

Delivering bad news in the perspective of patient rights

Krzysztof Sobczak^A, Katarzyna Leoniuk^B✉, Agata Janaszczyk^C

Medical University of Gdańsk, Department of Medical Sociology and Social Pathology, Tuwima 15, 80-210 Gdańsk, Poland

^A ORCID: 0000-0002-8354-2299; ^B ORCID: 0000-0001-9802-1771 ^C ORCID: 0000-0002-8650-3981

✉ katarzyna.leoniuk@gumed.edu.pl

ABSTRACT

Introduction: The necessity to deliver bad news to patients is one of the classic challenges of medical communication. The applicable patient rights oblige doctors to communicate full information concerning adverse condition tactfully and cautiously. The purpose of the study was to determine the level of knowledge of the rights and responsibilities of the patient in people who had received bad news, to identify the fields in which knowledge is lacking and to check if the level of knowledge affected the patient's behaviour.

Materials and methods: The study was conducted with 314 people who had been given bad news. An original Computer-Assisted Web Interview (CAWI) online survey questionnaire was used. Reaching the respondents was possible thanks to our cooperation with national patient organisations and electronic media.

Results: One in 5 respondents (21%) was characterised by little knowledge concerning patient rights and responsibilities; 67% had a moderate level of knowledge or were almost fully aware of their rights. A vast majority of the respondents knew that they were entitled to full information about their condition, prognosis and treatment, as well as an inspection of their medical documentation.

Conclusions: The knowledge of patient rights seems to be at an unsatisfactory level. Respondents with a higher education and those suffering from cancer had more knowledge. Patients with little or a moderate level of knowledge of patient rights and responsibilities were more likely to change their attending physicians or discontinue their treatments.

Keywords: patient rights; doctor-patient relationship; truth disclosure.

INTRODUCTION

The degree to which the rights of the those being contacted when medical services are provided is one of the key indicators of a health care system's sensitivity. There are those who perform or supervise providing medical services, and those receiving the services, both healthy and sick [1]. The situation when a doctor gives a patient bad news is a unique ground for a meeting of these 2 perspectives. Article 17 of the Polish Medical Code of Ethics obliges the doctor to give the information to the patient "tactfully and carefully". At the same time, it indicates that such a notification can be abandoned in a situation where the doctor is deeply convinced that this kind of information would be harmful to the patient (it would cause suffering and have adverse consequences on the patient health). However, at the patient's explicit request, the doctor should provide him or her with full information.

Our previous research has revealed that there were substantial problems connected with the interpretation and implementation of patient rights by doctors in the situation when bad medical news has to be communicated to a patient [2, 3]. As we intended to deepen the research perspective, we sought patients who had received bad news from their doctors, asking them to share their opinions and experiences connected with this situation. We assumed that by bad news we would understand the diagnosis of an illness which is permanently or relatively permanently connected with abnormalities in the

body which require constant and/or long term treatment or regular application of measures aimed at pain management. In such a perspective, the term 'bad news' refers to lifestyle diseases (e.g. diabetes, coronary disease, serious allergies, cancer, etc.), as well as mental or genetic illnesses and incurable terminal diseases.

A part of the study was an attempt to answer the question whether patients who were in the situation of being diagnosed with a serious disease were familiar with their rights and responsibilities. This problem seemed significant to us primarily because there are not enough studies which would at the same time concern the analysis of familiarity with patient rights and responsibilities, patients who use different institutional forms of health care (without reducing the research perspective to a single medical facility or hospital ward), and people who have a relatively permanent (non-accidental or not several days long) patient status.

MATERIALS AND METHODS

We conducted the study between February and October 2017. Data was obtained by Computer-Assisted Web Interview (CAWI). The self-prepared e-survey questionnaire was used as a research tool. The study group (n = 314) was of a completely inclusive character and was selected randomly (Tab. 1).

TABLE 1. Characteristics of the respondents

Gender	n	%	Marital status	n	%
female	248	79	unmarried	111	35.5
male	66	21	married	167	53
Education			widow/widower	17	5.5
primary	4	1.5	divorced	19	6
junior high school	4	1.5	Age		
vocational secondary education	15	5	18–30-years-old	78	25
secondary school education	105	33	31–40-years-old	84	27
higher education	186	59	41–50-years-old	65	21
Place where the news was delivered			51–60-years-old	44	14
public clinic	47	15	61-years-old and more	43	13
public polyclinic	45	14.5	Visit payer		
private polyclinic	20	6.5	national health fund	254	81
private clinic	8	2.5	insurance company	5	1.5
private doctor's office	29	9	patient's own funds	46	14.5
hospital	165	52.5	do not remember	9	3
Kind of disease			Doctor's specialization		
cancer	119	38	neurologist	54	17
nervous system diseases	61	19	haematologist	41	13
endocrine gland disorders	29	9	oncologist	37	12
blood and cardiovascular diseases	26	8	surgeon	29	9
musculoskeletal diseases	18	6	gynaecologist	25	8
genitourinary diseases	14	5	endocrinologist	21	7
mental disorders	9	3	primary care physician	21	7
skin diseases	9	3	rheumatologist	10	3
eye diseases	8	2.5	cardiologist	10	3
other causes	21	6.5	other: psychiatrist, geneticist, etc.	66	21

n = 314

Participation in the study was anonymous and voluntary. Information about the study being conducted was delivered to patients via national independent patient organisations and associations as well as electronic media.

To assess the patients' knowledge of the rights and responsibilities which apply to them, an original self-made test was prepared. Primarily, it consisted of 10 statements – 5 true and 5 false. Ultimately, the answers to one of the statements were not included in the statistical analysis due to a change in regulations which was introduced during the course of the study. The respondents' task was to state whether each statement was "true" or "false". Then, 1 point was assigned to each correct answer and 0 points to every wrong one. Therefore,

a respondent could get a max. of 9 points and a min. of 0 – in a situation when he did not give any correct answer.

SPSS v.26.0 software was used for the statistical analysis. The opinions and scores of the respondents were juxtaposed with sociodemographic variables (age, gender, marital status, education and residence), health variables (type of disease) and medical variables (specialization of the doctor who delivers the news, the place where the patient was in contact with the doctor as well as the visit's payer). Pearson's χ^2 test was used for analysing the correlations between discontinuous variables and the statistic heterogeneity of the groups. The difference was assumed as statistically significant at $p < 0.05$.

RESULTS

Awareness of patient rights and responsibilities

The vast majority of the participants of the study were aware of their rights concerning complete information about their condition, prognosis and treatment (98%), and the right to view medical records (89%). Almost all the respondents (97%) realised that the doctor was obliged to remain tactful and careful when communicating an unfavourable diagnosis (Tab. 2).

TABLE 2. Knowledge of patient rights

Statements about patients' rights	Correct answer (%)	Incorrect answer (%)
It is the doctor's responsibility to present to the patient full information on the diagnosis as well as the proposed and possible diagnostic and treatment methods	97.8	2.2
It is the doctor's responsibility to inform the patient about an unfavourable prognosis in a tactful and careful way	96.8	3.2
The doctor is not obliged to provide the patient's medical records at his or her request	89.2	10.8
The patient is obliged to inform the doctor and/or medical facility that he is not coming to an appointment or that he is not able come to it	81.2	18.8
The patient has no right to object to a medical opinion	79.0	21.0
A patient who is undergoing treatment may request for the doctor to call a medical case conference	68.5	31.5
The patient may request for the doctor not to inform him about his condition	65.3	34.7
The doctor may not turn down the patient's request for him to call a medical case conference	32.2	67.8
The patient is obliged to familiarize him with patient rights	24.5	75.5

n = 314

It is worth mentioning here that 33% of the respondents believed that their doctor's behaviour was in violation of this responsibility. According to 47% of the patients, the doctor's behaviour at the moment of giving them bad news was tactful.

Every 5th respondent (20%) was not able to assess this aspect of the doctor's behaviour.

Less than 1 in 5 patients was not aware of the obligation to inform the doctor or medical facility that he would not come to his appointment or was not able to come. One in 3 patients was not aware of his right to ask the doctor not to inform him about his condition (35%) and to request the doctor to hold a case management conference (31.5%). Two thirds of the respondents (68%) mistakenly assumed that a doctor could not refuse to hold a case management conference or to consult another doctor. The largest number – as much as $\frac{3}{4}$ of the respondents (75.5%) erroneously thought that it was a patient's obligation to learn about patient rights.

Assessment of patients' knowledge

When it comes to assessment of the patients' knowledge of their rights, it must be stated that the average score for all respondents was 6.34 while the median was 6.00. The min. score by the respondents was 3 points while the max. was 9 points (Tab. 3).

TABLE 3. Level of knowledge of patient rights

Knowledge test results	n	%	Level of knowledge
3	5	1.6	low
4	11	3.5	
5	50	15.9	
6	93	29.6	moderate
7	119	37.9	
8	32	10.2	high
9	4	1.3	

(n = 314)

Every 5th respondent (21%) was characterised by a low level of knowledge of patient rights, while more than a half (67.5%) were characterised by a moderate knowledge. Only 1 in 10 respondents (11.5%) was fully aware or almost fully aware of their rights. It is worth mentioning again that the study group consisted of people who had struggled with chronic and often very serious diseases, so most of them had used the health care services regularly. From this perspective, the knowledge of patient rights seems lacking, especially when it comes to the respondents with a min. of knowledge.

People with high knowledge of patient rights were less likely to change the physician who conducted their therapy or terminate treatment after receiving bad news, than those with a moderate or low levels of knowledge, with 43% of people with a high level of knowledge changing doctors compared to 58% of the those with a moderate or low level of knowledge of patient rights ($\chi^2 = 7.318$; $df = 1$; $p = 0.007$).

Patients with cancer had more knowledge of their rights. Over a half of oncological patients (57%) had a high level of knowledge, and for other diseases, 44% had a high level of knowledge ($\chi^2 = 4.845$; $df = 1$; $p = 0.028$).

When the moderate result in the patient rights test was compared to sociodemographic variables, the impact of the

level of education on the knowledge of patient rights was visible. The Student's t-test results showed that those with higher education received a higher average score (6.45) compared to those with up to secondary education (6.19) [$t(312) = -1.980$; $p < 0.05$]. No other sociodemographic variables (gender, age, marital status and medical variables, the visit's payer, and the place in which the visit was held) – had an effect on the level of knowledge of the respondents.

DISCUSSION

There are many regulations concerning fields connected with patient rights. The applicable provisions in the Constitution of the Republic of Poland as well as the Acts and Regulations are among the most important. Some other legal references which constitute regulations in this field are: the Act of 30 August 1991 on health care institutions (Journal of Laws of 2007 No. 14, item 89), the Act of 5 December 1996 on doctor's and dentist's professions (Journal of Laws of 2005 No. 226, item 1943, with amendments), the Act of 5 July 1996 on the nurse's and midwife's professions (Journal of Laws of 2001 No. 57, item 602, with amendments), the Act of 27 July 2001 on laboratory diagnostics (Journal of Laws of 2004 No. 144, item 1529, with amendments), the Act of 19 August 1994 on Psychiatric Healthcare (Journal of Laws of 1994 No. 111, item 535), the Act of 6 November 2008 on Patient Rights and the Commissioner for Patient Rights (Journal of Laws of 2009 No. 52, item 417), the Act of 6 November 2008 on accreditation in healthcare (Journal of Laws of 2009 No. 52, item 418), the Act of 6 November 2008 on consultants in healthcare (Journal of Laws of 2009 No. 52, item 419), Minister of Health Regulation of 9 November 2015 on the kinds, scope and samples of medical records and the ways of processing them (Journal of Laws of 2015, item 2069), The Medical Code of Ethics passed by the National Congress of Doctors based on Art. 4 section 1 point 2 and Art. 33 point 1 of the Act of 17 May 1989 chambers of physicians (Journal of Laws 1989 No. 30, item 158). All of these regulations define the scope of Polish patient rights. It is worth emphasizing that they do not formally determine the patients' obligations. That was already noticed in studies by Public Opinion Research Center in June 2001 concerning analyses of the familiarity with patient rights, that such sets of patient responsibilities often accompanied information about patient rights, which was pointed out by 53% (n = 1032) of those respondents [4]. From the formal point of view, the internal regulations of medical facilities can define patient responsibilities, such as observing the principles of hygiene, sticking to the daily routine, informing a doctor or nurse if they are leaving the ward, obeying the facility's regulations, etc. There are no formally sanctioned responsibilities assigned to the status of patient. In other words, the responsibilities which rest with the patient are, *sensu stricto*, the responsibilities of every citizen and result from other legislation or regulations than those concerning patient rights, such as obeying the smoking ban in health care facilities and in rooms of other facilities where medical services are provided – Act of 8 April 2010 amending

the Act on the protection of health against the consequences of tobacco use, as well as the Act on the State Sanitary Inspectorate (Journal of Laws of 2010 No. 81, item 529).

Extensive legal regulations are, in a way, an expression of the awareness which is emerging on the part of medical service consumers [5]. On the other hand, there are many reports which analyse the patients' knowledge in this area. Representative comparative studies by the Public Opinion Research Center from 1996 and 2001 showed a growing patient awareness when it comes to the declarative knowledge of their rights (from 11 to 19%) and a decreasing fraction (from 43 to 27%) of those who have not heard of the regulations which would protect them [4]. In 2003, when Wroński referred to the reports by the Public Opinion Research Center, he pointed out progress (33%) in the patients' knowledge in this field. However, Wroński's study was not conducted on a representative group and was limited to patients who had been hospitalised in an oncology clinic, therefore comparisons of the results obtained in both the investigated groups is problematic. Secondly, the variable of the place where the research is conducted (focused on surgical oncological patients), as suggested by the results we have obtained, may determine the results [6].

The actual execution of patient rights must also constitute a significant element of the discussion. There is a serious deficiency in references concerning this issue in literature. An analysis of the complaints filed with the Patients' Rights Office shows that patients most frequently request intervention concerning the long waiting time before they receive medical services, problems with referrals to specialist treatment or diagnostics, and not receiving medical services in an emergency mode [7]. From the formal perspective, the concerns reported by Polish patients are common problems when it comes to the organisation and completion of services in other healthcare systems [8, 9].

The question of the quality of the patients' knowledge is a completely different issue. According to studies by the Public Opinion Research Center, most patients fail to notice the patient rights on notice boards in health care centres. Hajduk et al. showed that 30% of patients (n = 200) gained their knowledge concerning their rights from other hospitalised patients. Less than half of the respondents indicated that this kind of information had been given to them by medical staff, while 20.4% indicated their doctors as the source of information. Every 5th respondent claimed that they had not been informed about their rights at all [10]. The study by Gotlib et al. from 2014 showed that 19% of doctors (n = 100) and 7% of nurses (n = 100) evaluated their knowledge of patient rights as good. The authors emphasized the fact that the medical staff's knowledge of patient rights was lacking and that they had hardly any role in providing this kind of information to patients [11]. This viewpoint seems to correlate with the results of studies which assessed the training needs of young doctors (n = 1608) where 77% revealed that they had only taken part in classes concerning matters like medical law as well as the principles of health system organization and functioning for no more than 1 day and just once [12].

The results of studies presented above must constitute a background for the results we received in our analyses. We have not encountered Polish reports which would focus on the viewpoint of capturing the awareness of patient rights in the situation of bad news being delivered to them. Most of the presented studies refer to the knowledge of medical staff concerning patient rights. If there are reports concerning the patients' awareness, they pertain to selected groups of patients hospitalised in particular health care facilities [10, 11, 13].

In spite of some methodological differences which have resulted from the adopted research perspective, certain similarities and differences in the results may be identified. Reports, including our results, show that there is a correlation between the patients' education and their awareness of their rights. Patients with higher education demonstrated the greatest degree of knowledge concerning their rights and responsibilities [4, 10, 14]. When it comes to differences in comparison to other reports, our study did not confirm a correlation between age and the level of knowledge of patient rights. Some reports present such a correlation and show that an older age correlates with a lower awareness of the rights they have [4]. The reason why such a correlation was not shown in our study may be the non-representative nature of younger people, which is typical of studies conducted with a CAWI technique.

Another important result of our research is the fact that a correlation between the type of disease and the level of knowledge of patient rights was shown. Those who suffered from ontological diseases had the highest awareness of patient rights.

The final result which seems important to us is the correlation between the fact that patients with a low awareness of their rights are more likely to change their attending physicians or terminate the treatment when a doctor gives them news about an unfavourable diagnosis. This means that the knowledge of patient rights may affect the patients' engagement in the therapeutic process or may be one of its expressions [15].

CONCLUSIONS

Based on the study which was conducted, it can be stated that:

- over 1/5 of the patients had a low awareness of patient rights,
- most of the patients' knowledge was at a moderate level,
- cancer patients have the highest level of knowledge concerning their rights, compared to patients with other diseases,
- patients with higher education are more aware of their rights,
- patients with a low level of awareness of patient rights are more likely to change their attending physician or terminate the treatment if they are given bad news by the doctor.

REFERENCES

1. Jacek A, Ożóg K. Przestrzeganie praw pacjenta przez personel medyczny. *Hygeia Public Health* 2012;47(3):264-71.

2. Sobczak K, Pawłowski L, Pietrzykowska M, Spolak N. Delivering bad news by physicians – Polish reality check. *JMS* 2016;85(3):172-7.
3. Sobczak K, Leoniuk K, Pawłowski L, Spolak N. Komunikacja kliniczna – porównanie opinii lekarzy i pacjentów. *Pomeranian J Life Sci* 2016;62(3):67-73. doi: 10.21164/pomjlifesci.186.
4. Wiedza o prawach pacjenta. CBOS. https://www.cbos.pl/SPISKOM.POL/2001/K_070_01.PDF, 2001 (9.11.2018).
5. Maciąg A, Sakowska I. Rola i prawa pacjenta w obszarze jakości usług zdrowotnych. *Studia i Materiały – Wydział Zarządzania UW* 2006;1:50-62.
6. Wroński K. Znajomość Praw Pacjenta przez osoby chore leczone w Klinice Chirurgii Onkologicznej Uniwersytetu Medycznego w Łodzi. *Onkol Pol* 2007;10(2):75-83.
7. Tułodziecka I. Przestrzeganie praw pacjenta podstawą partnerstwa. Biuro Rzecznika Praw Obywatelskich. Konferencja naukowa: Prawa pacjenta – czy są dostatecznie chronione? Warszawa: Agencja Master; 2003.
8. Hill Y, Fraser I, Cotton P. Patients' voices, rights and responsibilities: on implementing social audit in primary health care. *J Bus Ethics* 1998;17(13):1481-97.
9. Ryyänen SP, Harisalo R. A strategic and good governance perspective on handling patient complaints. *Int J Health Care Qual Assur* 2018;31(8):923-34.
10. Hajduk Ł, Binkowska-Bury M, Jacek A. Informowanie o prawach pacjenta przez personel medyczny. *Prz Med Uniw Rzesz Inst Leków* 2011;3:348-58.
11. Gotlib J, Dykowska G, Sienkiewicz Z, Skanderowicz E. Ocena wiedzy i postaw personelu medycznego Samodzielnego Publicznego Szpitala Klinicznego im. Prof. Orłowskiego w Warszawie wobec praw pacjenta. *Ann Acad Med Silesiensis* 2014;68(2):84-93.
12. Ocena potrzeb szkoleniowych oraz wiedzy lekarzy i lekarzy dentyistów w zakresie kompetencji miękkich oraz organizacji systemu ochrony zdrowia. http://www.nil.org.pl/_data/assets/pdf_file/0018/107343/Raport-Ocena-potrzeb-szkoleniowych_.pdf; 2013 (9.11.2018).
13. Moczyłowska A, Krajewska-Kułak E, Kózka M, Bielski K. Oczekiwania chorych wobec personelu lekarskiego. *Hygeia Public Health* 2014;49(1):142-51.
14. Wierzbińska-Karakuła S, Binkowska-Bury M, Burzyńska J, Januszewicz P. Respektowanie oczekiwań i praw pacjentów w podkarpackich jednostkach podstawowej opieki zdrowotnej jako element jakości usług zdrowotnych. *Prz Med Uniw Rzesz Inst Leków* 2015;1:19-30.
15. Sobczak K, Leoniuk K, Janaszczyk A. Delivering bad news: patient's perspective and opinions. *Patient Prefer Adherence* 2018;12:2397-404.