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# The Quality of Health Services as seen by the User[1]

## 1. Introduction

As suggested, my contribution to this Congress focus on the opinion of the users of health services in looking at the quality of these same services. Quality, apart from being viewed objectively using technical and scientific standards, is also subjective and assessed based on the experience of users, using the personal criteria of perception and judgement.

This is, therefore, a partial and limited perspective of quality evaluation, although undeniably indispensable. Although some progress has been achieved in the quality evaluation of Health systems in recent decades, one of the best processes used was that of asking users for their view and of taking the respective evaluation standards into consideration in processes used. This was done because, frequently, the evaluation standards of users are quite different from those of health professionals, and are therefore decisive for understanding the assumptions that underlie value judgements for both of these social groups to be able to weigh contradictory evaluations against one another.

In medical sociology this question has been given considerable attention and today the view of patients is always taken into consideration and an attempt

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made to understand the assumptions on which their views are based which, of course, depends to a great extent on social background, beliefs and values regarding illness, a cure and the curing agents that prevail in the different social groups. One could go as far as to say one of the topics examined in social studies of health that has been most developed is precisely that of the understanding and priorities shared by the patients, that is, the profane side of medicine and health (Boltanski, 1971 and 1981; Leridon, 1974; Porter, 1985; Waitzkin 1991; Carapinheiro, 1991 and 1995; Hespanha, 1986 and 1987).

From the analytical point of view that gave meaning to these different views that the social protagonists have of health care, a sociological study was done recently, in which I participated with Professor Graça Carapinheiro, and which I will use to deal with the topic of quality health services from the point of view of the user (cf. Carapinheiro and Hespanha, 1997).

On the whole, the aim of this study is to determine the factors that have affected, and still affect, the co-ordination of primary health care with hospital care in Portugal. Patients enter hospital directly without going through a family doctor, there is no regular contact between the family doctors and hospital doctors when dealing with shared patients, patients who have been released from hospital return to their family doctor without any information, thus causing latent conflict between family and hospital doctors, recognised by the patients themselves.

Since several factors can contribute for this situation, a better understanding is required and the determining factors that explain the relative inefficiency of services has to be assessed. To this end, the study involves

research into a) the reason and forms of direct access to hospital care; b) understanding and representation of the health system and, in particular, the family doctor; c) the strategies used by patients for getting around obstacles, respective resources for access and the social differentiation and intermediary agents; d) the circulation of clinical information between primary health care and hospital care and e) the extent of the conflict underlying these issues.

The undeniable practical interest of having a thorough understanding of these problems was recognised for decisions to be made and policies established in the health sector. Such an understanding would help not only to correctly adjust processes for the production and co-ordination of health care, widening the scope and coverage of the work of health professionals, as well as bringing together the structural conditions indispensable for designing innovative models, or even for consolidating innovative experiences currently practised, which encourage decentralising the biomedical model and strengthening the relationship between medicine and society.

Designing these objectives becomes even more important in view of the collapse of national health services in recent decades. This has been undeniably demonstrated in several European countries where health systems in which there is excessive administrative control of health phenomena, illness, life and death have led to suffocating other sources of understanding, means and procedures likely to improve formal health structures. Only through the latter will it be possible to find a practical model capable of promoting authentic decentralisation and democratisation of social relationships and practices in the

field of health, as well as giving rise to new forms of participation and protagonism, and even alternatives for handling this problem.

I will then move on to the results of this study best adjusted to the topic of quality evaluation through the experience of patients.

I will begin by mentioning the aims underlying the study and some of the methods used, and then discuss the results of interviews with patients regarding their experiences with the health services.

## 1. Patient experience of health services

### 1.1. Object and aim of the study

Since this is a study on co-ordination of health services, it focuses, in particular, on the effects of the autonomy of services that provide health care, while at the same time it looks into the expectations and ideas that the user public has on these.

The basic assumption rests on the idea that associating primary care with health centres, and specialist care with hospitals, or suggesting that these dichotomies should be removed, as happened recently in the Portuguese health system, has contributed towards obscuring two structural situations of extreme importance.

The first refers to the different models underlying health centres and hospitals, in terms of their institutional history, their political history, the specific nature of their organisational structure, their professional practices and, lastly, the nature and composition of their global resources.

The second refers to the different social approaches defined by the population as consumers of the health care provided by health centres and hospitals, giving rise to strategies geared towards reducing the inefficiency of system, using different resources available to different groups for gaining access to health care and for overcoming any factors hindering their way. The population selected for this study was that of a rural parish on the outskirts of Coimbra, a city that is one of the major centres of health resources in Portugal. The population studied had a local health unit (extension of a health centre) and it has easy access to hospitals in the city.

Hence the choice of units providing health care made by population and the types of co-ordination that this same population defines for itself, makes this study a model case for understanding the different internal and external structures in the Portuguese health system, in building a model for interpreting the co-ordination between different types of health care, likely to be valid for other regions of the country.

## 2.2 Methods

This research involved the combined use of different techniques, each one adapted to gathering a specific type of information.

The most important component in this study consist of the analysis of how patients moved between the different consultation and medical treatment areas: health centre, hospital, laboratories and auxiliary diagnostic examinations, administrative health services, private consulting rooms and private clinics. Hence the most important source of information has been

precisely that of the reports made by patients, or more precisely, the users of health services. These reports were gathered in interviews and took the form of focused biographies.[2]

Out of 1231 users of the health unit, 19 cases were selected of patients with different experiences in their contacts with different types of health. The reports were prepared using an open questionnaire which left wide scope for the replies given by the person interviewed.

The use of this technique also benefited from the joint use of two other techniques. Firstly, the direct observation and the verbal information accumulated over recent years by one of the researchers, as a family doctor working in the health unit, and secondly, a *contextual analysis,* based on documental information obtained from official statistics, parish records and information in the data base of the health unit.[3]

In parallel to, and co-ordination with, biographies on the patients and the *location monograph*, exploratory interviews were conducted with strategic agents who have political responsibilities in the sector of the region in which the health unit is located, and health professionals were interviewed in the different areas prepared for providing care. A total of 37 interviews were conducted, 20

[2] Focused biographies aim to obtain an exhaustive understanding of specific aspects in the life of those interviewed, by looking at these aspects as they are perceived and at the extent to which they have been experienced, the usual reference being a series of situations linked to a time of illness that has led the patient to several areas providing health care. These biographies aim to record the series of actions and reactions on the part of the patient throughout the process, and for each of these to determine the factors most likely to cause them.

[3] This data base was designed as an extended clinical case history of each user and has been built up since 1991, with the agreement of the actual users, and is regularly up-dated. It is, therefore, a strategic source of information.

of them in the health centres and 17 in central hospitals, and in the Coimbra Institute of Oncology.[4]

Cross checking information on the same object of analysis becomes particularly important when working with qualitative information, as is the case. The reliability of the interviews in reporting the opinions of professionals and the consistency of the experiences of patients is increased and understanding improved with this procedure. The multiplicity of records means that the facts can be better located in time and these trace the experiences of access and use of health services, and also detect the regularity of the social conduct making up these experiences.

To collect information on the social approaches defined by the patients – the only source that we are going to use within the context of this paper – a structured guide was prepared around four different dimensions, considered to be revelant to reconstruct the circuits included in these approaches.

The first dimension was arranged around the detailed description of what the patients experienced in their contact with hospital care, in terms of the approach selected, the agents giving their assistance and who made the select approach possible, the relationship with the services where they were treated and, in particular, the relationship with the professionals most involved.

A second dimension centred on identifying the situations considered most problematic in the circuits followed within hospitals. The aim was to understand the situations that arose most frequently in questions related to administrative

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[4] The interviews covered the following categories: 16 general clinicians and hospital physicians; 10 nurses and 11 administrative staff members. These interviews were conducted at the work site of these health agents, selected for the sample, through a prior request for authorisation addressed to the managerial department of the respective health units.

procedures, meeting basic daily needs or in the involvement of nurses outside the hospital.

A third dimension invited patients to explain the way in which they resolved these situations, in an attempt to understand what tactics, stratagems and skills they used.

Finally, an attempt was made to discover the possible use of other modes of health care production, including the reasons for using such means, the means themselves and the expectations in this type of supply.

## 2.3. Social approaches in gaining access to health care.

**Inventing approaches, building realities**

The information on the ways in which the patients interviewed organise their access to the different levels of health care, and also on the strategies used for gaining faster access, was based on what the patients had to say, preparing life histories for each patient in the random sample used. The main criteria underlying the selection of this sample was to include people who had a history of some form of illness, with many experiences in the public and private sectors providing health care, focusing particularly on the use of hospital care. In meeting this criteria it was possible to analyse the social strategies created to reduce the inefficiencies of the system, bearing in mind the different ways used by individuals to gain access to health care and to overcome any hindrances on the way.

Analysing these life stories revealed the sociological patterns associated with the approach defined by individuals in different circumstances in gaining

access to health care, the use of networks of social relations for resolving difficulties and problems arising in gaining access, the strategic importance attributed to physicians in health centres and hospital physicians and, finally, the way in which they viewed and assessed the health system resulting from their many experiences.

The approaches defined by patients demonstrate the enormous difficulties met in looking for professionals capable of effectively resolving health problems. All reports indicated the lack of continuity between primary health care and hospital care and the intervention of private sector.[5]

On the whole, the approach begins in the health centres with the family doctor. But when symptoms persist and the clinical situation becomes worse, or when complementary diagnostic tests and therapy are required, at the initiative of family doctor, patients are sent for specialist consultations in hospitals, with a doctor`s requisition, or are even instructed by a doctor and given a personal letter to a hospital colleague.

But approaches are also made at the personal initiative of patient, and this initiative can be reinforced by special recommendations made by family members, friends or neighbours, who, in each of these cases, may also be health professionals.

> "(...) This girl said, "Listen, neighbour, I will talk to my boss. He´s a cardiologist and he knows good doctors in the hospital, and he will fix up an appointment for you. He will make the appointment and I´ll tell

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[5] This intervention is brought about for different reasons: voluntary demand by patients (in most cases motivated by the failure of treatment given in the health centre or the failure of hospital treatment); suggestions made by the family doctors, family members, friends and neighbours; or even demand induced when professionals working in the public sector try to shift this demand onto the private sector, particularly to their private consulting rooms or to the private clinics where they practise.

> you which day you have to go there. We can even go in his car. She took us to hospital. That is we were attended to right away. He was waiting for us at the lifts, and he showed us everything. We went to his consulting room and he attended us right away and said "You will have to be hospitalised so that we can do some tests." And he stayed. He stayed in the hospital. We didn´t have to deal with any paperwork at reception, nothing at all. After that it was downstairs in the Out Patients Department. Later on I dealt with his hospitalisation, that is after he was already there. That´s the way it was done..."

On other occasions these approaches arise from a sudden crisis in the state of health or the sudden appearance of worrying symptoms in which the only solution is to go to the emergency department of a hospital, followed by immediate hospitalisation or instructions to go to hospital consultation.

> "(...) One day I was having a bath and I noticed I had a lump in my breast. So I went straight to my doctor and he told me I had to have a mammography done right away by a doctor he knew. When this doctor saw the mammography he told me: "You have a problem and it has to be removed as quickly as possible otherwise it could get really bad!" I took some papers to my doctor right away which he read and then told me to go and make an appointment right away in the IPO (Portuguese Oncology Institute). That was 4 years ago. In 3 weeks I had an operation and my breast was removed..."

Sometimes the approach may be made to the private sector, again using different ways, as mentioned earlier. Beginning with the voluntary demand made to private medicine, the inefficiency of the public system may underline this type of demand:

> "(...) My daughter was born at home and she was just fine. After 3 weeks I noticed when I was giving her bath that she was different. She didn´t hold her head like the others. I took her right away to the emergency department accompanied by my husband. We went on foot. When we got there they asked me where she had been born and I told them at home! Well, Madam, they said, the baby has had meningitis and we can do nothing about it now. And so she was left like that! She had meningitis after 3 days and I hadn´t noticed it. They gave her some medicine but it didn´t do any good and I decided then to go to a private doctor..."

This report shows the inevitability of seeking private medicine when the public health sector shows no hope of resolving this kind of problem, and expressing an implicit disapproval of the material conditions surrounding life, health and illness.

Another approach made in the voluntary demand for private medicine is due to the need to confirm a diagnosis, or decisions and therapy recommended. Generally this expresses a tremendous lack of faith in the practices and decisions taken by health professionals and decisions taken by health professionals when this is done in a hospital. The patients interviewed expressed a general lack of faith in the hospital and a general belief that they would be better attented by a private doctor.

> "(...) When I kept my appointment to have my breast examined one of the women there advised me to go to a gynaecologist because there is always a chance. That´s why before I had the operation I went to a specialist outside, who was also a surgeon in the clinic.

> That´s where I went for an appointment. And he said he would operate me there, but it would cost quite a bit, and after all there was no need, because the other doctors were good. So I remained where I was. But it was only because of that anxiety. People do not believe in hospital because we are not attended to as we would be by a specialist outside the hospital..."

But there are cases where the demand for private medicine is justified by the failure of the services provided by the family doctor.

> "(...) I was seeing the family doctor. Then I got these spots on my face and he recommended a creme and I didn´t want to be always complaining so I didn´t bother to go back too often! I kept going but the creme didn´t do anything. Then he gave me another prescription. In the meantime my skin began to flake off, just like burnt cloth. People began to tell me to go to a dermatologist and to see Dr. So-and-so who was from the same village and who didn´t normally charge anything. Then I went to him and he didn´t charge me anything, but he made me an appointment at the hospital..."

Cases were also detected in which the family doctor had suggested a consultation with a specialist colleague to fully confirm the therapy to be used, or where the need for private medicine is based on bad experiences in the hospital.

There were also reports made by patients of occasions when doctors had clearly encouraged patients to use their services not in the public sector but in the private sector:

> "(...) I went to this doctor whose name I won´t mention and he said "Madam, your eye is in a very bad state, you will have to have an operation as soon as possible, but only in the clinic because in the hospital it will take a long time." I said, "I will have to speak to my husband before I can decide anything but this is probably going to be very expensive!" At this point he told me that it would cost around PTE 300,000. Then the second time I went to him he told me that it would be closer to PTE 500,000 in a clinic in which he also operated. Having the operation in the clinic where he was also a private consultant, or in the hospital, wherever, he still earns the money. Then I spoke to my husband and he said that it was indeed a great deal of money for those who were poor, and on top of all that he is unemployed..."

There are patients who openly use private medicine because they think it will resolve their problems more quickly and efficiently. They also think the health centre can be used for "small things", such as controlling weight and blood pressure, getting a doctor´s certificate to be off work and medical attestations. This is what the patient who gave use the following report thinks:

> "(...) Right, well the problems are psychic. This has been going on for more than 5 years, or thereabouts. So I went to private doctor and he has been following my case since then. Then they stopped having a doctor here so I only came here to get prescriptions and things like that, right? Because this is the place for controlling blood pressure and whatever, and anything else that is necessary, such as the flu, and things like that, so then of course I come here. But for the psychic bit I now have to go to a specialist because I also did two silly things in taking my medication. I went to hospital, all of this because of my life at home, but they recommended this doctor to me

> and I always go to him, and I think he has helped me a lot. I also go to a private gynaecologist, of course I have to go there as well because he has been my doctor for 15 years and since he put in my device I have to be followed up by him, right? And I come here once a month because I am off work. I also go to private doctors because if you go to the welfare sector you spend your whole life there. Although it costs me a bit, that´s the way it has to be..."

This analysis shows the range of alternative health consumption that patients can use in gaining access to health care. Such approaches become irregular, difficult and, even incomprehensible, if we insist on interpreting them using the conventional model for co-ordination between primary and hospital care, politically laid out for the continuity between the two which should complement one another. What this information shows is the extent to which the image of harmony between the different forms of care is false, and the complexity of the web spun by individuals in using health centres, hospitals, clinics and private consulting rooms, with each personal report becoming a separate story made up of approaches driven by the way in which the system works and reaction to the actual system.

The inventiveness of individual rests on the use of some priceless strategies, the case with neighbourhood networks, relative networks and networks of friends and acquaintances, always mentioned in each personal report made as having successfully contributed towards facilitating the approach and reducing the difficulties in specific cases of illness. There is always a cousin or other, a relative, a godfather or godmother or a neighbour, a doctor or a nurse who is a friend, a known hospital administrator, someone

recognising the importance of the intermediary function between need, and satisfaction of the same:

"the doctor who is a friend":

> "I even asked a girl who was working there in the department, and she spoke to the supervisor who was a cardiologist and he phoned up the doctor on floor X who was a friend of his and asked for the patient to be admitted. So he was hospitalised thanks to the intervention of a friend."

"cousins and nieces":

> "It was a niece of mine who works there who made the appointment for me. I also have two cousins employed by the hospital. And one of them is the godmother of my youngest daughter. She made the appointment in the hospital."

"the best man at the wedding"

> "And it was Dr. X who was the best man at our wedding, he was one of the family, his wife is a relative of my husband´s, a direct cousin, and then since he was working in the private clinic he took me to the doctor working there".

"the maid who had an employer who was a doctor"

> "I had another crisis and I was very weak. And Dr. C´s maid, that´s the doctor who treated me later on, said "My dear, are you really feeling that bad? My God, I really don´t like to see you like that! If you like I can get you an appointment with my boss." "Oh, could you really get me an appointment with your boss? So how do we go about this? Won´t he be annoyed about this?" "No, don´t you worry. He´ll take a look at you." And so I went to see him. Well, he was a doctor of this and that! In fact he wasn´t even a doctor, he was a professor!"

"the cousin who was a nurse":

> "My doctor gave me the papers and told me it would take a long time, around a year. I went to my cousin who worked there as a nurse. I got a hold of her and she managed to make an appointment for me right away."

"the would-be cousin":

> "I didn´t want to get ahead of anyone else, did I? So I had to go to her. Someone who works in the Laboratories. Then she arranged that I would get there at 8.30 and so would she, and she would wait for me. Whenever we arrived I was called in, I didn´t even have time to sit down. She´s in the place of my cousin, you see?"

"childhood friends":

> "I went to the ENT trough a nurse, an old friend of mine, and still a friend. We knew one another as children. But I don´t know the name of the doctor. It was a favour."

"the doctor who was a friend of the brother-in-law":

> "My family doctor then gave me the paper to go there and then, I have a brother-in-law who works there and he took the papers and immediately got me an appointment. Perhaps it´s a department where he even has a friend who is a doctor."

"the friend who is a lonely widow":

> "She´s a widow who lives upstairs and lives alone and she has a lot of contacts. She is always ready to go with me. Even today, when I am ready to go, I can´t go without her because she is waiting to go with me. I never went there alone. Even after my breast was removed I was going for treatment, and she goes with me. That´s how it is agreed. She knows several staff members there and even the doctors."

"the nurse who is a neighbour and who became a cousin":

> "I went to speak to this man who is a nurse there: "Look, it´s like this, and there´s no way they can suggest an operation to me!" "Look, don´t worry! I´ll and talk to Dr. So-and-So, he´s one of the good ones, and whatever he can he will do, and what he can´t do, no-one else

> can do. So then you will go and speak to him." He sent me off to get an X-ray right away and then he said "Yes, you are in a bad state! He deals with patients like this, it was a walk-over! It´s a bit busy, but I´ll see what I can do! Say I´m your cousin (it so happens he was only an acquaintance, but the doctor thought he was my cousin) and give him a requisition."

This information gathered on how people begin or accelerate the processes for restoring their health shows that the approaches made, although they may seem erratic, chaotic, disorganised and dysfunctional, are full of social invention. Through them new innovative forms of coordination are created, adapted to a better, faster resolution of health problems for individuals, between health centres, hospitals, private medical consulting rooms. These forms of co-ordination are sometimes skilfully combined with the medical practices on the fringe of the official system, creating and recreating strategic resources for accessing the goods and services of health by using networks of relationships among friends, neighbours and relatives, and even the network of social relations extended beyond the community, which only a few have, but which they rapidly share with other members of the community.

The use of other forms of health care, possibly linked to medical situations, were only recorded in two reports. This lack of evidence suggests that only few patients use this type of approach because when interviewing health professionals on their knowledge of the extent to which patients use medicines and treatment systems outside the range of officially medicine, they say that this does exist, express their opinion on this demand and then give reasons for its use. What might explain the rarity of this type of evidence is the

fact that the patients were interviewed in the waiting room of the health centre. Since this is a place associated with official medicine, it is association with a social invisible but diffuse control, which restricts revelations and confidential evidence on other forms of treatment and cure. Only two patients referred explicitly to such an approach, one case using a witch, and the other homeopathy.

As we can see from the way in which they move in and out of official health systems, individuals seem to be the protagonists in taking social action, something not foreseen in political thinking or in the political action of those responsible for the sector, nor in the representation and practices of health professionals. These forms of social action:

- *By using entirely new forms of co-ordination*, break down the traditional conceptual, functional and organisational dichotomy between primary health care provided by health centres and the specialist care provided by hospitals;
- *Through infringement*, compromise the circuits through which a patient passes between these two types of care, administratively defined and bureaucratically established;
- *Through forms of patient-doctor relationship that vary depending on context,* make it possible for health professionals to be able to perceive and represent the relationships between care, far less as a care that is continuous and complementary, and far more as being a promiscuity of practices and confusion of objectives;

- *Through the experience of multiple contacts with doctors located in the different areas* (hospital, general clinic and public health), the unified view of doctors is destroyed as is the traditional hierarchy of priorities that has presided in the relationship between areas, founded basically on the nature of activities, the content of the work done and in the rules and regulations for exercising the profession. In this process of destruction they expose the differences in professional autonomies and authorities and the chain of structural dependencies arising from this, and they highlight the marginal position of some in relations to others.

We will now return to the question of how patients assess the services provided.

*What do patients think of the health services they use*?

The opinion drawn from the evidence given by the patients interviewed is very severe on the national health service: health centres and hospitals. The criticism most frequently made is that there is a lack of response in due time or the lack of a qualified response, as well as a major lack of co-ordination between services. Assessment of the institutions in the private sector, apart from the exaggerated price, seems to be viewed more condescendingly, but this may be due to the effect of the methods used in this study.

Interestingly, interviews with professionals (doctors and nurses) and the administrative staff of national health service do not entirely contradict this negative image suggested by users. To a certain extent they dedramatise, and

they also try to justify this image, transferring some of the responsibility for the poor use of functioning of services to users while reserving the rest of the responsibility for the State. Of course, there is no unanimity between professionals and other agents regarding the reasons for the shortcomings of the system, nor among the professionals themselves, but this is not the place for going into detail on this subject.

What has just been described clearly demonstrates that patients in their contacts with health institutions implement practical knowledge and adopt a pragmatic attitude which clearly places them out of harmony with the "normal use" of these services. From the point of view of users, the conclusion is that without strategies for getting round the system, and without a certain degree of instrumentalisation of resources, the services provided do not provide an adequate response to needs and expectations.

The most dramatic consequence arising from this conclusion is that violating the regulations underlying the way health institutions function also contributes towards making their deficiencies even worse. These strategies used for getting round the failings of the system, and the instrumentalisation adopted by patients to overcome the problem, then tend to become in themselves a part of this problem.

However, recognising that there is an informal order to the way in which health services function, and that being in order this functioning complies with informal regulations, reforms that are realistic and that take into account the sociological reality of those demanding services might be considered, in

particular evaluating which of these informal regulations could be accepted and made legitimate.

The results of this study should be viewed in this light.

The guidelines for suggested reflection are even more important in view of the collapse of national health services in recent decades in several European countries. This has demonstrated undeniably that health services run on excessive administrative control of health phenomena and illness have led to suffocating others sources of understanding, means and procedures likely to improve formal health structures. Only through these structures will it be possible to use models able to promote an authentic decentralisation and democratisation of social relationships and practices in health, as well as producing new forms of responsibility and protagonism, and even alternatives to managing this problem.

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