

A disabled person's human right to fair and equitable medical treatment as an example of an inalienable right

ABSTRACT

To make an analysis and evaluation of the disabled people's perception of their right to fair medical treatment. To obtain answers to the following questions: is the right to fair medical treatment in Poland viewed as non-transferable? Does this law function only in theory or is it put into practice?

The survey was conducted among the disabled with different degrees and types of disabilities. The questionnaire consisted of 45 closed questions and 3 open ones. The research was conducted from autumn 2016 to spring of 2017 in the Environmental Self-help Centres, Support Centres, Protected Accommodation Foundations and Activation Programs, selected hospitals around the voivodship, District Adjudication Teams, Social Security Institution branches, departments of PFRON (with the agreement of all the selected units) and the Institutions of Job Safety.

The research has concluded that the disabled right to fair and equitable medical treatment is frequently violated. This right is not respected by doctors, nurses, and other members of medical personnel, especially in the case of these patients suffering from mental disorders or coupled disabilities. The key factor here is the possibility of easily used patient's insanity argument. In addition, this group of people still lacks adequate knowledge about their rights, does not know how to react or who to turn to in such situations. And even if one has such awareness, a battle with the "well-tightened" medical staff circle and the "limping" system of the Polish health service is practically a no-win

situation. Especially since this sector seems to be most exposed to corruptive activities.

In Poland, the disabled's right to fair and equitable medical treatment is repeatedly violated. There is a lack of holistic model of diagnosis and medical treatment not only for this social group but also for all citizens. The research conducted and the NIK's audit have unequivocally demonstrated numerous deficiencies in respecting the basic (and non-transferable) rights of the patients.

Keywords: human rights, equitable medical treatment, hospital, patient, medical treatment

1. Introduction

It would seem that with the dynamic progression of technology, which today's medicine takes full advantage of, (Załużska, Kobrzyńska-Żochowska, Dyduch, Balicki, 2012, pp. 251–257)¹ and the changes in understanding of the world (and each other), people will be able to create a law that is fair to all citizens. Although the term “justice” is (nowadays) understood (what is important) as “giving according to the need,” it can be noticed that the use of it in practice already causes a great deal of trouble (Anczewska, Indulska, Raduj, Pałyska, Prot, 2007, pp. 427–434)². (though many say it does not)³. Apart from the UN Convention on the Rights of

¹ Modern technology, technology, neurons, medicine, etc.

² And above all: NIK, *Przestrzeganie praw pacjenta w lecznictwie psychiatrycznym*, nr ewid. 19/2012/P/11/093/KZD, Information on the results of the audit conducted in 2009–2011.

³ As an example you can give: *Osoby psychicznie chore w zakładzie zdrowia*, http://www.altea-poznan.pl/files/Osoby_psychicznie_chore_w_zakladzie_zdrowia.pdf (27.05.2017). The most interesting part is: “During psychiatric hospitalization, patients also have the opportunity to participate in programs that restore specific interpersonal and social skills that have been lost as a result of the disease. There are different types of programs aimed at shaping such behaviour as contact, expressing one's own needs, planning activities, controlling emotions, recognizing the first signs of recurrence, etc. There are special therapeutic sessions taking place in the following stages: 1) modeling (model behavior), (2) playing role (replaying this behavior), (3) social reinforcement (provided by group members), and (4) transfer of training (applying learned behaviour to everyday life situations). A private hospital, not a public one is taken into consideration here.

Persons with Disabilities (General Assembly of the World Program for Action for the Disabled. Resolution 37/52 of 3 December 1982)⁴ and the Convention on Vocational Rehabilitation and Employment of Persons with Disabilities⁵, Poland pays a lot of attention to Art. 32 (pt. 2), art. 67 (item 1), Article 68 (point 3), art. 69 of the Constitution of the Republic of Poland and the Charter of the Rights of Persons with Disabilities⁶. According to these documents, every human being has some *ad hoc* rights, that is to say, stemming from the very fact of “being human”⁷ and having the inherent human dignity.

⁴ The main point of the program was to equalize the chances of “pulling” the problem of the disabled into “daylight”. It was then understood that they could not be “pushed to the margin”. They should therefore be dealt with by the social services in the standard activities.

⁵ In Poland the Act on vocational and social rehabilitation and the employment of disabled people of 27 August 1997. At present, Polish legislation allows for the existence of three degrees of disability: considerable, moderate and light. They are granted by the County Disability Papers. The degree of recognition is granted to those who are physically impaired, incapable of work or able to work only under sheltered conditions. In addition, it requires constant or prolonged care and assistance from third parties to perform social roles (which is inextricably linked to the inability to live independently, that is, the inability to meet basic life needs alone without the help of others). Moderate has the same reference, but a person needs temporary or partial help from others in social roles. A high degree means lowered ability to perform the me work in comparison to the capabilities of a person with full mental and physical fitness in the same position. The condition that this level can be attributed to is visible restriction of the abilities to perform social roles that can be corrected by, for example, orthopedic, ancillary or technical means. Children up to the age of 16 are considered disabled without a descriptive degree.

⁶ The 1st August 1997 Charter of the Rights of Persons with Disabilities includes the right to an individual, independent and active life, the prohibition of discrimination on disability grounds, and in particular: 1) access to goods and services enabling full participation in social life; 2) access to treatment and medical care, early diagnosis, rehabilitation and therapeutic education as well as health services including the type and severity of disability, including orthopedic supplies, ancillary equipment, rehabilitation equipment; 3) access to comprehensive rehabilitation aimed at social adaptation; 4) psychological, pedagogical and any other assistance enabling the development, acquisition or raising of general and professional qualifications; 5) social security that takes into account the need to incur increased costs resulting from disability as well as the inclusion of these costs in the tax system; 6) living in a environment free from functional barriers.

⁷ And there is no need, in this place, to explain the concepts of *man, life, death, limits of humanity or dignity*.

Human rights, as expressed in the Universal Declaration of Human Rights, have, without exception, a universal, inborn, inalienable character (Garlicki, 2011; Nowicki, 2001; Nowicki, 2017; Gmitrowicz, Orzechowska, Talarowska, Florkowski, 2013, pp. 84–90.)⁸, and inviolable, natural and indivisible nature. They do not need to be justified (which does not exclude making an in-depth analysis of them). The only situations requiring justification are the ones which prove to be exceptions. One of the basic human rights is “the right to such standard of living that will guarantee a healthy life and wellbeing (...), including food, clothing, housing, medical care and necessary social protection” (Universal Declaration of Human Rights, adopted and proclaimed resolution of the UN General Assembly 217 A (III) on 10 December 1948, Art. 25, item 1).

For the purposes of my article, the key rights are therefore the positive ones covering social rights, like health protection (and therefore fair and equitable medical treatment)⁹ and social assistance. In that case, some other documents ought to be included here, namely the 12th March 2004 Law on Social Assistance (Journal set 2016 pos. 930, with changes), the 11th September 2015 Public Health Act (Journal set 2015. pos. 1916),

⁸ In the article the following understanding of the term “non-transferable” is adopted: the rights entitled to an individual (citizen-human) which can not be given up by any means, for example by a written renunciation. Any cases of renouncing of these rights do not matter from the beginning and are not taken into account by any “law enforcement” institutions. Currently there are two opposite concepts of understanding the relation between the citizen and authority. The first one points out to the precedence of power over citizens, and the rights it gives are of “kindness” and “goodness” shown by it. The second concept is based on the social contract: “the people” elect their representatives and are able to do something for the authorities (e.g. pay taxes, be punished for committed offenses or crimes, etc.), and the power “does something for the people” in return, eg it refrains from interfering in some areas of their lives (which is connected to the idea of freedom). The agreement may be equally beneficial for both parties, or one of them will be less favorable to the other. One form of such an agreement is the Constitution. It is worth mentioning that there is only one possibility of self “ridding” of all rights, and it is death, which is the consequence of, eg suicide.

⁹ The term “fair and equitable medical treatment” will be used in the following sense: treatment according to an individual case. This treatment will therefore have a material and non-material dimension. In the first case it is all about the means by which diagnosis and treatment can be made, ie diagnostic apparatus. The second one focuses on the knowledge and experience of doctors who are subject to the law while performing various activities.

the 19th August 1994 Law on Mental Health Protection (Journal set 2016 pos. 546, with changes), and the 27th August 2004 Law on Publicly Funded Health Care Services (Journal set 2015 pos. 581, with changes).

The NIK audit on the assessment of clinical hospital operations in the years 2013-2014 (NIK, 25.05.2015, p. 8) has shown that there is a lack of systemic solutions to the functioning of clinical hospitals (they play a vital role in the clinical, didactic and research areas), and the current regulation hinders their activity (some in a very bad economic situation, which threatens their further functioning), and the lack of well-established costs of clinical teaching (obsolescence of fixed assets) is observable. In addition, the obligation imposed on hospitals to treat and monitor the effectiveness of pain control is not properly performed by most health care units (NIK, 29.05.2017).

According to the NIK: "Most hospitals have not been investigated and no rules have been developed to ensure the treatment (...) of pain in all patients suffering from it. Therefore, patients are not provided with adequate access to the treatment of pain, which would be adjusted to the level of its intensity." (NIK, 29.05.2017). There is no comprehensive, coherent and effective health prevention system in Poland, which means that access to health services is insufficient, and some patients are cut off from the possibility of preventive examination (NIK, 11.04.2017). The NIK has vetted 13 clinical hospitals operating in Poland, and many concerns have been raised about the organization of clinical trials, particularly those commissioned by private pharmaceutical companies (NIK, 29.05.2017). Hence, my conclusion is that the right of people with disabilities to fair and equitable medical treatment is violated in many Polish multidisciplinary hospitals. Actually – it concerns most of our country citizens.

In the cases of mentally ill people (who are mostly disabled), attempts to implement an environmental model of psychiatric treatment are made. Its key assumption is to provide treatment in the patient's everyday environment as the main location where treatment should take place. At the same time, the literature points to numerous risks of total exclusion from hospital treatment, e.g. among others, the increased population of those with severe mental disorders whose aggressive behavior can be a serious threat to others (Załużska, Kobrażyńska-Żochowska, Dyduch, Balicki, 2012, p. 252.).

In Poland, however, obsolete methods of treatment and rehabilitation of psychiatric patients are still being used (Pawełczyk, 28.05.2017), because “changes (...) in fact consist in creating more and more specialized training sets that, in their assumption, are intended to compensate for the deficits triggered by the illness in cognitive, emotional or social sense.” (Bronkowski, Chotkowska, 2016, p. 14.) These training kits are implemented (albeit dubiously) by public daycare (therapeutic, rehabilitation) units and not by hospital services. Most people with mental illness can not afford private treatment, such as private day care. Most of them do not deal with serious cases, but people with “mild” disorders, like bulimia, anorexia or borderline. The NIK’s audit, whose results were publicized on 25th January 2017, concerning the implementation of the National Mental Health Program, clearly indicates that the program ended with a “fiasco”:

In addition to the low level of funding, the way in which psychiatric services are organized in our country is the main barrier restricting access to services for patients with mental disorders (...) The failure to fulfill the majority of the program’s objectives and tasks has prevented the environmental model dissemination. (NIK, 25.01.2017, p. 14.)

As early as 2012, the NIK pointed to the dangers that could have caused the program’s failure, which was reflected in the results of monitoring the patient’s compliance with psychiatric treatment. The NIK’s evaluation was negative due to the non-compliance with patients’ rights while being admitted to psychiatric hospitals without their consent and with the use of direct coercion (NIK, 8.05.2012, p. 5).

The right to fair and equitable medical treatment is a fundamental and therefore inalienable right of every human being. With regard to the disabled, however, it has a special meaning, because this social group’s needs for proper diagnosis and the application of appropriate treatment methods are much greater.

Method

The data on the disabled’s perception of the right to fair and equitable medical treatment as a non-negotiable right was gathered by means of a self-prepared questionnaire containing 50 questions divided into the following thematic blocks: 1) the disabled’s previous

and recent hospital stays experiences, 2) the disabled's subjective perception of those places, and, above all, their positive and negative aspects, 3) the disabled's subjective perception of institutions whose duty is to exercise custody and control over the disabled (ZUS, District Disability Adjudication Teams, Municipal Family Relief Centres, PFRON), 4) the disabled's material, professional and social situation; 5) the disabled's present psychological (emotional) situation, related to the type and level of their disability (how the disabled feel about their disabilities on daily basis and how these disabilities are perceived by others, e.g. by strangers), 6) their life goals, professional preferences, dreams, 7) their knowledge of the rules and regulations concerning people with disabilities, 8) their knowledge and understanding of the terms "disability", "dysfunction", "treatment", "illness", "decent medical treatment", "law", "non-transferable right".

In addition to the closed questions, the following three open questions were also included: what changes in the Polish law (including treatment in clinics, hospitals, reimbursement, refunding of supportive measures, granting pensions and deciding on the degree of disability) would they suggest themselves? Would they consider "Polish medical treatment" as fair and equal? If not – why? The research was conducted between autumn of 2016 and spring of 2017 in: foundations, associations and other charity organizations for the disabled, selected hospitals within the voivodship, District Disability Adjudication Teams, ZUS units, PFRON branches (with the consent of all selected departments). Persons with a mild, moderate and significant degree of disability were taken into consideration (if direct personal contact was possible, eg with people whose disability was a direct result of their mental illness).

A distinction was made – which is generally adopted while determining the degree of disability and its type – into people physically and mentally disabled. Individuals with coupled disabilities were also included in the survey. Respondents were asked to mark gender, education, the degree and type of their disability in the questionnaire.

Results

During the research, the survey was completed by 750 people filled, 45% of who were male and 55% female (all respondents marked their gender correctly). The structure of education was as follows: higher

education – 22% of respondents, secondary school – 53%, vocational education – 17%, basic primary school education – 8%. The respondents were predominantly well-educated and gender was well-balanced.

Positive responses

Within the closed questions the positive answers usually concerned: 1) doctors and nurses who were kind and positively oriented towards the respondents as disabled people. They were perceived as helpful, well-mannered, always willing to assist, sensitive to the patient's needs, knowledgeable, experienced in medical treatment.

Mentally ill people pointed to their favorite hospital activities, as well as the kindness of psychiatrists and psychologists; 2) access to the institutions that deal with their fate mainly via the Internet, including the possibility of sending e-mails; 3) their at least good professional, material and social situation. People with mild and moderate disabilities pointed to the help of third parties, such as parents, siblings, grandparents, friends and colleagues in a way that does not deprecate this assistance. Their professional situation was linked to their work in a Protective Work Plant or on the “free market” (if they had such a possibility); 4) positive reception of their “otherness” by the society. The respondents with physical and coupled disabilities often pointed to the fact of giving up seats to them on buses, letting them jump queues in shops, strangers offering help in carrying their shopping; 5) the respondents referred to their dreams and goals they would like to achieve in a clear and concrete manner, especially those ones related to their health improvement, rehabilitation stays, family holidays, getting employment “to the extent of their capabilities”; 6) the respondents positively rated the law, rules and regulations which give them the opportunity to: a) receive a disability degree which is directly connected to obtaining a special car park card, the possibility to shop more cheaply or to get free public transport tickets, to be employed in the Institutions of Job Safety (the workers receive subsidies from PFRON); b) receive a pension from Social Security (which for many of the respondents equals “survival”); c) get employment thanks to being subsidized (otherwise the employer would not take them to work); 7) The respondents who offered positive feedback on all of the above issues did not suggest their ideas for change in the open questions section; 8) They also expressed an opinion

that “Polish medical treatment” is “fair and equitable” and does not require any (at least radical) changes. However, it is worth noting one thing: in cases when the disabled themselves did not make any negative comments, their caretakers did so.

Negative answers

Respondents were more likely to make negative remarks regarding my undertaken subject of fair and equitable medical treatment and the rights of people with disabilities in this regard. They were also more accurate than positive responses. They were therefore divided into: 1) related to physical illnesses, 2) related to mental illnesses.

2. The specificity of physical disability

The disabled who are affected by physical disabilities most often pointed to the following negative occurrences: 1) too long ambulance waiting periods, physicians' discontent, “indelicate” behaviour of doctors and nurses, terrible quality of meals (which had to be replaced by their own food delivered by family members, friends or other visitors), too strict adherence to visiting hours, unprofessional care (and sometimes lack of it for extended periods of time), deficiency in available hospital beds, inadequacy in hospital admission possibilities and procedures, too much extended Emergency Room waiting periods (for the non-admitted); 2) officials' brusqueness, abruptness lack of understanding, their ironic approach, lack of possibility to self-access some basic information, being continuously sent back to others, not providing financial support or services to those in need, random disability adjudication, ignoring, not reading the patient's file, but making decision “just because” (“well, you never know, his hand might grow back one day”), taking away benefits according to the argument that “you'll manage somehow” or “someday you have to go back to work”; 3) receiving benefits not sufficient enough to be able to afford all the necessary means (eg medicine, funding rehabilitation classes or any medical treatment, in fact, for example in cases of rare diseases); the inability to get any job due to disability, which is conditioned by the negative attitude of many Polish employers; bad experiences connected with motor disability, including being mugged, robbed or beaten;

4) lack of possibilities to achieve goals or make dreams come true due to poverty or privation (as a result of the inability to get employment); their current situation is described as “bad”, “very bad” or “average” (with the emphasis on “bad”); they feel perceived as “social parasites” by the society that instead of going to work, they “get sick”; people with disabilities sometimes feel that they have no right to become ill (and in drastic cases even to live); 5) overriding the “consent to surgery” clause (as a result of will statement), which in some cases was signed on an operating table; failure to receive appropriate care and services in local clinics (eg, National Health funded consultation with a physician was to take place long after surgery, ie 1.5 years later), impossibility to perform surgical procedures covered by the NHF as quickly as the situation requires (respondents also indicated opinions expressed by certain doctors, working for the National Health Fund (NFZ), that all necessary tests and surgery itself ought to be paid “from the patient’s own pocket”); 6) in most cases the physically disabled know their rights (even in great detail), but because of the different occurrences they are violated, and no steps are taken or specific sanctions applied towards the perpetrators; 7) from the point of view of the disabled “Polish medical care” is dishonourable, their rights are repeatedly violated, the help received from the state does not cover their needs (“starvation-level” benefits); 8) as one example of a possible solution the respondents give, is simply respecting their rights, but also the importance of proper introduction of modern technology into Polish hospitals (which may prevent disability, improve one’s quality of life or offer someone a chance to get completely cured).

3. The specificity of mental disability

The mentally disabled have marked a comparable amount of negative responses as the people with physical disabilities. Open questions also included very detailed assessments. Typically, they concerned: 1) the implementation of forced medical treatment (admission to hospital without the patient’s consent); excessively rigorous control of all personal belongings, eg, some respondents indicated that they could not carry a phone charger cable (“they may attack other patients”), matches (“they may set the hospital on fire at night”), supplements (which must previously be

consulted with their psychiatrist); issues concerning receiving temporary passes to be able to leave the hospital ward; aggressive behavior amongst patients towards each other (related to hospital overcrowding, putting “serious” and “mild” cases together); some responses revealed detailed information about the types of reactions from hospital staff members when a patient behaves aggressively); lack of privacy (cameras, light switched on in the corridors, other patients walking around, overcrowded rooms); restricted visiting hours, no possibility television watching after 10:00 p.m.); noise (during the day and at night); terrible quality meals (“awful” and “cold”); toilets equipped with transparent panes of glass (which are often used by patients to peek at their mates) and the fact that toilets are co-joined with bathrooms (the respondents indicated that they were walked on by others while showering on numerous occasions); cigarette smoke coming from the smoking room and entering their living quarters was also a bit of an issue mentioned by non-smokers; 2) too few physician visits and meetings with a psychologist; too little psychological support, no interest in the patients’ life and fate, inappropriate behaviour on the staff members’ part (“malicious”, “nasty”, “aggressive”);

For questions from sections 3), 4), 5), 6) the responses were similar to the ones given the physically disabled. The successive blocks provided me with some discrepancies. People with mental disabilities had much less knowledge of their rights, as well as certain terms (which they were asked to define or explain). The respondents with vocational and basic primary school education top the hierarchy, followed by their secondary school educated peers (having or not having passed their final leaving examination), and finally – people with higher university level education close the list. Good knowledge of one’s rights results in informed reactions to their violations, so it concerns this group of people who are aware of specific occurrences and know how to act accordingly.

According to most psychiatric patients, “Polish medical treatment” (in the case of psychiatric care, to be precise) is not designed to cure patients or make them better. What it does serve to do, however, is that it violates their basic human rights. Also, the forms and methods of treatment used are so outdated and old-fashioned that one might assume they were adopted from “the Middle Ages”. The respondents clearly point out some possible and simple changes that could easily be implemented.

For example, amongst others: improving the quality and quantity of meals, the way the hospital admissions are conducted, the introduction of twin rooms, total and complete makeover and renovation of the hospitals, the restriction of pathological incidents (eg respondents often point to notorious ward theft of items such as shower washers, cigarettes, lighters or even clothes); raising awareness among doctors and nurses (who lack this level of empathy, and teaching them how things ought to be done), increasing the number of psychiatric appointments, admission to local clinics in emergency cases, facilitating the acquisition of disability degrees and making Social Security Institution (ZUS) benefits more easily accessible.

4. The specificity of coupled disability

In the cases of physical and mental disability co-existence, the respondents' feedback concerned the problems that the mentally ill people encounter individually (because their lives were determined by their mental illness) and the physically disabled experience (in their case the "physical" dysfunction was the key factor that put them into that group).

It was easily noticeable that people with conjugal disabilities point to similar ways how the human right to fair and equitable medical treatment is violated and have expressed similar ideas as well as offered similar suggestions to the two previously mentioned groups. Often, mentally ill people pointed to a number of inadequacies of the "only human body" health service. The research has also revealed a reversed trend.

5. Conclusions

By analyzing all respondents' answers, it must be explicitly stated that these negative remarks should be considered the most crucial. The respondents point to such areas of Polish medical care, which undoubtedly require a quick and comprehensive "repair". The positive aspects described by the disabled reveal their second face in the light of the negative opinions. The research has concluded that the right of people with disabilities to fair and equitable medical treatment in Poland is simply ignored. Health care needs to be reformed (not just because of this group of

people), due to the fact that most of the “difficulties” noted are the result of insufficient subsidies from the state. It is also important to seriously consider the existence of such pathological occurrence as the aggression of patients and medical staff members towards each other, drastically low quality of meals in multi-disciplinary hospitals, the suicide rate among the disabled, violations of the rights of persons with disabilities by doctors and officials in local clinics, District and Voivodship Disability Adjudication Departments or Polish Social Security Institution ZUS.

“Disability and suffering are great money-makers” (Żuraw, 2016, p. 41.) because people with disabilities, whose rights to receiving fair and equal medical treatment are repeatedly marginalized (ie violated), start seeking help elsewhere (just like people with no disability degree do as well). They usually go for private medical practices, outpatient clinics and hospitals. Whatever public health care is not able to provide (after all, the right to fair and decent medical treatment is a non-transferable right), is simply done outside of it. Particularly worthy of attention in my research, however, is the practice of signing surgery consent forms on ... operating tables (which is unacceptable), sending patients to private appointments (because “we have used up our limit and there are no vacancies left”), keeping patients for hours in the corridors of emergency rooms (because “I have not had a coffee break yet”), writing prescriptions for medicine pushed by pharmaceutical companies, forced (often aggressive) “admitting” mentally ill patients into closed units.

There is a marked absence of holistic medical care model in Poland, not only for disabled patients but for all citizens. Holistic approach, however, in practice treats a human being as a very complex “whole” in which there are multiple connections between “body” and “psyche”. Unfortunately, so far, this approach works only “on paper.”

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