Influence of Preconception Counselling on Perspectives and Psychosocial Wellbeing of Women Conceiving through Oocyte Donation

Visser, Amber

Influence of Preconception Counselling on Perspectives and Psychosocial Wellbeing of Women Conceiving through Oocyte Donation

Amber Larenzia Visser

Master Thesis Health and Medical Psychology
Faculty of Behavioural and Social Sciences – Leiden University, (September, 2022)
External Supervisor: Drs. K. van Bentem, MSc, Department of Obstetrics and Gynecology, LUMC, Leiden.
First Examiners: S.H.M. Peersmann & A.I.M. van Laarhoven, Health, Medical and Neuropsychology Unit; Leiden University
Second Examiner: D.S. Veldhuijzen, Health, Medical and Neuropsychology Unit; Leiden University

Table of Contents

Abstract

For women with a diminished oocyte reserve, for example due to premature ovarian insufficiency, oocyte donation (OD) is their only possibility to conceive. However, OD is related to a higher incidence of pregnancy complications and psychosocial challenges. Preconception counselling (PC) helps women who might opt for OD by explaining the risks of a pregnancy, guiding them in their decision making and focussing on the psychosocial wellbeing. This thesis aims to explore the perspectives on PC of women who conceived through OD. Furthermore, using a quantitative questionnaire design, this thesis aims to investigate the differences on psychosocial constructs (quality of life (QoL), contentment, anxiety, and distress) between women who did and did not receive PC. The perspectives of these women were investigated by conducting qualitative focus-group research. To summarize the perspectives of these women, analyses of the focus groups were done by both deductive and inductive coding. The questionnaire was based upon the validated FertiQoL questionnaire (measures QoL in people with fertility problems) and the GAD-7 questionnaire (measures anxiety and distress). Analyses of the quantitative outcomes were done with an independent samples t-test or a Mann-Whitney U test. The sample included 87 women who did receive PC, and 24 women who did not receive PC before their OD treatment. Analyses of the focus groups indicated the need for more clarity on the process of OD (e.g., finding a donor, possible risks), possibly by the development of a guideline. Also, the participating women would have liked to receive more psychosocial support. Analyses of the questionnaire showed no significant differences between both groups on the psychosocial variables, except for one scale on contentment, $U(N_{PC=no}=21,\ N_{PC=yes}=80) = 599.50$, $z = -2.02$, $p = .043$. Women who did receive PC were more content with the quality and availability of treatment. In conclusion, this research could be implemented into a national guideline, offering a helpful document on OD care for health care providers, and thereby improving OD care for these women and their partners.

Keywords: preconception counselling, oocyte donation pregnancy, quality of life, anxiety/ distress, contentment.

Layman's Abstract

Infertility is a worldwide problem. Some women are not able to get pregnant with their own eggs. In those instances, they are dependent on an egg donation (oocyte donation, OD). The process of OD comes with physical complications, such as high blood pressure. Next to that it can be an emotional rollercoaster, with feelings such as anxiety, sadness, but also hope. To support women in this process, a conversation with a doctor before they are pregnant could be helpful. This is called preconception counselling (PC). In these conversations, the doctor can inform women about the risks and help them making certain choices.

In this thesis the women in the process were asked about their experiences with PC. This was done in a group conversation. Furthermore, it was studied if there were differences between women who had a conversation with a doctor, and who had not had this conversation. The women are

compared on quality of life, anxiety and if they were content with their treatment. This is done with a questionnaire.

In the group conversations with women, it became clear that the care in the hospital and fertility clinics could be improved, especially the conversation with a doctor before pregnancy. Women highlighted that they would have liked to receive more support.

No differences in QoL and anxiety were found between the women who had a conversation with a doctor and the women who had not had this conversation. However, a difference was found on contentment. Women who had the conversation with a doctor where more content about the received health care.

This research could be used for the development of a national guideline, offering a helpful document on OD care for doctors, thereby improving OD care for women and their partners.

Introduction

Infertility and subfertility are worldwide problems that occur to millions of women every year. Infertility is defined as "impairment of a person's capacity to reproduce" (Vander Borght & Wyns, 2018, p. 2). Subfertility is defined as "any form or grade of reduced fertility in couples unsuccessfully trying to conceive" (Gnoth et al., 2005, p. 1144). According to Fertility Europe (2021), more than 25 million men and women in Europe experienced fertility issues in 2021, resulting in that one out of six couples struggles with reduced fertility or infertility. However, in the last decades new technologies make it possible for couples with reduced fertility to conceive. With assistant reproductive techniques (ART), such as *in vitro* fertilization (IVF), pregnancy can still be achieved (Carter et al., 2011). IVF is a procedure in which oocytes are retrieved after hormonal stimulation and are fertilized with sperm in a laboratory, after which the embryo is transferred into the uterus (NVOG, 2006). Due to rising infertility rates, in 2018 approximately one million ART cycles were reported by The European Society of Human Reproduction and Embryology (ESHRE) (2022), which is a rise of 7.1% in comparison to 2017.

For women with a diminished ovarian reserve, for example because of premature ovarian insufficiency (POI), the chance to achieve pregnancy in a natural way or with ART treatments using autologous oocytes is just five to ten percent (Fenton, 2015). Therefore, most of them are dependent on oocyte donation (OD) to achieve pregnancy. The first successful OD pregnancy was reported in 1984 (Lutjen et al., 1984). To achieve an OD pregnancy, the donor receives the IVF treatment to obtain oocytes, instead of the recipient (van Bentem et al., 2019). For the recipient it is necessary to prepare the uterus to receive the created embryo (Mackens et al., 2017).

Where OD was originally applied to women with POI, it is nowadays also commonly used in numerous other instances, such as age-related infertility (menopause), failure of IVF treatment, and to avoid the inheritance of genetic disorders (Klein & Sauer, 2002). The development of OD brought new opportunities for infertile women, but also came with new challenges (Melnick & Rosenwaks, 2018). Firstly, the increasing demand for OD is exceeding the supply. For women in the Netherlands, commercial and anonymous OD is forbidden (Rijksoverheid, 2021). Therefore, Dutch couples are dependent on a donor oocyte bank with poor supply, altruistic donation from for example their inner circle, or expensive treatments abroad (Janssens et al., 2006).

Furthermore, OD could present numerous physical, mental, and social challenges. To help women or couples making a considered decision whether or not to opt for oocyte donation, it is important to offer them preconception counselling (PC). PC consists of giving education, support, evidence-based recommendations, and individualized pregnancy care by health care professionals before pregnancy (Williams et al., 2012). The lives of infertile women are affected biologically, psychologically and socially. Therefore, it is important to address these biological, psychological and social issues in PC. According to the biopsychosocial model the biological, psychological and social domains are interconnected. In other words: "a change in one domain, necessarily results in changes in

the other domains" (Boyer & Paharia, 2008, p.352). If in the biological domain, for example, the possible risks are reduced, this will lead to better psychological wellbeing (e.g., less worry about the risks) and better relationships (e.g., less irritation, more positivity and better communication). This model explains physical pain not as a biological process where sensory information is transmitted, but rather as a "dynamic and reciprocal relationship between the social, biological and psychological domains of physical health problems" (Boyer & Paharia, 2008, p. 352; Engel, 1977). Because of the interactive nature of these domains, it is necessary to address all these domains simultaneously in order to provide good health care and improve the wellbeing of these women.

Starting with the biological domain, it is important to discuss the possible risk factors since OD pregnancies are accompanied with a higher incidence of pregnancy complications compared to IVF and naturally conceived (NC) pregnancies. The most occurring complications during OD pregnancies are hypertensive pregnancy disorders, bleeding complications, preterm birth (before 37 weeks of gestation), early preterm birth (before 32 weeks of gestation), children with low (<2500g) or very low (<1500g) birth weight and caesarean section (Berntsen et al., 2021; Keukens et al., 2022; Moreno-Sepulveda & Checa, 2019; van der Hoorn et al., 2010). The risks of preterm birth, a child with low birth weight, pre-eclampsia and caesarean section persisted in OD pregnancies, even after correcting for maternal age (Storgaard et al., 2017). OD pregnancies are unique since the foetal genome could be entirely allogeneic, meaning genetically different, to the recipient as the foetus inherits donor and paternal genes. The allogeneic nature of the foetus could possibly have an influence on the development of complications, such as hypertensive disorders (van Bentem et al., 2020).

According to Moreno-Sepulveda & Checa (2019), the increased risk of complications of OD pregnancies is one of the most important subjects during PC. The reason for this is that some risks could be prevented or minimized before pregnancy. Yet most women are unaware of these pregnancy risks and preventative measures. In the review of Anderson and colleagues, (2010), research has been done on PC for women with reduced fertility. For these women, lifestyle factors, either environmental (e.g., weight and smoking) or psychological (e.g., stress) should be addressed during PC. Although this is not yet implemented by all health care professionals, providing education on possible lifestyle changes may increase the chances for women to conceive and deliver a healthy baby. The development of a guideline could be an advisable step to support health care professionals in providing PC. More research into the risk reducing effect of PC for women conceiving through OD is needed.

Continuing with the psychological domain, it is important to understand the variety of emotions these women have to go through in order to provide mental support or a referral to a psychologist, since infertility could come with feelings of anxiety, depression, and a decreased quality of life (QoL) (Chachamovich et al., 2010; Faubion et al., 2015). Anxiety is defined as: "Autonomic hyperactivity short of panic, arousal and vigilance, tension, restlessness, worrying, and anticipation of misfortune to self and others" (Akiskal, 1998, p.67). QoL is defined as: "An individual's perception of

their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organisation [WHO], 2012). QoL related to infertility is divided into the following core aspects: "physical, emotional, social, relational and sexual" (Donarelli et al., 2016, p. 2062). Domar et al. (1993), found that depression and anxiety levels in infertile women were similar to patients with other chronic diseases such as cancer and cardiac rehabilitation. More recent research supported these findings; both the scores of people with fertility problems and cancer patients on the Generalised Anxiety Disorder (GAD-7) scale are qualified as mild anxiety (Omani-Samani et al., 2018; Sarkar et al., 2015). These scores were higher than the anxiety scores for the general population on the GAD-7, which were qualified as minimal anxiety (Löwe et al., 2008).

Additionally, factors associated with infertility or subfertility that have an impact on QoL are increased levels of sexual dysfunction and social isolation, the fact that women can feel worthless, or that women can have the feeling that they lost their identity as the urge to become a mother is part of their identity (Deka & Sarma, 2010; Greil et al., 2010; Stanhiser & Steiner, 2018). Therefore, to improve QoL and anxiety levels in these women, it would be valuable to integrate a conversation on mental wellbeing during PC. Research of Aarts et al., (2012), found that patient-centered care is related to QoL and anxiety. The patients who reported more patient-centered care had a better QoL and lower anxiety levels. As such, this study stresses the importance of paying attention to QoL and anxiety levels in health care for infertile people.

Lastly, for the social domain it is valuable to stress the importance of a positive support system in PC, since research found a positive effect of social support on dealing with infertility (Martins et al., 2011). As mentioned above, infertility or subfertility are associated with increased levels of isolation. This can for example refer to women attending fewer social activities with children or pregnant women such as birthday parties or baby showers, as these activities remind them of their infertility. This can also refer to feelings of isolation as infertile women may feel alienated from friends and family (Raque-Bogdan & Hoffman, 2015). Next to that, there are mixed findings on the effect of infertility on the relationship of a couple. Deka & Sarma (2010) reported that marriage can suffer from social pressure and medical choices. Other studies, however, found a positive effect on relationships of infertile couples compared to the fertile control group, because of better communication, more emotional intimacy, and adjustment skills (Drosdzol & Skrzypulec, 2009; Onat & Kizilkaya Beji, 2012). Maintaining and improving the social interactions of these women with their partner, family, friends and acquaintances should be encouraged by health care professionals.

Next to the psychosocial burden of infertility, OD treatment comes with more stressors. Bearing a baby that is genetically unrelated could cause distress. Not only because of losing the ability to pass on a genetic bloodline, but also because of the possibility of unforeseen genetic problems. Distress is defined as: "Discomfort related to signs and symptoms of infertility and pre- or post-treatment anxiety" (p.536). Distress also includes psychological distress: "The general concept of

maladaptive psychological functioning in the face of stressful life events" (Ridner., 2004, p. 539). Next to that, women can feel insecure about their feelings towards the newborn, since there will be no genetic similarity. Other stressors could be the disclosure of genetics when the child is older, the role of the donor in the life of the child and the relationship with the donor. The presence and meaning of these factors are dependent on the donor type, anonymous or not anonymous (Klein & Sauer, 2002). Furthermore, Bauer (2022) found that the perspectives and motives of receiving parents in choosing a donor type (anonymous or not anonymous) are changing continuously before treatment. This pre-treatment decision making is a stressful part of the process, which could come with satisfaction or regret retrospectively (Gartrell et al., 2015). In the literature it is emphasized that pre-treatment guidance in decision making is important. Information on the options and implications of donor anonymity could not only serve as an important factor in the decision-making process, but also help in understanding the concerns of the receiving parents (Bauer, 2022).

However, little research has been done on the effectiveness of PC for women wanting to conceive through OD. Since these pregnancies are associated with a high frequency of complications, it would be of value to investigate if PC is effective for risk-awareness. It is also not yet clear if women who received PC are content with the given information, support, and guidance. Furthermore, little research has been done on the psychosocial consequences of OD. The effectiveness of PC as a protective factor for psychosocial problems due to infertility and the OD treatment has not been researched yet. Again, it would be of great value to investigate if it is helpful for these women to receive psychosocial support during PC and to investigate the possible influence of this support on their QoL and the amount of anxiety and distress they experience. More research into the psychosocial consequences of OD, and the need for and effectiveness of PC is necessary to gain answers, which will be addressed in this research. Potentially, this research can contribute to the development of a national guideline for PC before OD, as well as health care before and during OD pregnancy.

Aims and Hypotheses

Therefore, the overall aim of this study is to obtain more knowledge on the perspectives, opinions and feelings of women on PC as well as care before and during OD. By mapping these perspectives, it is possible to investigate if PC has added value for women obtaining OD. This overall aim is addressed via two sub-aims. Firstly, to explore the perspectives and opinions of women on PC with qualitative research. As the overall aim is explorative, there is no hypothesis (O'Brien et al., 2014). Secondly, to investigate the psychosocial wellbeing of women conceiving through OD. This is done by comparing QoL (a), the contentment of health care (b) and anxiety and distress (c) during the OD process between women who did receive PC and women who did not receive PC. The second sub-aim is answered via quantitative research.

It is hypothesized that QoL is higher for women who did receive PC as compared to women who did not receive PC. Secondly, it is hypothesized that contentment of health care is higher for women who did receive PC as compared to women who did not receive PC. Lastly, it is hypothesized

that anxiety and distress during the OD treatment is lower for women who did receive PC as compared to women who did not receive PC.

Methods

Design

To answer the research questions, a qualitative in-depth focus group research design and a quantitative, cross-sectional, questionnaire research design were used. By using in-dept focus groups a variety of topics regarding OD were discussed. To create an open space in which new topics or ideas could come-up due to the group dynamics, focus groups were used to collect data, instead of personal interviews. Secondly, people tend to be more likely to speak openly on sensitive topics when they are supported by a group of peers, which is the case in focus groups (Guest et al., 2017). Adding quantitative research to the focus group through a questionnaire contributed to exploring the perspectives of women on PC and OD pregnancy. This research complemented the questions that emerged from the focus groups. Additionally, quantitative variables on psychosocial wellbeing were measured with this questionnaire. This study is part of a larger qualitative in-depth focus group research, combined with questionnaires, which aims to identify the different perspectives of women, their partners, and health care professionals on PC, as well as health care before and during OD pregnancy. The medical ethics committee of the Leiden University Medical Center approved the conduct of this study (N22.024). A schematic overview of the qualitative and quantitative methods section of this research is shown in appendix A.

Participants

For both the qualitative and quantitative research, women aged 18 years or older who are either in the preliminary process of OD, pregnant through OD, or have a medical history with OD were included. The preliminary process of OD was everything between the orientating phase until the embryo transfer right before the possible pregnancy. Having a medical history with OD included women that tried to conceive through OD with (ongoing pregnancy) and without success (no pregnancy established or pregnancy loss). Women were excluded if they did not speak or understood the Dutch language. Also, women with the Turner Syndrome or women with a child that has a congenital abnormality were excluded, because they could have received different care before and during the pregnancy. Women who went abroad for OD were not excluded.

Participants for the focus groups were recruited by Freya, the Dutch association for people with fertility problems, via an online advertisement. Drs. M. Vermeulen, health scientist, midwife, and external contacts officer at Freya, checked the eligibility and planned the focus groups with the participants.

Recruitment for the quantitative research was done in three ways. Firstly, participants from the DONOR study (van Bentem, 2019), a clinical prospective cohort study in which biomaterial and data of OD pregnancies were collected to study the development of pregnancy complications in relation to the immunogenetic differences between mother and child, were asked for participation. Secondly, the

participants of the focus groups were approached to fill in the questionnaire for participation. Lastly, a link to the web-based questionnaire was published on a Facebook group of Freya for OD peers. The women who filled in the questionnaire via the Facebook group were not directly invited as this was an open survey link. In the introduction of the questionnaire, it was clearly stated that women could only participate if they were either in the preliminary phase of OD, pregnant through OD, or had a medical history with OD, in order to select only the targeted group.

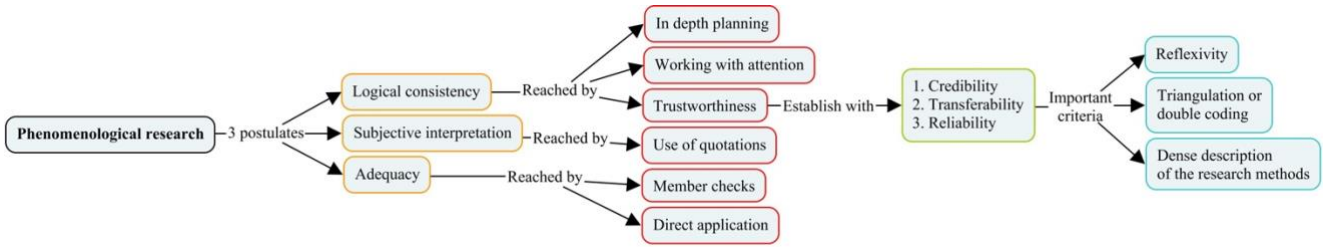
Measures

Qualitative Research

A phenomenological research approach is used as the qualitative method, based on the theory of social phenomenology of Schutz's. This approach is useful for analysing unquantifiable experiences. Social phenomenology is "a descriptive and interpretive theory of social action that explores subjective experience within the taken-for-granted, 'common-sense' world of the daily life of individuals". According to this methodology three postulates must be followed in the qualitative research process: logical consistency, subjective interpretation, and adequacy (Fereday & Muir-Cochrane, 2006, p. 81). Figure 1 shows an overview of the phenomenological research methodology.

Figure 1

Schematic Overview of the Phenomenological Research Methodology.



The first postulate, logical consistency, is reached by in-dept planning, working with attention, and increasing trustworthiness. To establish trustworthiness, the following three factors should be met: credibility, transferability, and reliability. For a researcher to meet the above-mentioned factors, the following criteria are of great importance: reflexivity, triangulation or double coding, and a dense description of the research methods. Reflexivity is "the assessment of the influence of the investigator's own background, perceptions, and interests on the qualitative research process" (Krefting, 1991, p. 218). It was important to be aware of the role of the researchers and for them to examine their own feelings, past experiences, and assumptions during the process as qualitative research is interpretive (O'Brien et al., 2014). One of the researchers had experiences with OD from past research. The other one also had an affinity with OD as she will be dependent on OD herself in the future to conceive. Both researchers analysed the focus groups with no presuppositions, but their characteristics, motives, and history may have influenced their choices in analysing the qualitative data. In this research triangulation or double coding was reached by encoding the data by the two

researchers separately, without any deliberation. The analysis will be more reliable if there is consistency in coding between the two researchers. The program Atlas.ti (https://atlasti.com) was used for the coding and analysis of the qualitative data. A dense description of the research methods is done in the qualitative methods section of this thesis by describing thoroughly which methods were used, and how they were used for analysing the qualitative data.

The second postulate, subjective interpretation, is reached by reporting the results with quotations of the participants of the focus groups to increase validity and credibility, and to secure that the interpretation of the researcher is in line with the personal perspective of the participant.

Lastly the third postulate, adequacy, is reached by member checks during the focus groups (e.g., asking for understanding by M. Vermeulen). Also, adequacy is reached by direct application: "understand, apply, and evaluate the findings", by presenting the research to groups of health care professionals (Fereday & Muir-Cochrane, 2006, p.82). By performing qualitative research with this approach, the experiences of participants on specific phenomena, in this case PC and health care before and during OD, can be described and interpreted in a valid way (Elkatawneh, 2016).

Furthermore, an iterative method was performed during the collection of data to improve and learn from the process. After the first focus group the researchers planned a moment for reflection and feedback, which was implemented in the second focus group.

Data was collected until saturation. Saturation was reached when no new information was mentioned anymore by the participants. This was the case after three focus groups, two with women who received OD treatment and one with partners of women who received OD treatment. Only the two focus groups with the women are discussed in this thesis. A total of 12 women participated in the two focus groups. These 12 women were randomly classified in focus group one or two.

Quantitative Research

To discover the perspectives of women on PC and health care during OD treatment and pregnancy, a web-based questionnaire was designed with the following aspects: open and multiple-choice questions on sociodemographic, OD-specific variables, and psychosocial variables. This questionnaire was created in and managed by the online data capture system Castor (https://www.castoredc.com/).

Sociodemographic and OD-specific variables were explored in the questionnaire with questions about background information, PC and preconception care, counselling and care during pregnancy, and postpartum care. Furthermore, to answer the research questions it was assessed if someone did or did not receive PC with a yes or no question in the second part of the questionnaire ("Did you receive, before the start of the treatment, information/education on the treatment and potential risks of oocyte donation pregnancy (preconception counselling)?"). See Appendix B for this part of the questionnaire.

Outcomes Quality of Life and Contentment. In Appendix C an overview is given of the measurements, number of questions with explanation and scoring for the outcomes QoL, contentment,

and anxiety and distress. To secure the validity of the questionnaire, the outcome QoL was measured with the core questions of the FertiQoL validated questionnaire, which measures QoL in people with fertility problems (Boivin et al., 2011). The 24 original core questions of the FertiQoL can be divided in four subscales: Emotional, Mind/Body, Relational and Social. The Emotional subscale shows the impact of having negative emotions due to fertility problems, such as jealousy, depression, and sadness on QoL. The Mind/Body subscale shows the impact of fertility problems on the mind and body: behaviour (e.g., changes in life goals, not able to do daily activities), physical health (e.g., physical pain and fatigue), and cognition (e.g., mental blurriness and attention). The Relational subscale shows the impact of fertility problems on the quality of relationships or partnerships, specifically on the components commitment, communication, and sexuality. The Social subscale shows the impact of fertility problems on social occasions or interactions (e.g., stigma, expectations, and understanding). These questions were assessed using a five-point Likert-scale with a score range of 0-4, in which a higher score indicates a better QoL, except for the reverse items. Small adjustments were made to allow for better connection to this target group. See Appendix D for the questions on QoL in the questionnaire.

The outcome contentment was measured with the ten treatment questions of the original FertiQoL. These ten treatment questions can be divided in two subscales: Environment and Tolerability. Whereas the Environment subscale shows the impact of the quality and availability of the treatment on QoL, the Tolerability subscale shows the impact of the fertility treatment on mental and physical health, and on daily activities. The higher the scores on these subscales the more content the participants were with the availability, quality, and impact of the fertility treatment. The scoring, measuring scale, and small adjustments were the same as for the core questions of the FertiQoL. Three new questions regarding the contentment of treatment and care were added to this part (indicated with '+' in results) in order to gain more insight into the contentment and quality of care during OD treatment. See Appendix E for the questions on contentment in the questionnaire. The outcomes QoL and contentment consisted of scaled scores, in the range of 0-100.

For the variables of the Emotional, Mind/Body, Relational, Social, and Tolerability subscales and Total Core questions, the original scoring of the FertiQoL was used. Starting with recoding the reverse items, meaning recoding the responses on the items with the reverse response (e.g., transforming a 0 into 4 and vice-versa). To indicate the raw score the sum of the scores per subscale was calculated. To indicate the scaled scores the following formula was used: raw score * (25/k), where k is the number of items in the subscale. For the variables Environment subscale, Total Treatment questions, and Total FertiQoL, the scoring needed to be adjusted due to the three self-created questions on contentment of treatment and care which were added to the treatment questions. These three questions were classified as reverse items in the Environment subscale. After reversing these three questions, the formula was adjusted by adding three to the number of items in the subscale (k). Meaning k = 9 instead of k = 6 in the formula for the Environment subscale, k = 13 instead of k =

10 for the Total Treatment questions and k= 37 instead of k = 34 for the Total FertiQoL. The ten women who were considering to conceive through OD, but have not yet started their treatment, did not receive questions regarding the contentment of treatment; *N* therefore differs in some domains.

Outcomes Anxiety and Distress. The outcomes anxiety and distress were measured with the validated 7-item GAD-7 scale (Spitzer et al., 2006). This scale consists of four-point scale questions with a score range of 0-3, in which a higher score indicates more anxiety. In the original GAD-7, the total raw scores are in the range of 0-21, where a score of 0-4 is associated with minimal anxiety, 5-9 with mild anxiety, 10-15 with moderate anxiety, and 15-21 with severe anxiety (Kroenke et al., 2007). Five new questions regarding anxiety and distress were added to the GAD-7 (indicated with '+' in results) in order to gain more insight into anxiety and distress specific for OD treatment. The sensitivity and specificity of the GAD-7 are 89% and 82% respectively for Generalised Anxiety Disorder (Kroenke et al., 2007). Since there were differences in the phase of treatment amongst the participants; 74 women (62 women who had delivered one or more children after OD pregnancy, and 12 women who had a history with OD treatment which did not lead to a successful pregnancy) received the instruction to recall how they felt during the OD treatment. See Appendix F for the questions on anxiety and distress in the questionnaire.

For the variable Total score GAD-7, the original scoring of the GAD-7 was used. The sum of the scores of the original seven questions was calculated to indicate the total raw score. For the variable Total score GAD-7 + the original scoring was adjusted due to the five self-created questions on anxiety and distress which were added to the GAD-7. The sum of the original seven questions and the five new questions was calculated. As a result, the total score was in the range of 0-36. Here, a score of 0-8 is associated with minimal anxiety, 9-16 with mild anxiety, 17-25 with moderate anxiety, and 26-36 with severe anxiety. This interpretation is in line with the original interpretation of Total scores.

Procedures

Focus Groups

The focus groups were performed online due to Covid-19 restrictions and recorded, for which written and spoken informed consent was obtained from the participants. The first focus group was organized in four sections with one main topic being discussed in each section. The main topics were: PC (e.g., did you receive information on the risks of OD pregnancy?), pregnancy (e.g., did you receive extra care such as additional ultrasounds due to OD?), childbirth (e.g., did you receive extra care such as induced labour due to OD?), and the need for a national guideline (e.g., what should be included in a national guideline on OD health care?). From the feedback process of the first focus group, it turned out that information on pregnancy and childbirth was overlapping. For that reason, in the second focus group, the parts on pregnancy and childbirth were merged. At the end of each topic, participants were able to report the main, or not yet discussed, points on an online jamboard. The focus groups lasted approximately two hours. M. Vermeulen chaired the focus groups without being too involved, and

only asked directing questions to introduce the above-mentioned topics. The participants were asked to tell something about the topics. They complemented each other, from which new questions arose, meaning only few guiding questions were necessary. Two members of the research team were also present. They had no medical treatment relationship with the participants, nor were they involved in the focus groups. Participants were able to withdraw from the study at any point for any reason, without consequences. During the focus groups Dutch was spoken. For this thesis all quotes were translated to English.

Questionnaire

After receiving the invitation from the researchers by e-mail or clicking on the open link via the Facebook group for OD peers, completing the questionnaire lasted approximately twenty minutes. This questionnaire was an online self-constructed questionnaire, which the participants could complete in their spare time. In the instructions the participants were asked to fill in the questionnaire with attention. Furthermore, it was emphasised that the questions were related to OD and not any other previous fertility treatment. Also, a clear description was given on the number of elements and themes. Participants were notified that some questions could evoke emotions.

For the women who filled in the questionnaire via the open link on Facebook no informed consent was necessary since the questionnaire was anonymous, no personal data was asked, and the data was encoded while processing. The participants from the DONOR study were able to indicate on their informed consent form if they were willing to participate in future research. The women who had indicated that they wanted to be approached, were invited to fill in the online questionnaire by e-mail. Likewise, the women who participated in the focus groups could indicate on the informed consent form if they wanted to receive the questionnaire by e-mail as well.

Statistical Analyses

Qualitative Research

Analysis of the focus groups was done to obtain more knowledge on the perspectives and opinions of women on PC and preconception care before and during OD. After transcribing the focus groups by one of the researchers, the data was encoded by two researchers independently in the first phase of the qualitative analysis. A hybrid method of deductive and inductive coding was used to derive specific quotes from the participants on their experiences of the phenomena. Themes were created deductively with topics originated from the focus groups (PC, pregnancy, childbirth, organization of health care, and the need for a national guideline). Deductive coding means that the codes were defined before coding the transcripts. Additionally, inductive coding was applied while analysing the transcripts. Inductive coding means that codes were created at the time of analysis. One researcher was working in a more structural way and created a couple more medical codes. The coding of the second researcher resulted in additional psychological codes. In the second phase, the researchers reached consensus on the codes by discussion and adjusting the codes together. This open coding resulted in 7 code groups and 69 codes. In the third phase, both researchers encoded the text of

the focus groups again, but this time together, to find consensus on all the separate encodings/quotes from the transcripts. This was done by discussion. In the last phase, a codebook and structure were created in which the overlapping codes were merged and the codes with low frequency were deleted. Consensus was again reached by discussion. This thematic analysis was submitted to and viewed by three more researchers to agree on the final codebook. All data were anonymized during the analysis, so only the researchers could know which data belonged to which participant.

Quantitative Research

Descriptive statistical analysis was performed using SPSS Statistics version 28 (IBM SPSS Software). To analyse the differences between the two groups (women who did and did not receive PC), the Mann-Whitney U test or the independent samples t-test were used for continuous data, and the Chi-square test or Fisher's exact test for categorical data. The outcomes of the quantitative variables were numerical, meaning an independent samples t-test or a Mann-Whitney U test was used to analyse the hypotheses. The second sub-hypothesis was rejected if there was no statistically significant difference in QoL, contentment, and anxiety/distress between women who did receive and women who did not receive PC. Since earlier research indicated that social support could have a positive effect on dealing with infertility, the post-hoc decision was made to compare QoL, and anxiety and distress, between the women who had a low score on social QoL (< 74) and the women who had a high score on social QoL (≥ 74). A p-value < .05 was considered statistically significant.

Results

Qualitative Research

The qualitative research was mainly performed to answer the first sub-aim of the research: to obtain more knowledge on the perspectives and opinions of women on PC and care before and during OD pregnancy. Encoding the transcripts resulted in a codebook consisting of 57 codes divided into four code groups: PC, OD treatment, pregnancy and (post-)delivery. These four code groups originated from the focus groups. Four themes were recurring within these code groups: health care, counselling, emotions, and improvement. This thesis only elaborates on the results of the first code group (PC), as PC is the main topic of this thesis. An overview of the final code book, including code groups, themes, and codes that resulted from the focus group analysis is shown in Appendix G.

An overview and summary is given of the qualitative data of code group 1 'Preconception Counselling', supported by quotes from focus group one (FG1) and focus group two (FG2). Due to the number of quotations and relevance of the codes related to this, several codes from code group 1 'Preconception Counselling' were not elaborated on. The relevant and highlighted codes are marked in bold and italics in Appendix G. The codes are highlighted in the following order: starting with the codes in the blue theme (Counselling), followed by the codes in the green theme (Emotions), and ending with the codes in the orange theme (Improvement). The yellow theme (Health Care) was not discussed, since there were no yellow codes in code group 1 'Preconception Counselling'.

Blue Theme: Codes on Counselling

By Whom/Where and Content. The code 'By Whom/Where' entails information on by whom and where these women received or found their information before the OD treatment. The code 'Content' entails information on the content of the received PC, for example on the possible risks of OD pregnancy or explanation of the OD process. These codes were taken together because they were often mentioned in one quotation. Women mentioned that they received information from coaches, social workers, and doctors. They also mentioned that they found information in Facebook groups for peers, on the internet, or in the Freya flyer. Most women were informed on possible complications. Some were told the very specific complications, such as hypertensive disorder or miscarriage. Others were only told that it would be a high-risk pregnancy. A minority did not receive any information on possible complications. Other subjects discussed were implications for the baby, disclosure and expectations of the donor and the receiving parents.

Self-search for information/taking initiative. This code entails information on the need for women to take initiative in information seeking and in asking questions. All the women indicated that they did a lot of self-search for information, mostly due to the lack of information received from the health care professionals. Next to that, health care professionals are legally not allowed to support OD that is received abroad, which is why women were dependent on self-study for information in those instances. Furthermore, women indicated that they needed to take initiative themselves to receive answers to outstanding questions on different subjects (e.g., disclosure, donor contact), find peers, and seek mental help*:*

> *"I had to show initiative myself to get in touch with peers." (FG2), "I personally think that Freya's folder on oocyte donation is very good. I also sent it to our friend who was our donor, it contains everything. But at the same time, you really must look for it yourself. If not, you won't find it and miss that information." (FG1), "You are involved in medical stuff, but mentally it did a lot with me and I just got very little guidance in that. In any case, to get there, I had to do a lot by myself." (FG2), "I did miss a proper explanation by the doctor about the different options for oocyte donation. Overall, she assisted me very well to ultimately be able to decide. But she could not tell me anything about the different options in the countries around us: in which countries around us it is possible to receive OD treatment, what kind of treatment these countries have, whether there are anonymous or non-anonymous donors? Those things are really just not spoken about at all. So, there is oocyte donation, but we cannot say anything about it, so you have to find it out for yourself." (FG2)*

Green Theme: Codes on Emotion

Difficult issues/questions around OD. This code entails information on difficult issues or feelings that come along with OD. The women talked about the difficulty of finding a donor, primarily due to the unsupplied donor banks in the Netherlands. They were open about their feelings of failure because they were not able to conceive with their own oocytes. From the conversations, it became

clear that there are different needs when it comes to PC and preconception care. Some quotes regarding these difficulties:

"The stories of the Dutch egg donation banks, the long waiting times, and the four eggs you receive were so depressing to me. I could not handle going through that rollercoaster again." (FG1), It is also important to acknowledge how many facets it entails. There is the medical part, but what I also found very hard is what it did to my mind. The fact that I could not provide the egg myself and the impact that has had on me, my body, my relationship. It has a huge impact." (FG1)

Emotions with OD. This code entails information on the range of emotions that comes with OD. From joy because it gives hope to still be able to become a mother, to grief because of the still unfulfilled wish to become a mother and also because of the inability to become pregnant with one's own eggs. One example of a positive emotion with OD:

> *"I think I had a slightly reversed reaction than most here, because of course we were already in the medical world for a long time, I mean everyone here in the focus group has been in the medical world for a long time, and therefore we already completely said goodbye to the chance that we would ever have a child at all. So, when you hear about such a thing as an egg donation, we both thought: okay really cool that this is even possible." (FG1)*

Most of the women, however, described the whole process of infertility and OD treatment as a heavy burden:

> *"It was a kind of assembly-line process or something like that, while we came out of a very emotional rollercoaster trajectory. I did miss someone who just occasionally said: 'Jeez, pff, it is a lot.' In that sense it felt like it didn't matter to the doctors whether I accidentally became pregnant for the 15th time or that we were already trying for so long, I missed that so to speak." (FG1), "You're just emotionally shaky. At least, I was." (FG1)*

One of the women also mentioned the feeling of bonding, in the sense that these may be different when the baby does not have your genes. It could be important to already discuss these feelings during PC in order to normalize these feelings or to offer mental support:

> *"At one point they were talking to us about the possibility that it could be an emergency caesarean section. And I had already read in advance that it would be possible to need a caesarean section because so and so [read: because of complications], but at that moment I thought: okay, she will be born, and they immediately will take her away from us and I don't want that. Because indeed what you said Case 5, you already have a feeling that it would be scary if I would recognize her as my child and then she is also taken away from me. So, I really think that was kind of a horror scenario." (FG1)*

Sensitivity. This topic entails information on the sensitivity of the health care professionals. Most of the women find it very important that health care professionals know that it is an OD treatment process, so that they can be sensitive about this. Most women mentioned the lack of sensitivity and knowledge:

"I think it is also important for the healthcare professional to see the patient sitting in front of you during the entire fertility process. For whatever reason she is sitting there. Everyone just likes to, well, be who they are and not be the next in line or number 100 of the day." (FG1), "The word mother could be very heavy loaded. It is important to keep that in mind as a health care professional." (FG2)

Orange Theme: Codes on Improvement

Positive opinions. The codes positive and negative opinions entail information on the opinions of the women on the received PC and the preconception care. The opinions on PC and care were divergent. Some of them received good care, with mental support and guidance:

"Well, it was personal. They knew who we were, and they really thought along. There was room for emotion and we always had extra guidance. […] To occasionally spit and say what is bothering you, and also talk about the struggle you have in considering egg donation. What does this decision mean for us? Next to the fact that you yourself are actually infertile and the impact this has. They guided me very well in this."(FG1)

Negative Opinions. Others felt not heard or supported in their decisions on OD or received less PC or preconception care:

"I also found it quite disappointing that they were not willing to advise us at all at the hospital. And I had the feeling, and they made it quite clear, that they were judgmental about receiving egg donation abroad. […] I thought they were a bit judgmental. I was also offered to talk to their social worker about this. As she was not a real psychologist, I also thought she had her own opinion about it. Because we initially wanted to go to Italy for an egg donation. I am Italian so for me it was easy to combine. And in Italy, you could only do an anonymous egg donation and I felt that she didn't think that was a good choice, the social worker that is."(FG2)

Some of the women would have liked more mental support:

"It was actually that they said to me: hey nothing found, there are no eggs, so start thinking about egg donation and if you are ready, you can come back. That's how that conversation went. I was like, okay I'm still processing the information that no eggs have been found and I'm sad about that and you're going to tell me right now: just think about egg donation. They did not give me any information, but I could come back if I had a donor. What is happening and how does the future look like?"(FG1), "Well, in my ideal world, we would have had some sort of after-talk at the hospital. Something like: hey we discussed this with you, how did that news hit you, what do you think about it, have you already thought about it and where can we help you if necessary? And right now the news has been delivered and after that we had to figure it out ourselves. So, there was no follow-up at all."(FG1)

Improvement. The code improvement entails information on possible points of improvement of PC and preconception care. One frequently mentioned point of improvement was more clarity.

Since there was a lack of knowledge by health care professionals and no national guideline, information on certain topics remained vague and no clear answer could be found (e.g., is there a higher risk for premature birth).

> *"I have only noticed, especially after the pregnancy, that so many things are said, especially in those Facebook groups. And nobody knows exactly what it really is or why certain things are said to one person and not to another. For example, premature birth, […] well I had never heard that one come along." (FG1), "I also missed some pieces of information in advance. At a certain point I started to ask: okay if we are going to do this, how are we going to do this, what are the steps, what do I have to think about, what do I end up with? I have so many questions. There could be a little more information on that, just upfront. Even if you haven't quite made the decision yet and you're still in the middle of that process of: am I really going to do this? Do we dare to do this and how?" (FG2*

Improvement for Preconception Counselling

Based on the information retrieved from the focus groups, some recommendations on how to improve PC and preconception care could be given. One important recurring subject was the absence of a national guideline for PC. The absence of a guideline causes differences in preconception care between both hospitals and health care professionals. More clarity and scientific-based research on the possible complications, (preventative) medication, psychosocial wellbeing, and disclosure would provide more information for health care professionals. This would lead to better health care and less stress for those women that receive PC. Furthermore, it would be helpful for health care professionals if there were guidelines from which they could learn.

The women in the focus groups confirmed the heavy burden of infertility. Next to that, most of the women already had a long medical history of fertility treatments before considering OD. To guide and support these women in the OD process, good preconception care is of great importance. Unfortunately, some women indicated that although OD was mentioned as a possible option to conceive, they did not receive a clear explanation of the OD process. Some women also mentioned that they had the feeling that there was a general lack of knowledge. On the other hand, others mentioned that they did not have this feeling, as they received PC from a specialized health care professional. To improve OD counseling and health care, health care professionals that may be involved in the OD process, such as general practitioners, midwives, fertility, and obstetric physicians, should be better educated. This entails ensuring more knowledge on OD, not only medically but also practically, including knowledge on where to find specialized care in the Netherlands (for referral) as well as abroad; knowledge and support in finding a donor and the decision making; knowledge on the possible complications resulting from OD pregnancies; and the skills to find possible resources when in doubt. The women were aware of the fact that health care professionals were legally not allowed to participate in anonymous OD. As an alternative it would be helpful if these health care professionals refer them to sources such as Freya, which can support women in making a considered decision.

Next to the above-mentioned aspects that could be improved by education, more knowledge could also help health care professionals in being more sensitive. The women mentioned that it is difficult if health care professionals are not supportive with their desire to receive OD treatment abroad. Even though these women were aware of the legal rules on participation of OD treatments taking place abroad, it would still help these women if the health care professionals accepted their decision and supported them in finding the required resources.

Another aspect which could be improved by implementing a guideline, would be to introduce a referral for mental support. It became clear that not all health care professionals are aware of the difficult feelings and emotions that come along with OD. It would help these women if good mental care was offered. Ideally, they would receive this psychological help from a health care provider that is specialized in helping infertile women.

Lastly, the women mentioned that peer support could be very helpful during the process, especially for questions and mental support. Some of the women found peers only after their pregnancy. It could be of value to mention this peer support during PC, by for example referring to the existing Facebook groups.

Quantitative Research

The questionnaire was sent to or viewed by a total of 292 participants. Only questionnaires with a progress of > 80% were included in the dataset, which resulted in 111 valid participants. From the 111 women, 10 were considering to conceive through OD but had not started their treatment yet, 11 had already started and possibly already had an embryo transfer, 16 were pregnant through OD at the time of filling in the questionnaire, 62 had delivered at least one child after OD pregnancy, and 12 women had a history with OD treatment which did not lead to a successful pregnancy.

Preconception Counselling

A distinction was made between the women who did and those who did not receive PC. The participants who indicated that 1) they did receive PC, 2) were satisfied with the information and 3) indicated that they did not miss certain information were classified to the group who did receive PC (N=87). The women who indicated that they did not receive PC, and/or who were not satisfied with the information received during this counselling, and/or who indicated that they missed certain information were classified into the group of women who did not receive PC (N=24). It was a post-hoc decision to classify the women who were not satisfied with the information received during the counselling and the women who indicated that they missed certain information, into the group “no PC”. This decision was made because the sample size would be too small if only the women who indicated that they did not receive PC were classified to this group. Information on the content of PC, the missed subjects during PC, and why there was insufficient attention for the mental wellbeing are shown in Appendix H. PC specific variables are shown in Table 3. Most of the woman that received PC indicated that they received information or education from a health care professional, yet still over

forty percent of the women indicated that they searched the information they needed and educated themselves.

Table 3

Characteristics of Women who did Receive Preconception Counselling, N=87.

	percentage	number
Mode of PC		
Received information/education from a health care professional	88.5	77
Self-search for information/education	42.5	37
Other	5.7	5
Form of PC		
Conversation with professional	95.4	83
Website	42.5	37
Flyer	31.0	27
Social media	25.3	22
Other	10.3	9

Note. PC = Preconception Counselling.

Participant Characteristics

The participant characteristics and OD specific variables are shown in Table 4. After observing the histograms and performing the Shapiro-Wilk Test to test for the normal distribution of the data for the variables that measure age at the start of the first OD treatment and the current age at filling in the questionnaire, the test showed that the data was normally distributed ($W(101) = .99$, $p = .313$), ($W(101) = .99$, $p = .383$). Therefore, an independent samples t-test was used to analyze these variables. No significant differences in these variables were found between the group who did receive PC and the group who did not receive PC.

The variables education, indication for OD, donor type, country of OD treatment, embryo transfer, and pregnant through OD are categorical and have >20% expected count less than 5, therefore a Fisher's Test is used for these variables. Most women were well-educated (higher professional education (HBO) or university education (WO)). Furthermore, POI was the most common indication in both groups, caused by either a cancer treatment or an unknown reason. Failed IVF treatment was the second most common indication in both groups. Also, there were more women with a non-anonymous donor than women with an anonymous donor. Looking at the source of the non-anonymous donors, there was a significant difference between the number of women who found a donor within their inner circle of friends or acquaintances when comparing the women who did ($N = 13$, % =26.5) and did not receive PC ($N = 8$, % = 61.5), $\chi^2(1, N = 62) = 5.62$, $p =$ **.025**, *Cramer's V* = .301, 95% CI [1.22,16.01]. In the group of women who did not receive PC, significant more women found a donor within their inner circle. Most women had their OD treatment in the Netherlands,

followed by Spain, Portugal, Belgium, and Finland. Furthermore, most women had an embryo transfer and had been pregnant through OD at least once.

After observing the histograms and performing the Shapiro-Wilk Test to test for the normal distribution of the data for the variable measuring the number of pregnancies through OD, the test showed that the data was not normally distributed ($W(82) = .65$, $p = <.001$). Therefore, the Mann-Whitney U test was used to analyze this variable. Furthermore, the variable measuring pregnancy complications is categorical and has >20% expected count less than 5, meaning a Fisher's Test is used for this variable. In total, the 82 women conceived 145 times through OD. From these 145 pregnancies, 117 pregnancies could be qualified as either complicated or uncomplicated; for the remaining 28 pregnancies, no clinical information was given. In more than half of these 117 pregnancies, a complication had occurred as reported by the participants. The number of pregnancies through OD and the incidence of pregnancy complications did not significantly differ between women who did receive PC and women who did not receive PC. The most reported pregnancy complication was pregnancy loss (death of the unborn fetus during pregnancy < 16 weeks and >16 weeks), followed by hypertensive complications (including pregnancy-induces hypertension and pre-eclampsia).

Quality of Life and Contentment

To answer the second sub-aim (a), comparing the QoL during the OD process, between women who did receive PC and women who did not receive PC, the data of the FertiQoL Core questions and Total FertiQoL were analysed. After observing the histograms and performing the Shapiro-Wilk Test to test for normal distribution of the data for the variables Total Core questions, Emotional subscale, Mind/Body subscale, Relational subscale, Social subscale, Total FertiQoL +, and Total FertiQoL the tests showed that the data was not normally distributed; ($W(111) = .97$, $p = .018$), ($W(111) = .96$, $p = .002$), ($W(111) = .94$, $p < .001$), ($W(111) = .97$, $p = .029$), ($W(111) = .97$, $p = .006$), ($W(101) = .97$, $p = .019$), ($W(101) = .97$, $p = .019$). Therefore, the Mann-Whitney U test was used to analyse these variables. No significant differences for the outcome variable QoL were found between the women who did and did not have PC (see Table 5). Since earlier research found that social support had a positive effect on dealing with infertility, the post-hoc decision was made to analyse if social support (Social QoL) could be an important factor for QoL. The total FertiQoL score between the women who had a low score on social QoL (< 74) and the women who had a high score on social QoL (≥ 74), was compared. The Mann-Whiney U test showed a significant difference on the Total FertiQoL, $U(N_{social<74}=55,\ N_{social\geq74}= 46) = 2375.50$, $z = 7.58$, $p =$ **<.001**. Women who had a higher score on the social QoL had a higher score on QoL compared to the women who had a lower score on the social QoL ($M = 79.54$ vs. $M = 58.68$).

To answer the second sub-aim (b), comparing the contentment of health care during the OD process, between women who did receive PC and women who did not receive PC, the data of the FertiQoL Treatment questions was analysed. After observing the histograms and performing the Shapiro-Wilk Test to test for normal distribution of the data for the variables Total Treatment

questions + and Total Treatment questions, Environment subscale +, Environment subscale, and Tolerability subscale, the tests showed that the data was not normally distributed; ($W(101) = .97$, $p = .017$), ($W(101) = .97$, $p = .038$), ($W(101) = .96$, $p = .003$), ($W(101) = .95$, $p < .001$), ($W(101) = .96$, $p = .004$). No significant differences for the outcome variable contentment were found between the women who did and did not receive PC (see Table 5). However, when eliminating the three self-created questions on contentment of treatment, there was a significant difference on the Environment subscale, $U(N_{PC=no}=21,\ N_{PC=yes}= 80) = 599.50$, $z = -2.02$, $p =$ **.043**. The women who did receive PC had a higher score on this subscale in comparison with the women who did not receive PC. The Environment scale is trustworthy with (9 questions; $a = .845$) and without (6 questions; $a = .773$) the three self-created questions.

Anxiety and Distress

To answer the second sub-aim (c), comparing anxiety and distress during the OD process, between women who did receive PC and women who did not receive PC, the data of the GAD-7 scale was analysed. After observing the histograms and performing the Shapiro-Wilk Test for Normality for the variables Total score GAD-7 + and Total score GAD-7 the test showed that the data was not normally distributed ($W(109) = .93$, $p < .001$), ($W(109) = .96$, $p = .002$). Therefore, the Mann-Whitney U test was used to analyze these variables. No significant differences for the outcome variables anxiety and distress were found between the women who did and did not receive PC (see Table 6). Post-hoc analysis comparing the total GAD-7 score between the women who had a low score on social QoL (< 74) and the women who had a high score on social QoL (≥ 74), was conducted, based on the results of earlier research on social support. The Mann-Whiney U test showed a significant difference, $U(N_{social<74}=61,\ N_{social\geq74}= 48) = 748.00$, $z = -4.39$, $p =$ **<.001**. Women who had a higher score on the social QoL had less anxiety and distress compared to the women who had a lower score on the social QoL ($M = 9.10$ vs. $M = 4.85$).

Table 4

Comparison of OD Specific Characteristics of the Participants, Between the Women who did Receive PC and the Women who did not Receive PC.

	PC = no, N=24		PC = yes, N=87				
	mean (SD)	min-max	mean (SD)	min-max	p-value[&]	*d*	CI
Age at start of first OD treatment	37.24 (4.77)	26-46	36.34 (4.81)	25-50	.894	-.188	[-.67,.29]
Age at filling in the questionnaire	38.46 (5.61)	27-50	38.95 (5.51)	26-52	.699	.090	[-.36,.54]
Missing	12.5%	3(N)	8.0%	7(N)			
	percentage	number	percentage	number	p-value[#]	*Cramer's V*	95% CI
Education					.651	.190	
Lower secondary education	0.0	0	1.1	1	1.000	.050	[.71,.86]
General secondary education	0.0	0	3.4	3	1.000	.088	[.70,.86]
Higher secondary education	0.0	0	2.3	2	1.000	.071	[.71,.86]
MBO	8.3	2	19.5	17	.239	.122	[.08,1.75]
HBO	54.2	13	47.1	41	.646	-.058	[.54,3.28]
WO	37.5	9	26.4	23	.315	.101	[.64,4.33]
Indication OD					.871	.217	
Wrong predisposition of genitals	0.0	0	2.3	2	1.000	.071	[.70,.86]
High age/menopause	0.0	0	6.9	6	.337	.126	[.70,.86]
Carrier of hereditary disease	0.0	0	5.7	5	.583	.114	[.70,.86]
Failed IVF treatment	25.0	6	21.8	19	.785	.031	[.42,3.43]
Endometriosis	4.2	1	5.7	5	1.000	.029	[.08,6.41]
High-tech surrogacy	0.0	0	1.1	1	1.000	.050	[.71,.86]
POI	66.7	16	48.3	42	.167	.143	[.79,5.29]
Reason unknown	4.2	1	4.6	4	1.000	.009	[.10,8.47]
Other	0.0	0	1.1	1	1.000	.050	[.71,.86]
Donor type					.252	.171	
Anonymous donor	29.2	7	37.9	33	.480	.075	[.25,1.80]
Non-anonymous donor	54.2	13	56.3	49	1.000	.018	[.37,2.27]

	percentage	number	percentage	number	p-value[#]	*Cramer's V*	95% CI
Source non-anonymous donor					.062		
- Family or relative	7.7	1	30.6	15	.154	.213	[.02,1.59]
- Friends or acquaintances	61.5	8	26.5	13	**.025**	.301	[1.22,16.01]
- OD bank	23.1	3	18.4	9	.703	.049	[.30,5.85]
- Advertisement	0.0	0	18.4	9	.184	.212	[.65,.88]
- Other	7.7	1	6.1	3	1.000	.026	[.12,13.41]
Still searching for a donor	4.2	1	1.1	1	.387	.093	[.23,62.09]
Other	12.5	3	4.6	4	.171	.134	[.62,14.72]
Country of OD treatment					.541	.192	
The Netherlands	41.7	10	47.7	41	.649	.050	[.31,1.96]
Belgium	8.3	2	8.1	7	1.000	.003	[.20,5.29]
Spain	16.7	4	25.6	22	.428	.087	[.18,1.89]
Portugal	12.5	3	5.8	5	.369	.106	[.51,10.47]
Finland	0.0	0	2.3	2	1.000	.072	[.70,.86]
Multiple countries	20.8	5	10.5	9	.182	.128	[.68,7.50]
Missing			.9	1			
Embryo transfer					1.000	.026	[.08,6.79]
Yes	83.3	20	86.2	75			
No	4.2	1	5.7	5			
Missing	12.5	3	8.0	7			
Pregnant through OD					.348	.122	[.08,1.84]
Yes	79.2	19	72.4	63			
No	8.3	2	19.5	17			
Missing	12.5	3	8.0	7			
	median	min-max	median	min-max	p-value[$]	IQR	
Number of pregnancies through OD	1	1-5	1	1-8	.465	1	
Missing	20.8%	5(N)	27.6%	24(N)			
	PC = no, N=27[a]		PC = yes, N=90[a]				
	percentage	number	percentage	number	p-value[#]	*Cramer's V*	95% CI
Pregnancies							
Uncomplicated pregnancies	33.3	9	34.4	31	1.000	0.10	

	percentage	number	percentage	number	p-value[#]	*Cramer's V*	95% CI
Complicated pregnancies	66.7	18	65.6	59	1.000	.010	
- Hypertensive complications	22.2	6	16.7	15	.570	.061	[.49,4.14]
- Foetal growth restriction	0.0	0	2.2	2	1.000	.072	[.95,1.01]
- Gestational diabetes	3.7	1	5.6	5	1.000	.035	[.07,5.85]
- Threatened preterm birth/PPROM	7.4	2	2.2	2	.227	.120	[.47,26.26]
- Ectopic pregnancy	7.4	2	0.0	0	.052	.241	[.97,1.20]
- Pregnancy loss	33.3	9	33.3	30	1.000	.000	[.40,2.49]
- Pregnancy termination	3.7	1	2.2	2	.548	.039	[.15,19.42]
- Placenta previa	0.0	0	1.1	1	1.000	.051	[.97,1.01]
- Foetal death	0.0	0	1.1	1	1.000	.051	[.97,1.01]

Note. PC = Preconception Counselling; PPROM = Preterm Premature Rupture Of Membranes; POI = Premature Ovarian Insufficiency

[&]*p*-value calculated with an Independent Samples T-Test, two-sided; [#]*p*-value calculated with the Fisher's Exact Test, two-sided; [$]*p*-value calculated with the Mann-Whitney U Test, two-sided; [a]N exceeds number of participants in the study because some women had multiple pregnancies.

Table 5

Comparison of the FertiQoL Results Between the Women who did Receive PC and the Women who did not Receive PC, to Measure the Outcome QoL.

	PC = no, N = 24		PC = yes, N = 87		
	median (IQR)	min-max	median (IQR)	min-max	p-value[$]
Total Core questions	70.31 (24.7)	42.7-92.7	68.75 (25.0)	22.9-92.7	.895
Emotional subscale	66.67 (31.3)	16.7-95.8	66.67 (33.3)	16.7-100.0	.977
Mind/Body subscale	72.92 (35.4)	25.0-100.0	70.83 (41.7)	8.3-100.0	.554
Relational subscale	79.17 (27.1)	41.7-100.0	75.00 (25.0)	8.3-100.0	.787
Social subscale	62.50 (28.1)	37.5-95.8	70.83 (29.2)	20.8-100.0	.628
Total Treatment questions +	63.46 (15.4)	44.2-82.5	69.23 (16.8)	32.7-94.2	.254
Total Treatment questions	67.50 (16.3)	42.5-87.5	71.25 (21.9)	32.5-92-5	.266
Environment subscale +	66.67 (19.4)	41.7-88.9	70.83 (19.4)	19.4-100.0	.103
Environment subscale	62.50 (16.7)	41.7 – 83.3	70.83 (19.8)	25.0-100.0	**.043**
Tolerability subscale	68.75 (28.1)	31.3-100.0	68.75 (25.0)	25.0-100.0	.830
Missing	12.5%	3(N)	8%	7(N)	
Total FertiQoL +	67.57 (24.0)	46.6-89.2	70.61 (21.8)	37.2-91.2	.887
Total FertiQoL	68.38 (23.9)	46.3-90.4	70.96 (22.6)	32.4-91.9	.923
Missing	12.5%	3(N)	8%	7(N)	

Note. PC = Preconception Counselling; + = Three self-created questions were added to the original FertiQoL scales and subscales.

[$]*p*-value calculated with the Mann-Whitney U Test.

Table 6

Comparison of the GAD-7 Results Between the Women who did Receive PC and the Women who did not Receive PC, to Measure the Outcomes Anxiety and Distress.

	PC = no, N = 22		PC = yes, N = 87		
	median (IQR)	min-max	median (IQR)	min-max	p-value[$]
Total score GAD-7 +	12.50 (9)	2-24	12.00 (13)	1-30	.958
Total score GAD-7	6.50 (7)	1-14	7.00 (9)	1-21	.970
Missing	1.8%	2(N)			

Note. PC = Preconception Counselling; + = Five self-created questions were added to the original GAD- 7.

[$]*p*-value calculated with the Mann-Whitney U Test.

Discussion

To improve health care and wellbeing for women undergoing an OD treatment, it is valuable to explore the experiences of these women. The perspectives of these women on PC and health care before and during an OD treatment were explored using qualitative focus group research. Furthermore, with quantitative questionnaire research the psychosocial wellbeing of women conceiving through OD was examined. The objective was to compare QoL, the contentment about health care, and the anxiety and distress during the OD procedure between women who did receive PC and women who did not receive PC. After analysing the qualitative research results, the main findings highlighted the need for more knowledge on OD among health care professionals. Next to that, the investigated women would have liked to receive more mental and peer support. The quantitative research showed no significant differences on QoL and anxiety/distress between women who did and those who did not receive PC. From the two tested scales on contentment, the scores on the Environment subscale (questions regarding the quality and availability of the treatment and its impact on QoL) differed significantly between women who did and women who did not receive PC. The scores on this subscale were higher for women who did receive PC.

Regarding the results of the focus group research, it is important to acknowledge the differences in perspectives between the women. Like ‘normal’ pregnant women, they all had their own wishes and ideas about their process. Some were content with the received care and most of all thankful for the opportunity; others were less content and less positive about the process. However, they all mentioned that a guideline for health professionals on PC and OD treatment would be helpful to improve health care. Currently, there is a lack of knowledge by health care professionals on various OD subjects, such as possible pregnancy complications and health care policies. Policies and arguments from physicians differed between clinics and hospitals, sometimes without providing clear sources or evidence-based research. Therefore, it would be helpful for health care professionals to have a national guideline that summarises the evidence-based research and recommendations in OD health care. However, the production of a national guideline is a time-consuming process. Hence, it is important that health care professionals educate themselves in other ways, such as by following seminars and conferences and by reading articles. For the women undergoing OD, a guideline and more education could result in less distress as they have to worry less about figuring everything out by themselves. Improvement of the health care provision could cause better wellbeing for these women. They would have liked to be seen and heard, not only medically but also mentally. The focus group analyses confirmed the heavy burden of infertility and the OD process. Therefore, it is important that these women are supported by health care professionals and peers and are offered specialized mental care.

In the questionnaire research, there were significantly more women in the group who did not receive PC who found their donor among friends and acquaintances compared to the group who did. No explanation was found for this difference. Hypothetically, this could be because they did not receive PC on the different options for finding an oocyte donor, meaning they had to search in their

inner circle. Also, it could be that these women already had a donor from their inner circle, even before PC. To be able to compare both groups on psychosocial wellbeing it is important to have comparable groups, which was the case in this research as all the other OD specific characteristics did not significantly differ between the groups.

Furthermore, no significant differences were found in the outcome QoL between the groups, indicating that women who receive PC did not have a better QoL than the women who did not receive PC. Therefore, the first sub-hypothesis (a: it was hypothesized that QoL is higher in women who did receive PC as compared to women who did not receive PC) could be rejected. This finding is not in line with earlier research, in which patient-centered care for infertile women was associated with higher QoL (Aarts et al., 2012). Hypothetically, this could be explained by the content and quality of PC. If the content of PC was not focused on psychosocial wellbeing, this could explain why no differences were found. On the other hand, based on the biopsychosocial model it is expected that support in one domain, for example medical support, should cause improvements in another domains, for example QoL. Another possibility is that social support was a more decisive factor for QoL. Post-hoc analysis showed that women whose social relationships were less affected by their fertility problems had a significantly higher QoL. This may indicate that the psychosocial wellbeing of women could be improved if there is more attention for maintaining and improving the social interactions of the patient with their support system. Another important finding is that the average scores on the FertiQoL of this sample were in line with the scores of people with fertility problems in other research studies, suggesting that the results of this study on QoL are representable for the population (Aarts et al, 2012).

Also, the outcome contentment of health care (Total Treatment questions) did not significantly differ between the groups. This total scale indicates the quality, availability, and impact of the treatment on 1) QoL (Environment subscale), 2) mental and physical health, and 3) daily activities (Tolerability subscale). However, it is notable that the scores on the Environment subscale were significantly higher for women who did receive PC. This subscale did not significantly differ between the two groups when the three self-created questions were added. Cronbach's alpha could not explain why there was no significant difference on the environment subscale with the three self-created questions added, meaning that these three questions were reliable for measuring the outcome. An explanation could be that the content of these three questions was less discussed during PC, which might have caused PC to have a lot less impact on these three questions. The results imply that both groups were equally content with the impact of the treatment on mental and physical health and daily activities. However, there was less contentment for women who did not receive PC on the availability and quality of the treatment. Also, the quality and availability of the treatment could have had more impact on their QoL, when compared to the women who did receive PC. An explanation could be that because these women did not receive PC, they experienced less availability and quality of care. Since a significant difference was found in the environment scale, the second sub-hypothesis (b: it was

hypothesized that contentment was higher in women who did receive PC compared to women who did not receive PC) could be retained.

In contrast to the hypothesis that anxiety and distress were lower for women who did receive PC in comparison to women who did not receive PC, no significant differences were found in the outcome anxiety and distress between the groups. Therefore, the third sub-hypothesis (c: it was hypothesized that anxiety and distress during the OD treatment is lower for women who did receive PC as compared to women who did not receive PC) could be rejected. This is not in line with earlier research, in which patient-centered care was associated with less anxiety (Aarts et al., 2012). Again, this could hypothetically be explained by the lack of focus during PC on reducing anxiety. But similarly as with QoL this would not be in line with the biopsychosocial model. Possibly, social support is a more decisive factor for reducing anxiety, as it might be with QoL. As highlighted before, post-hoc analysis showed that women whose social relations were less affected by their fertility problems had significant less anxiety and distress. Again, this implies that the psychosocial wellbeing of women could be improved if there was more focus during PC on maintaining and improving the social interactions of the patient with their support system. No earlier research is available to compare these results. However, the scores on the GAD-7 of the total population of this research are in line with earlier research. Omani-Samani et al. (2018) found nearly the same results for people with infertility problems, since both anxiety levels were classified as mild anxiety. This would suggest that the results of this study on anxiety levels are representable for the population.

Strengths and Limitations

The first strength of this research is its novelty. Little research has yet been done on PC for OD and the psychosocial wellbeing of women undergoing OD. Hopefully, this research will lead to more research into this subject. Secondly, the combination of focus groups and questionnaire research is a strength. Namely, the questionnaire was used to obtain a global view on PC and psychosocial wellbeing regarding OD treatment and was combined with more in-depth information that was collected using focus groups. Combining these two research designs resulted in a broad view of the perspectives and experiences of women undergoing OD. Another strength is the relatively high respondent rate on the questionnaire (111 participants) when compared to the number of women in the Netherlands that need OD to conceive. This makes the sample size representable for the Dutch OD population. In the Netherlands, from 2004 till 2020, 868 OD treatments were officially registered by Dutch clinics and hospitals (Fiom, n.d.). The exact number of OD treatments by Dutch women is not full clear as part of these women went abroad for OD treatment. Treatments abroad are not officially registered. Furthermore, analysing the data was done with accuracy to increase the reliability of the study. Especially with the qualitative research there was attention for using high-quality methods and reaching consensus within the research team through discussions. Lastly, to decrease the negativity bias (the tendency to focus more on the negative and less on the positive results), analysis of the focus

group results was done with a neutral view, meaning reporting both the positive and negative experiences if both occurred (Rozin & Royzman, 2001).

This research also has some limitations. Firstly, the expected number of women who did not receive PC was higher than the actual number. Therefore, the post-hoc decision was made to also include the women that were not content or missed certain information during PC into the group that did not receive PC. Even then, the number of women that did not receive PC remained low, which makes it more difficult to draw solid conclusions from this research. A possible improvement for future research would be to adjust the questionnaire as it was possibly not entirely clear for all participants what PC entails. The women were able to indicate what their PC was about in the questionnaire, but not all answers provided were clear or complete. A suggestion for future research would be to divide the question on PC in different parts. In that way it is possible to better interpret on what elements PC was given. For example, by adding 'yes' or 'no' questions on received information regarding possible complications, possible risk factors, donor information, disclosure, and medication. The higher expected number of women who did not receive PC in the questionnaire was based on the information gathered from the qualitative research. The actual small number is not in line with information received from the focus groups, in which a lot of statements were made on the low quality or absence of PC. However, the research sample of the qualitative research might not have been representative for the OD population due to a self-selection bias. The women who signed up for the focus groups may have been less content with the received care or may have had a negative experience, which made them to sign up. For future research it would be recommended to conduct more focus groups to prevent this bias. Another limitation is the recall bias. The difference between the age of OD treatment and the actual age when filling in the questionnaire was on average almost three years, with a minimum of 0 and a maximum of 17 years. It could be possible that not all women were able to exactly recall the different elements of the treatment, which could have lowered the reliability of this research. In future research, to avoid this bias, it is recommended to conduct prospective research, in which women who will receive PC and who will not receive PC are followed during their OD treatment. Data can then be collected while these women are in the midst of the process, limiting the recall bias.

Implications

The results of this study could be used for future research on OD and PC. As this research is relatively new and little has been studied yet, the current study could serve as a first step to more research. Furthermore, this research could also be of value for health care professionals working with women undergoing OD treatment, in order to learn about the potential points for improvement and by implementing this. These health care professionals could gain more insight into how these women experienced their OD treatments and as such educate themselves on the difficult issues of OD. These professionals could for example learn that it is important to be clear on the possible risks of OD pregnancy, be sensitive in their communication, and also that their patients would like to receive

specialized psychological care when needed. This research could also be helpful in developing a national guideline due to the amount of valuable data. Especially the focus group research could give insights into what women find most important to be implemented in a guideline. Also, some data from the questionnaires could be relevant for developing a guideline, for example the data on the importance of social support for better QoL and less anxiety. Based on this research, a national guideline for health care professionals on PC should include information and advice on the medical part of OD (e.g., possible risks and complications, and medication) (van der Hoorn et al., 2022), different options for OD treatment (or references on where to find information to receive OD abroad), guidance in donor options and tips on how to find a donor, peer support, social support, and mental support. With this guideline health care for OD would be improved, which implies a better wellbeing for these women. Furthermore, by reading this research, women who need OD to conceive may gain helpful information on PC for OD. Not only might they feel heard and possible recognize themselves in specific quotes, but they could also learn more about the potential points of improvement within the treatment. By learning more about these points of improvement they could potentially prepare better for their own upcoming treatment, give better feedback to health care professionals, and possibly advise peers in a better way. Since it could be a challenge for these women to extract concrete information out of this thesis, a suggestive intermediate step could be to create a written overview which can be found on an easy-to-find website.

Conclusion

In conclusion, new insights have been gained through this research: undergoing OD treatment is a heavy burden, both physically and mentally. There are various points of improvement for PC and there is a need for more psychosocial support. At the same time, more research is needed to learn more about the effectiveness of PC and the possible protecting factor that PC could have for psychosocial problems. It can be concluded that receiving PC makes no difference on QoL, anxiety, and distress. Social support was possibly a more decisive factor for these outcomes and therefore should be a focus point in PC, as the women whose social relations were less affected by their fertility problems had significant better QoL as well as less anxiety and distress. Nonetheless, PC makes a significant difference in contentment of health care as the contentment on the availability and quality of the treatment was less for women who did not receive PC. Furthermore, the development of a national guideline with recommendations on PC would be a possible solution to address the points of improvement. For women who need OD to conceive, it would be helpful if this national guideline is developed for health care professionals encountering OD pregnancies. As a result, these women will be more likely to receive the required counselling, health care, and personal attention. By implementing a national guideline, women would be able to focus more on the positive side of this unique pregnancy, instead of having to worry about the health care system, especially after the period of grief and disappointments that most of these women had to go through. However, more research is needed to exactly determine how the health care for these women could be improved.

References

Aarts, J. W. M., Huppelschoten, A. G., Van Empel, I. W. H., Boivin, J., Verhaak, C. M., Kremer, J. A. M., & Nelen, W. L. (2012). How patient-centred care relates to patients' quality of life and distress: a study in 427 women experiencing infertility. *Human Reproduction, 27*(2), 488-495. https://doi.org/10.1093/humrep/der386

Akiskal, H. S. (1998). Toward a definition of generalized anxiety disorder as an anxious temperament type. *Acta Psychiatrica Scandinavica, 98*, 66-73. https://doi.org/10.1111/j.1600-0447.1998.tb05969.x

Anderson, K., Nisenblat, V., & Norman, R. (2010). Lifestyle factors in people seeking infertility treatment - A review. *The Australian & New Zealand Journal of Obstetrics & Gynaecology, 50*(1), 8–20. https://doi.org/10.1111/j.1479-828X.2009.01119.x

Bauer T. (2022). A systematic review of qualitative studies investigating motives and experiences of recipients of anonymous gamete donation. *Frontiers in Sociology, 7,* 746847. https://doi.org/10.3389/fsoc.2022.746847

Berntsen, S., Larsen, E. C., la Cour Freiesleben, N., & Pinborg, A. (2021). Pregnancy outcomes following oocyte donation. *Best Practice & Research Clinical Obstetrics & Gynaecology, 70*, 81–91. https://doi.org/10.1016/j.bpobgyn.2020.07.008

Boivin, J., Takefman, J., & Braverman, A. (2011). The fertility quality of life (FertiQoL) tool: development and general psychometric properties. *Human Reproduction, 26*(8), 2084-2091. https://doi.org/10.1093/humrep/der171

Boyer, B. A., & Paharia, M. I. (2008). *Comprehensive handbook of clinical health psychology*. John Wiley & Sons.

Carter, J., Applegarth, L., Josephs, L., Grill, E., Baser, R. E., & Rosenwaks, Z. (2011). A cross-sectional cohort study of infertile women awaiting oocyte donation: The emotional, sexual, and quality-of-life impact. *Fertility and Sterility*, *95*(2), 711–6. https://doi.org/10.1016/j.fertnstert.2010.10.004

Chachamovich, J. R., Chachamovich, E., Ezer, H., Fleck, M. P., Knauth, D., & Passos, E. P. (2010). Investigating Quality of Life and Health-related Quality of Life in Infertility: a systematic

review. *Journal of Psychosomatic Obstetrics and Gynaecology, 31*(2), 101–110. https://doi.org/10.3109/0167482X.2010.481337

Deka, P. K., & Sarma, S. (2010). Psychological aspects of infertility. *British Journal of Medical Practitioners, 3*(3), 336.

Domar, A. D., Zuttermeister, P. C., & Friedman, R. (1993). The psychological impact of infertility: a comparison with patients with other medical conditions. *Journal of Psychosomatic Obstetrics and Gynaecology, 14*, 45–52.

Donarelli, Z., Lo Coco, G., Gullo, S., Salerno, L., Marino, A., Sammartano, F., & Allegra, A. (2016). The fertility quality of life questionnaire (FertiQoL) relational subscale: psychometric properties and discriminant validity across gender. *Human Reproduction, 31*(9), 2061–2071. https://doi.org/10.1093/humrep/dew168

Drosdzol, A., & Skrzypulec, V. (2009). Evaluation of marital and sexual interactions of Polish infertile couples. *The Journal of Sexual Medicine, 6*(12), 3335–3346. https://doi.org/10.1111/j.1743-6109.2009.01355.x

Elkatawneh, H. H. (2016). The five qualitative approaches: Problem, purpose, and questions/the role of theory in the five qualitative approaches/comparative case study. *SSRN Electronic Journal*, 1–17.

Engel, G. L. (1977). The need for a new medical model: a challenge for biomedicine. *Science, 196*(4286), 129-136. https://doi.org/10.1126/science.847460

European IVF-Monitoring Consortium (EIM) for the European Society of Human Reproduction and Embryology (ESHRE), Wyns, C., De Geyter, C., Calhaz-Jorge, C., Kupka, M. S., Motrenko, T., Smeenk, J., Bergh, C., Tandler-Schneider, A., Rugescu, I. A., & Goossens, V. (2022). ART in Europe, 2018: results generated from European registries by ESHRE. *Human Reproduction Open, 2022*(3). https://doi.org/10.1093/hropen/hoac022

Faubion, S. S., Kuhle, C. L., Shuster, L. T., & Rocca, W. A. (2015). Long-term health consequences of premature or early menopause and considerations for management. *Climacteric: the Journal of the International Menopause Society, 18*(4), 483–491. https://doi.org/10.3109/13697137.2015.1020484

Fenton A. J. (2015). Premature Ovarian Insufficiency: Pathogenesis and management. *Journal of Mid-life Health, 6*(4), 147–153. https://doi.org/10.4103/0976-7800.172292

Fereday, J., & Muir-Cochrane, E. (2006). Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development. *International Journal of Qualitative Methods, 5*(1), 80-92. https://doi.org/10.1177/160940690600500107

Fertility Europe. (2021, December), *Atlas of fertility treatment policies in Europe.* https://fertilityeurope.eu/atlas/

Fiom. (n.d.), *Cijfers en Feiten.* https://fiom.nl/kenniscollectie/kid-dna/cijfers-feiten

Gartrell, N. K., Bos, H., Goldberg, N. G., Deck, A., & van Rijn-van Gelderen, L. (2015). Satisfaction with known, open-identity, or unknown sperm donors: reports from lesbian mothers of 17-year-old adolescents. *Fertility and Sterility, 103*(1), 242–248. https://doi.org/10.1016/j.fertnstert.2014.09.019

Gnoth, C., Godehardt, E., Frank-Herrmann, P., Friol, K., Tigges, J., & Freundl, G. (2005). Definition and prevalence of subfertility and infertility. *Human Reproduction, 20*(5), 1144–1147. https://doi.org/10.1093/humrep/deh870

Greil, A. L., Slauson-Blevins, K., & McQuillan, J. (2010). The experience of infertility: a review of recent literature. *Sociology of Health & Illness, 32*(1), 140-162. https://doi.org/10.1111/j.1467-9566.2009.01213.x

Guest, G., Namey, E., Taylor, J., Eley, N., & McKenna, K. (2017). Comparing focus groups and individual interviews: findings from a randomized study. *International Journal of Social Research Methodology, 20*(6), 693-708. https://doi.org/10.1080/13645579.2017.1281601

Janssens, P. M., Simons, A. H., van Kooij, R. J., Blokzijl, E., & Dunselman, G. A. (2006). A new Dutch Law regulating provision of identifying information of donors to offspring: background, content and impact. *Human Reproduction, 21*(4), 852–856. https://doi.org/10.1093/humrep/dei407

Keukens, A., van Wely, M., van der Meulen, C., & Mochtar, M. H. (2022). Pre-eclampsia in pregnancies resulting from oocyte donation, natural conception or IVF: a systematic review

and meta-analysis. *Human Reproduction, 37*(3), 586–599. https://doi.org/10.1093/humrep/deab267

Klein, J. U., & Sauer, M. V. (2002). Oocyte donation. *Best Practice & Research Clinical Obstetrics and Gynaecology, 16*(3), 277–291. https://doi.org/10.1053/beog.2002.0288

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *The American Journal of Occupational Therapy, 45*(3), 214-222. https://doi.org/10.5014/ajot.45.3.214

Kroenke, K., Spitzer, R. L., Williams, J. B., Monahan, P. O., & Löwe, B. (2007). Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection. *Annals of Internal Medicine, 146*(5), 317–325. https://doi.org/10.7326/0003-4819-146-5-200703060-00004

Löwe, B., Decker, O., Müller, S., Brähler, E., Schellberg, D., Herzog, W., & Herzberg, P. Y. (2008). Validation and standardization of the Generalized Anxiety Disorder Screener (GAD-7) in the general population. *Medical Care, 46*(3), 266–274. https://doi.org/10.1097/MLR.0b013e318160d093

Lutjen, P., Trounson, A., Leeton, J., Findlay, J., Wood, C., & Renou, P. (1984). The establishment and maintenance of pregnancy using in vitro fertilization and embryo donation in a patient with primary ovarian failure. *Nature, 307*(5947), 174-175.

Mackens, S., Santos-Ribeiro, S., Van De Vijver, A., Racca, A., Van Landuyt, L., Tournaye, H., & Blockeel, C. (2017). Frozen embryo transfer: a review on the optimal endometrial preparation and timing. *Human Reproduction, 32*(11), 2234-2242. https://doi.org/10.1093/humrep/dex285

Martins, M. V., Peterson, B. D., Almeida, V. M., & Costa, M. E. (2011). Direct and indirect effects of perceived social support on women's infertility-related stress. *Human Reproduction, 26*(8), 2113-2121. https://doi.org/10.1093/humrep/der157

Melnick, A. P., & Rosenwaks, Z. (2018). Oocyte donation: insights gleaned and future challenges. *Fertility and Sterility, 110*(6), 988–993. https://doi.org/10.1016/j.fertnstert.2018.09.021

Moreno-Sepulveda, J., & Checa, M. A. (2019). Risk of adverse perinatal outcomes after oocyte donation: a systematic review and meta-analysis. *Journal of Assisted Reproduction and Genetics, 36*(10), 2017–2037. https://doi.org/10.1007/s10815-019-01552-4

NVOG. (2006), *Definitie IVF behandeling.*

https://www.nvog.nl/wp-content/uploads/2017/12/Definitie-IVF-behandeling-1.0-01-03-2006.pdf

O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine: Journal of the Association of American Medical Colleges*, *89*(9), 1245–1251. https://doi.org/10.1097/ACM.0000000000000388

Omani-Samani, R., Maroufizadeh, S., Ghaheri, A., & Navid, B. (2018). Generalized anxiety Disorder-7 (GAD-7) in people with infertility: a reliability and validity study. *Middle East Fertility Society Journal*, *23*(4), 446-449. https://doi.org/10.1016/j.mefs.2018.01.013

Onat, G., & Kizilkaya Beji, N. (2012). Effects of infertility on gender differences in marital relationship and quality of life: a case-control study of Turkish couples. *European Journal of Obstetrics, Gynaecology, and Reproductive Biology*, *165*(2), 243–248. https://doi.org/10.1016/j.ejogrb.2012.07.033

Raque-Bogdan, T. L., & Hoffman, M. A. (2015). The relationship among infertility, self-compassion, and well-being for women with primary or secondary infertility. *Psychology of Women Quarterly*, *39*(4), 484-496. https://doi.org/10.1177/0361684315576208

Ridner, S. H. (2004). Psychological distress: concept analysis. *Journal of Advanced Nursing*, *45*(5), 536-545. https://doi.org/10.1046/j.1365-2648.2003.02938.x

Rijksoverheid. (2021, August 17). *Opvragen donorgegevens van een kunstmatige bevruchting.* https://www.rijksoverheid.nl/wetten-en-regelingen/productbeschrijvingen/opvragen-donorgegevens-van-een-kunstmatige-bevruchting

Rozin, P., & Royzman, E. B. (2001). Negativity bias, negativity dominance, and contagion. *Personality and Social Psychology Review*, *5*(4), 296-320. https://doi.org/10.1207/S15327957PSPR0504_2

Sarkar, S., Sautier, L., Schilling, G., Bokemeyer, C., Koch, U., & Mehnert, A. (2015). Anxiety and fear of cancer recurrence and its association with supportive care needs and health-care service utilization in cancer patients. *Journal of Cancer Survivorship*, *9*(4), 567-575. https://doi.org/10.1007/s11764-015-0434-2

Spitzer, R. L., Kroenke, K., Williams, J. B., & Löwe, B. (2006). A brief measure for assessing generalized anxiety disorder: the GAD-7. *Archives of Internal Medicine, 166*(10), 1092–1097. https://doi.org/10.1001/archinte.166.10.1092

Stanhiser, J., & Steiner, A. Z. (2018). Psychosocial aspects of fertility and assisted reproductive technology. *Obstetrics and Gynecology Clinics of North America, 45*(3), 563-574. https://doi.org/10.1016/j.ogc.2018.04.006

Storgaard, M., Loft, A., Bergh, C., Wennerholm, U. B., Söderström-Anttila, V., Romundstad, L. B., Aittomaki, K., Oldereid, N., Forman, J., & Pinborg, A. (2017). Obstetric and neonatal complications in pregnancies conceived after oocyte donation: a systematic review and meta-analysis. *BJOG: An International Journal of Obstetrics and Gynaecology, 124*(4), 561–572. https://doi.org/10.1111/1471-0528.14257

Van Bentem, K., Lashley, E., Bos, M., Eikmans, M., Heidt, S., Claas, F., Le Cessie, S., & van der Hoorn, M. L. (2019). Relating the number of human leucocytes antigen mismatches to pregnancy complications in oocyte donation pregnancies: study protocol for a prospective multicentre cohort study (DONOR study). *BMJ Open, 9*(7), e027469. https://doi.org/10.1136/bmjopen-2018-027469

Van Bentem, K., Bos, M., Van Der Keur, C., Brand-Schaaf, S. H., Haasnoot, G. W., Roelen, D. L., Eikmans, M., Heidt, S., Claas, F. H. J., Lashley, E. E. L. O., & Van Der Hoorn, M. L. P. (2020). The development of preeclampsia in oocyte donation pregnancies is related to the number of fetal-maternal HLA class II mismatches. *Journal of Reproductive Immunology, 137*, 103074. https://doi.org/10.1016/j.jri.2019.103074

Van der Hoorn, M. L., Lashley, E. E., Bianchi, D. W., Claas, F. H., Schonkeren, C. M., & Scherjon, S. A. (2010). Clinical and immunologic aspects of egg donation pregnancies: a systematic review. *Human Reproduction Update, 16*(6), 704–712. https://doi.org/10.1093/humupd/dmq017

van der Hoorn, M. L., van Bentem, K., & Lashley, E. (2022). Evidence-Based Pre-Pregnancy Counseling for Oocyte Donation Pregnancies: a Systematic Review and Guide for Physicians. *Reproductive Sciences*, 1-10. https://doi.org/10.1007/s43032-021-00821-x

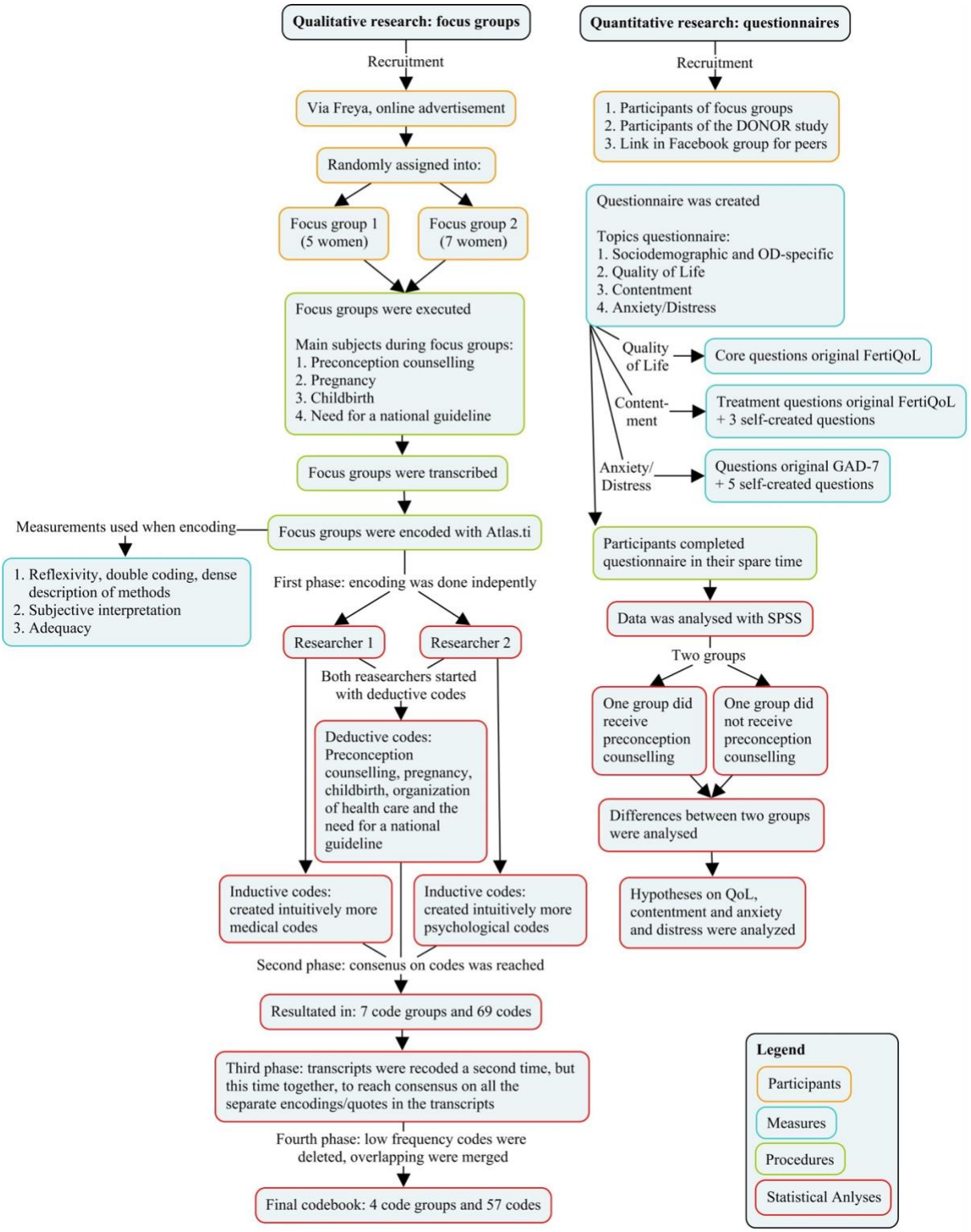
Williams, L., Zapata, L. B., D'Angelo, D. V., Harrison, L., & Morrow, B. (2012). Associations between preconception counseling and maternal behaviors before and during pregnancy. *Maternal and Child Health Journal, 16*(9), 1854-1861. https://doi.org/10.1007/s10995-011-0932-4

World Health Organisation (WHO). (2012, March 1). *WHOQOL: Measuring Quality of Life.* *https://www.who.int/tools/whoqol*

Appendix A

Figure 2

Schematic Overview of the Qualitative and Quantitative Method Section of This Research.



Note. Dense description of this overview is found in the Methods. Colours represents parts of the Methods.

Appendix B

Sociodemographic and OD Specific Questions in the Questionnaire

Survey 'Vragenlijst eiceldonatie'

Vragenlijst eiceldonatie - Introduction

Beste deelnemer, Deze vragenlijst is bedoeld voor: - Vrouwen die overwegen om via eiceldonatie zwanger te raken - Vrouwen die in een eiceldonatie traject zitten (als wensmoeder/ontvanger van eicel) - Vrouwen die zwanger of bevallen zijn na eiceldonatie Deze vragenlijst is dus niet bedoeld voor eiceldonoren. Wilt u de vragenlijst aandachtig invullen? Dit maakt ons onderzoek zo betrouwbaar mogelijk. Met uw inbreng hopen wij de zorg rondom eiceldonatie te verbeteren. Wij stellen vragen over uw ervaring met eiceldonatie en de zorg daar omheen. Daarnaast stellen wij vragen over psychologische aspecten, zoals tevredenheid, stress en kwaliteit van leven. Sommige vragen kunnen wellicht emoties bij u oproepen. De vragenlijst bestaat uit acht onderdelen. Let op: de vragen hebben alleen betrekking op uw ervaringen rondom *eiceldonatie* en **niet** over eventuele spontane zwangerschappen of andere vruchtbaarheidsbehandelingen (bijvoorbeeld IVF met eigen eicellen). Het invullen van de vragenlijst zal ongeveer 20 minuten in beslag nemen. Uw ingevulde gegevens zullen gecodeerd worden verwerkt, zonder het noemen van identificerende persoonsgegevens, zoals naam en geboortedatum. De resultaten van dit onderzoek zullen gepubliceerd worden in passende medisch-wetenschappelijke tijdschriften en/of de website van Freya. Hartelijk dank namens het onderzoeksteam van de afdeling Verloskunde in het LUMC! Amber Visser, onderzoeksstudent Drs. Kim van Bentem, promovendus Dr. Lisa Lashley, gynaecoloog subspecialist voortplantingsgeneeskunde Dr. Marie-Louise van der Hoorn, gynaecoloog-perinatoloog

Vragenlijst eiceldonatie - Achtergrondinformatie

Number	Question	Answers
	Voor extra toelichting bij sommige vragen, klik op het informatie-tekentje onder de vraag.	
1.1	In welke fase van het eiceldonatie traject bevindt u zich op dit moment?	○ U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase) ○ U bent gestart met de eiceldonatie behandeling en heeft mogelijk al terugplaatsing(en) gehad ○ U bent op dit moment zwanger na eiceldonatie ○ U bent bevallen na een (of meerdere) eiceldonatie zwangerschap(pen) ○ U bent in het verleden behandeld met eiceldonatie, maar dat heeft niet geleid tot een succesvolle zwangerschap (niet zwanger geworden of een miskraam gehad)
1.2	Wat is uw leeftijd?	..... jaar
1.1.1	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Wat was uw leeftijd aan de start van uw laatste eiceldonatie behandeling?	..... jaar
1.1.2	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Heeft u ooit een embryo terugplaatsing gehad na eiceldonatie?	○ Ja ○ Nee
1.1.2.1	***If 'Heeft u ooit een embryo terugplaatsing gehad na eiceldonatie?' is equal to 'Ja' answer this question:*** Hoe vaak heeft u een embryo terugplaatsing gehad?	.....
1.1.3	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Bent u ooit zwanger geworden door middel van eiceldonatie?	○ Ja ○ Nee
1.1.3.1	***If 'Bent u ooit zwanger geworden door middel van eiceldonatie?' is equal to 'Ja' answer this question:*** Hoe vaak bent u zwanger geweest door middel van eiceldonatie?	..... keer zwanger geweest
1.3	Wat is uw hoogst afgeronde opleiding?	○ Basisonderwijs lagere school (basisschool) ○ Lager middelbaar onderwijs - LBO, VMBO-B of -K ○ Algemeen middelbaar onderwijs - VMBO-T (MAVO) ○ Hoger middelbaar onderwijs - HAVO, VWO ○ MBO opleiding ○ HBO opleiding
1.3.1	***If 'Wat is uw hoogst afgeronde opleiding?' is equal to 'Anders' answer this question:*** Anders, namelijk:	

1.4	Wat is bij u de reden dat u eiceldonatie nodig heeft (gehad) om zwanger te worden?	☐ Onbekende reden ☐ Hoge leeftijd / de overgang ☐ Verkeerde aanleg geslachtsorganen ☐ Drager van een erfelijke ziekte en dit niet willen doorgeven aan uw kind ☐ Mislukte IVF behandeling ☐ Endometriose ☐ Donatie van de eicel van de partner (gedeeld lesbisch moederschap) ☐ Hoogtechnologisch draagmoederschap ☐ Vervroegde overgang (premature ovariële insufficiëntie) ☐ Anders
1.4.1	***If 'Wat is bij u de reden dat u eiceldonatie nodig heeft (gehad) om zwanger te worden?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
1.5	In welk(e) land(en) gaat u het traject van eiceldonatie volgen/heeft u het traject van eiceldonatie gevolgd?	
1.1.4	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** In welk ziekenhuis of vruchtbaarheidskliniek wordt of bent u behandeld?	

Vragenlijst eiceldonatie - Preconceptionele counseling en zorg

Number	Question	Answers
	Onderstaande vragen gaan over de informatie/voorlichting die u ontvangen heeft voorafgaand aan de start van uw eiceldonatie behandeling.	
	Voor extra toelichting bij sommige vragen, klik op het informatie-tekentje onder de vraag.	
2.1	Heeft u, voordat de eiceldonatie behandeling startte, informatie/voorlichting gekregen over de behandeling en eventuele risico's van een eiceldonatie zwangerschap (preconceptionele counseling)?	○ Ja ○ Nee
2.1.1	***If 'Heeft u, voordat de eiceldonatie behandeling startte, informatie/voorlichting gekregen over de behandeling en eventuele risico's van een eiceldonatie zwangerschap (preconceptionele counseling)?' is equal to 'Ja' answer this question:*** Van wie heeft u deze informatie/voorlichting gekregen?	☐ Zorgverlener ☐ Zelf opgezocht ☐ Anders
2.1.1.1	***If 'Van wie heeft u deze informatie/voorlichting gekregen?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
2.1.2	***If 'Heeft u, voordat de eiceldonatie behandeling startte, informatie/voorlichting gekregen over de behandeling en eventuele risico's van een eiceldonatie zwangerschap (preconceptionele counseling)?' is equal to 'Ja' answer this question:*** In welke vorm heeft u informatie/voorlichting over de behandeling en risico's van eiceldonatie ontvangen?	☐ Gesprek met zorgverlener ☐ Website ☐ Folder ☐ Social media ☐ Anders
2.1.2.1	***If 'In welke vorm heeft u informatie/voorlichting over de behandeling en risico's van eiceldonatie ontvangen?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
2.1.3	***If 'Heeft u, voordat de eiceldonatie behandeling startte, informatie/voorlichting gekregen over de behandeling en eventuele risico's van een eiceldonatie zwangerschap (preconceptionele counseling)?' is equal to 'Ja' answer this question:*** Kunt u beschrijven waar deze informatie/voorlichting over ging?	

2.1.4	***If 'Heeft u, voordat de eiceldonatie behandeling startte, informatie/voorlichting gekregen over de behandeling en eventuele risico's van een eiceldonatie zwangerschap (preconceptionele counseling)?' is equal to 'Ja' answer this question:*** Bent u tevreden met de informatie/voorlichting, die u ontvangen heeft voorafgaand aan de eiceldonatie behandeling?	○ Ja ○ Nee
2.2	Heeft u informatie/voorlichting voorafgaand aan de eiceldonatie behandeling gemist?	○ Ja ○ Nee
2.2.1	***If 'Heeft u informatie/voorlichting voorafgaand aan de eiceldonatie behandeling gemist?' is equal to 'Ja' answer this question:*** Welke (aanvullende) informatie/voorlichting had u voorafgaand aan de eiceldonatie behandeling graag willen ontvangen?	
2.3	Is/was er voldoende aandacht voor uw emotionele/mentale welzijn voordat de eiceldonatie startte?	○ Ja ○ Nee
2.3.1	***If 'Is/was er voldoende aandacht voor uw emotionele/mentale welzijn voordat de eiceldonatie startte?' is equal to 'Nee' answer this question:*** Er is/was onvoldoende aandacht voor uw emotionele/mentale welzijn voordat de eiceldonatie behandeling startte, want	

Vragenlijst eiceldonatie - Counseling en zorg tijdens de zwangerschap

Number	Question	Answers
	Onderstaande vragen gaan over de informatie/voorlichting en de zorg die u ontvangen heeft tijdens uw eiceldonatie zwangerschap.	
	Voor extra toelichting bij sommige vragen, klik op het informatie-tekentje onder de vraag.	
3.1	Heeft u een eiceldonor gevonden?	○ Ja, de eiceldonor is anoniem ○ Ja, de eiceldonor is niet-anoniem ○ Nee, ik ben nog bezig met het zoeken naar een eiceldonor ○ Anders
3.1.1	***If 'Heeft u een eiceldonor gevonden?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.1.2	***If 'Heeft u een eiceldonor gevonden?' is equal to 'Ja, de eiceldonor is niet-anoniem' answer this question:*** Hoe heeft u de eiceldonor gevonden?	○ Familie (bv. zus, nicht, schoonzus) ○ Vrienden-/kennissenkring ○ Via een eicelbank ○ Via een oproep ○ Anders
3.1.2.1	***If 'Hoe heeft u de eiceldonor gevonden?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.2	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '1' answer this question:*** Wat was uw leeftijd ten tijde van de eerste eiceldonatie zwangerschap?	jaar
3.3	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '1' answer this question:*** Heeft u complicaties gehad tijdens uw eerste eiceldonatie zwangerschap?	○ Ja ○ Nee

3.3.1	***If 'Heeft u complicaties gehad tijdens uw eerste eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad?	☐ Buitenbaarmoederlijke zwangerschap ☐ Miskraam <16 weken ☐ Zwangerschapsbeëindiging tussen 16 en 24 weken (bv. vanwege een aangeboren afwijking) ☐ Hoge bloeddruk in de zwangerschap ☐ Zwangerschapsvergiftiging (pre-eclampsie) ☐ HELLP syndroom ☐ Groeivertraging van het kindje ☐ Suikerziekte in de zwangerschap ☐ Dreigende vroeggeboorte (<37 weken) ☐ Te vroeg gebroken vliezen (<37 weken) ☐ Voorliggende placenta ☐ Bloedverlies in het eerste trimester ☐ Bloedverlies in het tweede of derde trimester ☐ Sterfte van het kindje in de baarmoeder na 16 weken zwangerschap ☐ Anders
3.3.1.1	***If 'Welke complicatie(s) heeft u gehad?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.4	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '1' answer this question:*** Is er tijdens uw eerste eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?	○ Ja ○ Nee
3.4.1	***If 'Is er tijdens uw eerste eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?' is equal to 'Ja' answer this question:*** Welke medicatie was dit?	
3.5	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '1' answer this question:*** Waar en door wie werd u tijdens uw eerste eiceldonatie zwangerschap begeleid? In de:	☐ Eerstelijns zorg (verloskundigenpraktijk) ☐ Tweedelijns zorg in het ziekenhuis (bij de klinisch verloskundige of gynaecoloog) ☐ Derdelijns zorg in een academisch ziekenhuis (bij de gynaecoloog) ☐ Anders
3.5.1	***If 'Waar en door wie werd u tijdens uw eerste eiceldonatie zwangerschap begeleid? In de:' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.6	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '2' answer this question:*** Wat was uw leeftijd ten tijde van de tweede eiceldonatie zwangerschap?	jaar
3.7	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '2' answer this question:*** Heeft u complicaties gehad tijdens uw tweede eiceldonatie zwangerschap?	○ Ja ○ Nee
3.7.1	***If 'Heeft u complicaties gehad tijdens uw tweede eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad?	☐ Buitenbaarmoederlijke zwangerschap ☐ Miskraam <16 weken ☐ Zwangerschapsbeëindiging tussen 16 en 24 weken (bv. vanwege een aangeboren afwijking) ☐ Hoge bloeddruk in de zwangerschap ☐ Zwangerschapsvergiftiging (pre-eclampsie) ☐ HELLP syndroom ☐ Groeivertraging van het kindje ☐ Suikerziekte in de zwangerschap ☐ Dreigende vroeggeboorte (<37 weken) ☐ Te vroeg gebroken vliezen (<37 weken) ☐ Voorliggende placenta ☐ Bloedverlies in het eerste trimester ☐ Bloedverlies in het tweede of derde trimester ☐ Sterfte van het kindje in de baarmoeder na 16 weken zwangerschap ☐ Anders

3.7.1.1	***If 'Welke complicatie(s) heeft u gehad?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.8	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '2' answer this question:*** Is er tijdens uw tweede eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?	○ Ja ○ Nee
3.8.1	***If 'Is er tijdens uw tweede eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?' is equal to 'Ja' answer this question:*** Welke medicatie was dit?	
3.9	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '2' answer this question:*** Waar en door wie werd u tijdens uw tweede eiceldonatie zwangerschap begeleid? In de:	☐ Eerstelijns zorg (verloskundigenpraktijk) ☐ Tweedelijns zorg in het ziekenhuis (bij de klinisch verloskundige of gynaecoloog) ☐ Derdelijns zorg in een academisch ziekenhuis (bij de gynaecoloog) ☐ Anders
3.9.1	***If 'Waar en door wie werd u tijdens uw tweede eiceldonatie zwangerschap begeleid? In de:' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.10	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '3' answer this question:*** Wat was uw leeftijd ten tijde van de derde eiceldonatie zwangerschap?	jaar
3.11	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '3' answer this question:*** Heeft u complicaties gehad tijdens uw derde eiceldonatie zwangerschap?	○ Ja ○ Nee
3.11.1	***If 'Heeft u complicaties gehad tijdens uw derde eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad?	☐ Buitenbaarmoederlijke zwangerschap ☐ Miskraam <16 weken ☐ Zwangerschapsbeëindiging tussen 16 en 24 weken (bv. vanwege een aangeboren afwijking) ☐ Hoge bloeddruk in de zwangerschap ☐ Zwangerschapsvergiftiging (pre-eclampsie) ☐ HELLP syndroom ☐ Groeivertraging van het kindje ☐ Suikerziekte in de zwangerschap ☐ Dreigende vroeggeboorte (<37 weken) ☐ Te vroeg gebroken vliezen (<37 weken) ☐ Voorliggende placenta ☐ Bloedverlies in het eerste trimester ☐ Bloedverlies in het tweede of derde trimester ☐ Sterfte van het kindje in de baarmoeder na 16 weken zwangerschap ☐ Anders
3.11.1.1	***If 'Welke complicatie(s) heeft u gehad?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.12	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '3' answer this question:*** Is er tijdens uw derde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?	○ Ja ○ Nee
3.12.1	***If 'Is er tijdens uw derde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?' is equal to 'Ja' answer this question:*** Welke medicatie was dit?	
3.13	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '3' answer this question:*** Waar en door wie werd u tijdens uw derde eiceldonatie zwangerschap begeleid? In de:	☐ Eerstelijns zorg (verloskundigenpraktijk) ☐ Tweedelijns zorg in het ziekenhuis (bij de klinisch verloskundige of gynaecoloog) ☐ Derdelijns zorg in een academisch ziekenhuis (bij de gynaecoloog) ☐ Anders

3.13.1	***If 'Waar en door wie werd u tijdens uw derde eiceldonatie zwangerschap begeleid? In de:' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.14	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '4' answer this question:*** Wat was uw leeftijd ten tijde van de vierde eiceldonatie zwangerschap?	jaar
3.15	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is equal to '4' answer this question:*** Heeft u complicaties gehad tijdens uw vierde eiceldonatie zwangerschap?	○ Ja ○ Nee
3.15.1	***If 'Heeft u complicaties gehad tijdens uw vierde eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad?	☐ Buitenbaarmoederlijke zwangerschap ☐ Miskraam <16 weken ☐ Zwangerschapsbeëindiging tussen 16 en 24 weken (bv. vanwege een aangeboren afwijking) ☐ Hoge bloeddruk in de zwangerschap ☐ Zwangerschapsvergiftiging (pre-eclampsie) ☐ HELLP syndroom ☐ Groeivertraging van het kindje ☐ Suikerziekte in de zwangerschap ☐ Dreigende vroeggeboorte (<37 weken) ☐ Te vroeg gebroken vliezen (<37 weken) ☐ Voorliggende placenta ☐ Bloedverlies in het eerste trimester ☐ Bloedverlies in het tweede of derde trimester ☐ Sterfte van het kindje in de baarmoeder na 16 weken zwangerschap ☐ Anders
3.15.1.1	***If 'Welke complicatie(s) heeft u gehad?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.16	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is equal to '4' answer this question:*** Is er tijdens uw vierde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?	○ Ja ○ Nee
3.16.1	***If 'Is er tijdens uw vierde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?' is equal to 'Ja' answer this question:*** Welke medicatie was dit?	
3.17	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '4' answer this question:*** Waar en door wie werd u tijdens uw vierde eiceldonatie zwangerschap begeleid? In de:	☐ Eerstelijns zorg (verloskundigenpraktijk) ☐ Tweedelijns zorg in het ziekenhuis (bij de klinisch verloskundige of gynaecoloog) ☐ Derdelijns zorg in een academisch ziekenhuis (bij de gynaecoloog) ☐ Anders
3.17.1	***If 'Waar en door wie werd u tijdens uw vierde eiceldonatie zwangerschap begeleid? In de:' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.18	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '5' answer this question:*** Wat was uw leeftijd ten tijde van de vijfde eiceldonatie zwangerschap?	jaar
3.19	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '5' answer this question:*** Heeft u complicaties gehad tijdens uw vijfde eiceldonatie zwangerschap?	○ Ja ○ Nee

3.19.1	***If 'Heeft u complicaties gehad tijdens uw vijfde eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad?	☐ Buitenbaarmoederlijke zwangerschap ☐ Miskraam <16 weken ☐ Zwangerschapsbeëindiging tussen 16 en 24 weken (bv. vanwege een aangeboren afwijking) ☐ Hoge bloeddruk in de zwangerschap ☐ Zwangerschapsvergiftiging (pre-eclampsie) ☐ HELLP syndroom ☐ Groeivertraging van het kindje ☐ Suikerziekte in de zwangerschap ☐ Dreigende vroeggeboorte (<37 weken) ☐ Te vroeg gebroken vliezen (<37 weken) ☐ Voorliggende placenta ☐ Bloedverlies in het eerste trimester ☐ Bloedverlies in het tweede of derde trimester ☐ Sterfte van het kindje in de baarmoeder na 16 weken zwangerschap ☐ Anders
3.19.1.1	***If 'Welke complicatie(s) heeft u gehad?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.20	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '5' answer this question:*** Is er tijdens uw vijfde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?	○ Ja ○ Nee
3.20.1	***If 'Is er tijdens uw vijfde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?' is equal to 'Ja' answer this question:*** Welke medicatie was dit?	
3.21	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '5' answer this question:*** Waar en door wie werd u tijdens uw vijfde eiceldonatie zwangerschap begeleid? In de:	☐ Eerstelijns zorg (verloskundigenpraktijk) ☐ Tweedelijns zorg in het ziekenhuis (bij de klinisch verloskundige of gynaecoloog) ☐ Derdelijns zorg in een academisch ziekenhuis (bij de gynaecoloog) ☐ Anders
3.21.1	***If 'Waar en door wie werd u tijdens uw vijfde eiceldonatie zwangerschap begeleid? In de:' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.22	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '6' answer this question:*** Wat was uw leeftijd ten tijde van de zesde eiceldonatie zwangerschap?	jaar
3.23	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '6' answer this question:*** Heeft u complicaties gehad tijdens uw zesde eiceldonatie zwangerschap?	○ Ja ○ Nee
3.23.1	***If 'Heeft u complicaties gehad tijdens uw zesde eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad?	☐ Buitenbaarmoederlijke zwangerschap ☐ Miskraam <16 weken ☐ Zwangerschapsbeëindiging tussen 16 en 24 weken (bv. vanwege een aangeboren afwijking) ☐ Hoge bloeddruk in de zwangerschap ☐ Zwangerschapsvergiftiging (pre-eclampsie) ☐ HELLP syndroom ☐ Groeivertraging van het kindje ☐ Suikerziekte in de zwangerschap ☐ Dreigende vroeggeboorte (<37 weken) ☐ Te vroeg gebroken vliezen (<37 weken) ☐ Voorliggende placenta ☐ Bloedverlies in het eerste trimester ☐ Bloedverlies in het tweede of derde trimester ☐ Sterfte van het kindje in de baarmoeder na 16 weken zwangerschap ☐ Anders
3.23.1.1	***If 'Welke complicatie(s) heeft u gehad?' is equal to 'Anders' answer this question:*** Anders, namelijk:	

3.24	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '6' answer this question:*** Is er tijdens uw zesde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?	○ Ja ○ Nee
3.24.1	***If 'Is er tijdens uw zesde eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?' is equal to 'Ja' answer this question:*** Welke medicatie was dit?	
3.25	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '6' answer this question:*** Waar en door wie werd u tijdens uw zesde eiceldonatie zwangerschap begeleid? In de:	☐ Eerstelijns zorg (verloskundigenpraktijk) ☐ Tweedelijns zorg in het ziekenhuis (bij de klinisch verloskundige of gynaecoloog) ☐ Derdelijns zorg in een academisch ziekenhuis (bij de gynaecoloog) ☐ Anders
3.25.1	***If 'Waar en door wie werd u tijdens uw zesde eiceldonatie zwangerschap begeleid? In de:' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.26	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '7' answer this question:*** Wat was uw leeftijd ten tijde van de zevende eiceldonatie zwangerschap?	jaar
3.27	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '7' answer this question:*** Heeft u complicaties gehad tijdens uw zevende eiceldonatie zwangerschap?	○ Ja ○ Nee
3.27.1	***If 'Heeft u complicaties gehad tijdens uw zevende eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad?	☐ Buitenbaarmoederlijke zwangerschap ☐ Miskraam <16 weken ☐ Zwangerschapsbeëindiging tussen 16 en 24 weken (bv. vanwege een aangeboren afwijking) ☐ Hoge bloeddruk in de zwangerschap ☐ Zwangerschapsvergiftiging (pre-eclampsie) ☐ HELLP syndroom ☐ Groeivertraging van het kindje ☐ Suikerziekte in de zwangerschap ☐ Dreigende vroeggeboorte (<37 weken) ☐ Te vroeg gebroken vliezen (<37 weken) ☐ Voorliggende placenta ☐ Bloedverlies in het eerste trimester ☐ Bloedverlies in het tweede of derde trimester ☐ Sterfte van het kindje in de baarmoeder na 16 weken zwangerschap ☐ Anders
3.27.1.1	***If 'Welke complicatie(s) heeft u gehad?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
3.28	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '7' answer this question:*** Is er tijdens uw zevende eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?	○ Ja ○ Nee
3.28.1	***If 'Is er tijdens uw zevende eiceldonatie zwangerschap extra medicatie gestart uit voorzorg voor complicaties?' is equal to 'Ja' answer this question:*** Welke medicatie was dit?	
3.29	***If 'Hoe vaak bent u zwanger geweest door middel van eiceldonatie?' is bigger or equal than '7' answer this question:*** Waar en door wie werd u tijdens uw zevende eiceldonatie zwangerschap begeleid? In de:	☐ Eerstelijns zorg (verloskundigenpraktijk) ☐ Tweedelijns zorg in het ziekenhuis (bij de klinisch verloskundige of gynaecoloog) ☐ Derdelijns zorg in een academisch ziekenhuis (bij de gynaecoloog) ☐ Anders
3.29.1	***If 'Waar en door wie werd u tijdens uw zevende eiceldonatie zwangerschap begeleid? In de:' is equal to 'Anders' answer this question:*** Anders, namelijk:	

3.30	***If 'Bent u ooit zwanger geworden door middel van eiceldonatie?' is equal to 'Ja' answer this question:*** Heeft u extra zorg gekregen vanwege de eiceldonatie zwangerschap(pen)?	○ Ja ○ Nee
3.30.1	***If 'Heeft u extra zorg gekregen vanwege de eiceldonatie zwangerschap(pen)?' is equal to 'Ja' answer this question:*** Wat voor extra zorg heeft u ontvangen?	
3.31	***If 'Bent u ooit zwanger geworden door middel van eiceldonatie?' is equal to 'Ja' answer this question:*** Heeft u behoefte (gehad) aan extra zorg tijdens de eiceldonatie zwangerschap(pen)?	○ Ja ○ Nee
3.31.1	***If 'Heeft u behoefte (gehad) aan extra zorg tijdens de eiceldonatie zwangerschap(pen)?' is equal to 'Ja' answer this question:*** Welke extra zorg had u graag (nog meer) willen ontvangen?	
3.32	***If 'Bent u ooit zwanger geworden door middel van eiceldonatie?' is equal to 'Ja' answer this question:*** Heeft u het gevoel dat u tijdens de eiceldonatie zwangerschap(pen) informatie/voorlichting heeft gemist?	○ Ja ○ Nee
3.32.1	***If 'Heeft u het gevoel dat u tijdens de eiceldonatie zwangerschap(pen) informatie/voorlichting heeft gemist?' is equal to 'Ja' answer this question:*** Welke (aanvullende) informatie/voorlichting had u graag willen krijgen tijdens de eiceldonatie zwangerschap(pen)?	
3.33	***If 'Bent u ooit zwanger geworden door middel van eiceldonatie?' is equal to 'Ja' answer this question:*** Is/was er voldoende aandacht voor uw emotionele/mentale welzijn tijdens uw zwangerschap(pen)?	○ Ja ○ Nee
3.33.1	***If 'Is/was er voldoende aandacht voor uw emotionele/mentale welzijn tijdens uw zwangerschap(pen)?' is equal to 'Nee' answer this question:*** Er is/was onvoldoende aandacht voor uw emotionele/mentale welzijn tijdens de zwangerschap, want	

Vragenlijst eiceldonatie - Zorg na de bevalling

Number	Question	Answers
	Onderstaande vragen gaan over de zorg die u ontvangen heeft na uw eiceldonatie zwangerschap.	
	Voor extra toelichting bij sommige vragen, klik op het informatie-tekentje onder de vraag.	
	Let op: indien u nooit eerder bent bevallen na een eiceldonatie zwangerschap komen hier geen vragen te staan.	
4.1	***If 'Bent u ooit zwanger geworden door middel van eiceldonatie?' is equal to 'Ja' answer this question:*** Bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?	○ Ja ○ Nee
4.1.1	***If 'Bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is equal to 'Ja' answer this question:*** Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?	____ keer bevallen
4.1.1.1	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '1' answer this question:*** Hoe bent u de eerste keer bevallen?	○ Vaginale bevalling zonder hulpmiddelen (evt. met een knip) ○ Vaginale kunstverlossing (bv. met behulp van de vacuümpomp of een tang) ○ Van tevoren geplande keizersnede ○ Spoedkeizersnede (niet van tevoren gepland)
4.1.1.2	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '1' answer this question:*** Zijn er bij uw eerste bevalling complicaties opgetreden?	○ Ja ○ Nee
4.1.1.2.1	***If 'Zijn er bij uw eerste bevalling complicaties opgetreden?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad tijdens de eerste bevalling?	☐ Overmatig bloedverlies >1 liter (fluxus) ☐ Koorts ☐ Trage hartactie van het kind ☐ Niet vorderen van de ontsluiting ☐ Niet vorderen van de uitdrijving (te lang persen) ☐ Vastzittende placenta ☐ Meconiumhoudend vruchtwater (kindje had in het vruchtwater gepoept) ☐ Anders

4.1.1.2.1.1	***If 'Welke complicatie(s) heeft u gehad tijdens de eerste bevalling?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.3	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '1' answer this question:*** Heeft u extra zorg ontvangen na uw eerste bevalling?	○ Ja ○ Nee
4.1.1.3.1	***If 'Heeft u extra zorg ontvangen na uw eerste bevalling?' is equal to 'Ja' answer this question:*** Wat voor extra zorg heeft u ontvangen?	☐ Extra controle door de verloskundige ☐ Extra controle door de huisarts ☐ Extra controle door een medisch specialist (bv. gynaecoloog of internist) ☐ Extra controle op suikerziekte ☐ Extra controle van de bloeddruk ☐ Extra groei echo's ☐ Psychologische zorg ☐ Anders
4.1.1.3.1.1	***If 'Wat voor extra zorg heeft u ontvangen?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.4	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '2' answer this question:*** Hoe bent u de tweede keer bevallen?	○ Vaginale bevalling zonder hulpmiddelen (evt. met een knip) ○ Vaginale kunstverlossing (bv. met behulp van de vacuümpomp of een tang) ○ Van tevoren geplande keizersnede ○ Spoedkeizersnede (niet van tevoren gepland)
4.1.1.5	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '2' answer this question:*** Zijn er bij uw tweede bevalling complicaties opgetreden?	○ Ja ○ Nee
4.1.1.5.1	***If 'Zijn er bij uw tweede bevalling complicaties opgetreden?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad tijdens de tweede bevalling?	☐ Overmatig bloedverlies >1 liter (fluxus) ☐ Koorts ☐ Trage hartactie van het kind ☐ Niet vorderen van de ontsluiting ☐ Niet vorderen van de uitdrijving (te lang persen) ☐ Vastzittende placenta ☐ Meconiumhoudend vruchtwater (kindje had in het vruchtwater gepoept) ☐ Anders
4.1.1.5.1.1	***If 'Welke complicatie(s) heeft u gehad tijdens de tweede bevalling?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.6	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '2' answer this question:*** Heeft u extra zorg ontvangen na uw tweede bevalling?	○ Ja ○ Nee
4.1.1.6.1	***If 'Heeft u extra zorg ontvangen na uw tweede bevalling?' is equal to 'Ja' answer this question:*** Wat voor extra zorg heeft u ontvangen?	☐ Extra controle door de verloskundige ☐ Extra controle door de huisarts ☐ Extra controle door een medisch specialist (bv. gynaecoloog of internist) ☐ Extra controle op suikerziekte ☐ Extra controle van de bloeddruk ☐ Extra groei echo's ☐ Psychologische zorg ☐ Anders
4.1.1.6.1.1	***If 'Wat voor extra zorg heeft u ontvangen?' is equal to 'Anders' answer this question:*** Anders, namelijk:	

4.1.1.7	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '3' answer this question:*** Hoe bent u de derde keer bevallen?	○ Vaginale bevalling zonder hulpmiddelen (evt. met een knip) ○ Vaginale kunstverlossing (bv. met behulp van de vacuümpomp of een tang) ○ Van tevoren geplande keizersnede ○ Spoedkeizersnede (niet van tevoren gepland)
4.1.1.8	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '3' answer this question:*** Zijn er bij uw derde bevalling complicaties opgetreden?	○ Ja ○ Nee
4.1.1.8.1	***If 'Zijn er bij uw derde bevalling complicaties opgetreden?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad tijdens de derde bevalling?	☐ Overmatig bloedverlies >1 liter (fluxus) ☐ Koorts ☐ Trage hartactie van het kind ☐ Niet vorderen van de ontsluiting ☐ Niet vorderen van de uitdrijving (te lang persen) ☐ Vastzittende placenta ☐ Meconiumhoudend vruchtwater (kindje had in het vruchtwater gepoept) ☐ Anders
4.1.1.8.1.1	***If 'Welke complicatie(s) heeft u gehad tijdens de derde bevalling?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.9	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '3' answer this question:*** Heeft u extra zorg ontvangen na uw derde bevalling?	○ Ja ○ Nee
4.1.1.9.1	***If 'Heeft u extra zorg ontvangen na uw derde bevalling?' is equal to 'Ja' answer this question:*** Wat voor extra zorg heeft u ontvangen?	☐ Extra controle door de verloskundige ☐ Extra controle door de huisarts ☐ Extra controle door een medisch specialist (bv. gynaecoloog of internist) ☐ Extra controle op suikerziekte ☐ Extra controle van de bloeddruk ☐ Extra groei echo's ☐ Psychologische zorg ☐ Anders
4.1.1.9.1.1	***If 'Wat voor extra zorg heeft u ontvangen?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.10	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '4' answer this question:*** Hoe bent u de vierde keer bevallen?	○ Vaginale bevalling zonder hulpmiddelen (evt. met een knip) ○ Vaginale kunstverlossing (bv. met behulp van de vacuümpomp of een tang) ○ Van tevoren geplande keizersnede ○ Spoedkeizersnede (niet van tevoren gepland)
4.1.1.11	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '4' answer this question:*** Zijn er bij uw vierde bevalling complicaties opgetreden?	○ Ja ○ Nee
4.1.1.11.1	***If 'Zijn er bij uw vierde bevalling complicaties opgetreden?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad tijdens de vierde bevalling?	☐ Overmatig bloedverlies >1 liter (fluxus) ☐ Koorts ☐ Trage hartactie van het kind ☐ Niet vorderen van de ontsluiting ☐ Niet vorderen van de uitdrijving (te lang persen) ☐ Vastzittende placenta ☐ Meconiumhoudend vruchtwater (kindje had in het vruchtwater gepoept) ☐ Anders
4.1.1.11.1.1	***If 'Welke complicatie(s) heeft u gehad tijdens de vierde bevalling?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.12	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '4' answer this question:*** Heeft u extra zorg ontvangen na uw vierde bevalling?	○ Ja ○ Nee

4.1.1.12.1	***If 'Heeft u extra zorg ontvangen na uw vierde bevalling?' is equal to 'Ja' answer this question:*** Wat voor extra zorg heeft u ontvangen?	☐ Extra controle door de verloskundige ☐ Extra controle door de huisarts ☐ Extra controle door een medisch specialist (bv. gynaecoloog of internist) ☐ Extra controle op suikerziekte ☐ Extra controle van de bloeddruk ☐ Extra groei echo's ☐ Psychologische zorg ☐ Anders
4.1.1.12.1.1	***If 'Wat voor extra zorg heeft u ontvangen?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.13	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '5' answer this question:*** Hoe bent u de vijfde keer bevallen?	○ Vaginale bevalling zonder hulpmiddelen (evt. met een knip) ○ Vaginale kunstverlossing (bv. met behulp van de vacuümpomp of een tang) ○ Van tevoren geplande keizersnede ○ Spoedkeizersnede (niet van tevoren gepland)
4.1.1.14	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '5' answer this question:*** Zijn er bij uw vijfde bevalling complicaties opgetreden?	○ Ja ○ Nee
4.1.1.14.1	***If 'Zijn er bij uw vijfde bevalling complicaties opgetreden?' is equal to 'Ja' answer this question:*** Welke complicatie(s) heeft u gehad tijdens de vijfde bevalling?	☐ Overmatig bloedverlies >1 liter (fluxus) ☐ Koorts ☐ Trage hartactie van het kind ☐ Niet vorderen van de ontsluiting ☐ Niet vorderen van de uitdrijving (te lang persen) ☐ Vastzittende placenta ☐ Meconiumhoudend vruchtwater (kindje had in het vruchtwater gepoept) ☐ Anders
4.1.1.14.1.1	***If 'Welke complicatie(s) heeft u gehad tijdens de vijfde bevalling?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.1.15	***If 'Hoe vaak bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is bigger or equal than '5' answer this question:*** Heeft u extra zorg ontvangen na uw vijfde bevalling?	○ Ja ○ Nee
4.1.1.15.1	***If 'Heeft u extra zorg ontvangen na uw vijfde bevalling?' is equal to 'Ja' answer this question:*** Wat voor extra zorg heeft u ontvangen?	☐ Extra controle door de verloskundige ☐ Extra controle door de huisarts ☐ Extra controle door een medisch specialist (bv. gynaecoloog of internist) ☐ Extra controle op suikerziekte ☐ Extra controle van de bloeddruk ☐ Extra groei echo's ☐ Psychologische zorg ☐ Anders
4.1.1.15.1.1	***If 'Wat voor extra zorg heeft u ontvangen?' is equal to 'Anders' answer this question:*** Anders, namelijk:	
4.1.2	***If 'Bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is equal to 'Ja' answer this question:*** Heeft u ooit behoefte gehad aan extra zorg na (een van) de eiceldonatie zwangerschap(pen)?	○ Ja ○ Nee
4.1.2.1	***If 'Heeft u ooit behoefte gehad aan extra zorg na (een van) de eiceldonatie zwangerschap(pen)?' is equal to 'Ja' answer this question:*** Welke extra zorg had u graag gewild?	

4.1.3	***If 'Bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is equal to 'Ja' answer this question:*** Heeft u mentale of emotionele problemen ondervonden na een eiceldonatie zwangerschap?	○ Ja ○ Nee
4.1.3.1	***If 'Heeft u mentale of emotionele problemen ondervonden na een eiceldonatie zwangerschap?' is equal to 'Ja' answer this question:*** Wat voor mentale of emotionele problemen?	
4.1.4	***If 'Bent u bevallen na eiceldonatie zwangerschap(pen) >24 weken?' is equal to 'Ja' answer this question:*** Is/was er voldoende aandacht voor uw emotionele/mentale welzijn na de bevalling(en)?	○ Ja ○ Nee
4.1.4.1	***If 'Is/was er voldoende aandacht voor uw emotionele/mentale welzijn na de bevalling(en)?' is equal to 'Nee' answer this question:*** Er is/was onvoldoende aandacht voor uw emotionele/mentale welzijn na de bevalling(en), want	

Appendix C

Table 1

Overview of the Measurements, Number of Questions With Explanation and Scoring for the Outcomes QoL, Contentment and Anxiety and Distress.

Outcome	Measurement and scales	Number of questions (explanation)	Scoring[a]
QoL	**FertiQoL**		
	Total Core questions:	24 (Emotional, Mind/Body, Relational, and Social subscale)	Original scoring FertiQoL
	- Emotional subscale	6	Original scoring FertiQoL
	- Mind/body subscale	6	Original scoring FertiQoL
	- Relational subscale	6	Original scoring FertiQoL
	- Social subscale	6	Original scoring FertiQoL
	Total FertiQoL +	37 (Total Core questions and Total Treatment questions +)	Adjusted scoring FertiQoL
	Total FertiQoL	34 (Total Core questions and Total Treatment questions)	Original scoring FertiQoL
Contentment	**FertiQoL**		
	Total treatment question +	13 (Environment subscale + and Tolerability subscale)	Adjusted scoring FertiQoL
	Total Treatment questions:	10 (Environment and Tolerability subscale)	Original scoring FertiQoL
	- Environment subscale	6	Original scoring FertiQoL
	- Environment subscale +	9 (Environment subscale and 3 self-created questions)	Adjusted scoring FertiQoL
	- Tolerability subscale	4	Original scoring FertiQoL
Anxiety/Distress	**GAD-7**		
	Total score GAD-7 +	12 (Total score GAD-7 and 5 self-created questions)	Adjusted scoring GAD-7
	Total score GAD-7	7	Original scoring GAD-7

Note. + = Three self-created questions were added to the original FertiQoL scales and subscales. Five self-created questions were added to the original GAD-7 questionnaire.

[a]Original and adjusted scoring is explained in the Methods of this thesis.

Appendix D

Questions on Quality of Life in the Questionnaire

Vragenlijst eiceldonatie - Psychosociale aspecten: kwaliteit van leven

Number	Question	Answers
	Voor extra toelichting bij sommige vragen, klik op het informatie-tekentje onder de vraag.	
	De volgende vragen gaan over uw kwaliteit van leven en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergeeft op dit moment. Dit onderdeel bestaat uit 26 vragen.	
	De volgende vragen gaan over uw kwaliteit van leven en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergeeft op dit moment. Dit onderdeel bestaat uit 26 vragen.	
	De volgende vragen gaan over uw kwaliteit van leven en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergaf **ten tijde van uw eerste eiceldonatie behandeling**. Dit onderdeel bestaat uit 26 vragen.	
	De volgende vragen gaan over uw kwaliteit van leven en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergaf **ten tijde van uw eerste eiceldonatie behandeling**. Dit onderdeel bestaat uit 26 vragen.	
5.1	Hoe is uw gezondheid volgens u?	○ Zeer slecht ○ Slecht ○ Niet goed, niet slecht ○ Goed ○ Zeer goed
5.2	Bent u tevreden met de kwaliteit van uw leven?	○ Zeer ontevreden ○ Ontevreden ○ Niet tevreden, niet ontevreden ○ Tevreden ○ Zeer tevreden
5.3	Worden uw aandacht en concentratie belemmerd door gedachten over onvruchtbaarheid of het eiceldonatie traject?	○ Absoluut ○ In hoge mate ○ In zekere mate ○ Niet zo erg ○ Helemaal niet
5.4	Denkt u dat u niet vooruit kunt gaan met andere doelen en plannen in uw leven vanwege vruchtbaarheidsproblemen?	○ Absoluut ○ In hoge mate ○ In zekere mate ○ Niet zo erg ○ Helemaal niet
5.5	Voelt u zich leeg of uitgeput vanwege vruchtbaarheidsproblemen?	○ Absoluut ○ In hoge mate ○ In zekere mate ○ Niet zo erg ○ Helemaal niet
5.6	Denkt u dat u uw vruchtbaarheidsproblemen en het eiceldonatie traject aankunt?	○ Absoluut ○ In hoge mate ○ In zekere mate ○ Niet zo erg ○ Helemaal niet
5.7	Bent u tevreden met de steun die u krijgt van vriend(inn)en met betrekking tot uw vruchtbaarheidsproblemen?	○ Zeer ontevreden ○ Ontevreden ○ Niet tevreden, niet ontevreden ○ Tevreden ○ Zeer tevreden
5.8	Bent u tevreden met uw seksuele relatie ondanks dat u vruchtbaarheidsproblemen heeft?	○ Zeer ontevreden ○ Ontevreden ○ Niet tevreden, niet ontevreden ○ Tevreden ○ Zeer tevreden

5.9	Veroorzaken uw vruchtbaarheidsproblemen gevoelens van jaloezie en wrok?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
5.10	Ervaart u verdriet en/of gevoelens van verlies over het feit dat u geen kinderen van uw eigen eicellen (meer) kunt krijgen?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
5.11	Wisselt uw stemming van hoopvol tot wanhopig vanwege vruchtbaarheidsproblemen?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
5.12	Bent u in sociaal opzicht geïsoleerd vanwege vruchtbaarheidsproblemen?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
5.13	Gaan uw partner en u teder en liefhebbend met elkaar om ondanks het feit dat u vruchtbaarheidsproblemen heeft?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
5.14	Staan uw vruchtbaarheidsproblemen uw dagelijkse werk of verplichtingen in de weg?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
5.15	Voelt u zich vanwege uw vruchtbaarheidsproblemen ongemakkelijk bij sociale gelegenheden als vakanties en festiviteiten?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
5.16	Denkt u dat uw familie kan begrijpen wat u doormaakt?	○ Altijd ○ Zeer vaak ○ Redelijk vaak
5.17	Hebben uw vruchtbaarheidsproblemen de band met uw partner versterkt?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.18	Voelt u zich somber en verdrietig door uw vruchtbaarheidsproblemen?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.19	Voelt u zich door uw vruchtbaarheidsproblemen minder dan mensen met kinderen of mensen die op een natuurlijke manier zwanger kunnen worden?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.20	Heeft u last van vermoeidheid vanwege vruchtbaarheidsproblemen of het eiceldonatie traject?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet

5.21	Hebben uw vruchtbaarheidsproblemen een negatieve invloed gehad op uw relatie?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.22	Vindt u het moeilijk om met uw partner over uw gevoelens met betrekking tot onvruchtbaarheid en eiceldonatie te spreken?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.23	Bent u tevreden met uw relatie ondanks het feit dat u vruchtbaarheidsproblemen heeft?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.24	Voelt u sociale druk om (meer) kinderen te krijgen?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.25	Maken uw vruchtbaarheidsproblemen u boos?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
5.26	Voelt u pijn of lichamelijk ongemak vanwege uw vruchtbaarheidsproblemen?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet

Appendix E

Questions on Contentment in the Questionnaire

Vragenlijst eiceldonatie - Psychosociale aspecten: tevredenheid en behandeling

Number	Question	Answers
	Voor extra toelichting bij sommige vragen, klik op het informatie-tekentje onder de vraag.	
	De volgende vragen gaan over uw tevredenheid over de behandeling en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergeeft op dit moment. Dit onderdeel bestaat uit 13 vragen.	
	De volgende vragen gaan over uw tevredenheid over de behandeling en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergaf **ten tijde van uw eerste eiceldonatie behandeling**. Dit onderdeel bestaat uit 13 vragen.	
	De volgende vragen gaan over uw tevredenheid over de behandeling en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergaf **ten tijde van uw eerste eiceldonatie behandeling**. Dit onderdeel bestaat uit 13 vragen.	
6.1	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Heeft de eiceldonatie behandeling een negatieve invloed op uw stemming?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
6.2	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Zijn de medische voorzieningen die u graag zou gebruiken beschikbaar voor u?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
6.3	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Hoe gecompliceerd is de procedure en/of toediening van medicatie voor uw behandeling?	○ Heel erg ○ Erg ○ Redelijk ○ Een beetje ○ Helemaal niet
6.4	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Heeft u last van het effect dat de eiceldonatie behandeling op uw dagelijkse of werkgerelateerde activiteiten heeft?	○ Heel veel ○ Veel ○ Redelijk veel ○ Een beetje ○ Helemaal niet
6.5	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Heeft u het gevoel dat het medische personeel dat u voor uw eiceldonatie behandeling ziet, begrijpt wat u doormaakt?	○ Altijd ○ Zeer vaak ○ Redelijk vaak ○ Zelden ○ Nooit
6.6	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Heeft u last van lichamelijke bijwerkingen door de eiceldonatie behandeling (door bijvoorbeeld medicatie)?	○ Heel veel ○ Veel ○ Redelijk veel ○ Een beetje ○ Helemaal niet
6.7	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Bent u tevreden met de kwaliteit van zorg op emotioneel/mentaal gebied?	○ Zeer ontevreden ○ Ontevreden ○ Niet tevreden, niet ontevreden ○ Tevreden ○ Zeer tevreden
6.8	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Hoe tevreden bent u met de eiceldonatie behandeling(en) die u heeft gehad?	○ Zeer ontevreden ○ Ontevreden ○ Niet tevreden, niet ontevreden ○ Tevreden ○ Zeer tevreden
6.9	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Hoe tevreden bent u met de kwaliteit van de informatie die u over medicatie en/of de eiceldonatie behandeling heeft ontvangen?	○ Zeer ontevreden ○ Ontevreden ○ Niet tevreden, niet ontevreden ○ Tevreden ○ Zeer tevreden

6.10	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Bent u tevreden over het contact dat u met het medische personeel heeft dat u voor uw eiceldonatie behandeling ziet?	○ Zeer ontevreden ○ Ontevreden ○ Niet tevreden, niet ontevreden ○ Tevreden ○ Zeer tevreden
6.11	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Is het zorgpersoneel voldoende op de hoogte van uw eiceldonatie traject?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
6.12	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Heeft het zorgpersoneel volgens u de benodigde kennis om uw vragen te beantwoorden?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet
6.13	***If 'In welke fase van het eiceldonatie traject bevindt u zich op dit moment?' is not equal to 'U overweegt zwanger te worden met eiceldonatie, maar de behandeling is nog niet gestart (voorbereidende fase)' answer this question:*** Als u specifieke vragen heeft over mogelijke complicaties, kan het zorgpersoneel deze dan beantwoorden?	○ In extreem hoge mate ○ In hoge mate ○ In zekere mate ○ Een beetje ○ Helemaal niet

Appendix F

Questions on Anxiety and Distress in the Questionnaire

Vragenlijst eiceldonatie - Psychosociale aspecten: stress en angst

Number	Question	Answers
	Voor extra toelichting bij sommige vragen, klik op het informatie-tekentje onder de vraag.	
	De volgende vragen gaan over uw stress en angst, en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergeeft op dit moment. Dit onderdeel bestaat uit 12 vragen.	
	De volgende vragen gaan over uw stress en angst, en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergeeft op dit moment. Dit onderdeel bestaat uit 12 vragen.	
	De volgende vragen gaan over uw stress en angst, en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergaf **ten tijde van uw eerste eiceldonatie behandeling**. Dit onderdeel bestaat uit 12 vragen.	
	De volgende vragen gaan over uw stress en angst, en kunnen wellicht emoties bij u oproepen. Kies bij elke vraag het antwoord dat het beste uw gevoel weergaf **ten tijde van uw eerste eiceldonatie behandeling**. Dit onderdeel bestaat uit 12 vragen.	
7.1	Ik voel me nerveus, angstig of gespannen.	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.2	Ik kan niet stoppen met mij zorgen te maken.	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.3	Ik maak me te veel zorgen over verschillende dingen.	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.4	Ik heb moeite om mij te ontspannen.	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.5	Ik voel me rusteloos en kan moeilijk stil zitten.	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.6	Ik ben snel geërgerd of geïrriteerd.	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.7	Ik ben bang dat er iets vreselijks zou kunnen gebeuren.	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.8	Heeft u door kosten voor het eiceldonatie traject financiële stress ervaren?	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.9	Heeft u de angst gehad dat u nooit moeder zou kunnen worden?	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag

7.10	Bent u bang geweest voor medicatie, bijwerkingen en/of de behandeling?	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.11	Heeft u zich zorgen gemaakt over de complicaties die bij een eiceldonatie zwangerschap kunnen voorkomen?	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag
7.12	Heeft u het gevoel gehad dat u gefaald heeft of dat uw lichaam heeft gefaald?	○ Helemaal niet ○ Verscheidene dagen ○ Meer dan de helft van de dagen ○ Bijna elke dag

Vragenlijst eiceldonatie - Laatste opmerkingen

Number	Question	Answers
8.1	Heeft u nog laatste opmerkingen of dingen die u kwijt wilt over deze vragenlijst?	

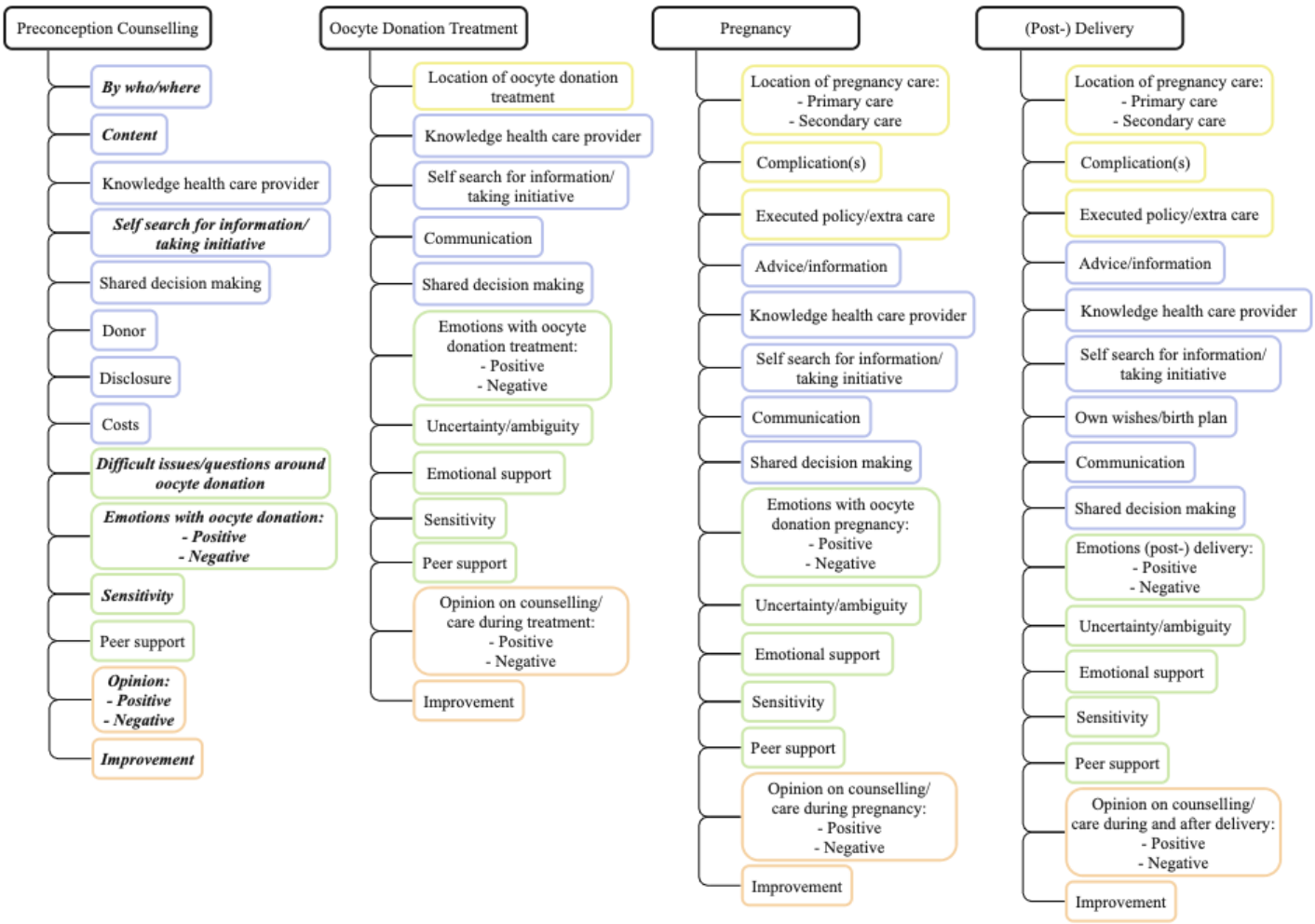
Vragenlijst eiceldonatie - Outro

Hartelijk dank voor uw deelname aan deze vragenlijst. Uw inbreng wordt zeer gewaardeerd! Uw ingevulde gegevens zullen gecodeerd worden verwerkt, zonder het noemen van identificerende persoonsgegevens, zoals naam en geboortedatum. Heeft u nog vragen? Neem dan contact op met donor@lumc.nl Uw gegevens zijn opgeslagen. U kunt dit tabblad nu sluiten.

Appendix G

Figure 3

Codebook Defined by the Researchers After Analysing the Focus Groups, With 4 Code Groups and 57 Codes.



Note. Main Themes: Yellow = health care, Blue = counselling, Green = emotions, Orange = improvement. ***Bold italics*** = codes discussed in this paper. OD = Oocyte Donation.

Appendix H

Table 2

Answers on the Questionnaire Given by the Participants on Content of PC, Missed Information During PC, and why There was Insufficient Attention for Mental Wellbeing.

Content of PC	Possible pregnancy risks
	Disclosure
	Wellbeing of OD children
	Social support
	Psychological support
	Laws and regulations
	Donor options
	The positive and negative points of OD treatment
	Difficult issues with OD
	Costs
	Changes of a successful pregnancy
	Information on the donation procedure
	Medication
	General information on the OD treatment
Missed information during PC	Success rate
	Quality of the different clinics
	Information on ultrasounds
	Practical and logistical information
	Information on the number of oocytes
	Shared decision making in primary and secondary care
	Information on the phases of emotional process
	Waiting time
	Requirements for the donor
	Psychological care
	Would have liked less self-search and taking initiative
	Possible risks
	Recognition for grief
	A clear overview on the OD options
	Information on communication with the donor
	More information on costs and compensation
Insufficient attention for mental wellbeing, because	There was no psychologist, but a social worker
	There was no attention for mental wellbeing
	No psychological support was offered
	No questions were asked about how I felt
	Only the technical part was spoken
	There was no support system
	I felt like a number
	There was no attention for my grief of the loss of passing my bloodline
	I had to search for mental support myself
	The social worker does not understand what I have gone through
	I had to pay for psychological help, which I could not

Note. OD = Oocyte Donation. PC = Preconception Counselling.