



Transitions in HIV Management: the Role of Innovative Health Technologies

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KEY FINDINGS

This project examined the transitions in HIV management that have occurred through Highly Active Anti-Retroviral Treatment (HAART) and the technologies that surround it such as viral load testing, genotyping and viral resistance testing. We also considered how these new technologies related to pre-existing HIV medical technologies such as HIV antibody testing, treatments such as AZT. We addressed how the recent advances in HIV management have been described and portrayed in the scientific, medical and mainstream literature. We also explored personal experience accounts of people with HIV and service providers with reference to the introduction and management of these technologies.

- HIV health technologies have transformed the meaning of HIV positive status from 'death sentence' to 'life sentence', HIV infection from terminal illness to a chronic manageable infection.
- The pharmaceutical industry, people living with HIV, clinicians and voluntary service providers display shared yet distinct understandings of these HIV health technologies.
- In general, HIV technologies have led to the medicalisation of HIV management. The experiential expertise of people with HIV has less importance in treatment, which emphasises viral management and medical models of living with HIV. This raises important questions about clinical practice.
- The HIV positive patient must assimilate HIV treatments into all aspects of daily life.
- There are clear contested notions of health and illness, and indeed quality of life, between medical constructions and those stemming from peoples lived experience.
- Stigma and the management of an HIV positive identity were major issues for many people. The psychosocial impact of the disfigurements associated with treatments was enough for some people to consider stopping their drug therapy.
- Positive people must engage with medical constructions of HIV and IHTs even when there are tensions and paradoxes concerning the meaning of treatments and these technologies.

RESEARCH FINDINGS

RESEARCH TEAM

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Innovative health technologies in the HIV field (HIV IHTs) have transformed HIV. HIV IHTs refer to HIV treatments and their associated tests (CD4, Viral Load and resistance tests). These technologies influence personal experience and clinical practice. They bring about radical changes to the nature of being HIV positive, transforming the meaning of HIV positive status from 'death sentence' to 'life sentence', from terminal illness to chronic manageable infection. The technologies bring with them a number of changes that reinforce global health inequalities, and affect the nature and pattern of incident infections, the future of HIV treatments and the organisation of HIV services. These new technologies also arise in a general social situation of increasing reliance on consumer orientation and therefore individualisation in health governance. HIV IHTs are an example of the interplay of developments in health governance and new technology.

This research addressed four arenas in which HIV and its IHTs are constructed: i) literature concerned with the evidence base for the efficacy of HIV treatments, ii) a pharmaceutical company's promotion of a 'new' HIV treatment, iii) the everyday experiences of a diverse sample of HIV positive people living in the UK and iv) the experiences of other key players within the HIV epidemic (clinicians, nurses, voluntary sector workers). We sought to examine the differences and similarities between and within these constructions and to trace their inter-connectedness.

Medical literature and the evidence-based medicine associated with it seek to generate 'truths' concerning the action of drugs upon HIV positive bodies. Whilst the drug efficacy literature produces useful information about treatments, it also implies certain assumptions of the identities and

conduct of HIV positive people. Because the epistemology of HIV treatment trials focuses upon the action of treatment upon the virus, it renders the HIV positive participants as passive receptacles of HIV drugs. HIV treatment requires that patients make themselves available for medical intervention. This is a radical shift for the HIV treatment advocacy of the pre-HIV IHT era, where patients were said to be more active in seeking and managing their treatment. The medical literature about HIV IHT's generates constructions of HIV positive people that renders the agency of patients as less important in the practice of managing HIV infection. For example, when we examined how the outcome of drug efficacy was measured within the drug efficacy literature, we found that psychosocial and socio-cultural factors were absent. Treatment efficacy was usually measured within the confines of test results (such as viral load) and rarely included measures like quality of life or treatment impacts on daily living. Since the advent of HIV IHT's there has been an apparent reduction in interest in personal account oriented research among people with HIV. This change also reinforces the sense that HIV treatment is a domain of medical intervention oriented to control of virus in bodies and where social setting, identity and personal experience have less value. This is something of a problem given that the long term effective use of HIV IHT will require the engagement of patients. Indeed, our analysis is suggesting that the emerging problems of treatment effectiveness will require a much more vigorous engagement with the social aspects of the treatment experience. The biomedical rationale for treatment efficacy is critical in shaping expectations of treatment success and the manageability of HIV, but is also deeply problematic as it minimises and silences many of the problems associated with treatments (complex drug regimens,

toxicity of the treatments, the psychosocial and socio-cultural difficulties associated with managing HIV positive identities).

Contrasting sharply with the medical constructions of HIV positive people, we also examined the advertising of 'Trizivir' three anti-HIV drugs currently prescribed separately, reformulated as a single tablet and relaunched in the market as a significant pharmaceutical advance. This highlighted a very different set of HIV positive subjectivities. In contrast to the lack of agency associated with the HIV positive subject illustrated within the medical literature, our analysis highlighted the salience of the HIV positive subject as consumer within the pharmaceutical industry's wide-reaching drug promotion reportage (targeted ostensibly at HIV clinicians). Within it we see the transformation of the HIV patient (faced with terminal illness) into health consumer (demanding treatments that always work and pose minimal interruption to seemingly vibrant social and work lives). But like the scientific literature, pharmaceutical constructions of the person with HIV also had investments in certain types of consumption practice that had tenuous connections with lived experience.

In terms of our on-going analysis of people living with HIV, we found that HIV positive people's accounts of their experiences and understandings of HIV IHTs stressed the constant and daily 'work' they must do with regard to HIV IHTs. Not only was their agency pivotal with regard to drug adherence and the management of often debilitating and stigmatising side-effects, but their HIV treatments required trust in a medical model in which health was no longer somatic (part of embodied experience) but delivered by means of monitoring test results in the space of clinical interactions (clinical markers took

precedence over subjective well being). Against the backdrop of both the glamorous constructions of the pharmaceutical industry and the apparent simplicity of biomedical constructions of being HIV positive, the participants presented rich accounts of how they responded to the demands of HIV IHTs. Unlike, scientific or pharmaceutical notions of living with IHTs, people with HIV were concerned with managing the stigma of being HIV positive. They were also oriented to optimising the benefits of treatment and managing some of its negative effects such as side effects, drug resistance or treatment failure. The logic of technologically derived indicators (i.e. CD4 and viral load test results), of when to start treatments, and the biomedical necessity of adherence to treatments, sometimes clashed with psychosocial and socio-cultural imperatives which offered alternative rationales to avoid treatment initiation and for non-adherence. In addition, the experience of being HIV positive was increasingly fragmented, with different understandings of being HIV positive discernable between our UK-born and African participants, and between participants diagnosed before and after the advent of HIV treatments.

Our on-going analysis of key players within the epidemic shows wide-ranging impacts of HIV IHTs. Because HIV IHTs are effective, the numbers of HIV positive people is increasing (fewer people are dying). To pay for HIV treatments, and as a response to the changed nature of being HIV positive, there has been a dismantling of many voluntary services and organisations. There is therefore decreased availability of services but increased demand. The clinic has become the primary place in which HIV positive people access services, yet simultaneously (in response to increased patient numbers) there has been a clear narrowing of focus

within clinical care. The role of clinicians has dramatically changed; where once HIV medicine could be characterised in terms of its holistic health care (addressing primarily psychosocial and socio-cultural issues), now there is pressure for clinical interactions to be shaped by a greater technological focus upon HIV IHT test results (CD4, viral load, resistance test results). Interactions now focus upon the virus rather than the patient.

Like many health technologies, HIV IHTs produce a range of both beneficial and harmful effects. HIV IHT's are incomplete in that they do not afford cure. They are subject to uncertainty traced into the character of the science that produced them. HIV IHT's offer hope for increased life expectations, but also unwanted side effects and drawbacks. This project addresses the management of these dualities and contradictions. Located at the nexus of medical innovation, infectious disease, sex, stigma and spoiled identities, HIV is ripe with competing significations. Critically, in this era of HIV IHT induced medicalisation, there is a danger that the interdependency of biomedical and psychosocial is overshadowed by the primacy of technological innovation.

About the Project

This project provided an opportunity to gain insight into an epidemic that has been transformed by medical innovation. It addressed a variety of issues shared by other areas such as genomics and post genomics.

However, the fact that HIV is a transmitted through infection rather than inherited disease also means that it involves many issues specifically associated with risk of infection. Nevertheless, Transitions in HIV Management has provided a basis from which to consider a range of social and ethical issues relevant and able to benefit from work on biotechnical innovation, for example: chemically induced mutation and genetically modified food.

From a methodological point of view, the opportunity to undertake qualitative research aimed at providing insight into the impact of medical innovation rather determined by a public health prevention agenda, has made it possible to devise conceptual tools able to deal with a changing epidemic both nationally and internationally. It has provided the basis for evaluating the impact of new technologies such as HIV vaccines and microbicides which herald yet another series of changes and challenges to the management of HIV. In summary Transitions in HIV Management will make a contribution to a field dealing not only with anti-retroviral therapies and associated diagnostics but with other medical technologies now under trial. As one external reviewer of the project remarked:

'This study will be the most authoritative voice in the UK on the impact of IHTs upon the management of HIV'.

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