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DOCTORAL DISSERTATION

DISCURSIVE REPRESENTATIONS OF ILLNESS AND HEALTHCARE: A QUALITATIVE STUDY OF PATIENTS AND DOCTORS

SUMMARY

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The year 2016 brought again to the forefront of public debate the longstanding crisis of the national Romanian health system – as regards material infrastructure, personnel and the legislative framework, among others. This crisis is reflected and re-created, at discursive level, through representations of illness and health care that inform patients' and doctors' decisions and interactions. These representations are the result and also one of the sources of present-day practices of doctor-patient interaction in the Romanian public health system.

The purpose of this thesis is to identify **types of representations of illness and health care in patients' and doctors' accounts**, in present-day Romania, focusing on illness and professional narratives. Discursive representations of illness and care are important because they inform decisions and structure interactions, thus contributing to patients' and doctors' quality of life. Furthermore, discursive representations allow the analysis of power relations between patients and doctors, which this thesis interprets through the concepts of 'voice of medicine' and 'voice of the lifeworld' (Mishler, 1984).

The main contribution of this thesis is to expand Frank's (1995) typology of illness narratives by introducing **the resignation narrative** for patients' accounts and **the professional narrative** for doctors. Furthermore, it expands the applicability of Mishler's concepts of 'voice of medicine' and 'voice of the lifeworld' through the narrative analysis of accounts, using them to **compare the different representations of legitimate medical authority and patient agency in doctors' and patients' narratives**, respectively.

This thesis relies on a sociological survey comprising 10 interviews with patients and 10 with doctors, complemented by documentary analysis of 10 illness accounts posted on online discussion forums. The criteria for selecting patients respondents was for them to have had at least one surgical procedure during their adult life, followed by a three-day minimum hospitalization in a public hospital. Doctors were selected from the medical staff of Bucharest public hospitals. Online illness account were selected based on their discussion of surgery in public Romanian hospitals. The results were then interpreted using the tools of discourse and narrative analysis.

On a descriptive level, this thesis presents **types of illness narratives** that patients construct and the professional narratives doctors tell about their experience with illness and healthcare. In the case of patients, the typology is based on Arthur Frank's (1995) conceptualization of three types of illness narratives: the quest narrative, the restitution and the chaos narrative. To this, I expand proposing a fourth type of illness narrative formulated based on the collected accounts: the resignation narrative. All illness accounts that patients formulate follow a temporal line and describe biomedical treatment practices and recommendations, self-care practices and health knowledge, as well as interactions with medical professionals and peers in relation to health.

While patients' accounts describe the experience of illness, doctors' describe the experience of the medical profession. Doctors' accounts are less temporally ordered and include fewer representations of illness signs, focusing on the treatment process, the state of healthcare practice and interactions with fellow medical practitioners. Their accounts point to a professionalized stance towards the patient, one that rarely implies empathy for the personal experience of illness, focusing instead on the impersonal practice of treatment.

On an analytical level, this thesis examines the **power relations and stances** represented in patients' and doctors' accounts. The doctor-patient interaction is a fundamentally unequal one, the doctor role implying the knowledge and ability to solve the issue presented by the patient. However, the unequal stances are also visible in the language each actor uses, how their conversation unfolds during the medical consult (see Mishler, 1984) as well as in the discursive representations each formulates about the other in accounts. For patients, representations of doctors quickly turn from an initial assessment of professional status to more personal attributes, such as signs of kindness and understanding towards the patient's complaint, or the ability to explain the treatment and diagnostic in common terms. Doctors, however, focus on a patient's compliance to treatment and appreciate the clear description of symptoms and patients who seek out medical help in a timely manner. Representations of doctor-patient interactions that are common to patients' accounts are sparse in the case of doctors and, when they are present, their apparent purpose is to demonstrate the patient's noncompliance. This thesis analyzes the difference between the discursive representations the two actors formulate about medical interactions and illness through the concepts of 'voice of medicine' and 'voice of the lifeworld' (Mishler, 1984), concluding that the **authority of medical professionals is legitimized differently by patients and doctors**. While doctors represent their authority as a given, justified by their professional status and training, patients' evaluations of medical authority can change after an interaction episode and focus more on practical demonstrations and personal attributes.

Illness is a cause of uncertainty and self-questioning, a situation in which one's biographical continuum is disrupted (Bury, 2001; Frank, 1995), forcing the individual to take a reflexive approach in narratively reconstructing one's identity (Giddens, 2000). Patients' representations of self-care practices and their integration of multiple, at times incompatible, treatment paradigms point towards the multiple knowledge systems which are now available to the individual in constructing one's own 'personalized' care. This increased availability of knowledge, stemming from more or less scientifically valid sources, is reflected by the representations of the ‘voice of the lifeworld’ in accounts and poses a discursive challenge to the ‘voice of medicine’ authority over the conceptualization and treatment of illness.

The introductory chapter of the thesis presents a short overview of the general context of the research, highlighting the main features of the biomedical discourse and its analysis by medical sociology and anthropology. Next, it provides a short description of the context of Romanian healthcare by presenting four events that reflected and impacted the public medical system in the past year: the introduction of the medical healthcare card for all consults and treatments in the public healthcare insurance system; the formation of a discussion group for doctors on Facebook and the subsequent registration of a new NGO for doctors rights, the Doctors Alliance; the fire in club Colectiv and the subsequent media revelations about the conditions in the hospitals that treated the victims; last but not least, the journalistic investigation into the contracts and products of the main disinfectant provider for public hospitals, Hexi Pharma, which revealed that the company diluted many of its products for years. The latter also lead to widespread investigations and further disclosures from doctors about the conditions of treatment in public hospitals. Finally, this section describes the research purpose, its motivation and how its focus has evolved over the years of my doctoral studies, which is also visible in the articles and book chapters that I published during my doctoral research (Borlescu, 2011; 2013; 2014; 2015).

The chapter on theoretical grounding presents the main concepts used to interpret and analyze the results of this research and discusses the relevant literature and studies for each argument. First, it considers the concept of discourse and its dimensions, distinguishing it from that of narrative. I argue that discourse has a larger interpretative coverage, being suited for individually produced accounts specific to a particular temporal, spatial or cultural setting as well as for a disembodied institutional discourse. On the other hand, I understand narrative as more dependent on its setting and more restricted in the range of contexts it can include. Next, I take a closer look at narrative and its functions – textual, ideational and interpersonal – in order to show how individuals use stories in their discourses about illness and healthcare, acting as identifiable episodes with which the listener can relate.

The presentation of the main theoretical aspects of this thesis continues with the distinction coined by Arthur Frank between multiple types of illness narratives – chaos, restitution and quest narrative – in order to discuss in more detail the meanings attached to the illness experience. I then propose the **resignation narrative** as a fourth type of illness narrative, based on the findings of this research. These types of illness narratives are analyzed through their narrative structure in order to see who they differ beyond the shaping of different understandings of the illness experience. I also propose a characterization of doctors' accounts as **professional narratives**, focused on their self-presentation and revealing their specialized approach to illness.

The next section of this chapter follows the temporal line of patients' interviews to discuss the main concepts and research pertaining to each discursive illness stage: pre-diagnostic, diagnostic, treatment and recovery stage. Following the unfolding of most illness accounts reveals the discursive representations that patients and doctors construct about their daily experience of illness. Then, I turn to the discursive representations of interactions and the actors encountered in patients' accounts and I use Erving Goffman's (1956) understanding of the performance of the self to highlight how individuals represent the other's image and identity in their own discourse.

The chapter then presents the concepts of 'voice of medicine' and 'voice of the lifeworld' coined by Elliot Mishler (1984). I discuss the distinction medical sociologists operate between the concepts of 'illness' and 'disease', informal payments and other discursive representations of resistance to medical authority as themes which can be analyzed to reveal the relation between the two 'voices'.

In relation to the 'voice of medicine' and its representation in narratives about illness formulated in the lifeworld setting, the next section briefly presents the concepts pertaining to the theory of **reflexive modernization** and how these are used in the present analysis. Risk, individualization, reflexivity, expert systems and the multiplying sources of knowledge are discussed in light of a unifying principle of reflexive modernity: the multiplying of boundaries and of attempts to draw boundaries. The advice provided by medical experts and represented in accounts through the 'voice of medicine' is often balanced again un-professionalized sources of health knowledge. Finally, the chapter on theoretical grounding concludes by briefly presenting past research on healthcare and medical practice in Romania.

The next chapter presents the **methodological approach** of this research, its objectives and core assumptions. It details the questions and presumptions with which I began the work and how these have changed along the way. By formulating the research questions, it specifies the three main objectives of this thesis:

- To identify **types of representations** of illness experiences and medical interactions in patients' and doctors' discourses;
- To discuss how these representations reflect the **power relations** underlying health-care interactions, conceptualized by the relationship between the 'voice of medicine' and the 'voice of the lifeworld';

- To identify and analyze comparatively the **types of narratives** that inform patients' and doctors' accounts.

Then, the chapter discusses the specific methodology which underlies data collection and analysis, discussing data sources and analytical and interpretive options. This study relies on a qualitative research based on 10 interviews with doctors and 10 with patients, complemented by document analysis – specifically, the study of 10 online textual accounts of illness. The section presents in detail the structure of each type of interview as well as the guidelines that informed the selection of particular online textual accounts of illness. The criterion for selecting a person as patient respondent for this study was to have had, during his or her adult life, at least a surgery followed by a hospitalization of minimum three days in a public hospital. For doctors the selection was limited to personnel working in public Bucharest hospitals. Online accounts were selected such as to refer to surgery in Romanian public hospitals. The chapter then discusses how online accounts differ in structure from interview accounts and distinguishes between *discourse*, as a term I will use in relation to the whole interview, and *narrative,* employed in reference to interview segments which present a coherent temporal structure. The findings are analyzed using a discourse and narrative analysis perspective in order to reveal types of representations of illness and healthcare in doctors and patients accounts. The chapter then positions this research as embedded in the local cultural setting. I aimed to conduct a situated analysis based on the situated knowledge of participants, more or less directly expressed, an aspect which takes foreground at multiple points during result presentation.

The third chapter takes a structurally descriptive stance towards the **findings** of this research, analyzing accounts format and how this shapes the representations they invoke. First, it looks at interview accounts and online textual accounts as narratives embedded in a particular cultural context, exemplifying the distinction between discourse and narrative presented in the theoretical grounding chapter with accounts extracts. The temporal and narrative structures are compared and used as a starting point for the coherence and narrative reconstruction of accounts. Individuals combine multiple narrative episodes in their overall interviews discourses, shifting between multiple perspectives and other actors' voices in order to formulate their narrative stake.

The narrative structure of the accounts also forms the basis for analysis in the case of illness and professional narratives types. This section provides examples for each type of illness narrative coined by Arthur Frank and for the resignation and professional narratives proposed by this thesis. **The resignation narrative** is demonstrated by accounts of patients who have not fully recovered after an illness episode and who, instead of returning to their health status from before the illness –

as in the case of the restitution narrative – or achieving a better understanding of their life and themselves – as in the quest narrative – are resigned to moving forward with a diminished health status. This narrative implies a certain amount of surrendering agency either to illness, or to family members who push forward to improve the patient's condition. Finally, I attempt to formulate a narrative interpretation of doctors' accounts by characterizing them as **professional narratives**. While illness is still the main subject of such accounts, it is more the object upon which doctors exert their practice, instead of a personal experience as in the case of patients. Doctors focus more on diagnostic and treatment phases; when they do mention patients in more detail, this is often to refer to their non-compliance with treatment.

The fourth chapter continues the presentation of research findings. It describes and interprets the content of collected accounts in light of the theoretical aspects of the **power relations conceptualized through the 'voice of medicine' and the 'voice of the lifeworld'**. The organization of this section follows the temporal line of patients' interviews, structured in three stages: it began by recounting the first illness signs of the affliction for which they eventually received surgery (the pre-diagnosis stage), progressing through the diagnosis stage and then the recovery and treatment stage. These will be complemented by the doctors' description of a consult and the symptoms patients present when seeking medical treatment, as well as a look at the same stages in fragments of online textual accounts. The discursive framing of illness representations will be of particular interest throughout this discussion, underlining the aspects used most commonly by each actor, but also how the 'voice of medicine' and 'voice of the lifeworld' are intertwined in both discourses. The analysis of illness signs in the pre-disease stage will particularly focus on patients' representations of feeling 'unwell' (ro. "stare de rău", "mi-a fost rău"), a diffuse concept commonly used to describe a **state of ill health which also includes social and personal aspects**. Next, diagnosis is interpreted as a categorizing action performed by medical practitioners and readily assumed by patients due to its ability to name and frame the issue. The section includes an analysis of the steps taken to reach a diagnosis as they are recounted by doctors, and also looks at how patients adopt the biomedical language of diagnosis in their narratives about illness. The analysis of the post-disease stage focuses on representations of patients' self-treatment practices. These are shown to be a pervasive approach to treatment in which multiple discourses about illness are combined in order to reach an attainable and satisfactory treatment. While for patients these are ways in which they manifest agency over illness and make efforts to secure recovery, doctors perceive self-treatment practices which deviate from their recommendations as revealing an irresponsible approach to one's health.

The **pre-diagnostic illness stage** is mostly constructed in the 'voice of the lifeworld', both in terms of the language used, and also in terms of the multiple sources of knowledge and approaches that individuals combine to understand illness. The illness signs are diffuse, as revealed by the common use of the term 'unwell' to describe a variety of states, and initial actions to alleviate them are chosen based on recommendations made by significant others or one's previous experiences with illness. In the **diagnostic stage** the 'voice of medicine' makes a strong appearance, reflected in both patients' and doctors' accounts through the language used and the repositioning of illness in the medical sphere of the consult.

However, **the treatment and recovery stage** is most revealing for the discursive interactions of the two voices. Both patients' and doctors' accounts include representations of the other's actions and approach to illness. The distinctions highlight the different modes of understanding and approaching illness characterized by the two voices. Doctors emphasize restoring measurable parameters to normal values, adopting a rhetorically objective approach. For patients, illness is integrated in their social lifeworlds and its representations include social consequences which are not of concern for the medical approach. This distinction is the basis of the dual concepts of 'voice of medicine' and 'voice of the lifeworld' and leads to a series of misconceptions, incomplete disclosure of symptoms or treatment practices and resistance on both sides.

The fifth chapter continues the discussion of research results and analyses patients' and doctors' representations of social interactions, personal and other's identity as well as informal payments and discursive representations of resistance. While the previous chapter discussed the knowledge differences between the 'voice of medicine' and that of the 'lifeworld', this final chapter expands the analysis to the social dimension. Using Erving Goffman's (1956) understanding of the performance of the self presented in the theoretical grounding chapter, I analyze individuals' representations of the other's image and identity in their own discourse. Patients' representations of doctors' identities take into account other social roles and labels, beyond their professional status, while doctors make such ascriptions based on the knowledge patients appear to hold about their illness and their manifested responsibility towards treatment.

Next, the chapter takes a closer look at **informal payments** and how these are discursively represented, arguing that they can be interpreted from the patients' perspective as another way to symbolically counter uncertainty and formulate a reciprocal relation with doctors. Medical professionals, in turn, are more opaque about the meaning they attribute to such practices, resuming themselves to naming them 'grounded habits' or 'humiliations'. Doctors' representations of informal payments shift their accounts from being formulated mainly in a 'voice of medicine' to responding in a more personal manner, indicative of the 'voice of the lifeworld'.

Finally, the fifth chapter presents patients' overt and covert manifestations of resistance to the 'voice of medicine' as a means to outline power relations through individuals' discourses about illness and healthcare. Biomedicine is the source of the professional 'voice of medicine' and it is an institutional discourse stretching beyond territorial boundaries, influencing the way we interpret illness. Discursive representations of resistance and informal payments make visible the standard representations of medicine by interposing lifeworld understandings.

The conclusions chapter provides a summary of the findings and main contributions of the research in regards to Frank's typology of illness narratives and the extended applicability of Mishler's concepts of 'voice of medicine' and 'voice of the lifeworld'. Based on the differences between the representations doctors' and patients have of illness and healthcare discussed throughout the thesis, I argue that the two actors have different understandings and representations concerning legitimate medical authority and the role and extent of patient agency. **While doctors construct their interactions with patients and subsequent accounts from an implied position of authority, supported by their medical training and practice, patients do not take the legitimacy of this authority as a given.** Instead, they seek confirmation of a doctor's expertise during the medical consult and make assessments based on the success of their treatment and the accounts of other patients treated by the same doctor. Patients' evaluation of doctors' legitimate authority can change, as their discursive representations of interactions with medical professional show.

Based on doctors' accounts, it appears that they do not typically take into consideration how patients perceive their authority. Instead, doctors conceive patients' manifestations of resistance as signs of noncompliance, or as a lack of understanding of biomedical practices, labeling the patients as irresponsible. Doctors' accounts seldom acknowledge the relevance of lifeworld elements included by patients in the descriptions of their illness, which, for the latter, are a main reference point of their illness experience.

As regards directions for further analysis, this thesis proposes a deeper discussion of discursive representations of the healthcare system, particularly those encountered at an institutional macro-level and those addressing private healthcare, in order to formulate a broader picture of the representations of the main institutional actors of the Romanian medical setting. Furthermore, it would be relevant to see if and how accounts have changed after the much publicized crises of the public system of the year 2016.

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