

Assessing the Role of Community Care Coalition in Providing Psychosocial Support to  
HIV/AIDS Infected and Affected People: The Case of Two Selected *Woredas* in Mekelle City

Binega Haileselassie Hagos

A Thesis Submitted to the School of Social Work Presented in Partial Fulfillment of the  
Requirements for the Degree of Master of Arts in Social Work (Community Health  
Development Concentration)

Addis Ababa University  
School Of Graduate Studies  
School of Social Work  
June, 2013  
Addis Ababa



ADDIS ABABA UNIVERSITY  
SCHOOL OF GRADUATE STUDIES  
MSW EXAMINING COMMITTEE

This is to certify that the thesis prepared by Binega Haileselassie Hagos entitled: Assessing the Role of Community Care Coalition in Providing Psychosocial Support to HIV/AIDS Infected and Affected People: The Case of Two Selected *Woredas* in Mekelle City; submitted in partial fulfillment of the requirements for the Degree of Master of Arts (School of Social Work) complies with regulation of the University and meets the accepted standards with respect to the originality and quality.

SIGNED BY THE EXAMINING COMMITTEE:

Ashenafi Hagos  
Examiner/*internal*

  
Signature

\_\_\_\_\_  
Date

Melese Getu (PhD.)  
Examiner/*external*

  
Signature

\_\_\_\_\_  
Date

Mengistu Legesse (PhD)  
Advisor

  
Signature

\_\_\_\_\_  
Date

## Acknowledgements

Above all I thank my God who gives me the patience and courage to finish my work productively.

My profound thanks go to my thesis advisor Dr. Mengistu Legesse who rendered unreserved scholarly constructive comments and technical advice early from the design of the proposal till this level. Dr. Mengistu... Oh! Your empathy and moral encouragement to pass all the hard moments even out of academic area was immense and beyond words.

I owe my unlimited thanks to my respondents for their cooperation in giving me genuine and pertinent information. I specially would like to thank Ato Tekelehaymanot G/Meskel Tigray region BoLSA head for his cooperative and support during the data collection. My greatest and heartfelt thanks also goes to Anagaw Derseh for his support in statistical methods and analysis and guidance to use STATA.

I would like also to express my thanks to my class mate Martha Fithanegest for her support in editorial works and continues encouragement during my work.

I also extend my sincere appreciation and thanks to my family, for they have been beside me throughout my academic life.

I am indebted to thank Addis Ababa University for its sponsorship, it provide me a sum of money to cover expenditures in writing this thesis.

## Table of Content

Abstract.....	1
Acknowledgments .....	i
Table of contents.....	ii
List of tables and figures.....	iv
Acronyms .....	v
List of Symbols.....	vi
<b>CHAPTER ONE: Introduction</b> .....	<b>3</b>
Background of the Study .....	3
Statement of the Problem .....	6
Objectives of the Study .....	9
General Objective .....	9
Specific Objectives.....	9
Significance of the Study .....	10
Scope of the Study.....	11
Definition of Terms.....	11
<b>CHAPTER TWO: Review of Related Literature</b> .....	<b>13</b>
Psychosocial Support Theoretical Frame work.....	13
Current Support to PLWHA .....	15
What is Psychosocial Support.....	17
Psychosocial Support to PLWHA.....	17
Inclusive provision of HIV/AIDS care and support service.....	18
Components of HIV/AIDS care and support.....	19
Who can provide psychosocial care and support?.....	20
The role of psychosocial support in addressing human rights.....	21
Ways of providing psychosocial support .....	21
Measuring effectiveness of HIV/AIDS care and PSS programs.....	22
Layers of psychosocial support.....	23

<b>CHAPTER THREE: Research Methods</b> .....	25
Research design.....	25
Selection criteria of participants.....	26
Population, sample size and respondents .....	26
Sampling technique for survey.....	28
Source of data .....	29
Method of data collection .....	29
Data quality assurance.....	31
Data collection tools.....	32
Data collection procedures .....	33
Data analysis .....	34
Ethical consideration.....	37
<b>CHAPTER FOUR: Findings of the study</b> .....	39
Demographic and general characteristics of participants .....	39
Psychosocial Support for PLWHA and Their Families.....	40
Types and dimensions of services provision by CCCs.....	44
Ensuring home and community based care as guiding principle of PSS.....	47
Factors affecting provision of PSS and mitigating ways .....	50
<b>CHAPTER FIVE: Discussion of Major Findings</b> .....	57
Psychosocial Support for PLWHA and Their Families.....	57
Types and dimensions of services provision by CCCs.....	59
Ensuring home and community based care as guiding principle of PSS.....	61
Factors affecting provision of PSS and mitigating ways .....	64
<b>CHAPTER SIX: Summary, Conclusions and Social work Implications</b> .....	67
Summary .....	67
Conclusions .....	69
Social Work Implications .....	70
References .....	vii
Appendices.....	xiii
Declaration .....	xx

**List of tables**

Table A: Table A. Demographic and General Characteristics of Participants.....	39
Table B: Participants Response to the Importance of PSS.....	41
Table C: Participants Response to whether the CCC service package included PSS Two-sample t test with equal variances.....	44
Table D: Two sample t- test Beneficiaries Satisfaction with Volunteers commitment and work engagement.....	48
Table E: Regress overall beneficiaries service satisfaction with Predictor Variables.....	53

**List of Figures**

Fig: A. Model of psychosocial support for HIV/AIDS infected and affected families; Source own Design.....	15
--	----

## Acronyms

AIDS	Acquired Immuno Deficiency Syndrome
ANOVA	Analysis Of Variance
ART	Anti Retroviral Therapy
BWOPSS	Beneficiaries without Psychosocial Support
BWPSS	Beneficiaries with Psychosocial Support
CBO	Community Based Organization
CCC	Community Care Coalition
CCG	Community Care Group
CHBC	Community and Home Based Care
CI	Confidence Interval
DSM-IV	Diagnostic and Statistical Manual of Mental Disorder [DSM- IV]
ETB	Ethiopian Birr
FGD	Focus Group Discussion
FHI	Family Health International
For. N.	For No Date
GAS	General Adaptation Syndrome
HAPCO	HIV/AIDS Prevention and Control Office
HIV	Human Immune Virus
NASCOP	National AIDS/STD Control Program
NGO	Nongovernmental Organization
OVC	Orphan and Vulnerable Children
PLWHA	People Living With HIV/AIDS
PSS	Psychosocial Support
PWG	Psychosocial Working Group
SP. Ed	Special Edition
UNICEF	United Nation International Children Emergency Fund
USAID	United State Agency for International Development
WHO	World Health Organization

**List of Symbols**

<	Less than
>	Greater than
=	Equal
$\bar{X}$	Mean average
$\sqrt{\quad}$	Square root
$\Sigma$	Sigma
$\alpha$	Alpha
%	Percent
&	Ampersand
"	Quotation Mark
$\sigma$	Variance

## Abstract

Communities have their own means of managing crisis faced by their members since time of immemorial; and local networks like community care coalition plays prominent role in addressing basic needs of members of the community and HIV/AIDS infected people. HIV/AIDS affects all dimensions of person's life: physical, psychological, social and spiritual elements. Providing psychological and social support can help the infected people and their care givers to cope up effectively with each stage of the infection and enhances quality of life. In light of this, the main objective of this study was to examine and evaluate the role of Community Care Coalitions (CCCs) in providing psychosocial supports to people infected with and affected by HIV/AIDS in two selected *woredas* of Mekelle City.

The research design employed was both qualitative and quantitative approaches. Participants were selected using both probability and non probability sampling techniques. Stratified sampling and purposive sampling techniques were used. Survey questionnaires, Focus Group Discussions and key informant interviews were data collection methods. The reliability of the survey questions was checked with Cronbach's alpha and measures of equivalence item analysis methods in pilot testing and found to be strong consistent ( $r=0.78$ ). The content validity of the items was also checked by the inter judge rater professionals and found to be relevant. Data obtained from survey questionnaires was analyzed quantitatively using Pearson product coefficient, mean, standard deviation, two sample t-test, multiple regression, and ANOVA. In doing so, STATA V.11.1 soft ware was used. Qualitative data was analyzed thematically in line with key elements of care and support to PLWHA and vulnerable groups as identified by World Health Organization.

The major finding indicates, provision of PSS for PLWHA and their families is found to be very essential. The role of such community based care and support networks also play paramount significance in addressing the need of these target group. The provision of psychosocial support as one separate care and support package within CCCs, create significant difference between beneficiaries level of service satisfaction, relationship between service providers and receivers for the t- value is less than the P, 0.05 with 95% CI. This easy could help social workers to undertake further researches about psychosocial support to vulnerable group that comes from home and community based supports.

According to APA 6<sup>th</sup> Ed page one starts at cover page and abstract is two and finally chapter one is three

## CHAPTER ONE: INTRODUCTION

### Background of the Study

Communities have their own means of managing crisis faced by their members. They have been supporting each other in time of difficulties such as during impoverishment, accidents, chronic problems, sickness and death of most important members of a family (Mezegbu, 2007). Their support also extended to the family breakdown, disability, psychological and emotional distress.

The researcher believed that, in most cases for such kind of panic and untimed problems immediate and timed reaction comes from local community based support systems like; community care coalitions, *Idirs*, *Equib*, *Mahiber*<sup>1</sup> and other community network systems. According to Kassaw (2006), however, the role of community based support systems is most of the time treated as informal and has been less emphasized in most literature. These community care support network systems are playing pivotal contribution in providing both individual and family based help for peoples living with Human Immune Virus/ Acquire Immune Deficiency Syndrome (HIV/AIDS) and other vulnerable members of the community. Community Care Coalitions (CCCs) are typical example of these local community based support systems.

According to Germann , Ngoma, Wamimbi, Claxton, Gaudrault (2009), CCCs may have different names in different countries depending on the local context and what national orphans and vulnerable children (OVC) policies use to describe such care groups. Community care coalitions are groups of individuals and/or organizations at local level that join together for common purpose of expanding and enhancing care for

---

<sup>1</sup> Ider, Ekub and Mahibers are local social networking institutions that bring community members together and providing backing support during time of immoral and crises.

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

HIV/AIDS infected and most vulnerable children in communities. Those groups who provide care directly are called Community Care Groups (CCGs); those who have mainly a coordination role are called Community Care Coalitions. Community care coalitions typically include representatives of churches, volunteers and other faith based organizations, the government, businesses, and other local nongovernmental organizations (NGOs) or community based organizations (CBOs) in the community. The service they provide ranges from material, financial to physical support (Caitlin, Medley, Michael, & Kevin, 2010).

The other concept in this topic need to define clearly is psychosocial support. The word 'psychosocial' is a combination of the concepts of the individual 'psyche' and the 'social' community in which the person lives and interacts. Psychosocial support recognizes the importance of the social context in addressing the psychological impact of stressful events experienced in emergencies and other problems (Binaga & Molla, 2011). In practice, this means facilitating the reconstruction of local social structures (family, community groups, schools and social settings) which may have been destroyed or weakened by an emergency, so that they can give appropriate and effective support to those suffering from severe stress, heart break frustration and hopelessness related to their experience.

Many programs for HIV/AIDS infected and other vulnerable groups have focused on material support and meeting their physical needs. Psychosocial problems are sometimes poorly understood or difficult to assess, they are often not adequately addressed by programs (FHI 2004). As per this report, HIV/AIDS undermines and then destroys the fundamental human attachments essential to normal individual and family life development.

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

Peoples' infected and affected by HIV/AIDS suffer from anxiety and fear during the years of illness, and then it follows with grief and trauma with the death of a family member (WHO, 2004). Group approaches, peer support and individual counseling are needed to offer even the primary psychosocial support. Professionals include school counselors, social workers, psychologists, social welfare workers, faith based organization practitioners and other existing structures with the potential to reach AIDS infected and affected families in their communities can offer much needed psychosocial support (UNICEF, 2004a<sup>2</sup>). Similarly, other publication outputs of UNICEF,(2008, 2010) also indicates teachers, health care workers, community groups and others can also contribute significant role in providing appropriate and demanding psychosocial and emotional support.

Although both government and community based supports are exerting efforts to provide comprehensive services and respond to the overall life aspect of the infected and affected people. Providing psychosocial support to affected family members and caregivers is the heart of the helping process. As many scholars point out, some of the elements that have been identified as key to the success of psychosocial support interventions are community ownership, engaging children and young people in planning and implementation, and tailoring activities to local cultural practices and beliefs. In addition, the researcher also believed that, community based support programs need to provide support that is developmentally appropriate, recognizing that the infected and affected people of different ages respond differently to trauma and loss, and need support

---

<sup>2</sup> UNICEF, 2004a UNICEF "Psychosocial Support for HIV/AIDS/AIDS infected people and Affected families" special publication

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

throughout their life. Therefore, coupled these and other issues inspire the researcher to study the above topic.

### **Statement of the Problem**

The treatment approach employed by the community care coalition for HIV/AIDS infected people are primarily planned to address problems related to material, economical and physical health issues. Usually, these approaches are criticized for that they underestimate the psychosocial and emotional problems of the infected people and affected families (UNICEF, 2004). This UNICEF survey report is from developing countries like Ghana and Tanzania.

Community based support activities such as those conducted by community care coalition, are helping to guide and protect HIV/AIDS infected and affected people. The community care coalition is a foundational feature of mobilizing and strengthening community led care for HIV/AIDS infected people, orphans and vulnerable parts of the community, and people chronically or terminally ill (Germann et al,2009).

As the National AIDS/STD Control Programme ( 2002), community care coalition are crucial social networking system at addressing the immediate demand of the HIV/AIDS infected and other vulnerable members of the family. Their supports are accessible for those in need of it since it is home to home mobile based service. However, this report fails to indicate the service dimension of these community care coalitions. On the other hand, HAPCO reports indicate that the main and articulated service of CCCs are physical and economical supports and has limited room for psychosocial support. Of course, economical and physical supports are necessary in solving immediate problems, but it is quite worthy to pay special attention to the psychosocial and emotional elements of the infected and

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

affected people which significantly determinant aspect of their life. This implies that, addressing psychosocial needs does necessarily require separate programs.

Some WHO,FHI studies and other unpublished thesis by Kassaw and Mezagabu (2006, 2007) and HAPCO (2009), have indicated, the role of such community based support system for HIV/AIDS infected and affected people plays important role in providing monetary, material and physical supports. However, these studies presented limited information on how community based support system can address the psychological, emotional and social problems of these people. They also failed to give us what challenges face these community care support system to offer PSS support. These studies also failed to compare and contrast the effect of absence or presence of PSS as one separate program in service beneficiaries' level of satisfaction. Furthermore, though these studies indicated the existence of both formal and informal community support for HIV/AIDS infected people in general, but none of them give special emphasis to the affected families and relatives of the infected people.

These studies never show us the dimensions of service provision by these community based support systems. In addition, they fail to articulate the level of satisfaction of beneficiaries about service gained from community based support systems. Moreover, these studies never attempt to compare and contrast between service beneficiaries who receive psychosocial support and not yet received. Finally, the study by Kassaw and Mezegebu use qualitative approach as their study method and the data collected from few participants could not be solid enough to include others view point. As a result, this essay used both qualitative and quantitative approach to have rich data. On the other hand, the HAPCO and NASCOP, reports have limited room for individual lived

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

experience since the studies were conducted at national level in the form of survey.

Similarly, research outputs of FHI, UNICEF & WHO are not context wise even though they were conducted in developing countries.

On the other hand, a study conducted by Helana, Abraham and Ayalew (2008) on beneficiaries' satisfaction on community and home based care (CHBC) and support in Jimma University Specialized Hospital. The main focus of the study was how this CHBC programs help in providing Anti Retroviral therapy (ART) to PLWHA and looking at beneficiaries' satisfaction with regard to ART service. The research method was quantitative in its design. This article try to mention the role of community and home based care and support for PLWHA in providing ART service. It was only emphasized on the importance of ART to PLWHA and its role in maintaining the quality of life of PLWHA. However, this article failed to look at other dimensions of care and support programs given by CHBC like psychosocial support. Beneficiaries' satisfaction was evaluated only from the provision of ART service and the role of thus CHBC was not seen from the inclusion of families of the infected people in the service package.

Therefore, the primary focus of this study was to evaluate the role of CCCs in providing psychological, social and emotional support for both the HIV/AIDS infected and affected people considering Ethiopian context. The study also explored the challenges that hinder these support groups from providing psychosocial support. Explore the level of satisfaction of beneficiaries about service gained both in presence and absence of PSS. This study examined the service type, dimension available and its role in addressing the need of the HIV/AIDS infected and affected people. Finally, the study attempted to compare and contrast between service beneficiaries who have been receiving psychosocial support and

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

those who have not yet received. Assuming the above research works, this research was attempted to fill the identified gaps and forward social work research, education, practice and community service implications.

### **Objective of the Study**

Comprehensive care and support providing to PLWHA and their families requires a broad range of services that include not only clinical care focusing on diagnosis and treatment. It is also supportive and complementary services that address emotional, psychosocial, and daily living needs and strengthens prevention wherever opportunities arise (Family Health International [FHI, 2004]). Considering this, while studying the role of community and home based supports of CCCs in providing psychosocial support, the following general and specific objectives were considered.

#### **General objective**

General objective of the study was to find out the role of community care coalition support groups in providing psychological, emotional and social support and assessing the effect of such support in helping the vulnerable group the case of two selected *Weredas*<sup>3</sup> in Mekelle city.

Specific Objectives of this study are:

1. To describe the types of care and support service provided to the HIV/AIDS infected and affected people of the two community care coalition.
2. To discuss the role of CCCs to address the PSS demand of HIV/AIDS infected and affected people in the selected coalitions.

---

<sup>3</sup> *Woreda* is typically to mean districts. It is the third-level administrative division of Ethiopia which composed of *Kebelles* (the smallest unit of government structure in Ethiopia) and managed by a local government.

3. To determine the level of satisfaction of beneficiaries about service gained from the selected CCCs.
4. To compare and contrast the reaction of those who received psychosocial support and not yet received within the two CCCs.
5. To identify factors that hinders these CCCs from providing psychosocial support specifically to these *Weredas*.

### **Significance of the study**

Looking specifically at the role of CCCs in providing PSS have plenty of significance at helping the CCCs to extend the dimension and level of their service to include the psychological, social and emotional life aspect of the targeted group. This is because the researcher believed that, psychological, social and emotional problems are triggering factors that can magnify the impact of HIV/AIDS in both the life of infected and affected people.

This study is also helpful for policy makers to design and develop effective strategies that primarily focus at meeting psychosocial and emotional problems of the targeted group. Moreover, it could pave the way for social workers intervention in helping practically the infected and affected peoples with psychosocial and emotional problems. This essay could be important for practical social workers to design and provide community services for such targeted group. This study could help social work students at both Post and undergraduate level for their field education as teaching and learning, reference material. Finally, this study may serve as base line information for other researchers to conduct similar research regarding the service of CCCs.

### **Limitation of the Study**

ned to study the role of CCCs in providing psychological, social  
people infected with and affected by HIV/AIDS with the main  
coalition support groups' of two selected *woredas* in Mekelle city.  
nected with and affected by HIV/AIDS but never receive a service  
led. Psychosocial support given by other professionals like  
n leaders and others out of the CCCs was not examined under  
rs of the infected people were not directly included in this study.  
ation regarding to them was collected from the infected ones.  
se two CCCs were not generalized hastily for other CCC support  
ata were not representative. Besides, researcher bias,  
nological constraints were considered as limitation of this  
ticipants bias appropriate time and place were scheduled with  
minimized by inviting peers to comment over the prepared tools  
as was minimized by using mixed research approach. The other  
the participants were vulnerable groups; at the beginning of the  
nce to participate and with negotiation and continuous

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

Psychosocial Support means emotional, affection, moral and social support given to the targeted people by CCCs

Care and Support is a service provided by the CCC members to the vulnerable group

Intervention means a strategy employed within CCC to provide support for the targeted group.

Community based support is a help which can be offered voluntarily from member of the community at local level.

Infected people are individuals those who are living with HIV/AIDS and receiving support from CCCs.

Affected people are individuals those are parent, family members, care givers or relatives of the infected one who look after them.

## **CHAPTER TWO: REVIEW OF RELATED LITERATURE**

In this section, topics and sub topics about psychosocial support like, theoretical frame work of psychosocial support, nature of psychosocial support, importance of PSS to PLWHA, inclusive provision of care and support to PLWHA, components of HIV/AIDS care and support are discussed. Moreover, issues like ways of providing PSS, who can provide the service, the role of PSS in addressing human right, effectiveness of the services in improving life of PLWHA and layers of psychosocial support are seen from different scholars view point.

Major Websites of international organizations working in areas related to HIV/AIDS such as the WHO, UNICEF, USAID and FHI, were also searched. Lists of references from original research publications or reports were also reviewed for additional relevant studies. The writer have tried to review studies done using qualitative, quantitative and mixed approach. Only publications available in English language were utilized and the literature search was limited to the period 2000-2012. Finally, the investigator would like to acknowledge the limitation of the review in comprehensiveness. The experience and range of problem to PLWHA may not be explained fully and these gaps are acknowledged by the researcher.

### **Psychosocial Support Theoretical Framework**

As the Psychosocial Working Group (PWG) states that, "The field of psychosocial support and intervention in complex emergencies like HIV/AIDS is currently characterized by a lack of consensus on goals, strategy and best practice to set single theoretical framework" (PWG, 2003, P. 4). However, as opposing to this statement, the

researcher stand is, there is widespread agreement that the use of theory is central to develop effective psychosocial support and intervention strategies or models. Social cognitive theory is aspect of social learning theory and one of the foundational theories of human psychology. Social learning theory holds that humans learn from one another by observing their actions and emotional states. This theory claims, theories like social cognitive and social capital are universally accepted theoretical frameworks to develop PSS models, goals and strategies.

According to Bravo, Costello, and Boland (2010, P.76), the concept of psychosocial support in social cognitive theory is summarized as:

Numerous psychosocial interventions can enhance self-efficacy, including providing role models with whom individuals identify who are successful in changing behaviors, social support that occurs in peer support groups or training of peer counselors, and skills (for example, group and individual counseling in which individuals have an opportunity to practice new behaviors) (Bravo, Costello, & Boland, 2010, P.76).

Similarly, the work of Gobopamang (2011) explained, the models of psychosocial support broadly defined as personal and social support of the individual that enhances positive coping mechanisms and behaviors. The cognitive models of psychosocial support, based on the theory that knowledge motivates productive support, have been fortified with concepts from the more complex models that describe psychosocial support as a process involving not only giving support to people, but also matrix of attitudes and beliefs about making the individual part of the productive society (Gobopamang, 2011).

In this case, I tried to connect the local community coalition groups as social capital in which their efforts was to support the community member and realize the importance of psychosocial support. Here is the model show how psychosocial support will be given by different groups.

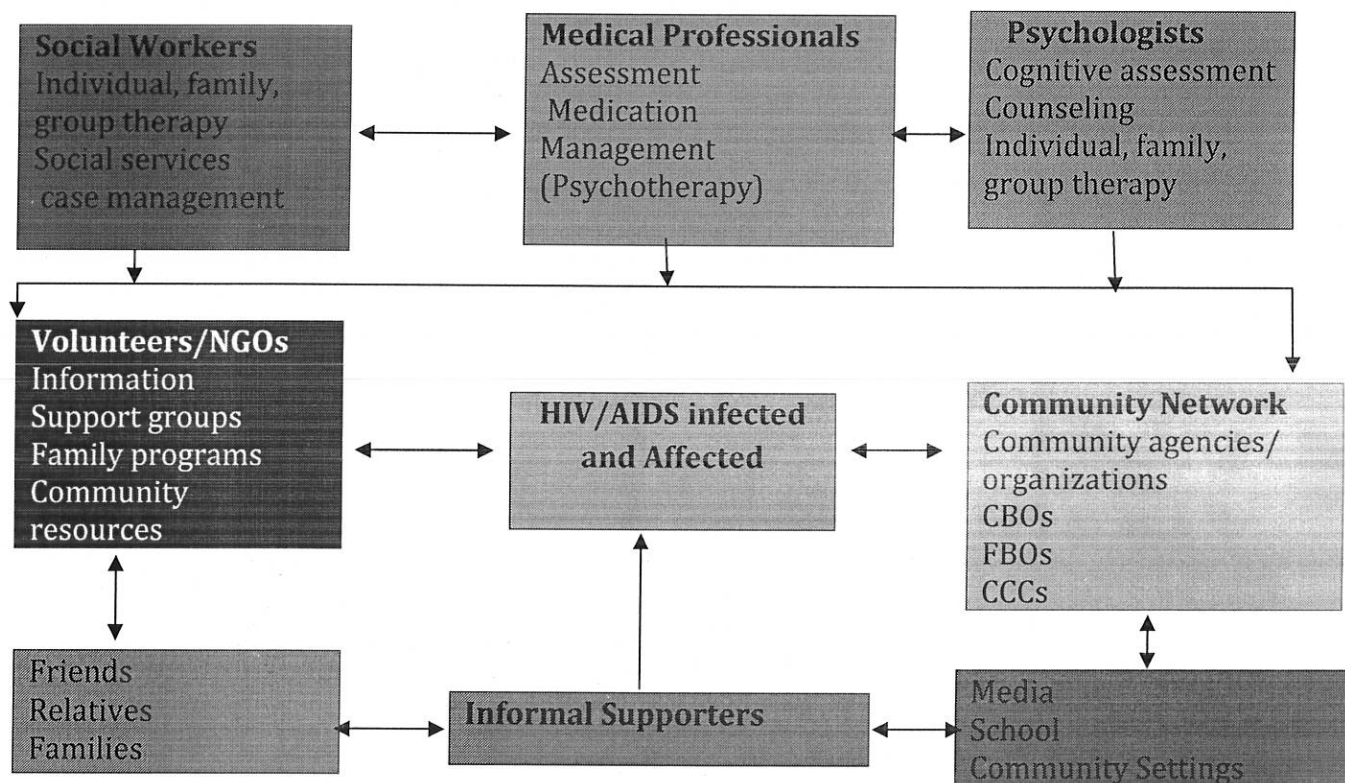


Fig: A. Model of psychosocial support for HIV/AIDS infected and affected families; Source own Design

### Current Support to PLWHA

According to Glaser (2010), international HIV/AIDS response efforts in recent years have concentrated on the scale up of comprehensive HIV/AIDS care and treatment services to poor and vulnerable populations, with a focus on expanding access to physical health aspect. This resulting increase in access to anti retroviral therapy (ART) has allowed HIV/AIDS positive individuals to live longer, healthier lives, while deemphasizes

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

the importance of addressing psychosocial issues in this vulnerable population. From the researcher view point, any model for the provision of comprehensive care for PLWHA and their families must therefore ensure that client psychosocial needs, in addition to their medical needs being satisfactorily addressed.

As literature indicates, for better HIV/AIDS care and support psychosocial issues in the context of HIV/AIDS; programs must increase the level of community involvement in the treatment, care, and support of PLWHA and their families. Achieving this goal will require enhancing PSS services for PLWHA and strengthening linkages between facilities, communities, and community based care and support organizations. While numerous strategies have been implemented in high HIV/AIDS prevalence settings to strengthen such linkages, PSS remains a significant gap in current HIV/AIDS programming (WHO & UNAIDS; 2004, 2008). Several challenges inhibit the provision of PSS services in resource constrained settings.

In practice, HIV/AIDS is not a problem that affects only the biological health of the infected individual; rather it has also a potential impact on the psychological life elements of both the infected individual and the rest of the family. As many literature supports FHI,WHO, & WHO ( 2004, 2004, 2008), HIV/AIDS infected people usually feel different psychological and emotional disturbances like fear, frustration, anxiety, feeling of hopelessness, and heartbreak which in turn affects the biological health homeostasis. Chronic illnesses such as cancer and at the end stage of HIV/AIDS have demonstrated associations between psychosocial variables and disease etiology (FHI, 2004). This implies that, if our coping capacity gets weaken because of psychological instability; now this is the most conducive time to be attacked by different disease and level of our physiological

reaction come to decline. State of body reaction to external threats may function in various stages from initial resistance to final exhaustion stage called General Adaptation Syndrome (GAS) (Diagnostic and Statistical Manual of Mental Disorder [DSM IV], 2000).

### **What is Psychosocial Support?**

It is generally believed that, psychosocial support is not single dimension in its nature. Because of the intense psychosocial stress related to HIV/AIDS infected and affected people frequently feel difficulty to cope up with normal day-to-day activities. According to Glaser (2010, P. 45), "Coping with HIV/AIDS infection is complicated by the fact that the people may be at risk of 'double-stigmatization' ". The researcher believed that, both infected and affected people are exposed to different state of psychological and social distressful feelings and mood disturbances. Therefore, providing care and support includes identification psychological and social variables such as social support, education, basic life skill training, sense of personal control and using different coping mechanism are important. When state of psychological disturbance feels, develop sense of understanding one's own environment comprehensively and adaptation need to be examined longitudinally to assess changes in psychosocial function, as disease progresses from early to advanced stages (Glaser, 2010).

### **Psychosocial Support to PLWHA**

As FHI stated in Dawit(2006), psychosocial support and counseling improves the quality life of the PLWHA and other vulnerable families through helping them to construct new dimension of life. Psychosocial support includes counseling, guidance, training, educating coping mechanism, enhancing self efficacy, and self esteem, confidence, and

rebuild the psychological and social aspect of life. Such kind of support helps to meet emotional, affection and spiritual needs of the infected and affected people. Helping them to disclose and risk reduction strategies; to confront isolation and discrimination, enhance good self image, sense of self management and adherence to medication (WHO, 2004). In general, the consensus about the importance of care and support highlighted the fact that PSS is a human right.

### **Inclusive Provision of HIV/AIDS Care and Support Service**

Witnessing the current care and support available for people infected with and affected by HIV/AIDS and other vulnerable members of the community has primarily focused on addressing their material/economical needs. The secondary focus of programs has been to address the needs for skill transfer and education for children (Mezegabu, 2007). The researcher personally believed that, may be few programs have been able to adequately address the medical, social welfare and psychological needs of these targeted groups. It is essential that medical care, socioeconomic support, human rights, legal support, and psychosocial support interventions are implemented in mutually reinforcing manner necessary to provide comprehensive care and support for infected peoples and other vulnerable families (FHI, 2001).

Although programs have responded to some of these needs and elements, they are often fragmented and lack a comprehensive approach. It is widely recognized that, one organization or program cannot address all of these needs alone. Yet, partnerships are still few and programs to date have had extreme difficulties in adequately reaching the number of infected and affected peoples need (HAPCO, 2007). Therefore, it is generally crucial if a care and support package for HIV/AIDS to be comprehensive, it should include elements of

voluntary counseling and testing for HIV/AIDS infection, psychosocial support, home and community-based care, and clinical management (including medical, nursing and counseling care).

### **Components of HIV/AIDS Care and Support**

HIV/AIDS care and support can be classified in to various dimensions.

#### **Medical Care**

For the maximum well-being of infected people and other vulnerable families to reach their need to have access to appropriate health care comprehensive programs are needed. These include clinical and preventive health care services, nutritional support, palliative care and complimentary home-based care, and full and relevant information (FHI, 2001).

#### **Economical Support**

People infected with HIV/AIDS and their families are confronted with enormous challenges throughout their life course which strongly smash their income, nutrition, and increase their cost of medication and other daily life necessities. According to Dawit(2006), most of these are directly or indirectly related to economical support of PLWHA.

#### **Psycho-spiritual Care**

As National AIDS/STD Control Program ([NASCOP], 2002) of the Ministry of Health, this includes reducing stress and anxiety for both PLWHA and families, promoting positive living, and helping individuals to make informed decisions on HIV/AIDS testing, plan for the future and behavioral change, make risk reduction plans, and involve sexual partner(s) in such decisions.

Basically, as a researcher I never concurred with classification of psychological and

spiritual supports as one category for that these two components are two distinctive features of life.

### **Social Support**

Includes information and referral to support groups, welfare services, and legal advice for individuals and families, including surviving family members, and where feasible provision of material assistance (UNICEF, 2004).

### **Who Can Provide Psychosocial Care and Support?**

According to Glaser (2010), there are many PSS interventions. These are: use of peer educators in clinical settings, family PSS groups, and local community based organizations, community care coalitions and faith based support volunteers, specialized professional counselors, home visits, and social workers, nurses, and religious leaders. As HIV/AIDS programs in resource limited settings should embrace the concept of integrating HIV/AIDS services at all levels, bearing in mind that PSS support is an essential core component of care for HIV/AIDS positive individuals.

In addition to this, taking the care and supports given to these vulnerable group in practice; it is possible to witness relatives, friends, traditional healers and those of religious faith are sources of strength and social support to many people. But more formal psychological support may also be needed as psychological needs vary, depending on status, stage of disease, prognosis and other factors. Individual and couples counseling can bring about behavioral changes in support of prevention among people living with HIV/AIDS, their partners and family (WHO, 2008).

### **The Role of Psychosocial Support in Addressing Human Rights**

People infected with and affected by HIV/AIDS are usually susceptible to different social isolation, stigma, and discrimination and other violation of human rights from neighborhood, family member, friends, coworkers, caregivers and rest of the society (Kassaw, 2006). Therefore, providing psychosocial support will meaningfully reduce the violation of human rights. The intention behind this support is helping the vulnerable group to develop sense of self confidence, strong self image and confrontation mechanisms.

The protection and promotion of human rights are necessary both to the protection of the inherent dignity of persons affected by HIV/AIDS and to the achievement of the goals of reducing vulnerability to HIV/AIDS infection, decreasing the adverse impact of HIV/AIDS on those affected and empowering individuals and communities to respond to HIV/AIDS (UNAIDS, 2006). By offering comprehensive psychosocial support to the vulnerable group, one can believe that, it is possible to make them part of the productive society.

### **Ways of Providing Psychosocial Support**

A key element in care and support is the provision of psychosocial support and ways of service delivery. Counseling and spiritual support, to enable disclose and risk reduction strategies, adherence to medication, and end of life sorrow feelings are important part of PSS(WHO & UNAIDS, 2000). This should be part of the care package at all levels of infected and affected people. At its most basic level, this requires the establishment and support of local community based support systems, peer support groups, CCCs, religion based organizations, volunteers those who are positive, and those affected by HIV/AIDS.

These support groups may offer many services such as education, training, and provision of material, basic economic, spiritual and psychosocial support. Those most affected often create such groups through a need for solidarity in the face of broader public stigma and discrimination (WHO & UNAIDS, 2000). The greater involvement of people affected by HIV/AIDS in the process is one way for generating psychosocial support in communities, and needs to be incorporated and encouraged in designs for care and support.

Home visits are very important approach for follow-up of a couple or an entire family affected by HIV/AIDS. As studies reveal, home visits can facilitate conflict resolution between married couples, HIV/AIDS testing of the male partner, and acceptance of the HIV/AIDS positive pregnant woman at home and in her spouse's family (Dawit, 2006)

### **Measuring Effectiveness of HIV/AIDS Care and PSS Programs**

Evaluating and measuring effectiveness of a given program can help to compare and contrast the performed task against the planned objective. A program can be only effective if it is constantly evaluated and measured to see its effectiveness (Dawit , 2006). Similarly WHO (2000, P.27) states:

HIV/AIDS comprehensive care programs must include a monitoring and evaluation component to refine, adapt and strengthen existing and new services and should be budgeted for and implemented in all HIV/AIDS comprehensive care programs.

Services will only be effective if they are consistently evaluated to measure effectiveness, efficiency, quality, usage and acceptability in the community (WHO, 2000, P.27).

The effectiveness of care and support service programs for PLWHA can be evaluated and measured in line with resource invested in the given service, the extent to which the program can bring about the desired behavioral changes, comprehensiveness of the program in addressing multidimensional problems of the target people, beneficiaries satisfaction and achievement of objectives of the program. Therefore, effectiveness of CCCs service can be evaluated and measured in relation to these conditions. Moreover in program evaluation multidimensionality is one of the parameter used to measure efficiency and effectiveness level (Dawit, 2006).

### **Layers of Psychosocial Support**

People living with HIV/AIDS and their families and care givers have many different needs, and their psychosocial status vary across social and economic contexts. Therefore, the psychosocial responses should be multilayered, taking into account all individuals, their families, peer groups, the community and the broader society at large. According to the PWG (2003) layers of psychosocial support for HIV/AIDS infected and affected can consists of four stages viz. stage I “Basic services and security, stage II, community and family supports, stage III, focused non-specialized supports and stage IV specialized service”(PWG, 2003, P.21).

#### **Basic Services and Security**

As indicated by Binega and Molla (2011) the well-being of all people should be protected through the (re)establishment of security, adequate governance and services that address basic physical needs. In most emergencies, specialists in sectors such as food, health and shelter provide basic services.

### **Community and Family Support**

The second layer represents the emergency response for a smaller number of people who are able to maintain their mental health and psychosocial well-being if they receive help in accessing key community and family supports (WHO, 2004).

### **Focused, Non-Specialized Supports**

The third layer represents the support necessary for the still smaller number of people who additionally require more focused individual, family or group interventions by trained and supervised workers (World Vision, 2005). This is similar with the care and support of CCCs volunteers to PLWHA.

### **Specialized service**

The top layer of the represents the additional support required for the small percentage of the population whose suffering, despite the supports already mentioned, is intolerable and who may have significant difficulties in basic daily functioning.

This assistance should include psychological or psychiatric supports for people with severe mental disorders whenever their needs exceed the capacities of existing primary/general health services (FHI, 2004).

### CHAPTER THREE: RESEARCH METHOD

This section deals with how the study was conducted. Participants, sampling techniques, instruments of the study, procedures of data collection and data analysis are explained. In addition, eligibility criteria, data quality assurance and ethical consideration are elaborated.

#### Research Design

This study adopts mixed research design with explanatory type; meaning that both qualitative and quantitative research approach are used. As De Silva (2010, P. 23) explained, "Mixed methods provide the opportunity for presenting a greater diversity of divergent views." From such point view, using a combination of quantitative and qualitative methods of analysis also reduces the limitation of each approach or helps to get more reliable data. In addition, De Silva(2010, P.24) indicate that "It is advantageous to use mixed research for analysis as together the data analyses from the two methods are juxtaposed and generate complementary insights that together create a bigger picture."

Similarly, John (2005,) confirms:

Other important reasons for doing mixed research are to complement one set of results with another, to expand a set of results, or to discover something that would have been missed if only a quantitative or a qualitative approach had been used(John, 2005, P.67).

Therefore, it is believed very relevant to use mixed research method for the present study.

### **Eligibility Criteria for Selection of Qualitative Participants**

The participants of this study were members of community care coalition service providers, people infected with HIV/AIDS and has got a service from the local CCC for the last two years and regional HAPCO officials whom they have clear contact with the CCCs. Under this study, people infected with HIV/AIDS but never receive a service from CCCs were not included (not members). Psychosocial supports given by other professionals like nurses, counselors, religious leaders and others out of the CCCs were not examined under this study.

### **Population, Sample Size and Respondents**

Relevant to this study, out of the twenty CCCs in Mekelle city, two are randomly selected; one from psychosocial provider CCC and one is not providing psychosocial support. The justification only two was to effectively manage the study and gain detailed data. One CCC consists of fifteen to twenty members with total of one hundred twenty service beneficiaries (PLWHA). Among the two CCCs, the first one is providing psychosocial support and the second one is without providing psychosocial support. In this case it is possible to make comparisons between the two CCCs in terms of the beneficiaries' service satisfaction level and organizational outcomes. Coordinators and HAPCO official were also participants of this study.

### **Sample Size**

Determining respondents and sample size is one of the most important parts of the method section (Brhanu, 2009). The researcher uses the terms like respondents and participants at the same time because the research has mixed nature. So the term participants were for the qualitative and respondents were for the quantitative section

respectively. There are different ways of determining sample size from a given population. As Krejcie and Morgan, (1970, Version, VI<sup>4</sup>) developed a means of determining a proportional and representative possible sample size. If the target population is two hundred fifty (250) a total of 132 participants will be selected. In case of this study, similar sample determination application was used. Therefore, out of the total population of the two selected CCCs service beneficiaries which are two hundred twenty (220), by taking  $\frac{1}{2}$  (50% CI 95%) of the sampling fraction, then one hundred ten (110) sample participants were selected. Proportional distribution of participants was allocated between the two selected CCCs (strata). In proportional stratified random sampling, the size of each stratum is proportionate to the population size of the strata when looked at across the entire population. This means that each stratum has the same sampling fraction.

### **Participants**

Apart to the above survey participants, two Focus Group Discussions (FGD) were held. Only two FGD were held assuming the time interval and data saturation. Each FGD had seven (7) service beneficiary members were selected from each CCC. In addition, three (3) key informant interview respondents from the service beneficiaries of each CCC were selected considering their experience on the service and duration of membership. With regard to determining the number of FGD participants, various scholars provide different number. For instance, Morgan (2009, P.4) explains, "The ideal number for FGD is between six and eight."

On the other hand, Escalada & Heong (2009, P.11) described that, "A good size for a discussion group is between eight to ten participants per session." Considering the above

---

<sup>4</sup> The original book was published since 1970 but the VI version of this book was republished in 2006

arguments, the researcher has taken an average of seven participants for one group per a session. Here special care was given not to select respondents those who are already participate on FGD again in the key informant interview or survey.

Besides, two (2) coordinators from each CCC and one (1) regional HIV/AIDS Prevention and Control Official (HAPCO) were selected assuming that they have better information about the CCCs functions. All these respondents were selected purposefully assuming that they could potential source of data for the study.

### **Sampling Technique for Survey**

In selecting the representative sample size of the service beneficiaries of CCC, probability sampling technique was employed. Of the probability sampling techniques, stratified sampling technique was used with the principle of the proportional allocation. The justification to use stratified sampling as Ashley (2010, P.34) describes it that, "Stratified sample is a probability sampling technique in which the researcher divides the entire target population into different subgroups, or strata, and then randomly selects the final subjects proportionally from the different strata." Moreover, the author expands his logical extension why researchers use stratified sampling as follow:

It is helpful when the researcher wants to highlight a specific subgroup within the population. Stratified sampling is good for this because it ensures the presence of key subgroups within the sample. It is also important to observe relationships between two or more subgroups. With this type of sampling, the researcher is guaranteed subjects from each subgroup are included in the final sample (Ashley, 2010, PP. 10).

Hence, firstly the sample size was determined to be 110 out of the total of 220 service beneficiaries' population. Using this principle, participants were allocated within their

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

respective CCC strata section. As a result, the following formula was used to determine how many participants could be taken from each CCC:

$$n_i = \frac{N_i}{N} * n \quad \text{OR}$$

$$n_i = \frac{\text{Sample Size} * 0.5}{\text{Population Size}}$$

Where;  $n_i$  = sample of each CCC service beneficiaries

$N_i$  = population size of each CCC

$N$  = Total population size

$n$  = Sample size (0.5 constant number)

Source: Jessica, M. U, & Robert, F. H. (2006). *Statistical ideas and methods*: Sample size determination concept.

Accordingly, the CCC are consisting of one hundred ten service beneficiaries, therefore using the above formula fifty five (55) participants were selected from each CCC assuming the proportional sampling allocation in each group.

#### Source of Data

To evaluate and assess the role of CCC in providing psychosocial support for infected and affected people, both primary and secondary sources were used. The primary data was collected from two groups of FGD participants of CCC members, 110 service beneficiaries of CCCs to fill the survey questionnaires, key informants consists of six service beneficiaries, two CCCs coordinators and one HAPCO regional official. Secondary data was collected from other additional annual reports of CCCs, previous research, and other relevant literature.

#### Methods of Data Collection

In order to study the role of community care coalition in providing psychosocial support for vulnerable group, it was necessary to collect the data as follows:

##### Document Analysis

Documents like articles, books, project reports on care and support implementation

guidelines, reports of the CCC and other relevant websites were used to collect necessary and supplementary information for the effectiveness of the study.

### **Focus Group Discussion**

Two FGD with total of seven service beneficiaries from each CCC were held and efforts were made to make homogeneous in terms of s sexes, age and educational, socioeconomic backgrounds. Literature recommends FGD participants with homogeneity have better feeling of involvement in the group. This gave the researcher the chance to collect members experience, perception, attitude and grievances on the service provision.

### **Interview**

To generate necessary data semi-structured interview was conducted with the six key informants of CCC service beneficiaries (three from each CCC). The reason only three from each CCC was; the researcher believes that, to consolidate the quantitative data from representative respondents, six key informant interviews were enough. Finally, two CCC coordinators from the two selected CCC and one HAPCO regional officials were participant in the key informant interview. From this key informant interview, relevant data like service dimension, future plans, challenges, experiences and communication styles of the support group were collected.

### **Survey**

Structured questionnaires were prepared to collect data with regarding to the level of satisfaction of service beneficiaries, significance difference between the two groups, the effects of communication, volunteers skill, and knowledge to PSS and to what extent the service provision was comprehensive enough in addressing the psychosocial demand of the targeted group. This questionnaire was also helpful to draw a conclusion about the

reaction of CCCs service beneficiaries between those who have been receiving psychosocial support and those who are not.

### **Data Quality Assurance**

Reliability of the questionnaire was checked by Cronbach Alpha, ( $\alpha$ ) and test- retest methods in 78 service beneficiaries of other CCC in pilot study before the actual dissemination (two weeks) of the questionnaire to the targeted group two times with one week interval. Of the total 78 pilot participants 39 were from CCC providing PSS and 39 CCC without providing PSS. The reliability of the survey questionnaires were found to be  $\alpha = .769$  by Cronbach Alpha and  $r = 0.78$  which was a stronger consistency.

For the interview and FGD items trustworthiness was assured by avoiding double barreled, long and complex questions. Efforts were also made to avoid leading questions and false premises. In tandem to this, six peers were invited to comment and debrief on the prepared questions (Peer debriefing). Triangulation by method and data source was held to keep the trustworthiness of the data. In other words, different methods were used to collect the qualitative data. To authenticate the genuineness of data, the researcher was established good rapport relationship between study participants.

Content validity or inter judge validity was conducted to find out if the questions were representing what they were intended to measure in a proportional way. In doing so, the variables of psychosocial support and components of care and support to HIV/AIDS infected people were well defined and then the questions were given to four raters, two of them were staffs in Mekelle University department of psychology, and the other two raters were second year post graduate students in the department of public health AAU. The rating for the questions were 1= bad, 2= good, and 3= excellent questions. As a result based

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

on the agreement of the raters, out of the total 25 items, four items were deleted to balance the validity of the tool. The questionnaires were translated in to Tigrigna version by staffs in Mekelle University department of Tigrigna in collaboration with researcher for ease of communication to get genuine information.

The formula for the quantitative data was checked by:

$$\alpha = \left( \frac{K}{K-1} \right) \left( 1 - \frac{\sum St^2}{Sti^2} \right) \quad \text{or,}$$

$$r_{xy} = \frac{N(\sum xy - \sum x \cdot \sum y)}{\sqrt{[N(\sum x^2 - (\sum x)^2) \cdot [N(\sum y^2 - (\sum y)^2)]}}$$

Where:

$\sum st^2$  = the sum of variance of each item

$Sti^2$  = variance total item response

$K$  = each item

$1$  = constant number

$\alpha$  = Greek small letter alpha

$\sum$  = Sigma

Where;

$\sum x$  = the sum of each item in test 1

$\sum x^2$  = the sum square of each item

$\sum y$  = the sum of each item in test 2

$\sum y^2$  = the sum square of each item

$\sum xy$  = the sum each item in test 1&

$N$  = Number of total items

Source: Joseph, A. G., & Rosemary R. G. (2003) Calculating, interpreting, and reporting Cronbach's alpha reliability coefficient for Likert-type scales

### Data Collection Tools

To collect important data for the study different tools were used. Semi- structured interview guide item which consists of eight questions; FGD guiding items consists of six questions. Ostensibly, twenty one structured questionnaires were prepared and distributed to evaluate and assess level of satisfaction and to compare and contrast the reaction of service beneficiaries. Besides in the survey, factors affecting PSS provision, communication, coordinating barriers and beneficiaries complain also assessed. The survey questionnaires were designed based on the Lickert five point scales. The scale had five point scales ranging from 1 (Strongly Disagree) to 5 (Strongly Agree). Questionnaire

was preferred to other tools of study for its simplicity for the nature of the study and ease for collecting data from such a large sample size where the target population is found collectively (Brhanu, 2009).

With regard to the number of interview and FGD guiding items there is no fast and hard rule. For example Escalada & Heong (2009, P.3) explained that, "The number of FGD and key informant guiding items could be determined by the information needed, time and staffs participating on the research." Similarly, according to Kerns (2005, P.9), "Survey questions needed for a quantitative data will determined by the nature of research and it consist of twenty to forty items." Considering the above literature facts, the researcher has taken average number of guiding items and survey questionnaires.

### **Data Collection Procedures**

After 110 participants were selected, certain procedures had to be followed. Deciding the venue where the questionnaire should be disseminated to the participants. Accordingly, the researcher submitted the official letters of collaboration from school of social work and *woreda* administrations to the CCC coordinators and received permission. Fortunately, the beneficiaries were under training at that time and they were oriented the purpose of the study and direction of filling the questionnaire in mass. The voluntaries were cooperative and they take the responsibility to coordinate the process. As of the next day, all the participants were returned the questionnaire paper. There were three (3) data collectors along with the researcher who disseminated and collected the questionnaires.

In the FGD, members of CCCs with proportional with sex distribution in each group with age, educational background, religion affiliation and economical status consideration were selected and conducted. The FGD participants were selected based on duration of

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

longevity in the CCC and willingness to discuss personal experience freely. Possible attempts were made to make the discussion open, free, no domination and unreserved to ensure equal participation of each participant. The researcher played the role of facilitator. Discussion time and place were determined with pertinent time of each group members. Not to make boring and tiresome the discussion was run only for an hour, even though some literature says FGD can be held to one and half hours.

With regard to the interview participants, all key informants were scheduled appropriate time and place with researcher. Each interview was held for half an hour assuming the average time of many scholars stated for key informant interview. To gather data during interview and FGD note taking was used for that most of them were not willing to record their response on tape recorder. Advance considerations were taken into account to other non verbal communications. In both the FGD discussions and key informant interview, respondents were given tea coffee health break and 40 ETB<sup>5</sup> each as transportation accommodation except for the HAPCO regional official. Above all, in line with the interview and FGD discussions the researcher has reviewed documents of the CCCs to consolidate the collected data.

### **Data Analysis**

In order to analysis the information obtained from the survey, descriptive and inferential statistics were employed. Mean and standard deviation were employed to see the service provision practice between the selected CCCs. Correlation (Pearson product coefficient) was used to see the relationship between services beneficiaries with and without psychosocial support and satisfaction of the targeted group was measured. One

---

<sup>5</sup> The Birr (ብር in Amharic), denoted by ETB, is the unit of currency used in Ethiopia, after 1979

way ANOVA and two sample T- test were used to look if there were significant effects and differences of CCC types on service provision, beneficiaries' satisfaction. Linear regression analysis was computed to predict if skill and knowledge efficiency problem could influence the effectiveness of the service provision. Multiple regression was used to predict states and conditions of lack of resources, community participation, coordination, skill, knowledge and efficiency problem of CCC voluntaries and coordinators could affects the provision of PSS. Percentage was used to know how many of the participants' are receiving psychosocial support from CCCs. In doing so, the Data Analysis and Statistical Software for Professionals (STATA SP. Ed. 11.1\*)<sup>6</sup> software was adopted.

On the other hand, relevant information obtained from key informants interview and FGD participants were analyzed and interpreted thematically in line with key elements of care and support to PLWHA and vulnerable groups identified by World Health Organization (WHO). The steps followed for the qualitative analysis is presented below.

### **Pre-coding**

In this research all interviews and FGD were conducted in Tigrigna, every day after data collection, data or field note transcription was done repeatedly until the intended main points of the interview were achieved and then followed by translation in to English. Following the translation pre-coding were started by highlighting significant participant quotes made during the interview. Significant statements that provide an experience of the participants were specially considered. In doing so, to make the process easy markers with various colors were used.

---

<sup>6</sup> Stata Special Edition 11.1\* Data Analysis and Statistical Software for Professionals Version 11

### **Coding**

The pre-coding process was followed by making final code. In this case, the pre-coded statements, ideas, experiences of interviewees and FGD participants were summarized and arranged in to meaningful segments. According to Tuckett (2005), this needs systematic arrangement or classification and such process was helpful to simplify and focus on some specific characteristics of the data.

### **Categorizing**

In this stage the researcher try to coupled similar, closer and related ideas, data, and statements together which have similarity with coded data. This categorization indicates, how the various codes were constructed into similar categorical values, how the data has given meaningful shape. Data categorization helps to sort out texts into meaningful groups, which make the data to be manageable (Tuckett, 2005). This is because; the coded data was categorized depending on the similarity and relationship of codes.

### **Themes**

This is the final output of the pre-coding, coding and categorizing with analytical reflection of the researcher. In tandem to this, the main theme in this study were developed considering the categorization and main guiding research objectives. According to Tuckett (2005), themes could be concepts that explain how ideas or categories are connected. In this study besides looking themes from the coded text segments the main care and support identified by WHO were also considered.

### **Write up**

After all these processes, writing the final composite of the findings and analyzing, interpreting and looking for meaning out of those themes were made. Initially the themes

were 38 and the reduced in to 20. Finally, themes are categorized under four major point's viz. psychosocial support for PLWHA and their families, types and dimensions of services provided by CCCs, ensuring home and community-based care as guiding principle of PSS, and factors affecting provision of PSS and mitigating ways. In line with this, major roles of these support groups in addressing the psychosocial demand of PLWHA and their families, service beneficiaries' level of satisfaction and main challenges that affect PSS service provision as guiding objectives of this research were analyzed.

### **Ethical Consideration**

Professional and research ethical values of this research were fully recognized and assured.

### **Informed Consent**

The ethical clearance letter was given from Addis Ababa University School of Social Work and the two local *Woreda* administrations. All participants in this study were decided their participation willingly and the researcher let them know the purpose of the study; give them all necessary information regarding the research. Participants were pre-informed that, they could quit their participation if they felt discomfort without looking permission from the researcher. Participants were not forced to sign contractual agreement with the researcher at the beginning of their participation.

Conducting interview, document analysis of PLWHA and their families profile was done only after the researcher has got consent of the participants. Since most of the beneficiaries were not willing, tap recording was cancelled and only used note taking. Moreover, issues of confidentiality, anonymity and privacy were communicated well. The

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

researcher also explained them that, the information they gave will be present to AAU School of Social Work. All personal information will be locked in a private folder and will be destroyed once the research is completed. The researcher and participants were also agreed to use pseudo name instead. Since they are a vulnerable group all possible efforts were done to treat them in advance. They were also communicated the risks like they may feel anxious and emotional during discussion time and they can take time in between and refresh themselves. They were also communicated about the benefit of their participation and the value of the data they gave, to themselves, community, to the CCCs and other concerned bodies. The FGD and key informant interview participants were given with transportation allowance and health break refreshments. The time duration of the FGD and key informant interview were explained in the consent and the place of interview and discussion was decided by the respondents and participants. Other possible research ethical considerations and norms were maintained accordingly.

## CHAPTER FOUR: FINDINGS OF THE STUDY

In this chapter, the data collected from key informant interview, FGD and survey questionnaire are presented. The qualitative data is pre-coded, coded, categorized and developed in to themes. In this vein, the major findings of the study are presented within four major topics namely: psychosocial support for PLWHA and their families, types and dimensions of services provision in CCCs, ensuring home and community-based care as guiding principle of PSS and factors affecting provision of PSS and mitigating ways. In line with this, major roles of these support groups in addressing the psychosocial demand of PLWHA and their families and service beneficiaries' level of satisfaction as guiding objectives of this research are analyzed. Data collected from the survey questionnaire also included and integrated with major themes.

### Demographic and general characteristics of participants

*Table A. Demographic and General Characteristics of Participants*

S.N	Variables		V. (N % within V.)	Total(N/P)
1	Beneficiary type	Beneficiaries with PSS	65(50%)	130(100%)
		Sex		
		Female	34(26.15%)	
		Male	31(23.85%)	
2	Duration of membership	Beneficiaries without PSS	62(50%)	130(100%)
		Sex		
		Female	35(26.92%)	
		Male	30(23.07%)	
3	Age	[2-4 Yrs)	69(53.07%)	130(100%)
		[>4 Yrs)	61(46.92%)	
4	Educational background	20-30 Yrs	72(55.38%)	130(100%)
		35-45 Yrs	58(44.61%)	
		Elementary level	63(48.46%)	
		Junior High school level	37(28.46%)	130(100%)
		High school level	23(17.69%)	
		Diploma(10+3)	5(3.84%)	
		Degree	1(0.76%)	
		Masters(HAPCO official)	1(0.76%)	

The above table presents the background information of the participants of this study. From the given data we can understand that the highest number of participants in this study were females in which 69(53.07%, N= 130) followed by males 61(46.92%). The distribution of participants in both beneficiaries receiving psychosocial support and beneficiaries without psychosocial support was equaled 65(50%, N=130). This was done considering the proportionate sample distribution among the two selected strata. This was also helpful to compare and contrast the level of beneficiaries service satisfaction with respective to their stratum.

With regard to duration of service receiving membership, while the range 53.07% of the participants was two to four years, the remaining 46.92% was more than four years. From this, it is possible to say all of the participants were satisfying the pre specified participants selection criteria which was two years and above. The above Table also indicates the total number of the study participants (130 or 100%) who are infected with the virus in which currently receiving care and support from CCCs. However, this does not mean that the current service provision system in CCC was only for infected people hence families of these participants are included in the service package.

### **Psychosocial Support for PLWHA and Their Families**

It is universally believed that HIV/AIDS has profound effects upon individuals, families, households, and communities. As the vast literature indicates, HIV/AIDS presents many challenges to health education, health services and policies particularly for family and community members who are assumed to be responsible for the care of people living with HIV/AIDS. It can be understood that the study participants need various care and support such as PSS, medical and palliative care. Psychosocial support addresses the

psychological, social and emotional problems of HIV/AIDS infected individuals, their partners, families and caregivers. The importance of PSS has been discussed in the literature section of this study. As per the overall collected FGD, key informant interview and survey data from service beneficiaries of CCCs indicates, it is found to be very essential to provide PSS as one component of HIV/AIDS care and support to PLWHA and their families.

The following table indicates the overall reaction of beneficiaries to the importance of PSS for their life. This table presents only reactions of beneficiaries participated in satisfaction survey.

*Table B: Participants Response to the Importance of PSS*

Nature of beneficiaries within the two CCCs	Providing Psychosocial support must be one of the major Component of the HIV/AIDS care and support in CCCs N=110; St.Dev.9261289 X= 4.509091					
	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree	Total
Non beneficiary of PSS	3	3	3	0	46	55
Beneficiary of PSS	0	0	3	21	31	55
Total	3	3	6	21	77	110

From this table it is possible to understand that PSS is strongly needed by PLWHA to be part of the major care and support service system. Out of the total respondents ( N=110) majority of them 77(70%) strongly agreed on the provision of PSS with mean average of X=4.51. This is followed by 21(19.1%) level of agreement. However, as compared to the beneficiaries receiving PSS; service beneficiaries those who are not given PSS are highly

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

demanding on the importance of PSS as part of the care and support given to them with a mean(  $X=4.2$ ) level of agreement on its importance. Similarly, the key informant interview and FGD participants had strongly indicated that, PSS is one of the most important types of care and support needed by PLWHA and their families. For instance one key informant said, “We PLWHA have lots of psychological, social and emotional problems and to cope up with such problems we need strong PSS and various professional helps.”

On the other hand, the participants were asked whether PSS support is offered as separate care and support plan in their respective CCC. The response varied between the two beneficiary groups. The beneficiaries receiving PSS rate 95.5% of their response as PSS is given as one separate care and support service package of the CCC. Whereas, beneficiaries without PSS responded to the same question 78.3% level of disagreement. Generally, from the above numerical values it is possible to understand that providing PSS as one major care and support benefit package is strongly required by both the beneficiaries with and without receiving PSS. Beside this, one CCC coordinator explained the importance of PSS as follows:

PLWHA are exposed and vulnerable to various psychological, emotional and social stresses. The physiological problem they have could be aggravated by such stressing factors. So, to strengthen the current care and support, providing PSS should be part of the CCCs service package at all level (Key informant, CCC coordinator 1, 2013).

In line with the above major idea, the survey respondents were also asked how they could see and evaluate major roles of CCCs in addressing their life demands and needs of their families. The overall research participant two sample T-test result indicates  $T= 0.00$ ,  $P<0.05$  with 95% CI which means the role of CCCs in improving beneficiaries quality of life

is significantly differ between the two types of beneficiaries. In other words, there was a significant difference between beneficiaries receiving PSS and beneficiaries without PSS in evaluating the role of CCCs. Beneficiaries receiving PSS show better level of satisfaction in the major role of CCCs in improving their life than the beneficiaries without receiving PSS and this is also proved with average  $X=4.75$ ,  $2.00$  of Max 5 respectively.

As part of this major issue, the survey respondents were also asked whether their families are included in the CCCs service provision package or not and their response was rated as mean of ( $X= 3.5$  and St. Dev of  $1.1$ ). This means that, more than half of the participants' families are included in the service package. However, significant numbers of beneficiaries' family are not still included in the program. The key informant interview and FGD participants from both types of group support even majority of the support and care was provided in the name of their families especially children. The HAPCO official and CCC coordinators also support the above statement by saying "Families of the infected people are treated in the service package despite any pre requisite."

Besides, the respondents were presented with a question whether the nature of service given by CCC is accurately reflected their family demand. The collected survey indicates, the nature of service package designed by CCC are not fully reflected the demand of beneficiaries family. This is supported by the overall mean( $X=2.1$  of Max 5) response of respondents with  $\sigma=0.854$  of variance. Means, the response of both service beneficiaries decline to support the statement that states; "The designed service package by CCCs is accurately reflected my family's demand" for ( $T=0.999$ ,  $P> 0.05$ ). The FGD participants also respond the question as, "It is undeniable that our family members are included in the

service package but it is very difficult to say the service package satisfies the need of our family demand." This idea is supported by both types of beneficiary groups.

### **Types and Dimensions of Services Provision by CCCs**

This study indicated that there is a great contribution of services and support provided by community care coalitions program to persons infected and affected by HIV/AIDS. An effective CCCs program for PLWHA can yield major health and social benefits for the patients and their families, and then to the entire community. According to WHO (2000), nutritional support, psychosocial support, medical and nursing care, community activity and health education are found to be the most common types and dimension of services to PLWHA. Similarly in this study, participants were presented with a question if the types of care and support chosen by CCCs were includes PSS. The response is computed by Two-sample t- test with equal variances and the result is presented below. This computation helps to see variation between the two groups to the types and dimension of care and support given by their respective CCC.

*Table C: Participants Response to whether the CCC service package included PSS*

#### *Two-sample t test with equal variances*

Beneficiary type	Obs	Mean	Std. Err.	Std. Dev.	[95% Conf.	Interval]
BWOPSS T2	55	2.163636	.1238105	.9182035	1.915411	2.411862
BWPSS T1	55	3.872727	.0822845	.6102381	3.707757	4.037698
Combined	110	3.018182	.1103349	1.157202	2.799502	3.236862
Diff		-1.709091	.14866	-----	-2.003761	-1.414421

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

As the above table indicates, beneficiaries' type one showed better satisfaction with the inclusion of PSS in the designed benefit package with an average of 3.8 mean with 0.6 standard deviation variations. This is high as compared to beneficiaries' type two rated their average satisfaction 2.1 and 0.9 St, Dev. This means that, the absence of PSS from the care and support service package influence the level of beneficiaries' satisfaction to the beneficiary type two(BWOPSS). The two sample T- test also indicates there is significant difference between beneficiaries with and without receiving PSS on the type of care and support designed package by CCCs. This is shown by  $T = -11.4966$ ,  $P < 0.05$  with 95% of CI. In other words, if PSS is included as part of the designed service package; level of satisfaction of beneficiaries will increase and vice versa. Supporting the above finding, the FGD participants from the beneficiary group without PSS revealed that:

Like other vulnerable and exposed segment of the population, we are also exposed for similar psychological, social and moral problems in which it aggravates our physiological problem. So, likewise what has been done in other CCCs; we are also in need of PSS. Our concern and problem is not only about material or financial issues, it is also about moral, feeling and personal emotion (FGD from BWOPSS, 2013).

When specifically coming to the general care and support designed packages, as literatures indicate, CCCs programs are mostly emphasize on psycho-social support and deliver their services primarily through volunteer networks in the community together with program staff, not specifically by health professionals. The Finding in this research indicates that the provision of PSS is only emphasized and valued in the CCC group one that providing PSS (see the mean average in the above table).

On the other hand, one way analysis of variance was also calculated for the general type of care and support designed if there was significant effect of beneficiary service satisfaction on the care and support design. It showed that, there was no effect on the overall service beneficiaries satisfaction with regard to major design of care and support,  $F(1, 108) = 132.17$ ,  $T = 11.5$ ,  $P > 0.05$ . In other words, even though the beneficiaries show variation of satisfaction in the presence and absence of PSS, one of the groups of beneficiaries of the two CCCs did not show difference on the general type and care designed service package by CCCs. The interviews and FGD discussions also support the above major finding.

Similarly, the participants were asked if the current service package aimed at future beneficiaries' empowerment. Both the beneficiaries respond the service package designed by CCCs was not aimed at future beneficiaries' empowerment. A one way analysis of variance indicates that, the designed service package has no special room for beneficiary's future empowerment. The one way ANOVA showed that, the beneficiaries never feel empowered and feel sense of ownership in their current situation, as the  $F = 0.89$ ,  $P > 0.05$ . Moreover, the two sample T- test also indicate, there is no significant effect between beneficiaries receiving PSS and beneficiaries without receiving PSS as, the  $T = 0.82$ ,  $P > 0.05$  with 95% of confidence interval. However, key informant interviews from both the beneficiary group revealed that, the service beneficiaries were given about three thousand ETB loan free of interest as part of empowering them and using this opportunity they engaged in mini trade activities.

Beside this, beneficiaries were also asked if they participate during the initial

service designing and if their contribution was considered in the final service package. The overall beneficiary response indicates 92.73% as they never participate in the initial service designing package and even those who have had participation; their contribution was not considered in the final service package. A one way analysis of variance also indicate, there was no significant value of beneficiaries participation in the service designing package which is  $F= 2.15, P >0.05$ . This means both type one and two services beneficiaries have no significant participation during the initial service designing package. Similarly, the data collected from key informant interview and FGD participants also show; beneficiaries were not participated in the initial service designing.

To sum up, beneficiaries showed better satisfaction with the provision of economical, physical (home maintenance) and medical care and support with correlation coefficient of  $r= 0.33$  as compared to satisfaction to PSS  $r= 0.011$ . This means both type one and type two beneficiaries showed positive service satisfaction in the medical and economical support than to PSS. In other words, despite the difference observed in the provision of PSS, there is no significant difference in the economical, physical and medical care and support provision between the two groups which was evident as  $T= 0.9839, P>0.05$  with 95% CI.

### **Ensuring Home and Community Based Care as Guiding Principle of PSS**

Home and community based care can be defined as the care given to an individual in his/her own environment (home) by volunteers and community members to meet not only the physical and health needs, but also the spiritual, material, and psychosocial needs. In this research participants were asked if the volunteers were committed, supportive, helpful and actively engaged during service provision time to ensure all the necessary care and

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

support. This question was raised because, literatures indicate volunteers' commitment, support and engagement matters for the success or failure of home and community based care and support. The following table presents participants response.

*Table D: Two sample t- test Beneficiaries Satisfaction with Volunteers commitment and work engagement.*

Two-sample t test with equal variances

Group	Obs	Mean	Std. Err.	Std. De.	[95% Conf. Interval]	T	(T > t)
BWOPSS T2	55	3.722222	.1103221	.8106989	3.500944 3.9435	-1.9860	0.9752
BWPSS T1	55	3.981818	.0710238	.5267268	3.839424 4.124212		
Combined	110	3.853211	.0662393	.6915587	3.721913 3.984509		
Diff		-.259596	.1307145		-.5187223 -.0004697		

The total response of participants was 77.99% positive agreement on the commitment and task engagement of volunteers during service provision time. Two-sample t- test with equal variances was calculated for beneficiaries' satisfaction if volunteers were committed, supportive, helpful and actively engaged during service provision time makes difference in beneficiaries' service satisfaction. It showed that there was no effect of beneficiaries satisfaction on volunteers commitment and task engagement for,  $T = 0.9752$ ,  $P > 0.05$ . This means, whether beneficiaries receiving PSS or not, never affect the satisfaction level with volunteers commitment and work engagement. In other words, beneficiaries from the two groups did not show variation in satisfaction with the volunteers' commitment and work engagement. This is also proved with the mean difference average on satisfaction for ( $X = 0.259596$ ).

Beside this, the key informant interview with beneficiaries of the two groups showed as the volunteers are committed and serving them with total dedication.

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

Supporting to this one FGD participant explain his opinion as “In our group the volunteers are committed, cooperative and helpful. They respect us and the work they have.

Volunteers make my experience of receiving CCCs services more enjoyable.” However, opposite to this finding, the FGD participants from the group without receiving PSS exposed that, the volunteers sometimes show disrespect, low work motivation and feel discouraged about their work.

Supporting to this main issue, the participants were asked whether they have complains about the skill and knowledge efficiency problem of CCC volunteers to provide all services. The cumulative response of both the beneficiaries revealed that, 81.82% they have complain about the volunteers’ skill and knowledge efficiency to provide the designed service package. To see if there is difference between the two types of beneficiaries one way analysis of variance and two sample T- test were calculated and it showed that, there is no significant difference between the two group of beneficiaries with regard to the volunteers’ skill and knowledge efficiency problem, for  $t=0.6248$ ,  $P>0.05$ . In other words, both the beneficiaries receiving PSS and beneficiaries without receiving PSS complained about the volunteers’ skill and knowledge efficiency to provide the necessary designed service package.

Similar question was asked to key informant respondents and FGD participants and showed that, all the participants and respondents of the two beneficiary groups have strong complain and claim about the skill and knowledge efficiency of volunteers to provide the necessary service. To explain this, one FGD participant says:

I think it would be valuable for volunteers to have access to various training courses, not necessarily related to their roles but generally about service provision for PLWHA and their families.

With regard to volunteers' skill, knowledge and efficiency problem one CCC coordinator says:

Providing care and support to PLWHA in general and offering PSS in particular needs professional training and experience. However, in our case the volunteers are untrained; their educational background is not greater than grade eight or ten. They are joining the program with three or four day's short training and such training is given only two times in a year. So, with such kind of manpower I don't think providing appropriate service could be an easy task for them. In addition, we have no training and guiding manuals at hand even to lead the volunteers in to action (CCC coordinator, Key informant, 2013).

On the other hand, the beneficiaries positively rate their satisfaction as they can directly explain complains to the volunteers at the time of service provision if they feel unhappy and discouraged, for  $r= 0.85$ . In other explanation, beneficiaries feel easily to explain their grievance to volunteers as compared to CCC coordinators for  $r= 0.0089$ .

Ostensibly, the FGD and key informant interview participants say:

If we observe bad things and feel discourage about the service; we can freely explain our grievances to the volunteers. We feel at easy to talk to volunteers about the problems than the CCC coordinators.

One FDG participant also explains the case as follows:

It is very important to get support from the co-coordinators. It can be slightly depressing & lonely maintaining a long time commitment to the volunteers. We are here with lots of problem and the volunteers alone may not answer all our problems. So the coordinators should personally engage and support the volunteers during the service provision time (FGD participant, 2013).

Similarly, the participants were asked if the volunteers request them feedback on the nature of service provision. The average response revealed that 63.64% volunteers ask feedback from beneficiaries on the nature of service provision. One key informant interviewee from beneficiaries with PSS explains his opinion as follows:

The volunteers usually ask us how we feel about their treatment, service and the relationship we have with them and we freely tell them all what we feel about them.

If there is difference between the two groups of beneficiaries with regard to the above question; one way analysis of variance and two sample t- test were computed and showed there is difference between beneficiaries for,  $T=0.0017$ ,  $P<0.05$ . The beneficiary group with PSS has better satisfaction in providing feedback on the nature of service provision than the beneficiaries without PSS. This means, the provision of PSS indicate a better communication relationship between volunteers and beneficiaries, as volunteers ask feedback on the nature of service provision than do volunteers in the CCC group without providing PSS.

### **Factors Affecting Provision of PSS and Mitigating Ways**

The service provision of care and support to HIV/AIDS infected individuals and their families could not be free of influencing factors. Factors like community participation, availability of resources, coordination problem, provision of training to volunteers and

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

relationship between providers and receivers of service could influence the success or failure of the program. In the arena of providing PSS and other care and support to PLWHA, community participation is far more than a requirement. It is a condition for success. Documented studies revealed that, communities that engage their citizens and volunteers deeply in the work of community development raise more resources, achieve more results, and develop in a more holistic and ultimately more beneficial way.

Similarly in this study, to see whether the above and other related factors could influence beneficiaries' service satisfaction and success of the program; survey respondents were asked to give their response. The collected response was computed by Multiple regression and showed that overall beneficiaries service satisfaction is influenced by various variables in which expressed as,  $F(4, 105) = 0.11$ ,  $F = 0.985$ ,  $P < 0.05$ . When specifically coming to which component of beneficiaries satisfaction, best predictors were coordination problem among CCCs coordinators,  $t = 0.187$ ,  $P < 0.05$  and lack of resource and community participation,  $t = 0.224$ ,  $P < 0.05$ , followed by relationship between service beneficiaries and providers  $t = 0.245$ ,  $P < 0.05$ , for all 95%CI.

In other words, lack of resource and community participation, relationship of service beneficiaries and providers, CCCs coordinators coordination problem; decrease overall beneficiaries satisfaction (with correlation coefficients of  $-0.203$ ,  $-0.265$  and  $-0.080$ ,  $P < 0.05$  for all), respectively. In addition absence of training to CCCs volunteers was found to be third best predictor variable to the deterioration of beneficiaries overall service satisfaction,  $t = 0.231$ ,  $P < 0.05$  with  $r = -0.0488$ . This result is also supported by key informant and FGD participants of the two groups. During the FGD discussion of beneficiaries from the group without PSS, one participant explains that:

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

In order to bring all the planned action in to ground, community participation should be assured, available resources should be effectively used, coordination problem must improved among all stakeholders. Availability of trained manpower is more than crucial to the success of this program. Whether we like it or not in the absence of such things, we should not think of success in the CCCs. All concerned bodies must think of these things (FGD participant without PSS, 2013).

The following table presents the computed influence value of each variable in beneficiary's satisfaction.

*Table E: Regress overall\_benfi\_serv\_satisf lack\_commpartici resource relationship\_benfi\_cccs managerial\_problem absence\_training*

Source	SS	df	MS	Number of obs = 110			
Model	.532338466	4	.133084616	Prob > F=0.9805			
Residual	132.785843	105	1.26462708	R-squared=0.0040			
Total	133.318182	109	1.22310259	F( 4, 105) = 0.11			
				Adj R-squared=-0.0340			
				Root MSE=1.1246			

Overall beneficiaries satisfaction	Coef.	Std. Err.	T	P>t	[95% Conf. Interval]	
<b>Lack of resource &amp; community participation</b>	.0501624	.1787613	0.280	0.224	-.3042882	.404613
<b>Relationship of beneficiaries &amp; service providers</b>	.0314092.	.0984709	0.32	0.245	-.1638405	.2266589
<b>CCCs Coordination problem</b>	.0138753	.457651	0.10	0.187	-.2751499	.3029005
<b>Absence of training to CCC volunteers</b>	.0117109	.2973523	0.053	0.231	-.7467046	.4324847
<b>Constant</b>	3.611737	1.812128	1.99	0.049	.018623	7.204852

**Predictor variables:** Lack of resource & community participation, relationship of service beneficiaries and providers, CCCs coordination problem, absence of training to volunteers.

**Criterion variables:** Overall beneficiaries Satisfaction

Supporting to this finding, literatures indicate care and support programs which run by volunteers could be affected its success, quality service and beneficiaries satisfaction through the type and nature of training given to volunteers. Beside this, to see if there was effect of the above variables on beneficiaries group type satisfaction and the computed T test revealed that there is no significant difference between the two groups for all the variables since t test is found to be greater than the  $P > 0.05$  under 95% confidence interval.

In addition to this, to identify additional hindering factors beneficiaries were also asked if they have complain and grievance with the specific group functioning of the general CCCs structure. The correlation coefficients showed  $r = -0.1448$  which means the CCCs specific group functioning negatively affected beneficiaries overall service satisfaction. Beside this, the two sample T- test indicate there is significant difference between the two types of service beneficiaries with regard to specific group functioning for,  $T = 0.0236$ ,  $P < 0.05$  with 95% of CI. In other words, beneficiaries receiving PSS show better satisfaction level with the specific functioning of their respective CCC group than do beneficiaries without receiving PSS.

Moreover, both service beneficiaries types also rate their satisfaction negatively ( $r = -0.11$ ) as the CCC coordinators are less supportive and collaborative. Beside this, participants feel difficulty even to explain complains about the service to the CCC coordinators. The two sample t test revealed being receiving PSS or not has not effect on improving the beneficiaries satisfaction on the CCC coordinators support, help and collaboration as  $T = 0.2430$ ,  $P > 0.05$ . The finding from the key informant interview and FGD

participants was also supporting the above result as they have complained on the specific group functioning of the CCC. One key informant says:

In most cases they are serving us in good way, but I have seen a problem in specific division of labor. All of them want to engage in one activity at the same time and sometimes some of the activities remain uncovered. This is the result of problem in specific group functioning; they must work as group than as an individual (key informant, 2013).

Beside this to see if the volunteers' skill and knowledge efficiency could influence the success and effectiveness of the service provision process; linear regression was computed to the beneficiaries' response and it showed that, problems associated with volunteers' skill and knowledge efficiency during service provision time negatively affect to the success and effectiveness of the service provision. These in turn affect the service satisfaction of the beneficiaries for,  $t = 0.200$ ,  $P < 0.05$ . Means, the existing skill and knowledge efficiency problem of volunteer to provide the necessary service lowered the beneficiaries' service satisfaction level. This result also supported by both types of beneficiaries as the t test indicate there is no significant effect between beneficiary groups for,  $T = 0.6761$ ,  $P > 0.05$ . Means both the two types of beneficiaries complained about the volunteers' skill and knowledge efficiency to offer the necessary care and support.

As recommended by the participants of this study, ensuring strong community participation, effective structural coordination, using available and local resources effectively, providing appropriate training to volunteers and building positive and trusting relationship between beneficiaries and service providers are forwarded as mitigating ways to the identified problems. In addition, as the participants' forward, appropriate division of

labor among volunteers and working in a coordinated ways could solve the observed problems. The coordinators should work at grassroots to the beneficiary level.

Moreover, they said, volunteers should be given incentives so that they felt motivated to carry on with their work. Service provision guiding manuals and other supportive resources should be accessible to the volunteers. The government should given special emphases to such community based care and support programs and separate government structure must be established. The programs must be focused on beneficiaries' empowerment and it should be sustainable.

## CHAPTER FIVE: DISCUSSION OF MAJOR FINDINGS

In this section of the study, the research findings are presented in relation to relevant findings of previous researches in the area specifically related to care and support to PLWHA and the role of community and home based supports are discussed. However, it should be noted that there is limited literature related to community care coalition and provision of psychosocial support for PLWHA and their families. Moreover, major findings of this study are presented in the previous chapter. Here, the findings are analyzed and discussed against the local and international literature in accordance with the sub-topics cascaded in the literature and finding part of the study.

### **Psychosocial Support for PLWHA and Their Families**

As Katherine (2010) indicates, being infected by HIV/AIDS affects many aspects of people lives and the goal of psychosocial support is to focus on the physical, psychological, social and spiritual well-being. In this study the findings also revealed that psychosocial support is meant to enable both those infected and their caregivers to be able to cope with their status, helping them to make informed decisions, cope better with illness and deal more with stigma and discrimination. People living with HIV/AIDS, their families and care givers need holistic care and support so that they can effectively deal with their emotional and psychological problems. They need the society to look after them and the community should be ready to play this significant and central role.

The current study shows that there was a statistically significant correlation between provision of psychosocial support as one component of service package within the CCC and overall beneficiaries' service satisfaction. In other words, beneficiaries receiving PSS showed strong service satisfaction as compared to beneficiaries without receiving PSS.

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

However, this does not mean that, beneficiaries without receiving PSS do not want psychosocial support as separate service. This means, even though beneficiaries without psychosocial support showed low service satisfaction, they have high demand for the inclusion of PSS in their service package.

This result was consistent with the findings of Malale (2011) who posited that PLWHA, families and their care givers receiving psychological and social support tends to show better self confidence, good self image, use appropriate coping style and could show better satisfaction in the care and support they receive than do PLWHA and their families without receiving psychosocial support. This is also confirms with the findings of World Health Organization (2010), provision of psychosocial supports in home and community based supports address the on-going concerns and social problems of HIV/AIDS infected individuals, their partners and caregivers.

On the other hand, the current study showed statistically significance difference on the role of CCC in improving the quality life of the two beneficiary groups. In case of this study, the two types of beneficiaries were presented with similar question if the role of community care collation care and support service improved their life. The t test result depicts beneficiaries receiving PSS had benefited more and have positive attitude as their quality life is improved with the help of CCCs. This finding supports the study of Ilebani and Fabusoro conducted in Nigeria (2011). According to their study, PLWHA and their care givers receiving holistic support including PSS form community based support improved their quality life than PLWHA without receiving psychological and social support. In other words, PLWHA without psychological and social support increase their vulnerability to stigma and discrimination with poor coping style which in turn affects their quality of life.

As indicated by WHO (2010), many families of PLWHA face stigma and discrimination because of their situation. Similarly, families of these infected people should also include in the designed service package. In this study attempts were also made to see whether families of the infected people are included in the service package and if their demand is fully recognized. The result indicates that majority families of the infected people are included in the service package but this result fail to support the idea. Hence the designed service package never fully satisfies their demand. In other words, the current care and support is only targeting at the demand of the infected persons. This finding is congruent with the result of World Vision (2005) in such a way that ideally HIV/AIDS care and support should focus on the most needy within the community including care givers but there are often difficulties identifying and accessing those who need the support and only inclined to the infected ones.

#### **Types and Dimensions of Services Provision by CCCs**

Literature findings about the types of care and support to people living with HIV/AIDS and their families are inconsistent. The vast literature identifies material, nutritional, social, medical and psychological supports as main care and support dimensions. As previous work of Mutombo & Namuunda (2007) indicated, out of the major care and support types to PLWHA and their families, psychosocial support is found to be the most essential. Similarly, the mean score of beneficiaries in this study showed there is strong demand of beneficiaries; if psychosocial support is given as a separate care and support package within CCCs. Besides, the service beneficiaries level of satisfaction also show variation in the absence and presence of PSS as one service benefit package since the

two sample t test indicate there is significant difference between the two groups of beneficiaries.

As part of this, beneficiaries overall satisfaction in line with service design in their respective CCC group was analyzed to find out if there was significant difference among them. It was revealed that there was no significant effect of satisfaction in the overall care and support design by CCCs. This finding is in contrast with the work of Germann et al. (2009) in such a way that service beneficiaries with psychological and social support show better satisfaction and feel sense of ownership in the service design than beneficiaries without psychological and social support in their major service package. This may be due to differences in methods, specificity, tools and objectives of the study.

As indicated by Cynthia (2010), every helping profession and program should instigate feeling of ownership and responsibility in the name of the individual to identify needs imposed on him/her and to take action toward change. As one way analysis of variance in this study indicates, the current program has limited role in empowering the beneficiaries and the available service only focus on immediate need of the beneficiaries. However, this result is not supported by the key informant and FGD participants since the collected data from these participants revealed that as there is some means of empowerment strategies like a loan free of interest. This variation may be due to problems of the survey participants to understand the tools (questions).

Participation of beneficiaries in the initial service designing package was analyzed if beneficiaries were participated and contributed to it. The collected data from survey respondents, key informant and FGD participants showed that they had limited or no participation in the initial service designing process. As a result of this, their satisfaction

with regard to participation in service designing is found to be very low. This is consistent with Malale (2011) who stated that care and support programs designed without active participation of beneficiaries usually end up with less beneficiaries service satisfaction. The poor performance of CCCs on beneficiaries' empowerment could be also best explained from the low beneficiaries' participation in the initial service designing. Supporting to this, Nturibi (2011) notes, in order to empower and provide comprehensive service to PLWHA and their care givers, program leaders should encourage the participation of service beneficiaries in the initial design. This is also consistent with the study of Folami & Katim (for n.d.), involved people living with HIV/AIDS in decision-making activities to create a feeling of ownership and to help them act as important component of the community. They should also feel and realize that, the society does not prejudice or undermine their capabilities. According to them, empowerment of PLWHA and their families is central to reduce stigma and discrimination.

Generally, beneficiaries showed positive satisfaction with material, medical and physical supports. However, despite its relevance the importance of psychosocial support is less emphasized in the care and support package which brings low beneficiaries service satisfaction. This is particularly true for the beneficiary group without receiving PSS

### **Ensuring Home and Community Based Care as Guiding Principle of PSS**

Relying mainly on the community care coalition as caregivers have become a significant contribution in the treatment, care and support of those infected and affected by HIV/AIDS. In providing home and community based care and support, the role of CCC volunteers is second to none. Results indicate that the nature of the CCC care and support depends on the inclusiveness and effectiveness of the initial community mobilization

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

efforts and volunteers participation. As indicated by Germann et al. (2009), good community mobilization process in the beginning is critical for future ownership; understanding of community and home based care and support . Further, it was discovered that CCCs with a more diverse membership volunteers tended to show better care and support services in the beneficiaries side.

Given that the volunteers themselves see service users as being the primary beneficiaries of their volunteering; it is important to have and obtain the perspective of service users as to the impact of volunteering. This was achieved mainly through a survey sent to service beneficiaries having contact with volunteers. Additionally, questions were asked relating to the impact of volunteers on beneficiaries satisfaction to the key informant participants and FGD respondents. The result indicates, volunteers' sense of work commitment, help and support found to be crucial for the success of ensuring home and community based care. As the two sample T test indicates there was no effect of receiving PSS or not in appreciating the value and contribution of volunteers to the success of the program between the two beneficiary groups. Despite one key informant participant from the beneficiaries without PSS claim about this, all the qualitative data also support this result.

As indicated by U.S. Department of Health and Human Services (2005) volunteers are necessary and extremely helpful for a healthy community development. Volunteers fill a key role in running organizations, handling day-to-day tasks, and raising funds. Many home and community based managing organizations realize the contribution, sense of work commitment and support of volunteers is beyond mere pivotal to their success.

Even though service users appreciate the support provided, the commitment and involvement of volunteers in the service provision time, they also commented on the volunteers' skill and knowledge efficiency. The skill, knowledge and efficiency of volunteers affect the beneficiaries' services satisfaction level. Both the qualitative and quantitative data revealed that, the existing skill and knowledge efficiency of volunteers is not enough to provide the necessary service. This is also congruent with Mohammad & Gikonyo (2005) in such way that, placement of volunteers in some positions of voluntary works needs special skill and knowledge efficiency trainings which in turn affect service users' satisfaction and quality of service provision.

Relationship between service beneficiaries and volunteers as determinant factor for satisfaction and quality of service provision was also analyzed. It was found that, beneficiaries feel comfort to explain their discomfort and grievances to volunteers than to CCCs coordinators. The correlation coefficient also indicates there is strong relationship ( $r=0.85$ ) between volunteers and service users as compared to the relationship of beneficiaries and coordinators( $r=0.0089$ ). Beside this the current study depicts, using the existing positive relationship; volunteers feel at ease to ask feedback from beneficiaries about the nature of service provision. This went in line with Mohammad & Gikonyo (2005), due to the frequent contact between volunteers and service users; beneficiaries usually feel comfort to have good relation with volunteers and can explain their claims than do with coordinators. Moreover, these writers exposed, in most cases unlike volunteers who are behavior oriented; coordinators are task oriented.

### **Factors Affecting Provision of PSS and Mitigating Ways**

Care and support programs run by community participation in general and the community care coalition in particular are influenced by many factors. As documented literatures depict much of the care for people living with HIV/AIDS is provided at home by immediate family and friends, as well as by home based care organizations. Providing care for people with HIV/AIDS at home level has many potential benefits for both infected and affected people, yet there are many gaps in the support given to the beneficiaries. Research evidence clearly demonstrates that, most people would rather be cared at home and that effective home care improves the quality of life for infected people, their family and caregivers. As indicated by Nturibi (2011), providing comprehensive and holistic care to PLWHA and their family could be influenced by strong community participation, availability of materials, coordination effectiveness and the existing relationship.

In the current study, lack of community participation, limited access of resources, lack of training materials, coordination problem and lack of trainings to volunteers are found to be the major factors negatively influencing the care and support program and provision of psychosocial support. The multiple regressions indicate; coordination problem is the best predictor followed by lack of resources and community participation to the success or failure of service provision in the selected CCCs. This is especially true to the beneficiary group without receiving psychosocial support.

The study by Folami & Katim (for n.d.) revealed that, community involvement and ownership are critical for community and home based care sustainability. Beside this, lack of supportive training to volunteers affects the quality of service provision. This also supported by U.S. Department of Health and Human Services (2005) as it reported that,

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

realizing effective home and community based support is consolidated by providing appropriate supportive trainings to volunteers.

The relationship between service providers (volunteers, coordinators) and service beneficiaries' also identified as one major factor that affect quality of service provision and beneficiaries service satisfaction. In other words, beneficiaries who have positive relationship with volunteers and coordinators tend to show strong satisfaction in the service provision than do beneficiaries who have poor relationship and the vice versa is true. This is supported by Mohammad & Gikonyo (2005), in such a way that, in the absence of positive and trusting relationship between service beneficiaries and providers; it is quite difficult to think of effective service provision. This went in line with work of Laura and Canaan (2009) as their work indicates, community and home based care provider organizations having positive relationship between service users and providers showed better quality services provision and receive positive feedback from their beneficiaries.

Division of labor between volunteers and group functioning are found to be determinant factors for the quality of service provision. As the data from participants revealed there is no clear division of labor between volunteers and this is the result of poor group functioning. As result of this all the necessary services including PSS are not given to the beneficiaries. Absence of supportive trainings to volunteers narrows the chance of providing comprehensive service to beneficiaries. This is congruent with report of U.S. Department of Health and Human Services (2005) on volunteers training and recruitment process. This report says, volunteers working for community and home based care should be supported and updated with various skill oriented training.

**Identified Mitigating Ways**

Strong community mobilization, effective use of local resources, providing appropriate training to volunteers, division of labor among home visitors and coordinators and accessing service provision guiding manuals are forwarded as mitigating ways to the problem. The participants also, recommend establishing separate government structure that totally committed and dedicated to the implementation of CCCs is more than important. Besides, according to the participants establishing positive and trusting relationship between services beneficiaries and service providers is more than requirement for the successful provision of care and support within CCCs.

As per the participants, in order to provide holistic and comprehensive service within all CCCs; the volunteers should be given appropriate training and should be given with positive rewards. The participant pinpoint one idea with regard to sustainability of the program and say the care and support should be sustainable and focused on long term empowerment. Moreover, the participants forward their recommendation to community care coalition coordinators to improve their relationship with beneficiaries and they must work deep to the beneficiary level.

According to them, if there is good coordination it is possible to provide multidimensional service. The community should be aware and involved in such kind of community based supports; because many component of the support is come from the community. According to the participants, if the community is fully engaged as owner of the program, the service provision efficiency and effectiveness will be improved unless any development that has limited room for community participation is ended up with failure.

## CHAPTER SIX: SUMMARY, CONCLUSIONS AND SOCIAL WORK IMPLICATIONS

### Summary

The tenet of the study was to assess the role of community care coalition in providing psychosocial support to people infected and affected by HIV/AIDS in two selected *Woredas* of Mekelle City. There are many situations that call for the study to be conducted. Most care and support programs targeting this population focus on material, medical and economical components. Despite its relevance the importance of psychosocial support is underestimated and excluded as part of the service provision system. People infected by HIV/AIDS and their care givers are exposed to various states of psychological, emotional and moral stresses which in turn disequilibrium their physiological homeostasis and amplify their biological disease .

It is widely accepted that HIV/AIDS affects various aspects of individual life. Persons infected by HIV/AIDS and their families need multidimensional services and much of the services that they received come from immediate relatives, volunteers, home and community based supports. As vast literature indicates, home and community based support plays vital role in providing door to door services to this population. As per to this study, the main service and support is given by groups of volunteer individuals named as community care coalition (CCCs). The CCCs are selected from two separate districts, as the one group was with the experience of providing PSS and the other one is without providing PSS.

The relevant data for this study were collected from the beneficiaries of the two CCCs. To consolidate the data collected from beneficiaries, coordinators of the two community care coalitions and officials from the regional HIV/AIDS prevention and control

## ASSESSING THE ROLE OF COMMUNITY CARE COALITION

office have also participated. Depending on its relevance, other secondary data like documents were also used. To have comprehensive data, both qualitative and quantitative tools were used and the qualitative data were analyzed thematically on their similarity and relationship and the quantitative data was analyzed both using descriptive and inferential statistics.

In this study, material support (stationery to children, uniform, blankets and house maintenance materials), physical support (maintaining house), medical and economical supports are identified to be the main care and support dimensions. In a very limited and unstructured way psychosocial support was given in one of the selected CCC. The results of the study revealed that there was a significant effect of beneficiaries' satisfaction in the absence and presence of psychosocial support with the service package as one separate program. In other words, even though beneficiaries never show difference with the overall service design, beneficiaries receiving PSS as one separate care and support package show better service satisfaction than beneficiaries without receiving PSS. Moreover, beneficiaries with PSS believed the role of CCCs is crucial in improving their life than beneficiaries without PSS. However, this does not mean that beneficiaries without PSS never benefited from community care coalition care and support.

In addition, volunteers' commitment, collaboration and help were more sounded by beneficiaries than to the CCC coordinators. The volunteers' commitment, work engagement and support are found to be essential for the success of the CCC care and support. Beneficiaries were also felt at ease to explain their complaint and to provide feedback to volunteers more than to coordinators. The other major finding of this study revealed that beneficiaries receiving PSS have better relationship with volunteers and coordinators than

beneficiaries without PSS. This implies that provision of PSS improves the relationship between service providers and service beneficiaries’.

On the other hand, lack of community participation, lack of training to volunteers, relationship between service providers and receivers, lack of coordination, lack of resources, training and service provision manuals and lack of division of labor and separate government structure (poor attention from government) are found to be the most influential factors for the failure of care and support provision within CCCs. In addition, lack of beneficiaries’ participation in the initial service designing and poor beneficiaries’ empowerment approach were also identified as major problems of CCC programs.

### **Conclusion**

Despite widespread recognition of the need of the CCC service beneficiaries to receive psychosocial support, in reality the CCCs designed interventions program continue to focus on material, physical, medical and economical support to meet the physical needs of PLWHA, families and their caregivers. Such supports are crucial but it must be accompanied by effective psychosocial support initiatives. In the selected two CCCs only a very small proportion of PLWHA and their caregivers reported having received some sort of psychosocial support. It was also discovered that provision of PSS to beneficiaries improves their satisfaction in the given services. The existence of PSS as one separate care and support package improves the level of communication between service beneficiaries and providers.

The focus group discussions, key informant interviews and survey data clearly indicate that the biggest obstacles to providing psychosocial support were coordination problem, lack of community participation and shortage of resources, lack of training to

volunteers, poor relationship between beneficiaries and providers. The volunteers in the two selected CCCs were reported having received no formal training on how to provide service and give advice and support to beneficiaries in the best way they could. As a matter of fact, skill and knowledge efficiency problems were found as major bottleneck to the quality of service provision. Besides, lack of participation by beneficiaries during the initial service design leads the beneficiaries to have low service satisfaction. The current service package has also limited room to empower beneficiaries.

As per the participants, working on areas of community mobilization, establishing separate governmental structure that improve the identified coordination problem, effective utilization of existing resources, providing appropriate trainings to volunteers and accessing guiding materials like manuals are forward as means of solving the problems. In addition, improving the relationship of service providers and receivers, encouraging beneficiaries' participation and consulting them in the initial service designing are also mentioned. Last but not least as the participants say, the program should focus on beneficiaries' long term empowerment than short and immediate supports.

### **Social Work Implications**

Based on the above conclusions the following social work implications are forwarded.

- While medical, economical and material needs of the PLWHA and their families are being addressed by the CCCs care and support programs, yet PSS as the most important aspect of their need is not being met. Therefore, once if PLWHA and their families have been identified as being in need of psychological and social support,

there should be provision of the service in such a way as to enhance adaptive coping strategies and the management of difficulties.

- In this study the provision of PSS as one separate care and support package improved the service satisfaction level and relationship of service beneficiaries and providers. Therefore, community care coalition program developers should incorporate PSS as one independent care and support program package.
- Families and caregivers of the infected people are found to be included in the service package. However, the components of care and support program never address their need. Since they are also victim of the problem; the care and support program should equally address their need too.
- The current program of CCCs has limited room to the empowerment of the beneficiaries'. As the literature indicates, empowerment is the best way to bring about productive change in the client side. Therefore, it is clear that the current program does not empower the beneficiaries as much as needed and that there has to be a role for stakeholders to ensure that this gap is filled.
- Poor beneficiaries' participation in developing the service package is found as one factor for low beneficiaries' service satisfaction. Beneficiaries' participation is the backbone of effective helping profession and must consider their contribution in all phases. Hence, the CCC coordinators and program developers should consult and encourage service beneficiaries to participate in the initial service designing stage.
- Care and support programs run by volunteers and group of individuals have invaluable contribution in helping PLWHA and their families. But, these helping

groups should be given with appropriate trainings and supports to provide their help effectively. Results in this study indicated volunteers' knowledge and skill efficiency problem is one factor for poor service provision.

- Results in this study showed that, coordination problem, lack of community participation and resources are found to be the best predictors of the poor service provision and low beneficiaries satisfaction level. In the absence of effective coordination and strong community involvement; realizing and providing community and home based support is unthinkable. Therefore, the *Woreda* HAPCO and bureau of social and labor affairs should work hard to establishing separate government structure that totally dedicated for CCCs coordination. Strong community mobilization works should be done at grass root level.
- As the result of this study indicates, beneficiary group having positive relationship with service providers tends to show better service satisfaction. So, hence this variable is found to be another determinant factor for provision of quality service and beneficiaries' service satisfaction, the CCC coordinators and volunteers should establish positive and trusting relationship with their service beneficiaries.
- Effective group function is a pre request for appropriate division of work among members of the volunteers. So, to provide comprehensive and holistic service to the beneficiaries and coordinators and volunteers should work as group. The concerned bodies should organize and reward these groups, so that they feel recognized. The government should pay special attention to the importance of such community and home based care and support programs.

**Implication to Social Work Education**

In course of their field education social work students could be placed in organization working for PLWHA and their families like CCCs. Hence, social workers should value and learn the importance of psychosocial support for vulnerable members of the society and its way of delivery.

**Implication to Social Work Practice**

Social work is a helping profession in which it works for social change, empowerment, problem solving and liberation of people. So, this paper gives an insight for social workers how to work with minority group like PLWHA and their families. Social workers are expected to be aware of the importance of cultural competency and establishing trusting relationship during work with diverse group. Lack of training to volunteers was one problem in these CCC; social workers should move one step forward to provide training to these volunteers on relevant areas.

**Implication to Social Work Research**

So far there are very few or no research outlets directly linked to the role of community care coalition in helping PLWHA and their families. This research could not be addressed all issues about CCCs and their role in addressing PLWHA need. Therefore, social workers should undertake researches on areas of importance of psychosocial support, how the families of the PLWHA react about the current service in CCCs, how the volunteers rate their care and support service and how the involvement of community could foster the service provision process.

**Implication to Social Work Policy**

The issue of PLWHA and their families' has been a concern of the Federal Ministry of Health, Regional Health Bureaus and HAPCO offices at all levels. More specifically, community care coalition coordinators are the immediate responsible bodies in developing rules and regulations. This research result indicates PSS is an important component of care and support for these targeted groups. Therefore, the policy makers, service developers and other concerned bodies should pay special attention to the importance of PSS. So, social workers should also lobby and advocate for the inclusion of PSS as one separate care and support package during their practice.

**Implication to Community Service**

Finding of this study revealed lack of community participation was one of the most determinant factors for the quality and success of the program. In providing community and home based care and support program, the role of community participation is far more than essential. So, social workers should participate in providing trainings and direct community services to strengthen the CCCs care and support service. Social workers should work on awareness raising and community mobilization strategies to increase the efficiency and effectiveness of the CCCs services.

## References

- American Psychiatric Association. *Diagnostic and statistical manual of mental disorders (4th Ed.) Revised*. Washington, D.C.: American Psychiatric Association, 2000.
- Amroffell, L., & Cnaan, R. (2009). Mapping volunteer activity: Nonprofit and Voluntary Sector Quarterly Winter 19 (23) ISBN 4 335-351
- Anne D. S. (2010). *Benefits of mixed methods in environmental reporting research*: Lincoln University, Commerce Building.
- Binega Haileselassie & Molla Haftu.(2011). Social, child protection and psychosocial Support: *Unpublished training manual*, Mekelle University Mekelle.
- Brannen, J. (2005). Mixed methods research: A discussion paper: *NCRM methods review papers*, ESRC National Centre for Research Methods.
- Bravo, P., Costello, T., & Boland, R. (2010). Tough decisions faced by people living with HIV/AIDS: A literature review of psychosocial problems. *AIDS reviews*, 12, 76-88.
- Brhanu Weldie. (2009). The relationship and effects of prejudice, states of de-individuation and aggression with and on conflict among groups of fans of the big four of the English premier league: *Unpublished thesis*, Addis Ababa University.
- Burns, S. N., & Grove, S.K. (2007). *Understanding nursing research: Building evidence-Based Practice ( 4<sup>th</sup> Ed)*. Saunders Elsevier: St. Louis.
- Cannon, C. (2010). *Handbook of HIV/AIDS and social work: Principles, practice, and populations*; Published by John Wiley & Sons, Inc., Hoboken, New Jersey
- Crossman, A. (2009). *Stratified sampling method*. Retrieved on March 2012 from Experiment Resources: <http://www.Experiment-Resources.com/stratified-sampling.html>.

- Dawit Tatek.(2006). Review and evaluation of the care and support of Mekidiem Ethiopia association for persons living with HIV/AIDS and their family: *Unpublished thesis*, A.A.U. Addis Ababa.
- Escalada, M., & Heong, K.L. (2009). Guide line how to conduct focus group discussion: *Guide line manual for novice researchers*.
- Family Health International. (2001). Care for orphan, children affected by HIV/AIDS/AIDS and other vulnerable children: A Strategic Frame Work; Wilson Boulevard, Suite 700 Arlington: AV 22201.
- Family Health International. (2004). Monitoring and evaluating community home –based care programs: *Facilitators training guide*, A USAID resource for prevention, care and treatment.
- Germann, S., Ngoma, F., Wamimbi, R., Ann, C., & Gaudrault, M. (2009). Mobilizing and strengthening community led childcare through community care groups and coalitions. *International NGO Journal*, 4 (1), 001-006: Lusaka Zambia.
- Glaser, E.(2010). *Strategies for integrating psychosocial support interventions in to HIV/AIDS prevention, care and treatment services*: Pediatric AIDS Foundation, USA.
- Harris F., & Touray, K. (for n.d.). *Situational analysis of people living with HIV/AIDS/AIDS and their support institutions in Gambia*: United Nations Development Programme; Banjul, The Gambia
- Helena Getenet, Abraham Haileamlak & Ayalew Tegegn.(2008). Clients' satisfaction with anti retroviral therapy services at Jimma University Specialized Hospital: *Ethiopia journal of health science*, 18 (3).

- HIV/AIDS/AIDS Prevention and Control Office. (2007). *The policy and legal framework protecting the rights of women and girls in Ethiopia: Reducing their Vulnerability to HIV/AIDS/AIDS*.
- HIV/AIDS/AIDS Prevention and Control Office. (2009). *HIV/AIDS behavior change communication framework (Ethiopia): Federal HIV/AIDS/AIDS Prevention and Control Office*.
- Ilebani, A., & Fabusoro, E. (2011). Effects of community-based care for people living with HIV/AIDS on Their Well-Being in Benue State, Nigeria: *Research journal of medical sciences, 5, 294-304*
- Jessica, M. U, & Robert, F. H. (2006). *Statistical ideas and methods: Sample size determination concept*. Thomson Learning Academic Center 1-800-423-0563
- Joseph, A. G., & Rosemary, R. G. (2003). *Calculating, interpreting, and reporting Cronbach's alpha reliability coefficient for Likert-type scales: Midwest Research to Practice Conference in adult, continuing, and community education*
- Kassaw Asmare. (2006). The need to strengthen the link between formal and informal community care givers for AIDS orphans: *Unpublished thesis A.A.U. Addis Ababa*.
- Kennedy, C. E., Medley, A.M., Michael, D. S., & Kevin, R O'R. (2010). The effects of HIV/AIDS positive prevention behavioral intervention in developing countries: A systematic review and meta analysis: *Bulletin of the World Health Organization, United States of America*.
- Kerns, I. (2005). *How to develop effective customer satisfaction survey: Guide Star Research Center White Paper*.

- Kija, M. (2011). *Home based care for people living with HIV/AIDS/AIDS: Assessment of Knowledge, Attitude and Practice among Family Care Givers at Ukonga ward in Ilala District.*
- Lesyna, K. (2010). A review of psychosocial support and the challenges faced in disclosing HIV/AIDS positive status to children in Kibera: *Independent Study Project (ISP) Collection Paper 965.*
- Letamo, G. (2011). *Social and psychological aspects of HIV/AIDS/AIDS and their ramification: Department of Obstetrics and Gynecology University of Ilorin Teaching Hospital, Ilorin Nigeria, ISBN 978-953-307-640-9.*
- Mezegabu Zemene. (2007). Psychosocial problems of AIDS orphans: *Unpublished thesis* A.A.U. Addis Ababa.
- Morgan, D. (2009). *Research tools: Participants determination for focus group discussion: Qualitative Research.* Sage, UK.
- Mutombo, H., & Namuunda, J. (2007). Care and support services for people living in Zambia: *Population Review, 46 (1), Published by population review publications DOI: 10.1353/prv.2007.0005.*
- Nadeem, M. ,& Juliet, G. (2005). *Operational challenges of community home based care (CHBC) for PLWHA in multi-country HIV/AIDS/AIDS programs (MAP) for Sub-Saharan Africa: AIDS Campaign Team for Africa (ACTAfrica).*
- National AIDS/STD Control Program Ministry of Health. (2002). National home based care Program and service guidelines for people living with HIV/AIDS/AIDS: *Population survey; Nairobi Kenya.*

Nturibi, D. (2011). *Community empowerment in HIV/AIDS/AIDS prevention: A Case Study of the Integrated Community Care and Support Project in Kenya.*

Robert, K.V., & Daryle, M .W. (1970, Version V). *Determining sample size for research activities*: University of Minnesota, Duluth & Texas A. & M. University.

The Psychosocial Working Group. (2003). *Psychosocial intervention in complex emergencies: A conceptual framework*: The Psychosocial Working Group Centre for International Health Studies Queen Margaret University College, Edinburgh Edinburgh EH12 8TS, United Kingdom.

Tuckett, A. (2005) Rigor in qualitative research: complexities and solutions, *Nurse Researcher* 13 (1) 29-42

U.S. Department of Health and Human Services. (2005). *Successful strategies for recruiting, training, and utilizing volunteers: A Guide for Faith- and Community-Based Service Providers; DHHS Publication No. (SMA) 05-4005,*

United Nations AIDS International Development & WHO. (2008). *Essential prevention and care interventions for adults and adolescents living with HIV/AIDS: Under difficult Circumstances working guideline.*

United Nations High Commissioner for Human Right and the Joint United Nations Programme On HIV/AIDS. (2006). *International guideline on HIV/AIDS/AIDS and human right consolidated version*, Geneva.

United Nations International Children Emergency Fund. (2008). *Psychosocial vulnerability and resilience measures for national-level monitoring of orphans and other vulnerable children: Recommendations for Revision of the UNICEF Psychological Indicator*

- United Nations International Children Emergency Fund. (2010). Providing care and support for orphaned and vulnerable children: *Working document*
- United Nations International Children's Emergency Fund; Joint United Nations Programme. (2004). The frame work for the protection, care and support of orphans and vulnerable children living in the world with HIV/AIDS/AIDS: *Synergy project*, Washington D.C.
- United States Agency for International Development. (2000). *HIV/AIDS/AIDS care and support projects: Using behavioral change communication techniques: Handbook* developed by the AIDSCAP Behavior Change Communication Unit.
- World Health Organization Joint United Nations Programme on HIV/AIDS/AIDS. (2000). Key elements HIV/AIDS/AIDS care and support: *Working draft document*.
- World Health Organization. (2004). Policy statement on HIV/AIDS testing and counseling in health facilities for refugees, internally displaced persons and other persons of concern to UNHCR: UNHCR – *Public health and HIV/AIDS section report* CP 2500 1202 Geneva, Switzerland.
- World Health Organization. (2008). *Essential prevention and care interventions for adults and adolescents living with HIV/AIDS in resource limited settings: Legal Published Book*.
- World Health Organization. (2010). Psychosocial support and home and community based supports: *Guideline to practitioners legal published manual*.
- World Vision. (2005). *Monitoring progress towards the UN declaration of commitment on HIV/AIDS/AIDS: Action for Orphans and Vulnerable Children in Africa: World Vision*  
UK Opal Drive Fox Milne
- Yin, R.K. (2003). *Case study research: Design and methods*. (3rd ed.). USA, California: Sage publication, Inc.

# Appendices

## **Appendices A**

Consent Statements  
Addis Ababa University  
School of Social Work

Date \_\_\_\_\_

Time \_\_\_\_\_

Venue \_\_\_\_\_

### **Consent Statements**

#### **Introduction**

My name is \_\_\_\_\_. I am a masters student at AAU school of social work and currently working my thesis entitled "*Assessing the Role of Community Care Collation In Providing Psychosocial Support for HIV/AIDS Infected and Affected People*". The purpose of this study is to assess the role of CCC in providing care and support to PLWHA and their families and how these people are benefited from such home and community based supports. Therefore, it is your cooperation that helps the researcher to accomplish the research objectives. So, I am kindly requesting you to share your experience and knowledge about CCCs. In the course of our discussion I will asked you about your personal information like age, marital status, family condition and duration of membership.

#### ***Confidentiality***

I want to assured you that, the information you will share me, will be kept confidential and will be used only for educational purpose. Of course, because of your privacy, your personal information will be kept in personal information folder and it will be destroyed ones the research completed. You have also the right to refuse not to participate in the research; you have full right to quite your participation at any time without any precondition if you feel discomfort. You are not forced to make any kind of contractual agreement that will abide you to stay till the end of the discussion. The interview will take approximately 40 minutes to 1 hour of your time. The interview place will be done on a convenient palace for you. If you are voluntary to participate in this research, the information you will provide will be recorded in tape.

### *Expected Benefits*

The finding of this study will be presented and reported to the school of social work AAU but your name is not mentioned and instead of your name we are going to use pseudo name. If the research is successfully accomplished, it paves the way to improve the service facility in the CCCs, the coordinators and volunteers will receive feed back of their work and this will help to strengths such kind of home and community based supports in the near future. As compensation to your time and transportation, I will give you 40 birr as transportation allowance and you will have health break refreshment while the discussion is going on.

### *Expected Risks*

Being you are participating in this research will not affect you status in the service provision and the coordinators are also informed about your participation. May be during our discussion we could raise previous experiences that induce you stress and anxiety so, you could take time and refresh yourself and we could continue our discussion after that.

So, are you voluntary to participate in this study?

Yes \_\_\_\_\_

NO \_\_\_\_\_

Thank you very much for your participation.

## Section I: Interview Guiding Items for Key informants of Service Beneficiaries

### Personal Profile

1. Age\_\_\_\_\_
2. Sex\_\_\_\_\_ Level Of education \_\_\_\_\_
3. Duration of Membership in CCCs\_\_\_\_\_
4. Service Beneficiary situation, at Infected\_\_\_\_, Affected level\_\_\_\_\_

### II. Main Questions (Interview Guiding Questions)

1. What kinds of services have you obtained from the CCCs (probe nature and dimension of service)?
2. Do you think the service you have received is sufficient?(Probe, their reaction)
3. Do you have received psychological and social counseling from CCCs?
4. Do your families members are beneficiaries of the CCCs service?
5. Do you think that the designed service by CCCs is according to your demand? (Probe what do you recommend to be added)?
6. What do want to add about the service given by CCCs?

### Section II: Interview Guiding Items for CCCs Coordinators

1. What are the major cares and support services offer to your service beneficiaries? (Probe, to psychosocial, medical, economical...)
2. Do the family of the infected people also include in your service provision?
3. How do you understand the reaction of service beneficiaries about your service? (Probe, means of feedback collection, what are the *major challenges* so far in service delivery)?
4. Do you think the service beneficiaries consider your support comprehensive enough?
5. What kind of support do you want to add to strengthen your service to the targeted population?(probe what seems the plan of the centers to widen the dimension of service)
6. Have you ever provide training to your members(volunteers) with regard to service delivery skill?(Probe to...psychosocial support training)
7. What points do you what to add regarding to this issue?

**III: Focus Group Discussion Guiding Items for CCCs Service beneficiaries**

1. What kinds of services do you have received so far from CCCs?
2. How do you express your complain about the quality of services given by CCC voluntary groups?
3. How do you explain your satisfaction about the current service?(Probe, what about your families)
4. What major challenges have you identified in providing PSS and other services?
5. How this service is important to you and your family's life?(Probe, what kind of service are you recommend to be added in the current service)
6. What points do you want to add?

**IV: Interview Guiding Items for RHAPCO Official**

1. What seems your relationship with CCCs?(probe, Have you ever visit them in practice, do you have regular meeting and what seems your means of communication)
2. What kind of supports your office have been provide to the CCCs to strengthen their service Provision?(Probe, technical, material, training....etc)
3. Do you think these CCCs are providing essential care and support for PLWHA?(probe, What do you think the main need of these targeted group, what are the components of effective care and support for PLWHA)?
4. What future plan can we expect from your office to support these CCCs?
5. What major problems have you notice with the service provision of CCCs?

## Appendix B

### CCC Service Beneficiaries Satisfaction Assessment Tool

This assessment tool is designed to assess and determine if the program designed and delivered by CCC met your needs. For each statement, please select (√) one statement from the listed that most closely matches your feelings about the nature of service currently under provision. From the given value under each statement, there is no correct or wrong answer. It is your satisfaction and view point that you will select.

Beneficiary Situation; infected----- affected\_\_\_\_\_ Sex\_\_\_\_\_

Duration of Membership in CCCs: .....Type of CCCs with PSS\_\_\_\_\_ Without PSS\_\_\_\_\_


Key: 5=Strongly Agree (SA) 4=Agree (A) 3=Neither (N) 2=Disagree (DA) 1= Strongly Disagree (SD)

S.N	Item describe type, dimension of services obtained and beneficiaries level of satisfaction	SA (5)	A (4)	N (3)	DA (2)	SD (1)
1	The type of care and support chosen by CCCs were appropriate for our quality of life.					
2	The nature of Service given by CCC is accurately reflected our family demand/need.					
3	Considering the overall CCCs care and support available to me, I am satisfied with its way of functioning					
4	All dimensions of care and supports including economical, medical, social and psychological are given to the beneficiaries					
5	Lack of community participation and resource are major problems to provide the necessary service					
6	The CCC volunteers are committed supportive, helpful and actively engaged during service provision time					
7	The service package at CCC is holistic and my family members has got the chance to join the program					
8	No matter how far it is true, I believed that, the role of CCC in improving our quality life is second to none					
9	In my view, there is strong relationship between service beneficiaries and CCC general structure.					
10	The support given by CCCs are aimed at future beneficiaries empowerment and give the chance to be independent					
11	I have no complain about the specific aspects of group functioning and achievement within CCC since they are					

	working well					
12	Despite the power relationship we have, I can freely explain my grievance and complain to the CCC coordinators when I feel discouraged about the service					
13	The CCCs coordinators are communicative, collaborative and understand our problems effectively					
14	As to me there is no skill and knowledge efficiency problem in the CCC volunteers to provide all services					
15	I think in my CCC group there is no separate psychosocial support benefit package given so far					
16	In my opinion providing Psychosocial support is considered as one major component of the HIV/AIDS/AIDSs care and support features in my CCC group					
17	I have had strong participation during the design of service development and my contribution was fully considered					
18	The CCCs volunteers understand that asking feedback about the nature of service provision from beneficiaries is part of their work					
19	I can directly complain about my satisfaction to the CCCs volunteers since the volunteers are willing to accept my complaint					
20	There is a coordination problem in providing psychosocial support					
21	Absence of training to the CCCs volunteers is one major challenge in providing PSS					

**DECLARATION**

This thesis is a presentation of my original research work. This work is not used for any other award at BA, MA or PhD level. Wherever contributions of others are involved, every effort is made to indicate this clearly, with due reference to the literature, and acknowledgement of collaborative research and discussions. The work was done under the guidance of Dr. Mengistu Legesse, at the Addis Ababa University School of Social Work.

Name. Binega H. Sig. 

In my capacity as advisor of the candidate's thesis, I certify that the above statements are true to the best of my knowledge.

Advisor Name. Mengistu Legesse Sig. 

Date: \_\_\_\_\_