A NARRATIVE MEDICINE PROJECT WITH PEOPLE LIVING WITH A STOMA

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INTRODUCTION

Narrative medicine is what occurs between the health provider and the patient, from the collection of information of events before the occurrence of the disease, how the disease showed up, through the physical, psychological, social and occupational features. Attention is therefore to the burden of illness and to find the best way to personalise the strategy of care. (Greenhalgh and Hartman of King’s College, 1999; “Narrative based medicine as an evidence based world”).

Among Disease, Illness and Sickness

Disease is the side of the mechanics, the performance and the causal effects of treatments bound primarily to the functionality of the “body” or even more of a “target organ”. Body as a “machine to be repaired”

Illness concerns the conscious or unconscious perception that the subject has of the disease, how is the living with, thus transforming the patient from object of care to a human being who feels and thinks and perceives the disease. Mind and Soul are embodied

Sickness is socially and culturally held conceptions of health conditions; these may influence how the patient reacts, as in the duality of cancer or the stigma of mental illness. The Others’ judgment.

We have developed a project of Narrative Medicine with people living with a stoma, with the following aims:

• To trigger the pathway of care to understand the needs of the patients to hypothesise new services
• Understand the emotional, social, relational impact of the ostomy
• Draw the healthcare professionals’ profile
• Understand the aspects of disease, of illness and sickness

ENGLISH LANGUAGE / NARRATIVE MEDICINE

FINDINGS AND ACTIONS

ENCRYPTING THE SURGERY

During the first meeting with the surgeon the person discours:

• “That he/she will have a stoma surgery
• “The reason why he/she has to do this kind of surgery”
• In the majority of the cases the patient discovers that he/she has a cancer and in many cases they don’t know if it is benign or malignant

THE PROFILES OF SURGEON

• The professional surgeon: gives information and psychological support to the patient
• The technical surgeon: gives information in a technical way
• The rushed surgeon: gives few information in a few minutes visit
• Other care: emergency; there is no time to talk to the patient before the stoma surgery

ENCOURAGING THE ET NURSE

The stoma specialist nurse is the reference point for the patients, he/she deals with strengthening communication, calms and reassures the patient, opens up new possibilities for stoma management, often he/she establishes a human relationship.

In the majority of the narratives the good relationship with the nurse is emphasized.

“Since the moment I have met the stoma therapy nurse I...I felt reassured, because I received an answer for all my doubts”

“I must admit that I didn’t feel ready from a psychological point of view to face this situation but, thanks to the support of the stoma therapy nurse I felt ready to face my new status with determination and serenity”

“It’s been nice because he is a very human person, understanding and calm. He gave me a lot of detailed information, and also a lot of confidence and calmness”

METHOD

The narrative plot was created by the stoma therapy nurses with the support of ISTUD team.

The Ointomy Centers involved in the research were 26:

The goal was to collect the narratives of 100 adult patients.

The patients interviewed were:

• People who had surgery at least 12 months before
• People who wanted to tell their experience

Three ways to gather the narratives:

• The patients could bring back the narratives putting it in a box or in a closed envelope.
• The patients could write narratives in word file and send it by email

RESULTS

Between October and December 2015, we collected 151 narratives (50% above the expected number)

In the narratives the encounter with the Surgeon is a crucial event during the pathway of care. The ET nurse is the reference point for the patients.

EDUCATIONAL QUALIFICATION

Primary school graduation

Secondary school graduation

Degree/Master

Secondary school graduation + Primary school graduation

Degree/Honors

High school graduation

Academic status

Professional 25%

Technical 12%

Rushed 30%

Normal 12%

Technical 20%

Emergency 15%

serene: 35%; 48%

angry: 15%; 15%

not good: 14%; 20%

resigned: 15%; 10%