

## Using a Patient-Centered Approach to Develop a Fertility Preservation Brochure for Pediatric Oncology Patients: A Pilot Study

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### ABSTRACT

**Study Objectives:** Most pediatric education materials are designed for a parent audience. Social marketing techniques rely on the principles called the "4 P's": product, price, place, and promotion. The objective of this study was to test the design, readability, likelihood to read, and overall opinion of a pediatric fertility preservation brochure with patients, parents, and providers.

**Design:** Qualitative face-to-face interviews.

**Setting:** The Children's Cancer Center in Tampa, FL, and All Children's Hospital in St. Petersburg, FL.

**Participants:** Male and female cancer patients and survivors aged 12–21 (N = 7), their parents (N = 11), and healthcare providers (N = 6).

**Interventions:** Patients, survivors, parents, and healthcare providers were given two versions of gender concordant brochures on fertility preservation designed for both pediatric oncology patients and their parents.

**Outcome Measures:** Design, readability, likelihood to read, and overall opinion from interviews in order to identify facilitators of involving patients in fertility preservation discussions.

**Results:** Parents and teens differed on the design, readability, and likelihood to read, the highest discord being preferences for medical terminology used in the brochures. While parents remarked that much of the language was 'too advanced,' the majority of teens explained that they understood the terminology and preferred it remained on the brochure. Overall feedback from all three groups was utilized to revise the brochures into final versions to increase the likelihood of reading.

**Conclusion:** Information about the development of the 4 P's of social marketing highlights needs from the intended audience. Barriers to patient education in pediatrics can be ameliorated when using the social marketing approach.

**Key Words:** Oncology, Reproductive Health, Adolescents, Brochure

### Introduction

Patient education materials are a vital part of any cancer healthcare setting. Patient education materials, such as brochures, can assist in managing patient expectations by navigating them through their disease and treatment and providing additional resources. Processing the new and sometimes frightening information of a cancer diagnosis is a complex task for pediatric patients and their families. When a pediatric patient is diagnosed with cancer, much of the information about their disease is filtered through a parent or legal guardian, often without consideration of what the patient wants to know. In 1993, Ellis and Leventhal<sup>1</sup> found that of 50 patients with cancer ages 8–17, 76% of the children wanted to be told their chance for a cure while only 38% of parents wanted them to know this information. This suggests that pediatric patients may not receive all their disease and treatment information if relying solely on parents.<sup>1</sup> Additionally, patient educational materials are often written by healthcare providers or

professional design companies and may miss important patient or family informational needs.<sup>2</sup>

A new movement in creating education materials like brochures is to involve the patients in the design and development through patient-centered approaches such as social marketing. Through the use of focus groups or interviews, patients and families can provide input on specific issues. Using a social marketing approach, patients become the teachers and lend their voice to address unmet needs which makes education more effective.<sup>3</sup> Involving patients in the development of education materials improves the quality of existing and future services, empowers the patient to ask questions, and minimizes distress by managing patient expectations.<sup>3</sup> Multiple studies show patient-focused education materials have led to improved clinical outcomes.<sup>4</sup> Social marketing is the application of commercial marketing techniques toward the development of interventions that promote voluntary behavior change. It was originally developed in business fields to sell products, but health education research has recognized the value of this approach in designing interventions specifically for a targeted audience. Social marketing in health education relies on the "4 P's" to promote behavior change. The first "P" – *product* – refers to the behavior change. The product is the identification of the

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behavior and the change that needs to be promoted. In this study the product is the goal of informing patients and families about potential loss of fertility and preservation options. The second “P” is *price*, which refers to the actual monetary or emotional cost respondents are subjected to in order to obtain or utilize the product. In this context, “price” are the barriers to knowledge and behavior change. The third “P” is *place*, referring to the physical environment or emotional mindset the targeted audience may be in where the product would be delivered or received. For example, social marketers consider that the best place is when people are in the right frame of mind to receive the information or the product. Finally, the fourth “P”, *promotion*, is the best marketing channel for delivering the product or health information that is offered to the audience to promote behavior change. Despite the recent value placed on patient education materials created by patients, it is rare to find these education materials within the pediatric oncology setting, especially any designed utilizing this systematic approach.

An emerging concern impacting survivors of childhood cancer is infertility due to cancer or its treatment. This can have long-term consequences as survivors of childhood cancer report lower marriage rates,<sup>5–8</sup> as well as a fear of rejection from partners that prevents them from disclosing their fertility status.<sup>9</sup> However, established and experimental options exist to help preserve the patient’s fertility before treatment begins, even within the pediatric population.

Brochures have been a preferred method of obtaining information due to their convenience and availability.<sup>10,11</sup> Brochures are designed not only to answer patient’s questions, but also to stimulate new questions. However, criticisms of brochures have included the use of medical jargon and high literacy level.<sup>11</sup> Fertility issues within pediatric oncology are a relatively new area, and so there are few patient education materials containing this information and they are not distributed in a standard manner. Barriers to discussing fertility with pediatric patients include ethical concerns about offering experimental fertility procedures to minors, parent receptiveness, physician awareness, lack of role awareness, and perceived patient receptiveness.<sup>12</sup>

To overcome these barriers, the research team took an innovative social marketing approach to develop fertility preservation (FP) brochures for pediatric oncology patients at a local children’s hospital. These brochures introduce FP, educate about FP options, answer questions or concerns about FP, and provide local resources for FP.

## Materials and Methods

The need for a pediatric FP brochure was identified through a local children’s hospital that had been progressively implementing fertility-related interventions for oncology patients. With the onset of new programs and studies, it was clear that many patients had never thought about cancer-related infertility. The majority of available brochures on FP were designed by and for adults, so they are not appropriate for pediatric patients. The research team reviewed available literature and existing brochures from

Moffitt Cancer Center, Fertile Hope, and the Oncofertility Consortium, and designed a preliminary brochure outlining cancer related infertility and the options available for pediatrics. Due to the vast differences between female and male fertility issues and options, a separate male and female brochure was developed.

## Participant Recruitment

Three feedback groups were recruited: Oncology patients and survivors (age 12–21), parents, and healthcare providers (HP). This study was approved by the institutional review boards at the University of South Florida and All Children’s Hospital; however, no identifying information was collected, therefore a waiver of informed consent was obtained.

The Children’s Cancer Center (CCC), a local non-profit that provides educational, emotional, and financial assistance to families dealing with pediatric cancer, was utilized as a recruitment site. Feedback groups with teens and parents were held during an open house.

For the HP feedback group, participants were recruited from All Children’s Hospital and University of South Florida In Vitro Fertilization clinic during staff meetings. HPs included reproductive endocrinologists(REI), pediatric oncologists, and nurses, recruited to assess the accuracy of the brochure’s content and to provide their perceptions of the tone and messages.

## Feedback Groups

Two tables were set up during the open house in separate rooms. Each table was managed by gender concordant moderators, one for each table. Moderators received prior training during qualitative data seminars and mock focus groups. Moderators solicited parents’ and teens’ input separately to provide feedback on the gender appropriate brochure. Parents of female teens first provided feedback for the female brochures, then the parents exited the room and the female teen feedback group was held. The same process was used for the male brochures, and each group lasted approximately 20 minutes. Each moderator utilized a semi-structured interview guide created by the research team that included questions about specific design features of the brochure and comprehension of the language. Prompting questions were included such as, ‘Which design would you be more likely to pick up?’ and ‘Would you like to see less or more medical language?’ For the HPs feedback group, all four brochures were distributed during morning rounds, and one moderator was present who also utilized the semi-structure interview guide. All participants were also asked to offer suggestions for improvement. Each participant completed a general demographic form.

## Data Collection

Each table at the CCC contained multiple copies of the brochure so that teens and parents could write comments; additionally the moderator took hand-written notes. Verbal responses were recorded by one moderator. After feedback

was obtained, participants completed the demographic form and selected a prize from a grab bag.

HPs gave oral and written comments on all versions of the brochures and provided feedback on effective strategies for distribution. One moderator attended this meeting and took handwritten notes of responses. All participants filled out a demographic form specific to healthcare staff and experience.

### Data Analysis

Three members of the research team (G.Q., K.S., and D.M.) reviewed the moderator notes and written comments on brochures. Hand coding techniques were utilized to delineate common patterns among each group and overall observations. A priori codes from the moderator guides were abstracted from the field notes, and the constant comparative method allowed for codes to be categorized and aggregated into patterns of feedback on the design, content, and concerns. Similar patterns were collapsed into classifications. The resulting 6 classifications include: female teens, male teens, parents of female teens, parents of male teens, HPs' feedback for females, and HPs' feedback for males.

Statistical tests to determine the grade comprehension level of the brochures, the Flesch-Kincaid Reading Level test (FKRL) and the Automated Readability Index (ARI), were performed. The Flesch Reading Ease test (FRE) to determine readability by counting average number of syllables and words per sentence was also performed. Scores of high readability from the FRE typically fall between 60–70.<sup>14</sup>

### Results

Demographic data on all three groups are shown in Table 1. Utilizing a convenience sample of families who presented at the CCC's open house, 11 parents and 7 teens participated. Convenience sampling was also used to obtain HP feedback during regularly scheduled morning rounds, wherein 6 HPs participated. We determined saturation was reached when no new information emerged during each feedback group; therefore, no additional groups were required. Main patterns were classified by design, content comprehension, and concerns. All direct quotes can be found in Table 2.

#### Design

##### Female Brochure

All female teens and parents preferred brochure version 1. Parents wanted to simplify the design as well as including shorter links on the resource page. One father suggested the resources listed on the back be moved to the front as he missed reading them until the moderator pointed it out. See Tables 1 and 2.

##### Male Brochure

There were differences between male teens and their parents regarding the design of the two brochures. The majority of parents preferred version 2, while the majority of male teens preferred version 1. Male teens felt the font of both versions was easy to read, despite some parents remarking the brochures were not easy to read.

**Table 1**  
Sociodemographic Characteristics of Participants

	n/N (%)
PARENTS (N = 11)	
Mothers	9/11 (82)
Hispanic	2/11 (18)
White	9/11 (82)
Single or never married	1/11 (9)
Married	10/11 (91)
High school graduate, or GED	5/11 (45)
Some college	4/11 (36)
College graduate or beyond	2/11 (18)
Catholic	4/11 (36)
Protestant	6/11 (55)
Has Health Insurance	9/11 (82)
Asked Oncologist about Fertility	3/11 (27)
HEALTHCARE PROVIDERS (N=6)	
Hispanic	1/6 (17)
White	5/6 (83)
Reproductive Endocrinologist (MD)	2/6 (33)
Pediatric Oncology Nurse (RN)	1/6 (17)
Pediatric Oncologist (MD)	2/6 (33)
Pediatric Oncology Practitioner (ARNP)	1/6 (17)
Catholic	2/6 (33)
Protestant	3/6 (50)
Ashkenazi Jewish	1/6 (17)
Practiced 4–6 Yrs	1/6 (17)
Practiced 8+ Yrs	5/6 (83)
TEENS (N = 7)	
Female	4/7 (57)
Hispanic	1/7 (14)
White	6/7 (86)
6 <sup>th</sup> to 8 <sup>th</sup> grade	2/7 (29)
9 <sup>th</sup> to 10 <sup>th</sup> grade	3/7 (43)
11 <sup>th</sup> to 12 <sup>th</sup> grade	1/7 (14)
Some college/Tech School	1/7 (14)
Catholic	2/7 (29)
Protestant	4/7 (57)
Other	1/7 (14)
Have health insurance (under parents)	5/6 (83)
Type of Cancer	
Brain Tumor	1/7 (14)
Papillary Thyroid	1/7 (14)
Neurofibromatosis	1/7 (14)
Synovial Cell Sarcoma	1/7 (14)
Lymphoma	1/7 (14)
Other	2/7 (29)
Off Treatment 0–2 Yrs	2/7 (29)
Off Treatment 2–4 Yrs	2/7 (29)
Off Treatment 5–7 Yrs	1/7 (14)
Off Treatment 9+ Yrs	1/7 (14)
Currently on Treatment	1/7 (14)

#### Overall Design

There was a split preference on designs of both brochures. HPs felt that the overall design should be simplified to look 'more exciting' and less 'for adults.' Some felt the section containing established versus experimental methods of FP should be removed to free up space and simply state that established and experimental methods of FP are available.

#### Content

##### Female Brochure

The majority of discrepancies between parents and teens were about the content of the brochures. All parents felt there was too much information provided, and that the language was too advanced. However, the majority of teen girls said they preferred to see medical terminology and

**Table 2**  
Direct Quotes from Feedback Groups

	Parent	Teen
Design: Female	"Version 2 is too busy." "Change the cover to say 'A Person's Guide,' or 'A Family's Guide.'"	"Version 2 is outdated." "The outside of version 1 is easier to read."
Design: Male	"This blue brochure is way too girly for my son; he would never pick that up." "Version 1 of the brochure is not even readable." "The design on the inside needs to be more child-friendly."	"Version 1 is more attractive." "I think Version 1 is more appealing."
Content: Female	"This is too much information." "The language is too complex. I'd be concerned that my daughter would shut down." "There should be financial information and assistance on the brochure." "There should be separate brochures for parents and teens."	"I understand and like the amount of information in there." "I understand this. I already knew about the side effects from cancer treatment." "Younger girls may need help reading it."
Content: Male	"Information seems slightly advanced. It should be more age appropriate." "The language should be more kid friendly." "A bit overwhelming but the amount of information is appropriate." "Teens won't understand 'starting puberty.'"	"The terminology is appropriate." "I understand it. I've already learned a lot from my doctor and health class." "All the information inside is necessary." "Good information overall. Very informative." "I would rather read this with my parents." "I would definitely read this if someone gave it to me, but I might not pick it up on my own, especially if my parents were with me."
Concerns: Female	"If I put my daughter through this invasive procedure would it even pay off?" "If she is meant to have children, God will protect her." "Would I have to delay my daughter's treatment in order to undergo FP?" "Are these options relevant to my daughter considering her age?" "I would not pick this up on my own if it was left in a waiting room." "I'd like the doctor to give me the brochure before treatment begins, or in the packet the Dr. gives you."	"I would prefer to read this alone." "I'd need this before my original treatment begins."
Concerns: Male	"I don't think I'd let my son read this. I don't think it applies to his diagnosis." "Now this makes me think about his (fertility) status and I'm a little concerned."	

that they understood it. Suggestions for improvement from parents were to include information on financial assistance for fertility preservation, and information on adoption for survivors. One parent wanted to see a personal story or quote from a survivor who had had a child after cancer.

#### Male Brochure

There was a distinct split between parents and their feedback on the content. Half of the parents thought the information provided was appropriate, while half of the parents said many teens may not understand and may find these options 'overwhelming.' Parents commented that some content may be confusing such as the concept of puberty. One parent remarked that whether or not the terminology is understood will depend on the age group. Another parent requested that an FP option, electroperm ejaculation, be removed. Similarly to the girls' parents, boys' parents also wanted to see financial information. Other suggestions included adding counselors and adoption agencies that do not discriminate against cancer survivors as resources on the back. Many parents suggested repeating that FP should be done prior to treatment.

The majority of male teens disagreed with their parents regarding the content and said that they want to see the medical terminology. Many of the parents' concerns such as adoption resources, and the options being overwhelming, were not a concern to the male teens. Further, the majority of males said they would rather read the brochure alone and ask their parents or doctor if they had questions or wanted more information.

#### Overall Content

Only one inaccuracy was noted on the brochure: radical trachelectomy is not generally performed in pediatrics and thus it was recommended to be removed. The majority of HPs expressed the need to revise the content to be more,

'optimistic,' 'hopeful,' and stressing a return to 'normalcy after cancer.' HPs explained that the brochure needs to stress the incredible progress and technological advances in this emerging field so that patients and families can feel empowered to take control over their lives. The majority said the brochure should encourage scheduling a consultation with a reproductive endocrinologist to learn the risk and benefits of each option.

#### Concerns

##### Female Brochure

Female teens did not express any concerns; however, all parents had concerns. Some parents said they were concerned about FP because they were unsure of the success rate. Others were concerned that not all the options presented in the brochure were relevant to their daughter's age or diagnosis, so they were unsure if the brochure was applicable to them.

Parents differed on how they would like to receive this brochure; in clinic waiting rooms versus included in new patient materials. Female teens commented they would most likely read the brochure with their parents and discuss afterwards.

##### Male Brochure

Male teens did not have any concerns; however, their parents voiced several issues. The brochure tended to make parents think about their son's fertility status, and weren't sure if the options applied to them. There was no consensus on methods of delivery as half of the parents preferred to have the brochures in a clinic waiting room so they could review the information and then discuss it with their doctor during the appointment. The other half preferred to be personally handed the information immediately after their son was diagnosed with cancer. Male teens did not indicate

they had a preference of where the brochure was delivered, as long as they received it prior to treatment.

#### Overall Concerns

The majority of HPs indicated the final version of the brochure should emphasize the importance of talking with a reproductive endocrinologist, either over the phone or in person, to assess each patient's specific situation. Some HPs were concerned that many families are living 'day to day,' and this brochure should encourage them to think about the future. The majority were concerned that the information provided was not presented in a captivating, exciting design format to solicit future REI consultations. Based on their experiences, reproductive endocrinologists said that even after initial consultations with patients, barriers that prevent uptake of FP still exist and are not addressed on the brochures. These barriers include parents' assumptions that FP will delay their child's treatment, FP medications and procedures will accelerate cancer growth or impair treatment, or that FP is only for males. The brochure should be a primer to address these concerns prior to the initial consultation.

#### Revisions

After reviewing the feedback from all three groups, the research team revised both brochures based on majority feedback and feasibility (Figs. 1 and 2). Table 3 summarizes the changes that were made.

#### Discussion

It was not possible to make every change suggested during the feedback groups; therefore the research team made revisions that would increase knowledge, likelihood of reading, and reduce barriers to learning more about fertility and preservation options. For example, teens and parents differed on preferences to have medical terminology included. Because parents are the primary gatekeepers of information for their child, it is important to address their concerns to increase the likelihood of educational materials being distributed to the child, while maintaining the brochure's ability to 'speak' directly to the teen. When patients receive materials that are concise and in a language they understand, they are better prepared to manage their expectations because many late effects, such as loss of fertility, happen when the patient is no longer under care of their oncologist.<sup>13</sup>

Some parents and HPs suggested making different brochures for parents and teens. This was most likely due to the concern that teens would not comprehend the language used to describe available FP options. The research team decided that having two different brochures would limit the information teens received and reported in the feedback groups that they wanted. Additionally, it was decided that creating one brochure would encourage reading together and facilitate dialogue.

Both brochures were analyzed using standard readability tests. Both the male and female brochure scored a 61.4 FRE,

demonstrating they are easily readable by the intended audience. Further, using the FKRL, both brochures are readable at grade 10, and at grade 9.7 using the ARI. We acknowledge that this grade level will be higher than the actual grade levels of many patients this brochure is intended for. However, this is an important finding as the majority of teens remarked that they liked being provided medical terminology. This may indicate that teens with cancer have higher health literacy than teens without cancer, or that even if the specific terms aren't understandable, teens with cancer desire all the information available about their options.

Adoption was also recommended to be included in the list of resources; however, the list continued to include websites that provided a multitude of family building options including adoption. It was not feasible to include specific cancer-friendly adoption agencies due to the variety that are available publicly and privately. Some agencies require a clearance from the physician stating the survivor is healthy enough to adopt.<sup>15</sup> Due to this limitation, general resources were provided to families that allow them to explore what option would be best for them.

Further discrepancies emerged involving the preferred ways of reading these brochures. Female teens were more likely to prefer reading the brochure with their parents, while male teens were more likely to prefer reading the brochure alone. This coincides with research indicating that many males prefer to have discussions about sperm banking without their parents present, as well as make the final decision to sperm bank on their own.<sup>16,17</sup>

Other studies have shown the disconnect between parents and teens regarding FP. Even physicians have disagreed on whether fertility should be discussed with teenage oncology patients due to their own discomfort, lack of knowledge of options, and values placed on fertility.<sup>12,18,19</sup> Pediatric oncologists have also commented they preferred to have a discussion regarding FP without the parent present. Parents frequently misjudged the maturity level of their child, believing that they could not fully comprehend information about fertility,<sup>16</sup> which was similar to the findings in the feedback groups.

The research team had unique challenges to make the brochure informative and appealing to both parent and teen, to increase awareness and facilitate discussion of fertility during a time of family crisis. The brochures are also intended to alleviate burden on hospital staff to initiate these discussions and to gauge whether the family is amenable to discussion. These revisions allowed the brochure to follow principles of best practice design by using one font, short sentences of no more than 15 words, and placing information in 'chunks.'<sup>20,21</sup>

This study has some limitations. The small sample size in this qualitative work limits generalizability. Furthermore, patients, survivors, and their parents who participated in providing feedback already received a cancer diagnosis and had had treatment; therefore, their feedback may not specifically reflect the thoughts and feelings of newly diagnosed patients.

The final version of the brochure created by patients, families, and providers will be distributed in clinics and

## A Version 1 Draft

## B Version 2 Draft



## C Final Revised Version



Fig. 1. Girls Brochure Draft and Final.

## A Version 1 Draft

**USF IVF CLINIC TAMPA, FL**

The USF IVF program offers a state-of-the-art Assisted Reproductive Technology Program for the Tampa Bay region, providing individualized, comprehensive infertility and reproductive endocrine care.

USF IVF has offices in North Tampa, South Tampa, Sarasota, and Lakeland.

With more than \$100.4 million in research grants and contracts last year, the University of South Florida is one of the nation's top 60 public research universities and one of only 25 public research universities nationwide with very high research activity that is designated as cancer-related by the Carnegie Foundation for the Advancement of Teaching.

**RESOURCES**

USF IVF  
13330 USF Laurel Dr.  
Tampa, FL 33612  
813-259-0692  
<http://health.usf.edu/ivf/medinfo/ivfinfo/>

Fertility Hope  
866-945-7205  
[www.fertilityhope.org](http://www.fertilityhope.org)

American Society for Reproductive Medicine  
205-978-5000  
[www.asrm.org](http://www.asrm.org)

OncoFertility Consortium  
312-503-2378  
[www.oncofertility.net/eastern.edu](http://www.oncofertility.net/eastern.edu)

**A young person's guide to CANCER & FERTILITY**

**HOW CAN MY CANCER TREATMENT AFFECT MY FUTURE?**

A diagnosis of cancer brings a lot of changes very quickly. You may start hearing words like "chemotherapy," or "radiation." Your doctor will go over common side effects from your cancer treatment and one of those side effects may be struggles with "fertility," or being able to have children naturally.

**Chemotherapy** can lower the amount of sperm you produce, or could make it difficult to fertilize an egg. Think of it as being "less physically fit" than normal.

**Radiation** is high-energy rays used to damage genes of cancer cells, however it can't tell the difference between cancer cells and healthy cells. It can damage sperm production temporarily or permanently.

**Surgery** may be necessary to remove part of the reproductive system which can make it difficult or not possible to have biological children in the future.

**Fertility Preservation** means the efforts involved in trying to keep the ability to have children biologically.

Not all treatments will cause fertility problems. Age, type of drugs, amount of drugs received, and if you had radiation, then location can also increase risk of having fertility problems.

**IF YOU HAVEN'T STARTED PUBERTY...**

Even if you haven't started puberty, there are still fertility preservation options you can discuss with your doctor.

There are established method like:

- Radiation shielding of the gonads

And experimental method like:

- Testicular Tissue Freezing

**OTHER OPTIONS TO CONSIDER**

- Donor Sperm
- Adoption
- Child-free living

It is important to discuss with your health care provider the risks and side effects associated with cancer treatment before it begins. The USF IVF clinic can answer questions and discuss fertility preservation options with you.

**IF YOU HAVE STARTED PUBERTY...**

If you've already started puberty, then there are options you can discuss with your doctor.

There are established method like:

- Sperm Banking
- Testicular Sperm Extraction
- Radiation shielding of the gonads

And experimental method like:

- Testicular Tissue Freezing
- Electroejaculation

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## B Version 2 Draft

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Fertility Hope  
866-945-7205  
[www.fertilityhope.org](http://www.fertilityhope.org)

American Society for Reproductive Medicine  
205-978-5000  
[www.asrm.org](http://www.asrm.org)

OncoFertility Consortium  
312-503-2378  
[www.oncofertility.net/eastern.edu](http://www.oncofertility.net/eastern.edu)

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It is important to discuss with your health care provider the risks and side effects associated with cancer treatment before it begins. The USF IVF clinic can answer questions and discuss fertility preservation options with you.

## C Final Revised Version

Let's face it, cancer is scary. Your doctor will go over common side effects from your cancer treatment, and one of those side effects may be problems with fertility.

Because everyone is different, talk to your oncologist and reproductive endocrinologist (REI) about your specific situation. You will get through this. It is important to think about life after cancer.

**Do I have to delay treatment?**  
In many cases no.

**Will fertility preservation impact my cancer and/or the treatment I'm getting?**  
It will not affect your cancer or your treatment.

**Do I have to talk to a specialist?**  
You will unless you're a pediatrician.

**REPRODUCTIVE ENDOCRINOLOGIST (REI):**  
A TRAINED IN REPRODUCTIVE MEDICINE ADDRESSING HORMONAL FUNCTION, INFERTILITY AND FERTILITY

**RESOURCES**

USF IVF  
Male and female fertility preservation counseling and treatment  
13330 USF Laurel Drive  
Tampa, FL 33612  
813-259-0692  
<http://health.usf.edu/ivf/medinfo/ivfinfo/>

Resolve: National Infertility Association  
<http://www.resolve.org/family-building-options>

Fertility Hope  
[www.fertilityhope.org](http://www.fertilityhope.org)

American Society for Reproductive Medicine  
[www.asrm.org](http://www.asrm.org)

OncoFertility Consortium  
[www.oncofertility.net/eastern.edu](http://www.oncofertility.net/eastern.edu)

Children's Hospital  
501 6th Avenue South  
St. Petersburg, FL 33701  
1-800-456-4543  
[www.allkids.org](http://www.allkids.org)

**A GUIDE TO CANCER & FERTILITY**

**FOR MALE PEDIATRIC PATIENTS**

**FERTILITY: THE ABILITY TO HAVE CHILDREN NATURALLY**

What is Fertility Preservation?  
Fertility preservation is an effort to try to keep the ability to have biological children.

Can my cancer treatment affect my future fertility?  
Chemotherapy, radiation and surgery may cause damage to sperm, making it difficult or not possible to have biological children in the future.

**YOU HAVE OPTIONS!**

Fertility preservation is a fast-paced field with new technologies and research emerging all the time. It is safe and exciting to offer this technology to you!

**ESTABLISHED METHODS:**

- Sperm banking
- Testicular sperm extraction
- Radiation shielding of testicles

**EXPERIMENTAL METHODS:**

- Testicular tissue freezing
- Electroejaculation
- Hormonal manipulation

**FAMILY BUILDING OPTIONS:**

- Donor Sperm
- Adoption
- Child-free living

Fig. 2. Boys Brochure Draft and Final.

**Table 3**  
Summary of Brochure Changes

Draft Brochure	Final Brochure
Repeating pattern and multiple text boxes inside	Background design taken out. Text condensed to individual bubbles.
Information explaining treatment's possible impact on fertility as well as formal names for FP options	Retained medical terminology; however, revised the rest of the text to be simpler. Language was also revised to stress the optimism in emerging FP technology.
Educational information provided and did not encourage making a consultation with an REI	Parent's concerns were put in question form on the opening flap of the brochure so that they can be alleviated prior to reading the material. In multiple places the brochure encourages discussing specific options with an REI, as well as stressing the need to think about the future.

included in new patient education materials to all patients diagnosed with cancer at All Children's Hospital. Follow-up will be maintained to determine if the brochures prompted an increase in REI consultations and uptake of FP options, elicit impressions from families, and determine which method of distribution worked most effectively.

## Conclusion

The social marketing approach to developing a pediatric fertility preservation brochure can be modeled in other institutions. Determining the 4 P's was paramount to its successful development. The product in this case is the feedback obtained from patients, parents, and healthcare providers that we used to revise the brochure. Price refers to the barriers identified that would prevent comprehension, seeking more information, and initially being provided the brochure to read. It was important to consider the emotional place the patients and families were in at the time of reviewing the brochure versus the emotional place patients will be in upon receiving the brochure in a clinical setting. Finally, determining promotion highlighted the preference for a brochure to deliver information about fertility and fertility preservation options; however, it also highlighted differences in preferred reading environments. The emergence of the social marketing approach to develop patient education materials will benefit patients and

survivors through empowerment and informed choices in order to minimize future distress.

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