AN EXPLORATORY STUDY ON ROLES AND ATTITUDES TOWARDS CAREGIVER SUPPORT: ZAMBIA CASE STUDY

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### Acronyms

<table>
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<th>Acronym</th>
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<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Anti-retroviral therapy</td>
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<td>CAFOD</td>
<td>Catholic Agency for Overseas Development</td>
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<tr>
<td>CBO</td>
<td>Community-based organisation</td>
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<td>CHAZ</td>
<td>Churches Health Association of Zambia</td>
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<td>FBO</td>
<td>Faith-based organisation</td>
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<td>HBC</td>
<td>Home-based care</td>
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<td>HIV</td>
<td>Human immunodeficiency virus</td>
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<td>INGO</td>
<td>International non-governmental organisation</td>
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<td>MoH</td>
<td>Ministry of Health</td>
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<td>NAC</td>
<td>National HIV/AIDS/STD/TB Council</td>
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<td>NGO</td>
<td>Non-governmental organisation</td>
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<td>OVC</td>
<td>Orphans and other vulnerable children</td>
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<td>RAISA</td>
<td>Regional AIDS Initiative of Southern Africa</td>
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<tr>
<td>STI</td>
<td>Sexually transmitted infection</td>
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<td>TB</td>
<td>Tuberculosis</td>
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<td>VSO</td>
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Introduction

Background and objectives of the study

This paper presents the findings of the Zambian case study which formed part of a larger investigation into compensation of caregivers providing home-based care (HBC) in respect of Human immunodeficiency virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) and other diseases and conditions. The study was commissioned by Tearfund on behalf of the UK Consortium on AIDS and International Development. Zambia and Zimbabwe were chosen as case studies because these two countries were those in which the largest number of consortium members were or had been active.

The objectives of the country case studies were to document the design and practice in respect of caregivers of two projects and explore staff and caregiver perceptions of the financial and other support caregivers received within the project.

Background to HBC in Zambia

In Zambia, the first official case of HIV was reported in 1984. Within a decade, the pandemic had resulted in a severely overstretched health system that was unable to cope with the increasing number of patients. While treatment became available to some extent in 2004, many patients either did not access formal health services at all, or were sent back home by health facilities where they lay ill and subsequently died.

As in other countries, HBC programmes in respect of HIV were initially developed and implemented by non-governmental organisations (NGOs), faith-based organisations (FBOs) and other voluntary organisations. In 1999, the Government of Zambia established the National HIV/AIDS/STI/TB Council (NAC) through an Act of Parliament. Its role was to coordinate national responses to the pandemic. In 2002 the Zambian government developed the National HIV/AIDS/STI/TB policy which, among other, prioritised HBC. According to the National Health Strategic Plan 2006–2010, by 2005, HBC programmes had been scaled up to all 72 districts of the country and more than 300 trainers had been trained to establish and strengthen palliative care at the community level.1 These efforts continued to rely heavily on financial and other support from external donors. The Ministry of Health (MoH) and NAC saw their roles as coordinating and regulating services.

Methodology

Two community-based organisations were selected. The criteria used were that they received support from a Consortium member, that one should be faith-based and one not, and that they should be based in or near Lusaka so as to minimise research expenses. The chosen organisations were:

- Mwazwini Home Based Care, supported by Voluntary Service Overseas (VSO)
- St Peters Parish, Garden Home Based Care, supported by the Catholic Agency for Overseas Development (CAFOD) through the Archdiocese of Lusaka

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1 National Health Strategic Plan 2006–2010, November 2005, Ministry of Health, Zambia
The fieldwork for the study was done during 2013. Qualitative data was collected through interviews and observation. Interviews were held with those overall in charge of the community-based organisations (CBOs). Current caregivers were engaged with through focus group discussions. Caregivers who were no longer working with the CBOs (past caregivers) were interviewed using a short schedule. The following interviews and discussion were conducted:

- one interview with the Catholic Archdiocese of Lusaka HBC coordinator
- two interviews with senior project managers
- two focus group discussions with current caregivers
- seven short interviews with past caregivers

To enhance comparability, the same interview and focus group instruments were used for both case studies. These instruments were also used in the Zimbabwe research. Unfortunately, the country-based Zambia researcher, Joseph Simbaya, did not complete his contract. This report was therefore written up from available (incomplete) interview and focus group transcripts and a very preliminary draft report. Each of the case studies is introduced with a short description of the approach of the supporting international non-governmental organisation (INGO). These introductions are drawn from the in-depth interviews done as another component of this study.

**Mwazwini Home Based Care**

**VSO’s approach**

While VSO’s support comes mainly in the form of professional volunteer support, under the umbrella of the Regional AIDS Initiative of Southern Africa (RAISA), VSO also provides small grants to partners who do work that involves home-based caregivers. The money is reportedly used for expenses such as bicycles and HBC kits, training and seed funding for income generation projects.

In Zambia, most of VSO’s work is done with CBOs. VSO has placed international volunteers to provide organisational support, strengthen monitoring and evaluation systems, strengthen service delivery, train CBO staff and home-based caregivers in palliative care and income-generating activities, and assist with advocacy skills. The caregiving supported by VSO reportedly focuses on people living with HIV, but also on orphans and other vulnerable children (OVC). In 2013, VSO was supporting ten caregiving organisations in Zambia.

While VSO does not provide support only to faith-based organisations, the Mwazwini director made frequent references to ‘the diocese’ during the interview. These references suggest that Mwazwini operates as a project of a church diocese.

**The organisation**

Mwazwini Home Based Care in Chazanga compound began operating in 1992 and established an office in 1996. The branch operating in Garden compound started around 1997–1998. At the time of the interviews, Mwazwini Home Based Care reported having funding from the Global Fund (through the Churches Health Association of Zambia (CHAZ)) and Norwegian Church
Aid, ‘reservoir’ funding from CAFOD, and non-funding support linked with research into psycho-social issues. The director did not refer to support from VSO.

The director emphasised community ownership and the autonomy and uniqueness of the projects, rather than ownership by Mwazwini. He said that grassroots community members would come together to start a community-based project, such as establishing a garden. After some years of operation, Mwazwini would register the project with the diocese and provide support in the form of supervision, monitoring and funding. At all times, however, the parish would discourage dependency so as to ensure that the project would continue even if the parish had no funds.

**Recruitment and retention of caregivers**

In line with the autonomous nature of projects, each carries out its own recruitment. At the time of the interview, Mwazwini Home Based Care had 24 caregivers of whom seven were men. However, three of the men were no longer active. In the discussion and interviews there were several references to the challenges posed by a shortage of male caregivers in terms of providing care and counselling to male patients.

The motivation for becoming involved in caregiving differed across caregivers. Some joined because they were encouraged by friends to serve suffering community members. Some joined because they wanted to learn how to take care of the sick and what it entails to be a caregiver. Others joined after losing a loved one, whereas yet others joined because they hoped for help for themselves and their family once they had joined as caregivers. As one of the past caregivers, a widow with a psychologically disturbed adult son, explained: ‘The main reason I joined was to get help for both my son and I in our livelihood.”

Mwazwini has challenges in retaining caregivers. One of the caregivers said that previously there had been as many as 45 caregivers but many had left because ‘akabomba akabiye kamunda’ (you can’t work when there is nothing eaten in the stomach). The need for food emerged repeatedly in the interviews and group discussion. The caregiver also said that she herself would not leave ‘because I even lost my child due to lack of information’.

Several of the past caregivers said that they had stopped caregiving on account of the lack of incentives. One said that this made it impossible to care for the young children of her daughter after the latter’s death. A current caregiver observed that widows with many children who were caregiving saw that others were making a success of small businesses and therefore left caregiving.

One past caregiver stopped caregiving work because she suspected that money and other aspects of the project had been mismanaged. Suspicion of fraud was also mentioned by one of the current caregivers. The one who left for this reason observed that donors had been informed of the need for incentives but had not provided any. Another past caregiver left because health-related problems that affected her legs prevented her visiting other patients in the community.

Some of the Mwazwini caregivers were engaged in income-earning activities before joining as a caregiver. Activities included selling second-hand clothes, gasoline, and foodstuff such as scones, beans, kapenta, groundnuts and vegetables. Others were involved in dyeing chitenge material and running ‘katemba’ (a small mobile business). Some continued with these activities after joining as caregivers, while others stopped because they could not combine both types of work successfully. In contrast, others used money from the ‘chilimba’ that was established (see
The current caregivers reported that those they cared for were bedridden, living with HIV and/or had related illnesses. They said that caregivers had an average of five patients. Among these, typically two would be bedridden.

One of the caregivers observed that five was ‘a manageable number’, whereas previously each caregiver had been responsible for about double this number. It had not been manageable time-wise to care for ten, but ‘with five you can afford in two days to check for two patients and the other days for the rest’.

The work undertaken by caregivers differs from one patient to another. Tasks described by caregivers included preparing food for patients; teaching them and their primary caregivers about prevention and how to take care of the sick; counselling the sick to encourage them to continue with medication; taking medication to patients; accompanying patients to the local clinic or hospital, and caring for children. The director also referred to HIV testing, nutrition support, education support for orphans, recreation activities for children, and assistance with livelihoods.

In addition, he said that the caregivers provided pastoral care as ‘when you look at the holistic approach to our clients, they have to be supported physically and spiritually’.

The caregivers reported that their role had changed over time. While previously most patients were bedridden, they were now (thanks to the availability of anti-retroviral therapy (ART)) able to walk and do some chores for themselves. This has reduced the workload for caregivers and also the number of times they need to visit patients each week. The director said that previously caregivers might visit a patient as many as eight times in a week, whereas now they might visit twice in a month. He said of the current patients: ‘At some point some of them are even working, some of them have married, and it’s interesting to see a change – a person was bedridden to death, to they are able to fend for themselves.’

However, a caregiver noted that there could also be negative effects of ART and the resultant health of patients. She said that because they now looked ‘good’, some women had become involved (again) in prostitution as a way of getting money to relieve their poverty.

Training

Caregivers need training, including in basic nursing skills, in order to provide adequate care. The director said that there was a national training package for HBC. However, many people had not read the relevant document and the Ministry did not itself monitor but instead expected organisations such as Mwazwini to assist with monitoring of minimum standards.

The director said that the caregivers needed regular refresher training so as to be able to keep up to date with developments. One of the caregivers similarly argued the need for refresher courses. She said that without this ‘some of the clients might be more learned than the caregivers and if it happens that way, the client will lose hope in listening to you’. There were references to an annual training retreat where caregivers also receive ‘a bit of money’.

Caregivers said that they would like further training. In particular, two referred to the need for guidance in how to persuade patients who did not want to go for HIV testing or take ART
because ‘they would be laughed at’. One caregiver said that because she had not been to school, she was unable to write down and remember the information she gathered from patients.

**Compensation**

The director said that the reduction in caregiver workload as a result of availability of ART had resulted in less emphasis than previously on caregiver incentives, and that the donor community was instead ‘focused on the livelihood for the beneficiaries and forgetting about the caregivers’. A caregiver said, somewhat similarly, that in the past when there were many bedridden patients, donors provided food supplements while the caregivers kept chickens.

The director and caregivers reported that previously they were given cooking oil, maize meal, kapenta (fish), beans and blankets as an incentive for being caregivers. They would also share any food remaining after they had distributed to patients. Indeed, one of the caregivers said that they received maize meal, soap and cooking oil only if these were provided for orphans, suggesting that there was no separate explicit provision for caregivers. Another caregiver said that they were given ‘clothes and a few necessities to help us fulfil the work of the caregiver’.

The diocese had also provided maize meal and medication if they were ill and money to engage in group income-generating activities. Caregivers in Mwazwini had reared chickens both so as to be able to supply patients and for earning money to buy beans, sugar, salt and cooking oil for themselves. These forms of support had, however, stopped because Mwazwini now received less funding than formerly. A past caregiver said that Mwazwini previously had brought in someone to train the caregivers in tailoring, but that this initiative had not lasted long because Mwazwini ran out of money to pay the trainer. The past caregiver who reported this said that as a consequence she had moved to another project, SOS, so as to continue being trained in tailoring. After completing one year of training, her daughter had died and all her time was taken up caring for her grandchildren.

The organisation had allocated about 6 million (kwacha) for income-generating activities, provided training in entrepreneurship and introduced a savings and loan association for caregivers. In terms of the latter, one of the caregivers referred to ‘chilimba’, a scheme in which each person contributes a given amount of money and this is given to each person in turn. The income-generation and chilimba were reported to have resulted in some successes. Caregivers in rural areas were said to have used money from the schemes to buy fertiliser during the rainy season, some had used the money for building structures, while others had used it for Christmas expenses.

These forms of collective support had been chosen by the diocese over individually based support ‘because as a programme you cannot be buying him [trousers], this one a chitenge’. The director observed that something that might motivate one person might not motivate another – ‘what would motivate you is not what would motivate me’. However, he argued that successful group-based income-generating activities and rotating credit would in time allow for people to get individual loans and be linked with micro-credit schemes.

One of the past caregivers, who was a widow, said that ‘the plight of us the widows’ needed to be addressed through provision of money or ‘income-generating kits’. It is unclear if this woman was active prior to Mwazwini introducing support for income-generating activity. Another past caregiver said that she did not gain much personally from the income-generating activity because ‘most of the profit’ was handed over to Mwazwini Home Based Care. It is not clear from the transcript whether contribution of part of the earnings was a requirement.
Caregivers were unhappy that the direct support, especially in the form of food, was no longer provided. As one said when asked which forms of support were most important: ‘Food is more important because without eating you can’t do the work.’

The director explained that the project had previously received assistance in respect of food from both the World Food Programme and ‘Euro’. The former no longer worked in Zambia while the latter’s assistance stopped when their project came to an end.

Services and support for patients

The reduction in available funds had affected the organisation in other ways, including its ability to provide food supplements to patients. This, in turn, resulted in some patients stopping their medication as the medication needed to be accompanied by adequate food. The saving on food expenses ultimately imposed higher costs, as patients developed resistance to the first-line drugs, and had to be put on more expensive second-line treatment. The fact that caregivers were not able to bring food regularly to their homes also made some patients resist and reject the caregiving services.

 Liked and disliked aspects of caregiving

When asked what they liked about caregiving, caregivers said that they were pleased about what they had learnt (both about caregiving and – in at least one case – about income-earning), were proud that they were able to prolong people’s lives (including their own), and felt personally affirmed. The latter reason was exemplified by a past caregiver who said that ‘because I am a loving and caring person [it] fulfilled my inner self and brought satisfaction’.

One caregiver was proud of the fact that they were offering a counselling service that was preferred to that offered in hospital and clinics where patients might ‘think they are being teased or fooled’. She observed that they also offered a more convenient service for patients who could avoid the congestion, queues and inconvenient times at hospitals and clinics.

When asked which aspects of caregiving they did not like, caregivers offered wide-ranging answers. For example, one complained about ‘senior officers’ from the project implying that they did the work only to obtain food and other benefits. This echoed the stance of a past caregiver who acknowledged that caregiving ‘should not be based on profit-making but… should come from deep down of someone’s heart’ but nevertheless argued that compensation in the form of clothing and other ‘necessities’ was needed.

Another caregiver complained about cases when patients started drinking beer as their health improved. Other challenges named included bad reactions from patients when they visited them; long distances and a lack of transport (to be faced on an empty stomach); the inability to assist patients who did not have means of transport to far-off health facilities; and difficulties in counselling men, given their reluctance to share information with women caregivers. Of particular interest for our purposes were the complaints about setting off to do the work on an empty stomach and coming back home to a house without food. One caregiver said that what she disliked was when patients were so sick that the caregiver was required to bath them and clean their sores. She said this was particularly unpleasant when the person was ‘too fat to slide him’.
The role of government

The researcher ended the focus groups and interviews by asking what respondents saw as government’s role. The coordinator argued persuasively that the work caregivers were doing was ‘on behalf of the Ministry of Health’ in that they were ‘filling the gap’. Government should therefore develop a uniform policy that was applicable to all caregivers. He said that the policy should provide for ‘the type of motivation one would receive in World Vision’. He said that government officials should visit on a regular basis so as to monitor and provide supervision. They should also organise forums at which stakeholders could be brought together after such visits to discuss challenges and how to address them. However, he said further that in line with the ‘laissez-faire’ approach of the Lusaka ‘architects’, the various churches might need to come together to devise a solution to the problems.

Going forward

The coordinator said that they had a pilot project in which they were giving money for children to go to school, money for food, and money to engage in income-generating activities. This approach was intended to avoid a situation where recipients said that they had used money given for another purpose to send their children to school. He said that the pilot would run for three years, after which they would decide whether to replicate it in other projects. More generally, the coordinator said that the donor focus only on beneficiary (ie patient) livelihoods was ‘wrong’ because caregivers were ‘important’ people in the community who needed basic necessities and tools in order to do their work better. He acknowledged that the lack of incentives was the most important challenge in respect of caregiving.

St Peters Parish, Garden Home Based Care

CAFOD’s approach

CAFOD is a faith-based organisation. The organisation works through partner organisations by funding and providing technical support for their programming. From 1986, when it started funding HIV work in Uganda, CAFOD has partnered for this work primarily with churches. In southern Africa, CAFOD partners include both faith-based and secular organisations. The church partners see the work of caregiving as an extension of the pastoral work of the church in responding to the needs of the community. Many who volunteer within these projects are motivated by their faith and see the work as living out, and based on, gospel principles such as ‘…I was hungry, and you fed me…’ (Matthew 25:35, NLT). This forms the basis for encouraging volunteer work by women and men.

The organisation

The Archdiocese of Lusaka is one of the six partners supported by CAFOD in Zambia. St Peters Parish falls under the archdiocese and operates the Garden HBC programme. St Peters Parish and the Archdiocese of Lusaka are both faith-based organisations.
CAFOD has been funding HBC through the Archdiocese of Lusaka since 2000. The archdiocese is also supported by other donors and organisations. The archdiocese have 39 operational sites run through their church parishes, of which 31 are supported by CAFOD.

CAFOD funding through the Archdiocese of Lusaka has been the main source of support to St Peters Home Based Care since at least 2000, the year in which the coordinator was appointed as the nurse for the project. Other funders include CHAZ and the FNB Sisters.

**Recruitment and retention of caregivers**

St Peters Parish, Garden HBC has 41 registered caregivers, but fewer than this are currently active. Caregivers were recruited through an announcement in the church which people responded to by raising their hand. There were no set selection criteria for volunteering aside from a willingness to serve the sick. One of the caregivers reported that she had only reached grade seven because of being ‘financially handicapped’ but was able to read, write and speak good English.

The coordinator confirmed that other HBC programmes offered more in material terms. However, St Peters Parish, Garden HBC continued because it was able to offer the ‘spiritual aspect’. He said that he himself, as a qualified nurse, was paid the same as a nurse on the government payroll because he was paid by the archdiocese. However, ‘What has made me work for all these years, it’s just passion for the sick and my spiritual stance.’

The caregivers said that some of their former colleagues had done the work ‘because of employment’ rather than ‘out of pity’. These caregivers had done the work at an earlier point ‘because a truck used to come loaded with things for caregivers’. One of the current caregivers said that she had been the first to stop caregiving. She had stopped for three to four months because she found a job that helped her provide for her children. She said that when the nursing sister asked why she had left: ‘I just gave an excuse and I even knew that it was a sin to lie. Even when I was working, I could think about patients but there was nothing I could do.’

One caregiver said that she had thought of ‘going to the Orthodox where they were recruiting caregivers’ because St Peters Parish, Garden HBC was not providing compensation. She had for the time being remained with St Peters Parish but said that all of the caregivers had planned to stop caregiving for them and ‘go where they can give us money’. The caregivers told the story of another caregiver who had stayed away for some time because she was not able to repay income-generating money given by ‘the Irish’ when they stopped funding caregiving. The coordinator agreed that some monetary compensation, even if small, was needed to attract back those caregivers who had left the project.

**The work of caregivers**

Caregivers in the focus group described their work as a service to the communities in which they lived. When asked to whom they provided care, they emphasised that they did not discriminate in terms of whom they visited. As one explained: ‘Us as Catholics, we visit anyone because our Lord Jesus never used to be selective when he was teaching, and so likewise we as caregivers don’t choose who to visit because today it could be the other person, tomorrow it could be me.’

The coordinator explained that they did not target particular individuals, but instead dealt with all types of ‘ailments’ related to chronic conditions. The conditions mentioned included tuberculosis
(TB) and cancer as much as, if not more than, HIV. It was unclear if these were HIV-related cancers or people living with HIV and TB.

The tasks mentioned by caregivers in the interviews included counselling, encouraging patients to take their medication, housework, ‘hygiene services’ (bathing), provision of painkillers, collecting medication from the clinic and delivering to patients who are not mobile, nutrition (including distribution of food), teaching primary caregivers how to care for patients and personal hygiene, and prevention and health education.

Some of the caregivers’ tasks are carried out at the clinic, while others are done after the patients are sent home. There is a book for each caregiver in which the sister notes down which members of their community need assistance or monitoring and assign related tasks to the caregivers. The caregivers also encourage community members to stay with their ill relatives ’so that they don’t feel stressed or stigmatised’.

The caregivers were reported to work from 8am to 2pm five days a week. The coordinator does ‘visitation’ on a Tuesday, while caregivers work alone on other days.

As in Mwawzini, in St Peters Parish both the coordinator and caregivers remarked on how the role of caregivers had changed with the availability of ART. Very few patients were now bedridden and the number of deaths had declined. The coordinator recalled a particular day in 2004 on which 12 patients died. He contrasted this with the current situation in which some months went by without any deaths. This change had been seen in respect of both TB and people with an HIV-related illness, given that TB was often linked to HIV.

**Training**

The coordinator acknowledged the need for training for caregivers, and said that all had received basic training on how to care for patients, coping skills and counselling. He said that caregivers should receive regular refresher training, but that this had not happened for some time due to lack of funds. The coordinator noted that caregivers expected to receive 10,000 kwacha during training, an amount he felt was ‘a lot’.

To compensate for lack of funds, some training was provided during strategic meetings. Those who received the basic training had received certificates of attendance issued by the diocese, but it was not clear whether these certificates would be recognised by other potential employers.

**Compensation**

The coordinator and some caregivers reported that in the past caregivers were given gumboots, umbrellas, blankets, vitenge and foodstuff such as cooking oil, mealie meal, sugar, kapenta and beans as incentives for being caregivers. Caregivers reported that provision of vitenge, umbrellas and gumboots had stopped as far back as 2006.

As a result, several caregivers reported, ‘we have been demoralised’. This was noted as a reason why some caregivers, especially those with school-going children, might have stopped caregiving and engaged in business. One of the past caregivers said that the amount of food given to caregivers was insufficient and the manner in which it was done was humiliating – ‘so you would imagine I am taking mealie meal to my family in a plastic [bag]; this did not give me pride as the head of household’.

The coordinator reported that the decision to provide food to caregivers was made after they discovered that some of the food allocated to caregivers for delivery to patients was not reaching the people it was intended for. The chitenge materials were provided in response to a request
from caregivers for uniforms. The blanket was provided because it ‘proved to be cheaper and affordable’ when compared with monetary compensation, although the signatories to the accounts who made this decision knew that caregivers would have liked to receive more substantial goods, such as mattresses. The coordinator noted that government did not provide guidelines on what form compensation should take.

Many caregivers engaged in income-generating activity alongside their caregiving work. They reported that the project had, with money from Ireland, assisted with income-generating activities through buying sewing machines and a piece of land on which they could grow vegetables. It seems that this assistance was intended to make the project better able to sustain itself, rather than necessarily to benefit individual caregivers. The initiative had, however, failed due to lack of cooperation by caregivers because they were too busy with their businesses in the attempt to provide for their own families. One of the past caregivers said that people had misused the money provided for income-generating activities. The caregivers had been divided into two groups and there were also references to the fact that one group – those rearing and selling chickens – had benefited more than the other.

One of the past caregivers felt that the absence of compensation reflected a lack of acknowledgment of the work done, and that the caregiver ‘is also just a person’. She elaborated: ‘You assume responsibility over a patient as your own… child… You need to care for them, for example to bath them, wash, feed them, and these patients would ask you for food, basically for anything, and yet you don’t get anything from here.’

The caregivers felt that they should be given money or other assistance to enable them to take care of their families, including sponsorship of their children for secondary school in the same way that orphans were sponsored. They pointed out that it was the absence of monetary compensation that had led to other caregivers stopping work. One of the caregivers suggested that it was government who should provide the assistance.

**Services and support for patients**

The funding shortage, as well as the World Food Programme’s withdrawal, had also affected the services that the caregivers and the organisation more generally were able to offer. Focus group participants reported that even clients were withdrawing from the programme to join other programmes which offered more, and in particular, food.

Caregivers reported that in the past they had been provided with toolkits that included soap, a hand towel, water, painkillers and oral rehydration solution, but now they were given only Panadol. They reported further that they needed to give transport money to patients who were due to visit health services for check-ups. They noted that in the past, there had been money available which allowed them to provide blankets, soap, maize meal, medication and even shelter to patients. While the money was never sufficient to meet the needs, caregivers were at that time able to give some material support to patients.

The coordinator explained that they were able to provide nutritional support to patients through ‘well-wishers’ who made donations that enabled them to buy food for the most vulnerable of the patients.
**Liked and disliked aspects of the work**

When asked what they liked about caregiving, caregivers said they liked visiting patients and ‘encouraging’ them as they would do for their own family members when they were ill. They said that they learnt a lot through the work, including ‘being humbled and how to keep secrets and how to maintain the relationship with different people’. One caregiver said simply: ‘We like our work as caregivers but the only problem is that it’s voluntary [ie unpaid].’

When asked which aspects of caregiving they did not like, the caregivers spoke about patients who stopped taking ART once they started feeling and looking better; patients who avoided their visits and pretended they were not at home, and the risks associated with visiting patients with TB who were not yet on treatment and in whose houses there were ‘so many things like insects’. In such a situation, they would ‘just commit ourselves in[to] the hands of God’.

Caregivers also used the opportunity of this question to reiterate that while they felt fulfilled by their work, they did not like working without any monetary compensation, and also to emphasise the struggle to balance the needs of their families and patients. One caregiver told how, as a caregiver, she would leave her merchandise at home and visit patients only to find, on her return, that her customers had already bought from others. Another referred to the difficulty of visiting patients without being able to take them something, such as fruit, while also not being able to provide fruit for their own families.

**The role of government**

The coordinator said that the project was dependent on donors for patients’ welfare as the government was not able even to provide painkillers – ‘they only give directions to communities’.

A past caregiver remarked that government should acknowledge that ‘caregiving is more like a doctor, a nurse as well as a midwife, because it involves carrying out the roles of the above-mentioned, for example bathing patients, washing sores and [much] more which demands ample time from a caregiver’. This, she said, meant that government should ‘show some kind of appreciation’ by providing allowances.

**Going forward**

Caregivers said that they had no suggestions to make other than that the ‘money issue’ be addressed.

**General discussion**

While the two case studies were meant to represent partners of different funders, the chosen two shared several funders, including CAFOD. Further, both organisations have strong church links. However, St Peters Parish more clearly used the church as the basis of recruitment, and caregivers at St Peters Parish were more likely than those in Mwazwini to refer to religious or spiritual motivations for engaging in caregiving.

There were other differences between the two organisations. In particular, Mwazwini works through relatively autonomous community-based efforts, while St Peters has strong central
organisation. This is reflected, among others, in the St Peters coordinator being a nurse and what seems to be a fairly formal link with nurses in the health services.

There were many similarities across the two projects, including the absence of educational requirements for recruitment, minimal training after the initial basic training, deterioration over the years in the compensation provided to caregivers, reflecting decreasing levels of international support, attempts to provide support for income-generation activities, and a changing profile and needs of patients cared for. The tasks carried out by caregivers for the two projects were very similar. The absence of regular follow-up training is particularly worrying, given the widespread acknowledgment of the changing nature of the care needed and thus, presumably, the skills and knowledge needed by caregivers.

One perhaps surprising aspect is that while both INGOs had said that they focused on OVC, this aspect was not mentioned much in the focus groups and interviews. There was also no mention of caregivers receiving psycho-social support, although this was emphasised in the interviews with INGOs.

Both organisations had caregivers who had stopped caregiving, and for both the issue of lack of, or diminished, compensation emerged as a key reason for caregivers stopping the work. However, while the St Peters caregivers were clear that compensation should take a monetary form, in Mwazwini, caregivers emphasised the need for compensation in the form of food.

Both organisations had provided assistance with income-generating activities. It is unclear to what extent these were intended to support the project beneficiaries and to what extent these were intended to support the caregivers themselves. The reports on the success or otherwise of the income-generating activities were mixed. The fact that many caregivers left caregiving to engage in their own income-generating activities suggests that the project-based ones were not enormously successful.

Overall, despite prompting, there seemed to be limited expectations as to the role government would play, especially from the caregivers. There was also very little reference to donors, other than as a source of funds.