ORIGINAL PAPER

Does Quality of Life and Sexual Quality of Life in HIV Patients Differ Between Non-treated HIV Controllers and Treated Patients in the French ANRS VESPA 2 National Survey?

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Abstract

People living with HIV who spontaneously control the virus without antiretroviral treatment are called HIV Controllers and their status places them at the limits of bio-clinical normality. The objective of this study was to investigate an unexplored field: HIV Controllers' quality of life (QOL). Using quantitative methods, we compared the QOL of untreated (by definition) HIV Controllers in the ANRS CO18 HIV Controller cohort study, with the QOL of treated patients in the French national survey ANRS VESPA 2. In particular, the physical, social, mental and sexual dimensions of QOL were examined. Results highlight that perceiving oneself to be ill or healthy is linked to stigma and to a lack of self-identification with a social group. Some components of the QOL were significantly impaired in HIV controllers. This study is the first to investigate this field.

Introduction

In the 1990s, physicians noticed that some patients infected by HIV for several years had a high and stable CD4 T cell count. These patients were called ''long-term non-progressors''. Research identified that they formed a heterogeneous group, as their viral loads were variable. In the long term, most progressed to AIDS [1]. In 2004, our collaborators identified rare HIV-infected patients whose HIV viral loads were repeatedly undetectable. These patients were named

''HIV controllers'' (HIC). They are defined on the basis of their virological status [2] as follows: a patient whose infection has been known for 10 years or more, who has never received antiretroviral therapy (except temporary treatment to prevent mother-to-child transmission) and for whom more than 90% of viral load measurements in plasma RNA are below 400 RNA/ml copies [2–4]. Although the presence of antibodies against HIV and the detection of HIV DNA in HIC confirm HIV infection, thereby technically making them PLWHIV, their undetectable viral load in the absence

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of any antiretroviral treatments places them in a specific category. Biological data analysis underlined the possibility that genetics played a role in this unusual occurrence [5]. HIC are rare, accounting for less than 1% of HIV-infected patients [2]. The discovery of HIC encouraged scientists to start investigating asymptomatic biological disorders.

Today, the World Health Organization (WHO) highlights the importance of cultural differences, which are factors that can influence the quality of life (QOL). Moreover, the WHO is aiming to develop a valid and universal QOL measure. It defines QOL as "an individual's perception, his/her place in the existence, in the context of the culture and value system in which s/he lives, in relation to his/her objectives, expectations, standards and concerns" [6]. In this context, QOL is a variable that depends on self-perception, determined by a complex set of factors, which concern not only patients' health but also their relationship with their community, family and caregivers [7].

Measuring QOL in terms of health is important as it helps understand the impact of a disease and its treatment on the different aspects of a patient's daily life. More specifically, it is essential to examine the effects of treatment on physical, psychological and social function, as well as on the subjective concept of well-being. Some treatment effects are not physiologically measurable but can be assessed by analyzing the patient's perception. QOL in HIV patients has been widely investigated, particularly since the advent of highly active antiretroviral therapy (HAART) (Jasmin [7], Liu et al. [8]; Lorenz et al. [9], Préau et al. [10]). These referenced studies showed that certain medical variables (i.e. biological markers, HIV-related medication use and clinical outcome indicators) and psychosocial factors (such as individual risk behaviors, the role played by disclosure and discrimination) can improve the QOL in patients, and that medical staff need to take these characteristics into account when providing care.

The HIV epidemic in France is currently characterized by a dynamic of stagnation, with approximately 6500 new disclosures per year. Some populations—men who have sex with men (MSM), migrants and sex workers—are especially affected by HIV. Combination prevention is the current model for its prevention, and incorporates all existing structural, biomedical and behavioral strategies [11].

In the context of HIV infection, the relationship between QOL and stigma has been well documented [12, 13]. Stigma is inherent to chronic diseases (Joachim and Acorn [14]) and especially to HIV/AIDS [15–19]. In fact, HIV/AIDS is often associated with promiscuous sex, drug abuse and social vulnerability. Acting on both the individual and societal dimensions, stigma also concerns the experience of rejection by medical staff, especially towards seropositive people infected through injecting drug use. That is why stigma and discrimination influence infected people's QOL. Other elements can

also affect QOL of PLWHIV. For example, treatment side effects [20] and their impact on a patient's body self-perception, can have different consequences for mental health which sometimes depend on gender [21]. Moreover, HIV-HCV coinfection can cause self-reported fatigue and depressive symptoms [22]. In France and in other cultural contexts, PLWHIV on HAART often declare that their sexual health has deteriorated [23], and that it is less satisfactory. This deterioration is often accompanied by desire disorders [24] and by depression [25].

People's QOL is also an important element in terms of the adoption of various types of behavior [26]. In the ANRS-VESPA survey (2003), it was shown that MSM who took sexual risks had a lower mental QOL. The particular situation of HIC is clearly a new context which we have very little information about, especially regarding the impact of QOL on HIC behavior.

As HIC are most often asymptomatic and considered to be in good health from an immuno-virological viewpoint, their QOL is rarely the subject for study. The scarce existing literature focuses on the clinical and virological perspective, with no references to HIC QOL. In a previous qualitative study based on the same data, we highlighted how beliefs, representations and behaviors of HIC are influenced by social discourse on seropositive people, something which has an impact on their daily life experience [27]. However, as we have seen in the previous paragraphs, it is essential that any investigation of people living with chronic diseases—whether asymptomatic or not—consider the impact on QOL and not simply examine roles, statuses and experience associated with representations.

Accordingly, the aim of this study was to compare the QOL of HIV patients on ARV treatment with those of HIC not on treatment (by definition). To do this, we compared treated patients from the ANRS-VESPA2 study with those from the ANRS CO18 HIV Controller and ANRS CO21 Codex cohort studies. In particular, our goal was to highlight the specific and hitherto unexplored condition of HIC. We supposed that this population's QOL might be quite heterogeneous and characterized by the incoherence between the "invisibility" of the physical condition and the negative impact that this invisibility could have on psychological and mental health. A greater understanding on HIC QOL could help providers follow up this very specific HIV population.

Methods

This study involved a comparison of QOL measured in the ANRS CO8 HIC cohort study with that measured in the ANRS VESPA2 cohort study. Both cohort studies were financed by the French National Agency for Research on AIDS and viral hepatitis (ANRS). ANRS CO8 HIC was

conducted between 2009 and 2012 using quantitative and qualitative methods. At each annual medical follow-up visit in hospitals, participants provided information on socio-demographic, socio-economic, socio-behavioral and psychosocial characteristics using a self-administered questionnaire. The cross-sectional ANRS VESPA2 survey was representative of all French HIV-positive individuals diagnosed at least 6 months before survey enrollment, followed up in 73 hospitals with HIV caseloads larger than 100 patients in 2011. These individuals are called "non-HIC" hereafter. In a face-to-face interview, the 3022 non-HIC from the ANRS VESPA2 survey provided information about their living conditions, including socio-demographic, economic, psychosocial and behavioral aspects. A self-administered questionnaire was also provided to assess QOL, and self-perception of both their health status and the quality of HIV care received. Medical information about patients' key HIV indicators, comorbidities, treatments and hospital-related characteristics, was provided by HIV care staff (see Dray-Spira et al. [28] for more details about the methodology of the VESPA2 study).

Both the ANRS CO8 HIC and the ANRS-VESPA2 cohort studies were approved by the consultative committee for the treatment of medical information (CCTIRS in French) and the French data protection authority (CNIL in French).

Study Population

The non-HIC group was constructed using the eligibility criteria of the HIC Cohort in order to ensure their comparability in terms of diagnosis time and duration of undetectable viral load. More specifically, participants in the VESPA2 survey diagnosed with undetectable viral load for at least 10 years were retained for analysis (n = 151). With respect to HIC, all 96 cohort participants completed at least one questionnaire during their follow-up and were retained for analysis.

Outcomes: The SF-12 and the PROQOL-HIV Instruments for Assessing Health-Related Quality of Life

In both surveys, two tools were used to measure QOL. The first was the medical outcomes study 12-item short-form health survey (MOS SF-12 [29], used to evaluate Health related QOL (HRQL)). Two aggregated scores were calculated from patients' responses to this questionnaire: the physical component summary (PCS) for physical health-related QOL, and the mental component summary (MCS) for mental health-related QOL. These scores range from 0 to 100, with higher values denoting better QOL. The second tool was the PROQOL-HIV specific scale [30] which comprises 38 items covering four psychometric dimensions: Physical health state and symptoms (PHS, 11 items, Cronbach's

alpha = 0.87), Health concerns and mental distress (COG, 10 items, Cronbach's alpha = 0.89), Social and intimate relationships (REL, 7 items, Cronbach's alpha = 0.82), and Treatment impact (TRT, 10 items, Cronbach's alpha = 0.98). Summary scores were calculated for each dimension (factor scores) and for the questionnaire as a whole (global score). Scores were standardized on a 100-point scale (0 = "worst" to 100 = "best" HIV QOL).

Statistical Analyses

Propensity Score Matching

The socio-economic and medical characteristics of patients from the two surveys were compared to assess differences between samples, using Chi square and Wilcoxon rank-sum tests for categorical and continuous variables, respectively. Characteristics included age, sex, employment, sexual identity, CD4 count, housing status, being a migrant, HIV transmission mode and history of hepatitis C treatment. Significant differences were found between the two groups, implying the presence of a sampling bias (i.e. non-comparable samples). This bias was reduced by implementing propensity score matching to create Vespa2-HIC (i.e., HIC/non-HIC) pairs of individuals with comparable characteristics. Accordingly, we were able to make a more accurate comparison of HQOL characteristics between HIC (i.e. the control group) and non-HIC participants using a logistic regression model adjusted for the following characteristics: age, sex, employment, housing status, and sexual identity (results not shown). HIC/non-HIC pairs were created when two probabilities were similar (± 0.001). Stata/SE 12.1 software for Windows (Stata Corp LP, USA) was used for all analyses.

Results

Table 1 shows the characteristics of HIC and non-HIC participants before and after the propensity score matching technique which corrected for sample bias. The HIC group principally comprised people who were significantly younger (45 years vs. 50 years in non-HIC, p < 0.001), female (47.9% vs. 18.5% in non-HIC, p < 0.001), employed (68.8% vs 42.4% in non-HIC, p < 0.001), tenants (66% vs 44% in non-HIC, p < 0.001), and self-defined as heterosexual (76.4% vs 51.7% in non-HIC, p < 0.001). No significant differences were found in terms of the proportion of migrants, transmission mode, CD4 cell count, or history of HCV treatment. Matching resulted in a sample of 150 participants (75 HIC/non-HIC pairs). The matching rate obtained was acceptable at 78%. Using quantitative methods, we next

Table 1 Characteristics of HIC and non-HIC groups before and after propensity score matching for sampling bias reduction

	Before matching by propensity analysis % or median (IQR)			After matching by propensity analysis % or median (IQR)		
	HIV controller patients (n = 96) %	VESPA 2 patients (n = 151) %	P-value[a]	HIV controller patients (n = 75) %	VESPA 2 patients (n = 75) %	P-value[a]
Age, years						
Mean	45	50	< 0.001	46	47	0.41
Gender identity						
Man	51	81.5	< 0.001	56	66.7	0.18
Woman	47.9	18.2		44	33.3	
Transsexual	1	0.3		0	0	
Employment						
Yes	68.8	42.4	< 0.001	69.3	57.3	0.13
No	31.2	57.6		30.7	42.7	
Housing status						
Tenant	66.2	44	< 0.001	65.3	60	0.76
Owner	28.3	46.7		30.7	32	
Staying with friends	1.1	2		1.3	2.7	
Staying with family	2.2	7.3		2.7	5.3	
Homeless	2.2	0		0	0	
Migrant						
Yes	15.6	12.6	0.5	10.7	17.3	0.24
No	84.4	87.4		89.3	82.7	
Sexual orientation identity						
Heterosexual	76.4	51.7	< 0.001	76	10.7	0.51
Bisexual	1.1	11.3		1.3	0	
Homosexual	19.1	36.4		22.7	28	
Refused to answer	3.4	0.6		0	1.3	
Mode of transmission						
Sexual intercourse	67.4	76.2	0.19	68.9	68	0.28
Injection drug use	15.8	15.2		17.6	22.7	
Transfusion	6.3	4.6		4.1	6.7	
Other	10.5	4		9.4	2.6	
CD4 cell count, cell/µl						
< 200	1	2.6	0.11	1.3	2.7	0.72
Between 200 and 350	6.3	12		8	9.3	
Between 350 and 500	15.6	22.7		14.7	20	
> 500	77.1	62.7		76	68	
History of treatment for HCV						
Yes	15.8	15.9	0.98	17.6	24	0.33
No	84.2	84.1		82.4	76	

[a]Chi square and Wilcoxon rank-sum tests for categorical and continuous variables, respectively

investigated QOL, in particular the physical, social, mental and the sexual dimensions.

Effect of Treatment on Sexual Disorders and Quality of Sexual Life

Table 2 shows characteristics of sexual disorders and quality of sexual life in the HIC and non-HIC participants.

Both groups were comparable for several characteristics. Differences could be attributed mostly to ARV treatment. Specifically, a lack of desire seemed significantly more common in non-HIC participants (62.1% vs 31.4%, p < 0.001). In terms of quality of sexual life, a tendency (p = 0.07) was observed whereby HIC participants were more likely to evaluate their quality of sexual life as not

Table 2 Comparison of sexual disorders and quality of sexual life between non-HIC and HIC

Among sexually active (N = 122)	Non-HIC %	HIC%	P-value
Lack of desire			
Yes	62.1	31.4	0.001
Not enough sexual intercourses			
Yes	48.3	35.2	0.16
Erectile disorder			
Yes	37.2	20.7	0.14
Pain during sexual intercourse			
Yes	13.8	8.3	0.38
Quality of sexual life			
Highly satisfactory	15.5	28.6	0.07
Satisfactory	58.6	34.9	
Not really satisfactory	12.1	19	
Not at all satisfactory	13.8	17.5	

[a]Chi square tests

Table 3 Health related quality of life (SF-12 and PROQOL) in the matched sample of Vespa 2 and HIV controller groups (N = 150)

	Non-HIC %	HIC %	P-value
SF-12 scale			
PCS			
Median (IQR)	48.1 (40.6;54.6)	45.4 (43.4;47.4)	0.09
MCS			
Median (IQR)	47.1 (32.4;53.4)	46.5 (33;54.7)	0.71
PROQOL scale			
Physical health and symptoms			
Median (IQR)	75 (59.1;90.9)	90.9 (70.5;100)	0.007
Health concerns and mental distress			
Median (IQR)	70 (55;87.5)	57.5 (40;75)	0.01
Social and intimate relationships			
Median (IQR)	75 (57.1;92.9)	89.3 (71.4;100)	0.006

PCS physical composite score, *MCS* mental composite score

[a]Wilcoxon rank-sum tests

really satisfactory (19%) or not at all satisfactory (17.5%) (vs 12.1% and 13.8%, respectively, in non-HIC).

Effect of Treatment on Health-Related Quality of Life

Table 3 shows the differences between the HIC and non-HIC groups in terms of QOL using the SF-12 and PRO-QOL measures. No significant difference between HIC and non-HIC participants was observed for the physical QOL dimension (Physical Component Summary: PCS) (median 48.1 IQR[40.6; 54.6] for non-HIC and 45.4, IQR[43.4; 47.4] for HIC). In contrast, PROQOL (adapted to the HIV population) revealed large differences between both groups.

Physical health and symptoms-related QOL in non-HIC was significantly lower than in HIC (median 75 IQR[59.1; 90.9] vs 90.9 IQR[70.5; 100], p = 0.007). Non-HIC also seemed to have a significantly lower QOL in terms of social and intimate relationships (median 75 IQR[57.1; 92.9] vs median 89.3 IQR[71.4; 100], p = 0.006). On the contrary, QOL in HIC, in terms of health concerns and mental distress, was significantly lower than in non-HIC (median 57.5 IQR[40; 75] vs median 70 [55; 87.5], p = 0.01).

Discussion

In this study, we compared quantitative data on the QOL of HIV controllers (HIC) with data from a representative sample of PLWHIV on treatment (non-HIC), in order to examine the specific features of QOL in the HIC population. In particular, we took into account every different dimension of their condition, in order to show contrasts and similarities. The comparative approach was also chosen to investigate whether biographical disruption occurred not only for non-HIC but also for HIC.

That is why the following discussion will examine our findings in terms of the social, mental, physical and sexual QOL dimensions of the HIV controller population.

First, HIC enjoyed a better *physical quality of life*. In order to explain this, we hypothesize that this QOL dimension is influenced by the absence of both antiretroviral treatment side effects and severe disease-related side effects [5, 9, 31]. Since HIV non-controllers have to deal with many treatment side effects, such as metabolic dysfunctions, gastrointestinal reactions, peripheral neuritis and abnormal hepatic functions, the absence of the same treatments in the HIC population could justify their better physical QOL.

Second, HIC had a better *social quality of life*. The non-HIC population had to deal more with the social stigma surrounding HIV. Having said that, a positive diagnosis may represent a "biographical disruption" for HIC. Although their identity and their QOL are influenced by the representations which non-HIC have about the illness, they do not belong to this group, and accordingly they may feel their situation is not recognized or supported.

Third, HIC *mental quality of life* was lower [8, 32]. They had difficulties planning their future lives. Moreover, their choices and adjustments suggested a need to develop a different relationship with the health care system. It is possible that this lower mental QOL was the result of both uncertainty about their own status [33, 34] and social stigmatization which associated them with the general HIV population [27, 35]. Furthermore, mental QOL had an important influence on social, professional and familial contexts.

Fourth, mental health had an impact on HIC *sexual quality of life* [36–38], affected not by functional

problems, but by psychological ones. Uncertainty in their life was associated with reduced sexual desire, something expressed by a third of HIC. With regard to satisfaction about sexual QOL, HIC did not express extreme opinions (Table 2). This differs from their responses about sexual desire, which is the most subjective and psychological dimension among all those analyzed here. We can hypothesize that a lack of desire is linked to the condition of uncertainty mentioned above, creating paradoxes for patients and leading to difficulties in planning for the future [27]. Moreover, with regard to HIV non-controllers, the more pronounced lack of desire could be linked to treatment side effects [39].

Therefore, for both mental and sexual QOL, we can argue that HIC have difficulties in autonomously distinguishing what is "normal" and healthy from what is worrying or pathological. Due to the lack of social recognition and of identification with a specific social group, HIV Controllers do not have common or shared criteria to be able to distinguish what is pathological from what is normal, especially in terms of sexual and mental QOL. Accordingly, this distinction tended to be very subjective in our study sample. Individuals must decide and understand when their symptoms and perception of a low QOL become pathological: they must understand the difference between feeling ill and being ill. Furthermore, they must cope with their circle of family and friends perceiving them as dishonest when they talk about their symptoms. In fact, the rarity and social invisibility of the HIC condition makes it difficult for this population to disclose their seropositivity, because they fear that their family, friends and even doctors will not believe them when they talk about their illness and suffering.

Consequently, it is important to highlight that the sexual and social dimensions of QOL are very specific to the experience of a "socially invisible" condition [14, 36, 40]. In this sense, we can argue that HIC have to deal with different forms of social stigmatization, concerning both the fact of being associated with non-HIC patients and the suspicion about the reality of their invisible condition. That is why "the representational processes surrounding HIV in general, and an understanding of the causes of their situation, help HIV controllers to reduce uncertainty about their particular status and their future" [25, p. 8]. With respect to biographical disruption, sexual life is one of the most affected dimensions of QOL. The theory of biographical disruption [19, 40, 41] proposes that there is a link between a biological crisis and a chronic pathology, leading to disorders and difficulties in everyday life. In particular, after HIV diagnosis, individual trajectories may be subject to biographical disruption depending on the priority the individual gives them—when identity building [42]—to the feeling of being ill or healthy. Accordingly, biographical disruption and adjustment of one's temporality also influence sexual QOL [37, 43, 44].

In conclusion, HIC have to deal with the unclear boundary between being healthy and pathologic. Even the slightest change in this feeling can influence the construction of reality and HIC QOL.

Some study limitations have to be acknowledged. First, participating HIC patients may have had better follow-up and satisfaction with care than HIC participants who chose not to participate. Having said that, this possible limitation is reduced by the specificity of the care system in France, which unlike other countries, is generalized and provides free-of-charge access to care for all HIV-infected patients. Second, these two cohorts may not be fully representative of the HIC and non-HIC populations.

This comparative study focused not only on the QOL of HIC and non-HIC, but also on the links between the physical, mental and sexual health dimensions of QOL and experience. It highlights crucial issues concerning the hitherto unexplored field of sexual QOL in HIC, and provides important insight for future research and for professionals providing healthcare to this population. More generally, a greater knowledge of the HIC population, especially regarding their daily experience and QOL, could lead not only to a better understanding of their ambiguous and incoherent health condition, but also an improved patient-caregiver relationship.

Conclusions

Using a qualitative and comparative approach, we examined the various dimensions of QOL in an unexplored population: HIV Controllers. The model used enabled us to consider the HIC population as a specific public, and highlight the connections and contrasts between different QOL dimensions. In particular, our analysis underlines how a deterioration in mental and sexual QOL can affect social insertion and provoke biographical disruption. Future research should examine how healthcare professionals perceive the ambiguous condition of the HIC population, caught somewhere between health and illness, and how it influences their relationship with them.

Compliance with Ethical Standards

Conflict of interest All authors declare that they have no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

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