



## Hurdles to cross over: being a child of HIV positive widow: a study from Karnataka, India

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Available online at: [www.isca.in](http://www.isca.in), [www.isca.me](http://www.isca.me)

Received 12<sup>th</sup> April 2017, revised 18<sup>th</sup> May 2017, accepted 12<sup>th</sup> June 2017

### Abstract

*Karnataka is home to nearly 25000 widow-headed households. 65% of these households have no lands, 31% are dependent on agriculture labour and only 20% have a regular income source. The average annual income is Rs. 40000/-. 31% continue to live in a rented households and 80% of the houses are semi-pukka/ mud houses. 60% of these households have poor sanitation facilities. Poor access to HIV treatment, family support, stigma and discrimination, results in poor quality of life and forced migration. There are more than 40,000 children who are in these households. The study is intended to understand the impact on the children. 35 questionnaires were administered with the widows and their children accessing care services, using purposive sampling and the data was analysed using qualitative study methods. Study reveals that the impact on the children is manifold. They are forced to poor nutritional, educational and psycho-social support; they drop out of schools and join trivial jobs. While the single mothers continue to play the dual role, they have put in efforts to ensure sustainable livelihoods.*

**Keywords:** Children, HIV, Stigma, Widows, Women.

### Introduction

In India, irrespective of religion, caste, class and education, millions of widows are deprived of their universally acknowledged human rights<sup>1</sup>. Becoming a widow is one of the most painful moment in the life of a women. The death of husband, has a substantial impact on the women's life. When the husband dies, the women not only loose a close and understanding relationship, but is also burdened with the additional responsibilities, which was shared by husband and wife. Further, widowhood denotes, a shift in position of the women, from an economic, social and financially independent to completely dependent on the family members. Further social change has impacted joint family to break into nuclear families; this situation leaves many widows of present-day Indian society unattended by family members. There is growing evidence of their vulnerability, socio-economic, physical and psychological, challenging many conventional views and assumptions about this 'invisible' group of women<sup>2</sup>.

The social and cultural factors have a great bearing on the women's position in Indian society. Especially, women from poor household are dependent on the men, because of lower level of education, limited access to resources, and poor economic decision making power. HIV has a greater impact on the widowed women, due to the stigma attached to it. Hence once the husband dies, the family also disowns the women and their children. Addition to it further, widows are disowned by their relatives and thrown out of their homes in the context of land and inheritance disputes. Their options, given lack of education and training, are mostly limited to becoming

exploited, unregulated, domestic labourers or turning to begging or prostitution<sup>3</sup>.

Karnataka is home to nearly 25,000 HIV – positive widow headed households, the women have been mostly infected from their husbands. Currently most of them are being disowned by the husband's family and continue to live alone with the children, with less or no support. Women, who have lost their husbands 6-7 years back, have even lost bonds with most of the husband's family members. Less than 10% of women currently reside with in-laws. Karnataka is one of the four large states in South India with a relatively advanced HIV epidemic, with the adult HIV prevalence in some districts exceeding 1% (HIV Sentinel Surveillance). It contributes to nearly 9% of the PLHIV population in the country. Based on NACO estimation, there are 2.45 lakh PLHIVs in the state. The cumulative number of HIV positives availing ART drugs in the state is 125000. There are totally 64 ART centres and 200 Link ART centres, providing ART care to the PLHIVs.

The study results further reiterate the findings from the other studies and highlights that as compared to other HIV households, the HIV widow households are economically worst affected. Despite all the efforts taken by them, they continue to live a life of struggle, due to financial constraints, less income and lac of employment opportunities. Most of these households are forced to survive on less than two meals per day. Due to the impact of HIV and medication, decline in health is being observed. The widowed households are below the poverty line as compared to others. Though, in rural India nearly 80% of

women are dependent on agriculture for livelihood, only 11% of rural landholders are women<sup>4</sup>. Another problem associated with widowhood is loneliness. Many widows live by themselves. They suffer the fear of being alone and loss of self-esteem as women, in addition to the many practical problems related to living alone. They feel the loss of personal contact and human association; therefore, they tend to withdraw and become unresponsive<sup>5</sup>.

Amidst the day-to-day financial challenges, loneliness, stigma and deprivation of basic human rights, the women have focussed, more than economic independence and betterment of their life, on their children's life, ensuring education of their children.

In spite of monetary problems, the widows continuously put efforts to ensure the continuity of children's education so that they get better job opportunities and are financially independent. Further they continue to spread the positive message across the society though they live with HIV and the stigma that comes with it.

### Methodology

The study was being conducted in two districts of Karnataka State – Davangere and Kolar. The primary data were both qualitative and quantitative in nature. Primary data was collected by using structured Interview Schedule, in-depth interview and focus group discussions. Thus the study followed a combination of both the qualitative and quantitative data methods, to answer the research questions in the best possible way. In total 352 widows participated in the study. The data was analysed using both qualitative and quantitative methodology.

### Results and discussion

**Table-1:** Demographical profile of the respondents.

Mean Age	38.2 years (21 years - 45 years)
Educational Status	Illiterate – 50.14% Primary – 30.5% Middle – 13.5% High School - 6% Graduate – 1.3%
HIV since	Less than two years – 11.29% Two – Five years – 44.6% More than 5 years – 44%
Duration since husband's death	1-3 years – 15.98% 3.5 – 6 years – 35.5% More than six years – 45%
Occupational status	Daily Wage Labourer – 35% Agricultural Labourer – 31% House Maid – 20.11% Unemployed/ Trivial Jobs – 6%
Mean Age of Children	16 years (2 – 26 years)

**Factors impacting the lives of the Widows: Education:** The data also reveals that 50% of the women are illiterate. Of the remaining 50%, around 44% of the PLHIVs have done some schooling and maximum to primary. Only 13.5% have completed high school education. Further only, 1.5% of the women have done some college education. This also reveals the fact that, most of the women, had poor access during their schooling days. The gender discrimination also has impacted on women being sent to schools. One of the primary causes has also been the lower number of high schools and accessibility to the same, which has resulted more than 50% drop among the women who completed primary and have not completed high schools. The 2011 census also reveals that as against, 59,555 primary schools, there were only 13862 high schools.

**Employment:** The education status of women has largely impacted on the occupation, which has a high impact on income sources. The data clearly reveals that 80% of the women are dependent on Agriculture labour, daily wage or work has house maid to address their day to day needs. It is also observed that a small portion of them remain unemployed.

**Income:** The data clearly depicts that the income of nearly 80% of the women is less than Rs. 2500. This coincides with the education levels as well as with the type of employment the women are able to avail. As it was observed in the earlier cases too that most of the women are dependent on daily wage – agriculture labour, which is seasonal, hence the income is quite low for the women as well as it is not regular. This largely impacts on the children. It has also been observed that 73% of the women have no land of their own, which also is evident that most of the women are forced to seek work in others lands. Only 26.7% of the households own a land of their own, of which 22.5% is less than one acre. Which further envisages that most of the women are forced to seek for work outside and have less dependency on their own efforts. It is also observed that 23.42% of the women have to return back the loan, which has been taken by their husbands before their death.

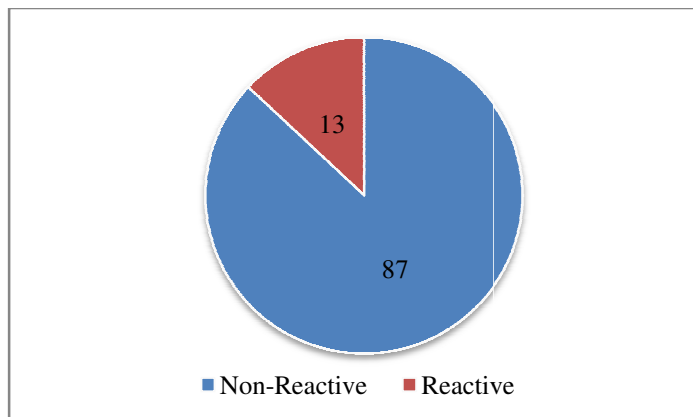
**Policies and Programmes for Widows:** The review of the study data, reveals that nearly 84% of the women have accessed widow pension, 90% have availed bank account, further 94% have availed an Aadhar card, which helps them to ensure they are able to submit documents for availing schemes. The challenge for most of the women, there is no access or opportunity for livelihood schemes, which would help them to increase the income source, for ensuring effective provision of Nutrition, Education and sustainability for the children. It has been observed that only 31% have been linked to some income generation program, which is being initiated by Non-Governmental Organisations.

**Impact on the Children:** There are in total 583 children in the respondent's households. The widows are not all alone, following the death of the husband. The major impact is on the children, who are forced to live a life of poverty and lack the

opportunities to live healthy life and access better education facilities. In this section the factors affecting the lives of children are being discussed.

The core threats to children's well-being when a mother becomes a widow: i. Fall in family's living standards, leading to hunger (poor nutrition, sometimes acute malnutrition) and poor child health. ii. Removal from school, iii. Entry into paid external employment or permanent domestic work in their own home and early or child marriage.

**Ensuring Access to PPTCT program:** The study clearly reveals that the women, have ensured access to PPTCT program, to ensure their children are born negative. An assessment of the children positive status clearly states that nearly 87% of the children are born negative. This has been possible due to the efforts taken during delivery and post-partum phase, where the PPTCT program has been accessed and ensured the child remains negative. An assessment of the 57 widows who are less than 30 years' states that the women have taken the responsibility and have ensured continues follow-up and availing of counseling and clinical services from the ART centre to ensure their children are born negative.



**Figure-1:** HIV Positive percentage among Children of Widows tested.

*28 yrs old widow – the only positive thing about my life is my child is negative. My husband and I put all the efforts to avail the services shared prior to my delivery. After my husband's death, my only hope is my daughter who is negative and I want to ensure that she grows up healthy.*

*35 years old widow – I have two children 15 and 16, I continue to work after I lost my husband and continue to support my children. My husband died when my children were very young and I continued to focus on the education of the children. My role will be to ensure my children are educated and settled well. I am not looking forward to any support from my children.*

*37 yrs old – I have three children, the eldest is educated and is doing BA, after the death of my husband I worked as tailor and educated my children.*

**Disclosure and HIV Experience:** All the children who were positive knew their as well as their mothers, HIV status. The disclosure experiences have been quite painful. All the adolescents felt quite emotional and some even cried, while sharing their experiences. In some cases, disclosure had happened during the time of their father's death or sibling death and this was more disturbing.

One of the adolescent child shared that, the disclosure of being infected with HIV, was in a situation, when the participant, herself was very sick and taken to hospital for treatment. 'My uncle took me for treatment and I came to know I had HIV. I was 7 years old'.

The HIV testing experience also has been when the parent was quite sick. Until then no one in the family had even discussed about HIV or how the father had died. One participant shares his experience highlighting, 'My mother was not well, they brought her for treatment and during that time I was also tested, and the doctor told me that I had HIV. I was in 9th standard, when they told me about HIV.'

The information that they got HIV from their parents was sometimes inadequately communicated. Further, the questions on how their parents got HIV or died keep rising in their minds. There are no answers for the same, as the other family members are not willing to discuss these topics with them.

**Growing up to Adulthood:** Financial struggle has been part of the life of the adolescent. Adolescents felt that they were considered to be a burden as their care is entirely dependent on their single mother or grandparents, with themselves having little or no support. As the child grows, she looks for a job to take care of the elderly parents. A participant share, 'I have to work and take care of my studies and my grandmother as she is not well...' Even in case where the mother is alive, due to health conditions and poverty, the adolescent is forced to work and mend for them.

It was observed that all the nine adolescents have not dropped out of the school, but only two of them were hoping to continue their studies beyond the 10th standard with the support of their Uncles and Aunts.

Doing household work was part of their childhood. Sometimes it was just helping around. However, two girls had done all the cleaning and cooking work in their homes. 'When at home I help in completing the household work, I get up and spend my time helping my mother, cleaning, get ready for school, after coming back I help in household work and then complete my studies and then at 10pm I have food and go to sleep.'

Emotional struggle in the childhood has been quite evident. The death of father, grandfather, whom they felt were very supportive, has been very painful. Sibling death is also quite hurting and distressing. The participants expressed that

whenever they remember their father and siblings, they get quite emotional and cry. They are faced with scolding from their uncles and aunts and though they stay with them, the participant is not allowed to play and sleep in the same place as the others. They shared that it is this discriminating experiences.

36 yrs old widow, living with 12-year-old daughter. From my childhood I had lot of problems to face. Always I had to struggle very hard. Born in a very poor family, I could not study beyond primary school. Joined for coolie work at a very young age and had to earn to take care of the family needs. Was married off. I hoped that at least with the support of my husband I would be very happy. But after marriage also I had to struggle a lot. I didn't get much support. During my pregnancy I was tested positive. My husband knew he was positive but he didn't reveal me. The saddest part of my life is - my daughter was tested positive. After my husband died, I continue living alone with my daughter. My desire in life is to work hard and educate my very well. She is currently studying in 6th standard. We help each other to adhere to treatment. I don't want my daughter to go through all the problems I went through. – KOL037.

**Loss of husbands' (or partners') income from paid employment:** The consequence of loss of income after the death of the husband is a straightforward issue, as the income he once earned is no longer available for the surviving wife and any dependent children. A programme by the World Bank and Indonesian government that focused on widows, started in 1999, stated, "the link between widows and poverty is well-known. Loss of an adult male is economically devastating to already poor families" In most cases added to the loss of income the women are forced to repay the loan taken by the husband during his life time.

36 yrs. widow - As long as my husband was alive he used to drink, come home and beat me...he had lot of negative habits, after he died I have started working as a daily wage labourer and ensure that my children continue to go to school – KOL071.

**Availability of adequately paid employment opportunities for women together with childcare:** Rural women in general face high restrictions on external activities, including paid work outside the home, low status work or work lacking dignity is often the job women are forced to get. As the education status is low the women are dependent on the low paid labour work at construction sites and lands, which impacts the lives of the women as well as the children. At instances it has been observed that women are forced to carry their young children in the age group of less than 3 to the work sites, which impacts the children's health further. Women are also forced to work in hazardous jobs due to the high stigma of HIV, which impacts their own survival.

37 yrs. old – I have three children, the eldest is educated and is doing BA, after the death of my husband I worked as tailor and educated my children - DVG019.

**Rules of inheritance of property, particularly land for rural women:** Loss of income from the death of the male head of the household driving widows and their children into extreme poverty is often compounded by disinheritance in developing countries. Disinheritance consists of the widow being dispossessed by her late husband's family. At its worst, it involves not only property, but also the confiscation of children, especially when the child is tested negative. Inheritance rights of women as widows are therefore a major area of concern for the well-being of widows and their dependent children, which has been officially recognised by the UN agencies IFAD – (International Fund for Agricultural Development).

Disinheritance takes several forms, differing in combination across developing countries; it includes: loss of control of the family land, housing and ordinary household property, farm assets of all kinds, outright eviction and complete loss of all property resulting in abandonment of the widow and her children (i.e. expulsion from the extended family); while in other cases it exists as eviction of the widows with complete property loss together with confiscation of her children by the husband's family.

Disinheritance of widows' property happen due to: i. Gender inequality that penalises women, ii. Economic pressures in rural areas – ever decreasing farm size in areas of increasing population density, and iii. Formal and customary inheritance laws that do not allow widows to inherit their husbands' property.

Due to these, the women are forced into acute malnutrition, pushed into prostitution and make them prone to debilitating and fatal diseases. If their children go with them, they face the same hazards. Though the right to property is a universal human right and each one are entitled for the same, still in many countries this has not become a reality.

**Forced child labour or early child marriage:** A widow is usually more concerned about being able to keep her children protective and safe. Child labour is often the only option or in the case of girl children, early marriage. Girls under 16 are often got married early by their widowed mothers in the hope that their daughters' well-being will improve in a new, more economically stable family. Widows' children bear the greater impact, when their mothers are subjected to the worst forms of abuse such as eviction.

Removal of children from school as a result of a negative economic event or shock such as the death of a father, is a much-studied area of education policy for human development outcomes. Widows' children from low-income families, when forcibly removed by extended family, often have to enter the labour force as child labourers in order to support their mothers and siblings. This is often the case where employment opportunities for most women, and therefore widows, are effectively non-existent, and those that exist, are low paid. In

these cases, the widows being referred to are from low skilled rural and poor urban households. Child labour often results in discontinuation of education and high risk of harm to physical health through hazardous employment, and additional heightened risks associated with children's employment such as physical and sexual abuse. Further Widows from low-income backgrounds or with few financial assets often see marrying their girl children as soon as possible as a way to ensure their daughters' economic and physical security.

## Conclusion

Government interventions specific for widows have been sparse and the impact of available interventions inadequately analysed, which has actually affected the sustaining livelihoods of the widows. It is important for Govt. to intervene with the right program and facility for the widows. The fate of widows' children mirrors the suffering of their impoverished mothers. It is not just 352 widows, who are impacted by HIV, but these are 352 families that goes through a journey of pain and struggle to survive after the death of the main earning member. The impact is largely on the children, who continue to face the burden on poverty along with stigma of HIV. Children are not just forced to take care of their sick mother at times but also need to do trivial jobs to addressing the financial crunch which the families continue to face often.

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