Implementation of the right to information among psychiatric patients

(Realizacja prawa do informacji wśród pacjentów opieki psychiatrycznej)

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Abstract – Introduction. One of the patient rights is the right to obtaining information on health status, diagnosis, diagnostic methods, and treatment methods along with their possible consequences, treatment outcomes, and prognosis.

The aim of the study. The aim of the study was to analyse the opinions of psychiatric patients on implementation of their right to information.

Materials and methods. A diagnostic poll was conducted using survey technique, by means of the following questionnaires: full-time inpatient opinion, day care patient opinion, outpatient clinic or community treatment patient opinion developed at the Institute of Psychiatry and Neurology in Warsaw and the VSSS-54 Verona Service Satisfaction Scale questionnaire. The study group included 219 full-time and day care patients together with mental health outpatients.

Results. A higher percentage of patients declared becoming acquainted with the regulations of the ward/outpatient clinic (80.4%) than with the Patient’s Charter (59.8%). The respondents reported obtaining the most comprehensive information on treatment methods (82.5% of full-time inpatients; 82.6% of day care patients; 80.0% of outpatients) and on their health status (76.3% of full time patients; 81.2% of day care patients; 87.1% of outpatients). In all the types of healthcare services, the strongest dissatisfaction was related to the information on the treatment-associated risk (32.6% of full-time patients; 26.1% of day care patients; 31.9% of outpatients).

Conclusions. No statistically significant relationships were found between the type of healthcare service and patient satisfaction with specific areas of information. In order to ensure full implementation of the patient’s right to information, special attention should be paid to informing the patient about the risk associated with treatment.

Key words – patient rights, healthcare quality, patient satisfaction.

Streszczenie – Wprowadzenie. Jednym z praw pacjenta jest prawo do uzyskania informacji o stanie zdrowia, rozpoznaniu, metodach diagnostycznych i leczniczych, ich następstwach, wynikach leczenia oraz rokowaniu.

Cel badań. Celem pracy było poznanie opinii pacjentów leczonych psychiatrycznie na temat realizacji ich prawa do informacji.

Materiał i metodyka. Przeprowadzono sondaż diagnostyczny, techniką ankiety za pomocą kwestionariuszy: opinii pacjenta na temat pobytu w oddziale całodobowym; opinii pacjenta na temat opieki w oddziale dziennym, poradni lub w leczeniu środowiskowym opracowanych przez Instytut Psychiatrii i Neurologii w Warszawie; kwestionariusza Verona Service Satisfaction Scale VSSS-54. W badaniu wzięło udział 219 pacjentów korzystających z opieki całodobowej, opieki dziennej, poradni zdrowia psychicznego.

 Wyniki. Większy odsetek pacjentów deklarował zapoznanie z regulaminem oddziału/poradni (80,4%), niż z Kartą Praw Pacjenta (59,8%). Pacjenci za najbardziej wyczerpujące uznały informacje na temat sposobów leczenia (82,5% pacjentów opieki całodobowej; 82,6% pacjentów opieki dziennej; 80,0% pacjentów poradni) oraz na temat swojego stanu zdrowia (76,3% pacjentów opieki całodobowej; 81,2% pacjentów opieki dziennej; 87,1% pacjentów poradni). We wszystkich formach opieki największe niezadowolenie wskazano co do informacji na temat ryzyka związanego z leczeniem (32,6% pacjentów opieki całodobowej; 26,1% pacjentów oddziałów dziennych; 32,9% pacjentów poradni).

Wnioski. Nie wykazano istotnych statystycznie zależności między formą opieki, a zadowoleniem pacjentów z poszczególnych informacji. W celu pełnej realizacji prawa pacjenta do informacji należy zwrócić szczególną uwagę na informowanie pacjentów o ryzyku związanym z leczeniem.

Słowa kluczowe – prawo pacjenta, jakość opieki zdrowotnej, satysfakcja pacjenta.

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I. INTRODUCTION

The attitudes of medical personnel towards patients may contribute to shaping their attitude towards the disease and its acceptance and thus respecting the patient’s rights seems to be a fundamental duty of the medical staff. People with mental diseases are often unable to express their informed consent to treatment, which is why they are especially at risk of their rights being violated [1]. The world was shocked by the reports on extermination of mentally ill people during World War II by Nazi Germany but even after the end of WWII, medical experiments were conducted among children with intellectual disability in several boarding schools in the USA until the 70s of the 20th century [2]. The safeguards for people with impaired consent capacity were only introduced by the commonly called European Bioethical Convention of 1997, which recommends the widest possible consideration of the will of individuals in the role of patients, including those with mental illnesses [4]. Although Poland did not ratify the above mentioned convention, it has been implementing its recommendations using the legal mechanisms described below. The primary legal act addressing the rights of a patient is the Act of November 6th 2008 on Patient Rights and the Patient Rights Ombudsman (UPP) [5], while the act regulating the duties of doctors towards patients is the Act of December 5th 1996 on the medical and dental profession (UZL) [6]. The general duty of informing about patient rights lies on nurses and midwives, which is included in the Act from July 15th 2011 on the nursing and midwifery professions. (UZP) [17].

The most essential patient rights, which are in a way the basis of all the other rights are the right to information and to expressing consent. A combination of those two forms the so-called informed consent [4]. The validity of consent to treatment depends on informing the patient beforehand. The right of patients to information is expressed in Art. 9 of the UPP as well as in Art. 31 of the UZL [8]. As stated in Art. 9 Par. 7 of the UPP, a juvenile patient below 16 years of age has the right to information on his or her health condition in a limited degree i.e. “to the extent and the form necessary for a proper course of the diagnostic and therapeutic process.” This information should be personally delivered by the doctor as, according to Art. 9 Par. 8 of the UPP, a nurse may only provide information to a patient who is over 16 years of age and only within the scope of nursing services. In the case of a juvenile patient, a statutory representative must also be informed and then give the so-called surrogate consent. However, when a patient turns 16, they have a full right to information and the so-called cumulative consent is required (consent of the patient and of the statutory representatives and in their absence, consent of a guardianship court) [4]. Individuals with mental disturbances, including those incapacitated due to psychiatric problems, are also entitled to a full right to information. Also, if a patient is fully incapacitated but is able to express his/her view on the examination with due discernment, a cumulative consent is required. Moreover, the UPP introduced a regulation that if a patient is unable to understand the information (this group includes both unconscious and mentally disturbed individuals), the doctor discloses the information to a person close to them. This regulation made it possible to provide the information to a wide range of people as the Act defines a person close to a patient as a spouse, a relative or a kinsman by affinity to the second degree in a straight line, statutory representative, common law spouse or a person chosen by the patient. The doctor is obliged to provide the patient with understandable information on his/her health status, diagnosis, recommended or plausible diagnostic and treatment methods, predictable effects of their use or omission as well as treatment outcomes and prognosis. Therefore, consent to treatment is valid if it is preceded by “comprehensible information” i.e. easy to understand and adjusted to the psychic and intellectual aptitude, patient’s age and delivered to the patient or eligible people [9, 10, 11]. Conveying incomprehensible information or failure to deliver information is considered as breach and may give rise to the liability from Art. 199 of the Criminal Code [12] for not obtaining consent for treat-
The aim of the study was to examine the opinions of psychiatric patients on the implementation of their right to information.

**II. MATERIAL AND METHODS**

The research material comprised opinions of psychiatric care patients. The selection of respondents was based on stratified random sampling. The strata included groups of legal age patients of full-time and day care wards and mental health outpatient clinics in the Zachodniopomorskie region. Two centres providing all the analysed types of service (full-time, day care, and outpatient service) under the contract with the National Health Fund were selected. The study commenced after obtaining the consents from the managers of the chosen healthcare entities. In full time wards, patient selection was conducted after consultation with the medical personnel. The duration of stay in the ward and health status were taken into account. Individuals whose stay in the unit was shorter than 5 days and those who were not able to fill the questionnaire due to exacerbation of disease symptoms were excluded. In the group of day care patients, the tests were conducted during sessions with therapists, after consultation with stuff members. The patients of the mental health outpatient clinic were handed in the questionnaire while waiting for their appointment. Both before and after seeing the doctor, the respondents were able to fill in the questionnaire with the help of a pollster or put in a specially prepared box. The recommended form of filling in the questionnaires at all the institutions was to work on it with a pollster who each time offered to read the questions.

The study encompassed 219 users of various forms of psychiatric health care: 80 full-time inpatients (36 of one unit and 44 of another); 69 day care patients (38 of one centre and 31 of another); 70 mental health outpatients (36 of one centre and 34 of another). Most of the respondents were at young age – 23.74% (52) were aged 18-29; 24.20% (53) were 30-39 and 21.0% (46) were 40-49 years old. The older groups were less numerous: 39 patients were 50-59; (17.81%); 21 were 60-69 (9.59%) and 8 were 70 years and older (3.65%). The mean respondent age was x±SD 42 years (±6 years). Women and man accounted for a total of 53.88 and 46.12%, respectively.

A diagnostic poll method conducted with survey technique was applied using the following tools: full-time inpatient opinion questionnaire, day care patient opinion questionnaire, outpatient clinic or community treatment opinion questionnaire, patient satisfaction with medical service questionnaire - Verona Service Satisfaction Scale VSSS-54.

The full-time inpatient opinion, day care patient opinion, outpatient clinic or community treatment opinion questionnaires were developed in 2013 at the Institute of Psychiatry and Neurology in Warsaw by Anna Indulska, Marta Anaczewska, Joanna Raduj, Katarzyna Port, and Maciej Pałys [11]. These questionnaires contain questions about patient opinions on facility conditions, personnel competencies, treatment efficacy, care quality and accessibility as well as patient opinion on respecting their rights with a special emphasis on patient right to information. A traditional “Patient’s Charter” term was used in the questionnaires to refer to the regulations on patient rights in Poland. The VSSS-54 Verona Service Satisfaction Scale is a shorter version of the full Verona Scale used for testing patient satisfaction with a medical service. This scale aims at the patients of community-based treatment and their families. It was designed by prof. Mirelli Ruggeri from Verona. The questionnaire was translated into Polish at the Institute of Psychiatry and Neurology. The scale contains the following 7 groups of questions: overall patient satisfaction, professionals’ skills and behaviour, access to service, unit efficiency, types of intervention, relative’s involvement in the treatment and the information obtained by the respondent [11]. The patients were asked to choose one of the following answers: terrible, mostly dissatisfactory, mixed, mostly satisfactory, excellent. Then, the answers were assigned to number values from 1-5, where 1 represented ‘terrible’ and 5 – ‘excellent.’ This allowed for calculating the mean scoring values for groups of questions referring to specific categories.

The statistical inference was based on the assumption of normal (Gaussian) distribution of the studied variables and on Pearson's chi-squared independence test, applied for analysis of nominal and independent variables and for assessing feature dependencies. The v2 value, the number of degrees of freedom (df) and the value of probability (p-value) were given for testing. The level of significance was set at α=0.05. Any differences in statistical population (n) during analysis result from the lack of data and partly filled questionnaires, which however does not affect the accuracy of the evaluation.
III. RESULTS

The psychiatric patients receiving all the forms of healthcare were asked to familiarize themselves with existing patient rights (a traditional “Patient’s Charter” term was used in the questionnaire) and with the full-time inpatient ward or day care/ outpatient clinic regulations.

Table 1. Familiarizing the patients with the Patient’s Carter and ward/outpatient clinic regulations

<table>
<thead>
<tr>
<th>Familiarizing with</th>
<th>Patient’s Charter</th>
<th>Ward/outpatient clinic regulations</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>Full-time ward patients (n)</td>
<td>61.3% (49)</td>
<td>36.2% (29)</td>
</tr>
<tr>
<td>Day care patients (n)</td>
<td>66.7% (46)</td>
<td>31.9% (22)</td>
</tr>
<tr>
<td>Outpatients (n)</td>
<td>51.4% (36)</td>
<td>45.7% (32)</td>
</tr>
<tr>
<td>TOTAL (n)</td>
<td>59.8% (131)</td>
<td>37.9% (83)</td>
</tr>
</tbody>
</table>

Statistical analysis

Chi²=0.045; df=1; p=0.833

Chi²=0.022; df=1; p=0.822

As shown in table 1, a higher percentage of patients declared becoming acquainted with the regulations of the ward/outpatient clinic than with the Patient’s Charter. There was no statistically significant relationship between familiarizing the patient with the Patient’s Charter and the form of care (p>0.05). There were no statistically significant differences between outpatients and day care or full-time patients. No statistically significant relationship was also noted between familiarizing the patient with the regulation of the outpatient clinic/wards and the form of care (p>0.05).

It is alarming that nearly a half of the respondents (47.0%; 103) were not instructed on the procedure for submitting complaints and suggestions. Among full-time ward patients this percentage was 55.05% (44), for day care patients it amounted to 39.1% (24) and 50.0% (35) for outpatients.

A vital patient right is the right to obtaining information on health status, treatment modes and the risk involved. The respondents were asked whether they had received comprehensive information on the above areas.

Full-time patients found the information on treatment modes (82.5% of “yes” and “rather yes” answers) and the information on their health status (76.3% of “yes” and “rather yes” answers) to be most exhaustive. The highest dissatisfaction expressed was related to the information on the risk associated with treatment (the total of 32.6% of negative feedback) (figure 1).

Figure 1. Full time patients’ opinion on comprehensiveness of information

As shown in fig. 2, day care patients also showed the highest satisfaction level with the information on the methods of treatment (82.6%) and on their health condition (81.2%). A significant percentage of respondents (26.1% each) pointed out to the fact that the information on the risk associated with treatment was not sufficient.

The outpatients expressed the highest level of satisfaction with the information on their health status and the methods of treatment (87.1% and 80.0% of positive feed-
back respectively). As many as 32.9% of individuals were not satisfied with the information on treatment-associated risk (figure 3).

Figure 3. Outpatients’ opinion on comprehensiveness of information

<table>
<thead>
<tr>
<th></th>
<th>Information on:</th>
<th>Chi²</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>the disease</td>
<td>3.241</td>
<td>0.518</td>
</tr>
<tr>
<td></td>
<td>the risk associated with treatment</td>
<td>1.032</td>
<td>0.597</td>
</tr>
<tr>
<td></td>
<td>treatment methods</td>
<td>0.807</td>
<td>0.668</td>
</tr>
<tr>
<td></td>
<td>health condition</td>
<td>1.668</td>
<td>0.434</td>
</tr>
</tbody>
</table>

Table 2. Statistical analysis of implementation of the right to information among full time patients, day care patients and outpatients

In almost all the cases, the information on patient’s current health status was communicated in all the health care centres discussed in this study. Although no statistically significant differences were shown in this range (p>0.05) (table 3), it should be noted that becoming acquainted with this area of information was most often declared by the outpatients (61 answers; 89.71%), while most rarely by the inpatients of full-time wards (13 answers; 16.88%).

Informing the patient on the method of treatment was conducted properly in the vast majority of cases (p>0.05) (table 3). The day care patients most often confirmed respecting their right in this area (57 individuals; 86.6%), while the full-time inpatients most often pointed out not receiving such information (14 inpatients; 18.42%).

The risk associated with treatment and the disease was the most rarely communicated information of all the analysed areas. The type of centre which run the therapy did not significantly affect the results obtained (p>0.05) (table 2). Taking into account the form of treatment, the greatest neglects were found with regard to the outpatients (23 individuals; 36.51%) while day care patients assessed the situation the most positively (45 individuals; 71.43%).

The results presented in tab. 3 were obtained by means of the VSSS-54 questionnaire, which was used to assess the level of satisfaction among the outpatients and the day care patients. The highest rated area of care was professionals’ skills and behaviour (the mean result amounted to 4.123 of 5.0 maximum number of points). The lowest rated variable was the type of intervention provided to the patient (3.768 points). Ultimately, information obtained by the patient was rated at 3.844 points.

Table 3. The level of satisfaction of outpatients and day care patients assessed with the VSSS-54 questionnaire

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean value</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall patient satisfaction</td>
<td>3.974</td>
<td>0.826</td>
</tr>
<tr>
<td>Professionals’ skills and behaviour</td>
<td>4.123</td>
<td>0.771</td>
</tr>
<tr>
<td>Information obtained by the patient</td>
<td>3.844</td>
<td>0.920</td>
</tr>
<tr>
<td>Unit efficacy</td>
<td>3.894</td>
<td>0.808</td>
</tr>
<tr>
<td>Access to service</td>
<td>3.777</td>
<td>0.894</td>
</tr>
<tr>
<td>Type of intervention</td>
<td>3.768</td>
<td>0.964</td>
</tr>
<tr>
<td>Relative’s involvement in the treatment</td>
<td>3.807</td>
<td>0.899</td>
</tr>
</tbody>
</table>
IV. DISCUSSION

Nesterowicz notes that on the ground of the Declaration on the Promotion of Patients’ Rights in Europe of the World Health Organization, patients should have access to information enabling them to take advantage of their rights. On the other hand, the personnel of healthcare units are obliged to provide availability of information on patient rights [14]. In the authors’ own research, 61.3% of full-time inpatients were familiarized with the Patient’s Charter (as well as 66.7% of day care patients and 51.4% of outpatients). In the study conducted by M. Anczewska et al. this percentage was only 54.9% and in the research by M. Zarzeczna-Baran et al. – 74.0%. The percentage of patients who in our study declared having been familiarized with the regulations of the ward amounted to 86.2% among hospitalized patients (88.4% for day care patients and 65.7% among outpatients). In the study of other authors the percentage of psychiatric full-time patients who were instruct- ed on the regulations of the ward amounted to 65.4% (in the study by M. Anczewska et al.) and 81.0% (Zarzeczna-Baran et al.) [15, 16].

In the authors’ own studies full time and day care pa- tients showed the highest satisfaction with the information on treatment methods: 82.5% and 82.6% respectively In the group of inpatients this value was 80.0%. In the study by M. Anczewska et al. 81.90% was satisfied with this area of information. In the authors’ research the outpatients received the most comprehensive information on their health status – 87.1%. In the study by M. Anczewska et al. this percentage amounted to 90.6% [15].

Similar results were obtained in the area of informing the patient on the risk associated with treatment. In the authors’ own studies, every third patient did not obtain enough information on this subject. Only 62.5% of re- spondents of M. Anczewska et al. confirmed receiving such information [15]. In other studies, patients paid attention to the deficiency of information on the method of treatment [16, 17]. J. Raduj claims that unsatisfactory results in this area result from the fact that patients themselves do not always seek information on the method of treatment and that they sometimes, contrary to facts, state that they were not given such information [18].

In the authors’ studies, outpatients and day care patients rated the information obtained on their health status at 3.844 points (in line with the results obtained with the use of the VSSS-54 questionnaire). In the study by K. Port, the outcome achieved was lower: 3.75 points [19]. Similar re- sults were obtained by P. Mavrogioriou (3.80) [20] and M. Ruggeri (3.75) [21]. In all the European cities examined by M. Ruggeri, except for Santander (2.93), the results obtained were also close [22]. Interestingly, in the studies conducted among convicts in a penitentiary institution on expectations as to outpatient healthcare, the first place was taken by the need for obtaining exhaustive information on the disease and the methods of treatment [23]. The literature indicates that the responsibility of spreading the knowledge on patient rights lies on the medical personnel. It is noted however, that patients themselves ought to take interest in their rights as their enforcement contributes to an increase in the quality of the services provided.

V. CONCLUSION

There was an unsatisfactory percentage of patients in all the examined types of psychiatric care who declared having been familiarized with the Patient’s Charter and with the procedure for submitting complaints and suggestions. In all the types of analysed units, the patients were most satisfied with the information obtained on the methods of treatment and their health status. No statistically significant relationships were shown between the type of health care and pa- tient satisfaction with particular areas of information. In order to achieve full implementation of patient right to inform-ation special attention should be paid to informing the patient on the risk associated with treatment.

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