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Desperate Option of the Dark Time: The Role and Challenges of ‘Shama’ Self Help Association of People Living with HIV/AIDS in Ethiopia

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Abstract

Our planet has been suffering from many calamities (both natural and manmade) which caused enormous damage on human life. HIV/AIDS epidemic can be a contemporary one which brought unforgettable and multifaceted crisis of the entire life of victims, their family and the wider society at large. Discrimination and isolation of HIV patients including their children was so harsh that makes the process of providing necessary care and support difficult. Therefore self-help associations of people living with HIV/AIDS are among the desperate option devised by people living with the disease to seek mutual help and support while the society was not ready to accept them. The main objective of this study was to assess the role of ‘Shama’ self help association of people living with HIV/AIDS in Ethiopia. In this study a cross sectional study design was employed. Qualitative research approach was utilized and used both primary and secondary sources of data. The primary data was gathered through in-depth interview, Focus group discussions and observations. Whereas secondary sources were obtained from books, articles and other relevant unpublished materials. The findings of the study show that ‘Shama’ association has been playing enormous economical and psycho social roles to its members; Such as providing income generating activities, financial support, door to door care and support, supporting AIDS orphans and educating the wider public. Sustainability problem due to lack of funding and the continuing stigma and discrimination are the current challenges repeatedly mentioned by informants.

Keywords: Shama; self help association; HIV/AIDS; kuy town; Ethiopia.

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1. Introduction

Our planet had suffered from so many calamities (both natural and manmade) which caused enormous damage on human existence of which one can easily mention HIV/AIDS epidemic as a contemporary one. It brought about unforgettable and multifaceted crisis on the entire life of victims, their family and the wider society at large. Many donors and nations have been striving to respond to the HIV/AIDS epidemic by putting into practice different care and prevention programmes. The success of the response in different countries depends on the degree of involvement of the necessary stakeholder at all levels including people living with the virus themselves.

On the basis of UNAIDS and WHO estimates, there were worldwide 34 to 46 million people living with HIV by the end of the year 2003. Of these more than 50% (25 to 28.2 million) were living in sub-Saharan [1]. The epidemic is more widespread in sub-Saharan Africa than anywhere in the world. As one of the countries in the region, HIV infections in Ethiopia, based on different estimates, ranging from 2.1 to 3.0 million have been available in 2000 and 2001 and an estimated 117,000 to 208,000 people within the age range between 15 and 49 died due to AIDS in 2001. But these are all merely rough estimates and the prevalence of HIV infections and AIDS cases seems to continue to rise quickly [2]. In Ethiopia the adult HIV prevalence is 2.4% (7.7% urban and 0.9% rural) and male female ratio of 1.9% and 2.9% respectively. A total of 397,818 people living with HIV are estimated to be in need of antiretroviral treatment (ART), and an estimated 137,494 new HIV infections was supposed to take place in 2010. Although prevalence is lower than many sub-Saharan African countries, the burden of the epidemic in the country is pronounced. The HIV/AIDS infection in Ethiopia is generalized with important differentiation across regional states and population groups [3, 4].

People Living with HIV/AIDS were and are still suffering from great extent of rejection, ostracism, moral judgments, in addition to the everyday traumatizing effect of their physical and emotional experience. This situation has deepened their feeling of seclusion and pushed them into misery [5]. As stated in [6], AIDS in Ethiopia will reduce life expectancy by 9 to 13 percent through 2050 and the number of deaths will increase by 27 percent between 2000 and 2015. AIDS orphans were also projected to rise to 2.5 million in 2014 with insufficient social services, including health care, school fee subsidies and shelter. Because of this many ended up in the street. In general, AIDS is now recognized as the leading cause of adult morbidity and mortality in the country. In Ethiopia the Federal HIV/AIDS Prevention and Control Office (FHAPCO) was established in 2002 mandated to manage and coordinate the overall activities of National HIV/AIDS Prevention and Control program within a broad-based multi-sectoral approach.

Since the outbreak of the HIV/AIDS pandemic, different measures were taken in response to prevent and provide care and support to those who are living with the disease. There is a global consensus that care and support for those who are living with HIV/AIDS or whose families are affected by the disease must be an essential part of the control programme, and that people living with HIV/AIDS are supposed to play a great role in every intervention [7]. This is particularly important to reduce the socio-economic risks the disease caused on those who are economically weak segments of the society.

According [8], *'People who are living with HIV/AIDS have developed diverse mechanisms to help them cope with the virus and the stigma associated with it. These mechanisms include tactical or strategic disclosure (disclosing status where care and support may be available and declining to do so where stigma is anticipated) and joining self help associations. Most tend to combine these two strategies to deal with the psycho social and economic consequences of the disease' [8].*

Hence, self help associations of people living with the disease as one means of coping mechanisms have become the foundation of emotional, material and economic support for the members. They have also been channels of communication whereby information and care carry on being available to the needy. The favorable conditions created by the associations benefit the members by giving them hope for the future and sense of purpose in life that promote an optimistic position for their future life [8]. The main objective of this paper was to assess and provide a qualitative account of the role and challenges of 'Shama' self help association of people living with HIV/AIDS in Ethiopia.

2. Materials and methods

The following is a discussion of the research methods used to conduct this study. This includes the study design, setting, sampling procedures, data collection tools and the method of data analysis.

2.1 Study design

This study employed cross-sectional qualitative study design. The rationale for the selection of this particular design is that assessing the role and challenges of 'Shama' self help association of people living with HIV/AIDS in Kuy town of Ethiopia can be possible by collecting data at one point in time. Relevant documents of the association were also extensively used to see the patterns observed in terms of various issues over the past few years since the association has started to operate in the town.

2.2 Source of data

In an effort made to gather the necessary data, the researcher used both primary and secondary sources of data on the basis of its relevance for the study objectives. The primary sources include informants such as manager of the association and members of the association. Regarding the secondary sources, both published materials such as books, journals and unpublished reports of the association were used.

2.3 The research setting

The study was conducted in the North Western part of Amhara National Regional state of Ethiopia located at distance of 310 km from the capital, Addis Ababa. Specifically kuy town is found in Debay Tillagin worada which is one of the eighteen woradas of East Gojjam zonal administration in Amhara regional state. The town is 62 km far from the center of zonal administration; Debre Markos and around 332 km far from the center of Amhara regional administration; Bahir Dar. Annual reports revealed that this area is among the high prevalence area in terms of HIV/AIDS epidemics.

2.4 Participant Recruitment

Participants were recruited to participate in the study based of the exhaustive list of Shama association members found in manager's office in Kuy town. The patients included HIV positive men and women only who are member of the Shama association. They have a regular coffee program where the exchange information and discuss the challenges they encounter in different settings (such as while providing door to door care, educating in public places and their general health conditions). By looking their profile on the list a variety of members were identifies to be potential informants. The initial visit of the coffee ceremony where members gather together was a time when the informed consent of members selected for the study was obtained. All the interviews were conducted in a flexible environment to allow them tell their life encounters and experiences in the association.

2.5 Tools of data collection

In this study qualitative research approach was employed and the data collection instruments include in-depth interview, focus group discussion and observation. Details of the data collection tool are discussed below:

2.5.1 In-depth interviews

Before engaging in data collection activities, it is important to determine who is going to be appropriate informant as to the relevance of materials to be obtained in meeting the objective of the study. In this study exhaustive list of members of the association is available so that it was possible to select the potential informants based on different criterion. Among this sex and age were the major variables used to stratify the informants. Hence, the researchers conducted six (6) interviewees with women in the age group above 35 years old and six (6) women who are below 35. Similarly twelve (12) men were selected out of which half of them are below 35 and the remaining above the age of 35. This purposely done to see if there is a difference in the challenges and experiences informants faced relation to their age and sex before and after joining the association. In-depth interview was also conducted with three (3) children below the age of 15 who are members of the association. In addition to this the founder and manager of the association was also one informant to collect crucial data regarding various issues right from the beginning of the association up to the data collection time. Generally a total of twenty eight (28) in-depth interviews were conducted on various issues using interview guide. The in depth interview helped the researcher to investigate and collect the data which is used to explain the general living condition of members of the association, the collection of stories of their experiences and meaning of those experiences to better understand the entire living situation they are living in.

2.5.2 Focus group discussion

Focus group discussions were conducted as main data collection tool that helps to collect valuable information from various members of the association. A total of five (5) focus group discussions were made. Out of which two of them were with women, two of them were with men and the remaining one was conducted with children. In doing so rich information was collected regarding the different benefits, challenges and their current state of affairs as a member of the 'Shama' self help association.

The focus group discussion was conducted by the researcher in permissive environment in order to reveal opinions and share ideas and perceptions with the discussants.

2.5.3 Observation

Observation is the very useful technique to understand the event in the normal setting. It was relevant to observe the state of things and cross-check the information thereby helps to identify the possible differences between what people say and do and assessing of relationship among individuals. The method may be helpful in gaining new sights when people may not want to reveal or hide some information during interviews or FGD. Hence the various businesses or income generating activities, regular coffee ceremonies and related issues were observed as it naturally happen just to supplement the data gathered through other research tools.

2.6 Method of data analysis

Since this study was a qualitative study, the information collected from the field through the in-depth interview, focus group discussion and observation was analyzed manually through careful understanding and interpretation of meanings and contents, organizing and transcribing and summarizing in line with the study objectives. All the data was collected in Amharic (the local language) and taped and directly translated into English by the researcher. Significant effort was made to keep the originality and clarity of information while translating it from Amharic to English in the form of text.

2.7 Ethical consideration

At first a written consent was obtained from the founder and manager of the association and all the study participants were informed about the purpose of the study and finally their consent was obtained before the actual data collection process started. Since all the members are known by the wider society when they are educating in different gatherings in the society, there is no need to hide them and refuse to be the study informant. Therefore winning their consent was not as such difficult.

3. Results and Discussion

The following section contains the analysis and discussion of the data gathered through all the qualitative methods of in-depth interview, focus grouped discussion and observation. In addition to this the analysis contains unpublished documents of the association which was extensively used during the data collection process.

3.1. Background of 'Shama' association

'*Shama*' is a self help association of people living with the virus found in Kuy town of Eastern Gojjam zone of Amhara regional state, Ethiopia. The association was founded by Mr. Amare Gashaye in 2006 by five individuals consisting of three men and two women who are living with the virus. After the association has got a legal recognition the number of its members had begun to rise.

Currently the association has a total of 535 members out of which 211 are females and 324 are men. Around 39 of them are children (23 females and 16 males). A total of 498 (197 males and 301 females) are taking the ART and the remaining 37 are PRE-ART. The association is playing a great role in the worada in reducing the psycho social and economical crisis resulted from the disease.

The association is organized by different committees such as management committee, board of director and general assembly. Each committee has specific job and their meeting is held in different period of time. The management committee meeting is held twice a month and the boards of directors meet whenever needed and the general assembly meet in a quarter basis. By the time there was high discrimination of members of the association in terms of social, economical and political participation in the local development process. There were also a number of members who were suffering from being bedridden, chronically ill and with all the harsh impact of HIV/AIDS. The association was supported by NAP⁺ and governmental. NAP⁺ supports the association through providing administrative cost like salary of employee of the association, giving of start-up capital to the member of the association, providing vocational skill training in small business management and entrepreneurial skill for members who took start-up capital, giving cloth and food support. On top of this covering medical cost for members and provide equipments (chair, table and computers).

‘Shama’ is Amharic term for ‘Candle’. The name Shama was given to the association by its founders with the idea that we are going to die soon so let us live the life of a candle by giving light for others while dying. Mr. Amare Gashaye who is the founder of the association, age 48 puts the situation as follows:

I was always thinking that I will be happy if I see people living with HIV/AIDS live the rest of their life peacefully without any discrimination. Because I know how the stigma and discrimination hurts as I am one of the victims. On top of this I was able to see the possibility of helping many people aware of the virus in our locality through public education. There were a lot of people who feared for their HIV status to be identified by the people so they prefer to hide themselves and remain far from the health centers and finally died. I have also observed many people who lost their spouse by death and who show symptom of the disease as some people suspect of HIV/AIDS. At the same time they continue sexual contact with different people and form marriage without any blood test. This worried me a lot as I see no way for the disease to be reduced under all these circumstances.

Hence the primary reason for the founder to establish the association was to help those who are living with the virus and educate the wider public to reduce the prevalence of the disease. In addition to this the worada is among the high HIV prevalence area in Amhara regional state specifically and in Ethiopia in general. It has been repeatedly argued that care and compassion for people living with the virus are missing or unreachable in many parts of the world. Even in the presence of different health facilities, attitudinal problems challenged the utilization and access to quality care. There is a need to build community based response of people of themselves who are living with HIV/AIDS in the effort of helping themselves to reduce the negative effects of the epidemic particularly those sections of the society in the lower socio economic strata.

In his words Mr. Amare further argued that:

I feel that the disease is just like a wildfire which can destroy humanity unless something is made as early as possible. So I decided to sacrifice myself to the stigma and discrimination by officially revealing my HIV status and establish the association by convincing other four people. I was optimist to educate and convince many people who are living with the virus to be member of the association than hiding themselves and dying at home. At first it was tough but I tried to stay strong. Finally I succeed in making more than 500 people living with HIV/AIDS to be member of the association and get all the benefits to live as long and happy live as possible.

Manager of the association strongly asserted that no one can feel the pain except those who are found in similar situation. No one can imagine the problems our children have been suffering except those who are living with the virus and have children. Therefore establishing such kind of support association of People living with the disease as a way of self-help is one among the important coping mechanisms. Members' emotional, material and economic needs can be perused through the association. In addition to this it can also serve as a channel of communication whereby information and support keep can be easily accessible to all members. The favorable environment provided by the association benefit members by facilitating the sharing of regular worries and opinions without any obstacle to safe guard their collective interests. In the long run this increases their optimism for the future and sense of purpose that promote a hopeful view of their futurity.

Those children of people living with HIVAIDS have been suffering from the negative consequences of the plague next to their parents. Ato Amare also argued that the other main reason to found the association is that children whose parents are suspected of living with the virus and even died of the disease suffered from stigma and discrimination. Sometimes children leave the area while playing when a child whose parents are supposed to live with the virus tried to join them. A 19 year old son of Ato Amare demonstrates his experience as follows:

I was experiencing a severe discrimination both at school and while playing with children. Once up on a time a disagreement happened with children while playing and they insult me by saying that 'ye edisam lij' or 'the son of HIV carrier'. I was so upset and cried a lot. When I go home I told the whole story to my father and he advised me not to be angered as they are ignorant. Few days later while playing with other children they offend me with similar insult. This time I couldn't stay calm and I stoned one of the kids. The kid's father came to our home and blames me to my father for beating his kid. My father energetically and angrily responded that your kid's physical injury will be healed soon but my son's psychological and spiritual damage will persist to his life.

It seems that Shama was established with sense of urgency by its initiators to reduce all the destruction directed at them as a result of the virus. The desperation experienced by them gave them no chance than revealing their status to the society and face all the necessary challenges. So, the association on the behalf of its members is meant to represent and reflect their very need and concerns and seek socio economic and emotional fulfillments in collaboration with both from government and nongovernment bodies.

3.2 **The contribution of Shama Association**

In addition to the efforts made to control and prevent HIV/AIDS epidemics worldwide and in our country, it is also equally important to support and treat those people who are living with the virus and suffering from it with their children. The one and probably the best way to do so is empowering the victims themselves and help them identify their needs in the community and get the necessary support and treatment from the concerned body. Therefore exploring and understanding such associations is very important to know the extent to which people are getting most out of it and to further strengthen and build its capacity. Among the practical values particularly of membership in the associations lies in the fact that the members find favorable situation that facilitates the sharing of regular problems and feelings without any difficulty. Hence, Shama association served as a source of financial, material and socio emotional support for its members. Each of them is discussed separately below.

3.2.1 **Economic contribution**

A lot of women in Ethiopia, including those who are living with the virus, work in the informal sector. Due to this when informal sector workers or family members are ill they do not get paid for the work they miss despite the flexible opportunities it provide them to earn a living. Moreover, the stigma and gender inequality come together to make it more complicated for HIV positive women to get hold of resources and customers for small businesses. Poverty and gender inequality leave women more vulnerable than men to its impact in addition to increase the risk of HIV/AIDS [9]. As it has been obviously known HIV/AIDS had brought about immeasurable economic costs on victims' families. As a result economic problem is one of the challenges people living with the virus face in their lives. In order to fill this gap Shama association is providing the necessary economic support and material provision to its members and their affected family members. Hence members are organized in different groups and provided the initial capital to run various income generating activities. Among the economic activities poultry, crop production, hotel business, weaving and building small shops to rent out are to mention some. On top of this women are given with short term trainings and acquire a skill to begin a small business and support them economically. For bed ridden patients who are unable to work on one of the income generating activities there is a regular financial and support to cover their daily expenses.

The 39 years old woman explains her situation as follows:

I was a housewife. My husband died a year and half ago leaving 8 and 11 year old children with me. Since then I was in a deep trouble to sustain our life as my husband was the only breadwinner for the family. After knowing my HIV status I see no any other option than joining Shama association unless I prefer dying with my children at home. Now I am working on the hotel business together with other five association members. In addition to this I received some amount of extra money for my children to cover expenses of their educational material and uniforms. 'Ahun fetarin alamaririm' Amharic term for 'now I am not blaming my God because I am much better than I was before'.

Bed-ridden and incapacitated patients particularly look for financial support to overcome their everyday problems.

So the association provides material support for the neediest members (such as blanket and cloths) and offer financial support during various holydays. Those who are able to work to sustain themselves also need to be supported financially so that they can be easily rehabilitated as productive and self supporting members of the society. In general Shama association played a tremendous economic contribution for its members due to the fact that most join the association primarily for economic reason. In addition to serving as a source of income, engaging on those economic activities reduce a sense of dependency and helped them a lot to feel self reliant just like other members of the society.

3.2.2 Home-based care

Home-based care is another key type of care and support service delivered by members of Shama association for bed-ridden patients and children affected by the virus. Team of home care agents who are themselves living with the virus and member of the association are the one who provide the service. The provision of home-based care by members has a number of advantages. Primarily it enables them show in practical terms genuine love and compassion to others under similar circumstances so that a cooperative spirit can be endorsed. The home based care includes washing their body when they are unable to do it by themselves and taking them to hospital if they are in need of medical treatment by looking their health conditions.

A 31 year old informant argued in her words in such a way;

We built a strong relationship which has helped us build cooperative spirit and mutual trust and confidence. This has also shaped our mentality to think of possibilities of making things possible for us to accept our circumstance and live with it comfortably rather than dismissing it. Because of this the home based care is doing a lot for our members who other ways have no chance of getting such treatments.

There are also well established teams in the association who are assigned to provide door to door care and support for those who are found in worst condition. The home based care includes following up their ART treatment, food supply and emotional support. Antiretroviral treatment (ART) has turned HIV into a more manageable situation which may no longer be a death ticket. Nevertheless, treatment is not just about providing ART; care and support are also essentially important. Changes needed to improve treatment; care and support include better transport services, health services near villages, income generation opportunities, and improved nutrition [8].

A woman age 47 explains the situation as follows:

I was a female headed woman who makes a living out of preparing and selling local drinks such as 'Tella' and 'Araki'. I used to have sexual contact with more than one sexual partner. Once up on a time I feel so sick and went to hospital to get medical treatment. I was asked if I want to have blood test and at first I was so frightened as if I will die as soon as I know being HIV positive. Finally I agreed to give blood and found HIV virus in my blood. After few days of emotional unrest, members of Shama association found and convinced me to be a member. Then I became member and now I am in a much better condition. Since I am living alone the team regularly came to my home give me the necessary care and support including how to take the ART.

I would have died had I was not member of the association. 'Enesun Kifu aynkachew'; Amharic phrase for 'May they be safe ever'.

Currently there are more than thirty members who seek regular home based care and support due to their serious health condition. This helped them to develop or maintain an optimistic view of life, place things in a pragmatic perspective and promise themselves that they are still needed despite their status. Therefore Home based care and support system lies at the heart of the rehabilitative component of Shama association to improve the life of people living with HIV/AIDS and their family members.

3.2.3 Psycho social and emotional support

Obviously stigma and discrimination in relation to the disease can destroy patient's psychological and emotional aspects of their life which can be mention as one of the greatest negative consequences. The fact that the wider society in this area was not ready to maintain normal social interaction with people living with the virus; they suffered from feeling of neglected and ignored. Because of this Shama association played a great role in providing psycho social and emotional support for members that they lost from the mainstream society. All informants acknowledged this fact. A man put the situation as follows:

I am 41 years old man. Before I join Shama association only few people were on my side to greet and ask me how I am doing every day. 'Amlaken endiwosdegn eyelemenkut neber' or Amharic statement equivalent to, 'During this time I was praying to my God to kill or take me' because one cannot live alone without the help of human beings. After I became member of Shama association praise to God I started to feel fullness as if I am healthy and feel safe with other members. My health condition gets better and better every time and I have no words to say but 'Aylekibet' or 'thanks to God' for not letting me down.

People living with the disease need to be exposed to appropriate and genuine empathy and affection, which, if they are sure they are given, will build up their spirit to live and defy the impact of the disease. In addition to this they also need access to participation in all social activities and events without discrimination. Due to fear of stigma and discrimination people living with HIV/AIDS do not want to be identified their HIV status by others. Shama association members work hard to conscience as many people as possible who are living with the virus to be member of the association and receive the necessary care and support. In this regard the emotional and social support Shama members enjoy makes many people member of the association than hiding them for fear of discrimination.

The counseling service includes both patients and their family members with rational of telling how to take care of them in ever all things and how to save the uninfected member of the family from the virus through teaching them to use few materials privately. In addition to this members are given regular awareness raising lessons on how to keep their personal hygiene and proper nutrition, not to drink alcohol and how to take the ART appropriately without interruption. During the first establishment of the association there were many problems in connection to religious- traditional and culture barriers for taking the ART which was the primary cause of death of many people with a possibility of elongating their life through.

A man age 48 who became member of the association puts his experience in this way:

I lost my wife three years ago. Right then I became male headed with my three dependent children and tried to make a living out of engaging in small businesses. Few months later I fall in bed and went to health center in my town. Having tested my blood I recognized that I am living with HIV/AIDS in my blood. During that time I was so 'pessimistic of life' or in Amharic 'Tesfaye Chelimobign Neber'. I worried day and night about my children. After that I joined Shama association based on the advice I get from senior members. Since then I am so happy by the psycho social and emotional support I get and sometimes I feel as if I am free of the disease. Thanks to God!

Moreover joining Shama association changed their mind that most feel as if they were the only ones who are living with the virus. Because before joining the association most rarely knew another person who lived with the virus. Informants conformed that not knowing another individual sharing the same problem led them to the mistaken belief that they are a unique people because of the virus and have little or no hope for achievement and pleasure.

3.2.4 Supporting AIDS orphans

It became common sense knowledge that children numbering in the tens of thousands have already been orphaned as a result of AIDS in Ethiopia. It has also been forecasted that large numbers will still be orphaned in the coming decade as people continue to die from AIDS-related causes in their child-rearing ages. Thus, orphanhood being an essential feature of the entire national crisis caused by the virus, no prevention and control effort is ever complete without duly addressing this growing social hazard [8]. Unless handled in great care it will raise the number of street children in the country which is more than enough already.

Children whose parents are living with HIV often experience many harmful changes in their lives and can start to suffer neglect, including emotional neglect, long before they are orphaned. In the end, they might suffer from the emotional trauma as a result of death of their parent(s). Then they have to adjust to a new situation with little or no support and with a high probability to suffer from exploitation and abuse. On top of this the loss of a parent to AIDS could have grave consequences for a child's access to basic necessities of shelter, food, clothing, health and education [8]. Children orphaned by AIDS drop out of school or perform poorly in school as a result of their situation besides the difficulty to cover expenses of school fees and school uniforms. These hinder them from getting higher self-esteem, emotional support, better job prospects and economic independence in their future life out of the educational environment.

The multi-faceted impact of the pandemic is exposing those children who lost either one or both parents to a multiplicity of problems which continue to become more intense and diversified. Upon parental loss in connection with the deaths widely suspected to have resulted from AIDS, the orphans are most likely to be stigmatized by community members, peers, and even close relatives. This problem is further aggravated by the commonly held belief by the society that AIDS orphans themselves have the virus in their blood just because they lost their parents to it [8].

Children in such situations are more likely to drop out of school and put their prospects for a normal life at even greater risk.

This study investigated all the activities that Shama association is currently carrying out in relation to AIDS orphans. Information was gathered on the types of services provided through interviews with the manager of the association and focus group discussions with recipient orphans. The findings revealed that the existing care and support services targeting AIDS orphans mostly include food, shelter, and clothing provisions, psychological support and supplies of educational and related material. Hence a total of 39 orphans are currently supported by the association. Being the hope of these children, the association first investigates whether an orphan lost one parent or both due to AIDS before providing any service. Once identified AIDS being the cause of orphan-hood, the child will be recruited as association member. Clothing and school uniforms are provided to the orphans once a year in addition to money given to pay monthly house rent. The orphans are also provided with basic health services arranged by the association. Last but not least psychological support is another component in the care and support process of the association. Children who have experienced grief and sorrow due to loss of parents in their loving years strongly need psychological support. Their problem is further worsened by the difficulties they keep experiencing in their efforts to stay alive and adjust to their losses.

3.2.5 Educating the wider society

The first benefit of educating the wider public is to convince those who hide their HIV status join Shama and get the necessary care and support. Fear of stigma and social isolation is a single major attitudinal factor precluding people living with the virus not to be member of Shama association and get the available benefit out from the care and support system provided by it. In many cases, people become shocked upon realizing their status as HIV positive. The state of disappointment and hopelessness causes them to lose purpose and meaning in life for which primary reason they generally tend to reject care and support services and stop looking forward.

A man, age 32 expressed his experience as follows:

Since I knew my HIV status I had begun to feel as I am holding a dead body. I couldn't find any courage to convince myself and plan to live my life. Because I repeatedly listen from people and radio that the disease has no cure and it kills with horrible condition. Therefore what is the need of going hospital or joining association I asked myself? Finally I received awareness raising lesson provided by members of Shama and after that thanks to God I started to calm down and think to get things better. Then I became member of Shama association. Now I am in a good condition.

The practical outcome after revealing their circumstances and joining Shama association has largely been such that they received economical, psycho social and emotional support to promote their self help mechanisms. This needs a tremendous effort of contentious education campaign about the benefits of revealing their status than hiding them at home and waits till death comes or till the virus reaches higher stage of the disease without prior treatment. The second significance of educating the public is the supply of adequate information concerning primarily on responsible sexual behavior and general facts of the disease.

Despite there is a growing recognition of the importance of people with HIV positive involvement in raising awareness of HIV/AIDS and their increasing participation in preventive and mitigation activities, there is much more to be done as a result of the continuing stigma against them. In this regard Shama association conducted different educational programmes about HIV mainly during public gatherings. There are 31 volunteer members who provide education in schools, churches, burial associations, market places, health centers and other gatherings. Until now more than 77, 442 people receive awareness raising education on different ways of HIV transmission. Informants confirmed that the HIV education and awareness raising campaign given by members of the Shama association had made an impact on different facts of the disease and changed the attitude the society towards those who are living with the virus. This can be mentioned as one of the greatest achievements of Shama association in the prevention of the disease and reduce stigma against them.

3.3 Major challenges of Shama association

During conducting the focus group discussion and in depth interviews, members were asked to identify the most common challenges they still face in both in their day to day life and during working out the task of the association (such as educating the public and challenges encountered in the process of providing support services for the needy and bed riding members). Almost all of them agree on the challenges of stigma and lack of funds as the two most pressing problems.

3.3.1 Stigma

From the very beginning of the HIV outbreak, stigma and discrimination have been identified as a complex social process that interacts with the preexisting stigma and discrimination in connection with gender, race and poverty [10, 11, 15]. Stigma and discrimination against people living with the disease pose a great obstacle in the way of effective responses to HIV [4]. Despite there is a growing recognition of the significance of the involvement of people living with the virus in raising awareness and the increasing participation the wider society in preventive and support activities, there is much more to do with the continuing stigma against people living with the disease in Ethiopia [2]. Many people always try to avoid having anything to do with people living with HIV/AIDS which forced them to conceal their HIV-positive status due to the stigma and discrimination in relation with the virus. As open discussion on one's private matters is not part of Ethiopian culture, at least among highlands, more or less certainly contributes to the situation of stigma. Almost all informants mentioned that there is still some form of stigma and ostracism different people directs on members in different occasions. This needs further awareness raising campaigns by the association in collaboration with the concerned bodies.

A 27 year old female headed woman explains the stigma she faced as follows:

It has now been four years since I knew of my status as HIV positive. For the first two years of this time, I kept the secret to myself suffering the pain alone due to fear of stigma and isolation. After that I exposed my status to my intimate friend who responded positively and immediately, extending all the necessary emotional and other forms of care and support.

Then she advised me to join the Shama association at least to support myself economically without which I would likely have died much earlier. This has been the main factor that prolonged my life for the following four years. After all of these periods I still face some form of stigma in my day to day social interaction even though it is now decreasing.

At the wider societal level, the fear of stigma and discrimination can lead to the refusal of Voluntary Counseling and Testing (VCT) for HIV, increased gender-based violence and marginalization of high risk individuals [12]. Community members may not seek VCT because of the fear of discovering that they are HIV positive and fearing of the resulting stigma and discrimination. Thus HIV/AIDS- related stigma and discrimination may have a profound impact on the disclosure of HIV status and the subsequent care, support or treatment that HIV positive persons receive by society at large [13]. Problem- focused coping strategies can target the self, the situation or others, and include strategies such as selective disclosure, compensating for the stigma and discrimination during social interactions, avoid situations where stigmatization and discrimination is likely to exist (i.e. disengagement), affiliating oneself with similar others, seeking social support, and activism. Emotion-focus strategies include downward social comparison, external attributions, denial or prejudice minimization, distract position reappraisal, and misidentification with the stigmatized identity [14]. In general Shama self help association of people living with the virus is played a far reaching role in educating the public to reduce the stigma and isolation directed against them despite it is not completely absent even today.

3.3.2 Lack of fund/ financial problem

The fact that membership is primarily motivated by the strong need for economic support; insufficient financial capital run by the association is the major challenge members currently face. The manager of the association asserted that Shama arranged few income generating activities to help members in the self help process but limited capital makes it difficult for adequate economic empowerment of members and their family. Currently the major source of fund for the association is NAP⁺ project support. Getting appropriate nutrition and keeping their personal hygiene needs sufficient financial resource which is lacking by now.

4. Conclusion and Recommendation

4.1 conclusion

Based on the information obtained from members of Shama association of people living with HIV/AIDS and AIDS orphans, important contribution of the association are economic, psycho social and emotional supports. There are some incomes generating activities members working on to support themselves economically such as trading of clothes, fattening of cattle/sheep, crop production, barber shops and Waving are some of the economic activities or income generating activities. The association support groups play a paramount role in helping members who have been enrolled on HIV antiretroviral therapy but not properly adhering so as to increase their adherences and lead these activities in organized way. In addition to this increasing the awareness of those who have not been enrolled on HIV antiretroviral therapy to enable them to be enrolled is among its contributions.

Home based care is among the crucial services provided by members for those who are bed ridden and most needy. Educating the wider public held in different gatherings to increase the awareness of the people about HIV/AIDS epidemics in the worada is also among the paramount contribution of the association. Continued stigma and ostracism are among the challenges members of Shama association currently face. Lack of funding and continuing stigma and discrimination is mentioned by most of the informants as challenges currently facing the association.

4.2 Recommendations

By taking into consideration what have already been discussed in this paper, the researcher is interested to provide the following recommendations:

- The participation all the concerned bodies is important if effective response to the disease is to be achieved
- Those children who lost both of their parents for the disease need much more better and comprehensive support than what is available now which needs coordinated effort all the concerned stakeholders.
- People living with the disease are often powerless in the face of discrimination and stigmatization, because of fear and shame. Therefore an efficient response to reduce the psychological and socio-economic consequences of the disease demands the full involvement of those affected and infected families and the communities.
- Financial support to empower them economically is vital as most of the members engaged in income generating activities of limited return.

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