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HIV/AIDS QUALITY OF CARE INITIATIVE (HAQOCI)



SITUATIONAL ANALYSIS REPORT ON

COMMUNITY HOME BASED CARE IN ZIMBABWE

**Based on the National Situation Analysis Survey of HIV/AIDS quality of care
conducted in June-September, 2002**

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EXECUTIVE SUMMARY

IMPROVING THE QUALITY OF HOMEBASED CARE IN ZIMBABWE

Title: To identify and describe the clients in home based care, their caregivers and the resources available for their care in the home

Background This paper will present the results of the Home-based care aspect of national HIV/AIDS care situation analysis survey. The aim of this section was to gather information that characterizes clients on home based care, their caregivers, and the provision of personnel and material resources for their care. The paper also presents the clients and caregivers views of the existing services and how quality of home based care can be improved.

Methods A nationwide situation analysis survey was conducted to collect data from 1610 clients on the chronic disease register, 709 formal caregivers, and 1475 informal caregivers Information elicited from clients and caregivers included demographic data, perceptions of quality of home-based care.

Results The most common complaints among clients were; pain, tiredness, weight loss, problems with walking, fever and night sweats, headaches, cough and insomnia, shortness of breath, lack of appetite, fevers, loss of memory, and diarrhoea. Clients were satisfied with assistance they were receiving from caregivers, which included assistance with bathing and dressing, mobilizing, getting out of bed, toileting, and feeding. They also received assistance in: food preparation, taking medication, shopping, housework, managing money, communicating with family, and attending doctors appointments. However clients were dissatisfied with: pain control, availability and cost of drugs and information on discharge.

The formal caregiver consisted of mostly untrained women volunteers; NGO and MOHCW employees. Informal caregivers were mostly female, consisting of wives, parent, children, siblings, grand parents, friends, volunteers. Most caregivers lacked the appropriate skills to care for the clients. Quality of care was perceived as hindered by lack of: standardized training in home based care, adequate care skills, care kits, counselling and social support, allowances for caregivers, transportation, adequate supervision, uniforms, poor supply of medication, pain control, clothing, blankets and food.

Conclusion Quality of home-based care could be improved considerably if continuity of care basic needs of clients and caregivers are met. Clients need supplies of basic care kits, skilled nursing care, drugs and food and social support. Formal caregivers need standardized training in home based care and self-care, financial and uniforms allowance, transport and social support. Discharge planning training should be integrated into the caregivers curriculum. This would assist in improving continuity of care in home-based care. Liaison with social services for food to improve client nutrition

PERCEPTION OF THE QUALITY OF HOME BASED CARE BY HIV/AIDS CLIENTS

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PERCEPTION OF THE QUALITY OF HOME BASED CARE BY CHRONICALLY ILL INCLUDING HIV AND AIDS CLIENTS

A. INTRODUCTION

This paper presents the results from the home-based care – client questionnaire that was part of a national HIV/AIDS quality of care situation analysis survey. The purpose of the client questionnaire was to find out the prevailing situation with regards to home-based care from the client's perspective. The questionnaire was composed of seven sections. Section 1 was demographic data pertaining to clients, which included data such as age, sex, marital status, educational level, employment and residence. Section 2 elicited questions on client 's health history. In this section clients had to state whether they experienced problems such as tiredness, fever and night sweats, pain, sleep, cough, shortness of breath, painful oral lesions, lack of appetite, nausea and vomiting, weight loss, bruising and bleeding tendencies, visual impairment, hearing impairment, impairment in sensation, edema, fever, oral thrush, ear infection, sore throat, skin lesions, loss of memory, diarrhoea and headache.

Section 3 elicited information on need for assistance with activities of daily living while section 4 elicited information on how the clients were satisfied with this assistance. Section 5 included information on client 's perspective on continuum of care. Section 6 elicited information on client's perception on psychosocial support from family, friends, neighbors and church members. Section 7 was on patient's perspective on medication/pain management.

B. RESULTS

The results are presented according to the seven sections of the questionnaire: description of the respondents, clients' health history, assistance with activities of daily living as well as rating satisfaction with this assistance, clients' perspective on continuum of care, psychosocial support and on medication/ pain management.

1. DESCRIPTION OF RESPONDENTS

The target population was derived from all the 10 provinces in Zimbabwe. A total of 1 610 respondents were interviewed comprising 40.1% males and 59.9% female. Most (47.3%) of the respondents were married, while 25.4% were widowed, 15.5% were single, and the rest were either separated or divorced. The median age of clients was 42 years old. Most (55.7%) of the clients had attained primary education, 25.5% secondary education, 0.8% tertiary; while 17% had no formal education.

A majority of these clients were unemployed (87.2%). Of those in employment, 7.2% were in formal employment and 4.5% were self-employed. The study participants were recruited from rural areas (67.0%), urban areas (23%), commercial farms (4.9%), mines (3.9%) and squatter camps (1.3%).

1.1 Conclusion, implications and recommendations

The median age of the clients from this survey is higher than expected for people suffering from HIV/AIDS. The reason for this discrepancy could be that the list of clients who were surveyed was obtained from the chronic diseases register in health facilities. The older clientele who were chronically ill affects the median age of this sample. The sample of patients reflected a high percentage of women (59.2%). This could suggest that more women are infected or that women survive longer than men.

2. Clients' Health History

The health history was elicited so as to ascertain the burden of caring for clients with the ailments. Clients presented with various ailments and these have been tabulated in table 1 below. Ninety percent of the clients reported having pain, 88% reported a feeling of tiredness, 77% had problems with weight loss, 74% had problems with walking, 71% reported experiencing fever and night sweats. Other health problems reported were headaches (70%), cough and problems with sleeping (67%), shortness of breath, (58%), had lack of appetite (56%), fevers (55%), loss of memory (53%), and diarrhoea (46%). All these symptoms are common in persons with HIV/AIDS as well as the elderly.

Table 2.1 illustrating the burden of care in chronically ill patients.

Ailment	Never	Sometimes	Always	N
Tiredness	190(12.0%)	839(52.0%)	578(36%)	1607
Fever and Night Sweats	460(28.6%)	767(47.8%)	379(23.6%)	1606
Pain	151(9.4%)	812(50.5%)	646(40.1%)	1609
Sleep	522(32.5%)	738(46.0%)	344(21.0%)	1604
Cough	516(32.06%)	690(42.8%)	403(25.0%)	1609
Shortness of breath	670(41.8%)	627(39.1%)	307(19.1%)	1604
Painful oral lesions	1133(70.5%)	337(21.0%)	136(8.5%)	1606
Lack of appetite	700(43.6%)	642(40.0%)	265(16.4%)	1607
Nausea and Vomiting	983(61.2%)	527(32.8%)	95(6.0%)	1605
Weight loss	365(22.8%)	614(38.3%)	623(38.9%)	1602
Bruising & bleeding tendencies	1306(81.3%)	239(14.9%)	62(3.8%)	1607
Visual Impairment	868(54.0%)	462(29.0%)	277(17.0%)	1607
Hearing impairment	1153 (71.7%)	311(19%)	142(8.8%)	1606
Impairment in sensation	751(47.0%)	592(37.0%)	262(16.0%)	1605
Problems with walking	416(26.0%)	640(40.0%)	549(34.0%)	1605
Oedema	989(62.0%)	454(28.0%)	165(10.0%)	1608
Fever	727(45.3%)	753(46.9%)	126(7.8%)	1606
Oral thrush	1168(73.0%)	340(21.0%)	98(6.0%)	1606
Ear infection	1189(74.0%)	354(22.0%)	64(4.0%)	1607
Sore throat	964(60.1%)	568(35.4%)	72(4.5%)	1604
Skin lesions	1193(74.0%)	297(19.0%)	116(7.0%)	1606
Loss of memory	745(46.7%)	585(36.7%)	264(16.6%)	1594
Diarrhoea	847(52.9%)	625(39.1%)	128(8.0%)	1600
Headache	464(29.1%)	856(53.6%)	276(17.3%)	1596

2.1 Conclusion, implications and recommendations

Most of the clients interviewed in this study complained of the above ailments in varying degrees. It is important that the training and orientation of caregivers includes the management of these conditions to improve the quality of client care. It is also important to note that these ailments are not only specific to those who are HIV positive but also clients with other chronic diseases.

3. Assistance from caregivers

The assessment of activities of daily living tool is helpful in assessing the assistance with basic care that the clients may need from the caregivers. These activities are divided into activities of daily living (ADLs) and instrumental activities of daily living (IADL). Activities of daily living include basic care such as bathing and eating. Instrumental activities of living include the more advanced activities such as shopping and management of finances. Less than 50% required assistance with activities of daily living. More than 50% of clients required assistance with instrumental activities of daily living. The most noted assistance required was housework (861), shopping (764), bathing (864), getting out of bed and managing money (1060).

Table 3.1 Showing assistance needed by clients regarding Activities of Daily Living (ADLs).

Activity of daily living (ADL)	No Assistance	Some Assistance	A lot of Assistance	N
Bathing and dressing	864(53.1%)	422(26.4%)	322(20.5%)	1608
Getting out of bed	997(62%)	358(22.0%)	253(16%)	1600
Walking	785(49.0%)	472(29.0%)	349(22.0%)	1606
Toileting	973(60.5%)	349(21.8%)	284(17.7%)	1606
Eating	1216(76.0%)	261(16%)	123(8.0%)	1600

Table 3.2 Showing assistance needed by clients regarding Instrumental Activities of Daily Living (IADLs).

Instrumental activity of daily living (IADL)	No Assistance	Some Assistance	A lot of Assistance	N
Preparation of food	344(21%)	520(32%)	744(46%)	1608
Medications and treatments	738(46%)	530(33%)	325(20%)	1603
Shopping	362(22.5%)	479(29.8%)	764(47.5%)	1606
Housework	268(16.7%)	475(29.6%)	861(53.6%)	1604
Managing money	531(33%)	589(36.7%)	471(29%)	1601
Communication with family and friends	795(49.5%)	504(31%)	304(18.9%)	1603
Going to visit the doctor	358(22%)	488(30.3%)	753(30%)	1609

3.1 Conclusion, implications and recommendations

The findings suggest that the majority of home based care needed assistance with instrumental activities of living compared to activities of daily living (ADL). It is important for those caring for clients on home based care to help clients with instrumental activities of living since there is tendencies to ignore them and only focus on ADL.

4. Satisfaction with assistance from caregiver

An assumption was made that the satisfaction a client had with assistance from caregiver is a measure of how the client rated the quality of care of their home care. If the client was very satisfied it was assumed that the client was quite comfortable with their home care. The results indicate that majority of clients reported being satisfied with assistance in care they received and only a few numbers reported being unsatisfied with their assistance from care givers.

Table 4.1 Showing Satisfaction with caregiver.

Satisfaction with	Satisfied	Dissatisfied	Not sure	Total
Bathing and dressing	710(44.1%)	83(5.1%)	815(50.6%)	1608
Getting out of bed	597(37%)	68(4.2%)	945(58.6%)	1610
Walking	760(47.2%)	97(6%)	753(46.7%)	1610
Toileting	599(37.3%)	82(5%)	929(57.7%)	1610
Eating	415(25.7%)	59(3.7%)	1136(70.6%)	1610
Preparation of food	1112(69.0%)	144(9.0%)	354(22.0%)	1610
Medication & treatment	810(50.4%)	120(7.4%)	680(42.2%)	1610
Shopping	1118(69.4%)	136(8.4%)	356(22.2%)	1610
Housework	1193(74%)	143(9.0%)	274(17%)	1610
Managing money	761(47.2%)	103(6.4%)	746(46.4%)	1610
Communication	936(58.2%)	140(8.6%)	534(33.2%)	1610
Going to visit a doctor	1073(66.6%)	173(10.8%)	364(22.6%)	1610

4.1 Conclusion, implications and recommendations

Clients' opinion on the care they received was done in the presence of the caregiver. The overwhelming satisfaction with the care could mean that the clients were actually satisfied or this was a conditioned response for fear of being abandoned by their caregivers. Factors that were of concern need to be further investigated such as bathing and dressing, getting out of bed, toileting and eating and managing money so as to come up

with solutions to improve quality of care for home care. Interviewing the client separately may have produced different responses.

5. Continuum of care

In this section information assessing continuity of care was elicited from the clients. Out of 1610 respondents 53.4% had been admitted to hospital for this current illness. Out of those who had been admitted information on discharge planning was elicited. On discharge 89% were given medication to take home. The most common drugs prescribed were antibiotics, analgesics, anti-hypertensive drugs, anti-epileptics, anti-Tb drugs, Co-trimoxazole, anti asthmatics, cancer drugs, and anti-retroviral.

Of concern is that 44% clients reported that they did not receive any information on follow up given the chronic nature of their illness, 60% reported that they were not told who to contact in case of problems, 61% did not have information about care at home, 65% did not get information on medication and possible side effects, 87% did not know where to get a counsellor from, 78% were not introduced to a community nurse, 62% did not receive information on nutrition, 44% did not know where to get the prescribed medication from, 56% did not have any information on self care.

Table 5.1 Showing Continuum of care.

Aspect of Continuum of care	Yes	No	Total
Medication to take home	766(89.3%)	91(10.7%)	867
Where to get medication	478(56.0%)	374(44%)	852
Discussion about follow up care	475(55.4%)	382(44.6%)	857
Self care	372(43.6%)	480(56.4%)	852
Who to contact when help needed	343(40.2%)	509(59.8%)	852
Information regarding care at home	328(38.4%)	524(61.6%)	852
What foods to eat and avoid	324(38.0%)	528(62%)	852
Medication and possible side effect	297(34.8%)	555(65.2%)	852
Introduction to Community nurse	189(22%)	663(78%)	852
Where to get a counsellor	113(13%)	739(87%)	852

5.1 Conclusion, implications and recommendations

There is need to examine discharge planning policy and practice at health institution level with the view to strengthening the critical aspects i.e. medication to take home, discussion about follow up care, who to contact when help needed, information regarding care at home, medication & possible side effects, where to get medication and where to get counselor.

6. Psycho- social support

Being chronically sick or ill is a stressful life event and requires emotional support from friends and family. Respondents verbalized that the family gave most of the emotional

and social support followed by the church. Neighbours gave the least emotional and social support and friends did not give much emotional and social support.

Table 6.1 Showing Psycho – social support for the client.

Aspect of life	None	A little	A lot	Totals
Emotional support from family	351(21.8%)	670(41.6%)	586(34.6%)	1607
Emotional support from friends	674(42.0%)	714(44.5%)	217(13.5%)	1605
Emotional support from neighbours	590(37.0%)	811(50.6%)	200(12.4%)	1601
Emotional support from church	692(43.2%)	595(37.2%)	314(19.6%)	1601
Social support from church	970(60.5%)	472(29.5%)	161(10%)	1603
Social support from family	519(32.3%)	671(41.8%)	417(25.9%)	1607
Social support from friends	980(61.2%)	512(32%)	110(6.8%)	1602
Social support from neighbours	966(60.2%)	548(34.1%)	91(5.7%)	1605

6.1 Conclusion, implications and recommendations

The low involvement of the neighbours and friends in giving support could be linked with fear of stigmatisation and discrimination. It may also have been because support offered by friends and neighbours was not perceived by clients as support or was inappropriate or considered interference. Families need to be made aware of the value that clients place on family and church support and is of no cost.

7. Medication

Most client are discharged on medication and it is important to ascertain whether they are able to obtain medication, what the medication is for and side effects of medications. Getting medication when required can be affected by many factors including unavailability, inability to purchase, knowing where to purchase and others. Getting

medication when needed was a major problem cited by 71% of all respondents. Inability to purchase medicines may have been one of the major factors in not getting medicines when needed.

The clients had a lot of problems in buying medication. At least 83% reported having problems in purchasing medications. Forty five percent had problems with medications working well

Table 7.1 Showing Rating related to patient's medication.

Rating of the following	No problems	Some problems	A lot of problems	N
Getting medication when needed	447(28.2%)	385(24.3%)	754(47.5%)	1586
Ability to buy medication	245(15.5%)	245(15.5%)	1090(69%)	1580
Medication working well	827(53.2%)	567(36.5%)	159(10.3%)	1553
Problems related to medication	1034(66.2%)	411(26.3%)	116(7.5%)	1561

7.1 Conclusion, implications and recommendations

Given the current socio economic problems where most people are unable to purchase basic food items, purchase of medications may be foregone by many. The problem of medications not working well may have been because the medication was not being adhered to correctly given the inability to purchase them. Perceiving medication as not working well can affect compliance.

Problems related to taking medication were uncommon and this may reflect that the medication was not being taken because it was not there.

8. Pain management in Home based care clients

Pain management is an important component of home-based care. To assess effectiveness of pain management of chronically ill at home clients were asked to rate

their perception of pain at the interview. Eighty-eight percent complained of pain. This high number suggests that there is need to improve pain control in order to improve the quality of care in the home

Table 8.1 Showing clients' perception of the effectiveness of pain management in home based care

Variable	No Pain	Moderate Pain	Severe Pain	N
Pain	169(10.6%)	946(59.5%)	474(29.9%)	1589

8.1 Conclusion, implications and recommendations

The management of pain in home-based care is an important component of care if the quality of care is to be improved. Pain management is often overlooked yet a patient who is free from pain is a comfortable patient who can sleep and eat the recommended nutritious diets. Therefore pain management should be an important component of home-based care.

PERCEPTION OF QUALITY OF HOME BASED CARE BY HIV/AIDS CARE FACILITATORS

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PERCEPTION OF QUALITY OF HOME BASED CARE BY HIV/AIDS CARE

FACILITATORS

INTRODUCTION

This paper presents the results from the Home based care – care facilitators' questionnaire, which was part of national HIV/AIDS care situation analysis survey. The aim of this particular questionnaire was to gather information that characterizes the prevailing situation with regards to home-based care services. This questionnaire incorporated four sections.

Section 1 included demographic data such as gender, age, employer and qualification. Section 2 elicited information on the caregiver perspective on services such as number of clients receiving care, the amount of care needed, provision of basic equipment for care, frequency of patient visit, support for primary caregivers, needs of primary caregivers, and record keeping. Also included was the care facilitators' perception of whether client services such as counselling, education client teaching, pain management, networking and providing assistance with activities of daily living where being provided.

Section 3 included the care facilitators' self-assessment of stress using the Brief encounter perceived stress instrument. Section 4 was a general section that consisted of open-ended questions aimed at eliciting a deeper insight into respondents' perception of the quality of care being delivered in their catchment area.

RESULTS

Results are presented according to the four main sections of the questionnaire: description of the respondents, care-facilitators' perspectives on client care, care facilitators' perceived stress and further perspectives of quality of home-based care.

1. DESCRIPTION OF RESPONDENTS

The respondents consisted of health personnel who supervised home-based care throughout the country. Although this group of health personnel mostly supervise the primary caregivers in caring for the sick person at home the group also gives direct care to the clients in the home. They may be registered trained nurses or Red-Cross trained nurse aids and other volunteers. These are sometimes known as Trainers of trainers, formal caregivers or Care facilitators. In this paper they will be referred to as care facilitators. The breakdown of respondents is shown on Table 1.1 below.

Table 1.1 showing demographic data of respondents

VARIABLE	FREQUENCY	PERCENTAGE
SEX		
Male	88	12.4%
Female	621	87.6%
Total	709	100%
EDUCATION LEVEL		
Never been to school	10	1.42%
Primary	344	48.88%
Secondary	293	41.61%
Tertiary level	57	8.09%
Total	704	100.00%
EMPLOYER		
Ministry of health	91	13.03%
Mission	14	2.00%
Private	13	1.86%
NGO	63	9.02%
Volunteers	422	60.45%
Church groups and other	95	13.64%
Total	698	100.00%
QUALIFICATIONS		
State certified nurse	29	4.1%
State registered nurse	66	9.3%
Bachelor of science nursing	2	0.3%
Non nurses	504	71.1%
Unspecified qualification	108	15.2%
Total	709	100.00%

Seven hundred and nine care facilitators responded to this questionnaire. As expected, a higher percentage (87.6%) of care facilitators were female compared to only 12.4% male.

Most (97.9%) facilitators had formal schooling. Almost half (48.5%) had attained primary education, 41.3% had reached secondary education and 8% had achieved tertiary education. These findings show an unexpected higher literacy rate for Zimbabwe, considering that most of the respondents were from the rural areas.

Most (59.5%) of the facilitators were volunteers. The Ministry of Health employees comprised only 12.8% and NGO employees only 8.8%, Mission 1.9%, private 1.8%. There was a sizeable number (13.4%) that were employed by other various groups that included church groups.

Regarding the qualification of all respondents, State certified nurses comprised 4.1%. State registered nurses, 9.3%, degree nurses, 0.3% and non-nurses 71%. There were also 15.2% who did not specify their qualification.

1.1 Conclusion, implications and Recommendations

Most of the care facilitators who responded to the questionnaire were women and non-nurses. There is a need to increase the number of care facilitators who are trained nurses to ensure uniformity in the provision of home-based care. There is also a need to increase more male facilitators to assist in caring for male clients and assist specific procedures in the home that require male personnel.

2. THE CARE-FACILITATORS' PERSPECTIVE ON PATIENT CARE

The following section presents the care facilitators' perspective on patient care. This included their assessment of the patient load in their area of practice, the load of supervising informal caregivers, the adequacy / provision of personnel and material resources within their area of practice

2.1 The patient load and supervision load.

Table 2.1 Showing facilitators' assessment of the degree of patient load

Patient Supervision load	Minimal	Satisfactory	Moderate	Maximal	Total
Facilitators' rating of patient load for all clients in their areas	48.04%	20.69%	8.24%	23.01%	691
Facilitators' rating of patient load for clients they care for directly	70.09%	16.07%	5.14%	8.68%	622
Rating of total patient care needed by clients in the areas	31.5	34.58%	24.31%	9.55%	691

Care facilitators were asked to rate the patient load in terms of numbers of patients cared for in their catchment areas. Patient load was rated minimum if there were five or less patients, satisfactory if there were six to ten, moderate if there were eleven to fifteen, and high if there were sixteen and above.

Three hundred and thirty two (48.04%) reported a minimal patient load, 143(20.69%), reported a satisfactory patient load while 57(8.24%) reported a moderate patient load and 159 (23.01%) reported a high patient load in their catchment area.

Out of the 691 clients reported in the catchment areas, the care facilitators reported that they cared directly for 622 clients. Out of these, 70.09% needed minimal care, 16.07% needed a minimal to moderate care, 5.14% needed moderate care and 8.68% needed a high level of patient care.

Patient load can also be seen in terms of the amount of care that a patient needs expressed in percentage of total patient care. Total patient care is a situation where the clients cannot perform any of the activities of living unaided. This requires a caregiver round the clock for such a person. This situation may arise when the patient is very ill. As the patients improves it is expected that the need for total patient care diminish until the client attains self-care. In this survey the rating of need of total care varied from minimal to total care. Just over thirty percent (31.54%) required minimal total patient care. Another 34.58% required satisfactory total patient care, 24.31% required moderate total patient care and 9.55% needed high level or full total patient care.

Table 2.2 Showing facilitators' assessment of the degree of supervision load

Supervision load	Minimum	Satisfactory	Moderate	High	Total
Facilitators' Perception of their supervision load	348 (54.3%)	141 (22.03%)	44 (6.87%)	107 (16.7%)	640 (100%)

The care facilitators also reported their supervision load in terms of the number of primary caregivers they supervised. Three hundred and forty eight facilitators (54.37%) reported their supervision load as minimal, 141(22.03%) reported a minimal -moderate load, 44 (6.87%) reported a moderate load and 107 (16.71%) reported a high load.

2.2 Conclusion, implications and Recommendations

According to the results most care facilitators reported minimal workload in terms of numbers of patient care given. Workload should not be seen as a function of only these two entities. Distance travelled to give should be factored in as well in the workload equation.

$Work\ load = number\ of\ patients \times percentage\ of\ total\ care \times distance\ travelled$

2.3 The adequacy in provision of personnel material, resources and record keeping in home-based care

Care facilitators were asked to rate the availability of staff, basic material for home-based care, and their record keeping skills. The most basic and essential materials for home-based care included (but not exclusive) provision of gloves mackintoshes, disinfectants and transport. These are shown on table 2.3 below.

Table 2.3 showing care facilitators' rating of record keeping, provision of personnel and material resources for home-based care

N = 709

	N	Poor	Satisfactory	Very good	Excellent
Provision of staff in catchment areas	690	31.44%	53.76%	12.17%	2.69%
Provision of gloves for care	685	63.35	29.63%	5.10%	2.18%
Provision of mackintoshes for clients	699	85.26%	12.44%	2.14%	0.1%
Provision of disinfectants	678	80.08%	15.48%	3.98%	0.4%
Provision of transport	698	88.25%	8.88%	2.29%	0.57%
Rating of record keeping	700	21.85%	54.28%	18.0%	5.85%

2.4 The provision of staff for home based

Introduction

The provision of adequate staff for home-based care is crucial for if the quality of care in the home is to be realized. the staff is composed of care facilitators, formal and informal caregivers. The best assessor of adequacy for the staff is usually the staff themselves. Care facilitators were asked to rate the provision of staff in their catchment area. Seven hundred and nine care facilitators responded to this question. The provision of staff was rated as poor (31.44%), satisfactory (53.76%), (12.17%) felt staff provisions were very good, and (2.60%) excellent.

2.5 The provision of basic material for home-based care

Introduction

The provision of basic materials such as gloves, protective clothing such as mackintoshes and disinfectants is essential in the delivery of home-based care

The respondents rated the provision of gloves as poor (63.35%), satisfactory (29.63%), very good (5.1%), and excellent (2.18%). The provision for mackintosh mats for incontinent clients was perceived as poor (85.26%), satisfactory (12.44%), very good (2.14%) and excellent (0.1%). The provision of disinfectants was perceived by most as poor (80.08%), and satisfactory (15.48%). Only a few felt the provision was very good (3.98%) or excellent (0.4%).

2.6 Provision of transport for home based care

Transport for home-based care is a problem. This is reflected by a rating of poor provision (88.25%), satisfactory provision (8.88%), very good provision (2.29%), and excellent provision (0.57%). This is quite disturbing since in home-based care patient are spread out and not grouped in one location as in an institution. This requires the care-facilitator to travel extensively either to supervise care or to give direct care

2.7 Care facilitators self-rating of record keeping

Introduction

Accurate records are crucial in documenting the quality of care and burden of care. Care facilitators rated their record keeping as poor (21.6%) satisfactory (54.28%), very good (18.0%) and excellent (5.85%). This self-evaluation indicates that care facilitators do not

always keep accurate records. This is not surprising since most of the care-facilitators in this survey were not trained professionals but volunteers.

A. 2.8 Conclusions, implications and recommendations

The provision of staff in home-based care is very poor. This low rating may compromise the quality of home-based care. Although the respondents had reported a minimal load of client care in the section above, their perception of poor availability of staff may indicate that the available numbers are not adequate to meet the patient load. There is therefore a need to increase the number of home-based care facilitators to improve the quality of care in the home.

The provision of basic material for delivery of care was rated low. There is a need to increase and standardize the supply of basic materials for home-based care. There is a need to standardize the basic home-based care kit and provide this equitable to every client.

Poor transport facilities further compromises contact with clients and primary caregivers. Transport issues need to be investigated and improved.

Record keeping is an important activity to ensure accountability, national statistics, monitoring and evaluation of programs. Care facilitators need to keep a register of clients, material, in terms of numbers. This facilitates planning for adequate personnel and material resources to meet the needs of the clients at home. There is a need to include record keeping in training of care facilitators.

2.9 Contact time with primary caregivers

Care facilitators keep in touch with primary caregivers to give support, counsel, to train, give information and to provide basic commodities for home-based care. The frequency of the visits depends on the needs of the primary care givers. Care facilitators were asked to state how often they were in contact with the primary caregivers, and also state what would be ideal frequency of these visits. Table below shows the distribution of the reported actual and perceived ideal frequency of visits to the primary caregivers.

Table 2.3 showing the actual and the perceived ideal frequency of contact facilitators have with caregivers

	N	DAILY	WEEKLY	FORTNIGHTLY	MONTHLY
Number of contacts with caregivers	676	15.9%	58.51%	8.57%	16.86%
Ideal number of contacts desired	685	40.29%	42.48%	7.44%	9.78%

Care facilitators reported they were in contact with caregiver's daily (15.9%), weekly (58.51%), fortnightly (8.57%), and monthly (16.86%).

Care facilitators reported that ideal they would like contact with caregivers daily (40.29%) weekly (42.48%) fortnightly (7.44%) and monthly (9.78%).

Care facilitators reported that they would like to be in contact with the primary caregiver in the home more frequently than was possible for them. Although no follow up question

was asked to enquire about the reason why they did not contact primary caregivers as often as they felt necessary, one of the problems could be the poor transport could be the issue here. Shortage of transport has been cited as a major problem in providing quality care.

2.10 Services available in the community for the client

These questions addressed the services that are provided in the community. The services such as counselling, client teaching, pain management, and assisting the client with activities of daily living are provided adequately as shown on table 2.4

Table 2.4 showing the frequency of services available in the community

N = 709

Type of service	Frequency	Percentage
Counselling		
B. Preventive	659	92.9%
Supportive	655	92%
Bereavement	602	84.9%
Nutritional	640	90%
Disclosure	466	65%
Client teaching		
C. On HIV/AIDS	671	94.6%
On infection	686	96%
On nutrition	683	96%
On family planning	552	77%
Pain management		
D. Assessing patients pain	595	83.9%
Pharmacological pain relief	450	63.5%
Non-pharmacological pain relief	425	59.9%
Evaluation of effectiveness	463	65.3%
Networking clients with other services such as		
E. Hospice care	239	33%
Social services	381	53%
Traditional healers	238	33.6%
Spiritual services	462	65.2%
Assisting client with activities of daily living		
F. Bathing and dressing	660	93.1%
Preparing food and feeding client	643	90.7%
Toileting and caring for soiled linen	635	89.6%
Medication	581	81.9%
Wound dressing	540	76.2%
Other activities	83	11.7%

However there is a paucity of networking for clients in the community. Other services provided included housework, prior supply of materials and projects.

2.11 Recommendation

There is a need to provide for or create awareness that there is hospice facility in the country to provide respite for caregivers.

3. CARE FACILITATORS' PERCEIVED STRESS

Stress related with care giving has been documented as caregiver stress or burden. Caregiver burden is detrimental to the caregiver's health and may compromise the care that the client is receiving. It is necessary to assess stress and offer counselling and stress management to improve the health of the caregivers. The care facilitators whom also provide care for the clients responded to five indicators of stress.

Table 3.1 showing care facilitators' perceived stress

	N	Never	Occasional	Sometimes	Often	Always
Emotional stress	697	47.34%	14.77%	26.82%	5.16%	5.88%
Frustrated	697	50.93%	16.49%	21.09%	5.30%	6.16%
Needs being met	696	41.09%	18.53%	22.12%	6.46%	11.78%
Apprehension about future	696	44.68%	15.37%	27.01%	5.45%	7.47%
Lost sight of important things	697	51.79%	17.50%	20.80%	4.59%	5.30%

Forty six percent of care facilitators reported no feelings of emotional stress on their lives, although 61.8% said that they felt emotional demands, which occurred, ranging from occasionally to always. Over half (50.1%) reported no feelings of frustration since they stated caring for the clients. 48.2% reported feelings of frustration. Although most (59.7%) felt that their need as individuals were being met quite a large number (40.3%) felt their need were not being met. Concerning the future, 43.8% felt no apprehension about the future while 56.2% felt apprehensive. Most respondents (50.9%) felt they had

so many hassles that they lost sight of important things. 17.2% felt this way occasionally, 20.5% sometimes, 4.5% often and 5.2%.

4. CAREGIVERS' PERCEPTION OF FACTORS THAT AFFECT THE QUALITY OF CARE IN THE CATCHMENT AREAS

Respondents were asked the following general open questions. Qualitative data was obtained as a response to each question. Responses were arranged into themes. The resulting themes in each question were quantified and expressed into percentages. Information from each question has is presented in related subheading and tables below.

4.1 Care facilitators' perception of the needs of clients with HIV/AIDS

Seven hundred and nine responded to this question. Each individual listed what he or she thought were the needs of HIV/AIDS clients. Multiple needs were cited. These were counted and are shown on table 4.1 below.

Table 4.1 Showing care facilitators perception of the needs of clients with HIV/AIDS**N = 709**

Need	Frequency	Percentage
Food Adequate Nutrition	603	85.0%
Drugs	329	46.4%
Clothing/Bedding	232	32.7%
Basic care supplies	379	53.4%
Counselling support	384	54.1%
Finance	289	40.7%
Transport	18	2.53%
Caregivers/care	23	3.24%
Health Education	18	2.53%
Accommodation	6	0.85%

The most common needs that were cited were food (85.0%), drugs (46.4%), clothing/bedding (32.7%), basic care material/supplies (53.4%), social/social support (54.1%) and financial support (40.7%), transport (2.53%), more caregiver (3.24%, health education (2.53%), and accommodation (0.85%).

Food and nutrition is a very important aspect in the care of the AIDS/HIV clients. The wasting characteristic of the disease could be controlled to some extent if the clients have adequate diet. Most of the clients in this survey came from the rural areas, an area that is hard hit by the current economic problems. There is a need to consider basic necessities such as food and clothing when undertaking HIV/AIDS programmes. Although there are many NGOs providing basic home-based kits, over fifty percent of care facilitators felt there is still a need to supply the clients.

4.2 Adequacy of home based care

Care facilitators were asked to rate the adequacy of home-based care in the country. While 183 (25.6%) felt home based care provided was adequate, the majority of respondents (74.4%) felt that the services were inadequate.

Table 4.2 showing care facilitators' perception of **adequacy of home-based care**

N = 709

Comments on adequacy of home based care	Frequency	Percentage
Adequate	182	25.6)
Inadequate	527	74.4%

4.3 Ability of primary caregivers to administer care

Respondents were asked to comment on the ability of primary caregivers to administer care. Various responses were given. The responses were grouped into three categories managing well, not managing, and managing but need training/equipment or support. Table below shows the distribution of responses.

Tables 4.3 showing care facilitators' perception of the Ability of primary caregivers to administer care

	Frequency	Percentage
Managing	457	64.4%
Not managing	190	26.7%
Managing but need assistance/training/equipment.	21	2.9%

Most (64.4%) of the care facilitators felt that primary caregiver were managing very well and 26.7% thought they were not managing at all. Just below three percent (2.9%) felt they are managing but need some assistance such as training or supply of basic equipment.

4.3 The support the Care facilitators' need from the health sector

Respondents reported that they need various forms of assistance from the formal health sector. These have been grouped into categories shown on table below.

Table 4.4 showing the type of support the care facilitators need from the health sector

N = 709

	Frequency	Percentage
Adequate drugs for clients	208	28.6%
Adequate basic resources to provide care to clients	709	100%
Financial allowance/Pay roll	64	9%
Training	51	7.1%
Clothing and blankets for clients	203	28.6%
Social support/ social	107	15%
Transport	18	2.5%

All the respondents stated that they needed the formal health sector to provide them with adequate basic resources to enable them to provide care for the clients. They also needed adequate drugs for the clients (28.6%), financial assistance or a form of payroll (9%), training in caring skills, (7.1%), clothing for clients (28.6%), social support and social (15%), and transport facilities (2.5%).

4.5 Factors that hinder the provision of quality care

Respondents stated many different aspects that hinder the provision of quality care.

Those have been grouped and shown in the table below.

Table 4.5 showing perceived factors that hinder provision of quality of care

	Frequency	Percentage
Allowance not given to care givers	170	23.9%
Bad attitude of workers	10	1.9%
Cultural factors	71	10%
Provision of food to patients	39	5.5%
Provision of drugs to clients	20	3.8%
Lack of information for clients	30	4.7%
Lack of emotional support	50	9.5%
Unsatisfactory performance of care givers	290	40.9%
Lack of Basic supplies	11	2.1%
Lack of transparency	10	1.9%
Insufficient workers	52	7.3%
Insufficient training of workers	55	10.5%
Unsafe environment	46	6.4%
Transport	50	9.5%

Although 64% of the care facilitators felt the primary caregiver was managing well in delivering the care to clients, 40.9% of these respondents cited unsatisfactory performance of the primary caregivers as one of the factors hindering delivery of care. The next largest percentage (23.9%) cited lack of allowance as another major factor hindering delivery of quality of care. Other factors included food, bad attitude, culture, drugs, information, emotional support, and basic supplies, number of workers, transport training and unsafe environment.

4.6 Factors enhancing quality of care

Respondents were asked to name factors that necessary that would enhance the quality of care in the home. Provision of adequate resources for care was the most cited factor (95%). Other factors included provision of adequate drugs (7.4%), commitment of the staff (8%), provision of social support and counseling for clients (8.9 %), community involvement 1.8%), training (6.2%), motivation for staff (6.3%), and transport facilities (7.8%). It is interesting to find that provision of basic care kits is seen as the most important here, followed by food supply

Table 4.6 showing perceived factors that enhance quality of care

	Frequency	Percentage
Adequate resources	680	95.9%
Adequate food	94	13.2%
Counseling	63	8.9%
Commitment of staff	57	8%
Adequate manpower	56	7.8%
Transport	56	7.8%
Adequate drugs	52	7.4%
Social support and counseling	55	7.7%
Training	44	6.2%
Knowledge	44	6.2%
Motivation	43	6.1%
Community involvement	13	1.8%

Care facilitators perceived needs of informal caregivers of HIV/AIDS

When care facilitators were asked to list what they thought were the needs of primary or informal caregivers, most 516 (72.2%) stated provision of basic care kits. This was followed again by food. In this case the food is not for clients but for the primary caregiver. This makes sense since most of the primary caregivers are family members; if the client needs food, the primary caregiver will certainly also need food. The same goes for the supply of basic supplies for care that would come from the family budget unless these are provided from the care agencies. Other basic commodities that surface in this section is the need for bicycles and transport, clothing/blankets 215 (30%) and uniforms for the primary caregiver. It is interesting how only a few 36 (5%) care facilitators cite financial support for the primary care givers.

Table 4.7 showing Care facilitators perceived needs of informal caregivers of HIV/AIDS

	Frequency	Percentage
Materials to give basic care	516	72.2%
Food	468	66%
Clothing/Blankets	215	30.3%
Training in Home Based Care	153	21.5%
Bicycles/Transport	73	10.2%
Drugs for clients	52	7.4%
Information/Education	47	6.6%
Financial support/ incentive	36	5%
Counselling/Support	35	4.9%
Uniforms	27	3.8%

4.8 Care facilitators' perception of their needs as caregivers.

This section required the respondents to list their needs as caregivers. The needs are summarized and presented in the table 4.8 below.

Table 4.8 showing care facilitators' perception of their own needs as caregivers

N = 709

	Frequency	Percentage
Supply of basic care materials	502	70.8%
Blankets/clothing	166	23.4
Transport	162	22.8%
Drugs, medication	145	20.4%
Food	123	17.3%
Bicycles	122	17.2%
Financial support/ allowances/	102	14.3%
Uniforms	82	11.5%
Counselling, support	47	6.6%
Training	41	5.7%

Most 502 (70.8%) care facilitators said they needed basic supplies to do their work. They also cited transport 162 (22.8%), medication for clients 145 (20.4%), food 123 (17.3%). Of interest is the need for financial allowance that was cited by almost three times as compared to the needs of the primary care givers. When planning distribution of resources a direct inquiry to the primary caregiver should be done to avoid bias.

4.9 Training received by care facilitators regarding home based care

The respondents were asked to list subject areas that were covered in training concerning home-based care. The list of the areas is presented in table 4.9 below.

Table 4.9 showing areas that were covered in home-based care training

N = 709

	Frequency	Percentage
Basic nursing care	619	87.3%
Information on AIDS	207	29.1%
Counselling	57	8%
Communication	48	6.7%
Giving medication	38	5.3%

Five different areas were covered in the training for home-based care. Two hundred and seven (29.1%) stated that they received information on HIV/AIDS, 57 (8%) stated they had information on counselling, 38(5.3%) information on giving medication, 619 (87.3%) received information on basic nursing care and 48 (6.7%) information on communication.

Although five areas important in home based care were cited, their coverage was inconsistent. For example very few people said they received information on the disease HIV/AIDS, counselling, communication, and giving medication. It makes one wonder how they are doing these procedures if they had not been given an input.

4.10 Adequacy of training received by care facilitators in home based care

Care facilitators were then asked to rate the adequacy of training they received. The respondents were split almost in half concerning the adequacy of the training, with the exception of 56 (8%) respondents who offered no comments. There is a need to standardize the training for home-based care for all home-based care personnel.

Table 4.10 showing rating of adequacy of training in home based care for care facilitators

N = 709

	Frequency	Percentage
Adequate	330	46.5%
Inadequate	323	45.5%
No comments	56	8%

Care facilitators' perception of how the training should be improved

The areas of improvement cited by the respondents were consistent with areas that were poorly covered in their training (see table 4.9). Care facilitators expressed that the training in home based care should be longer (11.2%), include bereavement counselling (26.3%), offer advanced courses (2.8%), include communication (13.6%), give more information on HIV/AIDS (15%), offer refresher courses (50.1%), and more basic care (16%). Only 114 (2.8%) people thought the training was all right as it was.

Table 4.11 showing care facilitators' perception on how training on home-based care should be improved

N = 709

	Frequency	Percentage
Refresher courses	357	50.1. %
Add bereavement counselling	187	26.3
More on basic care	114	16%
Give more information	107	15%
Communication	97	13.6%
Increase training	80	11.2%
Continuous training	47	6.6%
Give advanced courses	20	2.8%
Nothing needs to be done	14	1.9%

4.12 Other information concerning home-based care

Respondents provided other information that they felt was of concern in home based care. The table below shows the emphasis that is repeated throughout this section. The need for provision of food, social support, basic care resources, and training was repeated as important aspects of home based care. Other new aspects that evolved include the realization that home-based care is important but inadequately provided, the need to involve community and that caregivers need financial assistance in the form of allowances.

Table 4.12 showing other information concerning home based care.

N = 709

	Frequency	Percentage
There is a need to address lack of basic resources	307	43.3%
Home based care is inadequate	195	27.5%
Give allowance to care givers	124	17.4%
Home based care is important	70	9.8%
Provision of food	62	8.7%
Training	53	7.4%
Involve the community	48	6.7%
Caregivers need social support	38	5.3%

4.13 Overall rating of the quality of home based care in the country

Lastly the respondents were asked to give an overall rating of the quality of home-based care in the country. The results are shown in the table below.

Table 4.13 showing overall rating of the quality of home-based care by care- facilitators

N = 709

Overall rating	Frequency	Percentage
Poor	206	29.1%
Satisfactory	359	50.6%
Very good	114	16.1%
Excellent	29	4.1%

Most (50.6%) of the respondents thought the quality was satisfactory, 206(29.1%) said it was poor, 114 (16.1%) said it was good and 29(4.1%) said it was excellent.

PERCEPTION OF QUALITY OF HOME BASED CARE BY INFORMAL HIV/AIDS CARE GIVERS

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PERCEPTION OF QUALITY OF HOME BASED CARE BY INFORMAL HIV/AIDS CARE GIVERS

INTRODUCTION

This paper presents the results from the Home based care – informal caregiver questionnaire which was part of a C.E.U. HAQOCI situation analysis survey. The purpose of this particular questionnaire was to gather information that characterizes the prevailing situation with regards to home – based care services. The questionnaire incorporated five sections: 1. Demographic data, 2. Assessment of training received on home – based care, 3. Assessment of knowledge and skills on caring for the sick, 4. Caregiver perceived stress and 5. Perceived workload.

1.0 RESULTS

The results are presented according to the five main sections of the questionnaire: description of the respondents, assessment of the home based care training received, assessment of the knowledge and skills of the informal care giver, the results of the Brief encounter perceived stress instruments and the work load of the informal care giver.

1.1 Description of the respondents

Respondents were recruited fairly evenly from the 10 provinces of Zimbabwe. Each province yielded about 120 respondents except Harare, from which a sample of 40 respondents was generated. There were 1475 respondents, 84.3% of whom were female. Most of these respondents (27.8%) were wives looking after husbands, followed by parents looking after their children (24.1%), then 17.3% children looking after their parents and children looking after their siblings (8.7%). Grand parents (7.8%), friends (1%), and volunteers (2%) were also involved in caring for the HIV/AIDS and chronically ill

clients in the home. Over 50% of the respondents were educated up to primary school level, 28.1% reached secondary level, 19.1% and had never been to formal school. Quite a small number of respondents (1%) declined to state their educational experience.

2.0 Training on Home based care

Most respondents (83.7%) had not received training in home-based care. Of those who received training, the duration of training was reported ranging from 15 minutes to 3 years.

2.1 Conclusions implications and recommendations

The results concerning training on home based care seem to show a misunderstanding between training and giving of instructions on care. Discrepancy also existed in understanding of formal training and informal training. There is lack of standardization in the length of the training period for home-based care. Therefore there is a need to look into the available training program in terms of training content, duration and process for purposes of standardization. There is a need to develop training manuals in home-based care for the nurses, and volunteer caregivers to bring standardization.

2.2 Assessment of training in Home-based care

Respondents reported that they received training from various governmental and non-governmental agents ranging from informal health workers such as care givers/facilitators to State registered nurses. The majority received training from government employed nurses (123), while Red Cross care facilitators trained 36 and 61 were trained by other non-governmental organisations. Table 2 below shows the various areas that were covered in training.

Table 2.1 showing the percentage of respondents trained by area of training.

AREA OF TRAINING	FREQUENCY	%
General Training		
Chronic illness	208	86
Terminal illness	185	76.7
HIV/AIDS	169	70.1
Assessing vital signs		
Temperature, pulse, respiration and blood pressure	63	26.1
Nutrition		
Food preparation	222	92.1
-Feeding client	222	92.1
Assess hydration	159	65.9
Preparation of SSS	228	94.6
General client hygiene		
Bathing and dressing client	211	87.5
Assisting client with oral care	186	77.1
Assisting clients with toileting	210	87.1
Providing a safe environment		
Provide restful environment	231	95.8
Provide clean environment	238	98.7
How and when to use disinfectants	144	59.7
Handle soiled linen	182	75.5
Mobilization		
Assist client exercise	178	73.8
Turning client in bed	191	79.2
Lifting client	193	80
Medication		
Obtaining medication for client	204	84.6
Giving medication to client	208	86
Bereavement		
What to do when an emergency arises	145	60.1
What to do if client dies	119	49.3
Counselling of relatives	144	59.7
Caregiver self care		
Prevention of cross infection	203	84.2
Getting rest and sleep	188	78
Exercise	180	74.6
Eating well	215	89.2
Exercise	180	74.6

2.3 Conclusion implications, and recommendation

From the above results it would appear that the basic components of home based care were covered in most of the training, There is need to examine the quality of this training to ensure standardization

3.0 Assessment on knowledge and skills in home based care

Participants were asked to rate their skills performance on providing the activities of daily living to clients. The rating also indicated their competence in carrying out the skills. The table below shows how the participants rated themselves.

Table 3.1 showing the levels of competence of all informal caregivers in providing home care to the sick client at home.

Activity	Not competent	Somewhat competent	Very competent
Bathing	192	682	574
Dressing	163	680	606
Getting out of bed	162	674	609
Walking	166	694	583
Toileting	184	715	535
Eating/drinking	111	622	688
Medication	205	605	561
Housework	129	561	773
Managing finances	224	700	521
Communication	108	555	578
Providing a clean environment	114	531	808
Using disinfectants	878	343	235
Obtaining disinfectants	1074	219	165

3.1 Conclusions, implications, and recommendations

There appears to be a high level of knowledge and skills on HBC despite the low and inconsistent training in this population. The implications for practice are that care needs to be taken when recruiting informal care providers who may appear know it all. There is need to ascertain whether this knowledge is consistent with the proper way of carrying out these activities. The procurement and use of disinfectants that are crucial in maintaining a safe environment seem to be less known by this population. There is need to include this essential component in the basic HBC training.

4.0 Care-giver perceived stress

Participants were asked to rate their perception of stress in relation with caring for the sick at home. Each respondent responded to a five-item Likert scale that is designed to measure stress. The results of caregivers' self-perception of stress are shown on table below.

Table 4.1 shows the respondents' brief encounter perceived stress.

Encounter	Never	Occasionally /some times	Often/ Always
Demands emotionally and physically	431	581	468
Feel frustrated	425	619	427
Needs being met	399	637	424
Uncertain or apprehension about future	375	578	512
Every day hassles	467	687	415

4.1 Conclusions, implications and recommendations

The majority of the informal caregivers perceived themselves as having stress ranging from occasional to always. The consequences of this stress on care provision are that it compromises the quality of care provided and ultimately the health of the caregiver. The role of respite services in relieving stress in the community needs to be investigated. The role of family approach in managing illness at home needs to be investigated as well.

4.2 Support given to the caregiver whilst caring for the sick person

Respondents also completed a questionnaire on the different types of support they received from friends and family. The questionnaire elicited three different types of support from family and friends.

Table 5.1 illustrates the support given informal caregivers for caring for the client in the home.

Factor	Non	Some	A lot
Emotional support from family	405	669	395
Emotional support from friends	662	649	159
Emotional support from neighbours	550	774	144
Emotional support from church members	586	538	245
Social support from family	663	610	195
Social support from neighbours	776	620	71
Social support from members	774	625	96
Material support from family	648	590	230
Material support from church members	946	438	81
Material support from friends	1045	398	31
Material support from neighbours	1037	398	31

4.3 Conclusion, implications, and recommendation

Social support is an important buffering system for stress. Considering the high levels of stress reported, the support for friends and family was less than sufficient. The much more needed material and emotional support was not as forthcoming as would be expected from friends and family.

5.0 Work load

Generally 37-40 hours of work is recommended per week. This works out to 5 hours a day for seven days or 8 hours per day for 5 days a week. None of the 1474 informal caregivers reported working more than 28 hours per week. Given the reported stress levels and the low support, the hours reported may have been reflecting daytime hours only and not considering night time hours.

5.1 Leisure activities

Participants were also asked to state if they ever engaged in leisure activities. Of the 1474 respondents 57.4% reported involved in some leisure activities. The main leisure activities included going to church, gardening, visiting, resting/relaxing, knitting and selling/vending.

5.2 Perceived obstacles to taking leisure time.

Participants were asked to state any obstacles that would hinder them from taking leisure time. Most of the participants reported no known obstacles although they reported that they spent all their time was looking after the patient. However although fifty-eight respondents reported that they experienced some obstacles to leisure these were not made known.

5.3 Other assistants involved in Home-Based Care.

When participants were asked apart from themselves, who else took care of the clients; About a third (523) said no one else was available, and a small number, 38 cited non family members whilst the rest cited family members.

5.4 Conclusions, implications and recommendations

Caregiver burden has been reported in literature, which compromises the caring function. Informal caregivers need to take some respite from caring for the sick. That time can be used to go to church, library, visiting friends, or even for self-care. This is necessary maintain good physical psychological and social health of the caregiver. It appears that the participants were reluctant to leave the patient and take leisure time for themselves. There was a general feeling that they would be abandoning the client. It is necessary to give support and counselling to the caregiver to promote and maintain caregiver self-care.