HIV-positive people, risk and sexual behaviour

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Abstract

For a long time, the sexual behaviour of HIV-infected persons did not receive any serious attention for a variety of reasons. Initially, diagnosis of HIV-infection appeared to imply a death sentence. In this context, the sex life of those infected seemed a secondary issue making prevention focused on sexual behaviour hard to imagine. Furthermore, the conviction that stigmatisation should be avoided also precluded an interest in the sexual behaviour of HIV-infected persons. From an epidemiological perspective and in the context of the developments in the medical treatment of AIDS it is important to address the sexuality of HIV-infected people. The scarce research done until now shows that there are various ways in which an HIV-infection affects people's sexuality. It seems that the sexuality of HIV-infected people can be compromised by their infection, inducing various sexual problems. Research also shows that there are HIV-infected people who do engage in unprotected sex, just as there are HIV-negative people or people with unknown serostatus who do so. Studies into the determinants of unsafe sex in HIV-infected people suggest that to some extent the same determinants are operative as among people in general. These include intention and self-efficacy regarding safe sex. Recreational drug use also affects safe sex regardless of serostatus. However, safe sex as well as sex in general is different for seropositive persons than for people who are seronegative or have an unknown serostatus. Among seropositive people, sex is also related to dilemma’s involving disclosing their serostatus to potential sex partners, and their motivation to protect their partners as well as themselves against surinfection and STD. Furthermore, having to cope with a serious disease induces negative mood states (particularly depression) and may compromise sexual functioning. Comprehensive prevention aimed at HIV infected persons should address these various issues and should be an integrated part of general HIV-prevention. © 2000 Elsevier Science Ltd. All rights reserved.

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Introduction

Any attempt to assess the contribution of social science research and prevention policy concerning the sexual behaviour of HIV-infected people has to begin with the admission that information on the subject has until recently been rather limited (Nilsson-Schönnesson and Vincke, 1994; Green, 1995). Before the early 1990s, a few studies provided isolated scraps of knowledge, which were never arranged into a whole. It was only at the 12th
World AIDS Conference held in Geneva in 1998 that the issue of sexuality and HIV-infected people received more systematic attention.

We are led to wonder why both scientists and people involved remained quiet for so long. This reticence seems all the more paradoxical in that the matter is a central factor in controlling the epidemic. Regardless of the issue of responsibility, HIV-infected people play a central role in the maintenance of the epidemic.

In the first section of this paper we will try to understand why this subject failed to emerge more quickly as an important topic for research and prevention. In doing so, we suggest studying the emergence and growth of a group that suffered doubly at a time when medical science was developing in leaps and bounds but when the precepts regarding prevention were uncertain and continued to change. Subsequently we will present an overview of what is known about the issue of being HIV-positive and sexual risks.

While we recognise the importance of infected persons in Asia and Africa, no doubt very different from the situation described here in, given the scientific backgrounds of the authors, the inventory of research presented is limited to scientific works on AIDS in developed countries (North America, Europe, Australia). It is of course of major scientific interest to have more comparative research in that field between developing and developed countries.

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1 It may be recalled that, in 1987, the life expectancy of an AIDS patient was one year. There were specialists who went so far as to question publicly whether it was any use financing work on people who had only a short while to live (Le Monde, 26.02.87.). The early therapies delayed the fatal outcome, but contracting AIDS remained and for most people still is a terminal condition.

2 For many years, the virus was thought of as a time bomb lurking within the seropositive person's system, which would be triggered by a set of activating co-factors and other pathogens. The infected subject was the victim of a dread so grim and implacable that he reorganised his existence and personal habits so as to postpone the onset of the disease for as long as possible (Pierret, 1997).

3 This expression was originally applied to people who had lived for at least three years after AIDS was declared (VIIIth International AIDS Conference, Florence, 1991). It was next applied to persons who had lived with HIV for at least ten years without developing the disease (VIIth International AIDS Conference, Amsterdam, 1992). The harshness of the terms was disputed and the vocabulary was changed. “Long-term survivors” became “long-term non-progressor HIV-infected subjects”.

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Place of people with AIDS in social science research and HIV-prevention

Dominance of the lethal image of AIDS

When we first were confronted with the outbreak of AIDS, people with AIDS were the sole object of knowledge. In the absence of any form of treatment, AIDS disease was equated with death. The pioneering AIDS Associations were set up to provide the victims with medical, moral and financial support — in a word, to comfort them and “help them to die well”.

In 1985, when commercial tests became available, there was a redistribution of roles. In between the uninfected subject and the person who had AIDS an initially shadowy new character made his entrance: the person testing positive in the HIV-screening tests. At first, a positive test was regarded as a biological sign of an encounter with the virus. It was an indication, but not a proof, of infectiousness. At that time, it was thought that only a tiny proportion of the people who tested HIV-positive was doomed to contract the disease and die. The majority of the HIV-infected people were considered to be “healthy carriers”. With the passing of time, the chances of developing the disease were steadily revised upwards. Beginning in 1987, the term “seropositive” entered the language. The seropositive person, although not feeling ill, had indeed been infected by HIV and was ipso facto infectious.

In this context of omnipresent death the diagnosis of HIV-infection appeared as a death sentence against which the associations, the medical personnel and the patient needed to fight for survival (Pollak, 1988). At that time, volunteer organisations advanced the notion of “people with AIDS” latter becoming “people living with AIDS” (PWA) with the aim of mobilising the concerned to involve them in the fight against their own illness and social discrimination (Ouellette Kobasa, 1990; Pierret, 1992). Research and intervention developed around the problems of “coping with AIDS”. This expression of maintaining hope disappeared as new therapies prolonged life expectancies.

As more years went by, a sub-group of infected persons who lived longer than the rest came to light. In the early 1990s, researchers began taking an interest in the biological characteristics of these “long-term survivors”, who were subsequently more gently labelled as “long-term non-progressors”. The pessimism of the terms used to describe this group of HIV-infected people who had not yet developed AIDS, shows how thoroughly the death model had, right into the mid-1990s, impregnated their image — even though these people represented the only ray of hope (Giami and Veil, 1994). These people, with their doom-laden future, liable at any moment to topple into a state of incurable illness, were only valued as
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