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"We listen to them": A Qualitative Study of HIV Provider-Patient Relationship in the Management of Care

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Authors' contributions

This work was carried out in collaboration between all authors. Author AEA designed the study, wrote the protocol and wrote the first draft of the manuscript. Author AEA carried out all field work. Authors AEA and RD managed the analyses of the study. Author RD supervised the work. Author AEA managed the literature searches. Authors JB, RD and PL edited the manuscript. All authors read and approved the final manuscript.

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ABSTRACT

Background: Although previous research that considered a variety of chronic diseases have shown that quality of provider-patient relationship is related to health outcomes, key issues defining HIV care provider-patient relationship has not been well studied in Belgium. It is important to understand the key elements that define HIV care team-patient relationship and how they deal with psychosocial issues facing sub-Saharan African (SSA) migrant women with HIV/AIDS in Belgium.

Methods: Face to face in-depth semi-structured interviews with 8 HIV experts at an AIDS Reference Centre in Brussels were conducted between December 2013 and March 2014. Observations during patient-doctor consultations were also conducted. Experts were asked to

describe their experiences in the treatment and care of SSA migrant women with HIV/AIDS. Thematic analysis approach was used in the analysis of the transcripts.

Results: HIV care team viewed their role as encompassing both biomedical and psychosocial aspects of care, reported a bottom-up communication about HIV care and the ability to positively influence patients' acceptance and coping with HIV/AIDS as a long-term illness. The team described communication as a process, individualized approaches to recommendations and viewed their provision of care as satisfying. Some participants described their frustration at not being able to get some patients adhere to their treatment.

Conclusion: HIV care team reported increased job satisfaction in their interaction with patients. Further research is necessary to determine if educational interventions to improve non-HIV healthcare providers' interaction skills could improve patient-healthcare providers' relationship and reduce stigma and discrimination in healthcare settings.

Keywords: HIV/AIDS care team; treatment adherence; communication; information; patient education; healing process.

1. INTRODUCTION

The healthcare team-patient relationship is important for people living with chronic illnesses like cancer, diabetes, high blood pressure, mental illnesses and HIV [1-4]. There is evidence that healthcare provider-patient relationship is the cornerstone of medical and non-medical ethics, yet this relationship, crucial in achieving high quality and cost effectiveness of care may significantly differ in the management of care for patients with chronic illness [5,6]. Recently, the dynamics of healthcare providers' role as trusted advocates of patients has become more challenging since the advent of HIV. The way patients relate to their healthcare providers have changed since HIV. The assertiveness and knowledge may remain for a long time [7]. It is true that both healthcare providers and patients would like to have strong, personal and valueoriented relationships in order to achieve better treatment outcomes (survival and quality of life) and wellbeing [8-10].

Thirty years on, there remains compelling reasons to study the interaction and relationship between HIV care team and patients. Physician-patient interaction encompasses verbal and non-verbal interactions, and forms the basis of relationship [11]. Previous studies have shown that HIV care team-patient relationship may be centered on the care team behaving in a manner to facilitate questions being asked by the patients [9,12,13], during meetings to discuss treatment options [14,15] HIV care team-patient interaction may play an important role in defining treatment and care outcomes [16].

Adult HIV prevalence in Belgium is about 0.3% and about 27,005 people have been diagnosed HIV positive between 1985 and 2013. There are

an estimated 13,941 people with HIV/AIDS receiving treatment and care in Belgium as of 2013 [17]. A total of 1117 new HIV infections was diagnosed in 2013 and of these number, a third acquired infection might have heterosexual intercourse. However, there is still a high rate of new transmission among men having sex with men [18]. Migrants from sub-Saharan Africa (SSA) remain at high risk of contracting HIV [19]. There has been some recent complacency about the disease, treatment, and risk of acquiring the disease and people have become less aware of the risk of HIV transmission than they were 10 years ago. Many people may still be unaware of their infection [20].

There are no known studies that have examined the HIV care team-patient relationship from the standpoint of the team providing treatment and care to sub-Saharan African migrant women with HIV/AIDS in Belgium. This paper explored HIV care provider-patient relationship and how they deal with psychosocial issues facing sub-Saharan African (SSA) migrant women with HIV/AIDS in Belgium.

2. METHODS

2.1 Study Design, Setting and Participants

We chose qualitative study design consisting of semi-structured interviews. Observations during consultations with patients were conducted. This was to allow a deeper understanding of the providers 'perspectives on HIV treatment and care of sub-Saharan African migrant women attending an academic HIV clinic in Brussels, Belgium. Our study was part of a larger study relating to the experiences of sub-Saharan

African migrant women living and aging with HIV/AIDS in Belgium.

The first author recruited HIV experts through purposive sampling and by simply asking them if they could be interviewed. All experts accepted to participate and gave explicit verbal consent. The interview questions were designed to examine factors influencing HIV care teampatient relationship. We found it necessary to study this group for a better understanding and corroboration of patients' narratives as to provider-patient relationship.

This study was approved by the Ethics Committee (EC) of the Universitair Ziekenhuis Brussel, Belgium (Approval number B.U.N. 143201215911) and the Institutional Review Board (IRB) of the Institute of Tropical Medicine, Antwerp, Belgium (Approval number IRB/AB/ac/141). There were no monetary or other compensation provided to the participants.

2.2 Data Collection

Data was collected between December 2013 and March 2014. Interviews were semi-structured and face-to-face and conducted individually in a consultation room at a time scheduled by the expert. Interview guide was not pre-tested since the HIV care providers were bilingual (English, French), in addition to Dutch, their mothertongue. Interviews rather than group discussions [21-24] were chosen as most appropriate to document individual views on a sensitive issue like HIV and allow space to discuss behaviour that may criticized [25]. All interviews were conducted in English, audio-taped, transcribed and stripped of identifying data. HIV providers were asked to narrate their experiences treating and caring for women from SSA with HIV/AIDS attending the ARC. Additionally, probing questions followed where more clarification was needed. For example "What are the main issues you find with SSA migrant women that you don't see with other HIV/AIDS patients receiving treatment and care from the ARC or "do you see your patients as disease or as a person"? Table 1 presents sample interview questions. Some data were also collected from "corridor talk" with providers during observations at the waiting room of the ARC.

Observations were conducted during physicianpatient consultations. The provider obtained permission from the patient to allow the first author to be present during consultations. The first author observed the verbal and non-verbal communication during consultations. Notes were taken as to what was observed and heard during consultations with patients to allow for a deeper understanding of the experts-patient relationship. Handwritten notes on observations were typed into a word-processing program. No taperecording or filming was done during consultations in order to facilitate participation, minimize intrusion and ensure confidentiality.

Table 1. Sample questions for health experts

- How long have you been treating patients with HIV generally and those from Africa specifically?
- What are some of the biggest issues facing SSA migrant women living with HIV/AIDS in Belgium?
- 3. What are the strategies you use to see your patients as people and not disease?
- 4. Do you still have in care the same patients as when you started treating SSA women with HIV?
- 5. What are your views of ART today as compared to 10 years ago?

2.3 Data Analysis

We used thematic approach in the analysis of the qualitative data consistent with previous studies done in healthcare settings [26-28]. NVivo 8 software was used to manage the large amount of text. Audio-taped interviews were transcribed verbatim and coded for themes by the first author. All interviews were replayed and transcripts read several times. Transcribed interviews as well as notes on observations were used in data analysis. The first author did all the observations and interviews as well as the primary data analysis. Data collection and analysis was continuously reviewed, first with the last author and subsequently checked by all authors to validate the findings [29,30].

During initial coding, all data from interviews and observation notes were labelled with themes from physicians' statements relating to duty to treat and care, trust and confidentiality, inform, communicate and educate. We also identified themes highlighting areas of concern related to treatment adherence, housing instability and disclosure of HIV positive status.

3. RESULTS

All participants described their role in the treatment and care of SSA women with HIV in a variety of ways. The main themes that emerged

were treatment and care satisfaction and concerns; respect, trust and confidentiality in communication behaviour. Participants also identified their psychosocial role as a core professional responsibility. Characteristics of participants were limited to specialty, gender and length of contact with patients as presented in Table 2.

3.1 Characteristics of Participants

The 8 HIV care providers in the clinic were interviewed. There were five physicians (3 females and 2 males), one female HIV therapy nurse, one female social nurse and one male psychologist. All the providers have been involved in treating and caring for SSA women between 5 and 20 years at the ARC. Interviews lasted between 30 minutes and 1 hour. "Corridor talks" were held with some of the providers when the first author waited and observed activities at the waiting room.

Table 2. Characteristics of HIV care team

Variables	Moreshau
Variables	Number
Physicians	5
Psychologist	1
HIV therapy nurse	1
Social nurse	1
Experience treating/caring	5-20 years
(range in years)	

We observed 8 consultations with physicians and 1 with the HIV therapy nurse. Most of the consultations were not observed either because the physicians did not ask patients for permission for the first author to be present or permission for observation was refused by the patient. Observations were approximately 15 and 30 minutes and stopped at the end of the consultation.

The interviews and observations with the HIV providers demonstrated experiences in interactions with sub-Saharan African women with HIV/AIDS.

3.2 Satisfaction and Concerns Related to Treatment and Care of Patients

3.2.1 Satisfaction

Participants who had started working with HIV/AIDS patients before the era of antiretroviral therapy reported great progress in medical research in changing HIV from a death sentence

to a chronic and treatable disease. A participant commented.

It is a domain in medicine where I saw a rapid evolution. The progress that we saw and that we could also make for our patients is very big. In the beginning we had only one medication but now we have more than 20. We also see better results from the treatment that is now less complicated, simpler and patients take fewer pills, with less side-effect than in the beginning. Patients we saw many people becoming sicker and sicker although we gave some treatment with a lot of problem. We see now that patients are in good health. We they are sick they get better with simpler treatment that they do tolerate quite well. We saw a big evolution in antiretroviral treatment unlike in cancer or any other treatment. For us as doctors, it is encouraging. (HIV treating physician).

All the providers indicated that HIV has become a treatable chronic disease unlike in the era before antiretroviral therapy and patients have access to free HIV treatment and care and can now live a normal and productive life if they adhere to treatment and prevent other infections. One provider said:

Nobody pays for the medications. They are free. They [medications] are available to patients in care. (HIV therapist).

Treating physicians also reported satisfaction with the positive change of behaviour of most sub-Saharan African women in relation to health-seeking behaviour. Patients are now diagnosed earlier than had been the case as indicated by a treating physician.

I don't have the statistics but I have also the impression that sub-Saharan African population patients are diagnosed earlier. In the past we have what we call 'later presenters' and now it has become really rare. It means that people are tested earlier, whether it is here or in Africa. We have patients who are coming from Africa and if they are positive, they are already on treatment. I think it is a good sign. That was not the case 10 years ago. (HIV treating physician)

All treating physicians reported that at the ARC it is the culture for them to be available promptly to consult any patient who is registered and waiting.

The physicians indicated that exceptions are made if the patient expressly asked to see a particular physician, then that patient has to wait. Providers always referred to the patients as "our patients" as explained:

"We don't have individual patients. We attend to them as they come. We always see them as persons and not illness. We listen to them as long as we can so they can express their concerns and reassure them that those concerns are common in other communities". (HIV treating Physician)

Notes from observations at the waiting and consultation rooms indicated the compassion, warm and friendly manner in which the providers interacted with the patients. Before being ushered into the consultation rooms, the providers greeted and introduced themselves to each patient. Providers often asked "How are you today?" or "How are you doing with the medications?" The first author also observed that they talked to the patients as if they were regular friends.

3.3 Concerns

Cases of non-compliance and adherence with medications and missed providers' appointments because of personal, socio-cultural or religious factors were reported by all participants.

Some patients believe that they don't have HIV and are not infectious and some believe so much in God that they think they are going to be cured without medications and at some points they believe they are not infected anymore. (HIV treating physician)

Similarly, on patient's non-adherence a participant commented

We tell her that it [medication] is for free if she comes here, we will give it to her. Sometimes, it is difficult for her to get here for consultation on time because either one of the children is sick or she had to go to the school of one of the kids or whatever. It is hard for her, I know but she has to take her medications herself. We can't give it to her every day. (HIV therapist)

Some participants alluded to the few campaigns against stigma and discrimination that deters many people from HIV testing.

There is still too much stigma and most people don't like or think to test for HIV. This is not only peculiar to the African communities. I think there are too few campaigns organized to inform about HIV, why people should test and if positive inform them that they can have treatment and live normally as long as possible. There is still a lot of denial where prevalence is higher...We only have access to our patients and they are well informed but not the rest of the community. (HIV treating physician)

Participants also reported concern for stigma and discrimination in healthcare settings.

Some African women have been infected here in Belgium...so there is still a big problem...the stigma, the fear, not being tested; I think there are missed opportunities as well at the general practitioners' (GPs') or surgery or anywhere. Because it [HIV] is not talked about, people are still scared even in the hospitals. In the fertility clinic here, we have to do information session in a couple of months because the nurses and the operating theatre staff are still scared of using the same measures for HIV people as for non-HIV people. That means there is information problem everywhere...There is still stigma in the healthcare settings, so that tells a lot in the non-healthcare. (HIV treating physician).

The HIV providers also reported discomfort and inability not to influence disclosure to relevant people like intimate sexual partners of patients and feared risk of HIV transmission especially for patients who frequently missed their doses of pills and hospital appointments. No participant reported any breach of confidentiality. They all reported that they were legally bound not to disclose a patient's HIV positive status even to an intimate sexual partner as indicated by a participant:

Informing a third party about the HIV positive status of a patient won't work. It will break the trust, secret and the link with the patient. We always assure them that we will not tell anyone else. We try to convince the patient to disclose to her partner even if it can take a long time. In these cases we can treat them for HIV and that makes them less or really not contagious anymore. So the partners are not really in danger. Most patients who don't tell their partners claim that they use

condoms. We also have partners who are told but still don't want to use condoms or get tested for HIV. (HIV treating physician)

All providers also reported limited time with patients, making it difficult to know the patients better, for better treatment and care outcomes. One reported:

We don't have a lot of time to really devote to help patients with non-medical problems because of our work load. When there is a little time we talk about their children, education, training and work. This doesn't happen that often. (HIV therapist).

3.4 Respect, Trust, Confidentiality in Communication Behavior

Respect for the patients was recurrent in the discourses of the providers. All providers indicated that respect towards their patients fostered an environment of trust necessary in a partnership. The providers reported that they viewed their patients as responsible as they are in their health and wellbeing. Referring to shared responsibility one participant said:

Some patients are very thankful and do everything to be well quickly. The most common reaction we see with patients is one of cooperation. (HIV treating physician)

Providers used the language of the patients (English or French) to communicate with them. The providers believed that informing the patients through questions and answers was a way of educating the patients as to HIV infection, medications and wellbeing. Providers also believed that they had the ability to positively influence patients' acceptance and coping with HIV/AIDS as a long-term illness by encouraging bottom-up communication about HIV care. Participants believed that good information communication and education help them instill trust and address patients' medical and non-medical issues.

The HIV care providers also expressed the need for a comprehensive database for a better management of treatment and care trajectories, and also, systematically explore the adequacy of treatment and care of HIV/AIDS- infected SSA migrant women.

3.5 Psychosocial Role of HIV Care Team

In discussing their interaction with the patients, non-medical care was often mentioned as part of

the work environment of the providers. For instance, a participant reported efforts made to ensure access to free ART, provide support to patients who encounter domestic violence including intimate partner violence, and stable housing for the undocumented patients. The provider commented:

For people who are illegal here in Belgium, my main concern is to see that they have their medications and help them with their appeal process. I listen to their stories and but often it is urgent for them to get their medications. They may have only a week or two to put things in order when it is very urgent, when the medications are needed, that is my biggest concern. I have to call some organizations, see with the doctors and ask them for documents they may need. When everything is in order, then I can start talking to them to see how they feel. Sometimes I don't have the time to know how they are feeling because of the urgent need to do the paperwork for them to have their medications. (Social assistant).

Rapport-building is believed important to the therapeutic relationship. Rapport created with patients was perceived by participants as satisfactory. They reported that patients not only talk about their medical conditions but also family as well as profession-related matters. No participant reported differential treatment and excessive precautions with patients. Participants also reported that cultural differences may pose a problem to both provider and patient, as explained:

What is more difficult for us and I think also for the doctors, is to have an idea of what patients' beliefs and ideas about illness and health are. Sometimes we give an explanation and they say yes, yes, yes, that they understood it all but I see it is not true at all because of the other ideas and conceptions about health, illness. That is something I think we know too little about. A culturally different view about what is illness and what causes illness, how the body functions. Of course we are used to it that people have basic knowledge about a lot of things. Certainly, we don't know about people coming recently from Africa... what education they have or not and we often assume too quickly that if we can give some explanations... that people will understand what care is...and what is important to start with. To check on how people see

themselves and what they understand about general knowledge not only about HIV but about health and how the body functions is important. (Psychologist).

3.6 Message to HIV (SSA) Women

"HIV-infected women should be proud to be women, brave against the social pressures and be strong to do what is good for them because that will make life for their children and their family easier. They should remain women. They should not stop being women". (HIV treating physician).

4. DISCUSSION

The findings of this study have shown that HIV care team viewed their expert role encompassing biomedical and psychosocial aspects of care. We found that treatment and care satisfaction and concerns of the care team, respect, trust and confidentiality; information communication behaviours were the major findings. However, participants expressed concern in patients' nonadherence to treatment and non-disclosure of HIV positive status to intimate partners. Finally, participants also expressed a need to have a database where patients' specific treatment information and socio-demographic characteristics could be consulted without much searching. They further indicated the need for continuous training of non-HIV experts in the management of care of HIV patients referred to non-HIV care services.

Our study highlights the complex and challenging nature of providers' engagement in patients' chronic disease trajectories. Our results show some similarity with other studies that described disease management and the crucial role of the provider-patient relationship in fosterina interaction [31,32]. However, there was no evidence of paternalist role in which the providers assumed the dominant position by virtue of their specialist knowledge, as had been reported in previous studies [33,34]. The care team perceived patients as partners and allowed for shared decision-making when they realize that the patients understood the nature and causes of a chronic disease like HIV/AIDS. The care team reported providing the patients with information in order to understand what happened and what they should expect living with HIV/AIDS as a long term illness. The shared-decision in the partnership enabled the patients to relinquish the role of "vulnerable" and become "agents" in fighting against HIV transmission. These findings are similar to studies that were earlier performed on shared-decision between provider and patient [35-40].

However, there were indications from this study that revealed that there was the need for paternalistic approach to care in the early stage of the communication process, as some patients deferred decision-making to their care providers, thus allowing them the time to understand and gradually deal with the implications on their lives. The care providers in these cases found ways to engage patients only when it was acceptable to the patients. In doing this, there was the need to respect their patients as people and not illnesses, gain their trust and confidentiality of their medical situation. We found that it was necessary for the team to create a sustainable rapport with their patients in order to give the patients the power to choose their positions towards their care providers, their significant others (partners, families and friends) and the general healthcare.

In addition, this paper as part of an ethnographic study on the experiences of sub- Saharan African migrant women living with HIV/AIDS correlates with the narratives of patients [41] where respect for patients, trust in the relationship and support provided by the care team to the patients encourage treatment adherence, and the will to continue productive and meaningful lives for many patients [42]. The respect, trust and confidentiality that exist in the relationship helped the care team to positively influence patients' acceptance and coping with HIV/AIDS as a long-term illness through reported bottom-up communication about HIV care. Conversely, the care team showed concern for some patients who frustrated treatment and care efforts of the team. The providers revealed that these patients often came back to them in critical conditions because they [patients] refused taken their medications based on their religious beliefs that they will be cured by a miracle from God. Similarly, the care team highlighted the fact that some patients could not be stable on treatment because of their precarious housing and legal conditions and other psychosocial issues. In these cases, they had to exercise their nonmedical role of care providers.

5. LIMITATIONS

This study has a few limitations to consider. This study included only providers from a single academic clinic; as such findings may not be generalized to all HIV care settings in Belgium. It is possible that the observations may have made

physicians not to behave in their natural way with patients during consultations and may have made the consultations awkward. Another limitation is that the study may not be representative of the providers' usual pattern of care. Providers may not also report attitudes towards patients accurately due to social desirability bias. We tried to address this by asking a question with "compared to other non-SSA women with HIV". We believe that social desirability will undermine providers' overall interaction with the women. Although the observations only lasted for about 30 minutes, there were really no indicators that the observed consultations were not "normal".

Despite these limitations, to our knowledge, this is the first qualitative study on HIV providers' perceptions on treatment and care of HIV infected women from sub-Saharan African living in Belgium. The grounded method was relevant to deeply analyze HIV care team's experiences and concerns that could also be used to sensitize other healthcare providers in non-HIV settings. A better understanding of the role of the healthcare providers in managing HIV/AIDS maybe valuable for translating this study's implications from the hospital setting to ambulatory care.

6. WHAT DOES THIS PAPER ADD?

- An HIV care team can help reduce adverse behavioural effects of a disease like HIV/AIDS that carries stigma and misconceptions about the disease and mode of transmission.
- Highlights the growing need for HIV care team to transfer the patient-centered management skills to non-HIV healthcare providers to reduce stigma and discrimination in healthcare settings.
- Reinforces need for HIV care team and non- experts to be aware of how patients, the most important stakeholder in the reduction of HIV, perceive verbal and nonverbal communication
- Providers' training and assistance needs to extend into non-medical domains and HIV experts may help non-HIV healthcare providers communicate more effectively.
- HIV still requires understanding, coordination of health services and professional education beyond the scope of general practices.

7. CONCLUSION

We found the relationship between HIV care team and patients generally good and based on respect, trust and confidentiality. The team showed satisfaction in treating and caring for their patients despite concerns for nonadherence for a minority of patients. This study is important because it documents HIV care teampatient relationship in a healthcare setting that can be emulated by other non-HIV healthcare providers to improve relationship with HIV patients, increase retention in care and reduce stigma and discrimination in healthcare settings. However, we recommend further studies that build on these findings and further explore factors associated with interaction of HIV patients and non-HIV care providers be conducted. We also suggest a combination of longitudinal studies, direct observations and self-report from HIV patients and healthcare providers to test the transferability to non-HIV healthcare settings.

CONSENT

All authors declare that written informed consent was obtained from the patients. Data cannot be made publicly available due to ethical restrictions protecting participants' confidentiality.

ETHICAL APPROVAL

All procedures were approved by the Ethics Committees of the Universitair Ziekenhuis Brussel (Approval number B.U.N. 143201215911) and the Institutional Review Board (IRB) of the Institute of Tropical Medicine, Antwerp, Belgium (Approval number IRB/AB/ac/141). The confidentiality participants was respected by removing all identifying elements from data. Culturally sensitive words or questions related to sexual orientations and practices (homosexuality, lesbianism, or transgender) were omitted in the data collection process. Participants were free to withdraw from study at any time. There was no financial compensation. Authors are ready to submit a scanned copy of the IRB or ethic Committee Approval at any stage of the publication.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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