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ORIGINAL ARTICLE



Fertility-related information received by young women and men with cancer – a population-based survey

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ABSTRACT

Background: Infertility is a well-known sequela of cancer treatment. Despite guidelines recommending early discussions about risk of fertility impairment and fertility preservation options, not all patients of reproductive age receive such information.

Aims: This study aimed to investigate young adult cancer patients' receipt of fertility-related information and use of fertility preservation, and to identify sociodemographic and clinical factors associated with receipt of information.

Materials and Methods: A population-based cross-sectional survey study was conducted with 1010 young adults with cancer in Sweden (response rate 67%). The inclusion criteria were: a previous diagnosis of breast cancer, cervical cancer, ovarian cancer, brain tumor, lymphoma or testicular cancer between 2016 and 2017, at an age between 18 and 39 years. Data were analyzed using logistic regression models.

Results: A majority of men (81%) and women (78%) reported having received information about the potential impact of cancer/treatment on their fertility. A higher percentage of men than women reported being informed about fertility preservation (84% men vs. 40% women, $p < .001$) and using gamete or gonadal cryopreservation (71% men vs. 15% women, $p < .001$). Patients with brain tumors and patients without a pretreatment desire for children were less likely to report being informed about potential impact on their fertility and about fertility preservation. In addition, being born outside Sweden was negatively associated with reported receipt of information about impact of cancer treatment on fertility. Among women, older age (>35 years), non-heterosexuality and being a parent were additional factors negatively associated with reported receipt of information about fertility preservation.

Conclusion: There is room for improvement in the equal provision of information about fertility issues to young adult cancer patients.

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Cancer; fertility; fertility preservation; oncofertility; reproductive oncology

Background

Worldwide, nearly one million young adults (YAs) are diagnosed with cancer each year [1]. Negative impact on fertility is a well-known late effect of cancer and its treatment and may constitute a particular stressor for patients who have not started or completed their intended family [2]. Infertility can result directly from the cancer disease [3] or from cancer treatments such as chemotherapy, irradiation, and surgery [4,5]. Several fertility preservation (FP) methods, including cryopreservation of gametes and gonadal tissue [6,7] can

improve the chances of having biological children in the future. Sperm banking is a quick process, while embryo and oocyte freezing requires 2–3 weeks to complete and may not be possible if initiation of cancer treatment cannot be delayed.

Decisions about FP need to be made before initiation of treatment, at a time when the patient is dealing with the emotional and practical impacts of the cancer diagnosis [8,9]. Fertility counseling, as well as undergoing FP, have been associated with positive psychosocial effects such as improved quality of life, greater overall satisfaction and

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diminished regrets [10,11]. National and international guidelines recommend that health care professionals address fertility issues with all cancer patients of reproductive age as early as possible [12–15]. However, many young adult patients report not having received such information [16–19]. Male patients have been reported to receive fertility-related information and undergo FP to a higher degree than females [17,20–22]. In addition, patients' age, marital status, number of children and desire for children at diagnosis, as well as cancer type have been associated with fertility-counseling rates [17,21,23,24]. In order for young adult cancer patients to make informed decisions about their future reproductive life, it is essential that they receive information about their risk of impaired fertility, including no risk. In view of methodological limitations of previous research with regard to sample selection, and data collection many years after treatment [16], there is a need for population-based studies targeting female and male patients at closer proximity to potential discussions about fertility issues. The aim of the present study was to investigate young adult cancer patients' receipt of fertility-related information and use of fertility preservation. An additional aim was to identify sociodemographic and clinical factors associated with receipt of information.

Materials and methods

The present study is part of the population-based project 'Fertility and Sexuality following Cancer' (Fex-Can) and is a cross-sectional survey study based on the baseline assessment of the Fex-Can Cohort study. Details of the recruitment and study methods have been described previously [25] and are below briefly outlined in accordance to the STROBE guidelines [26]. The data were collected between 2017 and 2019 in Sweden, where cancer care and fertility preservation are included in the tax-funded healthcare available for the whole population.

Study participants

Inclusion criteria were being diagnosed with breast cancer (women only), cervical cancer, lymphoma, testicular cancer, ovarian cancer or brain tumor, at the age of 18–39 years, between January 2016 and August 2017. These diagnoses were preselected because the diseases and/or treatments have potentially negative impact on fertile ability or sexual life. Individuals meeting these criteria were identified in Swedish cancer quality registries and approached approximately 1.5 years post-diagnosis with a request to complete a comprehensive survey (on paper, online or over the phone).

Data collection

The survey included a number of validated patient-reported outcome measures concerning reproductive and sexual issues, psychological distress and health-related quality of life. For the present study, we selected study-specific

questions concerning fertility-related information and FP, adapted from a previous study [17].

Fertility-related information

Receipt of fertility-related information was assessed with two study-specific questions. First, participants were requested to report whether they had received any information regarding how their cancer or its treatment could impact their ability to have children (response alternatives: No, Unsure, Yes). Participants who reported having received such information were instructed to answer two follow-up questions. These concerned the source(s) of the received information (Physician, Nurse, Other health care professional, Brochure), and what they learned about their individual risk of impaired fertility (No risk, Some risk, High risk, Can't recall). Secondly, participants were asked to indicate whether they had received any information about FP options such as cryopreservation of gametes (response alternatives: No, Unsure, Yes).

Fertility preservation use

Participants were asked to indicate whether they had undergone any FP treatment (response alternatives: Yes, cryopreservation of sperm/oocytes, No, Other). Participants could choose several response alternatives and also leave comments to this question. Based on participants' comments (e.g., specification of 'Other' FP used), responses were categorized into the following groups: 'No FP', 'Cryopreservation of gametes/gonadal tissue' and 'Other FP' (including GnRHa, fertility-sparing surgery and hormonal stimulation for oocyte cryopreservation without producing a viable sample).

Participant characteristics

Sociodemographic variables collected in the survey concerned status at time of completing the questionnaire: country of birth, sexual orientation, educational level, occupation and partner status. Parenthood status at the time of diagnosis was based on participants' responses to two questions (parenthood status at time of study and children conceived post-diagnosis). Participants also retrospectively assessed their pre-diagnosis desire for children (or additional children). Clinical data were collected from the national cancer quality registries and included sex, age at diagnosis, and cancer type.

Statistics

The data were statistically analyzed using IBM SPSS® statistics 26. Student's t-test and χ^2 -tests were used for group comparisons of responders/nonresponders and men/women, respectively. Logistic regression models were used to investigate associations between independent variables, patient characteristics (clinical and sociodemographic variables), and dependent variables, receipt of information (Yes vs. No/Unsure). Independent variables included in the analyses were

selected based on previous research: sex [17], age [17,27,28], diagnosis [17], country of birth [29], education [24], sexual orientation [27], partner and parenthood status [27], and desire for children [17]. Univariable logistic regression was used to investigate associations between the independent variables and the dependent variables before performing multivariable logistic regression models for the two respective outcomes. $p < .05$ was used to indicate statistical significance.

Ethical considerations

All participants provided written informed consent. Ethical approval for the study procedures was obtained from the Regional Ethical Review Board in Stockholm (Dnr: 2013/1746-31/4; 2014/2244-32; 2017/916-32; 2017/1416-32).

Results

Participant characteristics

A total of 1535 potentially eligible individuals were identified in Swedish cancer quality registries, and 36 were excluded due to lack of valid postal address ($n = 18$), being deceased ($n = 12$), cognitive impairment leading to inability to complete the survey ($n = 3$), and administrative failure ($n = 3$). No exclusion based on prognosis was made. Of the remaining 1499 who were confirmed eligible, 1010 (67%) completed the survey and were included in the study. Comparison of responders and non-responders with regard to sex, diagnosis and age at diagnosis showed statistically significant differences. Participation rates were lower among men than women (59% vs. 72%, $\chi^2 = 23.89$, $p < .0001$). Among men, nonresponders were significantly younger at time of diagnosis than responders ($m = 29$ vs. $m = 31$, $t = -3.455$, $p = .001$), but no corresponding age difference existed among women. Participation rates differed significantly by cancer type among women (ovarian cancer 56%, brain tumors 62%, lymphoma 72%, cervical cancer 73%, breast cancer 75%) ($\chi^2 = 14.299$, $p = .006$), but not among men ($\chi^2 = 3.281$, $p = .194$).

Study participants were 694 women and 316 men with a mean age of 32 years at diagnosis. The most common diagnoses were breast cancer (35%), testicular cancer (20%) and cervical cancer (19%). At the time of diagnosis, a majority (59%) were already parents and half (51%) of the participants had a wish for children (or additional children). See Table 1 for additional clinical and sociodemographic characteristics and missing data for each respective variable.

Patient-reported receipt of fertility-related information

A majority of both men (81%) and women (78%) reported having received information about possible impact of the cancer or its treatment on their ability to have children ($\chi^2 = 1.383$, $df = 2$, $p = .501$). The most common source of this information was a physician (92%), followed by a nurse (33%), brochure or pamphlet (25%), and other health care professionals (5%). Among those who recalled receiving

Table 1. Participant characteristics.

	Men <i>N</i> = 316 <i>N</i> (%) ^a	Women <i>N</i> = 694 <i>N</i> (%) ^a	Total <i>N</i> = 1010 <i>N</i> (%) ^a
<i>Age (at diagnosis)</i>			1010
18–29	131 (41)	157 (23)	288 (28)
30–35	112 (35)	250 (36)	362 (36)
36–40	73 (23)	287 (41)	360 (36)
<i>Country of birth</i>			1008
Sweden	272 (86)	579 (83)	851 (84)
Other European country	23 (7)	37 (5)	60 (6)
Non-European country	20 (6)	77 (11)	97 (10)
<i>Sexual orientation</i>			989
Heterosexual	297 (95)	633 (93)	930 (94)
Homosexual	2 (1)	10 (1)	12 (1)
Bisexual	11 (4)	30 (4)	41 (4)
Other	1 (<1)	5 (1)	6 (1)
<i>Educational level (at time of study)</i>			1008
College or university	142 (45)	417 (60)	559 (55)
High school	155 (49)	222 (32)	377 (37)
Elementary school	7 (2)	26 (4)	33 (3)
Other	12 (4)	27 (4)	39 (4)
<i>Occupational status (at time of study)</i>			1008
Employed full-time	222 (70)	363 (52)	585 (58)
Employed part-time	22 (7)	130 (19)	152 (15)
Student	25 (8)	37 (5)	62 (6)
Unemployed	14 (4)	14 (2)	28 (3)
Sick leave	26 (8)	120 (17)	146 (14)
Other	7 (2)	28 (4)	35 (3)
<i>Diagnosis</i>			1010
Breast cancer	N/A	349 (50)	349 (35)
Cervical cancer	N/A	190 (27)	190 (19)
Ovarian cancer	N/A	32 (5)	32 (3)
Brain tumor	57 (18)	66 (10)	123 (12)
Lymphoma	59 (19)	57 (8)	116 (11)
Testicular cancer	200 (63)	N/A	200 (20)
<i>Parenthood status (at diagnosis)</i>			953
Parent	123 (42)	442 (67)	565 (59)
Childless	170 (58)	218 (33)	388 (41)
<i>Desire for children (at diagnosis)</i>			995
Yes	141 (45)	364 (53)	505 (51)
No	141 (45)	254 (37)	395 (40)
Unsure	30 (10)	65 (10)	95 (10)

The italic values indicate the total number of participants who had provided an answer to these specific survey question.

^aPercentages may not total 100 due to rounding.

information about potential impact of cancer/treatment on their future fertility ($n = 779$), about half were informed of a high risk of impaired fertility (45%), and about half were told there was 'some' risk that their fertility would be impacted (45%). Remaining participants were informed there was no risk to their fertility (5%) or could not recall what level of risk had been mentioned (5%). Among all participants, a higher percentage of men than women reported being informed about FP options (84% vs. 40%; $\chi^2 = 173.970$, $df = 2$, $p < .001$).

Participants' self-reports of received fertility-related information varied markedly by type of cancer, with the highest percentages reported by testicular cancer patients (>90%) and the lowest percentages reported by patients with brain tumors (<30%). Receipt of information by diagnosis and sex is presented in Table 2.

Patient-reported use of FP

A higher percentage of men than women reported having used FP ($\chi^2 = 315.784$, $df = 2$, $p < .001$). Cryopreservation of

Table 2. Patient-reported receipt of fertility-related information and use of FP, by diagnosis and sex.

	TOTAL		Breast cancer	Cervical cancer	Ovarian cancer	Testicular cancer	Lymphoma		Brain tumor	
	Women N = 694 n (%)	Men N = 316 n (%)	n = 349 n (%)	n = 190 n (%)	n = 32 n (%)	n = 200 n (%)	Women n = 57 n (%)	Men n = 59 n (%)	Women n = 66 n (%)	Men n = 57 n (%)
Information about impact on fertility ^{a,b}										
Yes	538 (78)	254 (80)	284 (81)	168 (89)	27 (87)	186 (93)	47 (84)	53 (90)	12 (18)	15 (27)
Unsure	40 (6)	18 (6)	24 (7)	8 (4)	1 (3)	7 (4)	5 (9)	2 (3)	2 (3)	9 (16)
No	112 (16)	42 (13)	41 (12)	12 (6)	3 (10)	6 (3)	4 (7)	4 (7)	52 (80)	32 (57)
Information about FP ^{a,b}										
Yes	274 (39)	265 (84)	197 (56)	29 (15)	8 (27)	195 (98)	37 (65)	54 (92)	3 (5)	16 (28)
Unsure	31 (5)	8 (3)	22 (6)	6 (3)	0 (0)	3 (1)	3 (5)	1 (2)	0 (0)	4 (7)
No	386 (56)	42 (13)	130 (37)	154 (81)	22 (73)	1 (1)	17 (30)	4 (7)	63 (96)	37 (65)
Use of FP ^{a,b}										
Cryopreservation	101 (14)	223 (71)	71 (20)	9 (5)	1 (3)	164 (83)	20 (35)	43 (73)	0 (0)	16 (28)
None	562 (81)	90 (29)	258 (74)	173 (92)	29 (94)	34 (17)	36 (63)	16 (27)	66 (100)	40 (70)
Other	28 (4)	1 (<1)	19 (5)	7 (4)	1 (3)	0 (0)	1 (2)	0 (0)	0 (0)	1 (2)

^aNumbers do not sum up to total due to missing data (4–6 for total group); ^bPercentages may not total 100 due to rounding.

gametes or gonadal tissue was utilized by 71% of men ($n=223$) and 15% of women ($n=101$). In addition, 3% of participants (28 women and 1 man) reported having used or attempted other FP methods (as described in materials and methods). Use of FP by diagnosis and sex is presented in Table 2.

Factors associated with patient-reported receipt of information about cancer/treatment-related impact on fertile ability

Variables associated with the outcome in the univariable analyses (age at diagnosis, country of birth, diagnosis, and desire for children at diagnosis) were included in the multivariable analysis, see results presented in Table 3. In comparison with brain tumor patients, individuals with all other cancer types (testicular, breast, ovarian and cervical cancer, as well as lymphoma) were significantly more likely to report having received information about the potential impact of cancer and treatment on their fertility. In addition, being born in Sweden and a pre-diagnosis desire for children was associated with a higher likelihood of reporting being informed about impact on fertility, while older age (>35 years) was associated with a lower likelihood of recalling such information.

Factors associated with patient-reported receipt of information about FP

Sex, cancer type, desire for children, parenthood status, age, and sexual orientation were associated with patient-reported receipt of FP information in the univariable analyses. Due to associations between sex and all other variables except sexual orientation, separate logistic regression analyses were performed for men and women. The results of the univariable and final analyses are presented in Table 4. Cancer type and a desire for children at diagnosis were significantly associated with patient-reported receipt of FP information for both men and women. In comparison with brain tumor patients, individuals diagnosed with testicular cancer, lymphoma, breast and ovarian cancer were significantly more likely to report having received FP information. Among women,

Table 3. Factors associated with patient-reported receipt of information about disease/treatment-related impact on fertile ability.

Variable	Univariable analysis		Multivariable analysis	
	OR	CI 95%	OR	CI 95%
Sex				
Female			–	–
Male	0.8	0.6–1.2	–	–
Age (at diagnosis)				
18–29	0.6	0.4–0.9	0.7	0.4–1.1
30–35				
36–39	0.5	0.4–0.8	0.6	0.4–0.9
Country of birth				
Other				
Sweden	1.9	1.3–2.8	2.2	1.4–3.4
Sexual orientation				
Other			–	–
Heterosexual	0.9	0.5–1.8	–	–
Educational level				
Other			–	–
University	1.1	0.8–1.6	–	–
Partner status				
Single			–	–
Partnered	1.3	0.9–1.9	–	–
Diagnosis				
Brain tumor(s)				
Breast cancer	15.4	9.3–25.5	18.0	10.3–31.5
Cervical cancer	29.6	15.7–55.5	25.8	13.5–49.0
Ovarian cancer	23.8	7.6–73.8	27.2	8.5–87.3
Lymphoma	23.5	11.8–46.8	23.8	11.7–48.3
Testicular cancer	50.3	24.8–102.0	58.5	27.9–122.6
Parenthood status (at diagnosis)				
Parent			–	–
Childless	0.9	0.7–1.2	–	–
Desire for children (at diagnosis)				
No				
Yes	1.9	1.3–2.6	1.9	1.3–2.9
Unsure	1.2	0.7–2.0	1.1	0.6–2.1

The bold values indicate significant results.
Reference group.

identifying as heterosexual and being childless at diagnosis increased the likelihood for recalling receipt of FP information, while older age (>35 years) decreased this likelihood.

Discussion

In the present population-based sample of young adults diagnosed in 2016 and 2017, the majority of both women and men reported being informed about impacts on fertility related to their cancer and treatment. However, women

Table 4. Factors associated with patient-reported receipt of information about FP.

Variable	WOMEN				MEN			
	Univariable analysis		Multivariable analysis		Univariable analysis		Multivariable analysis	
	OR	CI 95%	OR	CI 95%	OR	CI 95%	OR	CI 95%
Age (at diagnosis)								
18–29	0.9	0.6–1.4	1.1	0.6–2.1	0.5	0.3–1.1	–	–
30–35								
36–39	0.6	0.4–0.8	0.4	0.2–0.6	0.5	0.2–1.2	–	–
Country of birth								
Other								
Sweden	0.6	0.4–1.0	0.9	0.5–1.6	2.0	1.0–4.4	–	–
Sexual orientation								
Other								
Heterosexual	2.4	1.2–5.0	2.9	1.3–27.6	2.4	0.7–8.1	–	–
Educational level								
Other								
University	1.2	0.9–1.6	–	–	1.6	0.8–2.9	–	–
Partner status								
Single								
Partnered	1.1	0.7–1.6	–	–	1.3	0.6–2.5	–	–
Diagnosis								
Brain tumor								
Breast cancer	27.2	8.4–88.3	71.0	19.9–252.7	–	–	–	–
Cervical cancer	3.8	1.1–13.0	3.1	0.9–10.9	–	–	–	–
Ovarian cancer	7.6	1.9–31.4	6.1	1.3–27.6	–	–	–	–
Lymphoma	38.9	10.8–139.7	62.9	15.8–250.1	27.6	9.4–81.8	26.8	8.7–82.2
Testicular cancer	–	–	–	–	124.9	39.7–393.0	141.4	42.9–465.8
Parenthood status (at diagnosis)								
Parent								
Childless	1.7	1.2–2.4	2.4	1.2–4.1	1.1	0.6–2.1	–	–
Desire for children (at diagnosis)								
No								
Yes	2.8	2.0–4.0	3.7	2.3–5.8	2.4	1.2–4.7	3.4	1.3–9.2
Unsure	2.3	1.3–4.0	2.2	1.1–4.4	0.9	0.3–2.2	1.1	0.3–4.5

Reference group.

reported being less informed about FP, and using FP to a lesser extent than men. The patient-reported receipt of fertility-related information was predicted by a pre-diagnostic wish for children and by type of cancer, regardless of sex. Patients with brain tumors were less likely to report having been informed about potential cancer/treatment-related impact on fertility and about FP compared to patients with other diagnoses.

Patient-reported receipt of information about impact on fertile ability

The present results show that high and similar proportions of men and women reported having received information about the potential impacts of their disease and its treatment on fertility. This indicates a more equal provision of information in Sweden than reported in a previous population-based study of young adult survivors diagnosed in 2003–2007 [17]. This finding is in line with recent results [20,22] and may be partly due to the growing attention directed at fertility issues in cancer care. However, in comparison with Swedish natives, patients not born in Sweden were less likely to report having received information regarding potential impact on their fertility, despite being proficient enough in Swedish to complete the study survey. This finding may be related to patients' potential difficulties processing oral information in a language other than their mother tongue and suggests that the use of written information

should be advocated. In addition, cultural and religious beliefs may impact FP care [28,29]. Obtaining information about potential risks of fertility impairment is essential for patients of reproductive age, irrespective of the patient's risk level. A lack of information can lead to unnecessary worry among patients with low or no risk [30], and may hinder well-founded decision-making concerning future reproductive life among patients with some to high risk. This also concerns patients who do not recall any fertility-related discussions (that did occur) or feel they were suboptimal, and who may experience regret irrespective of fertility risks. Reported receipt of information regarding disease/treatment-related impact on fertility was positively correlated to a pre-treatment desire for children. This finding is in line with previous reports [17,24] and may reflect that patients who wish to have children ask for this information to a greater extent than those who do not, or that these patients are more likely to recall fertility-related discussions.

Patient-reported receipt of information about and use of FP

In contrast to our findings on information about the disease/treatment-related impact on fertility, the extent to which patients reported having been informed about and used FP differed between the women and men in our study. A greater proportion of men than women underwent FP procedures, in line with previous studies [17,22,31]. Public versus

private health insurance has in previous studies been recognized as a significant factor for FP counseling [31–34], but cannot account for the present low rates of FP among female participants as FP is included in the tax-funded healthcare available for the whole population in Sweden. Among men, most of those informed about disease/treatment impact on fertility were also informed about and used FP, indicating that sperm cryopreservation is a routine procedure in the oncological setting. No similar pattern of provision of fertility-related information and use of FP was seen for females, despite similar proportions of women and men reporting a pre-diagnosis desire for children. There are several potential explanations for these findings. Sperm banking is a relatively easy and noninvasive method that may be considered also by men with low risk of fertility impairment and men who do not actively plan for future children. As cryopreservation of oocytes and embryos are invasive and time-consuming procedures, physicians may refrain from discussing these measures with female patients who have no or low risk of fertility impairment. Also, the availability of FP procedures for female cancer patients is limited and restricted by treatment considerations [35]. This may have concerned women with several of the selected diagnoses of the present study, for example cervical cancer patients treated with definitive chemoradiotherapy, ovarian cancer patients treated with extensive surgery, and women with high-risk ER-positive breast cancer who benefit from anti-estrogen and GnRH-therapy for several years. Finally, oocyte and embryo cryopreservation may conflict with a need for immediate treatment start, which has been identified as a barrier to discussing FP among physicians [36]. Although cryopreservation of gonadal tissue is available at several Swedish centers [37], it is not yet widely established [38].

Among women, being older than 35 years and already having children at diagnosis were additional factors negatively correlated with reported receipt of information about FP. This finding is in line with previous research [17,29] and may reflect physicians' values [28], as well as national restrictions of subsidized fertility treatments (e.g., IVF with cryopreserved oocytes/embryos) based on the patient's age and previous children. The finding that heterosexual women were more likely to report having received FP information compared to nonheterosexual women was unexpected, as same-sex female couples and single women in Sweden have access to subsidized assisted reproduction with donor sperm. However, this finding is based on small numbers and a large number of women who identified as bisexual and should therefore be interpreted with caution.

Discrepancies in patient-reported information receipt between diagnosis groups

Participants with brain tumors were far less likely to report having received fertility-related information compared to participants with other diagnoses, in line with recent results from a population-based Australian study [21]. Possible explanations for the present findings are related to the patient, the organization of care, and the clinician [28,29,39].

First, it is possible that study participants with brain tumors to a higher extent than other patient groups were cognitively impacted by their disease and treatment [40], which may have affected their ability to process and recall received information. However, recent results based on medical records support that young brain tumor patients are less likely to have fertility discussions compared to other diagnoses [20,21]. Secondly, the organization of care may have an influence on information provision, as brain tumor patients' initial care often is provided by surgeons and neurologists who might have less experience of oncofertility care. Finally, clinicians may be reluctant to discuss FP options with brain tumor patients due to poor prognosis [29,40], common late effects such as cognitive and physical impairment, and concerns that a future pregnancy may trigger tumor growth [41]. Further studies are required to investigate the specific challenges of fertility-related information to patients with brain tumors. During the past years, several cancer and fertility programs have shown promise for increasing fertility-related information provision, referrals and FP use among a range of cancer types, including brain tumors [20,42]. In view of the specific treatment considerations for different tumor types, particularly for female patients, development of specific protocols to guide physicians and patients in decision-making concerning fertility preservation is encouraged.

Strengths and limitations

The present population-based survey study was conducted nationwide, including patients from all 21 regions in the country. Eligible participants were identified in national registries, lowering the risk of selection bias. The total response rate was high (67%), which suggests that providing different formats for survey completion (on paper, online, or over the phone) facilitated study participation. However, men participated to a lesser extent than women, and women with brain tumors and ovarian cancer responded at a lower rate than women with other diagnoses. Also, the proportion of study participants who reported being born outside of Sweden (15%) was lower compared to the corresponding foreign-born proportion of Swedish inhabitants of the corresponding age range (25%) [43]. This lower proportion may partly be due to language barriers as the study survey was only provided in Swedish. Furthermore, personal experiences and attitudes toward fertility issues and sexual function, as well as specific cultural barriers, might have had an impact on patients' willingness to complete the survey, although the potential consequences for our results are unknown. Finally, study participants reported on events that occurred up to 1.5 years previously, which constitutes a limitation. It is known that patients' recollection of medical information may be influenced by anxiety and stress [44] and differ from physicians' reports of provided information [45]. While recall bias may have resulted in underreporting of received information, it cannot explain the identified differences with regard to sex and type of cancer. In addition, relatively few participants reported difficulties recalling the presence/

absence and content of received information by selecting the response alternative 'Unsure'.

Conclusions

The present population-based study indicates a high and equal provision of information about the cancer/treatment-related impact on fertile ability to young women and men with cancer, although differences between types of cancer were identified. Our results support previous research showing disparities with regard to received information about, and use of, fertility preservation by patient sex and diagnosis. While health care to a greater extent appears to cater to the informational needs of young adults with cancer, there is room for improvement, particularly with regard to care of patients with brain tumors.

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