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Increased health care utilisation among 10-year breast cancer survivors

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Abstract *Objective:* We investigated self-reported health care utilisation of women who survived breast cancer for 10 years and identified predictors of health care utilisation. *Methods:* The population-based Eindhoven Cancer Registry was used to select all women who were diagnosed with breast cancer in 1993, in six hospitals in the Netherlands, and were disease-free at the time of data collection. Health status, psychological well-being, satisfaction with life and health care use were compared with same age controls. Logistic regression was used to identify predictors of health care utilisation. *Results:* Of the 254 women who were sent a questionnaire, 183 (72%) responded. Breast cancer survivors had a similar health status and psychological well-being and a better satisfaction with life compared to same age controls. The proportion of breast cancer survivors (79%) who visited a specialist in the past 12 months was significantly higher compared to controls (53%). Young breast cancer survivors (45–54 at time of completing questionnaire) more often

visited a physical therapist (56%) or complementary caregiver (26%) than controls (29 and 13%, respectively). Spontaneously reported problems (fatigue, arm problems) as a consequence of cancer and co-morbidity showed the strongest associations with health care utilisation. *Conclusions:* Although self-reported health, satisfaction with life and psychological well-being were similar or even better in long-term breast cancer survivors compared to those in population controls, survivors more often attended a specialist, physical therapist and complementary caregiver in the past 12 months. Survivors of young age appear to have the highest use of health care services compared to age-matched controls, especially related to fatigue and arm problems.

Introduction

Advances in the early diagnosis and treatment of breast cancer have led to increasing numbers of individuals who are either cured for their cancer or experience it as a chronic disease [1]. The number of survivors is also increasing as a result of the ageing of the population. As the number of breast cancer survivors has been rapidly growing (with >4% per year in the Netherlands) [2], more information on the

physical and psychological long-term effects of cancer and its treatment is becoming available. Studying the long-term (side) effects of different treatments is important to obtain insight into medical and psychosocial needs of patients and possibly to adjust current therapies to minimise late complications.

So far, most studies of the effects of breast cancer and its treatment have focused on long-term well-being (e.g. cancer or treatment related complaints, quality of life,

health status, etc.). These studies have demonstrated that fatigue, physical complaints and menopausal problems more often occur in breast cancer survivors compared to those in healthy women, even years after diagnosis [3, 4]. Young age at diagnosis [5], having undergone lymph node dissection [6–8] and chemotherapy [9, 10], seemed to affect well-being after many years. It is likely that these long-term side effects also result in an increased health care utilisation, as compared to the general female population, although little is known about this. Insight into the health care utilisation may reveal the need for specific care programmes for cancer survivors.

The present study compares self-reported health care utilisation of women who survived breast cancer for 10 years, with the general Dutch female population, and identifies predictors of health care utilisation.

Methods

Study participants

We used the population-based Eindhoven Cancer Registry to select all women ($n=254$) who were diagnosed with invasive breast cancer in 1993, in six community hospitals in the south of the Netherlands, and were still alive at the time of data collection (October 2003). The participants had to be disease-free and currently not in need of cancer treatment. We only included women who were younger than 75 at diagnosis and therefore younger than 85 at the time of data collection. Eligible women were sent a questionnaire by their (sometimes former) specialist. Completion of the self-administered questionnaires was considered to imply informed consent (Fig. 1).

Content of questionnaire

The CentERdata Health monitor was used to measure health status (eight items), satisfaction with life (five items) and psychological well-being (five items) [11], all with a five-point Likert scale. Higher scores indicate better health status (range 0–40), better satisfaction with life (range 0–25) and better psychological well-being (range 0–25). The CentERdata Health monitor has been validated with a high internal consistency of the three different subscales of 0.88, 0.75 and 0.82 [11]. Norm scores of this questionnaire are available for a Dutch population sample consisting of 1,893 men and women. For this study, we used norm scores and standard deviations (SD) of 149 women in the age group 45–54 years, 83 women in the age group 55–64 years, 66 women in the age group 65–74 years and 10 women who were 75 years of age or older. Health status, satisfaction with life and psychological well-being among survivors were defined to be clinically meaningful different from the norm scores when they were one or more SD(s) above or below the mean of the Dutch female population sample.

In addition to the validated CentERdata Health monitor, women were asked—in an open question—whether they had complaints that *according to them* were related to having had breast cancer in the past and whether they had co-morbid disease(s). In addition, women were asked if they had visited their general practitioner (GP), a medical specialist, a physical therapist or complementary caregiver in the past 12 months. The health care utilisation questions were asked in a similar way as is done via the annual monitoring of the health care situation of the Dutch

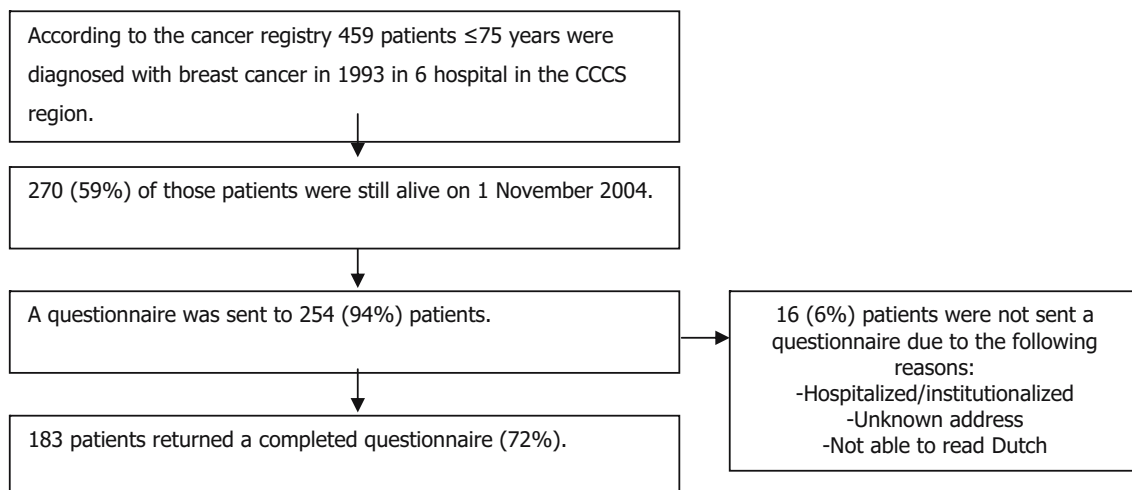


Fig. 1 Flow chart of the data collection process

population by Statistics Netherlands (<http://statline.cbs.nl>). Norm data of the year 2003 were used from 400 women in the age group 45–54 years, 313 women in the age group 55–64 years, 396 women in the age group 65–74 years and 325 women who were 75 years of age or older.

Statistical analyses

All data were analysed using SAS (version 8.02, SAS Institute Inc., Cary, NC, USA). Differences in characteristics of responders and non-responders were analysed by means of the chi-square statistic. Since age has repeatedly been reported to be an important factor for long-term well-being and is also related to health care utilisation, we analysed the results by four different age groups. Differences between the age groups with respect to mean scores on the (domains of the) CentERdata Health monitor were analysed by means of ANOVA, and differences between the survivors and controls were analysed using a *t* test. Differences between age groups with respect to physical problems or co-morbidity were also analysed by means of the chi-square statistic, as were differences in health care use between survivors and controls. Finally, logistic regression was used to identify statistically significant predictors of health care utilisation.

Results

Of the 254 women who were sent a questionnaire, 183 (72%) responded. Most participants (87%) were diagnosed with breast cancer stage I or II (Table 1). In almost all women, the axillary lymph nodes had been dissected (97%). The 71 non-responders were not different from the participants with respect to stage at diagnosis, surgical treatment or systemic therapy. The non-responders exhibited a slightly different age distribution: more women in the youngest and oldest age group ($p=0.06$), and they received radiotherapy less often ($p=0.03$). The latter was also shown when comparing treatment combinations between responders and non-responders.

Within the group of 10-year survivors, there was no difference when comparing the mean scores or distributions of the three domains of the CentERdata Health monitor among the four age groups (Table 2). Comparison with norm scores from a general female population of the same age revealed that health status and psychological well-being were similar to the general population. In contrast, satisfaction with life was significantly higher among breast cancer survivors in all four age groups. In those aged 45–54, 55–64 and 75+, this higher satisfaction with life was also clinically meaningful.

A strong age gradient was found when comparing spontaneously reported problems as a consequence of cancer and co-morbidity (Table 2). A painful, numb or

Table 1 Characteristics of 10-year, disease-free survivors of breast cancer ($n=254$)

	Responders $N=183$ (%)	Non-responders $N=71$ (%)	<i>p</i> value
Age at diagnosis (years) ^a			
35–44	25 (14)	17 (24)	0.06
45–54	63 (34)	18 (25)	
55–64	60 (33)	17 (24)	
65+	35 (19)	19 (27)	
Stage			
I	80 (44)	25 (35)	0.28
II	79 (43)	40 (56)	
III	13 (7)	3 (4)	
IV	1 (1)	– (–)	
Unknown	10 (5)	3 (4)	
Surgical treatment			
Breast-conserving therapy	105 (57)	32 (45)	0.18
Mastectomy	74 (40)	36 (51)	
Unknown	4 (3)	3 (4)	
Lymph node dissection	178 (97)	67 (94)	0.26
Systemic therapy			
Hormonal therapy	29 (16)	10 (14)	0.72
Chemotherapy	19 (10)	12 (17)	0.15
Radiotherapy	131 (72)	41 (58)	0.03
Treatment combinations			
Surgery alone	48 (26)	22 (31)	0.02
Surgery + Radiotherapy (Rth)	87 (48)	26 (37)	
Surgery + Rth +	17 (8)	7 (10)	
Chemotherapy			
Surgery + Rth + Hormonal	26 (14)	7 (10)	
Surgery + Chemotherapy	1 (1)	5 (7)	
Surgery + Hormonal	3 (2)	3 (4)	
Other	1 (1)	1 (1)	

^aAll survivors were approached 10 years after diagnosis; thus, current age is 10 years older

tingling arm ($N=64$) and fatigue ($N=18$) were the most often reported problems. Other spontaneously reported problems were problems with own appearance, fear and sexual problems. With increasing age, the frequency of self-reported cancer-related problems decreased (p trend <0.05), whereas the frequency of self-reported co-morbidity increased (p trend $=0.14$). A painful arm was reported by 52% of the youngest age group vs 29% of the oldest age group. Spontaneously reported fatigue as a consequence of cancer was almost non-existent (3%) in women who were 65 years of age or older when they completed the questionnaire, whereas it was a frequently (17%) reported problem in those younger than 65. Additional multivariate analyses revealed that—after adjustment for age and co-morbidity—having received chemotherapy increased the risk of reporting fatigue by more than five times [odds ratio

Table 2 Physical and psychological well-being in disease-free, 10-year breast cancer survivors and a control sample of the Dutch population

	Age at time of completing questionnaire (years)				<i>p</i> value
	45–54	55–64	65–74	75+	
CentERdata Health monitor	Mean scores (SD)				
Health status (range 0–40)					
10-year survivors	33 (6)	31 (8)	33 (7)	29 (6)	0.11
Controls ^a	30 (6)	32 (6)	33 (5)	29 (7)	0.02
Satisfaction with life (range 0–25)					
10-year survivors	22 (4)***	22 (3)***	21 (4)***	23 (3)***	0.42
Controls ^a	18 (3)	19 (3)	19 (3)	17 (3)	0.03
Psychological well-being (range 0–25)					
10-year survivors	18 (3)	19 (4)	20 (4)	20 (4)	0.51
Controls ^a	19 (3)	20 (3)	20 (3)	19 (4)	0.22
Current problems as a consequence of cancer	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>n</i> (%)	<i>p</i> trend
Any problem ^b	18 (72)	39 (62)	25 (42)	14 (40)	0.002
Painful, numb or tingling arm	13 (52)	24 (38)	17 (28)	10 (29)	0.037
Fatigue	5 (20)	10 (16)	2 (3)	1 (3)	0.003
Co-morbidity ^c	12 (48)	35 (56)	33 (55)	24 (69)	0.14

****p*<0.001, significantly higher than control group

^aControls from CentERdata Health monitor¹¹: 45–54 years, *n*=149; 55–64 years, *n*=83; 65–74 years, *n*=66, 75+ years, *n*=10

^bSpontaneously reported answers to the question ‘Do you have specific complaints/restraints that are a consequence of cancer or its treatment?’ Problems with own appearance, fear and sexual problems were the other self-reported complaints

^c‘Do you have any other diseases at this moment?’ ‘If yes, which?’

(OR)=5.2, 95% confidence interval (CI)=1.4–19; data not shown].

The percentage of breast cancer survivors who had visited their GP in the past 12 months was not different from the

general female Dutch population (Table 3). As expected, the proportion of breast cancer survivors (79%) who visited a specialist in the past 12 months was much higher (53%; *p*<0.001). Young breast cancer survivors (45–54 and 55–

Table 3 Health care utilisation during the past 12 months in disease-free, 10-year breast cancer survivors and a control sample of the Dutch population

	Age at time of completing questionnaire (years)			
	45–54	55–64	65–74	75+
%Visited GP				
10-year survivors	88	85	85	90
Controls ^a	80	81	88	89
%Visited specialist				
10-year survivors	83***	78***	80**	79*
Controls ^a	44	49	59	58
%Visited physical therapist				
10-year survivors	56**	47**	31	32
Controls ^a	29	27	27	32
%Visited complementary caregiver				
10-year survivors	26*	10	11	10*
Controls ^a	13	10	8	3
%Contacted patient support group	9	10	2	11

GP General practitioner

**p*<0.05, significantly higher than control group

***p*<0.01, significantly higher than control group

****p*<0.001, significantly higher than control group

^aData collected by Statistics Netherlands in 2003

64 years of age) more often visited a physical therapist (56 and 47%) than the general female Dutch population (29 and 27%; $p < 0.01$). The youngest group (45–54 years of age) also visited a complementary caregiver twice as often compared to the general female Dutch population (26 vs 13%; $p < 0.05$). Factors predicting health care utilisation are summarized in Table 4. Contact with a GP or physical therapist in the past 12 months was clearly related to a worse subjective health status, psychological well-being, co-morbidity and spontaneously reported problems presumably as a consequence of cancer (more specifically, a painful arm). In addition, a physical therapist was significantly more often visited by younger survivors than by older survivors. With each point increase of the health status or psychological

well-being score (e.g. better score), the chance of contacting a specialist decreased with 10 and 20%, respectively. Contact with a complementary caregiver was also predicted by worse psychological well-being and spontaneously reported fatigue. Women who had undergone a breast amputation more often had contact with a patient support group than women who received radiotherapy (e.g. breast-conserving therapy) 10 years ago. Additional analyses with treatment combinations as presented in Table 1 gave no different results.

In multivariate analyses, including only variables that were significantly related in univariate analyses, none of the variables reached statistical significance anymore, most likely due to the small numbers.

Table 4 Univariate association between patient- and tumour characteristics at diagnosis, questionnaire outcome and health care utilisation during the past 12 months (before the study)

	Visited during past 12 months				
	General practitioner	Specialist	Physical therapist	Complementary caregiver	Patient support group
	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)	OR (95% CI)
Patient and tumour characteristics					
Current age (years)					
45–54	1.0	1.0	1.0	1.0	1.0
55–64	0.8 (0.2–3.1)	0.7 (0.2–2.4)	0.7 (0.3–1.8)	0.3 (0.1–1.2)	1.1 (0.2–6.1)
65–74	0.8 (0.2–3.2)	0.8 (0.2–2.9)	0.4 (0.1–1.0)*	0.3 (0.1–1.2)	0.2 (0.1–2.3)
75+	1.2 (0.2–6.5)	0.8 (0.2–3.1)	0.4 (0.1–1.1)	0.3 (0.1–1.5)	1.3 (0.2–8.3)
Stage at diagnosis					
I	1.0	1.0	1.0	1.0	1.0
II	0.9 (0.3–2.3)	0.7 (0.3–1.7)	0.7 (0.4–1.3)	1.3 (0.5–3.4)	2.7 (0.7–10.6)
III and IV	0.3 (0.1–1.5)	0.6 (0.1–2.6)	1.0 (0.3–3.5)	^a	^a
Treatment (yes vs no)					
Breast amputation	1.0 (0.4–2.4)	1.0 (0.5–2.3)	1.4 (0.7–2.6)	0.7 (0.3–1.9)	5.0 (1.3–19.3)*
Hormonal therapy	0.8 (0.3–2.6)	1.4 (0.4–4.4)	0.7 (0.3–1.7)	0.6 (0.1–2.6)	^a
Chemotherapy	0.8 (0.2–3.1)	2.3 (0.5–10.6)	1.4 (0.5–3.5)	2.1 (0.6–7.0)	1.6 (0.3–8.0)
Radiotherapy	0.9 (0.3–2.4)	1.6 (0.7–3.5)	1.0 (0.5–2.0)	1.0 (0.4–2.8)	0.2 (0.1–0.6)*
Questionnaire					
CentERdata Health monitor					
Health status	0.8 (0.7–0.9)*	0.9 (0.8–1.0)*	0.9 (0.9–1.0)*	1.0 (0.9–1.1)	1.0 (0.9–1.1)
Satisfaction with life	0.9 (0.7–1.0)	0.9 (0.8–1.0)	0.9 (0.8–1.0)	0.9 (0.8–1.0)	1.1 (0.9–1.4)
Psychological well-being	0.8 (0.7–0.9)*	0.9 (0.8–1.0)*	0.9 (0.8–1.0)*	0.9 (0.8–1.0)*	0.9 (0.8–1.1)
Co-morbidity					
0	1.0	1.0	1.0	1.0	1.0
1	3.7 (1.2–11.8)*	1.5 (0.6–3.9)	1.6 (0.7–3.5)	1.6 (0.4–5.3)	2.0 (0.5–8.1)
≥2	19.1 (2.5–148)*	2.1 (0.8–5.4)	2.5 (1.2–5.3)*	1.8 (0.6–5.5)	0.8 (0.2–3.9)
Current problems as a consequence of cancer (yes vs no)	2.8 (1.1–7.0)*	1.1 (0.5–2.4)	3.0 (1.6–5.9)*	2.8 (1.0–8.1)	4.3 (0.9–20.4)
Painful arm (yes vs no)	3.3 (1.1–10.2)*	1.2 (0.5–2.7)	2.1 (1.1–4.1)*	1.1 (0.4–2.7)	1.3 (0.4–4.2)
Fatigue (yes vs no)	1.5 (0.3–6.8)	4.5 (0.6–35.2)	2.3 (0.8–6.3)	6.2 (2.1–18.5)*	1.7 (0.3–8.6)

OR Odds ratio, CI confidence interval

* $p < 0.05$

^aNumbers were too small to calculate the OR

Discussion

Long-term breast cancer survivors had a similar self-reported health status and psychological well-being as the general female population of the same age, whereas satisfaction with life was higher among survivors. Yet, more than half of the survivors reported current health problems that they thought were related to having had cancer in the past. In particular, a painful, numb or tingling arm and fatigue were frequently reported. Breast cancer survivors also had a higher medical consumption as shown by more visits to a medical specialist, physical therapist and complementary caregiver compared to the general female Dutch population. Factors associated with health care utilisation were self-reported health status, psychological well-being, co-morbidity and spontaneously reported problems as a consequence of cancer (a painful arm and fatigue). Women who had undergone breast amputation were five times more likely to contact a support group than women who had had breast-conserving therapy.

Long-term breast cancer survivors generally experience a good overall quality of life, but do report specific health problems [12]. Arm problems [8, 13–17] and fatigue [3] are frequently reported. Both complaints have mainly or most severely been reported by women who were relatively young at diagnosis [8, 15, 16], whereas fatigue more often has been reported by women who had undergone chemotherapy [3, 18], in accordance with our results. It could be that younger women possibly live under greater physical strain compared to older women when diagnosed, as they often combine work, taking care of—younger—children and running a household [19]. However, older women might also be more inclined to attribute their health problems to old age rather than to their breast cancer treatment.

The percentage of long-term breast cancer survivors who visited their GP in the past 12 months was comparable to the general Dutch female population. Although self-reported health status, psychological well-being and cancer-related problems were associated with GP contact, co-morbidity appeared to be the strongest predictor in the past 12 months. A previous study among persons with at least one chronic disease, based on the Netherlands Health Interview Survey, also showed that co-morbidity was strongly associated with the volume and variety of used health care services [20]. In a Medicare-based study among older cancer survivors, remote history of cancer (>6 years earlier) did not influence emergency room visitation, hospital admission or nursing home admission, whereas co-morbid conditions did [21]. The failure to find an increased use of GP service among breast cancer survivors can possibly be explained by the already high proportion of women in the general population who visited their GP in the past 12 months (>80%). In accordance with our results, a recent study among 258 Norwegian breast cancer survivors showed that the use of GP care was similar to that of age-matched controls [22].

However, as in our results, the use of specialist health care services was significantly higher among Norwegian breast cancer survivors (49%) than that among controls (27%). The high proportion of breast cancer survivors who visited a medical specialist in the past 12 months in our study is probably due to the routine, annual follow-up examination that many women and doctors still prefer, even at 10 years after diagnosis. Breast cancer survivors in the Netherlands are usually seen once a year from the third year since diagnosis. An analysis based on Medicare data of 5,965 elderly women diagnosed with non-metastatic breast cancer showed that survivors, compared to controls, received high-quality preventive services. The authors suggest that follow-up may provide regular contact with the health system, maximizing the likelihood of receiving appropriate general medical care [23].

The higher utilisation of physical therapy among young breast cancer survivors (<65 years) was related to the arm problems in this group. Co-morbidity also was an important predictor for the use of physical therapy. Fortunately, introduction of the sentinel node technique in the late 1990s has resulted in fewer women with axillary lymph node dissection and its related arm problems and increased health care use [24–26].

Among the youngest (45–54 years old) and oldest (75+ years old) breast cancer survivors, the proportion of women that visited a complementary caregiver was increased compared to the general female Dutch population. Self-reported fatigue appeared to be the strongest predictor for visiting a complementary caregiver in the past year. The rationale of that can only be speculated. Canadian breast cancer survivors using complementary/alternative medicine (CAM) rated CAM practitioners more highly on ‘providing emotional support’ compared to conventional practitioners [27]. CAM users were younger, more educated, had greater household incomes, were more likely to have attended a support group and were more likely to have had chemotherapy than non-CAM users [27].

Additional analyses in our study showed that—after adjustment for age and co-morbidity—having received chemotherapy at diagnosis increased the risk of reporting fatigue by more than five times. This phenomenon, which is supported by other studies, should be weighed against the tendency to broaden the indication for (adjuvant) chemotherapy. High income, high education and young age were important predictors for the use of complementary alternative medicine [28, 29]. In agreement with our study, patients who initiated the use of complementary alternative medicine after breast cancer surgery reported more depression, worse general mental health and greater fear of recurrence, as compared to those who did not [30].

Breast cancer survivors who had a breast amputation 10 years ago were more likely to have contacted a patient support group during the past 12 months than survivors who received breast-conserving therapy and additional radiotherapy. This may be explained by the preservation of

the woman's female identity and acceptance of body configuration among the latter [3, 31].

There are a few limitations associated with this population-based study on health care use in cancer survivors. First, this study is based on self-reported health status, complaints, co-morbidity and health care use. Estimates of health care use may be unreliable because of the difficulty of dating and recalling the contacts with health care providers, although we do not expect that this possible information bias is different for survivors and controls.

The cross-sectional design makes it difficult to draw conclusions about the causal relationship between self-reported health status, complaints, co-morbidity and health care use. We do not know whether the rather small proportion of non-responders is that of those who have refused because of poor health or, in contrast, were in better health. Based on information about the age, stage and treatment, the non-responders did not differ very much from the responders when comparing demographic or medical information at initial diagnosis. Lastly, some of the subgroups were so small that it is possible that we introduced type II errors, i.e. not finding an association which is actually present.

Nevertheless, this population-based study has certain strengths, especially compared to survivorship studies in a clinical (trial) setting with selected patients. The high response rate makes it possible to extrapolate our findings to other long-term breast cancer survivors. Furthermore, having information about cancer stage and treatment modality at diagnosis assists the clinician in predicting further health care utilisation, although one should keep in mind that treatment since 1993 has changed.

In conclusion, although self-reported health, satisfaction with life and psychological well-being were similar or even better in long-term breast cancer survivors compared to those in population controls, survivors more often attended a specialist, physical therapist and complementary caregiver in the past 12 months. Survivors of young age appear to have the highest use of health care services compared to age-matched controls, especially related to fatigue and arm problems.

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