Annexure 2: Positive Living and HIV

Definition

People living with HIV (PLHIV) often have to deal with many emotions such as fear, grief, depression, denial, anger and anxiety. Being ‘positive’ for HIV, does not mean end of life, it means that they have to start living positively. Positive living or living positively with HIV/AIDS means ‘to lead a normal life and practice HIV preventive and supportive measures’. Another aspect of positive living is to prevent the spread of HIV from an infected person to someone who is uninfected.

Dimensions of Positive Living

There are many dimensions of positive living usually considered essential in the development and provision of any comprehensive HIV/AIDS care system. With the aim of meeting the physical, emotional, social and economic needs of PLHIV, ‘positive living’ should ideally include the following dimensions.

1. Hope
   - Hope is a feeling that what is wanted can be had or that events will turn out for the best.
   - Hope is a powerful feeling that many PLHIV may lack.

2. Openness or disclosure
   - Positive living requires that there be an environment of openness wherein persons living with HIV can disclose their HIV positive status, ‘normalise’ their disclosure, and comfortably discuss HIV in their environment.
   - Openness or disclosure helps in reducing stigmas.
   - Openness or disclosure helps in dealing with internal HIV/AIDS phobia.
   - PLHIV are often much happier in their relationships when their HIV status is known to their partner.
   - Clinicians, counsellors and programs relating to HIV need to be sensitive to the complexity of the disclosure and understand that disclosure is not for all people and for all contexts.

3. Accepting one’s status
   - Long-term denial (of one’s HIV sero-status) is detrimental and should be discouraged.
   - Knowing and accepting one’s HIV sero-status helps to reduce stigma related to HIV.
   - Knowing and accepting one’s status enables a more informed planning for the future.

4. Respect for human rights
   - Respect for human rights is one of the important components of positive living, keeping in view the dignity of PLHIV.
Society should treat all persons, including children living with HIV, with respect and compassion.

PLHIV have the right to live life with respect and dignity regardless of sexual orientation. They should not be segregated, condemned or shunned.

5. Strong sense of purpose

- PLHIV often seem to lack or lose the sense of purpose in life after being diagnosed as HIV positive.
- PLHIV need assistance to retain a sense of purpose in life through job rehabilitation, and helping them improve their self-worth.

6. Accessibility and availability

- Accessibility and availability of healthcare services is important in ensuring positive living.
- Basic care provisions should be available at all levels.

7. Balanced and healthy nutrition

- Maintaining good general health and nutrition can contribute to the maintenance of immune system functioning.
- Living positively includes eating a healthy, balanced diet.
- Good and healthy nutrition can help in delaying the progression from HIV to AIDS.
- Nutritional care and support are important from the early stage of infection to prevent the development of nutritional deficiency.

8. Equity

- Health needs for positive living of the targeted population should be met in a fair and a just way.
- Geographical, economic and social barriers should be minimized to promote equity.
- Care should be provided to all PLHIV, regardless of gender, age, race, ethnicity, sexual identity, income, and place of residence.

9. Economic empowerment

- Many PLHIV are affected by loss of livelihood and poverty.
- Economic opportunities help PLHIV to live ‘positively’.
- Employment and engagement in business activities, financial independence and capacity-building training have empowered PLHIV, resulting in reduced social stigma and positive living.

10. Spirituality

- Positive living can also be achieved by addressing spiritual needs.
- Spirituality is an important resource that individuals use to cope with a chronic illness such as HIV infection.
- Spirituality offers a religious and an existential component encouraging us to find meaning in life, hope, self-transcendence, and rituals.
- Spirituality is a resource that PLHIV may find useful for coping with physiological and psychological challenges of the illness.
- It is important to remember that many PLHIV see their infection as a punishment from God and this belief needs to be addressed accordingly.
Techniques to Improve Positive Living

The lives of PLHIV can be definitely led in a positive way with multisectoral responses and interventions. These range from individual-oriented services to community empowerment programs, with involvement from different departments and agencies. The participation of PLHIV in designing, implementing and evaluation of the interventions is vital to their effectiveness.

1. Providing good HIV screening and diagnostic services
   - Laboratory capacity for detection and diagnosis.
   - Adequate set-up for providing results and counseling in a confidential, private manner.
   - Referral services should be widely available.

2. Counselling, psychological and social support
   - PLHIV should be encouraged physically, socially and spiritually so that they can live long. PLHIV should be encouraged to live positively through messages like, ‘Don’t worry about this disease, you will get better soon’, ‘Don’t worry, we are with you’. PLHIV should also be encouraged to engage in sporting activities, vocational training, and hobbies like gardening to keep fit and earn a living.
   (a) Counselling and psychological support
      - Psychological intervention for coping with the diagnosis and accepting one’s HIV sero-status.
      - Counselling to support development of individual plans of action.
      - Counselling after diagnosis and educating PLHIV help delay the onset of clinical manifestations and prevent re-infection.
      - Professional interventions for coping with severe emotional disturbances.
      - Adequate sources of spiritual support.
      - Multidisciplinary approaches such as meditation and other relaxation techniques help in positive living.
   (b) Social support
      - Financial support (insurance, loans, donations, subsidies).
      - Home-based care.
      - Referral systems (for legal, financial, educational, public administration concerns).
      - Assistance to orphaned children.
      - Advocacy and legal representation.
      - Food distribution and serving of meals.
      - Bereavement and funeral support.

3. Community education and participation
   - Community education can be provided by information, education and communication strategies to effectively improve positive living.
   - Community education can be achieved by distribution of pamphlets, posters, radio and television announcements, videos in waiting rooms, etc. to help PLHIV live positively.
   - HIV/AIDS education programs should be provided at schools and community centers.
Education for family members and caregivers should be provided by various programs and workshops.

Religious leaders and human resources personnel in private and public sectors should be sensitized on HIV. A supportive environment for PLHIV is needed in their workplaces.

Development of community support networks (PLHIV networks).

Distribution programs for condoms and lubricants.

4. Nutritional interventions

- A balanced diet keeps our bodies strong and our immune systems healthy, making it harder for us to fall sick.
- HIV-positive people are more susceptible to infections from food and water, so it is especially important to follow safe cooking guidelines and drink water that has been purified.
- Nutritional assessment.
- Nutritional counselling and education should include food safety.
- Plan for action to prevent weight and muscle mass loss.
- Dietary changes to address associated drug reactions.
- Provision of food supplements, if needed, but only in consultation with a doctor.

5. Living positively with HIV

Positive living can be promoted by PLHIV taking care of themselves as follows.

- Keeping a positive outlook in life, having plans, projects and dreams.
- Maintaining an active social life.
- Paying special attention to basic rules of good hygiene.
- Exercising adequately.
- Getting enough sleep.
- Avoiding stress.
- Eating well and avoiding alcohol, tobacco, foods that have been improperly preserved, potentially contaminated water, and food sold by street vendors that is exposed to contamination. Making sure that fruits and vegetables are thoroughly washed.
- Eating a balanced diet.
- Avoiding re-infection with HIV.
- Staying in close touch with one’s doctor and HIV advisor/counsellor.
- Staying well-informed about scientific advances in HIV/AIDS and about new local resources available.

6. Others

- Never agonizing on HIV status.
- Planning for one’s children and future.
- Considering the need for disclosure of one’s HIV status to marital/sexual/romantic partners. If disclosure has to be made, it should be carefully planned, as far as possible with back-up support from friends, healthcare providers and other PLHIV.
- Joining support groups (PLHIV networks) to share experiences, socializing with other PLHIV, and working on joint awareness and advocacy initiatives.