Summary

When the day breaks
With it,
Breaks my Heart
For who Knows?
The glorious morning
May be my last...

..........Geetanjali, HIV positive person
SUMMARY

Infectious diseases like malaria and tuberculosis burden the people around the world, lowering their productivity and weighing down already underdeveloped health care systems. A relatively new and more devastating epidemic—HIV/AIDS—has come along. It has swept a destructive path through sub-Saharan Africa and crept silently into some portion of populations in every country of the world. Also in India, under the shadow of continued controversy over the estimated size of HIV infected cases in the country, the attention has again been drawn on the burden of increasing HIV infections on the economic growth of the country. The epidemic emerged so rapidly that the political response and the planning strategies inevitably lagged behind the need. There is considerable heterogeneity in the epidemic pattern within the country; most states report HIV prevalence less than 0.5% among antenatal attendees while six states have prevalence among antenatal clinic women of 1% or more. However, because there is a long incubation period between HIV infection and development of AIDS counting, AIDS cases continually underestimates the scale of HIV infection. Twenty years after the first case of HIV infection in India was reported from Chennai in 1986, the virus has spread and according to revised estimates there are 3.1 million people presently infected, most of them in the most economically productive (15-49) year age group. Although the country has a low prevalence of just 0.35% of the adult population, the concern is that even a mere 0.1% increase in prevalence rate translates into over half a million additional HIV-positive cases. In addition, the epidemic is moving outwards, from specific “high risk” groups and urban centres to the general population and rural hinterland. The number of women infected is also steadily rising, with women accounting for approximately 39% of infections. Young people’s multiple vulnerabilities also make them more susceptible to HIV infection and today about 1/3rd of all AIDS cases in the country are amongst young people in the age group of 15-29 years.
Recent therapeutic advances have lowered mortality rates and transformed Human Immunodeficiency Virus (HIV) disease into a chronic condition (Kelly, Otto-Salaj, Sikkema, Pinkerton, & Bloom, 1998; Palella et al., 1998). Living with HIV/AIDS as a chronic illness, which like other serious illnesses intrudes on and reshapes a person's life and priorities, is a new and once unthinkable area for research. Such chronic illnesses do cause lot of stress due to agony, pain, stigma and discrimination issues attached to it. The impact of stress is not uniform; instead, the impact depends upon features of the social setting and upon characteristics of individual. Coping behaviours are important aspect of this stress process. Contemporary research on stress, coping, and adaptation includes the work Pearlin and Schooler (1978) who defined coping as “any response to external life-strains that serves to prevent, avoid, or control emotional distress” In exploring coping and adaptation to stressors, Pearlin and Schooler discussed the importance of social resources, psychological resources, and coping responses. Social resources include support systems such as friends and family. Psychological resources involve personality characteristics such as self-esteem (positive feelings about oneself), self-denigration (negative feelings about oneself), and mastery (feelings of control). Coping responses involve what individuals do during a stressful event, such as trying to change the stressful situation, or the meaning of the event. Further strides in the stress and coping research include the work of Lazarus and Folkman. Referred to as the transactional model, this approach proposes that stress involves the relationship between an individual and the environment. The transactional approach to stress and coping focuses on the concept of cognitive appraisal of the situation (Lazarus & Folkman, 1984). Cognitive appraisal involves individual assessment of a certain interaction with the environment of concern, for an individual's general well-being (Lazarus & Folkman, 1984). Primary appraisal involves evaluating the situation, and judging whether it is considered harmful, threatening, or challenging (Folkman & Lazarus, 1985). What is asked essentially is: “What is at stake”? "Do I have a goal at
stake, or are any of my core values engaged or threatened”? If the encounter is seen as irrelevant and unimportant to an individual’s well-being the encounter will be interpreted as non-stressful (Lazarus, 1999). Secondary appraisal involves answering the question “What can I do?” in response to a stressful situation deemed harmful, threatening, or challenging by a primary appraisal. Personal resources such as social support, physical health, and financial situation are assessed in preparation for a response to the perceived stressor (Folkman & Lazarus, 1985).

Although there is no consensus on the nature or number of coping responses, however, two general categories of coping are described in the literature: problem-focused, and emotion-focused. Problem-focused coping involves direct action, which seeks to change or eliminate the stressor. It involves two areas: preparation (information-seeking, planning) and action (problem solving, active coping). Problem-focused coping focuses on actions taken towards the stressor itself. Planning involves collecting and assessing information, and evaluating solution options for taking action. Seeking social support (instrumental) is also important in active coping, which involves requesting assistance from friends and family (financial, advice, or child-care) in order to help with solving the problem. Emotion-focused coping involves changing one’s emotional response to the stressor (Lazarus, 1999; Tamres, Janicki, & Helgeson, 2002). Emotion-focused coping often involves avoidance or distraction from stressors. A variety of activities, such as watching television, or leisure pursuits may be employed in order to avoid thinking about, and actively dealing with the stressor. Other emotion-focused techniques include: denial, isolation, rumination, wishful-thinking, self-blame, and seeking social support (emotional).

Different people may employ different types of coping behaviours, ranging from problem focused coping to emotion focused coping strategies. The choice of coping behaviour can moderate the degree of which
psychological distress results from social stress. Good coping skills can improve quality of life, and also strengthen the immune system. Moreover, understanding the role of personality in coping can broaden the person centred change efforts to encompass simultaneous growth in personal resources. There is a felt need to strengthen the psychological intervention by improving the counselling services being extended to PLHAs under professional settings where the clients may be facilitated for improving the coping strategies. Since, coping is one area of research to meet the health promotion and disease prevention of People Living with HIV & AIDS (PLHAs). Therefore, an inquiry into the utilization of effective coping strategies is crucial those living with HIV/AIDS. The present study entitled “Coping strategies among people living with HIV/AIDS - A psychological study” was hence undertaken with the following objectives and hypotheses.

OBJECTIVES:

1. To examine specific coping strategies in a cohort of HIV positive people and to see which coping strategy dominates in the target group.

2. To find out whether HIV positive people’s choice of coping response is a function of their more general personality dispositions (Extraversion, Neuroticism and Psychoticism).

3. To examine the contributions of number of psychosocial factors and coping in a cohort of HIV infected people’s well being and further to find out exact variance explained by each of these (psycho-socio factors and coping strategies) in predicting well being.

HYPOTHESES:

1. HIV infected people would adopt more of emotion focused coping strategies than problem focused coping strategies. As being infected with Human Immunodeficiency Virus (HIV) is highly stressful and uncontrollable state. Thus, the people living with HIV (PLHIV) will be
more passive in their coping efforts due to helplessness followed by an emotional outburst and even disbelief to HIV diagnosis (Lazarus & Folkman 1984).

2. There would be significant relationship between personal characteristics (age, sex, marital status); social (community, residential set up, perceived social support); economic (educational qualification, employment status, monthly household income) and psycho-therapeutic (period of diagnosis, number of counselling sessions attended, satisfaction with quality of counselling services provided) factors in coping response of HIV infected people.

3. The HIV positives would be high on extraversion scale of personality.

4. HIV positives would be low on Hope index. Since, HIV is a life threatening infection and it was assumed that such people typically may not expect much can be done about their health status (Phillips and Sowell, 2000).

5. The personality traits of HIV infected would be related to the type of coping strategy being used.

6. The coping responses adopted by the people living with HIV would be significantly predicted by their personality traits, level of hope, and socio-demographic characteristics.

7. The wellbeing of people living with HIV would be significantly predicted by personality traits, level of hope, type of coping strategy and their socio-demographic characteristics.

DESIGN:

Design of research is the blue print of study and incorporates variables to be studied, the mode of their manipulation, plan and procedure for data collection and analysis. The correlational design was adopted for
relating the coping strategies adopted by the HIV positive persons and their psycho-social characteristics. The relationships between various personality traits (extraversion, introversion, and neuroticism), hope, socio-demographic variables like age, income, education, marital status, educational qualification, employment status, monthly household income, community, residential set up, period of diagnosis, perceived social support, number of counselling sessions attended and satisfaction with the number of counselling services provided with the coping were examined among the people infected with HIV. Further, the relative contributions of all these variables along with different coping strategies were assessed in predicting the well being of the target population.

SAMPLE:

The target population of the present study was HIV infected people. The subjects were contacted through networks of positive people, Community Care Centres, Drop in centres, informal groups, etc. Owing to the difficulty of getting to the target population, the ones available from the possible sources were selected in the study. The self selected sample was initially restricted to 100 subjects in the reproductive age group of 15 to 49 years. But as the study progressed, researcher managed to reach out to a sizable sample of 247 HIV positive people in reproductive age group of 15 years to 49 years. The data put forth by National AIDS Control Organisation (2006) revealing approximately 90 percent of AIDS cases falling within most economically productive age group served as the basis of selection of this population as the target group of the study. Both males and females were included in the sample though the number of female participants was distinctly low.

The present study was conducted in National Capital Region and Delhi State since this region is hub of medical and care support services and caters to almost entire northern region (Haryana, Punjab, Rajasthan, Uttar Pradesh, Uttarakhand, Delhi etc.) of country. Furthermore, it is marked by heterogeneity and diversity of its population, in many spheres.
MEASURES USED:

(i) **Brief Cope Scale (Carver, 1997)**

The Brief Cope scale includes 28 items, which measure 14 conceptually differentiable coping reactions. The answer choices/response options ranged from 1 (I have not been doing this at all) to 4 (I have been doing this a lot). The scales include acceptance, active coping, planning, behaviour disengagement, denial, substance use, humor, positive framing, religious coping, self distraction, use of emotional support, use of instrumental support, and venting.

(ii) **Herth Hope Index (Herth, 1991)**

Hope was measured by using Herth Hope Index (HHI). The Herth Hope Index (HHI), is a 12-item adapted version of the Herth Hope Scale (HHS), The items of the scale were rated on a 4 point Likert scale. The responses range from strongly disagree to strongly agree.

(iii) **Eysenck's Personality Questionnaire-R (Eysenck and Eysenck, 1980).**

Three important personality dimensions: Psychoticism, Extraversion, Neuroticism were measures by means of 90 questions in this questionnaire. Since the personality questionnaires are subject to faking, EPQ-R had a lie scale comprising some questions intended to diagnose lying.

(iv) **PGI General Well Being Scale (Verma and Verma, 1989)**

This is a 20 item scale and takes little time to administer. It can be self administered or given verbally.

(v) **Socio-demographic data**

Socio-demographic characteristics were obtained using a demographic data form especially designed/developed for the present study. Participants provided information on age, sex, marital status, educational qualification, employment status, monthly household income, community, residential set up,
period of diagnosis, perceived social support, number of counselling sessions attended and satisfaction with regard to these counselling sessions was also acquired from the participants.

PROCEDURE:

The purpose of the study was to collect information on the coping strategies used by People Living with HIV/AIDS. Looking at the sensitivity of the issue dealt with certain ethical issues needed to be taken care of regarding the protection of rights of subjects participating in the research and organizations/ institutions facilitating the research. The researcher explained the nature and purpose of study to the target group. They were then requested to participate in the study. After establishing rapport with the subjects, an informed consent was obtained from them prior to survey. However, it needs to be mentioned that a lot of persuasion was needed to motivate them to be part of the present study. Though all the questionnaires/ inventories were self administered but for the sake of clarity with regard to the administration, the general instructions as well as each item in all the questionnaires were read out to them. The administration was completed at single time point.

RESULTS:

The data was analyzed by employing statistical tests viz. Pearson’s product moment correlation and Stepwise multiple regression. The statistical analyses revealed that:

1. People diagnosed with HIV infection used a mix of problem and emotion focused coping of which Acceptance was the most commonly used and Humor was the least used coping strategy. Therefore, the first hypothesis stating that HIV infected people would adopt more of emotion focused coping strategies than problem focused coping strategies has not been supported by the present findings.
2. Excepting Age which was correlated with only one coping strategy, other personal characteristics, social, economic and psycho-therapeutic factors were significantly related to the coping response of HIV infected people. Hence, the second hypothesis stating that There would be significant relationship between personal characteristics (age, sex, marital status); social (community, residential set up, perceived social support); economic (educational qualification, employment status, monthly household income) and psycho-therapeutic (period of diagnosis, number of counselling sessions attended, satisfaction with quality of counselling services provided) factors in coping response of HIV infected people has been supported by the present findings.

3. The people infected with HIV were found to have elevated extraversion score as compared to the other dimensions of Eysenck’s personality questionnaire. Therefore, the third hypothesis stating that the HIV positives would be high on extraversion scale personality has been supported by the present results.

4. The level of hope was found to be markedly high among the respondents. So the forth hypothesis stating that HIV positives would be low on Hope index has not been supported by the present results.

5. Out of three personality dimensions assessed in the present study, Extraversion was negatively correlated with turning to religion. It did not correlate significantly with any other coping strategy. Neuroticism positively and significantly correlated with acceptance, positive framing and planning. However, it was negatively correlated with emotional support. Psychoticism was positively correlated with seven coping strategies. Hence, the hypothesis stating that the personality traits of HIV infected would be related to the type of coping strategy being used has been partially supported by the present findings.
6. Regarding the socio demographic variables, *number of counselling sessions attended* predicted eleven out of fourteen coping responses, *perceived social support* predicted nine coping responses, *Community* and *employment status* predicted eight and seven coping responses respectively. *Sex* was significant predictor of only one coping response. As for personality, *psychoticism* predicted eight coping responses and *neuroticism* was significant predictor of seven coping responses whereas *extraversion* significantly predicted two of the coping responses. *Hope* was also found to be strong predictor of humor coping response. Therefore, the sixth hypothesis stating that the coping responses adopted by the people living with HIV would be significantly predicted by their personality traits, level of hope, and socio- demographic characteristics has been supported by the current study.

7. Out of the three personality dimensions, *extraversion* and *neuroticism* significantly predicted the wellbeing of HIV infected people. The other significant predictors of wellbeing were *hope*, *coping strategies like self-distraction* and *venting* and socio-demographic variables-*community*, *number of counseling sessions attended*, *period of diagnosis* and *satisfaction with the quality of counseling services*. In this way, the hypothesis stating that the wellbeing of people living with HIV would be significantly predicted by personality traits, level of hope, type of coping strategy and their socio- demographic characteristics has been supported by the present findings.

So, in brief it can be stated that Hypotheses second, third, sixth and seventh have been supported, the first and fourth hypotheses have not supported by the present findings, whereas hypothesis fifth has been partially supported by the present results.