Narrative Medicine for an Eco-Friendly Healthcare System
As it Relates to Patients Living with a Stoma

Milano 11 Aprile 2017   DNA I meeting
Maria Giulia Marini
Agenda

- Review systems in ‘balance’
- Differentiate between disease, sickness, and illness
- Define Narrative Medicine and its relationship to Evidence-Based Medicine
- Coping factors coming out from narrative medicine on patients
- How to start engaging in Narrative Medicine with your patients
- Across countries study on Italian and Australian people living with Stoma.
Symbiosis Allows for Coral in an Eco-Friendly & Balanced System

- Corals live in compact colonies of many individual polyps.
- Corals obtain energy and nutrients from algae that live within their tissues. In turn providing shelter and CO$_2$ to the algae.
- Their ecosystem is the largest vegetal-animal symbiosis of the world. And the oldest.
- Climate change, pollution, and disrespect can impact the whole ecosystem.
Achieving Good Symbiosis and Balance in a Healthcare ‘Ecosystem’

- Interconnection of the providers of care inside and outside the hospital, with a balance of negotiation and time constraints.
- Integrating technology with listening and relational skills for patients, associations, families, nurses, physicians, management.
- Understanding how to move the focus from “disease” to the “illness” and “sickness” approach by integrating evidence-based medicine with narrative medicine.
Differentiating Between Disease & Sickness / Illness

- **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”. Towards biological normalcy.

- **Sickness** is the socially and culturally conceptions of health conditions; these may influence how the patient reacts. The *others’ judgement*. Towards social normalcy.

- **Illness** concerns the conscious or unconscious perception, including feeling, thoughts, wishes, needs, that the person has of the disease. Mind and Souls are embedded.

*Arthur Kleinman, Harvard University*
Defining Narrative Medicine

- **PERSONALISATION**

  “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, with attention to physical, psychological, social and ontological features.”

*Greenhalgh and Hurtwitz, BMJ, 1999: “Narrative based medicine in an evidence based world”.*
Defining Narrative Medicine

- ORGANISATION

“Narrative Medicine fortifies clinical practice with the narrative competence to recognise, absorb, metabolise, interpret, and be moved by the stories of illness:… helps doctors, nurses, social workers, and therapists to improve the effectiveness of care by developing the capacity for attention, reflection, representation, and affiliation with patients and colleagues.”

Rita Charon, JAMA, 2001
What is Evidence-Based Medicine?

- The *conscientious, explicit, and judicious* use of current best evidence in making decisions about the care of individual patients” *(David Sackett, 1996)*

- It has been a *tool to take out medical science from a paternalistic* and superhuman approach displayed by the physicians and nurses.

- It consists of *protocols, guidelines, caremaps.*
Pollution Advances: Forgetting the Personalisation of Care

- “Is Evidence-Based Medicine broken” is a post by the epidemiologist and narratologist Greenhalgh (October 2014). She conducted a survey with UK doctors through the British Medical Journal, asking its readers whether evidence-based medicine was malfunctioning.

- Responses were almost evenly split: 51% answered positively, and 49% negatively.
Evidence-Based Medicine – Deciding to Stay Alone does not Promote an Eco-friendly System

“…. Research-derived facts about the average patient must not outweigh individual patients’ observations of their own bodies and illnesses. New processes for capturing and accommodating patients “personal experiences” – which are typically idiosyncratic, subjective, and impossible to standardise,”… are needed.

T Greenhalgh, BMJ, 2014
Narrative Medicine in Symbiosis with Evidence-Based Medicine

- The number provided on a quantitative scale by a single person can be interpreted mainly through the narrative
What is Culture & How is it Considered by Clinicians?

- Culture is a set of **practices and behaviours** defined by **customs, habits, language, and geography** that groups of individuals share.

- While much progress in medicine had been made through epidemiological and basic science research, the lack of systematic attention to culture is a significant deficiency.
Stories Communicate with Epidemiology & Evidence-Based Medicine

- The appropriate and rigorous use of narrative methods should be encouraged when assessing the cultural contexts of health because their use in communication with quantitative data support a more values-based approach.

In the end, the pathway of the coral through the sea is determined by the entire web of communications, from the coral mineral wheel, to the fish that fertilize it and the sun that provides it with energy and the sea from which it forms itself.
Entering Into the Realm of Narrative Medicine
The Plot of the Health / Illness Narratives

Illness is scanned into three main phases:

- “the falling ill”- the past- period in which the body starts to ache and the diagnosis tour begins, followed by
- the “being ill phase”- the present- with the therapeutic pattern displayed, and eventually, the
- “getting worse” or “getting better phase”, - the future- announcing both an objective healing or a subjective ability to cope independently from the severity of illness.
The Natural Semantic Metalanguage (NSM) is a linguistic theory based on universal semantic primes. That simple indefinable meanings appear to be present as meanings in all languages. It allows for the breaking down of complex concepts into simpler concepts. (Australian National University, Anna Wierzbicka and Cliff Goddard)

Here are some of the 65 semantic primes:

I, Me, You, Mine, People, Body, Good, Bad, to live, to die, to feel, to think, to know, to want, to happen, to move, to see, to hear, true, not, before, now, after, inside, outside, one, many, a few, maybe....
Coping - Definitions

- Coping is defined as the conscious **effort to solve** personal and interpersonal problems, and seeking to master, minimize or tolerate stress or conflict.


- *The narrative moves on when coping is achieved.*
Coping – Activating & Deactivating Factors

- Optimism, positive thinking
- Openess to new experiences, curiosity
- Awareness, sense of reality
- Availability, kindness
- Responsibility, taking care of.
- Obsessive thinking
- Introversion
- Denial

Clustering Narratives
Narrative Medicine Applied to People with Stomas

- Two differing continents and countries compared
- Italy
- Australia
Alice in Stomaland….. Some stories

- My gastroenterologist prepared me psychologically for the surgery, my family and my boyfriend were there with me. I was scared and I had many doubts.

- Immediately after my surgery I wanted to see the stoma. I was curious and fear and doubts slowly disappeared.

- The ET nurses encouraged me to manage the stoma therefore I learnt how to clean it and change the pouch. In that very moment the fear had completely gone.
Alice in Stomaland….. Some stories

- The meeting with the STN….confusing, as I had the surgery in Melbourne and had to seek out a stoma nurse in my area. I had to make contact with her, as there was no follow up by her.
- I felt supported and at ease. However, there was some complications with the meetings when she attended a conference of stoma care nurses (unbeknown to me) and I urgently needed her. No-one seemed to know where she was…
- On reflection, I need to know how to put in an order for colostomy bags, as the stoma nurses had taken care of this both in the hospital and when I attended the external stoma nurse appoint meant. …However, I still wasn’t aware enough of how to do so….
Two Different Continents and Countries: 
Two Perspectives of People Experience with Stoma

- Italy
- Australia
Objectives of the Narrative Research

- Trace the pathway of care to better understand patients’ needs and plan new services
- Understand emotional, social, and relational impact of the ostomy procedure
- Draw out a carer profile and role
- Understand aspects such as:
  - Disease (clinical aspects)
  - Illness (living with a stoma)
  - Sickness (social perception of disease)
Methodology

- **In Italy**

  The narrative plot for patients with ostomia was developed in partnership with E.T. nurses and the ISTUD research team. Methods to gather narratives: by mail, by email, and by website.  
  [www.medicinanarrativa.eu/diario-dna](http://www.medicinanarrativa.eu/diario-dna)

  Collection time: May 2015-January 2016

- **In Australia**

  The same narrative plot was distributed to ostomates by Survey Monkey to Liberty Medical ‘LiveWell member club’ and to 22 x Patient Associations on email. A pilot study. Collection time: November-December 2016.
The first meeting with the surgeon was …

During the meeting I felt…

The meeting with my Stoma nurse…

During the meeting I felt…

Along the pathway of care I wanted by my side…

Considering how I imagined the stoma, it is like…

The surgery for me was…

I wanted to know…

Considerating the experience I wish was different…

How do I feel about the stoma and myself today…

How did you feel writing your narrative?
Results from Patient Narratives

62 Australian patients
151 Italian patients
## Narratives to Share Experiences

<table>
<thead>
<tr>
<th>Italian respondents: venting</th>
<th>Australian respondents: sharing</th>
</tr>
</thead>
</table>
| "Telling my experience gives me a sense of liberation." | "I tell anyone who asks how it is with a bag. I'm willing to share because I don't feel it's something to be ashamed of and people should be educated about this."
| "Useful for other people" | "It's very beneficial to know how many people have a stoma."
| "A good opportunity to voice my concerns and hopefully make the transition easier for someone else." |
The Health Care Professionals
We know this is a crucial event during the pathway of care. During the first meeting the person discovers:

- In a majority of cases, he/she has a cancer and they don’t know if it is benign or malignant
- That he/she will have a stoma surgery
- The reason why he/she has to do this surgery

The patients’ reactions can vary
Patient’s Reactions

Patient sees the surgery and the ostomy as a way to save his/her life, in this case it is easy for the surgeon to explain the stoma surgery.

Patient is scared and shocked, not able to understand what is happening to them. In this case too much information could overwhelm them.

Patient is focused on the change of their life with a stoma - the surgeon has to persuade the patient that his/her life with the stoma will be "normal".
Surgeons are Better Perceived in Australia

**Italian Surgeons**
- Rushed 30%
- Professional 29%
- Technical 30%
- Emergency 11%

**The rushed surgeon:**
- gives few information in a few minutes

**The daunting surgeon:**
- gives information without detailed explanations and without reassuring

**The professional surgeon:**
- gives information and is empathetic with the patient.

**The technical surgeon:**
- gives information in a technical way.

**Australian Surgeons**
- Professional 67%
- Daunting 18%
- Technical 3%
- Emergency 12%

**The rushing surgeon:**
- gives information without detailed explanations and without reassuring

**The daunting surgeon:**
- gives information and is empathetic with the patient.

**The technical surgeon:**
- gives information in a technical way.
From the **Italian** Narratives

**Professional surgeon**
- “I thought that I would meet a cold and synthetic robot, I met a person instead. Clear, precise, but with human tones, informing me without scaring me, he already knew that I was scared“.
- "I was informed by the surgeon humbly and gently and it was helpful for me“.

**Technical surgeon**
- "The surgeon examined my previous reports and confirmed the diagnosis of “rectal adenocarcinoma” and prescribed me a further series of tests to do”. "The surgeon with a few words explained the situation and the whole procedure”.

**Rushed surgeon**
- “Good morning sir. R., during the operation there were complications ... I am very sorry ... diverticula were really many and even large ... but unfortunately there is cancer to the whole perineum! Later the oncologist will come and she will tell you what to do. **Best wishes! [7-8 minutes]**“
From the **Australian** Narratives

**Professional surgeon**

- “He was very **approachable** and down to earth recommended further investigation and chemo therapy. He gave me great **confidence**.”
- “I immediately **felt comfortable** with him. At ease and he **listened to** what I had to say.”
- “The surgeon was very **understanding and supportive**”.
- “He used layman's language to explain the procedure and answered all questions in detail with **patience and compassion**.”

**Daunting surgeon**

- “My surgeon was very thorough in providing the required information, a little **more empathy would have helped**”.
- **Scary** as we both had no idea why I was so sick”.
- “**Scary**.. you know you need the surgery but your **overwhelmed** just being there”.
- “**Daunting**. Not knowing anything at all about stomas. It was a life and death situation for me, so I had no choice.”
The Dynamic Process of Emotions During Surgeon Encounters

Italian Surgeon Encounters

- Confusion: 19%
- Fear/Panic: 43%
- Sadness: 7%
- Confusion: 19%
- Resignation: 12%

Australian Surgeon Encounters

- Fear/Overwhelm/Shock: 54%
- Sad/Depressed: 5%
- Resignation: 5%
- Hope/Reassuring: 36%

• In other cases there is an evolution from confusion to hope and a positive sense of reassurance and relief.

• The prevailing emotion is fear/panic, feeling overwhelmed by the bad information and the agitated moments, while the feeling of anger is absent. After the dialogue, hope is emerging in the end.
Encountering the Stomal Therapy Nurse

Italian ENT Encounters
- Information 68%
- Information & Psychological support 32%

Australian STN Encounters
- Reassuring/Caring 38%
- Informative 27%
- Daunting/Rushed 35%

• The E.T. nurse is the reference point for the patients, who reinforce communication, calms and reassures the patient, establishing an empathetic relationship.
  • “It’s been nice because he is a very human person, sympathetic and calm. He gave me a lot of detailed information, and also a lot of confidence and quietness”.

• Differing reference points: Informative for the patients, reassuring and caring, empathetic relationship; “she was caring and very understanding”; “excellent, xxxx was very helpful”.
• The daunting and rushed nurse, less empathetic. “she was rather rude actually. Didn’t like me asking too many questions”; “very business like, not much empathy”.
Emotions after meeting with the ET/STN

**Italian Emotions post-meeting**

- **ENT**
  - Confused with problems: 19%
  - Reassured/Comforted: 81%

**Australian Emotions post-meeting**

- **STN**
  - Confused/Shocked/Worried: 38%
  - Comfortable/Reassured: 62%

**Extracts from patient responses**

- "since the moment I have met the E.T. nurse Mr. …, 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 E.T. nurse I felt ready to face my new status with determination and serenity".
- "I felt lost and meaningless, everything was finished in that operating theatre"

- "I felt consulted and treated with dignity and care; I got information in a way I was able to cope with. I felt listened to; Grateful for her friendliness and kindness".
- "I felt uninformed, worried, apprehensive, frightened; belittled felt she had no sympathy to me felt that it was all my fault what had happened".
I Would Have Liked to Know….

**Italian 'Would have liked to know'**
- Return to normal life 10%
- More details 10%
- Nothing more/exhaustive 48%
- Information about life with stoma 29%
- Ostomy avoidable 3%

**Australian 'Would have liked to know'**
- Nothing more 21%
- Practical information managing stoma 20%
- Details on surgery/stoma 19%
- Prevention of complications/risks 16%
- Living with a stoma 13%
- About avoiding 4%
- Why it occurred 4%
- About the cancer 3%

- "I asked all the information that could make my life with ostomy easier. I followed every advice that the E.T. nurse gave me and I felt good".
- "I would have liked to know that there would have been outpatients’ visits after the dismissal".
- "The pathway of care and the timing".
- "...that I would have returned as before".

- "there were no unanswered questions or feelings".
- "I needed to know how to place an order for colostomy bags, I still wasn't aware enough of how to do so, and consequently ran out of bags on a couple of occasions".
- "what is a stoma, what does it look like?"
- "What complications or issues may arise".
- "what it would be like to go out in public with a stoma".
The Surgery
The surgery represents a **total life change** for the patients who will have a permanent stoma, it is a **traumatic break point**. For patients that will have a temporary stoma, it is a step on the way of the recovery, but also it can be a trauma.

**Italy:**

- "For me the surgery was the first step towards a possible solution. All health professionals, anaesthesiologist, the surgeon, nurses have guided and supported me in an extraordinary way."
- “It has been a traumatic experience not knowing what actually was going to happen”.
- “it was a lifeline even if I faced it with fear".

---

**Italian post-surgery**

- Traumatic/De-vastating: 26%
- Relief/Positive: 34%
- Weak/Painful: 23%
- Necessary/Lifeline: 17%
Australia: A Similar Experience of the Surgery

Australia:
• "Barely memorable. I had been very sick with infection due to an anovaginal fistula so it was like being in the middle of a cyclone just riding the waves until I got through”.
• "awful, I was in intensive care for 3 days and had 3 blood transfusions”.
• "Not a pleasant experience. Shock”.
• “Well done and comfortable. The surgeon had told me that he wanted me to be in hospital for four days so that I could learn how to care for the stoma. The registrar working under the surgeon kept trying to send me home after one day. The nurses reassured me that I must stay until the surgeon discharged me”.
Living with a Stoma today
The Stoma & Me (Italy)

Italy:

• "We became good friends because it keeps me alive".
• "awful, I was in intensive care for 3 days and had 3 blood transfusions".
• "Not a pleasant experience. Shock".
• “Well done and comfortable. The surgeon had told me that he wanted me to be in hospital for four days so that I could learn how to care for the stoma. The registrar working under the surgeon kept trying to send me home after one day. The nurses reassured me that I must stay until the surgeon discharged me".

Italian 'stoma and me'

- Serene 49%
- Normal 17%
- Not good 19%
- Resignation 15%
9% of respondents gave a name to the stoma.
I Would Like By My Side…..

**Italy:**

- In the majority of Italian narratives the **family members** are supportive to the patient. In addition, in some cases, the patients need also the support of a **professional**.

**Australia:**

- "In the majority of Australian narratives the **health care professionals** are supportive to the patient, in particular stoma nurses and associations."
The first encounter with the surgeon is a **crucial event** during which the diagnosis and the need of the ostomy are communicated. It is a hard task for the surgeon.

The importance of the communication by the healthcare professionals (both surgeons and nurses), the use of the right words and the proper setting of the encounters can help and foster the patient to cope.

Time to cope with the stoma: The reaction varies from one individual to the other.

The importance of listening the needs and the feelings of the patients. Consider a physiological time of accommodation.
Italy - The importance of the family, 62% would like to be assisted by a member of the family.

The stoma denial: Patients don’t want information. Before the surgery patients don’t want or can’t imagine how the stoma will be. After the surgery the patients neither want to see the stoma nor manage it.

Take care of the family/caregiver by the healthcare professionals: the ostomy has an impact not only on the patient but also on the family that helps the patient.

Give the opportunity to patients to share their own experience and meet people living with a stoma. Create awareness through social media about living with a stoma as social information in Italy is almost totally lacking.
Findings & Actions to Consider: Divergences (Australia)

Australia: Patient Support

- Require, main caregivers, nurses and peer groups.
- They don’t speak too much about family, they speak about their loneliness at home.

Education and Information

- Provide an «affordable amount» of information and training during recovery phase at hospital, by nurses and peer volunteers.
- Adapt tools for patients immediate discharge to reassure, reinforce training and monitor progress,
- Listen to patients’ narrative in the hospital and in their community/at home.
- Help them identify a person in their community to assist to overcome loneliness.
- Help healthcare professionals negotiate more time for recovery in hospital.
Conclusion

- These are the first studies utilising Narrative Medicine in Italy & Australia of people living with a stoma

- Different cultural contexts illustrate different findings:
  - Less stigma in Australia
  - Preference for best technical skills
  - Desire for more help from nurses at the discharge and at home
  - Fewer boundaries with the family and
  - Huge distances from centers of care

- The sharing of patients’ narratives can foster better dialogue with all members of the health care team

- Naming the stoma may assist with patients’ coping skills:
  - It might be as simple to ask some patients "give a name to your stoma".
Listening deeply to the patients’ satisfaction and venting. Narrative medicine provides a deeper insight, which can include also inconsistencies but we, as human being, are inconsistent, as we daily experience the dynamic movement of feelings and thoughts. Honoring the stories of illness means including complexity and providing dynamic solutions of care.
Creating an Eco-Friendly System

- A balance should be found for using both Narrative medicine and Evidence-based medicine

- Hot Climate can be «cooled down» by kindness and listening to needs of health care professionals

- The use of a Universal (not standardised) tool of language could be a symbiosis for allowing cross cultural narratives collection, without erasing the diversity *(atoms are the same everywhere: it is the way they mix up which makes the difference)*
Thank you for your attention

Mmarini@istud.it