

Discourses We Live By

Narratives of Educational
and Social Endeavour

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2. From Experience to Language in Narrative Practices in Therapeutic Education in France

Hervé Breton

Hervé Breton presents a clear exposition of a process that can make patients' lived experiences of illness visible to both themselves and the medical community. He reveals the stages of selecting, verbalizing and storying and — focusing on a patient account — enables the reader to grasp the theoretical approach, how to put this into practice, and what the stages might look like.

This chapter examines processes that assist patients to make their lived experiences of ill health audible, to enable medical practitioners to better understand the consequences of their approaches and interventions. It presents a way of working that facilitates the expression of the experience of enduring into language. It uses the dynamics of biographical inter-comprehension to help patients to express particular life experiences, and to enable others to receive their stories. This approach, which transforms lived experience over time into existential and expressible content, may enable improvements to guidelines for the facilitation of therapeutic education, resulting in an enhanced complementarity between experiential and experimental approaches. In these ways it complements and extends existing work in the Anglo-American tradition¹ in looking at ways to do this.

1 For example: Hurwitz, B. & Charon, R. (2013 Jun 1). A narrative future for health care. *Lancet*, 381(9881): 1886–87; Bradby, H., Hargreaves, J. & Robson, M. (2009). Story in health and social care. *Health Care Anal.* 17(4): 331–44.

The Motivational Context

On the occasion of the 2016 colloquium of the French high commission on health (Haute Autorité en Santé, HAS),² Professor Agnès Buzyn (who was named health minister in 2017) stated in her conference opening speech: 'The experience of the patient adds a perspective that is complementary to that of the health professionals. It has to be taken into consideration, if our health system is to evolve towards more democracy.'³ More than merely expressing a political will to take the patient's experience into account, Professor Buzyn reflected on ways forward:

We can no longer rely only on the analyses of patients' complaints and undesirable events to improve the quality of health care. We must go further. Patients are the ultimate beneficiaries of the HAS' commitment to quality care. We therefore we need their guidance as to the methods, service delivery and the way forward.

In this chapter I shall attempt to look at the concrete challenges this raises. Which methods may be used to foster acceptance of the patient's experience in a care setting? What really is at issue in counselling and in the facilitation of the expression of the patient's experience? In which ways can patients' stories, and the things they express, help make medical practices more pertinent? How can narrative approaches in healthcare and experimental medical sciences be complementary?

We will start with the quest for a definition of the patient's unique experience. This will provide the 'cornerstone' for studying narrative practices, the stakes they raise, their processes and methods. We will then examine the narrative forms that are at work by looking at two 'passages': one from the experience to its expression; and one that takes place as the stories are being shared in a group context. We will first study these transitions by examining a story written in the first person during a period in which its author received the diagnosis of the onset of a rare illness. After this example of an inaugural moment of a challenging experience, we will look at the processes by which the expression of an experience into words can transform it into a story, and

2 The author has translated French sources into English for this chapter.

3 HAS Website: https://webzine.has-sante.fr/portail/jcms/c_2728261/fr/patients-et-soignants-vers-un-necessaire-partenariat.

then into a story to be told in a joint storytelling session that aims to foster biographical inter-comprehension. The understanding of the processes by which lived experiences are shaped into existential and 'narratable' form helps to develop guidance that may enhance counselling and facilitation practices in therapeutic education, as well as new forms of complementarity between experiential and experimental approaches.

The Patient Experience: Elements of a Definition

That I stress the necessity of listening to the experience of a patient in care may surprise you: it suggests that the patient may become forgotten by a medical practice supposed to be entirely dedicated to him or her. This possible oblivion may originate in the will to increase what Illich (critically) names 'the efficacy of the medical act' (1975, p. 15) whereby patients have to learn to make themselves available, so that the gestures of medical intervention can be dispensed in an orderly way on their bodies, which are thereby reduced to passive matter. Forgetting the subject legitimizes a process of naturalization whereby the patient is merely the bearer of an autonomous phenomenon, personal experience a residual phenomenon in a medical practice, in which his or her reified body is merely altered material, the passive terrain of processes of decay and contamination. An alternative and non-competing view to that verbalized by Illich is to consider that the medical professions have a limited capacity to make space for the expression of patient experience, as this is not defined in medical sciences. Narrative work, *story-writing* and *storytelling* are viewed as strange, with a distant theoretical possibility to become an add-on during the treatment, or useful for interviews aiming to establish an 'educational diagnosis'.⁴

When the health sector shows interest in the expression of the patient experience, it signifies a change in its positioning. Indeed, seeking to understand 'from the viewpoint of the sick person' presents difficulties and constraints: it takes time and requires reciprocal engagement. It is complex as individuals will find the onset of an illness very different in terms of the depth of the experience, the forms of endurance, their

4 HAS guidance: *Recommandations. Education thérapeutique du patient. Définitions, finalités et organisation*: https://www.has-sante.fr/portail/jcms/c_1241714/fr/education-therapeutique-du-patient-etp

duration and intensity. In his conference with psychiatrists in 1992, the philosopher Paul Ricœur thematized a link between the notions of 'acting-enduring', which helps us to think through the question of suffering in the course of an illness:

As to the powerlessness to act, the gap between wanting and being in a position to act is, at the start, common to pain and suffering. This explains the partial overlapping of the two. The meaning of the old word 'to suffer' reminds us, that suffering first means enduring. Thus, the passivity of suffering contains a minimal degree of agency. (Marin & Zaccari-Reyners, 2013, p. 20)

Beyond its physical manifestations, perhaps even beyond pain, illness gives rise to a suffering that includes bodily experiences without it being exhausted by them:

thus, we shall reserve the term 'pain' to affects perceived as localized in particular organs of the body or in the whole body, and the term 'suffering' to affects that are open to reflexivity, language, relationship to self, relationship to others, relationship to the senses and to questioning. (ibid., p. 14)

These experiences of endurance and suffering impact on the life of the subject as it occurs, and on the life history as it occurs in daily life, given the new constraints linked to the illness and/or its treatment: the waiting times, the daily uncertainty, the pain in the organs. These are all phenomena that the subject endures and needs to negotiate. The illness impacts on the subject's history, because the characteristic reduction of agency in the experience of enduring originates in the lessening of physical abilities and in the deterioration of temporal structures that enable the person to perform and act in certain ways, and in the dependence on medical expertise. Undertaking narrative work to try to make sense of, and to bring into dialogue, the various forms of 'enduring/suffering' that result from extended dependence (on the medical world, the expertise of medical and nursing staff, the treatments and the manifestations of the illness) can contribute to the preservation and rehabilitation of the subject's agency.

The expression of the patient's experience, its crafting into a story and its reception by others (peers and medical staff) thus represents a dimension of the health journey, as we shall endeavour to show. This

activity of transforming the event of illness into a story takes time. Benaroyo (2013) stresses this when he identifies the phases through which the experience of illness presents itself, first in unspeakable forms that reduce the person to silence, sometimes to complaint, and then gradually evolving towards forms of expression that take the form of a story. Ricœur's enlightening thesis (1983) brings to light the processes of reciprocity between the temporalization of the experience (putting it into a meaningful timeline) and the story writing. The opening up of spaces in which the experience becomes 'sayable' represents a vital process that cannot be ignored in the health journey. From a biographical perspective, the fact that the experience of illness is being welcomed supports the endeavour of working on the experience, of passing it into language and making it 'speakeable' and 'tellable'. Such a process is a condition for the patient to retain agency and to find the strength of empathy in order to endure the illness. One of the values of narrative practices in healthcare is their capacity to support the maintenance of a sense of self through the opening up of spaces that allow endurance to be expressed, and to become known and recognized by communities of loved ones, peers, medical staff and perhaps even by the medical world. By becoming tellable, the experience can be shared with a view to a collective elaboration and formalization of knowledge acquired in the process. This can potentially complement knowledge constituted by experimental science.

Expressing the Lived Experience of Suffering: Expressibility and Wording

Understanding the process of expressing and then narrating the lived experience of a patient, and its being received by others, requires paying attention to transformative processes that take place during the activities of wording, meaning-making and storytelling. Composing one's story takes time. The story needs to take shape, to develop, to configure itself, and to turn into a story for others. The study of these gradual changes, as processes and as phenomena that unfold over time, provides a way of understanding what represents, to the patient, a transformation of his or her relationship with his or her lived experience and illness.

Expressibility of Suffering: Grasping the Experience and the Gradual Process of Wording

The passage from experience to language is the result of a journey: it starts with the evocation of a moment to be explored ‘in the living flesh’ and involves bodily sensations, impressions, anticipations and inferences. This experience is stratified (Petitmengin, 2010) and needs to find its way via wording into language. This journey transforms the experience itself and arises thetically for the subject in the act of narration and then becomes something that can be put into words, even in the form of speech. This change can be studied in the first person, notably with the help of the techniques of self-explicitation (auto-explicitation). Pierre Vermersch (2000b, 2007) modelled this, starting with the notion of ‘reference experience’ and then focusing on the selection of words by which to ‘say and tell’ the experience.

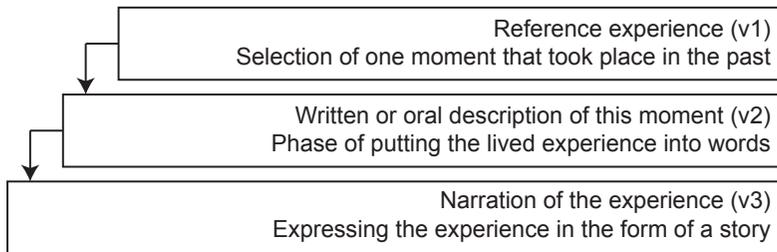


Fig. 2.1 Phases of the passage from experience into language.
Source: Breton, 2017a.

The diagram identifies three phases: choosing a singular moment to evoke (v1), wording it in a descriptive form (v2) and putting it into the form of a story (v3). To explore an event such as the onset of an illness and situating it in the course of a life begins with identifying its inaugural moment – of which the span is as yet to be determined. This first phase consists of the identification of this ‘primordial’ moment and its evocation. It is followed by a second process: that of the detailed description of its unfolding and its various aspects. The description of the aspects of this experience is part of the process of wording. It forms the basis for the third phase, which consists of configuring the experience within a storyline that holds its component parts together in an ‘experiential unity’ that is meaningful to the subject. This process in

three phases structures the gradual journey of the experience entering into language as description. This activity transforms the experience and renders it sayable. It thus creates the requisite conditions for the illness-event to become integrated into a biographical story.

A First-Person Story of a Journey of Diagnostic Delay

Let us put the question of the expressibility or sayability of the experience of enduring to the test, by looking at a story about a long journey of diagnostic delay in a case of a diagnosis of lupus, a rare illness. It is a story ‘radically in the first person’ (Berger, 2016, p. 105), that had been written up in the context of a research project undertaken by the working group on biographical research in health at CIRBE.⁵ It covers the inaugural moment of receiving a diagnosis from a GP, who diagnosed lupus after a quick examination. This ‘reference experience’ is a pivot in the patient’s life with the illness-event. It was put into words retrospectively, twelve months after the diagnosis was made.

On 31 December 2013, I went to see a countryside GP because I had two red blotches on my cheeks. The skin was inflamed. In spite of having applied a hydrating cream that I had found in a drawer and that had been used by my son a few years ago while he had bouts of eczema, things seemed to be getting worse. It was about 09h30 when I arrived at the doctor’s, accompanied by my spouse. After waiting for half an hour in a crowded room, I walk into the doctor’s surgery and sit down on a chair to the left of the room. The doctor is completing the medical file on his computer without saying a word. Then he turns towards me and asks: what brings you here?

Somewhat surprised that he’d ask me this question given the highly visible eruption on my skin, I reply: ‘I have been having two red blotches on my face for two weeks. I would like a cream to calm the eruptions.’ Without getting up and without examining me, the doctor responds: ‘You have got lupus. I will give you a cream to apply to your face. You can get it from the pharmacy next to the dispensary.’ A wee bit surprised, I ask him what a lupus is, gathering that it is a particular kind of eczema. He replies, that I need to see a specialist consultant close to my home after the Christmas holidays to get the diagnosis confirmed and the treatment adjusted. Back at home, I read up the notice for the cream and look up ‘lupus’ on google. That’s the beginning of six months of diagnostic delay.

5 The International College of Biographical Research in Education.

When the patient received the news in December 2013, the impact was massive. Getting to know a diagnosis of a chronic, potentially serious and disabling illness ‘first person’ represents a challenge to anticipatory structures and to the way of projecting oneself into one’s existential and professional future. It is worthwhile to note that the events as they happened represent an unusual account of a subject being ‘diagnosed with lupus’ when compared to existing research into the announcement of rare illnesses. The fact, that these illnesses are rare, that their symptoms are frequently systemic (which is the case with lupus), that they are gradual and come with changing levels of intensity, usually results in difficulty when it comes to diagnosis, which can in turn result in a process of diagnostic wandering for the patient.

Boucand (2010, p. 313) reveals for example that in a survey on ‘Ehlers-Danlos’ syndromes, ‘one person in four affected by the illness had to wait for more than 30 years before being given an accurate diagnosis and that 40% of the survey sample had been given the wrong diagnosis before being given the correct one’. Such a situation leads patients to doubt the ability of the medical world to listen to and understand their experiences and troubles, and to take them into account in their health journeys. Boucand notes that, in addition, this situation creates forms of dependence on the few medical experts in a given field, who are seen by the patients as the keepers of the expertise that can help their recovery. The story just presented illustrates a reverse situation. The ‘lupus’ diagnosis was established during the first consultation. The patient was given the task to have it confirmed by a specialist dermatologist. In the meantime, the patient had been prescribed treatment based on the conclusions of a first diagnosis, which can be quantified as ‘reliable, though not certain’. The historicization of the experience then requires biographical work on temporalization, by which this specific event finds its place within the duration of the journey. As this happens, the event becomes ‘thinkable’ as a trying period in a life journey.

The conditions for putting this moment into the shape of a story — and making it sayable — deserve attention. The text presented above was written thirty-six months after the event had taken place. It had shown itself to be the inaugural moment of the storyline and its power remained intact. In other words, the way in which the experience presents itself in the course of the storytelling process can be considered

a gauge of what still remains to be understood in it. As the experience becomes speakable, it reveals itself to the subject, or as Ricœur says: 'The experience can be told, it asks to be told. To bring it into the realm of language does not mean changing it into something else, but in articulating and in developing it, it becomes itself' (Ricœur, 1986, p. 62). There are experiences that need to be reflected on to find their place in a story. Their sayability takes time. It is a process of maturation that can be envisaged under three aspects: one, the possibility of reflecting on and of understanding different aspects of the experience that became an event; two, a gradual attempt at grasping the silent transformations happening in the 'living now'; three, a reconstitution of the temporal horizons of a given period of life that make it possible to situate the illness-event in the duration of a life story.

The Temporalization of the Experience: From the Pre-Figuration of the Experience to its Expression in the Form of a Story

The historicization of the illness-event proceeds from a complex temporality. Its study requires differentiating 'reflexivity in the course of the experience' and 'reflexivity after the experience'. Regarding the development of a storyline, Ricœur underlines the combination 'in variable proportions of two temporal dimensions: a chronological dimension and one that isn't. The first constitutes the episodic dimension of the story: it characterizes the story as being composed of events. The second is the "configuring" dimension proper, thanks to which the plot transforms the events into a story' (1983, p. 129). Seen from this perspective, the episodic dimension of the story arises from the chronological sequencing of salient moments of a period in life, while the configuring dimension confers duration and narrative unity to the story. The temporalization presents the storyline of the events situated on a timeline. Conversely, the narrative weaving harnesses the process of temporalization to explore and configure these moments together, and transforms the (linear) narrative regime of succession into a more integrated one of continuity. The creation of a story proceeds thus from an extension: triggered by the description of the reference experience (a moment), the narration then covers a period in one's life that may last

from a few months to a few years. In other words, the activity of the temporalization of the experience transforms the story with something like a ‘change of scale’. What happens here transforms the narrative work by letting it move from a regime of description / aspectualization (Adam, 2015) to one of periodization / historicization. This is illustrated in Figure 2.2 below, which follows on from and develops the expression, in the form of a story, of the experience of being given a diagnosis of ‘lupus’. In this example, the extension of the duration of the experience transforms the content of what is being narrated: the story of the inaugural moment, which includes this moment, is titled ‘Story of a period of diagnostic delay’.

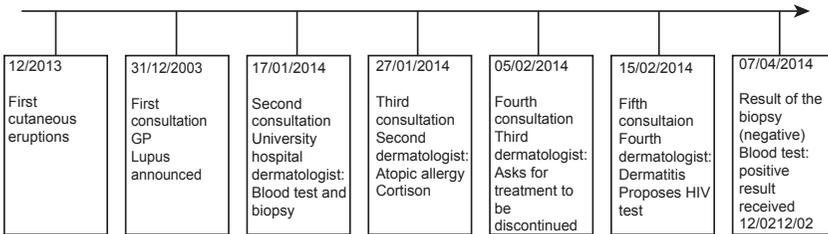


Fig. 2.2 Periodization of the experience of the patient between being given a first diagnosis and having it confirmed.

The above diagram sequences and punctuates particular moments in a journey of diagnostic delay by ordering them chronologically and making them appear in succession. The temporalization of the journey, which spanned a period of six months, makes seven salient moments apparent. The expression of these experiences into a story now needs to integrate each of these moments as a unity in themselves, and then, to explore the links existing between these moments together. It is indeed the configuration of these moments taken together that makes a stretch of experience (a period in life) appear, the scope and structure of which enable the identification of different themes of the first story: the erosion or loss of agency of the patient along a timeline, a variety of lived temporal experiences (waiting, inertia, stuckness, urgency...), daily acts and gestures to stay the course and to keep being engaged at work, the rehabilitation of anticipatory structures, knowledge of the illness acquired in the course of time, transformation of the modes of attention to oneself and to bodily sensations... A correlation can be envisaged

between the duration of the experiences explored and the thematic work, that developed in the context of the patient-carer relationship or through the patients' attempts to formalize knowledge acquired during their experience of illness. This observation highlights the forms of co-dependence between the temporal scales of the experience that is taken into account in the narrative work, and the processes of understanding that result from that work, for oneself, for peers (other patients) or for the medical professions.

From Expression of the Experience to the Reception of the Stories

At this stage, we have identified a first passage: the passage from experience to language, which has its own temporality that varies according to: the relationship the 'subject' has with his or her experience; the events experienced; and the domains and dimensions of existence that the experience touches. This passage also has a micro-dynamic that combines and alternates the activity of temporalizing the experience with the task of configuring it through wording and developing a story. Language transforms experience, owing to the thetic work that underlies it. This qualitative transformation of the experience is also that of the subject, who gives form to his or her existence by expressing it in the form of a story and who becomes a reflective and historical subject, who can think of him- or herself in time and tell his or her story. Putting experience into narrative form shapes and transforms the experience. The capacity to express experience arises from this process. We shall now examine the second passage, which allows the story to be re-viewed through the circulation of its modes of expression.

Reflecting on the Time of Passing the Story On to a Community

The expression of the story in a group context opens up to participants the possibility of a singular experience: the reception of the story. This process is the subject of particular attention for, and during, the sessions in which life stories are developed. The story of diagnostic delay outlined earlier could, for example, be shared and socialized

during a session of expressing and writing life histories (Lainé, 2004). During this phase, the stakes change. The presentation of stories in a group context requires a re-view of the story first written ‘in first person’ in order for it to be received by ‘others than oneself’. Conversely, one requires narrative abilities to make oneself available to listen to patient’s stories (Charon, 2015). These can be practiced as part of the experience of doing biographical work in a group. The patients, as well as the health professionals who engage with this process, experience the story as they articulate different levels of enunciation of the experience of the illness, when they narrate ‘in the first person’ (illness) and bring the different stories into dialogue (disease), when the collective thematization (in the third person) is likely to make new categories emerge, destined to support knowledge creation and medical science (sickness) (for further context see: Laplantine, 1992; Depraz, 2014). The circulation of these narrative modes starts in the training workshops on life stories and the lived experience of the subject and moves to the gradual facilitation of putting experience into words, for oneself first and then for others.

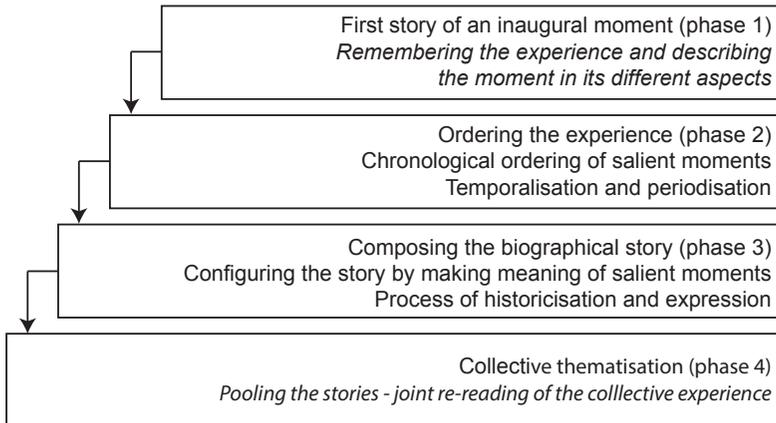


Fig. 2.3 Expressing experience in a story in sessions of expressing and writing life histories.

The approach presented here has four distinct phases:

Phase 1: the subject becomes involved in identifying and remembering a salient moment that s/he tells ‘in first person’ (Depraz, 2013). This phase of working on one’s own includes choosing a moment, remembering and describing it.

Phase 2: the subject presents the story to a sub-group. The interactions that take place following the first narration support the ongoing work of the narrator, remembering the moments that took place during the inaugural experience from which the plot originates. The successive remembrances of an event are chronologically ordered on a timeline that defines the event's place in a sequence of lived experiences.

Phase 3: the temporal plot that lists experiences chronologically prefigures the activity of composing the story. The narrative work is being initiated by the subject, with an exploration of the relationship that connects the different events that occurred during the temporalization of the experience and that has remained in part tacit. In other words, the historicization of the experience proceeds from an activity of configuration by which the different moments that constitute, for the subject, a period in his or her life 'hold together'.

Phase 4: the activity of shaping experience into the form of a story with a biographical dimension takes place at home. The fourth phase of the sessions of expressing and writing life histories is one of socialization. The experience happens in the community through work in a group and the reception of the story in a group, first in the first person, during the telling of the story or parts of it by everyone and in the processes of inter-comprehension that arises from it.

Reciprocity of Levels of Enunciation: First, Second and Third Person

The expression of experience during a biographical interview, or, as is the case here, during sessions of developing live stories, involves a second transformation of the experience, which occurs when stories are shared with a community. A set of processes take part in this transformation. We will present these succinctly while paying particular attention to the connections between the different modes of expressing stories. There are three modes with three distinct processes and effects:

In first person: in the course of his or her narrative work activity in the first person, the subject is immersed and existentially engaged, searching for propitious words to 'get as close as possible' to what s/he has gone

through and felt in the course of the event to be narrated. As mentioned earlier, this work presupposes access to these memories, and requires the person taking time to put them in the form of words through a reflexive grasp of the different moments and by historicizing the events within a duration or a journey. To become tellable, the experience needs to have been expressed in ways the subject considers to be true. This mode of expression is thus strongly infused with subjectivity. What is told contains the various dimensions of the felt experience of the subject, as well as what stands out in it or what has been understood about it. The interpretation of the experience expressed in this way reflects a way of seeing, of signifying and configuring a period of life with a view to making it tellable to loved ones, to peers, to the medical world. Stories shaped in this way become tellable and open possibilities for re-viewing the experience *as* it is brought into dialogue by others *or* owing to the reflexive reciprocity arising during the listening to and receiving of a life story from someone else.

In second person: the socialization of the story opens up different possibilities for re-viewing the story. The meaning-making in the story-making process follows on from bringing the experience into dialogue with others, e.g., during inter-personal meetings, in small or large groups. Dialogue may arise from an exchange of testimonials. This format opens up the possibility of mutual recognition and makes visible the unique nature of the stories, as well as the inter-comprehension of the dimensions of these stories that bring forth our shared humanity: anthropological dimensions of the course of life, the sharing of major historical events, the intrinsic vulnerability of the human condition (illness-events, grief, life-crisis, search for meaning...). The work in the second person thus transforms 'what is considered as true by the subject'. The exchanges and the reception of the story by others open up hitherto unconsidered perspectives for interpreting one's history and integrating social dimensions into the subject's comprehension of life.

In third person: work in the third person consists of the *thetic*, existential analysis of what appears as the fabric of 'humanity', beyond the uniqueness of everyone's stories. Here, there is potential for defining the recognition of experiential knowledge acquired in situations of vulnerability (Zaccaï-Reyners, 2006), for improving practices and frameworks for facilitation (Jouet, Flora & Las Vergnas, 2010; Jouet

& Flora, 2010) and for upgrading training in healthcare (Thievenaz & Tourette-Turgis, 2015). The third-person mode thus takes as an object what has been told and experienced by the group during the socialization phase, without referring to any specific story. The analysis of the experience thus takes place in the third person, and it includes all who take part in the training or in the 'recognition of experiential learning' sessions (Breton, 2017b).

The diagram below offers a model through which to cross-analyse the narrative modes of the story in the course of the biographical activity, when expressing and writing down experiences in life history sessions:

Phases of passage The narrative modes	From experience to language: composing the story	Expressing the story : circulation of modes of expression	Socialising the stories: unicity of experiences and reciprocity of the stories
Work "in the first person"	Remembering, temporalising and putting experience into words	Selecting passages of the story with a view to experiencing their expression	Reflexive activity linked to the reception of the experiences: joint and reciprocal attention
Work "in the second person"	First form of socialisation of the story with close ones (friends, family...)	Processes of inter-comprehension through bringing different stories into dialogue	Reflexive reciprocity owing to reception of the stories: processes of inter-comprehension
Work "in the third person"	Suspending generic forms (already there) of the translation of the experience	Collective experience of alternating expression and reception of stories	Collective thematisation owing to the reception of the stories: recognition of solidarity between the stories

Fig. 2.4 Narrative modes and transformations of experience during biographical activity.

The processes of understanding that take place in the course of biographical activity have several results, including the alternation of the modes of expression of experience (the diagram above attempts to visualize this). Bringing experience into dialogue on the other hand proceeds from co-reflexivity. Through this alternation of the narrative modes, the unique experience receives recognition as a singular experience. Understood by the group, which symbolizes the community of peers, it then integrates what Husserl calls 'the life world' (Bégout, 2007) and Dilthey 'vital wholeness' (Zaccaï-Reyners, 1995).

Facilitation Strategies in Therapeutic Education

The pertinence of narrative work, as seen from this perspective in therapeutic education, can be envisaged in two ways: the first relates to its contribution to the rehabilitation of the agency of the patient; the second concerns the possibilities opened up by the emergence and renewal of medical know-how and expertise. With regard to the question of 'contribution', the development of narrative work requires that the strategic and methodological dimensions of care practices that integrate narrative approaches are clarified. The story told in this chapter has been drawn from Colinet & Avenel (2017), who named it 'a situation of announcing the diagnosis of a rare disease' which they describe in the following way: 'the doctor's practice includes the task of announcing the rare disease, but also and above all, at a medical level, to accompany the patient in the decision-making process s/he needs to go through'. Seen in this way, the narrative work of the patient can contribute to the understanding of the things that support the taking of enlightened decisions in the course of his or her life.

I have tried to show that this work of recognition and rehabilitation of the patient's identity may necessitate the combination of different forms and phases of expression: for oneself (putting experience into the form of a story in the first person); in the patient-carer relationship (bringing stories into dialogue, involvement of a second person); transformations of the experiences (in a group, as the third person). I have also tried to show that the narration of a lived experience proceeds by successive stages that require time: firstly, for the experience to pass into language; secondly, for the story to configure itself; thirdly, for it to be expressed (making time available for this during the patient-carer relationship is then a matter of planning); and fourthly, for a dialogue to develop with a view to recognizing the experiential knowledge that has been acquired.

Describing the dimensions of narrative work, its processes and temporalities does have some implications for healthcare practices. The expression of lived experience does not take place in the organized and orderly fashion of standard practices described in manuals. Welcoming and listening to the patient's lived experience is an immersion in the 'singular' life with the risk of feeling involved:

[...] person-centered health care cannot be translated into a grammar of accountability indispensable for accreditation. The taking into account of the particular, on which health care is founded, finds itself diminished at the expense of the standardization of practices construed as a guarantee of quality, efficiency, throughput and productivity. And that means the death knell of much needed creativity. Thus, the possibility of a clinician trained in practical wisdom gets eroded. (Weber, 2017, p. 19)

The expression of a patient's lived experiences requires that the practitioner pay attention to the pain of the 'speaking subject', but also to his or her suffering, which is often expressed at the beginning in terms that are close to the intimacy of private language. Remaining sensitive to what is being said, while facilitating the activity of expressing, with the aim of individualizing the health journey (*parcours de soins*) requires from health professionals the ability to be close to the patient without identifying with the suffering contained in the stories.

In Conclusion:

Towards a Narrative Science in Medical Care?

In this chapter, I have tried to formalize concepts and methods with the aim of identifying the stakes and the process of narrative work in care settings. Further work is needed to define the conditions under which these approaches may become recognized by medical science. One important task is to research and/or substantiate the complementarities existing between experiential approaches that involve narrative practices (Depraz, 2009; Pineau & Legrand, 1993) and experimental approaches in biomedical science (Lemoine, 2017). A body of research already undertaken in the biographical domain exists. Many research papers, in the domain of the expression and writing of life histories and biographical research in education, interrogate the place allowed for the lived experience of the patient in medical practice (Dominicé & Waldvogel, 2009; Delory-Momberger & Tourette-Turgis, 2014; Jouet & Flora, 2010). A range of research projects have been carried out in the domain of alcoholology (Niewiadomski, 2000; Pentecouteau, 2013) and, for example, in the field of chronic illnesses.

More recently, innovative work has been published in the field of micro-phenomenology. This has made it possible to lay the foundations

of a ‘science of lived experience’ (Petitmengin, Bitbol, & Ollagnier-Beldame, 2015) and to reflect on its uses and potential contribution to healthcare (Petitmengin, 2005). These three authors respond to criticism addressed to introspective approaches in the first person (such as biographical approaches and micro-phenomenology), labelled as ‘subjective’ and ‘mentalist’ in experimental science. The authors defend and argue the case for a paradigm of a science of the singular (Vermersch, 2000a & 2003) by seeking to trace a ‘middle path’ between fragmentary and private subjectivism and reified and entrenched objectivism. Several criteria have been defined for advancing towards a science of the description of lived experience. They include the study of methods of collecting descriptions of lived experience, categories of analysis that allow the formalization of the structures of lived experiences to be recognized in singular stories, and the circulation between first-person and third-person expression. These research projects contribute to strengthen the validation of experiential approaches in health, while at the same time shifting the boundaries of power that organize the legitimacy of knowledge (Foucault, 1969). It is our belief, that this shift is needed for patient experience to become recognized as ‘the locus’ around which inter-disciplinary work in healthcare is organized.

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