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# First German Disease Management Program for Breast Cancer

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*The first disease management program contract for breast cancer in Germany was signed in 2002 between the Association of Regional of Physicians in North-Rhine and the statutory health insurance companies in Rhineland. At the heart of this unique breast cancer disease management program is a patient-centered network of health care professionals. The program's main objectives are: (1) to improve the quality of treatment and post-operative care for breast cancer patients, (2) to provide timely information and consultation empowering the patient to participate in decisionmaking, (3) to improve the interface between inpatient and outpatient care, and (4) to increase the number of breast-conserving surgeries.*

## BACKGROUND

A breast cancer scandal broke in the 1990s in the city of Essen, North-Rhine<sup>1</sup>, Germany (Koch, 2000). Qualifications of a local pathologist came into question after a review of the clinical histories of 76 patients revealed recurring inconsistencies. Arson in the pathologist's laboratory prevented a retrospective histological review. Based on the pathology reports in clinical records at least 300 females had been diagnosed with breast cancer. In the absence of a second opinion, many of these females had undergone mastectomy.

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<sup>1</sup> Part of the Federal State North-Rhine-Westphalia, Germany. The population in North-Rhine (Rhineland) is 9.6 million.

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In 2000 the Allgemeine Ortskrankenkasse (AOK) Rheinland, a large regional German statutory health insurance company, conducted a survey among females with breast cancer to recognize deficiencies of therapy and identify specific patient's needs (Düsseldorf, 2000). Only 71 percent of females felt that they had received sufficient medical information, and only 52 percent had been given information concerning the availability of psychosocial counseling. A year later, in 2001, the Advisory Council for Concerted Action in Health Care<sup>2</sup> at the Federal Ministry of Health and Social Security analyzed health care deficits in chronic diseases affecting large numbers of the population. Data were obtained with specific questionnaires for medical societies, patient support organizations, health insurance companies, and social agencies. A report by the Advisory Council for Concerted Action in Health Care demonstrates a dominance of acute medical care and a neglect of prevention and rehabilitation, both indicative of a lack of awareness of the social, psychological, environmental, and biographic references of chronically ill patients.

For breast cancer the following problems were identified:

- Lack of a quality-assured program for early detection of cancer (breast screening according to the European guidelines of 1994) (DeWolf and Perry, 1996).
- Inadequate diagnostic procedures (too many mammograms for females under

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<sup>2</sup> The council consists of well-known scientists in the fields of medicine, public health, health care economics, sociology, and finances.

age 50) and inexperienced radiologists (too many operators of mammography equipment see too few cases).

- Too many breast amputations (mastectomy instead of lumpectomy).
- Too many cases with high-dose chemotherapy with or without stem cell support.
- Too often expensive conventionally equipped technical post-operative care instead of symptom-oriented care.

Based on these and the findings for the chronic diseases, the Advisory Council formulated a series of recommendations for treatment of chronically ill patients and outlined requirements for quality assurance, patient contributions, coordination, evidence-based care, prevention, and training and education of patients and care providers. In response, the Federal health authority outlined structured disease management programs under the responsibility of the statutory health insurance companies and regulated the admission to such programs. The risk-structure compensation scheme was modified to assure statutory health insurance companies promoting disease management programs for patients with chronic diseases do not face disadvantages compared to statutory health insurance companies that do not introduce disease management programs. Admission criteria were defined for the disease management programs of diabetes type 2 and breast cancer; followed by those for chronic obstructive lung disease, diabetes type 1, and coronary heart disease. Described here are the design and experiences of the first disease management program for breast cancer.

## **PROGRAM OBJECTIVES**

The first contract for a disease management program for breast cancer in Germany was signed in October 2002

between the association of regional physicians in North-Rhine and the statutory health insurance companies in Rhineland, the AOK Rheinland being the largest. Selected regional hospitals were included in the contract. For the first time, an entire region offered a quality-assured, structured disease management program for females with breast cancer who are insured under the statutory health insurance company.

The goal of the project is with a patient-centered network of radiologists, gynecologists, pathologists, oncologists, radiological therapists, rehabilitation specialists, and psycho-oncologists to improve the quality of patient care for females with breast cancer in North-Rhine. The patient is guaranteed treatment according to state-of-the-art standards of evidence-based medicine. The objectives of the disease management program for breast cancer patients can be summarized as follows:

- To reduce errors in the diagnostic process.
- To improve the quality of treatment and post-operative care for breast cancer in accordance with current operative standards or standards of adjuvant therapy.
- To provide detailed information and consultation to surgery, throughout the course of treatment, and during post-operative care.
- To empower the patient to participate in decisions about treatment.
- To assure that sufficient time between diagnosis and surgery is allowed for decisionmaking.
- To increase the number of breast-conserving surgeries.
- To offer psychosocial support throughout the treatment process.
- To facilitate the interfaces between hospitals, local physicians, rehabilitation, and providers of medical supplies.

In terms of cost analysis, cost-effectiveness

or cost-utility analysis, the profile of the disease management program for breast cancer is not intended to reduce cost.

## **PROVIDER'S ROLE**

The cooperation of the different health care providers is essential to disease management programs. The treating gynecologist usually coordinates diagnostics and treatment with other providers. Gynecologists participating in the program must undergo disease management program-related training curricula and participate in quality working groups. The coordinating gynecologist informs the patient about the disease management program, counsels the patient about joining, enrolls the patient, assures that the patient is treated according to the program principles, and initiates individual treatment steps (e.g., in cooperation with a breast cancer center). This physician is also responsible for data collection (patient's history, date of diagnosis, staging information, treatment strategy, outcome, etc.) and submission of that data to a non-partisan database managed as a joint venture between the health insurance companies and the Association of Regional Physicians.

Participation of statutory health insurance company physicians in a disease management program is voluntary. Participating physicians must subscribe to the quality standards as defined in the disease management program contract and are monitored by the Association of Regional Physicians. Selected hospitals with special breast cancer centers in North-Rhine are also participating in the disease management program.

## **PATIENT'S ROLE**

The females with breast cancer are at the center of the disease management program. They are to be informed in a timely and structured fashion about their disease and are involved in the decisionmaking process. Physicians and patients discuss each step of diagnosis and therapy. Detailed consultations before and after surgery (generally involving relatives) and regular consultations during therapy and post-operative care are essential parts of the program. Counseling is made available to help the patients deal with psychological effects (e.g. fear, depression) and social consequences (in family, partnership, etc). They are not involved in organizational duties of the program. Patient participation in the program is voluntary and free of charge. The physician's office fee, an additional payment of \$12 due quarterly for visits to a general practitioner or coordinating physician, is waived for program participants on enrollment.

## **PATIENT'S ELIGIBILITY**

Patients diagnosed with breast cancer within the last 5.5 years are eligible if there is histological evidence of disease. Generally, patients are newly diagnosed and no previous therapy has been provided. The patient must be willing to actively contribute and participate in the breast cancer disease management program. The program is open to all patients insured with statutory health insurance companies; privately insured patients are not eligible for the program.

Participation in the breast cancer disease management program generally ends after 5 years. If the patient fails two times to

participate in a recommended training course or the coordinating gynecologist does not submit the required documentation forms two times within 3 years, the patient can be excluded from the program.

## **ADJUVANT THERAPIES AND FOLLOWUP**

An integral part of the therapy is timely care with adjuvant therapies and remedies as well as the introduction of specific rehabilitation measures as needed (e.g. psychotherapy, lymph drainage).

Post-operative care after breast cancer must start on termination of the primary therapy, no later than 6 months after histological confirmation of the diagnosis. Post-operative care involves more than monitoring the disease; it also contributes to the patient's psychological, physical, and social rehabilitation. Followup examinations are performed two times a year. The coordinating physician is responsible for follow-up and initiation of any diagnostic or therapeutic procedure the patient may need (e.g., in the case of post-traumatic stress syndrome, fear disturbances, and depressive disturbances).

## **ADDITIONAL BENEFITS**

In addition to the disease management program package, the AOK Rheinland offers a number of other non-medical services to insured members. These include the services of an adviser on cancer rehabilitation who will contact the patient on request, visit in the hospital or elsewhere, discuss rehabilitation options, and the rehabilitation program, and assist with any problems or special requests. At the AOK Clarimedis Service Center, an all female team of physicians, psychologists, nurses, and social insurance experts are available

for assistance and information. The team offers support in regard to breast cancer itself or cancer-related issues, such as household aid, additional care (breast prosthesis, wigs), travel expenses, alternative diagnostics, and treatments. In addition, the AOK Rheinland produces the *AOK Breast Book*, (Das AOK Brustbuch, 2003) a patient's guide to treatment and decisionmaking, and publishes the journal *JaVita*, a periodical for cancer patients with up-to-date information on malignant diseases and their treatment.

## **REIMBURSEMENT**

Standard outpatient medical services continue to be reimbursed the traditional way within a global budget. Disease management program-related services provided by the coordinating gynecologist, such as enrollment of the patient, documentation, counseling services before and after hospital stay, accompanying talks, and psychosocial counseling, are reimbursed outside of the global budget. Physicians in cooperating hospitals receive no extra remuneration for their inpatient medical services.

The Association of Regional Physicians' guarantees that the disease management program contract reimbursement of participating physicians is listed separately in the calculation papers.

Every quarter, the association submits proof of the calculated services to the health insurance companies. The physicians do not suffer any financial risk due to their patients' morbidity; this is covered by the health insurance companies. Within the risk structure compensation scheme, the morbidity risk is indirectly balanced between the health insurance companies for patients in accredited disease management programs. In the future, new legal

regulations for developing networks of integrated care in Germany may be used to bundle several disease management programs together.

## **PRELIMINARY EXPERIENCE**

The non-partisan database maintained as a joint venture between health insurance companies and the Association of Regional Physicians will allow scientifically evaluating the efficacy and quality of therapy applied within the disease management program for breast cancer. Currently, it is too early to provide this type of information.

A report on the disease management program for breast cancer published in December 2004 (Altenhofen et al., 2004) gives descriptive information on the characteristics of patients enrolled. At the time of analysis, 5,669 patients had been enrolled. The average age was 60.6 years (standard error 11.8). Twenty-one percent of patients were over age 70, and 24 percent of 5,682 patients were diagnosed prior to menopause (Figure 1). There was no significant difference in *T* staging among the different age groups (data not shown). The objective to treat 50-60 percent of the patients with breast-conserving surgery was reached (Figure 2, data not shown). As of January 31, 2005, 9,421 patients are enrolled in the disease management program for breast cancer in North-Rhine.

With patients in the center of the program, it is anticipated that they will play an important role in improving the program. Valuable information can be gathered by random telephone surveys and by interaction with patients' self-support groups. Females from one of these groups (Women after Cancer) participated in the development of the disease management program for breast cancer. To exchange experiences during the implementation of the

program (analysis of strengths and weaknesses/need for further action), the representatives meet at least once a year with the board of the self-support group.

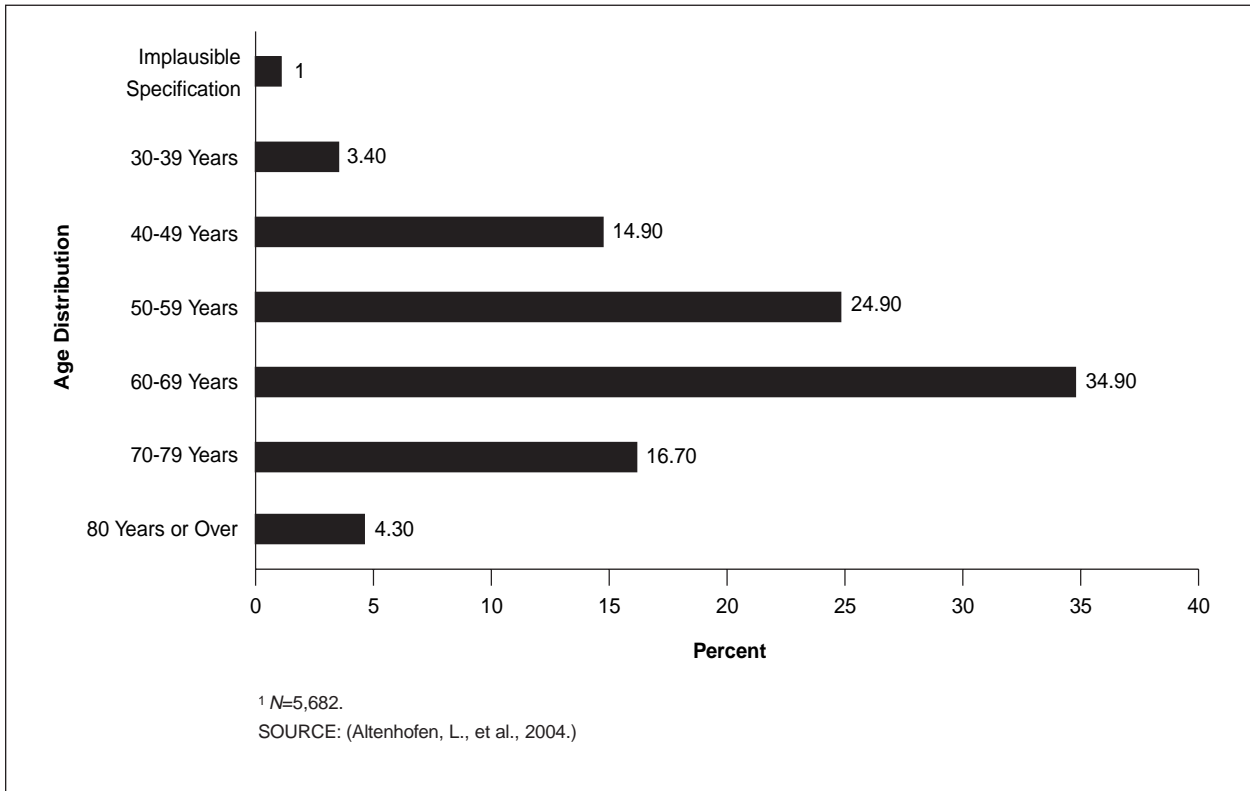
Currently, 976 of 1,382 gynecologists in the area of North-Rhine participate in the disease management program for breast cancer. Gynecologists in single practices who typically have few breast cancer patients face a number of practical problems. They may find the program less attractive and may be less willing to cooperate. Consequently, the AOK Rheinland will explore whether hospitals or existing group practice structures should play a stronger role in the disease management program. It has also become evident that standardization and quality control in the diagnostic process (pathology, radiology) are necessary requirements.

## **BREAST CANCER CENTERS**

With the implementation of the breast cancer disease management program the need for contracts between hospitals and insurance companies strengthened the concept of centralized care. The establishment of breast cancer centers (Richards, Sainsbury, and Kerr, 1997; Lungen, Rupprecht, and Plamper, 2004) was in part the result of the initiation of the disease management program. Simultaneously, the local government (Ministry of Health of North-Rhine-Westphalia) had established criteria for breast cancer centers (Fischer, 2003), which are compatible with the standards required for the breast cancer disease management program. A certification procedure was established for the breast cancer centers.

Breast cancer centers work according to international guidelines in an interdisciplinary fashion and cooperate with hospitals in the area as "satellites." A center has to perform a minimum of 150 primary breast

**Figure 1**  
**Age Distribution Percent of Patients' Enrolled in a Breast Cancer Disease Management Program in Germany: 2003**



cancer surgeries per year. If several hospitals are affiliated with one center, the minimal number of surgeries per surgical department, per hospital is 100 per year; with a minimum of 50 surgeries, per surgeon. Obviously, the number of surgeries is not a quality criterion by itself, but rather an indicator for the experience of the hospital or surgeons. Defined quality parameters will have to be added. In addition to minimal numbers of procedures, participating hospitals have to ensure continuing medical education of their staff as well as cooperation with self-support groups.

The contract between the disease management program for breast cancer and breast cancer centers specifies a number of details which are thought to optimize care. Two examples are: (1) the chief surgeon is required to see the patient prior to surgery and on the day of surgery, and (2) a detailed

discharge report must reach the disease management program coordinating gynecologist no later than 3 days after the patient's discharge to guarantee an optimal interface between inpatient and outpatient care.

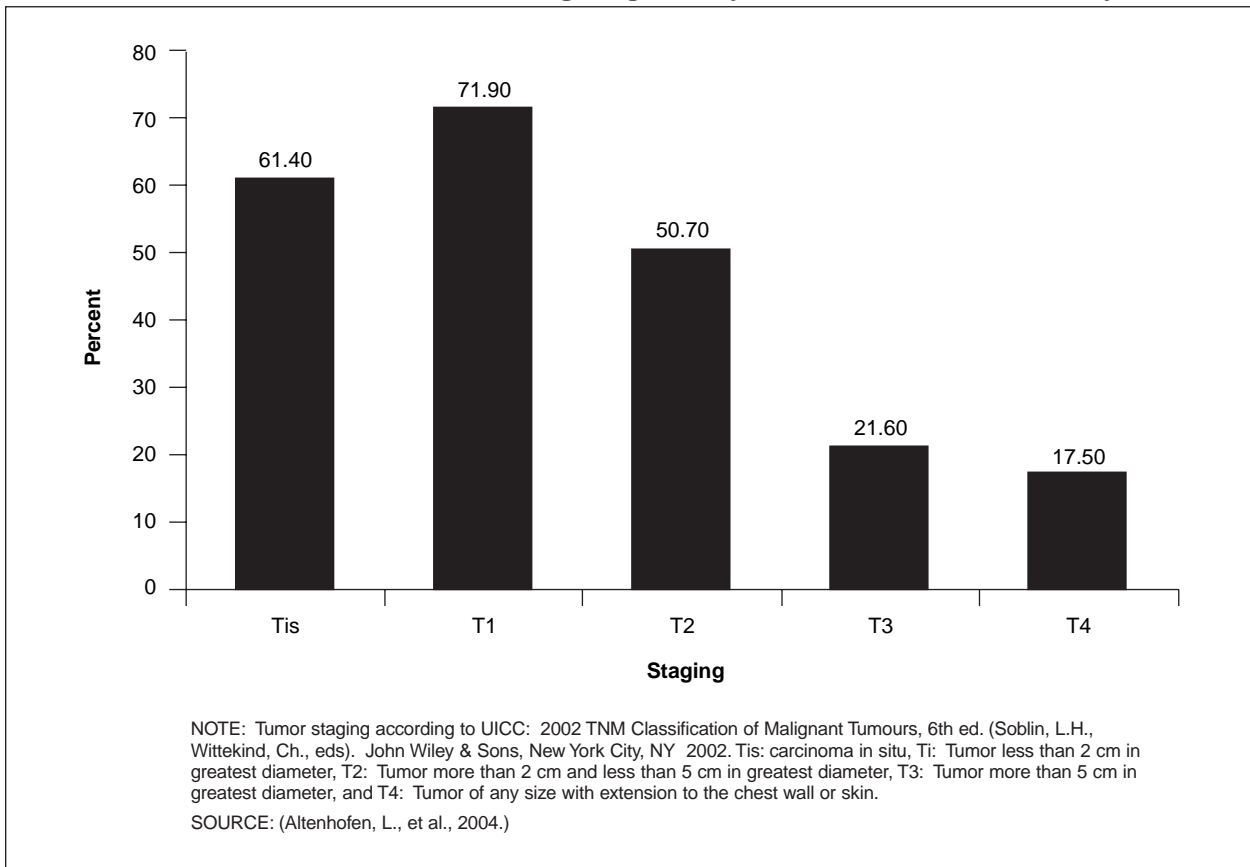
Currently, 39 centers have signed contracts with the disease management program. In January 2005, an additional 35 centers have been assigned to the regional hospital plan by the State government. Instead of 250 hospitals performing breast cancer surgery, 74 will be the providers in 2006. Each of the certified breast cancer centers will have a catchment area with a population of 360,000 to 450,000.

### **EARLY DETECTION**

Annually, about 48,000 females are diagnosed with breast cancer in Germany; 19,300 of these females are under age 60.

Figure 2

Percent Distribution of Breast-Conserving Surgeries, by Tumor Dimension in Germany: 2003



The number of females dying of breast cancer is estimated at 18,000 per year, which represents approximately 18 percent of overall cancer mortality. The relatively high mortality is a distinct characteristic of breast cancer. Therefore, improved early detection is seen as a chance to curb the high mortality rate.

A national breast cancer screening program for females age 50 to 70 was introduced in Germany in 2004. This program entitles a female to a mammography every 2 years. The new screening program is expected to reduce breast cancer mortality by 3,500 cases per year. Physicians offering screening must prove their qualifications and perform at least 3,000 examinations per year. By 2005, Germany plans to have established 80 screening units for early detection of breast cancer (Köhler,

Gibis, and Mühlich, 2003). Although screening implies the risk of a false positive diagnosis and critical reviews like those of the Nordic Cochrane Institute (Olsen and Gotzsche, 2001) have to be taken seriously, early detection represents an important step forward.

In the highly regulated risk-structure compensation scheme, screening programs for breast cancer cannot be a constitutive element of the disease management program, but maybe attached to it. With respect to the administrative level within the AOK, the breast cancer disease management program and early detection are combined. Patients already enrolled in the program can participate in breast self-examination classes, mind-body courses, and seminars.

## OUTLOOK FOR DISEASE MANAGEMENT PROGRAMS

The introduction of a morbidity-adjusted risk structure compensation scheme in Germany scheduled for January 1, 2007, will provide an additional incentive to the development of disease management programs. The disease management programs of the second generation—replacing earlier quality assurance structures in the area—will be more target-group-oriented and flexible than their predecessors. In a complex, fragmented health care delivery system the importance of disease management programs goes beyond patient navigation. Disease management programs have the opportunity to overcome obsolete treatment structures and to substitute these with efficient, high-quality centers of care. At the same time, successful disease management programs will produce spillover effects and stimulus for other models of integrated care, such as pilot projects for prostate and ovary cancer in the North-Rhine area.

The analysis of return on investments for traditional disease management programs (such as diabetes type 2) distinguishes between short-, mid-, and long-term returns. At times, health insurance companies focus too much on short-term effects (specific disease pattern or target groups) to avoid or reduce further consequences of the chronic disease and their expenses. For all accredited disease management programs, quality improvements are the primary objective. Cost reductions (drugs, hospitalization, sick leave payments) are side products. Return on investments plays no major role in the accredited disease management programs; instead programs are seen as an important tool to realize a long overdue structural change in the German health care system.

The success of disease management programs in Germany will depend on a number of critical factors. One prerequisite is a common action of the Association of Regional Physicians with all statutory health insurance companies despite a strong competitive market. All programs need to be endorsed by legal measures and adjustments of framework conditions. Insurance companies, health care providers, and patients will have to maintain an ongoing dialog; and lastly, the patient must be empowered to play an active role in decisionmaking. Compared to the health care systems in the U.S.<sup>3</sup>, with a high number of insurance carriers (Enthoven, 2003) the current circumstances in Germany may be more favorable for the introduction of quality health care management.

## REFERENCES

Altenhofen, L., Brenner, G., Haß, W., et al.: *Qualitätssicherungsbericht 2004, Disease-Management-Programme in Nordrhein*. Editor: Nordrheinische Gemeinsame Einrichtung Disease-Management-Programme GbR, December 2004.

Advisory Council of Concerted Action in Health Care: *Final Report Entitled Appropriateness and Efficiency, Volume III: Overuse, Underuse and Misuse*. August 2001.

Das AOK Brustbuch: *The AOK Breast Book*. KomPart, Bad Homburg, Kortijker Strasse 1. January 2003.

DeWolf, C.J.M. and Perry, N.M. (eds): *European Guidelines for Quality Assurance in Mammography Screening*. Luxembourg: European Commission, 1996.

Düsseldorf Press-Release: *AOK Rheinland, TNS Emnid: Verbesserung der Versorgung von Brustkrebspatientinnen*. July 2000.

Enthoven, A.: *Employment Based Health Insurance is Failing: Now What?* *Health Affairs*. May 2003.

Fischer, B.: *Brustzentren- Neue Wege in NRW und Europa*. Editor: Ministry of Health, Social Affairs, Women and Family NRW, Düsseldorf (8)17-26, December 2003.

<sup>3</sup> A medical group that deals with 15 different carriers must deal with 15 different drug formularies, and 15 different coverage policies for services. Moreover, there is a collective action problem.



Gøtzsche, P.C. and Olsen, O.: Is Screening for Breast Cancer with Mammography Justifiable? *Lancet* 355:129-134. March 2000.

Koch, K., Fehldiagnose B.: Defekte Diagnosekette. *Deutsches Ärzteblatt* 97(8):A-416, B-338, and C-316, 2000.

Köhler, A., Gibis, B., and Mühlich, A.: Mammographie-Screening: *Flächendeckendes Angebot Bereits im Jahr 2005*. *Deutsches Ärzteblatt* 100(19):A-1240, 2003.

Lüngen, M., Rupperecht, C.J. and Plamper, E.: Zentralisierung der Behandlung des Mammakarzinoms bei der Vorgabe von Mindestmengen: Empirische Auswirkungen in der Region Nordrhein. *Zeitschrift für ärztliche Fortbildung und Qualitätssicherung* 98(5):385-389, 2004.

Olsen, O. and Gøtzsche, P.C.: *Systematic Review of Screening for Breast Cancer with Mammography*. The Nordic Cochrane Centre, Copenhagen, Oct. 20, 2001. (Accessed May 2002.)

Richards, M., Sainsbury, R., and Kerr, D.: Inequalities in Breast Cancer Care and Outcome. *British Journal of Cancer*. 76:634-638, 1997.

Sobin, L.H. and Wittekind, C. (eds.): *TNM Classification of Malignant Tumours* (6th ed.). International Union Against Cancer. John Wiley & Sons. New York, NY. 2002

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