Gynecological cancer patients' attitudes toward follow-up care after cancer treatment. Do preferences reflect patients' experience? A cross-sectional questionnaire study

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Conflicts of Interest notification

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Abstract

Introduction Due to an increasing number of cancer patients, new follow-up models are being debated. One suggestion is for follow-up care to be provided by general practitioners (GPs), rather than by gynecologists in hospitals. The purpose of this study was to compare attitudes toward follow-up care among patients treated for gynecological cancer who had not yet started a follow-up regimen and those who had been attending a hospital-based follow-up regimen for >1 year.

Material and methods We conducted a cross-sectional survey among gynecological cancer patients recruited from three Norwegian hospitals in 2013-2015: Sørlandet Hospital Kristiansand, Sørlandet Hospital Arendal, and St. Olavs University Hospital.

Results 239 patients agreed to participate, 100 who had not yet started follow-up and 139 who had been attending >1 year of follow-up. Patients reported that they preferred to be followed up by a gynecologist rather than by their GP, whom they viewed as less competent for this purpose. However, patients who had not yet started follow-up were more willing to be followed up by a GP. Overall, patients rated detection of recurrence as the most important aspect of follow-up visits.

Conclusions The gynecological cancer patients in our study preferred the existing follow-up care model. However, patients who had not yet started follow-up were more willing to be followed up by a GP. If follow-up is to be provided by GPs for selected patients, it is important that these patients are informed early of the value and limitations of follow-up visits, to ensure that they feel safe.

Key Words Cancer patient, gynecological, attitudes, follow-up, experience, preference, general practitioner

Abbreviations

GP, general practitioner

Key Message

Gynecological cancer patients believed that detection of recurrence was the most important aspect of follow-up visits and preferred to be followed up by a gynecologist. Patients who had not yet started follow-up were more willing to be followed up by a general practitioner.

Introduction

Cancer patients are living longer due to improvements in diagnostics and cancer therapies. This has led to a growing demand for follow-up of cancer patients to detect recurrence, monitor comorbid conditions, and ensure general health maintenance. Due to the subsequent increasing workload in hospital outpatient clinics, new follow-up models are being debated. The traditional models of long-term, hospital-based follow-up of cancer patients have been challenged, and it has been suggested that selected cancer patients could be followed up by general practitioners (GPs) (1-4). In several studies, GPs have reported broad experience in providing follow-up care to cancer patients, and they acknowledge their responsibility regarding this task (3,5). Moreover, there is little empirical evidence that the current hospital-based follow-up regimen benefits gynecological cancer patients in terms of early detection of recurrence, quality of life, or survival (6-9). However, if the follow-up regimens are to be changed, it is important to assess the preferences and understand the needs of cancer patients in order to design patient-centered follow-up care.

It has been argued that patients′ views on cancer follow-up are colored by past experiences (10,11). For example, Salkeld et al. found that patients' health care preferences tended to favor the existing service (12). Most studies that have explored whether patients prefer to be followed-up by specialists in hospitals or by GPs have been conducted among patients already attending follow-up, thus the existing follow-up may have influenced their views (13-16). Therefore, the purpose of this study was to compare attitudes toward follow-up care among patients recently treated for gynecological cancer who had not yet started a follow-up regimen with those who had been attending a hospital-based follow-up regimen for >1 year.

Material and methods

Primary treatment of gynecological cancer in Norway is centralized; it is conducted at the four regional university hospitals, with the exception of low-risk endometrial cancer. Follow-up after treatment is provided by gynecologists either at the same regional university hospital or in local hospitals in collaboration with the regional university hospitals (17). In Norway, standard follow-up for gynecological cancers consists of a clinical examination three-four times annually for the first 2 years, twice a year over the next 3 years, and annually thereafter for selected patients, depending on the recommendations of the clinician (17).

Setting and participants

Participants were recruited from two local hospitals and one regional university hospital between January 2013 and December 2015: Sørlandet Hospital Kristiansand, Sørlandet Hospital Arendal, and St. Olavs Hospital- Trondheim University Hospital. To be eligible for inclusion, women had to have a diagnosis of gynecological cancer, be more than 18 years of age, and have no cognitive or language barriers.

Patients who had attended >1 year of follow-up were recruited in one of two ways: some were invited to participate during a follow-up visit to the gynecological outpatient clinic; others were identified in the hospitals' patient administrative system, and those who were alive and otherwise eligible received a written invitation to participate. Recently-treated patients were invited to participate by a gynecologist or a nurse at the end of primary treatment, either while they were still hospitalized after surgery or after completing chemotherapy at the outpatient clinic, before attending follow-up. All participating patients completed and signed an informed consent form.

Data collection

All participating patients completed a questionnaire on their attitudes toward follow-up care. As we were unable to find an existing, suitable, validated questionnaire, a written

questionnaire was developed by the research group (Appendix). Studies of cancer survivors′, GPs′ and gynecological oncologists′ views on cancer follow-up were reviewed and relevant issues identified in the studies were included (1,18,19). We also included questions from our previous study investigating GPs′ opinions on conducting follow-up visits for cancer patients (5), in order to compare the opinions of the patients with those of GPs. The questionnaires were then piloted by a gynecologist and a nurse in an outpatient clinic, by three patients attending regular follow-up visits, and by six hospitalized patients recovering from primary treatment for gynecological cancer. The final version was adjusted based on feedback from the pilot and collected demographic data, clinical data, expectations and attitudes toward follow-up in general, and attitudes toward the GPs´ role in follow-up care (Appendix). To evaluate patients′ attitudes about specific aspects of follow-up care, we asked them to rate given statements on a four-point scale (from not important to very important). The first 13 questions were identical for patients who had not started follow-up and for those who had attended >1 year of follow-up, but the questionnaire for the latter group included two additional questions regarding their follow-up experience. Questions addressing patients' views on follow-up by GPs included open-ended questions (Appendix). Information regarding diagnosis, treatment, comorbidity, and current medication, were confirmed in medical records.

Statistics and ethics

We used chi square tests to compare differences between patients who had not started follow-up and those who had attended >1 year of follow-up for categorical parameters. Multivariate logistic regression analysis was adjusted for age, comorbidity, and cancer type. Associations are described as odds ratios (OR) with 95% confidence intervals (CI). We considered a *p*-value of <0.05 to be statistically significant.

Ethical approval

Ethical approval was obtained from The Regional Committee for Medical and Health Research Ethics (reference no 2012/355 and 355b).

Results

In total, 239 gynecological cancer patients at three centres met the inclusion criteria and agreed to participate: 100 who had not yet started follow-up, and 139 who had attended >1 year of follow-up. Sørlandet Hospital Kristiansand was the only center that recorded response rates. At this center only 9 out of the 128 eligible patients (7%) declined to participate. Sixty-four percent of patients who had not yet started follow-up and 70% of those who had attended >1 year of follow-up had at least one comorbid condition, the most common of which were cardiovascular and musculoskeletal disease (Table 1).

Attitudes toward follow-up by a general practitioner or gynecologist

Regardless of which patient group they were in, most patients were reluctant to be followed up by their GP (not yet started follow-up: 65%, attended >1 year of follow-up: 83%). Among patients with at least one comorbid condition, 28% were willing to be followed up by a GP under certain conditions (good cooperation between GP and hospital, quick re-referral back to gynecologist when needed, or shared responsibility between GP and gynecologist), compared to 17% of those without any comorbidity, irrespective of cancer type. However, this difference was not statistically significant. In multivariate analysis, those who had not yet started follow-up were three times more willing to be followed up by a GP, either alone or under certain conditions (see above), compared to those who had attended >1 year of follow-up (OR 3.0, 95% CI; 1.59-5.59, p=0.001). A majority of the 239 participating patients preferred to discuss issues regarding cancer and its consequences with a gynecologist rather than with their GP (p<0.001), the only exception was economical issues (Fig. 1). In the open field where patients could give the reasons for their preferences, they cited specific competence as the main reason for preferring follow-up by gynecologists (Table 2).

Attitudes toward content of follow-up

The majority of patients who had not yet started follow-up (61%) expected to be followed up every 3 months for 5 years, which corresponds well with the present follow-up guidelines (17). Patients rated every aspect of the follow-up visit as important, and the responses did not differ between those who had not yet started follow-up and those who had attended >1 year of follow-up (Fig. 2). "Detection of recurrence" was rated "very important" by 93% of the total study sample, whereas "follow-up of late effects after treatment" was nearly three times more important to patients under the age of 50 years (n=44) than to patients who were over 50 years of age (n=193) (OR 2.7, 95% CI; 1.06-6.99, p=0.04).

Regarding what made them feel confident during follow-up visits, the statement "that the physician knows me" was rated as most important by 75% of the study sample, while the statement "that the doctor shows interest in me as a person" was rated less/not important by 27% (Fig. 3). Patients who had not yet started follow-up had lower odds of rating the latter statement as important/very important compared to those who had attended >1 year of follow-up (OR 0.48, 95% CI; 0.26-0.91, p=0.02). Undergoing a gynecological examination was also less important to those who had not yet started follow-up when compared to the other patient group (OR 0.48, 95% CI; 0.28-0.85, p=0.01). After adjustment for age and comorbidity, patient ratings for gynecological examination revealed that this aspect of follow-up visits was more important to endometrial and cervical cancer patients than to ovarian and vulvar cancer patients (p=0.044), while blood tests were significantly more important to ovarian cancer patients than to patients with other gynecological cancer types (p=0.009).

Most patients who had attended follow up for >1 year (89%) felt that the current follow-up model responded to their expectations to a great/very great extent. When asked to suggest changes that could improve follow-up, the most frequent suggestion was "meeting the same physician each time" (17%).

Discussion

Gynecological cancer patients preferred to be followed up by gynecologists rather than by their GP, whom they viewed as less competent for this purpose. However, patients who had not yet started follow-up were more willing to be followed up by a GP, provided there was good cooperation between the GP and the hospital, compared to patients who had attended >1 year of follow-up. Overall, detection of recurrence was rated as the most important aspect of the follow-up visit. Undergoing a gynecological examination and being met by a doctor who shows interest in them as a person were more important to cancer patients who had attended >1 year of follow-up than to those who had not yet started follow-up.

Our results are in line with findings of previous studies regarding patients' follow-up preferences (10,15-16,19,20-22). However, those studies were conducted among patients who were already being followed-up by specialists. To our knowledge, this is the first study to compare views on follow-up care between patients with and without experience from a follow-up regimen. Discrepancies in attitudes between our patient groups may be explained by the lack of experience and prejudices on the part of patients who had not started follow-up.

The preference of being followed up by a specialist may be founded on a belief that GPs have limited abilities to perform cancer-specific follow-up care (13-15,22,23). However, according to previous studies, not only do GPs feel competent to provide this kind of follow-up care, they regard themselves as better suited than specialists to provide psychosocial support to cancer patients (5,24). Contrary to our findings, cross-sectional studies of patients with breast, prostate, and melanoma cancer have shown that these patients prefer to see their GP for psychosocial matters and general care (14,25,26). The patients in our study thought that the main reason for attending follow-up is to detect possible recurrence, which is in line with most previous studies (19,23). However, it has been shown that recurrent gynecological cancer is often detected by the patient herself between scheduled visits, because of symptoms

(9). Thus many patients seem to have an unrealistic view of the importance of gynecological examination, which overshadowed the other aspects of follow-up in our study (such as psychosocial support, follow-up of late effects after treatment, and getting information about the disease).

According to a systematic review regarding models of follow-up care for patients with breast, colon, lung, and prostate cancer, follow-up provided by GPs is equivalent to follow-up provided by specialists in regard to detecting recurrence (27). The preference of follow-up by specialists in our study could indicate that this knowledge has not been passed on to patients. Indeed, a systematic review (28) showed that cancer patients are not well informed about the lack of effectiveness of examinations and tests, and therefore are not aware of the limitations of hospital-based routine follow-up.

We expected patients with comorbid conditions to be more willing to be followed up by their GP, due to their relationship and regular appointments with them; however, we did not find any such significant correlation. This differs from a study by Nyarko et al., which showed that cancer patients (with several cancer types) who visited their GP frequently rated follow-up by a GP significantly higher than patients who visited their GP less often (13).

Previous studies on cancer patients already attending follow-up have shown that most patients prefer to continue their current frequency of visits (12,18,23), which confirms patients′ tendency to favor the existing service (12). Guidelines available on the internet or information given before the end of treatment may influence patients′ expectations, even before they enter the follow-up program. Regarding desired duration of follow-up, one study showed that more than half of the surveyed patients preferred a longer follow-up period than that recommended, even up to the end of their lives, because of fear of recurrence (21). This shows that the patients find follow-up reassuring in terms of detecting recurrence and indicates that they expect a better outcome through life-long follow-up.

Age seemed to influence patients′ views on the importance of different aspects of follow-up visits, as younger patients (<50 years) rated “follow-up of late effects after treatment” as significantly more important than older patients. This could be explained by younger patients’ expectation that they will live longer while suffering from late effects, and perhaps more expectations regarding varying aspects of quality of life. We found no previous studies that investigated this topic.

Provider continuity in follow-up care seems to be important, as the statement “that the physician knows me” was the most important aspect in terms of making the patients feel confident in the follow-up visit. This corresponds well with the desire of the patients who had attended >1 year of follow-up to meet the same physician at each follow-up visit. The importance of provider continuity was also shown in a systematic review (29), which concluded that increased provider continuity is associated with improved patient outcome and satisfaction. However, this continuity may be easier to achieve when a patient is followed up by a GP than by a provider at an outpatient clinic, where several specialists share this task.

Endometrial and cervical cancer patients assigned the highest importance to gynecological examination, whereas ovarian cancer patients gave the highest importance to blood tests, which was also shown in a study conducted by Kew et al. (18). This indicates that patients with ovarian cancer are aware of the significance of the blood test (Cancer antigen 125) to detect recurrence.

A limitation of our study is the timing of questionnaire administration to patients who had not yet started follow-up. We aimed to explore patients′ attitudes before they were colored by experience with and knowledge of follow-up, but although these patients had not yet attended follow-up, they seemed to be informed about their future follow-up schedule. However, it is probably impossible to recruit patients who have completed primary cancer treatment and have not acquired any such information. The validity of the survey may be limited due to the

design of the questionnaire, which was self-developed. However, the questionnaire was piloted by a gynecologist and a nurse, and gynecological cancer patients were asked for comments and adjustments were made according to their feedback. The closed-ended nature of most of the questions restricted the response alternatives, affecting the level of detailed information obtained. However, there were some open-ended questions that enabled patients to give complementary answers. Furthermore, we were able to establish a true response rate at only one of the recruiting centers.

The strengths of the study are that we included patients with no experience with follow-up and patients who had >1 year of experience with follow-up, the geographical representativeness of the sample, and patients seen at both local and university hospitals. Moreover, the study sample was comparable to Norwegian gynecological cancer patients regarding age and distribution of gynecological cancer type (30).

In conclusion, gynecological cancer patients in our study preferred the existing follow-up regimen. They preferred to be followed up by gynecologists rather than by their GP, whom they viewed as less competent for this purpose. However, patients who had not yet started follow-up were more willing to be followed up by a GP. If follow-up is to be provided by GPs for selected patients, it is important that these patients are informed early of the value and limitations of follow-up visits, to ensure that they feel safe.

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Table 1. Demographics of participating patients (n=239)

	Not yet started follow-up, n=100	Attended >1 year of follow-up, n=139
	n (%)	n (%)
Age, years median (range)	62 (28-84)	63 (31-82)
Education level		
Secondary school	30 (30)	27 (19)
High school	43 (43)	51 (37)
Higher education	27 (27)	57 (41)
Cancer type		
Cervical	22 (22)	27 (19)
Endometrial	42 (42)	69 (50)
Ovarian	31 (31)	41 (30)
Vulvar	5 (5)	2 (1)
Treatment		
Surgery	51 (51)	61 (44)
Chemotherapy	9 (9)	4 (3)
Radiotherapy	0 (0)	2 (1)
Combination	40 (40)	71 (51)
Comorbidity		
None	36 (36)	42 (30)
1	31 (31)	58 (42)
>1	33 (33)	39 (28)

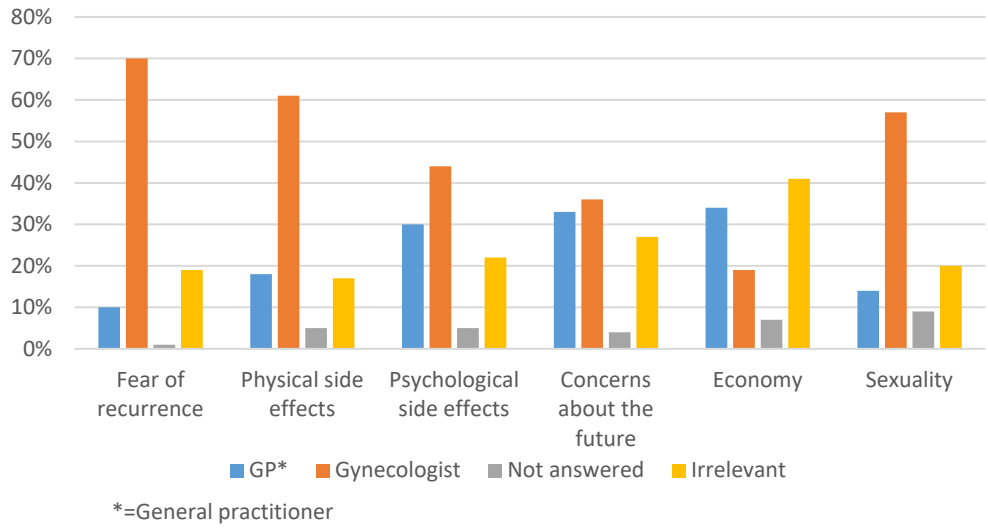

Figure 1: With whom would you prefer to discuss the following issues? (n=239)

Table 2: Attitudes toward follow-up by a GP* (n=239)

Why would you like to be followed up by your GP?**	**n**
- My GP knows me well	3
- I have a good relationship with my GP	3
- I have confidence in my GP	10
- My GP is easily accessible	5
Why would you not like to be followed up by your GP?**	
- Gynecologists are specialists	70
- My GP does not have ultrasound	8
- The gynecologist has more experience	6
- I feel more confident when I am being followed up by a gynecologist.	47
- I do not have confidence in my GP	6
- I have a male GP	2

* General practitioner
**Some answers are categorized because of similarity

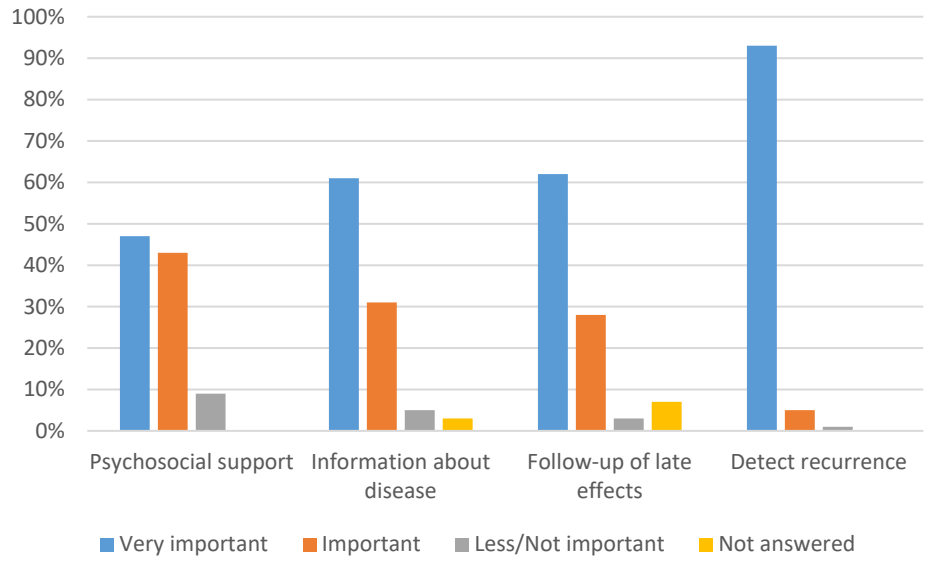

Figure 2: How important are these aspects of a follow-up visit? (n=239)

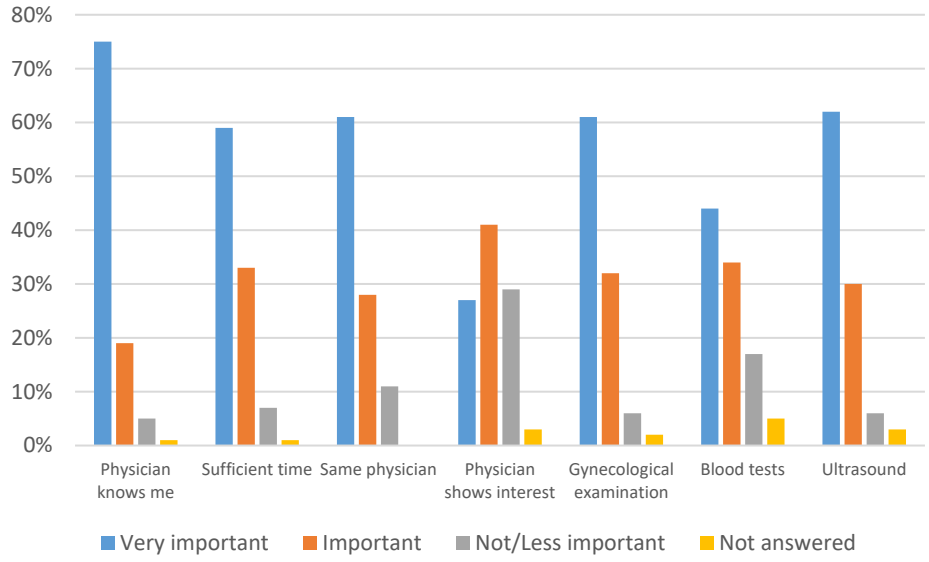

Figure 3: What makes you feel confident in the follow-up visit? (n=239)

Appendix

Questionnaire

1) Age (years)

< 30 30-49 50-69 ≥70

□ □ □ □

2) Education level

☐ Secondary School

☐ High School

☐ College

☐ University

3) Please list all medications you are currently taking:

_____

_____

_____

4) What type of cancer have you been treated for?

☐ Ovarian cancer

☐ Endometrial cancer

☐ Cervical cancer

☐ Vulvar cancer

5) What treatment have you received for your cancer disease?

☐ Surgery

☐ Chemotherapy

☐ Radiotherapy

☐ Endocrine therapy

☐ Combination of treatment types

6) You have now ended primary treatment, how often du you expect to come for follow-up visits?

☐ Monthly

☐ Every 3 months

☐ Every 6 months

☐ Annually

☐ Less often than annually

☐ If needed

7) For how many years do you expect the follow-up visits to continue?

☐2 years ☐3 years ☐5 years ☐>5 years

8) How important are these aspects in the follow-up visit?

	Not important	*Less important*	*Important*	*Very important*
To discuss how I am doing	☐	☐	☐	☐
To get information about my disease	☐	☐	☐	☐
Follow-up of late effects after treatment	☐	☐	☐	☐
Detection of recurrence	☐	☐	☐	☐
Other:_____				

9) What makes you feel confident in the follow-up visit?

	Not important	*Less important*	*Important*	*Very important*
That the physician knows me	☐	☐	☐	☐
Sufficient time	☐	☐	☐	☐
Same physican every time	☐	☐	☐	☐
That the physician shows interest in me as a person	☐	☐	☐	☐
Gynecological examination	☐	☐	☐	☐
Bloodtests	☐	☐	☐	☐
Ultrasound	☐	☐	☐	☐
Other:_____	☐	☐	☐	☐

10) Would you like to be followed up by your GP?

☐ Yes

☐ No

☐ Yes, if the GP and the gynecologist cooperate well

☐ Yes, if I can get a quick re-referral back to the gynecologist when needed

☐ Yes, I would like a shared responsibility (50/50) between the GP and the gynecologist

11) If ”no”, why not?

_____

_____

_____

12) If ”yes”, why?

_____

_____

_____

13) With whom would you prefer to discuss the following issues?

(Only one answer can be ticked in each line).

	GP	Gynecologist	Irrelevant
Fear of recurrence	☐	☐	☐
Physical side effects	☐	☐	☐
Psychological side effects	☐	☐	☐
Concerns about the future	☐	☐	☐
Economy	☐	☐	☐
Sexuality	☐	☐	☐

Additional questions for the patients treated at least one year ago:

14) To what extent has the follow-up program met your expectations?

☐ To a very small extent

☐ To a small extent

☐ To a moderate extent

☐ To a great extent

☐ To a very great extent

15) Do you have any suggestions for changes that could make follow-up visits better for you?

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