

## **Collecting stories of illness experience: an undergraduate medical curriculum to develop connectedness and togetherness with patients.**

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### **Abstract**

In Western culture, medicine is currently conceived as a complex discipline (Berlin et al., 2017), based both on biological and human aspects, related respectively to hard and human sciences. All of these aspects are considered crucial, when caring for a patient (Zannini, 2008). The development of Western medicine (Foucault, 1963) has progressively emphasized the biological and “hard” component of medicine, focusing physicians’ competencies on identification and management of physical disease, namely on the sick part of the patient’s body. Soft skills, related to the ability of setting up a relationship with patients, were often relegated to the personal characteristics and private background of the physician. Consequently, in the Sixties, during the development of hard medicine, little attention was paid to the improvement of those competencies useful to create togetherness and connectedness with patients and other professionals. In the last decades, a renovated interest for human aspects of medicine has been registered (Cowen et al. 2016): developing “soft” skills is currently considered crucial in the medical education literature. Diverse pedagogical strategies could be chosen to develop those skills, including both emotional and cognitive elements. Enhancing the consideration of patients’ life stories and their illness experience can be a way to develop soft skills in medical students and therefore the competencies useful to develop connectedness (Charon, 2014; Arntfield et al., 2013). Moreover, training narrative abilities (West et al., 2007) will help future doctors give meaning to their experience (Bruner, 1990), without losing human aspects in clinical practice (West, 2001).

The contribution will present a curriculum for 2<sup>nd</sup> year medical students (University of Milan, San Paolo Teaching Hospital), specifically oriented to develop soft skills during the preclinical years. During the second year, students are requested to go to the ward and gather a patient’s story of his/her illness experience. This paper will comment and discuss the students’ learning emerging from this writing experience, highlighting how it can contribute in creating connectedness with patients.

## **1. Developing soft skills in medical education: a route to create connectedness with patients**

The development of soft skills is a crucial and challenging point in medical education. Recently, literature has underlined that physicians, if trained to critical thinking and in communication skills, can enhance the relationship with their patients (Cowen, Kaufman e Schoenherr, 2016). Specifically, these abilities are fundamental to understand the bio-psycho-social-spiritual complexity of each patient, allowing medical professionals to experiment proximity to them.

Undergraduate education has an important role in training soft skills, even if the development of Western medicine (Foucault, 1969) has progressively emphasized the biological and “hard” component of medical practice, focusing physicians’ competencies on identification and management of physical disease, namely on the sick part of the patient’s body. Soft skills, related to the ability of setting up a relationship with patients and the other professionals, were often relegated to the personal characteristics and to the background of the physician. In the past, little attention was paid to the improvement of those competencies useful to create togetherness and connectedness with patients and other professionals, with evident consequences on patients’ and even professionals’ discontents. For example, healthcare professionals’ burn-out and depression have been lately related also to their incapacity of remaining connected to the patients, the others, and themselves (McKenna et al. 2016). In the last decades, a renovated interest for human aspects of medicine has been registered (Cowen et al. 2016) and developing “soft” skills is currently considered crucial in the medical education literature.

The term “soft skills” concerns different abilities, such as communication skills, empathy, problem solving, understanding of ethical dilemmas, and collaborating with other professionals (Ray, Overman, 2014). These competences are different and they involve both emotional and cognitive aspects. In order to train cognitive characteristics of soft skills, group-based activities as Problem Based Learning and analysis and discussion of cases can improve not only students’ abilities in problem solving and reflexivity, but also their communication skills and team building (Fabbri, Melacarne, 2015).

Studies have underlined that a fundamental strategy to train communicative, relational and ethical components of soft skills is the proposal of a clinical experience, where students can interact with patients and receive a formative feedback on their professional behavior from tutors (Melacarne, Bonometti, 2014). In this way, they also can learn to be empathic, a crucial

aspect in order to understand patients' feelings and to develop connectedness with them. Staying "on the field" is a necessary but not sufficient condition, in order to develop this crucial aspect of soft skills (Mortari, 2003). For this reason, a number of medical schools are proposing the use of portfolio to support students' training, in order to develop reflexivity (Perrella, 2016). A portfolio can include different materials, for example tutors' evaluation, samples of medical records that give evidence of the student's ability in the diagnostic and therapeutic process, bibliographical researches, participation in quality improvement projects, self-evaluations and narrative or reflective writings (Epstein, 2007).

Typically, in reflective writing activities, students report patients' experiences. Therefore, the proposal of those activities can be an educational chance to learn to grasp patients' experience, creating an opportunity to understand their perspective and to develop togetherness with them.

Enhancing the consideration of patients' life stories and their illness experiences can be a means to develop soft skills in medical students and therefore the competencies useful to develop connectedness (Charon, 2014; Arntfield et al., 2013). Moreover, training narrative abilities (West et al., 2007) will help future doctors give meaning to their experience (Bruner, 1990), without losing human aspects of clinical practice (West, 2001). Narration could be useful to take care of what has been experienced: it enables us to "give a name" to our experiences, reflecting on them and understanding them in a deeper manner (Demetrio, 2012).

## **2. Narrative Medicine and the attention to patients' stories**

Rita Charon, an American physician, defines narrative medicine "as a medicine practiced with the narrative competence to recognize, absorb, interpret and be moved by the stories of illness" (2006, p. VII). That competence is aimed to understand, in a deeper manner, what patients endure in their illness experience. This deeper understanding can be achieved by recognizing the metaphors or the images used by the patient in the telling, identifying the "unspoken subtexts" of that telling, and tolerating ambiguity and uncertainty of the story told by the patient. Narrative competence allows a person to understand the plight of another, through the use of imagination, interpretation and recognition.

Narrative features have always characterized medicine, but, especially after the Sixties, the huge development of technologies has progressively diminished the importance of telling the illness experience and the time dedicated to it, in the medical encounter. Nowadays "patients lament that their doctors don't listen to them or that they seem indifferent to their suffering"

(Charon, 2006, p. 3). This process caused discontents not only in patients but also in healthcare professionals, who need to find a meaning in their professional practice, as well as patients in their illness experience. It seems that healthcare professionals struggle to remain “connected” to their patients. Nevertheless, burnout and depression, which are increasing in healthcare contexts, have been related to their incapacity of remaining “connected” the others, and themselves (McKenna et al., 2016). Specifically, four aspects seem to divide healthcare professionals and patients: the conception of illness, which is conceived as a biological phenomenon by professionals, especially doctors; the beliefs about disease causality, according to the biomedical conception of illness; the emotions that arise in the patients from the illness experience, often shame, blame and fear; the relation to mortality, which is well known by physicians, who often consider it as technical defeat.

While patients need to narrate their experience, professionals often consider listening to patients’ narratives as a waste of time. Nevertheless, as the growth of the patient-centered care movement has shown, an integrated understanding of disease, referring it to the patient’s world, enhances clinical effectiveness through the construction of a partnership with him/her. Hence, “time is saved shortly down the road, by having developed a more robust clinical alliance from the start” (Charon, 2006, p. 67).

As a consequence, professionals need to develop their narrative competences. Yet, as Charon states, “achieving narrative competence is not a trivial goal” (2006, p. IX). Specific curricula must be implemented in undergraduate healthcare training. Referring to this, reading, writing and telling are fundamental to develop narrative competencies. In particular, writing seems to render visible aspects of our experience that would otherwise remain invisible or hidden.

Rita Charon (2012) has affirmed: “Without writing, I would not have realized the illness experience of my patients. Representing those interior events enabled me to see what goes on within myself as a clinician, as patients no doubt write illness narratives to make visible aspects of their own situation”. Hence, writing of patients’ experience can help healthcare professionals to become aware of their own experiences of pain and loss.

While writing clinical experience starts from the description of an event, it cannot be considered an act of reporting events objectively. It is a process related to personal “perception” of a certain experience, which, of course, prompts for a description of it.

A seminal example of writing to develop narrative competence is the “parallel chart” (Charon, 2006), a method aimed at enabling healthcare professionals to recognize what patients endure and to examine their own journeys through medicine. This exercise was implemented by

Charon with residents, and it consisted in writing about patients and clinical experience in an ordinary language. Residents were asked to write their lived experience in first person.

Studies have suggested that writing, and the reflective capacity that this activity improves, may develop communication skills, empathy, collaboration and, more generally, professionalism. In particular, writing reflectively has been shown as a means to increase students' observational and reporting skills (Cowen et al., 2016), to: allow students/professionals to recognize changes in their performance; to vent their feelings in relation to clinical experiences; to foster self-understanding and coping (Shapiro et al., 2006a).

Shapiro and colleagues (2006b) found that students who completed a "Point of View" (PoV) writing exercise (writing the experience of a patient in first person, from his/her point of view) were able to express more empathy and insight, if compared to a control group. Nevertheless, the authors advised that empathic skills developed through writing may not translate into future professional behavior.

In summary, narrative competence has received in the last ten years an increasing attention in undergraduate healthcare professional training and reflective writing has a pivotal role in the development of that competence. Educators, who have developed writing activities with students and/or professionals, may have experienced that "something important" happened in those situations, especially when students and professionals clearly demonstrated to have fostered their subjectivity and professional identity. Therefore, creating spaces in the curricula, in which students/professionals can deliberately tell and share their stories, finding differences and resonances, is pivotal to develop narrative competence and, more generally, to sustain the process that Gregory Bateson considered the basis of wisdom.

### **3. Collecting stories of illness experience: an undergraduate medical curriculum at San Paolo Teaching Hospital, University of Milan**

The use of writing as a reflective tool has been adopted in healthcare contexts since the Eighties, but medical schools show interest for it after 2000, when were published the first papers underpinning a direct connection between medical competence and reflexivity (Zannini, 2015). Health professionals' writings usually refer to two main categories of subjects: patients (and their families) and professionals themselves (Zannini, 2008). Writing and narrating clinical practice can be intended as chance to develop a closer contact with patients and their feelings about the illness experience, offering the possibility to health

professionals to become more involved , establishing a connectedness (Zannini, 2008; de Mennato, Formiconi, Orefice, Ferro Allodola, 2012). For all these reasons, narrating the experience and writing reflectively have a crucial role in training soft skills, particularly referring to the ability of understanding the others' lived experience and developing empathy (Biffi, 2010).

A recent review (Cowen et al. 2016) outlined that, notwithstanding an enthusiastic approval of those educational strategies, medical schools propose them as electives and not as compulsory activities. Different aspects can contribute to a scarce diffusion of writing activities, even if several studies showed their contribution to the development of empathy, reflexivity and communicative abilities (Chen, Forbes, 2014). Firstly, scientific evidence about their efficacy is not currently available, also because of the variety and diversity of the writing proposals. Furthermore, assessment of writing activities is really complex.

Moreover, educational activities for students based on writing request a considerable investment of human resources, able to read students' writing and to offer them a formative/summative feedback. In fact, students need to be accompanied not only in understanding the meaning of the writing experience, but also in gaining knowledge useful for their future professional activities. Giving feedback to students' writing, focusing it on a further development of reflexivity, is considered an activity of formative evaluation (Zannini, 2013). Certainly, this kind of evaluation is hard to be accomplished in medical schools, where teachers and supervisors are more used to train and evaluate clinical competences than to promote reflexivity.

Specific grids have been projected and tested in order to give feedback on reflective writings (Reis et al., 2010), showing different levels of reflexivity (Moon, 2004; Wald et al., 2012). This paper will present and discuss the medical students' learning emerged from a training proposal based on reflective writing referring to the Moon's scale for evaluating reflexivity, This activity was carried on in the A.Y. 2015-2016, in the Medical School of the University of Milan, at San Paolo Teaching Hospital, and it was proposed to the II year medical students. Starting from 2009, first year medical students attend a program aimed at introducing them to the patients' perspective: for three weeks they follow a nurse in the ward during the morning. This activity is accompanied by briefing and debriefing meetings held by the teacher of internal medicine. Subsequently, students have to write about the feelings and emotions they lived during their experience in the ward. These writings are inserted in student's electronic portfolio: the evaluation of this first writing contributes to the final mark of the Internal Medicine course.

In the second year, students are confronted with patients' stories: after attending a briefing focused on meaning and practical aspects of collecting stories, students are asked to collect the illness experience of one patient. Each student is introduced to a patient by the head nurse of the ward that was randomly assigned to him/her (Medicine, Psychiatry, Cardiology, Orthopedics, Urology, General Surgery, Oncology, Neurology). Students collect the illness experience, and write it using the first person, as the patient were narrating the story. Then, they share the collected stories in a debriefing meeting: working in small groups, they read their stories and then choose the most meaningful one. The student who collected the story chosen by his/her group has to tell it to the entire class, narrating it as if he/she were the patient (role-playing). Subsequently, students reflect on the story they have collected then re-write it (maximum 3500 words) using the third person, and adding their feelings, emotions, thoughts.

Other activities are proposed to students in the same curriculum: theoretical lessons aimed to explore the meaning and the characteristics of reflective writing; medical humanities path, based on the analysis of paintings and films, guided by an expert in art, in order to develop a critical gaze.

All of these activities sustain the development of soft skills, because they are based on sharing, mediating and reflecting. Moreover, there is a strong link with one of the objectives of the internal medicine course, focused on setting the basis for a history taking competence, where the capability of grasping the illness experience is fundamental.

During the third year, students are introduced to the first exercises of history taking: in this context, the attention is focused on clinical aspects and, as literature shows (Hojat et al., 2009), the risk of a disease-centered attention is high. The proposal of collecting the illness experience that medical students of the University of Milan had lived the year before can offer a valid countermeasure to that risk.

At the end of the third year, students also attended the compulsory course of communication skills, which is intended as the continuation of the precedent activities focused on soft skills, experienced in the first and second year.

This paper will report the findings that two blinded researchers individuated in the reflective writings based on the patients' illness experiences collected by second year students in the A.Y. 2015-2016.

#### **4. Commenting students' writings: can collecting stories be a strategy to promote togetherness with patients?**

A sample of 70 students' writings, casually chosen between the 101 collected in the A.Y. 2015-2016, were analysed, exploring the reflexivity expressed by students, according to the criteria proposed in the Moon scale (for the precise analytical procedure and results see Zannini et al., 2016).

Each writing was analysed considering not only its global level of reflexivity expressed, but also in light of the student's capability to grasp his/her feelings and the patients' ones, his/her ability to understand the social context of the patient and, finally, what the student learnt for his/her future medical profession. All of these elements contribute to develop closeness to patients, their lived experience and their world.

The general level of reflexivity emerged from the writings is high (4,31 on 6). Students mostly reflected on the emotions they felt when encountered the patient and on how this experience changed their attitudes or believes:

*I reflected on the meaning of suffering [...]. After meeting the patient I learnt that while a person is suffering, it's not easy to hope, it's necessary to have someone close, a parent, but also a professional, able to listen with humility and respect, being a source for more strength (student 68).*

According to what is reported above, we believe that the student can develop a professional medical identity also based on being close to patients and their suffering, developing togetherness with them.

Students' writings highlighted a good ability in reflecting about their emotions (average 1,5 on 2). The most cited ones are insecurity, fear, anguish:

*I was upset, terribly upset [...]. Anguish and insecurity went through me, probably because of my little experience in the medical field, but notwithstanding I also felt an insatiable wish of knowing and I was curious (student 33).*

The quoted writing emphasize the emotional impact of this experience on students and the necessity of an educational work to accompany them in grasping their emotions and elaborating the meaning of this experience with a patient. Understanding and recognizing their own feelings is a crucial aspect for empathy. Recognizing perceptions of a patient allows

health professionals to reflect on these aspects during the therapeutic relationship, also perceiving and understanding patients' feelings.

Reflecting on our own emotions is the first step in order to become able in recognizing others' feeling. We noticed that students' writing highlighted a higher capacity of grasping their own perceptions than the patients' ones.

*He really struck me. I tried to empathize but I wasn't able to do that, I felt it was impossible smiling and being calm as he was in that terrible situation (student 45).*

In this sense, students' writing make visible the necessity of an educational work, focused on reflecting on the passage between identifying their own emotions and the patient's ones, developing a broaden ability in understanding them. This step is really important in order to develop the student's capacity to perceive and act togetherness with patients' experience.

Students seemed quite skilled in recognizing patients' social context, reflecting on it: this aspect is crucial in understanding patients' world, in which the illness experience should be framed. A health professional who pays attention to social context will be able to grasp fundamental details, in order to stay connected with the patients' world.

*Referring to his words, I noticed that very few people was cited in his narrative... his sister was the person who was helping him more; her presence seemed fundamental in hard times (student 50).*

Fifty one students wrote reflections about professionalism. The experience with the patient seems to offer them the chance of thinking about the medical profession and about aspects of their future role:

*I'm reflecting to what extent, for a physician, it is important to understand the one who is in front of him/her, what kind of person he/she is. This knowledge is crucial to realize what the patient really needs. Only reaching this ability a doctor can act this wonderful profession in the best way (student 64).*

Trying to offer a final reflection, students writings show that the experience of collecting a patient's illness experience can be a crucial step in training soft skills. This abilities, as we underlined, are composed of different and various educational activities, all focused on

generating reflection. In this sense, collecting patients' stories can't be the only activity proposed to train soft skills, but the experience with the patient and the subsequent writing certainly outline a powerful effect of insight in medical students:

*This clinical encounter was interesting and formative for me, because it allowed me to grasp something different from the mere medical history. It gave me the opportunity to recognize the importance of putting aside the disease and listening to the patient. From his/her telling fundamental clinical details can also emerge. I realized that by stopping and talking with patients a physician can learn more than I thought (student 14).*

Referring to this last writing, we notice that the importance of integrating hard and soft skills has been internalized by the medical student, who seem to have understood that developing the ability to grasp the bio-psycho-social-spiritual complexity of patients helps in formulating a more accurate diagnosis.

Moreover, going beyond physical aspects of illness offers the opportunity to take into account the patients' lived experience, their emotions, their families, their social and cultural contexts. Medical students who have developed those skills could be better disposed to feel empathy for their patients, without losing their professional role, improving a clinical relationship based on connectedness with patients' experience.

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