

ORIGINAL ARTICLE

Quality of life in cancer survivors as observed in a population study of Swedish women

ÖSTEN HELGESSON¹, LAUREN LISSNER^{1,2}, JÖRGEN MÅNSSON^{1,3} & CALLE BENGTSSON¹

¹Sahlgrenska Academy at Göteborg University, Department of Primary Health Care, ²Nordic School of Public Health, Göteborg, Sweden, and ³Research and Development Unit, General Practice and Public Health, Falkenberg, Sweden

Abstract

Objective. To investigate quality of life, measured by the SF-36 scales, in a population-based sample of women who have survived cancer at any site and, specifically, breast cancer. **Design.** A representative cohort of women was observed over 24 years with regard to cancer prevalence, incidence, and quality of life. **Setting.** Gothenburg, Sweden. **Subjects.** A total of 1462 women aged 38–60 years at baseline. **Main outcome measures.** Differences in quality of life between cancer survivors and cancer-free controls measured by the SF-36 Short Form Health Survey, with adjustment for age and additionally for social status, and history of major disease (diabetes, stroke, and myocardial infarction) at follow-up in 1992–93. **Results.** In women who had survived cancer, a lower feeling of general health was the only score found to be significantly associated with having had cancer. Similar analysis was conducted separately for breast cancer cases. Survivors of breast cancer reported lower vitality and when controlled for major disease also lower general health compared with women who had not had cancer. All other results were independent when adjusted for social status, and also for history of major disease. **Conclusions.** Women who have survived cancer report lowered general health, and breast cancer cases lowered vitality, but considering the non-significant results for the other scores and summary scales it can be concluded that the well-being of women who have survived a cancer on the whole did not differ profoundly from that of other women.

Key Words: Breast cancer, cancer, population study, quality of life, SF-36, women

Cancer survivors are a growing part of the population [1,2]. In a study of cancer survival in Sweden [2] it was observed that the 10-year relative survival rate for all sites combined increased steadily in the 1990s. The term “cancer survivor” is generally used to refer to someone who has survived cancer for five years or more and is free from that disease [1,3]. Another definition is that a cancer survivor is anyone still living after a cancer diagnosis [4].

There is increasing research interest in the area of cancer survivorship suggesting that even patients in remission may experience long-term adverse consequences of the disease and/or its treatment [1,3]. Gotay [3] also notes that there is a considerable diversity of methods when measuring quality of life.

In the prospective population study described here, participants have been thoroughly interviewed

The Population Study of Women in Gothenburg started as a cross-sectional study of 1462 women in 1968–69.

- Quality of life was measured with the SF-36 survey after 24 years of follow-up.
- One hundred cancer survivors in general reported a quality of life similar to that of cancer-free women.
- Other major illnesses and social status only marginally affected the reported quality of life in cancer survivors.

and examined over 24 years with regard to cancer [5,6] as well as for the presence of various symptoms, complaints, and factors dealing with quality of

life [7]. The aim of this paper was to assess the possible impact of total cancer and, specifically, breast cancer on health-related quality of life. This was accomplished by comparing participants with and without history of cancer in 1992–93 in respect of quality of life measured by the SF-36 survey at that time. In this population study, higher socioeconomic status was associated with excess cancer mortality, particularly breast cancer [8]. For this reason adjustment for socioeconomic status was also performed. Additional adjustment for history of three major disease groups – diabetes, stroke, and myocardial infarction – was also made.

Material and methods

Study population

The Population Study of Women in Gothenburg started as a cross-sectional study in 1968–69. In total 1622 women were invited to the baseline examination in 1968–69, and 90.1% of them participated. The population sample was obtained from the Revenue Office Registers and consisted of women at ages 38, 46, 50, 54, and 60. The women were invited to follow-up examinations in 1974–75, 1980–81, and 1992–93 [9–12]. In the fourth phase of the study, in 1992–93, 836 of the women examined in 1968–69 were re-examined. The women were invited to each examination with a letter describing the study and offering a free health screening. Before each examination questionnaires were sent out describing socioeconomic status, earlier hospitalisation and diseases, present symptoms, present medical treatment, and gynaecological history.

Confirmation of the diagnosis of cancer

In addition to the questionnaires completed at home, supplementary information on health status was obtained by interviewing the women during a doctor's examination. During the examinations each participant was asked if she had any history of a cancer and, if so, she was asked to provide details on type of cancer, localisation, and type of treatment. Information on cancer that was obtained for the first 12-year period up to 1980–81 has been verified by studies of hospital records, and all pathoanatomical diagnoses were re-verified pathologically and anatomically by means of microscopic re-examination of slides from biopsies [5]. We have previously validated the Swedish Cancer Registry's 12-year incidence data by comparing it with our data obtained at the clinical examinations [6], and there was almost complete agreement between the data recorded in the population study and that of the Cancer Registry. Information for the total 24-year period 1968–69 to

1992–93 was, in addition to the health examination, obtained from the Swedish Cancer Registry and from the Regional Cancer Registry of Western Sweden, which by law receive reports of all malignant neoplasms diagnosed clinically or at autopsy. A list of all cases between 1958 and 1992–93 among women with the same dates of birth as the women participating in the population study of women in Gothenburg was provided by the Swedish Cancer Registry. Cases in the cohort could be identified from this list. Mortality data were obtained both on a national level from the Swedish National Death Registry and from the local parish registers, including reason for death and prevalence of co-diagnoses including cancer. Further information was obtained, for surviving subjects, from the Swedish Person and Address Register.

SF-36 health survey

At the follow-up in 1992–93 the subjects completed the SF-36 survey, a generic measure of health-related quality of life. Version 1.0 was used – a standard four-week recall short-form with 36 questions that are summarized into eight scales [13–16]. Symptoms and problems that are specific to a particular condition are not included. Raw scale scores are transformed to a 0–100 scale score. Additionally summary measures for physical health and mental health were used: the physical component summary and mental component summary [17].

Socioeconomic status

Information on the socioeconomic status of the women and their households was obtained in 1968–69 by questionnaire. Primarily the subjects, and if married also their husbands, were classified by their occupation into five socioeconomic groups according to Carlsson [18]. Housewives were classified as a separate group. A gender-neutral classification of social status of the women's households was constructed by combining information on both the women's occupation and, when married, their husband's occupation. Unmarried women were classified by their own occupational group. If they were housewives their social status was determined by their husband's profession. If the women and their husbands were both working the social status was determined by the highest ranked profession irrespective of gender.

Statistical methods

When analysing mean differences in SF-36 scores between cancer/breast cancer cases and controls (mean score in cases – mean score in controls) linear

Table I. Number of cancer cases in participants who attended examinations both in 1968–69 and in 1992–93.

| Birth year | 1930 | 1922 | 1918 | 1914 | 1908 | Total |
|--------------------------------------|------|------|------|------|------|-------|
| Cancer cases | 22 | 38 | 25 | 10 | 5 | 100 |
| Breast cancer cases | 3 | 12 | 6 | 5 | 4 | 30 |
| Major disease in cancer group | 1 | 3 | 4 | 4 | 2 | 14 |
| Major disease in breast cancer group | 0 | 1 | 0 | 2 | 2 | 5 |
| Participants in 1992–93 | 252 | 266 | 220 | 79 | 19 | 836 |

regression was used in order to adjust for age, socioeconomic status, and also history of other major diseases (diabetes, stroke, and myocardial infarction). Controls were the women without history of cancer.

Results

Cancer incidence and history of major disease

In Table I the numbers of women investigated both in 1968–69 and in 1992–93 are shown, and also their history of cancer/breast cancer and major diseases. In total there were 100 cancer survivors in 1992–93 among women ever having had cancer (cancer cases before 1968–69 included). Mean age at diagnosis of any cancer was 59.1 years (SD 9.3). Mean age at

diagnosis of breast cancer was 57.2 years (SD 9.5). At the investigation in 1992–93 the current mean age of the women with any cancer was 70.5 years (SD 5.8) and of the controls 70.2 years (SD 5.8). Corresponding values for women with breast cancer were 74.0 years (SD 6.1) and for the controls 70.2 (SD 5.8).

Quality of life in female cancer survivors

Among the female cancer survivors a comparison with controls indicated a significant association with cancer on one of eight scales: poorer general health (Table IIA). Women having had breast cancer had a significantly lowered vitality (Table IIIA). No significant associations were found between cancer in comparison with controls concerning the summary scales.

Adjustment for socioeconomic status and major disease

Adjusting for socioeconomic status and major disease did not significantly affect the differences in quality of life between women with cancer or breast cancer compared with controls, with the exception of slightly lowered general health for breast cancer cases after this adjustment (Tables IIB and IIIB). Higher socioeconomic status was associated with

Table II. Mean differences in SF-36 scores and summary measures between cancer cases and controls (n = 736, age adjusted): Best health in each score ranges up to 100 and poorest health to 0 (95% confidence interval in parentheses).

Table IIA

| SF-36 SCORE in 1992–93 | Cancer controlled for age |
|--------------------------|---------------------------|
| Physical functioning | –3.3 (–8.2, 1.6) |
| Role physical | –4.6 (–13.0, 3.8) |
| Bodily pain | –2.9 (–8.6, 2.8) |
| General health | –7.3 (–11.6, –3.1) |
| Vitality | –4.3 (–9.0, 0.4) |
| Social functioning | –3.5 (–8.2, 1.3) |
| Role emotional | –2.2 (–10.6, 6.1) |
| Mental health | –3.4 (–7.9, 1.2) |
| Physical component score | –1.4 (–3.5, 0.8) |
| Mental component score | –1.7 (–4.1, 0.8) |

Table IIB

| SF-36 SCORE in 1992–93 | Cancer controlled for age, social status, and major disease | | |
|--------------------------|---|-----------------|--------------------|
| | Social status | Major disease | |
| Physical functioning | –3.6 (–8.4, 1.2) | 4.5 (2.0, 7.0) | –6.2 (–11.2, –1.2) |
| Role physical | –4.9 (–13.3, 3.4) | 6.4 (2.2, 10.7) | –6.8 (–15.4, 1.8) |
| Bodily pain | –3.5 (–9.1, 2.2) | 4.6 (1.7, 7.5) | –4.3 (–10.1, 1.5) |
| General health | –7.6 (–11.8, –3.3) | 3.5 (1.4, 5.7) | –5.0 (–9.4, –0.7) |
| Vitality | –4.4 (–9.1, 0.3) | 2.3 (–0.1, 4.7) | –5.7 (–10.5, –0.8) |
| Social functioning | –3.7 (–8.4, 1.0) | 2.4 (0.0, 9.4) | 1.4 (–3.5, 6.2) |
| Role emotional | –2.5 (–10.8, 5.8) | 5.1 (0.9, 9.4) | –6.8 (–15.4, 1.7) |
| Mental health | –3.4 (–7.9, 1.2) | 0 (–2.4, 2.3) | –2.8 (–7.5, 1.9) |
| Physical component score | –1.5 (–3.7, 0.6) | 2.0 (0.9, 3.1) | –2.7 (–4.9, –0.5) |
| Mental component score | –1.7 (–4.1, 0.7) | 0.3 (–0.9, 1.6) | –1.5 (–4.1, 1.0) |

Table III. Mean differences in SF-36 scores and summary measures between breast cancer cases and controls (n = 736, age adjusted): Best health in each score ranges up to 100 and poorest health to 0 (95% confidence interval in parentheses).

Table IIIA

| SF-36 SCORE in 1992-93 | Breast cancer controlled for age only |
|--------------------------|---------------------------------------|
| Physical functioning | -2.0 (-10.9, 7.0) |
| Role physical | -4.4 (-19.8, 11.0) |
| Bodily pain | -0.7 (-11.2, 9.8) |
| General health | -7.3 (-15.0, 0.4) |
| Vitality | -9.7 (-18.5, -0.9) |
| Social functioning | -4.2 (-12.9, 4.5) |
| Role emotional | -1.5 (-13.7, 16.7) |
| Mental health | -6.0 (-14.4, 2.5) |
| Physical component score | -1.2 (-5.1, 2.8) |
| Mental component score | -2.0 (-6.5, 2.4) |

Table IIIB

| SF-36 SCORE in 1992-93 | Breast cancer controlled for age, social status, and major disease | | |
|--------------------------|--|-----------------|---------------------|
| | | Social status | Major disease |
| Physical functioning | -3.0 (-11.9, 5.8) | 5.1 (2.5, 7.7) | -7.7 (-12.9, -2.5) |
| Role physical | -5.6 (-20.9, 9.6) | 6.7 (2.2, 11.1) | -10.0 (-19.0, -1.0) |
| Bodily pain | -2.0 (-12.4, -1.7) | 5.2 (2.2, 11.1) | -5.4 (-11.5, 0.7) |
| General health | -8.1 (-15.8, -0.4) | 3.4 (1.2, 5.6) | -7.0 (-11.5, -2.5) |
| Vitality | -10.4 (-19.2, -1.7) | 2.7 (0.1, 5.2) | -8.1 (-13.2, -2.9) |
| Social functioning | -4.6 (-13.2, 4.0) | 2.2 (-0.3, 4.7) | -0.4 (-5.5, 4.6) |
| Role emotional | 0.6 (-14.5, 15.7) | 4.4 (0.0, 2.8) | -10.2 (-19.1, -1.3) |
| Mental health | -6.2 (-14.6, 2.2) | 0.3 (-2.2, 2.8) | -4.6 (-9.6, 0.3) |
| Physical component score | -1.7 (-5.6, 2.2) | 2.3 (1.1, 3.4) | -3.2 (-5.6, -0.9) |
| Mental component score | -2.1 (-6.6, 2.3) | 0.1 (-1.2, 1.4) | -2.7 (-5.4, -0.1) |

significantly better quality of life on several dimensions of the SF-36 survey and history of major disease gave results in the opposite direction.

Discussion

It is important for both physicians and patients to understand what the diagnosis of cancer means for an individual. There is evidence that cancer disease results in lowered quality of life, although defence mechanisms promoting an improved high quality of life have also been discussed [3]. To better understand these effects, there is a need for researchers to employ useful comparable methods of measuring quality of life. We have used the SF-36 survey, which is a well-established instrument [13-17].

Several previous studies have used SF-36 to study quality of life in cancer patients in general [3,19-21] and breast cancer patients [22-25]. In these studies lowered quality of life was seen in different degrees. In the present cross-sectional study we observed that cancer was associated with lowered general health and breast cancer with lower vitality compared with controls, whereas all other scales including summary measures scored non-significantly. It may be speculated that general health is the least specific of the SF-36 scales, and may be most likely to reflect

knowledge of having had cancer. It was defined as evaluations of personal health ranging from excellent to poor and likely to get worse. This may be contrasted with results from more specific and possibly more objectively defined categories.

Since our main objective was to compare cancer survivors with women who are free of cancer, we chose to use the same cancer-free control group for all-site and for breast-cancer comparisons. With specific regard to the breast-cancer results, inclusion of other cancers in the control group would be expected to dilute the observational differences, and this was the case. Specifically, when comparing breast cancer survivors with all controls (including other cancers), there was no longer any significant difference in general health even after adjustment for major disease. However, the difference in vitality was similar in magnitude and significance when comparing breast cancer survivors with either control group.

Otherwise all significant differences were statistically independent of socioeconomic status and other major illnesses.

Clinical relevance of small change or differences in health-related quality of life has been discussed [26]. This is a question of definition beyond the statistical power calculation, and it is proposed that the cut-off value for chronic diseases would be set at a level of

half a SD. In our study we find that this would be 1.1 for general health and 2.2 for vitality, respectively. Many of our observed differences were well in excess of this.

One limitation with this study is that the SF-36 questionnaire was assessed only once and no pre-diagnosis scores are available for cases. Also the data were collected in 1992–93, and reported quality of life may differ between now and then, due to changes in therapy. The social data were collected at baseline in 1968–69. Since there were cancer survivors among the women studied at this time there was a possibility that cancer disease could affect social status. For that reason we also ran the analyses using only 24-year incident cases, free from cancer at the baseline interviews. There were no differences in outcome concerning the significantly changed SF-36 scales before and after adjustment for social status and major diseases. The small number of cancer survivors to 1992–93 also limited us to analysing only total cancer and the single largest group of cancer, breast cancer, with regard to SF-36. We had no possibility to examine treatment effects, although this is a topic of interest. Also, a relatively large number of analyses were made and when interpreting the results one has to be aware of the possibility of chance findings. Strengths of the study, however, are the long study period and the high participation rate, both initially and in the follow-up studies, and the very complete registration, which supports the validity of our results.

Conclusions

Women who have survived cancer report lowered general health, but considering the non-significant results for the other scales and the summary scores it leads us to conclude that these women feel well on the whole. The experience of lowered general health in women with cancer, and also the lowered vitality in women with breast cancer, could be viewed in general practice as a “scar”, although possible to live with when adapted to. Knowing how to support and treat a cancer patient is of great importance in clinical praxis. If there is a belief that cancer disease always results in poor health, both physical and mental, this can disturb the communication between the patient and the physician. Such an opinion is, however, probably in contrast to the experience from daily care at a primary health centre, where the majority of cancer survivors appear quite healthy. Our study supports such an observation.

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This study has been approved by the Ethics Committee.

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