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Stigma and uptake of Antiretroviral Therapy Among Women in Rachuonyo North Sub-County, Kenya

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Keyterms: *antiretroviral therapy, stigma, women, uptake.*

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Stigma and uptake of Antiretroviral Therapy Among Women in Rachuonyo North Sub-County, Kenya

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Abstract- We investigated the effects of stigma on uptake of Antiretroviral Therapy among women attending Prevention of Mother to Child Transmission clinics in Kenya. This was a cross sectional descriptive study where all the 280 women who attended 6 health facilities in Rachuonyo North Sub County during the study period were sampled. Data were collected using questionnaires and Key-informant guide for PMTCT Health Officers in charge of the clinics. Data analyzed using descriptive statistics and using content analysis. The study established that enacted stigma influenced ART uptake by causing160 (65%) to stop taking anti-retroviral drugs, anticipated stigma influenced ART uptake by causing 177(63%) women to stop taking antiretroviral, consequently perceived community stigma influenced ART uptake by causing 168(60%) respondents to stop taking antiretroviral drugs and self-stigma led to stoppage of antiretroviral drugs among 184(66%) women. The study highlighted the need to address stigma to improve ART uptakein PMTCT settings.

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I. Introduction

Uptake of antiretroviral therapy was intended to effectively reduce mother to child transmission of HIV in order to create an HIV/AIDS free society (Giaquinto*et al*, 2005).However, women attending Prevention of Mother to Child Transmission (PMTCT) clinic continues to be heavily affected by HIV/AIDS. Globally, HIV/AIDS stigma is still a major issue hindering uptake of ART since more than thirty years after the start of AIDS epidemic (Johnson *et al*, 2015).According to Mwaura (2008), Kenyan women living with HIV are highly stigmatized and are culturally deemed worthless if unable to bear children. According to Spangler *et al* (2014), the impact of HIV related AIDS stigma must be taken into consideration in promoting HIV positive status disclosure in women attending PMTCT and maternal health services in Kenya. Thus the potential of PMTCT programmes to virtually eliminate vertical transmission of HIV will remain elusive unless HIV/AIDS related stigma is addressed (Gourlay*et al*, 2013).

According to WHO (2011) women still remains to be highly stigmatized, however the role that different types of stigma play on uptake of ART has been poorly understood highlighting the need to study the effect of stigma specific domains in order to employ stigma reduction strategies aimed at promoting ART uptake. This study investigated the effectsof stigma on uptake of antiretroviral therapy among women attending PMTCT clini inRachuonyo North Sub County in Kenya.

II. Statement of the Problem

According to UNAIDS (2001), PMTCT health care units is one of the main settings that are associated with HIV-related stigma and discrimination. Few studies have attempted to assess how these different dimensions of stigma affect uptake of antiretroviral therapy among pregnant women in high HIV prevalence settings.HIV and AIDS related stigma has been cited as posing a great challenge by inhibiting many women from seeking HIV testing services and accessing ART (NCPD, 2013).In addition, according to Stewart *et al* (2002), lack of utilization of HIV testing services is significantly associated with stigmatizing attitudes toward PLWHA which occurred due to social isolation and ridicule. This has a likely effect of affecting uptake of ART especially among women who ought to visit PMTCT regularly. Duffy *et al* (2005) further reports that issues of stigma among PLWHA are still poorly understood and often marginalized within national and international programs and responses. Stigma prevents the delivery of effective social and medical care, enhances the number of HIV-infections and diminishes the public health effects of ART because PLWHA are not able to interact with their families and the communities which is supposed to make them feel complete and be a part of the society. There is paucity of literature on how various domains of stigma influences uptake of ART in PMTCT clinics and the understanding of the mechanism on how stigma affects healthcare system remains limited (Piot*et al*, 2006)

III. Objectives of the Study

To study the uptake of antiretroviral therapy among women attending PMTCT in Rachuonyo North Sub County, the following were adopted as the objectives:

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1. To establish how enacted stigma influence uptake of ART among women attending PMTCT clinic in Rachuonyo North Sub-County.
2. To determine how anticipated stigma influence uptake of ART among women attending PMTCT clinic in Rachuonyo North Sub-County.
3. To assess the extent to which perceived community stigma influence uptake of ART among women attending PMTCT clinic in Rachuonyo North Sub-County
4. To examine the extent to which self-stigma influence uptake of ART among women attending PMTCT clinic in Rachuonyo North Sub-County.

IV. Literature Review

Uptake of anti-retroviral therapy for the sake of this paper is defined as utilizing ART services by women who are HIV positive while accessing PMTCT services in health facilities in Kenya. Literature review examining 150 journals conducted by Turan *et al* (2013) found out that HIV-related stigma can discourage pregnant women in low-income settings from seeking anti-retroviral therapy and to prevent mother-to-child transmission (PMTCT) of HIV. These findings highlight a serious challenge to international goals to virtually eliminate mother-to-child HIV transmission and reduce HIV-related maternal mortality by 50 percent by 2015.Global bodies such as The President's Emergency Plan For AIDS Relief (PEPFAR), has outlined in its Blueprint steps needed to achieve an AIDS-free generation (PEPFAR, 2012).However, a common element of these political initiatives is their recognition that reducing HIV-related stigma is critical to the success of the global HIV response and increased ART uptake. According to UNAIDS (2014), it is reported that although there is hope of ending HIV epidemic by 2030, widespread stigma still hinder uptake of antiretroviral therapy. This is attested by WHO (2011), that stigma is one of the main reason that women do not take antiretroviral drugs. According to WHO (2010), it is estimated that only roughly half of the HIV-infected pregnant women in low and middle-income countries receive ART for PMTCT despite the recent global scale up of PMTCT services, with wide country-level disparities in PMTCT coverage ranging from 5 to 10% in Sudan and Chad, to 80 to 90% in South Africa, Botswana, Swaziland, and Namibia. The poor uptake of ART could be attributed to experiences of stigma among the pregnant women. In another qualitative study conducted in Zambia, enacted stigma emerged spontaneously as the second most frequently listed reason women do not begin ART in a qualitative study in Zambia(Murphy *et al*, 2006).This parallels a large household-based study conducted in Kenya which found out that 75% of HIV-positive respondents had experienced "enacted stigma" (Odindo and Mwanthi 2008)

Many people living with HIV face high levels of stigma and discrimination despite comparatively high levels of awareness of HIV and AIDS in Kenya. Stigma and discrimination has been shown to affect women in Kenya from seeking vital HIV services (UNGASS, 2014).In a study in Rural Kenya by Turan and Cohen *et al* (2010),it was demonstrated that anticipated stigma regarding HIV/AIDS stigma can be a barrier to acceptance of HIV testing by pregnant women, even in an environment where HIV testing in the antenatal clinic is becoming the norm. In another study by Colombini *et al* (2014) conducted in Kenya, it was reported that women attending HIV integrated services experienced anticipated stigma and this was exacerbated by the actions of health care providers. Another study carried out by Dlamini *et al* (2009) in five countries viz: Lesotho, Malawi, South Africa, Swaziland and Tanzania found out that there was a significant relationship between perceived HIV stigma and self-reports of missed medications over time. Individuals who reported missing more ARV medications also reported higher levels of perceived HIV stigma. Therefore, the reason for poor uptake and adherence of ART is linked to stigma experienced by people living with HIV. Existing HIV related stigma may be thus properly addressed if the extent to which specific stigma domains affect uptake of ART is known of which this paper aims to answer.

V. Method

The research employed descriptive survey design. Since it was not possible to study the entire Rachuonyo North sub county, stratified sampling was employed to come up with 2 strata; each stratum belonging to each division. Thus the two divisions which were studied were Karachuonyo East and Karachuonyo West division. Three facilities in each stratum were purposively selected having met the predefined criteria. The criteria was arrived at looking at the number of new ANC clients received which had to be more than 160 clients per year and the location of the health facility. A sample of six facilities was used to establish parameters that may be used to generalize entire sub county. All clients who are issued with anti-retroviral prophylaxis are registered at the PMTCT clinic using PMTCT register which also contains demographic information accessible to District AIDS and STDS Control Coordinator (DASCO).The researcher worked closely with DASCO to identify 280 women in these facilities who were interviewed. Snowball sampling was used to recruit those who may have defaulted ARV drug prophylaxis in the course of taking the treatment regimen and did not present to the clinic. Questionnaires were used to collect data from women attending PMTCT while key informant guide was used to

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collect data from six health officers in charge of PMTCT clinics within the study region. Descriptive statistics was used to analyze quantitative data while qualitative data was employed to analyze qualitative data.

VI. Results

1. It was found out that 160 (65%) women stopped taking anti-retroviral drugs due to experiences of enacted stigma. It was also reported that enacted stigma did influenceuptake of ART since 57 (29.84%) women missed their clinical appointments once, 35(18.32%) missed their clinical appointments twice, 52 (27.23%) women missed their clinical appointments thrice, 30 (15.71%) women missed their clinical appointments four times and 17 (8.9%) women missed their clinical appointments five times.
2. Anticipated stigma led 177(63%) respondents to stop taking anti-retroviral drugs which resulted to decreased uptake of ART. It was also found out that 56 (30%) women missed their clinical appointments once, 38(20%) women missed their clinical appointments twice, and 51 (27%) women missed their clinical appointments thrice, 29 (15%) missed their clinical appointments four times and 15(8%) women missed their clinical appointments five times. This indicates that uptake of ART was reduced as a result of frequent interruptions of antiretroviral drugs.
3. Perceived community stigma was expressed heavily by women who were avoided due to their HIV status which represented 130 (46%) respondents. Findings showed that 168 (60%) women stopped taking antiretroviral drugs as a result of perceived community stigma which implied that ART uptake was reduced. It was also found out that 106 (38%) respondents missed their clinical appointments once suggesting that perceived community stigma hindered uptake of ART.

HIV self-stigma was widely reported among the respondents with 105(38%) women who preferred not to disclose their HIV status for fear of being stigmatized. Self-stigma experienced by women attending PMTCT clinic caused 184(66%) respondents to stop taking antiretroviral drugs leading to low uptake of ART. It was further revealed that 57(20%) respondents reported to having missed their clinical appointments thrice which implied that self-stigma is a barrier to improved uptake of ART.

VII. Discussions

Enacted stigma due to family members was noted to have influenced 155 women representing 55% of the respondents. Enacted stigma was expressed due to discriminating attitudes emanating from spouses, friends and those who lost their jobs. In one of the instances, one woman reported. ''*When my husband returns home in the evening he feels very reluctant to share with me supper…and sometimes I am left to take my meal alone with my children. Often times he has preferred not to share with me the same bedroom at night.''* In contrast, a study by Or za*et al*,(2015) revealed that discrimination from family due to enacted stigma contributed to violence within the family. Our study is consistent with another study in China which showed that enacted stigma manifestations within domestic spheres were most obvious (Yu *et al*, 2016). One respondent who missed her clinical appointment thrice due to enacted stigma had this to say: *'' I always fear what my relatives would think should they see me visiting PMTCT health facility to obtain the antiretrovirals. These hindered me from accessing health facility three times in order to replenish the stock of drugs I was given since the last visit.''* These findings are similar to another study done in Asia by Wasti*et al*, (2012) where one of the respondents reported that ''*I am worried about meeting my neighbours in hospital for refills [ART]. All the time I worry: "How can I hide from these people?" One day I did not refill my ART due to bumping into relatives (P - 4, Female, Kathmandu).''* These findings reveal that fear of exposure to the ART facility which may be in PMTCT setting is likely to lead to low uptake of ART

Anticipated stigma was also experienced within PMTCT settings. Our study shows that 113 (40%) respondents feared taking HIV test as a result of anticipated stigma. One of the respondents had this to say: *'' When I visit PMTCT health facility unit. I refuse to take HIV test fearing that the test results may indicate that I am HIV positive.I am disturbed on how I will be perceived as a result of my status.*'' This finding agrees with another study carried out in Uganda by Nannozi*et al*, (2016) which revealed that fear of a positive HIV test result emerged as a key barrier at HIV testing centers. . Findings revealed that as a result of anticipated stigma that was experienced by women attending PMTCT, 177(63%) respondents stopped taking antiretroviral drugs and thus leading to poor uptake of ART. This was further confirmed by a key informant, an officer in charge of a PMTCT clinic at Kandiege Sub-District Hospital, who reported as follows:*'' Anticipated stigma has particularly caused 61% of the women to stop taking antiretroviral drugs. This is quite alarming to us, but we are doing our best to talk to donors and other stakeholders in a move to increase uptake of ART.''* We found out that anticipated stigma was experienced by the study participants and this resulted to a reduced uptake of ART in the health facilities within the study area. One respondent who missed clinical appointment once due to anticipated stigma reported in this manner: *''I was ashamed to visit PMTCT clinic because of the way I was mistreated at Kendu Sub-District Hospital.I*

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heard a peer educator at the clinic who made a nasty comment about my HIV status and this made me to miss my clinical appointment.'' These findings agrees with another study carried out in Nigeria by Anígilájé*et al*, (2016) where a focus group discussant reported that ''*I stopped coming when I was treated with disrespect and contempt by the ANC nurse. She made uncomplimentary comments about my HIV status. I felt if she could behave like this now, how she will behave when she has to take my delivery dealing with my blood.''* This report suggests that anticipated stigma due to poor health care services at PMTCT clinics may contribute to women defaulting in taking of antiretroviral drugs and this may lead to poor uptake of ART.

Feelings of isolation due to perceived community stigma were expressed among 130 (46%) women. One respondent stated in this manner: *'' A number of times I have felt socially rejected when I have been isolated from taking leadership responsibilities within the community. Often I have felt very embarrassed but I have struggled to cope with it.''* These findings are in harmony with another study by Sandelowski *et al*, (2004) which revealed that women living with HIV/AIDS experience panic and social rejection within the community and this may affect their health seeking behavior for HIV care and treatment and thus leading to low uptake of ART.Findings showed that 168 (60%) women stopped taking antiretroviral drugs as a result of perceived community stigma. One respondent who stopped taking drugs as a result of perceived community stigma reported:*'' I got so embarrassed that I declined to visit Wagwe Health center to take my medication.''* This statement was further confirmed by a key informant at Wagwe Health Center who reported that: *'' Perceived community HIV stigma is common around this region.HIV infected women feel so ashamed of their HIV positive status that they prefer to be isolated. This has caused them to fear coming to the clinic to obtain their medication.''* This suggests that perceived community stigma result to a decreased uptake of ART by causing women to stop taking antiretroviral drugs. Perceived community stigma further contributed to at least 106(38%) respondents reporting that they missed their clinical appointments once. One of the respondents reported in this manner:*'' I have felt so isolated by my community due to my HIV status that I missed taking a refill of my drugs at Kendu Adventist Hospital once and instead I have resorted to take my drugs at Miriu Health Center where I am not known by majority.''*. This view was confirmed by a key informant at Miriu Health Center who reported that:*'' some clients have since transferred from their nearby health centers and have requested to be enrolled at Miriu Health Center. My greatest concern is that if they take long to come to our facility then it might affect uptake of ART.''* The findings were further confirmed by a study in Malawi by Elwell (2016) which found out that community based HIV stigma hindered participants (PMTCT patients) from accessing care and treatment in PMTCT program thereby leading to a poor uptake of ART.

Self-stigma was widely reported among the respondents with 105(38%) women who preferred not to disclose their HIV status for fear of being stigmatized. One respondent who preferred not to disclose her status reported in this manner:*'' I fear informing my husband of my HIV status because, he will beat me and accuse me of infecting him with HIV.''* This implies that women may not seek for PMTCT services because of physical violence which is likely to affect ART uptake. This is further confirmed by a study carried out in rural Kenya by Walcott *et al*, (2013) which reported that fears of abuse—including being blamed for the infection, break-up of the relationship, and bodily harm—served as contributing factors to non-disclosure of one's HIV status which has a likely effect of reducing uptake of ART. As a result of this situation, 184 (66%) women reported that they stopped taking antiretroviral drugs which brought a deleterious effect on uptake of ART. *'' most women who visit our facility suffer from self-stigma. Last month alone about 25% of women who visited PMTCT clinic reported to have suffered from self-stigma.''* These findings agree with previous study carried out in United States by Rao*et al* (2007) which reported that fifty percent of respondents skipped their doses because they feared family or friends would discover their status which highlights that self-stigma may lead to a low uptake of ART. Findings are also consistent with a study in Asia which found out that self-stigma experienced by HIV infected pregnant women hindered uptake of ART by causing these women to avoid seeking drug prophylaxis at parent to child transmission of HIV services offered in health facilities (Rahangdale*et al*, 2010).This suggests that interventions to reduce self-stigma is critical towards improving uptake of ART.

VIII. Conclusion

Our study concluded that enacted stigma does influence uptake of antiretroviral therapy. There is need to enhance ways of reducing enacted stigma among women to improve ART uptake. It was concluded that anticipated stigma caused majority of women to be mainly stigmatized at the health care facilities thus leading to a poor uptake of ART. There is need to review capacity of health care providers to ensure professionalism is maintained at health care facilities. it was concluded that perceived community stigma led to majority of women being avoided or isolated within the community and this led them not to access clinical appointments for fear of being noticed which resulted to poor uptake of ART. There is need to for the government

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to tackle this kind of stigma at community level by ensuring that resources are available. It was further concluded that self-stigma did influence uptake of antiretroviral therapy by causing women to feel embarrassed and ashamed of their HIV status and consequently this led to stoppage of antiretroviral drugs highlighting the need to enforce self-stigma reduction measures.

IX. Recommendations

1. The researcher recommended that the county health director should enhance awareness methods of enacted stigma and its impact on AIDS epidemic.
2. The researcher recommended that anticipated stigma-discrimination reduction workshops to be held especially at health care settings. This will ensure that suitable ways are identified to reduce anticipated stigma.
3. The researcher recommended that perceived community stigma can be tackled by disseminating and promoting the use of tools for effective advocacy and action, such as the evidence-based talking points and the case studies of successful interventions.
4. The researcher recommended that government should adopt national policies that seek to address self-stigma experienced by women. By allocating resources and involving health stakeholders and Non-Governmental Organizations women may be properly educated towards overcoming self-stigma.

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