Primary care management of women with breast cancer-related concerns—a dynamic cohort study using a network database

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Funding
The Julius Primary Care Network Database is funded by the University Medical Center Utrecht. The research fellowship of AJWS was partly funded by BBMRI (Biobanking and Biomolecular Research Infrastructure) and by the Mondriaan Foundation, an independent organisation which aims to link and enrich routine healthcare databases in the Netherlands for research purposes. The Mondriaan system is funded by TI Pharma, a public–private network. The funders had no role in study design or data collection, analysis or interpretation.

The aim of this study was to determine the incidence, management and diagnostic outcomes of breast cancer-related concerns presented in primary care. A dynamic cohort study was performed in the anonymised routine electronic medical records (EMRs) extracted from 49 General Practices in the Netherlands (163,471 person-years, women aged 18–75). Main Outcome Measures were: (1) incidence rates for breast cancer-related concerns in Primary Care, (2) proportions of these women with and without symptoms of the breast referred for further investigation, (3) proportions of referrals (not) according to the guideline and (4) proportions of women with breast cancer-related concerns diagnosed with breast cancer during follow-up. Breast cancer-related concerns are presented frequently in Primary Care (incidence rate 25.9 per 1,000 women annually). About half these women are referred for further investigation. There is room to improve General Practitioner management, mainly for women with an increased lifetime risk of developing breast cancer. Information concerning family history of cancer is often missing in the EMR. Since cancer is rarely diagnosed during follow-up, particularly when symptoms are absent, reduction of unnecessary concerns is plausible if identification of those without an increased risk is improved.

KEYWORDS
breast cancer, general practice, genetic counselling, primary care, referral

1 BACKGROUND

Breast cancer is by far the most frequently diagnosed cancer among women worldwide and is still the second cause of cancer death among women in more developed regions (Ferlay et al., 2014). This is the most plausible explanation why many women have concerns about breast cancer (Consedine, Magai, Krivoshekova, Ryzewicz, & Neugut 2004). Breast cancer-related concerns can be caused by physical complaints of the breast, by fear of breast cancer in general or by experiences with breast cancer, for example, in the family (Bennett, Parsons, ...
Brain, & Hood, 2010; Gibbons & Groarke, 2015). In the Netherlands, as in other countries with a gatekeeper health care system such as the UK, women with potential cancer concerns present first to their general practitioner (GP) if they decide to consult a health care worker. GP management should be focussed on identifying women with an increased risk of having or developing breast cancer, with as little delay as possible. Women without an increased risk of breast cancer should be reassured to prevent further anxiety and fear.

Research has shown that delays in cancer diagnosis can be caused in primary care (first presentation to referral) (Maclean et al., 2015; Neal, 2009). Furthermore, studies show that genetic risk assessment with respect to cancer in primary care is still inadequate (Ardern-Jones, Kenen, & Eeles, 2005; Carroll et al., 2009; McCann, MacAuley, & Barnett, 2005; Nippert et al., 2011; Vasen et al., 2010). This means there are indications that GP management for a number of women presenting with breast cancer-related concerns, is not optimal (Bell et al., 2015; Burke et al., 2009; Campbell et al., 2003; Febbraro et al., 2015). However, this problem has not recently been quantified. Also, no recent data are available on the frequency with which GPs are consulted by women with breast cancer-related concerns and neither have breast cancer outcomes among these women been related to the initial reason for encounter at the GP recently.

Therefore, we aim to determine the incidence, management and diagnostic outcomes of breast cancer-related concerns presented by women in primary care, by answering the following research questions:

1. What is the incidence of GP consultations primarily focussed on breast cancer-related concerns, for women with and without symptoms of the breast?
2. What proportion of these symptomatic and asymptomatic women are referred by their GP for further investigation (breast clinic or radiology department) and/or for cancer genetic counselling?
3. What proportion of women, from subgroups that present with fear of breast cancer or a positive family history of breast cancer, are identified by their GP as having an increased lifetime breast cancer risk?
4. What proportion of women identified by their GPs as having an increased lifetime risk of developing breast cancer (from question 3) are referred for annual screening or cancer genetic counselling in accordance to the guideline?
5. What proportion of women presenting in primary care with breast cancer-related concerns are diagnosed with breast cancer during follow-up in relation to the initial reason for the encounter?

2 METHODS

A flow chart of the methods used in this study is depicted in Figure 1. Data were obtained from the Julius General Practitioners’ Network (JGPN) Database (Dentler, Numans, ten Teije, Cornet, & de Keizer 2014; Hamoen et al., 2013; Kasteleyn et al., 2014;
Lacourt et al., 2013). This database comprises anonymised, coded data that are periodically extracted from the GPs routine electronic medical records (EMR). The data concern approximately 250,000 patients enlisted with 49 sentinel General Practice centres (120 GPs) in the region of Utrecht in 2010. Since every Dutch citizen is enlisted with a GP and the practices sharing their data are randomly spread around the city of Utrecht and surrounding villages, the involved population is considered representative of the Dutch primary care population (Hak, Rovers, Sachs, Stalman, & Verheij 2003). The available data include ICPC-coded consultations and episodes with diagnoses, Anatomical Therapeutic Chemical (ATC)-coded prescribed medication, laboratory test results and (for a large proportion of the patients) also coded referrals and coded letters from medical specialists.

General practitioner consultations in the Netherlands are registered according to the “SOAP system” (Van der Zanden, 2010). A SOAP journal consists of four data fields: Subjective: patient complaint, reason for consultation; Objective: clinical examination; Analysis (possible) diagnosis; and Plan. The A-line of a SOAP journal is coded using the International Classification of Primary Care version 1 (ICPC-1) of the 2009 coding system, published by the WHO (Bentsen, 1986). The S, O and P lines are usually registered using free text only. The Dutch College of General Practitioners published a Guideline for Adequate Registry (The Dutch College of General Practitioners 2013). According to this guideline, the GP decides how and when to code a diagnosis or symptom in the A-line. For breast cancer, this will usually be done after a letter has been received from a hospital where the cancer has been diagnosed.

General practitioners were not aware of this study at the time of registering their consultations neither did they receive specific training on coding.

### 2.1 Study population: selection of patients and extraction of data from database

Included were all female patients enlisted in participating JGPN practice centres that use the Dutch EMR system Promedico-ASP®. Relevant parts of the EMR records of all female patients between ages 18 and 75 years with one or more ICPC consultation codes that indicate breast cancer-related concerns in 2008, 2009 and/or 2010 were extracted from the database (Table 1). Age at the time of the first visit to the GP that was registered with the selected ICPC code was determined. Data that were extracted include year of birth; all dates and EMR records assigned to the selected ICPC codes; ATC prescribed medication; and referrals to departments of radiology, surgery, or clinical genetics.

The follow-up time for each patient was defined as the time period between the date of the first registered consultation with one of the selected ICPC codes and that of closure of the database for this study (31 December 2010).

For two subgroups of consultations registered with having fear of breast cancer (X26) and having a positive family history of breast cancer (A29.2), the complete, anonymised EMR data were extracted.

### 2.2 Data analysis

The data were analysed in four consecutive steps (Fig. 1) as follows.

#### 2.2.1 Step 1 (research question 1)

All women with one or more registered ICPC-coded consultations that indicate concerns-related to breast cancer in one of the study years were identified in the JGPN database using the 11 ICPC codes for either complaints of the breast, breast cancer, fear of breast cancer or a positive family history for breast cancer (Table 1). The results were grouped according to ICPC code at first consultation and to age category (18–50 or 50–75 years). Women between 50 and 75 years of age are invited to participate in the Dutch national breast cancer screening programme (National Institute for Public Health and the Environment, 2014). These women are advised to consult their GP in case of an abnormal mammogram; also the GP receives a notification. It was not possible to extract these notifications from the EMR.

Multiple consultations with the same code were counted as one; for women who had multiple consultations with different codes, the code at the first consultation was chosen as the reason for encounter. Corresponding incidence rates were calculated per 1,000 person-years.

#### 2.2.2 Step 2 (research question 1)

For women who were registered with an ICPC code X26 (fear of breast cancer) or A29.2 (family history of breast cancer), the EMR texts in 2008, 2009 and 2010 were studied to determine whether or not they also reported symptoms of the breast.
2.2.3 | Step 3 (research questions 2, 3 and 4)

General practitioner management of these women was determined in three sub-steps as follows.

Step 3.1
First, the number of women who were referred to a breast clinic, for a mammogram or ultrasound, and to a genetics department were counted by checking coded referrals in the EMR but also by manually checking all A and P lines in the SOAP journal of the selected women. Multidisciplinary breast clinics and radiology departments use referral forms, but the actual referral is written in free text. The text registered by the GP in the EMR or a referral letter was used in the analysis. Referral rates were calculated as percentages of the total population of women that consulted their GPs with concerns about breast cancer.

Step 3.2
For the subgroups of women with codes X26 (fear of breast cancer) and A29.2 (positive family history), the presence of an increased risk of developing breast cancer was determined, using the complete EMR, including free text. Increased risk was defined according to the primary care guideline “Diagnosing Breast Cancer” from the Dutch college of GPs, summarised in Table 2 (Zonderland et al., 2008).

Step 3.3
Based on the same guideline, it was determined whether women at risk should be referred for either annual screening, or genetic counselling (Table 2). These results were compared with the registered referral practice of the GP based on the EMR text and it was determined whether or not referral was done according to the guideline. If the available information in the EMR was insufficient to determine whether or not referral was indicated, this was also marked. Subsequently these numbers were converted to proportions of referrals for annual screening or genetic counselling (not) according to the guideline.

Step 4 (research question 5)
The proportions of women with a coded diagnosis of breast cancer (X76 or X76.1) during follow-up were determined for each subgroup of initially coded consultations.

All statistical analyses were performed using SPSS (version 20); EMR texts were extracted as.csv files and analysed using Microsoft Excel 2010.

3 | RESULTS

3.1 | Incidence rates

The total number of women between the age of 18 and 75 registered in the database was 54,947 in 2008, 52,885 in 2009 and 55,639 in 2010, giving a total of 163,471 person-years. As demonstrated in Figure 2 and Table 3, we found 4,240 women with one or more contacts with breast cancer-related ICPC codes within these years.

The mean age of the women at first consultation was 42.1 ± 13.7 years, and 72.4% were aged <50. Mean duration of follow-up in the data set was 1.6 ± 0.9 years. The overall incidence rate for women consulting their GP with breast cancer-related concerns was 25.9 per 1,000 women per year (4,240/163,471). This means that a Dutch GP with an average list size of 2,350 patients (Schäfer, van der Berg, & Groenewegen, 2016) and an age distribution comparable to the whole country, will be consulted by women concerned about breast cancer or having complaints concerning the breast about 22 times a year.

Of the 4,240 unique women with a breast cancer-related ICPC found, 3,619 (85.3% or 22.1 per 1,000 per year) were coded as presenting with physical symptoms and signs of the breast(s). Most of them reported pain (983 = 23.2% or 6.0 per 1,000 per year) or a lump (1,080 = 25.5% or 6.6 per 1,000 per year). Fear of breast cancer was registered with 340 women (8.0% or 2.0 per 1,000 per year), and breast cancer in the family history was registered as the first reason for encounter with 281 women (6.6% or 1.7 per 1,000 per year). Among the women registered with fear of breast cancer at first consultation, 138 of the 340 (41%) also reported having one or more symptoms. Among the 281 women initially coded with having a family history of breast cancer, 37 (13%) were symptomatic at the time of coding (Table 4).

In summary, the incidence rates are 22.1 per 1,000 per year for women presenting with physical signs and symptoms of the breast at the first consultation, and 3.8 women per 1,000 per year for women presenting with fear of breast cancer or a positive family history. The overall incidence rate for women consulting their GP with breast cancer-related concerns is 25.9 per 1,000 per year.

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### Table 2: Referral policies for screening and genetic counselling, according to Dutch guideline "Diagnosing breast cancer"

<table>
<thead>
<tr>
<th>Screening</th>
<th>Moderately increased lifetime risk (20%–30%): mammography requested by GP from age 40 to 50 possibly supplemented by clinical breast examination</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 1 first and 1 second degree relative diagnosed with breast cancer &lt;50 years old</td>
<td></td>
</tr>
<tr>
<td>• 2 first degree relatives with breast cancer regardless of age</td>
<td></td>
</tr>
<tr>
<td>• ≥3 first or second degree relatives with breast cancer, regardless of age</td>
<td></td>
</tr>
<tr>
<td>• 1 first degree relative with bilateral or multifocal breast cancer, with first tumour diagnosed at age &lt;50</td>
<td></td>
</tr>
<tr>
<td>• 1 first or second degree relative with ovarian cancer regardless of age and 1 first or second degree relative with breast cancer</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Genetic counselling</th>
<th>Strongly increased lifetime risk of developing breast cancer (&gt;30%), referral to a genetics department</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 1 first degree relative diagnosed with breast cancer &lt;35 years old</td>
<td></td>
</tr>
<tr>
<td>• ≥2 first degree relatives diagnosed with breast cancer regardless of age</td>
<td></td>
</tr>
<tr>
<td>• ≥3 first or second degree relatives with breast cancer of which at least one tumour diagnosed before age of 50</td>
<td></td>
</tr>
</tbody>
</table>
3.2 Management

As indicated in Tables 4 and 5, the overall referral rate for further investigation (breast clinic or radiology department) was 53.2% (N = 2,257 out of 4,240 consulting their GP). A quarter of these women were referred to a breast clinic, which is 11.7% of total referrals (N = 495, 19.7% aged 50–75 years, 8.6% aged 18–50 years); 1,762 women (41.6%) were referred for mammography and/or ultrasound without further diagnostic facilities, equally spread over the age categories. Only 47 women (1.1%) were referred to a genetics department, of whom the majority were in the age group 18–50 (Table 5).

Of the women registered with fear of breast cancer at first consultation but without physical symptoms according to the EMR text, more than half (52%) were referred for further investigation. For the group of women initially coded as having a family history of breast cancer, 109 (54%) were referred for further investigation, despite being asymptomatic (Table 4).

### 3.2.1 Identification and management of women with increased lifetime risk

Increased lifetime risk (subgroups X26 and A29.2 at first consultation) was established and registered by GPs in 46 and 128 women, in subgroups X26 and A29.2 respectively. For 324 of the 621 EMR files studied (52%), the information regarding family history was insufficient to determine whether women have an increased lifetime risk and should be referred for annual screening or genetic counselling (Table 6). This includes 89 (32 + 57) EMR files from patients that were actually referred.

### 3.2.2 Moderately increased lifetime risk (20%–30%)

A total of 34 (10%) women out of 340 with an ICPC code X26 (fear of breast cancer) at first consultation and a total of 105 (37%)...
women out of 281 with an ICPC A29.2 (positive family history of breast cancer) at first consultation were referred for annual screening and, thus, had been identified by the GP as having a moderately increased lifetime risk (Table 6). Of these referrals, 18%–25% were done according to the guideline, 13%–15% not according to the guideline, and for 62%–68% of referrals, the information in the EMR was insufficient to determine whether or not the referrals were done according to the guideline (Table 6). Three women who should have been referred for annual screening were missed.

### 3.2.3 Strongly increased lifetime risk (>30%)

For genetic counselling, 12 (4%) women who were coded as presenting with fear of breast cancer and 23 (8%) coded with a family history of breast cancer were referred and, thus, had been identified by the GP as having a strongly increased lifetime risk. Referral was according to guideline for 13%–33%, and not according to the guideline for 26%–42%. For 25%–61% of referrals, it was impossible to determine whether or not they were done according to the guideline due to insufficient data in the EMR text (Table 6). Seven women who should have been referred for genetic counselling were missed.

### 3.3 Outcomes

A total of 450 women (10.6% of N = 4,240 consulting their GP with breast cancer-related concerns) were registered as having breast cancer (ICPC code X76 and/or X76.1 at final consultation in our population during follow-up time). Of these women, 109 (2.6% of N = 4,240) developed breast cancer after first consulting their GP with complaints of the breast or concerns about developing breast cancer (Table 3, Fig. 2). Of the

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**TABLE 4** Presenting number and proportion of (a)symptomatic women referred for further investigation with A29 or X26 codes at first consultation

<table>
<thead>
<tr>
<th></th>
<th>A29.2 at first consultation</th>
<th>X26 at first consultation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Family history of BC</td>
<td>Fear of BC</td>
</tr>
<tr>
<td>Consulting GP, n (%)</td>
<td>Referred m (%)</td>
<td>Consulting GP, n (%)</td>
</tr>
<tr>
<td>50–75 years</td>
<td>8</td>
<td>28</td>
</tr>
<tr>
<td>18–50 years</td>
<td>29</td>
<td>110</td>
</tr>
<tr>
<td>Total</td>
<td>37 (13)</td>
<td>138 (41)</td>
</tr>
<tr>
<td>EMR info insufficient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50–75 years</td>
<td>8</td>
<td>28</td>
</tr>
<tr>
<td>18–50 years</td>
<td>33</td>
<td>67</td>
</tr>
<tr>
<td>Total</td>
<td>41 (15)</td>
<td>95 (28)</td>
</tr>
<tr>
<td>Total</td>
<td>203 (72)</td>
<td>109 (54)</td>
</tr>
<tr>
<td>EMR info insufficient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>50–75 years</td>
<td>8</td>
<td>28</td>
</tr>
<tr>
<td>18–50 years</td>
<td>33</td>
<td>67</td>
</tr>
<tr>
<td>Total</td>
<td>41 (15)</td>
<td>95 (28)</td>
</tr>
<tr>
<td>Total</td>
<td>203 (72)</td>
<td>109 (54)</td>
</tr>
</tbody>
</table>

**TABLE 5** Proportion of women referred to a multidisciplinary breast clinic, radiology department and genetics department

<table>
<thead>
<tr>
<th></th>
<th>Breast Clinic, n (%)</th>
<th>Radiology (Mammogram or Ultrasound), n (%)</th>
<th>Genetics Department, n (%)</th>
<th>Total number of women per age group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referrals</td>
<td>231 (19.7)</td>
<td>430 (36.8)</td>
<td>6 (0.5)</td>
<td>1,170</td>
</tr>
<tr>
<td>50–75 years</td>
<td>231 (19.7)</td>
<td>430 (36.8)</td>
<td>6 (0.5)</td>
<td>1,170</td>
</tr>
<tr>
<td>18–50 years</td>
<td>264 (8.6)</td>
<td>1,332 (43.4)</td>
<td>41 (1.3)</td>
<td>3,070</td>
</tr>
<tr>
<td>Total</td>
<td>495 (11.7)</td>
<td>1,762 (41.6)</td>
<td>47 (1.1)</td>
<td>4,240</td>
</tr>
</tbody>
</table>
remaining 341 women (8.0% of N = 4,240) that the GPs registered breast cancer as the reason for encounter, 278 (6.5% of N = 4,240) of them were within the age category 50–75 years and, thus, had been invited to participate in the national breast cancer screening programme. Leaving out the patients in this age category gives a percentage of 4% ((450–341 + 278)/4,240) of cases respectively.

Women consulting their GP with a lump in the breast, coded as benign neoplasm of the breast (X79) or breast lump (X19), were registered with breast cancer during follow-up in 11.5% (n = 7 of 61) and 5.9% (n = 64 of 1,080) of cases respectively. Of the women presenting with fear of breast cancer or with a family history of breast cancer, only 0.9% (N = 3 of 340) and 2.1% (N = 6 of 281) were diagnosed with breast cancer during follow-up.

4 | DISCUSSION

4.1 | Summary

This dynamic cohort study in the Julius GP’s Network database was performed to determine incidence rates, management, and diagnostic outcomes for women in primary care with concerns related to breast cancer. The overall incidence rate for breast cancer-related concerns is 25.9 per 1,000 women per year, the majority of them presenting with physical signs and symptoms of the breast (85.3% or 22.1 per 1,000 per year). The referral rate for further investigation is just over 50%, for symptomatic as well as for asymptomatic women. About a quarter of referrals for annual screening or genetic counselling were determined as performed according to the guideline, about a quarter were not, and the information in the EMR was ambiguous making it impossible to decide whether or not a patient had an increased risk.

Major strengths of this study are the size of the cohort and the quality of the data. The JGPN database is comprised of well-documented information of enlisted patients. Characteristics of these patients did not differ from the overall Dutch population, and the main characteristics of the GPs were comparable with total Dutch GPs with respect to age, gender, part-time and full-time workers, and practice in urban and rural areas (Hak et al. 2003). To the best of the present authors’ knowledge, this is the first report on the actual referral practice of GPs for this patient group and the first report where GP referral behaviour is compared with the national guidelines.

The use of routine care data has limitations that should be kept in mind when interpreting results. These limitations relate to the patient, the GP, coding and the EMR. The patient decides whether and when she consults her GP with a breast cancer-related concern. Others might have the same concerns without visiting the doctor. Second, GPs decide what they consider to be the most important symptom presented by their patients during consultation to be registered in the EMR. This might result in one GP registering a symptom as pain in the breast, while another registers worry about breast cancer. A third uncertainty in the present data is the ICPC-1 coding system. Misclassification, lack

### TABLE 6 Proportion of referrals for annual screening and genetic counselling in accordance with guideline

<table>
<thead>
<tr>
<th>X26 Fear of Breast Cancer</th>
<th>A29.2 Family history of Breast Cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referral in accordance with guideline</td>
<td>Referrals for annual screening, n (%)</td>
</tr>
<tr>
<td>Including BRCA positive family</td>
<td>6 (18)</td>
</tr>
<tr>
<td>Referral not according to guideline</td>
<td>5 (15)</td>
</tr>
<tr>
<td>Information not assessable</td>
<td>23 (68)</td>
</tr>
<tr>
<td>Total referrals</td>
<td>34</td>
</tr>
</tbody>
</table>

*Based on the EMR data, the patient was considered at risk and was referred as instructed according to the Guideline “Diagnosing Breast Cancer” from the Dutch college of general practitioners (NHG).

*Family with proven mutation in BRCA1 or BRCA2 gene.

*Based on the EMR data, the patient had an increased risk but was not referred according to the guideline or did not have an increased risk but had a referral.

*Information in the EMR was ambiguous making it impossible to decide whether or not a patient had an increased risk.
of available codes and differences in classification between years and GPs cannot be ruled out. This may have resulted in either an over-estimation or underestimation of the true incidence rates. However, we know that in larger populations and among larger groups of GPs sharing their data, differences in presentation, prioritisation and lack of detail become less significant (van Bommel, Numans, de Wit, & Stalman 2001). Furthermore, we know that variation in registration rules in different EMR systems may be a cause of heterogeneity in extracted data. To minimise the effect of heterogeneity in this study, we restricted data collection to only one type of EMR. Also, patient preferences discussed during the consultation for or against referral are not captured using ICPC codes. Finally, restrictions in registration possibilities in existing EMR systems should be taken into account (e.g. the limited possibilities in Dutch EMR systems to register family history information, leading to possible registration of this information as plain text). In this study, this information (in plain text) appeared to be insufficient to determine increased lifetime risk for a large proportion of cases.

However, the fact that information concerning family history is missing in a large part of EMR files could also mean that the information is available but not registered by the GP, that the GP lacks knowledge in this area or the guidelines are not readily available or unclear, or that the GP has other reasons to deviate from the guidelines. Previous studies have shown that GPs currently lack knowledge and confidence in this area (Watson et al., 2001) and that there is an urgent need for a genetics curriculum for postgraduate and continuing general practice education in this area (Houwink et al., 2012).

Another limitation might be that our study population was comprised also of women who participate in the national breast cancer screening programme (age category 50–75 years). Within the screening programme, abnormal mammography results are reported to GPs together with advice to refer to a multidisciplinary breast clinic. Inclusion of these women has probably resulted in an overestimation of the "true" rate of women that would consult their GP with complaints of the breast or concerns about developing breast cancer. However, an average Dutch general practice is faced with only three positive screening referrals per year, only one of whom will be diagnosed with breast cancer (Verbeek, van Dijck, Kiemeneij, & Broeders, 2011). Note that these women may also be less inclined to visit their GP with concerns about breast cancer in between screening mammograms.

Finally, in this study, the follow-up time was restricted to a maximum of 3 years after the first consultation. This is likely to be too short to determine the total number of women developing breast cancer, leading to an underestimation of this outcome.

4.3 Comparison with existing literature

The incidence rates for breast cancer-related concerns found in this study are considerably higher than those in older data presented in two UK studies (data from 1995 to 1996) but slightly lower than in another Dutch study (data from 1985 to 2003). However, we included patients that the GP registered as having breast cancer at first consultation (X76 and X76.01), in contrast to the other studies described here.

The Bridge Study group recorded presentation rates of breast symptoms in 34 general practices in South Wales in 1995–1996. These presentation rates ranged from 1.9 to 14.8 patients per GP per year (median = 6.5): 46.4% with breast lump, 28.2% with breast pain, 16.2% with lumpiness, and 5.5% with nipple discharge (The BRIDGE Study Group 1999). This translates to 2.2–17.0 per 1,000 women per year. In a study by Newton, Hannay, and Laver (1999), 257 GPs from Sheffield (UK) participated and recorded a mean number of 2.05 consultations over a 4-week period in 1995. If annual figures are extrapolated from these data, they suggest that each GP sees 15.8 women with new breast problems per year, or 18 per 1,000 women per year. These numbers include all "breast problems," including women that present with a positive family history. This study does not explicitly present women with fear of breast cancer as a separate group.

The incidence rates found in this study are slightly lower than the findings of Eberl, Phillips, Lamberts, Okkes, and Mahoney (2008) who studied routine family practice data from Dutch GP practices between 1985 and 2003 on breast symptoms. Breast symptoms were reported in 29.7 consultations per 1,000 active female patients per year, with breast pain (13 per 1,000 per year) and breast mass (9 per 1,000 per year) being the most common breast-related complaints. Note that this excludes 3.6 per 1,000 per year who consult their GP for fear of breast cancer (compared with 2.0 per 1,000 in this study). This means that Eberl found an overall incidence rate of 33.3 per 1,000 women per year, compared to 25.9 per 1,000 per year in this study. Incidence rates found in her study were 2.5 per 1,000 women per year for nipple complaints and 4.3 per 1,000 per year with other breast complaints. A possible explanation for the differences in incidence rates found could be that these are a reflection of the incidence trends of breast cancer. Toriola and Colditz (2013) summarises these for the US as having four distinct patterns: an increase over 45 years (1943–1979), a more rapid increase over 20 years (1980–1999)—punctuated by a gradual (2000–2002), then sharp decline (2002–2003), and a post 2003 period of stable incidence rates. Another explanation may be that there is a growing awareness in recent years among women concerning breast cancer, which prompts more GP visits. Furthermore, there may be slight differences in ICPC codes used in different studies, resulting in differing inclusion conditions.

Concerning referral patterns, limited literature was available. The Bridge Study group, mentioned above, reported that, in 1995–1996, 55% of all patients were referred (The BRIDGE Study Group 1999). This is consistent with the results found in the present study, with an overall referral rate 54.3%. Newton et al. (1999) found that, in 1995, at an initial consultation for breast symptoms, GPs referred approximately one-third of women to secondary care.

Eberl et al. (2008) who studied routine family practice data from Dutch GP practices between 1985 and 2003 on breast symptoms (mean registration time 5.6 years), found that of the women complaining of
breast symptoms, 81 (3.2%) had breast cancer diagnosed, which is much lower than the 10% found in this study. Note that we included patients who were coded as having breast cancer at first consultation, while Eberl probably did not (no information available in the published material).

Leaving out these patients means that only 2.6% developed breast cancer (450–341)/4,240; however, these numbers include women with a positive screening advise from the national breast cancer screening programme. Leaving out the patients in this age category (278 women aged 50–75 years) gives a percentage of 4% ((450–341 + 278)/4,240) as developing breast cancer, which closely resembles the Eberl data.

A recent UK CPRD study by Walker, Hyde, and Hamilton (2014) revealed that the PPV of breast cancer (diagnosed between 2000 and 2009) with a breast lump presented at the GP was 4.8% in women aged 40–49 years, rising to 48% in women aged >70 years. PPVs were lower in women who also reported breast pain. Hippisley-Cox and Coupland (2013) found, also using UK Primary Care data (2000–2012) that a breast lump was associated with a 51-fold increased risk of breast cancer. These studies confirm our finding that GPs should be aware of women presenting with a lump in the breast because they are most frequently diagnosed with breast cancer (5.9%, Fig. 2) during follow-up.

5 | CONCLUSIONS

This study demonstrates breast cancer-related concerns are presented in Primary Care frequently. The referral rate for further investigation is over 50%. There is room to improve GP Management, mainly for women with an increased lifetime risk of developing breast cancer. Information regarding the family history is often missing in the EMR. Furthermore, since only 2.6% of women with breast cancer-related concerns were diagnosed with breast cancer during follow-up time, substantial reduction of unnecessary concerns is plausible by improving identification of those without an increased risk of breast cancer.

5.1 | Unanswered questions and future research

Future research aimed at the underlying mechanism of low adherence to guidelines for referral by GPs in case of an increased lifetime risk, and poor registration of the family history in the EMR, could assist in the development of effective interventions to improve referral practice of patients at increased genetic risk.

Strategies to be evaluated include: (1) increasing awareness of the importance of registering an increased lifetime risk; (2) optimising the availability of [online] up-to-date and easy to use referral guidelines, for example by integrating them into the EMR; (3) developing training for GPs in taking, assessing and registering a family history and (4) enabling the registry of a family history within the context of the EMR.

ACKNOWLEDGEMENTS

We thank Julia Velikopolskaia for her assistance in extracting the necessary data from the Julius Primary Care Network Database, the general practitioners from the region of Utrecht and their patients for sharing their anonymous electronic medical records in the Julius General Practitioners’ Network.

DISCLOSURE

The authors declare that they have no competing interests.

AUTHORS’ CONTRIBUTIONS

AJWS and MEN conceptualised the study. Data extraction was done by AS. RJMA, AJWS and MEN analysed, validated and interpreted the data. MGEMA, JCW and CWH contributed to revisions with important feedback. All authors drafted the manuscript and read and approved the final version. Guarantor: MEN. All authors had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. MEN as guarantor affirms that the manuscript is an honest, accurate and transparent account of the study being reported; no important aspects of the study have been omitted and any discrepancies from the study as planned have been explained.

ETHICAL APPROVAL

The Research Ethics Committee of the University Medical Center Utrecht reviewed the study protocol and decided that approval of the Committee is not necessary since this study uses only anonymised patient data from the network database.

REFERENCES


