

Default Question Block

instruction. Physician-Patient Communication: Assessing physician strategies for informing children and adolescents about their cancer diagnosis and the risk of gonadal dysfunction

Disclosure: This study is a joint study with the Oncofertility Consortium lead by Dr.Teresa Woodruff, Ph.D. at Northwestern University and the Japanese oncofertility group lead by Dr. Nao Suzuki, M.D., Ph.D. at St.Marianna University school of Medicine. This work is supported by the Center for Reproductive Health After Disease(P50HD076188) from the National Institutes of Health National Center for Translational Research in Reproduction and Infertility(NCTRI) and a Japanese government grant.

If you have any questions or concerns please contact smz.yuriko@gmail.com or [312-503-2504](tel:312-503-2504). This survey should take no longer than 15 minutes. Participation is voluntary.

Confidentially: The records of this survey will be kept private. The information you provide will be kept confidential. Your answers are completely anonymous.

Risks & Benefits: There are minimal to no risks to your safety by participating in this survey. If you ever feel uncomfortable answering question during this online survey, you may exit it at any time.

Freedom to Withdraw or Refuse Participation: You have the right to stop and exit the survey at any time.

This study aims to describe patterns of communication at diagnosis between pediatric oncologists and children and adolescents with cancer. Here we will ask you if you tell the cancer diagnosis to child and adolescent patients and also if you discuss fertility issues at diagnosis with child and adolescent patients. We will take the same survey in Japan and compare the results and cultural differences. As for age range, we set the age between 7 to 17 years of age. In some questions, we will ask you questions by age such as 7-9 year-old (elementary school lower grade/ pre-pubertal), 10-14 years of age (elementary school higher grade/beginning of puberty), 15-17 years of age (high school/ puberty) .

I agree to participate in the survey entitled, "Physician-Patient Communication: Assessing physician strategies for informing children and adolescents about their cancer diagnosis and the risk of gonadal dysfunction." I understand my right to withdraw from participating or refusing to participate, by simply exiting the survey. I give this consent voluntarily. Check box:

YES

NO

Demographics

Q1. What is your gender?

Male

Female

I prefer not to say

Q2. What is your specialty?

Pediatrician

Pediatric oncologist

Pediatric Endocrinologist

Pediatric Urologist

Pediatric Gynecologist

Other (Please specify)

Q3. How many years have you been in practice?

- < 5 years
- 5 - 10 years
- 11 - 15 years
- > 15 years

Q4. How many years have you been working in cancer care?

- < 5 years
- 5 - 10 years
- 11 - 15 years
- > 15 years
- I have not worked in cancer care before
- I have not worked in cancer care for more than 2 years

Q5. Are you working at a university hospital?

- Yes
- No

Other. Please specify.(e.g. private hospital, private practice, public hospital)

Communicating the risk of gonadal dysfunction, future infertility, and/or fertl

Q6. We are interested in what you ALWAYS tell 7-17 years old patients about the following. Please select one from the girl, and one from the boy in each statement. As for age range, we set 7-9 years old as elementary school low grade/ pre-pubertal, 10-14 years old as elementary school higher grade to middle school/ beginning of puberty, 15-17 years old as high school/ puberty.

	Female. I tell if the patient is...					Male. I tell if the patient is...				
	>7-9 y.o.	>10-14 y.o.	>15-17y.o.	Never tell	I can not answer because it is out of my specialty	>7-9 y.o.	>10-14 y.o.	>15-17y.o.	Never tell	I can not answer because it is out of my specialty
Cancer diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cancer treatments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
General side effects of cancer treatment(e.g. fever, loss of hair, allergic reaction)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk of gonadal dysfunction associated with cancer treatment (e.g. delayed puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Risk of future infertility associated with cancer treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fertility preservation options (Egg cryopreservation, sperm cryopreservation)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (If there is anything else you always tell patients, please specify)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7. Do you refer child and adolescent patients to FP program or reproductive endocrinologist in your hospital?

- Yes
- No

Q8. Please tell us why you chose No.

Because even though there are FP program or reproductive endocrinologists in my hospital, our divisions are not working well together.
 Because there are not FP program or reproductive endocrinologists in my hospital.

Other

Q9. Do you refer child and adolescent patients to FP program or reproductive endocrinologist out side of your hospital?

Yes

No

Q10. Please tell us why you chose No.

Because there are FP program or reproductive endocrinologist in my hospital.
 Because I do not know any FP program or reproductive endocrinologist that I can refer to.
 I know some FP programs or reproductive endocrinologist but they are too far from my hospital.

Other

Q11. When and who do you describe **the risk of gonadal function (e.g. delayed puberty)** due to cancer treatment? Please check applicable circle in each age range.

	I do not tell anyone	Before cancer treatments start	I do not tell before cancer treatments, but tell them they need to follow-up	I only tell the parents before cancer treatments start	I can not answer because it is out of my specialty	Other
7-9 y.o. (Pre-pubertal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10-14 y.o. (Begin of puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15-17 y.o. (Puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q12. Please specify.

Q13. When and who do you describe the risk of future infertility due to cancer treatment? Please check applicable circle in each age range.

	I do not tell anyone	Before cancer treatments start	I do not tell before cancer treatments, but after puberty or after 20 years of age	I do not tell before cancer treatments, but when they are ready to achieve pregnancy	I only tell the parents before cancer treatments start	I can not answer because it is out of my specialty	Other
7-9 y.o. (Pre-pubertal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10-14 y.o. (Begin of puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15-17 y.o. (Puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q14. Please specify.

Q15. How often do you use teaching aid(e.g. pamphlet, website, textbook...etc)when you explain to child and adolescent patients about the risk of gonadal dysfunction and/or future infertility? Please check applicable circle by each age range.

	Always	Most of the time	Some of the time	Rarely	Never	I can not answer because it is out of my specialty
7-9 y.o. (Pre-pubertal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10-14 y.o. (Begin of puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15-17 y.o. (Puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q16. If you use any materials, please tell me particular method.(e.g. website, iPad, slide show...etc)

Factors: Communicating the risk of gonadal dysfunction, future infertility...

Q17. What influences your decision to describe directly to child and adolescent patients about the risk of gonadal dysfunction, the risk of future infertility, and/or fertility preservation options?

	A lot	Only a little	Not at all	I can not answer because it is out of my specialty
Age of child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Child's sex	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental understanding of the child situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental request regarding to how much information is shared.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The physician's perception of the family's ability to afford fees and storage	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your low confidence in knowledge of infertility risks for fertility issues	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Physician's attitudes: Communicating the risk of gonadal dysfunction, future inf

Q18. Please describe your opinions on the matters below. Please choose agree or disagree in each age range.

	7-9 y.o. (Pre-pubertal)			10-14 y.o. (Begin of puberty)			15-17 y.o. (Puberty)		
	Agree	Disagree	I can not answer because it is out of my specialty	Agree	Disagree	I can not answer because it is out of my specialty	Agree	Disagree	I can not answer because it is out of my specialty
"MDs have a responsibility to tell children about the risk of gonadal dysfunction. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"MDs have a responsibility to tell children about the risk of future infertility. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"MDs should describe the risk of gonadal dysfunction and/or the risk of infertility only to the parents. "	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
" The parents should describe the risk of gonadal dysfunction and/or the risk of future infertility to the child."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

"A child's knowledge enhances participation in fertility preservation decisions."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"A child's understanding of the risk of gonadal dysfunction and/or the risk of future infertility is different depending on sex."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"It is better to have teaching aids to explain the risk of gonadal dysfunction and/or the risk of future infertility."(e.g. pamphlet, slideshow, website, animation...etc)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Describing a cancer diagnosis

Q19. How often do you tell the **cancer diagnosis directly** to child and adolescent patients?

	Always	Most of the time	Some of the time	Rarely	Never	I can not answer because it is out of my specialty
7-9 y.o. (Pre-pubertal)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10-14 y.o. (Begin of puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15-17 y.o. (Puberty)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q20. If you describe the cancer diagnosis to cancer patients, do you obtain informed consent/assent for cancer treatment from the child and adolescent patients? Check all that apply.

	<u>Informed assent</u> from child	<u>Informed consent</u> from child	Informed consent <u>only from parents</u>	It depends on child's understanding ability	Other	I can not answer because it is out of my specialty
7-9 y.o. (Pre-pubertal)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10-14 y.o. (Begin of puberty)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15-17 y.o. (Puberty)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Q21. If you chose other, please specify.

Q22. If you do not tell cancer diagnosis directly to child and adolescent patients, do you **let the parents tell child** about cancer diagnosis?

Yes

No

 Other (Please specify)

Factors: Describing a cancer diagnosis

Q23. What influences your decision to communicate the cancer diagnosis to child and adolescent patients. Please check applicable circle.

	A lot	Only a little	Not at all	I can not answer because it is out of my specialty
Age of child	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental understanding of the child situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Likelihood of cure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Parental request regarding how much information is shared	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Physician's attitudes: Describing a cancer diagnosis

Q24. Please describe your opinions on the matters below. Please choose agree or disagree in each age range.

	7-9 y.o. (Pre-pubertal)			10-14 y.o. (Begin of puberty)			15-17 y.o. (Puberty)		
	Agree	Disagree	I can not answer because it is out of my question	Agree	Disagree	I can not answer because it is out of my question	Agree	Disagree	I can not answer because it is out of my question
"MDs have a responsibility to tell children about their cancer diagnosis"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"Child's knowledge enhances participation in care decisions and improves compliance."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"Child's awareness dashes sense of hopefulness"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
"Child should be told diagnosis only by parent."	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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