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Conscious and Informed Patients? Insights into the Legal Consciousness of Patients' Rights in Poland[1]

This study reflects on the state of legal consciousness surrounding patients' rights in Poland. Using a national survey, it investigates the level of knowledge, understanding, and awareness of patients' rights in the Polish population, as well as their readiness to take action in cases of violation. In addition, it presents findings from a series of in-depth interviews conducted with patients' rights lawyers to explore the motives and perspectives of patients and their families on legal action. Special focus is given to the role of patients in healthcare. Power relations, rights, emotions, and procedures form a complex framework that is at the root of both action and inaction. The concept of dignity and its place in the legal and social dimensions of healthcare is a primary trigger for possible action. Throughout the discussion, the issue of patient autonomy is raised.

Key words: legal consciousness, legal awareness, patients' rights, patients' autonomy

Niniejszy artykuł dotyczy stanu świadomości prawnej w obszarze praw pacjenta w Polsce. Za pomocą ogólnopolskiego badania ankietowego zbadano poziom wiedzy, zrozumienia i świadomości praw pacjenta wśród Polaków, a także ich gotowość do podjęcia działań w przypadku ich naruszenia. Badania sondażowe zostały uzupełnione o serię wywiadów pogłębionych przeprowadzonych z prawnikami zajmującymi się prawami pacjentów. Celem tych wywiadów było zbadanie motywów i perspektyw pacjentów i ich rodzin w obszarze działań prawnych. Szczególny nacisk położono na rolę pacjentów w opiece

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zdrowotnej: autonomię, współdecydowanie, dostęp i sposoby korzystania ze swych praw jako pacjent. Relacje władzy, prawa, emocje i procedury tworzą złożone ramy, które leżą u podstaw zarówno działania, jak i braku działania pacjentów. Jak pokazują badania, to pojęcie godności, wraz z jej społecznym i prawnym rozumieniem, jest głównym bodźcem do podjęcia przez nich ewentualnych działań.

Słowa kluczowe: świadomość prawna, prawa pacjenta, autonomia pacjenta, podmiotowość w ochronie zdrowia

Healthcare constitutes one of the areas of socio-legal life that concentrate on some of the key problems regarding power relations, inequalities, and exclusion. By definition, patients are the weak and vulnerable party in this system: entering an often new and possibly hostile environment, while fighting for their own or their loved ones' health, if not life. To balance these large power disparities and protect the most vulnerable groups in the area of healthcare, the idea of patients' rights as a specific set of human rights was introduced and developed. As one of the most established and earliest researchers of patients' rights put it: "The most powerful concept shaping the practice of modern medicine is the recognition that patients have human rights" (Annas 1989: xiii).

This paper aims to reconstruct the legal consciousness of patients' rights in Poland. The notion of legal consciousness was employed as the basic conceptual tool to understand how the legality of patients' rights is situated in Poles' everyday healthcare experience. It is a fundamental assumption that "the formulation of patients' rights can also help to raise awareness. For patients, this includes a more active role in their care, while for providers it involves a greater understanding of the impact of interventions on patients" (Palm et al. 2020: 347). The research presented here shows to what extent those hopes, more generally referring to the efficiency of any legal regulations, are fulfilled by the legislation on patients' rights in Poland.

The study discussed here stemmed from some initial questions on the place of patients' rights in the everyday lives and legal consciousness of Poles. Some of those initial questions on the legal consciousness of patients' rights are:

- What role do patients' rights play in (everyday) interactions in healthcare?
- Are Poles aware that they have a set of particular rights in their routine and non-standard healthcare interactions?
- Do Poles treat patients' rights as *their* rights, in other words do "patients' rights" have any practical meaning for them, or are they seen as something distant and unimportant?
- Are patients' rights just a *shell* introduced as part of the *ongoing* legal transformation (*juridization* or *legalization*) or are they embedded in the

everyday healthcare interactions and have both practical and axiological meanings?

This paper seeks to find answers to those questions using data obtained from a national survey on legal consciousness and a series of expert interviews with patients' rights lawyers. Before answering those questions, let us first take a brief look at the legal landscape of patients' rights in Poland.

Patients' rights in the international and transnational legal framework

Patients' rights constitute a specific category of human rights. "Therefore, the basic factor influencing the development of the concept of patients' rights is the prevention of a situation where patients would be treated as objects. (…) The fundamental aspect of patients' rights consists of the idea of protection of human life, freedom, dignity and privacy in a specific situation of one's life: when benefitting from health care services" (Drozdowska 2010).

"The patient rights movement is as slow as a glacier, equally relentless at changing the landscape but ultimately healthy", wrote George Annas (1989: 1), one of the leading American researchers of patients' rights. Much has changed since then, as patients' rights have become encompassed within human rights, and numerous regulations and institutional solutions safeguarding them have been introduced across the globe.

However, there are very few international or transnational binding legal instruments in this area. In the European context, the first such instrument was the 1997 Convention on Human Rights and Biomedicine (the Oviedo Convention, Council of Europe). Although it was primarily intended to protect human dignity against any misuse of biological and medical advances, it also contains some general patients' rights. The other one was the European Commission's Directive 2011/24/EU, which constituted an important milestone for the development of patients' rights in European countries. However, the directive "essentially focuses on the social and consumer patients' rights in the context of cross-border health care" (European Commission 2014: 19). Therefore, it does not fully incorporate the idea and values linked to patients' rights into the EU framework. Instead, it treats patients as "consumers" to ensure access to cross-border health services.

Yet the issue of patients' rights was pursued as early as 1984 in the European context, when the European Parliament adopted a Resolution inviting the European Commission to submit a proposal for a "European Charter on the Rights of Patients" (see: Palm et al. 2020: 351). It took almost two decades to complete, but in 2002 a group of European patients' organisations, the Active Citizenship Network, launched the European Charter of Patients' Rights. It contains fourteen patients' rights and three additional active citizenship rights (see: Box 1). Although not a binding legal instrument, it still constituted a landmark for future national regulations encompassing patients' rights.

FOURTEEN RIGHTS OF THE PATIENT
1. Right to preventive measures
2. Right of access
3. Right to information
4. Right to consent
5. Right to free choice
6. Right to privacy and confidentiality
7. Right to respect of patients' time
8. Right to the observance of quality standards
9. Right to safety
10. Right to innovation
11. Right to avoid unnecessary suffering and pain
12. Right to personalized treatment
13. Right to complain
14. Right to compensation

RIGHTS OF ACTIVE CITIZENSHIP
1. Right to perform general interest activities
2. Right to perform advocacy activities
3. Right to participate in policy-making in the area of health

Box 1: The European Charter of Patients' Rights (Active Citizenship Network 2002)

Patients' rights in the Polish legal framework

The idea of patients' rights was first introduced in Polish law in the 1991 Health Care Institutions Act. However, it included only a limited catalogue of patients' rights, with other rights spread throughout other, more specific acts (such as the Mental Health Act, regulating the rights of the mentally ill, or the Act on Infectious Diseases and Infections). The key regulation on patients' rights was the "Act of 6 November 2008 on Patient Rights and the Patient Rights Ombudsman" (binding from 5 March 2009). The said Act explicitly lists 11 rights: the right to healthcare provided according to present medical knowledge; access to information; the right to report adverse effects; right to secrecy; consent to medical services; respect for privacy and dignity; access to medical records; the right to make an objection to a medical opinion or a doctor's statement; respect for private and family life; pastoral care; and deposit of valuables.

This was put together as a result of the prolonged endeavours of patient organisations and individual activists for proper regulations on patients' rights. It was also linked to the establishing of the office of Patient Ombudsman. This independent body was enacted by the same Act to represent the interests of all patients, to maximize the protection of patients' rights, and to offer aid in cases of infringements, medical errors, or inaction by medical institutions.

Patients who feel that their rights may have been violated have several legal options. Civil proceedings are typically used for major violations and medical errors. These can be conducted in parallel with or following criminal liability, which some interviewees recommend due to financial reasons. In civil cases, the party who orders expert opinions is responsible for the cost, while in criminal cases the prosecution bears the cost. However, a dual approach involving both paths presents several risks, such as those related to the process itself, as well as temporal and financial risks. Such risks are outside the scope of this general overview.

The Act on Patient Rights and the Patient Rights Ombudsman provides patients with the opportunity to submit an official complaint. Although proceedings are free, they can be time-consuming. Some interviewees suggested this approach as an inexpensive preparatory measure, as the evaluation could later be used in court proceedings. Conversely, some lawyers have discredited this idea.

Another method, not involving litigation, redirects patients to one of the Voivodeship Commissions for the Evaluation of Medical Incidents (*Wojewódzkie komisje ds. orzekania o zdarzeniach medycznych*), administrative bodies that operate through the regional voivodeship offices. The said commissions have been assessed by the Supreme Audit Office (Naczelna Izba Kontroli 2018) and further discussed by the Commissioner for Human Rights (Rzecznik Praw Obywatelskich 2019) and deemed ineffective, particularly in terms of addressing patients' real needs and low damages and compensation, incomparable to the possible results of litigation. The lawyers who were interviewed are highly critical of the proceedings and their outcomes. Finally, there are other options available, including the ability to file complaints against medical institutions and professionals with the National Health Fund, the medical courts of regional medical chambers (via the Regional Screener for Professional Liability – *Okręgowy Rzecznik Odpowiedzialności Zawodowej*), or directly with the medical institution in question. However, it appears that these options only hold a symbolic or supplementary role. For instance, professional court proceedings of medical chambers can lead to several penalties for doctors and dentists, including suspension or revocation of their right to practice medicine. However, only a small number of doctors are removed from practice each year, making this act uncommon and atypical (see Niemczyk, 2014). In addition, medical courts do not address any financial grievances.

Legal consciousness – a brief and selective introduction

The study of legal consciousness has a long history. Initially, the focus was put on the knowledge of law (Ehrlich 1913). With time, it "has become a more general term which encompassed not only the knowledge of the legal system but also the ways ordinary people think of, talk about, and understand law in their everyday lives" (Horak et al. 2020: 10). It evolved to be "understood as the integration of terms such as legal knowledge, legal awareness, trust in law, and opinion about law, etc." (ibid.). The focus on the ordinary functioning of law in everyday life "makes us all legal agents insofar as we actively make law" (Ewick, Silbey 1998: 29). This drives the more recent research into identifying "the law outside of formal legal settings", searching for the "operation of law in everyday life, as well as the operation of everyday life in law" (ibid.), hence researching legal consciousness in diverse places. "Although legal consciousness is emergent, complex, and moving, it nonetheless has shape and pattern. The possible variations in legal consciousness are developed within historically defined contexts and encounters" (ibid: 88). On the other hand, as they conclude, "we not only report, account for, and relive portions of those lives, we participate in the production of legality" (ibid.: 61-62).

The now classic and influential "critical" approach to legal consciousness, as expressed by Ewick and Silbey, sees the law as "experienced as both strange and familiar" (1998: 25). They identify three approaches to law, or legality as they call it, namely "conformity *before* the law", "engagement *with* the law, and "resistance *against* the law" (ibid: 52). Legal consciousness is then used to "name participation in the process of constructing legality" (ibid).

It is widely acknowledged, and has been shown in legal consciousness research, that "law is present but is hardly the dominant set of frames ordering social life" (Marshall, Barclay 2003: 617). Marshall and Barclay (2003) point to "the push and pull of legal ideas (that lies) at the heart of modem explanations of the texture of law in our everyday existence" (ibid). The *pull* of the law constructs and constrains everyday lives through regulations. Lay people are more or less familiar with these regulations, but they nevertheless grow accustomed to those formal rules. On the other hand, the *push* of the law makes it a dynamic force, which enacts the "powerful frames" of legality in everyday life, giving people opportunities to incorporate the law in new practices and areas of social life, to redefine or challenge it or use its constraints for their own goals (ibid.: 617-8). This way of looking at the law does not encompass yet another possibility. What if the actors are by no means willing to take part or actually participating in any construction of legality? What if they are completely disappointed with the law and legal procedures? What if the disappointment goes as far as them feeling and seeing themselves completely outside of the legality as a system, structure, or point of reference? What if they feel completely distant from legal institutions and the law? What if only non-legal norms and structures shape their behaviours and meanings? As Sarat and Kearns point out, "scholarship on law in everyday life should abandon the law-first perspective and should proceed, paradoxically, with its eye not on law, but on events or practices that seem on the face of things, removed from law, or at least not dominated by law from the outset" (1995: 55). We should possibly see an additional aspect of legal consciousness, outside of this "hegemony" of law, where people no longer see the law or legality as their own set of frames. Marc Hertogh (2018) calls it legal alienation. Simply put, it is a situation where people "turn their backs on law" (ibid: 6). While the principal aim of his "secular" approach to legal consciousness "is to analyse both if and how law matters in everyday life" (ibid: 12), he focuses on how the law "does not play a central" role in our lives (ibid: 13). Instead, it becomes difficult to understand, remote, absent and alien with people's experience (see: Cotterrell 1992: 291; Engel and Engel 2010: 161, in Hertogh 2018: 13). We may point to a growing isolation or alienation of law in everyday social practices and experiences: "when people are listening to the discourse of the law, they are no longer able to identify their voice at all" (Hertogh 2018: 14). As Hertogh argues, "the current public discontent with law and the justice system (…) signals a process of *legal alienation*", which he defines as a "cognitive state of psychological disconnection from official state law and the justice system" (2018: 14).

Hertogh completely opposes the "critical approach", pointing to the only form of participation in legality – non-participation – as characteristic of today's societies. He claims that the state law is nobody's law, as people feel alienated by the complex, difficult-to-understand law, superseded by other norms and values. However, a society (a democratic society to be precise, as he focuses on the Netherlands and the EU) alienated from the state law, "where most people turned their backs on it", would be "a society that is governed through open and widespread repression, rather than largely through consent" (Halliday 2019: 871). As Halliday states in his critical review of the book: “If state law is nobody’s law, ordinary people expect little of it – consistently and generally – except arbitrary and oppressive enforcement” (2019: 871). Therefore, I would rather see legal alienation as yet another of the possible aspects of legal consciousness, albeit a very interesting one. Alongside the law as *pushing* and *pulling*, the law may also *be left out* of sight, adding to a multifaceted, fragmented, and complex legal consciousness.

On research into patients’ rights in Poland

Patients’ rights have had considerable attention in Poland. Leaving aside legal analyses, let me focus on the social research into certain aspects of awareness of patients’ rights. Most of the research has been limited in scope, often conducted in a single medical centre. The main area of research concerned patients’ knowledge of their rights. Sobaczak et al. (2020) investigated the level of knowledge of the rights and responsibilities of patients who had received bad news concerning their health, concluding that their knowledge was at an unsatisfactory level. Several years earlier, Krzych and Ratajczak (2013) found that patients admitted to a tertiary university hospital had “considerable awareness of their rights”. Some other research was aimed at checking how patients’ rights were respected and communicated (Wierzbińska-Karakuła et al. 2015), while Wroński et al. (2008) checked how well patients were informed about their health status. Research tended to be conducted among patients in particular medical centres (e.g. Karpińska 2016; Wroński 2008, Wroński et al 2009) or specific wards (Kozyra 2014), sometimes on very limited samples (e.g. Pawłowska, Perzanowska 2017).

Not many surveys on representative samples of Poles have been conducted so far. CBOS, one of the leading Polish public opinion research agencies, asserted that the knowledge of patients’ rights was rising, based on two polls from 1996 and 2001 (CBOS 2001). However, no such surveys have been conducted since the legal codification of patients’ rights in 2008. Two representative surveys were conducted in the project “Patients’ Rights – Your Rights” in 2008 and 2013 (Fundacja Ius Medicinae 2016). They both showed low awareness of patients’ rights. All the above results will be discussed in brief later, in the results section.

Methods

This article is based on two lines of research. First, a national survey on legal consciousness was conducted in Poland in the summer of 2020. This CAPI survey was conducted on a representative sample of Polish society (1000 adults). It consisted of 65 questions relating to legal consciousness in various areas of everyday life. The survey contained a set of 10 questions on patients' rights, relating to respondents' knowledge of these rights, their assessment of these rights' importance, dwelling on past experiences and perceptions of everyday cases. It is worth noting that the survey was conducted during the Covid-19 pandemic, after the initial spring 2020 lockdown but with pandemic restrictions still in place. The restrictions, alongside the all-encompassing face mask obligations and sanitary recommendations, were also related to healthcare, which this study is most interested in. Hospital visits were severely or completely restricted, and certain services were suspended or limited. Primary healthcare was mostly limited to telemedicine consultations. The rights to a dignified death and pastoral care were limited, as patients would often die alone, without family, loved ones, or a member of the clergy. The rights to confidentiality, privacy, and dignity were also indirectly limited through the pandemic measures (Piatkowska et al. 2021). At the time the survey was conducted all those patients' rights were in place, but there were as yet no Covid-19 vaccines or realistic prospects thereof, and knowledge of the SARS-Cov-2 virus was still very limited.

Having said that, it has to be admitted that this study may not help reconstruct how the attitudes, opinions, and practices shown here contribute to the construction of consciousness of legality (or – law in action). It is only a "snapshot" of legal consciousness at a given moment in time, in the initial phase of the largest global healthcare crisis to date. Therefore, to receive more comprehensive insights into some of the problems identified in the survey, in-depth interviews were conducted. The main topics included insights into patients' legal consciousness, their activity and inactivity, the significance of patients' rights, and the main violations of these rights. In total, 8 interviews were conducted with lawyers specifically dealing with medical cases, to different extents focusing on representing patients, doctors, and medical entities; and one interview with a patients' rights representative in a large hospital. The interviewees were identified through online desk research and approached by email or telephone. All lawyers contacted agreed to be interviewed, and the interviews were conducted online or in person.

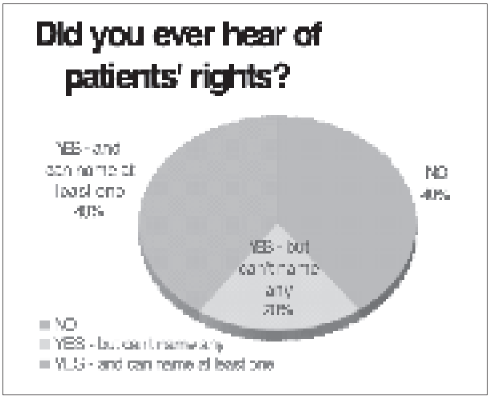
Results

1. Knowledge of patients' rights

The first questions in the survey were intended to identify whether the respondents had any knowledge of patients' rights in general, and if they knew any in particular. The topic of patients' rights is quite visible in the media, discussing certain high-profile cases – especially where medical malpractice lawsuits are concerned. The temperature of the discussions is also raised by ruling politicians, using criminal liability against doctors, and publicising (and politicising) certain cases. Punitive damages have not grown in the last decade, and rarely exceed 500,000 euros (Nowosielska, 2020), but the biggest verdicts are reported and discussed.

The Covid-19 pandemic brought the topic back to the mainstream news outlets. Far-reaching restrictions on hospital visits, the shift of primary care to practically only online or phone consultations, even paediatricians refraining from any in-person consultation – all this led to the mainstream media raising questions about *my rights* as a patient, and online discussions made them everyday topics. Especially since the subject of patients' rights has been quite widely discussed in the media, it was interesting to see how much Poles knew about their rights as patients.

Graph 1. Knowledge of patients' rights



It turned out that most of the respondents were not familiar with the rights that patients have in Poland. Almost 40% (exactly 39.6%) had never heard of patients' rights, while a similar number had heard of them but could not name a single one. Just short of 20% (19.3%) knew and could list some of the rights that patients have.

The above findings show some increase in the declared knowledge of patients' rights compared to a previous national survey (CBOS 2001), conducted before the passing of the Patients' Rights Act in 2008. In 2001, 27% of Poles had never heard of patients' rights. 54% had heard of them but could not give any details, while 19% knew "what they were about". No further details were inquired about. Another survey, conducted in 2008 and repeated in 2013 (Fundacja Ius Medicinae 2016), showed similar results.

Respectively 50% and 53% of the respondents had heard of patients’ rights, while 20% were able to name any. The leader here was access to medical care (mentioned by 11% of the total sample).

The rights given most frequently in this study were the most basic, namely the right to health services and free health services (interpreted as constitutional). Knowledge of any other, more specific rights, was rather marginal. Table 1 below lists all of the rights mentioned. Respondents were allowed to name as many rights as they wanted.

Have you ever heard of patients’ rights? If yes, could you name any?

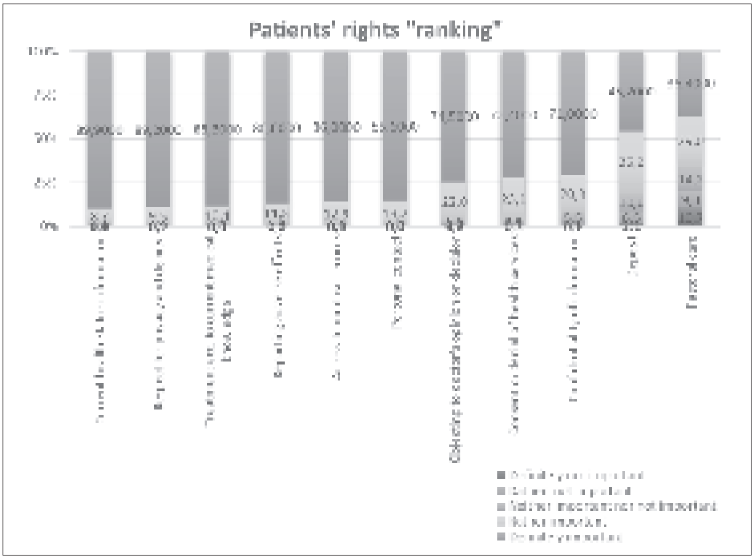
Table 1. List of all patients’ rights mentioned in the survey.

	Number	Percent
No, I haven’t	**396**	**39.6**
Yes, I have (but I can’t name any)	**193**	**19.3**
Right to free health services	105	10.5
Right to health services	98	9.8
Confidentiality and protection of information on health status	47	4.7
Right to information on one’s health status	36	3.6
Access to medical records	27	2.7
Right to dignity, privacy	19	1.9
Right to decide on one’s treatment	17	1.7
Consent or refusal of treatment	12	1.2
Right to file a complaint against a HCP or healthcare facility	12	1.2
Right to choose one’s HCP and healthcare facility	9	0.9
Right to being treated according to current medical knowledge	7	0.7
Right to check out of hospital	3	0.3
Right to aid in emergency situations	3	0.3
Right to equal treatment	3	0.3
Right for a loved one to receive information on one’s health status	2	0.2
Right to a loved one’s presence in hospital	2	0.2
Right to reimbursed medicines	1	0.1
Other	7	0.7
Patient has no rights	1	0.1

2. Importance of patients’ rights

Secondly, I asked the respondents how important patients’ rights are in their opinion. This allowed me to create a “ranking” of patients’ rights.

Graph 2. Ranking of patients’ rights



Based on this declared importance, the rights can be organised into several groups. The first and most important group for the respondents could be called “practical-medical”, and includes the right to information on the current status of one’s health, treatment according to current medical knowledge, access to medical records, and (interestingly treated as very important) being able to report adverse effects. The last of these could be attributed to vaccines and their side effects, a topic storming over mainstream media, but even more so over social media, one of the key factors in the vaccine hesitancy debates and discussions (see: Polak et al. 2021). This group encompasses all the *medical* aspects of healthcare, understood more in terms of their practical implications for therapy and further possible treatments.

The second group could be linked to one’s empowerment, agency, and *autonomy* in healthcare relations. It includes the second highest ranked respect for one’s privacy and dignity, but also the possibility of objecting to a doctor’s decision and consent or denial of health services, clearly less important according to data.

The least important rights could be put into a group called “everyday-practical” rights. These are actually linked to the more *everyday* side of healthcare relations, with data protection (confidentiality of information) being surprisingly among the less important. Other rights in this group involve the right to deposit valuables, and finally pastoral care. The latter is especially interesting, as this goes against possible preconceptions of Poland’s highly Catholic society (almost 92% declaring themselves Catholic, and 81% declaring themselves religious; GUS 2018), or how the public sphere is infused with and influenced by the presence of the Catholic Church. A typical manifestation of this in healthcare is that of priests, allowed, accepted, and present in most Polish hospitals, also during the pandemic (for more, see: Diduszko-Zyglewska, 2020).

The interviews with lawyers dealing with medical and patient-oriented cases enabled us to look deeper into the core values behind patients' rights. All interviews showed dignity as the central value for patients, especially those deciding to take legal proceedings related to their healthcare experiences. Though certainly not the main trigger of legal actions, violations of dignity practically always appear in court proceedings. One of the interviewed lawyers expressed the importance of dignity, which is often overlooked or neglected:

> *This aspect of dignity comes to the forefront. I often hear it in clients' stories. It's usually not the only thing, not the one thing you go to a lawyer with. But there are accompanying things concerning medical records, quality of medical care, access to medical records, and so-called medical errors. (Interview 2)*

This aspect of dignity is intertwined with abuse, but also communication deficiencies and neglect, which constitute the basis of patients' rights violations.

3. Awareness of rights. Patients' rights violations

The next issue in the survey concerned patients' rights violations – as experienced by the respondents or loved ones. The majority of respondents had no direct experience with any violations of rights, with only 10% acknowledging such experiences.

The fact that only 10% of the respondents claimed to have been victims of patients' rights violations may be attributed to several factors. First of all, to very well functioning healthcare, where HCPs and institutions fully respect the rights that patients should enjoy, have established good pro-patient social practices, and are open, informative, and interactive in regard to the procedures and medical services. However, bearing in mind the low level of knowledge of patients' rights, this might not be the case. Secondly, we could risk the explanation that the respondents were afraid of admitting such violations. This is probably also not the case, especially with common, heavy, and eagerly voiced criticism of healthcare and healthcare professionals.

The final explanation could be associated with a lack of a deeper understanding of patients' rights. This would mean that despite the declared significance of the PR, discussed above, respondents are not fully aware of how these rights translate to everyday social practices in healthcare, their decision-making capacities, having a say, and being a subject in medical relations.

Graph 3. Violations of patients' rights experienced by survey respondents.

Then, delving deeper, I checked what particular types of violation had occurred. Table 2 shows the results, ordering the answers by incidence.

Table 2. Violations of patients' rights by type.

How were the rights violated?	Number	%
Lack of respect for privacy and dignity	38	38.0%
Lack of current health status information	31	31.0%
Not being treated according to current medical knowledge	30	30.0%
Not being able to report adverse effects of medicines	21	21.0%
Lack of access to medical records	15	15.0%
Performing medical procedures without consent	13	13.0%
Not being able to object to doctor's opinion or decision	11	11.0%
Informing others of one's health status without consent	9	9.0%
No option of a deposit for valuables	5	5.0%
Not being able to contact loved ones	2	2.0%
No pastoral care	1	1.0%
Other	*13*	*13.0%*
Answer denied	0	0.0%
Total	100	

The violations cited the most frequently related to the key aspects of medical care as such: lack of respect for privacy and dignity (38%), lack of information on current health status (31%) and not being treated according to current medical knowledge (30%). These may not be attributed to any of the common issues that the healthcare problems are usually blamed on, such as underfinancing, long waiting lists, limited accessibility, or other institutional malfunctions. They rather show a lack of established good practices and procedures followed in healthcare, seemingly more so in specialist and in-patient care. Interestingly, lack of pastoral care was only listed once. This proves the point of the omnipresence of (catholic) priests in hospitals mentioned earlier. Here, we could suspect that the answer could rather refer to a lack of non-Catholic denomination pastoral care.

How respondents reacted to the violations they themselves or their loved ones encountered proved very interesting and telling in terms of legal consciousness. The largest group, almost half of all those who had had their patient rights violated, did not actually react at all. Moreover, of those who did react, most took a non-legal path, since the most common reaction was speaking to or reproaching a healthcare professional (18%). Other respondents intervened with the head of the ward or head of the hospital (13%), while some started a quarrel (3%). All the above, which could be called "mild" ways of dealing with a violation, encompassed 1 in 3 of all reactions. Legal reactions were marginal, with only a handful of respondents filing complaints or reporting their case, or (which happened once) calling the police. Interestingly, some respondents' reaction (3%) was limited to moving to a different healthcare centre. This shows discouragement and withdrawal, taking the place of any positive activity on the spot or afterwards.

Table 3. Reactions to violations of patients' rights.

How did you react to those violations?	Number	Percent	Percent of all
I did not react	**48**	**4.8**	**48.0**
I spoke to / reproached the HCP	18	1.8	18.0
I intervened with the head of the ward or head of the hospital	13	1.3	13.0
I filed a complaint (no addressee given)	5	0.5	5.0
I did not react because I was not directly involved (it concerned somebody else)	3	0.3	3.0
I reported the case to the Doctors' Council or the Patients' Ombudsman	3	0.3	3.0
I changed the healthcare centre	3	0.3	3.0
I started a quarrel	2	0.2	2.0
I called the police	1	0.1	1.0
Others	2	0.2	2.0
Irrelevant answers	2	0.2	2.0
TOTAL	100	10.0	100.0

No reaction as the most prevalent response is particularly striking. This is one of the issues that calls for further inquiry in qualitative research: to understand why this happens and what causes such non-activity. Is it the fear of revenge? Of not being treated properly in the future? Of a "bad patient" label? Of being "badly remembered" in an area where good relations may still be more important than procedures? Is there more fear than actual risk in this way of thinking? The lawyers interviewed could not identify all the reasons, but brought up some interesting points to follow. Firstly, the emotional load linked with patients' rights violations might be very heavy, especially when medical errors or malpractice are involved. Secondly, difficulties in the legal processes, not always well recognised by patients. I will return to this point further in the article.

As for patient rights violations, the interviews revealed an image of multiple problems adding up to chains of violations.

The catalogue of patients' rights is very broad and encompasses de facto the whole medical process. Depending on which right is violated, this may result from diagnostic or other errors. And it is often the case that the errors we find in medical records or other patients' rights violations show consecutive things. And we end up with an array of various errors, medical errors. (Interview 5)

In the vast majority of cases that ultimately end in courts, patients encounter a range of various violations of their rights, mixed with medical errors and attempts at cover-up. The most common violations, based on the interviewed lawyers' experience, include: negligent or inaccurate medical records; diagnostic and therapeutic errors; lack of informed consent for medical procedures; lack of proper information on medical condition; and also violations of dignity and privacy. One lawyer gave an account of a typical situation of violation of dignity:

A fundamental example of the violation of dignity is when you have a collective room in a hospital, with several patients. And a patient has to be changed or requires a procedure when their private parts are exposed. Doctors should set up a screen to shield them from other patients, but in the majority of cases that is not done. Often the door is left open, other patients come in and out, watching. What is more, there are groups of students who watch what's being done to a patient. These actions are simply humiliating to that person. (Interview 5)

There are several factors that create space for such violations. Most are structural or institutional (such as improper procedures) or individual (for example a lack of empathy or communication skills). Yet sometimes a shortage of basic equipment may be the simple, yet sad reason:

What can I say when I hear a doctor justifying himself in court, saying that they have no screen [to cover the patient]? Plain and simple. Or that the doors don't close. This is just unbelievable! (Interview 5)

This shows the complexity of the causes behind the violations, which must be considered. It also shows how different elements would have to be tackled to improve the structural context for patient agency and empowerment.

4. Active, passive, alienated? "Let's imagine that…" Checking legal consciousness in simulated interactions

In the survey, I wanted to check respondents' possible reactions and readiness to take action if faced with a violation of patients' rights. This was meant to show to what extent patients' rights are indeed embedded in the legal consciousness. Do they play a significant role in the legal consciousness of Poles? Or are they perhaps substituted by other norms or rationales (see: legal alienation, Hertogh 2018)?

Two situations involving the issues of dignity and privacy were chosen: one with an insensitive doctor in an overcrowded hospital room, and the other with an unconcerned staff member intruding on a patient's appointment. Both situations are quite typical of Polish healthcare. However, they are also subject to numerous legal regulations. The right to intimacy and dignity constitutes Chapter 6 of the Act on Patients' Rights and the Patients' Ombudsman. The right to dignity and intimacy are explicitly stated in Articles 20 and 22, which place the responsibility to respect these rights on healthcare professionals. Other medical staff may take part in any medical procedures only if necessary, and any other persons – only with the patient's and medical professional's consent. Similar regulations are included in other acts, including the responsibilities of healthcare professionals stated in the Act on the Professions of Doctor and Dentist (Article 36) and the Medical Code of Ethics (Article 12). Moreover, the presence of others during medical procedures has been at the centre of litigation concerning respect for intimacy and dignity (see: Paulińska 2021: 89-90).

Dignity and privacy 1

In the first case, the respondents were asked to imagine the following situation: you are in a hospital, in a 5-bed room with other patients. During the rounds, in the presence of other patients in the room, a doctor maliciously criticizes one of the patients in the room for obesity. In this question, the respondents were asked to give their opinions regarding such a situation.

Please imagine the following situation: you are in a hospital, in a 5-bed room with other patients. During the rounds, in the presence of other patients in the room, a doctor maliciously criticizes one of the patients in the room for obesity. How do you judge this situation? Please pick one answer

Table 4. Case study 1, dignity and privacy

	Number	Percent
A doctor doesn't have the right to criticize a patient this way	600	60.0
A doctor doesn't have the right to criticize a patient this way in front of other people	326	32.6
A doctor has the right to criticize a patient this way in some situations	51	5.1
A doctor has the right to criticize a patient no matter the situation	9	0.9
Other answer	7	0.7
Difficult to say	7	0.7
Total	1000	100.0

Most respondents expressed empathy and sensitivity towards the criticized patient, possibly being conscious of the patient's right to privacy and dignity, stating that a doctor doesn't have the right to make such criticism (60%). However, almost 1 in 3 of all respondents thought the doctor's behaviour was wrong only because it happened in a social setting, saying that a doctor doesn't have the right to criticize a patient this way in front of other people (32.6%). This answer was surprisingly high, showing a "keeping up appearances" approach, where what is visible and seen by others (*the form*) is more important than what happens (*the substance*). It also shows an absence of legal awareness of the patient's rights, which are valid independently of context or witnesses.

Fewer respondents accepted the total domination of doctors, allowing them any form and type of criticism in some (5.1%) or all situations (a marginal 0.9%). This attitude is one of yielding entirely to the established (traditional) paternalistic model (see e.g. Emanuel, Emanuel 1992; Beisecker, Beisecker 1993) and hierarchy in healthcare, with all decisions in healthcare professionals' hands, and doctors exercising full control over patients and other medical and non-medical staff. When adding those who allow doctors to behave in any way they choose, as long as this is not done in front of others, almost 40% of the respondents in some way still agree to the traditional paternalistic healthcare order, no matter what social and legal changes challenge it. Interestingly, this is in line with the results of Murgic and her research team, who noted this conflict. "Yet, it is somewhat confusing when, in some jurisdictions like Croatia, on the one hand, medical paternalism appears to be trumped by autonomy, while on the other hand, many individual patients still expect, hope for, and even urge (in both subtle and outright ways) the doctor to be paternalistic" (Murgic et el. 2015).

One must stress that this traditional clinical practice model has been heavily contested and weakened in Poland – through the activities of patients' organisations, legislation, and new institutions (such as the Patients' Ombudsman and patients' representatives in hospitals). Patients' rights constitute one of the pillars dispersing this once omnipotent power of doctors, embodied in the paternalistic model of medicine and clinical practice (see e.g. Komrad 1983). "Respect for these rights can transform the doctor-patient relationship from one characterised by authoritarianism to a partnership and simultaneously improve the quality of medical care" (Annas 1989: xiii). Their introduction contributed to the growth of patients' autonomy, widely recognised since Beauchamp and Childress (2019) published their "The Principles of Biomedical Ethics" in 1977. They helped transfer the agency and empowerment to patients and their loved ones (see e.g. Murgic et al. 2015). This translates to a shift away from the paternalistic model to one where patients' decision-making constitutes the pillar of medical care – certainly formally, and at least to some extent in real-life medical situations.

Dignity and privacy 2 – reactions

The second case referred directly to dignity and privacy in a clinical environment. Respondents were to imagine a situation where they were examined, not fully dressed, by a doctor. A receptionist enters the consultation room and pursues a lengthy conversation. First, the respondents were asked if they would react in any way. Over two thirds (67.8%) would, while 30% would not react in any way. This shows extreme passiveness, especially as no reactions were specified; it is probably guided by fear and consent to any behaviour by the medical staff (again, presumably mostly doctors). For this large bulk of respondents, it takes priority over any feelings of dignity – not yet taking the form of legal consciousness here.

Please imagine the following situation: you are being examined, not fully dressed, by a doctor. A receptionist enters the room during the consulta-

tion and starts a lengthy conversation with the doctor. Would you do anything in such a situation?

Table 5. Case study 2, dignity and privacy

	Number	Percent
Yes	678	**67.8**
No	300	**30.0**
Answer denied	22	2.2
Total	1000	100.0

Those who would react were then asked what specific actions they would take. Multiple, consecutive reactions were allowed. Table 6 lists the initial reactions during the event, as well as actions that would be taken afterwards.

Table 6. Case study 2, reactions to violation.

What would you do? Please pick all answers that you find fitting	Number	Percent
I would ask the receptionist to leave	373	55.0%
I would strongly demand the receptionist to leave immediately	178	40.9%
I would ask the doctor to stop the examination immediately	133	30.6%
I would talk to the doctor or the receptionist after the incident, asking them to avoid such situations in the future	150	34.5%
I would file a complaint against the doctor or receptionist after the incident	61	14.0%
I would consult what to do after the incident	30	6.9%
I would do something else	40	9.2%
Answer denied	1	0.2%

During the incident, the majority of reactions would involve asking (55%) or demanding (40.9%) the receptionist to leave, with a further 30.6% strictly asking the doctor to end the examination. As for the reactions after the incident, again most respondents would undertake non-legal actions and talk to one of the persons involved (34.5%). The only legal reaction would be filing a complaint, which 14% of the respondents (of those who would react at all) declared.

These reactions reveal an awareness that "something is wrong" in such an intrusion, possibly hinting at some sort of legal consciousness of the basic patients' rights involved in this situation. Of course, one does not need to see a concrete legal action undertaken to speak of "legal consciousness". Yet still, any "active" reactions only amount to 2/3 of the respondents, while the rest of them would do nothing at all, and carry on in the situation despite the intrusion.

Table 7. Case study 2, reasons for lack of reaction.

Why wouldn't you do anything in this situation?	Number	Percent total	Percent of answers
It's normal, it's their work	126	**12.6**	**42.0**
What for? It wouldn't change anything	104	**10.4**	**34.7**
I would rather keep my head down, as I'd be afraid of negative consequences	45	**4.5**	**15.0**
Other reasons	25	**2.5**	**8.3**
Total	300	**30.0**	**100.0**

Finally, and very interestingly, let us take an insight into the motives of those remaining respondents, who declared no reaction to the intrusion – hence abdicating their voice and rights. The majority simply saw it as something normal, or "part of the work". This means, similarly to the insensitive doctor in case number 1, that no rights of a patient (seen as an *object* rather than a *subject*) are granted in the healthcare environment, *home* to medical and non-medical staff. Furthermore, they set formal and informal rules, to which patients must adhere without objection. The second answer – not taking any action as it "would not change anything" – showed complete passivity and renouncing any agency (34.7% of the non-reacting). The third group (15%) admitted to being afraid of possible future consequences, showing intimidation and full obedience towards authority.

5. In search of what? Reasons for patients' activity

The interviews showed a complex net of reasons that patients manifest in the area of patients' rights and their violations. By searching for motives for actions undertaken, we could distinguish the two most visible paths. First, and possibly in line with popular beliefs, the active patients are those with financial motives. This attitude finds its extreme capstone in what could be coined as a "demanding patient". This attitude involves excessively high expectations towards medical professionals, coupled with very high levels of criticism and scepticism towards their decisions and reasons.

It used to be that what a doctor said was almost sacred. And now patients have doubts about the diagnosis and methods of treatment. I've had many patients coming to me saying that they haven't had this or that examination.

Because somebody told them so or they read it on the internet. And then we have it checked and it turns out that this particular examination could not be ordered for their condition. (…) This demanding attitude has a financial link. I have patients who come and tell me that they suffered no bodily harm, but they believe that a medical error was made. For example, they were kept in hospital for two weeks too long, so if they can get some money for it, then why not. (Interview 6)

I don't keep statistics, but I think it's about 1/3, maybe 1/4 of cases that I get when a patient is right. And it's still a long road from being right to me recommending litigation. (…) out of this majority of those who are not right, these are for example people who have objections about their 93-year-old grandmother's resuscitation, which they think should have lasted 10 minutes longer. Those types of cases. I wouldn't like to call them money diggers. But sometimes it is so, that the legal consciousness of patients' rights has shifted to another area, where people wonder whether they can make money on something. (Interview 4)

Despite some money-driven patients or families, the financial motives seem to be overshadowed by the more altruistic motives of seeking justice and not allowing things to "happen again".

From my perspective, financial expectations are not at the forefront. Often patients come with a case and say: "I don't want this to ever happen again to anybody, I wish nobody to experience it. So much pain, so much suffering, unnecessary medical visits". They seek justice, not really understood in financial terms. But these legal instruments are imperfect, and the law is actually about compensation – both symbolic (proving their point, apologies) and financial. (Interview 2)

Moreover, alongside the key motive of seeking justice, seeking the truth also emerges as an important factor. This encompasses knowing and understanding what happened, where intuition points to a violation of patients' rights.

They want to know the truth, what really happened. They often want to ease their conscience – or their family's conscience. (Interview 5)

These motives are often related to a common problem in Polish healthcare, also stressed by most interviewees, namely that of communication issues. Doctors do not speak to patients (or their families), and spend little time or effort discussing their condition or possible treatment. "They might also lack the ethical and social competencies and skills necessary to practice genuine patient-oriented care" (see: Róźyska et al. 2022). There are several possible reasons for this, starting from lack of time and being overworked amidst staff shortages, through lack of proper communication training, and a reluctance to discuss medical issues with laypersons. This is supported by reports on the experiences of European patients with their primary care doctors (OECD/European Union 2016, 2018, 2020). The reports showed Polish doctors as the worst in Europe in terms of respect for patients' autonomy and communication with patients. Primary care patients are rarely involved in decision-making regarding their care and treatment (47.9%), even more rarely are they allowed to raise concerns or ask questions about their medical condition (33.6%), while their primary care doctors do not spend enough time in consultation (59.6%).

> *How can a doctor, who works in three places every day, not violate patients' rights? He should inform a patient properly. Listen, instruct, explain. How can he do that having 30 or 40 patients a day in a private clinic? How do you imagine that? He might be a very good specialist, but the time and conditions in which he works don't allow him to do it. (Interview 5)*

6. Lack of communication in an environment saturated with power relations

The interviewees saw the lack of or limited communication as a major problem that could be resolved by a respectful, even short talk at the medical centre. This supports other research results, which show that a main problem among doctors lies in their communication with patients (see: Różyńska et al. 2022). This indeed constitutes a major problem, as the survey showed that patients' expectations actually involve being able to discuss problems with medical professionals. If they are not – which is often the case – this leads to the escalation of problems and legal actions, which could be avoided.

> *I feel that those issues of dignity, on the levels of communication or mutual respect, are not resolved in a hospital or medical centre. This triggers legal action. (Interview 2)*

In many interviews, this was shown as a simple and very effective solution, which would stop many future legal actions.

Not all, but many doctors don't have the time or are unwilling to speak to a patient. This results in patients seeking redress. If doctors had spoken, if they had spent some time and talked to family or the patient, I guarantee you that at least a quarter of cases would have never made it to court or prosecution. But they don't, and it is often simply a case of rudeness... That's the grey Polish reality. (Interview 5)

When I meet a patient who is determined to go to court or report a suspected offence to prosecution, they are practically always situations that in my opinion could have been resolved at the hospital level, by their patients' rights representative. (Interview 2)

An unequal struggle and power relations

Patients who decide to pursue legal action face a very long, costly, and bumpy road of litigation. Moreover, they lack the basic legal and medical knowledge and financial resources – while having experienced the physical and emotional hardships of medical proceedings that somehow went wrong. The struggle is very costly, which is especially visible in civil litigation.

We've had this one case, going on for five years now, concerning a child. And all court experts here have declined, pleading acquaintance with the defendant. So, we had to invoke an opinion of a German medical institute. And the court said ok, but it will cost 40,000 euros. We're in a good situation as we are exempted from court costs here [which is not always the case – Author] but imagine a situation where a person is not. They pass, as they can't afford it. Who can afford a medical opinion for 40,000 euros? (Interview 5)

Despite being presented with the worst-case scenarios for litigation, patients – as lawyers' clients – are still taken by surprise by the length and burdens of court proceedings.

It is an unequal struggle. Frankly speaking, even from my point of view, it's frustrating how long it all takes. Waiting 7 years for money... Let it be 100,000 zl [25,000 euros]. How much is it worth after all those years? A third? (Interview 5)

The costs and length of litigation often discourage those who approach lawyers with their patients' rights-related problems. Some lawyers are very open in presenting the possible future costs – financial, emotional, and temporal – of litigation to their clients:

> *It's usually the family who's fighting. It's an unequal struggle. These are usually people who are not well-off, and without money. And they have to stand up against the whole system. That's why we recommend starting with the Ombudsman, starting with the prosecutor's office. Why? To gain credibility. We don't have enough resources, or access to specialists. (Interview 5)*

The interviewees portrayed court proceedings as a whole as a risk that needs to be taken. At stake is not only money but also the longevity of the proceedings, and vested emotions need to be considered. This corresponds with data that show how patients succeed in less than half of all medical cases in Polish courts (45% according to research of 312 medical court cases conducted by Tyminski and Serocka, 2018, and in 40% of cases according to a report by Budzowska, 2015). Interestingly, Tyminski and Serocka found no settlements in their samples, which shows a "fight till the end" attitude of those who pursue litigation. In addition there is a lack of proper out-of-court compensation systems, generally seen as more efficient and fairer for patients (see: Palm et al. 2020: 367). Moreover, patients' claims are twice as high as the damages and compensation awarded by courts (Tyminski and Serocka, 2018). The average sums (41,000 and 115,000 zl respectively) are well below the highest reported in the media. Therefore, a patient has to be aware of all the possible consequences before they decide to go to court.

> *I've never had a case so clear in terms of evidence that I could suggest a trial, it's too much of a risk. I always have the patients, the clients, decide. I tell them about the options and possible negative consequences. And costs. And it's up to the patient to decide. (Interview 6)*

Power relations dominate patients' experiences in healthcare (Ocloo et al. 2020). Starting from possibly oppressive hospital environments, through interactions with medical and non-medical staff, at least to some extent infused with paternalism, they are still present in actions undertaken in cases of experienced or felt abuse.

However, under the influence of patients' rights legislation and litigation, a shift towards patients' autonomy has been taking place. "Patient empowerment can be an ongoing process, where active patient roles, information and knowledge, and positive, caring communications with professionals can all empower patients within health systems" (Ocloo 2020). It is "an enabling process or an outcome of a process involving a shift in the balance of power" (Cerezo et al. 2016). The key aspect of this autonomy is the assumption and assertion that a patient can make autonomous, informed decisions (see: Hickmann 2022). One of the interviewees delivered an illustration of this change in patients' ability to decide upon their health:

> *It used to be that a patient's health was treated as the highest priority, more important than a patient's will. Nowadays it's indisputable that a patient's will is the supreme right. No matter how we assess it individually, from the legal point of view it simply is. Even if it was more beneficial for a patient to undergo a treatment and they are aware of it and still don't want to, you can't go against their will. (Interview 04)*

The above quote illustrates very well the concept of informed consent as one of the key pillars of patients' rights. However, this shift towards patients' autonomy and free will in decision-making, to a considerable extent triggered by new patients' rights legislation, has found its darker side.

7. The paradoxical results of patients' rights

As noble as the concept of informed consent is, it has to a large extent transformed into an empty idea. Currently, highly proceduralised, it constitutes a vivid example of how patients' rights might only act as shells.

> *You have this example of information. Doctors and hospitals know that patients have more and more claims, so they formalise the process of informing and signing consent forms. And it's been driven to some sort of an absurdity. (Interview 6)*

This development was attributed by the interviewees to lawyers taking over the idea of informed consent. The result was the spread of written forms, in time inflated to an enormous extent, and covering all imaginable risks, consequences, and possible "what may go wrongs". This distances patients from their therapy. Above all, it changes their "informed" consent into an automatic signature, under piles of incomprehensible printouts. All this in a stressful situation, even making the patient feel pressured or coerced. A very experienced patients' rights lawyer reflected on the shift away from *informed* to just *consent*:

> *A trend has developed by which if a patient has been informed about the risks and agreed to them, this shifts responsibility – and in the case of any*

> *complications, the staff are clean. And this has led to consent forms sometimes covering dozens of pages, 50 pages. This is pure fiction. A patient is often under duress and will sign whatever is given to them. (Interview 4)*

"Defensive medicine" (see: Kessler 1994) is another paradoxical outcome of patients' increased autonomy that results from, among others, the dissemination of patients' rights. This increasingly common medical practice means that healthcare professionals depart "from normal medical practice as a safeguard from litigation". In short, it is when a doctor opts for a "treatment or procedure to avoid exposure to malpractice litigation" (Sekhar, Vyas, 2013). This cautiousness may at times benefit patients (with additional, precautionary treatments or examinations), yet it usually exposes them to additional risks (by avoiding procedures and excluding patients from treatments) or needless procedures (here, the contrary – doing all one can to make sure that no questions of neglect arise in the future). In such a way, "*negative defensive medicine* occurs when physicians curtail services to avoid high-risk patients or procedures" (Sethi 2010). The interviewees evoked this concept, mentioning how:

> *Some doctors are simply afraid to make decisions, and this works against patients. They will practice this type of defensive medicine, instead of treating patients properly (Interview 4).[Patients' rights] change doctors' attitudes, they are often afraid, and they quit working in hospitals, but they also improve the way they fill in medical records. (Interview 1)*

Of course, this might be questioned or treated as a justification for poor or uncertain performance. Yet, the phenomenon is well-researched and described globally, making it a real problem for both patients and the system as a whole.

8. Conclusions and next steps

The public opinion survey discussed here was conducted amid the Covid-19 pandemic, while the interviews were conducted in the post-pandemic environment. The pandemic context put healthcare-related problems in the spotlight and centre of everyday life. Health-related topics, including the disease and the virus, tests, vaccinations, and all-changing restrictions, were points of much media interest (see: Polak et al. 2021) and everyday private discussions. All this would seem to make Poles more sensitive towards their rights as patients. However, as the interviews showed, the pandemic and pandemic restrictions did not bring about much of an increase in medical legal actions related to patients' rights.

This research presents a complex portrayal of the legal consciousness of patients' rights in Poland. The survey shows that a large proportion of respondents are unaware of patients' rights, and would find it hard to name any rights that patients have. However, simply having a vague idea that one has certain rights as a patient might constitute a good starting point for further reflection and, possibly, action in the event of experiencing (or perceiving) violations or malpractice. This was backed up in the interviews. The interviewed lawyers presented patients as knowing that something was wrong, but unable to pursue any further actions. In other words, patients were described as knowing that *something* was wrong, but not knowing *what* could or should be done. This leaves room, if not the need, for further examination and learning about one's rights and the paths that they open.

The survey shows that most respondents had not encountered any violations of patients' rights. Again, this raises the question as to what extent being unaware of one's rights played a role here, as a large part of the respondents barely had any idea of those rights just several minutes earlier. However, the vast majority declared most of those same rights as very important for them. From the point of view of legal consciousness, there are a number of contradictions:

- According to the survey, patients' rights are recognised as existing, *but*
- Most patients are not aware of them as they can hardly name any.
- Much importance is given to patients' rights – but the legality (*form)* is not filled with *substance* (a deeper understanding of their rights).
- Many patients know that their rights have been violated.
- Yet their lack of readiness for taking action is apparent; when confronted with violations, patients deliberately suspend their rights in the name of a "more important" good.
- If patients do decide to act, they take a more conciliatory and deliberative approach, and are not generally keen on litigation or official reporting (which could also be part of a broader legal culture).
- This shows legal alienation, even apathy, as extra-legal norms still play an important role and expectations lean more towards apologies than compensation.

The interviews with patients' rights lawyers shed a slightly different light on these issues. Most interestingly, the problem of dignity was widely discussed. It was indicated as one of the most important patients' rights in the survey. Further dwelling on the topic, the interviews showed that violations of dignity are present in practically every medical case.

This leads us to the main motives of *active* patients. And here, perhaps surprisingly, justice and fairness come to the forefront, with altruistic reasoning, which could be summed as "let it never happen again to anybody else". This goes against the initial intuition of patients being money-driven, seeking record-breaking damages that are then reported by the media. Quite the contrary, the active patient was shown as emotionally damaged, lost, and looking more for an apology and the admittance of malpractice than for money. Of course, we cannot forget that the majority of patients never make it to lawyers with their claims, let alone the courts, especially when realistically presented with all the risks on the bumpy litigation road. The above refers to *active patients*, hence a minority of those who declared a willingness to take any action. Contrarily, the survey showed *passive patients*, unable and unwilling to undertake any action even in the face of obvious violations of patients' rights. This is the margin of *legal alienation* that Hertogh so convincingly drew and which contrasts with those who stand up for their rights. Not to mention those who stand up for *the rights* of all patients, who were not the focus of this study.

References

Active Citizenship Network (2002), The European Charter of Patients' Rights, https://ec.europa.eu/health/ph_overview/co_operation/mobility/docs/health_services_co108_en.pdf

Annas, GJ (1989), *The rights of patients: the basic ACLU guide to patient rights,* 2nd ed, Southern Illinois University Press.

Beauchamp, TL, Childress (JF, 2019), *The Principles of Biomedical Ethics* (8th edition), Oxford: Oxford University Press.

Beisecker, AE, Beisecker, TD (1993), Using Metaphors to Characterize Doctor-Patient Relationships: Paternalism Versus Consumerism, *Health Communication,* 5(1): 41-58.

Budzowska J (2015), Poszkodowany pacjent w sądzie i przed komisją. Kraków, https://bf.com.pl/aktualnosci/3751,poszkodowany-pacjent-w-sadzie-i-przed-komisja-%E2%80%93-raport-z-badania

CBOS (2001), Wiedza o prawach pacjenta, BS/70/2001, https://www.cbos.pl/SPISKOM.POL/2001/K_070_01.PDF, 2001

Cerezo PG, Juvé-Udina M-E, Delgado-Hito P (2016) Concepts and measures of patient empowerment: a comprehensive review, *Rev Esc Enferm,* U P.50:667–74.

Council of Europe (1999), Convention on Human Rights and Biomedicine (ETS No 164), https://www.coe.int/en/web/bioethics/oviedo-convention

Diduszko-Zyglewska, A (2020), Wchodzą bez pukania na oddział neurologiczny, ginekologiczny… Kapelani w szpitalach, *Krytyka Polityczna,* https://krytykapolityczna.pl/kraj/agata-diduszko-zyglewska-neurologiczny-ginekologiczny-kapelani-w-szpitalach/

Drozdowska, U (2010), Patients' rights protection model in the Patients' Rights and Patients' Rights Ombudsman Act of 6.11.2008, *Białostockie Studia Prawnicze*. 8: 239-253.

Emanuel EJ, Emanuel LL (1992), Four models of the physician-patient relationship, *JAMA*. 22-29;267(16):2221-6.

Ehrlich. E. (1913), Grundlegung der Soziologie des Rechts, Duncker & Humblot.

European Commission (2011), Directive 2011/24/EU of the European Parliament and of the Council of 9 March 2011 on the application of patients' rights in cross-border healthcare.

European Commission (2014), Patients' Rights in the European Union Mapping eXercise, https://op.europa.eu/en/publication-detail/-/publication/8f187ea5-024b-11e8-b8f5-01aa75ed71a1/language-en

Fundacja Ius Medicinae (2016), Projekt "Prawa pacjenta – Twoje prawa", http://www.ippez.pl/wp-content/uploads/2016/12/analiza_badania_prawa_pacjenta_2008-2013.pdf

Hertogh, M. (2018), *Nobody's Law: Legal Consciousness and Legal Alienation in Everyday Life*. Palgrave Socio-Legal Studies. Palgrave MacMillan.

Hickmann, E., Richter, P., Schlieter, H (2022), All together now – patient engagement, patient empowerment, and associated terms in personal healthcare, *BMC Health Serv Res* 22, 1116.

Horák F, Lacko D, Klocek A (2021), Legal Consciousness: A Systematic Review of its Conceptualization and Measurement Methods, *Anuario de Psicología Jurídica* 31 9-34.

Karpińska, A, Kopański, Z, Strychar, J, Małek, Ł (2016) ,Prawa pacjenta a model współczesnego pielęgniarstwa (Patient's rights and the contemporary nursing model), *Journal of Clinical Healthcare,* 3: 26-35.

Kessler, D, McClellan, M (1996), Do Doctors Practice Defensive Medicine? *The Quarterly Journal of Economics,* Vol. 111, Issue 2: 353–390.

Kozyra, O, Kotlarz, B, Pinocy, M, Majchrzak, M, Podsiadło, B, Achtelik, A, Gatnar, M (2014), Znajomość praw pacjenta wśród pacjentek oddziałów położniczo-ginekologicznych (Patient rights awareness among patients obstetric-gynecologic branches), *Zdrowie i Dobrostan* 1: 23-35.

Krzych, Ł, Ratajczyk, D (2013), Awareness of the patients' rights by subjects on admission to a tertiary university hospital in Poland, *Journal of Forensic and Legal Medicine*. 20(7): 902-905.

Komrad, MS (1983), A defence of medical paternalism: maximising patients' autonomy, *J Med Ethics*. 9(1): 38–44.

Murgic, L, Hébert, PC, Sovic, S, Pavlekovic, G (2015), Paternalism and autonomy: views of patients and providers in a transitional (post-communist) country, *BMC Med Ethics.* 16: 65.

Niemczyk, F (2017), Zakaz wykonywania zawodu, *Magazyn PULS,* 10/2017, https://izba-lekarska.pl/numer/numer-102017/zakaz-wykonywania-zawodu/

Naczelna Izba Kontroli (2018), Pozasądowe dochodzenie roszczeń przez pacjentów, KZD.430.005.2018. https://www.nik.gov.pl/plik/id,18515,vp,21114.pdf

Nowosielska, K (2020), Za błąd lekarza najwyżej milion rekompensaty dla pacjenta, https://www.prawo.pl/zdrowie/najwyzsze-milionowe-rekompensaty-dla-ofiar-bledow-lekarskich,496767.html

Ocloo, J., Goodrich, J., Tanaka, H. et al. (2020), The importance of power, context and agency in improving patient experience through a patient and family centred care approach, *Health Res Policy Sys* 18, 10.

OECD/European Union (2016), *Health at a Glance: Europe 2016 – State of health in the EU cycle*, Paris: OECD Publishing.

OECD/ European Union (2018), *Health at a Glance: Europe 2018 – State of health in the EU cycle*, Paris: OECD Publishing.

OECD/ European Union (2020), *Health at a Glance: Europe 2020 – State of health in the EU cycle*, Paris: OECD Publishing

Palm, W, Nys, H, Townend, D, Shaw, D, Clemens, T, Brand, H (2020), *Patients' rights: from recognition to implementation,* In: E. Nolte, S. Merkur, A. Anell (eds.) *Achieving Person-Centred Health Systems. Evidence, Strategies and Challenges,* Cambridge: Cambridge University Press: 347-387.

Paulińska, M (2021). Prawa pacjenta w Polsce i w regulacjach prawa międzynarodowego w dobie pandemii, *Palestra* 1-2: 80-95.

Pawłowska, E, Perzanowska, K (2017), Respektowanie praw pacjenta w samodzielnych publicznych zakładach opieki zdrowotnej – analiza przypadku, *Zeszyty Naukowe Politechniki Śląskie,* 100/1972: 383-396.

Piątkowska K, Zimmermann A, Pilarska A (2021), Limitation of patients' rights during the COVID-19 pandemic in Poland, *Eur J Transl Clin Med*, 4(1):79-85.

Polak, P., Rudek, T. J., Wagner, A., & Świątkiewicz-Mośny, M. (2021). D3. 2 Country reports on media analysis. In Vax Trust Consortium (Issue 965280) [Deliverable]. VAX-TRUST.

Różyńska J, Zawiła-Niedźwiecki J, Maćkiewicz B, Czarkowski M (2022), Tough Clinical Decisions: Experiences of Polish Physicians, *HEC Forum,* online first.

Rzecznik Praw Obywatelskich (2019) Funkcjonowanie wojewódzkich komisji ds. orzekania o zdarzeniach medycznych, https://bip.brpo.gov.pl/pl/

content/funkcjonowanie-wojewodzkich-komisji-ds-orzekania-o-zdarzeniach-medycznych

Sekhar MS, Vyas N (2013), Defensive medicine: a bane to healthcare, *Ann Med Health Sci Res.* 3(2):295-6.

Sethi, MK (2010), Defensive medicine: "glowing" with pain, *Patient Safety Network.* https://psnet.ahrq.gov/web-mm/defensive-medicine-glowing-pain

Sobczak K, Leoniuk K, Janaszczyk A (2020), Delivering bad news in the perspective of patients' rights, *Pomeranian J Life Sci* 66(3): 31-35.

Tymiński R, Serocka M (2018), Kto i ile płaci za błędy medyczne? Analiza linii orzeczniczej wydziałów cywilnych sądów powszechnych w sprawach o błąd medyczny (Who pays for medical errors and how much? Analysis of analysis of the case-law of civil departments at courts of general jurisdiction in medical error cases), *Ginekologia i Perinatologia Praktyczna.* 3(1): 32–39.

Ustawa z dnia 6 listopada 2008 r. o prawach pacjenta i Rzeczniku Praw Pacjenta (Act of 6 November 2008 on Patient Rights and the Patient Rights Ombudsman) (2008), https://isap.sejm.gov.pl/isap.nsf/download.xsp/WDU20090520417/U/D20090417Lj.pdf

Wierzbińska-Karakuła S., Binkowska-Bury M, Burzyńska J, Januszewicz P (2015), Respecting the Rights and Patient Expectations as a part of the Quality of Health Services in the Podkarpacie Primary Health Care Units, *Przegląd Medyczny Uniwersytetu Rzeszowskiego i Narodowego Instytutu Leków w Warszawie.* 1: 19–30.

Wroński K (2007), Znajomość praw pacjenta przez osoby chore leczone w Klinice Chirurgii Onkologicznej Uniwersytetu Medycznego w Łodzi, *Onkologia Polska,* 2: 75-83.

Wroński K, Cywiński J, Depta A, Bocian R, Dziki A (2008), Czy pacjenci są dobrze informowani o stanie swojego zdrowia przez lekarzy? (Are patients well informed by their doctors about their health?), *Współczesna Onkologia* 12; 5: 234–239.

Wroński K, Cywiński J, Depta A, Bocian R, Dziki A (2009), Przestrzeganie prawa pacjenta do intymności podczas udzielania świadczeń zdrowotnych przez personel medyczny (Medical staff's observance of patient's right to privacy while undergoing medical procedures), *Kardiochirurgia i Torakochirurgia Polska.* 6 (1): 77–81.