

Fall 1-1-2016

# The Ethical Analysis of the Connection between Hope and Fertility Preservation

Leah Jeunette

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THE ETHICAL ANALYSIS OF THE CONNECTION  
BETWEEN HOPE AND FERTILITY PRESERVATION

A Dissertation

Submitted to the McAnulty Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for  
the degree of Doctor of Philosophy

By

Leah Jeunette

December 2016

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2016

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BETWEEN HOPE AND FERTILITY PRESERVATION

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Approved November 10, 2016

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## ABSTRACT

### THE ETHICAL ANALYSIS OF THE CONNECTION BETWEEN HOPE AND FERTILITY PRESERVATION

By

Leah Jeunnette

December 2016

Dissertation supervised by Dr. Henk ten Have

Fertility preservation has many different indications and covers a wide variety of demographics. One major motivation for the use of fertility preservation is hope. When discussing fertility preservation, healthcare professionals present several options, but choosing which type of fertility preservation to pursue is a difficult decision. This dissertation will argue not only that hope is one of the basic drivers for making a decision regarding fertility preservation, but also the current methods for fertility preservation create a reliance on hope. Hope can determine if a patient chooses the safest option or seeks out more radical experimentation or whether to delay cancer treatment in order to seek fertility preservation. The role of hope in medicine has been researched for a long time. Although there have been studies aiming to understand the relation between hope, survival and recovery, the role of hope in fertility preservation is not well explored. This

dissertation will argue that fertility preservation can benefit from better appreciating the role of hope. Fertility preservation should take the dependence on hope seriously, but still be concerned that while promoting hope it does not create a false expectation. The aim of the dissertation is to ethically examine the connection between fertility preservation and hope.

## DEDICATION

To my father and mother, Douglas and Joan Jeunnette. I could not have done any of this without your prayers, encouragement, love, insight, support, and laughter. I love you both so much and am thankful for you every single day. You helped shape me into the person that I am and appreciate all the love and wisdom you have shared with me in this process and in my life. Thank you.

## ACKNOWLEDGEMENT

I want to acknowledge the support of my advisor Dr. ten Have. Thank you for your patience through this process. To Kellee Flatt, Alyssa Luteran, and Dee Johnson, you have been my encouragers and prayer warriors from day one. Thank you for loving me even when I was stressed and overwhelmed. Thank you to my family and friends who have prayed for several years as I have worked through this process. Please know that I could not have done this without your encouragement.



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## **Chapter One: Introduction**

### **I. Introduction**

Fertility preservation places hope in a future outcome for patients. While patients would not want to be at risk of infertility on purpose, sometimes it is unavoidable when patients are diagnosed with cancer and other serious diseases. The advancements in medicine including new techniques and technology, allows patients to not just survive disease for a short time, but to potentially live long, healthy lives. In order to seek a better outcome, aggressive treatments are pursued, but they also bring serious side effects including the risk for infertility or sterility. Precautions are taken, but not all risk for infertility or sterility can be eliminated. Many patients turn to fertility preservation to prevent this.

By having access to aggressive treatments, hope is fostered not only to beat serious diseases like cancer; but also the potential for a future pregnancy through the cryopreservation of gametes and tissues. By providing these possible cryopreservation options, hope is fostered not just in these specific treatments, but also for medicine in general. When patients experience successful treatments for difficult cases, patients may have a greater expectation for medicine to perform miracles in the future. It is important that patients are not looking for a medical miracle in the far off distant future, but understand the current state of medicine and research. Patients need to maintain a realistic and authentic view of their current circumstances; otherwise, they are bordering on a false hope that could lead to disappointment.

In trying to maintain this realistic view, there is a multilayered list of concepts and considerations for fertility preservation. Bioethics should be present to ensure patients'

rights, and to critically examine the hope that patients have towards fertility preservation prior to any procedures. This dissertation seeks to ethically analyze the relationship between hope and fertility preservation by understanding the basic science of fertility preservation, examining the basic definition of hope, considering all the different factors that fertility preservation brings about including a short discussion on research and its impact on medicine. Additionally, this dissertation will discuss the fundamental ethical concepts of autonomy, beneficence, nonmaleficence, truth-telling, informed consent, and decision making. It will demonstrate that by addressing the ethical considerations prior to any procedures, authentic hope can be fostered in fertility preservation.

## **II. State of the Problem**

Fertility preservation has many different indications and covers a wide variety of demographics. However, what specifically drives someone to choose to preserve fertility? One major motivation for the use of fertility preservation is hope. When discussing fertility preservation, healthcare professionals present several options, but choosing which type of fertility preservation to pursue is a difficult and complex decision. This dissertation will argue not only that hope is one of the basic drivers for making a decision regarding fertility preservation, but also the current methods for fertility preservation create a reliance on hope, and that reliance needs to be addressed in a manner that does not exploit the vulnerable or miscommunication of hope.

Over the years, the different types of fertility preservation available have increased including the availability and access for both standard of care and new research protocols. This may be due to the more open discussion of fertility, more transparency in healthcare, or even the marketing and advertisement of options. Many of these new

research protocols seek for new ways to provide the means to preserve fertility with minimal risks, time, and effort. The range of options for fertility preservation is from standard protocols like sperm freezing to experimental research like ovarian transplantation. Fertility preservation is available for males and females, and from young children through adults. It is critical not to categorize all fertility preservation into a singular discussion because of the myriad of factors and possible scenarios and decisions that have to be made. For instance, fertility preservation should be addressed differently when dealing with prepubescent patients as opposed to adult patients. While prepubescent children have access to a few research protocols, adults have standard of care options available. One must be concerned not only from a general view on fertility preservation, but also from specific details dealing with the different types of availability, demographics, ages, or methods.

The problem is that communication and understanding can be difficult between healthcare professional and patients. Patients have a certain level of expectation for medicine and research, and sometimes, it is challenging for patients to grasp that research is not standard of care. While patients may benefit from the research, it is not a guarantee or to be expected. Patients have a base level of hope in what medicine and research can do. It is the job of the healthcare professionals to communicate all the available options, but patients may not understand the nuanced difference between standard of care and research, the different levels of risk, or even the success rate of specific options.

Additionally, it is also important for patients to understand the difference between current research studies and the potential future research studies.

### III. Methodology

This dissertation will argue that fertility preservation can benefit from better appreciating the role of hope. In other words, fertility preservation should take the dependence on hope seriously, but still be concerned that promoting hope does not create a false expectation. The aim of the dissertation is to ethically examine the connection between fertility preservation and hope.

The basis for hope pulls from philosophy and theology, and the field of psychology has spent significant time explaining and expressing hope. Hope can determine if a patient chooses the safest option or seeks out more radical experimentation. Hope can determine whether to delay cancer treatment in order to seek fertility preservation or to focus on only the disease. Hope can also force a patient to face mortality and consider the future. The role of hope in medicine has been discussed a great deal.<sup>1,2,3,4</sup> Although there have been studies aiming to understand the relation between hope, survival and recovery or hope and cancer, the role of hope in fertility preservation is not well explored.

By looking at fertility preservation not only from a general description, but also from through application, it allows hope to take a very specific part in the discussion of fertility preservation. Because fertility preservation includes both standards of care and research protocols, the analysis of hope and fertility preservation needs to consider both standard of care and research.

In order to make the decision of pursuing fertility preservation, patients much consider their own lives and those around them. This consideration includes how the patients envisioned their lives regarding their diagnosis and for the future of the lives in

general. Patients have to decide what future goals and values are most important while at the same time balancing the options for treatment for a diagnosis or delaying parenthood. This hope in the future makes the decision much more complex. It is critical to ethically analyze the advantages and disadvantages of the reliance on hope in fertility preservation. By doing so, it can prevent the creation of false hope and give patients a more realistic understanding of their future, rather than the hope of an ideal future.

For the current methods of fertility preservation, many ethical principles are invoked- such as informed consent, protection of the vulnerable and best interest in surrogate decision making. Therefore, it is important to review these elements in light of the understanding of the reliance of hope in fertility preservation. By doing so, one can better review the current approaches to fertility preservation and provide a better process and understanding for patients as they make decisions that are complex and difficult.

#### **IV. Chapter Summaries**

In order to analyze the connection between hope and fertility preservation, it is critical to look at all the different aspects and pieces contained. The history and science of reproductive technology leading to fertility preservation will be discussed, specifically how ethics has sought to address the many difficult changes in medicine. The concept of hope specifically pulling from philosophy and theology, but also has been discussed specifically in relation to healthcare and research and as such can be discussed with fertility preservation. By examining the ethical role of hope in its relation to fertility preservation, this dissertation will discuss why hope is different in this context as opposed to other areas of healthcare. An ethical analysis of the reliance on hope in fertility preservation will discuss what specific ethical concepts need to be considered in

relation to hope and will also develop a critical ethical analysis of the advantages and disadvantages of the reliance on hope in fertility preservation. Finally, there will be discussion for improving the current practice of addressing fertility preservation on the basis of the ethical assessment developed in the various chapters (e.g. in connection to informed consent, protection of the vulnerable, and research ethics.)

Chapter Two will focus on fertility preservation. The history and science of fertility preservation will be analyzed, specifically the historical advancements of science and its contribution to medicine. Whether preventing pregnancy or combating infertility, reproductive technology has progressed quickly. Medical research has proven that it continues to find innovative ways to push the expectations and the applications of technologies. Even though the technology has progressed, law and ethics often is playing catch up.<sup>5,6,7</sup> Bioethics has struggled to address the advancement of science in a timely manner.<sup>8,9,10</sup> Cryopreservation technology has expanded beyond sperm, embryo, and oocyte into research of cryopreservation of ovarian and testicular tissues.<sup>11,12,13,14,15</sup> This expansion of innovative cryopreservation has widen the ethical discussion to include new research protocols.<sup>16</sup> While fertility preservation is recommended for those who are at risk for infertility, either due to delaying pregnancy/ parenthood<sup>17,18</sup> or side effects of medical treatments like chemotherapy, there is no fool proof way to predict the risks of infertility.<sup>19,20,21,22,23,24,25</sup> Fertility preservation for delaying parenthood does not guarantee a successful pregnancy any more than infertility due to medical treatment or illness. Differences in gender, age, and socioeconomics of the patient population automatically limit the methods that patients have access to before the first conversation with a healthcare professional. This division highlights the bioethical issues of decision



making, procreative liberty, invasiveness of procedures including risk, affordability of cryopreservation, and even disparities for referral patterns in addition to other bioethical issues of moral status of embryos, viability, value of life, federal funding, and cost and insurance coverage. The healthcare professional needs to be open and honest to discuss what best fit the specific patient.<sup>26,27,28,29</sup> Understanding the standard of care and experimental options are just as important as understanding the possible demographic issues that a patient may be facing as they move forward with their highly personal decision.

Chapter Three seeks to analyze the concept of hope specifically pulling from philosophy and theology both describing the nature and characteristics.<sup>30</sup> In addition, it will detail the specifics of hope in relation to healthcare and research.<sup>31</sup> Hope can be discussed in two separate ways, first in existential terms and second in a personal narrative.<sup>32</sup> It is important to consider the effect of the personal narrative (biographical understanding) in any decision making. By finding key descriptions from the existential discussion, such as realistic possibility and the future, one can better dictate how hope is used within a personal narrative like fertility preservation. One of the biggest concerns regarding hope is ensuring authenticity and preventing false hope.<sup>33</sup> Authentic hope has been connected to trustworthiness and honesty.<sup>34</sup> False hope sets up an individual for disappointment so hope must be based in reality.<sup>35</sup> Within healthcare, hope is part of the patient-healthcare professional relationship and can demonstrate respect for autonomy and the prevention of exploitation of the vulnerable.<sup>36,37</sup> Without understanding how the individual is using the word hope, it is difficult to manage and to foster such a concept.

Chapter Four will examine the ethical role of hope in its relation to fertility preservation. It will discuss why hope is different in this context as opposed to other areas of healthcare. Though discussed in the abstract to start, both hope and fertility preservation are part of a personal narrative for patients. There are two key players involved when it comes to understanding the possibility of fertility preservation: the healthcare professional and patient and families. It is important to consider how hope is communicated in fertility preservation and what role hope plays in the interactions between patients and healthcare professionals in the decision making process. For patients, they are facing two separate decisions: the initial cryopreservation and the attempt to get pregnant in the future.<sup>38</sup> There is a responsibility of both the healthcare professional to thoroughly explain the truth and the realistic expectations of fertility preservation and the patient to maintain hope in a realistic, possible way in attempting to get pregnant.<sup>39</sup> There are specific aspects to the future including genetic offspring, grandparenthood, and research protocols that are a part of discussion for the future of patients. Since hope and fertility preservation both involve the discussion of realistic possibility and the future, it is tough to adequately maintain realistic hope.

Chapter Five will present an ethical analysis of the reliance on hope in fertility preservation. It will discuss what specific ethical concepts need to be considered in relation to hope. Ethical principles such as autonomy, beneficence, nonmaleficence, and justice are extensively discussed in ethical considerations of fertility preservation. Hope allows patients to look to the future, and because of the principle of autonomy seek out medicine to attempt a successful pregnancy after fertility preservation.<sup>40</sup> Beneficence and nonmaleficence are not just part of the short term decision, but also a part of the long-

term future decision.<sup>41,42,43</sup> Standard of care and research protocols for fertility preservation should be made more readily available to promote justice.<sup>44</sup> Informed consent, truth-telling and decision making directly connects to how hope is fostered in fertility preservation. Because fertility preservation affects many different demographics and offer different methods to each, informed consent needs to be adequately addressed. Truth-telling can potentially promote or dampen hope depending on the information and how it is presented.<sup>45,46</sup> By fostering hope in fertility preservation, patients have sense of control to direct their own care, provides optimism which can effect outcomes, and build into the survivorship approach to disease. Patients can exert their autonomy, and work with a trust-worthy healthcare professional throughout the entire process.<sup>47,48</sup> While there are advantages to fostering hope in fertility preservation, there are also disadvantages. This can include false expectations and projection of the future of science, and trying to manage the involvement of parents and partners of the patients. By better understanding the ethical principles and concepts at play, hope is better managed.

Chapter Six will provide elements for improving the current practice on the basis of the ethical assessment developed in the previous chapter. There are several programs and advocacy groups that address fertility preservation, but most are aimed at providing information, not processing decisions or the role that hope has over these decision plays. These programs and guidelines should encourage the advantages and discouraging the disadvantages in fostering hope in fertility preservation. These groups provide expertise for the science, but must also take into consideration the expectations and hope that is established because of that science. By identifying commonality in fertility preservation programs and advocacy group guidelines, recommendations can be made on how to

approach fertility preservation while fostering authentic hope. Seeking fertility preservation does not necessarily make an individual vulnerable simply because of the future possibility of infertility. By trying to protect the potentially vulnerable, trust, honesty, and open communication can be established in all circumstances.<sup>49</sup> Clear, well-managed communication takes the routine information from a brochure or website into the practical, real life application of fertility preservation to a specific patient and applies their specific values and goals.<sup>50</sup> Bringing in an ethics consultation may provide an objective, non-threatening voice where a patient can be heard and respected while it provides an added layer to ensure understanding. Many oncofertility programs and guidelines focus on creating a multidisciplinary teams.<sup>51,52</sup> Including ethics to the table is crucial. An ethics consultation can help to eliminate conflict of interest concerns among healthcare professionals, and allows the patient to identify values and goal, not just for the disease, but also beyond into survivorship. The connection between hope and fertility preservation is present whether one acknowledges it or not. In order to protect patients, ethics can play a much larger role in communication with patients regarding fertility preservation.

Chapter Seven will be the conclusion of ethically examining the connection between fertility preservation and hope. The hope that fertility preservation fosters is based on the possibility to have children and on the realistic future of science in addition to the authentic relationship between the patient and healthcare professional involved. Fertility preservation covers a wide range of demographics creating a unique personal narrative for each person. Healthcare professionals need to refer patients to reproductive specialists in order to provide the best medical information, which will allow for truth-

telling and to manage the hope that fertility preservation may foster. Key discussions need to take place to address the common bioethical scenarios that a patient will face if and when they undergo fertility preservation. Fertility preservation will continue to foster hope as long as patients are at risk for infertility either by disease or delay in parenthood and even if current research protocols become standard of care, new research studies will be created. By fostering hope, patients are able to see beyond their circumstances and into the future for a realistic positive outcome.

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## Chapter Two: Fertility Preservation

### I. Introduction

In order to better understand the connection between hope and fertility preservation, it is important to understand what fertility preservation is and who it affects. Fertility preservation is a medical breakthrough category that has taken its cue from other reproductive technologies some of which are no longer used, while others that still remain in use today. Many developments in reproductive technology have greatly influenced the approaches for fertility preservation. For instance, the medical breakthrough of in vitro fertilization eventually leads to the ability to cryopreserve embryos. This influence of developing technology has led to many different types of fertility preservation and the continued push to develop new research protocols and better understanding of the human body and its development. The types of fertility preservation vary from standard of care including sperm, embryo, and oocyte cryopreservation to research protocols, including ovarian and testicular tissue cryopreservation, and ovarian transposition.<sup>1,2</sup> While there are differing options for the types of fertility preservation, the availability relies heavily on the demographic information of the patient including gender and age. These nuanced differences of the methods and patient demographics can affect the connection of fertility preservation to hope.

The struggle for bioethics with any type of technology is trying to keep the conversation current with the technology. For many, reproductive technology creates an even greater need for bioethics, because reproductive technology can be quite controversial. Ethical discussions including defining the beginning and intrinsic value of life,<sup>3</sup> moral status of embryos, the right to reproduce<sup>4,5</sup>, issues of access to reproductive



technology, federal funding of research involving controversial materials like embryos or fetal materials from abortion,<sup>6</sup> the cost for reproductive technology,<sup>7</sup> and the discussion of insurance coverage for reproductive technology.<sup>8</sup> While fertility preservation has its own unique spin on each of the major ethical issues, it takes its cue from past discussions and variety of the demographics of patients also affects the ethical discussion.

The demographics of patients heavily affect the discussion of fertility preservation. Demographic differences including gender, age, and socioeconomic affect the type of fertility preservation available. Therefore, fertility preservation cannot be a one size fits all discussion. The discussion must consider the specifics of the context including gender, age, and socioeconomics of the patients as well as the availability of standard of care and research protocols.

## **II. General History of Reproductive Technology**

Whether it is preventing pregnancy via birth control or restoring fertility through artificial reproductive technology, history is filled with old wives tales, research studies, experimental medicine, and proven scientific methodologies dealing with reproduction. The idea of trying to procreate or preventing procreation has long been a focus of medical research. Even the standard of care for reproductive technology has drastically changed. Each of these new technologies influences other methods of reproductive technology. As reproductive technology has developed, new protocols and uses for those technologies are continuing to be introduced. Major breakthroughs in the attempts to get pregnant include in vitro fertilization, cryopreservation of gametes, and most recently uterine transplants. In addition, responses to the reproductive technology have changed. In the last 50 years, fertility preservation has been pushing reproductive technology forward and

because of that push, ethics often has to play catch up.<sup>9</sup> Ethical issues such as the intrinsic value of life, moral status of embryos and viability, procreative liberty (including bodily self-determination), access to reproductive technology, federal funding for controversial materials, and the cost and insurance coverage for reproductive technology all affect not only fertility preservation, but also other reproductive technologies.

#### A. *Major Breakthroughs*

Reproductive technology has progressed quickly in recent decades. Because of these major breakthroughs like in vitro fertilization and cryopreservation, science and medicine has proven that it continues to find new technologies and push the boundaries expectations and the applications of such technologies have also widened.<sup>10</sup> In vitro fertilization started as a procedure in order to immediately attempt to get pregnant, but combined with cryopreservation, women can attempt to get pregnant at a later date. Sperm, embryos, oocyte, and now ovarian and testicular tissue are all being cryopreserved to aid in fertility at a later date.<sup>11,12,13</sup> However, ovarian and testicular cryopreservation remains experimental and are being improved with research studies. The eventual goal is transplanting these tissues back into the patients at a later date to allow for natural pregnancy.<sup>14</sup>

#### 1. Infertility

Infertility has long been an issue in many cultures. There are legends and stories all through history that focus on the inability to conceive. In both Christianity and Judaism, the story of Abraham and Sarah focused on their inability to have a son until they were well past child bearing age.<sup>15</sup> For many years, infertility was solely blamed on the women. Infertility has long been incorrectly associated with a women's inability to

fulfill her wifely duties and the social opinion that she was somehow less of a woman. In fact, infertility affects men just as often as women.<sup>16</sup> For men, infertility is most often based on sperm (semen) quality including size, motility, and morphology. For women, it includes both the quality of the oocytes as well as the health of the uterus. In some cases, infertility can be a result of both partners having issues. It may take some time in order to fully diagnosis a cause of infertility especially if there appears to be healthy people involved.

There are many different ways that infertility has been approached. Old wives tales detail the many different methods and techniques. Today, intrauterine insemination, in vitro fertilization, medication, and medical procedures like the removal of fibroids and endometrial tissue are all used to address various infertility issues. Fertility preservation however, addresses the potential of infertility (or sterility) ahead of time. Essentially, fertility preservation is a back-up in case someone does end up with infertility or sterility due to any number of causes.

## 2. In Vitro Fertilization

While Louise Brown may be known for being the first successful birth from in vitro fertilization in 1978, there are many years of research that went into this announcement. In vitro fertilization is a great example of how and why the purpose of medical research has added to the body of knowledge. Barry D. Bavister in his article, "Early history of *in vitro fertilization*", writes that the earliest development of in vitro fertilization can be traced by to 1878 with studies focusing on sperm capacitation.<sup>17</sup> As studies progressed, knowledge was gained about how to properly acquire and store sperm, hyperstimulate and retrieve oocytes, and how to properly introduce sperm and

oocyte together in a petri dish. It took decades of studies on animals before it was attempted in humans and even the first attempts were unsuccessful.

In the case of Louise Brown, this was not the first attempt at in vitro fertilization in a human; however, it was the first documented, successful attempt. For the Browns, having a child was a dream, but it also created vulnerability in their relationship.<sup>18</sup> Drs. Patrick Steptoe and Robert G. Edwards had never performed a successful in vitro fertilization before, but did not inform either Lesley or John Brown of this. In fact, it was 10 years between the first successful embryo fertilization until the first successful birth.<sup>19</sup> Because it was such a new procedure and newly successful, there were many concerns over the ethics of this procedure. Discussion from religious perspectives focused on the concept of souls and the use of artificial reproductive technology. Issues of informed consent were questioned especially knowing that the Browns were not informed of the risky nature of the procedure. Based upon earlier issues of informed consent due to studies like the Tuskegee Syphilis Study, there was a right to be skeptical and concerned about the importance of informed consent. Finally, there were discussions that focused on patient safety and the long-term survival and health of the baby. People wanted a guarantee that the baby would be healthy and normal as compared to spontaneous pregnancies. Guarantees like this can never be given in research, and to do so is irresponsible. Even today, while studies have shown that in vitro fertilization is safe and possess no additional risks compared to spontaneous pregnancies, there is not guarantee the health and safety of any pregnancy, live birth, and baby.<sup>20</sup>

At the time of the procedure, Lesley Brown was not informed that Drs. Steptoe and Edwards had never been successful with in vitro fertilization resulting in a live birth.

In fact, Lesley Brown admitted that she was unaware of the controversy of the procedure and even read news articles about herself during her pregnancy highlighting the controversies.<sup>21</sup> It is impossible to speculate as to what decisions would have been made if the Browns had known that the procedure had never been successful. However, history has demonstrated over and over the importance of informed consent for any and all participants- from the case of the Tuskegee Syphilis Study<sup>22</sup> to issues surrounding Henrietta Lacks Case.<sup>23</sup>

Because in vitro fertilization was new technology, many did not understand the nuances of what in vitro fertilization meant. There was speculation regarding the procedure, the safety to the mother and the fetus during pregnancy, and the long-term health effect of both. Today, in vitro fertilization has been shown to be an effective and safe procedure for both mother and fetus. The most successful in vitro fertilization rates are as high as 43% for those under age 35 and as low as 18% for those over age 41.<sup>24</sup> Long-term health of Louise Brown and her younger sister, Natalie (also produced via in vitro fertilization), has been long been established and both sisters have even given birth to children via natural means.<sup>25</sup> However at the time, no one knew exactly what risks of health the baby would have or if there were any long-term health effects- it was all purely speculative.

There were also concerns from a religious perspective. Some questions whether this baby produced would have a soul or whether this had the same value of life as those conceived naturally. It asked questions about whether or not it was acceptable to interfere with natural conception and God's will. Though the first case of in vitro fertilization took place in England, in the United States, right to life and discussions over

the start of human life were at an all-time high since *Roe v Wade* was ruled in 1973.<sup>26</sup>

Even today, the *Ethical and Religious Directives for Catholic Health Care Services* clarifies that procreation should not be attempted outside of sexual intercourse.<sup>27</sup> This means that artificial methods to conceive are not allowed by the Catholic Church.

According to Directive 4 medical research must also adhere to the other directives.<sup>28</sup>

While the Catholic Church is very specific on its stance, other religious groups leave more room for interpretation up to the individuals.

### 3. Cryopreservation

Cryopreservation has been a slow process with interest that depends on the need by society. The theory of cryopreservation has been discussed since as early as 1683. Robert Boyle wrote about the observations regarding death as a result of freezing and how meat is frozen as a means of preservation.<sup>29</sup> The major push for having successful cryopreservation for sperm was led by the farmers needing this technology for bull sperm. More specifically the first theory of cryopreservation was formulated in the 1930s by B.J. Luyet<sup>30</sup> and by 1949; Polge accidentally conducted a successful cryopreservation for sperm.<sup>31</sup> By 1954, the first live birth was reported using cryopreserved sperm.<sup>32,33</sup> While all this focus on sperm was rather quick in its overall success, embryo and eventually oocyte preservation took much longer. The first live birth for embryos that were cryopreserved was in 1980s.<sup>34,35</sup> The problem was found in the speed of cooling. Sperm was found to be best preserved in a slow-cooling process, while embryos and oocytes do better in fast-cooling process. The difference is in water content of the gametes, and the expansion of water as it cools became a recurring issue that saw damage initially during cooling, but even later during warming.<sup>36</sup> While sperm cryopreservation

took approximately twenty years, oocyte cryopreservation was not successful for decades. The first reported successful live birth following a successful oocyte cryopreservation was not until 1999.<sup>37</sup> On top of that, it was not until 2013 that oocyte cryopreservation became standard of care as recognized by the American Society for Reproductive Medicine.<sup>38</sup>

For many years, the use of cryopreservation was for the short term for example to preserve embryos that are not implanted during the first round of in vitro fertilization. Today, cryopreservation is used in preventative medicine for potentially long-term solutions. Fertility preservation continues to push the bounds of what can be cryopreserved. Currently, studies are being conducted to find ways to safely and effectively cryopreserve testicular and ovarian tissue. This is just the first step in what scientists are attempting to do. The idea is a complicated multi-step process which includes transplanting tissue back into the patient, maturing the tissue, and allowing for natural conception and pregnancy sometimes 20 years after the cryopreservation was done.

#### 4. Uterine Transplants

The most recent area of new and innovative reproductive technology is the focus on uterine transplants. Currently only successful in Sweden, uterine transplants seek to address infertility issues that are directly affecting women with uterine factor infertility.<sup>39</sup> Early studies with uterine transplants focused on the success of transplants in animals before any attempts were made on humans. As a way to learn from issues in previous studies, many of uterine transplant studies including those conducted on animals and

humans have made it a priority to discuss the ethical issues that are associated with the research and even include bioethicist on the uterine transplant team.

The first studies regarding uterine transplants were conducted in Sweden. In September of 2012, the first transplant was performed by a team that included ten gynecologists and transplant surgeons from the United States, Australia, and Spain.<sup>40</sup> The transplant was done using live donors from family members and all of those involved were voluntary participants with a clear understanding that this was a research project. Since the first transplant, a handful of live births have taken place through in vitro fertilization. These studies are still in the early stages of research. In early 2016, the Cleveland Clinic in Cleveland, Ohio announced their new research project focusing on uterine transplants specifically involving deceased donors.

Uterine transplants studies, while taking much care and consideration of the patients involved, are not conducted without risks and failures. In the case of Cleveland Clinic less than a month after the healthcare facility announced the success of the transplants and the details of the study, there was an infection which resulted in the transplanted uterus being removed. They took care to ensure the patient's well-being was priority before announcing that the transplanted uterus was removed.<sup>41</sup> The Cleveland Clinic has said it will continue its research study, but with each either successful or failed transplant, it will adjust its research accordingly.<sup>42</sup> Currently, this uterine transplant studies are for women who have uterine factor infertility, but as the research progresses, the application of the knowledge gained can be applied for other future research studies.



## B. Major Ethical Discussions

Because of increasing technology and major breakthroughs, ethics has had its hand full trying to balance the push of science with bioethical considerations of medicine and research.<sup>43,44,45,46</sup> Ethical discussions including defining the beginning of life, moral status, the right to reproductive, issues of access to reproductive technology, cost and insurance coverage for reproductive technology, or federal funding of research involving controversial materials (embryos, fetal materials from abortion).<sup>47,48,49</sup> These ethical issues are not exclusive to fertility preservation. They are a constant discussion in the area of reproductive technology, and every time a new study is reported or a new standard of care is announced, these ethical issues are brought to the surface again. These ethical issues have been in discussion since before the legalization of birth control in *Griswold v. Connecticut*<sup>50</sup> and *Eisenstadt v. Baird*<sup>51</sup> or the legalization of abortion in *Roe v Wade*<sup>52</sup>, or other legal cases and acts involving abortion, *Doe v Bolton*, *Planned Parenthood v. Casey*<sup>53</sup>, Partial Birth Abortion Ban Act of 2003<sup>54</sup>, and *Gonzales v. Carhart*.<sup>55</sup> Legal cases are what tend to bring the ethical cases to the public discussion, but within healthcare, these ethical issues have long been discussed.

### 1. Intrinsic Value of Life

There are some that argue that life has an intrinsic value and because of that should be protected at any and all costs. This intrinsic value of life begins with conception for many, although various stages throughout gestation have been identified as the beginning of life. Some even argue that gametes have potentiality for life and should be protected just as much as embryos or fetuses. The idea stems from the concept that life is sacred from the beginning. The idea of sanctity of life is often based in

religious concepts, with the Catholic Church being a good example<sup>56</sup>. The Catholic Church believes that all life has value and therefore should be protected.<sup>57</sup> This is because each human life is created by God and therefore if that life is destroyed, it disrespects the intrinsic value of life that God created. Those who support this position, often opposed abortion, destruction of embryos, and sometimes the use of contraception. The idea of intrinsic value of life can also be described as having human dignity. Each and every human has dignity by virtue of being a human from the point of conception to the moment of death. No one is able to remove that dignity and it should be respected in each person.

## 2. Moral Status of Embryos/Fetuses (Viability)

One of the ethical issues that has not been explicitly addressed by the laws in the United States is the moral status of an embryo or fetus. The idea of moral status is that something has interests that should be considered and possibly protected.<sup>58</sup> The discussion of moral status in reproductive medicine typically centers on embryos and fetuses. For some, since life begins at conception, embryos and subsequently fetuses have a moral status and their interests and rights should be protected to the fullest extent like a grown adult. The argument is that since the embryo has its own unique genetic material, it is a separate being from the mother; therefore, the embryo/fetus has a moral status and should be protected. For others, embryos/fetuses have the potential for human life and therefore have some moral status. They are not at the same level as an adult, but are not protected at the same level as a fully grown adult. The problem is where to draw the line with potentiality. For beginning of life issues, the potential life cannot express its wishes/desires and for a period of time cannot survive on its own. The issue here though

is that this same argument could be applied to a fully grown adult who is unconscious and dependent on others for care. It creates a slippery slope of whom and what falls under potential life.

In *Roe v Wade*, viability was defined as the time when a fetus can independently live outside the womb.<sup>59</sup> 45CFR 46.203(d) defines viability as "able to survive, (given the benefit of available medical therapy) to the point where it can independently maintaining heartbeat and respiration."<sup>60</sup> For others, moral status may not start until as late as at birth. In these cases, the embryo/fetus does not have a moral status and therefore has no rights or a moral interest that needs to be protected.

As pointed out in *Principles of Biomedical Ethics*, there are many different theories as what determines moral status.<sup>61</sup> One of the difficulties in trying to define moral status is that often by creating a definition, a specific group may be added or left out unintentionally. For instance, saying that anything that is life has a moral status, leaves the question of what defines life. For some they interpret this to mean human life, but others may want to include high functioning animals. Sometimes by trying to create a definitive definition, it creates more questions than answers. For Beauchamp and Childress, they identify five different theories as how to determine moral status: human properties, cognitive properties, moral agency, sentience, and relationships.<sup>62</sup> For each of these theories, a different trait of something that deserve protection is identified. Even within each theory there are pitfalls.

### 3. Procreative Liberty (Bodily Self-Determination)

Autonomy is often seen as one of the most important aspects in ethical discussions. Autonomy is thought to be the right or freedom to make choices. It gives

the individual the right to make decisions regarding their life and is acceptable as long as no one else is harmed in the process. Those who are dealing with reproductive issues, specifically those who are attempting to become pregnant, may be categorized as vulnerable, and need to secure their autonomy and dignity.<sup>63</sup> These individuals have rights based on the principle of autonomy to refuse or seek out treatments. Autonomy has both positive liberty and negative liberty included within it. Ultimately one must “balance autonomy and protection of the vulnerable.”<sup>64</sup>

Liberty is a fundamental value<sup>65</sup> that is often used to justify health care, but it can also be used to examine the implications for those seeking reproductive medicine. It is seen in values and ideas such as privacy, choice, civil rights, dignity, respect, and individuality.<sup>66</sup> At the same time, it provides a way for vulnerable populations to have protection. Liberty must be then taken into consideration such as equity. If those struggling with infertility or sterility are categorized as vulnerable then equity says that we must close the health disparity gap for those who are seeking reproductive medical treatment.<sup>67</sup>

Liberty can be divided into two parts – positive and negative liberty.<sup>68</sup> “One is to say that negative liberty is freedom from something and positive liberty is freedom to something.”<sup>69</sup> In reproductive medicine, negative liberty means that someone cannot force anything upon them. Individuals do not have to use certain medications or try certain procedures. Provided the individual is competent and has capacity, than they can even refuse lifesaving treatment. At the same time thought, these individuals need to understand the consequences of their actions and thus make an informed decision not one

based in fear or anger. While health professionals must respect that decision, they must also make sure that the patients are not taking that stance because of being vulnerable.

For instance, in the case of women with breast cancer, there is a recommendation to pursue fertility preservation in case of sterility due to the chemotherapy and radiation exposure. However, women cannot be forced to seek fertility preservation. She has the right to choose not to do anything. This could be based on her belief that her family is already complete, or she may not have any desire to be mother. The women does not have to provide a reason for refusing fertility preservation so long as she is competent and has capacity to make her own decisions. Other demonstrations of negative liberty can include refusing to abort a fetus or refused to be sterilization.

Positive liberty means that in addition to making choices, others have a duty to help that person achieve their request.<sup>70</sup> Those who are struggling with fertility should have a positive liberty to seek out healthcare professionals. This positive liberty can be a little more difficult to access because requesting specific medical interventions is much harder than refusing. So what should be done? There should be places and opportunities for the people to seek reproductive medicine. For many, there is access to good medicine, teaching hospitals, research studies, but in reproductive medicine often it comes down to the issues of cost and lack of insurance coverage.

#### 4. Access to Reproductive Technology

As part of positive liberty, patients have the right to seek our medical treatment. The problem is that accessing reproductive technology is not easy and may be costly. According to the principle of justice, to be just is to be fair and more specifically distributive justice is to be equal and fair in the distribution of goods or services.<sup>71</sup> In the

case of healthcare, the principle of justice says that access to medical treatment should be available to all- no matter of geographic location, gender, age, race, or any other demographic factor. The goal should be to provide the most healthcare for the most people. Necessary medicine should be distributed first, followed by elective medicine. The trouble is how to distribute it and what is considered necessary versus elective. Essentially, it creates a complex system of those who benefit more than others despite the attempt to be fair and equal.<sup>72</sup> In addition there is a question as to who makes the decisions and what should, if any, be done for those who still cannot access medical care.

In the case of reproductive technology, some may argue that parts of reproductive technology do not qualify as necessary medical care. The idea of necessary care or decent minimum care refers to the need for medicine in order to sustain life or the idea of catastrophic care, while elective medicine may be important but is not a life or death situation but focuses more on health wants as opposed to needs.<sup>73</sup> In the case of reproductive technology, there is some necessary care- care during pregnancy, ovarian or uterine cancer. In more recent years, the Affordability Care Act also added preventative reproductive technology- contraception- to the list of necessary care.<sup>74</sup> While still controversial regarding coverage, contraception is to be available and covered by all insurance plans unless the employer has religious objectives.<sup>75</sup> It gets trickier when discussing those are seeking medical treatment to get pregnant. Infertility or sterility is not life threatening and therefore is not viewed in the same as dealing with a life threatening disease.

For reproductive technology the idea of access also depends on other factors like age, gender, and location. One of the biggest issues is the concept of disparities. Under

the fair-opportunity rule, it says that no one should benefit or be denied anything based their social or biological properties.<sup>76</sup> This becomes problematic for those who do not fit into the normal category. Disparities such as gender or location can create such a disadvantage that it becomes burdensome, problematic, and cause harm just by having those social or biological properties. Going back to the example of cancer, if a woman has uterine cancer, but has no access to transportation to get to health care, her location has created a disparity that actually puts her at risk for death. Those who face those types of disparities are often found to have worse health as well.<sup>77</sup> It creates a difficult hurdle to overcome if they cannot access medical care and tend to have worse health. In reproductive medicine, accessing healthcare is complicated because it is not a guarantee for insurance coverage. In fact, most reproductive technology is not covered and is very expensive.

##### 5. Cost and Insurance Coverage for Reproductive Technology

The cost for reproductive technology is expensive, and most often not covered by insurance. As discussed before, reproductive technology is a broad category of medical advancements. It ranges from small things like Pap smears to experimental procedures like ovarian tissue cryopreservation. While the most routine and basic medical treatments are often covered by insurance, more invasive things like in vitro fertilization is typically not. It makes for a very frustrating process. The cost for these procedures can be high and can create a burden on those seeking to get pregnancy. So why the high cost for reproductive technology? The issue is a combination of the type of procedure, the expertise required for the procedures, the equipment and supplies needed for the procedure, and sometimes the number of steps involved and the invasiveness of

procedures. For example, let's compare the procedures of extracting sperm from extracting oocytes. For men, there are two main ways of getting sperm. One is through ejaculation through masturbation, the other is to have a healthcare professional extract it with a needle.<sup>78</sup> Either option is fairly simple, is an outpatient procedure and does not require a lot of equipment or prep time. In a single event, many sperm are provided at once time, making an effective one time procedure. For women, oocyte extraction is not as simple. Oocyte extraction is done through hyperstimulation of ovaries to encourage the body to release more than one matured oocytes during ovulation. The goal is to collect 14-16 oocytes at the time.<sup>79</sup> The procedure requires hormone injections, ultrasounds, and blood tests. It can only be done when the body is ready to release the oocytes. In rare cases, too many oocytes are released and it can cause hyperstimulation ovarian syndrome.<sup>80</sup> Just by understanding the nature of the procedures for oocyte extraction, one can understand why it is more expensive to retrieve oocytes over sperm. Because of this, when facing infertility, often the cheaper options are tried first, before the most expensive treatments. Artificial insemination is more likely to be attempted before in vitro fertilization because artificial insemination only requires sperm to be retrieved instead of also retrieving oocytes. However, if a few tries of artificial insemination does not work, then the more invasive in vitro fertilization is attempted. Add to that the potential for looking for a surrogate or an egg donor, the cost can quickly escalate. And none of these procedures for reproductive technology is 100% successful.

Insurance companies and those providing it, like employers, make decisions whether to cover procedures for infertility or not. Often tests that can diagnosis infertility are covered, but the procedures and treatments to address the issues of infertility are not



covered. It does not distinguish the reason for infertility like age (like being over 40) or biological condition (born without a uterus). All cases of infertility or sterility are lumped together. Insurance coverage for reproductive technology is even controversial for smaller procedures like contraception. In some cases, there are controversies as to what should be covered and what is unnecessary to cover. This leads to a discussion of the coverage, not just by insurance, but federal funding of reproductive technology that some may consider immoral.

More recently, some companies have started to take public stances in covering infertility treatments. Both Apple and Facebook have made public statements that claim that their benefits for employees will include infertility treatments.<sup>81</sup> Both of these companies will now cover egg freezing for employees. It relieves the financial burden off the employees. While it is impressive that these companies are leading the charge to encourage coverage for infertility, it does not mean other companies will follow suit. Smaller companies find even the most basic healthcare insurance to be expensive, but adding infertility coverage can create an even more expensive coverage. Those increased costs may then be passed onto the employees to pay for in some cases.

#### 6. Funding for Controversial Procedures and Materials

There are some that opposed the use of public money for controversial procedures and/or materials in health care. Procedures like abortion or the use of fetal material or embryonic stem cells in research may be viewed as immoral and therefore should not take place. Further, public funds should not be used to financially support these procedures or organizations that conduct such procedures or research. The ethical objection is that these controversial procedures and/or materials destroy human life.<sup>82</sup>

They believe that life begins at conception and any action that harms or destroys life is immoral.

a. Abortion and research with fetal material

With the passing of Roe v Wade, federal funds, specifically Medicaid, were being used to fund abortions for those who could not afford it.<sup>83</sup> This did not go over well with those who opposed abortion. People were upset that their tax dollars were supporting a procedure that they considered to be destruction of human life. Organizations like Planned Parenthood were receiving federal funding which helped offset the cost of abortions. In 1976 the Hyde Amendment was passed to ensure that federal funds were not used to fund abortions unless it threatened the life of the mother.<sup>84</sup> However, organizations like Planned Parenthood still receive federal funding for other aspects of their organizations and some believe that this still frees up other funds that can go towards abortions. The stance of some is that no federal funds should be provided to any organization that participates in abortion. Many on the other side of the issue object to the removal of federal funds. They believe that all women should have access to abortion especially those who cannot afford an abortion and even more, the cost of raising a child if they do not have an abortion.<sup>85</sup> They believe that women's right to choose should not only be upheld but supported financially. While many choose to object or support federal funds, the same issue also can be found with state funds or local funds. The argument is the same, there are some who object to any public money of the government used to support procedures that are deemed immoral.

In addition to the objection to federal funds being used for abortions, there is also the objection to the use of the terminated fetuses in research. Within the argument

against the destruction of life, are those who object to using that destroyed life to further the causes of research.<sup>86</sup> Even if this developed technology does not use fetal material in its modern day development or use, it was based upon knowledge gained from fetal material. There are some who object to even the association with an immoral act and can cause unease moving forward.<sup>87</sup> This can create a similar objection to that of the knowledge gained from the Nazi experiments during World War II.<sup>88</sup> While the knowledge gained may be useful to some, it was at the risk and harm of those who were not given a choice to participate.

b. Contraception

In 2010, with the passing of the Affordable Care Act, there were some that objected to the requirement that insurance plans were required to cover the cost of contraception, despite any moral or religious objection.<sup>89</sup> The argument in favor of this decision was that contraception is a preventative medication and should therefore be covered by healthcare insurance.<sup>90</sup> However, there were some who objected to the requirement of having to pay for this. The exception was those who identify as a religious institution that have an objection to the use of contraception. The Catholic Church is just one example. The lack of clarity for this part of the Affordable Care Act, was how it applied to organizations or businesses that although may not be an official religious organization, may have missions, values, or ethics that are associated with a religious belief.<sup>91</sup> For example colleges and universities that are religious may not want to pay for insurance plans that cover the cost of contraception. The objection to paying for contraception, again stems from the idea that all life has value and that the destruction of it is immoral. The Catholic Church has an official church position and their Ethical

and Religious Directives that forbids the use of contraception. The Catholic Church holds the position that the use of contraception is to interfere with God's plan of procreation and should not be used.<sup>92</sup> Businesses like Hobby Lobby also objected to this requirement and successfully sued in order to not be forced to pay for coverage for contraception.<sup>93</sup> This ruling confirmed the concept that business, although, not religious in nature, can have a religious viewpoint and conduct their business in ways that support that belief. There are some that object to businesses being allowed to refuse coverage for preventative medication like contraception. They argue that people have religious beliefs, not businesses.

c. Embryonic stem cell research

Embryonic stem cell research is considered a controversial way that federal funds are used. For some, the reason that embryonic stem cells is controversial is that the embryo is destroyed in order to use for research. If the embryo would have been implanted into a uterus, the fertilized egg would become a fetus and could be brought to term to be a baby. The moral status debate is similar to that in abortion. There are people who argue that life begins at conception and that the destruction of the embryos is the destruction of human life which has intrinsic value.<sup>94</sup> The moral debate here has impacted politics, legislation, and federal funding of stem cell research. The moral debate is often associated with religion, but those who opposed are not exclusively religious. The theory to this type of research is that these embryonic stem cells can be used to regenerate cells in the body that have been permanently damaged by disease or accident. Examples include heart disease, Parkinson's disease, spinal cord injuries, diabetes, muscular dystrophy, and vision and hearing loss.<sup>95</sup> For those who object to

embryonic stem cell research, they typically object to federal funding of such research. They do not want their tax dollars to support science that they believe to be immoral. Legally, the ways federal funds are used to support research for embryonic stem cell has changed.

In 1995, the Dickey-Wicker Amendment was established by Congress to prohibit federal funds from being used in research that involved the harm or destruction of embryonic stem cells. However, in 2001 President Bush gave an executive order to limit federal funding for embryonic stem cell research.<sup>96</sup> President George W. Bush limited federal funds being given to only those who conducted stem cell research with embryos created before August 9, 2001. This meant that any embryonic stem cell research done on new embryonic stem cell lines was to be funded privately. The purpose of all of these changes from the Dickey-Wicker Amendment was because of the progression of the science of stem cells. When embryonic stem cells were discovered, there was a push to allow federal funding to increase the research results. There was also a push by those opposed to the federal funding being used at all for embryonic stem cell research. Executive Order Number 13435 was created in 2007 as a follow up to the statement from 2001 as a point of clarification. This 2001 statement, 2007 Executive Order and the White Paper were established to satisfy both sides of the argument. However, neither side was happy with the compromise. In March of 2009, President Barak Obama issued Executive Order Number 13505 which removed the federal barriers to receiving federal funds for embryonic stem cell research.<sup>97</sup> Most recently on August 23, 2010 Federal Judge Royce C. Lambert struck down Executive Order Number 13505. This means that the Dickey-Wicker Amendment would have to be struck down in order to provide federal

funds for embryonic stem cell research. Meaning that at the current time, the federal laws are the same as what they were during the Bush Administration. This does not however, restrict private funding of embryonic stem cell research.

### **III. Science of Fertility Preservation**

Fertility preservation is recommended for those who are at risk for infertility.<sup>98,99,100,101</sup> This could be due to the side effects of medical treatments like chemotherapy for cancer or lupus or delaying pregnancy/ parenthood.<sup>102,103,104</sup> It is hard to predict infertility or sterility for anyone, but side effects from treatment are difficult to predict because each person reacts differently to treatments like chemotherapy and radiation. For those who delay parenthood, infertility can be discussed in general terms based on what is known regarding decrease fertility with age for both men and women, but specifics are difficult to predict. Either way, the purpose of fertility preservation is to prevent infertility risks.

There are both standard of care and research protocols available for fertility preservation. As more knowledge is gained, more research protocols will become standard of care as is typical in healthcare. Before a specific type of fertility preservation is chosen, it is important to consider the gender, age, severity of disease, treatment type and dosage, and geographic location amongst other demographics for the patient to find what is suggested best for the situation. For many healthcare professionals, it is vital to stay up to date on the different techniques or at least have access to a reproductive specialist as a resource.

#### A. *Reasons for Fertility Preservation*

Fertility preservation is recommended for those who are at risk for infertility or sterility. It is meant to be a preventative treatment option in order to address infertility or sterility if it happens. Infertility or sterility could be caused by various things including disease like cancer, lupus, kidney disease, Turner syndrome, or even delaying in having children. The causes and rate differ for every person so predicting infertility or sterility can be difficult, which creates the importance of fertility preservation. While infertility and sterility are different, preventing either through fertility preservation is the same. Essentially fertility preservation is meant to prevent the effects of infertility or sterility. With fertility preservation, those suffering from infertility or sterility are able to attempt to get pregnant anyways. Side effects from treatment for disease is one of the biggest causes of infertility/sterility. The other reason that people pursue fertility preservation is aging, which is often the major issue when delaying having children. The terminologies may vary- delay in child bearing, postponing having children, social egg freezing, age related fertility decline. All that it means is there is no diagnosed disease that has side effects due to the disease itself or its treatment that may affect fertility. Fertility will decline with age and by freezing oocytes or embryos at a younger age, there is a better chance for those materials to be healthy. No matter the cause of infertility or sterility, the end result is the same- the inability to get spontaneously pregnant through sexual intercourse.

##### 1. Side Effects of Disease and Treatment

Once a patient is diagnosed with a disease, the healthcare professional makes a recommendation of treatment. They are to make recommendation based upon the best

practice according to the diagnosis and the most up to date information and research. Once the healthcare professional determines the treatment options and what his or her recommendations will be, it must be presented to the patient. During this discussion, side effects of either the disease or treatment are disclosed and patients have to consider what the side effects mean for them both long term and short term. Most commonly for diseases such as cancer, kidney diseases, or autoimmune disease, there is a risk of infertility or sterility either due directly to the disease or the treatment of the disease. Patients should be concerned about the effects on possible anatomic problems (like irregularly functioning ovaries) or hormone issues (like a drop in testosterone) all which can contribute to infertility and/or sterility. There is no fool proof way to predict the exact risk of infertility, but fertility preservation is done for the just-in-case scenarios. Essentially, fertility preservation is a type of preventive medicine for infertility.<sup>105,106,107,108,109,110</sup> According to the American Cancer Society the risk of infertility varies on the gender, age, severity, and location of the disease in the body.<sup>111</sup> Women with uterine cancer are at a higher risk for infertility or sterility compared to women with cancers that do not involved reproductive organs simply because of where the cancer is located. There is the risk of the uterus no longer being function or even need to be removed. In order to understand fertility preservation, it is important to understand what creates the need and interest for it.

a. Infertility versus sterility

Infertility is defined as the inability to get pregnant over the course of twelve months after having unprotected sexual intercourse at the correct time each month.<sup>112</sup> According to the Centers for Disease Control, infertility affects around 7.5 million



women (12.3%) age 15-44.<sup>113</sup> Both infertility and sterility have multiple causes and is different for each person though age and family history can play a factor. For women, fertility is affected by ovulation, fallopian tubes, age, cervix, uterus, partner, and hormones.<sup>114</sup> While only one indicator is needed to cause the issue of infertility, a combination of factors can cause issues as well. While infertility is not a chosen condition, sterility can be chosen and purposeful by some, while, for others sterility is not chosen. Infertility can only be known by those who are trying to get pregnant and thus by being diagnosed with it, it means that the couple is purposefully trying to get pregnant. In some cases, sterility is chosen intentionally with the sincere desire to never get pregnant- either through a vasectomy or tubal ligation, or unintentionally due to side effects of a disease/treatment. In the case of fertility preservation, this is done just in case infertility or sterility happens. However, there is no guarantee that infertility or sterility will happen and so in some cases, despite taking precautions with fertility preservation, it is unnecessary. For instance, a young man in his twenties may be diagnosed with Ewing's sarcoma, freeze his sperm, undergo chemotherapy and radiation and is able to get his wife pregnant without any issues. In those cases where fertility preservation is proven unnecessary, patients have to decide what to do with the gametes and/or tissues that have been cryopreserved.

b. Cancer

According to the American Cancer Society men have a 1 in 4 and women have a 1 in 5 risk of some type of invasive cancer.<sup>115</sup> And while the types of cancers vary, there are some similarities in the initial approach in how to deal with cancer. The seriousness of cancer, forces patients to take stock of their lives including what their goals and quality

of life looks like. Before a patient can make a decision regarding fertility preservation, some of the things to consider are age, diagnosis, type of treatment, relation of cancer to reproductive organs, time frame for treatment delay, and any partners that may be involved, and cost.<sup>116,117</sup> All of these factors can be overwhelming to a patient that is still adjusting to being diagnosed with cancer. The information being provided to a patient can be intimidating and healthcare professionals need to be well-versed in the discussion of fertility or be willing to refer that patient to someone who is well-versed.

Chemotherapy and radiation are two of the most common treatments for cancer. The type of chemotherapy and the amount of radiation vary patient to patient. Since these treatments have been around the longest, the risk of infertility is best understood in these circumstances. In other treatments like immunotherapy, because they are still newer, there is not a longer term understanding of the risk for infertility. For male patients, since sperm is a cell that divides quickly, certain types of chemotherapy may wrongly kill sperm cells. It may take years for sperm production to return to normal, if it ever does.<sup>118</sup> For female patients, chemotherapy creates a different risk than men. Chemotherapy may reduce the number of years that women are fertile. Since women are born with their total number of eggs and chemotherapy may cause damage to those eggs. The other issue is dealing with pregnancy during and after chemotherapy. Pregnancy during chemotherapy will harm the fetus and cause serious birth defects so patients are encouraged to use very effective birth control and take multiple precautions. Attempting to get pregnant after chemotherapy needs to be done with the supervision of a healthcare professional ensuring that enough time has passed and to know what if any damage to eggs remains.<sup>119</sup> There are certain types of chemotherapy that are less of a risk for

infertility, more than others, but both male and female patients need to weigh the effectiveness of the chemotherapy against the risk of infertility. The American Cancer Society provides resources that allows patients to easily understand their risks and concerns. It encourages patients to ask questions and to seek healthcare professionals that are well versed in fertility preservation.

c. Other diseases

There are other diseases and conditions that can affect fertility. Disease like lupus, bone marrow disease, rheumatoid arthritis, multiple sclerosis can be treated with chemotherapy drugs which comes with a risk of infertility similar to that of chemotherapy for cancer treatment. According to review of ovarian cryopreservation studies, ovarian failure can be a result of other issues besides cancer including bone marrow transplantation, autoimmune diseases requiring chemotherapy, ovarian pathologies, and endocrine or genetic diseases.<sup>120</sup> In these cases, infertility is a risk due to premature ovarian failure. For example, girls with Turner syndrome are at an extremely high risk of ovarian failure. In most cases, there is not puberty development whatsoever.<sup>121</sup> In 2016, Kutluk Oktay and his team created practical guidelines for fertility preservation in women with Turner Syndrome. In their decision-making guide, the path follows the similar framework for others considering fertility preservation. It is broken into prepubescent and postpubescent options. The recommendation is to identify the best option for the patient's situation, but also take into consideration that Turner Syndrome has an extremely high infertility rate. The best way to go about this is to refer the patient to a fertility specialist.<sup>122</sup>

## 2. Delay of Childbearing

There are men and women who purposefully choose to delay having children. It could be due to not finding the right partner, choosing to focus on career first, or not feeling mature enough to handle children yet. The reasons vary, but the discussion of delay is similar. By delaying having children, there is the risk of infertility being a problem. Since the average age of a women having her first pregnancy has increased, fertility preservation has become a more go to option for some. The average age for a first time pregnancy is 26.3 years as of 2014 as compared to 24.9 in 2000.<sup>123</sup> The availability of birth control, sex education, contraception, and abortion may be reasons women delay having children.<sup>124</sup> By delaying the decision to have children, there are biological concerns that women and men should be aware of before they decide to delay pregnancy.

The biological affect for delaying having children affects women more severely than it affects men. Women are born with a finite number of eggs and as they release one each month, their number decreases. At the same time, the quality of the eggs decreases. Women who are over the age of 35 are considered to be at high risk for infertility. For men, the increase in age can correspond to the decrease in sperm count, motility, and morphology. However, while the health of the sperm does decrease over time, men's fertility does not start to decrease until late sixties.<sup>125</sup> With increase age, there is also the risk of defects to the fetus and other pregnancy complications. Chromosomal abnormalities like Down syndrome appear in a greater rate as age increases.<sup>126</sup> Freezing oocytes, sperm, and embryos when the gametes are younger and healthier, can help to avoid the potential problems that generally come with older and lower quality oocytes

and sperm. However, cryopreservation does not guarantee the health and safety of a pregnancy or fetus any more than a natural pregnancy.

Recently, there have been vocal support from celebrities, specifically women, who talk about freezing their eggs. Celebrities like Maria Menunos,<sup>127</sup> and Kim Kardashian<sup>128</sup> have gone public about their personal decision to freeze their eggs because they know that they will not have children until they are older. By freezing eggs now, they are able to keep the health of the eggs frozen and this will give them a better chance for fertility at a later date. The problem with celebrity endorsements, is that the referrals are from non-experts. Testimonies are not a bad thing, but a person seeing the celebrity endorsement should not assume that their situation is the same of the celebrity. Celebrities have the luxury of being able to travel for care options, may be in a better financial situation, and may even receive a kickback for advertising the service they received. While celebrity endorsements raise the profile of fertility preservation, it also can communicate false information or at the least, misleading information.

One of the newer trends to encourage women to participate in fertility preservation are egg freezing parties.<sup>129</sup> Companies like Egg Banxx host "Let's Chill" cocktail parties.<sup>130</sup> The idea is rather simple, a healthcare professional, usually a reproductive endocrinologist or obstetrician, provides information to encourage both singles and couples to consider egg freezing. The typical consumer for this party is those who are seeking fertility preservation due to delay in having children.<sup>131</sup> This type of direct to consumer advertising is new and the ramifications (and the legality) of it still be considered. Some may criticize this type of party because healthcare professionals are crossing the line from professional relationship to more personal due to the nature of the

party being in people's home. It creates a business strategy aimed for vulnerable women that are being marketed to by a company aimed to make money. It also takes a private issue and makes it a social, fashionable trend that needs extra care and consideration.<sup>132</sup> The purpose of the party though is just one part of the informed consent process-information. Healthcare professionals do not perform procedures or hand out medication. They only present the information about egg freezing and then schedule follow-up appointments for those who are interested. The follow up appointments should be much more thorough to ensure full informed consent for those who choose fertility preservation. Women should not feel pressure to make decisions in these situation, and they need to fully appreciate and comprehend the benefits, risks, and limitations of fertility preservation.<sup>133</sup> Egg freezing is not just a procedure, but a vital decisions that can affect the future for women.

#### *B. Methods of Fertility Preservation*

Fertility preservation methodologies range from standard of care interventions to experimental procedures, to methods that are in the mist of transitioning from experiment to standard of care. Each procedure comes with its own set of issues. Anytime that gametes, embryos, or tissues are cryopreserved it is vital that the owner of the material is in regular communication with the cryopreservation bank. It is necessary to consider the financial investment that is needed in order to have the procedures done, and to maintain the cryopreserved material for the necessary length of time before the person is ready to use their material. In the case of standard of care, those involved need to have a thorough understanding of what is going to take place not just in terms of the medical procedures, but also in terms of the psychological and emotional impact it may have on a person.

Additionally, any time that the cryopreservation involves a partner, it immediately becomes more complicated. Ownership of the cryopreserved material is not just the property of the sick patient or the person who initiated the process and in the case of disagreement or death, what happens to the cryopreserved material. It is equally owned by both people involved unless there is an anonymous gamete donor. In the case of research, it is important to understand the purpose of research and what participation the person will have in the future and what, if any, financial responsibility the person may have in the future. Additionally, it is important to know what happens with the cryopreserved material once the study has been completed.

#### 1. Standard of Care

Standard of care in fertility preservation is only available for those who have undergone puberty. The standard of care for fertility preservation for women is embryo freezing, but this requires access to sperm either through a partner or sperm donation.<sup>134,135</sup> Through the technique of in vitro fertilization, embryo freezing is accomplished. This is considered the most common and successful method for fertility preservation for women.<sup>136</sup> While this is considered standard protocol, this does not mean there are not difficult factors to consider like delaying medical treatment for the disease, introduction of high levels of hormones, or lack of a partner for sperm. For men, sperm freezing is a standard protocol.<sup>137,138,139</sup> It is cheaper, easier, and more reasonable to freeze their sperm and does not require a partner. In its simplest protocol, it is not invasive or a surgical procedure, only masturbation is necessary.<sup>140</sup> If need be, a physician can retrieve the sperm by aspiration. Sperm banking has proven to be effective and safe for many years with thousands of live births.<sup>141</sup>

a. Sperm

Sperm cryopreservation has been available since 1953.<sup>142</sup> It was initially introduced as a way to freeze bull sperm for cattle farmers. It was eventually adapted for use in humans. Sperm is more easily extracted than eggs and freezes quickly and easily. Either through a patient masturbating or a physician's aspiration, sperm is easy to access and is not invasive or considered a surgical procedure. Sperm can only be frozen provided that patient has gone through puberty. There is little to no delay in being able to access sperm and does not require a partner. It makes it the ideal option for men looking into fertility preservation. The sample can even be inspected for sperm count, motility, and morphology.<sup>143</sup> If needed, a second sample can be provided after 24-48 hours. Some of the problems that are often associated with sperm donation is the inability of a man to provide a sample through self-stimulation. There are a few methods for assisted stimulation that may help men provide sperm and before aspiration is done. Sperm cryopreservation has proven to show itself effect in dealing with infertility. Sperm is able to remain cryopreserved for decades.

b. Embryo

Embryo cryopreservation has been available since 1984.<sup>144</sup> The development of in vitro fertilization made for better understanding of the creation and development of fertilized eggs. Instead of implanting the fertilized egg during in vitro fertilization, the embryo is cryopreserved. In order to make an embryo, there needs to be both an oocyte and sperm. In these cases their either needs to be a partner for the patient or a donor.

If the patient is a woman, then either a male partner or a sperm donor is needed to create an embryo. The woman needs to undergo hyperstimulation of her ovaries in order



to release many oocytes to be retrieved. Hyperstimulation is on average a two week process that requires injections of medication in order to stimulate the ovary, mature the oocytes, prevent premature ovulation, and prepare the uterus all while being monitored by vaginal ultrasounds and blood tests.<sup>145</sup> When the matured oocytes are ready to be retrieved, a physician goes with a transvaginal ultrasound to aspirate the oocytes or in rare cases laparoscopically.<sup>146</sup> On that same day, either the male partner or the donated sperm are retrieved and once prepped, the oocytes and sperm are placed together into a petri dish. Once the fertilized oocytes have matured for five days, the embryos are frozen.

For male patients, either a female partner or an egg donor is needed to create an embryo. In this case the same procedures take place, including retrieval of sperm and the hyperstimulation of ovaries of either the female partner or the egg donor. The male patient can donate his sperm as needed and could even freeze the sperm if the male patient cannot wait for the oocytes to be retrieved before undergoing treatment of disease (like in the case of cancer).

In either scenario, embryo cryopreservation is an invasive and more expensive option than simply sperm cryopreservation. However, embryo cryopreservation has been around longer and proven safe for decades over the newer cryopreservation of oocytes.

c. Oocyte

In 2013, the American Society for Reproductive Medicine announced that oocyte cryopreservation moved from being research to standard of care even though the first reported live birth from frozen oocyte was in 1986.<sup>147</sup> With the advancement of vitrification, more knowledge was gained about oocyte cryopreservation and with enough studies, a decision by the American Society for Reproductive Medicine was made to no

longer label it research.<sup>148</sup> The complexity of freezing oocytes is the water content. Water expands as it freezes and in the case of oocytes this expansion and the defrosting of the water, can cause irreparable damage to the oocytes. Many studies for oocyte cryopreservation focused on speed of which the oocyte is frozen. According to the American Society for Reproductive Medicine's "Mature Oocyte Cryopreservation: A Guideline" over 981 studies were conducted. Common understandings from these studies show that length of cryopreservation had no statistical impact on the live birth rates, while maternal age at time of cryopreservation played a major role.<sup>149</sup> Additionally, it is shown that oocyte cryopreservation can be a cheaper option than in vitro fertilization for women over age 38, provide they cryopreserve their oocyte in their twenties.<sup>150</sup>

The medical indicators for oocyte cryopreservation are the same for embryo cryopreservation: cancers, genetic conditions, delay of child bearing. However, it should also be noted that this is a good option for a women who cannot cryopreserved embryos either due to lack of sperm, or simply refusing that choice.<sup>151</sup> Oocytes are retrieved through hyperstimulation of ovaries just like for embryo cryopreservation. The procedure is invasive and comes with risks. These risks do not include a higher rate of congenital abnormalities as compared to cryopreserved embryos.<sup>152,153</sup> There is also no long-term studies due to the new nature of these procedures and protocols.<sup>154</sup> Newer research is focusing on the variations within oocyte cryopreservation like the difference between mature and immature oocytes.<sup>155</sup> In one study, while the original hypothesis was that the immature oocyte would be protected, instead; other structural parts of the oocyte were damaged.<sup>156</sup> While a singular study does not stop research, it demonstrates

that even with the best of intentions, science and medical research still have a long way to go for many things, despite all the technology and knowledge we as a society have already gained.

The problem with new standard of care is that not everyone is well trained in the procedure and finding healthcare professionals with high success rates takes time that a patient may not have. It is always an issue of disseminating medical information to the public and in the case of oocyte cryopreservation, a survey by Brooke Hodes-Wertz, demonstrated that there is much confusion about the decline of fertility and the availability of oocyte cryopreservation.<sup>157</sup> Healthcare professionals need to be vigilant to ensure that women are aware of their decline in fertility in their twenties at not just at age thirty-five as many women assume.

## 2. Research in Fertility Preservation

There are many different research protocols available that are exploring new ways for fertility preservation. Due to the fact that there is over a 75% survival rate among pediatric cancer patients, finding ways to support quality of life and long-term goals of cancer survivors is a major concern.<sup>158</sup> The most common research studies in fertility preservation are ovarian tissue cryopreservation and testicular tissue cryopreservation. There are additional variations on these research studies which change the hormones involved, the type of freezing process, and other variables. These protocols are only available at places that conduct research.<sup>159</sup> There are rules for enrolling in these studies and not every patient is eligible. Unfortunately, not all patients live near places that conduct research and may never be told about such protocols. Healthcare professionals

have a professional responsibility to do their due diligence in order to ensure they are up to date on research protocols or at least have a resource they can contact.

a. Ovarian tissue

Ovarian tissue cryopreservation has been around for more than a decade. The main focus of most of these studies have been conducted with adults, but more recently has shifted towards the pediatric population.<sup>160</sup> While the cryopreservation technique of ovarian tissue is fairly consistent, the transplantation and subsequent pregnancy in adult women and live birth is rare.<sup>161</sup> Even with the decade of time for research, by 2010, ten babies were reported and by 2015, fifteen babies have been born after successful transplantation.<sup>162,163</sup> The goal of ovarian tissue cryopreservation is to freeze ovarian tissue through a proven freezing process.<sup>164</sup> Some research focuses on the different freezing techniques, like vitrification, for storing the ovarian tissue to ensure that there is not damage to the tissue when defrosted. In some cases, immature oocytes can be removed from the tissue and matured *in vitro* for preservation.<sup>165</sup> A separate research study can then be done to transplant the ovarian tissue back into the patient. Transplantation studies have only been conducted on adults.<sup>166</sup> In a few of those cases, spontaneous pregnancy took place, but *in vitro* fertilization is also an option.<sup>167</sup> For now, studies continue to pursue knowledge of how to approach ovarian tissue cryopreservation and eventually get a better read on the indications for when it is most medically called for.<sup>168</sup>

It is unclear what recommendation should be made for those under age eighteen and more specifically for those who are prepubescent.<sup>169</sup> Little data is known for successful transplantations especially in pediatric patients because of the newness of the

research.<sup>170, 171</sup> In most cases, the study starts in adults and is eventually expanded to pediatric patients and slowly include younger and younger girls.<sup>172, 173</sup> This unknown does not halt the research, but it does force those involved both from the researchers', parents' and patients' perspectives to be cautious.<sup>174</sup> During this time of research, there is a learning curve as to what type of patient will benefit most from this type of procedure and who should be enrolled in this study.<sup>175</sup> It is important to not only focus on the research and the knowledge that is being acquired, but also the individual patient. While the focus of this type of research tends to be on infertility due to the side effects of chemotherapy in treating cancers, some studies have been indicated for those with a risk of premature ovarian failure in cases of Turner syndrome, repeated surgeries causing ovarian torsion, or Fragile-X.<sup>176</sup> Parents should be made aware and clearly understand that the nature of these procedures are strictly research.<sup>177, 178</sup> It does not mean that it will successfully be transplanted back into the patient at a later date, nor does it promise that it cannot be transplanted.<sup>179</sup> All this means is that the patient is currently enrolled in a study that is cryopreserving prepubescent ovarian tissue.

b. Testicular tissue

There is no proven method for fertility preservation in prepubescent boys.<sup>180, 181</sup> Testicular tissue freezing is conducted one of the research protocols aimed for this demographic. It is considered highly experiment, and no lives births have resulted from this research as of yet.<sup>182</sup> The hope is that the cryopreserved tissue can be transplanted back into the patient to return spermatogenesis or potentially grow sperm in vitro for future use.<sup>183</sup> This experimental protocol is possible in the future<sup>184</sup> and so it fosters the hopes for better medicine in the fertility preservation.

Similar concerns are present for testicular tissue cryopreservation as is present for ovarian tissue. The parents and patients that are involved need to be certain they understand the nature and purpose of the research protocol.<sup>185</sup> The idea of sensationalism is a major concern as parents are looking for any possible means to preserve the fertility of their son.<sup>186</sup> Additionally, healthcare professionals should communicate that this type of study does not yet have conclusive evidence to move forward with either transplantation or potential to grow sperm.

There are some that are pushed for wider access and more involvement of those eligible for research studies. The more participants enrolled, the more knowledge gained. One of the issues in trying to conduct these studies is the long time frame between cryopreservation and transplantation.<sup>187</sup> This means that by preserving the tissues of boy now, by the time the boys have matured, there may be a transplant study available for him. It is important though, that parents understand they are only preserving testicular tissue and not enrolling in a transplant study.

c. Ovarian transposition

Another research study is ovariopexy and ovarian transposition. The proposed studies seek to displace the ovaries to shield them from exposure to radiation. This can be beneficial especially for those cancers like cervical, rectal, pelvic bone sarcoma, bladder are the main diagnosis that can indicate the use of ovarian transposition.<sup>188</sup> Due to the natural flexibility of ovaries to move, this type of study works well for treatments that have a specific location for radiation to be aimed at. This type of study is not indicated for someone who is also undergoing chemotherapy at the same time because the ovaries would still be affected no matter their location. However, after the

completion of chemotherapy and before starting radiation is a time for healthcare professionals to consider using ovarian transposition.<sup>189</sup> After the radiation is complete, the ovaries can be potentially moved back into position so natural, spontaneous pregnancy can be attempted.<sup>190</sup> The long term consequences and any functional problems of moving the ovaries is still unknown.<sup>191</sup> This also does not factor in any damage done to the uterus or fallopian tubes from the treatment. Essentially in some cases, ovarian transposition may be recommended, but it does not eliminate the risk for infertility due to other causes; it simply seeks to eliminate one cause. One of the risks though, is that cancer cells could still spread to the ovaries and in those cases, the ovaries may need to be permanently removed.<sup>192</sup> The overall success rate of ovarian transposition varies. While it has been shown to be as high as 85.7%<sup>193</sup> and as low as 33%<sup>194</sup> in saving the ovarian function in adults, there has not been solid evidence for ovarian transposition in children.

#### **IV. Demographics of Patients**

When determining what type of fertility preservation to pursue, it is critical to consider the demographics of the patients. Demographics determine what fertility preservation the patient is eligible for and also what is not. Gender of the patient automatically eliminates certain options by virtue of the patient not having either sperm or oocytes. Men have had options to cryopreserve without the need of a partner for a longer time than women. However, women are often the focus when it comes to discussions about fertility and future family planning. Gender also plays an important role in research. Because fertility preservation is more complex and requires more steps for women, there tends to be trend of more studies aimed at finding new and innovative

ways to preserve fertility for women than men. Age is also a limiting factor due to the need for patients to have already undergone puberty in order to access sperm or oocyte cryopreservation. For those who are too young to undergo puberty, they are limited to only research protocols. Other demographics like socioeconomic status tend to dictate if a patient has access to fertility preservation. Demographics like geographic location, race, sexual orientation, and socioeconomic status are factor into this issue.

#### A. *Gender*

Gender automatically puts patients into a specific grouping for certain types of fertility preservation. Infertility and fertility preservation decisions can affect males<sup>195,196,197</sup> or females.<sup>198,199,200</sup> Standard of care for men (sperm cryopreservation) is less invasive and has been proven effective for a long time. No partner is required. However, women's standard of care embryo fertilization, requires a partner (or at least a sperm donor) and oocyte cryopreservation is highly invasive and is only recent considered standard of care. According to one study, there is even gender disparity in the communication of fertility preservation to patients.<sup>201</sup> More fertility preservation research is focused on female fertility because of it being more complicated and more invasive than males.

#### 1. *Male*

Male fertility preservation is focused on sperm cryopreservation which has been available since 1953. This procedure is non-invasive, simple to conduct, and requires little time and preparation. The discussion of fertility preservation is often more focused on female patients rather than male patients. It creates a unique situation in that the procedure is simple, but the discussion is tough. Stereotypically men do not have the



same biological clock issue that women face. It creates the false belief that men do not need to think or plan for their future children. However, it is just as important to discuss fertility with men as it is with women. It should be standard in discussion at primary care appointments (to ensure men are being smart and aware) and especially necessary during diagnosis for disease appointments. If a man is diagnosed with cancer, he should be made aware of the details of which treatments are most effective, but also which is best to preserve fertility. Patients should be allowed to make well informed decisions regarding their current treatment, but also long term for their quality of life.

The process of getting the sperm can be embarrassing for the male too. Having to masturbate into a cup during a time frame can create a stressful and pressure filled environment. Sometimes bringing in his partner or using electric stimulation can help the process along, but if necessary a physician can aspirate the sperm out for the man. If the healthcare professional is not well-versed in the issues of fertility, than the man should be referred to a reproductive specialist.

## 2. Female

For many years, female fertility preservations is focused on embryo cryopreservation which required access to sperm either through a partner or a donor. However, since the development of oocyte preservation, females have another option. Fertility is a common discussion for women. Fertility should be standard discussion at primary care appointments, and in the serious conversation of diagnosis, fertility needs to be one of the many topics to discussion with the patient. Women are born with a finite number of eggs, and as women age, the quality of the eggs decrease.

The biggest problem with fertility preservation for women is that the procedures are invasive. For women who are facing a diagnosis, time is often not on their side and the patient must consider the risks and benefits of delaying treatment to do fertility preservation. Discussions and decisions must be done thoroughly and quickly so that fertility preservation can be started and treatment of disease can start afterwards. Researchers are working on ways to remove immature oocytes directly from the ovaries with stimulation so that there is little waiting time, and other methods that are less invasive.<sup>202</sup> These types of studies will take time to perfect, but if/when they do, it will provide a greater variety of options for women.

#### *B. Age*

Age places fertility preservation patients into one of three age brackets- prepubescent<sup>203,204</sup>, adolescents,<sup>205</sup> and adults.<sup>206,207,208,209,210</sup> Age factors into what the risk of infertility the person may face and what types of fertility preservation is available. Age automatically places the person into a category but should not factor into how they are treated by the healthcare professional. All available options for that age should be discussed in order to promote an ethical approach to informed consent. Adults have standard of care options available, and can seek out fertility preservation for a diagnosis or in case of delaying having children. Even without a medical diagnosis, adults, especially females, are facing the risk of infertility due to natural aging, which can be sped up by a medical diagnosis and treatment. Fertility preservation has been around the longest for adults and the issue of consent are fairly standard in these cases. Adolescent patients are caught between the same needs as an adult, but involve the consent of their parents or legal guardians. For adolescents, they are seeking standard of care fertility

preservation in the case of diagnosis. It is rare that an adolescent would be seeking fertility preservation because they are delaying having children. The informed consent process in this case involves both assent (and sometimes consent) of the adolescent and consent by the parents or legal guardians. This is in contrast to prepubescent which involves the consent of parents as the main form of consent. Prepubescent patients should only be seeking fertility preservation in the case of a diagnosis and there is a risk for infertility or sterility. Prepubescent patients only have experimental protocols available which make the decisions for parents much more nuanced.<sup>211</sup> The approach for each of these varies because of the age of the patient. Healthcare professionals need to be sensitive to the age of the person and make the discussion age appropriate to effectively communicate.

#### 1. Adults

As discussed before, adult patients have access to sperm, oocyte, and embryo cryopreservation. All are considered standard of care, and have proven to be safe and effective methods of cryopreservation. Adults are assumed to have decisional capacity and therefore consent for themselves. Adult patients may also seek advice and support for others. The person may consult with partners, spouses, family, and friends prior to finalizing a decision. Having children may be a far off future discussion, but when discussing fertility preservation, it suddenly goes from being in the future to being a current relevant discussion. Some of the issues involving a partner could be any of the following: it could be too early in a new relationship, the relationship could be in facing troubling times, the partner in the relationship may not want children, or some relationships may already have children and are feel their family is complete. In rare

cases, a couple may currently be trying to get pregnant, but discovered an illness instead and now have to delay becoming parents in order to seek treatment.

Whatever the scenario, the patient needs to understand the impact their age has on fertility. Fertility preservation decisions that are made before treatment or at a younger age, impact the potential decisions for the future. Some suggest that by pursuing fertility preservation, one is keeping all avenues open instead of taking the greater risk of potentially shutting the door on having a biological child in the future. However, some of the risks associated with disease while highlight the importance of fertility preservation, make the timeframe very narrow for these people to make a decision. Patients also have to keep in mind that certain types of treatments can affect fertility differently for each patient. Aggressive treatments could send a female patient into early menopause.<sup>212</sup> Male patients could end up completely infertile. Female have a limited number of eggs which decrease in quality with age.<sup>213</sup> Ovarian function and ovarian reserve may also decrease with treatment. These factors must be taken into consideration prior to treatment or delaying having children.

If the patient (or the couple) chooses to pursue fertility preservation, discussions need to be had regarding any unused gametes or embryos. The couple may feel their family is complete and no longer need the gametes or embryos, the couple may break up and ownership of the gametes or embryos are questioned, or one of the people may die, and the remaining person may need to consider what to do with the gametes or embryos. In rare cases, there is a custody battle for rights to the gametes or embryos which can create financial and legal burdens. The nuances of these discussions will be addressed in Chapter Five.

## 2. Adolescents

For adolescents usually between the ages of twelve to seventeen (although some consider adolescents until age nineteen), since they have undergone puberty, they have access to the same sperm, oocyte, and embryo cryopreservation as adults. The procedures are the same, but the approach to decision making and informed consent is what differs. In the case of adolescents, there is more than likely, no partner to consider in the cryopreservation process. In the case of embryo cryopreservation, an egg or sperm donor needs to be identified. This can be done through either a known or anonymous donor, but this needs to be a serious conversation to have between the parents and adolescent.<sup>214</sup> Since sperm and oocyte cryopreservation is a viable, safe, and effective options, healthcare professionals should recommend that over embryo cryopreservation for adolescents. In rare cases, embryos can be cryopreserved, but there is the need for donor gametes. Parents or legal guardians should be involved in this decision making process to ensure that the adolescent is not overwhelmed and can fully appreciate the nature and nuances of their decisions. There should also be a discussion of the maintenance and financial expectations with the cryopreservation bank. More than likely these cryopreserved material will be in storage long term. Patients and parents need to be aware of the arrangements of who is paying for how long and when does that financial burden change from the parents to the patients. There needs to be regular contact with the cryopreservation bank to ensure that everything is ok and that the finances are up to date.

For adolescents though, the most important difference is the concepts of assent and consent. For the patients that are still minors, parents still have to give consent in

almost all cases. However, the assent that the adolescent gives has much more nuanced meaning than that of a prepubescent child. These adolescents have started to form hopes, wants, desires, values, and goals for their lives and dealing with a diagnosis can disrupt those plans. They are being forced to think about the future in a real way which may or may not include having children someday.<sup>215</sup> These adolescents should have an important say in the decisions being made not just for their fertility preservation, but for their entire treatment. By including adolescents not just in the discussion, but in the decision making process, it can better integrate them into adulthood and help them to take charge of their healthcare both now and in the future. In some cases, adolescents may be legal adults (over eighteen), but are still live at home with their parents or are in college and on their parents insurance. While legally, they may be adults, their decision making ability may still need to include parents in the process. Having a support system is important in healthcare and these patients are especially vulnerable and parental or legal guardian support is vital to the process of fertility preservation.

### 3. Prepubescents

Prepubescent children create a difficult dynamic for fertility preservation. This age group, typically twelve and under, have not undergone puberty. They have a more limited set of options. Since the child has not undergone puberty, they cannot cryopreserve sperm oocytes, or embryos. It is a widely held belief that it is unethical to force puberty on a child. Because of this only experimental protocols are available for children. The option for prepubescent girls is ovarian tissue cryopreservation.<sup>216</sup> This option is only in the research phase. Ovarian tissue transplantation has never been performed on prepubescent children yet.<sup>217</sup> It is important to understand that just because

the child is enrolled in a research study for ovarian tissue cryopreservation, it does not enroll the girl in a transplantation study automatically. Parents should ask how and when transplantation should be discussed. It is also important to understand that parenthood may not be a want or desire of the children when they are of age to make that decision. For boys that are pre-pubescent, it is also unethical to force puberty. The risk of infertility due to disease is dependent on the type and dosage of chemotherapy.<sup>218</sup> Since sperm cannot be extracted from prepubescent boys, the option here is testicular tissue cryopreservation. There are currently no lives births recorded from this research.<sup>219</sup> Again, the same parameters concerning study enrollments apply to boys as it did to girls.

All of these cryopreservation studies, while important in the knowledge they gained, require that a parent or legal guardian consent. Prepubescent children cannot consent and if assent is done, it should be age appropriate.<sup>220,221</sup> For instance, a two year old will not be able to understand the nuances of illness and the different between treatment and research. However, an eleven year old may better understand that if they are undergoing surgery, the physician may remove a tumor, but also collect testicular tissue in the same procedure. Healthcare professionals needs to ensure that expectations of parents are realistic. The mindset of parents is often riddled with fear, apprehension, concern, survival, treatment, not to mention the risk of infertility in the future. Parents are still expected to make decisions in the best interests of the child no matter their personal feelings or emotions.<sup>222</sup> There is the possibility that the treatment will not affect fertility or puberty, and the child can go back to living a normal healthy life. In those cases, parents should think about what to do with the cryopreserved tissue.

### C. *Other Demographics*

Fertility preservation is expensive and may not be readily available for those who cannot afford it. Most insurance plans do not cover cryopreservation. The socioeconomic status of a patient dictates the issues of access for fertility preservation.<sup>223</sup> Additionally, socioeconomic disparities also play a role in referral patterns.<sup>224</sup> Living in urban or rural locations also can create an unfair access to fertility preservation.

Living in urban or low socioeconomic creates an access issue for not just fertility preservation, but for healthcare in general. Access to primary care physicians, good health insurance, transportation all factor into the issues. In many cases, just having access to things like antibiotics, and vaccinations can be a struggle. Those living in urban areas tend to be diagnosed for disease like cancer at a later stage and their need for treatment quickly is more serious.<sup>225</sup> This means either fertility preservation will postpone treatment too long or it is completely ignored. All patients should be given the option of fertility preservation and the financial impact will be considered, should not determine or prevent someone from preserving fertility.

According to a study from 2010, around 95% of oncologists claim to discuss infertility risks with patients about to undergo cancer treatments, only 38.9% refer patients for fertility preservation consultation with a reproductive specialist and only 30% of oncologists consider fertility when developing a treatment plan.<sup>226</sup> These statistics are troubling considering that those who are already at a socioeconomic disadvantage may not have easy access to their oncologist let alone access to a reproductive specialist. The cost alone could determine some from pursuing fertility preservation. Patients should be given equal access to information and allowed to make decisions of what they choose to



pursue and why. Healthcare professionals should never make judgment of what a patient can and cannot afford, but instead provide options and work with patients to pursue those options.

In another study conducted in 2012, found that age was the biggest factor in demographic disparities.<sup>227</sup> Women who were in their twenties were more likely to be referred to a reproductive specialist than women over age 35. The possible reason for this is the assumption that women over age 35 already may have fertility issues or have already had children.<sup>228</sup>

Other disparities that may factor into referral patterns is sexual orientation and race. In general, not enough data has been collected to effectively detail the rate of referral to a reproductive specialist for those who identify as homosexual. There is a belief that those who identify as homosexual will not have a need to seek fertility preservation, but that is an unfair assumption that has not been proven true or false. As for race, the 2012 study did see a high rate of Caucasian women over Latina or African American, but not a significant rate. Although the same study, did find that African American women did delay in seeking fertility preservation than Caucasian.<sup>229,230</sup>

All of these findings are not a surprise that younger, Caucasian women tend to be referred to reproductive specialist and encourage to seek fertility preservation.<sup>231</sup> It is important that healthcare professionals, particularly oncologist, are well trained to discuss fertility preservation to every patient in every instance. They should be willing to refer interested patients to reproductive specialists.

## V. Conclusion

By examining fertility preservation, one can better understand the complexities that accompany the decision making process. Reasons for fertility preservation due to side effect of disease is unpredictable, just as predicting infertility due to aging. While generalities can be made, specific statistics are hard to calculate because there are too many variables include gender, severity of disease, age, geographic location, type of treatment, dosage level of the treatment, and location of the disease in the body. By understanding the difference between standard of care and research, it becomes clear that those whose only option is research may be in a more vulnerable position. Care should be taken to not mislead patients making difficult decisions that may have a small time frame. There is a need for fertility preservation options and open and honest discussions that best fit the specific patient that a healthcare professional is working with to pursue options.<sup>232,233,234,235</sup> Understanding the standard of care and experimental options are just as important as understanding the possible demographic issues that a patient may be facing as they move forward with their highly personal decision. Healthcare professionals need to do their best to fully explain the risks for infertility, but also the risks of fertility preservation. Because fertility preservation is a preventative treatment, there is a risk that patients may have unrealistic expectations. The hope that patients put in fertility preservation and in healthcare should be addressed.

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## **Chapter Three: Hope**

### **I. Introduction**

Chapter Three seeks to analyze the concept of hope specifically using insights from philosophy and theology. In addition it will detail what hope is specifically in relation to healthcare and research. It will consider the issues of hope in the different contexts and turns. It will discuss related words and even how hope is used as both a verb and a noun. Finally, hope will be examined for authenticity. When hope is discussed, false hope is often brought up. This will take a look at what false hope means, what it does not mean and how that affects someone's approach to hope.

### **II. Defining Hope**

Defining hope is a difficult task without having a case scenario to frame it around. Philosophy and theology have different approaches to defining hope and the worldview of the different writer affect how they describe it. Philosophers like Ernst Bloch, Gabriel Marcel, and Immanuel Kant and theologians like St. Thomas Aquinas, Jurgen Moltmann, and William F. Lynch, have written extensively about hope in various contexts. Hope is a difficult word to define because of the numerous complexities associated to it. Defining hope by itself outside of a context can prove difficult because of its intangible nature.<sup>1</sup> Often when the word hope is used, the person may mean wish, desire, or expectation, all of which are slightly different than hope. Each of these writers defines hope slightly differently. Some prefer outlining the parameters for the outcome itself, while others focus on describing the ability to hope itself. It is important to understand what is meant when using the word hope before trying to discuss it within a context. In the circumstances of healthcare, most often hope is seen and studied in the context of

death and dying,<sup>2,3</sup> but that is not the only place that in healthcare where hope should be considered and discussed.

Hope does have limitations; mainly to what is realistic. Hope should also have an authenticity to it. The hope placed in outcomes should be reasonable and possible. These outcomes however are unknown or beyond the individuals control.<sup>4</sup> Additionally, it should make the distinction between how hope comes about in a given circumstance. Hope can have different connotations depending on the use of the word. It can take a more complex turn because hope can be used as either a noun or a verb. A patient can acquire hope; a physician can foster hope; a patient hopes. This section aims to clearly lay out the definitions of hope and which apply best in the healthcare context.

#### A. *Philosophy*

Philosophers like Ernst Bloch and Gabriel Marcel have written extensively about hope. Even Immanuel Kant in his work commented on defining and describing hope. Ernst Bloch is known for his writings on utopia. His concept of hope focuses on desiring and wishing. Utopia is not limited to just the perfect future, but is demonstrate in the culture around us. Gabriel Marcel wrote about existentialism and the connection of hope to something or someone outside itself. Marcel says that hope only exists when there is trust in something outside of itself. It requires intelligence to have hope or to hope for something. Kant describes hope through possible experience and imagination that is able to be constructed. All of these philosophers connect hope to the future. Hope only exists because there is a motive to improve the present.

## 1. Ernst Bloch

Ernst Bloch was a German philosopher from 1885-1977. He is primarily known for his philosophic writings about utopia and Marxism. His most widely known work is entitled, *The Philosophy of Hope*. Published in three volumes in 1954, 1955, and 1958, Bloch writes about the aim for a utopian society which he describes as the ability to wish and embodying what is wished for.<sup>5</sup> The idea stems from looking at the culture and world around that provides examples of perfection. Unless man lives in a world where fate determines everything, utopia is always a possibility.<sup>6</sup> He acknowledges not that everything is possibly, and those road blocks can make seeking utopia difficult to achieve.<sup>7</sup> In his work, Bloch uses this logic to not only justify, but support the actions of Marxism. Douglas Kellner describes Bloch's work in the following way:

For Bloch, hope permeates everyday consciousness and its articulation in cultural forms, ranging from the fairy tale to the great philosophical and political utopias. For Bloch, individuals are unfinished; they are animated by “dreams of a better life”, and by utopian longings for fulfillment. The “something better” for which people yearn is precisely the subject matter of Bloch's massive *The Principle of Hope*, which provides a systematic examination of the ways that daydreams, fairy tales and myths, popular culture, literature, theater, and all forms of art, political and social utopias, philosophy, and religion – often dismissed tout court as ideology by some Marxist ideological critique – contain emancipatory moments which project visions of a better life that put in question the organization and structure of life under capitalism (or state socialism).<sup>8</sup>

Kellner goes on to describe Bloch's work as one that is not just about negatively critiquing ideology, but rather finding the positive utopia. Bloch is developing a philosophy of hope for the future, which looks forward to a utopia.<sup>9</sup>

According to Jack Zipes, one of the major criticisms of Bloch's work is that he labels the opposing views, (what Bloch calls bourgeois) as irrational and does not take the time to refute it, but just dismisses it.<sup>10</sup> He describes Bloch's view of utopia is based in an active hope or belief.<sup>11</sup> The utopia that Bloch describes is one that fits into a Marxist worldview while moving towards something better than the present.<sup>12</sup> While Bloch's work title contains the word *hope*, what he is really describing is the possible future. This use of the word *hope* is very typical in literature in that word is actually being used to describe varying things. What Bloch is describing is placing faith, trust, wishes, and beliefs in a desired future- mainly utopia. The existence of hope (of beliefs, wishes or desires) highlights the troubles in the world around us and moves us to search out utopia.<sup>13</sup>

## 2. Gabriel Marcel

Gabriel Marcel was a French philosopher from 1889-1973. He is identified as one of the earliest known existentialist, focusing on technology's influence on society. His most well-known work, published in 1951 entitled, *The Mystery of Being*, focuses on existential philosophy. His focus on Christian existentialism distanced himself from other atheistic philosophers of his day. As an existentialist he wrote about the material, the physical realm. In his description of hope, one can see that as an existentialist he connects hope to something tangible, and permanent.<sup>14</sup>

Hope as described by Marcel is the relation to something outside of itself that is brought about on the basis of trust.<sup>15</sup> This means that hope has to have a connection to something or someone else so long as it is plausible.<sup>16</sup> Martin A Bertman describes Marcel's stance on hope as an aspect of experience, rather than from desire because hope is based in intelligence.<sup>17</sup> Because of this intelligence, hope is focusing towards something meaningful, while desire is temporal or even impatient.<sup>18</sup> Hope, for Marcel, ultimately has a connection to salvation, love and Christianity. Hope is rooted in the belief in Christianity and the ultimate hope for the future is based in that. Those who are non-believers can hope, but it more closely resembles desire or even wishing.<sup>19</sup>

The criticism of Marcel is that there are times when hope and desire are not as dissimilar as Marcel's claims.<sup>20</sup> The argument is that desire and hope can feed into each other which mean that desire and hope can both be based in intelligence and the temporal while still having meaning. Hope ultimately keeps possibilities open and that openness is to something difference or better than what is in the present.<sup>21</sup> It is looking to something greater to interact with and make a change.<sup>22</sup> Hope keeps the individual looking outward and moving forward in order move one from something that brings despair to pursue something that has been deemed valuable by the individual.<sup>23</sup>

### 3. Immanuel Kant

Immanuel Kant was a German philosopher from 1724-1804. He is known as one of the most famous modern philosophers in the world. His most famous work, *Critique of Pure Reasons*, focused on the relationship between reason and human experience. His deontological theories, also known as Kantianism, focus on duty dealing with epistemology and ethics. Within Kant's ethics is the categorical imperative. Kantianism

discusses the concept of what is possible versus what is actual. Hope is often discussed within the context of possibility. Sydney Axinn asks the question, “Can one hope for anything one desires, even for something inconsistent or irrational? Are we not free to think what we wish, or hope what we wish? The Kantian answer is, ‘No.’”<sup>24</sup> This is because according to Kant’s postulate of possible, possible is not based on thought or logic, but on possible experience.<sup>25</sup> This means that if a person imagines to hopes for something, it must not just be possible, but a possible experience. In order to imagine something, based on Kant’s work, one must be able to construct it. If a person is unable to construct what he or she is hoping for, that it is unreasonable hope.<sup>26</sup>

#### B. *Theology*

For theologians, hope is described in relation to God and Christianity. Hope is a word that is found in the Bible, often relating to faith and love. St Thomas Aquinas was one of the earliest writers about hope. His focus for hope is on the realistic and what is possible. His description of hope grows out of his discussion on the existence of God and the purpose of man. Jurgen Moltmann’s approach focuses on the hope of a specific future, based on the promise given by God. God’s promise for and fulfillment of salvation is a demonstration as to one can hope. William F. Lynch focused his description of hope based on imagination. He is the most practical of the writers in that he gives parameters of what can be hoped for and what is simply a want or desire.

##### 1. St. Thomas Aquinas

St. Thomas Aquinas was an Italian Catholic priest from 1225-1274. He is known as a philosopher that wrote extensively about topics such as theology and epistemology. His work *Summa Theologiae* was written in 1265-1274, focuses on basic theology of the



Catholic church including the existence of God and the purpose of man. Aquinas identified faith, hope, and love as three theological values that work best together.<sup>27,28</sup> Aquinas further says that love without faith and hope is impossible.<sup>29</sup> Faith is the first virtue, but must have hope and love. This theological virtue of hope is not the same as passion of hope.<sup>30</sup> This is essentially the difference between hoping for something and having hope. The passion of hope is a feeling, which is an internal response to an external something. Theological virtue of hope is just the opposite. It is an internal decision moving towards an external something. For Aquinas, God is the definitive object of hope.<sup>31</sup>

Aquinas wrote about hope within his book, *Summa Theologiae*. Aquinas simply says that hope is for a future good that is difficult but not impossible to achieve.<sup>32</sup> Essentially, there has to be realism and struggle for hope to be present. People have to be able to reason through realistic options and possibilities. If the thing someone is hoping for is unattainable, then there is no purpose to strive for it. If something is too easy to attain then there is no effort to make it worth hoping for. Aquinas also discusses that within the concept of hope that has to be rational thinking and the ability to make judgments. For instance, if one hopes for a cure from an illness, that one has to rationally understand what it means to be healthy or ill. One has to be able to judge if there is improvement or decline in health. By hoping to get better, this person is aiming for realistic possibility of health (due to the nature of colds not being life threatening) and the ability to strive for it (by resting, drinking fluids, taking medication). According to Donald Penelhum, hope is somewhere between the despair and presumption.<sup>33</sup>

Aquinas does warn against in putting hope in other people.<sup>34</sup> This is due to the belief that man is born with a sin nature and is unable to do right all of the time. Even for those who believe they are doing right, it may not be the right that the person hoping is aiming for in this specific instance. It is impossible to guarantee that the other person will participate.

## 2. Jurgen Moltmann

Jurgen Moltmann is a German, reformed protestant theologian born in 1926. His most well-known work is *Theology of Hope*. Moltmann connects faith in Jesus hope of the resurrection together. He wrote about liberation theology with culminates in the hope of the resurrection of Jesus. In today's world, while one hopes for the future, one cannot achieve that in the current world because it is filled with sin and depravity. Moltmann's description of hope is about promise of a specific future.<sup>35</sup> The resurrection of Jesus in the New Testament was the fulfillment of a promise made God in the Old Testament. Because of this hope of the resurrection, Christians have something to build their own hope on.<sup>36</sup> For now, the world is not perfect, but there is the promise from God that it will be one day, and since he has fulfilled other promises in the past, he is trustworthy for the future. Knowing that the world is filled with sin, man can still focus on God's promise for the future. The focus is not on what the world is not, but more of what it can be someday.<sup>37</sup> There is hope of God fulfilling his promise.

One of the criticism of Moltmann's *Theology of Hope*, is the focus on Christianity and theology itself. Additionally, there is criticism of links to politics. Moltmann was heavily influence by Ernst Bloch, who as discussed earlier, focused his writing on the

hope of utopia and its use in Marxism. David P. Scaer writes that Marxism and theology have similarities in focusing on the changing society.<sup>38</sup>

### 3. William F. Lynch

William F. Lynch was a writer from 1909 to 1987. While he was a Jesuit priest, he also was a college professor and psychiatrist and author of many books about philosophy, literature, and theology. His book, *Images of Hope: Imagination as Healer of the Hopeless*, sought to address the psychology of hope and its connection to imagination. His focus of hope was in the realm of mental illness and the overwhelming presence of hopelessness. He describes hope in its relation to help, wishing, and even specifies that there is a growth or maturation process with hope.<sup>39</sup> Lynch believed that there was a cultural issue in an attraction to hopeless over hope, and despair being too connected to hope.<sup>40</sup> Those who said, they hoped for something were actually aware (maybe too much) of the despair they are in and hope is a last ditch effort. Instead of focusing on the hope itself, people are actually focusing on the despair. Donald Capp writes about the three central ideas in Lynch's book:

1. The first is the equation of the life of hope with the life of the imagination, that is, the realistic imagination.
2. The second is that this imagination is not a private affair but an act of collaboration or mutuality.
3. The third is that there is a strong relationship between hoping and wishing.<sup>41</sup>

Capp writes that hope and its connection to the imagination allows for a wider perspective than the present situation.<sup>42</sup> Wishing has no limitations, but once realistic

possibility sets in, there is the presence of hope. This does not mean that the end result is easy to obtain, but it must be at least plausible.<sup>43</sup> It is recognizing the current situation for what it is and focusing on a way out of that current situation.<sup>44</sup> Lynch argues that is one veers outside of what is realistic and is unaware of the limits of hope, then hopelessness and despair set in.

A criticism of Lynch, by Christy Simpson is that Lynch seems to assume that hope and imagination always heads towards the positive.<sup>45</sup> In some cases, imagination can go negative to worse case scenarios and that does not lead to hope, but rather to despair, concern, fear, and avoidance. There are even some who despite knowing the limits of hope, may still hope in unrealistic imagination and set themselves up for disappointment.

### *C. Comparisons of Descriptions of Hope*

These theologians and philosophers have defined hope based upon their worldview. It has influenced how the rest of the world approaches and defines hope. There is commonality in their approach to hope. Hope is more than a feeling. As Thomas Aquinas described there is a difference between the passion of hope and the theological virtue of hope. Hope is can be described as a belief, desire in a specific future. Most of these writers focus on the positive nature of hope. People are hoping for something. That something has to be determined. Hope cannot be for something vague. For Bloch, hope was in utopia, but for Marcel it is hope for something specifically outside of itself. The determination of what to hope for is based on the ability to understand the current situation and to make a judgment of what could take place. Hope requires an imagination which means the ability to think about the current situation with a

different outcome. Both the philosophers and theologians focus on the positive outcome, hoping for a better situation than before. However, there are cases when someone may hope for the absence of something or are hoping to avoid something worse than the current situation. For the theologians, hope has a connection to God and without that basis, hope is no longer hope, but rather wishes or wants. There is also a problem with hopes of people may conflict. These authors address the individual hoping, but what about hope of more than one person. Lynch describes hoping as a collaborative process, but the collaborative is in the effort to reach the outcome, not in deciding what to hope for.

### **III. Aspects of Hope**

There are many different aspects to hope. Hope can be described in many different ways, with many different contexts. Each situation highlights something different. Based on the discussion of the definition and descriptions of hope in the previous section, this section aims to look at three things.

First, hope in differing terms. Context for how hope is used is important to understanding the discussion. One can better comprehend how hope is defined by examining it in a specific situation. Hoping for something has a specific description to it. Living in hope is more vague and existential. It does not require details to the situation, but rather a demonstration of action. Hope can be specific to a situation or it can be a state of being.

Second, the key factors in hope will be examined. Words like desire, want, wish, belief are all used interchangeably with hope many times, but there is a slight difference in the mean and implication of each of those words. Concepts like imagination, the future, possibility, uncertainty and realistic all are associated with hope in how it is

described. These synonyms needs to be considered so there is a clear understanding of hope.

Third is the word usage of hope. When hope is used as a noun or a verb it can mean very different things. Hope as a noun is an object that can be given or taken. It implies that something can do to make hope appear or disappear. When hope is used as a noun, the focus tends to be on the hope itself, how to get it, how to keep it, how to lose it. Hope as a verb reflects an action taken by the person who does the hoping. It gives action to the person. Hope as a verb focuses the potential future outcome. Hope is simply one of the means to the end. This does not mean that using hope as a noun versus a verb is right or wrong. There needs to be clarity in the discussion as to what the purpose of hope is and is not. By considering hope in differing terms, key factors, and word usage, it clears the way to discuss hope within a specific context like healthcare or more specifically in fertility preservation.

#### A. *Hope in Differing Terms*

In order to better understand hope, context needs to be discussed. By providing descriptions and parameters, hope moves from being a feeling to a practical virtue that can participate in a given context. Hope can be specific to a situation or it can be a state of living. Living in hope can be vague and non-specific. It comes across more as a state of being. This type of hope can be unclear when try to explain it or define it. When someone hopes for something, it has a specificity to it. There is an identified outcome or future.

Judith Fitzgerald Miller writes about hope within the context of nursing and pulls useful observations from her experience with hope and patients who are dying.<sup>46</sup> She

argues that hope is essential to life. If one does not have hope, one does not move forward in life. She describes hope in two ways: living with hope and hoping for something.

Living with hope is complex state that has no specific outcome in mind. It is a general way of being that does not consider the reality of situation. This is the nature of hope, it describes what hope is.<sup>47</sup> For Fitzgerald Miller, this is dangerous when dealing with end of life patients.<sup>48</sup> Living in a perpetual state of hope, means living in a state of denial. The patient is unable to identify the reality of death and the finality of life. Futile treatments are sought out and attempted based on the push to keep hope alive. While it may keep the patient in a positive mood, it also can make those around uncomfortable or unable to deal when death happens. It is important to seek closure at the end of life, not just for the patient, but for those around them. Facing death is a process that will eventually leading to dealing with grief. If a patient is living in hope that they will not face death, it is can be hard for them to have tough end of life discussions. Death is inevitable; no makes it out of this life alive. There is nothing wrong with being positive and focusing on the good in life, but living in a state that is unrealistic. This is reminiscent of Ernst Bloch's description of hope. Bloch describes hope in its relation to utopia.<sup>49</sup> As Bloch encourages people to look at culture for examples of utopia, it can keep a person from understanding the realistic issues around them. While there is nothing wrong with setting future goals, making an effort to have a good life, or avoid suffering, it does not guarantee that everything will go smoothly. While Bloch does discuss the roadblocks, it is not necessarily used to decide an outcome to hope for.

Rather noticing the roadblocks is just that- noticing. In the end of life illustration, the roadblock is death. It does not change the outcome- living in hope.

Hoping for something on the other hand has a specific context. It gives a personal narrative to the discussion. It provides a context and a framework for the realistic, possible future outcomes making it much easier to understand.<sup>50</sup> According to Kant, having the ability to construct what one is hoping for aids in the personal narrative of hope. These outcomes however are unknown or beyond the direct control of individuals.<sup>51</sup> Nothing in life is definite and the same is true regarding hope. This type of hope, is really describing the characteristics of hope.<sup>52</sup> This includes possible experience, imagination, and ability to construct what is being hoped for. According to Webb, when a person hopes towards something, it is important to have basic trust and feeling of safety and security.<sup>53</sup> Trust, especially in the healthcare setting, is between the many different stakeholders. This could include the patient, a healthcare professional, family and friends. The feeling of safety and trust comes from having experience. Knowing (because of the ability to construct the goal) provides the feeling of safety and security to continue hoping. It does not actually provide security or safety, just the feeling of them. By hoping for something, a person is automatically goal and future minded. St Thomas Aquinas emphasized the importance of being future oriented which also must be possible, but difficult to achieve.<sup>54</sup>

#### *B. Key Factors*

Within the philosophical and theological definitions and discussions of hope, authors find commonality. Hope can be describes in terms of desire and wants,<sup>55</sup> relation to the future,<sup>56,57</sup> and imagination.<sup>58,59</sup> Most often discussions on hope usually



have two key factors: realistic possibility and the future. In order to better understand hope, it is important to know what other factors play into the discussion and how that affects context. According to Christy Simpson, there are four aspects of hope that need to be considered when describing hope.<sup>60</sup> First are the desires and wants. Second is the connection to values and goals. Third is the role of imagination and uncertainty. Fourth is the action component. The four components were identified because hope is directly tied to an emotional attitude.

#### 1. Wants and Desires

Hope as desires or wants is one of the most common descriptions.<sup>61</sup> Hope at its most basic level involved the need, want, or desire for a specific future outcome for an individual. These wants or desires can branch either out of the current circumstance or the second aspect of connection to values and goals. When describing hope, many times the word want or desire can easily replace hope and the context would still make sense. However, want or desire is not always the same.

#### 2. Connection to Values

Hope that is identified and held is a reflection of their values and reveals meaning and importance of their lives.<sup>62</sup> When dealing with a serious illness, understanding the meaning of life and clinging to ones' values can become very important and reinforce the idea and action of hope. Hope roots itself in the goals of "promise, potential, provision of curative treatment for a disease."<sup>63</sup> However, goals or values can change or be prioritized differently in the face of serious illness.<sup>64</sup> This instance tends to reflect a long standing belief, like living to old age or refusing to compromise morals. Values are different for each person and therefore hope can manifest itself differently.

### 3. Role of Imagination and Uncertainty

While the description of imagination and uncertainty may seem a little out of place when dealing with a serious medical concern, they play an important role in the description of hope. Imagination and uncertainty allow the individual to look forward beyond the time of illness or disease. It allows for the creation of a future.<sup>65</sup> It builds into the desires, wants, goals and values of that individual as well. Imagination is a powerful motivator in creating hope.

### 4. Action Component

The action component of hope mainly refers to hope as a verb. The individual hopes for something; the individual conducts themselves in a way indicating hope. This could be as simple as taking medication or continuing with a specific medical treatment.<sup>66</sup> This action whatever it may be not only instills the idea of hope, but also helps to reach the outcome that is hoped for by the individual. This means that there must be something to hope about. Hope in its most general state, can fall flat. It may not inspire someone to take initiative. Hope with action is specific. It gives context and meaning to the situation.

### C. Word Usage

Understanding how hope functions as a part of language can aid in the examination of hope. Jaklin A. Elliot and Ian N. Olver write about hope focusing on the two different it as a noun and a verb.<sup>67</sup> This means depending on the context, hope functions in two different roles. When someone uses hope as a noun it reads like this, “Hope changes people’s lives.” It is more of a general statement that a specific context.<sup>68</sup> As a verb, it would read, “I hope this book changes someone’s life.” It is more of a

specific statement as opposed to the general concept.<sup>69</sup> There is a distinct difference in what these words are implying. This different uses of the word, *hope*, is sometimes one of the explanations as to why it is so difficult to define or describe.<sup>70</sup> The context changes and so does the connotation. Even within the same conversation, a person can use hope as a noun or verb interchangeably.<sup>71</sup> There are even times when hope is used as an adjective (hopeful) or an adverb (hopefully).<sup>72</sup> Those words are simply used as descriptors to add to the main text so they will not be discussed here.

When hope is used as a noun, is an object that can be given or taken. Something or someone acts in a way to change the idea or amount of hope. In this case, hope can be quantified which reinforcing it as an object. Therefore hope must have an object or a state that it is also affecting.<sup>73</sup> Hope is something that can be possessed.<sup>74</sup> By possessing hope, someone can feel encouraged, optimistic, happy, or joyful. It is in these situations that hope should be fostered and encouraged to at least maintain a consistent level of hope.<sup>75</sup> According to Begley, hope can be desired or one can place confidence in it.<sup>76</sup> To just desire something it to lust after it, but to hope, there is confidence that understands that something good can take place. Taking it one step further, hope can even be identified as a resource or motivator for a specific action or feeling. For instance, one could say, “Hope sustained her in the tough times.” That is not to say that without hope she would not have survived or that hope is the only resource she relied on. Instead it just attributes some of the success to a concept that kept her optimist and looking towards the future. The more that hope is instilled, the more it aims to dictate a specific action or idea.

There is also times when hope as a noun is in the negative context. One could say, “There is no hope.”<sup>77</sup> This phrasing is more similar to the feeling of hopelessness, despair, or disappoint. It could also mean that there is a loss or absence of hope.<sup>78</sup> In these cases, it is usually because someone faced a situation where the outcome was not as expected. Hope let someone down, it made the person feel discouraged. In those situations, it can be hard to foster hope. Bad experiences have a way of defining people internally.<sup>79</sup> When saying there is no hope, it implies futility and in the case of healthcare that means there are no more medical options. A patient may have to face the reality of death.

When hope is used as a verb, is usually implies the idea of possibilities. There is also an element of the unknown and the future being outside of the individual’s control. Hope as a verb reflects an action taken by the person who hopes.<sup>80</sup> It implies the possibility of a positive future.<sup>81</sup> To hope is to have a wish for a future outcome, to trust or believe in something.<sup>82</sup> It looks at this possibility with anticipation or excitement.<sup>83</sup> It stems from imagination and seeks to better what is the current situation. Positive outcomes could mean many different ideas for patients - whether it is a complete cure, prolonging life, or managing symptoms, amongst other outcomes. It allows patients to see and chose to hope in outcomes for which they see as possibilities. Hope as a verb is about possibility in the future, not about promised and foregone conclusions. Because hope as a verb does not guarantee any outcomes, it allows the patient to change their mind and to dream and imagine new possibilities. There must be a limit to these possibilities however, otherwise, the hope turns into wishing. In contrast to hope as a noun, hope as a verb makes the person the subject of the situation.<sup>84,85</sup> Joe hopes he get

the new job. Mary hopes she is not seriously ill. Matt hopes to get married one day.

Hope as a verb tends to be more focused on the future than hope as a noun.

There are cases where hope as a verb can go negative too. In those cases (similar to hope as a noun) reflecting on something that has happened. One can say, “I had hoped the treatment would work, but it did not.” This response confirms that what someone had hoped for did not happen as the person wanted. The possible, future outcome was not to be expected. In healthcare, this usually means that a treatment or medication did not work. The body did not respond as was anticipated. It can be discouraging to the patient when this happens. Trying to get that person to hope again can be a struggle.

#### **IV. Authenticity of Hope**

One of the biggest concerns regarding hope is making sure that hope is authentic or preventing what is often called false hope. Some argue that in order to create true hope there is a direct connection to trustworthiness and honesty.<sup>86,87</sup> Others write that hope can be authentic when connected to autonomy while protecting the vulnerable to prevent exploitation.<sup>88,89</sup> Hope is limited to what is realistic.<sup>90</sup> Hope must base itself in the concepts and outcomes that are possible. When a patient hopes in a specific outcome, it is important that the outcome is within reach. In healthcare, this can be a delicate balance because research is conducted with hope of a certain outcome, but that does not guarantee it. In order to better understand the realism of the hope, a patient must have an honest, truth-telling relationship with any member of the medical team, whether a physician providing recommendations or a researcher conducting a research protocol. If hope is not based in realism, then one is being set up either by their own expectations or someone else's, to fall into the trap of hopelessness which can lead to despair and

resentment. When patients know and understand that their hope is limited to that which is realistic, it becomes authentic hope.<sup>91</sup> Hope because of the importance of being realistic and authentic, hope will vary.<sup>92</sup>

Hope needs to have an authenticity to it in order for it to be the best version of itself. In order to foster hope, the authenticity of hope needs to be rooted in truth-telling and a balance between beneficence and autonomy. There is an argument made by some that beneficence should be the most important principle even over riding autonomy.<sup>93</sup> While some may do this in order to create hope, it is not authentic hope. It fails to foster hope that has a realistic outcome, that is possible, that is both something that one can gain and do. In order to foster this type of hope, there must be a relational aspect to hope. It connects the patient, the family, the healthcare worker to each other, all feeding off each other to foster realistic, authentic hope.

#### A. *Hope and Healthcare*

Adrienne Martin identified two ways that hope tends to be approached in healthcare. First is the approach to hope studying its relation to physical and mental health. It is a set of beliefs about oneself as it relates to healthcare. This is similar to the concept of living in hope. The second approach is hope as a commodity. This is to hope in something. The first approach, hope as it relates to one's self, was used to create Snyder's Hope Scale back in 1991.<sup>94</sup> The premise is that people are goal-oriented. This scale measures hope based on the individual looking inward. The test itself does not evaluate the type of goal that the individual is aiming towards. The difficulty in any of these, is trying to measure a feeling or intangible concept.

## 1. Snyder Hope Scale

Snyder defines hope as “cognitive set comprising agency (belief in one’s capacity to initiate and sustain actions) and pathways (belief in one’s capacity to generate routes).”<sup>95</sup> This scale was developed as way to self-evaluate hope. There are 12 statements. The first four evaluate pathways thinking. This is belief in one’s capacity to generate routes. Pathway thinking is the planning of how to meet one’s goals. The next four are to evaluate agency thinking. Agency thinking is the motivation or energy to generate the routes. The remaining four are filler statements.<sup>96</sup> The statements are as follows:

1. I can think of many ways to get out of a jam. (Pathways)
2. I energetically pursue my goals. (Filler)
3. I feel tired most of the time. (Agency)
4. There are lots of ways around any problem. (Pathways)
5. I am easily downed in an argument. (Filler)
6. I can think of many ways to get the things in life that are important to me. (Pathways)
7. I worry about my health. (Filler)
8. Even when others get discouraged, I know I can find a way to solve the problem. (Pathways)
9. My past experiences have prepared me well for my future. (Agency)
10. I’ve been pretty successful in life. (Agency)
11. I usually find myself worrying about something. (Filler)
12. I meet the goals that I set for myself. (Agency)<sup>97</sup>

For those which are labeled pathway (#1, 4, 6, 8), each sentence reflects solving an issue or problem. For example, number 6 reads, “I can think of many ways to get the things in life that are important to me.” As a pathway statement its purpose is to evaluate whether the personal believes they have the ability to generate a route to get to a solution(s).<sup>98</sup> For those labeled agency (#3, 9, 10, 12), each statement is determining the energy/successful of the person taking the test. For example, number 10 reads, “I am pretty successful in life.” As an agency statement its purpose is meant to evaluate the motivation to reach those routes. It gives a sense if the person is headed in the direction they are headed.<sup>99</sup> For those labeled filler (#2, 5, 7, 11), these statements give an over of what would affect pathways or agency.

So when taking the evaluation, the original design was to rank each state on the following four point scale: 1) Definitely False, 2) Mostly False, 3) Mostly True, and 4) Definitely True.<sup>100</sup> The goal is to total the points from 12-48. The higher the score, the more hope someone has. Originally this scale was test on college students. One of the conclusions is that pathway and agency are indistinguishable on the scale.<sup>101</sup>

These numbers were compared to the actual goals that the students set for themselves. The study revealed that those who had a higher score, set harder goals for themselves.<sup>102</sup> It is difficult to know why this is true, but for those who score higher and set harder goals, they appear to experience smaller risk factors. This is due to their agency of being hopeful and accomplishing their goals.

## 2. Children’s Hope Scale

After the success of Snyder’s Hope Scale, he created one that could be used to evaluate children ages 8-16.<sup>103</sup> It uses the same concepts of pathway and agency.



Developed in 1997, the idea came from the concept that if sick children can think hopefully than they can imagine a future where are no longer sick, or at least better than they were. If these children are goal-oriented as, assumed by the study, than there is a constant need to continue creating new goals.<sup>104</sup> Overall, the relationship between children and goals is has shown that children who meet their goals feel positive, while those who struggle feel negative.<sup>105</sup> While the initial thought is that this scale applies to physical health, there is consideration that it could apply to mental health as well.<sup>106</sup> There are six statements. The even numbers evaluate pathways thinking. The odd numbers are to evaluate agency

1. I think I am doing pretty well.
2. I can think of many ways to get the things in life that are most important to me
3. I am doing just as well as other kids my age
4. When I have a problem, I can come up with lots of ways to solve it
5. I think the things I have done in the past will help me in the future.
6. Even when others want to quit, I know that I can find ways to solve the problem.<sup>107</sup>

So when taking the evaluation, the original design was to rank each state on the following six description scale: None of the time, A little of the time, Some of the time, A lot of the time, Most of the time, and All of the time. The results of the scale showed similar results found in the adult hope scale. Those who were found to be hopeful, were goal-oriented, and set high goals for themselves purposefully.<sup>108</sup> The reason is that those who set high goals did so because they knew they could reach them.<sup>109</sup>

### 3. Evaluation of the Hope Scale

These studies, as with all studies, have limitations. Snyder's premise is based on the intersection of goals, pathways, and agency. His interrelationship approach is unique, but it leaves out other descriptions of hope including optimism. Snyder also assumed that children behaved the same way adults do, which in subsequent studies is only true some of the time.<sup>110</sup> Both the adult scale and the children scale are used to evaluate goals that are tangible. For Snyder, he compared the test score and academic achievements of college and high school students.<sup>111,112</sup> These goals are things that the individual can take action to increase the odds to achieve them. This same strategy may not be as applicable in healthcare. While one can take medicine or consent to a procedure, one cannot force the body to heal itself or to improve by action alone. Healthcare professionals have noted over the years that health care is both a science and an art form. It is unpredictable.

#### *B. False Hope*

Hope that is based in fiction or a false reality leads to the term known as false hope. Unrealistic expectations sometimes set of an individual for disappointment. Hope must be based in reality.<sup>113</sup> Hope that is not based in reality can leave a patient vulnerable and there is a risk for exploitation or manipulation.<sup>114</sup> When the patient, the family, and the healthcare professional are honest and realistic with the circumstance, hope that is realistic and authentic is fostered.<sup>115</sup>

There are some like, Charles R. Snyder, who do not believe that false hope exists.<sup>116</sup> As the developer of the hope scale, he is well versed in the discussion about hope. He argues that hope is a sliding scale that can either be more or less, but the term false hope is incorrectly used. The term false hope is an illusion and should not be used.

He prefers the term loss of hope which implies that it move to a lower point on his hope scale. He writes that hope is lost when goals are undermined.<sup>117</sup> He cites three criticism of why the term is inappropriate.

1. False hope are illusions that are out of touch with reality.
2. False hope are built on inappropriate goals.
3. False hope reflects poor planning.<sup>118</sup>

Snyder's criticism of false hope is based on his own, though well known, definition of hope based on goals, pathways, and agencies. The problem is if one does not subscribe to his definition of hope, that his criticism of false hope is mute. Paul Kwon notes that Callahan who argues about the importance avoiding false hope and fostering genuine hope<sup>119</sup>, his definition of hope is different than Snyder's.<sup>120</sup>

For the purposes of this dissertation, the definition previously established will continued to be used while discussing false hope. Hope being the ability to believe in a future outcome that is realistic as possible. Based on this definition, believing in something that is unrealistic or impossible is false hope.<sup>121</sup> It is wishing or wanting, but it is not hope. It might be described as misguide hope or unrealistic hope. False hope would better be described as hope that is untrue. Meaning the person that claims to be hoping is not really hoping in whatever they are claiming.

For better clarity, the issue is not whether or not false hope actually exists. It exists based on the definition society as assigned it. Meaning, that false hope is the same as misguided hope or unrealistic hope or even wishful thinking.

## 1. Hope and Imagination

Hope is not the same as doing. Hope cannot heal. Hope cannot restore. Hope cannot prevent. Hope is not a promise. Hope is not a guarantee. Hope can motivate. Hope can encourage. Hope can inspire. Hope is limited by two main things: imagination and possibility.<sup>122</sup> Hope can only be hope when the imagination is involved. Imagination is only limited by the individual. Imagination is free; it does not require education or creativity. Imagination is a thought process that allows the mind to wander. For hope, imagination is important. Imagination allows one to dream, desire, or fantasize. Imagination pushes the boundaries of what is possible.<sup>123</sup> Inventions and discoveries would have never happened without imagination. However, imagination is reined in by reality and possibility.

## 2. Unrealistic Hope and What is Possible

Now that false hope, misguided hope, and unrealistic hope are all identified as the same thing, it is important to understand what is meant by unrealistic. This term is a subjective word. It implies that something is not based in reality, but that may not be enough. Using additional descriptors like possible and probably help to create a better understanding.<sup>124</sup> By trying to define hope, false hope, unrealistic hope, it ends up being a game of words and alternating definitions. It is easier to just try to clarify exactly what is meant rather than try to define the term (that may actually use the wrong words anyways).

For instance, someone can hope there is a pizza in the oven. It is completely reasonable to think that someone made dough, added sauce, cheese, and pepperoni to the top. It is even reasonable to think that a mom is baking pizza in her oven. If the day is

Friday and mom always made pizza on Fridays when one was growing up, then again it is a reasonable assumption. Now, if a mom even mentioned that she would be making pizza on Friday when you visit, the hope that there is pizza in the oven is a belief in something that is possible and realistic. However, if anyone of those parameters is known to be false, than hope has become realistic. For example, if one knows that Mom is sick and has not been to a grocery store to buy ingredients, than hoping for a pizza in the oven is impossible. This may seem like an overly simplistic example, but it makes understanding the concept of realistic and possible easier to grasp. Hope in something unseen is to be expected. Hope in something that is not a one hundred percent guarantee is to be expected. However, hope is misguided if one bases it on false or inaccurate information.

In the case of healthcare, this is where healthcare professionals need to be proactive in preventing false hope. Patients are not medical experts, there are many who are well read, highly intelligent, but they are not the expert. It is vital that a healthcare professional inform the patient of truth and any false information that is affecting the patient's judgment.

### 3. Despair and Disappointment.

The opposite of hope is despair and disappointment.<sup>125</sup> It is the belief that nothing good will happen in the future, or that every option is impossible or unrealistic. Despair keeps someone from feeling hope. It leaves one feeling hopeless. Lynch wrote that hopelessness is the sense of impossible, too-muchness, or just a lack of feeling.<sup>126</sup> It is leaves the person feeling only futility. Hopelessness grows just as hope can die. One of

the ways to combat hopelessness is to confront it.<sup>127</sup> Hope than has the opportunity to grow. This is why fostering hope is so important.

#### 4. Fostering Hope

Also known as nurturing hope, fostering hope is important. Being hopeful for good outcomes and impressive goals keeps humanity moving forward. By fostering hope, one encourages people to think beyond themselves. William F. Lynch says that the best way to grow hope is to live contextually.<sup>128</sup> It means having an understanding of the world around you. It means getting outside of one's own head and into the world. When one does this, one fosters hope. It deepens and grows. There is a risk when trying to nurture and instill hope. If the outcomes that had been hopes for does not happen, the patient may turn very quickly to despair.<sup>129</sup> When talking about hope in healthcare, hope in a future outcome is not the same as hope for a cure. Hope for a cure is not an unrealistic or impossible outcome, but it needs to be managed with probability. This is where healthcare professional keep the conversation honest. The healthcare professional cannot provide hope.<sup>130</sup> Hope is from the perspective of the patient and healthcare professionals cannot predict the future one hundred percent of the time. They can evaluate diagnosis, prognosis, risk, and benefits, but it is not a fool proof system. Even patient temperament plays into how a patient accepts information and responds with hope or despair. When fostering hope a key element is to consider quality of life. This takes into account how the patient wants to live his or her life. Fostering hope can connect the patient and healthcare professional in a meaningful way that creates a trustful relationship.<sup>131</sup>

## V. Conclusion

Hope as a realistic possibility and hope in the future allows for authentic expectations and understanding of a given situation. However, without understanding how the individual is using the word hope, it is difficult to manage and to foster such a concept. Defining hope can be a difficult task and it can be a question that goes in circles. Moving forward, the definition of hope that will be used is one that says hope is a belief in a future outcome that is based in reality and possibility.

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## **Chapter Four: Hope in Fertility Preservation**

### **I. Introduction**

Chapter Four will examine the ethical role of hope in its relation to fertility preservation. It will discuss why hope is different in this context as opposed to other areas of healthcare. It will address the communication of hope to the patients in fertility preservation. It will analyze what role and impact the notion of hope is playing in the interactions between patients and health professionals. Hope is defined with the concepts of the possibility and future, and fertility preservation has those same two components. In the previous discussions though, both hope and fertility preservation were discussion in the abstract, and in reality, they are part of a personal narrative for patients and families.

There is a shift from the abstract concept of fertility preservation and hope to a personal discussion of the relation between these two. Fertility preservation has standard of care options of sperm, oocyte, and embryo cryopreservation. Research protocols include ovarian and testicular tissue cryopreservation. These methods have estimated success rates that change and adjust on a regular basis. However, the probably of having success can be more closely determined when dealing with a specific patient. Hope is defined as a belief in a future outcome based what is realistic and possible, the personal experience and information affect the reality and possibility of the situation. With specific information, one can better understand what is realistic and possible.

In fertility preservation the considerations for what is possible deals with addressing the two perspectives- that of healthcare professionals and patient. Healthcare

professionals are expected to know and understand their roles and responsibilities, how to function as part of a team, respect and adhere to professional standards, and how to address conflict of commitments. Patients need to remember their roles as the primary decision maker, an advocate, and the sick role. Together the healthcare care professional and the patient relationship is critical accomplishing anything in healthcare. It is important for the healthcare professional to attempt to know the patient as a way to establish trust and be transparent. The trust that is established in this relationship allows for the patient to have an easier process of decision making, both in the decision to preserve fertility and the later decision to attempt to get pregnant.

In fertility preservation, the considerations for what it in the future and how to address the future centers on determining values and quality of life. Patients need to consider what is important and how to go about accomplishing that. Fertility preservation is a way to attempt to have genetic children, even if the patient is deemed to be infertile. It is necessary to consider why there is such an importance place on genetic (biological) children. The desire for children is strong and it follows a linear narrative that is determined by tradition. However, there are alternative ways to seek to have children that do not involve genetics. The potential for grandparenthood as a future outcome can also steer parents to make decisions for their child. Grandparenthood is a conflict of interest and should not factor into the decision making or consent process to determine if it is appropriate for fertility preservation in minor patients. The question becomes is there an obligation for parents to consent? Lastly, there is the impact of research protocols on determining the future. The decisions for research are very different than the decisions for standard of care.

It is crucial to examine the way the patients, partners, families, and healthcare professionals approach fertility preservation with the inclusion of hope. The considerations for what is possible can influence the patient's thoughts about the future. Because of that, there needs to be critical look at the ethical issues in the connection between hope and fertility preservation.

## **II. Shift from Abstract Argument to Personal Narrative**

Authors such as Kalbian (2005), Garvelink et al. (2013), Chambers (2013), and Corbally and O'Neill (2014) discuss the importance of the personal narrative.<sup>1,2,3,4</sup> Kalbian expresses the distinct regarding moral abstracts and personal experience, but the same can be said for approaches to healthcare.<sup>5</sup> As part of their personal narrative, patients are choosing fertility preservation. They are doing this to prevent the risk of infertility. However, in some cases of fertility preservation, there is the possibility of no standard of care options, but rather patients must enroll in a research study for any "hope" for successful fertility preservation. In order to make the best choice according to Quinn et al. (2008) and Gracia et al. (2012), both the patient and the healthcare professionals must work together to choose the best option for this personal narrative.<sup>6,7</sup>

### *A. To Be In the Abstract*

Defining the abstract simply means to talk in generalities. The discussion does not focus on one particular case or patient. This means discussing issues in the broadest sense of the situation. It gives a summary of the situation and applies to the most typical of circumstances. It considers the definition and development of the topic.

For fertility preservation, in the abstract, it focuses on the methods and reasons. As discussed in Chapter Two, standard of care includes oocyte, sperm, and embryo

cryopreservation and research protocols include ovarian and testicular tissue cryopreservation. In Chapter Three, for hope, this means consider both the philosophical and theological definitions and descriptions of hope. The definition of hope used for the purposes here is the belief in an outcome that is based on a realistic and possible future.

When discussing hope in fertility preservation, it is important to consider the discussion of fertility preservation in light of the definition of hope. For those pursuing fertility preservation, there are considerations that are specific to the concepts of possibility and future. When considering possibilities in the abstract, the focus for fertility preservation is based on the medical facts of the general concepts. For those diagnosed with a serious disease, the risk of infertility is due to the side effects of disease. The possibility of the risk of infertility is a genuine concern. As discussed prior, infertility can be a concern due to the risk and benefits of chemotherapy for treatment of diseases such as cancer or lupus. Infertility has many factors and predicting the exact risk is difficult in the abstract. Fertility preservation allows the patient to consider preventing infertility. Part of thinking about the future is the consideration of patients as to their desire to have children in the future.<sup>8</sup> While many people think about having children in the abstract, it is usually in the distant future. When patients are told that there is a risk for infertility, the reality of having children becomes a necessary discussion. For many, they desire to have children when they are old enough, have enough money, have the right partner, or are far along enough in their career. For those postponing children for reasons other than disease, they are thinking about the age-related fertility decline. For those considering fertility preservation as a result of a diagnosis, they are thinking about preventing infertility. Either option is thinking that in the future; the patient would like

the option to attempt to have a child. There is no guarantee of a successful cryopreservation, a successful attempt to get pregnant, a successful live birth, or healthy child. The patient is hoping for the best in the situation. Patients are aware of risks and know that nothing is guaranteed.

*B. To Focus on Personal Narrative*

To shift to the personal narrative is to put a name and a face to the case at hand. Patients are more than just a name or a number. They are people with a personality, family, friends, jobs, and hobbies. It is to make the abstract become personal. It becomes a part of the person's story and life. To consider the personal narrative is to think about the specifics that makes a person's story unique and stand out from the rest. Personal narratives come in different forms, one of which, the linear narrative will be explored later in the chapter.

When considering a personal narrative in healthcare, it takes into account all the details of a person's life including age, race, gender, geographic location, family life, past experiences, health, illness, intelligence, personality, likes and dislikes to create a well-crafted story. It considers the good and the bad, the easy and the hard. The personal narrative is not about generalities, but about specifics.<sup>9</sup> When a patient and a healthcare professional are dealing with a specific case, it can influence the way that they approach medicine in the future.<sup>10</sup> It can either reinforce or tear down perceived truths or biases. Personal narratives can be powerful to change someone's mind.

In fertility preservation, that means focusing on the person's specific reason for considering fertility preservation. If a 22 year old female patient has breast cancer, this means looking into the specific treatments that are most beneficial and least risky for her

specific case. This can include looking at research protocols for disease if she meets the demographic and clinical requirements to be a participant. This means looking at the current state of her fertility and investigating for specific odds for risk of infertility when she undergoes cancer treatment. It may mean referring the patient to an oncofertility specialist who can give specific numerical risks for infertility, survivability, and longevity of life. Additionally, it may mean investigating into the specific type of breast cancer to understand the nature of her disease because there are cancers that love estrogen. This means in rare cases, the method of fertility preservation that requires hormone injections may actually speed up the rate of the cancer cells spreading. Oncofertility specialist may need to even refer the patient to a plastic surgeon if a lumpectomy or mastectomy is recommended. The reason for this is trying to preserve what is necessary so the mother could possibly breast feed once she has a child. As part of this example, all of this information is still in the abstract. It still is not a specific patient, but rather a representative of this type of patient.

In some cases, patients do their own homework and search for methods and reasons that best fit their story. They connect with others on social media, support groups, organizations, and events. The personal narrative can be tricky to navigate for healthcare professionals who are used to focusing on the numbers based on trends, research, and data evaluation. Many healthcare professionals do not feel comfortable pursuing a treatment if a patient can only provide the personal narrative of one individual. There may be too many differences in the patient and the person in the story that the healthcare professional recognizes, the patient fails to acknowledge or understand. The



healthcare professional may believe that the personal story took too many risks and is not a recommended protocol by the professional organization.

For many years, this was true about oocyte cryopreservation. It was not until 2013, that oocyte cryopreservation was recognized as standard of care by the American Society for Reproductive Medicine.<sup>11</sup> Still it was gaining attention from the media including celebrities that were openly talking about oocyte cryopreservation. While celebrities may have had access to experienced physicians, other physicians were still not comfortable with the method as it was still being studied, understood, and skills were still be acquired by many. It created a false story that as long as you could afford it, oocyte cryopreservation was available to the masses. When in reality, before 2013, these celebrities may have been enrolled in a research protocol to cryopreserve their oocytes. While the personal stories of celebrities are valid, it is not always applicable to everyone. Delay having children and choosing to cryopreserve material still does not guarantee a pregnancy or live birth. A woman at age 25 could already have oocytes that are decreasing in quality, while another woman at 32 may not have any signs of aging in her oocytes. So while fertility preservation may be done at 25 and 32, it does not mean the odds of having a successful pregnancy or live birth are the same. It also depends on the sperm, the uterus, and any other risks that affect pregnancy and live birth.

What this means is that although patients are told they have autonomy, can act as primary decision maker, and advocate, it does not mean that every method for any reason is available for every patient. It is a very complex statement to say that a patient is completely autonomous, fully informed and decisions are not affected by any outside

influences.<sup>12</sup> The personal narratives that include the specifics of the patient automatically limit the options that a patient has available by a healthcare professional.

### **III. Hope as a Possibility in Fertility Preservation**

As discussed before, hope has various concepts and considerations that help to define and describe it. Hope involves both the need to be realistic and possible. The focus on hope is on the future. Part of being realistic and possible is the different approaches to fertility preservation. There are two key perspectives- the healthcare professional(s) and the patient (family). The healthcare professional must approach fertility preservation keeping the goal in mind, to preserve the fertility of the patient. Healthcare professionals have specific roles and responsibilities that must be done and maintained in order to keep the process of fertility preservation moving forward. Knowing ones role and responsibility is important to being part of a functional and effective team. The healthcare professional must know their own expertise and what expertise is not their own. In fertility preservation that means know how one's role relates to the patient. Since the healthcare professional is the gateway to healthcare, the healthcare professional must know how to access what the patient needs and wants (when appropriate) and how to access other members of the team who are better equipped to aim the patient in their treatment. There are also concerns that come with the healthcare professional's perspective. The healthcare professional may have conflict of commitments which is a form of conflict of interest. This conflict can affect how to the healthcare professional approach the team and the patient. Patients (family) are the other perspective. The patient is the most important role because the patient is the reason that there is an issue in the first place. The patient is seeking to determine whether fertility

preservation is possible for the future. As part of the consideration, patients have to consider their role as the primary decision maker, an advocate, and the sick role all as part of their identity. These roles influence how they approach fertility preservation.

In conjunction with the two perspectives is the actual division of the decisions at hand. In fertility preservation, there are actually two separate decisions. First is the decision to during the initial diagnosis. The patient has to decide how and when to cryopreserve materials. They have to consider the risks, benefits, and harm that are associated with fertility preservation. They need to talk to the various stakeholders and maybe consider their opinions. The second decision is deciding to attempt to get pregnant. This means that the patient has to consider the method that best suits what materials they cryopreserved and what are the best benefits, risks, and harms of the various methods to attempt to get pregnant. Methods such as artificial insemination, in vitro fertilization, donor gametes, and surrogacy can all be considered.

#### A. *Two Perspectives to Fertility Preservation*

There are two key perspectives when it comes to fertility preservation. First are the healthcare professionals which can include physicians, researchers, nurses, and any additional team members. The healthcare professionals have a unique perspective that includes knowing their roles and responsibilities, working as part of an interdisciplinary team, and maintain professional standards. The healthcare professional must be careful to be aware of any conflicts that may appear to exist or actually exist. Altogether, the goal of the healthcare professional and the team are seeking to aid the patient in fertility preservation. Second is the patient which can also include family. The patient as the primary decision maker must be heavily involved. They must be their own best advocate

if they decide to move forward so that there is proper care and treatment and no medical errors. The patient may be labeled as various roles such as primary decision maker, advocate, and the role of being sick. These roles influence the patient's considerations for deciding to do fertility preservation. It is also important for the healthcare professional-patient relationship to be one of trust and transparency. This dynamic is the most important part of the process and the interactions of the two perspectives. Both of the participant's perspectives need to be considered and approached with respect and support. All those involved are aiming for one goal- to preserve the fertility of the patient.

#### 1. Healthcare Professional(s)

Healthcare professionals have a major role in the process for fertility preservation. When patients consider the possibility of fertility preservation, there are those who can help them reach this possibility. The healthcare professional at every stage is an important member of the team. There are many roles that are a part of this process. Physicians can include someone from oncology or immunology or other areas depending on the patient's diagnosis. Oncologists are probably those who are most familiar with the risk of infertility caused by chemotherapy and other cancer treatments. Understanding one's roles is important in order to work as part of the team dynamic. It is vital to know one's expertise and the expertise of others. These healthcare professionals should be familiar with at least how to refer a patient to each other. For instance, an oncologist may diagnose a patient with cancer, but cannot speak to the success rates of fertility preservation. In that case the oncologist can refer to a reproductive specialist who is willing to talk through the various fertility preservation options or research new options.

The physicians are usually the gateway to the various referrals so that the patient can see the best healthcare professional for their needs. Nurses can help to support the patient through the tests and procedures. These men and women are the ones carry out the tests and procedures and often spend the most time with the patient. Having good rapport between the nurses and the patient is vital. Reproductive specialists are the ones who have the expertise regarding fertility preservation and should always be brought in. They are the ones who oversee the fertility preservation process including possibility doing any necessary surgery like mature oocyte extraction. Clinical ethicists, social workers, psychiatrists, psychologists, and spirituality are other disciplines that may be an appropriate resource to talk with the patient regarding any questions or concerns. Patients may struggle to accept their diagnosis and choose to ignore the need for fertility preservation. A healthcare professional that can talk about the patient's needs and wants can be a valuable contribution. It can help the patient to identify what they are hoping for in terms of a realistic and possible future outcome.

a. Roles

Roles and role morality is about defining the rights and duties of the individuals and others that are a part of the organization.<sup>13</sup> Roles define relationships among individuals and relationships between institution and individuals. Roles can be as simple as job descriptions and expectations of employees. However roles go much further than that. Roles also define how professionals are to act in general and sometimes in specific statements. Role morality examines whether the individual is fulfilling the duties and obligations of the role. This role can either be taken on or assigned by the organization, professional standards or the individual. Judith Andre argues that the roles were establish

to create a steadiness and a direction because humans are familiar and open to establishing relationship.<sup>14</sup> Roles were created because there is a sense that individuals are willing to follow and fulfill what is asked of them. The sources may vary, but the end result is the same – act according to the assigned role.

Roles can be defined from three distinct sources.<sup>15</sup> These sources together make up a role complete. The organization defines descriptions and expectations of roles based upon the mission, vision, and values. They describe the job and the actions that an individual part takes in. The organizational ethics must make sure that they are consistent across the organization. Roles should not conflict with one another. The organizational ethics balances the roles between the individual and the organization. The organizational ethics addresses the problem that organizations cannot act on by themselves. The organization lays out expectation of that relationship between the individual and the organization because individuals act for the organization. There are obligations laid out by the organization. They are to act in accordance with these obligations.

b. Responsibilities

Healthcare professionals have a responsibility to educate themselves on the current methods of whatever treatment is being discussed. They are to ensure that information is current and accurate. Healthcare professionals (physicians and researchers alike) are expected to maintain an up to date understanding of the protocols.<sup>16</sup> The physician is the person who is the gateway to all the medical expertise available. They are to lay out all of the options and provide recommendations for treatment and referrals to other specialists. The researcher is trying to enroll patients into their study. They

accept or reject a patient based on an approved protocol. They can also be a source for medical information. It is important to each member of the healthcare team to ensure that they know what their responsibility and role is and what it is not. Expertise in medicine can be very narrow and no one should speak outside of their own. Expertise is developed based on education, training, testing, and experience. Unless someone is qualified to give an expert opinion, it should not be included in the discussion. When asked as question that is outside the expertise, it is acceptable to indicate that someone cannot answer that question because it is outside their scope of expertise. In many cases, the lines get blurred and individuals who have the experience (and may even know the answer) struggle with not addressing an issue. It is better to bring up an issue as a question, rather than stating it as an expert. For instance, a clinical ethicist may be asked a question about informed consent. A clinical ethicist can speak to the function, purpose, and process of the document, but he or she cannot speak on how it relates to a specific law or comment on legal implications. It is important for healthcare professionals to stay vigilant that they do not speak to what is not their expertise.

c. Teamwork

Healthcare professionals cannot possibly know everything about everything (in fact no one can). This means there is a need to find other experts to share in the professional responsibility of caring for the patient. Teams should be made up of a diverse group of experts from various professions and disciplines. A team should identify a leader and as a group work together to care for the patient. In cases of a cancer patient, the team that cares for the patient may not meet on a regular basis or collaborate with each member of the team. This does not mean that the team is dysfunctional. If

teams are truly working together, they may be making referrals, reaching out to others to discuss an issue, and following up on the patient's care.

Teamwork is not an easy process. It takes time and effort to purposefully work as team and to strive for the best care of the patient. The best teams communicate well and resolve conflict even when it is difficult. It takes effort and time to commit to being a good team. The patient should be the number one priority. Understanding the patient's needs and wants is vital, and so is knowing the way to access those needs and wants.

When a patient decides to pursue fertility preservation, they are considering the possibility of the procedure. They are considering benefits and risks, listening to opinions from family and friends. When the patient then decides to pursue it, they can only do so with the involvement of the healthcare professional team.

In one study on ovarian tissue transplantation, Gracia et al. (2012) has discussed a more multidisciplinary approach to fertility preservation. No one single healthcare professional can be expected to know all information. The more collaborative the process, the better the outcome for the patient. For this study the team included a pediatric oncologist, reproductive endocrinologist, pediatric surgeon, pediatric and adult clinical/research nurse and a psychosocial counselor. The goal was to spread the responsibilities to the appropriate team members.<sup>17</sup> It found that patients were comfortable knowing that each member of the team had a designated role which allowed the patient the freedom to ask questions and seek out various answers.

d. Professional standards

Professional standards describe a person that has a specific set of skills.<sup>18</sup>

Professional standards lay out guidelines, ethics, actions that are to be held not just by an



individual, but all individuals that claim a specific role. These professional guidelines are not law and are not necessarily bound by the organization. The role can be guided by the professional standards so that there is a consistency across a role.

The individuals can lay out their own roles because they are moral agents themselves. As mentioned before, individuals are their own moral agents. They act according to their own decisions. While in a specific role an individual can choose to act in accordance with the role description by the organization and the role description by professional standards. If they act in accordance with their obligation and recommendations of that role, then the individual is in compliance.<sup>19</sup> A nurse can be a good example. A nurse is to act in her role according to the job description, the nursing license board, professional nursing standards and any of the moral standards chosen to live out. However if a nurse, chooses to act outside the obligations and recommendations, it cannot only cost them their role, but also in a certain organizations affect the consumers as well. This is where role morality steps into play.

However, healthcare professionals must adhere to their professional organizations for licensing and credentialing. The professional organizations are meant to ensure that healthcare professionals are kept up to date on current best practice and maintaining skills and knowledge. For these professional organizations, they keep healthcare professionals up to date on changes to standard of care and new research discoveries. For instance, in 2013, the American Society for Reproductive Medicine officially announced that mature oocyte cryopreservation is no longer to be considered experimental. They reviewed the literature to look for trends and success regarding this procedure. As part of standard of care, healthcare professionals who deal with fertility preservation (reproductive

specialists) need to ensure they are trained on the methodologies and best practices for success. They need to gain both the intellectual and physical skills to do fertility preservation. Oncologist and immunologists, or any other physician recommending fertility preservation, need to inform themselves about the current benefit and risk so that they can have a conversation with their patients that is informative and beneficial to the informed consent process.

e. Conflict of commitment

Conflicts of commitments are the struggle between several sets of commitments that compete for preference in honoring those commitments adequately.<sup>20</sup> This often is seen in professional roles. Conflicts of commitments are impossible to avoid. Everyone has them in their lives. By trying to avoid the conflict of commitment, means that one commitment is either ignored or placed below another.<sup>21</sup> The conflict that is ignored or placed below others, may be just as important as the other commitments, but not treated as such. Individuals may have conflicts of commitment within themselves and organizations can have conflicts of commitment within itself. Healthcare professionals have multiple obligations in their roles. There are the commitments to their patients, to their profession, to their employers, to committees they are on, to their personal lives, or to their research. Each commitment has a value and has the potential to make the healthcare professional's life better or worse. The conflict of commitments not only affects the healthcare professional, but also those around. The first step to addressing conflict of commitment is to acknowledge that it exists. Conflict of commitment is not inherently wrong, but it needs to be kept in check to ensure it does not have harm to those it may affect. Patients, especially those who are recently diagnoses, are vulnerable.

There needs to be serious consideration to protect those who are vulnerable in order to ensure ethical actions.

For example, an individual may sit on an ethics board and be a transplant physician. He has an obligation to his patient to get an organ, but also an obligation on the ethics board to act evaluate cases with integrity. He cannot abuse his seat on the ethics committee in order to get an organ for transplant. The physician must act in the patient's best interest and yet he must act ethically on the committee. He must choose which obligation is more important for him to honor. The organization can also give a recommendation as to how the physician's role should be laid out in the conflict of commitment predicament. Sometimes in cases of conflicts of commitment and conflict of interest, there is an important need to gain outside help and this is where clinical ethics can come into play.<sup>22</sup> This is true of the dynamic between physician and researcher. Because fertility preservation is only in research phases for prepubescent children, there may be a conflict if a physician is recommending a patient to enroll in a research study they are conducting or involved with. The institutional review board needs to ensure that the conflict is disclosed and monitored.

## 2. Patient/Family

The patient holds the most important role. It is their diagnosis (or delay in having children) that brings about the entire discussion. If the patient is an adult, assuming they have decision-making capacity (which is always presumed), they have the autonomous right to make decision about fertility preservation and treatment. Cancer survivors are more determined than ever to live life to the fullest, which for many includes biological children.<sup>23,24</sup> Patients who are realistic understand that to receive medical care can mean

weighing the risks and benefits of the care. The responsibility of aiding the patient in understanding the risk-benefit ratio is the health care professional. The patient trusts the health care professional has minimized the harm and risk and maximized the benefit. The trust of the patient in the health care system plays an important part of relationship between not just the patient and physician, but also between the patient and the system as a whole. The level of trust that the patient puts into the system, reflects the confidence that the patient has in the competence and best interest of the health care professional and the health care system. Patients trust that the relationship with their health care professional is based upon honesty. They trust to be included in the discussion of their own health.<sup>25</sup> While medical error can erode this trust, the health care professional and health care system must constantly work to earn and maintain the trust of the patient. One way to earn and maintain this trust is for the health care system to involve the patient in the medical care process. The patient should be treated as a member of the team and not just the means to an end in the medical care process. This can create an extra layer of safety to increase the quality of the medical care experience. Ultimately, patients have the right to expect safety and high quality of care in medicine.<sup>26</sup> There is no exception. However, health care professionals do need to help the patient maintain a balance between expectations and reality of the health care system.

The involvement of patients in healthcare is an expectation that some patients have. More and more patients want to know more than ever before. For many years patients were passive victims in medicine, but now they can be active safety advocates in medicine.<sup>27</sup> There are three roles that the patient plays that will be considered: primary decision maker, advocate, and the sick role.

a. Primary decision maker

Patients have a level of expectation in terms of the medical care that they seek out. No one wants to seek out a health care system that will cause harm, increase their risk, or be unconcerned with safety or quality. To a limited extent, patients have the right to certain expectations. Patients expect to get the medical care they seek. As primary decision maker, the patient exercises autonomy on a regular basis. The healthcare professional is to ensure that beneficence and nonmaleficence are considered in the decision making process. In addition, the patients can expect to have the personal right not only acknowledged but also promoted. These rights can include autonomy, truth telling, informed consent, confidentiality.<sup>28</sup> While these expectations are reasonable, there is a fine line between the expectations and the reality of what medicine can provide. Patients' views of medicine whether realistic or overly reaching, affect the current medical system and how patients respond to their medical treatment. As primary decision maker, the patient should be involved in the entire process. Signing the informed consent form is not the only responsibility they have. Asking questions is important. If they are uncomfortable with something that is happening, patients need to speak up. By patients increasing their involvement, they can create an extra layer of safety to their medical treatment. This is important and built into the system of medicine now. The patient should take their involvement seriously. Because of the importance of autonomy and informed consent, assuming the patient is competent, the patient is the primary decision maker before any medical procedure is done. They have the final say to go forward or refuse treatment.<sup>29</sup> Making the patient highly involved in their treatment is crucial. The patient can easily control the treatment by not following instructions on

therapies or medications. This can be on purpose or by simply having ignorance about the circumstances.<sup>30</sup> Patients, in most cases, also witness their own medical care. They see the health care professional check them for symptoms, diagnose, and perform treatments.<sup>31</sup> This witnessing can give the patients an active role to make sure the safety measures are being met.

b. Advocate

Patients need to be their own advocates for health. They need to speak out to be clear what they want and speak out to be clear what they do not want. Patients cannot expect a healthcare professional to do both their own responsibility and the patient's responsibility. It is a partnership that both must be active in to have the best possible outcome.

Some simple ways things that patients can do include double checking medications or making sure that the healthcare professionals wash their hands. This involvement of the patient makes them an advocate for their own safety. This involvement though, does not make the patient solely responsible for their safety. The organization and individuals within the system ultimately have the most responsibility for the patient safety, but patients can take part.<sup>32</sup> Patient can advocate for their own health include speaking up about concerns, paying attention to the received care, participating in decisions, asking questions, knowing medications, educating oneself about diagnosis, and using health care organizations that have proven themselves to meet quality and safety standards.<sup>33</sup> This allows patients to take part in their safety while health professionals provide care in a safe manner.

Where it gets complicated is when a patient requests treatment that is medically unnecessary or not medically necessary. In those cases, healthcare professionals have to weigh autonomy and nonmaleficence. There are times when patient request medical treatment that is not indicated for the circumstances, but patients are willing to take the risk anyways. Patients need to keep in mind that being a decision maker and an advocate is not an opportunity to demand any and all treatment. Healthcare professionals have to consider other factors when recommending treatment. The relationship between the patient and healthcare professional can be very difficult, if neither is willing to listen to the other.

c. Sick role

Sociologist Talcott Parsons suggested a concept he termed the sick role. The sick role is social concept that is meant to describe a patient that has been diagnosed with medical ailment and their goal of getting well.<sup>34</sup> The concept of the sick role is based on the idea that those who are sick are unique in their situation. The sick role addresses rights and obligations that a patient may have as they address their diagnosis. This concept is debated as to how appropriate it is to label someone into the sick role. The sick individual is not responsible for their diagnosis (although some argue that this is not true in every circumstance) and can be exempt from social norms due to the illness.<sup>35</sup> The individual needs to prioritize their health over other priorities in order to get well. The sick role is also described to have obligations to seek to get well and to seek appropriate medical treatment.<sup>36</sup> In cancer diagnosis, instead of focusing on the negative connotation of the sick role, there are those who prefer the term survivorship. This

focuses on the long term goals of surviving and thriving, not just on being labeled by a single diagnosis. Survivorship will be discussed more thoroughly in Chapter Five.

While it is an easy explanation of the role, the execution is not as simple. There are additional external barriers that affect these obligations. Individuals, who are sick, depending on the severity, can struggle to accept their role and may be in denial for a period of time. Seeking counseling can help someone to at least accept their illness. There are some who once diagnosed, do not want to be treated as such. They want to continue their lives as close to normal as possible. They refuse to be vulnerable and work hard to maintain normalcy. Being vulnerable and asking for help can be a challenge. Also a problem with the obligations is that seeking appropriate medical care may not be readily available. Healthcare is expensive even with insurance, and that cost can become a burden and may even affect the way patients make decisions regarding their healthcare. Healthcare costs is one of the leading causes of bankruptcy in the United States and the financial burden that healthcare creates can be troubling for many.<sup>37</sup> It can be a continuing issue when patients have to continue to seek medical treatment for chronic conditions.

### 3. Healthcare Professional-Patient Relationship

The healthcare professional-patient relationship is a vital part of the concept of possibility for future outcomes. This dynamic is built upon trust and transparency. The patient and healthcare professional are a team that together determine goals for the future and work together towards those goals. It is imperative that they work together and not against each other. The patient is in a vulnerable place and needs someone who can be straight with them on benefits and risks. The healthcare professional is expected to do



everything that can to help the patient get well. If either party does not feel that the other is being trustworthy or transparent, it can create a hostile environment. It is important for the healthcare professional to know the patient- who he or she is, what are his or her values and preferences, and how he or she thinks. Healthcare professionals need to be aware of non-verbal cues to understand the patient. Trust needs to be established between the two in order to function as a team. Trust includes honesty, integrity, and care. Transparency also needs to be established. Transparency means that there are no secrets or deception between either party. If trust is broken, it is very hard to reestablish. This dynamic is not always easy to establish or create. It may take multiple interactions to establish the patient-healthcare professional relationship, but it may only take one interaction to ruin it.

a. Knowing the patient

Eric J. Cassell correctly points out that knowing someone is incredibly difficult. In fact he goes so far to say that “individuals are unknowable.”<sup>38</sup> The philosophical debate of knowing someone will always occur. It takes effort and purpose to know someone, but knowing and understanding someone for everything they are or are not is challenging. An individual has many parts to them beyond the physical. In order to know that individual one must understand the characteristics, past, family, experiences, personality, culture, roles, relationships, jobs, behaviors, spirit, emotions just to name a few. There is no way to know the individual as well as one knows the self. An individual struggles with knowing oneself, which means knowing another is impossible. The struggle to apply compassion upon another is then even more difficult because one never really knows them. In medicine, it is almost impossible for the

healthcare professional to really know the patient for the whole person that they are.<sup>39</sup> This should be done by attempting to know the person as best as they can even despite recognizing that this relationship cannot be perfect. This does mean that the attempt to know that patient should be made. Healthcare professionals should strive to know the patient in a meaningful way that allows the patient to open up and work together. If a patient trusts the healthcare professional, they are more willing to share about themselves. This means it is important to strive to know someone, despite the fact that one can never really know someone.

b. Importance of trust

Patient expectations always come with a level of trust in the system of healthcare. If they did not trust the healthcare system, they would not seek any level of medical testing or treatment. Patients place their trust in the organization and the individuals in the system with their health and lives. Medical error can not only weaken the level of trust, but can irreversibly destroy the trust as well. Trust is an essential part if the relationship between the patient and the healthcare professional is to function well.<sup>40</sup> If there is no trust, there is no patient; then there is no relationship. While to a certain extent there is an unequal power between the healthcare professional and the patient, the assumed trust of the patient towards the healthcare professional accepts this.<sup>41</sup> The trust of the patient towards the healthcare professional is made up of two parts – trust that the healthcare professional is competent and trust that the healthcare professional has best interest of the patient.<sup>42</sup>

The competency of the healthcare professional of course is crucial, healthcare professionals need to know their job better than anyone else. No one would purposely

seek out a healthcare professional who did not know the anatomy of the human body. Healthcare professionals are expected to maintain their knowledge and expertise as well as learn new skills. This trust allows the system to function well. When a healthcare professional is incompetent, it puts the patient at unnecessarily at risk. It is the responsibility and obligation of the healthcare professional to protect the patient and one of the ways it to maintain competence.

Trust that the healthcare professional has the best interest of the patient is as important as trust that the system has the best interest of the patient. A patient does not want a healthcare professional or a healthcare system to only have their own interests in mind. They need to have a conscious about conflicts of interests that are present is vital to safety and quality of care for the patient. This means that there is accountability and transparency for everyone in the healthcare system.<sup>43</sup> Trust is easy to lose, but hard to gain back. Patients put their trust in the system, but one mistake, one error can destroy that trust. The trust that the patients puts into the healthcare professional, gives an opening to a relationship between the patient and the entire healthcare system.

#### *B. Decision Making Process*

Ultimately, the patients have the decision making authority. The decision to pursue fertility preservation can be quick decision for some, but a long draw out process for others. However, the longer the delay for a decision regarding fertility preservation, the longer the delay for treatment.<sup>44</sup> Patients must determine if they want to attempt to have children in the future.<sup>45</sup> These concepts together allow the patient to move forward with a procedure which ultimately is two separate decisions.<sup>46</sup> The first is the decision to preserve fertility. The second major decision is later, after the treatment of disease is

complete- the attempt to get pregnant. Ultimately, there are two separate decisions that must take place in order to attempt to have a child. The decisions are not to be decided at the same time. There needs to be focus on the decisions as completely separating entities. The informed consent process for both of these should also be completely separate. This allows the patient the opportunity to focus on the medical treatment and focus on health. Once a patient is in the clear regarding their treatment, there is a period to ensure they are healthy and recovered. It is only then that the patient can pursue the decision to attempt to have a child.<sup>47</sup> Patient values and goals may shift in the time between these decision one and decision two, not to mention life and circumstances change as well. An individual may undergo embryo freezing, but later decide that he or she wants to adopt or remain childless instead. This is why the decisions are completely separate.

Patients who are minors do not make the first decision. The parents are to act in the best interest of the child.<sup>48</sup> If the parents do consent, they do it on behalf of the patient, and the patient provides assent.<sup>49</sup> In the case of the minors, the first decision is technically not theirs to make. There are circumstances where mature minors opinions are heavily considered in the informed consent process, (emancipated or married minors are categorized differently). However, since informed consent is also a legal document, those under eighteen cannot legally sign the document. This means that for anyone under eighteen, the decision is only assent, though usually required by the institutional review board, and is not legally binding. However, the mature minor patient is generally not forced to do something if they have a well-thought out reasons to oppose such a decision.<sup>50</sup> In any case, legally the only decision the mature minor can consent for is the

decision to attempt to have a child in the future once that patient is over eighteen. This ability to attempt to have a child is dependent on many factors including what materials were cryopreserved and what the current standard of care and research protocols are available at the time. The children are adults at the time of the second decision. By separating these two decisions, parents are not forcing their child into having biological children, but rather giving them the option in the future.<sup>51</sup>

#### 1. Decision One at Initial Diagnosis

Fertility preservation is a two-step process that emphasizes hope in the first part, and either confirms or rejects the possibilities in the second part. It is necessary to separate the initial preservation of fertility gametes, and the second step of actually trying to have a successful pregnancy.<sup>52,53</sup> The first decision is the method of preservation. This is an autonomous decision made by either the patient, if an adult, or the parents or legal guardian, if the patient is a minor. The age of the child and the parent's interest in the child's welfare are all important in involving the child in the decision making process. This decision and procedure should take place before the treatment for the disease by the patient or the parents. The patient must consider the risk, harm, and benefit of moving forward with fertility preservation. They must consider whether the risk of infertility is more or less compelling than the risk of the procedures for fertility preservation. Infertility is unpredictable as a side effect of disease treatment. For those delaying having children, there is a consideration as to risks of the procedures as well, but this is in contrast to the decision to address age-related fertility decline. Unless, there is a need to remove reproductive organs (ovaries, testes, uterus, etc.) there is the possibility of being able to have a spontaneous pregnancy, but the odds are different for each person.

Fertility preservation is a preventative method just in case infertility happens. This is a chance that the preserved materials are no longer needed. This decision is a result of identifying that the patient believes the value of having children in the future as a realistic and possible outcome. This is the hope that patients are placing in healthcare to potentially reach a specific outcome. This hope not only encourages them to do fertility preservation, but to also decide to attempt to get pregnant in the future.

a. Concept of risk, harm, and benefit

The concept of risk, harm and benefit is very important in the discussion of ethical considerations and patient expectations. Anyone who seeks medical care should know there is a risk to medicine, because medicine is not an exact science. Risk is always present in medicine. The level of risk is what changes. The amount of risk is based upon the exposure to harm.<sup>54</sup> Risk is also based upon perception of the hazard and the probably of the hazard taking place.<sup>55</sup> What both of the explanations amount to is that presence of risk is situational and the effect of that risk is dependent of the views of those involved. In healthcare, health professionals and patients each have risk to consider. The health professionals' job is to judge the risk and the patient (or the surrogate decision maker) is to decide whether to face that risk. However, risk is not a guarantee for negative results. Risk only shows the possibility of harm.

Harm on the other is the negative result. Harm also has various levels though from minor to death.<sup>56</sup> According to the Hippocratic Oath, a physician is to do no harm.<sup>57</sup> This basic mandate has changed over time. Now, harm is to be minimized and benefit is to be maximized. This means that harm is acceptable to an extent. This extent is when the harm is appropriate is to ultimately support the final benefit. For example, to

perform an appendectomy, a surgeon must cut open a patient and remove the inflamed appendix. The risk here is two-fold. To remove the appendix is to open the patient up, which can lead to a risk of infection or cutting too deep or many other complications that can come with surgery. The opposite risk is that to not remove the appendix is to leave the patient vulnerable to the appendix bursting and causing a greater harm internally. By performing the surgery, there is a minimal harm, but the maximization of benefit here is important. Sadly there is not standardization to determine harm, or risk, or even benefit.<sup>58</sup> In every case, everyone involved should acknowledge and understand all possible risks, harms, and benefits. The patient however, is not guaranteed to always understand or comprehend all of the risks, harms and benefits involved in health care. This is why the patient looks to the healthcare professional for guidance and reassurance as to the decisions that the individual has to make. They put trust that the health care system is competent and has the patient's best interest in mind.

b. Assent

Assent is a type of consent for those who do not have capacity or competency. They do not have the legal or medical right to consent. The assent process still involves informing the individual and ensuring he or she understands, all at an appropriate level. Assent is important for those who are minors. In the case of fertility preservation, prepubescent children do not have any standard of care options available. This means parents can only choose to enroll their child in research studies to cryopreserve either ovarian or testicular sperm. Patients who are prepubescent may not understand the implications and intricacies of the protocols. It is important that the researcher communicate with the patient at the appropriate age level to obtain assent. Minor

patients are all different ages, different levels of intelligence, and different levels of understanding. There are various ways to effectively communicate with minor patient but it may take extra effort. The goal of assent is to see if the patient agrees with the parent's decision. This is not a test or a compliance question. It is to better understand if the patient and the parents are genuinely on the same page. As the patient ages, it is important to understand that so does the patient's understanding. Mature minors have a greater say than a two year old. Mature minors are included in the discussion because it is important to grow them into the role of being an adult patient. At eighteen they are expected to take full responsibility for their healthcare. The patient is expected to be the primary decision maker, their own advocate while maintain the sick role. Eighteen is an arbitrary number. There is not magic age when patients suddenly gain capacity.<sup>59</sup> A sixteen year old may have a better understanding than a twenty-one year old. The age of becoming an adult that makes his or her own decisions at eighteen is a legally established number.

The rule of sevens is a concept that is aimed to help in approaching the involvement of minors during decision making. The rule of sevens is a recommended grouping that describes capacity for variously age children. This rule of sevens is not in fact a rule, but a guideline for how to approach decision making for minors. Healthcare professionals and parents should be sensitive to the intelligence and maturity of the patient and adjust accordingly.<sup>60</sup> This is true for any standard of care or research participation for a minor. For those who are under seven, they do not have capacity to make his or her own choices. Under seven, patients can understand some of what is going to be done in the treatment, but they are not able to appreciate the benefits and risks



of the treatment. Patients should still be included in the discussion at an age appropriate level. Parents and healthcare professionals should work together to communicate effectively with the young patient. From ages seven to fourteen, children are presumed not to have capacity, unless there is a proven exception. This means there is a higher level of understanding and comprehension than children under age seven, but not full understanding and comprehension. There is concern if these children can truly be voluntary, pressure from parents or the healthcare professional or even the desire to please them. Those over fourteen are presumed to have capacity and make their own decisions. This age group can best appreciate the information being given and decide if they are willing to consent. Still in this age group, there is a need for parental consent in most cases. This group is often referred to as mature minors, but not all patients in the age group are necessarily mature. There is a presumption of maturity, but healthcare professionals should still evaluate. However, none of these age ranges allow for a minor to consent for themselves without the parent or legal guardian also consenting. There are a few exceptions including emergency medicine, specific reproductive medical procedure and treatments, and in some states mental health treatment.

In 1999, Dr. Foreman wrote about something he deemed the family rule. This is a type of collaborative effort between child and parents in order to gain informed consent. Foreman argues that a child consents to the rules as established by being a part of their family. Within this family, this rule is based on the importance of promoting the welfare of the child. By promoting the welfare of the child, the parents then have the right to consent on behalf of the child.<sup>61</sup> Children can provide consent within the context of the family, but cannot consent outside of that context. As the child ages, the parent's right is

decreased because the child's ability to consent for themselves increase. When considering a decision, there are five steps that take place during the process.

- a) Inform the child what will happen if nothing is done.
- b) Describe the intervention.
- c) Describe how the proposed intervention will improve things.
- d) Whether the child agrees with the practitioner that the proposed intervention does indeed produce a better outcome than doing nothing.
- e) Only then, should the child's consent to proceed be sought.<sup>62</sup>

It may take time and some navigating through these steps in order to make a final decision regarding consent on behalf of a child. Foreman clarifies that in cases of disagreement, there must be attempt to reconcile the opposing viewpoints.

## 2. Decision Two to Attempt Pregnancy

The second decision should be about having a child. The patient should make this decision with input from the physician, when or if the time is appropriate. This may be in a few months or few years after the treatment is complete. It is important to note that if the parents made the initial decision for fertility preservation, the patient, once they become an adult, now have full decision-making capacity to make the second decision. The decision to attempt to get pregnant could take years before it is attempted.<sup>63</sup> Patients and the healthcare professional should work together to determine if the patient is in fact infertile. This could be from conducting tests and blood work and attempting to get pregnant spontaneously. In the cases of those who have a partner, it may be valuable to have the partner tested for infertility as well. Patients and healthcare professionals then must consider what type of reproductive technology is best based on the current health of

the patient and the current methods available. This second decision may also mean a change of heart. Patients may be exhausted from undergoing treatment and no longer desire to do the same to attempt to get pregnant. They may have reconsidered the option of fostering or adoption. The second decision is a separate decision and a separate informed consent process. For minors, it could take many years before this option is available. Minors need to wait until they are at least eighteen, but it may mean waiting until later in life, when they are ready to be parents. This shift from a minor patient to a legally consenting adult is significant. Parents cannot and should not force the formerly minor patient to attempt to get pregnant. Because the minor is now an adult, they have the same autonomy as any other competent and capable adult to decide for themselves. Patients are still focusing on the hope they place in order to have a child in the future. For the second decision, the decision to attempt to get pregnant is the attempt to fulfill the hope. This is where the accuracy of the realistic and possibility is discovered.

a. Current state of methods to attempt to get pregnant

When attempting to get pregnant, there are many methods and procedures to consider. Patients can continue to attempt to get spontaneously pregnant, but at the same time they can pursue options like artificial insemination, in vitro fertility, donor gametes, or surrogacy. The biggest issue here is the limited resources of the cryopreserved material. Healthcare professionals need to carefully consider how and when to use the cryopreserved materials. They want to ensure the most responsible use and the use with the highest potential to get pregnant. This may mean that the sperm is used carefully for an attempt at artificial insemination, while still considering to save sperm to use in intracytoplasmic sperm injection during in vitro fertilization to increase the odds that an

embryo can be created. This also means that the partner if involved should also be tested for risks of infertility. For example, if a male patient is attempting to use his sperm to get his wife pregnant, it is important to consider the quality of the woman's oocytes. If she has oocytes that are damaged or she has inconsistent menstruation, there may be an issue with attempting artificial insemination or intra-cytoplasmic sperm injection during in vitro fertilization. It is a team effort with the patient, partner, and healthcare professional working diligently to attempt to get pregnant in the most effective and responsible manner. After all, the goal is still to have a child, and the hope from fertility preservation hangs in the balance.

#### **IV. Hope in a Future in Fertility Preservation**

Part of the concept of hope as discussed earlier, focuses on the future. It is impossible to know the future. People can create the ideal future in their minds. They can imagine how they want any given scenario to play out. They can even think of alternatives or ways to troubleshoot if the situation does not go according to plan. However, all the thinking in the world will not predict the future. No one can make perfect predictions. So what can be done in order to address the future? People can make decisions that will help them to obtain the future that they are seeking. They can participate in activities and reach out to experts to provide assistance. However, they cannot force the future to happen exactly the way they want it too. They can set goals and attempt to reach them, but it does not guarantee anything. For fertility preservation, the future plays a major role in the decision making process. Thinking about the future, is part of the process for fertility preservation. It is important to consider what the future means and what it looks like for those who are considering fertility preservation. Does

the future include attempting to have a child? Is the goal to contribute to research? Maybe the goal is to not do fertility preservation, but attempt for a spontaneous pregnancy. There are even some who would rather not have children. All of these options are part of the imagination of the future. Each patient has to consider what values are most important and how they work towards those goals.

For those considering fertility preservation, there are parts of the discussion that are specific to the concept of future. The discussion of genetic children, grandparenthood, and research protocols are all focused on the future. Patients have to consider why they want children and what would life look like if that never took place. It is interesting the emphasis on having genetic children and the length patients will go to make sure that happens. Additionally, parents of adolescents can be thinking about grandparenthood. Since the parents are the decision maker for minors, the decision to preserve fertility may be affected by the desire to be grandparents. Additionally, contributing to research may affect the future as well. Most patients are not well-versed in research lingo and beyond having to sign for informed consent, may not understand the difference between research and standard of care. Patients need to understand how research affects their future.

#### A. *Future Considerations*

When considering the future, what should be the parameters? Imagination can go in any direction. When is there a shift from thinking something to working towards it? There are many self-help books and seminars that teach about how to envision the future, how to set goals, how to manifest what you want. However, the future decisions discussed here are about quality of life. What does a good life look like to the patient?

Each and every person answers that question differently. It can be hard to identify what makes a good life. It is impossible to reach a consensus.

For those considering fertility preservation, the patient has to decide the importance that attempting to have a child plays into his or her life. For instance, there are some who would identify themselves as not kid friendly. That does not make them bad people. It just says they are unsure or uncomfortable being around children. That does not mean the person does not want children. While the person may not enjoy other's children, they know they will love their own. By considering the future with and without children, one can better understand the personal values and quality of life that are important.

Future concerns are usually determined by two distinct things. First are the personal values of the person. So where do values come from? Values are beliefs about one's own self and the world around them. Values determine how a person acts, thinks, and lives. Values vary person to person and so it is hard to have a consensus on all values. Determining those values is part of the experience of being a human. Values then help to inform choice and actions that are taken. It can help a person determine their own quality of life they want to lead.

#### 1. Determining Values

When a patient is considering fertility preservation, there should be a lot of thought and consideration before choosing or refusing it. Patients need to consider their values and preferences at an overview level which can better inform the choices they are making. For instance, a patient may say that family is the most important thing in their lives. They enjoy spending time with their parents, siblings, nieces and nephews, aunt

and uncles, and cousins. They have always wanted to have a family to raise and enjoy. This may mean that having children is very important to the patient's definition of a good life. Maybe the family values freedom, the ability to go and do whatever they want, whenever they want. This may be a life style that the patient is unwilling to ever give up. In that instant, the patient's values may indicate, they have no interest in having children. While these are examples are straight forward, it is almost always more difficult to identify someone's values in a singular meeting. The patient may express competing desires which in turn may express competing values. Determining values may include discussions with partners and families to get a better sense of what is truly considered a value to them.

## 2. Determining Quality of Life

Once values are determined, one can begin to consider what impact these values have on determination for quality of life. Quality of life can help a person to determine what type of future a person can envision for themselves. The forming of an exact, consistent definition for quality of life is difficult. It is a subjective determination that can have many different inputs. What one person considers good and important another person may consider it irrelevant. Quality of life is important to the individual patient or the family involved. Even if the determination is left up to the patient there are still a plethora of concepts of quality of life. Some include endurable, higher than survival, returning to ordinary life; and still other patients use their own criteria. Healthcare professionals need to place the quality of life of the patient at high importance, because ultimately, assuming the patient is competent and capable, the patient gets to make the final decisions. The autonomy of the patient relies of the healthcare professional because

the patient is to work within the framework provided for the patient. For example, if a patient is facing cancer diagnosis, they may be given several options for how to approach treatment of disease. Though the healthcare professional may have a personal opinion, the patient has the right to make the decision to have the best possible quality of life according to the patient. In the same example, the patient also has the negative right to all treatment because they do not want to deal with a specific side effect or found it too risky. For fertility preservation, the consideration is that the quality of life focuses on a future filled with health and children.<sup>64,65</sup> These two outcomes are not guaranteed or necessarily tied together. When considering quality of life, the patient has to consider their personal values which may include the desire to have genetic children and in the case of women, carry a child to term.

Studies have shown the younger cancer survivors place a greater importance on having children and losing the ability to have children, can negatively affect a person's quality of life.<sup>66</sup> To some losing the ability to have children is a grieving process and they have to adjust to a new normal for their lives. This pursuit for the specific goal of children in the future and the important of the quality of life does not necessarily encourage patients to seek out fertility preservation. In a 2012 study regarding quality of life and fertility preservation, about 60% were counseled about fertility preservation, but only 4% actually did fertility preservation. The fact that only 60% of patients were informed is much too low. Healthcare professionals have a responsibility to inform patients about the side effects of treatment and taking the time to address fertility (which is highly associated with high quality of life) is vital. Excuses such as lack of knowledge, lack of time to discuss the issue, the importance of not delaying treatment or the belief



that patients should bring it up are unacceptable in making sure patients are making an informed, capable, and voluntary decision regarding their pursuit for what they deem as necessary for their quality of life.

#### *B. Genetic Children*

Fertility preservation is chosen by patients with the hope to have children in the future. The importance of genetic parenthood is evident by the increased discussion of fertility preservation<sup>67</sup> even though genetic children are not the only way to have children. Having the desire for genetic children is considered normal and the most traditional route to having children. Genetically related children are a want and desire that many people have. They hope to have children someday; women want to experience pregnancy. People desire to have a family. For many women it is a not only a personal hope, but a social expectation as well.<sup>68</sup> When a disease such as cancer interrupts a life, sometimes desires and wants change; others times it reinforces them. Values and goals may change or adapt based upon the circumstances as well. The importance of family and being parents<sup>69</sup> are often instilled from an early age and are built into the values and goals of an individual. Because of this, many seek medical intervention when faced with possible infertility. This obviously does not guarantee children, but establishes the possibility of children. This is said not to deter patients from taking the appropriate steps in fertility preservations, but to better understand the realistic circumstances that they find themselves in currently. This is done by reconsidering an individual's values and goals. In the case of facing infertility from aggressive treatment, patients may reconsider the importance of genetic parenthood. For pediatric patients, this is more difficult to do. This is where parents step into the discussion. Parents (or legal guardians) are the once

who give consent and decide the values and goals for the life of the child. It means trying to act in the best interest of the child to ensure them the possibilities for the future. They are providing hope for fertility in the future should this become an issue. The desire for children is a valuable goal and desire and the pursuit of that should be respected by healthcare professionals. There does need to be consideration for alternative ways to have children. Having genetic children is part of a linear narrative that encourages traditions and normalcy. There is concern that the pressure to pursue genetic children above all else may not be the end all be all of parenting. Alternative are important to consider and some may choose to pursue parenthood through other options such as fostering or adoption or may choose to not have children at all.<sup>70</sup>

#### 1. Desire for Children

Hoping to have children someday is considered normal. Most people in the world at some point in their life get pregnant and raise those children. For some, it is a plan in place since they were young. At a young age, being a mom or a dad is so far off in the future. They want it to happen someday. As people age, there is more to the imagined family life. What type of person to marry, how to raise the kids, names that are beloved (or hated). The imagination focuses on the excitement of raising children- teaching the children sports or music, creating memories at the amusement park, or celebrating the place first in the spelling bee. The focus is not on the process of how to great pregnant. Everyone that wants children starts by assuming, it is easy to have a spontaneous pregnancy. Infertility is a taboo subject that is avoided in conversations. The desire to have children for many is strong so being told that there is a risk of infertility can come as a shock and disappointment.

Once the patient understands the risk of infertility, decisions need to be made regarding infertility. Fertility preservation tends to be time sensitive. Those who may delay having children need to cryopreserve sperm, eggs, and oocytes, as soon as they decide because as their age increases, the health of the sperm, eggs, and oocytes decreases. For those who need to start treatment for disease, the sooner fertility preservation can be done, the sooner treatment can start. Even with the hope for children being addressed with fertility preservation, it does not guarantee a pregnancy, a live birth, or a healthy child. The process of becoming a parent can be long and difficult.

## 2. Linear Narrative

In 2000, Douglas Ezzy conducted a study on HIV/AIDS patients about how they viewed themselves and their lives.<sup>71</sup> By quantifying the results, Ezzy looked for trends in how the participants answered. One of the most common was what Ezzy entitled, linear restitution narrative. The idea is fairly simple. People, who are ill, hope to do everything they can in order to restore back to their normal pre-ill self. They want to return to normal. In Ezzy's description he included the notion that linear narrative is oriented towards the future, no matter how uncertain it is.<sup>72</sup> What is being described is hope. For someone with HIV, since there is no cure for the disease returning to normal is impossible. For patients diagnosed with a disease, fertility preservation is one thing that patients can do in hopes to return to normal after treatment is complete. There is no guarantee, but the hope is based on what the patient has identified as important for their quality of life.

The problem with describing something as normal is the subjectivity of it. Normal is based on culture, society, other external influences, and personal bias. Having

children is considered normal, but attempting to get pregnant with reproductive technology may not be considered normal. This does not mean that normal is wrong or immoral. It only means that normal is in the majority, encouraged by society and culture, while abnormal is the minority. For cancer patients, it is very difficult to return to normal during or even after treatment. Their perspective on life has changed. Survivorship programs support cancer patients to adjust to their new normal. It recognizes that disease changes someone's life even if they are no longer ill. It affects perspective, values, finances, relationships, work or school, even one's view of self.

### 3. Alternative to Genetic Children and Families

As there is great importance place on the need for genetic children, there are other alternatives to having children. Using donor gametes and fostering or adoption are ways of becoming a parent, but it does not have the biological component that many desire. There are actually different types of parents that can be involved in the creation and development of a child. This list of parents can be confusing because varying sources use different terms, but may mean the same thing. The following are a list of the types of parents:

Biological: a parent who contributed genetic material to the child

Gestational: a parent who gestated the child in the uterus (also known as a surrogate, birthing mother, or carrier)

Intended: a parent who raises the child with the expectations of taking charge of the child's physical, emotional, mental, and financial well-being.

This may or may not be starting with the child from birth or fostering/adopting at an older age.

The patient that is seeking fertility preservation in order to have a biological child in the future is the intended parent. In the case of fertility preservation, the patient who is fertilizing gametes or embryo made from their own DNA is the biological parent. When it becomes time to attempt to get pregnant the intended mother can either attempt to get pregnant or they can contract a surrogate. There can be a number of combinations of the roles applying multiple roles to one person. In fertility preservation being a biological parent is one of the important factors. That is not the only way to become a parent though

There are some who despite doing fertility preservation are not able to attempt to get pregnant, or stay pregnant. This may be discouraging to the patient, whose future goal was to have biological children. It may mean reevaluating the desire to have children, or to find alternative methods to have children. It at least forces the patient to consider changing their future goals. In those cases, patients may consider using donor gametes (with or without a surrogate) or even fostering, and domestic and/or international adoption. Being a biological parent is not the only way to become an intended parent. There are many families that have fostered or adoption and are just as happy and successful as biologically related families. There may be concern over not knowing the history or the background of the adopted child, but there is no guarantee for a well-behaved, healthy biological child either.

There is also the future outcome of not having children. There are people who are content to not have children either by choice or due to age-related fertility decline. The imagination of a future may not have included children. Often, this group is negatively judged for their choice not to have children. Many (usually those who already have children) voice concern that these people are making a selfish choice and will regret not

having children. It is vital to remember that because of autonomy and positive rights, one can seek out a way to have children, people also have autonomy, and negative rights reo refuse to have them.

### C. Grandparenthood

In cases of patients who are minors, parents are making the future decisions for their children. The possibility of becoming grandparents should not be the primary reasons for pursuing fertility preservation. There is an inherent conflict of interest when parents are the decision makers for a child regarding fertility preservation. Parents have the added benefits of preserving fertility for grandparenthood. Parents are to make decisions that are the best options for their child, which may or may not preserve fertility.<sup>73</sup> The importance of best interests in decision making will be discussed more in Chapter Five. As part of making a decision on behalf of a minor patient, there is also a consideration if parents have an obligation or duty to consent for fertility preservations. Some of this obligation is often discussed within the context of the child's right to an open future.

#### 1. Conflict of Interest

Conflicts of interest come into play many times while seeking medical care. The Association of American Medical College defines conflict of interest as a conflict between the personal and professional interests. This can include financial or compromises in judgment.<sup>74</sup> However, there can be times when conflict of interest is true in a person's daily life. In the case of parents, they are to make decisions for their child based on best interests standard. However, it is hard for parents to make decisions for the child without having any of their personal feelings affect the decision. Just as people can

desire to have child, so can those same people desire to have grandchildren. This desire to be a grandparent could, in theory, be so strong, that it influences the decision to freeze their child's material so that the child, when an adult, can attempt to get pregnant. The thinking of the parents in this case is over stepping their bounds. When a parent consents for fertility preservation, they are consenting only for the first decision, to cryopreserve material. They are not consenting for the second decision, to attempt to get pregnant or in the case of research, attempt to transplant the ovarian or testicular tissue back into the patient. The expectation maybe that because the parents made the first decision, give them the right to decide the second decision is false. Due to the nature of patient autonomy, once a patient is deemed to be capable and competent, in this case turning eighteen, then authority to consent shifts from the parents to the newly legal adult. Now, in many cases, eighteen year olds are still living at home or at least still on their parent's insurance plan. It is reasonable to expect that the eighteen year old patient may bring his or her parent to appointments and ask the parent for their opinion. However, the patient is the one who ultimately signs the informed consent document.

Parents need to be sure that their personal desires do not get in the way of deciding what is best for the children. Parents need to engage with their child, especially adolescents, to understand the child's values and hopes for the future. By including the adolescent in the discussion, the parent is engaging with the child which in the future can help the adolescent, once they become a legal adult, to feel more comfortable navigating the world of healthcare. One thing to note here is that the conflicts of interest relay on the individual with the possible conflict to act with integrity and the honesty to acknowledge a conflict of interest.<sup>75</sup> Individuals need to be able to see the ethical

dilemmas and any conflicts that may come their way. This requires the individual to know their role, know their situation and independently identify any problems.

There are ethical concerns for conflicts of interest. Conflicts of interest are not unethical just because they are conflicts of interest. Everyone has a back-story or involvement in something – whether good or bad. No one can predict the future and know what is going to be presented to them all the time. The problem is acting despite a conflict of interest.

## 2. Parental Obligation to the Child

So what is the parental obligation to the child? Does a parent have to preserve fertility because it protects the future for the child? Do the parents have to refuse research because the science is unrealistic and impossible today? Does the parent have to defer to the assent of the child or the authority of the healthcare professional? The concept of duty and obligation is a tough concept to establish. Duty or obligation means that there is something greater than the individual compelling them to act in a certain way. The most common duty to discuss in healthcare is the duty to warn, but that is not what is being discussed here. Duty or obligation here is a positive right. Does that parent have a duty or obligation to do something- in this case fertility preservation?

There are some who hold to the concept that parents have the duty or obligation to act in a ways that protects (or promotes) the child's right to an open future. This means that the child should be given the opportunity to every available future that is possible. In the case of fertility preservation, the right to choose to have children is based in the future. But the question is still is there a duty? (More on right to an open future is discussed in Chapter Five).



For prepubescent children, because there is not standard of care option for fertility preservation, there is a strong argument that parents do not have an obligation to consider fertility preservation research. It is well established that those who choose not to participant in research have the right to refuse to participate. One of the purposes of research is to add to the body of knowledge and it cannot guarantee any therapeutic benefit for the participant.

For adolescents, parents must consider the wants and desires of the mature minor. Parents have a duty to consider the opinion of the mature minor patient. These patients have the ability to think about their future. They can reason and consider risks and benefits. They can understand the risk of side effects and concept of harm. While parents still sign the consent form, adolescents should be involved in the informed consent process.

#### *D. Research Protocols*

Research is crucial to the development of science and medicine. Research seeks to gain information in order to add to the body of knowledge with the hope of helping patients in the future. Today within the field of bioethics, research ethics has developed into its own discipline.<sup>76</sup> In research, a patient must understand that they are no longer a patient, but rather a participant in a study. Participants must join the protocol willingly and free from exploitation, coercion, or manipulation. These participants may have their hope in a specific outcome, but that is not the purpose of research. Those conducting research need to be aware if this is guiding the patient's decision making. Fertility preservation is not unlike other areas of medicine that have both standard of care or research protocols available to patients/ participants.<sup>77</sup> It is crucial to building a realistic

hope for a specific outcome that patients/ participants are able to make the distinction between standard of care and research when choosing a type of fertility preservation.

Consider the future in light of fertility preservation can be difficult, because reproductive technology is constantly changing. While hope is a universal concept, it is a very individual experience.<sup>78</sup> The way that hope is describes is better understood within the context research. Hope in the future of research is more abstract than hope in standard of care. The hope, having children in the future is the same, but the possibility and realistic nature of that coming true varies. Patients need to consider why they are aiming for children and if the pressure from partners, family, or friends plays a role in the decision making process. It is important to keep in mind though, that the decision to preserve fertility is not the decision to attempt to get pregnant. The fertility preservation decision is in the present regarding the future, while the attempt to get pregnant is a future decision. The decision now may affect the ability to have the decision in the future. For some patients, the only options are experimental and can add to the body of scientific knowledge that may one day make fertility preservation standard of care for those who do not currently have that option. More will be discussed on research, fertility preservation, and hope in the following chapters.

## **VI. Conclusion**

Since hope and fertility preservation both involve the discussion of realistic possibility and the future, it is tough to adequately manage and maintain realistic hope. There is a responsibility of both the patient and the healthcare professional to thoroughly understand the truth and the realistic expectations of fertility preservation. By moving from taking about abstract to discussing personal, there is a context that provides valuable

and specific information that inform the perspectives and ultimately the decisions being made. Personal narrative allows patients to take ownership of the situation and work together with the healthcare professional to examine the realistic and possible outcome for the future.

Healthcare professionals and patients have specific roles and responsibilities to consider when dealing with the situation. While having a commitments to their profession, healthcare professionals also need to consider their commitments to the individual patient. The patient and seeking health should be the priority. Working towards honoring beneficence and nonmaleficence can do a long way in establishing trust with a patient. When healthcare professionals know their role and responsibilities, they function better as part of a team and can refer patients to those who know better when necessary. Patients in turn need to understand their roles. Being the primary decision maker can be challenging, but it also allows the patient to take charge. As an advocate, patients work tirelessly to keep themselves involved and safe. In the sick role, patient can take ownership of their interactions with healthcare professional. By examining the two perspectives, those involved can better understand where the other is coming from and how to address issues of understand being realistic and possible.

The decisions with fertility preservation are to be separate. Decision one should focus on the risk from the side effects of treatment or aging, and the consideration as to which fertility preservation method is best. Some may find that gamete cryopreservation is a better option than embryo cryopreservation and should be allowed to pursue one over the other. The decision of choosing fertility preservation, being separate from the decision to attempt to have a child, is focusing on the risk of infertility and the future

outcome of having a child. The second decision of having a child is separate and must be done so in a separate informed consent process. Patients should be legal adults and know and understand the complications that can come with attempting to get pregnant.

Material that is cryopreserved is limited and so resources need to be used carefully.

When it comes time to attempt to get pregnant, patients need to still maintain the desire to have children. Patients are allowed to change their mind to not pursue attempting to get pregnant even if they choose fertility preservation in the first place.

When looking at the future, patients may consider the importance of having biological child, but it is in their best interest to consider what that means and the alternative options. Working towards having biological children is not simple and methods like artificial insemination and vitro fertilization take time and money. Additionally, there are other factors that may still prevent the patient from attempting to get pregnant like problems with the uterus or legal confusion over the rights to embryos. Understanding what it means to hope for success of fertility preservation can be confusing and overwhelming. Patients, with the guidance of healthcare professionals, need to determine what their future outcome to aim towards is and to evaluate the realistic and possible natures of that outcome. Ultimately, to pursue fertility preservation or not is the patient's decision. There are ethical issues to consider that are brought about when discussing the connection between hope and fertility preservation.

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## Chapter Five: Ethical Issues with Hope in Fertility Preservation

### I. Introduction

Chapter Five will present an ethical analysis of the reliance on hope in fertility preservation. It will discuss what specific ethical principles and practices need to be considered in relation to hope including autonomy, beneficence, nonmaleficence, justice, informed consent, and truth-telling decision making. It will also develop a critical ethical analysis of the advantages and disadvantages of the reliance on hope in fertility preservation in light of the ethical principles and practices. Advantages include right to direct care, optimism, and survivorship, while disadvantages include projecting the future of research, false expectations, and the involvement of other people.

### II. Ethical Principles

In the United States, the four principles as developed by Tom Beauchamp and James Childress dominate the discussion for ethical principles. Autonomy, beneficence, nonmaleficence, and justice were developed out of the Belmont Report. After the Tuskegee Syphilis Experiment a committee was formed to create a report in order to respond to the terrible actions that took place. Respect for autonomy, beneficence, and justice were three principles that were identified as necessary for ethical research. Beauchamp and Childress expanded this in the four principles in the *Principles of Biomedical Ethics*. These four principles can be applied and discussion anywhere in healthcare. While these are not the only principles, they are the main ones. Balancing the principles can be difficult because to a certain extent prioritizing one principle of any another can be at times subjective. Balancing the principles can be difficult because to a certain extent prioritizing one principle of any another can be at times subjective. These



principles then affect ethical practices like informed consent, truth-telling and decision making. When these ethical issues and practices are considered in light of hope and fertility preservation, there are advantages like right to direct care, optimism, and survivorship. However, there is also a risk of false expectation, inappropriately projection the future of research, or the inability to manage the involvement of parents or partners.

#### A. *Autonomy*

Autonomy is the most prominent ethical principle in the United States. This is due to the US being a rights based society. Individual rights are important to the foundation of the country and it manifests itself in every area of the culture.

##### 1. *Defining Autonomy*

Autonomy in health care is the ability to direct one's own care. Respect for autonomy is respecting the right that people have to direct their own care. Patients are assumed to be competent and capable to make their own decisions. Those same patients often base their decisions on the hope for a specific outcome in the future. When a patient is diagnosed with an illness like cancer, the patient has the right to direct their care include who their healthcare team encompasses, what treatments are important, and how to approach the risk of infertility. In order to make the best decision for themselves, patients need to be given all the information available and provided expert recommendations. In fertility preservation, patients are hoping to avoid infertility and one day and hope to have a successful pregnancy. Hope gives patients the ability to look to the future for possibilities like having children, and because of the principle of autonomy, not only can patients seek out health care to preserve fertility, but also through positive liberty seek

out medicine the attempt a successful pregnancy. There are two main parts of autonomy when dealing with diagnosis: 1) the deliberation, and 2) choosing and acting.<sup>1</sup> Together this is how a patient acts with autonomy. Patients have to consider all their options. Healthcare professionals are most often the gateway to those options and need to be prepared to provide all the necessary and relevant information. Once a patient chooses and acts, the healthcare profession either supports the patient or refers them to someone who can.

There are times when respecting patient autonomy may conflict with professional responsibility. A patient's right to direct their own care cannot encroach on a health care professional's right to provide medicine.<sup>2</sup> If a health care professional cannot in good conscience provide the type of care that the patient is requesting, they should refuse and refer the patient elsewhere. Refusing a patient should be in rare cases, rather than the norm. It should only be in cases of moral uncertainty.

## 2. Positive Right in Fertility Preservation

Deciding how to approach fertility preservation can be difficult with so much information communicated to a patient all at once. Autonomy has both positive and negative rights in how healthcare is addressed. Positive rights mean that patients have the right to seek out specific care. This may mean patients actively do their own research. They may disagree with the healthcare professional's recommendation. They may choose to seek out a physician that actively supports their decisions for their treatment. Healthcare professionals need to be supportive of patients that want to be active in their care.

Reproductive autonomy is a term that has been used to describe a women's right to access infertility treatment. This term is a bit of a misnomer. As stated earlier, autonomy is the ability to direct one's own care. However, it does not guarantee access to every treatment or technology available. This is especially true for research protocols. For many years oocyte cryopreservation was only considered experimental. There was not enough data to support it as standard of care.<sup>3</sup> This meant that women could not just walk into a doctor's office and demand to freeze their eggs. They need to enroll in a research study where they fit the criteria. Trying to communicate the difference between research and standard of care can be difficult. Before 2013, many assumed oocyte cryopreservation was a valid option, but it was not until 2013 the American Society for Reproductive Medicine announced guidelines for oocyte cryopreservation and the official stance that it was no longer experimental.<sup>4</sup> Reproductive autonomy also does not mean that patients can throw out healthcare professional recommendations and demand care that is not appropriate for them. Healthcare professionals walk the line of respecting patient autonomy while maintaining professional expertise. In cases where patients are seeking a specific treatment or procedure, they may have to search for a healthcare professional willing to do what they are asking. For a long time, fertility preservation was a new concept; many did not know the term or the options available. Today, there are now oncofertility doctors and experts whose sole focus is fertility preservation. For those who are diagnosed with disease that can affect fertility, it is critical for healthcare professionals to discuss fertility preservation with them. This dialogue allows that patient to decide for themselves what is appropriate and best for their situation.

In some cases patient can be over eager to seek out medical treatment. This is where hope may no longer be rational, but can verge into the false hope area. In some cases, patients are requesting procedures that are unproven or for which they do not fit the demographic and it makes for a difficult conversation. Patients may be placing hope in something that is no longer possible. The line between hope and wish fulfillment is narrow. While imagination of what is possible reinforces hope, in some cases it may be too much. It is the responsibility of the healthcare professional to ensure that the patient understands what options are realistic and possible. This can better manage hope in a way that is supportive, and yet based in reality.

### 3. Negative Right in Fertility Preservation.

Patients also have the right to refuse treatment. This negative right means, provide the patient is competent and has capacity, that he or she can refuse treatment or care being offered. They may need to sign a waiver acknowledging their actions, but healthcare professional cannot force them to start or continue unwanted treatment. (Side note: This discussion may or may not be true for those suffering from mental illness, but that is a separate discussion). It may seem irrational for a patient to refuse treatments. There are a number of factors that go into why a patient refuses treatment- fear, unwilling to enter research protocols, tired of all the medicine, tired of the side effects, ready to die, cannot afford treatment, want to go home, and many others. When the patient is younger, it can be especially heartbreaking. In the case of fertility preservation, a patient is making a decision (fertility preservation) in time that may or may not be true at a future date (infertility or ability to have a biological child). In refusing care, patients are weighing their benefits and risks and deciding that the risks are too high, and the benefits

are too low. It may not appear rational and patients may be stubborn and difficult, but that does not mean they do not have autonomy. So long as they are competent and have decisions capacity, they have the right to refuse.

There are times when patients are refusing treatment because they no longer have hope. They have determined that the options are impossible or unattainable. It is also the responsibility of the healthcare team to make an effort to restore or instill hope. One of the most consistent ways to address hope is through a solid patient-healthcare professional relationship.<sup>5</sup> This is done through providing support in the demonstration of truthfulness and empathy. Both Marcel and Lynch note that hope must have a plausible outcome. It is the healthcare professionals' responsibility to address that when a patient seems to see no plausible outcome. This is not to say that beneficence is thrown out the window, but it does acknowledge that plausible outcome is a broad term that does not have to focus solely on health and recovery.

There are times when someone may refuse a type of treatment for moral or religious objections. It is crucial that the healthcare professional does not reject the patient simply on their moral or religious objections. In an effective patient- healthcare professional relationship, a healthcare professional must still move forward supporting the patient, but also not retreading a topic that the patient has already decided upon. In fertility preservation, a patient who is Catholic may refuse to cryopreserve sperm, oocytes, or cryopreservation. Because the Catholic Church does not condone artificial reproductive technology, there are patients who follow the church's doctrine.<sup>6</sup> If a patient is facing cancer and the risk of infertility, healthcare professionals should still outline the risks of infertility and the benefits of fertility preservation, but the healthcare

professional must respect the patient's autonomy. Healthcare professionals can provide additional support but look for chemotherapy or radiation options that are effective in treating cancer, but low risk for infertility. The healthcare professional can also be a support system as treatment, when the patient is ready to attempt to get pregnant by providing resources for addressing fertility in a way that supports the patient's moral and religious views.

#### 4. Autonomy for Children

When dealing with pediatric patients in fertility preservation, the view of autonomy is a bit different. It is assumed and well accepted that pediatric patients cannot consent for themselves. While there are exceptions, but this is the general rule. Parents are expected to consent on behalf of their child, and if the child is age appropriate provide assent.<sup>7</sup> There is then a high level of trust that is placed in parents that they act in the best interest of the child. In the case of fertility preservation, parents make their decision for the best interest of the child's current health and future.<sup>8</sup> The child, when old enough, may decide to have a child, but in some cases, an early childhood diagnosis could make this difficult, but not impossible. By enrolling the child in a fertility preservation study, one could argue that the parents are preserving the child's autonomy.<sup>9</sup> The child's right to an open future is not only considered, but respected and encouraged.

##### a. Best interests of the child

In the case of pediatric patients, parents or legal guardians are to provide consent on behalf of the child. This does not just include signing the informed consent document, but also includes making the decisions for the child. When a parent is to make a decision for their child, it is hard to stay objective and neutral. Parents have their own set of

expectations for the child's life, but it may not be the same as what the child would see for themselves. When deciding on behalf of their child, parents are expected to make decisions using the best interests standard. Best interests standard is when a surrogate decision maker maximizes the benefit and minimizes the risk in order to decide what happens next.<sup>10</sup> The parents are to consider the benefit of the treatment, the risk of the side effects, the quality of life, the values, preferences, and perspective of the child. The problem is that with a child so young, it is difficult to determine the values, preferences, or perspective of the child because parent's own values, preferences, or perspective may get in the way. Healthcare professionals can step in if they believe that the parents are not acting in the best interests of the child, especially when direct harm may result.<sup>11</sup> As the child ages, he or she can begin to participate in the decision making process.

b. Child's right to an open future

Joel Feinberg originated a concept in 1980 called a child's right to an open future.<sup>12</sup> He argued that child have future autonomy that needs to be protected at all costs. His claim is that by protecting an open future for the child, then their possibilities are not limited by decisions that someone else made in the past. In theory, this may sound grand, but determining what is good and bad, and what constitutes open versus close, is one of the biggest criticisms of this concept.<sup>13</sup> It would be impossible to keep all options for a child's future open at all times. Feinberg notes that keeping all options for everything open at all times would be impossible, but he strives to provide most to allow the child to be happy and self-fulfilled. This means that the child's right to an open future is to protect, the natural and typical future options available.

Claudia Mills give the example in choosing a career. In the attempt to provide education for a child, there are certain subjects that are taught in school over others.<sup>14</sup> Now, according to this argument, all information should be taught equally so that a child, when of age, can choose whatever career path. Since that have had equal education in all subjects, then the child's future career path is completely open. In practice, this is impossible. There are certain topics that society has deemed necessary for a good education to become a contributing member of that society, and others which are not bad, but are more optional in their broad need for education.<sup>15</sup> Additionally, there is not enough time in the day or in a lifetime to learn all information equally. This does not mean that there are times when the determined education needs to be reexamined or changed. This illustration is just meant to highlight that keeping a child's future completely open is too difficult to do all the time.

In the case of fertility preservation, there is a limit to what healthcare can do to keep a child's future open. If an adolescent girl is diagnosed with lupus, there will be a life-long battle with symptoms of the disease and side effects of the treatment. Some of the treatments for lupus, including chemotherapy, can affect fertility of the patient. Parents should consider oocyte preservation as a way to keep the option for a child open for the adolescent girl.<sup>16</sup> This should only be done though if it is in the best interest of the child, and not just about the parent's desires.<sup>17</sup> However, in cases where the patient has not undergone puberty, it would be irresponsible to force puberty on the patient as a way to do fertility preservation. Forcing puberty on a young child can be dangerous and many consider it to be unethical even though the production of a mature oocyte or sperm would be the best methods of fertility preservation. Instead, parents have to consider research



protocols like ovarian or testicular tissue cryopreservation that are available.<sup>18</sup> By enrolling the child in a fertility preservation study, one could argue that the parents are preserving the child's autonomy.<sup>19</sup> The child's right to an open future is not only considered, but respected and encouraged.

### *B. Beneficence and Nonmaleficence*

Beneficence and nonmaleficence are discussed as part of fertility preservation, emphasizing risk, and its contrast to realistic benefits versus possible benefits.<sup>20,21</sup> The protocols for fertility preservation have risks just like any other invasive procedure in medicine. In the case of fertility preservation, while the initial risk, preserving one's fertility, is undertaken as soon as a decision is made, the benefit, a successful pregnancy, may not happen for many years. Cancer patients are recommended to wait up to two years after remission to ensure that there is not a relapse of cancer.<sup>22</sup> Therefore beneficence and nonmaleficence are not just part of the short term decision to preserve fertility, but also a part of the long-term future decision.

#### 1. Defining Beneficence

Beneficence was first identified as an important healthcare principle in the Belmont Report as part of the benefit-risk assessment.<sup>23</sup> In *Principles of Biomedical Ethics*, there is a distinction between beneficence and nonmaleficence. Beneficence has 3 norms: “1) one ought to prevent evil or harm; 2) one ought to remove evil or harm; 3) one ought to do or promote good.” Nonmaleficence is only “one ought not to inflict evil or harm.”<sup>24</sup> More specifically beneficence is about positive action. For many, beneficence creates an obligation to provide care. For healthcare professionals that can be difficult to work through, when healthcare professionals are supposed to respect patient autonomy at

the same time. For some the competing principles of autonomy and beneficence can create a difficult dynamic in the patient-healthcare professional relationship.

Jennifer Beste writes that the competing values in situations where prognosis and survival is troubling, can justify beneficence to override autonomy.<sup>25</sup> She writes that paternalism is justified because patients are vulnerable and need to be protected from themselves. Healthcare professionals have the obligation to instill hope in patients who are struggling with accepting their current diagnosis. With cancer patients, acting in a way that promotes beneficence can reflect the importance of promoting a hopeful outcome for patients.<sup>26</sup> However, it is risky move by the healthcare professionals to withhold information. This contradicts informed consent both ethically and legally. Even in the best patient-healthcare professional relationship, withholding information can appear as manipulation. The most common argument against this is that the positive attitude or optimism towards the diagnosis and treatment can provide actual better outcomes.<sup>27</sup> There have been protocols that have studied the correlation between attitude and outcome, but what is really being described is hope for recovery.

For fertility preservation, beneficence focuses on how to promote good and prevent harm. By preserving fertility, one is avoiding the harm age or the treatment of disease may cause. Promoting good may involve seeking out the best cryopreservation technique for the current circumstance. For prepubescent children, there are no standard of care protocols available for the only option is research protocols. Parents have to weigh the benefits and risks of the research, knowing that it is an unproven option.<sup>28</sup> This means there may not be solid data or recommended protocols for things like ovarian or testicular tissue cryopreservation. This also means there is little data for transplantation

of the tissue back into adults, and no data for transplantation into children. However, if this is the only way to potential preserve fertility, parents may strongly consider doing so. It is important for the healthcare professional to consider beneficence and nonmaleficence before conducting fertility preservation research on prepubescent children. There is the risk that parents can have hope for a medical procedure (transplantation in the future) that does not and may never exist.

## 2. Defining Nonmaleficence

Nonmaleficence was originally incorporated in the principle of beneficence in The Belmont Report. However, Beauchamp and Childress, however, separated it when developing their *Principles of Biomedical Ethics*. Nonmaleficence as mentioned before has a norm of “one ought not to inflict evil or harm.”<sup>29</sup> Inflicting harm could be intentionally leaving out information during the informed consent process or could be the side effect that come from treatment of disease like chemotherapy.

In the case of fertility preservation, the harmful thing is infertility. This could be due to either age-related fertility decline or side effect from treatment of disease. There are two perspectives for this harm. One, the prevention of infertility describes beneficence; and two, the not inflicting infertility describes nonmaleficence. By doing fertility preservation, the patient is preventing the harm of infertility which is more similar to beneficence. By choosing treatments that does not inflict infertility is more similar to nonmaleficence. By considering future fertility, one is protecting the autonomy of an individual. In addition some would argue that even non-maleficence, the idea of do no harm, suggests that fertility preservation should be considered because removing the autonomous choice of possible reproduction in the future can be harmful to that patient.<sup>30</sup>

Harm should not come to these patients especially because they are in a vulnerable place already. By protecting their future, harm can possibly be avoided.

### 3. Balancing the Principles

There is an argument made by some that beneficence should be the most important principle even over riding autonomy.<sup>31</sup> Balancing the principles is highlighted by understanding the patient's values and preferences. Whether the focus is on avoidance of harm or actively seeking a preventative solution, the end result is the same- trying to preserve the fertility of a person. The benefit-risk assessment is one that can focus on a number of things.<sup>32</sup> When a patient is diagnosed with cancer, the benefit-risk assessment tends to center on the cancer diagnosis, treatment, and long-term survival. Within this assessment is the consideration for fertility preservation. It is important to have a separate, but equal consideration for the benefit-risk assessment for fertility preservation. For instance, benefit-risk assessment for cancer focuses on the type of treatments available, the side effects of the treatment options, the effectiveness of treatments both for short-term and long-term survival. For the benefit-risk assessment of fertility preservation the consideration are about delaying treatment for disease, invasiveness of preservation technique, cost of preservation both the initial cost and the long term cryopreservation fees, the importance of children for the future, the opinion of a partner, or the lack of a partner. These benefit-risk assessment is more straight forward when dealing with adults (or adolescents) than when dealing with prepubescent children.<sup>33</sup>

### C. Justice

Justice was originally included in The Belmont Report and also in *Principles of Biomedical Ethics*. The idea of justice is fair and equitable treatment of all people.

Someone who has a justified right to claim something, is due that claim.<sup>34</sup> The According to Beauchamp and Childress some of the biggest issues in dealing with justice is determining fair opportunity, dealing with unfair discrimination<sup>35</sup>, racial, ethnic, and gender disparities,<sup>36</sup> vulnerability,<sup>37</sup> exploitation,<sup>38</sup> and allocation.<sup>39</sup> Two very prominent writers, John Rawls and John Stewart Mills have written extensively about what justice is and how it applies.

#### 1. John Rawls

According to John Rawls, justice is all about fairness.<sup>40</sup> Rawls theory of justice starts with the original position of thought. This is to say that hypothetically individuals and societies promote principles of justice in a manner that is based upon free and fair cooperation. The idea of a “veil of ignorance” is used are part of this thought experiment. The “veil of ignorance” is the idea that you do not know your defining characteristics are to you social situation prior to determining what is just.<sup>41</sup> Rawls concludes two principles of justice from the original position thought experiment.<sup>42</sup> First, everyone has equal right to the most extensive liberty compatible with the same liberty for others. Second, if there must be inequalities, then social and economic inequalities are arranged so that positions are open to all and provide the greatest benefit of least advantaged. These principles apply to the “basic structure of society and govern the assignment of rights and duties and regulate the distribution of social and economic advantages.”<sup>43</sup>

Rawls theory says that everyone should be guaranteed liberty. This means in terms of healthcare, should everyone have that as a right? As a society, we agree that at a minimum level, vulnerable populations deserve health care. Medicare and Medicaid both serve and provide health care to the poor and elderly. Legally these groups are protected

and given justice. But what about those who currently do not have access the health insurance? Rawls might argue that people deserve to have health insurance in order to receive the minimum amount of health care.

## 2. John Stewart Mill

John Stuart Mill explains justice from utilitarianism. Utilitarianism is all about promoting the good and by doing that there is a greatest total of happiness. Mill has five attributes of justice. First, it is unjust to deny someone their personal liberty, property and legal rights.<sup>44</sup> Individuals should be able to pursue their personal liberty and legal rights without interference. The justice is found in the respect for these and injustice is to infringe on the legal rights of an individual. Second, some laws may have been unjust and deny a person moral right, but legally allowed.<sup>45</sup> This is to say that although legally, someone's actions may be permitted, that does not make them just or morally right. Third, it is universally just to have individuals get what they deserve and to not get what they do not deserve.<sup>46</sup> This essentially means that promoting good results in deserving good and doing wrong results in deserving wrong. Fourth, it is unjust to break your word with someone.<sup>47</sup> Keeping someone's trust is very important however, it can be overruled if there is someone more. Fifth, showing favorites is unjust and impartiality is in line with equality.<sup>48</sup> Impartiality is not a duty in and of itself; however, Mill says it helps support other duties. Injustice is created by two things – a wrongdoing and an individual was wronged. Injustice is not just about breaking laws that are established and but also about breaking the laws that ought to be exist. Mills examines justice in light of utility. He says that justice is the most important obligation in the span of social utility. The moral requirements that set a high standard for justice and in turn create a great duty or

obligation. The connection here is found in the principle of utility – making sure that the great good (or as the case may be happiness) is achieved.

As for Mill, his theory of justice is also difficult to apply to a specific model like healthcare. The attributes easily apply to the legal system, but not as easily to healthcare. In attribute three, there is not clear definition of good or wrong. This gets more complicated in healthcare because of the issues of life and death. There are few who would refuse medical care if it spared a child from death. But to declare something unjust in healthcare is difficult. Mill says that injustice is created by two things – a wrongdoing and an individual was wronged. Again, who defines the wrongdoing? It is also important to think about whom the individual is – the patient, the family, the medical team, or the insurance company. There are so many people to consider in any healthcare case. In theory it seems easy to say you take away a healthcare worker's license. But how do you punish a patient who breaks the rule? In terms of utility, there are the same arguments that were presented with Rawls. Promoting the good or happiness is important and this should allow for patients to make decisions for themselves, but this is not always the case.

### 3. Application of Theories of Justice

In the case of fertility preservation, what is considered just? According to Rawls and Mill, it is just to promote the good. Again, defining good in fertility preservation is difficult. Is good considered preserving fertility, or is good no becoming infertile in the first place? Or maybe good is being able to get pregnant when one chooses. Good is subjective and if everyone demanded their own version of good, it could become a drain on the entire system. There are only certain number of resources and allocation of those

resources have to be done in a just manner. As stated before, it is important to be just for those who are vulnerable, but if everyone is deemed vulnerable, than no one is vulnerable.

### III. Ethical Practices

By applying principles of autonomy, beneficence, nonmaleficence, and justice, there are practices that have been developed. They play a significant role in how patient approaches healthcare and how they hope in something. The application of these principles is demonstrated in the practice of informed consent, truth-telling, and decision-making. Informed consent, truth-telling and decision making directly connects to how hope is fostered in fertility preservation.

#### A. *Informed Consent*

Several sources such as *SAGE Handbook of Health Care Ethics*,<sup>49</sup> *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*,<sup>50</sup> and *The Oxford Textbook of Clinical Research Ethics*<sup>51</sup> discuss informed consent. Informed consent has become a main tenant in health care because of past abuse, changes in the patient-healthcare professional relationship, and the defensive medicine due to the litigious society.<sup>52</sup> Inadequate informed consent has been shown to be one of the major ethical and legal issues for reproductive technology.<sup>53</sup> Informed consent is not just a signature on a form, but a process of communication that patients and healthcare professionals must participate in together.<sup>54,55</sup> It is a reflection of the autonomous choices made by a patient.<sup>56</sup> All three components to informed consent- fully informed, fully capable, and fully voluntary need to be addressed adequately for all patients pursuing any type of fertility preservation.<sup>57,58</sup> Informed consent for fertility preservation is not the same for



every patient. Because fertility preservation has many different demographics, and some types are standard of care, while others are research protocols, informed consent needs to be adequately addressed and approved by the institutional review board.<sup>59</sup>

#### 1. Fully Informed

To be fully informed is to know all the information for a given situation. This does not just mean the process of the treatment and the risks (side effects) of the treatment. This means patients should be told how effective the treatment is, how experience the healthcare professional is with this particular treatment, alternatives that may better suit the patient's needs, or even changes in protocols.<sup>60</sup> Disclosure of information is critical to the informed consent process and healthcare professionals have a professional responsibility to disclose all necessary and relevant information.<sup>61</sup> While there are many different ways to disclose information, the end result should be the same- the patient has understanding about the information provided. In rare cases, it may be appropriate to withhold information, but that must be justified on a case by case basis. Healthcare professionals are also expected to give their professional recommendations. They are well versed in health care and understand the nuances of the side effects, benefits, and risks.

This information being disclosed to the patient affects the concept of hope. Hoping in something can only be done when the patient is given all the information and can imagine a realistic possible outcome. Without all necessary information, patients cannot hope in a way that is realistic. Hope based on false or missing information can be problematic because the outcome that is imagined may not be the same as the outcome that happens. This may create distrust in healthcare for the future.

## 2. Fully Capable

Being fully capable is the ability to understand and reason. Every adult is assumed to be both capable and competent. Having capacity is a medical determination while competency is a legal determination. Unless there is a formal medical or legal determination, every person makes decisions for themselves. This means that decisions made by patients are the decisions to be followed. This could mean either refusing to consent or consenting to a treatment. Healthcare professionals are expected to treat patients as they are capable and competent unless there are signs otherwise indicating they are not.<sup>62</sup> This does not mean that everyone has the same level of intelligence. When providing information, healthcare professionals need to be aware of the intelligence of the patient in order to best communicate with them. It make take a few different techniques to ensure that a patient has understood the information being presented.

Hope in something can only be done if the person has the ability to understand and reason in the situation. The person needs to be aware of the current situation, what can or should be done to make the change, and what the potential outcomes are. If a person is unable to appreciate those things, or make reasonable sound judgments, there may be an issue with capacity or competency. However, either an evaluation from a medical professional or an evaluation by the court can remove capacity or competency. For adults, being capable of informed consent is part of the ability to hope. Patients that can provide consent, have the intelligence and ability to appreciate the nature and risks of the medical treatment and hope for a future outcome. Parents who consent on behalf of a

child must have capacity and as the child ages, getting assent can be a way of making the child feel included.<sup>63</sup>

### 3. Fully Voluntary

Being fully voluntary, means that patients are making decisions on their own, without the influence of others. Manipulation, coercion, or persuasion are all potential ways that patients may not be making their own decisions.<sup>64</sup> Guilt from family and friends may also be a factor in continuing futile treatment. Being voluntary does not mean that patients cannot take advice or opinions from family, friends, or healthcare professionals. It means that the patient has the final say and their opinion matters more than anyone else. One form of undue influence could be the withholding of information or questions a patient's ability to reason.

The decision to do fertility preservation must be voluntary. Patients be fully informed and fully capable to voluntarily consent. The purpose of fertility preservation is to attempt to get pregnant in the future. Patients should only consider fertility preservation, if having a child in the future is even remotely in the future plans. Many people have the hope of having children one day. If the risk of infertility is imminent, preserving that hope is important. If someone is undecided about future children, they should still consider fertility preservation, because if infertility is a risk, they may not have another chance to take any preventative measures. Their hope may be more for the option of having children in the future. However, no one can force someone to do fertility preservation. Partners should be supportive, but they should not force fertility preservation if the patient is not interested or participate in fertility preservation if the partner does not want children. Cryopreservation of sperm and oocyte eliminates the

complication of involving a partner. It allows the decision and hope for the future to be a singular person's voluntary decision. In the case of minors, it can be more difficult to determine if parents are acting voluntarily on behalf of their child when agreeing to informed consent. Parents are biased in the process and dealing with a sick child is already difficult, but adding have to make decisions about an unknown, but hopeful future can be problematic.<sup>65</sup>

#### 4. Informed Consent in Fertility Preservation

Being informed includes know exactly which is best recommended for the patient's situation. If there is a partner involved, embryo could be better than sperm or oocyte cryopreservation.<sup>66</sup> It is important to at least approach the topic of alternative is fertility preservation does not work. For instance, if there oocytes have poor quality, discussing donor gametes or adoption may be appropriate. Healthcare professionals that are in any way connected to risks of infertility or fertility preservation need to state up to date on the current state of fertility preservation. For example, oncologists should be well versed in the basics of fertility preservation and have a reproductive specialist for referrals.

Men and women should be fully informed of all the process and risks of fertility preservation. In the case of research, patients should be fully informed about the unknown and uncertainty that goes along with cryopreservation. This should include maximum storage time and any data on efficiency and safety of the process.<sup>67</sup> A major part of clarity that should be discussion before procedures take place is the ownership of the cryopreserved material. Patients who are consenting for fertility preservation do with

the understanding that it is their gametes and only that patient has the authority to access it in the future.

### *B. Truth-telling*

Hope and truth-telling have an interesting relationship. One would assume that by telling the truth, hope would be encouraged. However, this is not always the case. There is concern that truth-telling can either promote or destroy hope depending on what information is being shared or withheld. Truth generally concerns being factual about prognosis, treatments, benefits, risks, side effects, or longevity all attached to the health care issue being addressed. As healthcare professionals are sharing this information, they are editing and subjectively deciding what is relevant and adequate to share with the patient.<sup>68</sup> There is so much medical information to know and not enough time to explain everything to every patient. That is why it takes healthcare professionals such a long time to earn their degree and become licensed to practice medicine. So how do healthcare professionals determine what truth to share with a patient and by extension their family and friends? Many question if there is an ethical obligation to tell the truth or it is better to exercise professional judgment in order to have the best chance for a positive outcome?<sup>69</sup> There are several examples of how truth either promotes or destroys hope.<sup>70</sup> And finally, how should the patient-healthcare professional relationship be approached to encourage hope, when there is an assumption of truth-telling by the patient, but not necessarily by the healthcare professional?

#### 1. Ethical Obligation

So do healthcare professionals have an<sup>71</sup> ethical obligation to tell the truth? Some would argue that no, healthcare professional do not have a moral obligation to the truth

based on the four principles by Beauchamp and Childress. By looking at differing approaches to healthcare, one may reach different conclusions. The question about truth-telling focuses on delivery negative news<sup>72</sup> and sometimes delivery negative news is hard for the healthcare professional to give, rather than the patient to hear. Some would describe this type of behavior as paternalist towards patients who have the right to direct their own care.

In order to respect patient autonomy and in turn participate in informed consent, healthcare professionals must disclose all relevant and adequate information for patients to make a fully informed choice.<sup>73,74</sup> Only in rare cases can a healthcare professional claim therapeutic privilege, therapeutic use of placebos, or withholding information from research subjects.<sup>75</sup> In these situations, all of which are research based, revealing information may affect the outcome of the research and it generally communicated up front during the informed consent process. By considering principles of beneficence and nonmaleficence, there may be times where not telling the truth is justifiable. There are some who argue that there are times where it is more beneficial to the patient to not disclose every piece of truth regarding the diagnosis and prognosis. This is generally discussed when serious or even fatal prognosis are discussed.<sup>76,77</sup> There is the fear, that by communicated negative information, patient may not have any hope for their future and in turn refuse any and all treatment. Instead, by withholding information, patients have a better outlook and potentially a better chance for recovery.

In the ethics of care approach to healthcare is the emphasis on the patient-healthcare professional relationship.<sup>78</sup> Originally developed as a feminist approach,

ethics of care holds to the belief in caring for others and emphasizes the importance of interdependency and empathy.<sup>79</sup>

Ethics of care recognizes the vulnerability and dependency that healthcare creates between patient and healthcare professional.<sup>80</sup> Because of this relationship, the patient is trust the healthcare professional to act in a caring way and the healthcare professional must act with compassion. Because of that compassion, there are times when not telling the truth may be acceptable. The key is getting to know the values and preferences of the patient including whether or not they would feel comfortable with withholding information.<sup>81</sup> There is concern thought that not telling the truth can damage the patient-healthcare professional relationship<sup>82</sup> and so not telling the truth should never be the standard, but rather the exception.

## 2. Promoting or Destroying Hope

In many cases, physicians do not feel comfortable taking hope away from patients and by telling the truth, they run the risk of that happening.<sup>83</sup> They may feel that they are destroying hope that patients have for the future. It may be too difficult to deal with the emotional reactions from patients and by either editing the truth or withholding information, it is easier to address patient needs and treatment. In telling the truth, hope is destroyed and so are the therapeutic effects that are associated with it.<sup>84</sup> However, to justify not telling the truth or withholding information every time, give little credit to the patient to have perspective and intelligence to their situation. Patients may even lose hope if they discover the healthcare professional had treated them differently and justified withholding information. And along with the loss of hope goes trust as well.<sup>85</sup>

By focusing on promoting hope in patients, healthcare professionals are acting in a way that focuses on patient-centered care now more than ever. The perpetual focus on veracity demonstrates that truth-telling is no longer a suggestion or an opinion, but an important principle to consider with equal weight as autonomy or justice.<sup>86</sup> Many professional codes of ethics include truth-telling as an important part of being an ethical professional. In the case of fertility preservation, healthcare is offering this as a way to hope for a specific future of attempting to have children. The risks of aging or side effects of disease can be overwhelming to a patient, but unlike delivery fatal news, patients have an option on how to address the risk being presented to them. Healthcare professionals are the gateway to understanding fertility preservation and knowing the risk of infertility should encourage them to share about the options for fertility preservation. Patients can rest their mind that even though they have a risk of infertility, they did all they could to preserve fertility in a difficult time in their lives.

### *C. Decision Making*

As discussed in the previous chapter, fertility preservation is actually two separate decisions- one is to preserve fertility and the other is to attempt to get pregnant. There are also two distinct tracks that these decisions can do.<sup>87</sup> In the first track are the adults that make decisions for themselves which may or may not include a partner.<sup>88</sup> At the time of preservation, the patient (and their partner) decide to do fertility preservation and what method makes the most sense for their situation. During the second decision of the first track, they work together to determine when is best to use their preserved material and attempt to get pregnant. In the second track, parents make decisions with the assent from an adolescent or a child.<sup>89 90,91</sup> For minors, the first decision to preserve fertility lies



with the parents acting with best interest, but the second decision to attempt a successful pregnancy is the decision when the minor becomes a legalized adult.<sup>92</sup> It creates an unusual dynamic by forcing the child or adolescent to make a decision in the future- either in favor or against getting pregnant. There is a third decision that needs to be made in both tracks, discussed prior to decision one and resolved before decision two can move forward- what to do if the patient were to pass away before a pregnancy can be attempted. Questions suddenly provoke answers for who owns the preserved material that was preserved and should anything be done with it.<sup>93</sup>

There are a few difference scenarios of who owns the preserved material and what that means for the family and friends of the patients that are still alive. Below is a list of potential options for the cryopreserved material that a patient can do. Ultimately, patients are hopeful for a successful pregnancy that leads to having a child.

1. Patient uses cryopreserved material to attempt to get pregnant. May need donor gametes for sperm or oocytes to create embryo (either before fertility preservation or after defrost of material).
2. Patient uses cryopreserved embryos to attempt to get pregnant in conjunction with partner.
3. Patient uses cryopreserved embryos to attempt to get pregnant without the support of the partner.
4. Patient decides that the cryopreserved material be donated either to someone else to attempt to get pregnant or to research.
5. Patient is discards all cryopreserved material and does not attempt to get pregnant.

The decision making regarding the use of the cryopreserved material is also depended on the prognosis based on the conclusion of treatment or at the appropriate age and the quality of the cryopreserved material. Patients who are able to have a supportive partner willing to be involved in the process makes for the easier option, but that is not always realistic. In some cases, partners may change their minds and no longer want to be involved in the process of attempting to get pregnant. Unfortunately, in those cases, there can be a custody battle for the right to use the already existing embryos.

From 2010- 2015 there was a case over the rights to embryos from a couple that had broken up.<sup>94</sup> The couple had created the embryos with the hope to have a child one day after the woman completed her cancer treatments. The woman, Karla Dunston argued that this was her only chance for a child after infertility due to cancer, and the ex-boyfriend, Jacob Szafranski was preventing her from using the embryos. Dunston's goal was to attempt to get pregnant and raise the child alone. The man argued that he no longer had interest in having children with the woman and by allowing her to use the embryos he was being forced into fatherhood and child support for which he wanted no part of. Szafranski's goal was to throw out the embryos so that no child would result. The informed consent document from the cryopreservation bank signed by both parties noted that in the case of death for one of them, the embryos would be donated and the embryos could not be used without the consent of both parties. The informed consent document did not qualify as a contract.<sup>95</sup> Since there was an only oral contract, the courts had to consider the interests of both parties. This was the Dunston's only chance to have a biological child which was ruled to our weigh the Szafranski's concern for privacy.

The courts ruled in favor of the Dunston and the judgment was affirmed on appeal in June 2015.<sup>96</sup>

In the cases of death of a patient, access to the cryopreserved material is more complicated. The goal in these cases is often to hope for a child that has the genetic material of the deceased loved one. The justification is often because this is fulfilling the deceased hope to become a parent. Below are a list of the options.

1. Patient dies and designates their partner has the right to access the cryopreserved material in a way they deem appropriate. This could include disposing of the material, or attempting to get pregnant.
2. Patient dies and parents or other family members have the right to access the cryopreserved material in a way they deem appropriate. This could include disposing of the material, or attempting to get pregnant. The use of a sperm or oocyte donor may be needed.
3. Patient dies and designates a friend has the right to access the cryopreserved material in a way they deem appropriate. This could include disposing of the material, or attempting to get pregnant. The use of a sperm or oocyte donor may be needed.
4. Patient dies and designates that the cryopreserved material be donated either to someone else to attempt to get pregnant or to research.
5. Patient dies and designates that none of the cryopreserved material can be used to attempt a pregnant by anyone.

In these cases, it is extremely complicated when a patient dies and their designation is not discussed with partners, family, or friends ahead of time. There has been controversy

over the use of the cryopreserved material after the patient passes away. This is especially true since there have been instances where a mom applied for benefits on behalf of a child born from her deceased husband's sperm. These requests are often taken on a case by case basis depending on the laws in the state.<sup>97</sup> While attempting to get pregnant with the deceased partners cryopreserved material is rare it does happen. Decision making is generally transferred to whomever is designated on the form or to whomever is next of kin. This becomes complicated if the partner was not legally married to the deceased at time of death. Autonomy says that patients have the right to make decisions for themselves and by handing over the cryopreserved material to the designated person, this respects the patient's autonomy. However, beneficence and nonmaleficence question what is the benefit or harm for this situation. Is it acceptable to bring a child into this world already having a deceased parent?

For parents or other family members using a deceased patient's cryopreserved material can be even more convoluted. Most discussions about consent from the parents and assent from the patient are focused on the initial decision to preserve fertility and not on the decision if the patient dies.<sup>98</sup> The case involves patients who were minors at the time of cryopreservation, they may not have designated a person to take over custody if they die. One has to question as to the purpose of parents or family members attempting to have a child from the cryopreserved material.<sup>99</sup> Are they trying to fulfill the hope of the deceased patient to become a parent? Or maybe their fulfilling the hope of their own to be a grandparent, aunt, uncle, or cousin? It becomes challenging when trying to explain to the child how they came about and who the biological parents are.

#### IV. Advantages to Fostering Hope

Ethical principles and concepts foster hope in fertility preservation. By doing so, it give patients a sense of control over their own care, provides optimism which can effect outcomes, and build into the survivorship approach to disease. The advantages of fostering hope can create a better bond between the patient and the healthcare professional. Even though the patient is making the decisions, by fostering hope, patients feel as if they are part of the team seeking to address the healthcare needs. If a healthcare professional rejects the patient's wishes and crushes their hope, the relationship may remain irretrievable broken. When fostering hope, there should always be a goal of supporting the patient's right to direct care, maintaining an optimistic view of the situation, and focusing on survivorship.

##### A. *Right to Direct Care*

The principle of autonomy says patients have the right to direct their own healthcare.<sup>100</sup> By encouraging patients to establish their own goals and priorities, it gives patients a sense of control and ownership to their treatment. By fostering hope in the discussion of fertility preservation, patients can exert their autonomous wishes, but be managed by the trust-worthiness of an honest physician. It demonstrates respect for the patient throughout the entire process.<sup>101</sup> Healthcare professionals may disagree with the patient, and there are free to do so, but need to communicate with the patient about the disagreement. The patient-healthcare professional relationship can only function with respect, trust, and honesty that has mutual understanding and good communication.<sup>102</sup>

## 1. Meaning of Directing One's Own Care

To direct one's own care, means to take charge in making decisions for one's own life. It gives authority to the patient, provided they are capable and competent. To have the right to direct one's own care is based in autonomy. This means that final say goes to the patient and the healthcare professional needs to support that decision (provided it is a reasonable request).<sup>103</sup> As discussed before, this can be a positive or a negative right. The positive right is to seek out treatment, while the negative right is the refusal of treatment. In the case of hope in fertility preservation, directing one's own care means allowing the patient to determine what is best. Patient has to determine if having a child in the future is something that the patient may desire. The hope is that in the end, the patient can attempt to have a child. Patients may also choose not to pursue fertility preservation because they do not hope for children. Their focus may be solely on overcoming and illness and wants to have the most aggressive treatment available.

## 2. Establishing Goals and Priorities

When patients choose to exercise their right to direct their own care, establishing goals and priorities can make the process more manageable. This must be done once the patient knows what options are available as standard of care or research.<sup>104</sup> For those who are delaying having children, there should be a consideration as to the why and how this choice has been made. Fertility decreases as age increases, and spontaneous pregnancy can be difficult. For those who are facing an illness like cancer or lupus, there should be consideration for what is important moving forward. This is an evaluation in the importance of quality of life for the patient.

Quality of life for the patient is also a matter of making a judgment call. A patient's values, preferences or beliefs about what constitutes as a better quality of life over another is personal and provided it does not harm someone else, should be open for discussion with the healthcare professional. Today, medical technology is made available around the world. There are machines and procedures for everything imaginable. The idea originally behind most, if not all, is to prevent death, but with the creation of reproductive technology, life can be created. Fertility preservation ultimate success is the live birth of a healthy baby. Since hope is defined as the ability to imagine a future outcome that is realistic and possible, quality of life is part of that imagination process. Patients may believe that the quality of their life will be diminished if they are unable to have a child in the future.<sup>105</sup> A patient determines what is important and imagines how he or she wants to life live.

Healthcare professionals have a responsibility to ensure that the goals and priorities are realistic. There are patients who may hope for a child, but knows that based on their current prognosis, that their quality of life is not suitable for that child. This still reflects the patient's right to direct their own care, specifically refusing to preserve fertility. Others may want to delay treatment in order to have to do in vitro fertilization right away. In those cases, patients may not understand the severe risk of postponing treatments.<sup>106</sup> In some cases, a pregnancy can actually feed a cancer because it contains estrogen loving cells.

### 3. Hope in the Process

Once a patient chooses to pursue fertility preservation, their hope shifts from one part of the process to another. Hope goes from being general- hoping to survive or

hoping to have a child in the future to something more specific. They hope that the medication works, the retrieval of oocytes or sperm is easy, and the freezing process goes smoothly. Once, the cryopreservation process is complete, hope shifts from the worry about undergoing fertility preservation to the treatment of disease. After the treatment is complete hope shifts again to hoping that are not infertile or to hoping that the disease does not return. Healthcare need to foster hope in each and every stage of the process. There are trends that show fostering hope may help with a better outlook on life and in a patient's evaluation for their own quality of life.<sup>107</sup>

### *B. Optimism*

Optimism is a positive response to a situation either negative or positive. For instance, someone may apply for a job, but get turned down. While one would assume, a pessimistic response, the person may response optimistically because they did not want the job in the first place. Optimism in the face of hard circumstances has demonstrated a positive outcome in healthcare. Many have attempted to study and quantify optimism in the face of challenging diagnosis and prognosis.<sup>108,109,110,111</sup> Hope and optimism are not the same although the terms have been used interchangeable. Hope is a belief in a future outcome that is both possible and realistic. Hope looks forward but is affected by outward variable. Optimism looks both forward and back based on inward criteria.<sup>112</sup>

#### 1. Optimism as a Response

When someone responds positively to a give situation, the response is called optimism. Determining whether someone is positive or optimistic can be subjective. Studies have tried to qualify optimism in light of healthcare. The look at factors of psychology, emotions, confidence, projection of goals, feelings satisfaction, stress, anger,



hurt, mistrust, distress, and hope.<sup>113</sup> These types of studies look for correlation between satisfaction of the physician or nurse and optimism, the interpersonal perception and optimism or even the emotional distress level and optimism.

## 2. Links to Positivity

There are some who believe that being optimistic more closely relate to having positive disposition<sup>114</sup> as opposed to a response from a positive outcome. This means that the person is naturally optimistic or positive as part of who they are instead of it being conscience choice. This positive or optimistic disposition may help patients who are trying to cope with the current healthcare crisis. In fertility preservation, an optimist outlook may not mean that more oocytes are harvest when it comes times for ovarian hyperstimulation, but it may mean that the patient is better able to cope if there is only a few oocytes collected. While hope for a child may diminish in knowing there are fewer oocytes than expected, the optimistic patient knows that all it takes is one oocyte to get pregnant. In the study done by Lancaster and Boivin, research showed “dispositional optimism was significantly related to several aspects of reproductive health, which together indicated a more favorable biological response to fertility treatment.”<sup>115</sup> One of the interesting finds from the study showed that those were optimistic tended to act in ways, lack of smoking or increases sexual intercourse that promoted better health and increased reproductive success.<sup>116</sup>

## 3. Risks with Optimism

For those who are optimist, there are some risks that can come about as well. For instance, those who are demonstrating optimist solely as a response to something positive, may have hope for a positive outcome. However, if a negative event happens,

there is the risk of losing hope in the future. Changing in emotional states are difficult to predict. For healthcare professionals who are looking to improve hope or optimism, caution should be taken in the methods being used. As discussed before, withholding information will initially may increase hope or optimism in the current situation, it does not guarantee long term success. If a patient were to discover they were being manipulated and lied to, all trust could be broken and emotional or psychological harm may come to the patient.<sup>117</sup>

### C. *Survivorship*

Survivorship is a strategy when dealing with cancer in ways to find support, information, and community in order to deal with diagnosis, live with cancer, and thrive after cancer. This terminology is growing in popularity due to the increased survival rates. With nearly 14 million people living with cancer as of 2016, cancer affects even more people than that number.<sup>118</sup> Survivorship is meant to be a strategy of support for the patient. Some studies have approach the cancer discussion not just regarding the diagnosis and treatment decisions, but with an approach that guides the patient into addressing long-term survival including present and future goals.<sup>119,120,121</sup> Advancements in medicine allow patients to think beyond the immediate diagnosis and hope for a realistic and possible future. Once the long-term goals are established steps, such as fertility preservation, are taken to ensure that everything possible is done prior to treatment to protect those long-term goals in the future. There is no guarantee of these goals, but patients cling to the notion of hope that they are realistic and possible in the future.

There are various challenges that cancer survivors face like secondary primary malignancies, cardiotoxicity, infertility, amputation, psychiatric affects, education and social function, and financial issues.<sup>122</sup> Within each one of these issues are smaller issues which are unique depending on the type of cancer and demographics of the patient. For instance, one of the biggest challenges for the young adult demographic is fertility unlike survivors in the fifties. Family, friends, and any support system that the survivor has in place as well as the healthcare professionals are all affected and can gain more in site by accessing survivorship programs. It is important to show the continued support to the cancer survivor. Dealing with the issues after remission can be just as challenging as fight the disease itself. Organizations like the American Society for Clinical Oncology or the Center for Disease Control and Prevention, or the National Cancer Institute all provide resources to all those affected by cancer. Survivorship is about looking forward and with hope, cancer survivors can do that realistically and with possibility.

#### 1. Patient

According to the CDC, a cancer survivor is a “person who has been diagnosed with cancer, from the time of diagnosis throughout his or her life.”<sup>123</sup> This means from the moment of diagnosis, patients are called cancer survivors. While this may seem a bit premature, by labeling someone a survivor, it provides optimism going into a very intense healthcare battle. Some have described adjusting to cancer as adjusting to a new normal. Cancer has a way of completely changing someone’s life. In just looking at the fertility issues along, cancer survivors are forced to deal with questions about parenthood, pregnancy, infertility, sterility, research protocols- all before even starting the actual treatment of cancer. Many young adults (or even adolescents) want to have children.

While it may not have been a verbal confirmation, when imaging the future, having a family is part of that picture. Being told that not only is cancer in your body, but in trying to treat cancer, a cancer survivor may no longer be fertile, can be devastating to the life that was imagined. With the advances in medicine, fertility preservation has bridge the gap between wanting children and attempting to have children after cancer.

Survivorship can provide resources to access oncofertility programs and resources to support groups for dealing with infertility. It can even provide questions and suggestions of ideas of what you ask the healthcare professional during the appointment.

## 2. Caregivers

Family and friends of cancer survivors are known as caregivers. They can be formal caregivers who are trained to provide health care or they can be informal caregivers who provide care out of love and respect for the cancer survivor.<sup>124</sup>

Caregivers may provide aid in the hospital, at home, daily or periodically. They see to the physical, emotional, and mental well-being of cancer survivors. For cancer survivors dealing with fertility issues, they may be healthcare experts who know the medical information or they could be a support system that drives and attends doctor's appointments.

## 3. Healthcare Professionals

There are also healthcare professionals that are involved in survivorship. The idea is a way to better coordinate healthcare for the cancer survivor. Healthcare professionals who deal with cancer survivors, need to maintain education on the increasing changes in survivorship and how best to approach their patients. This means having access to resources and good clinical data. Cancer survivors are at great risk for

many issues including unhealthy lifestyle behaviors, underlying genetic issues, underlying risk factors that contributed to the initial cancer diagnosis, and even developing a secondary cancer.<sup>125</sup> Healthcare professional needs to be aware of the signs and symptoms for these. It is important for the healthcare professional to be aware of the signs of mental health changes as well. Cancer is a disease that can completely change a person's perspective and so it is important to be aware of changes.

#### 4. Impact of Survivorship on Fertility Preservation

Survivorship plays a bigger role once the cancer treatment is complete. Fertility preservation is done before treatment. While these two things may seem at odds regarding their timing, there is still important things that survivorship covers, especially once the cancer survivor is ready to attempt to get pregnant. As discussed before, fertility preservation is two separate decisions. The first is the decision to cryopreservation material, and the second is attempting to get pregnant. Survivorship can help to address the first decision at initial diagnosis and the second decision when in remission. For women, chemotherapy can send women into early menopause which can complicate the attempt to get spontaneously pregnant after remission.<sup>126</sup> The ideal situation is for a cancer survivor to seek a reproductive specialist as early as possible.

#### 5. Impact of Survivorship on Hope

Survivorship is a manifestation of the hope that cancer survivor has. It is a way for the cancer survivor to live life, with support. Survivorship provides cancer survivors with realistic and possible options. As cancer survivors, caregivers, and healthcare professionals work together, they form a cancer survivorship plan. It is a strategy on how to approach life. It can include what concerns that are greatest for the patient, and what

signs and symptoms the caregiver needs to be most concerned with. Creating a survivorship plan is the process of verbally identifying and physically writing down what the patient hope is possible in the future. It voices concerns in a manageable, even optimist way.

## **V. Disadvantages to Hope in Fertility Preservation**

While there are advantages to fostering hope in fertility preservation, there are also disadvantages. These disadvantages can affect how patients approach healthcare, how they interact with their healthcare professionals, how they think about their disease and treatment, and how they reason through their options for fertility preservation. There is only one chance to make a decision regarding fertility preservation. Patients either choose to preserve fertility before they age or before they start treatment for disease. If they do not preserve fertility, they may lose the opportunity. Since time is critical, healthcare professionals and patients need to do their due diligence in order to make a decision regarding fertility preservation. When fostering hope in fertility preservation that patients are at risk for disadvantages like inaccurately projecting the future of research, including false expectations and the inability to manage the involvement of partners and/or parents. The future of research is hard to predict. It is difficult enough to predict the risks and benefits of treatment and the severity of side effects. Fertility preservation has standard of care procedures that are effective for adults, but there is always room for better methods. Trying to pinpoint when something will become standard of care can be complicated. False expectations can lead patients to be disappointed. Most patients are not well versed in the purpose of research. They may expect research to provide a cure or improvement. There is also the risk of the return of

disease. Cancer provides a risk of recurrence and that may affect the fertility preservation. It may mean being unable to use the cryopreserved material because there is the risk the cells contain cancer or having to delay attempting to get pregnant because treatment needs to take place. There is also a concern that patients will put too much hope in futile treatments. When patients fail to be realistic in their expectations, they may struggle to comprehend why treatments are futile.

A. *Projection of Research*

Science, health care, and research is constantly changing, adjusting, and improving. It takes time to conduct research which in turn improves health care. Unfortunately, the ideas and imaginations in science work faster than the actual research study. It is difficult to predict where science will be in the distant future. However, that is also part of the greatness of science. At any given time, a new breakthrough is possible. It can completely change the landscape of science and medicine. As discussed earlier, different aspects of hope which includes imagination and uncertainty.<sup>127</sup> Those are foundational to the concepts of science and medicine. While those conducting research work meticulously to get everything precise and consistent, imagination and solid scientific work is what drives research.

Uncertainty as to how and why things do what they do is part of the nature of researchers. They seek and hope to discover something new, improve the status quo. Patients put their hope into science and research for a treatment or therapy to address their diagnosis. Hope is fostered in fertility preservation because, at its core, the options in fertility preservation are not a guarantee for a child. Not everyone is eligible for the standard protocol of oocyte, embryo, or sperm cryopreservation.<sup>128,129</sup> Instead, patients

participate in these research protocols hoping that when the time comes, they can overcome their infertility because of the research they participated in and knowledge gleaned from other studies conducted. Unfortunately, time and science do not always line up. So while hope is important to foster, it must remain realistic and possible, otherwise patient can lose sight of the current state of medicine.<sup>130</sup>

One example of the unpredictable nature of fertility preservation is the process of moving oocyte cryopreservation from research to standard of care. As discussed earlier, sperm cryopreservation was as early as the 1950s. By the 1980s, embryo cryopreservation was around. However, it was not until 2013, that oocyte cryopreservation became standard of care.

#### 1. Predicting the Future of Research

So the question becomes how accurate is the prediction when it comes to research? Can science, health care, and research know exactly what the standard of care will be available in five years? Maybe, the standard of care could be related to studies that have been in process for years. Can researchers know what the major diseases will be in ten years? It is always possible to make educated guesses that come true, but more than likely, it will not be accurate. It is possible that healthcare professionals know exactly what time of treatments will be most effective in twenty years? The answer is not surprising. No one knows. Whether it is five, ten, or twenty years, there are too many variables that affect the success of research. It depends on the current science, the financial support, enrolling participants, getting government approval, creativity of the researcher, and potential risks that are discovered. It depends on the location of the patient, access to teaching hospitals and research institutions, and the knowledge of the



healthcare professional. It depends on the changes in disease and priorities of the researchers.

All healthcare professionals are expected to keep current on their expertise. They need to continue their education and improve their skill sets. This means reading journals, attending conferences, and meeting with others in their field. This is not just a task of enjoyment, but one that is required in order to stay licensed and insured.

Healthcare professionals are trusted by patients to be truthful and honest about the best way to treat a disease. For fertility preservation, patients trust that their reproductive specialist recommends what is best based on the patient's medical history, diagnosis, prognosis, treatment, and other factors like age. They assume that healthcare professionals are not recommending outdated or irrelevant cryopreservation techniques. If the healthcare professional would violate that trust, healthcare professional is putting his or her entire career in jeopardy.

## 2. Imagination of the Patient

Another issue in predicting research is the imagination of a patient. Earlier, imagination as one of the most important components of hope was discussed. Imagination and uncertainty allow the individual to look forward beyond the time of illness or disease. It allows for the creation of a future.<sup>131</sup> It builds into the desires, wants, goals and values of that individual as well. As said earlier, imagination is a powerful motivator in fostering hope. Imagination pushes the boundaries of what is possible.<sup>132</sup> However, patients do not always imagine based on risk-benefit assessment, statistics, professional experience, or research data. They imagine based on personal experience of the past and goals for the future. Patients are not solely embedded in the

world of medicine. They may not understand the difference between research and standard of care, and they may never care to understand. In their imagination any medical treatment that is being offered is good enough. Anything that provides improvement is worth a chance.

Capp writes that hope and its connection to the imagination allows for a wider perspective than the present situation.<sup>133</sup> However, in the case of medicine this wider perspective can be troubling. Not all information available is good or helpful. While the internet is a powerful tool that is able to bring information into the homes of millions of people that previously would have never had access to it, it is also a place that has false and misleading information. There is no standard of what can be posted on the internet and very fake information can look and sound very legitimate. Healthcare professionals have their hands full trying to address every imaginative and discovered treatment that comes into their office. The best thing that healthcare professionals can do is educate people on where to go for good scientific information. Providing resource recommendations can help turn the disadvantage of imagination into an advantage.

### 3. Example: Delay in Oocyte Cryopreservation

One example is the delay in oocyte cryopreservation to change from research to oocyte cryopreservation. In 2013, the American Society for Reproductive Medicine (ASRM) published their guidelines on oocyte cryopreservation based on the evaluation of the numerous studies that were conducted over the last few decades. The ASRM noted that mature oocyte cryopreservation success rates (meaning oocyte survival, fertilization success, and pregnancy success) was very low until 2011.<sup>134</sup> Many of the techniques that were used to cryopreserve sperm and embryos were not successful or effective on

oocytes. By thinking outside of the normal cryopreservation protocols, researchers were able to find success through new methods. The development of vitrification aided the success in oocyte cryopreservation. It has been shown to be effective for women who are facing both age-related decline in fertility and those facing infertility due to cancer treatments.<sup>135,136</sup> This technology allowed numerous studies to be conducted to prove the safety and efficacy of mature oocyte cryopreservation.

The approval of oocyte cryopreservation as standard of care did not remove all the concerns about the process. There is the question of the financial cost. Since this is no longer research, women have to pay for the procedure and storage fees. Research is no longer going to fund basic oocyte cryopreservation. Instead research is going to investigate new ways to cryopreserve oocytes.<sup>137</sup> These new research protocols, while possibly making great strides, now have to consider it if is worth it for patients to enroll in these research studies, when mature oocyte cryopreservation is available. For example, there are studies which are investigating the difference in cryopreserving immature or mature oocytes. The goal is that by cryopreserving immature oocytes, they can be matured at a later date when ready to be fertilized. By retrieving immature oocytes, hyperstimulation of ovaries would no longer be necessary. This would remove almost two weeks of hormones, blood tests, and ultrasounds. It could allow women to only delay treatment as long as it would take to schedule the retrieval procedure.

#### *B. False Expectations*

Another disadvantage of fostering hope in fertility preservation is false expectations by patients and families. There are many who do not understand the purpose of research and how participation in research is not the same as treatment to cure.

In addition, patients may not understand the time delay in both preserving fertility and attempting to get pregnant. It is not an overnight process by any means. While preserving fertility is done as soon as possible because the patient needs to start treatment, attempting to get pregnant after treatment has a greater delay. There are many serious medical issues to consider before attempting to get pregnant.

#### 1. Understanding the Purpose of Research

Research in medicine is crucial to the development of science. Research seeks to gain information in order to add to the body of knowledge with the hope in helping patients either in the present or future. Research has grown into an industry of its own over the years. Some go into the practice of medicine today to only conduct research for their entire careers. Because of the prominent level that research has reached, concern over the operation of research and the need for regulation followed. Most of these regulations were developed in response to some form of abuse or harm. Today within the field of bioethics, research ethics has developed into its own discipline.<sup>138</sup> Research is heavily regulated by the Institutional Review Board at the given institution as an impartial evaluator on everything from the science, to the protocol, to the language, recruiting methods, to compensation to government regulation. The FDA and NIH have their own sets of regulations that must be met in order to maximize benefit and minimize risk. Research involving human subjects get an extra level of concern to avoid additional harms. Because of such high concern over research, there are many publications about the considerations that need to be taken in research. Below is a few of the considerations. Evidence-based medicine has derived out of the concept of research. In order to practice and give the best medical recommendations, it is vital that there is evidence to back up

medical claims. This stems out of the data that is collected by research either during a protocol or in a review of the current standard protocols. Research participation is heavily monitored to ensure safety of the participants. This includes discussions regarding voluntariness, informed consent, and capacity. There are also additional issues to consider in research that include regulations in that specific country where the research is being conducted.

a. Evidence-based medicine

In clinical medicine, clinicians are expected to use the best evidence available for patient care. This concept of evidence-based medicine is a rigorous way to examine all of the available research for a given set of parameters in order to ensure the best possible outcome for the patient. Evidence-based medicine is constantly evolving and changing, but the most important part should remain the same - it is patient-centered.<sup>139</sup> Research protocols that are done effectively add to this body of knowledge and the practice of evidence-based medicine. Unfortunately, since medicine is an ever changing field, evidence-based medicine is constantly in a state of flux. Therefore, evidence-based medicine may determine one option is the best practice today, but tomorrow another study may prove another option better. It is important to keep pushing forward with evidence-based medicine in order to best serve the patient. One of the important parts of evidence-based medicine is that there are personal considerations to make that include patient's values, goals, beliefs, hopes in addition to the tradition concepts of benefits, risks, and financial considerations.<sup>140</sup>

One of the issues with evidence-based medicine today is how to incorporate that model into the move towards personalized medicine. Evidence-based medicine is based

on large populations, evaluation of statistics, the search for trends and repetition of results. Personalized medicine will mean a smaller pool of participants, which affects the ability to evaluate the statistics and search for trends. It may take years before repetition of results forms any good evidence-based conclusions. It may be important to start looking for new and innovative ways to evaluation medical research in a way that both adds to the body of knowledge and builds into need to help patients.

b. Research participation

When a subject enrolls in research, there a few important things to consider. First is the concept of voluntariness. Participants must join the protocol willingly and free from exploitation, coercion, or manipulation. This must be carefully monitored not just by the researcher, but also by the Institutional Review Board. Second, is informed consent. Participants need to be given all available information in order to make an educated decision. Third is the concept of capacity. Patients need to be able to comprehend the benefits and risks of research. They need to understand the difference between standard protocols and research protocols. It is important for participants to grasp that while research provides hope, it does not necessarily provide a cure.

In order to better protect those who are having to consider fertility preservation, it is important that they meet with an expert in this area. Getting recommendations from the oncologist or specialist is not enough. The patient needs to meet with a reproductive specialist. However, the current rates for this are discouraging. Ten years ago in 2006, it was reported that less than 50% of patients are referred to a reproductive specialist by their oncologist.<sup>141</sup> In general, the main purpose of research is to produce knowledge that is available for anyone that can aid patients.<sup>142</sup> However between the two concepts of not

referring patients to specialists and simply being a means the end of general knowledge, somehow patients can get lost. They end up being labeled as vulnerable in the research world. Children especially can fill this category because the lack decision-making capacity. It is important the oncologist refer their patients to specialists for a closer examination of fertility preservation research protocols, because there is the possibility of gaining enough knowledge the help that current patient, but also, protect them from being exploited or harmed. Patients should still meet required criteria to enroll in study, but also approach the research protocol with capacity, voluntariness, and fairness to ensure protection.<sup>143</sup> According to the 'Common Rule' in the US, vulnerable groups include children and pregnant women. While in fertility preservation children definitely meet this description, the adult patients are not vulnerable because of the fertility status. They can be identified as vulnerable because there is the risk of economic disadvantage or participation without personal benefit, or who cannot protect their own interest.<sup>144</sup>

## 2. Future Cancer Concerns

There is also the concern of the impact of the disease either for a relapse or risk of transmission. Cancer patients always have a concern about the possibility of relapse. There is no formula for predicting relapse of a disease. However, studies continually do not show any cause effect relationship between pregnancy and cancer relapse.<sup>145</sup>

There is a concern that in the fertility preservation process, the cells that are being cryopreserved may contain cancer.<sup>146,147</sup> The fear is that after a patient has entered remission and in cases such as the transplantation of ovarian or testicular tissue, there is also the chance for reintroduction of cancer cells in the body. Some physicians may be more or less uncomfortable with the transplantation depending on the healthiness of the

cryopreserved cells and the length of time the patient has been in remission from the disease.

Another concern is the risk of transmission to future children. There is such a big push today for the knowledge of genetic diseases. Cancers such as breast, nonpolyposis colorectal, and ovarian amongst others are autosomal dominant, causing further concern. While hereditary cancers are only about 5% of all cancers, when the risk of transmission deals with a specific patient and their future child, the concern is suddenly a very real issue for that patient.<sup>148,149,150</sup> Techniques such as preimplantation genetic diagnosis (PGD) can be used to screen embryos for these genetically inherited cancers, but do not guarantee that the child will never get cancer in their lifetime. PGD testing always has a series of ethical issues that are discussed. This can include, but are not limited to the morality of screening embryos for specific traits, moral status of the embryos, and the autonomous right of the parents to choose. Additional concerns of birth defects for the future children have proven to be unfounded.<sup>151</sup> Studies show that the rate of birth defects is the same for parents who have had cancer and those who have not.<sup>152,153</sup> Most importantly, it is important to have moral support in making these difficult decisions.<sup>154,155</sup> Getting this support allows the patient to talk through their options and concerns while getting input as to their mindset and thinking processes.

Patients with cancer have a right to be concerned about the cancer returning. While the rates and data are available for those who disease reoccurs, there is not perfect predictor as to which patient faces this. The more time passes, the better the chances of no recurrence. The greatest chance of recurrence is in the first 1-2 years, but after five years the recurrence drops 4% with every year.<sup>156</sup> There is no guarantee that a disease



will or will not recur. However, one cannot live in fear of that recurrence. The hopes that fertility preservation fosters can aid in overcoming that fear and looking at the possible positive outcomes.

Future cancer concerns also balance the delicate relationship between the personal autonomy of the patient and the professional autonomy of the physician. Most commonly the recommendation is to delay pregnancy for one to two years to avoid recurrence.<sup>157</sup> There is the risk that the patient will simply ignore the physician and go to another seeking someone who is willing to perform the fertility treatment they are asking for. Physicians need to be aware of this possibility and do their research into the background and history of a patient prior to conducting any treatment.

### 3. Futility in Treatment/Research

The philosophical notion of futility plays an interesting dynamic when it comes to providing care. The idea of futility is based upon the idea of uselessness. Futility can be discussed at any point in life, but in most discussions tend to focus on the end of life. While this definition may seem too simple, according to Eric Chwang, this is the most effective term to describe a notion that many fail to address effectively.<sup>158</sup> There is the idea that if a treatment in medicine is futile it is useless, that is to say it does not have the intended function. For example, a patient can stop responding to chemotherapy to treat cancer. In this case, chemotherapy is a futile or useless treatment. In this example, the patient may still have high levels of pain and that symptom still needs to be addressed. In order to determine if something is futile, though, there must be an analysis of the balance of autonomy, beneficence, harm, and distributive justice. This balance recognizes that though the patient or family has the right to make their own decisions, this is only when

the decision is determined to benefit the patient. Based upon distributive justice, it is a waste of medical resources to provide a futile treatment to a patient.<sup>159</sup> The futile treatment could in turn bring a greater harm to the patient. The strength of the autonomy of the patient is questioned because of the notion of futility of a treatment.

So for patients facing futility in their treatments, there is the question of what to do regarding the material that was cryopreserved. If the patient is facing end of life issues, trying to attempt to get pregnant or finding a surrogate to carry the pregnancy is generally not at the top of the list for importance. However with false expectations, there is a concern that patients may not understand the reality of futility. Again, healthcare professionals have a difficult responsibility to address this issue.

### *C. Involvement of Other People*

Parents and partners that are involved in the decision making process of fertility preservation of the patient bring their own biases and hope for the future into the discussion. These biases introduce additional issues, they cannot be eliminated. Most survivorship discussions emphasize that support for patients in the form of family.<sup>160,161</sup> Partners may have their own expectations for having children, and these expectations may clash with the patients' expectations. Parents of children and adolescent patients also have their own expectations regarding grandchildren and that may cloud their ability to make the best decisions for the patient.<sup>162</sup> Because of these biases, it creates an additional consideration to manage hope in fertility preservation.

#### 1. Multiple Stakeholders

In the case of fertility preservation, there are many participants in the discussion and many feel that they are stakeholders in the case at hand. They can include the patient,

parents, spouse or partner, physician, and/ or researcher. There can also be conflicting views as to what should be done between the stakeholders.<sup>163</sup> These opinions and views come back to the fundamental concept of decision-making process. While each stakeholder may believe that they have a valid view point, the patient should have the final decision-making power. It goes back to the ethical principle of autonomy. Each stakeholder does play an important part.

Patient: The patient holds the most important role. It is their diagnosis that brings about the entire discussion. If the patient is an adult, then assuming they have decision-making capacity (which is always presumed) then they have the autonomous right to make decision about fertility preservation and treatment.

Parents: Parents play a part in this as family members. If the patient is a minor, then the parent have the legal right to give consent, while the patient give assent. In adult patients, parents are sometimes included for moral support.

Spouse/ Partner: A spouse or partner also plays a supportive role for the patient. This could also mean providing either sperm or eggs to aid in the fertility preservation process. This means that they would have to give consent and have decision-making authority over their own involvement.

Physician: The physician is the person who is the gateway to all the medical expertise available. They are to lay out all of the options and provide recommendations for treatment and referrals to other specialists.

Researcher: The researcher is trying to enroll patients into their study.

They accept or reject a patient based on an IRB approved protocol. They can also be a source for medical information.

Each of these participants play a unique role in the diagnosis. However, it all centers on the patient. Respecting autonomy and the decision-making capacity of the patient should be of utmost priority of everyone involved. There may also be barriers effective communication because all of the stakeholders come from a different mindset and may not understand the others' point of view.<sup>164</sup> It is important to continue discussions even when it becomes difficult.

## 2. Forms of Influence

Those who are involved with the patient may have undue influence over that patient. The patient is already in tough spot if they are considering fertility preservation. Many times when patients are making decisions that need to talk it through and receive input from those that care about them. Partners and parents are most often the two types of support system for those who are considering fertility preservation. Partners not only can contribute a verbal opinion, but can contribute a gamete to create an embryo for cryopreservation. Because minors do not have the right to make decisions for themselves, parents are the ones who are making the final decision and consent for the procedure. The issue with dealing with partners or parents is the risk of undue influence over the patient and it could result in the patient making a decision they neither wanted nor hoped to be a part of.

There are different types of forms of influence. Beauchamp and Childress identify the following three: persuasion, manipulation, and coercion.<sup>165</sup> No matter what it

is called any undue influence over a patient is inappropriate and unethical. As discussed earlier, patients have the right to determine their own care. While most of the conversation regarding respecting autonomy tends to focus on the healthcare professional. This is also true for the partner and parents of the patient. Ultimately, the decision belongs to the patient (or at least the assent of the minor patient). Partners and parents can provide opinions and recommendations. They can even participate in the imagination of the future. They can encourage the patient to consider all their options. They can speak about their experiences and concerns. However, no one should ever force a patient to do fertility preservation and no one should ever force a patient to refuse fertility preservation. This decision must be left to the patient. If a patient is not making their own decisions that can directly affect how and why they hope in something. Instead of focusing on a future outcome that is realistic and possible, the patient may actually dread the future outcome because it was not necessarily what the patient truly wanted to do.

### 3. Paternalism

Paternalism becomes a major concern in bioethics literature when there is a call to protect or help a group especially one that is labeled vulnerable. Michael Kottow addresses paternalism by stating that it “is only acceptable in those cases when an authorized agent makes decisions in the name and to the benefit of disautonomous beings.”<sup>166</sup> An authorized agent would be a surrogate that has been officially recognized whether it was appointed by the individual or by the courts.

Paternalism is divided into three major categories – hard paternalism, soft paternalism and maternalism.<sup>167</sup> Hard paternalism is direct coercion. This gives not

consideration to the individual autonomy. It is difficult if not impossible to justify hard paternalism in any case when the individual has full capacity and autonomy. For example, forcing an adult to undergo fertility preservation is a form of hard paternalism. The agent may see the end result as the individual is able to have a child. However, it is not justifiable to the procedure; this is not just paternalism but assault. Soft paternalism is providing unwanted information and avoiding other information in order to achieve a desired outcome. This is a manipulation of the individual. An example would be telling a person that they can only use one chemotherapy drug for his cancer and it will cause permanent sterility so he must cryopreserve his sperm immediately. Maternalism controls the individual with a guilty conscious. Telling a woman that she is a selfish because she does not want to have children and to undergo fertility preservation is to be less selfish is an example of maternalism. Though these examples are obvious, it is not always as easy to identify or agree upon as a society.

The issues here are those considering fertility preservation are not disautonomous. These individuals most often have full capacity and full autonomous rights.<sup>168</sup> Paternalism undermines patient autonomy,<sup>169</sup> and ignores the elements of informed consent. Those who are vulnerable need to be protected, but what needs to be protected is their autonomy. Protecting the vulnerable does not mean stepping in to make decisions for them, but rather reinforcing equality and preventing harm or danger to come upon them. Paternalism is often seen as an active process; agents take action in order to do what they believe is best. However in protecting the vulnerable it is usually about not inflicting harm or removing the harm or exploitation.

## VI. Conclusion

By better understanding the ethical principles and concepts at play, fertility preservation can better be managed through the employment of the discussion of hope. Autonomy, beneficence, nonmaleficence, and justice all build into the discussion of hope in fertility preservation. It gives patients the authority to make their choices known. It allows them to imagine many options and weigh the benefits and risks. Ethical practices such as informed consent, truth-telling, and decision making when done well, reinforce the patient's hope in fertility preservation.

However, it is important to consider what the advantages and disadvantages of hope in fertility preservation mean. Advantages like right to direct care, optimism, and survivorship build not only into the patient's current circumstance, but also prepares the patients for any future issue that come along. Disadvantages however make fostering hope in fertility preservation more difficult. Healthcare professionals may have to address the disadvantages because it could affect the entire plan for how to address disease or age-related fertility decline.

By considering all these points, it is still important to foster hope in fertility preservation. It encourages the patient to think about their future, one that is based in reality and possibility.

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## **Chapter Six: Programs and Recommendations for Fertility Preservation**

### **I. Introduction**

Chapter Six will discuss elements for readdressing the current approach to fertility preservation discussions. There are current programs and guidelines used for fertility preservation, but most are aimed at the science of fertility preservation, and only a few consider the decision making process or the influence that hope has over these decisions. These programs vary from registries to consortiums, to professional organizations, to for-profit companies. The chapter highlights examples of the different groups, but it is in no way meant to be an exhaustive list. Recommendations will be made in order to encouraging the advantages and discouraging the disadvantages in fostering hope in fertility preservation (Chapter Five).

Oncofertility programs were created to be an information resource for patients and healthcare professionals who are struggling to understand and make a decision regarding fertility preservation. They provide information directly from the healthcare professionals and testimonials from patients who have experienced what this patient is about to undergo as they consider fertility preservation.

Registries are a way to collect data about cancer patients. It can track the patient's information including age, gender, race, disease, health, treatment, and other variables before, during, and after treatment looking for trends and new information. Registries are meant to be long-term studies that consider factors over a period of time. It can help in the understanding of cancer to investigate rates, risks, and additional issues that were previously unknown or unsure of.

Consortiums allow healthcare professionals to exchange information and collaborate on new information. It provides up and coming research for science, ethics, law, psychology, oncology, and other areas while keeping the patient's personal narrative at the forefront of the case. Healthcare professionals can better equip themselves by working with a consortium to education themselves on fertility preservation. It can better prepare a healthcare professional to discuss fertility preservation with a patient and/or know where to refer them to.

For-profit companies seek to provide a needed service for those considering fertility preservation. Many companies offer exclusive meetings or internet consultations for patients at their convenience. They are trying to go to the patients instead of making the patients comes to them. It takes time and effort by a few individuals to start a business that will actually turn a profit.

Advocacy groups like the American Cancer Society and Fertile Action seek to help patients as they deal with cancer. They raise money and provide necessary resources in order to help patients with the difficulties of oncofertility. Fertile Action seeks to provide financial aid because of the costly nature fertility preservation, while the American Cancer Society provides information, support groups, and encouragement before, during, and after cancer. The American Cancer Society seeks to highlight the importance of survivorship as a way for patients to adjust to their lives during and after cancer. It can even connect patients with others to provide a bond and a kinship. Those who have had similar experiences can share their personal narratives.

SaveMyFertility.org is unique in that is an advocacy group, but is geared towards helping

healthcare professional communicate well towards patients. This is done by providing toolkits to use during the conversation.

Professional organizations provide insight into the healthcare information for healthcare professionals. American Society for Reproductive Medicine and American Society for Clinical Oncology both seek to better education and provide resources for healthcare professionals that are members. These organizations can create guidelines and publish official statements on current issues of the moment.

Together all the groups, seek to address fertility preservation. Some track data, while others provide resources. The problem is that with so many options, it can be confusing and overwhelming not just for the patients, but for the healthcare professional too. It is important to remember the goal in all of this- to foster hope in fertility preservation. This means trying to improve the advantages of hope that were identified in Chapter Five- directing one's own care, optimism, and survivorship. This can be done by recognizing and addressing issues of vulnerability, managing communication, and including ethics consults in the process of decision making. This means being aware of issues relating to harm, inability to protect one's own interest, exploitation, and susceptibility. Vulnerability can affect a patient's ability to direct one's own care in a way that is free from coercion or undue influence. It means being truthful with patients and seeking to communicate clearly and effectively. Truth and trust work together to create an effective patient-healthcare professional relationship. It means including ethics consultation in the process of decision for fertility preservation. This can be done by various means, but what it does is provide a mechanism to address ethical issues that may arise.



## II. Evaluation of Fertility Preservation Programs

Colorado Oncofertility Program<sup>1</sup> and the Oncofertility Consortium®<sup>2</sup> are just two examples of fertility preservation programs aimed to provide information and support for patients. They provide literature that is easy to understand and relevant to the current state of fertility preservation. There is a slight difference in fertility preservation and oncofertility. Fertility preservation is the bigger category that describes cryopreserving material for any reasons in order to prevent fertility in the future. Oncofertility is a type of fertility preservation that deals only with those diagnosed with cancer. Since this is the most common reason for fertility preservation, there is no surprise that the programs and groups focus on oncofertility specifically. It is important to consider the purpose, methods, and information that the program is supplying to the patient. There are positive and negative aspects to each approach. It is important to look for commonality and explicit differences in these approaches in order to best understand the current methods and to make recommendations on how to improve or change. The critical nature of looking for ethical and legal behavior is vital in order to protect patients as they pursue fertility preservation. If a physician refers the patient to the program, he or she must ensure that it is a good source of information. Otherwise, the healthcare professional is putting the patient into a possibly risky situation. It is necessary to be critical of these groups to ensure they are acting ethically and legally responsible. There are groups that may struggle with the conflict of helping the patient while trying to make money. Since the procedures and storage of cryopreserved materials are so expensive, there is reason to be concerned.

### A. Registries and Programs

There are many different groups that seek to address the issue of fertility preservation. Most are concerned with disseminating information to the masses. Oncofertility programs and centers are usually based at a university or healthcare facility and are established as a group in order to direct research funds and grants directly to oncofertility program. Consortiums are mainly focused on providing education for those in healthcare. It can be an effective resource if used properly. There are times, when the information can be overwhelming and it may not be possible to find what someone is searching for, but consortiums aim to do more good than harm. Some websites are an offshoot of something else, like in the case of myoncofertility.org. This site was designed to be used by patients, parents, and partners for those considering oncofertility. By including success stories and testimonials, patients can better connect to the process and decision making that is coming.

#### 1. Colorado Oncofertility Program

The Colorado Oncofertility Program (COP) seeks to provide the most accurate and timely information regarding fertility preservation for their patients. This was done through the creation of a registry program. The intentions of programs similar to this are to empower patients without compromising ethical concepts like confidentiality and promoting quality insurance.<sup>3</sup> The goal is to provide accurate and timely information but that can only be done when information is shared and known. If information is kept secret until it is published or until an organization deems it standard of care, progress will take much longer. If patients are well informed it empowers them to make informed

decisions about their treatment and care. In addition, it can set them up for an effective survivorship plans in the future.

By understanding the quality of life for survivors, the program seeks to understand the side effects from cancer treatments for the long-term.<sup>4</sup> Long-term understanding can help to investigate rates, risks, trends, and additional issues that were previously unknown. Quality of life is key to addressing and planning for survivorship. As discussed before, survivorship is a way for survivors, caregivers, and healthcare professionals to learn about their roles and to support each other in adjusting and thriving in the new normal. Cancer is serious diagnosis and those who survive will be affected for the rest of their life. It is hard to predict what kind of outcome a patient will have, but the more that is studied and known, the better predictions for trends can be made.

Colorado Oncofertility Program stands out from the others by the “direct integration of clinical care and research.”<sup>5</sup> As part of the Advance Reproductive Medicine at University of Colorado, it offers a wide variety of services having to do with fertility. It works to help patients achieve their goals, reduce the cost of healthcare, provide experts in fertility, invest in cutting edge technology, and be resource for anyone struggling with fertility issues.<sup>6</sup> Services include more than fertility preservation. It includes infertility diagnosis and treatment, fertility treatments, male fertility treatments, in vitro fertilization, donors and surrogacy, LGBT family planning, support groups, menopause treatment, polycystic ovary syndrome treatment, intracytoplasmic sperm injection, and fertility weight loss.<sup>7</sup> All of these services can be combined in various ways to help a patient best address their fertility needs. In time, this may need to be updated based on changes in success rates of their procedures.

For those considering oocyte cryopreservation (labeled egg freezing), the program makes a distinction between medical reasons and social reasons. In both cases, oocyte cryopreservation is done in order to attempt to get pregnant at a later time. Despite oocyte cryopreservation being a standard of care technique, the program still recommends embryo cryopreservation when possible. This is due to the much better rates of success for embryo cryopreservation than egg freezing.

As part of the Reproductive Medicine Network, there is a great resource of sharing research information concerning infertility and anything related to it.<sup>8</sup> By being associated with this organization, the healthcare professional can be better equipped to consider research option when standard of care is not available. In addition, it provides access to REDCap projects, which connects healthcare professional in a controlled access to share new information in order to provide the best care for patients.<sup>9</sup>

The Colorado Oncofertility Program fertility preservation resources focus mainly on women and cancer. As discussed earlier, there are other diseases like lupus that use chemotherapy for treatment which puts patients at risk for fertility preservation also. The information on the site provides a minimal introduction and healthcare professionals have a responsibility to fill in the gaps with the necessary information. However, it does recognize the need for special consideration when facing issues of infertility due to treatment for disease. The oncofertility team includes two psychologists as a way to recognize that many struggle with the decisions regarding fertility preservation.

## 2. Oncofertility Consortium®

The Oncofertility Consortium® based out of Northwestern University is a nationwide program at over 50 sites in order to study oncofertility and collaborate on

research and data. The goal is to provide opportunity for collaboration among those studying oncofertility. Being such a new area of research, there is constant change to the science, ethical, and legal issues, and administrative responsibilities. This increase in information must be digested by the healthcare professional in order to ensure they are competent in their knowledge and skills and able to answer questions or make the necessary referrals to those who have the knowledge and skills. It is not just about conducting studies that are focused on ways to preserve fertility, but also on why infertility happens due to cancer treatments, addressing communication barriers, and addressing legal and ethical issues that arise during fertility preservation.<sup>10</sup>

With a large database of information, patients, healthcare professionals, educators, and researchers can search through the hundreds of documents on anything from institutional review board documents to new articles that are in main stream media to website for advocacy groups and organization. It provides guides on current research techniques, up to date information on the success or failure of the research, and what things that healthcare facilities need to consider before conducting a study. It allows users to narrow the search based on the audience, gender, age, reason for fertility preservation, and even language.

One of the Oncofertility Consortium's® projects is the FIRST Registry. FIRST is an acronym that stands for Fertility Information Research Study. As part of a study funded by the National Institutes of Health, the study is registering young survivors to critically look at how cancer affects them and their ability to survive and thrive.<sup>11</sup> Being an observational study, this research is only meant to collect information and look for

trends, commonality, and differences. It provides no clinical or therapeutic benefit, but tracks the life of a survivor.

The consortium presents itself to emphasize the importance of collaboration in research. It allows for growth, new information and understanding as healthcare professional, researchers, and patients seek out additional information. Projects focus on anything from the science of ovarian tissue cryopreservation to research of ethical and legal issues regarding fertility preservation. The site provides names of researchers, purposes and progress of projects. The goal of connecting and collaborating on research is clearly the main objective.

One study seeks to debate the ethical and legal issues that are dealing with the ovarian tissue that was cryopreserved for prepubescent children. As discussed earlier, there are significant ethical and legal questions regarding the nature of this research. Issues such as decision making including both the patient and parents have a tremendous importance in determining the ethical nature of the studies that are focused on the long-term use of cryopreserved material.<sup>12</sup>

Patients may be overwhelmed at this site. It appears to be more focused on supporting the healthcare professional and researchers. Healthcare professionals can find this site helpful as they try to navigate the science of fertility preservation. There is so much information to read and evaluate, sites like this one can better help healthcare professional navigate the information. However, once one digs into the site, there is a referral to a patient focused site called [myoncofertility.org](http://myoncofertility.org). This patient-centered site is to educate and answer questions patients may have as the start to navigate oncofertility.

### 3. My Oncofertility

Designed to be patient friendly, there are numerous question and answers available to patients, families, partners, and others that are involved in the process of oncofertility. The site is designed to be interactive including the opportunity to submit questions and watch videos of experts talk about the information about oncofertility. Patients can consider questions like “What is oncofertility?” and “What is normal male fertility and how is it affected by cancer treatment.?”<sup>13</sup> By starting at the most basic information, patients are able to slowly increase their understanding as the can be quickly overwhelmed by the information presented.

By working through the question and answers, parents are able to have a better understanding for the discussion of fertility preservation when it concerns their child. Beyond explaining the options for adolescents being the same as adults, it also explains why there are only research protocols available for prepubescent children.<sup>14</sup> Parents are facing not only the illness of a child, but a real risk that the child may end up infertile. It seeks to answer questions in a way that is not overwhelming, but informative and helpful. One particularly interesting question is “What is Oncofertility research revealing?” As most parents are unaware, this is an extremely loaded question. It discusses the importance of research regarding laparoscopic surgery to remove the entire ovary prior to cancer treatment. The purpose is to cryopreserve the ovary and use it at a later date. Immature follicle cryopreservation allows for immature follicles take from thawed ovarian tissue could potentially be matured and used identical to a mature oocyte to be fertilized and turned into an embryo. However, this type of research is currently not being done in humans, only animals.<sup>15</sup> Other studies focus on new cryopreservation

methods, long term effects of chemotherapy and tracking those who have done oncofertility.

For partners, the site is designed to explain the role the patient and the partner play in oncofertility. Similar to the question and answers in the other sections, the information provided is clear, concise, and focused on explaining complicated information in an easy manner. It also provides resources on how to be and show support to the patient. Cancer does not just affect the individual patient, but anyone that is around them.

There are twenty videos dedicated to the topic of decision making by cancer survivors, partners, and parents. These videos address questions about issues of how does insurance affect non-married couples, or why someone chose to delay treatment in order to do sperm cryopreservation. Topics of gamete donation, in vitro fertilization, intrauterine insemination, ovarian suppression, timing fertility preservation with cancer treatments, testicular shielding, legal concerns, the effect of not having a partner, and decisions regarding specific drugs for treatment are all covered in the video topics.<sup>16</sup>

These videos allow those dealing with oncofertility to gain insight and information from those who have been in the exact same shoes. It allows the patient, partners, and parents to not feel so isolated in their pursuit of fertility preservation. Decision making regarding fertility preservation is a serious discussion and many struggle with understanding all the information and balancing the risks, benefits, and harm that accompany the various decisions. By being a comprehensive resource for those considering and going through fertility preservation, it provides a needed source of comfort and strength.



#### 4. International Programs

In Australia and New Zealand, there is also a high level of interest regarding oncofertility and fertility preservation. The National Perinatal Epidemiology and Statistical Unit at the University of New South Wales has its own web-based registry developed in 2013 called The Australian and New Zealand Fertility Preservation Registry (ANZFPR). The goal of this project was to create evidence on the research for fertility preservation and to determine outcomes of assisted reproductive technology. By focusing on specific types of cancer, different methods of cryopreservation, both short and long term consequences to cryopreservation, success and failure of pregnancy, and many other areas, the registry seeks to look for medically indicated methodologies in order to provide safe and effective medical recommendations and treatments for fertility preservation.<sup>17</sup>

This program does not have much information available for those looking to either participant or gain additional information or progress update. As of 2014, the project is listed as complete, but no additional information is given.<sup>18</sup>

FUTuRE Fertility is an Australian based registry program for oncofertility. FUTuRE stands for Fertility Understanding Through Registry and Evaluation. In associate with The Kids Cancer Center at Sydney Children's Hospital, The Bright Alliance Cancer Centre at the Prince of Wales Hospital, The Royal Hospital for Women and the University of New South Wales, all are contributing data and research to this registry. The purpose is to evaluate the use of fertility preservation and the risks that are associated with it in the long term.<sup>19</sup>

The website is completely dedicated to the registry including information regarding ethical issues such as privacy and confidentiality, ownership of data, registry publication, consumer involvement, registry governance and custodian.<sup>20</sup> The data is aggregated by age, gender, socioeconomic status, and cancer type in treatment. This is then compared to the use of fertility preservation, the continued health status of participants in the registry, family planning outcomes, and interpretation of data.<sup>21</sup> This data is annually published. In addition there are studies focusing on the health economics and psychological health outcomes that are associated with fertility.

Because of these studies, an Oncofertility Consortium® was started in 2015, launching in 2016. Its goal is to create interdisciplinary collaboration to address oncofertility needs. It will continue its work on the registry and the current research studies, but it will also begin to expand to include general reproductive health, hematology, economics, epidemiology, translation of information, and policy research. These areas all can contribute to the knowledge regarding fertility preservation and specifically oncofertility. It is only through continued research, can information be gleaned and used to create new research and eventually standard of care for any demographic that is available. This goal is a long way off, but it is important to establish benchmarks that can drive energy and enthusiasm forward. Without those, research can become stale and no longer identified as needed due to lack of interest.

Lastly, FUTuRE Fertility provides valuable resources for patients facing cancer and the decision of oncofertility. There are categorized by ages including: adults, adolescents and young adults, and pediatrics. This is important, because recognizing the

differences in the science of fertility preservation is valuable to those making decisions. It also refers people to reliable funding sites, advocacy groups, and fertility societies.

#### 5. Companies Seeking Patients

Some companies are set to make a profit in the world of fertility preservation. Having this type of company is not inherently unethical or illegal. However, there is great concern for those who are being deceptive or withholding information. Companies that list all treatments as being equal are not fully informing the patient of the differences between standard of care and research.

##### a. Fertilitypreservation.org

Fertilitypreservation.org is a company that provides infertility and fertility preservation services directly to the consumer. Dr. Kutluk “Lucas” Oktay is the physician and his support staff includes a financial coordinator, certified ultrasound technician, academic affairs and public relationship person. It does not include any type of additional medical experts in reproductive technology. Services include egg freezing, elective oocyte cryopreservation, ovarian tissue freezing and transplantation, fertility preservation in children, in vitro maturation, random start ovarian stimulation, infertility treatments after chemotherapy, pregnancy after cancer, and post-mortem emergency fertility preservation.<sup>22</sup> While this is a comprehensive list, one should be concerned if a single physician is offering all of these services, both standard of care and research as the same.

This type of company concerns many people. By claiming a domain name that is fertility preservation and having that domain name (fertilitypreservation.org) match the name of the company, there is concern over the exploitation and vulnerability of patients.

When a patient types fertility preservation into search engines, this is one of the top search results. With a physician establishing this company and lending his credentials to this company worries some that there is little to no oversight. Services like ovarian tissue and testicular tissue cryopreservation and transplantation are not clearly identified as research protocols, which can be misleading to the patients. Instead, they are listed right alongside sperm cryopreservation which has been around since the 1950s. There is not a clear delineation between standard of care and research. Additionally, there is concern for the ethics and legal issues that accompany this type of business. There is no university or healthcare facility that is associated with the company. There is no discussion as to the process for institutional review board approval or anyone who can double check Dr. Oktay's work. Patients that are vulnerable may get confused on the information provided on this site. It appears official and well researched, but the trouble is the lack of explanation for research protocols. It make one think is this company offering services for a fee that are not considered safe, effective, or standard of care.

b. ReproTech Limited

ReproTech Limited is a long-term storage bank for cryopreserved materials. Patients, families, parents and partners can contact one of the four ReproTech Limited locations to store embryos, oocytes, sperm, ovarian tissue or testicular tissue. All of these options have a charge associated with them as so long as the person pays the fee, the material continues to be cryopreserved. They are very clear that they are not involved with gamete donation or assisted reproductive technology services. They only store reproductive material. They are advertise affordable and cost effective prices and refers to programs that can provide additional funding.<sup>23</sup>

The storage fees are based on the various time frames a person may need. This can include quarterly, one year, two, three, five, or ten years of storage. Those cryopreserved materials which are believed to be potentially infectious are stored separately are charged a higher fee. Embryos are also charged at a different rate compared to gametes. In addition, there are typical administration fees and shipping fees if needed.<sup>24</sup>

As a part of the Fertility Preservation Network, it provides resources places that sperm oocyte, embryo, ovarian tissue and testicular tissue can be cryopreserved and conveniently shipped to ReproTech Limited. It breaks the information down by method of cryopreservation and then by state. These referrals to clinics are mostly healthcare facilities and teaching hospitals and universities. Most provide multiple services for cryopreservation and some also include access to advocacy groups like LiveStrong.<sup>25</sup> There are no recommendations to oncofertility programs or registries.

c. Other companies

Companies such as EggBanks<sup>26</sup> and Eggsurance<sup>27</sup> are both for-profit companies that focus solely on oocyte cryopreservation. Their focus is primarily on those who are pursuing fertility preservation in order to prevent age related fertility decline. These women are often seeking methods, which they know are costly, in order to prevent eggs from declining in quality. Usually associated with a single physician, there is the same concern about how they are regulated and whether or not they take advantage of vulnerable people. These companies offer private consultation and party consultations. By doing that, it creates an atmosphere of relaxation and provides a fun and interesting way to both advertise the cryopreservation and consider the offer. Companies like

EggBanks and Eggsurance are providing service that is requested by the consumer/patient. There is still the necessity of informed consent and the assurance that the patient understood the information presented, the capacity to appreciate the nature of the procedures, and the voluntary nature to consent to the procedure. These companies should only be allowed to use standard of care options because it is important for safety and efficacy in moving forward with oocyte cryopreservation.

*B. Commonalities*

There are commonalities in these programs, registries, consortiums, and companies. These groups are seeking to provide access to fertility preservation with the intended goal of helping a patient have a child. Having a child is not a guarantee and even in the best cases, rates vary patient to patient. There are inherent risks and benefits to pursuing fertility preservation and attempting to get pregnant as discussed before. There is a concern though that the patients reading the information from these various programs, registries, consortiums, and companies may get the wrong information or understanding because the information provided can be very dense, confusing or inaccurate. This is not to discount the intelligence of those reading the information. It is just the nature of the information and the risk of miscommunication.

Oncofertility programs are mainly designed to aid patients in seeking out resources in order to do fertility preservation. Patients can go to these sources and read about fertility and infertility, the risks of infertility due to cancer treatment, and the concern about effectiveness of methods. Program likes the ones at University of Cincinnati Oncofertility Services, University of Connecticut Center for Advanced Reproductive Services, or Penn Fertility Preservation Program all aim to provide

information and services that are beneficial to a patient who is ready to undergo cancer treatment. These types of programs are great for healthcare professionals to refer their patients to in order for the patient to receive the best care and the best information.

Patients are relying on the healthcare professional to know who to go to with questions and who to recommend for treatment.

Registries allow patients who choose fertility preservation to be monitored and tracked for a long time. Patients can enroll and these registries take demographics, diagnosis and treatment information, and survivorship in an automated way in order to examine data and look for useful trends and statistic. The down side is that patients may never learn of the long-term information that was gleaned from their personal information. There are ethical questions as to whether a patient has the right to access their own health information. In most cases, the research protocol explains that patients do not have the right to their own information and it would be impossible to supply individuals with meaningful data. Depending on the results, there is also a concern that if results are negative, is there is an obligation on the part of the registry to provide that information. If a registry found conclusive evidence that a certain type of chemotherapy drug cause infertility in females 98% of the time, does the registry have an obligation to inform past and current participants in the registry of the danger? There is no consensus as to the answer.

Consortiums aim to collaborate and connect healthcare professionals. This is designed to provide up to date information about research studies and discussions that are currently being considered. Consortiums have the goal of education and teaching in mind as the structure their group. Healthcare professionals can use this as a way to connect

with other research and as a way to increase their skill and knowledge about fertility preservation and oncofertility. Consortiums function best when there is thought and planning into how the search for information is sorted and obtained. Consortiums like the Oncofertility Consortium® created a database of resources that allows the person to narrow their search to the topic at hand.

For-profit companies are the most difficult. There are also problem with some of these. Those with companies offering fertility preservation and oncofertility services have a conflict of interest. They are seeking to make money from the vulnerability of someone facing the risks of infertility. These sites are not regulated or collaborate outside of their company. It runs the risk of containing false information and setting up false expectations, and remaining isolated from the current information available.

There is also a concern on how these groups deal with the issue of hope for these patients. As discussed prior, patients pursue fertility preservation based on hope in order to attempt to have a child in the future. This hope is based on the possible and realistic nature of the health care information available. In the cases of the oncofertility programs, registries, and consortiums, the goals seems to be the importance of providing information. It seeks to give the best knowledge out there into the hands of those facing the need for fertility preservation. These groups try to maintain being fair and balance in terms of discussing the possibilities in the future with regarding to have a realistic view of the future. Companies that are focused on making money may struggle to adequately address hope. This is because hope is a reason the business exist. If there was no hope, there would be no need for the business because infertility would not be as big of an issue as it has become.



These companies are hard to just shut down due to legal protections for companies and the way medical claims are advertised. Patients that are seeking methods for short cuts, cheap options, unproven methods, and unclear claims will always be available as long as there is the internet. That is not to say that companies like ReproTech Limited or Fertilitypreservation.org are unethical or attempting to create for short cuts, cheap options, use unproven methods, and advertise unclear claims. One can only go by the information provide on the website. There may be a more thorough informed consent process once the patient meets with a healthcare professional.

### **III. Advocacy Groups and Professional Organizations**

Special interest and advocacy groups such as the American Society for Reproductive Medicine,<sup>28,29</sup> American Society for Clinical Oncology,<sup>30</sup> and American Cancer Society<sup>31,32</sup> provide their own approaches and recommendations for how to handle fertility preservation. Fertile Action is a not-for-profit focusing on relieving the cost of fertility preservation. They provide recommendations for both the patients and the healthcare professionals. These groups provide expertise for the science, but must also take into consideration the expectations and hope that is established because of that science. Additionally, they comment of issues that are currently facing our world, but providing expert opinions from committee members. While each organization has a slightly different focus, they all address fertility preservation, fertility and cancer, oncofertility, age-related fertility decline, and information about research.

#### *A. American Society for Reproductive Medicine*

The American Society for Reproductive Medicine is a “multidisciplinary organization dedicated to the advancement of the science and practice of reproductive

medicine.”<sup>33</sup> It seeks to provide information about reproductive medicine to those that need or want it. This is done through research, education, and advocacy of patients and healthcare professionals and providers. Members can join the organization for a fee and join groups and committees to discuss various reproductive medicine topics. Some committees respond to an event in the media or results from a research project. Either way, this organization is one of the authorities for reproductive medicine including fertility preservation. There are events and conferences that members and non-members can attend. The website provides many resources and basic definitions and opinions on various topics.

The ASRM allows non-members access some introductory information as well as the latest news, research and resources.<sup>34</sup> For instance, the Department of Defense Secretary Ash Carter announced in a partnership with the ASRM and the Society for Reproductive Technology, started a two year pilot project in January 2016, to provide fertility preservation for active duty service members.<sup>35</sup> This means that any active duty service member can cryopreserve oocytes, sperm or embryos prior to going overseas to service in military duty. This opportunity is very important to active duty service members because war is dangerous and there is no predicting what could happen to active duty service member. So by preserving fertility, a military family may be able to attempt to have children someday upon the return of the military member. In 2013, the American Society for Reproductive Medicine announce that it was no longer considering oocyte cryopreservation experimental. This meant that there was a shift from research to standard of care.<sup>36</sup> According to the American Society for Reproductive Medicine's "Mature Oocyte Cryopreservation: A Guideline" over 981 studies were conducted.

Common understandings from these studies show that length of cryopreservation had no statistical impact on the live birth rates, while maternal age at time of cryopreservation played a major role.

ReproductiveFacts.org is a companion site to the ASRM site. It is geared toward patients to better communicate information directly to them. While similar documents are available, there is easier language on the reproductivefactors.org. The most common topic on the site is infertility including a guide to infertility and state laws regarding insurance coverage.<sup>37</sup> It also provides information on how to find a healthcare provider, additional risks factors for infertility, and other reproductive medicine issues.

#### *B. Fertile Action*

Fertile Action is charity focusing on cancer and its effect on fertility. Seeking to educate, support, and advocate, the organization works with patients to reduce their cost of fertility preservation. The goal is to reduce it by as much as 50%<sup>38</sup> because the cost of fertility preservation, due to medical reasons, is expensive and rarely covered by insurance. Either patients have to take on the burden of the cost or they apply for assistance in other ways.

Started by Alice Crisci, in 2008, she experienced the real life situation of cancer at 31 years old. Her personal narrative of struggle to pay for fertility preservation struck a chord and she was able to take her knowledge and experience and pass it along to others. Through the contribution of private donation, patients are given the opportunity to apply for scholarships.<sup>39</sup> It programs information on fertility risks from cancer treatments,<sup>40</sup> fertility preservation,<sup>41</sup> parenthood after cancer, and other resources.

Part of the organization is aimed at helping patients navigate the cost of fertility preservation through accessing insurance. As discussed before, there are issue of justice when it comes to the cost and insurance issues surrounding fertility preservation. Action Fertile focuses on the right to appeal initially because it recognizes that most claims will be denied and there are time limits for appeals. The goal is to apply the issues as related to cancer and not fertility.<sup>42</sup> The reasoning is the more information that is linked to cancer, the more likely it is to be covered. Even with the passage of the Affordable Care Act, fertility services even beyond fertility preservation are not likely to be covered.

Beyond helping the individual, there is also the opportunity to help build oncofertility programs. The goals is to aid in the process of creation to implementation. The Fertile Action organization aims to help in the following ways:

- Establish an Oncofertility Program
- Write short-term and long-term strategic plans
- Conduct patient insurance advocacy and/or train billers to handle cancer patients and their insurance needs in a specific manner
- Promote your Oncofertility Program in the local community
- Bridge key relationships between oncology providers and your REI's
- Organize and host Oncofertility receptions
- Schedule in-services and grand rounds on behalf of your REI's
- Market your program through social media, print materials and online content
- Conduct localized research on referral sources, health insurance benefits and legislative initiatives

- Implement operational toolkits
- Create PPT templates for educational presentations to clinicians.<sup>43</sup>

The problem with these types of organizations is the lack of funding or expertise to continue to maintain the information provided. The site has few pages that are blank and provide little or no information for the patient.<sup>44,45</sup> It continues to be an issue because many women search “fertility preservation” on the internet and sites like this one with good intentions, but little information, are often at the top of the search results. While the board includes many physicians and advocates, it does not include bioethicist, psychologist, social workers, nurses, or other healthcare professionals that can provide additional perspectives. It also appears to be an isolated organization, meaning it is not involved or connected with others to pool resources or discuss changes in the current information.

### C. *American Cancer Society*

The American Cancer Society is a nationwide organization that is “dedicated to eliminating cancer as a major health problem.”<sup>46</sup> By working with local offices nationwide, the goal is to save lives, reduce suffering, and promote research, education, advocacy, and service.<sup>47</sup> This organization provides information all about cancer from the different types to various cancer topics to sharing encouraging stories of hope for those who have been affected by cancer. It provides information on both standard of care and research options to treat cancer. It encourages people to stay healthy which can include stop smoking, a healthy weight, eating right, and getting regular preventative checkups. It provides tool to evaluate health and cancer prevention.

One of the most important pieces of information provided by the American Cancer Society is the information regarding support and treatment. While the site provides lots of resources to read about types of treatment, success stories of treatment, risks of treatment, there is also information about getting support while dealing with cancer. It provides resources for caregivers and support programs. Survivorship programs are encouraged as a way to adjust to the new normal of living with and after cancer.

The American Cancer Society know that fertility preservation is a major topic for those who are facing cancer. The American Cancer Society provides two documents in order to help address the multiple issues of fertility preservation. *Fertility and Women with Cancer* is a document that provides comprehensive recommendations with how to deal with fertility preservation.<sup>48</sup> It provides recommended treatments, question to ask ahead of time, the various fertility options, as well as suggestion to avoid pregnancy during treatment. One of the standout things from the documents is that all options for fertility are listed, not just the ones concerning fertility preservation and biological children. Other options including adoption, surrogacy, and donor gametes are listed as just as reliable of options as in vitro fertilization or artificial insemination. In a separate section, it discusses the issues as they relate to both prepubescent and adolescent girls. This document is not meant to just be a list of fertility preservation options, but to engage the cancer patient into considering all options that are about fertility and cancer. The second document, is similar in that it focuses on the same issues, but addresses fertility preservation and infertility as it relates to men.

*D. American Society for Clinical Oncology*

The American Society for Clinical Oncology is an organization dedicated to “conquering cancer through research, education, and promotion of the highest quality patient care.”<sup>49</sup> There are over 40,000 oncology professionals members found in 120 countries worldwide. It has many committees and groups that discussion and respond to the current issues of the day including making public statements on issues. It trains and teaches healthcare professionals to keep their knowledge and skills sharp.

It has practices and guidelines that all members must follow which can include quality improvement, practice management, billing, coding, and reporting, as well as resources for patients. The American Society for Clinical Oncology is active in research, publishing studies, and providing opportunities to collaboration and work together. It keeps track of data to create reports and studies that allow better understanding of certain issues.

The American Society of Clinical Oncology Clinical Practice Guidelines was updated as of 2013. It highly recommends that all healthcare providers should address the issues of infertility before undergoing cancer treatment. There should be discussion at the time of diagnosis and the treatment plan meeting in order to provide access to fertility preservation as soon as possible. Because there are great standard of care options, fertility preservation should be pursued as soon as possible in order to allow the patient the most time and opportunity to see it through. Fertility preservation discussions should take place with cancer anticipating treatment meetings. All healthcare professionals are expected to know the specifics or know how to refer the patient

elsewhere. There are seven key recommendations as provided by the American Society for Clinical Oncology in order to best address fertility preservation.

- Discuss fertility preservation with all patients of reproductive age (and with parents or guardians of children and adolescents) if infertility is a potential risk of therapy
- Refer patients who express an interest in fertility preservation (and patients who are ambivalent) to reproductive specialists
- Address fertility preservation as early as possible, before treatment starts
- Document fertility preservation discussions in the medical record
- Answer basic questions about whether fertility preservation may have an impact on successful cancer treatment
- Refer patients to psychosocial providers if they experience distress about potential infertility
- Encourage patients to participate in registries and clinical studies.<sup>50</sup>

It recognizes the three types of standard of care- sperm, embryo, and oocyte cryopreservation as well as many research methods including ovarian tissue and testicular tissue cryopreservation and transplantation. It does warn that the guidelines are not to replace any type of clinical judgment by a trained healthcare professional. As of 2013, there was no new changes that was warranted by the literature review. Just like the American Cancer Society, there is special mention of fertility preservation and dealing with children and adolescents. Parents are to make decisions based on best interests. For now those who have not gone through puberty cannot participate in any standard of care



options. Additionally, no cases of live births after ovarian tissue transplantation in prepubescent children has been reported. Any attempt at this should be carefully supervised under the watchful eye of an institutional review board.<sup>51</sup> The communication between the patient and the healthcare professional needs to be thorough and complete. This includes discussions on individual risk of infertility, options for fertility preservation, timing regarding fertility preservation, cost of fertility preservation, risks of pregnancy and children after cancer, and the possibility of referring the patient to a reproductive specialists.<sup>52</sup> Every conversation with a newly diagnosed patient should include that entire list of topics. It is important to know that patients have the right to be informed of all their options. Healthcare professionals should not skip the discussion because it is too hard or there is not enough time.

#### **IV. Fostering Advantages of Hope in Fertility Preservation**

By identifying commonality in fertility preservation programs and advocacy group guidelines, recommendations can be made on how to approach fertility preservation while fostering authentic hope. These recommendations will be based on trying to support the advantages to fostering hope in fertility preservation (Chapter Five). This will be done through establishing the need to protect the vulnerable, managing the communication between patient-healthcare professional, and requesting for outside ethical consultation. Protecting the vulnerable is the ability to keep a patient free from exploitation or being taken advantage of in circumstances where there is a risk for those. Managing communication means trying to understand the person where they are at and not expecting them to do all the work in the relationship. Without communication, there is no opportunity for fertility preservation. Communication can between the healthcare

professional and the patient, between two healthcare professionals, or even between the patient and someone in his or her support system like a partner or a family member. An ethics consultation may be best equipped to address both the need to protect the vulnerable and the ability to manage communication. Ethics consultants can evaluate if there is an ethical issue present that would prevent the patient from moving forward with a decision. If those three things are done on a consistent and regular basis, then there is a good chance that the advantages to hope and fertility preservation will be fostered. It will allow the patient to have the freedom to direct his or her own care, the pursuit of remaining optimistic even in times when there is bad news, and the reliance on survivorship to help the patient adjust to the new normal. Together the system can foster hope in fertility preservation.

A. *Protection of the Vulnerable*

Fertility preservation may leave patients and families feeling vulnerable. They struggle to make sense of their diagnosis, the understanding of the material, and the overwhelming feeling that nothing is going right and there are no other options. Protection of the vulnerable is part of the responsibility of healthcare and research. Seeking fertility preservation does not necessarily make an individual vulnerable simply because of the future possibility of infertility, but healthcare professionals have a responsibility not to take advantage of these patients either, but rather leave them feeling protected and secure. Hope can leave a patient open to vulnerability and if they are truly vulnerable, there may be little the patient can do to protect him or herself. By protecting the vulnerable, trust, honesty and open communication can be established.<sup>53</sup> This allows for the fostering of hope in the decisions that the patient makes and prevents false hope.

In order to better protect those who have to consider fertility preservation, it is important that they meet with an expert in this area. Seeking out the appropriate healthcare professional can aid in the decision making process. The patient needs to meet with a reproductive specialist that is up to date on not only the standard of care, but also the research protocols. However, the current rates for this are discouraging. In 2006, it was reported that less than 50% of patients are referred to a reproductive specialist by their oncologist.<sup>54</sup> Since children and adolescents make up some of the fertility preservation population and because they lack decision-making capacity, they need to be protected from being exploited or harmed. Parents should only act in the best interest of the child, leaving any and all personal feelings aside. All patients should still meet required criteria to enroll in a research protocol, and enroll with capacity, voluntariness, and fairness to ensure protection.<sup>55</sup>

#### 1. Vulnerability

Vulnerability is a difficult concept to pinpoint in a sentence or thought, and even more difficult to justify applying the notion or the principle. It has many different terms and aspects that cannot be overlooked. “There is no single approach to the definition of vulnerability,” according to Alexander Morawa.<sup>56</sup> Vulnerability also has implications that must be addressed when applied to specific conditions. When protecting the vulnerable, it must be addressed in terms of harm, inability to protect one’s own interest, exploitation and susceptibility.

##### a. Harm

According to English Oxford Dictionary, vulnerability is susceptibility to physical or emotional attack or harm.<sup>57</sup> So many times in bioethics literature the most

basic definition of vulnerability is in terms of harm. So the question becomes what is harm and how does it relate to vulnerability. No rational person enjoys seeing harm to come others especially when they are in a worse off state. Vulnerable populations are often categorized as expose to harmful circumstances.<sup>58</sup>

Harm though can be too vague of a definition. It may not convey the seriousness or the authenticity of the situation. Florencia Luna wrote that “[g]eneral labels suggest general answers.”<sup>59</sup> Harm cannot possibility address vulnerability in its entirety. For example, if children are at risk for harm such as a poor education, then the general answer would be to change the education. This does not provide adequate answers or any solution to the problem. Is the poor education from the school system, the specific instructor, or maybe the student’s refusal to learn? By labeling something as harmful, it does not signify an agent of where the harm comes from. It only states that harms exist. Luna goes on to argue that its implications create false ideas about protection.<sup>60</sup> It again gives no clear solution or means of protection.

Vulnerability usually relates to the possibility of being harmed. But what does the possibility of being harmed mean? Doris Schroeder and Eugenijus Gefenas argue that harm is part of being human.<sup>61</sup> Everyone is subject to harm at some point in their life no matter their circumstances. The potential for harm is not enough of a definition to label or create vulnerability. “Vulnerability concerns integrity as a basic principle for respect for and protection of human and non-human life.”<sup>62</sup> According to Peter Kemp and Jacob Dahl Rendtorff, there are four important basic ethical principles – autonomy, dignity, integrity, and vulnerability.<sup>63</sup> Vulnerability, being last, incorporates the previous three well. In order to understand vulnerability one must acknowledge an

individual's autonomy, and the dignity and integrity of that person to create respect for the vulnerable.<sup>64</sup> Integrity provides respect not just for the individual as a person, but also as a human being with a life and a story.

By using the element of harm in the definition of vulnerability, one does bring in the external elements of vulnerability to the surface.<sup>65</sup> This external element of vulnerability can be reduced to danger. Vulnerable populations are in a state of current or possible danger. This element explains again a broad definition, but gives more dimension to the idea of harm. This external element also gives small direction as to where the corresponding action should be. If there is danger, one must address where the source of the danger is to be found. For example Schroeder and Gefenas use the disease of malaria. The external harm or danger is from the mosquitoes. The action to remove the external harm or danger would be to eradicate the mosquitoes.<sup>66</sup> This cannot be the only element of vulnerability. Schroeder and Gefenas go on to explain the intrinsic element which is the inability to protect one's own interest.

For fertility preservation, the concern for harm is one that includes the risks of the procedure to preserve fertility. Patients who choose to undergo fertility preservation, choose to do so knowing there is a risk to hyperstimulation of ovaries or accessing sperm. In some cases, the risk of harm is extremely low, but that is not always true. Patients are to decide what level of risk they are willing to face, but healthcare professionals also have a responsibility to ensure that no unreasonable level of harm comes to the patient.

b. Inability to protect interests

Vulnerability also must include the idea that there is the inability to protect one's own interest.<sup>67</sup> This means that there is the inability to recognize or exercise specific steps to keeps one either safe or free from harm or danger. This inability is summarized as a lack of power of control. It can take many forms. In terms of economics, this could mean that an individual lacks the money to provide for themselves even at a day to day level. This could be education, where an individual does not have the means to either seek out a good education or the education provided to them is lacking. This could be in terms of intelligence and how to address the inability to reason or think logically. Protecting one's own interest is a basic assumption that is taken for advantage of by the individual. The problem here is that those who can protect their own interest often fail to understand what it is like to not be able to protect one's own interest.

The Council for International Organization for Medical Science defines vulnerability as, “ the incapacity to protect one's own interests owing such impediments as lack of capability to give informed consent, lack of alternative means of obtaining medical care...”<sup>68</sup> This is usually in the context of international research. However, it is important to include this aspect of vulnerability in the basic understanding as well.

Protecting one's own interest is a matter of the internal component of vulnerability.<sup>69</sup> It is the aspect that indicates the level of control the individual or group has when or if they are labeled vulnerable. The example of malaria can be taken further in this definition. As explained previously, a population can be vulnerable to mosquitoes giving them malaria. That harm or external vulnerability is the need to

eradicate the mosquitoes. The internal component here is that the individuals are vulnerable to malaria because they are unable to protect themselves from the mosquitoes.<sup>70</sup> The population cannot protect their own health in this case. By acknowledging the vulnerability, one can help this population. The solution would be to provide nets. By providing the nets for those who cannot protect themselves, one can help the vulnerable, but the vulnerable have to choose to use the nets.

By using both the external and the internal components of vulnerability one can see the importance of this principle. For example, children are vulnerable to chicken pox. As first glance this is too broad of a statement. Are all children vulnerable to chicken pox at all times? The answer is obviously no because chicken pox is not constantly surrounding the child. From the external component, chicken pox does cause harm to an individual. They cause itching, burning, and result in red bumps all over the skin. Unless there is the internal component, one could argue that using the term vulnerable is a misuse of the word. All children have the potential of catching chicken pox sometime during their lifetime. These children become vulnerable once they are exposed to the virus. Either they are near another individual with chicken pox or shingles. The child here is unable to protect one's own interest because chicken pox is an air born disease. The most contagious time for someone with chicken pox is up to two weeks before the red spots appear. In order to protect children from the vulnerability, two things can happen. First from an external perspective, remove the carrier of chicken pox. If someone knows they have chicken pox or have been exposed to chicken pox, they should not go out into public. Second from an internal perspective, the child could be vaccinated with the chicken pox vaccine to curb the

disease and give the child immunity. This then reduces the vulnerability of the child from chicken pox.

For fertility preservation, cost and access to fertility preservation can be a major issue that leaves a patient unable to protect one's own interest. They may not be able to pay for the cost or drive to a specialist to perform the procedure. Healthcare should try to intervene when it can. In some cases, the cost can be reduced by scholarship or grants. As time and skills become more streamline, costs may decrease. If companies followed the example set by Facebook and Apple to provide coverage for infertility treatments that would also go a long way to protect the vulnerable.

c. Exploitation

Exploitation is another element to vulnerability. English Oxford Dictionary defines exploitation as “the fact of making use of a situation to gain unfair advantage for oneself.”<sup>71</sup> Exploitation is using someone in a situation that is less than ideal. The phrase “unfair advantage” adds another dimension to this definition. Most would agree that taking advantage of someone is not socially acceptable; however, there is a certain small scale at which taking advantage of someone is tolerated (though this may be not morally right). Adding the piece of unfair changes things. It brings in the question of this advantage being morally wrong and it also treats the individual or group as a means to an end rather than the end itself.

Exploitation is wrong from a moral standpoint.<sup>72</sup> Labeling an action wrong does not mean that it is exploitation.<sup>73</sup> Exploitation adds intent to the mix, although this is not necessarily a requirement. Intent to harm or take advantage of someone is not acceptable. The problem is that those who are vulnerable may not be able to identify



the harm or escape the harm. The exploitation does not take into consideration the individuals or groups that are being exploited. Rather it is the utilization of people, circumstances and opportunities in order to gain something else.<sup>74</sup>

Exploitation sees the individual or groups as a means to an end. It does not look at the impact on the individuals or groups. The action focuses on the benefit of the agent and has no regard for the interests of the individual or group.<sup>75</sup> The individual or group cannot be seen as a means; the must be treated as the end. In circumstances, it is easy to see exploitation when it has obvious negative effects on the individual or group. However, exploitation gets difficult to identify when it fails to have obvious negative impact. Those who are deemed vulnerable must have some type of exploitation in their path. The question here is do we deem someone vulnerable because of the future possibility of exploitation or because exploitation has taken place.

Two examples for the possibility of the exploitation for the obese population are seen in consumerism. First, fast food restaurants, companies the process with hydrogenated oils, and grocery stores that sell unhealthy food as a cheap rate are all using the obese population as a means to an end. These examples knowingly put out products that are unhealthy because they know that people will purchase them. They produce food that people will consume. They do not always take into consideration that what is in their product is making people unhealthy and contributing to obesity. Consumers, especially in a poor economy, buy what is cheap and available to them. Fast food restaurants have menus with items for a dollar. Companies process food with cheap and unhealthy ingredients to save their budget to make a bigger profit. Grocery stores carry what sells, not what is necessarily the healthiest. Second, diet companies,

fitness facilities, and at home gym products all target groups such as those trying to lose weight, those trying to maintain weight or those trying to curb obesity. While being a healthy weight is important and trying to curb obesity is very commendable, the companies do not look at each individual as their end result. They are in the business to make a profit. The advertisements for the companies make grand promises and display unrealistic success stories. They know that such extreme examples are not normal and acknowledge this in the fine print that results are not typical. Obese individuals that are trying to lose weight want to be the success stories that are not typical. They see a product promise more than they can deliver and are willing to pay to get healthy. So what is to be done?

For fertility preservation, there is a risk of patients being exploited. They may be desperate to have a child and desperate to do fertility preservation. There may be too many barriers that are preventing the patient from accessing it though. Companies like EggBanxx, Eggsurance, and Fertilitypreservation.org are seeking to provide a service, but they are at risk for their conflict of interest to possibly exploit those who are seeking fertility preservation. They see the patient as a consumer first, then as a patient. The lack of access to fertility preservation, can create a desperate situation where a patient may be willing to compromise safety or efficacy in order to access fertility preservation.

d. Susceptibility

A criticism that often goes with the vulnerability discussion is susceptibility. Vulnerability and susceptibility are two distinct claims that are often either intertwined to mistaken for each other. It is important understand these both separately and

together. Michael Kottow has written extensively on the difference between vulnerability and susceptibility. “By insisting on the distinction between vulnerability and susceptibility, an ethical claim is brought forth that will require on one hand justice and respect for universal human rights in order to protect the vulnerability, and on the other institution of specific social actions to take care of the susceptible.”<sup>76</sup>

Kottow argues that vulnerability is a human condition.<sup>77</sup> All are vulnerable. This description of vulnerability creates an equality among all human beings. It is not just that certain individuals or certain groups experience something, but rather all human beings experience the need to be protected.<sup>78</sup> There is always a condition or circumstance that makes us fall into a category or group. At some point everyone will need protection or help. Vulnerability “is an essential attribute of mankind to be acknowledged.”<sup>79</sup> It describes an attribute that makes everyone equal as a human being. Vulnerability is not a situation to be protected from or gotten rid of, but rather a way to create a universal condition and universal protection to everyone. In order to increase the argument of vulnerability, one must also include other ethical principles to gain respect and protection. It brings the idea of universal justice as well as dignity, worth and autonomy.<sup>80</sup> There is not eliminating vulnerability. Political justice seeks to create a sense of equal protect, but by no means erases the human condition of vulnerability. The human condition is vulnerable because of the need to respect human life and the need to protect all humans from harm.

Susceptibility on the other hand is a “condition of being biologically weak or disease which an increased predisposition toward additional harm.”<sup>81</sup> This does above and beyond the vulnerability of the human condition. Susceptibility is instead what has

been previously described as the possibility of harm and inability to protect one's own interest. Here susceptibility is "a determined state of destitution and therefore can only be reduced or neutralized by measures that are a) specifically designed against the destitution in question and b) actively applied."<sup>82</sup> Unlike vulnerability, susceptibility is the indication that suffering is taking place.<sup>83</sup> This requires an awareness of that harm or suffering. Susceptibility is action driven.

This contrasting notions of vulnerability and susceptibility are not as different as Kottow argues. Vulnerability, though as Kottow argues, is a human condition and susceptibility, is a condition predisposed to additional harm, and neither is exclusive of each other. Susceptibility is instead of more specific aspect of vulnerability.

Susceptibility also implies a potential for additional harm. Being vulnerable, though universal, is specific to the individual. Not all individuals are vulnerable to the same universal injustice. Susceptibility is also broader because circumstances and situations can become too congested with specifics and details and loses focus of the condition that causes harm. While it is important to acknowledge the difference in the overall definition of vulnerability and susceptibility, they are more alike at the practical level.

In fertility preservation, patients may be susceptible to make a rushed decision in order to seek out treatment for their disease in a quick and timely manner Healthcare professionals need to work hard to ensure that a patient is able to fully understand, capable to appreciate the situation, and voluntarily consenting.

#### *B. Management of Communication*

Management of communication goes back to the importance of truth-telling. Being honest with patients can establish a relationship between those who are

communicating. There is a strong connection between truth-telling and hope.<sup>84,85,86,87,88</sup>

When someone hopes is a specific goal or outcome, patients need to be informed of the realistic and possible nature of that outcome. Patients need to believe in the words that the healthcare professional is telling them so they can either change what they are hoping for or continue to hope in the outcome. Truth-telling provides a stable and effective foundation for the healthcare professional and patient relationship. It means using layman's terms and not scientific jargon that can overwhelm the patient. This can be tiresome for the healthcare professional who is taught to speak with correct medical terminology in order to engage with other healthcare professionals. The American Society for Clinical Oncology (like many other groups) created fertility preservation brochures to help communicate better with patients,<sup>89</sup> while this may be helpful as a jumping off point, healthcare professionals should never rely on a brochure to provide all the necessary information or as a tool to allow follow up questions. Brochures are someone else's thoughts as to what information is relevant and necessary to make a decision. However, brochures are designed to be general and broad. Healthcare professionals need to be more specific in order to address the personal narrative of the patient that is sitting in the office. Patients need to be treated as a partner in the decision making process. After all, they are the primary decision maker and it is the patient's name (or their parents' name) that goes on the informed consent document. Clear, well-managed communication takes the routine information from a brochure or website and brings it into the practical, real life application of fertility preservation to a specific patient and applies their specific values and goals.<sup>90</sup> It fosters hope in the future of having children as a realistic and possible outcome.

## 1. Truth and Communication

Communication is closely tied to truth, honesty, and integrity. By being truthful, communication can be accomplished between two individuals. Patients are assumed to have autonomy. They have the right to determine their care and to request or refuse treatment. Because there is an increased number of options available, patients need to be informed about all of these options in order for the patient to make an educated decision.<sup>91</sup> In some cases, a healthcare professional may believe that it is appropriate to leave out an option or withhold information. However, by doing this the healthcare professional risks damaging.<sup>92</sup> In cases where patients find out that the healthcare professional lied, there is a risk for constant distrust of the healthcare professional by the patient. They may continue to second guess every piece of information shared with them. It could go as far as not following directions for treatment, which can affect the efficacy and well-being of the patient.<sup>93</sup> There is the question though as to what extent a patient should be informed. There may be times when not informing the patient is to their benefit because it keeps their worry at bay or prevents nervousness before a procedure. In the majority of cases, the reason to withhold information is related to a terminal diagnosis.<sup>94</sup> Patients may not be accepting of hearing a terminal diagnosis and some argue that in those cases it is okay to omit information. However, in the case of fertility preservation. The information regarding fertility preservation is not about a terminal diagnosis. The diagnosis of cancer may be terminal (but rarely is a terminal diagnosis of cancer encouraged to undergo fertility preservation) and therefore it may be acceptable to withhold information. But fertility preservation is not terminal. In fact, it may be seen as the opposite of it. Fertility preservation is about the opportunity to cryopreserve material

in order to attempt to have a child in the future. There is no justification for withholding fertility preservation options, considering that none of them are terminal in any way.

## 2. Save My Fertility®

Save My Fertility® is an online education toolkit created for aid patients and healthcare professionals in communicating about fertility preservation. It is a resource for healthcare professionals as they seek to communicate effectively with patients and their families. The goals, determined by The Hormone Foundation® and the Oncofertility Consortium®, is to increase the awareness of fertility preservation for cancer patients to the public and healthcare professionals, and to educate about cancer treatments and its effect on fertility.<sup>95</sup> They created tools in order to prepare the healthcare professional to speak with authority and expertise. SaveMyFertility.org provides provider pocket guides as a handy resource. This resources can guide the healthcare professional as they communicate with the patient either before or during the discussion. There are three guides: Fertility Preservation for Children Diagnosed with Cancer,<sup>96</sup> Fertility Preservation for Men Diagnosed with Cancer,<sup>97</sup> and Fertility Preservation for Women Diagnosed with Cancer.<sup>98</sup> Fertility Preservation for Children Diagnosed with Cancer provides information about fertility preservation options and risks that include discussions the issues of consent by the parents and assent by the minor patient. Fertility Preservation for Men Diagnosed with Cancer and Fertility Preservation for Women Diagnosed with Cancer contain similar information, but geared towards the appropriate gender. All of the pocket guides provides resources for additional information and questions. Also available as an app for smart devices, the pocket guides provide prompts on how to start a discussion. It provides decision trees to work through as a group in

order to see if fertility preservation and what options are best for you. There is a table that contains a list of the possible cancer treatments and whether they are considered high risk, intermediate risk, low risk, no risk, or unknown risk for infertility. There are also facts sheets available that go through the definitions of all the terms in fertility preservation, and poses questions and answers that patients (or parents need to consider).<sup>99,100,101,102</sup>

### 3. Communication and Hope

There are also be issues of culture and language barriers that affect the ability to communicate.<sup>103</sup> Healthcare facilities and university have resources available to address those needs when they may arise. Again this cannot be enough of a reason to avoid communication but rather a reasons to strive for it. Hope can be understood across languages and cultures. Patients in any culture can understand the desire to have children at a future date. Healthcare professionals need to work harder to ensure the information and experts opinions are being effectively communicated and encourage patients to be bold to ask questions. When information is appropriately disclosed, it can increase the hopefulness in the patient.<sup>104</sup> In order to communicate effectively to continuing fostering hope there needs to some practical steps to ensure good communication. Making sure that there is privacy, well managed time, and lack of interruptions for either party as well as the willingness to allow the patient to include family or friends to the meeting.<sup>105</sup> Healthcare professionals should strive to speak at the literacy and comprehension level of the patient. This can include having them repeat information and confirm understanding.<sup>106</sup>



As patients are striving to take in all the information provided, it can be a daunting task. There is a reasons that medical school take four years, plus residency, and psychologists often earn a PhD, and social workers put in hours towards clinical experience. It would be impossible for a patient to learn all the material that the healthcare professional has learned over the lifetime of his or her education and work.<sup>107</sup> Healthcare professionals should also do their due diligence to listen well. A healthcare professional's job is not to just speak, but to listen to the patient. Patients may be hesitant to voice questions or concerns, but good communication, encourages a patient to speak up.

### *C. Ethics Consultation Meetings*

Fertility preservation programs need to consider bringing in outside consultation to better manage the hope that is created in the discussions of fertility preservation. Some programs bring in social worker or a psychologist. The recommendation here is to bring in a clinical ethicist. The clinical ethicist can work with both the healthcare professional and the patient to establish values and determine quality of life. This determination can then inform the goals for treatment and fertility preservation that the patients feels best fits their needs, goals, and quality of life. This can lead to a discussion concern decision making and making sure the patient is participating in the informed consent process. Healthcare professionals can sometimes be rushed in the process and it is important to ensure understanding. Patients can be overwhelmed with diagnosis and prognosis of a disease (like cancer) and may not be equipped to advocate on their own behalf in the initial fertility preservation discussions. Bringing in an ethics consultation may provide an objective, non-threatening voice where a patient can be heard and respected.<sup>108</sup> An

ethics consultation can help to eliminate conflict of interest concerns with researchers or physicians, and allow the patient to identify values and goal, not just for the disease, but also beyond into survivorship.

In the case of uterine transplantations (discussed back in Chapter Two), a clinical ethicist was included on both the Swedish team<sup>109</sup> and the Cleveland Clinic team.<sup>110</sup> The interdisciplinary team saw the need to bring in an ethicist to help address moral and ethical issues. Ethics consultations can be used to address both clinical and organizational ethical issues that may arise in the development of protocols or to help patients in their own personal narratives.

In moving forward, it is worth reviewing both the CASES and ISSUES model as modeled by the Veteran Administration National Center for Health Care Ethics. For many providing the recommendation of bringing in an ethics consult is meaningless. They do not necessarily know what that is or how it functions. The VA lays out an easy to follow model for both clinical ethics (CASE) and organization ethics (ISSUES) both of which may be necessary in order to address ethical issues in fertility preservation. The goal in all of this is to foster the hope that has been established in its connection to fertility preservation. These provide step by step instructions that can be easily taught to whomever is going to conduct an ethics consultation.

#### 1. CASES: Clinical Ethics

CASES is a model by which one can conduct clinical ethics consultations. A lot of what goes on in the CASES model is reading and thinking. The actual write up is a final thorough summarization and recommendation, not a detailed report of every single

piece of information and thought. The CASES model provides a tangible process to move forward with for ethics consultations for clinical cases.

Clarify the Consultation Request. This step is to determine the type of consult request and gain basic information regarding the request- including expectations and ethical questions. It is important to establish why the request was called, and if it is appropriate for ethics to be involved. It is also important to identify if this is a current active case or not.<sup>111</sup>

Assemble the Relevant Information. Step two is all about gaining the important and necessary information. This includes relevant medical facts, patient values, and anything else that is important to the consult. It may also include talking with others who have expertise that can help in the consult - including healthcare professionals, the patient or the family. Once the information is collected it is important to identify what is relevant and to summarize the information.<sup>112</sup>

Synthesize the Information. Step three is all about determining what to do with the information. It is important to recognize what kind of consult is necessary - meaning individual, team or full committee. This step also goes into the ethical analysis of the situation and as well as identifying the appropriate decision maker.<sup>113</sup>

Explain the Synthesis. Step four is all about communication and documentation. This means talking with the person who requested the consult and possibly patient as well. It covers discussion of the recommendations and documenting everything in the records. It also provides additional resources if necessary.<sup>114</sup>

Support the Consultation Process. Step five is a reflective look at the consultation. It allows feedback for the consult, and follow up with the participants. It

may also go further to adjust the consultation process if there is a problem or concern. Additionally, there may be a need to address a system issues that resulted in the consult in the first place.<sup>115</sup>

In fertility preservation clinical ethical issue that may arise are the determination of capacity for a mature minor, issues of analyzing for benefits, risks, and harm, undue influence from a partner, parents, or family, parents conflict of interest in consent on behalf of their child, or issues of access regarding access or resource allocation.

## 2. ISSUES: Organizational Ethics

In order to best use ISSUES, it is important to identify a gap between the current practices and the best practices.<sup>116</sup> While each step has a set description and goal, the pieces often overlap and are a continuation of the previous step to a certain extent. One step follows the next because the flow of the ISSUES in this specific order is well thought out. This is a way to analyze the organizational ethics at the hospital. Often this is the results of knowledge gained in step five of CASES.

Identify an Issue. This step seeks to as it clearly states, identify ethics issues. According to the VA, this step clearly must be a proactive step. It cannot expect issues to suddenly arise and need tending. It requires an ethicist to review the current systems and processes, review previous ethics cases, review outside literature, and compare other systems and processes. It takes work to identify an issues, characterize each one and create a priority of what issue to tackle first.<sup>117</sup>

Study the Issue. When studying the issues, this mean an in depth review of the current practice within the facility and an in depth review of the best practice for that facility. The final piece to this step is creating and perfecting the goals for improvement

to bridge the gap between the current practice and the best practice. The VA even suggests creating a flow chart or diagram to better understand the process or system that is being studied.<sup>118</sup>

Select a Strategy. When selecting a strategy, it is important to have completed a thorough research and study of the issues. By studying the issue, one is able to identify the major causes of the quality gap in that issues. The strategy must then reflect the way to bet address the gap and seek a solution to narrow it. It may be important to try more than one strategy because the major causes may be extremely diverse and require individual attention. An important piece is to think creatively and allow questions and adjustments to be made as strategies are developed.<sup>119</sup>

Undertake a Plan. Undertaking a plan involves knowing how to carry it out, knowing how to evaluate it, and then actually executing it. It is important to know who does what and when. Everyone must be in the know, in order to work effectively. Knowing how to evaluate the strategy is important not only after the strategy is complete, but also during the strategy as well. It allows time for review and gives the opportunity to address unforeseen weaknesses as well as address known problems that were a possibility. It keeps the strategy from being a waste of time and resources.<sup>120</sup>

Evaluate and Adjust. This is the actual evaluation and adjustment of the strategy as the plan is being undertaken. So while the previous step made a plant to evaluate and adjust, this step does that part of the plan. It ensures that goals are being met, participants are doing their jobs and being informed of the strategy changes, and ultimately is narrowing the gap between the current practice and the best practice. Once the entire

plan is complete, it is also important to do a complete and thorough evaluation of the strategy as a whole.<sup>121</sup>

Sustain and Spread. This step seeks to ensure that the best practice is maintained. The use of the new strategy should leave the practice with a permanent improvement. It always requires additional monitoring to make sure that it continues to be the best practice. It may also be important to additionally spread the strategy to others whether it is within the same facility or other systems entirely.<sup>122</sup>

Organizational issues may include conflict of commitment for a healthcare professional between the patient and employer, financial conflict of interest if the healthcare professional owes stock in a cryopreservation bank that she or he refers patients to, or repeat offenses of withholding information in order to speed up the family meeting.

Both of these models have their flaws, but by attempting to do each step, it can help to better understand and address the ethical issue. Patients may not fully comprehend the presence of ethics at a meeting, but the ethicist needs to explain that the goal is to address whatever issue is at hand, while simultaneously fostering hope for the patient.

## V. Conclusion

By examining the current approaches, programs, and advocacy groups, one can better understand the complexities of fostering hope in fertility preservation. The connection between hope and fertility preservation is present whether one acknowledges it or not and therefore healthcare has to manage it better. In order to protect patients,

ethics can play a much larger role in communication with patients regarding fertility preservation.

Groups like oncofertility programs, registries, consortiums, for-profit companies, advocacy groups, and professional organizations are all seeking to provide patients and healthcare professionals with the necessary information and resources to aid in decision making regarding fertility preservation in the cases of disease, especially cancer. The problem with some of these groups, is the lack of accurate information, misleading in methods of fertility preservation, or focusing on long term instead of helping the current patient. Still these groups provide information that patients and healthcare professionals may not get anywhere else. However, providing good information does not justify unethical behavior.

Oncofertility programs are to provide fertility preservation information for patients and healthcare professionals who are trying to understand and make decisions regarding fertility preservation. They provide information directly from the healthcare professionals and testimonials from patients who have experienced to better connect and explain fertility preservation. The problems is that the focus is solely on cancer patients so patients with other disease may struggle to find information and resources to preserve fertility. It does not provide any support after the cancer. The decision to attempt to get pregnant is just as difficult as the first decision. There needs to be resources on how to approach the second decision as well.

Registries are a way to collect data about cancer patients. It can track a patient for many demographic information before, during, and after treatment looking for trends and new information. Registries are meant to be long-term studies that consider factors over

long periods of time. The problem is issues of privacy, notification and ownership. There are some who believe that the ownership of the data belongs to the organizations, but the organization may have a responsibility to notify patients if negative or dangerous information is discovered.

Oncofertility Consortium® allows healthcare professionals to exchange information and collaborate on new information. It provides cutting edge research for science, ethics, law, psychology, oncology, and other arenas while keeping the patient's personal narrative at the forefront of the case. This is one of the best resource opportunities for healthcare professionals. However, that does not mean healthcare professionals will use it or spend time improving their knowledge and skills.

For-profit companies are providing a service for those considering fertility preservation. Many companies offer exclusive parties or international consultations for patients at their convenience. There is an ongoing issue of conflict of interest by the owners who are usually physicians. They are making money off of people who are in a very vulnerable state and this could be considered exploitation.

Advocacy groups like the American Cancer Society and Fertile Action help patients as they deal with cancer and the specific needs that arrive thereafter. Patients tend to use these types of sites as a resource most often. Healthcare professionals need to be well educated so they can address any proposed treatments from the patient. It may mean that the healthcare professionals have to do research and get back to patient.

Professional Organizations provide insight into the healthcare information for healthcare professionals. American Society for Reproductive Medicine and American Society for Clinical Oncology both seek to better education and provide resources for



healthcare professionals that are members. These organizations can create guidelines and publish official statements on current issues of the moment. These organizations are the standard for healthcare professionals to get their information from.

In all of these cases, the vulnerability of the patient is important to consider and watch. If a patient is vulnerable there needs to be extra consideration regarding harm and a risk of exploitation. Groups like the for-profit businesses may not be seeking out vulnerable patients, but the need to be careful that their conflict of interest does not cause undue influence over the patient.

Managing good communication means that healthcare professionals need to do their homework, find good resources to encourage communication, and work to establish and maintain trust. Once trust is broken, there is very little that can be done to repair it.

Ethics consultations can be brought in to help address the ethical issues that may arise in the process of decision making for fertility preservation. The VA's methods of CASES and ISSUES provide structure and follow through to ensure that ethical issues are identified, addressed and reviewed to prevent recurrence.

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## Chapter Seven: Conclusion

### I. Introduction

Fertility preservation places hope in a future outcome for patients that are realistic and possible. We must work hard to foster that hope. This can be done by having open and honest communication, working hard to identify ethical issues, and seeking to protect those who may be vulnerable. While patients do not want to be at risk of infertility, sometimes it is impossible to avoid when patients are diagnosed with cancer and of other diseases like lupus or rheumatoid arthritis. Infertility is unpredictable and varies person to person. The advancements in healthcare including innovative treatments, allows patients to not just survive disease for a short time, but to live long, healthy lives as other healthy people do. Survivorship is put in place to help guide the patients into adjusting with their new normal and moving forward in life. In order to seek a better outcome, aggressive treatments are done, but they also bring side effects including the risk for infertility among other concerns. Fertility preservation is the precaution, but it does not guarantee a patient will not be infertile nor will it guarantee them a healthy child. It is a preventative procedure that may not be necessary in the future, but it is better to have it and not need it than to need it and not have it.

By having access to aggressive treatments, hope is fostered not only to beat serious diseases like cancer; but also the potential for a future pregnancy through the cryopreservation of gametes and tissues. Options such as sperm and embryo cryopreservation have been around for a while, and methods like oocyte cryopreservation is only newly standard of care. By providing these possible cryopreservation options, hope is fostered beyond fertility preservation and into healthcare in general. Patients will

be more likely to return to their physician and seek any treatment that is needed in the future. When patients experience successful treatments, patients may have a greater expectation for healthcare to work wonders in the future. Healthcare professional need to do a successful job of keeping patients maintaining realistic and possible hope. It is important that patients are not looking for a medical miracle in the far off distant future, but understand the current state of medicine and research. Projecting wants and desires that are not based in reality can be damaging not only to the patient, but also to the healthcare professional. Patients need to maintain a realistic and authentic view of their current circumstances; otherwise, they are bordering on a false hope that could lead to disappointment and despair.

In trying to maintain this realistic view, the considerations for fertility preservation are numerous. Clinical ethicists should be present to ensure patients' rights are being respected, and to critically examine the hope that patients have towards fertility preservation prior to any procedures. By understanding the basic science of fertility preservation, examining the basic definition of hope, considering all the different factors that fertility preservation brings about including a short discussion on research and its impact on healthcare, one can see how hope and fertility preservation are connected. By discussing the ethical concepts of autonomy, beneficence, nonmaleficence, truth-telling, informed consent, and decision making, it better demonstrated the connection between hope and fertility preservation. It demonstrated that by addressing the ethical considerations prior to any procedures, authentic hope can be fostered in fertility preservation.

## II. Chapter Summaries

A critical look at fertility preservation helped to better understand fertility preservation and its connection to hope. The history and science of reproductive technology leading to fertility preservation was discussed, specifically how ethics has sought to address the many difficult changes in medicine. The concept of hope specifically pulled from philosophy and theology, but also was discussed specifically in relation to healthcare and research and as such can was discussed with fertility preservation. The ethical role of hope was examined in its relation to fertility preservation, in order to discuss why hope is different in this context as opposed to other areas of healthcare. The ethical analysis of the reliance on hope in fertility preservation was discussed about specific ethical concepts that were considered in relation to hope and developed a critical ethical analysis of the advantages and disadvantages of the reliance on hope in fertility preservation. Finally, by considering the current practice of hope there was a better understanding that more need to be done on the basis of additional ethical analysis.

Chapter Two focused on fertility preservation. The history and science of fertility preservation was analyzed, specifically the historical advancements of science and its contribution to medicine. By understanding the various methods of reproductive technology, one is able to better understand and see the growth in healthcare. Whether preventing pregnancy or combating infertility, reproductive technology has progressed quickly. Medical research has proven that it continues to find innovative ways to push the expectations and the applications of technologies. Even though the technology has progressed, law and ethics often is playing catch up.



<sup>1,2,3</sup> Bioethics has struggled to address the complications that come with the advancement of science in a timely manner.<sup>4,5,6</sup> The expansion of innovative cryopreservation has widened the ethical discussion to include new research protocols some of which are so new there have only been a handful of live births attributed to that method.<sup>7</sup> While fertility preservation is recommended for those who are at risk for infertility, either due to delaying pregnancy/ parenthood<sup>8,9</sup> or side effects of medical treatments like chemotherapy, there is no fool proof way to predict the risks of infertility.<sup>10,11,12,13,14,15,16</sup> Fertility preservation for delaying parenthood does not guarantee a successful attempt at pregnancy any more than infertility due to a diagnosis. Differences in demographics like gender, age, and socioeconomics of the patient population limits the methods that patients have access to before the first conversation with a healthcare professional. It puts patients at an unfair disadvantage that may never be equaled out. The bioethical issues of decision making, procreative liberty, invasiveness of procedures including risk, affordability of cryopreservation, and even disparities for referral patterns in addition to other bioethical issues of moral status of embryos, viability, value of life, federal funding, and cost and insurance coverage are all affected by issues of access. The healthcare professional needs to be approach all reproductive technology with the purpose of establishing trust to discuss what best fits the specific patient.<sup>17,18,19,20</sup> Understanding the standard of care and experimental options are just as important as understanding the possible demographic issues that a patient may be facing as they move forward with their highly personal decision.

Chapter Three sought to analyze the concept of hope specifically pulling from philosophy and theology both describing the nature and characteristics.<sup>21</sup> In addition, it

detailed the specifics of hope in relation to healthcare and research.<sup>22</sup> Philosophers Bloch, Marcel, and Kant and theologians Aquinas, Moltmann, and Lynch did not agree on a singular definition of hope. But recognizing trends and commonality in their individual description can lead to creating a working definition. It is important to consider the effect of the personal narrative (biographical understanding) in any decision making and how that differs from the abstract concept of hope. Context is vital to being able to flesh out the concept of hope in a way that is useful and practical. By finding key descriptions from the existential discussion, such as realistic possibility and the future, one can better dictate how hope is used within a personal narrative like fertility preservation. One of the biggest concerns regarding hope is ensuring authenticity and preventing false hope.<sup>23</sup> As discussed false hope is really an inappropriate term to describe hopelessness, disappointment, and despair, but yet the term false hope continues to persist. Authentic hope has been connected to trustworthiness and honesty.<sup>24</sup> False hope sets up an individual for disappointment so hope must be based in reality.<sup>25</sup> Within healthcare, hope is part of the patient-healthcare professional relationship and can demonstrate respect for autonomy and the prevention of exploitation of the vulnerable.<sup>26, 27</sup> Without understanding how the individual is using the word hope, it is difficult to manage and to foster such a concept. The conclusion of the discussion on hope led to the working definition that hope is the belief in a future that has a realistic and possible outcome.

Chapter Four examined the ethical role of hope in its relation to fertility preservation. It discussed why hope was different in this context as opposed to other areas of healthcare. Though discussed in the abstract to start, both hope and fertility

preservation are part of a personal narrative for patients. By creating a personal narration, one better understand the impact that hope has on fertility preservation. There are two key players involved when it comes to understanding the possibility of fertility preservation: the healthcare professional and patient/families. It is important to consider how hope is communicated in fertility preservation and what role hope plays in the interactions between patients and healthcare professionals in the decision making process. Healthcare professionals have to do their due diligence to ensure that they are aware of the roles and responsibilities, they understand their expertise and the expertise of others, and they maintain their competence for their field. For patients, they are facing two separate decisions: the initial cryopreservation and the attempt to get pregnant in the future.<sup>28</sup> There is a responsibility of both the healthcare professional to thoroughly explain the truth and the realistic expectations of fertility preservation and the patient to maintain hope in a realistic, possible way in attempting to get pregnant.<sup>29</sup> There are specific aspects to the future including genetic offspring, grandparenthood, and research protocols that are a part of discussion for the future of patients. Since hope and fertility preservation both involve the discussion of realistic possibility and the future, it is tough to adequately maintain realistic hope and yet the goal is to continue to foster it.

Chapter Five presented an ethical analysis of the reliance on hope in fertility preservation. It discussed what specific ethical concepts were considered in relation to hope. Ethical principles such as autonomy, beneficence, nonmaleficence, and justice are extensively discussed in ethical considerations of fertility preservation. Hope allows patients to look to the future, and because of the principle of autonomy seek out healthcare to attempt a successful pregnancy after fertility preservation and after given

the all clear from their disease.<sup>30</sup> Beneficence and nonmaleficence are not just part of the short term decision, but also a part of the long-term future.<sup>31,32,33</sup> The balance of benefits, risks, and harm are hard to analyze, but must be done so the patient can make a informed decision. Standard of care and research protocols for fertility preservation should be made more readily available to promote justice.<sup>34</sup> Issues of access will continue to plague the system until there is a new way to make the procedures cheaper and reduce the cost for insurance. Informed consent, truth-telling and decision making directly connects to how hope is fostered in fertility preservation. Because fertility preservation affects many different demographics and offer different methods to each, informed consent must include understanding, capacity, and voluntariness. Truth-telling can potentially promote or destroy hope depending on the information given or withheld.<sup>35,36</sup> By fostering hope in fertility preservation, patients have sense of control to direct their own care, provides optimism which effects outcomes, and builds into the survivorship approach to disease. Patients can exert their autonomy, and work with a trust-worthy healthcare professional throughout the entire process.<sup>37,38</sup> By fostering hope there is also a risk for disadvantages. This can include inaccurate expectations and projection of the future of science in a way that may not be truthful, and trying to manage the involvement of the patient's support team. By better understanding the ethical principles and concepts at play, hope is better managed and even can be fostered.

Chapter Six provided elements for improving the current practice on the basis of the ethical assessment developed in the previous chapter. There are several programs and advocacy groups that address fertility preservation, but most are aimed at providing information, not addressing the processing of decisions or the role that hope has in the

decisions of fertility preservation. These programs and guidelines should encourage the advantages and discourage the disadvantages in fostering hope in fertility preservation, but there is a risk that it may negatively affect the patient. These groups provide expertise for the healthcare, but must also take into consideration the expectations and hope that is identified in the process of decision making. By identifying commonality in fertility preservation programs, registries, consortiums, for-profit companies, professional organizations, and advocacy group guidelines, recommendations can be made on how to approach fertility preservation while fostering authentic hope. Seeking fertility preservation does not necessarily make an individual vulnerable because of the future possibility of infertility. However, there is a risk of vulnerability because the patient is in a state that puts them at a disadvantage and encourages the need to reach out for help. By trying to protect the vulnerable, trust, honesty, and open communication can be established in these circumstances.<sup>39</sup> Clear, well-managed communication takes the routine information from a brochure or website into the practical, real life application of fertility preservation to a specific patient and applies their specific values and goals.<sup>40</sup> Bringing in an ethics consultation may provide an objective, non-threatening voice where a patient can be heard and respected while it provides an added layer to ensure understanding. It can address any outstanding clinical or ethical issues that may result as part of the healthcare professional- patient relationship and the decision making process. Many oncofertility programs and guidelines focus on creating a multidisciplinary team.<sup>41, 42</sup> Including ethics in that team is important because someone needs to be the expert in ethical issues that arise. An ethics consultation can help to eliminate conflict of interest, issues of capacity, issues of vulnerability and exploitation

which are concerns among healthcare professionals, and allows the patient to identify values and goal that will follow the patient into the survivorship phase. The connection between hope and fertility preservation is present whether one acknowledges it or not and every action affects the hope. In order to protect patients, ethics can play a much larger role in fostering hope in fertility preservation with patient.

### III. Conclusion

The hope that fertility preservation fosters is based on the possibility to have children and on the realistic future of science in addition to the authentic relationship between the patient and healthcare professional involved. Fertility preservation covers a wide range of demographics creating a unique personal narrative for each person. Healthcare professionals need to refer patients to reproductive specialists in order to provide the best medical information, which will allow for truth-telling and to manage the hope that fertility preservation may foster. Key discussions need to take place to address the common bioethical scenarios that a patient will face if and when they undergo fertility preservation. Fertility preservation will continue to foster hope as long as patients are at risk for infertility either by disease or delay in parenthood and even if current research protocols become standard of care, new research studies will be created. By fostering hope, patients are able to see beyond their circumstances and into the future for a realistic positive outcome.

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