIV status. More than one-third of the respondents (n = 132) were asked to move out of their houses because of their HIV status and only a very few (n = 4) were threatened with being hurt physically and refused housing because of their HIV status.

Table 2. Enacted stigma

	Variable		*Frequency*	*Per cent*
Enacted Stigma	Has a hospital worker mistreated you because of your HIV?	Yes	38	10.2
		No	334	89.8
		Total	372	100.0
	Have people looked at you differently because you have HIV?	Yes	46	12.4
		No	326	87.6
		Total	372	100.0
	Has a healthcare worker not wanted to touch you because you have HIV?	Yes	10	2.7
		No	362	97.3
		Total	372	100.0
	Have you been told not to share your food or utensils with family because of your HIV?	Yes	46	12.4
		No	326	87.6
		Total	372	100.0
	Have you been asked not to touch or care for children because of your HIV?	Yes	60	16.1
		No	312	83.9
		Total	372	100.0
	Have you been refused medical care or denied hospital services because of your HIV?	Yes	46	12.4
		No	326	87.6
		Total	372	100.0
	Have family members forced you to move out of your home because you have HIV?	Yes	132	35.5
		No	240	64.5
		Total	372	100.0
	Has someone threatened to hurt you physically because you have HIV?	Yes	4	1.1
		No	368	98.9
		Total	372	100.0
	Has someone threatened to hurt you physically because you have HIV?	Yes	4	1.1
		No	368	98.9
		Total	372	100.0
	Have you been refused housing because people suspect you have HIV?	Yes	4	1.1
		No	368	98.9
		Total	372	100.0
	No Experience		187	50.3
	One manner		121	32.5
	More than one manner		64	17.3

Vicarious Stigma

Vicarious stigma was very prevalent among the respondents and all the respondents had experiences of vicarious stigma related to HIV/AIDS. As Table 3 depicts, all the respondents had frequently heard about the incidents of HIV stigma and discrimination in terms of mistreatment by hospital workers (n = 342), untouchability (n=171), denial of treatment (n = 94), the revealing of HIV status by a health worker (n = 280), refusal of care by family members when they were sick (n = 93), disclosing of HIV status by the marking on records (n = 127), avoidance of family members (n = 93) and ostracisation by community or the village (n = 93). The incidence of untouchability was heard sometimes by half of the respondents (n = 186). The respondents had sometimes heard about the incidents of refusal or denial of hospital services (n=186), refusal of care by family members (n = 233), forcing one to leave the home (n = 179), disclosing the HIV status by marking on records (n = 186), avoidance of family members (n = 231), discrimination (n = 247) and social ostracism (n = 232).

Table 3. Vicarious stigma

	Variable		*Frequency*	*Per cent*
Vicarious Stigma	…a healthcare worker not wanting to touch someone because of his or her HIV?	Rarely	15	4.0
		Sometimes	186	50.0
		Frequently	171	46.0
		Total	372	100.0
	…people being mistreated by hospital workers because of their HIV?	Rarely	19	5.1
		Sometimes	11	3.0
		Frequently	342	91.9
		Total	372	100.0
	…people being refused medical care or denied hospital services because of their HIV?	Rarely	92	24.7
		Sometimes	186	50.0
		Frequently	94	25.3
		Total	372	100.0
	…a healthcare provider talking publicly about a patient with HIV?	Rarely	46	12.4
		Sometimes	46	12.4
		Frequently	280	75.3
		Total	372	100.0
	…someone being refused care from their family when they were sick with HIV?	Rarely	46	12.4
		Sometimes	233	62.6

	Frequently	93	25.0
	Total	372	100.0
…people being forced by family members to leave their home because they had HIV?	Rarely	46	12.4
	Sometimes	279	75.0
	Frequently	47	12.6
	Total	372	100.0
...a hospital worker making someone's HIV infection known by marking HIV on their medical records?	Rarely	59	15.9
	Sometimes	186	50.0
	Frequently	127	34.1
	Total	372	100.0
...families avoiding any relative who has HIV?	Never	7	1.9
	Rarely	41	11.0
	Sometimes	231	62.1
	Frequently	93	25.0
	Total	372	100.0
...people looking differently at those who have HIV?	Never	4	1.1
	Rarely	27	7.3
	Sometimes	247	66.4
	Frequently	94	25.3
	Total	372	100.0
…a village/community ostracising someone because they had HIV?	Never	10	2.7
	Rarely	36	9.7
	Sometimes	232	62.4
	Frequently	94	25.3
	Total	372	100.0

Felt Normative Stigma

The prevalence of felt normative stigma related to HIV was also higher among the respondents. All the respondents had experiences associated with the felt normative stigma and aroundhalf of the respondents (n = 174) reported that the felt normative stigma is less in their society. Around half of the respondents (184) revealed a high level of normative stigma in the community. Half of the respondents (n = 186) revealed that most people in their society think that the people with HIV are paying for their karma or sins and some people would not want an HIV-infected person cooking for them. More than one-third of the respondents (n = 140) opined that most of the people in their society would not share dishes or glasses with someone who has HIV and think that HIV-infected people have brought shame on their families (Table 4).

Table 4. Felt normative stigma

	Variable		*Frequency*	*Per cent*
Felt Normative Stigma	…how many mothers would not want someone with HIV to hold their new baby?	Very few people	186	50.0
		Some People	139	37.4
		Most People	47	12.6
		Total	372	100.0
	...how many mothers would not want an HIV-infected person to feed their children?	Very few people	186	50.0
		Some People	139	37.4
		Most People	47	12.6
		Total	372	100.0
	...how many people would not share dishes or glasses with someone who has HIV?	Very few people	186	50.0
		Some People	46	12.4
		Most People	140	37.6
		Total	372	100.0
	…how many people think that HIV-infected people have brought shame on their families?	Very few people	174	46.8
		Some People	58	15.6
		Most People	140	37.6
		Total	372	100.0
	…how many people avoid visiting the homes of people with HIV?	Very few people	279	75.0
		Some People	47	12.6
		Most People	46	12.4
		Total	372	100.0

…how many people think that if you have HIV you have behaved wrongly?	Very few people	186	50.0
	Some People	47	12.6
	Most People	139	37.4
	Total	372	100.0
…how many people would not want an HIV-infected person cooking for them?	Very few people	186	50.0
	Some People	186	50.0
	Total	372	100.0
…how many people think that people with HIV should feel guilty about it?	Very few people	186	50.0
	Some People	139	37.4
	Most People	47	12.6
	Total	372	100.0
...how many people think that a person with HIV is disgusting?	Very few people	186	50.0
	Some People	135	36.3
	Most People	51	13.7
	Total	372	100.0
…how many people think people with HIV are paying for their karma or sins?	Very few people	186	50.0
	Most People	186	50.0
	Total	372	100.0

Internalised Stigma

As indicated in Table 5, all the respondents reported the internalised stigma (n = 372) and more than one-third of them reported (n = 139) a lesser extent of the internalised stigma. A few respondents (n = 46) shared a higher level of experience of internalised stigma. Around one-third of the respondent (n = 31.7) think to a fair extent that they should avoid feeding children because

of their HIV and this very thought was shared by another 19.4 per cent of the respondents and they opined it a great deal. There was a fair deal of agreement among a quarter of the respondents (94) that they should avoid holding a new infant because of their HIV status. A fair deal of agreement was among the quarter of the respondents (93) regarding the avoidance of sharing dishes or glasses just in case someone might catch HIV from them. There was a fair deal of agreement among a quarter of the respondents (n = 93) in the thoughts regarding bringing shame to their family because of HIV and another 12.6 per cent of the respondents think a great deal that they have brought shame to your family because they have HIV. More than one-third of the respondents (140) think a great deal that they should avoid visiting people because of their HIV status. A quarter of the respondents (n = 93) think a great deal that they have HIV because they have behaved wrongly and around one-third think a fair amount that they should avoid cooking for people because they have HIV. Around a quarter of the respondents (94) think a fair amount that it was disgusting because of their HIV and another 45 of the respondents share this same thought to a great extent.

Table 5. Internalised stigma

			Frequency	*Per cent*
Internalized Stigma	…that you should avoid holding a new infant because of your HIV?	A Little	274	73.7
		A Fair Amount	94	25.3
		A Great Deal	4	1.1
		Total	372	100.0
	…that you should avoid feeding children because of your HIV?	A Little	182	48.9
		A Fair Amount	118	31.7
		A Great Deal	72	19.4
		Total	372	100.0
	…that you should avoid sharing dishes or glasses just in case someone might catch HIV from you?	A Little	232	62.4
		A Fair Amount	93	25.0
		A Great Deal	47	12.6

	Total	372	100.0
…that you have brought shame to your family because you have HIV?	A Little	232	62.4
	A Fair Amount	93	25.0
	A Great Deal	47	12.6
	Total	372	100.0
...that you should avoid visiting people because of your HIV?	A Little	232	62.4
	A Fair Amount	140	37.6
	Total	372	100.0
...that you have HIV because you have behaved wrongly?	A Little	279	75.0
	A Fair Amount	93	25.0
	Total	372	100.0
...that you should avoid cooking for people because you have HIV?	A Little	242	65.1
	A Fair Amount	115	30.9
	A Great Deal	15	4.0
	Total	372	100.0
...guilty about having HIV?	A Little	288	77.4
	A Fair Amount	69	18.5
	A Great Deal	15	4.0
	Total	372	100.0
...disgusting because of your HIV?	A Little	233	62.6
	A Fair Amount	94	25.3
	A Great Deal	45	12.1
	Total	372	100.0
...that you are paying for karma or sins because you have HIV?	A Little	233	62.6
	A Fair Amount	108	29.0
	A Great Deal	31	8.3
	Total	372	100.0

Conclusions

The study found that HIV/AIDS-related stigma is still prevalent in Kerala, while among health workers the stigma is not as strongas amongst the general public. The study concludes that the awareness programmes conducted among the public are not attaining these objectives fully. The serious issues regarding the mistreatment, delay or denial of treatment and the discrimination by health workers indicates the lack of effectiveness of the hospital sensitisation programmes. The results indicate that the misconceptions regarding the disease are prevalent and the concerned authorities failed to address this issue, especially among the public. The wrong notion about HIV and the lack of scientific approaches among the public make the life of HIV-infected people miserable. The stigma associated with the disease prevents the people from revealing their status and thus results in the inhibition to treatment adherence and care and support programmes. The disease restricts the people from participating in social gatherings and maintaining social relationships. The results pointed out that the health sector is facing many challenges, especially when addressing the issues related to communicable diseases.

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