

Therapeutic patient education: a paired vision

Natascia Bobbo¹, Renzo Marcolongo²

¹Università degli studi di Padova, ²Azienda Ospedaliera Universitaria di Padova

Abstract: Chronic illness is a major challenge for both patients and clinicians since their prolonged and sometimes unpredictable evolution threatens patient's quality of life and, at the same time, defies clinician's expertise and self-confidence (WHO, 2013, 2023). Thus, to better cope with it, patients and doctors should learn to work together. Yet, hidden defence mechanisms and concealed emotions often represent a major obstacle to communication and collaboration (Oliveira et al., 2012; de Vries, 2019; Despland et al., 2009). This intriguing, yet debated topic is discussed here by two experts who spent their life in the arena chronic disease from two different yet complementary perspectives: a veteran hospital practitioner with a prolonged clinical practice in chronic immunological diseases and TPE, and a professor of Pedagogy, who interlaced her academic work with a singular personal history of chronic illness.

Keywords: Therapeutic Patient Education; illness lived experience; clinicians' expertise; paired vision

Abstract: Le malattie croniche rappresentano una sfida importante sia per i pazienti che per i medici, poiché la loro lunga e talvolta imprevedibile evoluzione nel tempo minaccia la qualità di vita del paziente e, allo stesso tempo, sfida la competenza e la fiducia in sé stesso del medico (OMS, 2013, 2023). Pertanto, per affrontarla al meglio, pazienti e medici dovrebbero imparare a lavorare insieme. Tuttavia, i meccanismi di difesa nascosti e le emozioni spesso non espresse rappresentano un grosso ostacolo alla comunicazione e alla collaborazione (Oliveira et al., 2012; de Vries, 2019; Despland et al., 2009). Questo tema complesso e molto attuale viene qui discusso da due esperti che hanno trascorso la loro vita ad affrontare la malattia cronica da due prospettive diverse ma complementari: un medico ospedaliero con una lunga pratica clinica alle spalle nelle malattie immunologiche croniche e nella TPE, e una docente di Pedagogia che ha intrecciato il suo lavoro accademico con una singolare storia personale di malattia cronica.

Keywords: Educazione terapeutica; esperienza di malattia; competenze cliniche; intervista doppia

Introduction¹

Chronic illness is a major challenge for both patients and clinicians since their prolonged and sometimes unpredictable evolution threatens patient's quality of life and, at the same time, defies clinician's expertise and self-confidence (WHO, 2013, 2023). Thus, to better cope with it, patients and doctors should learn to work together. Yet, hidden defence mechanisms and concealed emotions often represent a major obstacle to communication and collaboration (Oliveira et al., 2012; de Vries, 2019; Despland et al., 2009). Actually, doctors are usually trained not to express their emotions, fearing that it could be interpreted as weakness (McNaughton et al., 2013; Richards, & Gross, 1999). Additionally, with the conviction that direct and complete information might frighten patients, some doctors avoid open and frank conversation (D'Errico et al., 2015). On their part, many patients hide their doctors some important details about their situation because they feel ashamed or afraid of being blamed (Cerna et al., 2022). Consequently, frequent misunderstandings undermine the chance to build a solid therapeutic alliance that is of vital importance for both patients and doctors.

Therapeutic patient education (TPE) is an educational strategy that was developed with the purpose of enabling healthcare professionals to share part of their knowledge and expertise with patients and or their families with the aim to make them active partners in their own care (WHO, 2023). TPE has a long history, and its conceptual development passed through different schools of thought from the beginning in the far fifties of last century to present-day, becoming a sort of battlefield among different academic disciplines and educative agencies. Nevertheless, while doctors, nurses, psychologists and educators claim TPE as their exclusive domain, patients are increasingly unsure who to trust, preferring readily available information on the internet (Jia et al., 2021).

This intriguing, yet debated topic is discussed here by two experts who spent their life in the arena chronic disease from two different yet complementary perspectives: a veteran hospital practitioner with a prolonged clinical practice in chronic immunological diseases and TPE, and a professor of Pedagogy, who interlaced her academic work with a singular personal history of chronic illness.

Renzo Marcolongo (RM): you are a professor and a scholar in Educational Sciences and Pedagogy, but you have also a singular, if not unique, personal experience of chronic illness. Hence, I would like to know the experience of a person who is both a pedagogist and a patient with a congenital heart disease that received two consecutive heart and kidney transplants. This is of great interest to me because, as a doctor, I have been always interested in understanding the actual needs and points of view of my patients. For this reason, I would like to know your feelings about your illness and how you and your family dealt with it.

Nataschia Bobbo (NB): Despite some ups and downs, some good days and some bad days as Charmaz (1997) could say, my current condition is of general wellbeing and good balance. However, in consideration of the fact that I had to receive repeated corrective heart surgeries, two heart and two kidney transplants with the necessity to take immunosuppressants for about thirty years, my daily habits have been distorted and I must permanently do a medical management, using the words of Corbin and Strauss (1988), adapting to an ever-changing situation, such as the introduction of a new medication rather than a dietary variation. So, during my lifetime I have grown up throughout many adversities, as Joseph and Linley (2005) could state: I cannot remember, indeed, a time in my life when I wasn't on treatment. Since early childhood, I had to learn to cope with the side-effects of medicines, struggling to integrate the "pill timetable" into my daily routine. When things get more difficult due to the appearance of a new side effect and my diet becomes difficult, or when I have a problem with my skin, which is thin and breaks easily, then my "creative side" comes out to devise an effective strategy for coping with them to regaining control of my life as Taylor (1983) suggested. Concerning food, for example, I developed a whole assortment of alternative cooking recipes to limit the sources of animal fats and sugar excess. I find particularly unpleasant the adverse effects of some medications on my physical appearance. As a matter of fact, I don't have a great appreciation for my

¹ This article was conceived and realised jointly by the two authors. However, specific attributions are given in the interview section. Nataschia Bobbo also wrote and edited the introduction and conclusion. The entire article was edited by Nataschia Bobbo.

body image, thus I put into practice some “disguising” strategies, such as wearing heavy stockings to hide my swollen ankles or long skirts and trousers to prevent or hide the appearance of inaeesthetic ecchymoses on my legs. These little strategic interventions help me to carry on with my daily life and to prevent what Frank define “a sign on the surface of the body making it as dangerous, guilty or unclean” (1991, p. 64), which is often that I perceive.

RM. After spending my life with patients suffering from systemic immunomediated diseases (SIDs) who were taking immunosuppressive drugs, I have been deeply impressed by their creativity in terms of adaptation to the restrictions caused by their illness. Since I started to practice TPE, I have often drawn inspiration from what may patients spontaneously devised to overcome some routinary problems in the management of their illness. In my TPE activity I also encourage patients to share their knowhow between them because, as many other colleagues such as Zhang & Hu (2022), Longley et al. (2023), Husain et al. (2020) and others, I think that reciprocal counselling between peers is much more effective and convincing than the best doctors’ advice. But, in your opinion, which are the features of an “ideal” doctor? And, considering your long history of disease, what would you expect from such a doctor?

NB. I’m aware to be an “experienced” patient, as Donaldson (2003) calls patients like me, and consequently a potential “troublemaker” for doctors. Indeed, the common perception that many doctors have of this kind of patients is that they usually ask for a different therapeutic relationship, based on constructive dialogue and collaboration rather than on passive obedience as Hickmann et al. state in their revision recently published (2022). Personally, I need a doctor who clearly explains to me his/her therapeutic proposal, leaving to me the last choice to undergo or not a given therapy or to take a new drug. I have developed a deep knowledge and understanding of my body language, because since the early years of my life my body has never been dis-apparent (Becker, 1997): various symptoms have always made my body present to me. So, when I feel a sensation, even if I’m not a doctor and I can’t make a medical diagnosis, I often guess it, in the sense that what I feel usually then coincides with the diagnosis made by the doctor. Nevertheless, in some cases I have met doctors who, instead of listening to me and trusting my sensations, using my voice as said Addario and her collaborators (2020) as a means for the diagnosis, rather bothered me a lot with their explanations. That’s why my “ideal” doctor should always pay great attention to what I feel.

RM. I’m very impressed by what you said. I would like to emphasise that in clinical practice, rather than with “diseases”, doctors are confronted with “people” who are suffering from a disease, as Kleinman (1988) pointed out a long time ago. This is particularly true for patients who develops a SID, as, for example, a systemic lupus erythematosus (SLE). Every SLE patient experiences his/her own personal illness with a peculiar clinical presentation and evolution (Case et al., 2021), which requires a personalized treatment. Thus, rather to provide patients with a “global” medical view of SLE, TPE should be rather aimed to help every single SLE patient to better focus on her or his “own” SLE with its peculiar expression and react properly. For the same reason, patients don’t need a “global” knowledge about SLE treatment, but just to know and how to manage properly and safely their “own” treatment. Concerning who prevails in the power balance between doctors and patients, I think that, at least in some cases, what truly predominates is neither the doctor nor the patient, but the disease itself. In other words, both doctors and patients are often submitted to the erratic and adverse behaviour of the disease that ultimately imposes to both “its rule”. For this reason, I have no doubt that you had to accept from your disease a tough lesson of humility, but I must admit that the disease of my patients caused also to me a deep sense of frustration and powerlessness. In such a situation, the only way out to react is working together. I wonder to know which were the most difficult obstacles that you encountered, and which strategies you deployed to cope with them.

NB. Rather than obstacles, I remember two particularly difficult moments of my life when, for a while, I really felt lost. It was when I had to receive a second heart transplant and a second kidney transplant as well. I was in a condition that Charmaz (1997) defines as “immersion in illness”, i.e., when you can’t do anything else than surviving or just checking your symptoms and trying to take under control pain, suffering and discomfort. In such a condition there is no room to do anything else and your life loses every normal feature, it was as yourself, your precedent identity is lost, and the biography you have built throughout your lifetime are disrupted as Bury (1982) states. I remember that I firmly held on two things: the first was my ability to fill my time, which suddenly slowed down

becoming unbearably empty, with my hobbies, i.e., intensive reading and knitting. Thankfully, I had the chance to grow in a family of tailors where I learnt sewing, embroidery, crocheting, etc. I remember that I knitted frenetically with both my arms full of intravenous needles and lines and the nurses putted the hands in their hairs fearing that I might pull out them. However, the simple idea of starting and finishing something gave a sense to my time, because when you are immersed in your illness and the time loses its significance, you risk losing your past, your present and, as consequences, even your future as Frank (1999) talks about narrating his experience of illness. A further life-saving strategy, which I had to learn very early in life, was the capacity to search and accept the aid of my family and other people. I have never hidden my illness to anyone, speaking openly of the limits of my physical condition with my family, my friends and colleagues, I have embraced my pathology as Charmaz (1997) states, because for me in many moments of my life there are no other choices. And, if on one side it excluded some people from my life, on the other it attracted other persons who became for me true reference points.

RM. And, if I well understand, your family have been always supporting you in every choice and decision.

NB. My family has been my first and main stronghold. My parents, my brother and my sister have been always besides me. Then, while I was still a young girl at the high school, I met my future husband. All these people not only have been always accompanying me along my entire story of illness, but they also never ceased to trust me as a person who was able to overcome the obstacles of life. Besides this, I had little opportunity to make good friends because, as you know, illness often frightens people (Lewis et al., 2024). As a child I missed a lot of school and this, combined with the fact that I was a young patient afflicted with heart failure and was not very good at classic children's games such as running, made it difficult for me to make friends or simply share time and activities with my peers. However, I have had some very good friends since my teens, all of whom I met at high school and university, and their support has been very important in allowing me to see the world through the eyes of their youthful strength and health. I think all this supporting network, family and friends together, was the distinguishing factor for my survival, so I can only confirm what many authors state about the significance of the supporting network for a chronic ill patient (for example, Schulman-Green et al., 2021, Iovino et al., 2021 and others).

RM. Your experience seems to suggest that a disease should never be considered an experience restricted to the patient, but that impacts also on the people around him/her. Actually, the emotional impact of the disease on patient's family sometimes can be so intensive to cause even more suffering among the family members than to the patient him/herself as the research of Rodríguez-González, Rodríguez-Míguez, and Claveri stressed (2021). Unfortunately, deep suffering and prolonged struggle caused by chronic disease, instead of reinforcing solidarity between the patient and the family members, sometimes can produce even more distress, depleting the intrinsic "healing resources" of the family. For this reason, in my opinion, at least in long-lasting and disabling disorders or in life-threatening diseases, TPE should always involve patient's family caregivers (Tanas et al., 2007).

NB. Since I was a child, my parents never hide anything to me, while the parents of many other children who, like me, were hospitalized waiting for surgery, hid them everything. On the contrary, I was always told about what it was going on because probably my parents thought that silence isn't golden rule, as stated in their book Drigo and colleagues (2010). Besides that, I must admit, often with little or no discount: I wasn't pampered just because I was sick child and, after recovering from a surgery, when I felt better, I was expected to do the same thing that my brothers had to do. They were incredible because they understood what they had to do with me without the support of anyone: at that time (my diagnosis was communicated to my parents in 1971) there were no therapeutic solutions to my problems, nor any association of patients that could help my mother and father to understand what was happening to us. So, they learned by doing, sometimes they were wrong, but most of the time they were very good, especially with me: they never stopped seeing me as a healthy child who could become, anyway, a good person.

RM. Certainly, your parents gave you a precious albeit "hard" lesson of life. Indeed, when a disease strikes early in life, it can heavily interfere with the development of a balanced personality and cause psychological and behavioural distortions (WHO, 2013). What would you say to a doctor or a nurse to encourage them to get more motivated and involved in TPE?

NB. Perhaps, I would try to convince them that sometimes patients have a level of knowledge and self-management skills that, at least in some cases, is even better than the one they think to have. Without understanding this point therapeutic relationship can't progress. Indeed, it is unlikely that a patient might accept his/her condition if the doctor doesn't give him/her also a strong confidence in what he/she can become despite the disease. Patients and doctors must walk together. Thinking that a patient cannot contribute consciously and actively to the therapy program is the worst way to approach a therapeutic relationship, because it inhibits every possibility to face the disease unpredictability.

RM. Nowadays, health information on the internet and social media tends to reinforce the idea of an "almighty" medicine. According to this vision, technology and new miraculous drugs look capable to magically solve every health problem, completely disregarding the "relational dimension" of the therapy. In your long story of illness, have you noticed any change in doctors' attitude towards you? And, if the case, have you perceived an improvement or a worsening trend?

NB. I didn't notice any significant change over time. Thirty or forty years ago as well as in recent years, I've been meeting doctors and nurses who are skilful, sensitive and attentive, but also others who are totally apathetic, arrogant and unprepared. Then, in my opinion it isn't a matter of time but probably of personal attitude. There is no doubt that health workers are living in an increasingly stressful condition, not only because of recent pandemic, but mainly because human resources in health service were already scarce even before as I stressed in one of my articles (Bobbo, 2023). However, in my opinion, what really makes the difference are not the working conditions, but rather something that is inherent to the single person, such as humility and the ability to look to patients as possible partners, rather than taking with them an authoritarian position. I have done some research about the "vocational" features of health professions. What came out is that, sadly, human solidarity and the interest for the patient as a person are no more the main motivations of many people who choose to be a doctor or a nurse, and, believe me, patients immediately feel it (Bobbo, Lazzaro, 2017).

RM. Unfortunately, as a clinical practitioner still involved in hospital practice, I can confirm, at least in part, your findings, though they appear in contrast with the widespread rhetoric about "therapeutic alliance" and an alleged "humanisation" of contemporary health service. In last decades I observed a progressive over-structuration and increase of workload, with the consequent reduction of the time devoted to the dialogue with the patient. However, I agree with your idea that the cause of this relational impoverishment does not lay in work overload, but that it rather depends on the choices and motivations of every single operator. There is no doubt that to improve the situation we must train our students to therapeutic relationship, but also to look to their deeper and intimal motivations. Indeed, when choosing a health profession, every student should ask him/herself some crucial questions such as: why did I choose to be a doctor or a nurse? And what kind of doctor or nurse do I want to be? Anyway, going back to your personal experience, to what extent the doctors that you encountered were able to build a true therapeutic partnership with you? Did they rally teach you the knowledge and the skills that you needed to self-manage your disease? And, in that case, how much it changed your situation?

NB. Who really changed the game was a cardiologist. In mid 1970s, when I was five or six years old, this doctor followed me with an incredible dedication and, in my opinion, she was also a great educator. I was particularly impressed when she told me: "you won't be always able to rely on your little body because you will never have enough strength to do everything you want, but don't forget to rely on your little head, that's why it's worth that you keep studying". What she said was probably the main motivation that prompted me to choose my career. I remember that, when I was crying because I was afraid to undergo another cardiac catheterisation, she told me: "No one can force you to do anything if you don't want to. Remember that you have the final choice but, before taking any decision, you must clearly know also what it means to say 'no'". I was only six years-old and she had already charged me with the responsibility to choose for my health. It was exactly from that moment that I learnt to say 'yes' or 'no' to every therapeutic proposal only after receiving enough clarifications and a careful personal evaluation. That doctor, she was a woman, teach to me the true significance of freedom, as Mounier (1962) described: a power linked with a charge.

RM. I just want to remark some key words and sentences from your speech, such as "you have the final choice" and "responsibility", which is closely linked to the former. I would like also to remark the ability of your cardiologist-educator to "ignite" in your mind the awareness that you were free to

decide for your-self. After all, education (from the Latin verb “ex-ducere”) literally consists in “pulling out” from someone what he or she has inside to develop his or her empowerment. Do you agree with me?

NB. Yes, that is the Socratic lesson! But as far as my story is concerned, there is no doubt that she gave me a decisive lesson, showing me a direction that I never left in my life. In addition, my mother, who more frequently accompanied me (unfortunately, my dad worked in a factory and couldn't joint us all the time) had a great appreciation for this doctor. We always paid a great attention and consideration to her words. Thus, I received a paired education and influence from both my doctor and my parents, and I completely absorbed it.

RM. Another key word that, in my opinion, is pivotal in every relationship is “trust”: no matter if in an educational or a therapeutic setting, the key factor is always a solid trust based on mutual confidence and solidarity. Otherwise, there is a considerable risk to slide toward legalistic and defensive positions that can be extremely detrimental to therapeutic relationship and the favourable evolution of patient’s situation (Bester, 2020). In other words, distrust itself can be a cause of “sickness”. How would you define “therapeutic education”? This term that recalls the generic idea of “health education” is still unfamiliar for many hospital practitioners who hardly acknowledge it as a professional task. How could we fill the gap? Could we rather speak about disease and TPE as a virtual “space to meet each other”, where doctors and patients can share goals, decisions, actions and responsibility about therapy?

NB. As I told you before, TPE can be defined as a “road” that doctors and patients should walk together, possibly including patients’ family. Certainly, TPE can be also defined as a “space to meet each other” where doctors can share their expectations and needs together with their fears and limits. However, doctors should renounce to part of their power (and fears) and find the humility to acknowledge and valorise the experience and the skills of patients. In my opinion, TPE cannot be limited to a mere “patient training”, as some documents of the World Health Organisation seem, at least in part, to suggest. Indeed, in my personal experience, mainly nurses tend to approach TPE in terms of “patient training”, with the risk to reduce it to a mere technical or mechanistic procedure, which can be really deleterious (Bobbo, 2020). The word “training” belongs to the military language and presumes a dynamic of power that is unsuitable to therapeutic relationship. We should remember that we are talking about “patients”, not about “soldiers”, and that TPE is not just matter of teaching simple procedures or actions, but it goes far beyond (Bobbo, 2021). When you receive the diagnosis of a severe disease your life comes to a dead end you can easily go mad or lose your main reference points if who take you in charge doesn’t show a way out. Bury described very well this moment of life patients live: “First, there is the disruption of taken-for-granted assumptions and behaviours; the breaching of common-sense boundaries. (...) Second, there are more profound disruptions in explanatory systems normally used by people, such that a fundamental re-thinking of the person’s biography and self-concept is involved. Third, there is the response to disruption involving the mobilisation of resources, in facing an altered situation (ivi, pp. 169–70). Then, beyond training patients to self-management skills, doctors and nurses should teach them how to regain self-confidence and the control on their life. Moreover, patients need something else, that is the chance to regain a sense, a significance of what has happened in their life, as Williams (2000) stressed. I believe that this should be the true essence of TPE.

RM. I came to the same conclusion because, as you know, I’m also living a personal experience of serious disease. Thus, deep in my heart, I live the same perspective of my patients. The irruption of a major disease in life usually triggers a transition from the condition of a putatively “healthy person” to that of a “sick person”, causing a deep change in self-perception and existential perspective. In the mid-seventies, a great French physician, Norbert Bensaïd, wrote that “in order not to get lost, who gets sick becomes to some extent another person, trying at the same to remain the same, yet otherwise”. Since, in the end, the healing process can be seen as an evolution to another balance, TPE can help patients to elaborate this transition preserving their identity.

NB. May I ask you one more question? When did your interest for TPE start and, above all, why?

RM. Since I was a student, I was early confronted with people suffering from aggressive or fatal diseases, hence I soon met the “limits” of medicine. Every idea of “omnipotence” disappeared, and I quickly lost the “pride of the novice doctor”, feeling to be unprepared to face something that was

“greater” than me and that I would have better understood only later in my life. Then, it became gradually clear that, to find the energy to face the hard reality of diseases, I needed also the help of my patients. Every serious disease is a test for both patients and doctors: on one side it reveals your limits, while on the other it gives you also the opportunity to bypass them by working together and gathering all available resources. Thus, I realized that TPE offered this opportunity to both doctor and patients. Nevertheless, at the same time, I clearly realized that not all doctors and patients were ready for TPE.

NB. In my personal view, the choice to become a doctor is very personal decision, a sort of mission, and not just a rational decision. Which is your opinion?

RM. The word “vocation”, nowadays, might sound a little bit rhetoric. I think that choosing a health profession doesn’t lay just on rational motivations but can be at least in part attributable also to a “vocation”, i.e., to an “intimal call”. Medicine is certainly a rational science that investigates the nature of diseases with the aim to find new or more effective treatments but, in the end, it also demands a certain degree of intimal propension to empathy and to help people who are in troubles.

NB. You asked me about my “ideal doctor”, but what about your “ideal patient”?

RM. I never looked for “ideal patients”, simply because they don’t exist. I am rather looking for an “ideal relationship” with my patients. I said “ideal” because, among the countless variables of disease and therapy, such as relapses, complications, treatment failures and drug side effects, etc., there are also the peculiar characteristics and reactions of every single patient. For instance, you mentioned the impact of the disease and medicines on your body image. Indeed, some drugs, such as corticosteroids, can produce deep changes of your body but also of your mood, sometimes with disrupting emotional and relational consequences. In such a case, to prevent dangerous misunderstandings, social isolation and therapeutic derangements, it is particularly worth that doctor and patient keep in constant touch to “navigate” together throughout the difficult moments. In conclusion, my “ideal” therapeutic relationship consists in a dynamic and tireless mutual exchange and collaboration with patients.

NB. Going back to the “vocation”, it is well known that, after working for many years as a doctor, it isn’t so easy to preserve initial enthusiasm and motivation for the job. This should be particularly true for someone who, like you, tried to break some traditional schemes of doctor-patient interaction. I would like to know how did your colleagues and working environment react to your way of approaching patients as partners?

RM. Certainly, it wasn’t easy and, to be honest, it is still difficult. When I was a student, senior doctors were not used to speak with patients and communication was mainly limited to prescriptions. I clearly remember that my boss told me that patients shouldn’t know everything about their condition to keep under control of the situation. Unfortunately, after spending about three decades in the practice and promotion of TPE, I must admit that, at least in Italy, little is changed in doctors’ mentality and mostly on the surface. Indeed, many so called “educational” interventions, rather than on patients, tend still to be centred on the disease or treatment, if not on doctors’ perspective. Often TPE has still the feature of a simple unidirectional information and is not followed by a learning assessment. In addition, today doctor-patient interactions are even more difficult than in the past. Nowadays, the great complexity of contemporary medical care, its increasing costs, the progressive reduction of health workforce and the proliferation of legal and bureaucratic aspects seriously threaten the quality of human relationships in the health system. At the same time, health expectations of patients and general population have greatly increased creating potentially conflictual conditions, while therapeutic relationships tend to shrink, becoming defensive and distrustful. When I started my interest in TPE, some colleagues asked me if I thought to be a “psychologist” or even a “priest” ... Nevertheless, I think that trying to establish with patients an empathetic and pedagogical dialogue should be a standard feature of every therapeutic relationship. Concerning the comparison to a “priest”, I can only say that the capability of warmly welcoming and taking care of a patient are absolutely “laic” actions. Other colleagues objected that empathy is not helpful to “scientific “medicine and that it rather belongs to the so-called “complementary medicines”. As a matter of facts, most of colleagues who appreciate my commitment to TPE think that I am a bit too idealistic. Being credible is a challenge and I try to show that in medical practice the integration of empathy, relational ability and a scientific and rigorous disciplinary approach is always possible. Some colleagues are convinced to be “naturally gifted” educators, irrespective of their real pedagogical expertise. They do not take in adequate consideration the point of view of patients, never assessing their actual needs and knowledge and

simply imposing their own agenda. Behind this attitude there is probably the need to take under control their anxiety. Yet, I'm not saying that TPE should be a "democratic way" to do medicine: on the contrary, I think that when you are "fighting together" there is no room for indiscipline or extemporary behaviours. Therefore, both doctors and patients must be prepared and ready to play their own role in the hard "arena" of disease. One more problem today is probably represented also by the increasing fragmentation of medical disciplines and professional competences. Doctors and nurses often compete for primacy in the ground of TPE, while other professionals, such as psychologists and, more recently, educators entered the world of healthcare, claim their role in TPE. In this "territorial competition", all these professionals consider themselves as the only ones to be qualified for providing TPE. However, TPE is an "interprofessional area" requiring "harmonic teamwork" and the integrated contribution of all the professionals who have in charge the same patient. In other words, TPE could be considered as a "collective home" where doctors, nurses, psychologists, other therapists, educators and, above all, patients and their families must find a space to meet and work together. This should be clear not only to all healthcare workers but also to patients who often, rather than as a partner, behave like mere "health customer" who pretend only therapeutic ready-made solutions, declining any active involvement and responsibility in the management of their disease.

NB. I am particularly interested in the "customer-patient" relationship because, as Giroux (2020) might put it, it is clear how the relationship between patient and doctor has changed over the last thirty years in a mercantile public health system, always in competition with the private sector. In Italy, over the last 15 years, primary care, regional public health services and emergency services have been underfunded because of government decisions to reduce public spending. This has created space and customers for an expanding and growing private system, often financed by public funds (Buzzelli, Boyce, 2021). However, private systems are not able to absorb all the patients who need help, and patients often do not have the means to pay for the assistance of the private systems. The result is an increase in hospital admissions of chronic patients who are not adequately followed up by general practitioners, who are overloaded with patients to see, and overcrowded public emergency rooms. Nevertheless, most patients today continue to avoid the disastrous conditions of our health care systems, behaving like children who believe that they are the centre and the law of a world that, instead, is falling apart. So, they turn to doctors and nurses, thinking they are their only patient, and they are always right, simply because "the customer is always right", not understanding doctors' and nurses' tiredness, fatigue and demotivation (Bobbo, 2023). However, this makes doctors rigid when a patient asks for or suggests their own solution. For example, I have noticed that when a doctor rejects "a priori" what I am trying to suggest, based on my feelings and experiences, we hardly find an agreement or a common decision in the end.

RM. Nowadays, we often speak about "patient's empowerment" (Aujoulat et al., 2007). As a matter of fact, many people take their decisions on the base of their health beliefs, emotions and suggestions they collected from the web or social, rather than after getting an authentic and rational picture of their health problems. In other words, they act as "empowered citizens" but without being truly empowered. This is probably a consequence of the influence exerted by the wild mediatic diffusion of incomplete, unclear, uncontrolled, wrong, when not manipulated or fake, news about health and diseases. This feeds a "consumeristic" mentality, fuelling unrealistic health expectations and encouraging irrational health behaviours in general population. For this reason, when taking in charge patients, healthcare professionals should carefully evaluate their representations and expectations about disease and treatment.

NB. And going back to humility?

RM. Humility is another key word in therapeutic relationship. No doubt that for some people humility is an innate gift, whereas for many others, like me, it is something that must be learned with time and practice and, certainly, not for free

NB. And what about the patient's family, how do you perceive them?

RM. As in your experience, the family can be the greatest resource for a patient. Anyway, we should also remember that the support of the family should be never taken for granted. As a matter of fact, sometimes the family can be absent or more problematic than the patient him/herself. For this reason, when approaching a new patient with severe or chronic disease, healthcare personnel should always explore also his or her family to assess the presence of both internal resources and restrictions.

Sometimes, the family becomes the main target of TPE and, consequently, family caregivers deserve the same systemic pedagogical approach as patients. A particularly delicate feature to be addressed in family TPE concerns sexual partners, i.e., contraception, intimacy, loss of desire, painful intercourses, etc. caused by disease or treatment, which frequently are denied or neglected. One more reason to reaffirm the importance of interdisciplinary and interprofessional work in TPE. Nowadays, psychologists are a standard presence in many hospitals, but when I started TPE at my Haematology and Clinical Immunology Unit in early nineties, for the first time in my hospital a psychologist was always involved in TPE.

NB. So, what would you say to young doctors and nurses to approach them to TPE?

RM. As a pedagogist, you know better than me that there is no better teaching than giving your example. First, in doing my job I try to be coherent with my statements about TPE and therapeutic relationship with patients. I don't give any "magic rule" to my students but, at the end of a consultation, once the patient is gone, I briefly discuss the methodological bases of every part of my educational intervention, with the purpose to show them that, behind an apparently spontaneous conversation, there was the precise intent to address specific pedagogical issues. TPE is not the result of improvisation, but it relies on a competent professional "posture" that can be acquired following a specific training. Obviously, people can be more or less inclined to therapeutic relationship and, as I told you before, this issue should be addressed to young students who chose a health profession to better focus their motivation and if they are more inclined to clinical medicine rather than to other activities, such as laboratory, health management, basic investigation, etc. This would likely help them to become happier professionals who will not leave behind "wounded" patients. I have known so many "great" clinicians who were perfect from the technical point of view, but completely incapable in the relationship with patients. Doctor House is surely fine in challenging cases, but he is not the best in therapeutic relationship.

NB. I know exactly what you mean! Some time ago, a very important doctor (I saw him on television many times after that moment because he was awarded of an important position in the Italian Health System) asked me whether I would have preferred a "competent" doctor or a "sensitive" doctor, and I replied that I wanted both!

RM. In my opinion, these two things cannot be divided: a doctor who is genuinely interested to patients, should be at the same time both technically skilled and empathetic. I am not talking about paternalism. Empathy and sensitivity don't mean giving patients "gold-coated pills", as in past centuries, but giving them a frank support and sharing the right choices and steps to face the disease. Being an "all-round" doctor does not mean being a "super-doctor" but simply a "complete" doctor both in terms of scientific knowledge and of relational skills. Medicine students must know that the practice of clinical medicine is also an area of uncertainty and ambiguity, not always supported by scientific evidence, where empirical intuition, good sense, humility and communication skills are essential professional requirements.

NB. Do you think that now young doctors are more interested to TPE than in the past? Have you the impression that TPE has changed over last decades? Do you think that now TPE has a greater local, national and international diffusion?

RM. While there is no doubt that, nowadays, TPE is better known, yet its diffusion is not large and homogeneous as expected. Out of the classical domain of diabetology where TPE is disciplined by a specific law, a general national law that regulates the practice of TPE is still lacking (Marcolongo, Bonadiman, 2004). Certainly, there is no comparison with the nineties and, nowadays, TPE" is regularly included in the professional training of health professionals, particularly nurses, but, in my opinion, it is still perceived as "uncomfortable", at least by doctors. In general, doctors still think that someone else should take care of it, such as nurses, psychologists or educators. Moreover, health administrations and decision makers still have other priorities in their agenda.

NB. Notwithstanding the growing number chronic patients and chronicity in our society ...

RM. Thanks to the developments of modern medicine, at least in western countries, many once untreatable or fatal diseases now can be cured or have a chronic evolution. However, as the recent pandemic has shown, it takes little to turn back the clock. I would like to remind that, except for western countries, in the rest of the world public health services are still insufficient or lacking, and many people continue to die of "treatable" diseases. At the same time, also our health welfare

achievements are becoming more and more precarious and could break down at any moment, putting at risk the universal access to modern, more expensive treatments. In such a scenario, as it already happens in developing countries, also therapeutic relationship, reciprocal trust, teamwork and the capacity of patients to self-manage their disease would play an essential role. Direct and active involvement of citizens and patients in the management of their health contributes to the general health of the community and could reduce the costs of public health service by the reduction of improper hospitalisations and access to health utilities, relapses of illness, wasting of medications, waiting lists, etc.

NB. I wonder how your professional “posture” and your tireless engagement in the co-construction of therapeutic path with patients has influenced your way to be a doctor.

RM. I have always tried to go beyond the simple drug therapy. Indeed, even though today we have wonderful medications, many diseases are still not curable. Consequently, I had no alternative to the development of a good partnership with patients and their families. From this point of view, the partnership with patients can be used as an authentic therapeutic tool that strongly promotes patient’s empowerment. In my clinical experience, I have seen some chronic patients who progressively reached high levels of well-being, emotional balance and human emancipation that I would define as a “state of great health” very close to wisdom, despite the presence of a severely debilitating or lethal disease. Certainly, death is a mystery, but I remember with emotion the journey of these people through their illness until the end of their life. After all, the limitations imposed by prolonged and fatal illness, like other restraints and obstacles of life, do not necessarily represent the end of everything but, by contrast, they can establish a new starting point in the relationship with the reality and the people around us.

NB. In conclusion, what is TPE for you?

RM. In its very essence, TPE consists of working “with” rather than “for” the patient. Becoming a “patient educator” means to take an “educational posture”, harmonically integrated with standard clinical skills and in everyday practice. It requires the introduction of basic pedagogical knowledge and skills to the standard primary professional training of every health professional, as you have pointed out in your book (2014). After graduation, the training to TPE could be further oriented and contextualized. Ideally, the training to TPE should be interprofessional since the beginning of students’ training to help the functional integration and teamwork of the different professional profiles involved (i.e., doctors, nurses, etc.) (Berger-Estilita et al., 2020), and the acquisition of common pedagogical skills, techniques and teaching tools. Recent technologic innovation, such as artificial intelligence, could greatly contribute to the training, implementation and diffusion of TPE. However, TPE cannot be reduced to a pure matter of teaching and learning technology irrespective of a direct human emphatic contact and frank interchange.

Natascia Bobbo. I think that doctors and nurses should remember that chronically ill patients not only need the tools to manage their illness, but above all they need to restore the map and purpose that their experience of illness has damaged. To do this, patients should have the opportunity to tell their stories, to talk about what they feel, what they want, what they expect, which is the only way to repair the damage that illness has done to their sense of self (Frank, 2013, p. 53). The lack of time, space and will that doctor and nurses often live in our health care systems make them often interrupt the patient's narrative so that he/she remains silenced (Frank, 2013, p. 58): but the self needs to be told in order to be regained (Frank, 2013, p. 55). My studies and research as an educator, but also my experience as a patient, make me understand that even a patient, in order to be human, needs the possibility to experience security, safety, closeness, and to be cared for, to feel like a *who* and not just a *what*, this is the characteristic of an elective contact that ensures that he/she can feel loved and valued by someone else (Van Manen, 2016, pp. 112-116), who wants to listen to his/her tale.

Conclusion

This conversation was designed for training purposes and to share the authors' experiences and views on this crucial issue in clinical medicine. The synergetic vision of TPE that emerged was a very special moment for both authors, because for them it was a kind of meta-reflection on the relationship between their life course and the course of their illness, even if for Dott. Marcolongo it was a vocation,

for NB it was her life. Even so, they were able to understand each other's because of their familiarity with illness and the suffering it causes in people's lives. Illness has passed through their lives, albeit in different ways, making them different from what they could be without this encounter, perhaps more vulnerable, that is, more human.

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