

### WORLD JOURNAL OF PHARMACEUTICAL RESEARCH

SJIF Impact Factor 5.990

Volume 4, Issue 11, 796-802.

Review Article

ISSN 2277-7105

# IMPACT OF HIV/AIDS: A MULTIDIMENSIONAL VIEW, COPING STRATEGIES OF CAREGIVERS AND IMPLICATIONS FOR THE HEALTH CARE PROFESSIONALS- A REVIEW.

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Article Received on 12 Sept 2015,

Revised on 04 Oct 2015, Accepted on 26 Oct 2015,

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#### **ABSTRACT**

HIV/AIDS diagnosis and its disclosure causes a spectrum of changes and challenges in the family structure, socioeconomic dimension of the family, it also differs based on the infected individual and their coping strategies. Definitely it burdens the health professionals in order to understand their specific response to the threat and to plan, implement relevant care to overcome it and to help the individual to lead a productive life.

**KEYWORDS:** Hiv/Aids, Family Impacts,Socioeconomic Dimensions, Coping Strategies, Health Professional.

**INTRODUCTION**: HIV / AIDS is a major threat or challenge to the humanity. It is also viewed as a leading cause of burden for humanity.

Especially which the children are affected, means, it will arrest the manpower of the society. The emotional turmoil begins from the moment it is diagnosed as "HIV/AIDS". If an adult or a child in a family is diagnosed as HIV/AIDS, it will naturally influence the child whether the child is positive or not.

# IMPACT OF HIV/AIDS ON STRUCTURE OF THE FAMILY and Issues on specific population Single parent families/women and HIV/AIDS.

HIV / AIDS also contribute towards the raise of single parent families because of death of one adult due to AIDS by deserting their family after knowing the positive status of their partners. It also causes female headed households very commonly young widows living with their small children and elderly grand parents. Also paternal death causes a negative impact

on child development and paternal survival in protective and plays vital role in maternal management. The impact of HIV/AIDS is more among in women in many ways, such as, their vulnerability for the infection, caring the sick, death of spouse or children, isolation by the society, refusal of family asset, refusal or loss of job, even these factors forces her to commit suicide or indulging in survival sex. Studies showed that Male positives were accepted, taken care by their spouses, whereas more percentage of females were discriminated by neighbors, relatives, and friends even at workplace because of factors like customs, morals, and taboos. [1,9,11]

#### Grand parents headed households / The elderly and HIV/AIDS

Grandparents are compelled to take up the responsibility of family and grand children after the mortality of their adult children. They also become emotionally and economically burdened.<sup>[1]</sup> A study conducted by Isaranurugs (2009) reveals about 87% of the children were taken care by their grandparents.<sup>[6]</sup>

### Child headed households and children. [1,3,8]

Nearly 50% of the HIV infected children were short and 42% were underweight and their emotional development scores found to be less. It impacts them in two major ways as a disease it infects them and it kills their parents. Shah J (2008) found in a study at a tertiary hospital in India showed that 40% of the infected children were orphans and their mean age ranges from 3-10 years. The children whose parents died because of AIDS are double time burdened not only losing their love, care and support but their sources of support like land and housing etc. reduces their standard of living, makes them poor, malnourished prone for infection or for opportunistic infections and increases the number of dropouts from schools to take care of sick parents and other siblings or denied schooling, denial of health care, places them at risk for begging, theft, child labor, child abuse, risk to become juvenile delinquent. There are evidences of orphaned children living near to their parents tomb or under the trees in the graveyard because of social ostracism.

The under-aged children are propelled to generate money, because of the compulsion to play the role of the head of the family to take self care, younger siblings,look after the sick parents and caring for elderly grandparents. It positively impacts their maturity, personal growth whereas negatively it causes physical fatigue, observing multiple deaths in the family, loss of family support, psychological fear, not developed enough to express their grief,, dropout from the school, sometimes they are diverted to perform some socially undesirable activities.

#### **Extended family**

When the dependency and burden is more the number of individual are fewer to generate the money, the extended families become an invaluable support.<sup>[1]</sup>

#### No family-Orphans

While the children not having grandparents and external family support the death of both the parents due to HIV / AIDS makes the children as parentless a study reports about 49% were orphans.<sup>[1,5]</sup>

### IMPACT ON THE SOCIO-ECONOMIC DIMENSION OF THE FAMILY Financial burden

If the individual having AIDS is the earning member of the family becomes too ill, the expenditure becomes more. The care giver's burden increases even financially in order to provide nutritious food, medications, to visit healthcare centers and to meet the expenses associated with deaths. It becomes a cause of poverty by forced dropouts from schools, refusal of family assets, altered family structures and by marginalization of the people living with HIV/AIDS and family.<sup>[2,10]</sup>

#### **DEPENDENCY**

The number of people living with HIV/AIDS increases the dependency on the unaffected family members. The dependency may be either partially or totally for economic and emotional aspects. If the person living with HIV/AIDS shoulders the financial demands of the family compels the other family members to make some earnings for the family In turn it will influence the self-esteem of the individual and the family members. It also increases their dependency towards the social organizations for better coping, treatment, financial aid, and seeking any sort of assistance for the children's education and future.<sup>[1]</sup>

#### **STIGMATIZATION**

The people living with HIV/AIDS naturally experience stigma, but marginalization of the family and ostracism adds strain for the care giver and family. It causes the feeling of isolation, negligence in social gatherings, even discrimination in working places and in their community. A study showed that Maximum number of patients were discriminated by friends (71.01%) followed by discrimination at workplace (67.12%), by neighbors (56.14%), and by relatives (43.80%). [1,9]

#### **EMOTIONAL STRESS**

The individuals with HIV/AIDS undergoes the emotional reactions from the moment it is diagnosed as positive, fear of disclosure such as denial, anxiety, anger, guilt, depression, affected self-esteem and also it extends up to the fear of death. The care giver and the family members will experience added stress in all the aspects because of the burden of AIDS related care with their traditional roles, fear about their own life, fear of infections, lead them to learn more about HIV/ AIDS and its care etc. The most common immediate reaction by the HIV patients after getting diagnosed as seropositive was fear (74.03%) followed by depression (48.06%) and suicidal thoughts (12.25%).<sup>[1]</sup> Trocme(2012) found that Maternal positive status causes psychological stress among 80% of the mothers because of abstinence of breast feeding, increased infection rate and isolating from the child etc.<sup>[7,19]</sup>

#### MARITAL DISHARMONY

Umesh S Joge (2013) found that (96%) had spouse and of these maximum number of patients (653, 84.92%) had disclosed HIV status to their spouses. Most common immediate reaction by spouse after disclosure was crime (42.13%) followed by horror (38.23%) and anger (36.29%) ultimately leads to marital disharmony.<sup>[2]</sup>

## COPING STRATEGIES OF FAMILY AND CAREGIVERS OF PEOPLE LIVING WITH HIV/AIDS.<sup>[12,16,17]</sup>

The UNAID categorized the coping strategies used by the households /primary caregiver as they undergo the process of experimentation and adaptation when adult illness and death impacts whilst an attempt is made to cope with immediate and long term demographic changes. The factors which determine the coping ability of the household are identified as the access to resources, household size and composition, access to resources of the extended family and the ability of the community to provide and the interaction of these factors will determine the impact of HIV/AIDS in the household.

The factors which contributes for better coping among the family members and the caregivers such as their Gender, Age, Type of caregivers (primary, secondary) stage of HIV/AIDS of the person living with HIV/AIDS, number of persons affected in the family, Relationship with them, number of deaths in the family because of AIDS, caregivers knowledge about AIDS, Family support and other supportive systems available.

The predisposing qualities for positive coping, such as readiness to learn new skills, confident, strict adherence to the therapies, drawing happiness in achievements even if it is small, adopting positive behaviour change in negative situations, sharing experiences with the family members or with the health professionals.

#### Common coping mechanisms used by the family members and primary caregivers

Active coping mechanisms: physical exercises, doing housework, gardening, involving in spiritual activities and ventilating to someone.

a.Passive coping mechanisms: reading, listening to music, being alone, resting and sleeping. b.Emotion focused coping strategies': it includes the cognitive and behavioral action thatdo not intervene directly with the problem but it enhances personal coping example: denial, distractions.

c.Problem focused coping strategies: it targets the problem and sources of stress treated as action oriented responses such as seeking medical attention, makes healthy changes, being socially and politically active and seeking for updated information on HIV/AIDS.

#### Common coping strategies used by the households of PLHA

- 1. To maintain their food security such as substituting with cheaper commodities, replacing food item with indigenous item, reducing the consumption of costly item, sending the children to live with relatives and at the extreme begging.
- To supplement or to raise the income to maintain the expenditure pattern income
  diversification, using savings or investments, migrating in search of jobs, loans, sale of
  assets ,re-allocation and withdrawal of children from school, working for extra hours,
  seeking relatives help.

#### IMPLICATIONS FOR HEALTH PROFESSIONALS.

- Need to equip with adequate knowledge and skills in counseling.
- Assessment of needs and problems and early detection and early management of them.
- Planning individualized need based programs.
- Strengthening the family and facilitating healthy interaction among the family members
- Guiding effective coping strategies.
- Providing updated information on governmental benefits, legislation and availability of service.

- Formulating indigenous and culture specific models to have right knowledge and to correct the misconceptions if present.
- Conducting need based training workshops for caregivers and family members.
- Strategies to improve HIV testing of fathers.
- Strategies for fathers to facilitate to view childbirth from a family perspective.

#### **CONCLUSION**

The growing awareness among the caregivers about the illness, coping strategies, availability of services, recognition of their strengths and needs makes the health professionals to be more specific in their planning and provision of services to the families and persons living with HIV/AIDS. Even professionals can conduct a error analysis of themselves in understanding the reasons of dissatisfaction among caregivers and work towards healthy family and caregivers of persons living with HIV/AIDS through a healthy caregivers and professional partnerships.

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