

Perceptions of Hijra Sex Workers Living with HIV Infection towards the Disease in Punjab, Pakistan

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Abstract

Hijra sex workers are potential reservoir of HIV infection and contribute to spread of HIV in the general population through their clients who act as a bridging population. The present research mainly focused to study the perception of Hijra Sex Workers (HSWs) with positive HIV infection toward HIV/AIDs as disease in Punjab. The researchers adopted the phenomenological approach for both data collection and its analysis. The study population consisted of HSWs AID/HIV patients receiving symptom relief care at AIDs preventive program initiated by the provincial health department of the Punjab. The researcher conducted 12 in-depth interviews by applying qualitative technique. Locale of the present research study was Treatment Centre for HIV/AIDS at Jinnah Hospitals, Lahore working in the Hospital with an out-patient ward. The research team developed themes reflected during the entire study were as awareness about HIV/AIDs, social support system, post HIV/AIDs sexual conduct in clientage process and challenges in their treatment. The present research study highlighted about Hijras as key source for the transmission of HIV/AIDs. It is find out that Hjr as clientage process is prevailed in Punjab by varies ways. In the study area it was identified that Hijras had one regular sex partner called *Girya* in their local terminology, this person support and guide HIV positive patient for their regular checkup and treatment. Among the major challenges faced by HIV positive Hijras are social stigma and low income, which negatively associated with the treatment process of the HIV positive patient. The present study recommended about the normal life of HIV/AIDS positive person's because of their regular checkup and treatment.

Key Words: Hijras Sex Workers; HIV/AIDs Positive Patient; Regular Treatment

Introduction

Hijra is a unique form of gender role expression in South Asia and is an umbrella term used for individuals who are transgender, trans-sexual, or bi-sexual, and identify as female, although most often biologically male (Lev, 2013). The other studies stated Hijras are phenotypic men who wear female clothing and ideally renounce sexual desire and practice by undergoing a sacrificial emasculation. Most Hijras live together in residences that serve as both physical and social units of identity or lineage affiliation (Reddy, 2006). *“There is a wide range of classifications of men who have sex with men”* (Rajabali, 2008). On the basis of biological differences Hijras are categorized in two categories in Punjab including 'khusra'; (eunuch; individuals who have been castrated or, rarely, born with a sexual deformity) and 'Zanana'(transgender; a biological male who identifies as a female) (Jami, 2005). On the basis of their ways in which they operate, Hijras were categorized in two categories as that home based Hijra Sex Workers (HSWs) and Dera (the residence of Hijras) based HSWs. Although every Hijra is associated with a Guru (literally meaning a teacher or a spiritual leader), home based Hijra Sex Workers (HSWs) visited to Deras (the residence of Hijras) for socializing with community members and/or sex work.

Hijra Communities are extremely well defined and close-knit groups governed by a 'Guru' (literally meaning a teacher or a spiritual leader) who adopts and takes up a Hijra as his 'Chela'(student) to include in the Hijra Community. The Chela usually lives under supervision of the Guru, shares his income with the Guru, and overtime becomes a Guru himself (Mithani, 2003). The mapping survey estimated, a total number of 13,209 Hijra sex workers in four cities. *“In addition to the HSWs the mapping survey also estimated 1,454 gurus in the said cities. The highest number of HSWs were indicated at Faisalabad (38.9 percent, N=5,147), followed by Lahore (32.93 percent, N=4,350) and Multan (21.89, N=2,891) respectively”* (PACP, 2014). According to Provincial AIDs Control Program Punjab since 2003, HIV is spreading with rapid growth; the main source for its spreading is sex workers and injected drug users. Beside this HSWs are the key risk factor, so there is an urgent need for strengthening and improving HIV/AIDS preventive program. Hijras sex workers (HSWs) remain the key affected population for HIV transmission in Punjab, province of Pakistan (Altaf, 2008). In 2014, *“Among 1,521 HSWs who were tested for HIV the overall weighted HIV prevalence was recorded as 3.1 percent; with the highest prevalence reported in Lahore (4.1 percent; N=16) followed by Faisalabad (2.9 percent; N=11) and Sargodha (2.4 percent; N=9); all other cities had less than 5% prevalence”* (IBBS-2014). *“In 2009, the estimated prevalence of HIV was less than 1% among FSWs (an increase from the previous low prevalence of 0.02% in 2007), 0.9% among MSWs and 6.1% among Hijra sex workers”* (NACP, 2015). In 2006, HIV occurrence among Male Sex Workers (MSWs) was *“highest in Karachi (7.5%),*

Bannu (4%), Faisalabad and Larkana (2.5% each). Hijras have greater than 2% prevalence in Karachi, Hyderabad, Larkana (14%) and Bannu” (NACP, 2010).

The preventive program intervention must be more focused on behaviors change and condom use. As a result Hijra's perceptions towards the HIV/AIDS and towards sexual conduct, social support system and their clientage process is the important indicator to take innovative initiative regarding the program and to ensure full implementation for the eradication of this incurable disease (Siddiqui, 2011). The present study is focused on the individual experiences of the HSWs living with HIV infection with the objectives; to find out the individual experiences of the HIV positive HSWs about the disease and safe sex practices, to find out the feelings of the key affected population about the social support and stigma attached with the disease as per their individual experiences and to find out the socio-cultural barriers faced by the HIV/AIDS positive HSWs both in their local community and treatment centers as well with reference to treatment.

Material and Methods

In the present qualitative research study the phenomenological approach for data collection and analysis were used, which seeks to describe the meaning of phenomena from the perspective of an individual's actual experiences, as the interpretative approach of the qualitative research suggest that there is no objective, external reality for the researchers as for addressing the phenomena, but to understand the reality from the perspective of those living with the phenomena (Ormston, 2014). Manly to check phenomena in a qualitative study is through the personal experience of those living the phenomena being investigated (Woody, 2014). This study was conducted at the Treatment Centre for HIV/AIDS at Jinnah Hospitals, Lahore. It is located in the Hospital with an out-patient ward. The study population consisted of HSWs AID/HIV patients receiving symptom relief care at AIDs preventive program initiated by the provincial health department of the Punjab. Researcher interviewed 10 patients and then realized that increasing the number of patients would not add to our preconceived set of categories. In keeping with the qualitative approach, researcher then interviewed two additional patients, which confirmed the sense that this research had sufficient information and data. Total 12 in-depth interviews were conducted throughout the research process, among the total population sample all the interviewed were living with HIV/AIDSs.

As it is common in qualitative research, that the interviewees were not selected randomly; rather, the choice was dictated by convenience and availability (Teddlie, 2007).

In the present research study verbal consent from respondents were taken and it was ensured that information shared by respondent will be kept confidential and socio-cultural barriers identified will be highlighted only to control the spread of HIV/AIDSs.

The interviews began by inviting patients to share any thoughts or observations about their condition, and proceeded to trace the patient experiences. After this introduction, conversations took the form of semi-structured interviews. The interviewer asked leading

questions on pre developed themes such as Awareness about HIV/AIDs, Social support system, Post HIV/AIDs sexual conduct and clientage process and Challenges in treatment. Then, patients were asked to reflect on the most important things at this stage of life and to describe what lent their lives meaning. Nonspecific stimuli (such as "tell me more") were used to help uncover the patients' perceptions and probe for more information. The interviews took one to two hours. The interviews were recorded and transcribed verbatim, and then content was analyzed. During structural analysis (interpretative reading) and text classification into broader categories the researcher made separate classifications and then discussed and unified the categories. Finally, researchers met several times to review and compare the findings of each interview and across all the interviews according to comparative, analytical methods.

Qualitative Findings & Results

In the present research study main focus of the transcript analysis initiated for the entire study was to dig up the emerging themes and understand the patients' perceptions towards the HIV/AIDs, as a result, the findings were not presented numerically; researchers have supplied broad indications of the extent that patients expressed each theme. With this, researcher presented the interview themes that were considered the most closely related to the main focus.

Awareness about HIV/AIDs

The researcher tried to understand about the Hijras awareness toward HIV/AIDs as disease. It is interesting to mention here that majority of the respondents heard about the disease and they were worried about their current status. They are trying to hide it from other. During the interview one of HIV/AIDs positive patient shared:

“I had heard this word since many years ago, but I knew that this is a dangerous disease when I face it. I know that nothing happen to me. When someone knows about my disease and his behaviors suddenly changed to me I became upset about it, I am physically fit and act as normal but my medical report tells me that you are AID’s positive patient. This is the type of disease with which one could not leave for a long time. Our Hijra’s Community tells us not to tell about your disease to your clients, because they will not pay you your reward. With the awareness of NGOs and provincial HIV/AIDs control program now I knew that actually this is one type of virus. Due to this virus the immunity of the human being became week and he/she could not fight against other disease which attacked him/her, this make the human being destabilized until the proper treatment had not been taken”

The most of Hijras living with HIV/AIDs knew about the transmission of the disease that it was transmitted from one person to another and also informed about that it was transmitted to us by doing unprotected sexual intercourse. One of the respondent comments this way:

“Now I know that it is transmitted from one person to another but before I became patient of it, I did not know this.... Of course, it was transmitted to me by other HIV/AIDS patient (client). If I were able to find him and asked him why did you transmit it to me?”

Majority of the respondents were worried about their future, their income, their survival when they heard first time about the disease. They also added about the treatment which is possible but we could not do treatment for it. One of the respondents explored this phenomenon as:

“When first time I heard that I was HIV/AIDS positive, it disturbed me as much as one person heard that you will die soon. Later I find some satisfaction about my status that it can be treatable. But the main hurdle in my treatment is that my GURU instructs me not to tell others about your disease. If others know about your disease you will be useless.”

Majority of the Hijras sex workers living with HIV/AIDS had a view that we are much worried about the disease, and we tried to get rid of it. Respondent shared the view:

“I want to get rid of this life but I got fear when I think to do suicide, no body show sympathy to me except my community, my community liked me but they could not provide me treatment. My Girya always encouraged me not to worry about your disease, you will get soon healthy. But I know I will die. But when I will die... I don't know.... (And then asked the interviewers) when will I die... do you know?”

Social Support System

Most of the respondents pointed out that stigma are attached in Hijra's Community due to this incurable disease is of low income. One of the HIV/AIDS positive patient shared:

“After getting HIV positive status my income became very low that's why my importance in the community also became minimized. I perceiving that they think about me as that I would not continue this for a long time. They behave me like a patient; they are doing extra care of me, from which I am guessing that I am not like others.”

HIV/AIDS as disease is one of the main factor which changed the perception of Hijras Community toward HIV/AIDS positive patient. The community attached negative stigma with HIV positive patient which negatively affect the personality and client circle. It is highlighted in the study that due to negative stigma the HIV/AIDS positive patient did not shared about the disease in community and particularly with client. The phenomenon was further explored in the following way by respondent;

“I am trying not to tell about the disease anywhere including in our Hijra's Community. This is one type of my weak point and I don't like to tell my own weak point to other. But the issue I face is that at the beginning, when I faced with the disease some closed one knew about the disease when I was brought by them to the hospital and the disease was diagnosed. My closed one just had told in our community that he is very

serious ill. Take care of him/her and all my Community take care of me but majority of them did not know about it. But I try to be careful in my Community about all that actions by which this disease can be transmitted to others like sharing of blade, doing unsafe sex, sharing injections etc.”

Due to the available health facilities most of the HSWs had a hope of normal life: Availability of free of cost Anti-Retroviral Viral Medicine (ARV) from special HIV/AIDS Clinics being operated at Public Health Facility, the encouraging behavior of regular sex partner and from the members of their community, availability of free of cost condom for protected sex, free of cost STI Treatment from Preventive services program, free of Primary Health Care, free of cost Referral facility for HIV Treatment through Preventive services program.

This phenomenon is hereby addressed by one of the respondent as:

“When I diagnosed HIV positive, I become stun and could not understand for few moments that what should I do and how can I survive with this incurable disease? I think that my life is ended, but, when I heard from my peer that there are free of cost preventive and treatment services available at public health facility as well as in private sector. Then, I was little bit gratified and a ray of hope grasped me to save my life. I reached the HIV Clinic for treatment then again another stigmatic behavior met me from medical staff. They called me with strange negative words, which showed that I am socially excluded and seems my-self an unnatural creature. However, I satisfied when I saw to HIV Physician and he counseled me as well and said that it is just disease like other diseases i.e Blood Pressure, Diabetes, TB etc and there is nothing to do more worry about this disease. Physician advised me to take ARV treatment un-interrupted (long life treatment) and virus will not defeat me in life and I will not die due to this virus. Now, I was slightly satisfied and enjoying all activities of DERAs (dance parties and other celebrations etc) with full confidence and also availing the services provided by the service delivery programs run through public private partnership. Now I am acting as normal healthy individuals as I was earlier.

Majority of the respondents shared their views as they are normal because of continues and free treatment from government as well as nongovernmental organization. One of the respondents shared;

“When this disease attacked me, I was much worried; I did not know what happened to me. At that time I could not do anything and want to sleep forever, when I was diagnosed with HIV/AID, the preventive center started my treatment. Within few days I was able to participate in all that events and which I was participated in my normal life”

Post HIV/AIDS Sexual Conduct and Clientage Process

In fact despite the HIV disease the HSW's still continue sex with their client because this is the only source of their income. But now they are taking all the safety measures like use of condom to ensure safe sex. HSW shared about sexual conduct as following:

“I always use condom during the sexual conduct. I know this is good for me and for my client as well. Sometimes client insists not to use condom during sexual intercourse, I refused simply from sexual conduct. I did not want to suffer other due to my careless behavior. I aware about this due to the attainment of seminars, workshops conducted on safe sex, organized by health preventive program”

The most of the HIV positive Hijra Sex Workers pointed out the common clientage process method as that they get clients by sources as, Gurus/Dalal, through Mobile Phone Calls, through DERAs, through old clients references, wandering in parks or other public places. One of them shared about clientage process;

“It is pleasurable fun for me to do these entertaining activities and it's my passion to do dance, singing and other sexual activities as well, because the society is not fit place for me, even my home is not a peaceful place for me than DERA is so calm and cool. However, the DERA in the guidance of Guru, is the best Place from where I can get clients easily and can do fun. Other Places have secondary importance for getting clients”.

The majority of HIV positive HSWs responded pointed out that their relations with their regular sex partners (GIRYA) remained unaffected; loyalty of regular sex partners did not changed or become lesser. Although, the sympathy level increased in their regular sex partners with patient. HIV/AIDS positive patient shared about the regular client loyalty and care in the following way;

“After getting HIV positive status, I was so much surprised and expecting that my GIRYA may be leave me due to this incurable disease i.e AIDS. But, fortunately he did not left me alone and promised to support me throughout his life. My Girya (regular sex partner) told me the words which I memorize that ‘you are my life and I am your life so we will be leaving together and will be dying together’. Now, he is very touchy about my health and encouraged me to take treatment on time that is very encouraging for me to fight against the virus of the AIDS”.

Challenges in Treatment

It is very painful for HIV positive Hijra Sex Workers to share about the society response and behavior toward them because of their sexual orientation with clients is considered as sin, they don't like their dressing/get-ups even, their positive status is the main hurdle to accept the society to HSW's as respectable citizen and most of the society members treat

them as a very strange type of human being. They give HSW's shut call and consider them as a carrier of HIV for other community members. The HIV Positive HSWs said:

Behavior of the society depresses us and some time we think that we have to leave this world because this is not fit place for us. Due to societal discriminative behavior we assume that HIV positive people have no right to live in this world and this world is only for healthy human being not for HIV positive people.

It is very harsh for HIV/AIDS positive patient to visit for checkup and treatment in public hospitals due to the fear that everyone in the hospital gets the information about their disease. Furthermore heavy dose of medicine is one of the challenges in their treatment. View shared by HSW positive patient as:

"This was my thinking that if I started treatment then everyone will know about my status and I will become useless in my Community. I was also afraid of heavy doses of medicine, at start of my treatment I would not be able to bear the medicine but latter the dose was minimized, now I am taking one tablets daily. And my secret was not exposed to anyone. I am happy and thankful to the HIV/AIDS preventive program guidance. I am telling you an interesting story about doing safe sex, when I brought packet of condom from the HIV/AIDS preventive center, usually I given condom to my peers and guided them to do safe sex but often my GURU asked me that you have been used the packet of condom but your income is not equal to the use of your condom. I mean that due to the use of condom we become accountable for our action to the Guru. That's why some Hijras hesitate from condom use and safe sex".

It is good to share about the HSW's free treatment in public sector hospitals and government support in provision of medicine. But the behavior of the entire health practitioner is not accommodative and supportive. Some of them discourage HIV/AIDS visitors to the hospital. — The HWS shared about the health practitioners:

"I am taking regular treatment from HIV/AIDSs treatment Center and no one had taken any cost of my treatment yet, but sometime I feel that the official staff of the center did not give us value, they torture us by saying strange words".

Discussion

In the present research study a qualitative technique of In-depth interview were used to study the perceptions of Hijra's sex workers living with HIV/AIDS toward the disease. The researcher developed various themes to measure the perception of HSW's. In present study the results and findings were gathered about the Awareness regarding HIV/AIDS, Social Support System, Post HIV/AIDS Sexual Conduct, Clientage Process and Challenges in Treatment. The study reveal about the knowledge of HSW's toward HIV/AIDS and its worse affect on their health. The HSW's HIV/AIDS positive patient

were already adopted the strategy to avoid spread of the disease among their client. The same results are also supported by a study conducted in 2014. *As 58.5 percent (N=890) of HSWs reported that they always used a condom with paid clients in the past month; however the proportion was even lower with regular non-paying partners at 17.1 percent (N=200)* (IBBS-2014). While in the case of FSWs it is opposite *“Around 2% of FSWs above and below the age of 25 could correctly identify the ways of preventing sexual transmission of HIV, and rejected major misconceptions about HIV”* (USAID, 2008). However,

Only 33.2% FSW reported that they always used a condom with their clients in the last month, with brothel-based FSW reporting substantially higher condom use than all other categories of FSW. It was also observed that the overall condom use declined with age (vaginal: 15-19: 4.4%; 20-24: 10.7%; 25+: 26.4%; anal: 15-19: 2.7%; 20-24: 7.8%; 25+: 20.9%) and was positively associated with education: the longer the number of years in school, the more consistent condom use (GARPR, 2015).

In the present study Hijra's with HIV/AIDS positive patient shared about the transmission of disease as because of unsafe sexual intercourse, by sharing of injection with other colleagues, by sharing shaving blades etc. As a result they guide other colleagues not to share these risky materials. The same guidance by HIV/AIDS positive shared in Hira community stated in a report *“ Male and Hijra sex workers fared much better in this regard, with 29% and 34% of those below and above 25 having comprehensive knowledge, respectively”* (NACP, 2010). However, it is evident from different studies that HSWs/MSWs have adequate knowledge about the ways of HIV transmission from one person to another. *“It was found that 62% of the MSWs/HSWs were aware of three ways of HIV transmission. Further the report shared that more than one third percent (38%) were not aware about these three ways of transmission of HIV/AIDS disease. On the other hand all the respondents declared unsafe sexual practices as a way to transmit HIV”* (PACP, 2013).

The study indicated that HIV/AIDS are the type of the disease to which one can fight with the social and technical support of their community and HIV preventive program as well. Usually, at the beginning of the disease the patient loss their courage and guess to be die in near future. But, it is the peer counseling, the preventive and treatment services which provide the hope to living with the HIV Virus. However, the HIV positive HSWs confessed that diagnostic facilities like Rapid HIV Testing, ELISA Testing, CD4 Count, Viral load and free of cost ARVs medicines are available at Jinnah Hospital, Lahore that provide hope of living them with the virus.

In Punjab province there are 09 ART sites providing treatment to 4263 patients. 102 Punjab started through WHO support got 2 mobile points of

care CD4 machines (PIMA) that is being successfully used by rotating the machine to far flung HIV treatment centers that are providing treatment. This effort has saved lot of human and financial cost and has provided the crucial facility at the door step of the patients (GARPR, 2015).

This was also finding out in the study that a stigma is attached with the disease, due to which the patients hesitate in taking proper treatment. This stigma is negatively affect the treatment process and safety measures as that some patients did not expose themselves and avoid treatment, and did not care of sharing all that things through which the chances of the disease transmission is high. Without taking proper treatment the patients showed themselves as normal, which cause the prevalence of HIV/AIDS.

HIV/AIDS stigma exists around the world in a variety of forms, including ostracism, rejection, discrimination and avoidance of HIV infected people; compulsory HIV testing without prior consent or protection of confidentiality; violence against HIV infected individuals or people who are perceived to be infected with HIV; the quarantine of HIV infected individuals and Stigma-related violence or the fear of violence prevents many people from seeking HIV testing, returning for their results, or securing treatment, possibly turning what could be a manageable chronic illness into a death sentence and perpetuating the spread of HIV (NACP, 2010).

It was find out that Hijra's sex workers were taking safe measures while conducting sexual act, they find the safety measures from the HIV/AIDS preventive centers.

Condom use by MSWs and HSWs with their most recent client increased from 22% in the last reporting period to 33% in 2009. Thirty-two percent of MSWs and HSWs under the age of 25 reported using a condom with their last client, while 34% of the older group used a condom with their last client (NACP, 2010).

They get their clients by various tactics; most often they get their clients in DERAs (the residential place of Hijra's community), get client through cell phone. *“The majority of clients of sex workers are either solicited by “madams/Guru” (26%) or found on the streets (32%). The remainders are solicited by “pimps” and network operators³ (12%), referred by clients (7%) or through the telephone (20%)”* (NACP, 2010).

The HSWs has strong networking system for their Sex work and dancing activities as well. *“The extent of the HSW network was analyzed according to the linkages between HSWs ,gurus and deras .Unique among sex workers communities in Punjab, the Hijra*

community is strongly linked in most cities, and each guru knew of several other gurus and HSWs. Hijra network is quite strong and connected to each other” (IBBS, 2014).

The Hijra’s community had a wide range organized network, which is functional for clients receiving. They also receive their clients from public places (parks), Urs (Religious gatherings, shrines etc), Bus /truck Stations, often. *“Truck drivers, miners and migrant workers are some of the common clients of sex workers” (Khan, 2005).*

It was identified during the discussion that each of them has one regular sex partner called *GIRYA* the local term used in Hijras’ community. *GIRYA* is the person to which one is extremely emotionally attached, *“men who marry Hijras or zenanas, and assume the role of the husband” (Collumbien, 2012).* He gave them courage to fight against the disease and motivated them to take regular treatment, and he takes the financial burden of the Hijras. This person plays a vital role in the prevention of the disease.

It was diagnosed that the patient found some challenges while taking treatment. Discriminatory behaviors of the society compelled most often to be the agent of HIV/AIDs transmission. *“Physical abuse, sexual violence or coercion, discrimination due to their sexual orientation are factors limit Hijras\’ ability to control the terms of protection during sex by either reducing the number of clients they must engage or by negotiating condom use” (MoH, 2004).* It was added that with the involvement in treatment process they became exposed, and their community blame them that it will affects your income, they did not want to expose their weak point to others, it was added that by taking safety measures we would then accountable to the *GURU* (spiritual leaders), the *GURU* count condoms in packet and asked them why your income is lesser as compare to the use of condom.

Gender issues are the root to provision of preventive and care services to Key Populations since HIV risks of MSM, HSW, and FSW, are driven by existence of extensive underlying gender inequalities and social marginalization. For this population stigmatization occurs in large part because society perceives their behavior as violation against the accepted norms of what women or a man should do. Stigmatization in turn makes the task of reaching key population with HIV prevention care and treatment services difficult (GARPR, 2015).

It was declared by them that our treatment is free of cost and the HIV/AIDS preventive center gave us full attention in taking treatment, they provide us free of cost Anti-Retroviral Viral Medicine (ARV) from special HIV AIDS Clinics being operated at Public Health Facility, free of cost condom for protected sex, free of cost STI Treatment from Preventive services program, free of cost Primary Health Care and Referral facility for HIV Treatment through Preventive services program.

Conclusion

The study concluded that Hijras are the network active for sexual orientation, this is the key source used for the transmission of HIV. They are aware about the disease and getting all that measures to ensure safe sex practices. Their clientage process is prevailed in Punjab by varieties of ways as they get their clients on *Deras* in the supervision of Guru, get clients by mobile phone and by visiting to public places. Almost all the Hijras had one regular sex partner called *Girya* in their local terminology, this person support and guide HIV positive patient to take regular treatment. The present study stated about the HIV/AIDS positive patient regular treatment as the only possibility which could led a normal life and make them able to participate in events.

The study highlighted social stigma and low income as the challenges faced by HSW's due to HIV/AIDS disease. It also shared during In-depth interviews that some of the HIV/AIDS positive patient are not taking proper and timely treatment of their exposition to other people within Hijras community. Finally all the HIV/AIDS positive patient agreed about their free treatment and other medication from public designated hospitals due to which AIDS is controlled to great extend.

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