

TRUST project: Narrative Medicine to listen to the voice of patients, caregiver and physicians on heart failure in Italy

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Introduction

Heart failure (HF) is a progressive chronic disease that needs lifelong management. Dyspnea, fatigue, tiredness, ankle swelling are the main symptoms affecting patients' everyday routine and quality of life. Narrative medicine is an interdisciplinary methodology based on the collection of illness narratives directly written by patients, caregivers, and healthcare practitioners [1]. This approach allows the accommodation of both patients' and physicians' cultural construction, including emotions and values on the illness and the pathways of care.

Objective

The aim of the TRUST (The Roadmap Using Story Telling) project is to integrate patients', caregivers', and physicians' point of views on the pathway of care and on how living with heart failure affects the everyday life through the use of Narrative Medicine.

Methods

From June to November 2018, patients, caregivers and HF specialists have narrated independently and anonymously about their experiences with heart failure by writing, on a dedicated online platform, illness plots and parallel charts, two majors narrative medicine tools [2]. These are specifically structured to help respectively patients and their families, and HF specialists to overcome the writer block, and designed to minimally influence their telling [3].

The Grounded Theory methodology will be used to analyze the narratives with the support of a software (NVivo 10).



Results

Up to date, the online platform for collecting narratives has been inactivated, and the analysis phase will end in January. 256 narratives were collected: 84 from patients, 63 from caregivers, and 109 from HF specialists. 21 Italian HF specialists have actively written of their own experiences and informed patients and caregivers about the possibility of freely and anonymously participate to the project. Among participating professionals, 76% are cardiologists, 19% internal medicine, and 5%geriatrists. (38% from the south or islands, 33% from the center, and 29% from the north of Italy). From data, patients were often males (73%) with the average age of 69, while caregivers were mainly females (85%), about 55 years old on average, and mainly spouses or sons/daughters (34% and 35% respectively). Patients described by HF specialists were mainly males (78%) aged 65 years on average, usually accompanied by their caregiver (64%).

Preliminary results are available and highlight new qualitative insights on pathway of care. First interesting result is the participation itself; caregivers, indeed, participated more than expected and their narratives were particularly long and rich in details. Furthermore preliminary analysis show that caregivers have felt fear and apprehension for the patients' health condition more than the affected people themselves. On the other hand, the majority of patients and caregivers who decided to participate to the project described the relationships with their physicians as good and trustworthy.

In the bubbles are reported fragments of the collected narratives: in blue patients', violet caregivers' and black HF specialists'



Fear of death

The disease became part of my life... fortunately not part of my death!!

Sometime, I would like to scream against him that his condition is crittical and that he could die!

While his caregiver told me she is afraid and she can't stop thinking he could die.



Doctor-patient relation

The hearth failure gave me the possibility to know such a wonderful doctor as she is (women are the best) who has a big hearth with me

The relation with the physician who assist my affected family member is superb.

From the relationship with this patient and his family I have learnt that the relation is the foundation of the care



Emotions today

I feel depressed, I want to cry, although my family try to take me up

Nowadays living with heart failure has become easier, my husband has found unexpected energies, he doesn't need my daily assistance anymore.

Today this person is more active, less depressive, opened to her social life (aspect she had abandoned before)..

Conclusions

For the very first time, a Narrative Medicine project, combining the three major point of view, patients, caregivers, and physicians, is applied to the field of cardiology, and in particular of heart failure. This innovative approach could be particularly informative, since it integrates information on symptoms and drugs, with feelings, thoughts, and action of the entire pathway of illness of affected people, from the first signs of disease to the diagnosis and its communication and management.

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