

# **COMMUNITY Based Intervention in HIV/AIDS Treatment in the Under Five Children in Zambia: a sociological investigation**

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## **Summary**

The determinants of behaviours which are the root of disease and ill-health are often exposed to epidemiological analysis and not to the behavioural methods. To understand the nature and patterns of HIV/AIDS treatment at community level requires exploration of various behaviour intricate.

## **Methodology**

Qualitative techniques were used to collect data that describe ARV accessibility at community and household level. Seven compounds into which interventions had taken off were randomly sampled. Key informants were tape-recorded and extensive field notes compiled.

Results Anti-retroviral therapy relied heavily on health care providers with no community support. Mistrust and poor understanding of drugs by caretakers, hindered interventions' success. Language, concepts and norms, influenced performance of interventions. Caretakers' prior knowledge of the disease was important as 23/29 informants mentioned combined symptoms used to recognise HIV/AIDS. Anti-biotic self treatment was mentioned by 23 key informants. Community norms, social values and cultural realities hindered the success of interventions.

## **Background**

Community interventions are popular in HIV/AIDS, prevention and treatment, especially among the adults, although little is known among the children five years and below. The determinants of behaviours which are the root of disease and ill-health are often exposed to epidemiological analysis and not to the behavioural methods. To understand the nature and patterns of HIV/AIDS treatment at household or community level requires exploration of various behavioural intricate. The paper explores how community values and norms operate in order to understand HIV/AIDS treatment seeking behaviours. Secondly, Ndola communities provided useful information on the dynamics that emerge where policy makers, researchers and communities work together in identification of problems that hindered improvements in children's accessibility to antiretroviral therapy.

According to the Zambia Demographic and Health Survey in 2001/2002, 16% of adults between the ages of 15 –49 were living with HIV/AIDS. The main risk behaviors for HIV transmission in the country are unprotected sex and mother to child transmission. Young women between the ages of 15–25 represented the most highly affected group for HIV infection. On other hand, the number of orphans due to the AIDS pandemic was over a million. The magnitude of the problem invited the team to look for information that was necessary to describe the treatment patterns at community level.

The problem also appears to be more related to lack of understanding of the concept of gender and its critical role for AIDS related interventions. HIV/AIDS home based care entails that care for the family members suffering from HIV/AIDS complications, becomes the responsibility of women and girls, who in return tend to lose income generation opportunities, in turn increase the risk of exposure to HIV.

## **Drug Availability**

The introduction of the Home Based Care (HBC) is a principle under the Almaty Declaration in 1971, which reinforces that drugs are available at community level, by trained government arms. Zambia has deployed ARVs in both rural and urban areas, which is currently being dispensed by health facilities. However, with the rising resistance of communities to use of facilities including VCT, most of the African governments are trying to obtain data to enable them increase use of facilities.

In terms of treatment costs for each diagnosis, the younger children require special attention since they tend to have higher mortality rates. The higher incidence of HIV in our communities may increase the probability of drug wastage, especially when drugs are deployed in the communities under the care of less qualified individuals. People with other complications (fever) that untrained eye may not see will be given ARVs, therefore delaying urgent referral to specialized health services that are run by qualified health care providers. The government future worries will be on drug resistance if not carefully protected; therefore researchers as well as administrators are made accountable to their work.

Health care providers are conscious of the need for quality of drug management to ensure accessibility, affordability and compliance to the treatment regime. However, caretakers' ability to consent can affect adequacy of care of the sick relatives. Referrals from the community to the hospital have shown that there is some consistency to effectiveness of reducing loss of life and complications (2003). The freedom investigators assume when providing a new drug and therapeutic measure that they believe offers hope of serving life in the HIV/AIDS people require re-examination.

A number of studies have identified factors associated with HIV/AIDS treatment behaviours, some of which have contributed to death of people. The major areas of concern have been the possibility to use alternative health care such as traditional healing system in case of severe illness, higher frequency of dependency upon other members of the family for decision making, community, and caretakers' attitudes, all correlate to delay in seeking effective treatment and or even completion of the course for the already commenced treatment. The study was descriptive to afford the team gain insights about how HIV/AIDS was treated in the community.

### **Objectives**

The study was set to fulfill the following specific objectives:

1. Assess whether families distinguish between different presentations of the same symptoms
2. Describe community beliefs related to each of the signs and symptoms identified
3. To document treatment-seeking behaviour for under five children suffering from HIV/AIDS related conditions
4. To identify factors hindering utilisation of ARVs in children under five Years of age

### **Methodology**

This was a descriptive study involving mothers and other caretakers of children under the age of five years living in the community or admitted in the children's hospital. Qualitative techniques were used to collect data that describe ARV accessibility at community and household level. Seven compounds into which interventions had taken off were randomly sampled. A total of 29 key informant interviews were conducted. The in-depth guidelines covered topics on current practices regarding identification and treatment of HIV/AIDS conditions.

The purpose of this type of guide was to facilitate focusing on factors that influenced and motivated treatment-seeking behaviour in caretakers of children under the age of five years old and below at community level. This included perceived social norms, beliefs about the causality of HIV/AIDS, past experience of and perception about the efficacy of different types of healing systems (e.g. traditional healer as compared with biomedical practitioner or faith healer) for HIV/AIDS, availability of financial resources required to undertake or complete treatment, sense of self-efficacy in managing treatment, expectations of outcome and perceived benefit to communities by the various HIV/AIDS interventions.

Observations and informal discussions to gain insight into people's attitudes to treatment of HIV/AIDS and into public health interventions were explored. Through a long period of stay in the communities and through discussions with key informants, researchers were able to identify and gain access to caretakers whose children had suffered from HIV/AIDS related ailments and admitted at Arthur Davison Children's Hospital. In all instances, all interviews with key informants were tape-recorded, and extensive field notes compiled.

## **Results**

Anti-retroviral therapy (ART) relies heavily on health care providers with no community support. A 64 Year old traditional healer stressing the point said, *'it is only them who know what to give us, they never allow us to ask even questions.'*

Self-descriptions of health workers at lower level hinder disclosure of their weaknesses to investigators. Mistrust and poor understanding of drugs by caretakers, are major methodological issues that hinder interventions' success. A mother of six children, who many times failed to give her patient medicine had this to say, *'sometimes they only set us, they give us things that do not work, then we stop using them that is all.'*

Language, concepts and norms, are factors influencing the performance of the interventions. Caretakers' prior knowledge of the disease was important as the majority of informants (23 out of 29) mentioned some of the combined symptoms that were used to recognise HIV/AIDS related problems. The symptoms were excessive vomiting (25 out of 29 key informants), TB or continuous coughing (18 out of 29), loss of weight and poor appetite (all 29 key informants). *'You see the sick person becoming thin and thin. You give him this; he refuses because nothing pushes him to eat'*. (Meaning he loses appetite.

Key informants reported that treatment of HIV/AIDS related conditions commenced with the family and moved into the community as the illness progressed. When asked to mention some of the drugs used, various regimens used in Zambia include lamivudine, nevirapine, and zidovudine or stavudine.

Young and married (15-25 years) were more prone to having HIV/AIDS and less likely to take Voluntary Counseling and Testing and less likely to continue taking ARVs. A 33 year old caretaker had this to say, *'these little ones though married, they are sick and cannot go for those who look at blood'* (Referring to counseling and testing), *but even when sick they stop taking medicine because of children.*

Apart from the ARVs, anti-biotic self treatment was mentioned by 23 key informants. *'We try those red and black kapsols, you know them docotala.'* Mothers were the important arms for administration of ARVs once obtained from health facility or pharmacy (18 out of 29 mentioned this repeatedly).

Risk increased among those living in less developed compounds 72.3%. The majority wanted to continue having children (14 out of 24 key informants). Over 12 key informants had indicated that life threatening complications such as anaemia and delivery by caesarean section did not worry them as much as having children

All health care providers mentioned two or more symptoms associated with HIV/AIDS. Specialised training in ARV provision was lacking among health care providers.

## **DISCUSSION**

### **Relationship between health facility and Community Participation**

Social Sciences have been a valuable tool in raising extensive discussions in HIV/AIDS treatment and prevention in the under five years children. In Ndola, various urgencies have been participating in control and treatment interventions and great results recorded by National AIDS Council. However, mass drug deployment tends to rely heavily on health facility which is rarely accessed by the majority of residents. We have found out that self-descriptions of an individual health care provider accepting to work for communities with poor conditions of service and in frustrating environment tended to create a situation of unfaithfulness, (not trusted). It further hindered the effective means of implementing well intended interventions.

Access of the intervention (ARV) was hindered because of loss of trust and confidence in the health facility staff, which may be due to misconduct, for instance, suspect of giving good drugs to those they knew or by prolonged services in one place. Some members of public health sector had been in the same clinics for more than 15 years. Long years of service in one place have made some of them less effective and had started imposing their authority over the members of their communities.

Most methodological studies have often looked at issues such as validity and reliability of information, with little or no regards on the difficulties that are deeply embedded and perhaps unconscious beliefs in the newly introduced ARV drugs. However, we need to stress the desire which may shift according to the characteristics of the community and eventually the individual. Provision of ARV through health facilities has raised critical issues which include the language, the concepts and norms that were underlying and used in the intervention. Levels of confidence in available healing systems, beliefs and values about treatment had effect to under utilisation of services. Child who is positive and develops severe malaria, may not be allowed to get an injection as it is believed that receiving an injection whatever the medicine would cause death to child, so families will normally avoid using the intervention.

The effects of the intervention may also be reflected in the presuppositions which are held by individuals, which they may not be aware of and require to challenge. For instance, it has been observed that communities delay treating severe malaria with effective anti-malarial drugs, however, at the end they fail to see themselves as contributors to the death of an under five child. Similarly, it is rare for investigators to examine at what stage a caretaker of the under five years child becomes a causer of death. In all these circumstances, part of the trouble stems from the investigators' nature of concept assumption. It may also be

regarded as psychological, putting something into words makes it happen or exist [1996]. As investigators we feel to be better left in the realm of the not said.

### **How does our intervention fit in the Theory of Reasoned Act (TRA)?**

Let us dwell a little on the Theory of Reasoned Act (TRA) which was developed from the KAPB studies [1996]. We apply this theory in our paper because of its strength in assumption of a causal chain linking beliefs to behaviour. It also attempts to take into account the effect of norms, social approval, as well as the expected utility of action.

In introducing ARV in communities, we are trying to change the existing behaviours of individuals. The changing of behaviour is seen as being a primary matter of changing cognitive structures, or of changing underlying beliefs. When health care providers were stressing on the counseling and signing of consent in order to have HIV test, mothers got surprised and wondered why one would commit his or her child to receive the drug, if the drug is meant to make him better. They often got suspicious and continued to ask whether the action being taken was criminal, *'I will just sign since I came for treatment.'*

Investigators should not assume that a caregiver has consented because of signing the paper, get deeper and discover the people's feelings. The socially relevant behaviours are under the individual's conscious and control. The option to various treatment behaviours are related to the individual caretaker's ability to react to the underlying beliefs. Investigators stand on the borderline, wondering whether to reinforce community values or play the role of experts which becomes more palatable.

In Zambia, communities with limited access to formal health care, normally result to self-medication. This point has been stressed by the Sudanese study [Hameed 2001]. The inner-self and community behaviour makes a home a major setting where diagnosis and treatment of most HIV/AIDS related cases is based. Malaria which contributes heavily to child mortality in Zambia starts with self medication. As early as 1995, Mnyika, Killewo and Kahabalimu, identified self-medication with anti-malarial drugs in Dar-es-salaam as crucial in malaria control. The Ndola study reveals that the way symptoms of HIV/AIDS are identified; greatly affect decisions on rapid and appropriate course of action to be taken.

Having set clinical criteria for identification of HIV positive child, several difficulties have now arisen. The major issues have been the linkages between beliefs and action taken by caring for the child. In this paper, we have not been dealing with validity, but the methodological issues affecting cultural and community social values. A child who is microscopically malaria positive and who eventually develops severe malaria and convulsion, there is a belief that giving an injection to such a child is a direct 'death sentence'. This fear and consequently the belief and values communities have, present few cases of

mismanagement of cases, *'they went to see the healer immediately the child started convulsion,'* or *'they decided not to take the child to the health facility, so finally the child died.'* These are sad stories coming out of our study.

### **Why Communities Fail to Participate**

We can only explain some of the methodological failures of our communities' participation in mass rolling of ARV in Ndola, through the observations and investigator experiences in the past months of the study. Actions that were taken by caregivers had depended on the severity of the illness: go to healer, reach or not reach the health facility, accept or refuse a referral. The severity could not only be medical but could also be due to social consequences. The perceived barriers have been used loosely in the paper to stress on the potent for understanding attempts to modify behaviours that may require long term changes.

### **Conclusion:**

Evidence from the study shows that community norms, social values and cultural realities are a hindrance to the success of the intervention, which eventually affect health related behaviours in utilisation of ARV in at community level.