



**Positive Deviance among Stigmatized
People Living with HIV, Leprosy,
Schizophrenia, and Diabetes in
Indonesia**

Article and Portfolio

ABSTRACT

Being sick and stigmatized by others are unpleasant experiences to be had. Many people struggle with health-related stigma, but some people succeed to overcome such stigma in their everyday lives and thrive. This article explains such positively deviant strategies.

Annisa Ika Putri

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Author: Annisa Ika Putri

Commissioning organization: Athena Institute

On-site supervisor: Sarju Sing Rai, MSc

VU supervisor: Elena V. Syurina

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Athena Institute

Faculty of Science

VU University Amsterdam

De Boelaan 1085

1081 HV Amsterdam

The Netherlands



Positive Deviance among Stigmatized People Living with HIV, Leprosy, Schizophrenia, and Diabetes in Indonesia

Annisa Ika Putri (2589209)

Abstract

Background: Stigma related to infectious conditions like HIV and leprosy, and non-infectious conditions like schizophrenia and diabetes are known to severely impact the lives of people affected and the management and control of their condition. In some cases, there are people who are able to overcome these unpleasant experiences of stigma and turn their condition around towards a positive direction, who are called positive deviants. This study aimed to explore the factors and strategies of positive deviance across the four stigmatized health conditions and compare the quality of life between positive and non-positive deviants.

Methods: This study used concurrent mixed-methods with interactive learning and action approach. Thirty-nine interviews, eight FGDs, and eighty WHOQoL-BREF questionnaires were collected from people living with HIV, leprosy, schizophrenia, and diabetes in Jakarta and West Java, Indonesia.

Results: This study found commonalities of positive experiences and support which resulted in similar quality of life between both positive and non-positive deviants across the four conditions. However, the origin and nature of the factors and the use of strategies were different. The outcomes indicate that positive deviants across the different health conditions underwent a similar recurring loop comprising three steps of positive deviance. First, the individuals empowered themselves through self-acceptance, positive spiritual belief, active use of technology, and support from healthcare providers. Second, the persons reclaimed control of their lives and life decisions through selective disclosure, resilience, and indifference to others' stigmatizing responses. Last, the persons developed a passion and desire to help other stigmatized people through advocacy and peer support. Based on the discussions with the stakeholders, life-skills training and community sensitization were the best possible intervention to reduce stigma and create positive experience among those stigmatized people.

Conclusion: The main strategies employed by positive deviants across the four conditions were recurring in three steps comprising active self-empowerment, reclaiming control of their lives, and passion and desire to help other stigmatized people.

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