

Appendix S3

SUPPLEMENTARY METHODS

The NVivo software analysis added rigour to qualitative research, since it reduces human error (27), especially in cases of high volumes of narratives. NVivo facilitates a careful textual analysis of recurring words and semantic expressions. Words are clustered in nodes based on specific text search, word frequency, coding, compound, group; information can be analysed through comparisons and logical correlations to create models, graphs and charts (28). Frequencies and semantic analysis, indeed, reveal concordances and disagreements among the different points of view.

It is shown that a combination of both thought and computer-assisted methods is likely to achieve the best results; and the quality, rigour and trustworthiness of the research is enhanced (29).

Patients' narratives were also classified on the basis of the style of narration, which combines content with used language.

Classification by the anthropologist Arthur Kleinman (18) identifies 3 words to describe the pathology:

- *disease* concerns the mechanics, performance and causal effects of treatments, bound primarily to the functionality of the "body" or even more of a "target organ";
- *illness* concerns the conscious or unconscious perception that the subject has of the disease, and how it is living with the disease, thus transforming the patient from the object of care to a human subject who feels, thinks and perceives the disease;
- *sickness* concerns the perception of the disease by the society, according to the anthropological beliefs of the particular environment.

Three clusters, were identified, according to the classification by Kleinman:

- *disease-centred narratives* – focused on the clinical and mechanistic point of view, with a technical language and harsh texts that are not open to emotional considerations;
- *illness-centred narratives* – focused on living with a particular condition, with an open language and a flowing narration from an emotional, familiar and social point of view;
- *sickness-centred narratives* – focusing on the impact of the public perception of the disease.

For the emotional analysis, the classification used (19) distinguishes between 4 primary emotions: *fear*, *anger*, *sorrow* and *joy*. These are supplemented by the social emotion *shame*.

For a general taxonomy of collected narratives, with the aim of researching meaning, the classification provided by Arthur Frank (20) was used to detect 3 types of narrative:

- *chaos*: the narrative describes a loop situation in which the patient sees no end to the disease situation. This narrative is typically associated with a total lack of coping strategies.
- *restitution*: the narrative describes the disease as pain, which can be overcome by undergoing proper tests, medical consultations, and treatment, and the patient eventually sees a restitution of his/her health. This narrative is associated with a poor gain in awareness.
- *quest*: the narrative describes the disease as a trigger for inner and outer research, and is a typical classification of chronic disease. This narrative is associated with a strong increase in awareness.