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Conceptualizing Couples' Decision Making in PGD: Emerging Cognitive, Emotional, and Moral Dimensions

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Abstract

Objective—To illuminate and synthesize what is known about the underlying decision making processes surrounding couples' preimplantation genetic diagnosis (PGD) use or disuse and to formulate an initial conceptual framework that can guide future research and practice.

Methods—This systematic review targeted empirical studies published in English from 1990 to 2008 that examined the decision making process of couples or individual partners that had used, were eligible for, or had contemplated PGD. Sixteen studies met the eligibility requirements. To provide a more comprehensive review, empirical studies that examined healthcare professionals' perceptions of couples' decision making surrounding PGD use and key publications from a variety of disciplines supplemented the analysis.

Results—The conceptual framework formulated from the review demonstrates that couples' PGD decision making is composed of three iterative and dynamic dimensions: cognitive appraisals, emotional responses, and moral judgments.

Conclusion—Couples think critically about uncertain and probabilistic information, grapple with conflicting emotions and incorporate moral perspectives into their decision making about whether or not to use PGD.

Practice Implications—The quality of care and decisional support for couples who are contemplating PGD use can be improved by incorporating focused questions and discussion from each of the dimensions into counseling sessions.

1. Introduction

In 1990, groundbreaking reports surfaced from London [1] and Chicago [2] that outlined the procedures for diagnosing genetic disorders in human embryos or oocytes *in vitro*. The London scientists also reported healthy pregnancies following their procedures, now known as Preimplantation Genetic Diagnosis or PGD, making this novel approach a valid option. In the next twelve years, about 1000 babies were born using PGD [3–4]. In recent years, the use of PGD sharply increased; over 600 babies were born worldwide in a one-year period alone [5].

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As the knowledge and techniques of molecular genetics continue to evolve, so does the use and applications for PGD. In 1992, PGD was introduced as a way to identify single gene disorders [6]. PGD is now used to test embryos for more than 50 genetic conditions [5]. This number may be much higher as several predominant private laboratories have reported testing embryos for more than 150 genetic conditions on their Internet web sites [7–8]. Other applications for PGD include the selection of embryos according to their human leukocyte antigen (HLA) type in order to treat an ill sibling [9] and identifying sex chromosomes for non-medical sex selection. The number of requests for PGD for different genetic applications continues to grow, driving a need for highly technical skills and reliable procedures for any given genetic disorder [10–13]. Recently, there has been a trend towards using PGD for adult-onset inherited predispositions [14–15] including Alzheimer disease [16] and familial adenomatous polyposis coli [17], foreshadowing the potential expansion of PGD to other applications.

As the applications for PGD expanded, it developed an application for screening purposes, currently referred to as preimplantation genetic *screening*. In this instance, embryos are assessed for chromosome aneuploidies (i.e. too many or too few chromosomes) to enhance the chance of establishing an ongoing pregnancy. While initially thought to improve the pregnancy success rate, current research has challenged the benefit of preimplantation genetic screening [18–19], prompting some professional organizations to recommend against preimplantation genetic screening for women with advanced maternal age, previous implantation failure, or recurrent pregnancy loss [20].

Since the inception of PGD, there has been a call for research that addresses the impact of this new and rapidly developing technology that alters the basic human elements of reproduction and genetics. Scholars from a variety of disciplines suggest that it is essential to understand how the merging of genetic and reproductive advances affect the lives of individuals, couples, families and society [21–23]. Moreover, specific efforts aimed at understanding the decision making process facing couples contemplating this burgeoning technology will be beneficial to both scientists and clinicians as they attempt to understand and provide accurate and relevant information as well as decisional support [24–27].

Understanding couples' decision making surrounding the use of PGD is supported by professional practice groups that have developed guidelines recommending adequate patient counseling and informed consent for PGD [20,28–29]. Decision making surrounding PGD also provides an important real world opportunity for understanding naturalistic decision making among couples [30] since PGD is inherently dependent upon both male (sperm) and female (oocyte) gamete contributions. Furthermore, leaders in medical decision making have strongly encouraged investigators to undertake the long, tedious, and often difficult task of understanding decision making as it occurs in natural settings to acquire conceptual knowledge [30]. Therefore, the purpose of this review of published scientific and bioethical literature is to illuminate and synthesize what is known about the underlying decision making processes surrounding couples' PGD use or disuse and to formulate a conceptual framework derived from the literature that identifies the essential dimensions of couples' decision making.

2. Methods

This systematic review targeted empirical studies published in English from 1990 to 2008 that examined aspects of the decision making process of couples or individual partners that had used, were eligible for, or had contemplated PGD. Several search strategies were used to identify relevant literature including computerized searches of electronic databases (i.e. ERIC, ISI Web of Knowledge, PsycINFO, PubMed), ancestry approaches, and citation

index searching [31]. Sixteen published research reports were identified for inclusion (see Table 1).

Due to the limited number of empirical studies identified that met the eligibility requirements, the search was expanded to include (1) empirical studies published in English that examined healthcare professionals' perceptions of couples who were contemplating or undergoing PGD, and (2) key publications that addressed aspects of the PGD decision making process. The latter consisted of commentaries, professional guidelines, policy reports and other reviews published in English and represent a collective voice of distinguished and emerging scholars from anthropology, bioethics, law, medicine, social sciences, and women's studies. The three-tiered inclusion approach, with the sixteen empirical studies guiding the analysis, allowed the focus to remain on couples' decision making surrounding PGD use yet provided more depth and completeness to the review and emerging framework. The exclusion of non-English publications was necessary as neither author is multilingual and budgetary constraints prevented the use of a professional translator.

After the empirical studies and key publications were identified, an interpretive synthesis [48] guided the analysis to meet the aims of the project. The sixteen empirical studies were read in their entirety and then re-read with a distinct focus of identifying aspects or indicators of the couples' underlying decision making processes. Although the sixteen empirical studies did not examine decision making processes explicitly, aspects or indicators that provided evidence of the underlying decision making processes of couples or individual partners in the published text were identified as raw data and coded. This substantive coding approach has been articulated by Glaser [49] and Glaser and Strauss [50]. The particular code was a term that best described the raw data. During the initial coding and throughout the analysis, we were astute to the evolution and trajectory of PGD, whereas PGD subjects in the early studies were often combined with subjects contemplating or undergoing preimplantation genetic screening. When possible, we would tease out the two subject groups and did not include coded data in the analysis that could be linked to the preimplantation genetic screening group.

As the process of coding the sixteen empirical studies continued, we began to identify codes that could be grouped into sub-categories that reflected the meaning in the data. Concurrently, we read and re-read all of the healthcare professional studies and key publications. It should be noted that data derived from the sixteen empirical studies identified in Table 1 led the analysis so that all emerging sub-categories were directly related to one or more codes from these empirical studies. The healthcare professional studies and key publications provided context, understanding, and hence more depth and complexity to what could otherwise be synthesized from the sixteen empirical studies themselves. The identified sub-categories were integrated and emerged into the three dimensions of couples' decision making thereby grounding these data to the conceptual framework.

As described, this process may appear linear. Yet it was often iterative as is typical for an interpretative synthesis that seeks to combine the findings from several studies into a whole that provides a new conceptual development [48]. Furthermore, in developing the conceptual framework, there were instances of creative and inventive processes that occurred while immersed with these data and identifying conceptual relationships. We acknowledge these cognitive processes that were first articulated in detail by philosopher Carl Hempel [51], who sought to understand conceptual and theoretical development among investigators.

3. Results

Three critical dimensions of PGD decision making emerged from our review: (1) cognitive appraisals, (2) emotional responses, and (3) moral judgments. Figure 1 depicts this conceptual framework. In this article, each dimension is described separately; however, we caution that the dimensions are not mutually exclusive and fixed but rather are iterative and dynamic. We also acknowledge there may exist other factors involved in decision making beyond the scope of this review, such as couples' interpersonal communication with providers (e.g. framing effects) and between themselves [52–53]. A discussion of these factors is beyond the scope of this initial paper that aims to describe the underlying decision making processes of couples who were eligible for PGD, in the process of contemplating PGD, or had used PGD.

3.1. Cognitive appraisals

The PGD decision making process is cognitively demanding and complex. Couples are often presented with a vast amount of information about success rates, procedures, and short- and long-term health risks. Additionally, couples must appraise financial costs and the amount of time necessary to complete the PGD procedure. Adding to the complexity of the decision, PGD requires in vitro fertilization (IVF) to allow access to developing embryos. Furthermore, intracytoplasmic sperm injection is often performed in addition to IVF to provide a clear sample of the nuclear material and optimize the genetic analysis [54].

3.1.1. Success rates—Currently, the overall success rates for IVF when PGD is used fall below the general live birth rates for IVF alone (see Box 1). For example, the overall IVF success rates in the United States for fresh non-donor cycles that result in pregnancy is about 35% and the rate for a live birth is about 29% [56]. In contrast, the pregnancy rate for IVF with PGD is lower (19%), according to the ESHRE PGD consortium [5] although trending upward. This consortium consists of 39 centers that include but are not limited to centers in Europe, Argentina, Australia, Brazil, Israel, Korea, Taiwan and the United States that complete IVF with PGD and therefore provides a worldwide picture of IVF with PGD success rates [5]. If data are available, couples may also appraise IVF with PGD success rates from specific centers, some of which have reported higher birth rates than the current worldwide consortium data [15,57].

Box 1

Success Rates in Assisted Reproductive Technology

Assisted Reproductive Technology success rates and hence PGD success rates are reported in a variety of descriptive ways (e.g. oocyte retrieval clinical pregnancy rate, oocyte retrieval live birth rate, embryo transfer clinical pregnancy rate, embryo transfer live birth rate). There is a growing call for standardization to enhance understanding in the field. Additionally, success itself can be interpreted in various ways. For many investigators and clinicians, success is often understood as a noted positive heart rate of a developing fetus where as others consider only the birth of a *singleton* healthy child a success. For further discussion, see Soini [25] and Min [55].

Success rates can also vary depending on the specific application of PGD. Higher success rates are observed when PGD is used to identify chromosomal abnormalities (23% implantation rate) compared to non-medical sex selection (19% implantation rate) [5]. Patient history is also a factor when appraising PGD success rates. Couples who had previously undergone PGD or who were at high risk for transmitting a genetic disorder have reported that the low success rate of PGD was a main deterrent for its use [32,41].

3.1.2. Procedural risks—Couples who undergo PGD are faced with the potential for embryo misdiagnosis or undiagnosis resulting from the PGD analysis procedure. In the case of misdiagnosis, an affected embryo believed to be normal is transferred to the uterus. Alternatively, a normal embryo believed to be affected is discarded. In the case of undiagnosis, there is an inability to determine whether or not the embryo is normal or affected. Although the potential for misdiagnosis is relatively low overall, the risk of misdiagnosis for single gene disorders is estimated at about 2% for recessive disorders and about 11% for dominant disorders [58]. Work aimed at refining the precision of the genetic analysis is ongoing [12,59].

The ability of couples to evaluate procedural and probabilistic risk information can be difficult yet little is known about how couples process the information and assess risk in this context. Even when providers assist patients in understanding information and risk, misinterpretation and selective listening can occur. In one empirical study, a woman recounted her PGD experience and openly acknowledged that she received counseling about undiagnosed risks but stated that the information, “didn’t hit home” [44].

3.1.3. Human risks and safety—Since PGD is used in conjunction with IVF, informed couples need to cognitively assess and appraise the risks of IVF as well. The IVF procedure can lead to multiple gestation and the associated risk of preterm birth. Prospective PGD users should consider these risks, as multiple gestation can put the family at financial risk and prematurity can adversely affect the health of the pregnant woman and developing child [60]. Indeed, Snowdon and Green [35] found that a majority of men (79%), who are carriers of recessive disorders, indicated that risk to their partner’s health was an important disadvantage to using PGD. Women in the same study, however, viewed health risks to themselves or their partner as much less of a deterrent to using PGD. With regard to weighing health risks, it is important to note that not all couples view health risks equally. In a survey of 36 couples who had undergone 76 PGD cycles, 96% of couples voiced a potential advantage of PGD use was the increased possibility of undergoing a multiple pregnancy and having twins [41].

Adding to the concerns of immediate health risks of PGD in pregnancy and birth, there is uncertainty about the long-term consequences of PGD. Most notably, studies examining the outcomes of children following PGD are ongoing and conclusive results are not yet available. What is presently known is that babies born following PGD appear to be healthy [15,61] and the prevalence of birth defects does not differ from the reported population prevalence [62]. However, an accurate assessment of the long-term consequences of children conceived using PGD is complicated, as it is used in conjunction with other procedures including IVF and intracytoplasmic sperm injection.

Present knowledge of children conceived via IVF is accumulating worldwide and most reports indicate the incidence of childhood abnormalities is low and children do appear to develop normally [60]. However, some reports have aroused concern and there is a need for prospective longitudinal multicenter studies both nationally and internationally [60,63–64]. What may be of particular concern to potential PGD users is the question of a possible link to IVF use and an increase in genetic birth defects such as Beckwith-Wiedemann [65]. The potential for genetic birth defects may be especially perplexing to couples considering PGD as they are often trying to prevent a genetic disorder in their offspring. The lack of conclusive data about the health of IVF conceived children, albeit among studies using small sample sizes, contributes to the uncertainty and complexity of PGD decision making. What is known is that among couples who have used PGD there are expressed concerns about risks and safety including what the long-term effects on their PGD conceived children might be [44].

3.1.4. Financial costs—For many couples, the financial cost and insurance coverage of PGD can greatly influence their decision on whether or not to use PGD [32,41]. Worldwide, the cost of IVF alone is clearly prohibitive to many people [66–70]. In the United States for example, the cost for IVF ranges from \$10,000 to \$14,000 US dollars per IVF cycle and often more than one cycle is needed to achieve pregnancy [71,72]. PGD adds an additional cost of \$2,500 to \$5,000 US dollars per cycle [71]. Adding evidence to the significance of the financial cost as a consideration in couple's decision making is that in nations with national health insurance where there is IVF coverage, higher rates of couples seeking treatment are reported than couples in the United States where no national system for insurance is in place [73,74]. Additionally, when an individual state within the United States mandates health insurance for IVF, overall rates for utilization typically rise [75,76]. For many couples who must incur the financial cost of both PGD and IVF, this can be an insurmountable barrier that can completely determine whether or not the couple will use PGD [77–78].

3.1.5. Time—Another factor in PGD decision making is couples' appraisal of time. The pressure to establish pregnancy within a short period of time, the age of the individuals in the couple and the time needed to organize, schedule and attend office visits with physicians, education sessions with nurses, counseling sessions with geneticists and psychologists, and the time required to undergoing hormonal stimulation, can influence the couple's decision [79]. Women, in particular, may view the lengthy period of time to undergo and complete PGD as problematic [35]. Furthermore, in some cases, couples may also consider that their agreement to proceed with PGD will affect the timing of when they can pursue adoption [43].

3.2. Emotional responses

Emotion is an important dimension affecting PGD decision making. Although few of the empirical reports examined this dimension, couples or individual partners have reported that their responses to actual or potential sensations of pain, suffering, joy, and happiness have significantly shaped their decision making.

3.2.1. Pain and suffering—According to reports of potential and actual PGD users, the primary reason for undergoing PGD is to avoid or reduce the probability of future pain and suffering by the couple and their offspring [32,35,39,41,43]. Couples who are raising a chronically or terminally ill child have openly described the suffering their children experience and the tremendous emotional stress this places on their family [44]. As one couple reflecting on their use of PGD reported, "...we see it [PGD] as something that can... prevent children dying, basically, that's why we're using PGD" [43]. The desire to alleviate pain and suffering is more pronounced among families who use PGD to have a HLA matched offspring to save a dying child [44]. With the advent of PGD for adult onset genetic disorders such as breast and ovarian cancers, women with the BRCA gene mutations have also expressed a desire for diminishing the emotional trauma among their future offspring who would be free of the mutations via PGD [47].

Other emotions that influence PGD decision making include a desire to avoid or minimize regret, guilt, shame, sadness, and despair. Investigators from two separate studies have indicated that previous experience of pregnancy termination for a genetic disorder is influential in accepting PGD for some couples and, in particular, women [34,36]. Yet, there is no clear consensus among couples at high risk for transmitting a genetic disorder that the decision to use PGD is overwhelmingly influenced by a desire to avoid the emotional trauma related to a pregnancy termination [35,38].

3.2.2. Joy and happiness—Couples considering PGD have expressed expectations of optimizing the joy and happiness of raising a healthy child of their own and experiencing parenthood during the raising of one's own prodigy. Studies supporting the influence of these positive emotional responses include Kalfoglou and colleagues [44] and in particular Snowden and Green [35] who found that 85% of childbearing age couples who were known carriers of a recessive genetic disorder acknowledged that having a genetic link to the child was an important consideration to using PGD. Similarly, studies of couples who use IVF [80] and donor oocytes [81] have demonstrated the extent to which couples may go to establish a genetic connection with their child. Not many investigators have addressed the emotional responses as a dimension of the decision making process; however, the magnitude of the impact that emotions play on decision making in this context may be significant. Research incorporating emotions into the decision making process is in the early stages, not only in PGD but in other decision making contexts [82].

3.3 Moral judgments

While PGD decision making is heavily influenced by cognitive appraisals and emotional responses, several of the sixteen empirical studies and a substantial amount of literature has focused on moral judgments. Although none of the sixteen empirical studies set out to explicitly examine how couples weigh the moral implications in their own decision making, moral judgments were imbued within aspects of the decision making process uncovered among the sixteen studies. These judgments comprise the third underlying dimension of decision making and center on the couple's moral evaluations related to the status of the embryo, the technological imperative, disability and disease prevention, social significance, and the underlying application for PGD.

3.3.1. Status of the embryo—The decision to use PGD is often guided by the couple's judgment and understanding of the moral status of the embryo [77,83–86]. In general, the moral status of the embryo includes the couple's personal assessment of the embryo's genetic uniqueness, its potential for full and healthy development, sentience, brain activity, level of cognitive development, human physical form, capacity for survival outside the uterus, and its ability to establish relationships with other persons [87,88].

Determining an embryo's status and its potential looms large for PGD users since by design, PGD selects embryos for immediate implantation or cryopreservation (i.e. freezing for the future) and typically disposes of other embryos. Although cryopreservation is an option for many couples in whom "spare" or supernumerary embryos are formed, the decision about what to do with supernumerary embryos is viewed as a clear disadvantage of using PGD [35]. This settlement or disposition issue is complicated and novel approaches are evolving [89] for which there is little empirical evidence to support one option over another. One caveat however, as discussed previously, is that PGD analysis may not be accurate; thus couples may consider the possibility that healthy embryos maybe inadvertently destroyed during the PGD procedure.

Despite the labyrinth of complexity of the moral judgments about embryo status, couples worldwide, experts in the field, and members of the general public, who are grappling with moral evaluations about embryo status related to PGD, are likely to agree that PGD is more morally acceptable than the standard clinical option of prenatal diagnosis with subsequent termination of pregnancy [36,40,46,77,90,91]. Some couples formulate an alternative configuration of moral judgment and grant embryos with severe genetic abnormalities a different moral status than healthy embryos [42]. Other couples openly acknowledge that they have chosen not to undergo PGD because it involves the destruction of embryos [44].

How couples determine and ultimately judge the moral status of the embryo and its related consequences has immediate implications for their decision surrounding PGD use.

3.3.2. Technological imperative—Couples contemplating PGD formulate moral judgments over the use of advanced technologies for the timeless, naturally-occurring phenomenon of reproduction and genetic selection. Determining whether or not it is morally acceptable to use available technology to examine genetic material *in vitro* when conceiving a child addresses the technological imperative [see 92]. According to focus groups throughout the United States and couples at high risk of transmitting a genetic disorder, views range from thinking that manipulating embryos through technology “is unnatural or playing God” to believing that there is a moral obligation to improve the human condition through available technology [35,77]. Couples at high risk for transmitting a genetic disorder and who are eligible for PGD have also indicated to their healthcare professionals that choosing *not* to use PGD is guilt-engendering as they fear that their future child might be disadvantaged if PGD technology is available but not used [79].

3.3.3. Disease and disability prevention—A formidable challenge for couples contemplating PGD is to confront their underlying moral judgments about disease and disability prevention [93,94]. Whether or not PGD affects attitudes about disease and disability prevention is widely debated in the literature. Some couples, especially those at high risk for transmitting a genetic disorder, reported that they consider PGD but decline to use it because of the message their decision would imply - that children with a genetic disorder are not valuable or that their affected children are somehow less valuable than “normal” children [44]. Support for this position has been found among others [95] including Freeman [87] who suggested that PGD can cause increased injustice, stigmatization, and discrimination against people with disabilities. There is also concern about the increasing use of PGD for genetically predisposed adult-onset cancers with a lower penetrance such as breast, ovarian, and colon cancers. Krahn [96] contends that this use of PGD could promote further stigmatization and discrimination of people with genetic disorders or their parents and may ultimately “entrench a culture of prevention and perfectionism and promote a culture of intolerance”. Although the concern that PGD may promote stigma, intolerance, and discrimination is found in the literature, opposing views do exist [97–98] and this is also apparent in the increasing numbers of couples who decide to use PGD even with consideration of these moral implications.

3.3.4. Social significance—The importance of the role of PGD in shaping society is widely discussed in the literature and of concern to couples [43–44]. For example, concerns about the eugenic potential of PGD represented the major argument against its development in an international survey of 17 PGD centers [99] and among focus groups representing a broad background of individuals in the United States [77]. However, with steady growth in PGD centers and increasing use worldwide, there appears to be an alternative moral judgment affecting couple’s decision making. Suter [100] referred to the term “neoeugenics” to describe couples who exercise their individual reproductive and genetic rights by using PGD in contrast to a broader social eugenic perspective, where state coercion determines whether or not couples can have offspring with or without certain genetic characteristics.

3.3.5. Application—The specific application of PGD plays a role in couples’ decision making. In a cogent example from research completed in Germany, a survey of couples at high risk for transferring a genetic disorder, couples undergoing IVF, and a representative sample of the German population, 76% of respondents indicated acceptance for PGD when it would be used to detect a genetic disease in which a child would likely die during the first year of age [45]. In contrast, in another similar sample of individuals, only 8% of the

respondents indicated acceptance for PGD when it would be used for non-medical reasons [101]. The application of PGD for non-medical use (such as determining gender) is often a divisive point among patients, clinicians, and professional groups where strong and varied opinions abound on whether or not PGD should be used [95,102–112]. The relationship between PGD application and its acceptance has been reported among high risk couples' from Saudi Arabia [46], members of the general public in the United States [77], and staff working or linked to a center offering PGD in England [111]. The evidence supports a relationship between couples' decision making surrounding PGD and their determination of the appropriateness of their application for using PGD. Determining precisely how this affects couples' decision making and to what extent, is yet to be uncovered.

4. Discussion and conclusions

4.1. Discussion

The ethos of couples' decision making surrounding PGD use or disuse stems from three interrelated and dynamic dimensions: cognitive appraisals, emotional responses, and moral judgments. Couples are challenged to think critically about uncertain and probabilistic information regarding the PGD procedure and health risks, grapple with positive and negative emotions, and incorporate personal and societal moral views into their decision making processes. Ultimately, couples must decide what they believe is in the best interest of their family and their future well-being. The conceptual framework, derived from published literature, supports the growing evidence that PGD decisions are complex, they challenge the couple with an array of probabilistic options with little certainty, they arouse pleasant and unpleasant emotions about what the future may hold and they force couples to grapple with their personal moral positions.

4.2. Theoretical and research implications

The conceptual framework presented here adds to theoretical knowledge in decision making in several areas. In classical decision theory, researchers typically investigate how individuals *should make* decisions to maximize positive outcomes [113–114]. The prescriptive process found in classical decision theory posits that the decision maker should gather information, evaluate alternatives, and then determine which option from among the choices maximizes the greatest expected value [113–115]. Classical decision theory is often used to examine rational thinking and our findings demonstrate a relationship to the cognitive aspects of classical theory. Clearly, decisions about PGD involve cognitive appraisals where information processing, perceptions of risk, and evaluating options (i.e. using or foregoing PGD) were reported. We were able to identify what information PGD decision makers may think about but a large gap remains in understanding how the information is actually processed cognitively and how values are applied to each option.

Our findings also support behavioral decision theory where researchers work towards describing and understanding how decisions *are made* by individuals in an imperfect world [116–118]. In seminal behavioral decision theory research completed by Simon [119–120], the human capacity for a completely rational decision making process was challenged. Our findings pertaining to emotional responses and moral judgments support this aspect of behavioral decision theory. What we were unable to report, however, were specific elements within behavioral decision theory that couples use when contemplating PGD use. For example, Simon demonstrated limits to an individual's decision making processes and coined this process "bounded rationality" [119–121].

Other theoretical work in behavioral decision theory has demonstrated the use of heuristics or cognitive shortcuts that allow decision makers to control the task of information

processing [122–124]. We provided little knowledge about what are the processing limitations, if any, among couples considering PGD. Furthermore, our review did not shed light upon how particular heuristics might be used by couples. To answer these questions, in-depth research with the couples themselves is needed and we are currently working with couples to understand underlying aspects of decision making processes.

New developments in theoretical constructs in decision theory have espoused the importance of emotional responses in decision making [125–127]. Findings in neuroscience research has recently suggested that emotions are not only the basis for thinking, but that emotions play an integral part in good judgment and rational thought [82,128] thereby providing “hard” evidence for theoretical conceptualizations that link emotions to decision making. The conceptual framework delineated here adds to this existing literature yet extends present knowledge in the field by incorporating a third significant dimension – moral judgments – into the decision making process.

Although this review provides an initial synthesis of empirical studies and key documents, the conceptual framework of couples’ decision making processes is limited by what has been empirically studied and subsequently published in English. Yet the framework makes a significant contribution by conceptualizing three distinct dimensions that influence couples’ decision making surrounding PGD use. Providing a conceptual framework is important since there was minimal explicit evidence about theory or conceptualizations found among the sixteen empirical studies that guided this review. Focused research is needed to examine the precision of the conceptual framework described here and to further identify and refine the dimensions. Moreover, what remains unknown and yet ripe for research is the impact and relationships between the dimensions of the couples’ decision making processes in PGD. For example, in what contexts, if any, does the dimension of cognitive appraisals have precedence over the emotional responses dimension or the moral judgments dimension? Additionally, because the review included a broad range of genetic disorders and was limited to publications in English, it is possible that there are other dimensions and sub-categories that are specific to other cultures and contexts that have not been described. Since PGD use is expanding, future research that addresses a variety of cultural and contextual areas will provide much needed insight.

Couples confronting PGD are facing evolving reproductive and genetic testing and technology that stretches across cognitive, emotional and moral lines. Yet little is known about how this decision is made interpersonally. Research that provides understanding about how couples resolve divergent aspects of the cognitive, emotional and moral dimensions would be helpful in not only understanding the PGD decision making process but understanding decision making in other emerging areas where familial genetic linkages come into play.

4.3. Practice implications

The conceptual framework can assist healthcare professionals in the clinical setting by facilitating couples’ decision making surrounding PGD use. Incorporating focused questions from each of the dimensions into counseling sessions would be beneficial. Furthermore, because the framework is built upon understanding both clinical options for PGD use – couples who accept PGD and those who decline PGD – the framework can be used as a visual tool to prompt clinicians about important dimensions of couple’s decision making when they are contemplating PGD use. This may facilitate meaningful discussion between clinicians and couples as they move through the decision making process.

Understanding couples’ decision making surrounding PGD use from a conceptual perspective is an important step in improving the quality of care and guiding future research.

Our initial conceptualization, derived from current literature, can guide clinical discussion and direct the science of decision making in PGD - a highly controversial, complex, and rapidly evolving technology for which there is currently no clear or optimal imperative.

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Figure 1.
Framework for the Emerging Dimensions of Couples' Decision Making PGD.

Table 1**Empirical Studies Examining PGD from the Perspective of Couples or Individual Partners at High Genetic Risk**

Publication	Country	Sample	Aim
Pergament, 1991 [32]	United States	58 American women at high genetic risk	Describe impressions and attitudes towards PGD by potential women users at high genetic risk for transmitting a genetic disorder.
Miedzybrodzka <i>et al.</i> , 1993 [33]	United Kingdom	Surveyed: (A) 46 women who had genetic counseling and were at risk for transmitting single gene disorders, (B) 18 women who had undergone CVS for a single gene disorder, (C) 158 women who had undergone CVS for other reasons, (D) 200 women who had recently delivered a normal baby, and (E) 50 women who used IVF unsuccessfully and were awaiting another IVF treatment cycle.	Assess women's attitudes and preferences to PGD and CVS for genetic disorders.
Palomba <i>et al.</i> , 1994 [34]	Italy	180 pregnant Italian women at high risk for β -thalassaemia. The participants were recruited several days before undergoing CVS.	Ascertain the degree of acceptability of PGD in women at high risk for transmitting β -thalassaemia.
Snowdon & Green, 1997 [35]	United Kingdom	245 carriers of recessive disorders.	Describe the attitudes of couples, known to carry a recessive disorder, towards PGD use.
Chamayou <i>et al.</i> , 1998 [36]	Italy & France	Surveyed four different population types: (A) 54 high risk couples for β -thalassaemia presenting for their initial PND, (B) 51 similar couples presenting for their second or further PND without previous experience of therapeutic pregnancy termination, (C) 50 similar couples presenting for their second or further PND with previous experience of therapeutic pregnancy termination for a β -thalassaemia affected fetus, and (D) 74 infertile couples undergoing routine IVF.	Describe the willingness of four different population types to undergo PGD for β -thalassaemia as an alternative to PND and the willingness of infertile couples to undergo PGD for aneuploidies.
Alkuraya & Kilani, 2001 [37]	Saudi Arabia	32 Saudi parents attending an outpatient clinic with one or more children affected by hemoglobinopathies.	Describe the attitudes of high risk Saudi parents toward PND and PGD and to examine the effect of an educational intervention about religious ruling on attitudes.
Henneman <i>et al.</i> , 2001 [38]	The Netherlands	287 adult patients with cystic fibrosis and 288 parents of a child with cystic fibrosis.	Examine attitudes towards reproductive issues and carrier screening and parents' reproductive behaviors and choices regarding adoption, artificial insemination, and PGD.
Hui <i>et al.</i> , 2002 [39]	China	141 Asian women at high risk for transmitting α - or β -thalassaemia to a future child.	Assess whether PGD was an acceptable alternative to PND in Asian couples at high risk of giving birth to a child with α - or β -thalassaemia.
Katz <i>et al.</i> , 2002 [40]	Australia	Three groups of couples consisting of: (A) 41 subjects (20 couples + 1 mother) presenting for PGD of single gene disorders, (B) 48 subjects (24 couples) undertaking PGD for aneuploidy screening, and (C) control group of 32 subjects (16 couples) that were about to begin their first IVF treatment cycle.	Describe social and moral concerns and attitudes of couples, who have experience with genetic disease, chromosomal abnormalities, or infertility, toward PGD use.
Lavery <i>et al.</i> , 2002 [41]	United Kingdom & Spain	36 couples who had undergone PGD from centers in London, England and Barcelona, Spain.	Describe the experiences and attitudes of couples who have undergone PGD and detail their perceived advantages and disadvantages of using PGD and PND.

Publication	Country	Sample	Aim
Fernández <i>et al.</i> , 2004 [42]	Argentina	130 Latin American subjects (83% women and 17% men) comprised of: (A) 58% with infertility problems, (B) 26% presenting with a history of conception, (C) 16% having no children. Of the sample, about 21% had a history of recurrent miscarriages and 17% had undergone a pregnancy termination.	Explore the acceptance of PGD versus PND, the moral status of the embryo, acceptance of novel applications of PGD, and considerations on the disposition of abnormal embryos among Latin Americans.
Roberts & Franklin, 2004 [43]	United Kingdom	21 patients undergoing PGD in two clinics in England. Seven patients had one child with a fatal genetic disorder and one case had two children with a fatal genetic disorder.	Describe parent's experiences of making the decision to undergo PGD and of making reproductive choices based on genetic information.
Kalfoglou <i>et al.</i> , 2005 [44]	United States	13 individuals at high risk for transmitting a single gene disorder to their future children (10 subjects had undergone PGD). Included in the sample were 19 PGD providers (nurses, genetic counselors, physicians, embryologist, and lab directors).	Describe the experiences and attitudes of PGD patients and providers about the use and regulation of PGD.
Krones <i>et al.</i> , 2005 [45]	Germany	Survey composed of: (A) 1017 subjects who were representative of the general population of reproductive age individuals, (B) 879 subjects in five expert professional groups, (C) 324 subjects who are high genetic risk couples, and (D) 108 cases (54 couples) undergoing IVF.	Assess the attitudes on PGD in the general population, expert groups, high genetic risk couples, and couples undergoing IVF in Germany.
Alsulaiman & Hewison, 2006 [46]	Saudi Arabia & United Kingdom	30 couples offered genetic counseling following the birth of a child with a single gene or chromosomal disorder.	Explore the acceptability of PGD in high genetic risk Saudi couples.
Menon <i>et al.</i> , 2007 [47]	United Kingdom	52 BRCA gene mutation carriers attending a Familial Cancer Center in London, England.	Describe the views of BRCA gene mutation carriers on the use of PGD for hereditary breast and ovarian cancers.

Abbreviation Key: BRCA = Breast and Ovarian Cancer Susceptibility Genes

CVS = Chorionic Villus Sampling

IVF = In Vitro Fertilization

PGD = Preimplantation Genetic Diagnosis

PND = Prenatal Diagnosis