

Objective:

The study examined the psychosocial backgrounds and dynamics that lead to HIV late diagnosis in Germany. It was aimed at identifying relevant starting points for enhancing prevention strategies.

Introduction:

- Presenting for care at a progressed stage of HIV infection may result in severe physical and psychosocial consequences for PLWHA and poses considerable challenges for treatment, counselling and prevention. Compared to “early” diagnoses and therapy start, studies hint at higher mortality and morbidity, higher medical costs, worse response and overall effectiveness of ART as well as a reduced quality of life of “late” diagnosed and treated PLWHA.
- In Germany nearly 40 percent of patients get HIV-diagnosed with less than 350 CD4+ cells and sometimes experience AIDS-defined diseases. Similar epidemiological situation can be found in other European and North American countries. While many studies have not found evidence for a significant alteration of these figures since the introduction of ART in 1996, recent data of the EMIS survey indicate that a minor decrease in the incidence of HIV late diagnosis in Germany might have occurred (RKI 2011).
- The significance of HIV late diagnosis is reflected in the number of studies being published in international journals in recent years. From a social psychological perspective this discursive boom reflects the difficulties in coping with the limits of effective action of medical practitioners and prevention professionals with the phenomenon.

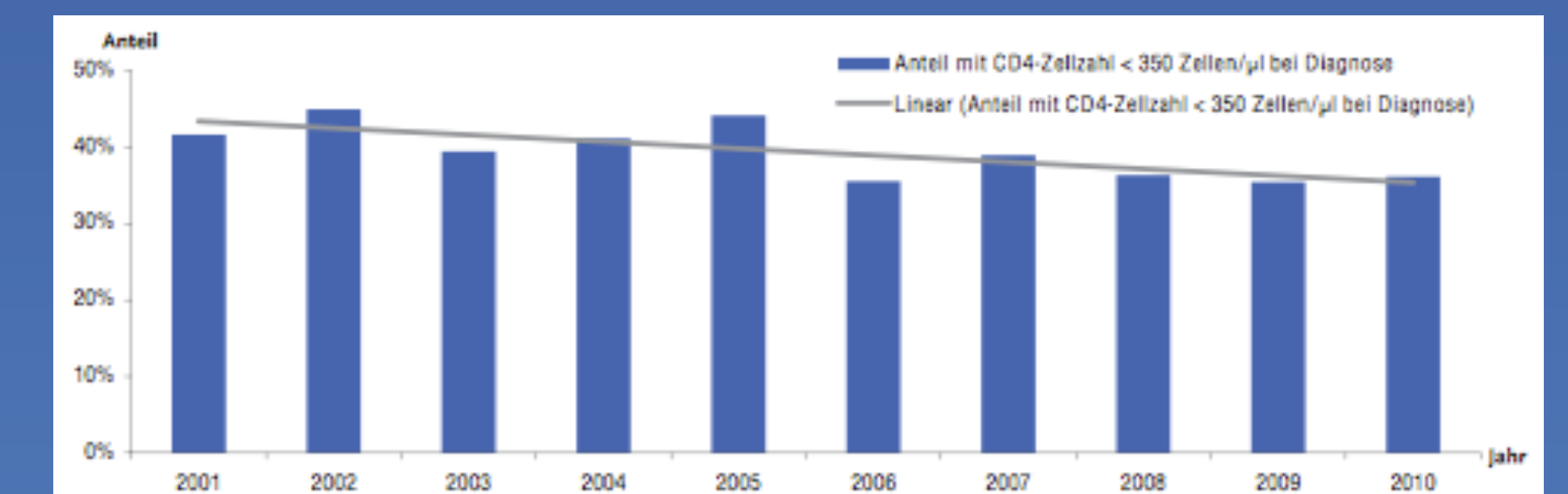


Fig. 1: Number of HIV late diagnosis in Germany (RKI 2011)

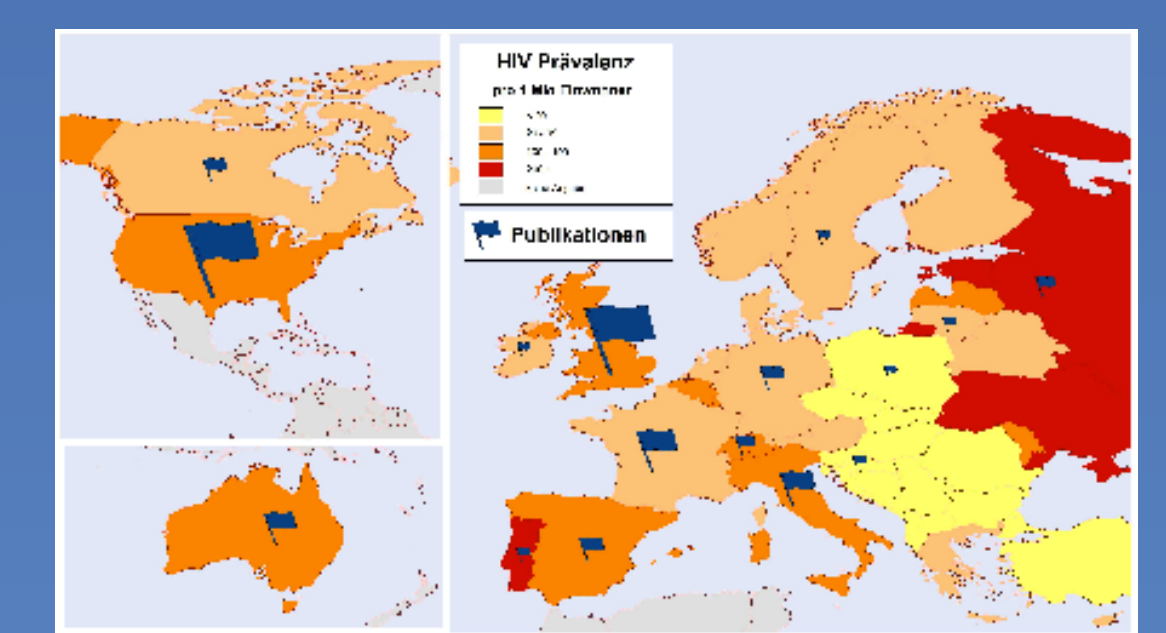


Fig. 2: Regional foci of studies published in late diagnosis/presentation 1996-2009

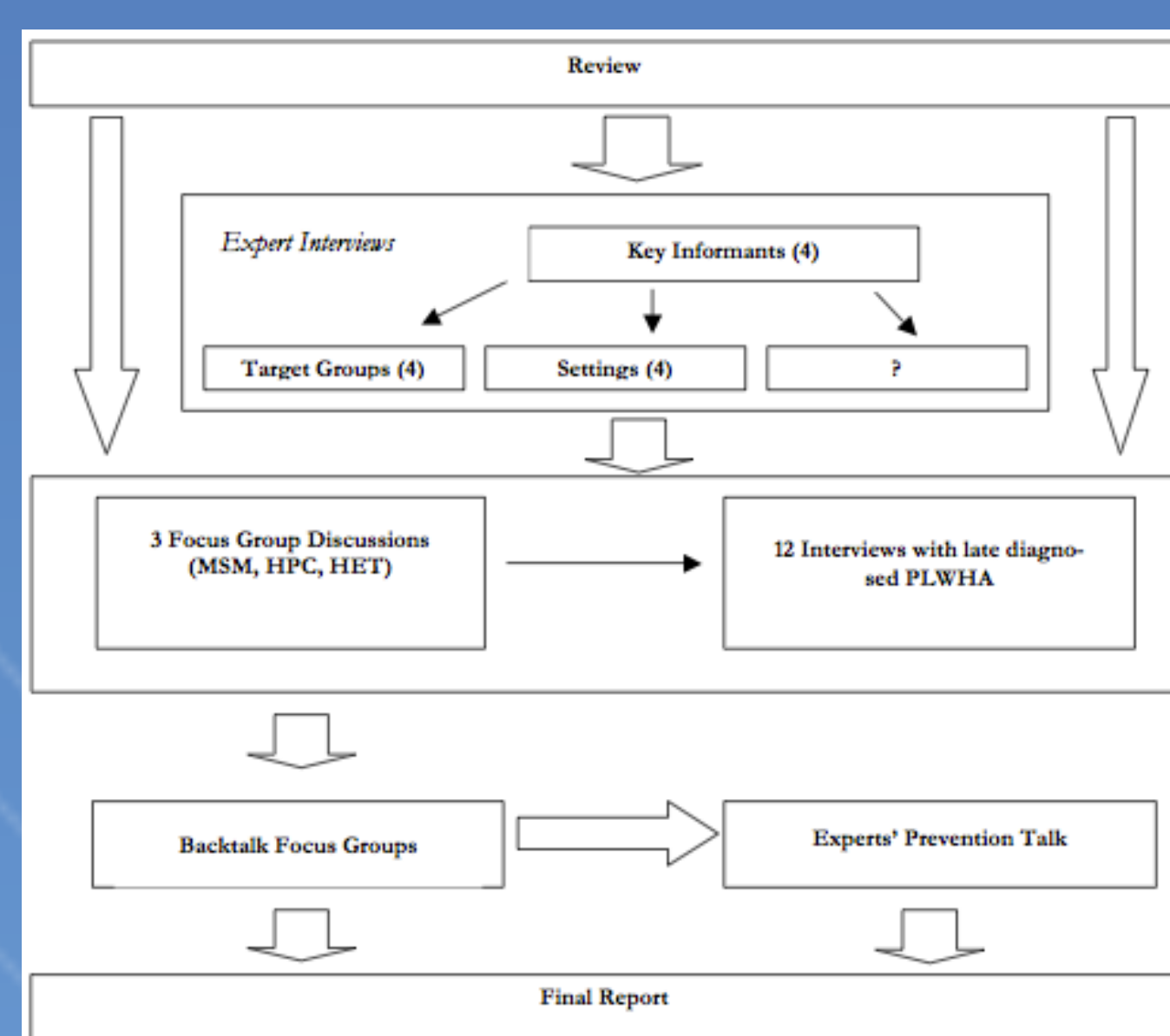


Fig. 3: Intended study design; focus group discussions could not be realized.

Methods:

- The study was conducted as a community-based research project on behalf of the AIDS service umbrella organization in Germany, the Deutsche AIDS-Hilfe e.V.
- Based on a comprehensive review on medical and social science literature on late presentation a qualitative research design was developed. Following Grounded Theory 32 interviews with medical, psychological and prevention experts and patients recently diagnosed with AIDS-related diseases were carried out in 2009/10. The interviews were analysed using content and psychoanalytic approaches.
- Focus group discussions that were an integral part of the methodical design could not be realized due to lacking participants. This failure, however, pointed at the difficult process of coping with HIV late diagnosis that was associated with shame and separation in the interviews.

Selected Results:

- Data analysis revealed distinct differences between heterosexual women and homosexual/bisexual men as those groups being most affected by late presentation in Germany. 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/assumption of being affected by HIV/AIDS is a predominant pattern for homosexual and bisexual men for not getting tested or presenting for care late.
- Both dynamics are based on stigmatized perceptions of the disease in images of “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 adaptively cope with the infection. Added to that are feelings of shame and guilt because 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.

Discussion:

- The results demonstrate the inappropriateness of test-and treat-strategies to counteract HIV late presentation in Germany. Low-threshold target-group and community test offers should be accompanied with de-stigmatizing approaches that foster rational test decisions by the individual. The supporting role of general practitioners in this process should be strengthened by developing symptom-based manuals and advanced training for communication skill enhancement.
- Recourse to the term “late diagnosis” that implies a normative valuation based on seemingly neutral medical criteria should not be made in psychosocial practice because 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.

