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## Misconception and Self-Perception of HIV/AIDS Patients: A Qualitative View

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### Abstract

*The spread of HIV/AIDS has affected millions of people worldwide. The misconceptions of the disease ascend because of different causes, general ignorance and misunderstanding about scientific knowledge of this infection's disease. The present study deals with misconception associated with the HIV/AIDS disease regarding its remission. People get information and definition of things, behaviours so on from their surroundings, so that perception of patients about their disease is always very stigmatized. People are more concerned about stigmas rather than the disease itself. The current qualitative study highlights some stigma which involved in developing self-perception of HIV/AIDS patients at DHQ Dera Ghazi Khan. Ten interviews were conducted from Patients and Five from medical staff, along with two technicians. There is a number of factors which needs to be included in prevention mechanism to aware the population of how this disease spread and what is just illusion or misunderstandings.*

**Key Words:** Misconception, HIV/AIDS, Contiguous Disease, Self-Perception

### Introduction

The spread of HIV/AIDS has affected millions of people worldwide; it is considered an epidemic. The misconceptions of the disease ascend because of different causes, general ignorance and misunderstanding about scientific knowledge about this infection's disease. With the grace of God and some other socio-demographic factors at a greater extent maintained the spread of AIDS, from the last two decades its prevalence growing. Globally, the country has been identified as the low-prevalence state but with a higher risk of HIV infection. As per the statistics of the NACP's official website stated 0.102 million HIV infected patients, NCP has 17224 registered patients from them 8133 giving treatment. There were 2316 patients who were IDUs (NACP, 2016).

According to the Global HIV statistics (2015), there were 36.7 million people from the 1.8 million children; who were HIV positive, and from the total registered patient, 40 percent do not become conscious about health position. HIV remained the major global public health issue with a prevalence rate of 0.8 percent (USAIDS, 2016). According to the report, the majority of the world's infected population living in developing countries. Report again stated there was an estimation that annually 1.1 million people died due to HIV/AIDS related health illnesses. The number of infected patients in Pakistan belonged to Male population over female numbers, and mode of transmission major included drugs, sexual relations and blood transfusion. From illness, limited knowledge of HIV/AIDS is more injurious to the inhabitant of Pakistan.

The present study deals with misconception associated with the HIV/AIDS disease regarding its remission. People get information and definition of things, behaviours so on from their surroundings, so that perception of patients about their disease is always very stigmatized. People are more concerned about stigmas rather than the disease itself. The definition of such disease is very critical in the Pakistani community. The current research study highlights some stigmas involved in developing self-perception of HIV/AIDS patients and the community as well. The behaviour of peoples around patients matters, due to lack of knowledge they treat patients like the patient of touchable/contiguous diseases.

### Research Question

Like other diseases, AIDS is a disease, but people are more concerned about the stigma which create hinder in the medication of the disease. The present study deals with the stigmas, which are prevailing because of misunderstanding and misconceptions regarding HIV/AIDS. What people think about the spread of disease

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and why they always look very strict and unwilling to participate in social affairs with HIV/AIDS patients in daily affairs.

## **Background of the Study**

The infection of HIV is divided into three-phase or three stages according to the status of antibodies and the destruction of the Immune System. The overall stages divided into three categories, e.g. a) window period b) asymptomatic period and c) symptomatic period which is discussed in detail as under;

### **1<sup>st</sup> Stage**

If someone infected with the HIV virus, they do not become positive instantly. After the attack body produced a lot of antibodies abruptly; likewise, it produces whenever we attacked by other viruses, e.g. influenza etc. and this antibodies' management system took 2 to 12 weeks. And in some cases, if the patient had a very good diet or daily exercise routine, it took more time. The first stage is known as the window stage. In this time frame, the HIV test always negative because antibodies worked properly, and there would be no chances for a positive test. But, the virus inside the body may have infected other peoples around the infected one. In the window stage, low antibodies individuals observed flu within 2-4 weeks, but this condition varies from person to person. Certain type of symptoms may occur during the first stage but not necessarily the same for all the patients, e.g. fever, Rash, fatigue, mouth ulcers, muscle aches and chills are some of the major symptoms.

Stated symptoms were commonly diagnosed by other illnesses, e.g. allergy, depression and some skin allergies that is why in the first stage, it is very much unpredictable even through tests that anyone has HIV positive virus.

### **2<sup>nd</sup> Stage**

The second stage started after the completion of 12 weeks. The disease establishing its roots under the shadow of different viral infections, there was no change observed in the physical structure of the patient for years in up until the later second stage. As stated earlier, proper diet and their daily routine made them healthy and lived a number of years without any symptoms of HIV infection. The period could be 8 to 12 years, and in some cases, the signs appeared within five years or in some cases it needed less than five years.

If, the sickness was not diagnosed and the patients were not on ART, the virus continuously weaken the immune system, which leads towards acquired immunodeficiency syndrome 'AIDS'. The late second stage has some symptoms of HIV positive patients such as; weight loss (the rapid destruction in body mass), an abundance of night sweats and periodic fever, tiredness, diarrhoea (for more than one week), pneumonia, sores of genitals and mouth and coloured marks on and under the body skin or inside the soft parts of the mouth, e.g. inside the mouth, nose and eyelids and some of the neurological disorders.

### **3<sup>rd</sup> Stage**

This is the last stage which is known as the sickness stage. This health situation emerged after the fall of the immune system. The patient continuously suffered from different viral attacks, e.g. diarrhoea, influenza and other stated illness that majorly cured by medicine. But, if such illnesses do not cure by any medicines the stage is known as the third stage in which all antibodies destroyed or at the edge of destruction which provides a free hand to other contagious illnesses to attack the body, which does not have any antibodies or immune system to fight against such virus attacks.

## **Opportunistic Infections**

The later part of the 3<sup>rd</sup> stage is highly dangerous for health. Due to the destruction of the immune system, a number of infections may occur and which would not cure by any medicines. These adaptable infections attacked human body repeatedly and the condition known as AIDS. The third stage of HIV leads towards AIDS, and in this situation, the infectious diseases become lethal. Averagely HIV-AIDS patients died within 8 to 10 years of struggle; some may sooner or later after they infected with HIV. The HIV virus infection would be the whole life disease if you infected ones the virus remained in the body for the rest of life even after complete medication, their cells present in the body.

## **Why AIDS is Syndrome?**

A question arose regarding the patterns of AIDS by different scholars, generally speaking, different health condition and illness combine together diagnosed as AIDS. The deficiencies in the immune system provide an

open way for other illnesses and diseases that also present in T.B, Hepatitis and tumours.

### Transmission of HIV

Folks get infected by HIV through particular means. Majorly, in Pakistan, sexual behaviours are one of the ways of transmission; the prevalence of heterosexuality is the main reason. Drugs use through syringes are the second one; both types of behaviours very common in different communities; and the third one is the blood transfusion; without such particular type of transmissions, the HIV virus would not transmit from infected to the healthy person. A number of ways and fluids of the infected patient could cause the infection and transmission of HIV virus; Blood, Semen and pre-semen, rectal and vaginal fluids and breast milk. Such fluids of the patient contained damaged tissues which directly transmit infection into the healthy body or in certain causes drug users when uses same syringes or in medical units where no precautionary measure have been taken could cause the infection and spread of HIV infection transmission.

### The misconception of HIV Spread

It is the fact that without a human body, the HIV virus does not survive or reproduce. In communities, there are very common misconceptions existed which produce some social and psychological disorder in the function of the society. The virus does not transmit through air or water; it does not transmit through Mosquitoes [Malaria] or any other insects, social processes and interaction among the community members, e.g. hugging, sharing toilets, sharing eatable utensils, kiss on the forehead, or sexual activities which do not involve the exchange of body fluids were not the means of its transmission.

### A Confusion

The terms HIV, AIDS was commonly perceived as the same one, because in the locality, it carried the same disease and patients, as well as their relatives, were not aware of the causes of illness. Particularly, HIV represents the virus name, and AIDS represent the last stage of the body caused by HIV. Before the invention and the prescription of ART to the patients, those who have positive HIV very shortly progressed to the late-stage AIDS within a few years because it infects the immune system rapidly in certain situations. Advancement in the medicine industry, ART is continuously given to the HIV positive patients which boost the immunity through artificial ways that is why the average spread of HIV throughout the body remained very slow and lower the risk of transmitting the infection.

### Methodology

Triangulation of research tools was formulized to collect specific information under the objectives of the research. For In-depth, an interview schedule was formalized after content analysis of existing literature for prevention, stigmas and misunderstandings of the disease. Overall, ten interviews were conducted from patients in the centre who are coming for monthly meetings. Five interviews from medical staff, e.g. project head, one doctor, one lab attendant and one mobilizer.

### Sample of the Research

All the patients were male, though females were there during interviews the cultural values were the major issues for getting their perspective. During interviews, it was observed male patients were hesitant to checkup their females by male doctors as well as taking case studies by the male mobilizers. Some information regarding sample patients are as under,

**Table 1.**

Status	Interviewee
Marital Status	All were married
Age bracket	Ranging from 29 to 48
Family Structure	All were living in joint families before the identification of disease Out of 10, now six were living in Nuclear families
Education	<ul style="list-style-type: none"> <li>• Five were non-literate</li> <li>• Two were primary</li> <li>• Three were middle</li> </ul>
Stage of Infection	<ul style="list-style-type: none"> <li>• Seven at the 3<sup>rd</sup> stage</li> <li>• Two were on 1<sup>st</sup> stage and</li> </ul>

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Economic status	<ul style="list-style-type: none"><li>• One on 2<sup>nd</sup> stage</li></ul> Middle class <ul style="list-style-type: none"><li>• Three have their shops</li><li>• Four working in their fields</li><li>• Three are return migrants from the Middle East</li></ul>
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Source: In-depth interviews

The table showed general information regarding patients, their social status and their current state of infection. When asked about how you get information about this infection, and when you encounter this information that you are HIV/AIDS positive patients? The responses were different and very interesting that any of the patients do not come directly to the AIDS centre. They have different infections which are not medicated; HIV tests advised by the concerned doctors turned 'lives into a mess' (a respondent was very disturbed). After interviews, a list of commonly misunderstood factors was documented. The underlying data is the compact thematic description of interviews which were conducted from medical staff and the patients. First themes (most of them contain information about the virus and the lifetime as well as transmission mechanisms etc.) were taken from interviews of medical staff; there are some stigmas associated with the HIV career also discussed in detail and in second phase misconception prevailing in native communities taken from interviews of patients.

### **Transmission with Direct Intact of HIV Infected Body Fluids**

The transmission of the infection is not as easy as people think generally. Systemically, fluids which contained infected HIV viruses caused the infection to the new bodies. There are only a few ways which stated earlier, the factors why HIV prolonged in some bodies and destroys some bodies sooner still not well understood. Some viruses like influenza transmitted from infected one to another through coughing or sneezing, such type of viruses dependent upon the nature of the virus and their lifetime in the air outside the body. It was evident, the air-born viruses produce more danger, people found when they get infected from the virus, but in the case of HIV, it is a different one.

### **Lifetime of HIV**

According to doctors, 'HIV is not air-born virus outside the human body there is no chance it remained active, the virus warped into a cover that is called the envelope. Only some of the viruses have such coatings which are least durable. Under the controlled environment like in laboratories, HIV exists in purified non-chlorinated water for several days. According to the project assistant, 'research findings mostly locked inside the laboratories or in bookshelves, misinterpretation of the disease is more powerful than the disease itself. In the community, there was a common misconception about the virus 'it transmits from using the same drinking or eating utensils, e.g. when patient drink water in a glass, if used by the healthy one he/she got infected, or even swimming in the pool may cause infection.

A respondent shared, *'in summer season people bath in tube-well water pound due to high climate temperature, when I arrived on tube-well for bath, neighbours who know about infection cannot be permitted to enter the water pound until they finished (it was three years ago). Now the villagers know about the disease, and they avoid when I'm around tube-well water pound.'*

A doctor stated, *'outside the body in tap or pool water the virus destroyed quickly.'* Regarding the outer envelope of the virus, the envelope is sensitive enough to the chemicals, e.g. detergents or the chlorine bleach. But in a controlled environment for official purposes in laboratories, it sustained on the room temperature under dry surfaces. Washing clothes and cleaning of washrooms and washbasins, it is unbelievable that even a virus may sustain.

### **Hairdressers may be the Reason of HIV/AIDS Spread**

In villages, people are not much concerned about the health and hygiene conditions of themselves. It could be possible that the Hairdresser may cause of HIV transmission. According to a doctor, *'During hair-cutting it is commonly observed phenomenon that a customer gets a blade or scissor if the patient bleeds during the haircut, much care is needed to avoid the direct contact with the fluid, without direct contact, the risk of transmitting the infection reduced up to zero.'*

## Who have HIV, the patient must have AIDS?

This is another misconception present among patients who were interviewed, they are taking ART, but their misunderstanding remains. It was evident that the patients, who have HIV, died with AIDS-related illnesses due to their negligence. Only a small number from HIV infected patients remained alive up till ten years (various studies concluded the result) without further developing into AIDS. A case study was shared by the doctor shared the initial fact that a patient celebrates his six birthdays after getting infected by HIV.

Professional stated, *'HIV could be controlled through social capital (love and affection of the family members and the supporting peers are one of the key tools which delay further progresses). Advance treatments and medicines are here with us if the patient or the caretaker promised us the intake of ART on a regular basis we positively hoped them a long life. In the centre, we have ten patients they are on 3<sup>rd</sup> stage of their illness from last 4-6 years, and they are still progressing and spending their days with their loved ones and living a normal life with some precautionary measures.'*

If, we hypothesises the lifetime of the patient, it conclusively depend upon the intake of ART, more regular, long lifetime; less regular or some delays in taking ART further progress into HIV or AIDS-related diseases.

## Damage of Nerves System

'The supportive cells which protect, and nurture primary brains cells contain CD4 and therefore vulnerable to HIV infection' a doctor stated. He again stated about the functioning of the nerves system and working capacity of the brain as'

*'When a person gets infected with HIV, very shortly virus entered into the nervous system of the carrier. In the long run, the infected cells produce some sort of chemical compositions which directly interfere with the functioning of the brain. The patients who are on 3<sup>rd</sup> stage sometimes feel memory gaps, short memory disorder and slowness in thinking processes.'*

The memory problems may result in the opportunistic illnesses of the brain. Such stated problems could be the cause of anxiety, over-burden, family issues or any other disorder or depression. In this regard, HIV or AIDS is not the only cause of mental illnesses. According to the doctor *'in our centre, we had one patient (he died 18 months ago). Otherwise, it is very rear that the patient may have AIDS DEMENTIA COMPLEX or any memory loss or mental related disabilities in his/her medical case study.*

## AIDS and TB (Tuberculosis)

TB is the bacterial infection and direct effect on the lungs, but usually present in the whole body. Coughing and the sneezing are the prominent and most effective ways of its transmission from a contaminated, infected individual to the natural human being. Mycobacterial may be remained inactive in the host without causing any symptoms or transmitting from host to the new carrier. It was evident that the cells become more active in those carrier bodies which have HIV. Because HIV is destroying the immune system and so the TB attacked the body easily. A number of patients who were registered patients of the centre had both the symptoms, three from the list had TB, and then their HIV diagnosed. Diagnosing TB is very difficult in the later stage of HIV infections;

*Respondent had the same case, 'he was sick because of TB, his brother called the disease 'گندی بیماری', he shared, 'we brothers working in a stone factory (natively known as 'کریش' at Sakhi Serwer, he got a cough and after some days of coughing blood comes with saliva, when we checked to doctor he said it is 'گندی بیماری' you have to be very careful. Do not share utensils with your brother keep away children from your brother and always cover his mouth for the safety of remaining family members. He is my brother, how we can act like strangers with him. It is a very tough condition for the family, let see what God have for him.'*

The doctor shared the case as *'the patient is on the 3<sup>rd</sup> stage, and he has multiple infections along with T.B. that is why the ART is not working effectively.'*

## Doctors' Instruments and Tools

A major misconception among the natives regarding the transmission of the infection is that the instrument and the tools used by the doctors are not tools of spreading HIV/AIDS. Patients belong to different areas of the district DGK, villages which are situated around the city have medical practitioners most of them are not professional [the majority of the practitioners in the villages are assistants of doctors or lab attendants, they

have just general information about medicine for pain, temperature, headache as well as surgical knowledge. A respondent shares his case as,

*'I was healthy; I think I get this disease from my village doctor. Three years ago there was a fight among two tribes in the village, and people get injured, some were seriously injured, but more or less twenty people were injured from them only seven were referred by the doctor to the DHQ D.G.Khan. Other go to their homes we four people go to the doctor for treatment, he stitched the arms and hands at once. I think I get infected from that incident because, from that 4, another man and I are infected and registered for ART.'*

Dental and surgical tools usually have direct exposure to blood, and HIV-carrier tools may cause infection to a healthy one. Sterilizing the tools after every patient remained one of the effective techniques to avoid further transmission; washing tools with detergents could be the other source of disinfecting HIV cells, but the technique is not much common.

### **HIV-Patient and Work Ethics**

Like the other body fluid tests for certain checkups, the doctor needs consent from the patient. But, in the case of HIV

diagnosis test, it is prohibited to force the patient or forcefully get the sample from his body, which is against the work and medical ethics as well as against the liberty and freedom of everyone's choice. It is beyond work ethics if doctors refused to treat any patient due to his/her health scenario; he would not have any right to force the patient to get a test for HIV. A different case shared by the patient,

*'I was injured in a road accident by motorbike; a neighbour was crossing the road he found me injured and helped me to the medical centre of the village. My leg was cursed, with the grace of God's bone was not broken, the doctor refuses to stitch the leg because I am AIDS patient, he is MBBS doctor, but he referred me to DGK, I cover the leg with my shirt and tie the headcover cloth on the injured leg, travelled 13 Km for the medical treatment. Due to the loss of blood, one blood bottle was arranged and given to me.'*

The case study narrated a different story beyond the work ethics, medics, and paramedical staff could remove possible risks through routine infection control guidelines. In the real world, people with HIV-AIDS suffer discrimination. Pre-survey have been conducted before interviews, per-medical staff found reluctant when treating HIV positive patients and thus the quality of care-taking compromised.

### **Working Together**

Another misconception regarding HIV spread among the patients is working together with an HIV positive co-worker. As stated earlier, the chance of getting the infection through the surface is zero, but people don't want to work with the HIV positive individuals. One of the respondents is the owner of the shop, and he is too much concerned about his medical life in the community.

He stated, *'I have listened many times that this disease spread through touching others, that is why I am not touching my children, and if villagers found me patient of this disease it even cost my life, that I am polluting the health of villagers by giving them goods by my hands.'*

A doctor stated, *'as stated earlier in lifetime and nature of the HIV, it is not possible to get infected if someone from the office or market used patients' gadgets, or working together in a commonplace.'*

### **Cleaning Cloths Can Cause HIV**

A respondent shared, *'I cleaned and washed my clothes by self, my children and grandchildren are not washing clothes because they think it leads them to the disease. I don't know the cloths transfer the virus to them, or they get sick.'*

HIV does not remain active in the air or on cloths, and all the cleaning detergents clean up the infected viruses. Cloths that contained blood, either fresh or dry' must be cleaned with proper care as per doctors instructed to the laundry workers of the centre. Gloves and cleaning solutions reduce the risk of HIV infection.

### **School Going Children and HIV**

There is another misconception regarding the involvement of HIV positives parents' children with other children in playgrounds or in schools. Patients cannot send their children for education because they faced discrimination from teachers and other school fellows. A respondent shared,

*'My child was a dropout from school not because of his poor performance, but due to the disease of mine, that is why I left the village and now living in a city in a rented home.'*

### **Wearing Ornaments**

Male and female ornaments are shared among friends and family members. But the sharing of ornaments and sitting together becoming prohibited because people think anything which touches the HIV infected person gets polluted and may cause of the disease. As stated in the earlier discussion, detergents and cleaning chemical materials disinfect the virus. Washing the ornaments with any of the stated material surely neutralized the ornament, and that could be used by anyone. If there is any blood clot on ear-rings or rings that could because of infection, but after washing it the ear-rings and rings become useful.

### **Sharing vicinity with HIV/AIDS patients**

Regarding sharing the vicinity with the HIV, AIDS patients various long-term and short-term studies have been conducted in the USA and some of the African states. Those who had the responsibility of the patients inside the home, partners, children who used the same vicinity and other services, care-takers in health providing centres have been observed closely. Results of the studies showed a clear understanding that without any contact with body fluids or sexual intercourse, it is not possible to get infected from the patients.

*According to the respondents, 'people living with them are not willing to stay with them or being around because they think, HIV infection is easily transmitted to living with the patients, it was observed from all ten respondents, six are living with their immediate families in nuclear families. Families of brother and other relatives and two cases parents also living in other houses.'*

### **Children risking their lives**

A common reaction with the families, having HIV infection, is that people tend to prevent their children from going near them. When adult family members unreasonably dread the unknown, they may respond by ensuring extra protection for their kids. It was very terrible and awkward situation when the family member who have HIV maintained a distance from children. It is not commonly practised phenomenon in the culture that grandparent or the elders avoid children in families.

### **HIV patient rebuild their Immune System**

With a proper diet, and a healthy lifestyle will provide a better life to everyone. For HIV patients it is more important that with the help of proper diet and exercise the patient can overcome the infection. ART provide additional help to reduce the risk of further growth on the other hand the healthy daily routine is incentive towards a good and energetic life. Such type of lifestyle is not reverse the effects and damages off HIV but it hinder the further growth, a number of studies showed positive inclination towards the healthy life if ART and exercise and good eatables work cooperatively.

### **HIV Patients Detected from Appearances**

Because of advancement in mass communication and exaggerated images of the effects of AIDS, many people believed that the HIV patients always appear in a certain way, or at least different from usual/normal or uninfected healthy persons. However, the disease progression occurs a long period of time before the destruction of body cells. In-fact HIV infection cannot be detected based on appearance of the infected individuals.

### **Some other Positive Direction**

Maintaining avoidance from things that could further decrease the immunity to fight against the sicknesses is the first direction of the healthy lifestyle. It may prove to be a medical advantage for individuals with HIV disease. Expanding exercises that support resistance against ailment can also have wellbeing benefits. Eating appropriately and staying fit offer the medical advantages to individuals who have HIV infection. *'Proper rest, reducing stress, exercise and the healthy diet are some of the other tricks'* advised by the doctors and the mobilizers who visited in their respective areas for follow-ups.

### **Quitting the Smoking habit is Beneficial**

Smoking is lethal for immune system and it reduce the immunity regarding external attacks of viruses and bacteria. Smoking also hinders the process of healing of the lungs, which is significant when a person has

pneumonia. It is general advice by the doctors to quit smoking for effective results of ART, and this could increase the body's immunity.

### **Tab or Bottle Water is Healthy**

Purified water through different water plants, and household water purification filters can remove bacteria and other minor water particles from the water which may cause serious water-borne diseases. Generally, the drinking water channels under city administration department or the freshwater channels contained contaminated water from different service and development sectors. A large number of the population used such contaminated water for drinking which leads in rainy seasons towards diarrhea and other water-borne disease in children generally and patients particularly. *'The HIV patients have very low immunity and they easily get infected from water'* as per doctors. According to the patients, *'we are not much rich to practice such a lavish lifestyle.'* Two of the patients are used boiled water. But rest of the patients using the tab water and not considering water is dangerous for their health; the major emphasis of the spread of HIV is on two things Drugs and sexual activities.

### **Conclusion**

Study concluded that, behavior of the family members and peers towards the HIV positive patient is the influencing factor towards positive attitude or destruction of existing health. Socialization and stigmatization of the diseases in the cultural manners destroy the social bondage among the members of the society and the social institutions. Natives were less aware about the major causes of disease and how this disease spread or transmits; the interpretation and the stigma related to HIV/AIDS forced patients to think in a stigmatized way. Some misconception and misunderstandings are discussed in the article but there is lot to discuss on serious note for achieving the goal or eradication of HIV/AIDS in 2030.

### **Suggestion**

The campaign for the prevention mechanism and for the involvement of the local communities around the country way be helpful to provide a clear and scientific knowledge to the general masses because without involvement of general masses it is not possible to overcome the transmission and stigmatization of the disease which create hinder in eradication of the epidemic from country.

1. For the awareness campaign, involvement of school's teachers is very important because teachers may work as change agents, they have huge voice and number of students when listen their lectures it raises the awareness level among local communities. Govt. of Punjab under the Nutritional Project in Schools, the mobilizers of that program also be helpful for awareness campaigns. They have all the record of the schools and the children.
2. The second type of campaigns were for those who are not sending their children for education (less economic class), with the help of *Muhallah Masjid Imams* in their Jumma speech. The close involvement of the *Imamas* is the strong voice to teach the people what to do and what is more reliable for them in prevention and making themselves healthy.



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