

DO WE NEED A LAW ON PATIENTS' RIGHTS?

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There is in Norway consensus across party lines that everyone should be assured of necessary aid when health fails, and that it is a government duty to ensure that this aid is provided, in either the public sector or the private. This unanimity is embedded in legal enactments. Under the Municipal Health Service Act (1982), sec. 1(1), the municipalities “provide necessary health services for everyone dwelling or temporarily staying in the municipality”. The municipal health service includes public health (medical) services and home care and nursing home care. As for hospital medical services and similar or specialist services, the Mental Health Act (1961) and the Hospitals Act (1969) state that the county councils “are to provide planning, development and operation so that the needs of the populations within their areas are covered”.

These general but basic provisions form only part of a quite comprehensive set of legal provisions, directives and regulations of more or less obligatory character which have as their objective to make it possible to prevent, diagnose and treat illness and injury, or to provide care where actual treatment is not possible. The goal of prevention is predominant in the Public Health Act of 1860, which is the legal basis for the activities of the municipal boards of health. The Mental Health Act and the Hospitals Act are rather directly concerned with diagnosis and treatment of illness and injury, while prevention and treatment receive equal consideration in the Municipal Health Service Act (1982), which also, as mentioned, refers to nursing care.

The aim of a number of provisions is to secure implementation of the objectives of the legislation. Moreover, patients have certain protection under rules and regulations not specified in the statutes. Some of the most important of these are:

1. *Technical competence* is required of health personnel in the form of approved professional training.
2. There is a general requirement that health personnel will carry out their work in a *professionally responsible way*.
3. Both municipalities and county councils have the duty of formulating *plans* for solution of the problems and tasks imposed on them under the Hospitals Act, the Mental Health Act, and the Act on Planning of Experimental Activity in the Social Welfare System and the Health Service in the Municipalities (1982) (the Planning Act). Plans following

the provisions of the Hospitals Act and the Mental Health Act must be approved by the Ministry of Social Affairs. Such approval is not required under the Planning Act, but the Ministry of Social Affairs can impose binding requirements on objectives. In this connection one can mention the assumption in the Planning and Building Act (1985) that municipal and county council health plans will be included in the continuous planning activities imposed on these bodies according to the Act.

4. There is a requirement that health institutions and places providing care be *approved* by the Ministry of Social Affairs.

5. The Ministry of Social Affairs has broad powers to issue *directives* regarding almost every aspect of the content of the health services both inside and outside institutions.

6. The Directorate of Health has a statutory *supervisory responsibility* and, as one aspect of this, legal competence to issue binding orders to municipalities and county councils to correct deficiencies in the health services they offer, in accordance with the Hospitals Act and the Mental Health Act, if the activity “is conducted in a way which may be presumed to have damaging consequences for the patients or their environments—or otherwise in an irresponsible way”. An equivalent, and perhaps even more sweeping, resolution is to be found in the Municipal Health Service Act.

7. In order to empower municipalities and county councils to carry out their statutory duties and to assure a more or less uniform level of service throughout the country, statutory provisions are made that the state will provide the health system with *subsidies*. Conditions for the subsidies can be set, and the subsidies can be withheld if the conditions are not met. In a similar context, there was in 1988–1989 a provisional Act regarding the employment of physicians which, among other things, authorized the Ministry of Social Affairs to decide that physicians can be directed to serve in communities or counties where there is a great shortage of physicians.

8. Patients are granted certain *rights*. According to the Municipal Health Service Act everyone “has the right to necessary health care” and under the Hospitals Act and the Mental Health Act everyone has the right to immediate admission to an institution if it is “of urgent necessity”. All health services are free or are charged at only a fraction of cost. It is of crucial importance that patients have the right to examine their own medical records and to have any mistakes in them corrected. Patients who believe that they have been incorrectly treated can lay their grievances before the Public Health Department or the

Parliamentary Ombudsman. Complaint to the ombudsman, to be sure, presupposes that it is a matter of "public administration", but the expression must be accepted as also embracing private health services if the government carries a large part of the expense and the service is part of an officially recognized health plan.

9. The fundamental principle is that examination and treatment are *voluntary* for the patient. Examination and treatment without consent can occur only if there is legal authority for them, and in such cases there are a good many rules which take special care to protect patients' legal rights. Among these are the regulations regarding supervisory commissions in mental health care and the regulations on court trials in the Code of Civil Procedure, ch. 33.

10. Patients have the right to *compensation* if an injury occurs because of fault or because of a technical failure, and also on a non-fault basis following injury from treatment in a hospital for physical illnesses and injuries. This latter right is specified in an agreement recently concluded between the state and the county councils.¹

This enumeration could easily be extended. However, despite the various protections given, a demand for a special enactment on patients' rights is being ever more forcefully put forward by such organizations as the Norwegian Association of Patients and the Norwegian League of Handicap Organizations. The Ministry of Social Affairs has given terms of reference for a special investigator to put forward a draft Act. Do we need such a special Act?

It is tempting to paraphrase Snorre, the author of the old sagas: "Kill me, your Highness, but not with regulations!" In a similar spirit the deputy secretary of the Legal Affairs Department, Mr Stein Rognlien, when the question of protection of rights in the health system came up for discussion, remarked laconically, "If I break a leg, I put treatment ahead of the protection of rights!"

Despite the mass of regulations on rights and the authorities'—admittedly somewhat indirect—rejection of the idea of a separate law on patients' rights, it is clear that the idea is worth consideration. The following discussion will be divided into two main sections. First there will be consideration of what resources should be devoted to the health system and what groups of patients should be given priority. The

¹ The agreement, in force from January 1, 1988, is printed as an appendix to Kirsti Strøm Bull, "Midlertidig ordning med pasientskadeerstatning. Erfaringer etter ett år" (Temporary Agreement concerning Patients' Right to Economic Compensation. Experiences through the First Year), *Lov og Rett* 1989, pp. 243 ff.

question will then be raised of how these priorities can be implemented. Related to this comes the question of whether the establishment of rights is a viable procedure. First, however, some observations on the framework of this paper.

In what follows it will be assumed that the public sector will continue to have the politically agreed prime responsibility for providing the population with health services. In making this assumption the present author takes no position on whether the health system should be conducted under private or public direction (today we have a mixed system). Furthermore, only health services will be considered which involve examining, treating, nursing or taking care of people who are, or think they are, ill. Thus, preventive medicine falls outside the scope of this paper. Not that the preventive health measures are unimportant: it is just that the legal regulation of preventive health work raises different questions from those dealt with here.

The words "ill", "illness" and the like refer here to all physical and mental conditions which can advantageously be treated by medically trained personnel.

A distinction can be drawn between the right to *be* a patient and rights *as* a patient. Here only the first right will be discussed.

WHAT RESOURCES SHOULD BE ALLOTTED TO THE HEALTH SYSTEM, AND WHAT GROUPS OF PATIENTS SHOULD BE GIVEN PRIORITY?

There are great variations among the OECD countries with regard to the size of resources devoted to health services (health expenditure). In per capita health expenditure in 1986, the United States was highest, with almost eight times that of Greece, which was at the bottom of the scale. Norway was above the average, with half the per capita health expenditure of the United States.²

With the exception of the extreme cases, such comparisons tell us little or nothing about how good or poor a range of health services any country has. For such an evaluation, far more detailed information is required on the clinical picture, the concrete use of the health services in each country and other matters. The contrasts reveal absolutely nothing about how extensive the resources devoted to health services

² *Stortingsmelding* no. 41 (1987–88) *Helsepolitikken mot år 2000. Nasjonal helseplan* (Health Policy towards the Year 2000. National Health Plan), pp. 34 f.

ought to be at any one particular time, unless the overriding goal were that the OECD countries should use approximately the same per capita amounts. That cannot be the goal—among other reasons, because of the great differences between the countries. It is true that countries which have ratified the UN Convention on Economic, Social and Cultural Rights of 1966, are obliged to recognize “the right of everyone to enjoyment of the highest attainable standard of physical and mental health” (Article 12). According to Article 2 of the Convention, however, the state’s obligations can be required to be met only *gradually*—“to the maximum of its available resources”. This shows very clearly that varying national health service priorities can be accommodated to international law.

The answer to the question on how extensive the resources allotted to the health system should be must depend on what medical conditions we think the health system should take responsibility for, and how far this responsibility should extend. The answer will express a subjective choice of values, which in its turn will depend on the individual’s views on the importance of the population getting a response to its medical needs, and on what priority the response is to be assigned in relation to other requirements, medical and otherwise. On the whole, these choices will probably work out about the same for many of us—if they are clearly enough formulated. At any rate, the Lønning Committee managed to advance the decision to a priority list with regard to what needs ought to be covered before others.³ The Committee divided needs—and thereby the health services—into five *priority levels*:

The first priority: measures that are *necessary* in the sense that the illness has life-threatening consequences for individual patients, groups, society as a whole, if the measures are not initiated *immediately*. Examples here are acute psychiatry, surgery or internal medicine, treatment of newborn babies, prevention of and preparedness for serious contagious diseases, and preparedness for catastrophes.

The second priority: measures which are *necessary* in the sense that failure or deficiency will have catastrophic or very serious consequences *in the longer term* for individual patients, patient groups, or society as a whole. Examples here are serious and chronic mental and physical illnesses (e.g. cancer, heart failure, psychoses), and care and nursing measures for patients with great chronic need for help, such as persons with severe mental retardation.

³ See NOU 1987:23 “Guidelines for Establishing Priorities in the Norwegian Health Services”.

The third priority: measures with documented effectiveness, where the consequences of failure to act are *clearly undesirable*, without being so severe as under the first and second priorities. Examples here include treatment of persons with moderately high blood pressure, or the common child diseases, uncomplicated hernias, varicoses, and moderate psychiatric problems.

The fourth priority: measures with the supposed effect of promoting health and quality of life, and for which the damaging effects in case of failure to act are clearly less weighty than in cases of failure in measures of higher priority. Examples here are high-technology medicine with poorly documented effectiveness and physical therapy which has no documented effect on severe and crippling illnesses.

Zero-priority: health services which are requested but which neither are necessary nor have clearly documented effectiveness. Here we find, e.g., high-technology medicine without known effectiveness, parts of the school health service, and special offers to sports competitors.

The order of priorities implies that a higher level of coverage must be striven for, the higher the priority; but not necessarily that the higher priority must be entirely covered before any provision is made at lower levels. The higher the degree of coverage within a level, the less becomes the marginal utility of granting further funds to that level, while the marginal utility of granting funds to a lower level can be great, because the degree of coverage here is at present low. Besides, it is clearly easier to accept a lower degree of coverage where a need is given lower priority. Thus a certain waiting period can be tolerated at priority levels 2 and 3 but none or the least possible at level 1. As a rule of thumb one can agree with the Lønning Committee that a higher priority level ought to be covered "to a satisfactory extent" before appropriations are made to a lower priority level.

The discussion has so far concerned an "internal" assignment of priorities of need. This assignment is not decisive for the size of resources to be granted to the total health services. Decisive for this question is how many of the priority levels one wishes to cover to a satisfactory degree. The Lønning Committee assumed that it would be possible to achieve a satisfactory coverage of priority levels 1, 2 and 3 by means of revising priorities within the existing economic framework for the total health system.⁴ If such is the case, this will have especially practical significance for patients with chronic mental illnesses, elderly

⁴ NOU 1987:23, pp. 97 f.

persons requiring nursing or care, and the retarded. All three groups receive too low priorities in relation to a demand for satisfactory coverage on priority level 2.

The Lønning Committee's proposed priority levels have received qualified support from nearly all political and professional groups and in essence are used as a starting point in the White Paper "Health Policy towards the Year 2000—National Health Plan",⁵ which was issued by the government on March 25, 1989. The priority principles are also accepted by Parliament.⁶ The way therefore lies open for working out means of assuring that the value choices that have been made—the priorities—will be effective in practice. The question "Do we need a law on patients' rights?" becomes, in this perspective, a question whether creating a legal right to health services for those groups that have been chosen to have high priority is an effective means of realizing the choices. The discussion now turns to this question.

DO WE NEED A LAW ON PATIENTS' RIGHTS?

In what follows the starting point will be the present arrangement regarding the responsibility of the municipalities and the county councils to provide necessary health services for the population. For the sake of simplicity the term "municipality" will mean both primary municipalities and county councils.

The term "right" to health services will refer to needs which the municipalities are by law obliged to meet. At the *political* level—under budgetary discussion—this means that the expenditure necessary to meet the demands must be entered as so-called committed expenditure in budget items which can, and if necessary will, be exceeded. At the *health service level*—when the health service is to deploy its resources and come to a decision about demands by individuals—it means that the demands will be met, if necessary, by exceeding given appropriations and by the demands being given precedence over other (non-priority) demands.

The main grounds for giving the population the right to health services in this sense must be that it will contribute to realizing approved priorities. As background to a discussion which must also include the

⁵ See footnote 2 above.

⁶ See *Innst. S.* no. 120 (1988–89).

effectiveness of other means of realizing the priorities, we shall first glance at some chief features of the present arrangement and its effectiveness.

The most characteristic feature is the combination of a high-ideal goal at the *legislative level* and a great degree of freedom at the *political level* where general decisions are to be made in order to achieve the goal. In the first place, the municipalities have a legal duty to ensure that the population's need for required health services is met. But consideration of local government shows that this duty, in the main, does not extend further than a point decided by the municipalities themselves. Thus, the duty of the municipalities is not officially required to correspond with individual rights for each person.

In the second place, the state has a statutory duty to subsidize municipality expenditure for health services, but there are few commitments as to the size or purposes of the subsidies. The principal rule is that the subsidy is included in the state's total subsidies to the municipalities. This means basically that the municipalities are not obliged to use the subsidies for health purposes at all, nor for specified health purposes. Even here, then, the consideration of municipal self-government has taken precedence over a national determination of priorities.

The most characteristic feature of the present situation at the *health service level* is the relatively weak commitment about what patient groups will benefit from the available range of services at any one time. As Professor Asbjørn Kjønstad has said, we find ourselves in space without laws.⁷ The Lønning Committee has expressed the same point by comparing the resources of the health system with a reservoir to which thousands of health workers have applied separate drain cocks.⁸ Such a system does not provide any great basis for systematic direction. At any one time it is very difficult to see which plants are getting the most water. That can only be established later.

These features—along with other circumstances—have led to substantial resources being concentrated in quite different areas from those which the legislators and politicians say they have assigned, or wish to assign, highest priority. This is especially clearly illustrated for three groups of patients: psychiatric patients with serious and chronic illnesses, elderly people who need nursing and care, and the mentally retard-

⁷ Asbjørn Kjønstad, "Rett og rettferdighet ved fordeling av helsetjenester" (Law and Justice in Distribution of Health Services), in *Samfunn, Rett, Rettferdighet* (Society, Law, Justice), Oslo 1986, p. 425.

⁸ See *NOU* 1987:23, p. 64.

ed. Although there has for years been a broad political consensus on giving high priority to measures for these groups, nationwide they receive far less help than politically agreed.⁹

The difference between ideals and realities when establishing health service priorities has, of course, many and complicated causes, and it is correspondingly difficult to form firm opinions on what means are effective in reducing the gaps. In the present author's opinion, however, it is quite obvious that a necessary basic premise for creating better correspondence between approved and actual disposition of priorities is that the latter be clearly formulated through decisions binding on all parties. This will necessarily imply limiting the present freedom of the municipalities and the health system. It is self-contradictory to put certain patient groups before others at the national level while giving the municipalities and the health service formal and actual freedom to establish different priorities. Such a step could be defended only if one assumed that the municipalities and the health service would make use of the freedom in accordance with the approved priorities; but, as indicated earlier, one cannot count on this. Thus the question cannot be whether the freedom of the municipalities and the health service must be limited—this belong with the decisions on priorities. The question is: What are effective means for realizing the priorities in practice? Here, five possibilities will be discussed:

1. The health system can be made a direct responsibility of the state, in line with defence, the social security system and the inland revenue.
2. State subsidies to the municipal health system can be earmarked for specified health purposes.
3. Municipal health operations can be subject to state supervision.
4. Complaint and control provisions can be instituted which make it possible to correct mistaken large-scale decisions on priorities and mistaken individual decisions.
5. Rights for patients in the priority categories can be legally specified.

The first possibility, the health system as a direct responsibility of the state, is politically unrealistic in the short- and in the medium-term perspective. However, it is worth reflecting on this alternative. The advantage is primarily that it would be possible, in quite a different way than under current arrangements, to organize an approximately equal range of services to all inhabitants of the country, no matter where they

⁹ *NOU* 1987:23, pp. 60–62.

might live. At present there are differences between the regions and districts in regard to health service availability, inequalities which, significantly, do not correlate with different needs in different parts of the country. One considerable disadvantage of making health service a state responsibility is that political decisions will have to be taken by people who are farther from those they affect than under the present arrangement.

A more important disadvantage, however, is that governmental responsibility does not imply any guarantee that what is offered will be in better accordance with the approved assignment of priorities. A classic but isolated example is the Reitgjerdet hospital scandal in the late 1970s. For many years the hospital's chief physician and the state's chief psychiatrist in the Directorate of Health, among others, had pointed out to their superiors—in the first instance, the Health Director—highly reprehensible conditions at the state's own institutions for especially difficult or dangerous psychotic patients. The main problem was that the hospital did not get the resources absolutely necessary for operating the hospital at a minimal level of technical competence. The investigating commission concluded, without beating about the bush, that a number of injustices towards patients had been committed, including the use of far more coercion than the regulations permitted. The investigating commission provided the following general characterization of medical treatment at Reitgjerdet:

The conditions at Reitgjerdet until the end of the investigation period (i.e. until 1980), with the strict maintenance of watch and a passive existence for the majority of the patients under sometimes very humiliating conditions over many years, were such that one might ask whether the hospital did not to a great degree have the effect of prolonging the illness, or directly producing it, rather than curing it.¹⁰

Thus the state failed to meet the minimal elementary demands one must make on a health service, and especially on a health service forced on the patients. (All the patients at Reitgjerdet were committed, and the average committal period was sixteen years!)

Another example of governmental deficiency over a long period toward an entire group of people unable to perform effectively in society is the state's appropriations for tuition for the functionally disabled. In 1967 Arne Skouen gave his legendary address to the Stu-

¹⁰ *Rapport om forholdene ved Reitgjerdet sykehus* (Report on the Conditions at Reitgjerdet Hospital), 1980, p. 86.

dent's Association in Oslo, "Do We Have Concentration Camps for Children in Norway?" It was the state's special schools he was talking about. The address was the opening shot in a long debate, which revealed a number of reprehensible conditions for our weakest children and youth in state schools. The debate resulted in a change in the Public Schools Act (1969) in 1975, with the main goal of giving the primary municipalities the responsibility for equivalent public school instruction for all pupils, including those in need of special instruction. This exposed the municipalities to increased expenses. The presumption was therefore that the state would cover these by means of earmarked grants under the Act's sec. 38, no. 1, then in force.

It quickly became clear that the state's subsidies were far from adequate to provide equivalent instruction for functionally disabled pupils. The municipalities, led by the Norwegian Association of Local Authorities, then maintained that a municipality had no obligation to provide special instruction exceeding what was covered by the state subsidies. Thus the state failed to fulfil an explicit premise for the reform, a reform which in turn was brought about by state neglect of its responsibility for the instruction itself.

One must of course be careful about drawing general conclusions from historical experience in limited areas. But surely one cannot assume that the state will act more loyally than the municipalities do today in relation to established health service priorities, even if the priorities have been established in legally binding forms.

Alternative no. 2—earmarking of state subsidies—is contradictory to the main principle of broad governmental financing of municipal tasks, where the municipalities receive a total subsidy which is not earmarked for specific purposes. Exceptions can be made, however, if sufficiently weighty grounds suggest them. The question therefore is whether earmarking of state subsidies is a necessary and effective means of covering the needs which are given priority.

It is clear that earmarking in itself gives no guarantee of effectiveness. First, the earmarked appropriations must be large enough to cover the high-priority needs but, as demonstrated with the example on special instruction, one cannot take this for granted. Secondly, earmarking will be effective only if one can count on the municipalities' using the subsidies for the earmarked purposes, which is probably not always the case either. Here one can refer to research by the social scientist Jan Inge Hanssen. Investigating how earmarked state subsidies to the social sector in Nordland county council were used in 1977 and 1978, he found that as much as 28% was used outside the social sector, thus

'reasonable minimal standards' ".¹³ One might compare this pronouncement with one that the right to health care "is limited to what finance, access to health personnel and equipment make possible".¹⁴

This leads us to the fifth alternative, namely the question whether the establishment of rights can be considered an effective means of control. First, the establishment of rights is the natural consequence of making definite choices with regard to priorities at the national level, in the sense here used as a starting point, namely that certain needs will be favoured over others. The question then becomes first whether from a legalistic point of view it is possible to formulate resolutions in such a way that they can have a guiding effect on decisions made at a political level and at a health service level. Sometimes one sees statements that it is difficult if not impossible to formulate the conditions and contents of demands for payment-in-kind precisely enough to provide any significant guidance. For example, the Social Welfare Act Committee alleged that the question of who is entitled to social services "had in that case to be described in very general terms. This would imply also that one could not state what the individual can demand".¹⁵ This is too categorical. It is not difficult to find examples, in public law as well as in private, of statutory provisions which give the parties rights but which are very imprecisely formulated. Of course it cannot be desirable to have very imprecisely formulated regulations about rights, but linguistic limitations ought not to lead to a failure to establish, in terms of rights, requirements whose fulfilment we believe is so important for the general public that they should be rooted in legislation. But will the establishment of rights be an effective means of control?

One cannot give any simple answer to this. To what extent regulations on rights will be observed in practice rests on a number of circumstances beyond the judicial contents and formulations of the regulations. In closing, a few words will be said about this.

EFFECTIVENESS AND THE ESTABLISHMENT OF RIGHTS

Politicians and health service administrators make a number of choices as to which groups of patients will get what. The art lies in preparing the conditions in such a way that the actors make their choices in accord-

¹³ *Ot.prp.* no. 66 (1981–82), p. 32.

¹⁴ *Ot.prp.* no. 66 (1981–82), p. 31.

¹⁵ See *NOU* 1985:18, p. 70.

ance with the approved priorities. It is clear that the establishment of rights in itself implies no guarantee that "approved" choices will be made. Historical experience—some already mentioned—has taught us that. On the other hand, the establishment of rights will certainly be a contribution in the right direction. But what more is needed?

It is crucial that the resources for health goals are adequate and are so composed that priority needs can be met. In the present system the appropriations are provided in addition to the municipal budgets. The municipalities have a very limited opportunity to decide the size of their own income from taxes, and no chance to fix the size of the state subsidies. In principle, therefore, it is clear that there are limits on how far the municipalities will, or can, extend themselves in order to appropriate enough to honour the population's rights, including those in the health sector. A major theme in the government's broad financing arrangement is that the municipalities are to be responsible for their own expenditures, whether or not these are mandatory, and thereby be forced to determine priorities precisely and make their own operations more efficient. This is fine, as far as it goes. But one cannot get blood from a stone. The state therefore has a responsibility to ensure that the municipalities have the chance to appropriate adequately for the practical fulfilment of the population's legally established rights. However, one cannot here expect the state to be especially responsive. On the contrary, the state will, on the whole, assert that it is not its problem if the municipalities cannot make ends meet with the substantial subsidies they are already receiving. What must be avoided is that "the solution" to this conflict between state and municipality becomes inadequate municipal health budgets, which is largely the situation today. At the same time, the inadequate budgets by and large, but not always, lie within the framework of the law, precisely because the law specifies no requirements as to the content of the health service. Were rights to be established, a breach would be implied if budgets were not adequate to meet demands based on these rights. It could then be argued on legal grounds as well as on political and moral that the proposed priorities were not tenable. In the final analysis, this implies the possibility of mobilizing the courts. But even this is not enough. We have today well-documented information from many fields—including social and health jurisprudence—that the realization of rights is no automatic consequence of their establishment. Thus it is very important that the shaping of the system of governmental supervision is given serious attention, and also that the patients themselves have sufficiently strong organizations.

This brings us back to the question of one's rights as a patient. If the overriding goal of a new law on patients' rights is to be to reduce the number of "mistakes" in the relationship between the population and the health system, then the greatest gain lies in finding the correct priorities regarding the right to be a patient. A principal reason for the many mistakes being made in the health system at present is precisely that there is too great a gap between urgent needs and available resources in such areas as psychiatry, care of the elderly and care of the mentally retarded. Patients' rights, such as the right to examine one's own medical records, the right to information, the right to competent treatment and the right to complain, cannot be realized in a reasonably effective way within systems where those responsible feel forced to compromise with professional, ethical and judicial standards. Only when conditions are arranged that allow these standards to be followed in practice will rights as an individual patient take their natural and warranted place within a general law on patients' rights.