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A study of practicality of home based care in HIV/AIDS in district Ahmednagar, Maharashtra

[1] Dr. Marcia Waran, [2] Dr. Arun Tyagi, [3] Dr. Sharad Garudkar

[1] MD (Medicine), Chief Medical Officer and Senior Physician, the Salvation Army Evangeline Booth Hospital, Ahmednagar Maharashtra, India

[2] MD (Medicine), FISC, FIACM, Professor (Medicine), PDVVPF's Medical College, Vilad Ghat, Ahmednagar, Maharashtra, India

MD Medicine, Professor (Medicine), PDVVPF's Medical College, Vilad Ghat, Ahmednagar, Maharashtra, India

Abstract

HIV infection today affects about 5.2 million individuals in India. In 2006 the most accurate NACO statistics showed a natural HIV prevalence in India of 0.36%. Every year throughout the world and particularly in Asia, an increasing number of people are infected by the HIV/AIDS pandemic either directly or through someone they care for. AIDS is a chronic condition lasting months or years and a person with AIDS may move several times from home to hospital and back again. Much of the care of those with AIDS therefore occurs at home. The Salvation Army has been working with HIV since the beginning of the epidemic. We studied the effectiveness of home based care whereby care in the homes helps in reducing frequent infections, increases ownership of the problem, increases longevity and improves the quality of life. 1029 HIV positive patients from October 2010 to June 2015. There were 693 males, 297 females, and 39 were children. The average age ranged from 25 to 40 years. Those who participated in the program had better quality of life, learned the participatory health care and were not/ less afraid of the stigma of the disease. Moreover, the home based care is significantly more cost effective.

Keywords: HIV, AIDS, Home-Based Care

1. Introduction

The HIV epidemic has reached previously unimagined levels in the worst affected countries of Sub-Saharan Africa. The global attention is also focusing on the spread of HIV in Asia and in particular in its most populous countries. HIV infection today affects about 5.2 million individuals in India. In 2006 the most accurate NACO statistics showed a natural HIV prevalence in India of 0.36%. If an average figure is taken, this comes to 2.5 million living with HIV/AIDS; almost 50% of the previous estimate of 5.2 million. Prevalence rates among adult females is 0.29% and that among adult males 0.43%. Prevalence is high in the age group of 15-49 years (88.7% of all infections).In high risk groups (or key populations, as they are now called) the prevalence is still higher. It is 8.7% among Intravenous Drug Users (IVDUs), 5.69% among MSM (Men Having Sex with Men) and 5.38% among Female Sex Workers [1].

1.1 Magnitude of the problem

The brief history of HIV/AIDS in India is worth recapitulating.
1986: The first case of HIV was detected in Chennai (Madras) by Dr. T. Jacob John and Dr. Eric Simoes from the Christian Medical College Hospital in Vellore and Dr. Suniti Solomon from YRG Care in Chennai.
1990: HIV levels among high-risk groups like sex workers and sexually transmitted diseases clinics attendants in Maharashtra and injecting drug users in Manipur reaches over 5 percent.
1994: HIV no longer remained restricted to the high risk groups in Maharashtra but alsostarted spreading in the general population. Not only this, HIV cases also started appearing in the neighbouring states of Gujarat and Tamil Nadu where high risk groups had over 5 percent HIV infection rate.
1998: Rapid HIV spread in the four large southern states of India not only in high risk groups but also among the general population where it reached greater than 1 percent.
Every year throughout the world and particularly in Asia, an increasing number of people are infected by the HIV/AIDS pandemic either directly or through someone they care for. AIDS is a chronic condition lasting months or years and a person with AIDS may move several times from home to hospital and back again. Much of the care of those with AIDS therefore occurs at home.

1.2 Role of Salvation Army

The Salvation Army has been working with HIV since the be-ginning of the epidemic. They are represented in approximately 104 countries around the world and have 52 HIV related programs in India.
The Salvation Army Evangeline Booth Hospital, Ahmednagar in Maharashtra has been working with HIV/AIDS since 1992. The vision of the hospital that we as doctors must look beyond curing disease to keeping people healthy in the family, the community and the environment. Paradoxically, the only way in which one can deal effectively with the problem of the rapid spread of HIV/AIDS epidemic is by respecting the human rights of those already exposed to the virus and those most at risk.

2. Objectives

We studied the effectiveness of home based care whereby care in the homes helps in reducing frequent infections, increases ownership of the problem, increases longevity and improves the quality of life. By making people responsible for their health, the financial burden on the family is reduced.

3. Methodology

The Salvation Army Evangeline Booth Hospital, Ahmednagar in India has a community-based program that is linked with hospital work. All HIV positive patients in the program are seen with other multi-disciplinary patients in the outpatient department/inpatient department.

Most patients are either referred to the program by outpatient General Practitioners, physicians, gynaecologists or other specialists. No mandatory testing is done. Their clinical status is assessed with a complete baseline physical examination that includes a chest x-ray, to rule out tuberculosis, which is rampant in India, especially among HIV positive people. All patients are counselled and encouraged to participate in the program, the support group, the home visits, care, and demonstrations in the home and in the community.

Counselling forms the backbone of our program, which is done by full time trained social workers. This helps build a rapport and is the foundation of the positive peoples' support group that consists of patients and their families. This is the entry point into the homes of people and the communities they live in. Some of our patients are members of the team and help in team activities and community counselling [2].

We studied 1029 HIV positive patients from October 2010 to June 2015. There were 693 males, 297 females, and 39 children. The average age ranged from 25 to 40 years. Level One HIV positive people were diagnosed on the basis of the WHO criteria with one and one Western blot test of two ELISAs done by different methods. An average of 10 to 15 HIV positive patients are seen every day. Of these, two or three are new patients and the rest are previously detected patients who have come for a follow up. More than 400 patients come for a regular follow up. Of these 84 have died. There is a high fall out in numbers due to various reasons like denial, poverty, distance from the hospital, fear of identification and discrimination.

Follow up is difficult because many patients do not want us to visit them in their homes and in their communities. We respect this and do not force home visits but continue to encourage them to come and meet us in the hospital and in the support group.

Observations

It is possible to use safe and effective home remedies that vary from place to place. The guidelines of home based care remain the same. Local treatment and traditional medicine is used to care for a large number of HIV/AIDS related problems. Patients learn to better control their own finances, leaving the more serious problems to be dealt with in the hospital. They become more involved and careful with their own health issues. They are more open to counselling and care. Through prevention and behaveour, change is happening from within communities with the participation of people and families affected by HIV/AIDS.

4. Results

The following were the important findings of the study

- **Improved quality of life:** Those patients who have participated in the program have been found to live longer, have fewer infections, have a better quality of life, live with less fear of the disease and achieved far more than those who appear to have an unlimited life.
- **Active participation in health care:** We have helped turn them from passive receivers of health care to active participants, thereby involving them in prevention and care in the home and community. The patients and relatives alike have learned about early intervention and learned how to stay healthy longer.
- **Removing the HIV/aids stigma:** Through home visits to HIV positive patients, families learned to accept the disease. Stigma and fear decreased. By sharing skills people learned correct facts about HIV/AIDS and this has made them less afraid. They have learned to overcome fear and discrimination.
- **Role of Facilitator:** We have moved away from awareness programs, which by themselves do not change behaviour, to a participatory approach. Communities are willing to work with their own people. Here our role is of facilitator. Community to community transfer is happening, but the process is slow.

We have, through counselling, found most families are willing to care for the HIV infected individual in the home. Death usually occurs in the home (or in the hospital depending on the financial status of the patient). This is encouraged if there is no response to treatment, if the patient does not want to go on, or if as mentioned cannot afford the cost of treatment.

5. Discussion

HIV in India is increasing at an alarming rate although prevalence levels of HIV are still very low in India (<1 percent of the adultpopulation). The number of infected individuals however, is extremely large, doubling in the last four years to an estimated 3.6 million. Data from sentinel surveillance points to a rapid evolution of the epidemic in the southern and western parts of India. A distinct but continuing epidemic among injecting drug users in Manipur risks spreading to neighbouring states.

The pattern of HIV is shifting towards young people and to-ward women-over 50 percent of all new infections are in young adults below 25 years of age. Approximately 25 percent of all HIV infections in India are among women- a majority of whom do not have any other risk factor than being married to their husbands.

Cost of triple drug therapy is now within the reach of HIV positive people in India. Earlier when the initial study was done this was not so. Many resort to using drug therapy or treatment with no authentication or proven efficacy. Many turn to homeopathy, Ayurvedic and Unani medicine.

Feasible strategies now exist to prevent transmission of HIV from mother to child [3]. All antenatal mothers are put on lifelong ART. This is given to all pregnant and breast feeding women with HIV during the mother-to-child transmission risk period and then continuing life-long ART for those women who are eligible for treatment for their own health [4]. There is still fear among the treating gynecologists and many women are refused admission for delivery. Very few doctors do Caesarean sections as an elective procedure to prevent vertical transmission.

Low cost home based care will be made more effective if the government uses the already existing health care set up in the primary health care centres at the village levels to reach into the homes of people who are sick or dying. The government needs to work with NGOs and CBOs (Community-Based

Organizations) and those working with home-based care to reach more sick people affected by this epidemic.

6. Conclusion

The study shows that the home-based care for HIV/AIDS patients is an effective and economically beneficial option for long term management of this chronic ailment and must be encouraged and discussed with every patient and his/her relatives. This removes fear, stigma, taboos and makes the community active participant in the health care.

7. References

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