# Meaning-making and narrative in the illness experience: a phenomenological-existential perspective

Daniele Bruzzone\*

Università Cattolica del Sacro Cuore (Italy)

Submitted: November 1, 2020 – Accepted: January 20, 2021 – Published: March 31, 2021

#### Ricerca di senso e narrazione nell'esperienza di malattia: una prospettiva fenomenologicoesistenziale

The experience of illness raises profound issues concerning the sense or non-sense of human existence as a whole: does life have meaning when it is marked by suffering? And what meaning would it bear, in this case? These questions are asked by both caregivers and recipients of care when they come into contact with limits, pain, and death. In this regard, the existential condition of homo patiens is ambiguous: it can lead either to nihilism and despair or to a higher level of awareness and responsibility. Studies on resilience, post-traumatic growth, and meaning-making processes seem to suggest that in difficult situations the search for meaning comes most clearly to the fore, so that the possibility of finding meaning in life can be a protective factor and a key therapeutic resource, while meaninglessness increases weakness and vulnerability. But what is meant by "meaning" in the illness experience and how may it be integrated into one's personal life story? This question is answered here in terms of narrative methods that can enhance healthcare practitioners' capacity to approach their patients with sensitivity and deep understanding and guide them to find meaning in their lives, despite all.

L'esperienza della malattia pone interrogativi radicali sul senso o il non-senso dell'esistenza nel suo complesso: ha senso vivere se si deve soffrire? E qual è, allora, il senso della vita? Sono domande che scaturiscono in chi cura e in chi è curato dal contatto con il limite, il dolore, la morte. Da questo punto di vista, quella dell'homo patiens è una condizione ambigua: può condurre al nichilismo e alla disperazione oppure a un livello più alto di consapevolezza e di responsabilità. La letteratura sulla resilienza, la crescita post-traumatica e i processi di meaning-making sembrano dimostrare che proprio nelle situazioni difficili, l'esigenza di significato emerge prepotentemente, tanto che la capacità di ridare un senso alla vita costituisce un fattore protettivo e una inestimabile risorsa terapeutica, mentre la perdita di senso acuisce la debolezza e la vulnerabilità. Ma che cosa si intende per "significato" nell'esperienza di malattia e come lo si può integrare nella propria storia personale? A questa domanda si tenta qui di rispondere attraverso i principi del metodo narrativo, al fine di sviluppare nei professionisti della salute l'attitudine ad accostarsi ai loro pazienti con sensibilità e capacità di comprensione e di aiutarli a trovare un senso alla vita, nonostante tutto.

Keywords: Meaning; Illness; Narrative; Phenomenology; Health care.

<sup>\* ■</sup> daniele.bruzzone@unicatt.it

Being and reality are pure lack of meaning, He who possesses meaning and gives meaning is the existent, the human being.

(E. Lévinas, *Existence and Existents*)

When Albert Camus opened his 1942 novel *The Myth of Sisyphus* with the claim that there is only one truly serious philosophical problem — that of suicide — he meant to suggest that the single big question human beings are called to answer is "whether life is or is not worth living." This is especially apparent to us when we perceive the meaninglessness of our fate or, rather, when fate causes us to doubt that life has meaning: in other words, when we are confronted with intractable situations that make us feel insecure and impotent. Threatened by a lack of meaning, "living is giving life to the absurd" (Camus, 2017, p. 50). In its original context, this statement was an argument for the heroism of human beings who — like Sisyphus — daily fight for their lives despite everything. Yet, upon closer examination, it applies equally to those who do not share the French writer's atheist and nihilistic *Weltanschauung*: each time we are faced with an unfortunate or incomprehensible fate, we discover inside of ourselves a mysterious impulse to search for its meaning — which we nevertheless doubt — and to reconfigure our existence to metabolize whatever it is that is getting the better of us.

Experiencing illness — especially in its more severe, chronic, or terminal forms — is one of those limit situations (Jaspers, 1983) in face of which individual existences are at risk of being shipwrecked. And yet, it is in the "tragic triad" (Frankl, 2000, p. 128) of our struggle, suffering, and death, that the *quest for meaning*, which can keep us alive in even the most extreme of circumstances, emerges most clearly. Indeed, our very need for meaning acts as an invaluable protective factor in adverse situations. As such, it should be fostered and supported as much as possible in care work, which — when conducted from this perspective — is highly educational in nature (Bobbo, 2009).<sup>1</sup>

### 1. Each body is a story

If there is one thing that illness proves to us most starkly, it is that a person is first and foremost *a body* and yet, at the same time, is never reducible to this body. Indeed, experiencing illness is bound up with a meaning attribution process that shapes the patient's perceptions and personal style of coping. We are "simultaneously material and metaphorical beings" (Charon, 2019, p. 98), hence events at the physical level are instantly pervaded by cultural preunderstandings (Quaranta & Ricca, 2012) and bear emotional, existential, and spiritual implications that cannot be overlooked when listening to a patient (Good, 2006). Each body is a *story*, in that it carries the mnestic traces of the events it has been involved in, and at the same time it is a *project*, in that it incarnates the individual's distinctive manner of being-in-the-world.

As a well-known semiologist has put it:

The body is *written*. It is the first and most fundamental medium for writing in the human world. On it, we constantly trace the signs that allow us to organize its relationship with other bodies, with non-human nature, and with society. All modifications of the body (...) act on these signs and "edit" them. (Volli, 2002, p. 251)

This process of writing and re-writing the body include all *modifications enacted* upon it (we dress it in a certain way, covering it or exposing it, we decorate it with temporary or permanent embellishments, we train it, we discipline it, etc.) and the *modifications undergone* by it (growth, aging, violence, disability, illness): each of these events takes on a particular meaning and retrospectively changes our

<sup>1.</sup> In reality, the question of meaning and lack of meaning in wounded existences (Moravia, 1999) is also of some concern to healthcare practitioners, who are constantly in direct contact with suffering and the questions it raises. In their case too, the quest for meaning is all the more necessary when they work in settings marked by limits and irreversibility: when pain can no longer be avoided, a process of radical questioning is set in motion (Natoli, 1996). In the basic and in-service training of practitioners, the demand for meaning must be embraced, made explicit and explored, with the aim of fully humanizing places of care and the organizations with responsibility for them (Mori & Varchetta, 2012) and, above all, to help those delivering healthcare to remain motivated and hopeful, develop a reflexive attitude, and enhance their emotional competence (Bruzzone & Musi, 2007).

overall experience of self. It is clear, therefore, that personal identity is rooted in our lived experience of the body, and especially in the story that we tell about it.

Jerome Bruner (1991; 1992) taught us that the reality we engage with is always the outcome of a narrative construction process that we use to order and make sense of events. Analogously, the self is constructed as a text that endows our existence with direction and coherence. It does not resemble a solid, indestructible edifice, however, but rather a constantly evolving building-site.

The notion of *narrative identity* was further developed in the hermeneutics of Paul Ricoeur (1986; 1996). According to the French philosopher, our relationship with reality is a form of *mimesis*, that is to say, a creative imitation that constructs a personal story based on objective events. This process relies on three basic principles: *prefiguration* (each individual life possesses a narrative pre-understanding that makes it susceptible to being told), *configuration* (the active weaving of the narrative), and *refiguration* (the meaning of a story is only completed when it is read or listened to by others). The stories that persons construct of their lives narrate both what these lives are and, at the same time, what they have the potential to become. In other words, we are both the authors and the products of our own stories, and they represent the narrativization of our lived experience (White, 1981).

Within a narrative understanding of existence, *facts* and *meanings* are not the objective and subjective poles of experience, respectively — to be conceptualized as in opposition to one another or overlapping. Rather they are two elements that when taken together actually constitute experience: the event (*Geschebnis*) and our experience of it (*Erlebnis*) are indeed inseparable from one another, given that events are immediately experienced as bearing a certain meaning (Straus, 2011). Nevertheless, life events do not have a fixed, immutable meaning, but rather their meaning may change over time and as a function of personality development.

The occurrence of an undesired event (but even sometimes the unoccurrence of a desired one) can potentially give rise to a "biographical disruption" (Bury, 1982), that is to say, an interruption of our life story that threatens to undermine our sense of meaning, self-perception, framework of values, and most deeply held convictions. Serious illness, from this point of view, can be a traumatic event that forces patients to completely rewrite their self-narratives. Caring for the ill thus requires us to grasp the biographical (and not only biological) valence of disease. Vice versa, excluding the biographical dimension of meaning would mean stripping it of all that is personal. This is of particular importance to the epistemology of medical care: we need to develop an understanding of illness that does not reduce the body to a mere organism, because — in the words of a famous psychiatrist — "one's theory of other as organism is remote from any theory of the other as person" (Laing, 2001, p. 10).<sup>2</sup> While on the one hand, conceptualizing the body as an organism allows us to remain objective and detached, on the other hand, engaging with the body-person necessarily entails an inter-subjective relationship.

The body is medicine's ontological field: "According to the model of body that is drawn on, different avenues of meaning will open up, leading to the marking out specific regional ontologies on which medical knowledge will take root" (Costa & Cesana, 2019, p. 16). The regional ontology that unfolds based on the dead body (*Körper*) is radically different to that which unfolds based on the living body (*Leib*): the former is an object, similar to a mechanism that may be broken and repaired, but does not contain lived experience, desires, or projects (or, if it does, these are viewed as irrelevant); the latter in contrast is invariably a subject, which cannot be reduced to a machine, because it implies an inner life and intentionality (Galimberti, 1987; Zannini, 2004). In other words: the living body cannot be reduced to a thing to be observed, but rather should be acknowledged as an(other) observation point on the world.

Consequently, doctors and patients will have different ways of perceiving and attributing meaning to the experience of illness (Toombs, 1993). This discrepancy can cause a partial inability to communicate (Jaspers, 1991), which however may be corrected by the attentive practice of empathic understanding.<sup>3</sup>

<sup>2.</sup> For background on phenomenological epistemology and the ontology of personal existence, cfr. Bruzzone (2012b); on the ways in which phenomenological insights can contribute to humanizing the educational relationship and helping relationships in general, see Bruzzone (2016). On the phenomenological approach in the education of care practitioners, see Bruzzone (2014) and the entire Focus section of *Encyclopaideia*, n. 39 (https://encp.unibo.it/issue/view/461).

This epistemological alternative may be exemplified by observing two famous works of art. The first is: The Anatomy Lesson
of Dr. Nicolaes Tulp, painted by Rembrandt in the middle of the Scientific Revolution (1632), and held at the Mauritshuis

A patient's illness represents "an alteration of his relationship with the world" (Costa & Cesana, 2019, p. 89): it is therefore essential to understand how exactly it has become part of the patient's personal story, and what imbalances or adjustments it has caused in the area of identity; and, even more, the patient must be helped to find a way of being in the world that is compatible with their present situation. A physician who overlooks this twofold aspect of illness, "from the point of view of the patient and from the point of view of the doctor," is "a practitioner in half" (Rugarli, 2017, p. 74). And that goes for any health care professional, of course.

# 2. Illness experience and search for meaning

In the field of psychology, the question of meaning has always been viewed as ambiguous and unscientific, because it is difficult to objectify. Paradoxically, what was meant to be a science for explaining the meaning of subjective experience, long excluded (at least at the academic level) all inquiry into this domain. Nevertheless, as naturalism increasingly proved inadequate to the task of advancing our understanding of human behaviour and motivation, an alternative perspective on psychological research began to emerge, one that was arguably more uncertain but closer to human experience (Armezzani, 2002). Humanistic-existential, constructivist, and phenomenological approaches (the last-mentioned, moreover, has been rediscovered in recent years by cognitive neuroscience in relation to investigating the *embodied mind*) have all contributed to the development of theoretical models that feature the dimension of meaning.

If we were to pinpoint the exact moment when meaning became a variable of interest within experimental psychology, it would be probably the publication of a study by Crumbaugh and Maholick (1964) that presented an instrument for measuring the meaning of human existence: the Purpose In Life test (PIL). The authors of the article were students of the Austrian psychiatrist Viktor E. Frankl, a well-known concentration camp survivor, who had based his Logotherapy and Existential Analysis on the construct of will to meaning (Wille zum Sinn), namely the basic need of the human spirit to find meaning and purpose in concrete day-to-day existence (Bruzzone, 2007; Bruzzone, 2012a). Frankl was persuaded that the existential vacuum into which persons fall when they lose a sense of meaning in their lives requires a therapy "centering on life's meaning as well as man's search for this meaning" (Frankl, 2010, p. 51). Hence, Frankl is viewed as the standard-bearer of existential and positive psychology and a key reference author for further researches on existential meaning (Wong & Fry, 1998; Batthyany & Guttman, 2005; Batthyany & Russo-Netzer, 2014).

Frankl first observed the *survival value* of seeking meaning as a prisoner in Nazi concentration camps during World War II (Frankl, 2017): research subsequently confirmed that meaning-making is a key resource that can foster resilience and post-traumatic growth (Calhoun & Tedeschi, 2006). The impact on patients' quality of life of experiencing illness (Glaser & Strauss, 1975) is shaped in great part by how the patients themselves subjectively perceive and process events. Thus, meaning-making processes play a key role in determining the effect of critical situations and stressful events in the lives of individuals (Park, 2010) and directly affect patients' wellbeing and salutogenic process (Antonovsky, 1987).

One well-developed and promising line of inquiry has examined *meaning-focused coping*. Crystal L. Park, at the University of Connecticut, proposed a theoretical model of meaning-making that is divided into two levels: *global meaning* and *situational meaning* (Park & Folkman, 1997). Global meaning comprises three main factors: beliefs and convictions; ideals and aspirations; sense of self and purpose. Each of these three aspects is directly related to a person's well-being and psychophysical health. More specifically, global meaning

in The Hague; the second is *Ciencia y caridad*, painted by Pablo Picasso at the height of Positivism (1897) and on display at the Museu Picasso in Barcelona. In both cases, the subject is the medical profession. But while in the first painting, it is clear that medical science is being developed based on the body-corpse (an object without a story or identity), in the second, the artist depicts a doctor at the bedside of a sick woman and the entire scene suggests that the patient has feelings, desires and projects, to the extent that it prompts a crucial question: Who is going to address the fact that, despite being a patient, this woman is still a mother? Her concern for her young child makes the story of her illness different to that of any other patient suffering a similar fate.

<sup>4.</sup> Logo-therapy (from *lógos*, meaning) literally means "healing through meaning" (Frankl, 2010, p. 125).

plays an essential role in how individuals deal with situations of crisis or serious illness, influencing their adjustment and, some research suggests, even their survival. (Park, 2013, p. 41)

Situational meaning, on the other hand, is essentially the meaning that individuals attribute to what they are experiencing at a given moment: their way of representing and reacting to events. Such attributions of meaning are largely determined by a person's cultural background and life story, but also by the contingent resources (whether relational, affective, religious, etc.) that they have access to at a given point in their lives.

The model is discrepancy-based: a perceived discrepancy between the meaning of a particular situation (as actually experienced) and our overall framework of reference (what we believe and desire) generates a tension that may be resolved by means of *assimilation* (modifying the meaning of a concrete situation) or *accommodation* (changing ourselves or our framework of reference),

Serious, chronic, or terminal illness can upset a person's system of meanings, challenging their convictions or identity, prompting radical doubts, destabilizing their sense of control, making them more aware of their own precariousness, objectively limiting their opportunities for self-realization, and ultimately making them lose confidence and hope for the future. Meaning-making contributes to mitigating the stress caused by the critical situation, "helping patients either assimilate the illness into their pre-illness global meaning or helping them to change their global meaning to accommodate it" (Park, 2013, p. 43). It is an educational, rather than a clinical, task insofar as it does not act on diseases but on persons, helping them to engage in a reflective process of reinterpreting themselves and what they are experiencing, with a view to restoring order to chaos and, ultimately, once more setting a meaning-ful direction for their lives. And indeed *intentionality* is a vital component of any quest for meaning, that is: being oriented towards a purpose, reaching towards something or somebody. Frankl termed this quality *self-transcendence*; the philosopher François Jullien has recently renamed it *de-coincidence*, that is to say, "*that tension that keeps one alive*" (Jullien, 2019, p. 33) and without which life would be meaningless.

# 3. Towards a narrative integration of the experience

If desire and intentionality are the driving forces of life, therapy for the ill must be designed to intercept not only their psychological and physical needs, but also their spiritual requirement for consistency and direction, helping them to make explicit the existential questions prompted by their situation, and to piece together a framework of values and meanings in which their illness is not only a cause of disruption but also a paradoxical opportunity for personal growth and development.

Narrative meaning-making concerns "the existential dimension underlying coping and adjustment" (Hartog et al., 2017, p. 4): its aim is to support existential change and the corresponding narrative reconstruction process. In light of an experience that is undermining the solidity of their worldview and lifeview, patients must face the challenge of generating a new narrative: this presupposes changing their perspective on events, sometimes undertaking a challenging process of self-reinterpretation (Bruzzone, 2018) and, in all cases, revisiting their expectations and aspirations. This process involves at least three dimensions: evaluation, in terms of evaluating an event as positive or negative for one's life, agency, in terms of one's ability to decide how to react to the event, and scope, in terms of the extent to which the event impacts their life goals.

Indeed, a person "reveals himself through his biography: it reveals (...) what this man really is, in terms of both the meanings he has actually lived out and his possibilities of meaning" (Frankl, 2005, p. 68). This distinction is of supreme importance in defining the term *meaning* from a

S. Research has shown that a high percentage of cancer patients experience significant personal growth following their illness. A number of meaning-oriented approaches have been developed to enhance these personal resources. For example, William Breitbart at the Sloan Kettering Cancer Center in New York devised a method for individual and group therapy (Breitbart & Poppito, 2014a; 2014b) that has informed several projects conducted in Italy, including the implementation of LÆOn (Logotherapy and Existential Analysis in Oncology) groups at the Istituto Nazionale dei Tumori in Milan as well as at the Centro di Riabilitazione Oncologica in Florence. These support programs involve working on a range of themes including: core life values; illness-related fears and causes of suffering; personal and social resources for coping with the illness; resilience mentors; existential lessons drawn from the experience of being ill; existential plans and resolutions for the future (Murru et al., 2014).

phenomenological-existential perspective. Meaning, according to Frankl, is not simply something that a person produces, but a particular existential possibility that must be identified and realized.<sup>6</sup>

Narrative integration may be said to have taken place "to the extent to which the life event is integrated in the life narrative, given a new meaning and becoming a part of someone's identity" (Hartog et al., 2017, p.8). In this regard, it has been observed that patients may adopt four different attitudes:

- 1) Denial: the circumstances of the illness are downplayed or set aside and the life narrative is tenaciously kept going as though nothing had happened. This situation is at strong risk of collapse, and may last for a longer or shorter length of time before imploding.
- Acknowledgment: the disease is recognized as disruptive and as having an impact on the patient's life, but this awareness is still not enough to trigger a truly transformational process.
- 3) Acceptance: the patient tries to find ways of compromising with the illness and to reinterpret their existence in light of the new situation, embracing the necessary changes.
- 4) Reception: the patient successfully integrates the illness into their life narrative, revisiting priorities and goals, developing new values frameworks and sometimes even transforming the limits of their situation into unexpected resources.

Clearly these are not a series of phases in coping with illness, but rather some of the existential stances that patients adopt in practice, sometimes immediately fixing on one of them, but more frequently passing from one to the other in search of a new equilibrium. Hence, therapeutic intervention based on the narrative reconstruction of experience should be designed to help beneficiaries to gradually progress towards fully integrating their critical situations into their life narratives. Indeed, narrative *per se* — and especially autobiographical writing — can potentially reinforce the tendency to emplot one's life events according to fixed schemas; in contrast, the aim of narrative care work is to facilitate a more flexible interpretation of events and the emergence of new stories of illness.

To this end, it may be useful to recall that, in Frankl's existential analysis, the "two essential qualities of human existence" (Frankl, 1994, p. 110) are *self-distancing* and *self-transcendence*: the former refers to the ability to detach from oneself and from one's symptoms of illness, contemplate oneself from an outside perspective, and even laugh at oneself; the latter requires the ability to devote to something other than oneself: a person to love, a task to complete, a challenge to embrace. The dynamics of responsibility are especially effective in helping patients to avoid the self-pity and fatalistic outlook that sometimes go hand in hand with serious illness, allowing them to retain authorship of their own life narratives. It sometimes happens that people are not the victims of their fate, but of the story within which they have framed it (Hillman, 2006, p. 21): their existence is no longer free to unfold, but seems "increasingly surrendered over to one particular world-design, possessed by it, overpowered by it" (Binswanger, 1963, p. 142). There is thus a difference between free and spontaneous narration (which can spontaneously take a constructive direction) and that proposed in an educational setting, such as autobiographical counselling (Demetrio, 2008): in the latter case, it is important to watch out for potential recurrent narrative scripts and suggest alternative modes of storytelling.

In this process of reconstruction of meaning and reorganization of experience, alongside the *cognitive* aspects, a key role was also played by the *emotional* aspects. Indeed, in phenomenological terms, experience consists of a pre-reflective flow that is immediately picked up by feeling before it can be conceptualized or verbalized (Gendlin, 1962). It is crucial therefore that narrative intervention with patients (and their caregivers) should not be a solely intellectual exercise, but should also enhance the beneficiaries' awareness of the emotions, moods and feelings (Iori, 2006) that colour their personal experience and shape their approach to dealing with events. Phenomenological analysis has shown that

<sup>6.</sup> Hence, every situation has an intrinsic meaning to be recognized or discovered, similarly to how the "requiredness" (Kohler, 1938) or "affordances" (Gibson, 1979) of a perceived object invite an appropriate response. In other words: each specific life situation challenges us anew to seek and find its latent possibilities as constructively as we are able. However, the narrative work to be done is not purely arbitrary, as radical constructivist positions would have it: reality features constraints that a story cannot change. Indeed when narrative becomes unanchored from the constraints of experience, it may slide — for the most part inadvertently — into delirium and psychosis.

we perceive values and the valuable qualities of things thanks to our emotional intuition (De Monticelli, 2003): emotions and feelings, therefore, are partly evaluative in nature, and as such guide our choices and behaviours. Our very interpretation of the events that happen to us is filtered, in some sense, by what we are experiencing at a given moment, in that our mood can reveal or preclude certain possibilities of experience (Bollnow, 2009). This means that the expression, sharing, and transformation of emotional experience is a crucial stage in any educational intervention based on a narrative approach to illness. When our emotional perceptions of an event changes, this is reflected in how we narrate it. Hence, as María Zambrano (2014, p. 87) teaches us, "what we call thinking should be, in the first place, deciphering what we are feeling."

#### 4. Conclusions

Illness is a time in a subject's life experience that can disrupt the narrative plot of existence. The phenomenological-existential approach gives us to access to the ways in which patients' intentionality changes as they go through the stages of an illness and as their narrative of that illness evolves. The impact that being ill will have on their existence depends to a significant extent to the opportunity they are given to integrate it into their personal life story. The existing literature offers several models of meaning-making that may be drawn on to better understand how persons relate to their suffering. This understanding can help us to fine tune our inquiry into personal coping with illness and to more consciously take emotional and existential dimensions into account in the accompaniment of our patients. Especially in the case of chronic or terminal conditions, indeed, a failure to resignify the experience can actually hinder the patients' recovery process and self-planning, whereas narrative work may help them to keep the meaningfulness of their existence alive.

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Daniele Bruzzone – Università Cattolica del Sacro Cuore (Italy)

- https://orcid.org/0000-0002-2497-0277
- daniele.bruzzone@unicatt.it

Daniele Bruzzone, Professor of Education at the Università Cattolica del Sacro Cuore (Milan). Vice president of the Italian Association for Viktor Frankl's Logotherapy and Existential Analysis (ALÆF). Coordinator, with L. Zannini, of the research group on the "Pedagogy for healthcare professionals" of the Italian Society of Pedagogy (SIPed). He's been working for years in the development of the emotional and relational competence in education, social work and healthcare contexts.