

# Community health workers, recipients' experiences and constraints to care in South Africa – a pathway to trust

Nonhlanhla Nxumalo, Jane Goudge & Lenore Manderson

To cite this article: Nonhlanhla Nxumalo, Jane Goudge & Lenore Manderson (2016) Community health workers, recipients' experiences and constraints to care in South Africa – a pathway to trust, *AIDS Care*, 28:sup4, 61-71, DOI: [10.1080/09540121.2016.1195484](https://doi.org/10.1080/09540121.2016.1195484)

To link to this article: <http://dx.doi.org/10.1080/09540121.2016.1195484>



© 2016 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 26 Jun 2016.



Submit your article to this journal [↗](#)



Article views: 1100



View related articles [↗](#)




View Crossmark data [↗](#)



Citing articles: 1 View citing articles [↗](#)

## Community health workers, recipients' experiences and constraints to care in South Africa – a pathway to trust

Nonhlanhla Nxumalo<sup>a</sup>, Jane Goudge<sup>a</sup> and Lenore Manderson<sup>b</sup> 

<sup>a</sup>Centre for Health Policy/MRC Health Policy Research Group, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg; <sup>b</sup>School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg

### ABSTRACT

Community health workers (CHWs) affiliated with community-based organisations are central to the implementation of primary health care in district health services in South Africa. Here, we explore factors that affect the provision of and access to care in two provinces – Gauteng and Eastern Cape. Drawing on narratives of care recipients and the CHWs who support them, we illustrate the complex issues surrounding health maintenance and primary care outreach in poor communities, and describe how the intimate interactions between providers and recipients work to build trust. In the study we report here, householders in Gauteng Province had poor access to health care and other services, complicating the impoverished circumstances of their everyday lives. The limited resources available to CHWs hindered their ability to meet householders' needs and for householders to benefit from existing services. CHWs in the Eastern Cape were better able to address the needs of poor householders because of the organisational support available to them. Based on an ethos of integrated and holistic care, this enabled the CHWs to address the recipients' context-related needs, and health and medical needs, while building greater levels of trust with their clients.

### ARTICLE HISTORY

Received 4 April 2016  
Accepted 8 April 2016

### KEYWORDS



Barriers to care; community health workers; integrated care; primary health care; policy; social determinants of health; South Africa

### Introduction

The persistence of health inequities in low and middle income countries has been a strong driver for changes in health systems and in mechanisms for the provision of health care. This has also fostered strategies that draw in various sectors other than health in order to address the social determinants of health: “the social conditions in which people live and work” (Irwin & Scali, 2010, p. 4). In the 2000s, several countries started to make progress to address these determinants (Kickbusch, 2010; Motevalian, 2007; PHAC, 2008). Their success, however, has been constrained by the capacity for inter-sectoral action among state, for-profit and non-profit actors (PHAC, 2008), as a result of lack of political commitment and conflicting interests and objectives amongst government sectors, and difficulties between and within different levels of government. While difficulties in ensuring synergies and collaboration have continued at national policy levels, primary health care (PHC) has been emphasised as central to achieving better health outcomes. In the delivery of PHC, community health workers (CHWs) are commonly identified as critical because of their capacity to work closely with vulnerable

communities and individuals, and to address problems arising from limitations in the number of trained health workers able to work at this level (Christopher, Le May, Lewin, & Ross, 2011; Maes & Kalofonos, 2013). CHW programmes have had varied, mostly limited achievements, however, particularly because of poor ongoing training and supervision, and limited or lack of support (Christopher et al., 2011; Perry & Zulliger, 2012). In contemporary South Africa, the district health system remains poorly structured and unintegrated, and is characterised by lack of resources, health worker shortages and weak managerial capacity (Kautzky & Tollman, 2008). These all continue to limit the efficacy of CHW programmes.

In this article, we draw on research conducted by the first author (NN), which examined the experiences of CHWs in providing primary health care outreach. The study included three case studies of community-based organisations (CBO) in two provinces, Gauteng and Eastern Cape. To illustrate the complex issues that CHWs faced as they sought to provide care in poor communities, we present the experiences of select clients of CHWs. The clients were selected to illustrate household barriers in adhering to treatment for HIV and TB

**CONTACT** Nonhlanhla Nxumalo  nonhlanhla.nxumalo@wits.ac.za  Centre for Health Policy/MRC Health Policy Research Group, School of Public Health, Faculty of Health Sciences, University of the Witwatersrand, 3rd Floor, Education Campus, 27 St Andrews Road, Parktown, Johannesburg 2193, South Africa

© 2016 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited.

without food, and in accessing care to address a wide range of needs. While the two CBOs in Gauteng, reliant on state support, had limited capacity to respond to broad social problems, in the third example, in the Eastern Cape, the CHW was able to act effectively because of the support she received from the NGO. This latter case provides insight into the mechanisms necessary to support CHW programmes, to enable CHWs to gain the trust of the clients. We define trust, following Gilson (2003), as the belief by a householder that the CHW will attend to their interest. In illustrating the interactions of householders and CHWs, and the actions taken by CHWs, we elucidate the relationships of the CHWs and their clients and show how through these interactions, CHWs have the potential to build the trust of clients themselves, if the programme provides sufficient support and resources, and so potentially in the broader health system that has often been limited in responding to their needs. At the same time, we draw attention to the limited capacity of CHWs to change health services. Trust and quality of care, therefore, is limited to CHWs and their clients.

## Background

South Africa is in the process of reforming its health system by strengthening PHC implementation, so as to move from an individualised, passive, curative, vertical system to a population-based, integrated, proactive model (Naledi, Barron, & Schneider, 2011). A core principle of this approach has been emphasis on the social determinants of health at a community level. The community-based model has been conceptualised with three streams: district health specialists to provide core support; school-based PHC to provide school health services; and ward-based PHC outreach teams, primarily constituted of CHWs and led by a nurse. In this model, CHWs are recognised to be central to the “re-engineering” of PHC. As part of their role within the health system, this group of approximately 65,000 cadre is envisaged to provide integrated health and social care to households, and seen as forming a link between government and other services and poor communities (Colvin & Swartz, 2015; Schneider & Lehmann, 2010; van Pletzen, Zulliger, Moshabela, & Schneider, 2013). As a result, there is personalised engagement and relatively holistic care provided by CHWs to householders.

The use of CHWs to provide community-oriented primary care in South Africa dates from the late 1930s and early 1940s (Tollman, 2002), well prior to the global recognition of this approach at and following the Alma Ata Conference in 1978 (Van Ginneken, Lewin, & Beridge, 2010). The CHW programmes that followed

Alma Ata in the 1980s were a response to the poor availability of health care to Black South Africans, especially due to discriminatory policies from the early twentieth century, well before (but exacerbated by) the institutionalisation of apartheid from 1948. Although acting as unrecognised players external to the health system, the CHWs of this period filled a gap created by an inequitable health system through the innovative leadership, hands-on supervision and ongoing training of health professionals and academics (Van Ginneken et al., 2010). In 2016, CHWs are recognised by the post-apartheid government as partners in the health system, and many are incorporated as government employees, paid directly by the state and managed by government health facility managers and/or nurses. Others are formally employed by local community-based organisations or international non-governmental organisations (hereafter NGOs), contracted to provide particular health outreach. The ability of CHWs to form a link between the formal health system and vulnerable communities, and so establish personal relationships of care, has been poorly documented (Perry & Zulliger, 2012).

In the District Health System (DHS) in South Africa, the clinic is the lowest stratum in a hierarchy of health services; it is envisaged as the first point of contact of care for a catchment population in close proximity to it. It implements programmes that are fully operational at district level, such as HIV (ART and PMTCT) and TB programmes (Naledi et al., 2011). However, barriers to care and variant quality of care at different levels still hinder the provision of equitable comprehensive health care services across the country. Moreover, the poor integration of PHC services creates fragmentation and quality of care inefficiencies, disadvantaging those who are most vulnerable. Community-based health programmes and CHWs work in this context.

## Methods

In the research on which we draw, we compared three CHW programmes, delivered by NGOs and providing services in two provinces in South Africa, Gauteng and the Eastern Cape. In Gauteng, South Africa’s best resourced province, services and infrastructure are relatively close in proximity to communities. The Eastern Cape is a poorly resourced area manifesting from the apartheid regime’s policy of the forced relocation of Black South Africans to sparsely populated, isolated and poorly developed areas. Here, services and resources are scarce and populations often reside at considerable distances from clinics.

This comparative approach allowed us to examine contextual factors impacting on access to care by clients,

and the CHWs' ability to address these, in the different settings.

In the study we report here, we conducted case studies, using ethnographic methods, to capture and analyse the intricate interactions that occur between CHWs and clients at the interface between the formal health system and the community, providing a richer perspective of CHW services and experiences and whether the interactions established intimacy and trust. Pertinently so, Stake (1995) and Yin (2009) add that the main importance of a case study is to learn at a more in-depth level. Rule and John (2011) propose one of three types. A case can be "a person, a classroom, a programme, a process, a series of developments, an institution or even a country" and here its defining feature would be its singular form. In this study, we relate the definition of a case study to this one type. We define each case study to include the community, the NGO and the programme implemented by each NGO.

In conducting the study, I (the first author, NN) employed an ethnographic approach because it allowed me to be personally immersed in the daily activities of individuals or communities in order to understand the nuances involved in the "socio-cultural contexts, processes, and meanings within cultural systems" (Whitehead, 2005, p. 4). Many studies on CHW programmes have focused on the structural elements, overlooking the everyday experiences of CHWs and the recipients of the services (Sheikh & George, 2010). In contrast, anthropologists and others have highlighted the importance of describing and so understanding the experiences and functioning of community-based programmes on the ground, and to explore how policies are translated at local levels (Kalofonos, 2014; Maes & Kalofonos, 2013; Mishra, Hasija, & Roalkvam, 2013; Walker & Gilson, 2004).

### **Selection of the CHW programmes**

A representative from the Department of Health of Gauteng Province provided us with a database of CBOs. The selection process was in two stages. First, for this study, the decision was taken to select those located in the largest district in the province, the City of Johannesburg, and to focus only on CBOs that addressed diverse needs (as opposed to those providing specific services, e.g. for HIV care). The first step was to identify all CBOs in the City of Johannesburg as detailed in the database. The second stage was to select CBOs that were functioning at a reasonable level. In discussion with the Department of Health, CBOs were viewed to be reasonably functional if they had the basic components – a manager, at least 10 CHWs to ensure wide coverage, and provided a wide

range of services to meet the variety of needs in their respective communities. Two CBOs in a Gauteng sub-district were identified, and their managers were interviewed to confirm that their organisations met the criteria. Their willingness to participate in the study determined their final selection. A third CBO, in the Eastern Cape, identified by the South African National Council (SANAC)<sup>1</sup> as well-functioning, was purposively selected to further explore the reasons for success and failure.

### **Data collection**

Data were collected in 2010. Twenty three key informant interviews were conducted with government representatives, policymakers and relevant stakeholders to collect their views on the role and experiences of CHWs, their management and support, and the institutional contexts of the NGOs. Three focus group discussions were conducted with CHWs to obtain their views on the management and support they received from the NGOs and their experiences of dealing with other sectors. In addition, to gain practical experience of the CHWs' daily experiences, I (NN) joined the CHW teams, and subsequent to the observations, recorded field notes of daily activities. These included details on the type of services provided, the strategies used to navigate formal government services, how CHWs negotiated access for their clients to service providers, and factors that enabled and/or constrained them in providing inter-sectoral outreach services. Seventy four participant observation sessions were conducted. Narratives from these observations form the basis of this article.

### **Ethics**

This study was approved by the Ethical Committee for Research on Human Subjects of the University of the Witwatersrand and the Policy and Planning Unit of the Gauteng Department of Health and Social Development. As the NGO from the Eastern Cape was an independent organisation and did not receive funding from the province, approval was granted by the NGO. Consent was sought from individual participants prior to all interviews, focus groups and observations. For the purpose of confidentiality, pseudonyms are used throughout this article for CHW clients, geographical areas and the names of the NGOs.

### **Data analysis**

Using transcripts, field notes and the fieldwork diary, themes were coded with Atlas.ti, identifying *a priori* and emergent themes in each case study. This was

followed by a comparison of data within and between the case studies. The data were then examined collectively to identify any divergent themes, and in these cases, we returned to the original data to substantiate unexpected evidence. To further ensure validity of the data, triangulation of the multiple methods included an iterative process of re-checking the themes from each method used. Subsequent to identifying the core themes, transcripts were shared with the research team to ensure collective agreement. Although the Eastern Cape case study was identified for its potential to provide lessons, care was taken to remain critical of any weaknesses and this was included in the analysis.

## Results

### *The CHW programmes*

The first programme we considered, the Khanya Programme, provided services to a marginalised community in an informal settlement in the south of Johannesburg, the provincial capital of Gauteng Province and largest city in South Africa. The CHWs delivered medication for patients on chronic treatment who were unable to physically reach the clinic, provided home-based care,<sup>2</sup> and traced patients who were on long-term treatment for chronic illnesses, including HIV and TB, particularly those defined as “defaulters”. The second programme in Gauteng, the Zola Programme, was located in an informal settlement in the west of Johannesburg. In this programme, CHWs conducted door-to-door dissemination of information on prevalent infections and diseases, including HIV/AIDS, TB and cervical cancer, and provided information on how households could access the services of various government departments that dealt with issues such as housing, water and sanitation, social welfare, and home affairs (for birth certificates and identity documents).

In the Eastern Cape, the Eden Programme dealt primarily with child and youth care, focusing on child health outcomes in households affected by HIV/AIDS. Here, CHWs linked those who they identified as neglected or abused to health and legal services, and provided daily care (such as meals, accompanying younger children to school and assisting with household cleaning) to child-headed households and to households where children were particularly vulnerable as a result of circumstances such as extreme poverty.

### *Households and the CHWs*

Although the CHWs worked in different areas and communities in the two provinces, the context in which they

provided services highlighted common themes. Household poverty in all three communities impacted the capacity of household members to access health care and other services, and often to undertake caregiving and basic health maintenance at a household level. As elaborated in the cases below, poor households struggled to survive, but also, the poverty-related barriers to care were partly created by a poorly integrated district health system. The cases also illustrate how CHWs experienced and dealt with poor integration in their efforts to provide the outreach services and care required to address clients’ multifaceted needs.

### *Gloria and lucky: unemployed*

Gloria and Lucky, both of whom are HIV positive, own their modest house; it looks very bare, with only one chair inside. Gloria was sitting outside and looked very emaciated and weak; she said that she had not eaten in four days. Both Gloria and Lucky are unemployed, and when Lucky goes away to try to find work, Gloria has no means of finding anything to eat. Both Gloria and Lucky were required, by their local hospital, to attend a three-day adherence “course” before they were put on antiretroviral (ARV) treatment, but due to prohibitive transport costs, they could not attend. Generally known to have poor follow-up processes, the hospital did not appreciate why they had not attended; as a result, they were not on treatment. Because understanding of social barriers is not sufficiently incorporated into the decision-making that influences the delivery of care, the CHWs could not address Gloria’s needs. As one CHW reflected, “this is when it becomes difficult for me to assist any further. Everything requires financial means and I can’t help with that”.

### *Mandla and Phumzile: multiple needs*

The disjuncture between a poor household’s needs and the services provided extends beyond the health sector. Mandla and Phumzile are elderly residents of a farm house abandoned by its previous owners. They are both too frail and too poor to access health care and other services that were intended to address their needs.

Together with two CHWs, I entered the damp and very dark house, without water and sanitation, to visit them. Both Mandla and Phumzile had been laid off from farm labouring work following a change of farm owners and employers, and they had no formal employment benefits. They relied on scraps of food from equally poor neighbours. The woman, Phumzile, was seated on the mattress and had extremely swollen feet. She was

too sickly and her feet too painful to walk to the nearest clinic.

One CHW inquired if they had bought food, because there was no sign of food in the house. The couple mentioned that they both received a pension grant, but they often could not collect it at the government office in the nearest town because they could not afford the transport costs and did not have the strength to walk 20 minutes to the main road for public transport. Mandla mentioned that at times he walked up to the road to stop a taxi, which would drive to collect Phumzile. After the CHW looked for a tap or a source of water around the yard to wash Phumzile's feet, Mandla informed her that they could only access water from a hose that irrigated the fields on the main farm: he places a bucket under a leaking section of the hose and waits for it to fill. The CHWs did not have transport to ensure regular visits or to ensure that the woman received the requisite care, and they left without certainty that they could return anytime soon to take Phumzile to a clinic, although one CHW assured her, "We will try to come back and fetch you with a car."

This elderly couple had multiple needs. With few resources and lack of access to the social welfare and health system, the CHWs were their only link to receive formal care. But the CHWs, in turn, had limited capacity to attend to Phumzile's foot and the couple's other needs, and they provided the bare minimum: one CHW washed Phumzile's infected foot. As this case study illustrates, unintegrated and poorly resourced services inadvertently create barriers for poor households and impact on access and quality of care, and hence on the clients' trust that the health system will be able to assist. Illuminated by the conclusion of the visit, the CHWs' non-committal assertion that they will return conjured up little trust in the clients that they would do so.

### ***Vusi: the internal immigrant***

Vusi, aged 65, was sleeping in a shack built with corrugated iron. He had come to Johannesburg 46 years earlier from Eastern Cape Province looking for work. He was a TB patient of the CHW, and she monitored his treatment and ensured that he took his medication. The shack was bare, with no sign of any food except for a jug filled with what he said was a sweetened drink. There appeared to be no basin or taps to wash. The nearest water source was a communal water tank a walking distance from his house, but walking was difficult for him because he was ill and had limited mobility.

Vusi reported that he felt weak. Close to his bed there was a small table, full of containers with TB tablets from several months ago, indicating that he had not taken his

medication regularly. The CHW asked him why this was so and Vusi replied that he often had no food, and that it was difficult and unpleasant to take the medication on an empty stomach. Thus while the clinic provided the medications and the services of the CHWs, it did not provide food, and Vusi could not adhere to his treatment without it. As a passive recipient of health services, Vusi followed the instructions to return to the clinic after a particular period to collect his treatment. As noted in Lucky and Gloria's case, the health provider at the clinic seldom has the space (and time) to allow clients to voice their constraints with the treatment. The clinic visit is prompt, instructive and paternalistic. Regardless and with limited knowledge of his difficulties, Vusi was expected to comply and he obliged. The CHWs created the process that was lacking in his clinic visits: they provided both personal care and time for Vusi to express his difficulties.

### ***Zodwa and Andile: the HIV positive mother and son***

Both Zodwa and her 6 year old son, Andile, are HIV positive. Andile had just started on ARVs, which Zodwa collected from a major public hospital in Johannesburg, about 14 kms from their home. Zodwa started taking treatment also, but she stopped due to side effects. She says that half the time she has no food and has had enough with taking tablets on an empty stomach. "Those tablets make you terribly hungry." She therefore decided to stop after a few months, saying that she preferred to take traditional medication and herbs instead.

One CHW asked her about the advice she received regarding administering treatment to her son. Zodwa replied that she was not sure. She had collected the medication a day earlier at the clinic, but she cannot read and therefore she was not sure of the dosage. The CHW started to read the instructions, and explained and showed her how she should be administering the medication. Another CHW inquired if this was not explained to her at the hospital. Zodwa replied that the nurse attending to her spoke mostly in a language she did not understand. The CHW explained that if she were to take her ARVs, the symptoms that made her feel ill and weak would be alleviated. But Zodwa said that she believes that she has AIDS and she would rather die. The CHW explained that she did not yet have AIDS but she was suffering from HIV symptoms, and that the purpose of the ARVs was to prevent these symptoms. Zodwa rejected the suggestion that she go on treatment, and reiterated that she would rather die. The CHW explained that once she is on ARVs, she would receive a grant from the government so that she could buy food. But Zodwa seemed unconvinced, and continued

to say that she was also tired of taking her son to the clinic. “They [health care providers] often do nothing to help, even when his treatment is not effective.” Barriers to services are not only encountered at the point of access but are also created by service providers, as this case illustrates. Zodwa’s experiences with health care professionals and services are manifested in her despair and sense of hopelessness. Due to the language barrier, her encounter with the health services left her with limited knowledge of her own treatment and its side effects, and without knowledge of how to administer treatment to her son. The CHWs were left to deal with the repercussions of the inadequate care and treatment Zodwa had received at the health facility. They had to provide care to a woman who had lost trust in the health system, which hindered the opportunity and potential to build trust between them. Of course, the unspoken tragedy is that if Zodwa dies, as she surely will if she fails to take ARVs, her son’s future will be even bleaker.

These CHWs working in the Gauteng programmes had access to limited resources. The accounts above illustrate that the range of social issues requires that the CHW has the capacity to negotiate complex issues, and so has multiple skills and resources. For example, the elderly couple, Mandla and Phumzile, faced a life of chronic food insecurity, lack of adequate shelter, and could not access social services that might be a pathway to accessing care. The CHWs in all cases acted alone, without the support of the health system, and so they were not able to respond to the needs of their clients, to ensure that they were able to collect their pension regularly to ensure that money was available to purchase food and to pay for transport to the clinic. Consequently, poor support of CHWs makes it difficult for them to establish trust with their clients.

### **Responding to multifaceted needs: an NGO from the Eastern Cape**

The case study from the Eastern Cape, below, illustrates how the capacity of CHWs to provide comprehensive care is determined by the capacity of the NGO to provide an integrated structure as a means of support, despite operating within an unintegrated policy environment. As the following accounts reflect, the CHWs were able to circumvent systemic bottlenecks to assist the households. One CHW provided the following account of her capacity to care:

The children stayed with the grandmother but it was difficult financially [to assist her]. I went to The Department of Social Development to help her to apply a foster care grant<sup>3</sup> and an old age pension grant.<sup>4</sup> She could not access either grant (as she did not meet the

criteria) and there was no other person to look after these children. She was the only next-of-kin. Then I was stuck at this point with Social Development until this year. I found a neighbour who will be taking over the care of the children so that they can get the foster care grant. I just asked the neighbour if she could take over the care of the family and the children. You see, we work with MDT [Multidisciplinary Therapy]. You *must* ask the neighbours if the family does not have another family around. You ask the neighbours as community members to look after the family and the children. The neighbour agreed, so they are now processing the foster care grant as we speak.

The Department of Social Services declined the application for the two social security grants, due to bureaucratic requirements that were beyond the grandmother’s and the CHWs’ capacity to resolve. Faced with an unresponsive system, the CHWs’ ability to respond to the complex needs of this household required the capacity to harness a diverse range of resources. The CHW drew on social networks in the community rather than formal state resources. Moreover, the CHWs, with the assistance of their supervisors, worked with a community forum to organise a community meeting. The community was galvanised to identify a piece of land, secure building material, and collectively build a home for the grandmother. In this case, the CHW had gained the trust of the community members, such that they were willing to contribute scarce resources to assisting this elderly woman.

### **CHW advocacy**

The extent of institutional support with the programme enabled the CHWs to use advocacy and the media as a tool to respond to the needs of poor people, who often have limited agency with state service providers. The account of one CHW in the Eastern Cape illustrates this:

We (patient and CHW) used to get ARVs from a hospital in Easterly (113kms from the patients’ and CHW’s residence). I had to be up at 4am, rushing to get the ambulance at the local hospital (which goes to the hospital in Easterly). I would sometimes sleep over there, so that they can take my client to the Easterly hospital. Then one day, the child and I arrived on time (at the Easterly hospital) to find the dispensary closed. The child was there. No treatment. I mean, they say once a person is on ARVs, they cannot stay even a day without that treatment. I called the (NGO) coordinators to tell them of the changes. The coordinators arranged for me to get a *Daily Dispatch* journalist, who went and witnessed this in the Easterly hospital. It was in the *Daily Dispatch* the following day. That was the day they started to have the ARVs here in our town, because the coordinators and the journalist exposed them. Because of the type of support, we have to speak out

on services, (and now) we don't only have to collect ARVs in distant hospitals like we used to.

The CHW did not trust that the health service was going to resolve this problem, and instead called on the media to publicly shame the health department into taking action. The efforts of the CHW and the NGO facilitated a change in implementation that not only benefited the patient in question, but all those who needed to collect ARVs from health facilities. Actions such as this built client trust in the CHW programme, such that they were confident that a wide range of actions could be taken to assist clients.

## Discussion

The narratives presented above offer a vivid picture of the multifaceted social factors that influence health and wellbeing in poor households. They also describe the spectrum of the barriers to care, and their pervasiveness. In Gauteng, Gloria and Lucky needed ARV treatment but encountered barriers both because they were unemployed and poor, and because they were required to travel several times to a clinic before they were considered eligible to receive treatment. Poor food security experienced by Vusi, who was on TB treatment, highlights how health systems with limited integration lack the capacity to respond to the social circumstances of the communities they aim to serve. Zodwa, who with her son was HIV positive, experienced barriers at the point of service, where a language barrier translated into her inability and reluctance to administer treatment to herself and her son, her consequent frustration, despair and expressed lack of will to live. The Eastern Cape clients encountered barriers due to policies from several state services. One led to ARV treatment interruptions, as it required that people travel long distances to receive treatment, while the other was required to undergo a cumbersome process of documentation to receive a social security grant. Despite the barriers in both programmes, the CHWs in this context were able to address these barriers differently, so determining the level of trust built between them and their clients.

The CHWs in both programmes illustrate that this cadre meets the need for services which the health system is not able to provide. CHWs offer personal care and the space for patients to voice difficulties and barriers to benefiting from health care and treatment. However, the Gauteng CHWs received limited support and so had limited means to provide care to their clients, hence compromising the extent of trust; in contrast, the Eastern Cape CHWs were able to problem solve and negotiate to provide care to their clients. With the support of

their NGO, they built trust with their clients and others in the local community. A range of problems are faced by patients in accessing care, and as illustrated in the cases presented here, the barriers are numerous and multifaceted. One review of health services research, consistent with our findings as illustrated by several patients' poor adherence to treatment due to lack of food, indicated that chronic care patients in South Africa, faced poor access to and limited continuity of care (Steyn & Levitt, 2006). Studies that are specific to diseases clearly show that lack of finance (for instance, to pay for transport and food) is a prominent constraint of South African patients to attend clinic visits regularly (Matwa, 2001; Rutherford, Mulholland, & Hill, 2010; Rutherford et al., 2009) and adhere to prescribed behaviour, including a recommended diet (Jacobs, Ir, Bigdeli, Annear, & Va Damme, 2012; Khoza & Kortebout, 1995). As in our study, these studies have highlighted that transport costs deter patients from attending regular hospital visits, with interruptions to treatment when they run out of medication (Jacobs et al., 2012; Khoza & Kortebout, 1995), and that lack of sufficient food consistently results in poor adherence of ARV therapy (Cousins, 2016; Kalo-fonos, 2010).

Barriers are consequently not only experienced by poor householders, but also by those who care for them, the CHWs, despite that they are considered part of the health system. Without a system that fosters integration and is able to provide support, as the Gauteng case studies illustrate, CHWs are not able to provide comprehensive services to households. Several studies have indicated a range of challenges experienced by CHWs that further translate into their lack of capacity to respond to community needs. As with the Gauteng case studies, one study in South Africa alluded to poor organisational support, with poor provision of supervision, unreliable financial support, and inadequate management (Languza, Lushaba, Magingxa, Masuku, & Ngubo, 2011). A study in Kenya identified similar challenges with limited supplies, as indicated by the CHW attending to Phumzile, and inadequate supervision, as experienced by the CHWs from both Gauteng case studies (JICA, 2013). Another study, analysing the context in which CHWs provided services, highlighted the barriers for patients of travelling to health facilities due to transport costs, leading to unfulfilled referrals (Zerihun, Admassu, Tulloch, Kok, & Datiko, 2014). Without adequate support for all aspects of health care that require integration and coordination, the CHWs in Gauteng were not able to circumvent the systems barriers and so provide the kind of practical and supportive care that would assist households.



The CHWs and the householders in the Eastern Cape experienced similar barriers, but the CHWs were better able to address these constraints and so build relationships with their clients. The capacity of the NGO to provide support linked to the context is reflected in the CHW's response to a patient's inability to access ARV treatment. Although the organisation provided HIV/AIDS focused services, the demand for integration harnessed the organisation to employ a comprehensive paradigm, albeit outside the health system. This ensured that management, resources, and services were inter-related. The intervention of the supervisors illustrates the close link of management with its CHWs, to enable them to navigate a policy environment that creates barriers for both users and providers. It is evident that the independence of the Eastern Cape NGO provided room for managerial support to CHWs, in contrast to the state-funded ones in Gauteng, which had limited scope with funding and capacity to provide support.

The ability of these CHWs to respond to community needs cannot solely rely on the capacity of the NGO to provide support and CHWs cannot operate in an environment with limited inter-sectoral links and poor integration, as this is not sustainable. As noted above, this cadre addresses community needs that manifest from social circumstances, and this requires a broad-based response. CHW programmes need to function in a supportive and coordinated environment where various sectors and stakeholders collaborate and formally recognise the role of CHWs. A review by Haines et al. (2007) indicates that a key factor determining the success of a CHW programme is an established relationship with the formal health system. This requires the involvement and coordination of multiple actors at the district level, such as community groups, health care providers, municipal level stakeholders (MCHIP, 2013) and multiple sectors, for example, social development, environmental services (water and sanitation) and education. As illustrated by the Eastern Cape case study, a mobilised community also contributes to enabling CHWs to function in resource-constrained communities (Borghi et al., 2005; Haines et al., 2007).

An overarching theme in the experiences of CHWs services in our study is the role of trust. It is important that beneficiaries have trust in the services they are receiving as that determines the choices they make regarding their use of services, their uptake of advice, and continuity of care. Gilson and Erasmus (2007) emphasise that this aspect ensures effective health service delivery as it fosters co-operative relationships and collective action. People tend to associate CHWs with the state and its health system, and lack of trust in the government is also levelled at the CHWs (Glenton, Scheel,

Pradhan, Lewin, & Hodgins, 2010; Palazuelos et al., 2013). This is well illustrated in various studies where women opt for traditional birth attendants, rather than the conventional maternal and child health services, due to concerns of lack of competence in health staff and to feelings of disrespect and being undermined in health facilities (for Malawi, see Kumbani, Bjune, Chirwa, & Odland, 2013; for Tanzania, see Kruk et al., 2009; for Kenya see Essendi, Mills, & Fotso, 2011). Poor trust in state services is pervasive in South Africa, particularly among poor communities, and in response to a neglected and deteriorating PHC and clinic services, people routinely by-pass these services (Francis & Edmeston, 2012). The CHWs in this study function in an environment where households have little reason to be confident in the health services. Zodwa's negative encounter with the health care providers clearly had broken her trust in the system if she had had any before. CHWs work to re-build this trust by establishing personal relationships with their clients, spending time with them, and providing simple care of the kind that might be administered by kin and neighbours in other contexts. Community level health workers elicited trust through their language of communication, modifying messages in ways appropriate to the needs and priorities of the communities instead of using the language of clinical health practitioners (Mishra, 2014). Similarly, the CHWs in our study were able to communicate to Zodwa on her treatment regimen in a language she could understand and in a way that acknowledged her experience. The CHWs in the Eastern Cape challenged the state in order to tend to the health and non-health needs of their clients, and as we show, this layer of care enabled the development of trust and supported further communication. Although with limited capacity, the interactions between CHWs and clients in the Gauteng NGOs as well as in Eastern Cape highlight the extent to which the communities have accepted their services, illuminating the texture of intimacy and how that translates into trust.

Moreover, the CHWs in our study illustrate that they fulfil a fundamental function that the health system has limited capacity to provide. They provide personal care in contexts where this is not provided informally, and allow for clients to voice their constraints with the formal care they receive. Despite the lack of support for the CHWs in Gauteng, they were able to create time to listen to why Vusi had defaulted on his treatment, despite diligently returning to the clinic to collect his treatment. This is in direct contrast to his visit to the clinic where often time-constrained nurses had not inquired as to whether he had completed his previous medication. His visit to the clinic was taken as an indication of

adherence, which it clearly was not. The study reported by Maes and Kalofonos (2013) similarly alludes to this premise: that the services offered by CHWs move beyond the notion of traditional health services. They provide a layer of care beyond that offered by front-line health care workers. Tsolekile, Puoane, Schneider, Levitt, and Steyn (2014), writing on the role of CHWs in NCDs, clearly show how their functions transgress those that clients could find at a health facility. This level of personal care is lacking in health care facilities and CHWs have the potential to fill this gap. Their characteristics set them apart from health professionals too, strengthening their ties with fellow community members (Gold, 2010).

As South Africa makes efforts to recognise CHWs as formal health care providers within the health system, the integration of multiple players and redress of constraining factors need to be taken into consideration. Support for CHWs requires multisectoral engagement both at the district level and in national policy that recognises a comprehensive and integrated approach, to ensure stable financial support, adequate supervision and sufficient resources (Perry & Zulliger, 2012). The Eastern Cape case study illustrates the factors that enable CHWs to provide comprehensive needs-oriented services and to build trust and personal relationships. The Gauteng examples, in contrast, highlight what governments need to consider across the health system and at different levels, and take action on in order to establish CHWs supportive to PHC revitalisation and the delivery of multisectoral outreach services.

## Conclusion

Limited multisectoral coordination results in CHWs with little capacity to work with and support people in poor communities with complex upstream factors of health and wellbeing. Although patients requiring ongoing care for chronic conditions receive clinical care and treatment, other components of care contribute to prevention and wellbeing. Often, these are met neither by household members nor by health care professionals, who at most times are facility-based. CHWs have the potential to fill this space. They are in the position to generate social capital and social networks within their communities, including trust – which they can utilise to link householders to resources in a way that health professionals cannot. In light of the expectations of CHWs in revitalising PHC (Department of Health, 2011), support strategies are required to address various social determinants of health. A key factor to aid efforts towards supportive mechanisms is to strengthen the links between sectors and departments at different levels

of government. The implementation of ward-based teams in South Africa calls for actions on these factors to realise the intended PHC objectives.

## Notes

1. A voluntary association of institutions to build consensus across government, civils society and other stakeholders to drive an improved response to HIV, TB and STIs.
2. The provision of comprehensive services, including health and social services by formal and informal caregivers in the home. It often includes physical and psychosocial care.
3. A grant provided for the care of a child who has been placed in (one's) custody by a court as a result of being; orphaned, abandoned, at risk, abused, neglected.
4. An older persons' grant paid to people who are 60 years and older.

## Acknowledgements

This study was carried out with support from the Global Health Research Initiative (GHRI), a collaborative research funding partnership of the Canadian Institutes of Health Research, the Canadian International Development Agency, Health Canada, the International Development Research Centre, and the Public Health Agency of Canada. Supplementary funding was contributed by the African Doctoral Dissertation Research Fellowship, Carnegie Corporation New York (Carnegie Cooperation Transformation Programme at Wits), and the National Research Foundation, South Africa.

## Disclosure statement

No potential conflict of interest was reported by the authors.

## ORCID

Lenore Manderson  <http://orcid.org/0000-0002-7883-1790>

## References

- Borghji, J., Thapa, B., Osrin, D., Jan, S., Morrison, J., Thamang, J., ... Shrestha, S. (2005). Economic evaluation of a women's group intervention to improve birth outcomes in rural Nepal. *The Lancet*, 366, 1882–1884.
- Christopher, J. B., Le May, A., Lewin, S., & Ross, D. A. (2011). Thirty years after Alma-Ata: A systematic review of the impact of community health workers delivering curative interventions against malaria, pneumonia and diarrhoea on child mortality and morbidity in sub-Saharan Africa. *Human Resources for Health*, 9(27), 2–11.
- Colvin, C. J., & Swartz, A. (2015). Extension agents or agents of change? *Annals of Anthropological Practice*, 39(1), 29–41.
- Cousins, T. (2016). Antiretroviral therapy and nutrition in Southern Africa: Citizenship and the grammar of hunger. *Medical Anthropology*. doi:10.1080/01459740.2016.1141409

- Department of Health. (2011). *Provincial guidelines for the implementation of the three streams of PHC Re-engineering*. Pretoria: Department of Health.
- Essendi, H., Mills, S., & Fotso, J. C. (2011). Barriers to formal emergency obstetric care services' utilization. *Journal of Urban Health*, 88(Suppl. 2), S356–S369.
- Francis, K., & Edmeston, M. (2012). Beyond band-aids: Reflections on public and private health care in South Africa. State and Nation. F. A. K. Francis. Parktown, The Helen Suzman Foundation, 41–46.
- Gilson, L. (2003). Trust and the development of health care as a social institution. *Social Science & Medicine*, 56, 1453–1468.
- Gilson, L., & Erasmus, E. (2007). *Improve health service delivery through building trust: Trust and accountability in health service delivery in South Africa*. Johannesburg: Centre for Health Policy.
- Glenton, C., Scheel, I., Pradhan, S., Lewin, S., & Hodgins, S. (2010). The female community health volunteer programme in Nepal: Decision makers' perceptions of volunteerism, payment and other incentives. *Social Science & Medicine*, 70, e1920–e1927.
- Gold, R. B. (2010). I Am Who I Serve' – Community health workers in family planning programs. *The Guttmacher Institute, Guttmacher Policy Review*, 13(3). Retrieved from <https://www.guttmacher.org/about/gpr/2010/08/i-am-who-i-serve-community-health-workers-family-planning-programs>.
- Haines, A., Sanders, S., Lehmann, U., Rowe, A. K., Lawn, J. E., Jan, S., ... Bhutta, Z. (2007). Achieving child survival goals: Potential contribution of community health workers. *Lancet*, 369(9579), 2121–2131.
- Irwin, A., & Scali, E. (2010). *Action on the Social Determinants of Health: Learning from previous experiences*. Social Determinants of Health Discussion Paper 1 (Debates). Geneva, Switzerland.
- Jacobs, B., Ir, P., Bigdeli, M., Annear, P. L., & Va Damme, W. (2012). Addressing access barriers to health services: An analytical framework for selecting appropriate interventions in low-income Asian countries. *Health Policy and Planning*, 27, 288–300.
- JICA. (2013). *Performance of community health extension workers (CHEW): Operations research on strengthening community health strategy in Kenya*. Nairobi: Japan International Cooperation Agency.
- Kalofonos, I. (2010). All I Eat Is ARVs: The paradox of AIDS treatment interventions in Central Mozambique. *Medical Anthropology Quarterly*, 24(3), 363–380.
- Kalofonos, I. (2014). "All they do is pray": Community labour and the narrowing of "care" during Mozambique's HIV scale-up. *Global Public Health*, 9(1–2), 7–24.
- Kautzky, K., & Tollman, S. M. (2008). A perspective on primary health care in South Africa. In P. Barron & J. Romareardon (Eds.), *South African health review* (pp. 17–28). Durban: Health Systems Trust.
- Khoza, S. R., & Kortenbout, W. (1995). An investigation of compliance in type II diabetic patients attending clinic at the Church of Scotland Hospital. *Curationis*, 18, 10–13.
- Kickbusch, I. (2010). Health in all policies: The evolution of the concept of horizontal health governance. In I. Kickbusch & K. Buckett (Eds.), *Implementing health in all policies: Adelaide* (pp. 11–13). Adelaide: Department of South Australia.
- Kruk, M. E., Mbaruku, G., McCord, C. W., Moran, M., Rockers, P. C., & Galea, S. (2009). Bypassing primary care facilities for childbirth: A population-based study in rural Tanzania. *Health Policy and Planning*, 24, 279–288.
- Kumbani, L., Bjune, G., Chirwa, E., & Odland, J. O. (2013). Why some women fail to give birth at health facilities: A qualitative study of women's perceptions of perinatal care from rural Southern Malawi. *Reproductive Health*, 10(9), 1–12.
- Languza, N., Lushaba, T., Magingxa, N., Masuku, M., & Ngubo, T. (2011). *Community health workers: A brief description of the HST experience*. Durban: Health Systems Trust.
- Maes, K., & Kalofonos, I. (2013). Becoming and remaining community health workers: Perspectives from Ethiopia and Mozambique. *Social Science & Medicine*, 87, 52–59.
- Matwa, P. N. (2001). *Experiences and food care practices of patients with diabetes mellitus*. Rand Afrikaans University, Faculty of Education and Nursing.
- MCHIP. (2013). *Developing and strengthening community health worker programs at scale: A reference guide for program managers and policy makers*. Maternal and Child Health Integrated Program.
- Mishra, A. (2014). "Trust and teamwork matter": Community health workers' experiences in integrated service delivery in India. *Global Health Health*, 9(8), 960–974.
- Mishra, A., Hasija, S., & Roalkvam, S. (2013). Multiple voices and stories: Narratives of health and illness. In A. Mishra & S. C. Chatterjee (Eds.), *Numerical narratives: Accounts of lay health workers in India* (pp. 121–140). New Delhi: Orient Blackswan.
- Motevalian, S. A. (2007). *A case study on intersectoral action for health in I.R. of Iran: Community based initiatives experience*. School of Public Health Iran University of Medical Sciences.
- Naledi, T., Barron, P., & Schneider, H. (2011). Primary health care in South Africa since 1994 and implications of the new vision for PHC Re-engineering. In A. Padarath & R. English (Eds.), *South African health review* (pp. 17–28). Durban: Health Systems Trust.
- Palazuelos, D., Ellis, K., Im, D., Peckarsky, M., Schwartz, D., Farmer, D. B., ... Mitnick, C. D. (2013). 5-SPICE: The application of an original framework for community health worker program design, quality improvement and research agenda setting. *Global Health Action*, 6, 19658. doi:10.3402/gha.v6i0.19658
- Perry, H., & Zulliger, R. (2012). *How effective are community health workers? An overview of current evidence with recommendations for strengthening community health worker programs to accelerate progress in achieving the health-related millennium development goals*. Departments of International Health and Health, Behavior and Society Johns Hopkins Bloomberg School of Public Health.
- PHAC. (2008). *Healthy equity through intersectoral action: An analysis of 18 country case studies*. Ottawa: Public Health Agency of Canada.
- van Pletzen, E., Zulliger, R., Moshabela, M., & Schneider, H. (2013). The size, characteristics and partnership networks of the health-related non-profit sector in three regions of South Africa: Implications of changing primary health

- care policy for community-based care. *Health Policy and Planning*, 1–11. doi:10.1093/heapol/czt058
- Rule, P., & John, V. (2011). *Your guide to case study research*. Pretoria: Van Schaik.
- Rutherford, M. E., Dockerty, J. D., Jasseh, M., Howie, S., Herbison, P., Jeffries, D. J., ... Hill, P. C. (2009). Access to health care and mortality of children under 5 years of age in The Gambia: A case-control study. *Bulletin of the World Health Organization*, 87, 216–225.
- Rutherford, M. E., Mulholland, K., & Hill, P. C. (2010). How access to health care relates to under-five mortality in sub-Saharan Africa: Systematic review. *Tropical Medicine and International Health*, 15(5), 508–519.
- Schneider, H., & Lehmann, U. (2010). Lay health workers and HIV programmes: Implications for health systems. *AIDS CARE*, 22(1), 60–67.
- Sheikh, K., & George, A. (2010). India's health providers: Diverse frontiers, disparate fortunes. In K. Sheikh & A. George (Eds.), *Health providers in India: On the frontlines of change* (pp. 1–11). New Delhi: Routledge.
- Stake, R. E. (1995). *The art of case study research*. Thousand Oaks, CA: Sage.
- Steyn, K., & Levitt, N. S. (2006). Health services research in South Africa for chronic disease lifestyle. In K. Steyn, J. Fourie, & N. Temple (Eds.), *Chronic diseases of lifestyle in South Africa: 1995–2005* (pp. 226–248). Cape Town: Medical Research Council.
- Tollman, S. M. (2002). Roots, shoots, but too little fruit: Assessing the contribution of COPC in South Africa. *American Journal of Public Health*, 92(11), 1725–1728.
- Tsolekile, L. P., Puoane, T., Schneider, H., Levitt, N. S., & Steyn, K. (2014). The roles of community health workers in management of noncommunicable diseases in an urban township. *African Primary Health Care and Family Medicine Journal*, 6(1), 1–8.
- Van Ginneken, N., Lewin, S., & Berridge, V. (2010). The emergence of community health worker programmes in the late apartheid era in South Africa: An historical analysis. *Social Science & Medicine*, 71, 1110–1118.
- Walker, L., & Gilson, L. (2004). “We are bitter but we are satisfied”: Nurses as street level bureaucrats in South Africa. *Social Science & Medicine*, 59, 1251–1261.
- Whitehead, T. (2005). *Ethnographically informed community and cultural assessment research systems (EICCARS) Working paper series: Basic classical ethnographic research methods: Secondary data analysis, fieldwork, Observation/Participant Observation, and Informal and Semi-structured Interviews*. Maryland: University of Maryland.
- Yin, R. K. (2009). *Case study research: Design and methods*. Los Angeles: Sage.
- Zerihun, A., Admassu, M., Tulloch, O., Kok, M., & Datiko, D. G. (2014). *Context analysis: Close-to-community providers in Ethiopia*. Hawassa: Reachout Consortium.