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Results of the study

"Late HIV diagnosis. Backgrounds and approaches for improvement in prevention work"

Final report on exploratory study conducted

on behalf of the German AIDS Service Organisation (Deutsche AIDS-Hilfe e.V.)

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1 Results of the study "Late HIV diagnosis. Backgrounds and approaches for improvement in prevention work"

The study examined the psychosocial backgrounds of so-called late diagnoses. The key results are briefly outlined in this text. A summary of all results and the detailed final report are available on the DAH website (www.aidshilfe.de).

1. In Germany, it is assumed that incidences of late diagnoses are at about 30%, i.e. about every third HIV positive person is not diagnosed and/or treated until the infection has reached an advanced stage. At the same time, evidence shows that the introduction of ART has not reduced the number of late diagnoses in recent years.

2. There is, however, no standard definition of late HIV diagnosis. In specialized literature, the value of CD-4 helper cells is usually provided as criteria and a value of 200 CD4/ml is set as critical; in the context of new recommendations for starting ART earlier, the critical value also increases to 350 CD4/ml. Furthermore, reference is often made to the presence of AIDS-defined diseases as supplementary or alternative criteria. The term “late diagnosis” refers to a specialist medical discourse to describe the progression of an HIV infection and to determine the best start of treatment. Recourse to the term implies a normative valuation that is based on seemingly neutral criteria: “Late diagnosis” always implies the existence of a “correct” time for diagnosis and treatment. Ascribing “late” or “too late” to a diagnosis means to implicitly bring up the issue of individual blame, the blame not to have sought a test or medical attention earlier.

3. With regard to psychosocial dynamics, the study revealed distinct differences between heterosexual women and homosexual/bisexual men. Risk-group thinking often means that women feel unaffected by HIV/AIDS. At the same time and for the same reason, doctors fail to interpret manifest symptoms as HIV related and do not recommend testing. It was found that suppressing the fact of being affected by HIV/AIDS is a predominant pattern for homosexual and bisexual men. This

psychological defence mechanism can result in the preconscious or unconscious decision not to get tested.

4. Both dynamics are based on highly stigmatized perceptions of the disease in images of the “old AIDS”. The dominance of images of death, serious illness and infirmity in the context of AIDS result in suppression and distancing. Even when cognitive knowledge of the treatment options and actual life with the virus is available, this does not seem to have a considerable effect on the way the subject is handled, namely by defence (suppression, projection). In this way, these images promote an unconscious or preconscious distancing from the infection and from those “affected” by it, and make it impossible to handle the subject rationally. The “old” images of AIDS are, at the same time, charged with a deeply seated social stigma. A stigmatized perception of the illness is internalized by people diagnosed late and carried over into their self-image. This makes it difficult to come to terms with the infection. Added to that are feelings of shame and guiltbecause of having contracted the infection. These images continue to have an effect which goes beyond the diagnosis in that the self-perception of the “old AIDS” is not transferable to the current “mainstream” image of HIV as a chronic infection; personal experience with the illness, therefore, often remains unknowable and non-communicable in the positive community as well.

5. Given the significance of the anxiety-ridden and highly stigmatized perception of HIV and AIDS, which contributes considerably to late diagnoses, a conscious and strategic development of “positive role models” is recommended. The challenge lies in how to deal with the contrariness of the diverse images and self-images.

6. In the international research literature, the clear trend is towards broadening and intensifying the HIV test to prevent late diagnoses. The experts polled in the study, however, unanimously oppose an opt-out model for Germany (which is often brought up in this context) as unbeneficial. With this in mind, the role of doctors in prevention is to be seen as detecting symptoms early and supporting the patient’s potential test decision. This requires from general practitioners and specialists – particularly outside major cities – a risk-group-independent awareness for HIV-related symptoms. The future

challenge consists in the development and implementation of strategies to properly test “the right people” and, simultaneously, to enable and responsibly accompany a self-determined test decision. The basis for this is voluntary testing, the reinforcement of community based low-threshold testing options, the need to de-stigmatise HIV/AIDS and the right not to know.

At this point, I would like to sincerely thank the participants in the study once more. Without their commitment and candour, this study would not have been possible.

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