

## KEYNOTE LECTURE

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# Patient experiences and preferences: development of practice guidelines in a cancer imaging department

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### Abstract

**Objective:** To improve patient management based on analysis of the results of a survey conducted during their visit to the imaging department of a cancer centre. **Materials and methods:** A questionnaire comprising 30 single-response questions on a dichotomous scale or a 3- or 4-modality scale was developed by three radiologists specialized in oncology, the head of our quality assurance department, a psycho-oncologist, a psycho-sociologist, a biostatistician and a member of our institute's Patient Committee. Questions concerned reception, information provided about the examinations, examination experiences, the relational qualities and availability of health care professionals, the interview with the radiologist and announcement of the examination results. **Results:** The questionnaire was given to 190 patients in the waiting room before a standard radiography or ultrasound examination (33%), mammography and breast ultrasound (33%), computed tomography (CT) or magnetic resonance imaging (MRI) (34%). The return rate was 81%. This article analyses the responses to the various questions in terms of either percentages or detailed replies and suggestions. **Conclusion:** Analysis of the patients' experience and their suggestions provided objective elements concerning their real wishes in relation to each step of their management and identified changes and improvements to be made to the organization and daily functioning of the department.

**Keywords:** *Doctor–patient relationship; patient preferences; cancer; communication skills; imaging department.*

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## Introduction

Improvement in global patient management requires the active involvement of all members of the medical and non-medical personnel, as the slightest dysfunction in the hostile context of disease can deteriorate the patient's perception of the quality of his/her relationship with the technical and human environment. In the imaging department, the reception, waiting room, the relationship with the various members of staff, the unpleasant nature of certain examinations, and especially apprehension concerning the results are all sources of anxiety. All elements of communication, what is said and the way it is said, non-verbal communication, and thoughtless comments can increase the fragility of these patients.

Very few studies concerning the quality of life of patients have assessed patient experiences and preferences during their repeated visits to the medical imaging department in the course of their disease. A survey conducted by Adamsbaum *et al.*<sup>[1]</sup> evaluated the experience of pregnant women undergoing foetal MRI. North American studies, performed in the 1990s<sup>[2,3]</sup>, looked at the preferences of referring physicians and radiologists concerning the way to announce the results, but no survey has been designed to analyse the responses of patients concerning their experiences and their preferences and to define practice guidelines or set up specific training in announcement of the results of an imaging examination. The purpose of this study was to set up and conduct a survey among patients during

their visit to the imaging department with a triple objective:

- (a) Determine and objectively confirm patient preferences and expectations concerning all aspects of their management in the department.
- (b) Based on quantitative and qualitative analysis of the responses to a questionnaire, provide the expected changes and improvements to the organization and daily functioning of the department.
- (c) Publish the results to inform as widely as possible and to involve other imaging departments, especially in cancer centres.

The results of this survey are presented in this paper.

## Methodology

The project was presented to our institute's Patient Committee, which gave a very favourable opinion. A questionnaire, taking into account the specificities of the Imaging Department, was prepared by the investigators and validated by the Survey Evaluation Committee and our Quality Assurance Department.

The objective of this questionnaire was to evaluate the patients' expectations in relation to their management, especially in terms of reception by the department, the information provided concerning the examinations, the patient's experience of the examination, the relational qualities and availability of professionals, the interview with the radiologist, and announcement of the results.

The various issues to be evaluated were identified and chosen on the basis of the opinion of three expert radiologists with more than 20 years of full-time experience in medical imaging in oncology and the authors of numerous publications concerning improvement of patient management, the specific features of the doctor-patient relationship in cancer imaging (adults and children) and organization of the imaging department around the patient<sup>[3-8]</sup>.

The issues selected and the clarity of the questions were evaluated and validated by an expert committee composed of the Quality Assurance Department, a psycho-oncologist, a psycho-sociologist, a biostatistician and a member of our institute's Patient Committee.

The 30 questions of the survey covered the following topics:

- information needs (desire for explanatory brochures, information concerning the identity of the various members of staff, explanations about the reasons, constraints, procedure and risks of the examinations, need for reassurance),
- the patient's experience (waiting time, information received, psychological state, relationships with the radiologist and other personnel),
- preferences in relation to the mode of announcement of the results,

- patient satisfaction with the various aspects of their management.

Questions were formulated in a simple form on a dichotomous scale (yes/no) or a 3 or 4 response modality scale and open-ended questions allowing detailed replies. Questionnaires were distributed by randomization from the day's appointment list, organized according to a neutral mode, with the same oral presentation of the survey by a person external to the department. Three imaging rooms were chosen: mammography/breast ultrasound, standard radiology/general ultrasound and magnetic resonance imaging (MRI)/computed tomography (CT). The strictly anonymous questionnaire was dispensed within a stamped envelope, addressed to the centre, and filled in by the patients outside the department to facilitate free expression. A box was also available for collection of questionnaires at the hospital and Imaging Department reception areas.

This was a prospective descriptive study. Responses to the questionnaires were analysed by the statistics department. The results for qualitative variables are expressed as percentages.

## Results

The overall response rate was 81% (154 of the 190 questionnaires distributed were returned): 33% after standard radiography or ultrasound, 33% after mammography/breast ultrasound and 34% after CT or MRI. Due to the recruitment, particularly related to breast disease, 90% of responses were derived from women and 10% were derived from men. The mean age was 56 years (range 21-92 years). Among the patients who answered the questionnaire, 22% were at the screening or diagnosis phase, 32% were on treatment and 46% were at the surveillance stage.

### *Reception and waiting*

Opinions concerning the department were positive overall with 91-98% of patients satisfied or very satisfied: reception by administrative personnel, 96%; availability of personnel, 98%; comfort of the waiting rooms, 91%. However, regardless of the stage of the disease, the number of unsatisfied patients was higher for CT/MRI than for other examinations.

Concerning overall management, 96.5% of patients had a positive opinion and 98% considered the personnel to be highly skilled, 21% were very satisfied and 62% were satisfied with the way in which they were reassured and supported. Respect of privacy and modesty was considered to be very satisfactory by 55% of patients and satisfactory by 39% of patients. However, 22% of patients undergoing mammography considered that these two aspects were insufficient.

The waiting time before an examination was less than 15 min for 33% of patients, between 15 and 60 min for

43% of patients; 9% did not wait at all, but 15% had to wait for more than an hour. Nevertheless, this waiting time was considered to be acceptable by 93% of patients, although the waiting time for CT/MRI was sometimes considered to be excessively long and 18% of patients had to wait for more than an hour for mammography/ultrasound.

### *Examinations*

Did the radiology examinations worry you during the days before the appointment: yes, 51% (yes considerably, 13%; yes slightly, 38%); no, 49%. However, 65% of patients with breast disease replied yes, even at the stage of surveillance (62%). For patients who reported being worried by the examinations, by far the most frequent reason was anxiety about the results (76% for radiology/ultrasound and breast examinations, 51% for CT/MRI). Fear of the examination was reported by 17% of patients before CT or MRI and by 10% for the other examinations. Three of the patients not worried by the examinations nevertheless reported organization problems, travel expense or the need to take sick leave.

The examinations themselves were considered to be distressing by 68% of patients (71% for mammography and 73% for CT/MRI). The reasons reported (detailed reply) were fear of the results, waiting for the results and fear of the risks and the examination procedure: 'fear of not having the results after the examination', 'fear of recurrence', 'lack of dialogue', 'feeling of isolation', 'fear of x-rays', 'fear of the injection', 'risk of irradiation with old equipment'.

### *Information and reassurance*

In reply to questions about information, 71% of patients would like explanatory brochures and 29% did not consider such brochures to be necessary. A greater demand for information was observed for mammography (79%). The explanations given by the doctor ordering the examination concerning the purpose of the examination were considered to be sufficient in 89% of cases and not at all sufficient in 11% of cases (18% at the diagnostic phase and 17% overall for breast disease).

Were you informed about the identity of the people looking after you: no (36%) or not always (32%), yes (32%). Would you like to be informed: yes, 66% (72% for breast disease and 74% at the surveillance phase); no, 34%. For patients waiting for ultrasound, 50% did not know that this examination was always performed by a doctor. Overall, 2/3 of patients said that they were poorly informed about the identity of the personnel and would like to be better informed.

Do you need to be reassured before a CT scan or MRI: yes, 68% of patients (yes 36% and yes slightly 32%); 74% of patients undergoing mammography answered yes to this question. Would you like explanations from a member of the radiology team concerning: the

examination procedure, yes 82%, no 18%; possible risks: yes 85%, no 15%. For what reasons (detailed reply): to avoid the stress and anxiety of the examination itself (claustrophobia, isolation, 'MRI is a nightmare', risks (allergy and magnetic field) and fear of the results); 32% of patients said that they did not need to be reassured and 15–18% did not want any explanations: 'I already know, I am optimistic, I am completely confident, I prefer not to know'.

### *Interview with the radiologist: reality and wishes*

Did you meet with the radiologist before the examination: no, 88%; yes, 12%. Would you like to meet with the radiologist before the examination: no, 64%; yes, 36%. Why (detailed reply): yes, 'to obtain more explanations and to understand the purpose of the examination and the examination procedure and to be reassured', 'to tell the radiologist about painful zones'; no, 'it is unnecessary before the examination'; it is better not to waste the radiologist's time', 'it is not essential, as too many visits only increase the stress'.

Did you meet with the radiologist after the examination: no, 76%; yes, 24%. Would you like to meet with the radiologist after the examination: yes, 77%; no, 23%, regardless of the type of examination and the stage of the disease. Why? (68% of detailed replies):

- For those patients wanting to meet the radiologist: in 86% of cases, to have information about the results: 'to obtain explanations', 'to be reassured and to avoid waiting for the results', 'to have the preliminary results', 'an overview of the results', 'rapid results before the visit with the doctor', and 'if there is a problem', 'the radiologist is the most qualified person to give the results'.
- For those patients not wanting to meet the radiologist: 'I prefer my referring physician', or 'the radiologist provides a good explanation during the examination (ultrasound)' and 'the radiologist is part of a team that discusses the results'.

Did you consider the information given by the radiologist after the examination to be satisfactory: yes, 90%; no, 10%, regardless of the type of examination or the stage of the disease.

### *Announcement of the results*

In your opinion, who should give the results of radiology examinations: the referring physician, 36%; the radiologist, 33%; both the radiologist and the referring physician, 27%; the radiologist and the general practitioner, 2%; the general practitioner, the radiologist and the referring physician: <1%. Overall, the radiologist was involved in 63% of replies. The radiologist's opinion was considered to be slightly more important at the diagnostic phase, but patients appeared to prefer the referring physician to

give the results of CT/MRI (54% vs 36%); the radiologist was expected to give the results slightly more frequently by patients undergoing breast examinations and radiology/ultrasound.

Detailed replies: 'After the examination, I would like to systematically meet with the radiologist so that he can give me the partial results and then see the referring physician fairly rapidly when there is a problem'. 'It would be good to have the results after each examination to avoid stress'.

### *Preferences concerning waiting for the results*

The waiting time for the results was considered to be globally satisfactory by 89% of patients (acceptable, 78%; or even negligible, 11%), excessive (9%) or unacceptable (2%). The waiting time for results was usually considered to be excessive for CT/MRI (19%). Our dictated, typed and validated reports are available within 24 h in 97% of cases, but visits with the referring physician are often scheduled 2 to 3 weeks after the radiologic examination and patients complain that they have to wait all that time before obtaining the results.

### *Final detailed reply: experiences and preferences*

Most patients expressed their thanks, congratulations and expressed their confidence and satisfaction. As expected, the waiting time and the verdict of the results generate the most anxiety as well as isolation related to cancer. The examination itself is also stressful (risk, pain, anxiety). Patients would like to obtain clear explanations so that they can understand why the examination is being performed, what we are looking for, why a CT scan is performed rather than MRI and vice versa, what are the respective advantages of the two techniques, what are the dangers and risks associated with the examinations. Patients clearly expressed a preference for 'progressive' announcement of the results, to have 'an idea of the results, the first comments'.

Patients very clearly expressed an absolute preference to perform follow-up imaging in the centre in which they are treated, which results in an excessive number of surveillance examinations in our centre (an average of 46% and 76% for mammography).

Patients suggested the need for better coordination between examinations (mammography and breast ultrasound) and between departments (venous line removed). They also preferred examinations to be grouped to limit travel and disruption of their work. They also suggested that letters should not display the Institute logo.

The importance of the radiologist in the process from detection to treatment of the disease was emphasized: 'I realised as a result of this questionnaire that the radiology department is a department in its own right and it is in this department that everything is confirmed at the

time of diagnosis or remission. The radiologist should therefore be considered to be just as important as another specialist in the process of screening and treatment of the disease. Why do we not see the radiologist more often?'

## **Discussion**

There is a high risk of poorly adapted behaviour and thoughtless comments at all steps of management of patients during a radiology, ultrasound or MRI examination that can have a disastrous effect on patients who are already particularly susceptible as a result of their disease. The slightest dysfunction, lack of organization or poor communication skills can be experienced very negatively and have a lasting impact on the patient's perception of the quality of the technical and human structure taking care of him/her. Imaging departments must be organized and personnel must be trained to avoid errors and optimize all aspects of the relationships with patients. It is essential to identify their experiences and their expectations in order to achieve this objective. The very high response rate to this questionnaire supports the rationale for this type of approach.

For more than 10 years, we have been particularly interested in studying the complexity of the doctor-patient relationship in the field of cancer imaging<sup>[4-9]</sup>. This research initially led us to examine our practices by analysing our relational mode with patients, resulting in the acquisition of a number of basic skills inherent to the doctor-patient relationship and announcement of bad news<sup>[10-12]</sup>. We subsequently wanted to structure our approach by designing a patient questionnaire to more clearly understand their perceptions during their visit to the Imaging Department.

In order to improve patient management and the relationship between the patient, the personnel and the radiologist, it is important to take into account all phases of the patient's visit to the department, not just announcement of the examination results, but overall management from the time of making an appointment until leaving the department. All of the team must be motivated to effectively place the patient at the centre of the organization and, in order to optimize this management, it seemed important to determine the patients' opinion, expectations and experiences. How many patients would like to have information booklets available in the waiting room, explaining in simple terms the examination that they are about to undergo, and how many patients do not want this type of information? Are patients sufficiently informed about the identity and function of the white coat personnel caring for them? What is their personal experience of waiting for an examination, what stress factors are involved? Analysis of the responses to the questionnaire provided objective elements that will help to improve certain dysfunctions. For example, the fact that 18% of patients waited more than an hour before mammography and ultrasound

demonstrated defective organization. Conversely, a mean waiting time less than 15 min was a source of satisfaction. A larger proportion of patients were also dissatisfied when undergoing CT or MRI than for other examinations. This is not the responsibility of personnel, as the same people operate the various examination rooms. The causes are multiple: the waiting time is often considered to be too long and waiting rooms are therefore less comfortable, patients at the diagnostic phase are anxious about the result and patients on treatment are often more tired. The more unpleasant nature of the examinations and isolation also play a role. Personnel must make an effort to provide explanations, reassurance and support in order to limit the causes of stress and negative experiences.

The fact that almost one-quarter of breast patients consider that their privacy is insufficiently respected indicates the need to take certain measures, particularly providing patients with a smock for mammography on ultrasound, even if the two rooms are contiguous.

It is somewhat surprising that only one-half of patients reported being anxious about undergoing an imaging examination. Patients were also most anxious before a breast examination. The examinations themselves were considered to be distressing especially because of fear of the results, uncertainty, and lack of information. Some patients wanted to be more actively involved, while others described their lassitude and their desire to think about something else, and others did not want to know anything about the examination. Expectations therefore differed considerably from patient to patient and no stereotyped approach can be proposed. As a result of their training, empathy and listening capacity, medical and paramedical personnel must try to detect the patient's demands and provide an appropriate response. Patients wanted to be more clearly informed about the identity and role of the various people tending to them. It is essential for each member of staff to wear a badge indicating his/her name and position, and secretaries, radiographers and doctors must systematically introduce themselves each time they see the patient. Residents present during examinations must also be introduced and identified.

Only slightly more than one-third of patients wanted to see a radiologist before the examination. This choice obviously cannot be known in advance and it would be useful to set up a way of identifying the patient's choice in relation to this aspect and inform the radiologist in charge of the patient and the examination.

All studies concerning announcement of the results after an imaging examination<sup>[13–16]</sup> have shown that slightly more than 90% of patients wanted the results to be given directly by the radiologist after the examination when it was normal and slightly less than 90% in the case of an abnormal examination. These figures, derived from North American surveys, appear to be higher than in our daily practice in French Cancer Centres. The percentage

of cancer patients not immediately requesting the results of a CT scan or ultrasound would appear to be greater than 10%. This survey was conducted in order to answer this question, among others, which concerns all radiologists. This survey shows that although three-quarters of patients did not see the radiologist after the examination (apart from ultrasound), three-quarters of patients (77%) would have liked to see the radiologist, in 86% of cases not to obtain the results but to obtain 'information' about the results and an overview of the results. Overall, one-third of patients preferred to obtain the results exclusively from their referring physician at the institute, while the radiologist was mentioned in 63% of replies.

The 'I' of 'SPIKES', a protocol proposed by Baile *et al.* to help doctors break bad news to patients<sup>[12]</sup> is the 'I' of 'Invitation' which could be applied to radiologists in some cases. It consists of inviting the patient to express his or her desire to be informed: 'Would you like me to give you some information about the examination results or would you prefer to discuss all of the results with your doctor?' This type of request could be systematically envisaged before examinations for example by means of a short questionnaire given to the patient at the time of the appointment.

### *Future prospects*

This first survey demonstrated the validity of the questionnaire, which could probably be improved by decreasing the number of questions. Our current objective is to prepare a new questionnaire and to extend this survey to other imaging departments. We also want to set up specific training for the various categories of personnel in contact with patients in an imaging department.

## **Conclusions**

Globally, the majority of patients were satisfied with their management in our Imaging Department. However, they would have liked more information about the reasons and purpose of the examinations, the possible risks and the identity of the various personnel tending to them. The radiologist must be involved in announcement of the results, as three-quarters of patients would like to meet the radiologist to obtain a first impression of the results, but about 20% did not want to know anything about the results. This desire must be respected, but a system must be set up in order to determine this preference before the examination. For patients wanting to meet with the radiologist, this meeting should be held after the examination and not in a doorway or corridor. In order to improve the functioning of imaging departments, the whole process of the information given to patients must be revised. The number of simple surveillance examinations also needs to be decreased, which would require informing patients that, after a certain time after treatment, surveillance

should be performed elsewhere than at the Institute. CT/MRI examinations raise specific problems, indicating the need for improvement of management before, during and after these examinations. The ultimate objective is reorganization of imaging departments to achieve patient-centred practice, by restoring the patient's place as an active participant in his/her management.

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