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ART special issue: Social rebirth and social transformation? Rebuilding social lives after ART in rural Uganda

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Abstract

This paper examines how HIV-diagnosis, illness and Anti-Retroviral Therapy (ART) have an impact on the social dimensions of people's lives in rural Uganda, focusing on identity, relationships and membership of groups. Using concepts drawn from sociological research on experiences of illness and recovery ,`getting back to normal', `rebirth' and `turning point', we present findings from qualitative research that explored the social changes brought about by HIV and ART among 70 men and women taking ART since 2003. With a second chance at life, some people's narratives revealed a pursuit of getting `back to normal', restoring and resuming their place in their families and communities. Others sought to change or transform their new lives, what we term a 'social rebirth', moving away from old social networks and lifestyles. Regaining health was associated with a desire to make the most of life by joining social groups and civil society organisations, establishing new relationships and advising and supporting others. However, earlier losses of family and friends due to AIDS-related deaths made `social rebirth' hard for many people. Our findings also show that the process of responding to ART is not linear and the pursuit of change following diagnosis and treatment may be difficult to sustain, as the months and years on ART progress and the struggles of getting on with life take their toll. Sustaining social rebirth was challenging and complex due to the nature of HIV infection itself (for example new intimate relationships pose challenges) and the harsh economic environment. Maintaining changed lives for those living with HIV and ART is important because this will contribute to better disease self-management and so demands an understanding by support organisations of the nature of these changes and challenges.

284 words

Keywords: HIV and AIDS, anti-retroviral therapy, social support, social rebirth, Uganda

Introduction

The idea that serious illness may be a source of personal transformation is not new. Frank (1993), for example, cites `Devotion's upon Emergent Occasions' (1623) in which John Donne describes `a self-change and a deepening of his religious faith' as a result of serious illness. The sociological literature on managing life with chronic illness provides many examples of the ways in which social and spiritual adjustments or transformations occur in people's lives as they re-establish their place in the world through their work, relationships and social activities (Williams, 2000; Kralik, 2002; Lubkin and Larsen, 2005). In this paper our focus is on these social changes among people living with HIV in Uganda who have experienced AIDS-related illness but have had their health restored through Anti-Retroviral Therapy (ART).

The advent of ART more than a decade ago, and the so called `Lazarus effect' of these drugs that brought many people living with HIV back from the edge of death, has driven research to understand how people rebuild their lives following the commencement of treatment (Ware et al., 2006). Taking ART means people must make an adjustment to living with and managing HIV as a chronic condition. We use the broad concept of *transition* to explore people's narratives of recovery on ART (Kralik, 2002). 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 (Russell & Seeley, forthcoming). Transition does not just happen with the passing of time. It is achieved by people taking action and making changes in their lives (Kralik, 2002; Pierret, 2007).

Rofes (1998) was among the first to describe the effects of ART on people's social lives. Looking at the lives of gay men living with HIV in the USA when they first had access to treatment in 1996, he presents both the realisation of infection, as well as the reconstruction of lives once treatment was found to work, as '*turning points*' in the men's lives. He describes a `turning point' as being a crisis or crucial/decisive point or situation that makes a person see things differently (1998: 67).

Research on people's lives following diagnosis of HIV-infection has also contributed to an understanding of the *transformative* nature of infection and terminal illness (Hassin, 1994; Davies, 1997; Ezzy, 2000; Trainor and Ezer, 2000; Pierret, 2007). We define transformation as a process whereby the illness is perceived as an opportunity to learn and to live a better life, with a new outlook, new personal aims, new social roles and a new status, rendering one's condition and identity meaningful (Pierret, 2007; Robins, 2005).

In South Africa these transformative experiences after starting ART have been examined by Robins (2005), who argues that people's testimonies reveal that AIDS and then the recovery on ART has been a blessing in disguise, triggering a positive transformation in people's lives. Robins uses Turner's (1969) ritual analysis framework to plot a linear process of transformation: beginning with a 'ritualised separation' caused by the profound stigma and 'social death' associated with AIDS; then an uncertain state of 'liminality' soon after treatment begins when health stabilises but one's response to ART and one's future remain precarious and uncertain; and finally a '*social reincorporation*' into the wider community, often as a patient-activist linked with organisations like the Treatment Action Campaign, empowered with knowledge, a new lease of life and an ability to speak openly about one's status. The extremity of near-death and 'ritualised separation' produces the conditions for AIDS survivors' social reincorporation.

While the experience of regaining life, and a future, through treatment is indeed an understandable cause for joy, other commentators point to a more mixed set of emotions that come with regaining health (see, for example, Carrieri et al. 2003, Simoni et al. 2004, Sacajiu et al. 2009),. The very nature of HIV, a stigmatized condition long associated with sexual promiscuity, may mean that people have to adjust to regaining a sense of self-worth while continuing to manage other people's attitudes towards them because of their infection (Poku et al. 2005). There are similarities with cancer as Mathieson and Stam (1995) and Sontag (1978) remind us, as some people diagnosed with that disease experience the physical withdrawal of family and friends once their condition is known, their stigma often resulting from unfounded fear of contagion or simply fear from not knowing what to say.

We draw on the analysis of individual experiences of change arising from illness and recovery from cancer, to explore the social transformations that HIV and ART may have brought about. Shapiro et al. *(*1997), for example, describe three different types of response and adjustment to the experience of surviving cancer after successful treatment: `back to normal', `turning point' and `rebirth'. A person whose experience may be described as `back to normal' may find diagnosis and illness traumatic events, but once treatment has restored health there is a sense of being `back to her "old self"' (1997: 544). The illness is in the past and life carries on as before. Those whose experience corresponds to `turning point' and `rebirth' talk of change in their lives, the `turning point' experience corresponding to illness providing a chance to get life back on track, and the `rebirth' experience resulting in a changed life and self as a result of illness (1997: 545). Shapiro et al. (1997: 545) observe that a turning point is `change understood not as being different but rather as "becoming more in accord with who I was"', whereas `rebirth' resulted in a fundamental change or transformation, not just getting life back on track. Shapiro et al. quote the partner of a woman who had experienced rebirth through her illness as saying `it's kind of like being married to a different person [...] the person of five years ago and the person now are of course two different types of people' (ibid).

Background and methods

The study was situated at a home-based ART programme in rural Eastern Uganda with a participant catchment area covering a 100 km radius around Tororo town. The ART Programme, which started in 2003, delivered and monitored ART and tuberculosis medications to the homes of approximately 1000 people with HIV, recruited from The AIDS Support Organisation (TASO), a large non-governmental organisation operating at national level providing counselling and support services.

Subsistence agriculture is the main livelihood activity in the area, and fishing and cross-border trade are other important activities for some sectors of the population. The majority of people in the area have not received education beyond primary school level. Women, particularly those over 40, are less likely to have been to school than men.

The findings presented here are from qualitative research that explored participants' lives and activities following the introduction of ART. The aim of the study was to build understanding of people's adjustments and transitions to living with HIV as a chronic condition when on ART. In the first phase of research (2005) a small sample of 12 people, six women and six men, were purposefully selected from among people receiving free ART in the Programme. These participants and their families were visited once a month over a 12 month period by interviewers. On each visit a loosely-structured interview was conducted with the participant and observations were made. The first interview used a life history instrument to gather data on changes to people's lives since the illness had began to disrupt their lives, and changes following the start of ART. In the second phase (2006) an additional 58 participants were selected to explore key themes further. These participants were visited twice. The 70 participants (36 women, 34 men) were selected to be typical of the programme's overall participant age profile.

Data were collected by trained interviewers, all of whom had received a tertiary education and were proficient in more than one of the seven local languages. The interviewers took notes during the interviews and wrote these up as detailed transcripts in English. The interviews were analysed and coded manually, initially by the interviewers, then by the authors and the coding compared. Through this process a final list of themes and sub-themes were identified across all the data. The prominent themes relating to people's social lives are presented below, and case study participants' stories are described as 'illustrative' or 'typical' cases in order to enrich understanding of the processes observed and some of their complexities (Mitchell, 1983).

The study received ethical approval from the ethical review boards of the Uganda Virus Research Institute and the University of East Anglia.

Findings

Disruption and social marginalisation

Narratives of coming to terms with a positive diagnosis and subsequent illness reflected upon the earlier disruption resulting from HIV. This disruption was characterised by the loss of loved ones and a process of social marginalisation as friends and family distanced themselves because of the stigma and fear associated with the disease. Our participants told vivid stories of this period in their lives. One of these people was a 40 year old man, who we will call Okecho[1], who had a CD4 count of four when he began ART. He described his poor mental state, serious skin complaints and other ailments to the interviewer in great detail. As a result of his physical and mental condition he told how some of his family and former friends wanted nothing to do with him and mocked him in his mental confusion.

Like many of the participants, Okecho was experiencing profound prejudice, increasing isolation and a 'social death'; the loss not only of health but also of relationships with friends and family. People were waiting for him to die.

Disruption and loss were features of the narratives that were precursors to 'getting back to normal' or a 'transformation' following the start of ART. In the case of Okecho, once he had started ART he began to get better and it was not only his health that was restored but his sense of self-worth. He told us: `to tell you the truth I started liking myself and wanted people to know that I liked them and needed their support'. As he regained his mental competence and looked better, people started to re-engage with him, curious to see how he had made such a dramatic recovery.

Getting back to normal

Okecho's experience, the wonder he conveyed about the restoration of dignity, his reintegration into his family and the re-establishment of a friendship network, allowed him to remake his life, to start again; a `rebirth' in Shapiro *et al.* (1997) terminology. For half of our participants the change seemed less dramatic, perhaps because their physical deterioration had not been so great but also in many cases because `getting back to normal' was demanding enough as they worked to get back into a life that was full of challenges. The way they told their stories, often dwelling on the post-ART difficulties of getting enough food, paying school fees, managing relationships and their families, reflected their more muted response to the rebuilding of their social world.

Recurrent themes that emerged from the narratives focused on the work of rebuilding or normalising existing relationships; the return to `normal worries' and economic difficulties and struggling with transition as they faced loneliness and difficult relationships. This mix of experiences is shown in the story of Susan, below, which illustrates what `normal life' consisted of before and after AIDS-related illnesses and ART for many women in this setting:

> *Susan was born in 1977. Her childhood had been affected by poverty and war which had resulted in her having to move home several times. In the late 1980s, when peace had come to Uganda, she worked for a short while in Kampala as a maid*

> *before going to live with an elder sister back in her home district in eastern Uganda. While in primary school, when Susan was 16, she became pregnant. Her sister threw her out of her home and she went to live with the father of her child. Four years later (in 1997) her husband, who was older than she was, began to fall ill and his small shop had to be sold to finance his treatment. In 1998 Susan and her husband were tested for HIV and found to be positive. They sought help from The AIDS Support Organisation (TASO) and a local church. When her husband died after a distressing period of illness that frightened Susan, she continued to get help from TASO and the church. However, she did not have enough to eat, so she tried to start a small shop but this was hard because she was often falling sick. Then her youngest child, a baby, died after a long period of illness leaving her with one son. She knew she needed to support her son so she carried on trying to keep the shop going with some help from the church. At this point she joined the ART project. With her restored health she worked to diversify her business by joining the trade in smuggled goods across the Kenyan border. She had limited success because of problems with a business partner, who cheated her. She left the church because members disapproved of the fact that she has had two new partners since her husband died. She was pregnant at the time of the final study visit to her home in 2007.*

As Susan's story illustrates, `getting back to normal' was hard and, because of the disruption and loss that HIV-related illness has caused, many people cannot get back to a `normal life' again; too much has changed.

Other women told similar stories to Susan, of early pregnancy and marriage, struggles with poverty and partners who had other relationships (or partners with others wives with whom they competed for resources) and also, for many, the challenges of bringing up children once their husband had died. One woman, for example, had had to sell most of her possessions and borrow heavily from relatives to afford bail for two sons who at different times were imprisoned for defilement. Men too faced challenges. One man talked of the strain of being a single parent and justified his earnest search for a new partner as a part of getting life back to as it was before his wife died.

Getting back to normal was not so challenging for those who had good social support. For some religion was a key source of this support; not all study participants experienced the same rejection from church as Susan. Belief in God is widespread in the study area, and churches and mosques are important organisations offering not only spiritual support but also social and material support. People who had been life-long believers or had joined a faith perhaps as result of their HIV infection found that the religious community provided strength and motivation that helped people in their work towards a normal or new life. One 60 year old woman described her faith in the following way:

> “So let’s be sick now, but when we die and resurrect nobody will say I am sick…So only to think about paradise makes your heart lift --- and when you feel downhearted, you go to a sister and tell her --- I have this problem; or a brother. We [or he] will generously help you with the scriptures...”

For these people, with an established faith or social position, ART certainly transformed their health but the social world into which they had been `reborn’ was little different from before.

For others a change was necessary for them to adjust to the new challenges of the future, to rebuild their lives, to take the opportunity at a second chance at life, and to take treatment every day. A `return to normal’ would also have been detrimental because of the nature of their previous life, something that Ware *et al.* (2006: 906) also mention for some of their study participants in the USA who had been drug users. One man in our study for example used to spend his days drinking and relied heavily on his brothers for support. Treatment transformed his life because he realised that his old life style was incompatible with his treatment regime (where drinking too much may cause pills to be forgotten, a fear expressed by a number of participants). He had to consciously change his habits and friends; he experienced a conscious transformation or `social rebirth’. This man, like Okecho described above, did feel that his social world had been changed because of treatment.

Social Rebirth and Transformation

Social rebirth and transformation require support and encouragement, particularly if there is either no `normal life' to slot back into or there is a desire for change. Mobilising support and resources was a prominent part of many participants' narratives. For those who described a process of social rebirth (just under half the participants), the contribution of civil society organisations such as TASO and community-based `Post Test Clubs' was striking. Through these organisations the process of social rebirth had started before ART. One woman, Agatha, described the social isolation and despair she had felt when after the loss of two children, her husband and then her mother died and she began to get recurring sickness. Comfort and friendship came from members of the post-test club who stopped her from feeling alone and gave her new strength; her transformation had already started when she later began ART. Another woman, Monica, experienced similar pre-ART transformations. A trained teacher, she described in detail the discrimination she had faced at work once her colleagues had found out that she was HIV-positive. She had had to retire early because she could not cope with the way they treated her. When she joined TASO and realised she was not alone and got encouragement from others, she began to regain hope. When her health began to improve as a result of taking cotrimoxazole (septrin) prophylaxis (a medication widely used for people living with HIV before they require ART), she started a second hand clothes business, then with money she had saved from her teaching days she bought a plot of land and built a small house for herself. After starting ART she continued to invest in her new life on the land. She told us `I want to tell the whole world my experience—it may help other people also who are struggling'.

New social relationships and new roles had been developed by some participants, especially women, through their links with organisations involved in HIV and AIDS work. This involvement in the public sphere reflected a transformation in these people's lives. Living with HIV as a chronic illness had generated a new meaning to life, motivated social action and the pursuit of fulfilment through community-outreach and HIV awareness campaigns, service in their church or through providing support and advice to others. These participants' identities in the community had been transformed from somebody isolated and 'already dead' to someone who people sought out for advice on getting tested or living with HIV.

Membership of organisations provided companionship and a sense of belonging, helped people to acquire a sense of order and control over their lives, and to harness and express their new hope and energy for the future:

> *Lydia, a 50 year old woman, described to the interviewer her experience at the hands of an abusive husband, then her separation and remarriage to a kinder man. She told of the struggles they had had with money when he had lost his job because of recurrent illness and the problems she had experienced with his relatives when she had been accused of causing his death in 1990. She had managed to get a job as a manual worker in the hospital but had lost this when her HIV-status became known. The turning point for her came through her association with TASO. TASO workers offered her a salaried position: the interviewer wrote in her account: `She was overwhelmed, she saw life in a new way, she saw a miracle from God [...] even with HIV, life has meaning after all'. In the years that followed she kept her job through recurrent bouts of illness, she began ART, suffered severe side-effects until her drugs were changed, and struggled with difficult teenage sons. For her, TASO had provided the fresh start she had needed and the access to the future care and support she had required.*

Others talked of their joy at finding intimate companionship and building a new family, with a new partner, after regaining their health, a process we have described elsewhere (Seeley et *al.* 2009). Often these changes were not a result of treatment, but of diagnosis and sickness. For one man, it was the death of his first child in 1992 and his fear that he and his wife were HIV-positive that dramatically changed his life. He had been brought up as a Muslim but with the trauma and disruption following the death of his child he joined a Pentecostal church that offered him moral support that he claimed not to have found among his Muslim fellowship. He found friendship and support in that church and eventually trained as an evangelist. His decision to change his faith strained his relationship with his family but church fellowship and, importantly, TASO, helped him make new friendships and rebuild his social world.

The experience of one participant serves as a reminder that ART may not be able to transform life as much as may be desired. This man, as a result of untreated AIDS-related illness, has been left permanently disabled. While ART has prevented further sickness he was wholly dependent upon his 80 year old mother and teenage son for all his care. He faced the future with trepidation because he knew his mother could not manage his care for much longer. He had few friends and spent his days sitting outside his hut watching the world go by. His disability, rather than his HIV-status, was a barrier to his social and physical reintegration into his former life.

Discussion

All study participants were grateful for the chance that ART had given them to continue their lives. All had gone through periods of transition during which they sought either to `get back to normal' or to make a fresh start, a 'social rebirth'. Adjusting to life on ART was dependent upon the support of key people and organisations as well as participants' own determination to live life as fully as possible. The lengthy period between learning of or suspecting one's HIV status, and living with HIV and then AIDS-related illness before life on ART, afforded many opportunities when social worlds may have been, or needed to be remade. As our findings show, ART has seldom been the starting point for adjustment or the sole occasion promoting a transformative social rebirth.

Indeed it is difficult to see in many of the varied narratives of infection, sickness and treatment, a linear progression that Robins (2005) suggests of moving from `ritualised separation' to `a state of liminality' while treatment takes effect, to `social reincorporation' once health is restored. While there were two key events in our study participants' lives, HIV diagnosis and getting on to treatment, their progress was seldom linear. Regaining their place in a social world was challenging and not a clear transformation from one state to another as a result of illness or of treatment (Kralik *et al*. 2004: 260). Most experienced a prolonged period of transition after the restoration of health and the rebuilding of their lives. Even then the sense of change may be difficult to sustain, as the months and years on ART progress and the struggles of taking medicine for life, rebuilding livelihoods and supporting a family in a harsh economic environment, as well as continuing stigma, take their toll. The process of social rebirth is challenging because of the obstacles that make life difficult for all poor people in that social and economic context, obstacles compounded by managing life on ART.

While the experience of living with HIV as chronic illness can draw on parallels from the literature on other chronic conditions such as cancer, where those affected have experienced the prospect of early death and the loss of their future, plus a distancing from their social world as some friends and relatives withdraw contact and then successful treatment, there are important differences with HIV. In high-prevalence settings such as Uganda, those living with HIV are part of a wider epidemic and not isolated cases. The loss of husbands, wives, friends and relatives as well as children, leaves gaps in survivors' lives that are hard to fill. In addition, the very nature of HIV as a sexually transmitted infection undermines or makes far more complex the ability of a person to sustain or remake intimate relationships, while the need to take life-long treatment may affect interaction with certain social networks and social activities like drinking beer or travelling away from home for long periods to places where it may be hard to maintain a routine.

In a resource-constrained setting such as our study site, where many people subsist on rain-fed agriculture, are income-poor and face constant challenges to make ends meet, rebuilding social relationships is an essential part of making a living: friends and relatives lend support when times are difficult and thus the quest to rebuild social networks is important for material as well as emotional wellbeing. This is where post-test clubs, TASO and religious groups provide much needed social protection and support as well as friendship and understanding. Reconstructing a social life that revolves around the acceptance of HIV as a part of one's identity, through joining HIV-related groups and speaking about infection to others, was one adaptive strategy, but not the way all study participants looked for social-rebirth. `The quest for ordinariness' (Kralik 2002) for a few participants involved the desire to forget their HIV-diagnosis and try to rebuild a new social life, including intimate relationships, free of that label.

Conclusion

Our findings illustrate the different ways in which people living with HIV respond to ART; we show that the process is not linear and building or rebuilding a social life can be taxing. In addition, in a high prevalence setting the people on ART, the survivors, must manage social lives changed irrevocably through high morbidity and mortality.

Sustaining changed lives for those living with HIV and ART demands an understanding by support organisations, as well as by relatives and friends, of illness and treatment transitions so that social transformation, where it has occurred can be maintained. This is particularly important if someone has given up a habit incompatible with their treatment regime. However, social organisations, friends, relatives and acquaintances contribute beyond emotional and social support; they also promote and support new livelihood initiatives. Helping people living on ART rebuild their social life has many benefits. This is an important message for policy: providing drugs is not enough, social and economic support is essential to the sustenance of ART programmes now and in the future.

Notes

1. We have used pseudonyms for participants.

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