



with the support of the College HIV Reference Centers and HIVRC : CHU Charleroi, CHU St. Luc, CHU St Pierre, CHU Liège, CHU Erasme, UZ VUB, UZ Ghent, UZ Leuven, ITG Antwerp, AZ ZNA Middelheim, AZ St Jan Brugge, Jessa ZH Hasselt.

Background: The purpose of this study was to identify and quantify needs among Persons living with HIV (PLHIV) aged 50 years and more with a view to improve, develop and implement a therapeutic education and positive health program focusing on physical, mental, social and sexual health.

The survey contained 4 parts:

1. HIV and its treatment.
2. The relation with the health professionals and the organisations.
3. The emotional life of PLHIV.
4. The social and professional life of PLHIV.

Results: The study was based on a sample of 86 patients (83% of the sample were men and 14% were women). The percentage of participants of age class 51-60 was 59% and of age class 61-70 was 32% and 70+ was 6%.

1. **HIV and its treatment :** Of the patients treated, 69 % felt that sufficient attention was paid to their medication and 59% felt that they had no knowledge of the evolution of HIV complications.

Q. Have you experienced one or more side effects from the drugs? Yes 40% No 48%

Q. What side effects from the drugs did you experience?

- o Excessive fatigue, loss of energy 50%
 - o Decreased or absence of libido, sexual desire 40%
 - o Sleep disturbances and / or nightmares 38%
 - o Changes in fat distribution (lipodystrophy) 35%
 - o Muscle pain 34%
 - o Neuropathic pain 17%
 - o Concerning the side effects of treatment 36% of the patients felt that they had not received any remedies to relieve the undesirable effects of their medication.
 - o 58% expressed a good or excellent physical and mental health, but only 31,4% a good or excellent sexual health. 42% are not satisfied by their sexual life, and 11,6% have no sexual life at all.
2. **Relation: Q. Is there any topic (s) other than your treatment that you would like to talk more about?** Yes 54% No 37%
 - o HIV-related complications (comorbidities) 31% My health / sex life 30% My illness experience 26% My mental health 22% My emotional health 15%
 - o 64% of the patients stated that they had often or very often spoken about HIV to a hospital practitioner, while just 14% to nurses and 31% to their general practitioner.
 - o 33,7% of the patients stated that they did not find support.
 3. **Emotional life:** 19% of the patients felt isolated and more than 23% think that they have been discriminated because of HIV.
 4. **Social life:** Almost 21% patients did not know the existence of HIV association and more than 31% patients felt a need to join an HIV association or support group.

PLHIV requested following services: medical info on HIV 66%, psychological aid 42% and a support group 37%.

Q. What are your priority needs today to live better with HIV?

- Medical information on HIV 56%
- A place of conviviality (support group, etc.) 38%
- Information on existing support structures 30%
- Psychological help (by professionals) 26%
- Information on the procedures of allowances and indemnities 20%

Conclusions: The results suggest the need to implement an educational, social and mental support program. The results suggest the need to improve the ability of patients to express their needs, especially those who are not members of an association. In addition to setting up an education program, a mental support program is also needed. The results helped in the development of a Positive Health HIV program (ie. National Day on Positive Health HIV)

Messages:

- We cannot reduce the well-being of PLHIV and its reality to quantifiable data (blood results, 90-90-90, ...). A Quality of Life assessment is important by means of Patient Reported Outcome measurement or in depth interview on physical, mental, social and sexual health.
- It is possible today to reduce physical issues but much less on a mental, social and psychological level.

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