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“HUMAN” EXPECTATIONS AND NEEDS, THAT IS AN *EMPOWERED PATIENT* AS A “SURVIVAL STRATEGY” OF CONTEMPORARY PATIENTS

The aim of the article is to present unmet expectations and needs of patients concerning the scope and quality of medical care. The complaints submitted with the Patients Ombudsman at the Ministry of Health have been deemed as exemplary, since this is a central authority of governmental administration relevant in cases regarding the protection of patients specified in the act, which encompasses the entire country in the scope of its powers. This is also the authority which has most often appeared in the mass media, hence it is the most probable that the patients will address exactly this institution with any problem they may have (very often without knowing any other way or procedure). The aim of the article is also to present selected strategies assumed by the patients to allow them to solve the encountered difficulties. Recipients of benefits more and more effectively manage and undertake effective actions aimed at obtaining assistance to the extent they expect. They adopt attitudes proving the assumption of responsibility for their own health (*empowered*), which is proved even by their Internet activity to the extent of which they search for information on e.g. disease prevention, treatment, application of medicines or good nutrition (however, the conclusions in this regard one cannot generalize in terms of the whole population of people enjoying medical benefits). In addition, the article presents also a process of changes with respect to the attitudes towards the value of health and changes occurring in the profile of the modern patient. Presentation of the selected problem area was made on the basis of the results of qualitative analysis of the scope and nature of the complaints submitted with the Patients' Ombudsman (2009–2013) as well as a selective review and survey of the literature and its analysis.

Keywords: health, the profile of the contemporary patient, socialisation to the Polish empowered patient, complaints and requests, Patients Ombudsman

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INTRODUCTION

The process aimed at reformation of the Polish healthcare system, which has lasted since the 1980s, facing problems of recipients of health benefits, about which the media have often spectacularly reported, still seems to have a dual, inconsistent and unsatisfactory nature. It is even considered that the implemented restructuring changes bring about the healthcare system is deemed as complicated and unfriendly towards the patient, where the procedures and formalized standards are more important than the good of humankind. Nevertheless, the entity which in this compound structure is forced to take action is precisely the patient, who has to independently take care of his own welfare and that of his closest persons.

The phenomenon of life medicalization (e.g. Sokołowska 1980; Piątkowski and Nowakowska 2012; Wieczorkowska 2008: 107–139; Skrzypek 2008: 81–94; Słońska 2008: 81–94), the process of modernization of the healthcare system (see Gałuszka 2008: 129–140), the media, and widely accessible (thanks to the application of modern technology) knowledge of medical nature (thanks to which, *inter alia*, there is formed a laic vision of health and disease), on the one hand cause a desire for accessibility to medical services of the highest level, and on the other hand – in the clash with reality: anger, frustration, and feelings of inability and unmet expectations and needs.

The changes refer to the market of medical benefits (see Mielczarek 2010: 53–82), the ways of dissemination of information about it, and the methods and tools for obtaining recipients of medical benefits. As well, the profile of the contemporary patient has changed to that of one who more often would like to consciously and actively take part in choices. The patient more often wishes to consciously and actively participate in the treatment process, to be a partner in the discussion on the implemented methods and procedures, and to participate in their selection. Paradoxically, the implementation of legislative, structural and organizational solutions which are “theoretically” aimed at the provision of safe healthcare at the highest possible level, cause opposite effects: consequently, we have more bureaucratization and unmet needs and higher expectations of recipients of medical benefits, which repeatedly have resulted in the submissions of request/complaint with an entity formed for this purpose. Reasons for submission of complaints vary in nature, from often personal and subjective, to more practical ones – it turned out that “Every thirteenth sick person stops treatment due to lengthy waiting time for a visit and the lack of funds for private treatment. Many patients do not buy the prescribed medicines” (GUS 2016).

The issue of this study relates exactly to these unmet expectations (a category generally constructed from my adopted methodology and my previous analyses) which concern the areas of patients’ rights which are violated by entities providing medical assistance. Expectations and needs of recipients medical benefits seem to be included in the area of powers due to them, although their infringement may result in, *inter alia*, submission of a complaint to the relevant institution. The aim of the article is therefore to characterize unmet needs and expectations of the patients and present the selected strategies assumed by the patients, which constitute their reaction to the encountered difficulties. The recipients of benefits more and more effectively manage and undertake effective actions aimed at obtaining assistance in the scope they expect. More often they adopt attitudes proving the assumption of responsibility for their own health (in

the process of socialization to health), and they expect particular support from healthcare units. Presentation of the selected problem area was made on the basis of the results of qualitative analysis of the scope and nature of the complaints submitted with the Patients Ombudsman (2009–2013) as well as a selective review and survey of the literature and its analysis.

In order to clarify the methodological assumptions of the analysis, the results of which have been presented in the paper, one has to indicate that the most adequate method of analyzing the distinguished sphere was the qualitative method of research, since this has made it possible to fathom the issues and area of the research, corresponding with the aims of the research. The adopted ethnographic perspective seemed the most adequate since it has assumed conducting research in a natural environment, which has made it possible to describe the phenomena in their real context and has provided the possibility of obtaining a reliable view of the given issue, taking into consideration the specificity of the topic, and subsequently of interpreting its social context.

The application of publicly available legacy materials in the research has made it possible to conduct non-invasive research in a natural context. The research material was obtained as part of the implementation of the sociological analysis of the legacy materials, public instruments. Sociologists and methodologists classify documents and official data amongst the most valuable sources of information (Sulek 2002: 103). Public instruments, due to their diverse nature, are a category preventing the elaboration of a methodology constituting a cohesive corpus, therefore the arrangements and rules are formulated with specific types and kinds of documents in mind (the research methodology regarding them is not strict).

The general limitation of the analysis was also, unfortunately, related to the methodology of the documents itself, since they are created both in special registration institutions, as well as in offices accomplishing goals other than recording goals. In such cases, they serve the needs of these institutions, and describe their surroundings, personnel, actions, and effects of their work. They also describe a fragment of social life entrusted to the care of these institutions. Therefore, document analysis is documentary research which conditions the acceptance of the procedure and methodology, similar to the sociological research of personal documents and their methodology (Sulek 2002: 105–106). Public instrument data serve heuristic goals better than the data in question, since these are gathered for the analysis of an already formulated problem or for the verification of a hypothesis. “Official data, being a natural product of social life, do not have such a limitation” (Sulek 2002: 110).

In reference to the completed research regarding the analysis of reports prepared by national authorities (the Bureau of the Commissioner for Patients’ Rights) for 2009–2013, one must state that: the source material was not prepared by an office implementing tasks of recording nature, it contains data regarding cases being considered by this body; the documents are of a formal and duplicate nature; they are the result of a constant recording of events and refer to the group level of data analysis. One should also emphasize that, due to the fact that the analyzed official data were not gathered for scientific purposes, the categories and criteria of choice applied in them do not correspond to the analytical criteria applied in social research, hence the necessity of an authorial creation of them. Moreover, the gathered data are selective in nature and their recording took place via various methods; however, this was not to only source material on the basis of which one could conduct an analysis of a chosen problematic area on the nationwide Polish scale.

CHANGES OF ATTITUDE TOWARDS “HEALTH” AS WELL AS THE PROFILE (ROLE) OF THE CONTEMPORARY PATIENT

Contemporaneity enforces changes in the perception of “health” and assumption of a particular “role of a patient”, although technological advances allow for the initiation of actions aimed at effective management of one’s own health and the health of one’s closest persons. Therefore, one should initiate the reflection from a remainder of changes that took place in terms of an attitude towards health, since these changes initiate other changes – concerning actions contributing to the new roles of a patient.

Hippocrates, a father and the founder of Western medicine, was of the opinion that well-being means health, whereas discomfort means illness. Traditional interpretations of the term “health”, identify it with the state of “lack of illness”. We talk about a healthy person as one who is not sick. His health is assessed through the prism of actions against disease (Suchecka 2010: 93). The state of health is a condition that enables the individual to optimally and effectively fulfill social roles and tasks set by the process of socialization. Thus, in a sociological perspective, “health” is the state of optimum ability to effectively realize valued and desired tasks (Kulik and Latałski 2008: 132–133).

In the past, “being healthy” meant being able to work. The state of health could easily be distinguished from the disease, thanks to specific symptoms, rules and norms that strictly defined the term “health”. However, at present, all the criteria and norms, including those defining “being healthy”, have been diluted. Such a state of affairs is to be found in the fact that medicine offers an increasing range of benefits justifying the introduction of modern intervention methods. In addition, disease has become an inseparable companion of life with which one has to fight 24 hours a day, because healthcare requires such sacrifices. Health in modern society is increasingly perceived in terms of risk optimization (Bauman 2006: 119–124). Contemporary society in the face of civilization diseases is forced to live in conditions that are harmful to health, despite efforts made to reduce the harmfulness. Human life is constantly oscillating between health and disease, since both states are not permanent. Every person fluctuates between one state and the other. It depends on the individual characteristics and conditions in which a person lives. Individual choices and daily behavior form one’s lifestyle, which in turn is determined by the psychophysical properties of an individual and their immunity (Pawelczyńska 1976: 155–158). All these phenomena are related to a new perception of “health”. In 1984 the World Health Organization assumed that health is an interpretation of the balance between the psychic, physical and social spheres of a person (Rutkowska 2006: 14). The change in the perception of “health” has triggered another discussion concerning the doctor-patient relationship and the redefinition of the role of the patient.

The traditional approach of the activity was the domain of a doctor, who was supposed to act professionally for the good of the patient without being emotionally involved in the relationship. The doctor had the right to intervene in the patient’s “entire person”, along with wide autonomy in making decisions and undertaking therapeutic actions. The patient was passive. The disease was perceived by the prism of biology, and the emotional needs of the patient were marginalized (cf. Kaliszuk 1999: 111).

The change in the perception of health, disease and the relation between doctor and patient resulted from the “extension” of the patient’s role, his assumption of a “new role”, an active one with different needs and expectations as to the course of the interaction and the way in which the therapy is conducted. Currently, medicine and health psychology promote a holistic approach towards the patient, who has been involved in the therapeutic process and fulfills an active role in it. The aim of the treatment process is to satisfy the bio-psycho-social needs of the patient. According to the paradigm of holistic medicine, each patient requires an individual approach, not only pharmacological but also psychosocial. The patient becomes an active partner in staying healthy and fighting disease. On the other hand, directive behaviors are useful in situations of apparent danger to a patient’s life or health (Sztangierska and Horst-Sikorska 2007: 59). Patients demand information about diagnosis, general health, causes and effects of diseases, prognoses and courses of therapy. Doctors often cannot understand the patients’ need for obtaining complete information about a disease classification or the course of a therapeutic and diagnostic process. In their opinion, the patient’s trust is built up by selecting the content that he provides, especially unfavorable information which is difficult to accept (Krot 2008: 150). That is why patients more often undertake independent actions to obtain the knowledge they need.

Not only are the needs of patients changing, but their expectations and requirements towards modern medical care system are as well. Today an active, healthy lifestyle-oriented patient is a digital patient, an “online” patient. Authors of the Report (*Pacjent w świecie cyfrowym* 2016: 11–13) point out that most patients are ready to use telemedicine¹ or internet services. The development of the private healthcare market, easy access to online services and modern technology, and cheaper solutions offered in this sector are just some of the factors contributing to the development of telemedicine. Certainly, increasingly widespread general dissatisfaction with the course of appointments at the doctor’s office has significant influence on the growing interest in services of this type. Recently, there has been more and more talk about problems and disagreements in the patient-doctor relationship, and in consequence this leads to conflicts and serious errors in the treatment process (Makara-Studzińska 2012: 48). The most frequent factors that disrupt the patient-doctor relationship include mutual criticism and assessment, commanding, giving advice, moralizing, inappropriate and excessive questioning both on the part of a doctor and a patient, as well as doctor’s jargon which is incomprehensible to the patient (Makara-Studzińska 2012: 48–57). Patients most often complain, *inter alia*, about: not enough time spent on medical examination and conversation; disrespectful attitude of doctors; a lack of regard for the feelings of the patient; and the inability to communicate difficult and sensitive content (Sudra and Gwara 2014: 77).

The fact of changes of modern patients, their expectations and imagination about the scope and quality of medical care is, to some extent, demonstrated by their Internet activity. The patient will more often prepare before a medical consultation, searching for initial information

¹ Telemedicine is a new branch of medicine. This concept concerns information, diagnostic, consulting, therapeutic and scientific services relating to the transmission of images and sound. On the foundations of this phenomenon a new concept called e-health has emerged. In a broader perspective, this term refers to a certain way of thinking, a commitment to improve the quality of medical services provided by the application of modern communication technologies. It involves the use of the Internet and IT networks in medical care (Karski 2009: 97–98).

on the Internet. The authors of the report on trends in Polish healthcare (*Pacjent w świecie cyfrowym* 2016: 11) indicate that currently about 70% of Polish citizens have access to the Internet and 30% of patients possess a smartphone. They predict that in 2019 the percentage of internet users will increase to 85% and smartphone owners to 60%. The Internet and new technologies open up access to specialized knowledge which was previously reserved only for doctors. Patients want to be equal partners in the therapeutic process. Access to knowledge, thanks to the mass media, including the internet, allows them to meet these expectations. More often, patients also benefit from medical services due to them. It has been observed that in 2016 their number increased by 20% compared to the previous 2–3 years. When visiting a specialist, patients first select the most appropriate clinic for them and then the doctor with the highest rating in the “doctors assessment system”. The individualized treatment process and continuity of therapy are of the greatest importance. It is important, as results from the presented report, that the cost of medical services is no longer of decisive importance for patients (though certainly not for everyone). Much more important is the range of services offered, the length of time a patient must wait to see a doctor, and the convenience and proximity of medical facilities. The possibility of making a doctor’s appointment online is also popular. Compared to 2015, the percentage of people taking advantage of teleconsultation through the use of video has increased from 10% to 25%. Interestingly, patients are also ready to use medicine-related services, such as dietitians or psychologists. All these activities are directed at increasing both knowledge and awareness among patients in the enforcement of their rights and claims. This new attitude of patients is referred to as *empowered*.

EMPOWERED PATIENT – ONE OF THE STRATEGIES ALLOWING FOR OBTAINING EFFECTIVE, ANTICIPATED MEDICAL ASSISTANCE

The expression *empowered patients* refers to “independent”, “strengthened” patients. Today we are dealing with an increasing number of such patients, autonomous and conscious. These patients can independently make important health decisions. They are resistant to coercion or persuasion on the part of other people. In Poland, this is a new era, that of empowered patients. They are independent, but they share responsibility for their own health. They actively seek information on health, and they learn how to fight the symptoms of a disease, but most importantly, they learn about healthy lifestyles to stay well as long as possible (*Zdrowy styl życia Polaków* 2012). Thanks to the knowledge they acquire, mainly through the Internet, they can become a partner for a doctor and not only a subordinate person, as in Parsons approach (Parsons 2009; Dolińska-Zygmunt 2001: 274). *Empowered patients* seek the widest possible knowledge of broadly understood health, and in particular, through the use of a variety of medical and health-related websites, seek knowledge regarding:

- specialists, authorities dealing with particular branch of medicine;
- the selection of relevant medicines;
- patient’s rights, in cases of a medical error;
- ways to obtain a copy of their medical records (Nazarko-Ludwiczak 2012: 13).

Therefore, it can be suggested that shaping a new attitude is one of the strategies implemented by patients to meet their health needs and form more effective doctor-patient relationships.

E. Cohen, the journalist considered to be the creator of the idea of *empowered patient*, claims: “[...] there is a difference between being a difficult patient and an independent patient, emphasizing that the empowered patient concept is in no way aimed at striking the medical environment but is a response to the natural need of everyone to have the feeling that we are receiving good medical care” (Nazarko-Ludwiczak 2012: 13).

Contemporary patients strengthened by knowledge assume an attitude which, on the one hand, is a response to the lack of trust in the poor, changing, and more and more complex medical care system, and on the other hand, would like to draw attention to the patient’s principal rights, such as subjective treatment, respect for entitlements in the personal sphere and the right to full medical knowledge of disease classification, full diagnosis and alternative treatment procedures (Hallisay 2008: 273–286; Cohen 2010: 6–13). Some people believe that the appearance of the empowered patient in Poland is also caused by problems with obtaining good quality healthcare (*Euro Health Consumer Index* 2009).

A co-responsible patient, first of all, would like to cooperate with the doctor, to have a good rapport with him, and not just follow the instructions. Empowered patients, through engagement in the treatment process, are doomed to the poor quality of health services to a definitely lesser extent (Olesch 2012: 11), and this is mainly because they know where to go to obtain treatment, where to obtain higher quality of services, and where the best specialists are. In addition, they are more aware of their rights.

THE EMPOWERED PATIENT IN THE DIGITAL WORLD

Patients also have more and more knowledge of how to use the Internet for health purposes (see Łaska-Formejster 2014a: 17–29; 2014b: 186–202). The number of internet users in Poland in mid-2016 exceeded 18 million, and the average time that Poles spent every day on the Internet was about 4.5 hours on computers and over an hour on mobile devices (*Mobile and digital in Poland and around the world* 2016). Empowered patients are those who more often want to control their health and manage it online; they can also define their needs and want to be satisfied with the medical care they receive. A modern patient living in the empowered age “[...] derives knowledge about the health from the Internet, consults on discussion forums, expects high quality of services, is mobile, carefully chooses a doctor, clinic, hospital” (*Mobile and digital in Poland and around the world* 2016). The results of research confirm these tendencies, as 70% of Poles declare that they use the internet every day and most willingly when they want to learn about health, diseases and treatment process (88%) (*Aktualne problemy i wydarzenia* 2011; *Serwisy o zdrowiu* 2011; *Pacjenci w sieci* 2012). Second, the information searched concerns doctors and health services (ranked second in terms of popularity of websites) (73%) (*Pacjenci w sieci* 2012). The next sources of information are the press, the television, and family and other persons who have faced the same problems. Therefore, assuming the “role” of the modern patient is (to a large extent) takes place in the mediated reality. The media create social reality, influence the perceptions of

its recipients, build their opinions, and shape their knowledge. At present, the media are not merely information carriers, but they promote specific patterns of behavior, and implement rituals that are essential to shaping the identity. The modern man (a patient) often reacts as required by the media, which is the source of values and patterns of behavior.

There are over 800 Polish-language websites dealing with health, diseases, and medicines. The number of websites and above all internet users' activity proves the growing interest, the high popularity of medical content and the possibility to express one's opinion in terms of health. The fact that almost 90% of internet users are searching for health information on the internet indicates a high interest and demand for information of this type. The popularity of medical websites and the need to share knowledge, opinions and evaluations on medical internet forums can also prove the topicality of the following problems: incorrect course of doctor-patient interaction, and failure to implement a patient's basic rights, such as access to complete and comprehensible information on health and alternative methods of treatment.

Patients' internet activity is also supported by actions undertaken by the state directed at increasing access to medical information. Here we can list the following system initiatives:

- eWUS system (Electronic Verification of Entitlements of Benefit Receivers) – allows for an immediate confirmation of the patient's right to state-funded healthcare benefits;
- *e-system* – Patient Health Information (ZIP) – allows patients to have constant access to information about the type and cost of health care provided by the health care facility;
- P1 project – Electronic Platform for the Collection, Analysis and Sharing of Digital Resources on Medical Events, implementing, among others: Internet Patient's Account, e-Prescriptions, e-Leaves and e-Referrals. An example of this is the currently functioning website of the National Health Insurance System (OSOZ), which allows a patient to create one's own electronic health account (Individual Health Account) to which the patient has access via the Internet.

These changes in the system organization of medical care are also conditioned by the strategies adopted by the European Union binding also in Poland (Lisbon Strategy – 2000 and documents: eEurope 2005 Information Society for All and Action Plan 2004). As a member of the EU we are obliged to implement appropriate tools allowing for computerization of medical care enabling, among others, the possibility to control and manage one's own health by means of the Internet.

Thanks to the progressive technological development and computerization of social life, patients have greater and easier access to medical knowledge and services. As a result, the media and interactive computer networks (see Castells 2007: 20) become the dominant source of socialization for a new role of the patient, the empowered patient.

SOCIALIZATION TO THE CONTEMPORARY PATIENT'S ROLE (EMPOWERED PATIENT)

The role of the patient is influenced by many factors, including social and cultural ones. In the process of socialization for the role of the patient, an individual learns to function in medical facilities, learns the rules governing these facilities, and adopts the norms and rules

that determine the doctor-patient interaction. Thus, socialization for the role of the patient includes:

- vocabulary (medicine-related nomenclature such as hospital, referral, morphology);
- knowledge of medical facilities and scope of their activities;
- a description of the specialization of doctors and nurses;
- principles and rules of interaction between doctor and patient;
- procedures in medical facilities;
- patient’s rights and obligations;
- methods of dealing with health problems;
- promotion of healthy behaviors (Drozd-Garbacewicz 2015: 37).

The family plays a significant role in socializing for the role of the patient. As the primary society, it conveys key hygiene behaviors, rules and principles concerning health and illness. It performs an elementary function in shaping healthy attitudes, providing knowledge in the field of promotion and strengthening of health. It is also responsible for creating emotional attitudes as an autotelic value. Since the assumption of the patient’s role, a need for help appears. A family influences a sick person to behave according to his role. Sometimes it can interpret the condition of the sick person as not requiring consultation with the doctor and focuses on self-healing. The family is also an important source of support in the course of the disease. It affects the course of therapy, adherence to doctor’s instructions and motivation for a quick recovery of a close relative playing the role of a patient (Włoszczak-Szubbda and Jarosz 2012: 207). However, the type of support given is conditioned by its material, emotional and functional resources (Tobiasz-Adamczyk 2000: 170–171).

Another socializing agenda for the role of the patient are the medical facilities whose task is to develop a patient’s obedience to the existing institutional and organizational requirements of medical facilities. The health system not only provides certain formal rules but also strengthens the patterns of behavior that have been shaped by the family (Mumford and Skipper 1967: 59).

One should also point towards another possible area of analysis of socialization issues for the role of the patient in which the patient is treated by medical facilities as a client of medical services, which shapes the contemporary market of these services based on their own subjective feelings. Inadequate care of the needs of the patient-client may result in the loss of reputation of the clinic or doctors (Małecka and Marcinkowski 2007: 19). This is why so many businesses now offer their services online. The doctors themselves also have their own websites/internet profiles providing potential recipients with easier and faster access to them, as well as an assessment of the services they provide, and this in turn will establish new types of rules and patient activity. In consumerism theory, health requires the patient’s active attitude, and the relationship with the doctor is an organized system of behaviors that the patient-consumer (client) must learn in order to be able to effectively negotiate the terms of service. With the availability of online medical services, an active patient is able to anticipate the results of medical interventions and thus seek to better meet his or her individual medical needs (Mielnik-Błaszczak, Ziolo and Kawiak-Jawior 2011: 97).

With the change (expansion) of the role of the patient, there is also a change in the dominant sources of socialization to this new role. Contemporary health socialization is based on a broad understanding of “health” as physical, mental and social well-being. This is a multifaceted phenomenon that ensures a balance between man and the environment. The starting point for this concept of health education is an ecological model of health that has emerged from holistic philosophy. According to its assumptions, the person located in the center of the ecosystem is composed of body, mind and spirit. He or she is a member of a family where he or she has formed values related to health, attitudes and behaviors. The factors that determine the health of a person in this model are as follows:

- biological factors, e.g. innate predisposition;
- individual behavior, e.g. nutrition habits;
- physical environment, e.g. housing environment;
- psychosocial environment, e.g. social status;
- lifestyle;
- healthcare system;
- professional status;
- local society;
- man-made environment.

A prominent feature of this system is the distinction between lifestyle and the environment that determines health (Kulik 2014: 11–12). Socialization to the present role of the patient primarily consists in an increase of the competence of individuals in the sphere of independent activity for one’s own health. Not only knowledge, but also the awareness of one’s rights and duties is supposed to play an immanent role. It is supposed to enable an entity to purposefully make common decisions, taking the responsibility for its own health, building up a good relationship with the doctor (and medical staff), and adapting the method of the treatment to one’s own needs and expectations. The creation of a medical service through the combination of patient activity and the willingness of the doctor to cooperate will satisfy the patient’s imagination on the high quality of benefits (Krot 2008: 149–151).

WHAT DO CONTEMPORARY PATIENTS WANT? EXEMPLIFICATION OF THEIR EXPECTATIONS AND NEEDS THROUGH AN ANALYSIS OF COMPLAINTS AND REQUESTS SUBMITTED WITH THE PATIENTS’ RIGHTS OMBUDSMAN

For substantive reasons, it seemed indispensable to find an “objective” factor of patients’ expectations and needs. Research resources in this area are rich but heterogeneous, and through analysis of the results of rankings (e.g. Consumer Index, “Health Barometer 2009”), examination reports of opinion polls or published results of individual social researchers’ projects, we can differentiate the categories of unmet expectations and desires of patients, which to a large extent coincide with the problem areas reported to the Patient Rights Ombudsman and other institutions established to protect the patient’s rights. The decisive factors with respect to the

selection of complaints and requests, as an exemplification of unmet expectations and needs of the patients were as follows: the fact that, in the opinion of patients, the cases addressed to the Ombudsman infringed upon their particular interests or generally accepted principles and norms, and the fact that the source material can be deemed homogeneous, as the patient (or the patient’s family) makes an (most often) autonomous decision to report a specific problem.

Because of the lack of access to original source materials (content of requests and complaints), the analysis includes an annual statement prepared by the Patient Rights Ombudsman Office. The analysis covered the period from 21 May 2009 (the beginning of the reporting period of the Patient Rights Ombudsman at the Minister of Health) until 31 December 2013 (the last published report) and its source was the existing data and reports available on the website: *Sprawozdanie Rzecznika Praw Pacjenta*, <https://www.bpp.gov.pl/sprawozdania-roczne/>. The scope of the analysis was out of necessity narrowed to the issues referred to in the documents in question. However, in spite of these limitations, the most important issue was even an approximate characteristic of the scope of failed entitlements and patients’ expectations in the all-Polish scale, as that would illustrate the scope of the problem and emphasize the phenomena and areas where more work is still needed on the implementation of measures that respect the medical rights of entities on a nation-wide scale.

As regards the procedure for reporting cases, complaints and requests can be addressed to the office in various ways, using various tools. Table 1 illustrates the number of complaints reported via the Helplines of the Patient Rights Ombudsman’s Office, letters and e-mails, and personal cases reported in the examined years.

Table 1. Number of cases reported to the Patient Rights Ombudsman in the years 2009–2013

Years	Cases reported by way of the Helpline of the Patient Rights Ombudsman’s Office	Cases submitted by way of letters and e-mails	Personally reported cases	Total
21.05.2009 31.12.2009	2 382	1 903	34	4 319
2010	12 612	7 979	283	20 874
2011	22 725	10 161	445	33 331
2012	35 887	16 532	731	53 150
2013	36 563	16 108	485	53 156
Totals	110 169	52 683	1978	164 830

The total number of complaints and requests reported during the reporting period is alarming (164 830). Although it should be stressed out that some of them concerned requests for clarification of queries, provision of specific information or indication of existing legislation, it does not change the fact that almost 150 thousand patients decided to address the Patient Rights Ombudsman with a specific problem (even if it was due to a lack of knowledge or information, as this is also a manifestation of needs of patients, unmet through other methods).

Among the issues reported via the helpline were infringement of the right to medical care, including the indication of problems with obtaining health insurance benefits; breach of the right to health benefits in accordance with standards and terms of agreements; and medical errors by the doctor. The next category of reported problems related to infringement of the right to documentation. According to the patients, the medical staff violated this by refusing to make copies, refusing to temporarily share originals, refusing to send electronic versions, refusing access to documents after a patient's death, and by general refusal of access and inappropriate keeping of medical records. The right to information is another breach reported through the helpline. Patients complained about the laconic nature of the information provided and the refusal to provide information. The right to respect private and family life was also not observed by medical staff. Patients most often indicated refusal to the presence of a close relative when providing benefits, the presence of unauthorized persons during examinations, the refusal of additional nursing care in the hospital, and violation of principles of respect for the patient's dignity. The right to consent was primarily violated in situations where medical procedures were performed without the consent of the patient. These situations occur when (1) the provision of the benefit was contingent upon the signature of a statement of consent for performance without prior information, (2) When the provision of the benefit was contingent upon the signature of a statement of consent, without prior information, (3) In situations of failure to obtain conscious consent to perform the procedure, and (4) and when patients reported problems with establishing the entitlement for health insurance benefits.

According to the decreasing number of indications, patients further reported failure to respect the right to dignity. Disregard of the right to intimacy and dignity manifested in the violation of the principles of respect for dignity of the patient, in the implementation of the medical procedure in the presence of others and in the implementation of medical procedure without the consent of the patient. Violation of the right to object and voice an opinion was reported least frequently.

Another way of filing complaints and request was through a written form, and 52 683 persons took advantage of this method in the analyzed period. The largest number of cases was reported in 2012, which could have been caused by the protests of medical staff, the so-called stamp protest, and the restriction of medicine reimbursement rights related to it (with respect to the reimbursement act). The scope of the cases reported in the submitted letters was extremely broad. Patients also sought information by use of this method, and wanted to make sure as to application of specific redress procedures. The scope of complaints and requests addressed to the office mainly related to (1) cases of people waiting in queues for outpatient specialist care (2) matters (cases) of patients waiting for hospital care, (3) and (related to hospital care) denial of registration of a referral to hospital and a place in the waiting queue (proceedings explaining the possibility of breaking the right to medical benefits are dominant every year, e.g. in 2012 they constituted 68.4% of all cases). There were frequent signs of long waiting periods for health benefits in primary healthcare. Those interested reported that they had limited access to basic, specialized and highly specialized diagnostic tests, including computed tomography and magnetic resonance imaging. Patients have complained about refusals to provide benefits and a long waiting periods for such benefits.

According to a decreasing number of indications in the cases sent to the Ombudsman, which were implemented in the explanatory proceedings, the following complaints were dominant: breach of the right to medical documentation, information, violation of the right to intimacy and dignity, consent to provide healthcare services, lack of respect for private, family life, and in individual situations violating the right to hold valuables in deposit. As well, an increasing number of complaints were received by the Patient Rights Ombudsman related to medical error by a doctor, failure to exercise diligence while providing medical benefits, violations of the Code of Medical Ethics, hospital infections, and unethical behavior of medical staff.

Another form of contact with the ombudsman was a personal visit to the office. Patients are more often willing to report cases here. The upward tendency is systematic, with the exception of the year 2012, where the so-called stamp protest also caused an increase in the number of visits to the office; however, the scope of the cases reported this way was not distinguished in the published statements.

SUMMARY

The analysis of the data in the statements shows that patients’ rights to healthcare, medical documentation, information, and respect for intimacy and dignity were most often violated.

Patients complained about:

- refusal to: provide benefits; register a referral and locate in a queue; perform examinations under general anesthesia; issue a certificate of temporary incapacity to perform work; postpone the date of an appointment; order sanitary transport; issue referrals for outpatient specialist care, for sanatoriums, for hospitals, orthopedic items and aids, and for additional nursing care; change GPs, reimburse of medical expenses under the European Health Insurance Card; and to provide treatment outside the country;
- refusal to: provide information about treatment; provide detailed medical information for discharge from a hospital in the event of inability to perform prescribed health benefits at home; and provide information on treatment method, prognosis and other alternative treatments;
- failure to: inform the patient of the expected effects of applying certain medical procedures; issue a certificate of health condition; provide medical documentation; correct errors in medical documentation; and accept the presence of a close relative;
- dependence of hospitalization on the performance of diagnostic tests by primary health care physicians;
- limiting access to diagnostic and therapeutic services;
- in-hospital infections, lengthiness of the proceedings regarding the requests, extortion of bribes, probability of medical errors, decreased quality of service, no response to complaints, disclosure of data concerning the treatment to unauthorized persons, breach of secrecy of medical documentation, and undertaking actions without patient’s consent.

Patients had reservations with respect to: waiting queues, charging fees due to lack of insurance documents, failure to respect special rights, and medical documentation. There was a widespread criticism of the availability of rehabilitation services.

The majority of cases (mostly over 50%, and in the year 2013, 74%), after examination, ended with the indication of legal remedies. About 12–15% of cases were considered and referred to competent authorities (District Inspectorate of Prison Service, National Health Fund, self-governments of medical professions, the Ministry of Health, the Social Insurance Institution). On average from 7% to 12% were cases undertaken by the Ombudsman and about 5–6% were not considered cases because they went beyond the Ombudsman's competence and there was no possibility of referring them to the relevant authority. The violation of patient rights ranged between 25% and 29% (e.g., in 2012 there was a violation of patient rights in 29% of cases conducted both on request and, on the ombudsman's own initiative, while in 2013 there was 38% of such cases).

The most frequently justified complaints related to (on average, according to the decreasing number of indications) violation of the patient's rights to: medical documentation, medical benefits, information confidentiality, respect for the patient's intimacy and dignity, information, respect for private and family life, objection to the opinion or decision of the doctor, granting consent for examination and treatment, and pastoral care.

CONCLUSIONS

The analysis of the material clearly demonstrates the wide spectrum of problems that still face the recipients of healthcare benefits, which can be deemed as an exemplification of their unmet expectations and unsatisfied needs. It turns out that most of the "human needs and expectations" concern obtaining the professional and competent medical care, and respecting universally accepted values and principles. Some of these needs and expectations reported to the office concerned systemic and organizational issues. However, one should point out the tendency is that patients (at least part of them) develop strategies and "learn" their roles "from scratch" using tools (almost) universally available. Their activity in the area of pursuing their own rights has increased; willingness to enforce them. The contemporary patient wishes to participate in the treatment process, establish a dialogue with the doctor (to be heard and understood), to create interactive "contact". However, he or she often encounters barriers and faces organizational, personnel and quality problems regarding the provided health benefits. Adopting strategies to deal with these problems is probably the most difficult, and one of them is to file a complaint with the competent authority. Contemporary patients with their health problems have to find themselves in a bureaucratized environment, conditioned by a complex network of legal, structural, organizational, social, market and marketing relationships. In the area of health activities, the subject is not only a person expecting a specific form of medical aid, but also (or perhaps above all) a social object that is increasingly familiar with its rights and informed, which is influenced by social, economic, political, cultural (+ religious) and psychological factors and principles (Mruk 2009: 49–52).

Summarizing, the most important strategies adopted by contemporary patients to solve their difficulties seem to be:

- the empowered patient’s attitude: when a patient with the attitude of an empowered patient, supported with knowledge, shares the responsibility and assumes a role using technological developments, tools which are available (almost) everywhere nowadays;
- the acquired ability to manage health: ‘the new role-taking’ allows them to take autonomous actions aimed not only at effective management of the physician-patient relationship, but also at protecting their own health and that of their relatives;
- using technological developments: internet activity, being a part of the new role, is facilitated by the regulations of the European Union (in force in Poland) concerning systemic organization and digitalization of healthcare.

Technologization and informatization of social life make knowledge of medicine and health services accessible, and both media and interactive networks are becoming main sources of socialization to the new role of a patient, that of an ‘empowered patient’:

- Another indicator of socialization to the contemporary role of the patient (described in the article) is an increase in the asserting and exercising of rights.
- The patients’ strategy involves making a complaint to the appropriate institution. The next step in the strategy adopted by patients is to lodge a complaint with a competent authority. Dissatisfaction with patients’ needs perceived through the prism of unfulfilled expectations and disrespected rights may emphasize areas that require special attention and engagement of those who decide on the shape and function of the healthcare system.

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„LUDZKIE” OCZEKIWANIA I POTRZEBY, CZYLI *EMPOWERED PATIENT*
JAKO „STRATEGIA PRZETRWANIA” WSPÓŁCZESNEGO PACJENTA

Celem artykułu jest prezentacja niezaspokojonych oczekiwań i potrzeb pacjentów dotyczących zakresu i jakości opieki medycznej. Za ich egzemplifikacje zostały uznane skargi składane do Rzecznika Praw Pacjenta przy Ministerstwie Zdrowia, gdyż jest to centralny organ administracji rządowej, właściwy w sprawach ochrony pacjentów określonych w ustawie, obejmujący swoimi uprawnieniami całe państwo. Jest to także organ, który najczęściej pojawiał się w środkach masowego przekazu, stąd większe prawdopodobieństwo, że wszelkie „bólączki” pacjenci zgłaszają właśnie do tej instytucji (często nie znając innych ścieżek i procedur). Celem artykułu jest także prezentacja wybranych, przyjmowanych przez pacjentów strategii, umożliwiających rozwiązywanie napotykanych przez nich trudności. Świadczeniobiorcy coraz efektywniej radzą sobie i podejmują skuteczne działania w celu uzyskania pomocy w oczekiwanym przez nich zakresie. Przyjmują postawy świadczące o przejmowaniu odpowiedzialności za własne zdrowie (*empowered*), świadczy o tym chociażby ich aktywność internetowa, w ramach której poszukują informacji na temat, np. profilaktyki chorób, leczenia, zażywania leków czy prawidłowego żywienia (choć oczywiście wniosków w tym zakresie nie należy uogólniać na całą populację osób korzystających ze świadczeń medycznych). Zaprezentowany został także proces zmian w podejściu do wartości zdrowia i zmian zachodzących we współczesnym profilu pacjenta. Wybrany obszar problemowy omówiono na podstawie wyników jakościowej analizy zakresu i charakteru skarg składanych do Rzecznika Praw Pacjenta (2009–2013) oraz selektywnego przeglądu literatury i jej analizy.

Słowa kluczowe: zdrowie, profil współczesnego pacjenta, socjalizacja polskiego *empowered patient*, skargi i wnioski, Rzecznik Praw Pacjenta