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Prenatal Examinations for Down Syndrome and Possible Effects on Maternal-Fetal Attachment

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1. Introduction

The pregnancy and the adaptation to motherhood is one of the most significant events during a woman's life time. The pregnancy is associated with major psychological and physical changes. The woman expects to attach to the fetus and prepare for the life as a mother. Interventions during pregnancy must be implemented with respect for the sensitive period as a pregnancy is.

The aim with this chapter is to describe and discuss possible effects of prenatal examinations for Down syndrome during pregnancy on maternal-fetal attachment. Additional aims are to illuminate experiences and reactions during the waiting-time for test results, the experience of false positive results from screening examinations and the perception of complex information from prenatal examinations. There is of great importance to explore and highlight these questions to minimize the risk for negative affection on the maternal-fetal attachment by prenatal screening or diagnosis for Down syndrome.

2. Maternal-fetal attachment

One of the basic prerequisite for the survival of a new-born baby is that there is a relation of attachment to the parents. This means a lasting emotional relation to a person who will secure the baby's trust and safety. The theory about attachment was developed by John Bowlby in England in the 50s. Maternal-fetal attachment (MFA) is a concept used to describe the relationship between a pregnant woman and the fetus. It describes the process in which the pregnant woman experience feelings and emotions for the fetus. At the same time her maternal identity is developed. This concept is rather new and is still not well studied or fully defined. MFA is based on representations of the fetus according to qualitative descriptions of maternal attitudes and adaption to pregnancy (Salisbury et al., 2003). The attachment between the pregnant woman and the fetus during the pregnancy had been described as the first important relation to the baby and has strongly been associated with the following mother-child relation after the birth. The attachment to the fetus and later to the baby is developing successively. It starts in early pregnancy and increases during the pregnancy to be most intensive during the last trimester (Alhausen, 2008, Yercheski, 2008). The concept maternal-fetal attachment was defined by professor

Mecca S. Cranley and are described as “the extent to which women engage in behaviors that represent affiliation and interaction with their unborn child” (Cranley, 1981, s 282).

There is not consensus about the concept attachment/bonding during pregnancy. The definitions are in generally split in definitions which describe attachment as emotions and those who describes attachment as behaviours during pregnancy which indicates the pregnant woman’s attachment to the fetus. Three scales based on each definition of the concept have been developed to quantify MFA. The original maternal-fetal attachment scale (MFAS), developed by Cranley (1981) contains 24 items and intends to measure maternal-fetal attachment. The scale measures to what extent the mother-to-be is engaged in behaviour which is expressing a sense of belonging and an interaction with the unborn baby. The attachment is defined as how the mother-to-be cope with the development as the pregnancy means. It was developed from the attachment theory of Bowlby (Bowlby, 1969). The 24 items were divided into five subscales; differentiation of self from fetus, interaction with the fetus, attributing characteristics to the fetus, giving of self, and role taking. The response format is Likert-like with scores of 1 (definitely no), 2 (no), 3 (uncertain), 4 (yes) and 5 (definitely yes). Regarding the reliability of the scale, in previous studies. In previous studies the Cronbach’s alpha for the total scale ranged from .82 to .91 and for the subscales .52 to .73 (Bloom, 1995; Lindgren, 2001; Shieh, 2006).

In 1990 another, the second, instrument intending to measure prenatal attachment was developed by Müller. This instrument – prenatal attachment inventory (PAI) was designed to measure the relationship that develops between the mother-to-be and the fetus. Müller defined prenatal attachment as the unique, affectionate relationship that develops between the pregnant woman and the fetus (Müller, 1993).

According to Condon & Corkindale, 1997, the concept prenatal attachment include the following five factors; wishing for knowledge about the unborn baby, happiness for the interplay with the baby, wishing for protecting the baby and satisfying its needs, worrying about losing the baby or that something will be wrong with the baby, and that the baby’s needs have priority over the own needs. They developed the instrument MAAS (maternal antenatal attachment scale). Condon’s definition was closer to the attachment theory of Bowlby. Condon described attachment as love, his definition of attachment was “the core experience of attachment is love” and proposed five subjective experiences of love.

The disposition to:

1. Know
2. Be with and to interact
3. To avoid separation or loss
4. To protect and
5. To identify and to gratify the needs of the object (Condon, 1993; Condon & Corkindale, 1997).

There are some difficulties to measure maternal-fetal attachment with the self assessment instruments which are available today. One difficulty is the limitation of the scales in their sensitivity to cultural differences and experiences. An adaption of the existing scales may be possible. Cranley’s maternal-fetal attachment scale has been modified to a Japanese version with 20 items. The results of that study of 275 women confirmed previous studies. MFA increased significantly from gestational week 5 to gestational week 40. Feeling fetal movements had a particularly positive effect. Women with ambivalent feelings responded lower in the scale (Narita & Maehara, 1993).

Another close concept to maternal-fetal attachment is maternal/fetal interaction. A questionnaire to measure maternal/fetal interaction was developed in 1997 by Nelson. By this instrument the mothers spontaneous talk to herself or to the fetus assessed and emotional words such as "happy", "sad", "bored", "excited", "calm" or "anxious". Higher scores on the scale indicate higher level of maternal/fetal interaction (Ji & Han, 2010).

3. Factors which may affect maternal-fetal attachment

The development of the technologies which are used in the context of pregnancy and child birth may have psychological consequences for the expecting mother. There are normal psychological changes during pregnancy. It is a period of psychological and physiological adaptation and causes strong emotional reactions and sometimes even ambivalent feelings. It is a complex process. It is also related to the partner, the own mother and friends (Bibring et al., 1961; Shereshefsky & Yarrow, 1975). The first part of a pregnancy is characterized as a vulnerable period when the woman has to accept the fetus as a part of herself (Raphael-Leff, 1992). All interventions during pregnancy must be done with the normal psychological changes in mind.

Some factors are known as such which may facilitate the attachment; the experience of fetal movements, support from family, friends and the partner. Higher age of the expectant mother, depression, worry and abuse may affect the attachment in a negative way. Higher levels of maternal-fetal attachment are reported when the woman has a positive relationship with the expectant father. Women with high- risk pregnancies do not seemed to attach to their fetus in a lower extent than women with normal pregnancies. Failure to attach to the fetus during pregnancy seems to be more common in women from poor social and economic conditions (Alhausen, 2008). Patient education courses seem to positively influence the prenatal attachment (Bellieni et al., 2007).

In a study of 252 pregnant women MFA had a positive relationship with positive health practices, such as diet exercise, drug and alcohol use (Lindgren, 2001). The author discuss the practical problems about interventions intended to increase maternal-fetal attachment. There is not yet evidence which effects different interventions have on MFA. However, some reasons for delayed or low levels of maternal-fetal attachment are well-known, for example self-protection for emotional trauma suffering during a previous loss. In the antenatal care the care givers can try to identify women with poor maternal-fetal attachment and help them improve their health practices trying to improve woman's health and pregnancy outcome.

Effects of an intervention based on mind and body interconnectedness, called Qi, on maternal-fetal interaction were studied. Totally 70 women were included in the study. Qi exercise was carried out in the second half of the pregnancy. The exercise lasted for 90 minutes, twice a week. This study showed effect of Qi on maternal/fetal interaction as well as on maternal depressive symptoms and physical comfort. In this study the maternal/fetal interaction was measured by the Interpersonal Communication Questionnaire (Talking to the baby) (Ji & Han, 2010).

Hyperemesis gravidarum is a rather rare complication of pregnancy, which means a severe form of nausea and vomiting. This may lead to problems to intake food and fluid. Among women with hyperemesis gravidarum there were an association with less developed maternal-fetal attachment in gestational weeks 7-16, but this negative effect was very small compared to pregnant women without hyperemesis gravidarum. At follow-up after 26th

weeks of gestation this negative effect could not be proved anymore (McCormack et al., 2011).

Maternal-fetal attachment is not studied in developing countries. It is reasonable to assume that the MFA is affected of the high mortality rate for both women and infants (Salisbury et al., 2003).

When using assistance with IVF – in vitro fertilization to get pregnant there may be stressful for the woman compared to getting pregnant the “normal” way. However, it does not seem to affect the attachment to the baby during pregnancy (McMahon et al., 1997, Stanton & Golombok, 1993). Prenatal attachment was in a study by Hjelmstedt and colleagues (2006) compared between 56 women who had underwent IVF and 41 controls. A self-rating scale was completed in gestational weeks 26 and 36. As the pregnancy progressed the prenatal attachment was increased in the same way in both groups. A conclusion of this study was that marital satisfaction, age, ambivalence and detachment was significant contributors to prenatal attachment. As proved in other studies the same results are presented regarding women who get pregnant with assistance. When women are less positive about pregnancy, childbirth and childcare they show weaker attachment to their unborn child (Stanton & Golombok, 1993).

When having an increased risk for having a child with a genetic condition one possibility is PGD (prenatal genetic diagnosis). In vitro fertilization is used to produce embryos which are genetic tested and selected on the absence of particular genetic conditions. There is often a need for repeated cycles of ovarian stimulations, IVF and transfers of an embryo. This is trying and results in fluctuations in the woman’s anxiety (Karatras et al., 2011), which may affect the attachment.

4. Prenatal examinations in general and its possible effects on maternal-fetal attachment

An ultrasound examination in the second trimester is offered to all pregnant women in Sweden. This examination is accepted of the vast majority (SBU 1998). To many expecting parents the ultrasound examination has such a strong confirming effect that they wait until after the examination before they tell family and friends about the pregnancy (Ekelin, 2004). The possibility to see the fetus on the ultrasound screen has shift the focus from the time point when the pregnant woman felt the movements of the baby by herself to the time point when you can see the fetus on the screen.

If, and in what extent, prenatal examinations affects the attachment are fairly insufficient explored. Ultrasound examination usually takes place before the woman recognizes the first movements of the baby and may be a facilitator for maternal-fetal attachment. However, studies of ultrasound examination and its effects on the maternal-fetal attachment show contradictory findings. The relationship between the expectant mother, and even the expectant father may start earlier in pregnancy (Stormer, 2003, Zeichmeister, 2001). The time point when the woman reported movements from her baby, so called quickening, used to be a very important moment, but have in those days been replaced by seeing the fetus on the ultrasound screen. Studies of attachment between the expecting mother and the fetus in relation to ultrasound examination have showed contradictory results (Lumley, 1990). Some studies do not present any differences between the attachment to the fetus (Heidrich & Cranley, 1989), whereas other studies present a positive effect (Caccia, 1991), especially the first ultrasound examination during pregnancy (Sandbrook & Adamson-Macedo, 2004) and ultrasound examination early in pregnancy (Stormer, 2003). According to a meta-analysis of

the effects of ultrasound examination on maternal-fetal attachment, the attachment increased to some extent (Yercheski et al., 2008). Several studies of the effects of 3 D- or 4 D ultrasound have not proved any improved attachment compared to 2 D ultrasound (Righetti et al., 2005; Rustico et al., 2005, Sedgmen et al., 2005), but may cause a positive change in the parents-to-be's feelings for the fetus (Pretorius et al., 2006). The attachment seems to increase and the worry about the health of the fetus decrease when the ultrasound examination is combined with a discussion with a health care professional. The discussion contained an explanation of the woman's and the fetuses anatomy and a demonstration of fetal movements. Except the discussion in relation to the examination the strategy also contained a follow-up discussion (Boukydis et al., 2006). When assessing the ultrasound examination's effects on the maternal-fetal attachment there are, except the general difficulties to measure maternal-fetal attachment, some methodological factors to take into consideration. The length of the examination, the information related to the examination and the communication between the health care giver and the parents-to-be affects the experience of the examination and may even the maternal-fetal attachment (Alhausen, 2008). Comparing studies are difficult to perform due to the fact that almost all women undergo ultrasound examination during pregnancy (Lumley, 1990).

The aim of an ultrasound examination in the second trimester is not primarily screening for Down syndrome but it is possible to detect malformations soft markers or anomalies which are associated with Down syndrome.

5. Prenatal examinations for Down syndrome and its possible effects on maternal-fetal attachment

Today, many of the prenatal examinations and screening such as nuchal translucency measurement in early pregnancy, maternal serum screening, combined ultrasound examination and biochemical screening and invasive diagnostics are aimed to find risk pregnancies for Down syndrome or Down syndrome. The invasive test being used are amniocentesis or chorion villous biopsy. To be offered early screening, either early ultrasound examination including measurement of nuchal translucency or maternal serum screening has in one study showed an increase of the maternal-fetal attachment. However, this increase seemed to be small and temporary (Kleinveld et al., 2007). A conceivable reason that the attachment will increase may be that the women receive information about the examination which lead to improved awareness about the unborn baby. The awareness will, of course, be improved if the woman undergoes the examination. Even following invasive test may the attachment to the fetus increase. Among women who underwent chorion villus biopsy the attachment increased five week earlier than for those who underwent amniocentesis. When the women received normal test results the attachment increased. However, there are even results from studies which show the opposite. Women who had underwent serum screening on the indication advanced maternal age showed less attachment than those who underwent amniocentesis for the same indication or those who refused the test. The reason for that may, due to the discussion by the authors, that screening do not result in a diagnosis but a probability for Down syndrome which may lead to an additional feeling of insecurity (Lawson & Turiff-Jonasson, 2006).

There is insufficient research in the field of how risk or perceived risk for the baby during pregnancy influences the MFA. One study which had the underlying assumption that women in high risk groups would have less MFA than women in low-risk groups failed to

proved that (Cannella, 2005). In a qualitative study by Hedrick (2005) of women who expected a child with a nonlethal abnormality, the participants did not express less maternal fetal attachment, rather a feeling of a wish to protect the baby who was not perfect. However, information about an increased risk for carrying a baby with Down's syndrome from an early ultrasound examination including nuchal translucency measurement strongly implies the worry about the baby (Georgsson Öhman et al., 2006).

In a sub study of large randomized controlled trial aiming at evaluating the effects of screening for Down syndrome by means of an ultrasound scan including measurement of nuchal translucency in early pregnancy (gestational weeks 12 to 14), the aim was to investigate how the early scan compared to a ultrasound examination in second trimester, may have affected maternal-fetal attachment in mid-pregnancy. There were 2026 women included in the study. Women were randomly allocated either to the intervention or to a control group where the routine care with an ultrasound scan in gestational week 17 to 20 was offered. Data were collected by questionnaires before randomization and in gestational week 24. MFA was measured by a modified version of the Cranley maternal-fetal attachment scale. One item (I grasp my baby's foot through my tummy to move it around) was excluded in the present study because it seemed irrelevant to use in gestational week 24. Another item (I enjoy watching my tummy jiggle as the baby kicks inside) was replaced with "I like to read about the development of the baby, how it grows, how it looks like". Mean scores were used for comparisons and were calculated for the total scale and individual subscales. The results of the study showed that the mean score of MFA was 3.50 in the intervention group compared to 3.44 in the control group ($p=0.04$). The mean scores on all subscales were slightly higher in the intervention group, but only statistically significant regarding "Differentiation of self from fetus" $p = 0.01$. The conclusion of this study was that ultrasound screening for Down syndrome in the first trimester may have a modest positive effect on MFA in mid-pregnancy, compared with a ultrasound scan in the second trimester (Georgsson Öhman & Waldenström (2010).

In a study by Berryman and Windridge (1996) a lower attachment to the fetus among older women was shown. The authors interpreted this result as they restrain the attachment because they were aware about the risk of Down syndrome associated to high maternal age and as a consequence a possible loss of the pregnancy.

6. Reactions and experiences during waiting-time for test results

To wait for results from invasive testing, such as amniocentesis and chorion villous biopsy, seems to be worrying and a period full of concerns. This seems to be a difficult time period irrespective of nothing is expected to deviate, and irrespective of the invasive test has preceded of information about increased risk for chromosomal abnormalities or not (Cederholm et al., 2001). Women who have undergone an amniocentesis described that they had an emotional distance to the pregnancy until the health of the fetus had been confirmed by the result of the test (Rothman, 193). The waiting time are often experienced as hard irrespective of normal test result or not (Cederholm et al., 2001, Green & Statham, 1996).

Many women who had received information about risk for the fetus having Down syndrome in relation to an early ultrasound examination including nuchal translucency measurement, describes the waiting time for having an amniocentesis and further to wait for the test result as a time when they repressed the pregnancy. They avoided to think about

the baby, and denied their pregnancy in different ways. This can be interpreted as a strong feeling but still the question if this period of repression of the pregnancy affects the attachment is unanswered. Information about increased risk for something being wrong with the baby may lead to great consequences for the pregnant women, such as denying the pregnancy - taking a "time-out", until the test shows normal results. The women did not feel happiness about the pregnancy, they didn't tell anyone about it, didn't look for baby equipment or thought about names for the baby. This "time-out" lasted until a normal result from the invasive test was received in about one month. Considering one month of denying the pregnancy it is still reasonable to assume that prenatal examinations may affect the attachment (Baillie, 2000; Georgsson Öhman et al., 2006).

7. False positive results

To receive false positive results that there is an increased risk for the baby having a chromosomal abnormality lead to unnecessary worry about the health of the baby. Women have describes the time from receiving an increased risk that the baby have Down syndrome until they receive a normal result from the invasive test as a "time-out" a repression of the pregnancy as mentioned above (Baillie et al., 2000; Georgsson Öhman et al., 2006). There are reasons to assume that this time with decreased interaction with the fetus may affect the attachment and the feelings for the unborn child in some way. This is an important question for further research. Including waiting-time for the invasive test and the test result this period when the women repressed pregnancy could last for about a month.

In general, to reduce the number of false positive results is an important ethical issues about screening. Even after a reassuring diagnostic test can some worry remain (Green et al., 2004). In a study by Baillie et al. (2000), 24 women who received a false positive result from an ultrasound examination including measurement of nuchal translucency and a calculation of the probability for having a baby with Down syndrome were interviewed. Two thirds of the women in the study still experienced anxiety up to four weeks following the normal diagnostic test. In a study by Weinans and colleagues in 2004 anxiety in association with false positive results from nuchal translucency screening and from serum screening was compared. There were 20 women in each group in both groups the risk was presented as a numerical value. In this study the women in the group who underwent nuchal translucency screening stated they were more worried about the health of the baby than those who underwent maternal serum screening. A possible explanation to this finding is that the fetus was visualized in the "NT-group". In a study including 33 women who received false positive results from serum screening, 20% remained worried two months after a normal diagnostic test (Santalahti et al., 1996). Feelings of worry could easily be recalled as long as ten years after maternal serum screening (Smedler & Bremme, 1992). In a study of 102 families who had received false positive results from screening for congenital hypothyroidism, 78 families experienced strong emotional reactions. As many as 18 of these families stated that they still felt insecure about the baby's health after a period of 6 to 12 months (Bodegård, Fyrö & Larsson, 1983). This link of studies presented above, all show that false positive results make a deep mark on those who are affected. There are still no studies which explore the effect of those strong feelings on the maternal fetal attachment.

8. Importance of information

Information about prenatal screenings and diagnostic is very complicated and complex. To give equal information in early pregnancy to all women who want to have the information is a great challenge. The ambition is to give equal information to all women irrespective of social and cultural background, education and age. The information will be standardize, evidence based, comprehensible and not generate worry (SFOG, 2008).

The content of the information will be;

- that most of the newborn children are healthy,
- the purpose with the screening or the examination,
- the pros and cons,
- that the participation is voluntary
- about the methods – the procedure, possibilities, limitations
- that a assessment of probability is not a diagnosis
- the meaning of the test results
- the probability for false positive and false negative results
- possible consequences and possible alternatives after the test results
- that the parents-to-be will be faced difficult decisions and dilemmas in cases were a abnormality is detected
- how common the abnormalities are and possible consequences for the child
- alternatives after diagnosis
- references to were additional information can be reached. (Halsey Lee et al., 2005)

The aim with the information about prenatal diagnosis is to enable the woman to make an informed choice (Dormandy et al., 2002). One common definition of informed choice adapted from O'Connor et al. (2009) is that “the informed choice is based on relevant knowledge, consistent with the decision makers’ values and behaviourally implemented”. When talking about prenatal screening or diagnosis this means that an informed choice to undergo prenatal examinations is when the woman has relevant knowledge about the test, a positive attitude towards it and actually undergoes it (Marteau et al., 2001, Michie et al., 2002, Potter et al., 2008). Sufficient knowledge is not enough to be able to make an informed choice. The choice should also reflect one’s values and attitudes towards undergoing the test.

There are several difficulties with information regarding prenatal examination. Many pregnant women do not know that prenatal screening is an option; they do not know the meaning of false positive and false negative results and what it means to live with DS but they have more knowledge of practical aspects of prenatal screening (Dahl et al., 2008). Pregnant women can receive information about prenatal screening from different sources such as health care, pamphlets, books, the internet, friends and family (Park & Matthews, 2009). Film as a source of information has shown to increase the knowledge (Björklund et al., 2011, Hewison et al., 2001).

Regarding information about prenatal screening, a study was performed with the aim to compare the growth of maternal-fetal emotional attachment in groups of women whose decisions about participation in screening were informed or not informed. The result of the study showed that the group who made an informed choice had significantly lower attachment scores than the group who had not made an informed choice. The authors pointed out that the findings of this study have uncertain consequences. Delayed emotional attachment can be interpreted as a psychological defense, a way to keep distance from the fetus in case if the pregnancy will be terminated due to diagnosis of fetal abnormality

(Rowe, 2009). Delayed attachment may prevent positive behaviour which protects well-being of both the woman and the fetus such as good diet; non smoking and alcohol use (Rowe et al., 2009). On the other hand is it an important purpose in the antenatal care to strive for so many women as possible to be able to make an informed choice (Halsey Lee et al., 2005).

9. Conclusion

The human being is malleable and most difficulties and crisis we are able to cope with. Despite traumatic experiences, such as information about something may be wrong with the baby, with following crisis and repressing of the pregnancy most of the women seem to recover and develop a strong attachment to the fetus and bonding to the new born baby. However, some women may show stronger reactions such as depression or considerable worry. There is also a risk for remaining distrustfulness for the health of the child during the childhood. So far, there is a lack of concordant methods to measure maternal-fetal attachment, with some contradictory results from research. Further development, validation and assessment of the available scales for self assessment of maternal fetal attachment are in a great demand. Further research is required to verify possible effects of prenatal examinations on the maternal fetal attachment in general. Additionally, there is a need for scrutinizing the field of information, and the possibility for the expectant mothers to make an informed choice regarding prenatal examinations. There is a lack of knowledge about conceivable adverse effects of prenatal examinations for detecting Down syndrome during pregnancy.

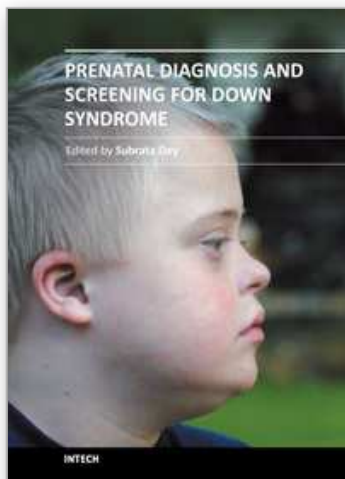
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Prenatal Diagnosis and Screening for Down Syndrome

Edited by Prof. Subrata Dey

ISBN 978-953-307-355-2

Hard cover, 232 pages

Publisher InTech

Published online 17, August, 2011

Published in print edition August, 2011

This book provides a concise yet comprehensive source of current information on Down syndrome. Research workers, scientists, medical graduates and paediatricians will find it an excellent source for reference and review. This book focuses on exciting areas of research on prenatal diagnosis - Down syndrome screening after assisted reproduction techniques, noninvasive techniques, genetic counselling and ethical issues. Whilst aimed primarily at research worker on Down syndrome, we hope that the appeal of this book will extend beyond the narrow confines of academic interest and be of interest to a wider audience, especially parents and relatives of Down syndrome patients.

How to reference

In order to correctly reference this scholarly work, feel free to copy and paste the following:

Susanne Georgsson Ohman (2011). Prenatal Examinations for Down Syndrome and Possible Effects on Maternal-Fetal Attachment, Prenatal Diagnosis and Screening for Down Syndrome, Prof. Subrata Dey (Ed.), ISBN: 978-953-307-355-2, InTech, Available from: <http://www.intechopen.com/books/prenatal-diagnosis-and-screening-for-down-syndrome/prenatal-examinations-for-down-syndrome-and-possible-effects-on-maternal-fetal-attachment>

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