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Experiencing life as migrants living with HIV in Sweden

Akademisk avhandling

Som för avläggande av medicine doktorsexamen vid Sahlgrenska akademien, Göteborgs universitet kommer att offentligen försvaras i föreläsningssalen, Infektionskliniken, Diagnosvägen 21, Östra sjukhuset i Göteborg.

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av Manijeh Mehdiyar

Fakultetsopponent, Docent, Nina Wies

Institut for Klinisk Medicin, Köpenhamns universitet, Danmark

Avhandlingen baseras på följande arbeten

- I. Mehdiyar M, Andersson R, Hjelm K, Povlsen L. HIV-positive migrants' encounters with the Swedish health care system. *Glob Health Action*. 2016; 9: 31753.
- II. Mehdiyar M, Andersson R, Hjelm K. Swedish HIV Caregivers' Experiences of Providing Care to HIV-Positive Migrants: A Qualitative Study. *J AIDS Clin Res*. 2018;9(2):758.
- III. Mehdiyar M, Andersson R & Hjelm K. HIV-positive migrant's experience of living in Sweden. Revisions submitted
- IV. Mehdiyar M, Andersson R & Yilmaz A. Quality of life among migrants and Swedish born people living with HIV in Western Sweden – a register based study.

**SAHLGRENSKA AKADEMIN
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Manijeh Mehdiyar

Department of Infectious Diseases, Institute of Biomedicine, Sahlgrenska Academy,
University of Gothenburg, Sweden

Abstract

The focus of this thesis is on the life situation of migrants living with HIV in Sweden. The overall aim of this thesis was to explore the knowledge of HIV-positive migrants' life situation in Sweden, with a focus on health and well-being as well as healthcare contacts. This thesis comprises four studies. Studies I-III were designed as explorative and descriptive with Study IV being designed to be quantitative. **Study I** is a Grounded Theory study based on the encounters of migrants living with HIV with the Swedish health care system (no=14). The results indicated that experiences of discrimination in general health care were combined with an appreciation of the free access to advanced ART. **Study II** is an explorative qualitative study based on the experiences of HIV care givers (no=14) in providing care to migrant patients living with HIV. Data was analyzed using content analysis. The findings revealed the challenges that arise due to limited time available for adequate communication and support for the patients, related to the patients' perceived stigma and their migrations status. Further, the process of migration causes various levels of socio-economic vulnerability for the patients. **Study III** explores the life situations of migrants living with HIV (no=14). Data was analyzed using content analysis. The results indicate vulnerability in social relationships, due to perceived stigma and the stigmatized condition as well as the lack of a social network and social support. Fear of disclosure of HIV was also experienced in everyday life. This resulted in loneliness and difficulty finding a partner and close friends. Further, the findings revealed that migrants living with HIV are also resilient. It revealed their struggle to cope with the existential uncertainty, to live a life with integrity, and to look positively at life. **Study IV** is a quantitative study from the national health survey InCare HIV. It investigated whether there were differences in Quality of life between HIV-positive migrants and HIV-positive Swedish-born receiving care and treatment at the Infectious Disease Clinics in Western Sweden. The migrants were younger, a higher proportion was female and a higher proportion with heterosexual route of transmission compared to the Swedish-born. They had lower CD4-nadir and more frequent detectable viral load indicating inferior treatment outcomes. Further, migrants reported both side-effects and missed doses of antiretroviral treatment more often and a subgroup had lower satisfaction with their physical health. In conclusion, the need to define the different forms of limitations and discrimination towards migrants living with HIV within the general health care system and other arenas should be combined with holistic and individualized social support in order to strengthen their social networks and offer patient associations. Targeted interventions are needed to enhance the healthcare professions and social actors' access to updated information and knowledge within the field of HIV, vulnerability, racism and migration. Migrants living with HIV and their self-defined needs should be prioritized in the context of treatment, care and social support.

Keywords: migrants living with HIV; life situation; health care system; Sweden

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