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Fertility and Fertility Preservation: Scripts to Support Oncology Nurses in Discussions with Adolescent and Young Adult Patients

Susan T. Vadaparampil, PhD, MPH, Joanne Kelvin, MSN, RN, Devin Murphy, MSW, Meghan Bowman, Ivana Schovic, MPH, and Gwendolyn P. Quinn, PhD, MEd

ABSTRACT

- **Objective:** To describe a script-based approach to assist oncology nurses in fertility discussions with their adolescent and young adult (AYA) patients.
- **Methods:** Scripts were developed by a team that included experts in fertility and reproductive health, health education, health communication, and clinical care of AYA patients. Individual scripts for females, males, and survivors were created and accompanied by a flyer and frequently asked questions sheet. The script and supplementary materials were then vetted by oncology nurses who participated in the Educating Nurses about Reproductive Health Issues in Cancer Healthcare (ENRICH) training program.
- **Results:** The scripts were rated as helpful and socially appropriate with minor concerns noted about awkward wording and medical jargon.
- **Conclusion:** The updated scripts provide one approach for nurses to become more adept at discussing the topic of infertility and FP with AYA oncology patients and survivors.

In the United States, over 70,000 adolescents and young adults (AYAs) are diagnosed with cancer each year [1,2]. Treatments are available that are associated with improved survival for these cancers. Unfortunately, cancer treatment may significantly impact AYA survivors' future fertility. Infertility or premature ovarian failure can occur during or after cancer treatment (eg, chemotherapy, radiation) for females, and males may be temporarily or permanently azoospermic [3]. There are a number of established methods of fertility preservation (FP) that are available; these include oocyte and embryo cryopreservation and ovarian transposition for females and sperm banking for males [3]. Experimental options

for males include testicular tissue freezing and for females ovarian tissue cryopreservation.

The American Society of Clinical Oncology (ASCO) and the National Comprehensive Cancer Network [4,5] recommend discussing FP with patients of reproductive age, ideally before initiation of treatment. In 2013, ASCO updated guidelines extending the responsibility for discussion and referral for FP beyond the medical oncologist to explicitly include other physician specialties, nurses, and allied health care professionals in the oncology care setting [3]. However, multiple publications, including patient surveys and interviews, physician surveys, and medical record abstraction studies suggest these discussions do not consistently take place. In an analysis of 156 practice groups submitting data as part of ASCO's Quality Oncology Practice Initiative, only ~15%–20% of practices routinely discussed infertility risks and FP options [6]. A recent review of medical charts of patients aged 18–45 treated in 2011 at 1 of 4 large U.S. cancer care institutions found that documentation of discussions for infertility risk was 26%, 24% for FP option discussion, and 13% for fertility specialist referral [7].

Oncology nurses play a key role in patients' care and, compared to other health care providers, are more likely to have multiple interactions with patients prior to the initiation of treatment [8]. They are often attuned to the medical and psychosocial needs of the patient and family and can advocate for their needs and desires [9].

From the Moffitt Cancer Center, Tampa, FL (Dr. Vadaparampil, Ms. Bowman, Ms. Schovic, Dr. Quinn), Memorial Sloan Kettering Cancer Center, New York, NY (Ms. Kelvin), and Edward Via College of Osteopathic Medicine, Auburn, AL (Ms. Murphy).

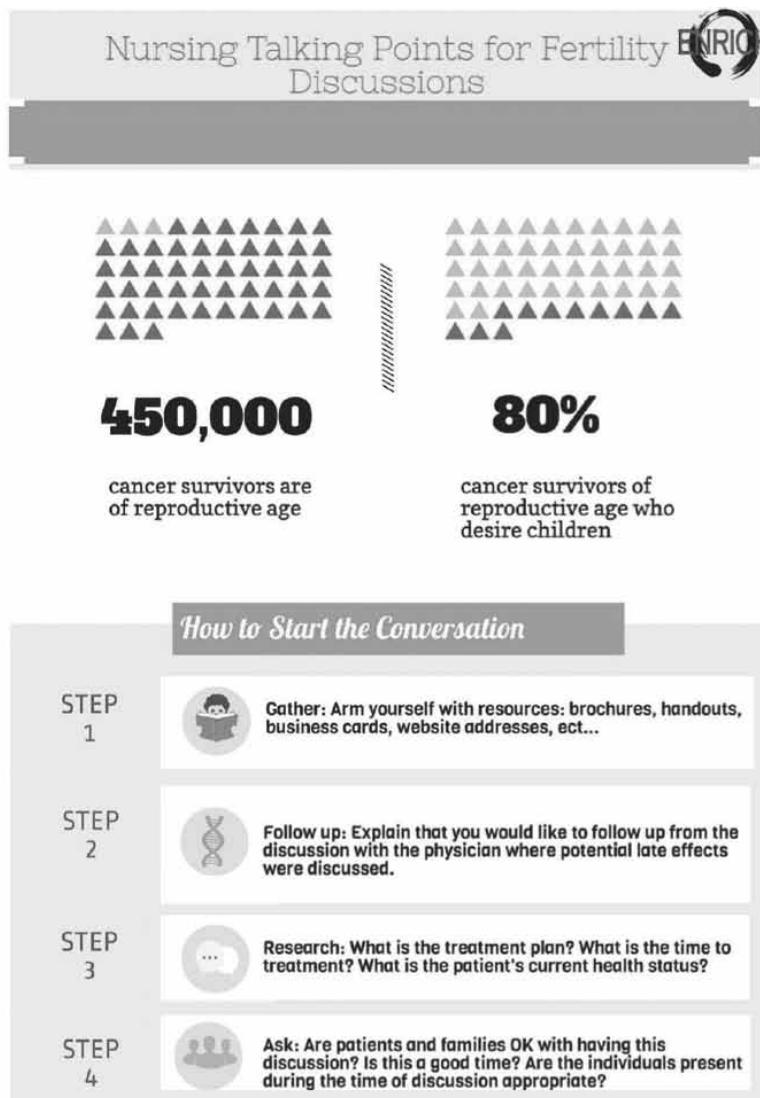


Figure 1. Nurse talking points flyer.

However, existing research finds few oncology nurses discuss this topic with AYA patients. Studies examining barriers have identified factors that may hinder discussions about infertility and FP with AYA oncology patients. These barriers include lack of knowledge about cancer related infertility and available FP procedures; access to reproductive endocrinologists or sperm banking clinics; time constraints in busy clinics and concerns about delaying treatment; discomforts discussing reproductive health; patient's ability to afford FP; bias about the suitability of FP for young or unpartnered or LGBT patients or those with a poor prognosis; and personal religious or moral values about the use of assisted reproductive technologies [10–15].

Equipping nurses with content-specific communication may overcome some of the barriers described. A method often used in nursing education and communication interventions is scripting [16–18]. Scripting provides precise key words that ensure consistency in the message, no matter the messenger [19]. This paper reports on the development and refinement of a series of scripts to guide discussions about FP for male and female AYA patients and survivors.

Script Development

In 2003 Studer developed the *AIDET* (Acknowledge, Introduce, Duration, Explanation, and Thank you) model

Frequently Asked Questions for Fertility Preservation 	
Question: What's my risk?	Answer: Your risk depends on many things. Your age, your type of cancer, your treatment, and your fertility before you were diagnosed. While we don't know for sure who will and who will not have fertility problems, based on your treatment, we know you fall into <<[high, intermediate, low]>> risk.
Question: Do I have to do something about this now?	Answer: If you want to pursue fertility preservation, this must be done before you start treatment. We know it can be difficult to make this decision so quickly, but if you are uncertain, you may want to consider a referral to a fertility specialist to learn more and help you decide.
Question: What happens if I don't freeze my sperm/eggs/embryos/tissue?	Answer: This is definitely not something you have to pursue. However, we want to be sure you know about your risks and options. If you are not able to have a biologic child in the future, there are other ways to build a family.
Question: How can I think about having children? I have a 20% chance of survival.	Answer: Not everyone wants to undergo fertility preservation before treatment, but we want to be sure you know this is an option for you. Although we have no way of predicting with certainty how you will respond to your cancer treatment, we hope you will do well and want to be sure you have the opportunity to have a biologic child in the future if this is important to you.
Question: What if I don't need my frozen sperm/eggs/embryos/tissue?	Answer: Once you have decided you will not be using your frozen s/e/e/t you can direct the center that is storing these for you on how you want them to be handled. You may choose to discard them, donate them, or designate them for use in research.
Question: How can I afford this?	Answer: The good news is that more and more organizations are realizing the risk of infertility. Some even have special financial assistance programs just for people diagnosed with cancer. This can be up to 75% off of the procedure, free medications, and reduced rates for storing your frozen sample.

Figure 2. Frequently asked questions sheet.

of communication for health professionals [19]. AIDET is an effective tool in facilitating communication practices among nurses and physicians in adult and pediatric settings [20–24]. The AIDET model was adapted by our team to develop *AIDED*: Assess, Introduce, Decide, Explain, and Discuss, a script-based approach to assist oncology nurses in fertility discussions with their AYA patients. Our team included experts in fertility and reproductive health, health education, health communication, as well as clinical and psychosocial care of AYA patients.

We developed 3 scripts. Two were targeted to AYA females and males at or near time of diagnosis (Female Script and Male Script) and one targeted to AYA survivors who had completed treatment (Survivor Script). Each script contained dialogue guidelines using the AIDED format. The scripts were accompanied by a flyer that provides a brief overview on how to start a discussion about FP (Figure 1) and a frequently asked question (FAQ) sheet that addresses common questions regarding fertility risk, FP time lines, survivorship, and financial concerns (Figure 2). The goal was to produce

a packet of materials for future use in communication research and ultimately, dissemination into clinical practice.

Educating Nurses about Reproductive Issues in Cancer Healthcare (ENRICH) is a web-based communication skill building curriculum for oncology nurses to initiate reproductive health discussions with AYA patients [25]. Because these individuals are actively engaged in the care of AYA patients and familiar with the content and process of providing information about fertility and FP to AYA patients, we elicited feedback from this group to improve our scripts and other materials targeting AYA oncology nurses. Overall, the nurse reviewers found the scripts socially acceptable and appropriate. The problems identified included awkward or vague wording and poorly or undefined terminology. The team addressed these issues by replacing the awkward wording, clarifying or softening some language, and using more simplistic terms. The revised Female script is shown in the Table; the Male and Survivor scripts are presented at the end of this article.

Table. Female Script

<p>Assess patient's general understanding of their diagnosis and their potential impact on fertility as well as current and future desires for parenting</p>	<p><i>Has anyone discussed how your cancer treatment may affect your ability to have children? I know this is something you may not be thinking about right now, but do you think you may want to have (more) children in the future?</i></p> <p>Note: A patient is more likely to refuse to consider fertility preservation if she feels pressured; speak slowly and clearly and avoid projecting a sense of urgency.</p>
<p>Introduce the topic of fertility and why you are discussing this topic</p>	<p><i>I would like to talk with you about these issues. Is this something you would like to hear about? Is this a good time to talk about this? Is there someone you would like to have with you when we talk about this? Before I begin, tell me what you already understand about the possible effect of treatment on your fertility.</i></p>
<p>Describe potential impact of a cancer diagnosis and/or treatment on fertility and available options to preserve fertility</p>	<p><i>Females are born with about one million eggs and cannot make any new eggs. Certain chemotherapy drugs, as well as exposure of the ovaries to radiation, can destroy eggs. Depending on how many eggs are lost, you may not be able to have a biologic child after treatment. Unfortunately we cannot predict with certainty exactly how you will be affected.</i></p> <p><i>However, there are steps you may be able to take before treatment to preserve your fertility. The option that has been used the longest is embryo freezing. Eggs are removed from your ovaries and fertilized in a laboratory with sperm from your partner or a donor to create embryos. These are then frozen for you to use in the future if you need them. At that time they would be thawed and placed in your uterus to attempt pregnancy.</i></p> <p><i>Another option is to remove eggs and freeze them without having them fertilized with sperm. If you need to use them in the future, they would be thawed, and fertilized with sperm from your partner or a donor to create embryos. The embryos would then be placed in your uterus to attempt pregnancy.</i></p> <p>Note: The patient may have questions about other options for fertility preservation. If so, be prepared to discuss options such as ovarian transposition, ovarian suppression, and ovarian tissue freezing.</p>
<p>Explain the timeline for various fertility preservation options and refer to relevant specialists</p>	<p><i>The process for embryo and egg freezing takes 2-1/2 to 3 weeks. Treatment cannot begin until this is completed. If this is something you want to consider, the first step would be to see a fertility specialist; these doctors are called reproductive endocrinologists.</i></p>
<p>Discuss and provide patients with information and offer support to facilitate decisions about fertility preservation</p>	<p><i>Some women are very clear about whether or not they want to pursue fertility preservation. Others have a harder time making this decision. Some things to consider as you make a decision for yourself include the opinion of your oncologist; the safety of delaying treatment for about 3 weeks; how important it is to you to have a biologic child; your ability to cope with the effort it will take to pursue this; your religious, ethical, and personal beliefs about using reproductive technology; your ability to afford the treatment; and the opinions of your family. There is no "right" decision. Our goal is for you to have all the information you need to make the best decision you can for yourself. Regardless of the outcome, we want you to have no regrets.</i></p> <p><i>If you would like to see a reproductive endocrinologist to learn more about this, I would be happy to call his/her office to get an appointment scheduled for you.</i></p>

Benefits of Scripts

Communication difficulties may present an obstacle for oncology nurses to address the infertility, FP information, and supportive care needs of AYA cancer patients [15]. While guidelines from leading health and professional organizations support the need to discuss these issues

with patients, implementation requires providing practical tools that meet the needs of nurses' practice setting and patient population [26].

The use of scripts has a long history in the medical profession and is growing in importance for "breaking bad news" and end of life discussions [27]. For clini-

cians, scripts provide networks of knowledge adapted to the goals of clinical tasks. Scripts also incorporate the notion of Hymes' communication competence by demonstrating the underlying traits that enable speakers to be perceived as effective communicators: knowing what, how and when to say something [28]. Scripts provide structure to describe a medical sequence of events within the most appropriate context, such as discussing the risk of infertility from cancer treatment prior to the initiation of the treatment. Importantly, scripts are best used with communication skills training that incorporate empathy and listening skills [29–31].

Conclusion

These scripts provide one approach for nurses to become more adept at discussing the topic of FP with AYA oncology patients. We will continue to update and refine these scripts and ultimately test their efficacy in improving psychosocial and behavioral outcomes for AYA patients. While scripts are effective, they must be updated to reflect relevant advances in clinical care. In addition, it is important to identify local resources to facilitate discussion and referral for those who seek additional information and or services related to FP. Such resources include psychosocial support, reproductive endocrinologists with expertise in the unique needs of AYA oncology patients, providers who accept pediatric patients (if needed), and financial assistance.

Corresponding author: Susan T. Vadaparampil, PhD, MPH, 12902 Magnolia Dr., MRC CANCONT, Tampa, FL 33612, susan.vadaparampil@moffitt.org.

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THE FOUR OF US

sit there in the hospital room.
 My patient talks with the intern,
 while I sit in the corner, listening
 as if uninvolved.

The fourth, my patient’s
 unseen roommate, lies in his own bed
 behind the curtain that pretends
 to give us privacy, shields
 our secrets.

The conversation moves along
 ‘til Dr. Youth asks my suffering patient,
 “Just how bad was your chest pain, anyway?”
 We all expect the usual answer, “Pretty bad”
 or “Not so bad” or maybe a number like
 six out of ten, but no, the unknown voice
 that answers from behind the curtain
 firmly proclaims,

**“Your chest pain was the worst chest pain
 I have ever seen.”**

—Frederick W. Platt, MD

Male Script

Assess patient's general understanding of their diagnosis and their potential impact on fertility as well as current and future desires for parenting

Has anyone discussed how your cancer treatment may affect your ability to have children? I know this is something you may not be thinking about right now, but do you think you may want to have (more) children in the future?

Note: A patient is more likely to refuse to consider fertility preservation if he feels pressured; speak slowly and clearly and avoid projecting a sense of urgency.

Introduce the topic of fertility and why you are discussing this topic

*I would like to talk with you about these issues
Is this something you would like to hear about?*

Is this a good time to talk about this?

Is there someone you would like to have with you when we talk about this?

Before I begin, tell me what you already understand about the possible effect of treatment on your fertility.

Describe potential impact of a cancer diagnosis and/or treatment on fertility and available options to preserve fertility

Within the testes are continuously dividing germ cells that mature into sperm. When a male ejaculates, mature sperm are released into the semen. These sperm can fertilize a woman's eggs, resulting in pregnancy. Certain chemotherapy drugs, as well as exposure of the testes to radiation, can destroy the germ cells. Depending on how many cells are lost, you may no longer produce sperm and might not be able to have a biologic child after treatment. Unfortunately we cannot predict with certainty exactly how you will be affected.

However, there are steps you may be able to take before treatment to preserve your fertility. Sperm banking enables you to collect and freeze sperm. This process involves ejaculating into a specimen cup. Your semen or "sample" will be tested to be sure the sperm are alive and healthy. The sperm will then be frozen for you to use in the future if you are not producing sperm on your own after treatment. Frozen sperm can be thawed and instilled directly into your partner to attempt pregnancy or they can be used to fertilize eggs in a laboratory to create embryos that can be placed in your partner or a surrogate. Your samples belong to you, and only you can decide how they will be used, if ever, in the future.

Note: The patient may have questions about other options for fertility preservation. If so, be prepared to discuss options such as electroejaculation and testicular sperm extraction.

Explain the timeline for various fertility preservation options and refer to relevant specialists

We generally recommend that men collect 3 separate specimens, with 2-5 days between each collection. That takes a week to 10 days. If there is not enough time for this before you are scheduled to begin treatment, you can collect 3 days in a row. Even if you have time for only one collection, it is worthwhile to consider sperm banking.

Treatment cannot begin until sperm banking is completed. If this is something you want to consider, the first step would be to schedule an appointment at a sperm bank.

Discuss and provide patients with information and offer support to facilitate decisions about fertility preservation

Whether or not you want children now, we recommend you consider sperm banking. You don't have to use the frozen sperm, but having it will give you more choices in the future if you decide you want to have children. Many men who have been through this and didn't sperm bank before treatment, wish they had done this.

If you would like to consider sperm banking, I would be happy to call the sperm bank to get an appointment scheduled for you.

Survivor Script

Assess patient's general understanding of their diagnosis and their potential impact on fertility as well as current and future desires for parenting

*Has anyone discussed how your cancer treatment may affect your ability to have children?
I know this is something you may not be thinking about right now, but do you think you may want to have (more) children in the future?*

Note: A patient is more likely to refuse to consider fertility preservation if she feels pressured; speak slowly and clearly and avoid projecting a sense of urgency.

Introduce the topic of fertility and why you are discussing this topic

*I want to talk with you about something you may or may not have thought about before.
When you come for your checkup we look at all sorts of things that could have been affected by your treatment, like your heart and lung function or your bone density. Some kinds of cancer treatment can affect your fertility, affecting your ability to have children in the future.*

I would like to talk with you about these issues.

Has anyone discussed fertility with you before?

Is this something you would like to hear about?

Is this a good time to talk about this?

Is there someone you would like to have with you when we talk about this?

Before I begin, tell me what you already understand about the possible effect of treatment on your fertility.

Describe potential impact of a cancer diagnosis and/or treatment on fertility and available options to assess current fertility and future biological and nonbiological parenting options

FEMALE

Females are born with about one million eggs and cannot make any new eggs. Certain chemotherapy drugs, as well as exposure of the ovaries to radiation, can destroy eggs. Depending on how many eggs are lost, you may not be able to have a biologic child in the future. Unfortunately we cannot predict with certainty exactly how you will be affected.

However, there are ways of evaluating your fertility now. You can see a reproductive endocrinologist who will evaluate how your ovaries are functioning using an ultrasound to look at images of the ovaries and measuring hormone levels in your blood.

MALE

Within the testes are continuously dividing germ cells that mature into sperm. Certain chemotherapy drugs, as well as exposure of the testes to radiation, can destroy the germ cells. Depending on how many cells are lost, you may no longer produce sperm and might not be able to have a biologic child in the future. Unfortunately we cannot predict with certainty exactly how you will be affected.

However, you can have your fertility evaluated by a semen analysis. This is done at a special lab where you would ejaculate into a specimen cup. Your semen would be examined under a microscope to count the number of sperm present in the sample and evaluate how well they swim in the fluid.

Explain the timeline for assessing fertility and pursuing future parenting options and refer to relevant specialists

FEMALE

We recommend you wait one year after chemotherapy has been completed before seeing a reproductive endocrinologist. This allows time for the ovary to recover. If the tests indicate that your egg supply is lower than expected, keep in mind that women continually lose eggs as they age. If you will not be having children in the near future, you can speak with the reproductive endocrinologist about the possibility of freezing eggs for you to use in the future if needed.

MALE

We recommend you wait one year after chemotherapy has been completed before having your semen analyzed. This allows time for the testes to recover. If the tests show you are not producing sperm, or that your sperm counts are low, there may be continued recovery of sperm production in the first few years after treatment. If no sperm are found in your semen at the time you are ready to start a family, you can consider seeing a urologist to discuss the option of testicular sperm extraction, a minor surgical procedure to remove small pieces of testicular tissue which are then examined to try to find sperm.

Discuss and provide patients with information and offer support to facilitate decisions about fertility preservation

Whether or not you want children now, it's good to start thinking about this. If you would like to see a reproductive endocrinologist or have a semen analysis, I would be happy to arrange this for you.

Many men and women will be able to conceive naturally after cancer treatment. However, if you did not undergo fertility preservation before treatment, and testing shows you are no longer fertile, keep in mind that there are many ways to build a family. Options include using donor eggs/embryos/sperm and adoption. And, for women who cannot become pregnant after treatment, you can arrange for another woman to carry a pregnancy for you. There are a number of resources for you to learn more about these options.