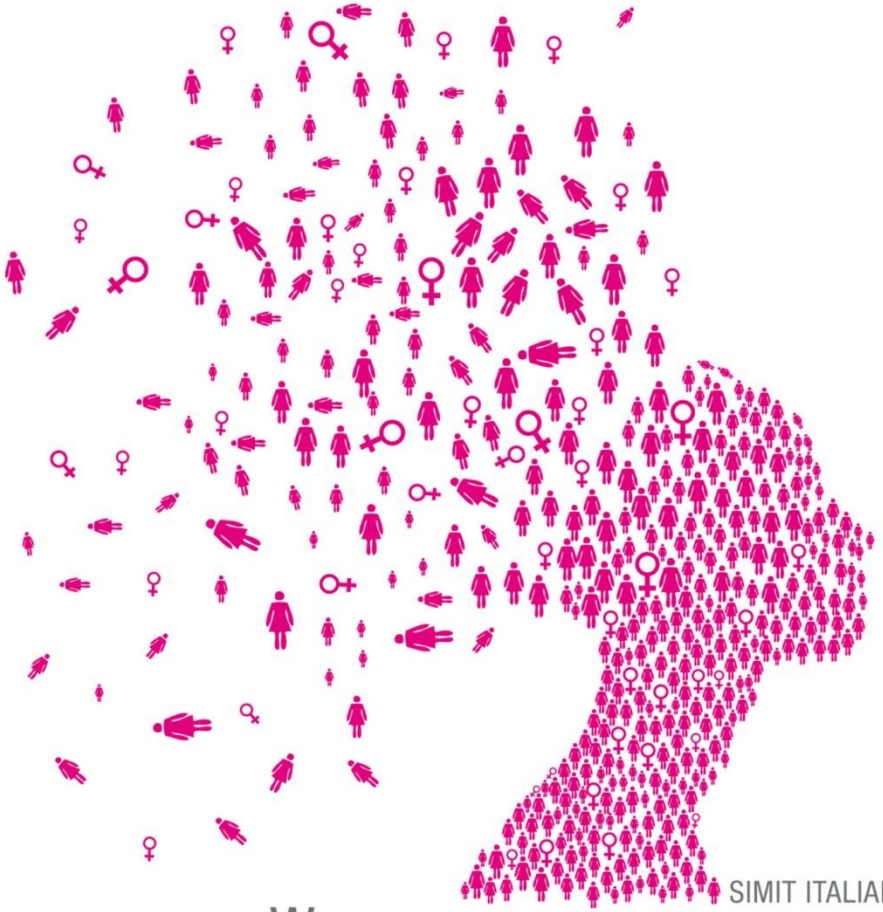


SIMIT ITALIAN PROJECT

Women
Infectivology
Network

WIN

WIN, WOMEN INFECTIVOLOGY NETWORK

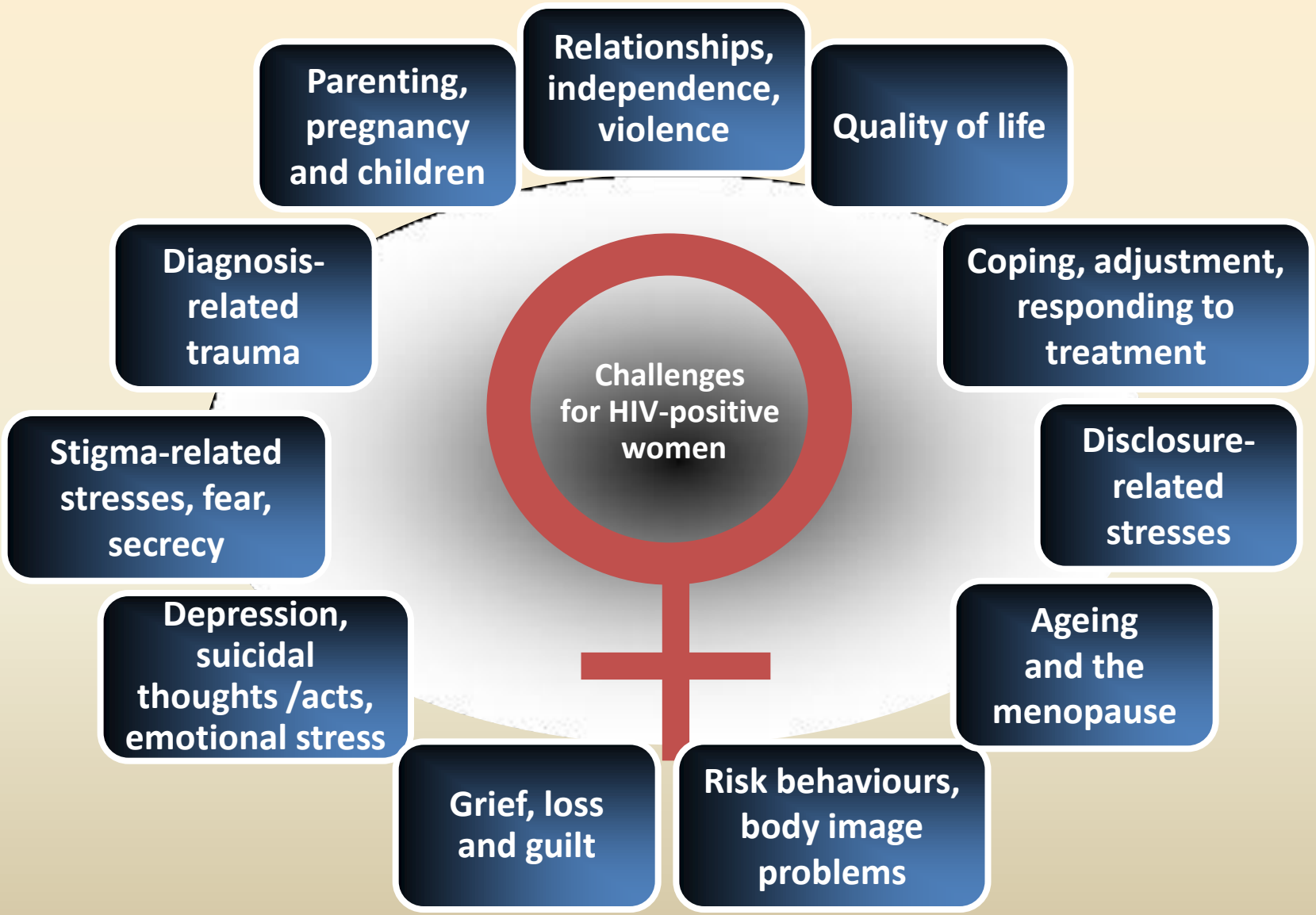
11 Donne, per le Donne, contro le malattie infettive in Italia

Relationship between emotional well being, body image changes, sexual health, and adherence to HAART among women living with HIV

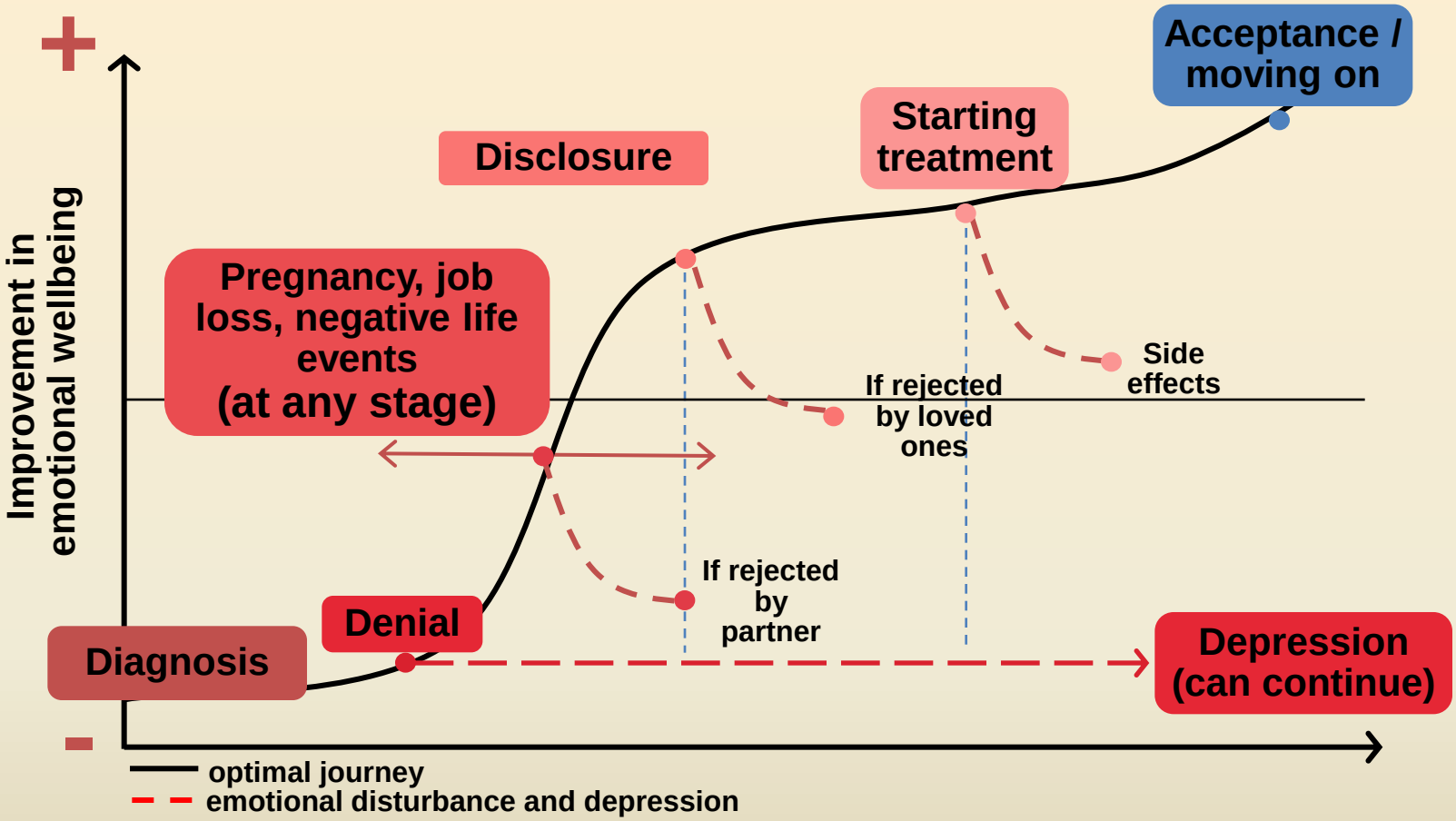
Women Infectivology Network WIN

Emotional well being

HIV often has mental and emotional consequences



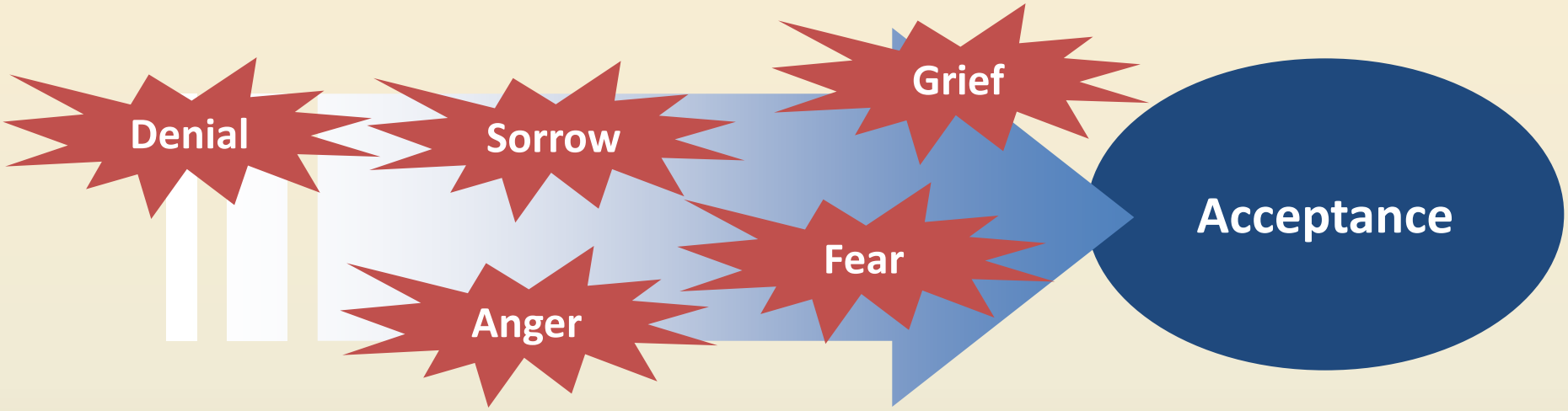
How women experience HIV: the patient journey



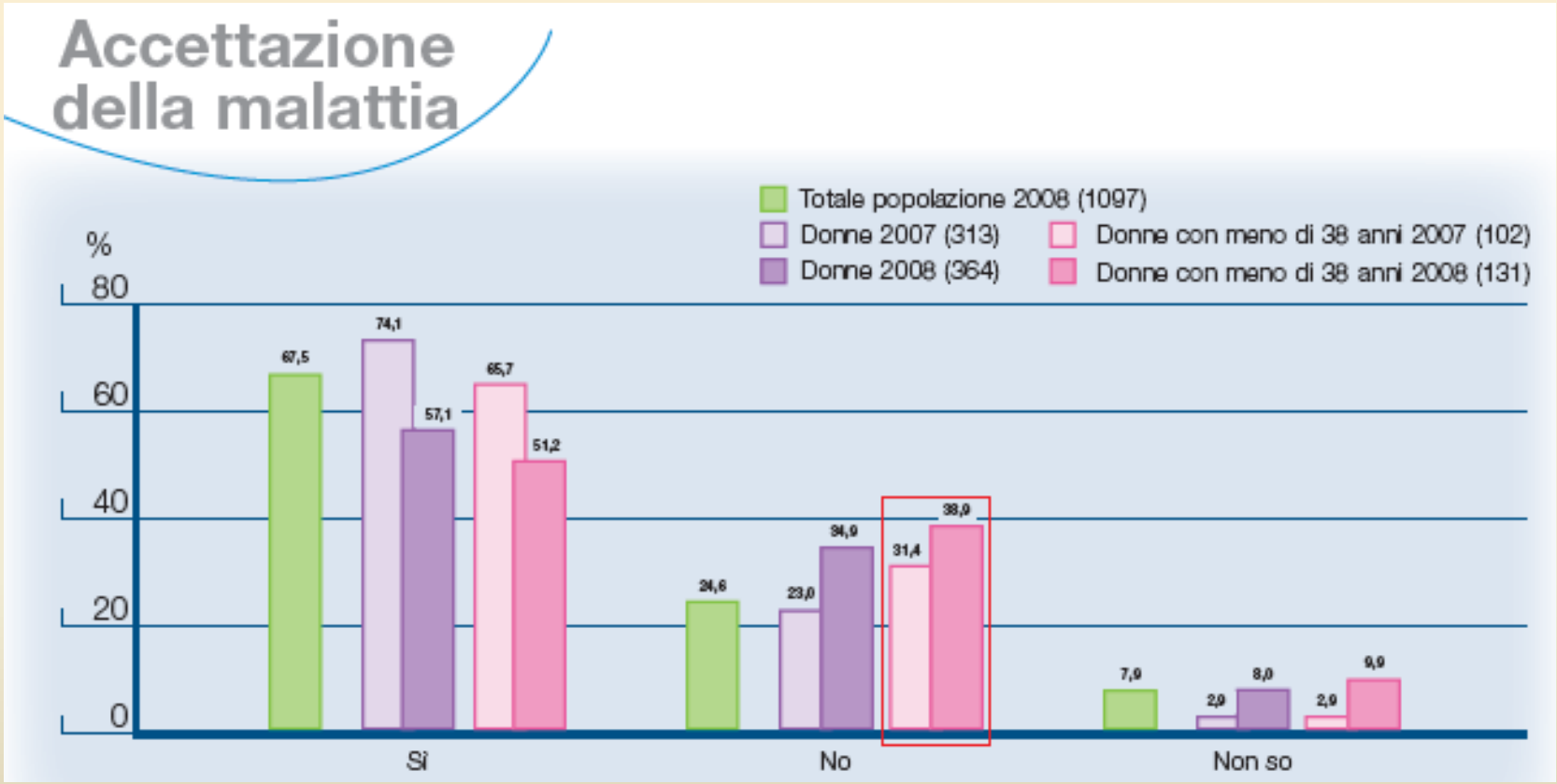
The journey is characterised by many emotional ups and downs and varies from woman to woman. It adheres to the classic grieving model

The Planning Shop International Women Research, July 2008

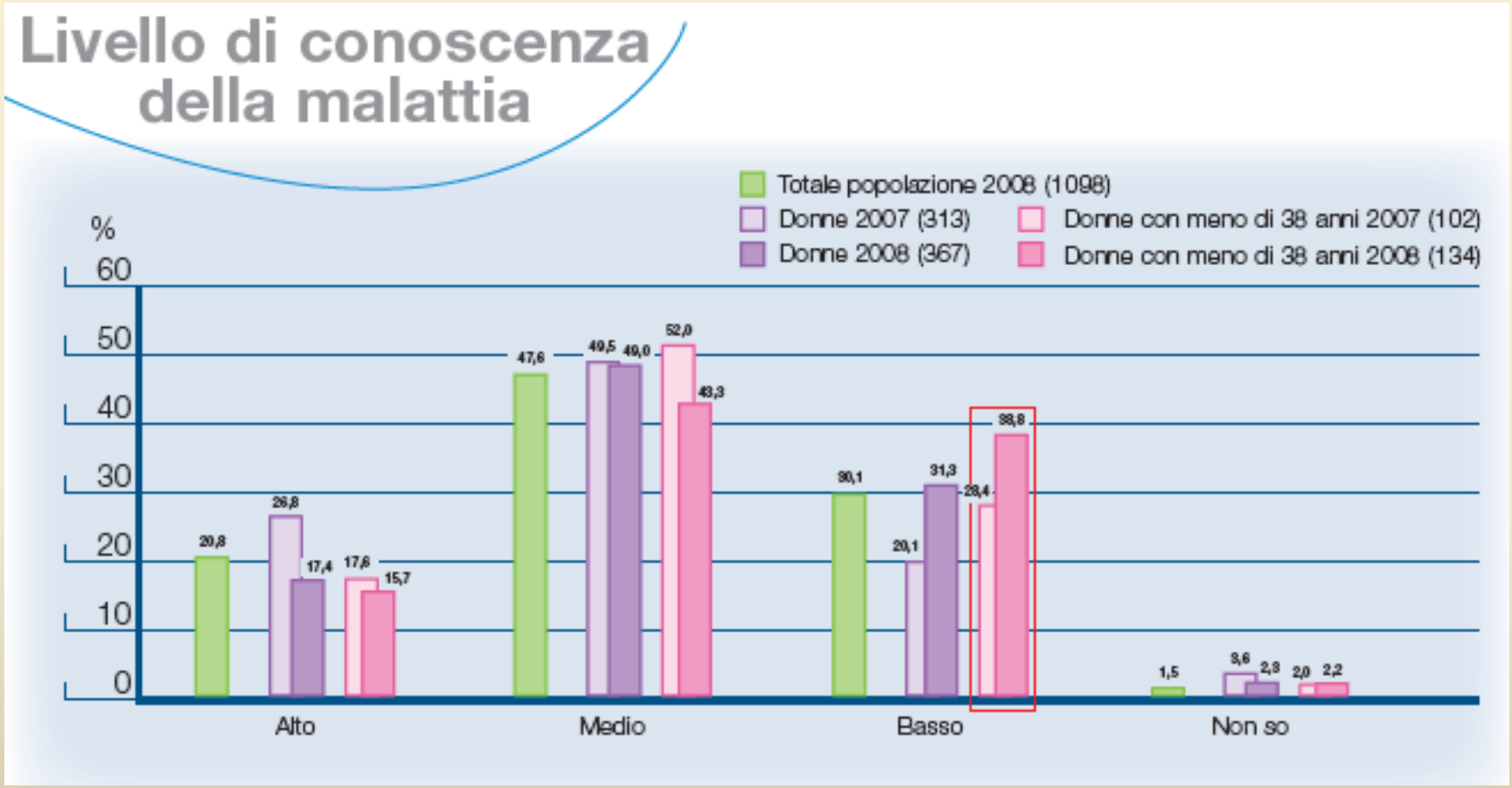
The challenge of . . . diagnosis



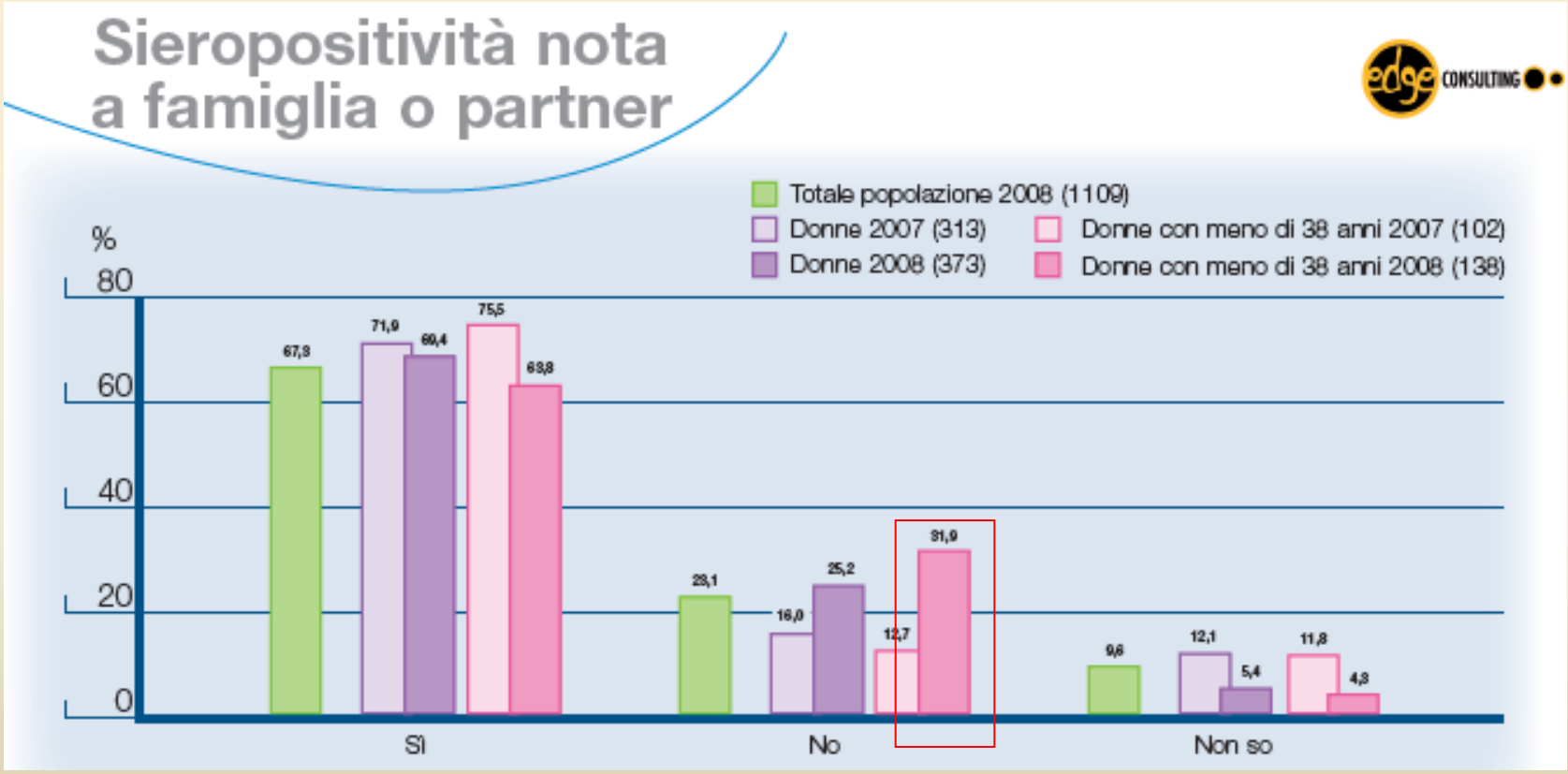
Accettazione della malattia



Livello di conoscenza della malattia



Sieropositività nota a famiglia o partner



HIV-related stigma in women

- In some cultures, HIV-positive women are treated differently than men
- Effects of HIV-related stigma include:
  - Loss of income and carer options
  - Loss of marriage, partnership and procreation options
  - Poor care within the health sector
  - Social rejection
  - Loss of hope and feelings of worthlessness
  - Loss of reputation
  - Exclusion from religious/cultural communities

Range of emotional health issues associated with HIV

- Depression
- Anxiety
- Coping problems
- Suicidal thoughts and actions
- Trauma
- Post-traumatic stress disorder (PTSD)
- Stigma
- Psychosexual problems
- Relationship issues
- Pregnancy
- Menopause
- Body image
- Confidence

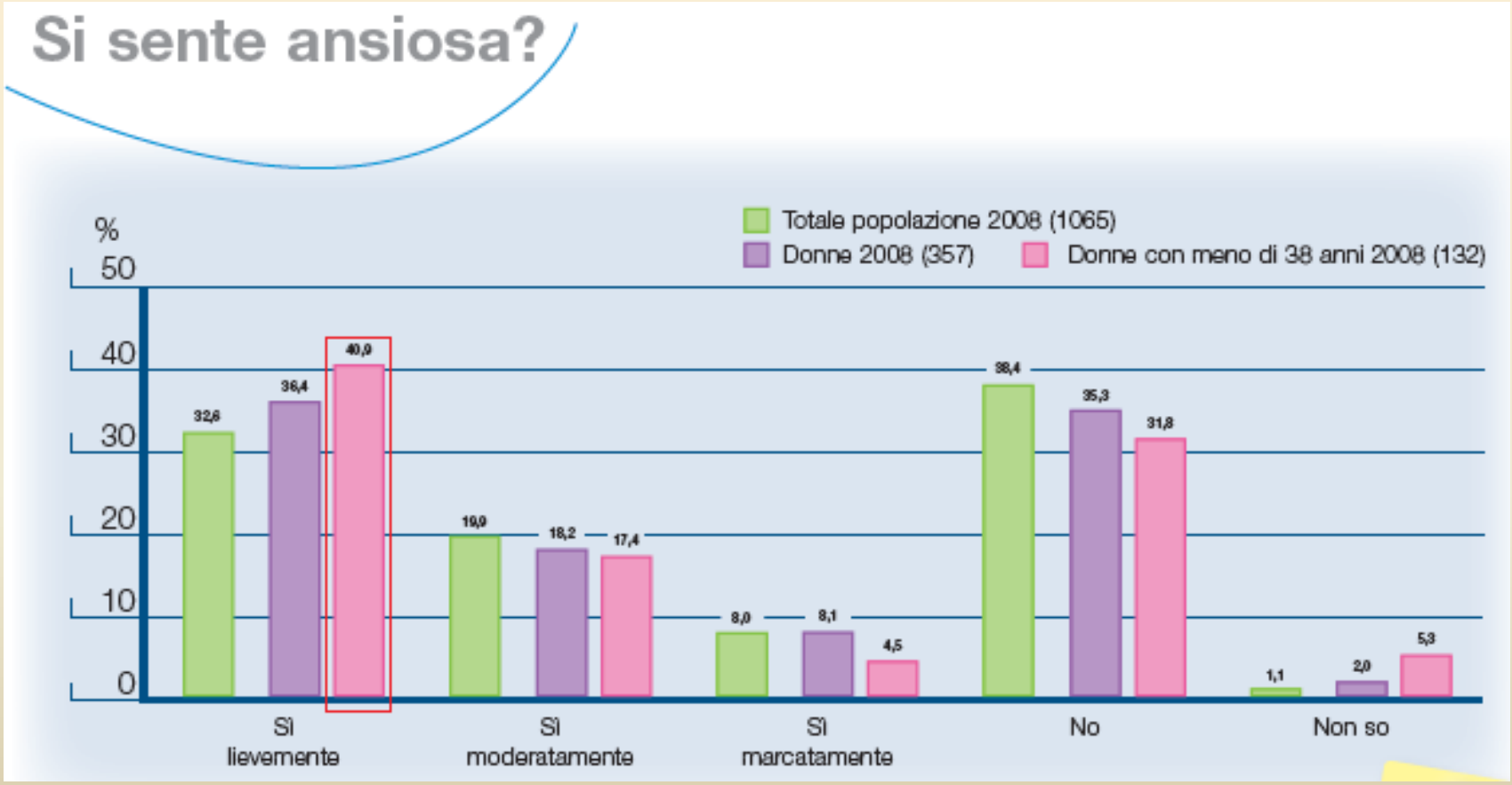
Published studies of the impact of HIV on emotional health of women

Author	Study population	Findings
Chandra et al 2009	109 adults with HIV	Women had lower QOL facets of positive feelings, sexual activity, financial resources
Wisniewski et al 2005	61 adults with and without HIV	Women had more depressive symptoms and lower QOL than men
Joseph et al 2004	30 HIV-positive women	Majority were primary caregivers. Suffer problems with financial issues, child care and support, help-seeking, sexual interactions and experience gender discriminatory and inadequate care
Summers et al 2004	93 HIV-positive adults	Bereaved women had intensified bereavement responses, greater generalized anxiety disorder, elevated thoughts of suicide
Te Vaarwerk et al 2001	78 HIV-positive European women	High levels of distress and low HRQOL, especially if drug users

PTSD in HIV-positive women

- 16–54% of HIV patients suffer from PTSD[1]
- PTSD is positively associated with female gender[2]
- Women at risk of PTSD are more likely to have experienced traumatic events[3] e.g.:
  - Childhood sexual abuse[1,3]
  - Severe physical abuse[1,3]
- Depression and PTSD often co-occur[4]
- PTSD is associated with[1]:
  - Poorer medication adherence
  - HIV risk behaviour

Ansia


Si sente ansiosa?
%
50
40
30
20
10
0
Totale popolazione 2008 (1065)
Donne 2008 (357)
Donne con meno di 38 anni 2008 (132)
32,6
36,4
40,9
19,9
18,2
17,4
8,0
8,1
4,5
38,4
35,3
31,8
1,1
2,0
5,3
Sì lievemente
Sì moderatamente
Sì marcatamente
No
Non so

Influence of HIV on a woman's role as a mother

- Parenting issues for HIV-positive women
  - Disclosure to children
  - Confidentiality
  - Guilt/shame
  - Fear of passing infection to children
  - Adhering to complex treatment regimens
  - Stress of logistics of attending medical consultations
  - Managing childcare during periods of ill health

Disclosure to children

- The decision to disclose HIV serostatus to one's children is very complex
- Rates of disclosure range from 30% to 66%
- Possible concerns of disclosure include not wanting to scare the child, and wishing a care-free childhood for him/her
- Benefits of disclosure may include:
  - opportunities to openly discuss the diagnosis and any concerns the child may have and to clarify misconceptions
  - providing the child with time to grieve
  - opportunities for the mother to gain comfort from her child

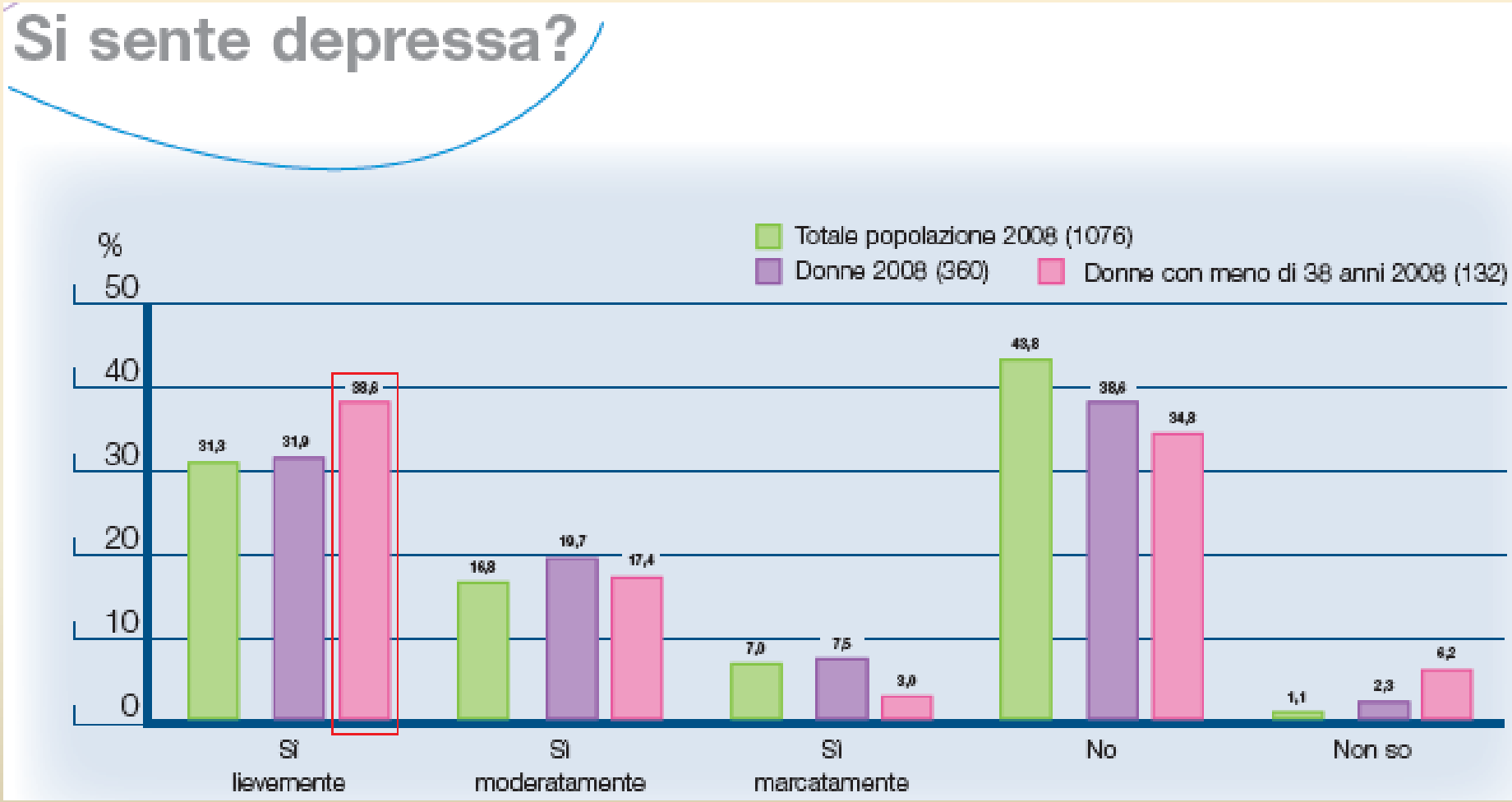
Delaney RO et al (2008) AIDS Care

Depression

Vulnerability of HIV-positive women to depressive symptoms

- **30–60% of women with HIV in the community and clinic samples report depression[1]**
- **17% higher likelihood of acute stress disorder among women compared with men[2]**
- **34% of women diagnosed with depression compared with 29% of men[3]**
- **54% HIV-related mortality rate for women with chronic depressive symptoms[1] compared with little or no depressive symptoms**

Depressione



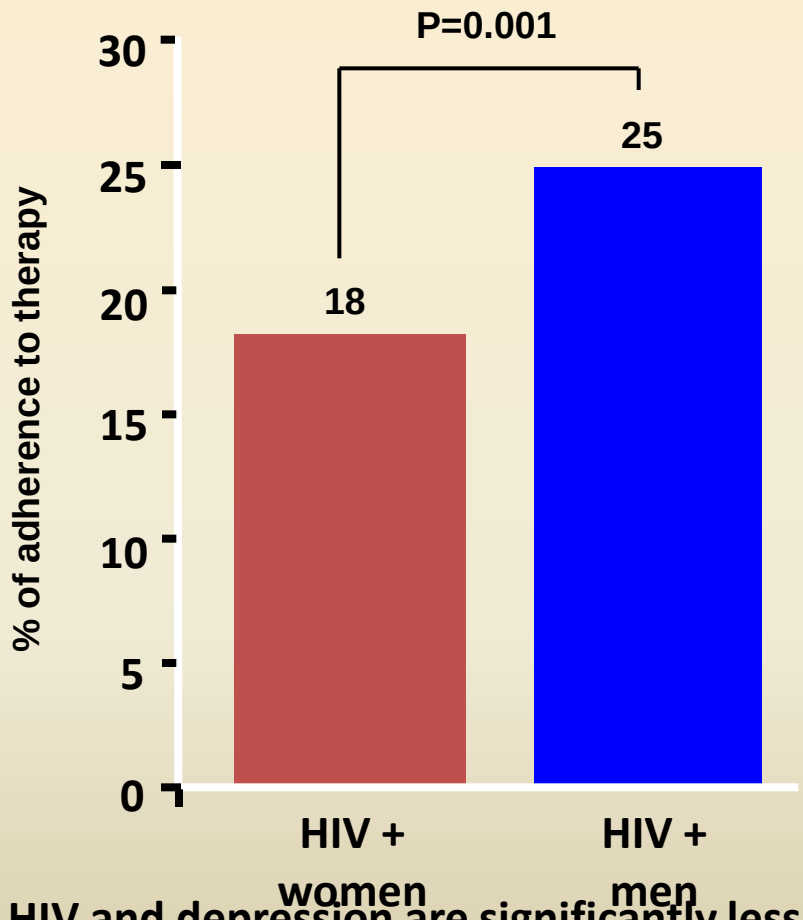
Addressing depression in pregnancy

- Guidelines should be updated to recommend
  - Preconception counselling
  - Guidance on reproduction options
- Identify modifiable factors associated with prenatal depression
- Integrate routine screening into prenatal HIV-care
- Enhancing education to lower depression rates
  - Reduces perceived stress and social isolation
  - Encourages positive partner support
  - Alleviates fear over treatment effects and adherence concerns

HIV in menopausal women

- Due to improved therapies many HIV-positive women now survive to experience menopause[1]
- 24–65% increased likelihood of experiencing symptoms in menopause with HIV[2,3]
- Commonly reported symptoms include:
  - Depression
  - Reduced sexual interest[2,3]
- Lower CD4 cell count is significantly associated with hot flushes/night sweats[4]

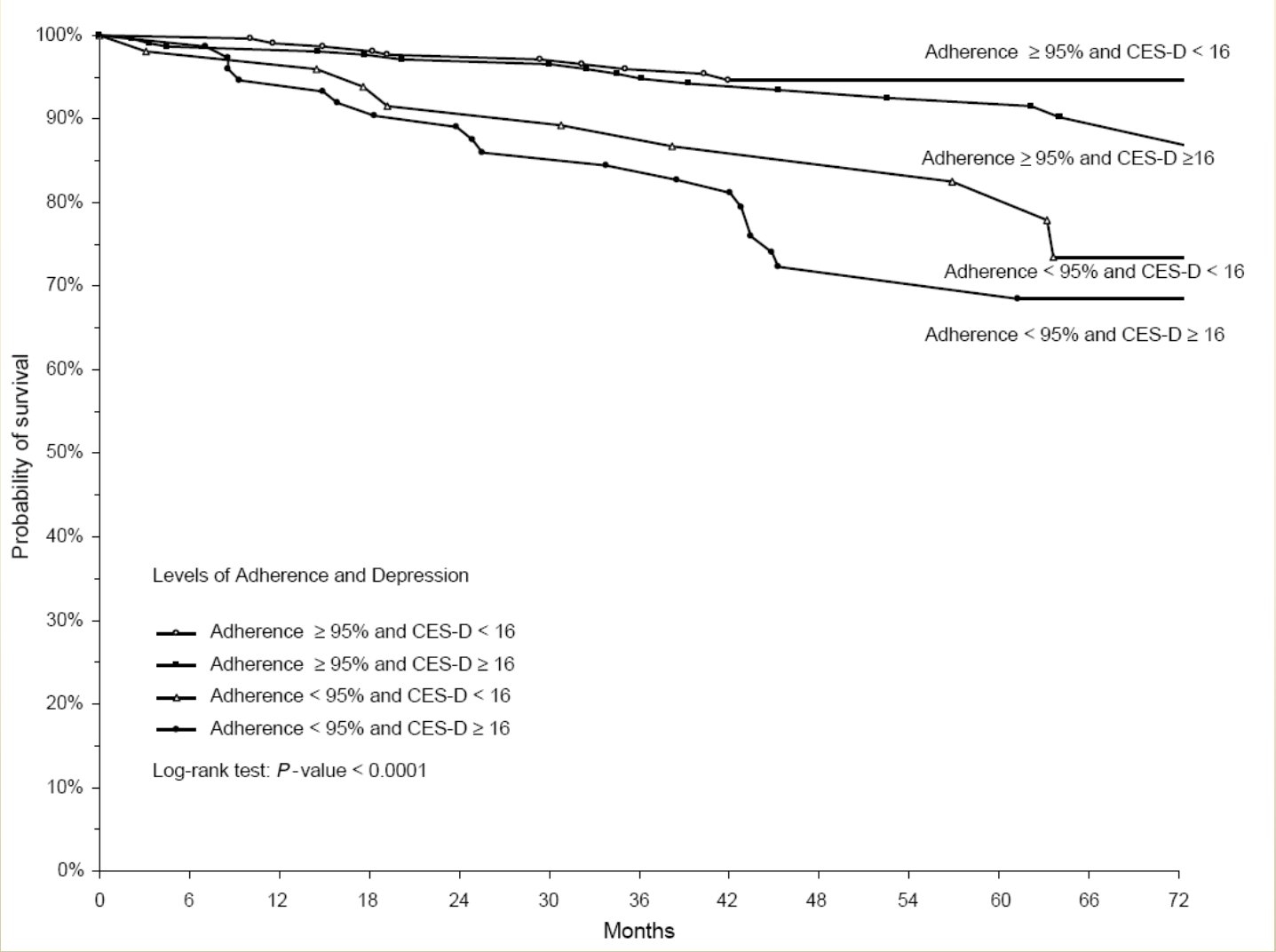
Reduced adherence to HIV therapy in depression



- **Women with HIV and depression are significantly less adherent to therapy compared with HIV-positive men**

Turner BJ et al (2003) J Gen Intern Med

Poorer survival in persons with depression and lower adherence to treatment



Lima VD et al (2007) AIDS

High level of suicidal ideation in HIV-positive women

- Predictors of suicidal ideation and attempts include:
  - HIV diagnosis
  - Other psychiatric symptoms
  - Physical/sexual abuse
  - Drug/alcohol history
  - Isolation
- People attempting or considering suicide often do not ‘seek death’ but simply cannot ‘face life’

Body image changes

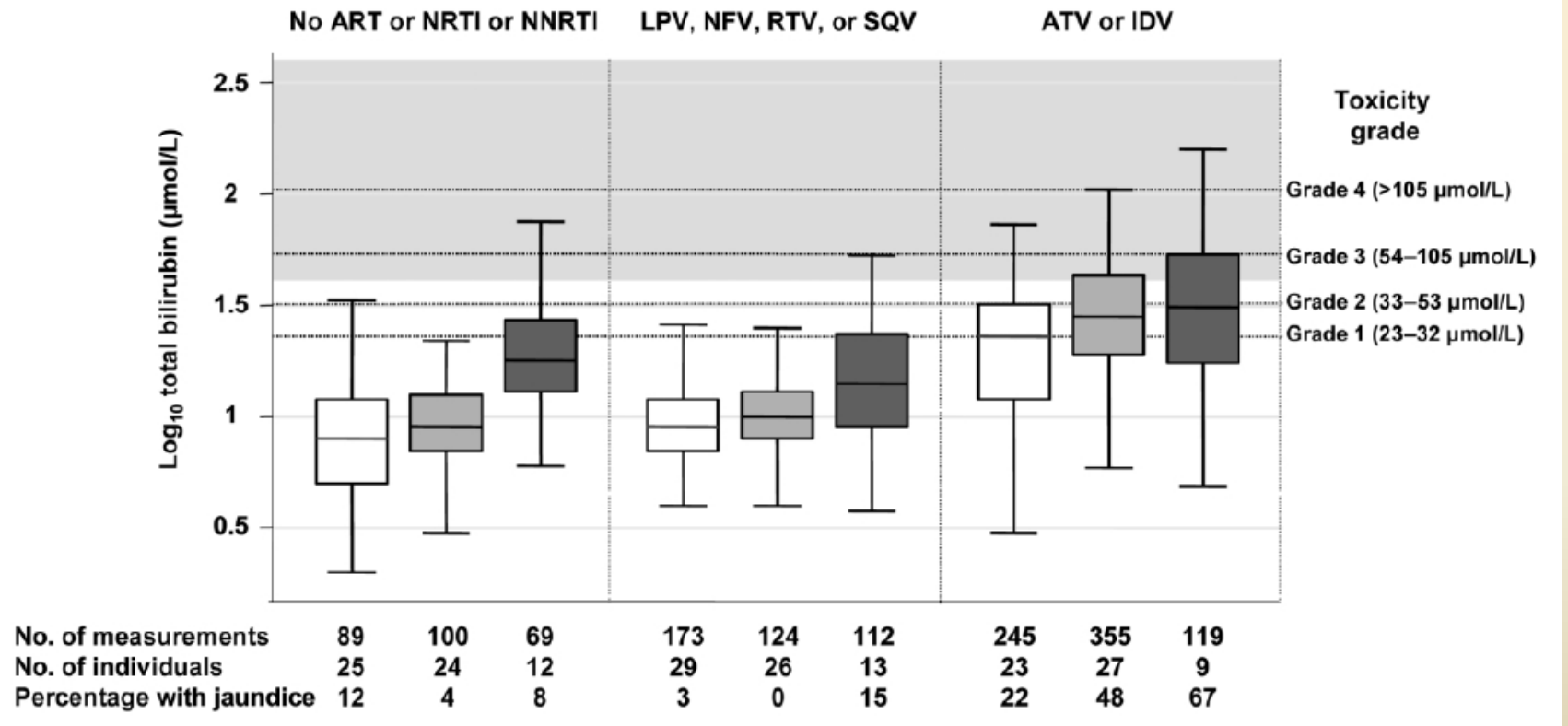
Body image changes

- Types of body image changes
  - Fat abnormalities:
    - Lipodistrophy
    - Lipoatrophy
  - Jaundice and scleral icterus

Jaundice or scleral icterus

- Frequent with some ARVs (IDV, ATZ)
- May have great impact on visual appearance
- Concerns about the social meaning of the bodily changes, and stigmatization.
- Temporary

Distribution of bilirubin levels according to *UGT1A1* genotype



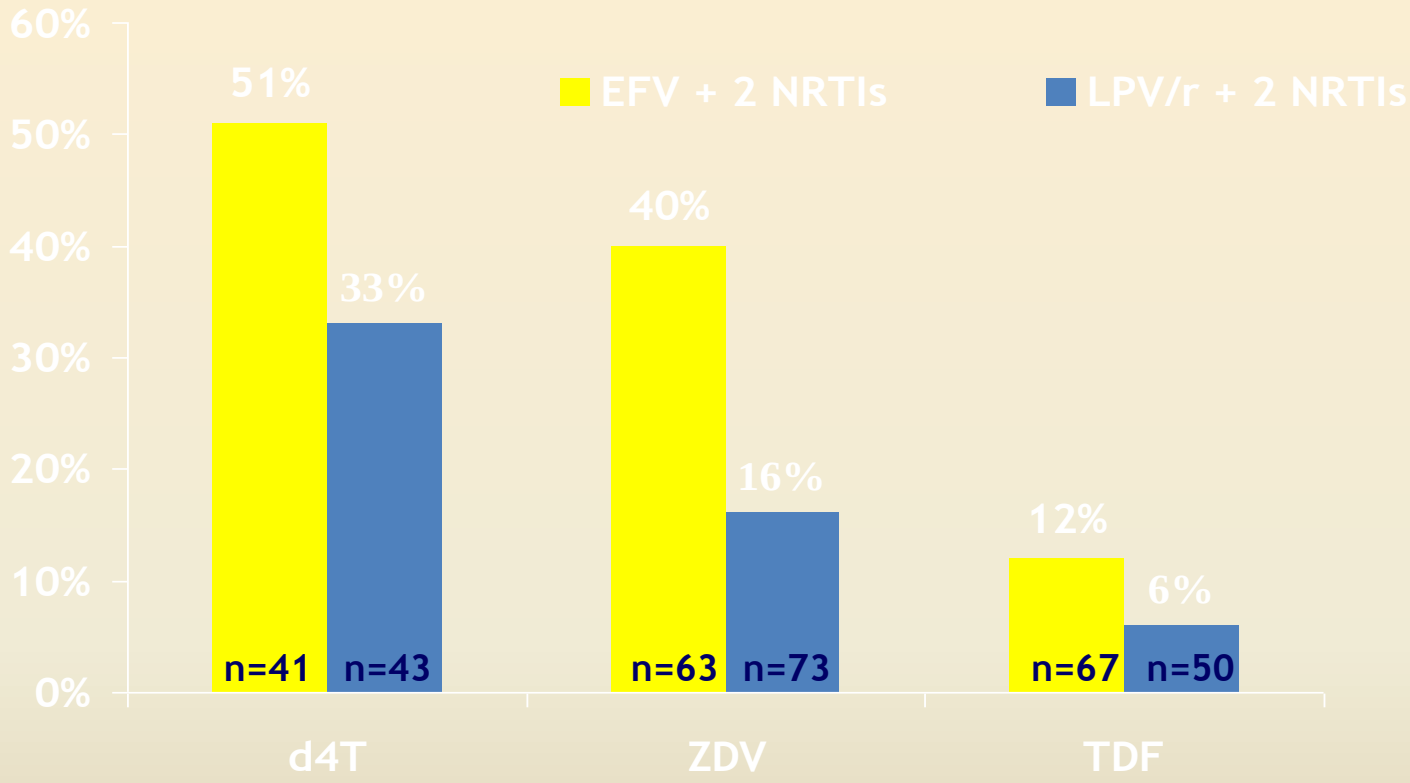
Rotger M et al. JID 2005

Lipodystrophy is associated with a negative body image in women

- Lipodystrophy among HIV-positive women is associated with a negative body image[1]
- Makes HIV status evident by outward appearance[1]
  - HIV+ women with lipodystrophy are more likely to believe that others know HIV status due to their appearance
    - 22% of 0% (p=0.003)
  - Impacts on quality of life and sexual behavior
- Women are also more likely to experience depression than men, compounding negative self-esteem[2]

1. *Huang JS et al. AIDS Res Ther 2006;3:17.*
2. *Turner BJ et al. J Gen Intern Med 2003;18:248-257.*

Lipoatrophy and HAART: ACTG 5142



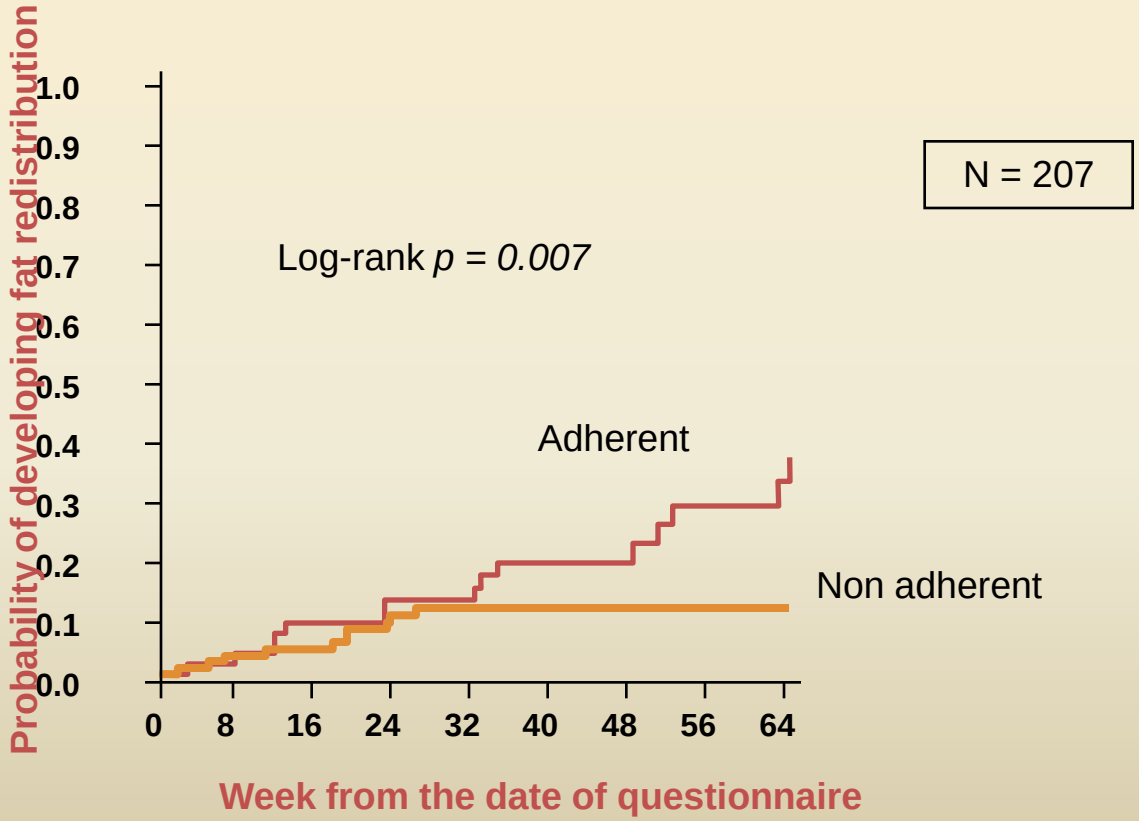
Logistic regression Week 96 lipoatrophy

Factor	OR (95% CI)	P
EFV *vs* LPV/r	**2.7** (1.5- 4.6)	<0.001
d4T *vs* ZDV	**1.9** (1.1-3.5)	0.029
TDF *vs* ZDV	**0.24** (0.12-0.5)	<0.001

Haubrich R et al. CROI 2007. Abs 33

Patient-perceived fat redistribution is more likely in adherent patients

- AdICoNA & LipoICoNA Cohort
- A self-report questionnaire was administered to measure adherence and patient perception of body fat redistribution

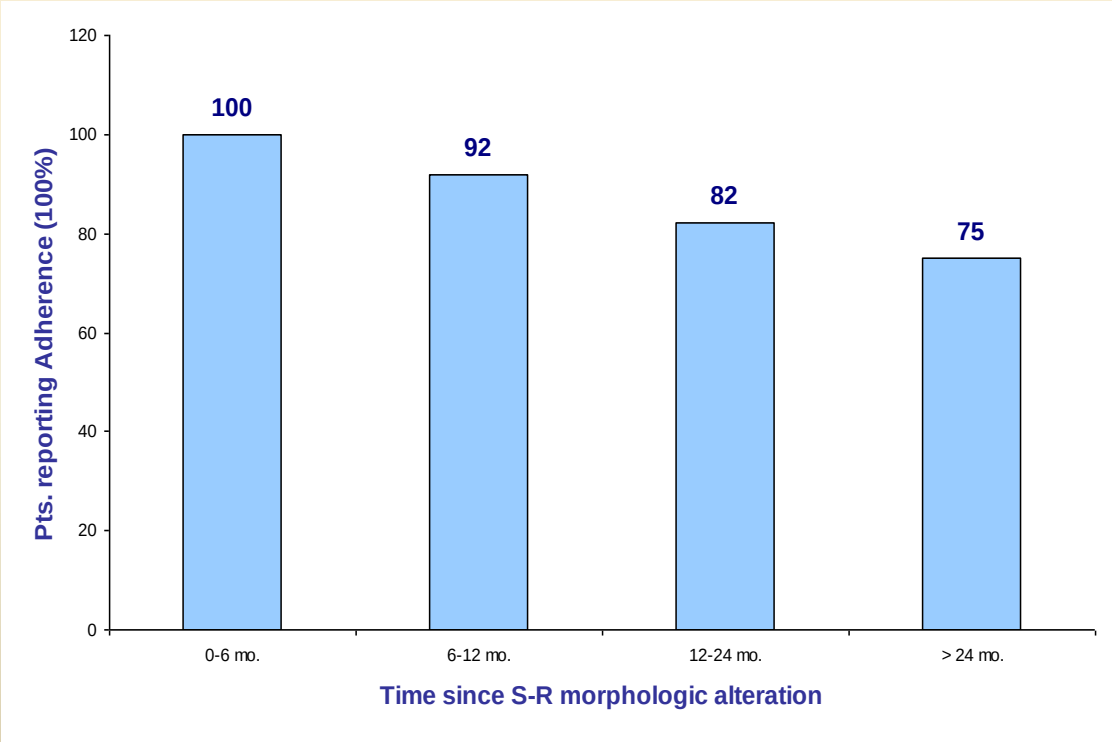


Ammassari A et al. *J Acquir Immune Defic Syndr* 2002

Development of body fat changes reduce future adherence to HAART

N = 83 patients on HAART with self-reported morphological changes

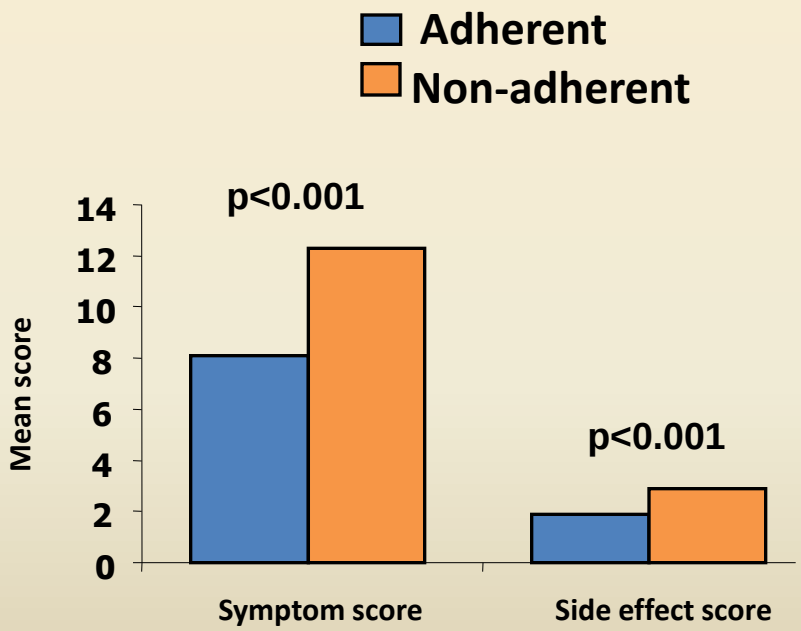
- Self-reported adherence declined with time



Guaraldi G et al. *HIV Clin Trials* 2003

Symptoms and side effects negatively impact on HAART Adherence

AdICoNA cohort[1]



British Columbia cohort[2]

Variable independently associated with self-medications	OR (95%CI)	P
Total Symptoms	1.25 (1.10-1.43)	<0.001
VL<400cp/ml	0.35 (0.21-0.61)	<0.001
> High school	0.43 (0.24-0.78)	0.006
Severe symptoms	2.24 (1.16-4.33)	0.016

1. Ammassari A, et al. *J Acquir Immune Defic Syndr 2001*
2. Heath KV, et al. *J Acquir Immune Defic Syndr 2002*

Sexual health

Sexual health: the WHO definition

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity.

Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence.

For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

Sexual dysfunction in HIV-positive women

- Multi-factorial etiology: psychological and physical
- Same physical reasons as in men:
  - HIV- or drug-related peripheral neuropathy
  - endocrine alterations
  - atherosclerosis
- Body changes (lipodistrophy)
- Fear of (horizontal or vertical) HIV transmission
- Stigma associated with HIV infection
- Necessity to negotiate use of condoms

Sexual Dysfunction & Body Image

- Several studies found that the presence of self-perceived alteration in body image was independently related to reporting sexual dysfunction. [1]
- Both biological and psychological reasons could explain this association:

Adipose tissue alterations determine an increased peripheral aromatization of androgens to estrogens in the sites of pathological adipose tissue activity with subsequent raised estrogen levels that can explain low sexual desire in patients with HIV-related lipodystrophy.[2]

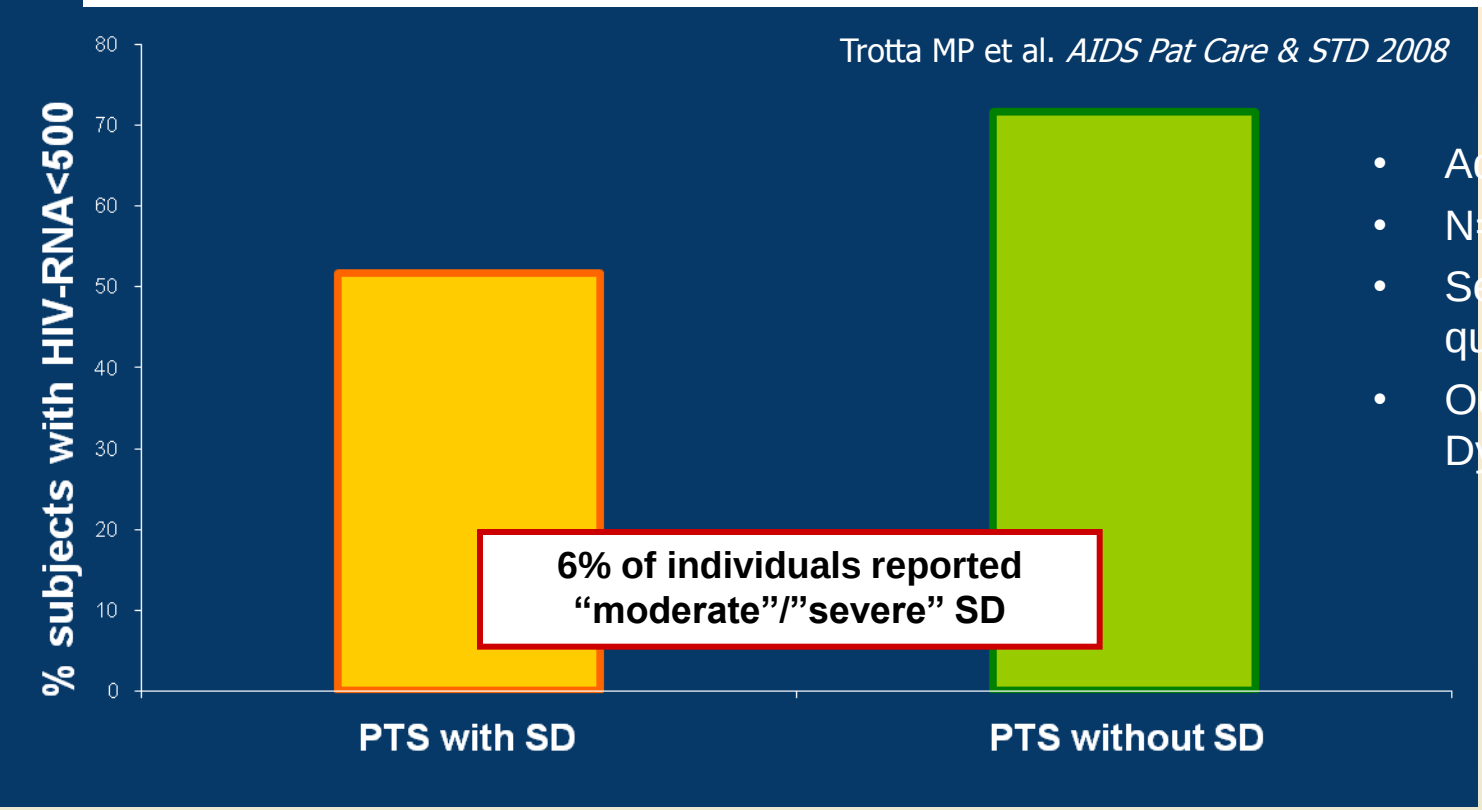
Patients who perceived disfiguring signs in body shape displayed a propensity toward stigmatization, demoralization and depression, which can have a substantial role in determining impairment in sexual activity. [3]

[1] Schrooten W, *AIDS* 2001; Richardson D, et al. *Int J STD AIDS*. 2006; Trotta MP et al. *AIDS Pat Care & STD 2008*

[2] Goldmeier D, *Sex Transm Infect* 2002

[3] Collins E, *AIDS Read* 2000

Body change and adherence are predictors of sexual dysfunction

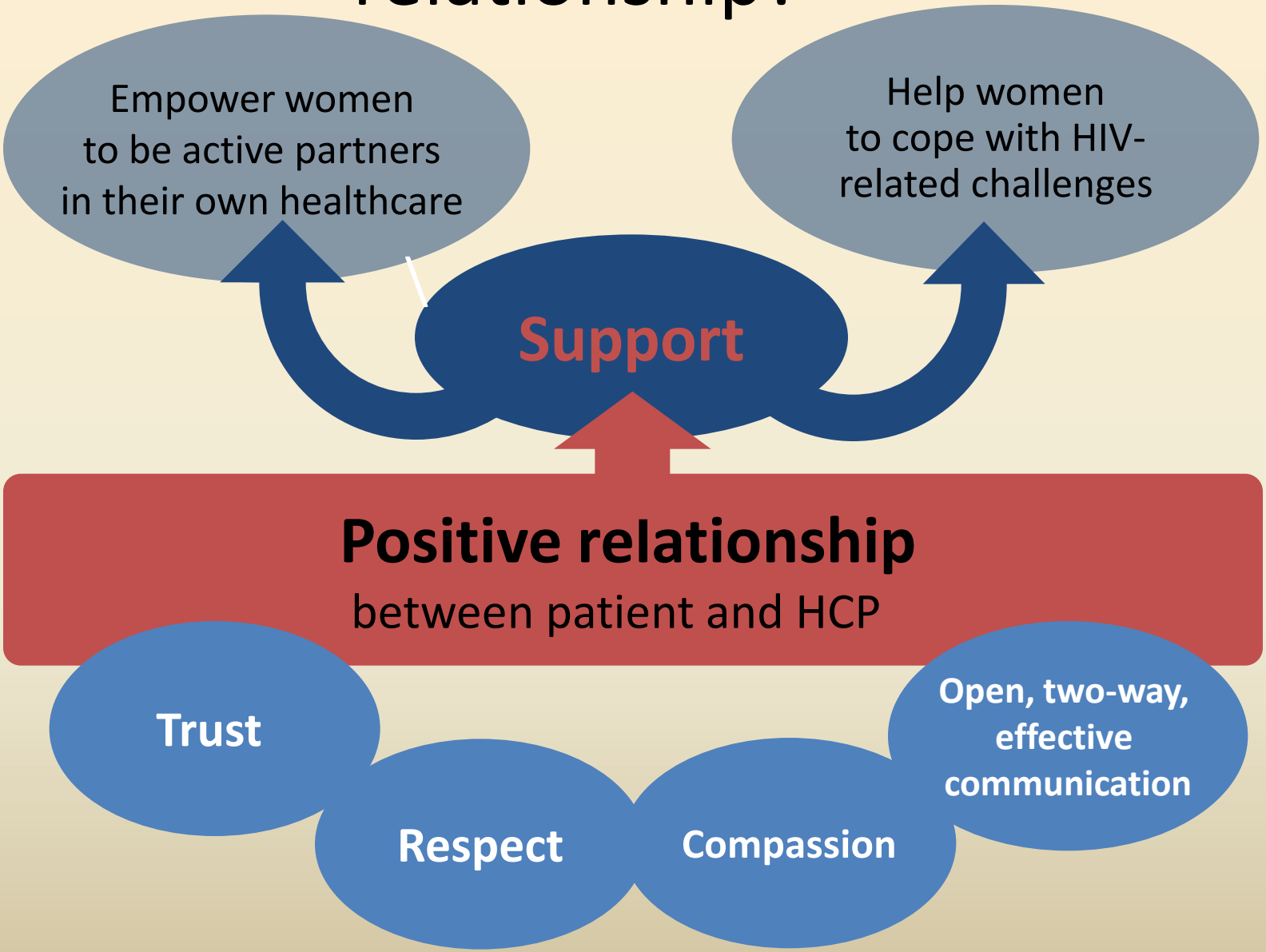


- AdICoNA & AdeSpall
- N=612
- Self-reported adherence questionnaire
- Outcome: Sexual Dysfunction

Predictors of "moderate"/"severe" SD	Adj OR (95% CI)
Perceived worsening of viroimmunological markers	3.90 (1.08-14.18)
Self-reported HAART non-adherence	**3.44 (1.30-9.08)**
Symptom score (for each increase)	1.13 (1.05-1.22)
Self-reported abnormal fat accumulation	**4.33 (1.55-12.11)**

Supporting the patient–HCP relationship

Why support the patient–HCP relationship?



Empowering women to be active participants in their own care

The preferred model of medical care has evolved towards a partnership or alliance approach

Women are encouraged to:[1–4]

- ✔ Question and elicit information from HCPs
- ✔ Raise psychosocial as well as medical issues
- ✔ Participate in decision making
- ✔ Take responsibility for their well-being

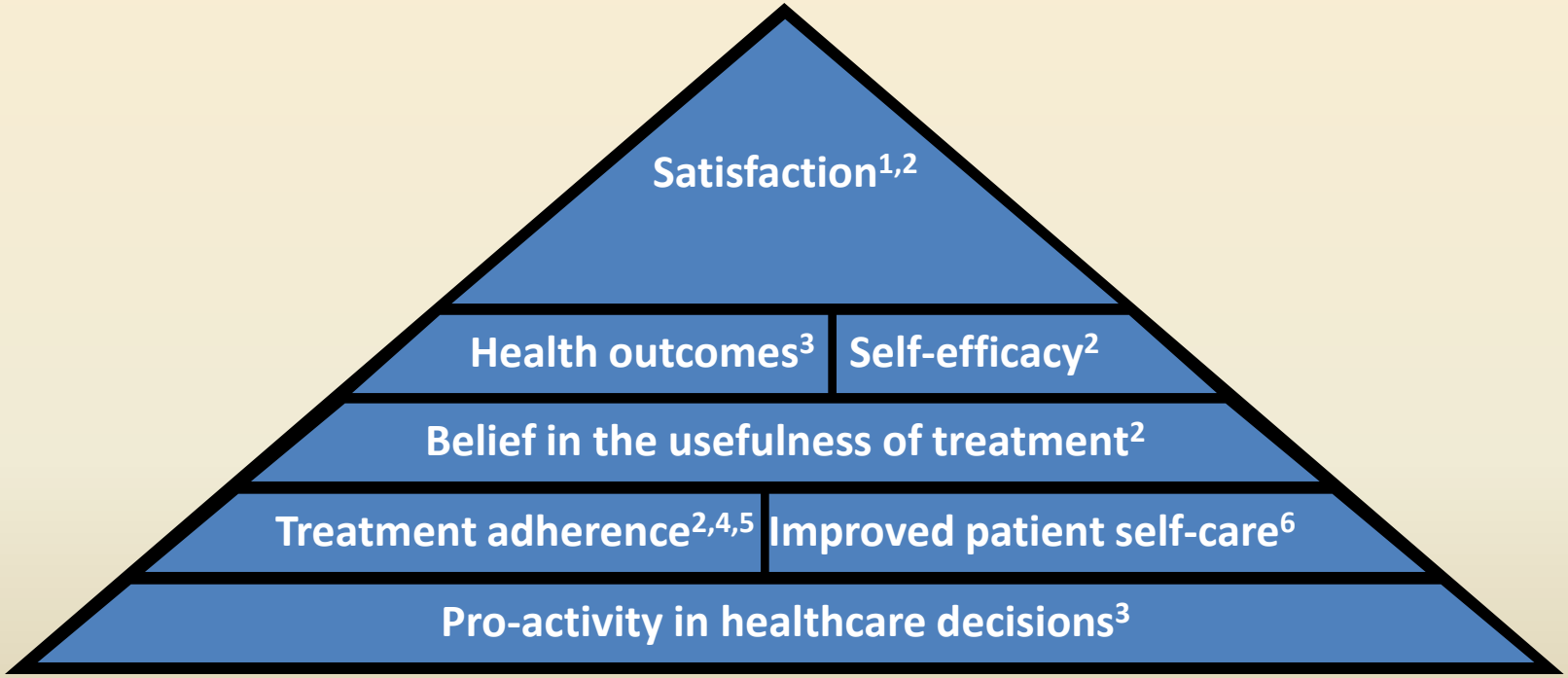
Facilitating treatment adherence

Measures to maximize adherence

- ✓ Ensure patients are knowledgeable about treatment
- ✓ Reinforce the value of treatment
- ✓ Engage patient in management decisions
- ✓ Select a regimen most likely to be adhered to
- ✓ Provide social and psychological support
- ✓ Be vigilant for and treat depression and other mental disorders
- ✓ Offer extra support during the early months
- ✓ Regular long-term follow-up to monitor / reinforce adherence

Benefits of an effective partnership between patient and HCP

A patient-centred working alliance between patient and HCP is associated with improved patient:

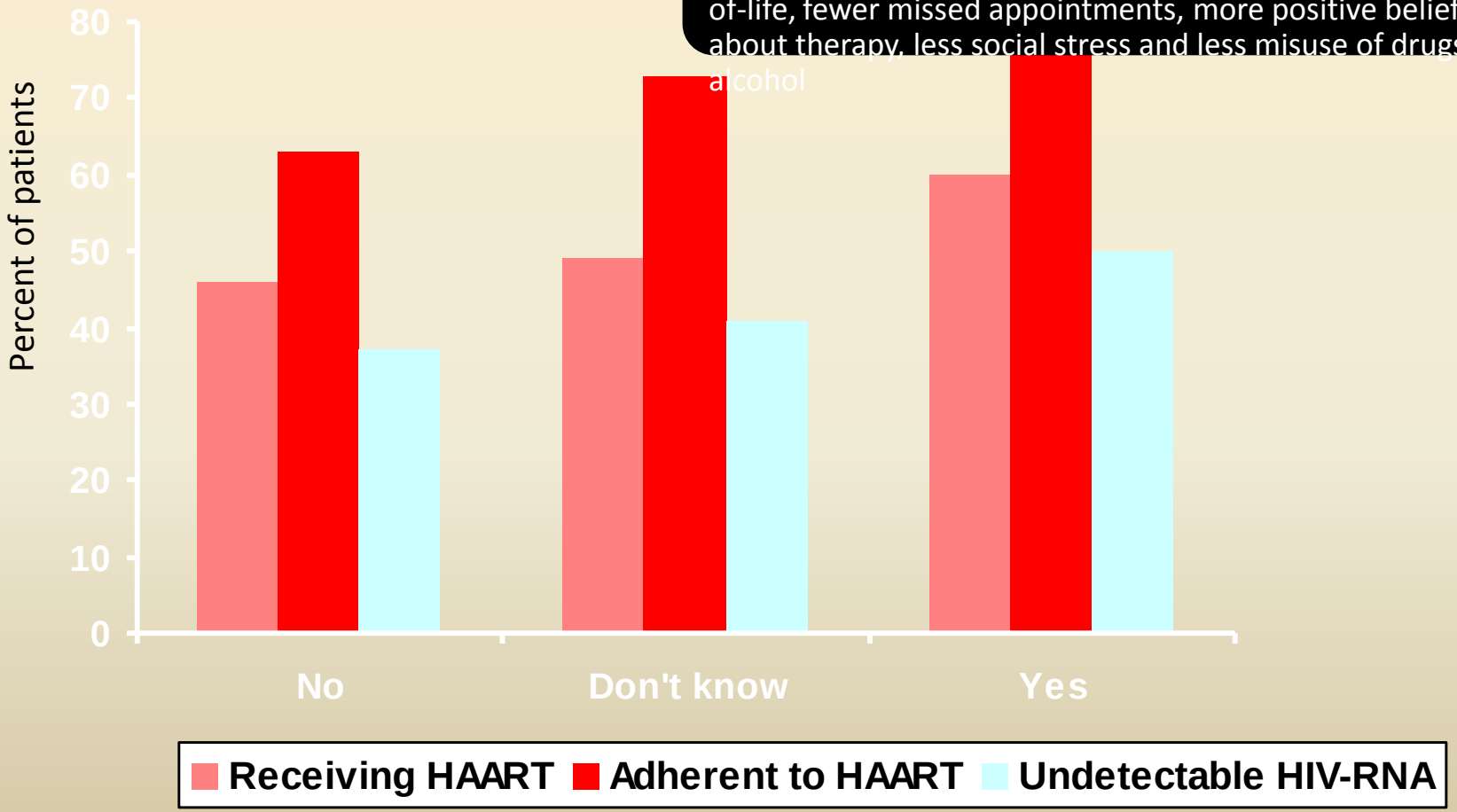


. . . and helps patients remain in care[7]

Health benefits of feeling “known as a person’’ by HCPs

(n=1743)

Patients “known as a person’’ by their HCP were more likely to receive ART, adhere to their ART, and have an undetectable viral load. They also reported higher quality-of-life, fewer missed appointments, more positive beliefs about therapy, less social stress and less misuse of drugs or alcohol



Beach MC et al. J Gen Intern Med 2006

Individualizing care

Individualizing care

. . . and consider women in their
social context

e.g. as a mother, a partner,
a daughter, a caregiver