People and Health

Giovanna Declich

People’s rights in health services: the changing scene

Patients’ expectations and rights, and the defence of their rights, are discussed on the basis of a survey conducted in Italy. The influence of socioeconomic conditions is examined, and the prospects for avoiding infringements of people’s rights in the health services of developing countries are considered.

A range of questions was recently put to providers and users in Italy’s health service, with a view to throwing light on people’s rights in this sector (1). The survey, which covered 15,541 persons and 226 health facilities, was carried out by the Federative Democratic Movement with the scientific support of CERFE (February ’74 Research and Documentation Centre) and organized from a central operations room and 21 regional centres, involving some 10,000 people and 2,400 associations, groups and bodies of various types and sizes.

Raised expectations

By affecting the status of individuals in society, processes of modernization have produced a far-reaching change in health culture, as evidenced in particular by people’s behaviour in relation to health institutions. Among the broad tendencies that have emerged are an increase in the circulation of information on health and a diversification and enlargement of health demand.

Just over 90% of the people interviewed had heard of prevention, 54% possessed publications on health, 81% had seen articles on the subject, 87% knew of specialized publications on health-related matters, and 79% listened to radio or television broadcasts dealing with health problems.

Nearly a third of the people questioned had had medical checkups for purely preventive reasons. Gynaecological examinations accounted for a substantial proportion of these checkups: nearly half the women questioned had had a Pap test, 26% had had an ultrasound scan of the pelvis or breast, and 21% had undergone mammography.

Dr Declich is with the Applied Research Division of the February ’74 Research and Documentation Centre (CERFE), 160 via Flaminia, 00196 Rome, Italy.
For 64% of the people questioned the decision to have a preventive checkup had been theirs alone, without consulting anyone; 11% had acted in the light of information obtained from the press or from publicity and information campaigns; 10% had done so on the advice of a medical specialist; and 9% had acted after discussions with friends or members of their families.

During the preceding two years, 70% of those questioned had consulted their own doctors at least once, 49% had obtained services from public or classified health facilities, and 30% had been to private physicians. Almost a third of those questioned went to their own doctors in response to symptoms of illness, whereas 12–64% treated themselves, usually by taking drugs, the proportion varying with the severity of the condition experienced. One in five people sought help from medical specialists, while one in ten turned to the emergency services. In cases of serious illness it was claimed by 72% of the people affected that they had complied with their doctors’ indications; 28% had not done so, for instance by failing to buy the drugs prescribed or by using dosages other than those recommended.

Infringement of rights

Italy’s national health service has not yet adapted to the increase in and diversification of demand. The health structures cannot guarantee continuity of medical and nursing care, and waiting times for hospital admissions are often longer than the legal limit (over 90 days instead of 15 days).

A conflict is looming between emerging social processes and the old pattern of health care, manifested essentially as infringed rights, harmed interests and frustrated expectations of patients. The threat to health care, accommodation, information and personal respect is clear.

It should be noted, however, that some rights have been only partially codified, for instance the right to services provided by the national health service, many of which are not covered by legislation, and the right to full information, which is frequently mentioned in regional laws or national or regional health plans but is not subject to explicit directives. In order to examine this matter it was necessary to make direct observations in health facilities and to conduct interviews with users and providers of services.

The spread of preventive behaviour, such as the taking of exercise, suggests that health is an increasingly important dimension of personal life.

The first approach to objective assessment consisted in making comparisons with standard parameters, either quantitative, as with the number of beds per toilet, or qualitative but capable of numerical
expression, as with the presence or absence of a pharmacy in a hospital. The standard parameters were divided into those that were prescriptive, i.e., stipulated in national legislation and therefore obligatory, and those that were indicative, i.e., included in guidelines in national regulations or contained in regional legislation or the patients’ charters promulgated in many parts of the country.

The standard prescriptive and indicative parameters had to do with matters such as the following:

- availability of services, e.g., pharmacies, beds dedicated to patients with infectious diseases;
- organization of work, e.g., nurses’ duty rots, team meetings;
- spatial organization and technical conditions of access to health services, e.g., waiting time for admission to hospital, numbers of beds per ward;
- the existence of certain facilities, e.g., lifts;
- hygiene, e.g., number of patients per washing facility;
- food, e.g., meals timetable, provision of glasses, serviettes and disposable plates;
- amenities, e.g., alarm bells, chairs;
- possibility of identifying staff;
- ancillary services, e.g., areas for social life, public telephones;
- privacy, e.g., bolts on toilet doors.

On the basis that fulfilment of the standard prescriptive and indicative parameters meant compliance in at least 90% and 75% respectively of the places surveyed, seven of the former were respected whereas 14 were not, and 25 of the latter were met while 37 were not.

The second approach to objective assessment was to determine the numbers of sentinel events demonstrating infringement of rights, such as mouse infestation in hospital wards, ill-treatment of patients and unjustifiable payments to staff. The events in question are not so much linked to specific provisions of health legislation as to standards of a more general nature, laid down in the penal, civil or administrative codes; also involved are professional ethics, technical and scientific protocols, and respect for the dignity of the human individual.

Some sentinel events were reported by one person in four, such as addressing patients in an improper manner, and making them undress for doctors’ rounds in the presence of other staff or patients. Other abuses occurred in one service in five (for instance, the presence of dirty linen and used dressings in unacceptable locations). Such occurrences are so common that it is doubtful whether they can properly be called sentinel or early-warning events. It should be noted, however, that the revelation of details of patients’ illnesses to third parties by doctors without consent, and harmful comments by health personnel, affect some 200 000 patients annually.

Indexes of infringement were developed for the right to health services, the rights of the person, the right to information, and accommodation rights, with scores ranging from 0 to 10 and account being taken of 83 factors at all levels of the health service, varying from the presence of medical personnel at specified times to the cleaning
of toilets. The final indices were: 5.0 for the right to health services, 3.9 for the rights of the person, 5.4 for the right to information, and 5.7 for accommodation rights. These figures are rather high and the differences between them are not large. The violation of rights in the health service emerges as an important and widespread phenomenon.

**Safeguard**

Although there were widespread infringements of rights, the survey also revealed that a system of social safeguard, non-judicial and non-administrative, is already woven into the fabric of Italian public health. It is activated by signals and complaints from users or providers and tends to counter such infringements. In order to identify this form of safeguard the relevant answers given in 15,000 interviews with providers and users of the national health service were analysed and certain health care facilities were visited periodically.

Acts of safeguard by 6,646 individuals were identified. One citizen in three and one patient in five were responsible for such acts. The percentages of active subjects were highest among people under 50 with high educational qualifications, in communes with populations exceeding 100,000 and in the central part of the country; high figures were also noted for the south as regards patients and in the islands as regards citizens. Eight out of ten providers were active subjects, the highest rates being among the higher grades, such as head physicians and matrons in the major public hospitals, and in the centre and south of the country.

As well as those who complain directly, the social safeguards system clearly also involves the people to whom the complaints are addressed. Among the health care providers interviewed, 82% of doctors said they had received such complaints from users, followed by 77% of nurses, 60% of nursing aides, 74% of technicians and 67% of non-medical graduates (pharmacists, biologists, etc). Members of the public who were interviewed both inside and outside health facilities tended to address their complaints to in-house personnel, such as doctors, nurses and nursing aides. In cases regarded as serious the range extends to people in the health structures who are less directly connected with the services, such as health directors and social workers, and, to a lesser extent, to people outside the health structures. One of the main characteristics of this system is that complaints can be communicated relatively easily to a variety of people without having to go through bureaucratic machinery. In this connection it is worth noting that only one in seven acts of safeguard on the part of patients is submitted in written form.

Complaints are essentially concerned with everyday matters, including hygiene, nursing care, food, accommodation, waiting times and conflict among providers and between providers and users, which cannot be handled in law, by trade unions or by charities, as they nearly always have to be resolved within a few hours.

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With respect to those situations considered to be the most serious by interviewees, the processes set in motion by acts of safeguard were successful or partially successful in one case in three; the time involved only exceptionally exceeded ten days for users.
Social safeguards are apparently a self-regulatory mechanism, although they are not without limitations and risks. They appear to contribute to the manageability of the health service, particularly in the face of mass public defection from the usual systems of safeguards, both juridical and administrative.

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On the question of the human resources available for the protection of rights, special attention was paid to questionnaires completed by 2163 people (out of some 10,000) who collaborated in the study. It was clear that not only single citizens but also a network of organized groups, traditionally classified as charities, were available to safeguard the rights of citizens. It has been suggested that a readiness to mobilize for the protection of rights is a particular feature of the new health culture.

International perspective

Increased demands, infringed rights, and new forms of safeguard might be seen as typical of industrialized societies, where the welfare model, although in crisis, has produced irreversible changes in people’s habits, consumption and expectations.

Concern about rights to specific services, personal respect, health information and even hospital accommodation might seem remarkable when viewed from countries where famine is rife and doctors are extremely scarce. However, where health systems have yet to be built up it is undoubtedly desirable to do so in such a way as to avoid the mistakes of the past. Furthermore, it is increasingly necessary to count on people’s ability to organize themselves so as to protect their rights. This is especially true in countries that cannot provide essential services at all times throughout their territories. In this connection it should be recalled that, in the field of cooperation for development, special attention has been given for several years to the needs of the people in developing countries for health and social services. Finally, it is surely unthinkable today that qualitative and quantitative diversification in demand for goods and services in the field of health, as in other fields, should be confined to the developed world. This would certainly be unwelcome, not least because of the growth of populations in the developing countries and the ever-increasing dissemination of information and cultural influences.

Reference