

Full title: ‘We Are the People Whose Opinions Don’t Matter’. A Photovoice Study Exploring Challenges Faced by Community Health Workers in Uganda.

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Abstract

Understanding the experiences of community health workers (CHWs) through the use of participatory visual methods (PVMs) has been relatively underexplored.

One such PVM is photovoice, which involves the capture of photographic images related to issues of social importance. In this study, we explore challenges faced by eight CHWs in Mukono District, Uganda through the use of photovoice. Over a six-week period, CHWs captured 62 relevant photographs. Subsequent individual interviews and group discussions were held with the CHWs regarding the content of the photographs. Using traditional content analysis, a range of themes related to perceived challenges faced by the CHWs were highlighted, including poor infrastructure, insufficient on-going training and supervision, relationships with other health professionals and equipment supplies. Suggestions were raised as to why such challenges existed and how they could be addressed; mainly through increased roles of the government and supporting NGOs. Overall, photovoice was generally a feasible method to highlight the challenges faced by CHWs, however community acceptability regarding image capture and consent taking may prove challenging, given past historical experiences. The use of photovoice in this study highlighted the need to address the multiple and complex challenges faced by CHWs in order to help them fulfill their roles.

Key words: Photovoice, Participatory Visual Methods, Uganda, Community Health Worker, Village Health Team.

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Introduction

The principle of 'Health for All', advocated for in the 1978 Alma-Ata declaration, placed Primary Health Care (PHC) at the centre of achieving this goal (Ozano, Simkhada, Thann, & Khatri, 2018). Yet, despite this aim, many low- and middle-income countries (LMICs) face a severe shortage of professionally trained health workers, representing a major barrier towards achieving a comprehensive PHC system. As such, many LMICs have adopted PHC models underpinned by a cadre of workers known as Community Health Workers (CHWs).

The term 'Community Health Worker' is often used as an umbrella term to describe community based lay people trained to deliver health interventions in the area they live (Lewin et al., 2005). They belong to the formal health system, are managed by the government or an implementing partner (such as a non-governmental organisation), and although they receive formal training, they have no paraprofessional certification (Lewin, et al., 2005).

One country that has adopted the CHW model for delivery of PHC is Uganda, where CHWs are referred to as members of a Village Health Team (VHT). In Uganda, CHWs have been active since 2001 in a voluntary capacity (O'Donovan, Stiles, et al., 2018). Following a period of sensitisation and awareness raising led by an officer from the district health team, CHWs are selected from the community through a popular vote (Kimbugwe et al., 2014; Turinawe et al., 2015). The Ugandan Ministry of Health suggests that a CHW should be, 'at least 18 years of age, a village resident, able to read and write in the local language, a good community mobilizer and communicator, a dependable and trustworthy person, someone interested in health

and development and someone willing to work for the community' (Sekimpi, 2007). The original remit of the CHW in Uganda was relatively broad with the aim of "recording demographic and health data, educating on health and hygiene topics, mobilizing families to engage in health programs such as vaccination campaigns, monitoring for illness, making referrals, and providing post-discharge follow up" (Ministry of Health Uganda, 2015). However, according to a Ministry of Health statement released in 2015, the VHT strategy has been implemented in different ways across Uganda's 134 districts since 2001. Funding of the programme by the government has been gradually reducing since its inception, leaving the IPs [implementing partners] to fund most of the activities" (Ministry of Health Uganda, 2015). As such, this has resulted in a disjointed approach to CHW programme implementation, with significant variability across districts in CHW training. This means some CHWs are trained and equipped to deal with a variety of illnesses including childhood diarrhoea, malaria and pneumonia, HIV and TB, whereas other CHWs have been trained in a more vertical approach to address specific groups of diseases. Despite this, several successes of the CHW model have been reported, especially improved access to maternal and child health services in rural or resource poor areas (Ekirapa-Kiracho et al., 2017; Mangwi Ayiasi, Kolsteren, Batwala, Criel, & Orach, 2016; Namukwaya et al., 2015).

Yet, despite the reported successes of the CHW model, multiple challenges have also been documented. These include CHWs receiving no financial remuneration for their work, a lack of on-going training, poorly organized and dysfunctional support networks, and a lack of resources, such as medicines and basic equipment (Kimbugwe, et al., 2014; Lee J, 2015; Mays et al., 2017). Of the small body of work

that explores the challenges faced by CHWs, little has been conducted that explores challenges from a more participatory standpoint. As such, community based participatory research (CBPR) which is “geared towards planning and conducting the research process with those people whose life-world and meaningful actions are under study” has been proposed as one alternative method to challenge ‘top-down’ research designs (Bergold and Thomas, 2012).

One CBPR method through which to explore the views of CHWs is photovoice (O'Donovan, Thompson, et al., 2018). Photovoice is a participatory visual method (PVM) where individuals can “identify, represent, and enhance their community through a specific photographic technique” (Wang and Burris, 1997). It involves participants using a camera to capture photographic images on a topic of community importance. The photographs are then used as discussion points and aim to promote “critical dialogue and knowledge about important issues”, with the ultimate goal of bringing about social change (Wang and Burris, 1997).

In this study, we document the use of photovoice with a group of VHTs in rural Mukono, Uganda, to explore the challenges they face in their role as PHC providers.

Materials and Methods

Context and Setting

This photovoice study was embedded as the first phase part of a larger action-research project aimed at improving the training and supervision of CHWs in Mukono District, Uganda. As such the aim of this photovoice study was to try explore the wider issues faced by this particular group of CHWs, prior to the later implementation of more specific interventions aimed at addressing training and supervision. The central focus of this study was to engage in participative inquiry and practice, with our work being underpinned by a constructivist philosophy.

The study took place between October 2018 and January 2019, in Seeta Nazigo Parish, located in the Nakisunga sub-county of the Mukono District. According to the most recent Uganda Population and Housing Census, Nakisunga has a population of 48,000 people, the majority of which are subsistence farmers residing in rural areas (Mukono District Local Government, 2015). Nakisunga has one Level Three government-only funded health centre, Seeta Nazigo Health Center III (SNHC III), located in a rural area of the sub-county. The health centre employs a facility manager, three nurses, two lab technicians, two midwives, a data assistant and a clinical officer. These staff are supported by CHWs, who work in the surrounding community and refer patients to the health centre for review when necessary. According to the Mukono District Health Office, there are approximately 1700 volunteer CHWs in the district, supported by a range of non-government organisations (NGOs).

Implementation Partners

This study was implemented in partnership with Omni Med, a NGO that has been training CHWs in Mukono District since 2009 with the support of the Mukono District Health Office and Ugandan Ministry of Health. A partnership was also formed with Makerere University School of Public Health, as they have previously undertaken photovoice studies with CHWs in Wakiso District of Uganda, and have significant expertise in this method of enquiry (Musoke, Ekirapa-Kiracho, Ndejjo, & George, 2015; Musoke, Ssemugabo, Ndejjo, Ekirapa-Kiracho, & George, 2018).

Participants

The participants were CHWs, purposively selected from those attached to SNHC III, in order to capture a range of experiences. The aim was to have a balanced number of males and females, and a diverse range of ages. Unfortunately since all of the CHWs were recruited between 2009-2010 it was not possible to have a wide range of years served as a CHW, however this would also have been part of the purposive sampling strategy had this been possible.

In order to be eligible, CHWs had to be over the age of 18, actively practicing, and willing to take part in the study. There were no exclusion criteria based on age, language, gender, sex or tribe. Participants were assured of the right to accept or refuse to take part in the study without consequence.

The Local Chairpersons (LC1s) from Seeta Nazigo and Makata villages in Nakisunga subcounty were informed of the study by a staff member from Omni Med. They mobilised individual CHWs within their respective villages to attend an initial meeting at SNHC III. Eight VHTs attended the initial information session, which was facilitated by two Ugandan Research Assistants (RAs) who hold bachelor level university degrees. The initial information session lasted for three hours. CHWs were

informed of the specifics of the photovoice project and were given the opportunity to ask questions. They were provided with an information sheet and a copy of an informed consent form, both of which were written in the local language (Luganda). Participants took the information sheet and informed consent form home, and returned a signed copy to the research team at the end of the week if they were happy to participate in the project.

Training Workshop

CHWs reconvened a week after this initial meeting. All eight CHWs who attended the initial information session were in attendance. Signed consent forms were returned and CHWs were given another opportunity to ask any questions to the RAs who facilitated the meeting. The first two hours of the workshop were dedicated to discussing the ethical aspects of photovoice, and training the CHWs on how to take informed consent from members of the community they might photograph (Devakumar et al., 2013; Harley, 2012). This was considered of vital importance, given the potentially sensitive nature of the photographs that might be taken and in keeping with best practice guidance for conducting photovoice studies (Hannes and Parylo, 2014; McIntyre, 2003). It was explained that written informed consent was considered the gold standard; however, in certain situations where this would not be possible or acceptable, verbal consent could be gained (Devakumar, et al., 2013). In such instances, CHWs were encouraged to document in their note books that consent was granted for the photograph to be taken , and the reason as to why written consent was not obtained. For example, if an individual granted permission for a photograph to be taken, but was reluctant to sign a consent form due to personal reasons it would be acceptable for the CHW to take the photograph as long as verbal consent was

granted and recorded in the CHW's note book. CHWs were also given example scenarios on how to take consent and were given the opportunity to practice doing this in pairs. CHWs were then trained in the use of cameras, which lasted approximately four hours. This was the first time that any CHW had used a camera. CHWs were first shown the basic features of the camera, such as how to turn it on and off, and how to charge it. They were then instructed on how to take photographs and use features such as the flash setting and zoom, before working in pairs to practice capturing photographs.

Following a group discussion facilitated by the RAs, CHWs reached a consensus that they wished to capture issues they felt challenged them in their role as CHWs. This topic was decided following a process of CHWs shortlisting topics they wished to capture photographs of, and collectively ranking them in order of preference and importance.

Materials

CHWs were supplied with a ZOOMK 2.7-inch display digital camera, a note book, pens, and consent forms. CHWs also received a small monetary reimbursement (\$5 USD) each time they attended a meeting in order to assist with transport costs.

Photovoice Assignment

During the photograph taking process, CHWs had the ability to contact the research team at any time via mobile phone to discuss challenges or concerns they had. The research team also visited the health centre at least twice a week to allow CHWs the opportunity to meet face-to-face and raise any concerns or problems they faced.

Every two weeks, over a total period of six weeks, CHWs met at the health centre to present and discuss their photographs with the research team. One-to-one interviews were conducted in Luganda by the two RAs to discuss the perceived challenges represented by the photographs. Both RAs had received formal training in conducting semi-structured interviews by the study PI. Prior to the interviews taking place, photographs were transferred from the cameras to the RAs' laptops. Interviews were explicitly framed to elicit and explore challenges faced by the CHWs and the photographs were used as the focus of the discussion. The discussion for each photograph was framed around the 'SHOWED' mnemonic; a commonly deployed method in photovoice projects (Wang and Burris, 1997). As part of the framework, five questions are asked about each photograph, including:

1. What do you **S**ee here?
2. What is really **H**appening here?
3. How does this relate to **O**ur lives?
4. **W**hy does this condition **E**xist?
5. What can we **D**o about it?

As part of the individual interviews, all of the photographs taken by the CHWs being interviewed were discussed. The individual CHW was initially asked whether or not the photograph related to the central theme of challenges they faced as a CHW. Where photographs were not relevant to the central theme (e.g. a personal photograph of the CHW with their family) they were not discussed. For those that did relate to the central theme, an in-depth discussion was held facilitated by the RA using the SHOWED method (Wang and Burris, 1997). In

partnership with the CHWs we conducted a visual thematic analysis on each of the images. Each CHW was asked what each photo represented before we engaged in an in-depth discussion around the photograph. Interviews were recorded using a handheld audio recorder and then immediately transcribed and translated into English. Each interview lasted between 40 minutes and 2 hours.

At the end of the individual interviews, a focus group discussion (FGD) was held, where all of the relevant photos identified during the interviews were discussed. The decision was made to discuss all of the relevant photos so as to avoid potential selection bias by the researchers. The FGD was done in order to share the photographs taken by each CHW, and to explore the opinions of the whole group as to whether or not the issues raised by individual CHWs were considered as challenges by others. All eight CHWs attended the FGDs and photographs were discussed among the group, facilitated by an RA. Photographs were projected onto an empty wall at the health centre using a low-cost projector. Finally, the RAs reviewed the notebooks with the CHWs to capture any further relevant information, or to clarify any points of ambiguity. At the end of FGD CHWs were asked to review all of the photographs and group similar photographs into clusters (e.g. photographs relating to equipment challenges all were put into one folder). This helped to guide the final thematic analysis. In total the study lasted for six weeks.

Data Analysis

Interview transcripts were formatted for style consistency by the lead author in Microsoft Word. They were then exported into NVivo (Version 12) for Mac qualitative analysis software (QSR International Pty Ltd, 2018).

Transcripts were read several times, independently, by both the study PI and the one of the RAs. The first read through aimed at ensuring accuracy of the typed transcript, and that meanings of words and phrases had not been misinterpreted in the translation process. The same researchers then re-read the transcripts a second time, following Braun and Clarke's six-step framework for conducting thematic analysis (Braun and Clarke, 2006).

Following this process, initial codes were generated relevant to perceived challenges faced by CHWs. An open-coding framework was used, meaning the codes were developed and modified throughout the process of reading the transcripts. Once an initial set of codes was compiled by each researcher, these were discussed jointly and a preliminary unified set of codes was determined. Each set of transcripts was read by both researchers and codes were modified, generated, or changed throughout this process. After generating the final set of codes, the researchers grouped these into themes. Themes and coding nodes were then reviewed in NVivo to ensure they were coherent, had supporting data, and to see if there were any potential sub-themes or missing themes. The final themes were then refined and defined, which Braun and Clarke describe as “identifying the ‘essence’ of what each theme is about” (Braun and Clarke, 2006). A random sample of codes and example quotes were also checked by the second RA to ensure consistency in code application.

Dissemination

Following the analysis process, key findings and photographs were shared in a community-based workshop held at the local health centre. This was attended by

community members, CHWs, NGO officials, and District Health Officials. The workshop involved using a projector to display key photographs onto a wall. These photographs were selected by the CHWs based on the images they felt best illustrated the key themes. The CHW who took the photograph made a brief presentation about what it represented. A summary of suggestions was created in partnership with the CHWs and distributed to District Health Officials and Omni Med programme managers.

Ethical Considerations

The study received approval from The Uganda National Council for Science and Technology (Number: SS 4723). Investigational Review Board (IRB) approval was obtained from the Mengo Hospital Research Ethics Committee (Number: 114/07-18), and The Department of Education ethical review board at The University of Oxford (Number: ED-CIA-18-218). Written informed consent was obtained from all study participants. All consent forms were provided in Luganda and were approved by both IRBs prior to use. Finally, we obtained explicit written informed consent from individuals appearing in the photographs which have been used in this publication.

Results

CHW Characteristics

A total of eight CHWs took part in the study. There was an equal split of males (n=4) and females (n=4), all of who had served for eight years as a CHW. The majority of CHWs were subsistence farmers who had undertaken secondary school education. Full demographic details for each CHW can be found in Table 1. A total of 107 photographs were taken by the CHWs over the six-week period. 62 were relevant to the topic of interest.

[Table 1 near here]

The following sections detail: (1) the themes related to challenges developed through the photovoice analysis process; (2) the suggestions raised by the CHWs as to why they feel such challenges exist; (3) suggestions raised by the CHWs as to how the challenges could be addressed.

1. Challenges Identified Through the Use of Photovoice

1a. Infrastructure challenges

Several CHWs highlighted issues with private and communal infrastructure which directly challenged the communities they served, and was thus perceived as a challenge to their role. These ranged from poorly constructed homes, to malfunctioning communal water sources. For example, one of the CHWs photographed a house common to the area where the study took place, and cited that the poor construction and lack of mosquito screens results in high rates of malaria in this particular area (Figure 1).

[Figure 1 near here]

People who stay in such houses are trapped in some sort of a cycle...they keep contracting and treating the disease (malaria) instead of preventing it. This is caused by poverty. Everyone would love to sleep in a plastered house, with high roofs and screens over the windows...but poverty. You know most people in the villages are low-income earners. I am in charge of those people and now if they keep suffering from malaria it challenges me. (Male CHW, 40 years old)

Other infrastructure related challenges related to communal services, such as protected water sources (Figure 2). In recent years several protected water sources had dried up, forcing residents to queue for several hours to fetch water. CHWs felt this was a challenge to their role since certain individuals would prefer to use unprotected sources as an alternative way of collecting water, which meant CHWs had to manage the community members who fell sick as a result of water borne illnesses. There were also unexpected consequences as a result of poorly functioning water sources, including disruption to infant vaccination schedules:

[Figure 2 near here]

...water is essential when it comes to health, and that's my biggest concern as a CHW. Without clean water people are bound to fall sick since they are forced to use water from unprotected water sources. (Female CHW, 44 years old)

The women who have children are mainly responsible for fetching water. If a water source is drying up she might find herself in a difficult situation on a

Wednesday which is the day for immunisation. She needs the water, she needs the immunisation, but of course she is more likely to prioritise water so the baby misses out on being vaccinated. (Female CHW, 50 years old)

1b. Training and supervision challenges

The second subtheme concerning perceived challenges faced by CHWs was a lack of appropriate on-going training and supervision to deal with the shifting disease burden (such as the increase in non-communicable diseases (NCDs)). To illustrate this challenge, many CHWs took photographs of community members who suffered from NCDs such as diabetes, hypertension, and cancer, and stated they had not received appropriate training to help address community members concerns, manage their conditions, or give appropriate advice.

We appreciate the trainings we have had on child health, but we don't get enough in other diseases like diabetes, eye disease, cancer... and there is a weakness in supervision. (Male CHW, 45 years old)

RA: Have you ever had training in how to deal with these (eye disease) issues?

CHW: We have never had any, but we need it. My knowledge on this is limited so I can't give proper advice. (Female VHT, 34 years old)

Similarly, CHWs lacked training on issues pertaining to mental health. This was highlighted when one of the CHWs took a photograph of a man with post-traumatic stress disorder, and stated:

Such a person is a threat in society so I have to be concerned. Those mentally ill people are rapists! He may end up raping children on their way from school or even women along the way. As a CHW I have to ensure he is treated to avoid such scenarios from happening. (Male VHT, 40 years old)

When the issue of mental health was raised during a group discussion, several of the CHWs commented that mental illness was perceived as a curse for evil deeds in a previous life, or viewed as a divine punishment. All eight CHWs were unaware; however, that there were different sub-types of mental illness:

RA: Have you ever had any training on mental health?

CHW: No. We have had training in other things, like HIV and TB, but not that.

RA: Do you know about the different types of mental illness?

CHW: Huh?...there are types? I just thought all mental illness was the same!

(Male CHW, 48 years old)

1c. Relationship challenges with staff from the formal health system

Another theme perceived as a challenge by the CHWs concerned relationships with staff at the government health centre. One CHW stated that they had challenging relationships with the staff from the health centre, due to the government health workers failing to turn up to the health centre at weekends, which they reported to the district councillor:

Earlier on we met the district councillor and told him about nurses not being at the health centre during the weekends - a matter that he took seriously and called for a meeting...Now they work on weekends, but for some time our relationship with them was so tough as they knew we had reported them and some failed to even speak to us (*Female CHW, 34 years old*)

Other CHWs indicated that health centre staff often failed to turn up for work, and as a result the CHWs had stopped making referrals as they saw this as futile if there were no staff at the health centre to manage the patients who attended:

Supervisors come (to check on the staff), but the few health workers they find at the work station cover up for their colleagues who are not around...One may defend another by lying to the supervisor that their colleague went for burial, yet the person just decided not to show up. It's a common problem and frustrates us. Why would we refer a patient if there are no staff to see them?... It impacts badly on our reputation with the people we serve (*Female CHW, 50 years old*)

1d. Equipment challenges

Several CHWs took photographs of equipment they were lacking to fulfil their role as CHWs, including gumboots, mobile phones, umbrellas, means of transport, and water bottles (Figure 3 a-d). Photographs of these items were taken with the permission of other community members who owned them.

[Figure 3 near here]

For example, one role CHWs have is to check the status of pit latrines in the households they are responsible for. Yet, many mentioned how passing through such areas without protective footwear was unhygienic. They therefore took photographs of gumboots to represent the protective footwear they lacked, but wished to own. Others cited the challenge of the long distances between the homes they serve, and the need for provision of transport such as bicycles or a communal motorbike (*boda-boda*) to assist them in completing more home visits. Interestingly, the government provided bicycles to the CHWs in 2002; however several of them fell into disrepair and are no longer in use. Some CHWs blamed the government for allowing this to happen, stating that they purchased poor quality bicycles and misappropriated the remaining money. Others, however, felt that because the bicycles were distributed freely, many CHWs failed to maintain or take care of them due to lack of perceived ownership:

To some, who received the bicycles for free from the district, they don't care because after all it was given for free, they didn't incur any cost themselves, so why look after it? (Male CHW, 45 years old)

Several CHWs also felt a major challenge was a lack of medications and properly functioning equipment. One of the CHWs had been provided with a medicine box by the Ministry of Health in 2002, however; had not been supplied with medicine since 2004 (Figure 4). The box now lies unused in his home.

[Figure 4 near here]

People always ask me why we don't receive medicine, yet we got this box. It affects me because we are the immediate health workers who have to give first aid to the people, so it frustrates me and them when there is nothing to give!

(Male CHW, 67 years old)

2. Underlying reasons for the challenges identified by the CHWs through the photovoice study

As part of the individual interviews and FGD, we explored the reasons as to why the CHWs felt the challenges they identified exist. The underlying reasons for the challenges were attributed to two main groups; the government and broader system in which the CHWs work, and the supporting NGO.

2a. Government and system level factors

There was a strongly held belief among many of the CHWs that the government were to blame for the challenges they faced, especially regarding the lack of medicines at the health facility. During a group discussion one of the senior CHWs stated:

I blame the government for all that. I remember very well in Obote's regime every health centre used to treat all kinds of diseases freely! Medicine was there in plenty.... Now corruption and theft are the order of the day! Can you imagine they stole the money meant to buy Anti-retroviral therapy (ART) for HIV and

AIDs patients? If they stole that what of that meant for diabetes patients?

Developed countries give us so much money for ART but it keeps getting stolen by the government officials. (Male VHT, 45 years old)

Others cited a lack of empathy from those in ministerial or positions as to why challenges in a rural area such as Seeta Nazigo had not been addressed:

When their children fall sick, they take them to expensive private health centres, so they don't even feel touched about the person who can't afford. For example, you never see the children of Government officials in government run health centres. (Male CHW, 45 years old)

Nobody cares about these challenges apart from us at the grass roots who are facing them. We are the people whose opinions don't matter. The government don't care. They sometimes come, hear about our problems, and then do nothing. They show their face like it is a requirement to check a box, but don't really care. (Female CHW, 34 years old)

2b. The supporting NGO

Some CHWs attributed their challenges, especially those regarding on-going training and supervision, to the supporting NGO. For example, they felt the feedback they received on their performance was irregular and infrequent, and that the training which they were responsible for delivering did not reflect the diseases encountered by the CHWs:

Personally, I put the blame on our supervisors of Omni Med. They have not taken time to supervise and also find out what is taking place in the villages and how the CHWs are working, the transport means, and how the CHW communicates with the people. You may give your concerns but the year goes by without even getting feedback. (Male CHW, 45 years old)

Omni Med need to provide us with medications and train us in different things. We get the same training all the time. (Male CHW, 40 years old)

3. Suggestions made by the CHWs for addressing challenges identified through the photovoice study

Various suggestions were raised by the CHWs as to how the challenges could be addressed. These included roles for the government, the NGO, and individuals (such as the CHWs themselves).

3a. Government roles

The majority of the CHWs suggested the government had an important role to play, through the provision of medicine at the health facilities, increasing the number of staff at rural health centres, and improving the quality of communal infrastructure.

It all goes down to the government. They must provide medicine for all types of diseases so that all patients can benefit. (Male CHW, 40 years old)

The government, through the Ministry of Health, should send more health workers to coordinate with the VHTs and CHWs – we are overwhelmed with patients in this area and can't deal with them alone. (Female CHW, 44 years old)

The government should improve the quality of the roads so that people can move easily when they need treatment. (Male VHT, 67 years old)

However, despite these suggestions, tensions were raised when discussing the role of the government in addressing the challenges. Some CHWs felt that even when they highlighted challenges to government officials, many did not listen or respond to them, citing a lack of respect for workers at the village level and self-interest as reasons why:

My efforts as a CHW would be to focus on applying pressure to the government. But we have tried this, and even if you approach them after discussing the issues, they don't do follow up. The moment you leave their offices they start doing their other things... They undermine us, the CHWs, they don't take us seriously. Some say we don't know English and we can only write in Luganda...so it appears useless to write to them or approach them. (Male VHT, 45 years old)

We want the government to help but they claim they have no money... but we know they do since they buy expensive cars for the members of parliament and

giving money to those who support constitutional amendments. You just cannot trust the government. (Female CHW, 42 years old)

3b. NGO roles

There were calls from CHWs for their supporting NGO to play a more critical and involved role in addressing their challenges. Instead of just delivering trainings on disease recognition, management and prevention, CHWs wanted them to play a greater role in advocacy.

Omni Med can write to those who are responsible, because as a registered organisation in direct contact with the government it can be heard and feedback more easily than a CHW... Another thing that I think that must be done is that when Omni Med comes here it just brings training, but they need to understand more about the issues at the health centre asking questions like is the medicine enough, are the facilities working well etc. (Male CHW, 45 years old)

Omni Med should convince the government to provide diabetes medicine freely. I am sure they will listen to them. (Male CHW, 40 years old)

3c. CHW roles

Although conveyed less strongly than potential roles of the government and NGO, some CHWs highlighted their own potential role in addressing some of the challenges they identified, by taking on the role of community advocates and activists:

What I can do is what I am doing right now. Raising awareness! If I weren't responsible enough, I would either not have bothered finding out the problem or just kept quiet after finding out. (Male CHW, 45 years old)

I think we can address some of the challenges by speaking up, for example the way I am doing now. Imagine if all us CHWs talk about it! Then it would be considered a serious concern. (Female CHW, 34 years old)

Others, however, felt they were unable to affect change, or did not have the time given their own personal commitments alongside their volunteer work as a CHW:

As people at the grass root level we cannot do much to effect change. I would love to help but I also have my own responsibilities. (Male CHW, 40 years old)

Discussion

By exploring and framing challenges faced by CHWs through the use of photovoice, unique insights were obtained into the complexities of PHC delivery in Mukono, Uganda. Challenges identified by the CHWs included poor infrastructure, inadequate training, challenging relationships with staff from the formal health system, and a lack of appropriate equipment. Resulting discussions revealed that CHWs mainly blamed the government and supporting NGO for these challenges, and suggested opportunities to address the challenges which will require coordinated and multisectoral response.

Several CHWs highlighted problems with the structure and design of local houses, which they felt resulted in higher rates of malaria among the community members they served. In other settings, such as Kenya, working with designers and engineers to modify ceilings of traditional houses has proven to be one low-cost and acceptable way of reducing exposure to malaria vectors, and would warrant exploration in this context (Atieli, Menya, Githeko, & Scott, 2009). Similarly, some CHWs highlighted that poorly maintained water sources had resulted in community members being forced to use alternative, unsafe sources of water, thus resulting in higher rates of water borne illness.

Addressing the social determinants of health and improving the broader contexts in which communities live, for example their homes and water sources, are important ways of improving community health. One way to achieve this could be to reshape CHW training to encompass the social determinants of health, and to encourage CHWs to act as community advocates. This concept of “community-oriented primary

care” is not new, and has successfully enacted in the past (Mullan and Epstein, 2002). For example, after receiving training in advocacy and leadership skills, a collaborative of CHWs in Arizona were successfully able to engage their community to make positive systems and environmental change to improve their households and lobby policy makers to address their living environment (Ingram et al., 2014). In the Ugandan context NGOs could play an important role in supporting the development and holistic training of CHWs to fulfil this role by adopting a role as stewards to ensure promotion and advocacy for relevant provision of community based health services, and championing the needs of the CHWs they support (Delisle, Roberts, Munro, Jones, & Gyorkos, 2005).

The second challenge, regarding a lack of training and on-going supervision to address the changing burden of disease, has been cited across other CHW programmes in Uganda (Ojo et al., 2017). This potentially reflects a weakness in the Ugandan CHW training model, which to date has largely focused on maternal and child health issues and infectious diseases, and has not been updated to reflect the epidemiological transition that the country is going through. It is therefore important that CHW training is updated to reflect the changing and complex disease burden, and that vertical training approaches are avoided. This is further supported by the aspirations expressed by the CHWs in this particular district to increase their scope of practice in order to reflect the disease burdens they are expected to manage.

Furthermore, thought should be given to how such training is delivered, in an on-going fashion. mHealth strategies have been suggested to have a potential role in supporting the delivery of ongoing training, and have previously been demonstrated to be feasible with a similar cohort of CHWs in the Mukono District (O'Donovan,

Kabali, et al., 2018). Ensuring that such strategies are co-designed with CHWs and take local resource constraints into consideration are likely to facilitate in their uptake and sustainability, especially as they are scaled (Winters, O'Donovan, & Geniets, 2018).

Another issue facing CHWs involved relationship challenges with other staff members from the formal health system. Tensions between CHWs and facility-based health workers in Uganda have been documented previously in a study conducted in Luwero District (Musinguzi et al., 2017). In this study CHWs demanded preferential treatment for the patients they referred to government health centres, which resulted in tensions arising between the facility-based staff and CHWs. In addition, the authors cited minimal communication between the two cadres as exacerbating tensions. Finding a way to improve the working relationship between CHWs and the facility-based health staff is of vital importance, since the success of CHW interventions “depends on high levels of community involvement and participation and a positive relationship between the CHW programme and the formal health system” (Grant et al., 2017). This is also an important challenge to highlight, since advocates of CHW programmes often state the benefits of CHWs could be in linking the community to the formal health system (Haines et al., 2007).

However, unless functioning relationships between key stakeholders exist, improving links to the formal health system via CHWs can prove extremely challenging, and even damaging to community perceptions of CHW programmes if referrals fail (Musinguzi, et al., 2017). Addressing this particular challenge could be an important role for a new cadre of paid health workers, known as Community Health Extension

Workers, who were initially expected to be deployed in Uganda in 2019 (O'Donovan, Stiles, et al., 2018). It is hypothesised that one of their key responsibilities will be to supervise CHWs and to act as links between the government health facilities and the community.

The final challenge, regarding a lack of equipment, is common findings across several CHW programmes in different contexts (Jaskiewicz and Tulenko, 2012; Oliver, Geniets, Winters, Rega, & Mbae, 2015). It is clear there is a pressing need for the District Health Office and Ugandan Ministry of Health to ensure CHWs have appropriate supplies of medications and working equipment. It is not enough to simply train CHWs in the recognition of disease and community concerns; it is vital to also provide the necessary and proper equipment in order for them to manage the issues they identify. This holistic, multifaceted approach to strengthening CHW programs has been suggested in the 2018 WHO guidelines to optimise community health worker programmes to achieve maximum impact (Cometto et al., 2018). This includes supporting CHWs with appropriate remuneration, career advancement, and on-going support. It should be noted that the criticisms by the CHWs are only reflective of our sample, and that with a wider sampling strategy, different perspectives may have been uncovered (including debates regarding the role of the government locally).

Study contributions and limitations

In terms of how this study contributes to the wider literature, it adds to the relatively narrow body of existing evidence regarding the role of photovoice with CHWs, given that a 2018 systematic review identified only six studies utilising photovoice with CHWs (O'Donovan, Thompson, et al., 2018). This is important because although

challenges faced by CHWs in Uganda have been explored in the literature before (Kimbugwe, et al., 2014), this has largely been done using surveys or semi-structured interviews. Such methods have been criticised in the past for only providing “a partial insight into the view and concerns of CHWS” (Smith and Blumenthal, 2012).

In addition, challenges are also context dependant – for example challenges faced by CHWs in Mukono District are likely to be different to those in other regions of Uganda, given the difference in supporting providers and cultural factors. Similarly challenges faced by volunteer CHWs in Uganda are likely to be highly different to those faced in Liberia for example, where CHWs are a paid cadre. Understanding these contextual challenges is important as the global evidence base on CHW programmes continues to grow. As such this paper answers the call from researchers such as Scott et al. who have suggested the need to expand the evidence base for CHW programmes with context-specific methods (Scott et al., 2018). These close-to-the-ground findings are also timely given the planned changes to community health delivery in Uganda and the planned introduction of a new cadre of Community Health Extension Workers (O'Donovan, Stiles, et al., 2018). By highlighting key challenges from the perspectives of current CHWs, it may help policy makers and practitioners responsible for reshaping the Ugandan CHW programme ensure responsiveness to the needs of those delivering PHC on the front line.

In terms of limitations, the use of photovoice was not without its challenges. Although the CHWs reported that the majority of people were happy to sign a consent form and have their photograph taken, a small minority were resistant, even after the process was explained to them and their anonymity guaranteed. This was out of fear that the

photographs might be misused, or result in government persecution against them. One CHW stated:

Some of them had never seen anything like that (a camera) their entire life. It's almost like they were afraid of being a part of something they had never been a part of before. Others felt like we were going to exploit their photos for our own benefit... You know these days they hear stories from the media about the government arresting people and people don't like having their image taken.
(Female CHW, 34 years old)

Another stated that some community members did not want to sign consent forms, out of fear of subsequent reprisals:

They just fear signing documents, they think something wrong may happen to them after signing. I tried to explain but they did not understand me. (Female CHW, 50 years old)

Other CHWs found that some people did not want their photograph taken as they were tired of false promises from previous research projects:

They say "Don't waste my time, we are tired of those things... there is no change, just promise...it's the same story." (Male CHW, 45 years old)

In contexts such as Uganda where there are levels of suspicion and resistance to having a photograph taken, photographic methods of enquiry may not be culturally

acceptable to certain members of the population. Second, although the majority of individuals provided informed written consent, some participants did not want to sign a consent form. Alternative methods of obtaining consent, such as oral consent should therefore be adopted. It is also important to note that some of the CHWs felt the initial period of two weeks to collect photographs was too short, and required an additional month to complete the study in a satisfactory manner. We would therefore recommend that other researchers ensure appropriate time is allocated for capture and discussion of photographs. Two CHWs faced technical issues related to the use of the camera, including freezing and issues with the formatting of the memory card, however these were quickly resolved following meeting with the RAs.

Finally, although public dissemination meetings have been suggested as one important way to attempt to engage with key policy stakeholders and share findings (Liebenberg, 2018), how the findings are acted upon and addressed in a meaningful way remains a key challenge. Despite inviting several government officials to the community workshop, only one District Health Official was in attendance. It is therefore not possible to claim that our photovoice project was able to truly “empower” the CHWs since true empowerment involves engagement and change of complex support structures, as well as the resources to bring about change; something which our photovoice study, in isolation, cannot address. Critically by simply taking part in the process of photovoice, CHWs were not necessarily able to enact change themselves. Rather, it provided the opportunity to reflect more deeply on the issues challenging their daily work. We were unable to capture examples of participants expressing advocacy outside of the study, although this may have taken place. In order to capture such examples, a longer

observation period in the community would be required, with this as a specific evaluation aim.

Reflexivity statement

The direct research team interacting on a daily basis with the CHWs consisted of a white British PhD researcher (who was the Principal Investigator) and two Ugandan graduates acting as RAs.

Although some commonalities were shared between the research team and the CHWs (for example two of the RAs were Ugandan and from Mukono District), other aspects of our identities were very different (for example none of the direct research team were CHWs). Similarly, all of the research team had achieved a minimum of a bachelors level qualification, whereas the majority of CHWs had stopped formal education after secondary school. In addition, all of the direct research team were employed in full-time, relatively well paying jobs in either the NGO or academic sector. It is not fully clear how these dynamics were perceived by the CHWs, but it is important to note that our positions might have influenced the interactions with the CHWs, and the answers they provided in the one-to-one in-depth interviews. For example, one of the RAs stated:

Because a mzungu (a white person) was involved in the project, VHTs might have been more fearful of giving truly honest answers. This might have been out of fear that if they provided an answer you did not agree with you might have dropped them from the project.

Despite the aim of a participatory process, the direct research team had relative privileges over the CHWs which made discussing some of the challenges they faced uncomfortable at times. For example, one of the major challenges identified by the CHWs was access to reliable transport, something which the research team did not face as we owned a private vehicle. Therefore, despite our best efforts to co-construct the narrative through joint interpretation of the data during the individual interviews and FGD, it is very possible that the different identities and experiences of those involved in the research study resulted in a narrative which may not truly reflect all of the challenges perceived by the CHWs.

Finally, the position of the white British researcher as the PI could be considered potentially problematic in this context. In the past white researchers have come to this particular community, taken photos and then used the photos in resulting publications, with the community seeing no benefit from the process. One of the Ugandan RAs notes:

Some people strongly believe *mzungu* currently use manipulation to steal from Africa instead of the initial direct theft that existed in the colonial era. They think *mzungu* take their photos and use their stories to fundraise for money that they instead use for their own selfish gains and give a small percentage to them if at all.

This view has been echoed by other researchers, such as Chisomo Kalinga, who states that there is often concern amongst communities about “their knowledge being used by Westerners to enrich themselves, whilst they remain poor” (Kalinga,

2019). Understanding and openly addressing such concerns from the outset could be an important part of the community engagement process for similar projects in the future.

Conclusion

The use of the photovoice in this study helped uncover unique insights into the challenges faced by a group of CHWs in Nakisunga sub-county of Mukono District, Uganda. The photographs and resulting discussions revealed the diverse challenges faced by CHWs, ranging from a lack of appropriate training and equipment, to complex socio-political challenges. It is important to note that although photovoice was generally perceived as a feasible methodology to explore daily challenges from the perspectives of CHWs, a small number of community members expressed concern with how their images might be used due to negative past experiences of non-native researchers capturing their images without gaining their permission. Future work should draw upon the challenges identified in this study, and explore ways in which they can be addressed to contribute to the overall strengthening of the Ugandan PHC system. This can only be done by engaging key stakeholders from multiple domains. It also represents a renewed and important role for NGOs to act as community advocates, by speaking truth to power and championing the needs of frontline health workers, such as CHWs, to deliver quality PHC, commensurate with the needs of the communities they serve.

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Data sharing statement

The data that support the findings of this study are available on request from the corresponding author, JOD. The data such as individual photographs are not publicly available due to information that could compromise the privacy of research participants or community members who took part in the study.

Authors contributions

Conceptualisation: JOD, NW, DM, CS. Data Curation: JOD, RH, ASN. Formal Analysis: JOD, RH, ASN. Funding Acquisition: JOD and NW. Investigation: JOD, RH, ASN. Methodology: JOD, NW, DM. Project Administration: JOD. Resources: JOD, NW. Supervision: NW and DM. Writing – Original Draft Preparation: JOD, RH, ASN. Writing – Review and Editing: JOD, NW, DM, RH, ASN, CS.

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Table(s) with captions

| CHW | Sex | Age | Years of Education | Highest level of education | Job | Number of years as CHW | Number of households served |
|------|-----|-----|--------------------|----------------------------|-----------------|------------------------|-----------------------------|
| CHW1 | F | 50 | 9 | Some secondary | Farming | 8 | 50 |
| CHW2 | F | 42 | 12 | Some secondary | Farming | 8 | 38 |
| CHW3 | F | 44 | 9 | Some secondary | Peasant | 8 | 30 |
| CHW4 | M | 45 | 7 | Some primary | Builder, farmer | 8 | 120 |
| CHW5 | M | 45 | 11 | Completed secondary | Farmer | 8 | 30 |
| CHW6 | M | 67 | 8 | Some primary | Farmer | 8 | 35 |
| CHW7 | F | 34 | 9 | Some secondary | Farmer | 8 | 68 |
| CHW8 | M | 40 | 11 | Some secondary | Peasant | 8 | 35 |

Table 1. CHW demographic details. A table outlining the demographic details of the CHWs involved in the study.

Figures

[See separate file attachments]

Figure Captions (as a list)

Figure 1. A poorly constructed house. A house common to the area where the study took place. Note the lack of mosquito screens across the windows, vents and cracks in the cement.

Figure 2. A poorly functioning water source. A women and her child wait in line to fill jerry cans at a poorly functioning protected water source.

Figure 3 a-d. Missing equipment. Equipment CHWs lack which they felt would help facilitate their work; (a) Mobile phone; (b) Gumboots; (c) Motorbike; (d) Backpack.

Figure 4. No medicines here. A male CHW holding a medical supply box provided by the Ministry of Health to CHWs in 2002, but which has not been stocked since.