

PAPER

Physicians' self-reported practice behaviour regarding fertility-related discussions in paediatric oncology in Sweden

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Abstract

Objective: The aim of this study was to investigate practice behaviours of Swedish physicians with regard to discussing the impact of cancer treatment on fertility with paediatric oncology patients and their parents, and to identify factors associated with such discussions.

Methods: A cross-sectional survey study was conducted targeting all physicians in Sweden working in paediatric oncology care settings. Participants responded to a questionnaire measuring practice behaviour, attitudes, barriers, and confidence in knowledge. Multivariable logistic regression was used to determine factors associated with seldom discussing fertility.

Results: More than half of the physicians routinely talked with their patients/parents about the treatment's potential impact on fertility (male patients: 62%; female patients: 57%; $P = 0.570$). Factors associated with less frequently discussing fertility with patients/parents were working at a non-university hospital (male patients: OR 11.49, CI 1.98–66.67; female patients: OR 33.18, CI 4.06–271.07), concerns that the topic would cause worry (male patients: OR 8.23, CI 1.48–45.89; female patients: OR 12.38, CI 1.90–80.70), and perceiving the parents as anxious (male patients: OR 7.18, CI 1.20–42.85; female patients: OR 11.65, CI 1.32–103.17).

Conclusions: Based on our findings, we recommend structured training in how to communicate about fertility issues in stressful situations, which in turn might increase fertility-related discussions in paediatric oncology.

KEYWORDS

Cancer, Communication, Fertility, Fertility preservation, Oncology, Pediatric oncology, Physician, Survey study

1 | BACKGROUND

The deleterious effects of cancer treatment on reproduction are recognized,¹ and the likelihood of having children after cancer in childhood is reduced compared with siblings² and matched controls.³ A majority of adult childhood cancer survivors (77%) express a desire to have children,⁴ however, worry about the risk of infertility is commonly

reported.^{5,6} Fertility preservation (FP) options are available to increase the possibility of having genetically related children, such as cryopreservation of sperm, oocytes, and gonadal tissue.⁷ According to the American Society of Clinical Oncology⁸ as well as the Swedish National Program on follow-up after childhood cancer,⁹ health care providers are recommended to discuss the treatment-related risks of infertility with children diagnosed with cancer and/or legal guardians (hereafter called parents). Physicians have a responsibility to provide information about the

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potential risk of infertility. However, both young adults treated for cancer in childhood⁵ and parents of children who have undergone treatment for cancer¹⁰ commonly report that they do not recall having discussed the issue. Also, those who have received information about possible treatment effects on fertility are not always satisfied with the amount of information they received.¹¹ Earlier studies have mainly reviewed institutional routines across countries^{12–16} or presented results for multi-professional groups.^{17–20} Two studies were found that had assessed the practice behaviour of paediatric oncologists showing that discussion about what impact cancer treatment might have on fertility (ie, the risk of infertility) was discussed with the majority (60%–89%) of the patients/parents,^{21,22} while discussions about FP were less common (13%–22%).²² No studies were found that look into the impact of perceived barriers and attitudes on practice behaviour. Recently, our group investigated perceptions of fertility-related discussions among physicians working in adult oncology care.²³ In the present study, we investigated physicians' practice behaviours regarding fertility-related discussions with paediatric oncology patients/parents and sought to identify factors associated with such discussions.

2 | METHODS

Paediatric oncology treatment in Sweden, with a population of around 10 million people, is centralized around 6 tertiary referral centres in close collaboration with smaller hospitals where less toxic treatments can be administered. Paediatric oncologists are mainly assigned to the tertiary referral centres, while physicians or physicians in training (eg, paediatrics, paediatric oncology) usually staff smaller hospitals. Paediatric oncology care in Sweden follows the ASCO guidelines about fertility discussions,⁸ as well as national guidelines about FP directed to children diagnosed with cancer²⁴ and their follow-up care.⁹ Programmes for FP exist at reproductive clinics of university hospitals, and in addition to the clinically established FP methods, such as cryopreservation of oocytes and sperm, some of the clinics perform ovarian tissue cryopreservation.²⁵ FP in connection with a cancer diagnosis is included in the publically funded health care system and is available at a very low cost for the patient.

2.1 | Sample

Physicians working within paediatric oncology in Sweden were identified through the national record of healthcare personnel (HSAR). The register combines data about specialized physicians retrieved from the National Board of Health and Welfare with data about physicians working in oncological and haematological care obtained from all clinics in Sweden. Because HSAR records are only updated once a year, we also retrieved data directly from the National Board of Health and Welfare and from the 6 tertiary referral centres in Sweden. Of 121 identified physicians, 10 were excluded; 5 due to unknown address, 3 were retired, and 2 was involved in the present study.

2.2 | Measure

A questionnaire was developed based on items from 2 questionnaires used in adult oncology in the United States.^{26,27} Selected items were

translated and adapted to fit a paediatric oncology setting in the Swedish health care system by a multidisciplinary team consisting of specialists in reproductive medicine, oncology, haematology, paediatric oncology, psychology, and nursing. Two paediatric oncologists reviewed the questionnaire to evaluate feasibility and face validity, leading to some additional modifications. In the present study, a selection of items was used from 4 of the questionnaires' domains: *Practice behaviour*, *Barriers*, *Attitudes*, and *Confidence in knowledge*. Physicians were instructed to respond in relation to their care of paediatric patients (0–18 years) and their parents.

Practice behaviour Physicians were asked to indicate to what extent they discussed the impact of cancer treatment on fertility (ie, the risk of infertility) and to what extent they discussed FP with female and male patients and their parents (4 items). They were also asked if they assigned the discussion to another person (eg, nurse) or another clinic (2 items). Responses were given on a Likert scale ranging from 1 ("Never") to 5 ("Always") with the additional alternative "Not applicable". Responses were dichotomized into "Seldom" (responses 1–3) vs "Often/Always" (responses 4–5) in order to facilitate the analysis and interpretation of the results.

Attitudes were measured by asking physicians to indicate their level of agreement with 15 statements. Responses ranging from 1 ("Strongly disagree") to 5 ("Strongly agree"), and were categorized into "Disagree" (responses 1–2), "Neither disagree nor agree" (response 3), and "Agree" (responses 4–5). For the regression analyses, the responses were dichotomized into "Disagree/Neutral" (responses 1–3) and "Agree" (responses 4–5).

Barriers to discussing fertility-related issues in the face of specific circumstances were measured by physicians indicating the likelihood of bringing up fertility with patients/parents in 7 hypothetical situations (eg, poor prognosis). Responses ranged from 1 ("Not at all likely") to 5 ("Very likely") and were dichotomized into 2 categories—the presented situation being considered to be a barrier (responses 1–2) vs not considered to be a barrier (responses 3–5).

Confidence in knowledge was assessed by 10 items measuring perceived knowledge about risk of infertility and FP methods. Response alternatives ranged between 1 ("Not at all confident") and 5 ("Very confident") and were dichotomized into "Low confidence in knowledge" (responses 1–2) and "Moderate to high confidence in knowledge" (responses 3–5). The items were also subjected to an exploratory factor analysis. The domain had a Kaiser-Meyer-Olkin (KMO) index of 0.807 and statistical significance for Bartlett's test of sphericity ($P < 0.001$), and thus proved suitable for exploratory factor analysis which revealed 2 components (eigenvalues >1), respectively, explaining 55.9% and 16.7% of the variance. Based on this result, the items were divided into 2 subscales: *Confidence in knowledge about the risk of infertility* with 4 items (loadings 0.72–0.91) and *Confidence in knowledge about FP* with 6 items (loadings 0.66–0.94). Summary scores for both domains were calculated with the possible score of 4–20 and 6–30, respectively. Missing responses were replaced with the individual's mean subscale value if at least 50% of all items within the same subscale had been answered.

Data about the physicians' demographics and clinical background included age, sex, years of experience, specialization, working at a university hospital or not, access to a reproductive clinic, and number of paediatric cancer patients seen per week.

2.3 | Procedure

The identified physicians ($n = 111$) were contacted via mail in 2015 and invited to participate in an anonymous survey to be completed on paper or online. Three reminders were sent, 2 by post and 1 by e-mail. Returning a completed survey was considered to giving informed consent. According to the Regional Ethical Review Board in Stockholm, Sweden, the study did not require ethical approval.

2.4 | Data analysis

Statistical analyses were conducted in IBM SPSS statistics 22. Chi-square and Fisher's exact test were used to compare proportions of categorical variables. Multivariable logistic regression analyses were performed using the backwards method (likelihood ratio [LR]) with the dependent variable "Discussing treatment impact on fertility" with male and female patients, respectively (2 models). The relationship between dependent variables and independent variables (*Barriers*, *Attitudes*, summary scores for *Confidence in knowledge*, demographics, and clinical/organizational factors) were tested in univariable logistic regressions. All variables significant in univariable regression were considered for entry into the multivariable regression models. Due to high correlation and/or skewed distribution between 3 organizational variables ("Working at a university hospital," "Access to reproductive medical centre," "Number of patients seen per week"), only "Working at a university hospital" was used in the models. The barriers "Perceiving the parent as anxious" and "Perceiving the patient as anxious" were highly correlated, and only the one with the highest odds ratio (OR) was included in the models. Because the sample was small, only 5 independent variables could be entered in each model. In order to prioritize, variables with higher ORs were favoured. Significance was defined as P -values <0.05 .

3 | RESULTS

A total of 67 physicians responded to the survey (response rate 60%). Among them, 9 had not worked clinically with the patient group for the last 2 years and were excluded. Of the remaining 58 physicians (median age 53, range 34–72), the majority worked at a university hospital (67%), were specialized in paediatric oncology (55%), and had access to a reproductive medicine clinic that provides FP (71%) (Table 1).

3.1 | Discussions about oncological treatment's impact on fertility and FP

Over half of the physicians reported that they often/always talked with their patients/parents about the potential impact of the treatment on fertility (male patients: 62%; female patients: 57%; $\chi^2 = 0.322$, $P = 0.570$). The physicians reported that they discussed FP with their male patients more often than they did with their female patients (male patients: 55%; female patients: 33%; $\chi^2 = 5.705$, $P = 0.02$). Nine physicians (16%) reported seldom or never discussing the treatment's impact on fertility or FP with their patients/parents. All but one of them worked at non-university hospitals and reported

TABLE 1 Demographics and work practice of participating physicians ($n = 58$)

Characteristics	Physicians n (%) ^a
Sex	
Males	31 (53.4)
Females	26 (44.8)
Areas of specialization ^b	
Paediatric oncology	32 (55.2)
Paediatrics	20 (34.5)
Haematology	2 (3.4)
Oncology	1 (1.7)
No specialization	2 (3.4)
Years of experience	
<5	9 (15.5)
5–10	17 (29.3)
11–15	10 (17.2)
>15	21 (36.2)
Number of paediatric patients/week	
0	1 (1.7)
1–4	20 (34.5)
5–10	19 (32.8)
11–15	8 (13.8)
16–20	5 (8.6)
>20	3 (5.2)
Working at a university hospital	
Yes	39 (67.2)
No	18 (31.0)
Access to a reproductive medicine clinic	
Yes	41 (70.7)
No	16 (27.6)

^aPercentages do not sum to total due to missing data.

^bOne physician had double specialization.

that they often or always assigned the discussion to another clinic (eg, the clinic initiating the cancer treatment).

3.2 | Perceived attitudes, barriers, and confidence in knowledge

The majority agreed that patients/parents consider having children after cancer treatment as important (90%), and that it was their responsibility as physicians to discuss possible impairment of fertility following treatment (88%) (Table 2). The most frequently indicated barriers to initiating fertility-related discussions were the patient being of pre-school age (50%) or having a poor prognosis (47%). Additional barriers included the need for immediate treatment start (28%), the patient or parent appearing anxious or overwhelmed by the diagnosis (26% and 24% respectively), a high workload (24%), and unclear referral paths for FP (22%). Only a few physicians reported a low confidence in knowledge about the risk of infertility following cancer treatment (9%–14%), while a higher proportion indicated a low confidence in knowledge about FP methods (15%–68%), especially those methods appropriate to female patients (Table 3).

TABLE 2 Physicians' attitudes to discussing fertility-related aspects (*n* = 58)^a

Attitudes	Agree <i>n</i> (%)	Neither agree nor disagree <i>n</i> (%)	Disagree <i>n</i> (%)
<i>Risk of infertility after cancer treatment</i>			
Discussing fertility-related aspects of treatment with patients/parents is my responsibility	51 (88)	3 (5)	2 (3)
Discussing fertility after cancer with my patients/parents is awkward because it's a sensitive and intimate subject	10 (17)	7 (12)	39 (67)
Bringing up the risk of infertility is worrying for patients/parents	15 (26)	18 (31)	23 (40)
Bringing up the risk of infertility may cause patients/parents to choose to refrain from life-saving treatment	1 (2)	2 (3)	53 (91)
By talking about fertility after cancer one risks giving patients false hope about good chances of survival	4 (7)	4 (7)	48 (83)
Patients/parents think it is important to be able to have children after cancer	52 (90)	3 (5)	1 (2)
Girls are more worried about their fertility than boys are	12 (21)	21 (36)	22 (38)
<i>Fertility preservation</i>			
It's important to me to discuss fertility preservation measures with recently diagnosed patients/parents	46 (79)	6 (10)	4 (7)
Treating the cancer disease is more important than fertility preservation	50 (86)	4 (7)	2 (3)
Discussing the procedure for collecting a sperm sample with young boys is awkward	9 (16)	18 (31)	29 (50)
Discussing the procedure for harvesting oocytes with girls is awkward	4 (7)	8 (14)	44 (76)
Informing patients with a different religious or ethnic background about fertility preservation is difficult	15 (26)	17 (29)	24 (41)
Freezing ovarian tissue and testicular tissue are still experimental methods	44 (76)	9 (16)	3 (5)
The procedure for freezing ovarian tissue causes too much pain for a young girl	5 (9)	23 (40)	27 (47)
Freezing unfertilized oocytes gives girls a good chance of having children later in life	23 (40)	24 (41)	9 (16)

^aPercentages do not sum to total due to missing data.**TABLE 3** Proportion of physicians reporting low confidence in knowledge about oncologic treatments' impact on fertility and fertility preservation^a (*n* = 58)

Risk of infertility as follows of cancer treatment	<i>n</i> (%) ^b
Risk of delayed/non-puberty in boys	8 (14.3)
Risk of delayed/non-puberty in girls	7 (12.5)
Risk of infertility/early menopause in girls	7 (12.5)
Risk of infertility in boys	5 (8.9)
Fertility preservation methods	
New methods of expediting oocyte harvesting with less delay of cancer treatment	38 (67.9)
The possibility of carrying out fertility preservation after completed cancer treatment	32 (57.1)
Cryopreservation of	
Testicular tissue	26 (46.4)
Ovarian tissue	26 (46.4)
Of oocytes	18 (32.7)
Sperm	8 (14.8)

^aIndicating 1 or 2 on a 5-point Likert scale (1 = very low and 5 = very high).^bPercentages do not sum to total due to missing data.

3.3 | Factors associated with discussing oncological treatment's impact on fertility

Factors associated with the outcome variables in the univariable logistic regressions and the variables selected for the 2 multivariable regression models are presented in Table 4. Physicians were less likely to discuss the treatment's impact on fertility with patients/parents if they worked at a non-university hospital (male patients: OR 11.49, CI 1.98–66.67;

female patients: OR 33.18, CI 4.06–271.07), believed the subject would cause worry (male patients: OR 8.23, CI 1.48–45.89; female patients: OR 12.38, CI 1.90–80.70), or perceived parents as anxious (male patients: OR 7.18, CI 1.20–42.85, female patients: OR 11.65, CI 1.32–103.17). The model summary for discussing the treatment's impact on fertility (LR backwards, step 3): male patients χ^2 25.29, $P < 0.001$, Nagelkerke $R^2 = 0.521$, 64.2% classified; female patients χ^2 27.17, $P < 0.001$, Nagelkerke $R^2 = 0.627$, 58.5% classified.

TABLE 4 Factors associated with seldom discussing treatment's impact on fertility in connection to oncologic treatment with child patients/parents in univariable logistic regression analyses

Variables	Male patients		Female patients	
	OR	95% CI	OR	95% CI
Background				
Working at university hospital				
Yes*				
No	13.00 ^a	3.33–50.77	25.83 ^a	4.95–134.72
Access to reproduction clinic				
Yes*				
No	6.71	1.34–33.71	—	
>8 patients per week				
Yes*				
No	6.50	1.94–21.78	9.00	2.55–31.80
Attitudes				
Subject will cause worry				
No*				
Yes	4.35 ^a	1.24–15.31	4.50 ^a	1.26–16.04
Important to discuss FP				
Yes *				
No	2.77	0.64–11.90	3.63	0.80–16.48
Barriers ^b				
Preschool age				
No*				
Yes	2.80	0.91–8.61	3.08	1.03–9.24
Poor prognosis				
No*				
Yes	4.79 ^a	1.48–15.54	3.82 ^a	1.25–11.70
Patient being intellectually impaired				
No*				
Yes	4.69	1.47–15.00	3.02	0.99–9.19
Immediate treatment start				
No*				
Yes	4.55 ^a	1.34–15.48	4.74 ^a	1.36–16.46
Perceiving the patient as anxious				
No*				
Yes	8.80	2.29–33.84	10.00	2.39–41.84
Perceiving the parent as anxious				
No*				
Yes	12.10 ^a	2.81–52.08	15.50 ^a	3.01–79.79
Patient having genetic mutation				
No*				
Yes	5.50	1.24–24.40	4.12	0.94–18.05
Confidence in knowledge ^c				
...about risk	1.41	1.12–1.78	1.47	1.16–1.87
...about FP	1.24	1.07–1.43	1.24	1.08–1.43

— Model not valid due to uneven distribution.

*Reference category.

^aSelected for multivariable regression.^bResponses to statements about possible scenarios.^cContinuous variable.

4 | DISCUSSION

The present study shows that physicians in paediatric oncology in Sweden consider it important to discuss fertility and state that it is their responsibility to do so. About 60% of the physicians stated that they often discuss the treatment's impact on fertility with paediatric patients/parents, a proportion that is in line with²² or higher than that reported in earlier studies conducted in paediatric oncology settings.²¹

Physicians were less likely to discuss the treatment's impact on fertility if they believed that the subject might cause worry or perceived the parent/patient as being anxious. This finding supports qualitative findings showing that paediatric oncologists considered patient's/parent's emotional distress to be a hindrance to understanding the information they received regarding such topics.²⁸ In our corresponding study carried out in adult cancer care, univariable analysis showed that perceiving patients as anxious/overwhelmed was associated with seldom discussing fertility with both adult men and women.²³ However, this association did not remain significant in multivariable analysis.

While being sensitive to the patient's/parent's emotional status is critical when working in paediatric oncology, it is also important to initiate discussions in order to enable patients/parents to make informed decisions about future fertility. Having children after cancer is described as a way to achieve normality and to form an identity,²⁹ and even though childhood cancer survivors have been reported to worry about the risk of heredity or health issues in connection with pregnancy,⁵ most want to have children in the future.⁴ Our findings indicate that there is a need to increase the training in how to communicate about sensitive issues such as the treatment's impact on fertility and FP with worried patients/parents.

The findings showing that working at a non-university hospital was associated with less frequently discussing the treatment's impact on fertility might be explained by smaller hospitals usually not having a reproductive medicine clinic on the premises, as have earlier been described as a barrier to fertility-related discussions.³⁰ Still, it remains important that all physicians involved in paediatric oncology care discuss fertility after cancer because the patients/parents might want to address the issue at different time-points during or after treatment. The physician could, for example, initiate discussions about fertility when monitoring pubertal development³¹ and provide repeated information about the treatment's potential impact on fertility, as recommended in guidelines.⁹ When needed, the physician should refer the patient to a fertility specialist. It is also important to discuss post-treatment FP if there is a risk of premature ovarian failure.

Our results show that discussions about FP are carried out to a lower extent among female patients than male patients, which is in line with previous findings.²² This is especially interesting because 20% of the physicians in our study generally regarded girls as being more worried about fertility than boys are. One explanation could be the physicians' lower confidence in knowledge about FP relevant to female patients, which has also been reported elsewhere,^{20,21,28} and which might make the physicians refrain from raising the topic.

Poor prognosis and/or the need for immediate treatment start have previously been indicated as barriers to fertility-related discussions in both qualitative^{28,32} and quantitative studies.^{21,30} In the

present study, these barriers were associated with seldom discussing the treatment's impact on fertility in the univariable analyses. However, this did not remain significant in multivariable regressions, which could be explained by the lack of power in the analysis.

In the present study, 22%–24% of the physicians indicated a high workload and unclear referral routines as barriers to initiating fertility-related discussions, which is in line with previous studies.^{17,21,28} The latter organizational factor could relatively easily be rectified through the introduction of local guidelines at the clinics as to what steps to take if FP is considered to be possible, which ideally would be developed in close collaboration between fertility and cancer clinics.

4.1 | Study limitations

The present study was based on the total population of physicians working in paediatric oncology in Sweden, with an acceptable response rate that was comparable to²¹ or exceeded¹⁸ earlier studies among physicians in cancer care. However, there is a risk of selection bias because physicians who consider fertility issues more relevant might have chosen to participate to a greater extent. While the separate assessment of physicians' fertility discussions with female and male patients is an additional strength, we might have identified other variables associated with fertility communication if we had also studied discussions by patient age.²² Another potential limitation is the use of hypothetical situations when assessing barriers to fertility-related discussions. The physicians might act differently when faced with an actual situation. We used multivariable analyses to identify factors associated with discussions about the risk of infertility with patients/parents. However, the small sample size decreased its power, and the variations in answers led to large confidence intervals. Therefore, some caution is advised when interpreting the models. We believe that the present study findings are generalizable to paediatric cancer care across western countries with publicly funded healthcare, and in part also to privately funded care.

4.2 | Clinical implications

While the majority of the physicians working within both adult²³ and paediatric oncology in Sweden reported discussing treatment impact on fertility with their patients and/or parents, a relatively large proportion seldom did so. In the present study, we found that the lack of such discussions was associated with physicians' perceiving that the subject could worry patients as well as parents. Fertility issues are crucial for young patients and should not only be discussed in connection with cancer treatment. The subject might be even more appropriate during follow-up care as the patient reaches adolescence and adulthood. In an effort to increase fertility-related discussions in paediatric oncology, we therefore recommend structured training in how to communicate fertility in stressful situations. Such a training program is suggested to be evaluated by measuring the frequency of fertility-related discussions and the level of comfort and confidence in discussing fertility with patients/parents before and after the intervention.

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