# Improving default-rates

## Improving default rates in Ambulatory Therapeutic Feeding Programmes in operations by Médecins sans Frontières-Operational Centre Amsterdam

Thesis for Master in International health (MIH),
KIT (Royal Tropical Institute) and Vrije Universiteit, Amsterdam

Ellen van der Velden

March 2008

# Declaration

The thesis “Improving default-rates” is my own work. Where other people’s work has been used (either from a printed source, internet or any other source) this has been carefully acknowledged and referenced in accordance with departmental requirements.

Ellen van der Velden

……..

Total word count: 22.500

Date:

# Attribution

For six years I worked with my partner and later husband Chris Maas in many feeding centres in a variety of countries. 'Nutrition' is specifically a topic where technical knowledge goes hand in hand with anthropology and logistics, fields in which our experiences and skills were complementary.

It was Chris who encouraged me to do the masters in International Health; in fact he arranged at least half of the courses I took while I was away on mission… He promised to assist me with the research for my thesis and I was looking forward to making use of his analytical skills.

Unfortunately Chris could not keep his promise… He is greatly missed. This thesis is attributed to him.

Ellen van der Velden

# Acknowledgements

Writing this thesis would not have been possible without the constructive criticism and support of many people.

I had the privilege to be able to work with five supervisors who each from their experience and viewpoint contributed to the final result.

First of all I'd like to thank Prof. Patrick Kolsteren (Institute of Tropical Medicine, Antwerp) for his time and valuable suggestions and Barend Gerretsen (Royal Tropical Institute, Amsterdam) for his support in keeping an appropriate time-schedule.

I am equally thankful to three of my direct colleagues and managers within Médecins sans Frontières-Operational Centre Amsterdam Claire Mills (Medical Director), Leslie Shanks (Head of Public Health Department) and Saskia van der Kam (Nutrition Advisor) who have read and commented on all versions of the thesis.

In addition I thank all my friends and relatives who morally supported me throughout the entire time in which this thesis was planned and written.

Ellen van der Velden

# Table of contents

## Abstract

Severe Acute Malnutrition is a serious medical condition prevalent in many areas with chronic or acute conflict. Organisations providing emergency relief in disaster-struck areas, such as Médecins sans Frontières-Operational Centre Amsterdam (MSF-OCA), have established feeding programmes in many of these countries. Since a predominantly centre-based treatment mode was replaced by an ambulatory treatment approach some of the programmes have been subject to relatively high defaulter rates. Defaulters are people who are absent from 2 or 3 scheduled weekly visits. When more than 15% of children leave the programme as defaulters the programme is generally regarded as not having an acceptable outcome.

The central problem of this thesis is: how can MSF-OCA decrease its default-rates? It's aim is to identify key factors that underlie the phenomenon of defaulting which can be addressed in the set up of Ambulatory Therapeutic Feeding Programmes and during the implementation of MSF-OCA's new and existing programmes.

Research in the topic of defaulting from feeding programmes is limited. Therefore an inventory of possible reasons for defaulting was made from the area of tuberculosis treatment. Since defaulting is behaviour research areas were focussed towards the 3 main categories distinguished in the theory of reasoned action: behavioural beliefs, normative beliefs and control beliefs or "barriers".

Five countries were visited to carry out observations. In these five contexts both quantitative information and qualitative information from interviews, reports and observations were included. In order to widen the range of data collected as much as possible, all relevant documents available in 2007 within MSF-OCA were included.

The main findings are:

Basic parameters of defaulters

Age, gender and Weight-for-Height on admission do not vary significantly between cured and defaulting children. Roughly half the defaulters are 'early defaulters' (people who start being absent immediately after admission or after making one follow up visit), the other half are 'late defaulters' (who default after making 2 or more follow up visits) and benefit more from the treatment offered. Whether child should be admitted into the Ambulatory or In-patient Therapeutic Feeding Programme-component needs to be discussed with caretakers and their relatives.

Behavioural beliefs

Although malnutrition is poorly recognised as a condition requiring medical care (children are presented to the clinics for other (perceived) medical problems and are consequently diagnosed with malnutrition) caretakers do feel capable of improving their children's health with assistance from the programme, In general caretakers appreciate the programme, especially the therapeutic food items and medication.

The objective of the treatment (target weight) and how long children need to each that objective are poorly known among beneficiaries. In general people do not default because they have reached a certain (satisfactory) weight or experienced relatively rapid weight gain; late defaulting is more a function of time spent in the programme than anything else.

Normative beliefs

Most caretakers discuss visiting the clinics and feeding programmes with relatives, mostly with their husbands and/or fathers. Key-community members also play a decisive role here. Relatives and friends around the mother with the malnourished child are generally positive about the programme and appreciate the attempt to improve the child's health; consequently they are supportive towards the treatment provided in the feeding centres.

There seems to be no strong stigma attached to having a malnourished child.

Sedentary populations show fewer defaulters than (semi) nomadic populations and community involvement in the programme is very relevant, both to increase coverage among malnourished individuals and to reduce defaulting.

Out Reach Workers play an important role in achieving community support and prevent absentees from becoming defaulters. The required number of Out Reach Workers varies between programmes and areas, but close management and follow up on their achievements is essential.

Control beliefs and barriers

Of all barriers people perceive as hindering their (weekly) visits to the feeding programme they mention distance and security most often. In relation to that decentralisation of the feeding programme is relevant. Regular opening hours and avoidance of stock rupture are of paramount importance in order to promote regular visiting of the programme until a target weight has been reached.

In the discussion section these findings are commented on and direction for changes in the set-up of programmes is given. The thesis ends with a set of advice to MSF-OCA specifically aiming at reducing default rates to an acceptable level.

## 1. Introduction

Severe Acute Malnutrition* is a serious medical condition that affects 13 to 20 million children worldwide and is associated with between 1 and 2 million preventable deaths among young children each year (Collins, S. 2006-i; WHO, 2007). Expectations for the future are that the problem may increase as a consequence of global changes, such as changes in economic structure of the world, climate change and the potential increase in violent conflicts in the world. Already many of the areas in which Severe Acute Malnutrition is prevalent are areas of chronic or acute conflict. As a consequence organisations providing emergency relief in disaster-struck areas have established feeding programmes in many of their project countries. Since the predominantly centre-based treatment was replaced by an ambulatory treatment approach some of the programmes have been subject to relatively high defaulter rates. Defaulters are people who are absent from a number of scheduled weekly visits and consequently do not benefit fully from the feeding programme. Médecins sans Frontières-Operational Centre Amsterdam (MSF-OCA) has been specifically affected by this problem. Considering the size of many of MSF-OCA's feeding programmes and the defaulter rates observed it is safe to say that defaulting is the biggest contributor to not-(fully)-benefiting from the feeding programmes. Therefore this issue deserves further consideration.

## 2. Problem statement and objective

The central problem of this thesis is: how can MSF-OCA decrease its default-rates? It's aim is to identify key factors that underlie the phenomenon of defaulting which can be addressed in the set up of Ambulatory Therapeutic Feeding Programmes and during the implementation of MSF-OCA's new and existing programmes.

This thesis explores causes and proposes measures to reduce defaulting obtained from literature, observations and field-research.

## 3. Background

The treatment of Severe Acute Malnutrition has evolved over the last decades of the previous century. Initially malnourished patients were being treated in hospitals, but a lot of discussion arose about the efficiency and cost-effectiveness of their treatment. Specialised Therapeutic Feeding Centres were developed, with a 2- or 3-phase treatment approach (stabilisation phase

* Severe Acute Malnutrition (SAM) is defined as a Weight-for-Height (or Weight-for Length) measurement of 70% or less below the median, or 3 SD or more below the mean NCHS reference-values or WHO standard-values, the presence of bilateral pitting oedema of nutritional origin, or a MUAC of less than 110 mm in children between 1 and 5 years old

and rehabilitation phase, later with a transition phase in-between). The concept of these centre-based Therapeutic Feeding Centres was embraced by emergency relief organisations.
MSF-OCA established its first Therapeutic Feeding Centres in 1988 in Sudan. The first formally protocolised programmes were implemented in Somalia around two years thereafter (Shoham, J. 2005). The treatment was organised in Therapeutic Feeding Centres where through the use of specialised milk-based diets and standardised medical treatment high-quality treatment was achieved. Children mostly stayed in the centre together with their caretakers (usually the mother or another relative) for approximately 3 to 4 weeks. Many children gained weight at a rate of 10-20 grams per kg bodyweight per day. This "classic" approach showed a high treatment-quality, but sometimes had a relatively low coverage among malnourished children.
Although feeding programmes with ambulatory components had been executed for many years a break-through in the development of ambulatory treatment methodology was made from 2002 onwards. The development of Ready To Use Food items (Briend, A. 1997-2) inspired the further development of ambulatory treatment systems. Ready to Use Therapeutic Food is specialised food for patients with Severe Acute Malnutrition. It is energy dense and nutrient dense food, which, because of its low water-content, cannot be contaminated with bacteria and is therefore much safer to be consumed at home than milk and liquid milk-products. A number of products have been developed in this food-category:

- BP100; a bar based on milk components and cereal
- Eezee paste; a paste based on milk components
- Plumpynut; a paste based on peanut and milk components

A fourth product, BP5, a nutritious bar designed for supplementary feeding, is not counted as a Ready to Use Therapeutic Food item, but is sometimes used in Ambulatory Therapeutic Feeding Programmes. Its contents are less favourable to promote rapid body growth in children with Severe Acute Malnutrition. The same applies to Corn-Soya-Blend. In exceptional circumstances this porridge-mixture is used as a last-resort food item in an Ambulatory Therapeutic Feeding Programme. It is, however, intended for use in Supplementary Feeding Programmes and General Food Distributions.

Emergency relief organisations saw important advantages of this “new” ambulatory treatment approach:

- Rapid set-up of Ambulatory Therapeutic Feeding Programmes generally requires less preparation time than a centre-based Therapeutic Feeding Programme; allowing more rapid start of intervention and implementation under poorer security conditions (Collins, S. 2002)

- Higher coverage among severely malnourished children is achieved more rapidly. This related to the possibilities to decentralise the treatment in ambulatory locations and to the higher acceptability for families with a malnourished child as the new treatment does not often require the caretaker and the malnourished child to stay overnight in a centre (Collins, S. 2001)
- Lower risk of nosocomial infections between children admitted for severe malnutrition (Collins, S. 2002)

Advantages for the (families of) patients include:

- Lower time-investment required for the caretaker of the child; programmes require most of the admitted children and their caretakers to visit the centre only once per week
- Most care-takers do not need to stay overnight in a facility and those who do only need to stay overnight for a few days, something which makes the programme more culturally acceptable in many places, and lowers the threshold for early presentation of malnourished children

The ideal set up of ambulatory feeding programmes includes a number of ambulatory sites with one in-patient facility (In-patient Therapeutic Feeding Centre) to treat the most severe cases. To distinguish between children who can be treated in the ambulatory sites versus the ones who need to be admitted as inpatients the terms ‘complicated’ and ‘uncomplicated’ malnutrition were introduced. ‘Uncomplicated' are generally the children with moderate forms of kwashiorkor, and marasmus, without obvious medical complications and with –most importantly- good appetite. Children who have developed advanced forms of kwashiorkor; extremely severe marasmus, serious additional medical conditions and/or a poor appetite are labelled with ‘complicated malnutrition’ and advised to accept treatment in an in-patient facility.

MSF-OCA has established Ambulatory Therapeutic Feeding Programmes in many of its areas of operation. Although the choice between “classical” centre-based Therapeutic Feeding Centres and “new” Ambulatory Therapeutic Feeding Programmes is based on local circumstances, the latter has become the organisation’s principle mode of intervention in Severe Acute Malnutrition (MSF, 2007). In 2005 a total of 41 Therapeutic Feeding Programmes had been developed, 13 of those following the “classical” principle, while 18 had ambulatory components. The remaining 10 were “classic” Therapeutic Feeding Programmes based in hospitals. Out of the 16.368 individuals treated for severe acute malnutrition in 2005, more than half, 8.730 (53%) were treated in ambulatory programmes. In 2006 there were 33 feeding programmes, of which 21 had an ambulatory component. A total of 11.707 children were treated in therapeutic feeding programmes 7.081 (60%) of whom in ambulatory programmes.

## 3.1 Ambulatory treatment: various names and strategies

The different organisations that shifted from predominantly centre-based interventions to ambulatory programmes for treatment of Severe Acute Malnutrition use a number of different names for their programmes. Until some time ago the term Outpatient Therapeutic Programme (OTP) was often heard, but this term seems to have fallen into disuse. One organisation refers to its pilot-projects as Community-based Management of Acute Malnutrition (CMAM) (Save the Children, 2007), but most organisations, including Non-Governmental Organisations as well as United Nations-agencies, use the term Community-based Therapeutic Care (CTC). With both terms implementers indicate to have their focus on treatment of severe malnutrition while working closely with the community. Often key-community members (e.g. village elders, religious leaders, Traditional Birth Attendants and traditional healers) are contacted and requested to participate in or to facilitate the programme. Generally these organisations carry out a thorough preparation of the programme before engaging in treating severely malnourished children.

MSF-OCA calls its home-based therapy programmes for Severe Acute Malnutrition: "Ambulatory Therapeutic Feeding Programmes". Focus is on the immediate implementation of treatment of severely malnourished children and, compared to most other agencies, less on the connection with the local community. Irrespective of whether the Therapeutic Feeding Programme is centre-based or ambulatory, MSF maintains similar principles of nutritional and medical treatment (MSF, 2006).

## 3.2 Defaulting in feeding programmes

The word 'default' means different things in different contexts. In nutrition the word defaulter is used for every patient who is absent from 2 or 3 consecutive scheduled feeding centre visits. When a patient does not show up for the first time he/she is labelled "absent". After 2 or 3 consecutive absences the patient is labelled as a "defaulter". While some organisations consider someone a defaulter after being absent for 2 consecutive weeks others organisations count someone as a defaulter after 3 consecutive weeks of absence (MSF, 2006; Valid International, 2006).

MSF-OCA has always considered an absence of 2 consecutive scheduled visits as the cut-off for labelling a person to be a defaulter. In the times when all Therapeutic Feeding Programmes were centre-based the cut-off was 2 consecutive days of absence (MSF, 1995). This definition has been changed to 3 consecutive days in In-patient Therapeutic Feeding Centre (in order to create sufficient time for tracing the patient) and 2 consecutive weeks in Ambulatory Therapeutic Feeding Centre (MSF, 2006). Reason for the latter definition is the notion that when a child misses the therapeutic food and medication for 2 weeks he/she does no longer enjoy any of the program's benefits. The same definition for defaulting from ambulatory therapeutic feeding is

suggested by the Department of Human Nutrition in India (Gupta, P. 2006) and was used by Save The Children in Ethiopia. They found low default-rates in their programmes using this definition of labelling someone a defaulter after missing two consecutive weekly visits (Chaiken, M.S. 2006).

Other organisations and programmes suggest slightly wider definitions. According to Collins et al in 2006 general practice was to count someone as a defaulter upon missing his/her 3rd consecutive scheduled visit; this to allow enough time for follow-up and encouragement to return to the programme (Collins, S. 2006-ii). It is certainly advised to do so by his organisation's general guidelines for the set-up of ambulatory feeding programmes (Valid International, 2006). MSF-programmes besides those operated by MSF-OCA also define a defaulter as a patient who misses 3 subsequent visits (personal communication, 2007).

Many organisations working in the field of emergency nutrition highlight the importance of community-based treatment programmes. Valid International, one of the organisations that have contributed a lot to development of ambulatory therapeutic treatment, has always highlighted the importance of community participation as a key component of the approach. Next to compliance (i.e. attendance, the opposite of absenteeism and defaulting) community participation is linked to early presentation and sustainability (Collins, S. 2007). Community participation is, however, a rather broad term that covers a wide variety and degrees of participatory activities.

Concern, an organisation working closely with Valid International, defines community participation in CTC as: "encompassing involvement in mobilisation and awareness-raising activities, planning, decision-making, and management of interventions, and as active involvement in community outreach work, which includes active screening, follow-up of defaulters, and health-promotion activities" (Gatchell, V. 2006).

Not all programmes and individuals involved use the same terminology. As synonyms for defaulter, terms such as absconder, abandoner or "lost-to-follow-up" are used. A complete overview of the most relevant differences in definitions used by different organisations is presented in annex 3.

### ***3.2.1 Generally accepted defaulter rates***

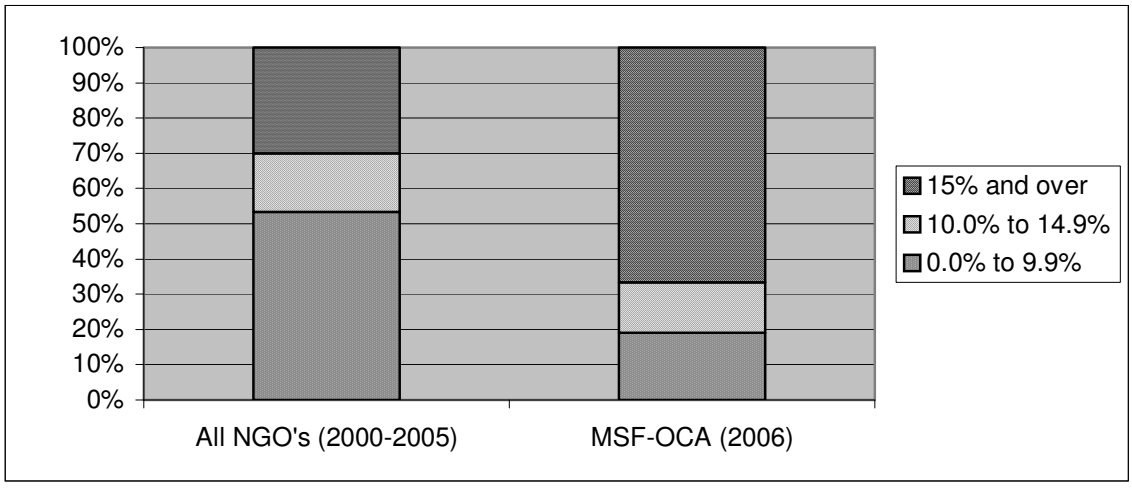
All standard outcome indicators used to measure the output of feeding programmes are ratios against the total number of children leaving the programme over a certain period of time (usually a week or a month). Out of all children leaving the programme most organisations –as is also agreed in the multi-agency SPHERE guidelines- aim at curing at least 80%, while a maximum of 15% defaulters and 5% deaths are accepted (Sphere Project, 2004). Note that these guidelines

do not take into account the difference in definitions of cured, defaulters and deaths between programmes as indicated in annex 3. MSF-OCA has always aimed for maintaining its defaulter rate below 10%, as was the case with centre-based Therapeutic Feeding Centres.
These standard-indicators have been developed during the decades in which treatment of severe acute malnutrition was mainly centre-based. It could be argued that an ambulatory feeding programme requires a different level of output indicators. MSF's new nutritional guidelines have, however, set the target for defaulters from therapeutic feeding programmes at 10% (MSF, 2006), as the organisation choose not to change its aimed output criteria beforehand.

### ***3.2.2 Default rates obtained by various agencies***

Output indicators are not often presented in peer-reviewed magazines, but a recent overview of output indicators from Community-based Therapeutic Care programmes from different Non-Governmental Organisations (including programmes carried out from 2000 to 2005) shows how out of 30 programmes 14 present a defaulter rate higher than 10%, 9 of which with a higher default-rate than the current SPHERE standard (15%) (Collins, S. 2006-ii).

*Graph 1: Default rates obtained in Ambulatory Feeding Programmes by MSF-OCA (2006, n=21) and other Non-Governmental Organisations (2000-2005, n=30) in various countries*




### ***3.2.3 Default rates obtained by MSF-OCA***

In 2005 most of the Ambulatory Therapeutic Feeding Programmes presented defaulter-rates over 10%. Centre-based Therapeutic Feeding Centres tended to do better in that year, although it must be noted that some of the centres were hospital-based facilities that did not always comply with the same discharge criteria as standardised feeding programmes. In hospital-based feeding programmes children are often admitted and discharged on criteria related to disease status and not on Weight-for-Height ratio as in standardised feeding programmes.

In 2006 out of the 22 ambulatory programmes operated by MSF-OCA only 4 ended with an annual defaulter rate under 10%, 3 with defaulter rate between 10 and 15% and the remaining 14 with a defaulter rate over 15% (see graph above).

### ***3.2.4 Causes of defaulting from feeding programmes***

Remarkably little has been published about the problem of defaulters in feeding programmes in peer-reviewed media. One article that has been published dates back to 1992 and is based on research from a "classic" feeding centre following a centre-based approach. It explains how families who default from feeding programmes do not vary clearly from families that finish the treatment. The main reason for mothers to leave the centre prematurely was concluded to be the perception that their child is no longer ill and therefore fit to return home (Nielsen, C.C. 1992). A similar importance of the perception of disease was found in a study looking at this topic in relation to ambulatory follow up treatment of Severe Acute Malnutrition (Kolsteren, P. 1997).

Although peer-reviewed publications may be limited in number, different organisations involved in therapeutic feeding have issued a variety of handbooks, papers and reports providing information on defaulting.

The SPHERE handbook for example –an inter-agency handbook with standards for disaster response- discusses defaulting and links it mainly to programme-accessibility, which it suggests to be affected by distance, security, the level of support offered to care givers, the number of dependants left at home by care-takers and the quality of care provided (Sphere Project, 2004). Valid International considers community mobilisation as a pre-requisite for follow-up of absentees and defaulters (Valid International, 2006). A handbook issued by Action Contre la Faim divides defaulters in two groups, based on the approximate duration of treatment before absence and default. Defaults happening towards the end of the treatment are said to be caused by the perception of the child having improved and are considered less serious than defaults of children who only recently started their treatment. Defaulting in those early stages is connected to provision of inadequate explanations about the treatment and poor organisation of the feeding centre (Prudhon, C. 2002).

In more recent literature the issue of defaulting was touched upon, and a decentralised set-up is advised: "In order to present early and comply with treatment, people must be able to access care. People must have physical access to the service, they must understand what the service does and be aware of the implications that their use of the service will have on their day-to-day lives. Physical barriers to access and compliance can be overcome by providing care close to where the target population lives. In humanitarian responses it often involves creating new temporary [ambulatory] access points" (Collins, S. 2007).

### ***3.2.5 Causes of defaulting in other diseases***

Defaulting plays a role not only in the treatment of severe acute malnutrition but also in different medical conditions. Contrary to the field of nutrition a lot of research into defaulting has been done in the area of tuberculosis and leprosy; both areas in which adherence and complete finishing of treatment are of paramount importance. A wide variety of factors related to defaulting were identified. Although factors leading to defaulting are inter-dependent they have been separated and/or grouped under five main headings.

Personal characteristics of defaulting patients

- Age of patient
- History of defaulting
- Sex of patient

Accessibility of the programme by the patients

- Transportation cost
- Distance to centre
- Income
- Migration
- Problems of other (family members) that may have higher priority

Acceptability of the programme by the patients

- Motivation
- Structural non-compliance
- Perception of disease-status
- Treatment (side) effects

Community support by key-community figures, like elders, religious leaders, Traditional Birth Attendants, traditional healers for the programme and out reach by the programme

- Social support
- The use of family members for compliance-improvement
- Community participation
- Active follow up of defaulters

Set-up and implementation of the programme by its staff (programme quality)

- Education of patients (by the programme)
- Provider-patient relationship
- Duration of treatment (and time-trend on defaulting)

- Decentralisation
- Adequate supply of drugs

### ***3.2.6 Defaulting is behaviour***

The factors mentioned above are all underlying aspects explaining patient-behaviour. Defaulting can be seen as a manifestation of people's behaviour and in order to disentangle its different aspects a theoretical frameworks exploring aspects of behaviour was chosen for application in this study.

A wide range of theories have been developed attempting to explain factors involved in execution of (health) behaviour, one of which the theory of planned behaviour. This theory, developed by Ajzen, based on the theory of reasoned action he developed with Fishbein in 1975, is one of the most commonly used and therefore applied in this study.

Ajzen distinguishes three categories of beliefs playing a role in the execution of behaviour. Beliefs are the perceptions of the patients that influence their behaviour (Ajzen, I. 2002):

1. Beliefs about the likely consequences of the behaviour (behavioural beliefs); in our example: do people feel or believe that the regular visiting of a feeding programme will lead to improvement in their child's health?
2. Beliefs about the normative expectations of other people (normative beliefs); these result in perceived social pressure or subjective norm; from there the questions arise concerning the role of people around the caretaker in the decision to visit the feeding programme (on a weekly basis)
3. Beliefs about the presence of factors that may hinder performance of the behaviour (control beliefs or "barriers"); these lead to perceived ease or difficulty of performing the behaviour; in other words: what are difficulties that people experience in coming to the Ambulatory Therapeutic Feeding Programme (every week)?

The combination of these three beliefs is assumed to lead to the formation of a behavioural intention. Given a sufficient degree of actual control over the behaviour, people are then expected to carry out their intentions when the opportunity arises.

Specifically the third belief (about the control of difficulties connected to carrying out the behaviour) is assumed to serve as a proxy for actual control and thus -when measured- predict the execution of the behaviour in question. To come to recommendations to decrease defaulter-rates in Ambulatory Therapeutic Feeding Programmes research into these beliefs are expected to provide useful clues for aspects that MSF-OCA could change in the way it sets up and executes these feeding programmes.

## 4. Study areas, methods and case studies

Based on the theory gathered in chapter 3 a number of study areas were identified and a methodology was designed to investigate these. A total of 5 countries were visited to carry out observations; each of these countries is introduced in this chapter.

## *4.1 Study areas*

The following study areas and questions were identified and investigated in the study.

0. Basic parameters of defaulters

   Defaulters may vary from non-defaulters in terms of age, sex, weight and height on admission or history of being absent (prior to the absence leading to defaulting); these aspects are relevant as they might help identifying high-risk groups for defaulting and provide clues on what aspects need to be further investigated. Also the likelihood of excess-mortality among the defaulters is looked at

1. Behavioural beliefs

   Defaulting may be related to the caretakers' perception on the effect the programme may have on their children. This study area starts from the perception of disease of the child (related to the reasons to bring children to the feeding programme), continues with the caretakers' view on the objective of the treatment, communication of the objective of treatment and comparison of Weight-for-Height ratio of the child by the time it starts being absent from the programme as well as average weight gain of defaulters versus cured children (do patients default because they feel they have reached a good Weight-for-Height ratio?) and caretakers' appreciation of the treatment provided as well as their knowledge about what the programme intends to versus beliefs about the programme's (and caretakers' own) effectiveness

2. Normative beliefs

   Normative beliefs of people around the patients are assumed to play an important role in defaulting. In this study area the following aspects are included: investigation of who, other than the patient's caretaker, is involved in the decision to bring the child to the feeding programme, in social pressure in favour or against weekly follow up visits, the potential of stigma attached to having an undernourished child and the role of key community members in the decision making process to visit the programme. The latter aspect is regarded in the light of importance that some organisations attribute to it in the set-up of ambulatory feeding programmes. In association to this the role of Out Reach Workers is looked at. Follow up of absentees and defaulters with Out Reach Workers makes a difference in adherence observed, but what is the exact output of Out Reach Workers and how is this related to the default rate observed?

3. Control beliefs and barriers

   Limited access to the programme and barriers people experience is likely to be associated with defaulting from the programme. Issues under this heading include: distance between programme and the patient's home, the number of decentralised sites of the programme, insecurity in the area around the programme and the lifestyle of the population (being sedentary or nomadic). Barriers investigated are those mentioned by people during interviews as well as possible direct costs (e.g. for transportation) and opportunity costs (caretakers cannot attend to other tasks or work when visiting the programme) associated with attending the programme

## *4.2 Methods*

In order to obtain the highest possible degree of quality, validity and reliability triangulation, a combination of methods and techniques allowing these to complement each other, has been applied in this study (Hardon, A. 2001). The core of the thesis is formed by the data gathered in South Sudan and Darfur. In both places therapeutic feeding was carried out in a setting "typical" for MSF-OCA; a relatively insecure setting in which movements of patients and programme staff were still possible. Both programmes were already set up before the data gathering started. Next to observations also quantitative data was gathered and interviews were carried out.

Additional data for three more countries, Burma, Ivory Coast and Ethiopia was also included in the analysis. Besides quantitative information and qualitative information from regular reports observations about the set-up of these programmes were included. The programmes in the two first mentioned programmes are specifically interesting because of their relatively low defaulter-rates, providing insight in characteristics of programmes that have favourable outcome indicators.

In order to widen the range of data collected as much as possible, all relevant documents available in 2007 within MSF-OCA were included. Thus information from two additional contexts (Beluchistan, Pakistan and Zimbabwe) is added to this study.

### *4.2.1 Quantitative methods*

In order to identify whether defaulters differ significantly from non-defaulters in the feeding programmes statistical data obtained from patient files from projects in South Sudan and Darfur were analysed using Excel and Epi-Info. Variables studied include: age, sex, weight and height on admission as well as last known weight and height. The number of visits made before being absent was assessed in Burma, Darfur and South Sudan. To identify the influence of "distance" (from the patient's home to the nearest treatment location) travel data from defaulters and cured children was gathered in Darfur.

### *4.2.2 Qualitative methods*

Qualitative techniques were used to validate all the other hypotheses and questions. Techniques used include interviews, observations and data obtained from regular reporting.

Interviews

In two case studies individual in-depth interviews, in particular semi-structured interviews, with programme beneficiaries were conducted.

In the first main case study (South Sudan) a topic list was prepared and relied upon for open questions to introduce topics of interest and allow for asking further questions depending on the circumstances and spontaneous remarks by respondents. The topic-list used is displayed in annex 1. These interviews functioned as pilot-tests for further interviews based on a questionnaire conducted in the second main case study (Darfur); this questionnaire is available in annex 2. On average the interviews took between 20 and 30 minutes.

Interviews were recorded on tape, as was the instant translation. The questions and the translations were transcribed literally; these transcripts are available in annex 4 (available on request).

*Table 1: Included data per main case study area*

| Country | Quantitative data analysis | Observation | Regular report | Beneficiary interviews | Staff interviews |
|---|---|---|---|---|---|
| South Sudan | + | + | + | 9 | 2 |
| Darfur | + | + | + | 6 | - |

*Table 2: Included data per secondary case study area*

| Country | Quantitative data analysis | Observation | Regular report | Final report |
|---|---|---|---|---|
| Burma | + | + | + | + |
| Ivory Coast | - | + | + | - |
| Ethiopia | - | + | + | - |

Observations

By spending several days in the feeding centres and clinics where feeding activities were conducted additional information could be gathered and data from interviews could be verified. Observations were focussed towards the study areas of paragraph 4.1.

Regular reporting

Within MSF-OCA all projects with feeding programmes of more than 20 children are required to conduct regular (weekly or monthly) reporting. Ideally a quantitative report (containing numbers of admitted and discharged patients) and a narrative report are provided. These reports are provided by all projects, although sometimes some questioning and probing was needed to acquire additional relevant information in order to derive a full picture of the situation.
Some projects produce additional reports, e.g. reports after closing or handing over a project. When available and relevant data from these are included as well.

## *4.3 Case studies*

This research was conducted while being employed by MSF-OCA as Field Nutrition Advisor. The position has been filled from January to December 2007 with "improvement of defaulter-rates in Ambulatory Therapeutic Feeding Programme" as its main objective.
During the study-period five field visits to areas with Ambulatory Therapeutic Feeding Programmes have been conducted.

Visited areas were selected based on requests from the different Medical Coordinators employed in each area. In MSF-OCA's head quarter these requests were gathered and evaluated. When agreed and possible a visit was scheduled. Each context is described in the paragraphs below.

*Table 3: Overview of field visits to areas with Ambulatory Therapeutic Feeding Programmes (2007)*

| Country | Date of arrival | Date of return | Number of days in the area |
|---|---|---|---|
| Burma | January 2nd | January 18th | 3 |
| South Sudan | February 9th | March 10th | 15 |
| Ivory Coast | May 23rd | June 6th | 7 |
| Ethiopia | June 13th | July 7th | 14 |
| Darfur | September 10th | October 12th | 18 |

As can be seen in the table above field visits were between two and five weeks in duration. During this time data was gathered and context-specific activities were carried out. Next to the actual project included in the case studies also other project locations were visited. Each visit

ended with a debriefing with the Medical Coordinator in which final agreements on required changes were made. Because immediate output in the form of staff training or advice was expected during each visit the time available for objective research was limited. More limitations are discussed in chapter 6.

For convenience the respondents for interviews were selected among beneficiaries present at the time of field-visit. No systematic approach was used to identify the respondents among the beneficiaries present at the programme-site. In addition respondents were found randomly during walks in the vicinity of the clinics. During such walks families were identified that had at one point been admitted into the feeding programme with at least one of their children, but who had defaulted from it.

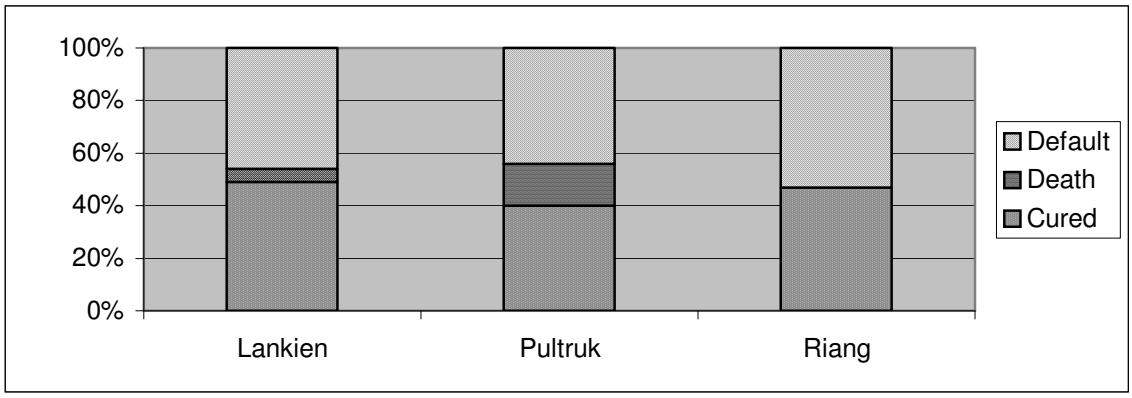
### ***4.3.1 The context of Jonglei province, South Sudan***

In South Sudan MSF-OCA has been operational since the mid-eighties. Therapeutic feeding has always been part of the programmes, initially purely centre-based, while more recently an Ambulatory Therapeutic Feeding Programme has been introduced. In the project included in the case study there is one main location (Lankien) with a two satellite clinics (in Pultruk and Riang). The main location has both an Inpatient Therapeutic Feeding Centre as well as an Ambulatory Therapeutic Feeding Centre, while the satellite locations only carry out Ambulatory Therapeutic Feeding Programme activities. In theory patients with complicated malnutrition are referred to the nearest Inpatient Therapeutic Feeding Centre (Lankien), in practice this hardly ever happens.

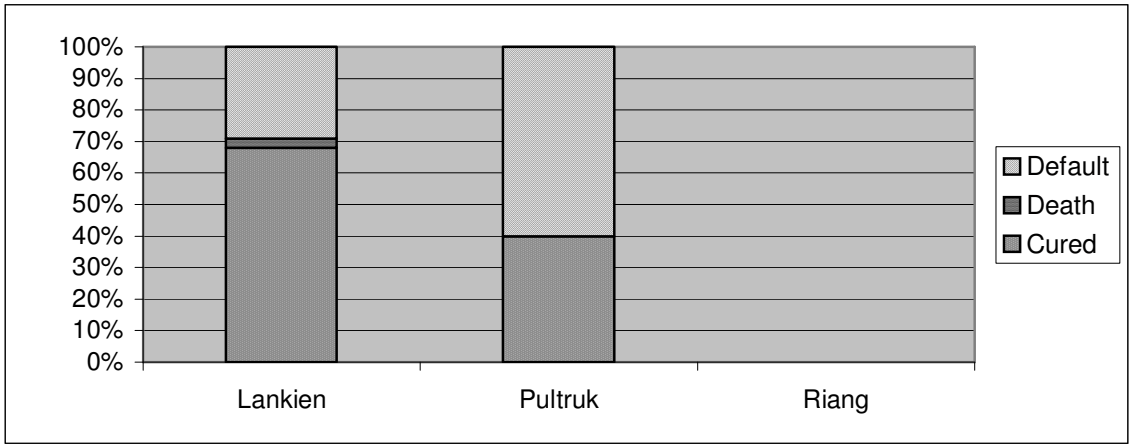
The programme's coverage area is probably the largest of all areas in this study. Population is (semi) nomadic and thinly spread all over the area. The programme is the only health care facility in a vast area.

Despite the current peace and an era of relative calmness in South Sudan Severe Acute Malnutrition is still prevalent among young children. Therapeutic feeding is still a relevant programme component.

*Graph 2: Outcome indicators obtained in 3 programme-locations in Jonglei province, South Sudan (2006, January-December; n= 364)*




*Graph 3: Outcome indicators obtained in 3 programme-locations in Jonglei province, South Sudan (2007, January-June, n=320)*




Outcome indicators have often been below standards set, also when treatment was predominantly centre-based. Presentation of data per month was not possible due to erratic data collection. Data for 2007 in Riang are lacking completely.

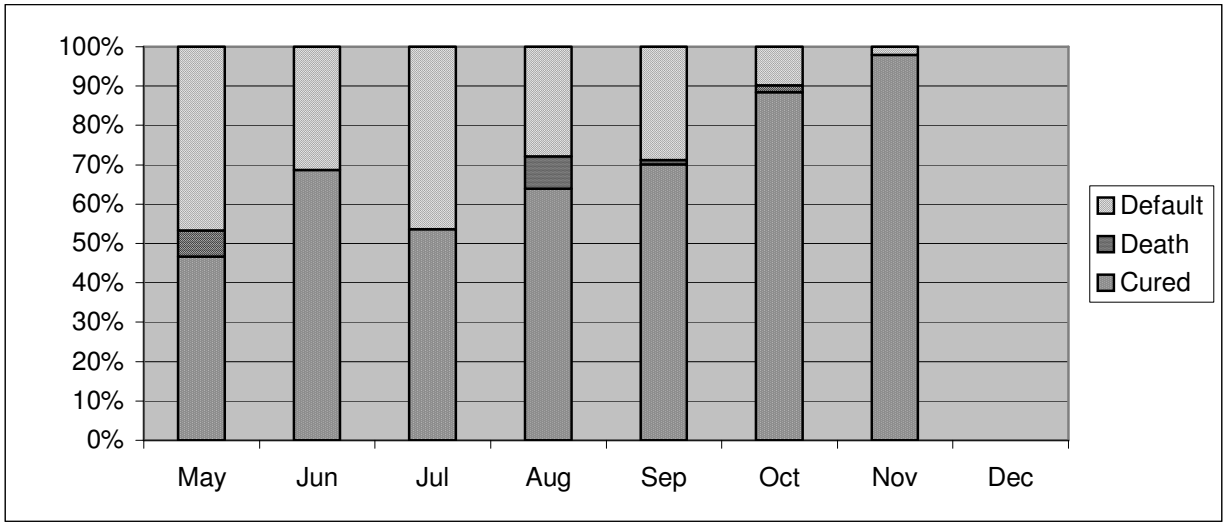
### ***4.3.2 The context of Feina, Darfur***

MSF-OCA started working in the complex conflict-area in Darfur in 2003. Since then the conflict has continued with attacks on villages on-going and people becoming internally displaced. Malnutrition-treatment has been a relevant programme component for all projects MSF-OCA established in Darfur.

At the time of the field visit the program consisted of two projects with nutritional activities. Included in this study is the programme in Feina in the Jebel Mara, which is newly started in April 2007. There is one location from where in-patient as well as ambulatory care is provided for children with Severe Acute Malnutrition. The level of care in the In-patient Therapeutic Feeding

Centre is as high as possible as the programme location is very remote and for nutritional cases there is essentially no referral option.

*Graph 4: Outcome indicators Ambulatory Therapeutic Feeding Programme in Feina, Darfur (2007 May-December, n=399)*



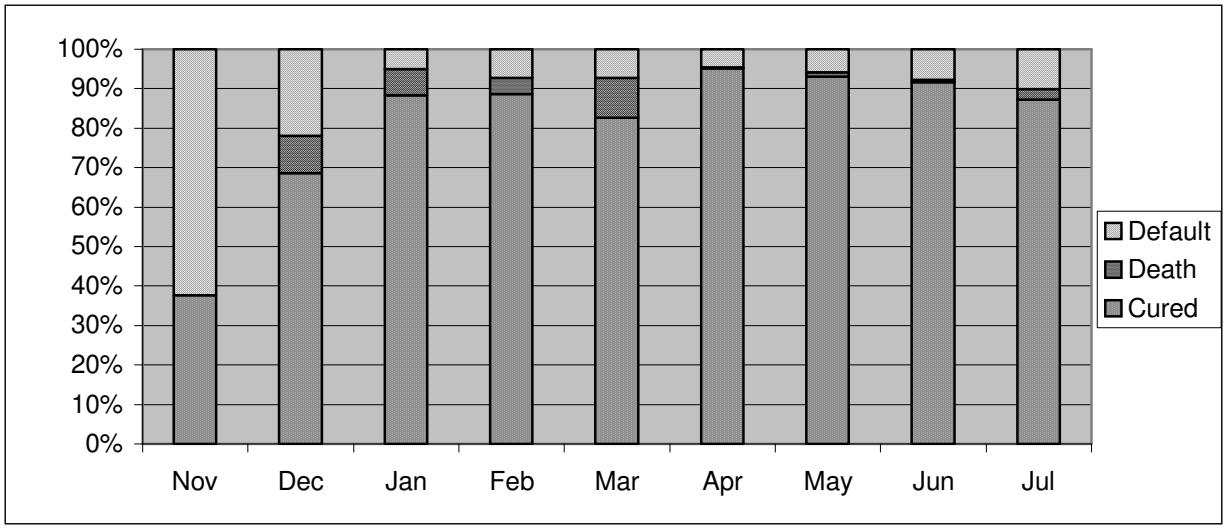

After an initially difficult start in terms of output indicators the output has improved over the last months of 2007.

### ***4.3.3 The context of Sittwe, Burma***

MSF-OCA has been operational in Burma (also called Myanmar) since 1992. Current project-locations, besides in the former capital Yangon, are in border-areas with neighbouring countries as these are the areas where the most marginalized populations reside. During 2006 it was noticed that prevalence of Severe Acute Malnutrition increased in the area around Sittwe, a harbour-area in the northeast of the country, inhabited by both Buddhist citizens as well as Muslim populations. Severe Acute Malnutrition was noticeably more prevalent in the young children of the latter group.

The township Sittwe is a group of one island and several peninsulas covered with small villages and towns. The total number of people in the township is estimated to be 240.000, of which 65% live within 5 miles of Sittwe town in the southern half, with the north-eastern part less densely populated. MSF-OCA has a clinic in Sittwe town, normally focussing on malaria, HIV/AIDS, tuberculosis and Sexually Transmitted Diseases. Initially an Ambulatory Therapeutic Feeding Programme was started from this clinic in Sittwe town only, but by the end of 2006 six more ambulatory treatment locations and one Inpatient Therapeutic Feeding Centre were set-up. The research data collection in Burma was extremely limited as it was felt that any obvious data-collection could have negative implications on MSF-OCA operationally. Observations and conclusions are for a large part based on post-visit communications.

*Graph 5: Outcome indicators Ambulatory Therapeutic Feeding Programme in Sittwe, Burma (2006-2007 November –July, n=1565)*



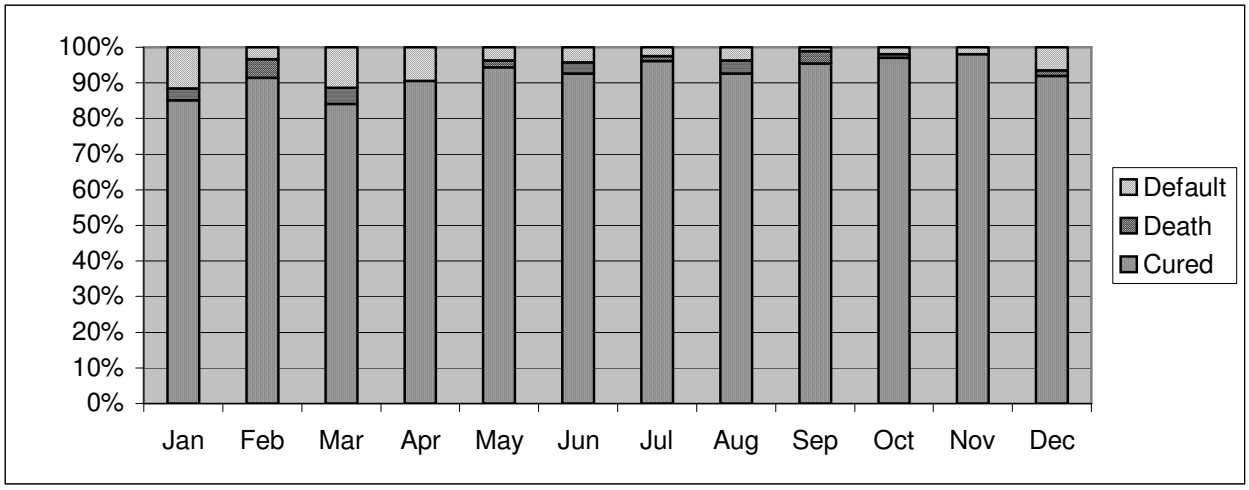

Besides the initial start-up phase in which low cure rates are common and accepted the programme has had favourable results until its handover to Action Contre la Faim in August 2007.

### ***4.3.4 The context of Bin Houyé, Ivory Coast***

Following a coup in 1999 a civil war broke out in Ivory Coast in 2002. It was in this time that MSF-OCA had its biggest operations in the country. Project locations Danané and Bin Houyé are set up respectively north and south of the corridor ('zone de confiance') that was set up to separate armed forces from the North and the South of the country.

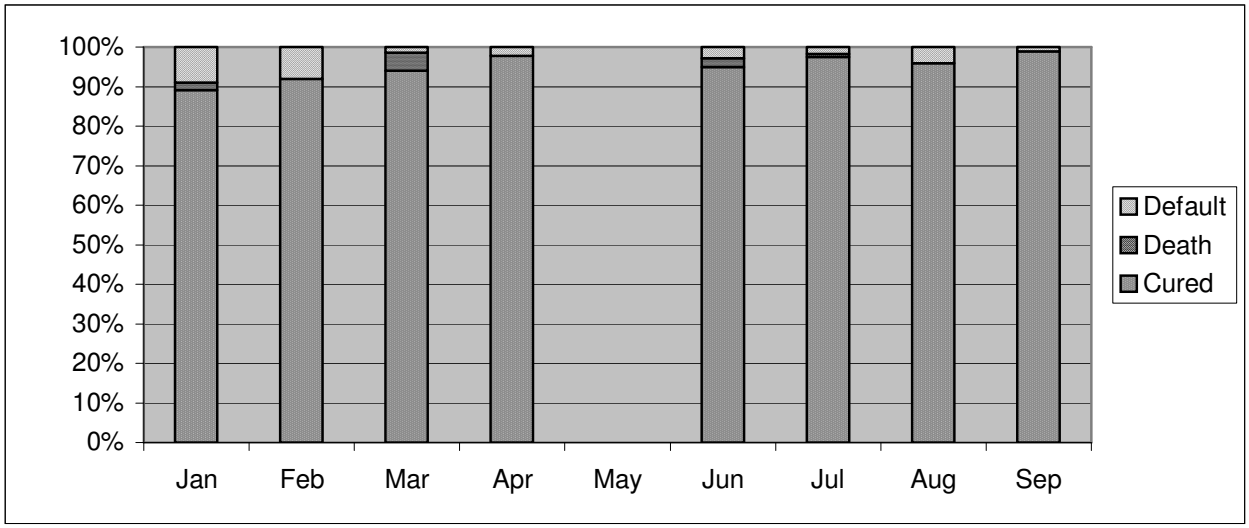
In Bin Houyé therapeutic feeding activities have always been part of the project, while in Danané these were started in May 2007. Data and observations from Bin Houyé are included in this thesis, as the project in/around Danané had not developed enough to gather useful data.

*Graph 6: Outcome indicators Ambulatory Therapeutic Feeding Programme in Bin Houyé, Ivory Coast (2006, January-December n=1305)*




Default-rates in Bin Houyé project are well within the standards set and have been maintained so until the programme was closed in 2007.

*Graph 7: Outcome indicators Ambulatory Therapeutic Feeding Programme in Bin Houyé, Ivory Coast (2007, January-September, n=907)*



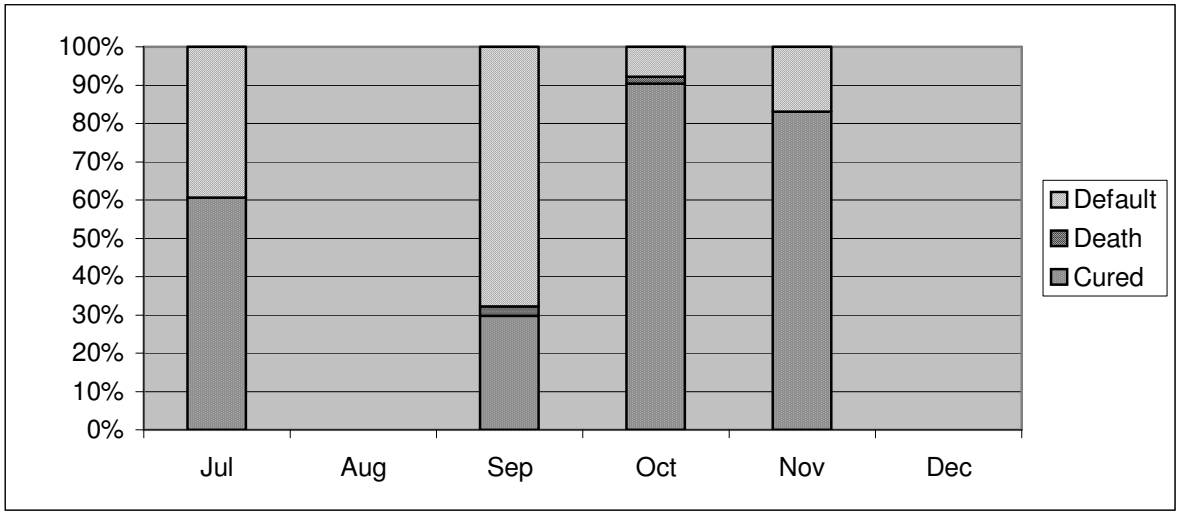

### ***4.3.5 The context of Abdurafi, Ethiopia***

A field-visit was carried out in order to assist the programme with improving their ambulatory feeding programme. The programme in Abdurafi has been operational since 2003. A large centre-based programme has been operated since then, but in order to improve coverage the decision was made to expand the programme with four ambulatory sites. Each of these sites would be staffed with one Nutrition Assistant who would be permanently based in the location to

do early case finding, with help of local Community Health Educators who are volunteers. Once per week the Nutrition Assistant would see all the children in the Ambulatory Therapeutic Feeding Programme, and a team from Abdurafi would be travelling to each location on this specific day in order to assist the Nutrition Assistant. The Nutrition Assistant would also carry out absentee and defaulter follow-up.

Because the programme had just been set up further information about beneficiaries, their views on accessibility, reasons for admission, aim of treatment, the facilities, appreciation of the programme, and possible obstacles hindering their regular visits to the project could not be assessed. Find below remarks on the issues that were commented on in monthly reports throughout the first months after opening.

*Graph 8: Outcome indicators Ambulatory Therapeutic Feeding Programme in Abdurafi, Ethiopia (2007, July-December, n=298)*




## 4.4 Ethical considerations

Guiding principles on ethical dilemma's in any form of research are focussed towards three basic area's; respect for the people involved in the study, maximizing the potential benefits of results of the research for people –including the studied individuals, and the avoidance of harm to the people investigated (Hardon, A. 2001).

Data collected in the study was as much as possible limited to data already collected for programme execution. Additional data was obtained only through interviews with a small number of programme beneficiaries.

In order to mitigate the most relevant ethical considerations people were approached with the question whether they would be willing to take part in an interview about the feeding programme.

Beneficiaries of the programme were recruited from the waiting area or after their treatment had taken place. It is recognised that doing this may make people feel to have little choice in the matter; in order to mitigate this risk both interviewer as well as translators were alert on non-verbal signs possibly indicating people's discomfort or unwillingness to participate.

Informed consent was obtained specifically before each interview, including permission to tape the conversation; the tape was started only after the respondent expressed his or her agreement. None of the respondents refused collaboration.

Confidentiality of the data obtained was ensured before and kept during each interview and data processing; to ensure anonymity names were avoided, although occasionally first names of children were used; these names were not included in transcripts of interviews

Conclusions drawn from the interviews were discussed with programme staff in each location in order to improve the service to the patients.

## 5. Results

# *5.0 Basic parameters of defaulters*

Numerical data on the defaulters and on cured children were collected for a comparison in South Sudan and Darfur. Both data sets indicate relatively few differences between both groups.

### *5.0.1 Age, sex and Weight-for-Height on admission*

Based on a cohort of patients from 2006 (selected were those patients from whom reliable data could be obtained, meaning children admitted in Lankien between June and December 2006, in Pultruk between February and October 2006 and in Riang between August 2006 and January 2007, as during this period an adequate level of supervision was carried out over this part of the data collection) the following data were obtained.

*Table4: Characteristics of defaulters (sample from Jonglei-province, South Sudan)*

| | Lankien | Riang | Pultruk | Total |
|---|---|---|---|---|
| N | 22 | 24 | 23 | 69 |
| Age (mean, years) | 1.48 | 1.85 | 1.04 | 1.46 |
| Sex (M-F, absolute number in sample) | 8-14 | 18-6 | 12-11 | 38-31 |
| Weight-for-Height on admission** | 69.2% | 69.8% | 66.4% | 68.5% |

Observed differences between the locations are attributed to the relatively low numbers in the separate samples.

*Table 5: Characteristics defaulters versus cured (sample from Lankien, South Sudan)*

| | Cured + discharged | Defaulters |
|---|---|---|
| N | 36 | 22 |
| Age (mean, years) | 2.04 | 1.48 |
| Sex (M-F, absolute number in sample) | 19-17 | 8-14 |
| Weight-for-Height on admission | 68.2% | 69.2% |

The only observed difference is that defaulters seem to be slightly younger than children who get cured. A gender difference was proven not to be significant.

** Presented is the average percentage of the median weight according to height, based on the NCHS-reference (South Sudan) and WHO-standard (Darfur)

A comparison between 106 cured and 63 defaulting children from Darfur who left the programme during its first 3 months of operation did show no significant differences. Age did not come up as significantly different. The only factor the groups varied in, was distance to the project. This is discussed in paragraph 5.3.

*Table 6: Characteristics defaulters versus cured (sample from Feina, Darfur)*

| | Cured | Defaulters |
|---|---|---|
| N | 106 | 63 |
| Age (mean, years) | 1.62 | 1.68 |
| Sex (M-F, absolute number in sample) | 56-50 | 43-20 |
| Weight-for-Height on admission | 75.9% | 74.2% |

The observed gender in-balance is statistically significant (p=0.049). In the light of other gender imbalances that seemed relevant in the early weeks of the programme, but which disappeared after the programme was open for a longer period of time the observation was not regarded as relevant.

### ***5.0.2 "Expected" mortality***

From the above it becomes clear that defaulters and cured children do not vary much in terms of disease-status on admission. This is confirmed when comparing the "Prudhon-index" of both groups. This index quantifies the theoretical risk of mortality per case based on the child's weight, height and oedema-status on admission, and thus represents the "expected" mortality of a group of patients.

*Table 7: Expected mortality defaulters versus cured (sample from Jonglei-province, South Sudan)*

| | Cured | Defaulters |
|---|---|---|
| N | 36 | 69 |
| Number "expected" to die | 2.2 | 4.7 |
| Percentage "expected" to die | 6.1% | 6.8% |

*Table 8: Expected mortality defaulters versus cured (sample from Feina, Darfur)*

| | Cured | Defaulters |
|---|---|---|
| N | 106 | 63 |
| Number “expected” to die | 3.4 | 2.6 |
| Percentage “expected” to die | 3.2% | 4.2% |

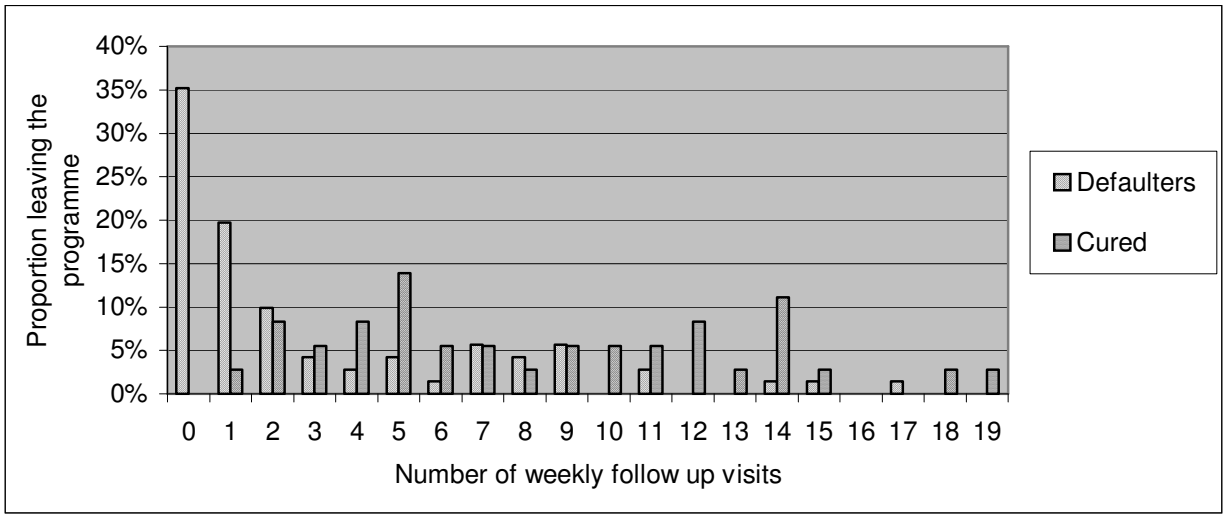
In both contexts the difference observed proved not to be statistically significant (stratified analysis: p=0.4).

The Prudhon Index was developed to compare “expected” mortality with observed mortality. Due to the fact that defaulters –by definition- are lost in to follow up this was, however, not possible. The assessment is only relevant as a comparison of the start-position of both patients groups.

### ***5.0.3 The number of visits before defaulting***

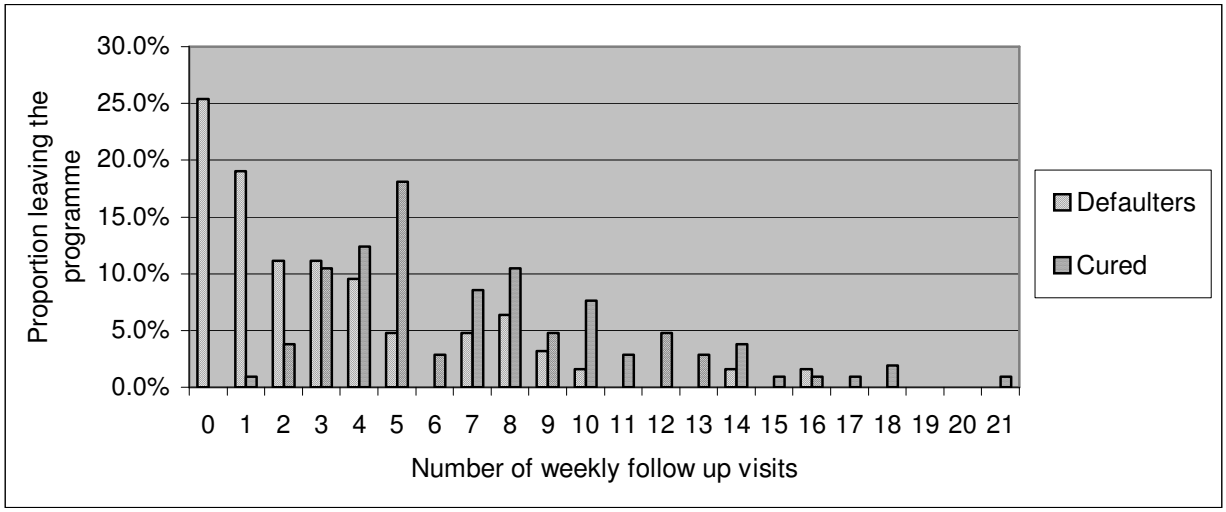
In all programmes the biggest group of defaulters start being absent immediately after being admitted into the programme.

*Graph 9: Difference in number of weekly follow up visits defaulters versus cured children (sample from Jonglei province, South Sudan)*



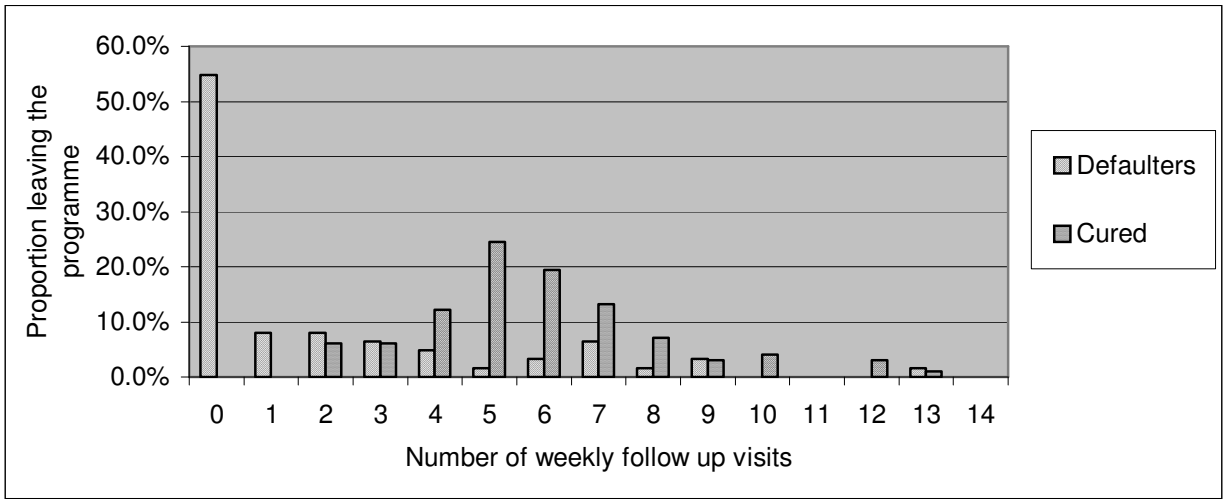

One can see the vast majority of defaulters default in the early part of treatment, with 35% defaulting after only one visit to the centre and another 20% after having made only one weekly follow up visit.

*Graph 10: Difference in number of weekly follow up visits defaulters versus cured children (sample from Feina, Darfur)*




A similar picture is derived from the analysis of patients cured and defaulting from Feina (Darfur). Around half of the defaulters have occurred after having made a maximum of 2 return visits to the programme.

*Graph 11: Difference in number of weekly follow up visits defaulters versus cured children (sample from Sittwe, Burma)*




Also in Sittwe the majority of the defaulters visit the programme only once.

A division has been made between early defaulters (defined here as making no or one return-visit) and late defaulters (children who are brought for 2 or more follow up visits, but default after that.). This splits the group roughly in two: half the defaulters can be assumed as early defaulters and half as late defaulters.

### ***5.0.4 The connection between ambulatory and in-patient treatment***

While examining the number of visits before defaulting a noticeable difference between locations was observed in South Sudan. The difference appeared to be in-line with standard treatment policies in each location.

*Table 9: Comparison average length of stay versus Weight-for-Height ratio before defaulting between 3 locations (Jonglei province, South Sudan)*

| Location | Length of stay (overall) | WfH last known (WHPM, mean) | Standard admission policy |
|---|---|---|---|
| Lankien | 47.5 days | 73.3 | Children admitted into 24-hour-care until cured |
| Pultruk | 11.7 days | 70.3 | Children admitted into day-care for first week, weekly care thereafter until cured |
| Riang | 5.6 days | 70.4 | Children admitted into weekly care until cured |

Referrals between Ambulatory Therapeutic Feeding Programme locations and In-patient Therapeutic Feeding Centre were also problematic in Sittwe (Burma). Various people defaulted because they did not want to go to the in-patient facility that they were referred to, or they defaulted after staying in the centre for several days.

Some patients prefer being admitted as in-patients over weekly visits to the feeding programme. Security implications of travel play a major role in this (Source: Interview 12, page 4).

| | |
|---|---|
| *Interviewer:* | *[…] What could MSF do in order to help her overcome these difficulties or to decrease these obstacles?* |
| *Translator:* | *She is saying that the main [thing] what the MSF should have to do for her is that there is a ward […] because she lives very far, that to be keep here till her child will be cured, then she will be discharged and because the time and the risk is just obstacle for her to come [weekly…]* |

*Source: Darfur, Interview 12, page 4*

More information on security-implications and other barriers people perceive will be presented in chapter 5.3.

## 5.1 Behavioural beliefs

In relation to how caretakers view their ability to improve the condition of their children with the assistance provided by the feeding programme it is interesting to investigate how people perceive the disease status of their children. Aspects of this are the care-taker's reason to bring their children to the feeding programme, their appreciation of the treatment, their view on the objective of the treatment, communication of the objective of treatment and the Weight-for-Height ratio of the child by the time it starts being absent from the programme (do care-takers default because they feel the patient has reached a good Weight-for-Height ratio?)

### 5.1.1 Actual perception of disease

When people are asked about the reason their child was admitted or what the condition was at the time of admission many mention health complaints as the main reason for visiting the clinic and admission into the programme (Source: Interview 02, page 1; Interview 13, page 3; Interview 14, page 2).

| | |
|---|---|
| *Interviewer:* | *[…] why in her own words are her children admitted in our feeding programme?* |
| *Translator:* | *Because of the sickness and of the weakness of the children, that led her to bring them here, after the prescription of the doctors […] they [have been] admitted here, because of the bad health […]* |
| | *Source: Darfur, Interview 13, page 3* |

Few mothers, however, do mention "malnutrition" or weight loss specifically as one of the reasons for admission into the feeding programme (Source: Interview 03, page 1; Interview 06, page 1; Interview 08, page 1).

| | |
|---|---|
| *Interviewer:* | *So, why was one of her children admitted and the other one not?* |
| *Translator:* | *She say[s] that, because the weight was loose, that is why we admit the child* |
| | *Source: South Sudan, Interview 06, page 1* |

### 5.1.2 Appreciation of the programme

Staff observed was friendly and professional (as far as can be expected of moderately educated staff members). Most patients explain to be treated well by the clinic staff; no complaints were heard during the interviews (Source: Interview 13, page 5).

| | |
|---|---|
| *Translator:* | *[…] when we come here [...] we become very relaxed because the people are treating us very well and […] all time they are welcoming us, there is mats for us this is a very good treatment […]* |

*Source: Darfur, Interview 13, page5*

All facilities were observed as quite primitive and simple. Toilets were often of moderate quality and hygiene standards, but none of the structures seemed "strange or poor" in their context. Drinking facilities for patients were quite limited, especially in the out-reach facilities.

Critical remarks against the facility were not made during any of the interviews, although this may well be related to the fact that overall people were happy with the result of the treatment (Source: Interview 01, page 4; Interview 02, page 1).

*Interviewer:* *All right. Is there anything else about the programme that she would like to tell me?*

*Translator:* *I can't say something because in that time my child became OK*

*Source: South Sudan, Interview 01, page 4*

*Interviewer:* *Does she have any suggestions of how we can make this clinic better?*

*Translator:* *She say the clinic, the child, first is malnourished, but now is good the child*

*Source: South Sudan, Interview 02, page 1*

Also in Darfur no relevant changes to the facility were suggested. One parent hoped the centre would be supplied with electricity (Source: Interview 14, page 3) and expresses her gratitude for the treatment she received (Source: Interview 14, page 5).

*Interviewer:* *All right. Well thank you very much. Is there anything else they would like to tell me that is relevant for the feeding centre?*

*Translator:* *OK, well they say they have nothing, but only they say "khiberkay" which is "thank you very much"*

*Source: Darfur, Interview 14, page 5*

### ***5.1.3 Appreciation of therapeutic food provided***

Mothers indicated that they (or the child) had to get used to the therapeutic food (Plumpynut), but that after that they were eating it well; they liked the taste and consequently the mothers were happy for their child to eat it (Source: Interview 01, page 2; Interview 02, page 2; Interview 05, page 2 Interview 13, page 3 Interview 14, page 2; Interview 15, page 1 Interview 17, page 1 Interview 13, page 3).

*Interviewer:* *And did she like the taste, the child? Did the child like the taste of the food?*

| | |
|---|---|
| *Translator:* | *At first time she will fear with that food, because she is new and when it was putted to his mouth he would taste it and would sign it is very sweet and then he will allow to eat it* |
| | *Source: South Sudan, Interview 01, page 2* |

### ***5.1.4 Side effects therapeutic food and medication provided***

Among the caretakers interviewed negative side effects of the therapeutic food (Plumpynut) were not mentioned; quite the opposite: mothers believed the Plumpynut to have positive capacities beyond just helping the child to gain weight (Source: Interview 12, page 3; Interview 14, page 3; Interview 17, page 1).

| | |
|---|---|
| *Interviewer:* | *Did the child ever show any negative side effects from eating the Plumpynut?* |
| *Translator:* | *She says that Plumpynut is very OK, it has no any side effects, because but she thinks that this Plumpynut has the medicine of the diarrhoea because the child [had] very watery diarrhoea, but when she start to eat this the diarrhoea stopped.* |
| | *Source: Darfur, Interview 12, page 3* |

Dislike of Plumpynut is only reported in Burma in week 16 when Out Reach Workers report that: the majority of the defaulters refused to attend the Ambulatory Therapeutic Feeding Programme because “the child does not like Plumpynut”. According to the programme-team the mothers do not want Plumpynut because there is no market for it and they cannot sell it… (Source: Narrative week 16; note that before week 16 the programme provided Corn-Soya-Blend porridge mix instead of Plumpynut).

### ***5.1.5 Effectiveness of the programme and perceived self-efficacy***

In Darfur parents were asked whether children –in the perspective of the caretaker- really needed the (weekly) visits to the feeding centre (Source: Interview 12, page 2).

| | |
|---|---|
| *Interviewer:* | *Does her child really need all the weekly visits in order to become healthy? Does she think this?* |
| *Translator:* | *Yes, she think that her coming weekly here it is very good as the health of her child so coming here weekly it means more health for her child* |
| | *Source: Darfur, Interview 12, page 2* |

In addition people were asked about the effect of the programme and about their own abilities to –with assistance from the programme- cure their children from malnutrition. Caretakers were confident in their ability to cure the child with help from the programme (Source: Interview 12, page 3 and 4; Interview 13, page 4; Interview 14, page 3).

| | |
|---|---|
| *Interviewer:* | *Another thing about the weight gain. Is it the Plumpynut and the BP5 that has caused this weight gain or some other factors?* |
| *Translator:* | *She says that mostly the thing that led the child to be better and getting better than before is the eating of BP5 and Plumpynut. Although she eats other food, but that food is not like this one that she receives here daily or weekly […]* |
| *Interviewer:* | *Do you feel that your personal effort and the food, which she is receiving from the feeding programme helps together to make the child better?* |
| *Translator:* | *Ya, she says only one word: it is very good, very good the getting better of the child is come from receiving and eating this Plumpynut and BP5 the child is become very happy taking this one* |

*Source: Darfur, Interview 14, page 3*

### ***5.1.6 Duration and objective of treatment***

Since in South Sudan many of the (key) staff members in the feeding programmes were not able to mention how long on average a treatment of malnutrition would take it was assumed that many of patients were also unaware of the expected treatment duration.
During interviews it was indeed noted how patients often have no idea until when they have to be admitted, in other words: they may not be fully aware to be in a programme that requires them to come to the clinic every week for a number of weeks in a row.

The objective of the treatment is not well understood by the caretakers. From observations in the clinic it became clear that some patients in South Sudan were told that they should be coming to the clinic until their child is "well" and therefore this issue was further questioned in the interviews in Darfur.

In Darfur the objective for most caretakers seems to be the reduction of disease and improvement of the child's development. Mothers do not often mention weight gain as an objective of treatment. Also they are unaware of how many weeks the therapy is expected to last.

This links in with the following observations of consultations in the ambulatory feeding programme;

- Target weight is not discussed specifically
- The patient files used do not allow for the weight to be plotted in a graph

- Weekly instruction often include the advise to “come back next week”, without explaining that it will probably be necessary to come back a few weeks in a row in order to meet the exit-criteria

The following quote illustrates much of the above (Source: Interview 12, page 3).

| | |
|---|---|
| *Interviewer:* | *How many weeks will her child have to come here in order to become fully healthy?* |
| *Translator:* | *[…] how many times she will come her depend to the doctors […] she don’t know exactly how many times she keep coming here* |
| *Interviewer:* | *Did the doctor give her an estimate on how many times she will have to come?* |
| *Translator:* | *The doctor not yet told her how many times she should have to come here to the treatment of her child […]* |
| *Interviewer:* | *And which conditions will have to be met before her child will be considered cured by the doctor?* |
| *Translator:* | *What led her to know that the health of the child is considerable is when the child is walk[ing] and run[ning] and play[ing…] so that will make her to make sure that [her child is] well and became well cured […]* |
| *Interviewer:* | *And how much should the child weigh before she will be considered cured?* |
| *Translator:* | *Because they have no scale of weighing, she don’t know* |
| | *Source: Darfur, Interview 12, page 3* |

Some caretakers seem to take the programmes orders quite literally and simply come because they are told to (Source: Interview 14, page 2).

| | |
|---|---|
| *Interviewer:* | *Does [name child] need the weekly visits in order to become healthy?* |
| *Translator:* | *She says that the decision of discharging or staying it is not from her, but from doctor […]* |
| | *Source: Darfur, Interview 14, page 2* |

One caretaker does mention weight gain as one of the objectives of treatment (Source: Interview 14, page 2).

| | |
|---|---|
| *Interviewer:* | *Can the mother in her own words say why [name child] is admitted in our programme? […]* |
| *Translator:* | *She is saying that [name child] admitted here so as to nutritive food like biscuits and BP5 so as to get fat* |

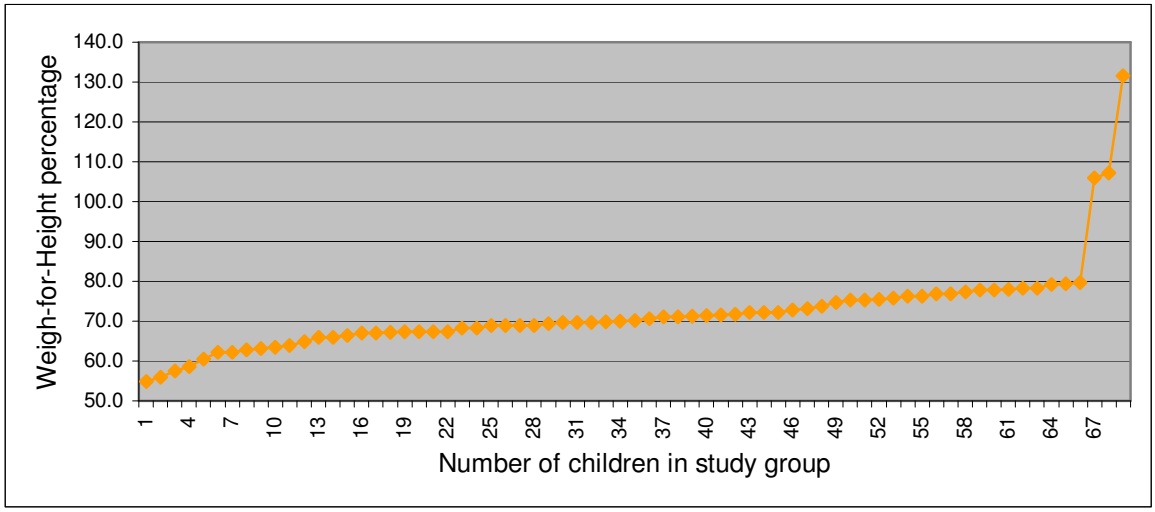
| | |
|---|---|
| *Interviewer:* | *Did she use the word 'fat'?* |
| *Translator:* | *Yes* |

*Source: Darfur, Interview 14, page 2*

### ***5.1.7 Last known weight for height of defaulters***

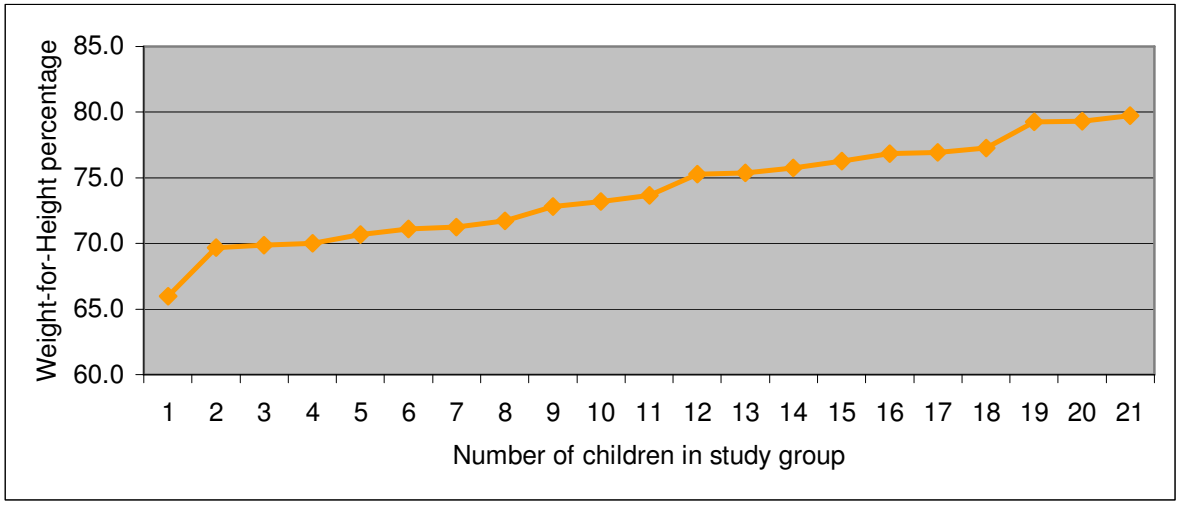
Under the assumption that people default because they approach the target weight and parents are satisfied with the weight gain achieved the last known Weight-for-Height ratios were plotted against the number of defaulters. It was expected that a vast majority of defaulters would be approaching the 80% line; a curved line was therefore expected in the graph. As can be seen the lines found are straight lines, indicating Weight-for-Height ratio does not specifically influence the decision to default.

*Graph 12: Last known Weight-for-Height ratio of all defaulters (sample from Jonglei province, South Sudan)*



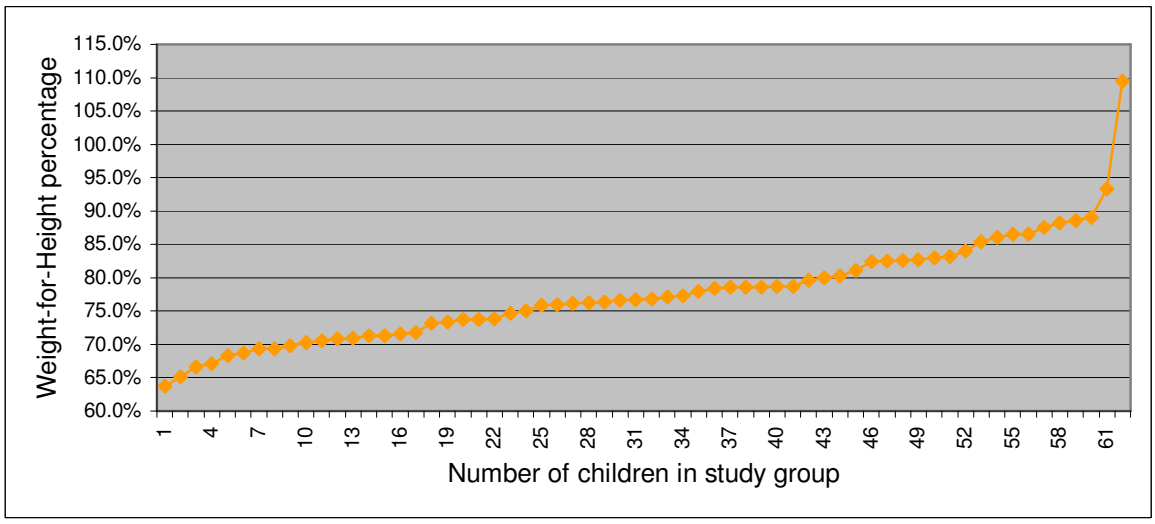

When looking at the defaulters who stayed in the programme more than 20 days (n=21, Lankien=16, Pultruk=4, Riang=1) a similar straight line is obtained; all individual children left the programme at the following Weight-for-Height median% (NCHS reference table).

*Graph 13: Last known Weight-for-Height ratio of defaulters who stayed over 20 days (sample from Jonglei province, South Sudan)*



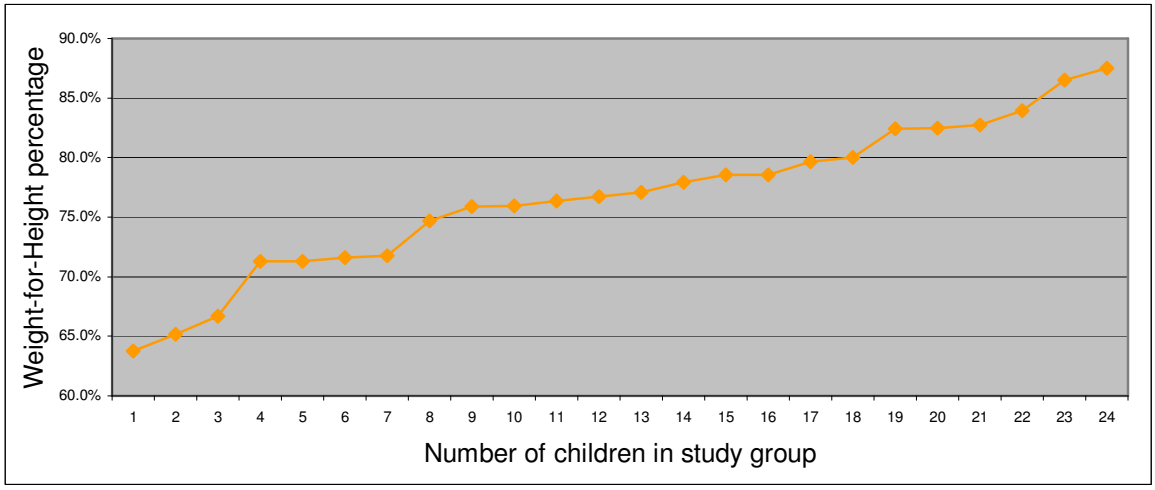

A similar picture is derived from the defaulters in Darfur.

*Graph 14: Last known Weight-for-Height ratio of all defaulters (sample from Feina, Darfur)*




A similar picture arises when looking at the defaulters who stayed in the programme >20 days again not supporting the idea that people default primarily because their child approaches target weight.

*Graph 15: Last known Weight-for-Height ratio of defaulters who stayed over 20 days (sample from Feina, Darfur)*




### 5.1.8 Average weight gain

The standardised manner to assess weight gain in feeding programmes is to calculate the average weight gain in grams per kilogram starting weight per day. The rate of weight gain observed among cured children in South Sudan is relatively low: 6.3 g/kg/day and appears to be around the same level in Burma: 6.0 g/kg/day in 2006 and 4.2 g/kg/day in 2007. In both locations there were hardly any cases of kwashiorkor (oedematous malnutrition, possibly leading to a different average weight gain).

The defaulters from the South Sudan, excluding the group who have come only once (those who after admission never came for a follow up visit) and excluding the ones who lost or didn't gain any weight (under the assumption that these might have defaulted because of dissatisfaction with the effect of the programme), (n=69-25-9=35) did present an average weight gain of 5.6 g/kg/day, which is comparable to the cured children.

*Table 10: Average length of stay in therapeutic feeding programme (all programmes MSF-OCA 2006 and 2007)*

| Year | 2006 | 2007 | Reference value (MSF Nutrition Guideline 2006) |
|---|---|---|---|
| Average length of stay (days) | 62.0 | 62.6 | <60 days |

### 5.1.9 Defaulting from different style programmes

Additional information about the length of stay before defaulting can be obtained from annual reports of all the feeding centres. These reports are standardised throughout MSF-OCA and data

obtained from different programme locations are comparable. A division has been made between (Ambulatory) Therapeutic Feeding Programmes with a Supplementary Feeding Programme and Therapeutic Feeding Programmes without a Supplementary Feeding Programme

In 2006 a total of 11.707 children were treated in therapeutic feeding facilities (classical centres, hospital-based feeding programmes and Ambulatory Therapeutic Feeding Programmes taken together); 6032 in facilities with a Supplementary Feeding Programme and 5675 in facilities without a Supplementary Feeding Programme. As can be seen in the table below the programmes without Supplementary Feeding Programme take longer to treat the children (see average length of stay) and have a higher default rate. The difference in default rate is statistically significant; $p < 0.00000$; OR = 0.42 (0.38-0.46).

*Table 11: Default rates in Therapeutic Feeding Programmes (Ambulatory Therapeutic Feeding Programme + centre-based Therapeutic Feeding Programme + hospitals) with and without Supplementary Feeding Programme (all programmes MSF-OCA, 2006)*

| | Number treated (total) | Average length of stay (cured) | Cure-rate | Default-rate | Death-rate |
|---|---|---|---|---|---|
| With SFP | 6032 | 29.4 days | 70.4% | 11.7% | 7.5% |
| Without SFP | 5675 | 41.8 days | 63.6% | 24.1% | 5.3% |

When looking at all the total of 7348 children treated only in Ambulatory Therapeutic Feeding Programmes in 2006 the difference between children defaulting from programmes with and without Supplementary Feeding Programme shows also significant; $p<0.00000$; OR=0.66 (0.58-0.74).

*Table12: Default rates in Ambulatory Therapeutic Feeding Programmes with and without Supplementary Feeding Programme (all programmes MSF-OCA, 2006)*

| Individual | Defaulters | Non-defaulters | Total |
|---|---|---|---|
| With SFP | 508 (18%) | 2245 (82%) | 2753 |
| Without SFP | 1175 (26%) | 3420 (74%) | 4595 |

Programmes without a Supplementary Feeding Programme aim to discharge children at a higher Weight-for-Height ratio than programmes with a Supplementary Feeding Programme. This means that children admitted in a programme without Supplementary Feeding Programme need to be admitted longer than those treated in a facility with a Supplementary Feeding Programme; consequently more of them default.

## 5.2 Normative beliefs

Normative beliefs of people around the patients play a role in defaulting; therefore it was investigated who, other than the patient's caretaker, is involved in the decision to bring the child to the feeding programme, their opinion about the programme and other forms of social pressure in favour or against weekly follow up visits, the potential of stigma attached to having an undernourished child and the role of key community members in the decision making process to visit the programme.

### 5.2.1 Deciding to come to the programme

Although some women operate independently from their husbands (Source: Interview 06, page 3; Interview 09, page 2) most caretakers in South Sudan and in Darfur mention their husbands when asked who was involved in deciding to bring the child to the feeding centre initially and for follow up visits during the treatment (Source: Interview 12, page 2; Interview 12, page 2). Other relatives like (grand)fathers are also mentioned (Source: Interview 17, page 2) just as neighbours and community members (Source: Interview 17, page 2). Specifically the support from community leaders appears to be important (Source: Interview 13, page 2).

| | |
|---|---|
| *Interviewer:* | *[…] who in their family has decided to bring these children here?* |
| | *[…]* |
| *Translator:* | *OK, umda walla, chief, with the chief and umda of their area, but unfortunately their umda has [been] killed…* |
| *Interviewer:* | *But normally they would ask the umda first before coming to the clinic?* |
| *Translator:* | *Ya, there is a sheikh or umda, just they collecting them some place and tell them there is a very necessary and important clinic now for your children that you should have to go there […] for treatment of your child, then they will have permission from him […]* |

*Source: Darfur, Interview 13, page 2*

In other areas like Sittwe (Burma) husbands also have a lot of influence in deciding whether or not to visit the programme. Various Out Reach Workers mention cases in which husbands blocked the weekly visits to the feeding programme.

### 5.2.2 Perceived social pressure

Social pressure from relatives and village members was assessed in Darfur. All respondents mention how the people around them all are positive about the programme and stimulate the caretakers to take their children for treatment (Source: Interview 12, page 2; Interview 14, page 4; Interview 17, page 3).

| | |
|---|---|
| *Interviewer:* | *OK, are there also some people around her who do not agree with her bringing the child here?* |
| *Translator:* | *Not at all* |
| *Interviewer:* | *Does she know more people who have a child that is admitted in our programme?* |
| *Translator:* | *Yes, yes, yes… she is saying that she know more than 10 of the mothers [who] brought their children here and all of them are admitted and all of them are their neighbours and the same time and this is a very good chance for her to be here today* |

*Source: Darfur, Interview 12, page 2*

### ***5.2.3 Stigma***

Having a malnourished child does not seem to be stigmatising at all (Source: Interview 12, page 5). People seem aware of the dangers of malnutrition and therefore stimulate each other to seek treatment (Source: Interview 13, page 6; Interview 14, page 4; Interview 17, page 4).

| | |
|---|---|
| In*terviewer:* | *Is it difficult to admit that you have a malnourished child or do people think negatively about you when you have a malnourished child?* |
| *Translator:* | *Has no defects or negative sides because they think that it is very good when you have a malnourished child and you have already a treatment of your malnourished child it is very good because it will not have negative effects […]* |

*Source: Darfur, Interview 13, page 6*

### ***5.2.4 Livelihood characteristics***

South Sudan in general and the area around Lankien in particular are extremely sparsely populated. People depend on cattle farming and live a semi-nomadic lifestyle. During the dry season most families bring their cows to a cattle camp, situated near to rivers and ponds. Part of each family moves to the cattle camp, while other family members stay behind. Throughout the season almost all members spend some time at the cattle camp, resulting in a high mobility among project beneficiaries. Having a limited number of ambulatory feeding sites is on one hand very appropriate in the setting of South Sudan as people are used to travelling long distances on foot, but on the other hand –mainly because of their cattle-based mobility- many are not able to finish treatment before discharging themselves from the programme.

The population in the area around Feina (Darfur) are almost all people from the Fur-tribe. Their main source of income is from farming and petty trade (sales of firewood, sometimes live-stock etc.). Although people have basically a sedentary life-style, many families seem to travel between

various locations on a regular or irregular basis. Many people have had to flee from their village at one or more moments in time. When asked many consider themselves to be Internally Displaced People. Movement patterns are not well known, but a considerable number of absentees are not found in the locations where they claim to live, indicating that they have moved during the time they have been under treatment in the feeding programme.

Population in Sittwe (Burma) is almost completely sedentary. A system of permits prevents people from travelling between townships and also avoids people from outside the township accessing the feeding programme in Sittwe Township. Nevertheless movements influenced the programme, be it on limited scale; reports by Out Reach Workers explain how some families moved out of Sittwe-township.

The population in the area around Bin Houyé (Ivory Coast) is sedentary; no movements are reported.

Population in the area around Abdurafi (Ethiopia) are mainly farmers who have been relocated from higher and more densely populated areas in the highlands of Ethiopia. They are sedentary in their new location, although families or family members do move back and forth between the area of origin and their new locations.

*Table13: Population's life style versus defaulter-rate observed*

| Area | Population | Defaulter rate |
|---|---|---|
| Jonglei province (South Sudan) | Semi-nomadic | Poor |
| Feina (Darfur) | Sedentary | Good |
| Sittwe (Burma) | Sedentary | Good |
| Bin Houyé (Ivory Coast) | Sedentary | Good |
| Abdurafi (Ethiopia) | Sedentary | Poor |
| Baluchistan (Pakistan) | (Semi) Nomadic | Poor |

### ***5.2.5 Community involvement***

Community involvement is a broad term including all activities that take place in collaboration with or in the communities being served by the feeding programme. Community involvement is known to be important in all projects, but the extent to which it is achieved varies. In all locations efforts are made to inform mostly key-community members and/or the general public.

In South Sudan community members were informed through meetings organised in the health units. These meetings were relatively seldom; one was observed, but due to various reasons hardly any of the invited leaders attended and the amount of information given was limited.

The main local leader of the area around Feina (Darfur), the Sultan, who resides near the project location, governs the area around Feina. On regular basis contact exists between him and the project and he has been asked (and seen) to promote the clinic, including the feeding project among his umda's, chiefs, elders and people. As a consequence caretakers of children who are brought to the clinic feel supported by their community leaders (Source: Interview 17, page 4).

| | |
|---|---|
| *Translator:* | *But we, in our village there, we have already advice from our elders that it is a very good chance for us to send our children* |
| | *Source: Darfur, Interview 17, page 4* |

Meetings with community leaders and with groups of the general public have been on going since the start of the project. Specifically meetings with women (members of women-groups and women passing through the market) were held. Although the number of women spoken to is only a minor fraction of the total women living in the area it is felt an important programme component to communicate with them.

Before the opening of each feeding location on Sittwe-island (Burma) a meeting was held with religious leaders (e.g. Mullah's), village committee members and interested civilians. Also mullah's were involved when rumours about the programme were endangering its smooth functioning: several meetings were held with religious leaders following rumours that were picked up by Out Reach Workers suggesting that Plumpynut might be a method to convert children from Muslim faith to Buddhism.
Reports show that in case of any relevant problem the project-staff communicates with caretakers and community members: "The best to do this is Abdul, the Out Reach Worker supervisor, a Muslim staff with great understanding of nutrition […] and a great communicator. He knows very well how to talk to mothers, fathers and religious authority. He is highly respected by the Muslim community and even the Rakine beneficiaries [Buddhists, EV] consider him a good man" (Source: mail about week 26; Re: Sittwe nut stat; 9th August 2007; 11:06 AM).

Community leaders in Ivory Coast are contacted by Out Reach Workers before home visits to beneficiaries are made. Structurally meetings are not held. In the area around Abdurafi (Ethiopia) key community members are contacted on individual (incidental) basis, there is no structural or otherwise frequent contact with them.

### ***5.2.6 Out Reach Workers***

There are no Out Reach Workers in South Sudan. A decision was made by the management not to employ any due to shortage of qualified personnel. The projects visited did therefore not do any early case finding, standard visits, absentee-follow up, or defaulter tracing.

In Darfur the project for its first 3 months had only 1 Out Reach Worker. This person appeared to be very well known in the area and able to draw upon a large system of local ties to assist him in finding the caretakers and children who are absent or default. A second Out Reach Worker was employed after 3 months.

A total of 11 people were employed as Out Reach Workers in Burma; approximately 3 per ambulatory feeding site. Their tasks were to identify potential cases in the communities, carry out ambulatory feeding clinics and follow up of patients at home (mainly absentees and defaulters). The fact that the Out Reach Workers were hired locally was very beneficial as families with malnourished children knew the Out Reach Workers and could even seek for their advice when necessary. All Out Reach Workers were accountable to one supervisor. These Out Reach Workers were able to locate over 90% of all absentees and defaulters in the area.

In Ivory Coast each project location had at least one Out Reach Worker. These Out Reach Workers were involved in weighing and measuring all children who came for admission or follow up in ambulatory feeding; this way they were in contact with all of the children and their caretakers. They know the names of various children in the programme by heart. They conducted standard home visits on weekly basis, visiting 90% of all patients in their first 2 weeks of treatment.

Every location in the programme around Abdurafi (Ethiopia) has 2 or 3 Community Health Educators who are volunteers from the community who work without payment. They have committed one day per week to the project to do health education and are also asked to do early case finding and absentee and defaulter follow up for the feeding programme.

### ***5.2.7 Output of Out Reach Workers***

Out Reach Workers should identify malnourished children in the communities (early case finding), follow up the children who are on treatment (standard visit) and follow up those who are absent or who default (follow up of absentees and defaulters).

Early case finding

The two Out Reach Workers in Feina (Darfur) are instructed to carry out early case finding and during one supervised visit they were indeed seen to assess many children while looking for a defaulting child.

The area is, however, very hilly and villages and settlements are scattered throughout the entire area. As a result of this it is unlikely if not impossible to measure the MUAC on a significant proportion of the children.

From week 42 in 2006 children visiting the health clinic in Sittwe-town were screened systematically for acute malnutrition. Active case finding, e.g. by sending Out Reach Workers was carried out from early in 2007 onwards.

Active case finding is carried out by Out Reach Workers in Ivory Coast and in addition screening is done at all clinics the entire week.

Standard visit

In Bin Houyé, Ivory Coast standard visits to all children admitted in the Ambulatory Therapeutic Feeding Programme are carried out. An estimated 90% of all children are visited by an Out reach Worker in their first or second week in the programme. In none of the other projects this task is carried out with a comparable rigor.

Follow up of absentees and defaulters

The third task of Out Reach Workers is to follow up on absentees and defaulters. In Feina (Darfur) a system was set up to display the output of the Out Reach Workers in this respect.

*Table 14: absentees and defaulters traced and found (Feina, Darfur, August-November 2007)*

| Absentees | Aug | Sep | Oct | Nov | Total |
|---|---|---|---|---|---|
| Total number traced | 35 | 34 | 47 | 27 | 143 |
| Number found by Out Reach Worker | 26 | 28 | 44 | 27 | 125 |
| Number returned after visit by Out Reach Worker | 24 | 25 | 42 | 26 | 117 |
| Defaulters | Aug | Sep | Oct | Nov | Total |
| Number found during trace but not returned to programme | 2 | 3 | 2 | 1 | 8 |
| Number not found during trace | 9 | 6 | 3 | 0 | 18 |
| Number not traced | ? | 19 | 6 | 0 | 25 |

| | | | | | |
|---|---|---|---|---|---|
| Total number of defaulters | 11 | 28 | 11 | 1 | 51 |

Defaulters in the table above are split in 3 groups:

1. Those who were visited at home, but could not be effectively convinced to return to the programme (Number found by Out Reach Worker minus Number returned to programme)
2. Those who could not be found (Total number traced for minus the Number found by Out Reach Worker)
3. Those not looked for (Number not traced). These are people known to live in areas more than 8 hours by donkey away from the project location or from areas known to be insecure (too insecure to send an Out Reach Worker). The parameter of the area considered insecure changes over time, and as a consequence the area where people cannot be traced changes as well.

Default-rates in Sittwe (Burma) were high in the year 2006 but reduced considerably in 2007. According to the team this was mainly due to:

- More staff allocated to carry out home visits
- New "strategy" in order to carry out more accurate home visits (the new strategy included hiring of local Out Reach Workers per feeding site, and making all of the Out Reach Workers accountable to one supervisor)
- Better Health Education approach about nutrition, given during home visiting and in all Ambulatory Therapeutic Feeding Programmes and In-patient Therapeutic Feeding Programme
- From week 14 onwards, the programme's Out Reach Workers provide regular updates on the absentees and defaulters identified.

Out Reach Workers in Bin Houyé (Ivory Coast) are able to find almost all absentees in the week after being absent and persuade them to return to the programme. Over 90% of absentees are visited by Out Reach Workers before they become defaulters. Out of the people found in their homes the vast majority return to the programme, only few choose not to return.

## ***5.3 Control beliefs and barriers***

People default because of limited access to the programme and barriers they experience; issues under this heading include: distance between programme and the patient's home, the number of decentralised sites of the programme, insecurity in the area around the programme and lifestyle of the population (being sedentary or nomadic).

### ***5.3.1 Barriers people perceive***

According to all staff involved the main reasons for absenteeism are far distance, illness of caretakers, funerals, donkey problems and recent harvesting. Out of these "distance", "travel to and from the project" and "security implications of travel" were most frequently mentioned during the interviews (Source: Interview 12, page 4; Interview 13, page 5; Interview 14, page 3). Note how in one reply almost al of the "standard reasons for defaulting" are mentioned…

| | |
|---|---|
| *Interviewer:* | *In the month of May and June there were many weekly visits that she missed, that she failed to come, is that correct?* |
| *Translator:* | *OK, she's saying that really it was not she who brought the child that time, because she was ill and she was also travelled to somewhere, inside the mountain there and also when she came back she start to work in the farm, so the work did not give her chance […] to come here and also the daughter who brought that child here [didn't tell] her the importance of bringing the child here [weekly] so she […] neglected this point till doctor Mussa [the Out Reach Worker] went and check her to come she came here, and after that […] she recognised the importance of bringing the child here so she [will] keep on bringing the child here and she hope[s] that she will not miss again* |
| | *Source: Darfur, Interview 14, page 3* |

The most obvious difficulty involved with visiting the programme on a weekly basis according to the caretakers is the travel back and forth; distance and security are mentioned (Source: Interview 13, page 5: Interview 14, page 4; Interview 17, page 2).

| | |
|---|---|
| *Interviewer:* | *What are the main difficulties that she has in order to come here every week?* |
| *Translator:* | *She says that the coming here is related with 2 things. The first thing is that because she has only one donkey, and this donkey sometimes is sent somewhere there, and not be found so that let […] her to be late or to miss visit. Also, secondly, the first thing is the absence of the husband. When he's absent she's just waiting for the husband to come to have permission from her to [come] here […]* |
| *Interviewer:* | *What can MSF do to help her overcome these difficulties?* |
| *Translator:* | *The daughter says something and the mother agrees. She says that just to be more facilities for them to come here and difficulties is that if it is possible for them to be like transportation for […] remote areas […] that to bring them by car, […], particularly for those who are about to deliver. And also she thinks that the clinic must be also established near them so as to help them not to come or not to move, so long this….* |

*Source: Darfur, Interview 14, page 4*

### ***5.3.2 Distance***

During the field visit in South Sudan most programme staff suggested that defaulting was possibly related to the distance people have to travel from their houses to the health centres. These distances were, however, not recorded and could therefore not be assessed in detail.

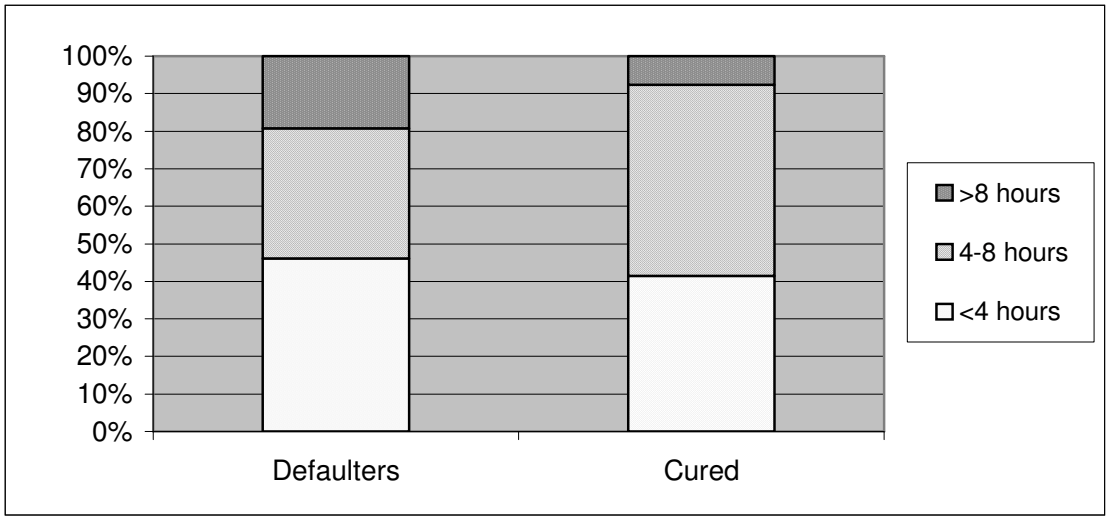
It was felt that, although some patients indeed come from very far away (up to 2 days walk), the majority was living much nearer, probably within a circle of 4 hours walk from the programme. This was illustrated during some random walks from the out reach locations when (ex) beneficiaries, including two defaulters were found within half an hour walk from the clinic.

Based on this observation the factor "distance" was specifically looked at in Darfur. The main Out Reach Worker was able to estimate distances from and certain locations. Very accurate, estimates could be made of the average and median distance of all children that had been cured or defaulted during the first months of the programme's operationality. The distance was expressed in "donkey-hours", the time it would take to travel to the area where the child lived on donkey.

*Table 15: Average and median distance (in donkey-hours) between cured and defaulters (sample from Feina, Darfur)*

| | Cured (n=106) | Defaulters (n=63) |
|---|---|---|
| Average | 4.1 | 5.3 |
| Median | 5.0 | 5.0 |
| Mode | 5.0 | 4.0 |

*Graph 16: Distance (in 3 categories) to the project, cured versus defaulters from the programme in Feina, Darfur*




Average distance is significantly different (p=0.0013). From the graph it is also clear that people coming from "very far" (i.e. more than 8 hours by donkey) are less numerous among the cured (10%) than among the defaulters (20%). Living "very far" is thus significantly correlated with defaulting.

As has been shown in paragraph 5.0.3 the majority of defaulters do so after visiting the programme only once (day of enrolment) or twice. For this reason specific testing was done to find out whether coming to the programme only once, twice or three times or more before defaulting is associated with average distance. This could not be proven; all groups live on average between 5.3 and 5.8 hours by donkey away from the feeding centre.

Distance is, however, one of the perceived problems people have to deal with when visiting the programme (Source: Interview 12, page 4). More information on perceived problems is discussed in paragraph 5.2.5 and 5.3.7.

| | |
|---|---|
| *Interviewer:* | *[…] What is for her the main difficulty in coming every week here?* |
| | *[…]* |
| *Translator:* | *She is saying that it is only the distance. The distance from here to the village and also the forest that she told you about, because it is very isolated the forest and people are expecting that forest will be some of risk […]* |
| | *Source: Darfur, Interview 12, page 4* |

Some people voluntarily change the place they live to be closer to feeding centre (i.e. temporarily move in with relatives in Feina-town or move to the camp for displaced people one hour away from the clinic). Some people express that because of the distance they would rather be admitted as in-patients. This is discussed later.

In the other countries distance to the programme was less. Sittwe-island, for example, was divided in 3 zones and each zone in 3 sub-groups. 5 Ambulatory Therapeutic Feeding Programme locations were chosen in the "middle" of each of these zones, based on where most population was situated. Patients were asked to come for weekly follow up in the location nearest to them. Thus distance to the nearest Ambulatory Therapeutic Feeding Programme site was kept to a minimum (up to a maximum of 1 hour walk). Difference in distance between defaulters and cured was not assessed. It did not come up as a reason for defaulting from the reports of the Out Reach Workers who followed up all absentees and defaulters.

In Ivory Coast the average distance was assessed by programme staff and appeared to be around 10 km, with a maximum of 21 km.

In Ethiopia the treatment locations are situated in the biggest villages in the area. Only one concentration of population across a wadi (seasonal river) could not be serviced. The plan is to gain experience with the current sites and possibly expand the programme over the wadi next year.

### ***5.3.3 Decentralisation***

The association between the number of sites and outcome of treatment is not clear-cut. The two areas with the highest number of ambulatory treatment locations (Sittwe and Bin Houyé) have the lowest default rates, but also areas with only few locations can have low defaulter rates (Feina), and programmes with an adequate decentralisation (Abdurafi) may not always have favourable out come indicators. The number of locations in Jonglei province does not seem low, but it should be kept in mind that the locations are extremely far away from each other.

*Table 16: Number of treatment sites versus defaulter-rate observed (all case study areas)*

| Area | Number of sites | Defaulter rate |
|---|---|---|
| Jonglei province (South Sudan) | 3 | Poor |
| Feina (Darfur) | 1 | Good |
| Sittwe (Burma) | 6 | Good |
| Bin Houyé (Ivory Coast) | 9 | Good |

| | | |
|---|---|---|
| Abdurafi (Ethiopia) | 4 | Poor |
| Baluchistan (Pakistan) | 1 | Poor |

### ***5.3.4 Seasonal access problems***

The rainy season seems to come with significant limitation on accessibility of the feeding programmes. Large areas of South Sudan develop into a swamp and people are seen wading through chest-deep water for several hours in order to access the nearest clinic. Sometimes the water is too high and people cannot cross.

In Burma numerous accounts are made by Out Reach Workers about people who are absent or defaulting from the feeding programme because of inaccessibility of the terrain or not having an umbrella. (Source: Narrative week 20, 21, 23 and 24).

### ***5.3.5 Security***

Programme staff in South Sudan suggested that default rates could possibly be related to insecurity in the area. An attempt was made to create an independent overview of relevant context information and then comparing it to the rates of defaulters in the same period. It proved, however, difficult to objectively assess the level of insecurity or other environmental factors (e.g. water-level in rivers) from the information sources available. In addition to this impact of insecurity on default rates could not be assessed because it is un-clear what it means to patients south from an Ambulatory Therapeutic Feeding Programme if there is insecurity in the north of the project area or vice versa. An additional difficulty is that defaulting (in this context) means “3 times absent”, meaning there is always a 3-week lag-time between onset of the insecurity and effect on defaulting. As a consequence “defaulting” could not directly be linked to “security”.

At the time of assessment the security situation was stable. Besides some localised inter-tribal cattle raids the area was considered safe. This topic was therefore not discussed during patient-interviews.

In Darfur the area around Feina is among the safest, however, security on the road is still an issue people have to take into consideration before travelling. Attacks by Janjaweed are feared and mentioned in some of the interviews (Source: Interview 12, page 2).

| | |
|---|---|
| *Interviewer:* | *OK. Is there any problems with security with her coming here to this clinic?* |
| *Translator:* | *Ya, between here there is very, you know, isolated forest that we are covering and we are afraid from it but anyhow now it's OK we have not [been] attacked, we have not found anything danger on our way, we are OK now* |
| | *Source: Darfur, Interview 12, page 2* |

The busiest days in the Feina clinic are the market days. People come to the clinic in groups or families, thus reducing the risk associated with travel.

Security implications in Sittwe (Burma) are of a complete different nature. Movements within Sittwe-township are limited as travel permits are needed to cross borders between municipalities, but there are no further direct threats during travel.
No violence related security incidents relevant to the project have been observed in and around Sittwe.

In Ivory Coast and Ethiopia there are no security implications that need to be mentioned.

### ***5.3.6 Direct cost***

Most patients in South Sudan are cattle farmers who walk to the clinic, and thus not spend any money to access the facility.
One patient in South Sudan, however, mentioned that she was required to bring grass to the clinic before her child could be seen (the clinic was using this for constructing a fence and for improving the roof of one of the structures). She did not see this as a barrier impossible to overcome, but it is a limitation of accessibility that potentially may have hindered people (who have more problems bringing grass) to access the health unit (Source: Interview 01, page 1).

In Darfur monetary costs of coming to the Ambulatory Therapeutic Feeding Programme are also limited, just as in any money-poor society. One caretaker suggested that she might have to work on the farm of the person she borrowed a donkey from to visit the programme (Source: Interview 13, page 1).

| | |
|---|---|
| *Interviewer:* | *OK, and how has she travelled? Has she been walking? Or…* |
| *Translator:* | *On donkey* |
| *Interviewer:* | *On donkey, OK… and this is her own donkey, or this is a donkey that she is borrowing from anyone?* |
| *Translator:* | *[…] it is borrow[ed] from some of her neighbours in the home* |
| *Interviewer:* | *And does she have to pay the neighbour in order to use the donkey?* |
| *Translator:* | *She says, that sometimes she's just going to help her on his farm and sometimes it's free without anything…* |

*Source: Darfur, Interview 13, page 1*

In Sittwe (Burma) some people do use public transport in order to come to the treatment facility. Anecdotes from the first weeks of the programme suggest that transportation time and transportation costs were among the main reasons for being absent or defaulting.

Direct costs in Bin Houyé are limited. Most patients are walking to the nearest Ambulatory Therapeutic Feeding Programme-site. The number of sites is high (9), thus people automatically live relatively close to the facility. Hence costs involved in travelling are limited.

### ***5.3.7 Opportunity cost***

Opportunity costs also need to be taken into account. Opportunity costs include household-duties and income-generating activities that are not carried out (Source: Interview 14, page 1; Interview 17, page 2).

| | |
|---|---|
| *Interviewer:* | *And because they are here today they cannot carry out their home duties. What are their tasks, which are suffering because they have to come here every week?* |
| *Translator:* | *The daughter is saying that really because impact not more but already coming here so as our children to be treated, but in the same time there we have […] a lot of work there to do to the farm to collect the firewood, also to work in farms […] to collect money, for daily life expenses, so really we left some responsibility, but responsibility of being [with] your child in the clinic it is better than that* |

*Source: Darfur, Interview 14 page 1*

Other families do not have to take opportunity costs into account, simply because they have limited opportunities after having become displaced (Source: Interview 13, page 1 and 2).

| | |
|---|---|
| *Interviewer:* | *[…] which activities she is not carrying out because she is travelling to here?* |
| *Translator:* | *They say that as usual we are farmers, but during these days we are very, very, very afraid of attacking of Arabs or Janjaweed because we just making ourselves all the time ready to flee from the area because we are not stabilised in one place, move from place to place […]* |
| | *[…]* |
| *Translator:* | *we are already spending our days without doing nothing, because there is no farm […] all our farms are spoiled by the cattle of the Arabs and now we are just jump and clamping from health to health with our children […]* |
| | *Source: Darfur, Interview 13, page 1 and 2* |

In Burma opportunity costs were also mentioned in an Out Reach Worker report that explained how a mother could not visit the feeding programme after her husband stopped her from travelling claiming he needed her to work on the rice field.

Opportunity costs in Ivory Coast are increased from what they could be by the long queues people are observed to wait in before being seen by the programme staff. When treatment teams arrive generally already a long queue of patients is present at the clinic. People wait up to all morning to be seen, but after mid-day all are on their way home, with the exception of some patients who arrived at the site much later.

### ***5.3.8 Opening hours of the feeding programme***

Ambulatory Therapeutic Feeding Programme locations tend to be open either once a week or every day of the week. Planned and un-planned closures are often not communicated with the patients, as there are limited possibilities to contact them. When opening hours are changed patients might come in vain on the original day. Patients interviewed in South Sudan or Darfur did not mention any problems concerning opening hours, in Ivory Coast opening days and hours were never changed, but in Burma and Ethiopia changes occurred.

In Sittwe (Burma) opening days (once weekly per location) were chosen for each location and were kept throughout the duration of the programme. Exceptions to this rule were around the Water-festival (a national holiday that is known to generate a lot of festivities as well as drunk people in the streets) and after a small cyclone hit the island of Sittwe. During the year one location was completely closed because there was only one patient left in the programme and a new location was opened.

In Ethiopia rain hindered the travel to the project locations, leading to defaulting. In addition there were organisational and managerial problems in many of the ambulatory feeding sites leading to

closure of the feeding location on many of the planned days of opening and admitted patients not being seen.

### ***5.3.9 Supply of therapeutic food and medication***

In South Sudan two mothers indicated that a rupture in supply of the therapeutic food (Plumpynut) from the clinic was the reason behind them defaulting from the programme (Source: Interview 01, page 4).

| | |
|---|---|
| *Interviewer:* | *So, what is the reason that after 2 weeks she stopped collecting it?* |
| *Mother:* | *I went, but the people in the programme told me the food is finished* |
| *Translator:* | *He say that I went 2 times then the third time workers told me the Plumpynut food is finished* |
| *Interviewer:* | *And after that she did not go again, after they received the new Plumpynut?* |
| *Mother:* | *No* |
| *Translator:* | *They say: up to now I didn't return there* |
| | *Source: Darfur, Interview 01, page 4* |

After patients walked to the clinic in vain they did not return to it again; note that these were defaulters who lived within half an hour walk from the health unit and that one was a wife of a clinic employee.

Stock ruptures were not documented and could therefore not be further assessed in South Sudan, but continued to be included in assessments of other programmes. The programme in Darfur has had Plumpynut and BP5 available at all times. Initially the programme in Sittwe (Burma) was not providing therapeutic food items, but supplied the admitted patients with Corn-Soya-Blend-sugar-oil mixture for porridge preparation. After some weeks Plumpynut was introduced. From each of these food items no stock ruptures have occurred in any of the locations.

In Ivory Coast Both Plumpynut as well as BP5 was available in all ambulatory treatment sites. Stock ruptures were rare, but if occurring at least one of the two products was available to be taken home by the patients.

Shortages in the supply of medication did also happen in South Sudan. In Darfur the same thing happened, but the shortage has been hidden from beneficiaries. Supply of medication has been steady in Sittwe (Burma); no ruptures were reported, likewise for the programme in Ivory Coast.

Huge supply problems happened in Ethiopia after rain made the area inaccessible for longer periods of time than anticipated on forehand. In September 2007 there were ruptures in supply of Plumpynut in almost all locations and many people had to be recorded as defaulter as they stopped coming to the programme following these shortages.

## 5.4 Further country-specific information

Two messages from the field, specifically focussing on the issue of defaulting, are added to the results of this research. Besides reconfirmation of earlier results they also mention some new, relevant issues.

### 5.4.1 Baluchistan-Pakistan

An end-report about the ambulatory therapeutic feeding programme in Baluchistan (Pakistan) was received. A total of 106 children were admitted between June and September 2007. 53.4% of exits were cured, while 43.6% defaulted, the last 2.9% of exits were reported dead. The programme was influenced from the outside by fighting, insecurity and floods (after a cyclone on June 25$^{th}$ 2007). Also the semi-nomadic lifestyle of many inhabitants of the area is identified as one of the main causes behind the high defaulter rate. One of the programme limitations was the replacement of a key staff member with someone less experienced in therapeutic feeding.

Lessons learnt:

- It is essential that all employees in the program are trained on the management of the program and are familiar with the case definitions
- A proper registration needs to be in place (use the nutrition book per location) such that monitoring of particular problems areas is possible e.g. defaulters by age/location etc.
- The community needs to have clear explanation about the nutrition program; this is not a blanket food distribution, but a Nutrition Health Program which takes at least 4 weeks and where adherence is strictly required
- An intake procedure for care takers might be required and a clear explanation and expectation to and from the care taker
- Defaulter tracing team is essential and involvement of the community as well
- Knowledge of the population; nomads, cultivation season, etc, etc, to better anticipate on movements and act accordingly

Future Planning:

- Focus more on defaulter tracing, education of the program to care takers and try to readmit the previous defaulters

- As for the near future; restart the program, give a refresher training to all workers, prior starting of the program raise awareness to the program in the community with community leaders and health authorities
- Employ and train an MSF-OCA outreach team, who will conduct education and raises awareness of the program as well as tracing defaulters

### *5.4.2 Zimbabwe*

In their regular reporting team in Zimbabwe explains the following: "The number of defaulters is decreasing due to several reasons- both through improved outreach program (Community Health Workers following them in their homes) as well as recently revising the definition to MSF guidelines (child not returned for 3 wks). Women from the community and Ministry of Health nutrition staff members give the following reasons for defaulting:

- Other commitments (work, funeral),
- Fear of paying by coming to the clinic
- Distance and time to get to the centre
- Mothers are often sick themselves
- Grandmothers are taking care of the child (in case parents died) and for older people its too difficult to come"

## *5.5 Main findings*

Based on the observations in chapter 5 the main findings are summed up below.

### *5.5.0 Basic parameters of defaulters*

Age, gender and Weight-for-Height on admission do not vary significantly between cured and defaulting children. Roughly half the defaulters are 'early defaulters' (people who start being absent immediately after admission or after making one follow up visit), the other half are 'late defaulters' (who default after making 2 or more follow up visits) and benefit more from the treatment offered. Whether a child should be admitted into the Ambulatory or In-patient Therapeutic needs to be discussed specifically with caretakers and their relatives.

### *5.5.1 Behavioural beliefs*

Although malnutrition is poorly recognised as a condition requiring medical care (children are presented to the clinics for other –perceived- medical problems and are consequently diagnosed with malnutrition) caretakers do feel capable of improving their children's health with assistance from the programme. In general caretakers appreciate the programme, especially the therapeutic food items and medication.

The objective of the treatment (target weight) and how long children need to reach that objective are poorly known among beneficiaries. In general people do not default because they have

reached a certain (satisfactory) weight or experienced relatively rapid weight gain; late defaulting is more a function of time spent in the programme than anything else.

### ***5.5.2 Normative beliefs***

Most caretakers discuss visiting the clinics and feeding programmes with relatives, mostly with their husbands and/or fathers. Key-community members also play a decisive role here. Relatives and friends around the mother with the malnourished child are generally positive about the programme and appreciate the attempt to improve the child's health; consequently they are supportive towards the treatment provided in the feeding centres.

There seems to be no strong stigma attached to having a malnourished child.

Sedentary populations show fewer defaulters than (semi) nomadic populations and community involvement in the programme is very relevant, both to increase coverage among malnourished individuals and to reduce defaulting.

Out Reach Workers play an important role in achieving community support and preventing absentees from becoming defaulters. The required number of Out Reach Workers varies between programmes and areas, but close management and follow up on their achievements is essential.

### ***5.5.3 Control beliefs and barriers***

Of all barriers people perceive as hindering their (weekly) visits to the feeding programme they mention distance and security most frequently. In relation to that decentralisation of the feeding programme is relevant. Regular opening hours and avoidance of stock rupture are of paramount importance in order to promote regular visiting of the programme until a target weight has been reached.

## 6. Discussion

Ambulatory Therapeutic Feeding Programmes are operated by emergency relief agencies since the start of the current century. They have a very different momentum from the centre-based treatment methods that have been implemented in many countries during the last decades of the previous century. During the week the families and the patients from ambulatory programmes are to a large extent outside the view of the programme. In such a setting other factors influence the decision to default from the feeding programme than the decision to leave a centre where the child has been admitted around the clock for several days or weeks.

Despite the fact that several programmes showed relatively high default rates the issue has not been discussed much in literature. This study could perhaps serve as a starting point for further discussion, not just within MSF-OCA, but also between agencies involved in Ambulatory Therapeutic Feeding Programmes.

In this study the projects and patient-groups from different countries, on different continents and from very different contexts have been investigated in order to explore the factors that are associated with defaulting.

### ***6.0 Basic parameters of defaulters***

The observation that defaulters do not vary from non-defaulters in terms of age, sex or weight and height on admission has both a positive as well as negative implications. Negative, as it is, regrettably, not possible to identify high-risk groups for defaulting based on these physical characteristics. Positive, because the absence of significant differences is reassuring, as there is always a concern that a certain proportion of the defaulters have in fact died. Although excess mortality among the defaulters cannot be ruled out based on the available data there are no specific indications that they have indeed died disproportionately.

In this research only already available patient-data were regarded, specifics about the caretaker were not included. From other medical fields we know that characteristics of the mother or caretaker are relevant predictors of a wide variety of risk factors. For this reason further research in defaulting should include looking into maternal or caretaker characteristics.

Half of defaulters start being absent immediately after their admission or after one weekly follow-up visit. These patients are labelled as “early defaulters”. The observation of defaulting early on in the treatment is in-line with what is found by Manary et al. During a field trial of ambulatory therapeutic feeding in Malawi they also found 66% of their 47 defaulters not returning after their initial enrolment or returning only once (Manary, M.J. 2004). When the issue of early defaulting would be dealt with successfully the defaulter rates could potentially reduce by 50% in all

programmes. Discussing the programme, its objective and its expected duration with the caretakers and their relatives is crucial to help decrease the number of early defaulters.

## *6.1 Behavioural beliefs*

Central question in the area of behavioural beliefs is to what level caretakers are convinced that their efforts, in collaboration with the programme, are effective to improve the condition of their children. Next to directly questioning this it was assessed whether caretakers have appropriate ideas about the reason for admission, the treatment provided, the goals of treatment and weight gain as a risk factor for defaulting.

All caretakers indicated that they felt capable of improving the child's condition with the assistance provided by the feeding centres. At the same time, however, many caretakers have a very different perception of their child's condition from the programme implementers. Only very few caretakers mention weight loss and wasting as reasons for their admission into the feeding programme. Also very few mention weight gain as the objective of treatment. When asked for reasons of admission and aims of treatment mainly physical symptoms of disease and aspects of child-behaviour (walking, running, playing) are mentioned. Others discover similar findings in different parts of the world. In Nepal, for example, it was found how for severe cases of malnutrition some awareness did exist in the community. Less severe states of malnutrition were, however, considered "normal". When, in severe cases, a problem was perceived people would seldom think of it as a nutrition-related disease and no link would be made between the state of the child and its food intake (Kolsteren, P. 1997).

In-line with the limited perception of disease the objective of the treatment is often not well understood by caretakers either. Incidentally also relevant feeding staff could not explain the objective of treatment and had no idea of "average treatment duration". Some patients were told that they should be coming to the clinic until their child is well; and obviously many parents define "well" not necessarily as "having a certain Weight-for-Height ratio". Only few of the respondents actively mention weight gain as an objective of treatment, none of them know their child is supposed to reach a certain target weight and most of them see improvement of the child's condition as the main aim of treatment.

It is no surprise that caretakers whose disease perception is focussed around immediate symptoms of disease like cough or diarrhoea and who do not know the goal of treatment nor its expected duration and who do not know, or have not fully understood (why) they have to come back next week, let alone having to come back for a number of weeks start defaulting from the feeding programme. Many will probably be told to "come back next week" on a weekly basis

without ever being told that they are likely having to come back for 4 to 6 weeks before their child is cured… People who are simply told to “come back next week” are likely to perceive this only as relevant when the general condition of their children is still unsatisfactory. If the child improved and immediate symptoms of disease have disappeared (which it is likely to do after a dose of therapeutic food and standard medication) they may not see the need to follow up on the instruction to come back after a week.

And telling the patient all of the above is maybe not enough… Parents who may not agree with coming back every week, may not say so during their first visit; this is in-line with observed clinic consultations: very often patients are silent while programme-staff explain the programme, decisions are thus made for the patients and not with them. Extensive counselling and explanation to the caretakers are imperative to come to a common understanding of the diagnosis, its causes, the programme and its goals.

The lack of counselling the patient and coming to the best treatment solution for their individual situation was very apparent when comparing the 3 treatment facilities in and around Lankien where duration of stay in the programme before defaulting was closely linked with the set-up of treatment in each of these locations. Differences in average time in programme before defaulting go hand in hand with differences in standard treatment between the sites. The vast majority of people started being absent from the moment that they were released into the weekly (ambulatory) treatment scheme. Knowing that population characteristics do not vary significantly between the 3 locations this finding suggests that for the defaulters the ambulatory treatment concept was possibly not ideal. On the other hand it is known that standard admission in in-patient treatment may prevent certain families from accessing the centre altogether. The solution for all of this is the same as already mentioned above: offer both in-patient treatment as well as ambulatory treatment and discuss with each individual patient what is best for him or her.

While “complicated malnutrition” is a well-used criterion for admission in the in-patient facility “caretaker preference” is not. Caretaker preference should be taken into account when deciding to treat the child in In-patient Therapeutic Feeding Centre or in Ambulatory Therapeutic Feeding Centre facilities. Programme staff should discuss with caretakers what is best for them: admission in In-patient Therapeutic Feeding Centre or in Ambulatory Therapeutic Feeding Programme.

Late defaulting

During the field visits some programme staff suggested defaulting might be more frequent among late defaulters who are approaching target weight, but no association between the last-known Weight-for-Height and defaulting could be proven. The fact that so many patients default after first

complying with the programme leads us to a next topic that requires our attention: the speed of weight gain.

Compared to centre-based therapeutic feeding Ambulatory Therapeutic Feeding Programmes are known and accepted to produce slower weight gain in children enrolled in the programme (Sphere Project, 2004). In many ambulatory feeding programmes slower speed of recovery (slower compared to centre-based treatment) have not resulted in increased mortality and default rates in various ambulatory therapeutic feeding programmes (Collins, S. 2006). The lower rate of weight gain observed in Ambulatory Therapeutic Feeding Programme is usually attributed to sharing of the therapeutic food item (Collins, S. 2007). Most MSF-OCA programmes have acceptable rates of weight gain and consequently the average length of stay remains within the standards set. In this study weight gain (measured in grams per kilogram bodyweight per day, g/kg/d) was not found significantly different between defaulters and cured. It was also not different between one successful project (Sittwe, Burma) and one less successful programme (Jonglei-province, South Sudan).

Combined with the observation that defaulting is more frequent from programmes with higher target weights and consequently higher length of stay (i.e. the programmes without associated Supplementary Feeding Programmes) it seems that (late) defaulting is closer related to time-spent-in-the-programme, than to weight gain achieved or the approach of a target weight. Therefore the introduction of a new growth standard (WHO growth standard 2005), which MSF-OCA has started to use in the course of 2007, is expected to have a positive impact. Target weights under the new standard are lower than those suggested by the NCHS growth reference, probably reducing the time to be spent in the programme.

## ***6.2 Normative beliefs***

Most communities in which malnutrition is prevalent are under-developed, rural populations in which normative beliefs are known to be strong regulatory mechanisms.

Social pressure

The caretakers of malnourished children, in most cases the mothers of the children, are not alone in their decision to bring their child to the programme; a network of husbands, other relatives and community members around them is involved. Some women operate independently from a husband, mostly because their husband is absent. All women have other family and community members around them who are (potentially) involved in the decision to visit the feeding programme.

Interviewees explain how the people around them are equally worried as they are when a child's condition deteriorates and that consequently the search for medical help is applauded. If any

pressure is applied from the community it appears to be positive pressure aimed at promoting the optimal treatment of the child. It is likely that people around the caretaker evaluate the child even more on symptoms of disease and certain sorts of behaviour (walking, running, playing) and even less on weight gain compared to their immediate caretakers. In order to prevent defaulting explanation towards people around the main caretaker of the child is required.

The information obtained from programme beneficiaries in this research does not prove that defaulters had less social support, but highlights the need to engage closely with the immediate circle of relatives around the patient and their caretaker. Community connections are a first step in that direction, but next to those also the caretakers' husbands, brothers and sisters need to be counselled or at least informed about the reasons for admission of the child into the programme, the programme objectives and its requirements.

Stigma

No indications were found that having a malnourished child is frowned upon or is otherwise perceived as stigmatising. Note that this question could only be asked to beneficiaries of the feeding programme, and it is therefore not proven that stigma plays no role at all. From other sources it is known that a wide variety of traditional beliefs might play a role in the perception of the onset of malnutrition, but these are unlikely to be an important underlying factor for defaulting. It also means that active case finding and follow up visits at home can be carried out without much hesitation.

Follow up and community connections

Unlike some other organisations working with ambulatory treatment methods MSF-OCA makes no use of community participation in the set-up of its programmes. It considers active screening (early case finding), follow-up of absentees and defaulters key-activities in an ambulatory therapeutic feeding programme (MSF, 2006), but does generally not involve community members in planning and decision-making for its programmes. This is one of the reasons MSF-OCA does not use the terminology "Community-based Therapeutic Care", but chose "Ambulatory Therapeutic Feeding Programme". Moreover: there is no need for community involvement to precede the actual programme set-up, it can be sought during or after the set-up of the programme equally well.

Setting up the programme together with the community is a time-consuming activity that for an emergency organisation as MSF-OCA is not a priority in acute crises and conflicts. Compared to MSF-OCA, programmes of other agencies often have a relatively long preparation phase in which community mobilisation takes priority over the actual treatment of patients. Where for other

organisations leaving behind treatment capacity is a specific objective of the intervention (Valid International, 2006) this is not specifically the case for MSF-OCA. Being an organisation that chooses to work under circumstances of armed conflicts it operates primarily in areas where pre-existing health care systems have collapsed or were non-existent. Most of MSF-OCA's Ambulatory Therapeutic Feeding Programmes are in locations where Internally Displaced People and refugees are the main inhabitants. The existence of a clearly structured community that can be easily mobilised to participate in and take ownership over the programme is therefore less likely. Nevertheless it should be noted that more could be done to obtain a stronger sense of community-connectedness than is now often the case. The organisation has developed guidelines on the establishment and maintenance of community connections, but these are not always implemented with the rigour required. In addition, as discussed before, more attention needs to given to the social circle of relatives around each individual patient.

Out Reach Workers

An important component of community participation is the establishment of a team of Out Reach Workers.

Out Reach Workers generally have 3 main tasks in an Ambulatory Therapeutic Feeding Programme:

1. Early case finding; early presentation is a key factor for treatment success (Collins, S. 2007) and reduction of risk for complications and mortality.
2. Standard visit in first week of treatment and on indication; this is a task, which was only found being carried out in Ivory Coast. All children entering the programme are visited by an Out Reach Workers in their first or second week on treatment and on indication
3. Follow up of absentees and defaulters

The tasks of these workers should be at least early case finding and follow up of absentees and defaulters; whether standard visits need to be carried out in the first week of ambulatory treatment, based on the findings of this study, remains inconclusive and is therefore only advised if other measures to limit the default rate to an acceptable level fail.

An association between having a team of effective Out Reach Workers and having favourable outcome indicators is clear. Having an appropriate team of Out Reach Workers should be common practice in every Ambulatory Therapeutic Feeding Programme.

Having a team of Out Reach Workers is suggested in the Nutrition Guidelines, but not all programmes put this into practice. In Beluchistan (Pakistan) the team is being planned, thus was not set up at the start of ambulatory feeding and in Lankien (South Sudan) a conscious decision

was made not to set one up. Knowing how essential Out Reach Workers are for achieving proper outcome indicators then such indicators should not be expect from projects where there are no Out Reach Workers in the entire coverage area.

Some patients admitted into the feeding programme live far away from the treatment location. These people are of course equally welcome as everybody else, but when people from outside the area covered by Out Reach Workers default they should perhaps be included in the programme-statistics separately. Programmes should know exactly where beneficiaries are living and submitting a separate report on this should be no problem. In Feina (Darfur), for example, an experiment with such a report shows promising results. Out of the 28 defaulters in Feina (Darfur) in September 2007 19 (68%) were not traced, either because their home-area is too far away (more than8 hours by donkey) from the programme for the Out Reach Workers to cover or the area is too insecure to send an Out Reach Worker to. Based on 28 defaulters the programme reported a 29% default rate in September. Based on the corrected number of 9 (28-19) defaulters this rate would have been only 11%.

The number of Out Reach Workers

For the required number of Out Reach Workers versus the target population no standard ratio can be given, as programmes with one Out Reach Worker work well, while some others with many Out Reach Workers are unable to find an acceptable proportion of the absentees and defaulters. Per context a reasonable number of Out Reach Workers must be employed and default rates obtained should provide guidance on the number of Out Reach Workers required.

Note that there is a tendency to pile a wide variety of tasks on to the plates of the Out Reach Workers; although having multiple tasks may lead to some synergistic effect in efficiency and effectiveness care needs to be taken not to over-burden these employees.

Another matter is that in many projects Out Reach Workers work on voluntary basis. It should, however, be recognised that more demands on their input and their output can be made when their job is paid. When the work of Out Reach Workers is considered a corner-stone-activity this should be reflected in the management of this group of workers, including the remuneration.

## *6.3 Control beliefs and barriers*

Control beliefs are assumed to serve as a proxy for actual control over behaviour and strongly predict the execution of the behaviour in question. Of all barriers people perceive as hindering their (weekly) visits to the programmes distance and security are mentioned most frequently.

Programme staff indicated the same issue as the most important reason for defaulting among programme beneficiaries. In close relationship to the distance as a separate factor additional barriers people mention are security implications of travel and sometimes costs involved with travel. These are clearly the biggest obstructions for (regular) visiting of the project.

In the projects visited the most cited suspected reason for defaulting is “distance”. Phrases as: “Some of our patients live more than xx hours away” were frequently heard. And although this is undoubtedly true, it does not discharge the team from the obligation to investigate and address the other factors leading to defaulting.

In Feina (Darfur) a comparison in average distance to the project-location between defaulters and cured children, as expected, showed a significant difference; people who live further away default more often than people living near-by. The observed difference appeared to be much smaller than expected on forehand, but confounding factors may have caused this. It was –for example- not possible to correct the data for mode of travel as it can be assumed that those living further away will make more use of donkeys to travel compared to those living nearer by.

Besides being a direct reason for defaulting distance is likely to be an aggravating factor for all other reasons for this phenomenon.

Livelihood characteristics

Programmes in areas with sedentary populations tend to do better than programmes in areas with nomadic or semi-nomadic people. Nomads, although used to travel great distances in order to access services, probably move on to new areas before their children are fully cured from malnutrition. Of course the living-conditions and life-style of the populations served by the feeding programme cannot be changed, but in the set-up of the programme and/or the interpretation of its outcome indicators these need to be taken into account.

Costs

People are to large extent rational beings who conduct certain behaviour if the costs are outweighed by the benefits. Costs for treatment can be divided in direct costs and opportunity costs.

Direct costs of admission like transportation costs only play a role in areas where public transport is available and required to visit the feeding programme. In the areas researched these appeared of limited relevance.

Opportunity costs are another matter: the investment of time and effort into visiting the programme (travel, waiting time, follow up of instructions) can be quite substantial, especially when distances to the programme are long, security in the area is poor, waiting time is considerable and much effort needs to be put into feeding the child the therapeutic food and standard medication. Some people, especially in settings with large numbers of Internally Displaced People, may have lower opportunity costs because of being displaced, but for most patient's opportunity costs can be relevant barriers for regular adherence. Opportunity costs include the lost time for activities as care for other family members, farming activities, collection of firewood (for home-use or sales) and the like.

A reduction of travel time by decentralisation of the feeding programme is probably the single most influential factor. Additionally identification bracelets should be provided to all beneficiaries so that during follow up visits they do not have to wait in front of the treatment facility together with all other patients in order to reduce waiting time. Those who gained weight satisfactorily and who have no health complaints could be given the option to receive their weekly supply of Plumpynut without being seen by a medical supervisor.

A special kind of opportunity costs is the increased insecurity that is the consequence of travelling and/or leaving family members at home behind. In some cases insecurity, reducing possibilities to farm, may decrease opportunity costs, but for most people the stress and fear involved in travelling or leaving loved-ones behind is likely to be a potential reason for not attending a scheduled weekly visit.

All of the above highlights the importance of decentralisation of Ambulatory Therapeutic Feeding Programmes into as many as possible treatment locations. More locations means less travel time of opportunity costs. In a decentralised programme travel distance is less for beneficiaries and consequently security implications and opportunity costs are reduced to a minimum.

Reliability of the programme

Most patients interviewed indicated to be very satisfied with the programme. None of the respondents mentioned negative effects or side effects from Plumpynut and those who did not appreciate it were given an alternative therapeutic food item. Some patient specifically mentioned that they were happy about the food because their child's diarrhoea disappeared after Plumpynut was eaten. It is not difficult to imagine how people whose child developed diarrhoea after consumption of Plumpynut could easily blame the food for it and never return to the programme again.

The only obvious negative appreciation of the programme came from people who travelled to the treatment site only to find it run out of Plumpynut. Stock ruptures were mentioned in two programmes (Lankien; in its out reach location Riang and in the out reach locations around Abdurafi), both programmes with many defaulters. Two interviewees explained they did not return to the programme, even after knowing that the therapeutic food item was again available. Out reach locations around Abdurafi (Ethiopia) were supplied with 2-weeks worth of Plumpynut. When, however, the locations appeared unreachable for 3 consecutive weeks patients were sent home without any therapeutic food, creating a peak in defaulting. Sufficient stock of therapeutic food is of paramount importance for the functioning of a feeding programme and stock ruptures should not be accepted.

Equally important are the opening hours of the facility. Programmes that have regular opening hours, like in Bin Houyé (Ivory Coast) and in Sittwe (Burma) have fewer defaulters than those with irregularities and changes in their opening times. Managerial reasons are important causes for unplanned closures or changes in opening hours, but regardless of their possible justification the effect on the reliability and the success of the feeding programme should be acknowledged before changes in opening hours are made.

## *6.4 Limitations*

### *6.4.1 Research while working with MSF-OCA*

All study material was gathered while being employed with MSF-OCA and research carried out was meant to result in recommendations for this organisation. All research activities carried out needed to fit within the terms of reference of the job that needed to be done; field visits were conducted with the objective to provide technical support to the projects.

All activities were carried out under limitation of the general MSF-OCA security regulations. Most noticeable is the relative lack of material gathered directly from the defaulters. Practical reasons (e.g. programme staff not knowing where their defaulters lived and inability to locate them and security circumstances limiting travel options) hindered the search for defaulters and inclusion of their specifics into the data gathering. Defaulters included were two people found in the community, almost by coincidence, and those who had been defaulters but who had returned to the programme.

Within the limitations listed above research goals and methodologies were determined and chosen freely and the conclusions obtained are those of the researcher and not necessarily those of the organisation.

### *6.4.2 Convenience sampling*

Convenience sampling, as practised for both the selection of case studies (project areas and countries) as well as respondents for interviews is more prone to bias than other forms of selection (Hardon, A. 2001). In order to mitigate the biasing effect all areas visited within the year the job was held have been included in the research, but in selecting areas visited the fact that research data were sought was not a consideration.

By incorporating data from as many as possible contexts selection bias has been limited. It is regretted that it was impossible to add a third main area where interviews could be held and quantitative data could be gathered. The data obtained and conclusions derived from it are, however, all pointing in similar directions. For this reason it is felt that conclusions can indeed be drawn from the available data.

### *6.4.3 Interviews*

Semi-structured interviews as conducted in South Sudan and Darfur are useful to collect ideas and opinions from the study group, but are generally difficult to analyse and the interviewer may inadvertently influence the respondents. There is, in addition, a recognised risk that the data-collector will see or hear only the things that he or she is interested in or will miss information that is critical to the research (Hardon, A. 2001). On the other hand: other methods have even larger limitations in the different case study countries. Many members of the patient population are illiterate, and circumstances in each project area differ tremendously. As a result standardised or even self-administered questionnaires are contra-indicated. In order to limit the bias obtained through the use of semi-structured interviews and observations topic lists are prepared in advance. The topics on these lists are based upon relevant factors collected during literature-research in the field of defaulting within comparable medical fields and the questionnaire used in Darfur is based on the outcomes of the “pilot-test” in South Sudan.

Of specific consideration is the use of interpreters during the interviews in South Sudan and Darfur. Different translators were involved in data collection during the semi-structured interviews. As these interviews were held in various locations it was necessary to work with a variety of translators. In practice this was often one of the employees of MSF-OCA, usually someone attached to the feeding centre or clinic. Next to the obvious limitation on respondent’s freedom to speak the ability to speak the English language proved a concern. In both settings where interviews were held none of the available translators spoke English well enough to successfully discuss some of the more sensitive issues of the topics lists and in some cases the answer received was not felt to be related to the (intention of the) question asked. As a result some topics were not discussed in-depth. Despite all this valuable information was obtained from the interviews.

### *6.4.4 Quantitative data-collection*

The quantitative data-collection is based on patient cards and other programme information. This information was collected and recorded in order to facilitate case management and programme monitoring. The information was not collected for a research purpose. In practice this means some medical records did have blanks or were unreadable. Likewise for collection of weight and height (used to decide whether the patient could be admitted and discharged); in some cases these were of poor quality, which limited the amount of data that could be included. Included are data sets from two locations (South Sudan and Darfur), essentially from one country; inclusion of data sets from the other case study countries was not possible or appeared less relevant, but nevertheless the low number of countries from which quantitative data were gathered is regretted. Since the available data are, however, leading to very similar observations and conclusions, which in their turn are in-line with findings from other components of the research this limitation is felt not to have biased the end-result in an unacceptable manner.

## 7. Recommendations to MSF-OCA

Reduction of default-rates is multi-facetted; there is no one-size-fits-all, easy-to-implement panacea and therefore various complementary measures must be taken. Note that some of these have already been implemented throughout 2007. Many of these recommendations are already incorporated in the guidelines used by MSF-OCA, but more emphasis must be placed on implementation of these guidelines.

## ***7.0 Basic measures***

- MSF-OCA appears the only organisation that officially holds its defaulter rate aimed for at less than 10%. In order to comply with all other relevant organisations and looking at what can be considered as a realistic target the acceptable default rate should be raised from 10 to 15% of all exits from the programmes. In addition defaulters from areas where no Out Reach Workers are present from should be separated in a monthly analysis of the outcome indicators; this requires the project to explain clearly how many (which) children are really from areas where Out Reach Workers are not operational
- Likewise for the definition of defaulters: identify these as people who missed 3 days from Inpatient Therapeutic Feeding Centre or 3 weeks from Ambulatory Therapeutic Feeding Programme; practicalities in many MSF-OCA projects are that although Ambulatory Therapeutic Feeding Centre patients are often requested to return to the programme on a certain day, many locations also provide weekly therapeutic care on other days of the week. This means that before the child is really considered to have missed its first scheduled visit he/she is close to already missing a second scheduled visit. Following the observation of the child being absent time should be allowed for Out Reach Workers locating the child. The amount of time required to attempt having the child back into the programme without having to label it as defaulter should therefore be increased to 3 weeks, i.e. the definition of defaulting would best be changed to being absent for 3 consecutive visits.
- Use standard Ambulatory Therapeutic Feeding Programme patient file including graph and communicate with caretakers about the target weight and why this needs to be obtained (reduced risk of relapse into malnutrition and reduced risk of morbidity/mortality)
- Evaluate output indicators per Ambulatory Therapeutic Feeding Programme location to achieve a healthy level of competitiveness between the sites

## ***7.1 Measures associated with behavioural beliefs***

- Assessment on people's ability and willingness to come to the feeding centre on a weekly basis (offer admission In-patient Therapeutic Feeding Centre if this suits the care-taker better), and discuss the requirement to continue treatment until target weight has been

reached together with an estimation on how many weeks it may take for this weight to be reached

- Use new weight for height -tables as these suggest discharge at lower weight for height compared to old tables and provide a 2-week Plumpynut supply on discharge
- Emphasise (rapid) weight gain throughout treatment; provide Plumpynut when available, including to those who in previous weeks may have refused it. In some programmes such children receive other (therapeutic) food items, without ever attempting to get the children back to the most preferred food. Also: all children who did not gain weight that week should be counselled

## ***7.2 Measures associated with normative beliefs***

- Provide the child with a bracelet, as a sign of being part of a programme
- Collect exact information on the location of residence of each newly admitted patient; information should be sufficient to find the child if an Out Reach Worker was to be sent out to visit the child
- Follow up of absentees and defaulters with (a team of) Out Reach Workers; programmes who manage to follow up most of the absentees and defaulters have lower rates of defaulting than those who are unable to locate most of the absentees and defaulters and programmes
- Defaulters from areas where Out Reach Workers cannot be included should be separated out in the monthly analysis
- (Enough) Out Reach Workers; the number of Out Reach Workers per patient or per inhabitant is hard to give, how many Out Reach Workers are “enough” has to be established per location
- Out Reach Workers should be paid; many programmes suggest the task of the Out Reach Workers to be voluntary while all other functions in the programme are paid… Paid Out Reach Workers seem to be more productive than volunteers and also more demands can be made on them, when Out Reach Workers are seen as crucial team members –which they should- the same job-conditions should be offered
- Target immediate circle of relatives and community members around the patient and their caretaker

## ***7.3 Measures associated with control beliefs and barriers***

- Bracelets may help to reduce waiting time as patients with bracelets can be arranged to jump the queue and in addition they are helpful in identifying the child during out reach follow up

- Reliability towards beneficiaries (opening days/hours constant, mobile teams carrying out their activities on the same day every week, constant stock of Plumpynut and BP100 etc.) is of vital importance for people to come to the programme on regular basis
- Allow and accept moderate over-stocking, especially when more than one location needs to be stocked
- Decentralisation; programmes with many Ambulatory Therapeutic Feeding Programme-sites within their coverage area reduce distance and greatly improve accessibility from beneficiary perspective
- Provide an exit-gift (e.g. jerrycan) to emphasise the need to stay in the programme until programme-staff are satisfied with the improvement of the child. An exit gift may have an impact on the cost-benefit analysis of the family with a malnourished child

## 7.4 Additional measures for programmes with high defaulter-rate

- Check if all standard measures from the guidelines and those identified above are implemented
- Produce specific information about each defaulter (just like sometimes happens for deaths)
- For projects with high default-rate: make comparison between cured and defaulting children including age, gender, Weight-for-Height- ratio on admission, number of visits to the programme, distance from home to the programme, observations from Out Reach Workers etc.
- Standard follow up visit of children at home during their first week on treatment is advised in all available literature and observed to contribute well to the low defaulter rate seen in Bin Houyé (Ivory Coast). Because programmes that who don't manage can be equally successful it is not advised as a standard measure, but it has to be kept in mind for programmes that show unsatisfactory default rates
- Investigate patient perception
- Develop increased community support

## References


| | |
|---|---|
| Ajzen, I. 2002 | Ajzen I.; Perceived behavioural control, self-efficacy, locus of control and the theory of planned behaviour; Journal of Applied Social Psychology; 2002 (32); page1-20 |
| Briend, A. 1997 | Briend A.; Treatment of Severe Malnutrition with a Therapeutic Spread; Fieldexchange, 1997-2; page 15 |
| Chaiken, M.S. 2006 | Chaiken M.S., Deconinck H., Degefie T.; The promise of a community-based approach to managing severe malnutrition: A case study from Ethiopia; Food and Nutrition Bulletin, vol. 27, No 2, 2006 |
| Collins, S. 2001 | Collins S.; Changing the way we address severe malnutrition during famine; Lancet; 2001; 358; page 498-501 |
| Collins, S. 2002 | Collins S., Sadler K.; Outpatient care for severely malnourished children in emergency relief programmes: a retrospective cohort study; Lancet; 2002; 360; page 1824-1830 |
| Collins, S. 2006-i | Collins S., Dent N., Binns P., Bahwere P., Sadler K. and Hallam A.; Management of severe acute malnutrition in children; The Lancet, September 26th, 2006; page 69443-9 |
| Collins, S. 2006-ii | Collins S., Sadler K.., Dent N., Khara T., Guerrero S., Myatt M., Saboya M., Walsh A.; Key issues in the success of community-based management of severe malnutrition; in SCN Nutrition Policy Paper No. 21; Food and Nutrition Bulletin, vol. 27, no. 3 (supplement); The United Nations University, 2006 |
| Collins, S. 2007 | Collins S.; Treating severe acute malnutrition seriously; Arch. Dis. Child. (BMJ); 2007 (92); page 453-461 |

Gatchell, V. 2006 — Gatchell V., Forsythe V., Thomas PR.; The sustainability of community-based therapeutic care (CTC) in non-emergency contexts; in SCN Nutrition Policy Paper No. 21; Food and Nutrition Bulletin, vol. 27, no. 3 (supplement); The United Nations University, 2006

Gupta, P. 2006 — Gupta P., Shah D. Sachdev H.P.S., Kapil U.; National Workshop on "Development of Guidelines for Effective Home Based Care and Treatment of Children Suffering from Severe Acute Malnutrition"; Indian Pediatrics; 2006; (43); page 131-139

Hardon, A. 2001 — Hardon A., Boonmongkon P., Streefland P., Tan M.L., Hongvivatana T., Geest S. van der, Staa A. van, Varkevisser C., Acuin C., Chowdhury M., Bhuiya A., Sringeryuang L., Dongen E. van, Gerrits T.; Applied health Research (Manual), Anthropology of health and health care; Het Spinhuis; 2001

Kolsteren, P. 1997 — Kolsteren P., Lefèvre P., Lerude M.P.; Nutrition rehabilitation and the importance of the perception of malnutrition in the follow up of rehabilitated children; Asia Pacific Journal of Clinical Nutrition, Volume 6, Number 2; 1997

Manary, M.J. 2004 — Manary M.J., Ndkeha M.J., Ashorn P., Maleta K., Briend A.; Home based therapy for severe malnutrition with ready-to-use food; Arch. Dis. Child.; 2004; 89; page 557-561

MSF, 1995 — Médecins sans Frontières; Nutrition guidelines; 1st edition; 1995

MSF, 2006 — Médecins sans Frontières; Nutrition Guidelines; 2nd edition, 2006

MSF, 2007 — Médecins sans Frontières; New Nutritional Strategies MSF-OCA 2007 (internal document)

Nielsen, C.C. 1992 — Nielsen C.C., Islam M.A., Thilsted S.H. and Ishrat F.; Why do some families become defaulters in a hospital based nutrition rehabilitation follow-up programme?; Tropical and Geographical Medicine, 1992 Oct; 44(4); page 346-51

Prudhon, C. 2002 — Prudhon C. for Action Contre la Faim; Assessment and treatment of malnutrition in emergency situation: manual of therapeutic care and planning for a nutritional programme; 2002

Save the Children, 2007 — Save the Children; Emergency Health and Nutrition Forum; Issue 1: The emergency nutrition portfolio; March 2007

Shoham, J. 2005 — Shoham J.; Agency profile, Artsen zonder Grenzen; Field Exchange-24, March 2005; page 24-25

Sphere Project, 2004 — Humanitarian Charter and Minimum Standards in Disaster Response; 2004 edition

Valid International, 2006 — Community-based Therapeutic Care (CTC), a field manual; first edition, 2006

WHO, 2007 — WHO, WFP, UN-SCN, UNICEF; Community-based management of severe acute malnutrition: a joint statement by the World Health Organization, the World Food Programme, the United Nations Standing Committee on Nutrition and the United Nations Children's Fund; March 2007

## ***Annex 1; Topic-list for interviews South Sudan***

Numerical parameters:

- Age of patient
- History of defaulting (or rather: absence, compared to cured children)
- Sex of patient
- Additionally (based on "logic thinking"):
- Weight-for-Height ratio on admission, Weight-for-Height ratio on last visit before defaulting, Weight-for-Height ratio comparison with patients known to be dead, number of visits before defaulting in order to develop some general ideas about "who" the defaulters are (and –although not completely within the topic of this thesis…- whether we must assume they have suffered from increased levels of mortality)

Accessibility of the programme by the patients:

- Transportation costs
- Distance to centre
- Income
- Migration
- Problems of other (family members) that may have higher priority
- This results in the following topics to be discussed and/or observed:
- Opening days and opening hours; regularity of opening; information about opening of relevant Therapeutic Feeding Programme-location
- Staff at the gate (appropriate in providing/denying access)
- Distance to centre; mode of travel; costs involved (time, money, effort, risk)
- Livelihood of patients; main professions in the area; opportunity costs of coming to the Therapeutic Feeding Programme/carrying out the requirements of the Therapeutic Feeding Programme
- The level of (in)security and the decision to visit the Therapeutic Feeding Programme or not
- Which persons and which factors (other than discussed already, including costs) are involved in decision-making process to bring child to Therapeutic Feeding Programme or not?

Acceptability of the programme by the patients

- Motivation
- Structural non-compliance due to stress and other
- Perception of disease-status

- Treatment (side) effects
- This results in the following topics to be discussed and/or observed:
- Facility: distance, location, the building in general, waiting area, toilets/latrines, patient facilities like drinking options etc.
- Staff: friendliness in communication, professionalism
- Food provided: taste/appreciation (by child and by parent), effectiveness of the food, side effects of the food
- Medication provided: appreciation, effectiveness, side effects
- Perception of malnourished child and cured child of respondents

Community support (by key-community figures, like elders, religious leaders, Traditional Birth Attendants, traditional healers) for the programme and out reach by the programme

- Social support
- The use of family members for compliance-improvement
- Community participation
- Active follow up of defaulters
- This results in the following topics to be discussed and/or observed:
- How are community members and leaders informed about the programme?
- What role do they play in early case finding, adherence, defaulting?
- What are their general perceptions of the programme?
- Do Out Reach Workers link with community leaders or other members of the community and if so: how?
- What role do family members play in the decision to (continue to) bring the child to the feeding centre?

Issues in the organisation of the treatment programme

- Set-up and implementation of the programme by its staff (programme quality)
- Education of patients (by the programme)
- Provider-patient relationship
- Duration of treatment (and time-trend on defaulting)
- Decentralisation
- Adequate supply of drugs

## ***Annex 2; Questionnaire for interviews Darfur***

Introduction

| | |
|---|---|
| Explanation | I'd like to invite you to a short (20 minutes) interview. Your opinions and experiences are important to us, so I hope you could be honest and truthful in answering our questions. Your answers will be held in confidence. I do not work for the clinic, so there's no need to consider my feelings as you give your answers. |
| Consent | Do you want to take part in this interview? If you prefer not to this will have no implication on how your child will be treated |
| | Can we tape (audio) this conversation? |

Access

| | |
|---|---|
| Cost of transport | How much time have you spent today to travel to the Ambulatory Therapeutic Feeding Programme? |
| | How much money has it cost you today to come to the Ambulatory Therapeutic Feeding Programme? |
| | How long did you have to wait before being seen by our programme staff? |
| | Which activities that you are normally carrying out suffer from having to come to the Ambulatory Therapeutic Feeding Programme today? |
| Deciding | Who decides to bring the child for weekly follow up visits? Describe the relationship to the child. More than one answer may apply. |
| | Does everyone around you agree with the fact that you are bringing your child to our Ambulatory Therapeutic Feeding Programme every week? If no: why do some people not agree? |
| | Which security considerations play a role in the decision to visit the Ambulatory Therapeutic Feeding Programme? |

Perception

| | |
|---|---|
| Disease | Does your child need weekly visits to the Ambulatory Therapeutic Feeding Programme in order to recover or do you think he could also recover without the weekly visits |
| Objective | Why -in your own words- is your child admitted into the Ambulatory Therapeutic Feeding Programme? |

| | |
|---|---|
| | Why -in your own words- is your child admitted into the Ambulatory Therapeutic Feeding Programme? |
| | How many weeks -in total- do you think your child will have to be admitted in this programme? (was this explained by the programme staff?) |
| | What "conditions" will have to be met before your child can be discharged from this programme? |
| Facility | Do you have any suggestions how we can improve the Ambulatory Therapeutic Feeding Programme -locations (waiting area, water supply, toilets)? |

Appreciation

| | |
|---|---|
| Child | Does your child like to eat the Plumpynut? |
| Caretaker | Do you like your child to eat Plumpynut? |
| (Side) effects PPN | Did the child have any negative side effects from eating Plumpynut? |
| | Do you think the child gained weight since the start of treatment in the Ambulatory Therapeutic Feeding Programme? |
| | Do you think this weight gain (or lack of weight gain) is due to the Plumpynut or due to other factors? |
| Side effects medical tx | Were any negative side effects observed from medical treatment |
| Centre and personnel | Did the staff explain you enough about the treatment programme? |
| | Has the staff treated you correctly (friendly, knowledgeable)? |

History

| | |
|---|---|
| Treatment duration | How many weeks has the child been under treatment in the Ambulatory Therapeutic Feeding Programme? |
| Absenteeism | How many times has the child missed a visit to the Ambulatory Therapeutic Feeding Programme since the start of its treatment? |
| | If >0: what was the reason the child was not brought to the Ambulatory Therapeutic Feeding Programme that time? More than1 reason may be given. |
| | Are you planning to bring the child to the Ambulatory Therapeutic Feeding Programme every week from now on? |

| | |
|---|---|
| | If no: why not? |

Blockades

| | |
|---|---|
| Perceived self-efficacy | Do you feel the Ambulatory Therapeutic Feeding Programme and your personal effort enables you to cure your child? |
| Potential obstacles | What are the main difficulties you have to come to the Ambulatory Therapeutic Feeding Programme every week? More than one (potential) obstacle may be mentioned. |
| | What could MSF do to (help you) solve these problems? |
| | Suggest possible changes in the project set-up and in communication with the community |
| Perceived social pressure | How do people around you react on the fact that you and your child are attending the Ambulatory Therapeutic Feeding Programme? |
| | Do you know any other people with a malnourished child? If yes: do they visit the Ambulatory Therapeutic Feeding Programme? If no: why not? |
| Stigma | Is it difficult to admit your child is malnourished and needs treatment in Ambulatory Therapeutic Feeding Programme? Are there negative connotations to malnutrition? |

## ***Annex 3; Definitions used in therapeutic feeding programmes***

| | | |
|---|---|---|
| Entry criteria | | |
| Oedema | Bilateral swelling starting in the feet as consequence of interstitial fluid accumulation | Used by all programmes for children 6-59 months of age |
| Weight-for-Height<70% | | Used by most programmes for children 6-59 months of age |
| Weight-for-Height<-3 z-score | | Following the development of a new Weight-for-Height-table commonly referred to as the 2005-WHO-standard MSF-OCA has chosen to implement its use and define SAM based on z-score (since mid-2007 only) |
| MUAC< 110 mm | | Used by most programmes, but age or height cut-off for its use vary (MUAC criteria may apply to children over 65, 70 or 75 cm in height) |
| Treatment | | |
| Initial phase of treatment | | Programmes may include a component for inpatient care. Often only children with complicated forms of malnutrition are admitted, but in other cases all children are internalised for the first few days of treatment. Inpatient phases may be offering treatment around the clock, while some others provide only day-care. Although less preferred, some programmes do not include any inpatient phase |
| Diet | | Products and quantities per kg may vary, potentially resulting in slower and quicker weight gain. Also: some programmes provide rations for siblings of admitted children |
| Frequency | | Programmes may require weekly or bi-weekly visits |
| Exit criteria | | |
| Cured | Weight-for-Height >85% | Generally children are considered “cured” when they present a Weight-for-Height >85% for 2 or 3 consecutive weighings |
| | Weight-for-Height >80% | In some cases, e.g. when caseload is high or when an SFP is available children are considered “cured” when they present a |

| | | |
|---|---|---|
| | | Weight-for-Height >80% for 2 or 3 consecutive weighings. When SFP is available they are generally included in this programme until they reach WfH>85% for 2 or 3 consecutive weighings |
| | WfH>-2 z-score | Programmes that use the 2005-WHO-standard use the –2 z-score as the target weight for treatment (since mid-2007 only) |
| | No oedema | Some children presenting with oedema on admission are not extremely underweight. Most –but not all- programmes require children to be free from oedema for at least 1 or 2 weeks before discharging them as “cured” from the programme |
| | MUAC | Some programmes have an additional exit-criteria based on the MUAC, e.g. MUAC must be over 120 mm |
| Defaulter | | Children may be counted as defaulter after 2 or 3 consecutive visits are missed. For children in a weekly programme this may mean a period of 2 to 3 weeks, for those in fortnightly programme it may mean 4 to 6 weeks while for those in 24-hour or day-care it may mean 2 or 3 days |
| Death | | Most programmes count a child as death-within-the-programme when it dies before technically becoming a defaulter, i.e. within the period of 2-3 weeks (or days in case of inpatient treatment) after its last visit to the programme. Programmes may vary in rigour with which defaulters are traced. If limited tracing is carried out some children who have died may be counted as defaulter |
| Transfer | | Some programmes may have a referral possibility (i.e. a hospital) to where extremely critical patients are referred. As a result heir death-rate may be relatively low compared to programmes that lack a referral option |
| Failure to respond | | The duration that children may spend in the programme without reaching the target weight varies. In addition the rigour by which this discharge criteria is followed up on varies as well |