CHAPTER 13

HIV-RELATED PSYCHOLOGICAL DISORDERS

Abstract

The psychological reactions experienced by an individual to the news of HIV positive test result depends on factors such as available social support systems and pattern of coping with major stresses in the past. In order to avoid anticipated social stigma, some individuals deny reality or bear the additional burden of secrecy from family, friends, and colleagues. With the onset of symptoms and visible signs of illness, denial, and secrecy cannot be sustained as coping mechanisms. Some individuals strive to achieve a purposeful life, and associate themselves with self-help groups of HIV-infected persons. There is a need for ongoing guidance after pre- and post-test counselling sessions. Counselling sessions are also necessary when patients develop new symptoms. Anxiety and stress should be treated. The individual may be referred to organisations that provide counselling and support services. Persons involved in care of HIV patients may also face psychological stress due to the emotionally demanding task of giving bad news, fear of accidental occupational exposure to HIV, distressing manifestations of the disease, and a feeling of powerlessness at the limitations of some treatments. Hence, HIV care providers should take regular breaks, develop a range of professional and personal interests and relationships outside the workplace, recognise early signs of excessive stress and seek support, when necessary.

Key Words

Burnout, Closet homosexuals, Denial, Depression, Dichotomy, Frustration, Gays, Guilt, Impact on providers, Isolation, Secrecy, Social stigma, Withdrawal

13.1 – PSYCHOLOGICAL REACTIONS TO DIAGNOSIS

The reaction of an individual to the news of HIV positive test result involves a sequence of psychological reactions that may require specialist intervention. Diagnosis of HIV positive status precipitates a great amount of changes in life, which has been rated as equivalent to the death of a spouse or a prison sentence. Thus there is a need for pre- and post-test counselling sessions. Counselling sessions are also necessary when patients develop new symptoms. The individual's response may depend on factors such as social support system available to the individual and pattern of coping with major stresses in the past. These factors are also predictors of both physical and psychological illnesses (Cohen, 1988). The stages of psychological reactions have been studied in asymptomatic homosexual

men, but these are similar in heterosexuals and persons infected by non-sexual routes. All individuals do not go through these stages (Ross *et al*., 1989).

On receiving the news of HIV positive test result, the individual experiences emotional shock, leading to feeling of "guilt" (self-blame) or "denial" (refusal to accept the diagnosis). Due to denial, the individual may get the HIV test repeated at different laboratories hoping for a negative test result. Guilt about their high-risk behaviour (promiscuity or use of injecting drugs) is another source of psychological stress. Once the individual realises the truth, *frustration* sets in. If the individual knows others who indulge in the same type of high-risk behaviour but are HIV negative, the reactions vary from anger, distress, feeling of powerlessness, and blaming one's fate or destiny. "Dichotomy" is an issue to be tackled. People are seen as infected ("us") and non-infected ("them") and responded accordingly. For such persons, HIV status becomes the central defining issue in life. On realising the gravity of the situation and the ultimate outcome of the condition, the person may go into *depression*. Worry about social stigma leads to *withdrawal* and *isolation*. The individual may start worrying about his or her spouse and family members and may have fear of infecting others.

13.2 – DENIAL

Some individuals cope with early HIV infection by denying its reality. The onset of symptoms and visible signs of illness creates a situation of *disclosure* and denial is difficult to sustain as a coping mechanism. Dealing with loss of denial is equivalent to dealing with emotional shock at the time of diagnosis. If the diagnosis of HIV infection has not been revealed to family members and close contacts, it can create psychosocial problems, both at home as well as at the workplace, and aggravate the stress experienced by the patient.

13.3 – EFFECT OF SOCIAL STIGMA

Family members and close friends may not be aware of sexual habits of some male homosexuals (also called "gays"). These persons have been called "closet homosexuals". Such persons may not be able to share the news of their HIV positive test result with their family members and close friends. This leads to lack of social support that aggravates their stress. The social reality is that people generally react to HIV-infected persons with fear and prejudice. Homosexuals and drug users are socially marginalised and stigmatised. Irrespective of mode of infection, HIV positive individuals suffer from the prejudiced assumption that they may have been infected through "deviant" or illegal activities. This assumption challenges the social identity of persons who may have been infected by heterosexual contact or through medical interventions such as blood transfusion. Anticipation of social discrimination complicates the psychological response to the news of HIV positive test and affects the person's ability to cope.

It may damage self-esteem of HIV-infected persons and may cause or worsen feeling of depression. In order to avoid anticipated social stigma, some individuals bear the additional burden of *secrecy* from family, friends, and colleagues (Miller, 1987).

13.4 – LIVING WITH HIV

A great amount of courage is required to face a disease that seems to have no cure so far. Many HIV-infected people experience fear, anxiety, hopelessness, loneliness, and depression. Some patients accept their diagnosis and come to terms with their condition. During the time period between diagnosis and the onset of serious illness, some strive to achieve a purposeful life. They may test the reactions of others; look for other HIV positive persons for sharing and positive reinforcement (Miller, 1987). Group cohesiveness leads to altruistic behaviour and a feeling of belonging to the group. These groups usually have a positive attitude to being HIV positive and also have role models that are open about their HIV positive status. Some individuals select their sexual and other partners only from within the community of infected persons. This solves problems like fear of rejection by a prospective partner and of transmitting HIV to an uninfected partner (Miller, 1987). Though yoga cannot replace professional counselling, yoga techniques are known to help in reducing excessive fear and anxiety, and learning stress-coping skills. Meditation helps in self-awareness and in building inner strength through relaxation.

13.5 – ROLE OF THE DOCTOR

The infected persons experience considerable anxiety about becoming dependent on others for basic physical care and stress related to actual or anticipated discrimination or abandonment. Psychological reactions such as denial, anger, and depression that occur in HIV-infected individuals may result in lack of trusting relationship with health care providers and missed opportunities for prevention and treatment of opportunistic infections. Psychological reactions such as shock, denial, and depression also occur in family members and may affect their ability to care for the HIV-infected person. Hence, family members also need to be considered while managing the HIV-infected individual. It is the responsibility of the doctor to provide accurate HIV-related information, address and treat anxiety and stress, and refer the patient to organisations that provide counselling and support services (Miller, 1987).

It is essential that the patient be fully informed so that both the doctor and the patient make their decisions with full knowledge of the circumstances. Lack of rapport between the doctor and patients results in poor compliance with prescribed treatment, visits to multiple doctors who may use multiple drug regimens, and self-medication with traditional or alternative medicines that lead to interactions.

13.6 – SYMPTOMATIC HIV INFECTION

The emotional and psychological conflicts are related to changes in life circumstances caused by symptomatic illness and can be as varied as the symptoms themselves. The social support systems that worked well before the onset of symptoms may become irrelevant. The responses may include fear, anxiety, and uncertainty about dependence on others, depression, and suicidal ideas. The psychological state can affect the quality of life beyond the impact of physical illness. The patients and their family members usually experience these psychological problems during the phase of recovery, when investigations and medical interventions do not distract them. These problems may also manifest when the patient is discharged from the hospital. Hence, the family physician may have to provide patients and their family members with support and interventions that include: (a) information on likely opportunistic infections, (b) information on legal issues (Will, pensions, and power of attorney), and occupational issues (sick leave, loss of capacity to work), (c) psychiatric interventions including specific counselling, and (d) spiritual support. If the patient and family members are mentally primed to deal with symptomatic illness, the onset of symptoms may have a positive impact because they can prepare themselves for further significant changes in life. When HIV seropositivity is discovered late in the course of an illness, the psychological stress may be aggravated and coping becomes more difficult (Kelly *et al*., 1997).

13.7 – PSYCHOLOGICAL IMPACT ON PROVIDERS

13.7.1 – Psychological Stress

Persons caring for HIV patients may face psychological stress due to the emotionally demanding task of giving bad news such as HIV positive status and likelihood of death, fear of contracting HIV infection through accidental occupational exposure, the distressing nature of manifestations of the disease, increased scrutiny by consumer rights organisations and AIDS activists, and a feeling of powerlessness at the limitations of some treatments (Kelly *et al*., 1997).

13.7.2 – Burnout

"Burnout" refers to physical and emotional symptoms caused by task-related stress (Ross & Seeger, 1988). This condition is caused by working harder for long periods of time, without being able to set reasonable time limits. This leads to development of indifference and negative attitudes. Burnout may lead to feeling of lack of personal accomplishment; emotional exhaustion or emotional numbness, depression, and anxiety; antagonised relationship with patients; and estranged family relationships. Health care personnel should be aware of these problems and be able to take preventive measures and seek assistance if required.

13.7.3 – Coping Strategies: Dos and Don'ts

- Set limits to occupational commitment that one can take.
- Take regular breaks (clearly defined work-free time, holidays).
- Maintain personal interests such as hobbies, physical exercise, and relationships outside the workplace.
- Recognise early signs of excessive stress, and seek advice and support from friends and colleagues.
- Avoid using self-medication such as sedatives or alcohol to cope with symptoms of stress.
- Develop a range of professional interests to balance the intensity of occupational commitment and avoid professional isolation.
- Participate in institutional activities that promote healthy coping – continuing medical education (CME), in-service training, and team meetings (Kelly *et al*., 1997).

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