Pedagogia della cura
Famiglie, comunità, legami sociali

Collana diretta da
Francesca Marone

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a una doppia procedura di peer review

Stories that make a difference

Exploring the collective, social and political potential of narratives in adult education research

Edited by
Laura Formenti & Linden West

Pensa
MultiMedia

Volume stampato con il contributo del Dipartimento di Scienze Umane per la Formazione "Riccardo Massa" dell'Università degli Studi Milano-Bicocca

ESREA – European Society for Research on the Education of Adults
LHBN - Life History and Biography Network
Department of Human Sciences for Education
Milano Bicocca University

ISBN volume 978-88-6760-360-2

73100 Lecce • Via Arturo Maria Caprioli, 8 • Tel. 0832.230435
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www.pensamultimedia.it • info@pensamultimedia.it

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43. Narrative medicine and stories of illness: Caring for the sick requires active listening

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Narrative medicine and caring for the sick

Within the theoretical framework of Medical Humanities and Narrative Medicine, the present qualitative study adopted a narrative paradigm to analyse the role of narrative in the complex experience of illness and medical care. Specifically, it investigated doctors' and nurses' narratives of care experience as well as their representations of patients (Bateson, 1979) and patient needs (the need for containment, care and information about illness, the need to be treated as a person and not just as a patient). Modern medicine has shown that complex psychological factors, such as trust in one's doctor and belief that one can get well, affect patients' brains, causing cellular and molecular changes. The significance of illness is constructed via narrative practices and illness narratives are socially shared products (Bruner, 2002).

The case study was conducted at Bologna University, School of Psychology and Educational Science (within a broader interuniversity research project led from 2011 to 2015 by the University of Milano Bicocca, entitled *Narrative/writing practices in healthcare and educational contexts*). It involved six doctors and six nurses (6 female and 6 male; mean age 45.37 years; all with over 10 years' professional experience) at large and medium-large hospitals and elderly care units specializing in chronic, degenerative and oncological illness. Methods included semi-structured narrative interviews, focus-group discussions and workshop informed by the co-operative inquiry approach (Reason & Hawkins, 1988; Heron, 1996).

The research aims were to investigate: a) how nurses and doctors represent medical knowledge; b) how they interpret their caring profession in their daily practice; c) what role, if any, they attribute to their patients' *narratives* and to narrative methods (and whether they use them alongside a traditional approach); d) what role they see for narratives and for narrative approaches in the care of the seriously ill (Pennebaker, 2004). In Phase I of the research, focus group discussions were held with the participating doctors and nurses, to explore these questions and to assess how narrativity (and narrative) as well as stories of illness and care (e.g., good *versus* bad stories of illness and care) affect patients. In Phase II, textual analysis was applied to the focus group data and the main themes identified using a phenomenological method.

The study was designed to evaluate whether active listening on the part of nurses and doctors of the narratives that all patients offer of their illnesses, both in terms of the illness itself and in terms of their emotional experience (i.e. how they feel and perceive themselves when in pain or in a state of suffering connected with their illness) represents a component of care and a generator of wellbeing. One aim was to assess whether active listening is a key element of the encounter between nurse (or doctor) and patient; whether it lays the bases for a *significant relationship* between nurse (or doctor) and patient and whether it represents the first step towards establishing the relationship as well as designing a *personalised* care intervention, tailored on the patient's *story* and *representation* of his/her illness. The doctor's (or nurse's) intervention is therefore understood as imparting both medical and educational care (or *cura sui*) with an aim to enhance *proximity*. The Italian neologism *prossemicità*[1] (Gallerani, 2012) stands for empathic nearness and solidarity with others, and connects to *in-between-ness* as formulated by Arendt (1958).

We observed that active listening was a key element of the encounter

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[1] The neologism *pros-se-mi-ci-tà* refers to a *colloquy* with the other (*à la* Heidegger); each syllable contributes to its general meaning. In extreme synthesis, the word has a root (*pros-*) which refers to the role played by proxemics and non-verbal language in meeting the others; the particle *se-* indicates the pronoun, third person singular (self) which explains the relationship established between me, him or her; the syllable *mi-* implies me (my *intentionality*, my active participation in the relationship); the syllable *ci-* stresses the relationship established between *us* (me and others) and therefore commits *us* to share *responsibility*. Finally, the particle *-tà* indicates the direction in which the relationship is going and refers to the idea of a wider community, in which everyone participates (see Gallerani, 2012: 49-56).

between doctor/nurse and patient [henceforth D/N and P]. *First*, the results showed that nurses' and doctors' active listening to their patients' illness narratives was considered a component of care that generated wellbeing. In particular, in the relationship between D/N and P (and families), the heuristic-generative interaction between *narrating* and *writing about* pain or illness (Pennebaker's *writing technique*) set off cognitive processes allowing P, by means of *negotiated interpretation*, to gradually and consciously *work through* and reorganize/transform the painful event. P acquired enhanced *conscious awareness*, as the outcome of a trans-formation that I call *cura sui*: caring for their own potential for *change* and self-education.

Second, *active* and non-judgemental *listening* (Rogers, 1951) between D/N and P was key to: a) reinforcing reciprocal *trust* and *empathy*; b) acquiring in-depth understanding of the various levels of significance of both the words exchanged and the relationship itself; c) enabling the recipient (D/N) of a *narrative* to grasp the *significances* that it held for its author (P) with the associated wealth of emotional nuance (and implicit and non-verbal aspects). By listening actively, D/N activated a *mirroring* process, inviting P to make their experience explicit and ultimately to construct a different perspective on and interpretation of their illness via *reflective* and *metanarrative* processes: this in turn made patients aware of the profound significance of their own *narrating* and of their own resources of resilience. In fact, paraphrasing the opening words of the novel *Anna Karenina* by Lev Tolstj, all the stories on health are alike, while any story about an illness is unique in itself. All the variety, all the charm, all the beauty of life is made up of light and shadow.

In relation to the questions and aims of the research, the participant D represent their medical knowledge above all as a unit of knowledge and medical-scientific competences. They do not possess sufficient knowledge of Narrative Medicine yet (except one of them) and those who are interested in finding out about it prove quite sceptical with regard to its usability in daily routines, mostly due to lack of *time*. This belief is well reported by a doctor who in relation to his profession said: *'I consider myself as a professional, a technician who has to keep updated on a constant basis [...] and has to maintain a correct balance between the appropriateness of the care and the transparency in communication and avoid therapeutic futility'*. He replied to the question regarding how the relationship between D and P develops by saying: *'A doctor is a bit like a parent with their child [Patient] undergoing a troublesome adolescent crisis'*. Then his words became less technical, when he was asked a metaphor that he would associate to the healing work and the care relationship. He said: '*I see the care as a canvas, with brushes and colours*' and also '*I see this relationship as an artist's painting*' (LL, D anaesthetist, m., 56 years old)[2].

Older female nurses seem to display greater listening ability than Ds or younger Ns. A nurse, for example, said: '*It is a great satisfaction to see that a patient is feeling better, to see them smile, thus knowing they are out of the tunnel and I have given my contribution to this*' (DG, N, f., 53). Another nurse associated her job to the metaphor of a mother helping her daughter, even when she does not ask for help:

> *the nurse is close to the patient, even the ones who refuse pain and treat you badly, insulting you. We help them to draw out their pain and do what needs to be done, i.e. ask for the help of those who are near them and can assist them. It should be we nurses to understand when and how to offer our help, because understanding the condition in which an ill person is, is not always easy* (LT, N, f., 44).

Thus, active listening laid the bases for a *significant relationship* between D/N and P, representing the first step towards designing a *personalised* care intervention for the individual patient.

Starting from here, a theory on care can be hypothesised, to build a frame for designing an effective policy for prevention, health and well-being, promoting both basic medical research and narrative medicine in the virtuous intertwinement between Evidence Based Medicine (EBM) and Narrative Based Medicine (NBM), as suggested by the Italian National Institute of Health (see *Linee di indirizzo per l'utilizzo della medicina narrativa in ambito clinico assistenziale*, www.iss.it/cnmr).

Care as a dialectic process between *listening* and the postures of proximity

The relationship between *active listening* and the development of proximity is the basis for effective communication, relationship and care between D and P. On the track of Narrative Medicine, listening and *ethical* care are

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[2] Initials in capital letters = name; D = doctor; N = nurse; m. = male; f. = female; number = age.

essential for caregivers in order to guarantee *respect* and *autonomy* of *choice* for patients in relation to medical care. Active listening is an essential tool for identifying the correct diagnosis, and deciding together the most effective therapeutic course, respecting the quality of life of the ill person. It constitutes the founding moment of every significant *relationship* of the equality and dialogic type, since it establishes the relationship itself giving birth to co-planning and patient-tailored intervention. More specifically, the *quality* of non-judgmental active listening between D and P proves essential for establishing a relationship which allows *first*, to understand the complex and multi-factorial origins of the illness and the ill person's *feelings*, through which: a) to *reinforce* reciprocal trust and develop *empathy*; b) to *understand* the different levels of intrinsic significance of the relationship and its verbal and non-verbal language (silences, the unspoken, gestures); c) to grasp, by means of *introspection* on the part of D/N, deepest significances that the *telling* (in all its wealth of emotional nuances and different levels of reading) has for P. *Second,* D who displays active listening shows real interest towards the experiential world of P, therefore he listens with a *non-judgemental* and *proactive* respectful attitude. *Third*, D can induce a real *mirroring* process, prompting the patient to express emotions and resistances that it is necessary to bring out in order to co-build a different point of view and a second reading of the illness-event. This process eases *meta-reflection* and *meta-narration*, as required for the Ps to develop awareness and significance about their own *telling*. It is only after a real raising of awareness of deep reasons for their discomfort (elaboration and meta-reflection) that Ps can activate transformational processes.

The experience of illness is often unknown, or considered undesirable and repressed, instead of deserving *comprehension* as an integral part of human existence. In this sense, narrating or writing about one's own illness recreates an authentic *contact* with ourselves (but also with caregivers, and the outside world), the loss of which might be caused by the experience of illness itself. This contact, favoured by *symbolic* and *imaginative* narration, is able to draw *out* (and share with others) that sense of impotence, disintegration or desperation that accompanies serious illnesses. The capacity to create stories and narrations allows the ill person to find a new form of balance through the elaboration of negative feelings and the recovery of sense and significance in the continuity of life.

Writing is a way to represent the illness, to perceive it, to recognise and interpret it (meta-narration) in all its complexities and phenomenology (Good, 2006; Greenhalgh & Hurwitz, 1998; Borgna, 2000), since it triggers a process of care (found in a context, or eco-systemic environment and in a phenomenological time and space) capable of generating *participation and involvement*, *responsibility* and *commitment* both in the caregiver and in the person in cure and, most of all, it can generate a *change* and *transformation* of 'self'.

Active listening and *educational intentionality* are essential for the successful achievement of any care intervention, through its aims, that are: *respect* for the patient (instead of formalism), *accompaniment* of the patient (instead of assistance), *autonomy* (instead of dependency), *research* (instead of repetition of thoughts, conversations, actions, behaviours), *co-building* of *knowledge* (instead of the transmission of knowledge from D to P), *change* and *transformation* of experience (instead of stasis and interior *monologue* of the P). They are linked, coherently with the systemic and ecological approach developed by G. Bateson – in the constant research for a lifestyle and an inner-equilibrium in the search for a better quality of life.

On the educational side, care implies the planning of a *significant relationship*, which unties an active (deep) listening. In this way the care is reinterpreted in its constitutive (and educational) aspects going in the direction of a heuristic perspective even before being considered as medical care or clinical therapy, although the latter are equally essential. The relationship between *active listening* and *nearness* intended as a *colloquy* with the other (*à la* Heidegger) is therefore marked by *intentionality* and responsibility. Care is achieved by exercising a reflective and thoughtful co-responsibility, a style and a posture that is conducive to a deep understanding of the other. On the other hand, the patient has the opportunity to express by words and other means his/her profound personal experiences (cognitive and emotional) and elaborate together with the D/N new meanings and new behaviours. Hence, a new balance can be regained, between their expectations of healing and reality, as *narrations* and *actions* (triggered by them) create a true and transformative relationship of nearness (with oneself and others).

Finally, the creativity of the educational intervention stimulated by narrative medicine is strictly linked to the type of *relationship* that caregivers and patients are able to co-build, trying to find together the words that heal. Active listening is essential to identify the deeper significance of pain, that leads to *reflecting* (*in* and *on* the relationship), and to *acting* in the wake of a non-mechanistic and reductionist vision of the therapeutic relationship.

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