

## Research Article

# Unmet Needs and Quality of Life: Questionnaire-Based Survey in a Follow-Up Program for Patients with Breast Cancer

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## Abstract

**Introduction:** The objective of this self-report survey was to detect unmet needs and evaluate the quality of life of patients attending a follow-up program after breast cancer surgery.

**Methods:** Patients were asked to complete a standardized questionnaire consisting of 16 questions on different aspects of follow-up. The return rate of questionnaires was 84% (147 of 174 patients).

**Results:** All patients considered follow-up visits as useful; however, 24% of patients did not understand the basic rationale behind it. Only 38% of patients favored annual follow-up visits, while 46% demanded individual scheduling. The surgeon was the preferred follow-up specialist for 70% of patients, 59% chose the medical oncologist. Interestingly, 81% agreed that a specialized breast care nurse could coordinate and perform independent follow-up visits. Importantly, 78% of patients stated that they did not consider follow-up by phone call a valid alternative to personal follow-up, and 58% of patients reported anxiety before follow-up visits.

**Discussion:** The psychological burden of breast cancer follow-up seems relevant; better patient education and common decision-making may be indicated.

**Keywords:** Breast cancer; Follow-up program; Quality of life

## Abbreviations

ASCO: American Society of Clinical Oncology

## Introduction

Breast cancer is the most frequent malignant tumor in Swiss women and worldwide, comprising 32.2% of all cancer cases [1] and accounting for 15% of all cancer-related deaths in women [2]. Mean age at diagnosis is 62 years, but the incidence of breast cancer in young and middle-aged women seems to be rising [3]. This can in part be explained by the broad implementation of screening programs and the introduction of more sensitive imaging techniques, such as digital mammography and MRI, both of which increase the detection rate of early stage breast cancer [3].

Since the 5-year survival rate of early stage breast cancer is as high as 96%, the rising detection of early stage breast cancer as well as improved treatment options have led to an increasing number of women undergoing regular follow-up after their primary treatment [2].

Only scarce scientific data exists on follow-up recommendations for patients with breast cancer. Guidelines of the American Society of Clinical Oncology (ASCO) recommend physical examinations every 3 to 6 months for the first 3 years, every 6 to 12 months for years 4 and 5 and annually thereafter [4]. For women who have undergone breast-conserving surgery, a mammography should be

performed 1 year after the initial mammogram and at least 6 months after completion of radiotherapy, and annually thereafter [4]. The recommendations of the Health Canada's Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer suggest regular follow-up visits at individual frequency [5], whereas the UK guidelines recommend routine follow-up for three years only [6]. More intensive follow-up with liver ultrasound, chest radiography, biochemical profile and regular bone scans has not shown any survival benefit [7]. Therefore, routinely searching for asymptomatic metastatic disease is generally not recommended [7].

At the University Hospital of Basel Breast Center, follow-up is commonly performed by breast surgeons, radiation and medical oncologists, and consists of medical history and physical exam every 3 months for the first 3 years, every 6 months for years 4 and 5, and annually thereafter. Mammograms are obtained according to the ASCO guidelines [4].

The main goals of routine follow-up are: 1) Detection of new primaries and locoregional recurrence; 2) Diagnosis and therapy of treatment-related adverse events and complications; 3) Evaluation of quality of life including sexual well-being and of psychological sequelae, such as depression and anxiety; 4) Treatment update.

The UK recommendations to stop routine follow-up after 3 years, based on the lack of evidence of improved survival by ongoing follow-up [8], may not account for the other goals described above.

[7]. Regular follow-up visits have the potential to reduce anxiety, long-term concerns of survivorship and psychosexual or body image related issues [9]. The psychological burden of breast cancer depends on the tumor stage and prognosis, therapy and side effects, the personality of the patient, and the availability of psychosocial support [10]. Therefore, psychosocial support must be regarded as an integral component of follow-up [10]. A survey on patients' perception of follow-up in the UK revealed that 69% did not feel comfortable raising psychological concerns for various reasons [11]. A questionnaire-based study of 79 breast cancer patients in the UK suggested that patients were not fully aware of the rationale to perform routine follow-up [7].

Due to the overall limited evidence on unmet needs of patients after surgery for breast cancer, the aim of the present study was to detect such needs and evaluate the quality of life of patients attending a standardized follow-up program. In addition, since follow-up by a specialized breast care nurse has been emphasized by several authors [12,13], we evaluated preferences regarding different follow-up concepts.

## Patients and Methods

### Patients

During a 1-year period, 174 patients followed after breast cancer surgery at our breast Center at the University Hospital Basel were asked to complete a standardized questionnaire consisting of 16 questions on different aspects of follow-up. Questionnaires were sent out with pre-paid return envelopes. The questionnaire contained 11 closed questions with only one-answer possible and 5 questions with multiple possible answers. For closed questions, patients had the possibility to answer on an ordinal scale from 1 to 6, with 6 being extremely satisfied, 1 being not satisfied at all, and 4 being sufficient.

Information on clinical features such as type of surgery, sociodemographic data and histopathological data (TNM stage) was obtained from our prospectively collected database (Table 1).

### Statistical analysis

Data was collected in an anonymized manner and analyzed by using descriptive statistics with GraphPad (Prisme, Version 5.00).

## Results

In total, 147 of 174 questionnaires were completed and returned (84%). The majority of patients (n=76/52%) had pT1 tumors and no lymph node involvement (n=118/80%). Most tumors (n=107/73%) were invasive ductal carcinomas. The clinicopathological features of the patients are outlined in Table 1, and the detailed answers are shown in Table 2 and visualized in Figure 1.

All patients acknowledged that the follow-up visits were useful, and 11 (76%) felt adequately informed on the basic rationale behind the follow-up. When asked about their satisfaction with the follow-up (n=111/76% of all patients reported a satisfaction of  $\geq 4$ , whereas 36 (24%) of patients were not satisfied with their follow-up visits (score below 4).

Approximately two-thirds (n=101/69%) of patients reported examining their breasts on a monthly basis by self-palpation and inspection. When asked about their level of anxiety before the follow-

**Table 1:** Basic demographics of 147 patients with breast cancer undergoing follow up.

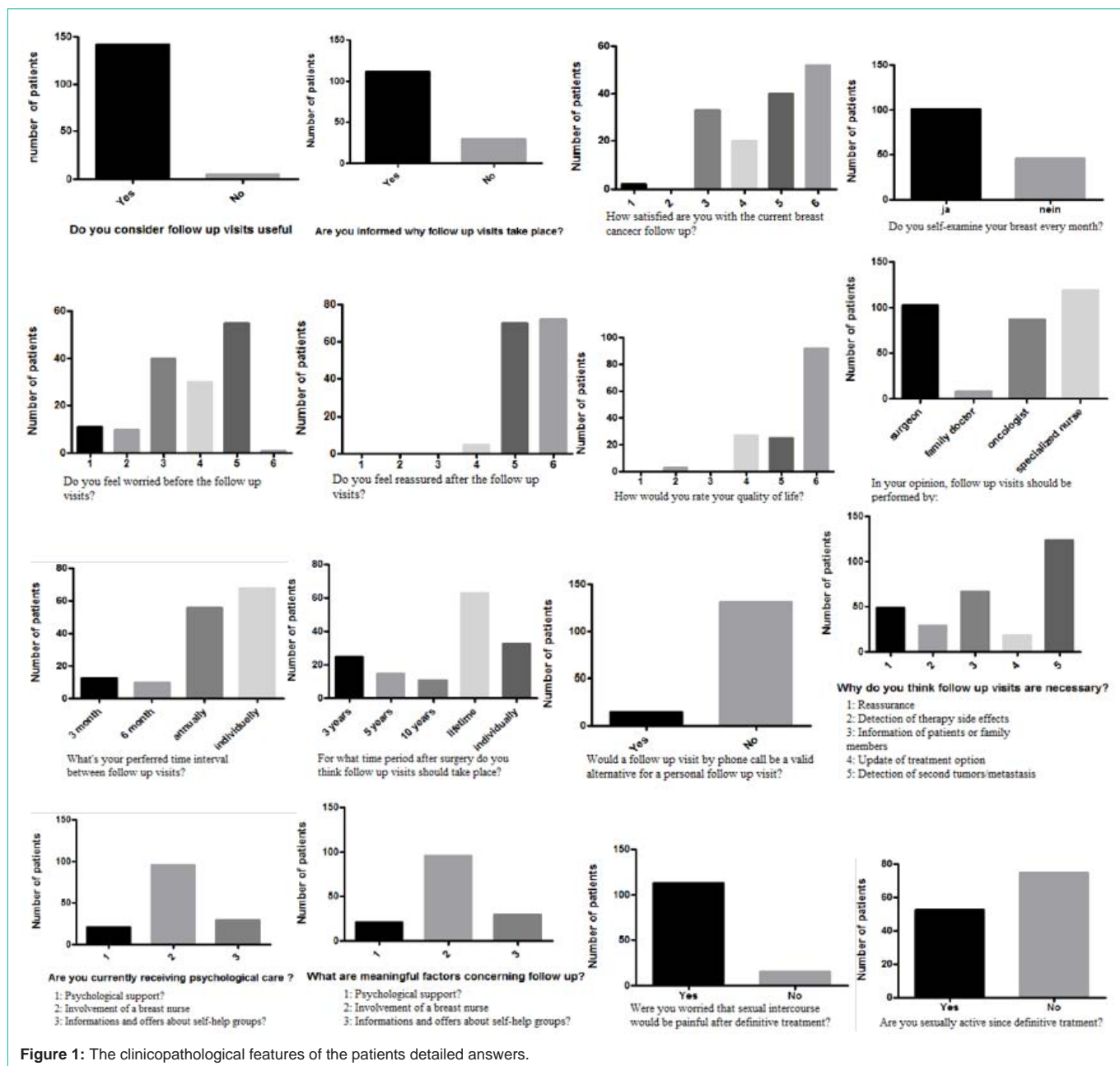
Mean age at diagnosis (years) $\pm$ standard deviation (SD)	69 $\pm$ 11.2	
Tumor stage	Number (n)	Percent (%)
pT1	76	51.7
pT2	45	30.6
pT3	17	11.6
pT4	9	6.1
Lymph node involvement		
pN0	118	80.3
pN1	23	15.6
pN2	6	4.1
Tumor grade		
1	39	26.5
2	58	39.5
3	50	34
Histologic subtype		
Invasive ductal	107	72.8
Invasive lobular	17	11.6
Mucinous	6	4.2
Apocrine	4	2.8
Other	13	8.6
Intrinsic subtype		
Luminal A (ER <sup>+</sup> and/or PR <sup>+</sup> , HER2 <sup>-</sup> , Ki-67 < 14%)	16	10.9
Luminal B (HER2-negative) (ER <sup>+</sup> and/or PR <sup>+</sup> , HER2 <sup>-</sup> , Ki-67 $\geq$ 14%)	71	48.3
Luminal B (HER2-positive) (ER <sup>+</sup> and/or PR <sup>+</sup> , HER2 <sup>+</sup> )	21	14.3
HER2 type (ER <sup>-</sup> or PR <sup>-</sup> , HER2 <sup>+</sup> )		
Basal-like (ER <sup>-</sup> , PR <sup>-</sup> , HER2 <sup>+</sup> )	12	8.2
	27	18.3

up visits, with 1 being not worried at all, and 6 being extremely worried, 85/58% stated that they felt worried ( $\geq 4$ ), while 62 (42%) were not or only little worried. In contrast, all of the patients felt reassured after the follow-up visits, with 140 (95%) being very or extremely reassured.

Of all patients, 56 (38%) felt that the follow-up visits should be performed annually, while 68 (46%) of patients thought that they should be scheduled on an individual basis. A majority of patients 63 (43%) stated that the follow-up visits should continue for the rest of their lives, whereas a minority thought that they should be stopped after 3, 5 or 10 years (17%, 10% and 8%, respectively). Even so, 33 (22%) of patients stated that the duration of follow-up visits should be adjusted individually.

The quality of life was reported as good (score 4 and above) by 144 (98%) of patients, with 92 (61%) rating their quality of life as excellent.

When asked about their sexual well-being, 111 (76%) of patients reported that they were afraid that sexual intercourse would be painful after treatment. While 53 (36%) of patients were sexually active, 75 (51%) denied any sexual intercourse, and 19 (13%) chose not to answer.



The answer to the question who should perform the follow-up visits was surgeon in 70% of patients, while 59% chose the medical oncologist (multiple choices were possible). Interestingly, 81% of all patients agreed that a specialized breast care nurse could independently perform follow-up visits, a concept that has not yet been implemented in Switzerland. Only 5% of patients wanted that the family practitioners perform the follow-up visits.

Most patients (78%) denied that a follow-up by phone call would be a valid alternative to a personal follow-up exam performed by a specialized health care professional.

When asked why they thought the follow-up visits should take place (with multiple answers possible), 84% of the patients stated that their purpose should be the detection of second tumors or metastases,

while 46% thought that they should be used to inform the patient as well as family members about the disease and course of treatment. One third of the patients thought that the follow-up visits should reassure them, while 20% believed that they should detect therapy side effects, and 13% expected an update on treatment options during the follow-up visits.

The majority of patients (88%) was not seeking professional psychological care at the time of answering the questionnaire. When asked about measures that could be important for follow-up care, two-thirds (65%) of patients stated that the follow-up visits should involve a specialized breast care nurse, while 21% wished to receive informations about support groups, and 14% requested psychological support as part of their follow-up visits.

**Table 2:** Answer all patients.

Questions	Yes		No									
	n	%	n	%								
Do you consider follow up visits useful?	142	96.6	5	3.4								
Are you informed why follow up visits take place?	117	79.6	30	20.4								
Do you self-examine your breast every month?	101	68.7	46	31.3								
Would a follow up visit by phone call be a valid alternative for a personal follow up visit	16	10.8	131	89.1								
Are you currently receiving psychological care?	17	11.6	130	88.4								
Were you worried that sexual intercourse would be painful after definitive treatment?	111	87.4	16	12.6								
Are you sexually active since definitive treatment?	53	41.4	75	58.6								
Questions	1		2		3		4		5		6	
	n	%	n	%	n	%	n	%	n	%	n	%
How satisfied are you with the current breast cancer follow up?	2	1.3	0	0	33	22.4	20	13.6	40	27	52	35.4
Do you feel worried before the follow up visits?	11	7.5	10	6.8	40	27.2	30	20.4	55	37.4	1	0.7
Do you feel reassured after the follow up visits?	0	0	0	0	0	0	5	3.4	70	47.6	72	50
How would you rate your quality of life?	0	0	3	2	0	0	27	18.4	25	17	92	62.6
<b>In your opinion, follow up visits should be performed by:</b>	<b>n</b>		<b>%</b>									
surgeon	103		32.5									
family doctor	8		2.5									
oncologist	87		27.5									
specialized nurse	119		37.5									
<b>What's your preferred time interval between follow up visits?</b>	<b>n</b>		<b>%</b>									
3 months	13		8.8									
6 months	10		6.8									
annually	56		38.1									
individually	68		46.3									
<b>For what time period after surgery do you think follow up visits should take place?</b>	<b>n</b>		<b>%</b>									
3 years	25		17									
5 years	15		10.2									
10 years	11		7.5									
lifetime	63		42.9									
individually	33		22.4									
<b>Why do you think follow up visits are necessary?</b>	<b>n</b>		<b>%</b>									
reassurance	49		17									
detection of therapy side effects	29		10									
information of patient or family members	67		23.3									
update of treatment option	19		6.6									
detection of second tumors/ metastasis	124		43.1									
<b>What are meaningful factors concerning follow up?</b>	<b>n</b>		<b>%</b>									
psychological support	21		14.3									
involvement of a breast nurse	96		65.3									
informations and offers about self-help groups	30		20.4									



## Discussion

The present study is –to our knowledge– one of the first to comprehensively assess patients' perception of key elements of breast cancer follow up. Even though response bias cannot be excluded in a questionnaire-based study, the return rate of 84% and the pragmatic design of the questionnaire suggest that the results can be interpreted with confidence. While all patients considered follow-up visits as useful, 24% of the patients did not fully understand the basic rationale behind it. Hence, the need for more comprehensive patient information is obvious and has been implemented in our clinic.

In addition, the fact that 24% of patients were not satisfied with their follow-up visits is alarming, and the underlying reasons could not entirely be explored by the limitation of this questionnaire-based approach. However, the involvement of a specialized breast care nurse, support groups and structured psychological support were identified as unmet needs in this patient population.

Even though self-examination is controversial [14], 69% of patients in this series reported to examine their breasts on a regular monthly basis. In our opinion, breast self-exams can be encouraged, since it has been reported that a total of 30–40% of potentially treatable relapses are detected by patient self-examination, and patients with ipsilateral breast relapse detected clinically do worse than those detected by self-examination or mammography [15,16].

The psychological burden of routine follow-up seems relevant, with 58% of patients reporting anxiety before their follow-up visits. This percentage is comparable with a study by Paradiso et al. in which 70% of women reported feelings of anxiety before such visits [17]. Montgomery et al. stated that the benefit of follow-up might not justify its psychological burden [16]. On the upside, almost all patients (95%) in our study felt reassured after the follow-up visit.

Importantly, only 38% of patients agreed on annual follow-up visits, while 46% thought that the visits should be scheduled individually depending on symptoms and personal needs. Annual visits are recommended by ASCO [4], while the Canadian Committee suggests individually scheduled follow-up visits according to individual patient's needs, and emphasize the fact that patients should be encouraged to report new persistent symptoms promptly without waiting for the next scheduled appointment [5]. Judging by our results, these later guidelines seem to be more consistent with patient's conceptions. A considerable percentage of patients (22%) stated that the duration of follow-up visits should be adapted individually.

Potentially treatable relapse occurs at a constant rate of 1–1.5% per year for at least 10 years, the majority of relapses occurring after 3 years of follow-up [16]. Since patients with late relapses tend to do particularly well, every effort should be undertaken to diagnose these late relapses at an early stage, and thus it is our belief that the offered follow-up should not stop at 3 years [16], as it has been suggested by the UK guidelines [8]. We support the ASCO recommendations, which suggest 6-monthly clinical visits for the first 5 years and annually thereafter [4].

A majority of patients (76%) reported that they were afraid that sexual intercourse would be painful after treatment for breast

cancer, and only 36% were sexually active. These findings confirm previous reports of significant deterioration of sexual well-being after diagnosis and treatment for breast cancer [18]. Health professionals involved in follow-up visits play an important role in alleviating concerns surrounding sexual well-being after breast cancer, and it is thus important to address the issue of sexual function during follow-up visits [19,20].

The prediction of a 48% increased need for cancer services by 2020 forecasts a parallel increase in workload for clinics performing oncological follow-up [21]. In this study performed on a breast surgery service, 70% of patients preferred follow-up by a surgeon, and 59% by a medical oncologist. Importantly, 81% of patients agreed that a specialized breast care nurse could coordinate and perform independent follow-up visits, a concept that has not yet been widely implemented in Switzerland. Similar results were reported in a study by Kwast et al. [22]. Patients stated that breast care nurses were easily accessible, had more time for the individual patient and were perceived more socially empathic [22]. Koinberg et al. who investigated nurse led follow up on demand versus physician (surgeon or oncologist) follow-up after breast cancer treatment reported no difference in anxiety and depression as well as patient satisfaction between the two groups [23]. Furthermore, there was no difference between the groups regarding time to recurrence of disease or death [23]. These results are confirmed by Kimman et al. who demonstrated that overall patient satisfaction was similar if patients were followed by a physician alternating with a breast care nurse compared with follow-up by a physician alone [13]. In the trial by Baidam et al. the Fallowfield Satisfaction with Consultation Questionnaire revealed that women were significantly more satisfied with their consultation with a nurse than those seen by a doctor ( $P < 0.001$ ) [24].

The role of specialized breast care nurses has also been discussed at the 2013 St Gallen consensus conference, where the panelists agreed that regular follow-up supervised by a nurse specialist in person or by telephone would be acceptable for surveillance [25]. While in our survey, patients agreed with a more important role of the breast care nurse during personal follow-up, 78% of patients stated that they did not consider follow-up by phone call a valid alternative. This is contrary to results from a recent Australian study encompassing 722 breast cancer patients suggesting that telephone interviews could play an important role [12]. Similarly, a study from the UK compared traditional outpatient clinics follow-up with phone based follow-up by breast care nurses and reported that patients with telephone follow-up had higher levels of satisfaction but not higher levels of anxiety. No difference between the two groups was found regarding detection of recurrent disease [26]. Therefore, even though telephone follow-up is not widely accepted by patients and health care providers in Switzerland, some authors suggest that it could be a valid alternative to clinical follow-up visits [26].

Most patients (84%) felt that the main purpose of clinical follow-up was to detect local or distant relapses of disease. Even though this certainly is a key element, a study by Montgomery et al showed that the majority of relapses in a cohort of 198 breast cancer patients was not detected by physical exam, and clinicians must be aware of these limitations [27]. Almost half of the patient's (46%) felt that these visits should be used to inform patients and their families about the disease

and treatment course, an aspect that is frequently underestimated by the treating physician. Only 20% of the patients thought that the follow-up visits were performed in order to detect therapy-related side effects. This is important, since a study by Schmitz et al. showed that at 6 years after diagnosis, more than 60% of breast cancer patients were experiencing one or more adverse treatment effects that could be influenced by targeted intervention [28].

Although psychological syndromes such as depression and anxiety are common among cancer patients [29], the majority of patients (88%) in our study population were not receiving psychological care. One potential explanation is that these needs are not detected and sufficiently addressed during follow up, and psychological support was not offered. This is supported by the fact that 21% of patients would like to receive information about support groups and 14% requested psychological support as part of their follow-up visits. In many contemporary breast centers, a psycho-oncological unit provides specialized care and could be used to meet those needs in addition to the important contribution of breast care nurses.

The present study at a University Hospital in Switzerland shows that current standards in breast cancer follow-up do not fully meet patient needs, and that not all patients are aware of the rationale behind routine follow-up. As a consequence of this study, a more significant role has been assigned to a specialized breast care nurse at our institution, who coordinates the multidisciplinary approach and remains the reference person for our patients. Additionally, patients are informed more comprehensively and special attention is given to their requests.

## Statement of Ethics

The study protocol was approved by the local Ethics Committee (Ethikkommission beider Basel, EKBB, Number/ID of the approval(s): 322/10) and all patients gave written informed consent.

## Author Contribution

SD Soysal and KM Schaefer contributed equally to this study. WP Weber and CT Viehl contributed equally to this study.

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