

A Retrospective Study about Autonomy of the Patients with Neurological Disorders: A Record base Analysis

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Abstract—In the case of neurological disorders, patient autonomy is a fundamental principle which must be taken into consideration. In the case of this pathology, fluctuating mental deterioration is encountered most frequently in the case of mild forms of dementia. In the case of severe forms of dementia, the patient loses any autonomy and requires permanent medical care, as well as a permanent legal representative.

Aim of this study was to know autonomy of the patients with certain neurological disorders about ability of making decisions for their medical care.

Material and method: It is a quantitative retrospective observational study and data for which is gathered from the observation charts of 323 patients attended in either emergency or outpatient, between April to December 2006, in "Prof. Dr. Nicolae Oblu" Clinical Hospital of Emergency, Iasi, Romania. Study subjects were split into 2 groups: Group 1 (with a number of 215 cases) – a group of patients with the diagnostics of acute cerebrovascular accident, aphasia and dementia. Group 2 (with a number of 108 cases) – patients known or recently diagnosed with amyotrophic lateral sclerosis, multiple sclerosis and myasthenia gravis. Consent informed given by patient in the observation charts of above two groups was observed and number of patients who has given consent was compared in both the groups.

Results: On the cases under study, only for 13.6% of the patients of the first group there is consent informed in the observation chart, while for the patients in the second group this percentage was slightly smaller (9.3%).

Conclusions: As very few patients have given written informed consent and more severe the neurological disorder less the chances to have written informed consent by patients. So it can be concluded that medical performance brings indisputable benefits, however it should be done by a careful selection of the subjects and by following ethical principles.

Keywords: Autonomy, Neurological Disorders, Competency

I. INTRODUCTION

Autonomy principle¹ is sometimes broken to the benefit principle, especially when the persons with psychiatric and neurological disorders are at a risk of harming themselves or those around them. However, breaking patient autonomy can be the source of numerous ethical and legal conflicts^{2,3}. Respecting autonomy has been a priority in the recent years⁴ and the patient increasingly becomes an active participant in taking decisions related to his health. Thus, in the 21st century, doctor-liberal patient pattern has been more and more promoted.

When there is a patient with the fluctuating or reversible mental status, decisions must be postponed till he is capable of deciding for himself. Repeated episodes of paroxysmal brain dysfunction from epilepsy can produce loss of consciousness, alteration of perception, etc. Cognitive impairments at the patients suffering from epilepsy may include attention, memory, linguistic abilities and perception. Besides the impairment of the cognitive functions, executive functions may be altered as well. These can be referred to the person capacity of having an independent behaviour and self-control. Most of the patients with neurological disorders imply the impairment of the cognitive, emotional, functions, the effectors and of synthesis.

So this study was conducted to know the status of written informed consent form in observation charts of neurological disorders.

II. METHODOLOGY

Data for this record based retrospective quantitative observational study was taken from the observation charts of 323 patients attended either in emergency or in outpatients, between April and December 2006, in “Prof. Dr. Nicolae Oblu” Clinical Hospital of Emergency, Iasi, Romania. Regarding the cases under study were divided into 2 groups: Group 1 (with a number of 215 cases) – a group of patients having acute cerebrovascular accident, aphasia and dementia. Group 2 (with a number of 108 cases) – patients known or newly diagnosed with amyotrophic lateral sclerosis, multiple sclerosis and myasthenia gravis.

Written informed patient consent is specified in Law 95/2006, published in MO no. 372 on 28th of April 2006. Consent informed given by patient in the observation charts of above two groups was observed and number of patients who has given consent was compared in both the groups.

Statistical Analysis: Univariate descriptive statistics included the frequency of distributions for categorical demographic. Significance was inferred by Chi-square test. P value less than 0.05 was considered significant.

III. RESULTS

3.1 Subject characteristics

Regarding the cases under study, sex distribution has highlighted the females as being preponderant 62.6% from the group with amyotrophic lateral sclerosis, multiple sclerosis and myasthenia gravis, respectively 53.7% from the group with acute cerebrovascular accident, aphasia and dementia ($p=0.163$). Also, the patients' age from the second group under study varied from 18 to 78, recording an average value of 46.81 ± 15.36 , while for the first group the variation was between 26 and 89, recording an average value of 68.14 ± 10.91 ($p=0.001$).

The group distribution according to background highlighted a higher frequency of the patients from the urban areas at the second group with 68.2%, comparing to that recorded in the first group of 51.9%. For the groups under study the patients with medical insurance are more preponderant, especially in the first group, of 96.7%, comparing to the second group, of 87.9%. ($p=0.006$)

Regarding the cases under study, only for 13.6% of the patients from the first group there is the informed consent in the observation chart, while for the patients from the second group the percentage was slightly reduced (9.3%), but the differences in percentages were not statistically significant ($p=0.365$) (Fig.1).

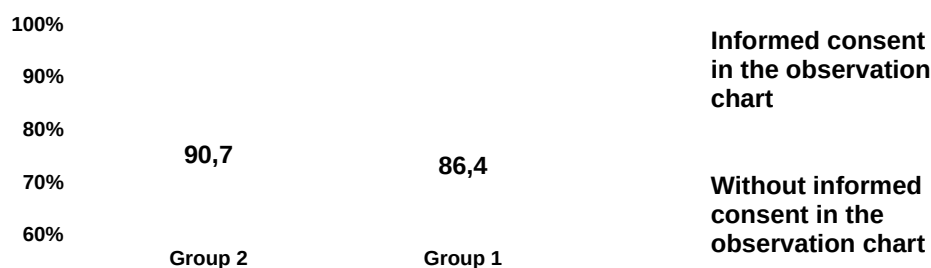


Fig.1. Case distribution according to the existence of informed consent and the observation chart

Analysing the cases according to the person who signed the informed consent, the following aspects have been highlighted: 6.5% from group 2, and 5.1% from group 1 had the informed consent signed by the patient ($p=0.797$). For the patients from group 1, 7.5% the informed consent was signed by the next of kin, comparing to 1.9% for group 2 ($p=0.04\%$). The group 1 has a percentage of 8.9% regarding the informed consent which was signed by the doctor, comparing to 5.6% for group 2 ($p=0.418$) (Fig. 2).

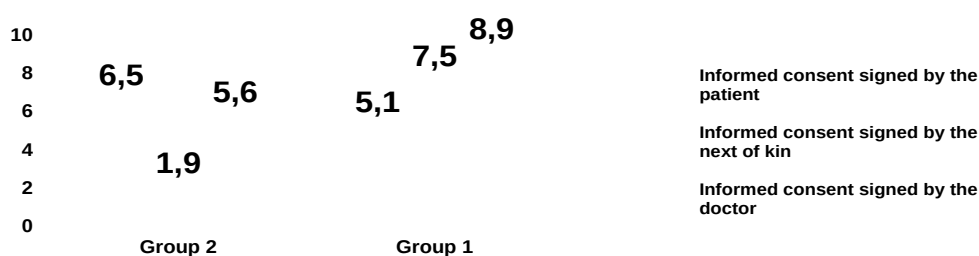


Fig. 2. Case distribution according to who signed the informed consent form

In terms of completing the informed consent form, the following aspects have been noticed on the groups under study: the form is completed with name/surname/CNP for only 6.5% of the patients from group 2, and 10.7% of those from the first group ($p=0.309$) (Fig. 3).

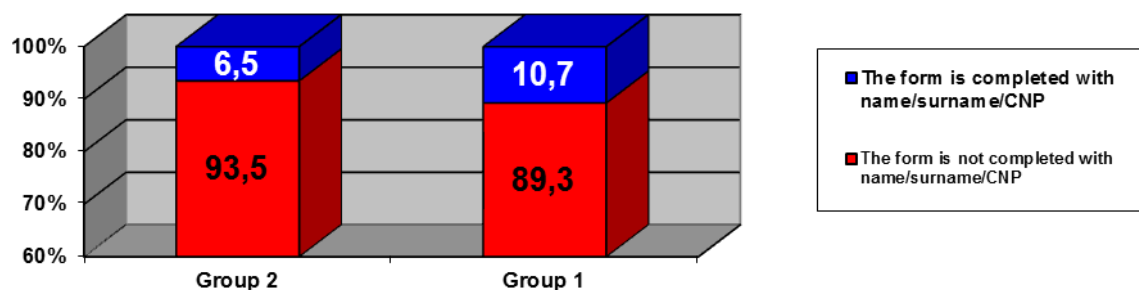


Fig.3. Case distribution according to the existence or not of the completed boxes in informed consent form

We have noticed on the cases that for invasive manoeuvres (lumbar puncture, nose-gastric procedure etc) the informed consent was obtained, as being signed by the next of kin, from group 2, for 0.9% (1 patient) and 1.4% (3 patients) from the first group (Fig. 4).

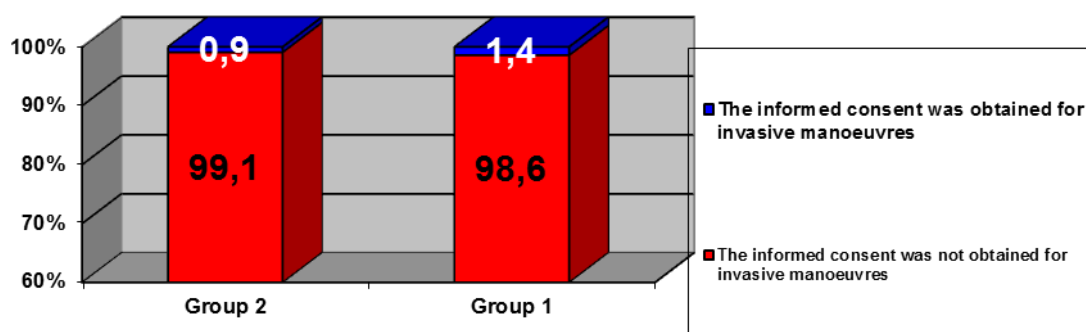


Fig.4. Informed consent obtained from the next of kin for invasive maneuvers

According to the number of hospitalisation days, we have noticed the followings: for group 2 the number varied from 1 to 24 days, recording an average value of 9.52 ± 5.13 days while for the first group the variation was between 1 and 35 days, recording an average value of 11.22 ± 6.13 days ($p > 0.05$) (Fig. 5).

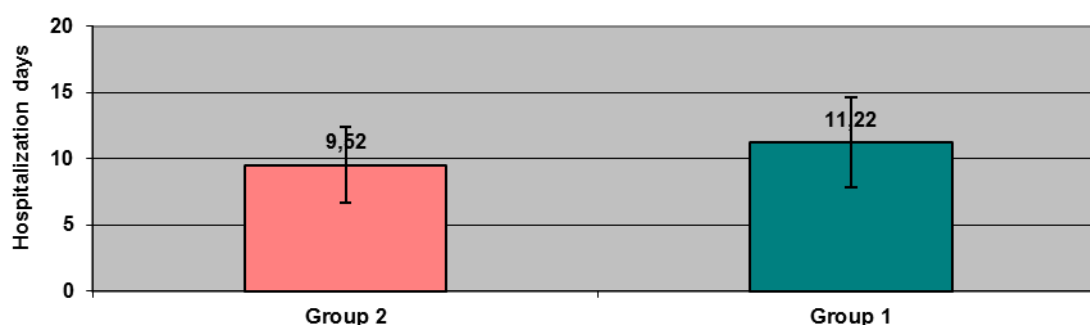


Fig.5. Case distribution according to the number of hospitalisation days

Regarding the cases under study, the patients hospitalised as cases of emergency are predominant, 66.4%, from group 2, and 63.1% from the first group ($p = 0.651$). Dynamically analysing the groups: only 76.6% of the patients from group 2 and only 41.6% from the first group were outpatient hospitalised ($p = 0.001$). On the cases under study: only 12.1% of the patients from group 2 and 10.7% from the first group were psychologically evaluated, for evaluating the cognitive function by MMSE scale (Mini Mental State Examination) ($p = 0.001$).

IV. DISCUSSION

In this study, out of 323 observation charts of study patients studied, 46.13% were from Group '1' (215 cases) i.e. patients with acute cerebrovascular accident, aphasia and dementia and 53.87% were from the group '2' (108 cases) i.e. patients with amyotrophic lateral sclerosis, multiple sclerosis and myasthenia gravis.

Written informed consent were obtained in very few observation chart of both the groups i.e. 21.93% in Group '1' and 13.93% from Group '2' with significantly more less in group '2' ($p=0.018$) who were more severe form of neurocerebral disorders. When person who signed the informed consent in both the group was observed in this study it was found patient himself/herself were signed in only 5.1% from Group '1' and 6.5% from Group '2' otherwise other persons either next to kin or doctor has signed the informed consent. When individually type of person who signed the informed consent in both the group was revealed it was found that it was found significant in case of person next to kin ($p<0.001$) otherwise not in others. In present study complete informed consent form was filled only in 6.5% of observation chart of patients from Group '2' and 10.7% of those from the Group '1'.

So it can be observed from this study that written informed consent in observation charts were signed in less than one forth of subjects and that to one forth by patients only. Even in some cases doctors has signed the informed consent which is not advisable at all.

Literature says that the patient suffering from dementia has a series of symptoms which include, apart from the impairment of the cognitive functions (attention, memory, perception, sensation, thinking and imagination), emotional touch functions, of synthesis and effectors as well. Thus, abilities of reasoning and communicating are affected. An autonomous patient has the capacity of taking decisions related to taking care of his health, the nature of the proposed treatment, the risks and the benefits, the alternatives of the treatment or the consequences of a therapy, the options being according to own value system. Dementia makes the patient not be always capable of taking informed decisions; however we must not automatically suppose that they lose their capacity of consenting. This capacity becomes gradually and progressively limited, as the cognitive impairments get worse and worse. As the cognitive impairment advances, various changes in the sick person behavior take place. One can ask ourselves: does the patient having the diagnostic of dementia with this symptomatology, have discernment in these moments? Does he have autonomy and are they capable of reasoning related to their medical care?⁵

When it is said that the patient with dementia is capable of taking decisions regarding his medical care, what are the limits of this capacity? Such patients should be involved in the process of therapeutic care as much as possible, even if we need the legal representative signature as well. According to the laws of each country, the representative of the patient with dementia either is a person appointed by him (family members or a third person), or the relatives who are appointed to represent the patient interests are ranked (if he hasn't been already appointed). Following the autonomy principle is done in some countries through an "advanced directive". In Romania, however, in the medical care of the patient with dementia, his family, his personal representative is involved.⁶ Of the neurological disorders, the patients with dementia form the most vulnerable and weakest category, this is why they require a special attention in medical care.⁷ Some studies show that the patient with dementia abuse raises numerous ethical and legal discussions. The most frequent forms of abuse involved negligence and emotional abuse, followed by the physic abuse.⁸ Dementia represents a challenge in medicine, society and law.

In the case of the patients with neurological disorders, the doctor must very carefully evaluate their decisional capacity. Epilepsy is defined as a disorder in which repeated episodes of paroxysmal brain dysfunction can appear, due to a neuronal discharge. In epilepsy, for some patients, this disease may reduce their self-control capacity. In almost all the cases, consciousness is altered throughout the period of crisis. When we refer to respecting the epileptic patient autonomy, we must take several aspects regarding the neuropsychological tests into consideration. In other words, a society that wants to follow

the European rules must more increasingly focus on respecting the epileptic patient autonomy.³ The epileptic patient-neurologist relation must be deliberative, and include several bio-psycho-social aspects. A special attention must be paid to the damaged cognitive functions of the epileptic patient, with memory, attention, reason impairment. Besides the cognitive functions impairment, there is an accent on both emotional functions impairment and the executive ones. These executive functions involve an independent behavior from the patient, and for some epileptic patients their capacity of self-management can be affected. Thus, self-management skills working independence and social relations may be reduced. In conclusion, when we analyze an epileptic patient, we have to give him the same independence of taking decisions as to any other patient with any medical problem, without stigmatising this category of patients.

Another neurological disease, like amyotrophic lateral sclerosis (motor neurone disease) which involves central and peripheral motor neurone degeneration, generates cognitive impairment in 20-30% of the cases. During the disease, special efforts must be made for respecting the patient autonomy, and his indications must also be anticipated in the advanced stages of the disease when palliative care is needed. During the disease there must be put a great emphasis on a doctor-patient relation – which includes both detailed information regarding the diagnostic of the disease, as well as information regarding impaired cognition in advanced stages of the disease. All this information make the patient take informed decisions which involve respecting his autonomy (provided by the family or by a legalized decision), according to the cultural and social rules.

Are other neurological patients with haemorrhagic or ischemic lesions capable of correctly reasoning regarding their medical care? Can we say that these take an autonomous decision based on the information acquired from his neurologist? We must also specify that these lesions involve the cognitive functions impairment with attention, perception, memory, reason and imagination being altered.⁵ Besides the cognitive impairments, these patients have behavioral manifestations such as an aggressive potential and reduced executive functions.

V. CONCLUSIONS

Recently, things that “revolutionised” the medical world, advanced techniques manoeuvres, new therapeutic approaches have happened but they have produced reactions regarding the ethics of their practicing and their moral consequences. It was found that ethical issues like signing of written informed consent was not taken place in most of cases here which should be taken care of. Medical performance brings undeniable benefits, however its accomplishment must be done through a careful selection of the subjects and respecting the ethical principles. The purpose of the accomplishment must always be the best interest of the patient and must never create any slippery slope thinking that, actually, showing the “good” only as a purpose, it is acted as using the patient as a “tool” to getting performance.

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CONFLICT

None declared till date.

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