

Poster Discussion

Social Science and management of HIV beyond antiretroviral therapy

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Title: Clinical research integrated with narrative-based research to understand living and managing HIV: TMC114FD1HTX4011 - DIAMANTE study

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Abstract body

Background: Despite the successful reduction in the morbidity and mortality in the HAART era, living with HIV (LWH) is still difficult with regards to the associated psychological burden. Narrative-based research is an interdisciplinary method based on the collection of patients' written narratives to gain insight on how a person lives his illness.

Material and Methods: The DIAMANTE study started in June 2018 involving 20 centers throughout Italy. This retrospective and prospective, non-interventional study collects data on LWH patients treated with D/C/F/TAF, on therapy effectiveness, and Patient Reported Outcomes (PROs). The study aims to enroll 250 LWH patients, subdivided in 3 groups based on their treatment history. Patients will be observed for 48 weeks after the study enrollment. PROs will be registered by the administration of HIV-Treatment Satisfaction Questionnaires together with the completion of narrative plots at enrollment and at last study visit. Researchers analyze the narratives according to Grounded Theory methodology with the support of the NVivo 10 software.

Results: Since end of February 2019, 138 LWH patients were enrolled in the study, of whom 49 already completed their narrative plots at the first visit. Sociodemographic data are reported in table 1. Narrative showed that patients felt mostly fear and anguish at HIV diagnosis and just 17% expressed confusion. Nevertheless, 73% of LWH patients felt reassured after the first visit thanks to the optimal relationship with clinicians described in 90% of narratives. Therapy is depicted as a doom only in 12% of the narratives; indeed 84% described as relief and protection the moment of the first prescription. HIV infection doesn't impact on daily activities of patients, nevertheless, just 62% coped with the disease. Furthermore, 20% of patients developed new interests and started taking better care of themselves after the diagnosis. The main difficulties arise from the stigma associated with HIV depicted in 86% of experiences. This stigma influenced particularly relationship with friends and colleagues respectively in 92% and 89% of cases: patients decided to keep the secret with people around them because they fear about prejudice and isolation. Nevertheless, when the secret was shared with relatives, partners and close friends, patients surprisingly felt supported and loved. Moreover, 24% of narratives described the fear of infecting people around them while 20% the worry of not finding a partner or having a family. Regarding their future, patients hope in a cure (35%), the end of stigma (12%), having a family (14%) and serenity (23%) while just 16% described fear

Conclusions: For the first time, a clinical study includes patients' narratives as PROs, pointing out as HIV impacts on patients' lives despite the HAART (i.e. poor symptoms and/or limitations on daily activities). Narratives correlated with clinical data will highlight new information for HIV management and prevention

Table 1 Patients' sociodemographics	Patients (n=49)
Sex	
Men	94% (n=46)
Woman	6% (n=3)
Mean Age	
Years	41 (min:23, max:76)
Marital Status	
Unmarried	55% (n=27)
Married/ living with a partner	29% (n=14)
Divorced	12% (n=6)
Widowed	4% (n=2)
Children	
Yes	31% (n=15)
No	69% (n=34)
Educational Level	
Bachelor or Master degree	22% (n=11)
High school degree	47% (n=23)
Secondary school degree	29% (n=14)
Elementary school	2% (n=1)
Work status	
Employed	31% (n=15)
Self-employed	49% (n=24)
Pensioners	6% (n=3)
Unemployed	6% (n=3)
Student	8% (n=4)
Time living with HIV	
Years on average	2,6 (min:1, max:14)
Therapy before treatment with darunavir/cobicistat/emtricitabine/tenofovir/alafenamide	
Always been treated with darunavir	41% (n=20)
Not been treated with darunavir before	12% (n=6)
Naive	47% (n=23)