LIFE AFTER NUTRITION REHABILITATION: FOLLOW-UP OF CHILDREN DISCHARGED

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All children identified as HIV positive during the research were referred into services to be monitored for HIV progression and assessed for suitability to start anti-retroviral therapy (ART), medication which helps slow the replication of the HIV virus and the damage it consequently causes to the immune system.

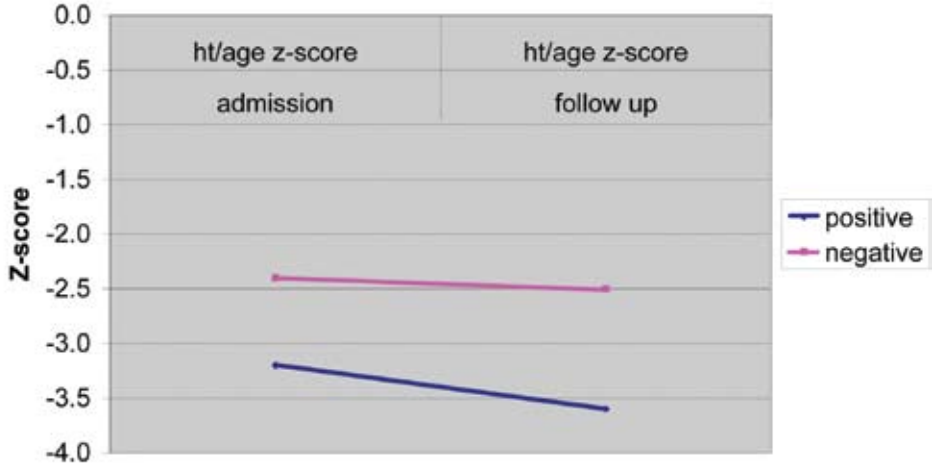
Due to funding difficulties it was not possible to continue with long term follow up of the children from the research study as planned. Most children were followed for approximately four months on average. In 2007 as a part of the Hunger Watch series on HIV/AIDS it was decided to revisit some of the households of the children and carers involved in the research to see how they were managing having received their HIV diagnosis and appropriate referral. Previously in the nutrition units it had been noted that the same children and their siblings were returning with repeated episodes of severe malnutrition indicating an inability to cope at household level. The aim was to see how the positive households were faring in comparison to the HIV negative households, to look at the impact that HIV has on a household after diagnosis and linkage into referral services. Thirty eight households from the Lilongwe area were visited individually to see their current nutrition status and the food security of the household. Questions were also asked about what services each family were using with regards to nutrition and HIV care. Fifteen of the households had an HIV positive status, while 23 had no member known to be infected with HIV.

Nutrition status

Children were checked for weight, height, and mid-upper arm circumference (MUAC). Family members also received MUAC screening. When measurements were taken, the average time since discharge from nutrition therapy and diagnosis was 13 months. In this time none of the children had relapsed, although one HIV negative child had died of causes unrelated to malnutrition or HIV.

Of the children who were diagnosed with HIV whilst receiving therapeutic feeding, 85% of them are now receiving ART. None of these children showed even moderate signs of acute malnutrition and all reported less illness since discharge. Stunting, a recognised sign of chronic malnutrition, remains prominent, and is more pronounced in the HIV infected group, though on a downward trend in both the negative and positive children. There is an extremely high proportion of stunting in Malawi, linked to long term food insecurity.

Figure 6 Stunting data 13 months post-discharge of HIV- and HIV+ children



The fact that the children were all doing so well may be largely due to the response to ART. ART will help the immune system to recover, leaving less room for infections that cause acute loss of weight and help increase appetite with the general feeling of well being. It is normal that ART cannot turn around stunting at this stage, and that MUAC will also take longer to improve. After an average of 13 months since discharge, it is a promising step that the children have maintained their weight for height and are experiencing less infection that would increase their risk of malnutrition.

Family health

According to MUAC screening, with the exception of two households, all of the positive families are apparently in good nutritional health. This is in line with the negative families who share the same essential influencing environmental factors; the HIV affected families are no worse off at this stage.

Psychosocial health however is a different matter, and it was clear from the households interviewed that there were issues of stigma and depression affecting maternal and child health. One mother was clearly depressed; she said she would not access services even if they were there, and consequently she puts the health of both herself and her child at risk. Depression and isolation affects not only the adult but also has an impact upon quality of maternal care and interaction with child practices influencing the child's health and development. A young mother explained how stigma and discrimination was a problem for her child, as other mothers did not allow their children to play with her, affecting her child's natural development through absence of interaction with other children. A grandmother told of the abrupt removal of a child from his mother by the extended family as they felt she was incapable of caring for him due to her psychological health.

Maternal and child access to health care were reportedly seldom adequate as the demands on female labour in the household did not allow the time for long queues at health centres except for serious illness. Whilst it was good that none of the children fell into the 'really sick' category, this is not a good indication for the proportion of under fives accessing primary health care and growth monitoring clinics which is where early health and nutrition problems would ideally be identified and treated.

Whilst the number of children accessing HIV services was extremely encouraging there was a major concern highlighted. In the process of HIV counseling and testing, it is made clear to the mother that a positive HIV result for the child is a strong indication of her own positive status. What has become clear is that although mothers/carers are willing to acknowledge HIV status in their children in order to access treatment there is still a reluctance to attend to their own health needs and face up to their own HIV status. There is a huge gap in adults accessing services for parental health once the child has been diagnosed through the nutrition units. One of the main factors for child health and well being is the physical and psychological well being of the mother, affecting childcare practices, childhood nutrition status and childhood psychosocial development and education. Out of 15 positive households only 2 reported that the adults were accessing services and treatment. These mothers may be in good health but there was no indication that any services or monitoring of their HIV status had taken place since diagnosis. If a mother is ill or passes away, the chance of her young child's survival is significantly reduced regardless of their HIV status[44].

So, whilst those children on ART may be doing well now, if the remaining thirteen households are not able to address the mother's HIV status and access the relevant treatment and care for her, this advantage will not be long lived. Family ART clinics are starting to become more widespread and may help significantly to address this issue.

Access to services - limitations

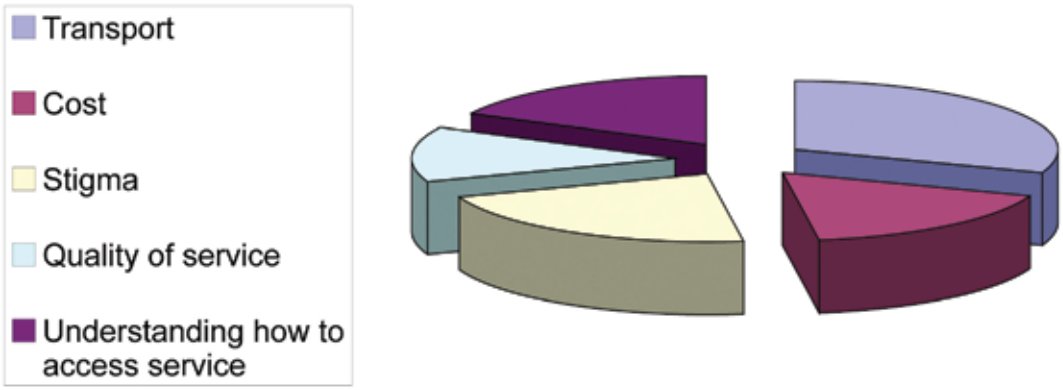
Despite children being on ART, this remains in many cases the only service that the family are accessing. Despite functioning referral systems in place from the original point of contact with these households in an area of multiple HIV services, few were accessing other support services such as home based care, nutrition benefits or peer support groups offered by many of the CBOs in the area. One family was accessing a loan facility from CARE. Two possible explanations for limited take-up could be proposed; either information is not digested at time of hospitalisation (those who say they are not aware) and needs follow up by way of a community liaison person after discharge, or stigma and transport issues (the main barriers reported by mothers) are preventing families from following referral recommendations.

None of the households mentioned distance as a barrier (all are urban) but transport is still required as children may be too young and possibly too weak to walk long distances. Positive households reported worse access to health services than negative households and costs of transport were reported by both groups as the primary reasons for difficulty of access. Cost of services was also a significant problem for 33% of positive households. Positive households however, were more likely to say that access is improving, perhaps due to increasing services linked to the widening coverage of ART.

Stigma and a lack of understanding about how services are accessed and how they can help are other main barriers. For some the quality of the service is not worth the risk of increased stigma and discrimination in the community, or the time that it takes to access the benefits offered.

The main problem is being given advice that is not practical. There are many national guidelines in place now for nutrition needs in HIV infection, but many are completely impractical, as they do not consider at all what the average family earn and can afford to eat. There is a need to look at locally available and affordable foods and suggest diets accordingly. If food is not affordable then there is a place for nutrition supplements, either where there is a gap in nutrients available locally or a gap in household resources to source an adequate diet. Families report barriers which obstruct access to health care services, as summarised in figure 7.

Figure 7 Multiple factors reducing access to health care for PLWHA



Income as a key factor

When these households were questioned in more detail it appears that the loss or maintenance of income is the main factor on the household ability to cope with the impact of HIV. For those who have lost an income earner, every other aspect of household life becomes affected; access to healthcare, access to water and adequate nutrition intake. Those who manage to maintain income report few other effects on the household although they may have to make some intra-household adjustments to maintain the level of income. Most of the adaptation is done within the household unit, changing responsibilities, with fitter family members covering for those who cannot manage, even if this involves extra labour for children and elderly. On a positive note, nearly all the HIV infected carers interviewed are working in some capacity.

Increase in petty trade and casual labour, including those members of the household who were not previously working, is the main line of coping strategies. The tradition of the extended family, which offers support to all its members in times of hardship, provides a safety net for many families. However, this support network is often strained due to the HIV epidemic, both financially and emotionally. One household reported the excessive psychological strain on the grandmother as she watched her family suffer.

Some have been helped in the past by NGO loan facilities, which have proved successful in managing to balance a precarious household situation. Stigma as well as physical health affects the ability to earn income and this is certainly still a massive battle to be waged despite the gains in HIV awareness and sensitisation. Although those who maintain income appear to be doing well, they still report an increase in spending mainly due to healthcare and hired help in the household. This raises the question as to when spending needs will outweigh income and raises the argument of how to effectively target those with HIV, a practice that is most commonly done on traditional vulnerability criteria. This may prove however, not to be timely enough to curb economic downfall, with interventions arriving too late.

The most reported need is for money to cover everyday needs, and for nutritious diet. Those who had financial assistance (one family assisted by CARE) and others who were financially stable, clearly had less impact from HIV in all other areas of their lives. However, stigma remained an issue for the financially secure, as some say they would not access services even if they were there and one interestingly said they did not require any services. This was a household with their own car and a stable income from self employment, tap water and a flush toilet, but there was an underlying feeling of either lack of acceptance about the family illness or else some discrimination from a 'well off' family who feel they are not in the same category as the majority affected by HIV. It is true that their current financial needs are met, but services such as psychological, peer support and even medical services will be required at some stage. This illustrates how stigma can infiltrate at all levels to block access to services.

As already stated, the main additional expenses are for health care and access to health care by public transport. Many reported the need to hire help for looking after other family members when attending health care facilities for the sick child or when out earning income. Also hiring help for heavy or traditionally 'male' tasks in the absence of a male head of household was reported, as found in a study by the ACF International Network on HIV and water[45], where the building of latrines and wells proved significantly more problematic if there was no man in the household. The message for better quality food is getting through but there are few who can follow the advice to the maximum. Those who are able, whether by home gardening or through income generating activities, are doing so.

Water, sanitation and hygiene

All the study respondents were in an urban location where water is easily available, so the majority were not affected by inability to access water. Most (66%) report needing more water for health and hygiene needs particularly related to washing and cleaning of clothes in sickness and diarrhoea.

Households in both groups struggle with water acquisition in the dry season, but even more so for positive households. In the three months before the rains, over three-quarters of positive households report sometimes lacking water to meet their 'nonessential' needs (agriculture, etc.), compared to approximately half of the negative households. Primary water sources stayed more or less the same for negative and positive households in wet and dry seasons – unprotected wells/springs and taps are the most important – but 72% of positive households reported depending on rainwater as one of their primary water sources during the wet season compared with only 9% of negative households. Distance and time were listed by positive households as the most important factors limiting water access, a factor in why they prefer to depend on rainwater during the wet season.

Types of accommodation and sanitation facilities were similar for both groups, with an average of 65% having access to a covered latrine. Interestingly, the use of soap before feeding, after baby hygiene, personal toilet, and before food preparation seems to be higher among positive than negative households (27% compared to 4%). This could possibly be due to greater exposure to hygiene promotion.

Food, HIV and morbidity

Whilst lack of water and other issues were reported as important causes of illness, lack of food was stated as the main factor in 32% of the households despite the good harvest. This may relate to income generating capacity and it is important to point out that although there may have been a better harvest and people reported having more food, it may still be insufficient, especially for households affected by HIV.

The main sources of food consumed at household level were similar in affected and non-affected households. Most purchased goods from the market or through ganyu exchange (casual wage labour) but there was a higher mention of 'gifts' received in the HIV affected households (27% of households compared to 9% of negative households).

There was no strong variation reported in length of the hunger gap last year between positive and negative households – the countrywide good harvests of the past year led to relatively lower food prices, and nearly all households reported that their food situation was improved compared to the year before. However, the improvement does not necessarily signify food sufficiency; 73% (11/15) of positive households and 65% (15/23) of negative households reported problems in obtaining food last year.

On average, the HIV positive households own less land (0.48 acres) than negative households (0.88 acres) which may affect their safety net of locally grown produce if market prices or ganyu become inaccessible. It could also be a consequence of earlier survival strategies.