

# 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 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 all participants' cultural construction, including emotions and values on the illness and the pathways of care.

## Objective

The aim of the TRUST project was to understand the pathway of care and how HF affects the daily routine of patients, their caregivers and HF specialists.

## Methods

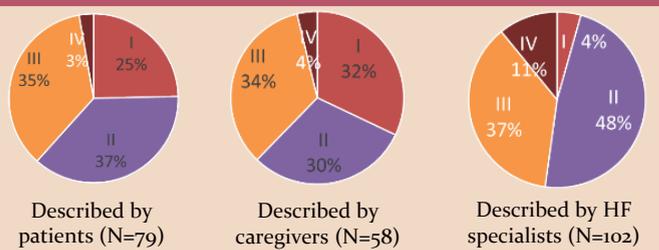
From June to November 2018, the project involved 21 Italian HF ambulatory specialists which reported their parallel charts and invited patients and caregivers to narrate independently and anonymously about their experiences by accessing a dedicated on-line platform. The two main tools used are illness plots to help patients and caregivers to completely express their emotional, social and personal illness experiences, and parallel charts, a specific tool for physicians. The Grounded Theory methodology was used to analyse the narratives with the support of a software (NVivo 10).

## Results

Within the project 257 narratives were collected: 82 from patients, 61 from caregivers and 104 from HF specialists. Patients who independently decided to write their narratives were mostly males (75%) and 68 years old on average, while caregivers were mainly females (85%), 55 years old on average. Patients were mostly retired (67%) while caregivers were still working in the majority of cases (56%). According to the participating caregivers, when they were partners the time dedicated to taking care of their beloved ones was higher than 6 hours per day (93%), while adult children spent 1-2 hours/day (45%).

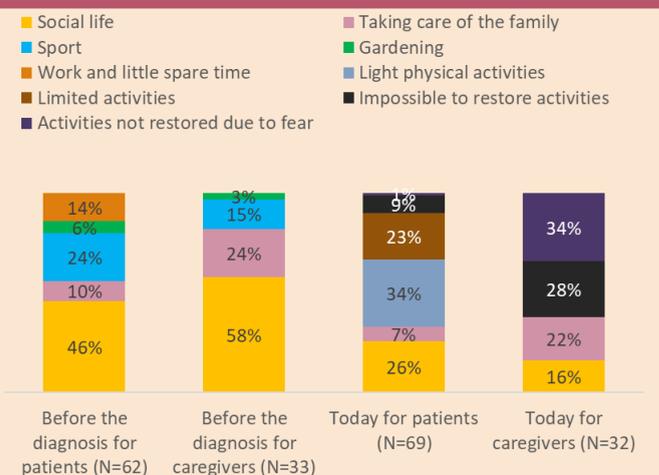
Both patients and caregivers stated not to have initially recognized first symptoms of disease in 69% and 84% of cases respectively, and this underestimation of first signs was also confirmed by the physicians describing their assisted patients (44%). Furthermore, several elements in both patients' and caregivers' narratives showed a diffuse lack of awareness on the disease (85% of patients and 74% of caregivers), as confusing clinical terms, and lack of knowledge about what exactly the heart failure is. Both patients and caregivers experienced high level of fear and anguish and this emotional status affected most participants, and 36% of family members even limited their personal activities due to the fear of leaving their beloved one alone. Indeed, a strong impact on living with HF emerged from narratives: all the caregivers' narratives described limitations in their daily past activities, 29% had to quit their job and 43% experienced limitations at work. While patients had to interrupt their activities such as sport, gardening, and traveling replacing them with lighter hobbies, like playing cards, watching TV, or reading books. Doctor-patient relationships were generally described as positive and trust in therapies diffusely emerged in all the groups investigated.

## NYHA class described by participants



While HF specialists directly declared the NYHA class, patients and caregivers were asked to define it based on the full definition of the NYHA classes

## HF impact on activities



69% of patients didn't recognize initial symptoms

8 drugs per day

85% of patients and caregivers lack of awareness

100% of caregivers bring patients to check-ups

## 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 project outlined strongly the issues of living with heart failure and, in particular, the burden of caregiver and the general lack of awareness on HF.

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