

Stigma in Access to HIV Treatment in African Settings: The importance of social connections¹

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Abstract

Access to antiretroviral therapy is desperately needed in Nigeria. Increased access to anti-retroviral therapy for HIV treatment contributes to improved quality of life and reduced health care costs. It may assist in reduction of stigma and risk of HIV transmission. Although a lot of global funding has been mobilised to improve access to HIV treatment, many people in Nigeria still do not have access. The HIV treatment access rate in Nigeria is 16.6%. It is often assumed that with the provision of antiretroviral therapy, patients will readily access HIV treatment. However, as this grounded theory (GT) study suggests, *stigma* stands out as a major barrier to HIV prevention and treatment services in Nigeria. The main concern of the participants that emerged in this GT study was the fear of different types of stigma that stand as barriers to access. *Self stigma*, *familial stigma* and *community stigma*, *institutional stigma* and *organisational stigma* surfaced as issues that influence access. The participants were also able to overcome stigma and other barriers to accessing HIV treatment through the use of social connections. *Social connection* emerges as the core category of this theory. The core determinant to engaging with social connectors is the type of disclosing strategy utilised by the research participants. The social connection theory on access developed from this study suggests that although stigma poses a major barrier to HIV treatment, social connectors can play a major role in supporting the patient in overcoming barriers to access HIV treatment. Social connectors were identified as trusted acquaintances that influenced how and

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when HIV patients access treatment. I therefore argue in this paper that in African settings, social connectors should be targeted in access programs and not just the individual patient. The theory may be adapted for other diseases associated with stigma, such as leprosy or mental illnesses. It may also be relevant for African patients living in western or non-African contexts or in contexts within developed countries where there is strong social capital.

Introduction

Human Immunodeficiency Virus (HIV) infection is a global health issue that affects 33.4 million people worldwide. Sub-Saharan Africa bears the main brunt of the epidemic accounting for 67% of the HIV infections and contributing to 75% of all AIDS death in 2007 (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2009). With a population of 140 million and a HIV prevalence rate of 4.4%, Nigeria has the 3rd largest number of People living with HIV/AIDS (PLWHA) in the world (UNAIDS, 2009). The impact of an unchecked HIV epidemic include increasing number of AIDS orphans, increasing funeral costs, loss of time and resources caring for the sick, reduced economic productivity and stigmatization of those infected and affected by the HIV virus (Otur, 2006; Tindyebwa, et. al., 2006).

With the advent of anti-retroviral drugs (ARVs) for HIV treatment, people infected with HIV infection are able to live longer and have better quality of life (Alonzo, A., & Reynolds, R. (1995). However, despite a lot of initiatives, many PLWHA in Nigeria still do not have access to ARVs (POLICY, 2004). Although there are currently about 215 ARV treatment sites in Nigeria, it is estimated that only 16.6% of the 550,000 people who require ARV treatment are actually on the drugs (United Nations General Assembly Special Session, [UNGASS], 2007).

This GT study discovers that stigma still remains the main concern of PLWHA who access ARVs in Abuja, Nigeria. Unlike most diseases, the issue of stigma surrounding HIV infection provides a uniqueness that makes it difficult for patients to access treatment (Parker & Aggleton, 2003; Castro & Farmer, 2005). The need for theoretical development in HIV

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studies is buttressed by Attawall and Mundy (2003) and Abadia-Barrero and Castro (2006) who assert that there is a desperate need for theoretical tools to investigate stigmatization within social processes.

Methodology

The GT methodology was used for this study. It is an approach in research where data are collected and used to generate rather than verify theory about a group of individuals within a social setting (Glaser & Strauss, 1967). The primary source of data collection was through semi structured interviews. The interview site was in Abuja, Nigeria. This location was selected because it is a multicultural setting and has a high HIV prevalence rate of 8% (UNAIDS, 2006). Ethical approval was obtained for the study from the Research Ethics committee of Queen Margaret University, Edinburgh, Scotland, United Kingdom.

Thirty HIV positive patients who had attempted to access HIV treatment were recruited through a National HIV support group and interviewed. Data collection took place over 6 months (February 2009 to August 2009). The research instrument used was an interview guide. The interviews were adapted as necessary for the participants' need to take a break or to allow a close associate to support them during the interviews. Theoretical sampling was employed whereby participants were recruited who could provide more information to the emerging social connection theory.

Four stages of analysis were undertaken in this research. These are transcription, open coding, selective coding and theoretical coding. The author conducted all the interviews and analysis of the data. Throughout the course of the research, field notes, theoretical memos and reflective memos were kept to keep track of the ideas emanating from the research.

Transcription. The interview data was collected with the aid of a digital recorder. Field notes were taken and the audio recordings were transcribed. The transcription was not done mechanically. As I began to transcribe, I noticed concepts that had not been apparent while I was doing the interviews. I started having successive series of eureka moments that

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guided the analysis. It was a pleasurable experience as concepts began to emerge from the data. This kind of experience has been termed 'the drugless trip' (Glaser, 1998). The term 'transcoding' is developed to describe this innovative technique of transcribing and coding simultaneously. Each code developed during the transcription also had a corresponding memo that provided information on the theoretical ideas underpinning the codes, in a process termed 'transmemoing'. Behind these conceptual labels is the application of standard Classic Grounded Theory (CGT) technique to the non-classic GT (Qualitative data analysis) procedure of transcribing recordings of interviews. Within the remit of this doctoral research, it is difficult to do a 'pure' CGT (such as not transcribing or not using the computer) because of the need to meet departmental requirements. Attempts were made to overcome this by drawing on the simultaneous property of CGT in transcribing and coding/memoing simultaneously (Glaser, 1998:15). Transcripts were transferred to Nvivo8 computer software for detailed analysis. The transcripts, codes and memos were also printed out of the computer and sorted manually.

Open coding. In this process concepts derived from the analysis are labelled and categorized. Each category was delineated in terms of properties and dimensions. During open coding, an open mind was maintained as I read through the data. Different texts were labelled with relevant codes as depicted by the data. Reading through the data and thinking about what it is saying, allowed different concepts begin to emerge from the data through the process of subconscious processing (Holton, 2007). Constant comparisons were also undertaken. Different incidents within the same transcript were compared with each other. Incidents in later transcripts were also compared with incidents in earlier ones for similarities and differences.

Selective coding. In this process, a core category was identified and systematically related to other categories. The core category is the central phenomenon of interest that links all the other categories (Strauss & Corbin 1990; Cresswell, 1998; Holton, 2007). Relationships between categories are refined and developed. Categories are then integrated

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together. In selective coding, the most significant codes are used to sift through large amounts of data with the aim of determining as much information with regards to the properties and dimensions of these codes (Charmaz, 2006). Codes that could be merged to explain higher level concepts are then organised into categories. As codes are selected, a code is identified that is central to the analysis and links all the various codes together. This is called the 'core category'. In this study, *social connection* was identified as the core category that linked the various codes together.

Theoretical Coding. The last stage of the analysis is theoretical coding. When the core category is identified, it is systematically related to other categories. Relationships between categories are refined and developed. Categories are then integrated together using theoretical codes (Scott, 2008). Theoretical codes specify the possible relationships between the different categories that have been developed from the selective coding (Charmaz, 2006). In other words, they integrate the fractured theoretical story back together again (Glaser, 1978:72). The theoretical code that emerged from this research was based on the relationships implied by the research data (Glaser, 1978, Holton, 2007). The theoretical code used in this study is the 'stages theoretical code' (Glaser, 1978). A GT was then developed that is grounded in the data. The GT tests of fit, relevance (grab), modifiability and workability were also applied on the theory (Glaser & Strauss, 1967; Glaser, 1998).

Fear of Stigma as a Main Concern

Stigma stood out as the major barrier to accessing HIV treatment in this current GT study. There were other barriers to access discovered including poverty, lack of political will, religious/spiritual influences, poor health care service and lack of functional health care facilities in the rural areas. The role that these factors play on access to ARV therapy is beyond the scope of this paper. In this paper, I focus largely on stigma and the *fear of stigma* which was discovered to be the main concern of the participants. Goffman (1963) suggests that for a person to be stigmatised, the person needs to have a discredited attribute. The stigma is brought about by the discredited attribute that is socially constructed as

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being deviant by the mainstream society.

This stigma you are seeing is a big barrier oh! ...The stigma in the village and community is very high...The stigma was so high. The stigma even makes some people not to access their drugs.'(Patricia).

The fear of stigma and other obstacles to accessing ARVs are dealt with mainly through different types of disclosure / non-disclosure to social connectors that enable them overcome the access obstacles. The fear of being exposed to the community following awareness of the diagnosis stops people from accessing ARVs. It is the fear of HIV stigmatisation that may actually cause more people to die than the actual presence of HIV. The fear of stigmatisation causes the patients to have stress, isolate themselves, lose appetite and not feed well. This exacerbates the whole disease process and leads to death. It is fear that stops people from accessing treatment. The fear of seeing a friend or relative at the health care centre who then knows of their diagnosis is very great.

In order to tackle the problem of stigma, it is important to have an accurate conceptualisation. A good theoretical framework could serve as a foundation for an effective program to tackle stigma. The absence of an effective theoretical framework that serves as an evidence base for stigma reduction strategies is a major limiting factor in the fight against stigma (Jewkes, 2006). In this current GT study it is argued that stigmatisation occurs as a typology along different concentric levels as the patient attempts to access treatment.

So many people are afraid of stigmatisation and they don't want to see their family members and they don't want their friends to know that they are accessing such a treatment.

But that fear...because if a Nigerian is seeing you, because there is a sign board...Even when I go there, ... I will be thinking if I come down from the lift and somebody will see me.

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The fear of people finding out and spreading rumours with the consequent stigmatisation is very real. This fear is what makes patients to try other alternative therapy such as herbs. The herbal practitioner usually engages the patient in psychological therapy. The herbal practitioner takes cognisance of the patient's belief in God and the belief in the spiritual aetiology of HIV. This is in contrast to the local ARV centre where confidentiality is destroyed by the mass treatment of HIV patients in a secluded area.

...So, when em this girl, I've known her for some time. She lost her husband. We've been in committees. Other committees in the church... But, one day she was so surprised that I met her at the hospital and she was about to access her drugs when I came in... There was nothing she could do.

Due to the large number of patients being seen at the ARV centres, the health care workers do not have enough time to spend with patients. The physician often does not have the luxury of time to discuss social or spiritual matters. The discussion is often technical and focusing on laboratory tests and patients symptoms. Patients are seen quickly and in some cases, mechanically.

In this GT research study, different forms of stigma were found to stand as barriers to access. These occur in a typology and include *self stigma*, *familial stigma*, *community stigma* and *organisational stigma* (Figure 1). These are related to the 5 main stages of access identified in the study. During each of these stages, the patient may experience one form of stigmatisation or the other. The role of *social connectors* is crucial in helping them overcome these barriers.



Figure 1. Oтуру's typological stigma framework

Self stigma refers to the state whereby a patient feels that everyone is aware of his/her diagnosis and attempts to isolate himself/herself. The patient may experience emotional turmoil, fear, depression, anxiety or other emotional problems. It is critical that support from the health and social services be available to the patient as he/she weighs available options.

Isolation... I can isolate myself because I will begin to look at everyone passing believes that I'm HIV positive or people are discussing about me. Somebody begins to isolate himself. He begins to dissociate himself from people when they are doing something.

Familial stigma connotes stigmatised reaction that emanates from people familiar to the patient. These could include family members or friends. It is often assumed that people familiar to the HIV patient will readily support the patient. People familiar to the patient may stigmatise or

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dissert the patient. They may also detract the patient from accessing ARVs so that other people do not know of the HIV diagnosis. Post Diagnostic Violence occurred following disclosure to family members. This connotes domestic violence on the HIV positive person following disclosure of his/her HIV status.

When I left my husband, I did not just leave because of the HIV... because at a point I was like a problem to him and every day beating, beating. The last time I left was because he beat me to coma. I was in coma. So, when I got up, I was looking at myself as a ghost. I said 'Ah ah! So it's true that if you are dying you will know but you can't just help yourself.

These suggest that unless members of the family are targeted in ARV access programs, they could actually provide emotional or physical harm to the HIV patient.

Community stigma occurs when the community discriminates against the patient. It could occur in the neighbourhood as neighbours refuse to buy wares of PLWHA. It could also occur in institutions. Institutional stigmatisation is differentiated from organisational stigmatisation in that policies within the institution are purposely set to discriminate against a HIV positive person and reduces their life chances compared with persons who are HIV negative. This has been noticed in commercial organisations such as banks in Nigeria that make it mandatory for staff to be tested for HIV/AIDS before they are employed.

The only area I have problems with HIV is...I begin to see that when people want to go for scholarship, they begin to ask them to come and test for HIV. So does it mean that if you are infected in this country, they don't give you scholarship again...No bank employs you when you are infected.

Organisational stigma emerged as an issue that prevented patients accessing treatment. Due to the nature of vertical funding, the HIV treatment sections of hospitals are placed in a different geographical location from the mainstream hospital. When other patients see anyone going to the 'HIV centre' for treatment, they assume that they are HIV positive.

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This also occurs when certain 'HIV days' are set aside for treating HIV patients. This leads to an inert form of stigmatisation. Nevertheless, the impact is real in stopping some people from accessing treatment.

I remember specific days are given to see people who are HIV positive in almost all the hospitals. On that particular date, you find out that most other patients feel reluctant to go to the hospital...You know these are HIV people... if you go to national hospital, they are a complete section you have for HIV.

Projectory stigma also emerged as a concept. In this case, the family and friends of a person known to be HIV positive is stigmatised even though they may be HIV negative. One of the participants recounted how in one school, his children were segregated from other children because a rumour went out that he was HIV positive. This type of stigma is similar to Goffman's (1963) courtesy stigma. It could also occur with health care workers that work with HIV positive persons. Health and social staff that work with HIV positive patients could also experience projectory stigma as people feel that they are helping HIV positive persons because they too are HIV positive.

My son was already in school, he was given a single long bench alone to sit.... All the others were sharing 6...7 to one bench but my child was given one.... You see?

Disclosure to Social Connectors

Different forms of disclosing strategies emerged from the study. Due to the long incubation period of HIV infection, the disease is not visible until it progresses to AIDS. Hence, it is possible for the patient to hide the diagnosis. However, in order to access treatment, the patient has to confide in or disclose to someone. This disclosure however, makes the patient vulnerable to stigmatisation as evidenced by discrimination by those that he/she discloses to. In other words, disclosure effectively moves a person closer from the state of being discreditable to the state of being discredited. Notwithstanding, disclosure is useful if the patient needs to access ARVs. The patient who because of fear of stigma

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refuses to go for treatment ultimately enters the stage of being discredited. Thus, ARVs can help a person from being discredited. However, the person still remains discreditable because of the continued presence of the HIV infection in the body.

Selective disclosing refers to the strategic disclosing of HIV status to people who will support and not discriminate against the patient. This is often a difficult decision to make. In order to disclose, some of the participants engage in 'stigma testing'. Issues surrounding HIV are discussed informally and the responses of the potential confidant are gauged. If the responses are discriminatory, then the patient will not disclose. However, in most cases, there was no rational strategy about who to disclose to. Usually, participants disclosed to their spouses or partners. Others disclosed to religious leaders or close family members.

Supportive disclosing. This involves informing a friend, religious leader or close relative was trusted for emotional support. With supportive disclosing, there was no rational criterion that was used. The basic ingredient appears to be trust. Some patients decided to disclose to their partners, while others preferred to disclose to strangers who could help them access treatment.

Compassionate non-disclosing. This refers to the non disclosure of the HIV status to very close family members such as parents because of the emotional trauma that such disclosure may have. Some of the participants are held in high regard by their parents. They feared the loss of respect from their parents and the shame of being diagnosed with HIV. Some of the participants preferred to access treatment at a location that is far from where they live so that people close to them do not know about their HIV status.

Open disclosure. This was a strategy utilised by people who had high self esteem and felt that they should not be ashamed of their HIV status. This often involves going on national radio or television programs, campaign rallies and openly disclosing their HIV status. Although it could be argued to be empowering, it also opens the door widely for stigmatisation. One of the participants who 'openly disclosed'

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was barred from having any contact with her sister's family. She expressed regret at having openly disclosed. Another participant who openly disclosed was forced to resign from his political position since he was said to be 'weak' in contracting HIV. Shocked at the familial and societal reaction to open disclosure, most of the participants tend to use other forms of disclosure.

Indirect disclosing. The patient leaves clues about the diagnosis but does not overtly disclose his/her status. This may include leaving hospital appointment cards openly for everyone to see or asking children to bring their bottle of ARVs so that they can take their medication. If or when the disease begins to manifest in form of signs (weight loss, rashes) and symptoms such as chronic fever, the patient is forced to look for treatment of these ailments. The patients usually disclose to a social connector that can link them to where they can access treatment.

The findings of this GT study are also in agreement with those conducted by Apinudenchai et al. (2007) in Thailand. They suggest that disclosure of HIV status to the community could lead to increased stigmatisation. Who disclosures are made to and how they are made can potentially increase or reduce HIV-related stigma.

The different disclosure strategies discovered in this GT study are reminiscent of Glaser and Strauss' (1965) awareness strategies discovered in their seminal work on awareness of dying. However, in this GT study, it is not 'awareness of dying' that is as much of an issue the 'fear of stigmatisation.' There are some links however, in that the fear of stigmatisation emanates from the awareness of the society of the HIV diagnosis. In a similar GT study examining the way physicians communicate with patients to enable them adhere to HIV treatment, Barford (2007) argues that physicians are able to motivate patients to adhere to treatment when they 'de-shame'. HIV patients in this current doctoral study do feel shame of diagnosis. Due to this shame, some of the patients decided not to disclose to close relatives such as parents or siblings. Instead, they preferred to disclose to strangers who helped them access treatment. The core emotion that stops participants from accessing treatment is 'fear'. In order for

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social connectors to help, the patient needs to disclose to them using different disclosure strategies.

A Theory of Social Connection

The social connection theory suggests that in resource poor settings, people access HIV treatment following support from social connectors who encourage them to access the health care service. This support may be through the provision of information, encouragement and counselling, informal connections, giving 'notes' or letters. Social connectors help patients overcome treatment accessibility issues which in turn are caused by fear of stigmatization or shame.

For the purpose of this paper, a social connector is a social actor who is able and willing to connect the patient to a health care facility where they can have access to treatment. I suggest that the patient passes through some phases, with each successive phase building on the former till the climax of access is achieved. Most of the participants had to confide in someone that they could trust. The social connectors vary in terms of their social function. Individual social connectors could be family members, friends, religious leaders, politicians, or health care workers. Social connectors could range from very close confidants to complete strangers. These social connections are very important to help the patient overcome different barriers such as cost of transportation, lack of knowledge and fear of stigma.

Institutional social connectors

There is a thin line dividing individual and institutional social connectors as the individual social connectors often are part of a wider institution. Amongst the religious institutions that supported PLWHA, the Catholic Action Committee on AIDS stood out as being very active. Also active were the Redeemed Christian Church of God. The religious leaders were very useful in supporting members to access treatment. However, some religious institutions stood as barriers. In some churches, members were urged to pray instead of taking the ARVs. In others, patients were discriminated against by their church members. Discrimination took on different forms, ranging from exclusion from the church, open

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announcement of the HIV status to members of the congregation, to refusal of marriage of HIV positive couples. These suggest that much work is needed in providing religious institutions with knowledge about HIV. Other civil society groups help support patients to access HIV treatment. Of particular importance are the roles of community support groups. Some of the participants gained access after being introduced to the right procedures by a member of the Network of PLWHA organisation in Nigeria.

Social connection tools

The use of social connections tools, made it easier for some people to access treatment. These include notes, letters and phone calls. Note giving is a common influencing tool used in Nigeria. An influential person writes a request on a small sheet of post it paper, complimentary sheet or complimentary card.

It is my sister. That my younger sister. She works there... She is em. She is with the house of rep.

She gave me referral (note).

A letter is a more formal approach to helping people have access to treatment. The letter is usually written from a reputable organisation that knows that the health care centre concerned should have enough resources to provide access to treatment.

Then the doctors were not ready to give me drugs again because they felt I have done shakara (showed off) for them. (giggle) That is why I had to come to the network(of PLWHA in Nigeria) to get a letter. With that letter, they attended to me quickly.

A phone call can help facilitate access although it does not appear to be very common. One of the participants admitted that she was given access to the life saving drugs after her physician made a phone call to a colleague who was conducting a research trial on a new antiretroviral drug.

'So he phoned the woman... The following day, I went to the hospital. I saw the lady. Immediately the lady saw me, she felt sooo, so you know, so sympathetic.

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She said there's nothing we can do. She just registered my name. So, everything was free.

Social connectors can directly intervene by following the HIV positive patient to the ARV centre to access treatment. Family members and close friends and other social connectors can play a key role as 'facilitators' that support patients to access HIV treatment. However, they could also serve as 'detractors' who stand as a barrier for people accessing treatment through discriminatory behaviour. For example, one of the participants was advised by family members to use herbal medication instead of going to the ARV centre. With the right policies and strategies in place, these family members could serve as social connectors who directly assisting them to access the service or providing them with support and information on how to access treatment.

Stages in the access continuum

In order to access treatment, the patients have to pass through different successive stages to access treatment. These stages are hereby outlined.

The stage of non desire

The patient often passes through a stage of contemplation and guilt following exposure to high risk behaviour (such as unprotected sexual intercourse). This prompts the patient to do the HIV test. When the patient starts developing symptoms that are non responsive to medical treatment, they start thinking of doing the HIV Elisa test. This is followed by a stage of affirmation, when the HIV test is done and the result is positive. There is a stage of denial whereby the patient refuses to believe the HIV diagnosis. There is the stage of reaffirmation, when the HIV test is redone or some other confirmatory test (Western Blot) is done to confirm the HIV diagnosis. This is followed by the stage of emotional turmoil. The patient is often distraught with the diagnosis. During this stage, the patient may pass through bouts of self stigma, isolation, anxiety or depression. He or she may try to reject the diagnosis. Those that are religious will attempt to use faith to fight the infection. Usually, there is no desire to access treatment because of the lifelong implications of taking ARVs. During this period, the

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patient may then enter into the stage of disclosure. The patient has to make a decision as to who to disclose and when. Depending on if the disclosure is made and to whom it is made, the patient then follows some other main stages. He or she may receive social connection support or religious support or may be advised to try alternative remedies.

The alternative access stage

At this point, the patient tries various alternative treatments. These could range from spiritual treatment such as prayers and incantation, to using of local herbs, to using of organised herbal products from Chinese companies or food supplement companies. The social actors involved at this stage could range from the traditional pharmacist, the herbal marketer, herbalist or pastor of a church. Forever living products ranked high as a product that was used as an alternative to ARVs. Others used local herbs. When these fail, then the patient begins to look for pharmaceutical treatment from the organised health care system.

They said the man used to (giggles) that has a cure for HIV. But there is no any cure. If you go, they will give you leaves. You will go and cook. You'll cook, you'll drink and you'll bath. I took it for many years.

The stage of desired access

It is at this stage that the patient attempts to get information about how and where to access antiretroviral treatment following failure of the other alternative treatment regimes. Usually by this time the disease would have progressed. Friends and relatives may be commenting that the patient is losing weight or looks ill. It is important that these social connectors support the patient at this stage to access treatment. Prior to 2004 when the ARVs were made free, people passed through a lot of problems before they could access the drugs.

It was a hell even to put your name on the list. It was a hell. Some people passed through hell before they accessed the ARVs. (Patricia)

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Realised access stage

During this stage, the patient passes through the hurdles of laboratory tests and hospital bureaucracies to access treatment from the medical centre. The limiting factor is the ability of the patient to get a HIV positive laboratory result and a CD4 count of less than 200 cells. The patient may then start taking the ARVs. Following realised access, the patient may pass through a stage of 'normalisation'. The signs of symptoms of HIV disappear and the person begins to live a 'normal' life.

Disrupted access stage

During this stage, the patient may stop taking the drugs. This could be due to a number of reasons. Some may realise that they are 'normal' as evidenced by being physically healthy and therefore decide that there is no need to continue treatment. Some may be encouraged by religious leaders not to take the drugs as they are now 'healed'. Others may drop out due to the organisational arrangements that lead to stigmatisation. Some of the patients may drop out due to financial reasons.

Continued access

Those who overcome the above barriers they may continue accessing treatment. Some of the other patients who go through the disrupted access stage may overcome these obstacles and continue treatment. Most of the patients continue to access treatment in centres that are far from where they live so that people that live around them do not know of their HIV status. Essential to people who continue to access treatment is meeting the same health personnel, friendly service and professional care. Despite the long waiting times, people prefer to continue receiving treatment from the place where they were first started treatment.

The effect of access to ARVs on stigma is mixed. A form of stigma reduction termed 'non-associative stigma reduction' was discovered in this GT research study. However, the stigma reduction is due to non association with HIV. Due to the fact that the person on ARVs looks healthy, he/she is not associated with HIV and so is not stigmatised. However, if the

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community knows that he/she is HIV positive and is on ARVs, they may still stigmatise.

These stages are not necessarily linear. A patient may start with anti-retroviral treatment and stop due to financial or reasons. He/She may switch to traditional medication and/or prayers and later switch back to ARVs. Some patients do not pass through all the stages. For example, a patient who got diagnosed at antenatal care may simply have direct access to the ARVs without trying alternative therapy. These stages also do not depict the ease at which patients obtain access.

Discussion

Link and Phelan (2001) argue that stigma, prejudice and discrimination are different dimensions of the same phenomenon. However, differentiating the labelling difference (stigma) from the reactions of the society may make it easier to target the different actors that influence stigma. Kurzban and Leary (2001) argue that stigmatisation comes about as a the society uses psychological processes designed by natural selection to avoid people with a stigmatised attribute and join forces with normal people for competition and exploitation purposes. However, a lot of stigmatised diseases such as cancer or incontinence are not easily contacted.

Pescosolido, Martin, Lang, and Olafsdottir (2008) made an ambitious attempt to merge all the theoretical frameworks from psychology, social science disciplines on stigma. The attempt provided a complex representation of a truly complex problem. However, complex and diverse conceptualization makes it difficult to grasp in a programmatically useful way. The conceptualisation of stigma in this GT research is unique in the sense that it goes beyond the individual level to examine the familial (interpersonal), community and organisational domains of stigma. It looks at the structural and contextual dimensions of stigma and the impact of not only the relationships, but also of the context in which stigma takes place.

Nigeria is a very religious country. Instead of trying to contradict the religious leaders, it may be more productive to involve them in the formulation of ARV access programs. All

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the participants in the study were religious and believed that their faith in God helped them to access treatment. Most of the participants suggested that they are able to overcome their fears by having faith in God. The God theory suggests that there is a Being who created human beings and the world and desires human beings to live under His guidance (Grudem, 1994). As Adogame (2007) argues, Nigerian people's belief in divine healing (theotherapy), gives them hope to cope with the HIV diagnosis. This assertion is reflected renditions of participants in this current GT study.

'People's belief in God plays a major role in helping them cope with their HIV diagnosis and access treatment. Nigeria is a very religious country. When there is no more hope, people turn to God. I believe that I am being kept by divine healing of God as I am not on ARVs but am still healthy'(Tama).

The findings of this current GT study are similar to those identified by Makoe et. al., (2008), whose study across 5 African countries showed that Africans turn to God as one of their coping strategies of dealing with HIV stigma.

Oke (1995) and Adegoke (2007) discovered that cultural perception of illnesses as having evil spiritual undertones (such as witchcraft) was strongly associated with the use of spiritual healing churches as an alternative to modern health care in Western Nigeria. There is a strong belief in the spiritual aetiology of HIV infection that is often not recognised by health care practitioners. This further helps in alienating the patient from the health care worker. One of the participants suggested that she believed she was HIV positive because she refused to marry her former boyfriend. She believed that he had placed a curse on her for disappointing him. Due to this belief, a lot of the participants disclosed their HIV status to their religious leaders before disclosing to their close friends.

Implications and recommendations

This work theorises how social capital can be useful in improving health. It is simplistic to believe that having large social capital will necessarily translate to improved health or improved access to ARVs. This GT study highlights the fact

that close family members and friends can and do stigmatise HIV patients. Social connection theory suggests that social networks and links need to be stimulated or nudged in the right direction to improve health. There is the need to appreciate the fact that in the African context, rational decisions and behavioural activities based on analysis of evidence of the effectiveness of health care interventions may not necessarily apply. Religious beliefs and cultural norms may play major roles in influencing health seeking behaviour.

This research identifies that stigma occurs at different levels. There is no one size fits all strategy for tackling stigma. Different types of stigma will require different strategies. Self stigma will require counselling, self help literature and support from social connectors. Familial stigma will require family counselling and health promotion strategies that go beyond the individual patient to target family members. Community stigma will require innovative health promotion, film, social marketing and social media strategies. Having separate infrastructure for HIV patients creates a form of organisational stigma as every patient going to that centre is already assumed to be HIV positive as that is the only illness being treated there. This effectively violates the confidentiality of the patient's condition. There is need for mainstreaming of HIV treatment with the main health care system to prevent this. Comprehensive health care services that take cognisance of socio-economic, spiritual, religious and psychological needs to the patient, is urgently needed. Health care workers also need to be trained on customer service relations and how to empathise with their patients. It is necessary for functional, well equipped health care centres be made available in the rural areas. Political support is needed to provide a good environment for supporting social networks that facilitate access to ARVs. Advocacy to politicians and formulation of anti-stigma legislation is needed to protect the rights of PLWHA. Social connectors should be included in formulation and implementation of anti-stigma strategies.

Limitations

Some of the descriptive findings may be biased to reflect factors that affect PLWHA that belong to HIV support groups and not all PLWHA in Nigeria. Notwithstanding, the results of

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the research could provide insight on strategies that members of HIV support groups employ in accessing ARVs. It may not provide answers to systemic and structural problems within the health care system. The sampling techniques and small sample size may limit the possibility of generalizing all the descriptive findings. However, the theory derived from the research may be generalised and applied to other settings and circumstances that applies to treatment for diseases associated with stigma (such as leprosy and mental health illnesses).

The CGT Learning Curve

This paper is a reflection of my utilization of GT to study access to HIV treatment in Nigeria at a point in my learning curve. GT is used in this paper as a methodological approach of undertaking research without the restriction of a preconceived theory. My adventure into GT began as I searched for a methodologically sound strategy for my PhD research that would help in theoretical development. After reading through the literature, it was clear to me that there was a gap in the theoretical debates on access to HIV treatment. GT was chosen for this study because it is a rigorous methodology with well documented systematic set of procedures for analysing data.

It was challenging to differentiate my professional concerns from the main concerns of the participants of the study. Although Glaser (1998) suggests that the researcher ought to go into the study without any preconceptions, it is difficult to do this within the remit of a PhD. In order to meet departmental requirements of the University ethics committee, I had to demonstrate that I had a professional concern. As Glaser (2008) advises, this should not deter the researcher from doing GT as the concerns of the participants will still emerge in the context of the professional concerns of the researcher. Notwithstanding, the researcher needs to be theoretically sensitive and keep an open mind. As Holton (2008) suggests, the researcher should do what he/she needs to do to meet departmental demands and get the PhD while innovatively following the principles of GT that allow the main concerns and new theory to emerge.

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I was in a 'minus mentoring' situation where I had to rely on GT books to actually do the GT (Glaser, 1998). As Glaser (1998) advises, the best way to learn GT is to do it. I read through the different articles and books on GT to understand the different variants and the rationale behind them. Reading widely provided me with the arsenal and zeal to undertake the study. One of my fears was that concepts may fail to emerge from the data. With patience, reflection and subconscious processing the concepts emerged.

It was challenging not allowing preconceived ideas from the literature to influence the research. Doing a literature review was also necessary to meet the University Ethics committee and to argue why a GT methodology was preferred for the study. It was necessary to demonstrate that I had a good understanding of the GT methodology and debates. Consequently, two waves of literature review were done. There was a first wave, which looked at GT literature and access studies broadly. The bracketing technique was used to overcome this. With bracketing, previous knowledge and ideas are suspended so as not to influence the research (Backman and Kyngas, 1999). The second wave of literature review which was directed by findings of the research was more focused and more relevant to the emerging theory.

It is also important to differentiate the use of GT as a method of analysis from the use as a methodology. Some researchers only use the coding and memoing components of GT when analyzing data. For the purpose of this research, GT was used as a methodology. In using GT as a methodology, the iterative process was utilized that allowed the results of the analysis of the data to guide further research directions, literature reviews and modification of questions and selection of participants to contribute to the emerging theory.

It was challenging coming to grasp with the different variants of the GT methodology. Charmaz (2006) provides a constructionist view of performing GT. However, she argues that the GT process involves the active involvement of the researcher in constructing the theory and plays down the importance of allowing the theory to emerge from the data. Strauss and Corbin (1998) provide a symbolic interactionist version of GT. Glaser (1992) makes ad hominem arguments in

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his publication that criticize Strauss and Corbin's (1998) version of GT; as he suggests, their early prescription of a 'one size fits all' coding paradigm framework stifles the analysis. The artificial inculcation of the coding paradigm also defeats the aim of doing GT. This is to develop a theory that emerges without the constriction of a framework.

Glaser is quoted as saying that grounded theory is 'aphilosophical' (McCallin, 2008). Glaser's aphilosophical stance about grounded theory suggests that anyone can do grounded theory irrespective of his/her philosophical position; be it critical realist, objectivist or social constructionist (Holton, 2008; McCallin, 2008). As a social constructionist, I suggest that data do not speak for themselves. As Bryant and Charmaz (2007:38) aver, the constructionist researcher engages the data in conversation and works in synergy with the data to develop the theory. However, engaging in research from a social constructionist position does not necessarily preclude the theory from emerging from the data.

As Covan (2007), a student and protégé of both Glaser and Strauss (1967) argues, behind the classic grounded theory method is the positivist epistemological paradigm that suggests that the researcher is objective; separate from the data and that the data emerges irrespective of the professional or cultural characteristics of the researcher. Viewing grounded theory as a method, places a limitation on the theoretical development as the researcher is restricted in working along prescribed dictates within the 'GT method box'. However, when GT is viewed as a methodology, it allows the theories to emerge 'out of the box' as it were. A broader perspective is utilized in which the potential for theoretical developments are limitless. Viewing grounded theory as a methodology, rather than a method opens the door for the emergent properties of grounded theory to be demonstrated on the GT methodology itself. Hence, it could be argued that different variants of Grounded Theory may emerge from the core Classic Grounded Theory methodology. As Bryant and Charmaz (2007:50) argue, it is critical to reposition Grounded Theory in the light of current philosophical landscapes in a manner that recognises different perspectives of researchers.

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This will enable us to move beyond simple criticisms that label grounded theory as being positivist or limited to micro analysis.

Conclusion

GT is a useful approach for developing high quality research that is grounded in the data. The social connection theory provides a useful framework for investigating and planning access projects. The theory attempts to bridge the link between the micro process of access and the macro environment. It reveals the vital role that social connectors play in influencing access to HIV treatment at the individual, community and organisational levels. In order for HIV treatment access rate to increase, these social connectors need to be targeted and empowered to facilitate access to treatment. Health promotion programs should be developed not just for the individual but for the social connectors in the society that can assist the patient in accessing treatment.

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