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Special Issue

March 2013

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Special Issue

ETHICAL ISSUES IN CLINICAL AND CULTURAL CONTEXT

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EDITORIAL:

ETHICAL ISSUES IN CLINICAL AND CULTURAL CONTEXT

DANIELA-TATIANA AGHEORGHIESI¹, ANDRADA PÂRVU²

In the 21st Century, health care professionals all over the world are faced with situations that rise serious ethical challenges; some of them could be solved involving the knowledge and collaboration of legal professionals, psychologists, social services or clergy. Contemporary medicine is centred on patient's autonomy and rights, as well as on health care models provided by multidisciplinary teams, adapted to the patient's needs and specificities. All these issues are challenging the Romanian health care deciders to draft better policies and medical staff to improve their services.

This supplement of *Studia UBB. Philosophia* aims to gather a broad spectrum of empirical and theoretical research focused on the role of moral values and on ethical issues in the realm of health care and public health policies in Romania. The papers are focused on complex, multi-dimensional and interdisciplinary models of care, some of them related to cultural patterns. Also, the management issues of care system and ethics programs implemented in hospital institutions are approached.

Important challenges for medical staff in nowadays Romania are represented by *ethical issues in clinical and cultural context*, like communicating the severe diagnosis, the patient's access to medical information, respecting the patient's autonomy, patient's access to medical services, and substance misuse and addiction. In order to offer high standard health care to chronic patients, the medical personnel must address the patient's psychological needs and enhance its cultural competence for a better understanding of the ethnic minorities.

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In this context, end-of-life care and making decision is one of the most important bioethical problems. Dying patient are a vulnerable population and their rights must be protected. In Romania, palliative care services are insufficient and legislation regarding end-of-life issues is deficient.

Another problem rises at the very threshold of clinical and cultural context: the healthist ideology, a socio-cultural phenomenon which has consequences like the presence of medicine in everyday life, self-medication, new types of health practitioners, or the growing social anxiety in connection with health, illness and medicine.

Another important issue, both for practitioners in health and social services and for the political deciders, is substance abuse and addiction. The widespread biomedical model has positive and negative aspects. Medicalisation (pathologization) is not always the best solution for helping these people. The approach of the addictive behaviour must be therefore multidisciplinary, culture-adapted, and opened to alternative solutions. In the Romanian integrated service system for consumers of psychoactive substances, case management is considered a key procedure. However, reports shows that the degree of integration is low and case management is barely functional. In conclusion, in order to a better management of the substance abuse, there is a need to develop a social level kind of case management in order to increase the social responsiveness to the issues of substance abuse.

For all that, the problem of addiction cannot be studied without making strong sense of reality of the Internet, which can be “enemy and ally” while solving the problem. Two relevant researches bring into focus the power of the internet in this way, the impact on young people. This force, if properly understood, could be avoided or used in a positive way. First at all, the impact of Internet use has been investigated by a qualitative research, aiming at analyzing the current experience as Internet users of 20 Romanian adolescents of 15-16 years old. The results could contribute to a better understanding of the development of the excessive Internet use or addictive behaviours of adolescents. Moreover, the role of virtual communities of students, as important tools in supporting the post-treatment of persons with substance addiction is the subject of an extended comparative research.

We hope that the papers included in this issue will help extended medical care teams, which include not only physicians and nurses, but also psychologists, social workers, spiritual counsellors and so forth, to better understand their patient’s needs and rights and to provide high quality efficient services.

OBSERVANCE OF PATIENT RIGHTS IN ROMANIA. RESULTS OF A PILOT STUDY

ANCA BOJAN¹

SUMMARY. Romania was situated in next to last place in the European Report on “The Empowerment of the European Patient – Options and Implications”, due to the deficits in all analysed areas (patient’s rights, information, health technology assessment – HTA and financial incentives). Two important areas studied in the Report were patient’s rights and their access to information. In Romania, these areas fall under the incidence of Law nr. 46/2003, The Patient’s Rights Law.

The article reveals the results of a pilot study conducted in Cluj-Napoca Hematology Clinic that has the purpose of evaluating the acceptance of patient rights regarding diagnosis communication, observing the confidentiality of medical information, patient access to medical information. The study also has an aspect with regard to coping of patients with chronic conditions, as part of which we present as the results of the Hospital Anxiety and Depression Scale.

The results indicate that the majority of patients know their diagnosis and have access to medical information, although some patient right infringements do exist, preponderantly in the area of confidentiality and communication with the patient’s family.

On the basis of this study a number of seminars for physicians can be conceived to further the knowledge and application of patient rights in practice and on the other hand informational campaigns for patients regarding their rights.

Key words: patient rights, confidentiality, diagnosis communication, access to medical information

Introduction

With the formulation of the principles of Human Rights in the first half of the previous century, the foundation for the development of patient rights had been laid. The same period saw a change in the approach healthcare professionals took

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to patient care from the paternalist to patient centered medicine, the patient's right to information, patient participation in the decision-making process (1, 2).

Currently, the European Union desires to achieve a standard regarding patient rights, the sharing of medical information with the patient, their access to health care services and the finance of each member country's healthcare services. To this end, starting in 2004, The Health Consumer Powerhouse, a partner of the European Commission issues a regular report "The Empowerment of the European Patient – Options and Implications". The objective of this report is evaluating 18 indicators grouped in four categories (patient's rights, information, health technology assessment-HTA and financial incentives). Evaluation of these categories supplies an image of patient care in a number of healthcare systems in different countries of the European Union. The information collection process is also centered on patient involvement in medical decision-making and individual responsibility (patient's power) in each country's healthcare system. The motive behind this 'European patient barometer' is to offer each European State recommendations to improve their healthcare policies. The latest Report, which was based on analysis of data from 31 countries (The European Union members plus Norway and Switzerland and the candidate countries) was published in 2009. Of the four categories the Report was centered on, the greatest emphasis was placed on patient rights and the offering of information to patients (3).

One of the report's conclusions was that most European Union countries experience a gap between the political theory and the reality the patients are faced with, lack of patient information can restrict patient access to medical services and the chances to take active part in healthcare or the therapeutic process.

Romania is situated in a worrying position (next to last, just before Bulgaria) in the general ranking of this Report in the four mentioned fields. The first three positions being occupied by Denmark, Germany and Switzerland.

In the "Information to patient" category, Romania is situated in position 20-24, tied with Switzerland, Luxemburg, Cyprus, Spain and Croatia, the best positions being occupied by Denmark and Sweden. The evaluation was based on patient's access to their own medical documents, to information regarding their illness, to catalogs containing the specialists in the medical system, to non-stop information phone lines and to information on the medical treatments in layman's terms, without jargon (4).

¹ Health Consumer Powerhouse. *The Empowerment of the European Patient 2009 - Options and Implications*. Available at: <http://www.healthpowerhouse.com/files/EPEI-2009/european-patient-empowerment-2009-report.pdf> (Accessed on 23.11.2011).

² Fong Ha J, Longnecker N, "Doctor-Patient Communication: A Review", *The Ochsner Journal*, vol. 10/2010, p. 38–43.

³ Health Consumer Powerhouse, *Ibidem*, 1.

⁴ Health Consumer Powerhouse, *Ibidem*, 1.

In the “Patient’s rights” category, Romania was situated in 22-27th position, tied with the United Kingdom, Ireland, Croatia, Spain and Macedonia, the first position being occupied by Switzerland, and the second a tie between Slovenia, Latvia and Luxemburg.

The Report states that the countries situated in last positions failed to implement patient rights recognized by law, restricted or obstructed patients’ rights to second medical opinions or to take possession of their own medical documents. In Romania, these rights are recognized under Law nr. 46/2003, The Patient Rights Law, art. 11 and 12, a vital law in the medical field (5). The Romanian patient’s right to information regarding their illness, treatment and prognosis is recognized in art. 6 of the aforementioned law: ‘The patient has the right to be informed about their state of health, of the medical procedures proposed, the potential risks of each procedure, of the alternatives to the proposed procedures, including forgoing treatment as well as information on the diagnosis or prognosis.’(6) The patient’s right to stem the flow of information and to name a proxy for communication with the physician is also recognized in art. 7 and art. 9 ‘The patient has the right to decide if they desire to be informed in case the information presented by the physician might cause them suffering’, ‘The patient has the right to explicitly demand not to be informed and to choose a proxy to be informed in their place.’ (7) The same law also recognizes patients’ right to confidentiality of medical information, art. 10: ‘The patient’s family and friends can be informed about the tests, diagnosis and treatment with the patient’s approval’. (8)

Another important right is the option to refuse a test or treatment, informed refusal, as stipulated in art. 13: ‘The patient has the right to refuse or stop the medical procedures they are undergoing by claiming in writing responsibility for the consequences; these consequences must be explained to the patient.’ (9)

In conclusion, Romanian law is centered on patient autonomy and maintaining the confidentiality of medical information that cannot be revealed to third parties without the patient’s approval.

Based on the results of the European Report revealed in this study and from the conclusion that the Romanian patients are among the least informed in Europe, we decided to attempt this transversal prospective study on the knowledge and observance of chronic patient rights and the influence that the infringement of these rights might have on psychological coping.

⁵ Law nr. 46/2003, Patient’s Rights Law, available at: http://www.dreptonline.ro/legislatie/legea_drepturilor_pacientului.php (accessed 20.08.11).

⁶ *Ibidem*, 5.

⁷ *Ibidem*, 5.

⁸ *Ibidem*, 5.

⁹ *Ibidem*, 5.

This article is intended to reveal some preliminary results of a pilot study done on patients admitted and treated in Cluj-Napoca Hematology Clinic.

Materials and Method

The patient selection criteria were: age of over 18, expressing consent to participate after receiving explanations about the study, patients with malignant hematological diagnosis that were known and well established, diagnosed at least 3 months in advance. The exclusion criteria were: patients that refused to participate. The subjects included in the study were randomly chosen from the patients admitted and treated in the Hematology Clinic Cluj-Napoca.

All patients signed the informed consent form devised for the study. The patients were administered a semi structured interview based on following topics: knowledge of the diagnosis and understanding it's severity, knowledge of The Patient's Rights Law and the rights it confers, the manner of diagnosis communication and observing the legal aspects of doctor-patient communication, access to their own medical information, to a second medical opinion, possible interference from the family in doctor-patient communication, in the decision-making process, refusal of a medical test or treatment. The patients were also administered international tests to assess quality of life (EORTC QLQ-C30), psychological coping (COPE, MAC), anxiety and depression (HADS- Hospital Anxiety and Depression Scale).

The interviews and questioners were conducted between March and November 2012 by a neutral person, with a background in social and human sciences. The language used was neutral and medical jargon was avoided. Patients were granted the right to interrupt the discussion, questioner or test and even to opt out of the study in the event that they should feel any adverse effects.

The Methodology of the study, the Informed Consent Form and the interview topics were approved by the Ethics Comity of UMF "Iuliu Hațieganu" Cluj-Napoca.

The data was processed both qualitatively and quantitatively using Microsoft Excell and SPSS.16.

Results and Discussions

All approached patients consented to be a part of the study, there were no situations of consent being withdrawn. Of the 33 patients included in this pilot study, 22 were male and 11 female with ages between 18 and 79. 15 patients were from an urban environment and 18 were from a rural environment. 52% of the patients had a high school education, 24% had elementary or intermediate education, 15% vocational school and 9% had a higher education.

We will now reveal the study results that have to do with the moment of first learning the diagnosis and the infringement of some patient rights and ethical principles regarding the disclosure of the diagnosis.

All patients interviewed knew their diagnosis, even if they did not offer the medical nomenclature of the illness, they demonstrated that they were aware of the severity of the illness or the malignant diagnosis. When asked if they had wished to learn the diagnosis, 9% of the patients answered that they did not, and still they knew it, which points to a lack of observance of patient rights, as the latter can refuse to be informed about certain medical situations.

When they were asked to name the source of the information (diagnosis), approximately 75% of the patients answered that their doctor told them. 3 patients read the diagnosis on medical documents, without finding out from the attending physician, one patient learned of their diagnosis from a nurse, and another patient learned their diagnosis from another source. 25% of patients learned their diagnosis from another source than their attending physician, as indicated by other research (10) that also indicate that these patients may lose their trust in their attending physician, choosing other sources of information as their disease progresses. Also, these patients can obtain false information from other sources that can decrease their compliance to treatment.

The questioner contained a number of questions about the moment of communication of the malignant diagnosis, as this was a moment of great psychological impact. To start with, the patients were asked if they had desired to learn their diagnosis. Some 25 patients were told of their diagnosis without being asked if they desire to learn of the illness they were suffering from, which represents a breach of their rights. Knowing the diagnosis is a right the patients have, not an obligation. According to art. 6 and 9 of The Patient Rights Law (quoted in the theoretical part of this article) the patient may refuse certain medical information that could potentially cause suffering and can assign a proxy for communication with the physician.

Another part of our research was on the details the doctor offered to the patient upon communicating the diagnosis. Patients have a right to know these details, as they are even stipulated in the Health Ministry's Informed Consent which is signed upon admittance by all patients in this study. As revealed in Chart nr. 1, 9 patients were not informed about the proposed procedures, 12 were not told of the risks of the medical procedures proposed, 15 were not informed about the therapeutically alternatives that may or may not exist, 17 were not informed about the risks of not complying with treatment and 12 patients did not receive information on the prognosis.

¹⁰ Pârnu, A., *Optimization of blood transfusion (creating a predictive model for the necessity of transfusions and psychological counselling of leukaemia patients)* [PhD thesis], Cluj-Napoca: University of Medicine and Pharmacy, 2009.

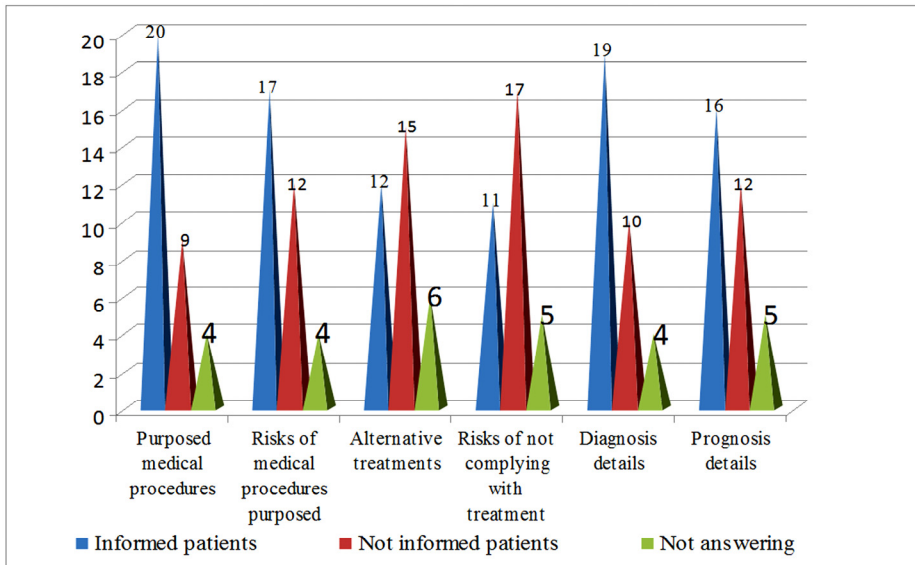


Chart 1. The number of patients informed about different aspects (on the horizontal axis)

Another section of the interview was centered on diagnosis confidentiality, specifically the fashion in which the patient's family and friends learned about the diagnosis. Contrary to the provisions of Law nr. 46/2003, 63% of the patients were faced with the physician communicating the diagnosis to family without asking permission to do so. Only 3 of the 33 patients in the study were asked to express their consent for the physician to divulge the diagnosis to their family. When asked what they thought of their family learning the diagnosis, most patients thought it was a beneficial idea. There were however 5 patients that did not feel comfortable about their family finding out the truth about their illness, admitting that family should be informed only with the patient's permission. When asked what the ideal method family should learn of the diagnosis 57% of patients felt that the doctor should be the one to inform them, with the patient's consent, and 40% felt that the patient should be the one to inform the family of the diagnosis.

The communication of medical information to the family of the patient is also covered in the Romanian Doctors' Association's Ethics Code, where all information pertaining to illness is considered professional secret, and communicating the diagnosis to family without the patient's consent is considered a breach of professional secret (11).

¹¹ Romanian College of Doctors. The medical deontology code. Available at: <http://www.cmb.ro/legislatie/codulDeontologic/cod.pdf> (accessed 20.09.10).

In this study we have also touched on the problem of patients' access to medical information, especially the medical procedures done during hospitalization, as this problem is also underlined by the European Report that we have made reference to in the theoretical part of this article. 78% of patients answered that they have access to medical papers. When asked if their families should have access to the patients' medical documents 70% answered affirmatively, independent of patient consent, and the other 30% answered affirmatively provided the patient is in agreement.

At the end of the interview the patients were asked if they knew about the existence of a law in Romania that defines their rights and, if so, how did they come to find out about this law. 55% answered that they had found out about the existence of this law, mostly from the media. A minority declared that they had found out from other patients or from posters.

The data presented reveals that there are certain aspects that could be improved upon regarding physicians' knowledge of patients' rights and applying them in practice and regarding patient information. These results concur with the ones observed in the European Report, where Romania was situated in the second half of the ranking in these fields.

In this pilot study we interpreted Hospital Anxiety and Depression Scale for each patient as standardized psychological state measurement instruments. Test interpretation situates patients in the normal limits, bordering on abnormal or in the pathological category for both anxiety and depression. Applying the scale did not indicate depression or anxiety for 27 of the patients. One patient did manifest pathological levels of depression and anxiety. There were also two patients with borderline anxiety, one patient with borderline depression and another one with a pathological level of depression. Because of the small group of patients the correlation between anxiety and depression and other parameters was not statistically relevant.

Conclusions

After the analysis of the first group of patients we noticed that a great majority of them discovered their diagnosis from their physician. Some violations of The Patient Rights Law were observed with the effects of infringing on the patients' autonomy or confidentiality of medical information.

A small number of patients show signs of depression, anxiety or values bordering on the abnormal, they could benefit from psychological support.

Taking into account the lack of knowledge or will to apply the patient rights law by both doctors and patients, informational programs for doctors might prove useful. Also, media driven informational campaigns regarding patient rights might also prove useful.

Future Directions

Taking into account the conclusions we reached following the preliminary analysis of a first group of patients, we wish to continue the study, to extend the group and to also include patient relatives in the study. Another objective would be including a group of patients with benign chronic conditions for comparisons (regarding knowledge and observance of patient rights and also psychological coping with illness). For the extended groups, the research methodology will be the same as for the pilot group.

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The study was designed with the collaboration of Asistant Professor Andrada Pârnu, MD, PhD – Hematology Department, “Iuliu Hațieganu” University of Medicine and Pharmacy, Cluj-Napoca and Lecturer Anca Fărcaș, MD, PhD, Internal Medicine, Cardiology and Gastroenterology Department, Medical Clinic I, “Iuliu Hațieganu” University of Medicine and Pharmacy, Cluj-Napoca

The Author thanks Mr. Nicolae Deac for his involvement in the data collection process for this study.

ETHICS OF PALLIATIVE CARE IN ROMANIA FROM PRINCIPLES TO PRACTICE

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ABSTRACT. Background: According to the World Health Organization, „palliative care is an approach that improves the quality of life of patients and their families, in the face of the problems associated with life-threatening illness, through the prevention and elimination of suffering, through early identification, proper assessment and treatment of pain and other physical, psychosocial and spiritual problems”. WHO considers that palliative care: ensures the removal/reduction of pain and other symptoms; promotes life and approaches death as a natural thing, which it does not withhold or quickens up; integrates the psycho-social with the spiritual aspects of care for the patient; provides a support system to help the patient to live a life as close to normal until death; and offers a support system to help the family cope during the patient's illness situation and after his death.

In order to address all the needs of the patient and his family, palliative care is based on a team approach. Palliative care can improve quality of life and can influence positively the progress of disease. This approach can be applied early in the course of illness, possibly in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, including the investigations needed to understand and manage clinical complications.

Objective: Highlighting how the fundamental principles of bioethics can be found in the practice of palliative care in the context of the current socioeconomic context in Romania.

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Method: Enrolling in the holistic ethic trend, this paper examines the four principles of bioethics used in current clinical practice through a scenario of case studies selected from an extensive qualitative research that aimed to identify factors affecting the dignity of terminally ill patients.

Research Results: The analysis revealed the ambiguous way in which medical decisions are made in relation to the fundamental principles of bioethics, the ineffective management of the physical, psychological, social and spiritual needs, in the context of personal values, cultural, religious beliefs of patients and their families, the effects of communication difficulties, ineffective or insufficient professionalism of care staff, deficient legislation, and the lack of visibility of the commissions of clinical ethics activity.

Conclusions: Socio-economic context and legislative framework, the level of development and professionalization of this medical field are making a considerably footprint on the application and observance of ethical principles in the practice of palliative care and, consequently, respect for the rights of terminally ill patients. In order to remedy this state of fact, an approach from the particular to the general is needed, starting from each patient individually to identify the needs of this category of patients, and to identify the barriers that interfere with the application of principles in clinical and ethical and diminishment of these through new management strategies. SWAT evaluation of the clinical realities will enable system-level changes in order to permit application of the fundamental principles of bioethics in the practice of palliative care in Romania.

Keywords: palliative care, bioethics, patient's rights, principles, legislation

Introduction

The World Health Organization defines palliative care in a complex way as “an approach that improves the quality of life of patients and their families, in the face of the problems associated with life-threatening illness, through the prevention and elimination of suffering, through early identification, proper assessment and treatment of pain and other physical, psychosocial and spiritual problems”¹⁰.

According to the same source, cancer specialists have emphasized the role and benefits of this type of medical care, which includes in the therapeutic equation the patient and also his family. Palliative care is a complex form of assistance covering all aspects relating to the terminal ill patient and his family, by ensuring the removal/reduction of pain and other symptoms; promoting life and approaching death as a natural thing, which it does not withhold or quickens up; integrates psycho-social

¹⁰ www.who.int/entity/cancer/palliative/en/

with the spiritual aspects of care for the patient; providing a support system to help the patient to live a life as close to normal until death; and a support system to help the family cope during the patient's illness situation and after his death.

Palliative care is based on a team approach in order to address all the needs of the patient and the family, including through support services during the period of mourning; improves quality of life and can influence positively the progress of disease. Palliative care can be applied early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, including the investigations needed to understand and manage clinical complications.

Objective: Starting from this wide definition, accepted and used internationally, it was intended to highlight how the fundamental principles of bioethics can be found in the practice of palliative care in the context of the current socioeconomic context in Romania.

Methodology: Enrolling in the holistic ethic trend, this paper examines the four principles of bioethics used in current clinical practice through a scenario of case studies selected from an extensive qualitative research that aimed to identify factors affecting the dignity of terminally ill patients. The research that has been carried out in the framework of the project "Postdoctoral studies in the field of ethics of health policies", had as theme the identification of the factors affecting the dignity and quality of life of terminal ill patients, and the methodology used was of a qualitative type one, using as a tool for data collection a phenomenological interview. For this research, were conducted 49 phenomenological interviews, in period June-July 2012 in Iasi and Cluj, with terminal patients, hospitalized in palliative care and oncological departments, aleatory selected, the criteria for inclusion were: terminal stage of the disease, patient's consent to participate in the interview. We used in the interview guide the operationalization of the concept of dignity of terminal patients realized by Dr. Harvey Max Chochinov. The interviews were analyzed qualitatively phenomenological. Out of these interviews were checked out the cases significant for the proposed evaluation, inclusion criteria being the presence in the patient's speech of the four variables analyzed below: autonomy, to do good, not to harm, justice.

Results

Autonomy

The principle of autonomy refers to a person's right to self-determination, independence and freedom. This principle implies therefore the respect of the right of each person to make decisions about their own lives and supposes the person's ability to process information, to understand, to take a decision concerning this

information, but also to enforce the decision. The implementation of this principle should be done by providing to the patient all the information necessary to reach a decision, aid in order to understand the information and support to implement the decision, even if it is in contradiction with the opinion of the medical team.¹¹

Respect for autonomy is the basis for the concepts of informed consent, confidentiality and of the truth about the prognosis, treatment options and side effects. Hospice Palliative Care Association sustains that the fundamental principle that underlies all care actions is the respect for the rights, dignity human values and human dignity, entails the recognition of patient's rights, especially the right to self-determination.¹²

In practice, however, compliance with this principle contrasts with the medical paternalist model that governed for a long time Romanian medicine, and that deals with the patient as a passive recipient of care.

Analysis of the cases surveyed in the study revealed that approximately 70% of patients did not know their diagnostic, treatment details and that decisions were taken by their families without their consent, although there is an informed consent signed by them in internment.

The case of a patient diagnosed with leukemia, in advanced stage, in palliative care, illustrates the difficulties of communication inside the medical team, but also the involvement of the family in hiding the truth from the patient. Thus, the patient was informed that he is suffering from anemia, and will be treated for it. The patient expressed in the interview the desire to know more about his disease:

"I am 80 years old and I no longer see well to read what the doctors write, but I want to know what treatment should I take and how long it would take, in order not to stand too much in hospitals".

In the case of the observance of this principle, in addition to communication barriers, cultural barriers may occur, Romani patients refusing themselves categorically to know the diagnosis, especially if it is an oncology type one.

A Romani woman from the family of a terminal ill cancer person mentioned that she herself was ill with cancer and if she knew the diagnosis she would no longer be alive because she would have had refused any treatment that was proven to be effective – "If I knew I had cancer I wouldn't have wanted any treatment. I am more emotional and I would have died for sure as I am easy to be scared". The literature emphasizes that terminally ill patients have a high degree of vulnerability, which is confirmed by the patients surveyed, and their families.

¹¹ Gavrilorvici C., *Introducere in bioetică*, Ed. Junimea, Iași, 2007

¹² Sulmasy D.P., *Health care justice and hospice care*, Hastings Center Report, 2003. Available online at: http://www.thehastingscenter.org/pdf/access_hospice_care.pdf

The vulnerability is given by the health condition, by the dependency on a physician's decision, and also the dependency on the family through limitation of mobility of physical and financial capacities. In this context these persons require special protection and promotion and respect of their rights.

Beneficence

Any treatment should be initiated for the benefit of the patient, taking into account the risks and discomfort to which it is subjected. Refraining from treatment, palliative sedation and interruption, applied with the aim of reducing the burden of disease and useless treatment, have created ethical dilemmas in the context of controversy created by passive euthanasia. European Association for Palliative Care (EAPC) requires that decisions of this sort should be taken together with the patient, family, and other specialists, according to legal and ethical standards.¹³

From the interviews conducted in the framework of our study, we noted the case of a patient diagnosed with neoplasm of colon, terminal stage, after having passed through all stages of treatment, surgery, chemotherapy and radiotherapy. Although in terminal ill stage, in palliative care, the patient did not know the diagnosis, the family restricted the medical personnel to tell him about his illness. What the patient knew is that he is treated for an ulcer. In these circumstances all therapeutic decisions were taken by his family, without to require the patient's opinion. After surgery was practiced also a colonostoma (anus-against nature), and the patient's general condition was heavily influenced. In the interview conducted with the patient it was sed that he would have wanted to know the effects of medical treatments which have been applied, considering that they have done more harm than good:

"If I knew how I would get, I would refused all treatments and maybe I would not agonize so hard".

Barriers identified by us in compliance with the principle of benefit were represented by the reduced number of specialists in the field of palliative care, making that the existing ones do not have the time to talk with patients; aggressive family involvement in care and hindering of the medical team and reduced or non-existent activities of the clinical ethics committees.

Non-maleficence – „do not harm" is closely related to the previous principle, claiming in turn the balance between benefit and risk in health care and advocating for abstention from medical acts that could do more harm than good to the patient.¹⁴

¹³ Sulmasy D.P., *Health care justice and hospice care*, Hastings Center Report, 2003. Available online at: http://www.thehastingscenter.org/pdf/access_hospice_care.pdf

¹⁴ Gavrilorvici C., *Introducere in bioetică*, Ed. Junimea, Iași, 2007

According to this principle one should not engage in unnecessary treatment, the results of which will not be for the benefit of the patient. EAPC exemplifies this with results on the quality of life communicated in various studies about maintaining the patient in a state of permanent unconsciousness by sedation or the results of artificial water uptake or the enteral nutrition.¹⁵

Out of the same study, we selected the case of a patient diagnosed with esophageal neoplasm which had a gastrostoma to be fed. The patient has given her consent to be fed that way without understanding exactly what it is and what will be the shortcomings. In this context, she considers that she does not have a better quality of life as a result of this treatment. "Eating is a way of telling. Food gets in me through the hose. I don't know if it helps me, I struggle like that, I have to go also to the bathroom and it's hard."

A more commonly seen situation is the initiation or abstaining from cardio-respiratory resuscitation of a dying patient, Romanian doctors faced with such situations which do not have the legal basis to make decisions for the purposes of refraining from this medical maneuver that, in such cases, produce more suffering than real benefit to the patient.

The barriers that we have identified in our study to the practical application of the principle of non-injury were: poor legislation and low activity of the ethic committees.

The principle of Justice promotes the fact that terminally ill patients have a high degree of vulnerability, which requires special protection for the promotion and observance of their rights and the equitable allocation of resources, so as to enable equal access to quality medical care to each patient.¹⁶

Observance of patient's rights and equitable access to medical services should, however, be legally regulated. Although palliative care in Romania has already had 20 years of existence, the current medical laws do not include this type of care, as are all other medical specialties. This fact is negatively influencing on settlement of medical services by the health insurances and maintaining an extreme low financing. The National Association of Palliative Care from Romania (ANIP) has proposed to change the law 95/2006 and inclusion and the definition of palliative care, in order of a more efficient allocation of funds.

The Catalogue of palliative care in Romania, powered by ANIP in collaboration with Hospice "House of Hope", in 2010 recorded the existence of 46 specialized services in palliative care provided by 32 vendors (12 in the public health system, 19 non-governmental organizations and 1 LTD.) which covered 5% from needs.

¹⁵ Pellegrino E.D., "Emerging ethical issues in palliative care", in *Journal of the American Medical Association*, 1998

¹⁶ Regis A., Dayde M.C., *Soins palliatifs ethique et fin de vie*, Ed. Lamarre, France, 2010

The need for services in Romania is between 150,000 and 160,000 people per year (approximate).¹⁷

Barriers to compliance with the principle of Justice that we have identified are: poor law – in relation to palliative care and the extremely low financial resources allocated to this scope.

Conclusions

Socio-economic context and legislative framework, the level of development and professionalization of this medical field are making a considerably footprint on the application and observance of ethical principles in the practice of palliative care and, consequently, respect for the rights of terminally ill patients.

In order to remedy this state of fact, an approach from the particular to the general is needed, starting from each patient individually to identify the needs of this category of patients, and to identify the barriers that interfere with the application of principles in clinical and ethical and diminishment of these through new management strategies.

SWAT evaluation of the clinical realities will enable system-level changes in order to permit application of the fundamental principles of bioethics in the practice of palliative care in Romania.

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5. *Palliative Care in the European Union Report*, Policy Department Economic and Scientific Policy, European Parliament
6. www.who.int/entity/cancer/palliative/en/

¹⁷ *Palliative Care in the European Union Report*, Policy Department Economic and Scientific Policy, European Parliament

DISEASE IN RROMA COMMUNITIES – AN ARGUMENT FOR PROMOTING MEDICAL TEAM CULTURAL COMPETENCE

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ABSTRACT. Doctor-patient cultural differences influence the patients' attitudes towards medical care, their ability to cope with disease, their explanation about the cause of the disease, and the acceptance of medical treatment. Many studies emphasize that the concept of cultural competence was developed to promote the importance of adapting medical care to patient's cultural background. As a consequence, many medical care systems and several medical organizations around the world have instituted cultural competence guidelines for their memberships.

The Romanian Health System lacks a coherent policy in adapting medical care to patient's cultural specificities although several ethnic minorities live in this country.

This paper aims to analyse the beliefs of Rroma people about the significance and the cause of diseases and also the ethical and psychological issues raised by these beliefs. The paper presents the results of a qualitative research, which was part of an ample study that analysed for the first time in Romania perceptions and attitudes in regards to death, terminal stages of life and dignity within the Rroma, in the context of Romania's health services.

Our research reveals that Rroma patient from the communities we have done the research offer particular explanations and meanings to illness (for instance disease as impure, as punishment, as shame), some of them with a mystic meaning that can create problems with the patients' coping mechanisms, and certain behaviours when facing with disease or specific attitudes towards the ill people (stigmatisation).

Knowledge of Rroma cultural values and traditions could help the members of the medical team, including the professionals who offer psychosocial support (psychologists, social workers, priests) to avoid misunderstandings, prevent ethical dilemmas and provide better care, adapted to patient's cultural particularities.

Keywords: cultural competence, Rroma communities, Rroma patients, disease, coping

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I. Introduction.

Importance of cultural background of the patient in health care

People from different cultures have different systems of health beliefs to explain illness. They accept different treatments or different people to be involved in their decision making system regarding their healthcare. For example, the Western approach considers that disease is a result of natural scientific phenomena, accept sophisticated technology to diagnose the illness and accept pathogenic treatments. People from other cultures (from Far and Middle East, Africa, South America) believe that illness is the result of mystic phenomena and promote prayer or other spiritual interventions as treatment. In contemporary medicine is accepted that cultural issues play a major role in patient's efficient interaction with the healthcare system and compliance.

The expectation of many health care professionals has been that patients will conform to the cultural values and beliefs of the majority of the population. However, many studies has shown that each ethnic group has its own health perspectives, values, beliefs and practices and these may differ from those of the native health care culture.

Cultural differences influence the patients' attitudes about medical care, their ability to cope with the disease, their explanation about the cause of the disease, and the acceptance of medical treatment. Patients and their families bring culture specific ideas and values related to concepts of health and illness, reporting of symptoms, expectations for how health care will be delivered, and beliefs concerning medication and treatments. In addition, culture specific values influence the patient roles and expectations, how much information about illness and treatment is desired, how death and dying will be managed, bereavement patterns, gender and family roles, and the decision making process (5).

Cooper and Roter defined cultural competence in medicine as "the ability of providers and organizations to effectively deliver health care services that meet the social, cultural, and linguistic needs of patients". A culturally competent health care system can improve health outcomes and quality of care and can contribute to the elimination of racial and ethnic health disparities. The researchers showed that if medical staff donot offer their patients culturally competent medical care, patients could have negative health consequences, could be non-compliant to treatment or dissatisfied with their care (6).

⁵ Mc Laughlin L., Braun K., "Asian and Pacific Islander cultural values: Considerations for health care decision-making", in *Health and Social Work*, No.23 (2)/1998, 116-126.

⁶ Cooper L.A., Roter D.L., „Patient-provider communication: The effect of race and ethnicity on process and outcomes of healthcare”, in B.D. Smedley, A.Y. Stith, A.R. Nelson, *Unequal treatment: Confronting racial and ethnic disparities in health care*, The National Academies Press, 2003, 552-593.

Cultural competence is an ongoing learning process. Many medical care systems developed learning programmes addressed to their specialists in order to teach them how to approach patients in a culturally competent manner and several medical organizations around the world have instituted cultural competence guidelines for their memberships. These guidelines have some common key points: awareness of the influences that socio cultural factors have on patients, clinicians, and the clinical relationship; acceptance of the physician’s responsibility to understand the cultural aspects of health and illness that may influence the behaviour of their ethnic minority patients, recognition of personal biases against people of different cultures; respect and tolerance for cultural differences; and acceptance of the responsibility to combat discrimination that occur in health care settings.

Approaching the patient in a cultural sensitive manner could create stereotypes. Because of that, medical professionals should respect patient’s cultural values and avoid generalisation (7).

Health care professionals should understand that variations also exist within cultures or ethnic groups and cultural generalizations will not fit every patient. Knowledge of patterns of behaviour and belief can give physicians starting point from which to provide the most appropriate care possible, but health care providers should individualise medical care to each patient (8).

Many authors underline the importance of knowing what patients believe about the cause, significance and appropriate treatment of their condition because these beliefs could influence self-treatment strategies and the sort of help that they seek (9,10,11).

In Romania, the medical higher education institutions (high schools, universities, etc.) that contribute to the education of medical professionals (save for UMF “Gr.T. Popa” Iași) have not highlighted their students regarding the necessary adaptation of the medical act even to the patient’s cultural characteristics.

⁷ Center of an Aging Society - Georgetown University, “Cultural Competence in Health Care. Is it important for people with chronic conditions?”, in *Challenges for The 21st Century. Chronic and Disabling Conditions*, 5/2004, 1-8.

⁸ Galanti G.A., “An introduction to cultural differences”, in *West Journal of Medicine*, 172/2000, 335-336.

⁹ Helman C.G., “Limits of Biomedical Explanation”, in *The Lancet*, 337/1991,1080 – 1083. 1991

¹⁰ Scheppers E., van Dongenb E., Dekker J., Geertzend J., Dekker J., “Potential barriers to the use of health services among ethnic minorities: a review”, in *Family Practice*, 23/2006, 325–48.

¹¹ Ioan B., “Ethical issues in clinical context”, in Loue S., Sajatovic M., *Encyclopedia of Immigrant Health*, Springer, 2012, 6-16.

II. Roma communities in Romania

The Roma represent an ethnic minority in Romania, counting of about 3.2% of the population of the country (12). They are divided in numerous communities, with different degrees of acculturation. The traditional Roma, with a low or absent level of acculturation, live in a world filled with their taboos, cultural values and laws. These communities resist to change, remaining closed off from the influences of the majority Romanian population, considering tradition to be sacred and believing that it should be passed on to all those born within the community (13,14,15).

In different Roma communities there are various perceptions of illness which are strongly influenced by the cultural environment and the traditions kept.

The specific elements of Roma culture influence the disease-driven experience and behaviour, a fact that also has been noticed with individuals belonging to other minorities or ethnic groups (16).

In traditional Roma culture, death and illness are taboo. Discussing these topics is considered a bad omen and can bring ill fortune upon the house and the community. Like many other beliefs (for example the belief in the strength of unclean thoughts, of curses and of the evil eye), the word is considered an element of inductive force and modulation of reality depending on its magical power and the will of the user. For instance, in Roma symbolism, saying the word `death` can bring about death, speaking of illness can bring misfortune, and saying the name of a dead person will bring his ghost (17).

III. Methodology

In this paper the authors analyse the beliefs of Roma people about the significance and the cause of diseases and also the ethical and psychological issues raised by these beliefs.

¹² Population and lodging census. The Central Commission for Population and lodging census. Available at: <http://www.insse.ro/cms/files%5Cstatistici%5Ccomunicate%5Calte%5C2012%5CComunicat%20DATE%20PROVIZORII%20RPL%202011.pdf> [cited on 15.04.2012].

¹³ Cemlyn S., Greenfields M., Burnett S., Matthews Z., Whitwell C., „Inequalities experienced by Gypsy and Traveller communities: A review”. Available at http://www.equalityhumanrights.com/uploaded_files/research/12inequalities_experienced_by_gypsy_and_traveller_communities_a_review.pdf [cited on 10.11.2011]

¹⁴ Wamsiedel M., Vincze E., Ionescu I., “Roma health. The perspective of healthcare professionals – doctors, mediators, patients”. *A Romanian Criss study*, 2011.

¹⁵ Douglas M., *Purity and Danger: A Cultural Analysis of Concepts of Pollution and Taboo*, Routledge Kegan Paul, 1966.

¹⁶ Ioan, *Ethical issues in clinical context*, 6-16.

¹⁷ Grigore, D., *Curs de antropologie și folclor rrom. Introducere în studiul elementelor de cultură tradițională ale identității rrome contemporane*, Credis, 2001.

This study is a part of an ample qualitative research that aimed to analyse the perceptions and attitudes in regards to death, terminal stages of life and dignity within the Roma, in the context of Romanian healthcare services.

The research received the ethical approval of the Research Ethics Committee of the University of Medicine and Pharmacy from Iasi, Romania, and was held under its auspices.

The study was conducted amongst the Roma population that resides within two areas of Romania – the counties Cluj and Iasi. We conducted 48 semi-structured interviews in 6 communities from Iasi (23 interviews in: Morilor, Vântu, Dancu, Pietriș-Dolhinești, Zanea-Ciurea and Zmeu-Lungani), and in 3 communities from Cluj (25 interviews in: Cluj-Napoca, Mera and Bonțida). The study participants were chronic patients (25) and carers (23).

The inclusion criteria were: age over 18 years old; mentally competent; suffering from serious chronic illness or caring for a chronic seriously ill.; Roma ethnicity; given consent to participate in the interview. Participation in the study was voluntary, without constraints or rewards. The participants signed the informed consent form after being informed in regards to the study and before applying the research tool. The respondents were given the right to opt out the conversation whenever they wanted or to not answer questions that they regard as pertaining to sensitive matters.

The investigating tool was the individual phenomenological interview. The interviews were recorded and transcribed in Romanian. The obtained data was coded according to passport data, the interview's number, the situation of the interviewed person and the caste they belonged to.

The fact that there is a great degree of variability within the Roma population, depending on their degree of acculturation and the caste they belong to, we conducted the interviews within traditional communities belonging to several different castes: Kalderash/bucketmakers (caldarari), coppersmiths (aramari/spoitari), bearhandlers (ursari), boyash/mine workers (rudari), goldsmiths (zlatari), silversmiths (argintari), spoon makers (lingurari), fiddlers (lautari), etc. (named according to their occupation) and acculturated Roma, integrated within the majority of the population.

The interviews were taken within communities in order to avoid the psychological discomfort that could have been induced by the necessity to adapt to an unfamiliar environment. The research in the community was facilitated by the communities' leaders (bulibașii), as well as other individuals who are trusted within the community (physicians, health mediators, people who are helping the community, health organisations etc.). The questions were asked using simple language, in accordance with the participants' level of education. Before conducting the interviews, the interview guide was reviewed with the help of a representative of the Roma population, in order to avoid asking questions that would offend the culture and customs of the investigated population.

The results were qualitatively analysed using a phenomenological approach, which allowed us to understand the beliefs, values, knowledge and behaviours of Roma patients and their relatives when confronting serious diseases.

The limitations of this research arise from the fact that the data was collected using qualitative methods, therefore the results cannot be generalised to the entire Roma population from Romania, but are relevant to the communities in which the research took place.

IV. Results and Discussion

The data from the interviews revealed multiple opinions and interpretations of disease and its causes. Some ideas regarding disease are specific to the Roma minority and explain the behaviour of community members when faced with disease. Some of the meanings ascribed to illness can raise ethical issues and coping problems.

Disease as an impure (pollution) concept

In some Roma communities, people revealed us the interpretation of disease as impure. This is a Roma culture characteristic described in the literature. Not only health and disease are interpreted by Roma people as pure and impure, but the entire life philosophy behind the traditional Roma culture is based on the opposition **pure-impure**, with ritual purity being represented by respecting universal order and harmony (18).

The concept of purity, involves, in Roma culture, a physical aspect as well as a spiritual aspect, as the first requires the second. Purity of the body is considered a reflection, cause and effect at the same time, of moral purity. For Roma people, purity of the body includes the absence of diseases.

For the Roma, disease is a calamity associated with mystical phenomena, caused by touching the impure in its numerous aspects, be they material or immaterial (for example, adultery, touching the dead or the belief in the power of unclean thoughts, of words, curses and the evil eye) (19, 20,21,22).

¹⁸ Douglas M., *Purity and Danger: A Cultural Analysis of Concepts of Pollution and Taboo*, Routledge Kegan Paul, 1966.

¹⁹ Costin-Sima, D., "Starea de sănătate a romilor: evaluare, factori individuali și instituționali", in: Zamfir C. & Preda M. (ed.), *Romii în România*, București: Expert Publishing House, 2003, pp. 86-104.

²⁰ Dion X., "Gypsie and Travellers: culture influences on health", in *Community Practitioner*, 81/2008, 31-4.

²¹ Grigore D., Neacșu M., Furtună A., *Romii... în căutarea stimei de sine. Studiu introductiv*, Vanemonde, 2007.

²² Honer D., Hoppie P., „The enigma of the Gypsy patient”, in *Modern Medicine*, 67/2004, 33-36.

Impure (pollution) is represented by elements of *gajii*'s world (world outside community), dead people and their personal belongings, impure parts of the body (lower parts of the body), tainted objects. Having a contact with impure causes a sort of contamination of the spiritual aspect and morals of the perpetrator (23).

Roma people have a specific belief about the hospital which is considered a polluted place because here they can find ill people and death. They consider polluted all the object from the hospital (medical devices, patient's clothes, the dishes) and all the persons from the hospital (medical personnel, other patients, dead bodies).

In one of the interviews conducted in Iași, a Roma woman underlined the concept of disease as impure:

“You will not see a gipsy that eats in the hospital. The Gipsies don't eat on the hospital. There a dead man dies, there's blood, there's nails, understand me? They fear the blood because somebody died there... There's more! All in all polluted! You just sit there and think that it's not somewhere clean...” **SI.2-i13af2-rr**

A Roma male from “badanari” caste told us that this avoidance behaviour is characteristic for old Roma people:

“Roma do not eat in the hospital. That's tradition (...). Someone died in the hospital... That is the impression of the Roma, the older ones that have been admitted... It is an unclean place in other words. When we have someone who is (...) we take sheets, even from our own home, it is no problem, a pillow or a bath robe. The food for the sick... We do not use the hospital's cutlery or plates. We take to them from home a plate, a glass, towel, this and that...” **SI.2-i20am1-bd**

The association of *disease-impure* gives birth to a superstitious belief that the Roma patients should not interact with a doctor who had a patient which recently died, as the doctor is considered polluted.

“If the doctor goes to a case and that case dies, he is not visited by Roma for a few days. Yes, that's how it is! He touched the dead and he may not touch that living person. He may not touch that gypsy...” **SI.2-i5af2-cl**

The habit of avoiding using objects (sheets, pyjamas, cutlery) or eating the food served in the hospital due to their pollution was not described in the interviews conducted in acculturated communities in the County of Cluj, but was present in an acculturated community in Iași. The absence of the relationship between illness and impure might be determined by the degree of acculturation and also by the variability that exists among the members of one ethnicity, as an uneducated female from a community of Romanised gipsies eloquently put it:

²³ Vuolasranta M., “Ghid pentru Practicienii din Serviciile de Sanatate”, available at: www.coe.ro/down_pdf.php?abs_path=documente ... sanatate ... pdf [cited on 16. 11. 2011]

'Not all races of gipsies have the same notions.' **SI.2-i13af2-rr**

The medical personnel's knowledge of this fact (that Roma consider disease an impure element) can trigger an adaptation of the medical act to the Roma patient, thus reduce hospitalisation time to a minimum and increase the choice of ambulatory treatment or in a day hospital regimen, as well as accepting of the patient's personal objects or understanding their reluctance towards doctors.

The disease – an opportunity to show solidarity

The ill Roma are accompanied to the hospital by the members of the family and the community, who thus show their solidarity, their dutifulness, even their obligation towards the person stricken by misfortune. The community's support reduces grief and problems become easier to overcome. A record of compliance to this custom is even held amongst the people.

"...we are very united! Even strangers are obliged! If a stranger doesn't come, it means he bears hatred towards us! If I don't get involved in one of my sister's relatives' problems, when they arise, they won't get involved in mine. And when we do run into trouble, they'll say: "When we were in the hospital or at the courthouse, you didn't come to us either...!" **SI.2-i13af2-rr**

Sometimes the Roma custom to accompany the patient to the hospital in large numbers is observed, thus breaching sanitary protocol that enforces patient isolation and causing conflict between the patient's relatives and the medical staff that are not aware of this custom. Some conflicts recounted by the patients were consecutive to the abrasive fashion in which the medical staff reacted to the high number of Roma that appeared in the hospital thus causing dire consequences, leading up to the discharge of patients at their, or their relatives request. The solution to avoiding these conflicts could be the understanding of these Roma habits and empathic communication with them.

Disease – consequence of introvert personality

A 74 year old, uneducated Roma woman believes that there is a direct link between the stress and the illness that her husband was suffering from. She tells us that in her husband's family arguments were frequent, a fact which caused him a great deal of suffering, and eventually disease:

'And they would always start to mock this man, his brothers mock him beyond words and he would blush and not say a word, and they beat him... He said nothing... He would swallow it all and say nothing. And that's what I say that him, he kept it all in for years, 10-15 years and he kept it and kept it and it built up...' **SI.2-i15af3-rr**

The Roma consider themselves communicative. The process of communication is part of their cultural model of explaining disease. Thus introversion and lack of communication play a part in pathogenesis, while promoting communication has a healing attribute:

“the Roma are noisy! They constantly communicate! ... they consume energy by communicating, they open their hearts at any given time. While others are closed off, judge, are consumed from the inside, and this is where many diseases come from. But a Roma, when he talks, he no longer thinks at the fact that it hurts! ... and he forgets about that pain...” SI.2-i18af1-rr

Disease as a punishment or as a test from God

From a religious standpoint, illness is perceived by Rroma as a punishment inflicted on them by the God for evil deeds. For example a patient from a community in Cluj who suffered from many severe diseases explains away his struggle as a Godly punishment for presumed past mistakes.

‘Every 6 months I would go and be tested, and I was thinking: God, since you gave me all, I have to bear it because I did things that you might not have liked, and You are making me go through all this.’ SI.2-i27pm1-cj

This outlook was confirmed by a woman of the căldărari cast:

‘They think not because of the situation that they have. They think about sin. Why did this disease come and how it is happening ... They consider a sin ... draws a disease.’ SI.2-i5af2-cl

From a psychological stand point, perception of illness as a divine punishment constitutes an ineffective pattern of religious coping, according to the classification done by Paragment (24), as it is associated with self-blame for the emergence of illness, this coping pattern is also considered ineffective and intensely debated in psycho-oncological literature. These patients require psychological counselling as this ineffective coping pattern is associated with increased levels of stress and are correlated with a less favourable outcomes to illness (25).

These religious coping patterns, regarding the stress agent as a punishment and passive coping was also discovered in the oncological patients in the general population within a psychological support group organized in the Cluj Hematology Clinic(26).

²⁴ Pargament K.I., *The psychology of religion and coping: Theory, research, and practice*, New York: Guilford Press, 1997.

²⁵ Spencer S., Carver C., Price A., “Psychological and Social Factors in Adaptation”, in Holland J.C., *Psycho-Oncology*, Oxford University Press, 1998, 211-212.

²⁶ Pârnu A., „Grupul de suport psihologic pentru pacienții maligni - un pionierat”, in Tașcu A., *Sănătatea și calitatea vieții*, Editura Universitara, 2012, 163-191.

The literature cites the Roma perception on disease as a Divine punishment brought about by evil deeds or as a consequence of a curse. This fact suggests the acceptance of faith and, consequently delays the patient's decision to consult a physician. The same context of reconciliation with faith also demonstrates the belief that all life events are predetermined and inevitable. As such, the majority of the Roma patients, even the ones that have received information on the risks their disease entails do not adhere to the recommended treatment.

Some interviews revealed that the illness was sometimes interpreted as a test they were subjected to by the Divine rather than as a punishment. For example the wife of a patient suffering from prostate cancer and the daughter of a patient with advanced genital cancer offered us the explanation that:

'I have thought about this many times, that these are tests from God' **SI.2-i38af2-cj**

This pattern, illness interpreted as a trial constitutes a beneficial evaluation of the stress agent and redefines the negative event as having potentially beneficial aspects (a call to fight with disease). It also creates an effective coping pattern as it causes inception of a will to fight in order to pass the test.

The disease as a shame, a stigma

Disease is associated in some communities with a sense of shame and in consequence with isolation from the community because disease is considered a depiction of spiritual and moral impurity.

A 28 year old woman, the daughter of a cancer patient recounts the attitude of members of the community towards her mother's disease:

'They really did not care... No! Even worse, they mock her. They mock, 'cause when they see a sick man, they mock. They believe that she cannot get cured. Because when someone is suffering from a disease, what hurts them more? That you're mocking the disease that they have!' **SI.2-i34af1-cj**

In this context, disease becomes shameful, as multiple interviews reveal, the Roma prefer to hide the fact that one of them is ill. Interviews conducted in different communities have demonstrated different explanations of this interpretation.

A young Roma from Caldarari caste told us that there is in the communities a kind of pride, pride to be rich, pride to be happy, pride to be in good health. When a Roma people is ill, he loses a kind of pride:

"They do not take disease as is. They, when they have a disease or something, they are not taught to say ...they simply shut up and tell nobody... if he's sick with the liver, they laugh at him, they laugh at each other. They want someone to come to them. You know, to compete like cars ... in riches and in spiritual state and in physical state, for example to look as good as possible..." **SI.2-i1am1-cl**

We can see that, upon contracting disease the Roma patient becomes isolated to avoid any negative attitude from the community, as that would affect their dignity. The wife of a diabetic patient that had undergone a lower limb amputation surgery notes:

'He did not allow anyone to come and see him. He shut everyone out from the moment they cut off his leg. Everyone knew, but he could not dare someone to come and say... to pity him.' **SI.2-i14pf2-rr**

Multiple interviews have demonstrated that cancer is most frequently associated with shame, a 65 year old male with colon cancer confesses:

'I am ashamed to admit I have cancer...' **SI.2-i45pm2-cj**

When asked why Roma do not reveal the illnesses they suffer from, a Roma youth suffering from cancer and his proxy answers:

'I don't know...Out of shame... That's how some people are, yes.' **SI.2-i36af1-cj**

"In our village here, there is that tradition, that each hides his disease. Like they are ashamed...They are ashamed...Don't know, don't know why..." **SI.2-i35pm1-cj**

There are situations when disease is interpreted as shameful and, from a lack of health education, the Roma believe that all disease is transmissible. It is for this reason that isolation and stigmatisation of the Roma patients can be felt. A colon cancer patient recounts his neighbours' attitude towards him upon learning that he was ill:

'They did not come (over) even before... they act like enemies. They are enemies on us. That's how they are, this breed. They are afraid of this sickness... Because it's dangerous... they avoid this sickness, the ones that know better... So they don't get it themselves!' **SI.2-i45pm2-cj**

Among the communities where illness is associated with shame, the medical personnel must respect confidentiality and the patients' wish to not reveal the diagnosis to the community. Maintaining confidentiality becomes problematic due to the Roma custom of accompanying the patients to the hospital. The interviews revealed that often times the ones that accompany the patient interfere in doctor-patient communication causing ethical problems regarding patient autonomy and confidentiality.

Some interviews have revealed the exact opposite situation, in which case the patients are cared for and sheltered by the entire community in accord with the traditional model of Roma culture where care for the ill is a duty of the entire community. A patient with a rhynofarinx tumour said:

'I was lucky that the village has so many people who were good to me! (...) And wherever I would go, men and children and old men and everyone: Take care of you, Feri, man! And they encouraged me, everyone encouraged me, children, old men and all encouraged me! And that I found I had a little life in me! Look how the people encourage me! If I would go to the shop, all would stop me, all would stop me! Even today they would all stop me and say: Be strong! Be strong! Don't give up! And I started to get courage and I kind of got used to it...' **SI.2-i35pm1-cj**

The same patient describes with a tone of regret the fact that he is excluded from the social life of the community, and this causes him to feel alienated and estranged.

'Before the sickness, every party in the village, anything that was in the village – I was there! Now if they make a wedding they don't call me, if they christen a child they don't call me, anything they do in the village I am not there...' **SI.2-i35pm1-cj**

In the Roma communities included in our research we have discovered a dual attitude. On one hand we discovered an attitude of traditional care for the ill and their families through both spiritual and material support, on the other hand we find that some of the patients interviewed were marginalised and stigmatised.

Many authors described that for the Roma, caring towards the ill or the elderly is considered a sacred duty; they are cared for within the family, which is capable of great sacrifice. The community promotes this care model, rejecting the idea of institutionalising the ill within chronically sick units, hospices, or nursing homes. The literature also shows that in Roma culture illness is associated with the impure, and is also associated with shame and the patient must be isolated. In this context, isolation of the patients is a form of protection, as the patient is impure, and can bring about contamination and physical and spiritual illness for the other members of the community. As such, many Roma patients hide their illness (refuse to admit to other members of the community that they are ill), or refuse to accept that they are ill which can sometimes have dramatic consequences regarding the prognosis. Furthermore, some patients prefer to leave the community in order to avoid the feeling of shame and isolation (27,28, 29).

Impure behaviour (pollution) brings bad luck, an extremely dangerous thing for both the perpetrator as well as the community, because luck, once forged follows the individual and the family for a lifetime. It is possible that being impure can be limited to 'being tainted' but also dangerous for the community by possessing

²⁷ Romani Criss Foundation, *Health and the Roma community: analysis of the situation in Romania*, Fundacion Secretariado Gitano, 2009.

²⁸ Weyrauch W.O., *Gypsy law: Romani legal traditions and culture*, University of California Press, 2001.

²⁹ Földes M.E., Covaci A., "Research on Roma health and access to healthcare: state of the art and future challenges", in *International Journal of Public Health*, 57/ 2012, 37-39.

power that can become evil threatening the balance of the community. Those declared impure are excluded from the community and do not eat with the others because impurity is considered as being contagious with touch, food and personal belongings as vectors.

Also, within the community there are individuals that have either one or the other attitudes towards the patients. Ideally doctors should know this variable attitude when treating Roma patients and to ask whether they would prefer to keep the diagnosis confidential.

Conclusions

Patients differ in many ways. Some of these differences are due to patient illness, personality, socioeconomic class or education, but the most profound differences are the cultural ones. Many health professionals think that if they just treat each patient with respect, they will avert most cultural problems. But that is not always the case.

The Roma community offers some explanations and meanings to illness, some of them with a mystic meaning that can create problems with the patients' coping mechanisms as well as certain behaviours when consulting a physician.

Some knowledge of Roma cultural customs can help avoid misunderstandings, prevent ethical dilemmas and enable practitioners to provide better care.

To this end we recommend the introduction of a class on minority communication and the adaptation to their needs in the curriculum of the medical universities and other institutions for the formation and continuing education of medical professionals.

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UPDATE IN THE MANAGEMENT OF PATIENTS WITH HEART FAILURE

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ABSTRACT. Heart failure is the functional end-stage of heart conditions and represents a major public health care problem to whom proper importance is given in almost every country in the world. Developed countries have devised and implemented nationwide coherent programs that provide an integrated and multidisciplinary care for these patients.

Our paper is focused on the status of patients with heart failure in Romania and on the disparities/mismatch between the Ministry of Health's strategic plan and the actual status of the healthcare system. The paper briefly presents the multidisciplinary team that could provide optimal care for these patients. The topic of coping in heart failure is illustrated with excerpted results from a study that included 150 patients admitted and treated in the Cardiology Department of the Clinical Emergency County Hospital in Cluj-Napoca about coping, anxiety and depression in these patients.

To summarize, heart failure represents a complex disorder that generates both physical and psychological effects and requires an increased level of awareness nationwide leading to the establishment of national multidisciplinary programs of care for these patients.

Keywords: heart failure, coping, national policies, funding/resourcing

Heart failure is the functional end-stage of heart conditions and represents a major public health care to whom proper importance is given in almost every country in the world. There are some 14 million Europeans with heart failure³ with a projected increase to 30 million by the year 2020⁴.

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³ Remme WJ, McMurray JJV, Rauch B, Zannad F, Cezar Macarie et al. „Public awareness of heart failure in Europe: first results from SHAPE” *European Heart Journal* 26(22)/2005, 2413-2421

⁴ Davies MK, Hobbs FDR, Davis RC, Kenkre JE, Roalfe AK, Wosornu D, Lancashire RJ. „Prevalence of left ventricular systolic dysfunction and heart failure in the Echographic Heart of England Screening Study: a population based study” *Lancet* 358/2001, 439–444.

In Romania, 4.7% of people enrolled to a primary care physician have heart failure, caused mainly by ischemic heart disease and hypertension.^{5,6}

Despite advances in prevention and treatment of these conditions, heart failure prevalence continues to rise and so does the number of hospital readmissions⁷. In Romania patients with heart failure have an average rate of 4-5 hospital admissions per year³, starting from the diagnosis⁸ – a situation that imposes a heavy burden on the cost of care, for example 2-2.5% of the healthcare costs in developed countries. The cost is due to repeated hospital admissions (that account for 70% of the total⁹) but also to the loss of job and the cost of medication. The social cost of heart failure is also high and is due to absence from work and burnout of relatives who fill in for the patient¹⁰.

The strategic plan of the Romanian Ministry of Health for 2008-2012 focused on the increase of the share and weight of primary care and home care in order to lower the cost and number of hospitalizations. This goal can also be achieved by a relevant analysis of causes for (re)hospitalizations and finding means to control them. The most frequent causes for readmissions include: lack of adherence to recommended lifestyle changes (high intake of salt and alcohol, weight gain, excessive exercise or lack of rest), non-adherence to medication (not purchasing medication due to lack of money, patient-initiated dosage modifications due to urban myths or faulty communication), acute cardiovascular events (ischemia, arrhythmias, hypertension, infection etc.) and various conditions (thyroid or pulmonary disorders, use of NSAIDs or drugs)¹¹. For example, in order to control the non-adherence to lifestyle changes or treatment, the Ministry of Health aims to devise and implement programs to increase awareness and adoption of a healthy lifestyle.

⁵ Hobbs F.D.R., Jones M.I., Allan T.F., Wilson S., Tobias R., “European survey of primary care physician perceptions on heart failure diagnosis and management”, in *Eur Heart J.*, 21/2000, 1877–1887

⁶ Remme W.J., Boccanelli A., Cline C., Cohen-Solal A., Dietz R., Hobbs R., Keukelaar K., Lopez Sendon J., Macarie C., McMurray J., Rauch B., Ruzyllo W., Zannad F., “Increasing awareness and perception of heart failure in Europe and improving care – rationale and design of the SHAPE study”, in *Cardiovasc Drugs Ther.*, 18/2004, 153–161

⁷ Stewart S., MacIntyre K., MacLeod M.M.C., Bailey A.E.M., Capewell S., McMurray J.J.V., “Trends in hospitalization for heart failure in Scotland 1990–1996”, in *Eur Heart J.*, 22/2001, 209–217

⁸ Feldman D., Thivierge C., Gu  ard L., Dery V., Kapetanakis C., Lavoie G., Beck E.J., “Changing trends in mortality and admissions to hospital for elderly patients with congestive heart failure in Montreal”, in *Can Med Assoc J.*, 165/2001, 1033–1036

⁹ Masoudi F.A., Havranek E.P., Krumholz H.M., “The burden of chronic congestive heart failure in older persons: magnitude and implications for policy and research”, in *Heart Fail Rev.*, 7/2002, 9–16

¹⁰ McMurray J.J., Stewart S., “Epidemiology, aetiology, and prognosis of heart failure”, in *Heart*, 83/2000, 596–602

¹¹ Grady K.L., Dracup K., Kennedy G., Moser D.K., Piano M., Stevenson L.W., Young J.B., “Team Management of Patients With Heart Failure: A Statement for Healthcare Professionals From the Cardiovascular Nursing Council of the American Heart Association”, in *Circulation*, 102/2000, 2443-2456

Next we analyze factors regarding the patient-disease interaction (physical and psychological effect and treatment) and healthcare in order to find solutions.

Whereas in the past the treatment of heart failure was performed by physicians and nurses using conventional medication (diuretics and digitalis), the current treatment guidelines (based on novel therapies and their trial-based proven efficacy) provide patients with complex medications that are complemented by interventional therapies such as cardiac pacing (implanting a subcutaneous device that sends electric signals to the heart in order to correct the rhythm), defibrillation (implanting a subcutaneous device that uses electrodes attached to the heart in order to interrupt life-threatening ventricular arrhythmias) or surgical methods. Because a single physician has neither the expertise nor the time needed to address all the aspects of care, a multidisciplinary team of practitioners is needed. The complexity of the treatment also requires considerable effort and responsibility from the patient.

On the other hand, living with chronic heart disease produces a major stress the patient has to cope with. Coping is influenced by many individual factors and employs adaptive or disadaptive mechanisms and can determine anxiety and/or depression.

Disadaptive mechanisms hinder the rehabilitation process, patients' adherence to lifestyle changes (such as diet, exercise and sexual activity restrictions, medication intake, regular checkups, social and professional reinsertion, keeping up with the changes etc.) and have a negative long-term effect on the morbidity (rehospitalizations, complications etc.) and mortality.

Quality of life in patients with heart failure is influenced both by the disease per se (causing discomfort and disability) but also by the psychological reactions triggered by the disease.

Prevalence of this cardiac condition increases with age¹², thus patients with heart failure are more frequently elderly, thus they can also have associated conditions related to balance, sight and hearing, thus impairing their daily activity¹³. Cognitive dysfunction is also frequently present (moderate in 24% and severe in 15% of patients) and in addition to limitations to daily activity adversely affects the self-care of the patients¹⁴.

¹² McMurray J.J., Pfeffer M.A., "Heart failure", in *Lancet*, 365/2005, 1877-1889

¹³ Lien C.T.C., Gillespie N.D., Struthers A.D., McMurdo M.E.T., "Heart failure in frail elderly patients: diagnostic difficulties, co-morbidities, polypharmacy and treatment dilemmas", in *Eur J Heart*, 4(1)/2002, 91-98

¹⁴ Gure T.R., Blaum C.S., Giordani B., Koelling T.M., Galecki A., Pressler S.J., Hummel S.L., Langa K.M., "Prevalence of cognitive impairment in older adults with heart failure", in *J Am Geriatr Soc.*, 60(9)/2012, 1724-9

Comorbidities are frequent in this age group and have a significant impact on the number and effect of medication. All trials in elderly patients with heart failure have concluded the impossibility of reaching the target levels of medication due to multiple limitations (associated renal, digestive etc conditions) and fear of adverse effects¹⁵.

Therefore, in order to achieve a correct and complete management of patients with heart failure requires a multidisciplinary team that performs according to a complex bio-psycho-social model that is well-established and structured in some European countries and in the US.

This multidisciplinary team includes primary care physicians, cardiologists, internists, geriatricians, nurses, pharmacists, dieticians and social workers – each of them having their well-established role.

Primary care physicians are the first to address acute and/or chronic health issues, they provide advice and solutions and refer patients to the specialists when their competence limits are reached. Cardiologists and/or internists perform the management at outpatient or inpatient level by means of clinical and additional investigations and they recommend the treatment plan (including diet and medication) – sometimes together with geriatricians. Nurses provide care and information, education and counselling, they follow-up and monitor treatment. Pharmacists provide information on medications, their delivery and interactions. Dieticians provide information on how to achieve a balanced, low-sodium diet and how to achieve optimal weight. Nurses perform home follow-up visits for patients unable to walk and provide educational advices and help with medication. Physical rehabilitation and occupational therapy specialists help patients recover after hospitalization or various procedures, help patients live actively and include them in a cardiac rehabilitation program. Psychological aspects are dealt with by specialized psychologists who help patients and their relatives cope with emotional stress, anxiety, depression and other psychological issues caused by heart failure. Social workers introduce patients to available community programmes and activities. They also provide patients with help in dealing with complex financial or legal aspects arising from their status and include them in appropriate social care system.

The coordinated and combined actions provided by all these specialists are beneficial to patients under multiple aspects: improvement of physical (e.g. decreased or absent symptoms, increasing functional capacity) and psychological aspects (increased quality of life by enhancing patient education, adherence to treatment and lifestyle changes, improving self-esteem) thus having a favourable effect on comorbidity and mortality in heart failure.

¹⁵ Komajda M., Hanon O., Hochadel M., Lopez-Sendon J.L., Follath F., Ponikowski P., Harjola V.P., Drexler H., Dickstein K., Tavazzi L., Nieminen M., "Editor's choice: Contemporary management of octogenarians hospitalized for heart failure in Europe: Euro Heart Failure Survey II", in *Eur Heart J*, 30(4)/2009, 478-486

These benefits are further augmented if a customized, patient-centered management is performed^{16,17}.

This type of management is based on establishing, maintaining and reinforcing a partnership between the patient and the healthcare practitioners to manage all the aspects of the disease and promotes a joint decision-making process. It also identifies each patient's resources and possible impediments in the rehabilitation program and guides the planning and implementation of care. Ekman and colleagues have shown that "person-centred care" significantly shortens hospitalization duration and preserves functional performance without increasing the risk of rehospitalization and without decreasing the quality of life compared to conventional therapy¹⁸.

In the light of new guidelines for the management of patients with health failure, Romania still has relatively few studies and papers on this topic, that is why we designed and performed a study based on a complex management of the patient with heart failure. In our study, diagnosis and evaluation of the severity of adaptive/disadaptive reactions and mechanisms represented a necessary and mandatory stage in the diagnosis and treatment. The study included 150 patients with heart failure admitted to the Cardiology Department of the Clinical Emergency County Hospital in Cluj-Napoca with symptoms of worsening heart failure.

Our results show that 75.33% of the patients with heart failure have increased levels of anxiety¹⁹ and 52.6% of them have various degrees of depression²⁰ that affect their rehabilitation and quality of life²¹ and therefore need to be treated. Proposed management options included medication (antidepressants and anti-anxiety agents), psychotherapy and psychological counseling using cognitive restructuring and relaxation techniques..

Regarding mechanisms used for coping, 40 to 60% of the patients use emotional coping by disadaptive mechanisms such as „mental disengagement”, „denial”, „emotional release” and „behavioral disengagement”. We have also identified several clinical, demographic and social parameters that influence coping²².

¹⁶ Committee on Quality of Health Care in America IoM, "Crossing the Quality Chasm: A New Health System for the 21st Century", Washington, D.C.: The National Academies Press, 2001

¹⁷ Epping-Jordan J.E., Pruitt S.D., Bengoa R., Wagner E.H., "Improving the quality of health care for chronic conditions", in *Qual Saf Health Care*, 2004, 13:299-305

¹⁸ Ekman I., Wolf A., Olsson L.E., Taft C., Dudas K., Schaufelberger M., Swedberg K., "Effects of person-centred care in patients with chronic heart failure: the PCC-HF study", in *Eur Heart J*, 33(9)/2012, 1112-1119

¹⁹ Farcaş A.D., Pârnu A., Stoia M., Olinic N., "Nivelul anxietăţii influenţează evoluţia pacienţilor cu insuficienţă cardiacă sub tratament", in *Clujul Medical*, LXXX (2)/2007, 342-352

²⁰ Farcaş A.D., Olinic N., "Gradul depresiei se corelează cu evoluţia pacienţilor cu insuficienţă cardiacă", in *Clujul Medical*, LXXXII (2)/2009, 206-211

²¹ Farcaş A.D., Năstasă L.E., "Quality of life in patients with chronic congestive heart failure", in *HVM Bioflux*, 3(3)/2011, 239-245

²² Farcaş A.D., Năstasă L.E., "Coping in patients with heart failure", in *Bulletin of the Transilvania University Brasov Series VII Social Sciences and Law*, 4 (53)/2011, 65-72

All these data represent the fundamentals that allow physicians to choose the specific and customized treatment plan for each patient i.e. medication, types of psychotherapy, lifestyle changes such as diet counseling, smoking cessations, preventing a sedentary lifestyle etc. These data also enable healthcare decidents to comprehend the complexity of cardiovascular disease burden and to proper resourcing (funding and care providers) for the treatment of this condition.

The relevance of the study is augmented by the fact that mortality in patients with heart failure is higher than in most types of cancer²³, from 8-10% in mild cases treated with optimal medication and reaching 50% in severe cases²⁴. These data highlight the discrepancy in public resourcing of various fields of medicine such as cancer prevention and treatment programs, transplant programs compared to heart failure.

While oncology benefits from a series of national programs of prevention and early detection of cancers (uterine, prostate, lung, colon etc) and has significant funding for treatment (chemotherapy and radiation therapy), cardiovascular disease funding supports mainly medication for these patients but not the devices used in therapy (cardiac resynchronization therapy devices, implantable defibrillators, biventricular pacers etc.).

On the other hand, patients with refractory heart failure require palliative care (active and total care for patients whose disease does not respond to curative treatment) but they benefit from it more infrequently than cancer patients, due to lack of awareness both in physicians and patients.

To summarize, management of patients with heart failure is complex and specific, it requires dealing with both physical and psychosocial aspects of the disease. In Romania there is insufficient funding for the appropriate complex and multidisciplinary care these patients require.

These data allow us to recommend the establishment of comprehensive and coherent national programs for the prevention of cardiovascular diseases and also to expand the financing for treatment programs.

Proper care for patients with heart failure requires research and financial resourcing but also increased awareness of its clinical, social and economic aspects, not only from healthcare decision makers and healthcare professionals but also by the general population.

²³ Stewart S., MacIntyre K., Hole D.J., Capewell S., McMurray J.J.V., "More 'malignant' than cancer? Five-year survival following a first admission for heart failure", in *Eur J Heart Fail*, 3/2001, 315–322

²⁴ Braunwald E., "Chronic heart failure: a look through the rear view mirror", in *Eur Heart J*, 2012

MANAGEMENTUL ETICII – UN PREREQUISITE ÎN INSTITUȚIILE SPITALICEȘTI. STRATEGII ȘI PROGRAME DE ETICĂ

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ABSTRACT. Ethics is a prerequisite for any institution which perform in a complex social environment. Through its strategies and programs, the management of ethics has the mission to guide the behavior of the members of the organization, so it will be based on moral norms. It contributes thus to reduce the vulnerability of the organization.

This article discusses theoretically the role and the strategy of ethics programmes in the field of health care.

Key words: management of ethics; ethics strategies; ethics programme; health care

1. Managementul eticii – relații de calitate, bazate pe încredere

Orice organizație care își înțelege misiunea, motivul pentru care există în societate, care se respectă și dorește o reputație bună, fidelitatea consumatorului, retenția celor mai buni angajați, sau pur și simplu profit și stabilitate pe termen lung, conștientizează că este nevoie de un management al eticii. Deci, de o investiție pentru a crea și gestiona un sistem bazat pe politici, principia și standarde care să susțină conduita etică.

De fapt, orice organizație dorește să inițieze, să mențină și să dezvolte relații de calitate cu stakeholderii⁴ săi dar asta se poate materializa doar dacă este capabilă să le genereze sentimentul de *încredere* în acțiunile și comportamentele

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⁴ Indivizi sau grupuri de indivizi care au „o miză, un drept, o proprietate în organizație”, în rezultatele proiectelor sale. Își asumă unele riscuri prin investirea de capital, în resursele umane sau în ceva de valoare al organizației, deci un interes ca aceasta să existe și să funcționeze bine (a se vedea Leung & Olomolaiye, p. 75). Sunt stakeholderi interni – angajații, acționarii, și stakeholderi externi (clienți, furnizori, asociații profesionale, instituții educaționale și de cercetare, ONG-uri, autoritățile locale și centrale, organisme de acreditare naționale și internaționale, concurenți, comunitatea în general).

întreprinse, într-un context în care există riscuri. Încrederea se reclamă doar în situații în care există riscuri (cf. Deutsch, 1960, citat Kaptein, 1998, p. 33). Există două criterii de evaluare a încrederii (Kaptein, 1998, p. 32) – primul se referă la predictibilitate și consistență iar al doilea, care nu este implicat automat, este legat de *expectanțe*, convingerea celui alt că “cei de care depinde va reuși să îi îndeplinească așteptările” și să îi satisfacă interesele.

Multe dintre riscurile în relațiile organizațiilor cu stakeholderii săi sunt generate prin faptul că indivizii au valori și interese diferite, au o “lentilă” diferită de a aborda lucrurile, în situația în care sunt cerințe comune privind profesionalismul și respectarea unor valori și principii morale.

Încrederea se formează prin conduita pe care organizația și-o asumă față de ceilalți, în relațiile cu ei, iar din această perspectivă, etica devine o “extensie a unui bun management” (Treviño&Nelson, 2011, p. 18).

Cele două criterii anterior menționate, care sunt garanția încrederii, adică a minimizării riscului, nu pot fi îndeplinite însă fără asigurarea unui cadru formal de desfășurare și *orientare și învățare*, care să definească sistemul de valori comun care să fie împărtășit de toți membrii în organizație. Trebuie stabilite, formulate și comunicate: standardele morale și politicile de etică care decurg din acestea; definirea situațiilor specifice în care trebuie aplicate; rolul fiecărui membru și responsabilitățile; metodele care să asigure pașii care trebuie urmați pentru luarea unor decizii care să respecte morala; instrumentele de monitorizare în vederea atingerii obiectivului final.

În alți termeni, este necesar un management al eticii care, prin utilizarea unui sistem propriu de guvernare, are misiunea de a orienta și uniformiza comportamentul membrilor organizație, astfel încât acesta să fie bazat pe moralitate; să aducă toți angajații la același numitor privind promovarea puternică și reală a unor standarde morale (inclusiv stakeholderii externi, care trebuie să se alinieze acestora, pentru a minimiza riscul etic în relațiile desfășurate). Acesta este în responsabilitatea echipei manageriale care trebuie “să dea tonul” eticii, să facă vizibile importanța și avantajele sale. Este un proces, cu *input*-uri și *output*-uri, cu obiective și rezultate vizate, etape logice de urmat (strategii), care decurg una din alta spre aceeași finalitate, cu oameni care au responsabilități pentru a le duce la capăt, resurse alocate, termene de finalizare, indicatori și mecanisme de evaluare. Acest proces trebuie integrat în procesul de management general, să susțină obiectivul general al organizației, și în același timp să fie susținut în atingerea propriului obiectiv.

Pe baza definiției clasice a managementului dată de Richard Daft (Nica & Iftimescu, 2007), se poate spune că managementul eticii înseamnă un proces de planificare, organizare, coordonare-antrenare și controlul resurselor, desfășurat pe baza respectării standardelor morale și a criteriilor etice, în vederea atingerii în condiții de eficiență și eficacitate a unor obiective care corespund exigențelor scrutinului etic.

Managementul eticii este un termen larg, dar în esență, nu se poate realiza decât de oameni și prin oameni, *cu ajutorul cunoașterii*, iar responsabilitatea ultimă revine managerilor, prin exercitarea celor patru funcții manageriale de bază regăsite în definiția anterioară: planificare, organizare, coordonarea-antrenarea personalului și control.

Planificarea presupune stabilirea de obiective și standardele asociate acestora, evaluarea capacității organizaționale de a le îndeplini (evaluarea factorilor din mediul intern – puncte tari și puncte slabe, și a celor din mediul extern – oportunități și amenințări; strategii materializate în planuri pentru atingerea obiectivelor). Managementul eticii implică un consum consistent de resurse, și în consecință, are nevoie de un buget specific, luat în calcul la stabilirea bugetului general al organizației. Mai mult, este nevoie de oameni, de implicarea lor în activități specifice, dar acestea *nu trebuie impuse*, ci căutate mecanisme care să le câștige adeziunea, acceptul voluntar și susținerea din partea tuturor.

Organizarea implică alocarea resurselor, definirea rolurilor și responsabilităților, crearea structurii organizaționale de susținere care asigură cadrul optim de desfășurare a activității și luarea deciziilor. Coordonarea-antrenarea asigură motivarea angajaților și sincronizarea activității lor în vederea atingerii obiectivelor. Controlul permite monitorizarea permanentă, evaluarea rezultatelor în conformitate cu standardele, luarea măsurilor corective.

Gary B. Brumback (1998, citat de Menzel, 2012, p. 13) sintetizează managementul eticii în organizațiile publice în patru elemente: *recrutarea* (revizuirea ploticilor și procedurilor pentru a identifica dacă sunt etice și utilizate pentru posturile care trebuie; construirea unei reputații de recrutare bazată pe integritate; evitarea protejării mascate și explicarea politicilor noilor recruți; solicitarea noilor recruți pentru un angajament al eticii, prin jurământ solemn); *managementul performanței* (pentru a asigura că obiectivele legate de muncă sunt atinse într-o manieră etică), utilizarea continuă a *programelor de formare* pentru a amplifica mesajul că “etica contează”, dar și pentru a-i învăța pe cei care beneficiază de ele să gestioneze conflictele de etică prin formarea “raționamentului sistematic etic” (cf. Nelson, 2012); *auditarea* [etică] *periodică* bazată pe scrutinizarea angajaților sau “evaluarea vulnerabilității ocupaționale”.

2. Strategii și programe utilizate în managementul eticii

Strategia de etică

Operaționalizarea managementului eticii se realizează prin intermediul unei strategii de etică și/sau al unui program de etică și/sau conformitate (compliance).

Cele două modalități de acțiune sunt uneori abordate substituibil în literatura de specialitate, în sensul că unii autori se limitează la menționarea strategiei de etică

pentru instituționalizarea și managementul eticii în organizație. Totuși, termenul de strategie este mai limitat, deci într-un raport de incluziune inferior celui de program de etică.

Vallabhaneni (2008, pp. 85-87) propune termenul de *strategie de etică*, care poate fi aplicată în funcție obiectivele managementului (și abordarea respectivă) privind asigurarea eticii în organizație: evitarea oricărui comportament care ar putea afecta negativ interesele ei, satisfacerea preocupărilor stakeholderilor și obținerea de beneficii din crearea unei reputații pentru comportament etic, și crearea culturii în care toți membrii organizației respectă un set de valori etice și sociale asumat pe deplin de companie.

În acest sens autorul menționează trei stagii ale dezvoltării progresive (inclusiv obiectivul primar, standardul care ghidează, punctele tari și punctele slabe, precum și pașii necesari) a unei organizații care își definește comportamentul pe valorile eticii. Pe scurt, aceste stagii sunt următoarele:

Stagiul 1 – managementul pentru asigurarea complianței. Acesta are rolul de a preveni încălcarea legii și apariția scandalurilor. Se poate realiza prin stabilirea unui program care să asigure conformitatea la standardele legale și de etică impuse de opinia publică și stakeholderi (evitarea conflictelor de interese, protejarea proprietății organizației, păstrarea confidențialității informațiilor secrete);

Stagiul 2 – managementul relațiilor cu stakeholderii. Vizează consolidarea relațiilor pe termen lung și monitorizarea reputația în fața stakeholderilor, inițierea de programe pentru a veni în întâmpinarea preocupărilor lor de etică, deci, în alți termeni, crearea de valoare prin îndeplinirea expectanțelor pe care ei le au;

Stagiul 3 – crearea unei organizații bazată pe valori – definirea valorilor și realizarea de eforturi consistente și resurse financiare pentru ca aceste valori să fie parte din activitatea de zi cu zi a organizației.

Aplicarea strategiei de etică trebuie însoțită de programul de formare pe etică, care contribuie la comunicarea acesteia, stabilirea și consolidarea valorilor și a culturii organizației, și prin care se încurajează depășirea stadiului de complianță.

Donald C. Menzel (2012, p. 15) citează un studiu (realizat de Berman, West și Cava, 1994, în rândul a peste 1000 de directori de resurse umane din agenții municipale), în urma căruia au fost identificate patru tipuri de management al eticii, în funcție de combinația a două mari categorii de strategii utilizate: strategii formale de management al eticii care implică un “program de formare obligatoriu pentru angajați, utilizarea eticii drept criteriu în structura de recompensare, adoptarea de reguli organizaționale care să promoveze climatul etic”, cum sunt, de exemplu, demascarea [fraudei] financiare, și aprobarea desfășurării de activități externe care ar putea fi în contradicție cu interesul organizației. Strategiile informale ale managementului eticii au la bază promovarea rolului modelelor [de comportament etic] și consolidarea pozitivă a comportamentelor care au la bază asta.

Programele de etică

Programele de etică susțin misiunea eticii, arătând angajaților unei organizații ceea ce trebuie să se facă, asigurând cadrul optim luării deciziilor astfel încât să nu se încalce principiile morale. Nelson le acordă (2012) rolul de a “clarifica situațiile nesigure, de a rezolva conflictele relaționate cu valorile împărtășite”,

Cel mai adesea, în practică, regăsim programele de etică și conformitate (compliantță), acest din urmă termen reflectând partea “legală” (reguliile, “*standardele minime*” (cf. Verschoor&Dubinsky, 2003, p. 16) care trebuie respectate, ceea ce nu se poate face, astfel încât să se asigure o conduită morală. Altfel spus, evitarea tuturor comportamentelor care ar contravine atât politicilor și regulamentelor organizației, dar și normativelor legale în vigoare), ceea ce în final asigură încadrarea profilului organizației respective în nivelul de *acceptabil* (idem, 2003, p. 16), dar nu performanța etică, în adevăratul sens al cuvântului. Suprapunerea dintre programele de etică și programele conformitate (compliantță) [la lege] este explicată sugestiv de William Nelson (2012), pe baza legăturii dintre etică, lege și moralitatea comună. Programele de etică urmăresc asigurarea moralității comune, iar conformitatea la lege face parte din moralitatea comună.

Unii autori (Bikard, 2011, p. 56) adoptă termenul general de program de conformitate, cu provocarea legată de “încurajarea angajaților să se angajeze în comportamentul etic, și măsurarea efectivă a conduitei etice”.

În susținerea eficacității programului de etică, Bagget (2007, p. 66) aduce în atenție teoria psihologului Albert Bandura, care se bazează pe conceptul de *auto-eficacitate*, adică pe creșterea încrederii individului în abilitatea și capacitatea sa de a avea anumite comportamente pentru a atinge anumite obiective. Conform lui Bandura (citată de Bagget, 2007), această *auto-eficacitate* care arată “convingerea individului în capacitatea sa de a organiza și realiza cursul de acțiune necesar pentru a gestiona situațiile prospective” *se poate învăța*. În această idee, am putea trage concluzia că programul de etică este mai oportun (adică motivațional) decât un program de formare pe teme de etică, acesta din urmă având doar rolul de a schimba “atitudinea și credințele privind comportamentul”. Acesta este în opinia noastră un argument suficient care să valideze utilizarea cu succes a programelor de etică în instituții.

Verschoor&Dubinsky (pp. 2003, 16-17) propun 10 pași pentru asigurarea unui program de etică și conformitate efectiv: 1. Realizarea unei auto-evaluări riguroase (trecerea în revistă a valorilor organizației, evaluarea modului în care valorile sunt percepute în mod real de către angajați, identificarea elementelor din programul de etică efectiv aplicate în practică, identificarea a ceea ce trebuie creat nou); 2. Asigurarea sprijinului din partea managementului superior al organizației (obiectivele dorite de către acesta, ce așteptări sunt de la programul de etică în

termenii a ceea ce aduce diferit, evaluarea modului în care își manifestă dedicarea față de programul de etică; gradul de implicare a liderilor față de etică); 3. Publicarea și distribuirea unui cod de etică (asigurarea existenței unor ghiduri scrise pentru angajați care să le arate așteptările de la ei în ceea ce privește conduită etică, asigurarea cunoașterii acestora, evaluarea convingerilor lor privind realismul acestora); 4. Comunicarea insistent (consistentă, consolidată), (investigarea modului în care sunt comunicate mesajele, cum au acces angajații la mesaje și dacă le consideră credibile, mesajele cheie transmise, verificarea existenței unor canale multiple pentru transmiterea mesajelor); 5. Formarea (consolidarea mesajelor, construirea capacității angajaților de a-și exercita raționamentul moral); 6. Oferirea de resurse confidențiale (asigurarea sistemului/resuselor pentru raportarea problemelor de etică și demascarea practicilor incorecte, asigurarea confidențialității în cazul acestor demascări pentru consolidarea încrederii angajaților și a comportamentului de demascare); 7. Asigurarea unei implementări consistente a programului de etică (validarea eficacității procesului, realizarea acestuia în toate unitățile organizației, definirea clară a rolurilor și responsabilităților); 8. Răspuns și consolidare consistente, prompte și oneste (consistență în aplicarea valorilor, a standardelor și regulilor; recunoașterea și recompensarea conduitei optime, aplicarea uniformă a disciplinei, tratamentul aplicat în cazul în care angajații înalt performanți încălcă valorile organizației, realizarea investigațiilor interne); 9. Monitorizarea și evaluarea (măsurarea succesului, oferirea de feedback angajaților în urma controalelor interne); 10. Revizuire și reformă (evaluarea și actualizarea periodică a valorilor și a conținutului programului, îmbunătățire continuă).

Trebuie reținut că trecerea de la teorie la practică necesită unele prerequisite. Sfaturile pentru a evita cazul Enron⁵ sunt valabile în orice instituție: evaluarea climatului etic, a percepțiilor, a valorilor angajaților, a comportamentelor neetice, a presiunilor care se fac pentru a respecta standardele etice, a riscurilor și vulnerabilităților, a întregii culturi corporative; crearea de coduri de etică "vii", care să ofere angajaților ghidare reală în luarea deciziilor; crearea unei infrastructuri de etică solide, care "să se auto-susțină" (înființarea unui comitet de etică format din membri de conducere dar care să fie independenți de managementul executiv); evaluarea periodică a programului etic; organizarea unui program de formare pentru angajați, înființarea de linii de ajutor etic – "help line ethics" pentru angajați, formularea de politici clare de protejare a angajaților care dau semnale de alarmă pentru practici/comportamente incorecte în organizație; îmbunătățirea anuală a codului de etică⁶ în funcție de

⁵ Ethics Resource Center, *Ten Things You Can Do To Avoid Being The Next Enron*, <http://www.ethics.org/resource/ten-things-you-can-do-avoid-being-next-enron>, 29 mai 2009, accesat ianuarie 2013

⁶ Merită reținut că codurile de etică nu sunt o rețetă a reușitei, o "garanție a comportamentului etic", nu pot rezolva toate problemele și dilemele de etică complexe, astfel încât "să se facă alegeri responsabile într-o comunitate morală" (Harman&Mullen, 2006, p. 26). De aceea, ele sunt doar instrumente în programul de etică, care contribuie la susținerea filosofiei și obiectivelor acestuia.

dilemele nou apărute, alocarea de resurse financiare și umane, suficiente pentru departamentul/biroul/comitetul de etică; asumarea în fața opiniei publice a poziției de organizație etică; separarea funcțiilor de consiliere etică de cea de auditare etică, pentru a asigura obiectivitatea și evitarea conflictelor de interese; construirea conduitei etice printr-o comunicare adecvată din partea managerilor cu angajații de la toate nivelurile organizaționale, prin explicarea obiectivelor, a rolurilor, responsabilităților și expectativelor, prin oferirea de suport și ghidare, precum și prin organizarea de programe de formare formal, dar și prin formare informală; măsurarea succesului și recompensarea angajaților; păstrarea liniilor de comunicare permanent deschise.

Rolul ofițerului/consilierului de etică în gestionarea programului de etică

Un management adevărat al eticii trebuie să aibă printre actorii principali și un ofițer/consilier de etică.

Ricky Griffin (2009, p. 356, citat de Agheorghiesei (Corodeanu), 2013, p. 152) identifică 5 responsabilități ale ofițerului de etică în organizație: supraveghează aplicarea funcției etice în activitățile organizaționale; colectează și analizează informații cu caracter etic; dezvoltă și interpretează politicile cu privire la etică; dezvoltă și administrează programele de educație și formare pe teme de etică; monitorizează investigațiile cu caracter etic.

Ofițerul de etică este persoana care trebuie să îndrume angajații când se confruntă cu probleme și dileme de etică și să găsească soluții la conflictele etice, să monitorizeze respectarea politicilor și a codului de etică, să facă evaluarea programului de etică, să discute permanent cu managementul instituție (“mâna dreaptă” a acestuia) despre modul în care se aplică programul de etică, problemele nou apărute care pot perturba ritmul normal al activității, necesitatea îmbunătățirilor, resursele care trebuie alocate. El trebuie să își asume responsabilitatea de a determina indivizii “să acționeze în așa fel încât să promoveze ceea ce organizația dorește să fie” (Bikard, 2011, p. 57).

Ofițerul de etică trebuie să fie prezent în spatele “liniei de etică” unde angajații trimit mesaje, spun care sunt problemele de etică cu care se confruntă în desfășurarea activității, raportează încălcări ale politicilor. Trebuie să știe când și cum să organizeze programele de formare în funcție de problemele care îi frământă pe angajați, să fie creativ pentru a găsi noi modalități de a-i atrage să își mențină conduita etică (să nu își piardă încrederea).

În același timp, ofițerul de etică este *ombudsman*-ul, adică persoana neutră sau imparțială, specializată în rezolvarea disputelor, “a cărei funcție majoră este aceea de a oferi asistență confidențială sau informal managerilor și angajaților și/sau clienților angajatorilor⁷”

⁷ Ethics Resource Center, *Ethics Glossary*, <http://www.ethics.org/resource/ethics-glossary>, 29 mai 2009, accesat ianuarie 2013

3. Programele de etică în sistemul de îngrijire a sănătății

În cadrul sistemului de îngrijire a sănătății, Swansburg, Roussel și Swansburg (2009, p. 78) acordă programului de etică un rol de instrument “în dezvoltarea competenței etice și crearea unui climat care să conducă spre practica etică”.

Între elementele sale se numără în primul rând *educația* etică pe diferite teme, cum ar fi legea naturală, deontologie, utilitarism, etica feministă, explicarea diferiților termeni specifici, etc. (idem, 2009, p. 78).

Schlabach & Peer (2008, p. 31) subliniază rolul educației în etică pentru profesioniștii din îngrijirea sănătății aducând în atenție abordările pe care se poate insista în acest sens: principiile care guvernează practica medicală (respectul pentru autonomie, nonmalefiența, beneficiența și justiția, cf. Beauchamp & Childress, 2001, p. 12); etica grijii (“focalizarea pe valori cum ar fi atenția față de nevoia de îngrijire, disponibilitatea de a accepta responsabilitatea pentru ceilalți, precum și pentru rezultatele acțiunilor și receptivitate”, cf. Joan Tronto, citată de Sevenhuijsen, p. 70); teoria deciziei (care încearcă “să creeze calcule precise pentru acțiunile întreprinse, într-un mediu nesigur, cu ajutorul abordărilor probabilistice”, cf. Ksolowski, 2011, p. 132); alte aspecte comune (codurie de etică, păstrarea confidențialității, alocarea resurselor, alte elemente cu implicații etice). Educația etică trebuie să fie centrată pe “*descoperirea etică*”, printr-o integrare la nivel personal și profesional, prin împletirea gândirii raționale cu experiența subiectivă și prin abordarea altor aspecte complexe din domeniul îngrijirii sănătății (idem, 2008, p. 31). Poate fi puntea de trecere “de la atitudine la comportament” (Manolică, 2011).

Un al doilea element este *consilierea* (consultanța) acordată de indivizi sau de un grup de indivizi cu abilități și competențe în evaluarea eticii, derularea procesului etic și competențe interpersonale. Nelson (2012) consideră consultanța ca fiind elementul cheie al multor programe de etică în “adresarea chestiunilor de etică legate de conflictele de valori”.

Cel de-al treilea vizează *dezvoltarea de politici* pentru adresarea dilemelor etice și *revizuirea* acestora. Aceste politici pot viza aspecte specifice domeniului de îngrijire a sănătății (respectarea drepturilor pacienților, solicitarea consimțământului informat, păstrarea confidențialității informațiilor, dar și decizia privind întreruperea tratamentului, utilizarea tehnologiei reproductive sau transplantul de organe și donarea etc.), dar și aspecte generale, care să vizeze membrii și organizația în ansamblu (evitarea conflictului de interese, respectarea drepturilor angajaților, acordarea de șanse egale/non-discriminarea, protejarea proprietății, recrutarea și selecția, procesul de achiziții, etc.).

În același timp, acest program de etică este fundația pentru activitățile eficiente ale comitetului de etică, care are misiunea de a rezolva dilemele provocatoare din activitatea furnizorilor de îngrijire a sănătății (idem, 2009, p. 79).

Una dintre dovezile că aceste programe de etică funcționează în instituțiile spitalicești este un exemplu de două bune practici (Agheorghiesei (Corodeanu), 2012):

Prima este oferită de Calvary Hospital Palliative Care Institute (a se vedea Cassidy, 1998) care a înființat încă din 1991 un comitet de etică iar în 1997 un Comitet Funcțional al Drepturilor Pacientului și al Eticii Organizaționale, cu rol de consultare și educațional pentru întregul personal al spitalului. Acesta din urmă are în structura sa un subcomitet de etică organizațională, cu reprezentanți din toate entitățile organizației. Activitatea comitetelor este consolidată printr-o auditare a valorilor la nivel de departament, de asumarea unei declarații a eticii organizaționale și de implicarea a două echipe de consultanță [etică] la dispoziția personalului, pacienților și familiilor.

Al doilea exemplu este proiectul The Center for biomedical Ethics at the University of Virginia Health Sciences Center inițiat în 1990 în 10 spitale din Virginia și West Virginia (a se vedea Neft-Smith, ș.al., 1997). Acest proiect este derulat pe mai multe direcții: comitete de etică cu diverse funcții; programe educaționale în etica clinică și legislația specifică în domeniu, adresate atât personalului, pacienților dar și familiilor acestora; acordarea de asistență/consultanță etică de către consultanți formați persoanelor implicate direct în anumite cazuri sau care se confruntă cu unele chestiuni de etică; asigurarea de personal cu pregătire specifică în etică și lege în fiecare spital pentru a asigura și ghida auto-educarea comitetului de etică, educația clinică în cadrul sistemului, rolul de purtător de cuvânt în situațiile necesare și oferirea de consultanță (sau calitatea de resurse) pentru consultanți. La acestea se adaugă procesul de evaluare a eficacității direcțiilor menționate.

Concluzii

Deși ne preocupă etica organizațiilor, această sintagmă este ușor “forțată” deoarece etica se referă la oameni, este pentru ei, și se poate promova numai cu ajutorul lor.

Organizația *in sine* nu poate fi etică, ci angajații ei, echipa întregă. Organizația *in sine* nu poate să fie senzitivă sau să raționeze moral, să aibă competență etică. Comportamentul etic este al omului, și în consecință, “este un rezultat al implicării personale pentru angajarea în practica etică” (Harman&Mullen, 2006, p. 26). În același timp este un rezultat al învățării.

Exercitarea unui leadership etic din partea managerilor este vitală. “Etica este secretul unui leadership responsabil” (McKee, 2012, p. 25). Angajații au nevoie de modele, iar liderul organizației este cel care trebuie să dea startul în acest sens. Trebuie să fie primul care să respecte politicile de etică, să le aplice, să investească în consolidarea lor, alocând resurse, din timpul și energia sa. Transparența, onestitatea,

lipsa presiunilor asupra celorlalți, lipsa toleranței la încălcarea standardelor etice dar în același timp empatia, grija față de ceilalți, înțelegerea greșelilor și acordarea sprijinului atunci când este nevoie, consecvența sa în promovarea valorilor și susținerea conduitei etice sunt definatorii pentru câștigarea încrederii tuturor stakeholderilor.

Dincolo de formalism, liderul trebuie să se apropie de angajați pentru a le câștiga adevărată, dorința de a-l urma în demersul etic: sunt binevenite discuțiile clarificatoare și încurajatoare cu angajații de la toate nivelurile organizației, chiar și informal, pe holurile instituției; “cafeaua de la ora 10” când își poate strânge în jurul său oamenii pentru a discuta problemele de etică la locul de muncă; organizarea de mici ceremonii pentru a sărbători succesul și pentru a-i recompensa pe cei care au demonstrat un comportament exemplar. Peste toate acestea, “tărâmul trebuie să fie curat”, altfel spus, filosofia, obiectivele și strategiile instituției sunt etice, oamenii sunt tratați și recompensați etic, în funcție de rezultatul muncii lor. În caz contrar, “pe stomacul gol” un comportament etic este greu de crezut că va putea fi consolidat.

În același timp, avem nevoie să fim realiști și răbdători, punerea la punct al acestor programe de etică necesită timp, resurse și convingerea tuturor celor implicați să își asume responsabilități (decidenții de la nivel guvernamental, personal medical și administrativ, manageri, pacienți, familiile acestora, consultanți, furnizori, comunitatea în general). Mai mult, este nevoie de politici publice care să legitimizeze organizarea programelor, în contextul în care “banul public” trebuie justificat și mai persistă încă mentalitatea “acum avem alte priorități”.

Cel mai probabil, unitățile private vor fi pionierii, iar cele publice vor aplica treptat strategii de benchmarking pentru a prelua buna practică.

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THE HEALTHIST IDEOLOGY: TOWARDS A NEW FORM OF HEALTH AWARENESS IN THE CONTEMPORARY LIFE-STYLE?

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ABSTRACT. The study explores a salient social dilemma of the contemporary global society that is the health paradox. The health paradox is the result of modern medicine and refers to the growing illusion that humans have the right to live not only a life without diseases, but also a life without symptoms of diseases, having thus the right to perfection and harmony in all of their life domains (social, psychological, physical). Such paradoxical consequences of modern medicine imply a growing societal and scientific attention in connection with health. Among these are the following: healthism as a way of life; postmodern medicine; new forms of medical practices and knowledge (self-medication, the spread of medical knowledge among the general public, the presence of medicine in everyday life); new types of health practitioners (a wide array of holistic and alternative approaches in terms of health and medication and to a growing number of lay experts); the individual responsibility and guilt in connection with diseases (this can be conceptualized as the result of the ideology of individualism which determined the neglect of the societal and structural determinants of health and lifestyle); the growing social anxiety in connection with health, diseases and medicine. By summarizing a number of theories and studies, the analysis is focused on the benefits and risks of these phenomena which altogether structure the domain of the so-called healthist ideology.

Key words: healthism, meanings of well-being, medicalization of everyday life, moral responsibility, social anxiety.

Introduction

In the contemporary age, health has grown into a symbolic category of utmost importance, in relation to which a large array of analytical categories was created and developed to such an extent that they seem to have become inescapable: well-being, life-style, consumption and normality (Foucault, 1996).

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Over the last decades, the economic reforms and subsequent globalizing transformations produced both culturally significant themes (psychosocial ideologies) and behavioural changes. In the cultural evolutions of such notions as *responsibility* and *guilt*, these ideologies and forms of behaviour come to be essential for circumscribing properly the contents variously attributed to the expression “concerning culture” (caring for, being interested in: health, environment, global problems, etc.). At the heart of these changes lie the ideology and the life-style of the new consumer, as well as his/her health awareness, which were joined together by the political economist and sociologist R. Crawford (1980) under the name “*healthism*” defined as “a concern, a preoccupation with one’s own health [...] the fundamental drive for defining and obtaining social and individual well-being; a goal which will be firstly attained by transforming one’s own life-style, with or without therapeutic help” (Crawford, 1980, p. 366, cf. Colquhoun, 1991).

In other words, healthism expresses and seeks to justify the need of embracing a life-style perceived as healthy and “successful”, along such central values as *the high estimation of health/youth* and *the individual physical well-being*.

The reaction to this new philosophy of life consisted in developing large holistic-naturalistic and bio-medical industries, addressed to all ages, for conserving their youth, health and well-being. As part of the same value-oriented trend – attitude- and behaviour-wise –, conducts and attitudes develop which reflect the increase in public awareness regarding the environment, and, subsequently, the ecological alimentation (“bio”, “organic” foods, etc.), producing the so-called “spiral of public concern”. The mass-media contribution to these mentality trends is beyond doubt, reinforcing and legitimating the healthist ideology as a fundamental component of the contemporary man’s everyday life (Healy, 1997). As sociological research shows, the weight of concrete healthist attitudes and behaviours (the adherence to healthism) is positively correlated with a high standard of living, the degree of education and the affiliation or the systematic contact with the western culture. Therefore, embracing a life-style seen as healthy is generally characteristic for the middle and superior classes from developed countries (Greenhalgh and Wessely, 2004). The financial resources and the degree of information prove to be in this case essential variables.

The questions raised by this study are: *What is the nature of the belief system which leads to observable behaviours and declared attitudes, such as those ensued from the analysis below? Which is the relationship between benefits and the increase in individual and public anxiety in the framework of the hegemony of healthism on the level of social perception? To which extent the medicalization of everyday life and self-medication are enhanced by the invasion of “postmodern medicine”?*

The social and psychological dimensions of the healthist ideology in the global social space

The complex relationships of mutual determination between *life-style* and *health* are built on socio-economic and cultural axes (Bourdieu and Wacquant, 1992; Featherstone, 1991, 1995). After the 70s, through the steady increase in the integration of economies and in the velocity of information between the globe's societies, globalization led not only to the development of capitalist states, but also to the dissemination of certain health-related ideologies based on numerous studies more or less in line with the classical exigencies of science. An essential part of globalization is the neoliberal ideology, an economic, social and moral philosophy that champions individual initiative and free privatisation which should keep the intervention of the state within society and upon the affairs of its citizens to a minimum. Under the tutelage of this ideological system backed by the self-regulation mechanisms of the market, the nation-states afforded citizens the power and control required in the private sector business, and which contributed to the cultural ideology of consumerism. By way of generalization, one can infer that the neoliberal vision educates individuals to become entrepreneurs who manage their own life in such a way that their types of conduct abide by economic and social norms and responsibilities². It is somewhat a paradox that in this ideology the states play a regulator role that favours private capitalist activities (Etzioni, 2002; Robertson and White, 2003). We must note another consequence of this ideology, that is in the context of non-referential world, there occurs a confusion between the reality principle and the principle of individual, subjective purposes (desire principle) (Baudrillard, 1981, pp. 21-22).

In their study, suggestively titled: *'Health for me': a sociocultural analysis of healthism in the middle classes*, T. Greenhalgh and S. Wessely (2004) show that healthism is connected with consumerist values, but without overlapping them, seeing that the latter are not extensively focused on health issues. Gabriel and Lang (1998, cf. Greenhalgh and Wessely, 2004) identified the consumer's multiple facets: voter, communicator, explorer, identity seeker, hedonist or artist, victim, rebel, activist and citizen. They review five important meanings of the term "consumerism": a vehicle for power and happiness; the ideology of ostentatious consumption; an economic ideology for global development; a political ideology; a social movement

² In Baudrillard's terms, "Take your desires for reality!" can be understood as the ultimate slogan of power, leading to the danger of contagious hyperreality. The tool that is used to reinforce power is the idea of the real, as the author says. Power is itself a simulacrum, devoid of referentials, but it operates through the imagining of the real, through the simulated reclaiming of the real. Power is produced through the media, our daily interactions with people, and every aspect of our society which seems already generated (Baudrillard, 1981, pp. 21-24, in Poster, 1988).

for the protection of consumers' rights. This last dimension is closely related with the positive connotation of consumerism applied to the healthcare field, in such examples as the patient-centered medical practices, sharing and negotiation of decisions and partnership. In their analysis of the healthist culture³ of the American middle class, the mentioned authors propose a *set of demographic, attitudinal and behavioural characteristics of the adherents to the healthist life-style*:

- Typically of young or middle age, well-informed, with graduated studies and a semi-professional background;
- Vocals and well-spoken: they intend to involve themselves or already did in causes pertaining to citizens' and patients' rights;
- Concerned with health issues: they seek information about health and illness (books, magazines, internet);
- They usually make positive choices in their life-style: regularly exercise, go on diets according to official recommendations, tend to avoid alcohol and other harmful habits, even though, somehow surprisingly, there are numerous smokers among them;
- They consume food supplements (vitamins, minerals, fish oil, etc.), alternative medication (homeopathic, naturopathic) and stimulant substances (ginseng), i.e. elements to which are attached such qualities as "natural", "holistic", as well as diet-based "detoxifying", food supplements or other methods;
- They are worried about "unnatural" substances (chemicals, vaccines, drugs, additives), especially when the dimension of civil liberties is at stake (water fluoridation, mass inoculation, fast-food chains that serve diets rich in carbohydrates);
- Many of them, in particular, fear and are alert to an invisible, insidious threat from without, able to cross the boundaries of the body (fear of pollution, vaccines, additives, etc.);
- They associate science/medicine rather with danger than with safety (stating as arguments (in)famous cases of malpractice or conspiracy examples from the pharmaceutical-medical world);
- They usually make a wide range of choices (for example, they seek multiple opinions), especially from the (informal, non-formal) private sector of healthcare.

Analysts from various fields who tackle the phenomenon of healthism underlined its numerous effects, such as: the potential distortion of the priorities of the public healthcare system - for example, by backing up a single-theme oriented campaign; the potential of stagnating and increasing anxiety, especially through the amplification of risks by mass-media; the potential of some huge economic

³ Culture can be analysed along three levels: what people say they do, what they really do and the substrate (most times unconscious) of the beliefs system which channels their conduct (Hall, 1960, cf. Iluț, 2009).

effects brought about through a massive increase in demands addressed to official institutions, in tests and reports on certain medicines, vaccines, food groups, etc. (even though, paradoxically, healthist consumers live prevalingly in “profane health” environments, propagated by informal experts in health and life-style issues); and this situation represents a danger to the perceived morality of qualified persons, to the prosperity of health professionals and clinics, and to the credibility of researches from the public health domain. On a more positive note, other researchers choose to concentrate on the positive effects of healthism upon health: being well-informed persons, they collaborate better with doctors and therapists, keep and observe a life-style focused on prevention and body maintenance, and, in view of their valuable initiatives regarding the betterment of information and protection of the public health, they become authentic agents of healthism (Greenhalgh and Wessely, 2004).

Naturally, from what has been said until now, one cannot ignore *the negative effects of healthism*: its numerous solutions and recipes (various types of diets, miraculous equipment for body maintenance, holistic, palliative, natural medication, etc.) sustain the invasion of diverse supplies specific to the consumption culture. Health-conserving-wise, in addition to its obvious positive effects, healthism is an accelerator of individual and public anxiety. Bodily-wise, the intense and aggressive promotion in mass-media of *an ideal image for physical appearance* (the film industry and the promotion of filiform physical models for women and muscular ones for men are in this sense very suggestive) leads to the *fashion of easy physical fitness* (Waddington, 2006). For certain categories of people, such as youth or those persons burdened with difficulties in realistically adjusting their self-image⁴, the phenomenon may induce medium- and long-term unhealthy behaviours: severe diets, ill-suited exercises, “the weight race”, naturopathic treatments promoted by “specialized” sites, administered without the proper guidance of a specialist. All of these may prove to be counterproductive and thus detrimental to authentically healthy values and behaviours, the latter being the only ones that are long-term beneficial for the well-being of individuals.

Although A. Maslow (1960, cf. Greenhalgh and Wessely, 2004) when establishing the hierarchy of human needs did not use healthism-like ideas, his hierarchically structured model of needs from 1943 and the subsequently developed theory of

⁴ The interest for the theme of *self-identity*, increasingly manifested in the last decades in psychology and social psychology (Featherstone, 1991, Phillipson, 1998), envisages the analysis of the relationship between what an individual does and what he believes about himself. Concerning the self-identity with respect to embracing a certain life-style, there is highlighted the tension between *the interior identity of the individual* and *the identity within society*. With the proliferation of postmodern values, there is likewise at work a process of disintegration and dissipation of socially established norms. The ensuing confusion equally supplements the dysfunctions of healthist ideology on the level of private individuals.

motivation are able nevertheless to explain many types of behaviour analysed in studies from different fields of research. The concept of the *actualizing-self*⁵ proposed by A. Maslow means becoming what (who) one can become and reaching the apogee of one's own potential. Actualizing-self is a continuous, developmental process of the person's potential who, by using her physical and mental capacities, succeeds in doing as well as possible what she wants to do. Applied to the healthist phenomenon encountered in western societies, Maslow's model explicates the following problems: a) why healthism is a phenomenon particularly dominant in middle classes; b) why sometimes the individuals assign themselves so enthusiastically goals connected to perfect health; c) why the provided information and explications are never sufficient for the healthy-life consumers; d) why the ideal of mental fulfilment and of the body's aesthetic perfection may function as a mechanism of *self-perpetuating* (cf. Greenhalgh and Wessely, 2004). Additionally to the psychological perspective about the social importance of the body appearance, we must mention here about the corporeal sociology's main figure, P. Bourdieu (1990, 1992)⁶.

The Australian sociologist Deborah Lupton explored the concept of the *self* by conducting 60 qualitative interviews with ordinary persons, who, by profession and family, were outsiders with respect to the healthcare system and its promotion; the study envisaged to describe their attitude towards the professionals involved in healthcare practices (Lupton, 2002, cf. Greenhalgh and Wessely, 2004). Founding her research on the theories of *the rational, reflexive self* as a product of late modernity (namely, the self which acts in a calculated fashion in order to improve itself and which is sceptical about the relevance of the experts' knowledge), Lupton investigated *the ways in which the subjects relate to medicine and doctors*. Her findings confirmed the existence of a rational, goal-oriented self, of a "consumerist" type, but they also stressed a certain confrontation or coexistence between the traditional view of the "passive patient" and the new one of the "patient self-oriented towards the goal" (a kind of "self-doctor"). These identifications of the subjects appear and alternate according to context. Lupton concludes that the late modernity notion of "reflexivity"⁷ applied to healthism and consumerism themes, is not appropriate when it does not recognize the complexity and the changing nature of the desires, emotions and needs which characterize the patient-doctor relationship. In other words, although there is empirical evidence for the existence of healthist attitudes in the life of individuals, they very rarely appear in a pure form; therefore, stereotypes should be avoided when dealing with these topics.

⁵ For the extension of this concept in the approach of self identity in late modernity era, see also A. Giddens (1991).

⁶ Bourdieu argues that the body is a form of physical capital: "The body is in the social world, but the social world is in the body" (Bourdieu, 1990, p. 73), and that the "common sense (...) is a coincidence between objectives structures and embodies structures" (Bourdieu and Wacquant, 1992, p. 201).

⁷ See also: Bourdieu and Wacquant (1992), Giddens (1991).

In addition, the arguments provided by *the theory of rational choice* (Coleman, 1990, cf. Iluț, 2009) are satisfactory for explaining both the healthist attitudes of the middle classes from developed societies and their rational attitude, manifested in difficult contexts of life (harsh illness), to consult a doctor and to follow the prescribed treatment.

Greenhalgh and Wessely (2004) propose to refer to these categories of persons with the term “lay experts” because their ability to influence public debates and policies has grown, whereas the monolithic role of the doctor undergoes ever more significant changes in the public perception. These lay experts can be the survivors of real disasters or of extremely critical diseases, whose cases (sometimes true modern sagas about health, such as the excessively inflamed debate on the Gulf war syndrome), some of which are trustworthy (because their experiences are “authentic”, or the group/association that backs their voices is itself trustworthy), once they reach the ear of the public at large, help propagate this new vision about the role of individuals and of their true personal knowledge in dealing with and solving real problems. In the last instance, as Featherstone (1995) or Etzioni (2002) equally remark, these are the defining elements of the postmodern values that disseminate themselves constantly in the contemporary developed societies. They produce, nevertheless, as I have shown in the previous sequence of the paper, negative effects which must be taken seriously into account.

An array of established sciences, but also new domains of cross-cutting research, introduced in their thematic sphere issues related to health studying and promotion. With illustrative purpose, I expose in *Appendix* a list of magazines/journals (the list is incomplete and comprises only English language ones!) from various fields of research connected to promoting health issues for the sake of the public interest. These publications are taken from the site of an academic organization with an important profile in promoting healthist values through research and intervention: individual health, public health, nutrition, environment, communitarian facilities, naturopathic / alternative pharmaceutical products, sportive activities for promoting the physical and mental well-being of the public at large, etc. (see *Appendix*).

In the same vein, Kirk and Colquhoun (1989) and Colquhoun (1991) identify several processes that influenced this shift in research in certain domains: while erstwhile they were relatively autonomous and to a certain extent foreign to the medical field, now they involve themselves with health-related themes. Through this new synthetic research activity, the improvements of the public health sphere are evident, but so are the negative effects of the healthist ideology:

- The enhancement of the social interest towards medical topics (especially concerning cardiovascular diseases, obesity, mental illness, cancer), which is accompanied, not accidentally, by the upwards spiralling of medical costs;

- The fast-paced evolution of the health ideology in society is not completely unproblematic, seeing that many times this launches in the social framework partial or distorted perspectives on the causes of diseases and health (when they are attributed to certain factors in detriment of others). Adopting the concept of “healthism”, Crawford (1980, cf. Colquhoun, 1991) shows that health is within our control. In other words, “healthist” ideology emphasizes the idea of individual responsibility towards his/her own health and simultaneously distracts from hidden social processes (for example, poverty, unemployment, industrial pollution, limited access to medical services or their low quality – factors that may lead to a high rate of diseases) or from genetic aetiology. Consequently, to posit the responsibility of health within the individual’s remit (to hold personal *control* over one’s own health) diminishes in the eyes of the public which is constantly “fed” this kind of ideology the “blame” of big polluting, industrial producers, of governments/policies or other power-clawing groups and institutions; in this way, the responsibility of the governing institutions for health policies is more or less alleviated.

“The healthist regime” and the short-sightedness of the classic individualism

With the neoliberal focus on individualism and the emergence of late modernity and postmodern values, healthism constructs a vision about individual behaviours, attitudes and emotions whereby they become spotlights in the effort of gaining health and preventing diseases. The central element of this vision is the emphasis bestowed on self-awareness and personal health, namely on the *individual choices and responsibilities*. For the initiators of this new health awareness, the way towards a better health needs the individual’s determination to resist the temptations of the consumption culture, despite institutional and environmental constraints, to resist the agents that cause sickness and to refuse bad habits and sedentariness. Individuals are thus persuaded, informed or threatened by different public or private campaigns to feel personally responsible for their own health and are encouraged to involve themselves in a variety of activities in order to maximize their health, such as exercises, diets, reducing alcohol or tobacco intake (including through fines, when these take place in public spaces) (Crawford, 1980, cf. Colquhoun, 1991).

Once the idea that the individual holds complete control over his own health is socially integrated, the disease becomes automatically the result of his own mistakes with regard to a “healthy” life-style; and reciprocally to have and maintain a good health becomes a moral imperative for the individual. The new health awareness is accompanied therefore by other complementary values: *self-discipline* and *moral responsibility*. Hence, those afflicted with forms of illness deemed to be the result

of a harmful life-style take the risk of being seen not as innocent victims of certain processes beyond their control, but as people who, on grounds of negligence, laziness and carelessness (lack of discipline and self-control), “have it coming”.

Many cultural topics on the personalization of responsibility towards health, as propagated by the healthist ideology, are explicated in their turn according to the terms of a consumerist ideology rendered well functional in the new globalized capitalist system (Etzioni, 2002; Robertson and White, 2002). The beneficiaries of these changes are the private sector, the new middle class and the elite of powerful states (Scambler, 2006, cf. Hopwood, 2007). And indeed, we are used to hear high calibre politicians who in their public discourse peddle the cliché of the importance of individual responsibility in health matters or of attributing the blame for viral epidemic, for the high percentage of chronic diseases associated with unhealthy life-style to the individual behaviour. In USA and Europe such kind of examples are unfortunately numerous, starting with the discourses of certain people in public office (representatives of such ministries as public health, national security and emergency situations), of political officials with diverse ideological creeds, and ending with the presidential speeches addressed in times of epidemic crises (the swine flu, the mad cow disease, the avian flu, the AH1N1 virus) or with the publication of certain statistical reports on the evolution of chronic diseases in populations (cardiovascular diseases, diabetes, cancer) and on the morbidity rates associated with it (Hopwood, 2007; Rose, 1999; Greenhalch and Wessely, 2004).

But the risks of individual responsibilities consists precisely in the tunnel vision of classic individualism, whereby personal responsibility is seen as the sole principle and instrument available for someone in his/her endeavour to gain and maintain health. Consequently, as many analysts (Colquhoun, 1991; Hopwood, 2007; Rose 1999) remark, the notion of individual responsibility sustains the assumption of the individual’s blame for falling ill. Under the “healthism regime” (Hopwood, 2007), the individuals experience an intense social pressure to act in ways that diminish the pleasures produced by behaviours, motivations and emotions at the expense of health. To fail in the preventive enterprise represents a sign of irresponsibility not only individual but also social. In this way, our global economy dictates that the individual responsibility towards health is more valuable than our own freedom (Rose, 1999). Therefore, the conducts, attitudes and emotions which presumably entice individuals to take the risk of falling ill are medicalized and people will feel “morally bound” to mend their unhealthy habits. Disease and any other habit that could lead to sickness become a moral failure caused by personal deficiencies: will, responsibility, morality, etc. (Rose, 1999; Skrabanek, 1994).

Over the last decade, an upheaval in the comprehension of the role of responsibility in maintaining health has taken place especially in the middle classes of developed states; this significant change was accompanied by a tendency to stigmatize and impart blame to individuals and groups in bad health. A true social phenomenon, the individual responsibility towards health has strengthened its claims over the last 30 years, assisted by and correlated with other major cultural phenomena which flood public discourses and contemporary mentality with specific issues: globalization, healthist ideology and the problem of reducing global warming (which, translates at the level of individual responsibility, was known as “environmental concern”⁸). The social integration of the ideology of health conservation and improvement provokes the insertion in the socio-political system of punishing norms for those who seek to interfere with public health, such as drug traffickers and consumers, big polluters, etc. On the other hand, this kind of fight against “the villains” of health leaves out the structural determinants that induce and favour unhealthy behaviours. In other words, certain factors related to the socio-economic environment and to the value-attitudinal context (cultural environment) lead in a highly risky way towards unhealthy and problematic behaviours. In the case of drug consumers, of persons with health problems caused by an unhealthy life-style, of polluting companies, communities or states, the economic factors, the near environment and the low degree of education closely cooperate in increasing the risk of harmful behaviour, with personal and public repercussions. Healthist ideology and even the policies that base themselves on it, present the apparent advantage of masking the socio-structural factors which provoke the negligence of, or the attempts to personal or public health. Therefore, by omitting the said causes, the ideology works in fact to the detriment of those who should be protected by it: the categories of people whose chances to lead a healthy life-style are poor from the start.

In table 1, selecting the information provided by several bibliographical sources (Greenhalgh and Wessely, 2004; Healy, 1997; Kirk and Colquhoun, 1989; Waddington, 2006), I displayed the key-points of the historical and demographic origins of healthism, understood as “medicalization of everyday life”, as an undesirable, but inevitable consequence of the political ideology which grew dominant in the closing years of the 70s and which laid on the shoulders of the individual the responsibility for many health problems (overlooking thus to instil responsibility in the actions and carelessness of politicians and of their social policies); this political ideology altered healthism in an insidious and powerful movement “which transforms health in a super-power, in a metaphor for all that which is good in life [...] nurturing therefore the private character of the fight for generalized well-being” (Crawford, 1980, pp. 200-201, cf. Greenhalgh and Wessely, 2004)⁹.

⁸ Related to environmental concern of Romanian citizens, see Nistor (2009).

⁹ for other empowerment issues, see also Baudrillard (1981/1998).

Table 1. The historical and demographic origins of healthism

<i>The macro-social causes of healthism in the developed states</i>
➤ The development of health technologies starting with the middle of the XXth century, which significantly reduced the death rate of infectious diseases and raised the life expectancy.
➤ The ambitious mission embraced by healthcare institutions and organizations (The WHO Alma Ata Declaration) which defined health not only as absence of disease (that can be stopped or ameliorated through medical technologies), but as “total physical, social and psychological well-being” (an ideal which cannot be reached by the medical profession alone).
➤ The expectancies regarding longevity and health rise accordingly.
➤ The decrease in the fertility rate offers (to certain categories of people) more free time and increased incomes, arising therefore a category of people with time and money on their hands.
➤ The emergence of the consumerist movement, especially in the USA, related with left ideologies, anti-authoritarian and civil rights movements from 60-70s, followed by right movements and free market ideologies (neoliberal).
➤ The general tendency towards reflexivity and ego-orientation (the cult of individual) in western societies produces big expectations of personal fulfilment, as well as exaggerations of the importance of awareness in the face of minor corporal symptoms and deformities.
➤ The propagation of health commercialization, coupled with the growing interest of mass media towards health issues, leads to the creation of a climate of insecurity and alarm regarding diseases and potential risks.
➤ The progressive medicalization of all walks of life, including food choices, leisure activities, mood swings and strategies of dealing with the facts of life.

Source: personal elaboration

Healthism between benefits and anxiety: the paradox of the postmodern medicine?

In western states, the scholarly literature presents a controversial phenomenon which affects a big part of the middle class (the most numerous) and which is described by those worried and wary of its consequences as *the epidemic of healthism*. As stated by the Harvard psychiatrist Arthur Barsky, in a famous article *The paradox of health* (1988, cf. Greenhalgh and Wessely, 2004), where he recorded statistically a set of data concerning psychometric researches, as well as health-related statistical

data regarding the USA population for the last 30 years, although the collective health of the nation improved considerably – translated in parameters of mortality, morbidity, general quality of life and life expectancy – there is simultaneously a significant decrease in satisfaction towards personal health. The respondents increasingly accuse a big number of somatic symptoms, more disabilities and more sickness sensations. One might invoke here the expression “social hypochondria”. Barsky (2000, cf. Hopwood, 2007) showed that healthism may be likewise connected with the success of medicine over and against illness, raising the old standards and subsequently the expectations towards the medical sector. This spiral of expectations does not help in tackling with health, well-being and subjective life quality.

For the first time in history, the modern medicine, which can be called “the biggest gain of humanity”, strengthens the illusory perspective that people are entitled not only to a life without diseases, but also to a life without symptoms, and have the right to expect nothing but perfection and harmony between the social, psychological and physical dimensions of their lives. Thus ensue the paradoxical consequences of the successful medical development, which should provoke real concerns among the representatives of health(care) systems. It is a social phenomenon that Gray (2001, cf. Hopwood, 2007) attributes to the “postmodern medicine”, called as such because it is known as such at the common sense level which expresses peoples’ lack of trust in science, their choice to deal with health and life issues through personal methods, their increased attention for risks and a better access to information.

But, despite numerous studies and even theories on the impact of healthism (Healy, 1997; Hopwood, 2007), it is surprising how few researches were conducted on the nature of this socio-cultural phenomenon, so heavily criticised, rejected and sometimes feared by the authors from medical and sociological scholarly literature. In the Romanian society these phenomena are also present and visible at the common sense level (the explosion in the last decades of magazines and sites with alternative medicine profile, homeopathic services, the wide variety of food supplements and of diets based on recipes presented as “healthy”), but they are still weakly explored and investigated systematically.

The answers to our introductory questions are for the time being still speculative in nature, seeing that the scholarly literature is so vast and contradictory; but analysing empirical studies, such as that of Greenhalgh and Wessely (2004) or Hopwood (2007), a better understanding can be provided for the cultural components of the concern for health, as well as for the consequences of promoting healthism in terms of politico-economical mechanisms and resources, and consequently, in terms of socio-psychological benefits and costs.

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Appendix

Selected Journals from different academic and public interest's areas – the spread of health-related issues (illustration):

Aaohn Journal, Acta Paediatrica, Aging & Society, Ambul Pediatrics, American Journal of Clinical Nutrition, American Journal of Epidemiology, American Journal of Health Behavior, American Journal of Health Promotion, American Journal of Human Biology, American Journal of Preventive Medicine, American Journal of Public Health, American Psychologist, Annals of Behavioral Medicine, Annals of Human Biology, Annals of Nutrition and Metabolism, Annals of Regional Science, Appetite, Applied Physiology Nutrition and Metabolism, Archives of Disease in Childhood, Archives of Internal Medicine, Archives of Pediatrics and Adolescent Medicine, Archives of Pediatrics, Asia Pacific Journal of Clinical Nutrition, Atherosclerosis, Australian Family Physician, Australian and New Zealand Health Policy, Australian and New Zealand Journal of Public Health, Australian Journal of Political Science, Biomedical Environmental Science, BMC Health Services Research, BMC Musculoskeletal Disorders, BMC Pediatrics, BMC Public Health, Breastfeeding Review, British Journal of Nutrition, British Journal of Sports Medicine, British Medical Journal, Building and Environment, Canadian Family Physician, Canadian Journal of Dietetic Practice and Research, Canadian Journal of Public Health, Central European Journal of Public Health, Child, Care Health Development, Circulation, Clinical Pediatrics (Phila), Clinical Pharmacology and Therapeutics, Collegium Antropologicum, Community Practice, Computer Informational Nursing, Conf Proc IEEE English, Medical Biological Society, Contemporary Clinical Trials, Contemporary Economic Policy, Critical Care Nurse, Critical Social Policy, Current Opinion in Pediatrics, Dance Magazine, Diabetes, Diabetes Care, Diabetes Education, Diabetes Medicine, Diabetes and Vascular Disease Research, Down Syndrome Research Practice, Duke Law Journal, Eating Behaviors, Eating Disorders, Economics and Human Biology, Environment and Behavior, Environment and Planning, Epidemiologic Perspective and Innovation, Epidemiologic Reviews, Ethnicity and Disease, European Journal of Cardiovascular Prevention and Rehabilitation, European

Journal of Clinical Nutrition, European Journal of Public Health, European Physical Education Review, Evaluation and Program Planning, Family Community Health, Family Practice, Faseb Journal, Food and Nutrition Bulletin, Future Lipidology, Gastroenterology, Gerontologist, Gesundheitswesen, Health Affairs (Millford), Health and Place, Health Education and Behavior, Health Education Research, Health Promotion International, Health Promotion Journal of Australia Health Promotion Practice, Health Psychology, Health Technology Assessment, Homo- Journal of Comparative Human Biology, Housing Policy Debate, International Journal of Adolescent Medicine and Health, International Journal of Behavioral Nutrition and Physical Activity, International Journal of Clinical and Health Psychology, International Journal of Circumpolar Health, International Journal of Eating Disorders, International Journal of Epidemiology, International Journal of Health Geography, International Journal of Hygiene and Environmental Health, International Journal of Obesity, International Journal of Pediatric Obesity, International Review of Research in Mental Retardation, Japanese Journal of Physical Fitness and Sports Medicine, JOPERD, Journal of Adolescent Health, Journal of Aging and Health, Journal of Aging and Physical Activity, Journal of American College Health, Journal of Applied Behavior Analysis, Journal of Architectural and Planning Research, Journal of Behavioral Medicine, Journal of Biosocial Science, Journal of Bone and Mineral Research, Journal of Cardiopulmonary Rehabilitation and Prevention, Journal of Cardiovascular Nursing, Journal of Child Psychology and Psychiatry, Journal of Clinical Endocrinology and Metabolism, Journal of Community Health Nursing, Journal of Community Psychology, Journal of Environmental Planning and Management, Journal of Epidemiology and Community Health, Journal of Evaluation of Clinical Practice, Journal of General Internal Medicine, Journal of Health Communication, Journal of Health Economics, Journal of Historical Sociology, Journal of Human Nutrition and Dietetics, Journal of Interprofessional Care, Journal of Law and Medicine Ethics, Journal of Nutrition, Journal of Nutrition Education and Behavior, Journal of Paediatrics and Child Health, Journal of Park and Recreation Administration, Journal of Pediatric Endocrinology and Metabolism, Journal of Pediatric Psychology, Journal of Pediatrics, Journal of Physical Activity and Health, Journal of Physiological Anthropology, Journal of Planning Education and Research, Journal of Psychosomatic Obstetrics and Gynecology, Journal of Public Health, Journal of Public Policy and Marketing, Journal of Regional Science, Journal of School Health, Journal of School Nursing-, Journal of Science and Medicine in Sport, Journal of Sport and Exercise Psychology, Journal of Sports Science and Medicine, Journal of Teaching in Physical Education, Journal of the American College of Cardiology, Journal of the American College of Nutrition, Journal of the American Dietetic Association, Journal of the American Geriatrics Society, Journal of the American Medical Association, Journal of the National Medical Association, Journal of the Royal Society of Architectural Historians, Journal of the Royal Society of Medicine, Journal of Transcultural Nursing, Journal of Transport Geography, Journal of Transportation and Engineering, Journal of Urban Health, Journal of Urban Health-Bulletin of the New York Academy of Medicine, Journal of Urban Planning and Development, Journal of Women and Aging, Journal of Women's Health, Landscape Architecture, Leisure Sciences, Leisure Studies, Mayo Clinic Proceedings, Medical Journal of Australia, Medicine and Science in Sports and Exercise, Medicine and Sport Science, Morbidity and Mortality Weekly Report, New Directions for Youth Development, New Zealand Medical Journal, North Carolina Medical Journal, NSW Public Health Bulletin, Nutrition Journal, Obesity, Obesity Reviews- 20, Occupational Therapy International, Patient Education and Counseling, Pediatric Diabetes, Pediatric Emergency Care, Pediatric Exercise Science, Pediatric Nursing, Pediatric Research, Pediatrics, Pediatrics in Review, Perceptual and Motor Skills, Pharmacy World and Science, Physiology & Behavior, Plos Medicine, Policy brief (UCLA Center for Health Policy Research), Preventing Chronic Disease, Preventive Medicine, Proceedings of the Institute of Civil Engineers-Municipal Engineer, Proceedings of the Nutrition Society, Psychology Bulletin, Psychological Report, Psychology of Sport and Exercise, Public Health, Public Health Nutrition, Quest, Rehabilitation Nursing, Research Quarterly For Exercise and Sport, Review of Agricultural Economics, Scandanavian Journal of Public Health, Science of the Total Environment, Science and Sports, Sex Roles, Singapore Journal of

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Tropical Geography, Social Science and Medicine, South African Medical Journal, Southern Economic Journal, Southern Medical Journal, Sports and Leisure Management, Sports Medicine-, Transport Reviews, Transportation, Transportation Planning and Technology, Transportation Research Part A-Policy and Practice, Transportation Research Part D-Transport and Environment, Transportation Research Record, Trans R Soc Tropical Medicine and Hygiene, Urban Studies, Western Journal of Nursing Research, Wisconsin Law Review, World Development.

Source: *Active Living Research Organization* - www.activelivingresearch.org, last retrieved February 12, 2013.

Note: this list corresponds to 2008.

THE VIRTUES AND LIMITS OF THE BIOMEDICAL MODEL FOR INTERPRETING BEHAVIOURS RELATED TO SUBSTANCE MISUSE AND ADDICTION

ION COPOERU^{1,2,*}, SEBASTIAN MOLDOVAN^{1,3}

ABSTRACT. During the last centuries, medical models gained ascendance over other models for interpreting behaviors related to illness and suffering, which have been eventually almost entirely supplanted. In time, the medical model became one of the norms for the self-assessment of human behavior in general.

Our paper emphasizes the idea that, in connection with the social phenomenon of substance misuse and addiction, medicalization and medical practices have an ambivalent role to play in society: on the one hand, they help connecting with our fellow people in the process of taking care, health-wise, of them, and on the other hand, they possess an invasive, controlling and disciplinarian force.

The medicalization solution is nevertheless salutary in situations when all kinds of marginalized populations are still considered undeserving of medical treatment.

Key words: substance misuse; addiction; biomedical model; medicalization; ambivalence

Introduction

When one thinks about describing human behaviour, there are certainly many ways to do it. During the last centuries, medical models gained ascendance over other models for interpreting behaviours related to illness and suffering and which have been eventually almost entirely supplanted. In time, the medical model has been therefore internalized by individuals⁴ and became a norm for the self-assessment of the human behaviour in general.

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⁴ Robert A. Nye, "The evolution of the concept of medicalization in the late twentieth century", in *Journal of History of the Behavioral Sciences*, Vol. 39(2), Spring 2003, pp. 115-129.

Being successful, there is no wonder that this model has been largely applied to social, political, and cultural spheres of life and that its basic assumptions remained unquestioned. However, worries about the tendency to portray social and psychological aspects of life as *medical* problems slowly surfaced and they were examined carefully and earnestly at the time. The “*critique of medicalization*”, developed in the 1960s in the work of Thomas Szasz, R. D. Laing, Michel Foucault, and others, provided a new understanding of psychiatry, the penal system, and the public health systems⁵ and draw the major lines for their reform.

Medicalization theory has been at the heart of medical sociology or the sociology of health and illness for nearly 40 years (Zola 1972; Freidson 1970) and is also vital to medical anthropology (Hogle 2002; Lock 2001, 2004), the history of medicine (Nye 2003; Sinding 2004), medicine itself (Chervenak and McCullough 2005), bioethics (Bergeron 2007), and beyond. The still robust medicalization thesis is that the legitimate jurisdiction of Western or scientific medicine began expanding by including new domains of human life (such as alcoholism, drug addiction, and obesity) by redefining or reconstructing them as falling properly within *medical* (rather than legal, religious, etc.) domains (e.g., Ballard and Elston 2005; Conrad 1992, 2005, 2007; Conrad and Schneider 1980a, b).⁶

The term “medicalization”⁷ is charged with a multitude of meanings, sometimes even contradictory. In cultural contexts of tardive modernization, like Romania, medicalization kept rather a positive meaning especially when referring to helping people live their lives and reducing their suffering. However, treating deviances⁸ from societal norms constitutes its basic, fundamental sense. Shame and guilt became thus associated with all kinds of transgressive behaviour.

Just like medicalization, medical practices are, in their own way, a complex phenomenon. On one side, practice is always a kind of “mangle” of human and material agency, in which theory and material world mutually transform one another⁹. On the other hand, medical practice is a form of helping the other or caring for the other, distinguished, for example, from the adversarial practices¹⁰,

⁵ *Ibid.*

⁶ *Handbook of the Sociology of Health, Illness, and Healing, Handbooks of Sociology and Social Research*, 2011, Part 3, 173-199, DOI: 10.1007/978-1-4419-7261-3_10; Adele E. Clarke and Janet Shim, *Medicalization and Biomedicalization Revisited: Technoscience and Transformations of Health, Illness and American Medicine*.

⁷ Medicalization, <http://en.wikipedia.org/wiki/Medicalization>. Accessed on March 14, 2013.

⁸ It is significant that the inaugural work of this trend - Conrad's “The discovery of hyperkinesis: notes on the medicalization of deviance” (1973) - discussed aspects of deviance.

⁹ Pickering, *The Mangle of Practice. Time, Agency, and Science*, University of Chicago Press, Chicago, 1995.

¹⁰ Arthur Isak Applbaum, *Ethics for Adversaries: The Morality of Roles in Public and Professional Life*, Princeton University Press, Princeton, 1999.

such as the legal ones. Therefore, helping practices are tightly connected with our understanding of the other and of ourselves, with a particular cultural configuration or “epoch”. Moreover, they constantly help to build our own connections with the other. An epoch can be better understood if seen through the ways in which the other has been constructed within medical practices and institutional systems of health.

I. Medicalization and ambivalence

We are able to grasp by now that medicalization and medical practices have an ambivalent role to play in society: on the one hand, they help connecting with our fellow people in the process of taking care, health-wise, of them, and on the other hand, they possess an invasive, controlling and disciplinarian force which lends to all facts of life and society that fall within their remit a highly negative, almost unshakable connotation:

“Once a condition is classed as medical, a medical model of disability tends to be used rather than a social model. Medicalization may also be termed pathologization (from pathology), or in some cases disease mongering. Thus the process of medicalization is based on a biomedical model of disease, one that sees behaviours, conditions or illnesses as a result of malfunctions.”¹¹

But even this negative vocabulary sometimes reveals itself useful for certain clarifications, as for example in the case when the concept of illness helps the management of what seems unmanageable: the amorous passion¹². These happy exceptions aside, the fact is that medicalization, especially within scholarly literature, is depicted mostly through its many criticisable features: more and more areas of life are being defined in terms of health and illness; medicalization, gradually separated from the profession of medicine, came to target forcefully phenomena of deviance from all walks of life, which led to and enabled harmful and sometimes illegitimate forms of conformity (strictly clinical, medical ones, or social and psychological conformity); if seen from the point of view of a conflict with religion over the pool of improper human behaviours and which Barbara Wootton deplored in her article “Sickness or Sinn”, from 1956¹³, it might be said that medicalization won an improper victory: “the victory of medicine over morals”¹⁴. From a historical perspective, Robert Bernasconi proposes an analysis of

¹¹ Arunima, Sarvdeep Kohli, “Medicalization: A Growing Menace”, in *Delhi Psychiatry Journal*, Vol. 15, No. 2, October 2012.

¹² Mihaela Ursa, “The Theory of Amorous Illness”, in *Philobiblon* – Vol. XVII (2012) – No. 2, p. 434.

¹³ Cf. Barbara Wootton, “Sickness or sin?”, in *Twentieth Century*, 159, May, pp. 433-442.

¹⁴ See also, Joseph E. Davis, “How medicalization lost its way”, in *Society*, Volume 43, Number 6 (2006), 51-56, DOI: 10.1007/BF02698486, Symposium: The American Way of Medicalization.

what he calls the “medicalising or biologizing racism” of the last century, which resulted in segregation, apartheid, eugenics, and, eventually, sterilization and the holocaust¹⁵.

II. Tackling addiction

In view of this selective register of some of its genealogical traits, medicalization or the (bio)medical model of tackling addiction and other deviance phenomena has been mostly considered wanting with regard to its claims of universality: Caroline J. Ackera, for example¹⁶, studied the models of opiate addiction in the history of USA during the XXth century and contended that the significant changes in the patterns of defining this addiction (as a quasi-legitimate disease, a full-blown disease, a stigma, and, finally according to a non-stigmatising Parsonian disease model) were due essentially to the demographic and social modifications of drug-related practices from decade to decade. In this way, the author contests the claims to universality of the biomedical model of addiction, which, in fact shifts and changes from one epoch to another according to peoples’ new habits and behaviours. Likewise, Jennifer Carroll provides an analysis of the way in which the Western biomedical models, with their unexamined assumptions, are interpreted by the Ukrainian authorities and organizations from the field of addiction “according to the cultural presuppositions, existing networks, and organizational strategies of local actors”¹⁷. Furthermore, the author demonstrates how the alleged universal validity of these models is in fact denied when tried to be applied as such and put into contact with local mores, customs, and management trends; in reality, the idea of a smooth translation of the western biomedical models to culturally different areas and actors, remains only an ideal.¹⁸

¹⁵ Cf. Robert Bernasconi, “The Policing of Race Mixing: The Place of Biopower within the History of Racisms”, in *Journal of Bioethical Inquiry*, June 2010, Volume 7, Issue 2, pp. 205-216.

¹⁶ Cf. Caroline J. Ackera, “Stigma or Legitimation? A Historical Examination of the Social Potentials of Addiction Disease Models”, in *Journal of Psychoactive Drugs*, Volume 25, Issue 3, 1993, pp. 193-205.

¹⁷ Cf. Jennifer J. Carroll, *Addiction, Gender, and the Limits of Public Health Solutions to IV Drug Use in Ukraine*, submitted to the AIDS and Anthropology Research Group for consideration for the 2011 Graduate Student Prize; Submitted October 15, 2011.

¹⁸ For example, Jennifer J. Carroll shows in the same article (*Addiction, Gender, and the Limits of Public Health Solutions to IV Drug Use in Ukraine, op. cit.*) that the reinterpretation of western biomedical models of HIV- prevention and addiction treatment, when in contact with the Ukrainian local culture, comes to include traditional significations of Ukrainian gender roles: “this has produced gendered tropes of addiction, which frame to men’s addiction as a biomedical disease with potential for successful medical treatment and recovery and women’s drug use as a personal weakness that lies beyond the scope of medical help”.

These approaches to addiction and deviant behaviours emphasize the fact that the biomedical models are in fact much more influenced by cultural and social factors, and that ultimately their predominance over the other ways (social, legal, religious, etc.) of controlling such forms of human conducts should be challenged. The medicalization solution is nevertheless salutary in situations when all kinds of marginalized populations are still considered undeserving of medical treatment¹⁹.

On the other hand, there are also studies that go beneath the monolith surface presented by an all-around dominant biomedical model in defining and controlling problematic behaviour in general. They show that, in certain cases of deviant conduct, there is in fact a “layering of institutional control and a multi-institutional management of social problems”²⁰ that involve simultaneously medical, legal and sometimes even religious instances at play: for example, the criminalization of mental illness, the medicalization of criminal behaviour, or the already mentioned alternative “sickness or sin” discussed by Barbara Wootton. Against those who plead in favour of simply replacing a biomedical-style approach of problematic behaviour with a purely social one, there is thus proof that the two of them, being sometimes tightly blended together, must be jointly studied as different but interlaced layers of the same dominating and regulating inter-institutional system. Therefore, a simple swap between the two patterns of dealing with addiction and deviance in general – the biomedical and the social one – appears to be, in some cases at least, a hasty, insufficiently thought through solution.

Consequently, the ambiguity of the biomedical model of tackling deviance and addiction must be seriously emphasized, grasped and understood: on the one hand, there is nowadays not only a medicalization, but an over-medicalization of the forms that supposedly should rein in such problematic behaviours, which is more and more driven by non-medical players and which takes on progressively the negative meaning of “the corporate-sponsored selling of sickness”²¹. This is all the more worrying as the boundaries between ordinary life and medical illness become in this way more blurred and confusing. It seems therefore that in this context the solution to over-medicalization is twofold: de-medicalization, and putting a stop to the ever-increasing commercialization of medicine and medical practices.

¹⁹ David E. Smith, Editor's Note: *The Medicalization of Therapeutic Communities in the Era of Health Care Reform*, pp. 93-95.

²⁰ Cf. Tait R. Medina and Ann McCranie, “Layering Control: Medicalization, Psychopathy, and the Increasing Multi-institutional Management of Social Problems”, in *Handbook of the Sociology of Health, Illness, and Healing, Handbooks of Sociology and Social Research*, 2011, Part 2, pp. 139-158.

²¹ Cf. Arunima, Sarvdeep Kohli, *op. cit.*, p. 257.

On the other hand, the biomedical model must be also acknowledged according to its most successful features: it provides medical access to populations which were previously excluded on grounds of race, poverty, ethnicity, social status and standing in community, etc. Furthermore, we cannot escape this biomedical dimension because we all possess, in virtue of our very being and essence as humans, a body, which constitutes the genetic and physiological foundation of our entire life: our personal identity and life-long biography depend widely on the genetic inheritance and the physio-psychological well-being of our body.²² Since it is impossible to do away with it, we should pay attention to the implications that medicalization entails for the ordinary people exactly because we can thusly achieve two objectives: to highlight the negative effects of medicalization upon their life, and to emphasize the solutions to over-medicalization that stem precisely from the ordinary life of individuals. Moreover, the inter-personal relatedness of human behaviours, which cross-cuts professional and institutional settings and practices, seems to provide the fundamental framework for a comprehensive and concrete perception of the many different “ordinary” aspects of the life of an addicted or deviant person.

Conclusions

We tried in this paper to approach the problem of addiction by taking into account the ambiguities of the biomedical model which exerts a powerful influence upon all walks of life, in comparison with alternative or concurrent systems of controlling problematic behaviour, such as the moral, the penal or the social ones.²³ From this perspective, we underlined the negative and positive features of medicalization, providing equally a short inventory of the solutions already discussed in the scholarly literature: medicalization does not account for the dimension of co-construction, being grounded on unilateral professional perspectives; it is unable to form a common horizon of understanding of the intra- and inter-professional cooperation. Therefore, there is a need for an account of addiction which is situated beyond the professional practices that are currently associated with it: beyond the punitive practices, the unilateral practices and the professional practices as such, in order to give way to non-formalized interactions, wherein lay people and

²² See for example, the way in which even the notion of body autonomy is comprehended by taking into account the biomedical automatisms of the physical, physiological and physio-psychological body: cf. Regine Kather, *Autonomy: as Self-Determination against, or as Self-Trancendence to Other*, in B. Olaru (ed.), *Automny, responsibility and health care. Critical reflections*, Zeta, Bucarest, 2008, p. 39.

²³ These ones are analyzed in another paper, entitled “Paradigms and Politics of Addiction”, to be published in Philobiblon. Transylvanian Journal of Multidisciplinary Research in Humanities.

ordinary citizens (patients, family, relations) can have their contributions to the medicalization or de-medicalization of certain forms of addiction publicly acknowledged and recognized as such.²⁴

We also sought to justify the necessity of jointly researching both the external and the internal point of view on addiction: firstly, the treatment, the procedures and technologies should not be established solely from without, in a medical, mechanical manner, but also from within, by paying attention and fructifying the contribution of the lived experience of the addicted person. Secondly, the equivocation of medicalization produces consequences which affect primarily the ordinary life of ordinary people. Consequently, a shift in the approach of addiction from a purely external perspective to a more subjective, internal one seems appropriate precisely because it is in the power of common people to provide an important part of the solutions to the problems created by the biomedical model. This is all the more so as the ordinary people's life-decisions and self-identity are at stake when conceptualizing health or illness. Finally, a better knowledge about the addictive subjectivity helps in building the appropriate type of institutional strategies and policies for tackling addiction.

In time, addiction has been framed either as a knowledge problem, or as a will problem. In both cases, social or psychological stigmata were attached to this condition even when a parallel biomedical model was in place for curing or at least for dealing and controlling the addiction: for example, alcoholism, gambling, etc. But, from an interpersonal perspective that addiction is a problem of interpreting (socially, medically, religiously, etc.) the behaviour of the others and of ourselves. And if thought-out properly, addiction reveals itself to be ultimately a problem of misinterpretation: either in the historical sense of the multiple stigmas which straitjacketed the addicted person and obliterated our access to understanding addiction in conformity with its essential, subjective kernel; or in the hermeneutical sense according to which addiction is not the form of an insight in what someone is, but rather the form of an insight into what someone is not; it's the story of the blindness to the blindness of the other.²⁵

²⁴ See also, Linell P., *Discourse across boundaries : On recontextualizations and the blending of voices in professional discourse*, in: *Text & Talk. An Interdisciplinary Journal of Language, Discourse & Communication Studies*, Ed. by Sarangi, Srikant, DeGruyter, 2009.

²⁵ "Thus, paraphrasing Paul de Man, philosophical hermeneutics' interpretation of interpretation is "in truth" an "allegory of interpretation." The proper name of the interpretation it describes is misinterpretation; the event of understanding it recounts is a completely different event. The story is good but the characters and the plot are different. For it is not the story of its insight into insight but the story of its blindness to blindness as insight." (Adrian Costache, *Between Hermeneutics and Deconstruction: A Critical Approach to the Question of understanding in Gadamer*, Lexington Books, Lanham, in press.

THE ROLE OF CASE MANAGEMENT IN THE ASSISTANCE FOR SUBSTANCE USE DISORDERS IN ROMANIA

SEBASTIAN MOLDOVAN^{1,2}, ION COPOERU^{1,3},
DANIELA CORODEANU AGHEORGHIESEI^{1,4}

ABSTRACT. The case management appears in the National Antidrug Agency (NAA) documents as a *sui generis* service of a major importance for the integrated service system offered to consumers of psychoactive substances in Romania, in order to guide and facilitate the users' journey throughout the service universe they need. The study gives a brief description of the legislative framework of the NAA system, and the projected dynamics of its functioning, while detailing the role they envisioned for the case management. Based on the few evaluation reports on the way it functions, it may be stated that the degree of system integration is low, and that the case management is barely functional. As a way of responding to this situation, we propose that the NAA assume a complex adaptive systems approach to its own mission, and develop a social level kind of case management so as to increase the social responsiveness to the issues of substance abuse.

Key words: substance abuse, case management, services systems, complex adaptive systems, Romania, National Antidrug Agency

Introduction

Case management (CM) is largely considered one of the most important acquisitions in the panoply of methods in the field social services. The CM was developed during the last century, along with the profession of social worker, while more and more diverse public institutions were targeting the advancement of citizens' welfare - especially of at-risk and vulnerable groups -, as a strategy meant to reconcile and connect the activity of all relevant institutions for the benefit of a "case". It is employed in fields such as child protection, homeless persons support, elder care, palliative care, mental health, as well as in the treatment of alcoholism

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and toxic dependence (Vanderplasschen et al. 2004, Walsh and Holton 2008). In this last domain, CM appears particularly relevant, because of the usually complex issues of the addicts, who suffer from multiple pathologies, and who need a multi-faceted and continuously reconsidered assistance, and the more so, as the addiction becomes more and more acknowledged as a chronic condition that involves impaired self-control (Vanderplasschen 2006, Kelly and White 2010).

However, the CM also faces several conceptual and practical difficulties. Although highly widespread, case management is not very well defined, but rather characterized mostly by its basic functions: assessment, planning, linking, advocacy, and monitoring. In addition to that, the drug users' lifestyles, the real life situations, the limitations and requirements of the system and programs, they all prompt the application of CM to be highly subjective task, marked by decision-making dilemmas that significantly influence the outcomes of this intervention. The acute episodes and some other unforeseen problems make the CM hardly programmable, as many services function in isolation, entertaining but poor collaborations were even operating in a professional climate of diverging perspectives and rivalry. One of the toughest decisions to be made in the context of CM concerns the degree of active participation of the client, both paternalism and dependence on the manager, as well as exaggerated reliability on clients' motivation and ability to link with services should be avoided. What comes out of the CM practice is that the trust-based relationship between manager and user, through its motivational and educational force, is the most important success factor. From this point of view, to consider that CM is a set of standardized functions that could be done in an objective and unbiased way, does not seem realistic. CM varies not only from one domain to another, from one model to another, or from one program to another, but it also differs from one manager to another, and even within the framework of the activity of the same manager. Therefore, the dilemmas and the diversity are not disturbing factors, but rather the material and form of the CM (Vanderplasschen 2006, Kolind, Vanderplasschen, and De Maeyer 2008).

There is evidence that the typical problems of the social systems, particularly of the health care systems - and if we were to get closer to the issues of the consumption, of the mental health domain - are characterized by complexity and 'wickedness', which deems as inadequate any way of defining and approaching them through linear programming and control (Sweeney and Griffiths 2002, Tien and Goldschmidt-Clermont 2009, Raisio 2010, Hannigan and Coffey 2011, Sturmberg and Martin 2013). This aspect may be among the motives due to which, despite the degree of flexibility to the case, the CM efficiency proves inconclusive (Hesse et al. 2007, Vanderplasschen et al. 2007). In this situation, it would serve better to revise the CM philosophy on the basis of the notion of the adaptive complexity of social systems (Jervis 1998), and on the acknowledgement of the personal nature of health, illness, and recovery (Sturmberg 2009, Sturmberg, O'Halloran, and Martin 2010, Sturmberg, O'Halloran, and Martin, 2012).

The current study intends to analyse the philosophy and, insofar as data are available, the CM practice within the assistance service system for the consumers of psychoactive substances in Romania, a system that was created by the National Antidrug Agency (NAA), during the past decade. The only studies that were conducted up to the present, are the few self-evaluations done by the NAA on the functioning of the system. No research has ever confronted the principles of the system to its current situation.

At first, we shall give a brief description of the legislative framework of the NAA created system, and then of the projected structure and dynamics of its functioning, with some details on the role the CM is expected to play. After that, we shall compile a synthesis of the self-evaluation reports done by the NAA (2007-2009) on the actual functioning of its own services, and on their interaction with other existent services (state or NGOs). The image that emerges from these reports, its interpretation from the standpoint of the theory of adaptive complex systems, as well as a proposition regarding an alternative way of approaching the NAA mission, which was inspired by this theory in response to its current situation, these all complete the exposition.

The NAA service system

The NAA is a governmental organization set-up in 2002 under the supervision of the Ministry of Internal Affairs, with the mission of establishing the general notion and of coordinating, at the national level, the politics in the area of illicit drug consumption, and by extension of any psychoactive substance (Botescu 2008). The NAA has re-oriented the national strategy from an initial perspective that was dominated by the preoccupation with the control of trafficking and with preventing consumption, towards a more comprehensive approach, which would include an integrated and functional system of assistance targeting consumers and their recovery. Although a legislative framework, as well as a few medical and psychosocial assistance services, had already been launched, the “heart” of the entire system started beating only in 2004. Prior to it, 47 Drug Prevention and Counselling Centres subordinated to the county prefectures, were established through the cooperation between certain ministries, which shook hands in order to prevent the illicit consumption of drugs. In 2004, these were incorporated and re-organised in the NAA under the broader name of Drug Prevention, Evaluation and Counselling Centres (DPECC), which fulfilled the role of coordinating the NAA programs and campaigns at local/county level.⁵

⁵ For more detailed descriptions of the national legislative framework and treatment system, one can consult the yearly national EMCDDA Reports at the National Anti-drug Agency’s website <http://www.ana.gov.ro>, for example (National Report 2011, pp. 16-19, 46-52, National Report 2012, pp. 198-205). A brief presentation, on the EMCDDA Romania country profile, at <http://www.emcdda.europa.eu/>.

The legislative conditions necessary for the patient approved inclusion of the drug user into an integrated program of assistance, based on services of a medical, psychological and social nature, have been formulated by the Government Decision no. 1359/2000, and were later extended in Law no. 522/ 2004, and administered by the Government Decision no. 860/2005 for the approval of its Implementation Regulations.⁶ Chapter 4 of these Regulations provides the normative framework for the organisation and functioning of the integrated consumer assistance programs. Such a program is defined as “a complex set of therapeutic, psychological, and social programs, which are complementary, simultaneous, or sequential, and which materialise in an individual assistance plan” (art. 11.1). Also, chapter 5 sets the general functioning standards for the public service providers in the field. Another important reference points in the completion of the normative framework of the system are represented by the 2006 publication of the “Minimum compulsory standards of the case management in the care of drug user” and of the “Methodology for the formulation, amendment and implementation of the customised care plan for the drug users”, and by the 2008 publishing of the “Criteria and methodology for the authorisation of the centres that provide services for drug users and the Minimum compulsory standards of the organisation and operation of the centres that provide services for drug users”. The 2008 document inventories all types of service providing centres that are acknowledged by the Romanian system.⁷ At the core of the system the NAA has placed the DPECC units that have the role of a coordinating service, and as the central operating method of coordination was chosen the CM. The purpose of this was to ensure the structural integration and the functional continuity that are considered indispensable to the success in reducing drug demands through recovery and social reinsertion of consumers.

⁶ Government Decision no. 1359/2000 for the Enforcement regulation of the Law no. 143/2000 on preventing and countering the illicit drug trafficking and use, *Official Gazette of Romania*, Part I, no. 46 of 29 January 2001. Law no. 522 of November 24, 2004 amending and supplementing the Law no. 143/2000 on preventing and countering the illicit drug use and trafficking, *Official Gazette of Romania*, Part I, no. 1155 of December 7, 2004. Government Decision no. 860/2005 approving the Enforcement regulation of the Law no. 143/2000 on preventing and countering the illicit drug use, further amended and supplemented, *Official Gazette of Romania*, Part I, no. 749 of 17 July 2005.

⁷ NAA Decision no.16 of October 2, 2006 approving the Compulsory minimal standards of the organisation and operation of the centres that provide services for drug users and the authorisation methodology for these centres, *Official Gazette of Romania*, Part I, no. 899 of 06 November 2006. NAA Decision no. 17 of October 2, 2006 approving the Methodology for the formulation, amendment and implementation of the customised care plan for the drug users, *Official Gazette of Romania*, Part I, no. 899 of 06 November 2006. Order No 1389/513/282 approving the Criteria and methodology for the authorisation of the centres that provide services for drug users and the Minimum compulsory standards of the organisation and operation of the centres that provide services for drug users, *Official Gazette of Romania*, Part I, no. 830 of 10 December 2008.

The structure of the NAA system

The structure of the national system of medical, psychological, and social assistance created by NAA is the product of two perspectives, a geometrical or architectonic perspective that comprises the sum of services arranged in accord with the assistance offer, and a functional or dynamic perspective according to the assistance demand or, in other words, the providers and users standpoint. The NAA documents⁸ describe the architecture of the assistance system in terms of many taxonomies, whose purpose is a more and more complete approach of the multiple aspects that the interaction between the lifeworlds involved in assisting the target group engages, that is the personal universe of the consumer, the social universe in which this is immersed, the service system universe, and the professional activity universe.

The description of this architecture in the legislative texts, and especially in the accompanying Standards of the project is detailed, but the great number of taxonomical categories, and sometimes the lack of precision of the language the authors use, compelled us to re-systematise the information, in order to have a synoptic image of the system. In that aim, we shall also use a formal representation method specific to the sets theory. The system categories are the following:

1) Assistance domains. According to the bio-psycho-social model adopted, these are medical, psychological, social (including educational), and judicial.

2) Assessment areas: personal medical history and drug use record, biomedical conditions and current complications, psychological and/or psychiatric co-morbidity and complications, social and family conditions, and legal situation. $\{H, B, P, S, L\} = \{A_i\}$

3) The services and intervention types are elementary units of the system: biomedical, psychological, social, emergencies, harm reduction associated to consumption, detoxification, testing for drugs, maintenance on opiate agonists, maintaining abstinence with antagonists, syringe exchange, reinsertion, counselling and psychotherapy. $\{S_b, S_p, S_s, S_e, S_{hr}, S_d, S_t, S_m, S_a, S_{se}, S_r, S_c, S_{psy}\} = \{S_i\}$

The services may be classified under many categories, according to the institutional entities that provide them (centres), to the institutional specific ways in which they offer assistance (means), and to the role they play in the users' course throughout the system (levels).

4) The centre types that offer the services - in one or more of the assistance domains, through one or more assistance methods, and which are ordered according to assistance levels (see below) -, are as follows: DPECCs, detoxification program

⁸ Along with the last three documents quoted above, we based our analysis on a detailed accompanying volume, namely (Abraham 2005). Hereafter we will refer to (Abraham 2005) as the Standards.

centres (substitution and non-substitution detoxification), harm reduction centres (Methadone-substitution treatment, fixed and/or mobile centres for syringe exchange), rehabilitation and reinsertion centres (Integrated Addiction Care Centre, mental health laboratory, day centres, half-way houses, therapeutic communities, hospital wards, others). {DPECC, Dx, HR, IACC, MHL, DC, H, TC, W, ...}= {C_i}

5) Assistance methods refers to types of technology and professional expertise required in assistance, that is emergency assistance, low and high intensity outpatient assistance, residential or inpatient treatment. {E, LO, HO, R, I}= {M_i}

6) Assistance levels: 1st level – identification and referral of clients to specialised services and treatment attending to basic medical and social needs (emergency services, primary medical care, general social services, harm reduction services); 2nd level – consists of specialised units of the public health system and DPECC, which provides for specialised care (multi-disciplinary evaluation, formulation of the individualised plan of care, specialised care, simultaneous as well as continuous), monitoring and coordination between all levels of intervention (management case), and referral to the next level; 3rd level – ensures specific care at a high level of specialisation (detoxification, therapeutic communities, centres running in day-time etc) and social-professional reinsertion. {L_i}

7) The types of treatment integrated programs (TIPs) are another category that comes out of the principle of matching the services to the identified needs of the users. According to the gravity of the bio-psychosocial problems, there are three drug-free programs and one harm reduction program. Therefore: a) lower level detoxification program (TIP₁) provides basic and specialised medical services; abstinence support based on opiate antagonist medication; psychological and/or psychotherapeutic counselling; drug testing; social care; legal advice; information, education and training for social participation and access to community-support services; b) detoxification programme (TIP₂) which, in addition to TIP₁, provides substitution or non-substitution detoxification, outpatient or inpatient; c) detoxification and stabilisation programme (TIP₃) which provides, in addition to TIP₂ the medical/psychological or psychiatric/social and legal services specialised for drug related and/or drug caused diseases in need for immediate intervention; d) harm reduction programme (TIP₄), with the following options: substitution programme based on opiate agonist medication (methadone prescription and administration), syringe exchange and/or other harm reduction measures, providing counselling services for a risk-free drug use, information provision on current treatment services; coverage of basic needs: food, hygiene, clothing, and rest.

8) The last category comprises the service providers, both from the public governmental sector (NAA, the Ministry of Health, the Ministry of Justice), and from the non-governmental and private sector.

The architectonic structure of the system results from the way the services are distributed in a 4-dimensional space generated by the four major taxonomic categories: the centres, the methods, the levels, and the programs. Each service belongs - not entirely exclusively - to a centre, and offers assistance through a certain method, on a certain level, while it is included in at least one assistance program. Therefore:

$$S = \{C_i\} \times \{M_j\} \times \{L_k\} \times \{TIP_l\}$$

The other perspective, the functional or dynamic one, presents the way in which a problem consumer may use the assistance offer of this system. If we were to imagine the use as a spatial-temporal journey through the geometric structure of the system, then this has three clear stages: the entrance, the course, and the exit. The comprehensive, continuous, and integrated character of assistance – the fundamental requirement of the NAA strategy – demands that the trajectory of this course throughout space S be permanently passing through at least one service. In order to realize this ideal, the project managers have envisioned three ways of directing this course: the multidisciplinary evaluation (initial, continual, and final re-evaluation), the compilation of an individual assistance plan, and case management.

The evaluation is the one that practically makes the concept of users' "needs" to be operational. To be more precise, the personal universe U_p of the user is analysed from the perspective of the person's way of being in the five areas $\{A_i\}$ that we mentioned before, according to a series of variables that are specific to each area, which leads to the drafting of the biographic, clinical, and environmental portrait ("the characteristics", in the language of the Standards). This portrait contains, in addition to the individual use needs of the assistance system $\{N_i\}$, cultural information, implications of the life environment, and also the attitude towards assistance, as well as the relapse potential.

$$U_p \cap \{A_i\} = \{\{N_i\}, \text{Info, Environment, Attitude, Potential relapse}\}$$

Further on, the compilation of an individual, customized assistance plan is realized in two stages. First of all, there is the confrontation of personal needs with a vast set of orientation criteria $\{O_i\}$, which are over 100 (although not all distinct), that are distributed according to the five evaluation areas and in relation with the four types of susceptible assistance plans (therefore within the matrix of the product $\{TIP_l\} \times \{A_i\}$), which is a procedure that helps generate four risk categories $\{R_i\}$: 1) minimal risk in all areas; 2) minimal risk of severe acute intoxication, abstinence syndrome that is medically approachable immediately, and minimal risk in the biomedical area, although presenting more direct risk in any other area; 3) medium – high risk of severe acute intoxication, abstinence syndrome of a moderate/ raised acuteness, which is medically unapproachable in a quick way, or moderate risk in the biomedical or psycho-emotional area, in addition to a heightened

risk in any other area; 4) severe risk due to intoxication/withdrawal, or the biomedical or emotional/behavioral signs/symptoms.

$$\{N_i\}_p \cap \{O_i\} = \{R_i\}_p$$

Each of these risk categories recommends that the person follow one of the four treatment integrated programs.

$$\{R_i\}_p \rightarrow \{TIP_i\}$$

As each of the TIPs were conceived as a cluster of services, aggregated by the assistance goals, so as to cover as well as possible the universe of needs pertaining to the population of the problem consumers, the particular situation of each user determines the selection of the services out of the recommended TIP, in order to develop a specific program, which is called the customized assistance program (CAP). This selection depends not only on the set of personal needs and the risk category, but also on a series of contextual factors within the system (the availability of the specific services, the degree that these services are already burdened, the availability and work load of the personnel), as well as the expected assistance duration.

$$\{CAP\}_p = \{N_i\}_p \cap \{S \cap \{Availability\}_p \cap Duration_p\}$$

Obviously, the value of the whole assistance system depends on what happens after the user's journey through it. For any therapeutic journey, especially in the case of addictions - considering the multiple aspects of the issues, the necessity for more interventions or assistance services, the lengthy evolution and the long-term perspective of the recovery process -, the final result will depend on the outcome of each separate intervention (differential result), and also on the sequentially followed trajectory (integral result, path-dependence i.e., the every-moment dependence of the situation on the cumulated effect of previous interventions). In order to ensure the anticipated outcomes, it is essential to adequate each intervention to the user's evolving situation. This generally implies a permanent re-evaluation and any prospective re-adjustment of CAPs in the context of the system's availability. The task of achieving this permanent adaptation at the interface between the assistance system and the user's personal universe is entrusted to a *sui generis* service, which is the case management.

What is case management?

The law defines CM as follows: "a coordination method for all medical, psychological and social services, which consists in identifying the consumers' needs, in planning, coordinating, and monitoring the implementation of the measures stipulated in the personalised assistance plan for the drug consumer, to the degree that resources

allow it” (NAA Decision, No. 17/2006). Generally speaking, we may say that the role of CM is to facilitate the best possible interactions between U_p and S or, more specifically, to build a guiding service for the journey a user does through S , respectively through the subset of appointed services, at the best intensity, timing, and the maximum availability that his personal needs and identified risks demand, so as to have his journey lead to the social personal recovery and social reinsertion of the user.

Practically, the CM has to fulfil the following $\{F_i\}$ tasks: a) engaging or initiating a work relationship with the user; b) user evaluation, $U_p \cap \{A_i\}$; c) determining the risks $\{R_i\}_p$ and establishing the program TIP_p ; d) elaboration of plan CAP_p and its inclusion in the program; e) implementation of the measures from CAP_p ; f) monitoring and evaluating the implementation of measures in CAP_p ; g) re-evaluation CAP_p and the continuation of program or, if needed, modifying CAP_p or TIP_p ; h) ensuring the collaboration between providers; i) advocacy; j) termination of assistance. If we consider each user’s trajectory throughout the system has got the following major stages $\{P_i\}$, entrance phase (identification and “pre-treatment”), intensive assistance and “post-treatment” or continual assistance, then to each of them it might be necessary to exercise one or more CM tasks, in such a way that the progression of the assistance continuum through CM presupposes, according to case-based specific data, one subset in the set $\{P_i\} \times \{F_i\}$.

For the present discussion it is important that, all through this course, the functioning of the CM is based on a series of principles that are listed in the normative document as follows: 1. preserving the continuity of assistance services by means of a central contact element; 2. adequacy to the needs of the beneficiary; 3. promoting the interests of the beneficiary; 4. pragmatism; 5. anticipating needs; 6. flexibility; 7. observing human rights; 8. case management is based on community. Their meaning is detailed in the Standards, which depicts them slightly differently and in another chronology of priorities (unique element, mutual orientation, advocacy, community based, pragmatism, anticipatory, flexible, lightly cultural).⁹

The significance of these principles cannot be stressed enough than by saying that the whole purpose of the system created by NAA depends on how CM is understood and implemented. Documents place first the principle of continuity and seem to consider the purpose of the other principles as subsumed to this one, in the general perspective of ensuring an integrated system which is not only architectural, through the offer of services, but also functional through their use. However, the other principles, especially adequacy, flexibility, pragmatism and advocacy are actually critical to the type of system created, one based on

⁹ In the most part, the chapter on CM from the Standards translate excerpts from (SAMHSA 2000). Some translation options are debatable, yet the accuracy of the Standards text compared to its sources is beyond the purpose of this article.

standardization, programming and control or one based on adaptation and learning. To explain this we may start from the meaning of the advocacy function, considered as a basic function of CM. The Standards state that "CM is oriented to make services fit the patient rather than make patients fit the services." (p. 92)¹⁰ Obviously, the fundamental task of the CM is to mediate an on-going functional interface between the user's personal universe and the system's institutional universe, in its specific context or formally, to permanently generate a series of CAPs the implementation of which will lead to the positive results expected. But when specifying the difference between the treatment and CM, the Standards state that CM is focused on assisting the user to obtain the necessary support resources (p. 105), hence it can be understood that the user only has to choose from a pre-set menu of options provided by the system, situation in which he is just a consumer of personalized services, and CM is just a user friendly type of service (p. 65). In this case, although the principle of adequacy and the risk of inadequacy to the user's needs are often emphasized (e.g. warning against a literal application of the criteria of orientation {O_i} (p. 47), and noting that there are situations in which they cannot be applied (p. 62), or that TIPs have limitations (p. 65), the actual participation of the user remains within the boundaries of compliance, even though they are permanently required by interventions in the highest interest of the user. The Standards states, however, that this interest can be achieved by coercion ("the treatment should not be voluntary in order to be effective", p. 15), that it does not always coincide with the wishes of the user ("advocacy does not mean that the patient always gets what he wants", p. 117) or that he can sometimes be overcome by higher interest of the "public security" (p. 118), statements which are questionable and have major ethical implications.¹¹

On the other hand, the Standards state several times that, through the structure (p. 65) and its functioning (pp. 105, 111) the service system can be guided or even centered to the user. For example, "Case management is grounded in understanding of clients' experiences and the world they inhabit - the nature of addiction and the problems it causes, and other problems with which clients struggle" (p. 97). The purpose of the reevaluation of the user's experience and knowledge of the world he lives in, which can help increase the trust of the parties, seems to be also directed towards a more appropriate selection of the existing support resources, therefore towards a better compliance.

¹⁰ All the bracketed references within this paragraph are to the pages from the Standards.

¹¹ And which largely depend on the concept of addiction. The idea of the least restrictive intervention possible appears several times (pp. 45, 73, 80, 97), but the significance of these restrictions is never addressed. Note in this context that NAA does not yet have an ethics code of its activities. The ethical aspects of the coercion to treatment and confidentiality in Romanian context are addressed in (Vicol et al. 2008) and (Vicol et al. 2009).

On the other hand, however, if this knowledge of experience was itself recognized as a resource, perhaps the most important resource, which, although he holds it, the consumer cannot bring in the most beneficial self-worth, but can use the professional expertise for this purpose (including the CM), then the entire value orientation of the system can move from focusing on the professional expertise and on the professional world to a real focus on the individual user and his personal universe. Reorientation of the system equally involves the changing of the role from consumer to co-producer who is as active epistemologically as the professional producer and the capacity of all services and of the whole system to learn from the consumer's experience and adapt to the consumer's personal universe and to the social ecology in which this universe is incorporated.

In such a perspective, the reason of the first principle of CM, "offers the client a single point of contact with the health and social services systems" would be not only to ensure continuity of care through a single point of reference to guide the user, but also to ensure an adaptive response of the services to the user's situation, constantly learning from him.¹² This kind of intervention is already formalized in the advocacy principle, but its current meaning is to intervene to facilitate the use of the existing professional resources or, at most, to develop them according to the user's needs (p. 117, 119), but within the limits of the system and not necessarily through co-participation of the user. The active, two-way, mutually adaptive transfer of knowledge facilitated by the CM, through which the irreducible character of the personal health, illness and recovery could be recognized, may be the common value shared by all stakeholders in the system and could be the prerequisite condition to a proper attractor of centring the system of services in the user's personal universe.¹³

Does CM work?

In order to see CM at work, we realized a review of the self-evaluation reports done by the NAA (2007-2009) on the actual functioning of its own services, and on their interaction with other existent services (state or NGOs).

¹² A possible recognition of such a reverse transfer of knowledge can be identified in the Standards when it is accepted that a complete standardization of care is neither possible nor desirable - "clinical thinking cannot be substituted by any standardization instrument" (p. 44) – if we agree that clinical thinking is based on interacting experience with patients (Montgomery 2005).

¹³ This condition might not be sufficient. In addition to an equally coverage of the four dimensions of the user's U_p in space S , and to a balanced relationship on the expertise-experience polarization axis and directivity participation, also relevant for person-centeredness are both the centralization-distribution dynamics, regarding resources, and the individual - community dynamics, with regard to the aetiopathological topology of the "case". The medical model, for instance, insulates the "disease" of the addiction within the body, indeed the brain, of the addict. This is highly questionable (Graham et al. 2008).

In the first one, *“The evaluation of the quality and accessibility of services provided by the national network of Centres for Prevention, Evaluation and Anti-drug Counselling”*, was done in 2007, by the NAA Studies Centre (Lefter, A., A. Botescu 2008). The DPECC services had been evaluated nationwide by its personnel, by some of its users and by some drug - both licit (alcohol and tobacco) and illicit - consumers who did not access it.¹⁴

According to the DPECC professionals, the domain where the actual and ideal situation are at the greatest distance is that regarding the services portfolio, and the domain where the real and ideal situations are at the greatest closeness is the one covering the coordination and collaboration with other institutions. However, the 2007 situation concerning the access to DPECC services showed that the majority of beneficiaries had been sent in by law institutions, only a mere third had accessed them on their own, and under 10% had been referred there by local institutions or organisations, which cannot denote a good collaboration, as the authors of the study note (p. 8).

Most of the alcohol consumers benefited from the medical services provided by psychiatric hospitals, a part of them benefited from services rendered by NGOs and AA groups, and all too many of them underwent nothing more than detox programs. The illicit drug users accessed more frequently the detox departments of hospitals, the medical and social assistance services of penitentiaries, and the psychological, as well as social and vocational orientation counselling offered by DPECC.

The unmet needs that were identified in the consumers' answers refer to the improvement of existing services, so as to have them offer integrated assistance besides the medical one. Most of the participants asked for services that, in addition to medical treatment and accommodation, would provide them with individual or group psychological counselling - most appreciated within the DPECC -, with occupational and social reinsertion therapy, and facilitate their personal development. A recurrent failing of the system they noticed was related to group communication and peer education, as many of the respondents suggested the setting up of support groups similar to the AA ones, and of therapeutic communities. The illicit drug consumers showed support for the methadone substitution programs and recommended their expansion nationwide.

As for the CM, it is not directly addressed, however, a picture emerges that the deficit of services and the oblique and unproblematic mention of CM among the issues relevant in comparing ideal and real functioning seem to point to a underestimated importance of CM rather than an excellent practice of it.

¹⁴ In the case of professionals, the “Horizon Model” technique was used. This allows for the difference between the real and ideal situation of the services to be visible after the domains in need of improvement have been identified through the “Panel” technique.

A second ample study on the services targeting drug consumers took place in the capital city, Bucharest, in 2007 (Oancea 2007). It intended to “x-ray” the service system by starting from the premise that its actual state is due to some objective factors, pertaining to resources are allocated, as well as to some subjective factors, i.e. the perceptions of the service producers and users on the *modus operandi* of the system and of its components.¹⁵ The study highlights some main failings of the system: the reduced personnel, financial restrictions, and most frequently, the poor inter-institutional collaboration, which was noticed in most of the answers. The collaboration is seen as formal or dysfunctional (Oancea 2007, pp. 26, 28, 30, 31, 43, 57), and certain services are either insufficiently developed or utterly non-existent (Oancea 2007, pp. 30, 34, 36, cf. p. 67). Due to these reasons, there is no possibility to ensure the continuity of the assistance, especially during the “pre-treatment” phase, namely the preliminary evaluation of the consumers’ situations and needs, or during the “post-treatment” phase, as the support services for maintenance on a substitute or through abstinence, and those that aim the socio-professional community reinsertion of the person are the most deficient of all. Also, the centres most often lose contact with patients, which indicates the absence of the CM the law stipulates.

The accounts given by professionals also contain fragments of “subjective production” of the consumers. These confirm the lack of continuity in the therapeutic chain, as the latter focuses mainly on medical services, and that deprives patients of support for the most difficult issue of their transition from dependence to recovery, i.e. their motivational ambivalence. There is more than the acuteness of the craving to the matter. It is also about the lack of commitment to a lifestyle that would enable one to put aside the “nostalgia” about the addicted lifestyle, by way of experiencing satisfactions. (pp. 41-42)¹⁶

¹⁵ Through individual and group interviews, they have generated a description (brief historical account, objectives, services, beneficiaries, resources, collaborations), a SWOT analysis, and a series of recommendations from 16 service providers (6 sanitary units, 5 NGOs - offering prevention (4), harm reduction (3), maintaining abstinence (1), social reinsertion (3) services -, 3 law units, one social assistance unit, and a DPECC), all done considering the place these have within the local assistance system.

¹⁶ Among the 16 providers that we enquired there is also an association of past and present drug users from Bucharest, whose goal is the prevention of consumption through educational activities and the observance of drug users' rights regarding their access to high standard medical and social services, their legal right to information and communication. The declared scepticism towards the likelihood of positive outcomes in the fight against consumption of the respondent representing this group is rather interesting. He considers that the only efficient way is to cease the trafficking and conduct prevention campaigns, and that the direct interventions with addicts would only serve in emergency cases (p. 26).

Under the rubric “problems they face”, the report also presents a synthesis of the responses received after the direct inquiry of consumers. These state they face financial and material difficulties, health issues, and stigmatisation within the community and within the sanitary system (pp. 37, 38, 68), and police abuses (pp. 36, 38), that they have problems accessing the health and substitution services. Also relevant to us, they mention the lack of information on existent services, especially on the absence of psychological support services, the lack of those services that offer recreational activities simultaneously with and post detoxification, as well as of therapeutic communities.

Highly interesting is that, besides the evaluation of one of the 6 DPECC in the capital, the study also includes an insight into the entire national DPECC network.¹⁷ The legal framework created by the NAA confers DPECC the status of local coordinators of the demand-reduction strategy, among other things, a fact that inevitably places them at the core of the issue. The report notes that these centres “have to ensure the integration of all services (medical, psychological, and social) into on program for the assistance of the drug user.” (p. 27). A series of shortcomings are pointed out in a direct manner, such as attracting most of the beneficiaries through legal institutions (penitentiaries, police, probation, p. 28, cf. also the national reports), the absence of psychiatric services from the general services portfolio (pp. 27-28), a certain reticence coming from consumers (“at present, the offer of this centre is unattractive to the wards of the in-patient unit” p. 38) and also from the community. The last one is more likely due to what the report coins as the “contradictory” image the DPECC system, which is at permanent risk of being assimilated to a police service, because of its ascription to the Ministry of Internal Affairs (pp. 28-29; see also p. 30 for the reticent attitude of local authorities).¹⁸

However, as it was stated before, the main problem of the DPECC arises from the detection of the poor inter-institutional coordination. In the chapter dedicated to the national network, the SWOT analysis states that “Certain difficulties - unspecified though, our note - in the organisation of the services network at local level block the functioning of the system, specifically the development of the referral system between local institutions”. The report gives this issue the first final recommendations, stating that “in order that DPECC truly exercise its legally regulated functions, mainly the ones related to evaluation, and case management,

¹⁷ In addition, the report included two summaries - suggestively entitled “the incoherences of the system and mending propositions at local level...” - concerning the services rendered in the cities of Cluj-Napoca and Iași. The data provided, confirm the general trend; the services are relatively few, the ones that are missing are particularly those regarding the socio-professional reinsertion, their faulty accessibility, and the difficulties in the operation of the referral system.

¹⁸ A situation that would aggravate later, in the interval 2009-2011, by the temporary assignment of the NAA under the General Inspectorate of Police.

these centres should create their own service providers networks, which should function according to the model proposed by the legislation". A little below this statement, the report proposes "the creation of a unique referral system inside the addictions services system that would allow the observance of the current legislative framework, and the continuation of treatment for the beneficiaries of various services" (p. 66). The legislative framework favours DPECC both as an "entrance gate" for the assistance services system, and as regards the "case management", although it does not render it exclusive. In this context, it is worth mentioning that the services with the most promising experience regarding the insurance of an integrated services network that appear in the report are: an NGO (The Centre for Community Care, which has also a centre for the integrated assistance of addictions, similar with the IACC functioning under the umbrella of the NAA), and a service from the social assistance network (The General Direction for the Assistance and Protection of Children, District 1, that has a centre for the integrated assistance of drug users, which is different from IACC only in that it lacks the permanence of a doctor). This is the only place in the report where a statement like "there are cases that prove the efficiency of the program of integrated assistance for addictions" can be found (p. 55). This should be the reason why the authors call their report, "an alarm-signal regarding the need for a systematic and inter-institutional approach in the planning of the medical and psycho-social services targeting drug consumers" (p. 9).

Two years later, in 2009, a third NAA sponsored study comes to light (Lefter and Paiu 2009).¹⁹ The investigation domains were: the way the services could be accessed, the conditions of access, the types of services offered, the profile of beneficiaries, the self-evaluation of the assistance activity (the SWOT analysis), the integration of the service into the local assistance system ("difficulties in relating" and mending propositions), absent but necessary services.

The DPECC situation within the service system, just as the report presents it: of the investigated five units, only one reports good relations (with minor problems), two units admit rather formal relationships ("more on paper"), another one signals reservations coming from partners due to a confusion of roles (they think services are overlapping), while the appreciations of the last unit are missing from the report. Also, the other services deem the relationship with DPECC as: positive - 4 cases (pp. 21, 26, 26, 27), amendable - 2 cases (p. 21), dysfunctional - 1 case (p. 26),

¹⁹ Sixty interviews have been taken by professionals of the services in those regions. Most of them were conducted in the capital, where 26 1st level units (medical emergency services, referral services to specific programs - to penitentiaries, probation, social assistance), 5 2nd level (DPECC units), and 29 3rd level units (specific assistance and reinsertion) were investigated. 17 of them belong to the non-governmental sector. The publication simply contains the raw data of the research, without interpretation and discussions.

desirable - 2 cases (p. 26). Furthermore, CAIA, a specialised DPECC unit is appreciated as positive 3 times (19, 33, 34) and negative once (p. 33). Overall, DPECC/CAIA are mentioned only 13 times by the other 55 institutions.

With respect to the underdeveloped services, the most frequently named are detox services, therapeutic community, psycho-social reinsertion, substitution treatment, day centre, protected-dwelling place, self-help group, Centre for Mental Health, double-diagnosis services, protected workplace, which means the majority are in the "post-treatment" zone. Moreover, the insufficient number of services of any kind is to be lamented, as this situation can be correlated with two other problems that were frequently highlighted, i.e. the under-financing, and the lack of personnel or of a suitable qualification in the field of addictions.

The case management is rarely evoked, and that either suggests the poor preoccupation for it, or the unfamiliarity with the notion, or even both. To the question about which were "the services that were absent from the assistance system, but necessary at regional level", only one person responded "case management. I don't know who should do it, although I know it's absolutely necessary" (p. 30).

However, the issue of case management is prominent when identified in the subtext of the inter-institutional relations. A statement such as "there is no therapeutic chain, only separate institutions that offer services" (p. 35) appears to be far from marginal, and to add the missing services to the chain is only one of the aspects that need intervention. In this sense, the report emphasizes three propositions. "The setting up of a department with specialists trained in the provision of like services; which would insure the connections between various services that have the ability to grant support to potential beneficiaries, a contact that should be established at institutional level and regulated inter-institutionally" (p. 18). "There should be a network made up of representatives (workers) of each institution with responsibilities in the field. This group should elaborate a work procedure, so that each institution might know afterwards where to refer a beneficiary and to which services" (p. 27). In the end, "the unification at central level, of the responsibilities of all institutions that deal with the integrated assistance of drug users and of other beneficiary categories (alcohol users, children of the street, Aurolac huffers, etc.); the coalition of institutions (Ministry Of Health, Ministry of Justice, the National Anti-Drug Agency, Social Assistance and Child Protection General Directorate) into a unique Institution that would provide services to drug consumers" (p. 38).

Discussions

The results of these reports could be considered obsolete, given the period in which they were held - shortly after the beginning of DPECC, the support system units invested primarily with the achievement of CM. However, the institutional

uncertainty in which NAA found itself immediately thereafter (2009-2011) and which was completed only recently, the latest data presented by the national reports of the years 2011 and 2012 about the situation of the development of services, the fact that the year which has just ended was the end of the 2005-2012 Strategy,²⁰ all these warrant the prudent appreciation that the very problematic situation of the development of the integrated system and of the role of CM in using it has not changed significantly from the one seen in the three studies presented here. The causes and the implications of this situation are a very significant research topic. The assumption that the situation is due to the incomplete and difficult implementation of the law, namely of the standards of the national integrated system, is plausible. We believe that the research conducted here draws our attention also to the principles which form the basis of the system's design, and not just to the way they are applied.

A brief analysis of the first paragraph of the Standards (Abraham 2005, p. 8) may be illustrative of the relevance of such insights.

Drug consumption and trafficking constitute a concern for all the countries in the world. Given the complexity, the multidimensional nature and the characteristics of dynamism and change, the difficulties in the therapeutic, structured and efficient approach are obvious. It is particularly important to give priority in providing a comprehensive assistance to drug related problems, addiction and other consequences. Such an approach to assistance is a strategic component of demand reduction policies by defining the system of planned and monitored interventions in order to achieve maximum efficiency within the given time, with the minimum resources possible and in the least restrictive way for the patient.

Purpose: To develop a model for organizing support services for drug addiction, so that they respond to the needs of beneficiaries, allowing structured and systematic approaches that can be evaluated on the basis of some objective parameters that enable further implementation of minimum standards of quality and good practices.

Thus, the premise of the NAA strategy for assistance for psychoactive substance consumption is the complexity of the phenomenon and the difficulty of the structured approach. The significance of the complexity involved here can be easily underestimated precisely because of its emphasis. The Standards seem to interpret it only as a challenge that advocates for the identification of a strategy to plan and manage interventions capable of producing the predetermined

²⁰ The fact that out of the three therapeutic communities and 15 IACCs stipulated in 2005-2012 National Strategy documents no TC and only 5 IACC are functioning up to now, is surely telling. Moreover, the preliminary results of an on-going companion research point to the poor capacity of practitioners to develop efficient collaborative practices, related to excessive formalisation of professional interactions, associated with the prevalence of a style of management based on formal rules and purely administrative means (Copoeru et al., 2013).

outcome of consumption reduction. What if this complexity is not reducible because it expresses the nonlinear, unpredictable interactions of a multitude of human agents?

A number of details in the cited paragraph prove the adoption by the designers of the NAA system of a rather linear, reductionist and deterministic systematic approach. Firstly, the entire issue is placed in the consumption-trafficking or supply-demand paradigm and is the result of political and medical control options, as what is sought for is the social trajectory of the substance reifying its juridical (legal, illegal) and medical (psychoactive, non-psychoactive) status. However, the reduction of the demand is established from the very beginning as the central - if not the only - objective of the care system, regardless of the personal universe of the target group, of the significance of the interaction between the person, the substance, and the effects (both of consumption and trafficking), so that results may actually be quite different from those intended (e.g., shifting risk, changing addictive behaviors to others, and so on).

Even in the case of this objective, improved by the requirement to meet the needs of the beneficiaries, the idea of development of models and their trans-contextual replication is based on the premise that the most important aspect influencing the outcome of an intervention in a person's life is based on the expert application of some techniques and professional standards. In reality, at least in the field of psychotherapy - a vital part of the system - among the factors responsible for the success of the intervention, the model of the intervention and the technique used seem to contribute the least to the result, behind allegiance and especially the therapeutic relationship. As such, one should admit the superiority of the "weak", non-directive intervention as compared to the "hard", directive ones (Duncan, Miller, Wampold, and Hubble, 2009, Bracken et al. 2012).

We also recognize here the dominant paradigm of the "evidence-based" practice in curing and caring professions (medicine, psychotherapy, nursing, social work) which, despite good intentions, contribute greatly to reducing complexity through the statistical data which it operates with (Sturmberg and Miles 2013). Their logic, as well as that of the standards, is to eliminate subjective factors and give the possibility to plan and replicate, but what if subjectivity is, at least sometimes, the most important factor, though it introduce the unexpected? (Smithson and Bammer 2008, Lipsitz 2012) In the most general terms, the problem is to admit or not that beyond the "needs" of the consumers - which are "operationalized" through evaluation criteria -, beyond the professional standards and the objectives of political strategies, assistance is an interaction between two categories of complex dynamic systems, that of the consumers' personal universes and the professional universes, each embedded in their social ecology universes. Hence, the fundamental

question is whether planned and prescriptive approach allows a resonant interaction between these systems or, rather, causes dissipative interactions. When the second situation arises, then the alternative is that of an approach enabling mutually adaptive interactions, and this means that the dynamic systems of the policies of interventions and of the services *meet* the dynamic system of the consumer, i.e. learn from it (Grossmann et al. 2011). As argued above, CM looks like playing an important role in this respect.

Instead of conclusions

What could NAA learn from the situation revealed by their research, as well as from the complex adaptive systems' theory? If the need of development of assistance service network and the improvement of cooperation between them is obvious, what can be done while the financial and human resources are poor and professionals' inertia against required change is not negligible?

The NAA has just launched the draft of the new National Strategy, for 2013-2020, which is emphatically based on several principles, among which the "social participation" ranks the second, after "social responsibility".²¹

But as the principle stated in the Standards which reads "Case management is community-based" if understood only as an out-reach strategy really does not seem to capitalize on the recovery capital located in communities, so the community responsibility "within the sphere of action" and the participation only oriented towards the development and diversification of NAA defined services does not seem to address in a truly holistic manner the problems associated with psychoactive substances use, and therefore to promote more personalised initiatives and to entrain a whole community response (White 2009). However, the multi-sourced nature of addiction (Kovac 2013) do require complex adaptive, multi-looped knowledge production and transfer, in which the consumer contribution be much more than compliance, a life course in human flourishing (Broner et al. 2001, Daddow and Broome 2010).

The central roles that NAA and DPECC occupy in the system - that of coordinator of national policies and of coordination between all levels of care -, could be adapted to the present situation, responding to the needs reported by developing a strong advocacy component in relation to the communities, institutions, organizations and their services, which do not seem to be sufficiently aware of the extent, severity and complexity of drug consumption. Society itself, perhaps more than consumers, needs a case management.

²¹ The Romanian version is available at http://www.mai.gov.ro/Documente/Transparenta%20decizionala/Strategie%20_SNA%202013-2020.pdf

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COMUNITĂȚILE VIRTUALE DE STUDENȚI – PARTENERI ÎN MANAGEMENTUL POST-TRATAMENTELOR PENTRU PERSOANELE CU ADICȚIE LA SUBSTANȚE

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ABSTRACT. Romania is increasingly confronted with the issue of substance abuse, particularly among young people. This article displays and discusses the results of a comparative research concerning the perception and opinion of MA students from two university centers from Romania concerning the persons who are addicted to substances. On the basis of questionnaires applied to 152 participants, there have been collected data on students' availability to get involved in supportive virtual communities which contribute to the recovery of addicted persons.

Key words: substance addiction; virtual community; recovery; MA students.

Orice incursiune teoretică cu privire la existența și rolul comunităților virtuale trebuie să înceapă cu identificarea înțelesului său original, acel de comunitate.

Oxford Dictionaries⁴ definește “comunitatea” (substantiv) ca fiind 1. “un grup de persoane care locuiesc în același loc sau care au o anumită caracteristică în comun” sau 2. (substantiv de masă) “condiția de împărtăși sau a avea anumite atitudini și interese în comun”. Cuvântul își găsește originea în engleza medievală târzie care l-a preluat din franceza veche *comunete*, care l-a rândul său a avut drept sursă latinescul *communitas sau communis*.

Dicționarul US English Dictionary⁵ adaugă “2.Sentimentul de comuniune cu ceilalți, ca rezultat al împărtășirii de atitudini, interese și obiective comune”.

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⁴ <http://oxforddictionaries.com/definition/english/community?q=community>

⁵ http://oxforddictionaries.com/definition/american_english/community

Conform sintezei realizate de Amanda Styros⁶, etimologia cuvântului *comunitate* își are originile în limba latină clasică *commūnis* (comun, public); limba latină veche - *comoine*[m], **comoenus* (“împărtășit, general”), *communitatem* (nominative: *communitas*) – *com* (cu, împreună), *munire* (a apăra, a fortifica); din engleza veche *mænan* (“to mean, signify, consider”); din cuvintele Proto-Indo-Europene **ko-moin-i*, și **(e)meyə-* (“a schimba”). Punând în comun toți acești termeni, comunitatea înseamnă “ceea ce împărtășim, schimbăm, gândim în comun, înțelesul pe care îl punem împreună pentru a consolida ceea ce este comun”.

Apariția Internetului a făcut posibilă ca această comunitate să existe *virtual*, adică într-un mediu în care întâlnirile nu sunt față în față, ci *online*, prin intermediul tehnologiei informatice.

Toate definițiile date de diverși autori conceptului de comunitate virtuală au drept punct comun faptul că fac trimitere la un grup de mai multe persoane care interacționează între ele, colaborează, fac schimb de informații, soluții la probleme, discută și dezbate pe teme și cauze de interes comun, împărtășesc gânduri, emoții, sentimente, puncte de vedere și experiențe, “se consultă cu experții, oferă și solicită sprijin” (cf. Ilioudi, 2012, p. 2), într-un mediu online. Cu alte cuvinte, au același motiv de a fi în același loc, în același timp, chiar dacă sunt la mii de kilometri distanță, și uneori au altă profesie, vârstă, etnie, culoare sau naționalitate. Ei locuiesc virtual în această comunitate fiindcă au un avantaj, “câștigă” ceva, de obicei un câștig psihologic (comunitatea “WELL”, cf. Howard, Rheingold, *The virtual community: homesteading on the electronic frontier*⁷) dar poate fi și economic (se poate face publicitate la anumite afaceri care doresc să își consolideze valoarea brandului sau să acceseze ușor un anumit grup de clienți⁸, la produse și servicii). Trebuie remarcat că această “locuire” comună se realizează printr-un aport adus de fiecare. Este nevoie de o “monedă de schimb”, adică “furnizarea de informații de interes și de înaltă calitate, timp, resurse, onoare, legături spirituale” (cf. Riding Gefen, 2005), deoarece membrii comunității respective generează împreună conținutul informativ/educațional al acesteia. În esență, sunt rețele sociale dat fiind că membrii sunt “legați” între ei prin niște “ițe”, interesele comune, în special de împărtășire de cunoștințe, în ciuda faptului că nu întotdeauna se cunosc între ei, nu s-au văzut niciodată față în față.

⁶ <http://www.technologyofcommunity.net/the-etymology-of-community/>

⁷ *The Virtual Community*, the electronic version, Chapter One: The Heart of The Well, <http://www.rheingold.com/vc/book/1.html>

⁸ Silvia Nistor, *Valoarea comunitatilor virtuale depaseste un miliard de dolari*, <http://www.wall-street.ro/articol/IT-C-Tehnologie/26885/Valoarea-comunitatilor-virtuale-depaseste-un-miliard-de-dolari.html>; eResearchCorp, *Comunicarea dintre brand și social media 2012*, http://www.eresearch.ro/eR/#/news_ro

Există mai multe motive pentru care indivizii preferă să participe la rețelele sociale și de împărtășire a cunoștințelor: ajutor sau informații folositoare și recunoaștere în schimb, un simț al contribuției și sentimentul de a avea o anumită influență în mediul lor. Mai mult, din perspectiva psihologiei sociale, oamenii se simt gratificați dacă primesc un răspuns direct de la semenii lor în urma efortului depus (input-urilor oferite) (cf. Safko, 2009, p. 49).

Lapachet⁹ justifică existența comunităților virtuale într-o lume a consumerismului prin faptul că “este o încercare de atenua din alienarea cauzată de societatea modernă”.

Susan Baim (2005, p. 145) definește comunitatea virtuală ca fiind un grup de indivizi care interacționează pe Internet pe o temă de interes reciproc. Funcția sa (ceea ce o și diferențiază de un website de Internet) este de matrice multi-direcțională “pentru fluxul de informații între toți participanții” (idem). O caracteristică esențială este și faptul că este un loc virtual de întâlnire cu *o bază frecventă, în aceeași formulă*, cu “simțul permanenței și al consistenței între membri”, ceea ce o diferențiază de grupurile de discuții sau *chatrooms-uri* (comunicare de la persoană la persoană, iar actorii se pot schimba continuu (Ridings&Gefen, 2004). Mai mult, acestea funcționează pe baza respectării unor principii, și reguli, deoarece pot exista restricții la acces, în funcție de anumite condiții care țin de profilul comunității, și pot fi și excluseri din cadrul acesteia, dacă se încalcă valorile, principiile și chiar statutul comunității (Condiții și termeni).

Preece (2000, citat de El Morr ș.al. 2012, p. 2) consideră patru elemente care dau formă unei comunități virtuale: persoanele care interacționează social, pentru a juca diferite roluri sau pentru a-și satisface nevoile sociale; un scop - motivul pentru care comunitatea există, politicile care guvernează interacțiunea dintre persoane și un sistem computerizat care reprezintă suportul pentru aceste interacțiuni.

În abordarea lui Hemtsberger (citat de Baim,2005, p. 147), comunitatea virtuală este un “proiect colaborativ online” la care oamenii paticipă voluntar din mai multe motive: câștigă cunoștințe pentru uzul personal (adevăratul motiv care generează dorința de a participa), își îndeplinesc un obiectiv comun cu alți membri participanți la comunitate, experimentează plăcerea provocărilor ridicate de activitățile în care se implică, dezvoltă-apreciază relațiile în comun, materializează/validează definiția individuală a înțelesului de schimb. În aceeași idee, Ridings& Gefen (2004) menționează alte motivații ale participării: schimbul de informații, schimbul de sprijin social, prietenia, recreerea. Pornind de la enumerarea realizată de Lapachet¹⁰, pot fi evidențiate și avantajele: oamenii obișnuiți au posibilitatea

⁹ Jaye A.H. Lapachet, http://besser.tsoa.nyu.edu/impact/s94/students/jaye/jaye_asis.html, School of Library & Information Studies, University of California, Berkeley, CA 94720, accesat februarie 2013

¹⁰ Jaye A.H. Lapachet, http://besser.tsoa.nyu.edu/impact/s94/students/jaye/jaye_asis.html, School of Library & Information Studies, University of California, Berkeley, CA 94720, accesat februarie 2013

să valorifice avantajele aduse de tehnologia modernă (comunicare rapidă și comodă, fără deplasare); se crează forumuri unde se pot exprima opinii și găsi răspunsuri pe diferite teme de interes; se reunesc persoane din diferite locuri din lume, fără bariere geografice, politice și de timp; sunt eliminate într-o mare măsură comportamentele de discriminare (nu există bariere de rasă, sex, orientare sexuală, dizabilități); pot facilita întâlniri fizice în urma dialogului și interacțiunilor virtuale; oferă participanților un simț al autonomiei (fiecare individ poate căuta comunitatea care îl reprezintă, se poate exprima liber, direct, într-un mediu relativ anonim); oferă acces la informații validate (sfaturi, servicii - cum ar fi consultanța psihologică, medicală, alte tipuri de consiliere, etc.), deci “consumatorii” au o anumită siguranță, fiindcă unele domenii sunt moderate de experți; nu există constângeri în exprimarea opiniilor.

Studiul realizat în România în 2010 de către SMARK și eResearchCorp¹¹ în rândul a peste 800 de tineri între 18 și 34 de ani, arată că pentru aceștia rețelele sociale înseamnă libertate, alegere, și împărtășirea cu alții de “bucăți mai mari sau mai mici din viața reală” iar activitatea (postare mesaje, etc.) în cadrul acestora materializează „dorința de marcare a teritoriului în scopul de a crea sau crește vizibilitatea... în fața prietenilor săi sau a utilizatorilor dezirabili”.

1. Rolul comunităților virtuale în domeniul sănătății

Comunitățile virtuale în domeniul sănătății au căpătat formă la jumătatea anilor 1990, ele fiind integrate pe parcurs ca o parte a unui program de management pentru diferite boli sau patologii (King et al., 2009, pp. 331–338). În cadrul acestor comunități sunt oferite pacienților informații medicale, noutăți și descoperiri din cercetarea medicală pentru anumite boli, precum și suport psihologic pentru pacienții afectați care se confruntă cu aceleași probleme și, în plus, aceste comunități oferă un locus pentru “advocacy patient”. Aceste platforme bazate pe interacțiunile virtuale oferă pacienților și confort, comoditate și intimitate, prin faptul că ei se pot bucura de acestea de acasă, din fața calculatorului (idem, 2009, pp. 331–338), fără a se simți stânjeniți în actul de consiliere (Agheorghiesei (Corodeanu)&al., 2011).

Rolul lor de suport în gestionarea situațiilor în care indivizii se confruntă cu probleme de sănătate neprevăzute sau boli cronice este evidențiat în multe lucrări din literatura de specialitate medicală. Skiba&Dulong (2011, p. 282) menționează în acest sens unele studii care au confirmat efectul pozitiv al accesării comunităților virtuale: persoanele cu HIV au afirmat că pot afla informații și cunoștințe despre boala lor, găsesc sprijin social, pot să facă față activ bolilor și situațiilor cu care se confruntă (Kalichman 2002, Kalichman et al, 2003); pacienții-femei cu cancer la

¹¹ “Studiu SMARK: Cum se comportă tinerii români în rețelele sociale”, 8.07.2010, http://www.smark.ro/a_21166/studiu_smark_cum_se_comporta_tinerii_romani_in_retelele_sociale.html

sân s-au bucurat de un suport social general mai mare, de apreciere, tangibil, prin utilizarea de măsuri psihologice standardizate, dincolo de diferențele rasiale/entice.

La acestea se adaugă rezultatele cercetării lui Leimeister, Schweizer, Krcmar (2011, p. 72) care arată în urma unui studiu în rândul unor pacienți bolnavi de cancer germani că aceștia regăsesc prin participarea în comunitățile virtuale (și prin relațiile virtuale implicite acestora) îndeplinirea nevoilor sociale.

Gunther Eynsenbach (2005, pp. 97-98) consideră că în domeniul sănătății aceste comunități virtuale “au adesea funcția și caracterul unui grup de auto-suport, și de aceea sunt numite grupuri de suport electronic, unde [...] pacienții cu o anumită boală, consumatorii cu un interes legat de sănătate comun, cum ar fi lăsatul de fumat sau pierderea în greutate, sau furnizori informali de îngrijire a sănătății (nonprofesionali), fac schimb de informații și experiențe”.

În argumentarea privind efectul pozitiv al acestor comunități virtuale poate fi adus chiar numărul impresionant de Yahoo! Groups existente pe tema sănătate și stare de bine (care ajunsese în 2003 la 22000) iar autorul anterior menționat precizează că în general acestea sunt înființate și gestionate de participanți („consumer-driven”) și foarte rar de profesioniști în sănătate (fără referire la cele strict legate de caracteristicile sistemului spitalicesc, practica medicală, sistemul de plată a asigurărilor).

Această opinie face diferența clară între *virtual health community* și *virtual health-care community*. Aceasta din urmă reunește profesioniști din îngrijirea sănătății și pacienți cu scopul de a îmbunătăți calitatea serviciilor din acest domeniu, și în același timp asistă profesioniștii și cercetătorii în activitățile de zi cu zi (cum ar fi monitorizarea pacienților și consultațiile medicale), ceea ce va asigura un mediu sigur și consolidat, facilitat prin colaborarea din cadrul comunității virtuale respective. În cadrul lor se oferă membrilor servicii medicale universale cu ajutorul tehnologiilor ICT avansate. Membrii săi sunt medicii, pacienții, cercetătorii, membri ai familiei pacienților (Ilioudi, 2012, p. 1, 7).

2. Metodă

2.1. Scopul și obiectivele cercetării

Studiul nostru are ca punct de plecare rolul pozitiv al comunităților virtuale în susținerea pacienților și îmbunătățirea serviciilor de îngrijire medicală, prin implicarea furnizorilor informali.

Studiul este realizat în contextul în care frecvența mare a abuzului de substanțe - alcool, droguri și medicamente în rândul populației din România devine un motiv de îngrijorare pentru autoritățile medicale și societate. Țara noastră se

află pe primul loc la consumul de alcool, dar a fost numită "țara drogurilor" datorită poziției sale de "țară de tranzit pentru narcotice", ceea ce facilitează în ultima perioadă creșterea treptată a consumului de droguri ilicite.

Ultimele sondaje plasează România pe locul IV în topul consumului de droguri legale (substanțe etnobotanice) din Europa. Conform rezultatelor unui sondaj realizat de CIADO România (prezentate de ziare.com¹²), aproape 60% dintre tineri consumă aceste substanțe iar 57% dintre persoanele care au participat la sondaj indică Internetul drept principală modalitate de achiziție (Agheorghiesei (Corodeanu)&al., 2011). Aceste statistici au rolul unui semnal de alarmă cu privire la acest fenomen îngrijorător, dar și de a atrage atenția actorilor cu responsabilități decizionale în a căuta multiple metode și instrumente pentru a stopa adicția la substanțe, mai ales în rândul tinerilor. Mai mult, chiar tinerii sunt cei chemați să colaboreze pentru a-și salva de la adicția de substanțe membrii familiei, colegii și prietenii de aceeași vârstă, și chiar "adicția lor" la comunitățile virtuale poate fi "arma" secretă în lupta aceasta. Numărul utilizatorilor comunităților virtuale din România este impresionant și în continuă creștere: conform unei analize de eResearchCorp¹³, în septembrie 2010 erau înregistrați 1681240 pe Facebook (cu vârste cuprinse între 13-64; 7,4% din populația României, dar numărul adulților sporește¹⁴); 38907 pe Twitter, peste 82490 pe rețeaua TPU ("unde își oferă reciproc soluții la problemele cu care se confruntă"). Studiul recent realizat de iVox.ro arată că în 2013 Facebook ocupă primul loc, cu un procent de 95,1% din utilizatorii acestui tip de portaluri, iar Twitter 88,7% din piață.

În studiul nostru nu sunt aduse în discuție dezavantajele comunităților virtuale, acestea nefiind importante dacă luăm în considerare scopul nobil al acestor comunități în sănătate, acela de a fi în sprijinul persoanelor care au nevoie să își îmbunătățească starea de sănătate.

Cercetarea are drept scop identificarea gradului de disponibilitate a studenților masteranzi din două centre universitare importante din țară (Iași, Universitatea Alexandru Ioan Cuza și Cluj Napoca, Universitatea Babeș Bolyai) de a participa

¹² A se vedea [Ziare.com](http://ziare.com), "Raport american: Romania, tara drogurilor", <http://www.ziare.com/social/capitala/raport-american-romania-tara-drogurilor-255174>
[Ziare.com](http://ziare.com), Dependentele romanilor: alcool, droguri si medicamente, <http://www.ziare.com/social/romani/dependentele-romanilor-alcool-droguri-si-medicamente-1064833>
[Ziare.com](http://ziare.com), "Peste jumătate din tinerii romani consuma etnobotanice", <http://www.ziare.com/stiri/consum-de-droguri/peste-jumatate-din-tinerii-romani-consuma-etnobotanice-1059878>, 03 Decembrie 2010

¹³ Sabrina Răileanu, http://www.money.ro/cum-arata-de-fapt-social-media-romaneasca-un-portret-in-cifre-in-lucru_681631.html, accesat februarie 2013

¹⁴ cf. articolului scris de Mircea Anton, *Cât de mult iubesc românii rețelele sociale*, <http://www.geekreport.ro/retele-sociale/cat-de-mult-iubesc-romanii-retelele-sociale/>

voluntar într-o potențială comunitate virtuală pentru sprijinirea persoanelor care au adicție la substanțe (alcool, droguri ușoare, tutun, medicamente, droguri de mare risc, etc.).

Studiul aduce în atenție răspunsurile oferite de 152 de masteranzi în cadrul unei cercetări de natură cantitativă, bazată pe chestionar. Cercetarea a fost derulată inițial în Iași în 2011 pe 94 de subiecți, masteranzi la Universitatea Alexandru Ioan Cuza (Agheorghiesei (Corodeanu) & al., 2011) și continuată în 2012 în rândul a 58 subiecți de la Cluj Napoca, Universitatea Babeș Bolyai.

2.2. Obiectivele cercetării

O1. Identificarea comparativă a percepției și opiniei masteranzilor din cele două centre universitare privind PAS;

O2. Identificarea comparativă a disponibilității (și a motivelor și condițiilor necesare) masteranzilor din cele două centre universitare de a participa într-un grup online de suport pentru persoanele care au adicție la substanțe (PAS);

2.3. Ipotezele cercetării

I11. Există diferențe semnificative în ceea ce privește percepția și opinia masteranzilor din cele două centre universitare privind persoanele care au adicție la substanțe;

I12. Există diferențe semnificative în ceea ce privește percepția și opinia masteranzilor în funcție de tipul de master din cele două centre universitare privind persoanele care au adicție la substanțe;

I21. Există diferențe semnificative în ceea ce privește disponibilitatea (și motivele și condițiile necesare) masteranzilor din cele două centre universitare de a participa într-un grup online de suport pentru persoanele care au adicție la substanțe (PAS);

I22. Există diferențe semnificative în ceea ce privește disponibilitatea (și motivele și condițiile necesare) masteranzilor în funcție de tipul de master din cele două centre universitare privind persoanele care au adicție la substanțe.

2.4. Metoda cercetării

Pentru atingerea obiectivelor și testarea ipotezelor a fost utilizată o cercetare cantitativă, constând într-o anchetă de opinie bazată pe chestionar.

2.5. Eșantionarea și subiecții cercetării

Eșantionul a fost constituit aplicând metoda cotelor, aplicând aleatoriu chestionarul la 25% dintre studenții fiecărui master, condiția fiind ca aceștia să aibă un cont în cadrul unei comunități virtuale.

Masterele abordate în 2011 la Iași și constituirea lotului de 94 de subiecți s-a realizat astfel¹⁵: Comunicare și relații publice Publice - RP (19 studenți din 76), Studii europene - SE (16 din studenți din 62), Management turistic și hotelier Hotelier – MTH (16 studenți din 63), Managementul organizațiilor - MO (15 studenți din 57) și Managementul și dezvoltarea resurselor umane – MDRU (28 studenți din 110) (Agheorghiesei (Corodeanu)&al., 2011).

În anul 2012 cercetarea a fost replicată prin aplicarea chestionarului în rândul studenților de la 5 Mastere, anul I, de la Universitatea Babeș Bolyai de la Cluj Napoca pe un lot total de 58 de respondenți, astfel: Managementul Serviciilor Sociale – MSS (13 studenți din total 50), Didactica limbii și literaturii germane, cultura și civilizația germană a Europei Centrale și de Sud-Est - DD (8 studenți din total 30), Psihologie clinică, consiliere psihologică și psihoterapie – PC (12 studenți din total 45), Psihologia resurselor umane și sănătate organizațională - RUSO (12 studenți din total 45) și Management, consiliere și asistență psihopedagogică în instituțiile inclusive - MCA (13 studenți din total 50).

Din cei 152 de respondenți, 131 (86,2%) sunt de sex feminin iar 21 (13,8%) de sex masculin.

2.6. Designul chestionarului

Chestionarul final pentru studiul comparativ a fost structurat pe 79 de itemi (inclusiv cu datele de identificare a respondenților). Întrebările din chestionar au avut variante cu posibilitatea de alegeri multiple (cele referitoare la contul accesat, tipuri de activități, grupuri de participare) sau unice (frecvența accesării, timpul petrecut pe Internet în cadrul comunității) sau cu răspunsuri de tip scală pentru aspectele legate de percepția persoanelor care fac abuz de substanțe și cele referitoare la disponibilitatea respondentului de a participa în grupuri de sprijin online pentru PAS. Tipul de scală folosit este scala Likert, pe un interval de la 1 – în foarte mică măsură la 5 – în foarte mare măsură. Unele întrebări au lăsat libertatea exprimării unui răspuns deschis sau adăugării altor opțiuni din partea respondenților.

Prelucrarea datelor. Răspunsurile primite au fost prelucrate cu ajutorul programului statistic Sphinx Plus2. Interpretarea datelor are la bază analiza frecvențelor, mediilor și aplicarea testului t.

3. Principalele rezultate

Media răspunsurilor la întrebările numerice variază de la 4,53 (maxim) la 1,85 (minim), media pe ansamblul eșantionului fiind de 3,48.

¹⁵ Denumirea masterelor a fost codificată în cercetare pentru a facilita prelucrarea datelor și prezentarea extinsă a rezultatelor

Rețeaua virtuală – 150 (98,7%) de masteranzi au un cont pe rețeaua virtuală Facebook, 24 (15,8%) pe LinkedIn, 12 (7,9%) pe Twitter. *Frecvența accesării* – 63,2% (N = 96) în fiecare zi iar 19,1% (N=29) de mai multe ori pe săptămână. *Timp petrecut în cadrul rețelei virtuale* – 71,1% mai puțin de o oră, 26,3% între 1-3 ore. Activități la care se participă frecvent – 87,5% (N=133) trimiterea de mesaje, comentarii, anunțuri, iar 53,3% (N=81) postarea de fotografii. Afilierea la grupuri – de sprijin-suport pentru diverse categorii de persoane, 22,4% pe grupuri de solidaritate pe diverse probleme sociale, 38,8% grupuri profesionale, 37,5% nu sunt afiliați.

Solicitarea de ajutor din partea PAS - 84,2% niciodată, iar 11,8% uneori, 3,9% frecvent.

Profilul PAS

Asocierea PAS cu substanțele la care au adicție:

58,6% dintre respondenți consideră în foarte mare măsură persoane că sunt persoane care consumă droguri de mare risc ($m=4,05$, $\sigma=1,35$). Numărul cel mai mare de respondenți care afirmă acest lucru provine din Iași (58 față de 31 din Cluj Napoca).

Un procent de 41,4% le asociază în foarte mare măsură cu persoane care consumă droguri legale ($m=3,82$, $\sigma=1,26$); 38,8% cu persoanele dependente de alcool ($m=3,72$, $\sigma=1,30$);

23,3% dintre respondenți cred în mare măsură că sunt persoane dependente de tutun ($m=2,99$, $\sigma=1,34$); un procent mic (13,8%) susține în foarte mare măsură (și 20,4% în mare măsură) că sunt persoane care iau medicamente în exces ($m=2,90$, $\sigma=1,32$).

Valori scăzute la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat la variabila PAS - persoane care consumă droguri legale – MSS, Cluj (3,08/3,82).

Caracteristici PAS: în foarte mare măsură (43,4%) și în mare măsură (30,9%) persoane care nu sunt capabile de autocontrol ($m=4$, $\sigma=1,15$); 19,7% în foarte mare măsură (și 25% în mare măsură) – au probleme psihologice ($m=3,32$, $\sigma=1,23$); 37,5% în foarte mare măsură (și 25,7% în mare măsură) PAS – sunt persoane influențabile ($m=3,84$, $\sigma=1,13$). Un procent de 32,9% apreciază în foarte mare măsură (și 25,7% în mare măsură) că PAS nu au încredere în sine ($m=3,65$, $\sigma=1,25$);

Valori mari la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat astfel: PAS nu sunt persoane capabile de autocontrol (DD, Cluj – 4,50/4); PAS au probleme psihologice (MCA, Cluj 3,85/3,32); PAS sunt persoane influențabile (MO, Iași - 4,40/3,84); PAS nu au încredere în sine (DD, Cluj - 4,38/3,65);

PAS în societate: 45,4% în foarte mare măsură (20,4% în mare măsură) consideră că persoanele cu adicție la substanțe sunt stigmatizate ($m=3,95$, $\sigma=1,16$); 50% în foarte mare măsură (34,2% în mare măsură) că sunt privite cu neîncredere ($m=4,30$, $\sigma=0,86$); 46,7% în foarte mare măsură (27% în mare măsură) marginalizate ($m=4,10$, $\sigma=1,05$).

Valori mari la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat astfel: PAS stigmatizate – (MSS, Cluj, 4,54/3,95), (PC, Cluj 4,50/3,95) și MCA, Cluj (4,46/3,95); PAS privite cu neîncredere – MCA, Cluj (4,69/4,30); PAS marginalizate – MCA, Cluj (4,54/4,10).

Valori scăzute s-au înregistrat la variabila PAS marginalizate – (DD, Cluj, 3,38/4,10).

Din răspunsurile deschise date de respondenții de la Cluj, reiese că *“Nu se oferă sprijin real pentru a-i ajuta să își învingă adicția, în special dacă este adicție la substanțe de mare risc”*; *“Nu au destule cunoștințe despre substanța respectivă și efectele negative asupra organismului”*; *“Nu li se oferă șansă, speranță”*.

Motivele care generează adicția la substanțe – 16,4% consideră în mare măsură (9,2% în foarte mare măsură) lipsa de educație ($m=2,63$, $\sigma=1,27$); 27,6% în foarte mare măsură și 26,3% în mare măsură – lipsa de control din partea familiei ($m=3,52$, $\sigma=1,24$); 67,1% în foarte mare măsură – cultura grupului-anturajul ($m=4,50$, $\sigma=0,82$); 25,7% în mare măsură și 12,5% în foarte mare măsură – situația financiară bună ($m=3,19$, $\sigma=1,11$). Puțini dintre ei consideră că datorită unei situații financiare slabe (neutru, 34,2%, în mare măsură 15,8%, 9,2% în foarte mare măsură; $m=2,77$, $\sigma=1,24$). Un procent de 34,2% apreciază în mare măsură și 32,9% în foarte mare măsură că ajung în această situație datorită crizei de personalitate ($m=3,83$, $\sigma=1,12$); 38,8% în foarte mare măsură legislației permissive accesului la droguri (21,7% în mare măsură) ($m=3,75$, $\sigma=1,26$).

Valori mari la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat astfel: cultura grupului (DD, Cluj, 4,88/4,50); criza de personalitate (DD, Cluj, 4,38/3,83); prea multă publicitate – MTH, Iași (3,69/3,17).

Valori scăzute la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat astfel: lipsa de control în familie (PC, Cluj, 2,42/3,52); cultura grupului – (PC, Cluj, 3,92/4,50); situația financiară bună – (PC, Cluj, 2,33/3,19); situația financiară slabă – RP, Iași (2,16/2,77) și MDRU Iași (2,25/2,77); criza de personalitate – PC, Cluj, 3/3,83; legislația permisibilă – PC, Cluj, 2,58/3,75; boli psihice – MO, Iași, 1,87/2,70; boli fizice – MO, Iași, 1,67/2,16.

Sprijinirea PAS - 62,5% dintre masteranzi consideră în foarte mare măsură (21,7% în mare măsură) că PAS au nevoie de ajutorul celorlalți ($m=4,34$, $\sigma=1,06$); doar 21,7% cred în foarte mare măsură (19,7% în mare măsură) că avem o datorie

morală față de PAS ($m=3,28$, $\sigma=1,26$); 46,1% apreciază în foarte mare măsură (34,2% în mare măsură) că este nevoie să comunicăm cu PAS ($m=4,18$, $\sigma=0,95$); 23% sunt convingși în mare măsură (14,5% în foarte mare măsură) că numai experții pot da ajutor în aceste cazuri ($m=3,05$, $\sigma=1,26$).

Cei care susțin cel mai mult că avem în foarte mare măsură o datorie morală față de PAS sunt studenții de la MDRU, Iași (9 respondenți). Tot masteranzii de la această specializare consideră în foarte mare măsură (21 respondenți) că persoanele cu adicției au nevoie de ajutorul celorlalți. Pe ansamblu, cei care susțin acest lucru în foarte mare măsură sunt 61 din 94 respondenți din Iași față de 34 din 58 din Cluj Napoca.

Disponibilitate grup suport online pentru PAS – 31,6% dintre masteranzi își manifestă în mare măsură (și 21,7% în foarte mare măsură) disponibilitatea de a participa într-un grup de suport online pentru PAS ($m=3,45$, $\sigma=1,20$); 19,1% în foarte mare măsură (19,7% în mare măsură) afirmă acest suport ar consta din partea lor în sfaturi personale ($m=3,11$, $\sigma=1,31$); 35,5% în foarte mare măsură (31,6% în mare măsură) și-ar oferi sprijinul moral ($m=3,90$, $\sigma=1,05$); 65,8% în foarte mare măsură ar orienta persoanele cu adicție la substanțe către experți ($m=4,48$, $\sigma=0,82$); 26,3% în foarte mare măsură (25,7% în mare măsură) ar posta în acest sens experiențe personale ($m=3,36$, $\sigma=1,41$); 23,7% în foarte mare măsură ar opta pentru postare mesaje video sensibilizatoare ($m=3,40$, $\sigma=1,29$); 26,3% în mare măsură (21,7% în foarte mare măsură) s-ar implica în activități on-line curative ($m=3,34$, $\sigma=1,27$).

Disponibilitate în foarte mare măsură pentru participarea într-un grup de suport online o arată în special masteranzii de la Masterul MDRU, Iași (7), și cei de la MSS, Cluj Napoca (6).

Sprijinul moral ar fi acordat în foarte mare măsură de studenții de la Iași (32 față de 22 din Cluj).

Solidaritatea față de suferința aproapelui ar fi în foarte mare măsură motivul pentru a participa în grupul de suport online tot pentru studenții de la Iași (25 față de 19 Cluj).

Valori mari la media răspunsurilor față de media eșantionului, în funcție de tipul de master s-au înregistrat astfel: disponibilitate grup suport – (MSS, Cluj, 4,31/3,45); ajutor - sfaturi personale, (MO, Iași 3,67/3,11 și DD, Cluj, 4/3,11); orientare către experți – (PC, Cluj, 5/4,48); postare experiențe persoanele, (MCA și RUSO, Cluj – 4/3,36); disponibilitate sprijin – dacă PAS este un prieten – (MTH, Iași, 4,63/4,20); dacă grupul este coordonat de un expert – (PC, Cluj, 4,58/4,03); dacă participă și alți colegi (MSS, Cluj, 4,31/3,39 MSS și – PC, Cluj, 4,08/3,39); educația de a ajuta (RUSO, Cluj, 4,42/3,77); în virtutea deontologiei profesionale (MSS, Cluj, 4/3,41), (PC, Cluj - 4,50/3,41), (RUSO, Cluj, 4,25/3,41); datoria morală (RUSO, Cluj, 4,17/3,48).

Valori scăzute la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat astfel: disponibilitate grup suport – RP, Iași (2,79/3,45); ajutor posibil, sfaturi personale – PC, Cluj (2,33/3,11) și ajutor activități online curative (DD, Cluj, 2,13/3,54); motiv sprijin - motive religioase PC, Cluj (1,25/2,45); motiv sprijin - spirit civic – RP, Cluj (2,95/3,55).

Situații disponibilitate pentru sprijinirea PAS într-un grup online – 53,9% în foarte mare măsură – dacă este vorba de un prieten ($m=4,20$, $\sigma=1,10$); 32,9% în mare măsură – dacă PAS este recomandat de un prieten ($m=3,65$, $\sigma=1,19$); 44,7% în foarte mare măsură (28,3% în mare măsură) – dacă grupul este coordonat de un expert ($m=4,03$, $\sigma=1,13$); 25,7% în foarte mare măsură (24,3% în mare măsură) dacă la acest grup online participă și alți colegi ($m=3,39$, $\sigma=1,32$); 37,5% în foarte mare măsură (23,7% în mare măsură) – dacă se primește formare în domeniu ($m=3,76$, $\sigma=1,25$).

Motivele sprijinirii PAS într-un grup online. 12,5% în mare măsură din motive religioase ($m=3,45$, $\sigma=1,39$); 39,5% în mare măsură (28,9% în foarte mare măsură) datorită educației primite de a ajuta pe ceilalți ($m=3,77$, $\sigma=1,13$); 28,3% în mare măsură din spirit civic ($m=3,55$, $\sigma=1,20$); 21,1% în mare măsură datorită culturii grupului ($m=3,97$, $\sigma=1,14$); 34,9% în mare măsură (28,9% în foarte mare măsură) din solidaritate în fața suferinței ($m=3,87$, $\sigma=1,07$); 44,1% în foarte mare măsură (27% în mare măsură), din prietenie ($m=4,05$, $\sigma=1,06$); 32,2% în foarte mare măsură (21,7% în mare măsură) din motive de deontologie profesională ($m=3,41$, $\sigma=1,48$); 28,3% în mare măsură, (23,7% în foarte mare măsură) din datorie morală ($m=3,48$, $\sigma=1,20$);

Motivul deontologiei profesionale pentru a participa în grupul de suport este online este valabil în foarte mare măsură pentru studenții de la MDRU, Iași (27) și cei de la PC (22).

Elemente absolute necesare pentru înființarea/funcționarea unui grup de suport online: în foarte mare măsură (61,8%) cunoașterea problematicii PAS ($m=4,42$, $\sigma=0,85$); ghidarea din partea unui expert (61,9%; $m=4,53$, $\sigma=0,81$); 32% în foarte mare măsură (29,6% în mare măsură) crearea unei rețele de bază de recomandare ($m=3,78$, $\sigma=1,05$). Un procent de 46,7% afirmă în foarte mare măsură (31,6% în mare măsură) că participarea într-un grup de suport online este condiționată de nevoia de formare ($m=4,20$, $\sigma=0,91$). De asemenea, 46,7% apreciază în foarte mare măsură (27,6% în mare măsură) că este nevoie de mediatizarea necesității acestor grupuri de suport ($m=4,09$, $\sigma=1,06$).

Valori mari la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat la variabila cunoaștere problematică PAS – PC, Cluj (4,75/4,42).

Nevoia coordonării din partea unui expert este resimțită cel mai mult de către masteranzii de la Iași, master MDRU (10).

Valori sub medie s-au înregistrat la variabila *sprijin – grupul este coordonat de un expert* – DD, Cluj (3,0/4,03).

Bariere ajutorare PAS – 44,7% dintre masteranzi consideră în foarte mare măsură (28,9% în mare măsură) că PAS nu cer/nu doresc ajutor ($m=3,97$, $\sigma=1,23$); 28,9% în foarte mare măsură (25,7% în mare măsură) că acestia nu și-ar expune virtual problemele ($m=3,47$, $\sigma=1,34$); 25,7% în mare măsură (22,4% în foarte mare măsură) că vorbesc codificat/se relaționează între ei ($m=3,34$, $\sigma=1,29$).

Valori mari la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat astfel: PAS – nu cer/nu doresc ajutor – (SE, Iași, 4,50/3,97); PAS – vorbesc codificat/se relaționează între ei – (MDRU, Iași, 3,86/3,34).

Valori scăzute – PAS vorbesc codificat/se relaționează între ei - PC, Cluj (2,17/3,34).

Eficacitatea grupurilor online pentru sprijinirea PAS – 36,8% neutru; 22,4% în mică măsură; 17,1% în mare măsură; 9,2% în foarte mare măsură ($m=2,84$, $\sigma=1,15$).

37,5% dintre masteranzi sunt neutri în ceea ce privește șansa de reușită a unui grup online de suport pentru PAS, 32,2% apreciază în mare măsură că există șanse de reușită (33 din Iași față de 16 din Cluj). Doar 11,8% cred în foarte mare măsură acest lucru. Dintre aceștia, majoritari sunt studenții de la Cluj (11 în comparație cu 7 din Iași).

Valori mari la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat astfel: grupurile online nu pot avea eficacitate – (DD, Cluj, 3,50/2,84) și MCA, Cluj (3,38/2,84).

Valori scăzute – grupurile online nu pot avea eficacitate, MDRU, Iași, 32/2,8, ceea ce înseamnă că aceștia sunt cei mai optimiști cu funcționarea acestor comunități.

Rețineri participare într-un grup online de suport – 30,3% în foarte mare măsură (24,3% în mare măsură) ar avea rețineri de a nu da un sfat neadecvat ($m=3,49$, $\sigma=1,35$); 5,9% de a nu-și afecta imaginea personală ($m=2,05$, $\sigma=1,18$); 18,4% în mare măsură (și 13,8% în foarte mare măsură) fiindcă nu ar cunoaște persoana respectivă ($m=2,82$, $\sigma=1,35$). Doar 3,3% declară în foarte mare măsură că ar fi timp pierdut ($m=1,85$, $\sigma=1,08$).

Valori scăzute la media răspunsurilor față de media eșantionului, în funcție de tipul de master, s-au înregistrat la variabila *numai expertii pot acorda ajutor în aceste cazuri* – MDRU, Iași, 2,57/3,05 și variabila *timp pierdut* (PC, Cluj, 21,42/1,85), de unde, putem trage concluzia, că din partea lor ar putea da ajutor și nu ar fi timp pierdut.

Aplicarea testului t (mediile pe categorii semnificativ diferite) față de media eșantionului la risc de 95%, arată o diferență semnificativă între răspunsurile date de masteranzii de la Iași și cei de la Cluj Napoca în ceea ce privește următoarele variabile: *PAS sunt persoane influențabile*: (3.99 / 3.60, $t = 2.06$, $1-p = 96.01\%$); *motiv adicție – situație financiară slabă* (2.61 / 3.03, $t = 2.17$, $1-p = 97.0\%$); *motiv adicție – legislația permisivă* (3.90 / 3.50, $t = 1.96$, $1-p = 95.1\%$); *motiv adicție - boli psihice* (2.53 / 2.98, $t = 2.42$, $1-p = 98.4\%$),

Diferența este foarte semnificativă în ceea ce privește răspunsurile la următoarele variabile: *motiv adicție-boli fizice*: 1.94 / 2.53 ($t = 3.39$, $1-p = 99.9\%$); *motiv sprijin PAS -deontologie profesională*: 3.14 / 3.84 ($t = 3.12$, $1-p = 99.8\%$); *PAS sunt stigmatizate*: 3.72 / 4.33 ($t = 3.43$, $1-p = 99.9\%$)

Discuții și concluzii

Rezultatele obținute demonstrează că studenții percep persoanele cu adicție ca fiind în principal cele care consumă droguri de mare risc, ceea ce, pe de o parte, nu cuprinde întreaga realitate.

Studiul arată că ei ar avea disponibilitatea de a participa în grupuri online de suport organizate pentru PAS dar este vizibil că este nevoie de conștientizare și formare.

Mai mult, potențialii membri ai acestor comunități pot fi abordați în funcție de specificul studiilor, după un dialog care să scoată la iveală modul de percepție al acestor persoane cu adicție, gradul de disponibilitate și condițiile participării.

Analiza răspunsurilor scoate în evidență că există diferențe de abordare în funcție de centrul universitar și în funcție de tipul masterului. Pentru prima situație, studenții ieșeni par a fi mai orientați către ajutorarea acestor persoane, poate și datorită faptului că din Iași s-a mediatizat puternic situația îngrijorătoare cu adicția la droguri, înregistrându-se multe cazuri în rândul tinerilor.

Un studiu intercultural, care să ia în considerare variabila colectivism / individualism (rolul grupului versus rolul individului) din cercetările lui Hofstede ar fi extrem de interesant pentru a înțelege mai bine atitudinea studenților.

Studiul nostru poate fi util pentru luarea în considerare a comunităților virtuale de studenți drept instrument ce poate fi utilizat în managementul post-tratamentului pentru persoane care au adicție de substanțe, alături de metodele psiho-medicale tradiționale.

Totuși, ceea ce are importanță este mesajul general care reiese din cercetare: studenții ar fi dispuși să participe în comunități virtuale dar este nevoie de experți care să ia inițiativa, să îi pună la curent cu problematica PAS, să îi formeze să ajute, să îi coordoneze .

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ADOLESCENTS INTERNET USE – A REASON OF CONCERN OR A RELIEF?

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ABSTRACT. The impact of Internet use is being investigated increasingly, and scientists are beginning to address a greater amount of related issues. Using semi-structured interviews, in a qualitative setting, we addressed the current experience as Internet users of 20 Romanian adolescents of 15-16 years old. Following the Grounded Theory approach as a method, initial coding offers insight usage patterns, needs met, perceived risks or effects and personal aims in computer use. Further stages of analysis should reveal relational issues of context of the participants' experiences. The knowledge from current research will contribute to the better understanding of the development of the excessive Internet use or addictive behaviors of adolescents. Also, it will help identify patterns of the Internet usage development, with interest in health prevention strategies.

Key words: adolescents, internet use, addiction, Grounded Theory

Introduction

Internet is a popular informational, academic and entertainment tool of adolescents around the world. In the last decade there have been a growing number of academic papers about characteristics and effects of the Internet use among adolescents, while evidence of the effects of computer use by children is still ambiguous.

Researchers have described various issues related to the Internet use, namely a syndrome of intense preoccupation with using the Internet (Chou, 2001;

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Treuer, Fabian & Furedi, 2001), excessive amounts of time spent online, compulsive use of the Internet, difficulty in managing the time spent on the Internet, feeling that the world outside of the Internet is boring, becoming irritated if disturbed while online, decreased social interaction with “real” people (Kraut et al., 1998), and increased loneliness and depression (Nalwa & Anand, 2003).

Most of these studies focus more on the effects (positive or negative ones) or on certain predetermined dimensions (accessibility, time spent, online activities, interests) and less on the lived experiences or on how people build their identity as users. Several Internet researchers have developed tools for assessing Internet dependence or addiction (Tsai & Lin, 2001).

A variety of terms have been used to describe this behavior, including “Internet addiction” (Bai, Lin, & Chen, 2001; Mitchell, 2000; Young, 1998), “pathological Internet use” (Davis, 2001), “problematic Internet use” (Davis, Flett & Besser, 2002). “Compulsive Internet Use”. Even if describing internet behaviors as an addiction is contested, there is more and more agreement regarding the importance to further investigate ‘use’ of internet. In particular, our paper intend to reveal the children’s own perspectives and experiences of Internet use, with a focus on the contexts, influence factors and usage patterns.

Methods

The sample included 20 high-school students (10 girls and 10 boys) registered in the 10th grade, living and learning in Iasi area, Romania, 3 of them lived in rural areas and 17 lived in urban area. Their age varies from 16 to 19 years old, with an average age of 16 years old. All the participants respected the eligibility criteria for their conversations to be analyzed – completion of questionnaire, accepting to be recorded while telling their personal story about Internet use, having an IAT (Internet Addiction Test, Young 1996) score equal or over 30 points.

The Interview Schedules for the semi-directive interviews included questions about personal data – such as things teens like or don’t like; the internet use and its evolution – with emphasis on the story line of the evolution of Internet users; needs met – apps they use, emotions online, personal opinion about the Internet and parent’s opinion about the way they use the Internet; self perceived risks, advantages and disadvantages of Internet usage and personal aims concerning they way the use or will use the Internet. Time schedule for the interviews lasted from at least 38 minutes and maximum 88 minutes, with an average time of 58 minutes. The theoretical framework for analysis is based on the Grounded Theory approach (Strauss and Corbin, 1990).

Findings

During the text analysis, a number of themes and core categories have emerged; they were labeled and presented as: *becoming an user, usage patterns, needs met, perceived risks and positive effects* and *Personal aims for future usage*.

Becoming an user

All participants included in their story certain resources that influenced their development: friends and family, relationship between users and friends and family and parents' socio-economic status (SES). Participants' stories as Internet users, start at an average age of 10 years old (min. 4 years, max. 14 years. those who were able to use the Internet at a younger age, had parents with an average to a high SES; those who became Internet users at over 12 years old, came from families with parent's SES from low to average.

Beginners would use the Internet for games and homework and they would gradually learn how to use the Internet by being helped by their, friends, parents or self learning; those who had parents with a higher SES would get help in developing their abilities from their parents, and those who started using the Internet at an older age would be self learners. They would start by playing different games, appropriate to their age, and trying to use the Microsoft Office.

Differences between the way teens start the usage of Internet- those who started to use the Internet at an older age would skip the stage of playing games first, and start directly with using the Internet for homework and socializing. Three of the participants told us they even learned how to install Microsoft Windows program on their devices and learned in time how to install other programs in order to help them do their homework or even gain money. Most of the participants know how to browse the Internet and feel advanced in their usage.

Usage patterns

Usage patterns are similar for most of participants - they use the Internet from their PC and laptops, though they feel more comfortable if they can use it by phone, while being at school. Usage duration varies from a few hours per day to 16 hours a day, with higher rates during the weekend.

As reasons for being online, participant says Internet is a resource for information and entertainment but also a way to loose boredom. Some of the participants declared that they don't see any reason to change this pattern of usage, considering that they have nothing else to do. Participants would describe themselves as Internet users in terms of the content of the sites they visit most - messenger-ist, gamer, in psychological terms – normal user, addictive user or in terms of the evolution stages they feel fitted depending on their ability to use the Internet – advanced, intermediary, beginner.

Some of the participants (4 of 20) would develop their Internet usage patterns in order to gain money – as site administrator, game site owner, Corel Draw designer, gambling game user. All participants felt they would develop a certain ability by using the Internet – be that a personal one (feeling more secure, being less shy, making more friends, developing their vocabulary) or a professional ability for future job (developing blogs and sites, administrating sites, becoming a graphic designer).

The Internet seems to be a place where they could release their worries and negative emotions, and here they could share their happy thoughts, and thus The Internet became an coping instrument, where they could find peace by listening to music, talking with friends or playing a game.

Time restrains are often mediated or negotiated with parents. Some of them reported that parents are concerned about what web sites they visit on the Internet, but most of the adolescents told us their parents trust the content of the web sites they visit, therefore they never intervene.

The most visited sites were those who provided information for homework and school projects, game sites- especially for strategic games, entertainment sites – such as You Tube- and socialization sites – Yahoo Messenger and Mail, Facebook and Hi5. Some are visiting adult sites but out of curiosity and feel that this is normal; female participants felt disgusted by these kinds of images and declared they would not visit these kinds of sites voluntarily.

Needs met

As main reasons for using Internet, the adolescents claim it is a place were they can find information regarding homework and school projects, entertainment, information about some of their hobbies, and sites where they can communicate with friends and make new friends. It is also important to specify that another reason for Internet usage is avoiding boredom: nothing better to do offline and they prefer to spend their spare time on the Internet, where they can become heroes, monsters or policemen (for gamers), talk with friends and make new friends (for social sites users), find new information (for all of them).

As claimed, the Internet offer the feeling they have a role and the possibility to experiment something they could never experiment in real life: while being online they can be who they want to, they cad play a role of administrator or of a counselor for their friends, they can even be a policeman or a monster when playing a game; more on that, the Internet seems to be part of their life.

The Internet is more than a routine thing for them, therefore they feel they would miss it if it would disappear and they would even feel empty without it; usage of the Internet became in time a need in itself.

Perceived risks and positive effects

Most of the teenagers know about the risks they expose themselves to, and they often talk about health problems – site problems, head aches, stomach aches, not being able to sleep or to fall asleep during school program; social anxiety; being bullied; losing friends; having problems at school. Some of them even report these kinds of problems during the interview and place the blame on the Internet usage.

Another issue reported by teens is the compulsion they live when talking about restraining themselves to use the Internet – this happens mostly to Facebook users and gamers.

All participants reported positive effect as getting help with their homework and school projects, being able to talk to someone when feeling stressed about something, feeling more confident- socially speaking, being more calm and focused on a task, being able to find the information they like to know about and being able to entertain themselves by watching a movie online or listening to some music on YouTube.

Personal aims for future usage

When asked what they would like to change about the way they use the Internet, most of the respondents told they want to reduce the time schedule online. Some of them specified that their habits will change in time because their priority will probably change, therefore they would use different web sites and they would spend less time socializing.

In terms of help with this change, most of them told us they could be helped by their family and friends or that they would change things because they feel confident this is better for them, but with no help but their own.

Conclusions

Internet usage in adolescence is related to the age needs: homework and school projects, socializing and entertainment. Adolescents are aware of the risks they expose themselves, but the positive effects balance sometimes the negative ones. It is also difficult to draw a line between the influences of Internet in their daily life or to separate the “healthy behaviors” from the addictive ones where the addiction “begin”. We were able to observe that a good relationship with their parents may help adolescents develop healthy strategies when using the Internet in order to stay healthy and develop their cognitive and social abilities outside the Internet world. An important role is played in this scenario by the relationship with friends: the persons, who declared themselves addicted to the Internet, were able to break the pattern being helped by their friends who offered him alternatives of spending time on the offline world.

Considering all of the above we can conclude that the Internet is a powerful and practical instrument for teens, and psychological problems can be avoided by being close to the adolescents needs outside the Internet world, and offering them alternatives to spend their spare time.

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