

Narrative Medicine and Rare Diseases

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Introduction

Narrative medicine was born in U.S.A. in 80's as a link between doctor's clinical knowledges (*disease*) and patient's subjective experiences (*illness*).

Its aim is to reduce the distance between doctors, caregivers and patients and support them in the management of the disease, and it could be defined as a functional instrument to share "life stories" in disease field.

Use of narrative medicine in the field of rare diseases should be intended as an added value, in a context where the narratives of the patient are often the basic element –sometimes the only one- which the health worker has in order to organise his interventions.

Activities

The ongoing activities of the National Centre for Rare Diseases (CNMR) in the field of narrative medicine are:

- RESEARCH

reviewing scientific literature
collection and analysis of "life stories"

- TRAINING

for doctors, nurses, social workers, therapists
for people with rare diseases and their relatives

Collection of "life stories"

We collect written "life stories" in the field of rare diseases.

The "authors" are patients and their relatives, medical operators (MDs, nurses, psychologists etc.). We ask participants to provide their details in writing on a form and a signed consent in order to use all their personal details and an anonymity consent for the use of the "life story".

People check themes - *relationships* (among doctors, patients and their relatives), *illness* (e.g., researching information/diagnosis/access to services/clinical trials), *quality of life* (e.g. autonomy vs. dependency/management of chronicity/future prospectives) and category of "life story" - narrative, poetry, drawings, photographs - in the form, and then submit the form and the "life story": by e-mail or by post. CNMR, also, manages a web area in order to make available files of the collected "life stories".

Aims

- identify, through the analysis of "life stories", "authors" needs and use these in future public health intervention models to improve the relationships between patients and health operators
- improve the quality of life of rare disease patients and improve medical operator skills