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Challenges and Coping Strategies of People Living with HIV/AIDS Seeking Health Care at Manhyia District

Ramatu Agambire* • Cecilia Ackon Ansong • Christa Osei-Mensah

Hospital, Ghana

Department of Nursing, Faculty of Health Sciences, Garden City University College, Ghana.

Corresponding author. E-mail: ragambire@yahoo.com.

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Abstract. HIV/AIDS has emerged as a global public health concern requiring a multidimensional response. It is estimated that approximately 36.7 million people are HIV-positive worldwide with more than 70% of them in sub-Saharan Africa. Adherence, follow -ups and counselling by extension are key components of prevention. People living with HIV/AIDS (PLWHA) require lifelong treatment and it is essential that health care services are organized in such a way that it promotes healthy living, long life and also minimize the spread of the disease. The aim of the study was to explore the challenges faced when accessing healthcare and the coping strategies used by people living with HIV/AIDS at Manhyia District Hospital. The study was a qualitative study and it used in-depth interview with semi-structured questions. Purposive sampling was used to select 10 people living with HIV/AIDS (PLWHA) accessing healthcare at Manhyia hospital. Data collected was analyzed using thematic analysis. The common challenges were financial constraints, emotional disturbance, fear of stigmatization and the side effects of drugs. Most PLWHA used coping strategies such as attending prayer camps, counseling usually from faith healers and diversional activities such as watching TV and attending social gatherings. The study recommends that health facilities should offer periodic education to patients on how to cope with side effects of the anti-retroviral drugs and also work with faith healers to promote adherence.

Keywords: anti-retroviral, coping strategies, challenges, health care, non-adherence, stigmatization.

INTRODUCTION

HIV/AIDS has emerged as a global public health concern requiring a multidimensional response. Since the beginning of the epidemic, more than 70 million people have been infected with the HIV virus and about 35 million people have died of HIV (WHO 2016). Globally, 36.7 million [30.8–42.9 million] people were living with HIV at the end of 2016. An estimated 0.8% [0.7-0.9%] of adults aged 15–49 years worldwide are living with HIV, although the burden of the epidemic continues to vary considerably between countries and regions. Sub-Saharan Africa remains most severely affected, with nearly 1 in every 25 adults (4.2%) living with HIV and

accounting for nearly two-thirds of the people living with HIV worldwide (WHO 2016).

Like other countries worldwide, HIV/ AIDS is present in Ghana. As at 2014, an estimated 150,000 people were infected with the virus. HIV prevalence was at 1.37 % in 2014 and was highest in the Eastern Region and lowest in the Northern Regions of Ghana (Avornyo, 2013).

Despite major advances and successes achieved in the last 10 years, problems related with access to antiretroviral medicines (ARV) still persist and tend to increase in many developing countries (Eholie *et al.*, 2012) where there is confusion between medical treatment

and faith healers.

Individuals with HIV/AIDS suffer from co-infections such as TB, diarrhea, dry cough and rashes to name a few due to their low immune system. Oftentimes patients think their ARV drugs are not enough to protect them and stop taking the drugs when they feel healthy or do not keep to medical appointments and only visit the hospital when they are critically ill (Anozie, 2011).

Poor adherence to antiretroviral medications and avoiding status disclosure to healthcare providers or sexual partners for fear of public stigma have contributed to increased morbidity, mortality, and accentuated disease transmission (Kumarasamy et al., 2007). When public stigmas are internalized, people living with HIV/AIDS (PLWHA) suffer from depression, anxiety, and poor quality of life (Lee et al., 2002). Investigators have identified both theoretical and practical ways to reduce the stigma that may be internalized by a person with HIV. The side effect of the antiretroviral (ARV) medication negatively impact a patient's quality of life and adherence to treatment (Agu et al., 2012). The main strategies patients use for coping with the side effects were those categorized under information-seeking, social supportseeking and positive emotion focused coping, but sizable a portion will fail to cope appropriately and thus, resort to non-adherence (Agu et al., 2012).

Besides the suffering caused by the disease, people living with HIV/AIDS (PLWHA) have other challenges to overcome including being stigmatized. (Herrmann *et al.*, 2013).

While most studies on HIV/AIDS often identify stigmatization as critical problems in the control of the pandemic, very few studies have focused on the possible challenges of accessing health care by sero-positives within a country where there are constraints in the allocation of resources for healthcare. The psychosocial aspects of people living with the HIV infection are largely ignored (MacPherson *et al.*, 2012). Stigmatization has persisted despite improvements in the quality of life and life expectancy (MacPherson *et al.*, 2012). If these challenges faced by PLWHA are not investigated by extension it prevents them from accessing health care which leads to an increase defaulters' rate, non-adherence, psychological stress and loss to follow ups (MacPherson *et al.*, 2012).

People with HIV often become objects of scorn, hatred, violence and death (Odimegwu *et al.*, 2013). Some people living with HIV and other key affected populations are shunned by family, peers and the wider community, while others face poor treatment in educational and work settings, erosion of their rights, and psychological damage. These all limits access to HIV testing, treatment and other HIV services (Stangl *et al.*, 2013).

The emergence of the HIV/AIDS epidemic has stimulated world bodies, scientists, traditional healers, and medical experts to try to find a lasting solution that will eradicate the disease (Agyir-Binn 2005). One

important aspect of HIV/AIDS infection that has received little attention in Ghana is sustained psychosocial support for PLWHA. Some families accept PLWHA whilst others neglect and ignore them at a time when they are physically weak, financially poor and emotionally distraught. This situation is not different from what other people with the condition are experiencing throughout the country and PLWHA at the Manhyia District Hospital is of no exception. The aim of this study is to explore the experiences and the coping strategies of people living with HIV while seeking health care at Manhyia District Hospital.

MATERIALS AND METHODS

Study Setting

The study was conducted at Manhyia District Hospital which is located in the Ashanti Region of Ghana. It is about 9km on the Kumasi-Mampong Road, and a quick 15 minutes' drive from Kejetia which is a central business place. According to the 2000 population census, Manhyia has a population of 19 729. The hospital serves a lot within its environs to travelers as well because of where it is located. The hospital can boast of about 220 staff who provide 24 hour services in the area of surgery, outpatient department, obstetrics and gynecology, laboratory services, PMTCT/VCT, maternal health services, oral health, eye care, ear, nose and throat services, public health services and adolescent-friendly services. The hospital is a major outlet for PLWHA to access healthcare and all can be attributed to the area it is located.

Study Design

An exploratory design was used in the study to provide in depth information on challenges and coping strategies of PLWHA. Explorative study design was used because the problem has not been studied in depth and in an attempt to gain insight into the topic, this design was chosen.

Study Population

The study population were individuals diagnosed with HIV/AIDS for more than a year and visiting the chronic care clinic for outpatient services and had defaulted at least once in the line of treatment. Clients who were seriously ill but met the criteria were excluded from the study

Sampling and Sampling Techniques

Purposive sampling technique was used to select ten

(10) PLWHA from the target population. This type of sampling was used to intentionally pick people that satisfy the inclusion criteria.

Techniques and Instruments for Data Collection and Analysis

Informed Consent was obtained from clients prior to data collection. In-depth interview was carried out using semi-structured interview guide. The interviews were recorded audio taped with client's permission and transcribed verbatim. Thematic analysis was used in analyzing data collected. The first phase of data analysis consisted of free-floating readings of the interviews, so that the researchers would be able to familiarize themselves with the material. For emerging concepts and themes, the authors coded the transcripts independently, using a standard definition for each theme derived from the data.

RESULTS

On the challenges faced while accessing healthcare, six sub themes were developed. Most of the responses were centered on accessibility to healthcare, privacy and confidentiality, interpersonal relationship, services rendered, side effects of the drugs and fear of stigma.

Access to healthcare was not a problem because of where the facility is sited, and they all alluded to the fact that healthcare was easily accessible to them and even if they did not live within the community getting to the facility was not a problem. Some also said they travelled to get there which was a bit difficult to reach. They live far away from the hospital and spend hours travelling to the hospital, which intend increased the cost of health care. Mr. E. A3 who had travelled a distance to hide his diagnosis from the community had this to say;

Mr. E. A3 commented that; Healthcare is not easy to get here, since I live far away from the hospital. I take three different vehicles which takes about an hour and 30 minutes to get to the hospital. Though I have a clinic in my area, but for fear of stigma, I prefer the one far.

confidentiality, On ensuring they all confidentiality was ensured in everything they discussed especially with the doctors and most of them preferred to discuss these issues with doctors than nurses especially if it is one on one with the doctor and then they are sure the details are kept confidential. Mr. A. D1 commented; All private matters are discussed with only the doctor in his office. Every detail is kept confidential. I was taken to the doctor's office and was asked to sit and the doctor engaged me in some conversation about a certain chronic disease that break down the body's immune system, which is deadly and has no cure but can be managed through drugs. After the talk, the doctor told me

the laboratory test showed i had HIV and that i should bring my wife and kids to be tested as soon as possible. Beyond this, i have always spoken to a doctor about my problems and don't talk much when the nurse is around.

On the interpersonal relationship between healthcare providers and the PLWHA, most of them preferred talking to doctors than nurses due to the negative attitude of some nurses. They however described their relationship with health providers as good.

Mr. A. D1 commented that; The healthcare providers relate well with me and they are very nice to me.

Mr. EA3 who reported a negative attitude verbalized that; I think they do not understand us. Sometimes they do not even heed to some of the things we tell them. I told them i was experiencing side effects of the drugs but they still gave me the same drugs. If the drugs are not changed this time, am not taking them again.

Most of them reported that they do not join long queues, but there were inadequate sitting spaces for them. Which meant one had to stand while waiting for his or her turn to see the doctor.

Madam J. A5 verbalized that; The waiting area doesn't have enough seats so we have to stand and wait for our turn.

Responses from respondent indicated that all of them experienced at least two or more side effects of the antiretroviral drugs. These side effects affect them in one way or the other which they said affects their quality of life. Most of them did little to manage these side effects since they are not educated on the side effects. Their complains about the side effects were usually ignored and they were always given the same drugs without helping them manage side effects

Mr. A. D1 whose symptoms had affected his work commented that; I am a driver. I feel sleepy and weak and this made me stop working since sleeping while driving is very dangerous.

Mr. EA3 also added; I feel drowsy, experience muscle pull, feels empty after eating and i'm unable to eat adequately and sometimes feels hot and feels something moving through my body after taking the drugs.

In an attempt to find out whether they were stigmatized and discriminated, it became clear that, only a few of them complained of stigmatization. The rest of them said the health workers treat them with much love and respect. However, for most of them their status were not known to anyone not even their spouses because they were afraid that other people who found out and may stigmatize them. A few however reported of stigma while on admission.

Mr. EA3 who was stigmatized during hospitalization said that; I have been stigmatized once; I fell sick and was admitted at the hospital and the nurses did not want to get close to me. They preferred attending to others than me.

Madam M. A6 commented that; I do not experience any

stigmatization and discrimination from the health care providers. But i haven't told any family member due to fear of how they may react towards me.

From these results, majority of PLWHA were faced with challenges such as living in fear due to stigmatization, non-adherence to medications due to their side effects, inadequate sitting spaces and negative attitudes from nurses. However, privacy and confidentiality was ensured among most of the people living with HIV/AIDS and healthcare was also easily accessible to them.

Coping after HIV/AIDS Diagnosis

In the quest to find out how people living with HIV/AIDS cope with their diagnosis while accessing healthcare, it is imperative to explore their initial reaction to the diagnosis and how they coped beyond the diagnosis, three sub themes were developed. These are diagnosis, their reaction on diagnosis and the coping measures used beyond diagnosis.

Diagnosis and Initial Reaction to diagnosis

In an attempt to find out how they got to know of their HIV status, some said they got to know of it when they went to the hospital for antenatal clinic. Others too were diagnosed after series of ill health.

Mr E. A2 commented; I got to know of my status after a series of ill health and excessive weight loss, a pharmacist friend of mine suggested i do HIV test, which came out positive.

Narrations from respondents showed a wide range of experiences that included the following; sadness, shock, anxiety, disappointments, disbelief, loss of hope and feelings of hopelessness.

Madam O. G2 commented; I did not want to believe it. It was one of the saddest news i had ever heard. I felt like killing myself. When the news was disclosed to me, i suddenly felt my life has ended and as i sat i started shivering because i didn't believe I could get infected.

However, one of the respondents indicated he was neither worried nor shocked at the time he was diagnosed since he led a promiscuous life during his youthful age.

Mr E. A2 added; I wasn't surprised at all because during my youthful age, i used to have lots of ladies in my life and i was not taking any safety precautions during sexual intercourse.

Coping Measures

They all had ways in which they coped after they had been diagnosed and mostly after accessing healthcare

they relied on these coping strategies as their source of strength and these ranged from spirituality, family support and self-management.

Madam S. R4 bemoaned; I was only able to cope by believing that God is my comforter and that it is the will of God that this should happen. She tries to take her mind off what is happening to her by watching television, listening to radio but most often she prays to GOD for healing.

Madam D Commented; My family is my only source of support. I have not been able to tell them i am HIV positive but am sure they will find out and when they do my only source of support will be gone. I can pray to God that they don't find out.

Impact on life and relationship

In the pursuit to find out the impact of HIV on their lives, most of them reported that they have been negatively affected causing them to lose a lot of money since they were unable to work again. This caused financial difficulties for family members, however a few of them said the diagnosis have not really impacted negatively on their lives since no one is aware of their status.

Mr. A. D1 commented; It has affected me negatively, especially my relationship with my family and my finances. My wife was tested and the result showed she was negative and this brought about divorce. Also i am not able to go to work since i have become weaker and weaker. At first i was lonely but now i'm used to it and i'm able to stay alone.

Madam O. G2 commented; It has no impact on my family and relationship with others since no body is aware of my status. I have not even told my spouse. All they know is that i take medication what it is for no one knows. I now want to pay more attention to my children and how to cater for them.

Support and Availability of social support system

Most of the respondents mentioned that their husbands or wives provided them with emotional support by encouraging them to take their drugs and financially by assisting them to pay for their hospital bills. Others also added that their children helped them with household chores and also accompanied them to the hospital for their medication.

Madam R. A4 commented; My husband is the only one supporting me financially by assisting me to pay my hospital bills, also encourages me to take my drugs on time and prays with me.

All of them did not know or had never heard of any social support organization that offers help to PLWHA but were sure they could rely on their family and church for

support if need be. They mostly alluded to the fact that they will skip an appointment for medication if they had to attend a prayer meeting. According to them each time they were in the hospital it reminded them of their status and this usually made them sad unlike being in the church where no one knows.

Mr. EA3 also added; I do not know of any HIV support organisation. Supposing i did, the kind of support that i will need is financial and psychological support since i'm not working at the moment and my wife too is not working.

Most of them also reported that they received support from their family and friends. However, a few of them disclosed that they had interchanged their HIV/AIDS status with other chronic illness and if they found out about their status the support will cease. A few also reported that they support themselves since their families were not around to do so.

Mr E. A2 commented; I occasionally call on my friends for financial support, and they send me mobile money of 50 to 100 cedi for my upkeep. Also, a pharmacist friend of mine, usually gives me some food supplements to help with my condition.

Madam S. R4 who has not disclosed her status commented that; Family, friends and co-workers are not involved in my care since i haven't disclosed my status. I won't disclose my status because of the fear of stigmatization.

Madam O. G2 also said; My husband is the only one involved in my care. I haven't informed my friends because i'm scared of stigmatization.

DISCUSSION

For most PLWHA, confidentiality was not a problem as they discussed issues with the doctors, and all matters discussed were kept private but a few times in which they had the nurses around most of them were not comfortable discussing issues of their status. Although other studies done did not reveal the same. In a study by Dapaah & Senah (2016), most of the respondents accused some health workers of a breach of the concordat during counseling. This difference could have come about because in their study health workers were categorized as one and that did not leave room for them to determine if any category was trustworthy. For the current study a lot of trust was placed in the hands of the doctor and the patient was ever willing to discuss any issue with him. This is seen in the excerpt of Mr. A. D1 who commented that; All private matters are discussed with only the doctor in his office. Every detail is kept confidential. I usually beg the doctor to excuse the nurse if need be or i don't talk at all.

Although on the whole they commended the attitude of health workers, a few reported negative attitudes from

nurses. And preferred not to discuss private issues with them.

Beyond diagnosis, they expressed shock; they did not believe they will ever contract the disease and as such found it difficult accepting their status. Their reaction ranged from shock, suicidal ideation to extreme sadness (depression).

I did not want to believe it. I felt like killing myself. When the news was disclosed to me, i suddenly felt my life had ended and as i sat i started shivering because i didn't believe i could get infected.

This gives credence to a study by Agyir-Binn (2005) among PLWHA which revealed that, mostly, people's reaction to the diagnosis run through denial, acceptance, mixed feelings, fear and worry.

While battling these feelings, PLWHA are expected to cope with the disease while they try to face their challenges. In a study by Famoroti *et al.*, (2013), it reported that 45.8% of the respondent said they experienced discriminatory practice. This same study reported that a sense of stigma manifest itself when the patients have to interact in social settings or workplace where their diagnosis is known. So for a lot of patients, it was better to keep ones' status a secret and avoid stigmatization. However, within health facility, only a few complained of stigmatization when hospitalized or accessing care. The rest said the health workers treat them with love and respect but they were sometimes afraid that other people may find out and stigmatize them.

In this study, most of them reported that HIV affected them negatively causing them to either lose or guit their jobs thereby losing a lot of money. Their greatest fear was someone knowing their status at work and stigmatizing them or informing others. The impact was mostly financial difficulties and family problems since most could not explain to their spouse the reason they were always sick. However a few did not report of negative impact on their lives. These corroborates with a study by Kumarasamy et, al.(2007) which reported that HIV negatively affected individuals in their productive years and hence places considerable financial strain on household trying to pay for healthcare cost while making up for lost wages. For PLWHA, coping strategies used ranged from believing in God, looking up to their children and using diversion therapy such as watching television. These were also highlighted from a study conducted by Mwale (2006) in which for individual participants, coping meant relying on a higher being and in many cases God, to provide hope, trying to help themselves by doing work and caring for their children. But for his study it involved much more and sometimes included; disclosure of HIV status, projection, obtaining spiritual support and mutual support among PLWHA (Adevemi and Ademilua, 2012).

Madam S. R4 bemoaned; I was able to cope by believing that God is my comforter and that it the will of God that it happened. She took her mind off by watching

television, listening to radio and prays most often.

For most PLWHA in Ghana, they receive help from their family and friends. However, a few of them disclosed that they had to interchange their HIV/AIDS status with other chronic illness to be able to get support. A few also reported that they support themselves because they had not disclosed their status to anyone. This however was different in a study by Adeyemi and Ademilua (2012) where family which is the agent of socialization was dissolved due to the presence of the disease within the family and thus most PLWHA rely on the church and other institutional bodies as their form of support. The reasons for this could be because their HIV status was known by family members.

It however gives credence to findings from a study conducted by Nicholas *et al.*, (2007) in which the family was mentioned as the major source of support. Some of the participants received help from multiple family source and others from a single-family source. Even where a family member rejects the PLWHA, other steps were taken to care for him/her. In situations where the HIV status of the participant was known, majority of the family members continued to help him/her.

This is seen in the extract from Madam O. G2's words who said; My husband is the only one involved in my care. I haven't informed my friends because i'm scared of stigmatization.

Most PLWHA in this current study had no idea of the existence of any social support group that could offer them assistance when need be. They have never been told about it and as such they rely solely on family members when need be. According to Robinson et al., (1990), social support for PLWHA should include housing, financial assistance, support for physical and emotional needs and day care centers where they can share their experiences and get support. Other services included were transport, counselling and support, home loans, hospital discharge co-ordination and hospice. Agyir-Binn (2005) study also revealed that the type of support received from the support groups should be in the form of financial support, emotional support, assistance with basic needs (food, clothing, shelter), social (taking care of their children), medical and spiritual support. All these tend to improve the quality of life of people living with HIV and as such increase their life expectancies (Agyir-Binn 2005).

The study recommends that social support should be made available to PLWHA and the benefits explained to them, help them access such help when need be. Also, Nurses within the facility will need to improve on their interpersonal relationship since they are the first point of contact for the patient so PLWHA can trust them and make them know their problems. Furthermore, PLWHA need a lot more education on the side effects of the drugs, as this will help reduce the defaulter rate and also improve adherence. Finally, spirituality plays a crucial

role in the decision of PLWHA to either access healthcare or not and as such the churches can be used as an avenue to demystify HIV and reduce stigmatization. A lot of patients could not disclose their status to their partners and immediate families for the fear of stigma.

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