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The intellectually disabled person as a patient

Abstract

The study explores the issues associated with functioning of a person with intellectual disability in the health care system. Some legislative solutions normalizing the rights of patients (also disabled ones) were discussed. Also, presented were the results of the research conducted among the medical staff of a hospital by applying the method of interview. Due attention was paid to medical staff's knowledge concerning disability (particularly intellectual one). An image of the intellectually disabled patient as well as the ways of approaching patients with disability applied by the respondents were shown from the perspective of medical staff.

Keywords: intellectually disabled person, health care, rights of a disabled patient, approach to an intellectually disabled patient.

Osoba z niepełnosprawnością intelektualną jako pacjent

Abstrakt

Artykuł traktuje o zagadnieniach związanych z funkcjonowaniem osoby z niepełnosprawnością intelektualną w systemie służby zdrowia. Poruszone zostały kwestie rozwiązań legislacyjnych normujących prawa pacjentów, w tym również tych z niepełnosprawnościami. Przedstawiono wyniki badania przeprowadzonego wśród personelu medycznego Zakładu Opieki Szpitalnej przy użyciu metody wywiadu. Zwrócono uwagę na przygotowanie personelu medycznego z zakresu wiedzy na temat niepełnosprawności (szczególnie intelektualnej). Przedstawiono obraz pacjenta niepełnosprawnego intelektualnie widzianego oczami personelu medyczne-

go, a także sposoby podchodzenia do pacjentów z tą niepełnosprawnością, na które wskazywali badani.

Słowa kluczowe: osoba z niepełnosprawnością intelektualną, służba zdrowia, prawa pacjenta z niepełnosprawnością, podejście do pacjenta niepełnosprawnego intelektualnie.

Introduction

With growing frequency, a disabled person is in the spotlight both in the discussion of specialists and in general social discussion. Despite the increasing awareness of the environment, the intellectually disabled are still confronted with acts resulting either from the lack of understanding of their problems or from their limited functional possibilities. Special pedagogy teachers often undertake the issues associated with various dimensions of this group's life. What seems an interesting issue is the health care system, in which people with intellectual disability are assumed to feel comfortable. The modern times involve dynamic changes, which bring about new technologies, new therapeutic methods, innovative medicines for consecutive diseases and new treatment procedures. In the case of intellectual disability, there is no antidote, there are neither vaccinations against it nor miraculous drugs which will cure it. Knowing the causes of intellectual disability can only enhance prevention and avoidance of risk factors of its onset. The disabled live among people without disabilities and are also beneficiaries of the health care system. It is often emphasized that a disabled person has the same rights (also to medical services) as a person without disability. However, specific functioning of people with this type of disability poses certain challenges. How does the health care system handle these challenges? How does it view intellectually disabled patients? Does an intellectually disabled person require special treatment from medical staff? What level of knowledge (acquired during the studies or other trainings) do doctors and nurses have of intellectual disability? These questions and many others have drawn attention to this subject and necessitated some attempts to find answers.

The article is aimed at presenting the results of some studies conducted among medical staff of a hospital, which can be treated as exemplification of the approach to the intellectually disabled patient*.

* The article is based on the research conducted within A. Żabińska's diploma thesis: *Pacjent niepełnosprawny w służbie zdrowia – poziom wiedzy personelu medycznego o niepełnosprawności intelektualnej oraz sposobach postępowania z osobą z niepełnosprawnością intelektualną /The disabled patient in health care – the level of medical staff's knowledge of intellectual disability and dealing with an intellectually disabled person/* and contains its fragments.

Rights of a disabled patient

According to the definition provided by the World Health Organization, patients are people who make use of health care services irrespectively of whether they are healthy or ill. Other definitions recognize a patient as a person who is under medical care or is a doctor's client (I. Rudawska, 2005, s. 50).

In compliance with the binding legal acts, the disabled have the same rights to health care as people without disabilities. The Constitution of the Republic of Poland says that everyone has the right to health care and equal access to health care services financed from public resources, on the conditions and in the range specified in the Act (Journal of Laws No 78). Moreover – in accordance with the Act on Health Care Institutions of 1991, every person has the right to intimacy and personal dignity while receiving health services (Journal of Laws, No 91, 30th August 1991). This is also stated in the Act on Medical Doctor's Profession (Journal of Laws, No 28, 5th December 1996), in which additional obligation is imposed on doctors to carry out the application of these rules by their staff. As regards people with intellectual disability, the most important act is the Act on Mental Health Care (Journal of Laws, No 111, 19th August 1996), which is dedicated mostly to mentally ill and intellectually disabled patients. The act ensures these patients' right to charge-free health services, medicines and sanitary articles as well as to accommodation and food in a public Mental Health Care Ward (art. 10, item 1, 2), to the appropriate type of medical treatment in regard to health reasons, patients' good and personal interests and to aiming at health improvement in the least burdensome way for the patient (art. 12). This law also regulates the procedures in the case of difficulties resulting from functioning of the mentally ill and intellectually disabled, including legal care of third parties. All these principles of dealing with patients and their rights, both the general and disability-related ones, are comprised in the Patient Rights Charter. Since 1998, it has been the most comprehensive set of legal regulations in the form of a release and the first attempt at a complex approach to the patient's rights in Poland.

Moreover, the rights of disabled patients are focused on in the Disabled's Rights Charter. In art. 1, item 2, 3, it is said that a disabled person is entitled to the access to medical treatment and care, early diagnostics, rehabilitation and therapeutic education, as well as to health services related to the type and degree of disability, including the provision of orthopaedic appliances, supporting resources, rehabilitation equipment, also for multisided rehabilitation aimed at social adaptation (Parliament Resolution, item 475, 1st August 1997).

Looking at legal regulations, it can be claimed that disabled people are provided with the appropriate (adequate to their condition) medical care – both

as regards technical support and proper interpersonal approach. What will be investigated in the further part of this study is how the situation of disabled patients looks like in reality.

An intellectually disabled patient from the perspective of medical staff in hospital

A disabled patient requires an appropriate approach. What is required when such a patient appears is the knowledge how the disabled function. The first problem which may occur in the contact with such patients are difficulties in communication. Depending on the degree of disability, they might arise in various dimensions, from technical skills of using speech to some difficulties in communicating the needs and understanding the medical situation, which all result from the lowered level of intellectual functioning of such patients.

The ability to communicate constitutes the main medium of exchanging information between people and the lack or any disturbance of this ability brings about no correct communication and a barrier in the access to medical care. Intellectual disability frequently co-occurs with malfunctioning of other organs, also those involving senses, which makes the barrier bigger. As a result, the intellectually disabled have no possibility to express their thoughts or needs. They often manifest the needs in a hardly understandable way. In the case of more profound disorders, the legal guardians, who know the disabled person best, can notice some worrying symptoms through changes in this person's behaviour which might foretell health problems. No possibility to interview the patient directly is a real challenge for the doctor (www.magazyn-stomatologiczny.pl), who – through extended diagnostics – will be forced to detect the health information which the patient could not provide.

The information concerning the approach to disabled patients has been collected in one hospital. The examined group comprised doctors and nurses of various specializations and different work experience. They were interviewed. Among the respondents, there were: an orthopaedist – 38 years of work experience, a laryngologist – 19 years, a surgeon – 1.5 year, an anaesthetist – 23 years, and four nurses: a surgery nurse – 34 years of work experience, a cardiology nurse – 20 years, an operating suite nurse – 17 years and a laryngology nurse – 38 years.

All the interviewees had higher education with the exception of the laryngology nurse, who has secondary education as a medical secondary school graduate. The surgery nurse was also a medical secondary school graduate and had completed higher education in human resources management. Apart from medical university studies in nursing, the cardiology nurse completed university studies in care and school counselling pedagogy.

None of the respondents confirmed participation in additional courses in oligophrenopedagogy or any other training concerning the conduct with intellectually disabled patients. Irrespectively of their work experience, all the doctors indicated that the knowledge of intellectual disability was discussed only in psychiatry and psychology classes, yet in small amount, and concerned neither functioning of the disabled nor the approach to them. Among the nurses, the situation was more diversified. During their nursing studies, none was taught the subject matter related to intellectual disability – even in psychiatry classes, which were part of the curriculum. However, such knowledge was declared by the nurses who graduated from medical secondary school and the one who had studied care and school counselling pedagogy.

All interviewees declared that they had met intellectually disabled patients in their work but with different frequency, depending on their specialization: the doctor from the Anaesthesiology and Intensive Therapy Ward – once per several months; similarly, the otolaryngologist – once or twice per several months; the doctor from the Surgery Ward during his 1.5 year work experience has had 2 cases of people with mild intellectual disability, whereas the orthopaedist declared many such cases, even up to 10 a year. As regards the nurses, a couple of cases a year (up to 5) were declared. Still, the operating attendant (working in the operating suite) knew only about one case of a patient with profound intellectual disability. This might have resulted from her lack of information about patients admitted to the operating suite.

Despite the growing focus (resulting from social changes) on the intellectually disabled and the hope that they will not be marginalized and isolated any more, it turns out that medical staff has no expert preparation for work with intellectually disabled. None of the interviewed doctors and nurses undertook additional courses or trainings concerning the approach to disabled patients. The only information they have is what they acquired during studies or education in medical secondary school at subjects such as psychiatry or psychology. Scarce knowledge of this issue makes them not quite aware of how people with lowered intellectual ability see the world. Therefore, it would be worth re-thinking the curricula of medical studies and introducing some subjects which might – at least to a small extent – prepare students for understanding the needs of people with various disabilities. Another idea consists in additional trainings in this field, which would not only provide knowledge of disability but also sensitize the staff to the needs of this group of patients in the course of their treatment.

Ways of communicating with the patient

As it has been highlighted earlier, communication is one of basic difficulties in the contact with a disabled patient. The interviews with medical staff

indicated that communication depends on the degree of disability, on whether the patient is with or without a legal guardian and on a particular medical worker's knowledge concerning the disabled. The ways in which health care workers act are diversified. The orthopaedist declares that he provides information twice, talking both to patients and to their guardians. The anaesthetist aims at direct informing a patient but when this seems a fruitless effort, he talks to the guardian. The laryngologist says that when he deals with a person with more severe disability, he talks with the guardian because such disabled people are usually incapacitated and explaining medical issues to them brings no effects. The nurse from the cardiologic ward says: 'I inform the guardian about the patient's health condition but I never contact only him/her, because a patient should be treated subjectively, not like an object, and even when I know s/he doesn't understand, I think it is worth informing him/her directly'.

This problem is not presented by the operating attendant as she does not need to provide any information: 'the patient drives into the suite to a particular room, undergoes an operation, returns to the ward and here our contact with this patient and his/her family ends.' In contacts with patients with mild intellectual disability, the approaches differ slightly. The medical staff's statements imply that they always try to communicate directly with the patient. The anaesthetist emphasizes that: 'I try to do this politely and tactfully'. The surgeon pays special attention to accuracy in explaining to such patients their health condition: 'I make efforts to explain this to them precisely, I talk with them like with a person within the norm, yet – such patients often ask again and I explain to them again what their illness consists in'. The orthopaedist highlights that he informs the patient directly but makes sure if s/he has understood the information.

The nurses state that they inform an intellectually disabled patient directly but it is the best when this is done in the company of the patient's close people, who in the case of misunderstanding, will be able to explain the provided information. The nurses think the difference between disabled patients and those without disability is that the former ask more questions. One nurse said that she tried to explain and visualize their illness by drawing: 'I explain, draw, present on a picture, e.g. when there was a patient with a clogged vein, I tried to draw this and explain with peace'.

What is of prior significance in treatment is that the patient should follow medical indications in order to be appropriately treated and to achieve the expected results and progress in the course of the disease. Therefore, how does the medical staff inform an intellectually disabled patient about medical indications? The anaesthetist emphasizes that informing such patients about what they need to follow should be done slowly, peaceably and politely: 'these patients require slow and calm talking, not in a chaotic way, you have to make

sure they understand the indications'. In the surgeon's opinion, the way of formulating indications for such patients does not differ at all from indications for patients without disability: indications are in a written form, they are on the discharge sheet which patients get from the hospital office when they leave the ward. Moreover, they get additional sheet with the exact instruction how to apply their medicines, but such a procedure concerns all patients, not only those with lowered intellectual ability'.

The laryngologist has said that when a disabled patient appears, he informs the guardian about the medical indications and, additionally, writes them down on a sheet of paper. The information concerning doctor's recommendations after the hospital treatment is the same as in other wards and the indications are placed at the bottom of the discharge sheet under the epicrisis. All the doctors make efforts to pass the indications to patients both in the oral and written form.

During the patient's hospital stay in a ward, the nurses inform him/her about medical indications mainly by speech and gestures, they say that they try to provide possibly the most detailed explanation: 'I try to explain medical indications very thoroughly, I've noticed that, in the company of such patients, I use hand gestures very often and I demonstrate a lot'.

Apart from explaining, the cardiology nurse hands out some brochures: 'I explain plus hand them some information brochures, e.g. if a patient suffers from diabetes, I give him/her an appropriate brochure; if I explain and they don't understand me, I send them to the doctor, maybe he will explain this better'. The surgery nurse informs patients about medical recommendations in the same way as she informs them about their health condition. This is done by spoken words, writing on a sheet of paper, and if she is not understood, by turning to the guardian: 'More severely disabled patients are always with legal guardians, then the indications are clarified only to the guardian'.

What can be noticed about passing the medical indications is that both doctors and nurses make efforts to be understood by the patient. However, when this is not possible, they turn to the guardian. Slower or louder speaking, repeating or writing down proves insufficient awareness of medical staff concerning the cognitive functioning of the intellectually disabled. Among the interviewed doctors, there was one who pointed out that he does not apply any special approach, justifying this in the following way: 'diseases are the same as in people within the intellectual norm, hence – the issue of a correct diagnosis and careful treatment of the patient, I'm responsible for patients' physical health, their mental health is the matter of other doctors'. This confirms not only the scarce knowledge of disability but also the lack of appropriate approach and empathy.

The situation is completely different when the nurses' approach is studied. What is seen here is warmth and concern. Even if they do not understand

the specificity of functioning of this group of patients, the nurses compensate this with empathy and humane approach 'I try to be kind, smiling, to stroke, to hug, you must be warm to such people because they feel safe then'. The cardiology nurse notices that such patients require more time and attention and the operating suite nurse says that she promotes lenience in the case of such people. Understanding and patience were also highlighted by the surgery nurse.

Most of the staff is of the opinion that intellectually disabled patients can be treated with patients without disabilities. Doctors have indicated that a disabled patient turns to them with problems similar to those of a patient without disability and the course of illness and treatment is the same. A patient is a patient – therefore s/he should be treated as anybody else. What the interviewees have unanimously decided was that only when aggressive or autoaggressive behaviour appears, the patient should be accompanied by a legal guardian, who would be able to prevent unwanted behaviour. The nurses also believe that intellectually disabled patients should be treated with other patients. Yet, one nurse has indicated that: 'this depends on the disability, its degree, but if possible they should be brought closer to normal people so that they would not feel isolated, so that they could feel a part of the society'. This nurse has drawn attention to the social aspect and that integration with people in the intellectual norm is recommended. She has emphasized that owing to closer contact of the disabled with the society they will feel better and more accepted and they will experience a stronger feeling of safety. These statements seem to confirm that the knowledge acquired during the studies enables an appropriate approach.

Ending

Health care – 'care' should be associated with empathy and appropriate approach, 'health' is a notion strongly related to disability – seems to be exactly the place where the situation of the disabled ought to be good. Yet, it is obvious that understanding is hard to find in health care services. This brief study and the questions raised at the beginning show that, in spite of the efforts of medical staff, the situation of intellectually disabled patients is not always good. Even though some signs are visible that the staff tries to take into account the needs of such patients (by treating them in a friendly manner, gently, warmly, patiently and devoting more time to them), what appears is the lack of understanding the specificity of this group's functioning.

Answering the questions formulated initially, it can be seen that the approach to intellectually disabled patients is diversified. Most of the interviewees notice the need for a special approach to these patients. However, there are

also statements informing about treating them as objects, which is particularly transparent in the responses of this type: a patient is a patient – therefore s/he should be treated as anybody else. The changing reality of the disabled has eliminated extreme and open stigmatization in the field of living standards and education, yet – the situation of a disabled person as a patient makes some (not manifested openly) forms of discrimination visible (Z. Gajdzica, 2013, p. 156). Regardless of the work experience, this can be seen in scarce or hardly any knowledge acquired during medical studies. This fact reveals that, despite the changing model of disability and many actions undertaken to raise social awareness of disability issues, health care seems to be a neglected area.

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