My Brother’s Keeper? Care, Support and HIV Support Groups in Nairobi, Kenya
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SUMMARY

How would the lives of people living with HIV (PLHIV) in Kenya unfold without the contribution of HIV Support Groups fighting stigma, discrimination and providing HIV related information? 'My Brother’s Keeper’ is about people living with HIV caring and supporting each other. HIV Support Groups are a multi-faced phenomenon in Kenya’s HIV mitigation landscape. The main aim of studying HIV support groups is to examine how HIV transforms care and social support systems over the last three decades. It explores and examines relationships between individual members and the HIV support group structure, specifically, over time, it explores how social relations are created, shaped, and redefined around the HIV-positive status.

Since the first diagnosis of HIV/AIDS in 1980s, living with HIV has been a frustrating, painful and complex experience: it unsettles the physical, economic, cultural, and social person. A HIV-positive status comes with enormous psychological and emotional consequences. For most PLHIV, significant mental strength is required to adjust to the new identity as a HIV-positive individual. Even as effective antiretroviral treatment has allowed people to live longer with HIV, HIV chronicity means many PLHIV have to contend with lifelong care and support needs related to day-to-day living with the disease. Living with HIV can actually expand the social, psychological, and economic burdens of PLHIV. Chronicity of HIV also means shifting needs and organization of care and support from the government, formal health care system and communities. A strong social support system is one of the most important resources for coping with the HIV condition (Van Buuren et al., 1992; Rodgers, 1995). The HIV support group, organized in communities and health facilities, is a critical partner in the fight against HIV, offering various logics of care and support for coping with HIV.

Most scholarships have documented the value of support groups generally focused on only one group at a particular moment in time. This isolated and static approach makes a single story of support groups, and prevents us from understanding the ways that support groups have changed over time in relation to the needs of individual PLHIV, biomedical advancement, donor-demands and global political economies. To explore the contribution of HIV support groups in HIV response trajectory, this thesis uses the lens onto four distinct junctures: pre-treatment, HIV crisis, treatment and end of HIV crisis, and beyond HIV crisis. Support groups, the research shows, assume vital contributions in coping with HIV through various logics of care and support for PLHIV evolve over time. I also argue that the groups are also spaces where the interests of various actors intersect, and hold a significant contribution in HIV interventions. While support groups are seen by PLHIV as a space of hope, biomedical interventionists tend to define this space as a system supplementary to medical care provision and determine the content of care and success in that context. In this context, a HIV support group is a space where lives of PLHIV are being re-made and closely scrutinized and a forum for offering the HIV continuum of care.

The story of Joseph Jalang’o in the introduction sets the stage for exploring the biosocial relations, engagement of various players, logics of care and support, and relationships and meanings PLHIV have with an array of support groups. It draws the reader into ways PLHIV navigate care and support through support groups demonstrating opportunities and disillusionments, and how the groups imagined, utilized, and reworked by differently positioned actors to meet the shifting care and support needs of PLHIV over time. For this study, I draw attention to different models of HIV support groups in time and space: community-based, health facility-based and an organic support group model.
Chapter one of this thesis describes the methodology. I followed nine distinct support groups over a two-year period (2011–2012) in Nairobi, the capital city of Kenya, which has one of the highest HIV prevalence in the country. Specific study sites are Kenyatta National Hospital, Kibera informal settlements and River road area in Nairobi’s central business district. The Kenyatta National Hospital’s facility-based groups included adults, prevention of mother-to-child transmission (PMTCT) clients, youth, discordant couples, and an exclusive men sex therapy group. Community-based groups included three mixed-adults groups from Kibera informal settlements, and Freedom Corner - a group of male sex workers from the backstreets of Nairobi’s central business district. Each group was unique in their own right. I triangulated the sources of information and ethnographic data gathering techniques. Mapping of support groups, participant observations, conversations, in-depth interviews, focus group discussions, life histories and walking sessions were the primary data gathering techniques. Media reviews, a secondary data collection method, provided highlights into media reporting around stigma and activities of first groupings people with HIV/AIDS stretching back to the 1990s. Core to this study was PLHIV participating in support groups and key informants (government and development partners’ representatives, leaders of PLHIV led NGOs, CBOs and support groups, peer educators and HIV activists). The study also provides insights into negotiating ethical and social licenses on sensitive topics.

Grounded upon medical and biosocial relations anthropology, the study explores a number of support groups over time thus allowing me, first, to avoid a single-story danger, and second to avoid the tendency of disregarding the history of the development of support groups. In so doing, the study, in chapter two (theorizing HIV support groups) sheds lights on the concept of biosocial, HIV support groups, care and support. It also shed light on the engagement of different players in the support group arena, and ways in which PLHIV relate with and make meaning of the support group space.

Since the discovery of HIV/AIDS in 1980s in Kenya, PLHIV have played a critical in the fight against HIV. Three distinct eras in HIV support groups’ trajectory: pre-treatment, HIV crisis, end of crisis and beyond crisis are noted in my study. Chapter three and four provide a historical perspective on the development of HIV support groups. Chapter three focuses on the emergence of the first HIV support groups during pre-treatment time when HIV treatment was too expensive in Kenya. I drew on interviews with the legend HIV activists, and Chief Executive Officers and long serving staff of the HIV NGOs, and media reviews. The study show the ambivalence HIV response by the government resulting in the failure to protect and promote the healthy wellbeing of its citizens on one hand, and, on the other hand, acute stigma, preventing care and support of people with AIDS by the general society on the other hand show how during the first two decades of HIV in Kenya. During this time, I demonstrate how care and support moves from families to emerging HIV support groups. In these groups, people with HIV and AIDS become both providers and receivers of psychosocial/compassionate support through sharing of experiences, battling self-stigma and gaining HIV-related information. I demonstrate how the objectives of support groups and HIV identities are fluid as groups come into contact with outside contacts. I show how different logics of care and support emerge. I discuss how commercialization of individual HIV-positive identity for monetary gain, and competition for control of funding resources facilitated the emergence of a local economy of HIV support groups, and altered and interfered with the objectives and meanings of support groups resulting in tensions and discord but also opened diversification and dynamics of the NGOs/groups. I show how while this development challenged the identities and intentions of most NGOs/groups, the roles of these groups did not wane. They remained steadfast in putting a face to HIV, educating communities and fighting stigma and discrimination. In health facilities, support groups were crucial in psychosocial support.
In chapter four, I continue to explore the development of HIV support groups at a time of HIV crisis and the end of HIV crisis (1999-2009). The period 1999-2002 was the height and the end of the national disaster marked by high mortality and morbidity, heightened stigma, and weakened familial social support. I discuss how HIV/AIDS incapacitated people’s physical and social wellbeing yet there was a dire need for nursing care as well as material and psychological care and support. I demonstrate how support groups expanded in communities offering psychosocial and material care and support. I describe the national level norms, among others, multi-sectored response and the inclusion of PLHIV in the implementation of HIV interventions coinciding with UNAIDS campaign for inclusivity and the global inclusion strategy known commonly as the Greater Involvement of People with AIDS (GIPA) initiative in expansion of these groups. I analyze the effect of increased HIV funding and other material support in the communities on the HIV support groups’ objectives and structure. I also trace the emergence of support groups in health facilities in Mbagathi and Kenyatta national hospitals mainly focused on psychosocial support, and describe the export these groups moved to communities. I also examine the end of HIV crisis (2003-2009), which marks yet another milestone in the HIV response trajectory as well as HIV support groups’ landscape: a time of treatment accompanied by lucrative resources and proliferation of players, especially HIV support groups. Lucrative resources and treatment expanded a local economy of NGOs, CBOs and HIV support groups. In Kibera community, logics of care and support manifested in the form of material support for practical needs, nursing care and economic opportunities. I discuss how support groups rejuvenated people with AIDS who were bedridden and abandoned in their houses through their home-based care activities. I analyze how materialization of the groups twisted the meaning of care and support, and destabilized psychosocial support. As support (msaada) in the form of money, food, school fees and clothing came through support groups, the groups quickly transformed into material outfits. I also show the entry and effect of materialization of support groups in the Kenyatta National hospital. The study shows multiple support group memberships to benefit from various care and support provided through different groups.

Chapter four ends with an introduction of yet another critical development in the history of HIV and HIV support groups ‘beyond’ HIV crisis, the year 2009 and beyond. HIV prevalence is reduced to an unacceptable level of 5.6 percent. Donors demand for evidence-based strategies to halt new infections and increase access to HIV treatment. This donor demand coincided with the Kenya HIV Prevention Response and Modes of Transmission epidemiological study that revealed concentrated epidemics among most-at-risk populations. I show how redirecting attention and funding to ‘key populations’, among them men who have sex with men (MSM) and sex workers. Refocus on key population coincides with global activism for homosexual human rights. Redirection of funding to key populations destabilizes the hype of the support groups. A good number of HIV groups transformed into income-generating activity groups. Some groups became dormant only to come up again during HIV treatment advocacy activities. Some of the PLHIV on treatment resumed their economic activities. Despite this development, due to high food intake, HIV syndemics and stigma, the PLHIV were struggling with practical needs. Only a few PLHIV-led NGOs and community-based organizations transformed health facilities and other donor attractive activities. I show how the Kenyatta National hospital’s support groups become hypermedicalized and expanded in numbers promoting HIV prevention and treatment through living positively messages, while overlooking the much needed practical needs, especially food. Even within its context, support groups expanded in KNH as they diminished visibility in communities.

Chapter 5 of the thesis centers on difficult positions PLHIV in need of familial care and support found themselves in. I demonstrate how care and support needs of PLHIV in Kibera were not
met by families at a time when care and support activities were re-directed from HIV support groups to families. Beyond the HIV crisis, stigma denies PLHIV care and support from families and the general society even as a few active support groups and other community-based organizations assumed a watchdog role. In chapter six and seven, using case studies of exclusive male sex therapy groups and male sex workers who have sex with men respectively, I demonstrate how emergent needs and shifting needs shape biosocial relations. Using different cases in chapter six, I analyze how sexual and reproduction logics of care and support are employed in addressing sexual issues of men living with HIV on antiretroviral treatment. In chapter seven, I use a case study of an organic support group, Freedom corner, for male sex workers who have sex with men to demonstrate the critical role of PLHIV MSM sex workers in providing a more comprehensive care and support to one another. Often such support go unrecognized by NGOs targeting them with HIV interventions. This case shows how an intersection of survival needs, identities and human rights issues shape biosocial relations.

Overall, this thesis demonstrates the critical role of HIV support groups in lives of PLHIV and HIV response. HIV support groups brought the necessary visibility to HIV and played a critical role providing care and support for PLHIV though various logics of care and support. These groups are not a simple replacement of the traditional care and support system – they are psychological, socio-reintegrating, hope-propelling, stigma-fighting spaces that also provide emotional healing, love, acceptability, appreciation and respect. They also address sexual issues that cannot be handled by kin. As biosocial and bio-value spaces, the groups are a life-transition space and provide a foundation for coping with HIV. As biomedical innovations and interventions, they have implications in treatment adherence, HIV prevention and overall health of individuals. Social implications of participation in support groups include acceptance of a new identity, hope, fighting stigma, and change in relationships. Economic implications remained an illusion to many while tremendously changed the fortunes of a few, thus support groups produced opportunities as well as huge economic inequalities. Overall, support groups mitigated myth and misconceptions, denial, fears of side effects, isolation, psychological stress, and helped people living with HIV to cope with HIV. However, practicalities of support groups can be fragile. While these groups hold the potentially transformative power of the individual, they can also disappoint. Support groups have limitations that compromise the relationship between the individual and the support groups. Where support groups fall short of responding to such needs and desires, members drop out or hop from group to group in search of fulfillment. In spite of the fluid state and shortcomings of the groups, they are a life-transitioning space and provide a foundation for coping with HIV, and thus instrumental in HIV interventions.