

Quality of care in breast cancer indicator

Time between pathological diagnosis and surgery; reasons for delay -

A retrospective analysis

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Abstract

Background

In 2008 the incidence of breastcancer was over 13,000 in the Netherlands. From already 2005 on hospitals are encouraged to follow certain guidelines concerning treatment of breastcancer provided by the NABON (Nationaal Borstkanker Overleg Nederland, National Breast Cancer Organization of the Netherlands) and the CBO (Centraal Begeleidings Orgaan, central guidance committee) and in 2008 this guidelines were specified with indicators such as a maximum of 35 days between diagnosis and operation of breastcancer. Not all patients receive surgery within 35 days after diagnosis and with this explorative file review we search for reasons why this guideline is not met.

Aim

Aim of this research was to gain insight in the amount of delay and reasons of delay between diagnosis and surgery of breastcancerpatients.

Methods

Through the Cancer Registry 220 patientcases from 9 different hospitals in the North East of the Netherlands in the year 2008 were selected where the period of diagnosis to surgery was longer than 35 days. With guidance of the Cancer Registry these files were looked into, what was available digitally on sight at hospitals. Both male and female patients are included, neo-adjuvant patients are excluded.

Results

Of all patients in 2008 in the North Eastern region 16.1 % had a delay. In the researched hospitals 13% of treated patients was delayed. Within the four categories hospitals, patient condition, patient choice and immediate breast reconstruction, a number of reasons were found and a part remained unknown and made up the 5th category “unknown”. Hospital logistics occurred most often as reason of delay with a percentage of 60.5%, patient choice was 11.8%, immediate breast reconstruction 8.6%, patient condition 8.2% and unknown 25.9%.

Discussion

The guideline suggests a maximum of 35 days between diagnosis and surgery but former research has shown that delay caused by the physician does not affect the outcomes negatively and most of the delay found in this research is caused by the physician or hospital, partly due to waiting lists and partly due to further diagnostic research. The guideline of two days of diagnostic measures sometimes gets stretched by hospitals to more days or more

diagnostic means. Part of the delay is beneficial for patients' health due to better imaging of the status of the disease. Whether this has made a difference in survival rate is not clear from this research.

Introduction

Breast cancer is a common disease in the Netherlands with an incidence of more than 13,000 cases in 2008 (VIKC, 2010). It is one of the main death causes for women, with 3327 women dying of breast cancer in 2008 which is 5% of the total number of deaths among women. (CBS, 2010)

A breast cancer patient has several possibilities to go through the care pathway. Sometimes patients discover irregularities themselves at home and sometimes through the preventive screening program. In both instances, the patient will see the general practitioner for further research and be referred to a hospital or outpatient breast clinic within the hospital. In the outpatient breast clinic the patient will see a physician and receive diagnostic research, for instance a mammogram and biopsy. With a positive result of the pathological exam the patient will be informed of the diagnosis and a treatment plan will be drawn up. After that pre-operative consults take place and the patient will either undergo surgery or first receive other curative therapy, so called neo-adjuvant therapy.

In recent years more emphasis has been put on the efficiency of health care processes due to the wish for a more market/ competition oriented way of acting. For the treatment of breast cancer this has resulted in guidelines, based on scientific research, created by the NABON and the CBO. The guidelines should help gain more efficiency and also effectiveness and thus increasing the quality of care. Guidelines are recommendations on diagnosis, treatment and follow up. To measure these guidelines, indicators are drawn up to measure performance within the hospital and also give the possibility of comparing hospitals' performances.

In 2005 the NABON (Nationaal Borstkanker Overleg Nederland, Dutch Breast Cancer Organization of the Netherlands) and the CBO (Centraal Begeleidings Orgaan, central guidance institute for quality of Health care) have presented an adapted national guideline with several indicators regarding the treatment of breast cancer, this guideline should be seen as a scientific guideline for Dutch health care professionals (CBO, 2005) to improve the quality of health care.

One of the indicators concerns the maximum time between diagnosis and surgery, this should not be more than 35 days. In this process no more than two research days should be needed to set a diagnosis and the results from the pathology should be known within 7 weekdays. After that the patient needs to be informed of the diagnosis within 7 weekdays. Then another 3 weeks are allowed to plan the surgery if the treatment plan is set up in an adjuvant manner. Of all patients treated, 10% is allowed to exceed the total of 35 days between diagnosis and treatment, due to personal wishes or unique situations such as comorbidity.

All the time periods and the 10% margin are created by the NABON on the basis of scientific literature of what is possible in health care and what should be best for the patient. For instance already in 1978 Wilkinson et al. researched the possible correlation between delay in treatment and various other variables such as severity of the disease and time span of survival. In this research the delay caused by the patient had a rather serious effect on the seriousness of the illness. The delay caused by a physician was not subject of this research. Sainsbury, Johnston and Haward researched the effect of delay caused by the physician/ care providers in Yorkshire, UK. There was no evidence that provider delays of longer than 90 days adversely influenced survival. Patients who were treated in less than 30 days had significantly worse outcomes. (Sainsbury et al, 1999). This seems to point at the possibility of no negative effects when the provider causes the delay and if the delay is caused because of for instance further diagnostic methods, the patient is better off in the end because their disease is more thoroughly investigated. But ten years later research is more advanced and possibilities of full insight into a patient's disease can be gained in a much shorter time span. Another article shows how well hospitals in the south of the Netherlands have coped with the guidelines. Some guidelines are hardly adhered to and the authors see a lot of possibilities for improvement in the logistics of hospitals (Van den Hurk et al, 2006).

When the adherence of the 35 days indicator was recently checked in a hospital in the North East Region of the Netherlands a physician protested about the guideline and not adhering to it due to patients wishes. Apparently not every patient is treated within the 35 days time period, partly without fault of the physician. This can affect a hospital or physician negatively when judged on the basis of percentages alone. Therefore this retrospective, explorative and descriptive research is performed to research the size of this delay and the reasons why delay comes into existence.

Patients and methods

All patients diagnosed with breast cancer in 2008 were selected from the Regional Cancer Registry of the CCCNE (Comprehensive Cancer Centre North East Netherlands) and time from biopsy to operation was calculated. Data was gathered in cooperation with the Cancer Registry and through the CCCNE. A variety of 9 hospitals was selected, ranging from a small town hospital to a university medical centre (Streekziekenhuis Koningin Beatrix Winterswijk, Zorggroep Twenteborg Almelo and Hengelo, Gelre Ziekenhuis Apeldoorn and Zutphen, Deventer Ziekenhuis, UMCG and Martini Hospital in Groningen and Isala klinieken in Zwolle). In the year 2008 220 adjuvant patients were treated in the 9 selected hospitals. The patients selected in this research had all at some point undergone surgery before other kinds of treatment. Thus the patients who first received other kinds of therapy, for instance chemotherapy, also known as neo adjuvant treatment were excluded. In the guideline these patients are excluded because most of them will not meet the standard due to a different logistical and therapeutical time line. In the hospitals only the digitally available files were searched, because most hospitals already had most of their 2008 files digitalized and to gather the most information about the largest possible population, analog files were not looked into. From the digital files the following data were extracted: date of biopsy, the outcome and date of outcome known with physician and patient, all further diagnostic measures taken with dates, consult with patient about plan of treatment, meeting of the multidisciplinary cancer staff within the hospital, pre operative screening of the patient and date of operation. Furthermore any possible reasons of delay were searched for. In the first phase a few patient records were looked into to get a sense of what was available in the digital files and what kind of reasons we could come across. After that, in consult with a few experts, several categories were created to categorize the reasons for delay. Reasons for delay were categorized into different groups: patient condition, patient choice, logistics of the hospital, immediate breast reconstruction and unknown. These reasons were listed partly on basis of what was found in the files and partly what was suggested by physicians and experts. In the research the means of diagnosis and the number of diagnostic days were registered as well. In the next phase all files of selected patients were researched for earlier mentioned variables and with this information a data file was created in excel and later on in spss.

Results

There are 2956 patients treated in an adjuvant manner for breast cancer in 2008 in the North East of the Netherlands. Of these 2956 patients, 375 were overdue, which is 12.7% of the total. This is slightly more than the guideline which offers a margin of 10%.

In the care of breast cancer, a physician should be allowed to offer his patients the time to deal with the diagnosis and the consequences. Therefore some adjustment time is needed and this differs between patients. A 100% target can not be reached, but according to the NABON 90% is reasonable.

Looking at the group of 375 delayed adjuvant patients, the average number of days between diagnosis and operation in 2008 is 50.9 days. Of the 220 researched patients the average delay is 49.35 days with a standard deviation of 23.63.

For these 220 patients several reasons of delay were found, listed below in table 1.

Table 1. Reasons of delay between diagnosis and treatment of breast cancer patients in the year 2008 (n = 220)

Categories of reasons of delay	Number of patients with this reason (%)
Hospital logistics	133 (60.5%)
Patient choice	26 (11.8%)
Immediate breast reconstruction	19 (8.6%)
Patient condition	18 (8.2%)
Unknown	57 (25.9%)

All categories together add up to 100% because for each case one main reason was chosen as reason of delay. Most cases had one reason, some had two and a few three, but combining this would have made it too complex to discuss here.

The different categories each had their own stories and examples of found reasons are mentioned per category.

Hospital logistics (n = 133)

This consists of for instances further diagnostic research and waiting lists for surgery resulting in 133 delayed patients. Some cases turned out to be more complex and needed more diagnostic research in order to gain more insight in the ailment and thus being able to give the best health care possible. Some patients receive several different diagnostic measurements

and sometimes the same several times because of failures in research or testing and also when physicians are in doubt about the seriousness/ invasiveness of the ailment.

Beneath these category descriptions two tables with diagnostic measurements received by patients are listed.

A fair number of patients underwent a MRI and in hospitals this is always a time consuming option. Often there is a waiting list for the MRI and some hospitals also choose to time the MRI according to the menstrual pattern if the patient is female because the breast tissue density can differ during the cycle. Some hospitals also do not have a MRI or were under construction and patients were referred to other hospitals for the MRI.

Only 5 patients had a second opinion and 12 were referred to/ from another hospital. The main cause seems to lie in further diagnostics and waiting lists.

Patient choice (n= 26)

In patient choice there were 26 files that had some kind of remark about wishes of patients concerning treatment or vacation. In one specific file the patient in question had forgotten about her test results and a new appointment and her general practitioner accidentally stumbled upon her test results more then 9 months later. Some patients were also doubtful about having breast cancer treatment on top of other ailments.

Immediate breast reconstruction (n = 19)

Immediate breast reconstruction is made into a separate category because this is partly a patients' choice, but it will influence the process and the steps physicians will take in order to give best care to the patient as well. A plastic surgeon will be involved and extra consults are needed. 19 patients within this research decided on immediate breast reconstruction and went through with it. All the patients with an immediate breast reconstruction had at least two days of diagnosis and image-forming and more consults with physicians even though the guideline includes immediate breast reconstruction and the statement that this choice should not cause delay.

Patient condition (n = 18)

For patient condition there was a small overlap with patient choice, but 18 cases were mainly delayed by patient condition. Some files presented patients that were doubtful about treatment after already having a lot of treatments for other ailments and not wishing to have more involvement with hospitals and physicians and some patients also being of a certain age and not having the desire to go on anymore. Some patients had a co morbidity risk of for instance hart failure. One patient needed to stop taking her hart medicine for the operation but then

suffered a stroke before the operation took place. After restoring back to health, the operation has taken place but automatically a delay was caused, although there was no other option.

Unknown (n = 57)

The unknown category has a number of 57 files. In these 57 files no reasons could be found that led to a delay. The lack of information, either digital or scanned paperwork, was a main cause of this problem.

Discussion & conclusion

Patient files do not give conclusive answers about reasons of delay but some indications can be found, but there is almost never certainty about whether this truly led to delay. Only a few files had listed clear reasons that caused delay, most files did not list the causal relation between a decision and the delay, therefore for some files no reason of delay could be found at all. But most files did have some specific registration that did not match the regular guideline concerning treatment of breast cancer and especially more diagnostic research took place to create a better/ more complete image of the tumor. And for some files assumptions were made on the basis of patient/ physician's letters.

The results show that a lot of the delay is caused by the hospital, either because of waiting lists or due to more diagnostic measures. This may al seem rather serious, but one needs to keep in mind that the patients selected for this review had a clear delay and were probably all a deviation of the standard, in both treatment as well as disease. For most of the breast cancer patients the treatment has taken place within the guideline and according to the indicators. But within the 12.7% of delays is room for improvement.

Hospital logistics is the largest reason for delay with 60.5%. Waiting lists for surgery or delay due to MRI appointments is not necessarily negative for patients' survival but can be improved. Especially waiting lists should be looked into because waiting means longer uncertainty for patients. The quality of given care is not jeopardized, but the mental well-being of a patient also needs to be taken into consideration.

When a patient makes choices that delay surgery, it is their right to do so. In this research that is 11.8% of total delay. If this jeopardizes the patient's own well-being a physician will mention this but offer the patient space and thus improving the overall quality of care.

Immediate breast reconstruction is taken into account when the guideline and its indicators were created and should not be a reason for delay. Perhaps when the plastic surgery department is involved with the care of a patient from the beginning, this part of the delay can be reduced or eliminated.

Patient condition is something one can hardly influence. Fortunately this is a small part of the total delay and can be taken into account within the 10% margin offered by the guideline. Giving physicians the margin for these cases gives them breathing space to enhance patient condition or at least make sure patients can undergo the surgery properly.

The guideline and indicator, created by the NABON and CBO, does not need revising according to us. The margin of 10% is necessary and also large enough to offer

For the delayed patients, we can advise hospitals to especially look into their logistical planning and timeframe and try to adhere to the guidelines as much as possible to ensure best possible quality of care. By benchmarking hospitals a best practice might be found which can benefit all hospitals.

A suggestion for further research could be the option of looking into survival rates and comparing time periods before and after implementation of guidelines to see whether these have made any difference in the conduct of business of hospitals. Interesting research could also be the observation of the logistics concerning the care of breast cancer and exploring all the steps with physicians concerned in these steps. And to see how well they are informed on the guidelines and whether they feel the guidelines are adhered to and are of use.

We found more diagnostic measures per patient in this research but nothing is known about the amount of diagnostics measures that 'regular' patients receive. This should also be looked into.

This research can be expanded to include more time periods, more hospitals and more regions to be able to make a comparison between periods before implementation of the guideline.

Also adding an extra researcher to the project can reduce the researcher bias for more valid judgment and to prevent one researcher judging all outcomes and perhaps affecting the outcome subconsciously.

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