



HIV/AIDS, MALNUTRITION, STIGMA AND DISCRIMINATION

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This chapter is a summary of a study done in collaboration with REACH Trust Malawi

Background

In a pilot study conducted by the Panos Institute in Zambia, care providers claimed they found patients with HIV/AIDS more difficult because of their multiple infections; their “hysteria”, their “attention seeking”, and their “many thoughts”⁴¹ (i.e. the need for psychological as well as medical support). They also admitted that HIV/AIDS patients were often not given the same services because doctors knew they are going to die and, therefore spent less time on them. Stigma was also evident in mothers taking care of their children with HIV in hospitals. They tended to abscond from treatment because they believed that their child was going to die and their few resources should be used on those who would live.

As a part of the clinical research carried out in the nutrition rehabilitation units, an observational study was conducted to explore the impact of stigma on the quality of care for HIV infected and uninfected severely malnourished children. Like many PLWHA in resource poor contexts, HIV positive children are vulnerable to stigmatisation and discrimination. This stigma and discrimination can be experienced both in hospitals and in the communities in which they live. HIV/AIDS-related stigma seriously impedes effective care and support programmes. Stigma towards the affected family or individual often poses one of the greatest challenges for those living with HIV/AIDS and one that is extremely hard to address.

It is against this background that the study aimed to explore how stigma and discrimination on the basis of perceived HIV status affects the interactions between health staff, carers and children in the nutrition rehabilitation units in Lilongwe. The study elicited important information with regards to health workers’ attitudes towards HIV positive malnourished children and their carers. Such attitudes can negatively affect the treatment and feeding outcomes of malnourished children and the caring experiences of their carers.

The study, conducted between November 2005 and March 2006, looked at the dimension of experiences and relationships in the NRU to help shed light on differences in response to therapeutic feeding amongst severely malnourished children who are either HIV positive or HIV negative. Global literature suggests that health providers may discriminate against or act differently with PLWHA in the health care setting, but few of these studies to date specifically focus on children⁴².

Objectives of the Study

1. To document the challenges carers and health workers face in supporting malnourished children in the NRU setting.
2. To explore how the health workers and caregivers perceive the children’s HIV status.
3. To assess the extent of perceived and enacted stigma by health workers and carers and explore how this relates to perceived HIV status.
4. To explore whether gender, age, cultural norms and work experience shape staff’s and carers’ perceptions and behaviour towards malnourished children perceived as HIV positive.
5. To investigate hospital staff’s knowledge on nutrient and dietary requirements for HIV positive and negative malnourished children.
6. To make recommendations to hospital personnel and other stakeholders in order to reduce stigma in NRU and provide in-depth contextual information to help interpret the observation trial.

The study focused on exploring and understanding the in-depth context of the behavioural attitudes that affect the response of malnourished children to therapeutic feeding, alongside the clinical issues. This is critical in order to enable positive outcomes for children who are both malnourished and HIV positive. It was conducted on two sites: Kamuzu Central Hospital (KCH) and St. Gabriel's Hospital in Lilongwe district. The respondents included staff involved in care of the malnourished children and the children's primary carers who resided with them during treatment. The study was conducted during the assessment and treatment for severe malnutrition. Staff included nurses, ward attendants, home craft workers and doctors. In addition to selection of staff of different cadres, we purposively selected staff to include staff of different demographic groups such as age, sex and length of working experience at the study site in order to explore whether gender, age, cultural norms and working experience shape staff's perceptions and behaviours towards malnourished children who are HIV positive. Carers were also sampled to capture differences by age, whether the carer was a biological parent or another relative, and duration of stay in the hospital. The study used three complementary qualitative research methods: in-depth interviews, participant observation and focus group discussions. Many aspects of the findings highlight general challenges faced in the NRU by both carers and staff. This chapter will summarise the main findings of the study related specifically to HIV. The full report is available on request.

🌟 Findings

A complex interplay of findings emerged on the factors that contribute to the response of therapeutic feeding by the children in the NRU. These ranged from different challenges carers and health workers face, understanding of HIV/AIDS and malnutrition among the carers, knowledge of HIV status amongst health workers and carers, the extent of perceived and enacted stigma, and health workers' knowledge on nutrient and dietary requirements for HIV positive and negative malnourished children. The main themes that came out were "The milk is not enough" referring to resources available in the NRU such as milk, medicine, space, hygiene; "We have different blood" and "My other children back home" referring to the carer's multiple responsibilities and challenges.

🌟 Gender aspects

Over 90% of the children in the NRU were accompanied by their mothers. Fathers are mostly uninvolved with the children's care in the NRU. This often puts the mother in the position of making care, testing and treatment decisions without their husband's participation or consent. These types of family decisions are usually made by men in Malawian society. A woman returning home to inform her husband of HIV infection may be vulnerable. The lack of participation of fathers in the nutrition programme also means that the NRU is not acting as an entry point for HIV services for men who may be in need of HIV testing, education and treatment.

"...my husband doesn't know about this. If I stay here I will ruin my marriage because the husband will ask where I have been or why I accepted to stay in the NRU without his consent..."

🌟 Challenges: the milk is not enough

The theme of inadequate resources came out continuously and whilst this to a certain extent is the case throughout health structures in under resourced countries, it is sometimes felt that in particular, the resources dedicated to the treatment of malnutrition reflect the socio-economic status of those usually affected. Both carers and staff mentioned the lack of resources available and how this impacted on care. This included shortages of milk and medicine for the children, as well as lack of food, soap and blankets for the carers. Many of the carers travelled long distances to the NRU, and came without adequate food, money and supplies for their stay; leaving some of the carers hungry with a lack of

facilities and supplies for personal sanitation. Research staff observing in the wards reported that carers and children were often sleeping on the floor due to overcrowding. Not all carers and children had blankets for sleeping, although the ward was sometimes cold at night, and the guidelines for nutrition rehabilitation of severely malnourished children state that children must be kept warm to prevent hypothermia⁴³. Although the NRU has sinks with running water for the carers' use, soap is often not available. Children are playing and sleeping close to one another in unsanitary conditions, risking cross-infection. The researchers noted there were sometimes over 50 children on the ward with just one or two nurses on duty.

For the carers, it can make them question the suitability of coming for care. The health staff themselves mention understaffing, lack of training, lack of space, shortage of equipment, lack of coordination amongst themselves, and lacking understanding or being less cooperative as the challenges they face on their day to day operations mount. It is perhaps then, not so surprising that carers feel the stress and demotivation of the staff. Carers also reported that the care provided within the NRU was not holistic; that they had to move up and downwards to gain care for themselves and their children.

"In fact it pains because as my colleagues have pointed out we are made to wait for the doctor for almost the whole day. When you go there, they say 'I am busy so you have to wait'. When you go there next time, you are told the same thing. So as a person who is also in confinement together with the child you really feel like going home is the best you can do because even if you stay here there is nothing that is happening". (Focus Group Discussions with women, KCH)

Many carers reported ill treatment by staff whilst others see it as negligence and underperformance by some health workers:

"...we find most of them just sitting on a chair and claim they are busy and just two days ago a certain nurse literally shouted saying, 'I am fed up with pinching your children's feet'". (Focus group discussion with women, KCH)

Carers complained about lack of support in terms of material and financial resources and this is a big challenge for them to cope both before and during their time in the NRU. Some have done what they can to prevent malnutrition but resources are just too limited. Once their children are admitted with malnutrition there is always the feeling that they are somehow to blame.

"Then I went to a clinic with her where I was told to buy maize, beans, groundnuts to prepare porridge for her three times a day. The doctor assured me that she will be OK. However, because of financial constraints and the hunger crisis which was roaming then, I could not manage". (In-depth interview with male carer, St. Gabriel)

The carers were also seen to become psychologically affected by the way the health workers treat them. Health workers engage in practices that can demean or discourage the carers from adhering to treatment of their children. For instance they are reported to shout at the carers, abusing and mocking them when they are in the NRU. This was found through the study to greatly contribute to cases of absconding by the carers as they feel they cannot continue staying at a place where they are being disregarded or ill-treated. Through reports from observation, group education sessions appear to be quite hierarchical. Generally the health care worker stands at the front of the carers, who are sitting on the ground. The carers are often then asked to sing, clap and repeat back what the health care worker has said. While this may be a time-efficient and culturally familiar method of education, it is not patient-centred care and does not allow for an exchange of ideas.

🌟 **The impact of stigma: “We have different blood”**

The perceived or enacted stigma by health workers and carers relating to perceived HIV status of the children was reported in two strong themes from carers: “We have different blood” referring to staff attitudes and underperformance, and “What wrong did I do to God?” referring to stigma and malnutrition.

Differences between the staff and the carers are evident from the reports from researcher observation. Most hospital staff have higher socio economic status than the carers. This is evidenced by differences in dress, appearance and possessions; for example staff tend to be educated, have mobile phones, wear hair weaves and shoes, while carers have less education, wear chitenjes (fabric wrapped skirt) and are barefoot. The relationship in the NRU between carers and staff appears to be hierarchical. Carers often come and bow before nursing staff, or avert their eyes downward when they are requesting care.

Carers report that some of the staff are warm and welcoming with them, but that others are unkind. Illustrative quotes include:

“Some are good while others are harsh. Some they do their work as nurses, very friendly and humble while others instead of helping you they say bad things to you.”

“You can not interact with all of them nicely, some are good but others, we have different blood.”

Some of the carers reported being made to feel stupid in their interactions with staff:

“Because if the doctors are not considerate we feel underrated as if we are just stupid to be here, as if we asked God to be in the hospital.”

“There are some nurses who do not treat us with dignity. However there are others who treat us as human beings”. (In–depth interview with female carer, St. Gabriel’s).

This disparity is echoed in the interviews with staff. One ward attendant said:

“...so we can’t be the same because of our different backgrounds and upbringing. On the part of carers, I would say a carer is a carer, we can’t be the same.”

Staff expressed some frustration at lack of understanding and compliance in carers:

“As a health worker I can say that the relationship with carers is always good. As long as they agree and do whatever we tell them to do, we stay together without any problem.”

One staff member likened the relationship between staff and carers to the relationship between parent and child. Some of the language used by staff when referring to the carers seems to indicate a lack respect for the carer’s situation. Carers are said to complain about ‘trivial matters’, to offer ‘lame excuses’, to be ‘cunning’, to ‘lie’, and to ‘ignore responsibility’.

When asked, all staff members reported that they do not treat HIV infected and uninfected children differently:

“Actually there is no difference because all of them are our patients to seek care, and we treat them all as our patients. We don’t treat them differently”.

“Love is the fundamental tool for health workers in order to comfort them and make them forget their worries.”

Other statements however, reveal some differences in staff attitudes towards mothers of HIV infected and uninfected children:

“The difference in relationship is that as I have already said carers whose children are HIV positive become stubborn and cunning due to lack of hope.”

“... carers whose children are HIV negative are not that difficult to handle. They are always understanding and fast learners willing to implement whatever they are being told to practice, unlike their friends.”

✿ **What did I do wrong?**

There were different perceptions between the carers and health workers towards how each group regards the other when it comes to reaction upon knowledge of children’s HIV status. Some health workers perceive carers as people who become troublesome and non-compliant when they know that their children are HIV positive. They tend to lose confidence and hope in the therapeutic feeding and may abscond from treatment.

Carers associate their children’s illnesses with spirituality and divine punishment and report experiencing stigma in their interaction with other carers. One carer said:

“Ah I don’t know because I just say it is the making of Satan why others are OK like his twin brother is OK walking and good health and they are saying this one is malnourished. So I just say it is the work of the Satan.”

Some carers seemed to accept their illness and want “to live positively” while other participants revealed a sense of hopelessness about HIV. This theme of hopelessness was also explored in the interviews with staff members. One nurse told a story of a grandfather who refused treatment for his grandchild.

“He vehemently shouted at us, saying: ‘what’s the use of drugs even if he dies I thought this disease once you catch it you never recover, the end is death’. The grandfather left the hospital with the child, however the father later brought the child back for treatment.”

Carers manifested their disturbance upon hearing their HIV status, often becoming overwhelmed, concerned, fearful and desperate upon learning that they are HIV positive. These reactions may be attributed to the common concept that HIV is incurable and means a death sentence for most people. Carers need to be counseled about the availability of ART both for themselves and for their children. Not knowing about how to break the news of their HIV status to husbands has been another major cause of anxiety amongst carers. It is therefore important that the issue of disclosing to the spouse is highlighted during counseling sessions, and that the health systems should be flexible enough to allow the carers to refer their husbands to counseling.

Some of the positive responses captured on the part of carers were that some husbands support and encourage their wives to go for HCT. Those who receive support go to the extent of telling their fellow carers and health workers about their HIV status and counseling each other. This is encouraging and is an important step to fighting stigma and providing psychosocial support to people living with HIV/AIDS. However, there remains a need to encourage carers to be more open and to accept positive

living after being diagnosed HIV positive.

The issue of stigmatization and discrimination came not only from the health workers but also the communities where the carers live. The study shows that due to ignorance or misinformation, some relatives of the families whose children are in the NRU, spread news in the villages that the carers and their children have AIDS. As a result, carers are mocked and feel rejected by their relatives when they come to visit them and feel that they are being rejected on the grounds of being HIV positive.

✿ **Denial or multiple responsibilities? “My other children at home”**

Some carers also stigmatize and discriminate against their own children. Information elicited from the health workers indicated that once the carers know that their children are HIV positive, they abscond from treatment saying they cannot go on caring for a child who will inevitably die despite being in the NRU. They still think that once a child is HIV positive s/he can never be cured of other diseases, even malnutrition. According to health workers once a carer knows a child is infected with HIV/AIDS the immediate thing that comes to their minds is death. Then they categorise all that are critically ill as those with HIV/AIDS. The consequent denial of access to treatment for children by some carers is a true indicator of how discrimination towards people perceived to be HIV positive takes root in a society and is illustrative of the dilemmas and challenges faced by the mothers/carers of HIV positive children.

“...carers whose children are HIV positive become wild...they are always reluctant to accept or feed the child...”

(In-depth interview with an auxiliary nurse, KCH)

There were contradictory responses from the two sets of respondents that researchers interviewed. From the health workers’ perspective carers are likely to abscond when they know their children are HIV positive. The carers themselves cited things like the need to take care of other children at home, and farming, as the reasons that force them to abscond from treatment rather than the HIV status of their children.

✿ **How health workers and carers perceive HIV**

Some factors were observed that shape health workers’ and carers’ perceptions and behaviours towards malnourished children perceived as HIV positive. In this particular study, discrimination was observed through tactics applied by the nurses when carrying out their duties. They were observed to be touching some children but not touching those they perceive to be HIV positive. Equally, they seemed to have no interest at all in those children who seemed to be both severely malnourished and HIV positive. This was observed during assessments on admitted children or receiving new patients. Children that were not touched by nurses were those who looked to be severely malnourished. One nurse wondered why a mother had to come back to the NRU with a child who she said was HIV positive. This signifies stigmatisation in some relationships within the health care setting to children perceived to be HIV positive.

Others, however, correctly expressed concern that children were arriving in the NRU with already advanced malnutrition, and that the best opportunity to intervene and prevent mortality has passed:

“The moment they come to NRU it’s already too late. They should have had food at their home, they should have started ARVs earlier, they should have been detected to have TB earlier, so you are always lagging behind, and for some children it’s too late.”

✦ Understanding of HIV/AIDS and malnutrition among carers

Most of the respondents interviewed showed that they have little knowledge about issues of HIV/AIDS and malnutrition. This might be due to carers' low levels of education combined with lack of proper orientation by the health workers to the carers upon admission in the NRU. Carers were not properly told why they should be giving children milk only and not other foods when they are in the NRU; the health workers just tell the carers about it as a regulation they need to follow and not necessarily taking time to explain to them why they need to adhere to it.

However, some respondents showed that, to some extent, they do know something about HIV/AIDS, as well as the relationship existing between malnutrition and other chronic illnesses, as they were able to cite information such as modes of HIV transmission and the link between malnutrition and chronic illnesses. There remain however, many misconceptions as regards to how they can identify a person who is HIV positive.

"On AIDS a person is known to have the disease after giving birth because she suffers from malaria quite often and develops cough that is persistent. She also complains of pneumonia always whether the weather is hot or cold."

(In-depth interview with a carer, KCH)

"We can know that someone is HIV positive through the appearance of the hair. No matter how old a person can be, but with this disease the hair looks curlish and with stunted growth like that of a newly born baby or an infected cat"

(In-depth interview with female carer St. Gabriel's)

Some respondents equated HIV/AIDS to TB thus regarding any TB patient as HIV positive and vice-versa. In the community, malnutrition is often viewed the same way. Some carers and staff know or think they know the HIV status of the children and/ or carers in various ways. Many just suspect or guess, and this can be the basis for the start of stigmatisation.

✦ Conclusions

While it was clear that HIV stigma is present in the NRU, some of the most important findings coming out of the stigma study was that it was access to and quality and availability of HIV services integrated into nutrition care that made the biggest difference in terms of service uptake. Stigma was not the most important reasons for caretakers not to go for VCT. In fact, many carers are very willing to go for an HIV test provided they understand its importance and access to it is practical. HIV stigma needs to be considered in the design of services within the NRU, and education and counseling should be made available for staff and carers. The central recommendation from the stigma study is that HIV testing and treatment services should be better integrated into severe malnutrition. This should be done in a holistic way; addressing the issues of stigma through improving quality of care, and providing staff training on promoting positive living with HIV. Maternal and family care needs to be incorporated. An HIV integration study is planned to follow on from the stigma study looking at how HIV and nutrition services are integrated, how they are perceived and used, and their impact.