



## LISTENING TO COMMUNITY HEALTH WORKERS IN MOKHOTLONG, LESOTHO

By Thomas Quattlebaum

Lesotho is a tiny, mountainous country in southern Africa with a population of two million and the world's third highest rate of Human Immunodeficiency Virus (HIV) at 23.2%<sup>1</sup>. Lesotho faces three major challenges at this time: the HIV/Acquired Immunodeficiency Syndrome (AIDS) pandemic, extreme poverty, and severe food shortages due to drought. The health care system is overwhelmed, under-funded, and under-supplied. The phenomenon of the "Brain Drain" in southern Africa, where talented health professionals are leaving the region for better economic opportunities abroad, has left hospitals in Lesotho acutely depleted of health care staff needed to meet the demands of the AIDS crisis.

Lesotho is divided geographically into ten districts with 80% of the population living in the remote, mountainous "highlands" districts. Unfortunately, health care facilities are centralized in the "lowlands" districts making it difficult for the majority of people living in the highlands to access even the most basic health care. The highlands districts have a higher HIV infection rate than the lowlands districts, are hardest hit by drought, and experience severe weather conditions including snowfall and freezing temperatures throughout much of the year<sup>2</sup>.

In response to these conditions, Lesotho has developed a community home-based care (CHBC) system where local community health workers (CHWs) care for patients in patients' own homes to alleviate the burden on health care professionals and patients' families. In Mokhotlong, Lesotho (one of the highlands districts) this system is in place and, due to a lack of resources and funding, care is largely focused on palliation, counseling, and symptom alleviation rather than aggressive cure-based treatment, although this is changing as Lesotho is striving to achieve universal access to antiretrovirals by 2010<sup>3</sup>. With the growth of this community home-based care system and the specific constraints of the area, a need for appropriate CHBC training has emerged. CHWs need to gain the necessary skills to successfully manage their patients since most have never received any formal health education. The aim of my project was to evaluate the CHW's job satisfaction as well as their perceptions on previous CHBC trainings.

### Methods

To evaluate the CHWs' experiences in their role, their perceptions of previous CHBC trainings, and their opinions on how to improve them, I conducted individual interviews with five caregivers who had experience in the field. The interview consisted of two parts: one concerning the CHWs' workload and the second concerning their qualitative responses about field experience and their opinions on training. These CHWs have an affiliation with **GROW**, a local nonprofit based in Mokhotlong that works to better the Mokhotlong community and surrounding areas. I traveled to Lesotho with a team from the University of Virginia, which collaborates with GROW as part of the Lesotho Health Partnership, to help facilitate a two-day "refresher" CHBC workshop at GROW headquarters. We invited twenty caregivers to attend. I interviewed the first five volunteers from this group of caregivers utilizing the help of a translator who

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translated between English and the native Sesotho. I digitally recorded each 20-30 minute interview and later transcribed them so that I could accurately capture the CHWs' words.

## Results and Discussion

The CHWs describe great variability in workload and experience depending on where they work, their other duties besides CHBC, and their ability to test people for HIV. Each CHW lives and works in a different area of the Mokhotlong district and, as such, each follows a different structure regarding the number of patients cared for, the number of hours worked, and the extent of their training (see Table 1). Despite many differences in the amount and quality of training they have received and diverse personal life histories, the caregivers share certain experiences which I highlight below.

### Workload (table)

Each CHW works as part of a larger group which they call a support group. This group sees all of the ill patients within their community. With a high prevalence of HIV and tuberculosis in these regions, the CHWs all face challenges presented by these diseases, such as HIV-associated denial and stigma, symptomatic management of HIV-associated opportunistic infections, and the need to educate about appropriate nutrition habits as well as other preventive health measures. The CHWs also provide more than medical attention and will often help their patients clean their homes, counsel them, and provide food, clothing, and other necessities.

	CHW 1	CHW 2	CHW 3	CHW 4	CHW 5
Year first trained	2003	2005	2004	2003	2002
Current number of patients	5	16	4	6	75
Time spent traveling/day	1-3 hours	2-6 hours	1-2 hours	10-15 mins	2-8 hours
Time spent care-giving per day (hours)	4-10	4	2-3	4-8	Up to 10
Days worked per week	3	3	2	1-3	7
Compensation	None	None	None	None	None*
HIV testing capability	No	Yes	No	No	Yes

**Table 1. Workload of select CHWs in Mokhotlong, Lesotho. \* = has received compensation in the past**

As shown in Table 1, all of the interviewed CHWs had at least three years of CHBC experience at the time of the interview. The number of patients cared for by a single CHW varies considerably (range 4-75) and reflects the amount of time each CHW can devote to CHBC, the number of other CHWs in her support group, and each CHWs' skill set. For example, CHWs 2 and 5, who care for 16 and 75 patients respectively, both have the ability to test people for HIV and are trained in pre- and post-test counseling. Thus, they have more skills and are in higher demand by the community. The amount of time allotted to care-giving is also variable, ranging from 2-10 hours/day and from 1-7 days/week. CHWs must spend time and sometimes their own money traveling to and from patients' homes. This travel time sometimes exceeds time spent care-giving. Travel is mostly by foot on rocky, hilly, uneven terrain and is a considerable burden on the CHWs' time and energy. For CHW 4, travel is minimal because she cares for people who live in the same village as she does. However, the other four CHWs have to travel much greater distances. One CHW described an 8 hour round-trip in a day to check on a single patient.

With all these duties, it is often difficult to balance CHBC responsibilities with personal and family obligations making it even more remarkable that none of the CHWs receive payment for their services. This fact makes it difficult to recruit and retain CHWs, since purely altruistic motivation is hard to achieve when the caregivers themselves are often struggling to survive. CHW 5 stated that her support

group did receive monetary compensation three times, but that it has since stopped due to an overall lack of funding and resources, a common problem facing the CHWs and their communities.

All of the CHWs rated their stress level as high, especially when dealing with difficult or stubborn patients. However, helpful or cooperative patients ease their stress. Additionally their own personal and family problems may exacerbate the stress from working long hours doing CHBC and seeing tales of personal trauma and tragedy. One CHW notes that she suffers muscle pain from the high stress. The CHWs manage their stress both with their own strategies and with techniques they have learned in training. Some like to lie down or take a walk to relax after a stressful day. One CHW tries to address the person who caused him stress by appealing to his or her spiritual side and praying to God. Another uses a technique she calls memory work. She writes or draws her feelings and then goes back to read her favorite ones when she feels stressed.

## **Field Experience and Training**

While each CHW has received some sort of CHBC training, each agency and support group differs in the structure and content of the training workshops. The second portion of my interviews attempted to identify the aspects of the trainings that CHWs found most useful and to elicit suggestions on additional subjects that should be included in the future.

To begin this part of the interview, I asked each CHW which aspects of training were most helpful in the field. Responses varied, but four CHWs stated that the most helpful knowledge related to direct medical care such as the administration of an HIV test, wound care, and the use of a CHBC kit which contains such items as essential medications, basic equipment (such as dressings, soap, gloves, etc), and traditional medicines. While they placed less emphasis on these topics, they also acknowledged that health promotion information, covering topics such as nutrition, hygiene, and stress management, are important. In regards to non-medical skills, one CHW noted that she had learned leadership skills in a training session and found those especially helpful in the field. When asked about ways to improve future CHBC training, four of the five CHWs said the most important action is to take the trainings out to the community and invite everyone in the village to come, not only CHWs. The CHWs believe that doing so will show the community the importance of having knowledge about HIV/AIDS, create more open discussion about protecting one's health, and allow training facilitators to deliver health-related information directly so that individuals can draw their own conclusions. Additionally, it would allow the trainings to cater more to the specific challenges of the area and reduce the travel burden on the CHWs.

The CHWs also had suggestions about new topics that should be included in CHBC training. They wanted to learn more about multiple drug-resistant tuberculosis, directly observed therapy, mother-to-child transmission of HIV, and the administration and dosing of medications. These topics demonstrate the CHWs' desire to learn even more about their work both for their own knowledge and so that they can share the information with their patients. Training in directly observed therapy may be particularly important in the near future since Lesotho is currently working to provide universal antiretroviral access.

I also asked the CHWs to rate their perceptions of the quality of care which they deliver. Two CHWs said the quality of care is average, two said it was very high, and one was not sure how to rate the quality of her care because she says she does not always see the results of her work. The two CHWs who rate their care as average believe that the care they provide could be improved with greater resources and more incentives to deliver higher quality care. The two CHWs who rated their care as high believe that they have improved their community's health, and they are also proud to offer many services in addition to medical care. For example, one CHW reported that her support group raised money to send a child to school after his parents died.

## **Conclusions and Recommendations**

Although this sample size is small, there are several insights to gain from the CHWs' responses, and they provide a direction for future development of the CHBC program in the highlands of Lesotho. Clearly, community-based caregivers play a large role in delivering health and social support to their communities and sometimes may be the only ones to care for the residents who face monstrous epidemics. They face many obstacles in delivering this care including insufficient educational and material resources; long, arduous travel; and, frequently, their own struggle to survive. In caregiver discussion groups that my team facilitated outside of the interviews, many of the CHWs say that the most difficult thing for them to deal with is people refusing care or acting hostile toward the CHWs because they think

they are not sick and do not want to even think about HIV. They manage all of these challenges without receiving any form of payment or compensation beyond knowing that they are doing something to help. Further official recognition and prioritization of the role of CHWs by the government of Lesotho and the non-governmental organizations involved in delivering care is essential and in line with the World Health Organization's agenda of "task shifting," a process of delegation whereby tasks are moved, when appropriate, to less specialized health workers<sup>4</sup>.

Based on the information collected in this small study, I would also offer the following recommendations: 1) Organizations that train CHBC workers should coordinate more, so that the workers can best meet the community's needs. For example, more centralized planning might allow for a better distribution of CHWs, so that no CHW would need to walk for eight hours round-trip. In addition, a standardized curriculum for CHWs would assure that the most relevant topics are covered. It could also allow for better evaluation and subsequent improvement based on CHW and community input. Finally, an organized approach might allow for an assessment of health outcomes in the communities served, which would have the dual benefits of demonstrating the CHWs' effectiveness to themselves and others as well as assuring that health is truly improved. 2) The CHWs merit a more professional status. Increasingly, organizations like Partners in Health are advocating for paying CHWs for their critical contribution to community health<sup>5</sup>. In addition, other kinds of support for the CHWs are needed and are consistent with their important role in the community. This support might include continuing education, psychological support, and leadership training.

CHWs are the best way to provide care to those most in need. With the acute shortage of health professionals in Lesotho leaving many people without reliable access to regular care, the CHWs contribute strongly to improving the lives of these underserved populations. Most CHWs have lived in their current communities for their entire lives and as such, have in-depth knowledge about its specific needs and the ways to address them. They are ready to serve, and we must continue to find ways to help them do so<sup>6</sup>. Listening to them is a first step.

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