A comparison of quality of life, disease impact and risk perception in women with invasive breast cancer and ductal carcinoma in situ

van Gestel, Y.R.B.M.; Voogd, A.C.; Vingerhoets, A.J.J.M.; Mols, F.; Nieuwenhuijzen, G.A.P.; Repelaer van Driel, O.J.; Berlo, C.L.H.; van de Poll-Franse, L.V.

Published in:
European Journal of Cancer: Official journal for European Organization for Research and Treatment of Cancer (EORTC)

Publication date:
2007

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
van Gestel, Y. R. B. M., Voogd, A. C., Vingerhoets, A. J. J. M., Mols, F., Nieuwenhuijzen, G. A. P., Repelaer van Driel, O. J., Berlo, C. L. H., & van de Poll-Franse, L. V. (2007). A comparison of quality of life, disease impact and risk perception in women with invasive breast cancer and ductal carcinoma in situ. *European Journal of Cancer: Official journal for European Organization for Research and Treatment of Cancer (EORTC)*, *43*(3), 549-556.

EUROPEAN JOURNAL OF CANCER 43 (2007) 549–556

available at www.sciencedirect.com

journal homepage: www.ejconline.com

A comparison of quality of life, disease impact and risk perception in women with invasive breast cancer and ductal carcinoma *in situ*

Y.R.B.M. van Gestel[a], *A.C. Voogd*[b,*], *A.J.J.M. Vingerhoets*[c], *F. Mols*[c,g], *G.A.P. Nieuwenhuijzen*[d], *O.J. Repelaer van Driel*[e], *C.L.H. van Berlo*[f], *L.V. van de Poll-Franse*[g]

[a]*Institute for Health Sciences, Faculty of Earth and Life Sciences, Free University Amsterdam, The Netherlands*
[b]*Department of Epidemiology, Maastricht University, P.O. Box 616, 6200 MD, Maastricht, The Netherlands*
[c]*Department of Psychology and Health, Tilburg University, Tilburg, The Netherlands*
[d]*Department of Surgery, Catharina Hospital, Eindhoven, The Netherlands*
[e]*Department of Surgery, Máxima Medical Center, Eindhoven, The Netherlands*
[f]*Department of Surgery, VieCuri Medical Center, Venlo, The Netherlands*
[g]*Comprehensive Cancer Center South (CCCS), Eindhoven Cancer Registry, Eindhoven, The Netherlands*

ARTICLE INFO

Article history:
Received 29 June 2006
Received in revised form
3 October 2006
Accepted 23 October 2006
Available online 30 November 2006

Keywords:
Breast cancer
Ductal carcinoma *in situ*
Heath-related quality of life
Risk perception
Disease impact
Well-being

ABSTRACT

We compared the health-related quality of life, impact of the disease, risk perception of recurrence and dying of breast cancer, and understanding of diagnosis of patients with ductal carcinoma *in situ* (DCIS) and invasive breast cancer 2–3 years after treatment. We included all women ($N = 211$) diagnosed with DCIS or invasive breast cancer TNM stage I (T1, N0, and M0) in three community hospitals in the southern part of The Netherlands in the period 2002–2003. After verifying the medical files, 180 disease free patients proved eligible for study entry, 47 of whom had DCIS and 133 stage I invasive breast cancer. One-hundred and thirty-five patients returned a completed questionnaire (75% response). No significant differences were found between women with DCIS and invasive breast cancer on the physical and mental component scale of the RAND SF-36, nor on the WHO-5, which assesses well-being. In contrast, women with DCIS reportedly had a better physical health, better sex life and better relationships with friends/acquaintances than women with invasive breast cancer. Despite their better prognosis, the DCIS-group had comparable perceptions of the risk of recurrence and dying of breast cancer as women with invasive breast cancer. However, this did not appear to affect their well-being significantly.

1. Introduction

Because of the expanded use of screening mammography during the past two decades, ductal carcinoma *in situ* (DCIS) is diagnosed with increasing frequency.[1,2] At initial screening mammography, 15–40% of the detected cases of breast cancer represent DCIS.[1] The prospect to be cured of DCIS is almost 100%, while the chance of being cured of invasive breast cancer TNM stage 1 is currently approximately 80%.[2]

To date little attention has been paid to the long-term health-related quality of life (HRQL) of women with DCIS. DCIS and invasive breast cancer are both associated with physical and psychological distress, including anger, depression and fear for recurrence and dying of the disease.[3] Given

---

[*] *Corresponding author*: Tel.: +31 43 3882387; fax: +31 43 3884128.
E-mail address: adri.voogd@epid.unimaas.nl (A.C. Voogd).

0959-8049/$ - see front matter © 2006 Elsevier Ltd. All rights reserved.
doi:10.1016/j.ejca.2006.10.010

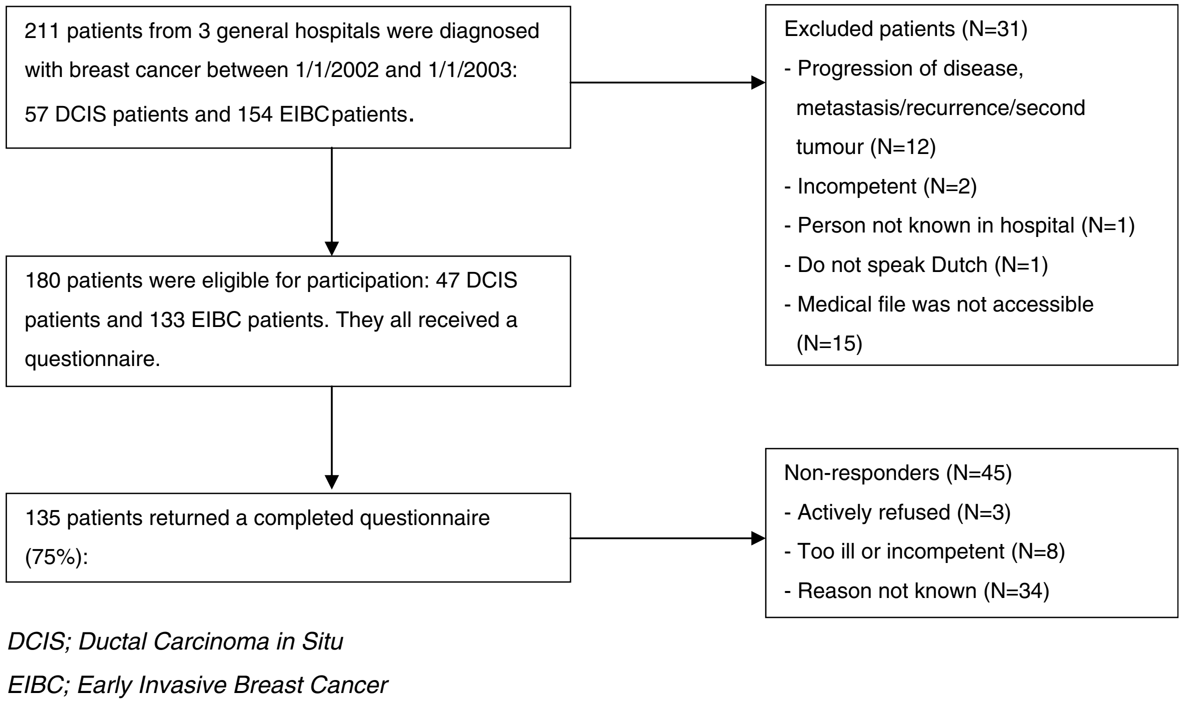
the better prognosis of DCIS, it might be expected that women with DCIS report a better well-being and HRQL compared to women with invasive breast cancer. However, an American study among 76 DCIS patients demonstrated that approximately two years after diagnosis, one third of the patients still expressed fear about breast cancer, recurrence and metastasis,[3] indicating that such worries may persist several years after diagnosis and completion of treatment. There was a close correspondence between the concerns of women with DCIS about recurrence and those of women with invasive breast cancer.[3] It was not clear whether this was due to the lack of adequate information the patients received from the treating medical specialists or to other factors. A Canadian study including 64 women with DCIS and 164 women with invasive breast cancer also revealed no significant difference in distress and risk perception of DCIS and invasive breast cancer patients four months after treatment.[4] Despite the better prognosis, women with DCIS reported the same level of psychological morbidity and their risk perception of recurrence and dying of breast cancer was also similar to women with invasive breast cancer.[4] These remarkable findings of both studies may be explained in two ways. Patients with invasive breast cancer could have underestimated their risk or, alternatively, women with DCIS overestimated their risk. In addition, the timing of the measurements may be a crucial factor. For example, the patients of the Canadian study completed the questionnaire shortly after their surgical procedure which can explain why women with DCIS expressed similar concerns as patients with invasive breast cancer.[4]

In the present study, we compared the HRQL, perceived disease impact and risk perception of recurrence and dying of breast cancer of patients with DCIS and early-stage invasive breast cancer (EIBC) 2–3 years after treatment. In addition, a comparison was made with HRQL norm data from an age-matched population of Dutch women. Finally, we evaluated the women's understanding of their disease. Given the findings of the studies by Bluman and colleagues[3] and Rakovitch and colleagues,[4] we expected that Dutch women with DCIS have the same level of fear and similar worries as women with invasive breast cancer, implying that surgeons or nurse-practitioners should put extra effort in explaining the differences between both disease entities.

2. Patients and methods

2.1. Patients

The population-based Eindhoven Cancer Registry (ECR) of the Comprehensive Cancer Centre South (CCCS) was used to select all women ($N = 211$) who were diagnosed with DCIS or invasive breast cancer TNM stage I (T1, N0, and M0) in the period of January 2002 – December 2003 in three community hospitals in the southern part of the Netherlands. Information about date of birth, gender, tumour stage and treatment are routinely collected by trained registration clerks of the ECR. Thirty-two patients with TNM stage I invasive breast cancer who had undergone axillary node dissection were excluded, as were patients with a previous diagnosis of cancer (including invasive breast cancer and DCIS), because these factors might influence the HRQL significantly.[5] A trained registration clerk from the ECR checked the medical files to exclude patients with a loco-regional recurrence or metastatic disease and non-Dutch speaking patients. After checking the medical files, 180 patients proved eligible for study entry, 47 of whom had DCIS and 133 stage I invasive breast cancer (Fig. 1).



211 patients from 3 general hospitals were diagnosed with breast cancer between 1/1/2002 and 1/1/2003: 57 DCIS patients and 154 EIBC patients.

Excluded patients (N=31)
- Progression of disease, metastasis/recurrence/second tumour (N=12)
- Incompetent (N=2)
- Person not known in hospital (N=1)
- Do not speak Dutch (N=1)
- Medical file was not accessible (N=15)

180 patients were eligible for participation: 47 DCIS patients and 133 EIBC patients. They all received a questionnaire.

135 patients returned a completed questionnaire (75%):

Non-responders (N=45)
- Actively refused (N=3)
- Too ill or incompetent (N=8)
- Reason not known (N=34)

DCIS; Ductal Carcinoma in Situ

EIBC; Early Invasive Breast Cancer

Fig. 1 – Study population.

2.2. Logistics

Mailing of questionnaires at each participating hospital was coordinated and facilitated by the CCCS. The surgeons sent their patients a letter to inform them about the study together with the questionnaire. The patients also received a stamped return-envelope in which they could return the completed questionnaires, which only contained a study number preventing the researchers from tracking patient names by means of the patient numbers. All questionnaires were sent in May and June 2005. Completion of the self-administrated questionnaire was considered to imply informed consent.

2.3. Data collection and questionnaires

The questionnaire included questions about marital status, level of education (low = primary school; medium = secondary school; high = college/university) and current (at the time of survey) co-morbid conditions (asthma, COPD, heart diseases, hypertension, stroke, renal disease, diabetes mellitus, tumours, osteoarthritis, rheuma, skin diseases, liver disease and thyroid disease). In addition, HRQL, well-being, perceived disease impact, risk perception and understanding of the diagnosis were assessed as the main outcome variables.

HRQL was assessed by using the Dutch version of the RAND SF-36 validated in Dutch cancer patients,[6] and well-being with the WHO-5.[7] As far as we know, the WHO-5 has not been used in cancer patients before. The Dutch version of the RAND SF-36 incorporates two composite scales;[8] the physical component scale (PCS) containing the sub-domains: physical functioning (PF), role limitations due to physical health problems (RP), bodily pain (BP) and general health perceptions (GH) and the mental component scale (MCS) containing the sub-domains: role limitations due to emotional problems (RE), general mental health (MH), vitality (VT) and social functioning (SF).[6] Each domain and summary scale is standardised on a scale from 0 to 100, with higher scores indicating better functioning. In accordance with the guidelines of the SF-36 Health Survey Manual,[9] the overall score was imputed by substituting the person specific mean scores for the completed items on that particular scale when less than 50% of the items for a particular SF-36 scale were missing. If more than half of the items for a scale were missing, that scale was considered as missing for that individual. One woman with DCIS and five with EIBC had missing scales on the SF-36. In order to compare the HRQL of women with breast cancer with the general Dutch population, SF-36 scores available from age-matched controls of the general Dutch population were used.[6]

The WHO-5 contains five positively stated items.[7] Each of the five items is rated on a 6-point Likert scale from 0 (=not present) to 5 (=constantly present). The score was obtained by adding these five items. The theoretical score ranges from 0 (worst thinkable well-being) to 25 (best thinkable well-being), so higher scores mean better well-being. A score below 13 indicates poor well-being.[7] Missing data were handled in a similar way as for the SF-36; women had to have three or more (out of five) items completed in order to compute an overall score. One woman with DCIS and four with EIBC had missing scales on the WHO-5.

The perceived disease impact scale (PDIS) was newly developed to measure the influence of the illness on various life domains, including well-being, lifestyle, activities, relationships, work, personality, interests and trust in own body. Its 20 items were based on several sources, such as the Illness Intrusiveness scale,[10] a similar instrument to assess the impact of depression,[11] and the literature on the effects of cancer[12] and multiple sclerosis[13] on the lives of patients. The response format consisted of a 7-point Likert scale ranging from 'very negatively' (−3) to 'very positively' (+3). The following scores were derived: (1) the grand mean, averaged over all items; and following Sears and colleagues (2) the identification of any positive effect (dichotomous coding, 0 = no single positive effect *versus* 1 = at least one perceived benefit) and (3) the number of items with, respectively, a positive, a negative and a neutral score.[14]

To assess the risk perception of recurrence and dying of breast cancer, the patient completed six questions originating from the study by Rakovitch and colleagues.[4] Three of these eight items concern the woman's estimate of her own risk of developing local recurrence, developing distance recurrence and dying of breast cancer and three items were more general items on risk perception issues. The patients were asked to answer these questions by giving an absolute percentage.

The women's understanding of their diagnosis was also measured by means of two questions from the study by Rakovitch and colleagues.[4] First, the patient had to describe her disease in an open question. In addition, on an illustration depicting a normal breast, DCIS and invasive breast cancer, respectively, the patient was requested to mark the term which she felt describes her type of breast cancer best.

2.4. Statistical analysis

All data were analysed using SAS (Version 8.02, SAS Institute Inc., Cary, NC, USA). Routinely collected data from the Eindhoven Cancer Registry (ECR) on patient and tumour characteristics enabled us to compare the group of non-respondents with the group of respondents. The group of DCIS patients and the group of invasive breast cancer patients were compared by using χ^2 tests for categorical variables. For continuous outcome variables, we used *t*-tests or Wilcoxon's signed rank test when appropriate.

3. Results

3.1. Patient and treatment characteristics

Fig. 1 describes the patient flow in this study. Of the 180 patients who received our questionnaire, 135 patients returned a completed questionnaire (75% response). The demographic characteristics of the overall respondents and non-respondents were not significantly different (data not shown). Mean age at the time of completing the questionnaire was 61 years for the women with DCIS (N = 33) and 59 years for the women with invasive breast cancer (N = 91). The women with DCIS did not differ from the patients with invasive breast cancer with respect to age distribution, level of education and co-morbidity, but were somewhat more likely to be married

Table 1 – Baseline characteristics of women with dutcal carcinoma in situ (DCIS) and early invasive breast cancer (EIBC)

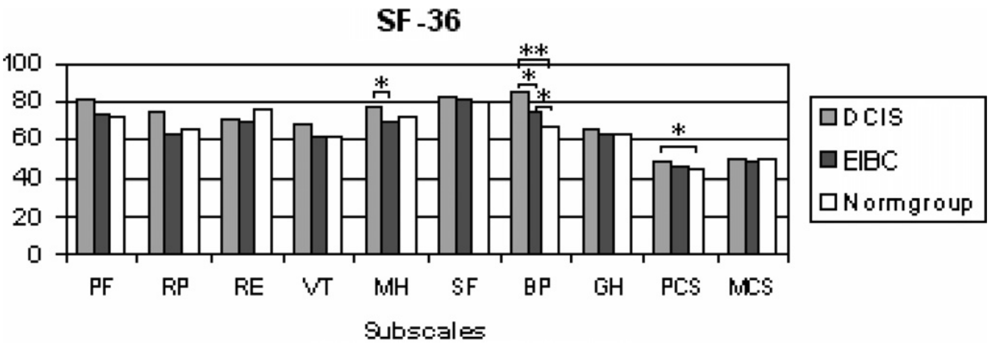
Characteristic	DCIS (*N* = 33)		EIBC (*N* = 91)		*P*-value
	N	(%)	*N*	(%)	
Age at survey					
< 50	4	(12)	18	(20)	0.61
50–69	21	(64)	54	(59)	
70+	8	(24)	19	(21)	
Marital status					
Married	28	(88)	57	(63)	0.07
Not married	2	(6)	11	(12)	
Divorced	1	(3)	7	(8)	
Widow	1	(3)	16	(18)	
Education level					
Low (primary school)	10	(30)	35	(38)	0.67
Median (secondary school)	16	(48)	41	(45)	
High (college/ university)	7	(21)	15	(17)	
Current number of co-morbid conditions					
0	19	(58)	35	(38)	0.28
1	9	(27)	35	(38)	
2	3	(9)	10	(11)	
> 2	2	(6)	11	(12)	
Treatment					
Breast-conserving therapy	19	(58)	78	(86)	<0.001
Sentinel node biopsy	19	(58)	91	(100)	<0.001
Radiotherapy	18	(56)	78	(86)	<0.001
Chemotherapy	0	(0)	13	(14)	0.02
Hormonal therapy	0	(0)	10	(11)	0.04

(*P* = 0.07) (Table 1). Women with invasive breast cancer were more likely to have had breast-conserving therapy (*P* < 0.001), sentinel node biopsy (*P* < 0.001), radiotherapy (*P* < 0.001) and chemotherapy (*P* = 0.02) or hormonal therapy (*P* = 0.04).

3.2. *Health-related quality of life and well-being*

The mean scores on the SF-36 summary scales and domains were compared between patients with DCIS and invasive breast cancer and the available norm data of Dutch women in the same age range. No significant difference was found between women with DCIS and invasive breast cancer on the physical and the mental component scale. Women with DCIS had a significantly better score on the subscales bodily pain (85.4 *versus* 75.2, P = 0.02) and general mental health (77.8 *versus* 70.5, P = 0.05) compared to women with invasive breast cancer. On the subscales bodily pain and the physical component scale, women with DCIS scored significantly higher than the norm data (85.4 *versus* 67.1, P < 0.001) and (49.6 *versus* 44.9, P < 0.05), respectively (Fig. 2). Women with invasive breast cancer also had a significantly better score on the subscale bodily pain compared to the Dutch population (75.2 *versus* 67.1, P < 0.05) (Fig. 2).

Twenty-one percent of the women with DCIS and 35% of women with invasive breast cancer had a WHO-5 score below 13, which indicates poor well-being (P = 0.14). Mean scores of women with DCIS and invasive breast cancer were 16.3 and 14.4, respectively (*P* = 0.06). These scores were not different from the score in the general Dutch female population of the same age, which was 15.3. The results of both the SF-36 and the WHO-5 did not change after adjustment for differences between the two groups with respect to the type of surgery and adjuvant systemic treatment.



* P < 0.05; ** P < 0.001

PF = Physical Functioning
RP = Role Limitations due to Physical Health Problems
RE = Role Limitations due to Emotional Problems
VT = Vitality
MH = Mental Health

SF = Social Functioning
BP= Bodily Pain
GH = General Health Perception
PCS = Physical Component Scale
MCS = Mental Component Scale

Fig. 2 – Mean scores on the RAND SF-36 of women with dutcal carcinoma in situ (DCIS), early invasive breast cancer (EIBC) and the general Dutch population.

The correlation between the WHO-5 and the physical component scale of the SF-36 was 0.58 ($P < 0.001$) and between the WHO-5 and the mental component scale of the SF-36 0.67 ($P < 0.001$). There was no association between low score on the WHO-5 (<13) and risk perception.

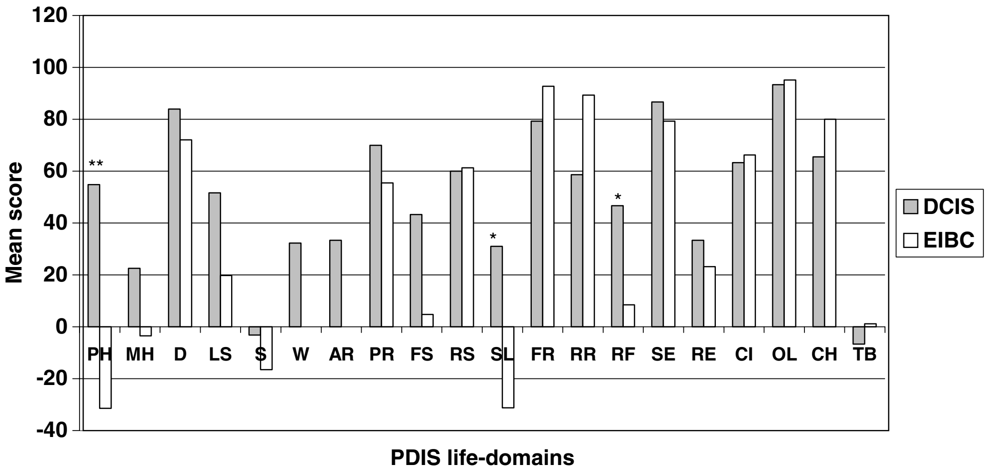
3.3. *Perceived disease impact scale*

Fig. 3 represents the mean effects of the disease and its treatment on the different PDIS life-domains. Both the patients with DCIS and the patients with invasive breast cancer reported a positive effect on most life-domains. The most positive influence of the disease was seen on family relations, relationships with relatives, self-expression and the outlook on life. Women with DCIS experienced a more positive or less negative effect on their physical health ($P < 0.001$), sex life ($P = 0.03$) and relationships with friends/acquaintances ($P = 0.01$) than women with invasive breast cancer. Comparison of the mean numbers of negative, neutral and positive scored items revealed that patients with invasive cancer reported significantly more negative effects than those with DCIS. For both groups the reported number of positive effects was significantly greater than the number of negative effects ($P < 0.001$). Women with DCIS reported a positive effect of their disease on 18 of the 20 items and women with invasive breast cancer reported a positive effect on 16 of the 20 items.

3.4. *Risk perception and insight into the disease*

Women with DCIS and invasive breast cancer reported comparable risk perceptions concerning the risk of recurrence and dying of their disease (Table 2). In contrast, women with invasive breast cancer felt it more likely that the medical treatment was doing them more harm than good ($P = 0.01$).

When asking women to describe their disease in an open question, women with DCIS often reported the term calcifications whereas women with invasive breast cancer frequently described their disease as a (malignant) tumour. Women with DCIS were significantly more accurate in stating their diagnosis compared to women with invasive breast cancer ($P = 0.02$). Of the women with DCIS, 56% stated their diagnosis correctly, by marking the correct illustration, compared to only 21% of the women with invasive breast cancer. Approximately one third of the women with invasive breast cancer marked the illustration which represented DCIS (data not shown).



* P < 0.05; ** P < 0.01

PH = Physical health
MH = Mental health
D = Diet
LS = Life style
S = Stress
W = Work
AR = Active recreation
PR = Passive recreation
FS = Financial situation
RS = Relationship with spouse
SL = Sex life
FR = Family relations
RR = Relationships with relatives
RF = Relationships with friends/ acquaintances
SE = Self-expression/ self-improvement
RE = Religious expression
CI = Community and civic involvement
OL = Outlook on life
CH = Character
TB = Trust in own body

Fig. 3 – Mean individual item scores on the perceived disease impact scale of women with dutcal carcinoma *in situ* (DCIS) and early invasive breast cancer (EIBC).

4. Discussion

The results of this population-based study suggest that patients with DCIS have a similar HRQL and well-being as patients with invasive breast cancer. Also their concerns about the risk of recurrence and dying of breast cancer were generally comparable. On the physical component scale and the mental component scale, women with DCIS had similar scores compared to women with invasive breast cancer. Unexpectedly both groups experienced less bodily pain compared to the Dutch norm population. Women with DCIS also had better score on the physical component scale than the average Dutch woman with the same age. Similar findings have been reported previously and are probably due to the so-called response shift.[15] Response shift includes changes in the meaning of one's self-evaluation of HRQL resulting from changes in internal standards, values, or conceptualisation.[16] The results were not different after adjusting for type of surgical treatment and the use of adjuvant systemic therapy.

Both groups reported more positive than negative effects of their disease on the different life-domains of the perceived disease impact scale. However, for patients with invasive breast cancer, the disease reportedly had more negative influences than for patients with DCIS. This seems logical because invasive breast cancer is a more serious disease than DCIS, but it is remarkable that this is not reflected in a worse HRQOL, well-being and different risk perceptions. We did not exclude women treated with mastectomy since a review comparing the impact of breast-conserving treatment and mastectomy on the HRQL found no differences between both treatments.[17] Significant differences were found on the life-domains physical health, sex life and relationships with relatives/acquaintances. A study of Collins and colleagues in 55 cancer patients, being diagnosed within five years, also found more benefits than harm from their experiences.[12] In the psychological literature, this phenomenon is referred to as post traumatic growth or benefit finding.[14]

There were no significant differences between the risk perceptions of recurrence and dying of breast cancer between the two groups. This is in accordance with the study by Rakovitch and colleagues who also found no significant difference on this item between women with invasive breast cancer and DCIS.[4] Women with DCIS made unrealistic risk estimations, given their better prognosis compared to the women with invasive breast cancer. This high risk perception of women with DCIS may reflect the limited knowledge about the specific nature of their disease. In a population of women with no history of breast cancer, Schwartz and colleagues found that for most women DCIS is an unknown phenomenon.[18] The majority of women who are diagnosed with DCIS only know about invasive breast cancer, undergo to a great extent the same surgical treatments by oncological surgeons, which makes it understandable that they fail to have insight into the specific differences between both conditions, unless they are well-informed by health professionals. As a consequence, they also may make a wrong perception about the risk of recurrence and dying of breast cancer.

The fact that more women with DCIS than with invasive breast cancer stated their diagnosis correctly, by marking the correct illustration, is probably a chance finding, because several women commented that they did not understand the question concerning their diagnosis. This may imply that these women answered the question by guessing. This once more suggests that although women with DCIS can recall the name of the disease, they are not able to differentiate DCIS from invasive breast cancer nor do they understand its excellent prognosis. This emphasises the need of better communication by clinicians. When asking to describe their disease in an open question, a lot of women with DCIS reported the term calcifications, which does not describe the reality. Bluman and colleagues additionally demonstrated that women with DCIS had major deficiencies about knowledge of their disease, which may clarify our findings.[3] In accordance with the present study, Rakovitch and colleagues also found more women with DCIS stating their diagnosis correctly and marking the right illustration compared to women with invasive breast cancer.[4] They gave no specific reason why more women with DCIS stated their diagnosis correctly compared to women with invasive breast cancer but still reported the same risk perception as women with invasive breast cancer.

More women with invasive breast cancer than with DCIS felt that medical treatment did more harm than good to them. This may be explained by the fact that more women with invasive breast cancer have undergone systemic treatment, which is known to be associated with adverse physical consequences possibly reducing the HRQL significantly.[19]

The results in general are in close correspondence with the findings of the study by Rakovitch and colleagues, who conducted a similar study among Canadian patients, although

Table 2 – Mean risk perception in percentages (and SD) of women with dutcal carcinoma in situ (DCIS) and early invasive breast cancer (EIBC)

Question	DCIS (*N* = 33)		EIBC (*N* = 91)		*P*-Value[a]
	%	(SD)	%	(SD)	
What is the risk that breast cancer will re-appear in the same breast?	14	(17)	19	(17)	0.13
What is the risk that cancer will appear somewhere else in your body?	24	(21)	28	(23)	0.32
What is the risk that you will die of breast cancer?	15	(16)	21	(22)	0.31
What is the risk of an average Dutch woman to develop breast cancer?	37	(27)	32	(24)	0.29
What is the risk that a mammogram is doing you more harm than good?	18	(21)	18	(19)	0.95
What is the risk that medical care is doing you more harm than good?	6	(8)	15	(16)	0.01

a Wilcoxon's signed rank test.

at a different time point after the diagnosis.[4] Like in the present study, these investigators also failed to find significant differences between patients with DCIS and invasive breast cancer concerning risk perceptions and knowledge about the disease. Given that the women in our study were treated already two to three years ago, this finding suggests that not only the short-term but also the long-term effects of a diagnosis of DCIS on the perceived long-term HRQL are to a great extent comparable to the effects of having had invasive breast cancer. Since we did only include patients with stage I invasive breast cancer, who had not undergone axillary dissection, the whole approach, including hospitalisation and treatment, may be an important determinant of how these women experience DCIS.

A potential limitation of the present study is that our DCIS sample was relatively small, despite the high response rate. This might have introduced type II errors, *i.e.* not finding differences which are actually present. A second limitation of the study concerns the differences between both groups with respect to the type of surgery and systemic treatment. However, adjustment for these factors in a multivariate analysis indicated that these treatment characteristics were not significant confounders.

In conclusion, the present study indicates that women with DCIS, despite their much better prognosis, failed to report a better HRQL and well-being and have similar perceptions of risk of recurrence and dying from breast cancer as women with invasive breast cancer. Concerning perceived disease impact, for the vast majority of the items no differences were found, only on some items (physical health, sex life and relationships with friends) more negative effects were reported by the invasive breast cancer patients. Surprisingly, this does not appear to affect the HRQL and well-being of these women significantly. Our findings once more seem to suggest that being diagnosed for DCIS or invasive breast cancer will not just have a negative impact on the HRQL and well-being. The confrontation with DCIS or invasive breast cancer rather paradoxically seems to have a generally positive impact. Both groups reported that their HRQL had improved significantly and that they had experienced many positive effects on several aspects of their life. Recent studies specifically address these issues, by focusing on concepts such as post traumatic growth and benefit finding.[20] Nevertheless, it is important that women with DCIS are informed with meticulous care about the precise nature of their disease and its very good prognosis in order to prevent unnecessary worries and distress.

Conflict of interest statement

None declared.

REFERENCES

1. Ernster VL, Ballard-Barbash R, Barlow WE, et al. Detection of ductal carcinoma in situ in women undergoing screening mammography. *J Natl Cancer Inst* 2002;**94**(20):1546–54.
2. Ernster VL, Barclay J, Kerlikowske K, Wilkie H, Ballard-Barbash R. Mortality among women with ductal carcinoma in situ of the breast in the population-based surveillance, epidemiology and end results program. *Arch Intern Med* 2000;**160**(7):953–8.
3. Bluman LG, Borstelmann NA, Rimer BK, Iglehart JD, Winer EP. Knowledge, satisfaction, and perceived cancer risk among women diagnosed with ductal carcinoma in situ. *J Womens Health Gend Based Med* 2001;**10**(6):589–98.
4. Rakovitch E, Franssen E, Kim J, et al. A comparison of risk perception and psychological morbidity in women with ductal carcinoma in situ and early invasive breast cancer. *Breast Cancer Res Treat* 2003;**77**(3):285–93.
5. Voogd AC, Ververs JM, Vingerhoets AJ, Roumen RM, Coebergh MA, Crommelin MA. Lymphoedema and reduced shoulder function as indicators of quality of life after axillary lymph node dissection for invasive breast cancer. *Br J Surg* 2003;**90**(1):76–81.
6. Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. *J Clin Epidemiol* 1998;**51**(11): 1055–68.
7. Bech P, Olsen LR, Kjoller M, Rasmussen NK. Measuring well-being rather than the absence of distress symptoms: a comparison of the SF-36 Mental Health subscale and the WHO-Five Well-Being Scale. *Int J Methods Psychiatr Res* 2003;**12**(2):85–91.
8. Ware Jr JE, Gandek B, Kosinski M, et al. The equivalence of SF-36 summary health scores estimated using standard and country-specific algorithms in 10 countries: results from the IQOLA Project. International Quality of Life Assessment. *J Clin Epidemiol* 1998;**51**(11):1167–70.
9. Ware JE, Snow KK, Kosinski M, Gandek B. SF-36 Health Survey manual and interpretation guide. Boston (MA): New England Medical Center, The Health Institute; 1993.
10. Devins GM. Illness intrusiveness and the psychosocial impact of lifestyle disruptions in chronic life-threatening disease. *Adv Ren Replace Ther* 1994;**1**(3):251–63.
11. Angst J, Gamma A, Gastpar M, Lepine JP, Mendlewicz J, Tylee A. Gender differences in depression. Epidemiological findings from the European DEPRES I and II studies. *Eur Arch Psychiatry Clin Neurosci* 2002;**252**(5):201–9.
12. Collins RC, Taylor SE, Skokan LA. A better world or shattered vision? Changes in life perspectives following victimization. *Social Cognition* 1990;**8**:263–85.
13. Mohr DC, Dick LP, Russo D, et al. The psychosocial impact of multiple sclerosis: exploring the patient's perspective. *Health Psychol* 1999;**18**(4):376–82.
14. Sears SR, Stanton AL, Danoff-Burg S. The yellow brick road and the emerald city: benefit finding, positive reappraisal coping and posttraumatic growth in women with early-stage breast cancer. *Health Psychol* 2003;**22**(5):487–97.
15. Rees J, Clarke MG, Waldron D, O'Boyle C, Ewings P, MacDonagh RP. The measurement of response shift in patients with advanced prostate cancer and their partners. *Health Qual Life Outcomes* 2005;**3**:21.
16. Rapkin BD, Schwartz CE. Toward a theoretical model of quality-of-life appraisal: Implications of findings from studies of response shift. *Health Qual Life Outcomes* 2004;**2**:14.
17. Kiebert GM, de Haes JC, van de Velde CJ. The impact of breast-conserving treatment and mastectomy on the quality of life of early-stage breast cancer patients: a review. *J Clin Oncol* 1991;**9**(6):1059–70.
18. Schwartz LM, Woloshin S, Sox HC, Fischhoff B, Welch HG. US women's attitudes to false positive mammography results

and detection of ductal carcinoma in situ: cross sectional survey. *Bmj* 2000;**320**(7250):1635–40.

19. Galalae RM, Michel J, Siebmann JU, Kuchler T, Eilf K, Kimmig B. Significant negative impact of adjuvant chemotherapy on health-related quality of life (HR-QoL) in women with breast cancer treated by conserving surgery and postoperative 3-D radiotherapy. *A prospective measurement. Strahlenther Onkol* 2005;**181**(10):645–51.
20. Calhoun LG, Tedeschi RG. *Posttraumatic growth: future directions. Posttraumatic growth: positive changes in the aftermath of crisis.* Lawrence Erlbaum Associates; 1998. p. 215–38.