JAMDA 13 (2012) 464–469

JAMDA

journal homepage: www.jamda.com

Original Study

Nonreferral of Nursing Home Patients With Suspected Breast Cancer

Marije E. Hamaker MD [a,b,*], Victoria C. Hamelinck MSc [c], Barbara C. van Munster MD, PhD [a,d], Esther Bastiaannet MSc [c], Carolien H. Smorenburg MD, PhD [e], Wilco P. Achterberg MD, PhD [f], Gerrit-Jan Liefers MD, PhD [g], Sophia E. de Rooij MD, PhD [h]

[a] *Department of Geriatric Medicine, Diakonessenhuis Utrecht, The Netherlands*
[b] *Department of Internal Medicine, Academic Medical Centre, Amsterdam, The Netherlands*
[c] *Department of Surgery and Department of Gerontology and Geriatrics, Leiden University Medical Center, Leiden, The Netherlands*
[d] *Department of Geriatric Medicine, Gelre Hospitals, Apeldoorn, The Netherlands*
[e] *Department of Medical Oncology, Medical Centre Alkmaar, The Netherlands*
[f] *Department of Public Health and Primary Care, Leiden University Medical Center, Leiden, The Netherlands*
[g] *Department of Surgery, Leiden University Medical Center, Leiden, The Netherlands*
[h] *Department of Internal Medicine, Section of Geriatric Medicine, Academic Medical Centre, Amsterdam, The Netherlands*

Keywords:
Breast cancer
referral
nursing home
dementia

A B S T R A C T

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 nonreferral 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 (34%) of 1239 ECPs; 249 (60%) of these had encountered one or more patients with suspected breast cancer in the past year. Seventy-four (33%) ECPs reported not referring the last patient. Reasons for nonreferral 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 nonreferred patients, hormonal treatment was started by the ECP without diagnostic confirmation of cancer.

Conclusion: In this survey, more than 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.

Published by Elsevier Inc. on behalf of the American Medical Directors Association, Inc.

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,[1] a nationwide network that 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 (an overview of current Dutch guidelines is supplied in Appendix 1). For example, using registry data, studies have demonstrated that older patients with breast cancer 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 task 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

* Address correspondence to Marije E. Hamaker, MD, Diakonessenhuis Utrecht/Zeist/Doorn, Department of Geriatric Medicine Professor Lorentzlaan 76, 3707 HL, Zeist, The Netherlands.
E-mail address: mhamaker@diakhuis.nl (M.E. Hamaker).

1525-8610/$ - see front matter Published by Elsevier Inc. on behalf of the American Medical Directors Association, Inc.
doi:10.1016/j.jamda.2012.01.002

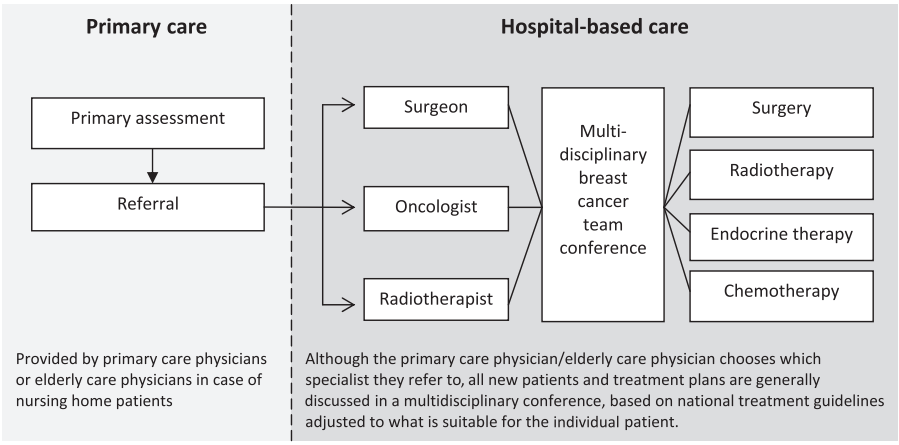

Fig. 1. Global overview of breast cancer care pathway in the Netherlands.

in the Netherlands results in an important limitation of the cancer registry: patients with a clinical suspicion of cancer who 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 nonreferral. Studies based on Medicare data in the United States show that little cancer care is claimed for patients living in a nursing home setting,[7] and that patients with Alzheimer disease receive less treatment for breast cancer than comparable female Medicare beneficiaries,[8] but the authors could not determine whether this was because of less cancer vigilance resulting in missed cancer diagnoses or to omission of referral for specialized cancer care. Even less is known about the motivation behind nonreferral 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 (1) the extent of non-referral of patients suspected of breast cancer by ECP, and (2) the motivations behind this choice.

Method

We developed a Web-based survey using the SurveyMethods, Inc. software.[9] 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 on 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.

To compare differences between referred and nonreferred patients, the SPSS (Statistical Package for the Social Sciences) version 19.0 (SPSS Inc., Chicago, IL) 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 was used.

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 women. Responses came from all over the country, covering more than 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).

Referral versus Nonreferral

Table 2 lists a comparison of patients who were or were not referred. Patients not referred were older (median age 86 vs 82 years, $P < .001$), although some unreferred patients were as young as 60 years. More than 99% of physicians discussed their decision on referral with at least one other party: in 54% of cases, it was discussed with the patient, and in 87% a family member was consulted; in 9% it was discussed only with another physician. Of note, of the patients who were not referred, fewer 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 the patient's or family's preference for referral (18%). Current or imminent ulceration was stated in 9% of cases, whereas 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, owing 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 the patient and/or family (29%), limited life expectancy (23%), poor functional status or somatic comorbidity (18% and 16%, respectively), and advanced age (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 who were referred to hospital, 7 were found to have a benign tumor (5%); 16% received no treatment and 24% received hormonal treatment only. Surgery was performed in 28% of patients, radiotherapy was given to 8%, and chemotherapy was given to one patient. For 18%, the diagnostic process was still ongoing. In addition, 12 (16%) unreferred patients were prescribed primary hormonal treatment by the ECP without confirmation of breast cancer.

The current health status of referred and nonreferred 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,

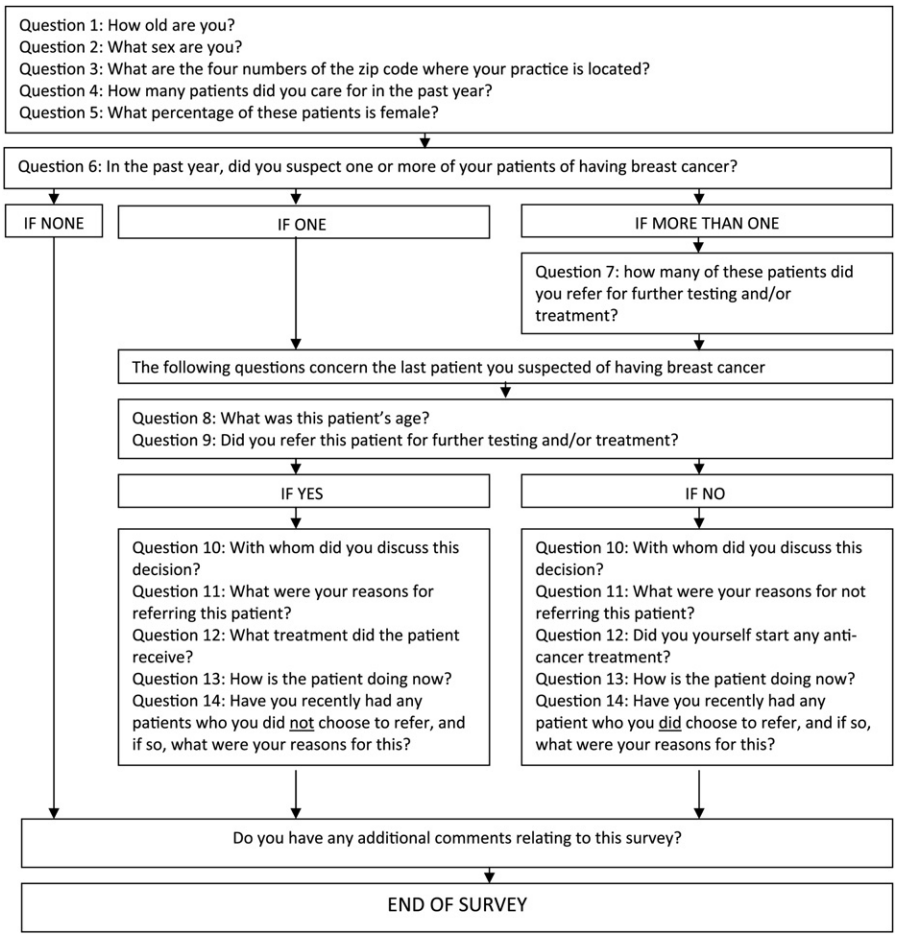

Fig. 2. Content of survey.

and 3 patients suffered from locally advanced or metastatic disease (2 referred and 1 nonreferred patient). Forty-four patients had died of causes other than breast cancer (17%).

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 nonreferral were dementia, poor functional status, co-morbid 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, whereas 40% received no oncologic treatment or primary hormonal therapy only. To our knowledge, this is the first study to address the issue of nonreferral 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, the response rate was 34%. This is an issue frequently encountered in survey-based studies.[10] For this survey, it is likely 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 organization of care and of cancer registries will differ from country to country, it remains unclear whether our findings can be extrapolated to other countries.

Table 1
Characteristics of Respondents

	Elderly Care Physicians
Response rate	419/1238 (34%)
Median age of respondents (range)	47 yrs (25–66)
% female respondents	66.1%
% with ≥1 patients suspected of breast cancer	59.4%
No. of patients suspected of breast cancer in past year	
0	170
1	140
2	81
3	20
4	4
5	3
more than 5	1
% of patients referred to hospital	67.1%

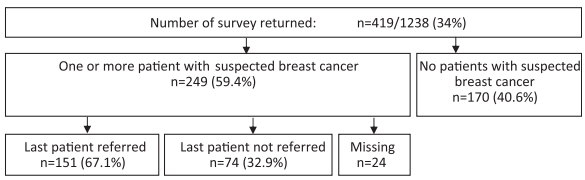

Fig. 3. Flow chart of response rate and referrals.

Table 2
Comparison of Patients Who Were and Were Not Referred

	Patients Referred (n = 151)	Patients Not Referred (n = 74)	*P*
Median age of patients, y (range)	82 (45–99)	86 (60–102)	<.001
(non-) Referral discussed with*			
No one	0%*	1%*	ns
Patient	61%	41%	<.001
Family member	85%	91%	<.001
Colleague	14%	23%	<.001
Clinical geriatrician	4%	1%	.02
Oncologist	13%	5%	<.001
Surgeon	29%	5%	<.001
Radiotherapist	3%	0%	.01
Others	7%	12%	.002
Nursing staff	6%	7%	

ns, not significant.
*Cumulative percentages exceed 100% because more than one answer option was possible.

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 nonreferral 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,[11] and the proportion of newly diagnosed patients with breast cancer aged 85 years and older will rise from 9% to 17% by 2030,[12] 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 patients with cancer who 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,[13] for a patient with advanced dementia, even the process of going to an outpatient clinic or undergoing physical examination can be of great burden. This needs to be weighed against the risks of leaving a suspected malignancy unaddressed, however. Uncontrolled breast cancer, particularly when ulceration occurs, may have a 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,[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 owing to lack of physical reserves.[15] Therefore, if the extent of remaining life-years is not clear, and there is a desire to start oncologic treatment, but the 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 who were not referred. As more than 75% of patients 80 years or older have estrogen receptor–positive disease,[16] and partial remission and loco-regional control can often be attained,[17] albeit temporarily, this is not an unreasonable option. There will be a proportion of patients, however, 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 the 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.[18,19] For example, all types of hormonal treatment can cause hot flushes, dizziness, gastrointestinal complaints, such as nausea and anorexia, and psychological effects, such as depression or agitation.[20] Furthermore, the very frail are more likely to experience adverse effects,[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 behavior 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 the nursing home to take biopsies of palpable tumors, 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, as this is the first study on nonreferral 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 nonreferred patients may provide additional information to supplement the survey data. Second, studies could look at nonreferral 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

Table 3
Reasons for Referral

Reason	Frequency (Of 163 Responses)*	%
Confirmation of diagnosis	46	28
Fear of future ulceration/metastases	35	21
Functional status	34	21
Life expectancy	31	19
Preference of patient and/or family	30	18
Suitability of primary hormonal therapy	19	11
Current or imminent ulceration	15	9
Maintaining optimal quality of life	11	7
Establishing prognosis	10	6
Part of palliative care	7	4
Resectability/size of tumor	5	3

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

Table 4
Reasons for Nonreferral

Reason	Frequency (Of 121 responses)*	%
Dementia/cognitive function	69	57
Preference of patient and/or family	35	29
Limited life expectancy	28	23
Functional status	22	18
Somatic comorbidity	19	16
Burden of referral too high for specific patient	16	13
Tumor characteristics	10	9
Advanced age	10	8
Lack of subjective burden of tumor	6	5
No expected benefit of referral for patient's quality of life	3	2

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

Table 5
Current Status of Patients

	Referred Patients n = 151		Nonreferred Patients n = 74	
Lost to follow-up	32	21%	2	3%
Stable/asymptomatic disease or disease-free	97	64%	46	62%
Locally advanced/metastatic disease	2	1%	1	1%
Died of other causes	19	13%	25	34%
Died of breast cancer or breast cancer treatment	3	2%	0	0%

nonreferral of patients into account and address in what way this could influence the outcome of their results. More important, however, studies should focus on the potential of nononcologic nonpharmacologic 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. More than 33% of patients were not referred for further testing, in particular those with advanced dementia and poor functional status, because the burden of referral was 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 patients with the care they need in a way that is suitable to their overall condition.

Acknowledgments

The authors thank all participating elderly care physicians, and in particular the chair of the Dutch Organisation of the Elderly Care Physicians, Mieke Draaijer, and the director, Franz Roos, for their willingness to collaborate with us.

The authors (V.C.H., E.B., G.J.L.) thank the Dutch Cancer Society.

References

1. Intergraal Kankercentrum Nederland. Nederlandse Kankerregistratie. Available at: www.cijfersoverkanker.nl. Accessed August 2001.
2. Hamaker ME, Schreurs WH, van Slooten HJ, et al. Trends in breast cancer treatment in the elderly at a breast cancer outpatient clinic: Guidelines followed better. Ned Tijdsch Geneeskd 2009;153:A562.
3. Hamaker ME, Schreurs WH, Uppelschoten JM, Smorenburg CH. Breast cancer in the elderly: Retrospective study on diagnosis and treatment according to national guidelines. Breast J 2009;15:26–33.
4. Bastiaannet E, Liefers GJ, de Craen AJM, et al. Breast cancer in elderly compared to younger patients in the Netherlands: Stage at diagnosis, treatment and survival in 127,805 unselected patients. Breast Cancer Res Treat 2010;124:801–807.
5. Bastiaannet E, Portielje JEA, van de Velde JH, et al. Lack of survival gain for elderly women with breast cancer. Oncologist 2011;16:415–423.
6. Koopmans RT, Lavrijsen JC, Hoek JF, et al. Dutch elderly care physician: A new generation of nursing home physician specialists. J Am Geriatr Soc 2010;58: 1807–1809.
7. Bradley CJ, Clement JP, Lin C. Absence of cancer diagnosis and treatment in elderly Medicaid-insured nursing home residents. J Natl Cancer Inst 2008;100: 21–31.
8. Sheinfeld Gorin S, Heck JE, Albert S, Hershman D. Treatment for breast cancer in patients with Alzheimer's disease. J Am Geriatr Soc 2005;53:1897–1904.
9. Survey Methods. Survey Software: Ask, Analyze, Improve. Available at: www.surveymethods.com. Accessed April 2011.
10. Dillman DA. Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method. Mail and Internet Surveys. Hoboken, NJ: Wiley & Sons; 2009.
11. Alzheimer Nederland. Available at: www.alzheimer-nederland.nl. Accessed August 2011.
12. Hayat MJ, Howlader N, Reichman ME, Edwards BK. Cancer statistics, trends and multiple primary cancer analysis from the surveillance, epidemiology and end results (SEER) program. Oncologist 2007;12:20–37.
13. Audisio RA, Bozzetti F, Gennari F, et al. The surgical management of elderly cancer patients: Recommendations of the SIOG surgical task force. Eur J Cancer 2004;40:926–938.
14. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: Prospective cohort study. BMJ 2000;320:469–473.
15. Gill TM, Gahbauer EA, Han L, Allore HG. Trajectories of disability in the last year of life. N Engl J Med 2010;362:1173–1180.
16. Diab SG, Elledge RM, Clark GM. Tumor characteristics and clinical outcome of elderly women with breast cancer. J Natl Cancer Inst 2000;92: 550–556.
17. Hind D, Wyld L, Beverley C, Reed MW. Surgery versus primary endocrine therapy for operable primary breast cancer in elderly women (70 years plus). Cochrane Database Syst Rev 2006;(1):CD004272.
18. Cella D, Fallowfield L, Baker P, et al, on behalf of the ATAC Trialists' Group. Quality of life of postmenopausal women in the ATAC trial after completion of 5 years' adjuvant treatment for early breast cancer. Breast Cancer Res Treat 2006;100:273–284.
19. Fallowfield L, Cella D, Cuzick J, et al. Quality of life of postmenopausal women in the arimidex, tamoxifen, alone or in combination adjuvant breast cancer trial. J Clin Oncol 2004;22:4261–4271.
20. Farmacotherapeutisch Kompass. Available at: www.fk.cvz.nl. Accessed September 2011.
21. Routledge PA, O'Mahoney MS, Woodhouse KW. Adverse drug reactions in elderly patients. Br J Clin Pharmacol 2004;52:121–126.
22. Intergraal Kankercentrum Nederland. Oncoline. Available at: www.oncoline.nl. Accessed December 2011.

Appendix 1. Overview of current breast cancer treatment guidelines[22]

Early stage disease T1–2N0–1M0	1. Lumpectomy with adjuvant radiotherapy or alternatively modified radical mastectomy 2. A lymph node staging procedure, either an axillary lymph node dissection or a sentinel node procedure followed by a subsequent axillary lymph node dissection if sentinel node is positive 3. Adjuvant radiotherapy to chest wall or axillary nodes 4. In high-risk disease, adjuvant systemic treatment, either endocrine treatment or chemotherapy, depending on hormone receptor status
Locally advanced disease T3–4N2–3M0	1. Neoadjuvant systemic treatment, either endocrine treatment or chemotherapy, depending on hormone receptor status 2. Surgery to reduce tumor load, with axillary lymph node dissection if nodes are tumor positive 3. Locoregional radiation therapy 4. Adjuvant systemic treatment, either endocrine therapy or chemotherapy, depending on hormone receptor status
Metastatic disease	1. Systemic treatment, either endocrine therapy or chemotherapy, depending on hormone receptor status
Palliative treatment	1. Systemic treatment, either endocrine therapy or chemotherapy, depending on hormone receptor status 2. Local radiotherapy (for example, for ulcerative disease or pain owing to bone metastases)