

Rita Charon's concept of narrative medicine as a strategy for humanization of clinical transplantology

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European Journal of Medical Technologies
2017; 4(17): 62-69

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www.medical-technologies.eu
Published online 29.12.2017

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Abstract

In the paradigm of *Evidence-Based Medicine* (EBM) the results of experimental randomized clinical trials (RCT) are shown as the basis for defining medical procedure standards, with a simultaneous reservation that medical decisions have to take into account the specificity of clinical situation and the patient's individual values and preferences. Rita Charon's concept of narrative medicine, which suggests the broad introduction of illness narratives into clinical practice, can be perceived as a realistic response to the postulate of the humanization of EBM, enabling clinicians not only to reveal the patients' highly-regarded values and preferences in order to take them into account in the decision-making process, but also allowing doctors to look into the non-medical problems of the patients. The possibilities of applying the approach in question in clinical medicine and the consequent benefits have been illustrated using the example of trials concerning the illness narratives of recipients of upper limb transplants.

Key words:

illness experience,
Narrative Evidence
Based Medicine,
clinical transplantology

Introduction: the question of humanization of medicine in the context of the assumptions of the EBM paradigm and technologization of contemporary medicine¹

The scientific foundation of contemporary medicine is jointly created first of all by progress in natural sciences [1], generated with the preservation of methodological standards defined in the Evidence-Based Medicine (EBM) paradigm, which point to the experimental randomized clinical trials as the optimal basis for defining medical standards of diagnostic procedures and therapeutic management [2,3]. At the same time it is explained in this framework that RCT results are necessary as the basis for decision-making in medicine but they are not sufficient because a doctor has to find them, critically assess, and apply to a specific patient, taking account of the specificity of his/her clinical situation and individual values and preferences. Fulfillment of the last of the foregoing conditions determines quality medical decisions, characterized by a preference-sensitive value, this being possible in the situation when medical professionals create a space for dialogue with the patient in a therapeutic relationship, within which the values of patient preferences can be defined, clarified, and then articulated [4]. This means that medical procedure standards based on EBM principles are the necessary foundation of treatment but are not sufficient because they do not replace the doctor's talk and empathy i.e. medical art because only this approach guarantees taking into account the unique, personal perspective of the patient, which should be an integral element of the decision-making process in medicine [3]. Those recommendations intended to humanize the EBM

paradigm can be treated as an answer to the repeatedly articulated fears in professional literature that the rules of medical procedures based on the EBM paradigm do not sufficiently take into consideration the specificity of a particular clinical situation, which may give rise to a risk of the dehumanization (i.e. de-individualization) of doctor/patient relationship [5]. E. Mykhalovskiy et al. [6] pointed out that EBM is characterized as being more doctor- than patient-centered and gives rise to a risk of ignoring the human experience of illness [6]. In the context of the leading problems in the *European Journal of Medical Technologies*, it should be also noted that dehumanized approaches to the patient in medical practice appear to be further reinforced by the progressive technologization of medicine, causing doctors to increasingly rely on the results of additional trials generated on the basis of the most recent medical technologies, and to put comparatively lesser emphasis on the personal ways of experiencing illness that can be revealed in a dialogue with the patient. This stance is presented inter alia by Ch. Heath et al., who argue that one of the consequences of the technologization of medicine is the progressive alienation and depersonalization of patients in contact with institutional medicine [7,8]. The common feature of the projects of humanized medicine, among which a significant position is occupied by Rita Charon's concept of narrative medicine, is an attempt to oppose the foregoing tendencies by introducing the sphere of human subjectivity into medical practice, taking the "soft", socio-psychic aspects of illness and being ill into consideration [9]. They are inspired by the conviction that the doctor who takes account of the patient's perspective and so-called "soft" parameters of illness experience will be a more effective diagnostician and therapist. They include a suggestion for a greater appreciation of the subjective illness experience, and at the same time of specifically human needs and problems of the patient, especially those that come into play in the situation of severe and chronic illness [10], taking into consideration the processes of illness becoming part of the personal biographies and the alteration of personal identities of patients [11].

¹ Regarding the content concerning the conception of narrative medicine and its reception in clinical medicine in this article, M. Skrzypek has used the results of earlier studies published in the article listed under Reference Item no. 39.

Rita Charon's concept of narrative medicine

A significant barrier, impeding the transmission of demands for the humanization of medicine to clinical practice that draw attention to the advantages resulting from taking into account the patient's perspective in diagnostic-therapeutic processes, is difficulties in the realistic translation of such directives into a language that could be understood and accepted by doctors, taking the realities of everyday medical practice into consideration. Among the doctors who try to show practical ways of the humanization of medicine, apart from George Libman Engel, professor of medicine and psychiatry, founder and promoter of the biopsychosocial model of health and illness [12,13], or Arthur Kleinman, U.S. psychiatrist and anthropologist, expert in the scientific and clinical problems of illness experience [14], is Rita Charon, U.S. professor of clinical medicine in internal diseases, literary critic and literature specialist, the founder and promoter of the concept of narrative medicine, which is the object of successful reception and is repeatedly discussed in prestigious medical journals [15-18]. Since the mid-1990s Rita Charon has implemented in New York's Columbia University College of Physicians and Surgeons an educational program intended to popularize narrative competencies in medical care (*Program in Narrative Medicine*) [19]: she is inspired by a conviction that if clinical practice is more open to patient narratives, this enhances the physician's therapeutic effectiveness. It should however be stressed that the rise of the conception was possible in the context of the earlier work by the founder of the biopsychosocial model of health, G. L. Engel, who demanded as early as the 1970s that doctors should pay more attention to the person of the patient and the dimension of subjective illness experience [12]. Engel's scientific and publishing activity inspired the creation of models of patient-centered health care, whose feature in common is to

try to enhance the importance of patient narratives [20]. Also Rita Charon accords a central position to illness narratives in the therapeutic relationship, suggesting that clinical interview be broadened in such a way as to create within it a space for presentation of subjective illness experiences [19]. We will not discuss here at length the strategies for clinical history taking, enabling the implementation of this goal; we will only stress that for this purpose the reconstruction of the clinical interview is necessary, consisting, inter alia, in the more frequent use by the doctor of open-ended questions and facilitating comments (for example: "tell me something more") [cf. 21,22], at the same time utilizing his/her attentive listening abilities [19]. According to Rita Charon, if the doctor-patient relationship is more open to illness narratives, the necessary condition for treatment is fulfilled, i.e. the establishment of "true human contact" manifested in openness to the subjective ways of illness experience [23]. Manzo et al. point out that, as a result, two separate worlds can be brought closer together: the world of the patient and the world of the medical professional, which are in a way united by narratives that are a socio-interactive phenomenon, jointly created not only by the narrator but also the addressee – the witness of the narrative [24]. However, Rita Charon does not confine herself to popularizing a broader presence of illness narratives in the therapeutic relationship but also encourages doctors (and trains them) to create their own narratives describing personal experiences related to practicing medicine. [19]. She suggests that they should have a "parallel chart" system, containing, apart from standard clinical documents, also notes on different "soft" aspects of clinical work, including attempts to understand the experience of patients, the ways of how patients react to the medical explanations they receive, etc. The proposal for narrative writing in medicine is inspired by a conviction that self-narratives about the doctor's personal experiences enable him/her to gain a better insight into therapeutic relationships, and deeper empathy [25].

Examination of the narratives of persons after limb transplantation as an example of the application of the theses of narrative medicine in clinical practice

In this part of the text we would like to present an empirical illustration of the importance of Rita Charon's narrative model in clinical practice as exemplified by the exploration of experiencing the body reconstructed by a limb transplant. The study, whose essence is to go beyond the clinical context, covered upper limb recipients (N=6) who underwent a transplantation procedure in Poland between 2006 and 2014². The aim of the study was to know how the patients after upper limb transplantation individually experienced their reconstructed body in the following aspects of its subjective experience: 1) fitness; 2) esthetic aspect; 3) sensory aspect; 4) interactive aspect; 5) personal identity. The patient's perspective is the only correct perspective in the doctor-patient relationship both before and after transplantation, not only because of the special character of the transplanted body part but also the benefits and costs associated with this kind of transplantation. The patient is the only subject entitled to describe the experiencing of his/her (in)complete body. The studies, whose subject matter combines medical sociology and the sociology of the body, were set in the qualitative trend with a clear reference to the principles of the methodology of grounded theory [26]. The empirical material collected during in-depth interviews allows the formulation of several important postulates addressed not only to medical professionals who qualify patients for limb transplantation procedures (transplantologists, surgeons), but also to doctors who take care of patients after amputation (orthopedists and traumatologists).

² The upper limb transplantation program was initiated in 2006 at the Department of General Surgery, Subdepartment of Hand Surgery and Replantation, St. Jadwiga Śląska Hospital in Trzebnica, which today is one of the world's leading hand transplantation centers. The center is also the place where the studies were conducted that are the empirical basis of this part of the text.

Firstly, to base the work of transplantologists on the narrative medicine model provides greater opportunities for knowing the patient already at the stage of qualifying him/her for limb transplantation. The humanized care for a potential hand recipient should be based on an individualized approach to his/her motives for undergoing a transplantation reconstruction of the body. Although there are fairly explicitly formulated criteria for the evaluation of recipient candidates, it is an individual assessment of each patient that should be decisive. Reference to the narrative medicine model in this case will help doctors to better understand the grounds for the recipients' participation in this procedure, especially as the hand transplantation involves large expenses of recipients, if we recognize as such their pain, immunosuppressive treatment with all the health burdens that might significantly contribute to shortening the recipient's life, as well as the necessity of long and arduous rehabilitation. The hand transplantation itself is an innovative procedure, its results being hard to assess. The development of specific empathic attitudes in medical professionals has to be preceded by the knowledge of how the recipient candidate has so far subjectively experienced his/her incomplete form of the body. Limb transplantation is not performed for life-saving reasons but it is a treatment method meant to improve the comfort of the patient's functioning. All the studied hand transplant recipients decided that they would prefer to live a shorter life but in greater bodily comfort than live longer but with the difficulties created by their fragmented body [27]. A manifestation of the presence of narrative medicine in the practice of clinicians involved in the limb transplantation program is "leaving the patient enough time to personally assess the benefits resulting from the anticipated improvement of their life quality after the procedure as compared with all transplantation-induced dangers" [28]. The abandonment of the medico-centric perspective in clinical work, and openness to the narrative of persons crippled by lack of limbs means that the choice of the method of body reconstruction (transplantation or prosthetic restoration) should be based on taking the patient's subjective decision into consideration, especially that the functional results of the use of both methods are comparable [29]. This

obviously does not mean that the doctor and his/her biomedical qualifications do not play any significant role here. This role is crucial, determined by the need to take into account the specificity of the patient's clinical situation in the management of his/her case.

Secondly, the presence of the conception of narrative medicine in the procedure preparing potential recipients for hand transplantation means the necessity of going beyond hard criteria for procedural qualification such as age, kind of amputation, or the condition of physical health, and of directing the clinical interview towards knowing exactly the patient's life situation. The knowledge about the social support for the recipient candidate is extremely vital both in the context of preparations for the procedure and the functioning of the patient during the especially difficult first months after transplantation. The point therefore is not only to enter a deep relationship with the patient but also to gain insight into his/her family situation. As external organ transplants are constantly "visible", they produce problems of essentially different nature than the transplantation of internal organs. The experiences of the studied upper limb recipients show that this type of body reconstruction changes the course of corporally mediated social interactions [27]. The status of a several-part and hybrid body acquired by the body of the limb recipient through the presence in him/her of a fragment of the body belonging to another human with all his anatomic and esthetic features) causes the appearance in the recipient's environment of emotional reactions disturbing the process of adjustment to living in the new body form. A transplantologist who refers to the assumptions of narrative medicine in his/her practice should also get to know the patient's social and living conditions, which should meet the needs connected with the recipient's future immunotherapy and rehabilitation.

Thirdly, a narrative-oriented medical professional, who gives ample explanations to the patient about each stage of limb transplantation treatment, should try to know the patient's expectations of the procedure. The last issue is particularly important because potential recipients formulate unrealistic, highly idealized expectations associated with this bodily reconstruction, which is confirmed by the present

studies. The subjects expected that the transplanted limb would be almost identical in terms of external parameters with their lost, biological hand. Failure to satisfy these expectations leads to the emergence of the recipient's feeling that the new hand is foreign. The ways of how the subjects interpreted the experience of their body after transplantation show that a limb transplant is something that threatens the recipient's identity [cf. 30]. The distance of the body from identity, maintained for some time, is a reaction to the recipients' disillusionment with the lack of physical unity in the body and its esthetic dubiety. The taking into account of the context of limb recipients' non-medical problems broadens the doctor's socio-somatic knowledge and, as a result, helps minimize the risk of a situation in which the recipient would demand the amputation of the transplanted hand³. If the doctor knows the subjective experiences of the limb recipient in the dimension of experiencing his/her reconstructed body in terms of identity, the doctor gains the store of biopsychosocial knowledge, which makes him/her a competent partner of the patient and allows him/her to better understand the latter's experiences.

Fourthly in the end, by basing the relationship with the limb recipient on the narrative medicine model, the doctor has a chance to go beyond the biomedical dimension of knowing the patient after the performed transplantation. While the doctor can, using the instruments of advanced medical technology, verify the efficiency of the transplanted hand, getting to know the other dimensions of experiencing the body reconstructed by the hand transplant requires reaching the patient's subjective experiences. And this means that it is necessary not only to abandon the reductionist perception of the body as an exclusively material being but also to utilize the doctor's narrative competencies. It follows from the presented studies that the body fitness is a relatively less significant benefit from limb transplantation as compared with having a complete form of the body, which

³ This situation took place in the case of the world's first patient who had upper limb transplantation. The surgery was performed in 1998 in Lyon, and the then 48-year-old businessman-transplant recipient, Clint Hallam, requested the amputation of his hand three years after transplantation because he could not accept its presence in his body [31].

enhances satisfaction with experiencing it in the esthetic, sensory, interactive and identity dimensions [32]. Only from patient narratives the doctor can learn that to a patient, of greater value than the fitness of a transplanted limb, however high it may be, is the visual experience of the body and treating it as a tool of sensory pleasure or social integration [33]. The effects of body reconstruction through transplantation are not confined only to the body's biophysical functionality. When the doctor departs from objective data in this case, it means s/he recognizes that the hand performs not only a mechanical function [34,35]. Turning towards the values preferred by the patient is also extremely important in the process of qualifying for the hand transplantation procedure. We have here in mind the inclusion, justified by the subjective experiences of upper limb recipients, of the group of patients with congenital defects in the hand transplantation program despite the potentially low transplant mobility. These procedures are still opposed by the transplantologist circles.

The foregoing arguments for taking into account the tenets of narrative medicine in the qualification procedures for limb transplantation indisputably prove the benefits of its use in this kind of surgeries, especially as these still have the hallmarks of medical experiments. Transplantations of external body parts, the development of which could not take place without significant progress in medical technology, do not have to mean the dehumanization of medicine provided, however, that the transplantation practice will utilize the achievements in the humanities and social sciences. Narratively profiled transplantation medicine should take care not only of the body reconstructed by a transplant but also of the person with such body. Above all, the doctor should try to understand the patient's experiences, which s/he should always view in the contexts of the patient's overall personal biography. Being open to the patient's narrative about experiencing his/her own incompleteness and disability will allow the doctor to better understand the significance and sense given by the recipient to the transplantation reconstruction of his/her body, and will consequently contribute to the humanization of the doctor-patient relationship.

Narrative Medicine or Evidence-Based Medicine? – A false dichotomy

Narrative medicine has been designed as a humanized way of practicing EBM, characterized by stronger recognition of “active listening, close reading and narrative writing”. Narrative medicine “considers the stories of patients and their caretakers as integral to the experience of ill health and healing” [16]. Attention is focused here on the function of taking into broader account the narratives of patients, which consists in the humanization of biomedicine, with continuing emphasis being placed, however, on medical professionalism [16]. For that reason, Charon defines her model of humanized medicine as *Narrative Evidence Based Medicine (NEBM)* [36], firmly stressing the consistency between clinical practice and narrative medicine – “[...] you can practice narrative medicine and still be a doctor!” [19] – and even the complementary nature of the two approaches. It yields notable therapeutic benefits consisting inter alia in that openness to illness narratives enables clinicians to know and respond to non-medical problems of their patients, and to reveal the patient's values and preferences in order to take them into consideration in the decision-making process in clinical medicine. As a result, it is possible to more effectively apply universal biomedical knowledge generated in the EBM paradigm to a specific, unique patient [16]. E. Avrahami and S. Reis stress that “Narrative medicine answers the overwhelming challenge of understanding the patient's unique illness story and at the same time expertly treating patients' diseases” [16]. Patients also gain clear benefits from this approach. These consist in that narrative activity has distinct therapeutic and palliative potential [37], stemming from the fact that in the course of narrative activity the patient's health problems are cognitively defined and it becomes possible to better understand and structuralize disordered and chaotic events (perceived as threatening) and related to illness experience [cf. 38]. The treatment of the patient's narrative activity exclusively in terms of a source of insight

into the ways of experiencing illness is certainly an incomplete approach because illness narratives also enable the re-examination of events associated with illness experience in order to understand and explain them. Arthur Kleinman points out that “patients order their experience of illness [...] as personal narratives. The illness narrative is a story the patient tells [...] to give coherence to the distinctive events and long-term course of the suffering”. This American anthropologist and psychiatrist emphasizes that “the personal narrative does not merely reflect illness experience, but rather it contributes to the experience of symptoms and suffering” [14]. It is through this function that the therapeutic potential of illness narratives is manifested consisting in facilitation of psychosocial adjustment to illness.

Conclusion

The conception of narrative medicine is an attempt to make clinical medicine more open to the perspective of the patient experiencing illness, trying to understand his/her own illness and place it in his/her personal biography. Rita Charon's conception deserves the attention of clinicians first of all because by recognizing the importance of the patient's perspective, and thereby individual illness experience, it has strong potential for the humanization of biomedically oriented medical sciences. It reminds us that an important therapeutic instrument that each doctor has is still – in the context of the progressive technologization of medicine – the ability to listen empathically.

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