

British Sociological Association: Phil Strong Prize

Multiple translations of HIV enactment in clinical environments: a study of practices, knowledges and experiences of HIV treatment in the presence of biomedical technologies.

MPhil/PhD Student Agata Pacho

Sociology Goldsmiths University of London

**Supervisors: Dr Marsha Rosengarten
Dr Monica Greco**

Overview of the study

This project applies novel developments in Science and Technology Studies to HIV health practice in the UK and Poland. Through an analysis of the multiple ways in which HIV care is practiced in two contrasting national settings and specific high standard clinics, I hope to offer tools for improving the lives of people living with HIV as well as contribute to the broader spectrum of public health. While this research employs a comparative mode, it concurrently realizes performative nature of the latter (Law and Urry, 2004). Conventionally applied forms of comparison assume similarities and divergences between considered elements, which are linked through enduring unvarying phenomena. In this way, it has the potential to enact a field of supposed stabilities. Yet, this study is dedicated to reveal complex ways in which various global phenomena assimilate themselves to heterogeneous environments and alter accordingly to various contexts. It shares the presumption with contemporary theorists that, even though universal forms have the ability to move across geographical or cultural boundaries, their dynamic is complex and regulated by existing socio-technical infrastructures, administrative apparatuses, or value regimes (Collier and Ong, 2005). The project focuses on antiretroviral therapy (ART). ART aims at prolonging and maximizing the quality of life for people living with HIV by preventing the onset of AIDS. Following arguments that otherwise presumed standardized research on HIV as well as experience of living with HIV differs accordingly to geographical location (see for example, Rosengarten & Michael, 2009a; 2009b; Davis & Squire, 2010) and drawing on the work of Mol & Law

(1998), the study is seeking to reveal how distinctive characteristics of clinics in Warsaw and London offer alternative perspectives on practices of HIV care. It involves investigation of different modes of engaging with the virus, biomedical technologies, medical practices and patients' adherence to therapies. Expectantly, it will reveal how what is often perceived in medicine as standardized procedures of managing an illness, may produce different outcomes in various contexts.

The necessity of such research cannot be overestimated considering the present state of HIV/ AIDS epidemic: the growing number of people being on the treatment, the persisting uncertainty of the effects of antiretroviral drugs on patients' lives, and shifting perceptions of the virus and risks of its transmission. Notably, the project will respond to aspects of the Polish pandemic where the number of new HIV infections has tripled in the past decade (Anna Marzec-Bogusławska, 2011).

The research is being undertaken in collaboration with The Training and Resource Initiative (JUSTRI) UK and Social AIDS Committee (SKA) Poland. Both are HIV specialist organizations. The advisory nature of this collaboration ensures that the research outcomes are tailored to assist practitioners and policymakers in advancing HIV health care.

Aims of the study

- To investigate how HIV medical care takes form through variations in clinical settings in Poland and the UK.
- To reveal how doctor-patient relations are being shaped by the main trends of epidemic as well as by available drugs and other technologies.
- To enhance the understanding of the concept of a good and safe health care and its markers.
- To contribute to the sociological model of chronic and stigmatized illnesses.
- To advance sociological research through introducing an innovative approach rooted within the field of science and technology studies and its intersections with medical sociology.

Methodology

Doing sociology of body and its disease

The research methodology is rooted within the field of Science and Technology Studies (STS), which essentially disturbs the idea that medical knowledge and technology can be implemented in a straightforward and predictable way to maximize the quality of life. Instead, STS methodologies consider a broader spectrum of a chronic disease which extends patients' bodies and interferes with their lives, the multiplicity of medical possibilities, and technologies which rarely subordinate themselves to their targeted results. In particular, the methodology of proposed research is inspired by Annemarie Mol (2002) who breaks with presuming disease to be a universal object located in human body and makes a shift to analysing bodies and diseases while they are being enacted in hospital practices. As the latter are many, there is not a single disease or a single body but multiple realities. Furthermore, material objects, such as the body, the illness, the technology, are not seen as passive and manipulated in various hospital routines. On the contrary, they come into being as well as disappear with the practices they are involved into (Mol 2002).

Enacting HIV in the clinic

In clinics providing ART, HIV is done through blood tests, diagnosis, prescribing of antiretroviral drugs, and patients' adherence. The ethnographies of chosen clinics will consider these practices to the extent that they reveal HIV as heterogeneous and dynamic (Mol 2002; Rosengarten, 2009; Rosengarten & Michael, 2009a).

The preliminary research has already indicated that the HIV epidemic is most commonly examined within the social sciences through the use of social structural or behavioural approaches. This project offers a different conception of the field by examining local environments in which the interchanging of doctors and patients' perspectives and biomedical technologies, including standardised diagnostic measures, can be shown to affect the use and effects of HIV medical care. Unlike the work of STS theorists such as Mol & Law (1998, 2002), the

project also considers how a shared memory of the early days of the epidemic affects ways in which HIV is enacted in today's clinic.

Through considering bodies as entangled with other human organisms, technological devices, and cultural phenomena, the research responds to the need to challenge one of the most influential discourses of late capitalism: the dichotomy of a healthy and confined body on one hand and the pathological self open to alien threats on the other (Haraway, 1991). It also questions the complex notion of choice, which is central to liberal democracies. While the HIV field has favoured patient's choice, allocation of it reflects the distribution of responsibility among individuals. It has been argued that the ideal of choice is neither necessary nor always a beneficial aspect of a good healthcare (Mol, 2006). This study may shed new light on the debate by considering Polish patients who appear less skilled in exercising their democratic rights and ultimately enrich the understanding of the indicators of a good and safe health care.

Progress to date

I spent the past academic year on developing my methodology and building a substantial literature review. The process has provided valuable insights into the field of research. I undertook a yearlong research methods courses provided by Goldsmiths, University of London, where I was trained to conduct sociological research at a professional level. While the procedure of ethical review at Goldsmiths has been completed, I am in the process of gaining NHS ethics approval.

Notably, the research is being undertaken in collaboration with the director of JUSTRI, Dr Mike Youle with whom both, the progress of the study and fieldwork plans have been regularly discussed. During the past year I have also strengthened my links with Social AIDS Committee as well as other non-governmental organizations and academics in Poland. Importantly, the Prize has not only supported the crucial phase of my research but it was also a significant consideration in granting me the Economic and Social Research Council scholarship which will fund the remaining years of my research.

Activities supported by the Phil Strong Memorial Prize

The Phil Strong Memorial Prize covered three activities. Firstly, it paid for my attendance at the only annual conference organized for social scientists working on HIV/AIDS in Poland. The conference provided an excellent opportunity to meet Polish academics, policy makers and social workers with whom I discussed my research plans. The conference made me realise ways in which I may contribute to the production of knowledge about the Polish epidemic.

Secondly, I attended an event in Milton Keynes that hosted a lecture and an interview with Annemarie Mol. Being part of the audience was an invaluable experience as not only my research is inspired by Mol, but also her writings introduce innovating ideas to the Sociology of Health and Illness.

Finally, the Phil Strong Memorial Prize has paid for my attendance at the conference organized by the European Association for the Study of Science and Technology. The conference takes place in two weeks time and it addresses the dynamics and interrelationships between science, technology and society. Attending the event will allow me to stay up to date with current trends in STS and, therefore, contribute to further development of research methodology.

Significantly, my project brings sociological research where social aspects of the epidemic do not receive sufficient attention. It also introduces an innovative methodology rooted within the field of STS and offers the possibility of altering the more traditional research on HIV epidemic. By supporting this research, the award aided enhancing understanding of HIV and other chronic and stigmatized illnesses and facilitated advances towards international strategies against HIV epidemic.

This PhD remains in progress. Expectantly, the thesis will be transformed into major publications and, therefore, contribute to the debate on HIV as well as chronic and stigmatized illnesses more broadly. I hope to disseminate my findings to the sociological community, health care professionals in HIV care and

policy makers. In addition, numerous presentations will be given throughout the duration of my PhD program.

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