Decision making in geriatric oncology
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Chapter 4
Non-referral of nursing home patients with suspected breast cancer

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W.P. Achterberg, G.J. Liefers, S.E. de Rooij

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Chapter 4

Abstract

Introduction: People with suspected breast cancer who are not referred for diagnostic testing remain unregistered and are not included in cancer statistics. Little is known about the extent of and motivation for non-referral of these patients.

Methods: A web-based survey was sent to all elderly care physicians (ECPs) registered at the National Association of Elderly Care Physicians and Social Geriatricians in the Netherlands, inquiring about the number of patients with suspected breast cancer they encountered and subsequent choices regarding referral.

Results: Surveys were completed by 419 out of 1239 ECPs (34%); 249 of these had encountered one or more patients with suspected breast cancer in the past year (60%). Seventy-four ECPS reported not referring the last patient (33%). Reasons for non-referral were end-stage dementia (57%), patient/family preference (29%) and limited life-expectancy (23%). Referral was frequently thought to be too burdensome (13%). For 16% of non-referred patients, hormonal treatment was started by the ECP without diagnostic confirmation of cancer.

Conclusion: In this survey, over 33% of nursing home patients with suspected breast cancer were not referred for further testing, in particular those with advanced dementia, limited life-expectancy and poor functional status. As the combination of dementia and suspected breast cancer is expected to double in the coming decades, now is the time to optimize cancer care for these vulnerable patients.
Non-referral of nursing home patients with suspected breast cancer

Introduction
Cancer statistics show that in 2009, a total of 13,177 women were diagnosed with breast cancer in the Netherlands.\(^1\) These data are based on the Netherlands Cancer Registry (NCR),\(^1\) a nationwide network which collects histo- and cytopathology data from all Dutch hospitals, supplemented by data from the national hospital discharge databank. After cancer cases are identified, trained personnel from regional cancer registries gather additional data on diagnosis, staging and treatment. As all oncologic treatment in the Netherlands is provided by hospital-based specialists, the registry can provide a comprehensive overview of current cancer treatment. It also allows for a comparison of actual treatment with treatment as recommended by guidelines. For example, using registry data, studies have demonstrated that older breast cancer patients are often treated less extensively than their younger counterparts and that they are at risk for being undertreated.\(^2\)\(^-\)\(^5\)

In the Netherlands, primary care physicians form an important first link in the cancer treatment pathway (Figure 1), as they are generally responsible for referral to hospital specialists – although some alternative routes are possible. For patients residing in nursing homes, either permanently or temporarily in case of rehabilitation, this tasks falls on specially trained physicians, called elderly care physicians (ECPs), for whom nursing homes are the primary place of work.\(^6\) This differentiation between primary medical care and hospital-based care in the Netherlands, results in an important limitation of the cancer registry: patients with a clinical suspicion of cancer that are not referred to hospital for further diagnostic testing will remain unregistered and will not be included in Dutch cancer statistics.

Surprisingly, little is known about the issue of non-referral. Studies using Medicare-data

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**Figure 1: Global overview of breast cancer care pathway in the Netherlands**

- **Primary care**
  - Primary assessment
  - Referral
- **Hospital-based care**
  - Surgeon
  - Oncologist
  - Radiotherapist
  - Multi-disciplinary breast cancer team conference
  - Surgery
  - Radiotherapy
  - Endocrine therapy
  - Chemotherapy

Provided by primary care physicians or elderly care physicians in case of nursing home patients

Although the primary care physician/elderly care physician chooses which specialist they refer too, all new patients and treatment plans are generally decided in a multidisciplinary conference, based on national treatment guidelines adjusted to what is suitable for the particular patient.
in the United States show that little cancer care is claimed for patients living in a nursing home setting, and that Alzheimer patients receive less treatment for breast cancer than comparable female Medicare beneficiaries, but the authors could not determine whether this was due to less cancer vigilance resulting in missed cancer diagnoses or to omission of referral for specialised cancer care. Even less is known about the motivation behind non-referral or the consequences for the patient.

For this study, we sent a survey to all members of the National Association of Elderly Care Physicians and Socials Geriatricians, to determine a) the extent of and reasons for non-referral of patients suspected of breast cancer by ECP, and b) the motivations behind this choice.

Method
We developed a web-based survey using the SurveyMethods, Inc. software. The survey contained questions relating to the incidence of suspected breast cancer in nursing homes, whether or not these patients were referred and the motivation behind referral choices. The content of the survey is depicted in Figure 2. After a concept of this survey was successfully tested in 19 ECPs, it was subsequently sent to all ECPs registered at Verenso, the National Association of Elderly Care Physicians and Social Geriatricians in August 2011. Of the 1525 ECPs active in the Netherlands, 1238 are registered at Verenso; consequently 81% of all Dutch ECPs were invited to participate in the survey.

Statistical analysis
To compare differences between referred and non-referred patients, the SPSS (Statistical Package for the Social Sciences) version 19.0 was used. The chi-square test was used for nominal and ordinal variables. For continuous variables with a normal distribution, the Student t-test was used, and for continuous variables with a non-Gaussian distribution the Mann-Whitney test.

Results

Response rate
Surveys were completed by 419 of the 1239 ECPs (response rate was 34%, Figure 2). Characteristics of respondents are listed in Table 1. The median age of respondents was 47 years (range 25-66 years) and 66% were female. Responses came from all over the country, covering over 90% of the 90 primary zip code-areas in the Netherlands. Almost 60% of respondents stated they had encountered at least one patient with suspected breast cancer in the past year; of these patients, 33% were not referred for further diagnostic testing (Figure 3).
Non-referral of nursing home patients with suspected breast cancer

Figure 2: Content of survey

Question 1: How old are you?
Question 2: What sex are you?
Question 3: What are the four numbers of the zip code where your practice is located?
Question 4: How many patients did you care for in the past year?
Question 5: What percentage of these patients is female?

Question 6: In the past year, did you suspect one or more of your patients of having breast cancer?

IF NONE

IF ONE

IF MORE THAN ONE

Question 7: How many of these patients did you refer for further testing and/or treatment?

The following questions concern the last patient you suspected of having breast cancer

Question 8: What was this patient’s age?
Question 9: Did you refer this patient for further testing and/or treatment?

IF YES

IF NO

Question 10: With whom did you discuss this decision?
Question 11: What were your reasons for referring this patient?
Question 12: What treatment did the patient receive?
Question 13: How is the patient doing now?
Question 14: Have you recently had any patients who you did not choose to refer, and if so, what were your reasons for this?

Do you have any additional comments relating to this survey?

END OF SURVEY
Chapter 4

Referral vs. non-referral
Table 2 lists a comparison of patients that were or were not referred. Patients not referred were older (median age 86 vs. 82 years, p<0.001), although some non-referred patients were as young as 60 years. Over 99% of physicians discussed their decision on referral with at least one other party: in 54% of cases, it was discussed with the patient, while in 87% a family member was consulted; in 9% it was only discussed with another physician. Of note, of the patients that were not referred, less than half were personally involved in making this decision.

The motivations for choosing to refer patients to hospital (Table 3) were primarily the desire to confirm the diagnosis (28%), the fear of future ulceration or metastases (21%), good general health and life-expectancy (19%), and patient’s or family’s preference for referral (18%). Current or imminent ulceration was stated in 9% of cases, while maintaining quality of life or optimizing palliative care were stated in 7% and 4% respectively. For 11%, the main reason for referral was to assess the suitability of primary hormonal treatment, as the ECP felt that due to cognitive or functional status, the patient was not a candidate for more invasive treatment.

The primary reason stated for not referring was end-stage dementia (57%, Table 4). Other reasons were the preferences of patient and/or family (29%), limited life-expectancy (23%), poor functional status or somatic comorbidity (18% and 16%, respectively) and advanced age in 8%. The expected burden of the hospital visits and subsequent diagnostic process and treatment for the patient was stated in 13%, particularly for patients with advanced dementia.

Treatment and outcome
Of the patients that were referred to hospital, seven were found to have a benign tumour (5%); 16% received no treatment and 24% received hormonal treatment only. Surgery was performed in 28% of patients, radiotherapy given to 8% and chemotherapy to one patient.

For 18%, the diagnostic process was still on-going. In addition, twelve non-referred patients (16%) were prescribed primary hormonal treatment by the ECP without confirmation of breast cancer.

The current health status of referred and non-referred patients is listed in Table 5. Thirty-four patients were lost to follow-up. Three referred patients died of breast cancer or breast cancer treatment, and three patients suffered from locally advanced or metastatic disease (two referred and one non-referred patient). Forty-four patients had died of causes other than breast cancer (17%).
Figure 3: Flow chart of response rate and referrals

Number of survey returned: n=419/1238 (34%)

One or more patient with suspected breast cancer
n=249 (59.4%)

No patients with suspected breast cancer
n=170 (40.6%)

Last patient referred
n=151 (67.1%)

Last patient not referred
n=74 (32.9%)

Missing
n=24

Table 1: Characteristics of respondents

<table>
<thead>
<tr>
<th>Response rate</th>
<th>Elderly care physicians</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age of respondents (range)</td>
<td>47 years (25-66)</td>
</tr>
<tr>
<td>% female of respondents</td>
<td>66.1%</td>
</tr>
<tr>
<td>% with ≥1 patients suspected of breast cancer</td>
<td>59.4%</td>
</tr>
<tr>
<td>Number of patients suspected of breast cancer in past year</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>170</td>
</tr>
<tr>
<td>1</td>
<td>140</td>
</tr>
<tr>
<td>2</td>
<td>81</td>
</tr>
<tr>
<td>3</td>
<td>20</td>
</tr>
<tr>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>more than 5</td>
<td>1</td>
</tr>
<tr>
<td>% of patients referred to hospital</td>
<td>67.1%</td>
</tr>
</tbody>
</table>

Table 2: Comparison of patients that were and were not referred

<table>
<thead>
<tr>
<th>(non-) Referral discussed with*</th>
<th>Patients referred (n=151)</th>
<th>Patients not referred (n=74)</th>
<th>p=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median age of patients (range)</td>
<td>82 (45-99) years</td>
<td>86 (60-102) years</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>No one</td>
<td>0%*</td>
<td>1%*</td>
<td>ns</td>
</tr>
<tr>
<td>Patient</td>
<td>61%</td>
<td>41%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Family member</td>
<td>85%</td>
<td>91%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Colleague</td>
<td>14%</td>
<td>23%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Clinical geriatrician</td>
<td>4%</td>
<td>1%</td>
<td>0.02</td>
</tr>
<tr>
<td>Oncologist</td>
<td>13%</td>
<td>5%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Surgeon</td>
<td>29%</td>
<td>5%</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Radiotherapist</td>
<td>3%</td>
<td>0%</td>
<td>0.01</td>
</tr>
<tr>
<td>Others</td>
<td>7%</td>
<td>12%</td>
<td>0.002</td>
</tr>
<tr>
<td>Nursing staff</td>
<td>6%</td>
<td>7%</td>
<td></td>
</tr>
</tbody>
</table>

* n=146 of these responses originated from question 9 and n=17 from question 14
Table 3: Reasons for referral

<table>
<thead>
<tr>
<th>Reason</th>
<th>Frequency (out of 121 responses)</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia/cognitive function</td>
<td>69</td>
<td>57</td>
</tr>
<tr>
<td>Preference of patient and/or family</td>
<td>35</td>
<td>29</td>
</tr>
<tr>
<td>Limited life expectancy</td>
<td>28</td>
<td>23</td>
</tr>
<tr>
<td>Functional status</td>
<td>22</td>
<td>18</td>
</tr>
<tr>
<td>Somatic comorbidity</td>
<td>19</td>
<td>16</td>
</tr>
<tr>
<td>Burden of referral too high for specific patient</td>
<td>16</td>
<td>13</td>
</tr>
<tr>
<td>Tumour characteristics</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Advanced age</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>Lack of subjective burden of tumour</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>No expected benefit of referral for patient’s quality of life</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

* n=146 of these responses originated from question 9 and n=17 from question 14

Table 4: Reasons for non-referral

<table>
<thead>
<tr>
<th>Reason</th>
<th>Frequency (out of 121 responses)</th>
<th>%</th>
</tr>
</thead>
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<tr>
<td>Functional status</td>
<td>22</td>
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<tr>
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<td>16</td>
</tr>
<tr>
<td>Burden of referral too high for specific patient</td>
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<tr>
<td>Tumour characteristics</td>
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<td>8</td>
</tr>
<tr>
<td>Lack of subjective burden of tumour</td>
<td>6</td>
<td>5</td>
</tr>
<tr>
<td>No expected benefit of referral for patient’s quality of life</td>
<td>3</td>
<td>2</td>
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</table>

* n=80 of these responses originated from question 9 and n=41 from question 14

Table 5: Current status of patients

<table>
<thead>
<tr>
<th></th>
<th>Referred patients n=151</th>
<th>Non-referred patients n=74</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lost to follow-up</td>
<td>32</td>
<td>2</td>
</tr>
<tr>
<td>Stable/asymptomatic disease-free</td>
<td>97</td>
<td>46</td>
</tr>
<tr>
<td>Locally advanced/metastatic disease</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Died of other causes</td>
<td>19</td>
<td>25</td>
</tr>
<tr>
<td>Died of breast cancer or breast cancer treatment</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>
Non-referral of nursing home patients with suspected breast cancer

Discussion
We found that 60% of the responding ECPs had encountered one or more patients whom they suspected of having breast cancer in the past year, and 33% of these patients were not referred. The primary reasons for non-referral were dementia, poor functional status, comorbid diseases and limited life-expectancy, as well as the expected burden of a visit to a clinic or the subsequent treatment. Of referred patients, only 28% received surgical treatment, while 40% received no oncologic treatment or primary hormonal therapy only. To our knowledge, this is the first study to address the issue of non-referral of nursing home residents with suspected breast cancer. We believe it provides valuable information on a vulnerable population that has thus far remained outside the scope of cancer research and national cancer statistics.

This study has some weaknesses. First of all, the response rate was 34%. This is an issue frequently encountered in survey-based studies. For this survey, it is not unlikely that those ECPs who had recently dealt with the issue of suspected breast cancer were more prone to respond to the survey than those who had not. This makes it difficult to know to what extent the incidence of suspected breast cancer in nursing home patients can be extrapolated from these results. Furthermore, as this survey requires ECPs to recollect their last patient, data may be somewhat influenced by recall bias. Another limitation is that this study was done in a single country only; as the organisation of care and of cancer registries will differ from country to country, it remains unclear whether our findings can be extrapolated to other countries.

This study highlights an important limitation of the current cancer registration in the Netherlands and consequently of cancer statistics, particularly for the very elderly where non-referral is likely to be more prevalent. Although there is a mandatory registration of confirmed cancer cases, there is no obligation to report suspected but unconfirmed cases; what is more, a procedure for reporting such cases is currently lacking. As the prevalence of dementia is expected to double in the coming decades, and the proportion of newly diagnosed patients with breast cancer aged 85 years and over will rise from 9% to 17% by 2030, the combination of patients with advanced dementia and suspected breast cancer will also increase greatly. If no procedure is developed for their registration, the number of very elderly or frail cancer patients that remain unregistered is likely to increase, making the cancer statistics for these patients increasingly unreliable. Addressing this issue in the registry will be challenging, however, as suspected cancer is not confirmed cancer, and these additional patients cannot automatically be added to what is currently recorded.

The increasing number of patients suffering from both dementia and suspected breast cancer asks for a careful evaluation of the current care process. Although the diagnostic process for breast cancer is not very invasive, and breast cancer surgery has a low risk of
perioperative complications,\textsuperscript{13} for a patient with advanced dementia, even the process of going to an out-patient clinic or undergoing physical examination can be of great burden. However, this needs to be weighed against the risks of leaving a suspected malignancy unaddressed. Uncontrolled breast cancer, particularly when ulceration occurs, may have serious impact on a patient’s comfort and quality of life.

Of course, as this study demonstrates, many patients who were thought to be too frail to refer for further testing have a life-expectancy that is limited, leaving little time to suffer the potential consequences of untreated breast cancer or the potential benefits of treatment. Watchful waiting with regular physical examination to determine rate of local progression and symptomatic treatment of cancer-related complaints such as pain, can be a useful strategy in such patients. However, estimating life expectancy is not always easy,\textsuperscript{14} particularly in those with advanced dementia who can experience a persistent level of severe disability and frailty over an extended period of time, before succumbing to a minor illness due to lack of physical reserves.\textsuperscript{15} Therefore, if the extend of remaining life-years is not clear, and there is a desire to start oncologic treatment, but burden of a visit to clinic is considered too great, what options are left?

One possibility is to start treatment with endocrine therapy without actual confirmation of breast cancer diagnosis or assessing hormone receptor status. In our study, this option was chosen for 16% of patients that were not referred. As over 75% of patients aged 80 years or older have oestrogen receptor positive disease,\textsuperscript{16} and partial remission and loco-regional control can often be attained\textsuperscript{17} – albeit temporarily – this is not an unreasonable option. However, there will be a proportion of patients who either have hormone receptor negative disease, or who have no breast cancer at all, and therefore will not profit from treatment but will be exposed to side-effects of treatment. These side-effects are limited, but even in fit subjects have been shown to affect their feeling of well-being, particularly in the first months of treatment.\textsuperscript{18,19} For example, all types of hormonal treatment can cause hot flushes, dizziness, gastro-intestinal complaints such as nausea and anorexia, as well as psychological effects such as depression or agitation.\textsuperscript{20} Furthermore, the very frail are more likely to experience adverse effects,\textsuperscript{21} and what is seen as a minor side-effect for a fit subject can have great impact on the quality of life, functional status and behaviour of the very frail.

Another option is to alter the diagnostic testing process in a way that minimizes the burden for these vulnerable patients. For example, one ECP explained that the pathologist came to their nursing home, to take biopsies of palpable tumours, offering the possibility of confirming the diagnosis and assessing receptor status. Although for some patients even this may be too burdensome, for many, a consultation in their own care setting – by a pathologist, surgeon or oncologist – may be a solution.
The results of this study can form a starting point for a range of future clinical studies. First of all, as this is the first study on non-referral of nursing home patients, from a single country, similar studies should be done in other countries to confirm our findings. In addition, a more in-depth case review of non-referred patients may provide additional information to supplement the survey data. Second, studies could look at non-referral of other patient groups, such as frail elderly patients living at home, or nursing home residents suspected of having other types of cancer. Third, studies on guideline adherence – particularly in older patients – should take the possibility of non-referral of patients into account and address in what way this could influence the outcome of their results. However, more importantly, studies should focus on the potential of non-oncologic non-pharmacologic interventions to optimize quality of life and minimize cancer-related symptom burden, and on developing new treatment pathways, such as a specialist consultation in the patient’s place of residence, suitable for these vulnerable patients. Possibly, the option of initiating endocrine treatment without histological confirmation of breast cancer – as is sometimes chosen already – could be evaluated in a placebo-controlled study weighing the benefit in disease control against the potential harmfulness of side-effects.

**In conclusion,** our survey shows that suspicion of breast cancer is not uncommon in a nursing home setting. Over 33% of patients were not referred for further testing, in particular those with advanced dementia and poor functional status, because the burden of referral is expected to be greater than the benefit for the patient. With the expected increase in the occurrence of both dementia and breast cancer, now is the time to start thinking about how best to provide them with the care they need in a way that is suitable to their overall condition.

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Chapter 4

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