

Research Article

# Experiences and Coping Strategies of Primary Caregivers of People Living with HIV (PLHIV)

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## A B S T R A C T

**Introduction:** HIV infection is a global pandemic that continues to escalate in several countries worldwide. United Nations and World Health Organization reported that the global figure of people living with HIV (PLHIV) ranged between 30.6 and 36.1 million in the year 2007. The present study was conducted to assess the level of experiences and coping strategies among primary caregivers of PLHIV.

**Method:** A descriptive research design was adopted to assess the level of experiences and coping strategies among primary caregivers of PLHIV. About 60 primary caregivers of PLHIV were selected from District Hospital Chitradurga. The convenient sampling method was used to select the subjects.

**Results:** The result revealed that most of the primary caregivers of PLHIV had no unusual experiences (76.67%) and good coping strategies (70%) while caring for the PLHIV.

**Conclusion:** Efforts should be made to educate individuals about the non-stigmatising fact and primary prevention. Good nursing practice and nursing education must also be included.

**Keywords:** Experiences, Coping Strategies, PLHIV, Primary Caregivers

## Introduction

HIV is the shorthand for the virus that causes immunodeficiency in humans. HIV targets the immunological system of the body. The immune system typically produces antibodies and white blood cells to combat germs and viruses. The cells that fight infections are known as T-cell lymphocytes. HIV destroys all T-cell lymphocytes in a person months or years after infection. The immune system's ability to protect the body from illnesses and cancers is weakened as a result. A number of diseases may arise, and these opportunistic infections prey on the body's compromised immune system.<sup>1,2</sup> "The cognitive and behavioural attempts made to master, tolerate or reduce

external and internal demands and conflicts among them" is the definition of coping. Confrontive coping, sometimes referred to as problem-focused coping, is the process by which an individual determines what caused an event and then comes up with appropriate ways to deal with it.<sup>3</sup>

When it was discovered that families were finding it difficult to manage the responsibilities of caring for people living with HIV on their own, home-care programs were launched in North America and Europe. Those who give PLHIV patients nursing care and practical assistance at home support are known as primary caregivers. These people are usually the patients' parents, siblings, partners, or friends. PLHIV receive financial support, emotional and physical nursing care,

and from these people despite their lack of professional expertise in caring for the terminally ill. In severe situations, such as those involving stages III or IV of the disease, these caregivers may be required to provide services such as bathing the patient, shopping for them, cooking meals, giving them medication, and driving them to appointments.<sup>3</sup> Mcgrath and colleagues interviewed families who had one or more adult members with PLHIV in Kampala, Uganda, and found that PLHIV had a direct impact on family functioning including diminishing mobility, negatively impacting the family and economic well-being. These outcomes caused heavy burdens for all family members.<sup>4</sup>

Caregiving is a mentally and physically demanding task that takes its toll, not only on aching muscles and bones but also on the psyche and spirit. The caregivers need help to maintain quality of care and a positive outlook towards PLHIV. Many caregivers go through periods of stress, depression, and frustration. These are normal human responses. Caregivers who receive regular emotional support are much more able to handle difficult decisions and situations and to help clarify the needs of care receivers.<sup>5</sup>

## Materials and Methods

A descriptive research design was used on 60 primary caregivers of PLHIV, selected by convenient sampling technique in a District hospital, Chitradurga. The study was conducted from October 1, 2011 to October 30, 2011. A three-point rating scale with 20 statements for each section was selected. The experiences and coping strategies were assessed using a structured interview schedule. The experiences and coping strategies questionnaire consisted of 20 items and the range of the score was 0–40. The scores of 31–40 indicated good experiences and good coping strategies, scores of 11–30 indicated nothing unusual experience and medium coping and scores of 0-10 indicated bitter experiences and low coping strategies.

The data analysis was done with the help of descriptive and inferential statistics. The statistical tests used were mean, mean percentage, standard deviation, and chi-square test.

**Table I. Characteristics of Study Subjects**

(N = 60)

Characteristics of Subjects	Frequency	Percentage
<b>Age of caregivers (in years)</b>		
• 20–30	23	38.33
• 31–40	32	53.33
• > 41	05	08.33
<b>Gender</b>		
• Male	24	40.00
• Female	36	60.00
<b>Age of patients (in Years)</b>		

• 25–35	34	56.66
• 36–45	22	36.66
• 46–50	04	06.66
<b>Education</b>		
• Primary	25	41.66
• Up to 12th	25	41.66
• Degree and above	10	16.66
<b>Religion</b>		
• Hindu	46	76.66
• Muslim	09	15.00
• Christian	04	06.66
• Others	01	01.66
<b>Occupation of caregivers</b>		
• In-service	11	18.33
• Business	13	21.66
• Agriculture	11	18.33
• House maker	25	41.66
<b>Duration of contact with the patient (years)</b>		
• 0–10	56	93.33
• 11–20	03	05.00
• > 20	01	01.66
<b>Type of family</b>		
• Nuclear	26	43.33
• Joint	34	56.66
<b>Number of children</b>		
• 1	17	28.33
• 2	27	45.00
• 3	16	26.66
<b>Place of residence</b>		
• Rural	34	56.66
• Urban	26	43.33
<b>Family income (monthly) (INR)</b>		
• < 5000	19	31.66
• 5001–10000	34	56.66
• > 10000	07	11.66
<b>Relationship with the patient</b>		
• Wife	25	41.66
• Husband	09	15.00
• Mother	14	23.33
• Father	11	18.33
• Brother	01	01.66

Table 1 shows that more than half of the subjects (53.33%) were 31–40 years old, among which most of them (36, 60%) were females, and only a few (10, 16.66%) were

educated with a degree and above, 76.66% belonged to Hindu religion. Most of them were housewives (25, 41.66%) and 56 (93.33%) had a contact duration of 0–10 years. It is noticeable that there are about 34 (56.66%) subjects lived within the joint family. Most people lived in rural areas (34, 56.66%) in which most of the people (34, 56.66%) earned a family income of Rs 5001–10000 and around 25 (41.66%) were wives of the patient.

**Table 2. Levels of Coping Strategies Used by Primary Caregivers of PLHIV**

(N = 60)

Levels of Coping Strategies	No. of Caregivers	Percentage
Used by Caregivers of PLHIV		
Good	11	18.33
Medium	42	70.00
Low	07	11.67
Total	60	100

As given in Table 2, the coping strategies of the primary caregivers were good, medium, and low, among which 42 (70%) caregivers had medium coping strategies. About 7 (11.67%) caregivers had low coping strategies and around 11 (18.33%) caregivers had good coping strategies.

**Table 3. Types of Experiences Expressed by Primary Caregivers of PLHIV**

(N = 60)

Types of Experiences	No. of Caregivers	Percentage
Good	08	13.33
Nothing unusual	46	76.67
Bitter	06	10.00
Total	60	100

Table 3 reveals that 46 (76.67%) caregivers had average experience, about 6 (10%) caregivers had bitter experience and around 8 (13.33%) caregivers had good experience.

## Discussion

PLHIV have had a great impact on society both as an illness and as a source of discrimination. So, it's a very great challenge for the primary caregivers of PLHIV to deal with. The findings in the present study show that the experiences of the primary caregivers were good, average, and bitter. Among the participants, 46 (76.67%) caregivers had average experience, about 6 (10%) caregivers had bitter experience and around 8 (13.33%) caregivers had good experience. The study findings are correlated with another research study conducted on caregivers of PLHIV. A study on care burden and self-reported health status of informal women caregivers of PLHIV in Kinshasa found

that the burden of care for these women included high stress levels, severe levels of isolation, low self-reported health status, and high levels of reported unhappiness. 97% of spouse caregivers said that taking care of PLHIV was difficult and 89% reported that caregiving of PLHIV was very stressful. Although most family caregivers had to deal with these negative impacts, some caregivers reported that they had positive experiences such as increasing their own emotional strengths and reducing family conflict.<sup>6</sup>

The study findings on coping strategies of the primary caregivers reported that 42 (70%) caregivers had medium coping strategies, about 7 (11.67%) caregivers had low coping strategies and around 11 (18.33%) caregivers had good coping strategies. The study findings are consistent with another research study conducted on caregivers of PLHIV which revealed that the majority of the women had financial problems following this devastating diagnosis. The women also reported the role strain and increase in caregiver burden.<sup>7</sup>

## Conclusion

The present study revealed that about 10% of primary caregivers have bitter experiences while caring for the PLHIV, 76.67% of primary caregivers have an average experience while caring for the PLHIV and about 13.33% of primary caregivers have good experiences while caring for the PLHIV. Similarly, 11.67% of primary caregivers have low coping strategies while caring for the PLHIV, 18.33% of primary caregivers have medium coping strategies while caring for the PLHIV, and 70% of primary caregivers have good coping strategies. Hence the study recommends that efforts should be made to educate individuals about the non-stigmatising fact and primary prevention. Good nursing practice and nursing education must also be included.

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**Conflict of Interest:** None

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