

“It’s better to have tried, no matter what” Psychological perspectives on pre-implantation genetic diagnosis (PGD)

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Disputation sker i ämnet psykologi för avläggande av filosofie doktorsexamen. Samhällsvetenskapliga fakultetsstyrelsens har godkänt att avhandlingen framläggs. Avhandlingen kommer att framläggas fredagen den 19 maj, 2017, kl. 10.00 i sal F1, Psykologiska institutionen vid Göteborgs universitet, Haraldsgatan 1.

Fakultetsopponent:
Professor Gunilla Sydsjö
Institutionen för klinisk och experimentell medicin
Obstetrik och gynekologi
Linköpings Universitet

The thesis is based on the following papers:

- I. Järholm, S., Broberg, M. & Thurin-Kjellberg, A. (2014) The choice of Pre-implantation Genetic Diagnosis (PGD), a qualitative study among men and women. *Journal of Reproductive and Infant Psychology*, 32 (1), 57-69.
- II. Järholm, S., Broberg, M. & Thurin-Kjellberg, A. (2016) Risk factors for depression and anxiety among men and women planning for pre-implantation genetic diagnosis. *Journal of Reproductive and Infant Psychology*, 34 (3), 282-292.
- III. Järholm, S., Thurin-Kjellberg, A. & Broberg, M. (2017) Is pre-implantation genetic diagnosis (PGD) more of a strain regarding satisfaction with marital quality for male or female partners? A three year follow-up study. *Journal of Psychosomatic Obstetrics and Gynecology*, in press, 10 April 2017.
- IV. Järholm, S., Thurin-Kjellberg, A. & Broberg, M. (2017) Experiences of pre-implantation genetic diagnosis (PGD) in Sweden: a three year follow-up of men and women. *Journal of Genetic Counseling*, published first online 12 February 2017.



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Abstract

Couples with the risk of transmitting a genetic disease face different diagnostic options when they wish to become parents. Pre-implantation genetic diagnosis (PGD) combines in vitro fertilization (IVF) with biopsy of the embryo. With PGD the couple can start a pregnancy knowing that the child will not be affected by the particular disease. PGD is however a difficult way to become a parent and little is known about the psychological challenges for men and women who undergo PGD. The overall aim of this thesis was to increase the understanding of psychological perspectives and to explore factors related to psychological health and relationship satisfaction, in men and women during the PGD process.

The thesis consists of four studies, all based on data from the same group of men ($n=17$) and women ($n=19$) undergoing PGD. Interview data and self-report measures were collected at the start of PDG treatment and three years later. Study I and IV are based on interviews with men and women when they applied for PGD, and three years later. Study II and III are based on self-report questionnaires from the same group at inclusion and three years later. The second study also includes a contrast group of men ($n=23$) and women ($n=24$) applying for first time IVF.

The aim of *Study I* was to investigate the psychological aspects of men's and women's decisions to undergo PGD, the influence of the healthcare system and ethical considerations. The aim of *Study II* was to investigate the presence of symptoms of depression and anxiety in men and women who made the choice to undergo PGD and to study the relationship between levels of depression and anxiety and six theoretically derived risk factors. In *Study III* the aim was to study the quality of the marital relationship in couples undergoing PGD at the start of PGD treatment and at follow-up three years later. In *Study IV* the aim was to investigate long-term psychological experiences of PGD on men and women.

In *Study I* the men and women were interviewed individually. The interviews followed a semi-structured guide. The material was analysed inductively using thematic analysis and resulted in a model where *Choosing* was seen as a master theme, affecting three underlying sub-themes 1) Choosing in relation to myself, 2) Choosing in relation to the child, 3) Choosing in relation society. On the next level, there were nine underlying categories. Men and women had similar reflections about the decision. In *Study II* a comparison was made between the PGD group and a group of men and women planning for their first IVF. The Hospital Anxiety and Depression Scale (HADS) was used to measure anxiety and depression. The main findings from *Study II* were that women planning for PGD did not differ significantly from women planning for IVF in symptoms of anxiety or depression. Men planning for PGD reported significantly more symptoms of anxiety than men planning for IVF ($p < 0.03$) and had lower SoC ($p < 0.05$). Of the analysed risk factors, reproductive history and SoC gave unique significant contributions and explained 64% of the variance in levels of depression among women in the PGD group. Having an affected child and lower socioeconomic risk gave unique significant contributions and explained 56% of the variance in anxiety among men in the PGD group. In *Study III* the participants answered questionnaires about satisfaction with the quality of the marital relationship (Dyadic Adjustment Scale), anxiety and depression (HADS) and perceived parental stress (Parental Stress Questionnaire) before PGD treatment, and three years later. Women who underwent PGD rated the quality of their marital relationship similarly to that of first time parents and IVF couples, whereas men rated the marital quality somewhat lower than the contrast groups. Satisfaction with marital quality was stable over the three-year period and men were less satisfied than women on both occasions. At both time-points there was a significant correlation between marital satisfaction and perceived parental stress in men (-0.83 and -0.70 , $p < 0.05$). For women, anxiety (-0.52 , $p < 0.05$) and depression (-0.61 , $p < 0.01$) correlated significantly with lower satisfaction with the quality of the relationship at follow-up. *Study IV* focused on men and women's psychological experiences of PGD three years later. Men and women were interviewed individually and data was analysed thematically. *It is better to have tried* was identified as a master theme, with three underlying sub-themes: *Practical experience of PGD*, *Psychological experience of PGD* and *Goals of PGD*. The results showed that men and women were still psychologically affected by their experiences three years later. The men and women in the study expressed the view that their relationship had been affected, both positively and negatively, and some reported that they still had feelings of anxiety and depression.

Both men and women were engaged in the decision-making process leading to PGD and they were still affected three years later. Men and women having the experience of miscarriages and termination before PGD, and/or having a child affected by the genetic disease, might be at increased risk of developing psychological symptoms. Men are equally, or even more, affected by the situation than their female partners, with consequences for their satisfaction with marital quality. Results from the four studies underline that men and women who apply for PGD constitute a heterogeneous group and the need for counselling can arise at different times and in relation to different areas, regardless of the outcome of the PGD.

Keywords: *Pre-implantation Genetic Diagnosis (PGD), Decision-making, Men and Women, Risk Factors, Depression, Anxiety, Marital Relationship, Counselling.*

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