

# The personal value of being a palliative care Community Volunteer Worker in Uganda: A qualitative study

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**Barbara A Jack** *Evidence-based Practice Research Centre, Edge Hill University, UK*  
**Jennifer A Kirton** *Evidence-based Practice Research Centre, Edge Hill University, UK*  
**Jerith Birakurataki** *Hospice Africa Uganda, Hoima, Uganda*  
**Anne Merriman** *Hospice Africa Uganda, Kampala, Uganda*

## Abstract

**Background:** Volunteers in palliative care play a key role, particularly in the hospice setting. The expansion of palliative care into developing countries has been accompanied by the emergence of volunteer workers, who are providing a main source of support and care for patients, many of whom never see a health professional.

**Aim:** The aim of this study was to evaluate the motivation for becoming a volunteer and the personal impact of being a palliative care Community Volunteer Worker in Uganda.

**Design:** A qualitative methodology using semi-structured individual and group digitally recorded interviews was adopted for the study. Data were analysed for emerging themes using thematic analysis.

**Setting/Participants:** Forty-three interviews were undertaken, 32 with Community Volunteer Workers and 11 with the Hospice clinical teams, using semi-structured digitally recorded individual, group and focus group interviews at the Hospice Africa sites in Uganda.

**Results:** The results identified the cultural wish to help people as a key motivator in becoming a volunteer. Additionally, the volunteers reported having a sense of pride in their volunteering role, and this role had a positive impact on their perceived status in their local community.

**Conclusion:** This model of volunteering is clearly having an impact on the volunteers, both personally and also in terms of how they are treated in their communities. Further research to explore the long-term personal benefits of being a palliative care volunteer is recommended.

## Keywords

Developing countries, palliative care, qualitative research, volunteer workers

## Introduction

Volunteer workers play a key role within palliative care, especially in the hospice setting, with an estimated 100,000 people volunteering in hospices across the UK.<sup>1</sup> Palliative care volunteers are involved in a wide variety of different roles, covering almost every aspect of hospice life. In a report commissioned by the Institute of Volunteering Research on Volunteering in UK Hospices it was reported that the most common roles performed

by volunteers are shop work and patient care, with about one in five volunteers involved in both these areas of work. Transport, day care services, administration and catering were other widely reported roles undertaken by volunteers. Less common activities for volunteers included bereavement services, creative activities and gardening.<sup>2</sup> These are referred to by Dein and Quamar Abbas as the broad categories of direct services for the patients and supportive roles.<sup>3</sup> Generally, in the western world, the majority of hospice volunteers are

## Corresponding author:

Barbara Jack, Evidence-Based Practice Research Centre (EPRC), Edge Hill University, Faculty of Health, St Helens Road, Ormskirk L39 4QP, UK  
Email: jackb@edgehill.ac.uk

female, white, middle-aged or older, have undergone further/higher education and have some religious/spiritual beliefs.<sup>4-6</sup>

There is a vast volunteering literature from the USA, Canada and the UK, much of it dealing with the organizational challenges of involving and managing volunteers within the hospice setting. In particular, the area of motivation for becoming a volunteer has been widely reported, including the development of the Inventory of Motivations for Palliative Care Voluntarism (IMPCV).<sup>4</sup> This tool highlights that there are four motivating factors for volunteering: to help ease the pain of those with life limiting illness, to help others cope with death and dying, to support the philosophy of palliative care and having a previous personal experience with the death of a loved one. There appears to be a consensus of opinion in the literature that a key motivating factor for volunteering is the altruistic reason of simply helping others.<sup>7-11</sup>

### **What is the impact of palliative care volunteers?**

Evaluating the impact of palliative care volunteers on organizations has been enhanced with the development of the Volunteering Impact Assessment Toolkit.<sup>11</sup> The toolkit offers organizations a method of evaluating the impact of volunteers in five areas: physical (the output gained by the recipient), human (skills and personal development), economic (financial results), social (social impacts, how people work with each other and the networks volunteering creates) and cultural (shared sense of cultural and religious identity, including language and heritage) capital. Although designed for other volunteer organizations, it has been used successfully in a Children's Hospice in Scotland.<sup>12</sup>

Despite the availability of Impact Assessment Tools, the literature around palliative care volunteers generally focuses upon the value of volunteers to patients, families and staff.<sup>10,13-15</sup> The negative impact of stress and burn-out is also reported.<sup>3</sup> Studies on the personal impact on the volunteer are fewer, yet studies that have addressed this issue indicate a perhaps more hidden value of the impact of being a volunteer in palliative care. Claxton-Oldfield and Claxton-Oldfield explored the impact of volunteering on volunteers, with a sample of volunteers from six hospice volunteer programs in Canada.<sup>7</sup> They reported that most of the volunteers indicated that they had changed in some way since volunteering in palliative care and experiencing death and dying. This change included personal growth and learning how to keep things in perspective, a finding supported by the earlier work of Andersson and Ohlen, who discussed how volunteering affected the lives of the volunteers.<sup>8</sup> An evaluation of volunteer workers in a children's hospice

in Scotland, which used the Volunteering Impact Assessment Toolkit on 16 volunteers, found that generally most respondents reported a positive impact on their personal growth and several reported an increase in self-esteem and motivation.<sup>11,12</sup>

### **Developing countries**

The expansion of palliative care into the developing world is accompanied by the emergence of palliative care volunteers. Volunteer roles in developing countries are significantly different from those in the western world. In developing countries volunteers are mainly community based and often work without direct supervision. Some of the models have had a specific focus; for example, the Neighbourhood Network In Palliative Care (NNPC), developed in Kerala, India, focuses upon community participation as an empowerment tool for local communities. They aim to help the communities take responsibility for identifying, and working together to solve, their own health and developmental problems. The volunteers are trained to identify problems in the chronically ill in their area and aim to support the services of the palliative care teams, particularly in acting as a link to the team and providing emotional support and encouraging medical compliance.<sup>16</sup> This successful programme has expanded across areas of India and is a designated WHO Demonstration Project for providing cost-effective community home care.<sup>17</sup> Recently, Sallnow et al. reported that the programme benefits patients, the community and the volunteers themselves.<sup>18</sup> Volunteers reported high rates of satisfaction and reward and personal growth, although the authors do not mention any formal evaluation of the impact of the service on the volunteers.

In Africa, the Diana, Princess of Wales Memorial Fund supported three palliative care programmes in Uganda, Kenya and Malawi; all had an element of volunteer engagement, which was positively reported, with the volunteers having a vital role.<sup>19</sup> In Malawi, the volunteers are chosen by their local communities; this programme reported a high retention of volunteers. Furthermore, they reported the impact of the programme on the volunteers themselves, after 10 volunteers had participated in two focus groups. The volunteers referred to the personal reward of undertaking the role and one referred to 'feeling honored'.<sup>19</sup>

### **Personal impact of being a palliative care volunteer**

The current literature on palliative care volunteers does not generally explore the personal impact of being a volunteer, yet this may have a wider effect, for example on retention. Furthermore, it does not assess the value

to volunteers, including personal well being, giving them additional skills and potentially motivating them to undergo some formal training. The literature on general volunteering, compared with palliative care volunteering, reports the personal benefits for the volunteer. For example, in a study of Arab and Jewish women volunteering in a Women's Health Programme in Israel, where focus groups were conducted with 45 volunteers, a key theme that emerged was the personal impact on the women volunteers in their local communities. The change in their status and development of leadership skills were reported particularly by the Arab women.<sup>20</sup>

With the expansion of palliative care services in developing countries and the increasing number of volunteer workers, it is important to explore the motivation behind volunteering. This may help in the recruitment process, as there are incidences of high attrition, as identified by Murray et al. in their study in Kenya.<sup>19</sup> This paper presents the findings from a study that explored the impetus for becoming a volunteer and the personal impact of being a palliative care volunteer worker at Hospice Africa in Uganda. Further findings from the study, including the impact of the volunteers on patients, families and the hospice team, are reported elsewhere<sup>21</sup>

### Community Volunteer Worker programme in Uganda

In Uganda an increasing number of people are living with HIV/AIDS, and there is now an escalating number of people developing AIDS-related cancers. However, access to medical care is limited due to a shortage of doctors and health workers, particularly in the rural area. This, coupled with the poor transport systems, results in fewer than 60 percent of patients ever seeing a health worker.<sup>22</sup> To try to provide more health care access for the terminally ill, the Hospice Africa Uganda team have developed their own Community Volunteer Worker programme. Hospice Africa Uganda has its main hospice in Kampala, a smaller outreach base in Hoima, and a mobile unit in Mbarara ([www.hospiceafrica.or.ug](http://www.hospiceafrica.or.ug)).

The Community Volunteer Workers augment the work of the Hospice team in identifying patients in need of palliative care, particularly in rural settings. In addition, they help to provide care for the patients, providing practical, physical, emotional and spiritual care for patients in their own homes.

The Community Volunteer Workers are selected by senior members of the local community and meet the following criteria: completed a basic education, identified as being respected and trustworthy, and available to volunteer for about 6 hours a week. Following an

interview, successful applicants undergo a 6-day non-residential course that covers an overview of the fundamentals of palliative care, practical aspects of home nursing care and communication skills. Ongoing education and support are provided by the Hospice team, with monthly meetings being held, and contact via mobile phone (mobile phones are widely used in Uganda) for day-to-day support and advice. The volunteers receive no payment, although they are provided with a bicycle and maintenance fund sundries (a kit that contains basic practical items such as Savlon, gloves, etc.) and a uniform T-shirt denoting their volunteer work with Hospice Africa Uganda. Active volunteers are defined as those who complete monthly reports of their activities (referrals, etc.) as well as attending the update sessions.

Currently there are 85 'active' Community Volunteer Workers, with 45 at Hoima and 40 in Kampala, and on average there are approximately 120 patients receiving ongoing care from the Community Volunteer Workers and Hospice teams. The degree of intervention for each patient clearly varies, especially with the fluctuating disease trajectory of HIV/AIDS, but it is estimated that for each of the volunteers approximately four of the patients they care for are likely to be housebound at any one time.

### Methods

The aim of the study was to evaluate the impact of the palliative care Community Volunteer Worker programme. Therefore a stakeholder evaluation with a qualitative methodology was adopted for the study in order to explore a plurality of perspectives and to maximize the information that is available for the evaluator.<sup>23,24</sup> The inclusion of a qualitative methodological approach allows exploration of participants' feelings, beliefs and experiences.<sup>24-26</sup> Further findings from the study are reported elsewhere (paper under review with *Palliative Medicine*).

Approval to undertake the study was obtained from the Hospice Africa executive team, and the research proposal was reviewed by the principal investigator's (BJ) university. All National Health Service and Royal College of Nursing Research ethics guidance was followed. This included the recruitment, consent and data collection processes. All data were collected by one researcher (BJ) during two visits to Uganda in 2008 and 2009.

### Sample and location of the study

The study was undertaken in the Hoima (Western Uganda) and Kampala regions of Uganda, where Hospice Africa has established Community Volunteer

programmes. Hoima has an estimated population of 435,537 people and Kampala approximately 1,420,000.<sup>27</sup> A non-probability sampling approach using a convenience sample was employed for the study. The sampling approach was chosen in conjunction with the Hospice clinical team due to the issues of safety and access.<sup>28</sup> In addition, it included the practical issue of the respondents being available during the data collection period. All 85 active Community Volunteer workers were invited to participate, and 32 agreed. Twenty-two volunteers from Hoima (nine male and 11 female, mean age of 39 years, range 28–52 years) and 10 from Kampala (four male, six female, mean age 39 years, range 33–48 years) took part in the study. The two clinical team members from the hospice at Hoima who had involvement with the programme and nine clinical staff (from a possible 12) from Kampala also took part in the study.

### Data collection and analysis

A pragmatic approach had to be adopted for the data collection phase due to language constraints and safety issues. For the data collection with the Hoima Community Volunteer Workers, three group interviews (comprising eight, seven and six participants) and one additional interview (with a participant who was delayed in arriving) were undertaken using an interpreter. The interpreter was attached to the Hospice and had extensive experience of this role within the clinical setting. For the Volunteer participants in Kampala, individual interviews were undertaken (no interpreter was needed). Hospice clinical staff at Hoima were interviewed individually (due to the low number of staff in the team) and at Kampala a focus group was used in order to promote group discussion and debate.<sup>29–31</sup> All interviews were digitally recorded, and, when an interpreter was used, the questions were asked in English by the researcher and translated. All aspects of the interview were recorded for quality checking, as is recommended for research that involves an interpreter.<sup>32</sup>

A semi-structured interview schedule was used, which focused upon the motivations for deciding to become a Community Volunteer Worker and the personal impact the role had on the worker. Questions were open-ended and participants were prompted to give examples where possible. For the focus group interview with the clinical team, participants were encouraged to interact in the discussion. The focus group resulted in a high level of participation by the majority of the group, particularly around the factors that motivated someone to become a Community Volunteer Worker. At the end of the interview, to ensure clarification of the key points raised and

enhance the trustworthiness of the findings, a summary of the key points raised was highlighted by the moderator (BJ).<sup>33</sup>

### Data analysis

Data were analysed using a thematic approach that incorporated the four phases of organization, familiarization, reduction and analysis.<sup>29,34</sup> Sections of the interviews undertaken with the interpreter were analysed independently and found to be accurate.<sup>33</sup> The third phase of the analysis process included data coding, whereby categories under each question were identified and coded.<sup>34</sup> The trustworthiness of the findings was enhanced by the use of an independent researcher, who analysed a selection of all data, and a consensus of the key themes was reached. In addition, QSR Nvivo 8 was used to aid the management of the data in the analysis process. Finally, the data sets were subject to a cross case analysis, as advocated by Patton, to see whether the themes identified by each group applied to all the data.<sup>25</sup>

### Results

When the data obtained from the Community Volunteer Workers and Hospice clinical staff were compared, there was a consensus on the key themes: the motivation for becoming a volunteer and the personal impact of being a volunteer. The verbatim quotations that are presented in this paper are the best exemplars from all groups of respondents and, where possible, refer to data from both sites.

#### *Impetus for becoming a Community Volunteer Worker*

There was a strong consensus amongst all the volunteers and the Hospice staff that the impetus for becoming a volunteer was based on the wish to care for the suffering in the villages. This is suggested as being based upon cultural/traditional values, which were referred to by several of the respondents:

‘Traditionally or culturally here, we believe in looking after one another. People believe in helping one another as a community. If something happens, if somebody falls sick, somebody moves in to give them a hand’ (Hospice Team, Hoima, respondent 2)

‘It comes from the heart – they were dying so much in the village, we could be burying two people a day’ (Community Volunteer Worker Kampala, respondent 7)

‘I volunteer because I saw many people suffering in the village like suffering of HIV and didn’t know what they were suffering from, so that’s why I had to come up for

training so that because I can help those people in the villages' (Community Volunteer Worker, Hoima, group 3, respondent 7)

Additionally, both the Hospice teams and Community Volunteer Workers from both sites referred to the volunteers' previous personal experiences. This issue resulted in a lot of discussion within the focus group, drawing upon the examples that the team had seen and the benefit of the volunteers' experiences prior to commencing the role, for example:

'In my experience, somebody wants to come in and give, and give hope, to the frail people of the community. That's what I have seen. People come and say they want to become community volunteers, so they can go and help people down in the village' (Hospice Team, Hoima, respondent 1)

'Some have a very personal experience, either they are patients with HIV Aids or cancer, so they have a really deep compassion to want to help others or to meet others' needs' (Hospice Team, Kampala, respondent 1)

### *Personal impact of being a Community Volunteer Worker*

Along with the skills obtained (for example, practical, emotional, physical and spiritual support), which are reported elsewhere, being a Community Volunteer Worker resulted in a high level of personal pride. Additionally, the role impacted upon their status in their local communities and the respect that was subsequently shown to them within their communities.

***Pride in being a Community Volunteer Worker.*** The community volunteers were generally very proud of their role. In particular, the respondents based in the Hoima region referred to the T-shirt that was their uniform, and how that helped them to be identified as a Community Volunteer Worker, as illustrated in the following responses:

'I was so happy that people can see I can help them' (Community Volunteer Worker, Kampala, respondent 7)

'Me I feel proud in my uniform' (Community Volunteer Worker, Hoima, group 3, respondent 4)

'I have that uniform, people they can point to me that one is a community volunteer of the Hospice. It is a good' (Community Volunteer Worker, Hoima, group 2, respondent 7)

'Whenever I put on that uniform I feel proud because many people whenever they see that uniform they just rush to me and ask me where to find him, the work we

do and I explain to them and if they need help, I gives them help' (Community Volunteer Worker, Hoima, group 3, respondent 5)

***Status and respect in their community.*** Both Hospice clinical teams and Community Volunteer Workers referred to the impact of the role within the local communities, for example:

'Their status is raised' (Hospice team, Kampala, respondent 2)

'They are recognized and respected in the community' (Hospice team, Kampala, respondent 9)

'I have the respect of the people, they speak to me, they trust me' (Community Volunteer Worker, Hoima, group 2, respondent 7)

'Gained friendship and popularity, so now in the village the people are respecting me' (Community Volunteer Worker, Hoima, group 3, respondent 7)

This issue of respect was also indicated in an example given by a volunteer and one of the Hospice team from Hoima, who referred to the recent selection of a volunteer to stand for a local election in their rural area:

'From that work of helping the people in the villages they came and told me this election we are now trust you to be our sub county councillor from this parish the sub-county' (Community Volunteer Worker, Hoima, group 2, respondent 7)

'The community has more trust and confidence in those volunteers, and some of them have even had a chance to join politics as a result of their voluntary work' (Hospice team, Hoima, respondent 2)

A similar illustration was given by one of the Kampala Community Volunteer Workers, who has recently been selected for a position in the village:

'I was selected to be the vice chair person in the village' (Community Volunteer Worker, Kampala, respondent 7)

### **Methodological issues**

There are certain methodological issues that need to be considered when looking at the transferability of the findings from this study. The practical constraints of setting up a research project in a developing country have to be considered, including language barriers and safety of the researcher. A potential source of sample bias with the selection of the respondents by the

Hospice team is acknowledged. Steps to strengthen the study included the triangulation of data from both Community Volunteers and Hospice staff and data collection from two sites.

Data collection from both sites was not conducted simultaneously, and the data may have been affected by the time delay. However, the same semi-structured interview guide and the same researcher to collect the data were employed, and the results do not indicate any major factors that may have been a result of the time difference in the data collection. Research studies that involve the use of an interpreter are a potential quality issue.<sup>31</sup> This study used interpreters who regularly work with the Hospice team for this purpose. The recording of the interview, discussion for clarification of meanings of words, and an additional quality check were all undertaken in the study. Additionally, some of the volunteers did speak English, which enabled a comparison with the themes identified by interviews conducted with an interpreter with those conducted in English.

## Discussion

This study aimed to explore the motivation and personal impact of becoming a palliative care Community Volunteer Worker in a developing country. One of the first observations made during this study was the demographic distribution of the volunteers. There was a younger age group (mean 39 years), more males (11/22; 59 percent), and the majority have not undergone further or higher education, whereas in the western world volunteers are generally female and aged over 55 years and have undergone further/higher education.<sup>2,4</sup> However, this has to be considered in the Ugandan context, including the average life span, which for Uganda is 49 years for males and 51 years for females, and a lack of access to education, especially in the rural areas, particularly during the years of civil unrest.<sup>35</sup>

Hospice staff and volunteers highlighted the motivation for becoming a volunteer as stemming from their cultural/traditional values of wanting to help other people. This altruistic motivation is in keeping with the literature.<sup>7-10</sup> However, whereas previous studies reported personal experience of a recent death as a motivating factor of someone wishing to volunteer in the hospice setting, this study refers to the multiple losses that the volunteers had experienced, particularly with the HIV/AIDS death rates in the previous decade.<sup>4</sup> Furthermore, some of the volunteers were people who had HIV/AIDS themselves and wanted to help others.

Being a palliative care volunteer resulted in enormous pride for the volunteer. This was widely reported by all respondents from both sites, in particular by the

respondents from the more rural Hoima region, who attended the interview wearing their uniform. Interestingly, several of the volunteers mentioned 'the badge of office' of the T-shirt and how this helped them to be identified as palliative care volunteer workers. It can be suggested that this increased pride is similar to the reportedly enhanced self-esteem that was identified by the palliative care volunteers in the children's hospice in Scotland.<sup>12</sup>

The impact on their status and the respect received from their local communities was identified by the clinical teams and the Community Volunteer Workers in the study. One interesting point included the invitation to some of the volunteers to take up roles in local government, which was reported from respondents at Hoima and Kampala. However, it is important to note that the Community Volunteer Workers in this study had to be proposed by their village leaders, and therefore had already undergone some preliminary selection and were already known by the village leaders. However, this impact on their personal status is similar to that reported by Daoud et al. in the study on the Women's Health Programme in Israel.<sup>20</sup>

## Conclusion

Palliative care volunteers play a vital role in helping to provide support for the terminally ill. The introduction and expansion of palliative care services in the developing world has also seen the emergence of a cadre of volunteer workers, who, as in the western world, are of paramount importance to the service. Interestingly, what emerged from this study was the strong personal impact of being a palliative care volunteer, in particular the great pride in being a volunteer. This personal impact of being a palliative care volunteer is clearly worthy of further research as to the potential benefits that volunteering brings, benefits not just for the patients, families and hospice staff but for the individual volunteer, who gains increased pride and self-esteem.

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## Conflict of interest

Dr Anne Merriman and Jerith Birakurataki are employed by Hospice Africa Uganda. No other conflict of interest is declared.

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