



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 CO₂ 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

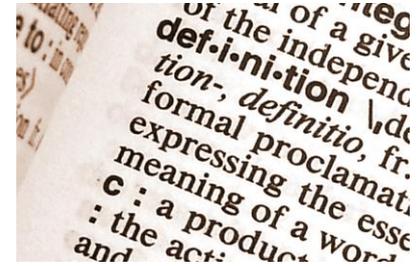
Defining Narrative Medicine

- 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 Hurwitz , 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

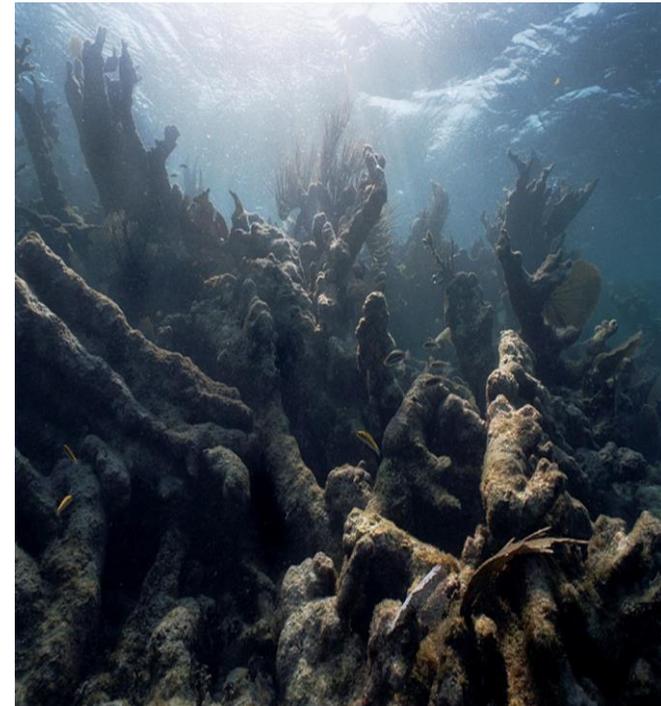
What is Evidence-Based Medicine?

- 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.

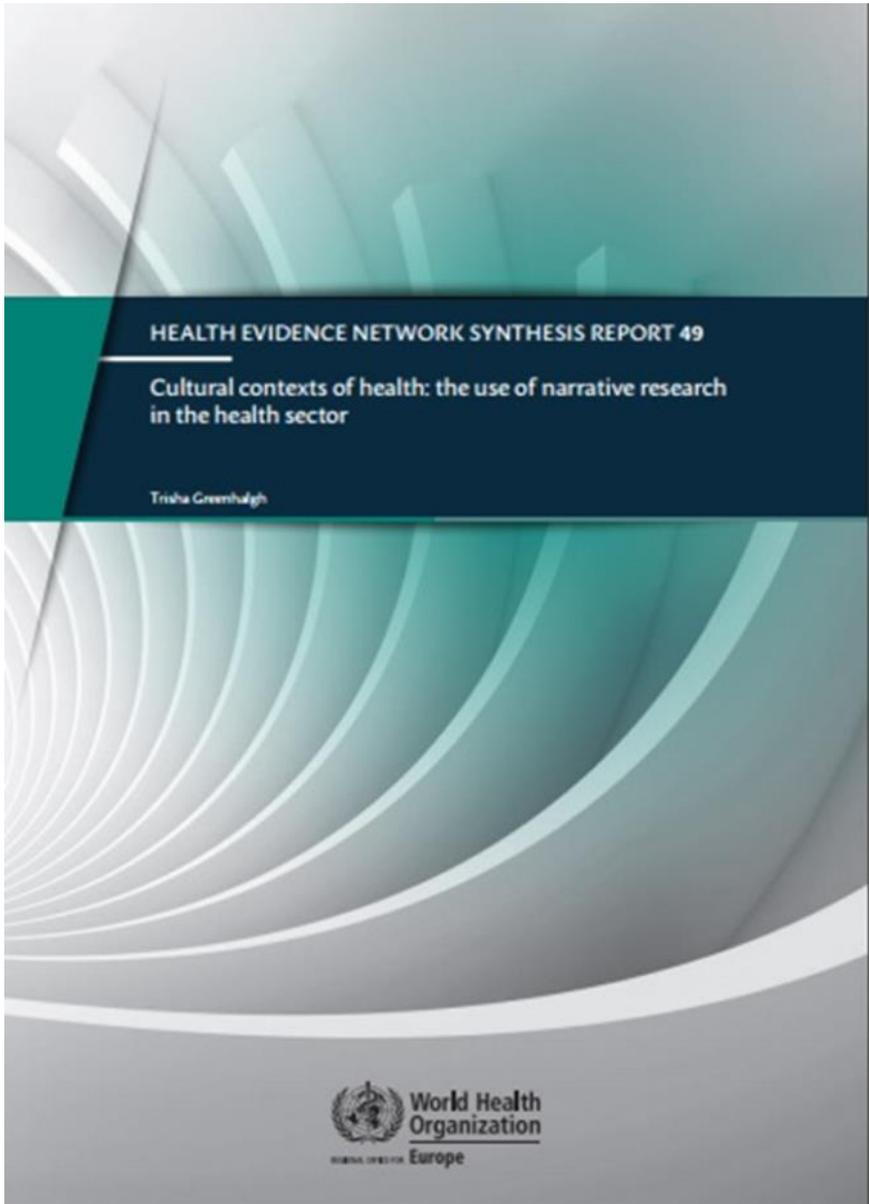


T Greenhalgh, BMJ, 2014

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?

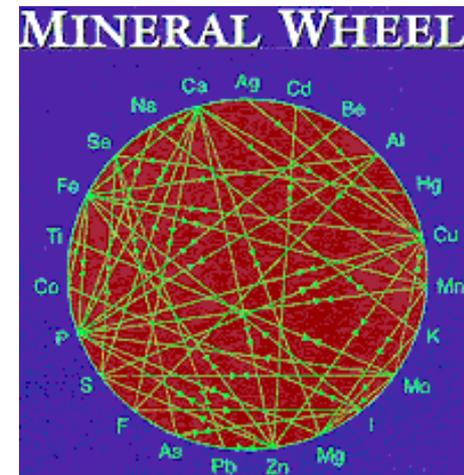
- Culture is a set of **practices and behaviours** defined by **customs, habits, language, and geography** that groups of individuals share“.
- While much progress in medicine had been made through epidemiological and basic science research, the lack of systematic attention to culture is a significant 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



Communication Across Countries – An Australian Discovery

- 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)*



Pangea – 250 million years ago

- 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.**
(Weiten, W. & Lloyd, M.A. (2008.
- *The narrative moves on when coping is achieved.*



Coping – Activating & Deactivating Factors

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

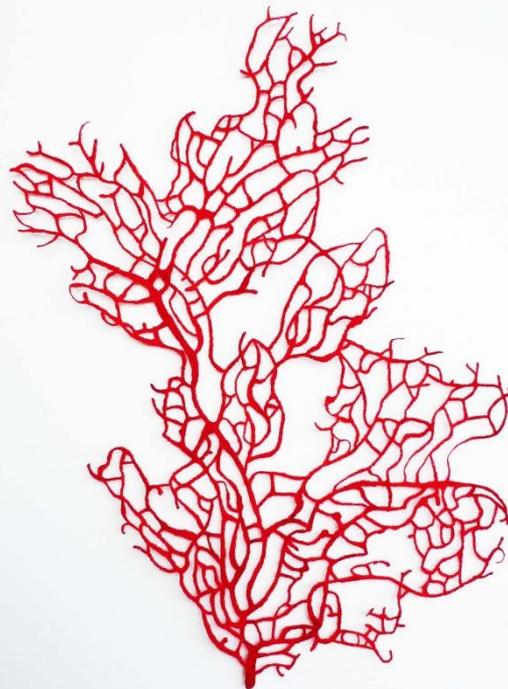


Carver C.S. et al. *Assessing coping strategies: a theoretically based approach.*
Journal of Personality and Social Psychology, 1989. Vol.56, N.2 267-283

Clustering Narratives



Disease
Illness
Sickness
Kleinman

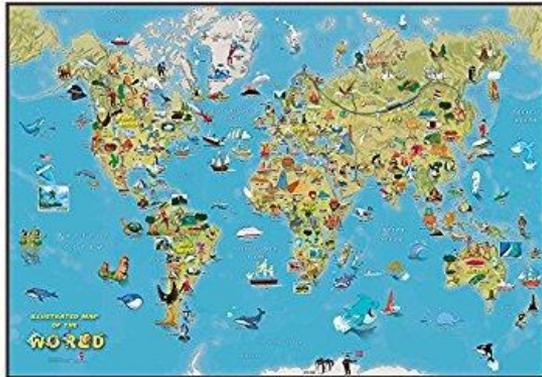


Progressive
Regressive
Stable
*Launer,
Robinson*



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

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 Narrative Plot

Natural Semantic Metalanguage

Metalinguage = a form of language or set of terms used to describe or analyse another 'language'.



Results from Patient Narratives

62 Australian patients
151 Italian patients



Narratives to Share Experiences



Italian respondents:
venting

Australian respondents:
sharing

"Telling my experience gives me a sense of liberation."

"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."

"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."

The Health Care Professionals



Encountering the Surgeon in Italy & Australia

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

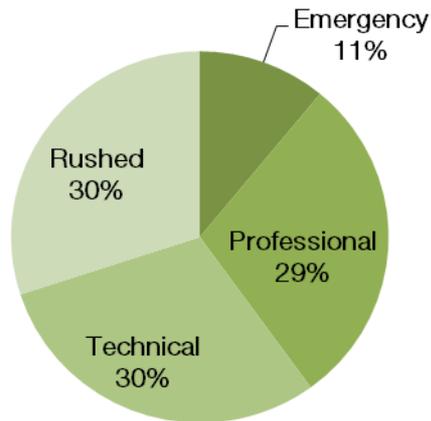
Patient sees the surgery and the ostomy as a way to save his/her life, in this case it is easy for the surgeon to explain the stoma surgery.

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

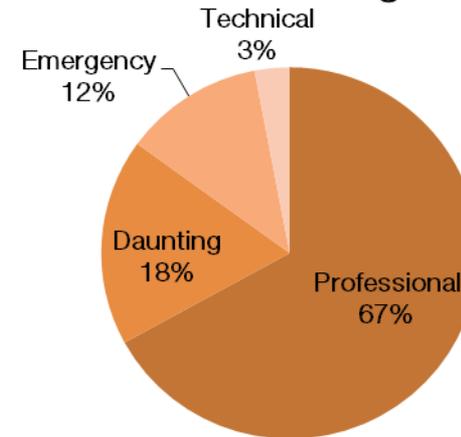
Patient is focused on the change of their life with a stoma - the surgeon has to persuade the patient that his/her life with the stoma will be "normal".

Surgeons are Better Perceived in Australia

Italian Surgeons



Australian Surgeons



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.

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

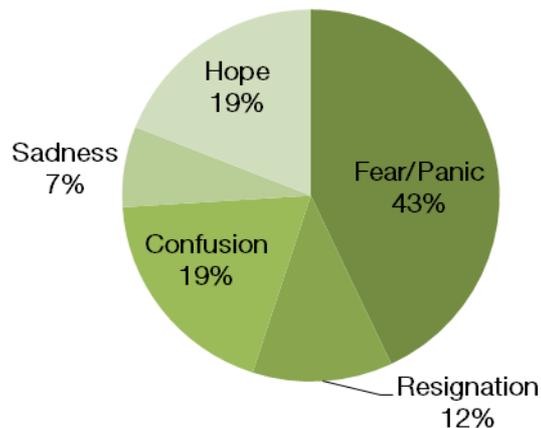
- *“He was very **approachable** and down to earth recommended further investigation and chemo therapy. He gave me great **confidence**.”
“I immediately **felt comfortable** with him. At ease and he **listened to** what I had to say.” “The surgeon was very **understanding and supportive**”.
“He used 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.”*

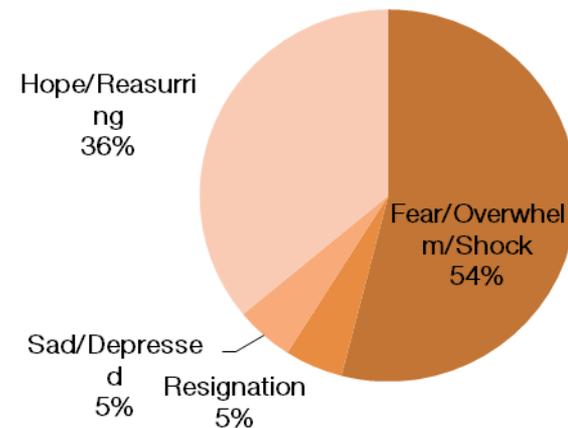
The Dynamic Process of Emotions During Surgeon Encounters

Italian Surgeon Encounters



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

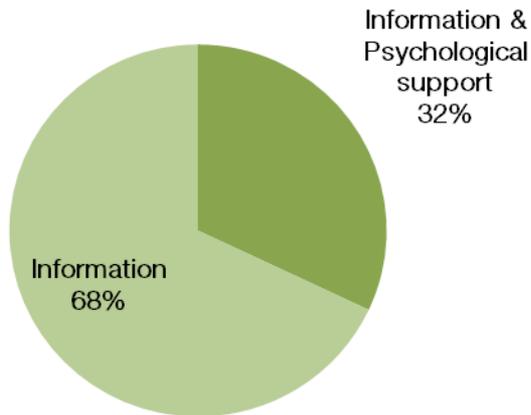
Australian Surgeon Encounters



- 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.

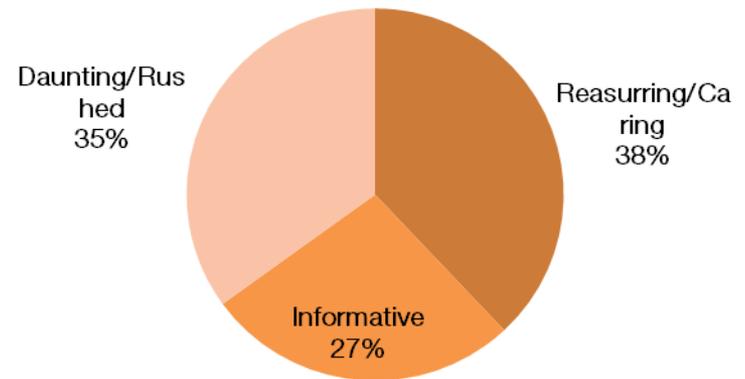
Encountering the Stomal Therapy Nurse

Italian ENT Encounters



- 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”.*

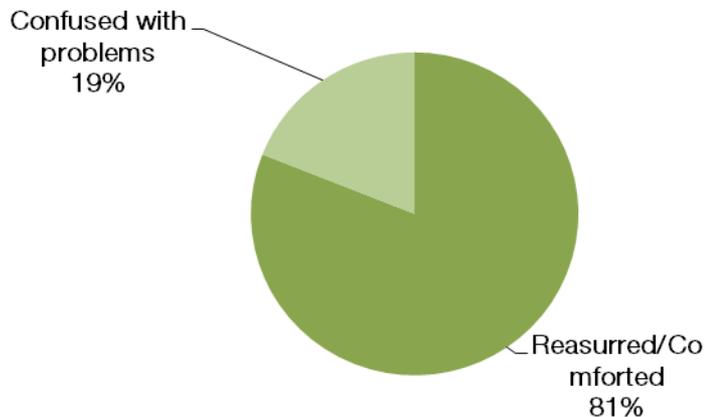
Australian STN Encounters



- **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”*.

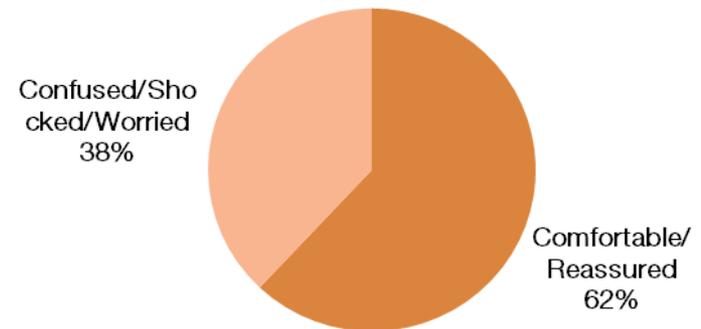
Emotions after meeting with the ET/STN

Italian Emotions post-meeting
ENT



- "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"

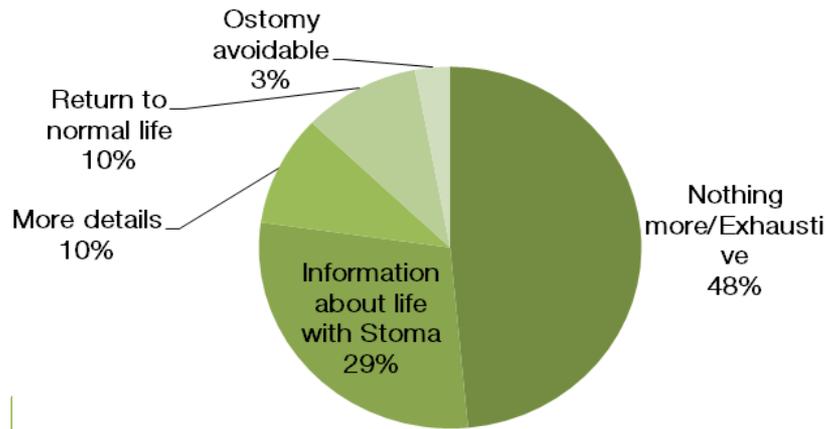
Australian Emotions post-meeting
STN



- "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".

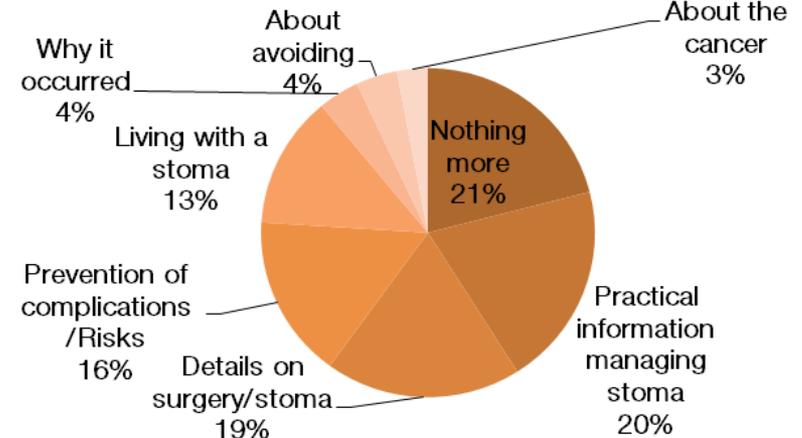
I Would Have Liked to Know....

Italian 'Would have liked to know'



- "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**".

Australian 'Would have liked to know'



- "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**".

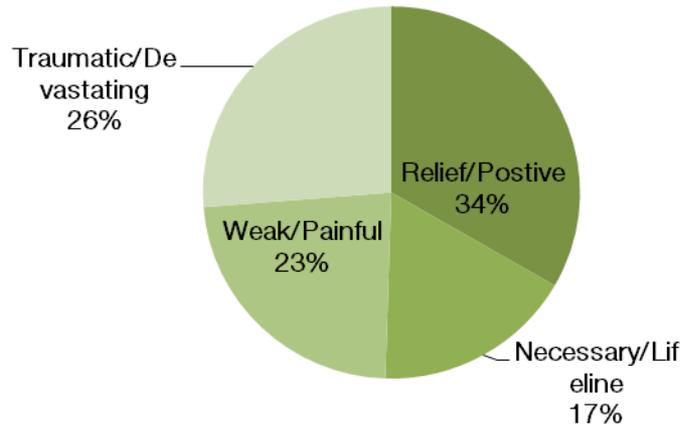
The Surgery



Life After Surgery - Italy

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.

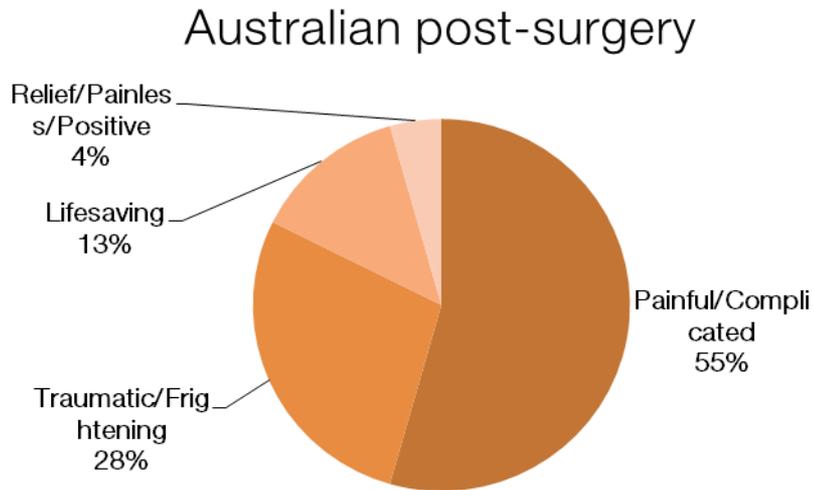
Italian post-surgery



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".

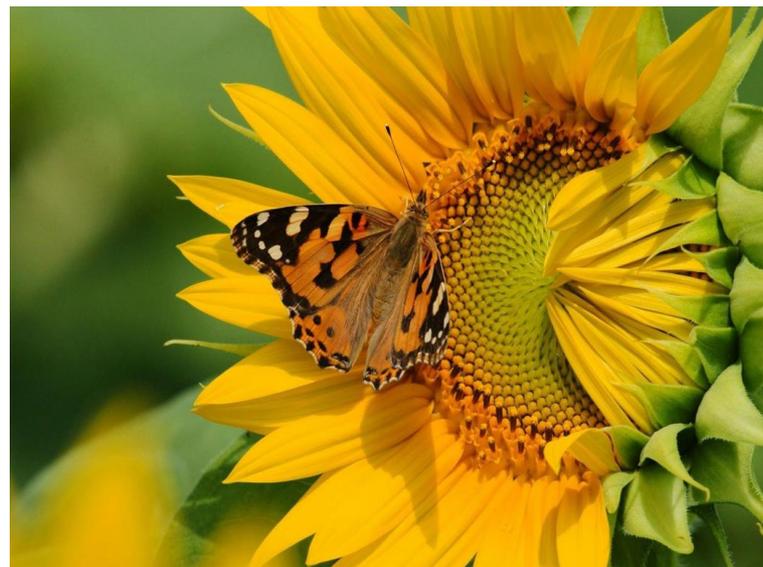
Australia: A Similar Experience of the Surgery



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

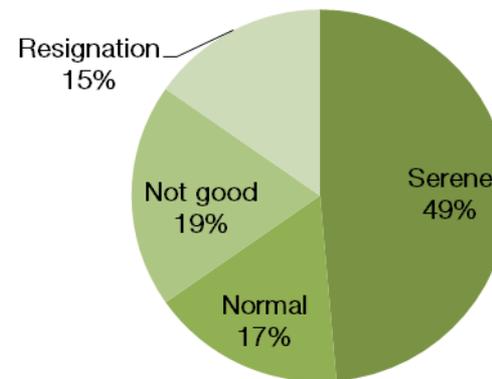


The Stoma & Me (Italy)

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'

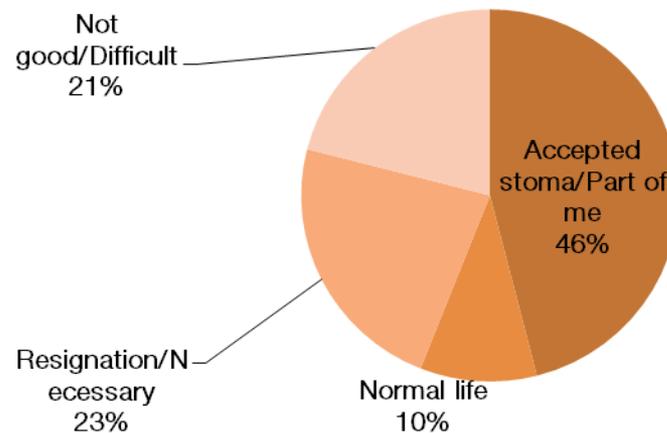


The Stoma & Me (Australia). The Importance of Giving it a Name

Australia:

- "It's a part of me".
- "We get along fine.. I have no problems with the stoma".
- "I have had to accept it as part of my body. I just don't like the look of it".
- "I accept it, but hate the look of it. And hate what women think of it".
- "I hate my situation".
- "My stoma today is very bad and life is closing in as I cant go out with out bag changes".

Australian 'stoma and me'



*9% of respondents gave a **name** to the stoma*

 **Black text**



Red text

ACCEPTANCE

part of me

new part of my body

good friend

my best friend

constant companion

Fred Stanley Harry Bubby

blessing lifesaver

RESIGNATION

little discomfort

ugly but necessary

wallet that needs to be empty

attached to my body

something tender, fragile

TECHNICALITY

efficient solution

temporary tool

pouch

mounting plate

little hole

little bag

little mouth

little tomato

raspberry

DIFFICULTY

disgusting

large slug

big handicap

Richard Nixon

large scar challenge

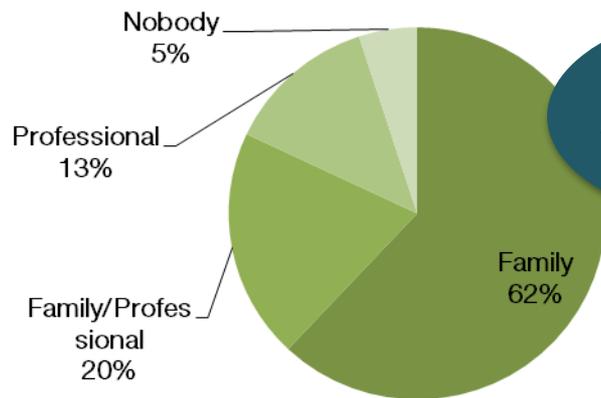
nuisance brick noisy

intrusion

extraneous body

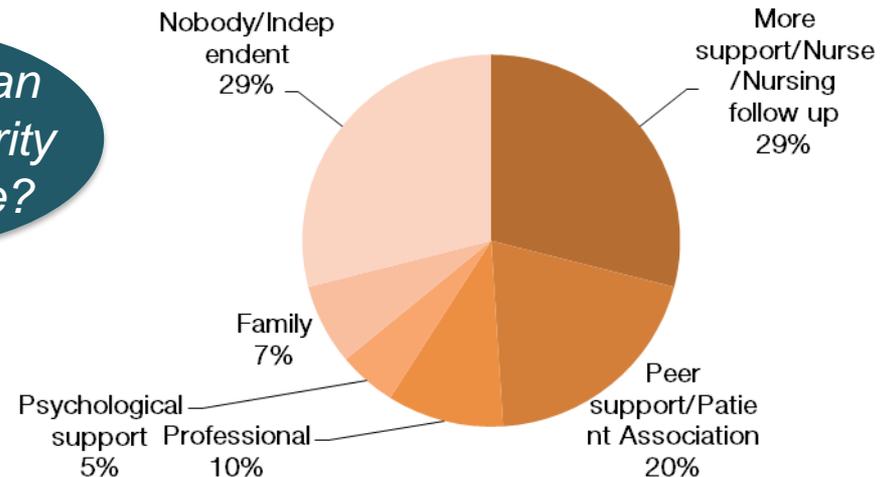
I Would Like By My Side.....

Italian 'by my side'



Family: is is an Italian peculiarity of the culture?

Australian 'by my side'



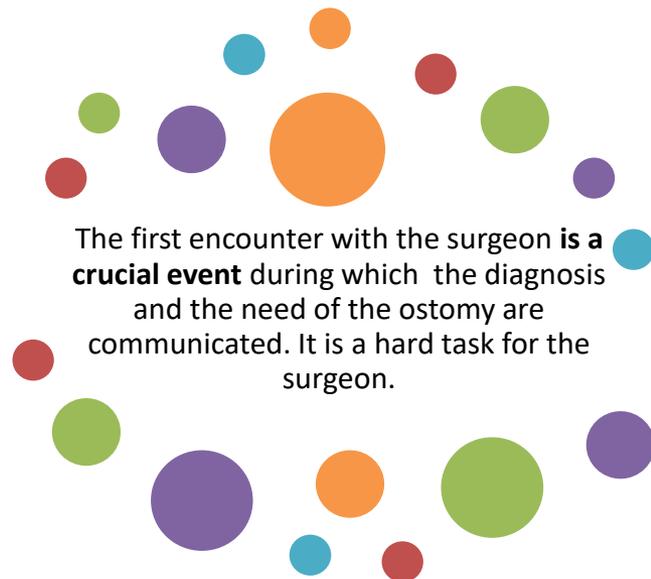
Italy:

- 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**.

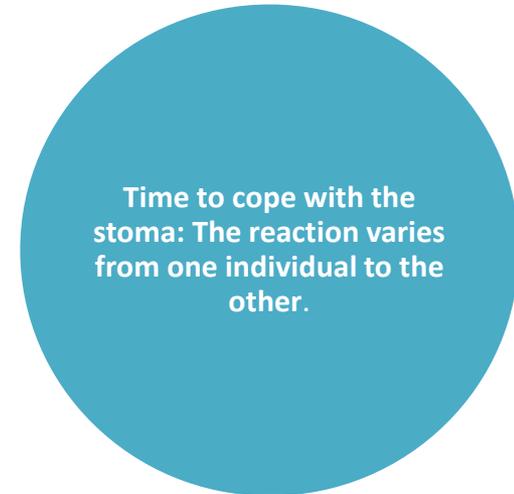
Australia:

- "In the majority of Australian narratives **the health care professionals are supportive to the patient, in particular stoma nurses and associations.**"

Findings & Actions: Common Elements



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.



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

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.

The importance of listening the needs and the feelings of the patients. Consider a physiological time of accommodation

Findings & Actions: Diversions (Italy)

Italy -The importance of the family, 62% would like to be assisted by a member of the family

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.

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.

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"*.

Honouring the stories of illness means...

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 you attention



Mmarini@istud.it