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Patients' needs and preferences in routine follow-up for early breast cancer; an evaluation of the changing role of the nurse practitioner

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Abstract

Background: In evaluating follow-up of early breast cancer, patients' views on care are important. The aim of this study was to evaluate the effect of the introduction of nurse practitioners (NPs) in a breast cancer unit on patients' informational needs, preferences and attitude towards follow-up.
Patients and methods: A cross-sectional survey was performed among two groups in 2005. Group A ($n = 89$) consisted of patients operated before, and group B ($n = 100$) after the introduction of a breast cancer unit (respectively in 1998–1999 and 2001–2004).
Results: Response was 72% in group A and 84% in group B. Median follow-up was 69 (54–86) and 33 (0–57) months, respectively. Aspects highly appreciated by patients in both groups were lifetime follow-up, information about prognosis, life style and additional investigations. Important discussion subjects were fatigue, pain, genetic factors, prevention and arm function/lymph-oedema. Less valued aspects were information about peers, conversations with psychologists or social workers, breast reconstruction, and acceptation by family members. The informational needs and preferences did not differ statistically significantly between both groups. In group B, communication with the caregiver was valued higher and more patients indicated that the caregiver took the time needed. More patients in group B indicated that follow-up could be performed by the NP. Duration of follow-up correlated with preferred frequency, not with informational needs in follow-up, only young age increased these needs.
Conclusion: Despite the limitations of this retrospective study, we conclude that while expectations and informational needs did not change with the introduction of a NP to the standard care, patient satisfaction increased and communication and time taken were appreciated more.

Keywords: Follow-up; Breast cancer; Nurse practitioner; Patient preference; Informational needs

Introduction

Early breast cancer patients are followed in a routine follow-up programme after intently curative treatment. This programme has four aims[1,2]; first, to detect recurrences at an early stage. Second, to detect early and late complications of treatment. Third, to offer psychosocial support to the patient to optimise quality of life, and last, to assess treatment outcome for research purposes.

It is generally accepted that the elements of routine follow-up are periodic visits for history and physical examination and annual surveillance mammograms.[1,3]

Due to better therapeutic strategies and increasing age of the population, numbers of breast cancer survivors increase over the years. Therefore, the need for routine visits is reconsidered as they will become a burden for both professionals and patients. Alternative strategies in follow-up have been proposed, including primary care involvement, less-intensive and shorter follow-up schedules and the introduction of specialised breast cancer nurses or nurse practitioners to perform the follow-up.[4–9] In an increasing number of

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practices in the Netherlands, these nurse practitioners or breast care nurses have become part of standard care.[10]

To implement new follow-up schedules, evaluation of patients' preferences and their opinion on the current practice is very important. Although patients' satisfaction with follow-up and quality of life have been studied, few studies have focused on patients' specific informational needs and preferences and attitude towards follow-up in breast cancer follow-up and their views on nurse practitioners.[2,8,11–15] We conducted this study to evaluate patients' views on the changing role of the nurse practitioner and their needs and preferences with different follow-up duration.

Aim of study

This study is a cross-sectional study to investigate patients' information needs and preferences regarding organisation of follow-up care and their satisfaction with care after treatment. We compared the results between patients treated before and after the introduction of the nurse practitioner in their treatment at the breast cancer unit in 2001 and evaluated the determinants of these needs and preferences.

Patients and methods

Organisation of follow-up

All patients participated in a standard routine follow-up schedule according to the Dutch national guidelines for breast cancer (www.oncoline.nl). This follow-up schedule recommends visits every three months during the first year, every six months during the second year and once a year until at least five years after treatment. Mammograms are performed annually. In our hospital, a multidisciplinary breast cancer unit started in 2001. Patients already in follow-up at that time were seen routinely by their treating surgeon and radiation oncologist and only incidentally by a nurse practitioner. After the start of the breast cancer unit, there was a major change in the role of the nurse practitioners. They now play a central role in the pre- and postoperative patient care, including information on surgery and adjuvant systemic treatment, and follow-up. Patients can still be seen by their treating physician, alternately with the NP. A physician is always available to the NPs for advice if necessary. All follow-up visits, either performed by the NP or a physician are scheduled for 15 min. After the introduction of the breast cancer unit, additional written information about their treatment became available for patients. Furthermore, all new patients are discussed in a multidisciplinary meeting.

Patients

All patients included in this study had been treated for early breast cancer, were participating in the routine follow-up, and were free of recurrence when sending the questionnaires in 2005. The first group, group A, consisted of patients operated before the introduction of the breast cancer unit (1998–1999, $n = 89$) and had previously participated in a patient satisfaction survey in 2004.[2] These patients were only incidentally seen by a nurse practitioner. The second group, group B, consisted of patients operated after the introduction of the breast cancer unit (2001–2004, $n = 100$) and were randomly selected from the 280 patients treated for early breast cancer in that period. These patients were routinely seen by a nurse practitioner. Patients had been treated with local and systemic therapy according to national guidelines.[3] For patient characteristics see Table 1.

Questionnaire

The questionnaire we used was previously developed and described.[2]

The first part of the questionnaire consisted of sociodemographic questions and medical history (stage of breast cancer, local and systemic therapy). The next part was a validated questionnaire on patients' attitude towards follow-up.[2,16] This questionnaire consists of four subscales: communication (with the physician), reassurance, nervous anticipation, and specific perceived disadvantages of follow-up. All scales are on a range of 0–100. For the communication and the reassurance scales, a higher score means a more positive evaluation. For the nervous anticipation and the disadvantages scales, a higher score means more negative effects. The third part of the questionnaire included items on the expected benefits of follow-up, from a patient's perspective, regarding the purposes of breast self-examination, breast examination by a doctor, mammography, and the patient's ideas about the curability of the disease after the detection of distant metastases (eight items in total). Answers were given on a four point scale: (1) not at all, (2) somewhat, (3) rather, and (4) very much. The fourth part consisted of 13 items concerning organisation of follow-up visits (current and preferred frequency, duration, oncologist versus nurse practitioner and additional tests). The fifth part contained items concerning needs and preferences in routine follow-up. These were subdivided into two main categories: information needs and medical technical preferences with respect to follow-up. The items had to be answered on a three point scale: (1) not important/do not wish this, (2) not very important/do not care, and (3) very important/I certainly want this. Two subscales were used based on previous research[2]: one for general topics and one for more specific topics. Per scale the scores were added up. The higher the score, the higher the informational needs. Subsequent items examined patient satisfaction with oncologic care using the Dutch version of Ware's Patient Satisfaction Questionnaire III (PSQ III).[17] This questionnaire (43 items) was designed to measure technical competence, interpersonal manner, and access to care. To get an impression of the general

Table 1
Patient and treatment characteristics.

Characteristics	Group A[a] ($N = 60$)			Group B[a] ($N = 81$)			p-value[c]
		n	%		n	%	
Age in years							0.09
Median (range)		57	(32–85)		54	(28–73)	
Follow-up in months							**< 0.001**
Median (range)		69	(54–86)		33	(0–57)	
Pathological Tumour stage							0.67
Tis		8	1		15	19	
T1		33	55		43	54	
T2		19	32		22	28	
Local therapy, breast							0.33
Mastectomy							
−Radiotherapy		30	50		29	36	
+Radiotherapy		7	12		12	15	
BCS[b]							
−Radiotherapy		0	0		1	1	
+Radiotherapy		23	39		39	48	
Local therapy, axilla							**< 0.001**
SLNB[b] yes		7	12		33	42	
ALND[b] yes		44	75		35	45	
Systemic therapy							0.92
Chemotherapy alone		8	13		13	16	
Endocrine therapy alone		5	8		5	6	
Both		10	17		12	15	
None		37	62		51	63	
Quality of life and psychological functioning							
QoL[b] on visual analogue scale; median (range)		85	(0–100)		80	(0–100)	0.21
HADS anxiety; mean; s.e. (range)	4.7	0.4	(0–14)	5.2	0.3	(0–15)	0.31
HADS depression; mean; s.e. (range)	2.0	0.5	(0–18)	1.9	0.3	(0–9)	0.91

Missing data not shown.

[a] Group A, consisted of patients operated before the introduction of the breast cancer unit (1998–1999). Group B, consisted of patients operated after the introduction of the breast cancer unit (2001–2004).

[b] BCS = Breast conserving therapy, SLNB = Sentinel Lymph node biopsy, ALND = Axillary lymph node dissection, QoL = Quality of Life.

[c] Chi-quare test was used for percentages, students-t test for continuous variables.

satisfaction, we also calculated an overall score on the PSQ III. Higher score means more satisfaction with the oncologic care received (range: 0–100).

The seventh part of the questionnaire consisted of the Dutch version of the HADS[18] to asses anxiety and depression. The higher the score, the more anxious and depressed the patient (range: 0–14). Last, quality of life was scored by means of a visual analogue scale (a 100 mm horizontal line, anchored at the extremes by ‘best imaginable quality of life’ and ‘worst imaginable quality of life’).[19]

Statistical analysis

All data were analysed using the statistical package SPSS for Windows 16.0 (SPSS Inc, Chicago, IL, USA). Descriptive data are given as mean (SD) or median (range). Pearson’s chi-square test was used to compare frequencies between groups and *t*-test’s were done to compare continuous variables between the two groups. All testing was two-tailed with 0.05 as level of significance. Cut-offs for the Hospital Anxiety and Depression Scale (HADS) were 8 points, based on Carroll et al.[20] For all scales, missing data were replaced by the individual mean for that scale if no more than 50% of the items on the scale were missing; otherwise, the entire scale was considered missing. Between needs and preferences for follow-up on the one hand and patient characteristics on the other, Spearman’s rank correlations were calculated. Finally, for patient characteristics that correlated borderline significantly with needs or preferences ($p < 0.10$), a multivariable model was constructed and β’s were calculated.

Results

Patients

The questionnaire was returned by 72% (64/89) in group A and by 84% (84/100) in group B. Four respondents in group A and three in group B were excluded from analysis, because they had stage three disease. Patients with in situ carcinoma were included as they were considered to have the same treatment and follow-up as early invasive breast cancer patients. Analyses were done in 141 patients; 60 in group A and 81 in group B. We have no information on non-responders.

Median follow-up was 69 (54–86) months in group A and 33 (0–57) months in group B. Patient and tumour characteristics are shown in Table 1. No significant differences were seen between the groups concerning patient characteristics, treatment of the breast and systemic therapy. The differences found in axillary treatment and in follow-up time can be explained by the different treatment periods.

Quality of life and psychological functioning

Quality of life (visual analogue scale) scored high: a median score of 85 in group A and 80 in group B ($p = 0.21$) (Table 1). The mean scores on the HADS for anxiety and depression were respectively 4.7 and 2.0 in group A and 5.2 and 1.9 in group B (n.s.) (Table 1). Using the cut-off of eight for the anxiety and depression subscales,[20] 15% in group A and 16% in group B would need psychiatric evaluation for anxiety ($p = 0.9$) and respectively 8% and 5% ($p = 0.4$) for depression. A total of 5% had scores higher than 11 on the HADS anxiety and were likely to have an anxiety disorder based on DSM-IV criteria, no statistically significant differences between the groups. More patients in group A than in group B (5% versus 0%) would classify for a depression disorder ($p = 0.04$).

Attitude and benefits

Attitudes towards follow-up differed significantly between the two groups on two subscales (Table 2). Communication with the caregiver scored higher in group B than in group A (resp. 89 versus 80, $p = 0.002$), as did nervous anticipation before follow-up (23 versus 16, $p = 0.04$).

In detail, more patients in group B ‘very much’ agreed to the question whether the physician or nurse practitioner took enough time during their visit compared to group A (66 vs. 35%, $p = 0.02$). No other statistically significant differences between the groups on attitude towards follow-up were found on individual items (data not shown).

Patients had high expected benefits from follow-up in both groups with no significant differences between both groups (Table 2). Especially mammography was thought to detect

Table 2
Attitude towards and expected benefits from follow-up.

Characteristics	Group A[a] ($N = 60$)		Group B[a] ($N = 81$)		p (chi-square)
	n	%	*n*	%	
Attitude towards follow-up; mean(SD)					
Fear of recurrence	33	(19)	39	(20)	0.25
Communication with caregiver	80	(19)	89	(15)	**0.002**
Nervous anticipation	16	(16)	23	(20)	**0.04**
Reassurance	72	(21)	75	(20)	0.33
Perceived disadvantages of follow-up	14	(14)	19	(18)	0.46
Expected benefits from follow-up	*Not at all/somewhat*	*Rather/very much*	*Not at all/somewhat*	*Rather/very much*	
To what extend do think that…					
PE[b] will detect a new tumour in the other breast?	35	65	27	73	0.69
PE will detect a new tumour in the operated breast?	26	74	24	76	0.70
Mammography will detect a new tumour in the other breast?	10	90	4	96	0.11
Mammography will detect a new tumour in the operated breast?	9	91	5	95	0.57
Self-examination will detect a new tumour in your breast?	40	60	42	58	0.28
Early detection of a new tumour in the other breast will contribute to your cure?	6	94	1	99	0.34
Early detection of metastases in the other breast will contribute to your cure?	6	94	4	96	0.39
Early detection of a new tumour in the operated breast will contribute to your cure?	4	96	5	95	0.28
Patient Satisfaction Questionnaire III: mean; s.e. (range)					
Technical competence	71; 2 (37–100)		79; 2 (40–100)		**0.003**
Interpersonal aspects	74; 3 (23–100)		81; 2 (14–100)		**0.03**
Access to care	70; 2 (31–100)		76; 2 (38–100)		**0.05**
Total score	75; 3 (20–100)		78; 2 (0–100)		0.51

[a] Group A, consisted of patients operated before the introduction of the breast cancer unit (1998–1999). Group B, consisted of patients operated after the introduction of the breast cancer unit (2001–2004).

[b] PE = Physical examination.

a new tumour or recurrence in almost all cases and most patients believed early detection of a recurrence or new tumour would contribute to their cure. Early detection of distant metastases was believed to contribute to cure by more than 95% of all patients. Less expected benefit was found for self-examination of the breast, as little over half of all patients thought that would detect a new tumour (Table 2).

Satisfaction with oncological care

In both groups, patients were satisfied with the general care received, with a median score of 75 and 78 for group A and B on the PSQ respectively (n.s.) (Table 2). Both groups were most satisfied with the interpersonal aspects, but a significant difference was found between the groups (74 vs 81, $p = 0.03$). Also on the other subscales of satisfaction (technical competence and access to care), a significant difference was found in favour of the group treated after the introduction of the breast cancer unit (group B) (Table 2).

Needs and preferences; content

Aspects highly appreciated by patients to be part of the follow-up programme were information about prognosis,

Table 3
Needs and preferences during follow-up visits.

	Not important/do not want this (%)		Not very important/do not care (%)		Very important/I certainly want this (%)		*p* (chi-square)
	Group A[a]	Group B[a]	Group A	Group B	Group A	Group B	
General topics							
How much would you like the following topics to be part of the follow-up visit?							
Information on own prognosis	4	5	10	12	85	83	0.92
Information on side effects of treatment	4	7	10	11	86	81	0.73
Information on the long term effect of treatment	4	10	20	16	77	74	0.47
Additional investigations (e.g. X-ray, blood tests)	8	6	29	20	63	75	0.41
Information on life rules after breast cancer (e.g. nutrition)	6	12	35	32	58	57	0.58
Specific topics							
How much would you like to talk about the following subjects during follow-up visits?							
Prevention of breast cancer	9	13	28	24	63	63	0.76
Changes in untreated breast	13	19	29	19	58	63	0.43
Hereditary factors	14	16	30	20	57	64	0.51
Arm function/lymph oedema	13	22	21	24	66	54	0.43
Pain (e.g. nerve pain)	21	18	21	29	59	53	0.60
Fatigue	12	16	38	27	50	57	0.47
Fear	25	20	33	36	43	44	0.82
Use of OAC or HT[b]	38	35	22	28	41	37	0.78
Dietary advise	22	17	49	46	29	37	0.66
Breast reconstruction	41	49	26	22	33	29	0.75
Acceptation by family/friends	49	33	38	50	14	17	0.29
How much would you like the following topic to be part of the follow-up visits?							
Information on breast cancer self-help groups	56	52	25	33	19	15	0.59
Consultation with psychologist or psychiatrist	62	60	34	27	4	13	0.26
Consultation with hospital social worker	42	39	44	49	15	12	0.81
Consultation with pastoral care provider	68	71	28	24	4	6	0.84
Organisation							
	Every Year (%)		**Every 6 months (%)**		**Every 3 months (%)**		
How often would you prefer to attend a routine control visit?	63	28	30	50	5	16	<0.001
	5 years (%)		**10 years (%)**		**Lifelong (%)**		
For how long would you prefer to attend routine control visits?	5	9	29	21	64	65	0.24

[a] Group A, consisted of patients operated before the introduction of the breast cancer unit (1998–1999). Group B, consisted of patients operated after the introduction of the breast cancer unit (2001–2004).

[b] OAC = Oral Anticonceptiva, HT = Hormonal replacement therapy.

side effects, life style habits and additional investigations (Table 3). Important discussion subjects were fatigue, pain, genetic factors, prevention of breast cancer and arm function/lymph oedema. Less valued aspects were information about peers, conversations with psychologists or social workers, breast reconstruction, and acceptation by family members. There were no statistically significant differences between the two patient groups.

Needs and preferences; frequency, duration and professionals involved

Group A preferred less frequent follow-up than group B. Preference for duration of follow-up did not differ between the groups, with almost two thirds in both groups preferring life long follow-up visits (Table 3).

Follow-up was performed by different groups of professionals: surgical oncologists, radiation oncologists, medical oncologists and nurse practitioners. There was no general preference for follow-up by a single group of professionals. Follow-up by a general practitioner was however seldom preferred (Table 4). More patients in group B indicated that they preferred follow-up by the nurse practitioner: 58 versus 32% ($p = 0.003$). No difference was found in the preference for other professionals.

Determinants of need and preferences

In bi-variate analysis, higher informational needs were correlated with more nervous anticipation before follow-up, higher fear of recurrence, lower quality of life, and higher anxiety level on the HADS anxiety scale (Table 5A). Lower informational needs were correlated with higher age, higher patient satisfaction on the interpersonal aspects, access to care subscale, and overall scale of the PSQ questionnaire. Preference for more additional investigations correlated with a higher quality of life and was lower with higher age. Lower preferred frequency of follow-up was correlated with longer time since diagnosis and high preferred frequency with good access to care. Preferred shorter duration was correlated with radiotherapy and long duration with higher sense of reassurance after follow-up (Table 5A).

In multivariable analysis, only young age remained an independent factor for high specific informational needs and longer time since diagnosis for lower preferred follow-up frequency (Table 5B).

Discussion

In this study we examined the needs and preferences in follow-up care among early breast cancer patients and compared these at two time points in follow-up and before and after the introduction of a breast care unit with the increased role of the nurse practitioner.

Needs and preferences; content

Aspects highly appreciated by both groups were information about long-term prognosis, side effects, prevention and life style advice. This is in line with previous research suggesting a shift from disease-related information needs to information on long term effects in the first year of follow-up.[21]

Patients in both groups still indicated additional investigations (like chest X-ray or lab testing) to be important, as found previously.[2,11,13–15] This suggests that patients wrongly believe that finding distant metastases at an early stage will improve their prognosis, while in fact research shows that detecting metastases at an early stage will not increase survival and will decrease quality of life.[22–26] This preference and expectation did not differ between the groups, so it was not influenced by written information or information given by nurse practitioners that patients in group B received. This might be explained by the fact that a large group of patient does not understand the written information available to them.[27] We can conclude that even more emphasis should be given on this subject to adjust patients' expectations.

Less valued aspects in follow-up were consultation by a psychologist or social worker, although one in six patients in both groups qualifies for psychological evaluation of anxiety or depression based on their HADS score. Patients also did not appreciate enquiries about acceptation of family and friends or information about peers although some studies suggest that patients use narratives from fellow patients to cope with emotions and impact of cancer in daily life.[28]

Needs and preferences; frequency and duration and professional involved

In a previous publication, patients in group A preferred multiple follow-up visits per year after a median follow-up of three years.[2] This is comparable to the preference of

Table 4
Preference for type of professional.

	Surgeon		Radiation Oncologist		Medical Oncologist		Nurse practitioner		General Practitioner	
Group (%)	A[a]	B[a]	A	B	A	B	A	B	A	B
By whom should the follow-up be performed?										
Yes	39	45	29	35	61	50	32	58	5	6
No	61	55	71	65	39	50	68	42	95	94
p-value (chi-square)	0.59		0.59		0.34		**0.003**		0.81	

[a] Group A, consisted of patients operated before the introduction of the breast cancer unit (1998–1999). Group B, consisted of patients operated after the introduction of the breast cancer unit (2001–2004).

Table 5
Determinants of needs and preferences in follow-up.

A. Bi-variate, spearman's rho

	General topics	Specific topics	Preference for additional investigations	Preferred follow-up frequency	Preferred follow-up duration
Age	−0.102	**−0.437**[b]	**−0.207**[a]	−0.081	−0.023
T-Stage	0.005	0.096	0.002	0.035	−0.150
Adjuvant endocrine therapy	0.098	−0.24	0.027	0.128	0.137
Adjuvant chemotherapy	0.040	−0.239	−0.189	−0.067	0.065
Radiotherapy	0.026	0.011	−0.042	−0.083	**−0.202**[a]
Duration follow-up	0.079	−0.049	−0.125	**−0.406** [b]	−0.087
Attitude towards follow-up					
Communication (with caregiver)	−0.168	0.019	0.132	0.075	0.042
Sense of reassurance	−0.034	−0.002	0.061	0.06	**0.221** [b]
Nervous anticipation	**0.231**[a]	0.139	−0.035	−0.024	−0.044
Specific perceived disadvantages	0.183	−0.016	−0.035	−0.037	−0.145
Fear of recurrence	0.115	**0.236**[a]	−0.004	0.079	**−0.211**[a]
Patient satisfaction questionnaire (PSQ)					
Technical competence	−0.158	−0.209	−0.010	0.133	−0.63
Interpersonal aspects	−0.160	**−0.283**[a]	0.068	0.146	−0.04
Access to care	−0.180	**−0.345**[b]	−0.23	**0.173**[a]	−0.04
Total score	−0.109	**−0.298**[b]	−0.081	0.059	−0.115
Quality of life					
Quality of life on a visual scale	**−0.199**[a]	−0.168	**0.196**[a]	−0.020	0.044
HADS anxiety	0.184	**0.269**[a]	−0.037	0.053	0.054
HADS depression	0.106	0.185	0.030	0.082	0.077

B. Multivariable analysis, β's

	General topics	Specific topics	Preference for additional investigations	Preferred follow-up frequency	Preferred follow-up duration
Age	n.i.	**−0.37**[a]	−0.21	n.i.	n.i.
T-Stage	n.i.	n.i.	n.i.	n.i.	−0.08
Adjuvant endocrine therapy	n.i.	0.13	n.i.	n.i.	n.i.
Adjuvant chemotherapy	n.i.	0.06	0.082	n.i.	n.i.
Radiotherapy	n.i.	n.i.	n.i.	n.i.	0.07
Duration follow-up	n.i.	n.i.	n.i.	**−0.40** [b]	n.i.
Attitude towards follow-up					
Communication (with caregiver)	0.10	n.i.	n.i.	n.i.	n.i.
Sense of reassurance	n.i.	n.i.	n.i.	n.i.	0.13
Nervous anticipation	0.02	n.i.	n.i.	n.i.	n.i.
Specific perceived disadvantages	0.12	n.i.	n.i.	n.i.	−0.16
Fear of recurrence	n.i.	0.10	n.i.	n.i.	0.13
Patient satisfaction questionnaire (PSQ)					
Technical competence	−0.17	0.26	n.i.	n.i.	n.i.
Interpersonal aspects	−0.01	−0.26	n.i.	−0.02	n.i.
Access to care	−0.06	−0.15	n.i.	0.08	n.i.
Total score	n.i.	−0.17	n.i.	n.i.	n.i.
Quality of life					
Quality of life on a visual scale	−0.17	n.i.	−0.20	n.i.	n.i.
HADS anxiety	0.33	0.06	n.i.	n.i.	n.i.
HADS depression	n.i.	0.08	n.i.	n.i.	n.i.

n.i. :variable not included in the multivariable model. [a]$p<0.05$, [b]$p < 0.01$.

group B in this study with a similar follow-up duration; almost 75% of these patients preferred visits more frequently than once a year. In our study, after a median follow-up of 5.5 years, group A preferred significantly less frequent follow-up visits than two years earlier. The difference between the two groups can be explained by the difference in time since treatment, as the preferred frequency was significantly correlated with follow-up duration in the multivariable analysis. The need for frequent follow-up decreases over time, as almost two thirds of patients indicated annual follow-up to be sufficient at 5.5 years after treatment. However, the preference for life long follow-up did not differ significantly between the groups and was comparable to previous data.[2]

Multivariable analyses of determinants of needs and preferences revealed only young age as independent predictor for high specific informational needs, which is in line with other studies.[2,29] Longer time since diagnosis was found to be an independent predictor of lower preferred follow-up frequency. As opposed to previous studies,[2,21] no correlation was found between informational needs and high anxiety or depression scores.

The nurse practitioner in follow-up was well appreciated by patients, as described previously.[8,30,31] They were appreciated significantly more by the group for whom the nurse practitioner was part of standard care from the time of diagnosis, which was also shown by others.[32]

Limitations

This study was not a case control study, but patients in group B were randomly selected from patients treated in that time period. Nevertheless, we are convinced this population gives a good insight in the needs and preferences of early breast cancer patients at two time points in follow-up in general, and in the effect of the introduction of the nurse practitioner in a breast care unit in particular. The effect of the introduction of the breast cancer unit and the difference in time since diagnosis between both groups might be confounding factors, although multivariable analysis did not show a correlation between needs and preferences and duration of follow-up. Patients with a longer follow-up, and hence a perceived better prognosis, might be more satisfied (since the cancer has not recurred), which we did not find. Moreover, patients who perceive they are at higher risk (more recent diagnosis), may feel obliged to express a (socially desirable) positive attitude.

Furthermore, from our data, the increase in perceived ‘time taken’ and patient satisfaction in group B cannot be distinguished between visits by NPs or physicians. The difference however may in our view well be explained by the fact that most visits were performed by the NPs in this group. Although they have the same scheduled time, NPs have less other tasks than physicians and are not distracted by other calls or clinical patients’ problems during the outpatients’ clinic, enabling them to focus more on their patient. They are also easier to contact directly for patients which may explain the increased perceive access to care. Furthermore, due to their background and training, they might have a bigger intrinsic motivation to talk more extensively with patients.

Finally, there is a chance of response bias, as patients who respond to the questionnaire might be more satisfied with follow-up than those who did not respond and we have no information of the non-responders.

Future aspects

In 2007, we implemented a tailored follow-up programme in our breast cancer unit.[33] In this tailored programme, patients are followed with a frequency according to their individual risk of local recurrence. Patients in this tailored program also receive questionnaires on their needs, preferences in and satisfaction with follow-up care. The present study can be used as a baseline to evaluate patients’ perspective on this program.

Furthermore, this study teaches us the caveats in the information to our patients, as 95% of patients still falsely believe that early detection of distant metastases will contribute to their cure, and will ask for additional investigations to detect these. More information on this subject is needed to establish realistic expectations of follow-up care.

Conclusion

In our breast cancer unit, patients were satisfied with the follow-up and the role of the nurse practitioner was highly appreciated. Duration of follow-up correlated with preferred frequency, not with informational needs in follow-up, only young age increased these needs.

Conflict of interest

The authors have no conflicts of interest to declare.

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