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Psychological distress and physical health in the year after diagnosis of DCIS or invasive breast cancer

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Abstract Ductal carcinoma in situ (DCIS) has an excellent prognosis, but its management can resemble that of early invasive breast cancer. We compared aspects of quality of life of women with DCIS to that of women with invasive disease during the first year after treatment initiation. Participants came from consecutive series of women with newly diagnosed, non-metastatic breast cancer treated in eight Quebec hospitals in 2003. Psychological distress and health-related quality of life were measured using the Psychiatric Symptom Index (PSI) and the SF-12 mental and physical component scales (MCS, PCS). Data were obtained 1, 6, and 12 months after the start of treatment. We used generalized linear models to compare mean scores and explored the possible clinical significance of between-group differences with effect size (ES). Participation and retention among eligible women were high, 86 and 97%, respectively. Among the 800 women who completed all interviews, 13.4% ($n = 107$) had DCIS and 86.6% (693) invasive disease. No statistically significant between-group differences were found at 1, 6, or 12 months in psychological state (PSI and MCS: P values from 0.065 to 0.904; ES from −0.01 to −0.21). Women with DCIS reported significantly higher levels of physical health, particularly when compared at 1 month to women with invasive disease who had chemotherapy (P value < 0.0001; ES $= 0.82$). Measured in symptoms of psychological distress, the better prognosis or less aggressive management of DCIS does not offset the general psychological effects of a cancer diagnosis to any great degree.

Keywords Breast cancer · Ductal carcinoma in situ · Psychological adaptation · Health-related quality of life · Psychological distress

Introduction

Increasing recourse to screening mammography in the past decades has led to the diagnosis of more ductal carcinoma in situ (DCIS). Indeed, DCIS now represents nearly 20% of all new screen-detected breast cancer [1]. The management of DCIS can resemble that of very early invasive cancer and currently can include breast surgery, radiotherapy, and hormone therapy but not axillary dissection or chemotherapy [2]. Prognosis for women diagnosed with DCIS is much better than for women with localized or regional invasive breast cancer: 10-year breast cancer survival for

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DCIS is about 98%, compared to 86 and 60% for invasive disease, which is localized or regional stage at diagnosis, respectively [3]. However, surveys conducted among health professionals in the United Kingdom and the United States indicate heterogeneity in their perceptions of DCIS and explanations given to patients [4, 5].

It is difficult to predict how the quality of life of women diagnosed with DCIS will be affected compared to that of women with invasive cancer. Knowing that survival is excellent after DCIS could be reassuring and if so, one might expect to see less distress and better health-related quality of life generally in women with this diagnosis compared to those with invasive disease. On the other hand, diagnosis of cancer, whatever its nature, could distress women independently of prognosis. As well, the quality of life of women with DCIS may be negatively affected given that they receive many of the same treatments as women diagnosed with invasive disease.

Although quality of life of women with DCIS has been studied [6–11] and compared to quality of life of women with invasive disease in two studies [12, 13], quality of life of these two groups of women was never compared at multiple points during the treatment trajectory. Our aim was to prospectively compare women diagnosed with DCIS to women with invasive breast cancer who had had or did not have chemotherapy, separately, in terms of psychological distress and health-related quality of life during the first year after treatment initiation.

Methods

Subjects

The design of this study has been described previously [14]. Briefly, consecutive series of women with a histologically confirmed new diagnosis of non-metastatic breast cancer first treated between January 1, 2003 and December 23, 2003 in one of eight hospitals in the province of Quebec who met study eligibility criteria were invited to participate in a study of costs associated with breast cancer. Women with previous breast or other cancer, distant metastasis at diagnosis or for whom a telephone interview was impossible (i.e. insufficient fluency in French, serious health problems) were ineligible. Women who died, had recurrence or a new primary cancer during the study period were also not considered in this analysis. Eligible participants were identified at each hospital through examination of operating lists for breast surgery and pathology reports. Detailed explanation of the study was provided to each potential participant by a nurse. Each participating hospital's Ethics Review Committee approved the study. All participants provided signed informed consent.

Data collection

Information on treatment and prognostic characteristics was collected from women's medical files. Histological type was categorized as DCIS or invasive breast cancer. Invasive cancer included invasive lobular, invasive ductal carcinoma, and special types of tumor as well as DCIS with microinvasion [2].

Data on psychological distress and quality of life were obtained through telephone interviews conducted 1, 6, and 12 months after the start of the woman's definitive treatment. General psychological distress was assessed using the 14-item Psychiatric Symptom Index (PSI) [15]. The PSI assesses the presence and intensity during the past 7 days of each of 14 symptoms, the majority related to anxiety and depression. Scores are expressed as a percentage of the maximum possible rating and can vary from 0 to 100; thus, higher scores indicate higher distress. The PSI was the principal measure of mental health in three population-based surveys of mental health in Quebec [15] and in our previous studies among breast cancer patients [16–18]. Among women in the present study, Cronbach alphas were $\geq$0.90 at each administration.

The mental and physical component summaries (MCS and PCS, respectively) from the SF-12 were used to measure mental and physical health-related quality of life [19]. Both the MCS and PCS are scored from 0 to 100, and higher scores indicate better quality of life. Scores for these scales were standardized to the US general population (mean = 50, standard deviation = 10) [19], and thus allow assessment of whether a group or individual has scores below or above the average for their country, age, or sex. Scores of Canadian women standardized in the same manner are very similar to scores of US women [20].

The first interview conducted 1 month after the start of definitive treatment also focused on socio-demographic and psychosocial characteristics possibly associated with psychological distress and quality of life generally. These included age, education, civil status, health conditions other than breast cancer, occupational status at diagnosis, family income, stressful life events, and social support [21].

Statistical analysis

With respect to the SF-12, 1 woman had missing data for all 12 items at the 6-month interview and so was not considered in this analysis. Fourteen other women (1.8%) failed to answer three or fewer items at one of the three interviews. Because complete data are required to calculate the MCS and PCS, which are composed of single items for each dimension included, for these women we used the mean of the missing item calculated among all similarly aged respondents within 10-year age groups [22]. Women's PCS and MCS means with or without this imputation were virtually identical.

A generalized linear model with an identity link function and normal errors was used to compare mean PSI, MCS, and PCS scores of women diagnosed with DCIS to those of women with invasive disease who had had or did not have chemotherapy, separately (GENMOD procedure) [23]. Correlations over time were taken into account by means of generalized estimating equations. The potential modifying effect of age and type of mastectomy on mean differences was evaluated by including appropriate interaction terms in the models. We also assessed the effects of potential confounders among socio-demographic (age, education, civil status, health conditions other than breast cancer, occupational status at diagnosis, family income) and psychosocial characteristics (stressful life events and social support) by comparing crude and adjusted effect estimates in both stratified and multivariate analyses. None of these variables was found to be a confounder as crude and adjusted betas measuring the difference between the groups hardly differed. However, in order to isolate any effect of chemotherapy, we did control for adjuvant radio- and hormone therapy. Two-sided score tests were used to assess statistical significance of mean differences and effects of time and time by group interactions.

We explored the possible clinical significance of mean differences between women with DCIS and invasive cancer by considering these differences in terms of effect size (ES). We calculated effect size as the difference in mean scores of women diagnosed with DCIS and those diagnosed with invasive cancer who had had or did not have chemotherapy divided by an estimate of the pooled standard deviation (square root of the deviance divided by its degrees of freedom) [24]. Effect sizes of 0.20–0.49 are generally considered to be small, 0.50–0.79 medium, and $\geq$0.80 large [25]. Recent evidence suggests that an effect size of 0.5 corresponds to a minimum perceptible difference and thus may represent a clinically important difference [26]. We also assessed differences between groups based on the proportions with a high PSI score ($\geq$26.2/100) using the cut-off for high distress established in 1987 for the Quebec population [15]. For MCS and PCS scores, we compared proportions in each group with scores that were 1 standard deviation above the mean scores. However, these latter two analyses are not presented as results did not change the interpretation presented here. All analyses were performed using SAS software (SAS 9 Institute, Cary, NC).

Results

During the study period, 1,397 women with breast cancer were identified. Of 962 patients meeting the cost study eligibility criteria, 829 (86.2%) consented to participate and completed the 1-month interview and 800 of the 962 initially eligible women (83.2%) completed all the three interviews. The 1-, 6-, and 12-month interviews were conducted on average 36 ± 17, 184 ± 15, and 365 ± 12 days after treatment start, respectively. Among the 800 participants, 13.4% ($n = 107$) had DCIS and 86.6% ($n = 693$) invasive breast cancer. Other disease and treatment characteristics are presented in Table 1.

Compared to women with invasive disease, whether or not they had had adjuvant chemotherapy, women with DCIS reported slightly lower levels of distress at each time point, but the mean differences between groups were small, not statistically significant, and effect sizes were mostly negligible or very small (ES from −0.03 to −0.21) (Table 2). Psychological distress declined in all three groups but the pattern of decline differed according to the type of breast cancer (P for the time-type of disease interaction: 0.028) (data not shown). For the MCS, differences between women with DCIS and those with invasive breast cancer were even smaller and all effect sizes negligible (ES from −0.1 to 0.15).

Finally, women diagnosed with DCIS did report significantly higher levels of physical health on the PCS, compared to women with invasive cancer. Sizeable differences were seen primarily for comparisons of DCIS to invasive disease plus chemotherapy (ES = 0.82; ES = 0.70; ES = 0.41 at 1, 6, and 12 months following treatment initiation, respectively), but only at the first interview when DCIS was compared to invasive disease without chemotherapy (ES = 0.55; ES = 0.17; ES = 0.10 at 1, 6, and 12 months following treatment initiation, respectively; P for the time-type of disease interaction < 0.0001).

Discussion

In the first year after the start of definitive treatment, women with DCIS experienced mental health levels that were generally comparable to those among women with invasive breast cancer, whether or not they had had adjuvant chemotherapy. No statistically significant or clinically important between-group difference was found on either of the two different mental health measures used here. One measure, the PSI, concentrates on symptoms of anxiety and depression, while the SF-12 MCS—a generic measure—assesses a broader concept of mental health including effects of mental health on daily and social functioning. However, women with DCIS reported better physical health than women with invasive disease in the initial months following treatment initiation.

These findings from a prospective cohort study advance our understanding of the effects of both DCIS and invasive

Table 1 Characteristics of 800 women newly diagnosed with non-metastatic breast cancer

Characteristics	DCIS		Invasive breast cancer	
	n = 107		*n* = 693	
	%	(*n*)	%	(*n*)
Socio-demographic and psychosocial characteristics				
Age at start of definitive treatment (years)				
23–49	20.6	(22)	29.7	(206)
50–88	79.4	(85)	70.3	(487)
Mean ± SD (years)	55.9 ± 9.2		55.5 ± 10.3	
Range (years)	23–78		29–88	
Highest level of completed education				
High school or less	57.9	(62)	49.4	(342)
Collegial level or university	42.1	(45)	50.6	(351)
Working at diagnosis	53.3	(57)	58.0	(402)
Living with a partner	70.1	(75)	67.4	(467)
Social support[a]				
Low (0.0–66.6)	19.6	(21)	17.2	(119)
High (66.7–100)	80.4	(86)	82.8	(572)
Stressful life events 12 months before diagnosis (number)				
0	37.4	(40)	41.4	(287)
1	36.4	(39)	31.9	(221)
2–6	26.2	(28)	26.7	(185)
Medical characteristics				
Type of mastectomy				
Partial	89.7	(96)	78.1	(541)
Total	10.3	(11)	21.8	(151)
No breast surgery	0.0	(0)	0.1	(1)
Most invasive axillary procedure				
No axillary procedure	94.4	(101)	5.5	(38)
Sentinel node biopsy	0.9	(1)	16.3	(113)
Axillary dissection	4.7	(5)	78.2	(542)
Presence of axillary invaded nodes (*n* = 661)				
No	100.0	(6)	62.7	(411)
Yes	0.0	(0)	36.9	(242)
Unknown	0.0	(0)	0.3	(2)
Had chemotherapy	0.0	(0)	54.1	(375)
Had radiotherapy and/or brachytherapy	84.1	(90)	87.0	(603)
Receiving hormone therapy	40.2	(43)	80.2	(556)
Number of types of adjuvant treatments				
0	8.4	(9)	1.0	(7)
1	58.9	(63)	11.7	(81)
2	32.7	(35)	52.2	(362)
3	0.0	(0)	35.1	(243)
Number of other health conditions than breast cancer limiting daily activities				
0	84.1	(90)	86.9	(602)
≥1	15.9	(17)	13.1	(91)

[a] Based on six items from the index of social support developed by Santé Québec for their 1992–1993 population-based survey. Low support indicates that the patient's score was in the lowest quartile of scores for the entire cohort of 800 women studied. Two women diagnosed with invasive cancer having missing values

disease on women's mental state during the first year after diagnosis. First, there were no significant differences in psychological measures between groups during one-year period. One previous study also reported similar levels of psychological distress in the two groups of women after the start of treatment, but participants were only assessed once right after surgery, and the number of women studied was somewhat smaller [13]. A Dutch study reported no

Table 2 Psychological distress and health-related quality of life among women with ductal carcinoma in situ (DCIS) and women with invasive breast cancer according to whether or not they had adjuvant chemotherapy, during the first year after the start of definitive treatment (adjusted for age, radiotherapy, and hormone therapy)

	DCIS ($n = 107$)	Invasive breast cancer							
		No adjuvant chemotherapy ($n = 317$)				Adjuvant chemotherapy ($n = 376$)			
Outcomes	Mean (CI 95%)	Mean	Mean difference[d]	*P* value for mean difference	ES[e]	Mean	Mean difference[d]	*P* value for mean difference	ES[e]
Psychological									
PSI[a]									
1 month	22.2 (18.7–25.7)	22.8	−0.6	0.772	−0.03	25.9	−3.7	0.065	−0.21
6 months	20.4 (17.0–23.8)	22.7	−2.3	0.249	−0.13	23.7	−3.3	0.092	−0.19
12 months	19.5 (16.2–22.7)	22.1	−2.6	0.178	−0.15	21.2	−1.7	0.361	−0.10
MCS[b]									
1 month	46.9 (44.6–49.2)	48.1	−1.3	0.353	−0.12	45.9	1.0	0.471	0.09
6 months	49.9 (47.9–51.8)	49.3	0.6	0.626	0.05	48.3	1.6	0.169	0.15
12 months	50.0 (48.0–51.9)	49.3	0.6	0.577	0.06	50.1	−0.1	0.904	−0.01
Physical									
PCS[c]									
1 month	46.5 (44.4–48.5)	40.7	5.8	<0.0001	0.55	37.8	8.6	<0.0001	0.82
6 months	46.4 (44.2–48.6)	44.6	1.8	0.160	0.17	39.1	7.3	<0.0001	0.70
12 months	48.4 (46.3–50.4)	47.3	1.1	0.364	0.10	44.1	4.3	0.0004	0.41

CI Confidence interval; *DCIS* ductal carcinoma in situ; *ES* effect size

[a] PSI: Psychiatric Symptom Index: higher scores indicate greater distress

[b] MCS : Mental component summary: higher scores indicate better function. One missing value at 6 months among women diagnosed with DCIS

[c] PCS : Physical component summary: higher scores indicate better function. One missing value at 6 months among women diagnosed with DCIS

[d] Calculated as DCIS minus invasive

[e] Small ES: 0.2–0.49; medium ES: 0.5–0.79; large ES: ≥0.8. ES ≥ 0.5 maybe considered clinically important

difference in adjustment after DCIS or invasive disease, but these women were studied 2–3 years after treatment, thus quite a bit later than in our study [12]. Even if women with DCIS may be cognizant of certain facts concerning their specific diagnosis, this does not seem to translate directly into lower distress because of an understanding of the more favorable prognosis associated with DCIS [27, 28]. Others have reported that although a greater proportion of women with DCIS than with invasive disease could accurately report their diagnosis and specific information about it, women with DCIS and invasive disease had similar perceptions of their risk of recurrence [12, 13].

Second, the two measures of mental health we used provide complementary information about the psychological effects of DCIS. Levels of general psychological distress measured by the PSI were probably higher for the women in this study than among similarly aged women from the Quebec general population, particularly in the first months following treatment initiation. In a previous study [29], we compared women with breast cancer to 4,557 women of the general population. The estimated mean PSI score for the general population after standardization for age was 15.8/100 (95% confidence interval: 15.2–16.4) (unpublished data), which is considerably lower than 1-month scores reported by women with DCIS in this study (mean = 22.2/100: 95% confidence interval: 18.7–25.7). This difference corresponds to women with DCIS reporting almost two more symptoms of distress at maximal intensity. However, general psychological distress did not appear to negatively affect daily and social functioning to any great degree as reflected by MCS scores. Indeed, MCS scores of both women with DCIS and invasive disease were very similar to the MCS population norms for women from the Canadian and US adult populations (50.9/100 and 49.4/100, respectively) [19, 20]. Others have also observed that with time, in many regards, generic quality of life of both women with DCIS and those with invasive disease comes to resemble that of women who have not faced cancer [11, 12, 18, 30].

Third, our findings demonstrate the role of chemotherapy in contributing to any differences between DCIS and invasive disease in terms of physical health-related quality of life. The main differences in perceived physical health that lasted for the first 6 months were seen when comparing women with DCIS to women with invasive disease who received chemotherapy. However, it should be emphasized that by 1 year after the start of treatment, when adjuvant treatment had been completed, differences between the DCIS and either invasive disease group were probably not clinically important.

Our study has a number of strengths. It is, to our knowledge, the first longitudinal study to compare both psychological and physical dimensions of health-related quality of life of women with DCIS and invasive breast cancer who were interviewed at similar time points during the 12 months after diagnosis, a conceptually important period that covers both active treatment and recovery. As well, the study was based on women from consecutive series of patients diagnosed and treated in different hospitals and geographical regions in Quebec. Participation among eligible women and retention of participants for all three interviews were both excellent, 86 and 97%, respectively. Thus, our results are likely to be relevant to North American women in treatment settings applying evidence-based treatment and comprehensive care of women with breast cancer.

A possible limitation of this study is that psychological distress and quality of life were first assessed 1 month after the first treatment received. The decision to conduct the first interview 1 month after the start of treatment was made so that we could measure the financial costs associated with surgery [14], which is still the first treatment for virtually all women with breast cancer. By 1 month, distress might conceivably have declined somewhat compared to the period immediately after diagnosis as some women may feel relieved that treatment has started. However, even if we had measured distress earlier, even closer to diagnosis, we think the results would have been similar. Among women recruited for a study of their own and their spouse's quality of life in the year after diagnosis of breast cancer [29] in which women were first interviewed 1 week after treatment start, we also found no difference in distress using the PSI among the 32 women with DCIS compared to the 275 women with invasive disease (unpublished data). However, measures that are more disease-specific than the generic measures we used—mental health-related quality of life and symptoms of anxiety and depression—might capture some differences between these groups.

These results have implications for clinical practice and policy. Healthcare professionals working with these women need to be aware that women with DCIS may need as much psychological support as women with invasive disease, because the better prognosis or less aggressive management associated with DCIS does not offset the general psychological effects of a cancer diagnosis to any great degree. Concerning healthcare policy, our results indicate that policy makers involved in cancer care planning should not base their decisions about the allocation of psychosocial resources for supportive care for breast cancer patients on type of diagnosis.

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