# HIV disclosure and stigma among women living with HIV in Denmark

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#### Abstract

Objective: To identify disclosure, stigma and predictors of non-disclosure among women living with HIV in Denmark.

**Methods:** A questionnaire study of women living with HIV in Denmark was performed. The enrolment period was from February 2013 to March 2014. Logistic regression was used to estimate predictors of non-disclosure.

**Results:** A total of 234 participants were included. The majority (94%) had disclosed their HIV status to at least one person outside their healthcare environment, although 29% had disclosed to fewer than three people. Confidantes were mostly partners (96%), siblings (63%), friends (63%) and children (41%). The primary reason for non-disclosure was a feeling that it did not concern others (55%), although reactions upon disclosure were mainly positive in 53%. Predictors of non-disclosure were being of black or Asian ethnicity. Following their HIV diagnosis, 40% no longer dared to have sex, 40% felt isolated and 23% felt that others were afraid and kept a physical distance. In contrast, after disclosure 75% felt better at taking decisions about life and 50% were in closer contact with family and friends.

**Conclusion:** Almost one-third of participants disclosed their HIV diagnosis to fewer than three people and black or Asian ethnicity predicted non-disclosure. HIV-related stigma regarding sex and contact with others is still highly prevalent; however, reactions to disclosure were mainly positive and associated with secondary positive gains. We strongly urge healthcare professionals to initiate a dialogue regarding stigma and disclosure with women living with HIV with a view to increasing disclosure and minimising stigmatisation in this vulnerable population.

Keywords: HIV, women, disclosure, stigma, black or Asian ethnicity

#### Introduction

In 2015, 37 million people were living with HIV globally, 51% of whom were women [1]. Within the field of HIV research, there is a profound under-representation of issues relating to women's health [2] including clinical trials on antiretroviral therapy (ART) [3], sexual and reproductive health, and ageing and psychological well-being [2,4].

One of the key obstacles to HIV treatment, prevention and care is stigma, and most women living with HIV suffer or fear stigmatisation [5–7]. However, in a national Danish survey from 2007 the majority of people living with HIV (PLWH) experienced mostly positive reactions when disclosing their HIV status [8].

HIV stigma is typically divided into three aspects: perceived, experienced or enacted, and internalised stigma [9–11]. Perceived stigma is the awareness among PLWH of negative public attitudes; experienced or enacted stigma includes acts of discrimination towards PLWH; and internalised stigma is the negative belief and feeling towards oneself and HIV.

This study aimed to evaluate disclosure and stigma among women living with HIV in Denmark – a setting where medical care and ART is provided free of charge with a majority of PLWH having fully suppressed plasma viral load [12] and living a 'close to normal' life. We further assessed predictors of non-disclosure.

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#### Methods

## Setting

Denmark has a total population of 5.6 million [13], 5000 of whom are living with HIV and of these, 1400 are women [14].

#### The SHADE cohort

The study on HIV, cervical abnormalities and infections in women in Denmark (SHADE), is a multicentre, prospective cohort study of women living with HIV in Denmark attending care for acquired HIV [15]. Women living with HIV, ≥18 years of age, were enrolled from six outpatient clinics in Denmark and followed up after 6, 12 and 24 months. Exclusion criteria were pregnancy and/or alcohol/drug use, for the potent to prevent adherence to the protocol.

# Questionnaire

Between February 2013 and March 2014, patients completed a paper-based questionnaire, containing nine questions regarding personal income, education, stigma and disclosure. The questionnaire was validated for the Danish Living Condition Survey in 2007 [8]. One question regarding personal income was incorrectly answered by the majority of participants and, therefore, excluded. Double manual data entry was performed, using the EpiData Entry program [16].

# Registration

#### The Civil Registration System

The Civil Registration System is a national registry of all residents in Denmark [17]. At birth or immigration, a 10-digit personal

identification number is assigned to each individual, which was used to link to the Danish HIV Cohort Study and the SHADE cohort.

#### Danish HIV Cohort Study

We obtained HIV characteristics and demographics from the Danish HIV Cohort Study, which is a prospective, observational, national, multicentre cohort study of all PLWH seen at Danish HIV clinics since 1 January 1995 [12].

#### Ethical statement

The study was approved by the Danish Data Protection Agency (2015-231-0126, 2012-58-0004 and 2012-41-0005) and the Danish Regional Committee on Health Research Ethics (H-3-2010-119 and H-2-2014-102).

#### Statistical analysis

Categorical variables were reported as counts and percentages and compared by chi-squared tests or Fisher's exact tests. Continuous variables were summarised as median and interquartile ranges and compared using the Wilcoxon rank-sum test. Univariate and multivariate logistic regression analysis was performed to identify predictors of non-disclosure (defined as disclosure to fewer than three people). Odds ratios and 95% confidence intervals were estimated and adjusted for six candidate predictor variables chosen a priori: age at inclusion (<40 vs ≥40 years of age); ethnicity; latest viral load (<40 vs ≥40 copies/mL); latest CD4 cell count (<350 vs ≥350 cells/ $\mu$ L); time since diagnosis (<10 vs ≥10 years); and educational level (<3 years  $vs \ge$ 3 years after elementary school). To control for repeated testing, a combined *P*-value was estimated for the ethnicity variable spending more than one degree of freedom in the logistic regression analysis. Individuals with missing explanatory values were excluded from the multivariate regression analyses. The validity of the model was tested using the Hosmer-Lemeshow goodness-of-fit test. SAS statistical software version 9.3 (SAS Institute Inc, NC, USA) was used for data analysis and *P*<0.05 (two-sided) was considered statistically significant.

#### Results

#### Baseline characteristics

A total of 234 of the 334 women living with HIV in the SHADE study attended the 24-month follow-up (median age was 44 years and median HIV duration was 13 years). Participants were predominantly of white (45%) or black ethnicity (40%) and mostly acquired HIV in Denmark (40%) or Africa (41%). Approximately 80% had a CD4 cell count of >350 cells/µL and the majority (86%) was on ART with an undetectable viral load (<40 copies/mL). Elementary school, which finishes at age 15, was the highest educational level achieved by 24% of the participants (Table 1).

## Disclosure

Almost all (93.6%) participants had disclosed their HIV status to at least one person (outside the healthcare profession), 34% had disclosed to more than 10 people. However, 6.4% had not disclosed to anyone (Table 2). The participants mostly confided in partners (96%), siblings (63%), friends (63%) and their own children (41%). Reasons for non-disclosure were mainly 'a feeling that it does not concern others' (55%), 'not wanting to be seen as HIV positive' (46%), and 'not wanting people to feel sad' (42%). The majority (88%) had not disclosed their HIV status to people at a current place of work. More than half (53%) of the participants had mainly experienced positive reactions upon disclosure. Black or Asian ethnicities were predictors of non-

Table 1. Baseline characteristics of 234 women, living with HIV in Denmark. Median duration of HIV infection was 13 years (IQR 8-18 years) and median age at inclusion was 44 years (IOR 39-51)

Characteristic	Study participants n (%)
Ethnicity	
White	105 (45.1)
Asian	32 (13.7)
Black	94 (40.3)
Other	2 (0.9)
Missing	1
Place of HIV transmission	
Denmark	84 (39.6)
Europe and USA	16 (7.6)
Africa	86 (40.6)
Asia	26 (12.3)
Other	0 (0)
Missing	22
Mode of transmission	
Heterosexual	210 (92.5)
IDU	12 (5.3)
Other	5 (2.2)
Missing	7
Latest CD4 cell count (cells/μL)	
<200	11 (5.0)
200–350	33 (14.9)
>350	177 (80.1)
Missing	13
ART	
Yes	220 (94.0)
No	14 (6.0)
On ART with HIV RNA <40 copies/mL	
Yes	182 (85.5)
No	31 (14.6)
Missing	7
Educational level	
Primary or elementary school (age 15 years)	56 (23.9)
Semi-skilled worker training	13 (5.6)
Apprenticeship or basic vocational training	19 (8.1)
Other vocational training	42 (18.0)
Short course of higher education	26 (11.1)
Medium course of higher education	28 (12.0)
Long course of higher education	14 (6.0)
Missing	36

disclosure (Table 3). The Hosmer–Lemeshow goodness-of-fit tests demonstrated sufficient fit (P=0.087, P=0.052).

#### Stigma

Data from questions about how life and relationships with others had been affected by an HIV disclosure are shown in Table 4. Notably, 40% (total of 'large', 'some' and 'small' extents) of women

Question	Study participant n (%)
Disclosure overall (other than to healthcare professionals)	
Have not told anyone?	13 (6.4)
1–2 persons	46 (22.6)
3–5 persons	45 (22.1)
6–10 persons	31 (15.1)
>10 persons	69 (33.8)
Missing	30
Other than to a healthcare professional, to whom have you disclosed?*	
Spouse/partner	158 (96.3)
Parents	97 (52.7)
Brothers/sisters	116 (63.0)
Own children	71 (40.6)
Friends	118 (63.1)
Others	61 (35.1)
Reasons for non-disclosure to the above mentioned people*	31 (33.1)
You do not feel it concerns them	46 (54.8)
You are afraid they will blame you for being ill	18 (21.4)
It is a life-threatening illness and you do not want them to be sad	35 (41.7)
You are afraid that they will reject you	29 (34.5)
You do not wish to be seen as someone who is HIV positive	39 (46.4)
You are afraid of being talked about behind your back	33 (39.3)
You will tell him/her them at a later time	16 (19.0)
Other	8 (9.5)
HIV disclosure to people at current place of work*	0 (3.3)
Yes, everyone knows	9 (5.3)
Yes, most people know	5 (3.2)
	12 (8.1)
Yes, some people know	
Yes, your immediate superior knows  Yes, your immediate colleague knows	12 (8.7) 3 (2.2)
No	119 (87.5)
	119 (67.5)
Reactions of colleagues when being told about the patient's HIV status	13 (34.2)
Very positive Positive	
Neutral	8 (21.2) 6 (15.8)
Negative	0 (0)
Very negative  Both positive and negative	1 (2.6) 4 (10.5)
Do not know	
	6 (15.8)
Missing  Reactions encountered within the last five years from people around you when revealing the HIV status	190
Mainly positive reactions	84 (52.5)
Mainly negative reactions	11 (6.9)
Reactions have been mixed	40 (25.0)
Do not know	25 (15.6)
Missing	74

no longer 'dared' to have sex, 40% (total of 'large', 'some' and 'small' extents) felt isolated and 23% thought that others were frightened and kept a physical distance. Half of the participants felt in closer contact with family and friends after disclosure. Following disclosure, 75% (total of 'large', 'some' and 'small' extents) of women felt more empowered when making life decisions. We stratified questions in Table 4 for disclosure status and found that women who had disclosed their HIV status experienced significantly more contact with family and friends and received more care and attention from other people. No differences between groups were found regarding the other questions (data not shown).

#### Discussion

In this questionnaire study on disclosure and stigma among women living with HIV in Denmark who were enrolled into the SHADE study, we found a low level of education in 24% of participants. The vast majority had disclosed their HIV status to at least one person and >50% of women were met with predominantly positive reactions upon disclosure. Furthermore, 75% felt that disclosing improved their ability to make life decisions. However, almost 40% of women felt isolated and 40% no longer dared to have sex.

The low level of educational attainment is a cause of concern, since a recent study found that PLWH in Denmark with low educational levels are at increased risk of lifestyle-related mortality as compared to PLWH with higher educational levels [18]. Elementary school is the highest educational level achieved in only 8% of women from the general Danish population (25-69 years) [13].

#### Disclosure

Disclosure is considered to be a gradual process of revealing HIV status to an increasing number of people over time [19]. Disclosure is associated with a better health status, less social isolation and facilitates access to social services and health support [20-22]. The majority of participants had disclosed their HIV status to at least one person. We chose a cut-off of fewer than three people, since confiding in only one or two people reflects a fragile support network. However, almost 30% had disclosed to fewer than three people. Non-disclosure was predicted by black and Asian ethnicity. This was an expected finding, as it is a clear impression in the outpatient clinics that women of African descent experience higher levels of perceived, experienced or enacted, and internalised stigma, compared to their white peers. In line with this, Stutterheim et al. found that fear of stigma was a profound reason of non-disclosure among

Table 3. Predictors of disclosure of HIV infection in 205 women living with HIV in Denmark, unadjusted and adjusted for: age at inclusion; ethnicity; latest HIV RNA; latest CD4 cell count; time since diagnosis; and educational level

Predictors of disclosure	Disclosure to n≤2 persons (total number of people=59) n (%)	Disclosure to n>2 persons (total number of people=146) n (%)	Unadjusted odds ratios (95% CI)	P-value	Adjusted odds ratios* (95% CI)	<i>P</i> -value
Age at inclusion (years)						
<40	21 (35.6)	38 (26.2)	1.00	-	1.00	-
≥40	38 (64.4)	107 (73.8)	1.56 (0.81–2.98)	0.18	0.72 (0.31–1.66)	0.44
Missing	0	0				
Ethnicity						
White	13 (22.8)	84 (58.4)	1.00	_	1.00	-
Asian	16 (28.1)	13 (9.0)	0.12 (0.05-0.32)	< 0.0001	0.15 (0.05-0.47)	0.0011
Black	28 (49.1)	47 (32.6)	0.26 (0.12-0.55)	0.0004	0.34 (0.14-0.82)	0.017
Missing	2	1				
Combined P-value				<0.0001		0.0038
Latest viral load (copies/mL)						
≥40	9 (17.3)	23 (16.5)	1.00	-	1.00	-
<40	43 (82.7)	116 (83.5)	1.06 (0.45-2.46)	0.90	1.28 (0.51-3.20)	0.60
Missing	7	6				
Latest CD4 cell count (cells/μL)						
<350	8 (15.4)	25 (17.9)	1.00	-	1.00	-
≥350	44 (84.6)	115 (82.1)	0.84 (0.35–1.99)	0.69	0.98 (0.38-2.50)	0.97
Missing	7	5				
Time since diagnosis (years)						
<10	29 (49.2)	50 (34.7)	1.00	-	1.00	-
≥10	30 (50.8)	94 (65.3)	1.82 (0.98–3.36)	0.057	1.43 (0.66–3.07)	0.36
Missing	0	1				
Educational level						
3 years after elementary school	40 (75.5)	88 (62.0)	1.00	-	1.00	-
>3 years after elementary school	13 (24.5)	54 (38.0)	1.89 (0.93-3.85)	0.080	1.24 (0.49–3.19)	0.65
Missing	6	3				

Table 4. Effect of disclosure on life and relations to others in 234 women living with HIV in Denmark

Have you experienced:	To a large extent n (%)	To some extent n (%)	To a small extent n (%)	Not at all n (%)	Not sure n (%)	Missing n
More contact to family/friends?	31 (16.0)	38 (19.6)	28 (14.4)	81 (41.8)	16 (8.2)	40
More care/attention from others?	21 (10.9)	36 (18.8)	31 (16.1)	91 (47.4)	13 (6.8)	42
More consideration towards you?	11 (5.9)	20 (10.7)	28 (15.0)	104 (55.6)	24 (12.8)	47
That you are better at making life decisions?	59 (30.1)	67 (34.2)	21 (10.7)	36 (18.4)	13 (6.6)	38
That you feel isolated?	15 (7.7)	33 (16.9)	28 (14.3)	113 (58.0)	6 (3.1)	39
That others are afraid/ keep physical distance?	7 (3.7)	17 (8.9)	20 (10.3)	129 (67.2)	19 (9.9)	42
That you feel infectious/keep distance to others	13 (6.7)	21 (10.8)	23 (11.9)	127 (65.5)	10 (5.1)	40
That you no longer dare to have sex	22 (11.2)	24 (12.2)	34 (17.3)	109 (55.3)	8 (4.1)	37
More than one answer is possible, therefore, percentages	add up to >100%					

PLWH of African and Afro-Caribbean descent living in the Netherlands [23,24]. Moreover, PLWH who have higher selfperceived HIV-related stigma have been reported to be less likely to disclose their HIV status to partners [25].

# Stigma

Participants in the present study showed evidence of perceived stigma, as more than two-thirds stated fear of rejection and of being talked about as reasons for non-disclosure. Experienced stigma was less frequent, although 7% of the participants had encountered negative reactions upon disclosure and 23% felt that others were frightened and kept a physical distance. However, after disclosure, 75% felt better at making life decisions, which implies that disclosure had a positive effect on the participants' ability to take action regarding life decisions. Internalised stigma was present in almost 30% of participants who felt infectious and kept

a distance from others and 40% who no longer 'dared' to have sex. In the era of life-saving ART [26] and with recent studies showing negligible or non-existent risk of HIV transmission for PLWH who have chronically fully suppressed plasma viral load [27], internalised stigma needs to be addressed globally in order to decrease both public- and self-stigma, as it is the person living with HIV's own belief that all the negative assumptions about HIV and themselves are true [28].

The strengths of the present study include the well-described cohort of women living with HIV from the data from the Danish HIV Cohort Study. Furthermore, the use of a validated questionnaire optimised results. An inborn weakness of many questionnaire studies is that answers are self-reported and not objectively verifiable. Data were collected 2013–2014; since then, an improvement in societal perceptions towards a better understanding of HIV and risks of transmission and thereby a reduction in stigma in our patient group is possible. A potential way of determining whether a change in stigma and disclosure has happened would be to repeat the same study, and compare results. We did not take gender-based violence into consideration in this study, which might be a potentially significant issue in our population, particularly when considering disclosure [29,30]. In addition, age may have had an impact on the results, as we expect that older women (who have been diagnosed for a longer period of time than younger women) have experienced more stigma and disclosure issues. They have experienced times when people living with HIV were more stigmatised and discriminated against, than perhaps have younger women. Finally, the exclusion of pregnant women, and alcohol/drug using women may generate results that underestimate the extent of disclosure and stigma among women living with HIV in Denmark.

# Conclusion

Perceived, experienced and internalised stigma still remains a burden among women living with HIV in Denmark. Importantly, once HIV status was disclosed, reactions were mainly positive and associated with secondary positive gains. We, therefore, strongly urge healthcare professionals to initiate a dialogue regarding stigma and disclosure with women living with HIV and (if consented by the patient) their networks, as a means to minimise stigmatisation in this vulnerable population. Asking about patient experiences of stigma would enable healthcare professionals to target help and pair patients with mentors who have had similar experiences in the same community. Furthermore, the potential for healthcare professionals to offer education for family members or at the work place, should be explored to increase an understanding of HIV and thereby reduce stigmatisation in patients' local communities.

# Acknowledgements

#### Conflicts of interest

MW has received an unrestricted grant from Gilead.KT has received research funding from Abbott and honoraria from Janssen-Cilag and GlaxoSmithKline/Viiv. NW has received honoraria from Bristol-Myers Squibb, Gilead, Roche, Janssen, Merck Sharp Dohme and Abbvie. TLK has received research funding/honoraria from, Gilead, Bristol-Myers Squibb, Merck Sharp & Dohme, GlaxoSmithKline/Viiv, Abbott, and Janssen-Cilag.

AML has received research funding from Abbott and honoraria from Bristol-Myers Squibb, Merck Sharp & Dohme, GlaxoSmithKline, Boehringer Ingelheim and Janssen-Cilag.

MS, FFR, IJ, GP, and LNN report no conflicts of interest.

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