Protecting Preimplantation Genetic Testing Patients: A Social Support Perspective

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By

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Abstract

Preimplantation genetic testing of monogenic disorder (PGT- M) is a relatively novel assisted reproductive technology that allows patients impacted by genetic disorders to select an embryo free of hereditary genetic disorder and conceive via in vitro fertilization. While outcomes for patients using PGT-M with IVF offspring seem promising, there are a multitude of factors that hinder patients' mental well-being and treatment adherence, specifically the intense isolation that is endured. This thesis uses available literature and data to argue that normative social support frameworks are effective but ultimately not tailored enough to promote a positive PGT-M patient experience. Social support would be more adequately sought through PGT-M concentrated support groups as they would unify patients experiencing a similar process. However, there is a deficiency in access for PGT-M patients. I advocate for the creation of concentrated PGT-M patient support groups as they administer an experience-conscious space that combats mental anguish, like isolation and depression, and promotes overall patient well-being and future use of PGT-M. Finally, utilizing the cultivation of PGT-M concentrated support groups, I encourage more widespread concentrated support group use to buffer the current inaccessibility for many who need mental health services.

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I. Introduction

Deliverance of a healthy child is something all parents dream and wish for. While some families get naturally lucky, those who carry genes for genetic disorders have to test their luck through assisted reproductive technologies like preimplantation genetic testing. Preimplantation genetic testing (PGT) allows couples or individuals to select a healthy embryo when looking to conceive. The testing of cells determines the health and viability of embryos by extracting embryos from a woman. If embryos are deemed healthy, they may be harvested, and the patient may become impregnated with an unaffected embryo. In 2016, PGT-assisted cycles in the USA comprised 21% of in vitro fertilization (IVF) pregnancies. That percentage is predicted to grow only as more clinics are becoming equipped to provide these services (Theobald et al., 2020).

Among the three existing PGT testing types, PGT-M mainly tests for monogenic, single-gene, and disorders that may impact the embryo or future child. It is commonly used amongst those predisposed to genetic disorders; these disorders may include Huntington's, sickle cell anemia, polycystic kidney disease, and the BRCA gene mutation which leads to breast cancer (Cooper Surgical Fertility). Single gene disorders are estimated to impact 1 out of every 100 children born and can lead to stillbirth, defects, and infant or child mortality (Cheng et al., 2022).

With consideration to the possible adverse health effects that the child can endure, patients who have inheritable gene disorders should be advised on the use of PGT-M to prevent disease in their offspring. However, seeking out and enduring PGT-M in hopes of preventing hereditary genetic disorders is not an uncomplicated pursuit. Although current literature heavily emphasizes the process as highly individualized, these notions promote the isolation IVF patients using PGT-M so frequently feel. This paper emphasizes the necessary unification of IVF patients utilizing PGT-M through the implementation of social support through employing support groups in order to combat mental anguish, like isolation and depression, and promote patient well-being and future use of PGT-M.

I.a. Background

Since being pioneered in the 1980s, testing has provided patients and couples who carry genetic disorders the relief of conceiving a child without a hereditary genetic disorder. Without using preimplantation genetic testing, couples afflicted with genetic disorders would likely remain childless, raise a non-biological child (adoption or embryo donation), or potentially conceive a child with a genetic disorder (Lavery et al., 2002).

Preimplantation genetic testing may be applicable for anyone with a single gene disorder, given that the gene and its marker have been located (De Ryke and Berckmoes, 2020). Using PGT-M requires conception through IVF, even if fertility issues do not exist. Patients utilizing IVF with PGT-M will likely have fewer embryos to transfer than IVF patients using IVF for fertility reasons due to varying inheritance amounts in the embryo (Tur Kaspa, 2012). Only 19% of patients will become successfully pregnant using IVF with PGT-M (Herschberger, 2010). In previous years, families utilizing preimplantation genetic testing were even advised to terminate in vitro cycles if they did not produce a sufficient amount of disease-free embryos (Tur Kaspa, 2012). Fertility specialists and other reproductive practitioners, like Dr. Ilan Tur Kaspa, are beginning to consider an additional clinical dimension of emotion for patients utilizing IVF for genetic testing purposes and a more individualized approach to support as the experience differs significantly from IVF for fertility patients.

Progression through PGT-M is one marked by length and multiple facets. Couples or individuals looking to conceive should anticipate a waiting period of eight months to over a year and a half before beginning the IVF process. Patients or couples must receive a clinical diagnosis done by DNA analysis to proceed to genetic counseling, where it is determined if PGT-M would be a viable test. After such, IVF cycles can begin, where multiple cycles may be necessary to receive a viable amount of embryos for a patient to become successfully pregnant.

PGT-M is not a fail-safe method for viable pregnancy nor the presence of an embryo free of genetic disorders. It is merely a tool that can assist couples and individuals in deciding on which embryo to utilize for conception. However, for those impacted by genetic disorders, it is the better alternative to naturally conceiving, which poses potentially traumatic and devastating results to both patient and offspring. Upon conceiving naturally, there is a chance the pregnancy may spontaneously end, or fertility specialists may advise a patient to end the pregnancy due to the genetic disorder posing life-threatening issues to both the patient and the embryo. Suppose an individual successfully carries a pregnancy to term. In that case, they risk delivering a child who is affected by the genetic disorder and may need treatment for it throughout their life (Hughes et al., 2021).

PGT-M's longevity, coupled with the financial strain and mental anguish caused by the uncertainty of pregnancy with healthy embryo feasibility and copious amounts of information from healthcare professionals, creates a sphere of ambivalence in deciding to proceed with PGT-M. Prospective patients' motivation to endure PGT-M with IVF has been widely studied by reproductive clinicians, psychologists, and other humanitarian specialists, including public health professionals, with the ultimate decision to proceed to be unique to their circumstances. However, with consideration to the unfavorable mental toll that is so often suffered *privately* by the patients using IVF with PGT-M, regardless of the personal motivation for utilizing genetic testing of the embryo, there needs to be a common place for support, outreach, and intervention developed to protect patient wellbeing.

While fertility clinics have begun to acknowledge the repercussions of using IVF regardless of reason on patients' mental health, therefore administering services for mental health, they lack specified networks that address navigating and coping with IVF besides fertility issues. Although motivations behind the use of PGT-M remain at a patient's discretion, IVF patients using PGT-M must have the opportunity to access social networks, like an IVF with PGT-M support groups, to link a subset of patients exploring IVF for alternative reasons. There, they can cultivate connections with patients who can understand the similar perspective that is endured and provide the skills to cope with the tribulations of the process. Support groups may additionally assist in delivering advice, clarifying medical terminology, and, most importantly, combating isolation. Engagement of patients in the support group will promote adherence to IVF and PGT-M treatment by ensuring the patient's confidence, all the while administering a safe space that combats previous stigmas associated with PGT-M and reshapes medical technology as preventative medicine.

I.b. Methodology

PGT-M with IVF is a novel and preventative technology that reduces the inheritance of genetic disorders. Through my work as a communications liaison at a non-profit that grants funding for PGT-M to patients impacted by polycystic kidney disease, I identified shortcomings in the support delivered to the patients, leading to feelings of loneliness and doubt. This piqued my interest in patient perceptions of social support while enduring the PGT-M process[1].

Utilizing scholarly literature from a variety of fields, including medical, psychological, and social sciences, that comprised information on solely IVF patients and, more specifically, PGT-M with IVF patients, I was able to compile both quantitative and qualitative data that supported comparable sentiments shared by patients.

The following sections will explore the potential navigation of patients into PGT-M and the increasing necessity of social support to assist in their experience.Chapter two discusses factors that impact patients affected by genetic disorders' decision to utilize PGT-M, and from the mentioned factors, the mental toll of the patient is prioritized in the remainder of the literature. PGT-M patients' mental health struggles will lead into Chapter Three, which entertains social support types and provides examples of how the variation of support may be provided but is ultimately insufficient for PGT-M patients. Chapter Four addresses deficiencies in access to social support and the necessary cultivation of experience-conscious areas of outreach. Chapter four provides methods for the initial implementation of PGT-M-centric support groups, while

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[1] While the wording in this literature tries to remain as inclusive as possible, it should be noted that referenced impacts of PGT-M and solutions mainly regard biological females, specifically mothers. However, it is acknowledged that all gender spectrums may be implicated and supportive measures should be provided to safeguard health and wellbeing.

Chapter Five entertains legal action of nationwide PGT-M support groups. Finally, a recap is provided, and future recommendations are specified.

II. Factors Impacting Use of PGT-M

The sections below will discuss common factors identified by published literature that influence patients' and couples' decision-making on using PGT-M. The later-mentioned influences may compound factors such as patients' perceived levels of social support. Concerning the holistic viewing of PGT-M patients and couples, the following factors that drive a patient to utilize, or on the other hand, abstain from, reproductive technology are described.

Presence of Genetic Disorder

Genetic disorders are usually marked with an extended family member lineage that has also been impacted or can be newly discovered upon carrier screenings before pregnancy. In the early stages of family planning, a couple or patient with a genetic disorder will likely be referred to a genetic counselor, who will assist in interpreting genetic results and how they may impact your child.

The use of PGT-M varies on a person-by-person basis based on the severity and onset of the disorder (Herschberger et al., 2016). Families who already have a child with a genetic condition may demonstrate interest in the utilization of PGT-M, but they typically do not follow through with the process. Reasons vary, but it may be due to the caretaking priority of the existing child. However, literature reviews on PGT-M patient motivations by reproductive specialists Hughes et al., demonstrate that parents were more likely to use the technology if they had previous education. Patients who are aware of the hereditary presence of the disease but have not yet shown symptoms or been diagnosed may choose to utilize exclusion testing, which permits families to conceive a genetically disease-free child without knowledge of their diagnoses (De Ryke and Berckmoes, 2020). Regardless of how the disorder was detected, affected individuals usually feel morally obligated to utilize any technology to avoid passing on a life-altering genetic disorder. For many, it’s less about having a “healthy” child and rather about preventing agony. (Hughes et al., 2021).

Financial Constraints

PGT-M with IVF typically costs a family about 30,000 USD, with genetic testing costing about $400 per embryo (Khorshid et al., 2021), and this is one of the top reasons for inaccessibility to IVF with PGT-M. While laws in certain states within the USA have enforced insurance companies to cover an extent of IVF for couples struggling with infertility, PGT-M is rarely recognized as a benefit (Roche et al., 2021). Moreover, coverage for IVF is for women who struggle with infertility, not genetic disorder risk. It is not uncommon for some families in the US to switch jobs or move states to obtain insurance coverage for IVF through their employer.

Economic barriers are exacerbated for a lower social class or minority women looking to utilize IVF with PGT-M. White patients with a college degree are most likely to pursue assisted reproductive technology (ART) services and follow through with them, which could likely be associated with higher-paying jobs and better insurance coverage (Insoga et al., 2020). Clinics typically have embedded financial counselors to assist families with payment procedures. However, for many, payment must be paid in full for the progression of testing or IVF, forcing many to take out private loans or open credit cards. IVF with PGT-M is not a necessity but rather a financial sacrifice couples or patients have to make if they want a biological child free of genetic disorders.

Physical Burden on Carrier of Child

Considering that PGT-M requires biological women to undergo IVF treatment for conception, the toll the process takes on only one counterpart is worth noting. IVF involves many potentially painful medical interventions, including repeated bloodwork, hormone injections, and egg retrieval, which utilizes a long, thin needle to be inserted into the vagina to harvest eggs (Mayo Clinic). Egg retrieval can cause perforation and damage to surrounding organs. In some cases, multiple egg retrievals are necessary to ensure chances of successful embryo implantation safely or if the eggs repeatedly are plagued by the avoided genetic disorder. There have been repeated condemnations of the ethics surrounding the process, especially without proper pain management.

Women undergoing IVF are at risk of developing ovarian hyperstimulation syndrome, a painful disorder that leaves the ovaries swollen and tender. Those who conceive are at higher rates for miscarriage or multiple gestations, which may cause infant death and disability to mother and child (Reynolds et al., 2003). Additionally, pregnancy complications such as preeclampsia and ectopic pregnancy are likely (Galbaya, 2009).

Mentally Taxing

While much emphasis falls on the women's experience (De Ryke and Berckmoes, 2020), couples pursuing IVF and PGT-M both experience negative emotional disturbances. A study in the United Kingdom found that 65% of patients and their partners who underwent the PGT-M process would utilize therapeutic services for future cycles (Laverey et al., 2002). While the stress of the process may impact patients' marriages negatively in the short term, fortunately, based on the stability and resilience of couples, marriages typically do not fail or have lower marital satisfaction than those who conceive naturally (Cebert et al., 2021).

The uncertainty surrounding every IVF or genetic testing stage is marked by stress, anxiety, depression, and loneliness. These feelings may follow the patient and partner for up to three years and are believed to act as defense mechanisms against adverse outcomes with IVF (Jarvholm et al.and Massarotti, 2019). This may be exacerbated when they become aware of a failed egg retrieval (embryos test positive for genetic disorder), a cycle of IVF fails, or do not understand the information shared by medical professionals.

Patients may also struggle with the notion that embryos that are not genetically fit are discarded. For many, embryos are regarded as people or the potential to be a person, and the guilt that individuals face upon essentially throwing away embryos is real (Guido de Wort, 2009). A lengthy discourse has surrounded the ethics behind the use of PGT-M. In the United States, where there are no limitations to the utilization of genetic testing of embryos, families are at free range to utilize ART services for anything from preventing a life-threatening genetic disorder to sex or eye color selection purposes. The United States has become an assisted reproductive haven for numerous foreign families, who are limited to specific uses of embryonic genetic testing as per their country's legislation. Most countries limit IVF for genetic purposes, even in the case of preventing genetic diseases. The onset and severity of genetic disorders are factors in deciding if foreign couples are eligible for services (Winkelman et al., 2015).

As preimplantation genetic services become more widely available and utilized to prevent genetic disorders, an “ableist-eugenics” perspective comes to the forefront. Eugenics is a theory in which humans can be perfected by selecting “good” traits and avoiding “bad.” Its history is rooted in racial and colonial views of a caucasian, physically attractive, and able-bodied society (NHGRI), so it’s no wonder why advocates denounce the use.

Upon thinking of PGT-M as the preferential selection of only healthy embryos, interpretation is left for those embryos deemed flawed or unviable. PGT-M patients are ultimately left with the choice to donate embryos to research or discard them. Critics of PGT-M question how living individuals who are impacted by genetic diseases interpret the destruction of embryos that carry the disease, especially as they are living and capable beings.

Disability rights advocates argue that as services and accessibility for testing increase, support for the surviving disabled will diminish due to carriers being eradicated by PGT-M. However, prospective parents who carry genetic disorders counter such statements. This is especially true if one of the parents has first-hand experience with watching a loved one suffer from the disease or is currently afflicted. Parents using PGT-M will proclaim that they aren't trying to "build" a perfect child but one that is unaffected and that their reproductive decisions should remain autonomous (Guido de Wort, 2009).

In a 2015 questionnaire conducted by the Harris Interactive Service Bureau, which questioned participants' support for pre-implantation genetic testing, most participants supported it if they were aware of the testing and its uses or knew someone who utilized the services. Interestingly, participants felt a need to support less for the potential of a healthy child but more to support reproductive autonomy.

Similar to the mentally anguishing sentiments of eugenics and PGT-M, religion may impact the decision-making process of pursuing PGT-M, especially in the context of discarding embryos. Couples and patients looking to utilize the technology may struggle with the notion that they are "playing god" upon deciding which embryo to use due to the lack of genetic disorder presence. They may even question if conceiving naturally and their offspring being affected with genetic disorders is "god's will" and using reproductive technology may impact their God-given natural progression.

The Harris Interactive Service Bureau's questionnaire on people's support for preimplantation genetic testing successfully identified religious values that may impact a person's decision to denounce the testing. Christian protestants were more likely to be against PGT-M, and Atheists, who do not believe in a greater power, were more supportive overall (Winkelman et al., 2015). Catholic/Christian deterrence for PGT-M derives from beliefs of embryos being human, and therefore, termination or selection based on pre-existing genetic conditions is immoral (Saint Joseph's University). Christian religious scholars are wary of the long-term use of PGT-M due to its impact on parent-child relationships and humanity (Olesen, Nor, Amin 2016).

However, for example, patients of Muslim and Jewish faith have fewer religious dilemmas upon utilizing PGT-M. This may be because of the prevalence of genetic disorders in their community, which has roots in their common ancestor. For Muslim patients, reproductive technologies are encouraged, with religious scholars stating that such interventions are "God-given knowledge" (Zuckerman et al. 2020, Olesen, Nor, Amin, 2016). Jewish patients are also encouraged, by community and religion, to participate in genetic testing, starting with the marriage of a couple (Dor Yeshorim). They often participate in prenatal genetic testing and the event of potential genetic disorder presence PGT. In Israel, where much of the population follows the Jewish and some of the Muslim faith, preimplantation genetic testing is widely accepted. (Zuckerman et al., 2020).

Ethical sentiments may haunt patients' psyche, but it is often better than the alternative of naturally conceiving and either miscarrying, having a child suffer from an avoidable genetic disorder, or the guilt that follows patients who knew prevention existed but chose against it (Zhang et al. 2020). Upon successful conception and birth, some negative psychological disturbances dissipate for patients (McMahon, 1997).

However, merely the acknowledgment of mental health disturbances and, for the lucky couples, the possibility of a successful birth via IVF only touches the surface of possible interventions in ensuring the mental health of patients and couples pursuing PGT-M. There needs to be accessible mental health interventions for those who are enduring the PGT-M process. The stress, anxiety, and depression correlated with feelings of loneliness and uncertainty through the process can be counteracted with increased measures of social support, specifically by individuals who have endured similar experiences.

The following sections will engage the importance of social support for IVF patients using PGT-M and explain how creating an experience-conscious PGT-M patient community is a public health necessity. Using Catherine Heaney and Barbara Israel's identified types of social support, a framework will emerge on how a mixture of social support can positively impact PGT-M patients. Reassurance and solidarity for PGT-M patients can be created through the development of social communities, such as the implementation of support groups, which assist in lowering mental load, increasing treatment adherence, and, therefore, improving physical health outcomes of the carrier and child.

III. The Social Support Framework

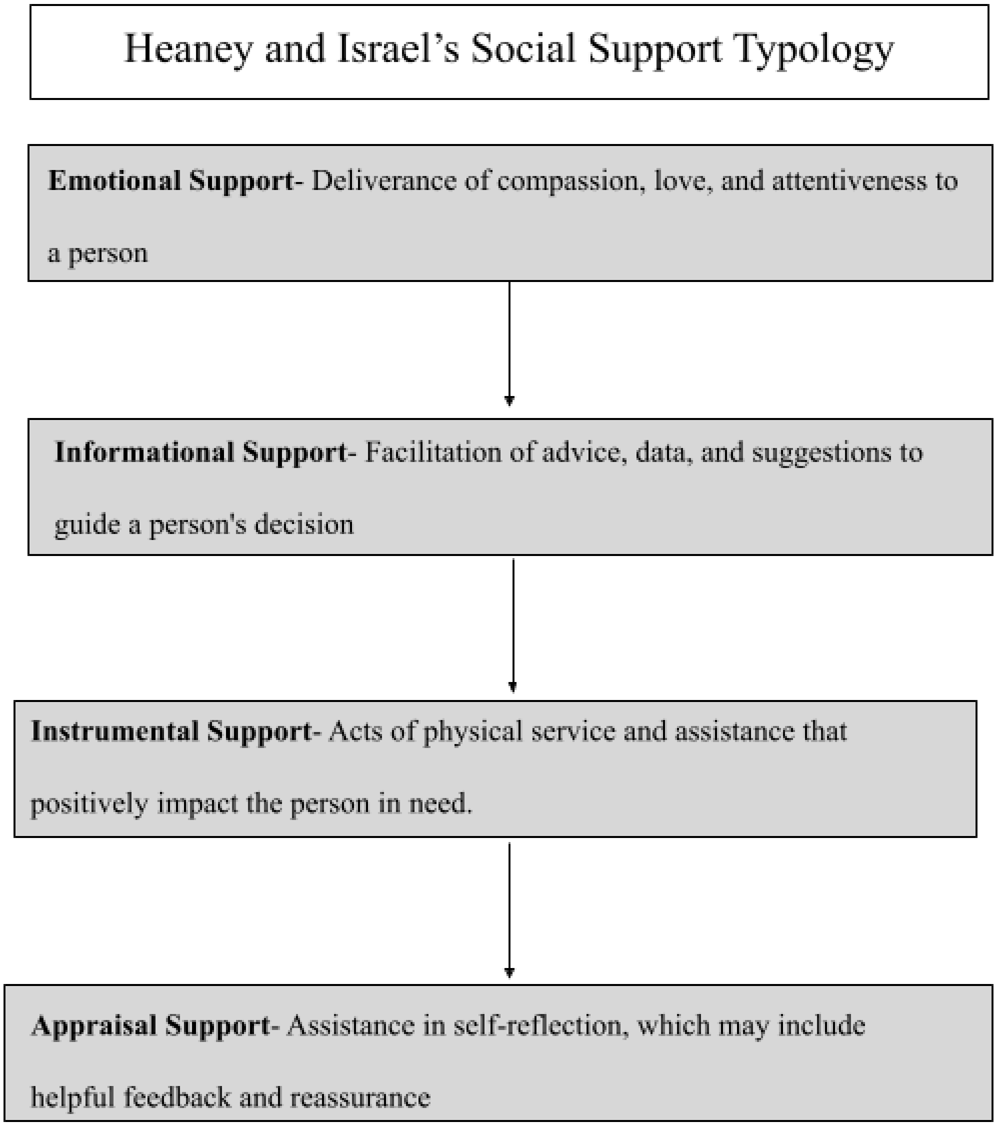
Reshaping perspectives and increasing awareness of the impact of social support and social outlets for patients utilizing IVF with PGT-M must be considered vitally important public health interventions. Similarly to primary prevention of chronic diseases like screenings, PGT-M *is* form a preventative medicine. With public health primarily concerned with preventing illness in a community, PGT-M successfully achieves the interception of genetic disorders in communities impacted by such. In turn, increased social support would protect and promote PGT-M patients' overall health by safeguarding their mental health, improving physical health outcomes and potential IVF treatment success (Wu et al. 2020), and preventing hereditary transmission of genetic disorders.

IVF with PGT-M comprises a small portion of IVF patients. Still, it is essential to consider the impact that the cultivation of specific social networks for IVF with PGT-M may have on more broad and current public health issues such as reproductive health and rising healthcare costs. Reproduction and women's governance over how they approach such have been frequent political pawns. While internationally, countries have increased child-bearing autonomy, allowing for practices such as abortion to be legalized, most recently in countries like the United States, federal law has allowed states to rescind abortion legality based on viewing embryos as humans; therefore, abortion is murder. All the more specific to IVF for PGT-M patients, in states like Alabama, bills have been signed that acknowledge IVF-created frozen embryos as people, and therefore, the destruction of them is potentially illegal. Such uncertainty that surrounds a woman's liberty to get pregnant by their means may increase an already stressful and isolating process, especially when accompanied by a potential genetic disorder. More prolific systems of social support must be in place to allow PGT-M patients to, as per Germain and Ordway's reproductive capabilities paradigm, “bear and raise healthy children" (Qadeer, 1998).

The ability to bear and raise healthy children, free of genetic disorders due to PGT-M, allows their offspring to have overall better health outcomes due to the absence of disease and their ability to receive health insurance coverage. It is widely known, specifically in the United States, that a lack of health insurance severely limits a patient's potential for healthcare access, leaving them vulnerable to treatable ailments. Unfortunately, discrimination against individuals with genetic disorders exists when trying to obtain health insurance, primarily when legislation only protects individuals who are at high risk of developing the genetic disorder as opposed to being symptomatic. In a four-year study by John Hopkins University on genetic disorder patients' experiences with access to health insurance, 27% of the respondents were denied coverage or offered at a prohibitive rate. 1⁄3 of respondents were concerned that they would lose coverage or that rates would become so costly they could no longer afford them (Kass et al., 2016). As demonstrated, advocacy of IVF with PGT-M does not solely address the clinical prevention of genetic disease. Still, it considers *conditions of environment* or non-biological factors that may influence a PGT-M patient and child's wellbeing, such as unstable reproductive rights and health care access, otherwise known as social determinants. These pitfalls can be mitigated effectively through social support.

Within the field of public health lies the social determinants of health, which address non-biological factors that impact a community's health and well-being. Community and social context manage social support systems, community engagement, discrimination, and stress one may face in a community (Kaiser Family Foundation). Social support falls under social networks, which are webs of individual relationships. Social networks are differentiated by the relationship dynamics and, therefore, impact the deliverance of social support. Social support is the positive and intentional function of social networks. Its main objective is to benefit the recipient and is always consciously delivered by the provider (Heaney and Israel, 2008).

According to Catherine Heaney and Barbara Israel, four types of social support exist in the lens of social support.



Heaney and Israel’s Social Support Typology

Emotional Support- Deliverance of compassion, love, and attentiveness to a person

Informational Support- Facilitation of advice, data, and suggestions to guide a person's decision

Instrumental Support- Acts of physical service and assistance that positively impact the person in need.

Appraisal Support- Assistance in self-reflection, which may include helpful feedback and reassurance

Figure 1: Types of Social Support, Source: Catherine A. Heaney and Barbara A. Israel

While types of support exist separately, differing types may be used in conjunction to help facilitate the recipient's decision-making and create a sense of comfort. For patients who are using IVF with PGT-M, a mixture of these types of support is imperative in assisting a woman holistically as they progress through IVF and upon achieving pregnancy. In addition, specific ethnic backgrounds, including black, Hispanic, and Middle Eastern groups, require elevated levels of culturally curated care and support due to specific cultural stigmatization regarding artificial insemination, although childbearing is highly valued. As well as ensuring trust between ethnic patients and providers (Armstrong and Plowden, 2013).

Social support is crucial in promoting health and resilience when faced with adversity (Dragaset, 2021). Upon encountering stressful or traumatic experiences, the deliverance of support by networks or individuals buffers adverse short and long-term health effects (Heaney and Israel, 2008). Increasing social support and networks for patients undergoing PGT-M cushion IVF shortcomings and re-establish perseverance to continue with the treatment. Studies on social support, specifically for support groups on stigmatized diseases such as HIV, showcase how positively impactful support can be on treatment adherence (Batengaya et al., 2016). Studies and surveys specific to IVF and PGT-M, which corroborate the positive implications of social support, have been done. In a 2009 study done in a hospital in the Netherlands that implored patient reasoning behind discontinuation of IVF services, the leading motive was **emotional distress**. Such negative emotions have a multitude of origins. Still, if patients had an opportunity to connect with groups of mothers and patients who underwent a similar process and could provide reassurance and support, they would have been likely to continue cycles of IVF and PGT-M (Rubin et al., 2018).

For those patients who undergo IVF with PGT-M and successfully conceive, the impacts of social support continue to prevail. Upon receiving a variety of differing support, women tend to have higher self-esteem, security and fewer mental health strains associated with pregnancy (Renbarger et al., 2021). The transition from pregnancy to motherhood is likely to be smoother, and patients are more prepared.

While genetic disorders may not impact a patient's conception, healthcare providers want to remain cognizant that intense emotional stress that is left untreated may result in low conception rates and a difficult pregnancy. Such complications are mutually problematic for the success rates of the fertility clinic and patient experience. Hence, the importance of fertility clinics are beginning to consider Heaney's and Israel's framework, which encompasses different types of social support to alleviate the cognitive load of PGT-M patients and improve patient outcomes. The following section will demonstrate how Heaney and Israel's social support framework may operate with patients who are using IVF with PGT-M but ultimately is not successful in fulfillment from a singular entity besides a focused support group.

III. a. Social Support at Play

Heaney and Israel identify four types of social support: emotional, instrumental, informational, and appraisal. While each stand-alone mode of social support may play an integral role in preserving the emotional well-being of IVF with PGT-M patients, patients must be capable of receiving all types of support for the best possible emotional and, therefore, physical outcome of the patient.

Emotional support may be derived best from intimate partners, close families, and friends. This support heavily emphasizes empathizing with the patient and providing them with loving comfort and acceptance when outcomes do not seem sure or bleak. While there is a level of professionalism a patient's care team should carry, it would benefit doctors and nurses of the patient to consider this type of support to deliver when handling a PGT-M patient.

Women utilizing IVF and PGT-M have expressed confusion and lack of provider empathy upon receiving news about genetic test results or the condition of embryos from their medical team. Psychiatrist Robert Klitzman interviewed dozens of ART specialists about provider and patient communication barriers. His work addresses the dynamics and challenges between fertility patients and their providers. The interviews demonstrated the physician's awareness of the importance of a solid provider-patient relationship and general understanding of each other. However, it noted the impediments in communication and providers' ability to understand the hardships when experiencing adverse IVF outcomes firsthand (Klitzman, 2018), which could be interpreted as being cold and dismissive by the patient. The interviewed providers mention differences in perceptions of outcomes and experiences that play a role in the disconnect. More importantly, patients only perceive success in taking home a child, or in PGT-M terminology, a healthy child. Providers, too, are impacted by failed cycles, especially as fertility centers are increasingly becoming competitive. Improvements in the patient's care team's bedside manner would increase comfortability and emotional reliability from providers. As mentioned, positive clinical experiences can be mutually beneficial for both patient and provider as they can promote the use of PGT-M and, therefore, patient retention and recommendation (Pastore et al., 2019). Emotional support would be perceived as being listened to and then cared for.

On the other hand, an individual, provider, or employee of a foundation providing guidance, tangible information, or reference on specific knowledge that can assist an IVF with PGT-M patients would be informational support. Informational support would likely be interpreted best by individuals who have utilized or are more progressed in their IVF PGT-M journey. Personal shared PGT-M experience can help alleviate some of the contemplation patients who are considering PGT-M often face and serve as a motivator to progress, especially if it is a positive experience. Support from other or prior PGT-M patients can also assist in clearing up confusion. It's prevalent amongst PGT-M patients to need help understanding medical advice delivered by their healthcare team. Lack of specificity and unclear medical jargon deter patients from further questioning and trusting their fertility providers (Pastore et al., 2019 & Barrier et al., 2019), often feeling burdensome to needing clarification on details. In a study by 28 fertility centers in France, 20% of IVF patients reported gaps in their understanding of their physician's explanation (Barrier et al., 2019), which clinicians should consider as they would be the most equipped to answer specific medical questions. Instead, confused PGT-M patients would receive information and support from social media forums of previous patients who have endured and overcome similar circumstances. Such patients cited that the informational support delivered from other PGT-M patients was precious due to feelings of mutual understanding and recognition. They felt advice delivered by PGT-M patients from their forum would not net any gain to the facilitator (patients often think that doctors are trying to 'oversell') and is meant to be helpful solely.

Instrumental support for a PGT-M patient could be perceived as anything from clinical fertility care administered by health care providers that allow for a pregnancy without a genetic disorder to a foundation that assists in funding PGT-M testing. Emphasis is placed on the **administration of provisions or services**. An example of such a foundation would be pkDO, which pledges up to 3000 USD for polycystic kidney disease patients' PGT-M testing of embryos and can assist the patient in the selection of a clinic for IVF and, therefore, a genetic company that would test the embryos. Instrumental support would provide tangible contributions to the progression of fertility treatment or make the overall process more accessible for the patient.

Likewise, appraisal support could be sought by utilizing the clinical expertise of the patient's care team because of the potential to clinically establish confidence that they can overcome difficulties in the process. Still, PGT-M patient support networks and close families can also reestablish patient esteem. Patient support networks would be uniquely beneficial due to the commonality of experience and the ability to reupholster patient confidence to continue progressing. Patients who have undergone similar procedures would be able to best reassure patients on anything from genetic testing protocol to cost ranges. As mentioned, with differing support modes, patients would likely prefer appraisal support from support networks due to knowledge being received without gain but based on assistance.

In a time of need, any type of support for a patient enduring IVF with PGT-M would be beneficial. Heaney and Israel's social support typology effectively identifies support methods to alleviate patients' mental burdens. Again, healthy emotional states for patients are mutually beneficial for providers and patients. A patient who is properly supported is more likely to adhere to treatments and become successfully pregnant with a child free of the avoided genetic disorder. However, trying to obtain a mixture of all the mentioned supports from a singular presence would prove to be complicated.

Sometimes, a patient may be underserved in one aspect of the framework. Each individual, clinical and intimate, that is a part of the patient's journey would likely only be successfully supportive in one domain. A provider can only provide so much emotional support without being unprofessional and forced to follow a schedule, and ultimately, would likely **not** be the foremost deliverer of such. On the other hand, a partner or family member would likely need help to clarify necessary clinical information regarding genetic testing results and processes; therefore, it is not an ideal liaison of informational support. However, an IVF with a PGT-M support group would be a readily available distributor of each support identified by Heaney and Israel.

A support group would allow for a community of individuals with similar lived experiences and trajectories the ability to administer support in addition to coping mechanisms and consequently promote feelings of camaraderie. Invalidation of negative experiences and isolation are common for patients undergoing IVF with PGT-M, as support and acceptance are not always accessible. However, the following section will demonstrate that while specified support groups are not an innovative creation, this is not an easily accessible solution for individuals pursuing IVF, not for fertility reasons but for the avoidance of a hereditary disease.

The ideal way to integrate social support for PGT-M patients would be through support groups or networks through the recommendation of their fertility clinics. Patients' healthcare providers would be best equipped to identify what support group would fit their needs. By taking a bottoms-up or grassroots approach, increasing social support can be resolved through the implementation of support groups spearheaded by individuals who have experienced PGT-M with IVF. This would be a fundamental step in improving widespread support, as it recognizes a current lack of care provisions for individuals using PGT-M with IVF. By facilitating such support groups, individuals can share their stories and experiences without fear of stigmatization.

III. b. Assessing the Deficiency

Fertility issues are at the forefront of most clinics. Infertility, or the inability to conceive after a year or more of consistent, unprotected sex (WHO, 2023), is identified as a disease of growing public health concern. IVF is increasingly being acknowledged not just as a solution but as a benefit worthy of insurance coverage. Political policy and major employer companies recognize a growing need for such services to be covered by health insurance. While there is increased advocacy for fertility services and reshaping views of family planning as equitable, there must be consideration for mental health.

There is no doubt that IVF, regardless of reason, can be an isolating experience. It may be difficult to reconcile feelings of loneliness, despair, and pain, and such emotions can vary in interpretation based on the reasoning for IVF. To mitigate such feelings of isolation, a patient's health team may advise psychological intervention and support groups. IVF for infertile patients may result in an inability to conceive even through ART and repeated miscarriages, which may lead to an increased feeling of shame and grief due to unsuccessful conception, even with medical intervention. For PGT-M patients, conception may not be an issue, but repeated results demonstrate embryo affliction of the disease. Shame and grief may also be a common emotion, but due to PGT-M-specific tribulations like the potential destruction of an affected genetically but otherwise healthy embryo or the temptation to use an affected embryo knowing it will come out sick. It is also likely that patients who are using IVF for genetic disorder purposes may already have a child at home who is affected and have no issue conceiving naturally. At the same time, infertile patients may have been trying to conceive for years and continue to falter. The element of "childlessness" may not always be suffered.

In the event that all women with different IVF experiences were put in a room to provide each other with consolation and group support, there surely would be general understanding. Regardless, any woman who endures IVF understands the physical, mental, and financial strain that it bears and would be more than capable of empathizing with others. However, divisiveness or lack of understanding amongst patient experiences may emerge upon going more profound than the surface-level impacts of IVF. This is heightened when the journey is not about the inability to conceive or carry to term but rather the prevention of a genetic disorder.

Most large-scale fertility clinics contain support groups within their practices. Such support groups provide much-needed social support that so many patients yearn for. Support groups may be held online or in person and consist of women who have experienced similar IVF struggles, which typically involve infertility. Fertility support groups bridge the gap, not only for discussion amongst patients with shared experiences, but are a proven cost-effective and personally acceptable resource for addressing mental health struggles. Support groups are typically offered at no cost or a lower fee without insurance implications. It also may be less daunting than meeting with a licensed counselor or psychologist due to the group setting rather than the one-on-one nature.

Support groups allow a diverse patient pool to reflect on specific hardships and can provide potentially insightful and uplifting feedback, such as coping skills after a failed cycle, clarification on results, or reassurance that the stress, pain, and anxiety are worthwhile. However, IVF support groups typically address infertility concerns rather than utilization of IVF for other reasons (Resolve), leaving PGT-M patients underserved and without a network to depend on. A quick Google search of IVF support groups demonstrates the need for more variability in support groups beyond infertility.

When searching for variations of support groups, the website RESOLVE appears. RESOLVE allows for searching and filtration of support groups for fertility and general family building. While they provide a plethora of outreach resources, including in-person and online support groups, the most prolific type of support groups are general for general infertility. There is no single support group for PGT-M patients except a support group that is generally focused on ART and may have the space to touch on PGT testing.

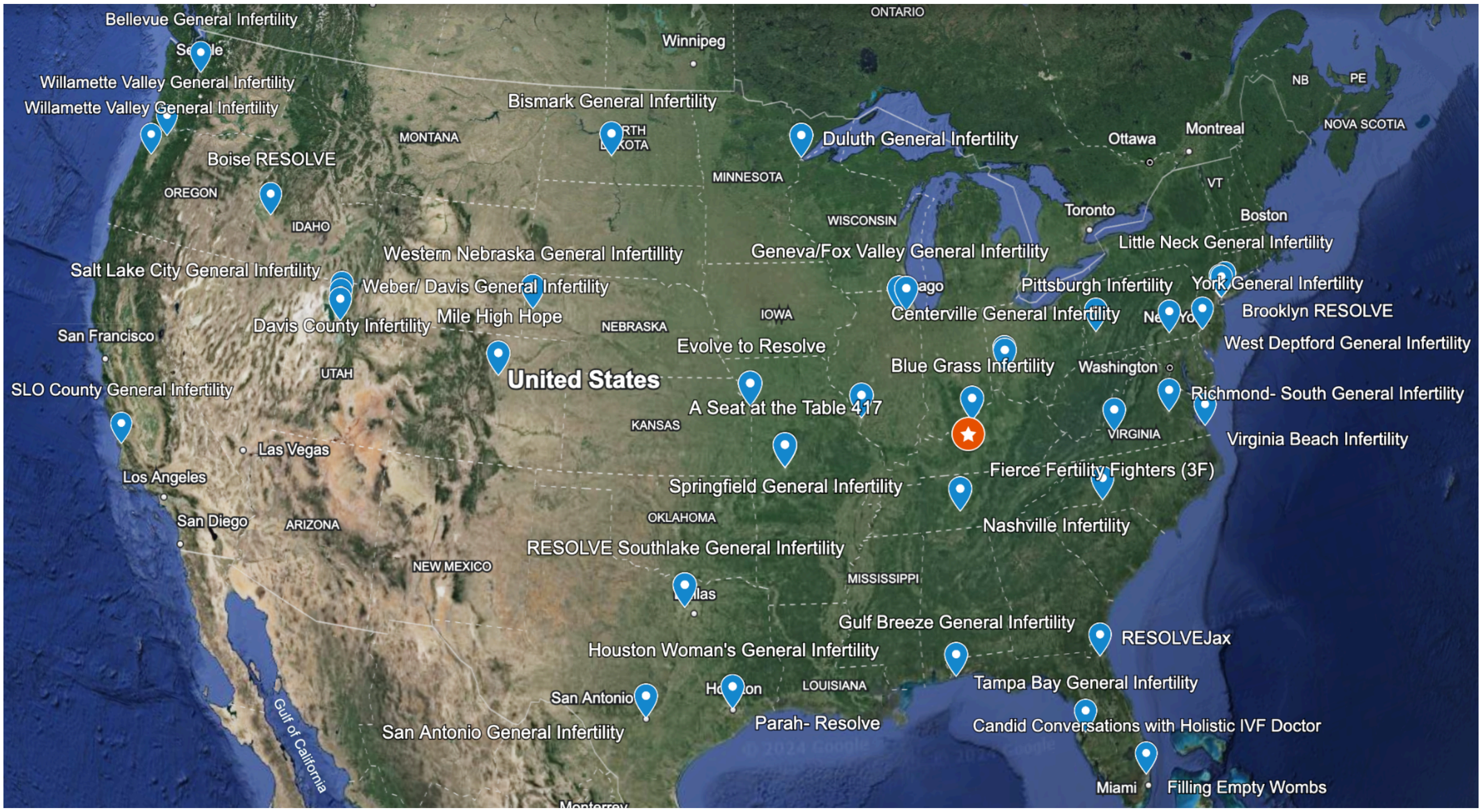


Figure 2: Locations of current in-person and peer led support groups for Infertility (blue pin) and Assisted Reproductive Technologies (orange star), Source: RESOLVE

From a broader search, the only PGT-M-specific group identified was an online forum. Thus leaving those who are using IVF for alternative medical reasons without a space that understands their current tribulations.

It is very plausible that fertility support groups address specific issues, such as strictly issues with conception, due to specified coping interventions. Support groups are meant to give users a sense of community, so the specification of group topics is not unusual. Understanding community refers to perceptions of belongingness, interdependence, and mutual commitment, which links individuals to a collective unity" (Kloos et al. 2017). Nevertheless, it's important to note that community is not intrinsically linked to positive outcomes. As showcased, with the specificity of support groups being only for patients struggling with infertility, it's possible that other groups, such as PGT-M patients, will be left out due to exclusivity. An infertility support group would likely address coping skills for the negative emotions, such as shame and disappointment, that can be experienced with the inability to conceive. While a PGT-M concentrated group may additionally address feelings of shame and disappointment, it stems from different reasons. For example, a PGT-M patient may experience shame involving the disposability of genetically abnormal embryos. Disappointment may arise when a small number of embryos are viable.

Additionally, with consideration to patient-provider relationships and care administered, which heavily influences patient outcomes, support group suggestions or commentary of fertility clinic care from patients of IVF for infertility and IVF for PGT-M would be vastly different. This notion is exemplified by the interpretation of treatment patients are receiving from fertility clinics, as there are different gauges on a measure of success for IVF usage. Since success in IVF facilities is based on the successful pregnancy rate per IVF cycle, there is very little room for interpretation of success for patients looking to use IVF with PGT-M as success for clinics is dependent on embryos free of the genetic disorder and not successful pregnancy (Troude et al., 2016). Issues and resolutions with conception and embryo feasibility at a fertility clinic are not transferable for IVF for fertility patients and IVF for genetic disorders. Therefore, discussion in a support group would likely not prove to be effective.

Considering such distinct tribulations experienced by the variety of patients who utilize IVF, various approaches and group-focused therapeutic interventions are necessary. Different stressors require different accommodations or support to alleviate insecurity (Wright, 2016), hence the rationale for support groups that serve particular sectors of IVF and can provide the proper methods to address concerns. The following section will engage policy advocacy to further develop support groups for PGT-M patients, as well as potential guidelines on how they can be best administered.

IV. Policy Advocacy

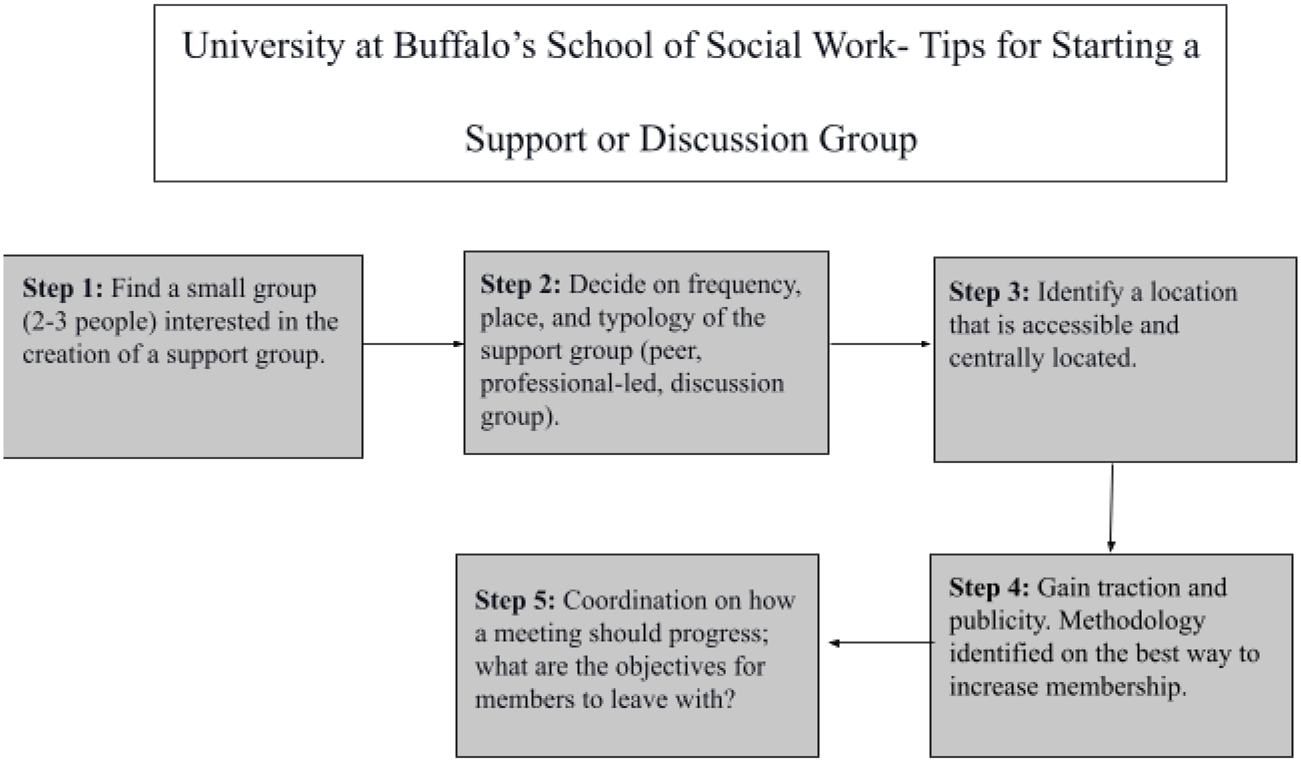
Mutual understanding of a shared experience is the key motivator in emphasis on the creation of support groups. The maternal experience, especially for those using reproductive technologies with genetic testing, is marked by an influx of information and trials and tribulations. IVF can be a physically and emotionally painful experience, often only *truly* understood by those with a similar experience (Montgomery, 2023). While both infertile patients and patients who have a hereditary genetic disorder undergo the same in vitro interventions, driving forces differentiate, leading to vastly different perceptions of success and experience of IVF. This necessitates a separation of support groups and, consequently, the creation of a PGT-M-focused group.

As mentioned in the prior section, support groups will adequately link individuals who are enduring similar situations. Supportive contributions and understanding from parties involved with the PGT-M patient may be hard to interpret. A provider relationship may not provide enough satisfactory support, specifically emotional support, that families and partners may need. But, even support from the patient's intimate sanctions may not understand the gravity of the PGT-M process. Public health professional Natalie Montgomery facilitated a small study on IVF patients to discover what leads them to seek additional social support beyond their personal support system. Montgomery's findings demonstrated claims of seldom adequacy in support from their spouses (Montgomery, 2023). In addition, a study done by the University of Toronto's School of Public Health on patients who have undergone IVF all claimed there is a level of disparaging insensitivity when attempting to discuss their shortcomings with IVF with inexperienced members in their immediate circle. Success in conceiving through IVF is not always promised, especially if accompanied by embryos that carry the disorder patients are looking to avoid, and repeated cycle failures can leave patients in a negative emotional state. When individuals experience an inadequate support system, they will likely divert from disclosing future issues and start a cycle of seldom internalizing thoughts. (Montgomery, 2023).

However, supportive communication, potentially via support groups, between patients who have experienced IVF leads to feelings of deeper connection and satisfies the need for understanding. Outcomes from support groups also ensure that PGT-M is continuously utilized by the population that is impacted by genetic disorders. Although a survey done by the University of Pennsylvania's Department of Obstetrics and Gynecology on genetically at-risk patients who attend a PGT-M consultation report that about 90% of patients employ the use of PGT-M, it's important to note that social support assists in adherence to treatment and reuptake of services (Casale and Carlqvist, 2021). An improper space to vent or the potential for emotional tribulations may even persuade patients who are in the "contemplation stage," which is the average of three months after consultation, where patients decide if they will utilize testing or not (Lee et al., 2020), out of the utilization of genetic testing services. Upon the separation and cultivation of specified support groups, dilemmas faced by patients utilizing IVF for differing reasons can be resourcefully and adequately addressed.

The creation and implementation of PGT-M-specific support groups should be a rather swift process. Although the literature below entertains a fixed administration of a support group for PGT-M patients, the establishment can vary to best serve the needs of the group. Certain demographics and ethnic groups should be considered to address topics that may be compounded by the use of PGT-M in support groups. However, regardless of cultural considerations, the mission of the support group would remain focused on providing a safe environment for women to converse and cope with the PGT-M experience.

When identifying what type of group would best address IVF with PGT-M support groups, a peer support group would be most feasible. Peer support groups emphasize members' similar interests, which is vital to IVF with PGT-M support groups, as all members will have a mutual understanding of the stressor that needs alleviation. A study was done on a group of pregnant women in England, and the impact of peer support was highlighted as practical, positive, and dependable (Rice et al., 2022). Through peer support, members will cultivate a wide range of coping mechanisms to combat hardships associated with IVF and PGT-M. Peer support would also be the most accessible form of mental health intervention, and if necessary, it could evolve into the patient reaching out to professional services (Rice et al.,2022). The University at Buffalo's School of Social Work designed a simple five-step plan to spearhead a support group successfully.



University at Buffalo's School of Social Work- Tips for Starting a Support or Discussion Group

Step 1: Find a small group (2-3 people) interested in the creation of a support group.

Step 2: Decide on frequency, place, and typology of the support group (peer, professional-led, discussion group).

Step 3: Identify a location that is accessible and centrally located.

Step 4: Gain traction and publicity. Methodology identified on the best way to increase membership.

Step 5: Coordination on how a meeting should progress; what are the objectives for members to leave with?

Figure 3: Tips for Starting a Support or Discussion Group, Source: University of Buffalo's School of Social Work

With consideration that fertility clinics are the home base for PGT-M patients, a fertility specialist of an independent clinic located in a populated suburb of a city would recognize a deficiency of support in their practice. An independent clinic would be preferential over allied health systems due to the ease of implementing additional therapeutics without potential disruption from company higher-ups. An IVF with a PGT-M patient may seek additional resources to learn more about the experience and how others have fared through the process. Knowing that it is in the best interest of the fertility clinic and patient outcomes, the practitioner would refer them to a previous patient who underwent a similar process and consented to share their contact information to assist others through the process.

The current and previous patients would connect and recognize a deficiency in locating a common area where other women undergoing IVF with PGT-M can connect and support each other. Both the current patient and previous patient notify the practitioner of the shortfall in concentrated support and deliver a recommendation on creating a "network" (future known as IVF with PGT-M support group) of patients in the clinic who are using PGT-M. The practitioner considers the recommendation and brings the idea up to other providers in the clinic to gauge their comfort and support. The physician reminds them of the efficacy of support groups on patients' mental health, which may, in turn, lead to better patient outcomes and, therefore, improved clinic success rates. If there is widespread support from practitioners, the initial practitioner and the patient can petition the clinic board to allow the clinic to be utilized as a facility for other IVF with PGT-M patients to meet and support one another.

Following approval from necessary internal institutions, practitioners can identify PGT-M patients who would likely benefit from support and connect them with the new network. The group coordinators would likely be the two initial patients mentioned, given that they have spare time. A vacant room in the clinic would be utilized as the “meeting room.” Initially, sessions would be held once a month until traction is gained, and the sessions would run for about an hour. Following more members joining or an overall improved attendance, the group can move to an every-other-week modality.

Every meeting would consist of brief introductions to new members, where they can promptly share as much information or as little as they would like. Questions and comments would then follow it, or concerns the other members may need to address. Following that would be the topic of discussion and, finally, closing sentiments. The patients could then chat with one another for half an hour, with light refreshments and drinks.

The two initial patients would be preferential group leaders since they would both possess unique but relatable experiences and guidance to share, given that one is currently experiencing IVF with PGT-M and would likely relate to situations the other group members endured. The old patient would serve as a beacon of hope and as a reminder for the patients to continue persevering.

The primary goal of the support group is to facilitate group discussion on navigating the trials and tribulations of enduring IVF with PGT-M. They would likely share resources that assisted them through the process. Having relations with other women who have faced similar experiences would remind them that they aren’t alone. It will reinstate the fact that they can continue with the PGT-M process. The common good of the group would be of the utmost importance.

While it is likely that members of the original group will stop attending sessions following successful conception or withdrawal from IVF services, advocacy of the group must remain in place long term. This is especially true as the use of assisted reproductive therapies is only expected to grow, leading to a wider network of patients needing mental health services to be covered. Patients are more likely to adhere to treatment plans, which benefits the patient and clinic.

Social media groups would be essential to linking patients not only in the USA but in international spheres with everyday PGT-M experiences. Something as simple as Facebook groups can be created to help develop social networks. This would allow patients to make a post on anything from an announcement to posing a question and receive feedback. It will likely be the preferred means of communication for younger PGT-M patients or those whose geography restricts access to support groups and can create a nationwide movement for the creation of support groups for PGT-M with IVF patients.

IV. a. Future Legal Advocacy

Ideally, as patients and providers alike are more informed on the positive impact of support groups, public policy will fortify further creation of support groups for a plethora of reasons. Support group expansion likely would be derived from word of mouth through social media forums or professional fertility specialist networks. Ideally, clinics will be notified of the benefits and thus inclined to start one. As local traction builds and more clinics instate their groups, a group of collegiate students at a local university investigate outcomes of support groups for subsections of IVF patients. Research would aim to demonstrate a greater need for support groups through the use of support group-patient narratives and a survey for both patients and providers, not solely sub-sections of IVF patients but all maternal demographics. Support groups will enable the safeguarding of maternal wellbeing and provide equitable access to mental health services, significantly as barriers to services drastically increase.

With the university's research publication, attention is brought to clinics that have already established support groups and nonprofits devoted to protecting maternal health, which demonstrate interest. The nonprofits would then award funding to clinics to expand support groups and continue to administer them. Funding can assist in technology that promotes the streaming of services in case specific underserved communities cannot access clinics repeatedly.

As more clinics roll out more specialized and concentrated support groups, advocacy for programs shifts to the political sphere. The patients and providers of the focused support groups spearhead the call for action, not just for specialized IVF groups but also for all vulnerable populations who require affordable and accessible mental health treatment, which support groups essentially administer.

Since COVID-19, the NIH reported that half of surveyed Americans had experienced anxiety and depression-like symptoms, with certain groups being more affected, including mothers and pregnant people, certain ethnic and racial groups, etc. (NIH, 2023). As mental health issues skyrocketed with the pandemic, available mental health services stagnated and even dwindled. It, unfortunately, became apparent that certain socioeconomic classes or plain lucky individuals could receive potential treatment, leaving a significant gap in access for those who could not afford it or could not identify proper resources.

Utilizing the plight of PGT-M patients' experience of receiving support, the IVF with PGT-M support group advocates would lobby politicians with a stark interest in protecting the well-being of civilians and healthcare. In order to promote equitable access for the growing number of individuals who desperately need mental health intervention, the politicians would seek governmental support and funding of support groups. Through the utilization of available research that demonstrates the success of support groups, input from a diverse set of medical professionals, and the sharing of support group members' anecdotes, the politicians and advocates would showcase how, until more mental health resources become readily available, support groups may buffer both financially and emotionally, extreme mental health dilemmas. Furthermore, they might identify when someone is in desperate need of emergency intervention and, upon that, may be able to provide the resources to that individual to prevent further distress. Political investment into the establishment of more nuanced support groups will assist in cushioning the repercussions of mental health professional shortage until it is properly resolved.

V. Conclusion

PGT-M and IVF allow families to bring life into the world without passing on potentially life-interfering genetic disorders. The ability to test and select an embryo marks a significant progression for reproductive technologies. Still, as procedures advance, so should the carrier's level of support and care, especially as discourse around obstetrics and eugenics evolve. Along with this, while Heaney and Israel's support types can be accumulated from different sources in the patient's circle, it can be more effectively sought by groups that share common experiences. Implementation of PGT-M-specific support groups is necessary to alleviate and cushion the emotional impact of the process.

It should be noted that support groups will not eliminate all hardships endured by the patients. There are many elements threaded in the PGT-M process that negatively impact patient’s PGT-M progress which require further investigation of IVF with PGT-M patient experience. Through an increase of research and interest, ideally more patient-centered resolutions will take hold.

Moving forward, it is crucial that spaces are developed that allow for transparency on differing maternal experiences and promote IVF and genetic testing to eliminate hereditary illness and provide the best level of care for the patient. It is hoped that cultivating support groups for PGT-M will inspire further development of support groups for patient networks who require experience-based support by equitable means.

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