

# Mediators affecting caregiving of people living with HIV/AIDS

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Presence of family members as caregivers has helped to identify HIV-related medical conditions and bring it to the notice of the health care personnel. Informal caregivers now not only monitor drug adherence but also provide psychological support and care to the HIV infected which has helped in improving their productivity and quality of life. As the informal caregivers are not prepared for the HIV caregiving, neither trained nor compensated, they experience psychological distress which results into symptoms of depression and anxiety. In addition, lack of support, stigma and discrimination heightens the psychological distress experienced by the informal caregivers. Studies on etiology of depression and anxiety indicate a number of demographic variables as predictor variables. The study aims to investigate the relationship of demographic variables such as age, education, and income affecting the caregivers' depression and anxiety. The sample consisted of 112 informal caregivers from NGOs in Mumbai. The results show that demographic variables such as education and income were associated with elevated levels of depression and anxiety. However, there was no significant relationship found between age and caregiver's depression and anxiety.

Keywords: informal caregivers, depression, anxiety, education, age, income

Care of HIV infected persons require a lot of physical and mental energy. The extent of care provided by the informal caregiver depends on the stage of infection. In the early stages of infection the HIV infected person does not manifest any overt symptoms, thus is in the asymptomatic stage, care extended to the HIV infected is minimal as the person is healthy and can perform self care activities. As the immune system weakens the person is open to various infections such as simple flu, or severe infections such as tuberculosis or herpes. During this symptomatic stage the infected person may suffer from fatigue, vomiting, diarrhoea, and weight loss which render him/her incapable of performing self care activities, and thus require help from others for daily living activities. As the informal caregivers are not prepared for the HIV caregiving, neither trained nor compensated, they experience psychological distress which results into symptoms of depression and anxiety. Besides, as HIV is considered as a self-inflicted medical condition, compassion and emotional support from other family members, relatives, and friends is practically zero. In addition, stigma and discrimination heightens the psychological distress experienced by the informal caregivers. Family caregivers have decreased the burden of health care system by providing long term care to the chronically ill person and being a link between the health care professional and the sick person. This has resulted in identifying symptoms of the illness before it turns severe and monitoring the medication regime. Caregiving literature indicates that a number of caregiver characteristics are associated with caregiving burden (Dura, Stukenberg, & Kiecolt-Glaser, 1990; McCullagh et al., 2005; Thompson et al., 1990). More recently, it has been acknowledged that caregivers' own characteristics may play a major role in determining how burdensome and stressful they find their role. These characteristics include such things as gender, availability of support systems, and relationship to patient, as well as the way the caregiver perceives the patient's symptoms (whether illness related or deliberate) and his or her attitude and behaviour toward the patient. Understanding the origins of caregiver burden has broad

implications both in terms of the well-being of caregivers and the quality of support that patients receive (Donaldson & Burns, 1999).

The present study investigated demographic characteristics of the informal caregivers such as age, education, and income affecting the caregivers' depression and anxiety as a result of caregiving process.

## Method

### *Instruments*

*The Beck Depression Inventory-2nd version (BDI-II)*: BDI is a 21-item self-report inventory. Each item is scored from 0 to 3 representing the severity of depressive symptoms. The BDI-II is the latest version of the BDI with the revision aimed at making the scale more consistent with DSM-IV criteria for major depressive disorders (Beck, Steer, Ball, & Ranieri, 1996). The BDI is the most widely used self-report scale in both clinical and nonclinical populations, and it has demonstrated good psychometric qualities (Beck & Steer, 1984; Beck, Steer, & Garbin, 1988b). In this study, Cronbach's for the BDI-II was 0.92 in the anxiety sample, and 0.90 in the student sample.

*Spielberger's State and Trait Anxiety Inventory (STAI)* (Spielberg, Gorsuch, & Luchene, 1970), only the State anxiety part of the scale was used to measure anxiety

*Socio Demographic Scale* was designed to gather in-depth information about the demographic variables.

### *Procedure*

After obtaining permission to conduct the study from staff of the concerned NGOs in Mumbai and informal caregivers, each caregiver was interviewed individually in a private area of the clinic and then tools selected for the study were administered.

## Results and Discussion

The average age of the caregivers was 34.9 years, ranging from 18 years to 60 years. The informal caregivers who participated in the study, 27% were between 35-39 years of age; 24.10% between 30-34 years; 21% in the age group of 25-29 years, and 16.07% were in the age group of 40-44 years. Nine of the caregivers were above 50

years of age. The age profile indicates that majority of the informal caregivers were young and in the productive stage of their life. Forty two caregivers were taking care of the infected person since more than four years and 107 caregivers were staying with the caregivers. Pearson product moment correlation was performed to find the relationship between age of the informal caregiver and level of depression and anxiety of the caregivers. The correlation value between caregivers' age and depression was 0.35 and the age of caregivers' and anxiety was .092, both the  $r$  values indicate a positive and small relation between age of the caregiver with depression and anxiety (Refer Table 1). The results were not in the expected direction as the  $r$  values were not significant at the accepted level of significance. It was expected that younger caregivers will experience more care burden than older caregivers, as the younger caregivers are also saddled with the responsibility of bringing young children and looking after the house and other family errands, in addition to caregiving responsibilities. Besides, as the younger caregivers are in such a stage of life where they have lot of commitments towards children and their education, HIV caregiving will now drain their attention, energy, and financial resources towards the care and support of the infected person. The younger caregivers will also have expectations of better future when their children complete their education, however, an unexpected diagnosis of HIV may cut short their dreams and ambitions for a bright future. Older caregivers on the other hand, are at such a stage of life where they have fulfilled their responsibilities towards their children. They have their grown-up, employed children to fall back in face of the crisis which they are currently facing. Besides, their children are mature enough to understand the implication of HIV/AIDS, and thus provide care and support to the infected person. The following reasons were specified for insignificant relationship between the age of the informal caregiver with depression and anxiety: the informal caregivers receive support from the staff of the NGOs; though they belonged to nuclear families, support from extended family in form of financial support was given by parents, friends, and relatives. The present finding was in line with other similar studies on chronic illness (Dura et al., 1990; McCullagh et al., 2005). On the other hand some studies quote consistent relationship between caregiver's age and burden. Cooper, Balamurali, & Livingston (2007) in a study on caregivers of dementia found association of caregiver's age with caregiver anxiety levels. Land, Hudson, & Stiefel (2003) revealed that younger age, greater role-related stress, and low self-esteem significantly predicted caregiver depression.

*Table 1 : Correlations of Demographic characteristics of the Informal Caregivers and level of Depression and Anxiety*

| Demographic characteristics | Depression | Anxiety |
|-----------------------------|------------|---------|
| Age                         | .035       | .092    |
| Education                   | -.291**    | -.207*  |
| Income                      | -.304**    | -.139*  |

Note. \*\* Correlation is significant at the 0.01 level

In terms of educational qualification, in a sample of 112 informal caregivers it was observed that 25.0 percent were illiterate, 33.92 percent did not complete secondary school education, and only 8.03 percent were undergraduates. The factor of education was investigated to find its relationship with caregiver's depression and anxiety. Education was found to be significantly inversely related to depression ( $r = -.291$ ,  $p < 0.01$ ), and anxiety ( $r = -.207$ ,  $p < 0.05$ ) (Refer Table 1). It indicates that the more educated the informal caregivers, lower the level of depression and anxiety or vice-versa.

The education level of the informal caregivers is an important correlate of caregiving burden as it helps the family members to become aware of the causes, transmission, and prevention of the incurable infection. It also helps the patient and the family member realize the importance of adherence to HIV medication regime so as to keep the opportunistic infections under control. Knowledge and information of HIV/AIDS also helps to bring about attitudinal change in the caregivers regarding HIV/AIDS. Fear, stigma and discrimination associated with the disease can also be positively handled by the HIV affected individuals and their caregivers. Lastly, education helps to provide training and intervention strategies to reduce the caregiving burden. Thus the level of education may play an important role in bringing about health-related behaviours which will directly help both the HIV infected person and the informal caregiver to engage in activities that will help in the prevention and control of opportunistic infections and also promote the psychological well-being of the caregiver and care recipient. Other studies also parallel these observations (Fuh et al., 1999; Lewinsohn & Hoberman, 1988). Li, Lambert, and Lambert (2007) in their study on caregivers of Schizophrenia report that the best predictor of family caregivers' burden was found to be their level of education.

Income as a mediator of caregiving stress was also studied. Majority of the informal caregivers were self employed working as maids and selling flowers (21.42%) and some employed full time (21%). Eleven percent were tradesman/business, and 32% were housewives. Majority of the informal caregivers (55%) had an income below Rs. 3000; 29% between Rs. 3000-Rs. 5000; and 13% between Rs. 5000-Rs. 10,000; and only 5% of the caregivers had an income of above Rs. 10,000. It was observed that income was significantly inversely related to depression ( $r = -.304$ ,  $p < 0.01$ ) and anxiety ( $r = -.139$ ,  $p < 0.05$ ). The findings indicate that as the level of income decreases, the symptoms of depression and anxiety increases or vice-versa. The participant of the study belonged to poor families, the medical facilities were provided free by municipal hospitals and other necessities were provided by the NGOs. However they had to spend on their own on transportation and also had to take leave from their work place to accompany the patient. Lower income is associated with more hardships, reduced resources and more conflicts. The higher the financial status of the family, better the infected person will be provided in terms of nutritious food, regular check-ups and expensive medications. High income also helps the caregiver cope up with demands of other family members, especially the demands of the growing children. When the caregiver, especially a woman is not able to provide for her children's education and other necessities, the feelings of guilt and frustration also goes up, leading to high levels of depression and anxiety. The present finding of the study was found to be in line with other studies. Dilip and Duggal's research (as cited in Mehta & Gupta, 2005) conducted in India found that the burden of health care in India is inversely related to economic status of the household, resulting in poorer households in becoming victims of an inefficient health care system. Studies conducted in different states of India reveal that the poor had greater problems in accessing treatment, leading them to adopt various coping mechanisms like selling of assets and taking out loans (Mukhopadhyay et.al. 2001 cited in Mehta & Gupta, 2005). Related studies indicate that caregivers with higher income have a better physical health (Pinquart & Soresen, 2007) and low income caregivers was related to depressive symptom score (Flaskerud & Lee, 2001; Land et al., 2003; Lewinsohn & Hoberman, 1988; Turner & Catania 1997). Krishna et al.

(2005) reported intense degree of burden due to financial difficulties as a consequence of HIV infection. They incurred debts for treatment and travel expenses. Providing nutritious food to the people living with HIV/AIDS was yet another problem these families had to face. In a study by Knowlton (2003) found that primary HIV supporter's reported care provisions was associated with their financial resources. Their results suggest that programs are needed to bolster network financial resources of disadvantaged populations affected by HIV to promote and sustain their informal HIV caregiving.

To conclude, it is pertinent to pay attention to demographic variables such as age, education, and income while designing treatment and intervention programs, which may be resourceful to both the caregiver and care recipient.

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