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## FROM EXPERIENCE TO LANGUAGE IN NARRATIVE PRACTICES IN THERAPEUTIC EDUCATION IN FRANCE

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 others to receive their stories, believing that 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 tradition<sup>1</sup> in looking at ways to do this.

### The motivational context

At the occasion of the 2016 colloquium of the French high commission on health (Haute Autorité en Santé, HAS), Professor Agnès Buzyn (who was named health minister in 2017) stated in her conference opening speech<sup>2</sup> : ‘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.’ 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.

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<sup>1</sup> For example: Hurwitz, B. & Charon, R. (2013 Jun 1). A narrative future for health care. *Lancet*, 381(9881): 1886–1887; Bradby, H., Hargreaves, J. & Robson, M. (2009). Story in health and social care. *Health Care Anal.* 17(4): 331-44.

<sup>2</sup> HAS Website: [https://webzine.has-sante.fr/portail/jcms/c\\_2728261/fr/patients-et-soignants-vers-un-necessaire-partenariat](https://webzine.has-sante.fr/portail/jcms/c_2728261/fr/patients-et-soignants-vers-un-necessaire-partenariat).

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28           We therefore we need their guidance as to the-methods, service delivery and  
29           the way forward.

30   Now in this chapter, with you the reader, I will attempt to look at the concrete challenges this  
31   raises. Which methods may be used to foster acceptance of the patient's experience in a care  
32   setting? What really is at issue in counselling and in the facilitation of the expression of the  
33   patient's experience? In which ways can patients' stories and what expresses in them help  
34   make medical practices more pertinent? In which way can narrative approaches in health care  
35   and experimental medical sciences be complementary?

36   We will start with the quest for a definition of the patient's unique experience. This will  
37   provide the 'corner stone' for studying narrative practices, the stakes they raise, their  
38   processes and methods. We will then examine the narrative forms that are at work by looking  
39   at two 'passages': one from the experience to its expression; and one that takes place as the  
40   stories are being shared in a group context. We will first study these transitions by examining  
41   a story written in the first person in a period in which its author received the diagnosis of the  
42   onset of a rare illness. After this example of an inaugural moment of a challenging experience,  
43   we will look at the processes by which the expression of an experience into words can  
44   transform it into a story and then into a story for telling in a joint storytelling session that aims  
45   to foster biographical inter-comprehension. The understanding of the processes by which  
46   lived experiences are shaping into existential and 'narratable' form helps develop guidance  
47   that may enhance counselling and facilitation practices in therapeutic education, as well as  
48   new forms of complementarity between experiential and experimental approaches.

## 49   The patient experience: Elements of a definition

50   That I stress the necessity of listening to the experience of a patient in care may surprise you:  
51   it suggests that the patient may become forgotten by a medical practice supposed to be  
52   entirely dedicated to him/her. This possible oblivion may originate in a will to increase what  
53   Illich (critically) names 'the efficacy of the medical act' (1975, p.15) whereby the patient has  
54   to learn to make himself available, so that the gestures of medical intervention can be  
55   dispensed in an orderly way on the body of the patient, thereby reduced to passive matter.  
56   Forgetting the subject legitimizes a process of naturalization whereby the patient is merely  
57   the bearer of an autonomous phenomenon, his/her experience a residual phenomenon in a

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58 medical practice, in which his/her reified body is merely altered material, the passive terrain  
59 of processes of decay and contamination. An alternative and non-competing view to that  
60 verbalized by Illich is to consider that the medical professions have a limited capacity to make  
61 space for the expression of patient experience as this is not defined in medical sciences.  
62 Narrative work, story-writing and story-telling are viewed as strange, with a distant theoretical  
63 possibility to become an add-on during the treatment or useful for interviews aiming to  
64 establish an 'educational diagnosis'<sup>3</sup>.

65 When the health sector shows interest in the expression of the patient experience, it signifies  
66 a change in its positioning. Indeed, seeking to understand 'from the viewpoint of the sick  
67 person' presents difficulties and constraints: it takes time and requires reciprocal  
68 engagement. It is complex as individuals will find the onset of an illness very different in terms  
69 of the depth of the experience, the forms of endurance, their duration and intensity. In his  
70 conference to psychiatrists in 1992, philosopher Ricoeur thematized a link between the  
71 notions of 'acting-enduring', which helps think through the question of suffering in the course  
72 of an illness:

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

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

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

84 These experiences of endurance and suffering impact on the life of the subject, as it occurs  
85 and on the life history. As it occurs in daily life ... given the new constraints linked to the illness  
86 and/or its treatment: the waiting times, the daily uncertainty, the pain in the organs. These

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<sup>3</sup> 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](https://www.has-sante.fr/portail/jcms/c_1241714/fr/education-therapeutique-du-patient-etp).

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87 are all phenomena that the subject endures and needs to negotiate. The illness impacts on  
88 the subject's history, because the characteristic reduction of agency in the experience of  
89 enduring originates in the lessening of physical abilities and in the deterioration of temporal  
90 structures that enable the person to perform and act in certain ways and in the dependence  
91 on medical expertise. Undertaking narrative work to try to make sense of and to bring into  
92 dialogue the various forms of 'enduring/suffering' that result from extended dependence (on  
93 the medical world, the expertise of medical and nursing staff, the treatments and the  
94 manifestations of the illness) can contribute to the preservation and rehabilitation of the  
95 subject's agency.

96 The expression of the patient's experience, its crafting into a story and its reception by others  
97 (peers and medical staff) thus represents a dimension of the health journey as we shall  
98 endeavour to show. This activity of transforming the event of illness into a story takes time.  
99 Benaroyo (2013) stresses this, when he identifies the phases through which the experience of  
100 illness presents itself first in unspeakable forms that reduce the person to silence, sometimes  
101 to complaint and then gradually evolve towards forms of expression that take the form of a  
102 story. Ricœur's enlightening theses (1983) bring to light the processes of reciprocity between  
103 the temporalization of the experience (putting it into a meaningful timeline) and the story  
104 writing. The opening up of spaces in which the experience becomes 'sayable' represents a  
105 vital process that cannot be ignored in the health journey. From a biographical perspective,  
106 the fact that the experience of illness is being welcomed supports the endeavour of working  
107 on the experience, of passing it into language and making it 'speakable' and 'tellable'. Such a  
108 process is a condition for the patient to retain agency and to find the strength of empathy for  
109 enduring. One of the stakes of narrative practices in health care consists in its capacity to  
110 support the maintenance of a sense of self through the opening up of spaces which allow the  
111 enduring to be expressed and to become known and recognized by communities of close ones,  
112 peers, medical staff and perhaps even the medical world. By becoming tellable, the experience  
113 can be shared with a view to a collective elaboration and formalization of knowledge acquired  
114 in the process. This can potentially complement knowledge constituted by experimental  
115 science.

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116 Expressing the lived experience of suffering: Expressibility and wording

117 Understanding the process of expressing and then narrating the lived experience of a patient  
118 and it being received by others requires heeding attention to transformative processes that  
119 take place during the activities of wording, meaning making and storytelling. The activity of  
120 composing one's story takes time to take shape, to develop, to configure itself and to turn into  
121 a story for others. The study of these gradual changes, as processes and as phenomena which  
122 unfold over time, provides a way of understanding what represents, to the patient, a  
123 transformation of his/her relationship with his/her lived experience and illness.

124 Expressibility of suffering: Grasping the experience and the gradual process of wording

125 The passage from experience to language is the result of a journey: it starts with the evocation  
126 of a moment to be explored 'in the living flesh' and involves bodily sensations, impressions,  
127 anticipations, inferences... This experience is stratified (Petitmengin, 2010) and needs to find  
128 its way via wording into language. This journey transforms the experience itself and arises  
129 thetically for the subject in the act of narration and then becomes something that can be put  
130 into words, even in the form of speech. This change can be studied in the first person, notably  
131 with the help of the techniques of self-explicitation (auto-explicitation). Pierre Vermersch  
132 (2000b, 2007) modelled this, starting with the notion of 'reference experience' and then  
133 focusing on the selection of words by which to 'say and tell' the experience.

134 [INSERT diagram 1 here]

135 The diagram identifies three phases: choosing a singular moment to evoke (v1), wording it in  
136 a descriptive form (v2) and putting it into the form of a story (v3). To explore an event such as  
137 the onset of an illness and situating it in the course of a life begins with identifying its inaugural  
138 moment – of which the span is as yet to be determined. This first phase consists in the  
139 identification of this 'primordial' moment and its evocation. It is followed by a second process:  
140 that of the detailed description of its unfolding and its various aspects. The description of the  
141 aspects of this experience is part of the process of wording. It forms the basis for the third  
142 phase, which consists in configuring the experience within a story-line that holds its  
143 component parts together in an 'experiential unity' that is meaningful to the subject. This  
144 process in three phases structures the gradual journey of the experience coming into language  
145 with the description. This activity transforms the experience and renders it sayable. It thus

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146 creates the requisite conditions for the illness-event to become integrated into to a  
147 biographical story.

148 *A first-person story of a journey of diagnostic delay*

149 Let us put the question of the expressibility or sayability of the experience of enduring to test,  
150 by looking at a story about a long journey of diagnostic delay in a case of a diagnosis of lupus,  
151 a rare illness. It is a story ‘radically in the first person’ (Berger, 2016: 105), that had been  
152 written up in the context of a research project undertaken by the working group on  
153 biographical research in health of CIRBE<sup>4</sup>. It covers the inaugural moment of receiving a  
154 diagnosis from a GP, who diagnosed lupus after a quick examination. This ‘reference  
155 experience’ is a pivot in the patient’s life with the illness-event. It had been put into words  
156 retrospectively, twelve months after the diagnosis had been made.

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

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

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<sup>4</sup> The International College of Biographical Research in Education.

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

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

201 The conditions for putting this moment into the shape of a story – and making it sayable –  
202 deserve attention. The text presented above was written thirty-six months after the event had  
203 taken place. It had shown itself to be the inaugural moment of the story-line and its power  
204 had remained intact. In other words, the way in which the experience presents itself in the  
205 course of the story-telling process can be considered a criterion as to what still remains to be  
206 understood in it. As the experience becomes speakable, it reveals itself to the subject, or as  
207 Ricœur says: ‘The experience can be told, it asks to be told. To bring it into the realm of



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208 language does not mean changing it into something else, but in articulating and in developing  
209 it, it becomes itself' (Ricœur, 1986, p.62). There are experiences that need to be reflected on  
210 to find their place in a story. Their sayability takes time. It is a process of maturation that can  
211 be envisaged under three aspects: one, the possibility of reflecting on and of understanding  
212 different aspects of the experience that became an event; two, a gradual attempt at grasping  
213 the silent transformations happening in the 'living now'; three, a reconstitution of the  
214 temporal horizons of a given period of life that make it possible to situate the illness-event in  
215 the duration of a life-story.

216 [The temporalization of the experience: From the pre-figuration of the experience to its](#)  
217 [expression in the form of a story](#)

218 The historicization of the illness-event proceeds from a complex temporality. Its study  
219 requires differentiating 'reflexivity in the course of the experience' and 'reflexivity after the  
220 experience'. Regarding the development of a story-line, Ricœur underlines the combination  
221 'in variable proportions of two temporal dimensions: a chronological dimension and one that  
222 isn't. The first constitutes the episodic dimension of the story: it characterizes the story as  
223 being composed of events. The second is the 'configuring' dimension proper, thanks to which  
224 the plot transforms the events into a story' (1983, p.129). Seen from this perspective, the  
225 episodic dimension of the story arises from the chronological sequencing of salient moments  
226 of a period in life, while the configuring dimension confers duration and narrative unity to the  
227 story. The temporalization presents the storyline of the events situated on a timeline.  
228 Conversely, the narrative weaving gets hold of the process of temporalization to explore and  
229 configure these moments together and transforms the narrative regime of succession into  
230 one of continuity. The creation of a story proceeds thus from an extension: triggered by the  
231 description of the reference experience (a moment), the narration then covers a period in  
232 one's life that may last from a few months to a few years. In other words, the activity of  
233 temporalization of the experience transforms the story with something like a 'change of scale'.  
234 What happens here transforms the narrative work by letting it move from a regime of  
235 description / aspectualization (Adam, 2015) to one of periodization / historicization. The  
236 extract below which follows on from and develops the expression in the form of a story of the  
237 experience related to being told the diagnosis 'lupus' illustrates this. In this example, the  
238 extension of the duration of the experience being referred to transforms the content of what

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239 is being narrated: the story of the inaugural moment which includes this moment is titled  
240 'Story of a period of diagnostic delay'.

241 [INSERT diagram 2 here]

242 The above diagram sequences and punctuates particular moments of a journey of diagnostic  
243 delay by ordering them chronologically and making them appear in succession. The  
244 temporalization of the journey, which spans a period of six months makes seven salient  
245 moments appear. The expression of these experiences into a story now needs to integrate  
246 each of these moments as a unity in themselves, and then, to explore the links existing  
247 between these moments together. It is indeed the configuration of these moments taken  
248 together that makes a stretch of experience (a period in life) appear, of which the scope and  
249 structure enable the identification of different themes of the first story: the erosion or loss of  
250 agency of the patient on a time-line, a variety of lived temporal experiences (waiting, inertia,  
251 stuckness, urgency ...), daily acts and gestures to stay the course and to keep being engaged  
252 at work, the rehabilitation of anticipatory structures, knowledge acquired in the course of  
253 time about the illness, transformation of the modes of attention to oneself and to bodily  
254 sensations... A correlation can be envisaged between the stretch of time of the experiences  
255 explored and the thematic work that can be the object of development in the context of the  
256 patient-carer relationship or work on formalizing knowledge acquired in the experience of  
257 illness. This observation highlights the forms of co-dependence between the temporal scales  
258 of the experience taken into account in the narrative work and the processes of understanding  
259 that result from it, for oneself, for peers (other patients) or for the medical professions.

## 260 [From expression of the experience to the reception of the stories](#)

261 At this stage, we have identified a first passage: the passage from experience to language,  
262 which has its own temporality that varies according to the relationship the 'subject' has with  
263 his/her experience, events experienced and the domains and dimensions of existence it  
264 touches. This passage also has a micro-dynamic that combines and alternates the activity of  
265 temporalizing the experience with the task of configuring it through wording and developing  
266 a story. Language transforms experience, owing to the thetic work that underlies it. This  
267 qualitative transformation of the experience is also that of the subject, who gives form to  
268 his/her existence by expressing it in the form of a story and who becomes a reflective and

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269 historical subject, who can think of him/herself in time and tell his/her story. Putting  
270 experience into narrative form shapes and transforms. The capacity to express experience  
271 arises from it. We shall now examine the second passage, which allows re-viewing the story  
272 through the circulation of its modes of expression.

273 [Reflecting on the time of passing the story on to a community](#)

274 The expression of the story in a group context opens up the possibility for a singular  
275 experience to participants: the reception of the story. This process is the subject of particular  
276 attention for, and during, the sessions in which life stories are developed. The story of  
277 diagnostic delay outlined earlier could, for example, be shared and socialized during a session  
278 of expressing and writing life histories (Lainé, 2004). In this phase the stakes change. The  
279 presentation of stories in a group context requires a re-view of the story first written 'in first  
280 person' in order for it to be received by 'others than oneself'. Conversely, it requires narrative  
281 abilities to make oneself available to listen to patient's stories (Charon, 2015). These can be  
282 practiced in the experience of doing biographical work in a group. The patients and also the  
283 health professionals who engage with this, experience the story as they articulate different  
284 levels of enunciation of the experience of the illness, when they narrate 'in the first person'  
285 (illness) and bring the different stories into dialogue (disease), when the collective  
286 thematization (in the third person) is likely to make new categories emerge, destined to  
287 knowledge creation and medical science (sickness) (for further context see: Laplantine, 1992;  
288 Depraz, 2014). The circulation of these narrative modes starts in the training workshops on  
289 life stories from the lived experience of the subject and moves to the gradual facilitation of  
290 putting experience into words, for oneself first and then for others.

291 [INSERT diagram 3 here]

292 The approach presented here has four distinct phases:

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

296 *Phase 2:* the subject presents the story to a sub-group. The interactions that take place  
297 following the first narration support the ongoing work of the narrator, remembering the  
298 moments that took place during the inaugural experience from which the plot originates. The

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299 successive remembrances of an event are chronologically ordered on a timeline that defines  
300 its place in a sequence of lived experiences.

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

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

313 [Reciprocity of levels of enunciation: First, second and third person](#)

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

320 *In first person:* in the course of his/her narrative work activity in the first person, the subject  
321 gets immersed and existentially engaged. He/she is searching for propitious words to 'get as  
322 close as possible' to what s/he has gone through and felt according to him/her in the course  
323 of the event to be narrated. As mentioned earlier, this work pre-supposes access to the  
324 memories, taking time for putting this into the form of words through a reflexive grasp of the  
325 different moments and by historicizing the events within a duration or a journey. To become  
326 tellable, the experience needs to have been expressed in ways the subject considers to be  
327 true. This mode of expression is thus strongly infused with subjectivity. What is told contains  
328 the various dimensions of the felt experience of the subject, what stands out in it or what has

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329 been understood about it. The interpretation of the experience expressed in this way reflects  
330 a way of seeing, of signifying and configuring a period of life with a view to making it tellable  
331 to close ones, to peers, to the medical world. Stories shaped up this way become tellable and  
332 open possibilities for re-viewing the experience as it is brought into dialogue by others or  
333 owing to the reflexive reciprocity arising during the listening to and receiving a life story from  
334 someone else.

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

347 *In third person:* work in the third person mode consists in the thetic, existential analysis of  
348 what appears as the fabric of 'humanity', beyond the unicity of everyone's stories. Here, there  
349 is potential for defining the recognition of experiential knowledge acquired in situations of  
350 vulnerability (Zaccai-Reyners, 2006), for improving practices and frameworks for facilitation  
351 (Jouet, Flora & Las Vergnas, 2010; Jouet & Flora, 2010) and for up-grading training in health  
352 care (Thievennaz & Tourette-Turgis, 2015). The third person mode thus takes as an object  
353 what has been told and experienced by the group during the socialization phase, without  
354 referring to any specific story. The analysis of the experience thus takes place in the third  
355 person, and it includes all who take part in the training or in the 'recognition of experiential  
356 learning' sessions (Breton, 2017b).

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

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360 [INSERT diagram 4 here]

361 The processes of understanding that take place in the course of biographical activity result,  
362 among others from the alternation of the modes of expression of experience (the diagram  
363 tries to show this). Bringing it into dialogue on the other hand proceeds from co-reflexivity.  
364 Through this alternation of the narrative modes, the unique experience receives recognition  
365 as a singular experience. Understood by the group, which symbolizes the community of peers,  
366 it then integrates what Husserl calls 'the life world' (Bégout, 2007) and Dilthey 'vital  
367 wholeness' (Zaccaï-Reyners, 1995).

### 368 Facilitation strategies in therapeutic education

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

381 I have tried to show that this work of recognition and rehabilitation of the patient's identity  
382 may necessitate the combination of different forms and phases of expression: for oneself  
383 (putting experience into the form of a story in the first person), in the patient-carer relation  
384 (bringing stories into dialogue, involvement as second person), transformations of the  
385 experiences (in a group, third person). I have also tried to show that the narration of a lived  
386 experience proceeds by successive passages which require time: firstly, for the experience to  
387 pass into language; secondly, for the story to configure itself; thirdly, for it to be expressed  
388 (making time available for this during the patient-carer relationship is then a matter of

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389 planning); and fourthly, for a dialogue to develop with a view to recognizing experiential  
390 knowledge acquired.

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

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

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

#### 409 [In conclusion: Towards a narrative science in medical care?](#)

410 In this article, we have tried to formalize concepts and methods with the aim of identifying  
411 the stakes and the process of narrative work in care settings. Further work is needed to define  
412 the conditions under which these approaches may become recognized by medical science.  
413 One important task is to research and/or substantiate the complementarities existing  
414 between experiential approaches that involve narrative practices (Depraz, 2009; Pineau &  
415 Legrand, 1993) and experimental approaches in biomedical science (Lemoine, 2017). A body  
416 of research already undertaken in the biographical domain exists. Many research papers in  
417 the domain of the expressing and writing life histories and biographical research in education  
418 interrogate the place allowed for the lived experience of the patient in medical practice  
419 (Dominic & Waldvogel, 2009; Delory-Momberger & Tourette-Turgis, 2014; Jouet & Flora,

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420 2010). A range of research projects have been carried out in the domain of alcoholology  
421 (Niewiadomski, 2000; Pentecouteau, 2013) and, for example, in the field of chronic illnesses.  
422 More recently, innovative work has been published in the field of micro-phenomenology. This  
423 has made it possible to lay the foundations of a 'science of lived experience' (Petitmengin,  
424 Bitbol, & Ollagnier-Beldame, 2015) and to reflect on its uses and potential contribution to  
425 health care (Petitmengin, 2005). These three authors respond to criticism addressed to  
426 introspective approaches in the first person (such as biographical approaches and micro-  
427 phenomenology), labelled as 'subjective' and 'mentalist' in experimental science. The authors  
428 defend and argue the case for a paradigm of a science of the singular (Vermersch, 2000a &  
429 2003) by seeking to trace a 'middle path' between fragmentary and private subjectivism and  
430 reified and entrenched objectivism. Several criteria have been defined for advancing towards  
431 a science of the description of lived experience. They include the study of methods of  
432 collecting descriptions of lived experience, categories of analysis that allow the formalization  
433 of the structures of lived experiences recognized in singular stories, and the circulation  
434 between first person and third person expression. These research projects contribute to  
435 strengthen the validation of experiential approaches in health, while at the same time shifting  
436 the boundaries of power that organize the legitimacy of knowledge (Foucault, 1969). It is our  
437 belief, that this shift is needed for patient experience to become recognized as 'the locus'  
438 around which inter-disciplinary work in health care is organized.

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- 515 -----
- 516 **NOTE: CAPTIONS**
- 517 Diagram 1: Phases of the passage from experience into language
- 518 *Source: Breton, 2017*
- 519 Diagram 2: Periodization of the experience of the patient between being given a first diagnosis  
520 and having it confirmed
- 521 Diagram 3: Expressing experience in a story in sessions of expressing and writing life histories
- 522 Diagram 4: Narrative modes and transformations of experience during  
523 biographical activity