



# Shared Decision Making Between Patients and Healthcare Providers and its Association with Favorable Health Outcomes Among People Living with HIV

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## Abstract

We assessed patient-provider communication in HIV care; data were from the 2019 Positive Perspectives Survey of people living with HIV (PLHIV) from 25 countries (n = 2389). A significantly greater proportion of recently diagnosed individuals were interested in being involved when it comes to decisions about their HIV treatment compared with any other group (72.8% [399/548], 63.1% [576/913], and 62.6% [581/928], diagnosis year: 2017–2019, 2010–2016, and pre-2010 respectively) but reported less understanding of their treatment compared with those reporting the longest duration (66.8% [366/548], 68.6% [626/913], and 77.3% [717/928], respectively). One-third of PLHIV with salient treatment-related concerns were uncomfortable discussing with providers. Of participants who felt that their HIV medication limited their life but did not discuss their concerns with their provider (n = 203), top reasons for not discussing were: perception nothing could be done (49.3% [100/203]), provider never brought up the issue (37.9% [77/203]), and not wanting to appear difficult (30.5% [62/203]). To continue to identify and address unmet treatment needs among PLHIV, providers need to ensure that there is ongoing open dialogue.

**Keywords** Communication · Barriers · Treatment needs · Quality of life · HIV

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## Introduction

There is increasing recognition of the need to extend the continuum of HIV care beyond diagnosis and treatment. Improving quality of life among people living with HIV (PLHIV) is espoused in the recently proposed “90” target, in addition to the three UNAIDS targets aimed at increasing testing, treatment, and viral suppression [1, 2]. Inherent in the fourth “90” target is the need for shared decision making between PLHIV and their healthcare providers (HCPs), because quality of life may be determined to a significant extent by subjective factors including pain or discomfort, self-esteem, perceptions regarding body image and appearance, satisfaction about sexual life, overall mental health, perceived unmet treatment needs, and social support, among others [3]. The impact of these factors on health outcomes cannot be overemphasized, as poor quality of life can impact treatment adherence and lead to non-retention in care, possibly resulting in a downward spiral into poor virologic control. In this way, the fourth 90 target is inexorably linked with the first, second, and

third 90 targets, as an improved quality of life perspective can encourage more to test for HIV, then start and maintain treatment, as necessary. This fourth 90 target can only be achieved through active engagement of patients as partners in treatment, to tailor care that addresses specific needs [1, 2]. Good two-way patient-HCP communication encourages joint decision making that may empower PLHIV to own their care, and perhaps, overcome emotional and psychosocial barriers of living with HIV and taking treatment.

Although not all patient care needs revolve around treatment, many PLHIV still face numerous treatment needs and challenges, including emotional, physical, and psychosocial [4–8]. There is currently no cure for HIV, and all recommended regimens for its management currently require daily dosing, which may pose adherence challenges [9, 10]. As treatment is lifelong, many PLHIV start their therapy soon after diagnosis and once they become undetectable continue this treatment without review for some time, however as their lives evolve when living with HIV, needs may change and newer treatments may emerge that could benefit them. More so, as PLHIV age and develop co-morbidities, new treatment-related challenges may arise, especially if they experience polypharmacy [11]. More discussions between patients and HCPs may be needed in such situations; a review of treatment decisions may also be necessary, even in the absence of treatment failure, to optimize care, reduce the risk of drug toxicities, and improve quality of life.

Besides the treatment related issues, overall care for PLHIV is evolving because of dramatic medical and technological progress [9]. Medical appointments are becoming less frequent [12], and as a result, self-care among patients is becoming increasingly important and the need for information sharing between PLHIV and their HCPs is critical now more than ever. The COVID-19 pandemic, coupled with other historical challenges, have increased interest in telehealth applications, defined as “the use of electronic information and telecommunications technologies to support long-distance clinical health care, patient and professional health-related education, public health and health administration” in both synchronous and asynchronous modes [13–17]. Telehealth is a broad term that encompasses both clinical (e.g., remote vital sign monitoring) and non-clinical services (e.g., education); the applications used vary widely, including wireless communication, store-and-forward imaging, portable electronic health records, videoconferencing, and streaming media [13]. This evolution of care may provide the opportunity to review patient-HCP communication as a whole and will offer PLHIV a different mode of communication with their HCP. However, regardless of the medium over which patient-provider interactions occur, encouraging PLHIV to ask questions, highlighting recent research, and providing

clear and accurate information on topics that impact the patients’ overall well-being can increase their health literacy and potentially health related outcomes.

Based on the Stages of Change model which posits that maintenance of a health behavior occurs through incremental stages [18], the achievement and maintenance of good quality of life among PLHIV may conceivably be related to intermediary positive cognitive and behavioral outcomes, but this is not well known. A better understanding of the relationship between enhanced patient-HCP engagement and various outcomes on the spectrum of health behavior change, from increased knowledge, to changes in attitudes, behaviors, and patient-reported health outcomes, can help foster better communication between HCPs and PLHIV. We assessed the extent of overall engagement between PLHIV and their HCPs in relation to HIV care and measured the association between HCP engagement and health-related outcomes among PLHIV in 25 countries.

## Methods

### Study Population/Sampling Approach

This was a cross-sectional study known as “Positive Perspectives” that was conducted during 2019 in 25 countries. Inclusion criteria were men and women aged  $\geq 18$  years who were diagnosed with HIV and on antiretroviral therapy (ART); a total of 2389 PLHIV aged 19–86 years participated. The study methodology has been previously reported [11]. Participants were recruited using targeted and snowball sampling approaches across multiple platforms and in collaboration with multiple HIV organizations; responses were collected over the web or in-person. Participating countries and the achieved sample sizes were: USA ( $n=400$ ), South Africa ( $n=179$ ), Russia ( $n=150$ ), United Kingdom ( $n=123$ ), Australia ( $n=120$ ), Canada ( $n=120$ ), France ( $n=120$ ), Germany ( $n=120$ ), Italy ( $n=120$ ), Spain ( $n=120$ ), Japan ( $n=75$ ), Mexico ( $n=63$ ), Portugal ( $n=60$ ), Brazil ( $n=58$ ), Switzerland ( $n=55$ ), Taiwan ( $n=55$ ), Netherlands ( $n=51$ ), Argentina ( $n=50$ ), Austria ( $n=50$ ), Chile ( $n=50$ ), China ( $n=50$ ), Ireland ( $n=50$ ), Belgium ( $n=50$ ), Poland ( $n=50$ ), and South Korea ( $n=50$ ).

### Ethics Approval

Ethical review was provided by the Pearl Institutional Review Board (no. 18–080622). In addition, specific approval for South Africa was obtained from the Sefako Makgatho Research Ethics Committee (no. SMUREC/M/223/2019).

## Measures

### PLHIV-Reported Indicators of HCP Communication

The following measures reported by PLHIV were used to assess communication with their HCPs, in each case, answers of “Agree” or “Strongly Agree” (vs. “Disagree”, “Strongly disagree”, or “Neither agree nor disagree”) were classified as an affirmative response: (1) “I am given enough information to be involved in making choices about my HIV treatment”; (2) “My provider seeks my views about treatment before prescribing an HIV medication”; (3) “My provider asks me if I have any concerns about the HIV medication I am currently taking”; (4) “My provider asks me frequently about any side effects I might be experiencing with my HIV treatment”; (5) “My provider tells me about new HIV treatment options that become available”; and (6) “My provider has told me about “undetectable = untransmittable” (U = U)”. Participants were also asked if they had ever wanted a different treatment from the medication they were taking and whether they ever communicated that with their HCP. Patient-HCP communication gaps were captured using the proportion of PLHIV not very comfortable with discussing a salient health issue with their HCP even though they perceived the issue as being important to them. Separate questions were asked to determine current treatment priorities (factors respondents would consider most important if they were starting treatment today), as well as their perceived comfort discussing with HCPs. Barriers to communicating with HCPs were further assessed among the entire population (perceived barriers) as well as among those who indicated that HIV medication limits their life yet did not discuss with their HCP within the past 12 months regarding those concerns (actual/experienced barriers). Individuals who reported concerns about the long-term impact of their ART were asked what they had done within the past 12 months to allay those concerns.

### Treatment Satisfaction and Perceived Unmet Needs in Received Treatment

The following measures were used to assess PLHIV’s knowledge, perceptions, and experiences in relation to their HIV care: (1) “I would like to be more involved when it comes to decisions about my HIV treatment” (“Agree” or “Strongly Agree”); (2) “I feel I understand enough about my HIV treatment” (“Agree” or “Strongly Agree”); (3) my “main HIV care provider meets [my] personal needs and takes into account the things that are most important to [me]” ( $\geq 4$  score on an ordinal scale from 1 to 5 with higher numbers indicating greater perception that their needs were met); (4) report of being overall “satisfied ... with current HIV medication” (“Satisfied” or “Very satisfied”); (5) perception

there was “room for improving the way my HIV is managed” (“Agree” or “Strongly Agree”), (6) perception there was “room for improvement with [my] current HIV medication” ( $\geq 4$  score on an ordinal scale from 1 to 5, with higher numbers indicating more perceived need for improvement); and (7) “My HIV medication prevents me from passing on HIV to others” (Supplemental Table 1).

### Measure of PLHIV-HCP Engagement in Care

To assess whether increasing intensity of patient-HCP engagement was associated with a corresponding change in the health outcomes of interest, we created a composite variable, partially adapted from the Observing Patient Involvement (OPTION) scale, a multi-item scale where each item is scored between 0 (the behavior is not observed) and 4 (the behavior is exhibited to a very high standard) [19]. We used eight different questions as shown in Supplemental Fig. 1. The scores across the eight items were summed, and divided into tertiles corresponding to low, moderate, and high patient-HCP engagement. This same modified scale was used throughout the analyses.

### Other Clinical Parameters and Demographic Characteristics

Clinical parameters included self-reported viral suppression, experience of ART side effects, number of times changed ART, co-morbidities, concomitant medications, and self-rated health status. Self-reported virologic control was defined as a response of “ ‘Undetectable’ or ‘Suppressed’ ” to the question “What is your most recent viral load?” Self-rated health as “Good”, or “Very good” was classified as optimal health.

Self-reported demographic characteristics included age ( $< 50$  vs.  $\geq 50$  years), gender (men, women, or other), sexual orientation (homosexual, heterosexual, other), region (Europe, Northern America, Latin America, Asia, Australia, and South Africa), domicile (metropolitan or nonmetropolitan), and employment status (employed or non-employed).

### Analyses

Descriptive analyses were performed to determine extent of overall patient-HCP engagement and identify the largest communication gaps. Chi-squared tests were used within bivariate analyses to examine associations between study outcomes and various independent variables.

Since the survey question on what participants would consider as important if they were starting HIV treatment today was asked only of treatment-experienced individuals, the denominator for assessing perceived current treatment priorities was persons who had been diagnosed with HIV prior to 2017 ( $n = 1841$ ). Perceived comfort discussing specific

health issues with HCPs was assessed only among those who rated the identified issues as important to them. Perceived barriers discussing salient health issues with HCPs were assessed among all participants ( $n = 2389$ ). Actual barriers experienced in the past in discussing with HCPs were analyzed only among those who indicated that HIV medication limits their life yet did not discuss those concerns with their HCP within the past 12 months ( $n = 203$ ).

Exploratory logistic regression analyses were performed to assess factors associated with the following two self-reported outcomes: (1) unmet desire to be involved in care, defined as a report by PLHIV that their HCP did not seek their views before prescribing new treatment despite their desire to be involved when it comes to decisions about their HIV treatment; and (2) unmet personal needs, defined as a report by PLHIV that their HCP did not “meet [their] personal needs and take into account the things that are most important to [them]”. Independent variables were included in the regression analyses if they were significant at the 10% alpha level within bivariate analyses; selected variables were age, gender, sexual orientation, education, geographic location, disease duration, employment, domicile, commute time to HCP, ART side effects, treatment-related confidentiality concerns (hiding medications), difficulty swallowing, any communication barrier with HCP, number of times changed ART, and past medication preferences. Multivariable logistic regression analyses were also performed to measure the relationship between the extent of patient-HCP engagement (low, moderate, high) and PLHIV’s self-reported ART-related knowledge (number of medicines in ART regimen), behavior (ART adherence), clinically oriented outcomes (virologic suppression) and surrogate markers for self-rated quality of life (overall well-being and treatment satisfaction). For each outcome, logistic regression analyses controlled for age, gender, sexual orientation, ethnicity, education, employment status, duration of disease, domicile, and region. All analyses were performed with R Version 3.6.2. Statistical significance was set at  $p < 0.05$ .

## Results

Of the 2389 participants, 46.8% were from Europe, 21.8% from Northern America (U.S., and Canada), and 31.4% from other international regions. Regarding non-HIV comorbidities, 58.4% had one or more non-HIV comorbidities. Overall, 65.1% (1556/2389) wanted more involvement when it comes to decisions about their HIV treatment, 62.6% (1495/2389) felt they were given enough information to be involved in making choices about their HIV treatment, and 59.1% (1413/2389) indicated that their HCP tells them about new HIV treatment options that become available. Furthermore, 62.8% (1500/2389) affirmed that their provider

seeks their views about treatment before prescribing an HIV medication, 71.5% (1709/2389) felt they understood enough about their HIV treatment, and 61.2% (1462/2389) perceived there was room for improvement in their HIV management (Table 1). Recently diagnosed individuals (during 2017–2019) reported the highest percentage of those interested in being involved when it comes to decisions about their HIV treatment (72.8% [399/548], 63.1% [576/913], and 62.6% [581/928], diagnosis year: 2017–2019, 2010–2016, and pre-2010 respectively) but reported less understanding of their treatment (66.8% [366/548], 68.6% [626/913], and 77.3% [717/928], respectively) as well as greater perceived room for improvement in their HIV management (67.0% [367/548], 63.2% [577/913], and 55.8% [518/928], respectively). However, prevalence for the later two indicators among those diagnosed during 2017–2019 differed significantly only when compared with those diagnosed pre-2010 (all  $p < 0.05$ ). A higher proportion of younger adults ( $< 50$  years, 67.3% [1138/1690]) were interested in being more involved when it comes to decisions about their HIV treatment than older adults (aged  $\geq 50$  years, 59.8% [418/699],  $p < 0.001$ ), yet, a significantly smaller proportion of younger adults felt they were given enough information to be involved in making choices about their HIV treatment (60.2% [1017/1690] vs. 68.4% [478/699],  $< 50$  vs  $\geq 50$  years respectively,  $p < 0.001$ ), or that their HCP sought their views before prescribing an HIV medication (60.7% [1025/1690] vs. 68.0% [475/699], respectively,  $p = 0.001$ ). Correspondingly, a larger proportion of younger adults reported that their HIV management could be improved than  $\geq 50$ -year-olds (63.1% [1066/1690] vs. 56.7% [396/699], respectively,  $p = 0.003$ ). A higher proportion of women than men wanted to be more involved when it comes to decisions about their HIV treatment (71.0% [494/696] vs. 61.7% [1002/1623],  $p < 0.001$ ).

Of all participants, 53.2% (1270/2389) had ever wanted a different HIV treatment than what they were currently receiving (Supplemental Fig. 2). Of these, 23.9% (304/1270) never discussed their preference with their HCP, 27.4% (348/1270) discussed but were never prescribed the HIV treatment, whereas 48.7% (618/1270) discussed with their HCP and were prescribed the HIV treatment. The reported reasons for not receiving a requested prescription among those who discussed with their HCP but were not prescribed ( $n = 348$ ) were: HCP felt the medicine was not suitable for them (53.7%, 187/348), the medication was not available for the HCP to prescribe (26.2%, 91/348), high cost (15.8%, 55/348), not covered by patient’s health insurance (9.2%, 32/348), or other reason (20.7%, 72/348). PLHIV engagement with HCPs to discuss their preference for a new HIV medication did not differ significantly between young men vs. young women but differed significantly between older men vs. older women (Supplemental Fig. 3). Among

**Table 1** Percentage of people living with HIV in 25 countries who reported various perceptions towards engagement in care with their healthcare provider (HCP), Positive Perspectives Survey in 25 countries, 2019 (N=2389)

| Characteristics          | N (%)        | HCP meets their personal needs and considers things important to them | HCP tells them about new treatment options that become available | HCP asks them about concerns with their medication | HCP frequently asks them about any ART side effect | Feel they understand enough about their HIV treatment | Feel informed enough to be involved in making choices about HIV treatment | Want to be more involved when it comes to decisions about HIV treatment | HCP seeks their views before prescribing an HIV medication | Feel there is room for improvement in their HIV management |
|--------------------------|--------------|---|--|--|--|---|---|---|--|--|
| Overall                  | 2389 (100.0) | 67.3  | 59.1   | 65.1   | 63.0   | 71.5  | 62.6  | 65.1  | 62.8   | 61.2   |
| Age, y                   |              |   |  |  |  |   |   |   |  |  |
| <50                      | 1690 (70.7)  | 65.3  | 57.6   | 65.3   | 63.3   | 69.0  | 60.2  | 67.3  | 60.7   | 63.1   |
| 50+                      | 699 (29.3)   | 72.1  | 62.9   | 64.8   | 62.2   | 77.7  | 68.4  | 59.8  | 68.0   | 56.7   |
| Gender                   |              |   |  |  |  |   |   |   |  |  |
| Men                      | 1623 (67.9)  | 68.9  | 59.3   | 65.6   | 63.0   | 72.2  | 63.3  | 61.7  | 63.8   | 59.0   |
| Women                    | 696 (29.1)   | 63.8  | 57.6   | 62.6   | 61.4   | 69.0  | 59.5  | 71.0  | 59.3   | 66.7   |
| Other                    | 70 (2.9)     | 64.3  | 70.0   | 80.0   | 78.6   | 82.9  | 77.1  | 85.7  | 74.3   | 58.6   |
| Housing status           |              |   |  |  |  |   |   |   |  |  |
| Own                      | 722 (30.2)   | 71.5  | 61.2   | 63.6   | 64.5   | 70.6  | 64.4  | 65.1  | 66.1   | 58.7   |
| Rent                     | 916 (38.3)   | 69.2  | 59.0   | 65.3   | 62.3   | 74.8  | 64.8  | 63.3  | 63.5   | 62.2   |
| Other                    | 751 (31.4)   | 60.9  | 57.4   | 66.4   | 62.3   | 68.4  | 58.1  | 67.4  | 58.7   | 62.3   |
| Domicile                 |              |   |  |  |  |   |   |   |  |  |
| Metropolitan             | 1335 (55.9)  | 70.6  | 59.0   | 66.1   | 64.9   | 74.2  | 64.4  | 65.8  | 65.5   | 61.1   |
| Non-metro-politan        | 1054 (44.1)  | 63.1  | 59.4   | 63.9   | 60.6   | 68.1  | 60.2  | 64.2  | 59.3   | 61.3   |
| Commute to HCP           |              |   |  |  |  |   |   |   |  |  |
| <30 min                  | 869 (36.4)   | 71.9  | 61.1   | 69.3   | 66.6   | 77.2  | 70.7  | 66.1  | 67.7   | 59.5   |
| 30–59 min                | 1027 (43.0)  | 66.4  | 61.6   | 65.7   | 63.9   | 69.8  | 61.1  | 65.3  | 63.8   | 61.7   |
| 60+ minutes/unknown      | 493 (20.6)   | 60.9  | 50.5   | 56.6   | 54.8   | 65.1  | 51.3  | 63.1  | 52.1   | 63.1   |
| Employment status        |              |   |  |  |  |   |   |   |  |  |
| Employed                 | 1653 (69.2)  | 70.1  | 59.8   | 65.9   | 64.7   | 71.9  | 63.9  | 65.2  | 63.8   | 63.8   |
| Non-employed             | 736 (30.8)   | 60.9  | 57.6   | 63.5   | 59.2   | 70.7  | 59.6  | 64.9  | 60.5   | 55.4   |
| Education                |              |   |  |  |  |   |   |   |  |  |
| ≤ High school            | 532 (22.3)   | 65.4  | 58.5   | 62.2   | 61.5   | 71.4  | 59.4  | 65.4  | 58.8   | 64.5   |
| > High school            | 1756 (73.5)  | 69.9  | 58.8   | 65.4   | 62.9   | 72.2  | 64.6  | 64.9  | 64.2   | 61.4   |
| Self-reported viral load |              |   |  |  |  |   |   |   |  |  |
| Not suppressed           | 619 (25.9)   | 64.3  | 62.2   | 65.9   | 66.1   | 63.7  | 63.5  | 72.1  | 64.6   | 67.0   |
| Suppressed               | 1770 (74.1)  | 68.3  | 58.1   | 64.9   | 61.9   | 74.3  | 62.3  | 62.7  | 62.1   | 59.2   |

**Table 1** (continued)

| Characteristics           | N (%)      | HCP meets their personal needs and considers things important to them | HCP tells them about new treatment options that become available | HCP asks them about concerns with their medication | HCP frequently asks them about any ART side effect | Feel they understand enough about their HIV treatment | Feel informed enough to be involved in making choices about HIV treatment | Want to be more involved when it comes to decisions about HIV treatment | HCP seeks their views before prescribing an HIV medication | Feel there is room for improvement in their HIV management |
|---------------------------|------------|---|--|--|--|---|---|---|--|--|
| <b>HIV diagnosis year</b> |            |   |  |  |  |   |   |   |  |  |
| 2017–2019                 | 548 (22.9) | 64.1  | 57.1   | 67.3   | 69.5   | 66.8  | 61.5  | 72.8  | 64.8   | 67.0   |
| 2010–2016                 | 913 (38.2) | 66.5  | 60.5   | 65.7   | 62.7   | 68.6  | 60.2  | 63.1  | 62.1   | 63.2   |
| Pre-2010                  | 928 (38.8) | 69.9  | 59.1   | 63.3   | 59.5   | 77.3  | 65.5  | 62.6  | 62.3   | 55.8   |

older adults who had ever wanted a different HIV treatment than what they were currently on, 14.6% (31/213) of men vs. 29.9% (35/117) of women reported *never* asking their provider; 41.3% (88/213) of men vs. 38.5% (45/117) of women reported *ever* asking their provider but *never* received the medication, while 44.1% (94/213) of men vs. 31.6% (37/117) of women *received* the medication on asking ( $p < 0.001$ ). Among older adults who were never prescribed the requested HIV medication after discussing with their HCP, the only barrier that differed significantly between the genders was cost (women = 28.9% [13/45] vs. men = 5.7% [5/88],  $p = 0.001$ ).

**Gaps in Patient-HCP Communication**

The top issues rated as being current treatment priorities among the treatment-experienced diagnosed prior to 2017 included concerns regarding side effects of ART (67.0%, 1234/1841), long-term impacts of ART (60.5%, 1114/1841), and transmitting HIV to partner (60.1%, 1106/1841) (Supplemental Fig. 4). Among those who rated these issues as important, about a third indicated they were uncomfortable discussing them with their HCP. For example, 32.4% (400/1234) of those concerned about side effects of ART, 38.2% (426/1114) of those concerned about long-term impacts of ART, and 33.2% (367/1106) of those concerned about transmitting HIV to a partner, were not comfortable discussing with their HCP about these salient issues (Supplemental Fig. 4). Of all participants, 28.9% (691/2389) indicated that their HIV medication limits their lives; of these, 63.7% (440/691) had spoken to their HCP about it. Among those who indicated that their HIV medication limits their life yet did not speak to a HCP ( $n = 203$ ), the top three communication barriers identified were: despair that nothing much could be done (49.3%, 100/203), HCP never brought the issue up or asked them (37.9%, 77/203), and the fear of being labelled a “difficult patient” (30.5%, 62/203) (Supplemental Fig. 5). Among all participants, the most prevalent perceived barriers to communicating with HCPs included the fear of being labelled a “difficult patient” (26.7%, 638/2389), the perception that the HCP knows best (22.6%, 540/2389), and despair that nothing much could be done to help (21.3%, 508/2389) (Supplemental Fig. 5).

Of those who wanted to be more involved when it comes to decisions about their HIV treatment, only 63.8% (992/1556) reported that their views were sought by their HCP before prescribing an HIV medication (Table 2). Within the total population, factors associated with an unmet desire to be involved in HIV care included being nonemployed vs. employed (AOR = 1.37, 95% CI, 1.09–1.74), reporting a communication barrier with their primary HCP vs. no barrier (AOR = 2.16, 95% CI, 1.66–2.81), and residing in Europe (AOR = 1.50, 95% CI, 1.12–2.03),

**Table 2** Comparison of people living with HIV in 25 countries with or without certain unmet needs in their communication with healthcare providers, among all participants (N = 2389)

| Exposure categories (N) and outcomes  | Prevalence, % | $\chi^2$ statistic | P-value |
|---|---------------|--------------------|---------|
| <i>Groups compared: With or without reported desire to be involved in treatment choices</i>   |               |                    |         |
| Outcome assessed: HCP seeks my views about treatment before prescribing an HIV medication   |               | 1.78               | 0.182   |
| Among those with less desire to be involved (833)   | 61.0          |                    |         |
| Among those with more desire to be involved (1556)  | 63.8          |                    |         |
| Outcome assessed: HCP tells me about new HIV treatment options that become available  |               | 8.66               | <0.001  |
| Among those with less desire to be involved (833)   | 55.1          |                    |         |
| Among those with more desire to be involved (1556)  | 61.3          |                    |         |
| Outcome assessed: I feel I understand enough about my HIV treatment   |               | 20.77              | <0.001  |
| Among those with less desire to be involved (833)   | 65.8          |                    |         |
| Among those with more desire to be involved (1556)  | 74.6          |                    |         |
| Outcome assessed: I am given enough information to be involved in making choices about my HIV treatment   |               | 1.19               | 0.276   |
| Among those with less desire to be involved (833)   | 61.1          |                    |         |
| Among those with more desire to be involved (1556)  | 63.4          |                    |         |
| <i>Groups compared: With or without report of side effects from ART</i>   |               |                    |         |
| Outcome assessed: HCP asks me frequently about any side effects I might be experiencing with my HIV treatment                                   |               | 3.16               | 0.075   |
| Among those reporting no side effects from current ART (1348)   | 64.5          |                    |         |
| Among those reporting side effects from current ART (1041)  | 61.0          |                    |         |
| Outcome assessed: HCP asks me if I have any concerns about the HIV medication I am currently taking   |               | 0.48               | <0.001  |
| Among those reporting no side effects from current ART (1348)   | 64.5          |                    |         |
| Among those reporting side effects from current ART (1041)  | 65.9          |                    |         |
| Outcome assessed: Comfortable discussing concerns about side effects of my HIV medication   |               | 11.14              | 0.001   |
| Among those reporting no side effects from current ART (1348)   | 63.5          |                    |         |
| Among those reporting side effects from current ART (1041)  | 56.8          |                    |         |
| <i>Groups compared: With or without perception that HIV limits their daily life</i>   |               |                    |         |
| Outcome assessed: Comfortable discussing concerns about the impact HIV is having on my life generally   |               | 34.90              | <0.001  |
| Among those not perceiving that HIV has a negative impact on life (1448)  | 61.3          |                    |         |
| Among those with perception that HIV has a negative impact on life (941)  | 49.0          |                    |         |
| <i>Groups compared: With or without reported privacy concerns (hiding/disguising HIV pills)</i>   |               |                    |         |
| Outcome assessed: Comfortable discussing concerns about privacy and not disclosing my HIV status  |               | 50.88              | <0.001  |
| Among those who never disguised/hid HIV pills (1006)  | 60.5          |                    |         |
| Among those who ever disguised/hid HIV pills (1383)   | 45.8          |                    |         |
| <i>Groups compared: With or without report of suboptimal adherence to ART</i>   |               |                    |         |
| Outcome assessed: Comfortable discussing concerns about skipping/missing medication or forgetting to take my pill(s) each day                   |               | 58.80              | <0.001  |
| Among those reporting optimal adherence (1814)  | 60.6          |                    |         |
| Among those reporting suboptimal adherence (575)  | 42.4          |                    |         |
| <i>Groups compared: With or without perceived stress from daily ART intake</i>  |               |                    |         |
| Outcome assessed: Comfortable discussing concerns about my emotional well-being   |               | 51.73              | <0.001  |
| Among those not perceiving stress or anxiety from daily dosing schedule (1594)  | 58.7          |                    |         |
| Among those perceiving stress or anxiety from daily dosing schedule (795)   | 43.1          |                    |         |
| <i>Groups compared: With or without report of any non-HIV comorbidity</i>   |               |                    |         |
| Outcome assessed: Comfortable discussing concerns about long-term side effects of my HIV medication (e.g., problems with bones, kidneys, liver) |               | 27.61              | <0.001  |
| Among those not reporting any comorbidity (993)   | 52.4          |                    |         |
| Among those reporting $\geq 1$ comorbidity (1396)   | 63.1          |                    |         |

Latin America (AOR = 2.36, 95% CI, 1.60–3.49), or South Africa (AOR = 3.91, 95% CI, 2.50–6.11) compared to Northern America (Table 3). Compared to PLHIV without

medication challenges, those with certain constraints also reported higher odds of reporting an unmet desire to be involved in HIV care, including those hiding/disguising

**Table 3** Adjusted odds ratios for factors associated with unmet desire to be involved in care as well as perception of unmet personal needs among people living with HIV in 25 countries (N = 2389)

| Characteristic  | Categories  | N    | Unmet desire to be involved in HIV care <sup>a</sup> |         | Unmet personal needs in relation to treatment <sup>b</sup> |         |
|---|---|------|--|---------|--|---------|
|   |   |      | AOR (95% CI)   | P-value | AOR (95% CI)   | P-value |
| Age, years  | < 50 (referent)                                       | 1690 |  |         |  |         |
|   | 50+   | 699  | 0.67 (0.52–0.88)                                     | 0.003   | 0.87 (0.68–1.11)   | 0.253   |
| Gender/sexual orientation   | Men who have sex with men (referent)                  | 1018 |  |         |  |         |
|   | Men who have sex with women                           | 479  | 0.59 (0.43–0.80)                                     | 0.001   | 1.01 (0.76–1.33)   | 0.967   |
|   | Women who have sex with men                           | 481  | 0.91 (0.69–1.20)                                     | 0.511   | 1.16 (0.89–1.52)   | 0.268   |
|   | Women who have sex with women                         | 62   | 0.59 (0.28–1.22)                                     | 0.153   | 0.60 (0.31–1.16)   | 0.131   |
|   | Other/Unknown/Missing                                 | 349  | 0.69 (0.50–0.96)                                     | 0.027   | 1.05 (0.78–1.41)   | 0.761   |
| Education   | ≤ High school (referent)                              | 532  |  |         |  |         |
|   | > High school   | 1756 | 0.90 (0.70–1.15)                                     | 0.393   | 0.84 (0.66–1.06)   | 0.132   |
|   | Prefer not to answer                                  | 101  | 0.68 (0.38–1.19)                                     | 0.175   | 2.31 (1.37–3.92)   | 0.002   |
| Geographic region <sup>c</sup>                                    | Northern America (referent)                           | 520  |  |         |  |         |
|   | Europe  | 1119 | 1.50 (1.12–2.03)                                     | 0.007   | 1.67 (1.28–2.19)   | < 0.001 |
|   | Latin America   | 221  | 2.36 (1.60–3.49)                                     | < 0.001 | 0.97 (0.65–1.43)   | 0.868   |
|   | Asia  | 230  | 0.96 (0.63–1.46)                                     | 0.859   | 1.79 (1.26–2.54)   | 0.001   |
|   | Australia   | 120  | 0.91 (0.49–1.70)                                     | 0.772   | 0.77 (0.41–1.46)   | 0.427   |
|   | South Africa  | 179  | 3.91 (2.50–6.11)                                     | < 0.001 | 1.74 (1.12–2.70)   | 0.014   |
| Year of HIV diagnosis   | 2017 to 2019 (referent)                               | 548  |  |         |  |         |
|   | 2010 to 2016  | 913  | 1.03 (0.78–1.36)                                     | 0.823   | 0.94 (0.73–1.20)   | 0.610   |
|   | Pre-2010  | 928  | 1.59 (1.16–2.17)                                     | 0.004   | 1.08 (0.81–1.44)   | 0.619   |
| Employment status   | Employed (referent)                                   | 1653 |  |         |  |         |
|   | Nonemployed   | 736  | 1.37 (1.09–1.74)                                     | 0.008   | 1.44 (1.15–1.80)   | 0.001   |
| Domicile  | Metropolitan (referent)                               | 1335 |  |         |  |         |
|   | Non-metropolitan                                      | 1054 | 0.83 (0.67–1.03)                                     | 0.099   | 1.22 (1.00–1.49)   | 0.049   |
| Commute time to HCP   | < 30 min (referent)                                   | 869  |  |         |  |         |
|   | 30–59 min   | 1027 | 1.10 (0.87–1.40)                                     | 0.411   | 1.06 (0.85–1.32)   | 0.627   |
|   | 60+ minutes/unspecified                               | 493  | 1.50 (1.13–1.98)                                     | 0.005   | 1.07 (0.82–1.40)   | 0.619   |
| Experience of ART side effects                                    | Not reported (referent)                               | 1348 |  |         |  |         |
|   | Reported  | 1041 | 1.14 (0.93–1.40)                                     | 0.214   | 1.15 (0.95–1.39)   | 0.161   |
| Hiding/disguising HIV pills in past 6 months                      | Not reported (referent)                               | 1006 |  |         |  |         |
|   | Reported  | 1383 | 1.60 (1.28–2.01)                                     | < 0.001 | 1.50 (1.21–1.85)   | < 0.001 |
| Difficulty swallowing pills                                       | Not reported (referent)                               | 1599 |  |         |  |         |
|   | Reported  | 790  | 1.29 (1.03–1.63)                                     | 0.026   | 1.70 (1.38–2.09)   | < 0.001 |
| Perceived barriers to discussing salient concerns with HCP        | Not reported (referent)                               | 717  |  |         |  |         |
|   | Reported  | 1672 | 2.16 (1.66–2.81)                                     | < 0.001 | 3.90 (3.00–5.08)   | < 0.001 |
| Number of times changed ART                                       | Never (referent)                                      | 699  |  |         |  |         |
|   | 1 time only   | 626  | 1.17 (0.88–1.56)                                     | 0.281   | 0.87 (0.67–1.14)   | 0.307   |
|   | ≥ 2 times   | 1064 | 1.07 (0.81–1.43)                                     | 0.616   | 0.90 (0.70–1.17)   | 0.434   |
| Ever wanted an HIV treatment different from what they were taking | No (referent)   | 1119 |  |         |  |         |
|   | Yes, but never discussed with HCP                     | 304  | 1.89 (1.40–2.56)                                     | < 0.001 | 1.48 (1.10–1.98)   | 0.009   |
|   | Yes, but was not prescribed after discussing with HCP | 348  | 1.86 (1.39–2.48)                                     | < 0.001 | 1.56 (1.18–2.07)   | 0.002   |
|   | Yes, and was prescribed after discussing with HCP     | 618  | 0.91 (0.68–1.23)                                     | 0.553   | 0.75 (0.58–0.99)   | 0.041   |

Logistic regression analyses controlled for all factors listed in table

ART antiretroviral therapy; CI Confidence Interval; HCP Healthcare professional

<sup>a</sup>Persons who agreed or strongly agreed that they “would like to be more involved when it comes to decisions about [their] HIV treatment”, yet did not agree/strongly agree with the statement “My provider seeks my views about treatment before prescribing an HIV medication”

<sup>b</sup>A perception of unmet personal needs was defined as failure to provide a strong affirmative response to the following question: “When it comes to the management of your HIV treatment, do you feel your main HIV care provider meets your personal needs and takes into account the things that are most important to you?” Those with scores of 1–3 on a scale from 1 (Does NOT meet my personal needs at all) to 5 (FULLY meets my personal needs) to the question above were classified as having an unmet personal need



**Table 3** (continued)

<sup>c</sup>Countries by region were: Northern America (U.S. and Canada); Europe (Austria, Belgium, France, Germany, Italy, the Netherlands, Poland, Portugal, Ireland, Russia, Spain, Switzerland, and the UK); Latin America (Argentina, Brazil, Chile, and Mexico), Asia (China, Japan, South Korea, and Taiwan)

their HIV medication (AOR = 1.60, 95% CI, 1.28–2.01), and those with difficulty swallowing (AOR = 1.29, 95% CI, 1.03–1.63). Odds of unmet desire to be involved in HIV care were higher among those diagnosed pre-2010 compared to those recently diagnosed during 2017–2019 (AOR = 1.59, 95% CI, 1.16–2.17). Conversely, odds of an unmet desire to be involved in HIV care were lower among older adults aged  $\geq 50$  years than those  $< 50$  years (AOR = 0.67, 95% CI, 0.52–0.88).

PLHIV commuting for  $\geq 1$  h to visit their HCP had higher odds of reporting unmet desire to be involved in HIV care than those with shorter commutes (AOR = 1.50, 95% CI, 1.13–1.98); perception that HCP did not meet their personal needs however did not differ by commute time. Compared to those who never wanted a different medication than what they were taking currently, odds of unmet desire to be involved in HIV care were higher among those who ever wanted a different medication but never discussed with their HCP (AOR = 1.89, 95% CI, 1.40–2.56), and those who wanted the medication, but were not prescribed after discussing with their HCP (AOR = 1.86, 95% CI, 1.39–2.48). Both of these groups that did not receive the medication regardless of discussion with HCP, also reported higher odds of perceiving that their personal needs were not met (AOR = 1.48 and 1.56 respectively, without and with HCP discussion respectively, all  $p < 0.05$ ). On the other hand, those prescribed the medication after discussing with their HCP had lower odds of reporting unmet personal needs compared to those who never wanted a different medication (AOR = 0.75, 95% CI, 0.58–0.99). Odds of unmet personal needs were higher among those residing in Europe (AOR = 1.67, 95% CI, 1.28–2.19), Asia (AOR = 1.79, 95% CI, 1.26–2.54), and South Africa (AOR = 1.74, 95% CI, 1.12–2.70) vs. Northern America; among those nonemployed than employed (AOR = 1.44, 95% CI, 1.15–1.80); hiding than not hiding HIV pills (AOR = 1.50, 95% CI, 1.21–1.85); reporting vs. not reporting difficulty swallowing (AOR = 1.70, 95% CI, 1.38–2.09); and those with vs. without a reported barrier to discussing salient issues with their HCP (AOR = 3.90, 95% CI, 3.00–5.08).

Of those with concerns about the long-term impact of their ART ( $n = 1808$ ), 76.7% (1387/1808) engaged in any health information seeking behavior within the past 12 months, including discussing with, or getting information from their HCP (53.4, 966/1808), accessing information from articles, forums, or research (48.6%, 878/1808), and discussing with HIV patient support groups/organizations (33.5%, 605/1808).

Within the total population, perceived comfort discussing salient issues with HCPs was, generally, significantly lower among PLHIV with than without the specified challenges listed below: discussing side effects (those experiencing side effects = 56.8% [591/1041] vs. without side effects = 63.5% [856/1348],  $p = 0.001$ ); discussing privacy concerns (those hiding medications = 45.8% [633/1383] vs. not hiding medications = 60.5% [609/1006],  $p < 0.001$ ); discussing adherence challenges (those with suboptimal adherence = 42.4% [244/575] vs. optimal adherence = 60.6% [1100/1814],  $p = 0.001$ ); and discussing impact of HIV on their life (49.0% [461/941] vs. 61.3% [887/1448] among those with vs. without a report that HIV negatively impacts their life, respectively,  $p < 0.001$ ). PLHIV with a non-HIV comorbidity were however more likely to be comfortable than those with no comorbidity in discussing concerns about long-term side effects of their HIV medication (63.1% [881/1396] vs. 52.4% [520/993],  $p < 0.001$ ) (Table 2).

### Associations Between Patient Engagement and Health Outcomes

As shown in Supplemental Fig. 6, all indicators of HCP communication analyzed revealed that good quality HCP communication with PLHIV on specific issues was associated with PLHIV reporting treatment satisfaction, enough understanding of their treatment, and perceiving their treatment needs as met. For example, PLHIV who reported that their HCP provided enough information for them to be involved in making treatment choices had 2.81 higher odds of reporting treatment satisfaction, 4.48 higher odds of perceiving their needs as being met, and 5.92 higher odds of reporting they understood enough about their treatment (all  $p < 0.05$ ). Some specificity was observed in the relationship between certain aspects of HCP communication and PLHIV's knowledge, attitudes, or behaviors (Supplemental Fig. 6). For example, the factor most strongly associated with the perception by PLHIV that they understood enough about their treatment was a report that their HCP provided them enough information to be involved in making choices regarding their treatment (AOR = 5.92); the factor most strongly associated with the perception by PLHIV that their personal needs were met was a report that their HCP frequently asked them about any side effects from their HIV medication (AOR = 4.64); the factor most strongly associated with awareness among PLHIV that HIV medications prevent disease transmission was a report that their HCPs told them of "Undetectable equals Untransmittable (U = U)"

(AOR = 2.40) (all  $p < 0.05$ ). The only reported HCP behavior that was associated with a desire to be more involved when it comes to decisions about HIV treatment, was HCP's discussing of new treatment options with PLHIV (AOR = 1.35,  $p < 0.05$ ).

A strong gradient was seen in the relationship between patient-HCP engagement and indicators of PLHIV knowledge, treatment adherence, self-rated health, and treatment satisfaction (Supplemental Fig. 7); those with less engagement with their HCPs reported greater likelihood of negative outcomes. For example, odds of treatment dissatisfaction were 2.85 (95% CI, 2.19–3.71) and 7.94 (95% CI, 6.10–10.33) higher among those with moderate and low engagement, respectively, compared with those with high engagement with their HCP. Odds of suboptimal overall health were 1.91 (95% CI, 1.55–2.35) and 2.83 (95% CI, 2.28–3.52) among those with moderate and low engagement, respectively, compared with high engagement. Consistent findings were seen for self-rated suboptimal mental (AOR = 2.43 and 3.61, moderate and low engagement respectively) and suboptimal physical health (AOR = 1.77 and 2.82, respectively, all  $p < 0.05$ ). Similar results were also seen for outcomes that were cognitive (e.g., lack of awareness about number of medicines in their ART, AOR = 1.77 and 2.24 respectively) or behavioral (e.g., suboptimal adherence, AOR = 2.30 and 2.10, respectively, all  $p < 0.05$ ).

## Discussion

Increasing patients' engagement in decision making was significantly associated with better indicators of quality of life, a finding that might be mediated by increased PLHIV self-care, greater health seeking behaviors, retention in care, and higher self-esteem. Different aspects of HCP communication were associated with varying PLHIV responses; for example, providing information to patients was most strongly associated with increased knowledge among PLHIV regarding HIV, but not with a desire to be more involved when it comes to decisions about HIV treatment; however, actively discussing new treatment options with PLHIV was associated with the desire to be more involved when it comes to decisions about HIV treatment. With the cross-sectional design however, the role of reverse causation cannot be ruled out entirely; PLHIV with better health outcomes that are proactively engaging may have better outcomes from their discussions with their HCPs, who in turn may have more substantive conversations with them. Regardless of who initiates the discussion, though, good quality patient-HCP communication can benefit patients greatly by helping to identify and address treatment-related issues before, during, and after they arise.

Distance from HCP, while not associated with perception that HCP did not meet their personal needs, was strongly associated with unmet desire to be involved in HIV care. PLHIV who commuted for  $\geq 1$  h to visit their HCP had 50% higher odds of reporting an unmet desire to be involved in their HIV care, compared to those with shorter commute times of less than 30 min. Patients who travel long distances to visit their HCP may face many barriers and practical hardships, including stress, transportation challenges, social isolation, and time constraints, all of which may impact the extent to which they are willing, able, or available to be involved in their care [20–22]. Telehealth has potential to help patients with such distance barriers in ensuring continuity of care delivery. By providing an opportunity where routine primary care, including non-invasive, and non-emergency issues are addressed remotely, telehealth could engender longer, richer, fuller, and more patient-focused discussions during the occasional in-person visit. Telehealth also has potential to accelerate progress towards the UNAIDS 90-90-90 targets. For example, hotlines operated by midlevel providers (e.g., nurse practitioners) could be used to screen and refer individuals with high-risk behaviors for HIV transmission (e.g., people with injection drug use behavior), or to answer specific questions PLHIV may have about their condition or treatment. By expanding medication access, telepharmacy could further be pivotal in reaching the second 90 target of getting diagnosed PLHIV on treatment [23]. Constant follow-up and tracking of patients through secure messages and video visits could help identify and address systematic barriers to virologic control. The success of telehealth, especially in low- and middle-income countries, may be contingent on increased public education and awareness, as well as incentives that promote penetration and adoption. For example, phone calls to designated hotlines could be subsidized or entirely toll-free to encourage usage.

For the top three issues deemed as current priorities to PLHIV (minimizing ART side effects, reducing long-term impacts of ART, and preventing HIV transmission to a partner), about a third of affected PLHIV reported they were uncomfortable discussing these salient issues with their HCPs. By proactively bringing up some of these topics of conversation, HCPs can encourage patients to voice their concerns, thus building on the HCP-patient relationship and showing willingness to listen to topics of future conversations that may cause discomfort. In line with the proposed fourth 90 which focuses on good quality of life [1], patients' priorities and emotional well-being should also be considered, in addition to medical reasons, when making joint decisions about changes in care such as new treatment regimen. Achieving viral suppression should not be the sole focus for care, rather, the end goal should be to promote a sustainable culture of health given there are multifaceted issues that can affect clinical outcomes.

Markers of treatment success must go beyond virological control if care is to be holistic and patient centered [1].

The capacity and ability of PLHIV to access quality, evidence-based, information; utilize available health resources; and make informed decisions as part of self-care, can contribute to the successful management of their disease [24]. Even though 3 in 4 PLHIV (76.7%) who were concerned about the long-term impact of their HIV medication engaged in some health information seeking behavior in the past 12 months, our results still suggest limited health literacy among a sizeable proportion of PLHIV. Overall, 1 in 3 indicated they did not understand enough about their treatment, especially among those recently diagnosed. Furthermore, many PLHIV perceived their role as a passive one when engaging with their HCPs. For example, many who had a pressing health issue to discuss with their HCP were hesitant to broach the issue by themselves during consultations and would rather hope their HCPs raised the issue spontaneously. Indeed, one of the leading reasons (37.9%) reported for important discussions not taking place with HCPs among those who had concerns with their treatment was because the HCP never raised the issue. Several factors may account for this hesitancy among some PLHIV in initiating discussions regarding salient health issues, including social or cultural norms; a paternalistic model to care; perceived provider indifference, time constraints, and anticipated stigma which may influence the patient-HCP relationship [25–28]. A paternalistic approach to care runs contrary to the spirit of the fourth 90 target because it primarily emphasizes what the HCP can objectively see, measure, and address, while giving less weight to subjective factors which, nonetheless, influence quality of life and treatment adherence [25, 29, 30]. Actively learning more about HIV, including treatment options, recent advances, and available resources within the community, can be empowering for PLHIV and can help them have more meaningful and productive engagements with HCPs.

Achieving the fourth 90 target calls for active engagement by PLHIV as a key partner in their clinical care alongside HCPs [1]. Given that the majority of PLHIV may see their HIV care provider only a few times in a year, whether because of having an undetectable viral load [9], living far from the clinic or finding it challenging to maintain appointments, it is thus important to ensure high and good quality engagement while in attendance. High quality engagements during clinic visits can help build trust, address concerns, and improve health outcomes, as demonstrated in our study.

## Strengths and Limitations

The strengths of this study include the use of a standardized protocol to collect information from persons living with HIV in 25 countries. Nonetheless, this study has some limitations.

First, because of the cross-sectional design, only associations can be drawn because of the inability to establish temporality. Secondly, there may be selection bias, especially with the non-probabilistic sampling and the use of web-based questionnaires. For example, we may have oversampled individuals with computer literacy and web access by virtue of the online survey mode. Finally, the self-reported measures may be subject to misreporting, including self-reported virologic status. Most of our outcomes were, however, subjective measures, including beliefs, attitudes, and aspirations, which can only be measured through self-report.

## Conclusion

Good quality HCP-patient engagement was associated with better health-related outcomes. A substantial proportion of PLHIV did not report having good quality engagement and this was associated with significantly poorer health-related outcomes. Clinicians should actively seek ways to increase engagement with their patients, including joint decision making and ensuring patient priorities are also discussed in consultations to achieve better health outcomes as markers of treatment success go beyond virologic control. Improving quality of communication between patients and HCPs may accelerate progress in reaching the 4th 90 goal of improving health-related quality of life.

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**Author contributions** All authors contributed to the study design, interpretation of analyses, and substantial revisions of the draft manuscript. All authors read and approved the final manuscript.

## Compliance with Ethical Standards

**Conflicts of interest** The following authors are employees of ViiV Healthcare: CO, BY, MM, NV, and PD.

**Ethical Approval** This study was performed in line with the principles of the Declaration of Helsinki. Ethical approval for this observational study was waived by the Pearl Institutional Review Board (no. 18–080622). In addition, specific review and waiver for South Africa was done by the Sefako Makgatho Research Ethics Committee (no. SMUREC/M/223/2019).

**Informed Consent** Informed consent was obtained from all individual participants included in the study. Research participants also provided informed consent for publication of the data in the aggregate form.

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