Perception of Stigma among SERO-Positive Patients In Vihiga County, Kenya

Thomas Ong'ondo Ng'ambwa[1]
Medical Surgical Nurse Practitioner: school of Nursing, Midwifery and Paramedical Sciences
Masinde Muliro University of Science and Technology

Lilian Amugutsi Isiaho[2]
Nephrology Nurse: school of Nursing, Midwifery and Paramedical Sciences
Masinde Muliro University of Science and Technology

Daniel Adany Komen[3]
Critical Care Nurse: Clinical Nursing and Health Informatics
Masinde Muliro University of Science and Technology

Abstract
Negative attitudes toward sero-positive patients have been studied extensively and established among community members and also within healthcare settings. Health-care services have also been described as a source of stigma in studies. However, no published studies addressing this topic have been performed in Kenya's Vihiga county. In this study, affected patients were invited to engage in focus groups or individual interviews, which were audio recorded on mobile phones, transcribed, and analyzed using thematic analysis, in order for the study to investigate sero-positive patients' perceptions of stigma by community members and health care providers in Kenya's Vihiga county. This research included a total of 48 sero-positive patients. The findings indicated that patients were not only aware of the potential effects of sero-positive patients' stigma, but that they had also been stigmatized as a result of their sero-positive status. Patients also believed that health-care providers could have negative attitudes about individuals who are seropositive, which may make it difficult for them to offer the best possible care. As a result, patients decided that these behaviors should be resolved in order for them to receive the highest possible level of care treatment. This study indicates that, like community members, people with seropositive status in Kenya's Vihiga County regard health care providers as a source of stigma. These results show how important it is to overcome negative perceptions among health-care providers in order for patients to receive the best possible care.
Keywords: *Stigma, attitude, Health care providers,sero-positive patients,Vihiga county*

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I.   Introduction

According to the latest WHO data published in 2018, HIV/AIDS Deaths in Kenya reached 35,856 or 14.05% of total deaths. Sero-positive patients struggle with the effects of HIV/AIDS as well as the emotional and behavioral responses of others (GhBarkish, F., Jalali, R., &Jalali, A. ,2019). Social distance, stereotyping, a lack of empathy, and patronizing behaviors are some of the most common interactions people with HIV/AIDS have in their communities, according to studies (Retno, L. and Wenny C,2016). Family members and close associates are often cited as the primary sources of stigma in most research (Harper, K. J., Osborn, C. Y., & Mayberry, L. S. ,2018). People living with HIV/AIDS, on the other hand, perceive health-care services to be sources of stigma and discrimination (Algarin, A. B.,et l 2020).

According to some research, health care providers have a hostile attitude toward sero-positive patients due to a lack of information about the illness, and therefore reject or make people with such diagnoses wait longer; and disregard and misattribute physical symptoms to patients' HIV/AIDS, resulting in delays in medical access (Martos, A. J., .et al,2019). In a similar vein, surveys of health-care providers have discovered evidence of stigmatizing perceptions and behaviors (Ashaba, S., et al. 2020). Other studies have shown that health care providers are more pessimistic about recovery than the general public, especially when coping with alleged treatment failures that continue missing appointments (Arbeit, M. R., Fisher, C. B., Macapagal, K., &Mustanski, B. ,2016).). Patients who are sero-positive often report feeling stigmatized by health care providers, as shown by a lack of interest in their personal or medical history; diagnoses provided with a negative prognosis and without

empathy; involuntary disclosure of their illness due to medication side effects; lack of information they receive about their diagnoses or treatments; being treated as children; and being treated as adults. This is particularly worrying since evidence suggested patients who are stigmatized are likely to commit suicide (Oexle, N., Waldmann, T., Staiger, T., Xu, Z., &Rüsch, N. ,2018).

The population of Vihiga County is 615,734, with 44 percent males and 52 percent females. The availability of antiretroviral therapy (ART) and expanded access to it have substantially reduced HIV-related morbidity and mortality (Ashaba S, et. al ,2019). While having a lower prevalence of 4.7 percent than the national average of 5.9 percent, the county has yet to meet the 90-90-90 target (set to be achieved by 2020) with only a small percentage of patients seek treatment yet were in 2021(Jamieson, D., & Kellerman, S. E. ,2016). Social stigma is thought to be one of the causes of this issue, among other things. In Kenya, little study has been done on this topic, with the majority of studies focusing on public stigma. According to studies conducted in developing countries, health care providers are the second most common source of stigma and prejudice, behind only family members (Cressman, A. E.,2020). The aim of this study was to find out how sero-positive patients in Kenya's Vihiga County perceived stigma from community members and, more importantly, health care providers, with the ultimate goal of developing a tailored anti-stigma intervention for health care providers.

II.   Methods

Design and Setting
This qualitative study used focus groups and individual interviews withsero-positive patientsattending CCC clinic in Vihiga county hospital, which provides comprehensive care Centre services to sero-positive patients. The researcher was one of the health care providers providing the care.

Patients
All Patients were outpatients; over 18 years old; treated by health care providers including, interns and consultants. The researcher invited sero-positive patients who were willing to participate. The patientswere chosen based on theoretical sampling, which facilitates identifying diverse possibilities that are theoretically relevant to our research questions; for example,the researcher aimed to include patients from both genders, at different levels of ARV initiation and use. This sample strategy also allowed for theoretical saturation, meaning that individual's recruitment ended when the ability to obtained new information was reached (Jameel et al ,2018).

Recruitment and Data Collection
The researcher invitedsero-positive patientsthrough the face-to-face invite while providing care to the patients in the hospital. Interested Patients were able to leave their details at the contact tracing desk where they were provided them with information sheets and consent forms. The researcher also invited patients who had been enrolled in differentpsychosocial support groups (PSSGs); suspectedtreatmentfailureclinic, prevention of mother to child transmissions (PMTCT), community units (CUS). There were no drop outs; however, two Patients had to leave focus groups early due to other commitments. All focus groups were conducted by the researcher. Focus groups and individual interviews were conducted in meeting rooms at the hospital. The researcher moderated every discussion using opened-ended questions from a topic guide, which included questions addressing personal experiences of stigma and discrimination from community members, experiences of stigma from health care providers and possible solutions to reduce stigma. A copy of the topic guide is available upon request.

Data Analysis
The researcher used thematic analysis to transcribe and interpret all of the interviews. Coding was done by putting together units of text that were all about the same thing. The researcher performed the data analysis, which was then checked by another researcher for accuracy. After that, the researchers discussed and compared the established codes, themes, and sub themes until they came to an agreement. By consensus and comparison with the original data set, themes and subthemes were later checked, updated, rejected, or substituted. The codes were categorized into groups, which were then divided into subthemes, which were then grouped into three main themes. Each subtheme was identified and refined in order to classify each theme and ensure that they were organized and classified in a logical manner. Credibility, dependability, and transferability were evaluated to maintain trustworthiness. The credibility of the study was built through theoretical sampling until saturation was reached, as well as finding consensus on themes with a second researcher. The degree to which data change over time as a result of the researcher's decisions during the process was evaluated by describing the recruitment process and interview procedures, as well as reflecting on how the authors' experiences could have affected the interviews and the creation of themes. Finally, since this research was performed in one location, transferability, which relates to the degree to which findings can be applied to other environments, was not evaluated. Since the

study was conducted in one location, it is impossible to be sure in the results' transferability. However, the researcher presented a detailed explanation of the study context, patient characteristics, data collection, and quotes from all of the subjects discussed, allowing readers to consider how transferable the results may be in a different setting.

III.   Results

Six focus groups with a maximum of eight patients were held, as well as two person interviews. A total of 48 people took part, with 39 women and 9 men. Group's duration ranged anywhere from 30 to 80 minutes. Interviews lasted anywhere from 10 to 25 minutes. Smartphones were used to document focus groups and interviews. Patients were not debriefed, but the information sheet did contain a statement that they might contact the principal researcher if they wanted to know the study's findings. No one contacted the researcher to inquire about the findings. The researcher identified subthemes from categories, which were then grouped into three main themes: community members' experiences of stigma; health care providers' perceptions of stigma; and interventions to change health care providers' attitudes.

Stigmatizing Experiences

The majority of patients were aware of and gave many examples of how they feel stigmatized by members of the group. Within this theme, two subthemes were identified: reactions from community members and reactions to getting HIV/AIDS, each with its own set of categories.

Community members' reactions: social distance and fear

Most patients believed that people with sero-positive status are rejected or avoided by the group, possibly due to fear of their condition, and that this has resulted in them losing meaningful relationships such as close friends or even spouses. Patient No. 1 says "As much as they love and care for us, they walk away,". "Many of them say that we don't obey orders, and the ones who are assisting us become exhausted and aggressive... then they condemn you." Patient No. 2 says... I get the impression that people are thinking, "There he comes, everybody gets busy, because he'll ask a hundred and one questions." 'Am I a bother or what?' That, I believe, has been extremely detrimental to my health.

Discrimination and Paternalism

Patients stated that they are often viewed as though they are incompetent or unable to care for themselves, while others believed that these derogatory stereotypes were linked to discriminatory practices. Even if you are good, there is no confidence. They don't believe in me, which makes me feel very uneasy. They let me go because they fear I'll infect others....

Empathy Deficit

Many Patients believe that most people don't seem to understand their disease, especially those with high viral loads>/1000copies per mill, since they tend to downplay symptoms and even accuse patients of making up for missed appointments. Some patients have noted that some people do not accept that using a condom consistently and correctly is difficult.Patients described feeling confused and even dismissed when people used phrases like you have to use condoms, which was seen as an indication of lack of empathy. Patient three says...Most members of my family don't accept that art's side effects may be intolerable at times; they think you're exaggerating, that you don't need it, that you should be able to handle it on your own. Patient IV says... There is no help from those close to you, and I already despise the term (do your best/make an effort). Most Patients indicated that the use of negative labeling and judgment were among the most common responses from community members. The term "drama queen" was the most often used. My ex-husband never stopped calling me a drama queen; his whole family called me a drama queen...even my own son told me so. Especially when I didn't remember to take my medication.

HIV/AIDS- Symptoms and Reactions

Reactions to getting HIV/AIDS were described as a subtheme, but most Patients' reactions were often linked to others' negative attitudes toward them. Most patients said they frequently feel compelled to keep their HIV/AIDS status a secret in order to prevent negative reactions (Setti, etal ,2019). Those who were unable to reveal their HIV/AIDS status were found to be more likely to internalize negative stereotypes about them or believe what others said about them (McKnight, C.t al, 2017). Nondisclosure and self-stigma were the categories used by the researcher. Patient V continues, "It's not anything you'd like to shout out to the world; it's something you'd rather keep to yourself because you never know how people would respond." They've referred to me as a drama queen, which makes me wonder if I am or am not a drama queen.

Aggression and emotional responses

Patients often report that they were more likely to feel depressed and lonely as a result of others' lack of empathy and avoidance, or even become hostile toward both other people and themselves. I told my siblings about it, and the reality is that they do point at you and say things like, "We told you were a drama queen... we saw something wrong with you." That makes you really angry... You're in a bad mood. Then I'd go to my room and start slamming stuff together... I used to hurt myself because I was so angry that I wanted to let it out. I once shattered a window... I feel like I've just responded....

Health-care providers' perceptions of stigma

Despite the fact that the majority of patients said their interactions with health care providers were positive, many Patients said they had encountered or observed a situation that they believed was related to stigma. The perceptions of stigmatizing attitudes in health care providers and the causes of stigma in health care providers were divided into two subthemes in this group. Health-care providers' perceptions of stigmatizing attitudes. Patients' most common concern was that health care providers were always cold, as if there was a barrier between them that prevented them from communicating effectively. Furthermore, some patients said that they are still unsure why their medication was modified or why they were having those symptoms. Others were worried about not getting enough details about their care, such as the reasons for a particular prescription or the amount of time they can expect to be on it. Patient Vi says, "There is a huge barrier between health care providers and patients, I mean, they only write when I'm talking about the deepest and most heart-breaking sections of my life." As a patient, I've sometimes felt misunderstood, as though there is no link. I went through multiple regimens, starting with SEPTRIN, then something like APHIA, then nevirapine, and finally dolutegravir. I was completely befuddled by all of the regimens I was given.

Medication and a lack of interest in one's own past

One of the recurring trends was that health care providers were uninterested in their patients' personal lives, concentrating more on their HIV/AIDS status and drug adjustments. While remarks about a lack of interest in their personal histories were uncommon, some patients claimed that they believe health care providers are uninterested in them if they do not read their medical records or ask repetitive questions. Patient VII expresses himself. "One health care provider assured me that adherence counselors are there for us to tell them about our issues, not that they are there for us to tell them about our problems. The health-care providers are only there to provide medicine... Why are you so cold, I asked? 'We are not here to listen to your problems; we are just here to medicate you,' he said. They really don't even have your medical records, and even if they do, they still ask, "What's your new regimen?" How much of this do you think you'll take? How have you been feeling? If that's the case, I'll have to change your routine.' They have no idea what's wrong with you; if we just go to them for treatment, they aren't even assisting us.

Labeling

Finally, some patients stated that they believe they are being handled unfairly because they have an unsuppressed viral load (</1000 copies/ml of blood) for the third time, or because they have seen health care providers disparaging other patients, which was classified as labelling. According to Patient VIII... "I do hang up with someone with viremia, so I told my health-care providers, and he said, 'no, stay away, because he does not take the medication and does not keep clinical appointments, he is worse than you, so stay away lest he mis-advise you and you will soon stop taking your drugs.'

Stigmatizing Attitudes of Health Care Providers: What Causes Them?

Desensitization, burnout, lack of experience, frequent change of health-care providers, and patients' expectations regarding HIV/AIDS treatment are among the key factors associated with stigmatizing attitudes among health care providers, according to patients. Since they are continually treating very ill people, many patients believe that some health care providers have lost their compassion and ability to feel empathy for them. However, others speculated that this desensitization is linked to the characteristics of health-care providers, since not every professional seems to be affected. "I suppose this is normal; if you're here all day listening to people complain about the same things, you must get used to or tired of it." says Patient VIII.

Burnout

Work overload and burnout were identified as potential factors in health care providers' negative attitudes. Indeed, some patients expressed concern for health care providers, describing their tasks as extremely stressful and potentially daunting. Patients reported that not getting enough training about stigma, or even how to handle such conditions, as well as a lack of clinical experience, may be linked to negative reactions in health care providers. "Sometimes I don't think it's so much that they don't care as it is that I believe it might be very overwhelming to listen to what the patient is telling you...," says Patient IX.

Table 1 Codes, categories, Subthemes and main themes emerged from the guide questions

Question guide	Categories	Sub-themes	Main themes
1. How do you think people react to HIV/AIDS patients?	Fear Paternalism Social distance	Reactions from members of the community members	Experiences of stigma from the community members
2. Which experiences have you had from people's reactions towards yourself?	Judgement Discrimination Lack of empathy Labelling		
3. What has changed since your diagnosis?	Non-disclosure	Reactions to having HIV/AIDS	
4. How have you responded to other reactions?	Emotional reactions Self-stigma Aggression		
5. Overall, how has been your relationship with them (health care providers)?	Cold treatment Lack of clear explanations Focus on HIV/AIDS or medication	Perceptions of stigmatizing attitudes in health care providers	Perceptions of stigma from health care providers
6. Have you ever felt uncomfortable with anything your health care provider has done or said?	Labelling		
7. Why do you think they (health care provider) behave in this way?	Desensitization Burnout Lack of training	Causes of stigmatizing attitudes in health care providers	
8. Are there any other reasons that could explain why health care providers behave in this way?	Change of health care providers Unrealistic expectations		
9. Do you think they (health care providers) also need some kind of program to reduce stigma?	Raising awareness	Proposed methods to improved attitudes in health care providers	Interventions to improve attitudes in health care providers
10. What do you think are the best strategies to reduce stigma in health care providers?	Formal training		

IV. Discussion

The aim of this study was to find out how sero-positive patients in Kenya's Vihiga county felt about being stigmatized by health care providers and community members. The findings revealed that, as in other research, patients viewed group members as the primary source of stigma (Harper, K. J., et al 2018). One of the most significant results was that patients believed health care providers had stigmatizing attitudes toward their patients, a topic that, although not previously studied in this group, appears to be an obstacle to optimal care quality (Geter, A., Herron, A. R., & Sutton, M. Y. 2018; Martos, A. J., .et al,2019). Patients believed that certain health care providers' behaviors could be due to stigma, despite the fact that they recorded overall positive experiences with their health care providers. Cold treatment and a lack of knowledge about regimens were the most widely identified issues, which are consistent with findings from another research (Retno, L.,andWenny, C. 2016). Patients also believe that health care providers are more focused on disease than on their personal lives, and that health care providers carry out labeling (SettiVPC,et l ,2019). Patients in this study thought that health-care providers' stigma may be a result of desensitization and burnout. Despite the fact that burnout has been identified as a source of stigma among health-care providers, many patients who complained about health-care providers' lack of empathy were members of focus groups created by patients with alleged treatment deficiencies who were alcoholics. Patients who are often regarded as challenging, demanding, and frustrating by health care providers (Steinauer, J. E., O'Sullivan, P., Preskill, F., Ten Cate, O., &Teherani, A. 2018). As a result, it's likely that their health-care providers' perceived desensitization was linked to health-care providers' negative attitudes toward patients who had already been diagnosed with alleged treatment deficiencies. Lack of training on the effects of stigma and frequent changes of health-care providers were not previously thought to be potential causes of stigma in health-care providers. Some scholars, however, advocate for anti-stigma approaches aimed at sero-positive patients (Mathew, R. S., Boonsuk, P., Dandu, M., & Sohn, A. H. ,2020). Patients found having set standards for their treatment to be partly a result of their own personality. They did believe, however, that this could be prevented if health-care providers clarified what their treatment entails from the start. The media's portrayal of HIV/AIDS can lead to unrealistic treatment expectations. Reactive patients, for example, may expect clinical checkups to resemble a psychotherapy session. The findings of this study not only support the need for anti-stigma interventions for health-care providers, but they also highlight the importance of improving health-care providers' knowledge of the implications of sero-positive patients' stigma, as well as the management of unconscious bias, which may be present in clinical care when a clinician classifies a patient as a member of a stereotyped group. Since this model of learning has become

common in health care education over the last decade, and its implementation has translated into better medical practice, adopting a reflective learning approach could also help improve the attitudes of health care providers in Kenya (Johan, B., Johan, B., Wilhelm, S., Gina, J.,2016).

Strengths and Limitations of the Study

The number of patients who offered various points of view and accounts of their experiences was a major strength of this research. Individuals may have felt more able to talk as a result of the inclusion of current therapy groups of patients, as they were already accustomed to expressing their experiences and thoughts within the community. However, including existing groups of patients may be viewed as a drawback, as existing dynamic groups could have affected individual involvement or skewed Patients' responses. While Patients were told that their involvement would have no negative effects, having focus groups on the hospital grounds could have made Patients fearful or unable to reveal any experiences of discrimination by the very health care providers who was interviewing them for fear of having their treatment jeopardized. Patients may have been inspired to participate because they were dissatisfied with their treatment and saw their participation as an opportunity to express their dissatisfaction. Since inpatient treatment varies from that provided to outpatients, the lack of inclusion of inpatients may be considered a restriction. However, more than 10% of patients had already been inpatients. Since this research was limited to a single hospital, we are unable to generalize our findings.

Recommendations for the study

In Kenya, anti-stigma approaches are needed not only for community members, but also for health care provider trainees and the very healthcare providers (Tesfaw, G., Kibru, B. &Ayano, G, 2020). Negative attitudes can emerge or be reinforced during this crucial time of academic training and continuous medical education sessions (CME), so interventions for health care provider students should be offered to reach all teachers. Since majority of specialty training focuses on teaching trainees how to recognize signs and treat them (Havnaer, A. G., Chen, A. J., & Greenberg, P. B. ,2017). To improve the quality of treatment and patients' experiences, detailed training on the impact of sero-positive status in people's lives, as well as training on how to handle people and how to cope with trainees' own burnout and implicit bias, should be included in HIV curriculum.

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