THE EXPERIENCES OF LAY COUNSELLORS REGARDING HIV AND AIDS CARE AND SUPPORT IN TSHWANE CLINICS

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ABSTRACT

Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) is a major burden disease in South Africa. The pandemic characterises the need for increased counselling and testing due to the availability of antiretroviral therapy (ART). This study describes the experiences of lay counsellors regarding care and support for HIV and AIDS. *A qualitative approach was used during focus group interviews at four Tshwane clinics. The purposive sampling method was used to select participants from each facility. Data were collected and data analysis conducted using Tesch's method. The results highlight that lay counsellors are not recognised as part of the health workers and multi-disciplinary team by the Department of Health. It was recommended that the lay counsellors be retained as stipend earning government workers with clearly stipulated and revised conditions of service. On-going support, managerial support and supervision are necessary to improve care and support of HIV and AIDS.*

Keywords:
AIDS, care, experiences, HIV, lay counsellors, support

INTRODUCTION

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) pandemic mark 34 years in existence to date. This pandemic is characterised by the need for increased counselling and testing due to the availability of Antiretroviral Therapy (ART). In 2009, more than 25 million people had died from HIV and AIDS related infections throughout the world (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2011). In 2010 people living with HIV/AIDS (PLHA) in Sub-Saharan countries were estimated at 22,9 million. The newly infected were at I,9 million and there were 1,2 million deaths due to AIDS related illnesses (UNAIDS, 2011). Different ranks of health care providers such as HIV and AIDS lay counsellors are involved to provide HIV and AIDS counselling including testing services.

Strategies to manage HIV and AIDS include prevention and education which is effective and necessary for all people to be protected from HIV and to help those living with HIV to lead positive lives (Avert, 2015). Emphasis is put on correct and consistent use of condoms as an integral component of a combination of prevention of HIV infection (Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Laabdarios and Anoya, 2014). Other strategies include HIV treatment, preventing mother to child transmission (PMTCT) of HIV as well as preventing and treating TB and HIV (Department of Health, 2014). To succeed in fighting HIV and AIDS, the South African population needs to be empowered and committed towards the prevention of the disease. Voluntary counselling and testing service is used by the population to know their HIV status and also assists in preventing and being protected from the infection.

Creating awareness as one of the strategies of preventing HIV and AIDS helped most people to access the HIV and AIDS counselling services (Department of Health (DoH), 2010). South Africa's Minister of Health, Doctor Aaron Motswaledi, launched an HIV and AIDS counselling and testing campaign in April 2010 to promote HIV counselling to all South Africans. The main aim was to increase the number of people who are aware of their HIV status to at least 15 million by the end of June 2011 as stated in the South African National AIDS Council Secretariat (DoH, 2010). All South African citizens were encouraged to participate in the HIV counselling and testing campaign, through the media and all health facilities including nursing colleges. The objective of the campaign was to mobilise people to know their status, promote a healthy lifestyle and healthy behaviour as well as to increase access to treatment, care and support as drawn by the SANAC Secretariat (DoH, 2010).

According to Mwisongo, Mehlomakhulu, Mohlabane, Peltzer, Mthembu and Van Rooyen (2015), HIV Counselling and Testing (HTC) services in South Africa are commonly performed by health care providers including lay counsellors and testers. Dlamini (2011) states that nurses used to be responsible for providing HIV and AIDS education, counselling, testing and support in hospitals and clinics around the country. However, due to an increased number of people infected with HIV and AIDS in clinics, it became apparent that additional human resources were needed to help nurses to manage the HIV and AIDS epidemic. According to the United Nations General Assembly Special Session (UNGASS) report of 2012, towards the end of 2011, 13.3 million people were tested for HIV out of the targeted 15 million nationwide (Republic of South Africa, 2013). By June 2014, 13.6 million people living with HIV were receiving ART globally (United Nations, 2015). Therefore, lay counsellors are more needed for the country to be conscious of the

rate of HIV and AIDS infection so that there is appropriate planning by the government and other stakeholders in the community to combat this infection.

PROBLEM STATEMENT

HIV and AIDS lay counsellors are facing challenges of pre-counselling, testing and post-counselling. They provide care and support to clients with limited knowledge and skills related to counselling and testing. Mwisongo et al. (2015) confirm that lay counsellors have limited counselling for specific vulnerable groups such as children, older clients, discordant couples, homo-sexuals and children. These counsellors work with a team of health care providers, alongside the professional health nurses (Rohleder and Swartz, 2005). Thurling and Harris (2012) add that as a result of the shortage of health workers such as nurses in South Africa, lay counsellors play an important role in the prevention of mother to child transmission (PMTCT) yet they are not recognised as health workers. Lay counsellors are not appreciated or recognised by the health care authorities, facilities and communities (Schneider, Hlophe and Van Rensburg, 2008). According to Mwewa, Saili and Simbaya (2013), no formal organogram exists that places and defines the role of lay counsellors within the health system. They are regarded as the exploited labour force without common labour benefits such as accumulated leave, maternity leave and pension (Schneider, Hlophe and Van Rensburg, 2008). They are expected to provide supportive and preventative services such as negotiating access to treatment, managing issues of stigma and prejudice (Teng, 2011). In addition, they do not receive a sufficient salary (Woolman, Sprague and Black, 2009). Mwisongo et al. (2015) further support that low morale and motivation of counsellors is partly affected by poor remuneration. A majority of lay counsellors serve as volunteers with the hope of finding stable employment (Schneider et al., 2008). The Health-E News further confirms that for many years lay counsellors are still regarded as volunteers that are paid a stipend (Health-E news, 2012).

OBJECTIVE OF THE STUDY

The objective for this study was to explore and describe the experiences of lay counsellors regarding care and support for HIV and AIDS in Tshwane clinics.

METHOD

A qualitative, exploratory and descriptive design was used to explore the life experiences of lay counsellors with regard to HIV and AIDS care and support in Tshwane clinics (Polit and Beck, 2012). This method was preferred because a deep understanding of the experiences of lay counsellors regarding care and support to clients were elicited.

Population

The population utilised included lay counsellors in Tshwane clinics. Participants were members of the community who have volunteered as lay counsellors and were 18 years and above and could communicate, read and write. These particpants were further trained as lay counsellors in Voluntary Counselling and Testing (VCT) services.

Sampling

Each group consisted of four to six participants. Purposive sampling (Polit and Beck, 2012) was selected to identify participants with related experiences and desired expertise while having undergone an HIV and AIDS counselling course for at least two weeks or more. They had also been working for at least six months. A total of 19 lay counsellors participated. The majority of the participants were women (n =15) and only a few men (n = 4).

Data collection

Data were collected from focus groups (Polit and Beck, 2012) in the clinic during working hours through semi-structured interviews. The researchers chose to collect data during working hours because the lay counsellors were only available during the day. A tape recorder was used by the researchers to record data and the interviews were transcribed verbatim. An interview guide was used to direct collection of data by the researcher. The research question - "*What are your experiences regarding HIV and AIDS care and support in Tshwane clinics*", was well understood by the participants. The researcher utilised various communication skills such as probing and listening to elicit more information. The participants promptly responded to the question while sharing their experiences openly and with confidence. Focus group interviews were conducted for 30-45 minutes at the clinics until saturation was reached. At the end of each focus group interview, the participants were thanked.

Data analysis

Before data analysis, all the transcripts as well as field notes were consolidated. The researchers commenced with data analysis immediately after the consolidation of transcripts. Data were organised, analysed and interpreted according to Tesch's method in Creswell (2014). Interviews were transcribed verbatim while data were organised and prepared for analysis, coded, categories and subcategories were formulated, description of subcategories, and interpretation of data was conducted. A few quotes were used in the presentation of results.

Ethical considerations

Permission to conduct the research was obtained from the University of Pretoria's Ethics Committee which granted ethical approval (reference number 117/2013), the Department of Health and the managers of the selected clinics. The purpose of the study was explained to the participants before commencing with the interview. Participants were made aware that participation was voluntary and they were not forced to answer any question if they were of the opinion that the question violated their privacy. The participants had the right to refuse to participate or withdraw without a penalty. Data collected from the participants were kept in a secure place to ensure confidentiality. The participants voluntarily signed the consent form after reading it, even without compensation. Participants were made aware that field notes would be drawn and an audiotape was used to record the interviews.

Trustworthiness

A criterion to ensure trustworthiness was used as suggested by Lincoln and Guba (1985). These include credibility, transferability, dependability, confirmability and authenticity (Polit and Beck, 2012). To ensure credibility of the study the researchers was engaged with participants for a period of six months to gain trust and rich information until saturation was reached. During the interview sessions, the researchers facilitated the interviews and made observations concurrently while listening to participants as they narrated the challenges they face. Following each encounter with participants, the researchers wrote field notes. The researchers used the member check strategy by providing feedback to participants in order to validate the authenticity and interpretation of data collected and further provided a summary of the information collected and presented it to the participants for comments. The study provided participants with sufficient evidence so that they believed the recounted events and accepted the interpretation as plausible (De Vos, Strydom, Fouché and Delport, 2011). Lincoln and Cuba in Polit and Beck (2012) state that it is the responsibility of the researcher to provide sufficient descriptive data. In this study, the researcher provided sufficient descriptive data to ensure transferability. Dependability is determined by the extent to which the findings of the study would be consistent if the enquiry is repeated with the same participants in a similar context (Polit and Beck, 2012). To enrich the dependability of data, the services of an independent coder were acquired to reach consensus on the results. In this study, confirmability was ensured with a thick description of data collection methods, recording of data into categories and subcategories and drawing conclusions on the findings.

RESULTS

The following categories were identified: financial constraints, lack of infrastructure, counsellors' morale and patient care followed by subcategories as indicated in Table 1.

Table 1: Categories, subcategories on experiences of lay counsellors regarding care and support for HIV and AIDS

CATEGORIES	SUBCATEGORIES
1. Financial constraints	• Late and non-payment of stipend • Improper implementation of signed contracts
2 Lack of Infrastructure	• Lack of space for counselling
3. Counsellors' morale	• Lack of recognition • Lack of motivation • Lack of support
4. Patient care	• Major role players in care of HIV and AIDS • Compromised patient care

The categories and subcategories were identified and supported by several quotes.

Financial constraints

Under financial constraints the following sub-categories emerged: late and non-payment of stipend and improper implementation of signed contracts.

Late and non-payment of stipend

The participants indicated that their main challenge in the care and support of HIV and AIDS patients is the fact that payments come late or they receive nothing at all. This was expressed as follows:

"Hmm we have a lot of issues as counsellors; ehh…The basic challenge is payments, even right now as we speak some people are paid and some are not paid since October last year (2013)" (FG2 participant 2).

"By the way we do not receive salary but stipend, no payslip, no medical, no sick leave……. If you are sick you see to finish. If you die your family and kids will only receive that monthly salary. That's it. No benefits" (FG1 participant 2).

The lay counsellors are dissatisfied due to late or non-payment of the stipend. The lay counsellors acknowledged that they volunteered to provide counselling services but they depend on the promised stipend as a source of income.

Improper implementation of signed contracts

The participants expressed that they signed contracts with the Department of Health, which stipulates terms and conditions of agreement but the agreement is not implemented as per contract which leads to emotional despondence.

"There are people who have signed contracts in October 2013, a contract that says we will be paid every month end and the contract is even expired but not yet paid, who is accountable for that. There are people who have been working for ten years and there is still problem till now" (FG2 participant 2).

"*We signed contracts with the department of health and the contracts do not follow the rules of a contract". The contract says we are working and we will earn R2, 500.00 every month and the very first month we did not receive anything and until three months lapsed* (FG3 participant 1).

Lack of Infrastructure

Lay counsellors complained about the lack of infrastructure such as limited space and rooms for individual or one-on-one counselling. Counsellors end up opting for group counselling which impacts on confidentiality and possibly inhibiting free expression of thoughts and feelings. Participants mentioned that group counselling was not as effective as individual counselling. In this category, lack of space for counselling emerged as a subcategory.

Lack of space for counselling

Participants noted that the lack of space to perform counselling affected patient confidentiality. The participants mentioned that:

"I can say we do not have rooms for counselling. We end up counselling them in groups and there is no confidentiality and some patients go back home without telling what they had in mind" (FG4 participant 2).

"Only three rooms and we are seven". "Sometimes if we have a bigger room like this one, we do group counselling. Because we have males and females..., one may like to ask question but cannot because he/she doesn't like the other one to hear what he is saying. They do not feel free" (FG 4 participant 1).

Lay counsellors were more concerned about the prevention of cross infection which could occur in a limited space. The participants expressed this as:

"When a patient coughs in a constricted room, we are infected by the infection from the patient because the room we are working in, is not well ventilated" (FG3 participant1).

Counsellors' morale

This indicates that infection control in a constricted space becomes difficult. Therefore, lay counsellors should take into consideration the ventilation of small rooms during home visits.

In this category, the following subcategories emerged: lack of recognition, lack of motivation and lack of support.

Lack of recognition

The participants emphasised a feeling of not being recognised as part of the health team. This was conveyed as:

"Basically our health department, our government do not recognise counsellors. What I see they do not take us seriously, because we are regarded volunteers and yet we are expected to come to work because we are called health workers, we do not have a place in the hierarchy... Recognition is a problem" (FG2 participant 2).

"We want to belong, belong somewhere with the NGOs or department of health. We are just in a space in the middle of the two. The NGOs transferred us to Department of health and the department also transferred us back to NGOs" (FG1 participant 5).

The lack of recognition stems directly from the lay counsellors' ambiguous employment status. It appears as though they believe they are not volunteers but health workers with the sole purpose of HIV and AIDS management. Furthermore, there is a misunderstanding as to who they are accountable to; whether the Department of Health or NGOs.

Lack of motivation

The researchers observed that there was a need for debriefing and that was not provided. Participants described their frustrations as:

"We do not go for debriefing. Whenever we go for debriefing we go straight to class. They will be asking us about HIV and what the patient are saying and nothing about debriefing.

When we go to debriefing, we are supposed to be enjoying ourselves and take out the stressors and also discuss money problems" (FG2 participant 4).

"When we get there (debriefing sessions) we want to relaxation activities. We are on our own, forget about the work challenges" (FG2 Participant 5).

Lack of support

The participants indicated that in trying to solve the problems regarding payments, they met resistance from their supervisors as well as the facilities' management. As such they resorted to strike action or a "go slow" as a way of expressing dissatisfaction.

"Eish, you know even the managers of the clinic are not concerned when we are not paid. They never ask whether the counsellors are paid. They never ask why we are not at work" (FG 2 participant 2).

"Sometimes when you complain about non- payment, they say 'ahh' these things of yours we do not understand them "(FG3 participant 3).

According to the researchers, lack of support and motivation could lead to subordinates' stress as was seen with lay counsellors. Managerial support though debriefing sessions was needed to provide a feeling of recognition.

Patient care

The participants remarked about the professionalism that should be displayed when dealing with a patient especially in HIV and AIDS cases. Health workers are obliged to be empathetic towards patients' needs including HIV. In this category, one subcategory emerged on the major role players in HIV and AIDS care, compromised care and compilation of statistics.

Major role players in the care of HIV and AIDS

The participants emphasised that they are major role players in the management of HIV and AIDS yet they are not recognised as such.

"We are the ones doing testing. We are the ones providing psychosocial counselling. We are the reason why patients adhere to treatment; why they cope with side effects. We are the reason why children are testing negative; the reason why pregnant women are taking treatment properly; ja we play a major role" (FG2 participant 1).

"I think we are playing a big role. For the fact that when we are not there the patients are returned back to come the next day, it means counsellors are here for that important task instead people are given appointments. The sisters also tell us that "when you are not there guys we are suffering" (FG3 participant 4).

Lay counsellors were aware of their role in the management of the HIV and AIDS epidemic. Their specialised role has formed an integral part of care and support.

Compromised patient care

The participants put across the fact that while trying to solve their problems related to remuneration, patient care is interrupted or rather compromised:

"Somewhere somehow, we stop working; strike; go to Jo'burg. In a way it means counselling stops. Even the sisters cannot do the work without us. Nurses end up compromising the on-going counselling. They only do adherence counselling, those who are receiving treatment the first time" (FG 2 participant 2).

"Even when the counsellor is not there, they just say the counsellor is not there and return the patient" (FG 2 participant 4).

"They are doing fast, fast move and that person does not want that. And even their response to the patient, ehh! Yes, let me say their attitude; they are not professional to this counselling and seriously so, and we are seeing those things" (FG 2 participant 1).

The above quotes indicate that patient care is continuously compromised due to the fact that on-going counselling does not take place.

DISCUSSION

Financial constraints

The majority of lay counsellors are facing multiple challenges regarding finance. These include salaries, transport and food supply. Black, Sprague and Chersich (2011) and Woolman, Sprague and Black (2009) state that the Department of Health contracted intermediary NGOs to manage and pay lay counsellors. It is deduced that the payment of counsellors is controlled by the Non-Governmental Organisations (NGO) rather than the Department of Health. Allegedly, this is the reason that the payment of the stipend is often late. Their employment is not well understood and who is responsible for paying them. It is this point that Black et al. (2011) further highlight that the ambiguity in employment status limits the counsellors' protection under labour laws.

Lack of payment in any organisation or institution is one of the main causes of stress as it emerged with the counsellors. Peltzer (2012) indicates that about 49,5% of HIV lay counsellors were not happy with their work environment including inadequate salaries (91,2%) and lack of training (68,2%). Papanna, Kumar, Shetty, Kulothungan, Poojary and Ballala (2013) state that counsellors in South India were not satisfied with the pay scale they received as it was not acceptable for their qualifications. This indicates that payment of counsellors is a serious issue in various countries. To remedy the lay counsellors' challenges, Schneider et al. (2008) suggest that for building a sustained and effective community health workers' presence in the South African health system would require, amongst others, improving the working conditions and basic entitlements such as leave and complaints mechanism of community health workers beyond the provision of a stipend.

Lack of infrastructure

In every primary health care service, lack of resources is a contributory factor towards ineffective service delivery. The lack of resources is a barrier and a concern in the management of HIV and AIDS (Mataboge, Peu, Chinuoya, Rikhotso, Ngunyulu and Mulaudzi,

2014). The shortage of resources; not only space but testing kits, treatment and others affect the management, care and support of HIV and AIDS. Legido-Quigley, Montgomery, Khan, Atun, Fakoya, Getahun and Grant (2013) refer to the lack of private space as a barrier to integrated HIV and TB management which indicates that privacy and confidentiality should always be provided to demonstrate respect and care of patients. These researchers further indicate that implementing HIV testing in TB services and vice versa, requires more organisational changes. This is particularly in terms of staff training and time; as well as alterations to physical infrastructure to make well ventilated private space for HIV counselling and testing. Vawda and Variawa (2012) further emphasised that the lack of space is related to a lack of adequate ventilation and ultraviolet light in many ARV facilities thus contributing to the spread of air-borne pathogens.

Poor infrastructure leads to inadequate rendering of services and the quality of care and support may be compromised because of the counsellors' dissatisfaction. Peltzer (2012) highlights that lay counsellors' job stresses emanate from inadequate facilities (67,3%), poor working environment (38,3%), lack of feedback on job performance and lack of supervision(31,7%).

Counsellors' morale

Lay counsellors had hoped to be recognised as part of the health system since they had been volunteering for a long period. Participation or involvement of lay counsellors in HIV Counselling and Testing (HCT) benefits the community. This is supported by Schneider et al. (2008) that several generations of AIDS interventions would not have been possible without lay counsellors.

Various researchers acknowledge the role of lay counsellors in HIV and AIDS care and support. This is evident during development of Community of Practice (CoP) with the aim of enhancing collaboration and capacity for health care workers in Tshwane district (Peu, Mataboge, Chiouya, Jiyane, Rikhotso, Ngwenya and Mulaudzi, 2014). The researchers realised the need for task shifting by including lay workers to support patients in complying with ART. Lay counsellors provide pre and post counselling, adherence and on-going counselling and therefore they are appropriate candidates to be involved in CoP in order to enhance continuity and sustainability of HIV and AIDS health promotion programmes.

A study conducted by Kabbash, Mekheimer, Hassan, Al-Nawawy and Attalla in Papanna et al. (2013) among HIV and AIDS counsellors, identified a lack of administrative support and unspecified working rules and regulations; a need for fixed job description as well as an improved working environment to ensure privacy and confidentiality. The aforesaid factors are sufficient enough to discourage a voluntary worker, in particular a lay counsellor. Furthermore, this might encourage counsellors to feel outright exclusion from the health system because they are not governed or controlled like other health workers. To boost the morale of the counsellors, Kerr, Grafsky, Miller and Love (2011) recommend training and debriefing sessions as well as increasing the feeling of successful achievement in one's work. The training, debriefing sessions and follow up thereof act as counsellors' recognition and the work they are doing. However, the success of this recommendation largely depends on counsellors being recognised in the health system and their performance rewarded appropriately.

Patient care

According to Black et al. (2011), lay counsellors prepare patients for ART regimens, counselling on adherence to ART regimens and on infants' feeding options. It was found that late payment of lay counsellors evidently affected negatively the uptake of HIV which remains the key challenge to performance of PMTCT services in South Africa. It is deduced that when lay counsellors are not available in facilities, the care and support of HIV patients is compromised. In support of the lay counsellors' role, Schneider et al. (2008) further state that community health workers, including lay counsellors, add value and meet new needs rather than simply substituting for professionals. Papanna et al. (2013) endorse that among the integrated counselling and testing centres, counsellors form the pillars and poles of the HIV/AIDS control programme.

The lay counsellors claimed that their contribution towards the management of HIV and AIDS was valuable, though the health authorities did not seem to recognise that. Rachier, Gikundi, Balmer, Robson, Hunt and Cohen in Papanna (2013) wrote a report suggesting that for voluntary counselling and testing to be effective, counsellors' views are crucial yet they are rarely consulted for their opinion. Hassim (2009) further supports that lay counsellors serve as the initial line of defence from which patients or clients obtain counselling services.

CONCLUSION

Lay counsellors expressed a high level of dissatisfaction regarding their working conditions. The results revealed that they play an important role in the provision of counselling and testing services. However, they are challenged by factors such as late remuneration of stipend or even non- payment. The working space is not adequate to allow for privacy and confidentiality. The lay counsellors are not recognised as part of the health system and lack motivation including lack of debriefing for emotional support. Lay counsellors are stressed by the lack of supervision and these factors have an effect on the low performance and low morale of lay counsellors. The quality of counselling and follow up of HIV patients is therefore compromised.

RECOMMENDATION

It was recommended that research should be conducted regarding the absorption of lay counsellors as part of the health workers in the Department of Health. This will assist with the provision of additional human resources because these counsellors are already trained and experienced with a primary focus of care and support for HIV and AIDS.

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