Meaning making as a psychoeducational intervention to sustain families struggling with mental health issues[*]

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La costruzione di significato come intervento psico-educativo per sostenere le famiglie che si confrontano con problemi di salute mentale

In the psychiatric field, since the first decades of the XX century, some phenomenologically-oriented authors pointed out the importance of gathering patients' experience of illness and meaning making. In the current literature, a few interventions for people suffering from mental illness and their families/caregivers, aimed at supporting them in making meaning, are available. Yet, also relatives have to confront with the "loss" of mental health in their family, just like patients themselves. Relatives could therefore perceive the need to make meaning through narrating that loss. In this paper, we will report a few narrative-based interventions for relatives of patients suffering from mental health problems. We will conclude with some reflections, guided by phenomenological-existential pedagogy, which considers search for meaning as a fundamental educational practice, when caring for a wounded existence.

La costruzione del significato, attraverso la narrazione, è considerata una pratica educativa/auto-educativa che può sostenere le persone che affrontano esperienze stressanti della vita, come la malattia, la perdita e il lutto. In ambito psichiatrico, fin dal XX secolo, alcuni autori fenomenologi-camente orientati hanno sostenuto l'importanza di raccogliere l'esperienza di malattia del paziente e dell'individuazione del suo significato. Tuttavia, nella letteratura sono reperibili pochissimi interventi rivolti a persone con problemi di salute mentale, e ai loro familiari, finalizzati ad aiutarli a costruire un significato della loro esperienza. Come i pazienti, anche i familiari devono confrontarsi con la "perdita" della salute mentale. Potrebbero pertanto sentire il bisogno di dare un senso alla loro esperienza, attraverso la narrazione. Riporteremo qui alcuni interventi basati sulla narrazione e rivolti ai familiari di pazienti con problemi di salute mentale. Nella prospettiva pedagogica fenomenologico-esistenziale, la ricerca di significato è una pratica educativa fondamentale, quando ci si prende cura di una esistenza ferita.

Keywords: distress/illness; meaning making; mental health; narrating; family members.

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1.   Suffering, narrating and meaning-making

In the phenomenological perspective, the encounter that characterizes the caring relationship, as well as the educational one, is conceived as an interweaving of meanings (Bertolini, 1988). "Every subjectivity [...] is found in intentional relations with the other and the world. Relationship is therefore at the very centre [of education]" (Tarozzi, 2016, p.11).

Education can be considered a relationship of care (Palmieri, 2000; Iori, 2006; Mortari, 2006). At the same time, caregiving is characterized by education, since the encounter between two existences, those of the health professional and the patient, allows to broaden their horizons of meanings and sometimes to build/rebuild a life story, especially when the latter has been challenged by a severe disease. "Narrating one's own stories to others leads, under certain conditions, to understanding them and thinking about one's life by discovering new meanings" (Smorti, 2018, p. 43) and, possibly, realizing that a new life plan is (still) possible. Education is aimed at supporting individuals in planning/re-planning their future and, since narrative can lead to discovering new meanings, useful to grasp new possibilities in one's own life, education and narratives are considered strictly interrelated (Connelly & Clandinin, 1986; Demetrio, 2012).

Making sense of one's life is not always easy and finding a meaning is considered particularly difficult when we experience challenging situations, such as incurable/chronic disease or mourning.

Nevertheless, the will to seek meaning in one's existence is, according to Frankl, "the main motivation in human life"*[1] (2017, p. 115), even in meaningless situations (Bruzzone, 2007). As he wrote in *Man's Search for Meaning* (2017), "we must never forget that we can find meaning in life even when we face hopeless situations, when we face a reality that cannot be changed"* (ivi, p. 126).

One of the first questions that people ask themselves, after a traumatic event that has directly involved them, revolves around a search for meaning, which is often identified with the primary need to understand why a certain adverse event has affected our person: "Why me? Why was I the one afflicted? How will the illness affect the functioning of my body? We seek to understand the causes of the illness and to relate the illness to our personal lives" (Hydén, 1997, p. 57).

Narration is widely considered a fundamental strategy to respond to that search for meaning (Zannini, 2008). In the healthcare contexts

> the narrative provides a medium whereby we can articulate and transform the symptoms and disruptions of illness into meaningful events and thus relate them to our lives and life courses. Through the narrative, the experience of illness is *articulated,* especially the suffering associated with illness. By arranging the illness symptoms and events in temporal order and relating them to other events in our lives, a unified context is constructed and coherence is established (Hydén, 1997, p. 56).

We learned about the effects of narrative on the experience of illness through a "paradigm shift," which in the 1970s introduced the biopsychosocial model in medicine (Engel, 1977). Later, in the 1980s, the concept of "illness experience" spread out, thanks the seminal work of Goffman (1963), Freidson (1970) and Kleinman (1988). When a distinction was made between illness and disease, the patient became an "expert" of their illness and this "opened up for the study of the patient's speech acts as an integral and important part of the course of the illness" (Hydén, 1997, p. 49). Later, in the 1990s, other authors — such as Frank (1995) — have shown how narratives "not only articulate suffering, but also give the sufferer a voice for articulating the illness experience apart from how illnesses are conceived and represented by biomedicine" (ivi, p. 51). In the middle of the Nineties, a narrative medicine approach was proposed (Charon et al., 1995), and honoring patients' stories became a new expected aim of medical practice.

In our society, where the individuals' experience has become increasingly fragmented and "liquid" (Bauman, 2005), personal narratives have gradually become one of the main forms through which we not only perceive, but also experience our lives (Ricoeur, 1984; Bruner, 1992).

Illness narratives have proven to be particularly useful when patients develop serious and disabling diseases, which can generate a real sense of "disruption" in their life, as pointed out by Bury (1982).

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1.   From here on, the symbol (*) will indicate the translation from Italian to English by Lucia Zannini.

Narratives have gained importance in the study of chronic illness as a means for understanding the attempts of patients to deal with their life situations and, above all, with the problems of identity that chronic illness brings with it. [...] Narrativizing the chronic illness within the framework of one's own life history makes it possible to give meaning to events that have disrupted and changed the course of one's life (Hydén, 1997, p. 51).

Studies conducted with patients' family members (i.e. oncological children's parents, and mental illness patients' families) have pointed out that this disruptive process does not only involve patients, but also their relatives (Stern, Doolan, Staples, Szmukler, & Eisler, 1999; Kuntz, Anazodo, Bowden, Sender, & Morgan, 2019). In the same way, mental illness has a disruptive effect not only on patients, but also on their families. They all have to reconstruct an identity — as individuals and as a family nucleus — that illness has disrupted. Charmaz (1991) went further and spoke of a "loss of self," in connection with chronic illness. This happens because when experiencing sickness "the 'lived body' which is simply us [...] turn up in the 'object body'" (Brody, 2003, p. 49). In a phenomenological perspective, we are our lived body and if we lose it we lose ourselves. Yet, narratives can play a pivotal role in the *reconstruction* of identity and personal life (Frank, 1993). "Telling our story does not merely document who we are: it helps to make us who we are" (Charon, 2006, p. 69).

First, the reconstruction of a lost identity is pursued by giving a form to suffering. "The narrative transforms symptoms and events into a meaningful whole, thereby creating the world of illness" (Hydén, 1997, p. 56). In this process, time, which intrinsically characterizes narratives, is very important. In order to reconstruct a continuity in one's own life, illness should be put in a timeline, and specifically within the framework of a personal biography.

Narratives offer an opportunity to knit together the split ends of time, to construct a new context and to fit the illness disruption into a temporal framework. Narratives can provide a context that encompasses both the illness event and surrounding life events and recreates a state of interrelatedness (Hydén, 1997, p. 53).

Furthermore, in chronic illness life dramatically changes, and patients and their families may be forced to look at the future in a totally new perspective. Even the past acquires a new meaning, and sometimes patients may reinterpret something they have done in the past as "wrong," perceiving it as the cause of the hurtful situations in the present. Often patients re-evaluate their lives in "moral terms," looking for "what kinds of circumstances, actions and attitudes [...] may have influenced or given rise to the illness" (Hyden, 1997, p. 58).

A common problem with illness narratives is that they do not have a clear and foreseeable "end." This lack "gives rise to a central problem with respect to illness narratives: they are narratives forever in search of meaning" (Hyden, 1997, p. 61). Stories, indeed, are characterized by having a beginning, a middle, and an end. The latter gives meaning and orientation to the whole narrative, and often contains a moral message.

This means that, in contrast to many other kinds of narratives, the illness narrative builds upon and relies on the possibility of a new or different ending, which means in turn that the illness narrative is always ambiguous, a continual negotiation (ibidem).

In this uncertainty, patients may feel the need to be helped to construct a coherent story of their future, deeply altered by severe illness. Healthcare professionals should not just prescribe and administer a therapy, but they should also involve patients in a co-construction of a story, regarding their future, in which their new condition is taken into account (Mattingly, 1991). This process, named "emplotment," has been proposed in healthcare contexts by Mattingly (1991) as a useful tool to foster the therapeutic relationship. In therapeutic emplotment, "a treatment whole is created in which separate events become linked and thus acquire new meaning, thereby making them endurable" (Hyden, 1997, p. 61).

Thanks to this co-construction of a "story of the treatment," that is, of a time horizon for the illness, hope of a possible cure, and thereby a continuation of life, may be prompted. This process seems to be very promising not only for patients, but also for family members, whose life can be disrupted by their relative's illness.

2.   Search for meaning in mental illness

In the field of psychiatry, some authors who refer to phenomenology have anticipated patient-centered approaches and the importance of illness experience, since the first decades of the last century. Binswanger (1947, 1970) counters the nineteenth-century biomedical psychopathology, which imprisons man in some nosographic categories, with the *Daseinanalyse*. The latter tries to understand who mental ill patients are, and what is the meaning of their existence. Husserl's phenomenology represents

> a "fundamental revolution" [...] in psychology and psychiatry for two reasons: it allows first to study psychological reality without using a naturalistic or a causal model designed for material reality, and it is moreover rigorous enough to give a real scientific status to psychiatry (Abettan, 2015, p. 534).

The focus of phenomenological psychiatry is not the brain with its dysfunctions, but "the subjectivity, the patients' interiority, their way of being in the world of social relations" (Borgna, 2019, p. 2)*. The patient is someone "with whom together [we can] understand the meaning of their existence, characterized by illness"* (Palmieri, 2000, p. 49). According to these authors, in fact, even when experiencing schizophrenia — perhaps the most emblematic mental illness —, the human path continues, though painful, but possibly meaningful (Borgna, 2019).

A cardinal principle of phenomenology can be found in the above positions, that is: the understanding of illness experience is irreducible to the scientific explanation of disease. Accordingly, the therapeutic relationship is intended by Binswanger (1947, 1970) as a constant attempt to "penetrate, relive the meaning of [patients'] words, instead of formulating generalizations and make judgments from them"* (ivi, p. 32). Therefore, "[...] symptoms should be comprehended according to the relationship that the subject establishes with the world" (Costa, 2017, p. 175).

In Binswanger's perspective, mental illness involves a process of "remaking of a world," which includes alterations in the lived experience of *time*, *space*, *body* sense and *social relationships*.

As we have seen above, patients' perception of time is crucial to understand the illness experience; even more so in the case of people suffering from a mental health disease. In this instance, the perception of time dramatically changes. As Minkowski (1933, 1968) pointed out, time stops, and patients do not perceive to have a future, but just the present time and the past. The future is constantly brought back to the past (Costa, 2017). This is often related to an experience of guilt and the defeat of hope, intended as openness to the future and to change. In the schizophrenic experience, time even crumbles, breaks down and shatters, and the perception of the self and the world is profoundly deformed (Borgna, 2019).

Sense of space and bodily self-perception may result altered in the mentally ill person, too. The ways of living one's own emotions are reflected in the body, which is intended in the phenomenological perspective, as a *living* body (*Lieb*), a body that expresses meanings. Many authors

> use the Husserlian concept of "passive synthesis," whose temporal stream is the paradigm and which describes how we can be tacitly in connection with something without having a reflective conscious of it. Some [of them] want to show how disturbances of these passive syntheses lead to disturbances of our own lived bodily experiences [...]. Whereas passive syntheses usually allow to assemble our many partial bodily experiences in a unitary and global one, their disruption leads to classical psychotic impressions of being disconnected from our own body, or of loss of bodily coherence (Abettan, 2015, p. 534).

Therefore, in order to understand the patient, the therapist should not just listen to their words, but also pay close attention to their body expressions. Besides, according to Binswanger (1947, 1970), it seems that understanding the patients' illness experience is not only the first step of the clinical encounter, but also the core of caring (Palmieri, 2000). The therapist should carefully listen to the patients' narratives, paying particular attention to how they describe time and space, and to their words and body expressions too.

> Listening to the patients' words and body language, and more generally to any expressive form adopted by the subject, means listening to their existence, as it was planned [...]. This

> means reconstructing their "inner life" […], starting from childhood, taking into account all the available information (diaries, family witnesses), but, above all, the patient, his/her memory, his/her current way of being in the world* (Palmieri, 2000, p. 50).

To promote that type of listening, the therapist should create a "common sphere" with the patient, which represents co-existence. This means "being-with-the-other" and "for-the-other," which both characterize some kind of relationships, such as friendship and love. In this type of caring relationship, the therapist and the patient create a new, personal world, and while constructing this world, they re-construct themselves.

The diagnosis is meant in this co-constructive manner, too: the other, the patient, cannot be intended, in a phenomenological perspective, as an external "object" in the diagnostic investigation; the understanding of patient's illness always occurs within the relationship between the therapist and the patient, which is based on mutual trust.

This phenomenological perspective seems lost in the current practice of psychiatry, which is based on objective nosographic criteria. This means that the phenomenological approach to psychiatry and its need for re-humanizing what should be considered a "human" science (psychiatry)

> cannot be taken for granted or acquired once and forever; on the contrary, re-humanizing psychiatry is a difficult and precarious feat, which requires close monitoring and constant exercising of those aptitudes (sensitivity, respect, attention, humility) that, before science, make 'human' the scientist* (Bruzzone, 2019, p. II).

Interestingly, in the current literature, phenomenology is often introduced just after having highlighted difficulties raised by the DSM (Diagnostic and Statistical Manual of mental disorders), particularly the "lack of validity" (Abettan, 2015) of this classification. "Many authors highlight operationalism is unable to define mental disorders in a satisfactory way, and then introduce phenomenology as an alternative method allowing a reliable description of *subjective experience* able to solve problems raised by DSM" (ivi, p. 538). But in doing so, "the authors assign to phenomenology the duty to set up a method able to make reliable diagnosis and which could be evaluated by quantitative analysis. If the DSM as a solution is criticized, its framework is conserved" (ivi, p. 539). It seems this interpretation of phenomenology leads to misunderstanding phenomenology, transforming it "into an empirical and objectifying discipline, which seems to be what we have always called semiology" (ivi, p. 539).

According to Binswanger, only the clinical encounter can determine "who suffers from psychiatric illness"* (1970, p. 288), and phenomenology cannot help with that. He sustained that phenomenological psychiatry "hasn't got any criteria allowing to claim what is pathological and what is not"* (ibidem). "Contrary to what contemporary authors claim, it is not for sure that phenomenological propositions could be directly applied to psychiatric practice" (Abettan, 2015, p. 538). Therefore,

> to the extent that we have no direct access to mental states of subjects who suffer from psychiatric diseases, and as their introspective reports do not give us any real and immediate access to what they are experiencing, it is reasonable to assume that only a hermeneutic phenomenology can fit psychiatric field. On this hypothesis, what psychiatric "phenomenology" describes is not the mental states of psychiatric patients, definitively out of reach, but only our interpretation of what they experience. Furthermore, the interpretation always remains a "hypothesis" whose truth is never fully and definitely demonstrated. Within this hermeneutic perspective, interpretation is not one possibility among others to approach the mental life of others, but the only one (ibidem).

As reported above, interpretation and meaning-making always require subjectivity. Therefore, in contrast to the most diffused biomedical approach to patients and illness — an approach which excludes subjectivity in history taking, considering it ineffective in the search for meanings, even in mental illness — we believe that the hermeneutical perspective — and therefore subjectivity — should be taken into consideration. This not only in diagnosing and defining the therapeutic plan, but also in supporting the "system" in which the patients are inserted: families, relatives, and possibly social context. This support, in our perspective, is related to meaning-making processes.

3. Facilitating the construction of meaning with relatives who went through the experience of a kin's illness

In the medical literature, several studies have addressed the theme of meaning-making in patients who suffer from severe diseases, such as cancer, and/or are receiving palliative care; some studies focus on patients suffering from other incurable diseases, such as multiple sclerosis, or severe disability, including mental illness or post-traumatic stress disorder.

Frequently, those illness experiences greatly transform individuals' existence. A timeline begins to be drawn, and a marking point separates what happened *before* and *after* the illness onset (Demetrio, 2012). Patients often draw a boundary between a past "remembered" as full of projects and a future "imagined" as hopeless, as well as full of uncertainty, fear, and sadness. That future is often saturated with melancholy, because it had commonly been imagined by patients with plenty of projects, which they now feel will never be realized. The loss of that dreamed future may therefore result in hopelessness and depression, and in anger and a sense of helplessness for an ungrateful destiny that has fallen on them (Rasmussen & Elverdam, 2007).

Even family members and people close to the person affected by a severe and disabling disease are often pervaded by grief and a feeling of helplessness, and by anger for what has been or has not been carried out, for what they can no longer do. Even if from another perspective (different from the patient's one), relatives begin to ask questions about life and try to imagine a new existence, for themselves and their beloved ones, an existence that is not always easily acceptable, even if perceived as unavoidable. Relatives begin to rethink their existence, as it was previously planned, and connect their life to the new situation of their loved one — who is now sick — in the attempt to reconstruct the line of a destiny that was quite clear before the illness onset, and which instead has been abruptly interrupted and has become chaotic. Every fragment of life, every relationship, one's vision of happiness, family, and even society, must now find a place in a world that has dramatically changed (Romanoff & Thompson, 2006).

Furthermore, in family members, pain, non-acceptance and anger are frequently associated with frustration, guilt and anguish (Iori, 2014). This is a well-known phenomenon in relatives of a person who committed suicide or in siblings of children who suffered from oncological disease (Spinetta et al., 1999; Delgado & Wester, 2020).

In addition, it seems particularly difficult to accept diseases that are not caused by organic factors. This is the case of psychiatric illness, a disease so "intangible," not characterized by visible/organic signs on which people can build a sense of "acceptability" that is both desired and refused, especially at a social level. Even if "invisible," mental illness can transform loved ones into someone whose new identity their own families struggle to recognize. This type of illness is commonly related to environmental, relational and — in some cases — biological factors, and relatives often feel they have had a certain role in its onset. At the same time, they may perceive themselves as victims of an existence trapped in their loved one's psychological discomfort. Relatives of patients suffering from mental illness often perceive their existence as characterized by failure; they blame themselves for not having intervened in time, not having done more, not having seen what was happening to their kin. On the other hand, when patients suffering from mental illness get involved in a treatment, relatives sometimes perceive it, paradoxically, as a failure, even if positive achievements attained by the healthcare team are evident (Stern, Doolan, Staples, Szmukler, & Eisler, 1999). That failure is often projected by families on the patient, who is blamed for not trying to do more in order to get their life back in their hands.

For family members of people with mental health problems, the meaning-making process seems particularly complex. These relatives are not just looking for a meaning for their new existence, and for that of their beloved one, totally transformed by the onset of psychiatric disease. They also struggle to make meaning of their previous existence, before illness, since the past is commonly considered prodromal in the onset of mental illness.

Therefore, how can these particular patients and their families be supported in making meaning of an existence so different from the one they had imagined? It is impossible to give an answer to this question, since the meaning attributed to our existence "[…] is unique and specific to each of us"* (Frankl, 2009, p. 115).

Nevertheless, as we have seen above, narrating allows to "[…] give order to disorder, finding meaning

in experiences that seem meaningless" (Zannini, 2017, p. 157). Telling one's own has revealed a way to satisfy "[...] man's constant need to understand reality in all its various manifestations"* (Smorti, 2018, p. 30); by narrating, human being is led to re-signify his/her experience (Bruner, 1992).

Making meaning and reflecting, through narration, on what happened *before*, in those families that developed mental health problems (often mental illness is understood within the family system), and focusing on what is happening now, how they had imagined the present time and how they think the future will be, are interventions that can sustain these families (Daiute 2015; Märtsin, 2019).

Narrating plays a central role in the psychiatric clinic and psychological therapy. Yet, it can also take place in other areas of intervention in mental health care, such as in psycho-educational interventions dedicated to patients or family members. Narrating, as we stated before, is an educational and self-educational practice (Demetrio, 2012). In the specific case of psychiatric illness, narratives could also, in some way, help to make the suffering concrete, to make it real and tangible, and therefore make that suffering worthy of being "listened to."

A few studies are available on meaning-making interventions based on narrating the illness experience. They frequently concern patients suffering from diseases such as cancer, psychiatric disorders or addictions, and are carried out with both patients and family members, in separated groups (Stern, Doolan, Staples, Szmukler, & Eisler, 1999; Lee, 2008; Smorti, Risaliti, Pananti, & Cipriani, 2008; Lazzarini & Leggio 2013; Augelli, 2014; Delgado & Wester, 2020). Next, we will describe the main characteristics of these narrative-based interventions, which could support patients and relatives who are facing situations of mental distress and frailty.

4. Experiences of meaning-making interventions to sustain patients and families struggling with mental health issues

Generally, when individuals think about people suffering from a psychiatric disorder, they tend to focus (regrettably), on their pathological characteristics or, even worse, on the supposed threatening behaviors of the "madmen," and the consequent problem of their (often taken for granted) "social dangerousness" (Palmieri, 2000); these misconceptions come from stereotyped ideas about mental illness, which concern both patients and their families and result in marginalization and exclusion. It is unknown to most that mental illness can also be intended as an individual's existential condition (and their family's), which should be comprehended and given a meaning, as proposed by Binswanger (1947, 1970).

Interestingly, the meaning-making process is not only pursued by phenomenological psychology/psychiatry. The importance of meaning making is also recognized in evidence-based medicine. For example, a study involving people suffering from psychiatric disorders pointed out that their condition was significantly associated with a reduced sense of meaning in their life (Huguelet et al., 2016). Consistently, another study involving a group of students showed that their competence in finding meaning in life was inversely related to suicidal ideation (Kleiman & Beaver, 2013). These studies suggest the role that meaning-making processes can play in mental disorders, and, therefore, the importance of sustaining meaning-making in those individuals who are at risk of developing mental illness or are already ill.

However, it may not always be useful to carry out meaning-making interventions — i.e. through narration — with patients suffering from psychiatric disorders, especially in the acute phase, which requires specific intervention by psychotherapists or psychiatrists. Narrating one's own history of illness means thinking about it first, then digging deeply, recognizing one's memories in the process. This work could have a negative effect, especially in the more acute stages of the illness, which the patient may not be able to bear (Huguelet et al., 2016).

The literature to date only reports a limited number of interventions based on narrative and autobiographical approaches, conducted with psychiatric patients, but those interventions can be mostly classified as therapeutic, and not as psycho-educational (Smorti, Risaliti, Pananti, & Cipriani, 2008). The latter are mostly conducted with patients' relatives (Stern, Doolan, Staples, Szmukler, & Eisler, 1999; Lazzarini & Leggio 2013; Augelli, 2014), who may feel the need to narrate their own experience. These individuals are likely to have "[...] not only a therapeutic need, but also an educational need, re-

lated to growth and development of autonomy" (Zannini, 2014, p. 238), which gradually they have to accomplish, in order to avoid dependence from mental health services. Moreover, educational meaning-making interventions with family members can have a positive impact also on patients.

Generally, the typical family members' reaction to their relative's experience of psychic suffering, fragility and dependence is keeping silent or hiding their situation, and assuming a behavior of closure, with the consequence of isolating themselves. These behaviors, over time, can become counterproductive and very harmful for the family and the patients themselves (Iori, 2014). Family members may start disconnecting themselves from ordinary social experiences and shared spaces of life, even if relevant in their existence, as hobbies, friendships, and, sometimes, work. By moving away from these vital experiences, they will eventually lack social connectedness, and therefore an important "resource for meaning-making" (Lichtenthal & Breitbart, 2015).

This progressive relatives' retreat within the domestic walls can be considered an expression of the transformation of family relationships, which are often characterized by new and unexpressed rules that are informally set after the disease's onset. In our opinion, it is particularly urgent to intervene in this phase, working with family members, in order to avoid closure and restore their voice. In social work, it is considered decisive to actively support the individuals who are directly connected with a person in a condition of fragility, such as mental illness, especially at the onset of the issue (Iori, 2014). Accordingly, trying to slowly transform families' silence — often full of "heavy thoughts" — into emerging words, and helping them share those thoughts, to give meaning to the experience they are going through, can be a first step to promote understanding and awareness (Smorti, 2018, chap. 4).

This process of meaning making was reported in a study conducted in the UK (Stern, Doolan, Staples, Szmukler, & Eisler, 1999), involving family members caring for their relatives suffering from psychiatric diseases. In this study, semi-structured interviews were administered, asking two main questions: one about the influence of the relative's mental health issues on their daily life, and one concerning their actual influence on the limitation/control of those problems. The researchers explored how relatives articulated the consequences of a devastating experience like their beloved's mental illness, and whether they were able to turn it into a significant experience, by emplotting mental illness into their life. An illness experience is, in fact, a story of a "broken" life. Therefore, narration, even within an interview, can become the primary tool for ordering, structuring, communicating and, therefore, reflecting on that experience. In this way, family members can try to understand and possibly start to manage that experience, which may lead to a willingness to start fresh with their lives. Nevertheless, this does not always happen. As also emerged from Stern, Doolan, Staples, Szmukler, and Eisler (1999), stories told by psychiatric patients' relatives are not always open to start fresh. Sometimes, families' narratives result in "chaotic stories" and, according to the researchers' interpretation (ibidem), chaos and disorder are often expression of the families' experience of immobility, passivity, confusion, restricted vision of life. These may cause a reduction of internal and external resources, which families would actually need in order to reconstruct and re-signify their existence.

This leads us to reflect, again, on the potential that group-facilitated narratives, and even more so, written narratives (reflective writing), may have in helping those people to rethink their lives, to see beyond the limitations that they are living due to their kin's illness. Going beyond those limitations, some resources could be discovered by listening to different stories from other people, who are coping with the same difficulties. Relatives can discover from those stories that people, who are dealing with the same "loss" — the mental illness of their kin —, are going on with their life, rather than just "surviving." They can learn that some families were able to find a new meaning in their existence and, in some ways, imagine a better future for themselves and their beloved. This is considered the strength of the group, particularly of self-help groups; they raise from hope, are fed by hope and can foster hope.

One of the few Italian experiences of psycho-educational interventions devoted to a group of mental ill patients' relatives was based on reflective writing (Lazzarini & Leggio, 2013). The group was composed by seven family members who met for fourteen times during a year, with the support of a social worker. In this intervention, writing about one's own story of mental illness promoted reflection and sharing of ideas and emotions. Participants wrote about their own life story, and then they wrote about how they lived their kin's illness experience. The combination of writing stories, telling them within a group and sharing ideas and emotions, led participants to deeply reflect on their experience, opening up

to different perspectives, and even to a new way of storytelling. This is a completely different experience from that of talking with a psychiatrist, during the first encounter with patients' family. Similarly, this experience is different from the conversation with a neighbor, who asks about the sick relative; or even from the exchange of experiences, perhaps in the waiting room of a mental health service, with another worried family member, who needs to be reassured. In group-based experiences, participants can tell their story in a safe environment. It is a dedicated time and space in which they can reflect, and possibly construct a story that could be addressed in new and different ways, thanks to the feedback received by other participants (Rogers, 1976).

The strength of the group, and particularly the group-based setting, strongly emerges in another meaning-making experience conducted in Italy and reported by Augelli (2014). In her work, the author refers not only to the strength of storytelling and reflective writing for people who are going through a difficult experience, but, above all, to the importance of a "storytelling environment" suitable for family members, who are facing mental health issues (in this case, their children addiction). If adequately organized, the group environment allows the participants to bring out thoughts and emotions, which range from the more private components of their experience to the social dimensions of mental illness.

In this case, the "loss" that professionals took care for was, firstly, the parents' breach of trust with their own child and towards themselves. In the experience reported by Augelli, parents involved in the group activity wrote a hypothetical letter to a child of one of them (whose story had been told before), which was therefore written by several hands. This is an interesting exercise aimed at sharing thoughts and emotions, and choosing the right words to communicate with a troubled family member, being supported by the other members of the group. Participants, up to that point, were introspectively and solitarily immersed in the narration of their own thoughts and emotions; by sharing their own perception of their difficult situation, they could open up to a wider vision of it, through the feedback received from the group. Furthermore, allowing other people to take their child to heart also meant recognizing the possibility that their child could also "exist" for other people, therefore understanding that they do not entirely depend on their parents. Hence, this group activity may let parents' sense of omnipotence emerge and be challenged, especially when it leads to an overload of blame.

In this type of group process, the others are co-constructors of meaning: their ability to help us depends on our capacity to negotiate meaning with them, and let them enter into our process of sense making (Daiute 2015; Märtsin, 2019). Welcoming a participant's story and sharing their suffering and emotions does not mean claiming to relieve them from their burdens; instead, the aim is to "hold space," building trust and a space in which each story can be told and possibly re-signified (Augelli, 2014).

The importance of sharing one's experience emerged in another proposal for a meaning-making intervention, in which photography was used as a narration and discussion tool (Delgado & Wester 2020). This intervention was devoted to the relatives of people who committed suicide; it regarded, therefore, the survivors, those who have to bear this dramatic experience of loss, whose lives have been stuck with the unanswered question of "why." Photos can be an active way to share one's experience with others and gain a sense of empowerment; moreover, their use, combined with group dialogue, may allow one to overcome previous ways of thinking about their pain and to open the possibility of new meanings.

In conclusion, even if the literature only reports a small number of interventions conducted with relatives of patients suffering from a mental disease, we can say that telling and sharing narratives of a kin's mental illness experience is a powerful tool to help family members to give voice to some untold stories, perhaps never completely heard even by themselves. In the studies we discussed, sharing narratives made the involved family members recognize themselves, their limits, resources and possibilities for a fresh start in life, no longer hiding the past, but sharing it, recognizing it and, therefore, circumscribing it at a given time. In this way, past can remain past; a past, however, which can be given a new meaning. Group-based activities for relatives who are facing a mental illness in their family, set up in a dedicated and safe environment, can represent an opportunity for finding a space and a time, which they may never have had, to tell their story and think about it, about themselves and their lives. This can allow to look at the future with new eyes, opening family members' minds to trust, hope and new possibilities.

References

Abettan, C. (2015). The current dialogue between phenomenology and psychiatry: a problematic misunderstanding. *Med Health Care Philos*, *18*(4), 533–540. https://doi.org/10.1007/s11019-015-9645-6

Augelli, A. (2014). *Quando le formiche spostano un elefante: Genitori di gruppi di auto-mutuo aiuto raccontano le dipendenze e la cura familiare*. Milano: FrancoAngeli.

Bauman, Z. (2005). *Liquid Life*. Cambridge: Polity Press.

Bertolini, P. (1988). *L'esistere pedagogico: Ragioni e limiti di una pedagogia come scienza fenomenologicamente fondata*. Firenze: La Nuova Italia.

Binswanger, L. (1947). *Zur phänomenologischen Anthropologie*. Bern: Francke. (Trans. Ita. *Per una antropologia fenomenologica*. Milano: Feltrinelli, 1970).

Borgna, E. (2019). Ha ancora senso la fenomenologia? Considerazioni di uno psichiatra. *Encyclopaideia*, *23*(55). https://doi.org/10.6092/issn.1825-8670/10082

Brody, H. (2003). *Story of sickness*. Oxford: Oxford University Press.

Bruner, J. (1990). *Act of meaning*. Cambridge: Harvard University Press. (Trans. Ita. *La ricerca di significato: per una psicologia culturale*. Torino: Borati Boringheri, 1992).

Bruzzone, D. (2007). *Ricerca di senso e cura dell'esistenza. Il contributo di Viktor E. Frankl a una pedagogia fenomenologico-esistenziale*. Trento: Erickson.

Bruzzone, D. (2019). Editoriale in Encyclopaideia

Bury, M. R. (1982). Chronic illness as biographical disruption. *Sociol Health Illn*, *4*(2), 167–182. https://doi.org/10.1111/1467-9566.ep11339939

Charmaz, K. (1991). *Good Days, Bad Days: The Self in Chronic Illness and Time*. New Brunswick, NJ: Rutgers University Press.

Charon, R., Banks, T., Connelly, J. E., Hawkins, A. H., Hunter, K. M., Jones, A. H., ... & Poirer S. (1995), Literature and medicine: contributions to clinical practice, *Ann Intern Med*, *122*(8), 599–606. https://doi:10.7326/0003-4819-122-8-199504150-00008

Charon, R. (2006). *Narrative medicine: Honoring the stories of illness*. Oxford: University Press.

Connelly, F. M., & Clandinin, D. J. (1986). On Narrative Method, Personal Philosophy, and Narrative Unities in the Story of Teaching. *J Res Sci Teach*, *23*(4), 293–310. https://doi.org/10.1002/tea.3660230404

Costa V. (2017), *Teorie della follia e del disturbo psichico*. Brescia: ELS La Scuola.

Daiute, C. (2015). Narrating possibility. In G. Marsico (Ed.), *Jerome S. Bruner beyond 100: Cultivating possibilities* (pp. 152–172). Cham: Springer.

Delgado, H., & Wester, K. (2020). Using Photovoice to Promote Meaning-Making in a Suicide Loss Support Group. *J Ment Health Couns*, *42*(3), 189–205. https://doi.org/10.17744lmehc.42.3.ol

Demetrio, D. (Ed.) (2012). *Educare è narrare*. Milano: Mimesis.

Engel, G. L. (1977). The need for a new medical model: A challenge for biomedicine. *Science*, *196*(4286), 129–136. https://doi.org/10.1126/science.847460

Frank, A. W. (1995). *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: Chicago University Press.

Frankl, V. E. (1963). *Man's Search for Meaning. An Introduction to Logotherapy*. Washington Square Press: New York. (Trans. Ita. *L'uomo in cerca di senso. Uno psicologo nei lager e altri scritti inediti*. Milano: FrancoAngeli, 2017).

Freidson, E. (1970). *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. New York, NJ: Harper and Row.

Goffman, E. (1961). *Asylums: Essays on the Social Situation of Mental Patients and Other Inmates*. Garden City, NJ: Doubleday.

Huguelet, P., Guillaume, S., Vidal, S. M., Mohr, S. M., Courtet, P., Villain, L., ... & Perroud, N. (2016). Values as determinant of meaning among patients with psychiatric disorders in the perspective of recovery. *Scientific Reports*, *6*(1), 1–9. https://doi.org/10.1038/srep27617

Hydén, L. C. (1997). Illness and narrative. *Sociol Health Illn*, *19*(1), 48–69. https://doi.org/10.1111/j.1467-9566.1997.tb00015.x

Iori, V. (2006). *Quando i sentimenti interrogano l'esistenza. Orientamenti fenomenologici nel lavoro educativo e di cura*. Milano: Guerini.

Iori, V. (2014). Presentazione. In A. Augelli (Ed.), *Quando le formiche spostano un elefante. Genitori di gruppi di auto-mutuo aiuto raccontano le dipendenze e la cura familiare* (pp. 7–9). Milano: FrancoAngeli.

Lee, V. (2008). The existential plight of cancer: meaning making as a concrete approach to the intangible search for meaning. *Support Care Cancer*, *16*, 779–785. https://doi.org/10.1007/s00520-007-0396-7

Kleinman, A. (1988). *The Illness Narratives: Suffering, Healing and the Human Condition*. New York, NY: Basic Books.

Kleiman, E. M., & Beaver, J. K. (2013). A meaningful life is worth living: meaning in life as a suicide resiliency factor. *Psychiatry Res*, *210*, 934–939. https://doi.org/10.1016/j.psychres.2013.08.002

Kuntz, N., Anazodo, A., Bowden, V., Sender, L., & Morgan H. (2019) Pediatric Cancer Patients' Treatment Journey: Child, Adolescent, and Young Adult Cancer Narratives. *J Pediatr Surg Nurs*, *48*, 42–48.

Lazzarini, C., & Leggio, G. (2013). *Cultura autobiografica, medicina narrativa, famiglie, salute mentale*. Roma: DDAPSI.

Lichtenthal, W. G., & Breitbart, W. (2015). The Central Role of Meaning in Adjustment to the Loss of a Child to Cancer: Implications for the Development of Meaning-Centered Grief Therapy. *Curr Opin Support Palliat Care*, *9*(1): 46–51. https://doi.org/10.1097/SPC.0000000000000117

Mattingly, C. (1991). The narrative nature of clinical reasoning. *Am J Occup Ther*, *45*(11), 998–1005. https://doi.org/10.5014/ajot.45.11.998

Minkowski, E. (1933). *Le temps vécu: études phénoménologiques et phychopathologiques*. Paris: D'Artrey. (Trans. Ita. *Il tempo vissuto: fenomenologia e psicopatologia*. Torino: Einaudi edizioni, 1968).

Märtsin, M. (2019). Beyond Past and Present: Meaning Making, Narrative Self and Future-Orientation. *Integr Psych Behav*, *53*, 669–678. https://doi.org/10.1007/s12124-019-09488-1

Mortari, L. (2006). *La pratica dell'aver cura*. Milano: Mondadori Bruno.

Palmieri, C. (2000). *La cura educativa: Riflessioni ed esperienze tra le pieghe dell'educare*. Milano: FrancoAngeli.

Rasmussen, D. M., & Elverdam, B. (2007). Cancer survivors experience of time disruption and time appropriation. *J ADV NURS*, *57*, 614–622. https://doi.org/10.1111/j.1365-2648.2006.04133.x

Ricoeur, P. (1983). *Temps et récit. Tome I*. Paris: Editions du Seuil. (Trans. Ita. *Tempo e racconto. Volume I*. Milano: Jaca Book, 1986).

Rogers, C. R. (1976). *I gruppi di incontro*. Astrolabio, Roma.

Romanoff, B. D., & Thompson, B. E. (2006). Meaning Construction in Palliative Care: The Use of Narrative, Ritual, and the Expressive Arts. *AJHPM*, *23*(4), 309–316. https://doi.org/10.1177/1049909106290246

Smorti, A., Risaliti, F., Pananti, B., & Cipriani, V. (2008). Autobiography as a Tool for Self-Construction. *J Nerv Ment Dis*, *196*(7). https://doi.org/10.1097/NMD.0b013e31817cf70f

Smorti, A. (2018). *Raccontare per capire: Perché narrare aiuta a pensare*. Bologna: Il Mulino.

Spinetta, J. J., Jankovic, M., Eden, T., Green, D., Martins, A. G., Wandzura, C., … & Masera, G. (1999). Guidelines for assistance to siblings of children with cancer: Report of the SIOP Working Committee on Psychosocial Issues in Pediatric Oncology. *Medical and Pediatric Oncology*, *33*, 395–398. https://doi.org/10.1002/(SICI)1096-911X(199910)33:4%3C395::AID-MPO9%3E3.0.CO;2-S

Stern, S., Doolan, M., Staples, E., Szmukler, G. L., & Eisler, I. (1999). Disruption and Reconstruction: Narrative Insight into the Experience of Family Members Caring for a Relative Diagnosed with Serious Mental Illness. *Family Processes*, *38*, 353–369. https://doi.org/10.1111/j.1545-5300.1999.00353.x

Tarozzi, M. (2016). Introducing Bertolini and his pedagogy as a rigorous science. *Encyclopaideia*, *XX*(45), 5–17.

Zannini, L. (2008). *Medical humanities e medicina narrativa: Nuove prospettive nella formazione dei professionisti della cura*. Milano: Raffaello.

Zannini, L. (2014). Interventi educativi con famiglie che hanno attraversato l'esperienza della malattia mentale: il valore della scrittura autobiografica. *La Famiglia*, *48*, 233–250.

Zannini, L. (2017). La *Narrative Inquiry*. In L., Mortari, & L., Zannini (Eds.), *La ricerca qualitativa in ambito sanitario* (pp. 155–187). Roma: Carocci Editore.

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