RELATIONSHIPS BETWEEN COMMUNICATING BAD NEWS, CANCER DISEASE ADAPTATION, AND RELATED MOOD DISORDERS

Anda Natalia CIUHU[1], T. SPIRCU[2], Liliana PADURE[3], C.D. BADIU[4], V. POROCH[5], S. OMER[6], M. RADOI[7],
Mihaela POPESCU[8], Roxana Andreea RAHNEA NITA[9], and Gabriela RAHNEA NITA[1]

[1] "Sf. Luca" Chronic Diseases Hospital, Department of Oncology – Palliative Care, Bucharest, Romania
[2] The Romanian Society of Palliatology and Thanatology, Romania
[3] National Rehabilitation Clinic Center for Children Neuropshychometric "Dr. NicolaeRobănescu" Bucharest,
"Carol Davila" University of Medicine and Pharmacy, Bucharest, Romania
[4] "Bagdasar Arseni" Emergency Hospital, Department of General Surgery, Bucharest,
"Carol Davila" University of Medicine and Pharmacy, Bucharest, Romania
[5] Oncological Institute, Department of Palliative Care, Iasi, "Gr. T. Popa" University of Medicine and Pharmacy, Iasi, Romania
[6] "Sf. Ioan" Emergency Hospital, Department of Internal Medicine, Bucharest,
"Carol Davila" University of Medicine and Pharmacy, Bucharest, Romania
[7] Institute of cerebrovascular diseases, Department of Neurosurgery, Bucharest, Romania. "Carol Davila" University of Medicine and
Pharmacy, Bucharest, Romania. E-mail: muguradoi@yahoo.com
[8] "Colentina" Clinical Hospital, Department of Hematology, Bucharest, Romania
[9] "Dr. Constantin Gorgos" Titan Psychiatric Hospital, Department of Oncology, Bucharest, Romania
Corresponding author: Gabriela RAHNEA NITA
"Sf. Luca" Chronic Diseases Hospital, Department of Oncology – Palliative Care, Bucharest, Romania
E-mail: gabriela_rahnea@yahoo.com

Background: Adapting to the diagnosis of advanced cancer is a complex process. Both the patient and his family suffer multiple personal losses of physical, emotional, spiritual, and social nature.

Aim: The aim of this study was to evaluate the perception and attitude of the patients, their families, and the healthcare professionals about communicating bad news as far as the end of life is concerned, in Romania. The study also aimed to raise the awareness of the patients for a life threatening illness and the psycho-emotional disorders (anxiety and depression) that can also occur.

Materials and methods: Cancer patients were evaluated by using three questionnaires regarding their opinion about communicating bad news, their adaptation to the disease and mood disorders. Moreover, the patients' families and the medical staff answered to the questionnaire about communicating bad news.

The statistical analysis consisted mostly in classical percentage computing. SometimesSomers' (delta) coefficient was computed and the Fisher's exact test was performed.

Results: With concern to whom should receive the bad news first, all the doctors, 45% of the patients, 40% of the families, 14% of the nurses, and 25% of the caregivers considered that patients and families should be informed at the same time.

24.14% of the patients adapt very well to the disease and 72.41% are partial with regard to coping with the disease.

36.78% of the patients exhibit anxiety and 21.84% have depression.

Discussion: A doctor-patient relationship based on truth can change the patient's perception on the disease, thus decreasing anxiety and depression with the benefit of an effective coping mechanism to the disease.

Conclusions: Communicating bad news pattern follows the characteristic model of South-Asia and South-East Europe, but with the preference to communicate the bad news at the same time to both the patient and his family.

Key words: bad news; cancer adaptation; anxiety; depression.

INTRODUCTION

Patients with cancer have to face some changes, both in terms of their health, and in the spiritual, psycho-emotional, and socio-economic field. Adapting to the disease represents a dynamic and complex process, which differs from one patient to another and depends on several factors, namely the stage of disease, the type of treatment, and the type of personality and environment[1-3].

A positive attitude is a mechanism to cope with illness and motivate patients to continue their physical and social activity, while denying represents a mechanism of maladjustment to the disease[3-5].

The role of the family in caring for patients is very important, the Romanian society being a model centered on family when compared with the Western countries, where the model is that of individual autonomy. Many patients in Romania are not informed about the diagnosis and prognosis, because of the application of this model.

While nearly all the patients in Western countries want to know their diagnosis, prognosis, treatment options and survival rate, studies have shown that patients in Asia and South and South-East Europe prefer that families are present when bad news are communicated[5-7].

In many cultures, the patient is maybe the last who it is said to have cancer, the culture having a huge influence on the way issues of cancer are discussed and especially on communicating the diagnosis and prognosis. Culture influences the perception of patients and their families about the disease and treatment and also the adaptation to disease[8-10].

In terms of communicating the truth about the disease, doctors, nurses, patients and their families have different perspectives. Communicating bad news must be performed by a person whom the patient trusts, and whom he/she feels comfortable being with. Doctors are inevitably forced to communicate bad news, which is not easy. There are few studies regarding the nurses' opinion; only in the United Kingdom communicating bad news is part of nurses' common practice. Regarding patients, some prefer to know the truth; others prefer to leave everything up to the doctors' account. Communicating the truth about the disease is an important step in the relationship established between the doctor and the patient, being based on mutual trust, which recognizes human values and respects the patients' rights. Bad news should be communicated in a way the patients could accept the information about the disease and also keep their hopes up, and the doctor must be honest, tolerant and understanding as a token of trust in continuing the relationship with the patient[11].

The quality of life depends on factors such as the support of friends and family, the ability to work and interest in own occupation, on realistic expectations consistent with reality, as well as the health status. A reaction to somatic illness could be the emotional disease; therefore, the anxious-depressive status assessment (demoralization caused by prolonged suffering, pessimism, feelings of panic) contributes to the management of the quality of life.

The aim of this study is to evaluate the perception and attitude of the patients, their families, and the healthcare professionals in Romania regarding the communication of bad news concerning the end of life, the patient adaptation to a life threatening illness and the assessment of the anxious-depressive disorder that could occur.

MATERIALS AND METHODS

Patients diagnosed with advanced loco-regional or metastatic cancer, were admitted in the Department of Oncology, Palliative Care for Chronic Patients of "Sf. Luca" Chronic Diseases Hospital, in Bucharest, Romania, over a period of two weeks. In February 2015, they were evaluated by using three questionnaires regarding their opinion on communicating bad news, their adaptation to the disease and mood disorders. In parallel, the patient's families and the medical staff answered to the questionnaire regarding the communication of bad news.

The first questionnaire – regarding the communication of bad news – dealt with the perception and attitude towards telling the truth, towards life and end of life[4-6]. This questionnaire was approved by the Medical Ethical Commission of the Hospital.

The second questionnaire – regarding the adaptation to the disease – was a Brief Illness Perception Questionnaire[12]. (The authors previously obtained the permission to use it.)

The third questionnaire was a Hospital Anxiety and Depression Scale (HADS), which is freely available online[13].

Of the 290 patients admitted in our department, 98 patients were excluded based on cognitive deficits or based on their functional status and other 18 patients refused to answer to the three questionnaires. A number of 174 were eligible for inclusion and enrolled (enrollment rate was 100%).

80 family members and 31 healthcare professionals (4 doctors, 14 nurses, and 13 caregivers) answered to the first questionnaire.

The participants to the study were explained the purpose and the importance of the study and the patients signed a written informed consent in which they freely agreed to join the study. The approval from the Medical Ethical Commission of "Sf. Luca" Chronic Diseases Hospital has been previously obtained.

The statistical analysis consisted mostly in classical percentage computing. In addition, Somers' (delta) coefficient was computed to assess concordance between two ordinal variables (such as, for example, the adaptation to the disease vs. the anxiety status), and the Fisher's exact test was performed to assess differences in opinions between different groups of respondents. Data obtained were analyzed by using Microsoft Office Excel 2013 and SPSS v.21.

RESULTS

The age of patients cover a range from 41 to 82 years, with an average of 63.0 years (std. deviation = 9.2 years). According to the usual age groups (30–45, 46–60 and over 60 years old) the patients' distribution was the following: 8 (4.6%) in the first group, 56 (32.2%) in the "46–60 years" group, and 110 (63.2%) in the "over 60 years" group.

The patients' distribution according to gender was: males 116 (66.7%) and females 58 (33.3%).

The patients' distribution according to life environment was the following: urban 104 (59.8%) and rural 70 (40.2%).

According to the education level, the patients' distribution was: elementary 96 (55.2%), secondary 56 (32.2%), university 22 (12.6%).

Moreover, the patients' distribution according to the disease diagnosis was the following: Lung 66 (37.9%), Breast 20 (11.5%), Prostate 18 (10.3%), Head and neck 18 (10.3%), Colorectal 14 (8.0%), Cervix 6 (3.4%), Gastric 4 (2.3%), Ovary 4 (2.3%), Renal 4 (2.3%), Sarcoma 4 (2.3%), Small Bowel 2 (1.1%), Lymphoma 2 (1.1%), Pancreas 2 (1.1%), Bladder 2 (1.1%), Hepatocarcinoma 2 (1.1%), Skin 2 (1.1%), unspecified 4 (2.3%).

The results obtained after processing the answers given to the questionnaires, were the following (see Figure 1).

Regarding the diagnosis of cancer, 92.0% of the patients, 85.0% of the families, 100% of the doctors, 92.9% of the nurses, but only 15.4% of the caregivers considered that patients should be informed.

It is clear that the opinion of caregivers differ from that of all other categories of respondents, and this difference is highly significant (p < 0.001) from the statistical point of view. The opinion of patients slightly differ from that of family members, but not significantly (p = 0.073 given by the Fisher's exact test).

Regarding the prognosis communication, 71.3% of the patients, 62.5% of the families, 100% of the doctors, 78.6% of the nurses, but only 15.4% of the caregivers considered that patients should be informed.

As far as specific oncological treatment failure was concerned, 69.0% of the patients, 57.5% of the families, 75% of the doctors, 71.4% of the nurses, but only 15.4% of the caregivers considered that patients should be informed.

Concerning the discussion about the end of life, 60.9% of the patients, 50.0% of the families, 75% of the doctors, 42.9% of the nurses but again, only 15.4% of the caregivers considered that patients should be informed about this issue (Fig. 1, right).

Regarding (not) informing the patients at family request, 72.1% of the patients, 72.5% of the families, 50% of the doctors, 64.3% of the nurses and 61.5% of the caregivers considered that patients should not be informed (Fig. 2).

The opinions of patients and of family members are similar (p = 0.946 given by the chi-square test). As well, the opinions of nurses and of caregivers are similar (p = 0.883).

There is a difference in opinions between the patients and family members, on one side (72.2% "yes"), and the nurses and caregivers on the other side (only 63% "yes"). However, this difference is not significant (p = 0.213 given by the Fisher's exact test).
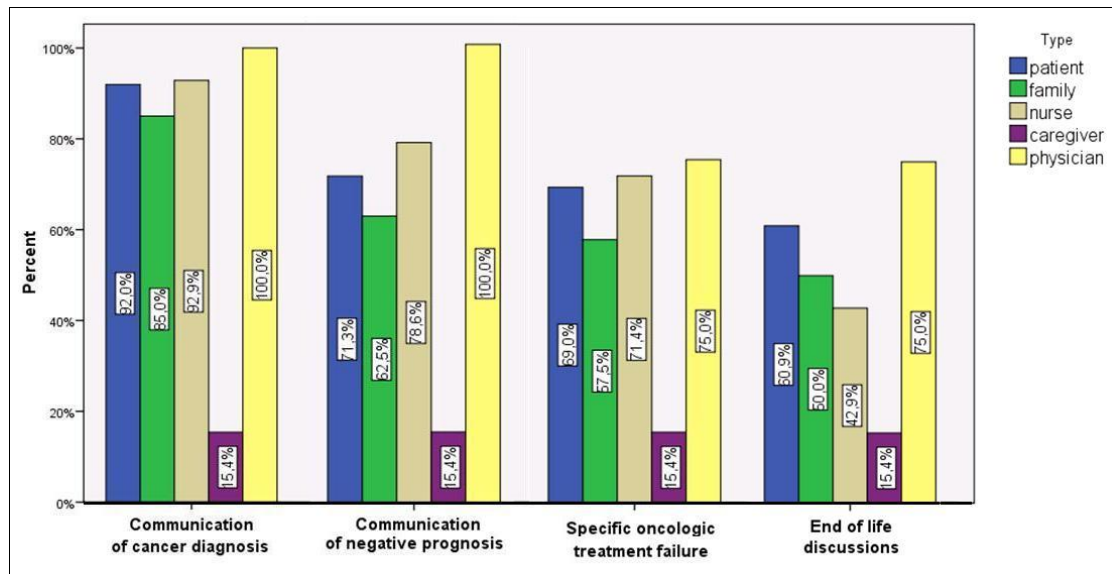
Fig. 1. Attitude of patients, family and medical staff regarding the communication of diagnosis, prognosis, oncologic treatment failure, and end of life discussion.
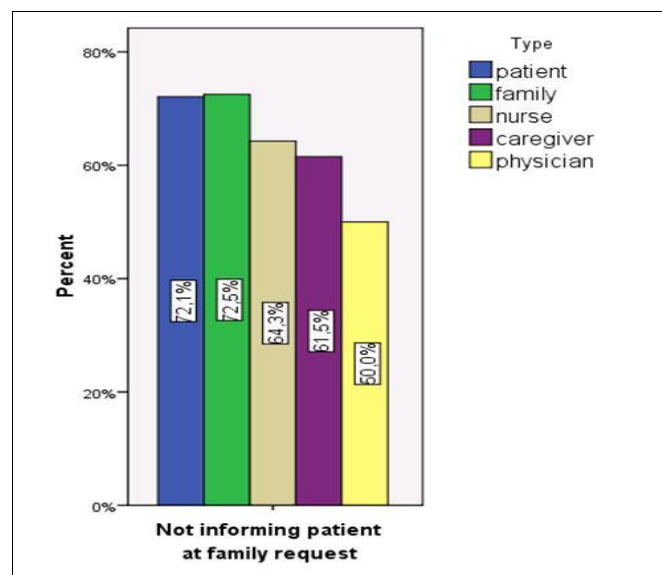

Fig. 2. Attitude regarding not informing the patient at family's request.

Regarding the person whom the bad news should be communicated first, only 24% of the patients and 14% of the nurses considered that patients should be the first to be informed; on the contrary, 30% of the patients, 60% of the families, 71% of the nurses, and 75% of the caregivers considered that families should be the first to be informed. All the doctors, 45% of the patients, 40% of the families, 14% of the nurses, and 25% of the caregivers considered that patients and families should be informed at the same time (Fig. 3).

The total score of the answers to the second questionnaire, Brief Illness Perception Questionnaire, regarding the adaptation to the disease, is presented in Figure 4.

The first 8 items of Brief Illness Perception Questionnaire measure the following: Item 1 – The consequences score, Item 2 – The timeline score, Item 3 – The personal control scores, Item 4 – The treatment control score, Item 5 – The identity score, Item 6 – Illness concern score, Item 7 – The coherence score, Item 8 – The emotional representation score.

The authors divided the total score into 3 categories: 1 – good adaptation to the disease (0–30 points), 2 – partial adaptation to the disease (31–60 points), and 3 – maladaptation to the disease (61–80 points).

The results regarding the adaptation to the disease were the following: good adaptation to the disease – 42 patients (24.14%); partial adaptation to the disease – 126 patients (72.41%); maladaptation to the disease – 6 patients (3.45%).
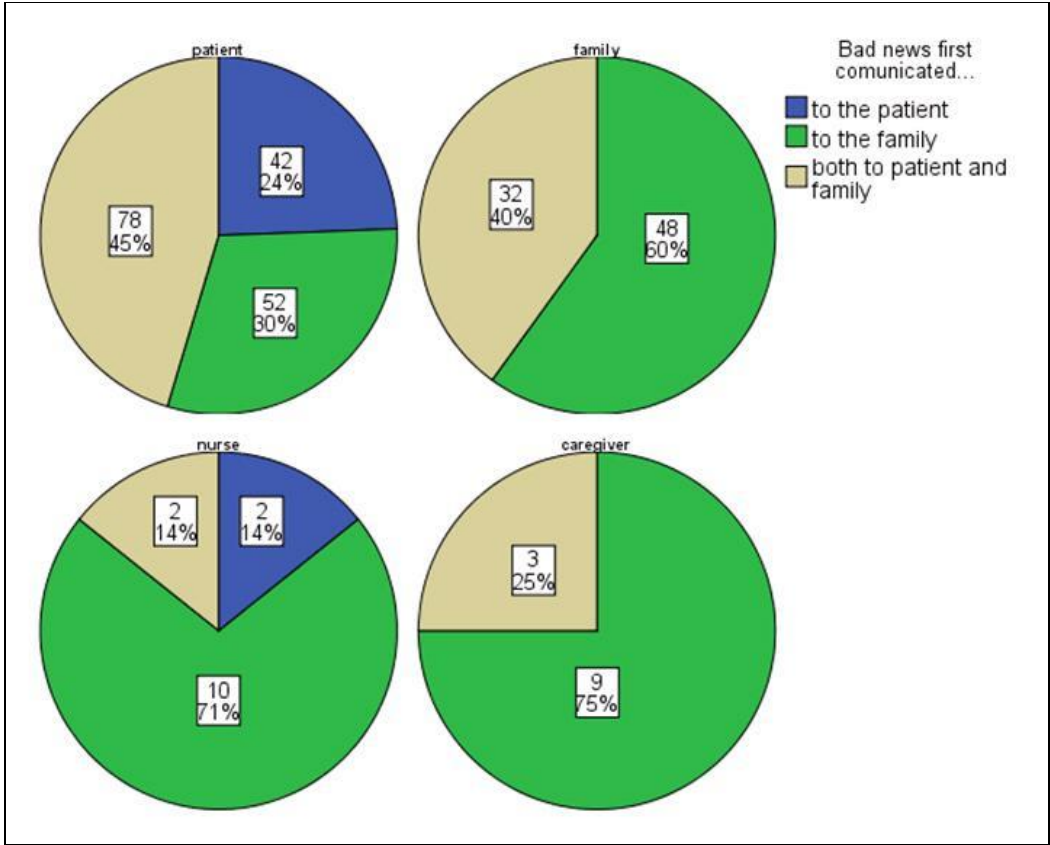

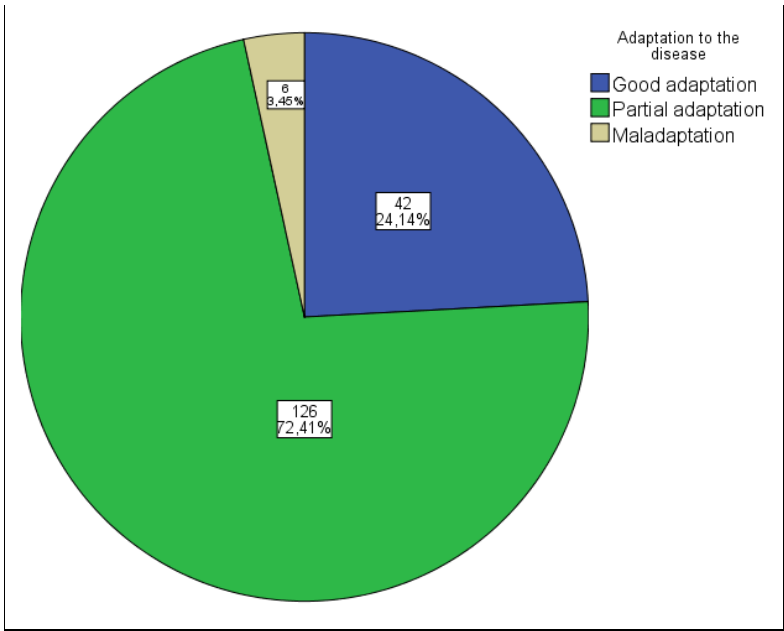Fig. 3. Attitude regarding who should receive the bad news first.

Fig. 4. The adaptation to the disease.

The last item of this questionnaire (Item 9 – The causal item) asks patients to identify the three most important factors believed to have caused their illness. Patients had to list in their own words, in rank-order, their choices being evaluated, according to the order of importance, with 3, 2 respectively 1 point.

The overall answer rate was 70.5%, usually the third choice remained unanswered.

The number of points obtained by each detected factor causing the illness was standardized, *i.e.* transformed in an index on a scale [0, 1], according to the following (customized) formula: *index =* = *points / (3× No. respondents).*

The results concerning the factors patients believed to have caused their illness – arranged in decreasing order according to their index obtained – are presented in Figure 5.
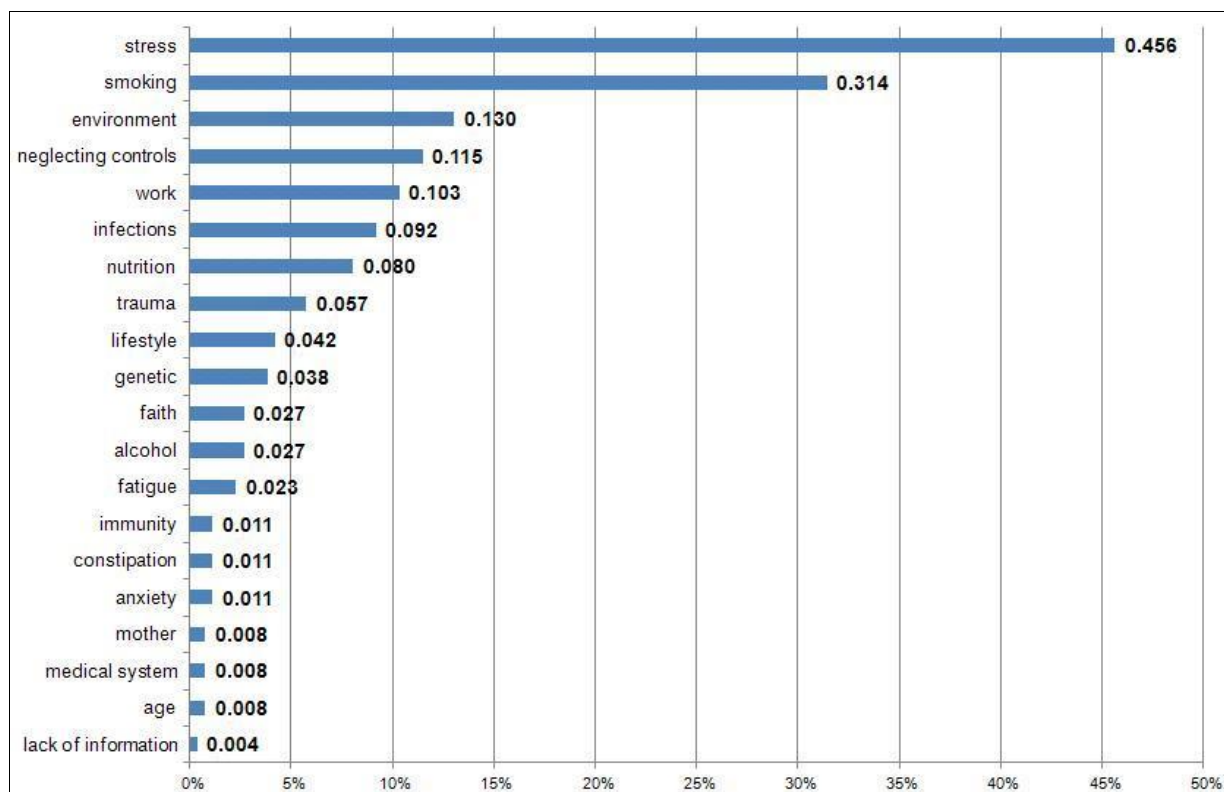

Fig. 5. The factors patients believed to have caused their illness.

The results were the following: stress – 238 points (index = 0.456), smoking – 164 points (index = 0.314), environment – 68 points (index = = 0.130), neglecting controls at the doctor – 60 points (index = 0.115), work – 54 points (index = = 0.103), infections – 48 points (index = 0.092), nutrition – 42 points (index = 0.080), trauma – 30 points (index = 0.057), lifestyle – 22 points (index = 0.042), genetic – 20 points (index = 0.038), faith – 14 points (index = 0.027), alcohol – 14 points (index = 0.027), fatigue – 12 points (index = 0.023), weak immunity – 6 points (index = 0.011), constipation – 6 points (index = 0.011), anxiety – 6 points (index = 0.011), age – 4 points

(index = 0.008), mother – 4 points (index = 0.008), medical system – 4 points (index = 0.008), lack of information – 2 points (index = 0.004).

The answers to the third questionnaire, the HADS, regarding mood disorders were based on the relative frequency of symptoms over the previous week, using a four point Likert scale ranging from 0 (not at all) to 3 (very often indeed). Responses were summed to provide separate scores for anxiety and depression symptomatology (each of the anxiety or depression scale has a score range of 0–21).

The total score was evaluated as follows: 0–7 = = Normal, 8–10 = Borderline abnormal (borderline case), 11–21 = Abnormal (case).
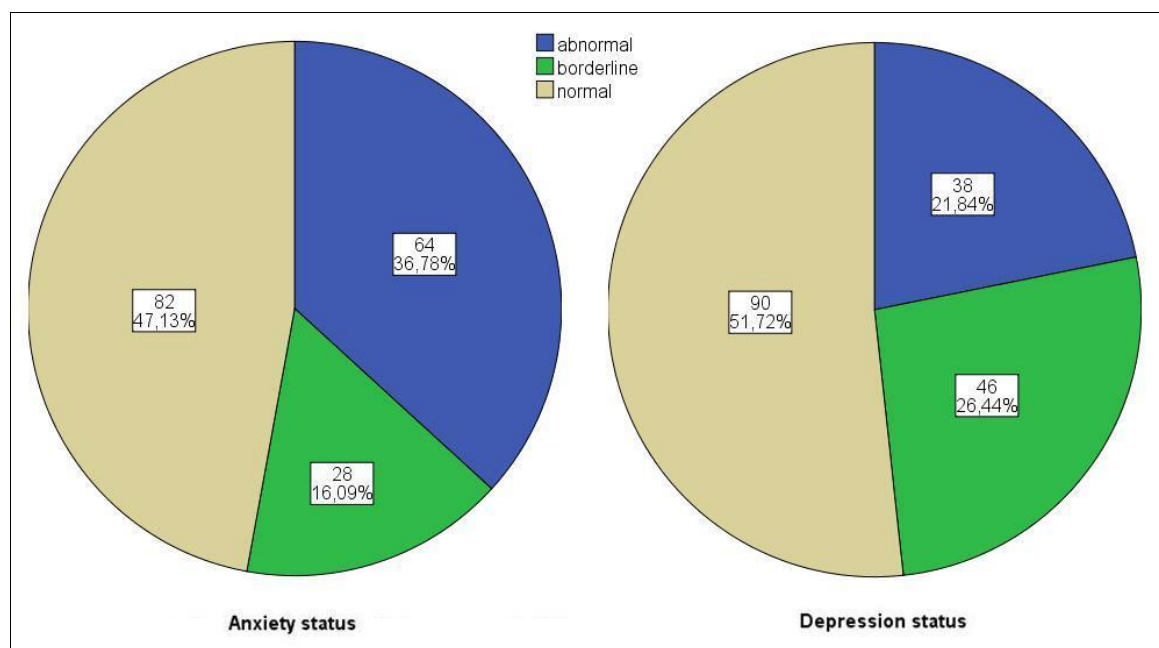
Fig. 6. The mood disorders.

The results regarding mood disorders are presented in Figure 6.

More precisely, the results regarding the mood disorders are the following:

ANXIETY: 82 (47.13%) normal case; 28 (16.09%) borderline case; 64 (36.78%) abnormal case.

DEPRESSION: 90 (51.72%) normal case, 46 (26.44%) borderline case; 38 (21.84%) abnormal case.

The degree of concordance between anxiety and depression status can be evaluated by computing the Somers coefficient. Its value, 0.543, shows a relatively moderate concordance between them.

If we try to evaluate how much the adaptation to the disease influences the anxiety status, a good indicator is the Somers concordance coefficient. Its value, 0.573, shows that this influence is also moderate. This influence is high for "very old" patients (coefficient = 0.605) and is even higher for patients with a low education level (coefficient = 0.634).

DISCUSSION

In Romania, until a few years ago, there has been a preference for not informing the patient regarding the diagnosis and prognosis of a severe disease, especially in the case of cancer. Moreover, there have also been cases in which the patient's family was not informed until the presentation to the oncologist. In the last 5 years, an alignment to modern ethics has been tried, with a legislative obligation to inform the patient about the diagnosis, prognosis, and therapeutic alternatives[14]. However, the adoption of modern principles from different cultures require a previous period of study, information, implementation and adaptation of the medical staff and health service consumer (patient and family) to the new regulations. The issue of whether, how and how much to tell cancer patients concerning the diagnosis is still being approached differently depending on the country and culture[5].

In these conditions, we are facing the pressure of families of cancer patients to hide the truth about the prognosis and course of the disease, in particular, but also the diagnosis of the disease, hoping to keep the patient's psycho-emotional balance.

Surprisingly, the analysis of the results of our study showed that 92% of the patients wanted to be notified regarding the diagnosis of the disease and 71.3% of them wanted to know the prognosis. Also, 85% of the families preferred the patient to be informed concerning the diagnosis, 62.5% wanted the patient to know the prognosis and a significant percentage of patients preferred to be informed about the possible failure of the specific treatment (69.0%).

The position of medical staff involved in oncology and palliative care was different. Thus, 100% of the doctors believed the patient should be informed about the diagnosis, prognosis, a position

which is found very often among medium-trained medical staff (nurses), except for a lower percentage regarding prognosis (78.6%). Lower trained medical staff (medical caregivers) was placed to the opposite side in our study, 15.4% of them considering that the patient should be informed about the diagnosis, prognosis of the disease, and failure or lack of curative treatment. However, there was a restraint in the medium and high-trained medical staff regarding the informing of the patient about the possible treatment failure (doctors – 75%, nurses – 71.4%).

Nevertheless, there is a relative consensus that information regarding the disease should not be hidden from the patient at the request of the family: 72.1% of the patients, 72.5% of the families, 64.3% of the nurses, and 61.5% of the medical caregivers, surprisingly only 50% of the doctors agreeing with this position.

Most of the doctors surveyed (75%) believed that patients should be involved in discussion about the end of life, so that they were able to prepare the future conduct of life, a position shared by 60.9% of the patients, unlike their families and medical staff (50% of the families, 42.9% of the nurses, and 15.4% of the caregivers). This attitude could be probably explained by the tendency to protect the patient, not to raise anxiety and fear and perhaps by the difficulty of addressing this topic. Generally, the concept of death and dying has become a more private and detached issue, with the level of fear and anxiety attached to it greater than previously[4]. Although culture is an important factor in attitudes towards death and dying, one must be careful not to overstate its importance[4].

The evidence suggested that the issue of truth-telling in health care – what a terminally-stage ill person wants to hear and how it is told – is so embedded in the culture that it cannot be seen as simply an ethical dilemma[10].

The significant differences inside the medical team, between doctors and nurses – on the one hand and the low-trained medical staff – on the other hand, may reflect the impact of information and the cultural level diagnosis regarding the communication of the diagnosis and bad news.

Considering the results of this study, that a percentage of the patients preferred to be informed regarding the disease by their family and not by the medical personnel, only 24% of the patients believed that any information related to the disease had to be provided only to them, while 30% of them and 60% of the families preferred that the

discussion about the disease were dealt first with the family, while reflecting. Moreover, most of the medical staff (nurses and caregivers) preferred that the information related to the disease was provided to families, on the one hand, because the psycho-emotional impact on the medical team would be lower, and, on the other hand, the correct information of the family was provided, thus lowering the pressure of it on the medical staff. 100% of the doctors, only 45% of the patients and 40% of the families considered that both patients and the family should be informed at the same time. The attitude of the doctors was explained by the completion of the palliative care team with the patient's family and its involvement in patient care and support, in the journey with the disease. The low percentage of patients who required family support the moment bad news related to the disease were communicated to them, as well as families, reflected poor relationships between the patients and their families, either by lack of trust or sincerity.

Most of the patients will inform their family if they suffered from cancer and doctor was the best person to impart the cancer diagnosis[5]. In Romania, the communication of the diagnosis and all the information related to the disease is preferred to be done by the doctor, being the person best informed about the disease, psycho-emotional aspects of the patient and his/ her family, communication and legislative responsibility.

Illness perceptions have proven to predict the coping and adjustment in many chronically ill patients. 15–50% of the cancer patients and their families have reported clinically significant distress, including extreme anxiety, depressive syndromes, or inadequate adaptation to illness[15]. Thus, 72.41% of our patients presented a mostly negative perception of the disease, and 3.45% of them a negative perception, which can lead to an ineffective illness adaptation. This was also found in the evaluation of anxiety and depression, thus 16.09% and, respectively, 26.44% of the patients showing a borderline level of anxiety and depression, most of the patients presenting normal clinical features of anxiety and depression (47.13%, respectively 51.72%).

When illness perceptions are mostly negative, the person tends to have a deeper feel of his conditions' symptoms, to believe that the disease will last for a longer period and that the recovery, if it happens, will be slow[16,17].

CONCLUSIONS

Patients with advanced stage cancer live a complex medical experience, with a severe impact of the disease on the quality of life, most often with limited therapeutic options and are partly informed on the prognosis and disease severity, which explains the mostly negative perception of the disease and the presence of psycho-emotional distress.

The communication of the diagnosis, prognosis, and therapeutic options to the patient with cancer can change his/her perception regarding the disease, leading to the decrease of psycho-emotional distress, respectively of anxiety and depression, and to rise of the benefits.

In Romania, the bad news communication model characteristic for South Asia and South and South-East Europe is applied, with a preference to communicate it to both the patient and his/her family at the same time[4,5,6,9,10,11,18].

LIMITATION OF THE STUDY

The study presented several issues that arose unexpectedly and, due to this, it was defined as "limitation of the study". This study employed the cross sectional design, whereby the patients, families and the medical staff preferences score, adaptation to the disease and mood disorders were only measured once throughout the study, this not reflecting however their preferences over the time.

A multicentre study with a larger sample size would have resulted into conclusions that are more definite.

Finally yet importantly, the lack of other studies in Romania and the lack of literature related to the subject of study in our country should also be mentioned.

ACKNOWLEDGEMENT

REFERENCES

1. Heim E, Valach L, Schaffner L. Coping and psychosocial adaptation: longitudinal effects over time and stages in breast cancer. *Psychosom Med*. 1997; 59(4):408-18.
2. Rahnea Nita G, Ciuhu AN, Georgescu DG, Rahnea Nita RA. Involvement of the palliative care team in the adaptation of the patient to neoplastic disease. *Archives of the Balkan Medical Union*. 2013; 48(4):406-411.
3. Grigorean VT, Rahnea Nita G, Rahnea Nita RA *et al.* Prostate Cancer – Peculiarities of the Process of Adaptation to the Disease. *Clujul Medical.* 2013; 86(2):133-137.
4. Rama R, Sallaku A. Perception and attitude toward end of life in Albania. *Adv. Pall. Med.* 2012; 11(1):1-5.
5. Zekri JM, Karim SM, Bassi S, Sadiq BM *et al.* Bad news: Comparison of perspectives of Middle Eastern cancer patients and their relatives. *Patient and Survivor Care. J ClinOncol.* 2013; 31, suppl., abstr. 9568.
6. Beqiri A, Toci E, Sallaku A *et al.* Breaking bad news in a Southeast European population: a survey among cancer patients in Albania. *J Palliat Med.* 2012; 15(10):1100-5.
7. Benowitz S. To Tell the Truth: A Cancer Diagnosis in Other Cultures Is Often a Family Affair. *Oxford Journals, Medicine & Health.* JNCI J Natl Cancer Inst. 1999; 91(22):1918-1919.
8. Miyata H, Tachimori H, Takahashi M *et al.* Disclosure of cancer diagnosis and prognosis: a survey of the general public's attitudes toward doctors and family holding discretionary powers. *BMC Medical Ethics.* 2004; 5:7.
9. Tsoussis S, Papadogiorgaki M, Markodimitraki E *et al.* Disclosure of cancer diagnosis: the Greek experience. JBUON. 2013; 18(2):516-526.
10. Buken NO. Truth-Telling Information and Communication with Cancer Patients in Turkey Department of Deontology and Medical Ethics. Hacettepe University, Faculty of Medicine, Ankara, Turkey.
11. Kazdaglis GA, Arnaoutoglou C, Karypidis D *et al.* Disclosing the truth to terminal cancer patients: a discussion of ethical and cultural issues. *East Mediterr Health J.* 2010; 16(4):442-7.
12. Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. *J Psychosom Res.* 2006; 60(6):631-7.
13. Snaith RP. The Hospital Anxiety And Depression Scale Health and Quality of Life Outcomes. 2003; 1:29.
14. Legea Drepturilor Pacientului, Legea nr. 46/2003; Published in Monitorul Oficial, Partea I nr. 70 din 03/02/2003
15. Hopman P, Rijke M. Illness perceptions of cancer patients: relationships with illness characteristics and coping. *Psycho-Oncology.* 2015; 11–18.
16. McLean LM, Jones JM. A review of distress and its management in couples facing end-of-life cancer. *Psycho-Oncology.* 2007; 603–616.
17. Petrie KJ, Weinman J. Why illness perceptions matter. Clinical Medicine. 2006; 6(6):536-539.
18. Suriani Ab R, Maziah M, Adie S, Ton M. Disclosure of Cancer Diagnosis and Prognosis from Patients' Perspectives at Hospital University Sains Malaysia, Proceedings of the Regional Conference on Statistical Sciences 2010 (RCSS'10), ISBN 978-967-363-157-5. Malaysia Institute of Statistics, Faculty of Computer and Mathematical Sciences.