EUROPEAN JOURNAL OF CANCER 45 (2009) 625–633

available at www.sciencedirect.com

journal homepage: www.ejconline.com

# Health care utilisation and characteristics of long-term breast cancer survivors: Nationwide survey in Denmark

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## ARTICLE INFO

*Article history:*
Received 30 July 2008
Received in revised form
15 September 2008
Accepted 30 September 2008
Available online 25 November 2008

*Keywords:*
Breast cancer
Survivors
Health care
Utilisation
Employment
Antineoplastic protocol
Epidemiology

## ABSTRACT

*Aim:* To investigate long-term female breast cancer survivors' (BCS') health care utilisation, health, and employment.

*Methods:* An age-stratified random sample of 2000 female breast cancer survivors (BCS) 5–15 years after primary surgery without recurrence was drawn from the *Danish Breast Cancer Cooperative Group* register. A self-administered questionnaire assessed sociodemography, health care utilisation, employment, and health-related quality of life (HRQOL). Associations with breast cancer treatment were investigated.

*Results:* Response rate was 79%. Significantly more BCS than the general women population reported health care utilisation (61% versus. 56%; age-standardised risk ratio (SRR): 1.10; 95% confidence interval (CI) 1.05–1.15), but significantly fewer BCS were disability pensioners (15% versus 19%; SRR: 0.77; 95% CI 0.64–0.93). 'Daily activities limited due to sequelae' were reported by 20%, and 'stopped working/changed job due to sequelae' by 11% of BCS.

In multiple logistic regression analysis, radiotherapy (odds ratio (OR) 2.54; 95% CI 1.34–4.80) and endocrine therapy (OR 2.48; 95% CI 1.13–5.45, postmenopausal women only) were significantly related to 'stopped working/changed job due to sequelae'. Time since surgery 5–10 years (versus >10 years) was significantly associated with 'daily activities limited due to sequelae' (OR 2.02; CI 1.43–2.84), which, in turn, was significantly related to poorer HRQOL (all $p < 0.05$). Chemotherapy, receptor status, and protocol allocation did not show significant associations in any analyses.

*Conclusion:* Significantly more BCS reported health care utilisation. Radiotherapy, shorter time since surgery, and endocrine therapy predicted daily activity and work limitations due to sequelae.

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doi:10.1016/j.ejca.2008.09.027

## 1. Introduction

When anticancer treatment is successfully finalised, it is life that matters. However, many cancer survivors are left with mental and physical sequelae,[1,2] functional limitations[3,4] and an increased need of health care[5,6] which often is not met.[7] As acute cancer-related symptoms such as pain may change into chronic conditions, and as some sequelae may occur late[8], population-based data on long-term sequelae, health, and health care utilisation are of increasing importance to better meet the needs of this population.

Breast cancer is the commonest incident form of malignancy among women in Europe with a 5-year-survival of about 80% in Denmark.[9] With one million new cases in the world each year, breast cancer represents a major public health issue,[10] and the number of breast cancer survivors (BCS) increases due to improved screening and treatment programmes. However, long-term data on BCS' health care utilisation beyond 5-years are relatively sparse.

We found previously that long-term BCS frequently reported sequelae such as chronic pain (42%), paraesthesia (47%), swelling of arm/shoulder (25%), phantom pain (19%), and allodynia (15%).[1] Interestingly, at the same time this population-based sample of BCS reported a similar to or even slightly better health-related quality of life (HRQOL) compared to the general population data.[11]

In this study, we aimed at investigating daily activity, employment characteristics, and health care utilisation by BCS using the same nationally representative approach. Some data on BCS could be compared to data from the general population derived from another Danish survey,[12] enabling us to identify findings characteristic for BCS.

## 2. Methods

### 2.1. Study design

Patients diagnosed with breast cancer from 1989 to 1999 were selected from the database of the *Danish Breast Cancer Cooperative Group* (DBCG) among those who had survived for 5–15 years after primary breast cancer surgery without recurrence or a second cancer. In total, 11,243 women of the DBCG database met the inclusion criteria. The sample design was an age-stratified sample, randomly selecting 500 BCS into each stratum (18–49; 50–59; 60–69; and $\geqslant$70 years). Subsequent analysis led to exclusion of women aged <40 years ($n = 23$), because this substratum was considered too small. Respondents with self-reported cancer recurrence or potential recurrence were excluded.

### 2.2. Contact procedure

The women were contacted via the secretariat of the DBCG, and the Multidisciplinary Pain Centre sent a questionnaire to those who agreed to participate by their return of the written informed consent during the period September 2004–February 2005 (Fig. 1). The local ethics committee and the Danish Data Protection Agency approved the study.

### 2.3. DBCG database

The BCS study population was based on the treatment protocols applied in Denmark from 1989 to 1999. All patients were treated according to the DBCG policy at the time of breast cancer diagnosis[13] as described previously.[11]

The following data were obtained from the DBCG database: type of surgery; time since operation; receptor status; radiotherapy; treatment protocol (low risk, high risk); and systemic therapy according to protocol. This database is considered representative of long-term BCS in Denmark.[14] The sentinel node technique was first introduced as a routine procedure in Denmark during 2001 and could therefore not be considered in this study.

### 2.4. Assessments

The questionnaire investigated sociodemographic characteristics, school and occupational education[15], health care util-

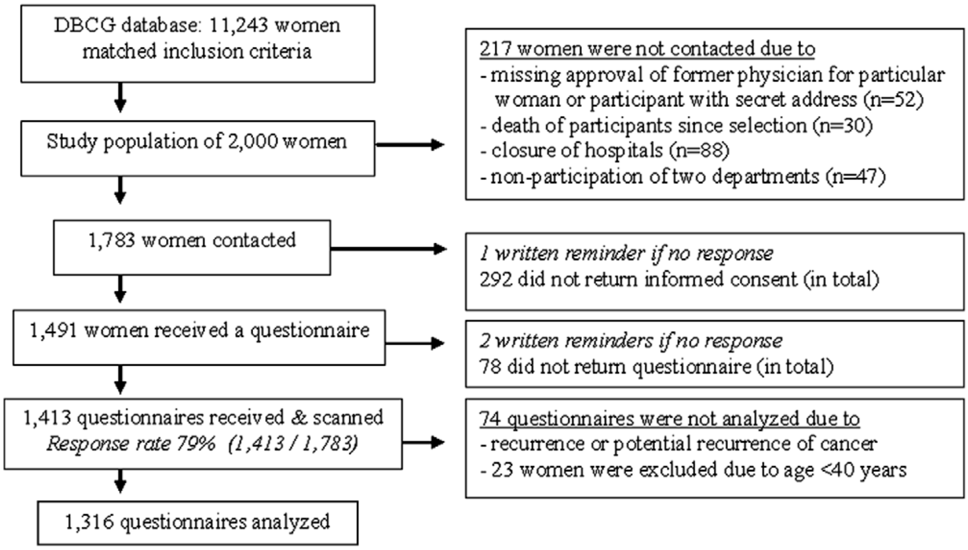

**Fig. 1 – Contact procedure and respondents.**

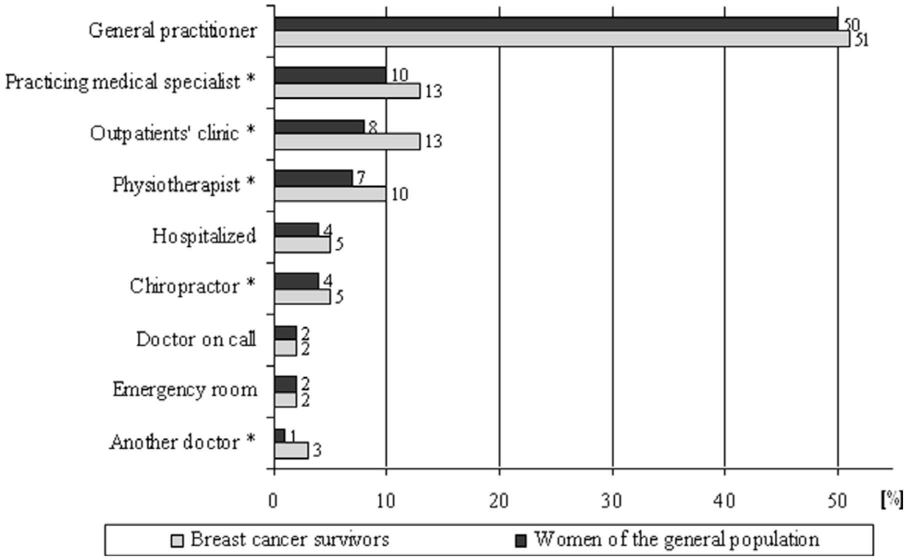

**Fig. 2 – Health care system contacts. Age-standardized percentage of those individuals who have had contact with different health care professionals within the past three months among BCS and women of the general population. * indicates statistically significant difference ($p < 0.05$).**

isation, physical activity, Body-mass-index (BMI), and employment (Appendix; Fig. 2). Further, questions on sequelae such as chronic pain and on health-related quality of life (HRQOL) by the use of the Short Form (SF-36) questionnaire were included as published previously.[1,11]

### 2.5. *Statistical analyses*

We were allowed to use data from a previous publication on the Danish national health interview survey 2000[12] to compare data from BCS with data from women in the general population concerning the following issues: health care system contact, physical activity, and employment status (women aged 40–66 years only). This comparison was performed by estimating an age-standardised risk ratio (SRR) with a 95% confidence interval.[16]

Those variables showing differences between BCS and the general female population concerning health care contacts and employment status as well as two variables investigated in BCS only ('daily activities limited due to sequelae'; 'stopped working/changed job due to sequelae') were additionally investigated by multiple logistic regression analyses with sociodemographic, breast cancer, and treatment variables as possible predictors. Further, responses concerning sick leave and

**Table 1 – Non-responders. BCS: Non-responders according to age, type of operation, time since operation, radiation, and protocol assignment among long-term breast cancer survivors. Results of a multiple logistic regression analysis.**

| | BCS sample | Non-responders | | | |
|---|---|---|---|---|---|
| | [n] | [%] | [n] | OR | 95% CI |
| Overall | 1783 | 21 | 370 | | |
| Age ($P < 0.001$) | | | | | |
| –49 years | 455 | 19 | 85 | 1.35 | (0.94–1.92) |
| 50–59 years | 454 | 15 | 66 | 1 | |
| 60–60 years | 445 | 19 | 85 | 1.37 | (0.96–1.97) |
| 70+ years | 429 | 31 | 134 | 2.61 | (1.85–3.68) |
| Operation type ($P = 0.0501$) | | | | | |
| Mastectomy | 1,238 | 23 | 284 | 1.40 | (1.00–1.96) |
| Lumpectomy | 545 | 16 | 86 | 1 | |
| Time since operation ($P = 0.3375$) | | | | | |
| >10 years | 656 | 23 | 148 | 1.13 | (0.88–1.43) |
| 5–10 years | 1127 | 20 | 222 | 1 | |
| Radiotherapy ($P = 0.7268$) | | | | | |
| Yes | 658 | 17 | 112 | 0.94 | (0.68–1.31) |
| No | 1125 | 23 | 258 | 1 | |
| Protocol assignment ($P = 0.2056$) | | | | | |
| Low risk | 834 | 21 | 172 | 1 | |
| High risk | 949 | 21 | 198 | 1.18 | (0.91–1.53) |

'feel well enough to do what I want to do' were analysed by calculating age-adjusted percentages because these variables were considered highly relevant for the current health status. To compare the HRQOL according to the report of 'daily activities limited due to sequelae', age-adjusted SF-36 mean scores were calculated using a direct standardisation method.

In all analyses, the weights for the standardisation variable were proportional to the age distribution among all BCS registered in the DBCG database in 2004. Because of the complex survey design we used SUDAAN 9.0 software in all analyses to obtain appropriate standard errors.[17]

## 3. Results

### 3.1. *Respondents and non-respondents*

Selection of BCS and participation are shown in Fig. 1. Table 1 shows characteristics of responders and non-responders among BCS. High age of participants (⩾70 years) was significantly associated with non-response.

Concerning the data of the general female population sample that we were allowed to access, 7256 women (⩾40 years) were randomly selected, of whom 5208 had completed the interview (72%). The final general population sample included 4865 women, because 343 were excluded due to report of current or former cancer. The demographic characteristics of the study population compared to the general population are shown in Table 2.

### 3.2. *Health care contacts and treatment*

Overall, significantly more BCS (61%) than women of the general population (56%) had been in contact with the health care system (SRR: 1.10; 95% CI: 1.05–1.15). Fig. 2 shows that, compared to women of the general population, significantly more BCS had been in contact with a practicing medical specialist, outpatients' clinic, physiotherapist, chiropractor, and with 'another doctor' within the past three months.

In BCS only (Table 3), individuals aged ⩾70 years (compared to persons aged 40–49 years) and singles (separated, divorced or widowed; compared to married persons) were significantly more likely to have had physician contact within the past three months.

Chiropractor contact was significantly less often reported when the BCS had received lumpectomy, but more often when they had received radiotherapy. Chemotherapy, receptor status, and protocol allocation did not show significant associations in any analyses (data not shown).

### 3.3. *Self-reported health*

Compared to the Danish female general population, a significantly higher proportion of the BCS reported to 'feel well enough to do what I want to do' (Table 2). This difference was particularly pronounced in BCS above 70 years (BCS 69% versus 52%; Fig. 3).

Among BCS, those with ⩽12 years' education, being single (separated, divorced and widowed), and with a BMI ⩾30 reported significantly less often not to 'feel well enough to do what I want to do' (Table 3). Fig. 4 indicates that those BCS who reported 'daily activities limited due to sequelae' related to breast cancer had significantly worse HRQOL on all eight dimensions of the SF-36 (all $p < 0.05$).

Concerning the question about what they did to stay healthy/improve their health, most BCS answered to stay in contact with their family, friends and acquaintances (79%), to eat healthy (64%), not to smoke (60%), to ensure sufficient sleep (55%) and to do sports/be physically active (46%). Nota-

**Table 2 – Demographics, physical activity, health-related quality of life, and employment. BCS and women of the general population: Body-mass-index, education (ISCED), marital status, physical activity, and employment. Age-standardised prevalence numbers and age-standardised risk ratios (SRRs) with 95% confidence intervals.**

| | BCS | | Women of the general population | | | |
|---|---|---|---|---|---|---|
| | % | *n* | % | *n* | SRR | 95% CI |
| Body-mass-index | | | | | | |
| 25 or more | 41 | 1283 | 43 | 4707 | 0.94 | (0.88–1.01) |
| 30 or more | 12 | 1283 | 11 | 4707 | 1.02 | (0.87–1.20) |
| Combined school and vocational education (ISCED) | | | | | | |
| 13+ years | 46 | 1255 | 31 | 4835 | 1.47 | (1.38–1.56) |
| Marital status | | | | | | |
| Married | 58 | 1293 | 56 | 4835 | 1.03 | (0.98–1.08) |
| Single (separated, divorced, widowed) | 11 | 1293 | 8 | 4835 | 1.35 | (1.16–1.58) |
| Physical activity | | | | | | |
| Mainly sedentary leisure activities | 13 | 1212 | 25 | 4813 | 0.54 | (0.46–0.63) |
| Mainly sedentary work[a] | 58 | 586 | 35 | 2359 | 1.65 | (1.45–1.87) |
| Health-related quality of life | | | | | | |
| 'Feel well enough to do what I want to do' | 77 | 1296 | 68 | 4848 | 1.12 | (1.09–1.16) |
| Employment | | | | | | |
| Disability pensioner[b] | 15 | 905 | 19 | 3546 | 0.77 | (0.64–0.93) |
| Engaged in employment[b] | 49 | 907 | 48 | 3546 | 1.02 | (0.95–1.10) |
| Sick leave[a] | 12 | 574 | 9 | 2360 | 1.28 | (0.88–1.85) |

a Analysis only carried out among 40–66 years olds engaged in employment.
b Analysis only carried out among 40–66 years olds.

**Table 3 – This table presents age-standardised prevalence numbers of those variables considered relevant for identification of potential predictors and tested significant in multiple regression analyses according to selected background variables: contact to physician within past three months, contact to chiropractor within past three months, 'feel well enough to do what I want to do', 'daily activities limited due to sequelae', disability pensioner, 'stopped working/changed job due to sequelae'.**

| | Contact to physician within past three months | | | | | Contact to chiropractor within past three months | | | | | Feel well enough to do what I want to do | | | | | Daily activities limited due to sequelae | | | | | Disability pensioner | | | | | Stopped working/changed job due to sequelae | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | % | N | OR | 95% CI | p | % | N | OR | 95% CI | p | % | N | OR | 95% CI | p | % | N | OR | 95% CI | p | % | N | OR | 95% CI | p | % | N | OR | 95% CI | p |
| **Total** | 61 | 1316 | | | | 5 | 1316 | | | | 76 | 1296 | | | | 20 | 1279 | | | | 12 | 859 | | | | 11 | 1125 | | | |
| **Age** | | | | | **0.0001** | | | | | 0.4202 | | | | | 0.2834 | | | | | **0.0010** | | | | | 0.0630 | | | | | 0.4931 |
| 40-49 y. | 49 | 326 | 1 | | | 5 | 326 | 1 | | | 82 | 325 | 1 | | | 29 | 323 | 1 | | | 7 | | 1 | | | 11 | 312 | 1 | | |
| 50-59 y. | 51 | 368 | 1.06 | (0.80-1.40) | | 6 | 368 | 0.99 | (0.55-1.79) | | 79 | 364 | 0.94 | (0.66-1.33) | | 27 | 363 | 1.12 | (0.82-1.52) | | 13 | 325 | 1.81 | **(1.10-2.98)** | | 13 | 354 | 1.03 | (0.66-1.60) | |
| 60-69 y. | 58 | 340 | 1.32 | (0.97-1.80) | | 7 | 340 | 1.15 | (0.57-2.34) | | 81 | 336 | 1.16 | (0.77-1.74) | | 18 | 328 | 0.57 | **(0.39-0.84)** | | 15 | 364 | 1.55 | (0.76-3.17) | | 11 | 283 | 0.91 | (0.52-1.59) | |
| 70+ y. | 75 | 282 | 2.43 | **(1.64-3.60)** | | 3 | 282 | 0.53 | (0.20-1.39) | | 69 | 271 | 0.76 | (0.50-1.17) | | 16 | 265 | 0.52 | **(0.32-0.85)** | | * | | | | | 9 | 176 | 0.58 | (0.27-1.22) | |
| **Education (ISCED)** | | | | | 0.1662 | | | | | 0.6355 | | | | | **0.0010** | | | | | 0.9689 | | | | | **0.0001** | | | | | 0.1372 |
| -10 y. | 61 | 278 | 1.08 | (0.78-1.49) | | 6 | 278 | 1.40 | (0.70-2.80) | | 70 | 267 | 0.54 | **(0.37-0.79)** | | 21 | 264 | 0.96 | (0.65-1.42) | | 23 | 136 | 3.86 | **(2.12-7.04)** | | 13 | 211 | 1.71 | (1.01-2.89) | |
| 11-12 y. | 66 | 206 | 1.38 | (0.99-1.92) | | 4 | 206 | 1.18 | (0.57-2.46) | | 73 | 203 | 0.55 | **(0.38-0.82)** | | 20 | 197 | 0.96 | (0.64-1.44) | | 13 | 128 | 1.82 | (0.92-3.62) | | 8 | 175 | 1.23 | (0.68-2.23) | |
| 13+ y. | 58 | 661 | 1 | | | 4 | 661 | 1 | | | 82 | 656 | 1 | | | 21 | 649 | 1 | | | 7 | 510 | 1 | | | 9 | 599 | 1 | | |
| **Cohabitation status** | | | | | **0.0139** | | | | | 0.7017 | | | | | **0.0145** | | | | | 0.1513 | | | | | **0.0051** | | | | | 0.0645 |
| Married/cohabiting | 57 | 875 | 1 | | | 5 | 875 | 1 | | | 79 | 863 | 1 | | | 20 | 852 | 1 | | | 10 | 656 | 1 | | | 10 | 790 | 1 | | |
| Single (separated, divorced, widowed) | 67 | 357 | 1.53 | **(1.13-2.08)** | | 6 | 357 | 1.07 | (0.54-2.12) | | 71 | 350 | 0.60 | **(0.42-0.86)** | | 23 | 344 | 1.30 | (0.90-1.88) | | 19 | 150 | 2.13 | **(1.18-3.84)** | | 14 | 263 | 1.72 | (1.03-2.87) | |
| Single (unmarried) | 67 | 61 | 1.50 | (0.82-2.74) | | 1 | 61 | 0.46 | (0.07-3.10) | | 80 | 61 | 0.68 | (0.35-1.34) | | 15 | 61 | 0.67 | (0.33-1.37) | | 23 | 47 | 3.10 | **(1.29-7.45)** | | 17 | 57 | 1.94 | (0.82-4.55) | |
| **BMI** | | | | | 0.6161 | | | | | 0.9078 | | | | | **0.0425** | | | | | 0.2047 | | | | | 0.0605 | | | | | 0.7401 |
| less than 25 | 60 | 766 | 1 | | | 5 | 766 | 1 | | | 79 | 753 | 1 | | | 19 | 745 | 1 | | | 11 | 503 | 1 | | | 10 | 658 | 1 | | |
| 25-30 | 62 | 374 | 1.13 | (0.84-1.51) | | 5 | 374 | 0.92 | (0.49-1.73) | | 75 | 371 | 0.81 | (0.58-1.14) | | 24 | 365 | 1.34 | (0.96-1.89) | | 13 | 257 | 1.13 | (0.64-1.98) | | 13 | 324 | 1.17 | (0.72-1.91) | |
| 30 or higher | 64 | 143 | 1.17 | (0.76-1.82) | | 4 | 143 | 0.80 | (0.28-2.33) | | 66 | 141 | 0.56 | **(0.35-0.89)** | | 20 | 140 | 0.97 | (0.58-1.63) | | 20 | 83 | 2.44 | (1.16-5.13) | | 9 | 114 | 0.89 | (0.40-1.96) | |
| **Type of surgery** | | | | | 0.9390 | | | | | **0.0381** | | | | | 0.0758 | | | | | 0.6682 | | | | | 0.8548 | | | | | 0.3597 |
| Mastectomy | 61 | 894 | 1 | | | 6 | 894 | 1 | | | 75 | 881 | 1 | | | 20 | 864 | 1 | | | 13 | 558 | 1 | | | 11 | 750 | 1 | | |
| Lumpectomy | 60 | 422 | 1.01 | (0.72-1.42) | | 4 | 422 | 0.44 | **(0.21-0.96)** | | 80 | 415 | 1.49 | (0.96-2.32) | | 21 | 415 | 0.91 | (0.61-1.38) | | 12 | 301 | 1.07 | (0.54-2.12) | | 11 | 375 | 0.75 | (0.40-1.40) | |
| **Time since surgery** | | | | | 0.7056 | | | | | 0.2679 | | | | | 0.2726 | | | | | **0.0001** | | | | | 0.8025 | | | | | 0.1411 |
| > 10years | 62 | 474 | 1 | | | 7 | 474 | 1 | | | 78 | 464 | 1 | | | 14 | 464 | 1 | | | 14 | 293 | 1 | | | 12 | 408 | 1 | | |
| 5-10 years | 61 | 842 | 1.05 | (0.81-1.37) | | 4 | 842 | 0.72 | (0.40-1.29) | | 75 | 832 | 0.83 | (0.60-1.16) | | 24 | 815 | 2.02 | **(1.43-2.84)** | | 11 | 566 | 1.07 | (0.62-1.86) | | 10 | 717 | 0.71 | (0.46-1.12) | |
| **Radiotherapy** | | | | | 0.6256 | | | | | **0.0014** | | | | | 0.4059 | | | | | 0.1517 | | | | | 0.6649 | | | | | **0.0041** |
| Yes | 59 | 504 | 0.92 | (0.66-1.29) | | 5 | 504 | 2.97 | **(1.52-5.79)** | | 77 | 500 | 0.83 | (0.54-1.28) | | 22 | 494 | 1.34 | (0.90-2.01) | | 11 | 400 | 0.86 | (0.43-1.72) | | 16 | 457 | 2.54 | **(1.34-4.80)** | |
| No | 62 | 812 | 1 | | | 4 | 812 | 1 | | | 76 | 796 | 1 | | | 19 | 785 | 1 | | | 14 | 459 | 1 | | | 9 | 668 | 1 | | |
| **Systemic treatment**** | | | | | 0.7003 | | | | | 0.1231 | | | | | 0.1835 | | | | | 0.6730 | | | | | 0.6667 | | | | | **0.0235** |
| Endocrine | 68 | 183 | 1.08 | (0.72-1.64) | | 6 | 183 | 2.16 | (0.81-5.75) | | 75 | 179 | 1.39 | (0.86-2.26) | | 17 | 174 | 0.89 | (0.50-1.56) | | 15 | 53 | 0.79 | (0.27-2.33) | | 13 | 125 | 2.48 | **(1.13-5.45)** | |
| None | 64 | 403 | 1 | | | 4 | 403 | 1 | | | 75 | 393 | 1 | | | 17 | 385 | 1 | | | 15 | 112 | 1 | | | 8 | 312 | 1 | | |

ISCED: International Standard Classification of Education (ISCED), combines school- and occupational education to describe educational status.

[*] Not analysed.

[**] Analysis only carried out among postmenopausal women at time of surgery (chemotherapy not analysed here due to low number).

bly, 20% of BCS reported that they had not been able to carry out usual daily activities due to sequelae related to breast cancer, but only 1% rated these difficulties to be very limiting, and 5% as somewhat limiting.

### 3.4. *Daily activities, physical activity, and employment*

Compared to women of the general population, significantly more BCS reported to have primarily sedentary work, but significantly fewer BCS reported mainly sedentary leisure activities (Table 2). Further, Table 2 shows that BCS were significantly less often disability pensioners, while there was no statistically significant difference concerning being engaged in employment or having had sick leave within the past two weeks, although BCS <60 years reported a higher prevalence of sick leave (Fig. 5). Among employed women the extent of employment (paid by the hour, temporary work, average weekly hours) was similar between BCS and the general women population.

With regards to employment among BCS only, 33% of BCS were employed at time of investigation, 38% reported receiving pension, 13% being early-retirement pensioner, 12% being housewife/staying at home, 9% being anticipatory disability pensioner, and others (all <10%; several answers were possible). Being disability pensioner was significantly associated with short education ($\leqslant$10 years) and being single.

Among BCS, 'daily activities limited due to sequelae' was reported by 20% of respondents. This was seen less often among older BCS ($\geqslant$60 years; compared to BCS 40–49 years) and significantly more often by those who had undergone surgery 5–10 years ago (versus surgery >10 years ago; Table 3).

Eleven percent of BCS reported having 'stopped working/changed job due to sequelae' related to breast cancer. The peak prevalence was seen for the age-stratum 50–59 years (13%), while it was lowest among those $\geqslant$70 years (9%; Table 3). This variable was significantly associated with radiotherapy and, among postmenopausal BCS, with endocrine treatment.

Limitations were most frequently reported by the BCS in the following activities: managing 'heavier work at home (floor cleaning, use of vacuum cleaner)' 28%, taking a 15-min walk with a 'rather healthy speed' 13%, climbing stairs 16%, doing the grocery 13%, and taking the bus 9%. Going outside the house, walking around in their home, getting out of bed, taking a bath, getting dressed, and managing light work at home were reported by $\leqslant$5% as troublesome.

## 4. Discussion

Overall, BCS were in contact with the health care system significantly more often than women of the general population, indicating more frequent needs in BCS. The finding that in-

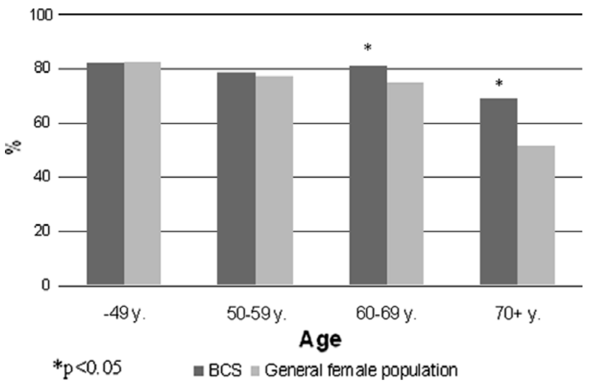

**Fig. 3 – 'Feel well enough to do what i want to do'. Breast cancer survivors (BCS) and women of the general population: Percentages given for those who answered the question 'Do you feel well enough to do what you want to do?' with "Yes, most of the time". Total percentage of BCS was 77% ($n = 1296$) versus 68% of general population women ($n = 4848$); SRR 1.12; CI 1.09–1.16.**

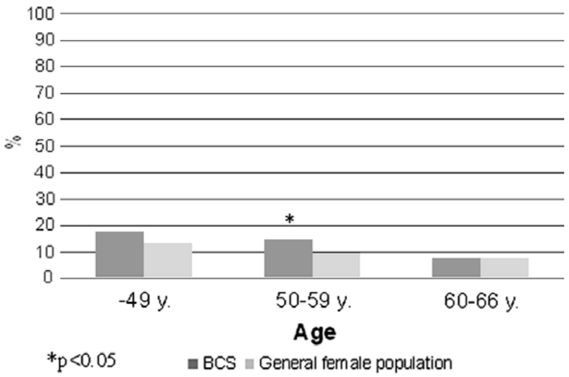

**Fig. 5 – Sick leave. Breast cancer survivors (BCS) and women of the general population: Percentages given for women aged 40–66 years who reported absence from work due to illness within the past 14 days. Total percentage of BCS was 12% ($n = 574$) versus 9% of general population women ($n = 2360$); SRR; 1.28; CI: 0.88–1.85.**

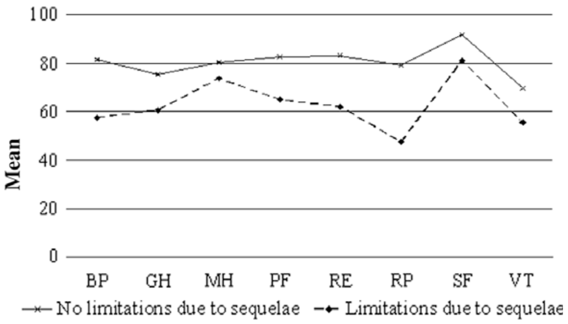

**Fig. 4 – Age-standardized SF-36 mean scores by report of limitations of daily activities due to sequelae of breast cancer-treatment (all $p < 0.05$). $N = 286$ BCS reported limitations of daily activities due to sequelae and $n = 979$ BCS did not report these limitations. BP: Bodily Pain; GH: General Health; MH: Mental Health; PF: Physical Functioning; RE: Role Emotional; RP: Role Physical; SF: Social Functioning; VT: Vitality.**

creased health care utilisation is prevalent 5–15 years after breast cancer treatment suggests that breast cancer survival is associated with chronic morbidity. This result is supported by evidence of higher comorbidity in BCS compared to survivors of other cancers[2] and compared to women without a cancer history.[3,18] Patients may fear the consequences of potentially toxic treatments (e.g. chemotherapy and radiotherapy)[19], and it is therefore important to investigate whether they are associated with late morbidity.

The overall pattern of the higher contact concerning outpatients' clinic, practicing medical specialist, physiotherapist, and chiropractor, but not to general practitioner, emergency room, doctor on call, or hospitalisation indicates chronic rather than acute morbidity. This interpretation is in accordance with our previous findings of significantly higher chronic pain prevalence in BCS compared to the general population[1] and findings of others[2,5,6], all of which provide evidence for radiotherapy being a major cause for the development of sequelae. Although we found only one significant association between radiotherapy and health care utilisation, namely increased chiropractor contact, the long-term effects of radiotherapy should not be underestimated. We found previously that chronic pain and other sequelae after breast cancer were significantly associated with radiotherapy.[1] Other authors have reported pathological changes affecting, e.g. the nerves[8] and functional limitations such as decreased shoulder motility associated with radiotherapy.[20]

Other potential reasons for higher use of health care include 'fear of the future' as identified in 6-year-BCS[21] and the findings that many BCS have 'unmet needs', which typically concerned survivorship issues such as cancer recurrence, the need to be informed, and coordination of medical care. Such issues were more often reported when anxiety and depression were present.[7] However, we can probably exclude poor mental health as a primary reason for health care contact among BCS, since it emerged from our previous HRQOL data that mental health was not significantly poorer compared to normative data.[11]

### 4.1. *Physical activity and employment*

Among BCS, 20% reported limited daily activities due to sequelae related to former breast cancer treatment, which matches findings from Stevens and colleagues.[22] However, the proportion experiencing chronic pain and/or paraesthesia is considerably higher[1,23], suggesting that not all sequelae hamper activities. When limitation of daily activities due to sequelae was reported, the largest difference in HRQOL was seen for the SF-36 subscale 'role physical' (Fig. 4), suggesting marked problems with work or other daily activities as a result of physical health. From a conceptual point of view this result is not surprising.

Interestingly, BCS more often reported sedentary work, but were significantly more active in their leisure time compared to women of the general population. Five-years after treatment, this has partially been shown by Bouknight and colleagues who found that heavy lifting on the job was significantly less associated with return to work 1 year after breast cancer diagnosis.[24]

We did not find any difference in sick leave or employment between BCS and women of the general population, whereas Maunsell and colleagues[25] reported that 3-year-BCS were at higher risk of being unemployed (21% of BCS versus 15% in the control group). Some studies have found that BCS needed social support from work life and wish to receive more support from occupational health services.[3,24,26]

### 4.2. *Sociodemographic predictors*

The age-standardised comparison of health care contacts by BCS and the general population excludes a sole age effect. High age of BCS was significantly associated with physician contact, which probably reflects the aging process. Interestingly, elderly BCS (⩾60 years) reported less often to be limited in daily activities due to breast cancer-related sequelae compared to younger BCS, and elderly BCS also rated their health better compared to equally aged women of the general population, which is consistent with our and others' findings that especially younger BCS report difficulties and sequelae.[1,5,11,27] In addition, Sweeney and colleagues found that elderly 5-year-BCS were functionally impaired concerning daily activities compared to normative data.[4] In general, however, it must be noted that the finding of better health in patients compared to general population samples may be biased due to response shift and other factors.[28] One significant difference concerning the demographics of BCS and women of the general population is the significantly longer education of BCS (Table 2), which matches the generally known observation that women with an academic education are at higher risk of developing breast cancer compared to women with short (non-academic) education.[29]

Being single and short education were significantly associated with being a disability pensioner as well as with less likelihood to 'feel well enough to do what I want to do', and being single was also significantly associated with increased likelihood to consult a physician. Having a BMI of ⩾30 was also associated with less likelihood to 'feel well enough to do what I want to do'. Similar results were found by others, e.g. concerning chronic pain in the general population[12] and depressive symptoms in association with diabetes,[30] stressing the role of these sociodemographic factors in comorbidity. Further, it is noteworthy, that an important variable such as 'feel well enough to do what I want to do' was only significantly associated with sociodemography and not with treatment. The latter suggests that the effect of former breast cancer treatment is not relevant for the actual self-reported health in long-term BCS, which also supports our previous findings on health-related quality of life (HRQOL). Specifically, we found that HRQOL of BCS was unrelated to type of surgery, radiotherapy, and chemotherapy.[11]

### 4.3. *Breast cancer treatment-related predictors*

Radiotherapy was associated with chiropractor contact and 'stopped working/changed job due to sequelae'. This may be explained within the context of our previous finding that chronic pain and other sequelae were typically associated with radiotherapy, which has been associated with, e.g. perineural fibrosis.[8] Since radiotherapy is co-administered when lumpectomy is performed, it would be expected that lumpectomy would also be associated with high chiropractor contact. However, we found the opposite, which may be related to the lesser extent of surgery opposed to mastectomy, although the role of surgery and its association with e.g. pain remains unclear.[31]

Shorter time since surgery (⩽10 years) was significantly associated with limitations of daily activities due to sequelae. This possible improvement over time has consistently been found by Sweeney concerning 2-year survivors versus 5-year survivors of different types of cancer including BCS.[4] While Tasmuth[23] also found a higher pain incidence with less time since surgery, Johansson described increasing incidence and severity of sequelae, including arm paralysis, in BCS up to 34 years after breast cancer treatment.[8] However, since Johansson and colleagues derived their cohort from the 1960s, it may be assumed that the treatment regimen at that time was more aggressive.

### 4.4. *HRQOL and self-rated health*

Interestingly, BCS reported slightly better health compared to the general women population, which also matches our previous findings using the SF-36 questionnaire[11]: in general, and in accordance with the literature, the BCS reported similar HRQOL with tendency in some scales towards better HRQOL compared to general women population.[5,32] This is an interesting observation since we also showed that BCS reported a significantly higher prevalence of chronic pain compared to the general female population[1], and report of chronic pain was associated with significantly poorer HRQOL in the BCS[1] as well as in the general population.[12] The fact that this association was not apparent as an overall impact on HRQOL in the BCS compared to the general female population may also be related to a phenomenon termed response shift as discussed previously.[11,33] Further, Mols and colleagues[34] found in their systematic review on the quality of life in long-term BCS that current medical condition, amount of social support, and current income level were strong positive predictors of quality of life.

### 4.5. *Weaknesses and strengths of the present study*

Only few other studies have investigated health, employment or health care system contact in long-term BCS (>5 years) and compared their data to normative data or to other cancer survivors.[2,4,5] Further, we were able to compare our data on BCS with those of the general population. The strength of this nationally representative approach is to identify characteristic findings in BCS and to avoid bias resulting from recruitment of patients from non-representative institutions (e.g. university hospitals only), geographical variation of accessibility to health care[35], and social differences, all of which can be associated with type of breast cancer treatment.[36] The DBCG register has previously been shown to be a valid and nationally representative clinical database.[14]

Limitations include the cross-sectional design of this study which does not allow interpretation in terms of causation; the time of investigations in BCS and the general population was different (BCS were investigated 3 years later); and, e.g. sociodemographic data in BCS were investigated by the questionnaire only, while the general population was personally interviewed concerning sociodemography. Clearly, non-respondents may have had poorer health and any study of this type carries the risk of underestimating morbidity and health care utilisation for this reason. Also, this study concerned survivors, and probably some of the women with high morbidity had died. Further, we do not know e.g. whether the BCS became anticipatory pensioner before or after breast cancer diagnosis. Nevertheless, we believe that our study yields high-quality data and represents findings that are representative of long-term BCS met in the daily clinical setting.

## 5. Conclusion

This study identified BCS as a population with chronic morbidity as reflected in the significantly higher prevalence of health care utilisation. While reporting a comparable, high-quality of life, BCS have limitations in daily activities compared to the general women population. Our data suggest that in the long run probably the combination of sociodemographic factors – mainly age, short education, and being single – as well as treatment-related factors – mainly radiotherapy and shorter time since surgery – is relevant for the health in long-term breast cancer survivorship. To reduce the risk that breast cancer – despite curative treatment – evolves into a chronic disease, doctors need to play an active role in providing health care to BCS, and need to ask these individuals specific questions about their emotional, psychological, and social issues.

## Conflict of interest statement

None declared.

## Acknowledgements

The project was financially supported mainly by the Danish Cancer Society. Further funding was also received from the following: 'Handelsgartner Ove William Buhl Olesen og ægtefælle fru Edith Buhl Olesens' 'Mindelegat', 'Krista og Viggo Petersens's Fond', 'Beckett– Fonden', 'Gangstedfonden', and 'Willy og Ingeborg Reinhards Fond'.

## Appendix Specific questions investigated

*Women aged 40–66 years.

## Questions investigated in BCS and women of the general population

### *Health care contacts*

This item was comprised by two questions: 'Did you within the past three months consult a doctor because of personal complaints, illness, or injury?' (Include only consultations accounting for your complaints – not your children's) and 'Did you, within the past three months, consult any other health care providers?' The response categories were 'No' and 'Yes', with a list of specialists/institutions provided.

### *Feel well enough to do what I want to do'*

'Do you feel well enough to do what you want to do?'

'(1) Yes, most of the time./ (2) Yes, occasionally./ (3) No (hardly ever)/ (4) Don't know'.

(1) was evaluated as 'good', (2) and (3) as 'poor' health; (4) as 'missing'.

### *Physical activity*

*Activity in leisure time*
'If we look back on the past year, how would you describe your spare time activities?' (1) 'Heavy training and competitive sports, regularly and several times a week'; (2) 'Exercise or heavy gardening at least 4 h a week'; (3) 'Walk, bike, or other easy exercise at least 4 h a week (Include Sunday excursions, light gardening and biking/walking to work)'; (4) 'Read, watch TV, or other sedentary occupation'. (3) and (4) were assessed as 'mainly sedentary' activities.

*Activity at work**
'How would you describe the physical strain of your chief occupation?'

'(1) mainly sedentary work which doesn't demand any physical effort; (2) work which to a great extent is performed standing or walking but apart from that doesn't demand any physical effort; (3) standing or walking with many lifts or much carrying; (4) heavy or speedy work, which is strenuous'. (1) and (2) were categorized as 'mainly sedentary' activities.

### *Employment**

'What is your occupation?'

A list of different kind of employment status according to the Danish system was provided, including the answers 'disability pensioner,' 'temporary occupation', and 'paid by the hour'.

*Sick leave*
'Within the past 2 weeks, how many days did you have to stay home from work due to illness, injuries or complaints?' – 'write number of days'. This variable was registered when at least one day was reported.

## Questions investigated in BCS only

'What do you do to stay healthy or to improve your health?' (A list of response options was provided.)

'Do side effects of your breast cancer or its treatment make it troublesome to pursue your daily activities?' 'Yes, very much.'/'Yes, somewhat.'/'Yes, a little bit'/'No'.

### *Limitations due to sequelae*

'Here we are asking you to report what you can do and what you cannot do'.

A list of different tasks concerning daily activities was provided (e.g. doing the grocery, climbing stairs).

'Did you have to stop working or change your job or tasks at work because of side effects of your breast cancer or its treatment?'*Response options were 'Yes, changed job/tasks at work'/'Yes, changed job/tasks at work and since then stopped working'/'Yes, stopped working'/'No'.

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