

# SELF-CARE AND INVOLVEMENT IN MANAGEMENT OF CARE AMONG PEOPLE LIVING WITH HIV IN EUROPE

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## Introduction

- With increasing emphasis on self-care, empowering patients is critical.
- We examined treatment challenges, efforts at self-care, and communication with healthcare providers (HCPs) among people living with HIV (PLHIV).

## Methods

- We analyzed data from the 2019 Positive Perspectives Study of people living with HIV for 969 adult PLHIV in 12 EU/Schengen countries
- The web-based survey assessed for presence of specific treatment challenges and experiences:

- "Optimal health" was assessed within the past four weeks; self-rating of health as "Good" or "Very good" was classified as "optimal" (vs "Neither good nor poor", "Poor", or "Very poor")
- Concerns regarding HIV treatment and interactions with healthcare providers (HCPs). Responses of "Agree" or "Strongly agree" were classified as a positive indication that the concern existed (vs "Strongly disagree", "Disagree", or "Neither agree nor disagree").
- Suboptimal adherence was defined as having missed HIV medication 5+ times in the past month because of 1+ reason.<sup>1</sup>
- Difficulty swallowing pills was defined as scores  $\geq 3$  (on a numeric scale from 1 to 5, with higher numbers denoting greater difficulty) in response to the question: "In general, how easy or difficult do you find it to swallow pills?" Scores of 1 or 2 were classified as absence of difficulty.
- Respondents were classified as having treatment satisfaction if they answered "Satisfied" or "Very satisfied" (vs "Neither satisfied nor dissatisfied", "Dissatisfied", or "Very dissatisfied") in response to the question: "Overall, how satisfied are you with your current HIV medication?"
- A report of being comfortable discussing health concerns with HCP was defined as a response of "Very comfortable" or "Comfortable" (vs "Neither comfortable nor uncomfortable", "Uncomfortable", or "Very uncomfortable").<sup>2</sup>

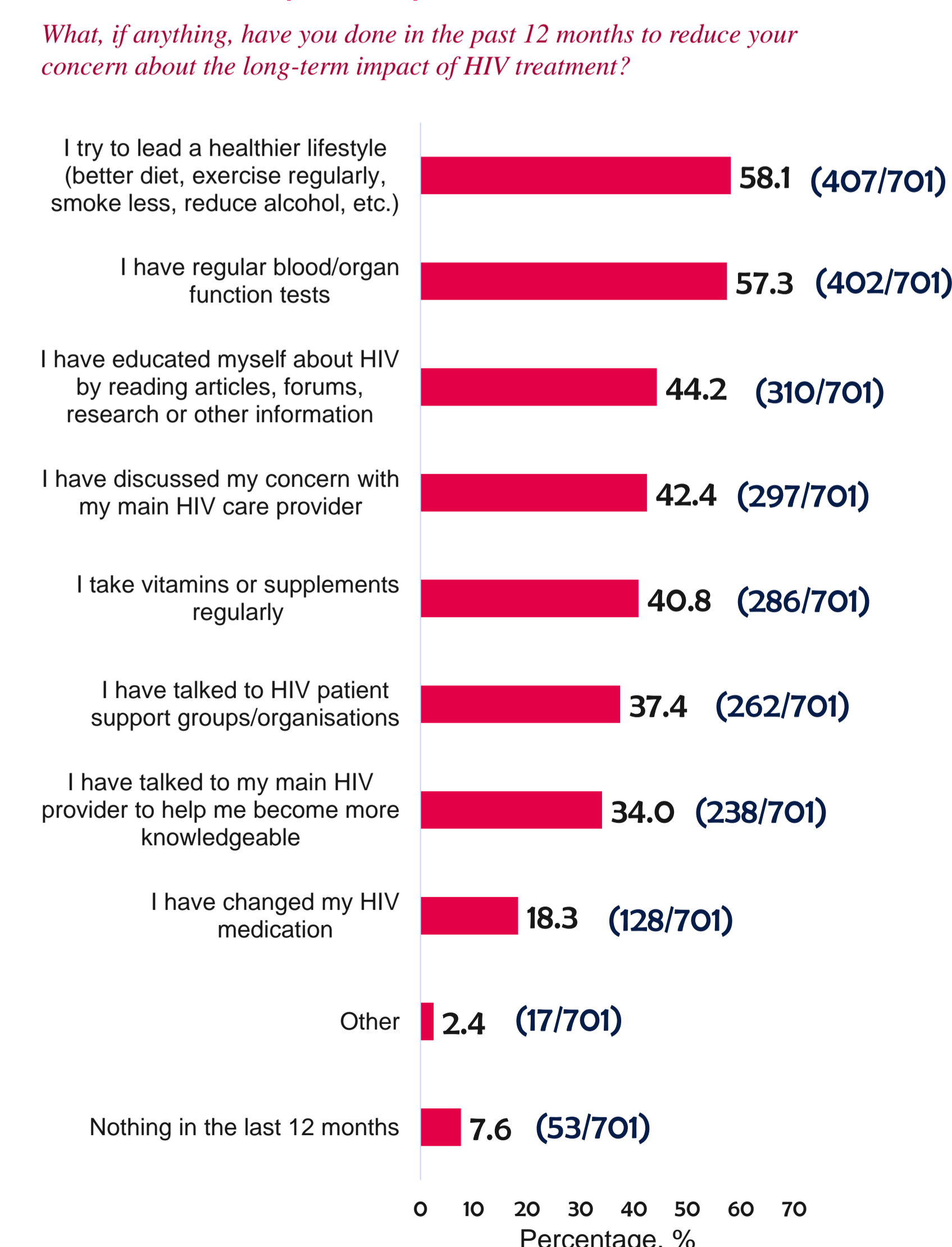
- Patient engagement in care (low, moderate, high) was adapted from the Observing Patient Involvement scale.<sup>2</sup>
- Analyses: prevalence estimates computed and compared with  $\chi^2$  tests at  $p < 0.05$
- Logistic regression analyses controlled for country, duration of HIV, age, and gender.

## Results

Figure 1. Characteristics of the study population (N = 969)

Characteristic	N	%
<b>Age, y</b>		
<50 y	642	66.3%
50+ y	327	33.8%
<b>Gender</b>		
Men	643	66.4%
Other (Nonbinary, prefer not to say)	32	3.3%
Women	294	30.3%
<b>Sexual orientation</b>		
Heterosexual	359	37.1%
Homosexual	461	47.6%
Other (Bisexual, asexual, pansexual, prefer not to say)	149	15.4%
<b>Year of HIV diagnosis</b>		
2017 to 2019	168	17.3%
2010 to 2016	347	35.8%
Pre-2010	454	46.9%

Figure 2. Self-care and health-seeking behaviours among those with concerns about long-term impact of their treatment (N = 701)



- Overall, 72.3% (701/969) reported some concern about long-term impacts of ART.
- Only 7.6% [53/701] of those with concerns about long-term ART impact reported doing "Nothing" about it.

Figure 3. Treatment concerns and challenges among people living with HIV in Europe (N = 969)

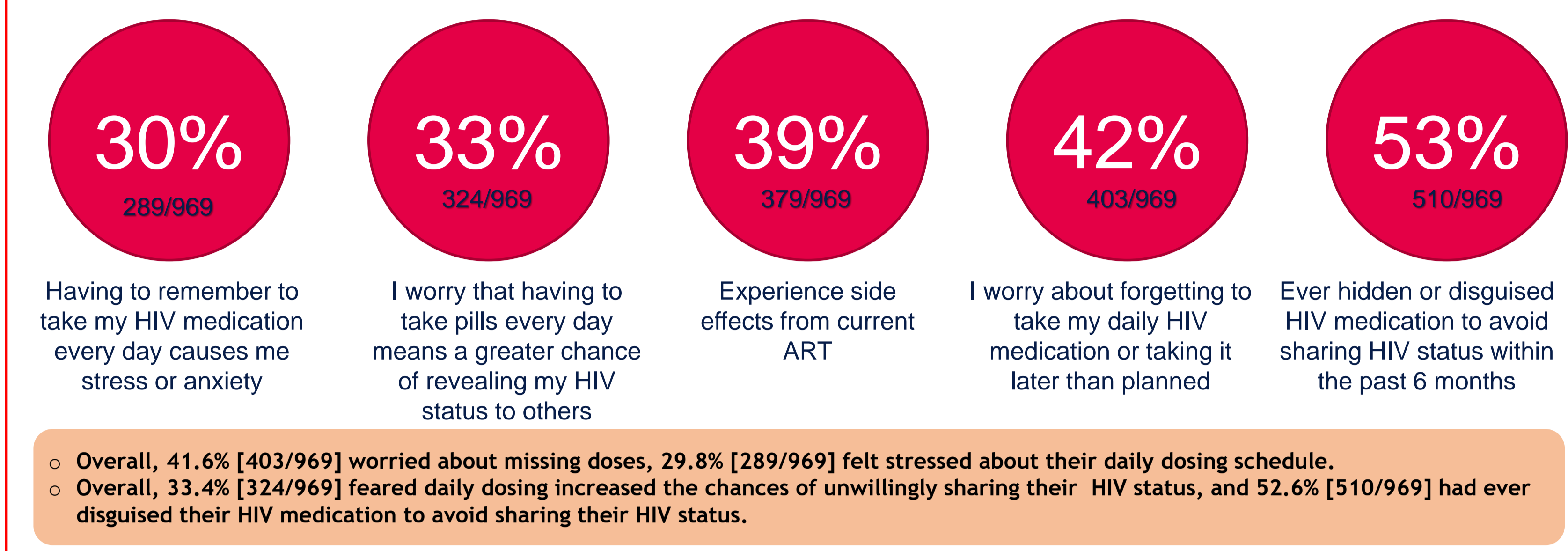


Figure 4. Relationship between treatment challenges and health outcomes among people living with HIV (\* $p < 0.05$ ,  $\chi^2$  tests)

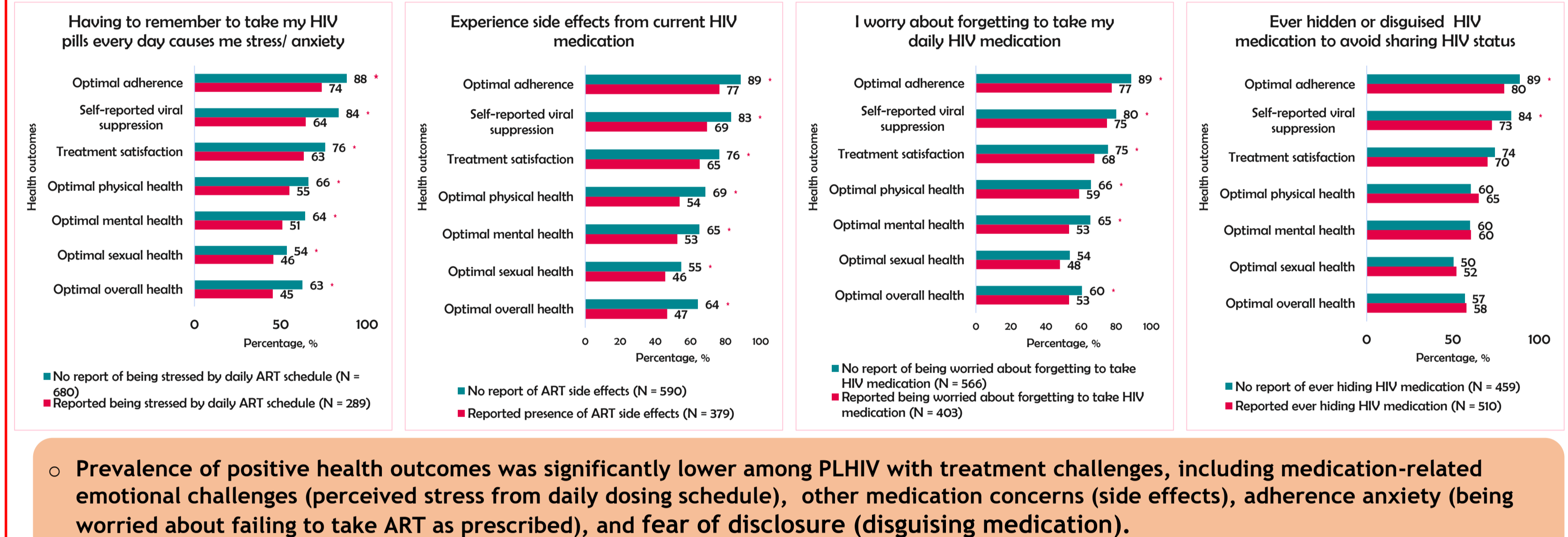


Figure 5. Perceptions towards treatment and interactions with healthcare providers (HCPs) among PLHIV (N = 969)

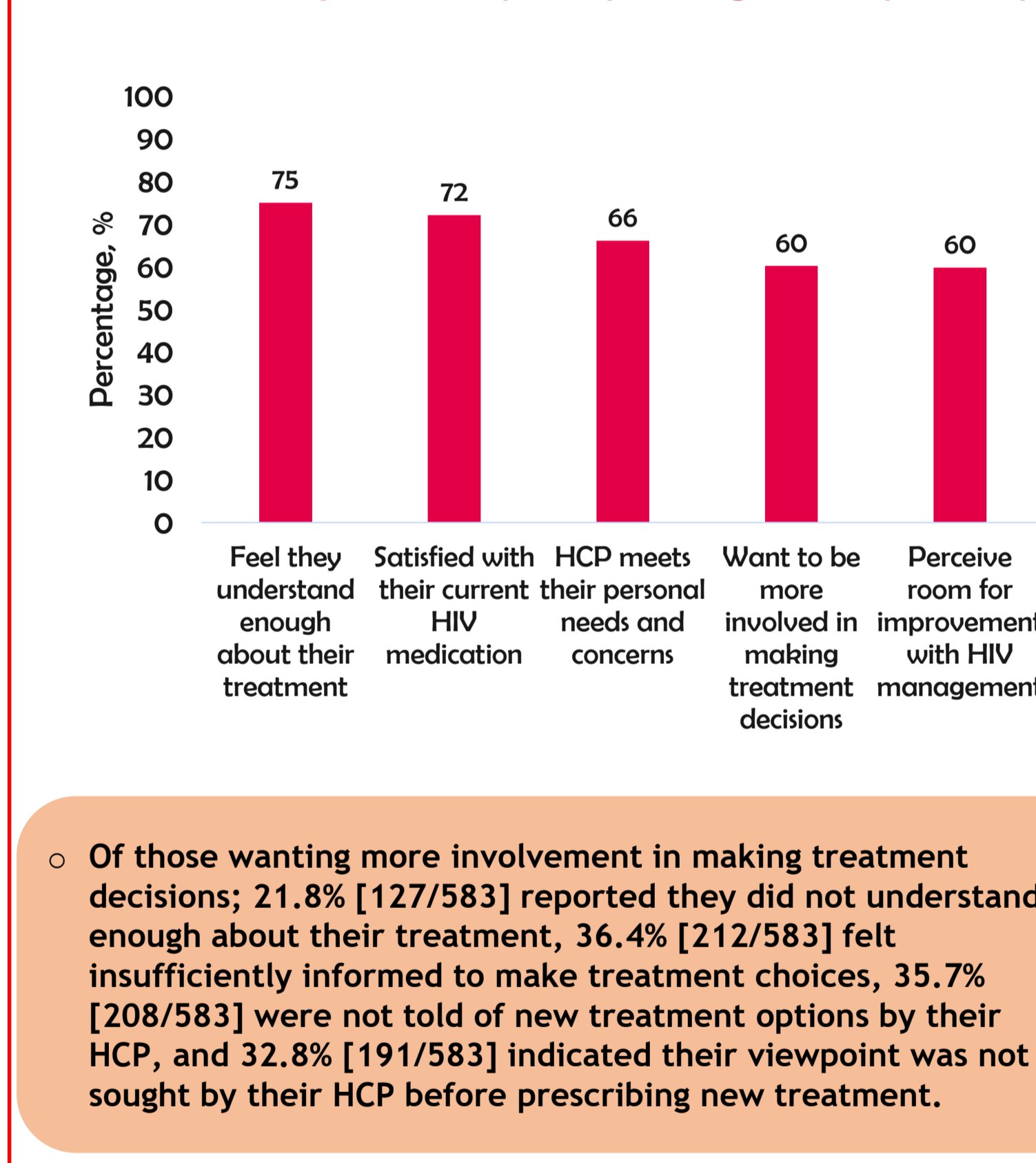


Figure 6. Percentage of people living with HIV who reported various positive health-related outcomes, stratified by extent of engagement in care (N = 969)

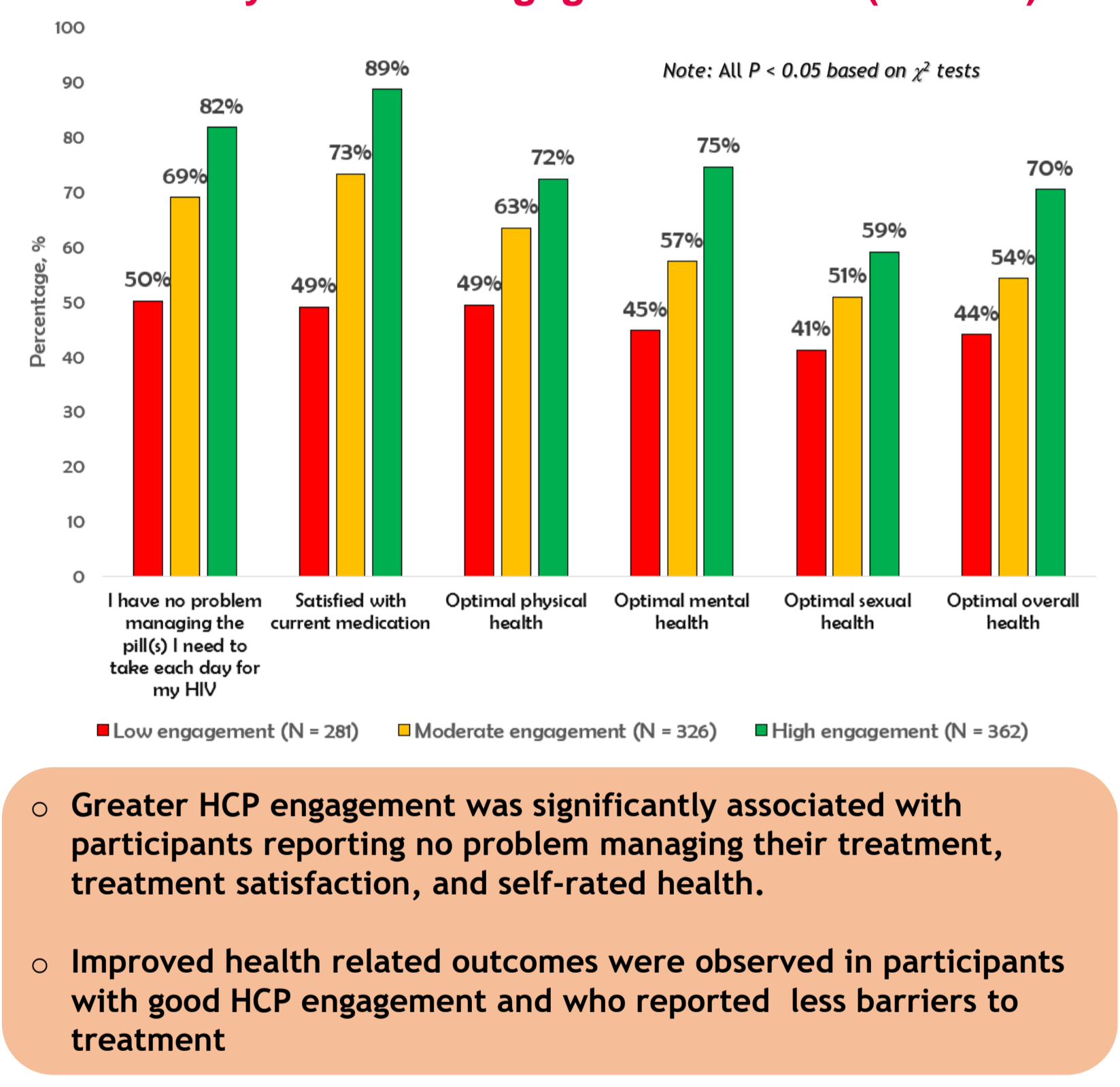
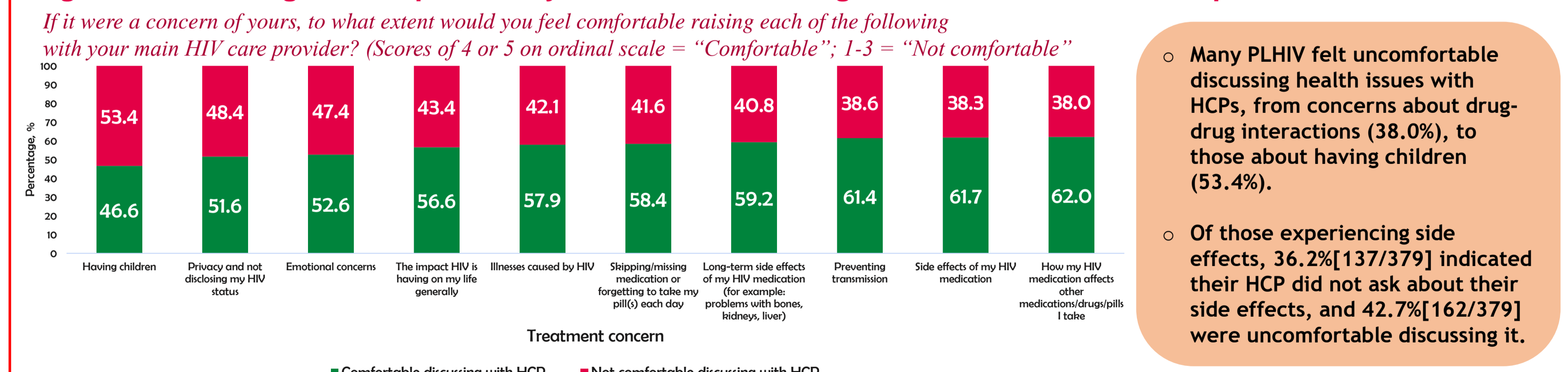


Figure 7. Percentage who reported any barrier to discussing salient health issues with providers



## Conclusions

- Treatment-related challenges are common among PLHIV and negatively impact aspect of quality of life.
- One-third of those wanting more involvement in care felt uninformed or uninvolved.
- Critical communication gaps existed, underscoring the need to better engage, educate, and empower PLHIV, to improve aspects of their health and overall wellbeing.
- HCPs should consider increased proactive engagement with patients taking into account their treatment needs and concerns as this may help significantly improve aspects of quality of life.

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References: 1. de los Rios P, Okoli C, Punekar Y, et al. Prevalence, determinants, and impact of suboptimal adherence to HIV medication in 25 countries [published online ahead of print, 2020 Jun 25]. *Prev Med.* 2020;139:106182. doi:10.1016/j.ypmed.2020.106182. 2. Okoli C, Brough G, Allan B, et al. Shared Decision Making Between Patients and Healthcare Providers and its Association with Favorable Health Outcomes Among People Living with HIV [published online ahead of print, 2020 Aug 3]. *AIDS Behav.* 2020;1-12. doi:10.1007/s10461-020-02973-4.