# CHAPTER 1: BACKGROUND

## 1.1 INTRODUCTION

WHO defines self-care as "the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health care provider"(1). Self-care means that people take much greater responsibility for their own health based on their understanding of how to promote and protect health and what to do when it does go wrong(2). It defines the right and duty of people to participate in planning and implementation of healthcare either individually or collectively.

The concept of self-care remains within the traditional health education literature focused on risk reduction and disease prevention at the level of personal action. It recognizes how individuals determine their behavior to seek health services and how they assess the measures to promote health. Self-care incorporates several issues related to hygiene, nutrition, and lifestyle. To manage health, an individual's role is to follow the measures that comprise self-care which according to WHO include promotion of health, prevention and control of diseases, self-medication, provision of care to the dependents; rehabilitative and palliative care(1). Self-care includes individual behavior to promote health, prevent disease and treat illness. It involves the patterns of living, individual's ability to obtain social support and to effectively interact with professional services.

The Astana declaration at the Global Conference on Primary Health Care in 2019 focused attention to human rights to improve individual's autonomy for self-care to empower individuals as self-carers and care givers and enhance self-care behavior (3) (4).

Self-care is not new, We have been engaging in self-care in our schools, offices and at our homes but self-care is much beyond these contexts (5). The concept of self-care is still trending. Self-care is not a singular skill, it fosters wellness. Self-care is a continuous process and paying attention to it promotes our mental as well as our physical well-being. Neglecting self-care and one's personal needs can cause suffering such as deterioration of sleep, wellness, empathy and compassion. An individual is more prone to stress, depression and other mental health problems (5).

WHO defines self-care in the form of self or user initiated interventions that enable individuals and communities to take charge of their own biophysical well-being with an intent to improve health, prevent disease, limit illness and restore both physical and mental well-being (10) (11). Self-care may be undertaken independently or in collaboration with medical and healthcare professionals, and social support systems (12) (13).

Self-care is among the most promising approaches to attain Universal Health Coverage (UHC). As per the Sustainable Development Goal (SDG)10 all individuals and communities can access promotive, preventive, curative, rehabilitative and palliative health services they need, of sufficient quality; to be effective, while also ensuring that the use of these services does not expose the user to financial hardship (13) (14) (15) (16). Self-care interventions have the potential to contribute to normative and positivist choice by providing opportunities to individuals for making informed decisions regarding their health and health care. Self-care interventions also have the potential to maximize the efficient use of domestic resources for health. Innovations in the health sector by using digital health management systems has enhanced self-care practices and improved access to medicines (17) (18). Self-care covers a gamut of health problems including Non-communicable diseases (NCDs) and mental health problems among others. With the increase in digital technology, new interventions in self-care have been made accessible and affordable to the community with for example, increased access to drugs and diagnostic services as well as treatment and management of complications. Self-care innovations can be enhanced with the cooperation of communities, technology developers, and practitioners and with political support. Self-care health needs for low resource settings hold promise of equitable health services.

Recent years have witnessed an unprecedented increase in self-care practices. Consequently, WHO is leading an initiative to support the process for developing normative guidelines that build upon existing WHO guidelines recommendations, and best practices on self-care interventions(1). Marginalized and vulnerable communities including Lesbian, Gay, Bisexual and Transgenders (LGBT) communities, long distance truck drivers, commercial sex workers (CSWs), HIV positive people among others face social, economic and political problems which results in health consequences.

With the increase in digitalization and more access to technology. People are increasingly choosing self-care which they prefer to professional care. Marginalized communities hesitate to visit health care providers because of stigma issues.

### 1.2 RATIONALE:

Research is needed for different regions, especially for growing economies and developing societies like India (6)(7) to understand how diverse population groups are using self-care methods. What interventions do they use, and how do they use self-care products such as protection devices like condoms, IUDs, self-testing kits etc. (8)(9).

In this study, three marginalized and vulnerable communities men who have sex with men (MSM), commercial sex workers (CSWs), and long distance truck drivers, are the focus of the research. These communities are poor and suffer from discrimination. Because of their economic conditions and cultural beliefs, they have less access to formal health care services. They are deprived of their basic human rights and have to face discrimination in society as well as in the health system. For example, people with same sex preferences are ridiculed and ostracized by their families and also by the communities. While health programs may achieve their goals by improving the well-being of easier to reach communities, they may exacerbate inequality if hard to reach populations are left behind. Evidence suggests that the LGBT communities are hard to reach (19) (20) (21). Therefore, it is important to undertake research to capture their self-care practices, values and preferences. Currently, there is a great paucity of research on their self-care practices. This study focuses on MSM, commercial sex workers (CSWs) and long distance truck drivers to examine their self-care practices, values and preferences with regards to sexual and reproductive health and rights (SRRH) and HIV prevention.

## CHAPTER 2: LITERATURE REVIEW

The World Health Organization's working definition of self-care includes "the ability of individuals, families and communities to promote health, prevent disease, maintain health, and cope with illness and disability with or without the support of a health-care provider (1). Self-care has been practiced for years.(2). It includes the lifestyle of an individual's capacity to overcome stress and obtain social support. Self-care defines the ability of an individual to identify health problems and to interact effectively with health care professionals (2). In the developing world, there are many ayurvedic practitioners and other healers who promote self-care behaviors. Many sources of the information

about such practitioners of health care remain untapped. Oratai Raunyajin examined the socio-economic determinants of self-care and found that traditional medicine such as ayurvedic, Chinese and others can be beneficial as well as harmful (2). For example, drinking hot tea for diarrhea can be beneficial but the use of cow dung on the umbilical stump is harmful. Self-care decreases the dependence on the healthcare system. However, it was surprising to note in a study that self-care did not decrease patients' visit to the physicians (2). In recent years, we have seen a rise in the practice of self-care. Self-care potentially benefits the individual's health and well-being. (3). Self-care can help in achieving Universal Health Coverage (UHC). Adopting self-care practices can help to improve health and well-being. There is a special need to focus on the marginalized and vulnerable communities as they are not reached by the formal health care system. Perjaje Vasu assessed the knowledge and self-care practices in Sullia, Karnataka and found that self-care practices were very poor among all sections of the community because people did not have access to information and knowledge (4). Socio-economic status also affect health-seeking behavior of individuals (5). Social determinants such as income, inequality are major contributors to morbidity and mortality. "People in the lower income brackets have lower levels of self-esteem, coherence and sense of mastery". There is a need to recognize human rights, gender equality and other ethical considerations to promote self-resilience (6).

The following is a review of literature of the three vulnerable and marginalized communities that were researched in the current study.

**Men who have sex with men (MSM)**

Viraj observed that men who have sex with men are at a higher risk of sexual health problems(7). Physicians and other health care providers have a judgmental attitude towards them because of their sexual identity MSM have a higher risk of HIV as they practice anal sex. Most MSM have multiple sexual partners and because they have infrequent health check-ups, they often live with undiagnosed HIV infection. Research shows that the use of condoms is inconsistent among them. Alcohol and drugs are common among MSM who are more likely to have unprotected sex with multiple partners increasing the risk of HIV. MSM who are living with HIV may forget to take their anti-retroviral medicines especially when they are under the influence of drugs (8). In one study only 40% of MSM living with HIV accessed treatment. Low and middle income countries criminalize same sex behaviors and report poor access to ART (9). MSM face stigma, discrimination and violence(10)

and are more likely to face isolation and social disconnectedness (11). Soohina in her cross-sectional study of MSM in the age group of 25-35 years observed that they were not open about their sexuality which resulted in depression (12). Among MSM, community based testing in private clinics is very common and pre-exposure prophylaxis (PrEP) is the single medicine taken by them every day (13*). Sakthivel et al carried out the study in Maharashtra for ensuring zero HIV among MSM through targeted interventions and observed that regular non-paying MSM are at high risk of HIV do to their unsafe sexual behaviors* (14).

**Long Distance Truck Drivers**

*A behavior and perception study of truck drivers by Narelle in 1991 showed that* a quarter of the truck drivers took pills to stay awake. Drugs and alcohols were very common among them and almost 40% of the truck drivers drank several days per week. Almost half drank after every route (15). A common practice among truckers was to take alcohol after visiting sex workers.

The study also showed that there was a strong link between truckers' lifestyles and their vulnerability to HIV. The majority of respondents were aware of sexually transmitted diseases and more than half could name at least one STDs. More than half of respondents were aware of HIV/AIDS. Mandy K Ng concluded that health care interventions are necessary for truck drivers as they are at high risk of chronic and other diseases (16). In 1993, Singh et al. (1993) conducted a study on HIV infection among 200 long-distance truck drivers and their helpers in Delhi (17). In this study 78% of the truck drivers admitted that they had multiple sexual partners. Rao et al. conducted a study in Bengal in 1994 to examine the sexual behaviors of truck drivers and their helpers in relation to FSWs (18) . They explored the lifestyles, attitudes and sexual behaviors of truckers towards FSWs. The researchers found that the majority of the truckers were away from their homes on the highway most of the year and some of them visited their homes once in a year and stayed with their family members for one to two months. They also found that in the initial stage of their life, when they were *khalasis*, they were forced to subject themselves for anal sex mostly as passive partners with their driver bosses. A common reason for visiting FSWs was uncontrollable sexual urge. The study also showed that most of the truckers practiced vaginal penetrative sex with sex workers and their wives but oral or anal sex with other truckers; 32% of the sampled truckers had experienced anal sex at least once. The use of condoms among the sampled truckers was infrequent and their knowledge about availability and proper use of condoms was poor. Many truckers reported that they had never used condoms or had done so only occasionally. Those who visited sex workers reported a history of sexually transmitted diseases.

In 1995, the National AIDS Control Organization (NACO) conducted a high risk behavior study in 18 cities having a population of 5 lakhs and more (19). The study focused on six groups, which are typical routes for the spread of HIV. Truckers were also studied as one group. The study revealed that truck drivers had multiple sexual partners.

Rao carried out a post-intervention knowledge, attitude, behavior and practice survey on STDs and HIV among truckers in the state of Bihar (18). The study showed that most of the truckers passing through Raxaul belonged to Bihar (57%), while 16% belonged to Uttar Pradesh and 5% West Bengal. Most (69%) were semi-literate (19). 70% of the truckers were married. This study revealed that 60% of sexually active truckers had never used a condom. The study also showed that 29% of the respondents reported to have suffered from STDs. In the past, 36% of the truckers, who suffered from STDs did not visit any medical practitioner.

Akash conducted a study on social work practice with mobile populations vulnerable to HIV (20). This study was conducted at major trucking centers located in different parts in of Delhi. The majority of the respondents hailed from North India, largely from the states of Punjab, Haryana, Himachal Pradesh and Uttar Pradesh. They were in the prime reproductive age group of 18 to 46 years. An overwhelming majority had sexual intercourse in the past six months, 46 % had paid sex with an unknown partner or sex workers.

A qualitative study on truck drivers' perceptions showed that the majority of truckers consumed alcohol before sex and had sex without protection (21). This made them vulnerable to STDs and HIV infection. It also made them efficient transmitters of HIV and STD infections.

Sanjeev et al. conducted a study on the knowledge, sexual behaviors and practices among long distance truck drivers (24). This study was conducted to understand the knowledge, sexual behaviors and practices of long distance truck drivers on the state highway connecting Punjab to U.P, Bihar and West Bengal. The study showed that 32.3% of the respondents had a single sexual partner; 56.6% were involved with multiple sexual partners. The use of condoms among those having multiple sexual partners was 64.3% but 35.7% had either never used a condom or had used condoms very irregularly.

Study on high prevalence of obesity in truck drivers also showed that one in the every three truckers visited commercial sex workers but only 18% of them used condoms (22). There is clearly an urgent need to generate awareness in this community regarding prevention of diseases including HIV.

**Commercial Sex Workers (CSWs)**

The Population Council (23) provided evidence of physical and sexual violence within marriage. Their study showed that violence has adverse effects on health. There is, therefore, a need to develop interventions for preventing violence. However, use of contraceptives was low. The reasons given for lack of usage includes poor access to services, carelessness, unplanned sexual intercourse and pressure from sexual partner. This study also indicated that young people engaged in sexual relationships at an early age without protection. There is a need to provide information on family planning based on the needs of the young.

Migrant sex workers had poor access to sexual and reproductive health services. An ethnographic study (2012–2015) on female sex workers showed that young people had lack of accessibility, affordability and faced stigma in accessing contraception and treatment for sexually transmitted infections (STIs). Vazirani observed that there was a moderate association of condom use and use of mobile phones for soliciting clients (24). Women who got clients through mobile phones were paid better and could insist on the use of condoms but women who did not use phones to solicit their clients were at higher risk. Ojebuyi (2009) studied people's knowledge of HIV/AIDS in Kolkata. He investigated the effectiveness of communications skills, to educate the public about HIV/AIDS. Financial barriers prevented people from accessing the necessary services. The researchers recommended that right-based sexual and reproductive health services should be provided. In 2013, B.K. Nimbalkar, provided targeted interventions for FSWs to prevent HIV infection. The program was implemented according to the guidelines of the Nation Aids Control Organization (NACO).The objective was to reduce the vulnerability of HIV infection among FSWs through awareness generation, to reduce STIs among the targeted population and to create an enabling environment to mitigate the impact of HIV/AIDS.

Hong and Li. reviewed the behaviors of FSWs in China and found that most sex workers were young women and had both commercial and non-commercial sexual partners (25). They also observed that they did not use condoms which resulted in sexually transmitted infections (STIs). FSWs faced stigma in accessing information related to HIV prevention, treatment and care. A study in Mumbai, Chennai and Kolkata showed that *"No woman suffers more discrimination in access to services, whether for health care, fertility regulations or safe abortions as much as women in sex work* (26)." This study highlighted the vulnerability of FSWs to the high risk of HIV. Some FSWs had limited knowledge of contraceptives and others did not use condoms for fear of losing their clients.

Sinha showed that flying or mobile sex workers were at high risk of HIV in Kolkata due to the limited outreach of services by NGOs (27). Studies on flying FSWs perceptions showed that women in sex work generally used condoms as contraceptives (28). Condoms are a cost effective method of contraception when used correctly. (29). In 2008, Sahsrabuddhe and Sanjay reviewed the health implications of the high burden of HIV among FSWs in India. They assessed the socio-demographic, biological and behavioral factors that predispose FSWs to the risk of HIV/AIDS. The study showed the prevalence of HIV transmission among sex workers, their clients and intimate partners. In 2019, Narasimhan described sexual and reproductive self-care among women and girls. The study showed that vulnerable women with low income and immigrants has unmet needs for contraception and abortion (28).

Self-care involves treating everyday health problems by obtaining medicines from pharmacies. It is beneficial because the formal health system cannot reach everyone. There is a need for research for developing innovative models to increase the potential of self-care in sexual and reproductive health. To deal with the barriers in sexual and reproductive health, systematic reviews are required. Self-care for sexual and reproductive health requires people to have knowledge and skills for regular HIV testing, condoms use and the use of other contraceptives. It is also important to be aware about healthcare barriers such as stigma, lack of privacy and social support. Peer support is necessary to enable vulnerable communities' access health centers for counselling. There is a need to provide them with information regarding sexual and reproductive health and sexually transmitted infections including HIV (28).There is also a need to prevent STIs by early diagnosis and regular check-ups (28).

A thorough literature review was done for self-care practices in all the three communities from papers published in the last 20 years in different national and international journals. It was found that very few studies were conducted specifically focusing on self-care practiced by vulnerable and marginalized communities. There is a general paucity of research on self-care and even less is available on vulnerable and marginalized communities. With the growing use of self-care, it is important to undertake research on different facets of this practice.

## CHAPTER 3: GOALS AND OBJECTIVES

The goal of the study is to add to the body of literature on the values, preferences and self-care practices of hard-to-reach, marginalized and vulnerable communities with regard to their sexual and reproductive health and rights and HIV prevention.

**The objectives are:**

1) To examine the values, preferences and practices of marginalized communities including MSM, truck drivers and CSWs in Delhi, India, with regard to self-care for sexual and reproductive health and HIV prevention.
2) To understand self-care behaviors of MSM, truck drivers and CSWs.
3) To understand their motivations and challenges including socio, economic and mental barriers they face in adopting self-care.
4) To understand the mechanisms that they employ to address accountability when self-care fails.

# CHAPTER 4: STUDY METHODOLOGY

## Describing the methods

*"The latest research on polls has turned up some interesting variables. It turns out, for example, that people will tell you any old thing that pops into their heads."* ***---Caption from a Cartoon by Saxon***

The survey research method is used to collect information from different community groups. It helps in obtaining information directly from the participants. Questions are asked orally and responses are obtained at the same time. Field research involves collecting data that is particularly suited to exploratory and descriptive goals(2). It defines a particular phenomenon to estimate the strengths or intensity of the behavior related to the issues are being explored and helps in assessing what exactly is going on.

## Justifying choice of the methods

This study was undertaken with the guidance of the Center for Human Progress (CHP). In this study, a qualitative research design was employed. In-depth interviews (IDs), focus group discussions (FGDs) and key informant interviews (KIIs) were conducted with marginalized and vulnerable communities. Qualitative research methods allow greater spontaneity and interaction with participants. They provide greater opportunity to the participants to respond elaborately and in greater detail. This degree of flexibility available in qualitative research helps in obtaining the kind of information that is sought. Marginalized and vulnerable communities include lesbians, gay, bisexual

and transgender (LGBT) communities, long distance truck drivers, commercial sex workers (CSWs), HIV positive persons among others.

The current study included MSM, CSWs and long distance truck drivers. In-depth interviews of key informants and leaders and focus-group discussions were conducted with men who have sex with men (MSM), long distance truck drivers and commercial sex workers (CSWs) to understand their self-care practices, values and preferences.

**Reconnecting methods to research goals**

A qualitative research design was used to examine values, preferences and practices of marginalized and vulnerable communities with regard to self-care for sexual and reproductive health and HIV prevention. To understand the self-care practices of marginalized and vulnerable communities, their motivations and the challenges they faced in adopting self-care including social, economic and mental barriers were assessed. The qualitative study was designed to understand the mechanisms they follow to address accountability if self-care fails.

"*Observation is a skill over and above passive reception of the raw data of sensory experience---Weimer (1979).*"

Sexual minority communities have low literacy, poor socio-economic status and are discriminated by society. Their human rights are violated and they suffer injustice and intolerance. They are ridiculed and ill-treated by their families and also by the community and are, therefore, oppressed individuals.

**Problems**

Challenges faced in data collection were due to mistrust and misunderstanding of the participants who feared disclosure of their personal information. There were differences in the language and perspectives of the participants and the researcher, and, therefore, questions related to the integrity of the data was a major challenge. The participants hesitated to consent to audiotaping because of their concern of invasion of privacy and concern about how the recordings might be used. They were worried that the researcher may take advantage of them and may have hidden motives. There was

difficulty in determining and capturing information in real-time. The participants had a hard time in remembering past events. Analyzing large volumes of qualitative data to assess the information of the self-care practices of vulnerable communities was time consuming.

**Methodological approach**

Interview guides were used to examine self-care practices adopted by vulnerable and marginalized communities. Data was obtained on their lifestyle, interventions they used to promote sexual and reproductive health such as condoms, gels, antibiotics, HIV testing kits and others. Information was obtained on mental health problems and violence by partners, community, police and others. This research provided an understanding of participants' views about their self-care practices, how they obtained information on self-care interventions and what were their motivations to use them. Information was also obtained on the barriers they faced, and what they did if self-care practices failed.

**How the data was collected**

The data were collected from randomly selected sites in Delhi. The duration for the collection of the data was from April 4, 2019 to April 13, 2019.

The interviews were conducted using the interview guides. Face-to-face interactions with the respondents (3) in all the selected groups were carried out. The interviews were approximately 90-120 minutes in length. The interviews were recorded. The recordings were transcribed and checked for accuracy before these were analyzed. Two IDIs, two (KIs) and one FDG were conducted with each group viz MSM, truck drivers and CSWs (4).

All study participants were asked about self-care practices related to sexual and reproductive health and HIV prevention. Information was also sought on the barriers they faced, issues related to their family, friends and communities, their motivation for self-care and how they handle issues of accountability if self-care failed.

The participants were also asked about their mental health problems and how they tried to overcome them. They were asked about violence (physical, mental and emotional) that they faced through community, friends, family, police, gurus and others.

Before initiating the study, participants were given consent forms which described the study. Their consent was taken and confidentiality was assured. The recordings of the interviews were done and

were then transcribed and checked for accuracy. The interview notes were sent to the interviewees for re-checking and validation.

**Selection criteria and description of study participants**

Quota sampling (*selecting sampling elements on the basis of categories assumed to exist within the population*) was used as we had to include certain number of participants for each identified sub-groups in order to have enough information from each category of participants.

For the key informant interviews, participants were selected on the basis of experience. They were peer educators working with NGOs. For in-depth interviews, outreach workers with 4-5 years of experience were selected. Focus group discussions, included peer educators, outreach workers and other young people.

**Critique of research methods**

In qualitative research, the subjectivity of the research leads to the various procedural problems. There is replicability of the data and research biases can occur. This method of research is time-consuming and sometimes unreliable. It draws out problems related to gender identities and class and also on the oppression of minorities within communities.

A major advantage of focus group discussions is that they enable us to explore multiple opinions of respondents. We can, thereby, obtain more varied details than with structured interviews which make it difficult to interpret the differences when responses are compared(4). Qualitative methods are effective in identifying intangible factors(5) whose role in research may not be readily apparent. They gives us a complex reality of the given situation but to gain contextual statistical information, it is much better to use a mixture of quantitative and qualitative research methods. For quantitative methods, generally inflexible and closed-ended questions for the respondents help in confirming phenomena and provide more rigid responses in a numerical form which can be generalized.

**Analysis**

For the analysis of data collected through interviews, the researcher gathered all the transcripts, documents and any other information. To get familiar with the data, the researcher read the transcript several times to make sense of it. After that the points which help in connecting and categorizing the data were highlighted and notes were made of the highlighted points. The data was coded by combining the recurring themes such as, language, opinions and beliefs of the participants about their

self-care practices related to sexual and reproductive health. Triangulation of data generated by KIs, IDIs and FGDs make it possible to obtain reliable information on complex issues.

# CHAPTER 5: ANALYSIS AND RESULTS

## RESULTS AND GAPS OF RESEARCH ON MEN WHO HAVE SEX WITH MEN (MSM)

### Growing Up

As these men were growing up, they felt more and more feminine. Most of them enjoyed dressing up in female attire. They began to realize when they entered high school, around the age of 14-15, that they were more attracted to men. This enhanced their feminine characteristics even more. It often manifested in effeminate body language which began to get noticed. In their childhood, most experienced discrimination and bullying, which resulted in fear. People called them "*Gur*". Most at this stage, were however, unaware about homosexuality. In their childhood they were sexually abused by older members of the family and the extended family, also bribed them and threatened them to prevent them from telling anyone.

### Self-care Interventions for Sexual and Reproductive Health

In the late 1990s and the early 2000s when NGOs were few and not always accessible, information and awareness about safe sex was meagre. Consequently, unprotected sex was a common feature. Now, almost all of them are aware that they should use protective measures. They generally use condoms and gels. NGOs provide them with information related to sexual and reproductive health. NGOs also provide condoms and organize demonstration on the

correct use of condoms. Some prefer to obtain these products from NGOs and others are not averse to buying these products from pharmacies, if needed.

**Information Sources**

MSM revealed that knowledge about sexual and reproductive health and HIV prevention is very important for them. They get information through social media, television, radio, and mass media and through the peer educators and NGO outreach workers about sexual health. NGO workers undertake behavior change communication (BCC) activities to generate awareness about interventions for sexual and reproductive health. NGOs also provide services for HIV and syphilis testing for vulnerable groups and these services are regularly utilized by these communities.

**Risks Faced by the Community**

MSM sometimes had allergies and irritation because they used shampoos, body lotions and saliva instead of gels during penetrative sex, which caused redness, boils, irritation, etc.

**Mental Health Problems and Violence**

This MSM community faced mental health issues of all kinds. Even though they are now becoming more accepted by society, it is still often an issue. People still abuse them verbally, calling them names such as "*Gur*" (homosexual) or "*hijra*". They are not accepted by their families and have to hide their identities, which causes anxiety and depression. They are also constantly concerned about partner faithfulness and this is a major cause of depression.

This community, for the above reasons, is more exposed and vulnerable to violence from family members, partners and clients (sexual, physical and emotional), as well as from police and the society.

**Motivation and Barriers**

The study showed that when MSM were unaware about the risks of unprotected sex and had limited knowledge, they took risks and frequently suffered the consequences such as illness and infection. Over the years, with greater awareness provided by NGOs, and development and advancement in the technology and social media, they are now far more aware of their risks. They

also have more information and are better able to practice self-care, which has become an important aspect of their lives.

## RESULT AND GAPS OF RESEARCH ON LONG DISTANCE TRUCK DRIVERS

### Lifestyle

The life of long distance truck drivers is not easy. They have difficult long hours on the road. They take long journeys with little or no sleep. They are stressed and worn down with tragic conditions on the road that they face with their jobs. Truck drivers said "*We have no life, people do not respect us''*. Truck drivers have less stability in life as they travel for several days continuously to transport their cargo on time, without any rest and sleep. They prefer to have processed food and sugary beverages while travelling which causes adverse effects. At times, they do not get water to clean themselves and so they suffer from illness.

### Sexual Behaviors

Truck drivers are a mobile population. They travel long distances being away from home for months. The intersection of truck drivers with CSWs is very common. They frequently have sexual encounters with CSWs without any protection. Long distance truck drivers present a unique challenge as they are at high risk of HIV. They said "*Most truckers prefer to have sex with CSWs and transgenders on their route as they carry condoms with them*".

### Self-care Interventions for Sexual and Reproductive Health

The study showed that long distance truck drivers prefer to use condoms when they have sex with CSWs and transgenders. CSWs and transgenders usually bring condoms with them. The use of gels and creams is very rare among long distance truck drivers because of lack of knowledge. The study showed that because of their regular drinking habits while driving,

truckers frequently have sexual encounters without protection. Some also have sex with their helpers".

**Information Sources**

Long distance truck drivers in Sanjay Gandhi Transport Nagar, Delhi revealed that it is really very important for them to have knowledge about HIV prevention and sexual and reproductive health. They get their information through their interpersonal contacts with peer educators and outreach workers. They get information related to condom use for safe sex. The study findings showed that because of lack of time, truckers do not access social media or television for information related to sexual and reproductive health. NGOs provide condom demonstration and information on hygienic practices but because they are travelling, not every trucker gets the information. It was also found that truckers visit private doctors for health- related problems and have to spend a lot for these consultations.

**Issues Related to Cost and Affordability**

Being a long distance truck driver is a very grueling job. Truck drivers have unattractive careers and poor pay. They have unhealthy lifestyles. Sometimes, they have no work for many days and they suffer from bankruptcy. They said "We are disadvantaged because of lack of knowledge; doctors charge us more for providing medicine. They charge Rs500 for a medicine that costs Rs10."

**Risks and Barriers Faced by the Community**

The study showed that the long distance truckers have sex most frequently with CSWs and transgenders. They have poor knowledge about sexual and reproductive health. They face difficulties because of their long journeys and not being at home. They suffer illness and other sexual health problems. While driving for long hours and having poor availability of public toilets on route, they are unable to take care of their hygiene.

**Mental Health Problems and Violence**

The study revealed that most long distance truckers face mental health problems. They are exposed to violence and abuse inflicted by the community, police and others. They said ‘’Many times police charge a fine for no reason and we have to pay from our pocket”. Because of their long journeys, they rarely visit their homes and so they face isolation and sometimes depression. At times, they go for days without work which may also causes depression, become alcoholics.

**Motivations**

The study showed that long distance trucker are less motivated and unaware about their physical and mental health and well-being. They have limited knowledge about sexual and reproductive health. They force CSWs to have sex without protection when they are drunk. NGOs organize workshops in Sanjay Gandhi Transport Nagar to improve the self-care practices of truckers but as they have mobile jobs, they are not always available to attend these workshops and so are left with limited information.

## RESULTS AND GAPS OF RESEARCH ON COMMERCIAL SEX WORKERS (CSWs)

### Involvement in Sex Work

Study participants including sex workers, peer educators, health care providers and counsellors indicated that social exclusion due to poverty, low income, unemployment, lack of education, little or no social support from the family and adverse living conditions drag women into sex work. Because they do not get well paid jobs and are harassed by their employers at their work place, women engage in sex work. Generally migrants from poor regions who are unable to find work to meet their basic needs, end up in the sex work industry.

### Self-care Interventions in Family Planning

The study showed that CSWs prefer to use condoms as they can either get them free of cost from NGO or their clients bring them. The use of creams and gels among CSWs is rare as the NGOs do not provide these and they have to purchase these products from medical stores. The participants also said that "Earlier we easily got ready for sexual encounters without protection." The study indicates that consistent use of condoms is difficult with partners, who refuse use of condoms and promise to pay more instead. The CSWs face violence and the risk of unwanted pregnancy and other sexually transmitted diseases. They have unmet needs for the contraceptives and require more comprehensive interventions for sexually and reproductive health (SRH). CSWs know about modern contraceptives but have limited access to them. Sometimes, for fear of losing their clients, they do not use contraceptives. The study shows that because of lack of social support, limited resources, fear of violence from the clients, poverty and unemployment, CSWs compromise their own health and well-being.

### Information Source

Data with sex workers in different places in Delhi revealed that for women who trade sex for money, it is important to have knowledge about HIV prevention and sexual and reproductive health. CSWs get information through social media, mass media and through their interpersonal contacts i.e. peer educators and outreach workers. Through television and radios, they get information related to condom use for safe sex. The study findings suggest

that women who are involved in sex work generally get information from NGOs and outreach workers. NGO workers undertake behavior change communication (BCC) programs to make them more aware about their sexual and reproductive health. NGOs provide condom demonstrations and also provide information on hygienic practices that CSWs should follow. CSWs generally get products such as antibiotics, condoms, creams and gels from the NGOs who also provide for their regular check-ups for detection of syphilis and HIV testing. Thus, NGOs provide CSWs services and also inform them about safe and protected sex.

**Issues related to Cost and Affordability**

Women who trade sex for money face poverty issues. They lack support from their families. When they have children, them have to bring them up alone. When CSWs are not aware about HIV and other sexually transmitted diseases, they frequently have sex without protection. At times their clients force them to have sex without protection by bribing them with extra money. Through their association with NGOs, they become more informed about sexual and reproductive health. Consequently, they refuse to have sex with their clients without protection even if they are offered more money.

**Risks Faced by the Community**

The study showed that because CSWs are stigmatized by the health system, they are afraid to visit doctors. When they have a problem, they prefer to take medicines from the pharmacies. However, they are unable to explain about problems related to their sexual health to the pharmacist and so they may take the wrong medicine which can result in harmful effects.

**Mental Health Problems and Violence**

Women in sex work trade sex for money, their sexual encounter are generally sex without any emotional attachment. The interviews revealed that these women face mental health problems and are exposed to violence and abuse by the community, police and others. They face stigma in the society which results in mental depression and isolation. They actively choose sex work because they find more perks in sex work than in other jobs. They also said that “If they have to get abused anyway, they might as well earn through sex work”.

**Motivation and Barriers**

The study showed when CSWs were unaware about the risks of unprotected sex and had limited knowledge about sexual and reproductive health. They had sex with the clients without protection for the sake of money. Consequently, they are at high risk of HIV and STIs. With increasing awareness, CSWs have become more concerned about their sexual and reproductive health. NGOs organize workshops to enhance awareness and motivate CSWs to follow self-care practices.

# CHAPTER 6: DISCUSSION

In this chapter, the research findings are interpreted and discussed within the context of prior research conducted and within the conceptual framework of this study. People practice self-care in terms of healthy eating habits, regular exercising and avoiding hazards. Even people who are ill or suffer disability, practice self-care to get better. Now, people are making more efforts to attain good health. Marginalized and vulnerable communities are stigmatized and so do not go to the formal health system. They prefer to adopt self-care. While self-care practices among people may be beneficial, they can also be harmful. For example, people practice general measures such as having tea when they have diarrhea. This is beneficial but applying cow dung on wounds is harmful. People undertake regular exercise, walking and other means to attain good health. Increased education and awareness of the importance of healthy living is reflected in the self-care practices of individuals. Some people are focused on their regular eating habits, healthy food, and exercising. Others think that healthy living is time consuming. Marginalized and vulnerable communities such as truck drivers, LGBT communities many others who are poor, less educated and have little knowledge may find it difficult to practice self-care.

Very few studies have assessed the self-care practices of these vulnerable and marginalized communities. The current study on MSM, long distance truck drivers and CSWs was undertaken to fill this research gap. The study showed that it is very difficult for these communities to manage healthy lifestyles because of the nature of their work and other factors. The findings of the study clearly showed that because of lack of education and knowledge, self-care had no meaning for them. They were focused on getting enough money for their survival.

Socio-economic status is one of the factor that influences self-care practices. Research shows that people having high parental income practice self-care more than those who don't have the resources (1). It was observed that mobile workers who earn more money than the non-mobile sex workers, practice more self-care. This study showed that socio-economic conditions have a direct impact on self-care practices. People who earn more are more aware and more concerned about their sexual and reproductive health. They use contraceptives to prevent unwanted pregnancy.

Self-care practices are also influenced by gender. The behavioral study on FSWs by Li X. in China (2008) showed than women are more likely to take alcohol than men possibly because they have more stress levels (2). Women carry the burden of the multiple roles that they play at their work place and at home. The study showed that FSWs who raise children alone face considerable

mental stress and so they are more likely to consume alcohol (3). The current research findings indicated that CSWs who are vulnerable and highly stigmatized in society were not able to practice self-care which resulted in illness and STIs (2). The study of unmet needs of sex workers and healthcare in 2009 showed that sometimes their clients were drunk and wanted to have sexual intercourse without protection (4). Health literacy and education have a direct impact on self-care practices. Education and information also play a major role in self-care practices among vulnerable and marginalized communities in India. Earlier when these communities were not aware about the use of contraception and protection devices such as condoms, they did not practice self-care. After they became aware of sexual and reproductive health, they started using condoms with their clients. They denied sex to clients who forced them to have unprotected sex (5).

**Men who have Sex with Men (MSM)**

Literature in India shows that sexual identities of MSM may or may not correlate with sexual behavior and/or practices. For instance, MSM took a penetrative role in sex if they found other attractive men. In addition, research shows that MSM get into a marital relationship with women but continue to engage in sexual relationships with other men. MSM reported bisexual behavior but very few considered themselves to be bisexuals. They identified themselves as MSM and engaged in anal sex. As a consequence, they were more at risk of HIV and STIs. The study on prevention and treatment of HIV and other STIs demonstrated that HIV is associated with high risk behaviors which include anal sex with multiple partners and inconsistent use of condoms (6). MSM experienced a high risk of genital ulcers. The study in 2017 reaching out to men and boys showed that MSM men had sex with other men and also with *hijra*s (7). The findings of the current study were similar showing that that MSM had sex with men, women and transgenders. It was also found that MSM who had sex with women or were in marital relationships also had sex with men. The current study did not document the prevalence of HIV among bisexual men, but other studies have reported that 13% of bisexual men have HIV prevalence (7). There was no significant difference in the HIV prevalence between men having sex with only men and men having sex with men and women. It is important to understand high risk behaviors among MSM and their sexual partners. The study findings on the prevention and treatment of HIV suggests that the HIV prevention interventions should include providing counseling to MSM. The counseling sessions should focus on reducing the number of sexual partners, making them realize the importance of practicing safe sex within and outside marriage and ensuring periodical screening for HIV at Integrated Counseling and Testing Centers (ICTC).

In India, MSM and bisexuals are not socially and culturally acceptable in society. In the current study in Delhi, MSM were not able to resist the social pressure to get married. Consequently, they suffered mental health disorders such as depression. Interventions implemented for MSM, should address the social and cultural problems faced by them. Families of MSM also needs to be sensitized. MSM should be encouraged to use sexual and reproductive health services.

**Long Distance Truck drivers**

Truck drivers have to travel for long distances. They are away from their home for extensive periods. The prevalence of STIs is high in truck drivers because they have unprotected sex with CSWs. In 2006, Chaturvedi et al. showed that truck drivers who were away from home for more than 20 days were 15 times more likely to have sex with CSWs. A study by Baishali et al. on 251 long distance truck drivers showed that they halt at road side *dhabas* for their food and have sex with CSWs (8). This study showed that the prevalence of HIV in truck drivers was 21.5%. The study also showed that most truck drivers were illiterate or had little education. Similar findings were shown by Baishali et al who reported that 28% truck drivers were illiterate. They were at high risk of STIs which increased their risk to HIV. In our study also we found that truck drivers had sex with CSWs and did not use condoms. A study by Mishra et al in 1998, reported that almost 80% of truck drivers visited CSWs and almost 75% never used condoms (9). A study conducted in 2000, showed that 66% of truck driver visited CSWs and 60.5% did not use condoms. Our study, showed that truck drivers were more aware of protected sex and even the CSWs, they visited, carried condoms with them. Condom promotion education brought about a change in behavior among truck drivers. Only consistence and correct use of condoms offers effective protection against HIV infection. Research indicates that truck drivers seek health care only when the disease progresses. They prefer to go to quacks or private practitioners who are more accessible. Since they are mobile, it is very difficult for them to go to health care facilities for regular check-ups. There is therefore, a need to design targeted interventions for truck drivers.

Consistent efforts are required to bring about positive behavior change among truck drivers. It is necessary to create awareness among truck drivers about sexual and reproductive health and the risk of STIs and HIV. They should be made aware about having protected sex with every partner and to protect themselves as well as their spouses. Company owners and union workers should participate in efforts to promote knowledge of safe sex among truck drivers. Research is needed to

design appropriate strategies to change sexual behaviors which are hazardous to truck drivers and their partners.

**Commercial Sex Workers (CSWs)**

The current study showed that some CSWs know that contraceptive can prevent pregnancy but their knowledge is relatively poor about termination of pregnancy and other sexual and reproductive health matters. A study in Bihar conducted among adolescent CSWs found that their sexual and reproductive health knowledge was poor and less than half (around 43%) reported consistent use of condoms (2). Only 28% reported using other contraceptive methods. The study showed that there were several factors linked to STIs that include number of clients, condom breakage and forced unprotected sex by clients. Unwanted pregnancy was more common among older women who had less knowledge about contraceptives. It was clearly evident that CSWs were exposed to difficult situations which impacted their overall health and well-being. Our study showed many CSWs did use contraceptives and some were forced to have unprotected sex. Some clients, offered to pay more to have unprotected sex which increase the risk of STIs and HIV among CSWs. It was also observed that it was difficult for CSWs to use condoms with their boyfriends, lovers and emotional partners. CSWs stated that they faced barriers in using condoms with their regular partners. Some programs empower CSWs to use condoms and also sensitize their clients. Studies have shown that inconsistent condom use is very common and there are multiple barriers to ensure have protected sex.

Research shows that CSWs face barriers which interfere with their trade such as continuous bleeding and nausea because of non-prescribed medicines (2). They regularly visit clinics to get tested for HIV. The government needs to provide client-friendly sexual and reproductive health services to CSWs.

Interventions should be designed to minimize barriers CSWs face in accessing and using contraceptives. There are myths and misconceptions among FSWs about losing their clients. Counseling services should be provided to CSWs so that they understand the benefits of contraceptives methods and safe sex.

The discussion covers many aspects such as lifestyle, sexual behaviors, and interventions in self-care barriers related to self-care practices, mental health problems and violence. The self-care practices among MSM, long distance truck drivers and CSWs were different. There is a clear need

for further research on their self-care practices to design appropriate self-care problems for them. To be effective, programs should be tailored to the needs of each community.

## CHAPTER 7: CONCLUSION

This study examined the self-care practices, values and preferences with regard to sexual and reproductive health and rights and HIV prevention among marginalized and vulnerable communities in India. The study focused on MSM, long distance truck drivers and CSWs. It is important to include the voices of vulnerable people and communities while developing policies and programs that are intended for them. The perceptions, awareness and information about self-care products and practices by these communities are of central interest for the development of any recommendations on self-care for them. It is essential to assess the needs of vulnerable

communities to design meaningful programs for them. The understanding of self-care variables and motivations that influence them would contribute in attaining the triple billion goal of Universal Health Coverage.

## CHAPTER 8: RECOMMENDATIONS

- Specific strategies should be designed to expand the reach of services to hard-to-reach groups such as MSM, long distance truck drivers, CSWs and others especially vulnerable populations who are at high risk of sexual and reproductive health problems.
- Regular workshops should be conducted to improve self-care practices in sexual health knowledge, attitudes and skills to enable vulnerable communities to engage in safe sex.
- Health-care providers should be trained to address sexual and reproductive health problems of vulnerable communities. Their communication skills should be improved to address problems faced by vulnerable communities.

- There should be increasing clinician involvement in promoting preventive sexual health behaviors to improve their levels of comfort in dealing with sexual health issues.
- There should be an improvement in the quality of services which should be accessible to vulnerable and marginalized communities.
- Self-care practices should be systematically evaluated and best practices should be implemented at scale.

## RESEARCH ETHICS

While collecting the material, I continually reminded myself to not follow any controversial research practices which were ethically wrong. To maintain an ethical balance, we treated participants fairly and tried to answer their questions and respond to their concerns.

Researchers must balance their obligations to promote intellectual freedom and contribute to knowledge with fair treatment of the very people to whom these obligations are owed and to whom the knowledge is to be distributed (1). Thorough preparation was done at the time of planning the project to maintain the ethical balance in the research and then the data was collected. Ethical approval to undertake the study was obtained from the Institutional Review Board (IRB) of The Humsafar Trust, Mumbai and Student Review

Board (SRB) approval from IIHMR, Delhi before conducting research. Study participants were debriefed in full about the research in order to adhere to ethical obligations.

Before the collection of the data, participants were informed about the project, its goals, objectives, and purpose. All participants completed a verbal and signed informed consent process ensuring that their participation was voluntary and informed. All participants were assured of confidentiality and anonymity. Voluntary participation of the participants was encouraged as the participants has the right to freely choose to subject themselves to the scrutiny inherent in research. The participants were aware about the kind of questions and the questionnaire but were not aware about what is being measured by it. Questions asked of participants pertained to their lifestyles, sexuality and sexual preferences, gender and gender identification, work, health practices, and self-care.

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