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EDITORIAL

Expanding antiretroviral therapy provision in resource-constrained settings: social processes and their policy challenges

The international policy and research context

Political pressure to provide antiretroviral therapy (ART) in poor countries, alongside falling drug prices, led to a dramatic increase in ART delivery from 2002. In that year the Global Fund for AIDS, TB and Malaria was established. In 2003, President George W. Bush pledged US\$15 billion towards his Presidential Emergency Programme for AIDS Relief (PEPFAR) and the World Health Organisation (WHO) launched the “3 × 5” campaign aiming to place three million people on treatment by 2005. Although the WHO goal was not achieved, the investment meant by the end of 2008 about four million people in low- and middle-income countries were receiving ART.

Research to inform and evaluate ART expansion in resource-constrained settings has, perhaps inevitably, focused on the impact of different drug combinations and clinical outcomes, related public health questions, and on the effectiveness and costs of different modes of delivery. Social or behavioural science research has tended to focus on the important question of patient adherence. Social research has recently started to explore the effects of ART on stigma, sexual relationships, new identities, political activism, and the inequalities that underlie HIV-infection and undermine ART delivery (Bunnell et al., 2006; Castro & Farmer, 2005; Domek, 2006; Robins, 2005; Seeley et al., 2009, for example). However, research about the social processes unfolding as a result of ART has been relatively rare (Russell et al., 2007). As social scientists, we expect the provision of an effective drug for a previously terminal, feared and highly stigmatised disease to have profound implications and meanings for social and economic aspects of life; for individuals, families, communities and health services, and for wider social norms, expectations and behaviours. These unfolding social changes will affect society, but also specifically ART programme processes and outcomes, for example, reductions in stigma and increasing numbers of support groups can speed up uptake and increase adherence.

In this special edition we consider several broad areas of enquiry. How is ART affecting the social construction of the disease, people’s identities and

stigma? How are people adjusting to a new chance of life, to living with HIV as a chronic condition, and what challenges do they face in rebuilding their social and economic lives as they return to the harsh realities of poverty? How is ART delivery affecting the working and personal lives of health workers and what are the implications for health systems?

This issue presents papers presented at a conference: *Expanding antiretroviral therapy provision in resource-limited settings: social dynamics and policy challenges*, held in May 2009 at the University of East Anglia (UEA), UK. The conference was organised by the School of International Development, UEA, and the Health Economics and HIV/AIDS Research Division (HEARD) of University of KwaZulu-Natal. It brought together international research organisations and partnerships to share original social science research on ART delivery and its effects in resource-constrained settings. This is one of the first collections of social research on patients’ and health workers’ responses to ART and its effects on their lives and livelihoods.

Summary of themes and papers

The diverse topics covered by these papers follow a broad analytical theme of *social actions and processes surrounding ART delivery and uptake, and their (often unintended) implications for policy*. The papers examine social actors and processes from the perspective of those accessing and taking the treatment, often people coming back from near-biological and social death and striving to build a new life on ART, and those delivering or funding ART interventions. They are organised into three themes: ART and changing identities; ART and living with HIV; and ART and its effects for health services.

ART and changing identities

ART provides effective treatment for a previously untreatable and terminal disease. It leads to improved health and enables a return to normal activities. These social facts could have profound implications for the way a society applies meaning to and “socially constructs” the disease and labels or categorises those people with that disease. Across societies, HIV has

been characterised by high levels of stigma and discrimination. While stigma must be conceptualised as a social process arising from structural inequalities and the exertion of power and control (Castro & Farmer, 2005; Parker & Aggleton, 2003), the nature of the disease itself makes it open to social processes of labelling and the categorisation of “undesirable” or “undeserving” “others”. In most societies’ moral frameworks it is associated with perceived “deviant” or “immoral” behaviour and groups; it is seen as the responsibility of the individual; it is contagious and a threat to the community; it was the equivalent of a death sentence with no treatment; and death was slow and painful (Alonzo & Reynolds, 1995). ART cannot necessarily address the structural inequalities or moral frameworks that drive processes of stigmatisation and discrimination, but does offer a chance to counteract some of the above processes through prolonged life and improved health and appearance.

The papers on this theme consider ART’s implications for the social construction of the disease and the identity of those people living with HIV (PLHIV). Does ART necessarily reduce people’s fear of getting tested or disclosing their status and reduce the stigma? How have political struggles for treatment affected identity and the place of PLHIV in public health discourse? Does a “medicalisation” of HIV through ART offer new opportunities for HIV organisations to link up with communities in the “fight against HIV”?

Virginia Bond draws on 20 years of living and working in a high HIV prevalence country, Zambia, to explore the reasons that lie behind people’s limited uptake of HIV testing or public disclosure of their status, despite increased availability of ART since 2004. She describes how PLHIV must carefully negotiate the pragmatic advantages of testing and disclosing alongside the fear of the result and a permanent shift to their identity following disclosure. When it is spoken, Bond argues, the “possibility” of infection, the “implicit knowing” of others becomes reality and a person’s HIV status becomes a prominent and fixed identity. Disclosure is a complex matter, taking many forms and often a gradual and careful process to a limited circle. Silence is often an easier option, perhaps with the presence of HIV implicitly known but not spoken. Better understanding of disclosure processes is needed to inform safe disclosure procedures in the VCT and ART programmes being rolled out in Sub-Saharan Africa.

Bernays, Rhodes and Terzić present qualitative findings from Serbia to look at the effects of treatment on stigma. Their analysis reveals that structural factors continue to make HIV a stigmatised disease despite the availability of ART. Here,

HIV affects mainly marginal and stigmatised groups (sex workers, gay men and drug-users). Public resource constraints mean moral-economic judgements construct ART as a diverter of scarce funds away from more “socially deserving” conditions. Structural obstacles to finding work add to feelings of disempowerment and dependency. HIV and ART are cast as threats to both the social and economic fabric of the country. They conclude that HIV treatment is insufficient alone to reduce stigma and needs to be supported by complementary employment and social support interventions enabling PLHIV to lead more empowered economic and social lives.

Kielmann and Cataldo examine how collective action around access to ART, involving political claims for social justice, human rights and health care, have forged new individual and group identities among PLHIV. Associated processes have constructed them as “expert” patients and “empowered citizens”, important actors at the inter-section of health services and communities. They argue that constructions of PLHIV as “responsible patients and public health citizens” are key but may not be applicable in all treatment settings, and the involvement of patients in health systems raises further ethical, political and policy questions.

Busher explores how ART delivery expansion in north-east Namibia is changing the way HIV organisations and programmes are perceived by traditional leaders and fit within the wider socio-moral cultural framework. Traditional leaders view interventions involving discussions of sex and condoms as a threat to local moral values and social order, preventing their involvement in these activities. However, the rapid expansion of ART after 2004 meant the emphasis shifted to advice about accessing tests and effective treatment. A new set of signs and meanings about HIV has enabled traditional leaders to engage with the fight against HIV, without undermining their role as cultural guardians.

ART and living with HIV

ART means HIV has become a manageable chronic condition rather than a terminal illness. The second theme looks more closely at the effects of this change for the social and economic lives of individuals and their families in resource-constrained settings. Restored health enables people to return to work, re-engage with family and participate in social activities. Numerous changes are required in the lives of PLHIV as they move from a situation of sickness and social isolation to a second chance at life. There are challenges to this adjustment, especially in

settings of poverty and where ART delivery systems offer varying degrees of support or security (Rhodes, Bernays, & Terzić, 2009; Russell et al., 2007). Patients who may have managed to accept their HIV status must now incorporate the treatment regimen into their daily lives – for the rest of their life.

When ART became more widely available in resource-constrained settings there was widespread concern about adherence levels. A feature of some ART programmes in Sub-Saharan Africa is the requirement for patients to choose a treatment supporter or medicine companion (MC) to improve adherence. Foster, Nakamanya, Amurwan and colleagues report on the characteristics and roles of MCs chosen for adherence support by Ugandan patients enrolling on ART. Women were more likely to choose one of their children and men more likely to choose their spouse. An important part of the MC system is that it entails disclosure of one's HIV status, which as Bond argues in this edition can pose a serious dilemma for people wishing to start ART. Foster and colleagues note that women may have been less likely to choose husbands as their MC because they had not yet disclosed their status to the husband. Such a disclosure can have serious consequences for women in Uganda. These conclusions echo those of Bond: ART programmes must consider the pros and cons of the requirement of disclosure carefully.

Adjustment to living with HIV as a chronic illness also requires people to make changes in their economic, social and personal lives. The challenges of rebuilding a livelihood, relationships and hope devastated by HIV are considerable, but vitally important for individual clients and the success of ART programmes. People need to be leading meaningful economic and social lives to live with and manage the disease, and more specifically to go on adhering to ART (Nam et al., 2008). They need to live with, as well as manage their chronic illness, and the management will be affected by the “living with” (Strauss, 1990).

Seeley and Russell's paper explores people's efforts to rebuild social relationships and social lives following a period of profound disruption caused by HIV. They use the concept of “transition” to explore people's narratives of recovery and change on ART, and the related idea of “getting back to normal”. Transition refers to a person's adjustment towards incorporating a chronic illness and treatment regimen into their lives, their identity and their interactions with others (Kralik, 2002). They also consider the transformative effects of HIV and ART, and the idea of “rebirth”, a process whereby the illness is perceived as an opportunity to live a better life, with a

new outlook, new personal aims, new social roles and a new status (Pierret, 2007; Robins, 2005). The key policy challenge is to provide support for people working to restore their social and economic lives, to accompany the medical intervention.

Chileshe and Bond also explore people's efforts to access ART and manage their condition under conditions of extreme poverty in a rural setting. They had experienced the long-term economic shock and impoverishment caused by a prolonged and serious illness, TB. Subsequent HIV diagnosis and access to ART was undermined by this pre-existing poverty. High transport costs to ART clinics, and a health service system requiring four visits before being enrolled on ART, posed serious economic barriers. Stigma, a recurring theme in this special edition, also presented barriers. The authors argue programmes delivering ART in poor rural areas need to consider the impact of transport and food costs on treatment adherence and appreciate how many poor households enter the ART programme with already depleted household resources.

ART and its effects for health services

Large-scale investment in ART delivery expansion in poor settings has changed the lives of health workers and generated considerable changes for health services. The scale of funding has also affected wider processes of health policy governance.

Schneider and Lehmann describe the expansion of lay health workers in the South African health system, which now outnumber professional nurses. They consider the implications for the organisation of the health system and professional relations between lay workers and health care professionals. Counselling and home-based care are routine roles for lay health workers, and they occupy a “mediating layer” between citizens and the formal health and social welfare systems. While they are essential to the delivery and functioning of health care, their proliferation has been uncoordinated and unregulated by the state, causing numerous organisational and human resource difficulties. The authors argue that research is needed to understand this complex phenomenon, to inform measures that can better harness the potential of lay workers.

Namakhoma and colleagues examine the pressures of delivering ART for already over-stretched health workers in Malawi, and the difficulties faced by health workers taking ART themselves as they wrestle with fears of disclosure.

George and colleagues examine the effects of ART delivery expansion on health workers at two ART sites in South Africa. Survey results comparing

ART and non-ART workers show that ART workers are less likely to regard their workload as heavy, have higher levels of job satisfaction, lower rates of sickness absenteeism and see more opportunities for professional development. This evidence contradicts that found in Malawi noted above, and many other studies that show ART scale-up creates additional burdens and stress for health workers. Qualitative interviews explored the reasons for these findings and found that higher satisfaction and morale and lower stress were related to their ability to bring treatment and hope to patients, delay deaths due to AIDS, and better training opportunities. The wider political context and better resource levels in South Africa also explain these findings.

Kudale and colleagues examine the ways social and political actors within the ART delivery setting affected the evolution of ART delivery systems in two high prevalence settings in Maharashtra and Andhra Pradesh in 2005 and 2009. The study goes beyond a static analysis of resource constraints to consider the roles of different actors, the wider political context and questions of leadership and ownership of the HIV programmes, and how these processes affected quality of care and patient pathways to accessing ART. They conclude that the evolution of ART programmes within local health systems must consider the wider socio-political environment.

Hanefeld moves to the wider shifts in health policy processes brought about by the advent of support for ART by PEPFAR and the Global Fund. She explores the role of these two global organisations in Zambia and South Africa over the past five years, focusing on their influence on policy content and the implementation of ART programmes. Hanefeld highlights their influence on governance at national and sub-national level, showing how because of the intervention of global players the actual implementation of policy bypasses the state.

The longer term challenge

The social processes examined here that are arising from the dramatic expansion of ART for PLHIV in resource-constrained settings point to the need for a vision for ART scale-up that must be broadened to go beyond medicine to incorporate complementary social, economic and health facility interventions that consider complex questions of identity, stigma reduction and disclosure requirements, economic and social measures that support people's adjustment to living with HIV as a chronic condition, and measures that can address the needs of health workers involved in ART delivery. The sustainability of ART programmes depends on this broader vision: in the rush

to scale-up ART delivery the important focus on clinical priorities must not "over-medicalise" the agenda and forget other notions of well-being.

These social processes must be placed into the wider context of funding for ART expansion and the immense challenges to long-term success. First, treatment coverage needs to expand further. Only about 40% of those who need treatment in middle- and low-income countries are getting it. The number of people needing drugs will continue to rise each year, and over time people will need more expensive second-line regimens. Funding is also needed for the complementary social and economic interventions discussed in this special edition. A key question for development agencies also centres on their long-term obligations to people supported on ART in resource-poor settings: will ART be guaranteed for life, regardless of the increased cost of different treatment regimens required as resistance develops?

Second, against these growing resource demands is a situation in which current funding for ART expansion in Africa is time-limited. Long-term funding commitments for ART had not been embraced even before the current international economic recession. Major HIV/AIDS donors may be forced to reduce their commitments due to acute budget constraints, and the global economic crisis will also affect domestic economies and government budget resources.

Third, even if donor support were guaranteed, health system weaknesses in many countries raise concerns about the feasibility of continued ART roll-out, particularly in rural and unstable areas. The foundation upon which success depends – the assurance of an uninterrupted, affordable and accessible supply of medication and care – remains absent in many countries.

Finally, there is the question of donor dependency. In many countries the provision of treatment is undertaken by donors and significant numbers of people's lives depend on the largesse of decision makers in Washington, London, Geneva and Paris. This is a unique situation which needs careful and immediate attention.

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References

- Alonzo, A., & Reynolds, N.R. (1995). Stigma, HIV and AIDS: An exploration and elaboration of a stigma trajectory. *Social Science and Medicine*, 41, 303–315.
- Bunnell, R., Ekwaru, J.P., Solberg, P., Wamai, N., Bikaako-Kajura, W., Were, W., & Coutinho, A. (2006). Changes in sexual behaviour and risk of HIV transmission after antiretroviral therapy and prevention interventions in rural Uganda. *AIDS*, 20(1), 85–92.
- Castro, A., & Farmer, P. (2005). Understanding and addressing AIDS-related stigma: From anthropological theory to clinical practice in Haiti. *American Journal of Public Health*, 95(1), 53–59.
- Domek, G. (2006). Social consequences of antiretroviral therapy: Preparing for the unexpected futures of HIV-positive children. *The Lancet*, 367(9519), 1367–1369.
- Kralik, D. (2002). The quest for ordinariness: Transition experienced by midlife women living with chronic illness. *Journal of Advanced Nursing*, 39(2), 146–154.
- Nam, S.L., Fielding, K., Avalos, A., Dickinson, D., Gaolathe, T., & Geissler, P.W. (2008). The relationship of acceptance or denial of HIV-status to antiretroviral adherence among adult HIV patients in urban Botswana. *Science and Medicine*, 67, 301–310.
- Parker, R., & Aggleton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science and Medicine*, 57, 13–24.
- Pierret, J. (2007). An analysis over time (1990–2000) of the experiences of living with HIV. *Science and Medicine*, 65, 1595–1605.
- Rhodes, T., Bernays, S., & Terzic, K.J. (2009). Medial promise and the recalibration of expectation: Hope and HIV treatment engagement in a transitional setting. *Social Science and Medicine*, 21(3), 315–321.
- Robins, S. (2005). *Rights passages from 'Near Death' to 'New Life': AIDS activism and treatment testimonies in South Africa*. IDS Working Paper 251. Brighton: Institute of Development Studies.
- Russell, S., Seeley, J., Ezati, E., Wamai, N., Were, W., & Bunnell, R. (2007). Coming back from the dead: Living with HIV as a chronic condition in rural Africa. *Health Policy and Planning*, 22(5), 344–347.
- Seeley, J., Russell, S., Khana, K., Ezati, E., King, R., & Bunnell, R. (2009). Sex after ART: The nature of sexual partnerships established by HIV-infected persons taking anti-retroviral therapy in Eastern Uganda. *Culture, Health and Sexuality*, 11(7), 703–716.
- Strauss, A. (1990). Preface to special edition on qualitative research on qualitative illness. *Social Science and Medicine*, 30(11), V–VI.

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