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Expanding Marginalisation in Pharmaceutical Citizenship: A Case Study of an Antiretroviral Therapy User

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Abstract In current global health discourse, access to medicine (pharmaceuticals) has been framed as a form of human right. Inspired by this global health agenda is a wide array of social scientific studies that articulate access to medicine as a form of citizenship. Prominent among these studies is the notion of pharmaceutical citizenship that articulates inaccessibility to pharmaceuticals as marginalisation, and access to medicine has ushered pharmaceutical citizenship – in bringing marginalised people back to society by removing the marginality imposed by their inaccessibility to medicine. Following the critique of marginalisation as inapplicable in resource-rich contexts or settings where access to medicine is free for certain health conditions like HIV in Argentina, Brazil, Nigeria and Venezuela, this paper however expands the domain of marginalisation by defining it as the loss of membership of social group(s) following the onset of health conditions. Through a case study interview that offer insights into the local world of an HIV-positive patient in Nigeria, it was found that HIV-positive individuals are marginalised based on their health conditions, and access to free antiretroviral medications in the Nigerian context offered pharmaceutical citizenship to HIV-positive individuals in regaining the lost social membership and reintegrating them into the mainstream of society. Expanding the notion of marginalisation has helped to expand and enrich the analytical value of pharmaceutical citizenship as a viable universal concept.

Keywords Pharmaceutical citizenship, Marginalisation, HIV-positive people, Human/citizenship rights, Nigeria

1. Introduction

The current global health discourse that conceptualised medication as a form of citizenship and human right (Nguyen 2005; Biehl 2007; Cataldo 2008; Persson et al. 2016) has inspired a wide array of social scientific studies that problematise citizenship within the context of biomedicine (Rose & Nova 2005; Nguyen et al. 2007). Prominent among these studies is Stefan Ecks' (2005) notion of pharmaceutical citizenship, which articulates marginalisation as a form of social inequality in term of access to biomedical treatment. Central to the concept of pharmaceutical citizenship is the relationship between marginalisation and medicine, in which inaccessibility of pharmaceutical drugs has contributed to depriving the patients of the basic human right to biomedical treatment. Using the marketing of anti-depressant drugs in India as a useful case, Ecks, therefore, posited that pharmaceutical citizenship is about restoring back to society those that are at the margins of society (disadvantaged and stigmatised people) by removing the marginality imposed by their inaccessibility to medicine. Ecks' work is significant for two reasons: first, it provides an important conceptual framework for articulating the biomedical promise of demarginalisation, implicit in the anthropological discourse on 'citizenship' across a range of cultural contexts. Second, Ecks' work deepens the social science engagement on biomedicine beyond clinical/medical purposes of protecting populations and empowering individuals (Persson et al. 2016). Despite this important contribution, Ecks' notion of marginalisation is limited to the resource-constrained contexts where access to medicine is restricted to patients who need them. Therefore, marginalisation cannot be unproblematically applied in resource-rich contexts or developing countries where access to medicine is available and free for users. For instance, access to antiretroviral medications is free for people living with HIV in Brazil (Biehl 2004, 2007; Galvao 2005), Nigeria (Monjok et al. 2010) and Argentina and Venezuela (Chequer et al. 2002), and therefore, marginalisation is not applicable in these contexts. Access to free antiretroviral therapy in these countries has achieved more than its original aim of health maintenance and survival. It has now constituted not only the appropriation of a set of rights and responsibilities associated with citizenship or what Nguyen et al. (2007) regarded as 'therapeutic citizenship', but the fulfilment of 'biomedical promise of demarginalisation' as encapsulated in Ecks' pharmaceutical

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citizenship. Despite this shortcoming associated with pharmaceutical citizenship, Persson et al. (2016) uncritically utilised the concept to a resource-rich context like Australia where antiretroviral therapy is free and accessible to HIV-positive individuals.

What is problematic in these studies, however, is that pharmaceutical citizenship as a conceptual tool rests on marginalisation, and if marginalisation is therefore not suitable in Argentina, Brazil, Nigeria and Venezuela in terms of access to HIV therapy, then the concept of pharmaceutical citizenship is not a viable concept that can be applied across global contexts. It is marginalisation, not pharmaceutical citizenship that is problematic in Ecks' framework. Therefore, pharmaceutical citizenship as a conceptual tool cannot be effectively applied to a wide range of contexts if not expanded.

To expand the scope of pharmaceutical citizenship, one possible way this paper posits is by expanding the scope of marginalisation to accommodate an alternative perspective, one located within the broader context of social membership, rather than inaccessibility of pharmaceuticals. Marginalisation, in this case, is defined *as the loss of membership of a social group due to the onset of health/illness condition*. The marginalisation that pharmaceutical citizenship removes is the restoration and regaining of lost social membership following the accessibility and use of medications by the marginalised. In this regard, expanding the scope of marginalisation here is not just about rescuing pharmaceutical citizenship, but about expanding the scope of pharmaceutical citizenship to accommodate a new reality. Therefore, the conceptual claim of pharmaceutical citizenship is not invalidated, as the concept still retains the explanatory power of its articulation.

This paper began by espousing marginalisation within the wider domain of citizenship and social membership, before mapping out the methodological background for this study and then presenting the result of this study. The discussion and conclusion would assess the findings of this study in relation to other studies on marginalisation and pharmaceutical citizenship and evaluating it in relation to current global health discourse on access to biomedicine as a form of citizenship/human right. Drawing from a case study of an antiretroviral medication user in Nigeria, this paper posits that pharmaceutical citizenship removes marginalisation through the restoration and regaining of lost social membership, following the accessibility and use of medications by the marginalised. The use of Nigeria as a case here is significant because the country has been offering free antiretroviral therapy (ART) to HIV-positive people since 2002, and the beneficiaries of the treatment (HIV-positive individuals) have appropriated the ART, not only as parts of rights and responsibilities, but 'as a political claim to belonging' (Nguyen et al. 2007: 34) to the Nigerian community and identification as citizens based on their biological/illness condition.

2. Citizenship, Marginalisation and Social Membership

The concept of citizenship has a long but contested trajectory in anthropology, sociology and political science. Following the articulation of 'social citizenship' by H.T Marshall (1950) in his analysis of the welfare state, the avalanche of studies spawned by this quest has ushered floods of conceptual discourses (such as inclusion, exclusion or marginalisation), in which anthropologists and sociologists have taken a keen interest. Using Britain as a useful example of a welfare state, Marshall defines citizenship as 'status bestowed on those who are full members of a community. All those who possess the status are equal with respect to the rights and duties which the status is endowed' (Marshall 1983 [1950]: 252). The incorporation of membership of a community depicts that Marshall's remit of citizenship seems more encompassing than just the legal status of an individual, and this provides the basis for the separation of legal and political questions of citizenship from social citizenship. The major thrust of the Marshallian thesis is about making a case for unemployed, poor single mothers, disabled people and others who possess legal status as citizens but have been left out of and excluded from participating in the labour market in the post-war era (Handler 2003).

Marshall's position is about how those who have been socially excluded by homelessness, poverty, sickness, disability, old age and hardship can be fully re-integrated into full citizenship through welfare provision and benefit systems (King & Waldron 1988). Therefore, social citizenship is about granting accessibility to state welfare provisions for the socially excluded as a member of a community/state. In this sense, the implication of Marshall's notion of social citizenship is the nexus between marginalisation and social membership. This stems from the fact that socially excluded people might possess legal/political citizenship of the state, but they are marginalised as social members of the community or state. The consequence of marginalisation for this group is the loss of sense of belonging as a member of a community (social membership), but not of legal/political rights as citizens of the state. The loss of social citizenship is the loss of sense of belonging/membership of a social group, which marginalisation explicates.

In the context of this paper, the social group is defined as a collectivity of two or more individuals who are in a state of interaction, and whose forms of interaction shape and influence one another in a reciprocal dimension (Pescosolido & Rubin 2000; Jenkins 2014). In this sense, family, friends, peer groups, community clubs, occupation group, religious associations and other social networks constitute multiple sites of a social group. The social relations that underpin the membership of these social groups are forged through mutual interactions with shared beliefs and values (Scott

1988). In sociological parlance, society is usually organised into groups, of which individuals become members (Watson 1970). Individuals often hold membership of more than one social group simultaneously. The loss of membership of a group may not necessitate the loss of membership of another group to which one belongs. Membership of any social group means having a sense of belonging, which is 'the ability to influence one's destiny by having a significant voice in basic decisions' (Rosaldo 1994: 402) in the group.

Individuals could be marginalised from a social group due to many reasons, but marginalisation based on health conditions has received renewed attention in social science literature (Secker et al. 2001; Faiers 2004; Spandler 2007). A wide range of literature has demonstrated how individuals suffering from leprosy (Grainger 1992; Bhatt 2007; Ramasamy et al. 2018), mental health (Scull 2015) and epilepsy (Grunitzky et al. 2000; Ani et al. 2011) have been marginalised in recent decades across the global context. For instance, Scull (2015) reported how over 2,000 mentally ill patients were confined to asylums/psychiatric hospitals in the 1930s. Scull asserted that state institutions in Europe justified the continued existence of psychiatric hospitals as a means of excluding mentally ill individuals from the rest of society. The account of Scull depicts that marginalisation is socially enacted based on health conditions.

However, in the contemporary epoch, one of the health conditions through which individuals could be marginalised is HIV. When HIV/AIDS emerged in the early 1980s, it was regarded as an acute condition which 'causes fear of contagion among those who are healthy' (Sandstrom 1990: 271). HIV/AIDS, however, generated public health concerns, moral panic, negative stereotypes and intense 'public reactions to persons presumed to be infected by HIV' (Herek & Glunt 1988) in western and non-western countries. In fact, the liberal toleration of the gay community in the United States became an uncertainty as the epidemic 'generated new fears and heightened old hostilities' (Brandt 1988: 367). Public understanding of the epidemic at the time was conceived as 'the gay plague', 'the intravenous drug user syndrome', and as a disease emanating from behaviours that were traditionally regarded as deviant (Herek & Glunt 1988). Due to this public perception of HIV, the marginalisation of people living with HIV ensued.

In the Nigerian context, when HIV emerged in the mid-1980s, its treatment (drugs) was not only expensive but also not readily available and HIV/AIDS became an acute illness with sure and certain death (Adedokun et al. 2006). HIV was a life-threatening disease that was feared and regarded as deadly, dangerous, contagious and depraved (Joffe 1999; Persson 2005). The media portrayal of HIV patients heightened the negative public perception of the disease, and hence entrenched the culture of marginalisation (Babalola 2007). Religion further reinforced the cultural inscription of HIV as a product of spiritual pollution and immorality that manifested from promiscuous, adulterous and sinful sexual practices (Palmer 1989; Aguwa 2010). Churches and other religious organisations, as Palmer (1989: 50) posited, 'condemn AIDS victims and excludes them from their congregation' and thus placed the burden of guilt on the victims or patients (Tocco 2010).

The social meaning of HIV, as Conrad (1986) pointed out, hinges on how cultures define an illness as devastating and its consequences as a moral shame to those who had the ill-luck to be infected by it. The loss of membership of social groups such as religious organisations, friends/families and other social networks for people living with HIV is the consequences of marginalisation that is based on peoples' responses to HIV. This loss of social membership does not invalidate their legal/political citizenship of the state, as HIV-positive individuals can enjoy all the rights, status and responsibilities of being citizens. Therefore, the loss of social membership is the loss of social citizenship, as people living with HIV are marginalised from the social group to which they hitherto had a sense of belonging.

The nexus between social citizenship, marginalisation and social membership illustrates how social relations are shaped and reshaped by health conditions, and how Marshall's project is significant in reintegrating the socially excluded and marginalised people (especially HIV-positive people) into full citizenship of the society or state. Despite this loss of membership, the question of how the biomedical promise of antiretroviral therapy can restore and reintegrate people living with HIV to the mainstream of society remains a largely uncharted course. This question, which is central to the overall argument in this research, shall be explored later in this paper.

3. Methods and Background to the Study

This research is based on the case study data of a participant that was recruited from HIV support group in south-western Nigeria through in-depth interview. The participant was the beneficiary of free antiretroviral therapy programme in Nigeria, as well as other HIV care services in Nigeria such as free pre-treatment testing and counselling services, Prevention-of-Mother-to-Child-transmission (PMTCT) for women, health education and post-treatment testing and counselling services (Ahmed et al. 2013; Oleribe et al. 2014; Ajagu et al. 2017).

The marginalisation that was experienced by the participant was not due to a lack of access to free antiretroviral drugs and other HIV care services. Rather, it was due to the loss of social membership within her familial context. In this study, the use of family as an important case of social group membership, stemmed from the role that it plays in fostering the marginalisation and neglect of HIV patients in terms of care especially in an African context in anthropological literature (Setel 1999; Dilger 2006; 2008; Mattes 2012; Seeley 2014; Moyer & Igonya 2014). In HIV context, a family's failure to care for HIV patients, as Moyer and Igonya (2014) observed, is underpinned by discrimination and marginalisation, where family members consider HIV patients as individuals who bring shame to their family (Dilger 2008; De Klerk 2013). In this sense, the evasion of care and responsibility by family of HIV patients formed the basis for discrimination and marginalisation for two reasons. First, family members neglected caring for the HIV patients and blame them due to the cultural understanding of HIV in Nigeria, which has been stated earlier. The second reason is the fear of contagion (Walusumbi & Okonsky 2004). Indeed, the family members fear that they might be infected with HIV if they provide a duty of care. Therefore, marginalisation rooted in the evasion of care for HIV patients by their families in anthropological research, is an important issue that this study explored.

The participant was purposively selected for this study because of two reasons. First, the participant's experience is suitable in understanding, explaining and describing how marginalisation was experienced, and how accessibility to ART ushered pharmaceutical citizenship that helped to regain lost social membership. The participant's experience challenges previously held assumption about marginalisation, and therefore, recognises the importance of new insights on marginalisation that differ from what was regarded as basis of the theoretical frame of pharmaceutical citizenship.

Second, the participant's accounts provided applicability of the global from the local world (Yin 2003). In this regard, the generalisability of results from the participant's accounts helps to strengthen the conceptual and theoretical framework of marginalisation and pharmaceutical citizenship across the global context and not to specific populations where multiple cases or samples might be required (Yin 1994). HIV support group was utilised to recruit the participant because it provides spaces that produce a sense of community and which are freer from judgement and are sites where information and experiences are shared (Barbuto et al. 2011). Following ethical approval by the Royal Holloway University of London Research Ethics Committee and Ondo State Health Management Board, interview was conducted between February and April 2018. The single case or case study approach was chosen because the study is theory-driven (Yin 2003) and the case helps 'to describe an intervention or phenomenon and the real-life context in which it occurred' (Baxter & Jack 2008: 548). The concept of marginalisation, which this study explores, is appropriately informed by theory, and the use of case study will help to expand the boundary of such theory. Therefore, the participant's account was oriented towards describing marginalisation in the health context in which it occurs, with a view to expanding the theoretical framework of pharmaceutical citizenship.

The interview was conducted in Yoruba and translated into English by the author. Prior to translation, active participation in the interview transcription helped the author to be familiar not only with the interview data but to understand the grammatical structures of Yoruba in which participants expressed themselves and translated the text into English. The mastery of these grammatical structures enabled the author to map out words that have several meanings and their appropriate meanings for translation purposes without alterations in meaning. The conversion and translation of data from Yoruba to English require not only the grammatical structures of both languages but proficiency and accuracy in both languages, which the author possessed.

Following the transcription and translation of the interview data, a deductive thematic method was used to analyse the data (interview) collected or the accounts that participants constructed around marginalisation and access to and experience of ART use. Deductive thematic analysis treats the entire thematic analysis as a form of data that emerged as a process of construction from the pre-conceived theoretical viewpoints of the researcher (Braun & Clarke 2006: 84). In other words, deductive thematic analysis is usually theory-driven where coding of data is fitted into the researcher's existing theoretical frameworks.

Below, a case study of Kunbi Joseph (a pseudonym), a 52-year-old-woman who has been living with HIV for 19 years, and has been using antiretroviral drugs for 18 years is presented, and her account or experience of marginalisation sheds important light into the local world of an antiretroviral therapy user. Insight into the local world of Kunbi (a participant) was unpacked through deductive thematic analysis, where the meaning of marginalisation and pharmaceutical citizenship that the participant acquires in their everyday life is fleshed out, which is a confirmation that ART has an important meaning in the life of its users beyond the treatment of HIV conditions.

4. The Familial Background of Kunbi

The family, as a social group is the first community in which a person is born and belongs. It is a group where one acquires an understanding of the world, culture, social behaviour, and social roles. As a site of kinship, network, and relationships, family serves as the significant fulcrum of social membership in terms of parent-child or sibling relationships (Arce 1970; Di Falco & Bulte 2011; Roberts & Dunbar 2011; Hedin 2014) and is the link through which social relationships with nephews, nieces, cousins and other family members are forged. Kunbi initially came from a nuclear family, which comprised of her father, mother and their eight children (five males and three females), all of whom living together in the family house and compound. The transition from nuclear to extended family began when the spouses and children of Kunbi's siblings lived together. Kunbi was the third child in the family and had a caring and loving relationship with her family until she was diagnosed with HIV:

> *I had a wonderful relationship with my brothers and sisters and their respective families. Our parents gave birth to eight of us, and I am the third child. As a family, we loved each other and cared for one another, and lived peacefully within our parent's house and compound. Even when our parents died, we lived peacefully and never quarrelled over their properties.*

> *Like siblings, we used to have small fights, and whenever we fought over something we called a meeting to resolve it..... During my first wedding ceremony, they were there for me, and offered child support when I had my first two children from my first marriage. To be honest, we loved each other and paid attention to each other's well-being until HIV ensued. It was when I built my house that I left the family compound. Even at my house, they (family members) used to come, sometimes every two weeks, and sometimes every month, and they stayed like for a day or two in my place.*

This narrative mapped out the contextual nature of Kunbi's familial structure, including the family size and the kind of social relationships that ensued among the siblings before the onset of HIV. Kunbi's family constituted an important social group, comprised of siblings and their spouses and children that formed the social membership of the group. The membership of this social group is associated with certain rights, responsibilities and statuses that are attached to it. The loss of membership of this social group means a loss of a sense of belonging and an inability to enjoy these rights, responsibilities, and statuses — which marginalisation indicates. This experience of marginalisation is explored in the latter part of this article.

5. Marginalisation at the Onset of HIV Diagnosis

Marginalisation is rooted in the cultural understanding of HIV in Nigeria. The cultural understanding of HIV was that there was no cure for it and whosoever is infected with HIV has got his/her death warrant. Therefore, people living with HIV are culturally regarded as morally perverted, adulterous, promiscuous or sex workers (Smith 2007). As a new terrifying disease, HIV possessed the 'emergence of a disease whose charge of stigmatization and whose capacity to create spoiled identity was far greater' than any other in modern history (Sontag 1978:16). Because of this, in most sub-Saharan African societies, especially Nigeria, HIV was regarded as a viral enemy which was 'identified with evil and attaches blame to its victims' (ibid). This negative stereotype associated with HIV in Nigeria provides the basis for the marginalisation of people living with HIV.

Prior to the onset of HIV, Kunbi was a small business entrepreneur who had a hotel business, properties (land and houses) and financial wherewithal. Kunbi is a single mother with three children, whose past life is characterised with sizeable financial wherewithal and she was not socially marginalised before getting HIV:

> *Then I live a good life. I have money and I don't experience any hardship. I eat whatever I want to eat. I can even eat six times in a day because I have the money and I worked hard for it.*

Living a good life, in Kunbi's narrative, is synonymous with having money to solve one of the basic problems – food, in a country where more than 80 million are living in poverty and malnutrition (Brookings Institution 2018). Despite her little education as a primary school graduate, Kunbi possessed significant business acumen and prowess that enabled her to resolve the problem of poverty and malnutrition prior to her HIV diagnosis. The onset of HIV, however, culminated into the outset of marginalisation for Kunbi among her significant others (family):

> *When I was diagnosed with HIV, I was told there is medication for it. The cost of HIV medication at the time was ₦200,000 (£760) then per month. I sold my land, my house and car to buy the drugs. Though, there was no way I can afford the medication cost without selling my properties. But what prompted me to sell those properties was when my family told my first son that if I die, they won't bury me in my house. Then the child said it is better to sell that house than to be buried anywhere other than my house.*

Being diagnosed with HIV inevitably triggers discrimination and marginalisation from her family members, who sever their ties with her. This is because if one member of the family dies due to HIV and neighbours and the public are aware of it, the entire family will be stigmatised and marginalised in the public space. The marginalisation of Kunbi by her family was orchestrated because they considered having HIV as a 'character blemish' (Alonzo and Reynolds, 1995), liable to bring shame to the family.

Therefore, the entire family did not want to have anything to do with Kunbi, and even her corpse (if she dies), and therefore contemplated burying her corpse at a public cemetery, far away from her home (which is a few meters to the family house). Although, the family would have permitted the corpse to be buried in her home, provided the house is far from the family compound. Due to cultural factors, Nigerians do not use community or public cemeteries; rather human remains are buried in either the individual's home or 'around family compounds, often in shallow and sometimes unmarked graves' (Zume 2011: 609). Public cemeteries thus provided the family with the opportunity to avoid public shame by dissociating themselves from the death of HIV-infected relatives / kinsmen. Kunbi evoked marginalisation from her family as the motivating factor for the sale of her properties, even when it was obvious that personal financing of her medical bill would be unsustainable over time.

However, when Kunbi sold her house and other properties, she moved to the nearby family house where she experienced the worst form of marginalisation within her family circle:

> *In my family house, I faced a lot of hatred and prejudices from my family member. While foods are served with ceramics/stainless plates with other members of the family, they serve me with plastic / rubber plates, rubber cups and rubber spoons. One day, I went to market to buy my own ceramic plates and cup, saying I don't like those plastic something again. One*

> *of my elder brothers forcefully took those ceramic plates I bought from me and said that I am not entitled to use them because very soon I will die.*

With an HIV diagnosis, Kunbi was marginalised from the participation in family activities, because of the expectation of her imminent demise. The family members were not happy that Kunbi resided in the family house (the house belonged to their deceased father) with them, and she was thus subjected to dreadful forms of marginalisation among family members. As De Bruyn (1999) noted, the marginalisation meted out to Kunbi by her family stems from the perception that HIV was considered as a contagious disease that constitutes a threat to the entire family. The threat in this case not only hinged on the contagious nature of HIV, but from the moral shame and reputational damage it may bring to the entire family.

In Nigeria, children below the age of 6 are often served foods with plastic plates, plastic cups and plastic spoons. Furthermore, plastic plates are usually used to feed pets (cats and dogs) and goats within domestic dwellings. Therefore, using plastic plates, cups and spoons to serve Kunbi means that she has been stripped of her personality, dignity and identity as adult and human, and relegated to the position of child or animal. Even when she objected to this relationship and procured her own ceramic plates, cups and silver spoons, they were forcefully taken away from her. This indicates that Kunbi, like other people living with HIV, was at risk of experiencing or being the target of physical violence (Sengupta et al. 2010). The loss of citizenship (as a member of a family) is the denial of one's membership of a social group, and thus necessitates the relegation of Kunbi to the margin of the group as inconsequential:

> *They separated themselves from me and separated my things from their things as if I am a leper. One day I told my immediate senior brother that I'm hungry and that he should give me money to buy food. But he said that I should go back to where I got my ill-luck (HIV) from and asked them to feed me. That word that came out from my direct brother made me to weep profusely, and I thought of committing suicide. I became worried not only about my condition but as a result of hatred and prejudices that I faced from my family members. In fact, one day I drank a poisonous chemical called Gamalin 20, and when I observed that I did not die, I hung myself with a rope on a tree, it was people from nearby church that came to the rescue. Because of these occurrences, I was placed on suicide watch. Also, I went to the market to buy a big knife to kill myself, it was our neighbour that forcefully took the knife from me. All my family members distanced themselves from me.*

The loss of social membership means relegation to a pariah status within the family space, where Kunbi was banished to the margin of a social group as outcast or leper. She was therefore pushed to the edge of the group by denying her identity, an active voice or her status and place within the family. Ostracising Kunbi from family activities means she was marginalised from family meetings where key decisions would have been made. In this regard, marginalisation for Kunbi was thus about being stripped of rights and status of a person or group who is a full member of a social group or society as a result of a health condition. This loss of rights means the inability 'to influence one's destiny by having a significant voice in basic decisions (Rosaldo 1994: 402) as a member of a social group.

From the account above, the structure of social relations that embed Kunbi within her family context, enabled marginalisation by facilitating social isolation, social rejection, decreased social support and verbal abuse (Buseh & Stevens 2006; Bogart et al. 2008; Dowshen et al.2009; Block 2009) that inevitably paved way for Kunbi to consider 'egoistic suicide'. Egoistic suicide occurs when individuals commit suicide because they are not sufficiently bound to social groups or were left with little social support (Berk 2006). For Kunbi, the loss of social membership meant having no sense of belonging to a group or family's collectivity and being socially disintegrated from one of the important social institutions in the society (family). This social disintegration ushered by the strained nature of socio-familiar relations, gave rise to loneliness and despair for Kunbi and contemplating suicide or struggling to find reasons to live. This strained nature of socio-familiar relations constitutes socially disintegrative consequences for the extended family, which is the pillar of social support in Nigerian family system (Unanka 2002; Okumagba 2011).

6. Towards Demarginalisation: Accessibility of Free Antiretroviral Medications

Despite the loss of social membership, Kunbi's rights and status as a legal citizen of the state (Nigeria) were intact and was invoked when the cost of ART medications was unsustainable:

> *After spending all my money on medications, it came to a point that I came out and went to [my] state government to assist in subsidizing my medical bills in 2002. When I went to ministry of women and youth affairs and disclosed my HIV status, the state government gave me an apartment to live, and I was shown on television, where I granted live interviews about my experience of living with HIV. I later anchored a weekly phone-in HIV programme on state television, and my telephone number was displayed on the television screen and people started calling me and asked If I am the one who used to own (hotel) at a specific place and I said yes. That was how I was known everywhere in the state. I was enrolled on free antiretroviral therapy programme where I was given drugs every three months.*

Kunbi and other people living with HIV in Nigeria are not marginalised or lived outside the society in terms of access to antiretroviral therapy, but are living inside the structure of familial relationship and membership that marginalised and made them 'others' in the society. The appropriation of antiretroviral drugs as a form of 'therapeutic citizenship' does not remove the marginalisation of HIV-positive people from social groups in society. Nevertheless, access to antiretroviral therapy as part of citizenship was appropriated by Kunbi, when she disclosed her HIV status and approached the state government for medical assistance in 2002 when the free antiretroviral therapy programme was launched in Nigeria. Kunbi's appropriation of ART as a form of citizenship right was regarded as legitimate by the Nigerian state, based on her biological condition of having HIV. In this regard, access to free antiretroviral drugs helps to kickstart the demarginalisation process for HIV-positive individuals to improve their health and be integrated into the mainstream as citizens.

In anthropological literature, conferring citizenship based on a biological condition is what Rose and Nova (2005) regard as 'biological citizenship'. This form of biological citizenship (Rose & Nova 2005) that was conferred on Kunbi became the basis for other HIV-positive individuals to access free antiretroviral medications as part of their legal rights as citizens of the state. Biological citizenship, therefore, becomes the basis of therapeutic citizenship for Kunbi, not only to access free medications but also other state largesse like housing and employment. Kunbi was later recruited as an HIV counsellor to encourage citizens for HIV testing and to demystify the cultural understanding of HIV through a television programme; and she was given a house by the state government to live away from her family house, a site of marginalisation.

7. Demarginalisation: Regaining Social Membership through Pharmaceutical Citizenship

As therapeutic citizens, access to free antiretroviral medications is central to the way in which HIV-positive people act upon their 'diseased-bodies' and live healthy lives (Petryna & Kleinman 2006). Antiretroviral medications, therefore, acted as resources for Kunbi, not only to appropriate therapeutic citizenship, but to challenge the negative perception of HIV, disprove the expectations of her family and the wider public about the imminent death associated with HIV, and regain social membership of her family:

> *After observing me for about 4 years and I am still alive and added weight (pound of flesh), they [my family] went to church to give thanks to God on my behalf, but they did not disclose my identity to the whole church. They later found that not all HIV patients die. In fact, when they discovered that I did not die and I was making wave on my weekly HIV television programme, they began to change their attitude to me. Because at that point, I was not afraid of HIV-related discrimination again because everybody knows my HIV status and I was frequent on television. My brother (who refused to give me money for food) and his wife came to my house to apologise on behalf of the family and reconciled with me. All family members changed their attitude towards me, and we became family again. We started relating like the way we relate when we are growing up and we returned to that level of relationship.*

Inaccessibility of antiretroviral medications would have accelerated the demise of Kunbi and reinforced the family expectation about the negative perception of HIV. The daily use of the medications transformed the health and body shape (weight) of Kunbi, and thus gave her the social leverage to challenge the cultural understanding of HIV held by her family and the public through the weekly television programme.

Having debunked the myth of death associated with HIV through the television programme, Kunbi's family had no social basis or incentive to marginalise or discriminate against her any further and were left with no further option than to accept her with HIV condition. The reconciliation ensued when her brother and his wife apologised to her on behalf of the family, and thus enabled her to regain social membership of the family. The family of Kunbi somehow understood the impact of antiretroviral therapy on her health and thus provided the basis for the re-assessment of their negative perception and lay knowledge about HIV. In this regard, access to antiretroviral medications enabled de-marginalisation for Kunbi because it enabled her family to reconsider their previously held assumptions about people living with HIV and the role that medications play in improving health.

Since Kunbi refused to grant the researcher access to her family member or any of her peer due to reason described later in this paper, it is perhaps difficult to triangulate possible divergent perspectives between Kunbi and her family. There might be other reasons why Kunbi's family members changed their minds about her. There are two possible explanations for this. The first could be that Kunbi's 'celebrity status' as the popular face of HIV on state TV has helped to reduce the stigma of HIV around her personality and placed her in positive public rating that her family cannot continue to dismiss. The second explanation could be the changed status of Kunbi as Government employees, with free and permanent house as houseowner. Being a state government employee with free government house did not only conferred middle-class status on Kunbi, but also demonstrated that she has moved out of poverty, which living in the family house depicts and the family wanted to identify with her due to class position. Living in family house in Africa might be interpreted as the indication of poverty — that is unaffordability or inability to rent apartment or flat due to financial constraints.

Nevertheless, regaining of social membership can sometimes occur after a certain period when marginalised individuals are eventually accepted as they are, in terms of their health condition. However, such restoration of social membership can only be facilitated when the positive transformations of medications on the health of the affected individuals are visible to members of the social groups who created the hostile space for marginalisation to ensue.

Access to antiretroviral therapy, therefore, ushered the 'biomedical promise of de-marginalisation' for Kunbi, in regaining the social relations of familiar membership she lost. By regaining the social membership through pharmaceutical citizenship, the rights, status, respect and sense of belonging that Kunbi lost in the context of family relations were restored:

> *Yes, they changed their attitude towards me. Many a time, I will deliberately do not take my drugs because I was tired of taking it, but my grandma and everybody was calling me on phone and begging me to continue taking my drugs. They are telling me that my life is more important to them. Now if they don't see me, they cannot make any decision. They even call me on phone, saying they are waiting for me at family meeting and that if I cannot be there, I should let them know the day and the time will be available for another meeting at the family house.*

The sociological insight implicit in Kunbi's accessibility to antiretroviral medications is the pharmaceutical citizenship that underpinned the changing nature of social relations associated with regaining lost familiar membership following HIV diagnosis. The regaining of lost social membership allowed Kunbi to enjoy the social support system that the family provides in the illness context. Through the restoration of social membership, Kunbi was able to exercise her rights and status by participating in family meetings and having a voice in the decisions that affected her and the entire social group. However, readmitting Kunbi into the family led to demarginalization and may not remove discrimination due to fear about the contagious nature of HIV. However, the readmission might rather reduce discrimination. Pharmaceutical citizenship offered by access to antiretroviral therapy is about how pharmaceutical drugs help those who are marginalised due to health conditions, to regain their rights and status as a full member of social groups in society. Therefore, pharmaceutical citizenship facilitates social change by altering the structure of marginalisation that was culturally and socially imposed.

8. Discussion and Conclusions

This paper provided a critical expansion of the concept of pharmaceutical citizenship by expanding Stefan Ecks' notion of marginalisation beyond accessibility to pharmaceuticals. This study explored marginalisation as a loss of membership of a social group, using the experience of an antiretroviral medication user (Kunbi) in a Nigerian context. The three key findings in this paper are as follows. First, HIV-positive people are marginalised because of their health condition, and such marginalisation is rooted and reinforced through the cultural understanding of HIV in Nigeria, that often leads to the loss of membership of a social group (for instance, family as demonstrated in Kunbi's case). The basis of marginalisation for Kunbi is not a lack of access to pharmaceuticals as Eck argued, but a loss of social membership. This finding corroborates with Alonzo and Reynolds' (1995) observation that HIV-positive people are marginalised because their illness is seen as a contagious disease and because a lack of a cure constitutes a threat to the community. As a result, HIV-positive people are shunned, rejected and ostracised by family/ relatives, friendship networks, peer groups, religious organisations, and other sites of social grouping where they experience harassment, threats of violence, public restrictions and sanctions (Busza 1999; Letamo 2004). The loss of social membership for HIV-positive people means the loss of rights, status, duties, and belonging as a full member of a group, which prevent them from 'participating in the lives of their communities and limit their access to critical social and economic resources' (Izugbara and Wekesa 2011: 874).

The second finding is that marginalisation does not remove the legal rights and statuses of HIV-positive people as citizens nor deprive them access to pharmaceuticals (antiretroviral therapy). This finding shares certain empirical support with Rose and Nova's (2005) articulation of biological citizenship. HIV-positive people in Nigeria have access to state-free antiretroviral therapy based on their biological condition, as their citizenship is activated and recognised by the Nigerian state based on their health situation. The shift from biological citizenship to therapeutic citizenship is reflected in how HIV-positive people in Nigeria utilised their biological status as a bargaining chip, in order to appropriate access to free antiretroviral therapy as therapeutic rights and resources (Nguyen 2005). Accessing free antiretroviral therapy as a form of biological and therapeutic citizenship, does not lead to the restoration of lost social membership (de-marginalisation) for HIV-positive people, until the efficacy of the medication is seen to have demystified the cultural understanding of illness (HIV) that has ushered the loss of social membership for the marginalised individuals. This finding revealed the weakness or pitfall of the notion of the 'biomedical promise of demarginalisation' implicit in Eck's pharmaceutical citizenship, that privileged free access to antiretroviral medications as the ''magic bullet'' that could solve not only biological problems but also social ones.

The third finding revealed that access to free antiretroviral medications offered HIV patients pharmaceutical citizenship; this removes marginalisation and restores them to the mainstream of a social group as full members. Indeed, access to antiretroviral therapy helps people living with HIV to normalise their health condition into a manageable 'enterprise of survival' (Squire 2010) and prevent their physical deterioration. This helps to forge a new social process through which de-marginalisation is produced vis-a-vis restoration of lost social membership over a period. This finding however shares empirical support with Persson et al.'s (2016) observation that pharmaceutical citizenship removes the marginalisation imposed by community and friends on HIV-positive people who take their medications in Australia—a pro-treatment and resource-rich context where access to subsidized antiretroviral medications is offered by the state. Despite the striking similarity between Persson et al's research and this research, one area where differences exist in both studies is the limited impact of pharmaceutical citizenship. Persson et al's study raised important questions about the differences between access to pharmaceuticals and the use of pharmaceuticals. Yet the purpose of Eck's pharmaceutical citizenship is to facilitate social change that agitates for an alteration in society's unequal structure of medication accessibility, not just about rights to access medications and the duties of taking them as Persson et al. claimed. Pharmaceutical citizenship offers a huge impact and significant social change in Nigeria for the marginalisation that precipitated it was socially and culturally imposed. This contrasts with the Australian case where marginalisation was self-induced, and pharmaceutical citizenship was only limited in addressing individuals' attitudinal change and not social change, which was the major thrust of its conceptual underpinning.

Despite these contributions, the limitation of this study as a qualitative research can be seen in its focus on single participant interviews in a Nigerian context, and given this constraint, it is difficult to conclude about the generalizability of these findings to HIV and other illnesses across different contexts. Another limitation of this study was its the inability to interview the family members, peers, and other individuals in the social relationships of the participant. However, the researcher attempted to interview these family members and peers, but the participant (Kunbi) refused to grant the researcher access because she did not wish to ''re-open old wounds'' or be reminded about certain aspects of her past life—including feuds with her family. Since people living with HIV/AIDS (PLWHA), especially in Nigeria, are vulnerable groups because they are susceptible to emotional harm when asked or reminded about certain aspect of their past lives, the researcher respected the decision of the participant in this situation.

Despite this study's limitations, the findings in this paper have far-reaching implications in three ways. First, this finding could help in achieving the policy objectives articulated in current global policies on HIV/AIDS such as the 'test and treat' policy (WHO 2013; 2015) and the 90-90-90 target (UNAIDS 2014). Although, access to antiretroviral medications in some developing countries has helped to consolidate and deepen the reinforcement of the current global health discourse that prioritised access to medicine/pharmaceuticals as a human right (Farmer 1999; Lohman et al. 2010), without changing the global policy agenda towards tackling and removing marginalisation (caused by the loss of social membership), the realisation of these laudable global goals and targets will remain an exercise in futility. The implications of marginalisation for these global agendas are discussed inter alia. Without combating marginalisation, the 'test and treat' policy will be unachievable in contexts and settings where marginalisation is rife. The new 'test and treat' policy of WHO aimed at reducing HIV transmission by suppressing the virus in those that were infected by early use of ART. This 'test and treat' policy was based on recent findings from clinical trials: that early use of ART keeps people living with HIV alive and healthier and decreases the likelihood of them transmitting the virus to their partners (WHO 2015). The marginalising nature of HIV negatively affects diagnosis and prevention (Aggleton 2000; Brown et al. 2001), and a significant proportion of people whom this policy is targeted at may refuse to undertake HIV testing to know their HIV status. As such the test and treat policy may not achieve its targeted result.

Furthermore, the realisation of the 90-90-90 target will remain a myth if significant efforts are not geared towards challenging marginalisation. The aim of the 90-90-90 target, as espoused by UNAIDS in 2014, is to ensure that by 2020, ''90% of all people living with HIV will know their status, 90% of those diagnosed will be on treatment, and 90% of those on treatment will be virally suppressed'' (UNAIDS 2014). Like the 'test and treat' policy, the fear of being marginalised from everyday life may undermine the realisation of the first 90 percent target, as people may be reluctant to undertake HIV testing and disclose their HIV positivity (Bond et al. 2002; Malcolm et al. 1998), and this will inevitably lead to the non-realisation of the other 90-90 targets. Therefore, marginalisation against people living with HIV is a big issue that will undermine global efforts and policies to combat the scourge of the HIV epidemic.

The second implication of this finding is the importance of visibility and the publicisation of treatment outcomes in shaping the local cultural understanding of HIV. Marginalisation is rooted in the cultural understanding of HIV. Without publicisation of treatment outcomes and the latest therapeutic advances in antiretroviral therapy that reduce the level of virus in the body to undetectable levels and render HIV sexually untransmittable (Keogh 2017), there would not be attitudinal and behavioural changes about HIV and towards people living with HIV. This therapeutic shift towards undetectability and non-infectiousness would not lead to a cultural shift in HIV understanding and reduce marginalisation if publicisation is neglected. Finally, this paper's findings highlight the importance of the family as a source of empowerment—one that HIV patients could utilise to gain dignity and social recognition in their everyday lives.

In conclusion, this paper expands Ecks' notion of marginalisation, with respect to how pharmaceutical drugs foster the 'biomedical promissory of de-marginalisation' of HIV-positive people. This study makes an important contribution to the anthropological and sociological understanding of marginalisation, where marginalisation could be seen as loss of social membership rather than a lack of access to medicine. The normalisation of everyday lives through pharmaceuticals has helped in transforming health conditions in a way that enables HIV-positive people to regain their lost social membership and be integrated to the mainstream of the social group or society. Therefore, expanding the domain of marginalisation has helped to enrich the analytical utility of pharmaceutical citizenship as a viable universal concept that is useful both in resource-rich and resource-constraint contexts and further provides a framework for theoretical and empirical research.

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