

# Patients' and physicians' expectations differ significantly during the follow-up period after completion of primary treatment of gynecological or breast cancer

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## Summary

**Introduction:** With increasing incidence, earlier detection, and better treatment of malignant diseases, the number of people with cancer is increasing. After the completion of primary treatment, patients enter the follow-up period. While numerous studies have been published regarding the influence of follow-up on survival, there is a lack of data regarding comparison of patients' and physicians' expectations. The aim of the study was to assess patients' and physicians' expectations about follow-up and evaluate potential discrepancies. **Materials and Methods:** This prospective study included 122 patients after gynecological or breast cancer treatment at the Department of Gynecological and Breast Oncology, Maribor, Slovenia, and 72 primary level gynecologists and general practitioners in the Maribor region. A questionnaire was used to compare the expectations of patients and physicians regarding the center and location of follow-up, the prognosis revealed, attitudes towards examinations, and sense of safety and stress. Descriptive statistics and chi-square test were used. The study was approved by the institutional review board. **Results:** Patients consider it more important to be followed-up at the center of treatment, closest to their home, and to be exactly informed about the prognosis. Unlike their physicians, patients consider the sense of safety and stress caused by regular visits as more important, wish to have consultations with the nurse, and many of them would rather visit the physician when symptoms occur as opposed to on a regular basis. **Conclusions:** Given the lack of evidence-based improvement of survival with regular follow-up, in accordance with the present results, individualization of scheduling follow-up visits with the lowest acceptable frequency and intermediate nurse consultations might be associated with meeting patients' expectations without compromising survival outcomes.

**Key words:** Patients' and physicians' expectations; Breast cancer; Follow-up.

## Introduction

The number of oncologic patients is increasing since the improvements in early diagnostics and treatment. In Slovenia, the prevalence of breast and gynecological malignancies increased from 17,381 in 2003 to 24,779 in 2013 [1, 2].

Cancer is a disease that is feared more than any other. It is considered a synonym for a slow and painful death, which follows a period of suffering and dependence. After completion of oncologic treatment, the patient experiences fear of relapse and insecurity with losing the regular contact with the medical staff they knew [3, 4].

Although enormous amounts of funds and time were spent on biomedical research of cancer, the literature offers barely any data on patients' and physicians' expectations from follow-up protocols at times when patients are symptomless and with no apparent signs of the disease [5, 6]. For this purpose, the authors conducted a study to compare directly how important the different aspects of follow-up are to patients and their primary level physicians, who are supposed to be included in the follow-up period.

## Materials and Methods

The prospective study included all consecutive patients who completed primary treatment of gynecological or breast malignancies at the Department of Gynecological and Breast Oncology, University Medical Centre Maribor, Slovenia, attending every fourth follow-up outpatient office during a three-month period. The authors aimed to include all regional public primary level general physicians and gynecologists, working at public healthcare facilities (104). Since a poor response rate through email, the authors visited all healthcare facilities and personally invited all physicians who were at work that day (75), among them only two gynecologists and one general physician declined to cooperate.

Questionnaires were prepared (Table 1). Patients and physicians were asked, how important [on a scale from 1 (not important) to 5 (extremely important)] is it for patients to be followed at the center of treatment, to be followed-up near home, to have the opportunity of specialized nurse and psychologist consultations, and to have cancer support groups (CSG) at the location of follow-up. Secondly, patients and physicians estimated the importance for patients to know exactly the prognosis of the disease, to know exactly when the disease might recur or progress according to the statistics, and to undergo the tests which could predict the recurrence of the disease, despite knowing there is no cure or prevention possible. Lastly, patients and physi-

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Table 1. — A part of the patients' questionnaire as an example. How much is important for you, from 1 (not important at all) to 5 (extremely important):

To be followed by the specialist at the centre where you were treated?	1	2	3	4	5
That your GP is informed about your disease and planned follow up	1	2	3	4	5
That your primary gynecologist is informed about your disease and planned follow up?	1	2	3	4	5
To be followed at the institution closest to your home?	1	2	3	4	5
To have the possibility at the centre of follow up to consult with specialized nurse (about life style, sexual issues, etc)?	1	2	3	4	5
To have the possibility at the centre of follow up to consult with specialized psychologist.	1	2	3	4	5
To have the possibility at the centre of follow up to join cancer support groups.	1	2	3	4	5

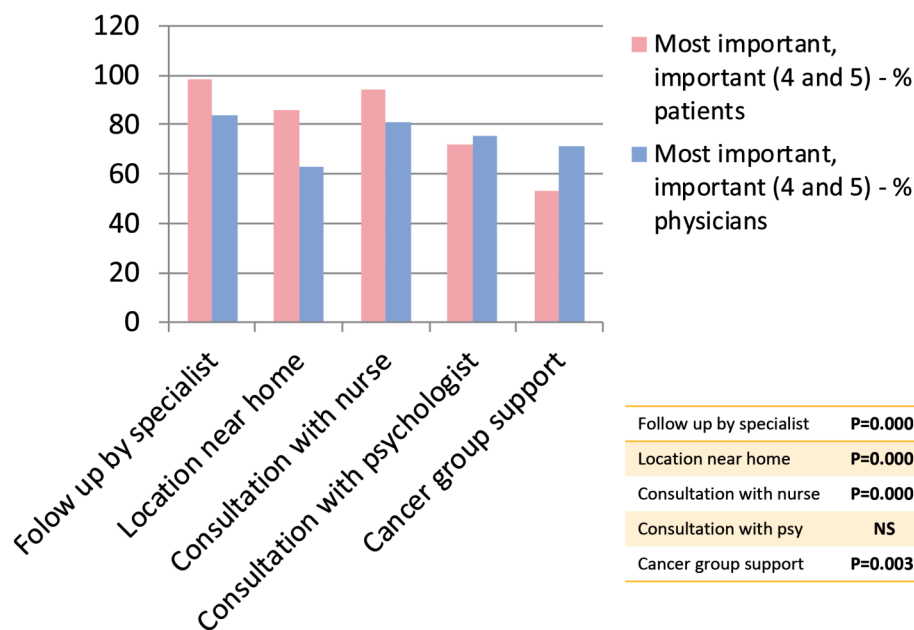


Figure 1. — The comparison between patients' and physicians' answers regarding the importance for the patients to be followed up at the center of treatment by the specialist, at location near home, to have specialized nurse, psychologist, and cancer support group available.

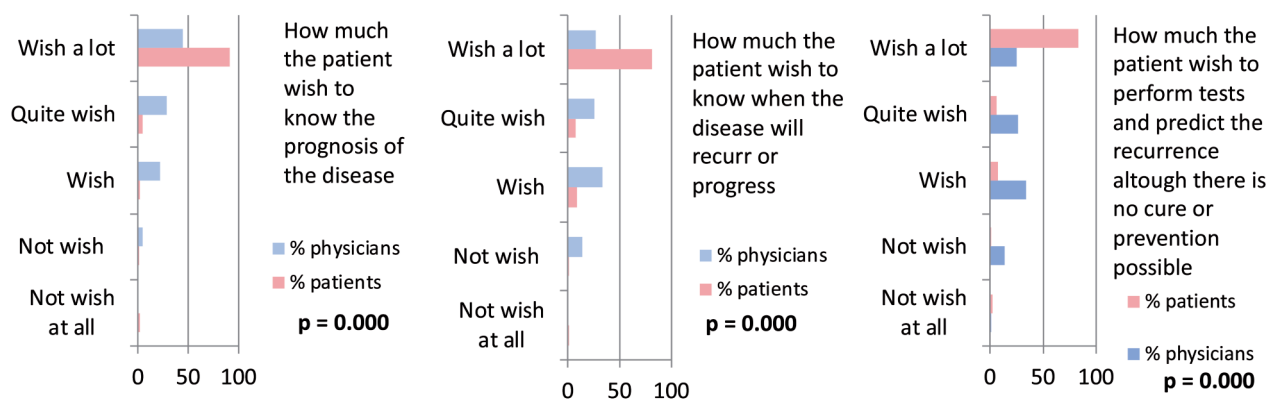


Figure 2. — Comparison between patients' and physicians' answers regarding the patients' desire to know the exact prognosis of the disease during the follow up period.

cians evaluated statements regarding regular visits making patients feel safe or stressed, and whether patients would prefer not to have regular visits. The institutional review board approved the research; included patients provided informed consent. Descriptive statistics and Hi-square tests were performed. SPSS was used.

**Results**

The study included 122 out of 150 (81%) invited patients and 72 out of 75 personally invited physicians. 54.1% of patients were diagnosed with gynecological malignancies

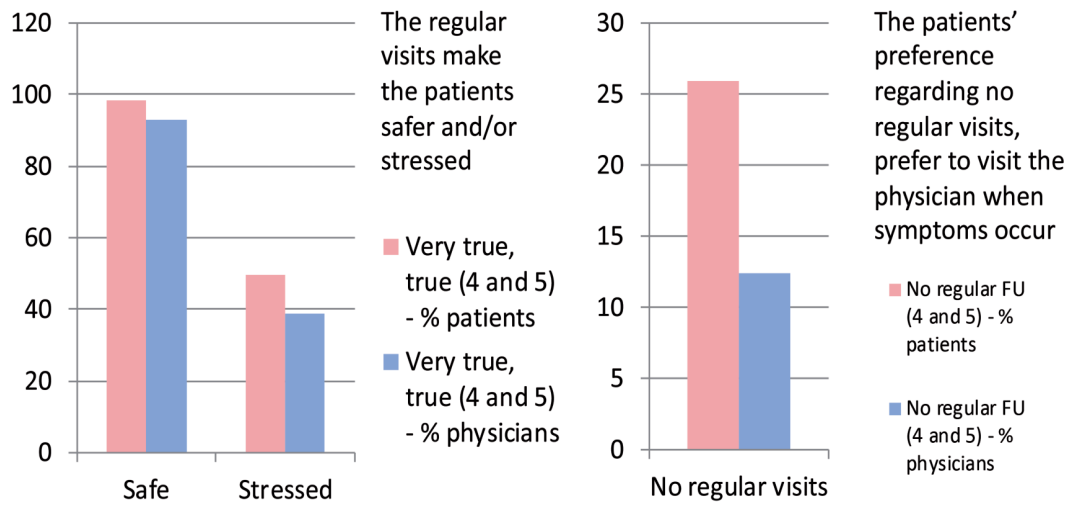


Figure 3. — Comparison between patients' and physicians' answers regarding feelings about regular follow up visits.

and 45.9% with breast cancer. 52.5% patients were diagnosed with cancer more than two years ago. The average age of patients included in the study was  $60.3 \pm 12.3$  years (29 to 85). 63.1% of the patients lived in rural areas; the rest were from urban centers.

Among the 72 included physicians, 34.2% were general practitioners and 65.8% primary level gynecologists. 37.8% of the doctors had < 5 years of work experience, 21.6% 6-15 years, and 40.5% had > 15 years of experience. 65.8% of doctors were female and 34.2% male.

Figure 1 shows the comparison between patients' and physicians' answers regarding the importance for patients to be followed-up at the center of treatment, at a close location, to have specialized nurse and psychologist consultations, and to have a CSG available. The older patients found it more important to be followed-up near home (95.6% of > 70 years old vs. 63.3% < 50 years,  $p = 0.001$ ). The physicians' answers did not differ significantly regarding specialty and gender. However, 82.1% of the < 5-years' experienced doctors estimated as very or extremely important for the patients' to be followed-up by the specialist, compared to 40% of physicians with 6-15 years' experience and 56.7% of the most experienced doctors ( $p = 0.012$ ).

Figure 2 shows the comparison between patients' and physicians' answers regarding knowing the prognosis, knowing the estimated recurrence time, and to undergo the tests to predict the recurrence despite knowing there is no cure or prevention possible. The answers did not differ between different patients' groups. The answers also did not differ between physicians' groups (gender, years of experience) however there was a small difference between gynecologists and general practitioners (47.9% vs. 58.3%,  $p = 0.028$ ) who estimated as very or extremely important for the patients to have these tests performed.

Figure 3 represents the comparison between patients' and physicians' estimations how regular visits are associated

with feelings of safety and stress and how patients and physicians believe the patients would feel about not having regular visits. There were no significant differences among patients regarding the diagnosis, the living location, and the time after the diagnosis. However, significantly more women aged 51-69 stated that they would prefer to make an appointment when symptoms appeared instead of having regular visits [32.8% vs. 13.3% (< 50 years) and 4.8% (> 79 years),  $p = 0.004$ ]. There were no differences between physicians' groups.

### Discussion

The present results show that the physicians' and patients' perspectives regarding important questions related to follow-up differ significantly.

For most patients, it is extremely important to be followed at the center where they were treated. 75.0% of patients also considered it extremely important to be followed at the institution closest to their home; the largest number of patients (95%) who would like to be followed close to their home were aged >70 years. For them, access to the physician may represent a significant logistical problem. Unlike the patients, 57.5% of physicians believed that it is extremely important for patients to be followed at the center where they were treated and only 34.2% of physicians estimated that patients consider it extremely important to be followed at the institution closest to their home. Similar results for Slovenia regarding patients who would like to be followed at the center where they were treated were published by a multidisciplinary group of researchers from the Institute of Oncology in Ljubljana. 69.1% of cancer patients consider the regular annual visits at the oncologist as absolutely necessary for their health [7].

Locally and globally, it still remains open whether to follow patients at the center where they were treated or at pri-

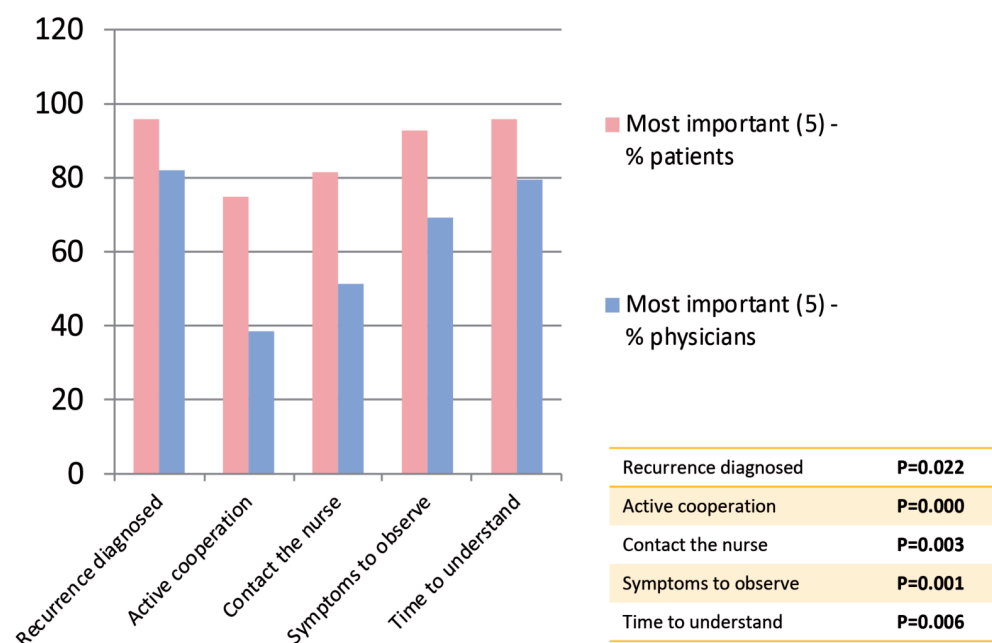


Figure 4. — The comparison between patients and physicians of grading the importance for the patients of different aspects of the follow-up visit.

mary level [8]. Follow-up by a specialist in the center where the patient was treated might be important to patients because the experts there are perceived to be more familiar with the disease. In this way, patient management is also centralized, plus there is the possibility of cooperation with a specialized nurse, psychologist, and cancer patient associations. Performing follow-up on a regular basis also enables centers to follow their own results. Not being familiar with the disease is represented by the fact that there are more referrals of cancer patients to emergency centers and hospitalization after the completion of treatment than expected considering their problems [9]. The cause of higher referrals might be the lack and loss of information when transferring the follow-up from the centers to primary level physicians; that is why several associations recommend creating the Survivorship Care Plan (SCP) [10]. The plan contains detailed information about the patient's diagnosis, received cancer therapy, follow-up plan, and responsibilities of individual healthcare practitioners. Associations recommend SCP despite not having clear evidence, indicating an improvement of follow-up. Two randomized controlled trials (RCTs) for breast cancer patients and two RCTs for gynecological cancer patients were published, but the results were inconclusive [11-14].

However, follow-up at centers is often associated with considerable burden and following of patients at tertiary centers is more expensive compared to primary level management of healthcare systems. The centers are also usually less accessible, which may represent a significant problem especially for older patients. Since healthcare systems differ significantly between countries, it is important to achieve

a local consensus regarding the location of follow-up to optimize advantages of centralization, expenses and accessibility. For example, in Slovenia approximately 5,000 patients per primary level gynecologist and 1,800 per general practitioner represent an above average European primary level physician burden [15]. Therefore, the movement of follow-up of cancer patients from tertiary centers to primary level physicians in our country would probably not be accepted and feasible.

Cancer is a difficult disease with a physical as well as an emotional impact. Cancer patients can develop fear of death, fear of chemotherapy or radiotherapy, and later fear of disease recurrence [16]. According to some data, the highest level of stress is expressed in patients with ovarian cancer [17]. These issues should be addressed in the follow-up period since this is the time when patients are virtually with no physical signs of the disease. Options considered are to provide patients direct contact with a specialized nurse, psychologist or the possibility of socializing among themselves. According to the present survey, 94% of patients consider it very or extremely important to have the possibility of directly consulting a nurse compared to 80% of physicians, meaning the physicians underestimate the role of the nurse. On the other hand, the physicians considered the consultations with the psychologist and entering the patients into cancer groups as more important compared to the patients themselves (Figure 4). It might be that expert psychological support and exposing in groups are still stigmatized in our environment which is not recognized by physicians.

Stress and fear related to cancer diagnosis also refer to the fact that the disease is expected to recur [17]. 90% of

patients stated it as extremely important to know the expected course of the disease and a solid 80% of patients considered it extremely important to be familiar with the statistics of expected recurrence or disease progression. It is interesting that no differences were established in these statements among patients regarding the type of cancer or time of diagnosis. On the other hand, only nearly half of physicians believe that their patients consider it extremely important to know the prognosis and only 27% of physicians think that patients consider it extremely important to know the estimated recurrence time. The large disagreement between the patients and the physicians in these issues is very important for everyday clinical practice. While the physicians think that patients would rather not know the poor prognosis, the patients on the other hand would like to be familiarized precisely. It is a known fact that healthy people have a different perspective on knowledge about a poor prognosis than those already having the disease [18]. It would be hence sensible to educate physicians to answer patients' questions about disease prognosis openly; although clearly not in the sense of taking away their hope.

Similar observations are related to the question asking about the importance of undergoing tests predicting recurrence of progression in advance, despite knowing that cure or prevention is not possible; the example being measuring CA 125 in patients with ovarian cancer. A solid 80% of patients consider these tests as extremely important, but only 24% of physicians think that this is extremely important for the patients. The physicians' replies were expected, as it can be quite stressful for them to familiarize the patient with the results of the test indicating a recurrence and not having the means to prevent it or cure it. On the other hand, patients would like to be acquainted with the prognosis; most probably to obtain a sense of control over their lives. The feeling of losing control over one's life is one of the most important factors related to stress in cancer patients [19].

Follow-up visits are defined as regular visits in patients having completed the primary treatment and currently without any symptoms – so they might not feel sick at all. This is why regular visits with the physicians are not necessarily related to a sense of safety [7]. In the present study, 92% of patients estimated that regular visits give them a sense of safety. As published, patients feel relief after the visit because they believe that the visit itself is a guarantee for recovery [20]. For this reason, it might not be surprising that only 65% of physicians think patients perceive the regular visits as a sense of safety, because as professionals we know that the visit itself will not prevent the progression of the disease. Physicians might perceive the intensive follow-up as a possible ethical dilemma since there is a lack of evidence that regular follow-up is associated with better survival or something not necessarily related to the patient's sense of safety [8].

On the other hand, 36% of patients, regardless of living location, diagnosis and duration since treatment, described the regular visits as something that causes them stress, compared to 14% of physicians. Each visit is associated with the fear of what the visit or test will show. To reduce the amount of stress, it is important to have the optimal frequency of visits to ensure the sense of safety and reduce the unnecessary stress. The introduction of intermediate consultations with a nurse could be one solution. Another option is not to schedule patients for appointments, but to let them decide when to come for a visit or to appoint when symptoms occur. 22% of the present patients expressed the highest level of agreement with this idea. This percentage was higher in the age group 51-69 years (32%) and expectedly the lowest among >70-year-olds (4.8%). Surprisingly, only 1.4% of physicians replied that patients would like to make appointments by themselves. The discrepancy is large and influences the everyday practice significantly. The majority of centers and associations recommend some sort of schedule of follow-up visits [5]. Again the patients would probably mostly want to have a sense of control over their lives, which is something the physicians are often not acquainted with or do not understand.

Most physicians in the present study did not recognize the patients' needs to actively participate in planning the follow-up, their need to consult a nurse, their desire to obtain clear information on the prognosis, and their feelings of safety and stress associated with regular visits. For these reasons, more studies and public discussions regarding this topic are required as it presents a public healthcare and financial issue which is expanding upon a daily basis.

## Conclusion

The present study confirmed important discrepancies regarding expectations and patients' needs from follow-up visits after completion of primary treatment for gynecologic or breast cancer. Most physicians did not recognize the patients' wish to be informed about poor prognosis openly, how regular visits are associated with feeling of stress and safety, how important it is for patients to actively cooperate with planning of follow-up visits and tests, and the desire to have a nurse available for consultations. Given the lack of clear evidence that the intensive regular follow-up of apparently symptomless patients is associated with better survival, the scheduling of visits, and tests should be carefully planned to meet the patients', physicians', and healthcare provider's expectations.

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