Supporting the sexual and reproductive rights of HIV-infected individuals

The past 10 years have seen major advances in health care policy and services that support sexual and reproductive rights in South Africa. Significant milestones include the legalisation of termination of pregnancy (TOP) and the provision of free public sector services for maternal and child health (MCH) and contraception.1 At the same time the HIV epidemic has expanded rapidly during the last decade, and today an estimated 29% of women of reproductive age (15 - 49 years) in South Africa are HIV-infected.2 Despite these parallel developments, little attention has been paid to the way in which advances in sexual and reproductive rights in South Africa are extended to HIV-infected individuals.

In some settings health care providers may have a negative attitude towards sexual activity and childbearing by HIV-infected women.3,4 These attitudes are also reflected in popular opinions regarding the sexual and reproductive rights of HIV-infected individuals – a recent survey of women attending primary care clinics in the Western Cape found that 57% reported negative attitudes to continued sexual activity by HIV-infected individuals, and 87% negative attitudes to childbearing.5 Related to this, the provision of contraception within services that provide antiretroviral therapy (ART) to HIV-infected women and men has received strong emphasis,6 with little consideration given to broader issues of reproductive choice. Here we examine the ethical, clinical and public health rationale for promoting the sexual and reproductive rights of HIV-infected women and men, and suggest approaches that may be used by health service providers and policy makers to support these rights and to improve the quality of health care services.

There is a strong ethical imperative to support the sexual and reproductive rights of HIV-infected individuals. Autonomy in decisions regarding whether and when to have children is a widely recognised component of human rights,7 and in South Africa this is explicitly supported by the section on ‘Freedom and Security of the Person’ in the Bill of Rights in the Constitution. Any health service that denies individuals the right to reproduce without their informed consent represents a clear infringement of established legal and ethical conduct; as a result, there are few situations in which individual choices around sexual activity or childbearing are overruled by health care providers or policies. Violations of individual autonomy in sexual and reproductive health, such as coerced sterilisation or mandatory contraception, are commonly cited examples of the ways in which health care services may threaten human rights.8,9

Services that support the sexual and reproductive health of HIV-infected individuals are also an important component of effective clinical care. Such services should be centred around patient-provider discussions on sexual activity and fertility desires, and how these shape the need for specific services. For example, sexually active HIV-infected women who do not wish to have children may require counselling on contraceptive options, including emergency contraception, and the importance of consistent condom use. Services for the early identification of unintended pregnancies, along with counselling on and access to TOP, are also critical in this instance.10 Women who wish to have children would also benefit from provider-assisted pregnancy planning (to maximise likelihood of conception and minimise risk to the patient, her partner, and their child) and referral to MCH services for the prevention of mother-to-child transmission (PMTCT) of HIV infection.

Clinical services for HIV-infected individuals that recognise and meet sexual and reproductive health needs can make a valuable contribution to improved HIV care more generally. Patient-provider discussions on sexual and reproductive health issues may provide a platform for enhanced communication for health promotion, including adherence to ART and sexual risk reduction.11 More generally, the recent rapid expansion of access to ART throughout South Africa has been aimed at improving the health and quality of life of HIV-infected individuals. However, the health and quality of life of HIV-infected patients does not depend solely on ART; instead, comprehensive services for HIV-infected individuals that include ART, sexual and reproductive health services, and a range of other primary care services are necessary to make the maximum contribution towards the quality of life of HIV-infected patients.12

In addition to the benefits for individual clinical care, supporting the sexual and reproductive rights of HIV-infected individuals can potentially have significant public health benefits. Recognising the rights of HIV-infected individuals is tantamount to destigmatising HIV disease. In turn, reduced stigmatisation of HIV can contribute to increased uptake of HIV-related services, including voluntary counselling and testing (for individuals who do not know their serostatus) and HIV care and treatment (for individuals who are HIV-infected).13,14 Moreover, throughout much of South Africa involuntary childlessness is associated with significant stigmatisation;15 as a result, denying HIV-infected women the right to have children may compound pre-existing psychosocial concerns for many women.

Given the importance of supporting the sexual and reproductive rights of HIV-infected women and men, strategies to address these rights require specific attention in health care services. In some cases, direct support may be required to improve the quality of care for HIV-infected women who are also pregnant. For example, the recent rapid expansion of access to ART throughout South Africa has been aimed at improving the health and quality of life of HIV-infected individuals. However, the health and quality of life of HIV-infected patients does not depend solely on ART; instead, comprehensive services for HIV-infected individuals that include ART, sexual and reproductive health services, and a range of other primary care services are necessary to make the maximum contribution towards the quality of life of HIV-infected patients.16

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services and policies. For health care providers the challenge is to support these rights by assisting HIV-infected patients to arrive at their own informed decisions, regardless of the provider’s personal opinions. Meanwhile, health policies must support the availability and accessibility of relevant services, including contraception, pregnancy planning, TOP, and MCH services that incorporate PMTCT. Involving men in discussions on sexual and reproductive health is particularly important, and couples counselling may lead to improved health outcomes; however, providers and services should constantly reinforce the autonomy of women in reproductive decision making.

It is important to note that health care interventions to support the sexual and reproductive rights of HIV-infected women and men require minimal additional resources, financial or human. In most settings, health care providers may need additional training on the evidence base regarding sexual and reproductive health issues among HIV-infected individuals. Specific input may also be necessary to assist providers in divorcing personal opinions from the provision of care that meets individual patient needs. Policy makers, both locally and nationally, can support providers through the development of best-practice guidelines for service delivery.

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Cot death controversies

Uncertainty as to the cause or causes of sudden and unexpected infant death and difficulty in excluding the possibility of infanticide, even after the performance of a ‘complete’ autopsy, was graphically illustrated in the London courts recently. A mother wrongly convicted of killing her two sons had her conviction quashed, and the eminent paediatrician who had given the court erroneous statistical information was struck off the medical register for serious professional misconduct.

In the developed world cot death or sudden infant death syndrome (SIDS) is the commonest cause of death among infants between 1 week and 1 year of age. Although it occurs in all countries and socioeconomic groups, the rates vary widely.

The particular poignancy of cot death and the elusiveness of its cause have engendered a vast amount of research in the Western world. Cot death associations have sprung up in many countries, and international conferences on the subject are held regularly. The list of proposed and discredited causes is a long one, including maternal overlaying, accidental mechanical suffocation, overwhelming viral or bacterial infection, a large thymus and hypersensitivity to cow’s milk, among many others. But several risk factors have been identified – the 2 - 4-month age group is at highest risk, and rates increase with parity, low birth weight, and maternal smoking and drug-taking.

Because of the need for a specialised autopsy to fully exclude other causes and because of the difficulties in ruling out suffocation or wilful infanticide, expert committees have attempted various definitions of SIDS. The most recent, in July 2004, defines SIDS as: ‘The sudden unexpected death of an infant under one year of age with onset of the fatal episode apparently occurring during sleep, that remains unexplained after a thorough investigation including performance of a