

Added value of spiritual well-being and coping in the compliance of people living with HIV

Nicolas Roussiau^{1,*}, Ana ã Ameline¹, Constance Mambet-Dou ã¹, Jean Philippe Lanoix^{2,3}

¹Laboratoire de Psychologie des Pays de la Loire, Nantes Universit ã, 44312 Cedex 3 Nantes, France

²Service maladie infectieuses et tropicales, CHU Amiens-Picardie, 80054 Cedex 1 Amiens, France

³UR 4294 AGIR, Universit ãPicardie Jules Verne, 80025 Cedex 1 Amiens, France

* **Corresponding author:** Nicolas Roussiau, nicolas.roussiau@univ-nantes.fr

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Abstract: The overall objective of this research is to identify the processes responsible for the effect of spiritual well-being on therapeutic adherence in the case of HIV. Empirical research shows that spirituality helps individuals cope with difficult life events by giving them meaning and that it offers a particularly helpful course of action on a daily basis. It is also known that coping style in chronic diseases that require long-term treatment is associated with or not with therapeutic adherence. A total of 132 HIV-positive people were recruited as part of their systematic medical consultation related to the follow-up of HIV infection in the Infectious and Tropical Diseases department of the CHU of Amiens-Picardie, France. The questionnaire consisted of three scales: The spiritual well-being scale, a compliance scale, and a specific coping scale, the CHIP. The results show that the search for well-being, distraction, palive coping, and avoidance mediate the relationship between spiritual well-being and therapeutic observance. This research concludes with a set of recommendations for my health care professionals, based on the results obtained. Patients can be encouraged to have “confidence in the future” by offering them the opportunity to make “future plans” (as a form of distraction), by encouraging them to “dream about pleasant things” (a cognitive avoidance strategy), by inviting them to “pay attention to their bodily sensations and listen to their body” (palliative adaptation), or by helping them reflect on the meaning they attribute to their life, focusing on what seems important to them (spirituality). This relationship between spirituality (spiritual well-being) and the different dimensions of adaptation (measured using the CHIP scale) allows for the definition of relevant sub-dimensions aimed at improving compliance.

Keywords: spirituality; HIV/AIDS; analysis mediation; compliance; well-being; coping

1. Introduction

Antiretroviral therapy (ART) has transformed the lives of patients living with HIV (PLWH) in part by requiring compliance with therapeutic and medication treatment that was a cornerstone of an extended life expectancy. However, more and more powerful ART upended this belief, allowing now four-days-a-week ART to be sufficient to maintain viral load suppression in 96% of cases (de Truchis et al., 2018; Trickey et al., 2023). Although there is no consensus over the definition of compliance either in HIV or in other disciplines (Dessie et al., 2019; Hawley-Hague et al., 2016; Hearnshaw and Lindenmeyer, 2006), the MeSH[®] definition makes it clear that it is more than just taking pills. It refers to the extent to which a patient follows prescribed treatments, such as keeping appointments, adhering to schedules, and taking medication to achieve the desired therapeutic outcome. This involves active responsibility shared between the patient and healthcare providers. Over time, various

terms have been used to describe this complex set of self-care practices (e.g., adherence, compliance), but they are all influenced by the health and social systems in which patients are embedded. Therefore, even if a patient takes over 95% of their medication but is lost to follow-up and later develops a myocardial infarction or other preventable comorbidities, it clearly does not constitute a desired therapeutic outcome. Consequently, improving both compliance and retention in care is crucial. Additionally, it is essential to identify and understand the factors that promote compliance and quality of life.

The aim of our study is to examine the association between spiritual well-being and medication adherence and to identify the mediators of this association. Indeed, it is well-known that spirituality/religion helps individuals to cope with difficult events by giving them meaning (Doolittle et al., 2018; Levin and Schiller, 1987; Maton, 1989; Medved, 2017). It offers individuals a particularly helpful course of action on a daily basis. It is also known that particular coping styles are associated with compliance, especially in chronic diseases that require long-term treatment (Zeidner and Endler, 1996). Indeed, it's the patient's assessment of the chronic disease (controllability) that will guide the style of coping (problem- or emotion-focused strategy, or seeking social support) (Lazarus and Folkman, 1984). In the HIV field, spirituality also plays a role in coping, especially with respect to sourcing and sustaining meaning, value, and religious support. While several studies have been done in this population, results are not consistent, mostly because tools are not standardized (Doolittle et al., 2018; Medved, 2017). It is not clear that spirituality might play a role in a very secular environment like France. Indeed, most of the religion/spirituality studies in PLWH have been performed in countries where religion/spirituality is common and well accepted (e.g., USA, Africa, Brazil) (Doolittle et al., 2018; Medved, 2017; Pinho et al., 2017); however, little is known about its impact in secular countries. It has been shown that religion plays a negative role in France on the disclosure of HIV status to the sexual partner due to the associated stigma and fear of discrimination (Pr éau et al., 2008). Taking into consideration the spiritual and/or religious dimension of people is increasingly a question for the medical institution. In a study conducted in France among HIV-positive African migrants (Mambet-Doue and Roussiau, 2016), magico-religious beliefs (mystical-esoteric spirituality) negatively mediate religion and medication-taking. The authors also highlight the role of certain mediators (such as coping) in the indirect effects of religion/spirituality on therapeutic compliance among HIV-positive people and argue that the religious and spiritual dimension should not be neglected by the medical institution. Many recent studies have shown the positive benefits of religion and spirituality on mental and physical health (Almaraz et al., 2022; Borges et al., 2021; Garssen et al., 2020; Lima das Chagas et al., 2023). Numerous studies have demonstrated the significant benefits of religion and spirituality on mental health, health behaviors (such as exercise, diet, smoking, and risky sexual activity), and physical health. Religious and spiritual beliefs and practices are not merely cultural traditions rooted in personal faith; they are recognized as important sociological practices that can influence human behavior, particularly among vulnerable populations like the elderly (Coelho-Junior et al., 2022). Although the relationships between spirituality/religion and conformity are complex, approaching spirituality from the perspective of spiritual well-being is an innovative

approach to better understand medication use in the context of certain chronic diseases, such as AIDS (Božek et al., 2020; Howard et al., 2023; Ryff, 2021). In the health field, a better understanding of medication uses in the context of certain chronic diseases, such as AIDS, is needed. Indeed, having a spirituality does not automatically mean that it is positive. The relationships between spirituality, religion, and health are complex to analyze (Lucchetti et al., 2021; Mancini et al., 2023). Some spiritual and religious practices are negative for individuals (Jordan et al., 2021; Koenig et al., 2020; Pahlevan Sharif et al., 2021). Spiritual well-being clearly identifies a positive emotional link with one's belief.

However, no research has been conducted on the processes responsible for the links between spiritual well-being and therapeutic compliance in HIV/AIDS infection, which is the objective of this study. If coping is a mediator between spirituality and compliance, there are several ways to measure it. The specific coping scale (CHIP) developed by Endler et al. (1998) is interesting for two main reasons. 1) Firstly, this scale is used in the case of chronic illnesses, such as AIDS; 2) This scale analyzes the coping process in detail with six dimensions: emotional regulation, well-being seeking, distraction, information seeking, palliative coping, and avoidance (Endler et al., 1998; Montel and Bungener, 2010). According to these authors, emotional regulation is a complex process. It corresponds to positive emotions (interpreting illness as an opportunity, a clue to change one's life, or to reflect on what is essential in life) but also to negative emotions (anger, disappointment) provoked by illness. Well-being seeking was defined as patients' actions to feel better (e.g., being at ease, seeking calm...). Distraction was defined as actions that distract patients from their illness, such as inviting people over and making plans for the future. Information seeking was defined as actions such as Internet searches or phone calls that would reassure the patient. Palliative coping was defined as negative coping strategies such as anxiety, staying in bed, feeling vulnerable... And avoidance is defined as actions aimed at denying, minimizing, or avoiding facing the disease directly (for example, falling asleep, daydreaming about pleasant things...). Since compliance is a complex phenomenon, there must be many causes behind it.

Analyzing the relationship between spirituality, coping, and compliance can help us to better understand the reasons why some people have difficulty following their treatment.

2. Materials and methods

2.1. Hypotheses and variables

We pose the general hypothesis of an indirect effect of spiritual well-being (independent variable) on therapeutic compliance (dependent variable) through the different dimensions of coping that we measured (6 possible mediation variables).

Operational hypotheses of mediation.

- H1: We posit that emotional regulation mediates the relationship between spiritual well-being and compliance. Concretely, we expect an indirect effect of spiritual well-being on compliance via emotional regulation.

- H2: We posit that the pursuit of well-being mediates the relationship between spiritual well-being and compliance. Concretely, we expect an indirect effect of spiritual well-being on compliance via the well-being-seeking strategy.
- H3: We posit that distraction mediates the relationship between spiritual well-being and compliance. Concretely, we expect an indirect effect of spiritual well-being on compliance via distraction.
- H4: We posit that information seeking mediates the relationship between spiritual well-being and compliance. Concretely, we expect an indirect effect of spiritual well-being on compliance via the search for information.
- H5: We posit that palliative coping mediates the relationship between spiritual well-being and compliance. Concretely, we expect an indirect effect of spiritual well-being on compliance via palliative coping.
- H6: We posit that avoidance mediates the relationship between spiritual well-being and compliance. Concretely, we expect an indirect effect of spiritual well-being on compliance via avoidance.

2.2. Participants

One hundred and seventy-one HIV-positive people were recruited (see **Figure 1**) as part of their routine medical consultation for monitoring HIV infection in the Infectious and Tropical Diseases Department of the Amiens-Picardie University Hospital (France), but 39 (23%) of them were too incomplete. In fact, some people did not complete all the answers in the questionnaire, which poses a problem for the analysis. In the end, 132 patients were included in the analysis: 75 men (57%), 31 women (23%) (26 missing data), and the mean \pm SD age was 48.6 ± 12 years (extreme: 20–85). The majority of responders declared themselves believers ($n = 67$, 51%), and 48 declared being non-believers (36%) (17 missing data). The majority of responders declared being born in France ($n = 82$, 62%); 38 (29%) declared being born outside of France (12 missing data). Among the 67 believing people, 48 are Catholics, 5 Protestants, 4 Muslims, 2 Evangelicals, 1 Pentecostal, and 1 Adventist (2 people indicated that their religion was personal and 4 did not wish to reply). Finally, 82 people were born in France and 38 in a foreign country (e.g., Côte d'Ivoire, Democratic Republic of Congo, Nigeria, or the USA; 12 people did not answer this question).

Because of the nature of our questionnaires (paper form and completely anonymous), the need for ethics board approval was waived. Every patient was free not to answer the questionnaire or to do so partially or completely.

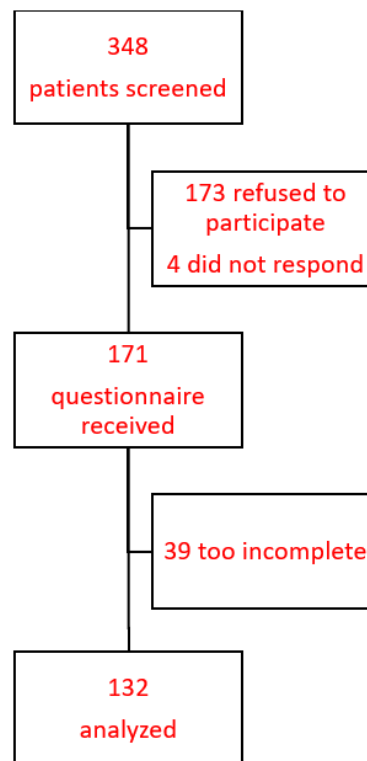


Figure 1. Patient eligibility flow chart.

2.3. Instruments

Patients were asked to fill out a totally anonymized questionnaire composed of 3 scales and socio-demographic data (gender, age, religion, country of origin).

The first scale was the French adaptation of the Spiritual Well-Being Scale (SWBS) by Paloutzian and Ellison (1982), translated and validated in French by Velasco and Rioux (2009). This 17-item scale assesses both the satisfaction resulting from a relationship with a power greater than oneself or with a god and the existential well-being, which refers to meaning and satisfaction in life in connection with others and the environment (Cronbach alpha (α) = 0.76).

The second scale was the French adaptation of The Coping with Health Injuries and Problems (CHIP) scale by Endler et al. (1998), translated and validated in French by Montel and Bungener (2010). This 24-item scale explores 6 dimensions of coping: emotional regulation, the search for well-being, distraction, the search for information, palliative coping, and avoidance (α = 0.65–0.83).

The last scale was the compliance scale from Tarquino et al. (2000). This 12-item scale assesses patients' general reaction to their disease, their treatment, and medical recommendations (α = 0.48). General well-being was defined as the feeling of being in good health and a general life satisfaction (Diener et al., 2009) that includes spiritual well-being.

2.4. Statistical analysis

In order to test these hypotheses, the statistical analyses were carried out using SPSS 22 software (IBM, Bois-Colombes, France), using model 4 of the PROCESS macros (Hayes, 2017). The advantage of the PROCESS procedure lies in the fact that

it gives the direct effect of the independent variable on the dependent variable and the indirect effect of the independent variable on the dependent variable via the mediating variable(s).

Descriptive analysis is expressed as mean and standard deviation (SD); normality was tested with the skewness and kurtosis tests. The final effect of mediation was expressed as indirect effect (IE) and standard error (SE).

3. Results

3.1. Descriptive analysis

Descriptive analyses show that participants have a relatively low level of spiritual well-being (3.02 ± 1.19). They favor well-being adaptation strategies (3.87 ± 1.11), avoidance (3.42 ± 1.14), information seeking (3.29 ± 1.27), or distraction (3.10 ± 1.06) over regulation or coping.

Finally, they report a high level of compliance (3.79 ± 0.86). All dimensions followed a normal distribution (except for well-being and compliance) (see **Table 1** for details).

Table 1. Statistical description of spiritual well-being scale, coping with health injuries and problems scale, and compliance scale.

	Mean	SD	Skewness	Kurtosis
Well-being	3.87	1.11	-2.50	6.47
Compliance	3.79	0.86	-3.47	12.78
Avoidance	3.42	1.16	-1.14	1.20
Information seeking	3.29	1.27	-0.88	0.43
Distraction	3.10	1.06	-0.93	1.53
Spiritual well-being	3.02	1.19	-0.90	1.33
Regulation	2.62	0.98	-0.29	0.62
Coping	2.32	0.95	-0.18	0.54

3.2. Regression analysis

Religious people have significantly higher spiritual well-being than non-religious people: 3.52 ± 1 vs. 2.57 ± 0.97 , respectively ($t(113) = 5.09, p < 0.001$). The effect size of the difference between these two groups ($d = 0.9$) corresponds to an important effect of religiousness. In addition, regression analysis indicates an association of religiosity with spiritual well-being ($p < 0.001$). Thus, the religiosity of the participants explains 19% of spiritual well-being.

3.3. Mediation analysis

Before carrying out mediation analyses, it is necessary to analyze the correlations between the different variables involved in these models. These analyses reveal that all the variables (independent, mediating and dependent) are significantly and positively related to each other (see **Table 2** for details).

Table 2. Pearson’s correlation of spiritual well-being scale, coping with health injuries and problems scale, and compliance scale.

	1	2	3	4	5	6	7	8
1. Spiritual well-being	-	0.237	0.427	0.241	0.201	0.333	0.379	0.304
2. Regulation	-	-	0.417	0.230	0.414	0.365	0.331	0.263
3. General well-being	-	-	-	0.542	0.597	0.438	0.708	0.589
4. Distraction	-	-	-	-	0.446	0.330	0.493	0.583
5. Information	-	-	-	-	-	0.272	0.556	0.503
6. Palliative coping	-	-	-	-	-	-	0.401	0.326
7. Compliance	-	-	-	-	-	-	-	0.505
8. Avoidance	-	-	-	-	-	-	-	-

All correlations are statistically significant.

Regression analyses indicate an association of spiritual well-being with emotional regulation ($p < 0.01$), with the search for well-being ($p < 0.001$), with distraction ($p < 0.01$), with seeking information ($p < 0.001$), with palliative coping ($p < 0.001$), as well as with avoidance ($p < 0.01$).

Spiritual well-being explains 18% of well-being, 11% of palliative coping, 9% of avoidance, 6% of emotional regulation, 6% of distraction, and 4% of information seeking. Finally, spiritual well-being explains 14% of compliance ($p < 0.001$).

Mediation analyses showed that the relationship between spiritual well-being and compliance was mediated neither by emotional regulation (IE = 0.04, SE = 0.03; 95% CI = [-0.00, 0.14]) nor by seeking information (IE = 0.07, SE = 0.05; 95% CI = [-0.00, 0.20]). Hypotheses H1 and H4 cannot be validated.

On the other hand, these same analyses reveal that the relationship between spiritual well-being and compliance is partially mediated by distraction (IE = 0.07, SE = 0.05; 95% CI = [0.00, 0.20]), palliative coping (IE = 0.07, SE = 0.04; 95% CI = [0.00, 0.19]), and avoidance (IE = 0.09, SE = 0.05; 95% CI = [0.01, 0.22]). Hypotheses H3, H5, and H6 are validated.

In addition, the relationship between spiritual well-being and compliance is fully mediated by the search for well-being (IE = 0.21, SE = 0.09; 95% CI = [0.06, 0.42]). In other words, spiritual well-being has a beneficial effect on compliance if and only if patients’ actions are to feel better. Hypothesis H2 is therefore validated (see **Figure 2**).

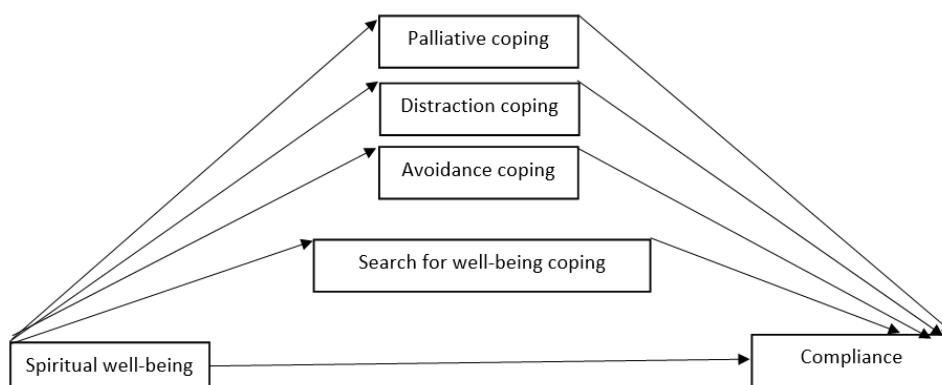


Figure 2. Mediation analysis summary.

4. Discussion

Our study highlighted that spiritual well-being has a significant, positive association with therapeutic adherence, mediated by general well-being. One important finding highlighted by our study is that therapeutic compliance is mediated by distraction, palliative coping, and avoidance, and these strategies could (and even should) be encouraged by healthcare workers to strengthen compliance.

For example, distraction refers to things like “I’m looking for someone else’s company” or “making plans for the future”; avoidance refers to things like “I imagine I’m healthy” or “I dream while I’m awake with pleasant things”; finally, the palliative refers to actions such as “I rest when I am tired”. These could be interventions that can be acted upon in a collaborative manner during education programs or consultations. The main point of this research is that compliance is most optimal when the strategies cited above have been associated with an initial high level of spiritual well-being. It would be helpful if health workers encouraged patients to work on their spiritual well-being in addition to the actions mentioned above. Patients can be encouraged to have “confidence in the future”, by making “plans for the future” (distraction), “dreaming about pleasant things” (cognitive avoidance strategy), “being attentive to body sensations, listening to one’s body” (palliative adaptation), or even trying to work on the meaning they give to their life, that is, what is important to them (spirituality). This association between spirituality (spiritual well-being) and the dimensions of adaptation (measured with the CHIP scale) specifies sub-dimensions useful for increasing compliance.

For example, the search for meaning is an essential dimension of spirituality and is found in many definitions (de Brito Sena, 2021; Kamitsis and Francis, 2013; Lima das Chagas, 2023; Muldoon and King, 1995). This meaning, whether or not linked to established belief systems, is an intimate dimension, and finding meaning in one’s life or illness leads to well-being. Several studies have demonstrated quite surprising physiological effects when people find meaning in their illness. HIV-positive men who lost a partner to AIDS had higher survival times—evaluated over a period of 4 to 9 years—when they had found meaning in the death of their partner (Bower et al., 1998). The immune status of these individuals had changed, including a less rapid decline in CD4 T-cell counts, which is a key immunological marker of HIV progression, independent of their initial health status, behaviors, and other factors that might have explained this change. Spirituality is also mentioned in the interviews (id., p. 981) as a factor (cognitive process) involved in managing the meaning of existence in the face of illness and death. Finding meaning in stressful events is therefore potentially linked to positive immunological and health outcomes. Working on the meaning people give to their illness can help them overcome certain problems linked to this illness. Logotherapy, developed by Frankl (1985), is a therapeutic practice (therapy on meaning) aimed at people confronted with existential questions. It offers different methods (Sarfati, 2024), which make it possible to re-establish the question of meaning and, in particular, the meaning of the illness through the processes of self-distancing and self-transcendence. The first step in the therapeutic process focuses on addressing the experience of suffering, whether from a psychological, somatic, or both perspectives. The second step seeks to overcome suffering by affirming a sense of

meaning. It emphasizes the spiritual dimension, which engages critical judgment, discernment, and the search for meaning through values. While the overall approach is rooted in phenomenology, subjective methods are adapted to explore questions about the meaning of life, as each individual defines the meaning they attribute to their life. There is no barrier to combining subjective analysis of suffering with the search for meaning and more quantitative, complementary approaches. Through logotherapy, the question of the meaning of the illness can be addressed in order to better manage it. This is a therapeutic possibility.

Distraction refers to a coping strategy that aims to divert attention from a stressor to other thoughts or activities unrelated to that stressor. It can be used in both adults and children, particularly in contexts such as medical procedures, where focusing on an external object or imagining a peaceful place helps manage pain and discomfort. Other forms of distraction include daydreaming or engaging in substitute activities to take one's mind off of concerns about persistent stressors, such as those associated with chronic illness. Coping strategies can be grouped in a variety of ways, and distraction is often considered an emotion-focused approach (Lazarus and Folkman, 1984) to reduce emotional distress related to a stressor. Finding a distraction helps ill people, when possible, to take a step back from a stressful situation by engaging in another activity. The relationship with nature has been the subject of studies for several years that show bio-psycho-social effects on the health of individuals (Li, 2019). Connection to nature (a dimension of spirituality) is, for example, associated with a significant increase in NK lymphocytes and other immune indicators (Li, 2010). This is another track that combines distraction and spirituality (spiritual well-being).

This promising orientation may also include the cognitive avoidance strategy, another strategy involved in the compliance process. Our research opens up avenues of reflection to associate, on the one hand, spirituality and spiritual well-being and, on the other, the sub-dimensions of coping assessed by the CHIP to stabilize the regular taking of medications.

5. Conclusion

Our study has several limits. First, the anonymous paper questionnaire yields necessarily missing data, which in our case decreased the robustness of our data but not the meaning of the findings. Second, it is surprising to see that a majority of patients refused to participate in the study (56% of the sample), citing a lack of interest or belief or that this belief is personal and intimate. We did not investigate the reasons for this lack of interest; was it because of a misunderstanding of spirituality? Was it cultural, as France is a very secular country? The term "spirituality" remains delicate to handle because it is the object of all kinds of projections (Hill et al., 2000). We used for our study a religious spiritual questionnaire. A problem that has been noted many times is the emotional dimension that some people have with this term. In our professional practice, we have been able to realize that questioning people about (or their) spirituality can lead to complex emotional responses to manage. One of the explanations for this "emotional barrier", that is to say the rejection of the word "spirituality", can come from its links with the strange and the paranormal (mystical-esoteric spirituality); in fact, the same terms: "Spirituality", "health", "psychology"

are used as much by health charlatans as by scientists. For most people, it is sometimes difficult to distinguish very different contents and postures behind identical words. For others, the rejection simply comes from the association of the term with the religious domain.

To avoid these different biases, we can also not use the word “spirituality” in which case we speak of “implicit spirituality”. The “implicit” dimension includes questionnaires that do not use any term related to religion, and the word spirituality is simply absent. We work from the dimensions of spirituality (transcendence, the feeling of connection, the question of meaning, etc.). For this purpose, there are several implicit spirituality scales (Abdel Halim et al., 2020; Ameline et al., 2019; Roussiau et al., 2023). These questionnaires are suitable for all forms of spirituality; to specify them, it is enough to add additional questions that will allow us to insert the answers in the religious domain or not. Specifically, the different dimensions of spirituality are presented through questions such as “I feel a connection with various forms of life,” “When I listen to certain music, I feel transported,” “I am awed by the beauty of certain natural places”. In research on the effects of non-religious spirituality in people with fibromyalgia (Ameline et al., 2019, p. 4), the questions proposed refer to spirituality without directly naming it: “All life is interconnected” or even, “Though deceased, people who were dear to me continue to influence my daily life through the images I have of them...” The implicit approach is a possibility in the French cultural context.

Much remains to be done to challenge prejudices and stereotypes regarding the role of spirituality and spiritual well-being in health. Although the journey is long, enhancing adherence by improving overall well-being and spiritual well-being in particular is a first step toward a deeper understanding of the human experience. The patient’s experience of the disease, along with the effects of the chronicity of the infection through spiritual well-being, can help them mobilize their cognitive, social, psychological, and emotional resources. Therefore, considering spiritual well-being in the management of HIV can be seen as a reasonable, effective, and feasible holistic approach.

Author contributions: Conceptualization, NR, AA and JPL; methodology, NR and CMD; validation, AA and CMD; formal analysis, NR, AA, CMD and JPL; investigation, JPL; resources, JPL; data curation, AA and CMD writing—original draft preparation, NR, AA and JPL; writing—review and editing, NR, AA and JPL; supervision, NR and JPL; project administration, NR and JPL. All authors have read and agreed to the published version of the manuscript.

Consent to participate: Informed consent was obtained from all individual participants included in the study.

Conflict of interest: The authors declare no conflict of interest.

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