

HIV sero-discordant couples and social capital in the great lakes region

Reflections on a theoretical framework

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- In 2004, a Multi-Country Programme (MCP) aimed at establishing and strengthening networks to undertake social science research into HIV and AIDS in sub-Saharan Africa was launched, in partnership with Dutch universities, the Dutch Ministry of Foreign Affairs, the AIDS Fund and other stakeholders. The countries covered by the programme were Botswana, Burkina Faso, Ethiopia, Namibia and Rwanda. Notable achievements were:
- 25 research projects carried out in five countries;
 - research coordination platforms established and strengthened in four countries;
 - increased quality and usefulness of research projects; and
 - on-demand training of researchers in proposal writing, data collection, data analysis and report writing (KIT, 2009).

The project formally ended in May 2009. During the last six months of the programme the focus was on: strengthening the bodies that had been established to coordinate the network; capacity-building in health system strengthening and social science research into HIV and AIDS; and developing the concept of a Great Lakes Applied Research Consortium (GLARC) focusing on social science research related to sexual and reproductive health and HIV. The project continued informally, and the 'terms of reference' were designed for this consortium. In 2010 a 'write shop' was held in Kisumu, Kenya, in which proposals were developed that looked into HIV discordance among couples, using a framework of social capital and vulnerability. The process was led by the Netherlands' Royal Tropical Institute (KIT) and Annemiek Richters of the University of Amsterdam/KIT.¹

This chapter reflects the last period of the project, the priority-setting of emerging topics to be studied and especially the development of new proposals focusing on HIV-discordant couples in the Great Lakes region. The theoretical framework used was inspired by the work of Annemiek Richters: the GLARC research programme aims to provide more clarity regarding hindering and facilitating factors for behaviour change in the specific

context of the Great Lakes region, within the theoretical framework of vulnerabilities and social capital.

Priority-setting

In the Great Lakes region, awareness of essential information related to HIV and AIDS is relatively high. Yet, as in other parts of the world, the available knowledge may not result in the behaviour change that is required to curb the epidemic – the prevalence of which in the countries of the Great Lakes region is estimated to range from 1.5-8.5 per cent (KIT, 2009). These data may be unreliable, however, due to the shared characteristic of many countries in this region: collective violence and social upheaval. Along with other common social and cultural characteristics, as well as the distorted HIV research arena (skewed towards quantitative studies) and the qualitative social science research capacity development process initiated under the MCP, all this provided the impetus for bringing together a number of countries under the GLARC banner: Burundi, DR Congo, Ethiopia, Kenya, Rwanda and Uganda.

The spread of HIV in the countries in the Great Lakes region may be specifically driven by people's high mobility in the region and by (related) sexual violence outside and inside marriage. A leading cause of HIV in the region is sexual violence against women by the military and rebels. Women who now live with HIV as a result of rape may infect their partners. Many of these women move within the region and also to neighbouring countries to avoid stigma and to search for survival opportunities, which include new marital and cohabitation relationships. In Kenya, post-election violence forced many people to move from one region to another, often leading to separation from family members. Cases of rape and new infections have been documented among internally displaced persons living in camps.

During both the MCP and GLARC processes, participants invested in strong stakeholder analysis and priority-setting. Towards the end of the project this resulted in the selection of key theoretical concepts that could guide the future research programme, such as accountability, value of life, risk perception and behaviour change. In addition, some desk studies regarding these concepts and their relevance were completed. There it was observed that the concepts of risk perception and behaviour change seemed over-used in the field of HIV and AIDS. Eventually the concepts of vulnerability and social capital were chosen as the most relevant for tackling the selected research themes. The topic of HIV sero-discordant couples

was selected as a binding theme across all participating countries, as it was considered to be a neglected issue, while at the same time allowing sufficient flexibility to work on country-specific issues.

Theoretical framework²

GLARC decided to use a theoretical framework of vulnerabilities and social capital to study the complex factors that prevent behaviour change. The underlying idea of this framework is that an individual's reaction to issues related to HIV and AIDS and the adoption of a particular behaviour are not influenced by the quality of the available information and an individual's risk perceptions and certain skills alone, but also by: biographical factors, such as people's perception of the value of life and death; relational dynamics, such as the social contexts in which relationships occur; and by individual life trajectories.

Vulnerability

The heuristic matrix of vulnerability that is suggested to guide the proposed research contains three levels: the social trajectory level (biographical fragility or identity vulnerability); the level on which two or more trajectories intersect (relational vulnerability); and the social context (contextual vulnerability). Delor and Hubert (2000) argue convincingly that any in-depth, comprehensive study of vulnerability should include in its focus these three levels, the particular links among them, and their respective impacts on behaviour related to HIV and AIDS.

To study complex situations of vulnerability, Delor and Hubert (2000) use a framework that consists of an objective and a subjective dimension of vulnerability, each of which distinguishes between the three levels of vulnerability identified above. The various elements of vulnerability can be re-situated in the process of identity construction, which can be described as a process aimed at maintaining, expanding or protecting the living space in which a person is socially recognized. An example related to the theme of HIV sero-discordance, presented by Annemiek Richters at one of the GLARC workshops, is the following: a woman is tested HIV-positive but does not disclose this to her husband; he is HIV-negative. She has been raped by soldiers and has witnessed brutal violence of war, which has made her lose interest in the future. Her husband forces sex upon her. Part of her family has been killed, others have gone into exile. Her remaining social network is small, and the social relations within this network are poor. As

a researcher, a number of questions can be posed, such as: why does this woman not want to disclose her HIV status to her husband, and why did she nonetheless have a number of children with him?

Specific situations of vulnerability create the most painful and perilous circumstances. But as we have seen from the example, there is also a need to look at how people act and relate in these vulnerable circumstances; also when we look at responses and interventions they need to be aimed at empowerment and empowerment. It was, therefore, agreed that the theoretical framework of social capital would be integrated into the operational aspect of the research programme.

Social capital

The key element of the concept of social capital is that 'relationships matter' (Field, 2003). In most studies of social capital a distinction is made between 'bonding' social capital and 'bridging' social capital. Within these two types of social capital a distinction between structural and cognitive social capital, both operating at micro (individual person or family) and macro (neighbourhood, community, formal or informal group) levels, is also made.

The hypothesis regarding the importance of access to social capital for behaviour change to occur is supported by experiences with socio-therapy as implemented in Rwanda (Richters et al., 2010). Participation in socio-therapy by people living with HIV reduced their levels of isolation and hopelessness and contributed to strengthening their perceptions of being recognized and respected by others as a valuable human being. Another example supporting the importance of social capital for behaviour change is the 'community conversation' strategy implemented by CARE in Ethiopia. This intervention functioned as a catalyst for stigma reduction and behaviour change (Geraneh et al., 2008). In rural Zimbabwe a positive correlation was found between social capital, education and avoidance of HIV among young women (Gregson et al., 2004).

HIV sero-discordant married or cohabiting couples

The research topic for the first phase of GLARC is 'vulnerabilities and social capital among HIV sero-discordant married or cohabiting couples'. On the basis of survey and clinical data collected in urban Zambia and Rwanda, it was estimated that 60-90 per cent of new heterosexually acquired infections occurred within marriage or cohabitation (Dunkle et al., 2008). The

Kenya National AIDS Strategic Plan (KNASP) recognizes HIV sero-discordant couples as a priority target because more than half of new HIV transmissions occur in stable couples (NACG, 2008). Further studies are needed to document HIV sero-discordance, given that the Kenya AIDS Indicator Survey from 2007 showed that HIV sero-discordance among married individuals is 45 per cent (National AIDS and STI Control Programme, 2008).

In a sero-discordant couple, the partner living with HIV is often confronted with difficulties – for instance, disclosing his/her HIV status to his/her spouse, relatives and friends – while the couple itself is often confronted with the issue of whether or not they should have a child. Even though HIV sero-discordant relationships are a recognized risky context for women and men, most HIV services in Africa currently deal primarily with clients as individuals. Voluntary counselling and testing, as well as behaviour change interventions aimed at couples have been shown to reduce HIV transmission among discordant couples. The premise of GLARC is that given the contextual vulnerability of the partners in these couples, various kinds of community interventions that enhance their social capital may be even more effective in HIV prevention (Kwagala et al., 2008; Richiers et al., 2011). The same applies to contraceptive use among these couples. With the increased availability of and access to antiretroviral therapy (ART) and prevention of mother-to-child transmission (PMTCT) services in many parts of the Great Lakes region, sexual activity and the pursuance of the desire for biological children have increased, also among HIV sero-discordant couples. This implies a need to improve the integration and responsiveness of HIV prevention and contraception efforts in a way that people living with HIV, including couples of which one or both partners are HIV-positive, feel that their needs are addressed (Odhiambo, 2007).

Research

To date, several research proposals have been written focusing on sero-discordant couples, of which several have been implemented. Qualitative and mixed-method research approaches are being proposed to gain an insight into the link between situations of vulnerability to various risks and situations of tension or upheaval in the complex system of relations with oneself, with others and with society at large.

In Uganda, several Master's students supervised by Dr. Betty Kwagala of Makerere University are working on violence between clients and their HIV sero-discordant partners in South Western Uganda, addressing issues

of sero-discordance, the time to start ART, and disclosure. In Ethiopia, a study was carried out by Daniel Tadesse under the supervision of Prof. Getnet Tadele. The study found widespread misconceptions about HIV sero-discordance among sero-discordant couples, health care providers and counsellors, such as: the belief that the other partner was already infected, but the test did not show it; biological immunity to HIV; and prevention of HIV through ART. As a result of these misconceptions, many couples were confused and unlikely to take the necessary preventive measures or they were not interested in being tested. While service providers informed and educated them, nevertheless, many of the HIV sero-discordant couples continued to engage in risky sexual behaviours. However, it was also found that for some couples the presence of HIV did not bring about any change in their relationship. Still, they experienced a variety of psycho-social problems such as fear of infecting and being infected, blame, neglect, guilt and uncertainty. Their coping strategies were found to be safer sex, abstinence, communication, disclosure, silence, secrecy, cooperation and religion (Tadesse, 2011).

Social capital was found to be a double-edged sword. While informants claimed they were receiving instrumental, informational, appraisal and emotional support from relatives, friends and acquaintances, these same groups of people were found to be a source of stress and anxiety by putting pressure on HIV sero-discordant couples to have children.

Concluding remarks

In the studies so far we have seen that the framework of social capital and vulnerability may help us to better understand problems related to HIV sero-discordance in relationships. The multilayered nature of vulnerability, not only individually and socially but also contextually and related to bridging and bonding social relationships, definitely facilitates an in-depth analysis of the problems faced by HIV sero-discordant couples. In other words, by not only focusing on exposure, liability and susceptibility but also on how people act and relate in a certain context, a better analysis of a situation can be made. Questions remain regarding how to use this framework for regional comparisons and how to best add the political dimensions. Finally, the concept of vulnerability evokes resistance and provokes associations with being passive, docile and susceptible, without any insight into the agency and resilience of couples. Do we need to deconstruct and demystify stigmatized ideas and labels associated with vulnerability? Does

social capital contribute to finding coping mechanisms or to resilience and the strengths people demonstrate? Future studies will support us finding answers to these questions.

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Notes

- 1 We hope that Annemiek stays connected to this process.
- 2 This part of the paper is based on the chapter written for 'Great Lakes Applied Research Consortium: Institutional networking, research approach and thematic alliances' by Annemiek Richters, Hermen Ommel and Anke van der Kwak in: Anke van der Kwak, Annemiek Richters and Hermen Ommel (eds.) (2011) *Knowledge generation and capacity development in Africa and beyond: reports of experiences and efforts*. Amsterdam: KIT Publishers, 2011.

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