## **CHAPTER - 5**

# THE PATIENT AND SOCIETY INTERACTION AND THE DISCRIMINATION PERCEPTION

## **5.1 Introduction**

HIV/AIDS is one of the deadliest and worst epidemics to ever affect humanity. The virus affects not only the afflicted individual but also the entire family, the community, and the nation. In addition to the fact that mortality is a given, the stigma and discrimination surrounding it have made it the most feared epidemic of the century. Unfortunately, the health sector is one of the main places where people living with HIV face discrimination and stigma. A lot of medical professionals have negative attitudes towards individuals who are HIV/AIDS positive, and sometimes they even won't treat those who are known to be infected. Numerous organizations have contributed to public education regarding HIV/AIDS-related concerns and the importance of treating infected individuals with dignity. Despite being aware that HIV cannot be transmitted through casual contact, a sizable segment of the populace continues to shun those who are known to be seropositive.

On the other hand, the Indian government is acknowledging the urgent need and exhibiting concern for HIV/AIDS treatment and prevention. Additionally, the government has started offering all HIV-positive individuals free antiretroviral therapy. Nonetheless, this epidemic is stigmatized in the community.

Shame and fear combine to create a powerfully negative social stigma associated with HIV/AIDS (Piot, 2001). According to Mr. Zahir Uddin Swapon, Secretary General of the Parliamentary Group on HIV/AIDS, "people stigmatize due to fear stemming from ignorance" (UNAIDS, 2004). According to Agglet al. (2002), stigmatization can result from a lack of knowledge about the illness, misconceptions about how HIV spreads, and a lack of awareness of preventative measures. Such discrimination and stigma can lead

to a host of detrimental outcomes, including social dysfunction such as strained relationships and feelings of melancholy, anxiety, and depression.

#### **5.2 Consequences of Stigma and Discrimination**

Stigma and discrimination are major contributors to the HIV/AIDS epidemic because they promote a culture of victimization, blaming, silence, ignorance, and secrecy (Taylor, 2001). This influences the health, behavior, and perception of the medical care received by PLHAs as individuals (Ganczak, 2007). Learning that one has been affected by such a disease causes unfathomable psychological suffering. Relationships are changed, both blatantly and subtly, and many people pull away from them. They also feel that the social support they had before getting sick has diminished. In addition to the direct effects the illness has on one's health, there is also the stigma associated with it to deal with. Managing the stigmatizing effects of the illness is one of the main challenges that study participants report facing in their daily interactions. In the discussion that follows, an effort is made to clarify the effects this discrimination has on them.

#### 5.2.1 Stopped Working

The lives of those infected with HIV/AIDS are negatively impacted by the stigma surrounding the disease. The main consequence of HIV infection is the person's inability to work in a job that pays a salary on a regular basis. Like in the current study, the shock of their illness caused 18% of the respondents to resign from their jobs. The respondents said that the family's lack of financial resources was a major burden.

When asked about their decision to marry, about 86% of those surveyed stated they had already been married, divorced, separated, or widowed. About 5% of respondents wanted to get married, but only to positive people, with the exception of one who was willing to marry a girl who was not infected and they were both in love with each other. A little over 4% of participants expressed their desire to remain single, while the remaining 5% were unsure about their desire to tie the knot.

## **5.2.2 Feeling to Die**

Being surrounded by friends, family, and loved ones is something that everyone enjoys. Although no one chooses to be alone or isolated, someone may begin to feel as though they are dying if they believe that their close friends and family are rejecting them. About 29% of respondents in the current study claimed to be waiting for death or to be praying to God to end their lives; however, about 59% of respondents claimed to have occasionally felt this way when they fell ill and had to visit the hospital on their own.

#### 5.2.3 Don't Want Further Treatment

Despite the fact that HIV/AIDS cannot be cured, there are drugs that can be taken to control the virus. However, a lot of PLHAs may experience worry and anxiety about who to tell, how to tell, and when to tell, which prevents them from receiving the necessary care and treatment.

The vast majority of respondents said it was very hard for them to tell people, they were positive. The majority of them said they would be interested in continuing their treatment when asked, but a small number of them also mentioned that they occasionally avoided using drugs, which resulted in problems with frequently falling ill. Overall, 17% of respondents stated that they did not want to receive any more medical care due to the unpleasant side effects of the medications and the fact that their doctors were not providing them with the recommended daily allowance of nutrients.

#### **5.2.4 Avoided from Family/Friends and Relatives**

Living with HIV has always involved coping with a progressive illness that could eventually be fatal. Despite recent medical advances, living with HIV still carries a lot of uncertainty about one's health. PLHAs have had to deal with challenges in their social relationships in addition to the physical health aspects of living with HIV. They make an effort to avoid their social circle in daily life because they feel that those who are infected are morally bankrupt and bear responsibility for the illness. They fear rejection (perceived stigma) or are experiencing rejection (felt stigma) from friends, family, and acquaintances. In line with the findings of the current study, more than half of the participants tried to keep their distance from friends and family, and more than 68% avoided seeing their relatives. They even said no to inviting their relatives and friends over for dinner. They avoid all social gatherings and thus cut themselves off from the outside world.

When asked why they didn't reveal their positive status when they saw friends and family, a sizable percentage of respondents who were visiting them said it was because they were afraid of their negative attitude.

## 5.2.5 Self-Blaming and Taking Revenge

Furthermore, because they feel they are to blame for contracting the virus, PLHAs could also hold themselves responsible for acquiring HIV. There are individuals who might feel driven to take revenge on those they suspect of having HIV. About 56% of respondents felt that people should accept responsibility for their actions, while 5% of respondents wanted to get revenge on those, they thought were the source of their infection.

The stigma associated with HIV/AIDS may negatively impact an affected person's health in a number of ways. For fear of rejection and stigma, some people might decline to have an HIV test. Those who try to hide their status out of such fear may experience poorer health and higher levels of stress when compared to those who seek appropriate treatment and express their emotions.

## 5.2.6 Other Consequences of Stigma and Discrimination

Individuals who experience stigma encounter a range of negative emotions, including depression, anxiety, and hatred. For someone living with HIV, it can be very upsetting to be rejected or turned away by others. Feelings of isolation, alienation, exclusion, and loneliness are common among PLHAs. There are positive effects of HIV/AIDS on relationships as well. Some affected individuals have also reported that their relationships with friends, family, and even medical professionals actually deepen when they show them their unwavering love and concern. However, a sizable portion of respondents indicated that they observed changes in their behaviour over time.

Stigma and isolation may manifest as symptoms of anxiety, depression, and suicidal thoughts, according to a small number of studies that have also examined how HIV infection affects patients' mental health (Chandra et al., 1998). According to Chandra et al. (2003), both men and women living with HIV express fear and embarrassment about tarnishing their family's reputation. Men with HIV expressed concerns about their growing reliance on others for care and the impact of their physical decline on the household income, while their spouses' expressed feelings of resentment, victimization, and helplessness (Bharat and Aggleton, 1999). (Chandra and Temoshok, 2000). Temoshok and Chandra (2000) posit that these women are unlikely to receive the necessary support to express their emotions, which may lead them to repress them or find coping mechanisms that are socially acceptable, such as seeking guidance and solace from religion.

## 5.2.7 Feelings of PLHAs about Meaning of Life

It makes sense that stigmatization occasionally leads to PLHAs experiencing negative changes in their self-perception and feelings about their lives. They usually internalize society's stigmatization and come to feel unworthy and corrupted. Just 14% of respondents said they thought life was worthwhile, with 6% strongly agreeing. Others said nothing or disagreed. About 35% and 58% of respondents, respectively, strongly agreed that their lives were special and purposeless.

## 5.2.8 Sadness and Unhappiness in Life

People experience a great deal of stress when they learn they are HIV positive. They begin to feel depressed and unsatisfied. Approximately 57% of the participants admitted that they were feeling unhappy and depressed as a result of their illness. About 45% said they didn't want to go anywhere because they were scared of meeting new people. Some of them, when left to their own devices, declared that they would rather die than live a life of suffering and terror.

## 5.2.9 Less Energy and Motivation

People living with HIV/AIDS face many challenges as the illness worsens and opportunistic infections occur. It was observed that the majority of respondents (about 51%) concurred that they lacked energy and motivation and had lost their confidence (about 53%).

Approximately 54% of the participants strongly agreed that this was the first time in their lives that they had experienced such self-pity. Nearly 64% of respondents strongly agreed that people should be educated about the issue when asked if they thought that was the case. The PLHA community should be encouraged and uplifted to make the most of their remaining years by being cautious and receiving the necessary care.

## **5.2.10 Feeling of Depression and Frustration**

Receiving an HIV diagnosis is a traumatic event that frequently causes psychological distress. The respondents become extremely irate and depressed when people approach them with suspicion and ask a lot of questions. When they would leave their homes to go to the hospital, many of the women who responded said that they found it very difficult and frustrating when their neighbors would ask them questions like where they were going and when they would return. They also showed a great deal of rage, which they attribute to internalized frustration, at other people's ignorance of their illness. Much like in the current study, the majority of respondents (about 49%) agreed—and about 45 percent strongly agreed—that they get depressed and frustrated because of their illness.

#### 5.2.11 Sexual Relationship with the Partner

It's common to experience anxiety when it comes to having sex after learning you have HIV. People ought to be informed about the risks involved in having sex. Many questions concerning the nature and number of sexual partners, the frequency of condom use, and the level of sexual satisfaction were asked about one's sexual life. Most married PLHAs (men) said that their spouse is the only person they have sex with. They believed that they were unaware of the source of the virus. However, the vast majority of married women claimed that their husbands might have inherited it. A mere minority admitted to having more than one sexual partner.

About 53% of respondents strongly agreed that the illness was causing problems in their relationship, and 18% agreed that the illness was causing them a great deal of problems. They thought that sexuality had changed over time. Roughly 13% felt they had no need to reply to this.

"After learning my positive status, sexual closeness does not appeal to me; I get irritated easily on my wife who is not HIV-positive," stated a man who responded. I'm always afraid that I'll contaminate my spouse when we have sex because condom use isn't 100% foolproof.

"Even though I don't want to get closer to my husband because he cheated on me, I always give up because if I don't have sex with him, he might find someone else and spread the infection," a female respondent who tested positive for HIV told the researcher. I'm hoping he doesn't spread this virus to anyone else.

Many women said that having to deal with their partner's illness on top of their own was causing them great depression. They assume greater responsibility for child care, housework, and tending to the ailing spouse. When needed, they give their partner financial support.

The participants' sexual dissatisfaction with their partners is evident from the conversation, and some of them persisted in risky sexual behavior even after receiving professional counselling during the testing process. It's also conceivable that they weren't getting the proper counselling in relation to the dangerous behavior.

The decisional jurisprudence pertaining to dignity has been established by the constitutional courts. In the case of Naz Foundation,<sup>1</sup> "At the very least, it is evident that

<sup>&</sup>lt;sup>1</sup> See Naz Foundation v/s Govt, of NCT Delhi and others, Writ Petition no.7455/2001.

the constitutional protection of dignity requires us to acknowledge the value and worth of every individual as members of our society," the Delhi High Court noted. It acknowledges that each individual is a free being free to develop their body and mind however they see fit. A person's autonomy, or their freedom of choice and action, is the foundation of their dignity. The foundation of human dignity is the acceptance of a person's inherent worth, humanity, and physical and spiritual integrity—regardless of the benefit they may offer to others."

Earlier in case of Prem Chandar Shukla v/s Delhi Administration <sup>135</sup> the SC observed that dignity forms part of our constitutional culture and in Francis Coralie Mullin v/s Administration, U.T. of Delhi and others<sup>136</sup>, "We think that the right to life includes the right to live with human dignity and all that goes along with it, namely, the bare necessities of life such as adequate nutrition, clothing, and shelter and facilities for reading, writing, and expressing oneself in diverse forms, freely moving about and mixing and commingling with fellow human beings," the SC noted through Bhagwati, J. Any action that violates or diminishes human dignity would be a denial of his right to life per se, and it would have to follow a lawful process that is reasonable, equitable, and just and that satisfies the requirements of other fundamental rights. As a result, it is clear from the aforementioned cases that the Indian judiciary recognizes the value and worth of every member of society, including those who are HIV/AIDS victims, and that maintaining one's human dignity entails expressing oneself in a variety of ways.

The first decision given to interpret the scope and meaning of life and personal liberty under article 21 of the Indian Constitution was the A.K. Gopalan v/s State of Madras<sup>137</sup> The Supreme Court interpreted the phrase "procedure established by law" in Article 21 to mean "due process of law" as specified by the U.S. Constitution, but only if it refers to state-made statutes laws. Any statutory law that specifies a process for taking away someone's rights or freedom must comply with Article 21's requirements.

<sup>135</sup> 1980 1 SCC 529 <sup>136</sup>
993 1 SCC 645.

<sup>137</sup> AIR 1950 SC 27.

However, after two decades this was over ruled in the case of R.C. Cooper v/s Union of India<sup>2</sup> fter this there where a series of decisions by the apex court including that of Maneka Gandhi v/s. Union of India<sup>3</sup> where it was decided that a law must be just and fair if it takes away someone's life or liberty. It was said correctly by Krishna Iyer J. that "procedure in Article 21 means fair, not formal procedure law is reasonable law not any enacted pieces" It is now established that positive rights to life and liberty are granted by Article 21. In Article 21, "life" refers to a dignified life, not merely the survival of an animal.

In the 1978, by 44th amendment, Article 359 was amended and it provided that Article 20 and 21 could not be suspended even during declaration of an emergency. In the case of P.Rathinam<sup>45</sup>, The court ruled that both mental and physical health are regarded as essential components of the right to life, maintaining that one cannot enjoy one's civil or political rights—as guaranteed by the Constitution—without good health. The judiciary has been essential to understanding and applying article 21 correctly.

Mudaliar Idol In of C.Masilamani v/s. of Sri Swami case Nathaswami<sup>141</sup> The SC noted that every human being has the intrinsic right to equity, human dignity, and the right to development. Everything that gives a person's life purpose, such as culture, heritage, and traditions along with personal dignity, is included in life's enlarged horizons. The supreme court expanded the application of article 21 and provided the rights that article 21 encompasses in Unni Krishnan v. State of Andhra Pradesh.

They include freedom to travel, privacy, opposition to solitary confinement, opposition to postponed execution, right to housing, opposition to custodial death, right to a public

<sup>&</sup>lt;sup>2</sup> AIR 1970 SC 564.

<sup>&</sup>lt;sup>3</sup> AIR 1978 SC 597.

<sup>&</sup>lt;sup>4</sup> P Rathinam v/s UOI 1994 3SCC 394.

<sup>&</sup>lt;sup>5</sup>, 8 SCC 525, Paragraph 22.

trial, and opposition to medical assistance. It was also noted that the right to education would be incorporated into the right to life along with all previously mentioned rights

In Naz Foundation Case<sup>6</sup>, which is a prime example in the context of MSMs and HIV/AIDS It was argued that Articles 14, 19, and 21 of the Constitution's protections are violated by Section 377 of the IPC. An important turning point in Indian jurisprudence on diversity and pluralism has been reached by the case's ruling. Crucially, it introduces intersectional jurisprudence, which analyzes constitutionalismrelated issues in relational terms that emphasize inclusivity. By this measure, the ruling is significant for more reasons than just the rights of LGBT (lesbian, gay, bisexual, and transgender) people. It turns the articulation of LGBT rights into a beacon for a broader comprehension of what freedom and dignity really mean, as well as of oppression, discrimination, social exclusion, and the denial of liberty. Morality according to the constitution is not an instinct. It needs to be 18 years old. We have to acknowledge that our people are still learning it. The court rejected the argument that homosexuality was against public and popular morality in India, citing Dr. Ambedkar. Instead, it upheld constitutional morality, the spread of which was dependent on Dr. Ambedkar's ideas of national change, as is clear from the lines quoted above. The ruling declared: "Diversity is acknowledged, safeguarded, and celebrated under the Indian Constitution. It is against constitutional morality to stigmatize or criminalize homosexuals based solely on their sexual orientation 1Q.<sup>7</sup> This is related to the Court's observation regarding the question of the horizontal application of rights, specifically referencing Article 15(2), a crucial but little-known provision of Article 15 that states that no citizen may prevent another from entering a public place on the basis of caste, sex, or any other specified ground. This intentional and intersectional interpretation of Article 15(2), which was previously primarily limited to untouchability practices against Dalits, provides a significant avenue for constitutional interpretation.

<sup>&</sup>lt;sup>6</sup> See Naz Foundation v/s Govt of NCT Delhi and others, Writ Petition no.7455/2001.

<sup>&</sup>lt;sup>7</sup> Paragraph 80 of the Judgement.

Judge P.N. Bhagwati's definition of the right to dignity in the Francis Coralie Mullins case serves as the foundation for the widely acknowledged national and international conversation about the value of privacy, self-worth, and self-respect in human social life. And when it comes to sexual relationships, privacy is especially crucial. As a general rule, "A breach of our privacy will occur if, in expressing our sexuality, we act consensually and without harming one another."<sup>8</sup>

## 5.3 Sources of Knowledge of PLHAs on HIV/AIDS

Healthcare professionals have a duty to educate and reassure the public about the likelihood of HIV infection as well as its impossibility. The patients look to the medical specialists each time they see them to provide an example of proper AIDS management.

The findings indicate that hospitals (about 96%) and non-governmental organizations (NGOs) provided the majority of the respondents' information regarding HIV/AIDS. It was found that sixteen percent of the participants learned things from posters, pamphlets, magazines, and newspapers. On the other hand, about 8% said that their primary information sources were friends and TV/radio (9%).

The study participants also stated that they had heard, seen, and heard advertisements for TV, radio, and other media on several occasions, but that they had initially ignored them because they were hard for them to understand.

Additionally, the respondents expressed dissatisfaction with the information provided by the medical professionals. They should be given more details about government assistance programs and avenues for reporting misbehavior or unfair treatment of medical personnel.

## 5.4 Problems faced by PLHAs in their day-to-day life

People who are HIV/AIDS positive are worried about future health issues and death. However, a person living with HIV/AIDS faces unique difficulties that a person with cancer or any other illness, like heart disease, does not usually encounter. People's

<sup>&</sup>lt;sup>8</sup> Paris Adult Theatre I v/s. Slaton, 413 US 49 (1973), page 63.

reactions to those who are HIV-positive are often influenced by stereotypes about behaviors that are associated with the virus. This explains the problems that PLHAs face as a result of HIV/AIDS.

#### **5.4.1 Physical Problems**

According to the respondents, they were suffering from severe cases of exhaustion, frequent colds, diarrhea, coughing, headaches, fever, and other opportunistic infections.

A few respondents also brought up the fact that ART had disadvantages of its own. When they told the doctor about the problems they were having from those medications, he would often advise them to maintain a healthy diet. However, the majority of respondents said that, when living in rental housing, it was very difficult for them to maintain a healthy diet on an income of Rs. 12,000 or less per month. They added that, despite the fact that the organizations' nutritional packets were very beneficial to them, they weren't consistently provided with them.

Furthermore, the participants reported that these side effects occasionally caused them to discontinue the treatment. Some started drinking to help them forget the pain for a little while.

"What will happen to their children if they die soon?" was a question posed by respondents who had small children and were worried about their future. HIV-positive women added that, although they were there to support their husbands and kids (who were also positive), they were mainly in charge of looking after themselves when they became sick. In addition, they were worried about what would happen to them in the event that their spouse died.

## **5.4.2** Problem within the Relationships

Married research participants blamed each other for a variety of circumstances that led to decreased or nonexistent communication, which resulted in high levels of conflict between them. Still, some of them added in about how encouraging their spouse had been.

The respondents, whose relatives knew about the illness, added that because of their improved status, their relatives' viewpoints had changed. They tried not to talk to them as much, especially not to their siblings.

#### **5.4.3 Financial Problems**

Money is very important in life, especially when you are sick and have no one to help you financially. For most of the research participants, it was also a significant problem. When they fell ill, they had to take time off work to recuperate and get medical attention. The majority of respondents expressed concern regarding travel as well, believing it to be an additional financial burden due to their need to go to the hospital. Furthermore, a few respondents indicated that the cost of travelling from their villages to the nearby hospital for checkups is high. They also thought that the government ought to pay for these expenses.

Financial hardships can cause stress in people, which is something that doctors recommend against. Additionally, medical professionals have observed that stress directly lowers the function of the immune system and may speed up the onset of AIDS.

#### **5.4.4 Stigma and Discrimination**

A person who is subjected to discrimination and stigma usually fears rejection from others all the time, which can make them feel even more alone in society.

PLHAs were terrified that their friends, neighbors, family, coworkers, or even their jobs would reject them. For fear of similar reactions, they often withheld information about their condition from the public.

The woman who answered said, "My husband passed away from illness, leaving me and my son behind." If I told the truth, no one would believe me, even though I'm positive that he died of AIDS and that I contracted the illness from him as well. My inlaws will throw me out of the house and put the blame on me. I haven't disclosed my status to anyone as of yet.

The respondents, especially the women, also expressed how challenging it was for them to leave their houses in order to pick up their prescription medications from the hospital. Sometimes, if they were both positive and living in the same home, they would make up an excuse, or send their husbands to pick up their prescription medications.

There was a correlation found between HIV and participant fears of discrimination and isolation, which is consistent with previous research (Bharat 1995, 2000). The study's findings demonstrate that HIV stigma has a range of detrimental impacts, such as emotions of helplessness and loneliness, internalized anxiety, stress, and depression, as well as guilt and shame. People may also experience low self-esteem, self-dislike, difficulty communicating their positive status, and worry about the future of their children as a result of it. The women who contracted the virus also had to cope with feelings of guilt about losing their husbands and about becoming widows.

Concerns about social isolation were also present.

## **5.5 Knowledge of HCPs on Universal Precautions**

Universal precautions, sometimes referred to as standard precautions, are a recognized set of techniques and barriers to prevent the spread of pathogens. This refers to the use of barrier techniques in the context of HIV to prevent the virus from spreading between patients and healthcare providers.

According to the World Health Organization (WHO), the goal of standard precautions is to reduce the risk of infections spreading from both known and unknown sources, including blood-borne infections. These are the absolute minimum steps that should be taken to prevent infections in every patient.

To prevent the spread of blood-borne infections and other illnesses, it is essential to continuously implement universal precautions and infection control measures. It is imperative to apply these safety precautions and control measures to all patients, irrespective of their occupation, financial status, or HIV status. All staff members, including those in clinical, housekeeping, and other roles where they might have direct physical contact with waste, bodily fluids, linens, or spills, should undergo universal precautions training (NACO, 2007). One of the most important steps in reducing stigma and discrimination is to follow universal precautions. Diverse levels of awareness regarding the application of universal precaution, fear of infectivity, discriminatory behavior, and willingness to treat PLHAs have been noted among HCWs worldwide (Kowal & Taneja, 2010). Health care providers who implement universal precautions against PLHAs alone display discriminatory behavior and an infection fear in both developed and developing countries (Bermingham & Kippax, 1998 and Kotwal & Taneja, 2010).

The World Health Organization advises medical professionals to take the following general safety precautions:

**Hand washing:** As soon as you come into contact with blood, bodily fluids, secretions, excretions, or contaminated objects, take off your gloves and contact the next patient.

**Gloves:** for coming into contact with blood, bodily fluids, secretions, infected objects, and non-intact skin and mucous membranes.

**Goggles, masks, and face masks:** When it's likely that your mouth, nose, and eyes will come into contact with blood or other bodily fluids, protect those mucous membranes.

**Gowns:** Avoid getting blood or other body fluids on your skin. When performing procedures that may come into contact with bodily fluids or blood, try to avoid getting your clothes dirty.

**Linen:** Make sure to keep dirty linens away from skin and mucous membranes when handling them. Soapy sheets should not be rinsed beforehand.

**Patient care equipment:** Cleaning reusable equipment before each use will help prevent clothing and surrounding areas from becoming contaminated. Handling soiled equipment should be done so as to prevent skin or mucous membrane contact.

**Environmental cleaning:** routine cleaning and disinfection of the furniture and equipment in patient care areas.

**Sharps:** Needles should not be put back in needle dispensers or removed from singleuse syringes. It is not appropriate to handle, bend, or break reusable needles by hand. Used sharps should be emptied into puncture-resistant containers.

**Patient resuscitation:** Use mouthpieces, resuscitation bags, or other ventilation tools to avoid mouth-to-mouth resuscitation.

**Patient placement:** Individuals who cause environmental pollution or lack the hygiene necessary to maintain good hygiene ought to be housed in private rooms (WHO, 2007).

It is evident from the above discussion that staff members lack knowledge about common sense precautions, despite them being an essential part of an effective and highquality healthcare delivery system. Ignorance of these common-sense precautions could lead to stigma and discrimination. However, it is the hospital administration's responsibility to guarantee that each staff member receives top-notch training.

#### **5.6 Exposure of HCPs to HIV/AIDS Training Program**

In order to provide their patients with compassionate care, health care providers must possess both the necessary knowledge and an optimistic attitude.

Medical personnel may be unable to apply reason and the scientific method, which is crucial, if they have a negative attitude. It could also result in incoherent care, indifference, and discomfort throughout the course of treatment—none of which would be ideal for maximizing outcomes. Prejudices and biases can only be mediated through the socialization process during training, as opposed to factual knowledge acquired through didactic attitudes (Radecki et al., 1999). According to Mathew (2006), training is the process of gaining knowledge, skills, and attitudes through the teaching of practical skills and knowledge related to learning specific practical skills that will improve your performance at work.

Training and education on the distinctions between HIV and AIDS, HIV transmission, general preventive measures, and updates on treatment protocols for opportunistic infections and HIV/AIDS should be provided to health professionals. Other important themes include nutrition, drug use, stress, sexuality, and stigma and discrimination in health services (Morrison, 2004).

The study found that approximately 55% of the medical professionals had completed either short- or long-term training. Of the participants, about 45% said they had never taken part in an HIV/AIDS education program. The fact that none of them had any training before dealing with PLHAs is astounding.

Despite attending, a sizable portion of the respondents who participated in the training programme also stated that they did not find it to be very helpful. They felt that no training had been provided to them specifically on stigma and discrimination against PLHAs. Basic information about HIV/AIDS was among the materials being discussed.

However, those who had not attended the training claimed that only a select group of employees who had close ties to higher authorities had been granted access to the program.

A lack of universal precautions, high work pressure, poor training, and few promotions may all have an impact on health care workers' reluctance to treat HIVpositive patients.

## 5.7 Efforts by the institutions to create awareness on HIV/AIDS among general public

The primary course of action for prevention initiatives is comprised of Information, Education, and Communication (IEC) strategies. Mass media, such as radio, television, and newspapers, is used to inform the public. The epidemic, associated risk factors, and the importance of prevention are all well-known to and understood by the general public. They also acknowledged the inadequate and unsatisfactory quality of the information they were getting from the medical staff. However, people must be adequately informed about the subject in order to avoid misunderstandings.

We asked the doctors about their efforts to increase public knowledge of HIV/AIDS-related concerns. They listed a range of communication techniques, such as flyers, brochures, periodicals, puppet performances, magic shows, skits, folk music, documentaries, films, and more, that are put up on department walls and used in the course of the department's community outreach initiatives. They also revealed that they hold a health lecture and exhibition in the neighborhood on World AIDS Day to increase awareness of HIV/AIDS. It was also mentioned that throughout the pre- and post-test counselling procedures, they provided all the information and answers to the people's questions.

## 5.8 The institutions' initiatives to educate medical professionals about HIV/AIDS

The public is expected to receive sufficient information about HIV/AIDS from healthcare providers. However, healthcare providers must possess sufficient knowledge about HIV infection in order to carry out this task. They should also be educated about doable measures to lower the risk of transmission, such as universal caution when handling bodily fluids like blood. It is imperative that healthcare professionals participate in multiple training programmes on these subjects in order to acquire the necessary knowledge.

The hospital hosts a number of internal conferences, workshops, and training program; works with other departments and institutions to host free faculty development series that cap the number of participants; and hosts skill-enhancement workshop sessions. These are just a few of the efforts being made to date to dispel myths and raise awareness among healthcare professionals about the fundamentals of HIV/AIDS, the researcher was informed. It was also mentioned that anyone who is curious about the epidemic can speak with their supervisors to get any information related to the areas they

are worried about and to access the resources that are available both inside and outside the organization.

Many medical professionals who were asked about how they obtained this kind of information said that they had a hard time leaving the facility due to a staffing shortage. A few individuals had also stated that they felt the training programs lacked creativity, which made them less helpful in their opinion.

It is usually difficult to participate in many social and private activities when ill. Physiological anomalies such as nausea, headaches, and vomiting can strike healthy individuals occasionally. Because these illnesses are treatable, people who have them can lead very normal, happy lives. Their lives are not completely affected by the illness. They are living their normal lives and are in good health. However, HIV/IDS patients and their families experience significant financial and psychological hardship. On a social level, not even other people accept the person. The study illustrates the detrimental effects of HIV-related stigma on the lives of individuals living with HIV/AIDS. Among these consequences are the incapacity to work and make a living on a regular basis, the inclination to stay away from their social circle in day-to-day activities, the reluctance to reveal their positive status due to possible negative reactions from others, and so on.

In order to increase public awareness of the HIV/AIDS crisis, health care providers (HCPs) employ a range of communication techniques, such as posting posters on department walls, handing out flyers and magazines, and hosting puppet shows, magic shows, skits, folk music, documentaries, and movies. Health care organizations hold a range of internal conferences, workshops, and training sessions to educate medical professionals about HIV/AIDS and to debunk misconceptions about its basics. Additionally, they host several faculty development series in collaboration with other departments and organizations.

## 5.9 Social Work Intervention in the Context of HIV/AIDS in India

The western world is where social work was first acknowledged and developed as a profession. It started in England and then made its way to America. The field of social work originated in welfare, social services, reform, and charity. From a welfare approach to a development and empowerment approach, social work has come a long way. Individual rights protection and promotion, along with a right-based approach, are now priorities for the profession. Early in the 1930s, social work education made its way to India. The profession of social work gained recognition when the Royal Commission of 1831 recommended the appointment of labor welfare officers who held a degree in social science, social work, or labor welfare. This recommendation marked a significant turning point for the field of social work.

Through a variety of techniques, social work aims to support individuals, groups, and communities in promoting their well-being. Social work differs from other professions in that it uses both primary (social case work, social group work, and community organization) and secondary (social welfare administration, social action, and social work research) methods.

"Professional service, founded on scientific knowledge and skill in human relations, which helps individuals, alone or in groups, to obtain social and personal satisfaction and independence" is the definition of social work (Friedlander, 1958). "The professional activity of helping individual, groups, or communities to enhance or restore their capacity for social functioning and to create societal conditions favorable to this goal" is how the National Association of Social Workers (NASW), the largest professional association of social workers in North America, defines social work. The professional application of social work values, principles, and techniques towards one or more of the following goals constitutes social work practice: assisting individuals in receiving concrete services; offering individual, family, and group counselling and psychotherapy; supporting communities or groups; supplying or enhancing social and health services; and taking part in pertinent legislative processes. Understanding human behavior and development as well as the workings of social, economic, and cultural institutions is necessary for the practice of social work (NASW, 1973). Similarly, social work is described as "the applied science of helping people achieve an effective level of

psychological functioning and effecting social changes to enhance the wellbeing of all people" in the Social Worker Dictionary (Barker, 1999).

According to the aforementioned definitions, social work has a scientific perspective and human relations abilities that assist individuals in enhancing their social functioning in order to achieve both social and personal fulfilment. It establishes social conditions that aim to improve people's wellbeing and avoid issues with social functioning.

An enormous accomplishment in the history of social work is the new international definition, which was approved by the International Federation of Social Workers (IFSW) General Meeting in Montreal, Canada, in June 2000. It emphasizes social work with a right-based approach and empowerment. The profession of social work "promotes social change, problem solving in human relationships, and the empowerment and liberation of people to enhance well-being," according to the revised definition. Social work intervenes where people interact with their environments by applying theories of human behavior and social systems. Social work is predicated on the concepts of social justice and human rights.

(http://apaswe.com/attachments/article/125/workshop\_part1.pdf)

## 5.10 Purpose of Social work

The goal of social work is to meet human needs and resolve interpersonal conflict by addressing social problems with vision, direction, and motivation. Enhancing the standard of living for people is considered to be one of the profession's clear objectives. The primary goal of social work is to support adaptive functioning in the interactions between people and social institutions. According to the CSWE (1988:120), "social work has historically contributed to the development of these relationships in such a way as to promote social and economic justice and protect the opportunities for all people to live with dignity and freedom."

Four goals of social work practice are listed by the Council on Social Work Education (CSWE, 1994): i) the support of individuals, families, groups, organizations, and communities in order to promote, restore, maintain, and improve their social functioning through task completion, the prevention and relief of distress, and the utilization of resources: the development and testing of professional knowledge and skills related to these goals (Thomas, 2009). ii) the planning, formulation, and implementation of social policies, services, resources, and programs needed to meet basic human needs and support the development of human capacities; iii) the pursuit of policies, services, resources, and programs through organizational and administrative advocacy and social or political action, in order to empower groups at risk and promote social and economic justice.

Through the application of professional social work values, principles, and practice methods, the goal of social work is accomplished. Social workers can, for instance, have conversations with people and families to help them manage stress and work through interpersonal issues. In addition, social workers support communities and society by preventing social problems and by delivering or enhancing social and health services. To create just and equitable social policies, they actively engage in advocacy for policies and legislative processes. In conclusion, social workers counsel people through difficult times, counsel decision-makers on important matters, and promote improved society. These social work initiatives show how the connections between individuals and society are the profession's primary area of concern. Social work is the only profession that takes into account people's interactions with their social and cultural environments to such an extent (Dubois, 1992:6).

## 5.11 Social Work in the Context of Health Care Setting

Health is harmed by inaccessible or insufficient medical care, and social issues like stress, unemployment, poverty, and a lack of social support systems aggravate health issues. Furthermore, difficulties with social functioning are frequently present in people who suffer from health issues. The five fundamental premises illustrate the close connection between social functioning and health: Social, cultural, and economic factors have a measurably positive impact on maintaining health as well as preventing and recovering from illness; ii) illness frequently upsets equilibrium and adaptive coping capacities; iii) institutionalization exacerbates all illness types, whether acute, chronic, or terminal; iv) community action and innovation are required to deal with issues related to accessing and using services appropriately; and collaborative efforts of a multiprofessional team for both individual and community health problems address the complexities of socio-medical problems (Bracht, 1978a).

Social workers in the health care sector engage in activities related to "institutional, community, state, and federal health policy formation; program planning and administration; the educational preparation of social workers and the professionals practice in the health field; and social research" in addition to working with individuals, families, and groups (Carlton, 1984:5). Almost all specialization areas within the health system employ social workers, including emergency room services, public health, mental health, oncology, pediatrics, general medicine, surgery, intensive care, and rehabilitation (NASW, 1990). Specific settings include: (a) preventive-educational agencies, such as public health departments, maternal-and child health projects, crisis clinics, health referral agencies, and pregnancy prevention programs; (b) hospitalinstitutional care systems, such as community hospitals, veterans administration hospitals and clinic, rehabilitation centers, psychiatric hospitals, long-term care facilities, and hospital-based home-health care; (c) primary care programs such as individual and group medical practices, health-maintenance organizations, free clinics, outpatient clinics, community mental health centers, and community home health agencies; (d) community healthplanning services, such as health system planning agencies, state developmental disability programs, mental health boards, and vocational rehabilitation offices; and (e) health professions education facilities, such as medical, public health, nursing, and allied health schools (Bracht, 1978a).

The discussion above makes clear that professional social workers are employed in every setting related to health care in western countries. The field of social work has a great deal of room for expansion and growth in India as well. Professionals in social work have the chance to work in a variety of environments, including hospitals, classrooms, prisons, industrial settings, ageing services, family and child welfare, youth development programs, and numerous government development initiatives. In a variety of governmental and non-

governmental organizations, they are referred to as social welfare officers, labor welfare officers, social workers, protection officers, assistant directors, and so forth. Even though there are many social workers working, the largest obstacle facing the field is that it is not as well-known and acknowledged as other professions like engineering, law, or medicine. Most people don't know if their organization employs social workers and mistake social work for sociology. The researcher encountered many healthcare professionals who were ignorant of the position of social worker in their organization and, moreover, of their qualifications, while gathering data from the healthcare setting.

## **5.12 Perception of PLHAs about Social Workers**

Since the beginning, social workers have taken an active role in the HIV/AIDS epidemic. They have consistently responded with their expertise to assist individuals, families, and couples in understanding the illness and coping with the trauma. They collaborate with non-governmental and governmental organizations to advocate for the rights of individuals living with HIV/AIDS and to educate the public. Let's examine how the respondents (PLHAs) in this study felt about the social work profession.

When requesting services from the health care system, individuals living with HIV/AIDS were asked if they had interacted with any professional social workers. Overall, 66 percent of the study's participants—99 out of 150—reported positive experiences; these participants included social work students connected to the organization and researchers corresponding with them for their studies. On the other hand, 34% of the participants had no knowledge about social workers. They reported in an extremely positive way regarding the differences in dealings compared to other health care professionals.

Approximately 97% of respondents stated that they treat them with respect, accept them for who they are, regardless of their illness, and listen to them intently and patiently—qualities they said are rarely observed in other medical professionals. Additionally, they reported that social workers: (a) treat them as unique human beings (about 85%); (b) advocate on their behalf (about 35%); (c) maintain confidentiality about their positive status and any private information they discuss with them (nearly 79%); and (d) offer adequate referral services (about 38%) if necessary. In addition, they said that the social workers do not treat them unfairly and give them enough time to talk about any concerns they may have. They also educate them about the unknowable facts about HIV/AIDS and provide them with information about the organizations that offer nutritional support.

The HIV care environment should be free of stigma and discrimination in order to support the infected and affected and give them hope, as this will maximize the effectiveness of NACO and NGOs' efforts (Castro and Farmer, 2005). This is primarily due to the possibility that HIV care centers are the only settings in which both men and women recognize and talk about the effects of HIV infection on mental and physical health (Kermode et al., 2005a). As mentioned in the previous chapter, a significant portion of health care professionals were not exposed to the training, according to study results. As a result, the government needs to make sure that health care professionals are exposed to training programs on HIV/AIDS awareness and knowledge, providing highquality care, universal precautions, and engaging in behavior and interactions that would challenge discrimination and stigma.

#### 5.13 Role of Social workers/Medical Social Worker

In a medical team, a medical social worker's function is just as crucial as a doctor's. The social worker addresses the social, physical, and psychological aspects of the patient who is receiving treatment, whereas the medical professional's role is restricted to providing medical care. In actuality, the social worker's main responsibility is to oversee the patient's care or arrangements. The social worker serves as a friend,

philosopher, and mentor to the patient and his family (Thomas, 2010). In the worldwide fight against the HIV epidemic and for the empowerment of individuals afflicted, social workers can be extremely effective. Social workers apply theory to practice while working in a variety of settings, such as HIV/AIDS, during their fieldwork placement. They work in a variety of hospitals as medical social workers as well. All social workers with professional qualifications possess the abilities, know-how, and mindset required to collaborate with afflicted and infected people. They provide patient care within a democratic and humanistic framework. A social worker assists the patient from the time they arrive at the hospital until they are able to adjust to their current circumstances. They support the patient in regaining their health and avoiding further personal decline brought on by the illness.

- A social worker prepares oneself by learning precise and specialized information about the illness, how it progresses, the range of tests available, prevention, treatment, care and management, moral dilemmas, patient rights, and the various resources both inside and outside of the hospital. Social workers, who have extensive knowledge of the subject, work directly with patients and their support system, particularly the family, to help them overcome feelings of stigma, discrimination, shame, and fear.
- The social workers engage in offering the PLHAs and their families counselling and educational services. Clearing up misunderstandings and improving understanding of the issue would be achieved by providing accurate information about HIV/AIDS. Social workers assist patients in regaining emotional stability and in making necessary situational adjustments. The only members of the medical team who can offer patients emotional support and satisfaction are social workers.
- Social workers have received extensive training in offering HIV/AIDS counselling to patients. They are knowledgeable about the syndrome and have the necessary abilities to offer pre- and post-test counselling, follow-up counselling, and counselling to those who are impacted, including spouses,

family members, friends, carers, and significant others. Through counselling, social workers encourage behavior modification so that an individual can avoid contracting HIV or passing it on to others.

- Even though a patient is prepared during pre-test counselling, nobody can predict how they will react once they learn they are HIV positive. A patient may experience shock, rage, denial, fear, numbness, and other emotions. A social worker can assist the client in accepting their circumstances and making future plans, as well as handle the patient's information regarding a positive test result. Also, he offers the patient crisis counselling and complete support.
- To keep the family running smoothly, they assist family members in developing stronger coping mechanisms and problem-solving techniques to deal with the stressful circumstances.
- The patient becomes isolated due to their protracted illness. Friends and family might stop being friendly. Social workers help patients in these circumstances by offering social and emotional support as well as facilitating their access to other resources and help.
- Social workers establish a relationship based on trust and confidence in the patient by getting to know the PLHAs well. It aids in the patient's development of sound decision-making skills and better coping mechanisms for an improved standard of living.
- Providing a client with genuine listening without passing judgement is one of the best treatments a social worker can provide. The social worker treats the patient with great respect and exhibits objectivity and friendliness.
- Everyone aspires to lead a life that is worthy of respect and dignity. They are entitled to health care, food, shelter, education, and protection from discrimination. In the context of HIV, the three most crucial rights are the following: the right to informed consent; the right to confidentiality; and the right to be free from discrimination. However, because they are ignorant of their fundamental rights, PLHAs' rights have been severely violated. The social

worker informs them of their fundamental rights. Social workers advocate on their behalf to uphold their rights and enable them to lead dignified lives.

- The social workers are quite knowledgeable about how health organizations operate. Additionally, they keep them well-informed about the various programs available to PLHAs and teach them how to use these services and programs for both preventive and curative purposes. Additionally, they offer PLHAs referral services to other community care facilities, Positive People Network, and other organizations that assist PLHAs.
- Social workers are also involved in the hospital's policy-making and program planning. Since they interact directly with PLHAs, they might suggest changes to deliver better and more efficient care.
- As members of a team of professionals, social workers perform the roles of coordinators of services, facilitators, mobilizers of resources, and mediators. In order to use the hospital's facilities that are only available to patients, he or she can mediate or facilitate interactions between patients and doctors as well as between administration and patients.

## 5.14 Application of Social work methods in HIV/AIDS care setting

There exist six widely recognized and widely applied social work approaches: social casework, social group work, community organization, social welfare administration, social action, and social work research. Based on the twenty-plus years of work that professor Gracious Thomas has dedicated to raising public awareness and educating the public about HIV/AIDS, six additional social work techniques are being advocated. These include networking, public interest litigation, advocacy, awareness campaigns, resource mobilization, and strengths-based practice (G. Thomas, personal communication, April 6, 2013). These are the approaches that can be used to practice social work. Eliminating these techniques would be equivalent to removing the soul from the body. In actuality, the special qualities of the social work profession are the aforementioned techniques. Social workers in a variety of settings are able to apply these

techniques with skill. Let's examine the application of social work techniques to the HIV/AIDS domain.

## **5.14.1 Social Casework**

Social casework is the practice of doing various tasks for various individuals while working together to improve both their own lives and society as a whole (Richmond, 1922).

People's needs go beyond their material desires since material gains by themselves cannot guarantee happiness for humans. When emotional needs are met in addition to material comforts, happiness is attained. Individuals living with HIV/AIDS experience not only their physical illness but also emotional trauma. The family plays a crucial role in these kinds of circumstances. A caseworker visits the sick person's home, holds discussions with the family, and organizes family support to provide care during the patient's critical moments. Additionally, the caseworker gives the family the support they need and assists them in understanding the needs of the HIV/AIDS patient.

One of the methods used in social casework is counselling. Because casework is client-oriented, while counselling is problem-oriented, it offers relief on the periphery.

A social caseworker works to help a client find a long-term solution to their issue by boosting their self-esteem. A caseworker examines the client holistically, taking into account the client's surroundings, prior experiences, relationships with important people, comprehension of the issue and ability to solve it, as well as the client's need for self-understanding.

Social caseworkers improve their clients' knowledge and information about the disease, their rights, prevention, and other topics that can cause new problems or exacerbate pre-existing ones. A caseworker also deals with the stigma and discrimination that the patient and family experience on a variety of levels.

After learning of their positive status, PLHAs frequently experience shock, feelings of rage, guilt, grief, despair, taking revenge, suicidal thoughts, and similar

emotions. It is imperative to relieve the client of these emotions in such circumstances. The caseworker helps the client express repressed feelings by paying close attention to what they are saying and accepting them for who they are. He or she values and respects each person for who they are as a unique human being. A caseworker encourages the patient to connect with other PLHAs groups and assists the patient in adjusting to reality. Additionally, he or she provides referral services to other appropriate resources. A caseworker can assist a person in achieving a higher degree of integration by presenting them with novel concepts and lifestyle options.

#### 5.14.2 Social Group work

Through social group work, people in groups in social agency settings receive assistance from a worker who facilitates their interaction in program activities so they can relate to others and experience opportunities for growth according to their needs and capacities for the purpose of the development of the individual, the group, and the community (Trecker, 1955).

Hospitals play a significant role in social work practice. There is a connection between psychological issues and physical health. Patients' health conditions may deteriorate due to adverse psychological factors. In India, and especially in developed nations, there is a widespread understanding that the healing process involves more than what the medical model recommended (Garvin, 2004). Group work allows for the holistic care of a client. A social worker facilitates the process of group work and plays a key role in setting up the HIV support and education groups. Knowledge regarding the illness, its prevention, and its treatment is shared in the educational groups. They impart knowledge to the group members regarding the pattern of progression and its impending debilitating effects. Additionally, they learn how to follow the prescribed course of action, such as taking their medications on time, and they are trained to abstain from behaviours that could exacerbate their condition.

The patients in the support groups receive the essential emotional and social support from the group members. For HIV/AIDS patients, it is a vital forum where they

can openly express themselves and discuss their issues in order to support one another. HIV-positive people are assisted in changing their mindset for the rest of their lives through social group work, which helps them live a happy life and deal with their circumstances.

## 5.14.3 Community Organization

Through the process of identifying its needs and goals, ranking them, finding the resources (internal and/or external) to address them, taking action towards them, and developing the confidence and will to work towards them, a community can become more organized. In doing so, the community fosters and grows cooperative and collaborative attitudes and practices (Ross, 1955).

In social work, community organization is a macro method. The community organizer has the necessary traits and abilities to interact with people and effectively disseminate information to them. The community organizer applies their fundamental knowledge and abilities of the concepts, procedures, and processes of community organizing while working in the community.

Regarding HIV/AIDS, this approach is used to spread knowledge about the illness, its modes of transmission, preventative measures, and the range of services and programmes available to those who are living with the virus. The role of the community organiser is to mobilise members of a community to take the necessary steps to stop the spread of HIV/AIDS. He or she plans awareness campaigns about human rights, government initiatives, and health in order to increase people's knowledge and comprehension. He or she performs street plays, puppet shows, lectures, and other events to get the word out to the broader audience. In addition, the community organiser informs the populace about HIV/AIDS while taking into account social stigmas, religious convictions, and general community sentiment. They are the most qualified to collaborate closely with and influence community members' attitudes in order to lessen stigma and discrimination against individuals living with HIV/AIDS. This is something that someone without experience in social work could never accomplish.

## 5.14.4 Social welfare administration

"Administration of social agencies translates the provisions of social legislation of social agencies and the goals of private philanthropy and religious charities into the dynamics of services and benefits for humanity," according to Walter A. Friedlander (1958).

Social welfare organisations are essential in providing HIV/AIDS patients with services. HIV/AIDS is a very delicate topic, and in order to accomplish desired goals, the service provider organisation must demonstrate professional competence. Social workers with professional training are employed by the social welfare organisations. With their extensive knowledge and active involvement in the community, the social workers utilise all available resources to effectively accomplish the program's objective.

## 5.14.5 Social action

Within the parameters of social work philosophy and practice, social action is any individual, collective, or community endeavour with the goal of advancing social justice, changing social policies, and enhancing social laws, health care, and welfare services (Friedlander, 1977).

Social action was defined as "a process of bringing about the desired changes by deliberate group and community efforts" by Nanawati (1965). The true test of whether social action is successful or unsuccessful is not the adoption and signing of social legislation, but rather the way the policies are carried out. According to Singh (1986), social action is defined broadly as the process through which certain elites or the people themselves make deliberate, methodical, and organised efforts to change the system in order to address issues and enhance conditions that restrict the social functioning of weaker and vulnerable groups. Since intimate behaviour patterns are the primary means of HIV infection transmission, health authorities frequently encounter obstacles in providing services to these high-risk behavioural groups. If the government and nongovernmental organisations (NGOs) have good working relationships and their social workers are professionally trained, then this gap can be closed (Thomas, 2010).

A social worker tackles HIV/AIDS-related issues through community action. They act as advocates by speaking out on behalf of those who are HIV/AIDS positive. It is commonly acknowledged that there is a serious violation of the PLHAs' rights. They are the targets of discrimination and stigma in the healthcare industry. Social workers use advocacy to persuade, inspire, and encourage democratic authorities to make decisions that will best serve the interests of PLHAs. They struggle to enact the necessary policy changes in order to guarantee the social system's fair distribution of resources, uphold their rights, and administer justice. One of the best strategies for social work is social action, which social workers can employ to advance the rights of PLHAs.

#### 5.14.6 Social work research

A methodical, critical, and meticulous examination of a social phenomenon is known as social work research. The results of social work research can assist policy makers, agencies, and social workers in developing programmes that are effective and tailored to the needs of a specific community (Thomas, 2010).

For any HIV/AIDS-related programme initiative to be implemented effectively, social work research plays a critical role. Research studies help with effective programme planning, policy formulation, and implementation by offering helpful information about the various facets of issues like HIV/AIDS. Since HIV/AIDS is such a delicate topic, social workers evaluate it from a wider perspective, using their professional expertise to make recommendations for appropriate action plans.

#### 5.14.7 Advocacy

Three main principles—independence, empowerment, and inclusion—are the foundation of the ethical activity of advocacy (Dunning, 2010). "Generally involves people making a case for themselves and advancing their own interests, or representing others and supporting them to secure and exercise their rights on an individual or collective basis," according to Dunning (2005), is how advocacy is defined. Cohen defines advocacy as the process of trying to change things that have an immediate impact

on people's lives, such as public policy and resource allocation decisions made within political, economic, and social systems and institutions (Cohen, 2001).

It is the process of speaking up for the underprivileged people who do not have access to financial or political resources. One of the key strategies employed by social workers to advance social justice, equality, and PLHA social inclusion is advocacy. In order to effectively address the members' unmet needs, social workers can act as their advocates, representing or persuading them to present their case to the relevant authorities. They can advocate on behalf of PLHAs in order to increase service quality or gain access to resources. Social workers can tackle the underlying causes of issues, defend the rights of PLHAs, and bring up discrimination and stigma through advocacy.

## 5.14.8 Awareness campaigns

In regards to HIV/AIDS, professional social workers have a significant task ahead of them. Social workers are deeply involved in their communities, so they have firsthand knowledge of their norms, customs, cultural practices, and behavioural patterns.

The general public can be educated about the fundamentals of HIV/AIDS, modes of transmission, prevention, and the care and treatment of people living with HIV/AIDS. PLHAs can be educated about their rights and how to exercise them by means of awareness campaigns. PLHAs can be supported and encouraged by social workers to advocate for themselves.

HIV-positive individuals frequently face discrimination due to their fears of infection and the negative associations that HIV has with unacceptable behaviours like drug addiction, homosexuality, and promiscuity. Social workers can bring up the subject of discrimination and stigma through awareness campaigns and by sharing information with relevant authorities. PLHAs can be made aware of the different government initiatives and programmes. With their expanded knowledge, they can effectively disseminate the message of risk reduction through a range of media. To raise awareness of HIV/AIDS, one can use print, radio, television, dance, and folk theatre, in addition to

other media. These are the most efficient ways to raise public awareness of such a delicate subject.

#### 5.14.9 Networking

An association of groups that get together to share resources, information, knowledge, and skills is referred to as a network. Each member's strengths and skills can be enhanced and sharpened through networking. They can share services and information with people and groups who share interests, and they can react to injustice more effectively. PLHAs rely on networking to support their effective selfmanagement.

The worldwide network for and by individuals living with HIV/AIDS is called the Global Network of People Living with HIV/AIDS (GNP+). The GNP+ represents all HIV/AIDS-positive individuals. They bring up concerns about human rights, health rights, and the empowerment of HIV/AIDS patients. They can get assistance from a social worker in bringing to light issues that they are ignorant of. Social workers can build coordinated and cooperative relationships through networking to gain access to the resources of different social systems. They can establish connections with powerful community leaders, human services organisations, and other social structures like business and industry.

## **5.14.10 Resource Mobilization**

The necessary resources must be gathered in order to carry out the suggested course of action. The resources could be external (funding, expert advice, other technical assistance, etc.) or internal (material, space, money, manpower, etc.).

The social worker can organize the necessary resources to deliver services to PLHAs in an efficient manner and with high-quality care. Resources for HIV/AIDS patients could be created, particularly since the majority of patients are unable to pay for their care. In addition to offering financial assistance for patient care, funders may be contacted to support other crucial tasks like organizing and managing training programmes, conducting research, and disseminating information. It's critical to mobilize resources from outside sources in these circumstances.

## **5.14.11 Public Interest Litigation (PIL)**

A Public Interest Litigation (PIL) is a type of legal action brought in a court of law to enforce a general or public interest in which the general public, or a class of the community, has a financial interest or some other interest that affects their legal rights or obligations. PILs, then, are legal proceedings in which a person \requests relief for the benefit of the public at large rather than for personal gain (Mathew, 2010).

Justice can be served to those who, because of their ignorance or socioeconomic limitations, are unable to defend their rights through Public Interest Litigation (PIL). Individuals who are denied their legal and constitutional rights can receive assistance from social workers. If they believe that PLHAs are being discriminated against because of their positive status and that their human rights are being violated, they can file a case with the constitutional courts to seek justice on their behalf.

## 5.14.12 Strength based practice

Put simply, strength-based practices highlight strategies that build resilience rather than addressing deficiencies (Pulla V., 2006). The focus of strengths-based practices (SBPs) is on utilising people's innate strengths as individuals, families, groups and organizations to support their healing and empowerment. When it comes to working with individuals, groups, and organizations, SBPs are empowering substitutes for conventional methods. SBPs avoid using dehumanizing, stigmatizing, or labelling language. SBPs provide a constructive means of challenging pathologies and descriptions held by individuals, groups, and organizations that imply acceptance of their condition as hopeless or helpless to change (Pulla. V., 2012).

Each person has certain assets and capabilities that they can use to further their own empowerment. A social worker can assist PLHAs in recognizing and leveraging their strengths through SBPs, enabling them to maintain or regain their independence in day-to-day living. By using this strategy, PLHAs can strengthen their capacity for selfcare and boost their self-worth and confidence, all of which will enable them to independently perform their daily activities.

## 5.15 Conclusion

In the care and treatment of individuals living with HIV/AIDS, the role of health care professionals is crucial. However, since they provide the best services to the PLHAs, professional social workers play an important role that cannot be undervalued. To find a solution, they bring up the problems of discrimination and stigma. Social workers advocate for PLHAs' rights and advance social justice in addition to their other roles. Throughout their studies at different colleges and universities, professional social workers with master's degrees in social work receive both theoretical knowledge and hands-on experience in the field. Working with PLHAs allows them to offer social, psychological, and emotional support that medical professionals might not be able to.

The chapter has covered the function of social workers in healthcare environments. The conclusions of this chapter show how professional social workers and other health care professionals interact differently. According to the respondents, social workers provide them with adequate referral services, advocate on their behalf, respect them for who they are, accept them as they are, listen to them carefully and patiently, and maintain confidentiality about their positive status. They also mentioned that social workers rarely saw them with other medical professionals. The chapter has also covered the use of social work techniques in HIV/AIDS care environments.

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