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Time, Stigma and Fear: Main Barriers for STI Testing among Spouses in Meghalaya, India

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ABSTRACT

Background: Fear and Stigma associated with STDs are considered as an important barrier to STI/RTI prevention and implementation of intervention. This study explores the barriers to STI testing in Meghalaya from the perspective of spouses and other key informants.

Materials and Methods: A descriptive cross sectional research design was used where quantitative and qualitative approach was adopted. Total three districts, namely East Khasi Hills, East Jaintia Hills and West Jaintia Hills in Meghalaya are purposely taken since they have the highest number of notified spouses' low turnout. Total sample size was 118 spouses of clients attending DSRCs. Data was analysed using SPSS and Thematic analysis.

Results: Of 89 (75%) notified spouses of clients attending DSRCs, only 3 (3%) did visited the DSRCs for testing, while 86 (97%) did not visited even after being notified. Among those not visited the DSRCs (n=86), 19% (n=16) were spouses of ANC clients and 81% (n=70) were spouses of general clients. The main barriers for not visiting the DSRC were due to unavailability of time (19%), stigma (17%) and fear of judgment if seen going for STI testing (16%).

Conclusion: Encouraging legislative and policy frameworks sensitive to social need is vital. Promoting community sensitisation campaign keeping in mind cultural sensitivity will improve testing uptake.

Keywords: STI/RTI, DSRCs, Barriers, Notified spouses for STI testing

INTRODUCTION

STIs/RTIs remain a global concern and have been identified as co-factors of HIV transmission. More than one-million curable sexually transmitted infections (STIs) are acquired every day worldwide in people 15–49 years old, the majority of which are asymptomatic [1,2]. The World Health Organization has renewed its strategy for the prevention of STIs because reducing STIs will prevent the spread of HIV. The National AIDS and STD Control Programme Phase V (2021-26) was launched with the aim to reduce syphilis, promote universal access to Quality STI/RTI services and eliminate HIV/AIDS-related stigma and discrimination. The fear of being stigmatised has impacted negatively with people's health seeking behaviour in accessing STI related health services [3,4]. [5] further explained that Stigma, guilt and fear are associated with emotional distress hence, individuals delay in getting treatment and health outcomes also is poor.

The Deputy Director of the Meghalaya AIDS Control Society (MACS) Dr.

Lyngdoh expressed that among all the districts in Meghalaya, East Jaintia Hills district has the highest number of people with sexually transmitted infection (STI) and among antenatal care attendees the prevalence of syphilis is high comparing to other states in India but more at risk are sex workers, drug users and other groups that are considered as 'left behind' included Men who have sex with men, and Transgender [6,7,8]. [9] suggested that research is one of the solutions that can secure a future of effective STI prevention, diagnosis, and treatment. Studies are limited that focuses on turning up of spouses to STI/RTI clinics for testing or treatment. Therefore, the aim of the study is to determine the causes for low turnout of notified spouses for STI/RTI services at the designated STI/RTI Clinics (DSRCs) in Meghalaya and to assess the factors for low turnout of notified spouses for STI/RTI services at the designated clinics in Meghalaya.

MATERIALS & METHODS

A descriptive cross-sectional study design with a mixed method approach (quantitative & qualitative) was adopted across three districts, namely East Khasi Hills, East Jaintia Hills and West Jaintia Hills of Meghalaya. These three districts were purposely taken since they have the highest number of notified spouses' low turnout. The study was conducted during financial year 2022-23 (March-April) among 118 participants (spouses of clients attending DSRC) who have been notified by the DSRCs counselors to visited the clinics for STI/RTI testing. For qualitative data, the total sample size is 17, where 5-in-depth interview was conducted with notified spouses who turned up at the DSRCs and 12-in-depth interview across medical practitioners, traditional healers, faith-based health facilities and counsellors of DSRCs. Notified spouses of clients attending DSRC with major mental health issues were excluded in this study.

This study was approved by the University Research Ethics Committee of Martin Luther Christian University and by Research and Evaluation-Strategic Information Division at NACO. Prior to data collection, pilot testing was done on the research tools where modification of the tools was done before conducting data collection in the field. Participants were informed about the study through a participant information sheet, and informed consent was obtained from all participants involved. For data analysis, quantitative data was analysed using SPSS and Microsoft excel sheet, whereas for qualitative data, thematic analysis was used by referring the Braun & Clarke's six-phase framework for doing a thematic analysis (*Step-1:Become familiar with the data, Step-2:Generate Initial codes, Step-3:Search for themes, Step-4:Review themes, Step-5:Define themes, Step-6:Write-up*).

RESULT

Out of the 118 participants (spouses of general clients and spouses of pregnant women) claimed to be notified by the DSRC counselors of the three districts of East Khasi Hills (EKH), East Jaintia Hills (EJH) and West Jaintia Hills (WJH), a majority of the participants (n=89, 75%) were notified about STI/RTI testing, whereas 25% (n=29) of the participants were not notified by the DSRC Counselors as claimed by the participants.

Among the notified spouses for STI/RTI testing (n=89) across all the three-districts (EKH, EJH &WJH), spouses in the age group of 26-31years and 32-37years comprised the largest portion in this study (32, 36% and 24, 27% respectively). Notified spouses belong to tribal and practices Christianity was predominated (84, 94.4% and 61,68.6% respectively). Sources of income of majority of the notified spouses is daily wage labourer (48, 53.9%) and monthly income of ≤10,000 represented the majority (52, 58.4%).

Similarly, among the 29-non-notified spouses (claimed to be notified by the DSRC counselor and claimed not notified by the participants) across all the three-districts

(EKH, EJH &WJH), spouses in the age group of 26-31years and 32-37years comprised the largest portion in this study (10, 34.5% and 8, 27.6% respectively). Non-notified spouses belong to tribal and practices Christianity was predominated (28, 96.6% and 22, 75.9% respectively). Sources of income of majority of the non-notified spouses is daily wage labourer (20, 69%) and monthly income of ≤10,000 represented the majority (21, 72.4%).

Table 1: Socio-demographic details of participants (notified and non-notified spouses of general clients and of pregnant women for STI/RTI testing) across districts (n=118)

Characteristics	District						Total (n=118) [Notified=89,75% Non-Notified=29,25%]
	EKH (n=51)		EJH (n=46)		WJH (n=21)		
	Notified (n=35)	Non-Notified (n=16)	Notified (n=36)	Non-Notified (n=10)	Notified (n=18)	Non-Notified (n=3)	
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Age group (in years)							
20-25	1 (2.9%)	4 (25.0%)	8 (22.2%)	1 (10.0%)	2 (11.1%)	2 (66.7%)	17 (14.4%)
26-31	10 (28.6%)	4 (25.0%)	13 (36.1%)	5 (50.0%)	9 (50.0%)	1 (33.3%)	42 (55.6%)
32-37	11 (31.4%)	5 (31.2%)	9 (25.0%)	3 (30.0%)	4 (22.2%)	0 (0.0%)	32 (27.1%)
38-43	8 (22.9%)	2 (12.5%)	2 (5.6%)	1 (10.0%)	2 (11.1%)	0 (0.0%)	15 (12.7%)
44 and above	5 (14.2%)	1 (6.3%)	4 (11.1%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	11 (9.3%)
Ethnicity							
Tribal	31 (88.6%)	15 (93.7%)	36 (100.0%)	10 (100.0%)	17 (94.4%)	3 (100.0%)	112 (94.9%)
Non-Tribal	4 (11.4%)	1 (6.3%)	0 (0.0%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	6 (5.1%)
Marital Status							
Unmarried	2 (5.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	2 (1.7%)
Married	26 (74.3%)	10 (62.6%)	22 (61.1%)	6 (60.0%)	11 (61.1%)	2 (66.7%)	77 (65.3%)
Cohabitation	4 (11.4%)	1 (6.2%)	8 (22.2%)	0 (0.0%)	3 (16.7%)	1 (33.3%)	17 (14.4%)
Separation	3 (8.6%)	5 (31.2%)	5 (13.9%)	4 (40.0%)	4 (22.2%)	0 (0.0%)	21 (17.8%)
Divorce	0 (0.0%)	0 (0.0%)	1 (2.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.8%%)
Religion							
Christianity	27 (77.1%)	15 (93.7%)	22 (61.1%)	7 (70.0%)	12 (66.7%)	0 (0.0%)	83 (70.3%)
Traditional Religion	4 (11.4%)	1 (6.3%)	13 (36.1%)	3 (30.0%)	5 (27.8%)	3 (100%)	29 (24.6%)
Others (Hindu, Muslim)	4 (11.4%)	0 (0.0%)	1 (2.8%)	0 (0.0%)	1 (5.5%)	0 (0.0%)	6 (5.1%)
Occupation							
Driver	9 (25.7%)	2 (12.6%)	9 (25.0%)	5 (50.0%)	6 (33.3%)	0 (0.0%)	31 (26.3%)
Daily wage Labourer	15 (42.9%)	12 (75.0%)	25 (69.4%)	5 (50.0%)	8 (44.3%)	3 (100.0%)	68 (57.6%)
Govt servant	2 (5.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	3 (2.5%)
Contractor	3 (8.6%)	1 (6.2%)	2 (5.6%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	7 (5.9%)

Mechanic	0 (0.0%)	1 (6.2%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (0.8%)
Business	5 (14.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	6 (5.1%)
Shop keeper	1 (2.8%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	2 (1.7%)
Monthly Income							
<10,000	16 (45.7%)	12 (75.0%)	23 (63.9%)	7 (70.0%)	13 (72.2%)	2 (66.7%)	73 (61.9%)
10,001-15,000	9 (25.7%)	4 (25.0%)	10 (27.8%)	3 (30.0%)	3 (16.7%)	1 (33.3%)	30 (25.4%)
15,001-20,000	1 (2.9%)	0 (0.0%)	2 (5.6%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	4 (3.4%)
>20,001	5 (14.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (5.6%)	0 (0.0%)	6 (5.1%
No respond	4 (11.4%)	0 (0.0%)	1 (2.7%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	5 (4.24)

The number of spouses visited the DSRCs for STI/RTI testing after being notified (n=89) was just 3%(n=3). Of the 86 participants who did not turn up for STI/RTI testing at the DSRCs even after being notified, 19% (n=16) were spouses of ANC clients, while 81% (n=70) were spouses of general clients. The causes and factors for low turnout of spouses to the DSRCs for STI/RTI services even after notification by the counsellors at the DSRC, was due to unavailability of time (19%) as mentioned by majority of the participants, followed by stigma associated with STIs and fear of judgment if seen going for STI testing (17% and 16% respectively). There are few participants mentioned due to religious belief, lack of services and attitude of the healthcare staff at the DSRCs (1% each).

Figure 1: Visited DSRCs after being notified and reasons for not visiting the DSRC after notification

Figure 1.i: Visited the DSRC after being notified (N=89)

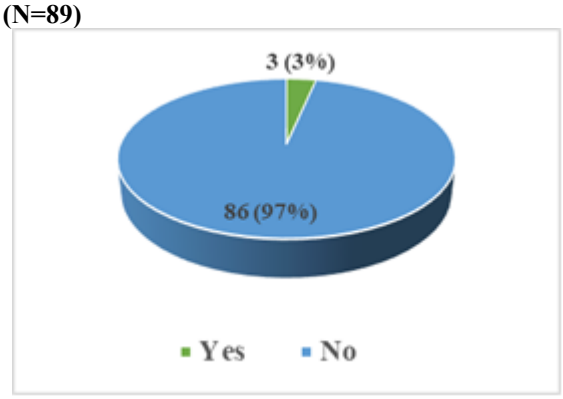
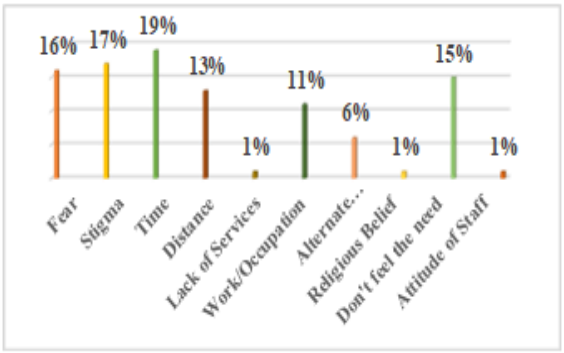


Figure 1.ii: Reasons for not visiting the DSRC after notification (N=86)



Qualitative findings for not visiting the DSRCs

Findings were presented in the form of narrative response with themes and verbatim. The following qualitative findings also support this quantitative finding and other reasons for not visiting the DSRCs are also highlighted.

Time, Work and Distance-

Many participants mentioned time, work and distance as the reasons for not visiting the DSRC even after being notified.

"Because of time and work I could not go to DSRC for testing" (RP3/26/M/DSRC-1)

"Because I have a tight schedule, I don't have time to go for testing" (RP25/27/M/DSRC-1)

"Because of time and work I could not go to DSRC for testing" (RP55/28/M/DSRC-3)
"Because I don't have time since I have to work" (RP73/35/M/DSRC 4)
"Distance from workplace to testing centre" (RP75/37/M/DSRC 2)
"Not suitable with hospital timing because of the distance from workplace" (RP90/27/M/DSRC-2)
"Distance of testing center and transportation fare problem" (RP94/24/M/DSRC-2)
"Distance from workplace" (RP100/35/M/DSRC-1)

Fear and stigma-

It was found that participants fear being positive for STIs/STDs besides having fear related to social valuation, discrimination and stigma.

"I am afraid for doing the test but if any sign and symptom appear surely, I will go for testing" (RP26/21/M/DSRC-1)
"I was afraid that other people might know about my condition and I might not be able to find another husband" (RP33/45/F/DSRC-1)
"Fear of people saying that I have this disease if I test in the center" (RP65/32/F/DSRC-5)
"Fear if report comes positive and want to do home testing" (RP93/39/Male/DSRC-2)
"Fear of neighbours, family and friends might think negative towards him" (RP99/40/Male/DSRC-3)
"Fear what if the report is positive" (RP104/43/M/DSRC-3 and RP113/27/M/DSRC-3)

Medical health officer, counsellors described about the low turn-up-

Primarily due to fear, stigma and discrimination among families, friends, and work places. Likewise, the professionals also mentioned stigma, fear as one of the main barriers.

"The low turn up of notified spouses in STI clinics is mostly due to stigmatization and discrimination among families, friends and work place. Also, when it comes to acceptance, even the closest mate doesn't support a person with such diseases, especially people with HIV (PLHIV) population are the ones suffering the most" (Counsellor, Private, 3 years of experience).
"Notified spouses may not even know that their partner has been tested or diagnosed with a sexually transmitted infection (STI). In some cases, the partner who received the diagnosis may be hesitant to disclose this information due to fear or the stigma associated with STIs….and they feel shy to come for testing due to stigmatization and lack of support" (Counsellor, DSRC 3, 6 years of experience).

Expression by a healthcare professional

A Health professional expressed that stigmatization, fear of isolation and lack of support from family members and the community can lead to relationships deteriorating.

"Most of the people are unaware about the effects of STI and they feel shy to come for testing due to stigmatization and lack of support and acceptance from family members and the community when they discover someone has contracted this disease. As a result, relationships deteriorate, and the affected individual's self-esteem is negatively impacted" (MHO, Govt hospital, 5 years of experience).
"*There's a feeling that people might judge them if they go to an STI/RTI Clinic. We need to change the way society thinks about this and make it clear that seeking help for STIs/RTIs is responsible and okay"* (Specialist, Govt hospital, 8 years of experience).
"Some people might be scared to go to these clinics because they worry about what other people will think or they might be afraid of the treatment process. We need to make sure these clinics are welcoming and safe places, and we should provide information to ease their fears" (Specialist, Govt hospital, 8 years of experience).
"Fear that they will be isolated or discriminated in society and by their peers…and for a few it's also because they

fear to test because what if it turns out positive" (Doctor, Private hospital, 4 years of experience). *"There is discrimination especially if they are partners of Female sex workers so they hesitate to come for testing"* (Counsellor, DSRC 5, 14 years of experience). *"Few clients are MSM, hence because of fear of stigma and discrimination their partners never turn up for testing"* (Counsellor, DSRC 4, 14 years of experience).

DISCUSSION

The unavailability of time was identified as a key barrier to STI/RTI testing among the participants in this study, even though after being notified by the counsellors at the DSRCs. Studies conducted in the United States and New Zealand have similarly identified time constraints as a key factor contributing to individuals' reluctance or delay in seeking STI testing. This was often attributed to perceptions of being excessively occupied and concerns about long waiting times/reporting time at clinics. Furthermore, participants agreement with the statement, 'I would use an STD test at home if one were available,' was associated with a decreased likelihood of testing delay. Additionally, perceived discrimination emerged in these studies as another significant barrier to accessing care [10,11,12].

Stigma associated with STIs and fear of judgment if seen going for STI/RTI testing were also found to be significant barriers to testing among participants in this study. Several studies have also highlighted that stigmatization and fear are the major barriers to seeking STI testing. In another [12,13,14] reported that individuals expressed concern about being stigmatized if seen requesting an STI test, and feared their partners would blame them if diagnosed with an STI.

Many a times, STI is associated with having multiple partners, this might increase stigma [2]. Supporting this finding [15,16,17,18] reported that participants diagnosed with STIs are concern about privacy due to the close-knit nature of rural communities and men continued to experienced self-stigma, feel embarrassed or ashamed to go to a clinic due to fear to be seen, fear of judgment or fear of social or relationship repercussions. This combination of psychosocial barriers- fear, stigma, and discrimination was found to contribute to delays or avoidance of testing among men, leading to undiagnosed and untreated infections and also might become the source in carrying the infections. [2] suggest that promoting timely care-seeking among symptomatic individuals, addressing societal stigma, and expanding access to testing options are critical strategies for improving STI care engagement.

CONCLUSION

In order to manage STI effectively, notification of spouse or partner is crucial, but in this study, 75% (n=89) were notified about STI/RTI testing and out of it, just 3% (n=3) visited the DSRCs. Of the 86 participants who did not turn up for STI/RTI testing at the DSRCs even after being notified, most of the them mentioned due to unavailability of time, stigma associated with STIs and fear (19%, 17% and 16% respectively) as the reasons for not visiting DSRCs for STI/RTI testing. Encouraging legislative and policy frameworks that address to social need is vital. Facilitating community engagement campaigns that respect cultural norms will support higher testing uptake.

Recommendations

1. Public awareness and sensitization programme in local languages using relatable analogies and culturally relevant narratives about STI/RTI and its ill effect if left untested and untreated at community level, educational institutions, work place through local newspaper, media, radio and influencers, local leaders, faith-based groups, traditional healers, campaigns, educational materials and through community outreach programs.

2. Share success stories of individuals who sought testing and received care without social repercussions.
3. Promote joint testing and counseling to build support and reduce spousal/partner relationship-related fears and also introduce and promote STI self-test kits, particularly for those with venereophobia or privacy concerns.
4. Refresh DSRCs staff training on stigma-sensitive counseling and confidentiality protocols.
5. Enable clients to provide feedback on services anonymously to help improve the DSRC experience and track non-turnout cases and conduct confidential follow-ups to understand evolving barriers.
6. Incentives to those spouses who both turn up for testing and complete treatment or transport reimbursement for attending STI testing.

Declaration by Authors

Ethical Approval: Approved by the University Research Ethics Committee (UREC), MLCU (Ref: III/DDSR/ UREC/EA/272/2015-1131, dated March 22, 2023)

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