

Barriers in service provision and service seeking regarding chbc for people living with hiv/aids in pokhara, nepal

Abstract

The Study was conducted entitled "Barriers in service Provision regarding community and home based care for people living with HIV/AIDS in Paluwa Paramarsha Kendra, Pokhara". The overall objective of the study was to find out the factors which hinders in provision of CHBC services by applying cross sectional descriptive research design. Non probability purposive sampling technique was used to collect data and the structured interview schedule and the focused group discussion guidelines were used as data collection tool.

The finding of the study reveals that majority of the respondents 26.00 percent were in between the age of 30-34 years. Among them Most of the respondents 91.00 percent were from urban areas, 96.00 percent were from the followers of Hindu religion. Majority of the respondents were underprivileged which comprised of 50.00 percent. Most of the respondents 95.00 percent were literate and the majority of the respondents comprised of 28.00 percent who had got primary level education. The high proportion 60.00 percent respondents got married and 35.00 percent got widowed. Majority of the respondents involved in agriculture followed by 38.00 percent. The high Proportion 71.00 percent respondent had known their HIV positive status through voluntary counseling and testing. Among the respondent, 2.00 percent had bore their infection since 15 years. The respondent who had got HIV infection, 77.00 percent was involved in the community organization or committee. Almost all of them had been receiving a CHBC service which is very much essential for their quality of life.

The finding of this study was that there are many factors which hinders in CHBC service provisions as knowledge and attitude of the family members and the community, stigma and discrimination, home care supplies by the organization, frequency of home visit, mismatch between service provision and service seeking practice. The distance to provide CHBC services was also the hindering factor. The CHBC team could not provide the quality services due to lack of time to spend with the client because three to four hour is not enough for the client to develop the knowledge and skill. The organization itself is very much responsible for the continuum and quality of care by scaling down the barriers. The service provider revealed that sufficient home care supplies as medicines and other long term care materials, regular monitoring and evaluation by the donor agency and the organizational designates and the motivation to the related staffs as promotion, trainings and other fringe benefits would be beneficial to decrease the barriers in service provision.

Keywords: PLHA, NACA, FHI, CHBC

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Abbreviations: AIDS, Acquired Immuno-Deficiency Syndrome; IDUs, Injecting Drug Users; ADL, Activities of Daily Living; IADL, Instrumental Activities of Daily Living; CBO, Community Based Organization

Introduction

Background of the study

In 1981, the first case of Acquired Immuno-Deficiency Syndrome (AIDS) was recognized. During the next year, additional case were recognized in numbers of other high risk groups including injecting drug users (IDUs), hemophiliacs and recipients of blood transfusion. By 1984, It was evident that Human immuno-deficiency virus (HIV) was already widespread throughout North America, Part of central Africa and Europe. Two decades later, more than 65 peoples had become infected with HIV causing AIDS. At the end of 2004, it has been estimated that 39.4 million people lived with HIV/AIDS.

Throughout the world, it was estimated that 16 thousand people become infected with HIV every day. In the world's entire population, 14.3 million people are newly infected and death due to AIDS is 3.1 million (UNAIDS/WHO, 2005). Sub Saharan Africa is now home to 25.4 million people living with HIV/AIDS among this, 13.4 million are of 15 to 49 years of age. In south and south East Asia, 7.1 million are living with HIV/AIDS. In India where almost 4 million people are living with HIV/AIDS (WHO, 2004).

The first case of HIV in Nepal was reported in 1988. By the mid -1990's Nepal had entered a 'concentrated epidemic, with HIV prevalence consistently over 5 % in some sub populations such as injecting drug users and female sex workers.¹ Infection rate has increased rapidly in recent years. Current date indicate that HIV prevalence is around 0.48% in the adult population (15-49 years). The estimated number of people, adult and children living with HIV in Nepal at the end of 2007 was around 62,000.²⁻⁴ Among them about half are living in districts along the high ways and a quarter of them

are women.⁵ According to the latest data disseminated by national center for HIV/AIDS and STI control under the ministry of Health and population, 15,043 are reported cases of HIV, out of these 2,729 cases are in the stage of AIDS.⁶ Among the total HIV Infected 933 are children, 6,694 are clients of sex worker and 3776 are house wives. Most of the people are unknown their infection. (NCASC/ UNAIDS, 2005).

Community and Home Based Care consist of care which responds to the physical social and emotional and spiritual needs of people living with HIV/AIDS in the home and community environment. It includes self care of patient, Care provided informally by family, love once, informal visit with peers, neighbors and formal visit by trained community and home based care provider.(which may includes nurses, patient one self, health assistants etc.) The goal of this service is to provide consistent care and support with and for people living with HIV/AIDS which helps to promote their self-reliance, their ability and their family's ability to care for them and make a decision to be actively linked to needed service such as ARV therapy, Counseling, Income generation, Child care etc., (FHI).⁷ Because stigma and discrimination are so serious in community and the negative impact of others knowing the HIV status of someone can be so severe, community and home based care service must be very careful at all times to only provide services to PLHA who request the service.⁸ Community Home based Care teams cannot make a home visit without first being invited to come to the home. If the workers make a home visit without previous approval from the PLHA and family they can cause harm to their clients. Community and home based care workers must sign a code of conduct in which they pledge to only provide services to PLHA who request them and to keep confidential of their clients at all time (International federation of Red Cross and Red Crescent societies and national societies 2003).

The government adopted an integrated and multi-sectorial approach for the implementation of the CHBC programme. The programme is implemented by the government in collaboration with nongovernmental organization and community based organization (CBOs). The ministry of health is responsible for the development of policies and standards and the provision of professional guidance and support on health care including counseling issues. On the other hand, the ministry of local government through the department social services is responsible for the development of policies and standards for provision of technical guidance for the social welfare component. In order to implement the programme national guidelines have been developed which provides the necessary procedures and tools (NACA, 2008).

Statement of the problems

Between 70(%) and 90(%) of illness care takes place within the home. Much of the care for people with HIV and AIDS is provided at home by immediate family and friends, as well as by home based care organization. Providing care for people with HIV and AIDS in the home has many potential benefits for both infected and affected people, yet there are many failing in the support given to careers. Research clearly demonstrates that most people would rather be care for at home and that effective home care improves the quality of life for ill people and their family care givers. Because CHBC uses a multidisciplinary approach and tries to bridge the gap between family and community on the one hand and the health system services on the other, full participation and support from both side is very much needed. Also the input and participation of people living with HIV AIDS is necessary to insure that the planning of activities is relevant in responding to the need of people (UNAIDS, 2009).

Surveys show that the overwhelming majority of people age 50 and over (84 percent) want to "age in place" and that those with disabilities (87 percent) prefer to live in their own homes. Consistent with these preferences, increasing numbers of individuals are moving from traditional institutions to home and community based settings. Those who leave institutional settings frequently have complex medical and psychosocial care needs. Care managers play a critical role in ensuring the individuals maintain their health, safety and overall well-being once they leave the institution. Provide® Enterprise helps care managers fulfill these responsibilities. Long term care refers to a wide range of medical, social and personal care services that are needed by PLHA as home and community based care (provide enterprises, 2009) .

PLHA who are functionally impaired. Such impairment may result from injury, chronic illness or some other physical or mental condition. Long term care is used mainly by the disabled elderly and such non-elderly persons as the developmentally disabled or the mentally ill. This paper focuses on the elderly, aged 65 and over, who are the primary users of long term care in the USA. It examines their use of long term care services, particularly home and community based care. It describes the kinds of data available on the functionally impaired elderly and their use of such care. The most reliable indicator of the need for long term care is the presence of functional impairment. A significant number of elderly persons have functional impairments, as measured by the Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL) or cognitive impairments. In 1985, there were about 5.5 million functionally disabled elderly persons aged 65 and over living in the community and an additional 1.3 million in nursing homes. Each of these figures is expected to almost double by the year 2020 to 10.1 million and 2.5 million respectively. There was about 1.1 million of the oldest old, i.e. persons aged 85 and over, who were functionally disabled and living in the community in 1985. An additional 600,000 lived in nursing homes. By 2020, the community-dwelling group is expected to grow 2.5 times to 2.6 million and the nursing home group similarly to 1.4 million. (U.S. Department of Health and Human Services, 2001).

Rational of the study

By the mid 1990's Nepal has entered the concentrated epidemic with HIV prevalence consistently over 5.00 percent in some sub population such as IDUs and female sex workers .Infection rate has increased rapidly in recent years. Current data indicate that HIV prevalence is around 0.48% in the adult population. As the rate increasing number of PLHA there is a great and immediate need for provision of accessible HIV AIDS care and support service. The quality of life Of those PLHA or affected by HIV/AIDS is largely determined by the kinds of care and support they receive. For many, hospital care is not always necessary to desirable, instead managing day by day illness and providing care and support takes place in the home. One palliative care client recently remarked, "The home care service is a lifeline. Without it, I would not be alive." CHBC teams have this powerful positive impact because they take the time to talk to clients and their families and to understand their individual needs. The teams can thus deliver excellent palliative care, because they address symptoms and concerns that overstretched hospital-based workers often overlook. Furthermore many researches and case studies sows that the life span of the PLHA seems dramatically increased as the impact of CHBC services in their own home setting therefore improving the quality of services regarding to community and home based care is the major concerned but still there are many hindering factors to provide a quality CHBC services. The study will suggest identifying and minimized the factors affecting to the service.

Research questions

1. What are the factors which hinders in providing community and home based care?
2. What are the services provided by the organization currently?
3. What are the gaps between service needed by the PLHA and service provided by the organization?

Research objectives

General objectives: The general objective of the study is to find out the factors which hinder in provision of community and home based care services for people living with HIV/ AIDS.

Specific Objective:

- i. To identify the factors that hinders in community and home based care service provision for people living with HIV/AIDS;
- ii. To assess the services that is provided by the organization currently;
- iii. To identify the gap between services needed by the PLHA and services being provided by the organization.

Research variables

Dependent variables: Barriers in service provision regarding community and home based care for PLHA.

Independent variables:

Education of care giver
Education of PLWHA
Economic status
Stigma and discrimination
Community resource
Family support
Distance to service
Distance to target home
Disclosure
Motivation of the staff/care giver
Sustainability of the programme
Monitoring and evaluation

Operational Definition

Barriers: In this study, barriers means those factors which hinders in service provision for those who are HIV infected and receiving CHBC services.

CHBC: In this study it means the care which response to the physical, social, emotional and spiritual need of PLHA in the home and community environment.

Education: In this study education means the educational status of the respondent at the time of interview. It will be categorized and measured.

Illiterate: who cannot read and write.

Literate: Who can read and write and it will be measures.

Informal education: Informal education means educated from informal institution.

Formal education: It means being educated from academic institution. It will be categorized as primary level, lower secondary level, secondary level, intermediate level, bachelor level, master level and above.

Economic status: In this study economic status is defined as sufficiency of the food for the family from their main source of income. It will be measured

- a. Sufficient for less than six months
- b. Sufficient for six months but not sufficient for twelve month
- c. Sufficient for twelve months
- d. Sufficient for more than twelve month

Stigma: In this study stigma means a label placed on people by people that are used to make them inferior or bad.

Discrimination: In this study discrimination means different attitude and behavior of the family and society based on persons status. It is measured.

- a. Hospital discrimination
- b. Community discrimination
- c. School discrimination

Community support: In this study community support reveals to the support for medical services, schooling support, and linkage in the support group and right based approach.

Family support: In this study family support means the support which the HIV infected get from the family members which is measured as : Support for,

- A. Love and affection
- B. Nutrition and basic home care
- C. Access to CD4 count and ART
- D. Access to support group

Distance to service: In this study distance reveals the time taken by the HIV infected to get service to the organization. It is measured in hour.

Distance to target homes: In this study distance means the time which is taken by the staff/care providers from the organization to the target homes. It will be measured in hour.

Disclosure: In this study disclosure gives the sense that either the family members or the community people know the status of the HIV infected by any means such as media, one to one contact and by shearing.

Supplies and equipments: In this study supplies and equipment refers to the home care kit which the care providers takes it the target home to serve the client from the organization.

Motivation of staff/care provider: In this study motivation means the inner effort which gives the positive result towards the clients by the staff /care providers. It is measured as the eagerness by the organization to provide training and the facilities.

Sustainability of the programme: In this study sustainability means since and for how long the programme is committed by the donor

agency and organization itself. It will be measured in year.

Monitoring and evaluation: In this study monitoring evaluation reveals the supervisory activities by the donor agency, organization itself and the CHBC supervisor. It will be measured in month.

Significance of the study

- i. The research finding help to boost up the quality of community and Home based care for the locally acting organization;
- ii. It will be helpful in providing effective care and support services to the PLHA by analyzing the gap between organization itself and the care seekers;
- iii. It will also be helpful to other students and organization to conduct for the research

Research methodology

Study area

Paluwa paramarsa Kendra pokhara will be used as study area.

Study design

The study design will be cross sectional descriptive.

Study population

All the HIV infected /affected people of any age religion and caste will be the study population.

Sample population

The HIV infected and affected people who are receiving CHBC services from Pluwa paramarssa Kendra will be the sample population.

Unit of analysis

HIV infected/affected people who are receiving CHBC service and participate in the Interview will be considered as unit of analysis.

Sample size

The sample size of the respondent will be 100 in number.

Sampling technique

Non probability purposive sampling technique will be used.

Data collection technique

Individual sampling unit will be interviewed.

Data collection tools

Structured interview schedule will be used.

Data management and analysis

In this study, the data obtained will be entered in the SPSS version 11.5. Prior to entry in SPSS programme a data based will be formed monitoring the name, label, value of variables and criteria of variables then after data cleaning will be done for increasing the accuracy of data. Simple statistical method like frequency, percentage, mean, median, standard deviation will be used.

Ethical consideration

Formal permission will be taken from Paluwa paramarsa Kendra pokhara; Informed consent will be taken with the individual before starting the interview; the interview will be completely confidential

and the name of respondent will not be associated with their answers. Objective of the study will be clearly explained; the data will not be personalized and confidentiality of the data will be maintained and will be used for the purpose of this study only; Respondents will not be influenced by any means of participate in the study.

Limitation of the study: This study will be exclusively academic study it will have sample limitation and time limitation so the result of the study cannot be generalized.

Research criteria

Inclusive criteria: All the HIV infected/affected individuals receiving CHBC services from

Paluwa will be included.

Reliability and validity: Interview schedule will be consistent with research topic, statement of the problem, research questions and research objectives; Interview schedule will be developed by using the guidance of preparing interview schedule; Interview schedule will be checked and verified by the advisor; Interview schedule will be pre tested in a similar setting and necessary correction will be made; The collected data will be back checked by the investigator to ensure the reliability of data; Collected data will be checked for errors and omission on the same day and the consistency of data will be maintained; The data will be collected by the researcher herself.

Results

The chapter deals with the analysis and interpretation of the data concerning with the barriers in service provision regarding community and home based care for people living with Human Immune Deficiency Virus/Acquired Immune Deficiency Syndrome. All the data were collected by interviewing patients from infected and affected people who are receiving community and home based care services from Paluwa Paramarsha Kendra, Pokhara. Data were collected from 100 respondents. All the obtained data has been computed, analyzed and interpreted by simple table, cross table, pie chart and bar graphs.

Distribution of the Respondents by Socio-Demographic Characteristics

Age and sex: The range of respondent's age was 10 to 64 years. Most of the respondents 28.00 percent were in between the age of 30-34 years and it was found that the least (1%) of the respondents were in the group of 10-14 years and 60-64 years each. Out of 100 respondents, 61.00 percent were female and 39.00 percent were male.

Ethnicity: Aryan (Brahmin, Chhetri), Mangolian (Gurung, Magar, Newar, Tamang, Jyawsal) and underprivileged

(BK, Nepali, and Pariyar) were the major ethnic groups in this research study. Out of 100 respondents, 27.00 percent were Aryan, 23.00 percent were Mongolian and 50.00 percent were underprivileged.

Religion: Hindu, Buddhist and Christian were the major religious group. Among them 96.00 percent were Hindu followed by Buddhist respondents with 2.00 percent and Christian respondents also consisting of the same percent.

Occupation: Agriculture, business, service, wage labor and foreign employee were the major occupation of the respondents. Majority of the respondents (34.00 %) were involved in agriculture followed by 28.00 percent of the respondents involved in service, 20.00 percent in wage labor, 15.00 percent in business and 3.00 percent of the respondents involved as foreign employee.

Type of family: Among 100 respondents, 37.00 percent had nuclear family and 63.00 percent had joint family.

Residence: Most of the respondent residing in urban were 91.00 percent followed by 9.00 percent in rural areas.

Marital status: Among 100 respondents, majority of the value as 60.00 percent respondents had got married followed by 35.00 percent, 3.00 percent and 2.00 percent as widow, divorced and unmarried respectively.

Education: Among 100 respondents, 95.00 percent were literate and 5.00 percent were illiterate. Among formal literate respondents, 28.00 percent were primary educated, 26.00 percent had passed lower secondary, 12.00 percent has passed S.L.C, Only 1.00 percent had bachelor degree of education.

Main source of income: Main source of income is the major foundation for the fulfillment of the basic needs of a family. Out of 100 respondents, 29.00 percent of the respondent's family had service as the main source of income followed by 26.00 percent of the respondent's family with agriculture, 23.00 percent with wage labor, 13.00 percent with business and 6.00 percent respondent's family had pension as the main source of income followed by 1.00 percent as foreign employer and sponsored by foreigner by each.

Sufficiency from main source of income: Sufficiency from main source of income signifies whether the main source of income is adequate to fulfill the basic needs of the family for the whole year. Out of 100 respondent's families, 15.00 percent of family's main source of income was sufficient for up to 6 months, 31.00 percent of family's income for 6-12 months and 37.00 percent of family's income was sufficient for 12 months and 17.00 percent families has sufficient for more than twelve months.

Alternative sources of income: Alternative sources are the substitution sources besides the main source of income. Among 100

respondent's families, Most of the families 38.00 percent had labor followed by 30.00 percent of service, 15.00 percent had agriculture as the alternative source, 7.00 percent as business and 10.00 percent of the respondent's family had no alternative source.

Distribution of respondents regarding mode of transmission of human immune deficiency virus

Table 2 shows that majority of the respondents 71.00 percent had come to know their HIV status through voluntary counseling and testing. Twenty six percent had known their status during hospitalization whereas 2.00 percent had known through their sexual partner and only 1.00 percent respondents had mentioned about the mode of transmission as donating blood.

Distribution of respondents according to the duration of being positive by human immune deficiency virus

Table 3 reveals that majority of the respondents 56.00 percent had duration of HIV positive for 4-6 years followed by 34.00 percent for 0-3 years, 4.00 percent for 7-9 years and 10-12 years each and the maximum duration of being HIV positive as 13-15 years is 2.00 percent which showed the fact that the people who is infected by HIV can also live a longer and healthier life. This message will be beneficial for those who are very much afraid about the life after their positive status.

Distribution of respondents according to the sharing of positive (HIV) status to the family members

Table 4 deals with the sharing of HIV positive status to their family members which is very crucial to them. Most of the clients do not want to disclose her/his positive status to the family members as well as in the community because of stigma and discrimination but in my study, 90.00 percent of the clients disclose the status to the family members which will be beneficial for them to get care and support for longer and healthier life.

Table 1 Distribution of the Respondents by Socio-Demographic Characteristics

Characteristics	Frequency	Percentage
Age Group	14-Oct	1
	15-19	2
	20-24	6
	25-29	18
	30-34	26
	35-39	24
	40-44	8
	45-49	9
	50-54	3
	55-59	2
Sex	60-64	1
	Male	39
Ethnicity	Female	61
	Aryan	27
Religion	Mongolian	23
	Underprivileged	50
Education	Hindu	96
	Buddhist	2
	Christian	2
	Illiterate	5
	Literate	95
	Informal	33
	Formal	67
	Primary	28
	Lower Secondary	26
	Secondary	12
Residence	Intermediate	0
	Bachelor	1
	Urban	91
	Rural	9

Table Continued...

Characteristics	Frequency	Percentage
Marital Status	Unmarried	2
	Separated	0
	Married	60
	Divorced	3
	Widow	35
Type of Family	Joint	37
	Nuclear	63
Occupation	Agriculture	34
	Service	28
	Business	15
	Daily Wages	20
	Foreign employ	3
Main Source of Family Income	Service	29
	Business	13
	Daily Wage	23
	Agriculture	26
	Pension	6
Sufficiency of Food	Sponsored by foreigner	1
	Foreign Employment	2
	Less than 6 Months	15
	6-12 Months	31
	Only for 12 Months	37
Alternative Source of Income	More than Twelve Months	17
	Labor	38
	Service	30
	Agriculture	15
	Business	7
	No alternative source	10

Table 2 Distribution of Respondents regarding Mode of Transmission of Human Immune Deficiency Virus

Mode of HIV Transmission	Frequency	Percentage
Through voluntary counseling and testing	71	71
Donating Blood	1	1
Through sexual partners	2	2
During hospitalization	26	26
Total	100	100

Table 3 Distribution of Respondents according to the duration of being Positive by Human Immune Deficiency Virus

Duration of being HIV Positive	Frequency	Percentage
0-3 years	34	34
4-6 years	56	56
7-9 years	4	4
10-12 years	4	4
13-15 years	2	2
Total	100	100

Table 4 Distribution of Respondent according to the Sharing of Positive (HIV) Status to the Family Member

Sharing of HIV Status	Frequency	Percentage
Yes	90	90
No	10	10
Total	100	100

Distribution of respondents with relation according to the sharing of positive (HIV) status

Table 5 shows that, Among 90 respondents who have shared their HIV status to the related members have the majority of 26.60 percent with their husband. The study also reveals that 3.33 percent respondent has also shared their status with their children and 17.70 percent, 13.33 percent, 7.77 percent with their siblings, Friends and mother/father.

It shows that 8.88 percent respondents have shared their HIV positive status with all the family members

Distribution of respondents having HIV infection to other family member

Table 6 shows reveal the HIV infection that has been transmitted either by their parents or by husband/wife. We have experienced that most of the HIV transmission has occurred in children due to their parents and also by the husband to wife and vice versa. In my study, Among 100 respondents, 51.00 percent of the family members are infected with HIV. The remaining 49.00 percent are not infected; it symbols the good indication to decrease the HIV infection rate as a whole.

Distribution of respondents regarding participation in the community committee and functions

Table 6 show that, 77.00 percent of the respondents have participated in the community committee or any organizations whereas 23.00 percent has not got the opportunity to participate.

Distribution of respondents regarding most caring family members of the client

Table 7 shows that, out of 86 respondents, 32.50 percent

respondents have cared by their husband and wife to each other. 13.95 percent, 11.62 percent by their children and mother/father respectively and only 4.65 percent are cared by their in-laws.

Distribution of respondents regarding type of family support receiving from their family members

Table 8 shows that most of the respondents 32.50 percent had access to CD4 count as family support whereas only 11.63 percent had nutrition and basic home care.

Table 5 Distribution of Respondents with Relation according to the Sharing of Positive (HIV) Status

Relation with Client	Frequency	Percent
Husband	24	26.6
Wife	20	22.2
Siblings	16	17.7
All Family Members	8	8.88
Mother/Father	7	7.77
Friend	12	12
Children	3	3.33
Total	90	100

Table 6 Distribution of Respondents having HIV Infection to Other Family Member

Infection to Others	Frequency	Percentage
Yes	51	51
No	49	49
Total	100	100

Table 7 Distribution of Respondents regarding Participation in the Community Committee and Functions

Participation Community	Frequency	Percentage
Yes	77	77
No	23	23
Total	100	100

Table 8 Distribution of Respondents regarding most Caring Family Members of the Client

Most Caring Member	Frequency	Percent
Husband	28	32.5
Wife	28	32.5
Children	12	13.95
Mother/Father	10	11.62
Sibling	4	4.65
In- Laws	4	4.65
Total	86	100

Distribution of respondents regarding type of community and home based care services provided by CHBC team

Table 9 deals about the community and home based care providing by the CHBC team which reveals that, majority of the respondent 34.96 percent responded that they provide management of opportunistic infections and 8.13 percent had received the linkage to community support. Although all the components are equally important for the quality service provision for the clients.

Relationship between the educational status and economic status of the respondents

Table 10 Majority of respondents are found to be educated informally. Among them, 36.36 percent had sufficiency of food for 6 to 12 months. The respondents who had received primary level of education, 46.43 percent had sufficiency of food for 12 months. Respondents who had received lower secondary level of education,

11.54 percent respondent had the sufficiency of food for less than 6 months. The high proportion 4(33.33%) had sufficiency of food for 6 to 12 months and for 12 months each who had received secondary level of education. The respondent who had received bachelor level of education had sufficiency of food for more than 12 months.

Relationship between the educational status and stigma/discrimination related to HIV/AIDS

Table 11 Out of 21 respondents who had discriminated by their family and society, 8(38.10%) respondents had received lower secondary level education, 7(33.33%) had received primary level education and 2(9.52%) had received informal, secondary level education in each and same percent respondents were illiterate also. Among the 79 respondents who had not faced stigma and discrimination by their family and society, majority 26(32.91%) had received informal education. Among them, 1(1.27%) respondent had received bachelor level of education.

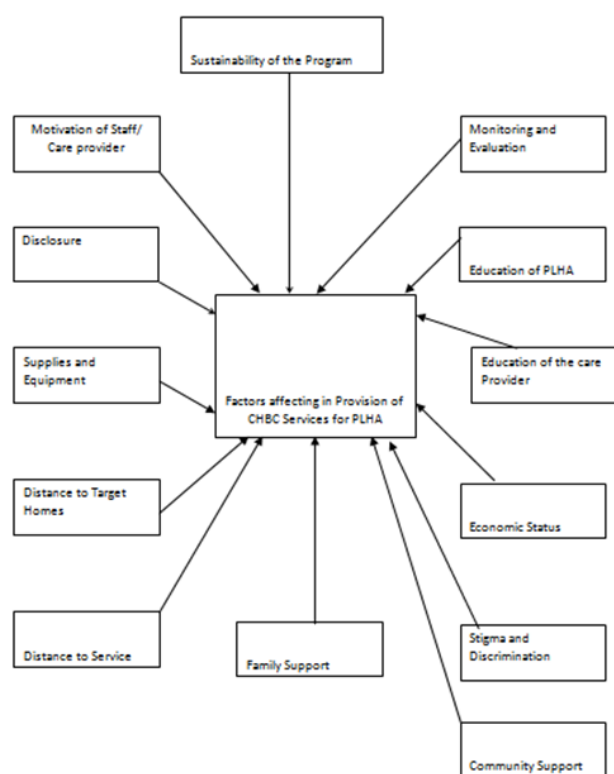


Figure 1 Conceptual Framework.

Relationship between means of disclosure and stigma and discrimination related to HIV/AIDS

Out of 21 discriminated clients, the majority 17 (19.10%) had disclosed not by their intension but by the community people, friends and anyone else. Whether, 2(50.00%) had disclosed by media and 2(28.57%) had disclosed by sharing in the community with their own wish. The respondents who had not discriminated in the society were also disclosed as 2(50.00%) by media, 5(71.42%) by sharing. The chapter deals with the comparison between the findings from literature review and the findings from the research. It mainly focused on what are the similarities and dissimilarities and what may be the possible causes of those similarities and dissimilarities of findings from literature review and from this research, the reasons for those types of findings are discussed on the view of researcher.

The Study was conducted entitled “Barriers in service Provision regarding community and home based care for people living with HIV/ AIDS in Paluwa Paramarsha Kendra, Pokhara”. The overall objective of the study was to find out the factors which hinders in provision of CHBC services (Table 12). The total sample size was 100 and 3 were of service providers. The finding of the study revealed that majority of the respondents 26.00 percent were in between the age of 30-34 years. Among them Most of the respondents 91.00 percent were from urban areas, 96.00 percent were from the followers of Hindu religion. Majority of the respondents were underprivileged which comprised of 50.00 percent. Most of the respondents 95.00 percent were literate and the majority of the respondents comprised of 28.00 percent who had got primary level education. The high proportion 60.00 percent respondents got married and 35.00 percent got widowed. Majority of the respondents involved in agriculture followed by 38.00 percent. The high Proportion 71.00 percent respondent had known their HIV positive status through voluntary counseling and testing. Among the

respondent, 2.00 percent had beared their infection since 15 years. The respondent who had got HIV infection, 77.00 percent was involved in the community organization or committee. Almost all of them had been receiving a CHBC service which is very much essential for their quality of life.

Table 9 Distribution of Respondents regarding Type of Family Support receiving from their Family members

Type Of Family Support	Frequency	Percentage
Access to CD4 Count and ART	89	32.5
Access to Support Group	83	32.17
Love and Affection	56	21.71
Nutrition and Basic Home Care	30	11.63
Total	258	100

Table 10 Relationship between the Educational Status and Economic status of the Respondents

Educational Status	Sufficiency From Food				Total
	< 6 Month	6-12 Months	For 12 Months	> Twelve Months	
Informal	9(27.27)	12(36.36)	9(27.27)	3(9.09)	33(100.00)
Primary	2(7.14)	8(28.57)	13(46.43)	5(17.86)	28(100.00)
Lower Secondary	3(11.54)	7(26.92)	11(42.31)	5(19.23)	26(100.00)
Secondary	1(8.33)	4(33.33)	4(33.33)	3(25.00)	12(100.00)
Bachelor	0(0.00)	0(0.00)	0(0.00)	1(100.00)	1(100.00)
Total	15(15.00)	31(31.00)	37(37.00)	17(17.00)	100(100.00)

According to study conducted by international labor organization in India (2004), about “Assessing the Socio-Economic Impact of HIV/ AIDS on People Living with HIV/AIDS and their families in India,” 92.00 percent of the respondents were in the age group 19-40 years. These findings are also supported by this study, 90.00 percent were of the age group 19-40 years. Similarly, according to the findings of ILO.^{9,10} regarding the religion, 68% were Hindu and 24% Christian. These finding did not support the study that showed 96.00 percent were Hindu followed by 2.00 percent Christian. The difference in the result and findings might be due to small sample size. Moreover, the findings from ILO [10], 93% respondents disclosed their HIV status to someone. These findings are also supported from this study whereas 90.00 percent respondents had disclosed their HIV status to someone. According to the NLM Gateway, a service of U.S National Institute of Health 2004, the study defined that the Community and Home Based Care consist of care which responds to the physical social and emotional and spiritual needs of people living with HIV/AIDS in the home and community environment. The study had also mentioned that, the CHBC service provider must be trained human resource as nurses, paramedics and the patient himself or herself which was also supported this study as the CHBC team was trained and the core theme of the service seemed alike.

According to UNAIDS 2004, the main objective of home-based care is to improve the quality of life and survival of PLWHA and to maintain their dignity.¹¹ It also aims to contribute to the reduction of stigma and discrimination against PLWHA (Table 13) and the further spread of the virus, and so reduce the impact of HIV/AIDS on individuals, families and communities. These findings supported this study. Likewise, according to the Pathfinder International 2007, the necessary supplies that should be provided in home based care kits are very often inadequate. Less than a quarter of home based care kits in the survey contained mild painkillers, and vitamins and iron supplements were largely unavailable. These findings are supported in this study as the service provider had mentioned. When a family

member falls sick as a result of HIV, not only does that individual's inability to work lessen family income, so too does the fact that careers will spend less time making money. Furthermore, at the time that the earning potential of a household is diminished, the cost of treatment, medicines and other healthcare provisions constitute an added financial burden on careers.¹² Similarly, older people may

have to return to work at the time in their lives when they might be expected to cease working and be cared for by their offspring. These findings are supported as most of the clients got illness due to the HIV infection created the problem to provide the service because most of the clients were expected income generation programme which added financial burden to the service providers.

Table 11 Relationship between the Educational Status and Stigma/Discrimination related to HIV/AIDS

Educational Status							
Stigma/Discrimination	Illiterate	Informal	Primary	Lower secondary	Secondary	Bachelor	Total
Yes	2(9.52)	2(9.52)	7(33.33)	8(38.10)	2(9.52)	0(0.00)	21(100.00)
No	3(3.80)	26(32.91)	21(26.58)	18(22.78)	10(12.66)	1(1.27)	79(100.00)
Total	5(5.00)	28(28.00)	28(28.00)	26(26.00)	12(12.00)	1(1.00)	100(100.00)

Table 12 Distribution of Respondents regarding Type of Community and Home Based Care Services

Type Of CHBC Services	Frequency	Percentage
Management of Opportunistic Infection	86	34.96
Linkage to Support Group or Self Help Group	84	34.15
Skill Development to Care Himself/Herself	56	22.76
Linkage to Community Support	20	8.13
Total	246	100

Table 13 Relationship between the Means of Disclosure and Stigma/Discrimination related to HIV/AIDS

Means of Disclosure	Stigma and Discrimination		
	Yes	No	Total
By Media	2(50.00)	2(50.00)	4(100.00)
By Sharing	2(28.57)	5(71.42)	7(100.00)
By others	17(19.10)	72(80.89)	89(100.00)
Total	21(21.00)	79(79.00)	100(100.00)

Similarly, Blair Research Institute/ WHO 2008 stated that the service provider's workloads may be very heavy they are often unable to make frequent home visits or stay with individual patients or households for very long. Any failures of home based care often stem from the shortage of investment in the individuals and organizations that carry out the work. The economic burden to the family, limited resources to provide service, insufficient M&E created the problem for the continuity of care to the clients. These finding fully supported to this study as mentioned by the service provider.

Findings from the focused group discussions

One of the objectives of this study was to find out the gap between the service being provided by the organization itself and services needed by the people living with Human Immune Deficiency virus/ Acquired Immune Deficiency Syndrome. The services which were provided by the organization has maintained earlier in the other chapter. So, to find out the services needed by the PLHA, Researcher had conducted two focused group discussion based on one with male clients and the other with female clients.

For the discussion, the FGD guidelines were strictly maintained as the FGD questionnaire had been prepared, there are 8 questions. The questionnaire had three types of questions as engagement, exploration and exit questions. The discussion was most focused on the exploratory questions because the main findings are expected from there. The same tool had used for both groups where there are 12 participants in each group. The participants were managed by the community and home based care Team of Paluwa Paramarsha Kendra, nagdhunga (INF). The FGD was facilitated by the researcher herself and was assisted by the section manager of the Paluwa section for taking notes and facilitation. The two FGDs had taken in the same day varying in the time schedule as well.

The numbers of years they have been receiving CHBC services were varying in year to months. Some had received since 4 years and some had started to receive since few months. The mean age of the participants was 24 years. Among the participants, 22.00 percent were Aryan, 33.00 percent were Mongolian and remaining 45.00 percent were from underprivileged group. Most of those participants were well known about the CHBC services. They evokes that community and home based care services can be provided wherever there is a demand for the services, the CHBC team can provide services to PLHA who request them, from the time of diagnosis and can continue to provide services throughout their life, during their death and offer the continuum support to their family/loved ones. The participants has questioned in the floor that what do you feel when you see other people like your status? For some time, they all become emotional and spoke that if we saw the clients like us, we encourage them as the disease is not curative but the care and support from the different organization will help to slow down the disease and keep healthier as well as the longer life.

They said that, since HIV is a disease which progress slowly, CHBC providers can help to build the knowledge and skills of PLHA long before they begin to experience HIV related illnesses so that they are knowledgeable in how to boost up the immune system, how to manage simple symptoms and to know when they should be referred to the hospital for specialty care. These all the care and supports are provided by the organization (Paluwa) as possible. The organization has provided home care supplies as medicine.^{13,14} health education for PLHA and the families, training for the skill development of the client to live longer and healthier. Further while there is the problem of stigma and discrimination everywhere in the community, which is one of the major barriers in the context of service provision, they suggest that Stigma and discrimination has been changed through number of

interventions. If the organizational CHBC team facilitate and conduct mass awareness programme to provide information about HIV/AIDS to the client, families and the communities which would help to reduce the clients worries and fear which is the main cause leading death to the client. They also shared that, the CHBC team is only focused on those schools where the positive children were studied. It will be further better if all the schools, organizations, hospitals and other related field might be included.

They said that most of the clients are underprivileged and they cannot afford their basic health care medicines themselves so that the home care supplies must be sufficient for them to spend some days. The CHBC team had visited to them either in the home or somewhere else should be frequent so that the health status of the client could be found out easily to precede the further treatment. The major factors which hinders in CHBC services are:

- a. Knowledge and attitude of the family members and the community
- b. Stigma and discrimination
- c. Home care supplies
- d. Frequency of home visit
- e. Mismatch between service provision and service seeking practice

For the successful provision of the CHBC services, the client had the major role to succeed the programme. In some organization there were more funds which could be used for the welfare of the client but the client had no idea to find out the organization and they could not seek the services themselves. In this sense, the client must have to help the other client.

The conclusion of this FGD was that there are many factors which hinders in CHBC service provisions as mentioned above but the services provided by the organization should be matched with the services needed by the seeker. Stigma and discrimination was the major factor so that the organization must have to be focused on get rid of this problem. The home care supplies such as medicine and other supplies should be sufficient for the service provision so that the welfare of the client could be ensured.

Conclusion

The Study was conducted entitled "Barriers in service Provision regarding community and home based care for people living with HIV/AIDS in Paluwa Paramarsha Kendra, Pokhara".¹⁵ The overall objective of the study was to find out the factors which hinders in provision of CHBC services by applying cross sectional descriptive research design. Non probability purposive sampling technique was used to collect data and the structured interview schedule and the focused group discussion guidelines were used as data collection tool. The finding of the study reveals that majority of the respondents 26.00 percent were in between the age of 30-34 years. Among them Most of the respondents 91.00 percent were from urban areas, 96.00 percent were from the followers of Hindu religion. Majority of the respondents were underprivileged which comprised of 50.00 percent. Most of the respondents 95.00 percent were literate and the majority of the respondents comprised of 28.00 percent who had got primary level education.

The high proportion 60.00 percent respondents got married and 35.00 percent got widowed. Majority of the respondents involved in agriculture followed by 38.00 percent. The high Proportion 71.00 percent respondent had known their HIV positive status through voluntary counseling and testing. Among the respondent, 2.00 percent

had bore their infection since 15 years. The respondent who had got HIV infection, 77.00 percent was involved in the community organization or committee. Almost all of them had been receiving a CHBC service which is very much essential for their quality of life. Regarding the sharing of HIV positive status to the family members, 26.60 percent female client had shared with their husband and 51.00 percent respondent had the HIV infection to their family members either to their husband/wife or children. The study shows that the most caring family member comprised of 32.50 by the couple themselves. Most of the respondent 32.50 percent had access to CD4 count and Anti-retroviral Therapy. The majority 34.96 percent had received the management skill of opportunistic infection by the CHBC team.

The finding of this study was that there are many factors which hinders in CHBC service provisions as knowledge and attitude of the family members and the community, stigma and discrimination, home care supplies by the organization, frequency of home visit, mismatch between service provision and service seeking practice. The distance to provide CHBC services was also the hindering factor. The CHBC team could not provide the quality services due to lack of time to spend with the client because three to four hour is not enough for the client to develop the knowledge and skill. The organization itself is very much responsible for the continuum and quality of care by scaling down the barriers. The service provider revealed that sufficient home care supplies as medicines and other long term care materials, regular monitoring and evaluation by the donor agency and the organizational designates and the motivation to the related staffs as promotion, trainings and other fringe benefits would be beneficial to decrease the barriers in service provision.

In my opinion, most of the HIV and AIDS home care is carried out by family members who have no contact with professional help and suffer through lack of support. This means that infected people are inadequately looked after despite the best efforts of their careers and families who face economic, psychological and social difficulty. Career workloads may be very heavy and they are often unable to make frequent home visits or stay with individual patients or households for very long. Any failures or barriers of home based care often stem from the shortage of investment in the individuals and organizations that carry out the work. It should also be remembered that home based care organizations cannot attend to patients around the clock, so there are limitations on what they should be expected to do. While they should be able to help with daily tasks such as changing bandages, assistance with more frequent occurrences such as going to the toilet will mostly be done by family members.

Acknowledgments

None.

Conflicts of Interest

None.

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