HEALTH INFORMATION AND THE ACTIVE PARTICIPATION OF USERS

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PRESENTATION

This publication presents a study carried out by Montserrat Busquets and Jordi Caïs into the current state of health information and the participation of service users in clinical decisions. The study consists of a series of interviews conducted with two patient groups: women with breast cancer, and men with angina pectoris. The aim was to identify whether the information provided to patients and their friends and family with regard to the patient's pathology, and the opportunities for participating in the related decision-making process are satisfactory or not. The authors gave a presentation to a group of experts of the information collected in the interviews, the analysis of this information and the conclusions they drew from it, and this presentation was then followed by a panel discussion. The contributions to the discussion are reproduced in the second half of this publication.

The society in which we live is ambitiously referred to as the 'information society', an expression coined to reflect the remarkable range of sources of information which is now available regarding every aspect of our lives. At the same time, individual freedom and autonomy together two of the basic values of liberal democratic societies, while the principle of autonomy is one of the foundation stones upon which bioethics is built. Within the new paradigm which is being introduced into the clinical relationship, the patient is not a submissive, ignorant individual who turns to the specialist and listens to and obeys whatever the specialist prescribes, but is rather an autonomous individual who wants to know what is happening to him or her in order to be able to participate fully in decisions about his or her body and welfare. Information is the fundamental precondition for the exercise of individual autonomy. A person who is poorly informed or misinformed cannot be master of his or her decisions.

As a result, bioethical research has become increasingly interested in how the demand for patient information is met in practice. The formula of informed consent is one response to this demand. However, it is important to identify what this consists of beyond the signing of a document which has been more or less understood and accepted. We need to investigate how patients and their families perceive the information process, and if they are allowed to participate in something which, above all, affects them. In brief, this study seeks to bring theory and practice closer together, to identify to what degree the theory which talks of autonomous individuals with the power to take decisions corresponds to a practice which facilitates such autonomy rather than obstructing it.

This is not the first time that the Víctor Grífols i Lucas Foundation has tackled the question of providing patients with information. Practical problems of informed consent, published in this series a few years ago, makes available a discussion which had a similar focus to the study being published here. The issue is a broad one, and can be tackled from many angles. Our hope is that by publishing this study we will encourage new research projects aimed at deepening our understanding of the problems faced when providing patients with information, and finding ways of solving these problems.

Victoria Camps
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HEALTH INFORMATION AND THE ACTIVE PARTICIPATION OF USERS

Project financed by the Víctor Grífols i Lucas Foundation for the Development of Bioethics

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Introduction

The study presented here considers health information from the viewpoint of health service users. The central aim is to identify whether, when people are diagnosed with an illness, they receive sufficient information to enable them to understand what is happening to them and to take an active role in the treatment and care process. It takes as its starting point the assumption that people can make choices about and participate in their care if they receive sufficient information and support. Autonomy is defined as the capacity to take responsible decisions about one's own life. However, when people become ill they usually lack knowledge and information, and they therefore need professional help in order to take decisions relating to their health situation, both with regard to health care – such as whether to follow a particular course of treatment or to undergo operation – and in regard to daily life – the need to change or modify habits or lifestyle. The aims of this study are therefore to:

- identify situations which illustrate how the exchange of health information is implemented
- describe the forms of interaction between patients, family members and health professionals, identifying those elements which hinder and facilitate the comprehension of information
- identify the role of families and associations in transmitting information and taking decisions
- understand, from the patients' perspective, their preferences, wishes and problems with regard to the process of obtaining and using health information.

Method

The data was obtained from in-depth standardized open-ended interviews. Twenty interviews were conducted, and the information was then profiled on the basis of two focus group discussions. The study universe consisted of two groups of people with illnesses which have a serious impact on their lives: ten interviews and one discussion group were held for each of the two types of patient. The first study group consisted of women who had had breast cancer for at least one year. Individual interviews were held with ten of the women and five more took part in the focus group. The second study group consisted of men with cardiological problems associated with angina pectoris or heart attack, for a year or more. Individual interviews were held with ten of the men and four more took part in the focus group. The sample was obtained from the Duran i Reynals University Hospital of Bellvitge, the Primary Health Care Service of Cornellá, the Ágata Association (for the group of women) and the Catalan Cardiology Support Association (for the men). The permission of each of the institutions involved was requested, and the authorization of the ethics committee was also sought in those cases where the individual's contact details where obtained as a result of hospital visits. All the individual and group interviews were conducted after obtaining the consent of the participants.

We believe that these are two types of situation in which information plays a central role. These health problems require:

a) That the health professional provide the information which the person needs in order to be able to understand what is happening to him or her, what the available treatment options are, the development of the illness, and the healthiest way in which to perform activities of daily living.

b) That the person takes informed decisions with regard to these issues.

c) That the person modifies (or not) their day-to-day habits and social role.

In a standardized open-ended interview, all interviewees must respond to the same questions in the same order. The interview questions are open-ended, and there are no predetermined response categories. The questions are drawn up as part of the initial planning stage in the light of the study objectives. Each question included in the interview protocol has the aim of collecting information about a particular aspect of the research objectives. This type of in-depth interview, followed by a discussion group analysis, has the advantage of producing a large quantity of varied data which is easy to standardize. It makes it easier to compare responses, and facilitates the subsequent processing of the data so that the content can be analyzed. The results obtained are not statistically generalizable, as they are not based on quantitative tools and they do not therefore have any statistical validity. This does not, however, mean that the results cannot be generalized at all, as in-depth interviews help to identify generalizable trends in people's behaviour which can then be studied on the basis of independent sociological variables such as gender, age, social class, level of educational attainment, or the generation to which the interviewees belong.

The appropriateness of the samples depends on the homogeneity and specificity of the groups, and the possibility of controlling the independent variables. The number of interviews should vary according to the information to be obtained. In this study, saturation point was reached with ten individual interviews and one group interview per patient type. After eight or nine interviews per group, it was apparent that the information was starting to become redundant.

Results[1]

1. The process of obtaining information

Information is essential for people dealing with a health problem. The attitudes of patients and their families to the illness and how they react to it are a major influence on patients' quality of life, and are heavily dependent on the help patients are given in obtaining and understanding information. Health professionals are increasingly expected to give individualized health information, and this is considered to be one of the criteria of professional competency.

There are many reasons for providing health information. From an ethical perspective, these include both bioethical principles and human rights, while a holistic notion of health as a way of living and being in itself provides grounds for encouraging the active participation of the person affected. For all these reasons, individuals need more knowledge about the clinical aspects of their illness and better information about how the condition will affect their daily living requirements. They need to receive ongoing education and support to improve the quality of their daily lives both at the physical and psychological level, and this means that the information and education must be adapted to the individuals so that they can integrate it into their lives as fully as possible. Illnesses such as cancer and heart attacks are clear examples of conditions where the active participation of the patient plays an essential role both in treating the condition and in responding to it as positively as possible. Health service users need to learn how to understand clinical information and take decisions; and health professionals have to learn how to provide this information, bearing in mind that the information can only be put to good use if it has first been understood in each specific set of circumstances.

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[1] Transcriptions of responses given by interviewees are identified as follows:

– In the group of women with breast cancer, individual interview responses are identified by the letter *f* followed by the interview number; and focus group responses are identified by the letters *gf* followed by the participant's seat number in the interview.

– In the group of men with coronary diseases, individual interview responses are identified by the letter *m* followed by the interview number; and focus group responses are identified by the letters *gm* followed by the participant's seat number in the interview.

In the text, the female pronoun is used to refer to nurses irrespective of whether the nurses are male or female, following the recommendations of the International Council of Nurses and of the College of Nurses of Barcelona. In transcriptions, the form used by the interviewee has been respected.

The data set out in this first section relates to how the interviewees obtained information about their illness, and the treatment and care options available to them.

The data from this study supports the notion that providing information is not an isolated, one-off activity performed by health professionals in accordance with where they work and the responsibilities they have. The need to understand the illness and the treatment and care options mean that information is important throughout the entire care process and does not just revolve around an understanding of the medical diagnosis. Patients, health service users and families obtain information both explicitly and implicitly (through behaviour, attitudes and expressions) and all of this builds up an image of what is happening and how to respond to it. We have organized the data around the type of information received, whether it was provided in an adapted, individualized form, and the content of the information.

Information about the illness and the treatment

The service user's rights to receive information and to be told the truth seem to be obvious prerequisites if individuals are to deal with the situations in which they find themselves. This has been reflected in changes to the discourse of professional ethics. And it is also reflected in the fact that citizens, to a greater or lesser degree, demand a helping relationship rather than one of authority; that they demand to know about and participate in decisions which have a fundamental effect on their lives; and at the very least they demand the right to know about what could happen to them.

The importance of information about medical diagnosis and prognosis is obvious. Awareness about what is happening begins with the first exchanges, and how these exchanges are handled helps set the pattern for subsequent relationships. Here we summarize patients' experiences of how the information was initially given. Clearly, giving somebody bad news is far from easy, and even more so when one does not know the recipient well. Interviewees were asked how they had been given the medical diagnosis. From their responses we can see that the specific words – 'cancer' or 'heart attack' - were used quite frequently, although this was generally accompanied by explanations or comments which may in some way have been intended to soften the impact of the bad news.

> *He told me. "It was malignant and I think we've managed to clean it out pretty well, I've left you in a good enough state to do a reconstruction." (f1)*
>
> *First of all they didn't tell me I had cancer, as I'd had tests recently ... In hospital they took a bit out and analyzed it, a biopsy, and they said yes, it's a tumour. Then they told me it was cancer. Whenever I've had any doubts I've been able to ask. (f4)*
>
> *First of all, at my annual medical check-up, the doctor told me that he had seen something but "not to worry". When I went to hospital they confirmed that it was cancer. They told me like that, that it was malignant, that it was cancer, and that the solution was to remove the breast. (f6)*
>
> *He told me: "It's cancer, and it's bad, it's three centimetres and we'll have to remove it. We'll reduce it and do three months of chemotherapy, operation, and three more months. We might do radiotherapy or not, let's wait and see ..." And that's how it was. (f7)*
>
> *It started when I went to my doctor and he saw that I was swollen and said, "You've had angina." (m1)*
>
> *He took my blood pressure and then he said, "You've got angina." (m2)*
>
> *I got the first information from the doctor in the emergency department. He told me, "This has almost certainly been angina." (m3)*
>
> *I went to the emergency department at Martorell. He told me, "You've got to stay in hospital, this is angina." He said, "We've got one hour to reduce the clot that has developed." (m4)*
>
> *The nurse and the doctor told me straight out what it was, none of that performance about how nothing was wrong, just the reality. This could happen, and so could that. I wanted the problems to have a solution, the nurse is the one who should know everything. (f3).*

> People want to be told the truth, even if this can be hard to take.
>
> *For me, how they treat you is important, and if you ask questions then you should be given the right answers and told the truth. If you don't know, then you're just like a robot, you can't contribute anything at all. This is true in general, everywhere, but when you have an illness, they need to explain the operation. That's why I say, if you ask then you should get an answer, the truth is always hard. I don't like lies, and I don't like half lies either, because they leave you in the dark, and I don't like that. (f8)*

When dealing with information we need to take into account the individual's capacity to interpret and/or imagine what is happening. People can anticipate results and imagine what is happening, and the result is that it sometimes seems that the individual is already aware of the information, and that the professional only has to confirm it. This occurs in clinical situations where there is not yet a definite diagnosis or prognosis, when the information has not been received clearly, where there is a prior history or where the diagnostic process is a bit longer. It should also be stressed that people tend to imagine the worst. It may be fear that pushes them towards this prognosis, and it may be that when health professionals have to give bad news, they use this approach (either consciously or subconsciously) as part of their information strategy, so that it is the patient who formulates the bad news for themselves. This operates as a process whereby partial information is offered and requested, with the end objective being the progressive acceptance of the diagnosis.

> *The doctor said, "Well, let's look at what we've got here, we've got the results." I said, "What have we got here? Well, I guess it's cancer." And he said, "Yes, it's cancer." I already knew it. (f3)*
>
> *I went to the doctor's for a check-up, they called me and that was when they told me I had cancer. They told me a little but it's not like if I'm stupid. He told me, "The X-ray hasn't come out very clear and we're going to have to do it again, we're going to take a look …," and then I suspected something was up. Eight days later they called me to collect the results and they told me what I already knew I had. (f5)*
>
> *I don't want stories, in the end you guess what it is, if they give you chemotherapy, they give you one thing and another, and you already know it's cancer. If you go to the doctor today and he says, "We're going to operate," you know it's urgent, an operation that isn't urgent, well you wait five months or a year, but in a case like this they do it quickly because you're in danger and you know it. (f5).*
>
> *When I complained to the doctor about my back pain, he did an MRI and on the 5th of April he saw the damage inside the vertebra. I asked him, "What is it, a primary tumour or a secondary one?" And he said, "Secondary." (f7)*
>
> *He took a sample, and the following morning he called me and said, "You should come with your husband." I said, "With my husband?" That means that it's bad. I already knew; I already knew. (f2)*

One of the features which help us to understand information as part of a wider process of communicating with and relating to the patient are appreciations of non-verbal communication. How we behave, how we move, even waiting time, are indicative and are interpreted. In this respect, two aspects are very significant:

> *When they've got to give you some bad news, they stretch it out. They stretch out the visit, beat around the bush, make you wait, you can already see it. They find it difficult, you realize because of how long they take to see you, if they leave you to last it's like an instinct, when you've been lots of times you already know the protocols and you say, "Bad news today." (gf2)*
>
> *You already know how it's going to go just by watching how they walk, how they look at you etc. … because I'm chronic I know how to read their faces, just by seeing them I know what's happening, if I'm doing well or not. (f5)*

Finally, we record the words of a patient who complained about the abrupt way in which she was given the results of a diagnostic test which revealed bad news which would have repercussions for the rest of her life.

> *They did an X-ray and said, "You're spine isn't right and it's never going to be right, and that's that." (m7)*

Adapting and personalizing the information

The idea that providing information is a process and a means of helping patients forces health professionals to consider, as in any other activity, how to adapt and personalize this information for the specific person and the circumstances in which they find themselves.

When the approach is not individualized, taking into account the specific needs of each person, minor or more serious errors can arise as a result. In our study, after being admitted to hospital for angina, one patient stopped putting salt on his food until he attended some informative talks at his health centre. In hospital they had advised him to watch his diet, and he interpreted this as meaning that he should follow the hospital guidelines: that is, not to eat salt. At the talks, three months after he had been discharged, he learned that unless you have high blood pressure there is no need to eliminate salt from the diet. He explained it like this:

> *For example, salt, it's not good but my pressure is normal and I can eat food with salt. You come out of hospital eating without salt, well if someone doesn't have high blood pressure give them a more logical diet, tell them what they have to do, not what the majority have to do. (m2)*

Sometimes, not personalizing care and taking account of the importance of previous experiences can create confusion with potentially serious consequences. An example of this is the case of a woman who did not attach a lot of importance to the advice to go to hospital if she had a temperature because of the immunosuppressant effect of the treatment she was receiving. Her previous experience at the emergency department, which had been very negative, meant that she didn't go to hospital until the day of her scheduled appointment, despite having a temperature of 38 degrees.

> *Because I had a temperature in the evenings and at the emergency department, well you know, I held on for three days. It was lucky I had an appointment, and they almost got angry with me, but it was just that I didn't want to go to the emergency department again. (f2)*

However, when patients are cared for by a nurse or doctor who is able to provide personalized information, they see this as evidence of professional competence which goes beyond technical skill. In this way, information can help patients to anticipate what is going to happen, allowing them to prepare themselves for it or, at the very least, to deal with it as well as possible.

> *When I came out, the head of nursing explained everything to me, she spent a long time with me. She showed me a colleague who had had both breasts removed, she showed me how they had been reconstructed again. She showed me what they were like and the reconstruction. We called the underwear department straight away. So as not to leave without doing anything. They explained everything I needed. Very friendly, all the nurses were good. They took a lot of interest, took care to explain what I would do after the operation. (f6)*

Content and ways of giving information

We end this section on the process of obtaining information by grouping the data on the basis of the content of the information. One feature which we found again and again was the reference by health professionals to the standard of 'normality' despite the fact that normality is a very personal and subjective concept. It may be that the word 'normal' is used relatively frequently in an attempt to minimize the side effects or to help people resume their daily life. However, from the perspective of health service users or patients the idea of normality is rather different. Sometimes, rather than helping the individual to adapt, this reference to normality focuses attention on the seriousness of the illness and the incapacity which it causes.

> *They told me, "You can lead a normal life." But that's relative because for example I live in Masnou next to the church and to get up there it's all stairs and hills. I remember there were days when I got home and thought, "Well, I hope I get better," because I was completely out of breath, I felt tired. In other words, I couldn't lead the normal life they talked about. (f10)*

> *I developed lots of ulcers, coughed a lot, and of course I asked … they told me, "Look, if you don't have a temperature don't worry, if you've got a cough go to your doctor and ask about that, if you don't have a temperature don't worry. It's normal." (f3).*

> *At the beginning of the chemotherapy you're going up the walls. You feel so awful and that's why you really dread going to the next sessions. If they explained it to you beforehand well, I don't know, maybe it would be better. They tell you it's normal but to you it seems too much to be normal. The first time my legs hurt a lot and my husband helped me, he gave me massages and I know they didn't do anything for me, but I had someone with me. Another thing, at the beginning you urinate a lot, you spend the whole night peeing, and they don't tell you about that either, they say, "Drink lots of water to get rid of the effects." You don't have all the effects, but you don't sleep at all either. (f9)*

We have to remember that situations which are normal and routine for a health professional are anything but normal for the patient. For example, the isolation required for a particular treatment or the use of invasive techniques may be daily events for the professional but may still have a tremendous impact on the person receiving treatment. One patient explained her concern on receiving information about the radioactivity related to her treatment.

> *When it came to brachytherapy, they told me what it consisted of. When I went in, a doctor told me, "Well, tomorrow you'll go to the operating theatre to have some needles inserted. Just now you can be with your family, but once they've put the needles in you can't. In the operating theatre itself they told me, "Well, look, we'll put you to sleep and put in the needles which have the radioactivity inside them. Your family won't be able to come in because of the radioactivity." (f7)*

Another important issue is the preventive value of information. Foreseeable situations should be identified in advance, and this awareness should be used to help patients to know what to do in given situations and to understand what could happen to them. We found informants who told us about experiencing fear or confusion which could have been significantly reduced by information. Some forms of care which are obvious to health professionals are not as obvious to the patient, and good information based on what the individual usually does can be helpful. One example of this is the need for sun protection while undergoing chemotherapy.

> *The last time I was having chemotherapy they told me, you've got to use protection. "Come on!" I said, "the summer's already over, it's not sunny." Then they said you've got to use protection because you're tanned. Of course, I hadn't put*

> *protection on my body, just on my face. You could see from the mark from my watch strap that I'd been in the sun, the nurse pointed to it and said, "You see, that's bad for you," and that's how I knew about the importance of protecting the whole body, all the time. (f9)*

At the same time, we note the positive aspect of information when it is aimed at helping to organize care. Patients have to attend hospital many times, and see lots of health professionals, particularly at certain stages of the process, with the result that ongoing explanations and guidance are very important. Such explanations can also help patients to feel that the situation is predictable and under their control, and this makes them feel more secure and leaves them better placed to deal with their situation.

> *They explain everything and give you a notebook showing all the appointments. You're monitored and you have a diary. They give you that as soon as you arrive … for example, they put down radiotherapy on this day at this time, chemotherapy on this day at this time, doctor's appointment on this day at this time. That way there are no problems at all, it's easy, easy … Then, in the kitchen, in a place where I'll see it, I make a note of all the days. That way you can't get the dates mixed up. (f8)*

> *The nurse of the functional unit explained everything that was going to happen to me, and was very encouraging ... that I could get mouth ulcers, that this or that might happen to me. I've read a bit of the book she gave me. She explained what to do if I had a temperature, how to wash my mouth, if I felt sick … I decided to cut my hair beforehand, but she showed us the wig. They give you an appointments calendar showing everything you have to do and where you have to go. In the morning, analysis, then to this doctor. (f5)*

However, we have found that in health problems where there is an acute, critical phase, such as heart attack, where there is an immediate risk of death, information on monitoring and care linked to daily life is not significant.

> *They informed me when I was discharged. My son went down to get the report and when we got home we read it and knew where we had to go. [The son of the interviewee adds:] "I met the doctor when I went for the papers and I asked her. She said this is the treatment, and nothing else. The information, really, didn't help us. The report was no use at all. (m1)*

> *Well, about the diet, I've always had information about that from my family doctor and the nurse at the health centre. The nurses at the hospital haven't talked about the relationship between diabetes and high blood pressure. They've talked about diet, but not too well. (m2)*

> *They told me, "You go home and here's a pill and if anything happens to you come to emergency, but well … you leave full of doubts because you don't know what's going to happen or what you've got to do. (m4)*
>
> *In the morning a lady I'd never seen before came and said, "You're going home tomorrow," without any more explanations. (m6)*

The psychological process of adapting to the illness is very closely linked to the information content. While the interviewees said they favoured obtaining information first-hand, as we will show later, they also identified the difficulties they went through with regard to their own process of suffering and of coming to terms with their condition. And that's where the problem lies, because suffering is a very personal affair. Knowing what information to give, how to give it, and the best moment for doing so is no easy task. Some people seem not to require a lot of information, and in fact at certain stages of the process they say they don't want information because they do not know how to take it on board. Below are some comments on this issue.

> *I don't feel able to ask about any doubts I have. There are things you'd like to know: Is this going to happen to me again? Am I completely well now? But as you know they don't know that, well you don't ask anything. (f4)*

These comments were made by a woman who had been diagnosed just over a year ago, and are backed up by the following comments from two women who had been diagnosed longer ago: two and seven years, respectively.

> *Because I'm afraid, well I don't ask anything, but the last time they did a bone scan I plucked up my courage and said to the doctor, "They took a bone scan and didn't tell me anything." Before, I never dared to ask. I know it's worse to think something than to know it, but before I couldn't. Once I'm in the thick of it I just go for it, but until then … oh my God! (f6)*
>
> *Until I felt better I didn't ask. At the beginning you just go along with things, that's why it's so important who's dealing with you, you depend on them. Bit by bit you turn back into your old self. (f3)*

Uncertainty about when is the right moment to provide information is explained like this:

> *I want information, but at the right time. That's where the problem lies. They've more or less given me the information when I needed it. Maybe not very clearly, they thought that it would arrive in time and that I would take it in gradually. Some things have become clearer as time has gone on. I didn't need to know anything other than what I was told. And maybe I was wrong there, of course if you don't know, well someone who doesn't know is like someone who can't see. (f4)*

> *When you've got an illness what you're worried about is that you've got cancer. I've always felt that the people who are there are in a better position to know what's happening to me, so they should give you more information, know when to give it to you. I don't know how I would have reacted if at the beginning of the treatment they'd told me I had two dark patches. Instead, at the second session when they told me I thought, well, I'm already being treated for it. That made it easier for me to handle the first session, which is the most difficult. (f6)*

We have found data which indicates that sometimes the individual does not receive the full information. The family member is the one who receives information about possible risks, prognoses or decisions. This means that the family member, in addition to dealing with the emotional impact of the situation, has to take on responsibility for taking decisions. As an example, here is a woman explaining how the decision to have a mastectomy was taken:

> *They operated on the first of December and in the surgical department the information was given to my husband. They called him up to surgery; I had been told that the pathologist would be in the surgery department, so I assumed that there could be something bad and, well, they put the situation to him that there could be a lumpectomy or a mastectomy. Of course, my husband at that point didn't know anything about the issue, and he went with the opinion of the surgeon. He told him, "If you ask me to choose, I would do a mastectomy," and that's what happened. In other words, the information, the impact and the shock were all received by my husband, and I couldn't decide, couldn't even think about it. (f1)*

Or, in the words of the wife of a patient belonging to the cardiology group:

> *They told him it was angina and they catheterized him, they put a stent in the worst bit. They told me about what could happen. They told me we had to wait six months to see if it worked, and if it works there's no problem. (m6)*

Assuming that the family member is in the best position to receive the information and to reach a decision runs a serious risk of not taking that person's own suffering into account. In the group of people with heart attacks the position of family members when the patient is in a critical situation was described like this:

> *The coronary patient, when he's in intensive care, doesn't know anything because he's very ill. You know what's happening but it's not the moment for them to explain too much to you, so it's the family that gets everything at once and that's there on the front line. The family suffers a lot because they see you and know what's happening to you more than you do yourself. They're in the corridor waiting to be told, and that's very hard. (gm1)*

2. Usefulness of the information

In this section we organize the data around how useful the interviewees found the health information to be. From a professional perspective, information is justified on the grounds that a person who is well informed is better placed to participate in their treatment and care. The aim is to build an ongoing relationship between patient and health professionals. However, when health service users are asked about this it becomes clear that, at least at the start of their treatment, they are not concerned with or even aware of the notion of participating with the health professional in their own treatment. It therefore appears that offering accurate information and helping users to understand this is a form of participation, but one which professionals offer to the service users for whom they are caring and not vice versa. Maybe this is just playing with words, but the notion that it is health professionals who participate in improving the quality of life of those suffering from illnesses, rather than it being the patients who participate with the health professionals in their treatment and care, leaves us better placed to help and support patients. We can group together the opinions of patients regarding the usefulness of information on the basis of what they use it for. According to our interviewees, the information can be used to:

- take decisions – often of a vital nature
- face up to and accept the illness
- help them to feel secure and in control of the situation.

Taking decisions

In the first place, providing information enables people to take decisions about their lives in a more responsible way. The information is a tool which allows them to take decisions from a position of greater knowledge. One might think that it is self-evident that a person needs such knowledge before they can take decisions. However, the fact that in the health field it has traditionally been assumed that illness limits the patient's capacity to decide, or even removes it completely, means that this argument has to be stated explicitly. Starting from the basis of a professional ethics which proposes that health decisions be shared between professionals and patients, we asked interviewees about the relationship between the information received and their personal decisions as to whether to accept or reject treatments, surgical operations and diagnostic tests. From the responses given by members of the two groups analyzed, it seems clear that, in their opinion, facing up to a health problem entails having the capacity to take decisions. This accords with the desire to be informed directly, not just about decisions regarding daily life, habits, diet and so on, but also about decisions regarding whether or not to carry out a given treatment or diagnostic test. Some people stated their views in this regard, and explained how the health professionals caring for them had acted.

> *I think it does, I think it does. Information helps you to decide. If someone tells me that I have to have chemotherapy because in my case this and that is occurring and it will be better for the tumour, well that will convince me. I think it is better if they explain the situation to me than if they play it down and say, "We're going to do it just in case." If it's just in case then I'd think about it, because chemotherapy is no laughing matter. (f3)*
>
> *He said I could wait a few weeks but I decided not to, the sooner the better. He said, "If you want to you can wait a month," but I decided not to. He said, "You don't have to have the operation tomorrow, but we've got to operate." (f4)*
>
> *Yes, it's important to have information because you more or less know what's going to happen, even though everyone is different. I was given the chance to choose. He told me after the operation I'd have chemo and he explained why. I trusted him fully, I always trust doctors. But that doesn't stop me asking why it has to be done or stop me wanting to understand it. (f6)*
>
> *I decided, of course I did. I have the right to decide whether I want to or not. They explained things to me carefully. The doctor told me, "Let's see – think about it," but he was straight. (f4)*
>
> *When the doctor suggested breast reconstruction he said, "I've kept the file open in case you want to operate to reconstruct." I asked, "Would you recommend it?" And he said, "That depends on what you think is necessary." (f5)*
>
> *I found an anaesthetist, a woman, who explained what the nine hours of anaesthesia required for the operation meant, because some people say well, let them put me to sleep, but they don't know the risks and I think they should be explained. The anaesthetist asked me if I wanted to do it, and I said I thought not and then she said that the one who had to decide whether to do it or not was me. She explained the possible advantages and risks, that post-op recovery was strongly linked to how you accept. (f2)*
>
> *You can decide when you really know everything and your limitations. I'm very happy that my doctor explained everything. He's always been very caring, for me he's been brilliant. (f7)*

This final comment makes clear the satisfaction which comes from knowing and feeling that one has been properly informed. This consideration was also emphasized by two women who added that, in order for a person to reach the best possible decision, they must be aware of the likely consequences of their choice.

> *It's not a question of them telling you what you have to do, but telling you why. The reason is important so that you know what they're doing with you, what benefit you'll get, what's happening to you. (f1)*
>
> *They say that some patients aren't interested in asking because they don't want to know, but that's not the case with me, I like people to explain things, even if they're difficult, so that I know that I'm doing something for a reason, to achieve something. If I have to take something, I want to know why it's going to be good for me. And I want them to explain in detail what they're going to do to me. (f8)*

Where treatment is rejected, the problem lies in knowing whether the person is taking their decision freely and is fully aware of what they are doing, and therefore how far one should go in helping the patient to better understand the consequences of their decisions. Explaining the clinical reasons for the treatment, clearly and carefully despite the fact that the situation may be emotionally charged, can be of great help to patients in deciding whether to accept or reject treatment. An example of this is provided by the statement of one of the women in the breast cancer group, with a long history of illness.

> *I reached a point where I was very tired and I couldn't go on and I refused any more medication or sessions. That was when the doctor explained what could happen to me if I didn't keep going. That was when he got me, and I'm lucky he got me, I couldn't go on, it was all just too much for me, it seemed as if the treatment was pointless. But he gave me clear information and I saw what could happen to me, he told me the whole truth and helped me a lot. He turned things around so that I could understand, he looked at it from the other side explaining the worst that could happen if I didn't carry on taking the medication and I understood. It depends on how they tell you. (gf2)*

Control

Having information about the illness and being helped to understand its consequences and effects creates a feeling of control which can help patients to adapt to their situation. It is no longer just the illness which dictates the course of events and the patient's life but rather, to a certain degree, patients themselves who, in the light of their clinical situation and their specific circumstances, take charge of what is happening to them. In contrast with the notion that knowledge of the diagnosis and prognosis creates feelings of defencelessness, isolation, denial and helplessness, in our study we found that knowing what was happening and knowing they were being looked after produced the opposite effect. It is precisely this knowledge of what is happening that allows the person to deal with it. In some way, having this knowledge influences the individual's will to live and desire to fight to survive.

> *To the patient: clearly and like it is. Because if they say it's like this, I think you get an idea of what's happening to you and how you have to fight; if you don't know, how can you fight? (m3)*
>
> *I think that if they tell you the truth then it makes you more eager to live. (f4)*
>
> *I think that if they tell you it, if they tell you the truth, you want to live and to fight more. (m7)*
>
> *If you don't understand what's happening to you, how can you deal with it? (f1)*
>
> *It's when they give you the reports and you read them, you see the cancer, the characteristics … you begin to feel a bit calmer. (f8)*
>
> *Now, with the relapse, my daughter looked for information. But she didn't want to give it to me so as not to scare me. I said, "Give it to me, it's daft." I like to know myself, if I know my cancer it doesn't worry me, if I didn't know, yes, I don't know how to put it, knowing helps me. (f6)*

Security

Apart from helping people to make decisions and remain in control of their situation, knowledge also creates a sense of security. Even in the case of bad news, the fact of knowing what it is and knowing that one is being treated and cared for creates a feeling of security. Information helps to keep anxiety and fear in perspective because it makes it possible to rationalize what is happening and, as we have just mentioned, it produces a feeling of control. This sentiment was echoed by our interviewees on several occasions.

> *Information gives you a feeling of security, yes, yes, a lot, you know? Because if not, you don't know what cancer you've got. If you know, it's like a friend you've got to live with and then yes, information gives you security. (f10)*
>
> *However hard it is, you know where you're going, and so you put everything into making sure that however bad it is it works. If you know you put all your will into eating properly, resting, all that kind of thing. (f8)*

> *It makes a big difference to the patient. If the doctor gives him explanations I think you are more committed and you get better more quickly. (gm2)*

> *They told me what the operation would consist of, what treatments they were going to do, that it would be radio and chemo and then I'd have to spend five years being monitored. About the radiotherapy, that it was to get rid of anything that might be spread about. I knew it had to be very well directed because it could affect other organs. I knew why because we had to do a simulation first. Seeing them explain it really helped me stay calm. (f8)*

> *We're going to give you a serum for the bones to see how you respond. In mid-April she said, "I'm really sorry but you're not getting better, on the contrary you're getting worse … we're going to change, your hair's going to fall out … I'll give you chemotherapy and radio…" At the end of October she said, "You're beginning to respond to the treatment." Last week she said, "You've gone down a bit … It looks like it's working and we have to wait and see what. Depending on how you develop we'll see; you've got to go down a lot more." The analysis is to know how my platelets are and how my cancer is. They told me when they did the second analysis, "We've got to do the analysis because we've got to know how your whole organism is doing." (f7)*

> *The nurse, in chemotherapy, the first thing she does is say, "Look, I'm going to give you this, I'm going to put this here, I'll try to cause as little pain as possible, you're going to be here for a couple of hours, I'm here for whatever you need." (f3)*

> *In hospital they warn you when they're going to do something; that way, you know what to expect. For example, they say, "Tomorrow you have to do this test." They say, "After such-and-such a time you can't eat anything." (m2)*

> *The oncologist is very serious but he also makes you feel very calm. He's a good doctor, you know? You've got it [the proof] here next to you, right in front of you. He's also a great psychologist. I realized with just a few words. The radiographer is also very quiet but he says what you need to know, what he knows he has to tell you. for example, if he needs to give you more radiotherapy he says, "Look, we're going to do this because of X, Y and Z." He doesn't say, "I'm going to do this," no, he always explains first. (f8)*

> *I think what the doctor says is gospel. I don't look for information in other places, I give more weight to what the doctor says. The doctor says what and the nurse says how you're going to do it, like this or like that … this gives me a lot of security. (f9)*

By contrast, a lack of information can generate fear and be understood as being synonymous with bad news.

> *At the bone scan I was afraid because I thought, "If they don't say anything it's because it's bad and they don't dare tell me." (f3)*

3. The main recipient of the information

One essential part of this study was to identify service users' opinions about who the main recipient of the information should be. For health professionals a major area of doubt concerns the role of friends and relatives. Indeed, paternalistic behaviour is sometimes defended on the grounds that patients are helpless and need to be protected from further harm, or by arguing that, because family members know the patient best, they are best placed to decide whether or not the patient should receive information and to what extent the patient should participate in taking decisions. However, our interviewees viewed the direct provision of information to the person affected as an advance.

> *I remember that they used to call your family, they'd ask you for the number, call the family and tell them. Now things are more advanced and they tell you, but choosing their words carefully. I'm the one with the illness. If I don't want chemotherapy, they don't give it to me. That's why we're developing and things are getting better. I think you've got to inform the patient, because she's the one who's going to deal with everything, accompanied by her family to help her deal with what's coming. Not that business of informing the family first and letting them decide; no, because one way or another they're deceiving the individual and I think that we're sufficiently grown up, aren't we, to be able to receive information about what you've got and to organize your life. Because if they tell me, look, you've got three years left to live, I want to know because even though it's really hard, I can live those years, I don't know, to the full for example, I want to know. Even though it's very hard. I think it's best if the patient and the family are informed at the same time. (f4)*

> *The treatment, I think that's for you to decide for yourself. I don't think the family should be saying this is right for you and this isn't, not at all. You listen to them but really you're the one who has to decide. If they explain to you properly what it's going to consist of, what it's about, what benefits you can get from it, the family doesn't have to decide, the family can give an opinion, support, yes, that's very helpful, if they support you. My daughter put all her love, all her patience, all her happiness into it when she came to the hospital with me when my husband couldn't; she sat [with me] during the chemotherapy and went through her university notes. I felt really supported by my daughter. And my husband didn't leave my side from morning till night. (f8)*

> *The participation of family members in the information process is important; they help you, but the one who has to decide is the patient, she's the one who has to know what she's letting herself in for, what she's got to do, what can happen to her if she*

> *does something or not. It's the individual who has to decide, because she's the one who has to go through it, in my case it's me. They can advise you, but in my case it's what I say. I don't want to be bossy but when it comes to illness I'm serious. Me on my own, it's my body and I'm me, and I didn't ask my husband if he wanted me to have a breast amputated, no; it's my body. I didn't explain it to anyone in my family, not to anybody. The only people who knew were my husband, my two children, and my mother who lived with us. Nobody else. In my opinion, the more information the better, even though I understand that every patient is different. (f6)*
>
> *I've got to go alone, I haven't got any family. Yes, I've got friends who have offered to do it but I've always preferred to go alone, whenever someone has come with me I've told them, I'm the patient, I'm the one who needs to know what's happening. Not everyone is like that; I've got a neighbour and she always has a companion who receives the information. Another one was going to sign without even reading the form; I told her, "If you do that you're signing your own death sentence, that's your affair." At the beginning you're really affected, but that doesn't mean they don't have to give me the information, and that I don't need to know. (gf5)*

Three interviewees had relatives who had experienced serious illness and had not been given information about it. While they were cautions when it came to criticizing health professionals and relatives who concealed information, they expressed their disapproval of such behaviour.

> *I believe the patient has the right to know, I think so, even if they say it's really difficult for you. My sister-in-law wasn't told because she gets really scared; they more or less told her she had cancer but not how serious it was, but not because they didn't want to tell her, it was her children who said, "Don't tell mum." That's just to give you an example, but I think it's much better to be told. (f7)*
>
> *My brother has cancer of the colon and, what's more, he's got a problem and the thing is he doesn't know the whole truth. For me, there's one thing about his case which I didn't like, and his wife didn't either. The doctor who treated him told him they could operate, and of course if you give someone hope they clutch at straws and my brother is still hoping because that doctor told him they could operate, and in the end it turns out, after they looked at all the information they had, that they couldn't operate and so that doctor then told us [my sister-in-law and me]; we could see that the doctor didn't want to tell my brother. Now, he didn't ask; that's important, too, some people want to know and some don't. Maybe he's not ready; the ones who know are my sister-in-law and me. You know what? I've also noticed that my brother doesn't ask many questions; he thinks "we'll see what happens as things progress;" there are people who don't want to know. I agree that you have to respect that, when I saw on the first day that the doctor was explaining to him and*

> *my brother didn't ask anything else, he just said: "But, can you operate?" For him that was fine. He's not stupid and because he isn't stupid he's working out what's happening. I don't know, but maybe with a bit of help he could talk. (f6)*
>
> *First of all, the person it's happening to should know. My niece's husband died suddenly: he was just told he had a cold, but they took her aside and told her he had no more than three months to live. They didn't tell him. He was very active, 45 years old, within a month he couldn't move. Then he said this must be serious; they misled him. Afterwards, my upstairs neighbour also died of cancer; they also told her she had this and that, but they told her husband the truth. No! Tell the truth to her, even if you can see it upsets her. (f7)*

4. Family participation

Following on from the previous section, another issue we considered was the role of family members. We have organized the ideas collected here around two functions: accompanying patients, and helping them to find information and take decisions.

Accompanying

The role of family members is to accompany the ill person, not to replace him or her. The principle of autonomy is supported by the interviewees, who referred to their family members playing a supporting role, but not replacing them.

> *I want to take my decisions. After three years with the illness I started to share information. (f6)*
>
> *I go to the doctor on my own, I don't want my husband to accompany me; I explain it to him when I get home. (gf3)*
>
> *The information is the woman's, and the husband's too; he accompanies me so that I can understand better, but I'm the patient and I'm the interested party, the one things are happening to. (gf3)*
>
> *I like to be accompanied, but I'm the patient. (f2)*
>
> *The family is very important, but you can't rely on them alone. (f2)*
>
> *My husband asks some things, sometimes; yes, he's taken a lot of care of me. I listen to him but the decision is mine. (f2).*
>
> *My husband accompanies me to the tests, but as I'm the patient, he lets me be the one who talks and asks. (f4)*

Sometimes there is so much information provided during a consultation or doctor's visit that it can be difficult to understand. This is why family members have the role of helping and supporting patients.

> *There's a lot of information to take in, and that's why I came with my daughter-in-law and said, "Make sure you're listening carefully." You can't take in everything in one go. It's the same when they give it to you in writing … I went to the second session and I hadn't read it. (f6)*

And more so when the news is bad.

> *Sometimes my husband asks more than me. Sometimes you can't understand what they're telling you at the time, you just can't. (gf4)*

> *When I had the relapse and they found the lump in my shoulder, then I made sure I was accompanied. I was afraid I wouldn't be able to ask. (gf2)*

> *My husband was with me, and he was shocked too. Although they said it was a malignant tumour, I didn't think that was cancer. I thought they removed it and that was that. I didn't associate the word 'cancer' with 'malignant tumour'. But he understood, he associated 'tumour' with 'cancer'. When the doctor told me I had to decide, I thought "What should I do? I don't have a clue!" But my husband asked him for more advice, asked about the alternatives. I went blank, I don't know why. (f9)*

> *When you go to the doctor, although you know you've got a 50% chance you always think it isn't going to happen to you. When they told me what I had, I didn't know what to say. Then my husband was the one who asked what they advised. (f9)*

Helping to take decisions

Family members have an important role not just in receiving information but also in understanding it and taking responsibility for what happens. Above all at critical moments and in unexpected situations, the relative helps to decipher information, to ask questions and, above all, to search for external information. Although the patient normally insists on playing an active role during the consultation, when there is a range of information or at critical moments, the patient's partner and children are a source of information and help.

> *I never hesitated to ask questions, although of course my daughter helped me. (f10)*

> *My daughter gave me advice, she had studied up about it, she asked. I don't know if it was on the internet or where. (f4)*

> *I asked my daughter. She looked for information, I'm not sure if it was on the internet or at university. (f8)*

> *Yes, my eldest son found it on the internet, when they told me what I had we looked for information, we got all the information about breast cancer and I had the information. (f6)*

> *Your family, above all your wife, is very important, because she's the one who looks after you, at least that's the way it used to be. Maybe it's changing now, but your wife is the one who worries about what you eat, if you walk enough, she takes care of that. Of course, you're the one who has to do it but she helps you a lot. (gm1)*

Specific help for family members

When discussing the role of relatives and information, one issue to arise was the need to provide specific information and care for family members. At times the suffering of family members is not addressed properly. The data reflects the fact that, while the family's role is to support rather than to replace the patient, this does not mean that the family is not important. Often family dynamics alter as people's circumstances and perceptions change. Without minimizing the need to protect the patient's privacy, providing relatives with information and helping them to understand the clinical process is clearly vital both for them and for the patient. Sometimes, patients not only have to cope with their own situation but also need to help their relatives to cope. Within this context, we can see how important it is to explain common emotional reactions, and how treatments may cause tiredness and affect what activities patients can perform.

> *Once, before going to my treatment I said to my daughter, "Come along, you'll like it." Because the people who are around you, they can't understand, how you can be on top of the world and then an hour later you're ready to drop. They find it really hard to understand that. (f5)*

> *Of course, you've got to inform the family, inform them and help them, maybe they should even be called separately and informed directly about what it is. My husband can't accept it and it gets to me. My husband accompanies me to check-ups but I'm the one who has to ask. If he asks it's like we're wasting time. (f10)*

> *I was the one who told my family, I got home in the evening and I said, "I've got to tell you something. I've got cancer and on Monday I start chemotherapy." Before the treatment I didn't tell them because I didn't want them to suffer. They went quiet and didn't say anything. (f10)*

> *It was as if my husband hadn't realized. He was always quiet, I couldn't understand it, he's always accompanied me, but always quiet. No one ever spoke to him either;*

> *of course, I'm the patient. My daughters were the same, it seems they hadn't noticed anything either. You see, they work too. (f6)*
>
> *Well it seems like they're starting to understand, at least my husband. It's a relief because otherwise you're suffering for them and for yourself. (f3)*

Providing information to relatives is not always seen as an integral part of the work, but rather as something which has to be requested explicitly. One of the patients interviewed, talking about her experience when her husband was ill, remarked:

> *No, they didn't explain things to me, they sent you to the waiting room, and if you wanted to talk to the doctor you had to put yourself down on a list, so that he knew that the relatives of this or that patient wanted to talk to him. When I asked questions the nurses said, "You've got to talk to the doctor." (f1)*

In the group of people who had suffered heart attacks, the role of family members was somewhat different as it appears that, above all at the beginning, it is the family which receives all the information about the process. This is not experienced as deception but rather as shared information, in which expectations and prognosis are shared with the patient's wife. This happens during hospitalization. The seriousness of the clinical situation may be one reason for this, as may the gender variable, as in this group the closest family member is a woman. The data obtained from the group of women with breast cancer supports the hypothesized importance of gender as the key variable when a family member receives information, and even when it comes to taking decisions. Some of the women interviewed had husbands who were ill, and although they said they wanted to receive the information when they were the patients, when the patient was their husband, decisions were shared or were taken by the woman.

> *My husband has cancer of the colon and I'm the one who goes, who asks, who takes action … In his case, I'm the one who deals with it. (f7)*
>
> *When my husband went into hospital, I received the information and then gave it to him, or the doctor gave it to him, but first he spoke to me. (f1)*

5. Consent

When giving consent, one of the first requirements is that individuals receive information before taking any decision and that this information is accurate and sets out the different options available. When deciding whether to accept a particular course of treatment, the patient first has to understand what he or she is being asked to decide, and must be able to weigh up the risks, the benefits and any alternatives on the basis both of the clinical information and of the patient's own interests. Indeed, when consent has been given without receiving adequate information it does not really constitute consent. Understanding the perspective of health service users and patients in this regard can help us to identify how such information is actually being provided and can allow us to put forward modifications to this process which are based firmly on the needs of the end user. In our study of health information, we have also looked at health service users' perception of what consent is, in an attempt to identify whether people see the consent process as something which helps them to better understand and decide between the available clinical options; we have tried to discover whether people believe that the consent process has led to improvements in health information, and how useful consent documents have been for them.

Perceived utility

Consent, in the first instance, is understood as the need to ask permission in order to do anything to the patient's body, and this notion of the need for consent for any clinical action comes out clearly in the study.

> *As I see it, if you don't give your consent they can't do anything to your body. (gf5)*
>
> *It means I agree, I've signed lots of them, because I've had several operations. It's when they explain what they're going to do to you and you agree. I've signed consent forms for operations, for everything they were going to do to me. (f6)*
>
> *They say where you're going and they say, "You've got to sign the consent for what they're going to do to you." Well, I don't think it's bad because I think, well, you've got to agree with what they're doing because if you don't want it, if you disagree and say, "Even if I'm going to die, I'd rather die, but I don't want them to do the tests." I don't think they need to hold a pistol to your head so they can do the test. They can't force anybody. (m2)*

One negative aspect which came out was the view of consent as carte blanche authorizing professionals to do whatever they want. Consent is not seen as a means to an end but rather as an end in itself.

> *It's so they can do what they want, because they say what they're going to do and that's it. You sign. (gf4).*
>
> *You sign a sentence. It's like living with a sentence. (gm2)*

Many patients also see it as a way for doctors to cover themselves, either because that is how it has been explained to them or because that is how they have understood it.

> *The doctor said, "I've got to cover my back, we're going to do conservative surgery and if afterwards we have to do more, bear in mind that you can sue me and the judges and all that. (f9)*
>
> *Yes, it's a piece of paper that if I kick the bucket it's nothing to do with them. In other words, if I kick the bucket, they're free, I laugh when I say it but it's true. (f5)*
>
> *Each time they catheterize you they explain the test and you have to sign it. I think it's fine, because if something goes wrong a lot of people blame the doctor, and that's it. Something's happened, the doctor's to blame. And no, there are lots of things, we all have some responsibility and we need to know. (m6)*
>
> *In general there isn't information, in my case it was the secretary. They don't do it to inform you. They do it in case something happens to you. I don't want to say that what they do is wrong, but they don't do it to tell you what they're going to do, it's so that you can't sue, we've got to be realistic. But sometimes the information is a bit formulaic. And of course you sign. (gm3).*

At other times it's seen as one more part of the hospital admission process, due to the fact that this is how the health centre presents it.

> *I don't think I read it. It wasn't the doctor who gave it to me, it was the administration of the clinic. When you go into a private clinic, you go through the administration department and there you sign the anaesthetic form. Downstairs in admin they ask you for consent for anaesthesia and for surgery. It's just one more administrative procedure, that's how I saw it and I signed. (f1)*

Finally, some people are afraid of not being treated if they reject what the health professionals suggest, and they sign while feeling that they are being forced to do so.

> *Let's see, the patient has the right to say no. She has the right to refuse everything and not pay any attention to what the doctor says, but then they send you home. What happens is that when you're ill it's very difficult to decide not to do something if they don't give you alternatives. (f5)*
>
> *The way they explained it, it was so I could consent to everything being done to me, because otherwise they can't work. (f4)*

Implementation

Limiting consent to the process of obtaining agreement and recording a signature as evidence of this is a form of reductionism which we should be careful to avoid. If we take this approach, consent is only required in specific situations where there is a clear risk to life or the potential for undesirable side effects. As a result the consent process is reduced to the act of offering specific explanations in order to obtain agreement without giving due importance to the process of providing information on an ongoing basis. This leads to neglect of the ethical notion of consent, which defines consent as a means by which the patient can remain in control of his or her life even though he or she may be very dependent and require high levels of professional care. Evidence of this approach by health professionals, based more on the process of obtaining signatures than on ongoing information, can be found in some of the accounts of instances where a request for consent was not accompanied by information and explanations.

> *When they operated on me, a few hours before, I had to sign to say whether I wanted a test done, it was a test for a study they were doing. They told me, "You don't have to do it if you don't want to, it's not compulsory, but it could help other patients." I said yes. That was a few hours before the operation. And I signed another form for radiotherapy, after they'd taken my measurements. Not for chemotherapy. They didn't give me any alternatives, they just said that it had to be done. Another time I remember they told me, "We're going to inject a liquid into you and you've got to sign here. It's a liquid so we can see everything better." (f7)*
>
> *In the exertion test the doctor said, "You've got to sign a consent form." He explained the test to me, but not the risks, he didn't say anything. He told me I'd have to get on a treadmill and he'd take the blood pressure in my arm ... and just to keep going as long as I could, when I couldn't do any more I should tell him so he could do whatever. (m2)*
>
> *They gave me written information about everything that was going to happen. They told me this gave consent for what they had to do to me, for where I was going. (f4)*
>
> *On Sunday afternoon they told me, "We're going to catheterize you, which involves this and that, and you have to sign." So I said, "Okay." Four years ago they removed a gall bladder, and they also explained it to me before I went in for surgery, and I had to sign, it's normal. (m5)*

Sometimes consent may even have the opposite effect to that which is desired. It increases the feeling of dependency and helplessness as the patient feels obliged to agree to something which he or she does not understand and of which he or she is afraid. The problem of patients feeling that they give their consent and sign forms without having received information is related to the practice of obtaining consent immediately before tests or operations without giving people enough time to try to understand what it involves and to compare opinions, if this is what they want to do.

> *They tell you to sign a form, they always do that. They said to me, "We're going to operate on you, sign here and that's it." I said, "So, I'm signing my death sentence," because there are lots of words I can't read, because I haven't got time, I just sign and that's that. Nobody informed me. (m1)*
>
> *The most important part of the consent should be the explanation, but it isn't because you don't understand a thing, you don't have enough time to understand what you're signing. (gf1)*
>
> *They don't inform you about what you're going to sign. They say, or at least this is what they've always said to me, "You've got to sign this so they can do the test." And that's all, so I asked, "But does it say about the risks or what?" and then they said, "Yes, do you want to read it?" And I said, "Well yes, I do want to read it." So I sat and read it. I always like to know because if you don't, well. (f2)*
>
> *The first time I went for an MRI nobody explained what it consisted of, and not the second time either. They didn't tell my husband either; when I came out from the tests I read the report. I would say that they don't give information about everything, they say that they're going to put a contrast fluid into you and that sometimes it's poisonous, but nothing more; and I've been to lots of places [mentions three private radiology centres]; they don't give you information anywhere [mentions hospitals], not at the MRIs [mentions a private clinic] that they do every year, no. They ask for authorization to inject contrast fluid because there can be a reaction, but they don't give you a sheet explaining it, and if you agree, that's fine. (f6)*
>
> *They explain it to you but because you don't understand anything they explain it superficially. "Do you agree?" Yes, you know that the people are there to cure you, but you don't understand properly what they want to do to you; you don't get absolutely all of the information. (m3)*

One aspect which is particularly important to study is the question of what happens when consent is given for clinical trials. The feeling of defencelessness is greater because the person understands that what is going to be done to them is not being done for their own good but rather to better understand the progress of the illness and the effects of treatment. To some extent people feel that they are being pressured into agreeing to participate in the trial. Furthermore, it may be that the fact of participating in a clinical trial means that all the information is concentrated in the trial request and that, once consent has been given, there is no follow-up on the information.

> *No, at least I don't' remember them giving me a range of options. He explained that they were doing some research. He told me that they were asking for my consent to look at the treatment. He said, "It's to see how you respond so that we then have more information to work with." I said, "Fine." There were two doctors in the office, mine and the nutrition specialist. (f8)*

> *She asked me if I wanted to take part in the study they do when there's breast cancer. I understood I was going to be a bit of a guinea pig with regard to the treatment, but that in the end it was so that women would get better treatment and so on. (f8)*

> *As I was part of the study I just signed the study, I didn't sign anything else. I read pages and pages … and signed. The form they give you should be easier to understand. They use words you don't understand. It's as if by giving you the form you've been informed. And if you sign you know what happens, you sign it and you don't hear anything else. Then they don't explain anything else. (gf2)*

Where there is a good relationship of trust and the doctor makes an effort to explain, the ethical scope of the consent process is greater, and really contributes to knowing, deciding and choosing.

> *To be honest, the language is a bit technical, I was lucky that my doctor was really great. He explained it in simple words that I was able to understand. Apart from that he did a sketch for me, a drawing of what it was going to consist of, he told me about the side effects of the treatments. He explained the side effects, but I don't remember that very well. He got me to sign a form so I consented to the operation, the treatment and the study. (f8)*

> *The only consent I've had was when they had to operate on me. They made me sign the protocol. The doctor told me, "In principle, we're going to do conservative surgery, but when I open up I don't know what I'm going to find, and then I'm not going to just leave it and sew you up and ask you, so that is really up to my judgement during the operation." That's the only form I signed authorizing the operation and that if there was anything else he had permission to do it and didn't have his hands tied. For me not reading it wasn't a problem, I understood it well, I have complete trust; what's more, I'd had such a bad time, mammography, scans … it had really gone on, I wasn't in any doubt; in fact, when they operated on me, he came out to talk to my husband and my son; he didn't do anything without discussing it first with them. I was also given a consent form for the chemotherapy*

> *and the radiotherapy. Yes, they gave me it for that too. I didn't ask what drug they were going to give me; I already assumed that they knew the scale of the problem and decide what's best for you. (f9)*

One aspect that is stressed is the notion that consent involves much more than just obtaining the patient's agreement in writing. Information must be provided both before and after obtaining consent. The individual must be able to reformulate and reaffirm the information more or less continuously so that they can understand it gradually, on an ongoing basis.

> *Yes, I read everything I fill in, you haven't got anything else to do anyway, you spend the whole day in hospital … Well, I want to know what it is and what they're going to do to me, and say if I agree, which I almost always do because I value the doctor's opinion very highly, so I sign it. If I don't understand everything, if there's a strange name, I ask him or one of the nurses about it afterwards, what's this that I've signed? You can understand it, except for the occasional word like lumpectomy. (f6)*

> *Of course I signed it. I read it and signed it, but then as soon as I could and the nurse came I asked her about what I'd signed. (m4)*

Documents

One issue which still has to be addressed is the design of the accompanying documents: how much information they should contain, and the nature of the language used. We know that some documents are too technical, too long or simply not presented in an attractive manner. The role of the document is to support the oral information and it should therefore be as easy as possible to read and understand. In this regard, we asked whether documents had been understood and whether they helped in comprehending the information received. The first thing that struck us was that some people do not even read it.

> *As far as I can see, people sign things without knowing, of course that's their problem, but they sign without knowing. (f2)*

> *Well, I know it might seem stupid, but no I didn't read it. They told me: you've got to sign, so of course I signed, without reading everything it said. (m8)*

One must also remember that, even if there is agreement, the fact of putting the information down on paper and being required to sign it makes people feel frightened, perhaps because it makes the dangers seem more real. Sometimes the act of reading the form can scare people because it is like facing up to what is happening all over again. Whatever the case may be, sitting down in front of a document and trying to understand it requires bravery and also takes time. We found that fear is one issue which prevents documents from being read.

> *No, what it does is put you on a spot: all of this could happen to me? Heart attack. All of this is what could happen to me? (f3)*
>
> *I didn't read those forms. No, no. I said, "If it doesn't help me maybe it will help someone else." In other words, I was so frightened I just couldn't. I love reading, but not informed consent documents [laughter]. (f7)*
>
> *No, I sign it and I don't read it, because I don't understand it and also because they're the ones who know. I've got enough with my own fear. (m8)*
>
> *I read it. It really scares me. The same thing happens with the form they give you for the operations. When I see the form I want to read it, but quickly. Because it scares me. (f1)*
>
> *I've signed a couple of them. You've got to sign them because there are risks. I told him, "That's how it is because you've got to do a lot." But signing them is scary. (f4)*

Another issue to bear in mind is the design of the document itself. An unattractive layout with lots of information makes people less likely to read it. And this is also the case here.

> *I read a bit, but it's like an insurance form, the print is very small and you don't understand anything. My daughters didn't read it either. (f5)*

6. Qualities of good information providers

Just as important as the content of the information is how it is provided. From their experience of dealing with significant numbers of health professionals, the interviewees offer a very clear idea of the importance of how information is provided and the person who provides the information. The notion that “it depends how they tell you” comes out when interviewees talk about how they would like to receive information. It is not so much the specific words which are used as the personal qualities embodied by the health professional, whether consciously or unconsciously. The notion that information is just one part of the communication process is not new. However, if we wish to make this notion a reality when giving information to people with health problems then we must identify the qualities which patients see as being most helpful. A man in the group of heart attack patients, interviewed after his second hospital stay, and a woman in the group of cancer patients, expressed this very clearly.

> *I think the information varies depending who gives it to you. You understand better depending who gives it to you. For example, in my case when I came in the second time, when the same thing happened to me as now, a doctor came in the morning and explained everything, everything that had happened and why. He really explained it well. He was the most accessible and the one who explained it best. I understood him much better. (m2)*
>
> *They need to talk clearly but choose their words, to be human, to remember when they’re talking that how they do it really affects us. (f3)*

Non-verbal communication

We will start by highlighting some statements which refer to non-verbal communication as an essential factor in understanding the message. The use of body language and facial expressions to show empathy, accompanying verbal communication with intimacy, speaking in a friendly tone of voice and smiling are some of the characteristics which were appreciated by interviewees.

> *When you go to the doctor you’re afraid, very afraid. For me, I don’t know about other people, I look at his face and if it doesn’t change I think everything’s fine. I don’t ask because I don’t have any doubts. (f1)*
>
> *The family doctor explains it very well, so you understand, and she also looks you in the eye when she speaks. (m2)*

> *He sat on the bed, he's someone who makes you feel very calm, his voice, his way of moving, even if he was in a hurry he talked slowly, I don't know. He said, "It was cancer but I've managed to remove it well." I understood and I was glad that they told me so quickly, as soon as I woke up from the anaesthesia. (f1)*
>
> *My nurse at the health centre has a really important quality for doctors or nurses, and that is that she always smiles, always smiles. It's important because you see that the person who's coming to see you is happy to deal with you, and that is obviously very reassuring. (m6)*
>
> *How they tell you is important. Smile a little, if you see a nurse or a doctor with a serious expression, you think the worst. If they tell you with a smile it gives you a good feeling. (gm2)*
>
> *No, I think they told me well. He took my hands and said, "Look, two years ago you were doing really well but now we've got to look at you again." I could see it was urgent. Because some people say, "Look, you've got this and that's it." No, none of that happened to me, he said, "Look, I'm going to explain what you've really got now, you've got cancer and it's bad. We know that from the tests they did on you." Maybe it was his gentle voice, the fact that he looked at me, I don't know. I don't think how the person dresses or looks matters; I don't personally like the way he dresses, but just then I didn't notice if his hair was long or shirt, just what he was saying and how he said it. Such a gentle voice, without shouting, smooth. He said, "It's bad and we're going to have to do this treatment. Above all, remember that there's a different treatment for every case," and he told me to ask about any doubts. (f10)*

In the last example, touch is included among the components of non-verbal communication. This stands out because touch is one of the elements of non-verbal communication to which least attention is paid in the health sector. Touching patients is something which occurs as part of the investigation and treatment of the patient's body. However, the beneficial effect of touch, the sensation of proximity or of emotional involvement, is something which should also be considered, as it can help to establish positive emotional relationships and to make the individual feel cared for. Another comment also referred to this.

> *That's why the role of the nurse and the doctor means everything to you then. If there isn't time, a smile for example, I've never been very touchy-feely and now I don't know what's happening to me but … (f2)*

Availability

We collected information regarding the importance of knowing that one can rely on the health professional to act in ways which go beyond their formal obligations. Having someone you can trust and who is available to answer questions outside of scheduled consultation times is viewed as highly positive. It is important that the care relationship is based both on the availability of the health professional and on a feeling of trust from the patient. This is a two-way relationship, in which availability fosters trust and vice versa.

> *Whenever I've had a doubt I've been able to ask the doctor. He said, "Whatever it is, you know where I am, just call me." I've gone to visit him or turned up there and he's always seen me. He says, you've got this or that and you've got to do this, and that and that. Also, on Friday afternoons he holds a surgery and I know he's there, that I can go on Fridays without asking for an appointment, be the last one to arrive, and I see him. He asks me how it's going and I can ask him everything. I know I can go at any time, turn up there, and he'll see me. (f6)*
>
> *Of the nurses, the one I remember most is the one in the breast unit, because she was the one who gave me the best information, she explained what was going to happen. It was clear, I could ask, she took her time in answering me, I was there talking for a while. (f5)*
>
> *A doctor once spent an hour with me. Not all the health centres are the same. The nurse is always available, there's something about her which draws you in, you can see she's there for you and that helps you to open up. It's important that they take an interest in you. (gm2)*

Knowing how to listen

Much of this is also true of listening. Some of the interviewees indicated that listening brings a human quality to the relationship between health professionals and health service users. Ensuring that the patient not only receives information but is listened to (and feels that he or she is being listened to) is identified as one of the important ways in which care can be individualized. Listening is one way for health professionals to show their interest in and empathy with the patient, and is vital if professionals are to inform patients properly and satisfy their requirements for knowledge. Just as we linked the availability of the health professional with trust, so we can link the professional's ability to listen with how well the patient understands the information.

> *I just want them to pay attention to me and to listen to me. They should realize that not everyone they see is the same, not in what they're like or in their illness, and that above all they are people. They should think that maybe tomorrow they'll be the ones who aren't being listened to. You need a bit of psychology and not to treat it as a routine job. If you don't like it you shouldn't do it. I don't know how to put it but it's not a job you can do just to make money. They're dealing with people and each of them is very different. Everyone has their weaknesses, their own history. (m4)*

> *Knowing how to listen, being patient, because we're disoriented, we're really afraid and what we need is to have things explained to us; at least I do, to have things explained in detail so I can understand. For me that's fundamental. (f8)*

> *For me the most important thing of all is listening. Just because there are 50 people in the waiting room, they can't get rid of you straight away, no. Listen, listen and listen to everyone, every person is different and reacts differently. Well, that's what the health centre nurses did with me. I compare my experience seeing the doctor and in the hospital with the educational talks I've attended. There whatever question I asked they answered, even after the talks if I had any doubts they answered it. You can see that the nurses who organize them do it because they enjoy it, sometimes they've got to fight for it, because they do it separately from their work with the doctors. It does people a lot of good because otherwise you don't know anything or the reason why. I know that they struggle to get people to go to the talks, they encourage people to go ... they do it in a way which makes you want to learn and to change. I think the most important thing is for them to realize they're not dealing with machines but with people. (m2)*

Sympathy

Some informants identified sympathy as a desirable professional quality. It may be that they understood sympathy as showing interest, friendliness, knowing how to get through to people, putting oneself in another person's shoes. In this section we present the opinions in which informants describe sympathy as a professional quality. For all of them it means relating to the patient in a way which is open, communicative and expressive. They confirm the notion that establishing communication which helps the person goes beyond simply providing whatever clinical information is available. The relationship between sympathy and extroversion is not clear, although several interviewees specifically referred to these two qualities as features which made them feel more trusting. Three interviewees drew comparisons between two professionals to emphasize the importance of sympathy.

> *I can compare because I've had two doctors, both women. The first one, well, she's very friendly, but she's not very outgoing. She's very polite but she's not the most outgoing of women. By contrast, I thought the second one was really great. She tells you everything, asks you about everything, talks to you about everything. I don't have any complaints about the other one, but the second one inspires much more confidence, that's how I see it. The difference is the person's sympathy and the interest that person has in you, at least that's how it seems. The questions she asks, the questions go with how interested she is. The more questions, the more of an interest she's taking in you; the first one is also polite, but she's more to the point, she just asks if you're okay, tells you about the test and the X-ray. She doesn't lie to me but she's not giving me the fullest information either, she just tells me how I am. It's very impersonal, very, I don't know, detached. A person is showing that really that they're interested in the person next to them, the patient, and how they care about the patient being well, so they ask questions and answer and patients can see that. That's something patients like. I think a lot of people are like me. (f8)*

> *At the appointments, for example, there's a nurse who looks at me and says: fine, you can go now. The nurse who does the chemotherapy is friendlier than the other one. There's one nurse who is very friendly and who explains things to me. I have more confidence in her, but if I have to ask the other one something well I don't, no. (f5)*

> *The doctor I have now is very good, very good, more talkative, she talks a bit more than the other one, I don't know, well I don't know, it's just as if I prefer her, maybe as doctors they're the same but ... (m8)*

> *I don't like it when they mollycoddle you and all that, but I think you have to get past just being polite, because some nurses are perfectly courteous but never cross the line, I think that patients and particularly ones with an illness like ours need a bit more affection. You can show affection with a smile. I've been very lucky because in both hospitals where I've been they're like that. (m3)*

Interest

Another factor which was identified as contributing to care was whether the health professional showed an interest in the patient which went beyond their basic duties. Some of the responses we recorded stressed the importance of feeling that the health professional is genuinely concerned for the patient's well-being, indeed, that he or she has a predisposition for this.

> *Above all, vocation, that they take an interest in you and in what's happening to you, and try to help you, that's very important. If they're also friendly, well, of*

> *course, that's even better. But it's not sympathy so much as being interested in you. You can tell, you know that they're interested. (m3)*

One patient explained that it is not a question of professional experience but rather that interest arises from personal sensitivity.

> *No, older nurses aren't better. Because there are some young ones who have treated me in a very straightforward way, very clear. I remember I had a nurse who wasn't even a staff member, I was in a really bad state emotionally, they'd already removed one breast and now the other, I was in a daze, and this girl said to me, "Look," – I'd never seen a woman without either of her breasts – she said "You know, to me you're as feminine as if you had them." Well, just then that was a viewpoint which was really good for me. (f2)*

Another woman who was interviewed made a direct link between showing interest and the information.

> *She was good because she was taking an interest, and she told me what they were going to do and asked me how I was feeling each time she saw me. (m5)*

7. Issues which make it difficult to obtain and understand information

In this section we present information relating to the behaviour of health professionals and to structural aspects of how healthcare services are organized which make it difficult to obtain information. The questions referred to areas where people had encountered problems in obtaining and understanding information.

Just as we have identified factors which facilitate the communication process, so we can also identify factors which obstruct this process. Sometimes the main difficulty in obtaining and understanding information comes from the health professional's communication skills. Sometimes the attitude taken by professionals can make it more difficult for people to receive information and to share their feelings, emotions and doubts with their doctor or nurse. Patients' perception of the health professional affects how likely they are to ask about, understand and accept what is happening. The interviewees found professional behaviour which focuses more on controlling symptoms than on the patient's experience of being ill to be detrimental to communication. How things are done, ways of answering, asking, listening, looking and so on are therefore essential. The other area identified by interviewees as a source of problems relates to how services are organized and managed.

Paternalism

Following the best course of action available and considering the patient's best interests without taking into account his or her wishes or agreement is still common. This is very negative for people who want to have as much control over their lives as possible. Under the heading of paternalism we have grouped together reports of authoritarian approaches which indicate a failure of the health professional to allow individuals to decide for themselves. This approach derives from a traditional model of health ethics in which the patient's role is to receive and accept treatment and care without necessarily asking about or understanding it. Some interviewees explained that professionals sought to infantilize people just because they were ill, and this approach was unpopular and was sometimes a reason for changing from one health service to another.

> *Talking about ethics, I had a very senior doctor who used to say, "The patient only has to know what's in his interest and that's all." I said, "Well, it's my life and I've got to know what I'm up against." For example, I asked the typical question, "Why am I not being given chemotherapy?", and he said, "I'm the doctor." Well, that's really arrogant, when you're ill you've got to learn to trust others but to trust blindly … you think it will be for your good, but it's much, much better to be able to talk about it. (gf2)*

> *Well, with the first plastic surgeon it was his opinion and he didn't give any other options, I already knew that other options existed and I thought he was treating me like a number, not like a person. Because I've been through it I still think that the connection between doctor and patient is really important. You need to know that he understands you and treats you like a person. (f1)*

> *One of the doctors wanted to take a sample and the other one didn't, and I was stuck in the middle not knowing what was happening. So I asked him and he said, "Don't try to know more than me." That was the answer he gave me. He told me I should just let myself be treated like a child. That's how it is with him. He's a good doctor but he said I shouldn't try to know more than him, even though I'm the patient with a 6 cm lump they can't remove. "Don't worry, don't try to know more than me." That's what he said. That's when I changed centre and switched to the public health service. I don't want to know more than them, but I do want to know what I've got. I'm the one whose life is on the line and I want to know a bit more. Just think about it, that I should let them treat me like a child. (gf2)*

When paternalism is very entrenched, the health professional is likely to believe that the clinical information belongs to him alone and that it is therefore up to him to administer it as he sees fit. As a result, questions which are of real importance to the individual are treated as trivial and at times the health professional even refuses outright to answer questions:

> *I asked the doctor, "Is it possible I don't have enough supply in this artery?" and he said, "No, no, forget it, I know what I'm doing, just try to calm down." But I still get the pain and when my chest hurts I can't stop worrying. At the beginning the changes in the weather are horrible, I know my mammary artery now. But no, I don't know if these people think they're gods, that they can decide everything. How can a doctor discharge a patient without having seen him and, what's more, when the patient has asked to see the doctor? (m3)*

At times, in what one hopes are exceptions, the answers are even disrespectful.

> *Another time I asked, "Why are there so many asterisks on the analysis results?" He said, "Ah, that's because the people downstairs don't have anything to do and spend their time making dots." He tried to make a joke about why there were so many asterisks without treating it with any importance. It was too much! (gf2)*

Paternalism may also be why professionals sometimes perceive questions as criticism of their work, and respond to patients in a confrontational manner:

> *Sometimes I've been given very rude replies, and that just provokes an argument. If they come across someone who doesn't know, who just goes in like a sheep, well that's what happens. But not with me, the doctor's a person just like me. There are annoying patients, I understand that, but they have to understand that everyone is different, when I'm at work I've got to know who's slow and who's faster … a doctor has to know who's coming through his door and if he doesn't know then he has to treat them like a person. What's the problem? Doesn't he like me knowing? I can read upside down and I see what he writes. If I ask him a question about what I've read him writing, he can't take offence and say it's his business. (m1)*

From another perspective, paternalism tries to minimize the damage by playing down the importance of what is happening and trivializing the answers.

> *When I went to see the doctor he said, "We've got to take some blood because we're going to start chemotherapy." Well, I said, "When?" And he replied with a joke: "If we tell you then you won't come! Don't worry, the chemotherapy's no big thing." (f3)*

Sometimes patients explain this paternalism in terms of power.

> *Sometimes it's like professionals are playing down what's happening to you. It's because they don't want you to know more than them. (gf5)*

It also makes it difficult or impossible for the person to discuss the possible alternatives clearly and with confidence and prevents the health professional from helping him or her to evaluate them. As a result information flows in one direction only – from doctor to patient – and if the patient has doubts then he or she is denied the possibility of analyzing the alternatives and their consequences with the doctor.

> *When they suggested a breast reconstruction, I decided not to have the operation. I'm not going back into an operating theatre and certainly not for that. I didn't have the operation and I'm very happy; it was really difficult because it's much easier for the patient to let the doctor decide. It's difficult to stand up to him and say, "You're not going to operate on me because I don't think I should have the operation." My doctor accepted it, I think, but he didn't like it much. I said, "You don't like it much, do you? Me asking for other opinions." And he said, "No, no I don't like it." But I said, "It's my life and I can't put myself in anyone's hands if I'm not sure." I think he accepted it, I'm not very sure. On the other hand, an oncologist told me that I was trying to do things which weren't my responsibility, in other words, she implied that deciding not to have an operation wasn't my responsibility. Fancy that, it's my life. Maybe she knows more than me because she's studied it, but in this life I also have the right to choose what I want. They have to tell you want they think you should do, but doing it or not is my affair. I've got every right to ask for second opinions. The problem is that you've got to make a real effort. (f2)*

> *Everyone should take their own decisions. But just now people's decision-making capacity is not taken into account. They decide and that's that. No, right now it's not taken into account. (m3)*

Paternalistic behaviour can increase the sensation of dependency and incapacity already caused by the process of illness and treatment. One man explained the possible negative effects:

> *People, both those who are ill and those who aren't, have to think about each other. Everyone has their own personality, you've got to look after this person, so you care for them but you don't boss them about, otherwise you blot them out. (m7)*

The paternalistic approach by which the professional lets it be understood that he and he alone is in charge of what happens may lead him to ignore or minimize the importance of the ill person's information and knowledge.

> *I think that, although hospitals are really overloaded, you've got to listen to the patient. I had to fight with the doctor because I went to tell her I had a lump, and she said I didn't. My oncologist had left and she introduced her replacement to me who had come from the US, she was a bit full of herself. When I told her about the lump and she felt it, she told me to go to the cinema and to go dancing with my husband, that she'd worry about my breast. That's the kind of thing you have to avoid. She treated me like a hypochondriac. Two weeks later I went back and told her I'd been to the cinema but that I still had a lump, she called radiology told them there was a lady whose examination results were normal but who was very worried and she asked them to fit me in. They did it and it came up as a tumor. Then she told me not to worry, that it was just one centimetre, that it could be benign, me benign, with my history! It's not going to be benign. Then, however, she admitted, "It's lucky I listened to you!" (f2)*

One example explained by a woman in the focal group shows how paternalism comes to the fore when doctors are treating patients. This was something she had experienced for herself. When her own doctor gave talks to the association of women with breast cancer, where she did not have direct responsibility for any of the women attending, she was very open and explained current knowledge about cancer and treatment options, responding to specific questions put by the women. In summary, she was good at providing information, and at using her knowledge to help cancer sufferers understand their illness. However, when our interviewee has a face-to-face appointment with her doctor as a cancer patient, the situation is very different and the interviewee felt that this could not be explained purely as a peculiarity of her doctor but instead saw it in more general terms of how all doctors behave:

> *When doctors put their white coat on they think they're gods; they possess the truth and they're going to sort you out. I've seen her come here to do talks and, to be honest, she's great, the pros, the cons, clear and concise. Everything, everything, but if you come in as a patient and see the same doctor, she doesn't explain anything, it's as if they put the white coat on and you have to just submit. (gf3)*

Lack of emotional involvement

Informing and supporting others means that health professionals themselves, to a degree, experience as their own the suffering of the person they are caring for. Some of the negative attitudes of health professionals can be explained as a result of the high level of personal involvement which dealing with ill people may entail. We therefore need to consider the intrinsic problems which arise when the involvement of health professionals goes beyond just controlling the illness. Otherwise, how can we explain behaviour which seems to be designed to distance health professionals from patients precisely when they are vulnerable? The empathy or compassion which are required when relating to patients on a personal level mean that to some degree health professionals must also work on their own emotions. Sometimes health professionals distance themselves from the patient as a human being, and focus on the symptoms of the illness rather than on the subjective suffering because otherwise the professional suffers too. At times the behaviour of the doctor or nurse in distancing themselves from the patient is due more to their own fear or inability to provide an answer than to the needs of the person being cared for.

> *They don't want to get too close, I guess that's okay. For example, if you say, "I've had a really bad time today," they bring the conversation to an end quickly. So I think they're a bit afraid, afraid of fear. It's all got to be cheerfulness, cheerfulness and 'come on!'. Well that's fine, but sometimes it's okay and sometimes it isn't. Sometimes it can be because there are other patients around who could hear, I'm very aware of not frightening others, but it's also good to be able to get things off one's chest. (f2)*
>
> *It would be good if we could explain better. With some nurses I've seen that that's possible; but I would say the doctors should spend a bit more time on it and not be so cold when they're talking. And the chemotherapy nurses too, they shouldn't be so cold. They go to plug everything in, start talking among themselves and get on with their business, and don't make any contact with you. The doctor asks, "How are you? Have you had a temperature, mouth ulcers? ..." but nothing else. When you've been having such a bad time you can't bring it all down to a conversation about temperatures and mouth ulcers and putting some serum into you. There are all sorts of things which at the time can just really get to you and you have to be able to ask about them. (f9)*
>
> *Uncertainty really undermines your trust, you go like a lamb to the slaughter. Yes, they ask you about your history, illnesses, but not about how you feel, or about how you're coping. Maybe it's because, of course, if they listen to everyone's problems … One nurse did a very good job of informing me. (f9)*
>
> *My surgeon lacked something, he lacked that ability to relate to people. He did his job well, but it's one thing for them to operate on you well, but sometimes you need something else, a bit more tenderness. (gm3)*

Sometimes emotional involvement with the patient's situation can be one of the reasons for professionals being too blunt when providing information.

> *They should be clear, but not blunt, because of how afraid you are ... if you can talk you take things in better and it gives you energy to fight, I don't know, I want them to tell me how everything's going, it really affects me at the emotional level. For example, the doctor told me, "You know you've got cancer?" and I said, "Just as well I'm not in the village with the goats. If I was, just imagine." For me, as a surgeon okay, but he could be a bit closer. (f3)*

At the same time, as we have already seen in other sections of the study, focusing exclusively on the illness and its symptoms can have a negative effect on the patient. One woman received her breast cancer diagnosis as follows:

> *They told me by phone when I was at work. It was just too much. In the morning I'd gone for a breast scan and they told me they'd have to take a blood sample. Then the person who did it told me to take the samples to the biology lab and to be sure to call my doctor in the afternoon. I was quite calm because they'd already done the test the year before and told me I had fibrocystic breasts. As I work in the afternoon, I took the opportunity and called my doctor who said, "I'm going to make an appointment with an oncologist and we'll probably have to give you some treatment and we might have to operate." Well, I said, "Oncologist, cancer." He said, "Yes, probably." It scared me to death, no discussion, if you don't like it find another doctor. He was really blunt and later on I told him. It really pulled him up short: "No, you see, it was because I didn't want you to lose any time." So he was worried for me, but just think about what he did. Apart from that he's really good. (gf5)*

Failing to listen

Possibly as a result of a degree of paternalism and the difficulty of becoming involved emotionally, professionals sometimes fail to listen to the patient. We noted that several interviewees in the group of patients with cardiological problems, when discussing issues for improvement, suggested that doctors and nurses should listen to them more and more carefully. Just as listening is identified as a quality of good health professionals, not feeling that one is being listened to is also a significant factor when forming a negative opinion of the quality of care received. Being able to share with professionals, talk to them, and establish a broad relationship is a criterion of good care.

> *Worst of all, in addition to being ill, is that they don't listen to you, they don't explain things, they don't have time … Well, I don't know if they don't have time, but it always annoys me because they don't give you time for anything. (m2)*

> *As far as medical questions go, I’m not happy, not with the health centre or with the monitoring they do in hospital. The last time I saw the doctor who deals with me, I had to say, “Listen to me!” (m4)*

> *If you can’t explain what's happening to you, you come out after your appointment and it’s like, no, no, you feel really powerless. They give you appointments from time to time; for example, you might be waiting for months and finally the next day you’ve got an appointment. You think, “Let’s see how I am. Have I got better?” And if he doesn’t tell you what you need to know, well it’s just so much waiting for a signature. (m6)*

> *The treatment is very blunt. You ask and they don’t answer or they say, “Don’t worry, we’ll deal with that.” For example, someone told me, “The thing is, there’s no solution for you.” But for me that’s not a solution, that I don’t have a solution, that’s not a solution for me. In other words, you don’t go to hospital to get a pat on the back or so they can sugar the pill, you go because you need to be listened to and if they don’t listen to you, you come out worse than you went in, because emotionally it’s bad, because firstly you don’t know the illness, and secondly you think you’re going to die; and of course that’s when you start listening to what your neighbours say and that’s even worse. When someone goes to a medical centre, the doctor, well he doesn’t have to be like a father to you but at least he should listen to you and look and tell you if it’s going okay. When you go in you're in shock and if they don’t help you to come out of that, you might be about to give them medication which is going to be really difficult for them, you need a lot of help. And I think that doctors, and unfortunately I’ve had to see quite a few, they focus on their specialism and don’t know how to understand what’s happening to the patient … I don’t keep quiet because I don’t see why I should, if that’s how it is I’ll ask them to give me a different doctor because I can’t have an argument every time I have an appointment. (m4)*

One of the interviewees testified to this kind of blunt treatment and saw it as a personal characteristic of his doctor. When he received the information about the treatment to be followed and about controlling his illness, the interaction was limited to the explanation of clinical data.

> *I would like her to be a bit more open, and to talk to me more clearly. Of course, it’s about talking; you don’t get another word out of these people, it’s like pulling teeth, they say the bare minimum, she says what she thinks and that’s it. She’s one of those people who are rather closed, serious, very serious, not a smile, and choosing her words. (m5)*

Curt relationships of this type make patients feel unvalued. This is how one of the women in the breast cancer focus group put it:

> *I've had doctors who were not very friendly who think we're all the same, and we aren't all the same. (gf3)*

Use of technical terms

Another aspect identified is the importance of adapting language to the people being addressed. The use of technical language creates a barrier between health professionals and health service users. The use of technical terms is frequent, but our interviewees did not complain so much about the words used as the fact that they were not accompanied by an explanation which made it possible to understand them.

> *Sometimes the words are very technical, because of course you're not an expert. And they give it a name which, if they don't bother to explain, well you're left in the dark. (m3)*
>
> *It's, like, very medical and not using general vocabulary. They tell you, "You've got this or that," and they don't explain it but just say it like that and we understand less than them. (m8)*
>
> *That's why I take somebody with me; what with the nerves and the words they use, sometimes you don't understand anything. (f1)*

Having to ask to obtain information

Several informants identified the continuous need to ask for information as one of the principal situations which should be modified in communication with health professionals. Sometimes information is reduced to responding to questions, and obtaining it depends on the skills of the questioner. The patient therefore has to make the first move, asking questions or looking for information. As a result, patients continue to believe that, in addition to fighting the illness, they have to struggle to find the knowledge they need and to get somebody to help them understand it. The data mainly refers to those health professionals who have not integrated the provision of information into all of the activities they perform on a daily basis. One woman with a long history of illness as a result of which she has been through various health establishments, both public and private, and who has had contact with many health professionals, made the following comment:

> *This sort of information doesn't exist. In other words, they don't explain, for example, where you can buy a prosthesis, what steps you have to take; so you have to go and ask about it, but because you're so afraid, you don't know how to put it on. When they*

> *give you chemo depending who your doctor is they don't tell you about the symptoms and so when you arrive you find out about it, if you don't have someone, whether it's a doctor or a nurse, to explain what's going to happen … it's very important to warn people, to know what symptoms you might have, it's good for the doctor too because that way you can warn him. The information's there but it's not there, I don't think it should be the patient who has to go and find it, I think they should already have dealt with this issue. Unfortunately, you go and look for the information and then depending on how determined you are about asking you might end up not knowing. What happens? One patient explains it to another one and sometimes that isn't good either, because that's shown me, well that everyone has their own body and people react differently to each illness, it's different; so you end up acting on rumours and it really shocks me that they don't realize how important it is. They gave me a portacap, later I found it what it was, because at the beginning nobody explained it. I came out of the operating theatre with it in without even knowing what it was. I had to ask and a nurse explained that it was like a drum which could be injected to administer medication. She told me it had something like a catheter which went to the heart, and that really scared me, straightaway I thought about the problem of infection. Later I asked the doctor about it and she explained that the risks were slight and finally she said, "Look, Carmen, I don't know how long I'm going to give you chemo for, that's why it's best if you use this to make it easier to inject you, and if I were you I'd try to get used to it and put up with the inconvenience of the portacap." So, what I'm complaining about is that you have to go and ask for the information. Another example, when I had a secondary tumor they wanted to do an operation on me which they'd only done a few times. They remove a rib, of course I asked about it. However, there are people who don't ask about that because they're afraid, but I did. I made another appointment because it seemed quite radical what they wanted to do. They said that that would finish off the cancer, but I didn't believe that because I know it's systemic. Of course, I had to want to know more, but I think it's wrong that there isn't any allowance for that, if I hadn't asked a bit more they would have operated on me already. In the end I didn't do it. (f2)*

This woman even had an intravenous device inserted into her to facilitate the administration of medication, because she was going to have long-term treatment, without any prior explanation, and she was only given an explanation after she asked for it. This example may seem extreme, but it clearly shows the importance of providing information as a daily activity which accompanies everything health professionals do. This complaint was backed up by other interviewees in both groups in the following terms:

> *I know because I've asked. 'Sort it out for yourself' seems to be their motto, you get bounced about like a rubber ball. They send you from one person to another …*

> *some days I saw three different doctors and by the time I got home I was exhausted. I've really had to learn quickly and go to places to find out about things. (m1)*
>
> *When you ask them, they tell you what there is, but sometimes I don't ask because I don't dare or I don't realize at that time. (f3)*
>
> *When I was discharged they didn't explain things to me, no. They told me that the gynaecologist would be monitoring me, but nothing else. I was the one who asked what I couldn't do. (f4)*
>
> *The doctor says things, but if you don't ask you don't find out. Of course, if you want to know you have to ask, but sometimes they should also help you to ask. (f5)*
>
> *When I was in hospital they give me a piece of paper with a timetable in case I wanted to ask questions. A nurse gave me a card for when I wanted to ask to see someone, the timetable was on it. (m5)*
>
> *I've always had to ask for explanations, I don't let them go without giving me an explanation, both the doctor and the nurses with the medication. They do things, they usually explain what they're going to do, but they don't realize that maybe you don't understand fully. (m2)*
>
> *There was a point when they didn't tell me anything and I got angry. I had a major recurrence and they didn't tell me anything. The doctor and the surgeon talked to each other. I was there right next to them and I said, "Maybe you understand each other, but I'm not getting any of it and you're talking about me. I want to know all the details." (gf2)*

The idea that you don't get information if you don't ask is even clearer in cases where there are undesirable side effects or where an error has occurred. For example, two of the cardiology patients who required surgery had problems of this sort. In neither case was either the patient or his family members informed until they themselves asked.

> *When I woke up I had a terrible pain in my shoulder. My back was twisted, all that on top of the six hours I'd spent on the hospital trolley. I said, well, it must be that, but the shoulder pain was much worse than the back pain. I asked them to look at me … I know they took some X-rays because they came to look for me, they didn't tell my son, and they didn't tell me about the X-rays at all. He went to talk to the doctor and asked him, "Why's my father in this pain?" and he replied, "Well, when we operated my hands didn't fit so I couldn't work properly. We had to force things a bit." I don't blame the doctor, at that point it was my life that mattered. I don't think professionals do things to hurt you, but he should have told me about it so I knew where the pain was coming from. (m1)*

> *My family weren't told about the problems after surgery. I was delirious and didn't wake up from the anaesthetic, I didn't stop talking and I was unconscious. My son said to the doctor that he should have told him about this possibility, they thought I'd gone mad. Why weren't they told? Even if it doesn't necessarily happen to everyone, it might happen. They weren't told about anything, they got the fright of their lives. (m8)*

Management of human resources

Another major block of data relating to difficulties in understanding information concerned the importance of the context in which health relations occurred. How the service is organized and how human resources are managed are both factors which can either add to or detract from the quality of such relationships, and they therefore have a direct impact both on the information process and on the more general relationships between health professionals and service users.

Of all the different organizational aspects, the one which causes most disquiet is the high job mobility among doctors and nurses. An important factor was the need to have a core relationship with one or two people, not because the other health professionals have nothing to contribute or are not important, but for reasons of trust. Very often, the patient does not have a stable point of reference either at initial consultation or in the hospital unit. Indeed, it is not uncommon for people not to know the person who is caring for them, a state of affairs which is sometimes a consequence of team working, or the result of shift systems or people changing job. And the fact that, in turn, the health professionals do not know the patients, simply adds to the feeling of powerlessness. This is an issue which has to be tackled by working together as a team in order to ensure that the health professional knows who the patient is, the nature of the patient's problem and what action has been taken. Many of our interviewees identified continuity as an essential aspect of care, but such continuity is undermined or destroyed when there are changes to the health staff:

> *I'm very unhappy with the oncology service in the private sector because you pay an insurance policy for a personal oncologist and then it turns out you get a team. In my case, for example, my own oncologist hasn't seen me for a year, if I'm lucky his son sees me, sometimes they want me to be seen by a South American who's probably still training, no way. When my husband got ill that was one of the reasons he went to the public sector. I think you've got to trust the doctor, you're*

> *really afraid, you always think of something you want to ask about or get advice on and then you go in for the appointment and say, “But I thought I’d made an appointment to see Dr. Whatever,” and they say, “Oh no, we’re a team, you’re going to be seen by a team.” I’ve been tempted to get up and leave but what good does getting angry do me? I agree that you’ve got to work as a team, but that’s a problem because we build up trust, I’m not talking about the flu, I’m talking about a more serious illness. I know that they've got lots of years of experience, but for me it’s the trust I have in the person who’s already treated me. (f1)*
>
> *For me, the fact that you see someone different every day means you can never build up trust. They’re students and they don’t know enough or they’re not fully familiar with your case. They give you information, but just the minimum. (m1)*

Another issue is that, when dealing with long-term illness, relapses and ongoing treatments, changes to the care staff may cause patients to experience feelings of loss.

> *For two years I was very lucky. I’d always been seen by the same oncologist. But then he went too and that’s where my problems started. Now I’ve got another problem, that every time I go there’s someone different, it’s awful. And there’s no way they’ve read my medical history, which is really long. The treatment I’m having just now means I have to go every three months, and every three months when I go I think, “I wonder who I’ll get this time.” You don’t have any confidence. (gf2)*

And it also gives rise to the feeling that the work of health professionals has to be supervised, to ensure that they are giving the appropriate treatment and care:

> *Sometimes they’ve said, “We’re going to give you this,” and I say, “No, they gave me that and it didn’t work.” Well, of course that’s no way to do things. What’s more, because they don’t ask you, they just give it to you like that without seeing who you are, well that’s it. Above all doctors need to be made more aware. A profession like this isn’t just a matter of science or shouldn’t just be, there’s also a human part which for example if every time you go in you see somebody different, well what confidence can you have? In situations like that it’s very important which doctor you get. When it’s the first time he’s seen you and, of course, he can’t see all the background, it really undermines your trust. (f2)*
>
> *It’s like there are so many nurses, well it’s impossible to remember the names. The doctors are the same, they change a lot. It’s never the same, it’s a team. Well, you can’t build up the same confidence as you do when you see your family doctor and it’s always the same person. But with so many changes, maybe they get lost too. Once in chemotherapy I said to the doctor I had at that time that I couldn't handle*

> *the red chemo, and he answered, "Well, I don't have a note of that here." I had to say again, "Listen, I turn into a monster, my mouth gets really itchy." And the doctor answered, "Well, it's not written down here." You've got to say it yourself, otherwise you end up suffering again. It's only now that the last two times I've been seen by the same doctor and of course now she knows. (f4)*
>
> *What I see is that every day the nurses change, I don't know what the person who's looking after me is called. For example, today there was a young guy who's a student, on other days you get someone else. It means you have to keep an eye on what they do to you, it's not that you don't trust then, well they know what they're doing, but you've got to be alert. (m5)*

Given the benefits of team working and the inevitability of changes, we clearly have to improve both our organizational systems and how we explain them to service users. The following example serves as an illustration of how the combination of constantly changing staff and a failure to properly organize the sharing of clinical information between professionals can generate a lack of confidence:

> *I've had experience at the health centre. I still haven't met my doctor in person, each time I've gone I've seen a different covering doctor, in less than a year and a half they've opened three different files. I said, "Every time I come here you open up a file and then you lose it." What confidence can I have? None. That's why I say that the doctors at the health centre don't inspire any confidence at all. I've had bad experiences; they don't look after you properly, they lose everything, I don't know why people go there. I don't have any complaints about the three individual doctors, they listened to me and opened a file. And they were patient, every time they opened a new file again, but at the next appointment because that doctor wasn't there any more and there was another one instead and my file had been lost, they had to start all over again. (f8)*

Lack of time

The possibility of building relationships of trust and having access to information is also an issue of time. If providing information and building relationships are key parts of a doctor's work and responsibilities, they should be treated as professional duties in the same way as the more technical aspects of the health professional's job. Many of the interviewees mentioned the issue of a lack of time, and whether patients received adequate information appeared to be directly dependent upon whether health professionals had enough time to provide it.

> *The doctor has ten minutes per patient, so if it's not your doctor who already more or less knows you and if instead you get someone else you say, well, what does this guy know about me? If you ask the nurses for something they give you it. But they're short of time, you can see they can't cope. I know they've got rid of a lot of doctors, and on my ward there were just two nurses for all the patients, and they can't cope, of course, they came when they could. (m1)*
>
> *The doctor should have time set aside for talking to you, I don't blame the doctors. When they don't have time they should say, "Look, I don't have time to give you the information." I could understand that. (m5)*
>
> *The problem is the lack of time and that they give you all the information at once. I find it difficult to understand it all at once. (f3)*
>
> *The problem we see is that doctors and nurses don't have time, in two minutes it's impossible. I go to the health centre to pick up the prescriptions, well, how can they deal with me, my doctor's friendly but all he can do is give me the prescriptions. He doesn't have enough time to ask me how I am. (gm3)*

Time pressure makes people afraid of causing inconvenience and is one of the reasons why they don't raise any doubts they may have:

> *When I go to hospital they seem to be so busy with everything and I see other people's situation and I think, how can I interrupt them? You don't ask because you don't want to bother them, sometimes you don't even think about doing it. People don't like knocking on the door because they don't want to interrupt, you can see they're busy, if they don't come out of the office it's because they can't, you wait and wait. (f9)*
>
> *It's the waiting I can't stand, because sometimes you arrive just in time and sometimes I tell you maybe I've got an appointment at 11 or 11.30 and it gets to 2.30 and you're still there. Two hours or more of waiting, you go in and you can see there are so many people waiting that you don't want to ask because of the time. I ask one or two things, but not for as long as I'd like. With the nurse I do, she explains what you need to know, what's best for me, what I'm taking, she seems to have a bit more time. (f4)*

The time factor is also mentioned with regard to waiting time for appointments. Often people have to wait for a long time with the result that, in addition to the illness itself, people suffer from anxiety and feel that they are being treated rudely.

> *When I was waiting to see the doctor I felt like a number, yes, that's how I felt. I guess it's because they're overloaded, there are so many people waiting for an appointment. Once the doctor made a mistake, and didn't ask me for everything they needed for the*

> *analysis. They told me, "I'm afraid we forgot to include your defences." I'd been waiting since 8 in the morning and of course you feel like you're being messed about, you're not well and it makes you feel worse. You don't spend seven yours sitting there waiting for some results just for the fun of it, I'm not well. They don't take that into account. It's not their fault, it's the hospital in general, the people at the top, the person in charge, these situations shouldn't happen. I don't think they value it, I think that's a problem. I think the problem is that they're overloaded. The doctors and nurses are overloaded. But what's not right is for example what happened the last time I went, the doctor, who's really good, the poor woman apologized and everything, it was 2 in the afternoon. Apparently her colleague was off and she had to do everything herself. (m3)*
>
> *It would be good if more resources were provided so doctors could be closer to us. That's bad. In the end health is what keeps a country going. The health system is in a mess and the people who work in it are overstretched. (m4)*
>
> *It's the same with the nurses, there are so many people to care for and very few resources. The doctors and nurses can't keep up when there are so many people. (m2)*
>
> *I'm used to it now, but at the beginning I didn't understand. I didn't ask because if you ask instead of making you wait one hour they might make you wait an hour and a half, that's a big daft but sometimes you prefer to keep quiet and keep your head down, let them do the test and off you go, because while you're there you're worried. (f1)*
>
> *Because I'm aware that the doctors are always in a hurry, until the day I left I didn't ask what I had had, what treatment and what I had to do. Then they explained to me that I'd had clots in my veins and what they'd done to me. (m4)*

Some interviewees identified other patients as a source of information, both in waiting rooms before appointments and in hospital units. Many of the members of the group of people who had had heart attacks said that room or ward companions were a source of information about hospital routines, diagnostic tests or administrative issues. It is not uncommon for the people who have already gone through the same process to act as a source of information, something which in principle is positive, as is evidenced by self-help groups. However, depending on the course of the illness and the particular circumstances of the individual patient, obtaining information in this way can generate a lot of anxiety especially where the patient does not have an opportunity to discuss it with a nurse or doctor.

> *Well, you've been scheduled so they can do a range of things to you which in theory have been explained to you and are for your benefit, to cure you, to make you better, so you feel better, although they also explain that you can have some setbacks. So you're waiting and someone says, "It can burn you." And you've got to work out what they mean, once I asked a lady, "But has that happened to you?"*

> *And it turns out she was talking about who knows what case. Some people like talking about misfortunes, but even if you know that, what the person says stays with you. (f8)*
>
> *I was really afraid, because of all the things you hear in the hospital. At the appointments everyone says how they're getting on. While you're waiting for your appointment, your fear and doubt are growing. I even asked the doctor if I could change the brachytherapy schedule because of comments people had made. (f3)*
>
> *What happens is that once you've already been in for a few days, because they don't catheterize you when you go in, once you've been in for a few days, well the companions in here start telling you what it's like and what it's not like and by the time you get there you more or less know. Everyone tells you something, how it's gone for him, and so when you get there, well, you know what's what. In the waiting room, wandering about here, your room companion. (m2)*

8. Nurses' participation in the information process

In recent decades, one of the big changes in the health environment has been the fact that nurses have acquired a greater range of healthcare responsibilities. In most services, the role of nurses in providing information to patients and other users is far more important than it used to be. This may be because they are employed in positions where they have a specific responsibility for the provision of information, as is the case with clinical nurses in functional units; it may reflect the fact that nurses work closely with health service users and therefore have a better understanding of what caring really involves; or it may be a response to the changing needs of patients in the light of their illness and the treatment they are receiving. As a result, stereotypical replies such as “you'll need to ask the doctor” or “I can't tell you about that" are less and less common. The role of nurses is reflected in the following comments:

> *I asked the nurse because she's the one I spend most time with, I asked her why, if they'd said it wasn't going to be much, they were doing so many things to me. She was the one who explained the importance of being treated. (f4)*
>
> *The nurse explained the operation process really well, and what could happen to me and that in surgery they analyze it and if necessary they remove your lymph glands. I understood, even though I was terrified of everything. (f3)*

> *I received the most direct information from the nurses, at the beginning you don't understand anything, but when I started chemo, it was the nurses; the wig, the advice. The doctor does his job but I got more information from the nurses, above all at chemo. I don't see any change now, it's four yours since I was back in with a recurrence, but I still get more information from the nurses than from the doctor. And I'm different to how I was at the beginning too. I ask more, maybe the doctors didn't give me more information because I didn't ask. (gf2)*
>
> *I've found the nurses much closer than the doctors, much closer in the way they tell you things. It's the nurses who help me during treatment, they tell me what to do when I get home. (gf2)*
>
> *I think this is more the job of the nurses, they're there all the time. The nurse gives you the information, not the doctor, whatever the reason. The nurse has the job of providing information and doing everything possible to help the patient. The doctor should answer your questions. Morally, I think it's the nurse's duty. (gf1)*
>
> *As far as I'm concerned, during treatment, it's the nurses. When I went in for an operation, in my case it was good, fast and good, but the problem comes afterwards, during treatment. You go in for your appointment, he reads your papers and tells you everything's okay. (gf2)*
>
> *In my experience, I was lucky with the nurse in the breast unit. She was the one who explained everything and helped me, always, the effects I would have, what I could do, where I had to go, she helped me with my family. (f3)*

A close and constant source of information

The closeness of the nurse's relationship to the patient, both because of the amount of contact with patients when they are in hospital or receiving treatment and due to the nature of the actions nurses perform, means that nurses often play an important role in supporting patients, as several of our interviewees noted. The nurse helps patients to understand the diagnosis, treatment and care. This involves providing information about nursing care, assisting patients in understanding medical information, and establishing a relationship which enables the patient to have the best possible quality of life, whatever the impact of the illness.

> *The doctor is the one who says, but the nurse is the one who does it, you're they're for a while and you open up. (gf1)*
>
> *Well, you open up more to the nurse, there's more trust. (m1)*
>
> *The nurses have helped me through a lot of difficult times. They've helped me more than the doctors who've done their job, and that's that. But all those difficult times*

> *I've been struggling with over the years, it's been the nurses. They're much closer and also they see that you're down and they come, there's more intimacy, you go to her so she can explain what the doctor's told you. (gf2)*
>
> *Sometimes it's better that the nurses tell you than the doctors, they're better at it. (f4)*
>
> *Of course, the nurse has to tell you, for example with the wig, she tells you how to put a headscarf on, smoothes the way a bit. (f8)*
>
> *The nurse tells me what the radiotherapy consists of, I don't see the oncologist without talking to the nurse first, when I go to the oncologist she explains it to me again. (f2)*
>
> *In chemo, the nurses explained it to you, yes, and they asked if you'd understood … When I went to chemotherapy, the nurses asked me and made notes and that gets passed to the oncologist. (f7)*
>
> *You're more intimate with the nurses. You can ask them and talk to them. But with the doctor it's hello and goodbye. But with the nurses, more or less, they've got time. (gf1)*

Ambiguities in the nurse's role as a provider of information

However, the nurse's role – particularly in regard to medical information – is far from clear. At times the nurse is seen as being caught between service users and doctors. Our interviewees noted that sometimes nurses are not entirely sure of the scope of their own responsibility for information, and this can cause them to provide incomplete information or to consider their own responsibilities as being inferior to those of the doctor:

> *It's as if nurses were afraid of getting in the way of the doctor, they only half tell you things, they don't want to tread on the doctor's toes. You can see that they know, but they tell you to ask the doctor. (gf1)*
>
> *The doctor told me, "You've got to do this." I asked him if the treatment was heavy and he said it was medium. I also asked the nurses and they said, "What did the doctor tell you? Well, that's it – neither heavy nor light." (f7)*
>
> *They gave me the results of the catheterization when they finished, because I was wide awake, they told me, "It's gone really well, couldn't have been better." But on the ward they still gave me six pills a day and they didn't explain why, and if I asked they told me to bring it up with the ward doctor. (m5)*

9. Support groups

Support groups are an increasingly important means for tackling health problems in general and chronic or long-term problems in particular. There is a wide range of associations and programmes which address people's demands for information, both in the form of officially sponsored education and health information groups, and in the form of groups set up by patients. Their principal concern is to identify shared interests and to pool experiences and information. These groups play an important role in health information, both by providing such information and by helping individuals to better understand what is happening to them and how to deal with it.

Information management

The aims of these groups include providing information and helping people to understand it, and they do this through a variety of means, including talks, lectures and leaflets. The interviewees reported having received help in understanding the illness process and the options available, and also having been given support. There is a clear need for this type of support which goes beyond what health professionals can provide:

> *At that point I can tell you that I didn't go looking for information, there were quite a few of us who were going to have the operation, more or less at the same time, and we said, "Well, why don't we set up an organization?" Everyone brought their own experiences, we met several times, we held talks and one of the oncologists gave a couple of lectures. The nurse from the breast cancer unit also came and it went really well. (f10)*
>
> *The association is a group of friends and that's what we have in common, it's really great. (gm3)*

Sometimes people turn to groups for support that they don't get from health professionals. These groups have a very clear role to play in the health information process.

> *When I came out after the operation I went to the cancer association. There they gave me lots of information, and I could ask them questions, above all about my arm. (f9)*
>
> *I started to find out about what I had after the heart attack when I went home. At the health centre they told me there was a group which organized talks, with two nurses who came every Monday. They give talks, I attend and that way I learn. I*

> *more or less knew about the food, but they explain what you have to do for everything. (m4)*
>
> *I got all the risk information and the rest of it afterwards, at the talks at the health centre. At the hospital they don't really explain it properly. You come out and you don't know what it is you have to do. They tell you superficially but not properly. (m3)*
>
> *Shortly after it happened, the doctor asked us if we wanted to go to some talks they give every Monday. Various people came and told us what it was, what was happening, what we should eat, exercise, activity. (m2)*
>
> *The association is to give information. That's why we have it. That's the reason why we have it. That's the main reason. The other things we do are in addition. (gf4)*

Benefits

Among the possible benefits of taking part in an association is the feeling of helping people in similar situations. The association puts people in touch with others who have the same problems and makes it possible for them to share experiences.

> *It was the only place where you could talk. If you were feeling okay emotionally you could talk, but also on Thursdays we had talks from various health professionals. I wondered whether I had anything to contribute. For example, sometimes somebody would come who wanted to have reconstruction but didn't know how it would turn out. Reconstruction involves making a lump which is as similar as possible to your breast, basically that's it. Of course, people come with the same worries I had, that cancer equals death. I understand their worry, I know that everything has a solution, or almost everything. Of course, you always fear the worst but there's so many of us in the association, the majority of us have been in it for years, we've been through it, we know from our experience for example that the effects of chemotherapy disappear, that your hair grows back at a rate of a centimetre per month, we know that you can start sunbathing again after a year, that you should always wear sun cream. That's essential in order to live with the cancer as well as possible, and you have to explain it. (f1)*
>
> *I've had a lot of solace from the association. Being with people like me, that really helps, people who already know what's happening to you. It's not a question of drawing comfort from others' misfortunes, there's understanding, nobody can understand it if they haven't been through it; some of my friends who haven't experienced the problem don't understand me. (f2)*
>
> *I came just by chance. I saw the association's leaflets and someone I knew told me I should go. I thought, I live alone and this might help me. I was aware that cancer*

> *is an illness that can have a psychological affect on you, and that's why I came. I did it just in case. You see that there are other people in the same boat and your self-esteem goes up, one by one we help each other, sometimes we're not aware of how much good we do each other. (gf5)*

It may be that using one's personal experience of the illness to help others is also positive for the individual providing this support. Working together to improve the lives of people with similar problems is another kind of benefit. This works in two directions: people are able to find help and feel that they are not alone, but they may also benefit from giving help and companionship to others, because this makes them feel useful.

> *I've helped people who go to the talks, new people. We have a real need to talk. Some people whose lives are difficult, people who are 40 years old and have had a serious heart attack but who need to carry on working, and depending on the company and the job they can't do it any more and they're afraid, of course, the mortgage, the kids. Sometimes this stops them from doing what they need to do or from looking after themselves properly, your personal situation has a big influence. (m3)*

> *Patients who have already been through it can help those who are beginning. I think so, a lot. Some people are more afraid and get themselves into a state and if there's nobody to encourage them they end up lost. (m7)*

The women in the focal group, who belong to an association, were unanimous in agreeing that the association met needs which were not addressed by health professionals. This was confirmed by one of the members of the cardiology help group:

> *In the association, we discuss the scientific information, even though we already know. What is a heart attack, the arteries of the heart, cholesterol? But the rest of how to do it, sexuality, your partner, attitudes … we discuss that here. The psychologist's help is very important. (gm3)*

10. Issues not included in the information on offer

Our interviewees identified two particular issues where there is a lack of knowledge and of support: sexuality and the therapeutic administration of cannabis. These were seen as major issues, the first because it is a basic human need, and the second as a means of controlling the side effects of chemotherapy and treating pain. However, neither of these issues is discussed at a professional level by the health services. They are not usually raised by health professionals or openly requested by patients. At the very least this is something which it would be interesting for external observers to consider in more detail, assessing the possible causes and what happens when there is a lack of adequate, specific information regarding people's day-to-day situations.

Sexuality

Both breast cancer and heart attack have a significant affect on patients' sexual needs. In heart attack sufferers, due to its link with a risk activity, and in women who have had a mastectomy, due both to the change in body image and to other personal factors, sexuality is one of the needs which is most likely to suffer. However, this is often treated as a secondary issue, or seen as something which will be resolved over time. Although we found that it concerned the majority of interviewees, it continues to be regarded as a personal issue which is not addressed within the context of the health relationship.

> *Of course they are interesting issues, but people don't talk about them and they are important. (f4)*
>
> *Oh, no, not sexuality, no. I'll tell you something, at the beginning it affected me a lot, you feel tired. But then I didn't ask, maybe because I got it when I was 59 and when you're 59 you think twice before asking certain things. (f7)*
>
> *Of course, and it's changed a lot. It's not like it was before for him or for me. They're difficult conversations to have. Within the relationship we haven't talked about it either, but I can see it. With the treatment, just now I don't feel like it. It seems this is a stage and I think well if I've got to go through some bad months, well that's how it is. Then it seems like it's because of the medication I'm on, you don't feel like it like you used to, you always come up with an obstacle. For me, when the chemotherapy is over. If I carry on like this, I'm going to ask someone, either the doctor or the nurse, who could also give me information. First I'd ask my family doctor. (f3)*
>
> *It's usually taboo. When he prescribed me these pills I told him I was doing very well and that my sex life was good because I didn't have any dryness. We didn't talk about it any more, I didn't ask him and he didn't ask me. But if it's another problem, he only asked me about the dryness because there are solutions, but I didn't need help because it didn't happen to me. (f8)*

The following woman expressed the problem clearly, identifying it as a personal matter which she finds very difficult to talk about:

> *The only thing is that we haven’t had sex the whole time, my husband says, “Don’t worry, I'll just think of it as a year off, it’s not a problem.” I suffer in this way because I’ve really lost all my sexual desire. It’s the only thing I’ve missed during the treatment, because of my husband. After surgery and before starting the treatment we had one attempt but it wasn’t very good because he didn’t take my pyjama top off; I thought "that’s not good". When you’re having sex the man goes for the breasts and that’s why I thought it wasn’t good, he didn’t even take my pyjamas off, but I thought it was because it was the first time and we had to give it time, but because I’ve completely lost my libido there haven’t been any more times. I haven’t talked about the issue because it’s personal and we need to sort it out between ourselves. I think I’ll get better with the reconstruction, but of course I’ve lost the sensitivity of that breast, I’m not going to have it. But I’ve got the other one, it’s to do with my husband. I haven’t discussed it with anyone else, you're the first person I've talked to it about, with my brother, with my friend, and with you. It’s too personal. Discuss this with the doctor at the appointment, when everything goes so fast? She asks you about the treatment, but tell her about what you feel, I think it’s too personal and I don’t know how to deal with it afterwards. I lack information, nobody has told me that sexually this could happen to you, I’ve read it in a book I found. I haven’t searched for it on the Internet, not at all. Thanks to the books the association has given me, everything at the association. Sexuality is always left as something for afterwards. When we were doing it he was very afraid of hurting me. (f9)*

Although sexuality may be a personal issue or something people discuss with their partners, there is also a more or less explicit expectation of health professionals.

> *I’ve never spoken about it to any health professional. When I go to a health professional it’s to talk about the illness. It's very cold at the beginning. My husband says just tell me when you want to. If years had gone by ... but it's not gone that far. (f6)*

> *The doctors and nurses, nothing, they don’t deal with the issue at all. It depends a lot on your partner. These questions don’t reach the nurse. (gf4)*

> *I think the one who’s at fault here is the nurse because you won’t go to her to tell her straight out, “Look, this is happening to me.” Just as she tells you about other things, she should tell you about that. She should bring up the issue, that concern, and help you to talk about it. Open the way so the person can explain themselves and then come right out with it and say, look, I don’t feel like it, it’s very difficult. (gf1)*

The effect on the partner is very clear in the group of men who say that they could resume normal sexual activity but the difficulty lies in the fear of their wives, who link it with the risk of heart attack.

> *Often, it's fear or more than fear it's knowing how to make love now. Sometimes the doctor says you can do it, but you speak to your partner and she's afraid. In my case, the heart attack happened five minutes after we'd done it, and obviously my partner was really affected by that and is afraid. (gm1)*

> *The fear is not so much for yourself as for your partner. Education should involve the partner. She's the one who's more afraid, she suffers much more than you do. I'd almost say it affects your partner more than it affects you, she's much more afraid. (gm3)*

The therapeutic use of cannabis

If sexuality is a taboo, the same is true of cannabis use. There appears to be a degree of agreement among professionals with regard to its positive effects; however, because cannabis has not been legalized, recommendation of its use is seen as lying outside the professional remit. Although its therapeutic effects are well known, particularly with regard to vomiting a result of chemotherapy, it is not offered as a treatment but rather as a specific resource to which the woman may resort. Despite this, information about cannabis is available and women are aware of it and make use of it.

> *For vomiting there are conventional antiemetics and there are other systems like marijuana, for example. Always for people doing chemotherapy and suffering from vomiting. You have to know that you have to take it the day before the treatment and the day afterwards. If I meet someone who's vomiting and can't control it with the antiemetics, I say, "Are you prepared to try something different?" I tell them to try to find pure marijuana, the female plant, you know by the flower. If you buy it to grow it's very easy to see it, if you buy it to consume it's difficult because it can be in pill form so you don't see what you're taking. The female plant has more properties; once the plant has flowered, you dry it and once it's dry you separate the buds, the leaves and the flowers, you need to consume what you need, for example as an infusion diluted with oils, either oil or butter. You put very hot oil in the frying pan and you chuck the grass in, before it starts smoking again you turn it off and you spread this oil on bread or make a salad; the properties of the marijuana are in the oil. If it is ingested dissolved, for example in an infusion, you add a bit of butter because the oil is what makes the grass release its properties. If it's in a cake, it's okay because it's already got butter. If you smoke it the effect is more immediate*

> *but shorter. I've got this information from anthropologists, a head of pharmacology and from the nurses in a public hospital. (f1)*
>
> *It really works. You take a pill when you need it, and that's that. It's impossible to get addicted. When you smell it afterwards, because you associate it with how ill you've felt, well you can't even look at it. They should legalize it and give it to you as just another pill. You take it on the day and that's it, so what, what's there to be afraid of? I tried it and it really works. It's something you use the day you need it and that's that. When you feel worried and desperate because you're vomiting and nothing is working. They give you Primperan pills which really don't work, I just need to look at them to feel nauseous. So this really works. (gf2)*
>
> *Afraid of becoming a drug addict? Get away! You should take it every day like any other medication, if you don't vomit you don't do it because you're a bit afraid, but it's just a drug you know. (gf3)*

Clandestinity is always a concern, and the legal issue is obviously decisive here. For example, one patient explained how the nurses gave her information, but outside of the care unit:

> *They give you this information too, there are oncology nurses who give you the information. In the association, we found out about this issue from some nurses. They didn't tell you in the department, they told you in the bathrooms. (f1)*
>
> *I just don't see why they don't tell you about cannabis. I smoke cannabis and it makes me feel better, I haven't got anything against people who think it's a drug, but it helps me a lot and that's why I take it. But I can't talk about it with everyone. (f7)*

It is also widely known that information can vary greatly and is sometimes more ideological than evidence-based. However, it appears clear that women feel the need for a health professional to confirm and endorse use. It therefore seems worth considering the issue of cannabis from a healthcare perspective.

> *I gathered the information and asked my doctor about it. We had a chat about it and I went to find out about it with my doctor's consent. (f5)*
>
> *I was lucky enough to have a nurse who worried about me and that's why I had the courage to go and find it and take it. The nurse was the one who told me, she told me about it. (f4)*
>
> *I didn't take it because I was a bit afraid, maybe if I'd carried on feeling ill I would have done it. I thought, "Maybe I'm going to get addicted." Without information I didn't dare. During the last round of physiotherapy, they gave me homeopathy. I asked about marijuana and they said it wasn't worth it. I thought, "I'm already in a bad enough state. All I need is to become a drug addict." (gf5)*
>
> *First I asked the doctor I had at the time and she said, "Bah!" I said, "I was only asking if it works or not, if it causes problems or not, I don't want you to give it to*

> *me, I know where to get it." She looked at me and didn't answer. Then I asked another doctor who said, "What? We don't give that sort of treatment here." (gf3)*

Information is obtained, to a large degree, from help groups:

> *A woman called saying she had a friend with lung cancer and a lot of pain and vomiting, and she asked if we could give her some marijuana. I said, "No, we don't give out marijuana, we don't have it here, and we're not going to. But I can explain how he should take it." And I explained. (gf4)*
>
> *The association has had this information for years. (gf2)*

Finally, we reproduce the testimony of a 73 year-old woman who took part in the focus group. She explains how she obtained marijuana and repeats the view already stated by others that it would be much easier if this was seen as a treatment.

> *You know, I've eaten both pots, but not because of vomiting, because of a back injury. I found out from a woman who said she'd take it, my son gave it to me. I couldn't take any more drugs, nothing was any good. I thought, "I'm not going to take anything else, I'm going to look at this marijuana." The medication the traumatologist gave me was for the attacks of epilepsy and on top of that it didn't get rid of the pain. I've already eaten two pots. The first time I went to an address they gave me and said I had cancer. They let you into a corridor at the back and then you go up some stairs to a first floor, and I thought, "If the police come I'm done for!" They had a few sacks full, and they gave me some when they saw what I had. Of course, because I didn't know I took too much and got stoned, a trip, I took too much. The thing is, if they gave it to you packaged it would already be the right dose. There are cannabis associations. Everyone knows that. It's an open secret. I went, so long as you have a document saying you're doing chemotherapy they give you a card, you join and they gave it to me, yes, as often as I needed it. (gf1)*

Issues for discussion

Having collected and analyzed the data, we can now identify some key issues for discussion and analysis in the seminar:

- People want to be informed and told the truth, in a sensitive, appropriate way.
- Family members have an important role to play in accompanying patients, but they should not replace them and they also need information and support.

- The need to include information as an integral part of all health interventions and the need to consider the right to information as the shared responsibility of all health professionals, whether care providers or managers.
- Because information cannot be separated from interpersonal relationships, it is important to work on the personal qualities which help the information process, helping health professionals to overcome any difficulties they encounter in establishing relationships which have an emotional component.
- Reformulate the culture of informed consent so as to move away from taking a purely defensive approach and seeing it primarily as an ethical rather than a legal requirement.
- Consider the criteria for managing and organizing services which treat the information process as just one more activity to be implemented using adequate material and staffing resources. We should reconsider the importance of ensuring that there are professionals who provide a continuous point of contact and of allowing more time for emotional issues.
- Teamwork is a guarantee of high quality care, but it can make patients feel insecure.
- The relationship between the health world and non-professional associations could be improved, with the aim of working together to provide information and support to people with life-threatening health problems.

We will end this report with the words of one of the participants in the cardiology focus group:

> *Information is something you have to work on, it's the nurses and doctors who have to work on it. When someone is ill, they put themselves in the hands of professionals, we're dependent; in the last instance you're the ones who know. When you're ill you want people to help you. You are the ones who have to work with information. For example, by helping associations become better known. The patient is the patient and all the information is necessary, but sometimes the patient doesn't know how to ask for it, doesn't know what he has to do. If you don't do it, then sometimes the patient doesn't make progress or has more problems. You don't realize until you've been through a process like this. It has to be professionals like you who think about*

the information we need and organize yourselves for that. You have to make the people around you aware that patients can take responsibility, but they don't know how to. You have to be very self-critical and realize that support is needed. People already do what they can, but sometimes they just can't do anything more. (gm3)

Appendices

Interview protocol

FIRST PART

Start the interview by talking about informed consent and the patient's opinion of it, including the family member if present. Discuss whether they have experience of informed consent and what it was like.

1) Consent and information

- Opinion regarding informed consent and how it is formulated (content and form).
- Opinion regarding the participation of family members in the information process.
- General assessment of the information that has been given and received, ease of understanding, language used, etc.
- General opinion regarding experience of information process and the obtaining of consent.
- Usefulness of information as applicable: deciding what to do, greater personal security, better understanding of what was happening, etc.
- Relationship with intimacy and private life, possible invasions of this either due to having to give very personal information or because of the high number of people providing care.

2) Information given to health professionals

- Opportunities of sharing with health professionals any information the patient thinks is needed to provide better care.

- Opportunities of talking about habits, customs or any issue which is relevant to the care.

3) Information and communication

- Opportunities of communicating needs and experiences with professionals, room mates or fellow patients, family members etc.

4) Opinion about public or private health care

5) Type of health cover and how it is used

SECOND PART

1) Information prior to illness

- Knowledge prior to illness.
- If you had any, how had you acquired it:
  - other family members with illness, or friends,
  - media: TV, newspaper health supplements, specialist magazines, general magazines, etc.
- Preconceived ideas – for example, about cure or type of treatments.
- Others.

2) Information about diagnosis and treatment (both in hospital and at health centre)

a) Information about the illness and its treatment:

- About diagnostic tests and/or monitoring.
- About the meaning of the symptoms and signs of illness.
- About possible treatments.
- About the expected development.
- About your specific case and situation.

b) Most significant people with regard to information and acquisition of knowledge during this period:

- Professional interlocutors: doctor or nurse or several health professionals all of whom provided knowledge and information.
- Significant health professionals who have supplied information and have helped during the information process. Do you recall anyone in particular? Qualities or attributes of this health professional which you liked and would like to see in other professionals.
- Degree of confidence and proximity of doctors and nurses to the patient.
- Information from room mate, or people you have met in the waiting room or during treatment. Were you able to check this information with a health professional?
- Other sources of information, for example the internet, scientific magazines, or information from other health professionals, e.g. second opinions, the doctor or nurse at your primary health centre, a friend who works in the health sector, etc.
- Patients' associations, neighbours, friends in similar situations, etc.

3) Help in understanding the information received

- When information was most often received: during ward visit, medical appointment, while care was being administered, when taking medication, etc.
- Where information was most often received: room, doctor's office, corridor, during diagnostic tests, in a room specially provided for that purpose, etc.
- Opportunities to ask questions and clarify doubts. Was there any health professional who was most important for this?
- Qualities, attitudes or ways of doing things that helped you.
- Negative aspects which you would not like to be repeated.
- Positive aspects which you would like to see repeated on other occasions and/or for other patients.
- Aspects which you feel are missing, in health professionals, at the hospital or during appointment, with regard to the primary health care centre, etc.
- Use of any patients' associations or self-help groups and other support information received.

4) Information about hospital or health centre routines, daily life in the unit and care

- Expectations regarding information on care, and information which should be received in this regard.
- Information about how to adapt one's life during hospital stay(s) or when attending for treatment.
- Identification of people caring for you:
  - Did you know their names? Did you know who to tell if you needed something?
  - Could you identify the people caring for you?: doctors, nurses, auxiliaries, medical or nursing students, etc.
- Organization of care: information about the organization of your care. For example:
  - Preparation for diagnostic tests.
  - Measures required for your safety.
  - Prevention of infections.
  - Changes in position.
  - Mobilization.
  - If you had to stay in bed.
  - If you had to follow a special diet.
  - Administration and effects of pharmacological treatment.
  - Information about hospital rules, food, hygiene, visits.
- Modifications to care. If there were any, were they explained to you? Or did you have to request any changes, or would they have been good?

5) Information about the medical treatment and development of the illness

- Expectations about information regarding the illness, its development and treatment.
- Health professionals who have played an important role. Role of doctor(s) and nurse(s).

- Help received (from professionals at the health centre or elsewhere, or from others not connected to health institutions) to understand information on diagnosis and treatment.
- Participation in clinical decisions. Possible questions:
  - Remember what has already been asked in the first section regarding consent and continue with the answer if necessary.
  - Opportunity of giving an opinion regarding treatment and/or diagnostic test decisions.
  - Refusal to undergo treatment or test, or to take medication.
  - Opportunity of choosing between two treatments or tests.
  - Cooperation and help from the nurse in understanding medical information.

6) Discharge (if applicable, depending on situation of interviewee)

- Expectations with regard to discharge information.
- Health information about habits of life, care at home, medication, development, etc. Modifications required due to illness, treatment, prevention of possible complications, etc.
- Relating the information with feelings of security in daily life. Aspects which would have helped you to do this.
- Usefulness of the recommendations received.
- Most significant people at this stage: doctors, nurses, family members, friends, other patients, etc.
- Do you think you should have known more? What subject should be more information about?

7) Subsequent monitoring

- Resolution of doubts which arise during the course of daily life. People and sources used: doctor, social worker, pharmacist, other patients, patients' associations, family member etc.
- Modifications to daily routines as a result of information received.

- Opportunities of relating the information received and care given by health professionals with the changes to life arising from the illness.

TAKE DOWN ANY COMMENT THE PERSON WANTS TO MAKE

1. **Focus on the characteristics, qualities, attitudes, etc. that the individual considers nurses and doctors need in order to be able to provide information and help patients to understand it.**
2. **Focus on relationship between information and decisions, relating both to clinical issues and to care.**

PERSONAL DETAILS:

- Male or female, level of education, level of education of partner, children.
- Background. Family details which may be relevant. Children or relatives who are ill.
- Other illnesses and/or hospital stays of interviewee, family member or close friend.
- Other details.

CONTINGENCY SHEET:

Impressions of interviewee:

- Housing, physical space, characteristics.
- Impression of cultural and socio-economic level.
- General impression of interview, ease of conversation, issues of most interest to interviewee, participation of family if applicable, etc.
- Consent for interview, formalities and need for additional information.
- Requests made by the patient or family member which we should respond to.

Sample profile

Description of participants in the group of women with breast cancer

Interviewer: Melinda González

INTERVIEW NO. 1

Source	Duran i Reynals Hospital. Interviewed at home.
Treatment	Conservative surgery.
Age	65 years.
Family	Married. Husband works at SEAT car factory. Two daughters with university degrees, second still at university, the older one married.
Education	Compulsory schooling; university studies.
Work	Worked until birth of first daughter and then took on care of her family, both immediate (husband and daughters) and parents, parents-in-law and aunts and uncles.
Housing	Old part of Gavà. Two-storey house.
Patients' associations	Belongs to Lliga Catalana contra el Cáncer.
Relevant issues	Requests information on sexuality. Has taken marijuana. Husband is at home during interview, but does not take part.

INTERVIEW NO. 2

Source	Grupo Ágata. Interviewed at home.
Treatment	Mastectomy and reconstruction. Currently being monitored. Private health care.
Age	54 years.
Family	Married. Two daughters aged 24 and 29. Husband is on sick leave for cancer of the colon, has undergone operation and has ileostomy.
Education	Compulsory schooling.
Work	Family business. Not working at present.

Housing	Flat in centre of Barcelona.
Patients' associations	Member of Ágata.
Relevant issues	She is responsible for her husband's illness. Decided to change to public healthcare system for her treatment. Afraid of talking about consumption of marijuana and involving the association in it. Has taken marijuana. Husband is present during the interview, but does not take part.

INTERVIEW NO. 3

Source	Grupo Ágata. Interviewed at home.
Treatment	Double mastectomy and reconstruction of one breast. Relapse after six years. Private health care in two clinics.
Age	49 years.
Family	Married, has two daughters aged 26 and 28. One is a teacher and the other works at the stock exchange. One lives at home.
Education	Compulsory schooling.
Work	Started working at 14 and has always worked in the film industry; in cinema labs and editing films, adverts. Currently on long-term sick leave.
Patients' associations	Member of Ágata.
Relevant issues	Gets all her information for monitoring and daily living from the association.

INTERVIEW NO. 4

Source	Duran i Reynals Hospital. Interviewed at hospital.
Treatment	Conservative surgery. Public healthcare.
Age	59 years.

Family	Married, has one daughter studying marine biology in the Canary Islands. Husband works making television documentaries. Her brother has stomach cancer.
Education	High school.
Work	Has worked with children with learning disabilities. Not working at present, and enjoying leisure.
Patients' associations	No, says she has the ability to deal with it herself because of the kind of work she has done.
Relevant issues	The interview is conducted at the hospital because her brother is in hospital and she doesn't have much time. Despite this she gives us two hours.

INTERVIEW NO. 5

Source	Grupo Ágata. Interviewed at home.
Treatment	Double mastectomy, reconstruction of one breast. Currently with secondary tumors in liver. First diagnosis and first mastectomy in private health system, rest in public.
Age	43 years.
Family	Married twice, divorced once. Two sons aged 14 and 6. Husband is industrial engineer.
Education	Secretarial studies.
Work	Executive secretary.
Housing	Flat in Barcelona's Zona Alta.
Patients' associations	Member of Ágata.
Relevant issues	Illness began while her second child was less than one year old. Has taken marijuana. Husband is at home during interview, but does not take part.

INTERVIEW NO. 6

Source	Duran i Reynals Hospital. Interviewed at home.
Treatment	Conservative surgery. Public healthcare.
Age	53 years.
Family	Married, has two children who have both left home. Husband has an aluminium company in Hospitalet.
Education	Compulsory schooling.
Work	Helped husband in company. Currently does not work.
Housing	Detached house 30 km from Barcelona, two floors and garden.
Patients' associations	Would like to participate to be able to help others in the same situation.

INTERVIEW NO. 7

Source	Duran i Reynals Hospital. Interviewed at home.
Treatment	Conservative surgery. Public healthcare.
Age	52 years.
Family	Married, has three daughters, only one of whom lives at home. Grandchildren. Husband is retired, used to work at the Sangrá factory. Daughters work as bakers.
Education	Compulsory schooling.
Work	Owns a bakery. Looks after house and family.
Housing	Flat in Sant Boi, second floor without lift.
Patients' associations	No, says she hasn't felt able to attend.
Relevant issues	Has taken marijuana, finds it difficult to talk about. Husband is present during the interview, but takes very little part.

INTERVIEW NO. 8

Source	Duran i Reynals Hospital. Interviewed at home.
Treatment	Conservative surgery. Two hospitals in the public healthcare system.
Age	38 years.
Family	Married. Has one son who is a mechanic. Husband is self-employed.
Education	Secretarial studies and IT.
Work	Has been office worker and administrator. Currently on sick leave, but helps her husband.
Housing	Flat in old part of Terrasa, second floor, no lift.
Patients' associations	No.

INTERVIEW NO. 9

Source	Duran i Reynals Hospital. Interviewed at home.
Treatment	Conservative surgery. Public healthcare.
Age	68 years.
Family	Married, has three daughters aged 23, 30 and 32. All are working, but only the eldest has gone to university. Social worker. Husband unemployed since 55 due to closure of company.
Education	Compulsory schooling.
Work	In a factory, cleaning houses, offices, until illness. Currently retired.
Housing	Flat in Hospitalet, fifth floor, without lift.
Patients' associations	No.
Relevant issues	Interview conducted with husband who is watching the television at the same time and contributes the occasional remark.

INTERVIEW NO. 10

Source	Duran i Reynals Hospital. Interviewed at hospital.
Treatment	Conservative treatment. Public healthcare.
Age	50 years.
Family	Married, has two adolescent sons who are at school. Husband has a restaurant.
Education	High school and commercial studies.
Work	Worked in a company until it closed. Helps husband in restaurant.
Patients' associations	No.
Relevant issues	Interview was conducted at hospital.

Description of participants in the group of men with cardiological problems.

Interviewer: Cándida González

INTERVIEW NO. 1

Source	Bellvitge University Hospital. Interviewed at home.
Illness	Myocardial infarction. Public healthcare, clinics covered by public health insurance.
Age	70 years.
Family	Widower. Has two sons, one of whom is married, the other lives with him and is a lorry driver.
Education	Compulsory schooling.
Work	Retired.
Housing	Flat in Hospitalet. Top floor with lift.
Patients' associations	No.

Relevant issues	Son arrives halfway through interview and starts getting food ready.

INTERVIEW NO. 2

Source	Bellvitge University Hospital. Interviewed at hospital.
Illness	Angina. Double coronary bypass. Diabetes. Public healthcare.
Age	62 years.
Family	Married, has two sons aged 27 and 33 who have left home.
Education	Compulsory schooling.
Patients' associations	No.
Relevant issues	Interview was conducted at hospital due to urgent admission.

INTERVIEW NO. 3

Source	Cornellá primary health department. Interviewed at home.
Illness	Angina, bypass. Last year had a relapse and new surgery. Diabetic since 32. Insurance and public healthcare system.
Age	40 years.
Family	Married, no children.
Education	Compulsory schooling.
Work	Works at a company in Martorell. Currently on sick leave, problems in obtaining invalidity benefit for long-term illness.
Housing	Flat in Cornellá.
Patients' associations	No, but regularly attends health education group of Cornellá primary health department.

Relevant issues	Won a case against insurance company for negligence. Interview conducted with wife present, who remained silent almost throughout.

INTERVIEW NO. 4

Source	Cornellá primary health department. Interviewed at home.
Illness	Angina. Stent inserted. Public healthcare.
Age	74 years.
Family	Married, has three children who do not live at home.
Education	Compulsory schooling.
Work	Blacksmith by profession, sculptor.
Patients' associations	No, but regularly attends health education group of Cornellá primary health department.
Relevant issues	His wife was treated for breast cancer 10 years ago. Interview was conducted in the presence of his wife, who played an active part.

INTERVIEW NO. 5

Source	Bellvitge University Hospital. Interviewed at hospital.
Family	Married, has two sons who do not live at home. Three grandchildren.
Education	Compulsory schooling.
Patients' associations	No.

INTERVIEW NO. 6

Source	Bellvitge University Hospital. Interviewed at home.
Illness	Heart attack 5 years ago. Has just had a relapse. Public healthcare.
Age	79 years.
Family	Married, has two daughters who don't live at home.
Education	Compulsory schooling.
Work	Retired.
Housing	Flat in Cornellá. No heating, no lift.
Patients' associations	No.
Relevant issues	The interview was conducted together with his wife, who took an active part.

INTERVIEW NO. 7

Source	Cornellá primary health department. Interviewed at home.
Illness	Myocardial infarction. Public healthcare.
Family	Married, has one daughter who does not live at home.
Education	Compulsory schooling.
Work	Retired for 25 years due to blindness.
Housing	House in the old part of Cornellá.
Patients' associations	No, but regularly attends health education group of Cornellá primary health department.
Relevant issues	Despite his blindness, is very independent and needs little help in daily life. Interview is conducted in presence of wife, who does not get involved.

INTERVIEW NO. 8

Source	Cornellá primary health department. Interviewed at home.
Illness	Myocardial infarction. First diagnosed in public health system, subsequently went to Montpellier [private hospital], and then went back to another hospital belonging to the Barcelona public health network.
Family	Married, has two sons, one married. His wife has worked in the textile industry and in gardening.
Education	Very basic.
Work	Odd job man, in agriculture, metallurgy.
Housing	Lives with in-laws. House is large, three floors.
Patients’ associations	No, but regularly attends health education group of Cornellá primary health department.
Relevant issues	Also has prostate cancer. Interview conducted with wife present.

INTERVIEW NO. 9

Source	Cornellá primary health department. Interviewed at home.
Illness	Angina. Public healthcare.
Age	53 years.
Family	Married, without children. Wife works in an office.
Education	Compulsory schooling.
Work	Worked in the steel industry.
Housing	Own flat in Cornellá.
Patients’ ssociations	No, but regularly attends health education group of Cornellá primary health department.
Relevant issues	Very critical of treatment received at start of illness. Interviewed with wife.

INTERVIEW NO. 10

Source	Cornellá primary health department. Interviewed at home.
Illness	Operated on for coronary bypass. Public healthcare.
Age	62 years.
Family	Married, with three children who have left home.
Education	Compulsory schooling.
Work	Worked in company administration since age of 16.
Housing	Own house in Cornellá.
Relevant issues	His wife has arthrosis and they currently seem more concerned about this problem.

FOCAL GROUPS:

Catalan Association of Women Affected by Breast Cancer (ÁGATA)

Interviewer: Montse Busquets

Observers: Melinda González and Pilar Antón

Participants: Five members of to Ágata who were diagnosed from two to thirteen years ago. Middle-aged, from 45 upwards. A woman aged 29 didn't answer the call. Two women are treated in the Spanish public healthcare system, two by health insurance companies and one in the private sector. One of them participates in the work of the association, the others are members and attend talks.

One has relatives who are nurses.

Place: The association's library.

Impression: Very good, conversation gets started quickly and active participation is easy to achieve. Woman no. 3 talks the most and is the only one who seems to be using the group for personal therapy, the rest stick to the questions and don't only focus on their own situation but are also able to generalize their opinions and experiences.

Catalan Cardiology Support Association (ACARD)

Interviewer: Montse Busquets

Observer: Ramona Bernat

Participants: Three men belonging to ACARD. Average age of 55. Diagnosed 7, 4 and 2 years ago. Two have had a heart attack and been treated with a coronary bypass and the third went for surgery but couldn't be operated on. One continues in the cardiac rehabilitation programme; two have been treated in the private healthcare system for their heart problem, but continue in the public healthcare system for other needs and to obtain medication; the third has received all his treatment in the public healthcare. All are very keen to participate and eager to discuss the importance of continuing with healthcare after the episode. Play an active part in the association. Two participants could not attend the session despite having agreed to do so in principle.

Place: Association meeting room.

Impression: Very good, contact was very easy and conversation about the problems of information got going immediately.

Contributions of the different specialists invited to the debate

1. Montse Artigas. Head of the Customer Service and Quality Division in the Catalan Health Service

"I don't think that information itself is really the problem so much as the ability of health professionals to interact with patients."

I think this is an interesting study which gives a very clear treatment of all the issues related to patient information. However, it discusses a very particular type of patient with, in my opinion, very specific requirements regarding the sort of information they need and, in many cases, these cannot be generalized to other types of pathology or patient.

When it comes to applying the results, the study may help to define information activities and to provide a basis for individualizing elements which take into account the health problems analyzed. One example is offered where the study states that "knowing the truth is one of the thing patients request, even though this can be very hard." However, we should note that the most recent experience we have regarding satisfaction studies and opinion surveys about services received from the public health system, organized on a service by service basis, indicate that, in the case of patients cared for in palliative care units, for example, this statement does not apply.

For me, the adaptation and individualization of information is fundamental. Considering the ability to adapt the information as a criterion of professional transparency strikes me as absolutely right.

With regard to decision-making, it is beyond doubt that being informed allows people to take better decisions. And I also agree that having enough information about the illness, in the majority of cases contributes to a feeling of being in control of the situation which is very beneficial.

Another issue brought out by the study is the error many health professionals commit when we seek to normalize situations because they are part of our daily experience, but which are absolutely extraordinary for the patient being treated.

In reference to Chapter 6, for me availability is one of the most important of the qualities discussed there (and it may be the easiest to achieve). Of course, this does not mean that other issues are also very important.

At the same time, it is still all too common for health professionals to believe that they are in possession of the truth, and that they can act in the patient's interest without taking into account the patient's wishes, an approach which is a source of complaints from the general public. I also agree that there are still health professionals who have not accepted that the provision of information is a care activity which forms part of the professional's daily practice.

Having spent twenty-five years working in a hospital, I do not believe that the lack of information can be justified by a lack of time. And, in any case, this has more to do with how each professional organizes his or her time. To quote Vallejo Nájera: "the more things you do, the better you organize yourself". In general, when people complain of a lack of time it smacks of making excuses.

In my opinion, nurses have a clear role in the information process, which arises from their professional training and responsibilities, and we need to believe in what we are doing. And I fully agree with the views put forward with regard to support groups.

In our experience, from a study carried out by the Catalan Health Service among people who received acute hospital care from the health services, in the qualitative phase (focus groups) those admitted to hospital believe that information is absolutely essential. The lack of such information about their health problem and the process to be gone through by the individual was a cause of considerable anxiety and uncertainty for members of the focus group. In those cases where information was provided effectively, patients were grateful for this and explained how this had helped them to deal with the process of hospitalization. Patients want information which is realistic and, above all, consistent.

Surprisingly, in this group there was considerable disagreement about who should provide the information. Among participants, those who preferred information to be channeled through the family in cases of serious illness were in the majority. However, a second group believed that the information which is given to the patient has to be given very clearly and that this is not easy, as it is not clear that all health professionals have been adequately trained to do this.

There were also some patients who stated that they did not want to know everything about their illness.

In the analysis of factors which provide a basis for predicting satisfaction, eight factors explain 73.2% of the results. The most important factor is feeling that one is in good hands (14.7%), followed by being able to express one's own opinion (10.8%); comfort in the room (9.3%); information about how the hospital functions (9.2%); time dedicated to the patient by the doctor (8.3%); attitude of the doctor in terms of listening and taking responsibility (7.6%); information about care after discharge (6.6%); wish for more information (6.5%). These figures mean that improving information would only give a 6.5% improvement in satisfaction.

The following responses were given to specific questions relating to information.

Would you like to have had more information about your illness, operation or tests?

78.4% of the population surveyed answered that they had all the information they needed.

10.01% of the population surveyed responded that sometimes they would like to have had more information.

11.5% stated that they did not have the information they needed.

Did your relatives or companions have the necessary information?

82.9% said they always had it.

7.9% said they almost always had it.

3.4% said they often had it.

Another factor to come out of the qualitative phase was that patients want direct information, given verbally, first-hand, and that not much value is attached to all the standardized written information.

As I have commented above, the need for information is valued differently in different parts of the service. In primary care the differences between what the different health professionals say and what they do generates mistrust and anxiety.

In this area, improving information would only have a 4.9% impact on satisfaction. Some 81.8% of those surveyed always or almost always have the information they need. In the social care sector, patients' information requirements and the importance they attach to information vary greatly, above all because this sector includes palliative care.

In palliative care, the family has more information than the actual patient, although this situation is often a source of disquiet when permission to provide this information has not been requested. Palliative care is a special case, because people do not want to know too much, only what they ask and nothing more; this is an ambivalent attitude in which the patient wants to know but at the same time wants to conserve a degree of ignorance. In this sector, information is not a predictor of patient satisfaction. In contrast, the need to feel that one is in good hands is far more important than in other service areas.

To conclude, and at the risk of being mistaken, I believe that in the health network in general and with the exception of some situations, all health professionals have to do a lot of work in every aspect of the information process. However, of the issues which came out of the workshop, for me there is one which is fundamental if we are to ensure that information is effective, and this is the issue of COMMUNICATION, in capital letters, because I do not believe that the problem is so much one of information as of the capacity which health professionals need to have to interact with patients. The training of different health professionals is, in my experience, an issue to which little attention is paid. I am sure we will all agree that good communication generates an atmosphere of trust and credibility, and that this, in itself, is of therapeutic value.

2. Margarita Boladeras. Professor of Moral Philosophy at the University of Barcelona

"There is no such thing as good information if it is not provided within the framework of individualized communication."

I would like to congratulate the authors of this study for making such a rigorous contribution to the debate: its subject was clearly defined, the results were precise, and the study as a whole is very useful for furthering our understanding of the situation and helping to plan new activities to improve this.

I would like to call people's attention to the mismatch between, on the one hand, the wealth of publications and conferences on the subject of health information and informed consent and, on the other hand, the many deficiencies apparent throughout the health professions. In 1997, the Department of Health of the Autonomous Regional Government of Catalonia published a Guide of recommendations on informed consent, written by the Advisory Commission on Bioethics. Although 20,000 copies were printed and distributed free of charge, during the past three years I have met several doctors who were completely ignorant of even the most basic issues.

It is clear that, in certain hospitals, many healthcare workers and clinical ethics committees are doing an excellent job of drawing up protocols for the relationship between healthcare workers and patients, with well-designed informed consent forms, and these developments are recognized and welcomed by patients. The study provides examples of excellent communication. However, this should not distract us from the seriousness of the poor practice which occurs all too frequently.

Both from the findings of the research conducted by Montserrat Busquets and Jordi Caïs and from the contributions of the participants in this discussion, it is clear that we can identify models of good and bad practice. There is no such thing as good information if it is not provided within the framework of individualized communication, as the results of the study show and as Milagros Pérez Oliva has stressed (contribution 15). This personalized care must take account of diversity, the other major emerging need referred to by Joan Manuel García (contribution 11). We need to think about how we can influence health professionals and their daily working practices. If books and conferences are not enough we will need to find other ways of promoting change.

The development of good practice is, in the first place, the responsibility of individual health professionals. However, the organization and management of services and of the different groups responsible for delivering these, how these groups relate to each other, the time allocated to tasks, good planning, and ensuring that all the members of the healthcare team have the right information, are all vital to ensuring that individuals are actually able to put this into effect. Effective, high-quality healthcare cannot treat patients like children.

We need to call upon those responsible for the management of our health services at all levels to help solve the problems which currently exist and to provide incentives to health professionals, and I therefore propose that we draw up a declaration of recommendations aimed both at those involved in managing health services and at anyone else who is able to exercise influence to this effect.

3. Ester Busquets. Nurse and Philosopher, Borja Institute of Bioethics

"Ethical symmetry is possible when the health professional starts from the principle that all individuals have an inalienable and intrinsic dignity and that this entails the right to be treated as a person and not as an object."

The study carried out by Montse Busquets and Jordi Caïs into health information and the active participation of users provides a valuable contribution which stimulates discussion of one of the key issues in the health relationship. As the results clearly show, this is an issue where there are major gaps and weaknesses which need to be addressed if we are to restore the social standing of health professionals and institutions.

I will base my contribution on three inter-related issues. Firstly, I will consider the question which precedes the study itself: what is the basis of the right to information? Secondly, on the basis of the study results, how symmetrical is the healthcare relationship with regard to information? And thirdly, with a view to the future, what should be done to improve the healthcare relationship and the active participation of service users?

1. Basis of the right to information

In a context where there is wide acceptance of a new model of the healthcare relationship in which patient autonomy is an important element, and which contrasts with the old paternalistic model, the right of the service user to obtain health information would appear to be beyond dispute. However, we should ask ourselves why the patient's right to receive information was not recognized for hundreds of years. Asking why this change is occurring is also to ask what it is based on.

Although the study seeks to justify the need for health information with reference to the principles of bioethics and human rights (we could also refer to the principles of patient rights) it is important to point out the fundamental assumption which underlies all these documents: that patients are individuals with moral autonomy, that is, that they have the capacity to manage their own lives and take their own decisions regarding their health, in accordance with their own ideals, beliefs and values. And this is an inalienable and intrinsic right of all human beings, and not something which is in the gift of health professionals or institutions.

As long ago as 1772 the doctor John Gregory wrote, "Every man has a right to speak where his life or his health is concerned." And in 1859 John Stuart Mill would write that, "Over himself, over his own body and mind, the individual is sovereign." Both these statements, then, clearly recognize the autonomy of the health service user. However, this right and the ability to exercise it are conditioned by a lack of information from which the patient often suffers due to the silence of health professionals. If one does not receive information which is straightforward, comprehensible, accurate and progressive, one cannot exercise autonomy. And therein lies the importance of providing information to health service users.

Although none of the interviewees mentions it, we should also remember that there is also a right not to know. Where a health service user renounces the right to be informed, this should also be respected, and the basis of this right not to know also lies in the autonomy of the health service user. This right not to know is clearly important, although we do not need to have recourse to old-style paternalism in order to defend it, as the words of breast cancer patient, Mariam Suárez, would seem to imply: "The doctor has to be at our side, inspire trust, help us to explain ourselves, be capable of lying to us. (…) They lied to me and I think they did me a big favour, because thanks to this lie I wanted to struggle. The deceptions of my relatives and my doctors gave me hope that I could come through it". (Cf. Diagnóstico Cáncer. Mi lucha por la vida). On the basis of her particular experience, Mariam Suárez appears to prefer lies to the truth: a perfectly respectable option, but one which is some way from the new model of the health relationship which seeks the active participation of health service users in the processes of illness and recovery.

2. Asymmetry in the healthcare relationship

The results of the study confirm that there are major gaps and weaknesses in the processes of informing users, and that these have their origin above all in the persistence of paternalistic attitudes, the use of technical terms, a lack of emotional involvement, a failure to listen, or a lack of time among health professionals. These are all attitudes which create a healthcare relationship which is vertical and asymmetrical and which to a greater or lesser degree reproduce features of the paternalistic model.

It is often argued, quite correctly, that asymmetry or inequality between professionals and service users is a feature of the healthcare relationship. This is because professionals have knowledge and technical skills which the service user generally does not have or need. Some health professionals hide behind this superiority and use it as a pretext for disregarding the fact that this technical asymmetry should not be in conflict with the absolute need to promote ethical symmetry. Ethical symmetry can only exist when doctors and nurses inform health service users properly, when they respond as clearly as possibly to health service users' questions, and give them enough information to take their own decisions on the basis of an understanding of the facts. Ethical symmetry is possible when the health professional starts from the principle that all individuals have an inalienable and intrinsic dignity and that this entails the right to be treated as a person and not as an object. In addition to providing information, this also includes respecting people's privacy, not discriminating against them, and respecting their other fundamental rights.

We believe that this study makes a very important contribution to healthcare by identifying the fact that many health professionals and health institutions are still a long way from embodying the new model of healthcare relationships based on promotion of and respect for the individual's self-determination in all issues affecting them and in particular those concerning their health or their lives.

3. Challenges in the health information process and the active participation of service users

The study confirms that the majority of users, in general, are poorly informed or misinformed, and we therefore need to identify some of the challenges which we must meet if we are to make the provision of health information and the active participation of users a reality. We propose the following:

1. *Doing away with the paternalistic model of the healthcare relationship:* this entails bringing an end to relationships in which health professionals wield power over patients, and creating channels so that service users can exercise their autonomy.

2. *Promoting team working:* health professionals must overcome their traditional isolation (or confrontation) to work together for the good of the patient. Health professionals and health institutions must be aware that team work is vital to the information process: deciding together

what information must be given, how it should be transmitted, who should do it, when etc. is the best way to give health service users the information they need to take decisions, and it is also the best way of showing them the respect they deserve. The act of informing is a shared responsibility in which there is no monopoly.

3. *Involving the user in decision-making:* if there is a clear wish to give up the paternalistic model and if health professionals are prepared to recognize, once and for all, the autonomy of service users, this automatically makes doctors, nurses and other health professionals modify their attitudes towards service users and towards the information to which they are entitled, with the clear objective of enabling service users to become involved in taking decisions.

4. *Respecting autonomous decisions:* recognizing the service user as an autonomous agent goes together with respecting that person's decisions. But this does not mean that health professionals shy away from informing health service users properly and presenting the various alternatives as clearly as possible, because these are the basic elements in taking any decision. However, we also believe that it is very important, when changing our model of the healthcare relationship, not to fall into the error of swinging too far in the other direction. In this regard, Victòria Camps has observed that: "replacing one principle (beneficence) with another one (autonomy) in an excessively radical way may ultimately lead neither to progress nor to respect for the rights of the patient." (Cf. Una vida de calidad. Reflexiones sobre bioética). The health service user, then, needs to be reminded that with greater freedom goes greater responsibility.

4. Josep María Busquets. Secretary of the Bioethics Committee of the Department of Health and Social Security of the Regional Government of Catalonia

“Consideration of bioethical issues goes beyond legal obligations; the moral commitment to the well-being of patients cannot and should not be governed solely by legal regulations.”

Qualitative research projects such as this, which explore how users of the health system perceive the information received from the professionals caring for them are extremely useful, above all if they are conducted with methodological rigour which ensures that the results have a firm foundation. There is a clear need for further studies such as this to build up our picture of other areas of the service and other illnesses.

In general, the results make it clear that significant progress has been made in raising awareness among both professionals and users, but they also identify areas which need to be improved such as the correct application of informed consent (IC). And it is for this reason that I will focus mainly on informed consent (a subject to which the Bioethics Committee has already dedicated two guides) and in particular on the failure to use the informed consent process as a support for the other information received by the patient.

Overcoming paternalism, exercising freedom, having the option of deciding – after receiving adequate information – obviously entails a degree anxiety for patients, but also poses greater dilemmas for professionals who must treat each patient as a unique individual and not as a subject to whom a standard protocol is applied. This is the cost of deciding.

Respect for the wishes of patients is included in the universal declaration of human rights and, more recently, in the WHO’s Declaration on the Promotion of Patients' Rights in Europe in 1994 and in the Council of Europe’s 1997 Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. It has also been the subject of special recognition in various declarations in the field of bioethics: the Nuremberg Code, the Helsinki Declaration, the Belmont Report, and the Hastings Center’s Goals of Medicine, among others. In Spain, the General Health Act of 1986, regulates the requirement to take the wishes and opinions of the patient into account by means of an informed consent process, and this was extended and made more explicit by the Basic Act regulating the patient's autonomy and rights and obligations with regard to clinical information and documentation of 14 November 2002, which introduces into law the principles embodied in the convention on biomedicine cited above, and which was preceded by Act 21/2000 of the Parliament of Catalonia on patient autonomy and the right to information.

These laws extend and specify various issues regarding informed consent and access to the patient's medical records. They also make it possible to draw up a document containing advance instructions and they clarify situations which had previously been subject to differing interpretations with regard to the health information required by the patient in order to take competent and responsible decisions. The proliferation of regulations both at the national and regional level within Spain is intended to ensure that the principle of autonomy actually becomes a reality and does not remain a mere declaration of intentions. And this is why it is welcomed by the majority of citizens, who recognize the basic, unquestionable nature of this principle.

However, we have also witnessed some undesired effects which undermine the intentions of those who promoted both the consideration of ethical issues and subsequent legislation in this area. While it is true that informed consent documents were initially introduced in the USA to protect health professionals from the threat of legal action, it soon became apparent that they could be a useful instrument for enabling patients to take responsibility for and participate in decisions affecting their health. Almost 20 years after their introduction into the Spanish legal system, we should recognize that such forms have made little contribution to improving such participation even though vast numbers of them are filled out, and both patients and doctors sign them as a matter of routine. Many patients see them as just one more piece of bureaucracy which is required for some operations, and only a few patients view them as supporting the information which they demand and to which they are entitled. The perception which service users have of the informed consent process is unquestionably one of the clearest and most disappointing results of this study.

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[1] M. A. Broggi Consentimiento informado o desinformado? El peligro de la medicina defensiva *Med. Clini* (Barcelona) 1999; 112:95-96

But this is not all. As Broggi[1] points out, informed consent can give rise to a variety of situations and problems, ranging from the possibility of reducing or eliminating dialogue, on the basis that the information is already contained in a supposedly ad hoc form, to the danger of promoting an approach to medical care which is based on a legal contract in which the informed consent document is the key element which underpins and enforces the contract. Armando Azulay[2] also identifies this danger when he reminds us that the possibility of drawing up a written will runs the risk of replicating the undesired effects associated with the introduction of informed consent documents, because many doctors see them as a mechanism designed to afford them legal protection. If this happened it would considerably strengthen a defensive and contractual approach to medical practice to which, at least formally, all of us are vigorously opposed.

As to whether this risk is inevitable, we must answer that it can and must be minimized if we wish to avoid encouraging healthcare relationships which are impersonal, bureaucratic, contractually based and lacking emotional involvement. Exercising one's freedom can and indeed does carry a cost in terms of responsibility, but it should not also become a tiresome bureaucratic burden.

At the same time, we should recognize that health legislation in general, and in particular the development of such legislation in response to bioethics, has strengthened a set of much-needed guarantees in defence of patient rights which did not exist before. Lawyers and legal specialists have found fertile ground in the health sphere for the development of new specialisms. However, in an effort to promote a less paternalistic relationship, the doctor–patient relationship has at times been undermined by growing levels of mistrust which can only give rise to a contractually based approach to medicine. While this is an approach which we reject, it is obviously attractive to those in the legal profession seeking new employment opportunities.

While this effect has already been well documented in other countries and is a growing trend in Spain, perhaps more worrying still is the belief that the law should be followed to the letter, as should protocols or clinical practice guidelines, in order to avoid legal complications or simply because no other course of action is even contemplated. Such an approach undermines the

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[2] Armando Azulay Voluntades anticipadas y práctica medica *Med. Clini* (Barcelona) 2004; 123, 15: 594-595

responsibility of both health professional and patient to address the specific requirements of each situation. It is not uncommon for the law or guidelines to be adopted as dogma, and this is far from helpful in any situation where a dilemma arises. Can a protocol indicate whether patients with advanced dementia should be fed using a nasogastric tube? Should a patient who refuses dialysis be compulsorily discharged? Although our health system suffers from many limitations and complexities, in situations such as these it is still possible to argue that the answer depends on the context, and that decisions should not be determined solely by the weight of the law. Bioethical reflection goes beyond the obligation which derives from legislation; the moral commitment to the patient's welfare cannot and must not be regulated solely by the law.

Often, in the face of the complexity of such dilemmas, bioethics turns to the law. Of course, bioethics and the law are closely linked, but we should remember that they belong to different spheres. Therefore, while a legal framework of guarantees for health professionals and, above all, for patients, is clearly necessary, this should not be at the expense of the relationship of trust which must be established between doctor and patient.

At present, initiatives are currently underway at both the legal and political level which aim to regulate the protection of the right to exercise personal autonomy in the health sphere from a moral perspective, which is concerned with the duty to provide care in accordance with one's conscience, and which is therefore much more demanding than the minimum required by the law. As health professionals we must go a little further and inform the patient just as we ourselves would like to be informed rather than simply requiring a signature on a document. Empathy, compassion and love cannot be legislated for, but we can behave as if we are motivated by love: giving a dying person one's hand because we know that it is reassuring, introducing oneself politely upon entering a room, making time for people to express their fears, anxieties and other emotions, but without being hypocritical.

In situations of vulnerability, and perhaps we are never more vulnerable than when we perceive the closeness of our own death, half-truths and evasion have little place. This is why love underlies the ethics of care, and why we should unashamedly and enthusiastically champion it.

Health organizations must make an effort to internalize the promotion of these values in their professionals. We therefore need extensive training in communication and information skills right through medical school, and for the strengthening of communication skills for all professionals and in particular for those whose specialisms mean that they are often called upon to deliver bad news.

Finally, I would like to point out that nothing can be achieved if we do not change the way in which health professionals are assessed. These often share the care task with a researcher and are encouraged to publish articles and results because these have become central to the evaluation of their work (to the prejudice of other aspects of their professional practice) and also determine the subsequent funding of other activities. We therefore need to promote the assessment of good care practice and ensure that good healthcare professionals do not feel compelled to choose other fields in order for their achievements to be recognized.

5. Jordi Colobrans. Lecturer in Communication Sciences, Blanquerna Faculty of Communication, Ramon Llull University, Barcelona

"Where does the problem lie? With the system or with individuals? ... If individuals are held responsible for the quality of interactions then organizations also need to be held responsible."

I will not consider the methodological issues in depth, as it seems clear that the authors of the study have successfully addressed these by carrying out well-structured fieldwork, which they have analyzed and interpreted convincingly. Instead, I will focus mainly on the consequences of the underlying hypothesis which this research explores. I will argue that one of the main contributions of Montserrat Busquets' work is that, without stating so explicitly, it reopens the old debate about the relative merits of efficient organizations and organizations with a human face. To what extent should or can the health system be efficient and/or have a human face?

To understand the scope of this implicit aspect of the study, we need to locate the study itself at the intersection of four variables: the users of the health system, whose satisfaction is at stake and whose rights are meant to be respected; a health system which, through a network of institutions, services, people and technologies, has to satisfactorily serve the users; health professionals with their expert training and a particular contractual and employment situation; and an organization whose requirements tend towards the infinite while its budget and resources tend towards scarcity.

When the service user receives health care or information about his or her situation or that of a relative, this encounter is not one in which the patient and the doctor or nurse face each other on their own but is, rather, one which occurs in the context of a health institution which conditions everyone involved in this encounter. The time which health staff can dedicate to any individual health service user is limited for a variety of reasons. Under these conditions, the quality of the information and of the treatment which the professional can provide to the user depends, in the first place, on the time available and, only secondly, on the professional's empathy and communication skills. If the system does not provide a situation which helps to minimize conflict and reduce tensions then individuals should only be held partially responsible for the problems which arise as a result. In other words, we are not dealing with a problem of a lack of training of health staff but rather with a more general organizational problem which is aggravated when the communication skills of staff working in the health sector are not as good as they could be. Therefore, the problem which the study raises regarding the nature of the relationship between the user and the health system cannot be resolved simply with a course on communication skills aimed specifically at doctors and nurses for the purpose of teaching them how they should talk to service users. Instead, it must also involve modification of how time is distributed so that care can be personalized: this means emphasizing, in the first instance, structural elements. But this solution would appear to be difficult to implement. Health institutions need resources, but these resources are scarce. This scarcity is compensated for by the good will and understanding of the people who work in the organization, but this has a limit.

At this point it becomes apparent that Montserrat Busquets' study, without intending to, opens up a can of worms, and one must question her underlying hypothesis that health service users' rights to information can be met by improving the communication skills of health staff.

Could it be a cultural issue? The cultural hypothesis is closely related to the communication hypothesis. In the study, this is not addressed explicitly. Apart from the greater or lesser communication skills of staff, is there an added problem of cultural origin which influences the quality of communication? In this regard, it may be helpful to consider a study conducted by Olga Aso, a nurse at the Hospital de la Santa Creu i Sant Pau in Barcelona, which looked at communication between patients of North African origin and doctors (UOC, June 2005). This study showed that, against the expectations of the researcher, medical issues were resolved independently of any intercultural communication problems, leading her to the uncomfortable conclusion that the figure of the cultural mediator (which had been demanded as being central to achieving understanding) was not necessary.

However, although the usefulness of the figure of cultural mediator did not appear to be convincingly justified, the study raised some other issues. Among these is the notion that cultural understanding is not so important for medical care (a provocative conclusion) and that patients are prepared to temporarily renounce their cultural experiences in order to save their lives or improve their condition (something which could be interpreted both as cooperation with the doctor and as adaptation to the health system). In intercultural situations, problems with service users are the same as in situations where there is a shared culture: lack of time per service user (which reduces the quality of the interaction), rotation of shifts (which, as Montserrat Busquets' research shows, is disorientating for patients) and the distribution of functions between staff (where the basis for this is not always understood by users).

To return to the main question asked by Montserrat Busquets at the start of her study of whether the quality of information received by service users allows them to participate actively in the treatment and care process, I would agree that improving the communication skills of health staff could indeed have a positive effect. However, I would reinterpret her conclusions and argue that this would not be enough, not necessarily because of people having inadequate communication skills or due to a lack of empathy (or sensitivity towards cultural differences) but rather because, from the outset, the system imposes structural conditions which limit the quality of interaction between agents. Of course, the author is aware of this problem, and dedicates a section of Chapter 7 to it. This question of how structural conditions hinder fluid interaction is an interesting issue which would reward further study.

I therefore believe that, before improving the communication skills of doctors and nurses (or in parallel), we should consider reviewing how the organization allocates time and care to individual patients. If individuals are held responsible for the quality of interactions then organizations also need to be held responsible. It is through dialogue between these two that efficiency and care with a human face, quantity and quality in an organization, can cease to be opposites and can instead become two sides of the same coin, so that we can offer users a higher quality service.

6. María Carmen Comella. Coordinator of the Catalan Cardiology Support Association (ACARD)

"... the participation of the family is very important at these times, they need to learn how to live with someone who is ill and needs a lot of support from his loved ones to get through this stage as quickly as possible."

Having attended the Seminar on Health Information, I believe we need a greater exchange of health information between doctor, patient and family members, and that people who are ill do not usually have the knowledge and information they need about their health situation. For this reason it is very important that everyone talks to each other so that the patient understands and has all the information about his diagnosis. It is also very important for patients to know how to change their daily habits.

I also believe that, because of the limited amount of time which medical staff are able to spend with each patient, associations such as ours can play an important ongoing role in teaching people to live with the limitations they experience after having a heart attack, suffering from angina or undergoing surgery, until they are able to return to work and resume their normal lives.

I think the participation of the family is very important at these times, they need to learn how to live with someone who is ill and needs a lot of support from his loved ones to get through this stage as quickly as possible. I would say the same about doctors and nurses with regard to listening to the patient, holding his hand, and making a friendly, affectionate gesture.

Where bad news has to be given, this should be done with great care and delicacy.

In conclusion, I believe that events such as this are very important and help raise awareness of bodies such as the Víctor Grífols i Lucas Foundation and others present at the seminar, so that they can exchange different points of view in order to improve the well-being of patients and those around them.

This experience has been very positive for me and for our Association, and I would like to give my thanks for allowing us to participate.

7. Esther Corrales. Specialist Clinical Nurse at the Catalan Institute of Oncology. Duran i Reynals Hospital

"Professionals have to make an effort to explain how we want to care for people, and why we are convinced that this is the best way to do it. We need to explain it to policy bodies and to managers."

A) OPINION ON THE STUDY PRESENTED AND THE RESULTS OBTAINED

Firstly, I should say that my contribution is based on my perspective as a nurse with nine years experience of working in the Palliative Care Service at the Duran i Reynals Hospital, Catalan Institute of Oncology. Below I will relate this context to my comments on the study results. However, before I discuss the results themselves, I would like to make a few observations regarding the methodology.

Firstly, I believe that the use of qualitative methodology in this study is without doubt the best approach. The proof is in the broad range of issues, aspects and perspectives mentioned by the interviewees.

As Jordi Caïs has already pointed out in the introduction to the study, qualitative methodology in general, and the results of this study in particular, help to promote the kind of debate we are holding at this seminar, to identify lines of investigation, highlight problems and areas for improvement, and so on.

With regard to the study process, many of the elements of this, such as the selection of informants and the interview guidelines, are clearly explained and defended in the report.

However, in the process of obtaining information – that is, in the interviews and the focal groups – the experience of interviewers and focal group facilitators are vital, as are the dynamics which develop in both these data collection techniques (the role of the observers). In this respect, I felt there was a lack of some information on such important aspects of this study. I should also observe that I feel that a single focal group for each group of users is insufficient, particularly when one of the groups only contained three informants.

With regard to the study results, in general I would say that both the statements of the informants and the explanations of these put forward by the researchers are consistent with my own experiences as a professional working in the health system.

I believe that two features of the study emerge as being of particular importance.

1) The subject of the study

It is clear from the study that this is a very complex issue involving questions such as: What is health information? What should we provide information about? When? Who should provide the information? What is the responsibility of the health system? What do decisions need to be taken about?

An individual with a health problem will have large numbers of interactions with the health system; with health professionals, with other patients, with the environment, with the community, with the media, and of course with his or her own life story. Health information is only one part of this wider picture. This is why it is important to talk about a process rather than a single event, and to talk about communication rather than just about information. Communication refers to a two-way process, the interrelationship between two people, non-verbal elements, and the study shows how patients make use of horizontal and non-verbal information sources.

2) The role of the nurse and how she can influence the impact of the illness

From my own professional perspective, both the subject of the study and the results touch closely on the role of the nurse: as interlocutor, as information provider, as a point of contact for patient and family, as the health professional who knows most about the overall situation of the patient and his or her family and the patient's life story, as the health professional who is closest to the patient throughout the health care process. When we talk about information and taking decisions, we tend to refer to major decisions relating to diagnosis, treatment and hospitalization. While these are indeed the key events of the illness process, in addition to dealing with these issues, the patient and the family also have to handle a whole series of other issues: physical restrictions (not being able to go for a walk, not being able to eat out, incontinence), and changes to individuals' roles are just a few examples. From this perspective, I would say that the study provides a very accurate reflection of this type of information: activities of daily living, quality of life and so on. And this is where the nurse's competency comes to the fore.

In a way, my own nursing experience working in a palliative care service condenses in practice all the principles and conditions of how we should include the patient in the communication and information process. Palliative care offers an organizational and management model in which the person and his or her family are the centre of attention, and the patient's needs are the basis around which work is organized. The therapeutic principles of this model are 'information and communication', together with the control of symptoms, caring for the family, and working as a team. In other words, from the training and selection of staff right through to the design of physical spaces, we should take into account that one of the key tasks and therapeutic aims of the palliative care team is to know how to give bad news at the end of life. As a result, palliative care professionals are highly experienced at managing the communication and information process. The principles of good communication and information which they develop take into account everything the informants mention in their contributions: individuality (starting from people's needs), taking account of physical space and non-verbal communication, allowing the patient to set the pace, the need for professionals to share emotions, and so on.

From my own experience as a nurse, I would say that the professional's attitude is the key element: knowing how to be with the patient at all times, taking an approach which encourages verbal expression and questioning, while accepting silences. In other words, having a real ability to make the patient feel like a person. This transcends any specific problems (lack of time, abrupt information, etc.) and is fundamental to building a relationship which allows us to detect the individual's real communication and information needs.

Another feature of the care model is that caring for the family is a key principle. The family is at once a care provider and a recipient of care from the team. As a result, just like the patient, the family must also be included in the communication and information process. Health professionals need to get to know the family very well: how they relate to each other, who their 'spokesperson' is, how they protect each other, and so on.

B) STRATEGIES WHICH ARE IMPLEMENTED TO IMPROVE HEALTH INFORMATION IN THE PROFESSIONAL SPHERE

The Catalan Institute of Oncology, in its management model, takes into account the active participation of users in all therapeutic processes. This is a very complex environment, as the institute cares for patients throughout the illness process, from diagnosis to death, passing through a range of therapeutic stages: clinical trials, hospitalization, etc. The strategies implemented include the following:

- One of the institution's objectives is to include informed consent in as many procedures as possible.
- Basic, Intermediate and Advanced Palliative Care Training Programme.
- Health Education Programme for patients and families.
- Ways of ensuring accessibility: telephone care delivered by specialist oncology and palliative care nurses.
- New roles of nurses which ensure continuity of care: functional units, consulting with nurses.
- Magazine, website.
- Specific physical spaces for providing information to patients and families.
- Research lines and participation in projects with other centres or institutions.
- Various user care programmes: charter of rights and responsibilities, etc.

C) POSSIBLE APPROACHES FOR THE MEDIA IN THE CARE, MANAGEMENT AND RESEARCH ENVIRONMENTS

In order to avoid becoming mired in unresolvable questions regarding information for users and active participation, we need to change our health model. This means moving from a medical model which revolves around the pathology to a model which revolves around the individual and those close to him or her, because including the individual is essential to the process of helping them. In this regard, I believe that there are some parts of the health service which have been committed to this approach for decades. Palliative care, geriatrics and psychiatry are all examples which show that it is possible to consolidate different models of care and organization and that we can offer care which is centred on the individual and his or her family.

As professionals we have to make an effort to explain to policy bodies and to managers how we want to care for people, and why we are convinced that this is the best way to do it.

At the same time, there are certain qualities which are indispensable for any good professional: respecting others, taking care to communicate with them, and being open. Institutions or universities need to find some way of filtering out the bad professionals.

Training has a key role to play in this process: undergraduate, continuing development, in-service, evaluation of competencies, etc.

Qualitative research aimed at professionals should help us develop strategies to improve the care we deliver.

8. Xavier Duran. Scientific journalist at TV3, Catalonia's public broadcasting television

"The media can use all the elements at their disposal to show how health information relates to other current issues."

From this study, I would highlight two key demands raised by the majority of patients. Firstly, they want health staff to understand them and to develop a close relationship with them. Secondly, they want clear explanations. These issues are probably partly interlinked. Clarity of explanations does not depend exclusively on the aspects I mention below, but also on how communication is established; intimacy and tone can help to ensure that messages are received more clearly and therefore understood more completely.

One important and widely recognized issue is the need to avoid overusing technical terms. This involves not just avoiding the use of terms with which patients or their family may be unfamiliar, but also avoiding words and expressions which are very common in the healthcare environment but which may be less common elsewhere.

Another issue which must be taken into consideration is how the listener interprets particular types of information. While statistics may be clearly understood by some people (including, of course, health professionals) others may find them confusing and may even draw the wrong conclusions from them.

Public understanding of science derives not just from how things are explained but also how individuals or groups of individuals interpret them. We therefore need to be aware of who is receiving our explanations, and not just of the person's socio-economic and cultural level but also of their personal situation and ethnic origin. In a society where there are growing numbers of people who speak different languages and come from different cultural backgrounds, we should take into account how these people assimilate the information they receive. This is not just because of the educational shortcomings which we all have, but also because the same facts or expressions can be interpreted very differently in different cultures. We should also bear in mind that new beliefs and superstitions are thus added to those which we already hold, and that this gives rise to very different attitudes to illness and death.

It would have been interesting to know how the interviewees use the media. In some instances, reference was made to a family member searching for information on the internet, but we don’t know if there are other sources, and what they are: television, radio, informative magazines and the press in general. With regard to the internet, we know that this can be a wonderful tool, but that it can also be a source of dangerous information. However, this is not new, because the same thing occurs with the other media; it is simply that the internet gives us access to much larger quantities of much more diverse information. But at times we have seen how television or radio programmes or press articles have sown confusion and have even caused people to abandon courses of treatment.

The only way of addressing this is for the media to be rigorous in its approach, and for journalists, doctors, nurses and patients’ associations to work together. Such cooperation can help to disseminate the key information as accurately as possible. Linked to the issue of comprehension and interpersonal relations, it would also help if medical information went beyond the latest scientific advances and attempted to describe the human and social aspects of illnesses.

It may seem from this that patients and their families are always asking for information. However, as the study shows, this is not always the case. Some people want to know everything, and some don't want to know anything. As a result, there will be some people who don't use the media at all as a source of information, while others will go in search of any text which refers to their specific problem. It would therefore be useful to know how much information people obtain from the media, and from which sources. And it would also be useful to evaluate the impact on patients and families of information which is freely available and which patients may receive without having looked for it.

It is important that the media, health professionals and patients’ associations work together to select some types of content. The media does not always address issues which would help professionals when it talks about patients and, above all, about prevention. In our society, health education is a key way of reducing risks. But this information does not have to be presented explicitly. The media can use all the elements at their disposal to show how health information relates to other current issues. You can talk about medicine with reference to the cyclist who overcomes cancer and goes on to win six Tours de France, the politician who is a victim of dioxin poisoning, or the health problems which arise as a result of rapid and chaotic economic development in some countries. This all helps us to offer more comprehensive information, but it can also help us to disseminate messages which educate the public. This can be addressed in any part of the media and also in other ways, such as through fiction. The high audiences of many TV series could be used to introduce characters with an illness or personal circumstances which would be not just a dramatic but also an educational resource. Take, for example, the ignorance about participation in clinical trials. If a character in a series were to take part in a trial it could be very informative.

By the same token, it would be useful to introduce some basic concepts of communication in medicine and nursing degrees. Here, what is required is not to create new courses, which would probably be optional and would almost certain just be seen as one more hoop to jump through, or to hold seminars which would do little more than provide an opportunity to preach to the converted. Instead, communication should be implemented across the curriculum, to be referred to in almost all courses. In other words, the aim would be not to introduce a new subject into the curriculum but rather to discuss at various points during the course – whether in ophthalmology, psychiatry or any other subject – how to communicate with patients, how to explain clearly what they should and shouldn’t do. As a result, future doctors and nurses would acquire these ideas while completing their degrees, almost without realizing it.

9. Susanna Escamellas. Grupo Ágata, Spokesperson for the Catalan Association of Women Affected by Breast Cancer

"We believe there should be monitoring of how information is understood."

First of all, I would like to express thanks on behalf of the Ágata Association for inviting us to participate in this seminar. We believe there is a need for more work like this to improve the relationship between the health sector and non-professional associations such as ours.

We have seen that, although the sample groups of interviewees are small, they show evidence of people's concern that they may not be adequately informed.

How can we make sure the information has been received?

We believe there should be monitoring of how information is understood. Maybe there should be a follow-up after the information has been given, because people sometimes freeze up as a result of the emotional impact of what they are being told. There is a growing trend towards multi-disciplinary groups, and the monitoring of how well information has been understood could be included in the work of the team.

In addition, as an association, we believe that the family should be given a more active role in the whole information process.

Strategies

The association brings together people who find themselves in a similar situation, irrespective of age or social class.

Initial contact with the association is usually by phone. A contact person is then assigned, usually a volunteer who also has breast cancer, and she talks with and listens to the individual, and explains what services we offer, from seeing a psychologist to participating in our groups and enjoying the opportunity of sharing experiences and interests.

We are now also concerned to reach out to immigrants, as there are growing numbers of women affected who only rarely contact the association.

Who is the carer?

Although all patients have a key role to play in dealing with their illness, they still need a carer, and there will inevitably be times when some of them find it difficult to cope.

Workshops and informative courses should be organized by doctors' surgeries and health centres. For example, the Duran i Reynals Hospital offers such courses which include both patients and family.

I attended them and they are very easy to understand, and provide a lot of very varied information on subjects such as diet, relaxation and general care.

We believe that the work we are doing as an association is very important. There is a lot of demand for what we do, and maybe people don't get enough support from their health centres, but this is precisely why we have to build more links between associations and health centres. We need to keep up to date about our illness and the progress which is constantly being made. As a result, we attend courses, talks, lectures, discussions and the like so that we can give our members the best information possible.

Plans for the future

We believe that taking part in studies such as this enables us to share, learn from and exchange experiences, for the good of patients and their families, because family members also need to be properly informed.

We fully agree that the informed consent process needs to be revised.

10. Paz Fernández. Nursing Research Coordinator at the Medical Oncology Service of the Catalan Institute of Oncology

"Nurses need to reflect upon how our action when providing nursing care can influence decision-taking by patients, in care teams and in organizations dedicated to cancer patients."

A NURSING PERSPECTIVE

For cancer patients, information is essential. Perhaps more than for other pathologies, patients ask to be informed and as health professionals we are aware that they need this information. The key question is how this information can be converted into active communication. Not all information has these qualities. Information can be negative in and of itself, it can be harmful if it is delivered in a non-therapeutic context, or it can be defensive if its purpose is to shield the health professional.

Both health professional and patient can learn how to exchange information when this is fostered by the wider care environment. Institutions and management should see this as an integral part of the therapeutic act and not as an 'extra', and they should take into account that the way in which this needs to be done will be different for each individual, for each family, for each health professional and for each situation. What actually occurs in daily practice is the opposite. The information process is not included in workloads or in the time allocated to each appointment. Often, people have to demand information, as if it were something special, when it should be seen as a general requirement.

THE NURSE AND INFORMATION AND DECISION-MAKING

The act of exchanging information involves the commitment and understanding of both participants. Receiving information is a patient's right, but it is also a duty in so far as there is a need to promote the patient's active participation in his or her care. How can someone participate in something which he or she does not know about or does not want to know about? At the same time, we must remember that, regardless of the fact that it is their right, not all cancer patients want to take an active role in making decisions (Rothenbacher, Lutz & Porzsolt 1997).

People are now aware of their rights and demand them more than in the past, but at the same time there has been a change in society as a whole, with a trend towards more active participation in healthcare, with people expecting to be more involved in caring for their own health and that of the community. This social change requires that both the public and health professionals adapt in order to establish the common ground needed for the exchange of information. For health professionals, this means giving up or sharing knowledge so that it can be jointly managed for the benefit of the patient and of the care process.

Nurses are particularly well placed to identify those patients who have problems in accessing or understanding information. There is evidence that the need for information changes over time, and that this requires a special effort from health professionals in order to ensure that patients maintain and update information about their health and that they feel able to ask for more information. In order to achieve this we need to create and design innovative strategies to meet these requirements in the best way possible. But what is required above all is for nurses to be permanently prepared to listen and to be alert to the patient's present or future needs. We need to bear in mind that information is only the first step in the process:

a) Inform---- Communicate -----Understand-----Take decisions----

We therefore need to remember that information and how it is presented can influence the decisions ultimately taken by the patient (and this raises controversial ethical issues). All professionals involved in caring for people with cancer have experienced situations where patients have changed their opinion with regard to treatment: some patients want everything even if that is not possible, while others refuse certain treatments at the start, claiming that they prefer to prioritize quality of life, and then accept them when they receive the right information and support. It should be stressed, in any case, that patients' attitudes towards treatment can change over time, and that nursing professionals are vital to ensuring that the wishes and preferences of patients are reconciled with their needs.

b) Role of the nurse in the information process

The role of nurses in the information process has traditionally been very much secondary. Nurses identify and resolve doubts, but historically their role in the information process was not formally recognized, while informing was itself understood as being limited to transmitting a message containing details of the diagnosis. There is now a broad consensus that the information must be given by all members of the health team and that nurses have an active role in the development of the process of caring for cancer patients and their families.

Nurses are involved in this dynamic information exchange in everything they do as a result of their immersion in nursing care. Because care is provided on a daily basis in close, even intimate, contact with patients, we see it as being more direct, but this does not always mean that care is carried out in the best possible way. Like any human action, care can be improved through professional training and development.

I believe that this process of learning to communicate with others not only consists of the transmission of informational content, but is also an enriching activity which in turn gives us information which confirms and reaffirms that our role in relation to patients is unique and enriching for our growth as people and as professionals.

Nurses need to reflect upon how our action when providing nursing care can influence decision-taking by patients, in care teams and in organizations dedicated to cancer patients. We need to assess what differentiates quality nursing care, including patient education and continuity in the assessment of patient needs, and how much the nursing perspective contributes to the end process of taking decisions. This involves objective research and evaluation of our activities, along the lines of this study.

This kind of qualitative research makes it possible to give a voice to patients and their families regarding the process they go through when suffering from cancer. This voice needs to be heard by health professionals and society as a whole if we are to achieve the highest levels of care.

11. Joan Manuel García Jorba. Lecturer in the Department of Sociology and Organizational Analysis at the Faculty of Economic Science and Business Studies of the University of Barcelona

"The study invites us to overcome the demarcations between functions and the delimitation of areas of responsibility, so that we can be open to an approach which incorporates clear ethical and political dimensions."

Montserrat Busquets' study, completed under the direction of Dr. Caïs, has a number of strengths, among which are the careful definition of the study objectives, the clear structure of the report, and the systematic way in which she addresses the different aspects of the question under consideration. In addition, the skill with which she draws inferences, makes links and establishes categories greatly enhances the transition from raw data to generalization and theoretical conclusion. In this regard, her incorporation of the perspective of users themselves as the basis for constructing arguments and categories is particularly impressive. This is a difficult thing to do, as there is a danger that some of the concepts will suffer from a degree of imprecision or ambiguity. However, it represents a coherent and realistic approach and makes it possible to present the needs recognized by service users themselves in an institutional and interactive context which has been clearly defined in methodological terms.

The report as a whole should stimulate reflection both among doctors and nurses, and among professionals in the social and communication sciences. One example of this is the question it raises of what model of citizen underlies the discourse of responsibility and co-responsibility which is put forward as desirable. The study invites us to overcome the demarcations between functions and the delimitation of areas of responsibility, so that we can be open to an approach which incorporates clear ethical and political dimensions. Should the author feel tempted to formalize this model, she will face a major challenge: how to combine the ethical basis of a model of communicative interaction with effective strategies for managing the heterogeneity which constitutes the social reality she analyzes. In this regard, the variables of gender, level of education, level of income or ethnic affiliation, may be key elements in establishing the margins of manoeuvre and the effectiveness of such initiatives.

Considering the transmission of information within a healthcare framework encourages us to redefine the roles of patients, doctors and nurses. The widely recognized loss of responsibility inherent in the role of patient is challenged by the expectations of service users themselves. The problem, however, lies in how to transmit information in a way which not only responds to the specific requirements of the service user, but which also requires the redefinition of relationships between health professionals, and between professionals and the institutional structure to which they belong. In this regard, the study reveals some worrying features of the current care situation. It demonstrates the lack of clear criteria when it comes to allocating responsibility for who has to inform patients, and how this should be done. This vagueness occurs within the context of a set of power relations which can, in the final instance, affect the quality of care. At this stage, it is important to remember that information is not simply the content of a communicative act: it is also influenced by management and by expressions of power. However, the existence of this dimension does not exempt us from the obligation to seek to establish effective coordination between the various health professionals in order to safeguard the service user's right to information.

The study makes clear the importance for the quality of care of the communication skills of health professionals. The evidence of major gaps in this area, together with the lack of interest shown by some health professionals who are keener to defend an exclusively prescriptive role, should help stimulate attempts to overcome these shortcomings. Overloading the basic or continuous training of health professionals with specific credits for courses in communication will not ensure that these are subsequently applied. It is better to present the advantages which come from informing the patient properly and winning their collaboration, and to opt for persuasion. The harmful effects of misinterpreting the message, the negative impact associated with the social image of certain words or illnesses, and the drawbacks which come from exposure to the unfounded speculations of other sufferers are all solid arguments in favour of paying attention to the contribution of communication to the effectiveness of health professionals.

Within the framework of communication processes discussed by the author, I think her references to non-verbal communication are particularly valuable, and in particular those which she makes regarding the importance of touch in relationships. One possible way of enhancing its contribution would be by attending to the spatial context in which doctor/nurse–patient interactions occur. The way in which space is distributed and managed in itself constitutes both a message and a far from neutral channel through which information is transmitted. And this information is itself very varied, containing both specific, highly specialized information – whose management may be restricted to doctors – and more general information in which there is not necessarily a conflict between accuracy and adapting it to the requirements and educational level of the service user, and which can be managed by nurses.

Another strength of this work is its ability to show that quality care requires the efficient management of information between different groups of health professionals, and between these and the organization within which they operate. One thing which stands out when reading this study is the lack of coordination in the management of medical records by the members of several teams. But what is even more surprising is that in none of the cases does the patient mention having been informed of the advantages which this care strategy affords. This example illustrates two issues. On the one hand, it highlights the importance of empathizing with the user, and not just assuming that his or her expectations are the same as or consistent with the strategic organization used by health professionals. It also points to the existence of two logical frameworks: an institutional one, and one describing the desired sate of interactions between professionals and service users, two groups whose relationships can be difficult. In this regard we need to design organizational frameworks which do not obstruct the delivery of adequate patient care. Attempting to build an efficient organization on the foundation of the voluntarism of health staff is an example of perverse institutional logic which can undermine the successful implementation of the improvements to the process of communication between health professionals and service users which this study shows to be essential.

12. María Gasull. Lecturer and Head of the Teaching Department of Legislation and Ethics of the University Nursing School of the Health Management Foundation of the Santa Creu i Sant Pau Hospital of Barcelona

"Often as professionals we take cover behind the principle of beneficence and fail to realize that we are not conducting the information process properly."

1. Opinion of the study and the results obtained, in the light of other studies and my own professional and personal experience

I would like to congratulate both Montserrat Busquets and Jordi Caïs not just for the quality of their work but also for their choice of subject and the fact that service users actively participated in the study. If the subject itself is important, given that both information and communication are two areas where our health service still needs to prove itself, more important still is that users are able to state their needs and preferences regarding information. Without this knowledge, health professionals can hardly be expected to offer quality information.

Identifying the needs and wishes of patients and respecting their autonomy are central to the clinical relationship between professionals and service users. Often as professionals we take cover behind the principle of beneficence and fail to realize that we are not conducting the information process properly. As a result of my participation in two studies of the information process, I have become aware of the seriousness of this problem. From 1998 to 2001, the Department of Nursing of the University of Turku (Finland) coordinated a study entitled Patient's autonomy, privacy and informed consent in nursing interventions, financed by the European Commission Programme BIOMED 2 BMH4-CT 98-3555. This quantitative study, which involved 4000 patients/service users and 4000 nurses in Finland, Germany, the United Kingdom, Greece and Spain, found major differences in the perception of the information process, in all of the participating countries. While nurses said that they had informed patients, the patients themselves did not feel that they had been informed. In our conclusions, the researchers highlighted this serious problem and called for further research to identify the causes. In another uncompleted qualitative study of Ethical and legal problems when taking health decisions at the end of life (RIMARED. Network for Research into Caring for the Elderly, Instituto Carlos III) the three groups studied – the elderly, their families, and health professionals – disagreed with regard to the information process. While the elderly and their families identified shortcomings with regard to the information delivered by professionals, the professionals themselves were unaware of the problem and believed that information was provided more or less satisfactorily.

This study could be of great help in improving the information process between professionals and users. The first thing I would highlight in the study is the importance ascribed to truth. Maintaining truthful relationships which are free of deception is essential to building trust between service users and health professionals. Secondly, I would mention the need that users express to receive information not just about diagnosis and prognosis but also about all the factors which allow them to have a better quality of life, such as, for example the possible impact of the illness on people's sexuality or the use of cannabis. Perhaps in the light of such demands from users, health professionals should look at how to incorporate existing bodies such as patients' associations into the health system, as being able to draw on their experience might help to meet service users' needs. Thirdly, there is the key role that the family plays in the information process. Their greater objectivity, despite the fact that they are also suffering, can be of great help to patients when they are called upon to take decisions. The family should be taken into account and included in the information process so long as this is what the patient wants and has given his or her consent. Finally, I would like to mention the qualities which health service users believe professionals need in order to achieve good communication. According to users, a good informer needs time, must be a good listener, and must show sympathy and interest. All of this requires an ethical analysis to identify the limits and responsibilities of professionals' clinical relationships.

2. Strategies which are implemented to improve health information in the professional sphere

The improvement in information has to be tackled from a variety of angles, but as somebody dedicated to teaching I would like to stress that professional training is very important to a good information process. Specific training to ensure that health professionals have the necessary knowledge and skills should start at undergraduate level, and should then continue through postgraduate and continuous development. The Diploma in Nursing has already included, among others, courses in Applied Social Sciences, Helping Relationships in Nursing, and Professional Ethics. We should stress the importance of the disciplines of Professional Ethics and Bioethics in order to ensure that students understand and accept the need for information in the health relationship. In the European Community study mentioned above, the results regarding information were better in those countries with more advanced education in ethics.

Training should also include how to communicate issues related to death. The information process is obviously more difficult when bad news has to be given, and health professionals find it hard to talk about death both because of their own emotional involvement and due to projection. We all know that if we are born then we must also die, that death is part of everyone's life cycle and that however much society may deny it, it is still present; it is therefore vital that health professionals receive specific training in this area.

Professionals need not just to go through a learning process and to acquire knowledge, but they also need to acquire the clinical skill of informing patients about the reality of what they are experiencing. To do this, what we learn from our experience of dealing with patients and their families is very important, as is the ability to recognize and be aware of the empathetic skills we possess as human beings. And the examples of well known and highly respected individuals can also be of great use.

I should also mention the need for sufficient time, and for health centres to have stable staffing, at adequate levels, together with the need for genuine teamwork. When the members of a team communicate well with each other, this makes a valuable contribution to their ability to provide high quality information/communication.

3. Possible approaches in the care, management and research sectors, and in the media

Research into health information provides data which can be very helpful when it comes to modifying the way in which we implement the information process. This data, however, is not sufficient, and we need to continue research not so much into whether or not we should inform people, as it is already clear that information is essential if service users are to exercise their autonomy, but rather into how information should be transmitted. This is because the system we use for informing people goes a long way towards determining the patient's state of mind. In other words, the way in which we give a piece of news may influence the intensity of its initial emotional impact and how it is then assimilated, and also influences the subsequent support system.

Perhaps we need to reflect in depth on the model of the relationship between professional and service user which exists in our hospitals. We could define this model as aseptic, one which seeks protection in the forms and customs which have arisen from the gradual development of contemporary medicine. We need to make major changes, even if these could give rise to fears of insecurity.

We should also think about teamwork, as this has given birth to a new type of relationship with service users. The old doctor–patient relationship has been replaced by a relationship between the care team and the patient. In this new relationship, the information process is more complex; the service user may not have the same sort of relationship with and level of trust in all the health professionals who intervene in the information process; and patients may confide in those professionals they trust most, creating issues of confidentiality which need to be considered. We may often find ourselves asking such questions as, "Should all the patient's secrets be shared with the team?" and "Should I ask permission before doing this?" These are questions which cannot be resolved by traditional professional secrecy agreements.

13. Albert J. Jovell. General Director of the Josep Laporte Library Foundation and President of the Spanish Patients' Forum

"The right to information is a basic ethical right. At the individual level, it is part of respecting human dignity and exercising one's right to autonomy. At the collective level, it helps to ensure that democratic processes are implemented fairly."

We can identify three key aspects when discussing the complex issue of the relationship between information and decision-making in health:

1. The nature of the right to information.

2. The relationship between information and clinical decision-making.

3. The advantages of an informed patient.

1) The nature of the right to information

The right to information is a basic ethical right. At the individual level, it is part of respecting human dignity and exercising one's right to autonomy. At the collective level, it helps to ensure that democratic processes are implemented fairly. For this reason, it is both an essential right and a democratic principle. In the case of modern health systems, the right to information is essential if they are to be democratized. In order to do so, we need unrestricted access to accurate, high-quality information which has been checked and which comes from reliable sources. When the right to information meets these requirements, it is possible to apply the other principles of high-quality democratic healthcare: freedom to choose, the existence of mechanisms for active participation in decision-making, and democratic discussion of health policies.

One important element of the provision of information by health systems is that patients need to be able to access information about the results of the care they receive. Accessing this information allows patients and health service users to exercise their capacity to choose better. Experience in the United States and Great Britain, based on the publication of mortality rates following cardiac surgery, by surgeon and by hospital, adjusted for underlying risk factors, has shown a gradual reduction in these mortality rates in the years following publication.

For patients, the right to information means that patients must be able to access the information they need in order to be able to understand the prognosis for their illness and then identify what different diagnostic and therapeutic options are available to modify or improve this prognosis. This process must be based on information which comes from reliable, high-quality sources and, above all, means that information must be obtained by those responsible for providing healthcare. Here, it is worth stressing the difference between information about illnesses and information about my illness. The first implies access to generic information regarding cause, diagnosis, treatment, expected clinical outcomes and prognosis, while the second involves applying this knowledge to a specific patient with a specific medical history.

2) The relationship between information and clinical decision-making

In most cases, the illness is a disorder which affects the individual rapidly and unexpectedly, giving rise to what I term the syndrome of unease, characterized by a range of feelings including dejection, unhappiness, dismay, misfortune, disappointment, unease, confusion, helplessness and mistrust. This makes individuals feel very vulnerable when required to search for information and take clinical decisions. This is why health professionals and patients' associations need to promote strategies aimed at supporting patients and helping them to regain their self-confidence. Apart from this asymmetry with regard to self-determination, which is an inherent result of the impact of the illness on patients' lives, patients also face asymmetry in the area of information and knowledge regarding the medical care they receive. This is why doctors and nurses should try to reduce this asymmetry by transferring knowledge and personalizing it for each patient, while bearing in mind three basic principles:

1. **Patients must be at the centre of all discussions and decisions regarding their illness.**
2. **Patients like to be treated according to the principle of reciprocity, so that others treat them as they would like to be treated themselves.**
3. **Patients have the right to express their values with regard to the benefits they expect from their care and the risks they are prepared to accept.**

In addition to these principles, doctors and nurses should adopt a model of the relationship between health professional and patient which satisfies patients' expectations of being treated and supplied with information in a way which complies with the principles of non-maleficence, beneficence, autonomy and confidentiality.

3) The advantages of an informed patient

The Barcelona Declaration, signed by 50 patients' and service users' organizations in Spain (www.webpacientes.org) promotes a set of principles relating to patients' rights, including the right to information, mutual respect, shared decision-making, and the formal democratization of health decisions. In order to ensure that these rights are promoted within the Spanish health system, the Spanish Patients' Forum was established (www.webpacientes.org/fep) with the aim of strengthening the rights contained in the Declaration issued at the First Spanish Congress of Patients, to be held in Barcelona on 20 and 21 October 2005 (www.congresodepacientes.org).

This movement to promote patients' rights believes that significant advantages are to be gained from having informed patients. These include the following:

- better understanding of the patient's illness
- better knowledge of the different diagnostic and therapeutic options available
- advice and support for other patients, in the role of 'expert patient'
- more likely to follow treatment
- helps to plan better strategies for dealing with illness
- closer cooperation with doctors
- more efficient use of consultation time
- improved self-confidence and self-belief
- promotes self-care strategies.

Of course, these theoretical advantages vary depending on the type of illness, how serious it is and the educational level of the patient. It is therefore important that the right to information be implemented within the context of a process which is tailored to the individual patient, based on a relationship of trust, in which the informer has prior knowledge of the patient's needs and of his or her ability to handle the information received. As a result, it is very important that there is a single doctor with responsibility for the patient and in whom the patient places his or her trust.

14. Meritxell Mollà and Isabel Rubio. Radiotherapist and Coordinator, respectively, of the Breast Unit at the Teknon Cancer Institute of Barcelona

"The information needs to be adapted for each type of patient, without taking a paternalistic approach."

In our professional experience, only the informed patient is really able to decide. Nothing should be easier than providing full information and taking decisions together, but the demand for information comes from patients themselves. As professionals we need to know which information the patient can deal with at each moment of their illness: that is, what information they are really asking for. Not all patients want to be fully informed about every aspect of their illness. This study interviewed women who had a high degree of awareness about their illness and were willing to talk about it, and who have a type of cancer in which one can almost always expect to live for more than a year after diagnosis. But not all cases are like this, and the information therefore needs to be adapted for each type of patient, without taking a paternalistic approach.

It is very important how we provide this information. This depends on the professional's capacity to communicate, something which is determined less by how much time the professional has than by what the professional is like as a person. Health professionals receive no training in this area and, as a result, their communication skills depend on their personality and on their interest in this issue. We believe that it would be a good idea to introduce communication skills within the different medical specialisms as part of medical training.

In our opinion there is a category of information which professionals always have the duty to explain. We refer to the fact that every treatment should be accompanied by information about the benefits; in other words, why the treatment is given, and any possible side effects. this is as valid for antibiotics as it is for radiotherapy or surgery.

The recipient of the information is the patient. The patient is the one who has to decide who else should participate in the information process or who he or she wishes to be the main interlocutor, should the patient not be able to assume this role or not wish to do so. And this is something which may change during the course of the illness.

Strategies to improve health information

- Copy of medical reports for the patient, both the initial report and any follow-ups.
- Joint signature of informed consent, with potential side effects of the proposed treatment to be recorded during the appointment itself.
- If the information we need to give is very extensive and the patient has to choose between one treatment and another on the basis of what has been explained, then a second appointment should be scheduled so that the patient has the opportunity of thinking about what has been discussed and asking any new questions which have arisen as a result of considering this.
- Having specialist nurses who help to ensure patients have someone they are close to who they can discuss specific aspects of their illness with.
- Having enough time to discover what the information requirements of each patient are. Health professionals must review schedules (lists of patients) so that if a patient is to be given bad news about the progress of his or her illness or if a complex new treatment is to be proposed, then more than ten minutes are available so that this information can be communicated in an appropriate manner.

Conclusion and options for the future

Between the paternalistic model and the informed model there lies the shared model. This model means that patients and medical professionals must change and must share responsibilities for information and for decisions. There is some evidence which suggests that when patients stand in an equal relationship to their carers both in taking decisions and with regard to treatment, the outcomes are better, costs are lower, and satisfaction is higher.

15. Milagros Pérez Oliva. Journalist and editor of the Society Section of Spain's El País newspaper

"The new patient is generally well informed or can easily obtain information, and is not prepared to accept inadequate information."

The information which is offered to patients in today's health system, with a few honourable exceptions, is very inadequate. This is one of the problems which hospitals and health centres have not resolved adequately, despite the fact that all the surveys and studies of the issue indicate that it is one of the main causes of complaint and dissatisfaction among health service users.

Information is one of the issues which urgently need to be addressed by health managers, because it is one of the factors which does most to undermine the legitimacy of the health system with the public as a whole. Many young people, disaffected with the health system, have turned to alternative medicine in search of more humane and personalized treatment. The growing number of people who have been resorting to these therapies and criticizing the health system in recent years should be of serious concern to advocates of public healthcare, as this could undermine the national health system and be used against it in the future.

Information is one of the essential elements of any communication policy, but it is not the only one. Instead, communication needs to be considered in its entirety and, while this obviously includes the question of patient information, it also includes communication between doctor and patient, communication between the members of the care team, and between different teams. For good communication to occur, information must flow in all directions, both vertically and horizontally.

The first shortcoming that has to be addressed relates to the training of doctors. Medicine faculties do not give health professionals the tools they need in order to facilitate communication with the patient, and this means that professionals are being deprived of an essential tool for the exercise of their professional. Given that the paternalistic model of relationships is in a terminal crisis, health professionals need communication skills, a requirement which is only likely to grow in the future. This is something which is vital for health professionals' own well-being, as doctors who are better at managing relationships with their patients will feel better, more valued and less stressed.

We must also take into account that the patient profile is changing very rapidly. It is true that waiting rooms are still full of people who are over 70 years old and have received little education (a fact which by no means should be taken to imply that they are uncultured) and who have been brought up to take a passive attitude towards the management of their health. But this profile is already changing and can be expected to continue to evolve rapidly. The new patient is generally well informed or can easily obtain information, and is not prepared to accept inadequate information. In addition, many patients have been brought up in a consumer culture and this can further complicate relationships. Another challenge to bear in mind is that information needs to be culturally adapted to each patient, and the increasing cultural diversity of Spanish society will therefore add a new level of complexity to the process.

Communication with the patient does not consist solely of the provision of information. It must also contain an element of empathy and of understanding which can only be achieved over time. While it is true that both communication skills and the ability to empathize depend on the individual's personality, there are also ways of ensuring that this personal aspect does not become an insurmountable obstacle to ensuring an effective communication process, if enough time is available for consultations to ensure that this process is complete. Nursing can play a particularly important role both in internal communication within the team and in communicating with patients and their families, given the central role it has in the provision of care. Both as a result of their training and a deeply-rooted professional culture, nurses, the majority of whom are women, are in a privileged position to improve communication. It would be a pity if the managers of health centres did not capitalize upon these skills and exploit this potential.

In any case, the existence or otherwise of plans for internal communication and patient information should be viewed as one of the basic indicators of the quality of care in any hospital or health centre. At present, there are hospitals which are leaders in terms of medical research and clinical advances, but whose performance is very poor when it comes to how they communicate with and inform patients. It may be that these hospitals offer good medicine but it cannot be argued that they provide a high quality of care.

16. Begoña Román. Lecturer in the Faculty of Philosophy of Catalonia at the Ramon Llull University in Barcelona

"I would like to focus on three underlying issues which I believe form the unstated background to this study. I shall focus on each of these in turn, with the aim of throwing more light on some of the areas which, in my opinion, have languished in darkness.".

1. The taboo around death

It strikes me as both surprising and somewhat perplexing that in neither of the two patient groups, both suffering from major illnesses, is the issue of death mentioned, either by health service users or healthcare professionals.

I am not questioning the importance of hope in the treatment process, but the fact that at no time is the possibility of dying even mentioned causes me to think that we view death as something which does not concern us, and which we cannot even talk about. The concept of success is latent in all the study literature, and intervention always takes place with the intention of curing.

In the seminar debate itself, when I brought up this issue, I was reminded that 70% of breast cancers are cured, but to my mind this means that at least 30% of people are not properly supported during their illness process. As a result, one has the sensation that any medicine which does not lead to a cure is considered as a failure. Indeed, patients may feel that, by failing to hope, they are somehow failing to cooperate with the recovery process, and they may even feel guilty about their despondency in the face of the illness.

I don't know how far the evasion of this issue is a cause or a consequence, whether it is a type of medicine and a concept of care which generates a type of patient, or a type of patient which proposes a type of medicine and care. I don't know if the service users themselves avoid the issue, reflecting a taboo which is widespread throughout our society; or if it is medicine itself, in a euphoria of technocratic, Promethean arrogance, which continues to consider death as something of a failure.

If health is a state of mental, physical and social harmony, then I would also include the existential or spiritual aspect, the search for meaning or whatever we wish to call it, our preparation to accept the end of life which nobody wants to think about, neither patients themselves nor health professionals. And I don't know if it is a taboo among the service users consulted or among all users, but there must be someone among users and professionals who wants to talk about the end, who wants to talk about death.

In fact, palliative care handles the issue differently when the expected outcome is not continued life but rather dignified death. Perhaps for this reason, in palliative care units relationships are more truthful and more committed, because it's clearer where things stand.

It is, incidentally, by no means incompatible to be aware of the possibility of death while also retaining hope, the only thing which denying the possibility of death achieves is to ensure that patients are not supported when they consider this issue because such thoughts are deemed 'uncomfortable'.

From this comes the ambivalent role played by truth in the issues under discussion here. If confidentiality and quality of care are based on a relationship of trust, but in this relationship nobody refers to one of the possible outcomes – death – and it is impossible to refer to it, what does it mean to insist on truth, confidence and quality of care?

If one of the aims of this study was to improve health information and, beyond that, to improve the communication process in order to help service users deal with situations and take difficult decisions at 'vital' moments, then discussion of death cannot be taboo, and yet in this study it is conspicuous by its absence.

2. An excessively physiological notion of the concept of health

One of the complaints of service users regarding the deficiency of information relates to the excessively technical and general nature of the information which professionals give to users. Ultimately, the security offered by evidence-based medicine has contributed to ensuring that information is reliable, accurate and has a low margin of error. But this means that we deal with illnesses rather than patients, and that we reduce people to physiological processes which can be monitored and controlled.

And throughout there is an overly biological approach: in training, in treatment, and in the entire process of managing the illness. Health, understood as physical-mental-social harmony, is not considered either in its full complexity or as an integrated whole. This is why alternative medicines are popular: because they appear to be prepared to accept the relevance of subjectivity, of approximation, of contextualization and of interpretation.

3. Organizational ethics

The Spanish and Catalan health systems remain excessively obscurantist and reluctant to establish 'hospitable' relationships. In our day and age, co-responsibility is the only reasonably efficient way of achieving our goals of satisfying expectations with regard to professional services, which is after all what constitutes quality. And on our own, with everyone ploughing their own furrow, this will not be possible. Relationships between care teams, the forging of real teams, relationships between these teams and the organization, and the relationships with help groups and patients' associations, are essential but as yet relatively unexplored.

The health system needs to break a structure which is excessively hierarchical, pyramidal and bunker-like, to become more hospitable, more flexible, more relational. And here, again, communication about what health teams are, what they do and where to locate them is crucial. Because information is a right which we have to demand, not beg for in the hope that it will be granted.

If we are to help build a more relational and hospitable system, we have to make professionals more accessible, institutionalize the participation of all involved, seek the opinions of a range of professionals, and strengthen and publicize the network of teams and centres.

If we are trying to build trust, we have to stop being 'moral strangers'. At heart, the type of communicative relationship which two people establish forms the basis for how just the treatment is, and the quality of the relationship. Communication between service users and professionals is an indicator of quality at both the professional and organizational level. The intangible element which is trust can be measured through the tangible satisfaction of expectations.

We should not forget that trust is a great moral resource. With environmental and economic resources the more we spend, the less we have. But with moral resources the opposite is true: the more we spend, the more we have. To invest in communication is to invest in trust, a good short, medium and long-term investment.

17. Ana Torrente. Nurse at the Mammary Pathology Unit of the Germans Trias i Pujol University Hospital of Badalona

"From the outset I was aware of the emotional impact and repercussions of having breast cancer, and I realized that this was something which I also experienced as a professional and as a person."

The immense majority of people who work in the 'helping' professions have at some point in our lives felt the need to teach, share, accompany, help, 'to be with the other'. Historically, medicine and therefore nursing have been concerned with illness and cure, neglecting the suffering of the human being who is ill. Care nurses have learnt how to treat the causes of illnesses, to be interventionist and to take action. And this is why we often find it difficult to take a calm, listening attitude, to show understanding and empathy. Fortunately, this is beginning to change, and the concept of care is gradually becoming more established; care which focuses on the person, rather than on the illness. For this reason, the new nursing professional is someone who knows how to be with other people, knows how to act, and undertakes continuous specialized training in order to maintain and develop her skills.

With regard to the subject of this seminar, we need to be aware of the importance of facilitating, maintaining and managing good communication, so that we can establish a helping relationship with the patient. This will allow us, firstly, to identify how the patient and his or her family have adapted to the diagnosis, and their response to the different treatments available, to possible relapses or to the terminal phase and, secondly, to combat the feeling of impotence which often overcomes health professionals. When we are combating the causes of suffering, we need to confront our own silences, our fears and those moments when we do not know what to say.

As a nursing professional I work in the Mammary Pathology Unit, which is where breast cancer diagnosis is performed, a range of therapies are offered, and people with this disease are monitored. From the outset I was aware of the emotional impact and repercussions of having breast cancer, and I realized that this was something which I experienced both as a professional and as a person.

Being a nurse involves not only the use of a range of techniques and materials, but also means having to deal with emotional issues relating to the illness, and with the personal, social, employment and family issues of each patient and his or family. How often in our work have we faced situations in which we don't know what to do or say? The close contact which, as nurses, we have with patients often makes us receptive of their fears, anxieties and suffering. In these moments, the specific skills and methods for helping people who find themselves in a critical situation, for comforting people when they receive bad news, and for providing emotional support can help to ensure that:

- the health professional uses self-control and is able to communicate appropriately
- communication is not distorted and ineffective
- we are able to detect the emotional difficulties of each patient, helping to bring about positive change and to create a therapeutic environment which is supportive and non-paternalistic
- If we wish to improve our relational competency and increase the quality of the care we provide as health professionals, we must be able to maintain effective communication in which words and expressions are in harmony.

Words are a tool which is available to all of us and which, depending upon how they are used, may have either a beneficial or a damaging effect, because it is not the same and does not produce the same effect to say one thing or another, to say something in one way or another, to say something at one moment or another.

Expressions, looking somebody straight in the eye, without subterfuge, with complicity, making somebody feel that they can express their pain. To lose oneself in this gaze creates the hope that one is not alone, that one is accompanied.

This is the start of a journey to become emotionally involved with the person who is suffering, and to establish a helping relationship free of fear and obstacles, to avoid harm.

Personally, this involvement, this complicity, has given me and continues to give me moments of profound satisfaction which make me feel that my profession is unique, and reaffirm my belief that I have chosen the right profession.

Strategies for improving health information in the professional sphere

Counselling is a set of tools which maximize the level of competency of both professional and patient, at the lowest emotional cost possible. It is based on a philosophy which promotes equity, respect and the autonomy of the patient. It encapsulates an attitude, a disposition, it is a tool which makes communication more effective. It is a vital tool in helping to maximize the patient's well-being, based on the right to receive egalitarian treatment which accepts individual differences, and on a professional–patient relationship of mutual respect.

Counselling and the application of counselling techniques represent a major advance in the field of care relationships. They are interpersonal communication techniques in which the first beneficiary is the health professional. The skills acquired allow us to attend to the emotional needs of patients diagnosed with breast cancer from the moment of diagnosis, and make it possible for us to establish more satisfying human relationships in the workplace, to channel emotions and improve communication. Counselling helps us to attend to emotional issues in the user by applying specific care; getting to know and understand the ill person, creating a secure environment which provides well-being, facilitating the process of adapting to health/illness, and promoting positive changes in practical behaviour and habits. At the same time, counselling also cares for the professional, reminding us that we are people with emotions, able to channel them, to communicate effectively, to bring about change in patients, and to enjoy our work.

Possible future approaches

- The need for training in communication skills and techniques, starting at university and continuing in the centres where we perform our professional duties.
- Creation of working groups of communication experts in centres, to act as a reference for training activities, to supervise and improve problems in this area.
- Awareness-raising by management and administration to optimize the required resources.

Opinion of the study presented

Information emerges as a key factor in the illness process, without forgetting that the patient needs to be informed at an appropriate pace and in the right language.

- Demonstrates users' needs to be recognized as individuals with their own anxieties, fears, concerns, rights, spiritual needs etc.

- The patient from the first appearance of symptoms, prior to diagnosis, has to deal with a number of threatening events which, depending on how he or she responds to these, can determine to what degree the patient adapts and what his or her quality of life will be.
- The study reflects the user's need to be informed and the difficulties which users face in obtaining information from professionals.
- Communication appears as a fundamental tool which can be either a protection factor or a risk factor depending upon how it is used. The aim is to promote a type of communication which magnifies the personal and social resources of the patient.
- The power of words is infinite: the right word at the right time can produce a feeling of well-being, and the wrong word can cause discomfort for the rest of a person's life.
- The study reflects the fear of some professionals of becoming emotionally involved.
- Time is identified as an obstacle by many professionals. Do we know how to manage our time? Do we waste the little time we have because we think we don't have it? How long does it take to give someone a look, a smile, a pat?

18. Ander Urruticoetxea. Doctor in the Functional Unit for Breast Cancer of the Catalan Institute of Oncology

"Health professionals prefer well-informed patients who take responsibility for the management of their illness, resulting in greater adherence to treatment and the acceptance of shared responsibility.".

The study presented here provides an excellent basis for addressing the most delicate, interesting and controversial aspects of the provision of information by health professionals to patients with serious illnesses.

Starting by acknowledging the biases inherent in any field study and without in any way attempting to hide the limitations which are inevitably associated with conclusions drawn from this sort of research, the study provides an invaluable framework for considering an issue which is becoming increasingly important in today's working environment.

As an oncologist, and therefore a participant in the information process on a daily basis, I will base my conclusions on my own practical experience. I will seek to avoid theorizing and identify in three paragraphs, some of the most significant difficulties faced by the informer, a brief reference to my belief in the benefits of the well-informed patient and, finally, a few suggestions about how the communication/information process could be improved.

As someone who is involved on a daily basis in an information process which is clearly lacking, and instead of just throwing my hands up and declaring my sense of guilt, I would like to identify some of the difficulties encountered by informers from day to day:

- Structural difficulties including lack of time and of appropriate spaces, far from being an attempt to evade responsibility, are one of the main obstacles to any information process.
- A lack of feedback so that the informer can identify how well he or she has performed in each specific case. As a result, the doctor, nurse or informer in general rarely knows whether he or she has dealt with the process well and what the patient has been satisfied with.
- The lack of specific training in information skills so as to be able to take a more professional approach to complex situations.
- The absence of professional incentives beyond that of personal satisfaction. Given the way the profession is structured and the types of

achievement which are recognized both in the academic sphere and in that of health care provision, it is hardly surprising that professionals choose to invest extra efforts in recruiting patients for clinical trials and writing research articles. At present, the formal recognition of professional excellence does not encompass the demonstration of human qualities or those of a good informer, or even good clinical skills. Instead, the only way of improving one's professional status is by publishing. This decline in the recognition of achievement, which is far from exclusive to the world of health professionals, does nothing to stimulate those professionals who are keen to improve good clinical practice.

- Providing the knowledge needed to conduct the informed consent process. The difficulty in 'training' the patient in the knowledge required in order to take responsibility for decisions about treatment and care derives, fundamentally, from the lack of time for this process. As a result, this fosters paternalistic attitudes among professionals, who see the informed consent process as a nuisance and who complete it as quickly as possible and thus generally in an unsatisfactory manner.

Even given these difficulties with an information process which is often inadequate, I should explain that, despite this, health professionals prefer well-informed patients who take responsibility for the management of their illness, resulting in greater adherence to treatment and shared responsibility.

I believe that work to improve the quality of patient information/communication should focus in particular on the following:

- Encouraging continuous development, with courses to improve basic skills in this area.

- The provision of feedback for health professionals. This should make it possible, for example, through frequent random studies of patients, for health professionals to receive information about the suitability of their actions, about what information is actually received by patients, and about patients' level of satisfaction with this.

- These mechanisms for auditing the quality of information could be also used as the basis for professional incentive mechanisms (including financial incentives if necessary) to reward those health professionals who best meet the information/communication needs of patients.

- We need to emphasize the process of informed consent by creating mechanisms which give the patient enough time to read the document and raise questions about it, and to ensure that all informed consent forms have been considered by an ethics committee recognized for this purpose.
- We need to strengthen cooperation between different health professionals (doctors, nurses, psychologists etc.) and coordinate their work so that a patient who is faced with information about a serious illness or one in which complex therapeutic decisions need to be taken is able to receive information from more than one person, and that there are different ways of tackling the communication process. This will undoubtedly help ensure that the information reaches the patient in the best way possible.

In any case it is fundamental to recognize that improving the process of communication/information between health professional and patient goes hand in hand with the personal maturation of the professional. How we are determines how we inform others and, in any process of improvement, the first step is to recognize how one's own limitations as an informer derive from what one is like. Recognition of one's own shortcomings and the desire to overcome them is in itself a guarantee of quality in the challenging art of informing patients.

Final summary

We end this publication by analyzing some of the information contained in the study and in the specialist contributions which we believe to be relevant.

The informants indicate that information is a key part of their relationship with health professionals. They suggest that it is useful in helping them understand what is happening to them, to deal with their health problems and the needs which arise from these, but above all they say that it helps them to feel more secure and to reduce their fears. In other words, good information is not just good because it helps people to understand and decide, but it is also good in itself because it produces or helps to produce well-being. They identify truth as an essential feature, both because patients need to know the truth in order to reach the right decision and because it consolidates their trust in the professionals. In addition, a high value is placed on the professional's ability to allow the patient to set the pace when giving information and to tailor the way in which news is adapted and given. In conversations with informants we have seen the enormous importance of the human aspect of interpersonal relationships and how users believe that a good professional must have good communication skills and be able to incorporate them into his or her professional practice on a daily basis. Professionals are valued for their technical and clinical ability, but also for their personal proximity. By the same token, when health professionals are distant, cold or authoritarian this has a negative impact.

With regard to this, the seminar discussion identified the difficulty encountered by professionals in acquiring and applying these professional skills. The fact that neither communication nor bioethics feature in medical curriculums was highlighted, and it may be for this reason that doctors sometimes view relational issues more as a personal issue than a professional one, and do not see them as part of their professional training. With nurses, the situation is different, as the curriculum for their university education includes psycho-social sciences and professional ethics among the core subjects. This does not mean, however, that nurses do not encounter communication problems, but it does appear that they are more sensitive towards the human aspects of clinical work. In the symposium, the high number of nurses who have engaged in continuing development in ethics, bioethics, support relationships and communication was noticeable.

Secondly, we would like to draw attention to the data about the role of family members in the information process. The gender factor and the traditional role of women in caring for the ill were reflected in the study results. The women in the study wanted to receive the information themselves and assigned their family (whether husband, partner or children) a secondary role. By contrast, the men interviewed stated that the women occupied the same role as them when receiving information. However, they agree with the women that information for relatives should not replace information for patients. Both groups argued that when relatives are well informed they can provide better help for the patient.

Thirdly, the study discusses the importance of team working. The interviewees attached great importance to there being cohesion between health professionals so that information can be provided gradually at each encounter with any health professional. This is important because there are always several professionals involved in each case and the patient is dealt with by various services. We would highlight the positive effect identified when nurses help reformulate information and actively participate in the information process. Team work has an ethical impact, as it significantly improves the form and content of relationships and makes the patient feel that he or she has access to the professional skills of all the members of the team. Perhaps in this regard we should analyze the criticism voiced by the interviewees with regard to the process of obtaining informed consent. Our data reflect a low ethical content both at the formal level – consent documents are difficult to understand – and in the way it is conducted. A high proportion of interviewees see it as a legal requirement which exonerates health professionals when mishaps occur. However, we should also note the ethical importance which some interviewees attached to it as a result of going through an informed consent process which was accompanied by relevant information, and the possibility of asking questions and obtaining considered responses.

In the seminar the issue of consent and its implementation in health centres was also discussed; and participants agreed that professionals lacked even basic training in ethics, that there was little discussion of difficulties and how to address them, and that scarcity of resources was a problem. The participants agreed with the study data that consent has often been implemented as just one more form to be completed by the doctor for use in case of emergency. As a result, the ethical scope of the informed consent process has depended on the sensitivity of the individual doctor. Neither does the role of nurses in this process appear to have been the focus of much consideration, with the nurse's role in obtaining the informed consent signature and in helping patients to understand information being left instead to personal preference.

Fourthly, we should note the data regarding health organization and planning. According to our interviewees, the possibility of obtaining the best information and establishing relationships and trust which make it possible to understand the complexity of the situation and take autonomous decisions is not just a question of care professionals. Organization is also a key factor; time, workloads, shift patterns and almost constant staff changes are the greatest obstacles. Informants understand that at times health professionals are asked to perform beyond the resources available to them, and highlight the responsibility of health managers in the belief that the role of management is to support good care.

Contributions to the seminar covered by this heading were organized around two aspects. Firstly, the enormous demands for health care and the mobility of health professionals as determining the nature and content of relationships on many occasions was stressed. But there was also criticism of the existing professional career system and accepted criteria for rating professional performance in health institutions, which take no account of the quality of care relationships. The criteria which currently matter are research, publication and participation in management activities.

Finally, the study highlighted the role of patients' associations in obtaining information. These were identified as sources of information from the start of the illness process. Some people turn to them as soon as they are diagnosed, others only get in touch after they have already had the illness for some time, some upon discharge from hospital, and others when they have a specific problem in their daily life. Associations are revealed not just as a source of key information, but above all as support groups where sufferers can process data and learn to deal with their illness. From the study data and the discussion, it can be seen that:

- Information is helpful when implementing a communication process which goes beyond the transmission of data; a process in which what the professional aims to achieve from the relationship with the patient is to help him or her to live through the situation in the best way possible.

- Being a good health professional means incorporating into one's daily work the skills and attitudes required to be a good communicator and a good informer. To do this, the professional must not only undertake continuous development in communication techniques but must also analyze the implications of communication in his or her work, and how to improve his or her skills and resources.
- Responsibility for health information and communication is not the exclusive concern of care professionals but is also, as is clear both from the study data and the seminar discussion, a matter for the administration and managers of health centres, because it is the health organization which defines the conditions in which relationships between patients and professionals occur, through its management criteria. As a result, management has an ethical responsibility both to include the right of users to receive information and take decisions, and also to provide the means and resources necessary to make this a reality.

List of specialists invited to participate in the debate about the study

1. **Pilar Antón.** Lecturer at the School of Nursing of the University of Barcelona
2. **Montserrat Artigas.** Head of the Customer Service and Quality Division in the Catalan Health Service
3. **Margarita Boladeras.** Professor of Moral Philosophy at the University of Barcelona
4. **Ester Busquets.** Nurse and Philosopher, Borja Institute of Bioethics
5. **Josep Maria Busquets.** Secretary of the Bioethics Committee of the Department of Health and Social Security of the Regional Government of Catalonia
6. **Victoria Camps.** President of the Víctor Grífols i Lucas Foundation
7. **Montserrat Casamitjana.** Coordinator of the Breast Cancer Prevention Programme at the Hospital del Mar in Barcelona
8. **Jordi Colobrans.** Lecturer in Communication Sciences, Blanquerna Faculty of Communication, Ramon Llull University, Barcelona
9. **M. Carmen Comella.** Coordinator of the Catalan Cardiology Support Association (ACARD)
10. **Esther Corrales.** Specialist Clinical Nurse at the Catalan Institute of Oncology. Duran i Reynals Hospital
11. **Xavier Duran.** Scientific journalist at TV3, Catalonia's public broadcasting television
12. **Susanna Escamellas.** Grupo Ágata, Spokesperson for the Catalan Association of Women Affected by Breast Cancer
13. **Paz Fernández Ortega.** Nursing Research Coordinator at the Medical Oncology Service of the Catalan Institute of Oncology
14. **Joan Manuel García Jorba.** Lecturer in the Department of Sociology and Organizational Analysis at the Faculty of Economic Science and Business Studies of the University of Barcelona

15. **Maria Gasull.** Lecturer and Head of the Teaching Department of Legislation and Ethics of the University Nursing School of the Health Management Foundation of the Santa Creu i Sant Pau Hospital of Barcelona
16. **Melinda González.** Study interviewer
17. **Albert J. Jovell.** Director General of the Josep Laporte Library Foundation and President of the Spanish Patients' Forum
18. **Meritxell Mollà.** Radiotherapist at the Breast Unit at the Teknon Cancer Institute of Barcelona
19. **Milagros Pérez Oliva.** Journalist and editor of the Society Section of Spain's El País newspaper
20. **Begoña Román.** Lecturer in the Faculty of Philosophy of Catalonia at the Ramon Llull University in Barcelona
21. **Isabel Rubio.** Coordinator of the Breast Unit at the Teknon Cancer Institute of Barcelona
22. **Ana Torrente.** Nurse at the Mammary Pathology Unit of the Germans Trias i Pujol University Hospital of Badalona
23. **Ander Urruticoetxea.** Doctor in the Functional Unit for Breast Cancer of the Catalan Institute of Oncology

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Jordi Caïs Fontanella. Lecturer at the Department of Sociology and Organizational Analysis at the Faculty of Economic Science and Business Studies of the University of Barcelona.

Publications

Bioethics monographs

13. *Health Information and the active participation of users.*
12. *The management of nursing care*
11. *Los fines de la medicina (Spanish translation of The goals of medicine)*
10. *Corresponsabilidad empresarial en el desarrollo sostenible (Corporate responsibility in sustainable development)*
9. *Ethics and sedation at the close of life*
8. *Uso racional de los medicamentos. Aspectos éticos (The rational use of medication: ethical aspects)*
7. *La gestión de los errores médicos (The management of medical errors)*
6. *Ética de la comunicación médica (Ethics of medical communication)*
5. *Problemas prácticos del consentimiento informado (Practical problems of informed consent)*
4. *Predictive medicine and discrimination*
3. *The pharmaceutical industry and medical progress*
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1. *Freedom and health*

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