

Research Paper

The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

Gautam Kr Ghosh^{1*}, Vanlalhumi²

ABSTRACT

In India the HIV positivity in among IDUs stands at a staggering 7.71. Women injecting drugs face greater undesirable consequence, though their drug use patters seem to reflect their male counterpart. They are still a group of population that lacks visibility, and are subjected to multiple layers of stigma because they belong to socially deviant and disenfranchised groups with facing gender-specific inequality and exclusion. The study aimed at understanding the ways in which FIDUs of Champai district in Mizoram, the indigenous minority community, feel the stigma and discrimination and the repercussions of the same that retard their ability to access health services. The study found several forms of stigma among female injecting drug user, that tend to adversely affect their required health service uptakes and suggested a range of specific gender-specific interventions at their personal, community-, and organization-levels.

Keywords: *Champai, FIDU, PLHIV, Stigma, Discrimination*

Injecting drug use is a notable HIV handler globally [1]. In India the HIV positivity in among IDUs stands at a staggering 7.71% [2]. Even though no global estimate of female IDUs exist, but recent study in India estimated female IDUs were 10,055–33,392 in numbers [2]. Injecting drug use among female appear to mirror patterns among males, but with greater adverse consequences. This group often face social adversity, high levels of exposure to drug and other substances at households, high rates of sharing of needles-syringes, notable involvement in sex work, high levels of stigma and low social support. Sexual and reproductive health problems, including abortions, frequent these females. [3]. While evidence suggests rise in the number of females injecting drug users (FIDU), they belong to socially deviant and disenfranchised groups with facing gender-specific inequality, stigma and exclusion [4]. This study attempts to focus on FIDUs of Mizoram state's Champai district, situated at Myanmar border, known for the illegal drug route. Mizoram estimated more than 28 thousand people injecting drugs for non-medical purposes – highest among all states [5]. The HIV prevalence of 19.8 % was considered stable to rising epidemic

¹Research Scientist with Health Research Institute & National Consultant, based in Kolkata, India

²Supervisor, New Hope Society, Champai, Mizoram, India

*Corresponding Author

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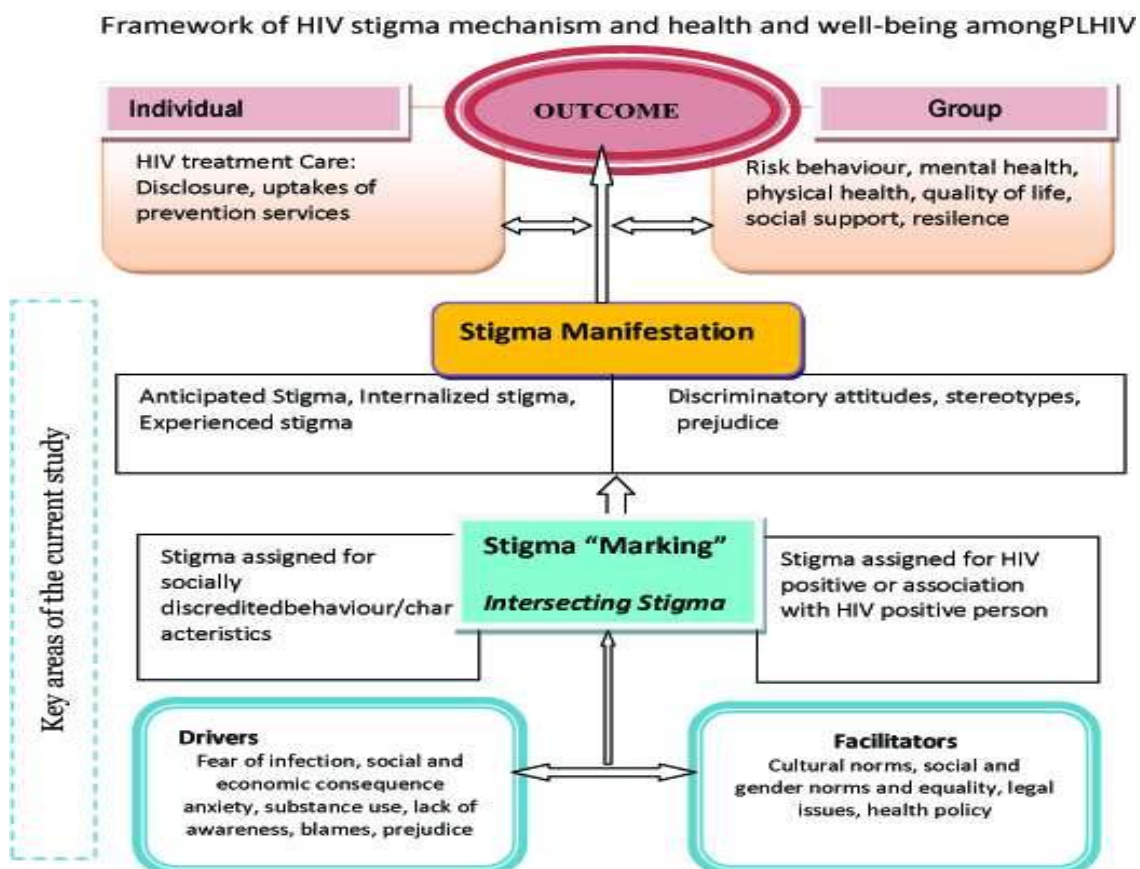
The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

[6]. Heroin addiction among young people of both genders stood at 81.7% and injecting drug use affected 96.2% young males and females of Champai district with 61.2% sharing of injecting paraphernalia reported for the district [7].

METHODOLOGY

The descriptive research design was employed among female HIV positive intravenous drug users in August and September 2019. The study had the approval of the Mizoram State AIDS Control Society, accorded by the Office of District AIDS Prevention and Control Unit, Champai, vide no. 11019/1/11/CMO(CPI)/DAPCU 2562 dated 23.09.2019. The data for qualitative study were collected through focus groups with 14 HIV positive FIDUs, conducted in local Mizo tawng dialect. Semi-structured questionnaire with broad open-ended question were framed for the study. Five individual interviews with ART service providers and Stakeholders were undertaken to obtain their ‘views on FIDUs’ experiences and perspectives. The study used content analysis based on Framework of health stigma and discrimination, as proposed by Stangl, Earnshaw, et al [8]. Authors of this study embarked at finding out the antithesis fallout on affected population i.e. persons or groups being stigmatized, their family members, friends or healthcare workers working in their cause. Accordingly, the focus has been on conceptualizing the study on diseases and identities of HIV, taking cue from the foresaid study, to construct relevant conceptual structure of health stigma and discrimination framework for the study, as in Figure 1 below.

Figure-1



Settings: The focus groups were conducted at participants’ convenient location near to New Hope Society- care & support center organization (CSCO). All the participants were linked

The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

to CSCO, but none of reportedly linked to any intravenous drug user (IDU) targeted intervention (TI) and not covered under needle-syringe exchange programme (NSEP), nor were they receiving opioid substitution therapy (OST). However, they received CSCO services as counselling, periodic CD4 count test guide, and referrals, as stated.

Participant selection and recruitment: In the current study a person who has injected at least once in the last three months is categorized as an IDU in keeping with the definition followed in the National AIDS Control Programme (NACO). She should be above 18 years of age and give consent to participate.

Sampling: Due to the cryptic nature of FIDUs, we attempted snowball sampling to recruit study participants. Altogether, 18 FIDUs were approached at the ARTC among whom 2 females declined to participate stating time constraints. Only 14 females consented to participate in the 2 focus groups organized. 5 Key Informants including ARTC Doctor, Nurse, Counsellor and 2 CSC functionary participated in the Individual interviews.

Data Collection & Analysis: Objective content analysis was used with some elements of ground theory to analyze the data. All individual interviews were conducted either in Mizotwang or English according to convenience of respondents. Focus Groups Discussion (FGD) were conducted in Mizo twang language and each focus group lasted between 60-75 minutes. A summary of sociodemographic factors related to drug use and HIV positive case were generated using Microsoft Excel systems. The discussion was transcribed verbatim by two note takers holding knowledge of the languages and verbatim responses capturing methodologies. Two separate transcripts were prepared and tallied for consistency. Rising themes were recognized as being ‘chief’ in the event that they were common overs sources. Transcripts were processed through QAD MINAR software and codes were created. Recurrent themes were identified with further examination of information for subtleties, likeness, and contrasts through steady comparison approach done [9]. In ways to construct themes relevant to women’s perceptions of stigma and its influence on their access to health services, final codes were listed. The socio-demographic profile of participants (n= 14) and years are summarized in Table-II below.

Sociodemographic Profile with Substance Use History & Art Status of Participants

Characteristics	Women (n=14)
Age	
20-35 years	78.6
Above 35 years	21.4
Education	
College level-	28.6
High School level-	50.0
Primary-	21.4
Illiterate	0.0
Employment status-	
Service-	14.3
Business-	35.7
Housewife-	0.0
Without formal job-	7.1

The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

Characteristics	Women (n=14)
Unemployed-	42.9
Income-	
No income-	42.9
Below 5000-	7.1
5000-10000-	42.9
Above 10000	7.1
Mean Income	5250.0
Marital status-	
Single-	28.6
Married-	21.4
Widow-	7.1
Seperated-	35.7
Single-	7.1
Substance use status	
Oral & Chasing –	0.0
Heroin & Ors –	100.0
Frequency	Daily (100.0)
Injecting drug use-	Heroin (100.0)
Frequency	
Weekly-	50.0
Monthly-	50.0
HIV treatment status	
Registered with ARTC-	
2-5 years	71.4
Above 5 years	28.6
Adherence in the last 12 months-	
Above 95% -	0.0
90 – 95%-	50.0
80% and below-	50.0

RESULTS

The study identified major forms of stigma as- Anticipated Stigma, Internalized Stigma and Experienced Stigma based on interface with respondents as enumerated hereunder-

Anticipated Stigma among FIDUs reflects their expectations of stereotyping, prejudice, and/or discrimination. Most of the participants stated that human interaction tends to be surrounded inside the setting of HIV, and gets to be the superseding viewpoint when managing with others. According to FGD participant 1 ‘*As a HIV positive female, I gotten to be exceptionally touchy to what individuals say and how they treat me. I feel ‘en dwang (looked down upon)’*’. Another FGD participant 4 pointed out “*I think particularly for ladies using drugs, it is difficult since we are anticipated to be a playing mother’s part, lookout for everything, continuously look great, always be upbeat and not care for ourselves as much as*

The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

we care for everybody else. While this narrative illustrates perception of female drug users' greater stigmatization based on traditional family norms, it also suggests a complex and contradictory power dynamic at play in gender role norms, particularly for women. Participants account suggested that women perceived a unique stigma of drug use, because injecting drug use ran contrary to gender norms of behavior. The ARTC counselor commenting on the prevalent negative perception of FIDUs said, *'maximum people feel it's far a disgrace for a lady to be an injecting drug user'*.

Most of the participants tend to perceive discrimination in general healthcare settings for FIDUs, as segregation practices intentionally used to differentiate people living with HIV (PLHIV) from the general care population. One FGD participant 6 informed *'my friend was referred to gynecologist in the hospital for her STI problems that didn't subside with presumptive treatment at ART centre. The doctor at the hospital noticed her ARTC green booklet (patient treatment history book) pulled his chair back and hurriedly jotted down some medicine and asked her to leave without explaining her anything'*. A few members shared that there was recent decrease in prejudicial mentalities and conduct in HIV health care settings, as they said *Professional in HIV treatment center treated us normally and they are helpful to PLHIV without being judgmental toward IDUs'*.

Internalized stigma- participants' account demonstrated a self-coordinated despicable cognizance of being an injecting drug using female and PLHIV. Disguise of shame was frequently connected with low confidence among members as - *'It is difficult to tell others of my HIV positive status, being IDU'* – FGD participant 2 stated. *'I feel worthless being IDU and also as HIV positive'* – another FGD participant 13 added. Both the statements carry participants negative reflection about self in varying degrees. Self-stigmatization came about because of participants disguised negative impression of injecting drug use within the study setting, where drug use was the most part understood as coming about because of a disappointment of individual ethical quality. FIDUs had been normally referred as *'hmeichhia ruihhlo ngai'* (female drug user) and they are often thought of as 'K.S.' (slang word for female sex workers). Not surprisingly, FIDUs found such identities shameful and they had an interest in hiding their shameful personalities. As FGD respondent 8 said, *'I usually don't like people to know my drug injecting status because I feel shame and when going out invariably use body covered clothes to hide injection marks'*.

Experienced stigma- Many participants stated to have experienced negative attitude towards injecting drug user from their communities. *'When I started doing drugs and injecting, others who do not use, refused to mix with me. I was able only to connect only with associate drug users'* – informed FGD participant 5. Two other FGD respondents also stated they were also stigmatized by friends and relatives: *'in my own point of view, even the CSC workers are more worried about us and love us significantly more than our near ones, 'If you try to reason out or explain something in the family settings, they brush you aside as an addict. It pains.''*

Among the participants 42% females were earning either from petty business or in some job. Stigma and discrimination at workplace seemed experienced by some. Said FGD participant 12, a 28 years old single female, *'I was working in a beauty parlor. Once my HIV positive status became known to the owner, he instructed that I leave the job in the interest of the parlor and find engagement somewhere. I felt devastated'*.

The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

Members portrayed how this disgrace was conjured inside a milieu of social elements and moralistic mentalities, conveying a perception of ethical judgements and suspicion: *‘People stated to me that a ruihhlo ngai (drug user) is a sinner’*- FGD respondent 14 stated. Another respondent 7, informed, *‘My school-day friends and neighbors become unduly alarmed by my presence near to their houses, as if I am thief. Very demeaning for me.’*

Apart from experiencing stigma and discrimination in public spaces, FIDUs frequently experienced the same in healthcare related settings. Respondent 10 reported *‘health care staff at the center have a queer look at us, and whisper among fellow staff on my doing drugs and injecting habits’*. Some participants also lamented over their non-existent access to harm reduction intervention services under the IDU TIs.

Stigma of being FIDU became layered over HIV-associated stigma, as respondent 11 defined antecedent HIV-connected stigma even from associate drug users. According to FGD respondent 3, *‘Once I was detected HIV positive through community based testing, my fellow drug user asked me not to come in their group’*. This assertion recommended that being HIV positive was diverse wellspring of disgrace among female injecting drug users.

Given these deeply ingrained cultural beliefs and taboos, coping with multilayered stigma is particularly challenging for females. Despite this, PLHIV FIDUs found to hold positive internal beliefs about themselves as- *‘I have changed throughout the long period. It resembles, I don’t mind who knows, everyone can know’*. respondent 9, a 36 years old lady, a separated from marriage and in a government, on ART for the last seven years asserted. Still another respondent-13, a 26 years old single lady, with college level education, on ART regimen for 5 years and doing petty business, stated- *‘I have understood that worrying won’t help. I take my ART medicines regularly and keep going.’*

Negative effect of stigma- Notwithstanding the origin, stigmatization of ladies appeared to bring about confinement and prohibition through prejudiced social procedures and institutional practices. Reacting to an inquiry concerning the effect of stigma, one member depicted how family members and partners *‘desert and stay away’* FGD respondent 1 said. Another FGD respondent 5 believed that *‘individuals cannot consent to be with somebody who is chasing or injecting drugs’*. Despite social isolation, out data suggest that the adoption of stigma – overtly discriminatory- has been a distinctive barrier to accessing health services. Participants characterized the actions of health system functionalities *‘impudent maltreatment’* as FGD respondent 2 commented. Another FGD respondent 7 stated, *‘once they know that one is drug user, they send the patient backward in the line or tell the person to come later.’*

Over and above the negative perception of people who use drugs, CSC functionary pointed out- *‘the health care workers did not understand why and how they need to serve female drug users.* Nonetheless, given women’s experiences, being stigmatized meant that *‘she had never gone back’* he added. But, studies indicated that many women inevitably found themselves forced by circumstances to seek health services, and in those conditions, they strived to conceal their identities, as a way to avoid being stigmatized or discriminated [12]. In Champai many individuals opted to be followed through by CSC outreach functionalities to the health facilities, to keep away from being feeling embarrassed. One FGD respondent-4 claimed, *‘if we go to hospital with the out-reach workers (ORW), health professionals give us the needed services without asking many question’*.

DISCUSSION

In review of relevant documents and published research articles, the study endeavored at analyzing the various forms of stigma and discrimination faced by PLHIV FIDUs of Champai; and accordingly conceptualized the stigma framework as in figure-1, to understand the stigma drivers and facilitators. Interactions with key informants indicated that lack of public awareness and knowledge on HIV issues concerning intravenous drug use, especially by females, existed, as the CSCO functionary said *“intravenous drug use is considered as synonymous with HIV paying no heed to the reality that intravenous drug use, per se, does not longer unfold HIV; it is the sharing infected injecting equipment that does so. IDUs within the area had been lamentably subjected to an excessive degree of stigma and discrimination, and unsubstantiated fear of infection existed as, FIDUs are blamed mostly for the infection”*. He also asserted - *“Drug use in Champai got started to be looked at as a fashion and a fad of young in the area. The unfortunate upward push of such stigma on the IDUs made them hide their dependency. They stopped gaining access to the services provided for their protection and wellbeing”*.

Notably, high literacy rate among females in Mizoram is recorded and all FIDUs participants at Champai held minimum of middle school education. Sharing of injecting paraphernalia by females with their male partner or spouse and unprotected sex were reportedly the dual modes of HIV transmission among FIDUs. In Champai, males continue to be main earning members for the family; and as such females have minimum say in economic matters, in decision making and obviously weak negotiating capacities in conjugal life. Again, among sensitized females, indulging in risky behavior under influence of drugs with male IDUs and partners found common, since IDU is considered by them ‘enjoyable group activity’. Said the ARTC counsellor, *“Females are discriminated within the husband’s family if both of them held HIV positive status. Females are often blamed for the death of her husband/male partner, even if the male had been diagnosed HIV positive earlier. Females reuse needles and injecting equipment with their male partners,”* she added.

In the socio-cultural domain, drug use in Mizoram existed since long and casual sex has never been a taboo in some tribal culture. Most of the girls doing drugs grew up in unmarried parent families, experiencing an volatile and unhappy childhood [10]. Champai’s geographical location reportedly gave rise to drug trafficking and human trafficking with Chins tribe people of Myanmar, stereotyped as drug peddlers and traffickers, fleeing and residing permanently in Champhai district mostly [10]. The strong group consciousness among the people in the North-eastern states has its negative elements toward drug users, people living with HIV/AIDS and especially female drug users. Their instantaneous households are frequently the target of fierce discrimination [10]. The numerous ethnic communities are affiliated to social and religious organizations such as Young Mizo Association and Churches of northeast; but these institutions plagued by incomplete and wrong information on drug use and HIV and holding narrow moral angle, too acted as a first-rate supply of stigma and discrimination [11]. The CSC functionary stated, *“easy availability of illegal heroin pushed young people to opioid use and also the sudden surge in wealth and property, which is attributed to profits made from smuggling the precursors, and stress arising out lack of suitable employment opportunities educated youth in the region were contributing factors”*. Also, he pointed out, *“many of females into drugs also act as conduit for drug peddling and peer influence push them into IV drug use”*. An ARTC service provider stated *“for FIDUs, treatment options through drug de-addiction and due*

The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

coverage under targeted intervention programmes not existed. "FIDUs are hesitant to go to opium substitution clinics, gone to by men, thus numerous female clients remain out of reach of treatment facilities". According to CSC functionary "gender bias against FIDUs and more so against PLHIV FIDUs in general healthcare settings, barring ART centre, in Champai often compel FIDUs, requiring specialized treatment for certain ailments, suffer.

Drug possession and peddling in Mizoram, is punishable offence and repeated case of Police arrests reported. Rigid law authorization against heroin trafficking and peddling, in the early 1990s, brought about in move towards the vein puncturing propensity of infusing heroin and other pharmaceutical items [11]. In the perspectives of the above drivers and facilitators, stigma 'marking', intersecting with socially discredited behavior/characteristics on one side and HIV positive status identification and association with persons living with HIV (PLHIV) on the other hand was evident. These caused the emerging of stigma 'manifestation' for PLHIV individual and groups; and FIDUs carry the multiple layers of stigmatization i.e. gender norms, intravenous drug use and HIV disease. The study thus found several forms of stigma, as shame of drug use, gender-related shame of being a drug pusher, and shame of being HIV positive female.

Within the above viewpoints it is imperative to address diverse shapes of felt shame to relieve their negative impacts on women's capacity to healthcare service administration at Individual, social and functional levels. At Individual level, mediation that bolster inversion of internalized stigma are required. Investigate among stigmatized populaces has appeared that peer-based support approaches can help in adapting and standing up to self and outside stigma by tackling collective self-efficacy, and giving an environment to redo self-esteem [13,14]. Publicly, it is fundamental to address moralistic judgements and attitudes that reinforce conservative, but often inequitable stigmatization of women. Working with community-oriented organization and devout pioneers and starting community-led advocacy and outreach has appeared to mellow difficult community positions and to diminish separation against drug users in Vietnam [15]. Thus, community sensitization can be successful approach adoptable.

At the structural level, interventions for eliminating stigma through proper sensitization of healthcare providers and zero discrimination rules enforced, given the fact that rising number of FIDUs would require health service access [16]. Training on globally recommended comprehensive package of harm reduction services need to be imparted [17]. In addition, peer navigation to health facilities would decrease encounters of shame and separation among FIDUs. The current harm reduction programme, supported by NACO across states, required to refocused with inclusion of effective community and socially situated harm reduction interventions in mitigating stigma, because it lay out path for employment, livelihood and skills development [17], dynamic policing [18], lawful bolster and ending violence with a rights-based approach [19,20,21].

In the current study, we embarked at understanding the stigma and discrimination issues concerning female injecting drug users based on the on the conceptualized stigma framework. This framework facilitated in analyzing the social and structural pathways in addition to individual pathways. This study observed that the stigmatization measures unfurl over socio-ecological range and changes over financial settings in low-, middle- and high-income nations [21]. The study attempted to investigate the drivers, facilitators, intersecting stigma and stigma manifestations and watched that drivers and facilitators decide stigma

The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

through which shame is connected to individuals or groups. The study team posited that stigma manifestations impact a number of people and groups' social acceptance, entrance to and uptakes of healthcare services, resilience and advocacy. The use of this framework enabled us to gauge stigma among PLHIV FIDUs in concise and comparable manner; and hopefully may be found suitable for use in future research studies, as well.

Limitations and future direction

This study had certain limitations as it involved participants though registered under antiretroviral therapy regimen, but not availing harm reduction service coverage. They were linked to a care and support organization as such their accounts and encounters of disgrace may vary from other ladies. It is undoubtedly conceivable that this study may be belittling the effect of stigma among female injecting drug users of Champai, because our purposively sampled participants were already accessing some psychosocial support and anti-retroviral treatment services.

CONCLUSION

Without intending to totally understand or cause over simplification of the context and encounters of stigma, it is apparent that injecting drug user women in Champai or anywhere in Mizoram frequently self-stigmatize, confront disgrace for injecting drugs, and are discriminated. These are deterrent in their accessing and availing of health services. Suggestively, to overcome the numerous forms of stigma experienced by study participants at the same time and guarantee that custom-made gender-sensitive mediations are accessible to them, a run of person-, social-, and structural-level mediations will be got to be actualized. For these to auger, necessary review of National Policy Narcotic Drugs and Psychotropic Substances 2012, to enable suitable inter-ministerial coordination on provision of addiction treatment under the Union Ministry of Social Justice, as well as access to Harm Reduction interventions and sexual health under Union Ministry of Health and Family Welfare are equally meted to female injecting drug users with suitable facilitation at state levels.

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The context of stigma and discrimination among immune-compromised Female Injecting Drug Users (FIDU)– A study in Champai, Mizoram in India

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Conflict of Interest

The author(s) declared no conflict of interest.

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