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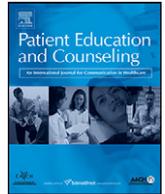
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Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: A study from the population-based PROFILES registry

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ABSTRACT

Objective: To evaluate perceived level of and satisfaction with information received by endometrial cancer survivors, and to identify associations with socio-demographic and clinical characteristics.

Methods: All patients diagnosed with endometrial cancer between 1998 and 2007, registered in the Eindhoven Cancer Registry, received a questionnaire including EORTC-QLQ-INFO25.

Results: Seventy-seven percent responded ($n = 742$). Most patients indicated receiving quite a bit of information about their disease and medical tests. However, most patients were not (54%) or a little (24%) informed about the cause of their disease, and possible side effects (36%; 27%). Especially information about additional help, rehabilitation, psychological assistance, and expected results on social and sexual life was lacking. Five percent was not or a little (36%) satisfied. Four percent found the information not or a little (35%) helpful. Fifteen percent preferred more information. Younger age, more recent diagnosis, radiotherapy, absence of comorbidities, having a partner, having received written information, and higher educational level were associated with higher perceived information receipt.

Conclusion: Many endometrial cancer survivors are unsatisfied with received information. Several areas of information provision are experienced as insufficient.

Practice implications: More patient-tailored information is probably needed to provide optimal information. Implementation of Survivorship Care Plans might be a way to achieve this.

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1. Introduction

Endometrial cancer is the most frequent gynecological cancer in industrialized countries, with an incidence of 15–25 per 100,000 women per year [1,2]. An ageing population with more diagnoses of endometrial cancer, increased risk factors, such as obesity, diabetes, and a lower parity, and more aggressive treatments in advanced disease all have resulted in increasing numbers of endometrial cancer survivors. In 2005, there were about 17,000 endometrial cancer survivors in The Netherlands, and this number is expected to increase to 25,000 in 2015 [3].

Patient information is an essential factor in the support for cancer survivors across the whole cancer trajectory. Appropriate information given to cancer survivors about their diagnosis, treatment, possible long-term and late effects and referral services can result in better informed decision making, lower levels of distress, and improved satisfaction with care and sense of control [4–7]. Cancer survivors who are satisfied with the information they received have a better health related quality of life, and lower levels of depression and anxiety [8]. Studies suggest that most cancer patients want as much information as possible [7,9,10]. However, the information needs of cancer patients differ by gender, age, cultural background, educational level, cancer type, stage of disease (at diagnosis, treatment and follow-up), and coping style [11,12]. Understanding factors associated with information provision might help health care providers to provide more patient-centered information by giving adequate information to those who need it, at the right time [13].

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Previous research has shown that likelihood of cure, information on (spread of) disease, and side effects of treatment are information needs of gynecological cancer survivors [14–16]. In addition, previous studies suggest that gynecological cancer survivors would appreciate more information concerning how the disease and treatment affect their self-image, sexuality [17], and fertility [18]. Identifying the specific information needs of endometrial cancer survivors might facilitate gynecologists, radiotherapists, medical oncologists, and oncology nurses in providing patient-centered information, which may contribute to improved quality of life of endometrial cancer survivors. However, until now, research investigating the specific information needs of endometrial cancer survivors is lacking. Investigating the current state of information provision and degree of satisfaction with information provision of endometrial cancer survivors is valuable to determine whether the current information provision is sufficient, or whether improvement is necessary. The present study therefore aims to assess the perceived level of and satisfaction with information received by endometrial cancer survivors, and to identify possible associations with socio-demographic and clinical characteristics.

2. Methods

2.1. Setting and participants

A cross-sectional study was performed among 1091 endometrial cancer survivors registered within the Eindhoven Cancer

Registry (ECR) of the Comprehensive Cancer Center South (CCCS). The ECR records data on all patients newly diagnosed with cancer in the southern part of the Netherlands. The ECR was used to select patients diagnosed with endometrial cancer between January 1st 1998 and October 1st 2007 in 10 hospitals. All individuals (age 18–84 years) diagnosed with endometrial cancer FIGO stages I–II (classification 1988) were eligible for participation. Deceased patients were excluded by linking the ECR with the Central Bureau of Genealogy (Fig. 1). Ethical approval for the study was obtained from a Medical Ethics Committee.

2.2. Data collection

Data collection took place between May and July 2008 and was done within PROFILES (Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship). PROFILES is a registry for the study of the physical and psychosocial impact of cancer and its treatment from a dynamic, growing population-based cohort of both short and long-term cancer survivors. PROFILES contains a large web-based component and is linked directly to clinical data from the ECR. Details of the data collection method have been previously described [19,20]. Data from the PROFILES registry will be available for non-commercial scientific research, subject to study question, privacy and confidentiality restrictions, and registration (www.profilesregistry.nl).

Gynecologists sent their (former) patients a letter to inform them about the study and a questionnaire. To avoid coercion and



Fig. 1. Flow-chart of the data collection process.

assure anonymity, patients were asked to send the informed consent form and questionnaire back to the researchers at the Comprehensive Cancer Center South in a pre-stamped envelope. Returned questionnaires contained only a study number. By returning the completed questionnaire, patients agreed to participate and consented with linkage of the outcomes of the questionnaire to their disease history as registered in the ECR. Patients were reassured that non-participation would not have any consequence for their follow-up care or treatment. Non-respondents were sent a reminder letter and questionnaire within 2 months.

2.3. Measures

2.3.1. Socio-demographic and clinical characteristics

Clinical and patient information was obtained from the ECR [21] (i.e., date of birth, date of diagnosis, disease stage, and primary treatment). The questionnaire included questions on socio-demographic data (i.e., marital status, employment status, and educational level). Comorbidity at the time of survey was categorized according to the Self-administered Comorbidity Questionnaire (SCQ) [22].

2.3.2. Information provision

To evaluate the perceived level of and satisfaction with information among endometrial cancer survivors, the Dutch version of the European Organisation for Research and Treatment of Cancer (EORTC) QLQ-INFO25 questionnaire was used [23]. This 25-item questionnaire incorporates four information provision subscales: perceived receipt of information about the disease (four items regarding diagnosis, spread of disease, cause(s) of disease and whether the disease is under control), medical tests (three items regarding purpose, procedures and results of tests), treatment (six items regarding medical treatment, benefits, side-effects, effects on disease symptoms, social life and sexual activity) and other care services (four items regarding additional help, rehabilitation options, managing illness at home, psychological support). The question format was as follows: “during your current disease or treatment, how much information have you received on ...?” Additionally, it contains several single items on having received written information or information on CDs or tape/video and items on the satisfaction with, amount of, and helpfulness of information. The answer categories were “not at all”, “a little”, “quite a bit”, and “very much”, except for four items which have a two point yes/no scale. Furthermore, an open question was asked on what topics survivors would like to receive more information on. After linear transformation, all scales and items range in scores from 0 to 100, with higher scores indicating better perceived information provision. The questionnaire has been internationally validated, and internal consistency for all scales is good ($\alpha > 0.70$), as is test-retest reliability (intraclass correlations > 0.70) [23]. A recent study also showed that the scale structure of the EORTC QLQ-INFO25 is valid [24]. Our data revealed Cronbach's alphas of 0.78 (disease), 0.91 (medical test), 0.85 (treatment) and 0.78 (other care services) for the four subscales respectively. Apart from the EORTC-QLQ-INFO25 questionnaire, two single questions about the use of Internet for seeking additional information were added (i.e., “Do you make use of the Internet?” and “Have you used the Internet to look for information about endometrial cancer?”), which could be answered with either yes or no.

2.4. Statistical analyses

All statistical analyses were conducted using SPSS version 17.0 (Statistical Package for Social Sciences, Chicago, IL, USA), and p -values of < 0.05 were considered statistically significant. Missing

items from multi-item scales of the EORTC QLQ-INFO25 were mean-imputed if at least half of the items from the scale were answered, according to the EORTC QoL guidelines [6,23,25].

Differences in socio-demographic and clinical characteristics between respondents, non-respondents, and patients with unverifiable addresses were compared using ANOVA for continuous variables and chi-square tests for categorical variables. Frequencies and percentages were used to summarize categorical data; means and standard deviations were used to summarize continuous data.

Differences between satisfied and unsatisfied survivors in perceived receipt of information, helpfulness of information, wanting more or less information, receipt of written information, and use of the Internet, were compared using t -tests for continuous variables and chi-square tests for categorical variables. Patients were categorized into two groups: (a) patients who were unsatisfied or only a little satisfied, classified as unsatisfied and (b) patients who were quite satisfied or very satisfied, classified as satisfied.

ANOVA and chi-square tests were performed to investigate mean differences between socio-demographic and clinical characteristics (independent variables), and the subscales of the EORTC QLQ-INFO25 (dependent variables). For all ANOVAs, Bonferroni corrections were used.

Multivariate linear and logistic regression analyses were performed to investigate the association of socio-demographic and clinical characteristics with the subscales of the EORTC QLQ-INFO25. In the multivariate analyses, all socio-demographic and clinical variables were included. This was determined a priori [26]. All predictors were entered simultaneously in the regression analyses.

3. Results

3.1. Patient and tumor characteristics

Of the 965 endometrial cancer survivors who were sent a questionnaire, 742 (77%) returned a completed questionnaire (Fig. 1). Respondents were younger than non-respondents ($p < 0.001$), with a mean age of 66.7 years (range 26.8–84.6). The mean time since diagnosis was 4.9 years (range 0.7–10.0) and most patients (93%) had stage I endometrial cancer at diagnosis. All patients were treated with surgery, followed by radiotherapy (23%) or chemotherapy (1%), if indicated (Table 1).

3.2. Perceived information provision

Most patients indicated that they received quite a bit information about their disease and medical tests (Table 2). However, most of the patients stated that they were not (54%) or only a little (24%) informed about the cause of their disease. Regarding their treatment, more than half of the patients stated that they received no (36%) or only a little (27%) information about the possible side effects. In addition, most patients indicated that they received no (34%) or only a little (27%) information about the expected results on disease symptoms. Most patients also indicated that they were not or only a little informed about the expected results of the treatment on their social life (52% and 30% respectively) and sexual life (56% and 27%). Furthermore, the majority of patients indicated that they received no or only a little information on topics related to aftercare, such as where to go for additional help (62% and 25%), rehabilitation (78% and 15%), or psychological support (80% and 14%), and how to cope with cancer at home (55% and 31%), different care locations outside the hospital (70% and 19%), or things to do to improve their health (42% and 35%; Table 2).

Table 1
 Socio-demographic and clinical characteristics of questionnaire respondents, non-respondents and patients with unverifiable addresses.

	Respondents N = 742	Non-respondents N = 223	Patients with unverifiable addresses N = 126	p-Value
Age at time of survey (mean, SD)	66.7 (8.5)	69.4 (8.9)	66.8 (10.2)	<0.001
<55	8%	4%	9%	0.01
55–69	55%	48%	58%	
≥70	37%	48%	33%	
Years since diagnosis (mean, SD)	4.9 (2.5)	5.3 (2.4)	2.4	0.06
<2	13%	9%	8%	0.26
2–5	41%	40%	43%	
>5	45%	51%	49%	
FIGO stage at diagnosis				
I	92%	92%	94%	0.89
II	8%	8%	6%	
Treatment				
Surgery alone	76%	77%	81%	0.42
Surgery + radiotherapy	23%	22%	17%	0.44
Surgery + chemotherapy	1%	<1%	2%	0.56
Comorbidity				
None	20%			
1	26%			
2 or more	54%			
Marital status ^a				
Partner	70%			
No partner	27%			
Educational level ^b				
High	10%			
Intermediate	63%			
Low	24%			
Employed				
Yes	16%			
No	85%			

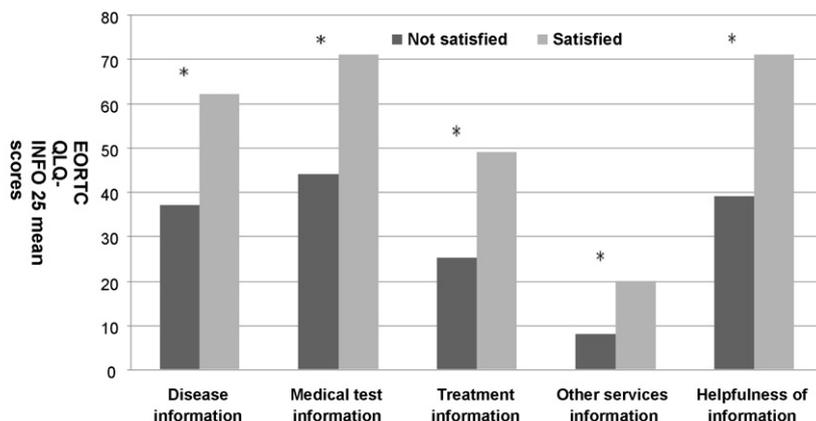
^a Marital status included: partner = married/living together; no partner = divorced/widowed/never married.

^b Education levels included low = no/primary school; intermediate = lower general secondary education/vocational training; or high = pre-university education/high vocational training/university.

Fifteen percent of the patients indicated that they wished that they had received more information. Seventy-five responses were given on the open question regarding the topics survivors would like to receive more information on. Most frequently mentioned topics were the possible causes of endometrial cancer, prevention and risk of recurrence, possible side-effects of treatment, effects of treatment on their sexual life, aftercare, psychological support, and overall information on endometrial cancer. On the other hand, 6% of the patients indicated that they wished that they had received less information. Thirteen responses were given on the open

question regarding the topics survivors would like to have received less information on. Most frequently mentioned topics were the effects of treatment, possible side-effects of treatment, and overall information on endometrial cancer.

Overall, 36% of the patients were just a little satisfied or unsatisfied (5%) with the information they received, and 35% found the information a little or not (4%) helpful at all. Most survivors (70%) stated that they received written information. The Internet was used by 39% of the participants of which 59% had used it to search for additional information.



Note: *All p<.001. EORTC-QLQ INFO25 scales 0-100; higher scores reflect better perceived information received. Not satisfied was classified by patients who were unsatisfied or only a little satisfied. Satisfied was classified by patients who were quite satisfied or very satisfied.

Fig. 2. Differences on information provision subscale scores between survivors who are satisfied (n = 396) and not satisfied (n = 284) with the perceived information provision and helpfulness of information.

Table 2
Perceived information provision characteristics.

	No information at all %	A little information %	Quite a bit information %	Very much information %
Disease				
Diagnosis	5	28	47	20
Spread disease	13	30	40	17
Cause disease	54	24	14	7
Under control	6	21	45	29
Medical tests				
Purpose test	12	26	42	20
Course test	8	29	43	21
Results test	5	24	48	23
Treatment				
Medical treatment	15	21	42	23
Non-medical treatment	92	5	1	2
Expected result	20	23	41	17
Side effects	36	27	27	10
Expected results on disease symptoms	34	27	27	12
Expected results on social life	52	30	12	6
Expected results on sexual life	56	27	11	6
Other services				
Additional help	62	25	10	4
Rehabilitation	78	15	5	2
Cope with cancer at home	55	31	11	3
Psychological assistance	80	14	4	2
Single items				
Different care locations	70	19	9	3
Things to do to get better	42	35	17	6
	Not satisfied %	A little satisfied %	Quite a bit satisfied %	Very satisfied %
Satisfaction with information	5	36	42	16
	Not helpful %	A little helpful %	Quite a bit helpful %	Very helpful %
Helpfulness of information	4	35	45	16
		Yes %		No %
Received written information		70		30
Received information on video or cd-rom		6		94
Wanted more information		15		85
Wanted less information		6		94

3.3. Satisfaction and perceived information provision

Satisfied survivors ($n = 396$; 58%) indicated that they received more information on all subscales of the EORTC QLQ-INFO25, and found the information more helpful than unsatisfied survivors ($n = 284$; 41%) (all $p < 0.01$; Fig. 2).

Unsatisfied cancer survivors indicated that they received less written information (54% vs. 82%), and wanted to receive more information (27% vs. 7%; all $p < 0.01$) than satisfied survivors. Some unsatisfied cancer survivors, on the other hand, indicated that they wanted to receive less information (10% vs. 3%) than

satisfied survivors ($p < 0.01$). There were no significant differences between unsatisfied and satisfied survivors in the use of Internet for additional information (22% vs. 28%).

3.4. Associations with perceived level of and satisfaction with information provision

In univariate analyses, younger patients indicated that they received less information about medical tests ($p < 0.05$) and other care services ($p < 0.01$), and wanted more information ($p < 0.01$) than older patients (Table 3). Having a partner was associated with

Table 3
ANOVA and chi-square tests evaluating the differences in mean information provision subscale scores (\pm SD) between the independent variables.

	Information about disease Mean (SD)	Information about medical tests Mean (SD)	Information about treatment Mean (SD)	Information about other services Mean (SD)	Satisfaction with information Mean (SD)	Helpfulness of information Mean (SD)	Want more information % Yes	Want less information % Yes
Age								
<55	53 (22)	64 (22)	45 (22)	26 (23)	57 (26)	60 (23)	23	4
55–69	53 (22)	61 (26)	39 (24)	14 (18)	57 (26)	58 (25)	17	5
≥ 70	48 (24)	56 (29)	36 (27)	13 (19)	54 (28)	56 (27)	10	7
Years since diagnosis								
<2	55 (23)	65 (27)	43 (26)	19 (21)	61 (26)	59 (26)	17	7
2–5	52 (22)	62 (23)	38 (24)	15 (19)	57 (25)	58 (25)	15	4
>5	50 (23)	56 (29)	37 (25)	13 (18)	54 (29)	57 (26)	15	7
Stage at diagnosis								
I	51 (23)	59 (27)	38 (25)	14 (19)	57 (27)	58 (26)	15	6
II	51 (20)	62 (25)	42 (23)	17 (19)	53 (22)	56 (26)	17	6
Employed								
Yes	53 (22)	63 (25)	43 (24)	18 (20)	57 (26)	59 (25)	26	2
No	51 (23)	59 (27)	38 (25)	14 (18)	56 (27)	58 (26)	13	7

Table 3 (Continued)

	Information about disease	Information about medical tests	Information about treatment	Information about other services	Satisfaction with information	Helpfulness of information	Want more information	Want less information
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	% Yes	% Yes
Radiotherapy			**					
Yes	50 (22)	60 (25)	44 (23)	13 (19)	55 (25)	57 (25)	18	7
No	52 (23)	60 (27)	37 (25)	15 (18)	57 (27)	58 (26)	15	6
Comorbidity	*				**	**	**	
None	56 (22)	64 (28)	42 (26)	14 (17)	67 (26)	64 (25)	11	9
1	51 (22)	60 (26)	40 (24)	16 (19)	58 (25)	59 (25)	9	3
2 or more	50 (23)	58 (27)	37 (25)	14 (19)	52 (27)	55 (26)	20	6
Marital status ^a	**		*			*		
Partner	53 (22)	61 (26)	40 (25)	14 (19)	58 (27)	59 (25)	14	6
No partner	47 (24)	57 (28)	34 (25)	16 (19)	53 (26)	55 (26)	19	6
Educational level ^b		**	**				*	
High	54 (20)	70 (24)	49 (24)	18 (20)	60 (24)	65 (24)	22	3
Intermediate	52 (22)	60 (26)	38 (24)	14 (19)	57 (27)	58 (25)	16	6
Low	48 (25)	55 (28)	35 (26)	15 (18)	54 (28)	56 (29)	9	8
Use of Internet	*	**					*	
Yes	55 (20)	65 (23)	42 (25)	16 (19)	58 (26)	60 (25)	20	5
No	50 (23)	58 (27)	37 (25)	14 (19)	56 (27)	57 (26)	14	6
Written information	**	**	**	**	**	**	**	**
Yes	55 (21)	64 (24)	42 (24)	17 (20)	62 (24)	63 (23)	13	5
No	43 (24)	51 (28)	30 (25)	10 (15)	44 (28)	45 (27)	21	

Note: EORTC-QLQ INFO25 scales 0–100: high scores reflect better perceived information received.

* $p < 0.05$.

** $p < 0.01$.

^a Marital status included: partner = married/living together; no partner = divorced/widowed/never married.

^b Education levels included low = no/primary school; intermediate = lower general secondary education/vocational training; or high = pre-university education/high vocational training/university.

more perceived information provision about the disease ($p < 0.01$), and treatment ($p < 0.05$), and finding the information more helpful ($p < 0.05$). Survivors who were younger, and survivors who had a partner indicated that they received more information on the

expected results of their treatment on their sexual life (both $p < 0.01$). Survivors who were younger, who were employed, had more comorbidities, had a higher educational level, and who used the Internet for additional information indicated that they wanted

Table 4

Multivariate linear and logistic regression analyses evaluating the association of independent variables with the information provision subscales.

	Disease (beta)	Medical tests (beta)	Treatment (beta)	Other (beta)	Satisfaction with received information (odds ratio ± 95% CI)
Age	−0.25	−0.05	−0.07	−0.10*	1.00 (0.97–1.02)
Years since diagnosis	−0.07	−0.11*	−0.03	−0.12**	0.96 (0.89–1.03)
FIGO stage					
I	Ref	Ref	Ref	Ref	Ref
II	0.01	0.03	−0.00	0.04	1.40 (0.71–2.76)
Radiotherapy					
Yes	Ref	Ref	Ref	Ref	Ref
No	0.03	−0.01	−0.15**	0.03	1.21 (0.79–1.86)
Comorbidity					
None	Ref	Ref	Ref	Ref	Ref
1	−0.13*	−0.07	−0.03	0.06	0.54 (0.31–0.92)*
2 or more	−0.11*	−0.07	−0.03	0.06	0.39 (0.24–0.63)**
Marital status ^a					
Partner	Ref	Ref	Ref	Ref	Ref
No partner	−0.09*	−0.04	−0.07	0.06	0.72 (0.49–1.06)
Employed					
No	Ref	Ref	Ref	Ref	Ref
Yes	−0.03	−0.03	0.01	0.02	0.88 (0.52–1.50)
Use of Internet					
Yes	Ref	Ref	Ref	Ref	Ref
No	−0.02	−0.01	0.01	0.03	1.10 (0.72–1.67)
Written information					
Yes	Ref	Ref	Ref	Ref	Ref
No	−0.20***	−0.18**	−0.21**	−0.17**	0.29 (0.20–0.42)**
Educational level ^b					
High	Ref	Ref	Ref	Ref	Ref
Intermediate	−0.02	−0.15*	−0.17**	−0.07	0.78 (0.43–1.39)
Low	−0.07	−0.18**	−0.17*	−0.02	0.62 (0.32–1.20)
R ²	0.08	0.08	0.32	0.25	0.16

* $p < 0.05$.

** $p < 0.01$.

^a Marital status included: partner = married/living together; no partner = divorced/widowed/never married.

^b Education levels included low = no/primary school; intermediate = lower general secondary education/vocational training; or high = pre-university education/high vocational training/university.

to receive more information. Patients who stated that they received written information indicated that they received more information on all of the information provision subscales, were more satisfied with the information, found the information more helpful, and less often indicated that they wanted to receive more information than patients who did not receive written information (all $p < 0.01$; Table 3). Patients who received less information about their disease, medical tests, and treatment, and patients who indicated to have received less useful information wanted significantly more information (all $p < 0.05$). Hospital of treatment and cancer stage were not significantly associated with perceived information provision, satisfaction with information, helpfulness of information, or wanting more or less information (Table 3).

In multivariate analyses, a shorter time since diagnosis was associated with more perceived information provision about medical tests ($p < 0.05$), and other care services ($p < 0.01$) (Table 4). Younger age was associated with more perceived information provision about other care services ($p < 0.05$). Having undergone radiotherapy was associated with more perceived information provision about treatment ($p < 0.01$). Patients who had one or more comorbidities indicated that they received less information about their disease ($p < 0.05$). Having a partner was also associated with more perceived information provision about the disease ($p < 0.05$). Higher educational level was associated with more perceived information provision about medical tests ($p < 0.01$) and treatment ($p < 0.01$). Having received written information was associated with all four of the information provision subscales (all $p < 0.01$). Higher satisfaction with information provision was independently associated with absence of comorbidities ($p < 0.01$), and having received written information ($p < 0.01$). Cancer stage, employment status, and use of the Internet for additional information were not significantly associated with perceived information provision in any of the four subscales (Table 4).

4. Discussion and conclusion

4.1. Discussion

In the present study, most patients indicated that they received quite a bit information about their disease and medical tests. However, a substantial percentage of the patients stated that they were not or only a little informed about the cause of their disease, and possible side effects of their treatment. Endometrial cancer survivors received the least information on topics related to aftercare, such as what to expect in their social and sexual life, where to go for additional help, rehabilitation, or psychological support, and how to cope with cancer at home, different care locations outside the hospital, or things to do to improve their health. Moreover, issues related to aftercare were mentioned most frequently as topics that endometrial cancer survivors wanted to receive more information about. The means of the EORTC QLQ-INFO25 scores of the endometrial cancer survivors in the current study sample were lower for all of the subscales compared to two validation studies who included cancer survivors with diverse tumor types [23,24].

Survivors who were not satisfied with the received information, indicated that they received less information on all information provision subscales, and found the information less helpful than satisfied survivors. Moreover, unsatisfied survivors indicated that they wanted to receive more information than satisfied survivors. Interestingly however, a small group of the unsatisfied survivors indicated that they wanted to receive less information than satisfied survivors. It is interesting to note that there was some overlap in the topics on which patients wanted to receive either more or less information. Whereas some patients indicated that

they wanted to receive more information on the possible side-effects of treatment and overall information on endometrial cancer, other patients indicated that they wanted to have received less information on these topics. These findings may imply that in order to improve satisfaction with information provision, health care providers should screen their patients by asking about their specific information needs.

Factors associated with higher perceived levels of information were younger age, higher educational level, more recent diagnosis, having undergone radiotherapy, absence of comorbidities, having a partner, and having received written information. Factors associated with higher satisfaction with information were absence of comorbidities, and having received written information.

The observed association between younger age and more perceived information provision is consistent with previous research [13,27]. Studies have shown that older patients tend to ask fewer questions during their visit with their physician, and might therefore receive less information [28,29]. Older patients are less interested in detailed information, but only want information about the most important aspects of their disease and treatment [28]. Furthermore, older patients have been found to have a greater reliance on information provided by their health care provider [10]. Doctors might also be prejudiced against older patients; some clinicians seem to provide older patients with less information [30]. Finally, older patients may have more difficulties processing and remembering medical information they receive than younger patients [31].

Survivors with a high educational level indicated that they received more information about their medical tests and treatment than lower educated survivors. Previous studies have shown that higher educated patients want as much information on prognosis as possible [32], are more likely to seek information from a greater range of sources, like the Internet [10], and show more perceived uncertainty [33]. For these reasons, higher educated survivors might ask their gynecologists for more explanation when the provided information does not yet answer their needs. It is also possible that doctors (who are higher educated themselves) are more prone to give more information to patients with a similar educational level. Higher educated patients may also be better able to understand and remember the information. To improve information provision for lower educated patients, health care providers could pay more attention to patients' health literacy levels, i.e. "the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" [34], by providing information on a basic comprehension level.

Patients who were diagnosed and treated shortly before completion of the questionnaire, reported that they received more information about their medical tests and other care services. This finding might indicate that information provision has improved with time. However, it could also be ascribed to the diminishing contacts of patients with their gynecologist after the completion of treatment and follow-up [35]. Patients who are still under supervision of a health care provider might have a clearer picture of the information they received. It is also possible that recall bias influenced these findings. Patients may forget the information they received, because it is often complex and emotionally charged [36]. The mean time since diagnosis was 4.9 years, which could hinder the recall of the received information. For future research, longitudinal studies are needed to be able to assess the perceived information provision over time.

Our results also showed that patients who had undergone radiotherapy reported receiving more information about their treatment. It is very likely that patients undergoing radiotherapy also receive information from their radiotherapist. In addition, it is likely that gynecologists provide more information to these

patients, as the treatment is more complex and can have more serious acute and long-term effects than surgery alone.

Patients with fewer comorbidities reported that they received more information about their disease and were more satisfied with the information. It is possible that patients with more comorbidities have more specific information needs, that are not fulfilled by the standard information provided to them. They might also have difficulties separating the information they received about their other condition(s) from the information about their cancer, or they might compare these sources of information with each other.

Patients who have a partner also indicated that they received more information about their disease. It is possible that the partner went to the consultations together with the patient, and also remembered the received information. Previous research indicates that accompanied patients are likely to benefit from the extra information that their companions remember [37]. The presence of companions has been found to increase patient understanding, involvement in the consultation, and decision-making [38]. Discussing the received information with their partner may help patients to better understand and remember the information they receive from their gynecologist.

Finally, patients who received written information indicated that they received more information, and were more satisfied with the information than patients who did not receive written information. This finding is consistent with previous studies, which have shown that providing patients with written information increases their recall, knowledge and satisfaction with information [39,40].

Some limitations of the present study should be noted. Although demographic and clinical characteristics were present of the non-respondents and patients of whom the addresses could not be verified, it remains unknown why non-respondents declined to participate. In addition, the cross-sectional design limits the determination of causal associations between the study variables. Furthermore, with a mean time since diagnosis of 4.9 years, the patients in the current study can be described as (long-term) endometrial cancer survivors, who are out of the acute phase of medical treatment and decision making. The results can therefore not be generalized to patients who are in the midst of their treatment phase or shortly after treatment completion. For future research, it would be interesting to compare the responses of these groups of patients. In addition, nothing is known about the relation with other patient-reported outcomes. For future research, it would be interesting to look at associations with other outcomes, such as psychological adjustment. Another limitation is that the EORTC QLQ-INFO25 response options (“not at all”, “a little”, “quite a bit and “very much”) do not give participants the option to respond with “somewhat” or “a moderate amount”. Patients were forced to choose between no information or a little information, and quite a bit of information or a lot of information. Some patients may have preferred a more moderate response option. Finally, the EORTC QLQ-INFO25 only measures the information patients indicated they received during their disease or treatment. It does not measure who provided the information, and when the information was provided exactly. It would be interesting to assess which aspects of information patients receive from their different health care providers (i.e., gynecologist, radiotherapist, medical oncologist, oncology nurse, general practitioner), at what point in their disease trajectory they receive the information, and whether this is associated with helpfulness of and satisfaction with the information received. Moreover, as the EORTC QLQ-INFO25 assesses patient reported outcomes, it is not clear how much information was actually provided. It would therefore also be interesting to compare data on actual information provision with data from questionnaires.

4.2. Conclusion

Despite the limitations noted, the present study provides important new information by showing the perceived level of and satisfaction with information received by endometrial cancer survivors, and the associations with socio-demographic and clinical characteristics. These results can help health care providers give adequate information to those who need it. The population-based sampling frame, high response rate, and large range in elapsed time since diagnosis make it possible to generalize the results to a broad range of endometrial cancer survivors.

4.3. Practice implications

As the number of endometrial cancer survivors is rapidly increasing, and provision of information is one of the most important factors in the support for cancer survivors, it becomes more important to investigate the current state of information provision and satisfaction with information provision in endometrial cancer survivors.

The present study shows that endometrial cancer survivors experience several areas of information provision as insufficient, suggesting room for improvement. Health care providers often have limited time and resources. With growing evidence that well-informed patients are more satisfied with their care, and do better clinically [35], efforts are needed to improve the information provision to endometrial cancer patients. The current identification of the specific information needs of endometrial cancer survivors and the factors associated with these information needs could facilitate a more patient-tailored approach of informing patients, which may contribute to improved satisfaction and quality of life of endometrial cancer survivors.

A way to achieve more patient-tailored information provision, recommended by the American Institute of Medicine [41] and the Dutch Health Council [42], might be the implementation of a Survivorship Care Plan (SCP), which is a summary of patients' course of treatment as a formal document, including recommendations for subsequent cancer surveillance, management of late effects, and strategies for health promotion [41]. The present finding that endometrial cancer patients who receive written information report to have received more information, and are more satisfied with the information supports this suggestion. We are therefore currently evaluating in a randomized controlled trial (ROGY Care), whether provision of an SCP to gynecological cancer patients improves satisfaction with information, satisfaction with care, and ultimately quality of life [43].

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Authors' contributions

In collaboration with the OOG-CCCS (Organization Oncologic Gynecology of the Comprehensive Cancer Center South), LP, CV, and RK contributed to the concept and design of the study. LP, CV, ML, and RK contributed to the acquisition of the data. OH and KN

analyzed the data. KN drafted the manuscript. All authors provided input into revisions of the manuscript and have approved the final manuscript.

Conflict of interest

None.

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