Information Given to Patients Undergoing Nuclear Medicine Procedures

Geir A. Pedersen[1], Liv I. Stenstad[1], Andreas D. Landmark[2], Berit Brattheim[3]

[1] Operating Room of the Future, St. Olavs Hospital, Trondheim, Norway
[2] SINTEF Technology & Society, Trondheim, Norway
[3] Sør-Trøndelag University College, Trondheim, Norway

Abstract. In this study, we have examined the information given to patients whom are undergoing nuclear medicine procedures – and in particular the information on radiation and exposure. We collected the written information provided prior and during the examination and conducted a small survey amongst patients on the information given. The main findings show that as these patients are sources of radiation to their surroundings, information about this should be made available for the patients in order to make the necessary precautions.

1 Introduction

Patients have a basic right to information about their illnesses, treatments and management [1]. This also includes information about possible risks and side effects. Advances in technology for both diagnosis and treatment combined with increased specialization, may challenge the balance in informed and shared decision-making, and the balance of rights and responsibility between the medical professional and the patient.

At the same time, the role of the patient is evolving. The availability of information and information technology has created new possibilities and relations between the health service and its users [2]. Patients are now also used to finding information in source and voices outside the regulated realm of the health service. As such, it is meaningful to discuss a "shift in the role of the patient from passive recipient to active consumer of health information" [3]. Patients search out information about their *specific* medical conditions for several reasons, including "*for reassurance or because of dissatisfaction with the amount of detailed information provided by the health professional during the encounter"* [ibid].

From the perspective of the health professional, providing information is also an act of balancing between a reasonably informed patient and not wishing to cause unnecessary fright or concern about upcoming treatment or prospective outcome. However, studies show that *"Patients very satisfied with their information had received the largest amount of information"[4]*. At the same time, an American study of 8 major sources of patient education material on radiation safety show that we fail to appropriately exploit these modern information channels. Their literature review

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showed that all of the 45 identified articles failed to meet the recommended level of readability for patient information [5].

Patients undergoing Nuclear Medicine (NM) procedures require specific and tailored information [4]. More specifically, they require information about their condition, information about the diagnostic or therapeutic procedure they are about to undergo, and lastly information about the fact that the patient can act as a radioactive source and constitute a dose and contamination hazard to their surrounding for some time after their procedure. The information must be provided in a format that is easily understood by the patient and is appropriate to the hazard presented. Hospital nuclear medicine departments are known to produce very varied instructions to patients[6]. The understanding of radiation and nuclear medicine procedures is not described in detail in research – and there is a need for further research into these concepts both for patient information, but for appropriate information to staff and professionals that come into contact with NM patients in other parts of the hospital. We have previously investigated the radiation from NM patients to their surroundings [8], and found that while the amount of radiation is small, current practices are not necessarily based on evidence-based evaluations. Better information and education of both patients and staff seems beneficial.

In Norway, the official recommendations from the Norwegian Radiation Protection Authority on nuclear medicine[7], clearly states that at the beginning of the treatment plan a whole range of questions concerning exposure to the surroundings should be covered. Individual counseling both oral and written of the patient and their kin should cover daily activities and how to reduce the risk of exposure to others where appropriate. The aim of this study is therefore to capture patient perspectives on the received information about radiation as well as to investigate current hospital practice on this issue.

2 Material and Method

Health care setting: The nuclear medicine center located at a university hospital owned by one of the four Norwegian Regional Health Authorities. The hospital's catchment area is approximately 700 000 people.

Study design: A mixed-method approach with use of a quantitative questionnaire accompanied by a qualitative review of practice documents.

Data collection: The questionnaire was handed over to 40 patients undergoing a nuclear medicine examination in the period February – March 2013 and recorded data on 1) how and what information the patient received from the hospital before the actual examination, and 2) patient satisfaction with received information as well as their perspective on how such information may be mediated. In addition, the patient information leaflets about nuclear radiation precautions (i.e. the information intended to be distributed to patients) were collected from 7 hospitals, of which one hospital was Danish.

Data analysis: Simple descriptive statistic was applied to describe the features of the questionnaire dataset. This was accompanied by a qualitative content review of the collected leaflet, for which the focus was on information about radiation precaution related to pregnancy, children/next of kin and other people. Authors 1 and 2 did the analysis and the interpretation of the data.

Ethical aspects: Informed consent was obtained from the participants, and they were assured that questionnaire and document data would be treated confidentially and were guaranteed anonymity in the presentation of findings. No personnel or health information data were collected. The study was approved by the hospital's research board, and the ward manager.

3 Results

37 out of 40 patients (93%) completed and returned the survey within the given deadline. Figure 1 shows that 14 of the 37 patients (38%) were informed orally by the nuclear medicine department about radiation. 15 of the patients had not received any information in advance. 6 Patients say they have received information in advance by an information letter sent from the nuclear medicine department.

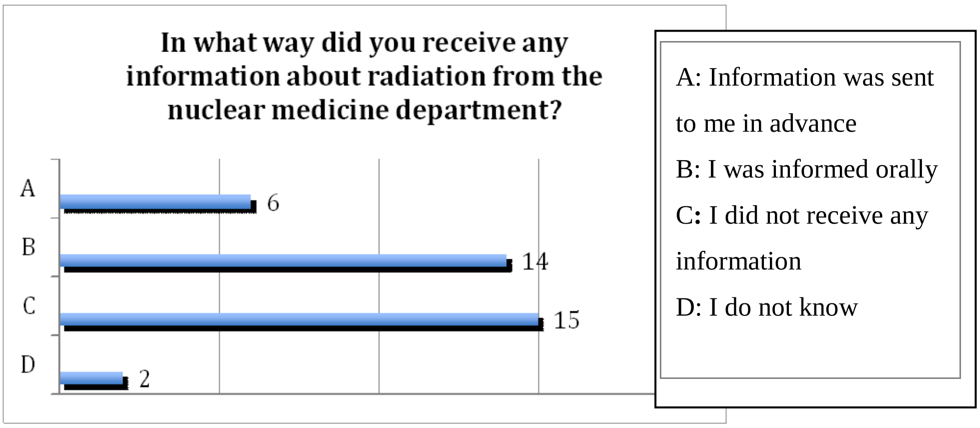
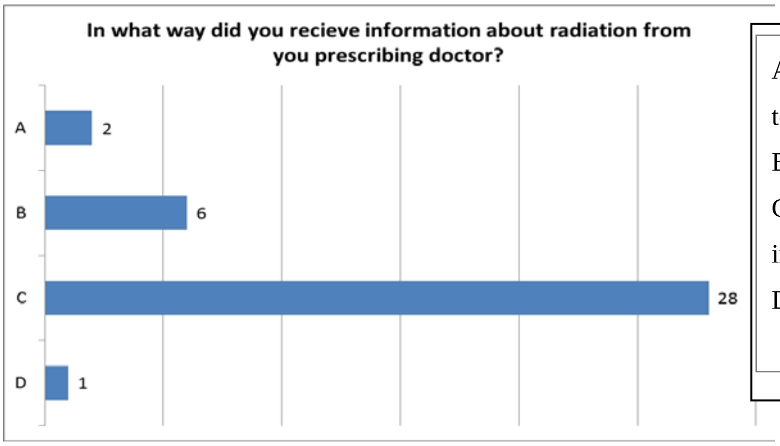


Figure 1. Information given from the nuclear medicine department to the patient.

Figure 2 shows that 28 of 37 patients (76%) had not been informed by the doctor who referred the patient to the nuclear medicine examination. 6 patients have been informed verbally by the physician.



A: Information was sent to me in advance

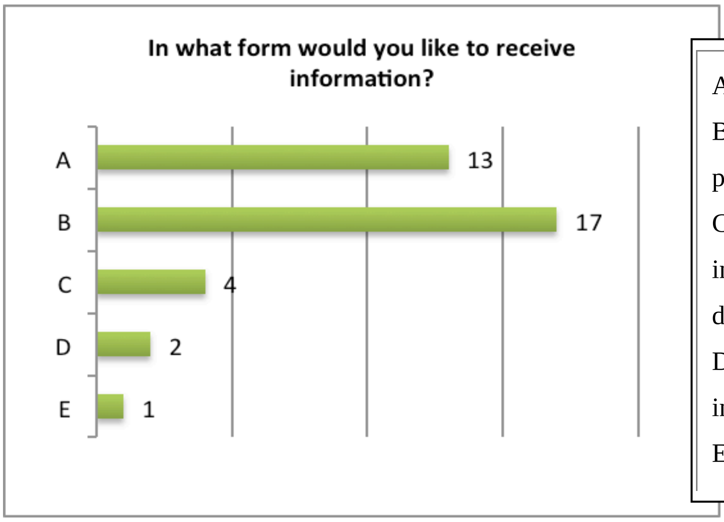
B: I was informed orally

C**:** I did not receive any information

D: I do not know

Figure 2. Information from the prescribing physician regarding radiation.

Figure 3 shows that when it comes to the desired way to get information, 17 (46%) answer that they want to get information in the notice letter, while 13 (35%) will prefer the information given orally. Only two of the subjects want the information via the Internet.



A: Orally

B: Information should be placed in the summons letter

C**:** I prefer to read information at the department upon arrival

D: I prefer to read information on the Internet

E: I do not know

Figure 3. In what form the patient would like to receive information.

Figure 4 shows that 20 (54%) of those surveyed believe they have received enough information about the survey, while 11 (30%) think they have not got enough information. 6 (16%) do not know.

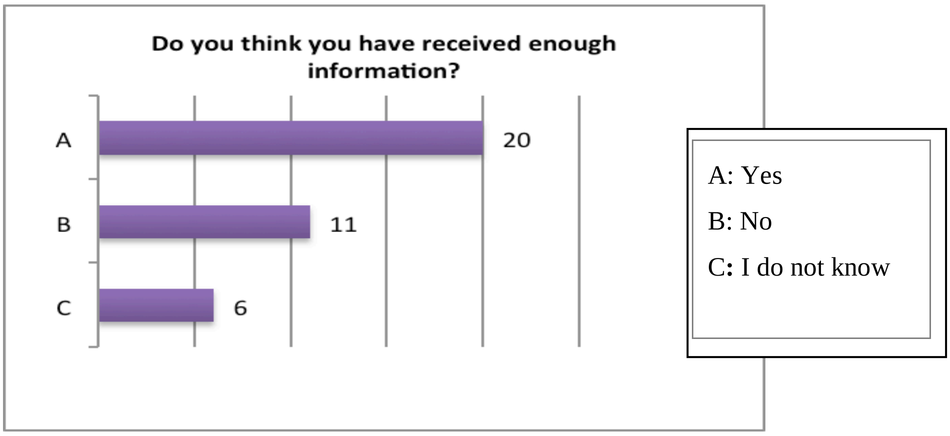


Figure 4. The answers to the question: “do you think you have received enough information?

As for the information hospitals give to this patient group by letter, all seven hospitals (Six Norwegian and one Danish hospital) send out general information as well as specific information related to the particular procedure. This includes information about radiation as well as which precautions the patient should undertake on a general basis.

However, concerning patient precaution when it comes to how they should keep clear of pregnant woman/children/others, Table 1 shows that there is only one hospital that lists such precautions in their information leaflet related to the three common NM examinations; skeletal scintigraphy, octreotide scintigraphy and MUGA.

Table 1. Whether or not the hospitals give their patient information regarding radiation comparing three common nuclear medicine examinations. One hospital give specific information about how far away the patient should keep clear of pregnant woman and children, and for how long.

Examination / Hospital	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Sceletalscint.	NO	NO	NO	Yes	NO	NO	NO
Octreotidscint.	NO	NO	NO	Yes	NO	NO	NO
MUGA	NO	NO	NO	NO	NO	NO	NO

4 Discussion

As shown in the results (Table 1), only 1 hospital out of 7 hospitals (= a Norwegian one) provided information about restricting contact with children and pregnant women (even though this is explicitly mentioned in the recommendations from the Norwegian Radiation Protection Agency).

As we saw, many patients indicate that they did not receive any written information prior to the day of the examination. However, according to our survey the hospitals do provide general information. In this general information there are sections on radiation safety and precautions. We speculate that this indicate that half of our study population does not read everything they receive. If so, this raises several questions around the form of communication: the readability of the content and whether or not the information is at an appropriate level for the patient's comprehension.

Similarly, Figure 2 shows that most patients did not receive any information about radiation precautions from the referring physician. This was expected as it is the hospital's job to distribute this type of information, Still 2 of 37 respondents replied that they did receive information about radiation precautions. This raises some doubt with respect to the comprehensibility of the posed question. Respondents were divided in their view between preferring information to be distributed in the letter from the hospital and whether or not they would prefer oral information at the department. This may reflect that information provided on the day of the injection is better remembered than the information received potentially some time prior to the examination day. During our period of data collection, we observed that some patients brought their information letters to the hospital at the day of their examination, which in turn created an opportunity to provide all the necessary information written as well as repeating the key parts verbally on the day. Based on observations, our impression is that the written communication has potential to contain *more* information, but again tailored to the specific needs of the patients. This ranges from practical issues such as where and when, but also to more information about radiation, restrictions and precautions that should be observed after the injection of radioactive material. We also noticed that our informants did not seem to be afraid of more information, but rather saw it as important and necessary.

Comparing this with the literature on information to patients, especially for patients undergoing nuclear medicine procedures, our survey is inline with what similar studies have shown elsewhere[4-6]. Research has shown that the radiation from these patients to the surroundings are close to negligible [8]. It is therefore close to a paradox that the information – and knowledge of – about radiation and exposure both for staff, patients and their kin is thin. One could argue that this is unimportant given the context and the relatively harmless dose of radiation, but at the same time there is a basic right to information to be observed as well as a general need for reinforcing the ALARA ("as low as reasonably achievable") principle in a time where the average patient is exposed to an increasing amount of radiation through diagnostics and therapy.

Further research could involve bigger patient groups, other types of nuclear medicine examinations, other types of radiopharmaceuticals and a larger amount of patients/hospitals.

As well, one hospital changed their information practice resulting from our research findings. They now inform collaborating departments about the patient radiation as a way to assure them that it is not harmful. One might argue that more general knowledge about radiation inside the hospital walls could break down some of the undue anxiety and wrong assumptions toward nuclear medicine examinations.

One of the authors of this paper has now focused her master's degree towards patient information related to radiography.

4.1 Strengths and weaknesses

The biggest challenge in this study was to ascertain how much information the patients received without biasing them through at the same time informing them. The premise for our investigations was measurement of the radiation from the patients that made it necessary to inform them about the study and through that also the fact that they did act as a radiation source. For some, this came as news to them – which indicate that this was not something they had been informed of or had not comprehended from the information given to them. This means that it is not possible to reliably distinguish between the information given to them outside the scope of our study and the informed consent obtained in the study (which contained necessary information).

Concerning question 4 (Figure 4), 20 (54%) patients respond that they have received good enough information, and 11 (30%) that they did not. It is possible that their interpretation confuses the details about the procedure and radiation protection in general. This of course impedes the interpretation of our results.

There is also a potential confounder in that patients may receive different information based on whether they were referred from their general practitioner or as in-patients from a different ward. We have chosen to focus on their subjective experience and how and through which channels they would prefer to receive information. As such not a test of the information they have understood, but their subjective experiences. This could of course be biased by the respondents wish to provide "socially acceptable answers", i.e. a social desirability bias to appear favorable to the surveyor. Additionally, the "power of questions" is an inherent confounder, the questions posed to the informants also influences how they respond. Due to the size of the study, there were only a limited pilot of the survey. So there is an underlying challenge in interpretation of the responses.

5 Conclusion

Patients have a fundamental right to information about their own illness, examinations and, treatment; including side effects and risk factors. As this study has shown, the nuclear medicine patients do not receive the information they are entitled to. This is a balancing act between providing information enough information, but at the same time not overwhelming or causing unnecessary worries in the patient population.

In order to truly provide patient-centered care, attention to supporting activities such as patient information is important in order to change the patient experience. Today, information is available everywhere, on the internet or in more traditional channels, but it differs to which extent patients seek out information – as well as it varies how much of the given information is comprehended by the individual patient.

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