

Original Research Article

Experiences of key populations in getting and sharing HIV and AIDS-related information: A descriptive phenomenological study

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Abstract

Despite the long-running targeted communication programs, the concentrated HIV epidemic in key populations has not declined as expected in Nepal. In this context, the present descriptive phenomenological study was carried out in Nepalgunj Sub-metropolitan City to explore the experiences of key populations in getting and sharing HIV and AIDS-related information. In-depth interviews were carried out with nine participants selected through snowball sampling from sexual minority people, and female sex workers. Colaizzi's descriptive phenomenological analysis method was adopted in data analysis. Participants were increasingly using digital means of communication. Peer approach was experienced as more confidential and training in drop-in-center a friendly mode of communication. Experiences of embarrassment, stigma, and discrimination were also prevalent. The findings of this study indicate HIV communication needs to be easily accessible, confidential, and friendly.

Keywords: communication, HIV, information, key populations, sexual minorities

Introduction

Exploring how the targeted population acquires information about HIV and what they experience about it, is essential to the effectiveness of communication programs. At present, most HIV communication programs are conducted targeting at-risk groups or key populations such as people who inject drugs, female sex workers, clients of sex workers, labor migrants, men who have sex with men, and transgender people. Globally, and also in Nepal, HIV infection seems to be concentrated in key populations. Global studies have shown that key populations are 13 to 22 times more likely to be infected with HIV than the general population (Shrestha et al., 2017). The HIV epidemic in Nepal is concentrated, with nearly 60% of infections occurring in key populations (Deuba et al., 2020). The uptake of HIV testing and counseling is still low (around 50%) among female sex workers, male sex with male and transgender people (Shrestha et al., 2017). Condom use is still below (61–73%) an optimal level in key populations like female sex workers, men who have sex with men, and transgender who received educational interventions (Deuba et al., 2020; National Centre for AIDS and STD Control [NCASC], 2018). In addition, there is a greater prevalence of condomless receptive anal intercourse among male sex with male and transgender people (Wilson et al., 2021). A study by Kakchapati et al. (2018) revealed that only about 29% of FSWs had knowledge about HIV and it was not associated with safe sexual practices. Some recent studies (Shrestha et al., 2017;

Kakchapati et al., 2018; NCASC, 2018; Deuba et al., 2020; Wilson et al., 2021) have indicated that despite the decades of targeted interventions including IEC activities against HIV and AIDS in Nepal, risk behaviors of key populations have not changed as expected and trend of the concentrated epidemic has not declined satisfactorily. This alarming situation demands research to explore the major means and modes of communication through which key populations frequently use to get and share HIV and AIDS-related information. Such a study would contribute to designing targeted HIV communication interventions to reduce the concentrated epidemic among those populations.

Due to its strategic location and high presence of key populations with the concentrated epidemic, Banke district, especially Nepalgunj Sub-metropolitan City is a vulnerable location for the spread of HIV (International Organization for Migration, 2019). Till the fiscal year 2074/075 B.S., altogether 1,012 local HIV positives were identified in Banke (Gnawali, 2017). Among them, 665 were male, 434 were female and 13 were transgender people, and 128 died due to AIDS. Among an estimated 7529 HIV-positive cases in Banke, sexual minorities, people who inject drugs, and female sex workers were 3696, 2093, and 1740 respectively (NCASC, 2016). Although 12 organizations have been organizing HIV and AIDS-related targeted communication campaigns in Banke, the concentrated epidemic has not reduced as expected in the key populations (Shrestha, 2018). There are many strategies in operation to provide HIV and AIDS information to key populations in the study area but their experiences while getting and sharing HIV and AIDS-related information through available means of communication have not been explored adequately. If these communication programs are to be effective in the target population, it is important to explore how the target group is receiving information and sharing it within their circle. In addition, it is important to find out in time what the targeted populations are experiencing psychologically as they receive and exchange HIV and AIDS-related information.

Most of the previous studies (Paudel et al., 2016; Shrestha et al., 2017; Kakchapati et al., 2018; NCASC, 2018; Deuba et al., 2020; Storm et al., 2020; Wilson et al., 2021) on HIV and AIDS-related communication in Nepal have used survey design, systematic review, and meta-analysis, but none has used a phenomenological approach. Most of these previous studies have focused on the general audience, young people, migrant workers, and students; while nominal studies have been carried out in the key populations, such as sexual minorities and female sex workers. Previous studies have not studied what key populations are experiencing while they get and exchange information about HIV and AIDS. Sufficient information is not available in the existing literature about common means and modes that the key populations used to get and share HIV and AIDS-related information and their psychological experiences during these processes. Without addressing this issue, communication programs could not benefit adequately to the targeted populations. Thus, I conducted this descriptive phenomenological research to explore key populations' experiences in getting and sharing HIV and AIDS-related information in Nepalgunj Sub-metropolitan City. This study was focused on two research questions, "how do research participants are getting HIV and AIDS-related information and sharing it within their group?" and "how do research participants describe their psychological experiences while getting and sharing HIV and AIDS-related information?" This study has attempted to fulfill the knowledge gap by acquiring adequate information through the exploration of the phenomena. Such exploration would also help the concerned stakeholders

design practical, accessible, and friendly HIV and AIDS communication programs for those key populations.

Methods and Materials

A descriptive phenomenological approach was used to uncover the common experiences of the participants who were targeted and exposed to HIV and AIDS-related information in the study area. Participants were selected through snowball sampling that included the adults (20 and 40 years) of sexual minority and female sex workers exposed to HIV and AIDS-related means of communication and living in Nepalgunj Sub-metropolitan City of Banke district. As estimated by National Centre for AIDS and STD Control (2017b), there are 824 female sex workers, 1709 men who have sex with men and male sex workers, and 639 transgenders in Banke district. But, such data are not available in the context of Nepalgunj Submetropolitan City. The program coordinators, focal persons, and peer educators of NSARC and Western Star Nepal assisted me to access the initial participants who then referred to the other participants. A total of nine participants from the key populations, including five sexual minorities (men who have sex with men and transgender people), and four female sex workers participated in this study. This number of participants was adequate to meet the saturation point as Starks and Trinidad (2007) and Wyman (2012) noted typical sample sizes for phenomenological studies range from one to 10 persons.

Three in-depth group interviews were conducted using a semi-structured interview guide in two drop-in-centers of NSARC and Western Star Nepal, and one group interview was conducted in a participant's residence. From October 2021 to September 2022, 349 female sex workers, 89 transgenders, and 708 people living with HIV got services from the drop-in-center of Nepal STD and AIDS Research Centre (NSARC) in Nepalgunj (Department of Health Services, 2022). Similarly, 614 men who have sex with men and male sex workers, 133 transgenders, and 55 people living with HIV got services from the drop-in-center of Western Star Nepal in Nepalgunj during the same period. The drop-in-centers were equipped with different types of HIV and AIDS-related audio-visual and reading materials to provide HIV and AIDS-related information and other care to the key populations. Interviews were carried out with help of the selected trained assistants familiar with the respective groups of participants. The interview guide consisted of six major open-ended questions which were modified as per the need of each interview context. During the interviews, some probing and supplementary questions were also asked to get in-depth responses related to the phenomena.

Interviews were carried out in three phases as recommended by Cresswell (2014): initial screening interview, main interview, and follow-up interview. Screening the participants, rapport building, informing them about the study, and obtaining informed consent were completed in the first phase. Each main interview, lasted between one to two hours, was digitally audio-recorded, transcribed immediately and sent to the participants to review for accuracy. I employed Colaizzi's method of descriptive phenomenological data analysis (as cited in Morrow et al., 2015). After reviewing the transcriptions, significant statements were listed, their meanings were formulated, and themes were identified and grouped as themes clusters. Recruitment of new participants continued until a new theme emerged. After completion of all interviews, themes clusters identified from all of the transcriptions were merged to generate the major themes. All the theme clusters, emergent themes, and formulated meanings were merged

into an exhaustive description to create an overall structure of participants' experiences as major findings. Repetitions in the exhaustive description were reduced to formulate a clear and concise structure of the major findings as an essence of participants' common experiences related to the phenomenon in question and it was verified with the available participants.

As explained by Lincoln et al. (2018) and Meyers (2019), I utilized methods such as pilot testing of the interview guide, bracketing my preoccupied assumptions and experiences, thick description, following transcription protocol, and member checking to reduce my bias and increase the credibility of data collected. The interview guide was piloted with three sexual minorities who were previously exposed to HIV and AIDS-related means of communication in the study area and obtained data were also combined with other data as mentioned by van Teijlingen and Hundley (2002, as cited in Wella, 2015). Ethical consideration was strictly maintained in this study. I provided a detailed information sheet about my study to each participant and took written informed consent before starting the interview. Anonymity and confidentiality were strictly maintained, and participation was voluntary. In this article, participants' pseudonyms are used to represent their identities.

Results

Participants' descriptions of their experiences were analyzed under the three emergent themes and the succeeding seven sub-themes. The verbatim descriptions presented in this section represent most of the participants' experiences.

Common Means of Communication

Participants of this study had been frequently exposed to both traditional and digital means of communication while sharing HIV and AIDS-related information in the study area.

Traditional Means of Communication

In this study, traditional means of communication refers to the means that exclude the internet and include physical representation of information (Yu, 2021), such as posters, pamphlets, flipcharts, hoarding boards, radio, television, etc. Pyari (pseudonym), a transgender, aged 28 shared her experience which represents most of the participants' experiences: "I came to know about HIV and AIDS after I attended the training conducted by our organizations, NSARC and Western Star Nepal. In the training, they [trainers] taught us a lot about HIV and AIDS by showing a flipchart, pamphlets, and posters." She added, "*Sathisanga Manka Kura* [the radio program] comes at night. A lot of things come to *Khulduli.com* at night. Sometimes, it also appears in advertisements on the radio." Similar to this description, Reshma (pseudonym), a female sex worker, aged 25 shared, "We got the information by reading the pamphlets and listening to the radio." These descriptions reveal that flipcharts, posters, pamphlets, and radio were the most common traditional means of communication among the participants while getting HIV and AIDS-related information.

Digital Means of Communication

Digital means of communication in this study refer to the means that include digital electronic technologies with the internet (Yu, 2021). Pyari, a transgender, aged 28 said, "We are also watching the video when we come here in DIC [Drop-in-Centre] and we are counseling each other." Junu (pseudonym), a female sex worker, aged 34 stated, "The madam [filed staff]

explained to us [about HIV and AIDS] showing it [tab] about 20 minutes when she used to meet us in the field.”Ramesh (pseudonym), a man who has sex with men (MSM), aged 30 shared, “We use the internet to get information about HIV and AIDS from time to time.” He added, “After clicking the website of *Merosathi*, there comes everything. Everything is explained about HIV and sexually transmitted diseases. It is on mobile. I can also explain and send it to my friend.”Chadani (pseudonym), a transgender, aged 28 expressed, “Things from all over the world are available on YouTube. It shows about HIV and AIDS as soon as searching it. It is given in Hindi, it is given in Nepali, and it is written there [on YouTube].”These statements revealed that digital means of communication, such as videos, tabs, internet websites, and YouTube, were other common means to get HIV and AIDS-related information among the participants.

Common Modes of Communication

The most common and preferred modes of communication for getting and sharing HIV and AIDS-related information were peer communication, teaching by the community-based staff, and training and counseling at drop-in-centers.

Peer Communication

In this study, peer communication refers to a mode of sharing information among peer circles of the participants (Namuleme, 2013). The more knowledgeable peers used to teach their friends about HIV and AIDS in their circle.Pyari, a transgender, aged 28 mentioned “We share what we learned, teach and counsel to each other.” She further disclosed, “They ask if we have anything to read that gives information about sexually transmitted infection and HIV. We immediately give them the leaflets. We have leaflets on nutrition, sexually transmitted diseases, HIV, and how to use condoms.”Similarly, Prema (pseudonym), a transgender participant, aged 39 affirmed, “I teach my friends in private so that others do not listen.”Reetu (pseudonym), a female sex worker, aged 27 further disclosed, “We share such materials and information to our many friends from tab and mobile phone.”These descriptions indicate that peer communication was a more confidential, easy, and preferred mode of communication for them.

Teaching by Community-based Staff

The participants had been getting HIV and AIDS-related information in their community through trained community-based staff (CBS) from the Nepal STD and AIDS Research Center (NSARC) and Western Star Nepal. Pyari, a transgender, aged 28 stated, “There are health worker friends called CBS in the village [from Western Star Nepal]and they provide information and teach us there.” Geeta (pseudonym), a female sex worker, aged 35 further revealed, “From here [NSARC] the sisters [CBS] go to the community and in the field and tell us from time to time.Supporting her description, Reshma, another female sex worker, aged 25 shared, “I use to call madam [CBS] when I need information immediately. I have saved her phone number.”Similarly, Junu, a female sex worker, aged 34 added, “They carry such posters and pamphlets. That [teaching site] may be a zoo, and a park also.”These descriptions reveal that teaching by community-based staff was another most common and preferred mode of communication for the participants.

Training and Counseling at Drop-in-Center

The participants had been getting and sharing HIV and AIDS-related information at drop-in-centers of NSARC and Western Star Nepal which were equipped with different HIV and AIDS-related information, education, and communication (IEC) materials (Field Note, Feb 16, 2021). Pyari, a transgender, aged 28 expressed: “I think the easiest means of communication is training. He [trainer] teaches all things in DIC clarifying the contents by showing video, flip charts, and posters.” Similarly, Reshma, a female sex worker, aged 25 revealed her experiences: “We come here frequently to learn about [HIV and AIDS]. They provide training. The sirs and madams [counselors] explain it to us. They teach us all the things that we don’t know. Many things are learned here.” Geeta, another female sex worker, aged 35 revealed the reason to participate in the training and counseling at the drop-in-center, “We feel it easier to come to this institution because there is also a confidential way of talking. That’s why our talk now doesn’t leak out anywhere.” These participants’ experiences and their descriptions indicate that training and counseling at drop-in-center was another common mode of communication that they felt was easier and more confidential.

Negative Experiences while Seeking and Sharing Information

The participants of this study experienced embarrassment, stigma, and discrimination while seeking and sharing HIV and AIDS-related information.

Feeling Embarrassed

In this study participants also expressed their feelings of hesitation and shyness while searching for and sharing HIV and AIDS-related information. Junu, a female sex worker, aged 34 revealed, “Still now, we feel embarrassed. It is a little difficult to tell and explain these things to anyone. When we ask other sisters [female sex workers] to come here, some even said: Who goes to such a place?” Reetu, a female sex worker, aged 27 described her experience while sharing HIV and AIDS-related information with her friends circle, “Some people become satisfied, but some people get angry saying why do you send such a thing in my mobile.” Prema, a transgender, aged 39 shared her shyness, “I tried to get information from the hospital but could not ask due to shyness.” She further revealed, “Due to shyness, we use secret language such as Helmet, Hat, Shell, etc. while asking for a condom within our circle.” Most of the Participants used these code words to refer to a condom while talking with their peers and sex partners if other people were present around them. These representative descriptions revealed that most of the participants were still experiencing embarrassment while seeking and sharing HIV and AIDS-related information.

Feeling Stigma and Discrimination

The participants of this study expressed their experiences of stigma and discrimination in healthcare institutions while seeking HIV and AIDS-related information. Geeta, a female sex worker, aged 35 expressed her negative experience, “They [health workers] treat us badly while we try to know about HIV and AIDS with them. They hesitate [to provide information and other care]. It has happened many times.” Similarly, Junu, another sex worker, aged 34 said, “They do not teach us. They show arrogance.” She further shared her bitter experience:

Some nurses explain, but some nurses don't explain. They ask; why do you need such a thing in secret; is your husband doing this . . . an aunt came and asked the nurse, Nani [affectionate address to the girl child in Nepali] tell me about AIDS. She told, why, does your husband do that?

Sharing her similar experience, Sonia (pseudonym), a transgender, aged 26 also described her negative experience as, "By looking at our gestures, the doctor knows that we are Meti (transgender), and they don't behave well." These descriptions represent the participants' common experiences of stigma and discrimination still prevalent in healthcare institutions.

Discussion

The present study revealed that most of the participants in the study area were getting and sharing information through the media like flipcharts, posters, and pamphlets. It was also found that use of digital means of communication such as video, tab, internet websites "Merosathi.net", and YouTube was increasing among the participants while getting and sharing HIV and AIDS-related information. Previous studies (ASHA Project & Family Health International Nepal, 2009; NCASC and ASHA Project, 2011) had identified the radio and television as the major sources of HIV and AIDS-related information. Current study indicates the need of shifting traditional modes of communication to address the information demand of target populations in this digital era.

It was evident that peer communication, teaching by community-based staff (CBS), and training and counseling at drop-in-center (DIC) were the most preferred and prevalent modes of HIV and AIDS-related communication for the participants. Peer communication was experienced easier and more confidential by the participants. This finding aligns with the study of Kakchapati et al. (2018) which found that compared to professional healthcare providers, meeting with peer educators was associated with less cost and was effective in Nepal. This finding also aligns with other previous studies in Nepal (ASHA Project & Family Health International Nepal, 2009; NCASC and ASHA Project, 2011) that identified peer communication as a major mode of getting and sharing HIV and AIDS-related information. Most of the participants also received HIV and AIDS-related information from the community-based staff of NSARC and Western Star Nepal in the field. This finding is in line with the finding of the Nepal Health Research Council (2018) which revealed that participants had experienced the information easy to understand provided by the community-based staff and they followed it. Similar to some previous studies (ASHA Project, & Family Health International Nepal, 2009; NCASC and ASHA Project, 2011; NCASC, 2017a; Kakchapati et al., 2018; & Storm et al., 2020), most of the participants in the present study also preferred the drop-in-centers of NSARC and Western Star Nepal to get HIV and AIDS-related information, where they were getting HIV and AIDS-related information through meetings, training, and counseling. The present study agrees with the conclusion of Wella (2015) that the information sources were viewed as not only residing within the participants' life world but outside also. My study indicates that the participants preferred friendly, confidential, safe, and easily accessible modes of communication for getting and sharing HIV and AIDS-related information. Such preference may be possibly influenced by their social context and life situation which needs further exploration.

Another important finding is that most of the participants had negative experiences like embarrassment, stigma, and discrimination while seeking and sharing HIV and AIDS-related information. Hesitation and shyness were still prevalent among participants and their peer circles. Sometimes, participants were badly treated and demoralized by the healthcare workers and they hesitated to provide information and other care at healthcare institutions. Such experiences of the participants might have negative consequences, such as obstructing them to visit the organization providing HIV and AIDS care, taking part in training, and ultimately seeking and sharing information. As explained in the communication persuasion matrix by Corcoran (2007), sources and receivers are both significant factors among the input communication factors. If the sources are not credible and the receivers feel embarrassed, stigma and discrimination against them, the output persuasion techniques like attending, liking, comprehending, and acting will not work successfully and an expected effect and a change may not happen. My study indicates that the fear of such stigma and discrimination would lead to information avoidance or covert information seeking as concluded by Namuleme (2013).

Conclusion

This study has explored an interesting fact that the use of digital technologies was increasing in searching and sharing HIV and AIDS-related information among the key populations and they found it confidential and convenient. Expansion of access to digital communication technologies among such populations to provide HIV and AIDS-related information can have a better output. As participants in the present study rely and trust more on peer educators and community-based staff for HIV and AIDS-related information, communication programs can be more effective if the mobilization of such educators is strengthened and expanded. Designing easily accessible, confidential, and friendly modes of communication, based on their real-life needs and living context, would be more effective to reach those populations. Participants' experiences of stigma and discrimination in healthcare institutions and their embarrassment while seeking HIV and AIDS-related information have created barriers to HIV and AIDS-related communication. Creating supportive environments for getting and sharing HIV and AIDS-related information would be more beneficial for such key populations.

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