

Perspectives on the acceptability of HIV cure trials: the challenges for physicians and PLWHIV (ANRS APSEC)

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Context

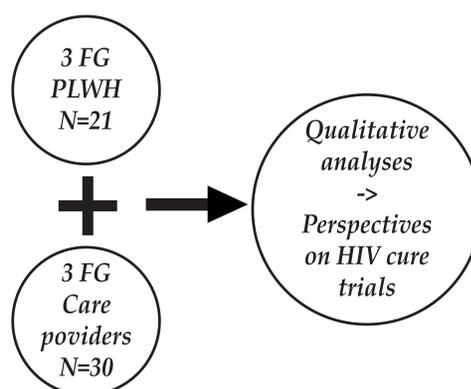
The latest progress in HIV medicine and research has reinforced the belief that HIV infection might be curable. As part of the International AIDS Society initiative "Towards an HIV cure", launched in 2012, a "Social Science" group is currently preparing surveys about the acceptability of HIV cure-related clinical (HCRC) trials to be conducted in several countries including France. The main goal of our survey was to collect data based on patients' and healthcare professionals' points of view about the HCRC trials and to identify the diverse motivations and barriers which may influence willingness to participate (WTP). Using data from this first part of the survey, we will create guidelines to ensure that recruitment in these upcoming trials is ethical and patient-focused.

Methods

Qualitative data were collected from 6 focus group sessions (5 to 10 participants in each FG) consisting of either PLWH or health professionals in 3 French Infectious Disease Units.

The objective of the thematic analysis was to identify ways to build and evaluate cure strategies and distinguish the various perspectives on therapeutic research in the HIV field today.

Data analysis was made with Iramuteq.



Focus group discussions were conducted in order to collect information on the collective norms of and beliefs about clinical trials without direct benefits.

The FG sessions included several group exercises including role-play. For example, playing the part of an eligible patient in a fictitious scenario where a HIV cure trial is proposed, in order to identify facilitators and barriers to participation in HIV cure trials and their specificities in the present context.

Results

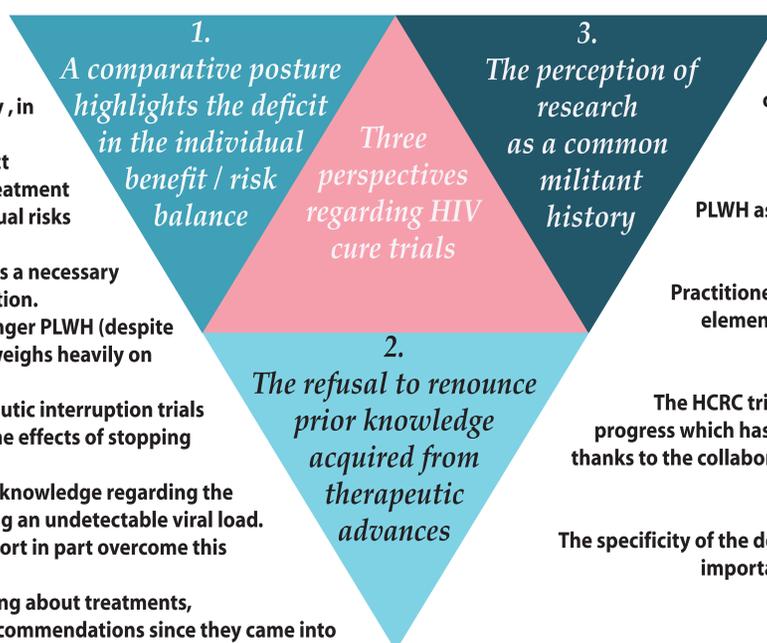
1. Evaluation of the potential membership in a HIV treatment trial involves:

- A comparison between the quality of current treatments and uncertainty about the tested therapy, in terms of its toxicity and effectiveness;
- The historical perspective, through direct or indirect experience, which highlights progress in terms of treatment efficacy and the joint decline in the benefits /individual risks balance;
- The reluctance to accept once again the risks seen as a necessary element in the adoption of a new therapeutic revolution.
- Remembering the cost of side effects which for younger PLWH (despite the fact they did not experience these side effects) weighs heavily on their daily life with HIV.

2. Assimilation between HIV - cure trials and therapeutic interruption trials leads to people highlighting treatment failure and the effects of stopping treatment to the detriment of innovation.

Cure trials seen as questioning previous therapeutic knowledge regarding the control of mutations, virus resistance and maintaining an undetectable viral load. For some PLWH, medical follow-up and regular support in part overcome this questioning.

For some practitioners, it means a new way of thinking about treatments, or even forst potentially dangerous breach of the recommendations since they came into being.



3. Trials perceived as a means of maintaining momentum in HIV research, as a collective concern and necessary to continue innovation efforts.

In this context, participation is perceived by PLWH as a contribution to the medical progress which their community depends on.

Practitioners recall the pioneering spirit and the militant element necessary to implement the first therapeutic revolutions.

The HCRC trials are considered part of the continuity of the progress which has evolved the medical and social history of HIV, thanks to the collaboration between the first generations of people diagnosed and researchers.

The specificity of the doctor / patient relationship constructed and its importance in the future acceptability HIV-cure trials.

Conclusion

Three perspectives emerge from the various sessions of the PLWH- and physician-based FG.

The first perspective involves beliefs and knowledge expressed from an individual point of view, and associates the HIV-cure trials with a loss of personal balance. In this respect, acceptance of the trials is complicated by the genuine positive results on infection acquired from previous trial participation and therapeutic progress.

The second perspective involves confusion between the implementation of the HIV-cure trials and their purpose in terms of direct benefits (cessation of treatment) on the one hand and a perception of these trials as a biological and epidemiological regression/flashback to a situation where the infection was not controlled.

The third perspective, which reflects a favourable attitude towards HIV-cure trial strategies is based on the motivations for participation, including scientific and social altruism, elements which reflect the historical specificity of research in the field of HIV (Barré-Sinoussi et al, 2013).

This position reflects general HIV culture which not only accepts the risks of participating in new trials, but embraces innovation and pushes others to continue innovation.

These findings underline the importance that one may need to consider both the specificity of the social and historical construction of HIV and the production of groups (not necessarily activists) involved.

Individual and experience-based factors must be taken into account, but those related to social identity also appear fundamental.

Indeed, this is all the more true as they complement the collective mobilization developed by the fight against HIV in general, something which HIV-cure strategies in particular are testimony to.

