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Original article

Stage-specific incidence and survival of breast cancer in Norway: The implications of changes in coding and classification practice

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ABSTRACT

To describe the association between coding and classification practices and observed stage-specific incidence and survival trends in Norway over time.

We identified all women diagnosed with invasive breast cancer in the period between 1980 and 2015. Changes in the coding and classification of breast cancer in the study period were described, and stage-specific incidence rates and relative survival were calculated.

A total of 90 362 women were diagnosed with primary breast cancer, stage I–IV, or unknown stage, in the study period. Stage-specific incidence was significantly influenced by changes in coding practice, classification systems and the implementation of the screening program. These changes have mostly affected the proportion of stage I and "unknown", but also stages II, III and IV. The proportion of stage I showed a clear increase during the implementation period of the national screening program, and was most pronounced within the age group 50–69. Stage-specific trends for relative survival were less influenced by changes in coding and classification of stage.

Our study showed that the stage-specific incidence trends in Norway were influenced by changes in the coding and classification practice. These findings should be taken into consideration in future research and evaluation related to stage-specific trends and stage migration of breast cancer in Norway.

1. Introduction

In Norway, breast cancer comprises more than 20% of all cancer cases in women, and the current incidence indicates that one in twelve women will be diagnosed with breast cancer by the age of 75 [1]. The incidence rate increased monotonically up to 2005, while the annual rate has fluctuated during the last decade [1]. Knowledge about exposure to risk factors, the prevalence of screening and the introduction of new screening and diagnostic tests are essential for interpretation and understanding of the observed incidence trends. Population-based screening for breast cancer aims at detecting tumours at an early stage. It is thus expected to affect the incidence and stage distribution of breast cancer in a population, specifically among women who participate in screening programs. Other factors possibly influencing the incidence and survival of breast cancer are coding and classification systems, particularly for stage. Continuous and consistent reporting and registration routings are needed for the comparability of stage distribution over time and between populations. However, during the last decades, there have been several changes in the coding and classification of breast cancer in Norway, which hampers the interpretation of stage-specific incidence.

The main aim of the present study is to describe stage-specific incidence and survival trends of breast cancer in Norway, taking into account major changes in coding and classification practice and the implementation of the Norwegian Breast Cancer Screening Program.

Abbreviations: CRN, Cancer Registry of Norway; RS, Relative survival; SEER, Surveillance, Epidemiology and End Results Program.

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2. Material and method

2.1. Study population

Information about all women registered in the Cancer Registry of Norway (CRN) with an invasive breast cancer diagnosis in the period between 1980 and 2015 were included in this study.

2.2. Settings

The CRN was established in 1952. The reporting of neoplasms has been mandatory since the implementation of a directive from the Ministry of Health and Social Affairs in January 1952. Two factors are crucial for the data quality of the Registry. Firstly, it is mandatory to report information on all cancer cases in Norway. Secondly, the registration of the cancer cases is based upon reports from several sources, including clinical and pathological notifications, death certificates and data from the Norwegian Patient Registry. For breast cancer, completeness has been estimated to be close to 100% [2], and a recent published report from the CRN showed that 99.2% of the cases were morphologically verified [1].

2.2.1. The Norwegian Breast Cancer Screening Program

The Norwegian Breast Cancer Screening Program started as a pilot in four counties in 1996. After a gradually implementation, the program became nationwide in 2005. The program invites all women in birth cohorts roughly corresponding to age 50–69 years at the beginning of each screening round to biennial mammographic screening [3,4]. The participation rate in each screening round is about 75%, while 84% of the invited women have participated at least once during the first 20 years of the program [5]. Full field digital mammography replaced analogue systems during the period from 2000 to 2011, while digital breast tomosynthesis was used in study settings in one county in 2011–2012, and in 2014–2015. The rate of screen-detected invasive breast cancer was 5.3 per 1000 screening examinations in the period 2006–2014, while the interval cancer rate was 1.8 per 1000 examinations [5].

2.3. The coding and classification of breast cancer at the Cancer Registry of Norway

The CRN has followed international guidelines for classification of stage. In addition, in-house coding and classification systems have been used. Table 1 gives a detailed description of changes in coding practice that have taken place at the CRN in the period 1980–2015. A general principle for classification of stage is that the recorded information should contain information on the most advanced extent of the disease reported from either histology or cytology reports, clinical notifications or autopsies.

2.3.1. The TNM system

The TNM system was implemented at the CRN in 1986. Stage classification has been performed according to the Manuals for Staging of Cancer, published by The American Joint Committee on Cancer. In the period 1985–1994 the second edition was used [6], the fourth edition was used from 1994 to 2008 [7] and the sixth edition has been in use since 2008 [8]. The system groups tumour characteristics according to size and extension of the primary tumour (T), the status of the regional lymph nodes (N) and the presence or absence of distant metastasis (M). The *pTNM* variable is based upon findings from the pathological examination of a surgical specimen, in contrast to the *cTNM* which is based upon information from clinical examination prior to treatment. The *pTNM* variable has been determined by information from pathological notifications and/or clinical notifications for cases that were histologically verified. The *cTNM* variable has been insufficiently registered until recently. After 2013, however, we have solely based the classification of the extent of the disease (M0 or M1) on information from the clinical notifications (the cM) or a histological specimen confirming metastasis. The distributions of pT, pN, pM and cT, cN, cM are shown in Supplementary Fig. 1a and b. The definition of TNM staging is described in Table 2.

2.3.2. General staging – localized, regional or distant stage (SEER stage variable)

Cases are reported both on pathological and on clinical notifications. The clinical notifications are structured forms that include information aimed to give a general staging of the extent of the disease. This system is consistent with the stage reported in the Surveillance, Epidemiology and End Results Program (SEER) Summary staging Manual 2000 (see https://seer.cancer.gov/tools/ssm/), also described elsewhere [9,10].

In the present study this variable is referred to as the *SEER stage variable*, and defines stage as following:

- *Localized stage* (the tumour has not spread to other organs (equivalent to stage I)
- *Regional stage*
  - o Metastasis to regional lymph nodes (equivalent to stage II)
  - o Local infiltration to skin and/or chest wall (equivalent to stage III)
- *Distant stage* (metastasis to distant lymph nodes or to organs within or outside the same segment of the body (equivalent to stage IV)
- *Unknown stage* (metastasis status is unknown or missing).

In the period 1986–1993, the *SEER stage variable* was not systematically registered at the CRN, but systematic coding was resumed from 1994 and onwards.

2.3.3. The CRN summary stage

In the present study, an in-house *CRN summary stage* is used as stage. The *CRN summary stage* is based upon information from the *pTNM, cTNM* and the *SEER stage variable*.

In the period before 1985, stage was based on the *SEER stage variable* only. In the period between 1985 and 1993 it was mainly based on TNM as the *SEER stage variable* was not systematically registered. The *CRN summary stage* is based on TNM, and for cases with unknown stage information in TNM, additional information from the SEER stage is included.

2.4. Analysis

Incidence rates per 100 000 person-years were calculated based on the Norwegian mid-year population, and age-standardized using the world population [11,12] as the reference population. Stage-specific incidence is also presented as a proportion of the total. Smoothed incidence curves were obtained using locally weighted scatterplot smoothing (LOWESS).

Relative survival (RS) was estimated using the method proposed by Pohar-Perme et al. [13]. Estimates were age-standardized according to the International Cancer Survival Standards for survival [14]. Changes in incidence and survival trends were examined using the Joinpoint program provided by SEER, version 4.5.0.1 [15].

All analyses and preparation of figures were performed using Stata, version 14 (Stata Corp. TX).