COMMUNICATING THE SEVERE DIAGNOSIS – PSYCHOLOGICAL, ETHICAL AND LEGAL ASPECTS

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ABSTRACT. From a psychological standpoint, communicating a severe diagnosis entails more than just naming a disease, it is a complex process with a number of stages: finding out what the patient already knows about the illness (some of which might be wrong, and thus psychologically detrimental), informing the patient while answering any questions (about the illness itself, the treatment, prognosis, recovery period, etc.) and last but not least, providing a minimum of psychological support depending on the patient's reaction. Romanian law regarding doctor-patient relationship and communication is modeled on the Anglo-Saxon model centered on patient autonomy and direct communication with the latter if the patient desires to know the truth about his condition. If this is not the case, the patient can name a proxy for doctor-patient communication. There are three legal documents that clarify these aspects: Law of Patient Rights, Medical Association's Ethics Code and the Health Reform Law. The first two are conflicting on several aspects that we will discuss in this paper. The few studies on doctor-patient communication published in Romania reveal that there is no unitary methodology in this field. The doctors attest that often times the patient's family, when faced with severe illness turn to the traditional model of communication, i.e. they desire to know the severe diagnosis first and pressure the physician to hide the truth form the patient, contrary to the letter of the law.

The aim of this paper is to discuss the issue of communicating severe diagnosis in nowadays Romania in a very complex context: 1. The model of doctor-patient relationship and communication has changed after communist era (from paternalistic to partenerial); 2. Conflicting and missing issues in laws; 3. Laws based on patient's

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autonomy principle in a traditional society based on another model of taking care (the patient is part of a family nucleus and the family wants to interfere into the medical communication process).

Communication has only recently entered the curriculum of some medical schools in Romania. The doctors questioned as part of a study reveal that they've learned to communicate a severe diagnosis by trial and error. This being said we recommend the inception of practical doctor-patient communication courses that could lead to improving doctor-patient relationships, communication of the diagnosis being their foundations.

Key words: diagnosis communication, coping, law, doctor-patient relationship

Introduction

Communicating the diagnosis or prognosis to a patient suffering from a severe illness is an experience that can cause both partners to concede defeat (the doctor finds it difficult to be the bearer of bad news and the patient finds it hard to receive bad news in a painful way) or to partner up and start a race to health. Communicating the diagnosis and/or prognosis in a realistic, sincere and tactful manner is the doctor's acknowledgement of a patient's dignity. The method a doctor chooses to communicate the diagnosis has an impact on the doctor-patient relationship throughout the duration of the illness, making it even more important in chronic conditions. A study published in Romania on cancer patients supports this theory and reveals that among the patients who found out about their condition directly and spontaneously from their doctor, 71% placed their trust in the doctor and chose that the latter remain their primary source of information. Only 11% of the patients that discovered their diagnosis in medical papers or from family had nurtured a relationship based on trust with their doctor. In conclusion, sincere diagnosis communication is the cornerstone of the doctor-patient relationship.4 The medical community's conception regarding communication of bad news to the patient has changed with the optimization of medical treatment and increase of patient survival. Starting with Hippocratic medicine, throughout the centuries doctors have communicated and practiced medicine utilizing a paternalist doctor-patient relationship. During the first half of the past century it was still considered inhumane and devastating to communicate a severe diagnosis (especially a malignant diagnosis) because the

⁴ Parker (2001), 2049-56.

chances of a successful treatment and survival were small. Communication of a cancer diagnosis was seen practically as a death sentence and the recommendation in many countries was the 'silence conspiracy'.^{5,6} For example the first ethical code of the American Medical Association (1847) the stipulated recommendation was to not communicate the unfavorable prognosis to patients, but to friends and family.⁷ As the last century unfurled in the US and Western Europe, communicating the diagnosis and prognosis became a duty for physicians and a law enforced right for the patients. This change in attitude (from the 'silence conspiracy' to communicating the truth to the patient) did not simplify things, but just the opposite, has increased the responsibilities of the physicians.⁸ As time went by even the type of bad news that the physician had to communicate changed. Initially, the severe diagnosis was considered the bad news. Later, as medical science evolved, new treatments were developed and patient survival increased, a whole plethora of other bad news appeared: the prognosis, relapse, metastases, irreversible side effects of treatment, degrees of disability etc. It thus became imperative that the physicians learn knowledge and communication skills to adapt his speech to the patient's needs.

As we have previously shown, the Western world (USA and most of Western and Central European countries) promoted a direct and sincere communication model based on patient autonomy and informed consent. In accordance with this model communication of bad news is done at the patient's discretion in an empathic, tactful manner. The opposite is true for the 'traditionalist' model of doctor-patient communication where the patient is considered to be part of a family nucleus, the family being the ones that care for the patient physically and emotionally and desire to filter the information that reaches the patient, and to make decisions on their own or in tandem with the physician regarding the illness and treatment. The countries that adopted this model are the European countries in the Mediterranean area, Central and Eastern Europe, countries of the former USSR, Latin America and the Far East. This communication model raises ethical concerns, diminishing patient autonomy, limiting his right to information (the physician often lets themselves be drawn in to the 'silence conspiracy') and to being a part of the decision-making process. This model also represents a breach of doctor patient confidentiality.⁹ The introduction of patient autonomy and self-determination to medical ethics was followed by a number of studies centered on asking if patients desire to know the severe (and

⁵ Benbassat, 81-88.

⁶ Fong Ha, 38-43.

⁷ Lee, 533-538.

⁸ Ibidem, Parker, Benbassat.

⁹ Olarte, 47-52.

especially malignant) diagnosis and the other bad news mentioned before.^{10,11,12,13,14} The results of these studies (many of them published in the Western world) have shown that patients wish to know the diagnosis^{15,16,17}, as well as additional information regarding the illness, a realistic estimate of survival, chances of getting better and the possible side-effects of the treatment.^{18,19,20,21} According to the principles of medical ethics, breaking bad news (diagnosis, prognosis) must be observed at the patient's discretion, and if the patient does not desire this, most medical systems allow the naming of a proxy that should be informed and make decisions for the patient. Manny publications illustrate what patient expectations are regarding medical communications (mentioned in this paper) and also reveal the fact that physicians do not fulfill these expectations unfortunately.^{22,23,24,25}

Communicating a Diagnosis. Psychological Aspects

Communicating the diagnosis represents more than just uttering the name of an illness, it is an entire process where the transmission of information is bidirectional and it is recommended to be done in a manner that is clear for the patients and adapted to their needs. It is recommended that this should start from the patient's knowledge, fears and the – sometimes preconceived – ideas referring to their clinical condition, as these can sometimes be erroneous, have false expectations regarding the chances of success or failure of the treatment. Baile et al. demonstrate that aside from verbal communication skills the physician should also have knowledge of other fields to ensure a good communication of

- ¹² Davidson, 11-20.
- ¹³ Moşoiu, 5-46.
- ¹⁴ Parvu, 56-120.
- ¹⁵ Benbassat, 81-88.
- ¹⁶ Davison, 1401-1408.
- ¹⁷ Dunsmore, 39-56.

- ²⁰ Sutherland, 260-263.
- ²¹ Loge, 878-882.
- ²² Davidson, 11-20.
- ²³ Degner, 1485-1492.
- ²⁴ Hoffman, 1-12.
- ²⁵ Lobb, 290-294.

¹⁰ Blanchard, 1139-1145.

¹¹ Cassileth, 832-836.

¹⁸ Ley, 353.

¹⁹ Meredith, 724-726.

the diagnosis and prognosis, some of which are: the ability to cope with emotional reactions from patients, to include the patient in the decision-making process, to face up to the high-stress situation generated by the patient's anxiousness to get well, to cope with interventions from the patient's family and in the doctor-patient relationship and communication and last but not least, the ability to maintain hope when the prognosis is severe.²⁶ To ensure the communication is adapted to each patient's needs, the physician should find out what type of information the patient desires and to adapt to his particular needs. As such, there are patients that desire more detail about the cause and mechanism of emergence of disease, while others want limited information on the diagnosis, but more details regarding the prognosis. There are also patients that only require details on the treatment and life style restrictions that their conditions impose. The ones that desire to resume their family, social or professional life as quickly as possible will express the need for information on the disabilities that will persist after the treatment. Communication of medical information must be done in a language adapted to the patient's background and education, in order to represent a premise for the inception of a dialog between the physician and the patient, one where the doctor provides the patient the opportunity to ask for additional information on what they do not fully understand. Today the protocol in effect for diagnosis communication recommends that after the disease is revealed, the patient should be presented the stages of treatment, and a description of the future, with chances of social and professional reintegration, as this information will serve to regain the patient's optimism. It is also recommended that at the end of the diagnosis communication process, the physician answer the patient's questions to receive feedback on the level of adaptation to the latter's needs.^{27,28} Other publications reveal that the goals to effective doctor-patient communication is not just the passing on of information, but also including the patients in the decision-making process and the creation of a professional interpersonal relationship between the physician and the patient.^{29,30} Consequently to receiving bad news (severe diagnosis) the emotional impact causes patients to develop psychological reactions like anxiety, denial, depression, anger, etc. The fear of the reactions sits at the basis of the "silence conspiracy" that is demanded by the family in order to protect the patient for fear that they will not cope well with the situation. Usually, physicians accept this wish of the family, feeling uncomfortable

²⁶ Baile, 81-88.

²⁷ Baile, 302-311.

²⁸ Fields, 32-35.

²⁹ Arora, 791-806.

³⁰ Bre´dart, 351-354.

and avoiding presenting the patients with bad news. In a review, Baile et al. have elaborated on the reasons why physicians avoid communicating bad news to patients: lack of knowledge and communication skills, lack of preparedness to cope with the patient's emotional reactions, fear of disappointing the patient or of destroying hope, embarrassment about their prior undue optimism, failure to recognize the patient's expectations. Solutions to all these fears do exist, techniques for communication or for providing psychological support that can facilitate overcoming the communication barriers described. The strongest premise supporting the 'silence conspiracy' is fear of the patient's psychological reactions and that they will not psychologically adapt to severe illness or to a poor prognosis. Practical observation and research of psycho-oncologists contradict this and demonstrates that the great majority of patients can overcome the psychological problems created by a severe diagnosis or poor prognosis, can cope with these based on their own psychological resources. It has also been proven that the practice of communicating the truth to the patient, providing psychological support and assisting them in decision-making is less harmful to the patient than lying, as they will eventually learn the truth and will feel betrayed and will lose faith in medical personnel.³¹ The patients' psychological coping with bad news was described in multiple models, the most complex being published by Elisabeth Kubler Ross, who describes five stages of psychological coping, some effective, that reduce stress and anxiety, some ineffective. For the study which was the basis for this model Kubler Ross interviewed 200 terminal cancer patients and proved that all of them underwent the same psychological stages: denial of the diagnosis or prognosis, anger towards the inception of illness, bargaining with God, depression and ultimately acceptance.³² Honest communication of the severe diagnosis or prognosis has a series of long term benefits including: decreased anxiety, positive fighting attitude after overcoming the initial emotional shock and effective psychological coping to the patient's new health status. The uncertainty of an uninformed patient is in and of itself a cause of stress so, simply by eliminated this, by communicating the truth positive effects appear which promotes wellbeing for the patient.³³ Cancer patients included in a clinical study have considered that the way in which bad news was communicated is crucial to the way it is perceived and accepted. As such, tactful and sincere communication, done in a supportive manner renders discovery of a severe/malignant diagnosis less stressful. Also for the patients, hiding the truth means depriving them of understanding their own suffering and the opportunity to express their fear and concern regarding the illness, these

³¹ Ibidem, 1.

³² Kubler Ross.

³³ Giris, 3-59.

aspects could help them understand that they are terminally ill and that there is nothing that can be done to help them.³⁴ A study done on 497 cancer patients has revealed that the predictive factors of patient satisfaction towards the manner in which the diagnosis was communicated to them were: the patient's perception that the doctor was personally interested in their suffering, the degree of understanding of the information communicated by the doctor, the patient being informed in an appropriate environment (preferably the doctor's office) and the doctor offering to spend time to discuss and clarify the information they are offering.³⁵ Another study on 351 cancer patients (different stages and affected organs) receiving treatment in M.D. Anderson Cancer Center has demonstrated what patients prefer regarding the manner the initial diagnosis was communicated as well as the recurring illness diagnosis: the physician should be familiar with the latest research in their illness or recurring illness, the physician should inform the patient about the most effective treatment and make time to answer the patient's questions, the physician should also be honest about the severity of the disease, the terminology should be simple and clear and the news should be directly communicated and the patient should be in the center of attention during the communication process. This study did not reveal any difference in preferences across age, sex and previous knowledge of the illness that the patient had prior to communication of the diagnosis to counteract false information or preconceived ideas for the patient's benefit. ³⁶

Legal Aspects of Communicating a Diagnosis

Promoting the patient's welfare is the oldest universal principle known to medical ethics as stated by Hippocrates and recognized over the centuries as defining and fundamental essential for medical practice. In the context of contemporary medicine, which values autonomy and the free will of the patient, identifying what is 'good' and 'beneficial' for the patient constitutes a serious challenge both for the physician and for the patient. Some researchers claim that an apparently autonomous choice a patient makes can be at odds with what the physician considers to be 'the patient's best interest' and this should not be a reason to abstain, but rather an opportunity for the former to intervene to reestablish, if possible the patient's wellbeing.³⁷ Trust in the physician can also have a deciding

³⁴ Olarte, 47-52.

³⁵ Sutherland, 260-263.

³⁶ Lobb, 290-294.

³⁷ Sgreccia, 197-229.

role in establishing the meaning of the patient's best interest.³⁸ The gold standard on diagnosis communication in Romanian law is The Patient Right Law no. 46 adopted on January 21st 2003. According to article 6 of this law the patient has the right to be informed about his state of health, the medical procedures in discussion, the potential risks carried by these procedures and therapeutic alternatives, as well as the consequences of not adhering to the medical recommendations or forgoing treatment. The patient has the right to know their diagnosis, prognosis and also has the right to decide if they wish to be informed in case the information supplied by the physician would cause them suffering (see art. 7 of law 46/2003). Furthermore the law stipulates the patient's right to explicitly request not to be informed and to choose a proxy (friend or family) to be informed in their place (art. 9-10).³⁹ In brief, the Law of Patient Rights does not leave room for interpretation: it is obvious that what is first and foremost is the patient's best interest and informing the family can only be done with the patient's approval or at their (the patient's) request. This confirms the patient's wellbeing as the most important factor by respecting their autonomy.⁴⁰ To this end, art. 15 and 16 of the Medical Ethics Code concur with the law, they state that professional secret, which includes the diagnosis, prognosis and treatment, must be kept, excluding friends and family if the patient so wishes. Furthermore, the duration of the professional secret is not finite, the confidential nature of this information preserving itself even after the treatment is finalized or the patient is deceased.⁴¹ The Medical Ethics Code, art. 63, stipulates the doctor communicating a severe prognosis with tact and care, and recommends taking into account the patient's psychological state. But the same article of the Code states that the family will be notified only with the patient's express consent (this confirms the principle of patient autonomy regarding the decision-making process). It also stipulates that the doctor 'upon concluding that the severe prognosis will harm the patient or when the latter does not desire to know' can reveal the prognosis to the family. If we take into account art. 7 of the Law of Patient Rights, which deals with the patient's right to decide if they wish to be informed if they feel that the information supplied by the doctor could cause them suffering, the Code leaves the decision to establish if the prognosis will cause harm to the patient with the doctor, but also leaves the possibility for the decision to reveal the prognosis to the family with doctor. In our opinion the two legal texts cited are conflicting and can leave room for interpretation regarding the communication of a severe

³⁸ Pellegrino, 17-37.

³⁹ Patients' Rights Law, art. 9-11.

⁴⁰ Ibidem 1, 2.

⁴¹ Medical Ethics Code, art 63.

diagnosis. We will elaborate a number of the aspects that can give rise to ethical problems: a) If the patient does not wish to be informed and does not express explicit approval regarding informing their friends and/or family, the doctor can not reveal information to the family, regardless of the pressure they exert, under which circumstances art. 63 of the Ethics Code no longer applies (this article can in fact be interpreted as the option that the doctor has, in case of a severe prognosis, to discuss the matter with the family without the patient's consent); b) The reference to art. 63 of the Medical Ethics Code to '... keeping the patient's psychological state in mind...' is interpretable. A surgeon or an oncologist might have difficulty correctly interpreting a patient's psychological state. This is a field in which a psychiatrist or a psychologist might be more at home. It is feasible and desirable to subject all cancer patients to a psychological or psychiatric evaluation? Or would it be more feasible to generate norms for interpreting the ambiguous situations in the Ethics Code? The Code leaves the communication of severe prognosis to the family at the surgeon or oncologist's discretion (in case the prognosis might be detrimental to the patient). On the other hand, according to the Patient Law, the doctor is forbidden to impose their options of any nature upon the patient including to inform the patient's family without the latter's consent. Furthermore, according to Law nr.95/2006 art 642 section 3 the physician answers in accordance with the civil code for damages that stem from violation of regulations on confidentiality, informed consent, and the mandatory nature of rendering medical assistance; c) Regarding art. 63 of the Ethics Code '...upon concluding that the dire prognosis will harm the patient...' it is known that all patients who are faced with a severe prognosis undergo a series of steps that lead to cope with bad news: denial, anger, depression, bargaining and acceptance. Some of these (long term denial, anger and depression) constitute in fact ineffective coping strategies that are harmful to the patients, but they can find the resources to overcome these difficulties even without outside support as demonstrated in psycho-oncological literature. ^{42,43} In other words how can the physician decide if a dire prognosis will harm the patient and furthermore inform the family without the patient's consent? d) Being faced with a severe diagnosis is a right the patient has, not an obligation. If they do not wish to know the diagnosis they can assign a proxy for the doctor to inform. But is the physician the one that should decide when it would be beneficial to communicate to a proxy and not the patient? The concept of patient wellbeing is considered by Sgreccia to entail the patient's notion of good, and the decision for medical action must conform to what the patient considers desirable in accordance with the

⁴² Kubler Ross.

⁴³ Spencer, 211-212.

circumstances and choices offered by their illness. It follows that when the patient has the possibility to express themselves they can best decide what is in their best interest; if the patient is unable to make their wishes known then those who decide as proxies should strive to be as close as possible to what the patient would choose if they were able make their wishes known.⁴⁴ Respecting a patient's right to selfdetermination becomes one of the fundamental premises of the doctor-patient relationship, one which is based on trust, and faced with communicating a grave diagnosis the premises do not change. Furthermore art. 376. (1) of Law no. 95/2006 (The Reform of the Health System Law) describes the situations when a doctor can act without the patient's or the family's consent 'except cases of utmost urgency or when a patient or legal proxies are incapable of making their will or consent known, the doctor acts respecting the patient's will and their right to refuse or stop a medical intervention'. To sum up, there are conflicts between provisions on patient communication - the Law of Patient Rights, The Reform of the Health System Law and the Medical Ethics Code that can complicate the physician's position on communicating a grave diagnosis to the family in a situation where the physician should quantify the gravity of the situation or the infaust prognosis. ^{45,46,47} On the other hand, a study on a group of 256 physicians of different specialties that practice medicine in Romania indicates that doctors do not know and apply the full letter and spirit of the law in their daily practice. The study identifies seven major vulnerabilities of the medical practice regarding informed consent and the confidentiality of medical data.⁴⁸ Unfamiliarity and disregard for the legal provisions demonstrates the need for doctors to permanently be instructed in these provisions and their interpretation so as to reduce the risk of malpractice complaints. It may prove useful to have doctors be more socially active in bringing about these modifications to the law.

On Doctor- Patient Communication in Romania

There are precious few studies on clinical psychology and doctor-patient communication in Romania, most of them being conducted as part of doctoral research in medical care institutions that deal also with the psychological support of patients. We will present and discuss the most relevant of that research. A national

⁴⁴ Sgreccia, 197-229.

⁴⁵ Law 95/2006, The Reform of the Health System Law.

⁴⁶ Patients 'Rights Law.

⁴⁷ Medical Ethics Code.

⁴⁸ Nanu, 31-42.

study on diagnosis and prognosis communication was done on oncologists, hematologists and palliative care professionals in the form of a questionnaire with 244 doctors responding. The results of this study indicate that although legally the doctor should favor the patient's wishes, this is rarely the case as 94.3% of the doctors questioned answered that the family should be the first to know the diagnosis. Often times the family pressures the doctor to not communicate openly with the patient, as revealed by 81% of the subjects. This being said, 70% of the doctors included in this study believe that the patients desire to know the truth about the diagnosis. When asked about their own practice, oncologists, hematologists and palliative care professionals communicate the diagnosis to the patient and to the family first in an equal proportion, the difference not being statistically relevant. The main problem in diagnosis communication, thus communicating the truth to the patient as identified by the participants was the real or imaginary fear of causing them suffering: 73% of the participants answered that the truth destabilizes the patient emotionally, 10% do not feel prepared to communicate with the patient. Low importance placed on patient autonomy is another problem: 55% of respondents do not wish to go against the family's wishes and 30% of the doctors decide for the patient, as they feel that finding out the truth is not beneficial to the patients. The study suggests that the physicians had not been trained in communication techniques during medical school, and as such 50% of them state that they acquired these abilities during their practice, learning from experience. A total of 96% felt that communication courses as well as guides in communicating bad news were necessary. Another study on a group of 1250 subjects from the general population had the aim of analyzing the importance of doctor-patient communication especially in response to a malignant diagnosis. The study indicated that a detailed clinical consultation is as important as the time reserved for communication, explanations about the illness and treatment in the population's perception. As for communicating the malignant diagnosis, 53% of the patients desire to know the diagnosis and prognosis in detail. The oncologist and specialist are the ones designated as responsible for communicating the diagnosis.⁴⁹ Another qualitative study based on semistructured interviews with 100 subjects suffering from acute leukemia aimed to find out how the patients had learned their malignant diagnosis, how they felt about the communication with the doctor and how they would have preferred to learn the diagnosis. Meanwhile the hematologists who participated in their treatment were administered questionnaires to identify the method they used to communicate the diagnosis. The results indicate that out of the 100 patients interviewed, 58 learned their diagnosis from the hematologist, 7 found out the diagnosis from doctors in other medical services

⁴⁹ Moşoiu, PhD Thesis.

which have diagnosed their condition, 5 found out from the laboratory doctors, 17 patients read their diagnosis in medical documents, 4 patients found out during a routine evaluation from the specialist in charge, 9 patients found out from family members. The patients that learned of their diagnosis from the doctor, or from laboratory doctors or doctors who diagnosed them, 68 % were happy of the manner in which they discovered the diagnosis. Pleased were also the patients for whom the doctors had taken the time to explain the positive prognosis factors or the fact that the treatment could be successful. The patients appreciated direct and spontaneous communication from their doctor and rewarded it with trust. There were also patients who learned of their diagnosis from doctors only after much persuading, which displeased them. Also displeased were the patients who were communicated the diagnosis without any further information regarding the illness, treatment or prognosis. When asked about their method of communicating the diagnosis of acute leukemia the doctors preferred several patterns: direct communication upon establishing the diagnosis; avoiding giving away the name of the disease, offering only information about it and letting the patient deduce the diagnosis from discussions with other patients or to find out the truth from medical documents; communicating the diagnosis only if the patient or family explicitly asked; the doctor lets the family communicate the diagnosis.⁵⁰ Another study done on lots of patients that had benefitted from specialized end-of-life assistance in Hospice House of Hope Brasov, indicated that complete disclosure of information regarding the gravity of the situation (diagnosis and prognosis) creates a heavy psychological burden but also forces the patient to seek out solutions and help, and this in turn facilitated rapid development of effective psychological coping mechanisms. In the lot comprised of patients who had psychoemotional support sessions, more patients knew the diagnosis and prognosis and fewer family members had intervened to block information from reaching the patient than the group of patients that did not receive psychological support. The study also indicated that there is a significant correlation between the educational level of the patient and the desire to know the diagnosis and prognosis. As such, 62% of the patients with higher education knew the diagnosis and prognosis in full as opposed to 28% of the patients with primary education and 30% of the patients with secondary education. As for the other variables, age, sex, and marital status of the patients no significant difference was found regarding knowledge of the full status of the illness among the patients in the studied groups. The study included a number of 1115 subjects from the general population, too, and analyzed if the respondents would desire to be informed completely or partially in case they

⁵⁰ Pârvu, PhD Thesis.

would develop an incurable disease. The results indicate that 44% of the respondents desired to know the diagnosis as well as the prognosis , 18% desired to know just the diagnosis and possible treatments and 28% desired to know only information on the treatment of their illness and that the physician would refrain from using the word 'cancer'. Only 5% of the patients preferred to be informed by another member of the family, a similar percentage to the one registered for the situation in which family members have intervened asking that information on the diagnosis/prognosis to be withheld from the patient. A percentage of 72% of the respondents with higher education expressed a desire for detailed information on diagnosis, progression of the disease and chances of recovery. The difference between this group and the others is significant, as 54% of the respondents with a high school education and 42% of respondents without high school education expressed this desire.⁵¹

Conclusions

Communicating the diagnosis represents the inception of the trust relationship between doctor and patient. Throughout the centuries the ideas and practices on communication of bad news (diagnosis and prognosis) in medicine changed, the middle of the last century saw more and more change in the concept of patient rights and their role in medical decision-making. The Western, Anglo-Saxon communication model is based on patient autonomy and informed consent, regarding diagnosis communication as one of the patients' rights, as is the case with Romanian law that provides for direct, sincere communication between doctor and patient, provided the latter wishes this. The traditionalist model for doctor-patient communication is preferred by the Eastern cultures and is currently being applied in Asia, Africa, Central and Eastern Europe and is centered on assisting the patient in the midst of their family, whose members take an active role in the healthcare providing process and the medical decision-making process and propose a 'silence conspiracy' to the physician. The physician usually accepts this and has their own fears regarding the communication of a severe diagnosis, fears usually generated by lack of communication skills. The results of research conducted in Romania and presented in this paper, although not representative on a national scale reveal a universal attitude in communication of the diagnosis, that family influences continue to interfere with doctor-patient communication, physicians admit that they do not have the proper background in

⁵¹ Gorog, PhD Thesis.

communication, as most of them learned from experience. There is also a conflict in Romania between the legal aspects and the medical practice regarding doctorpatient communication, the law being created based on the Anglo-Saxon model, while the little existing research reveals that in practice the patients' families adopt a traditionalist model of communication. The laws regarding communication of diagnosis contain certain loopholes which are susceptible to interpretation. For example if and how the physician decides whether the severe prognosis is detrimental to the patient in order to inform the family (according to the Ethics Code), meanwhile the law for patient rights and law 95/2006 does not state neglecting a patient's wishes regarding provision of information to a third party (except unusual circumstances). On the other hand, a previous study has shown that the physicians questioned do not abide by the full letter of the law applicable to the medical profession. Taking into account all this information, the practicing physician is often times under a dilemma regarding medical communication. The area of communicating a severe diagnosis, of a cruel truth still has many questions with no universally accepted answers for all patients. The only universally applicable answer is probably to go back to patient and medical act centered medicine and implicitly take into account the desires and needs of every patient. As such, one possible solution could be to ask the patient upon first meeting them if they desire direct, or mediated communication, i.e. if they desire to know their clinical situation all throughout the illness progression. To ease the adherence to these guidelines and to ensure patient centered diagnosis communication we recommend the creation of doctor-patient communication guides that would be adapted to Romanian law as well as the patients' needs. Keeping in mind that only some of the medical schools in Romania have recently added doctor-patient communication to their curriculum we also recommend courses to instruct the medical professionals and students in communication.

REFERENCES

- Arora N, Interacting with cancer patients: the significance of physicians' communication behavior, *Soc Sci Med*, no. 57, vol.5, 2003, 791–806.
- Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka A, SPIKES—a six-step protocol for delivering bad news: application to the patient with cancer, *The Oncologist*, vol. 5, no. 4, 2000, p. 302–311.
- Benbassat J, Pilpel D, Tidhar M, Patients' preferences for participation in clinical decisionmaking: a review of published surveys, *Behav Med*, nr.24,1998; p. 81-88.

COMMUNICATING THE SEVERE DIAGNOSIS - PSYCHOLOGICAL, ETHICAL AND LEGAL ASPECTS

- Blanchard CG, Labrecque MS, Ruckdeschel JC et al., Information and decision-making preferences of hospitalized adult cancer patients, *Soc Sci Med*, nr.27,1988, p.1139-1145.
- Bre'dart A, Bouleuc C, Dolbeault S, Doctor-patient communication and satisfaction with care in oncology, *Curr Opin Oncol*, no. 17, vol.4, 2005, 351–354.
- Cassileth BR, Zupkis RV, Sutton-Smith K et al., Information and participation preferences among cancer patients, *Ann Intern Med*, vol.980, nr.92, p.832-836.
- Colegiul Medicilor din România, Codul de Deontologie Medicală, disponibil la:

http://www.cmb.ro/legislatie/codulDeontologic/cod.pdf [accessed 20.09.10].

- Davidson JR, Brundage MD, Feldman-Stewart D, Lung cancer treatment decisions: patient's desires for participation and information, *Psychooncology*, nr.8, 1999, p.11-20.
- Davison BJ, Degner LF, Morgan TR, Information and decision-making preferences of men with prostate cancer, *Oncol Nurs Forum*, nr.22, 1995, p.1401-1408.
- Degner LF, Kristanjanson LJ, Bowman D et al., Information needs and decisional preferences in women with breast cancer, *JAMA*, nr.18, 1997, p.1485-1492.
- Dunsmore J, Quine S, Information, support and decision-making needs and preferences of adolescents with cancer: implications for health professionals, *J Phychosoc Oncol*, no. 13, 1995, p. 39-56.
- Fields SA, Johnson WM, Physician-patient communication: breaking bad news, W V Med J, nr.108, vol. 2, 2012, p. 32-5.
- Fong Ha J, Longnecker N, Doctor-Patient Communication: A Review, *The Ochsner Journal*, vol.10, 2010, p.38–43.
- Girgis A, Sanson, Fisher RW, Breaking bad news. 1: Current best advice for clinicians, *Behav Med*, nr.24, vol.2, 1998, 53-9.
- Gorog I, Boala incurabilă și terminală atitudini și asistență în România de azi, [rezumatul tezei de doctorat], Universitatea Babeş-Bolyai Cluj-Napoca, 2010. Disponibil la: http://doctorat.ubbcluj.ro/sustinerea_publica/rezumate/2010/sociologie/ Gorog ileana ro.pdf [accessed 20.09.2011].
- Hoffman JC, Wegner NS, Davis RB et al., Patient preferences for communication with physicians about end-of-life decisions. SUPPORT investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment, *Ann Int Med*, nr.127, 1997, 1-12.
- Kubler Ross E, On death and dying, Elena Francisc Publishing, 2008.
- Lee A, Wu HY, Diagnosis Disclosure in Cancer Patients –when the Family says "No!", *Singapore Medical Journal*, Vol. 43, nr.10, 2002, p.533-538.
- Ley P, Giving information to patients, Social Psychology and Behavioral Science, Eiser JR, editor. New York: John Wiley, 1982, p.353.
- Lobb EA, Butow PN, Kenny DT et al., Communicating prognosis in early breast cancer: do women understand the language used?, *Med J Aust*, no. 171, 1999, p.290-294.
- Loge JH, Kaasa S, Hytten K, Disclosing the cancer diagnosis: the patients' experiences, *Eur J Cancer*, no. 33, vol.6, 1997, p.878-82.

- Meredith C, Symonds P, Webster L et al., Information needs of cancer patients in West Scotland: cross sectional survey of patients' views, *BMJ*, nr.313, 1996, p.724-726.
- Moșoiu D. Comunicarea diagnosticului și prognosticului în cancer.Pregătirea, percepții și practici ale medicilor oncologi, hematologi și de îngrijiri paliative, așteptări ale populației și cadrul normativ [teză de doctorat], Universitatea de Medicină și Farmacie "Iuliu Hațieganu", Cluj-Napoca, 2009.
- Nanu A, Georgescu D, Voicu V, Ioan B, Locul și relevanța prevederilor legale în contextul practicii medicale din România, *Revista Română de Bioetică*, vol. 9, no. 4, p. 31-42.
- National Cancer Institute, *Basic Communication Skills*, available at:
 - http://www.cancer.gov/cancertopics/pdq/supportivecare/communication/ healthprofessional/page5, [accessed 04.01.2013].
- Olarte, JN, Gracia G, Cultural Issues and Ethical Dilemmas in Palliative and End-of-Life Care in Spain, *Cancer Control*, vol.8, nr.1, 2001, p. 47-52.
- Parker PA, Baile WF, de Moor C, et al., Breaking bad news about cancer: patients' preferences for communication. *J Clin Oncol*, 19 (7): 2049-56, 2001
- Pârvu A, Optimizarea transfuziilor sanguine (aspecte legate de crearea unui model predictiv al necesarului transfuzional și de consilierea psihologică a pacienților leucemici politransfuzați) [teză de doctorat], Universitatea de Medicină și Farmacie "Iuliu Hațieganu", Cluj-Napoca, 2009.
- Pellegrino ED, Thomasma DC, *The Good of Patients and the Good of Society: Striking a Moral Balance, Public Health Policy and Ethics*, editor Boylan M, Kluwer Academic Publishers, 2004, p.17-37.
- Sgreccia E, Bioetique et Medicine, Manuel de Bioetique. Les fondements et l'éthique biomédicale, Ed. Manu-Edifo, 2004, p. 197-229.
- Spencer S, Carver C, Price A, Psychological and Social Factors in Adaptation, Holland JC, (Ed.), *Psycho-Oncology* (211-212). New York: Oxford University Press (1998).
- Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA et al., Cancer patients: their desire for information and participation in treatment decisions, *J R Soc Med*, nr.82, 1989, p.260-263.
- ***Legea nr. 46/2003, Legea drepturilor pacientului, available at: http://www.dreptonline.ro/legislatie/legea_drepturilor_pacientului.php [accessed 20.08.11].
- ***Legea nr. 95 / 14 aprilie 2006, Legea privind reforma în domeniul sănătății. Available at: http://www.cdep.ro/pls/legis/legis_pck.htp_act_text?idt=72105, [accessed 04.01.2013].