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Patient Preference for Dissection of Sentinel Nodes Outside Level I–II of the Axilla

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In this study patients' and female doctors' opinions about harvesting sentinel nodes outside the axilla are evaluated and patients' ability to understand the concept of sentinel node biopsy is investigated. Information leaflets and questionnaires were mailed to 100 patients with breast cancer who had undergone sentinel node biopsy and to 300 female doctors. Seventy-three (73%) patients and 148 (49%) female doctors returned the questionnaire. Fifty-eight (79%) breast cancer patients and 71 (48%) female doctors wanted harvesting to be done in order to determine whether the nodes were involved. Sixty-six (90%) patients and 128 (86%) female doctors wanted the procedure if it changed the treatment. Sixty (82%) patients understood the outcome of the sentinel node procedure. Patients with breast cancer seem to value the information gained by harvesting sentinel nodes outside the axilla and want the procedure if there is even the slightest possibility that it might change the adjuvant treatment.

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The status of axillary and internal mammary lymph nodes (IMN) is one of the most significant prognostic factors for survival in breast cancer (1–4). The reappraisal of internal mammary node metastases as a prognostic factor and the results of recent publications of trials of postmastectomy irradiation have aroused discussion about adopting routine elective IMN irradiation despite potential serious cardiac morbidity (4–6).

Lymphoscintigraphy with biopsy of sentinel nodes outside the axilla may provide a promising method yielding information on the complete lymphatic drainage of the tumour area in the breast and enabling more accurate staging and targeting of regional and systemic treatment in breast cancer. Preoperative lymphatic mapping has been reported to visualize sentinel nodes outside level I–II of the axilla, predominantly in the internal mammary chain in 8–56% of patients when intraparenchymal tracer injection is applied (7–14). Retrieval of internal mammary sentinel nodes does not seem to carry any great risk for the patients, but extra skin incision(s) are often necessary (11, 13). Metastases in IMN have been found in up to 30% of patients with successful biopsy of the parasternal sentinel nodes (11, 13). The number of patients with metastases solely in sentinel nodes outside the axilla is under 10% (11, 13). Biopsy of sentinel nodes outside the axilla influences the choice of adjuvant chemotherapy in only a few breast cancer patients, but it may be helpful in the targeting of IMN radiotherapy (11–13).

The visualization of sentinel nodes outside the axilla has caused confusion among surgeons performing sentinel node biopsy because the clinical value of the procedure may be limited. On the other hand, the procedure provides information about possible regional dissemination of the disease that may be greatly appreciated by the patients. Patients with breast cancer seem to evaluate prognostic information as being more important than the risks of morbidity associated with the axillary clearance (15), but to our knowledge patient preferences for harvesting sentinel nodes outside the axilla have not been studied. In our clinical experience, the majority of breast cancer patients will rely on the judgement of an experienced surgeon and accept the biopsy of sentinel nodes outside of the axilla if their doctors consider this to be beneficial.

For these reasons our aim was to study the patients' perception of the value of harvesting sentinel nodes outside level I–II of the axilla regarding information about regional dissemination of the disease and the impact on the choice of adjuvant treatment. The other purpose of the study was to examine patients' ability to understand the complex concept of sentinel node biopsy in order to evaluate the reliability of our results and also the quality of our written and oral information concerning sentinel node biopsy.

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MATERIAL AND METHODS

The study was carried out at Maria Hospital, the Breast Surgery Unit of Helsinki University Hospital. The Ethics Committee of Helsinki University Hospital approved the project plan and the study was conducted in accordance with the Declaration of Helsinki.

The study population consisted of 100 consecutive breast cancer patients, who had undergone lymphatic mapping and sentinel node biopsy between 30 May 2000 and 13 February 2001. Patients with sentinel nodes outside the axilla were excluded because they had already made their choice about the procedure. Elderly patients and doctors (over 75 years of age) were not included because participating would have been burdensome or even impossible for many of them because of their weakened physical or mental condition. The median age of the patients was 57 (range 34–75) years. Sentinel nodes were identified in the axilla in 84% of the patients; 30% of the patients had lymph node metastases in the axilla. The other study group consisted of 300 female doctors of same age as the patients retrieved randomly from the database of the Finnish Medical Association. Both specialists and general practitioners were included.

Information leaflets and questionnaires were sent by mail to both the patients and the doctors (see the Appendix for the questionnaire). The sentinel node concept, the frequency of sentinel nodes outside the axilla and the existing knowledge of the clinical relevance of sentinel nodes outside the axilla, but not the precise prognostic impact of metastases in the axillary and internal mammary nodes were explained in the information leaflet sent to the patients. The information concerning the prognostic value of lymph node metastases in the axilla and the internal mammary chain was included in the doctors' information sheet. Subjects who did not return the questionnaire were not sent reminder letters.

Both the patients and the doctors were asked to imagine the hypothetical situation of having a newly diagnosed breast cancer and sentinel nodes outside the axilla in the lymphoscintigraphy. They were asked if they wanted the sentinel nodes outside the axilla to be harvested when the procedure provided only information about the status of the nodes. The possible change in opinion was also tested by asking the same question again if there was a 10%, 20–30%, 50%, 75% and almost 100% chance that the procedure would have an impact on the adjuvant treatment.

The feedback from 10 pilot patients who evaluated the contents of the information leaflet and the questionnaire was incorporated in the final version to ensure that the subjects comprehended the fairly complex issues. For the same reason the subjects were encouraged to explain the factors that affected their opinions and to contact the investigators by telephone for clarification when needed. The patients were also asked questions about the status of their axillary nodes, local and systemic therapy and if the axillary sentinel nodes were identified in their cases to evaluate whether they were able to understand the information they were given at the hospital during their treatment.

Seventy-three (73%) patients and 148 (49%) female doctors returned the questionnaires. No differences were found in median age, marital status and the proportion of childless women among the patients and the doctors. Nor the type of breast surgery (mastectomy or breast-conserving surgery) neither the success in axillary sentinel node identification had impact on readiness to participate in the study. The questionnaire was returned by a greater number of patients aged between 40 and 70 years than by patients in the youngest or the oldest age groups ($p < 0.01$). The characteristics of the study subjects are presented in the Table 1.

Table 1

Characteristics of patients and female doctors who returned the questionnaire

	Patients N = 73	Female doctors N = 148
Age (years)*	57 (34–74)	57 (33–74)
Sentinel node identified in the axilla	61 (84%)	
Axillary metastases	19 (26%)	
Breast-conserving surgery	60 (82%)	
Marital status		
Married or living with a partner or spouse	44 (61%)	92 (62%)
Living without a partner or spouse	28 (39%)	56 (38%)
Childless	20 (27%)	30 (20%)
Education		
Secondary school	20 (28%)	
Post-secondary school	38 (52%)	
University degree	14 (19%)	
Family history of breast cancer		57 (39%)
Examined because of breast abnormality		57 (39%)
History of breast cancer		9 (6%)

* Median (range).

Statistical methods

Fisher's two-tailed exact test was used to compare the percentages and the medians were compared with the Mann–Whitney U-test.

RESULTS

Fifty-eight (79%) breast cancer patients and 71 (48%) ($p < 0.0001$) female doctors definitively or most likely wanted the biopsy of the sentinel node(s) outside the axilla solely to gain information on whether the nodes were involved. Sixty-six (90%) patients and 128 (86%) female doctors definitely or most likely wanted the biopsy if there was even the slightest chance (10% or less) that it would change their adjuvant treatment (NS) (see Fig. 1).

Childless breast cancer patients were usually reluctant to undergo a biopsy of the extra-axillary sentinel nodes just to gain information on the involvement of those nodes compared with patients with children (47% vs. 11%, $p < 0.001$). Age, marital status, education level, the presence of axillary metastases, type of surgery, adjuvant treatment received, the identification rate of the sentinel node and the comprehension regarding the stage and treatment of breast cancer had no impact on patients' preferences for dissection of extra-axillary sentinel nodes. The readiness of three (4%) patients was dependent on whether extra skin incisions were necessary for the biopsy of sentinel nodes outside the axilla.

The female doctors who were married or living with a spouse or partner were more willing to undergo the biopsy of sentinel nodes outside the axilla compared to those who were unmarried, widows or divorced (54% vs. 38%, NS). Furthermore, those who had been examined for breast abnormalities were more likely to want the biopsy (58% vs. 42%, NS). The age, speciality, childlessness, family history or the history of own breast cancer did not have an impact for doctors' preferences for the biopsy, but the need for an extra skin incision influenced the preferences of 5 (3%) female colleagues.

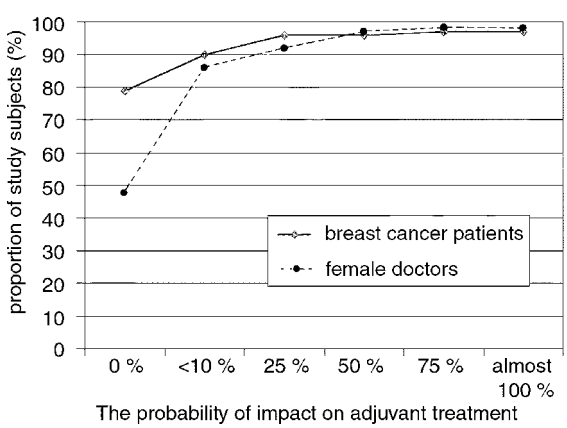

Fig. 1. The proportions (%) of study subjects who wanted harvesting of sentinel nodes outside the axilla when it provides only information about the status of the nodes (0%) or when it changes the adjuvant treatment with an increasing probability.

Sixty (82%) patients who returned the questionnaire understood the outcome of the sentinel node procedure. All the patients with the exception of one knew whether they had axillary metastases and which kind of adjuvant treatment they would receive.

DISCUSSION

The majority of the patients but less than half of the female doctors wanted the sentinel nodes outside level I–II of the axilla to be harvested and examined in order to gain information on whether those nodes were involved. Almost all patients and doctors would have accepted the procedure if there was even the slightest possibility that it would change the adjuvant treatment. The findings are in concordance with the results of a recent study by Galper et al. (15) who created a hypothetical scenario of newly diagnosed breast cancer and interviewed patients who were operated on because of invasive breast cancer or ductal carcinoma in situ (DCIS). Breast cancer patients valued the prognostic information obtained by axillary clearance and were more willing to accept the adverse effects of the procedure compared with those with DCIS (15). Patients with breast cancer tend to value all information available (even in a hypothetical situation) higher than patients with DCIS or female doctors because of subjective concern about their own prognosis.

Our findings are also in agreement with the clinical experience obtained in our hospital. Only one patient with sentinel nodes outside level I–II of the axilla in the preoperative lymphoscintigraphy had refused the procedure determining whether her axillary sentinel node had been involved, because the detection of a metastasis also in the parasternal sentinel node would not have changed the adjuvant treatment in her case. Thus far, none of the patients (out of more than 100) has totally refused the harvesting of those nodes.

On the other hand, the observed differences between the preferences of patients and female doctors may also to some extent reflect different perceptions regarding progression and prognosis of breast cancer between individuals with and without medical education. For example, some colleagues were quite pessimistic about breast cancer as a generalized disease at the time of diagnosis and regarded the information about sentinel nodes outside the axilla as useless. Therefore it is uncertain if our results represent differences between the preferences of breast cancer patients and healthy controls or those between professionals and laymen, or both. Nevertheless, the female doctors were selected for the other study group because we supposed them to be able to understand the complex information and because of professional and subjective interest about the issue.

A fairly high proportion of female colleagues had at least some family history of breast cancer and/or had been examined because of breast symptoms or abnormalities. However, only half of the doctors returned the questionnaire. The family history and subjective concern about breast cancer may have influenced the willingness to participate, although these issues seemed not to influence the doctors' preferences greatly. Doctors who had been examined because of breast abnormalities seemed to value the prognostic information somewhat more highly than those without this experience. The number of doctors with breast cancer was so small that no reliable conclusions about their preferences can be drawn.

Direct information about the effect of lymph node metastases in the axillary and parasternal basins on survival was included in the female doctors' information leaflet, but not in the version that was mailed to the patients. Disclosing all the details in patient information causes anxiety and is not preferred by all patients (16). We therefore preferred not to leave the patients to deal with the possibly alarming information about the prognosis received by mail on their own. The difference in the disclosed information does not explain the difference in readiness to undergo the procedure. If the exact information about the prognosis had also been given to the patients, they probably would have been more concerned about their survival and even more willing to accept the procedure. Concern over the prognosis and the desire to obtain all potentially beneficial treatment was emphasized in the preferences of patients with young children.

The reliability of the patients' opinions and answers could be questioned because of poor comprehension of the written information about the study. The sentinel node concept, lymphatic mapping and the sentinel nodes outside the axilla are complex issues. However, the breast cancer patients included in the present study had undergone lymphatic mapping and sentinel node biopsy. They had all obtained both oral and written information about sentinel node biopsy before surgery and this was exactly the reason for choosing these patients to take part in the study.

The great majority of the patients who returned the questionnaire understood whether sentinel nodes had been found in the axilla in their case. All patients except one knew whether their axillary nodes were involved and the sort of surgical and adjuvant treatment they would be given. Thus, the quality of our written and oral information about the sentinel node concept seems to be rather good at least in the light of previous studies (17, 18). According to previous studies, the vast majority of patients claim that they had understood all or most of the information provided in connection with clinical trials, but only half or less had really realized the purpose of the study or the method of treatment allocation (17, 18). The age or the educational level of the patients seemed not to influence the patient comprehension, contrary to the findings of a study by Hietanen et al. (17). However, the patients were younger and better educated in the present study. Some patients, especially the elderly ones, who did not return the questionnaire may not have understood the sentinel node concept at the time of surgery and may also have found the study material too complicated.

The sociodemographic factors examined, the axillary lymph node status or the treatment had little influence on the patients' preferences, which is in agreement with studies elsewhere (15, 19). The patients in these studies, as in the present one, were fairly young and highly educated. In general, the younger and better-educated patients tend to play a more active part in patient–doctor communication and decision-making (17). Thus the preferences of the participants may not represent the views of all women with breast cancer.

In conclusion, most breast cancer patients seem to value the information gained by harvesting the sentinel nodes outside level I–II of the axilla. They also seem to want it if there is even the slightest possibility that it may change the adjuvant treatment. However, indications for this or any oncological procedure should be based on results of prospective studies.

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APPENDIX

Questionnaire
Background information

Age:
Marital status:
1. Unmarried
2. Married or living with a spouse or partner
3. Widowed
4. Divorced

Education:
1. Primary or secondary school
2. Skilled worker
3. College
4. University degree
5. Other, which one?

Do you have children?

If you have children, how old are they?

Type of operation for breast cancer in your case was
1. Breast-conserving surgery
2. Mastectomy

In the lymph nodes of the armpit
1. Cancer was found
2. No cancer was found
3. I do not know

The sentinel lymph node
1. Was found in the armpit
2. Was not found
3. I do not know

The adjuvant treatment (please, tick one or several alternatives)
1. Nothing
2. Radiotherapy
3. Hormonal therapy
4. Chemotherapy
5. I do not know

Questionnaire

Imagine yourself in a situation, when your breast cancer has just been found but not operated on yet. The preoperative mapping shows sentinel lymph nodes not only in the armpit but also outside it. The sentinel lymph node in your armpit is going to be searched out during the operation and the other lymph nodes in the armpit will be removed only if there is cancer in the sentinel lymph node.

WHAT IS YOUR PREFERENCE FOR THE RETRIEVAL AND EXAMINATION OF SENTINEL NODES OUTSIDE THE ARMPIT?

Please, tick the statement (1–6) that best reflects your opinion

Question 1
If the examination of the sentinel lymph node outside the armpit only reveals whether cancer had spread there, **but does not change the treatment of cancer at all**
1. I would definitely want retrieval and examination of the sentinel lymph node outside the armpit
2. I would want retrieval and examination of the sentinel lymph node outside the armpit only if an extra skin incision is not made
3. I would most likely want retrieval and examination of the sentinel lymph node outside the armpit
4. I do not know
5. I would most likely refuse retrieval and examination of the sentinel lymph node outside the armpit
6. I would definitively refuse retrieval and examination of the sentinel lymph node outside the armpit

Question 2
If the examination of the sentinel lymph node outside the armpit reveals whether cancer had spread there **and changes the treatment of cancer in less than one patient out of ten**
1. I would definitely want retrieval and examination of the sentinel lymph outside the armpit
2. I would want retrieval and examination of the sentinel lymph node outside the armpit only if an extra skin incision is not made
3. I would most likely want retrieval and examination of the sentinel lymph node outside the armpit
4. I do not know
5. I would most likely refuse retrieval and examination of the sentinel lymph node outside the armpit
6. I would definitively refuse retrieval and examination of the sentinel lymph node outside the armpit

Question 3
If the examination of the sentinel lymph node outside the armpit reveals whether cancer had spread there **and changes the treatment of cancer in one patient out of four**
1. I would definitely want retrieval and examination of the sentinel lymph node outside the armpit
2. I would want retrieval and examination of the sentinel lymph node outside the armpit only if an extra skin incision is not made
3. I would most likely want retrieval and examination of the sentinel lymph node outside the armpit
4. I do not know
5. I would most likely refuse retrieval and examination of the sentinel lymph node outside the armpit
6. I would definitively refuse retrieval and examination of the sentinel lymph node outside the armpit

Question 4
If the examination of the sentinel lymph node outside the armpit reveals whether cancer had spread there **and changes the treatment of cancer in every second patient**

1. I would definitely want retrieval and examination of the sentinel lymph node outside the armpit
2. I would want retrieval and examination of the sentinel lymph node outside the armpit only if an extra skin incision is not made
3. I would most likely want retrieval and examination of the sentinel lymph node outside the armpit
4. I do not know
5. I would most likely refuse retrieval and examination of the sentinel lymph node outside the armpit
6. I would definitively refuse retrieval and examination of the sentinel lymph node outside the armpit

Question 5

If the examination of the sentinel lymph node outside the armpit reveals whether cancer had spread there **and changes the treatment of cancer in three patients out of four**

1. I would definitely want retrieval and examination of the sentinel lymph node outside the armpit
2. I would want retrieval and examination of the sentinel lymph node outside the armpit only, if an extra skin incision is not made
3. I would most likely want retrieval and examination of the sentinel lymph node outside the armpit
4. I do not know
5. I would most likely refuse retrieval and examination of the sentinel lymph node outside the armpit
6. I would definitively refuse retrieval and examination of the sentinel lymph node outside the armpit

Question 6

If the examination of the sentinel lymph node outside the armpit reveals whether cancer had spread there **and changes the treatment of cancer almost certainly**

1. I would definitely want retrieval and examination of the sentinel lymph node outside the armpit
2. I would want retrieval and examination of the sentinel lymph node outside the armpit only if an extra skin incision is not made
3. I would most likely want retrieval and examination of the sentinel lymph node outside the armpit
4. I do not know
5. I would most likely refuse retrieval and examination of the sentinel lymph node outside the armpit
6. I would definitively refuse retrieval and examination of the sentinel lymph node outside the armpit

Please give your reasons for choosing these alternatives.

THANK YOU FOR ANSWERING!