Narrative medicine as Patient-Reported Outcomes to understand living with HIV from patients’ experiences: TMC114FD1HTX4011 - DIAMANTE study


Background

HAART significantly reduced HIV morbidity and mortality, nevertheless its impact on people living with HIV (PLWH) remained less examined at an individual level. Narrative Medicine unveils the more intimate illness aspects investigating patients’ narrative, also allowing the comparison of different moments in the living with HIV.

Methods

The non-interventional DIAMANTE study aimed to collect data on PLWH treated with D/C/F/TAF addressing therapy effectiveness and Patient-Reported Outcomes (PROs). The study started in June 2018 and involved 18 centers across Italy; enrolled patients were both naïve and previously ART-treated and splitted in 3 groups; then followed up for 48 weeks: Group 1 always treated with DRV-based ART; Group 2 switching to D/C/F/TAF from a non-DRV-based ART and Group 3 starting D/C/F/TAF as naïve. PROs, HIV-Treatment Satisfaction Questionnaires and written narratives were collected at enrollment (V1) and at the last study visit (V4). Narratives were independently analyzed by 2 researchers through NVivo10 software on the basis of content analysis.

Results

The study enrolled 246 PLWH: 137 (56%) have completed V1 narrative, and 86 of them also V4 narratives (35%) so far. We compared the treatment experience in 73 patients having both V1 and V4. At V4, 45/73 (62%) reported improvements, especially at an emotional level (22/73-30%) and at an organizational level (15/73-21%). In Figure 1 we detailed improvements in each group. At V4, 7/73 (10%) reported difficulty coping with HIV condition compared to 16/73 (22%) at V1; 16/73 (22%) considered simpler HIV management (Fig.2). Overall, at V4, 33/73 (45%) patients remarked treatment effectiveness and tolerability; 25% stated current therapy is simpler to follow, while 12/73 (16%) also reported hoping for a definitive cure (Fig.3).

Conclusion

Compared narratives pointed out how D/C/F/TAF-based therapy had a positive emotional and organizational impact. Therapy allowed greater well-being and better management of the HIV condition.

Acknowledgements:

Authors are grateful to all center and all patients participating in this study. In particular to all those who shared their experiences and believed in this innovative methodology.

Funding:

DIAMANTE study was funded by Janssen-Cilag SpA, Italy.