Imperial Journal of Interdisciplinary Research (IJIR)
Vol-2, Issue-7, 2016
ISSN: 2454-1362, http://www.onlinejournal.in

Assessment of Emotional Problems faced by People Living with HIV/AIDS and to study the role of family support and role of a counsellor to manage the Emotional Problems.

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Abstract*: HIV/AIDS is one of the most alarming social challenges faced by the people in the universe. It has been described as the "most devasting epidemic humanity has ever known". Human immunodeficiency virus (HIV) is a lentivirus that causes the infection and acquired immunodeficiency syndrome (AIDS). As on today the disease is fatal, but it is totally preventable. AIDS is the end result of a viral infection, caused by a group of viruses known as Human Immunodeficiency viruses. UNDP 2010 reports that India had 2.39 million people living with HIV at the end of 2009.*

The present study highlights the effect of emotional problems faced by the person with HIV and AIDS. HIV infection has a major impact on the mental health of the person which has a chance of causing cognitive impairment, mood and anxiety disorders, and even psychotic manifestations[1]. Various psychological issues leading to manifestations among PLWHAs are acute-stress reactions, anxiety disorders, depression, mania, psychosis and Neuro-psychiatric manifestations of HIV associated neurological illness[1].

Testing for HIV is itself evokes a lot of anxiety. It is very general that most of them take lot of time to muster up courage to undertake the test. Not all will react in a positive way. The first reaction is anger, depression and failure to cope up with life. Suicidal thoughts will occur. At this time there is a need for proper counselling. Appropriate counselling or absence of any other social support can devastate an individual. They experience lot of stress mentally as many emotional problems occur to them. To cope up with these stressors there should be a need for social support, whom the PLHWHA could be able to tell them about the sero-status for moral, emotional and psychological support.

Results: *Our study population included majority Males (52.2%) and rest are females (37.8%). Majority of them had Primary (58.6%) and secondary (37.8%) level of education. 99.1% are infected through sexual contact. 38.7% of respondents receive support from spouse, and secondary family members. 95.5% respondents are satisfied which they get support from family members. Most of our respondents (41.4%) always sometimes (55.9%) get financial support to their medication, only 2.7% will never get support. 94.6% of respondents feel they have someone to listen their feelings and thoughts. 41.4% respondents get reminder to take ART medication from their family members. 81.1% of the respondents felt that they can always participate in family function.*

Conclusion*: present study highlighted the fact that adherence of ART treatment is better when family support is high.*

Introduction

The present study highlights the effect of emotional problems faced by the person with HIV and AIDS. HIV infection has an major impact on the mental health of the person which has a chance of causing cognitive impairment, mood and anxiety disorders, and even psychotic manifestations[6].

Emotional problems impair the quality of life of the person. It occurs because of the stigma attached to the disease. Ignorance regarding the transmission is one of the reasons to increase emotional problems among the PLWHA. Psychological impairment found among them affects the prognosis, adherence to the medications, and impede treatment. Hence treating these problems are essentially required to improve the health conditions of the people affected.

Maladaptive coping strategies or impaired solving ability decreases quality of life. Coping strategies could also be determined by the personality factors like pre-existing psychiatric problem, which will further lead to high-risk behaviour.

Various psychological issues leading to manifestations among PLWHAs are acute-stress reactions, anxiety disorders, depression, mania, psychosis and Neuro-psychiatric manifestations of HIV associated neurological illness[8].

The person with depression due to the illness may have several symptoms. It may include feeling of worthlessness, sadness, helplessness, feeling of guilt, lack of interest in doing any activity or lack of concentration, suicidal thoughts, and changes in sleeping and eating habits. They may have these symptoms because they know that this illness is incurable. These are the symptoms, which clearly indicate that the person may be undergoing depression.

Stress also leads to hopelessness, which develops suicidal ideation. Emotional problems resulted from few environmental barriers like reduction of care from the family members, negative attitude of the patient care provider, societal attitudes, and stigma. All these factors also decrease productivity of the infected persons. As there is decrease in the productivity, quality of life is also reduced.
Along with the fact that PLWHAs are facing emotional problems, it will also lead to few physiological symptoms which will exaggerate the severity of mental health problems. They may be digestive problems, increased blood pressure, changes in the immune system, changes in hormonal functions, activated defense mechanism which will lead into new psychological and behavioral problems. The psychological problems faced by the infected person may be nervousness and tension, chronic worry, inability to relax, inability to cope with life situation, emotional instability, excessive use of drugs, sleeplessness, poor motivation,

Emotional problems causes harm to the balanced functioning of an individual and retains them from leading a quality life. The main problem because of these emotional disturbances are decrease in adaptive efficiency among the individual. It will decrease the ability of the person to adapt to the situations and if the individual do not come up with the problems it will lower his/her efficiency to respond to the situations.

Social support and health behavior as investigated by various social scientists brings out various strategies to improve the life of the person infected with the HIV virus. Living with HIV/AIDS infected persons is not easy task. Social support, especially support of the family members play a vital role to reduce progression of the disease by also in improving quality of life. To ensure social support it is very much required to understand the health behaviour to bring out various strategies required to ensure emotional and physical stability. Some families try to avoid discussion of HIV/AIDS –related topics and they feel uneasy for several reasons. Every individual desires to lead a life with dignity. Traditional communicable diseases like leprosy, tuberculosis, syphilis have been associated with severe social stigmatization. With the passing time, and development of medical care and interventions most of these diseases lost stigma. With the pandemic of HIV, infection similar societal discrimination is seen. The fear is increasing because of the various modes of transmission. Whatever the mode of transmission is, the ultimate affect is on the family. As we have already seen most of the PLWHAs with serious, progressive illness confront a range of psychological challenges including the prospect of real and anticipated losses, worsening quality of life, the fear of physical decline and death, and coping with uncertainty. With the stigma attached and the risk of transmission, major and permanent changes are required, which need the support of the family. As like any other chronic diseases, partners and families often provide most of the physical and emotional care to the person who is suffering.
Among the PLWHAs, psychiatric conditions are commonly seen, hence along with the primary care physicians, mental health specialists and other support services are required to help them cope up with the situation. Total quality care is very essential to the infected people. When they are initially informed about the positive test result, they need psychological support as they need to integrate the new information into their existing identity. They need to rethink priorities and goals, and acquiring new skills to live a quality life.

Most of the people, when diagnosed struggle with issues of disclosure to others. During this period there is a greater need for someone who supports them to overcome the confusion. Patients are often resistant to initiating antiretroviral therapy because it is known to be a lifetime therapy. They will be confused especially when they are asymptomatic. One of the reason for this confusion to initiate the therapy is because they are aware of the side effects and are also concerned about the long term toxic effects. Hence most of them are uncertain, ambivalent and anxious about initiating therapy, and they need the support of someone who can guide them. Hence a family member who is confident to help the PLWHA is needed. Apart from the health issues what they are facing, the PLWHA should also need a healthy life style. Healthy life style includes, good physical health, social health and psychological well-being. Family or primary care providers can advice or advocate the PLWHAs to lead a quality life. The family should motivate them to practice exercise, control the substance use, alter their sexual risk behaviour. They also need to have a nutrition diet to maintain the health.

HIV disease is one of the major sources of emotional and physiological stress for the infected persons. Guilt, fear, denial, shock, loss of self-esteem, suicidal thoughts, hopelessness, shame, feeling of revenge, grief and isolation are some of the emotional problems faced by them during diagnosis. Depression, anxiety, stress, distrust and many more are the mental health conditions that occur during each stage of the disease. Chronic exposure to stressful events reduces immunity, contributes to increased symptomatology and hastens disease progression to AIDS.

These reviews focus on the key challenges faced by the infected persons due to their emotional problems. Literature pertaining to these issues will be one of the important step to focus on producing effective strategies to reduce the emotional effects on the life of the infected persons.

1. Kee MK et. al. conducted a study to investigate the factors associated with prevalence of anxiety and depression symptoms among HIV infected patients in Korea. 840 HIV infected patients participated in the study and State-Trait anxiety Inventory and Beck Depression Inventory were used to assess the symptoms of anxiety and depression. It was found that the prevalence of anxiety and depressive symptoms among HIV infected patients was 32% and 36% respectively. It was seen that the prevalence of anxiety and depression symptoms was higher than those estimated for the general population. Hence, the authors felt is necessary to evaluate symptoms of anxiety and depression and suggest psychological support for HIV infected patients who smoke or have persistent symptoms or have sexual partner or drink.

2. Psychological impact among the older and younger people living with HIV/AIDS were examined by Liu H et.al. The study examined and compared the self-efficacy, depression, well being, and quality of life among older and younger PLWHAs in China. The age group of younger PLWHAs were 18-49years and older PLWHAs were 50 years and above. 148 participants were interviewed and it was found that comparatively, older PLWHAs reported lower levels of well-being, higher levels of depression and poorer quality of life than the younger PLWHAs. Whereas it was found that self-efficacy was found similar between both the groups. A higher level of depression among older PLWHAs was associated with much lower levels of subjective well-being and quality of life (physical and psychological health). Hence, it was observed the study that older PLWHAs face psychological problems and mental health challenges beyond those experienced by the younger group. Further research was suggested to develop interventional programs to improve mental health and quality of life for HIV infected older adults.

3. Santha attempted to identify various psychological problems faced by HIV positive mothers and their comparison was made with those without HIV in her study in Tamil Nadu. 320 HIV positive mothers and as many negative mothers, attending OPD of Govt. Rajaji Hospital and Meenakshi Mission Hospital & Research Centre, Madurai having children was selected as the respondents. The result showed that the majority of the HIV positive mothers faced more social problems when compared with the HIV negative mothers.

4. Su X et.al. associated severe mental health problems and risk behaviours in their study conducted in China. Survey was done among 258 PLWHIAs in two cities in China. Perceived stress scale for PLWH (PSSHIV) and the perceived social support scale (PSSS) and perceived discrimination scale for PLWH (PDHIIV) was administered. It was found that the perceived discrimination was a major source of stress and social support could reduce the stress among PLWH in China. The results highlighted the importance to reduce discrimination toward PLWH and the difficulty to alleviate its negative consequences. It was warranted to improve mental health among PLWH in China and it still important to foster social support among PLWH as it has direct effects on perceived stress.

5. Guoping JI et al in their study on impact of HIV/AIDS on families and children, aimed at understanding the needs of families and children affected by HIV/AIDS. They focused on the local health workers, local schoolteachers, village leaders, persons living with HIV/AIDS, and caregivers for children affected by HIV/AIDS in Anhui, China. Interview was collected with 154 caregivers of HIV affected children. Result showed that among the care-givers 84% were parents. 80% were tested to be positive for HIV virus. Among the care-givers, 54% were rated to have poor quality of life and 85% have frequent negative feelings. They were suffering with the financial aspect also as the annual income per person for HIV/AIDS affected families was much lower than the provincial average. The impact of HIV was reflected in children's school performance also. It had an impact on the nutrition and

health of the children. It was also seen that HIV-related stigma and discrimination are important issues for HIV/AIDS –affected families. This lead to avoidance and isolation among the children as they are ignorant why people treat them differently. The poor economic conditions making coping more difficult. Children discontinue the education because they cannot afford it, or may be family need their contribution to family's income. It was also found that children's health and nutrition are compromised.

Methodology

Aim of the study: To understand the emotional problems faced by the HIV infected people and also to study the need for family support to manage the emotional problems.

Objectives of the study:

1. To assess the emotional impact on the respondents on diagnosis of HIV infection.
2. To assess the level of support by the family members to the respondents

Limitations of the study:

- The study was conducted in one ART centre instead of many other centres, it found difficult to obtain permission from the concerned institution.
- As the respondents were under medication, their physical and psychological state had to be considered and be flexible about their timings.
- The study sampling involved only the age above 18 years, because it was difficult to obtain permission from the concerned Departments.
- Due to the sudden death or hospitalization of their partner or children, the psychological state of the respondents affected and there were constant mood swings.
- Family members were not involved in this study.

Research design: The present study is the prospective cross sectional study.

Study setting: Kasturba Medical College Hospital, Attavara, Mangalore

STUDY POPULATION: All the people who are diagnosed to be HIV positive, registered for ART, visiting the hospital for the treatment

Sample size: 105 persons who are diagnosed to be positively infected with HIV virus and have visited the ART centre are considered to be the sample of the study.

Sampling criteria

Inclusion criteria

- ☐ HIV infected person with the age more than 18 years
- ☐ HIV infected person who are registered in ART centre of KMC hospital
- ☐ Respondents who are willing to be the part of the information of the study by giving consent.

Exclusion criteria

- ☐ HIV infected person with the age lesser than 18 years
- ☐ Respondents who are not willing for the study.

Collection of data: collection of the data was done during the period of 6 months.

Data source:

The investigator collected data from the person who was positively infected with HIV virus, and who were attending the ART centre at KMC hospital Attavar. The investigator interviewed the respondent individually and collected the data.

Tool of data collection:

1. Schedule to study the socio- demographic and background details. A structured questionnaire was used as a tool for collecting primary data

2. A structured questionnaire was used to assess the family support.

3. A structured questionnaire was used to assess the emotional problems.

Content of validity of the tool:

The constructed tool to assess the family support was given to three experts in the field of social work teaching, who have PhD. The experts were

identified on the basis of their experience and professional expertise. They were requested to give their expertise opinion on the relevance, accuracy and appropriateness of the questionnaire. And based on their recommendations the tool was modified and administered.

Informed consent:

- ☐ Prior permission was obtained from the institution and consent was taken before the data collection for the study.
- ☐ Respondents were informed about the study and then taken written consent from them.
- ☐ Only those patients who were willing to participate in the study was taken as respondents.
- ☐ Confidentiality was maintained during the process of data collection
- ☐ Collected data was used for study purpose only.

Data processing and analysis

- ☐ Analysis is done by descriptive statistics, association is found by using Chi- Square test, students unpaired t test, ANOVA and Logistic regression, Statistical package SPSS version 17.0 is used. $P< 0.05$ was considered as significant.
- ☐ Research final report includes introduction, methodology, results, discussion, conclusion, suggestion, and bibliography**.**
- ☐ On completion of the data collection, the data was scrutinized to record the problems indata.

Results:

Socio-demographic profile of the respondents clearly show that majority of the respondents in the present study was male (52.2%). The reason interpreted for this data was that most of the infected person was male. Further interpretation showed that the major transmission of HIV virus was through sexual route (99.1%). Only 0. 2% were found to get the disease through perinatal route and 0.7% through blood transfusion. Though the blood transfusion was done through the proper technology, it was understood that the virus was transmitted during the window period of the donor. This was a important factor that was to be handled properly as interrelated from our study.

The place of residence of the majority respondents (62.3%) were from rural area. This brought to the fact that the strategies provided to prevent the further transmission of the virus should be tailor made to suit these people especially for those living in the rural area

The data of the present study shows the place of residence and it is found that majority (62.3%) of them belong to rural area. The educational level of the respondents is seen in the above data. It was found that majority of the respondents had primary level of education (49.5%),he above data depicts the income level of the respondents. Majority of the respondents is seen to have the income of 2000-3000 (33.9%).90.2% of them belonged to the nuclear type of family, Majority of the respondents are found to be married (59.7%).

The data in the present study shows that 82.3% of the respondents have emotional problems like guilt, feeling of hopelessness, anger, shocked etc. and only 17.7% managed these problems efficiently.

The above table shows different emotions during the diagnosis. 57% of the respondents felt very anxious during the diagnosis and 43% felt they did not feel anxious. After understanding that they are HIV positively infected, 63.3% of the respondents felt sad of the condition and other did not feel sad. With the present status of being HIV positive, 63.3% felt ashamed to participate in their family function and to meet because of the innumerable queries, stigma and their health condition. 64.3% of the respondents showed an expression of feeling angry on themselves due to their condition and 60.3 % showed anger on the person who were responsible for the present condition. Significant number of respondents (92.5%) of the respondents were shocked to understand their HIV status. 68.2% of the respondents felt they lost their self confidence after the diagnosis. This is very dangerous since it may lead to the suicidal thoughts. 68.2% felt guilt about their unsafe behavior which caused the disease and 47.9% lost hopes in life after the diagnosis. Due to all these problems 43.3% of the respondents feel they are stressed when they work at home or at work place.

These analyses show that respondents have various emotional problems when they found that they are infected with the HIV virus. These emotional problems has major impact on the health of the respondents. Hence it is very much required to understand the strategies to cope up with these emotional problems so that they will lead a quality life.

Emotional problems was associated with the gender to find out the differences among male and female respondents on expressing the emotions at

the time of diagnosis of their infection. Very highly significant ($p<0.001$)

Level of family support	Percentage
Always	50.8
Sometimes	44.6
Never	4.6
Total	100.0

The level of family support is assessed and it was found that 50.8% of respondents always had family support. Family support here in the 44.6% of the respondents had family support only sometimes. And 4.6% of them reported they did not have any support from the family.

The family support is measured by a set of questions, assessing the type of help they get from the family. Like financial support, care taking themselves and children, to ventilate the emotions, adhering to the treatment, discussing the health issues, to do daily chores like marketing, social contacting, taking them to religious institutions, legal matters etc.

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