

Stigma and discrimination: A barrier to the utilisation of a nutritional program in HIV care services in Ethiopia

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Abstract

Background In Ethiopia, stigmatizing attitudes towards people living with HIV have reduced over time. This is mainly due to improved HIV knowledge and the expansion of access to HIV care and support services. However, HIV stigma and discrimination remain a key challenge, and have negative impacts on access to and utilisation of HIV services including nutritional programs. A small number of studies have examined the experience of stigma related to nutritional programs provided to people living with HIV, but this is limited. This study explored HIV status disclosure and experience of stigma among people living with HIV enrolled in a nutritional program in HIV care setting in Ethiopia and impacts on program utilisation.

Methods and participants As part of a larger study, qualitative in-depth interviews were conducted with 20 adults living with HIV, 15 caregivers of children living with HIV and 13 program staff in the nutritional program in three hospitals in the Tigray region of Northern Ethiopia. Framework analysis was employed to analyse the data and NVivo 11 was used to assist data analysis.

Results The study found varying levels of positive HIV status disclosure, depending on who the target of disclosure was. Disclosing to family members was reported to be less problematic by most participants. Despite reported benefits of the nutritional in terms of improving their weight and overall health status, adults and caregivers of children living with HIV revealed experience of stigma and discrimination and fear of discovery of positive HIV status due to: a) nutritional support (Plumpynut/sup) to HIV by the community; b) increased frequency of visits to HIV services.

Conclusion There is evidence that enrolment in the nutritional program is associated with increased concern about stigma and discrimination, which in turn negatively affected the utilisation of the nutritional program and HIV service more broadly. Nutritional programs in HIV care should include strategies which take these concerns into account by mainstreaming stigma prevention and mitigation activities. Further research should be done to identify innovative ways of social inclusion to mitigate stigma and improve utilisation.

Background

HIV/AIDS stigma is an important public health issue that negatively impacts health outcomes for people living with HIV [1–4]. HIV/AIDS stigma contributes to mental health issues such as depressive symptoms, anxiety, emotional and mental distress and compromises other health outcomes including physical health and overall quality of life [3, 5–7]. There is also evidence suggesting that HIV/AIDS related stigma is one of the key barriers to the utilisation of HIV care services [8, 9].

Stigma is a harmful societal phenomenon enabled by underlying social, political and economic powers labelling and linking differences into negative stereotypes, leading to a separation of “us” from “them,” and finally to status loss and discrimination for those carrying the trait [10]. Stigma can be perceived, experienced/enacted and internalized [11]. In terms of HIV, perceived stigma is the belief that a person will

be discriminated against or judged negatively when their positive HIV status is disclosed, while experienced/enacted stigma refers to the actual events of discrimination experienced by people living with HIV [11, 12]. Internalized stigma refers to the negative self-image felt by those diagnosed with HIV infection [11, 12].

HIV and AIDS as a stigmatizing condition varies by culture and context but common among cultures is linking of HIV and AIDS to immorality and social deviance, through an association of the disease with groups deemed 'deviant' from social norms such as commercial sex workers, drug users and homosexual men [11, 13, 14]. Fear and shame due to concerns of stigma and discrimination may affect a persons' status disclosure and behaviour such as distancing and isolation [15]. Thus stigma and discrimination experienced at various levels such as community, institutions and families internalised in the individual person contributes to social isolation and health inequalities [16, 17].

HIV stigma in sub-Saharan Africa

HIV stigma in resource-limited settings can have significant impacts on the use of health services, through deterring people from accessing HIV care and support [14]. For instance, HIV stigma is an established barrier to ART medication adherence in African context [18, 19]. Other studies from sub-Saharan Africa have also demonstrated that stigma and discrimination hindered utilisation of HIV services – participants believed that seeking care would lead to the disclosure of positive HIV status and then stigma and discrimination if positive HIV status was revealed [9, 20]. HIV stigma can also indirectly affect health whereby people living with HIV have more limited economic and social opportunities due to stigma and discrimination [21, 22] and encounter higher levels of poverty, poor livelihood and reduced availability of food and inadequate intake [23].

Studies have reported that the magnitude of HIV stigma and stigmatising attitudes in sub-Saharan Africa, including Ethiopia, is decreasing because of improved HIV knowledge and the expansion of HIV care and support [24, 25]. However, HIV stigma and discrimination still remain as a key challenge to people living with HIV and AIDS to access HIV care and services. A greater understanding of the impacts of stigma and discrimination it is essential for policy and practice to address these issues

HIV stigma and nutritional programs

Due to the fact that HIV and AIDS and undernutrition are interlinked and widespread in sub-Saharan Africa, nutritional interventions remain a key element of HIV treatment, care and support services [26, 27]. Nutritional care and support programs are designed to improve the nutritional status of adults and children living with HIV and improve treatment outcomes [28]. Nutritional programs range from nutritional counselling to the provision of micronutrient, macronutrient or fortified micronutrient supplementation [29, 30] and are operational in sub-Saharan Africa including Ethiopia [31].

A small number of studies have reported the experience of HIV related stigma in the context of nutritional programs provided outside and inside of health care settings [32–35]. For instance, Dibari and his

colleagues (2013) reported stigma experienced by people consuming nutritional support products [35]. Kebede, & Haidar (2014) also highlighted that stigma is a key reason for non-adherence of people living with HIV to the nutritional program [33]. However, none of these studies have identified the specific mechanisms by which nutritional programs may enhance stigma and discrimination. Thus, this study explored the experience and mechanisms of stigma associated with the nutritional program among people living with HIV and the impact of stigma on the utilisation of the nutritional program in HIV care settings in Ethiopia.

Stigma a 'fundamental cause' of health inequities

In this study we conceptualise HIV related stigma as a fundamental cause of health inequities. We draw on fundamental cause theory which is an extension of the basic cause theory by Lieberman, et al [36] and improved by Link & Phelan [37]. This theory argues that a social cause is a fundamental source of health inequities if it impacts multiple outcomes, affects the health outcome through multiple risk factors, involves resources that are essential to avoid or reduce risk, and the relationship between social causes and health is reproduced over time [38]. HIV stigma can thus be conceptualised as a fundamental social cause of health inequalities. This theory has been applied in a number of studies related to HIV and health disparities [38-40]. For instance, Turan et al 2017 reported that HIV related stigma has a negative impact on HIV related health outcomes by influencing adherence and retention in HIV care through affecting interpersonal, psychological factors, mental health, and stress process [40].

Methods

Study design: A qualitative inquiry was employed to explore the experience of stigma and discrimination among adults and caregivers of children living with HIV enrolled in the nutrition program in Ethiopia.

Study settings:

The Tigray regional state is located in Northern Ethiopia and is one of the nine administrative regional states of Ethiopia. In the Tigray region, at the time of data collection in 2016, 40,000 people received provider-initiated HIV testing and counselling and 1785 had tested positive up to the end of 2018, according to unpublished reports of the Tigray Regional Health Bureau.

This study was conducted in three selected hospitals in Tigray region, namely Mekelle, Shul, and Lemlem Karl hospitals. At the time of data collection, 737 HIV positive patients were nutritionally assessed and found to be clinically undernourished in the three selected hospitals. Out of those found clinically undernourished, 668 were provided with therapeutic or supplementary food. The catchment population under these three hospitals was greater than two million.

All HIV patients enrolled in HIV care are assessed for undernutrition during their regular follow up for the HIV service. Those with BMI < 18.5 kg/m² were enrolled into the nutritional programs for three months if

diagnosed with mild acute undernutrition ($BMI < 18.5 \text{ kg/m}^2$ and $16 \geq \text{kg/m}^2$ and six months for those diagnosed with severe acute undernutrition ($BMI < 16 \text{ kg/m}^2$). Those enrolled in the nutritional program are provided with nutritional support involving Plumpynut (moderate acute undernutrition) or Plumpysup (severe acute malnutrition) and nutritional counselling.

Participant recruitment and data collection

A total of 48 one-on-one face to face in-depth interviews were conducted with adults (n=20) and caregivers of children living with HIV (n = 15) ever or currently enrolled in the nutritional program. Health providers (n = 11) and program managers (n = 2) providing the nutritional service and managing the nutritional program were also included. These groups of participants were selected purposively because they were directly influenced and involved in the nutritional program and a proportional number of participants were recruited from each study hospital.

Sample size was determined based on data saturation. No participant refused to participate in the study and there was nobody besides the study participants during the interview.

The recruitment criteria for adults living with HIV were: age > 15 years, currently enrolled or up to six months since completion of the nutritional program. Caregivers of children (< 15 years) living with HIV, currently enrolled in the nutritional program were eligible for the in-depth interview. Patients visiting the health service were provided with information about the project and given the opportunity to approach the researcher if interested to participate in the study. Interviews with adults and caregivers of children living with HIV were conducted at the health facilities during their regular follow up for Antiretroviral Therapy (ART), nutritional and other HIV care and support services. Health providers were eligible to participate in this study if they worked in the HIV care and nutritional program for one year and more. The aim of this inclusion criteria were to ensure that they had adequate knowledge and experience about the nutritional program and encountered different patients in the program. Two program managers who worked at the programmatic level for at least one year were also recruited in the current study.

All interviews were conducted in the local language Tigrigna and audio recorded and the duration of each in-depth interview ranged from 30–66 minutes. The first author (FT) who is conversant in the local language and culture of the area conducted the interviews. He (FT) also transcribed and translated all interviews from the local language–Tigrigna to English. The first author (interviewer) were a male doctoral student at the time of interview. He has very good experience in quantitative research in the areas of HIV, community health workers and nutrition and some experiences of qualitative research prior to this study. He has previously worked in the area as an academic and research staff at Mekelle University-Ethiopia. While adults and caregivers have no prior knowledge about the research and researcher goals, some health providers know that the research is done for 1. to address challenges of nutritional program in HIV care, 2. for the fulfilment of doctoral study. Participant information sheet and consent form were the source of information for participants to know about the researcher and

educational status of the interviewer, aim and methods of the study and interview procedure to help them understand about the researchers' background and the purpose of the interview.

A semi-structured interview guide was developed in light of the literature and piloted before use. It explored experiences of the nutritional program more generally as well as disclosure of HIV status and mechanisms of stigma related to the nutritional program. Field notes were taken during each interview to note visual cues and body language to assist in understanding the context in data analysis and interpretation.

Trustworthiness and rigor

Rigour refers to the quality of qualitative evidence [41] and was assessed in this study in terms of the credibility, transferability, consistency, and neutrality of findings [42].

To improve the credibility of evidence, triangulation of study participants was employed by involving adults, caregivers, health providers, and program managers and the recruitment of study participants from different hospitals. Four transcripts were used to establish the coding framework. The four transcripts were coded by all authors to improve coding agreement, reliability and minimize bias and differences in coding were resolved through discussion. In addition, the first author (FT) conducted the interviews, translated, and transcribed the data which assisted the analysis, interpretation and also credibility of evidence. Description of the study setting and context of HIV may assist the transferability of the findings into a similar context where a detailed description of the study context is made above and it is believed that the nutritional program is similar across Ethiopia. While the interview guide was semi-structured, it was ensured that all questions were covered – a strategy to ensure the consistency of findings. Illustrative quotes presented in the results following each theme and sub-theme or concept helped support the neutrality of findings. Field notes and event log taken during data collection was also used together with the interview transcripts during analysis and writeup to contribute to the neutrality or confirmability of the findings.

Data coding and analysis

A framework thematic approach was employed to analyse the data [43, 44], which is particularly suitable for analysing semi-structured interviews [45, 46]. The analysis in this study involved five steps as recommended by Bryman and Burgess 2002 [43].

Data analysis in this study followed five clear and mutually exclusive steps that include familiarisation, identifying a thematic framework, indexing, charting and mapping and interpretation [43]. In the first step, familiarisation which involves translation and transcription of all in-depth interviews to English was done by the first author (FT).

Data was read and re-read to gain an understanding of the context, concepts, codes, and potential themes. In the second step, identification of an initial thematic framework was developed using four transcripts and codes, categories and themes were constructed in the subsequent analysis and

conceptualisation of data. Furthermore, themes and categories were formed to represent concepts around the research questions based on recurring concepts shared among participants. In the third step, indexing which involves application of the thematic framework to the data, was undertaken. All transcripts of adults, caregiver of children living with HIV, health providers, and program managers were coded in QSR NVivo version 11 using the framework matrix. In the fourth step, charting or the process of reorganising or sorting data, was done. As part of the broader study– which examined the challenges of nutritional programs in HIV care– the data was charted against the specific stigma and discrimination themes. In the fifth step, mapping and interpretation was done where the relationship between stigma and discrimination themes and categories were established and cross analysed between adults, caregivers, health providers, and program managers and patterns was examined in relation to demographic characteristics. Direct illustrative quotes were extracted and used to explain and describe the themes and sub themes.

Results

Characteristics of participants

In-depth interviews were conducted with 48 participants in three hospitals of the Tigray region, Northern Ethiopia. Participants included 20 adults, 15 caregivers of children living with HIV enrolled in the nutritional program in HIV care, and 13 program staff (11 health providers and 2 program managers). Adult participants were at different stages of the nutritional program – seven were in their second month, five were in their third month, five were in their fourth month or longer after the nutritional follow up. A further three adult participants had completed their nutritional follow up and recovered from undernutrition. Eleven adult participants were enrolled in the nutritional program for the first time while nine had previously been enrolled.

Of 15 caregivers participating in the in-depth interview, 10 reported that their children were in the nutritional program for the first time, while five had been previously enrolled. Regarding the stage of their enrolment, four children were at their second visit and four in their fifth visit and one on third visit. The remaining six had just completed the nutritional follow up at the time of interview. **Table 1** shows the detailed characteristics of the study participants.

Table 1: Characteristics of interview participants

Variables		Adult HIV patients	Caregivers of child HIV patients	Health providers and program managers
Mean age		37.2 ±9.7	36±7.3	35.3± 8
Hospital	Mekelle	8	6	5
	Lemlem Karl	6	5	3
	Shul	6	4	3
	Tigray region health bureau			2
Gender	Male	8	0	6
	Female	12	15	7
Residence	Urban	12	11	13
	Rural	8	4	
Educational status	No education	4	5	
	Primary education	10	5	
	Secondary education	6	5	
	BSc and above			13
	Single	6	1	4
	Married	6	9	8
	Divorced	5	3	1
	Widowed	3	1	

Experiences of stigma and discrimination in HIV

Fear of HIV status disclosure and subsequent stigma and discrimination was identified as a key concern of participants (adults and caregivers). The nutritional program was seen as potentially contributing to disclosure of HIV status through an increased frequency of visits to the service, and transporting, consuming and disposing of the nutritional support.

Status disclosure and fear of stigma and discrimination

All participant groups (health providers, adult patients, and caregivers) described the between the importance of HIV status disclosure and its association with HIV stigma and discrimination. The level of positive HIV status disclosure varied depending on the extent of concern of stigma and discrimination of the individual, where those with high concern had not disclosed to many or even any others, and those with less concern of stigma and discrimination disclosing their positive HIV status more broadly.

Those who were reluctant to disclose their positive HIV status expressed a high concern about potential stigma and discrimination related to their positive HIV status and its impact on their life such as rejection and abandonment. One participant presented her fear of disclosure of positive HIV status as follows:

About the stigma you said, I don't want anyone to know me [positive HIV status] because there is a stigma. For this reason, I live and act like HIV negative (Adult female, age 29 #15).

Another participant living with HIV also expressed her fear of disclosure of positive HIV status to anyone as follows:

Even my elder daughter suspects me and asks if I have HIV but I always convince her that I didn't have any problem. I didn't tell her because it could harm her psychologically (Adult female, age 31 #1).

Others felt that disclosure of positive HIV status to family members had some benefits such as extra care during illness, financial support, and assistance with housework and other duties. There was, however, higher reluctance for disclosure of HIV status beyond family members due to potential stigma and discrimination in neighbourhood and community.

Four of my brothers know about my positive HIV status. None of my friends know about my positive HIV status. Nobody [neighbours] knows about me (Adult female, age 20 #10).

Concerns included gossip and denial of social support:

There is also gossip that may run behind and around you. Some also may insult you and harm you emotionally at times of disagreement (Adult female, age 29 #15).

Participants also reported fear of being expelled from their house and denial of sharing toilets, baths, and common utensils if positive HIV status was discovered by house owners:

Because in house rent we share a toilet, bathroom, and other associated issues. So, if the house owners know that you are HIV positive and using Plumpynut or ART medication, they could expel you from the house (Adult female, age 30 #4).

More women (seven out of the 12 female participants compared to three out of eight male participants) expressed concerns about negative social consequences or discrimination related to HIV disclosure:

"If people know about me, it will have an influence on my work in the market. People didn't come and buy from you if they know their HIV status. If this happens, it will have to influence me and my children" (Adult female, age 29 #15).

A smaller number of adults and caregivers had disclosed their positive HIV status to a broader community and reported benefits such as getting support from friends, families, and others for their HIV condition. For example, one adult female said:

I am free with everybody and I didn't hide myself. Everyone knows about me. So, I have not experienced any problem so far. I didn't bother too much not to be identified by anybody (Adult female, age 37 #16).

While participants acknowledged improvements in stigmatising attitudes towards HIV, generally non-disclosure or limited disclosure of positive HIV status significantly affected the extent to which stigma and discrimination were mentioned as issues in relation to use of the nutritional program.

The nutritional program and stigma and discrimination

There were two key mechanisms by which the nutritional program contributed to stigma and discrimination among those attending the HIV clinics and using nutritional support – increased frequency of health service visits and the association of the nutritional support with HIV.

Enrolment in the nutritional program increased the frequency of visits to a health facility to collect the nutritional support and conduct nutritional follow up and monitoring. To collect ART and receive other HIV services, adults and caregivers visit a health facility once every three months. For those enrolled in the nutritional program, the frequency of visits needed to increase to monthly visits for a period of three to six months. This increase of visit frequency was seen by patients as increasing the chance of being seen at the service and hence their HIV positive status being disclosed:

“There are also individuals whom they don’t want to come more frequently to the clinic not to be seen by any other person whom they know” (Health provider, #2).

“Some say they can’t come every month because distance and even transportation is not a problem, they may be afraid of being seen by other persons as they visit the health facility frequently. They want to take it once for about three months or more” (Health provider #5).

In the community nutritional support is highly associated with HIV, particularly for adults. Being seen with the nutritional support in the community was thought to immediately raise suspicion of positive HIV status. This leads to challenges in relation to the transportation of the nutritional support, and the consumption and disposal of the empty sachets.

Some people relate it. For example, one of our drink shop client told me that the Plumpynut is given to HIV patients on ART. He told us that it is given to them for their ART medication (Caregiver, age 31 #5).

So, some patients enrolled in the nutritional program are worried of stigma and discrimination. Because the Plumpynut is seen as a food to be given to HIV patients in the community especially in the community (Health provider, #2)

The typical packing and bulky size of the nutritional support (Plumpynut/sup) are easily identifiable and revealing which made transportation difficult, as a number of participants highlighted:

I will not show them because instead of its own carton, I use a different bag to carry it home. So, nobody will identify it. When my neighbours ask me, then I pretend that it is cereal. I also don’t want anyone to know me that I am going to a hospital, to avoid stigma (Adult female, age 29 #15).

If some know that you are using the medication and Plumpynut because of your HIV status, there may be problems. People usually hide the Plumpynut during transportation and at their home especially when they live in a house rent (Adult male, age 54 #1)

Similarly, finding a convenient place to consume the nutritional support in private was a challenge due to the revealing nature of the packaging of the nutritional support and fear of being seen by others who would associate it with HIV, as the following account illustrates:

Even when I take the Plumpynut, I don't want to show them (neighbours) at all. I consume and bring the empty sachet back to here (the health facility) because I don't want to be seen. If there is a guest in my home, I will not use the Plumpynut but if there is no one, then I will use it. When using, I close my door to use my Plumpynut and ART medication. Why I did this is to avoid stigmatization. So, the only option I have is to use it like this (Adult female, age #29).

As alluded to in the above quote, the empty sachets were also seen as potentially identifying, and participants were concerned of being seen when throwing the empty sachets at home or anywhere else due to fear of disclosure of their positive HIV status.

My daughter had taken the empty sachet outside and our neighbours asked me from where I had brought it acknowledging that it is good food, but I didn't respond for the question and I kept quiet (Adult female, age 25 #17).

For one family, the discovery of one of the children's HIV positive status in this way had been devastating:

Yes, it is due to the empty sachet thrown that our neighbours identify us and asked him why he is eating it by that time. So, my neighbours usually don't allow my children to play with them because they know our positive HIV status as well as I told you, he has refused to go to school because the children in his school don't allow him to play with them" (Caregiver, age 35 #9).

Impacts of stigma and discrimination on the nutritional program

Stigma and discrimination contributed to the problems of effectiveness of the nutritional program in a range of ways. In this study fear of stigma and discrimination were found to contribute to the poorer outcomes from the program through refusal of the nutritional support, limited attendance at the service, and collecting the nutritional support and selling it in exchange of other foods.

Health providers identified that a fear of disclosure and stigma lead some patients to refuse to take the nutritional support:

They told me that they don't want to take the Plumpynut and they only want to use their own home made food. This is because they don't want to be identified as HIV positive. Because if you have Plumpynut,

they are afraid that they may be identified as HIV positive. So, the most important is that the clients are afraid of being identified as HIV positive (Health provider, #6).

Adults also identified this as an issue amongst HIV patients:

Previously there was fear by HIV patients being identified and some patients were not using the Plumpynut at all (Adult male, age 45 #7).

...others even though they are told to take it, they refuse to do so. The reason for this is the issue you raised it (the Plumpynut box) is big as well everybody knows it. There are individuals who doesn't take it (the Plumpynut) at all. The reason they fail to take it is because of the issue you raised (stigma and discrimination) but I don't know about others (Adult male, age 47 #22).

Health providers likewise identified that some patients also limited their attendance at the service to reduce the chance of being seen and subsequently identified as HIV positive:

There are also individuals whom they don't want to come more frequently to the clinic due to fear of being seen by other persons they know (Health provider, # 2).

Some patients see some improvement when they take the nutritional support after starting the second month. Because of this, they prefer to stop and don't want to come to this clinic monthly. You know coming to this clinic is also one reason patients don't want to happen frequently because they may be identified or seen by some they know. So, most patients don't want to come more frequently. They believe that they may be identified as HIV patients by someone and leads to stigma and discrimination (Health provider, age #6).

Selling of the nutritional support in order to purchase other foods due to fear of stigma and discrimination was also identified as a way that stigma was negatively influencing the utilisation of the nutritional program in HIV care. A caregiver stated this problem as follows:

People sell the nutritional support because they are afraid of being identified as HIV patients because of fear of stigma. It is now sold up to 6 Birr (Caregiver, age 41 #14).

Discussion

The aim of this study was to explore how stigma may influence utilisation of nutritional programs in HIV care settings in Ethiopia and more broadly. While some previous studies reported experiences of stigma in relation to nutritional programs in HIV care [33, 35] none had explored the potential mechanisms by which nutritional programs may enhance stigma and discrimination. This study sought to address this gap.

In the current study, disclosure of positive HIV status varied by the individual persons' relationship with the target of disclosure and also fear of perceived extent of negative consequences. People disclosed more to their families and close relatives and the main reason for non-disclosure beyond family members was related to concerns of stigma and discrimination. Generally, adults and caregivers in the current study had not broadly disclosed their positive HIV status. A recent study from Tigray region of Ethiopia similarly reported that few people disclosed their positive HIV status, beyond telling their spouse, because of fear of stigma and discrimination [47]. Furthermore, a systematic review conducted in low resource settings indicated that fear of stigma and discrimination is the fundamental source of positive HIV status non-disclosure [48]. The current study also found that caregivers also feared disclosure of positive HIV status and negative impacts for them and their children. Other studies have likewise found HIV stigma to be an issue for children living with HIV [49, 50].

Participants of this study acknowledged improvements in people's stigmatising attitudes and perceptions towards HIV patients. Reduction in stigmatizing experiences was reported in another study from Ethiopia [51] and a systematic review conducted in sub-Saharan Africa reported improvements in the level of tolerance to people living with HIV [20]. However, discriminatory attitudes in the community are still significantly high in Ethiopia, with one study finding that 48% of women and 35% of men as highlighted in the 2016 Ethiopian demographic and health survey report [51]. These attitudes include, not buying fresh vegetables from a shopkeeper or vendor if they knew that person is HIV positive or said "children living with HIV should not be allowed to attend school with children who do not have HIV [51]. Another study in Mekelle-Ethiopia reported that stigma and discrimination towards people living with HIV were still common and HIV-positive people are often isolated, [47] and another reported on health providers concerns about HIV stigma and discrimination against people living with HIV [52]. The findings of the current study also highlighted stigma as an ongoing issue of serious concern where participants reported felt, enacted and internalised HIV stigma.

Other than the present study there are no specific studies on how stigma and discrimination related to the nutritional program influences utilisation, but other studies indicated that stigma and discrimination was a barrier for HIV treatment adherence [12, 16, 18]. According to findings of the current study, nutritional programs in HIV care enhanced stigma and discrimination towards people living with HIV by increasing the frequency of visits to the health facility and due to the nutritional support during transportation and consumption.

Enrolment in the nutritional program increased the frequency of visit to the health facility, where participants were afraid of meeting someone they knew and their positive HIV status being revealed. Hence, participants preferred either to stop attending the nutritional program or skip appointment dates. According to Williams and Heikes 1993, stigmatised individuals may be reluctant to visit a health facility or be visited by health provider if it is felt that such visit may increase suspicion of positive HIV status in the community, undermining concealment of a discredited identity [53].

The other mechanism that the nutritional program enhanced the risk of HIV status disclosure was due to the widely held view in the community that the nutritional support is related to people living with HIV—meaning if someone is seen in the community with the nutritional support either during transportation or consumption, it could reveal their positive HIV status. Hence, adults for themselves and caregivers for their children were reluctant to use the nutritional support and expressed their fears of being identified while using the Plumpynut/ Plumpysup. Participants felt that it was more exposing than ART medication because of its bigger size and the longer time to consume it. Another study from Ethiopia also reported a strong association of the nutritional support with HIV in the community [33, 34] and a study from Kenya also reported experience of stigma related to the identifiable packaging box of the nutritional support [35]. This is similar to studies that identified concerns about disclosure through other HIV services such as ART medication [54], and its impacts on ART adherence [18, 19, 40].

The ultimate impact of HIV stigma and discrimination on the nutritional program is poorer outcomes such as drop out and non-response to the program. Stigma and discrimination can lead to poor attendance of the nutritional program which includes failing to consume the recommended ration, missing appointment dates due fear of disclosure of positive HIV status which will further contribute to default and non-response. There is no other external study that examined the impact of HIV related stigma on the nutritional program but a meta-analysis and systematic review on the impact of stigma on HIV outcomes pointed out the negative impacts of HIV stigma on a range of health outcomes such as lower levels of adherence to antiretroviral medications and limited access to and usage of health and social services [55].

We examined HIV stigma in light of social cause theory which argues that the fundamental social causes of health inequities are indicated when the social cause impacts multiple outcomes, impacts the health outcome via multiple ways, involves resources that are essential to avoid or reduce risk, and the relationship between social causes and health is reproduced over time [56]. More broadly, HIV stigma leads to poor socioeconomic status because people living with HIV have limited life chances due to the negative impact of stigma and discrimination [21, 57] and poor socioeconomic status leads to inequitable access to health and other social services, and health itself [58]. HIV stigma also affects health through loss of power, declining social status, internalised negative self image or 'spoiled' identity, and stress [17].

Stigma in this study was a fundamental barrier to utilisation of the nutritional program in HIV care settings where the nutritional program in HIV care potentially contributes to stigma through facilitating unwanted disclosure of positive HIV status. Stigma is one of the key factors that negatively influences health seeking behaviour of individuals [59]. In addition, HIV is more prevalent among certain groups such as commercial sex workers, the poor, and racial and ethnic minorities [59, 60], and as such can contribute to health inequalities by creating differences in access to health service and resources [61, 62]. HIV related stigma is a source of health disparity for many health outcomes other than the nutritional program which is consistent with the fundamental cause theory [63]. As such addressing HIV stigma is crucial in the fight to increase health equity.

Limitations of the study

The study drew on multiple perspectives from three different sites but was not without limitations. The study is qualitative and may not be more broadly generalisable. Some original meaning of the transcripts may be lost during translation, though substantial effort was made to maintain the originality of findings through verbatim translation, transcription and a translation accuracy test. Having a man interviewing women may also be a source of concern but the interviewer (FT) was particularly mindful of this and having grown up in the area and understanding the local culture was particularly aware of gendered communication. Furthermore, the interview was conducted in the health facility which may have made participants more reluctant to fully express their views about stigma related to the program for fear that they may be denied the service. However, participants were continuously reassured that non-participation and that any answers would not affect the service they receive both in the nutritional program and other HIV services.

Conclusion

HIV stigma is an important public health problem as stated by Kenneth Cole an international goodwill ambassador that "It has been said that stigma has killed more people than the HIV virus," [64]. There is evidence that enrolment in the nutritional program was associated with increased concern about stigma and discrimination. This negatively affected the utilisation of the HIV service more broadly and the nutritional program more specifically, potentially contributing to health disparities. Thus, nutritional programs in HIV care should include strategies which take these concerns into account. This should include the incorporation of stigma prevention strategies such as innovative methods of social inclusion and involvement of community support groups. Studies have also highlighted the potential role of religious leaders in the fight against HIV related stigma [65, 66] so involving these leaders is important. The packaging of the nutritional support should be modified into non-discriminatory colour, type and to resemble packaging used in the community. In addition, people should be given more rations to minimise the frequency of visit, but this study did not determine the optimal ration or frequency of visit acceptable for adults and caregivers of people living with HIV. Therefore, further research should be done to determine the optimal and less identifying number of visits to people living with HIV.

Declarations

Ethical issues: To address the concerns of anonymity and confidentiality of the qualitative study participants, strategies such as reassurance, maintenance of confidentiality and anonymity was employed. In addition, qualitative study participants were provided with compensation for the time spent during the interview.

Ethical clearance was also secured from Flinders University, Social and behavioural research ethics(SBRE) (7118) and Mekelle University Ethical review committee (ERC 06211/2016)

Consent to participant: Written informed consent was obtained from all study participants.

Consent for publication: Not applicable.

Availability of data and material: The datasets used and/or analysed during the current study are not available, due to the highly sensitive nature of the data and ethical concerns about confidentiality. In addition, the researchers assured to the ethical review committee and study participants not share the data to a third party.

Competing interests: The authors declare that they have no competing interests.

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Authors' contributions: **FT** designed the study, collected, analysed and interpreted the data as well drafted the manuscript. **SJ, AZ and LM:** Critically reviewed the design, analysis, and interpretation of data and critically reviewed the manuscript.

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List Of Acronyms And List Of Abbreviations

- **ART:** Antiretroviral Therapy
- **BMI:** Body Mass Index
- **BSC:** Bachelor of Science
- **ERC** Ethical review committee
- **HIV/AIDS:** Human Immune Virus /Acquired Immune Deficiency
- **SBRE:** Social and Behavioural Research Ethics

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