

# Representations of Self-care Treatment Practices in Patients' and Doctors' Discourses Between Non-compliance and Agency

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## Introduction

**T**HE PROCESS of treating an illness involves multiple actors who continuously reassess the efficiency of the treatment methods used, or provide advice on alternative means. However, illness treatment in modern medicine has been understood and applied as a unidirectional process structured by a doctor—as the professional incarnation of biomedical knowledge—and directed towards the patient—as the locus of disease. Other actors, such as pharmacists, nurses or a patient's family, and cultural or social factors which appear in the practice of treatment are commonly irrelevant as far as treatment decision making goes. This article discusses the representations of self-treatment practices in discourses of Romanian patients about their illness experiences in order to show how a patient's understanding of this experience combines the biomedical with a lay approach. Furthermore, the discussion will be completed by discursive representations of treatment encountered in interviews with doctors in public hospitals, in order to comparatively assess the understandings that the two main actors of the treatment process hold.

The qualitative data in this article is analyzed as representing discourses constructed in, revealing of and shaping specific contexts. Identifying speech or text instances as discourses implies a narrative process of construction and reconstruction of actions, events and interactions.<sup>1</sup> Furthermore, the accounts exhibit an internal coherence and narrative structure,<sup>2</sup> are coproduced in dialogue—in the case of interviews—and have an intertextual character, relying in their construction on previous discourses.<sup>3</sup> Thus, the accounts collected by this research represent a form of contextually based, situated knowledge.<sup>4</sup> They simultaneously draw on and reflect a local cultural system,<sup>5</sup> which provides sanctioned ways of constructing and performing illness and medical interactions. Actors actively select from these cultural resources to construct their discourse in accordance with their intentions and perceived expectations of the interlocutor and setting.

Hence, I understand “discursive representations” as being narratively constructed thematic discourse units, used by participants to express a specific stance on a given

topic. Admittedly, subjects can formulate both intentional and unintentional representations, leading to a secondary construction of certain representations during analysis. These are descriptive constructs of the emergent themes encountered in participants' discourses.

The accounts presented here are interpreted using the concepts coined by Elliot Mishler<sup>6</sup> in his study of medical consults: "the voice of the lifeworld" and "the voice of medicine." His research concludes that medicine's institutional organization and dominant position over health knowledge is reflected in and shapes the interaction between physician and patient by means of this "voice of medicine" which dominated over "the voice of the lifeworld" represented by patient attempts to address social life issues during the medical consult.<sup>7</sup> Mishler defines voice as "a particular assumption about the relationship between appearance, reality and language, or, more generally, a 'voice' represents a specific normative order"<sup>8</sup> of discourse. These two normative orders identified by Mishler in the interaction between doctors and patients are also evident in the two actors' accounts of these interactions, on which the present article is developed. Patient accounts of treatment practices, more so than doctors', appear as a reconstructed dialogue between the "voice of medicine" and that of the lifeworld meant to present illness as an experience integrated in one's social and cultural context. Doctors commonly re-enact the "voice of medicine" in discussing treatment practices, with the "lifeworld" being criticized for its interference in the healing process, which is discursively constructed as a socially independent, physiological event.

After patients leave the confines of the hospital and the direct supervision of treatment by medical personnel, they become responsible for their recovery progress. The dominant position of the biomedical discourse over treatment practices formulates a normative setting curtailing patient actions by means of its moralizing position. Non-compliance with medical treatment is associated on a discursive level with value judgments regarding an individual's ability to perform a responsible and self-sustainable identity. From an institutional point of view, non-compliance practices are viewed as sign of a patient's disregard for his/her own self, justifying a continuous paternalistic position.<sup>9</sup>

However, Stevenson et al.<sup>10</sup> show that non-compliance is not a matter of complete disregard for medical advice, but rather a patient's decision to pursue a different course of action. Adherence to medical treatment prescriptions is only a problem from an institutional perspective, which sees such behaviors as passive forms of resistance to the biomedical discourse. Instead, for patients, following a prescribed treatment is one decision among many others and it only takes precedence over others if the illness in question is urgent or serious enough to affect daily activity. Neither the study of Stevenson et al. nor my research make any claim regarding patients' health literacy or the informed character of such decisions. Based on the collected accounts and personal observations, I would argue that individuals are concerned with understanding their condition, but they consult a variety of sources to reach that understanding, many outside the medical profession. The validity of these sources is beyond the scope of my research.

A shift in orientation regarding non-compliance research has rebranded the subject in a more patient-friendly perspective. What was until recently studied under the term non-compliance has now been co-opted in the larger field of self-care practices, covering both decisions regarding medical treatment as well as patients' use of other healing and pre-

ventive practices. Self-care is defined as the active process of recovering, maintaining and increasing one's own health.<sup>11</sup> Such practices are not new or characteristic only of modern societies. Most care practices have traditionally been formulated inside the family context. Only after the professionalization of care through medicine has health left the personal space of the family. In late modern societies healthcare is being reshaped by multiple actors acting both on a level of public discourse and in the area of personal practices.

Individuals' active construction of illness discourses and the integration of biomedical information in their lifeworld accounts stand as evidence of the individualization of healthcare discourse and the erosion of medical dominance over the distribution and use of biomedical information. The formulation of illness narratives, which include but are not limited to biomedical information, are reflexive actions mostly developed on an individual level. The patients themselves are the authors of their discourses—regardless of the multiple sources they use in constructing them—and their integration of biomedical information can be interpreted as adopting a “lay expert” position in dispensing healthcare advice and recounting their experiences. From a theoretical standpoint, one could argue that individuals are constructing and re-constructing their identities and personal biographies to adapt to society's changing conditions, increased uncertainty and risk.<sup>12</sup>

These same discourses reveal that, when it comes to representations of treatment practices there are several actors which compose either the “voice of the lifeworld” or that of medicine. The healthcare system as an institutional actor involved in individual treatment practices, stands as “the voice of medicine,” represented by the medical personnel patients interact with. Second, individual discursive representations of treatment practices reveal that information dissemination agents, such as the media and the Internet, provide patients with a body of knowledge and a set of discursive positions, which they use in adopting particular treatments. Third, the treatment process is filtered through an individual's interpersonal ties, which influence both the discursive representations of treatment as well as their practical development.

Ziguras formulates a similar distinction between three levels of abstraction or integration: professional-institutional, face-to-face and disembodied integration which, he argues, have progressively switched places as the dominant influence of the construction of self-care discourses throughout history.<sup>13</sup> I will use these three levels in my analysis as dimensions for the two concepts discussed above, the professional-institutional level representing the “voice of medicine” and the face-to-face and disembodied integration level as dimensions for the “voice of the lifeworld.”

In Ziguras' understanding, the professional-institutional level mainly addresses the centrality of biomedicine in forming and regulating healthcare knowledge, manifested through the positions its representatives hold and the authority they wield. This level also includes the influence exerted by administrative and policy resolutions aimed at modifying health practices.

The second level, of face-to-face interaction refers to the integrative quality of personal communication and social relationships in co-generating and constructing self-care discourses and practices. Individuals rely on what Eliot Freidson<sup>14</sup> calls “lay referral

systems,” networks of advice through which people seek to make sense of their bodily states with help from friends or family, before consulting biomedical professionals. Personal, face-to-face interactions with significant-others shape one’s self-care practices and discourses, as well as one’s interaction with medical professionals. A significant amount of health issues, particularly minor ailments, are resolved by consulting others or through self-treatment.<sup>15</sup> The most common health practices are thus those that escape direct contact with the medical profession, being influenced by multiple sources of health advice, from biomedical knowledge to lay health knowledge and media discourse.

Ziguras argues that this personal level has been surpassed as the dominant mode of distribution and enactment of self-care knowledge with the advent of the professionalization of medicine, and more recently, by disembodied means of communication. However, in the case of this study, discourses about illness and treatment reveal that lay referral systems still occupy a gate-keeper position in patient evaluations of information and treatment options, as well as in doctor selections of treatment and problem solving. Patients’ individualistic and reflexive construction of illness discourses include representations of interpersonal decisions about treatment, while the institutional discourses of doctors include representations of the use of social relations with other professionals to secure medical treatment unavailable through institutional means. On the one hand, it can be argued that in the Romanian context, both strategies are personal adaptations to the scarcity of treatment resources in the Romanian healthcare system. On the other hand, the public healthcare system’s inability to ensure proper treatment options for patients and working conditions for medical professionals could be interpreted in a sociological perspective as the malfunction of modern institutions<sup>16</sup> and their failure to provide solutions for the vast array of risks produced.<sup>17</sup> In this perspective, the reliance on social relationships by both doctors and patients can be interpreted as an adaptive means to manage institutional instabilities and the uncertainty caused by the multiplying sources of health information in late modernity.

The third level of abstraction represented by disembodied integration involves the constitution of “subjectivity through technologically mediated relationships.”<sup>18</sup> Mass media allows for interactions and knowledge dissemination to take place, facilitating contact with absent others via technological mediation. A whole industry of self-care products and practices have blossomed in the wake of self-care discourses and continue to be promoted often for economic gain. Individuals come in contact with a vast array of messages about alternative health therapies, workout and food regimens, vitamins and a variety of dietary supplements from which they can bricolage their own lifestyle. In describing the disembodied level of integration, Ziguras generally refers to media channels through which individuals gain increased access to health information, but this level of abstraction can also include the knowledge used and produced by individuals in utilizing self-monitoring devices.

The use of Internet forums such as chat rooms and discussion boards to share information and disseminate illness accounts is another example of this level of interaction with health information, and the source of part of the data used in this article. Besides the disembodied character of subjectivity, which such an environment supports, being a means of expression for “the voice of the lifeworld,” online forums are also an oppor-

tunity for the construction of weak social ties, which expand an individual's social network.<sup>19</sup> Organizing interactions focused on a particular subject, in this case illness and healthcare, online forums provide an extended support network for both users and their families. It is not rare to find users inquiring about the symptoms or diagnosis of a family member on the health sections of online forums. In the context of uncertainty and risk constructed by health institutions' limited capacities to provide treatment and to explain the diagnosis and illness progress, individuals turn to this extended social network in search for answers. The criteria of the legitimacy of information are not being ignored in this environment, with users commonly requesting support from others who have experienced similar situations. Thus, we are returned to the integrative qualities of the lay referral systems' ability to provide support based on personal experience, but without the face-to-face character of interaction. This disembodied level of interaction ends up supporting the construction of self-care practices and discourses in an interpersonal setting, rather than an individualistic approach to treatment.

## Research data and methods

**T**HIS ARTICLE draws on a qualitative research including a total of 20 interviews—10 patients and 10 doctors—and 10 online textual accounts of illness posted by patients or caregivers on Internet forums. The criteria for selecting patients to interview and the textual accounts of illness was that the individual had some form of surgery, followed by a hospitalization of at least three consecutive days. As all selected accounts were based on patient experiences in the Romanian public healthcare system, the interviewed doctors had to work in a public hospital. The doctor's field of practice was irrelevant to the scope of my research, as was the type of surgery that the patients underwent, or their socio-economic background. In order to account for gender and age discourse variations, I aimed for an even representation of men and women and a varied distribution in regards to age when selecting respondents.

Data analysis was conducted using the tools and assumptions of discourse analysis (DA)<sup>20</sup> and critical discourse analysis (CDA).<sup>21</sup> For the present article, of particular interest is DA's concept of "interpretative repertoires" understood as sets of systematically connected terms individuals use to represent, describe or argue for a particular stance.<sup>22</sup> Similarly, the analysis is based on CDA's assumption that power relations are reproduced and enacted through discourse because individuals interact as members of certain groups. As my analysis focuses on accounts generated after the medical consult(s), this line of analysis serves to show the interrelation between the "voice of medicine" represented by doctors reproduced direct speech or actions, and the "voice of the lifeworld" consisting of individuals comments on those actions and their general discourse on the matter.

The transcripts render the pauses, repetitions, false starts and interruptions of the interviewer and respondent in line with this research's focus on interviews as a co-constructed discourse. Suspension points represent pauses, with more than three points signifying a longer pause, and words in parentheses are the interviewer's interruptions.

The interview extracts have been translated from Romanian by the author. Pseudonyms are used to ensure the respondents' anonymity.

## Integrating treatment in personal social contexts

**S**ELF-CARE DISCOURSES are constructed around multiple overlapping categories, reflecting the interaction between the three culturally mediated levels of knowledge<sup>23</sup> or, to use the language of discourse analysis, between the three major interpretative repertoires. There is little to no conflict between the various ideologies of these repertoires in individuals' accounts, as practices appear chosen in concordance with an individual's social, economic and personal situation. First, I will describe in short four main factors which emerge from patient discourses as influencing the construction of self-care practices and their discursive representations, after which I will perform a more thorough analysis on three illness account extracts.

*Attainability.* The attainability of health practices structures the types of information that individuals use in constructing and selecting self-care practices. Financial costs, the amount of time invested and any potential negative impact the decision or practice might have on one's activities are factors considered in the interviewees' self-care discourses. Paul, a 29 years old patient adapts his surgeon's recommendation to avoid physical effort for at least two months after abdominal surgery to his financial needs and responsibilities. He had refused a one month sick leave, minimizing its significance for his post-surgery recovery in his account, stating that there are monthly bills to pay, which he could not cover with sick leave pay. He underlines his quick recovery by recounting that he was out of bed the day of the surgery and down the stairs to the hospital's courtyard two days later to have a smoke, but always in the absence of his doctor or family. Discussing his post-operative plan, he states: "*no other treatment, just to avoid effort*" and later on he further minimizes this saying "*I just have to avoid lifting with my right side,*" despite acknowledging some abdominal pain.

*Perceived efficiency.* Respondents repeatedly refer in their self-care discourses to temporary solutions or the desire to find a quick cure for their affliction. Tiberiu relates having used a lot of pain medication to alleviate his symptoms before consulting a physician, while Florentina states that she has used two types of injections recommended by a neighbor as useful in strengthening the body and, consequently, alleviating the pain and improving the use of her knee. Others simply state having asked the doctor for "*something to make it go away*" indicating the disruption and instability illness has brought in their lives. Although diagnosed and under treatment, some recurrent or chronic illnesses are perceived as not being efficiently treated or explained, requiring further intervention from the individuals themselves. This is a recurring theme signaled by accounts of "self-trialing"<sup>24</sup> practices in adjusting treatment plans and searching for alternative cures.

*Self-trialing.* Individuals perform processes of trial and error, experimenting with a variety of self-care practices. They recount the concomitant use of multiple types of therapies or treatments with no contradiction in regard to different therapeutic ideolo-



gies, favoring the “demonstrable therapeutic effect, experienced or felt in relation to the amelioration of symptoms.”<sup>25</sup> The selected self-trials are embedded in the respondents’ lay referral systems,<sup>26</sup> accounts of the successful experiences of others with such practices being offered as a motive for their use. Besides trying all kinds of teas for her sleep issues and injections for increased body strength and pain alleviation, Florentina also mentions she intends to visit a spa, “*to try this one too, to see if it does something.*” She relates that some of her neighbors had visited a nearby resort the year before, thus making her lay referral system visible once more. Self-care practices vetted for by others become desirable and a reference point in structuring one’s own self-care discourse. Likewise, Nina repeatedly states in her interview her desire to visit an acupuncturist consulted some years back. She does not mention a specific affliction for which she had her initial consult or for which she wishes to return, but instead mentions: “*I was feeling unwell, like I am feeling now... He placed those needles in my ear and I stayed with them for two weeks. After that, I felt better for a few years.*” Also, she recounts a relative’s experience of not being able to walk properly and recovering only after visiting the acupuncturist as further motive and proof of efficiency.

The experiences that respondents bring up in discussing self-treatment practices are instances of the lifeworld voice in their discourses, as well as representations of the daily mixture between biomedical practices and other sources of information used to restore health. As these examples and the interview extracts below show, the path from prescription to treatment is sinuous and patients evaluate the efficiency of treatment against its cost and availability, but also considering their social network’s view on the matter. The next recurrent factor in discourses about treatment, however, reflect the influence of the voice of medicine on the individuals’ understanding of health as the state of a contained body.

*Self-efficacy* is the “perceived control over one’s environment and behavior.”<sup>27</sup> This construct is encountered in many health behavior theories and is relevant for understanding the construction of individuals’ subjective illness representations, which guide self-care practices. Health behavior theories use self-efficacy as a predictive tool for illness-related distress and positive health self-management behaviors,<sup>28</sup> but in light of the discursive approach of this research, self-efficacy can be interpreted as an expected health related discourse with an attached set of self-care practices. Furthermore, self-efficacy is a reflection of the biomedical discourse of individual responsibility for health status often encountered in respondent accounts of illness. Nina’s account is littered with references to a “lack of control over illness” repertoire. She occasionally shifts between relating past and present illness experiences, comparing the two and drawing conclusions about her current health condition. Stating, “*It’s true, I control my self-control*” after recounting a moment when she experienced high blood pressure, which made her feel afraid, she reasserts her need to regain control over the extent of her illness signs. Likewise, Florentina laments the loss of control over her body with “*this head of mine, it no longer listens to me,*” and her efforts to maintain the functionality of the leg after her knee surgery.

I will now turn to the analysis of interview and online accounts fragments in order to exemplify the factors described above and to show how individuals use social networks and interaction to secure more treatment information and options.

Extract 1—online textual illness account

*Initial post:* My father was diagnosed with polydiscopathy and disc hernia, in advanced stages, so that for about a month he can't walk straight, the nerve being pressed and the pain being strong and permanent in the right leg. Surgery is a must, but after a time when we are hoping that the pain will subside, through reducing the inflammation, and after he will change a little his heart medication (fibrillations).

My question is: do you know where you can find the best team of spine doctors in Romania, who has expertize (gained through trips abroad) and experience (gained through surgeries performed on Romanian patients) in this kind of surgery?—from what I found on the net the term in English is “lumbar microdisectomy” or better said [Romanian: microdisectomie] in Romanian, that is, a surgery through which the spine is entered and the disc piece which is pressing on the sciatic nerve is cut.

I think in Romania this illness (disc hernia) is very present, and I am actually surprised I did not find a topic with it on this forum, maybe even among the members there are persons who have had this and have studied the surgery option. I understand that surgery is to be avoided, as it presents various risks, like those connected to the sciatic nerve and anesthesia, considering the age of patient with this kind of illness. But I read that when the pain in the leg does not stop after 3-4 weeks with all the anti-inflammatory medication, surgery has to be done, otherwise the action of the detached disc over the nerve is accentuated and leads to complications.

*Reply:* My father-in-law as well as a neighbor had surgery 4-5 years ago in Iași. They are the best doctors, plus they do not ask for bribes [Romanian: mită] like in other Bucharest hospitals.

But I can give you an advice. 7-8 years ago my father was in an advanced stage of disc hernia. He had to have surgery. But because he couldn't get to Iași for the surgery because he couldn't sit too long on a chair (he had horrible pain) he went to Brăila at Lacul Sărat for treatment (we live in Galați). I can say that the 3 weeks the treatment lasted put him back on his feet. Now you do what you think. But still, it is worth trying.<sup>29</sup>

This extract is from an online forum topic on disc hernias which began in 2006 with the first fragment, and is still active today, with new users sharing their stories and searching for support in the framework outlined by this first post. This is a good example for many of the self-treatment aspects discussed above, to which I shall return in a moment. The second fragment, the reply, is the second answer the user received from another forum member with suggestions based on the experience of family and peers, similar to the position referred to in the initial post. The user making the initial post requests advice about the best doctors specialized in disc hernia surgeries for his suffering father. The reply offers this kind of information and also adds another treatment option, which the user could consider before selecting surgery. Requesting and offering information about doctors' abilities is one of the most common and popular subjects on medical forums, functioning as up-to-date patients' performance reviews. Users use this extended network to obtain information otherwise unavailable, as one's personal network has a more restricted coverage than that of an online forum.



Through the medium used and the actors involved, this is an account placed firmly in the lifeworld. The inquiry the forum user makes also addresses the lifeworld repertoire, specifically, informed opinions on the best surgical team for disc hernias in Romania. However, the fragment includes multiple references to a biomedical repertoire with the use of specific terms—polydiscopathy, microdisectomy, fibrillations. These representations of the “voice of medicine” act rather as auxiliaries to the lifeworld in this instance, providing easily identifiable labels for those with similar experiences and acting as domesticated signifiers of medical authority. The account generates a lay referral system meant to “vote” on the capabilities of surgical teams. Thus, the access to further biomedical treatment is mediated by the referral system of the lifeworld.

Extract I is itself an example of a disembodied mode of integration used to exchange healthcare information. However, it works to support and enhance the other two modes of interaction, interpersonal and institutional. Because the post is made by the son of a future patient, this medium indirectly impacts the treatment practices—thus, his interaction with the institutional medical environment—of a patient, through his interpersonal level of interaction. If this use of communication technology to obtain healthcare information would have been used directly by a patient—as it sometimes is—I could have argued that it is an indication of a reflexive and individualistic approach to treatment. However, as the patient’s son is the one making the request, the involvement of family and peers in a patient’s treatment is obvious, with the disembodied level of integration working to improve the face-to-face level. Furthermore, the user is not making a request for institutional knowledge, but for one based on previous experience of perceived efficiency. He asks forum members to evaluate their experience with similar surgeries or the recounted experiences of their peers and offer a rating of the best surgical team in Romania for disc hernia operations. The reply to the initial post cited here introduces a new subject: other possible treatments besides surgery, one which was expanded upon by other users in subsequent posts. The second user follows the request for a suggestion of the best surgical team in Romania as well as the first user’s desire that this would be made from personal experience. Using this personal experience aspect of the alternative treatment, she introduces a new theme for discussion, based on the self-trialing actions of family members.

This fragment shows the capacity of disembodied online accounts to generate new evaluative healthcare knowledge and influence treatment practices, even indirectly, through the actions and discourses of family and peers. Not only are the three levels of integration interconnected, but a clear hierarchy between these—as Ziguras argues—is not evident from the above fragment and a similar statement can be made for other discourses. These three modes of integration are used in concordance to a patient’s needs and values, with actors shifting between them constantly without interest in the structural differences between the three, or the character of the information obtained. In the daily experience of treatment, practical use is more relevant to patients than distinctions constructed from a scientific validity perspective.

## Extract 2—patient interview

*P: Medication, yes. Umm... at the beginning when I went there and I followed the diet for a month, two, three, don't know how long...ehm like it... three months I think I had..... or three I might have reached because I went to them and they found it good (I: Mhm). Then... I didn't follow the diet for long and they found me at 128, 100 and something, 130..... [The numbers are blood glucose levels] with no diet, only with pills..... But now, the last time I went .....76 or something like that...*

*I: Perfectly normal...*

*P: Yes, yes.....And.... now I don't know, I really...I want to figure out if truly walnuts have an effect, because then (I: Ooh) when I told the nurse she sneered [Romanian: a strâmbat din...] "Oh, I don't think so" (I: Ooh, you were eating walnuts then, yes) "Don't think" I don't know what, that ..eh. But I, treatment, I mean I have not followed a diet, just that I ate this and (I: Yes) it wasn't going down. Now, I want to see, I have to look in the wallet to see on what day I have to go, I think it's this month at the end ..... And that week, that week before... I will eat (Unintelligible).*

*I: But you can start now...*

*P: Yes, well I can eat now, tonight, I mean I can always eat, that's not the problem. But, I mean, and if truly that week I eat everyday five walnuts, (I: Yes) yes, and they find me again like this, it means that the walnut...is perfect. So, no more, they can sneer, they can do whatever, because no..... I won't believe. Now, I no longer told him [the doctor] when I went in the office (I: Yes) .... If I saw she sneered at it, I said "Never mind, I won't tell him anymore." He asked me, says "Well, ooh" says "You shoveled snow" (I: Yes, because it was..) says "from the effort, from I don't know what, because many that came here said they shoveled snow, they worked, I don't know what and from the effort the blood sugar drops." Well, I did because it was winter (I: Yes), but not that day or I don't know. Now we'll see truly what it is.....The effort or the walnuts.*

This extract is from an interview with a sixty year old man who had multiple hospitalizations after complications to a kidney stone surgery. Following one of these, he was discovered to have diabetes and began treatment. He recounts the beginning stages of treatment when he was prescribed medication, but also followed the recommended diet. Following this, his blood sugar levels reached normal values. Soon after, he stopped following the diet and he recounts his glucose levels while he was only taking medication. He continues with a moment closer to the time of the interview, when after eating walnuts following the indications of a magazine article, the test found his glucose levels within normal parameters. However, this coincided with the winter period, and the patient recounts that his doctor attributed the change to increased physical effort, as he had seen other similar situations in the same time frame. The patient appears unconvinced by the doctor's explanation, wanting to further test his own assumption about the effect of walnut consumption on glucose levels.

This conversation fragment shows that knowledge obtained by the patient through self-trialing practices is considered more valuable and trustworthy than knowledge provided by the representative of the medical profession, although the latter justifies

his assessment on experience with similar cases. After the nurse disagrees with the patient's finding, he does not contradict the doctor when the latter attributes the normal glucose levels to physical effort. Nursing staff is represented as more approachable in patients' discourses, at times working as mediators between doctor and patient. However, here the nurse does not agree with the patient, determining him to not pursue the subject further with the doctor. Using the nurse and doctor's reconstructed voices in order to present their comments, the patient distances himself from their assessments, while through the tonality he uses when recounting the nurse's words, he further portrays her disapproval. Here we have a direct "dialogue" between the "voice of medicine" and that of the lifeworld through the inclusion of the medical staff's direct speech. From the patient's account of the consult it appears that such a dialogue did not take place in the space where the "voice of medicine" directs and dominates the interaction, i.e. the doctor's office. Instead the patient takes it upon himself to test the perceived efficiency of the walnuts as an alternative treatment and enacts the dialogue between the two voices in the space of the lifeworld.

The perceived authority of doctors, along with their ability to pass judgments—diagnosis—on a person's health and use biomedical knowledge to restore it, is an attribute which appears to subvert the patients' intentions of openly discussing certain subjects. The patient is aware that his findings about the effects of walnuts on glucose levels are not the same as doctor's knowledge of factors, like physical effort, which influence the condition. This awareness does not make the finding less valuable to the patient—although he does not appear convinced by the consistency of the effect, considering his multiple false starts—as personal experiences seem to hold more relevance for treatment than institutional biomedical knowledge. This prospect is also supported by the example in Extract 1, where the user requests information based on others' similar experiences. Although in practice patients recount combining biomedical treatments and alternative ones without any ambiguities, at a discursive level the interpersonal level and the institutional level of integration are not perceived as compatible and are kept separate. Furthermore, the disembodied level of integration, represented by the magazine article which introduced the alternative treatment, is again used to expand and support the interpersonal level, similar to the previous example. Together, they are constructed as complementing biomedical knowledge from a patient's perspective, while for doctors' they often appear in opposition to it. As the next example will show, doctors perceive alternative approaches to treatment, or deviations from the prescribed biomedical treatment as evidence of a patient's non-compliance and lack of understanding of medical knowledge. The doctors' moralizing approach to patient practices could also be a reason for the latter's reticence at disclosing some treatment behaviors.

The professional-institutional level of abstraction represented by biomedical knowledge often seems to be filtered through the disembodied or face-to-face interactions individuals' recount. Representations of biomedical knowledge and treatments are sometimes accompanied in discourse by elements indicating an overlap with knowledge shared through lay referral systems and disembodied information. Furthermore, the recurrence of recounted delays in consulting a medical professional, as well as the use of multiple treatment options, show that patients compare biomedicine's perceived effi-

ciency and attainability with that of other health practices in terms of costs—which include financial (both formal and informal payments for healthcare) social, personal and emotional—and possible side effects. Thus, individuals resort to seeking a second opinion or a different treatment approach endorsed by significant others, and to modifying biomedical prescriptions in accordance to felt and perceived illness signs.

Extract 3 –interview with a specialist medical doctor

I: *Have you had it happen, I don't know, if you've met patients ... you give them a treatment, for a particular amount of time and they don't take it... (D: Yes) because...? Have they explained why, they refused, or just no?*

D: *No, they did not take it, pure and simple. Or afterwards they go to the family doctor and the family doctor who is not competent to modify their treatment, modifies their treatment.*

I: *And they prefer that one...*

D: *And they prefer that one and take it, and come back to the hospital... because "it still hurts, I still have this, I still have this" (I: well, why?) Well, why? "Did you take this treatment?" "No" (I: No) "Well why didn't you take it?" ..... Well... "It did not do me good"...*

I: *"It did not do me good," well how did it not do good?*

D: *Just like so, it did not do him good..... (I: Yes, hm)....It happens, often.*

I: *This is often?*

D: *Yes, depends, depends a lot on the patient, where he is from. If he is a patient from the countryside, it often happens.... Either he doesn't have money (I: Yes) to buy the medication which is expensive... Either he does not want to take them, either he doesn't follow .... Because besides treatment they get a series of recommendations. For cardiac patients, for example, to avoid physical strain, to avoid extreme temperatures,... uh.. hypo....sodic, hypolipidic, if he's a diabetic hypocaloric (I: Yes). But they.... That they can't give up the wine [Romanian: vinișor], they can't give up the brandy [Romanian: țuiculiță], that they.... they were. There was once a patient who really wasn't allowed to smoke anymore [Romanian: Domne'] no more smoking. He had the e-cigarette in his drawer... he showed it to me. What was I to do? Confiscate it? What was I to do? (I: Yes, of course).*

I: *They don't really follow the doctor's recommendations?*

D: *No. Only if they are super-conscientious.*

I: *Yes. Have you met any like that?*

D: *Yes ...*

I: *In general, have you noticed if it's women to respect them more often, or men... or?*

D: *It's not a... (I: It doesn't matter) No. It's about each person's kind, how much he wants to be alright and how much trust he has in what he is told at the hospital and not in what he read in Formula AS [a popular weekly magazine], or heard on the television, or some neighbor told him that she took (I: Yes).*

I: *Do many come in with, "I heard, I read that I don't know what would do me good"?*

D: *Plenty, plenty...*

I: *Yes? And with stuff from the Internet or these are ...*

*D: And usually they are young people. (I: Young people who do this) "What treatment did you take?" "Aspacardin"<sup>30</sup> "For how long?" "Six years."..... "Why?" "Well, I heard that it does good to the heart"..... "And since when have you had this pain?" "For four years." "And you stayed with the pain for four years?"*

The above fragment presents a cardiologist's discursive representation of patient treatment practices. The first issue he mentions regarding patient treatments is the misalignment with other medical professionals. He recounts that family doctors sometimes change a person's prescription and the patient ends up back in the hospital with the same untreated symptoms. Second, he recounts patients' non-adherence to treatment recommendations and how these sometimes depend on a person's social context. Medication cost and availability are mentioned as factors which sometimes limit patients from following the treatment. However, the doctor attributes most of the responsibility for treatment practices to the patient's personal attitude toward health and recovery, and one's individual sense of responsibility. He gives multiple examples of patients who, although suffering from conditions which require certain behavioral changes, still continue with these habits. Finally, I asked who is more likely to follow doctors' recommendations, and my respondent replied that it is less about gender differentiations but again, more a question of personal orientation toward health and the patient's trust in the biomedical information provided by physicians instead of the health information acquired from other sources.

This example is similar to those presented before in the patient accounts, in that here too there appears to be a discrepancy between the professional level of integration on the one side and the interpersonal and disembodied level on the other. As another respondent stated, doctors appear to be on one side of the barricade and patients on the other. The cardiologist recognizes his incapacity to make patients follow treatments but does not reflect further about ways of persuading his patients that biomedical approaches are more efficient than other treatments. I suggest that this is due to the lack of validity doctors attribute to treatment information procured from other sources. In this case, even family doctors are not considered qualified to alter a patient's treatment. Correct and complete knowledge about a particular affliction is considered to be an attribute of the specialist field, which commonly treats it. Interferences from outside the field are not constructed as legitimate or valid, even when they come from another category of experts. This account shows the doctor's resistance to other illness knowledge sources, an aspect not encountered in patient discourses, who did not construct the structural differences between the multiple sources of knowledge as problematic.

The respondent also brings up the issue of trust in the medical profession versus trust in other sources.<sup>31</sup> Based on the orientation of the whole interview and in particular on the use of the utterance "*how much he wants to be alright and how much trust he has in what he is told at the hospital,*" trust is constructed as stemming from the presumed validity of biomedical knowledge and, consequently, should be underlying all patient-doctor interaction on the basis of the latter's professional identity and cultural authority. However, this sits in opposition to patient perspectives who see multiple knowledge sources as being valuable. From a professional perspective, self-treatment practices

stemming from knowledge sources outside the medical field challenge biomedical authority and patients using such knowledge resources are represented in a moralizing perspective.

The doctor introduces the reconstructed direct speech of a “generalized patient” to illustrate the arguments brought forth by individuals who do not fully follow the prescribed biomedical treatment. Thus, responsibility for the patient’s health status is shared between the representatives of the “voice of medicine” and those of the “voice of the lifeworld.” Unlike patient accounts where the differences between the two types of knowledge represented by the two voices are not problematic, doctors construct the influence of the lifeworld on treatment as disruptive and ultimately hindering the healing process, rather than inherent to health-seeking and doctor-patient interactions. The “generalized patient” quoted in the cardiologist’s account appears to act irresponsibly, continuing with behaviors which aggravate the illness.

## Conclusion

**T**HIS ARTICLE has described representations of treatment practices in the discourses of Romanian patients and doctors in order to outline how the two main actors of the medical interaction construct the translation of treatment prescriptions into everyday actions. Both sides acknowledge the reorganization that biomedical prescriptions often undergo in order to be integrated into the daily lives of patients. However, perspectives diverge in regards to the value of lifeworld interventions in biomedical treatment. By analyzing accounts in light of the concepts of “voice of medicine” and “voice of the lifeworld” self-care discourses become examples of patients’ agency and reflexivity in the face of illness. Patients use multiple sources of health knowledge in resolving the illness episode, granting equal value to all until practice proves otherwise. On the other hand, doctors construct biomedical treatment options as the only valid care practice which patients should adhere to, and the ideal patient as one exhibiting unwavering compliance. Lifeworld interventions consisting of behaviors hindering or modifying biomedical treatment or other alternative practices are included in doctor discourses to exemplify a patient’s lack of responsibility in the face of illness, while similar behaviors are constructed as proof of responsibility and agency in patient discourses. A lack of open and direct dialogue between the two lead actors of a healthcare encounter works to amplify the differences in treatment discourses, producing lesser quality outcomes and increasing the distance between the enactment of biomedicine in the medical office and its translation into the context of the patient’s lifeworld.





## Notes

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### **Abstract**

#### **Representations of Self-care Treatment Practices in Patients' and Doctors' Discourses: Between Non-compliance and Agency**

Discourses about treatment reveal differences in the value and efficiency Romanian patients and doctors attribute to biomedical knowledge. Patients' accounts do not differentiate between the biomedical and alternative approaches regarding their perceived efficiency, while doctors view the former as superior. This article analyses discursive representations of self-treatment practices in light of the concepts of the "voice of medicine" and "voice of the lifeworld" coined by E. Mishler. This discursive approach highlights patients' agency and reflexivity toward treatment and doctors' disapproval of these same agentic constructions. For doctors the "voice of medicine" provides the only valid treatment option, with lifeworld elements interfering in the healing process. Patient representations of attempts to integrate and adapt biomedical treatments in the lifeworld are constructed by doctors as evidence of patient non-compliance.

### **Keywords**

self-care practices, self-care discourses, "voice of the lifeworld," "voice of medicine," discourse, agency