Chronically ill Patients, Life Incidents and Reactive Strategies: A Qualitative Study among Patients Suffering from four Types of Diseases, Followed-up in the North-Eastern of Italy

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Pazienti affetti da malattie croniche, situazioni critiche e strategie di reazione: uno studio qualitativo tra i pazienti affetti da quattro tipi di malattie croniche, seguiti in centri del nord-est d'Italia

Living with a chronic condition represents a strenuous experience that often could be lived as a sequence of waiting and crisis times. Therapeutic path incidents could represent however a catalysts and revelatory time, useful to patients to discover their own resources. A qualitative study according to the phenomenological hermeneutic perspective was conducted to understand the kind of skills expressed by the patients during a difficult episode, and the characteristics that identify patients who can overcome them better. From September 2019 to August 2020 twenty-three patients followed-up in four Hospital Units of Northeastern of Italy were enrolled. All the patients described an episode linked whit their pathological condition; they mentioned mainly supportive, reactive, or behavioral strategies and an acceptance attitude. The sample characteristics may explain the recurring acceptance attitude; however, the younger individuals, those with a higher level of education and those who faced precedent negative life experiences seem to better overcome challenging events. It can't be taken for granted that patients possess all the skills necessary to overcome the frequent challenging episodes they have to face; for this reason, healthcare professionals should assess their learning and reactive attitude in order to tailor for them therapeutic education paths.

Vivere con una malattia cronica rappresenta un'esperienza stressante che spesso può essere vissuta come un alternarsi di momenti di crisi e di attesa di nuove crisi. Gli incidenti critici presenti nel percorso terapeutico possono comunque rappresentare un momento catalizzatore e rivelatore, utile ai pazienti per scoprire le proprie risorse. È stato condotto uno studio qualitativo secondo la prospettiva della fenomenologia ermeneutica con l'obiettivo di comprendere il tipo di abilità espresse dai pazienti durante un episodio sfidante e le caratteristiche che identificano i pazienti capaci di superarlo meglio. Da settembre 2019 ad agosto 2020 sono stati arruolati nello studio ventitré pazienti seguiti in quattro Unità Ospedaliere del Nordest d'Italia. Tutti i pazienti hanno descritto un episodio legato alla loro condizione patologica; hanno menzionato principalmente strategie di ricerca di supporto, di tipo reattivo o comportamentale e un generale atteggiamento di accettazione. Le caratteristiche del campione possono spiegare il ricorrente atteggiamento di accettazione; tuttavia, gli individui più giovani, quelli con un livello di istruzione più elevato e coloro che hanno affrontato precedenti esperienze di vita negative sembrano superare meglio degli altri alcuni eventi difficili. Non è scontato che i pazienti possiedano tutte le competenze necessarie per superare i frequenti episodi sfidanti che devono affrontare; per questo motivo, gli operatori sanitari dovrebbero preventivamente

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valutare le loro capacità di apprendimento e le loro strategie di coping al fine di personalizzare i percorsi di educazione terapeutica.

Keywords: Chronically Ill Patients; Life Incidents; Reactive Strategies; Metacognitive Attitude; Health Care.

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1. Introduction

Living with a chronic condition represents one of the most strenuous experiences a person can face: it is a "disruptive experience" because it can reduce people functions, bring some invading changes into their daily routine, undermine their employment security, and negatively influence the quality of their relationships within family and friendship networks. Patients, forced to adjust their life projects to illness requests and limits, can often perceive the loss of a biography linearity (Bury, 1982; Giddens, 1991; Beker, 1997). However, the adjustment to illness is an essential target for a chronically ill patient and it requests different kinds of resources, skills, and talents: patients have to learn how to self-manage their medical treatments, follow proper indications about lifestyle, acquire decisional making skills to manage pathology daily challenges and process negative feelings (like anger, fear, sadness, etc.) (Corbin & Strauss, 1988; Sattoe *et al.*, 2015; Loring *et al.*, 2001; Radley & Green, 1994); last but not least, they should deal with a meaning-making process by which giving the disease a significant place in their life (Bury, 1997; Sharpe & Curnna, 2006; Kleinman, 1988).

Frank (1991, p. 27) and Charmaz (1997, pp. 30-31) defined a chronic condition as a sequence of waiting and crisis times where the former is often a wait of the latter, imagined as another unknown crisis, another challenging episode patients have to face (such as the sudden appearance of a new intrusive symptom, the communication of a worsening of the diagnosis, the loss of job, etc.). Life incidents, not necessarily dramatic but still challenging, represent specific moments in which ill people, like anybody else, should express conveniently both behavioral and high level cognitive skills (critical thinking, creative thought, problem solving, and decision making skills); at the same time, however, this kind of experiences could become a catalysts and revelatory time, useful to patients to discover their own resources and to understand the supportive quality of their social network (both personal and professional) (Norman *et al.*, 1992; Lipu *et al.*, 2007). Facing this kind of events, some patients seem to be more able than others both to overcome the difficulties they have to face and to learn new abilities (often stimulated by the difficulties themselves); in the same way, in those moments some patients are able to reach more self-awareness than others.

2. Aims and Methods

2.1. Aims of the study and methodologies used to collected data

Given the above considerations, a qualitative study was conducted with the aim to understand: 1) what kind of behavioral attitudes and cognitive skills chronically ill patients can express when facing a challenging event; 2) what kind of personal and disease-related characteristics can identify patients who are able to learn new skills or to reach a better self-awareness in a difficult moment from those who can't. This kind of understandings could give to health professionals further knowledge to support their patients in dealing with the countless experiences of sufferance or frustration they may encounter in the course of the disease.

Patients afflicted with a chronic condition were enrolled in four Hospital Units in Northeastern Italy. The study involved followed up patients suffering from osteoporosis, diabetes, kidney and liver transplantation. These conditions, all chronic but characterized by different pathways, can allow us to understand whether the type of disease has different impact on the targets we were studying. The inclusion/exclusion criteria were:

- age: 35-75 years;
- diagnosis dating back at least one year;
- lack of psychiatric or cognitive problems.

The study took place between September 2019 and August 2020, therefore including the Covid lockdown period March–May 2020. It was conducted according to the phenomenological and hermeneutic approach (Reinharz, 1983; Berger & Luckmann, 1966): this choice was made believing that a person can convert the lived experience into a tale to tell, making it visible, listenable, and

knowable and therefore scientifically analyzable by others (Van Manen, 1990). Moreover, people's stories, even when regarding a single moment of the person's life, can't be just factual reports, since they are what people perceive is happened, that is their lived, meant, experience (Thompson & Zahavi, 2007, pp. 69-71).

Given the aim of the study, the Critical Incident Technique (CIT) was chosen as qualitative research tool by which to turn anecdotes into data (Flanagan, 1954; Bradley, 1992; FitzGerald *et al.*, 2007): in particular, it lets the investigators of the present study (a pedagogist and a professional educator) elicit verbal or written information from participants (Norman *et al.*, 1992) while inducing them to give a meaning to their experience (Edvardsson & Roos, 2001; Norman, 1993; Sharoff, 2008). An original dialogue mediation tool was outlined in nine questions that can stimulate patients to tell about a challenging event they faced, speaking about: 1) *time*: when it happened; 2) *action*: what the patient did; 3) *persons*: who was involved in that situation; 4) *causes*: origin of the challenging event; 5) *consequences*: what happened after this episode; 6) *helper*: someone who helped the patient in those circumstances; 7) *thoughts*: what the patient thought in that moment; 8) *alternative actions*: what the patient could have done and he/she didn't do in that situation; 9) *learning*: what the patient will do if the situation recurs (Lipu *et al.*, 2007; Huges, 2007; Byrne, 2001). The tool, materially, was made up as a path inside an ideal garden drawn on a sheet of paper, as illustrated in figure 1: its itinerary included 9 stages, each of them corresponding to a question (written on the sheet).

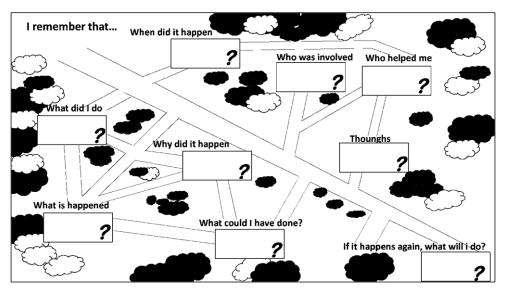


Fig.1: mediation tool drown-up for the study

Actually, during the interview, the educator first asked to the patient to think about an episode of the past she/he perceived as challenging; after the patient had identified the episode she/he would talk about, the educator asked to start the journey in the ideal garden and to stop where she/he wished, avoiding the stages/questions she/he didn't like. At each stage the patient chose to stay, the educator stimulated the answer to the relative question. Each interview lasted about 45 minutes. A demographic questionnaire was administrated before the interview in order to assess age, sex, level of education and employment of the subjects involved in the study. Moreover, we asked them to tell us a brief story of their life. During the lockdown period, in-person interviews were ri-modulated as telephone contacts, and the tool was emailed to the patients.

2.2. Methods of data analysis and ethical considerations

According to the chosen paradigm, and the tool that was used, the analysis was conducted by an inductive approach: patients reports were recorded, transcribed, and read more than once with the support of a memo-making strategy, useful to define the category of analysis convenient to the aims (Charmaz,

1997; Woolsey, 1986). After the first readings, it was evident that: firstly, there were different kinds of episodes the patients choose to tell; secondly, some of the stages of the path were avoided; thirdly, there were different kinds of resources patients used to face the events. So, the researcher decided to define as analysis categories these three elements: kind of episodes told, stage avoided and chosen, kind of resources used to face the events (Charmaz, 1997, p. 28), being aware of the demographic and disease-related characteristics of patients enrolled. After the definition of the categories, the coding analysis was conducted with the support of the software Atlas.ti 7.5.18. Two qualified Authors (N.B., C.B.) carried out the codifications separately; the two versions were then merged into a single Hermeneutic Unit in order to increase the rigor of analysis and give complexity to the data interpretation (Flanagan, 1954).

The study was approved by the local Ethics Committees of the four Units involved in the Study and the patients gave their written informed consent to participate in the study.

3. Results

3.1. Characteristics of the sample

Twenty-three patients were enrolled; the subjects' characteristics by pathology are reported in tables 1 and 2.

	n			Sex		
	n.	%	Age (yrs) (±SD)	Years since diagnosis (±SD)	F	M
Dia	7	30,4	60.7 (±10,4)	3,57 (±0,787)	2	5
Kidney TX	4	17,4	50.8 (±4,6)	3,75 (±0,5)	0	4
Liver TX	3	13,0	58,7 (±15,9)	2 (±-)	2	I
OP	9	39,1	67,2 (±8,2)	2,89 (±1,054)	8	I
tot	23	100	61,26 (±10,8)	3,13 (±10,8)	I 2	II
%					52,2	47,8

Table n. 1: Age, year of diagnosis, sex of the sample population

Employment Marital Education status status 1° grade 2° grade High Univ. Employed Unem-Retired Single Married Divorced school ployed Dia 0 Kidney 0 0 TX Liver TX OP 6 6 3 8 8 tot 3 1 Ι3 2 17 4 34,8 34,8 56,5 8,7 17,4 13 39,1 4,3 73,9 17,4

Table n. 2: Level of Education, Employment and Marital status of the sample population

3.2. Text analysis

The first category of analysis concerned the kind of challenging episode the patients chose to tell. Table 3 summarizes the results by patient's pathology.

	Dia	Kidney TX	Liver TX	OP	Row total
Communication of diagnosis	I	2	2	0	5
Consequences due to complications or worsening of the disease	2	I	0	6	9
Reconciling chronic disease requests and work or family's ones	2	I	0	3	6
Difficulties regarding adherence	2	0	I	0	3
Column total	7	4	3	9	23

Table n. 3: challenging episodes told by the patients.

All patients chose to talk about a challenging episode related to their pathology.

As reported in table 2, only one diabetic patient lived the communication of the diagnosis as a challenging event, whereas four organ transplanted patients identified this event as a very difficult moment.

"A difficult moment was when they told me that I had to undergo the transplant, I had hepatitis for years but up to that point the checkups had always gone well, then suddenly ...". ($t^{\circ 8}$)

Two diabetic patients, one kidney transplanted, and three osteoporotic chose to tell about the difficulties they found in balancing chronic disease requests with daily commitments and responsibilities.

"A difficult period was when I was unable to reconcile osteoporosis with my job as a healthcare worker". (ost^{12})

"When I was working, I found it difficult to reconcile diabetes with my employment". (dia¹³)

Only three patients reported episodes concerning some disabling side effects of drugs or problems linked with adherence to therapy, two of them were diabetic.

"Immediately after the diagnosis of diabetes I had to learn how to give myself insulin. The most difficult moment was during the lunch break: since I didn't know the exact time I would eat, I couldn't know how many minutes before I had to take insulin...." (dia $^{\circ}$ 6)

"Years ago, I was suffering from very disabling diarrheal episodes, they affected my work and my social life, as well as my body with weight loss and painful hemorrhoids...we couldn't get out of it, so I called the diabetologist and he told me to discontinue metformin because it was likely to be a side effect ...". (dia²³)

Regarding the second category of analysis, stage chosen and avoided by patients, as described in table 4, patients didn't stop in all the stages proposed. Even if most of the stages were considered by all patients (such as *time, action, causes*, and *consequences*), other were not taken into account.

	Dia	Kidney TX	Liver TX	OP	Tot
	n=7	n=4	n=3	n=9	n=23
Time	7	4	3	9	all
Action	7	4	3	9	all
Persons	5	4	3	9	2I
Cause	7	4	3	9	all
Consequences	7	4	3	9	all
Thoughts	6	2	3	2	13
Alternative actions	0	0	0	0	none
Learning	6	3	I	3	13

Table n. 4: mediation tool stages chosen and avoided by patients

Specifically, two diabetic patients didn't define persons involved in the episode, speaking only about themselves; one diabetic patients, two kidney transplanted and seven osteoporotic patients didn't mention anything about their thoughts in those challenging moments; one diabetic patients, one kidney and two liver transplanted, and six osteoporotics didn't speak about the learning they could have acquired in those times; finally, nobody considered alternative actions.

In the least considered stages (*thoughts* and *learning*) patients spoke about different kinds of matters. Regarding *thoughts* in those times, two patients told they thought about things they could do to prevent the worsening of their condition in a sort of contrafactual cognitive bias:

Diet, pay attention to nutrition and do more physical activity... (dia¹¹)

At that moment I did not think about the consequences, I was taken by daily commitments. I could have been more attentive to nutrition, lead a less sedentary life...(dia^{27})

Other patients tried to find a reason for their condition or simply to find in themselves the strength to face that moment:

I had to do it, I had to work, I was a freelancer, I had to do it ... (dia 13)

I tried to recover a good spirit within myself (lt°8)

Other patients, instead, took consciousness about their feelings, such as anger, frustration, or anxiety. Some patients thought about the need for independence and autonomy they deeply felt. Another patient thought about her inability to understand the real consequences of the surgery she underwent:

I tried to go on, but I wasn't ready mentally, I didn't understand the consequences of the surgery (ost¹⁷)

Regarding the *learnings* patients acquire in those moments, some of them told to have learned new strategies to face illness and its consequences (such as using the car to prevent falling); others instead learned not to try to control what isn't under their control (such as blood glycemic level), or to control what is instead under their control (such as negative emotions).

Other patients became aware of their condition and learned that they had to find in themselves the strength to face it; for one of them it became the purpose able to give a meaning to his life.

"What can I do? Seeking a purpose, an end like helping others to cope with their condition". $(kt^{\circ 1})$

Another, instead, told to have found this strength in thinking that everyone has problems, and everyone must face them: a sort of mindfulness thought helped him to adjust to his condition.

"I found in myself the strength to face that news and find a way to move forward ... everyone has problems, and it is necessary to learn how to face and solve them". (dia¹³)

The analysis of the tales made it possible to identify which are the protective resources that favor the positive resolution of a challenging event, according to the lived experience of the patients involved in the study (the third category of analysis). As reported in table 5, four kinds of strategies were identified: support from patient social network (15 patients), awareness and acceptance (12), reactive strategies of adjustment (13), and reaching a sense of mastery (9).

	Dia	Kidney TX	Liver TX	OP	n Tot (%)
Support from social network	3	3	3	6	15 (65)
Consciousness and acceptance	3	3	2	4	12 (52)
Reactive strategies	3	3	I	6	13 (57)
Reaching a sense of mastery	I	4	2	2	9 (39)

Table n. 5: strategies chosen to face the challenging event

Regarding the first dimension, support came to patients from different persons, mostly from their family members, but also from friends and colleagues.

Regarding the second dimension, acceptance represents a strategy able to let patients face those events and to acquire a sort of calm consciousness of what isn't under their control.

"Then I started to live with it, to reduce my fussiness because I couldn't keep everything under control, I had to learn that there are things that are controllable and others that are not". $(dia^{\circ 6})$

The reactive strategies mentioned by the patients are very different from each other: for some patients, asking for help or seeking information to learn more about their condition were effective strategies; for other patients, it was a rational problem-solving attitude that allowed them to overcome their difficulties; other strategies mentioned were behavioral, such as the redefinition of one's working role, or the change of some daily habits. For other patients, however, learning some practical skills to adhere to therapeutic prescriptions represented the solution to get better.

"I wanted to know everything, I asked the doctor not to hide anything from me, I had to know, and I also inquired". (lt^{oi})

[&]quot;My husband and my family helped me, knowing that I'm not alone helps". (kt⁰⁷)

[&]quot;My colleagues who helped me were good, but also my family...". (lt°2)

"...but then I said to myself why should I give up? What did I do? I asked for help" (ost¹²).

The last resources patients chose to tell about were metacognitive ones: it is, most of all, the reaching of a sense of mastery that, according to patients, let themselves face the challenging episodes but also their life condition at all.

"One of my great wishes was to be able to continue driving the car and I did it [...] I started working again, but also dancing salsa which is another great passion of mine" ($kt^{\circ 2}$).

4. Discussion and conclusion

4.1. Discussion

All patients choose to speak about a challenging event linked with their chronic condition; on the one hand, this could be due to the pervasiveness of a chronic disease which can become the focal point of a person's life (Charmaz, 1999), but, on the other hand, they could be conditioned by the setting of the meetings (the hospital) at the beginning and by the spreading pandemic situation after the lockdown was enacted. However, it is possible to identify some interesting differences between the four kinds of episodes patients told and the pathologies they suffered. Firstly, the communication of the diagnosis represents a more challenging event for organ transplanted patients than for diabetic or osteoporotic ones. Probably this is due to the widespread representation of the transplant as a frightening event as well as to the really demanding therapeutic path that a transplant inevitably requires, both before and after surgery (Wentlandt et al., 2017); these patients often wait for an organ donation immersed in their illness (Charmaz, 1997), having lost everything that make life worth living; at the same time they can't know if and when this situation could be resolved and this is a very anguishing condition (Bobbo, 2021; Engle, 2001). On the contrary, diabetic patients, at the moment of the diagnosis weren't generally scared, because they knew it is possible to live with diabetes (being one of the most diffuse chronic conditions, often they know someone who is afflicted with it) (Polonsky et al., 2017); moreover, immediately after the diagnosis their symptoms of glycemic decompensation disappeared: therefore, often the diagnosis represents a time of relief for these patients. Osteoporotic patients mostly take the diagnosis as an outcome of one of their pre-existing conditions (Rothmann et al., 2018), even if for many of them it could represent a sort of sword of Damocles, since they fear for the possible future complications. Indeed, for the patients suffering from osteoporosis involved in this study, complications represent the most cited causes of difficult moments probably because this pathology often lays as a silent condition till a severe complication, such as a fracture or a vertebral collapse, threatens patients' life routines or projects (Mafi Golchin et al., 2016). For many osteoporotic patients, however, therapeutic adherence seems not to be a major issue, perhaps because too often this kind of patients underestimate the importance of therapy due to the distracting effect of fake news spread by the mass media (which promote decisive effects of milk or waters with added calcium) and, more than that, due to the lack of symptoms that characterize this condition (Yeam et al., 2018; Adawi et al., 2017). Problems linked to therapeutic adherence were much more cited, instead, by the diabetic patients, probably because of the invasiveness of insulin therapy in the daily life (Peyrot et al., 2012). Finally, difficulties in reconciling chronic disease requests and work or family responsibilities regard more or less all the patients: the younger individuals for their work commitments, the older ones because they are often women (afflicted with osteoporosis) that hardly accept not to carry out their housework and care of their aged husbands (Peyrot et al., 2012; Whithe-Willams et al., 2005; Terrio & Auld, 2002; Stamm et al., 2016).

Considering the kind of resources patients activated to face the challenging episode they told, along with the stages they avoided, it is possible to see how most of the patients we interviewed didn't combine a behavioral reactive strategy with a cognitive one (they didn't make thoughts about what they are doing,

[&]quot;Together we created an ad hoc working role, based on my skills". (ost°4)

[&]quot;Within a few weeks I learned the mechanism, the procedure, I asked my father, who is also insulin dependent, for help to acquire the right technique". (dia^{o6})

particularly the osteoporotic patients), as well as others didn't combine a cognitive reactive strategy with a meta-cognitive one (few patients were aware they had the chance to learn something about themselves and their resources in those situations, particularly the osteoporotic and transplanted patients). No one, moreover, considered an alternative action: most of them, instead, gave up to a sort of unavoidable acceptance. In few words, even if most patients seem to have good reactive resources, both behavioral and cognitive, they activate and express few metacognitive skills, as well as they seem to lack a divergent thinking (McCrae, 1987). To interpret these data patients' demographic characteristics were considered, because those who were older were less able to express this kind of competences. Moreover, even if the average age of sample was above 62, only three patients had a university degree, and only eight had a high school diploma; this means that 12 patients had a low-level education. Furthermore, 13 patients were retirees, and considering their age it may mean that they started working very early, perhaps in not qualified duties. In addition, many of these patients came from the peasant and small-business province that characterizes the Northeastern of Italy. All considering, their lack of metacognitive attitude or divergent thinking, which implies creativity, can be explained. These characteristics of the sample can clarify also the propensity of many of the participants to use an acceptance-resignation strategy in place of exploring alternative chances, that is a behavior typical of those who perceive a limited power to influence the course of one's disease (perhaps even of their life) (Feifel et al., 1987). These data help to understand that not all the differences in coping strategies lies in the diagnosis.

Other data (emerging from the biographical tales), were used to identify how someone can employ metacognitive and learning strategies and somebody else can't, confirming our hypothesis. The first element that emerged from the reports of patients who seemed to have thought about what was happening and learned something from the difficult episode, was that they were the same that had faced other challenging experiences before those they talked about, not necessarily linked with their pathology (such as a divorce, the loss of a job or a previous diagnosis of cancer). Other suggestions came from their age at the moment of the challenging episode they talked and, last, their level of education: some of them were young when they faced the challenging episode (less than 50 years old), others had a good curriculum. Regarding the age of these patients, it could become diriment because it is known that youth is a prerequisite for the ability to reflect and learn, by virtue of the best potential, from a neurocognitive perspective, the person can have; it is already known that school education can offer more chances to develop open mind and reflexivity than an executive or non-qualified job. Finally, the former challenging experiences could be relevant because facing and overcoming a very difficult moment can force people to reflect about their talents and to become aware of their internal and external resources (Roalf *et al.*, 2014; Bielak *et al.*, 2013; Ryan, 2015; Colombo, 2011; Joseph & Linley, 2005).

In summary, our data seem to suggest that the diagnosis isn't the only element conditioning the kind of coping strategies patients adopt to face the countless challenging episodes of their chronic conditions: age, level of education and kind of employment could also play a significant role.

4.2. Limits of the study

The limits of the study lay in the small sample size and its uneven consistence for variables such as age, gender, level of education. In addition, the lockdown, and the need to change the way interviews were performed (from face-to-face to telephone) have certainly introduced a bias that is difficult to assess. For these reasons, the results of this investigation can't be generalized but, nevertheless, we believe that these preliminary results deserve further investigation in a larger and better characterized population.

4.3. Conclusion and implication for the future of patient education practices

It is undeniable that chronically ill patients have to face many challenging events in their therapeutic path and each pathological condition can present different challenging events. At the same time, it is evident that some metacognitive skills are necessary not only to overcome a single episode but to learn from a difficult experience something that could be useful in a later challenging moment (Aujoulat *et al.*, 2007). Chronically ill patients are mostly elderly and, in the same area where the study was conducted, most don't possess neither a high-level education nor high-profile cognitive skill. Given these evidences,

we believe that the patients should be supported to face the difficulties they can encounter in their therapeutic path by an educational approach that let them to acquire specific skills, such as problem-solving attitude and reflective thinking. For this reason, physicians and nurses should be interested in patients' perceptions and anticipations, worldview and fears, and assess cognitive and metacognitive skills patients possess in order to tailor an education path starting from their learning prerequisite and educational needs. Too often, even in our time, patient education is considered no more than a simple transmission of information or a friendly and comforting talk with the patients. Quite the opposite, within the therapeutic relationship, patients should have the possibility to develop specific experiential learning attitude and, moreover, a reflexive, divergent and meaning-making approach to life episodes. This imply that health operators should express more and more complex communicative, relational and training attitude and pedagogists, engaged in the training of physicians and nurses, must accept this demanding challenging task as a priority duty.

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