'A Bridge to the Hospice': the impact of a Community Volunteer Programme in Uganda

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Abstract

In Africa, the need for palliative care provision is escalating with an increasing number of people living with HIV/Aids, coupled with a rising cancer and Aids related cancer diagnoses. In Uganda there is a shortage of Doctors particularly in the rural areas. This coupled with poor roads and transport links means that access to effective palliative care is limited. To address this Hospice Africa developed a Community Volunteer Worker programme, to train Volunteers to help in providing affordable, practical, emotional, spiritual, social and cultural support to patients in their own homes. By using members of the local communities who speak the local dialects, this Community Volunteer Programme augments the work of the Hospice team.

The aim of this qualitative study was to evaluate the impact of the Community Volunteer Worker Programme. 64 interviews, with patients (21), Community Volunteer Workers (32), and the Hospice clinical teams (11) were undertaken, using semi structured tape recorded individual, group and focus group interviews at the Hospice Africa sites in Uganda at Kampala and Hoima.

The results reported a consensus across all respondents, of the value of the impact of the Community Volunteer Worker. This included the impact on the patients and their families, including physical care, practical help, counselling and education. How they acted as a 'Bridge to the Hospice' in identifying patients with palliative care needs was one of the strongest themes to emerge. Developing financial challenges that are impacting upon the maintenance of the bicycles, as well as the ongoing support and training of the volunteers were reported. The Community Volunteer Programme is clearly having a positive impact on patients, families and the hospice team, and is a model that could be transferred to other developing countries to allow the expansion of palliative care.

Key words: Palliative Care, Community Volunteer Worker, Developing Countries

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Introduction

In Africa the need for palliative care service provision is escalating with over 25.8 million people living with HIV/AIDS in Africa. Furthermore cancer rates are expected to grow in Africa with the World Health Organisation estimating there are 0.5 million annual cancer deaths in Africa and that by 2020 70% of new cancer cases will be in the developing world.[1] For the majority of Ugandans who endure these, and other life limiting illnesses, access to effective palliative care is limited as there is a shortage of doctors with approximately 0.08 physicians per head of population, of which it is estimated that nearly 80% of the physicians practice in urban centre. Coupled with a wide geographical distribution of which approximately 90% is rural and poor transport systems.[2]

Hospice Africa Uganda has three branches in Uganda, Kampala, Mbarara (South West Uganda) and Hoima (Western Uganda). Kampala has a population of approximately 1,420,000, and Hoima, an estimated population, of approximately 435,537. The hospice provides care for patients within a 20 kilometre radius.[3] To address this, Hospice Africa has developed a Community Volunteer Worker Programme to train volunteers to provide palliative care for patients with cancer and HIV/AIDS. This home-

based programme aims to provide practical, emotional, physical and spiritual support to people in their own homes. By using members of the local community who speak the local dialect, the Community Volunteer Worker augments the work of the Hospice team by identifying patients who often live in rural communities that would normally not be seen by the Hospice team, or even know of the Hospice or its work.

Palliative Care Volunteers

In the western world volunteers are integral to palliative care services especially in the Hospice setting.[4] A systematic review of volunteers in End of Life Care undertaken by Wilson et al[5] indicated that volunteers take on a wide range of roles. These roles can be broadly classified into two categories; direct services for the patient and supportive roles including administration, fund raising, drivers, gardeners, catering support and general maintenance/housekeeping roles. [4,6,7] The impact of the volunteer is widely recognised, with studies reporting that the volunteers help to enhance the care of the dying patients and their families.[6-8] Additionally it is reported that the presence of volunteers assist the staff and are referred to as providing an invaluable resource.[7,9]

However, in developing countries the role of the palliative care volunteer is very different and is in the main community based. In India, the Neighbourhood Network in Palliative Care (NNPC) developed in Kerala is an attempt to develop a sustainable community owned service that can offer long term care and palliative care. Volunteers are trained to identify problems of the chronically ill in their area and provide intervention with the support from trained professionals.[10] This programme aims to supplement the efforts of trained health care professionals particularly in psychosocial and spiritual support. Benefits of this initiative are said to include better emotional support, increased compliance with medical and nursing advice and the earlier reporting of symptoms. A key role is the community volunteer acting as a link between the patients in the community and the health care professional.

More recently, Murray et al [11] evaluated three palliative care programmes (funded by the Diana, Princess of Wales Memorial Fund) in Kenya, Malawi and Uganda. The programmes which were constructed differently, served different client groups and used

different mechanism and had differing staffing investment, all included an element of volunteer engagement. The input of the volunteers was reported as having a vital role including direct physical care. In Malawi (where the focus of the programme is primarily HIV patients), one of the key roles of the volunteer is the detection of patients who need the input of the palliative care team. The report indicated that the programmes were having a positive impact, although key issues emerged surrounding the ongoing provision of effective palliative care in resource constrained areas.

Hospice Africa Community Volunteer Worker

The Community Volunteer Worker is defined as being *"a person who willingly undertakes tasks, uses his/her skills and knowledge for the benefit of individuals within the local communities, without expecting rewards of financial gain"* (Hospice Africa Uganda p12)[12]. To meet the eligibility criteria the Community Volunteer Worker applicant has to be resident in the local community for one year, have a basic education, be able to read and write in the local language and selected by senior members of the community, ie religious leaders and councillors, as being respected and trustworthy. Additionally, the applicant must be able to volunteer for about six hours per week. The role of the Community Volunteer is to identify and care for people needing palliative care in their own homes, offering support and advice to patients and their families (see figure 1 for the specific activities).

Training and Education

Following a successful interview, the Community Volunteer Workers undergo a six day non residential course that covers an overview of: the fundamentals of palliative care, HIV and cancer, practical aspects of nursing care (bed bathing iin the home, wound care, infection control, and nutritional advice), communication skills, end of life care, emotional support for carers, bereavement support, and the ethics of palliative care.

Ongoing education, support and supervision is provided by the Hospice team in the format of monthly meetings where the volunteers review any difficult cases, gain advice as well as identifying areas in which they would like to have additional education. Additionally there are quarterly workshops that focus upon topics that the volunteers

have identified. Additional support for the community volunteers is made by the clinical teams who serve as day-to-day link.

Service Costs

There is no payment for the volunteers, although a bicycle is provided to enable them to travel to the patients along with a bicycle maintenance fee. Costs for attendance at all meetings, are reimbursed. Additionally they are provided with a kit that includes practical items such as Savlon, gloves, soap, cotton wool, bandages. Plus a t- shirt that identifies them as Hospice volunteers, which they are encouraged to wear whilst undertaking the role. Community Volunteer Workers are required to submit a monthly report that contains information on the number of new patients, referrals to Hospice and the number of talks/sensitisation sessions given in their communities. This completion of these reports along with attendance at the meetings and updates is used to define the volunteer as 'active' in the role. Currently the annual amount per volunteer for the bicycle maintenance and attendance at any updates, consumerables (t-shirts etc), stationery and equipment for their kits (soap, gloves etc) is 287,960 Ugandan shillings (93 Great Britain pounds, 148 US dollars, 101 euros) (2009 figures).

Community Volunteer Worker Programmes

Two intakes to the Programmes were in Hoima and Kampala in 2002/3 and 2006, with intake of 30 and 40 Volunteers respectively. The Volunteers who commenced in the first groups received little support and there were subsequent drop outs. From the second groups the funding included attendance at updates and meetings as well as the provision of bicycles and a bicycle maintenance fund. This additional funding was extended to remaining 'active' Community Volunteers from the first cohort at both sites. At Hoima all 30 Volunteers from the second programme are 'active' giving a total of 45 Community Volunteer Workers. In Kampala only nine from that original group remain active. 25 out of 30 Volunteers from the second programme are 'active'. An additional six Volunteers have been trained in 2007/8 giving a total of 40 Community Volunteer Workers.

Monthly reports are produced by the Community Volunteer Workers which include the number of patients they were seeing, referrals made to the hospice and the number of HIV sensitisation talks they had given. On average there are about 120 patients receiving ongoing care from the Community Volunteer Workers and Hospice team. From April 2009- March 2010, 612 patients were receiving input from the volunteers across both sites. For the patients that the Volunteers are caring for, it is estimated that usually four of them at one time are bed ridden and require increased intervention by the Volunteers

Study Design

The aim of the study was to evaluate the impact of the palliative care Community Volunteer Worker Programme. An evaluation approach was adopted for the study, which incorporated the key stakeholders who were involved with the service, namely patients, the Hospice staff and Community Volunteer Workers. This breadth of involvement of stakeholders enables a plurality of perspectives to be obtained and increases the range and quantity of information available to the evaluator.[13,14] It is generally accepted that stakeholder evaluation involves a qualitative research methodology approach. Such an approach is designed to enable exploration of participants' experiences, feelings and beliefs.[13,15,16] Therefore a qualitative stakeholder approach was deemed to be appropriate for the study.

The study was undertaken in both Hoima and Kampala locations where the Community Volunteer Worker programmes were established. Approval to undertake the study was granted by Hospice Africa Uganda executive team and the project proposal was reviewed by the principal investigators' (BJ) University Faculty of Health, Research Ethics Committee. All National Health Service and Royal College of Nursing Research Ethics standard guidance was followed. All participants were invited to participate in the research by a member of the clinical team; they were assured the participation was voluntary. Prior to the study, written consent was obtained (for those who could not write, a stained thumbprint was obtained as is standard practice in Uganda) and a statement confirming confidentiality was read out to all participants.

Sample

A non probability sampling approach using a convenience sample was adopted for the study, in conjunction with advice from the Hospice team, regarding issues of access. [13.16.17] For safety issues, all interviews took place at the Hospice and one selected community village hall location, in the rural area within the Hoima Hospice catchment area (approximately 18 kilometres from Hoima). Patients who were well enough to travel, had experience of been attended by a Community Volunteer Worker for at least three months and were available on the designated dates for the interview, were invited to participate in the study. Ten from Kampala agreed to participate in and eleven in Hoima. It was estimated by the Hospice team that this represented approximately 20 percent of the patients they had contact with at the time of the study, who met the selection criteria.

All active Community Volunteer Workers (85) who were available during the dates of the data collection were invited to participate in the study, and 32 volunteered to participate in the study. Hospice clinical teams were invited to participate in the study and in Kampala, nine of the twelve who were available, agreed to participate in a focus group. Additionally, two of the Hoima team with a key involvement with the Community Volunteer Worker participated in individual interview. Thus a total of 21 patients, 32 volunteers and 11 Hospice clinical staff participated in the study (see table one).

Data Collection

Due to the practical consideration and the language barrier, data was collected from the patients and the Community Volunteer Workers by audio taped group interviews using a semi structured schedule, in which each participant was asked the same question via the interpreter and no interaction/group discussion took place. The order of the questions was varied between the participants to minimise respondent bias from hearing other responses to the question. For the Hospice clinical staff, a focus group approach was adopted for the Kampala team as they are widely used when the aim is to promote group discussion and debate.[17-20] Due to the low numbers of clinical staff at

the Hoima site, individual semi structured audio taped interviews were utilised. The interviews/focus group all focused on the participant's experience of the community volunteer scheme and examples to illustrate the key points were encouraged (figure two).

All interviews were undertaken by one researcher (BJ) who was not part of the Hospice team, over two visits in 2008-9. Interviews with non English speaking respondents were in partnership with an interpreter. The interpreters were attached to the Hospice (one at each location) for this purpose, and had extensive experience of undertaking this role within the clinical setting. All questions were asked in English and the interpreter then asked the respondents. The responses were then interpreted into English. All aspects of the interview were recorded for quality checking. [21]

Data Analysis

Data were analysed using a thematic analysis approach. The four phases of organisation, familiarisation, reduction and analysis were adopted.[17,22] Interviews conducted via an interpreter were transcribed into English. As a quality control issue sections of the interviews conducted by the interpreter were analysed independently and found to be accurate.[21] The reduction phase involved the coding of the data where categories under each question were identified and coded. To enhance the trustworthiness of the findings the data was additionally analysed by an independent researcher and a consensus of the key themes was agreed. QSR Nvivo, assisted in the management of the analysis (see figure three).

Results

Identified Themes

There was a general consensus across all the interviews, of several key themes regarding the impact of the Community Volunteer Worker. These included the impact on the patients and their families; physical care, practical help, counselling /education and

how they acted as a 'Bridge' to the Hospice'. Challenges to the role were also noted by both community volunteers and the Hospice team. The role with HIV sensitisation, and the impact of the being a Community Volunteer Worker, were also widely reported but are presented elsewhere.

The impact of the community volunteer on the patients and their families

Physical care

The direct provision of physical care to the patients by the volunteers was reported by all groups of respondents from both sites. These included examples such as: bathing, wound care and helping to feed the patients.

> *"the volunteers have really made a difference in our lives because they are the main carers when they go down (African term for bedfast) and are* sick – the volunteers come first" *(Patient group 1 respondent 8,Hoima)*
>
> *"She made sure the wound does not smell and pain is controlled" (Patient Kampala 5)*
>
> *"When bed making I have to do their exercises, massages, and feeding" (Community Volunteer Worker Kampala 1)*

Practical help

Interestingly several respondents referred to a fairly diverse role that the volunteers have, this included providing practical help collecting medicines, and getting food and water for them. Examples included:

> *"the Community Volunteer Worker cooked me food, and made sure she mobilised people around me to collect water" (Patient Kampala 1)*
>
> *"Wash their clothes, clean their house, some we prepare them food" (Community Volunteer Worker Kampala 6)*
>
> *"--- we can help them, give them water, bring the grass to build the house" (Community Volunteer Worker, group 2 respondent 8, Hoima)*

The generosity of the Volunteers in giving the patients food and even clothes was also reported by several patients. This act of giving was noted by the Community Volunteer Workers:

> *"I did not have money to buy any food, the volunteer gave me money, even prepared food for me to eat ---at the next visit she brought me a skirt and blouse" (Patient Kampala 10)*
>
> *"If I find any one who has no food, when you have yours you share it because he is alone" (Community Volunteer Worker Kampala 4)*

Impact on the Families

The input to the family was widely stressed by the different groups of respondents and this included support and education for example:

> *"At the same time also the family appreciates it a lot because most of the time the families are really ignorant – they don't know what to do. So when the community volunteers go in they don't just care about the patient but they also train the carer on how to take care of the patient" (Hospice Nurse, respondent 2, Hoima)*
>
> *"I talk to the family and say to keep that patients we need to give the patient medication" (Community Volunteer Worker Kampala 3)*
>
> *"I have helped some families, where some of the patients have been isolated in their room. It is dark, people not caring for them, at least nowadays we are training these people who are caring for these patients – so you change them and they die in a good way" (Community Volunteer Worker, group,2 respondent 1, Hoima)*

Commented [DAM1]: I cannot understand this sentence.

Education and Support

Counselling

The role of the Community Volunteer Worker, in supporting and counselling the patients and families, was noted by all respondents:

> *"The Volunteer she encouraged my mother to stop worrying and told her that she did not think I was going to die soon" (Patient Kampala 9)*

> *" In most cases the family is in a panic because the patient is dying, so these Community Volunteers go in and they talk to them, prepare them and at least settle them" (Hospice Team Kampala 4)*

> *"Some patients are desperate; the Volunteers sit with them and give some counselling and guidance" (Hospice Nurse 2-Hoima)*

Education

Medication concordance was identified by several respondents across the groups including some of the patients.

> *"Encouraged me at first to keep going back for medication" (Patient Kampala 9)*

> *"Encourages the patients to take the medicines the right way" (Hospice Team Kampala 1)*

> *"they counselled me about the drugs because I had already lost hope in life" (Patient, group 1 respondent 4,Hoima)*

Examples were also given from patients and Volunteers of how the Volunteers would collect the medication from the Hospice and bring it to them in their villages. Following up the patients, to ensure they were still taking their medication was also referred to.

Bridge to the Hospice

The role volunteers played in finding the patients, particularly those located '*deep in the villages'* (Ugandan term for remote rural areas) and then informing the Hospice team. was identified by all respondents from both sites. Comments included:

> "At times they direct us to where the patients are, because at times we do not know that area" *(Hospice Team Kampala 2)*

"The Community Volunteer came first, then she brought the Hospice team" *(Patient Kampala 7)*

"I help the Hospice team as there are some villages that are very deep and the Hospice team cannot reach. I go there on my bicycle and get information and identify the patient for the Hospice team" (Community Volunteer Worker, group 1, respondent 3 Hoima)

"what has helped the Hospice is that I am active, between the patients and the Hospice team, because the Hospice team itself would not move around in the villages and identify those patients themselves" (Community Volunteer Worker, group 3, respondent 2 Hoima)

The partnership working between the Community Volunteer Workers and the Hospice team was also noted*:*

"We can manage the patients together" (Hospice Team Kampala 3)

"The hospice we are working hand in hand with them --- we cover the ground" (Community Volunteer Worker Kampala 5)

Challenges faced by the Community Volunteer Workers

Travel/Access

Most of the Community Volunteer Workers and the Hospice team commented about issues regarding travel/access, including the distance that they were travelling and the problems with the condition of the bicycles:

"We have bicycles but they are old and we have no spares for them" (Community Volunteer Worker Kampala 2)

"We are riding a bicycle to villages deep up country and the roads they are very bad and if it is raining we can fail to get there--- the bicycles are old" (Community Volunteer Worker, group2, respondent 7, Hoima)

"The bicycles are very old and some are broken and too bad to be repaired. If they don't have the bicycles the Community Volunteers can't get up country and see the patients. Patients will suffer" (Hospice Nurse, respondent 2)

Additionally the practical issue of dealing with the multiple languages and dialects that were spoken especially in the remote rural areas were reported by several Hoima respondents:

"Also there is a problem of language barrier, at times we move deep in the villages there and find the language they are using is not the one we are using, so there communication becomes difficult." (Community Volunteer Worker, group 3, respondent 5,Hoima)

Expectations of the Patients

The challenge of meeting the expectations of the patients was identified by most respondents and related to the community's lack of understanding of the Community Volunteer Programme. Examples included:

"Some of our patients need a lot of time – - a patient may need you to be with them at least four hours a day but you cannot manage that" (Community Volunteer Worker Kampala 10)

"Too much expectation of the patients from the Volunteers. Now they expect many things, now they ask you for sugar, soap expecting us to have it" (Community Volunteer Worker, group 3, respondent 1-Hoima)

"they think you have stuff like milk, coffee, beans, rice etc" (Community Volunteer Worker Kampala 1)

Financial Challenges

The Hospice Team identified increasing financial issues that were emerging. This has affected the provision and repair of the bicycled and the ongoing support and education provided by the Hospice. This had resulted in some of the update sessions having to be cancelled, as well as impacting on the bicycle maintenance fund that had recently been reduced to bi –monthly. Similarly, the deterioration of the bicycles and lack of funds to repair them was noted. Although to date, this financial challenge had not resulted in any Volunteer Workers leaving, there was a consensus that if this situation continued, it would impact on the sustainability of the programme.

Discussion

All respondents in the study indicated that the Community Volunteer Worker is having a positive impact on patients and their families, which is in keeping with the literature around palliative care volunteers both in the western world and developing countries.[6-8,10,11] The wide role that the Community Volunteer Worker undertakes, has been shown to be beneficial and includes both physical and non physical care.

The key role of the Community Volunteer Worker being a 'Bridge to the Hospice' and enabling palliative care to reach out into the rural community was strongly reported by all the respondents. The identification of the patients and the role of liaising with the Hospice are clearly benefiting patients. This finding is similar to the reported benefits of the community service in India [10] and Murray et al [11]evaluation in Africa. This aspect of the role can be suggested as being vital, as the identification of the patients is fundamental to enabling palliative care to reach a hidden population. A population that by being identified by the Community Volunteer Workers can be provided with palliative care and thus potentially reduce suffering.

Emerging Challenges

Although the Community Volunteer Worker is having a positive impact, there are several emerging challenges. Firstly the practical issue of the distance that the Volunteers are travelling, along with the deteriorating condition of the bicycles needs consideration. The need for the service and the recruitment of more Community Volunteers from these remote areas is undoubtedly required, along with replacement

bicycles for the existing Volunteers. This is coupled with the more recent financial issues of the funding that supports the clinical updates, monthly supervision, and the bicycle maintenance fund being reduced. Although at the time of data collection this had not been seen to have affected the service, however, the Hospice team felt strongly that it would inevitably impact, especially on the issue of the bicycles not being able to be repaired.

Limitations of the study

The selection of the participants by the Hospice team is recognised as a potential source of sample bias and must be acknowledged. However the practical implications of setting up a research study in a developing country, along with the language barrier necessitated this approach. The triangulation of data by the involvement of the three groups of participants on two sites does strengthen the study.

The use of an interpreter is recognised as presenting methodological issues that may affect the quality of a study.[21]. The use of interpreters who work with the Hospice team on a regular basis, the recording of the whole interview and discussion with the interpreters prior to the interviews, to clarify meanings of words, all enhance the quality of the study. Furthermore in this study some of the participants did speak English, and there was a clear consensus across the findings that the themes identified by interview with the interpreter were congruent with those conducted in English.

Due to practical constraints the study did not include any interviews with the patients' families or direct observation of the community Volunteer. Further research using a Ugandan multi-lingual researcher is undoubtedly required.

Conclusion

This study has shown that the Hospice Community Volunteer Worker Programme in Uganda is having a positive impact on patients, their families and the Hospice team. This model with an ongoing programme of education and support along with the provision of a bicycle to reach the outlying areas is helping to provide a valuable

service. By acting as a ‘Bridge to the Hospice’ many patients who are suffering are receiving palliative care, which enables them to receive pain relief and treatment.

The financial cost of this service is minimal and when this is considered against the number of patients that receive the input of this service, it is clearly worthy of funding. Reaching out with palliative care in developing countries is not without challenges, especially financial. This innovative model developed by Hospice Africa, is shown to be effective, sustainable, and transferable, with minimal costs. The potential to run this programme in other developing countries in order to provide relief to the suffering is worthy of consideration.

Funding: Sir Halley Stewart small grant scheme – award to Prof Jack (2009)

Table One: Sample for the study (Kampala)

Community Volunteer Workers			
CVW	**Number**	**Male**	**Female**
	10	4	6
Age	Range from 33-48 years, mean age 39 years		
Patients			
Patients	**Number**	**Male**	**Female**
	10	3	7
Age	Range from 29-65 years, mean age 41years		
Hospice Clinical Staff			
Hospice staff	9 members of the clinical team – years in post range 3-10 years, mean age 5 years		
Community Volunteer Workers (Hoima)			
CVW	**Number**	**Male**	**Female**
Group 1	8	2	6
Group 2	7 +1*	5	3 *(* the CVW who was interviewed on their own is included as part of group 2 to maintain confidentiality)*
Group 3	6	4	2
Total	22	9	11
Age	Range from 28-52 years, mean age 39yrs		
Patients			
Patients	**Number**	**Male**	**Female**
Group 1	8	3	5
Group 2	2	0	2
Single interview	1	0	1
Total	11	3	8

Age	Approximate 29-48 NB several patients were unsure of their age
Hospice Staff CVW programme team	
Hospice staff	2 members of the CVW programme team

Figure One: Role of the Community Volunteer Worker

(Hospice Africa Uganda 2006)

Identify and refer patients who need palliative care

Refer patients whose condition had become difficult

Educate carers and patients in care and well being including nutrition, hygiene, infection control etc

Provide social support to the family and patient and bereavement support

Patient and family care regarding management of common illnesses, administration of medicine

Spiritual support

Basic counselling

Support the patient with basic nursing care including washing

Train carers in basic nursing skills including bed making

Fight the fear and negative attitudes towards HIV/AIDS

Consultations with other relevant health care workers

Create links with the patients, their families and local communities

Identify the health needs of other family members and refer to appropriate support groups

Keep appropriate records

Figure Two: Areas for exploration in the interviews regarding Community Volunteer Worker (CVW)

Patients

1. What access have you had with the CVW?
2. Before you were sick did you know about the role of the CVW?
3. What do you think the role of the CVW is?
4. How helpful has the CVW been to you and your family?
5. How much contact do you have with your CVW?
6. Has the CVW made a difference?
7. Any other information?

Community Volunteer Workers

1. Demographic information
2. How long have you been a CVW?
3. What makes you continue as a CVW?
4. What does being a CVW mean to you?
5. What impact do they have on patients, families, Hospice team?
6. What challenges are you faced with in the CVW role?
7. Additional information

Hospice Staff involved with the Community Volunteer Programme

1. What do you think makes someone volunteer?
2. Why do you think some of the CVW drop out?
3. What impact do you think the CVW is having on patients, families and the Hospice?
4. What impact does becoming a volunteer have on the CVW?
5. Are there any challenges that you are facing regarding the CVW scheme?
6. Any other information?

Figure Three: Thematic Analysis and Coding Frame

Theme	Patients	CVW	Hospice Staff
1a) Impact on patients	X	X	X
physical care	X	X	X
practical (non nursing) care	X	X	X
education	X	X	X
counselling/wills etc	X	X	X
1b) Impact families	X	X	X
practical caring	X	X	X
education/counselling	X	X	X
2) HIV sensitisation	X	X	X
testing	X	X	X
families	X	X	X
general sensitisation/education	X	X	X
3) Bridge to Hospice	X	X	X
communication	X	X	X
finding patients			
4) Impact of being a CVW			
impetus to became a volunteer		X	X
pride		X	X
skills		X	X
respect		X	X
5a) Challenges - seen by Hospice team			
expectations			X
financial			X
5b) experienced by CVW			
practical issues		X	X
money		X	X
patients demanding		X	X

X = theme identified
CVW- Community Volunteer Worker

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