

# Level of Mental Health : A Study of Caregivers of HIV Infected Children.

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**ABSTRACT:** : *In common practice, the patient's caregiver is often overlooked, but it is essential to understand the importance of a caregiver in the management of a chronic disease. Sometimes caregiver can become overwhelming, physically and emotionally challenging and isolating. The present study aims to study the level of mental health of care givers of HIV patients. To measure their mental health, The Zarit Burden Interview was used. Study was conducted on 25 caregivers working in an NGO for HIV infected children. The results show that majority of caretakers scored high on the scale. High score correlates with higher levels of burden and poor mental health. Some suggestions are addressed for the caregivers so as to effectively take care of themselves while maintaining their responsibility to the care recipient.*

**Key Words:** *Care givers, Mental health.*

## Introduction

A care giver is an individual who helps with physical and psychological care of a person in need. As in the case for most caregivers, they are often family members, and they are usually unpaid. Caregivers can be called upon to provide a wide variety of assistance with activities of daily living, including bathing, toileting, dressing, transferring, cooking, eating, medications and managing at home or in institution. Care giving for a loved one with a chronic condition can be profoundly fulfilling as individuals often move closer together when challenges arise.

**Mental health:** Mental health is defined as the level of psychological well being or an absence of mental illness. It is the state of someone who is "functioning at a satisfactory level of emotional and behavioral adjustment. From the perspectives of positive psychology or of holism mental health may include an individual's ability to enjoy life and to create a balance between life activities and efforts to achieve psychological resilience.

As the demands increase physically, emotionally and cognitively for the care recipient, often less time is available to be devoted to the care giver's own needs, the children's needs, the home and the career. Thus, caregivers often feel a significant demand and burden to their own endurance and coping mechanisms. Caregivers commonly report a plethora of their own physical and psychological symptoms.

## Impact on the care giver

Individuals and families living with chronic neurological conditions deal with the kinds of care that they have not anticipated. Care taker faces emotional, psychological, physical and financial challenges. Sometimes it can be very lonely and frightening feeling.

**Impact on Social Relationships:** Care taking is a time-consuming affair. The person has to manage with decrease resources of time, energy and finances. Relationship with other family members and close friends may be neglected as increasing energy is directed to care provision

**Impact on Physical and Psychological health:** The physical well being of caregivers is often compromised. Care givers often neglect their routine health care needs, including health maintenance and treatment for their own health condition. Managing their own physical and psychological medical condition is usually low priority for caregivers.

**Emotional Impact:** When caregivers find themselves in a very real and unavoidable way with fewer opportunities to regain positive emotional energy, negative emotions understandably emerge. These emotions for caregivers can range from anger, to depression and regret at their own weakness, to a deep sadness about the loss of the life they had hoped and planned for as an individual. Grief is a normal and healthy emotion.



Caring for someone with chronic illness can lead to decreased quality of life, a decline in psychological health, increased stress, depression and anxiety.

### **Review of Research Literature**

Ma Teresa Gonzalez, Salvador, Celso Arango et.al. (1999) conducted research on the stress and psychological morbidity of the Alzheimer patient caregiver. They found that when compared to control, stress and psychological morbidity were higher in caregivers. Behavioural symptoms and impairment in instrumental activities of daily living were associated with care giver stress. Length of care was associated with caregiver psychological morbidity.

Hsing - Yi -Chang, Chil - Jun Chiou, et.al. (2010) opined that caregivers providing care to chronically ill are potentially at risk for caregiver burden and declining physical and psychological health.

Jung - Won Lim, Brad Zeback (2004) indicated that stress related variables are possible predictors influencing caregiver's quality of life.

Pauline Boss, Wayne Caron et.al (1990) concluded that the more a caregiver perceives a patient as psychologically absent, the less masterful and the more depressed he or she is.

In a research conducted by Richard Schulz, Paula R Sherwood (2008) on physical and mental health effects of family caregiving found that care giving role can be stressful and burdensome. Care giving has all the features of a chronic stress experience. It creates physical and psychological strain over extended periods of time and is accompanied by high levels of unpredictability.

David E Biegel, Sharon E Milligan, Patricia L Putnam (1994) concluded that lower the amount of perceived support from family members the higher is the level of overall caregiver burden.

Li-Yu Song (1997) conducted a study on predictors of depressive symptomatology among lower social class caregivers of persons with chronic mental illness. The results indicated that higher level of client's problems and insufficient support from mental health professionals related to the care giving role were associated with higher levels of caregiver depressive symptoms.

William E Haley, Ellen G Levine, S Lane Brown (1987) found that stress, appraisal, coping and social support are predictors of adaptational outcome of dementia caregivers.

**Aim:** The current study examines the Level of Mental health of Caregivers of HIV infected patients.

### **Materials and Methods**

**Sample:** A sample of 25 care takers working in an NGO for HIV infected children were taken. An informed consent was taken from the caregivers before including them into the study.

#### **Tool Used:**

- 1) The Zarit Burden Interview: a short 5 scale screening interview with 12 questions.

### **Results and Analysis**

The individual scoring of all 25 care givers show that all have scored high on questionnaire, (range 42 -46). It denotes that somewhere they are burdened and it reflects in their mental health.

**Discussion**

The result of the above study indicate that mental health care givers of HIV patients is not very good. Care giving not only has an impact on physical illness but also mental illness of individual although the kind and amount of impact may vary in both. The majority of caregivers experience significant deterioration in their mental health (Barer & Johnson 1990). The survey by Australian Bureau of Statistics (ABS 1998) found that approximately 30% of caregivers reported that their wellbeing has been affected by care giving and that they were often worried or depressed. Care gives burden, depression and life satisfaction have been identified as discrete aspects of caregivers well being by O' Rourke & Tuokko (2003). Cummins and Hughes (2007) also found that well being decreases linearly as the number of hours spent caring increases and caregivers are more likely to be experiencing chronic pain. Schulz & Sherwood (2008) also establishes the determinable physical effects of care giving are generally less intensive than psychological effects. Negative emotional consequences of care giving can lead to dysfunctional coping skills.

Working with HIV infected children is all the more stressful, caregivers are not only concerned about their own health and possible infections but become overly sensitive when they see the deteriorating physical health of children they take care of.

Suggestions for Caregivers to Improve their Mental health and to avoid Burnout

- 1) Become educated about the disease: The more they know about the disease, the more empowered and more comfortable caregiver is.
- 2) Take care of oneself: As flight attendant say "you must put on your oxygen mask before putting on the mask of others". If the caregiver is himself emotionally, physically or spiritually unhealthy he will not be able to help any one else.
- 3) Practice healthy living: One is more capable of being a help to others when one eats healthy, balanced diet, exercise regularly and is involved with one's own interest and get enough sleep.
- 4) Acknowledge Emotions: If a care gives sometimes feel hopeless, worthless helpless, sad, anxious or fearful, he should acknowledge these emotions. These are all normal reactions to situations.
- 5) Allow for healthy expression of feelings: Caregiver can seek help of mental health professional to vent out his negative emotions and feelings.

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