

# Ready-to-Use Therapeutic Food for Management of Wasting in HIV Infected Adults: A Qualitative Investigation of Views and Experiences of Patients in Ethiopia

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**Abstract:** HIV infection and poor nutrition status are interlinked. HIV infected individuals are more vulnerable to malnutrition than the general population. Poor nutrition status in HIV infected individuals is associated with disease progression, increased morbidity and reduced survival even when antiretroviral treatment is available. Adequate nutrition is necessary to maintain the immune system, manage opportunistic infections, optimize response to medical treatment, sustain healthy levels of physical activity and support optimal quality of life in individuals infected with HIV. WHO recommends incorporation of nutritional care and support as an integral part of a comprehensive response to HIV/AIDS. Ready-to-Use Therapeutic Food (RUTF) is widely in use in management of wasting among HIV infected adults. In Ethiopia, there was paucity of data on adults' views and experiences of RUTF though patients' perceived values of use and perceptions on a service are important factors in treatment success. The objective of this study was to explore views and experiences of HIV infected adults treated with RUTF in Addis Ababa, Ethiopia, 2012. The study explored issues related with attitude, believes, perceived benefits of use, misuses and challenges related with RUTF use. Phenomenological qualitative study based on in-depth interview and focus groups discussion was conducted on purposefully selected sample of 23 HIV positive adults on RUTF treatment in Zewditu hospital and Woreda-7 health center. The data collected was audio recorded, uploaded into opencode and analyzed using themes emerged from the data during constant comparative analysis. HIV infected adults had positive attitude, perceived many benefits of use and experienced favorable outcomes of RUTF use. Intention to use RUTF was also high. However, patients encountered significant challenges associated with their use of RUTF. They experienced side effects, felt more stigmatized and discriminated, encountered problems during handling and transportation. RUTF misuse was practiced frequently and in variety of forms. Modification of the current formulation and its prescription protocol, systematic control measures, provision of comprehensive nutrition counseling, harmonization of RUTF and other HIV clinical care appointments; and assessment and training on nutritional counseling skills of the health workers should be considered.

**Keywords:** Ready-to-Use Therapeutic Food, Wasting, HIV

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## 1. Introduction

HIV infection and poor nutrition status are interlinked. Despite major advances in treatment and survival outcomes of people living with HIV (PLWH), weight loss and wasting remain common problems. HIV and malnutrition have a cumulative effect in weakening the immune system. PLWH

are more vulnerable to malnutrition than the general population. The synergism between HIV and under nutrition leads to poor adherence to treatment and high mortality rate (1, 2).

Individuals with HIV undergo various physiological alterations beginning in the early phase of the infection. The impact of HIV infection on nutrition was identified early in the

epidemic with wasting being one of the most visible signs of malnutrition in patients who progress to acquired immunodeficiency syndrome (AIDS). Several studies have demonstrated association between lean body mass depletion and disease progression (3, 4). The impaired nutritional status of patients with HIV is partially caused by the reduction in calorie intake, the occurrence of opportunistic diseases and the hypercatabolic action of the body in an attempt to control viral replication and reconstitute the immune system (5). The rise in metabolic rate due to HIV infection is 10% and 20-30% in asymptomatic and symptomatic adults respectively. This increase in energy expenditure will often lead to weight loss. Thus, wasting may occur despite individuals maintaining their usual food intake after acquiring HIV and during all stages of the disease. Besides, through reduction of food intake, impairment of digestion, malabsorption and food insecurity, HIV progressively impairs nutrition status (6, 7, 8). Among PLWH, malnutrition is associated with incomplete HIV RNA suppression, CD4 cell decline, increased opportunistic infections, hospitalizations and HIV-related mortality (9, 10).

Malnutrition aggravates the effect of HIV infection including further weakening the immune system and increasing vulnerability to opportunistic infections, thereby accelerating the course of the HIV infection. Impaired immunity reduces the body's resistance to infection. Thus, despite major advances in antiretroviral treatment and survival outcomes, weight loss and wasting remain of significant health concern among HIV infected groups. Poor nutrition status in PLWH is associated with disease progression, increased morbidity and reduced survival even when antiretroviral therapy is available (11, 12). Poor nutrition status at start of antiretroviral therapy has been identified as an independent predictor of mortality irrespective of immune status. Patients who gain weight in the early phase of treatment have improved prognosis (13).

Adequate nutrition is necessary to maintain the immune system, manage opportunistic infections, optimize response to medical treatment, sustain healthy levels of physical activity and support optimal quality of life for PLWH (14, 15, 16). According to the World Health Organization (WHO), dietary therapy is an integral part of a comprehensive response to HIV/AIDS. The current WHO recommendations on nutrient requirements of PLWH call for increase in energy over the intake levels recommended for healthy, non-HIV-infected individuals of the same age, sex and level of physical activity. Increased energy metabolism in asymptomatic adults requires 10-15% additional energy; this additional energy requirement is 20-30% in symptomatic adults (16, 17, 18).

Nutrition interventions have been successful in the management of HIV/AIDS. Many patients enrolled into such programs have markedly improved both their body weight and general health (19). The Food by Prescription (FBP) program is one of the strategies that addresses under nutrition among PLWH through nutritional assessment, counselling, and support (NACS) (20, 21). Since 2010, the Ethiopian health system has been implementing FBP program, a facility based intervention which has targeted and enabled malnourished,

HIV infected individuals to receive therapeutic and supplementary feeding upon fulfillment of indications for nutrition therapy (22).

RUTF is one of the products in use for management of HIV associated wasting in adults. Based on their nutrition status at entry in the program and the rate of recovery while on treatment, patients receive 3-6 months of RUTF supply. RUTF is a precooked, peanut-based paste made of sugar, vegetable oil and skimmed milk powder, enriched with vitamins and minerals. It has a 2 year shelf life and requires no further preparation for use. Its composition is the same as the milk based therapeutic food, F100, except the latter lacks iron. Before the introduction of RUTF, severe acute malnutrition was treated with therapeutic milk and required hospitalization. Unlike F-100, RUTF can be administered at home and without medical supervision (23). Initially, RUTF was formulated and designed for management of acute malnutrition in children. Recently, it has been recommended for management of adult wasting especially in PLWH and evidences show the effectiveness of RUTF in HIV infected malnourished children and adults in improving body mass index (BMI), CD4 cell count, health and functional status (24, 25, 26).

Despite these benefits, there are reports of challenges in implementation of FBP program. High default and loss to follow-up rates after enrollment in the program have been documented in some studies (27, 28). Another challenge of the program is that it takes a longer time to complete because of misuses including food sharing (29, 30). A study in Kenya on consumption of RUTF (plumpy'nut) showed some challenging realities of RUTF use in adults like diet boredom, poor adherence and sharing. Most patients reported that they felt stigmatized for consuming RUTF more so than for HIV drugs. (30). Half of RUTF users indicated they could not comply with the full prescription due to the taste of the product, diet boredom and clinical conditions associated with HIV (esophageal thrush, lack of appetite, nausea and vomiting). Sharing RUTF ration with other household members was also common, mainly due to poverty and household food insecurity (30, 31).

Effectiveness of medical therapy is significantly associated with the extent of acceptance of a product, compliance to dose, timing and other relevant medical recommendations. The patient point of view regarding both preventive and curative health care has gained significant importance in decision-making procedures and has been considered a criterion standard to assess treatment efficacy. Thus, provision of health care service should be responsive for the values, needs and preferences of patients (32, 33, 34).

Although much has been done on availing nutrition services for PLWH, less is done on the quality of care which includes assessing patient's perspective (35). Data on adults' experiences and views about RUTF is limited in Ethiopia despite patients' perceived values of usefulness and attitude to medical treatment are important factors in determination of acceptance and intention to utilize the service. Cognizant of that, this study was aimed to explore the views of patients toward RUTF which include attitude, experience of use, the

different events and beliefs in the phenomenon, the connections and relations patients see among these events. The findings of this study would help health professionals and program implementing bodies to understand the realities of RUTF use as seen in the eye of the patient; and to design a user responsive approach.

Qualitative method is probably the best way to understand patients' views and experiences of clinical service; as it can give contextual description of a phenomenon, relation of events in the phenomenon and explore interpretative experience of individuals (36, 37). This study identified potential issues related with acceptance, adherence, distribution, consumption, handling, sharing, misuse and challenges of RUTF. Besides, it explored other potential issues related to nutrition care provision like patient provider relation during the care provision process. We present the result of the study in compliance with COREQ (consolidated criteria for reporting qualitative research) guide (38). To our knowledge, this was the first study in Ethiopia to assess the views and experiences of adults on RUTF.

## 2. Method

### 2.1. Study Area and Period

The study was conducted in Addis Ababa, Ethiopia in two health facilities: Zewditu hospital and Woreda-7 health center in 2014. The source populations were HIV infected malnourished adults on therapeutic and/or supplementary feeding program in Addis Ababa. The study populations were those HIV infected, malnourished adults on therapeutic and/or supplementary feeding program in the Zewditu hospital and Woreda-7 health center. In these two health facilities, there were a total of 560 individuals enrolled for nutrition care and support (400 in Zewditu hospital and 167 in Woreda-7 health center). The services provided in these health facilities also included HIV counselling and testing (HCT), prevention of mother to child transmission (PMTCT), antiretroviral therapy (ART), palliative care (PC) and nutrition assessment, counselling and support (NACS).

### 2.2. Study Design, Sample and Sampling

The study design was phenomenological qualitative study, based on semi structured in-depth interview and focus group discussion (FGD). Purposive sampling method was used in selecting study participants. The final sample size was determined by level of data saturation and composed of a heterogeneous sample of 23 individuals on RUTF treatment. Of these, 15 individuals participated in in-depth interviews and 8 individuals in an FGD. To ensure theoretical representation and obtain wide representation of views, participants were recruited from different sub categories and treatment plans. The sub categories were nutritional status at admission (severe acute malnutrition, moderate acute malnutrition), treatment outcome (success, failure), clinical condition, adherence (poor, good) and ART status (Pre-ART, on ART). The plan was to recruit 32 individuals for both

in-depth interview and FGD. However, due to data saturation, the final sample size was set at 23.

Study participants recruitment was done jointly by health care workers providing the treatment and the principal investigator of the study. Based on the inclusion and exclusion criteria, study participants were initially selected on bases of the information found in the FBP program registration book of the health facilities. Telephone communication and personal contact during follow up visits were primarily used to confirm individual's willingness to participate in the study. Recruitment of participants for in-depth interview and FGD was made on basis of relevance to the topic and representation of different categories of patients on the program. Inclusion criteria for this study were combinations of the followings:

- HIV infected adults
- Severe or moderate wasting at admission
- Patient taking RUTF currently or interrupted treatment for not for more than 3 months or completed follow up for not more than 3 months
- Good cooperation
- Disclosed HIV status (for FGD participants)

### 2.3. Data Collection

Data collection was done using a semi-structured interview guide developed for this study. Audio recording was done supported by note taking on non-verbal cues. After study of literatures, guidelines on RUTF and interview of experts on the field, a study guide was developed with open ended questions. The guide incorporated multiple question series as a device for opening a wider and flexible answering space. A trained interviewer, with one note taker on nonverbal cues, led each session. Data collection was done from January 15/2012 to March 30/2012. The interviewing was done in a private setting in the health facilities where the participants attended their regular medical follow-ups. The interviews lasted from 23 to 48 minutes with average duration of 37 minutes. Refreshment (tea, coffee, soft drink) was provided and travel expense was reimbursed at flat rate of 20 Ethiopian Birr at the end of each session. The FGD was done after the in-depth interview data was analyzed and insight gained about the study questions. The same study guide was used during FGD to allow comparison with the findings of the in-depth interviews.

### 2.4. Data Analysis

Transcription, translation, coding and constant comparative analysis were done soon after each data collection. Thus, findings and experiences learned from previous interviews guided the subsequent interviews. At the end of each data collection, the tape recordings were transcribed in verbatim and translated to English. Translation was done by two individuals working independently (the principal investigator and a data collector) and comparison was made. The transcripts and translations were rechecked with the tape recordings and field notes. Then, the data was loaded into opencode, a computer program for analyzing qualitative data.

After careful line by line reading and understanding, the data was divided into meaningful analytical units. Each meaningful segment was coded with descriptive words. An initial categorization scheme was established based on the interview guides. This first thematic index was modified, categories and sub categories being added as they emerged from the data during the constant comparative analysis. Numerous free categories were developed, discussed, adjusted and grouped during an iterative process which led to development of a final thematic index based on the data. Finally, all data was re-coded according to the final thematic index generated which was composed of a total of 5 themes (Tn), 15 categories (Ca) and 52 codes (Co). The themes found and used for analysis of the data were perception to RUTF, outcomes of use (T2), challenges of use (T3), patterns of use (T4); and others (T5) on concerns and suggestions raised by participants of the study. Refer table1 for summary of themes, categories and

codes.

The preliminary results of the study were presented in two meetings with study participants and comments were collected. Besides, peer review and comment on the findings of the study were done by three experts working on the program. However, the final results were not changed because there were no major ideas found after peer review and member check.

## 2.5. Ethical Approval

Ethical clearance for this research was obtained from the research and publications committee of University of Gondar and Addis Ababa city administration health bureau ethical clearance board. Written consent was taken from study participants using forms designed for the study.

**Table 1.** Summary of Themes, Categories, and Codes, 2012, Addis Ababa.

Themes	Categories	Codes
Perception to RUTF (T1)	Food (CA1)	Nut/Nut butter Supplementary food/Body building food Salty Sugary Oily Adaptable
	Characters (CA2)	Positive attitude on RUTF Negative attitude on RUTF
	Attitude (CA3)	Positive attitude on health workers Negative attitude on health workers Positive attitude on counselling Negative attitude on counselling
	Perceived usefulness (CA4)	Weight gain Health improvement Energy provision Ease of use Improve adherence to ARV drugs CD4 cell increment
	Effect on health (CA5)	Pain relief Alleviate anorexia Relief of depression
Outcomes of use (T2)	Effect on other treatments(CA6)	Improvement of adherence Reduce ARV drugs side effects
	Effect on weight(CA7)	RUTF helps to gain weight
	Effect on productivity(CA8)	Better functional status Improve ability to work
	Psychological effect(CA9)	Relief of depression Improved self-image Reduce stigma Nausea Anorexia Vomiting Diarrhea
Challenges (T3)	Side effects (CA10)	Diet boredom Heart burn Dyspepsia No side effect Stigma Discrimination
	Handling and transportation (CA11)	Heavy weight Bulkiness of supply
Patterns of use (T4)	Ways of intake(CA12)	Properly Improperly

Themes	Categories	Codes
Others (T5)	Miss use(CA13)	Sharing Selling Cooking Abuse by other individuals
	Concern(CA14)	Association with HIV Worry on supply continuity Separated follow-ups
	Suggestions(CA15)	Design of control mechanisms Patient awareness raising
		Product modification Increase supply

### 3. Result

A total of 23 participants (15 females, 8 males) were involved in the study. Of these, 15 (10 females, 5 males) were recruited for in-depth interview and 8 (5 females, 3 males) were recruited for an FGD. The study participants' age ranged from 22 to 46 years with mean and median ages of 29 and 27 years respectively.

#### 3.1. Perceptions to RUTF

##### 3.1.1. Attitude on RUTF

Participants used different terms when referring RUTF while they were responding to different questions. All considered and referred RUTF as food item. Most common terms they used when referring it were supplementary and body building food.

"It is a supplementary food taken after usual meal. This is what I know from my experience as well as from what they told me." ZH003

"It is given to substitute food. Individuals who cannot get food use it as food substitute. ...Thus, I take it as a food aid." FGDR1

Most participants expressed as they found RUTF salty, sugary and oily. While stating their experience of use, they referred these characters as disgusting and unpleasant.

"Other food should be taken before using RUTF because it reduces appetite due to the excess sugar and oil in it." ZH007

Participants' attitudes about RUTF were generally positive. All mention as they found RUTF useful and lifesaving. For example,

"The disease (HIV) affected my appetite. It could not be alleviated by medication. Neither tablet nor injection helped but RUTF did. RUTF is lifesaving. It saves life... I was bed ridden and unable to walk. Soon after using RUTF, I have started to eat well and gained weight. I was also able to walk. Generally, it is useful in many aspects." W7001

"RUTF is very good product not only for people like us but also for any healthy individual." ZH001

Most participants also said that they had positive relation with the service providers. Caring, compassion and concern were the most frequently mentioned qualities of the service providers.

"Before I took this, they asked me why I became wasted and sick. They gave us good accommodation. All including the

receptionist were good. They should be appreciated." W7002

As most participants implicitly or explicitly expressed, the nutrition counseling service was weak and not as helpful as expected. The major problems mentioned were the vagueness, irregularity and incompleteness of the counseling sessions.

"They give you attention when you become sick...They do not give in-depth information except saying take balanced diet. I do not understand it. Because they are busy, they could not give satisfactory advice. Thus, I do not want to ask further about it. I, rather, just say okay and leave the clinic." ZH005

"They did not tell me clearly how and how much to take in a day" FGDR7

##### 3.1.2. Perceived Usefulness of RUTF

All participants expressed as RUTF was useful. Body building (weight gain), health improvement (protection from disease), energy (strength) provision, ease of use and adherence support to other drugs were identified as useful aspects of RUTF. One participant said:

"As to my understanding, it is a body building food given to weak and undernourished individuals. It is the best of all food items. After starting to RUTF, I have lots of improvements in many aspects. I started to walk, my appetite returned and my health condition improved. It is comfortable and I pray God for continuity of the supply." W7001

As most participants expressed the condition that RUTF did not need any further processing and its ease to use were considered as positive aspects.

"RUTF provides balanced diet which could not be prepared in home for different reasons. You may not get food or may feel tired to prepare or may not be in good place." ZH005

#### 3.2. Outcomes of RUTF Use

##### 3.2.1. Effect of RUTF on Health

Participants stated that most of the time they were sick and physically weak before using RUTF. After using RUTF, all participants explained as they had gotten significant improvement in their health. Raise of CD4 cell count, relief of pain, anorexia, disease and depression were the most important aspects of RUTF stated as providing health improvement. Participants considered CD4 cell count as an important factor determining disease acquisition and overall health status. Most participants mentioned that their CD4 cell count was low before starting RUTF. Because of this, they believed, their health was poor. However, after use of RUTF,

their health had improved.

"I have used RUTF for three months and benefited a lot from it. It has increased my weight, CD4 count and strength. I was not like you see me today before using RUTF. I was thinner and weaker. It was because of these indications they prescribe me RUTF." W7006

"Before I used RUTF, I was weak and feeling palpitation and easy fatigability. Sometimes, I become faint. After using RUTF, my weight, strength and health have increased. I am fine now." FGDR2

Most participants described as they lost appetite because of the disease (HIV). After using RUTF, their appetite had returned and able to eat food properly. Besides, most participants stated as RUTF had enabled them to take more water than previously, a condition believed useful by participants for their health. They considered these effects of RUTF useful. For examples:

"I can say my appetite was almost none before starting RUTF but fine after starting RUTF. As I already told you, I was weak, very thin, wasted with around 35–36 kg of weight. My appetite and health condition were also poor. Because I am from poor family, I could not get balanced diet. I could not also eat well due to poor appetite. After I started RUTF, everything got improved. My health and appetite returned. Besides, it gave me strength and beauty. Now, I can work like any individual." W7008

"I was very sick. The drug (antiretroviral drugs) irritates stomach and I could not tolerate it in empty stomach. After starting use of RUTF, my appetite returns, the gastritis subsides, I could take more water and my health improved much." W7007

Some participants stated as RUTF enabled them to reduce depression or other related feelings. They associated this reduction of depression feeling with their health improvement and satisfaction after using RUTF.

"It is nice. It provides vitamin especially for those with poor appetite. It is as useful as eating meat or other meal. Anyone who eats one RUTF sachet and drinks water can stay the whole day as satisfied as others who eat anything else. Besides, it makes one alert." W7001

"I think it is good. It is a very good thing. It offers strength and consciousness. If you become healthy and strong, you will no longer be bedridden and can work like any healthy individual and support yourself. For example, I can wash clothes now. That satisfies me a lot really." W7006

### 3.2.2. Effect of RUTF on Other Treatments

Patients required taking food before swallowing ARV drugs. At times they did not get food, they missed schedule. Some patients stated that they were in much trouble of getting food due to poor socioeconomic status. These individuals used RUTF as food substitute. Thus, the use of RUTF had increased compliance of patients to other medications especially for individuals with food insecurity.

"It helps me to adhere to the drugs (ARV). I can take the drugs after eating RUTF...I do not feel any illness because RUTF helps to take drugs timely and properly." ZH001

When emphasizing the importance of taking food before swallowing drugs, some patients stated that they were unable to tolerate ARV drugs because it caused gastritis when taken in empty stomach. They stated as they got relief of ARV drugs induced gastritis which enabled them to comply with their drug taking schedule which subsequently enabled them to acquire better health.

"I was very sick. Besides, the drug (ARV) irritated my stomach because I was not taking food properly. I couldn't take food properly. After starting use of RUTF, my appetite returned, the gastritis subsided, and I was able to take more water and my health improved much." W7007

### 3.2.3. Effect of RUTF on Weight

All participants expressed that they were wasted and much worried of it because wasting was traditionally associated with HIV. Most participants had expressed as they got significant weight increment and physical appearance as result of using RUTF. They were happy with their weight increment because one would not be suspected of HIV/AIDS.

"After using RUTF, I had gotten much improvement in my health. My weight was 35 Kg. Now, it is 45 kg. Likewise, my CD4 cell count, BMI and strength have increased very well. These improvements enabled me to support myself." W7006

### 3.2.4. Effect of RUTF on Productivity

The use of RUTF in most patients also brought better productivity and functional status. Most participants stated that they were not fully functional and productive due to their poor health condition and physical weakness as a result of HIV. However, the use of RUTF had enabled them to utilize their potentials, become productive and avoid depending on others. The main enabling factors mentioned for their better productivity were health improvement and return of physical strength after using RUTF.

*"I feel healthy now. Before using RUTF, I was weak. I also had heart problem and was feeling fatigability. I could not even wash my clothes. Now, I can freely do any activity and walk like any healthy individual."* W7007

### 3.2.5. Psychological Benefits of RUTF

Most participants stated that they had suffered from varied psychological impacts of HIV and an associated wasting, too. Most participants also felt victimized due to association of wasting with HIV and self-image disturbance. After using RUTF, they got significant relief from these conditions.

*"Before using RUTF, I was weak, irritant, depressed, underweight and sick. I could not even talk or chat with people. It relieves me from illness, depression, irritability and weakness. Now, I can chat or talk freely with friends. I find RUTF very nice."* ZH005

## 3.3. Challenges of RUTF Use

### 3.3.1. Side Effects of RUTF Use

All participants mentioned as they were not comfortable and faced health impairment at beginnings of their RUTF use. The commonest side effects raised were nausea, diet boredom, anorexia, diarrhea, vomiting and heart burn. Due to these

problems, they were not able to use RUTF properly and other food items, too. Most were forced to reduce amount of intake, quit for some time and consider interruption of use. Even, some users used to give it to other individuals due to frustration over the side effects and contemplation of discontinuing. For example, two individuals expressed their experience as follow:

“At the first time, I did not think it was useful. Even, I was thinking to throw it on my way to home. Besides, I was much afraid of people when I took it. In the first 15 days, I felt nausea but I did not interrupt it. Of course, I was thinking discontinuation. However, I found it comfortable after I took it for some time.” W7007

“Taking RUTF is difficult at first times. It causes nausea, diet boredom and anorexia.” FGDR2

As characterized by most participants, most side effects were transient, adaptable, and occurred at early phases of use. In most participants, these side effects stayed for brief duration. With continued taking, the symptoms disappeared gradually.

“Initially, I felt nausea and much disturbed. I could not take even one at a time. I had to divide one sachet for three meals. I continued taking it in small amount. Then gradually, I adapted it and started taking two, then three per day. As a result, my weight and general health have improved.” W7001.

Most associated these side effects with the sugary, oily and salty nature of the product which they believed caused diet boredom and disgusting. Most participants believed these features of RUTF were responsible for their inconveniency with use of RUTF.

“Generally, RUTF is very good product not only for people like us but also for any healthy individuals. It is also easy for use except it tastes salty and sugary which cause discomfort at early times. I remember when I decided to quit taking RUTF due to these conditions.” ZH001

Participants tried different methods to alleviate the unwanted symptoms and get adapted to the product. Most tried to alleviate the diet boredom and gastrointestinal discomfort through dietary modification. The most common methods used as remedy were starting with low dose, drinking more water, reducing the amount of intake at time of discomfort, taking slowly, mixing with other food items such as bread and diverting attention while taking.

“I finish it soon. I suck it from the sachet and swallow with water. It will not stay much in my mouth. Thus, I will not feel the bad taste that causes nausea and vomiting. .... If it stays in mouth I cannot take more due to its taste. Thus, I take it with water to evade the taste.” ZH005

“at the beginning, I felt discomfort and diarrhea because I was taking it alone. When, I started to take smaller amount and drink water while eating, the discomfort disappeared. After that, I have not encountered any challenge.” ZH003

### 3.3.2. RUTF Associated Stigma and Discrimination

Most people associated RUTF with HIV/AIDS. There was a widely held idea in the community that RUTF was intended only for HIV patients. Thus, anyone taking RUTF would be

labeled as HIV infected. Fearing the consequences of this belief, most participants stated that they had tried to hide it during transportation and use. However, due to the bulky nature of the product hiding others was difficult. Thus, they felt more exposed, stigmatized and discriminated as result of using RUTF more than so for HIV drugs.

“When they (the community) see people using RUTF, they immediately link it with HIV (holding head and in bad feeling). As a result, they isolate us and our children, too despite we have been living and working together for long time. ... We are afraid of stigma, discrimination and being treated valueless (in crying mood).” W7001

“People say it is intended for HIV patients only. Because people believe that, I take it to home with precaution covering it with something.” FGDR5

### 3.3.3. Handling and Transportation

Most participants, when responding to questions about handling and transportation, indicated that RUTF was difficult for handling and transportation unlike other health commodities. The bulkiness and heaviness of the product coupled with the frailty of most beneficiaries were the main factors for the difficulties in handling and transportation.

“I cannot carry it myself because it is heavy. I do not also use laborers because they might rob me. Therefore, I have to bring one family member to support me. It is very heavy (with surprise). I cannot even move it from place to place inside home.” W7002

“I cannot take monthly supply at once. I have to come every 15 days for collection.” ZH006

RUTF use was widely associated with HIV. Using RUTF would disclose HIV status and predispose to stigma and discrimination. To mitigate the problem of stigma and discrimination that may follow if other people saw them using it, most participants (except those who disclosed their status) mentioned as they used different hiding means including keeping in lockable shelf, under bed and covering with other objects. While taking it home from health facilities, they covered it with materials like opaque plastic bag or sack so that others could not know the content. “...I take it home in plastic bag. Otherwise, people will see it. It is widely known nowadays... at the first time, I found it too heavy to carry on. From here up to the hospital gate, a girl who was here for clinical practice assisted me. Then, I used contract taxi to home. I used two contract taxis; one from here to midway and the other from midway to home. I changed the first taxi after midway because I do not want the driver to see my residence area.” ZH005

“Earlier, I was thinking that RUTF was prepared and given only for HIV patients. I was prescribed with RUTF a year ago. At that time, I was hiding it on the roof of the house due to fear of the consequences of its association with HIV.” FGDR3

### 3.4. Misuse of RUTF

While discussing on different issues about RUTF and patients' live experience of RUTF use, varied misuse areas were raised. The most common misuse areas mentioned by

most participants were sharing, selling, cooking and improper intake. Besides, most participants did not use RUTF for themselves only. Some considered it as family diet and share with other family members. Sharing was more common in poor households and in beneficiaries with children. Consideration of RUTF as food, lack of awareness about its possible side effects and household food insecurity were the main factors indicated that facilitating the sharing.

"It is useful for poor individuals who do not have foodstuff in home. It can substitute food. In some households with food insufficiency, children eat RUTF." W7007

"My cousin is weak, thinner and sick most of time. I was giving him RUTF because he was not healthy." FGDR3

Most participants were reserved when responding to their own experience and/or intention of selling RUTF. However, they explicitly explained that RUTF was widely available on market and the sources were patients on the program.

"There are people who sell it due to lack of awareness about its uses...It should not be sold and used for business purpose by any means. If you check, you can get it in every shop." W7008

"I pay 300 Birr every month for milk. I have to sell RUTF and cover the cost of the milk. As to my understanding, people sell it because they need money to buy some food items like milk and egg. I do not think it is bad selling RUTF to buy other food items. There are people like me who cannot afford buying milk. Besides, it will be better if they give us the money instead of RUTF." FGDR5

When responding on their own ways of usage, some participants stated that they cooked it by adding in soup. The main reason mentioned to do so was to crack diet boredom. Besides, some used RUTF as sugar substitute and used to add it in keshir (local tea made of ginger) and coffee.

"It is food. I was using it in different ways. When I got bored of sucking it alone, I boiled it and made keshir (local name for a tea made of ginger) or soup." W7006

"I have been using it in different ways. I use it in the form of porridge, soup and sandwich." FGDR1

### 3.5. Concern on Program

Most participants stated that though they had positive attitude and intention to start and continue using RUTF, they had doubt on the continuity of the supply.

"The nurse told me as the supply would stop when my weight stabilizes. I am worried on that and planning to ask her about it. It is a life for me. If it stops, I may deteriorate." ZH002

"It is good if the supply can be continued and if it can be given for more than three months. Otherwise, our weight may reduce further." FGDR8

Most participants stated that they had to visit health facilities more than once in a month. The main reason for this was lack of concordance between RUTF and other HIV service appointments. Most patients on both ART and RUTF used different follow-up schedules. Thus, they had to come at least twice in a month (at one time to collect ARV drugs and at another time to collect RUTF or for other clinical

appointments). Besides, some individuals who were physical weak and who did not have companion had to come more than twice in a month. They found these separated follow-ups for ART and RUTF unfriendly and costly in terms of time and money. Most wanted to collect both ART and RUTF on the same day. A woman who came from relatively far area explained the condition of separated follow-up as follow:

"For example, my appointment for ART is by 27th of every month and for RUTF by 15th of every month. I am afraid it may be vexing the health workers to ask rearrangement of appointment dates. Hence, I have to present at both appointments. When I do not have money for transportation, I ask my sister who knows my case. This, in fact, is problematic for people who have no money for transport.

### 3.6. Suggestions

While discussing on different issues, participants raised varied problems and challenges related with RUTF use. They made various (in few cases opposing) recommendations which they think would alleviate the problems. However, all recommend on design of control measures, modification of product and increment of supply. Most participants stated control measures should be taken on both sellers and buyers.

"Money people are in need of RUTF. Even, we also want additional supply because it will improve our health better and make us more productive. Some investigation should be done on this and corrective actions like education should be provided." W7008

"It is good if control measure is taken. Of course, controlling people, especially poor people, might be difficult as they sell it for different reasons." W7009

The provision of nutrition counselling was very limited and unsatisfactory. Most stated as they did not get adequate information about RUTF like on its way of use, amount and about its importance. Most believed that due to the lack of awareness, some individuals were selling RUTF.

"There are people who sell RUTF due to lack of awareness about its uses. When people sell it, they lose an important thing for their health. Thus, from the very beginning, people should be advised about the product. It should not be sold and used for making money by any means. Education should be given on the issue." W7008

Though all participants stated as they got much benefits from using RUTF, they identified problems related with RUTF use like diet boredom, anorexia, nausea, vomiting and diarrhea. According to the opinion of most participants in this study, the main contributing factors were the presence of excess sugar, oil and salt in the product; and they believed modifying these compositions would make the product palatable.

"RUTF is a fine product except it tastes salty. It will be better if this aspect can be modified." W7009

"The composition of the food should be modified especially for beginners. It is difficult for adaptation to new users. It will be better if the salty and sweet taste can be reduced. It is because of these features, new users feel disgusted." ZH001

Most participants also recommended on reduction of

volume and weight of the product so that it would be easy for transportation and handling.

“It is good if its weight can be reduced. Though not sure, I think, it can be prepared in flour form with all its contents maintained. It may be lighter in that way. Besides, it will be better if a single daily dose can be formulated instead of taking four times a day. This will help to eat other food at the remaining times.” ZH006

Patients believed they were not receiving adequate amount of RUTF. The amount also varied from time to time. Besides, they were afraid of immediate weight reduction and deterioration of health condition in case the supply interrupted. All participants remarkably recommended on continuity of supply and avoidance of any interruption that might occur. They all recommended that the supply should be individualized. For example some explained the situation as follow:

“They give me 54 sachets for a month which is not enough for me. It runs out soon. I need more. Because my child is also thin, they (the health workers) are giving her. Thus when I finish mine, I often use my daughter’s RUTF.”

## 4. Discussion

Although the design of this study precluded generalization, it provided many insights about patients’ views and their interpretative experiences of RUTF use. It explored the attitudes, beliefs, perceived benefits of use, misuse ways, misuse facilitators and challenges related with RUTF use. The different events and phenomenon with their interactions, interrelations, causes, consequences and contextual descriptions patients see among these events were identified. Besides, this study also identified other issues related to nutrition care provision like patient provider relation during the care provision process. It is notable that assessing patients’ perspective of treatment lead to a better understanding of the values, needs, preferences and experiences of patients and to design a better strategy to address these needs and preferences (32, 33, 37).

Most participants mentioned as they considered RUTF as food. Thus, they used it as a substitute for homemade food items. This was against the assumption of the nutrition care and support program which considered RUTF as drug and tried to integrate it with HIV service packages like ART and PMTCT programs (17). The practical implications of this were because patients did not consider it as drug, misuses like sharing, selling improper ways of use and reduction in intake of homemade food items are higher among users of RUTF. A recent qualitative study on RUTF acceptability in Homa Bay, Kenya showed high prevalence of misuse and sharing among beneficiaries (30). Another study done on effectiveness of RUTF among HIV positive adults also showed low cure rate of RUTF among HIV positive adults as compared to other groups (39). Thus, the consideration of RUTF as food among most patients might partly explain for the poor adherence among some patients (in this study and in previous studies) and the low cure rate of RUTF among HIV positive adults. A

study on outcomes of RUTF use done in sub-Saharan counties showed 50% failure rate where only half of patients achieved the intended nutritional and functional outcomes of RUTF use (39).

Patients had high intention to use RUTF and willingness to continue using. Almost all participants mentioned as the system was useful and they intended to use the product. They expressed positive attitude to most aspects of the system and had many perceived benefits of use. Attitude and perceived benefits of use are important factors in determination of intention to use and acceptability of a service. Users will adopt a system if they have positive attitude and perceived the system useful (33, 34). Thus, the presence of high perceived benefits of RUTF use and positive attitudes to most aspects of the system might be contributing factors for the prevailing high intention to use RUTF and willingness to continue its use among most patients in this study. However, the provision of nutrition counseling was weak. It lacked clarity, completeness and did not address important issues about RUTF. The weakness of the counseling service to aware patients about RUTF might be responsible for the prevailing miss conceptions and malpractices among users of RUTF like considering RUTF as food, sharing with household members, selling, improper use and poor adherence.

RUTF enabled most patients to attain better nutrition and functional status. The most important outcomes of RUTF use mentioned frequently by participants were weight gain, health improvement (like CD4 increment, relief of pain, depression and anorexia), better treatment outcomes and improved productivity through provision of better functional status which enabled beneficiaries to engage in different income generating activities. These findings were in general agreement with previous studies which showed dietary therapy helped to improve immune function, reduce the incidence of complications associated with HIV infection, attenuate the progression of HIV infection, improve the quality of life and ultimately reduce mortality associated with the disease. RUTF usage proved improving body mass index (BMI), CD4 count, health and functional status (14, 15, 16, 19).

Though participants had positive attitude, high perceived benefits of use and attained many benefits after RUTF use, they also showed the challenging realities of RUTF use among adults. All patients encountered some form of side effects while using RUTF such as diet boredom, nausea, vomiting, diarrhea, heartburn and other gastrointestinal symptoms. This finding was the same as the finding of a study done in Kenya on patients’ views and experiences of RUTF use which showed challenging realities of RUTF use among adults like diet boredom, nausea and vomiting (30). Another study done in Malawi on acceptability of RUTF among PLWH also showed that patients experienced gastrointestinal symptoms like nausea, diarrhea, vomiting and dyspepsia (29). Patients associated these side effects with the sugary, oily and salty nature of the product and believed the side effects would disappear if these contents could be modified. This was in agreement with the fact that RUTF is a precooked,

peanut-based paste made of sugar, vegetable fat and skimmed milk powder, enriched with vitamins and minerals (20, 21, 22). However, most of the side effects were transient, occurred at early phase of use and in most cases adaptable. This finding was the same as the finding of a study in Malawi (29) which remarked as the gastrointestinal symptoms patients felt were mild and overcome by the health improvement patients got after their RUTF use.

The use of RUTF was widely associated with HIV. Thus, patients using RUTF felt stigmatized and discriminated as result of using RUTF more so than with HIV drugs. Besides, patients faced handling and transportation difficulties. The main reasons for both stigma and handling/transportation problems were the bulkiness and heaviness of the product. This finding was in agreement with findings of a study done in Kenya (30) on the same topic which identified problem of stigma and discrimination as a challenging factor for patients taking RUTF. The same study also showed that the heaviness of RUTF together with patients' frailty to carry was a problem patients associated with RUTF.

The lack of concordance between RUTF and other HIV services appointments, which made some individuals to come more than once in a month, was another challenging issue that imposed extra cost in terms of time and money. This might, in part, explain the poor adherence of some patients to their RUTF follow-ups. The practice contradicted with the intention of the nutrition care and support program which aimed to offer the service in concordance with other HIV services' appointments (17, 22).

Misuse was a common and frequent phenomenon among most users of RUTF. Sharing, use of RUTF as family diet and selling were common practices among most users of RUTF. Some participants cook or boil RUTF, another form of misuse, which might denature some of the heat liable micronutrients. The facilitators for the misuses were patients' lack of awareness on different aspects of RUTF, notion of considering RUTF as food and limited nutrition counselling and patient empowerment on RUTF, lack of systematized control system at both facility and community level, and poor socioeconomic status. A recent study in Kenya also showed similar phenomenon where misuses were prevalent among patients on RUTF. Sharing RUTF ration with other household members was common, mainly due to poverty and household food insecurity (30). The practical implication of these misuses was achievement of intended outcomes might be delayed and/or reduced. A study on outcomes of RUTF use done in sub-Saharan counties showed 50% failure rate where only half of patients achieved the intended nutritional and functional outcomes of RUTF use (39). This high failure rate may be partly explained by the phenomenon of high misuse among patients as revealed by this study and another study done in Kenya (30).

## 5. Conclusion

Generally, the attitude of patients on RUTF was positive and there were many perceived benefits patients expect from

use of RUTF. Because of the presence of high perceived benefits of use and positive attitude among beneficiaries, patients had high acceptance and intention to use RUTF. Besides, there was a positive relation between health care workers and beneficiaries. However, the provision of nutrition counseling was poor and most participants did not get adequate information on RUTF. Lack of clarity, comprehensiveness and regularity were its peculiarities. The lack of concordance among the different HIV follow-up schedules had created discomfort on patients because one had to come more than once in a month, a costly situation in terms of time and money.

Adults who used RUTF encountered lots of side effects, felt more stigmatized and discriminated and faced difficulties in handling and transportation which were related with the bulky and heavy nature of the product. However, most of the side effects were transient, adaptable and occurred early in the course of use and stayed only for a brief period of time.

Misuse was a common phenomenon among most users of RUTF. It occurred at various levels and ways; and for different reasons. The most common misuse ways were sharing and use as family diet, selling and cooking. The most common factors that led to misuse were notion of considering RUTF as food, food insecurity in some households, poor awareness of patients on RUTF and absence of comprehensive nutrition counseling service in health facilities.

## Recommendations

The supply of RUTF should be strengthened so that timely therapeutic feeding would be provided before deterioration of health and nutrition status. Nutrition support has significant role to attain better survival outcome and improved quality of life.

The current RUTF formulation had resulted in many problems mainly related with the heavy and bulky nature of the product and its disgusting taste. Modifications of the current RUTF content, packaging and prescription protocol would be considered to make the product more adult suited especially in the context of the prevailing association of RUTF with HIV.

Control measures should be designed to ensure proper use of RUTF among beneficiaries and to reduce misuses. Thus, a systematic end use monitoring strategy, one that precludes unauthorized handling, use, selling and buying of RUTF should be designed like the practice for other drugs.

Concordance between RUTF and other HIV services appointments should be considered. Repeated visits to health facilities for different services were costly in terms of time and money. Thus, integration of RUTF supply with other HIV services like ART should be emphasized. This would enable individual to get all services as much as possible during one visit.

Assessment and interventions should be done on health worker's nutrition counseling skills. Besides, due consideration should be given to nutrition counseling and other patient empowerment activities.

Revision of the current supply (prescription) protocol should be considered. Most side effects occurred at early phases of RUTF use and stayed only for brief duration. Thus, a system of starting with low dose and scaling up gradually would help for easy adaptation. Thus, patients might not feel marked side effects and disgust at time of initiation of RUTF use and can safely enter into period of adaptation.

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