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***Refusal of medical recommendations:
bioethical and philosophical incursions***
DOCTORAL THESIS SUMMARY

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II. Keywords

refusal of medical recommendations, clinical bioethics, risk, therapeutic empathy, doctor-patient relationship, the person, ethical value, principle, quality of life, sanctity of life, informed consent, interpretative phenomenological analysis, irresponsible self-medication, patient objectification, anguish, medical decision, second medical opinion, trust in the doctor, subjectivity of perception, ethical dilemma of the Good Samaritan

III. Synthesis of main ideas

Introduction

The doctoral research debates, through a theoretical and an empirical approach, the implications of the Good Samaritan dilemma – it is about the distinction between obligatory and ideal beneficence – in the problem of refusing medical recommendations. In this context, we begin with the hypothesis according to which the attitude of the doctor and the way in which he will manage the moment of verbal expression of a medical refusal will have a decisive impact on the patient's subsequent behaviour towards the public health system, but also on the extent to which he will be compliant or not. Not taking into account the patient as a person, the reasons behind his refusal or his preferences will lead, in many cases, to non-compliance. If the doctor has poor management of the patient's medical refusal, this will shake the patient's trust. It may also lead to the radical breaking of the doctor-patient clinical collaboration, irresponsible self-medication, and distancing of the patient from the medical system.¹

A *bottom-up* approach is used in solving most cases of clinical bioethics: from case to theory. In poor ethical management – like in our case of the management of the medical refusal – a set of fundamental moral values specific to the context is overlooked. Therefore, the following two questions are fundamental to the research: *How can the patient gain the certainty that the doctor is acting in his best interest? What moral value is fundamental in the conduct in response to the refusal of the medical recommendation?*

The interdisciplinary and transdisciplinary approach of the present research aims both the theoretical and the methodological level. The theoretical part of the work is based on methods of interrogation and reflexive analysis specific to a philosophical approach². The second part of the thesis concerns an empirical study with a paradigm specific to narrative ethics – the interpretative phenomenological analysis, being a psychological type of approach in phenomenology.

The topic of refusal of medical recommendations is socially relevant in that Romania is among the first countries at European level in terms of irresponsible self-medication. On the other hand, the refusal of medical recommendations becomes even

¹See Jr. M. Lipkin et al "The Medical Interview: A Core Curriculum for Residencies in Internal Medicine.", 1984.

² Jaqueline Russ, *Methods in Philosophy*, (Translated by Vasile Tonoiu), 1999.

more relevant in the postpandemic context, when low vaccination rates against Covid-19 can be found in the Romanian geographical area. However, these issues are not only relevant in the Romanian context which is in our focus, but at the global level.

Summary of chapters

In the first chapter the aim was the theoretical explanation of the fundamental concepts and theories in order to make correlation with the present topic. The chapter is open by presenting the institutionalization of medicine, as the basis for the formation of a standardized approach³ on the patient in the clinical space. Michel Foucault presents, in his work *The Birth of the Clinic*, how the doctor-patient collaboration is deeply formalized due to the establishment of a medical jargon, often difficult to be explained to the patient. Language plays an important role in doctor-patient collaboration⁴ and therefore communication may be improved if the doctor speaks in the language used by the patient.

The clinical bioethics, to which the topic of the present research is subscribed, refers to the deontological aspects of the medical profession in collaboration with the patient.⁵ The protocols and guidelines of good practice of the clinical field are based on the four ethical principles formulated by Beauchamp and Childress (1994). Autonomy, beneficence and nonmaleficence aim the direct doctor-patient relationship; that is why, within the chapter, we focus on them. Some other elements of bioethics defined are: the concept of *person*, of *ethical value*, of *quality of life* and that of *sanctity of life*, the construct of *informed consent*. The concept of *person*, in the Kantian sense – of an individual capable of giving himself laws, is the intellectual foundation for the justification of a medical refusal. The moral value is part of the patient's motivation to express a certain decision in relation to the proposed treatment. *Quality of life*⁶ is a standard set by the WHO, World Health Organization, regarding the holistic level of health of an individual. *The sanctity of life*⁷ refers to the relationship of the patient to his own body in conjunction with the divinity. This concept is relevant to our subject because certain religious denominations impose some medical restrictions on their members.

³ Michel Foucault, *The birth of the clinic*, 2003, p. 110

⁴ Peter A. Peter A. Ubel, *Critical decisions : how you and your doctor can make the right medical choices together*. 2012 p. 61

⁵ Albert R. Jonsen, Mark Siegler, and William J. Winslade, *Clinical Ethics: A practical approach to ethical decisions in clinical medicine*, Seventh Edition, 2010, p. 1.

⁶ Stephen J. Walters, *Quality of Life Outcomes in Clinical Trials and Health-Care Evaluation. A Practical Guide to Analysis and Interpretation*. 2009, p. 2.

⁷ Maria Aluaş, *Medical Bioethics*, 2016, p. 33.

*Informed consent*⁸ is a construct established by law, which aims to provide the patient with the necessary context in order to be able to express his/her adherence to treatment or his/her refusal. The legislative demand to provide informed consent implies the responsibility for the doctor to offer clear information to the patient on his/her decision in an accessible language.

The issue of medical refusal is approached traditionally from two opposing theoretical perspectives of the morality origin in the decision-making process: the consequentialist perspective⁹ or that of the theories of respect¹⁰. On the other hand, in the context of a *top-down* ethical approach¹¹, there is no real collaboration between the doctor and the patient through a mutual exchange of values and information. In addition, ethical disputes can also arise because of *the prima facie duties* that David Ross talks about¹². Subjectivism inevitably appears in applying ethical theories that have a general character to a case. These issues may be solved through a *bottom-up* ethical approach¹³, when the ethical principles and moral values involved are inferred from a case.

In its early days, phenomenology was defined as a logical science (method) concerned with what things are themselves and which tries to present the subjectivism of consciousness in an objective, scientific, way.¹⁴ Two of its important stages are *the epoché* type reduction¹⁵, which involves putting in parentheses the researcher's bias and *the transcendental intersubjectivity*,¹⁶ which involves observing the traits that common to a certain type of experience. In order to be able to practice phenomenology, it is necessary to rid ourselves, as Martin Heidegger points out, of the natural attitude because the object itself is not observable to the fleeting gaze.¹⁷ Maurice Merleau-Ponty, however, brings to our attention the fact that the viewer will always be immersed in the world and we cannot have real scientific data that does not come from a human viewer.¹⁸ Thus, phenomenology

⁸Bruno Halioua, "Du procès au code de Nuremberg : principes de l'éthique biomédicale" In : Emmanuel Hirsch (ed.) *Ethique, médecine et société. Comprendre, réfléchir, décider.* 2007, p 159

⁹Philip Petit, "Consequentialism," In: Peter Singer, *Op. Cit.*, 2006, p. 259

¹⁰See M. Gochner, "Refusal of Medical Treatment: Taking Respect for the Person Seriously.", 1987.

¹¹Tom L. Beauchamp and James F. Childress, *Op. Cit.*, pp. 391-397

¹²Peter Singer, *Treatise on Ethics*, 2006, p. 249

¹³*Ibid.*, pp. 397-401

¹⁴Edmund Husserl, *Cartesian Meditations: An Introduction to Phenomenology*, 1994, p. 104

¹⁵Massimiliano Tarozzi and Luigina Mortar, *Phenomenology and human science research today*, 2010, pp. 27-28

¹⁶Edmund Husserl, *Op. Cit.*, 1994, p. 126

¹⁷Martin Heidegger, *Ființă și timp*, (Translated by Gabriel Liiceanu and Cătălin Cioabă), 2003, p. 47

¹⁸Maurice Merleau-Ponty, *Phenomenology of Perception*, 1999, p. 14

becomes the logical infrastructure on which the humanities can be based¹⁹ within which the phenomenological paradigm is used in research. The researcher adopts the phenomenological attitude as a continuous dance between phenomenological reduction and reflexivity. In this context, he approaches the study with the eyes of a novice, trying to look at the participants' experience from their perspective. In the empirical approach of the current research we are concerned with clarifying how the world around the research participants is constituted and how they give meaning to the experience lived by themselves.²⁰

In the second chapter, we present a few approaches from which the patient can be viewed in the clinical space in relation to the issue of refusal of medical recommendations. Thus, the first types of collaboration between doctor and patient were paternalism²¹ and consumerism²². The negative side of the first relational model was that, regardless of whether or not the patient was informed about the medical decision, the doctor was considered able to discern the best patient's interest and, therefore, his decision was always followed. Consumerism – also called the informational model – emerged as a reaction to the lack of autonomy of the previous one. In this context, the patient considered the doctor just a technician and a source of information, going so far that the doctor could not give advice to the patient in order to restrict his/her autonomy. In Romania, there was a rapid evolution of doctor-patient relationship from paternalism to consumerism and then to deliberative models, with the change of the political regime in 1989. The signing of the Copenhagen Convention, with its three amendments, represented an important step in the evolution of the medical system, the reform of which was continued by the introduction of Law nr. 95, published in 2006.

In order to establish the hypotheses of the present research, a short introductory study on the perception of resident physicians on the collaboration with patients who express their refusal of medical recommendations was carried out.²³ The study of the second chapter revealed the hypothesis according to which patients may go from medical refusal to irresponsible self-medication if they go through contexts in which the attending doctor does not take into account their personal values and fails to propose medical prescriptions

¹⁹Jean-François Lyotard, *Phenomenology*, 1997, pp. 45-49

²⁰Stuart J. Murray and Dave Holmes, "Interpretive Phenomenological Analysis (IPA) and the Ethics of Body and Place: Critical Methodological Reflections." 2014, p. 17

²¹Liviu Oprea et al., *Doctor-Patient Relationship*, 2013, p. 58.

²²*Ibid.*, p. 58.

²³ See Andreea-Iulia Someșan: "Non-compliant patient - ethical views", 2018.

that meet their expectations. As the study revealed, there are many cases in which the doctor is preoccupied just with the fulfilment of the norms and laws, by simply giving the form to the patient for assuming his/her medical refusal. However, these attitudes reinforce the decision of the patient, who does not accept to follow the proposal of the attending doctor, but informs himself from alternative sources. The underlying aspects of non-compliance can vary greatly in terms of their nature; we are talking here about social, economic and, cognitive factors (knowledge or ignorance in front of risks), psycho-emotional, religious aspects, etc. The sets of value that underlie the medical decisions are deeply rooted in the psycho-emotional life of the individual. This is a justification for bringing into discussion the relevant ethical values and principles from the perspective of the proposed topic.

The concept of *non-compliance*²⁴ designates an attitude of deviation of the patient from the recommendations of the attending doctor. The term *adherence to treatment* is more used²⁵ in literature to suggest the active role of the patient in the clinical doctor-patient collaboration. Refusal of medical recommendations is the expression of the intention (verbally or written) not to follow the doctor's recommendation.

The current Romanian medical context highlights the persistence of a conflictual and unfavourable perspective towards the medical system: Romania is on the top position in Europe in regards of irresponsible self-medication.²⁶ Irresponsible self-medication is a subject of interest because it can have undesirable consequences: the degradation of the patient's health and the negative impact on the marketing of medical services. Our presumption is that in the transition from medical refusal to irresponsible self-medication, the following steps may appear: (1.) Formulating a medical recommendation that is not in accordance with the patient's preferences; (2.) Verbal expression of refusal; (3.) The lack of a dialogue aiming the patient's values; (4.) Information from unauthorised sources; (5.) Accentuation of distrust in the doctor and in the public health system; (6) Recourse to irresponsible self-medication.

Then, we refer to three types of refusal, being about contexts with a strong psycho-emotional impact on the patient. The first one is the refusal of prophylactic treatments:

²⁴ Al. Secăreanu și T. Neamțu, *Compliance terapeutică: Coordonate medicale și psihologice*, 1996, pp. 8-9

²⁵ David B. Resnik, "The Patient's Duty to Adhere to Prescribed Treatment: An Ethical Analysis.", 2005, p. 168

²⁶ Alexandrina Constantinescu, "Automedicația la români.", 2012, p. 54

here the anguish appears in relation to the possible impairment of the quality of life. The second one is the refusal in the context of an undesirable existence: it leads to an anguish induced by the certainty of the impossibility to change the quality of life for better. And, finally, it is about refusal based on personal duties and beliefs: the transgression of the rules imposed by the *Superego* generates anguish. These three typologies of refusal reveal the fact that behind a medical refusal there may be reasons that come from other spheres of the patient's existence, which, most of the times, remain foreign to the doctor merely preoccupied with fulfilling his obligations by the protocol.

F. Svenaeus²⁷ talks about the descriptions in first-person that come to complete the causal explanations deciphered by the doctor, giving a personal meaning to the state of illness. Based on these, the doctor could come up with a medical alternative that will be acceptable to the patient from the perspective of his values. Then, it is important for the doctor to be aware of the relevance of the phenomenological perspective that T. Fuchs²⁸ brings to the emotions because they have an always intentional aspect, being oriented towards values; they are inseparable from the patient's decision. In this context, the affect is pre-given because there is no need for a specific cause of its existence; although it influences the decisions taken.

The third chapter concerns the empirical research, which had the purpose of highlighting the patients' feelings regarding the poor ethical management of their verbally expressed medical refusal. The study was conducted with the agreement of the *Center for Lifestyle and Preventive Medicine Herghelia*. The three participants in the study are the following: the respondent of the 2B questionnaire is Beatrix (infected with *Staphylococcus aureus*, she refuses medical prescriptions many times), the respondent of the 7G questionnaire became Georgiana (she refuses the recommendations on thyroid cancer and a gall surgery) and the respondent of the 11K questionnaire is named Karoly (patient with food deficiencies, he refuses psychiatric consultation).

The conduct of the study involved the following steps: providing questionnaires for sorting the possible participants in the study; signing of the individual participation agreement after studying the research information; conducting the practical exercise – an activity named *Scribble drawing therapy*²⁹; and, finally, the participation in the interview

²⁷Fredrik Svenaeus, "A Defense of the Phenomenological Account of Health and Illness", 2019, pp. 459–478.

²⁸ See Thomas Fuchs, "The Phenomenology of Affectivity.", 2013.

²⁹ See Carolyn Mehlomakulu, "Scribble drawings for relaxation." 2013.

itself. Each of the mentioned stages of the study took into account the fulfilment of specific objectives in order to achieve the goal set for empirical research: to analyze the patients' experience/embodiments lived in the context of verbal expression of medical refusal. Thus, the following objectives were targeted by offering questionnaires: obtaining demographic and quantitative data about the participants, as well as receiving the agreement for participation in the next stages of the study, after reading the documentation. The practical exercise, *Scribble drawing therapy*, aimed to remember the lived experience and building a relationship of trust between the participant and the researcher. And the interview, the essential part of the empirical study, supposed that the participants expressed in their own words the experience lived in the context of verbalizing the medical refusal in front of a doctor.

The interview was conducted according to the method of interpretative phenomenological analysis (IPA)³⁰, being a semi-structured type of interview, with in-depth questions. Within it, a limited number of cases are used (3-6) and attempts are made to find recurrent patterns/themes during the interview. The researcher who works with this paradigm, although he will still remain influenced by his subjectivism, is preoccupied with finding the meaning of the participants' experience from their own perspective. Therefore, the fundamental question of the phenomenological approach proposed by this research would be the following: *How do the patients experience the doctor's attitude in response to their medical refusal?* In order to conduct the semi-structured interview, 12 questions were formulated in which the main issues targeted during this research were structured.

Beatrix and Karoly have largely the habit of self-information and self-medication. Moreover, Beatrix sees autonomy as being an important principle. For Georgiana, the principle of the sanctity of life plays a significant role, as well as the duty to the family. With a behavioural tendency similar to that of Beatrix, Karoly suggests that the doctor's attitude towards the patient must take into account the respect for the person's dignity. Then, even though respect is important, the effectiveness of the treatment is the most important to Karoly and it can outpace the aforementioned aspects. After the presentation of each interview, we summarized the participants' experiences and attitudes in certain similar trends and behavioural differences, trying to provide a global perspective on the results. Thus, there is, predominantly, about some experiences of: sadness, fear and

³⁰ See Linda Finlay, *Phenomenology for Therapists. Researching the Lived World*, 2011.

disgust. However, Georgiana and Beatrix talk about the joy and hope of meeting doctors with different approaches, specific to alternative medicine. Then, Karoly mentions sensitivity as a feeling of vulnerability in relation with the doctor who sometimes does not treat him as a human being.

According to the data provided by the three interviews, the doctor has, in general, a paternalistic, consequentialist oriented approach, insisting on the treatment scheme or procedure with the most chances of success from a medical point of view. In this context, the doctor's unavailability to listen to the patients' personal values and preferences appears which is why the patient feels more like the object of medicine than the patient receiving an adequate medical care. In order to emphasize the experiences lived in the context of verbalization of medical refusal, patients use several metaphors and analogies regarding the type of doctor-patient relationship: *as a child*, *as a number* (Beatrix), *as animals* (Karoly).

The patients' concerns during the medical decision refer to the following aspects: the effectiveness of the treatment itself, the observance of the personal vision and values, the observance of the deliberative capacity of the patient, the doctor's empathy towards the particularities of the personal case. Patients value the following aspects as ethical principles: affirmation of autonomy, trust in the doctor and empathy of the doctor. However, the interviewed patients mention some unethical behaviour of their doctors in relation to the expressed refusal: annoyance (Beatrix), indifference (Georgiana), irony and disregard (Karoly). The doctors that the patients are talking about were working in the public health system, from where the distrust towards this form of organization of medicine appears. Therefore, patients express a greater preference and confidence towards doctors working in private or towards medical centers that practice alternative medicine.

The purpose of the fourth chapter, the final one, is to analyze the ethical-philosophical recurring topics in the patients' experiences of refusing medical recommendations and identifying an essential ethical value in the amelioration of its ethical management. A first topic suggested by the metaphors and analogies of the interview participants is the objectification of the patient, which is a philosophical construct that appears based on of over-technological surrounding. Günter Anders talks about the alienation of the individual who fails to remain "up to date" in rapport with the

objects produced by himself.³¹ In the medical context, objectification is in the first instance the result of standardized medicine. The "third person" approach on the patient according to a non-personal perspective supposes limiting it to a series of parameters and data provided by biotechnological devices. The body becomes an asset in the commodity market, and health is also a tradable good.

Thus, the anguish that appears in the medical space has as its source precisely the excessive development of biotechnologies whose intrusion into human life can no longer be controlled. Sigmund Freud³² talks about the Ego's trials to bring the outer world into harmony with the Superego and the Self. In the event of a failure to harmonize them, a type of anguish appears: anguish in the face of real danger, moral anguish or neurotic anguish. Analyzing the medical refusal by the three typologies mentioned in the second chapter, there will become observable the appearance of anguish which is translated into the patients' experience as an abhorrence to live a similar experience in the future. The patient's anguish concerns the extent to which he/she perceives whether or not he would have control on the outside world and the quality of his/her future life. On one hand, previous personal experiences with certain medical professionals, the stories circulating in his entourage, those in the media or social media can contribute to the development of mistrusts in front of the public health system. On the other hand, the language gap leads to an increase of the patient's anguish because he does not even have the words necessary to explain his refusal.³³

The over-technologization brings us to the reality of the risk society, an aspect of which the patient is not always aware. Thus, no matter what medical decision the patient will take, his/her option is exposed to a certain degree of danger: that of the disease itself or that assumed by following the treatment scheme. Most of the time, the individual looks at the individual risk and ignores the reality of the venture society in which we talk about the need to take a collective risk in order to reduce the real dangers at the level of society. Besides the fact that the patient wants as little as possible to take risks in his/her decisions, he/she tries to extend his autonomy as much as possible.

The paradox of autonomy arises by recognising the limits of independent autonomy by rapport to the autonomy gained through the deliberative process. This subchapter will

³¹ Anders Günter, *L'obsolescence de l'homme*, 2002, p. 30

³² Sigmund Freud, *Operas vol. 10, Introduction to Psychoanalysis*, 2004, p. 525

³³ Ivan Illich, *Medical Nemesis. The Expropriation of Health*, 1982, p. 62

prove that information from unauthorised sources is uncertain and full of risks, this not the path that will lead to knowledge. But, as in *The Myth of the Cave*, the patient needs a mentor or a counsellor to direct knowledge, exposing information that runs counter to evidence-based medicine.³⁴

The doctor still has the legal and deontological obligation³⁵ to respect the patient's right to a second medical opinion. But some confusion may arise precisely because there is possible to be discrepancies between the first and second medical opinion. The approaches of different medical specialties or different practitioners may differ, without there being, *de facto*, a correct medical approach and a wrong one. Moreover, this context reveals the importance of developing trust in the attending doctor because the patient's decision is based on it for the choose one of the two doctors in following a therapeutic scheme.³⁶

Instead, the doctor is faced with an abyss that targets the patient's feelings in relation to his medical decision. The patient is influenced, in the medical decision made, by the entire sphere of his/her existence – family, religion, etc. This surrounding world does not represent objective reality, but is *his/her surrounding world only to the extent that he/she knows it, coming into direct contact with it, as he/she understands it by its apperception*. In this context, the question for the doctor is: How is to be the patient who has to make a medical decision? That happens because often some aspects of the patient's personal sphere remain foreign to the attending doctor.

This abyss can be overcome only by cultivating an empathetic attitude towards the patient, as the patient himself expects. Michel Slote is among the promoters of empathetic altruism: empathy, although distinct from sympathy, presupposes a sense of warmth, of interest in the other.³⁷ Therefore, empathy is a moral value in the ethics of care – our argument is that it can be cultivated / learned. Nevertheless, we have to mention that it cannot constitute a system of ethical decision-making, although it is an essential value in the ethical management of the verbal refusal of medical recommendations.

The end of the chapter deciphers how empathy can play a significant role in doctor-patient collaboration in the context of medical refusal. Thus, we bring to attention the

³⁴ Oprea et al., *Doctor-Patient Relationship*, 2013, p. 60

³⁵ See *Code of Medical Deontology*, 2017.

³⁶ Edmund D. Pellegrino and David C. Thomasma, *Virtues in Medical Practice*, 1993, p.66

³⁷ *Ibid.*, pp. XXVI-XVIII

potential of therapeutic empathy as a moral value of the doctor-patient relationship.³⁸ An unexpressed expectation of the patient is that the doctor will show empathy for his case. Therapeutic empathy is an intentional act oriented towards the other and it has a pre-reflective character, assuming an immediate recognition of the other as another person. The doctor would go through the following stages in the manifestation of therapeutic empathy: (1.) contemplation and comprehension of other's emotion; (2.) transforming these apperceptions into an empathetic attitude oriented towards the patient.

Conclusions

The philosophical discourse of the ethical dilemma of the Good Samaritan in the context of clinical bioethics reveals the fact that, in medical practice, beneficence is not limited to the literal observance of the legislation, of the *Code of Medical Deontology* and of the protocols, but it involves the cultivation of a therapeutic empathy in relation to the patient. This is in line with the observance of the amendment of the *Code of Medical Deontology* on the continuous improvement of the moral conduct of the doctor. This implies the integration into clinical practice of an attitude that favors listening to the way the patient experiences, in the first person, the disease and the medical decision.

Our empirical research has revealed that, to the extent that the patient feels the doctor's empathy for his personal worries, he will be more inclined to maintain clinical collaboration and perhaps even adhere to treatment. Based on the empathy he perceives from the doctor, the effectiveness of the treatment and the comprehension of the language used, the patient will choose to collaborate with a particular doctor.

³⁸See Valeria Bizzari et al.: "Defining therapeutic empathy: the philosopher's view." 2019.

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