NARRATIVES OF SURGICAL CARDIOVASCULAR PATIENTS

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Abstract: *Patients narratives define as a stable linguistic entity through a series of specific traits. Firstly, patient and doctor narratives are defined by their timely limited quality, which is expressed on a temporal scale. The patient's story has a starting point, then it unfolds in a series of events which are narrated by the acting character. The acting character may be the patient himself or, as a first-person narrator, the patient may bring a series of events narrated by a third party. Lastly, the story must have a predictable ending. The ending of a patient's story is set at least on a temporal scale again if the story might not the end at the same pace as the narrated events. Secondly, once there is at least one narrator and one-story receptor, the story unfolding might be affected by the different vision and perception of both actors upon the narrated events. And thirdly, as the literature of Greenhalgh and Hurwitz show (Greenhalgh and Hurwitz, 1999) the narrated events are character centred, showing the way the actor is impacted by the story, in our case the story of illness and suffering. By analysing the stories of surgical cardiovascular patients about their experiences with the medical system and doctors, we research a piece of rich information offered on how the life of patients is affected and how the doctors might improve their communication with their patients. Therefore, it might not be sufficient to narrate, as events unfold - what the characters in the stories do and how they perform - but there is a secondary story, unfolding in the background of the main story - which is the way the being itself is affected and how the patients live with their illness. The context of narratives offers rich information on how the patients need to be treated and how their illnesses are to be addressed. One must not forget that fear, anxiety, despair, pain, shame and sadness, they all come together with the illness the patient is suffering of, most of the times being responsible for enhancing the illness's effects. (Greenhalgh & Hurwitz, 1999 : 48)*

Keywords: *patient, narrative medicine, communication*

Concepts used in pre-testing phase

The concepts used in the pre-testing phase of patient narratives future research will focus on medical narratives defined as "speech" and "physician and patient decoding health and illness", as well as the concept of "patient-centred care" (PCC), which is defined by the literature as "care, taking into account preferences, the patient's needs and values as an individual, with respect and attention, and ensures the compliance of all clinical decisions with patient values" (Morgan & Yoder, 2012) and narrative medicine understood as the medical model practice, providing the conceptual and practical means of attaining "the ideal care of the patient, in the definition of Rita Charon (Charon, 2001).

At the first research level, the pre-testing data process identifies the main dimensions of each concept, as well as indicators to guide empirical research. On the one hand, we will try to adapt the series of indicators existing in the literature, on the other hand the field provides profound and nuanced information to develop additional series, adapted to

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the concrete situation under investigation, namely the field of diseases and cardiovascular diseases, as well as communication within this field, with implications for general health, compliance with treatment, and consistent changes in the lifestyle of patients.

Methodology

From a methodological point of view, the present research project will be based on the qualitative methodology, which is favoured by the specialized literature existing in the field (Charon, 2006) As main working methods, we will use the personal interview and the analysis of social documents (Chelcea, 2001). From the perspective of the secondary methods used, we will use narrative analysis of social discourse, conversational analysis and speech analysis (Amia Lieblich, Tuval-MashiachT, & Zilber, 2006). We will also use the secondary analysis of the existing statistical data from the point of view of health and illness at the population level in Romania and the content analysis (Chelcea, 2001a) of the main regulatory documents aimed at the medical act in Romania (laws, standardized procedures, etc).

The Berg model

The assumptions of the qualitative research methodology in social sciences are summarized by Berg and Wiltfang (Wiltfang & Berg, 1990) as being subsumed in two directions: the "theory precedes research"-"theory-before-research model" (Frankfort-Nachmias & Nachmias, 2007) and "research before theory" (Franzoni & Sauermann, 2014).

In the paper "Qualitative Research Methods for the Social Sciences" (Berg, 2004), a model is proposed that goes beyond the linear frame in the sequential ticking of the research stages in the mentioned models. This model involves a spiral tracking of stages embodying both models, both "theory before research" and "research before theory". The merging of the two models is possible, in the opinion of Berg (2004), due to the spiral and not the linear path. Thus, the Berg model proposes the following segmentation in the research methodology: defining the idea, constructing the theoretical framework, reconsidering and refining the idea, examining a possible research design, refining the theoretical assumptions, and maybe even refining the initial research idea. Thus, in the proposed model, after a research step forward, there are one or two steps back, before progressing to the next stage. Illustration of the model can be exemplified graphically in the following way:

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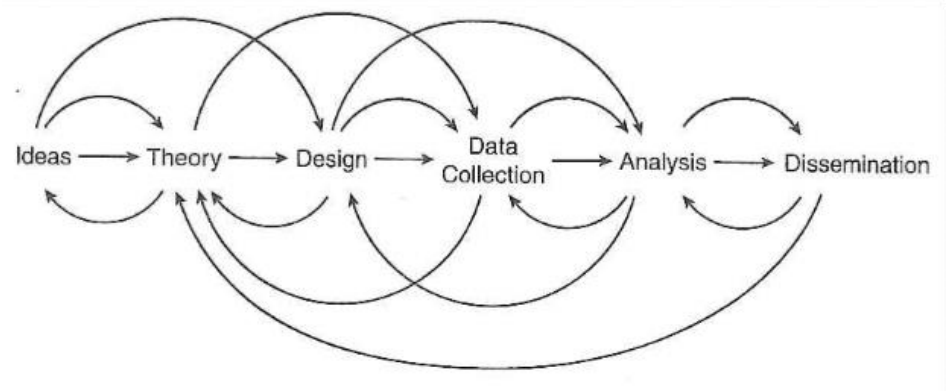


Figure 1 The Berg model

The pre-testing phase implied several difficulties due to unequal distribution of patients in the research area - most of them live outside the capital city and access to extensive interviews is limited. In the absence of an interview where narrative elements arranged in minimal discourse units (facial expressions, minimal vocal responses, etc.) can be recorded, the return to the data collected in the first phase is necessary to complete the table of the categories analysed in open coding. Interviewees are informed that the interview may be completed at a later stage if the narrative is incomplete due to various reasons: a fragile physical condition, real availability, geographical distance, etc. During the pre-testing phase only one patient out of 20 refused to answer the questions arguing that he had no time for an extended interview.

Certain research ideas may be more difficult to address because of limited access to the perimeter where research subjects have relevant activity - either gatekeepers[1] - limit and modulate access to studied communities or subjects themselves are unwilling to cooperate. The sphere of sociological research in the medical area is one of those where the cooperation and honesty of the patient to whom the semi-structured interview guide is applied are crucial.

Ethical standards

While performing a research within medical field, ethical standards require not only the patient's verbal consent to participate in the research, but an explicitly signed or registered consent. In the context of the GDPR legislation that entered into force on May 25th, 2018 in the European Union, the consent form for research participation must also include details on the use of personal data and the duration of its use, usually until the end research and publication.

[1] The role of "gatekeeper" is defined in The Sage Dictionary of Social Research Methods (Jupp, 2006) as the person who has the "ability to arbitrate access to a social role, research field or structure" (Saunders, MNK, 2006, Gatekeeper 'in the Sage Dictionary of Social Research Methods).

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Quality of field data

To initiate the research, we initially obtained a doctor's agreement to address her patients, and she agreed to play the role of mediator in this relationship, presenting me as a member of the treatment team. This approach has significantly reduced the feeling of suspicion towards the researcher, a person outside of the usual medical environment, which almost every patient who has come to consult feels. To avoid such a sense of suspicion and restraint in discussing health problems and exposing while being vulnerable, we held medical equipment at every discussion in the consulting cabinet, and in the sterile surgical environment, we received the appropriate apparel. Since most of the interventions have been done with deep sedation, every patient that we accompanied to the surgical ward, woke up from anaesthesia in our presence, which created a close relationship and a level of trust favourable to obtaining honest narration.

Each patient signed a written agreement when approached for the interview, and for those who were approached by phone (due to geographical distance, most patients in the care of the doctor who gave us access to consultations and surgical procedures were coming from different counties in the country), they expressed their verbal agreement for discussion, being recorded vocally or explicitly in electronic correspondence, and at the meeting in the clinic they were to sign and the formal consent to participate in the actual study. This approach - with the exploration of patient narratives at different times of treatment, is difficult and consumes many time resources, in addition to the one of the interview itself (with an average duration between 60 and 90 minutes with each patient). The written consent form is updated in accordance with GDPR provisions that entered into force in the Member States of the European Union on May 25th 2018, specifying the purpose of collecting personal data, the duration of its use, the preservation of anonymity, the exclusive use of demographic data and of the medical history, as well as the commitment to delete data from the archives used after the publication of the research.

Despite these time and geographic difficulties, the patient's repeated approach, relying on the added confidence of mutual knowledge, validates the Berg model, a spiral iteration of the field data collection steps, which are thus much more rich in biographical, medical and personal histories, opinion on the medical act or on the efficiency of communicating with healthcare staff. Since the patient's review can take place six months after the first discussion, this time period is valuable for sedimentation of beliefs and feelings, which then exposed in the narrative, are very useful for analysis for the purposes of this research.

Preliminary research hypothesis

Taking into consideration the qualitative specificity of the approach involved in this research project, the following statements are proposed as general working hypotheses:

1. In the case of Romania, the switch from clinical-centred medicine to medical-centred medical communication is at a minimal level, this delay having negative effects on both the patient's relationship and the way patients refer to their general health status.

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2. Medical narratives related to a particular illness will depend both on the narrator's position within the doctor-patient relationship and on a set of specific and highly personalized social and value factors.

3. The Romanian physician and patient have different understandings of health and illness and the way they define the social benefits associated with a patient-centred medical act will be divergent.

From the point of view of the possible outcomes for this research project, we identified two main impact levels: inclusion of Romania in the flow of academic communications addressing narrative medicine as a distinct field of specialization. Although narrative-based medicine studies have led to the creation of real "academic" schools (an example being the "Narrative Medicine" Center at Columbia University - USA[1]) in Romania this type of approach still is quasi-unknown. Through the articles and presentations of the results at various conferences in the country and abroad, we hope to awaken both the interest of the medical and academic factors in this field of research.

The research project will produce some results that will fill a "niche" of doctor-patient relations in the specific case of Romania. The data may be relevant to a specific field of medicine, namely preventive medicine. The relevance of an analysis of communication in preventive medicine - with the practical aim of contributing to the assumption of responsibility of the patient as an optimal form of preventive care and treatment compliance - is also found in the cost of public health services. Patient compliance reflects on optimizing and reducing subsequent treatment costs for chronic conditions or acute episodes. Patient-centred medical care studies show a tendency to lower health care costs, with the implementation of the Patient-Centred Care (PCC) principles (Davis, Schoenbaum, & Audet, 2005).

Research design

The sample used in pre-testing phase consists of 20 patients with cardiovascular diseases who received treatment in the country or in hospitals abroad - 6 male patients, 14 female patients, aged 18 to 75 years. The final diagnosis received by patients falls into the field of cardiovascular diseases, most of them having comorbidities that influence the main diagnosis.

As an example of this we have the 18-year-old V. B. patient, in Buzau, who was interviewed after a vascular consultation. The young man’s medical exposure, with congenital haematological disorders and *spina bifida* diagnosis, was sudden because all current affections were discovered within half a year. V. B. was exposed to a series of erroneous, inadequate and dramatic conclusions. At the hospital where he was initially admitted after accusing pain in his thighs, he was bluntly told that he has a tumour, requiring immediate surgery, to which the patient mother agreed in absence of other medical opinion. On the same day the intervention was scheduled, the pain "went down in the calves, so doctors realized that there was no tumour, but a valve defect or a non-functional vein" (V. B., 18 years, Buzau). Such a medical journey favoured an interview, allowing us

[1] Program overview at http://sps.columbia.edu/narrative- medicine/courses

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to explore references to "medical error", "bad news communication", "compliance to the treatment", "trusting medical professionals", but also "family relationship", "illness impact on the patient's daily life".

Exploring the comorbidities brings a specific discourse pattern in patient-doctor relationship, as most patients are familiar with medical language because of previous experiences. The research explores patient's narratives and their relationship to their doctors, after seeing a variety of other physicians, with whom they have failed to establish a relationship based on trust and respect.

The physician who offered access to the patient's records holds the role of a "gatekeeper", and interviewed patients judge past medical experiences as opposed to the one experienced with the current physician, "the gatekeeper". As a result, interviewers often refer to the "gatekeeper", evaluating the quality of the patient-doctor relationship, based on their perception of "ideal physician" and "ideal care". The rapport with this doctor also generates a set of features that can be extrapolated to the "ideal doctor / good doctor" category. During narrative analysis, a list of desirable traits, that a physician may possess enabling him to build the ideal setting for performing the medical act, can be identified. Patient discourse analysis also pursued the consistency of this set of desirable traits, regardless of the severity of the diagnosis and the identification of a variation in this set of traits, if the diagnosis is severe or less severe.

For example, if the patient has undergone a difficult surgery or has been taken care by a physician with whom he/she has established a partnership relationship in managing his condition, after repeated attempts to find this partner in the doctor, a proportionate rapport is sought in how the patient attributes these specific traits. Therefore, the more important the suffering is, the more the ideal physician's attributes are superlative. For example, V. M., a 63-year-old patient with recurrent, chronic conditions, who has been on the medical care for more than 40 years, speaks of G. C. as of a family member.

> V. M:. And I have undergone surgery three times on both legs, but in the meantime I did, as I walked, also because of Doctor C., because she is not just a doctor, or a human being, she is like my sister, as part of the family, so she treated me.
>
> Researcher: Yes, yes, yes. And I noticed that if she does not have the solution, she's looking for someone to solve the problem ...
>
> V. M.: At the times, if only I had a slight sign of pain, and she know me for so many years, she immediately took care of any of my pain and asked me what was going on.

The decision to apply a semi-structured interview was to allow coming back to specific replies of the interviewed patients. The aim was to ethnographically extract the experience of the disease, the treatment and the relationship with the doctor. A more detailed description of the experience and suffering that the patient has at a given time, it delivers a context that can be studied by healthcare professionals and healthcare workers, eventually adjusting the discourse with the patient and his/her family. The benefits are already shown by the literature, which states that narrative medicine contributes to patient comfort and compliance with treatment, increasing confidence in the medical act. The finality of narrative medicine as a discipline is defined by a successful medical act for the patient (Charon, 2004). At a time when technology, figures, analyses, everything building

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up evidence-based clinical medicine took the place of doctor-patient discourse and direct interaction into medicine, there is an increasing need to build a bridge between the two ways of practicing medicine (Charon, 2011). This connection is narrative medicine, discipline that is still medicine, but one practiced with understanding and empathy (Charon, 2001b), with the ability to recognize, absorb, metabolize, interpret and be moved by illness narratives.

Conclusions

The pre-testing stage of the research "The medical narrative in cardiovascular diseases in Romania" revealed two hypotheses that can be investigated at a later stage:

1. Satisfactory communication of the physician with his/her patient is the key to collaboration in the therapeutic act, with benefits for the patient's physical and mental health;

and

2. Investigating the roles that the narratives of the actors in the medical act express (physician, patient, family) provide valuable information in structuring public health policy narratives; in the case of the chosen field, cardiovascular diseases rank first in the statistics of deaths in both women and men in Romania, which confirms the importance of coherent policies of prevention and correction of patients' lifestyle.

> Cardiovascular disease is the main health problem, and in Romania, mortality caused by cardiovascular disease is three times higher than that caused by cancer. 60 per cent of all national deaths are caused by cardiovascular disease, compared with 19 per cent of cancer. From this point of view, cardiovascular diseases kill most Romanian citizens." (Dragoş Vinereanu, President of the Romanian Society of Cardiology)[1]

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