

Review Article

# The Anonymous Epidemic

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## Abstract

Infertility is a disease process in which many individuals suffer leading to increased levels of depression, anxiety, and negative affect. This research evaluates the ethical considerations of infertility reproduction, perspectives of infertility clinics, client stories, and a personal narrative, as well as a hope for future potential in reproductive science.

**Keywords:** Infertility; Reproductive science; Depression; Negative affect; Anxiety; Egg donor

## Introduction

Hope is a feeling that something will happen toward a desired outcome [1]. For the infertile individual or couple, hope can be very expensive; a necessary aspect of infertility which motivates and pushes many couples and individuals to strive for the strength to create a family. How can we change the outlook and enhance suitable and appropriate progression of advocacy and recognition for this disability?

### Disease

Infertility is a disease and a condition in which many women and couples struggle especially on an emotional level; depression, anxiety, negative affect, are some of the psychosocial and cognitive changes discussed in the literature [2-4]. Infertility is a chronic condition with long-term and detrimental effects to the infertile patient or couple. It has been reported that “infertility impacts 1 in 8 couples of reproductive age and can be a very isolating disease to face” [5]. This isolation creates an environment in which the affected individuals perceive they are judged and criticized. As a consequence of this isolation and social stigma the affected are fearful. Through mostly no fault of their own, the “fertile” community, those individuals who have not had the diagnosis of infertility, are unacquainted in dealing with those going through this disease. Inappropriate remarks are said and poor advice is given along with many unpleasant comments “why did you wait so long to have children”, “you’re in your forties and now you want to get pregnant”, “you should just adopt”, “you are young you have nothing to worry about.”

### Avoidance

Infertility is a client “suppressed” disease in that many people avoid speaking and conversing openly. Therefore, they turn inward, becoming more introverted and disengaged from society, masking their emotions and devising ways to withdraw from social interactions. For example during one of my encounters I engaged in conversation with a woman who shared she was not capable of producing eggs or able to carry a child,

“I make up any excuse to withdraw from social interactions, especially if it has anything to do with a child. I can’t handle the stress. I don’t want to see other people happy with their newborn, or expecting, when I have nothing.”

In this instance, diversion is key in creating opportunities to

avoid exposure of an infertile persons own inadequacy.

What is not known is typically this infertile woman has been through countless infertility treatments with zero success. At times, these individuals have nothing to show for their struggle but constant anguish and distress, as well as the financial burden these treatments have created. Typically, patients hide behind closed doors and suffer in silence.

Being Greek American, I can see within my own highly traditional patriarchal culture, the notion that women were meant to be child-bearers and housewives while men worked and provided financial stability. This type of outlook is unfortunately seen, in the vast majority, worldwide. Although infertility treatments have been around for years, this patriarchal ideology has suppressed progression of self-advocacy, the ability for infertile couples and individuals to rise against this negative association, and give voice to their disease. They have essentially become afraid.

Many times when a woman does decide to speak about her infertility, it often occurs after they have had success; having a child. However, not all cases end with this achievement. Many couples are frequently childless, a side often overlooked and ignored. People may suggest that infertility is just a temporary diagnosis; that after having a child this diagnosis vanishes. Even individuals going through infertility initially think of infertility as an acute illness.

### Assisted reproductive technology and religion

Fear also stems from various religious viewpoints. The use of in vitro fertilization (IVF) is one procedure that creates great controversy, including in the Christian faith. Being an Orthodox Christian, I thought to myself the impact of infertility in relation to my belief system. During a discussion I was having about IVF, one individual declared that treatments are wrong because children are, “begotten, not made.” I initially became angry. I thought how can God deny a good, faithful person the gift of a child? I believe God is one that wants to see us, as society, help each other. He wants to see the sacrifices we make for our persons and observe the ways in which we lead the “Christian” life. God creates miracles every day, and each child born, either done in the “traditional” sense or through the use of assisted reproductive technologies (ART), is still through His blessing. No ART treatment or any infertility treatment is a guarantee, and these individuals pray if not every day, multiple times a day, to receive His beautiful gift of a child.

Common infertility treatments by ART, is through IVF or intrauterine inseminating (IUI). In these cases, we still find a low percentage of success stories. Often, women try ART multiple times before achieving a pregnancy and even then not a viable pregnancy, in which the embryo would normally mature to optimal development. In other words, the pregnancy is unsuccessful.

Women could also be given a diagnosis of “unexplainable infertility,” premature ovarian failure, endometriosis, or many others. Passing judgment and speaking offensive questions, even said without any animosity, are examples of the limited knowledge we have of the infertility community as well as in the lack of ways we have in supporting them.

One form of ART with limited knowledge is found in the use of frozen embryos. Upon arrival to the fertility clinic for an IVF cycle, the clinic begins to thaw out a previously frozen embryo. We can refer to this thawing as trauma occurring to the egg, which may inadvertently cause the embryo to breakdown and become unusable. A woman going through her 7<sup>th</sup> IVF cycle, with all previous cycles unsuccessful, began speaking openly with me. She said that few people in her family knew she did so many cycles and even less know that she is doing yet another. One of the most profound things she said was, “I may not have children, but all these frozen embryos I have remaining, and all the ones that have never made it, those are all my children. With each cycle I go through, I feel as if I am killing each of my children.”

### Disease or condition

Another dilemma accounted for within the infertility community was brought to my attention; the struggle to even classify ourselves. A friend currently freezing her eggs, having severely decreased ovarian reserve soon to be diagnosed as premature ovarian failure, began speaking about my advocate work and the definition of infertility. I, stating infertility as a disease drew a great amount of criticism and reproach. She stated emphatically, “I do not have a disease.” Then soon replying, “I don’t care what you call it (infertility), I don’t have a disease.” Was this a reaction because she is limited to the resources or stories that other couples have gone through, or simply, maybe using the term “disease” to describe infertility attaches a stigma, which therefore leads individuals to become further inhibited in both speech and affect? With so few individuals who acknowledge and speak about their infertility, are we in the infertility community also subduing these individuals from speaking up about their struggle because we have labeled them as having a socially isolating term, “disease?”

### To each their own

Even among infertility clinics, I have personally found the lack of protocol among different types of reproductive endocrinologist. Each professional has their own distinct view on how to treat a patient. Given a diagnosis, certain clinics believe that a typical treatment strategy should be used, often becoming repetitive treatments interchanged among patients. However, research on what protocols should be used for these infertile patients vary. I have found one clinic suggest that natural killer cells are the source of why a patient cannot carry a child; another clinic suggesting that natural killer cells are not the source of the problem. In fact, the latter clinic stated that from past and current research, there is no underlying evidence that even supports the theory of natural killer cells and is not even an existing

diagnosis.

### Personal struggle

A few years ago, I was involved with the fertility treatments a friend of mine was receiving. I knew my friend had many failed IUT’s and IVF treatments and was currently going through yet another cycle of IVF. I started going to many of my friends appointments, because her husband needed to work and I knew she needed someone to be with her. It has also come to the point where I knew she only created one, or maybe two, mature follicles which is a drastically low number to produce. She eventually stopped making any. Typically during these treatments, about 10 to possibly even 20 mature follicles can be taken from a woman during one

IVF cycle. Her appointments were initially weekly, and then just about every other day.

Throughout this cycle, I gave her many of her nightly injections consistently and offered her all the comfort and support I could.

After my friend was given all these hormones and medications, she found out during her ultrasound that no matter how many hormones she is being given, or how much follicular stimulation, she can no longer produce a mature viable follicle, and in that case a viable egg. She was told she could not have her own biological child. Sitting with someone when they are told they cannot have their own child is one of the most painful experiences I have ever witnessed. Seeing a woman completely falling apart, watching her hopes, dreams, and wishes vanish time after time with each failed treatment, changed me immensely.

After waiting a few days, I approached her and told her about my idea to give her my eggs, which she greatly accepted. A reason why I decided to donate was because I could not bear to see this heartache. I was then giving hope to a hopeless woman. I was giving someone a chance to have at least a “½ biological” family. That is a powerful and emotional gift that I offered.

Throughout this time, I came to know and speak to many couples, but especially the women. You see the same people during each visit; everyone is scheduled on the same IVF “cycle.” Clinics typically group woman together to make them have procedures done on the same day. Speaking with these women, you get to understand infertility and the emotional impact more closely. Most of the woman I spoke with said they were embarrassed, ashamed, and felt “inadequate.” One woman actually said that when she got married to her husband they wanted to start a family right away and after trying IVF a couple times she is afraid he will leave her, to the point saying, “I can’t blame him if he left me.”

### Too close to home

My process began on a bright, clear, sunny day. I thought, possibly an indication from God giving me his blessing, at least I like to think so. I recall arriving in the waiting room with my friend, and I was given a patient form to fill. I was slightly nervous this day; my palms moist, glancing about the room nervously, shaking my leg rapidly along with the clicking of my pen. My handwriting on my form appearing scrambled and convoluted like the writing of my five year old nephew. Upon reflection sitting in that chair, with other couples around me, all seated with blank faces, I found I was turning into

the “typical” infertile patient and even community. I became nervous and quiet, withdrawn from the environment, and more introverted, but on further digression into my thoughts, I knew what I was doing was right and ethical. I came to the conclusion that if I were to do this process, I had to do it with my personality. I had to be more engaged, aware, and involved.

I met with my doctor and nurse and had a full work up. They consulted me on what to expect on the process of egg donation, along with an intense pelvic exam and blood work. During this process I had to meet with a lawyer to sign away my rights to the eggs and future embryos produced in the cycle. I also had to meet with a psychiatrist to evaluate my mental health and to acknowledge the true ramifications of what I was going to do. This psychiatrist went through every single relationship I have with my family. If there was a little problem she wanted to dig and dissect it. One of the questions she asked me, striking a nerve, was when she said, “You must understand this. You are giving your eggs away and they will no longer be yours. Any child made with those eggs are not yours and any decision on them is not yours.” I understood that going into donating but hearing it out loud struck me. Many donors have no contact to those individuals who have accepted their donor egg. In my case, if this IVF cycle works, I will see this child quite often. This goes for every future IVF or fertility treatment my friend will have. To me, I had to think of egg donation and recognize that yes, this potential child will have my DNA; however, what constitutes being a mother? I know that I am not the mother in any way, nor am I ready to be one. A mother is someone who cares for this child, watches them grow and develop. It is the person this child runs to when they are scared, hurt, happy, excited, etc. It is essentially that person where that child will stare into their eyes and call them mother.

With my story I hope can show you the pain and hardship that these couples go through and in turn you may also understand and help them cope. However, my story is still not finished. After my second cycle, I remember my nurse telling me she wanted to speak with me in her office. I thought this was odd at first, we speak through email or over the phone or even in front of others but now she wanted me in her office. So I sat with her and she had my file out on her desk. She is looking at my chart from the previous year, where I was 26 years old, and this current chart, making me 27 years old. She looks at me and says, “You really need to start considering to freeze your eggs for yourself, because your hormonal levels are not where they should be for a woman your age.” During this second cycle I knew my medications were increased compared with the previous year. So I asked her when I should start freezing my eggs, and she responds with “now.” I am 29 now and each year that goes by the thought is always in my head that I never want to be that woman on the other side of a doctor’s desk when he says you cannot have children.

Based on these findings and family history, I have been labelled as having a probable likelihood of having decreased ovarian reserve. However, because of the financial burden this places on me, I will continue to visit my reproductive endocrinologist annually to evaluate my hormone level status. If these levels were to get any worse, I will have to find a way to begin the egg freezing process. Therefore, with each repeated blood work, I pray that I have some follicles remaining. During this interview process, I knew I had a

problem or potential problem, but hearing and possibly being defined as potentially infertile was extremely difficult. Thinking that I may have to go through this process again is hard, these treatments are extremely intrusive and difficult. My story is far from over.

I have vowed to myself that I would be more involved with infertility advocacy. We as individuals should focus on not only infertility but how we can better handle and cope with patients who struggle with this disease. Infertility treatment has always been around but now the conversation is starting to build. As a people, I want us to fix the conversation and steer it away from those negative thoughts that infertility children are just those that are made in a lab. Many people refer to these children as “artificial.” It is hurtful, it is disrespectful, and in my opinion brought about by ignorance. I want us to speak up and correct these thoughts and lessen those negative connotations.

As an advocate for this disease, and because many individuals remain ignorant, I offer some advice. I first encourage individuals to assess whether you have a family history of this disease. If so, and you feel that having children would be in your future, to begin to understanding your body’s potential. Creating a family is one of the most important characteristic in achieving self-actualization for a woman, especially in one who desires a family. The common thought was that people felt less of a woman, ashamed, and embarrassed. By understanding that I myself may potentially have premature ovarian decline, I feel empowered to spread my message, so I can help others.

Can we justify further research to increase standards of care or create new protocols even when many times a viable pregnancy does not occur? Is it ethical to allocate funding to individuals in which many insurance companies consider not “life and death” or even for further research? Should legislature be more involved in creating laws and regulations to promote autonomy in patient care? The more we speak about our infertility troubles, the more recognition we will receive. We will encourage legislatures to further recognize our disability, to understand that we need a clear and distinct “path” to acknowledge and support our cause. We need to create more funding and more opportunities for research. We need to advocate for a change to occur so these couples receive the help they need. I understand that this topic is one that is highly controversial, that people refer to it as something not “life and death.” However, facts remain that these couples, especially those with poor coping strategies, have a positive correlation with increased levels of depression, anxiety, social isolation, and increased levels of negative affect.

Does infertility define us? Keeping silent we let it so. Being afraid to speak up, and being embarrassed about our lack of ability, in essence, makes this diagnosis overcome us. We live with this disease and we let it run our lives, changing our affect, inhibiting ourselves from living the life we want to live, one with happiness. The key to success with infertility is not even when you do have a child, because we all do not unfortunately have that ending, but it is being able to talk about your struggle, so that we in turn can help that other, or next, infertile person.

I also look upon this experience and believe God not only created this opportunity for me to help my infertile friend and discover my own probable problems with infertility, but also to give me the

strength and power to advocate, so that I may help others. This help and advocating, will lead to hope. Hope, that no matter how defeated we may feel, that even if we do or do not have a successful pregnancy, that we will have the strength and the faith to persevere and still find ways to help each other.

I prefer to look at this disease in a confrontational matter. I prefer to acknowledge that by having this disease I am empowered to establish some criteria, some ability, in which I may create a standard where other individuals may look upon and enhance their ability to treat when going through this same experience. Even though I myself may be considered to have some form of this disease, this disability, I do not define myself in this way. I define myself as one that uses her weaknesses to create strength. To look at her past, and after acknowledging all those inhibitions, those things that made me succumb to minute periods of inadequacy, created this outlook that encouraged me to overcome those weaknesses. I have acknowledged infertility as existing in myself, in my being. It exists and as it is a part of me; the only way we grow and gain strength is by acknowledging and overcoming our own weaknesses. I have become empowered and self-actualized in the sense that infertility does not define me, it just happens to be a miniscule part of me; that even though it has created a large impact, it does not delineate me to become something less, but more.

## Conclusion

By sharing our stories, we not only call attention to the disease of infertility, we inspire more individuals among the community

to understand and further advocate for this socially, emotionally, physically, spiritually, and financially debilitating disease. I have offered insight to a social stigma, to an anonymous epidemic, in which we see judgment and ignorant remarks made constantly. Helping individuals through this process has given me insight and a deeper understanding of my own fertile potential. Being a part of the infertility process I realized I have been battling my own potential infertility both directly and indirectly. Helping my friends and family and associates through this disease, and recently discovering my own proximate diagnosis, has now become a lifelong battle.

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