


# '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 rising cancer and AIDS-related cancer diagnoses. In Uganda there is a shortage of doctors, particularly in rural areas. To address this Hospice Africa Uganda developed a Community Volunteer Programme to train volunteers to help by providing support to patients in their own homes. The aim of this qualitative study was to evaluate the impact of the Community Volunteer Programme. Sixty-four interviews, with patients (21), community volunteer workers (CVWs) (32), and the hospice clinical teams (11) were conducted, using semi-structured digitally recorded individual, group and focus group interviews, at the Hospice Africa Uganda sites. The results reported the value of the Community Volunteer Programme, including the impact on patients and families, and how the CVWs acted as a 'bridge to the hospice' in identifying patients. Developing financial challenges that are emerging which could potentially impact on the programme were reported. The Community Volunteer Programme appears to be having a positive impact on patients, families and the hospice team, and is a model worthy of consideration by other developing countries to allow the expansion of palliative care.

## Keywords

Community Volunteer Programme, developing countries, palliative care

## Introduction

In Africa the need for palliative care service provision is escalating, with over 25.8 million people living with HIV/AIDS in sub-Saharan Africa. Furthermore, cancer rates are expected to grow in Africa, with the World Health Organization 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.<sup>1</sup> For the majority of Ugandans who endure these and other life-limiting illnesses, access to effective palliative care is limited. 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 practise in urban centres.<sup>2</sup> This is further

affected by the wide geographical distribution of the population, of which approximately 90% is rural, and poor transport systems.<sup>2</sup>

Hospice Africa Uganda has three branches: in 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.<sup>3</sup> The hospice provides care for patients within a 20 km radius. To address this limited service coverage, Hospice Africa Uganda has developed a Community Volunteer 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

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homes. By using members of the local community who speak the local dialect, the Community Volunteer Programme 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.<sup>4</sup> A systematic review of volunteers in end-of-life-care undertaken by Wilson et al.<sup>5</sup> 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, fundraising, drivers, gardeners, catering support and general maintenance/housekeeping roles.<sup>4,6,7</sup> The impact of volunteers is widely recognised, with studies reporting that they help to enhance the care of dying patients and their families.<sup>6-8</sup> It is also reported that the presence of volunteers helps the staff and they are referred to as providing an invaluable resource.<sup>7,9</sup>

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 support from trained professionals.<sup>10</sup> This programme aims to supplement the efforts of trained healthcare 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 patients in the community and the healthcare professional.

More recently, Murray et al.<sup>11</sup> evaluated three palliative care programmes in Kenya, Malawi and Uganda. The programmes, which were constructed differently, served different client groups and used different mechanisms and had differing staffing investment, but 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 detecting 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 Uganda community volunteer workers**

The community volunteer worker (CVW) 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,<sup>12</sup> p. 12). To meet the eligibility criteria the CVW applicant has to be resident in the local community for 1 year, have a basic primary education, be able to read and write in the local language and selected by senior members of the community, i.e. religious leaders and councillors, as being respected and trustworthy. Additionally, the applicant must be able to volunteer for about 6 hours per week. The role of the CVW 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 specific activities).

### **Training and education**

Following successful interview, the CVWs undergo a 6-day non-residential course that covers an overview of: the fundamentals of palliative care, HIV and cancer, practical aspects of home nursing care (bed bathing, wound care, infection control, 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 form 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. There are also quarterly workshops that focus on topics identified by the volunteers. Extra support for the CVWs is provided by the clinical teams who serve as a day-to-day link. Evaluation of the support provided by the hospice staff has reported that the CVWs find it of great value and that it helps them develop their knowledge and skills.

### **Service costs**

There is no payment for the volunteers, although a bicycle is provided to enable them to travel to see patients, along with a bicycle maintenance fee. Costs for attendance at all meetings are reimbursed. They are also 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 while undertaking their role. CVWs are required to submit a monthly report containing information on the number of new patients, referrals to hospice and the

<b>Hospice Africa Uganda (Uganda 2006)</b>
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 1.** Role of the community volunteer worker.

number of talks/sensitization sessions given in their communities. Completion of these reports, together 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 bicycle maintenance and attendance at any updates, consumables (T-shirts, etc.), stationery and equipment for their kits (soap, gloves, etc.) is 287,960 Ugandan shillings (£93, US\$148, E101).

### **CVW programmes**

Two intakes to the programmes were in Hoima and Kampala in 2002/3 and 2006, with intakes of 30 and 40 volunteers, respectively. The volunteers in the first groups received little support and there were subsequent drop-outs who identified problems with the cost of travelling to patients and the hospice as an influencing factor. 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' CVWs from the first cohort at both sites. At Hoima all 30 volunteers from the second programme are 'active', giving a total of 45 CVWs. In Kampala only nine from that original group remain active; 25 out of 30 volunteers from the second programme are 'active'. Volunteers who withdrew from the programme had generally secured paid

employment. An additional six volunteers have been trained in 2007/8 giving a total of 40 CVWs.

Monthly reports are produced by the CVWs, 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 per month receiving ongoing care from the CVWs and hospice team. From April 2009 to 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 bedridden 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 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 CVWs. 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.<sup>13,14</sup> 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.<sup>13,15,16</sup> Therefore

a qualitative stakeholder approach was deemed to be appropriate for the study.

The study was undertaken in at both Hoima and Kampala, where the CVW programmes are well established. A full review of the proposal by the principal investigator's (BJ) University Faculty of Health, Research Ethics Committee, in consultation with the Royal College of Nursing Research Society was undertaken and approval granted. Additionally, approval to undertake the study was granted by Hospice Africa Uganda Ethics Committee, following discussion with the Ugandan National Council for Science and Technology. All National Health Service and Royal College of Nursing Research Ethics standard guidance were followed. All participants were invited to participate in the research by a member of the clinical team; they were assured the participation was voluntary and their participation or non-participation would have no impact on their CVW role. Information about the project and research team were provided to the participants. 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 pragmatic 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 and safety of the researcher.<sup>13,16,17</sup> For safety reasons, all interviews took place at the hospices (Hoima and Kampala) and one selected community village hall location, in the rural area within the Hoima hospice catchment area (approximately 18 km from Hoima). Patients who were well enough to travel, had experience of being attended by a CVW for at least 3 months and were available on the designated dates for the interview, were invited to participate in the study. Ten from Kampala agreed to participate and eleven from 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.

Of the active CVWs (85) who were available during the dates of the data collection and were invited to participate in the study, 32 volunteered. Hospice clinical teams were also 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 CVWs participated in individual interview. Thus a total

of 21 patients, 32 volunteers and 11 hospice clinical staff participated in the study (see Table 1). Data saturation was reached fairly quickly and on the second data collection in Kampala, there was a clear repetition of the key findings that had been obtained in the initial data collection.

### Data collection

Due to the practical considerations of undertaking data collection in the rural setting and the language barrier, data was collected from the patients and the CVWs by digitally recorded group interviews using a semi-structured schedule that was used flexibly to enable the researcher to explore issues raised by the respondents. Each participant was asked the question via the interpreter and no interaction/group discussion took place. For the hospice clinical staff, a focus group approach was adopted for the Kampala team as this is widely used when the aim is to promote group discussion and debate.<sup>17-20</sup> Due to the low numbers of clinical staff based at the Hoima site, individual semi-structured digitally recorded interviews were used. The interviews/focus group all focused on the participant's experience of the CVW scheme and examples to illustrate the key points were encouraged (Figure 2).

All interviews were undertaken by one researcher (BJ) who was not part of the hospice team, over two visits in 2008/9. The data collection tool was developed and piloted by BJ in a previous research trip to the hospice. BJ had previous experience of undertaking research in Uganda, including undertaking interviews with Ugandan patients and families. Interviews with non-English-speaking respondents were in partnership with an interpreter, other interviews had no observers present. 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. At the conclusion of the interview, key points raised were summarised as a means of validating the data by obtaining participant approval of key issues identified. All aspects of the interview were recorded for quality checking.<sup>21</sup> Field notes were made after each interview to aid in the analysis process.

### Data analysis

Data were analysed using a thematic analysis approach. The four phases of organisation, familiarisation, reduction and analysis were adopted (see Figure 3).<sup>13,16,17,22,23</sup> All data were transcribed

**Table 1.** Sample for the study

Kampala: Community volunteer workers (CVWs)			
CVWs	Number	Male	Female
	10	4	6
Age	Range 33–48 years, mean age 39 years		
Kampala: Patients			
Patients	Number	Male	Female
	10	3	7
Age	Range 29–65 years, mean age 41 years		
Kampala: Hospice clinical staff			
Hospice staff	Nine members of the clinical team: years in post range 3–10 years, mean 5 years		
Hoima: Community Volunteer Workers (CVWs)			
CVWs	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 28–52 years, mean age 39 years		
Hoima: 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	Approximately 29–48 years (several patients were unsure of their age)		
Hoima: Hospice staff CVW programme team			
Hospice staff	Two members of the CVW programme team		

**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?

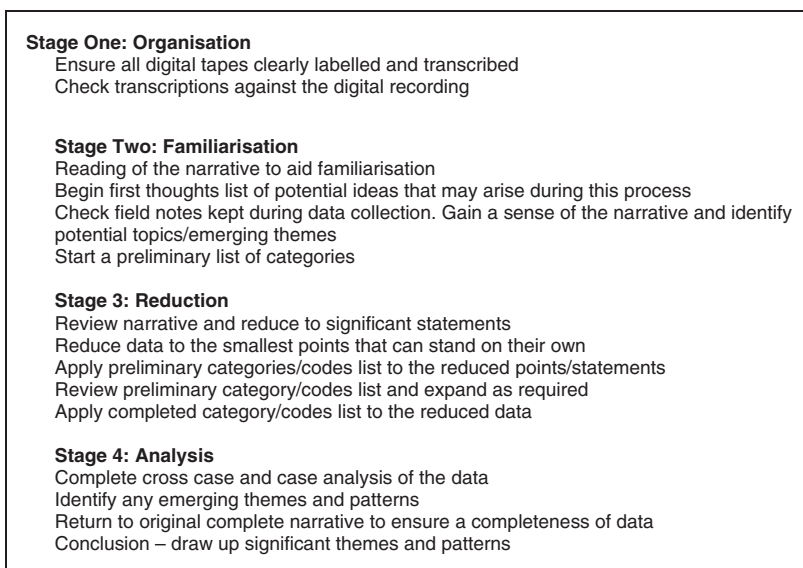
**Community volunteer workers**

1. Demographic information
2. How long have you been a CVW?
3. What makes you continue as a CVW?
4. What impact do they have on patients, families, hospice team?
5. What challenges are you faced with in the CVW role?
6. 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 CVWs drop out?
3. What impact do you think the CVW is having on patients, families and the hospice?
4. Are there any challenges that you are facing regarding the CVW scheme?
5. Any other information?

**Figure 2.** Areas for exploration in the interviews regarding community volunteer workers (CVWs).



**Figure 3.** Framework for the analysis (adapted from Patton<sup>13</sup>, Robbins<sup>16</sup>, Polit and Beck<sup>17</sup>, Miles and Huberman<sup>22</sup> and Collaizzi<sup>23</sup>).

and read in full along with the field notes that had been made at the time. 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.<sup>21</sup> The reduction phase involved the coding of the data where categories under each question were identified and coded (see Figure 4). For practical reasons the transcripts were not returned to the participants, but 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 8 was used to help manage the analysis.

## Results

### Identified themes

There was a general consensus across all the interviews and focus groups of several key themes regarding the impact of the CVWs. 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 CVWs and the hospice team. The role with HIV sensitization, and the impact of being a CVW, were also widely reported but are presented elsewhere. The verbatim quotations that are presented here are exemplars of the identified themes from across all groups of respondents and are identified by participant number.

### *The impact of the CVW on 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 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 5, Kampala)  
 'When bed making I have to do their exercises, massages, and feeding' (Community Volunteer Worker 1, Kampala)

**Practical help.** Interestingly, several respondents referred to a fairly diverse role that the volunteers have, which 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 1, Kampala)  
 'Wash their clothes, clean their house, some we prepare them food' (Community Volunteer Worker 6, Kampala)  
 'we can help them, give them water, bring the grass to build the house' (Community Volunteer Worker, group 2 respondent 8, Hoima)

Theme	Patients	CVW	Hospice staff
<b>1a) Impact on patients</b>	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
<b>1b) Impact on families</b>	X	X	X
practical caring	X	X	X
education/counselling	X	X	X
<b>2) HIV sensitisation</b>	X	X	X
testing	X	X	X
families	X	X	X
general sensitisation/education	X	X	X
<b>3) Bridge to hospice</b>	X	X	X
communication	X	X	X
finding patients			
<b>4a) Challenges – seen by hospice team</b>			X
expectations			X
financial			X
<b>4b) Challenges – experienced by CVWs</b>		X	X
practical issues		X	X
money		X	X
patients demanding		X	X

**Key**

X = theme identified

CVW = community volunteer worker

**Figure 4.** Thematic analysis and coding frame.

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

‘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 10, Kampala)

‘If I find any one who has no food, when you have yours you share it because he is alone’ (Community Volunteer Worker 4, Kampala)

**Impact on families.** The impact on families 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 alive we need to give the patient medication’ (Community Volunteer Worker 3, Kampala)

‘I have helped some families, whereby 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)

### **Education and support**

**Counselling.** The role of the CVW in supporting and counselling 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 9, Kampala)

'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 4, Kampala)

'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 9, Kampala)

'Encourages the patients to take the medicines the right way' (Hospice Team 1, Kampala)

'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 the 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 2, Kampala)

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

'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)

The partnership working between the CVWs and the hospice team was also noted:

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

'The hospice we are working hand in hand with them – we cover the ground' (Community Volunteer Worker 5, Kampala)

### **Challenges faced by the CVWs**

**Travel/access.** Most of the CVWs and the hospice team commented on issues regarding travel/access, including the distances they were travelling and problems with the condition of the bicycles:

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

'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, group 2, 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, Hoima)

Additionally the practical issue of dealing with the multiple languages and dialects spoken, especially in 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 10, Kampala)

'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 (patients) think you have stuff like milk, coffee, beans, rice etc.' (Community Volunteer Worker 1, Kampala)

**Financial challenges.** The hospice team identified increasing financial issues that were emerging. This has affected the provision and repair of bicycles 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 monthly bicycle maintenance fund that had recently been reduced to alternative months. 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 CVWs 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 Programme 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.<sup>6-8,10,11</sup> The wide role that the CVW undertakes has been shown to be beneficial and includes both physical and non-physical care.

The key role of the CVW being a 'bridge to the hospice' and enabling palliative care to reach out into the rural community was strongly reported by all respondents. Identification of patients and liaising with the hospice are clearly benefiting patients. This finding is similar to the reported benefits of the community service in India<sup>10</sup> and Murray et al.'s<sup>11</sup> evaluation in Africa. This aspect of the role can be suggested as being vital, as the identification of patients is fundamental to enabling palliative care to reach a hidden population and thus potentially reduce suffering.

### Emerging challenges

Although the Community Volunteer Programme 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 CVWs 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, 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 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.<sup>21</sup> 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 CVW. Further research using a Ugandan multilingual researcher is recommended. Additionally there are limitations to the design of the study that need to be taken into consideration when interpreting the results. The design of the study focused on a qualitative methodology and the need for further research that includes objective outcome data to assess the extent of the impact is undoubtedly required.

## Conclusion

This study has shown that the hospice Community Volunteer Programme in Uganda appears to be 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, enabling 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 Uganda appears to be beneficial, 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.

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### Competing interests

Dr Anne Merriman is the Director of Policy and International Programme at Hospice Africa Uganda, but has no daily operational role in the hospice. No other conflict of interest is declared.

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