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**WOMEN'S EXPERIENCES AND
REACTIONS WHEN A FETAL
MALFORMATION IS DETECTED BY
ULTRASOUND EXAMINATION**

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I watch the morning glory caress the misty landscape. A bed of flowers try to break through the layers of grey. I see a path leading through the landscape. It is the path of the future. I follow it and find scattered hopes laying like leaves along the side. I pick one up and softly ponder...

~ Pierre Zeylon

To my children
Lina, Anthon, August and Joar

ABSTRACT

Background: Second trimester ultrasound examination among pregnant women in Sweden is almost universal. The detection of a fetal malformation on ultrasound puts health care providers and pregnant women in a difficult and precarious situation. What information and how it is communicated is crucial to women's decision-making about continuing or terminating at pregnancy. The main aim of this thesis was to describe and analyze women's experiences and reactions following the detection of a fetal malformation on an ultrasound scan. **Methods:** Two semi-structured in-depth interviews were performed, with women informed of a fetal malformation following an ultrasound scan. A total of 27 women took part in the first round of interviews: women continuing their pregnancy were interviewed, either in gestational week 30 or three weeks after the diagnosis; those terminating their pregnancy were interviewed two to four weeks after termination (Paper I). A second interview with 11 women who terminated their pregnancy was conducted six months after termination (Paper III). Two questionnaires were also administered. The first, answered by 99 women (Paper II) and comprising 22 study-specific questions along with emotional well-being and socio-demographics variables and medical and obstetric history, was conducted at the same time as the first stage of interviews. The other questionnaire, answered by 56 women incorporated common self-report instruments and was performed three times: first in gestational week 30, and then two respectively six months postpartum (Paper IV). Qualitative data were analyzed through content analysis, and quantitative data were analyzed through descriptive statistics. **Results:** The timing, duration, and manner of women's initial counseling and ongoing support were shown to be important in the interaction between women and caregivers. Positive interactions improved the women's ability to understand the information and fostered feelings of trust and safety, which in turn reduced their anxiety. Most of the women who expected a baby with an abnormality expressed their need for information on several occasions to help them make this difficult decision. They also wished for information from different specialists and continuity of care. These needs were even stronger in women who chose to terminate their pregnancy. We found women continuing their pregnancy to be at high risk of depressive symptoms, major worries, and high anxiety levels, both in mid-pregnancy, and at two months and one year postpartum. Despite these findings, the results of the maternal-fetal attachment scale for women who continued their pregnancy with a fetus diagnosed with a malformation indicated a high level of attachment. **Conclusions and Clinical Implications:** Effective communication, empathy and compassion, and consistent follow-up routines are important to ensure good treatment and care of this group of women. Taking these results into account may improve caregivers' ability to counsel these vulnerable patients and to ensure that their needs are properly met.

Keywords: Prenatal diagnosis; ultrasound examination; information; decision-making; prenatal depression; postnatal depression; anxiety; attachment; care

LIST OF PUBLICATIONS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

- I. **Asplin Nina**, Wessel Hans, Marions Lena, Georgsson Öhman Susanne.
Pregnant women's experiences, needs, and preferences regarding information about malformations detected by ultrasound scan.
Sexual & Reproductive Healthcare 2012;3:73-78.
- II. **Asplin Nina**, Wessel Hans, Marions Lena, Georgsson Öhman Susanne.
Pregnant women's perspectives on decision-making when a fetal malformation is detected by ultrasound examination.
Sexual & Reproductive Healthcare 2013;4:79-84
- III. **Asplin Nina**, Wessel Hans, Marions Lena, Georgsson Öhman Susanne.
Pregnancy termination due to fetal anomaly; women's reactions, satisfaction and experiences of care.
Submitted
- IV. **Asplin Nina**, Wessel Hans, Marions Lena, Georgsson Öhman Susanne.
Maternal emotional wellbeing over time and attachment to the fetus when a malformation is detected.
Submitted

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RELATED PAPER NOT INCLUDED IN THE THESIS

- I. **Asplin Nina**, Dellgren Annika, Conner, Peter.
Education in obstetrical ultrasound – an important factor for increasing the prenatal detection of congenital heart disease.
Acta Obstetrica et Gynecologica Scandinavica 2013;92:804.

CONTENTS

1	Prologue.....	10
2	Introduction.....	11
3	Background.....	13
3.1	Brief history of obstetric ultrasound.....	13
3.1.1	Safety aspects, knowledge, and education.....	14
3.2	The fetal examination and detection of fetal malformation.....	15
3.2.1	Termination of pregnancy and Swedish law regarding abortion.....	16
3.2.2	Ethical issues connected to fetal diagnosis.....	17
3.3	Psychological aspects.....	18
3.3.1	Psychological aspects during pregnancy.....	18
3.3.2	Factors influencing maternal well-being.....	18
3.3.3	Psychological aspects following a detected fetal malformation.....	19
3.3.4	Psychological aspects after fetal loss.....	20
3.4	Counseling, care and treatment.....	20
3.4.1	Information and communication.....	20
3.4.2	Supportive and professional dialogue.....	21
3.5	Maternal-fetal attachment.....	21
3.5.1	Attachment process.....	22
3.5.2	Factors influencing maternal-fetal attachment.....	22
4	Rationale.....	24
5	Aims.....	25
6	Methods.....	26
6.1	Study design (I-IV).....	26
6.2	Sample and procedure (I-IV).....	26
6.2.1	Participants.....	26
6.2.2	Data collection.....	27
6.2.3	Interviews (I, III).....	29
6.2.4	Questionnaires (II, IV).....	30
7	Data analysis.....	32
7.1	Qualitative content analysis.....	32
7.2	Statistical analysis.....	32
8	Ethical considerations.....	33
9	Main findings.....	34
9.1	Experiences of information (I).....	34
9.2	Factors influencing the decision making process (II).....	34
9.3	Experiences of importance after a pregnancy termination due to a fetal malformation (III).....	35
9.4	Women's emotional well-being and maternal-fetal attachment (IV).....	36
10	Discussion.....	37
10.1	Reflections on the findings.....	37
10.2	Methodological considerations.....	40
11	Conclusions and Clinical implications.....	45
12	Further research.....	46
13	Summary in Swedish – Svensk sammanfattning.....	47
14	Acknowledgments.....	48
15	References.....	50

LIST OF ABBREVIATIONS

ALARA	As low as reasonably achievable
CWS	Cambridge Worry Scale
EPDS	Edinburgh Postnatal Depression Scale
GW	Gestational week
MBR	The National Medical Birth Register (Swedish National Board of Health and Welfare)
MFAS	Maternal Fetal Attachment Scale
MFR	Medicinska Födelse Registret (The National Birth Register, Swedish National Board of Health and Welfare)
SBU	Statens beredning för medicinsk utvärdering (The Swedish Council on Technology Assessment in Health Care)
SMER	Statens Medicinsk-Etiska Råd (The Swedish National Council on Medical-Ethics)
SPSS	Statistical Package for the Social Sciences
STAI	State and Trait Anxiety Inventory
STAI-S	State Anxiety
STAI-T	Trait Anxiety
WHO	World Health Organization

1 PROLOGUE

I hope with this thesis to contribute to improved knowledge and understanding of women's experiences and reactions when a fetal malformation is detected. It is important for us as professionals to learn how we can develop care in consultation with those in need of specialized nursing.

My interest in researching women's health and well-being is due to my own experience of prenatally detected fetal malformations working as a clinical midwife. This inspired and instilled in me the will to offer the highest quality care and treatment to women both before and after the birth of their children with prenatal diagnoses of malformation.

I believe that being a midwife is both an art and a science. The art of compassion, the intuition of knowing when something is "not quite right," the understanding and communication that comes of empathy are the cornerstones of good nursing. By integrating updated biological, psychological, and social knowledge we can assure the high standard of treatment and care that everyone should expect from professional caregivers.

2 INTRODUCTION

Second trimester screening via ultrasound examination is almost universal in pregnant women in Sweden. In most regions the examination is performed at 16 to 20 weeks of gestation and in some counties an additional scan is also offered during the third trimester to detect fetal growth retardation. The routine scan includes an extensive examination of fetal anatomy to screen for congenital malformations. Additional aims are to estimate gestational age, to localize the placenta, and to screen for multiple pregnancy. In European countries the detection rates of fetal anomalies vary widely between 13% and 88% (Eik-Nes 2010; Garne et al. 2005; Levi 2002; Nikkilä et al. 2006; Romosan et al. 2009; Saltvedt et al. 2006; SBU 2006). A correlation has also been found between high prenatal detection rates and early prenatal diagnoses. Early diagnosis may be important, although they may lead to more pregnancies being terminated (Garne et al. 2005). Detection rates are influenced by the gestational age at the examination, maternal body habitus, scanning time, and operator training and experience (Wong et al. 2003), and therefore are difficult to compare between studies. Differences in pre- and postnatal diagnoses and differences in definitions of malformations, detection rates, and quality of follow-up are also important (Boyd et al. 2004). In Sweden, screening ultrasound examinations are performed by specially trained midwives (SBU 2006). In Sweden the birth rate is approximately 113 000 per year. In 2011, 1850 children (17.2 children per 1000 births) were reported to be born with a malformation. All types of birth defect were reported to the Swedish Birth Defect Register (MBR 2012). Information about a fetal malformation may be traumatic to the parents-to-be, and the psychological aspects are equally important as the medical and social aspects for follow-up (SBU 1998). According to SBU there are only 5 to 10 minutes set aside for information about fetal diagnostic aspects before the first ultrasound examination (SBU 2006). Some women have a higher risk for poor pregnancy outcomes than others, for example women who have previously had a miscarriage, or those who are pregnant with twins or triplets, have pregnancies with a non-life-threatening congenital malformation, or pregnancies that were conceived through in vitro fertilisation (Damato 2004; Hjelmstedt et al. 2006; Tsartsara & Johnson 2006).

Fetal diagnoses involve ethical and moral issues and are subject to ongoing debate in our society. The debate around abortion is unavoidable when considering the difficulties women face in making choices following the detection of a fetal malformation. From a medical perspective, the earlier a fetal malformation is detected the easier it is to terminate the pregnancy (National Board of Health and Welfare 2011). If a society is less tolerant of a woman's continuing an affected pregnancy it could decrease the understanding and support available to the affected children and their whole families (Benn & Chapman 2009). Caregivers need more information about risk factors in order to improve our communication with women and our ability to assure their well-being. Psychological reactions due to the termination of a pregnancy because of a fetal malformation are comparable to those from intrauterine fetal death; the quality of care, support, and understanding from caregivers is important to women's recovery (Avelin et al. 2011; Trulsson & Rådestad 2004). Early treatment of any crises or somatic reaction is beneficial for effective consultation and treatment (Gudde et al. 2013).

To optimize and provide the best possible care for both women who terminate their pregnancy and those who continue, it is vital that we learn what information women need and

prefer when a fetal malformation is detected. It is also important to facilitate the decision-making process and to assess satisfaction with the care given. The woman's well-being and psychological attachment to the fetus may also influence both the expectant mother and the fetus during pregnancy and after, and should be explored at the time of diagnosis. Communication and teamwork are essential in dealing with the spectrum of medical, social, and psychological aspects of an adverse fetal diagnosis.



Photo: Allan Larsson. Sophie Reuss, and Nina Asplin performing 3D ultrasound at the Center for Fetal Medicine, Karolinska University Hospital Stockholm.

3 BACKGROUND

3.1 BRIEF HISTORY OF OBSTETRIC ULTRASOUND

The advent of ultrasound technology has had an impact on medical knowledge and treatment of pregnancy. Ultrasound examination during pregnancy was introduced in Scotland in the 1950s (Donald et al. 1958). Bertil Sundén at Lunds University was inspired by this work and bought a Diasonograph, the first commercially made ultrasound machine. Sundén's thesis concerned the use and value of ultrasound in obstetrics and gynecology (Sundén 1964). In the mid 1960s Stuart Campbell introduced his classic principle of, A- (amplitude) and B- (brightness) mode scans measuring the fetal biparietal diameter (BPD) (Campbell 1968). At the General hospital in Malmö, University of Lund, ultrasound was introduced for a routine screening programme in 1973-1974 to detect twins at 28 weeks of gestation (Persson et al. 1979). The use of ultrasound for dating pregnancy became routine in the 1980s (Oakley 1986). By 1993 all ultrasound units in Sweden offered routine examination in the second trimester, and 79% of all the ultrasound departments were screening for structural fetal malformations (Hagenfeldt et al. 1998).

In ultrasonic medical imaging, high-frequency acoustic energy over the human hearing range (approximately 20 kilohertz) is transmitted into the human body using a set of transducers attached to the skin. The transducer contains piezoelectric crystals, which all the introduction and reception of ultrasound waves through stimulation by an electrical current. The ultrasound waves reflect off the boundaries between organs and surrounding fluids, and between regions of differing tissue density. Different modes, such as the B mode, M (motion) mode or the Doppler mode, are then employed (Abu-Zidan et al. 2011) to observe the fetus(es) before birth.

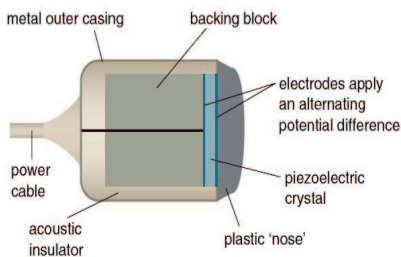


Figure 1. Illustration of how ultrasound is produced and detected. Used with permission from www.genesis.au

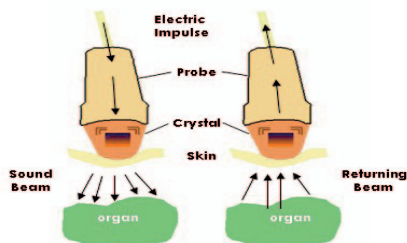


Figure 2. Illustration of generation of an ultrasound image. Used with permission from www.usra.ca

3.1.1 Safety aspects, knowledge, and education

The detection rate of prenatal abnormalities by ultrasound has increased with the development of the technique, and the importance of ultra sonographers' training and experience is evident (Levi 1997, Tegnander & Eik-Nes 2006). Detection rates will be influenced by gestational age at examination, maternal body habitus, scanning time (Wong et al. 2003), and operator training and experience (Asplin et al. 2013). Despite knowledge of these factors, detection rates have remained below 50% in recent publications, and the training and ability of the sonographer performing the routine anomaly scan seems to be the most important factor for the prenatal detection of malformation such as major congenital heart disease (Pinto et al. 2012). There are no specific requirements concerning the training and education of midwives and doctors performing obstetrical ultrasound in Sweden. The Swedish Society for Obstetrics and Gynecology offers basic courses as well as short 3-day courses in fetal echocardiography and Doppler ultrasound, which most ultrasound operators take during their first years in the profession. The lack of mandatory training and quality control means there is considerable variation in skills and screening results in different clinics (Hunter et al. 2000).

The safety of diagnostic ultrasound use during pregnancy continues to be debated in the medical literature. Basic knowledge of diagnostic ultrasound safety aspects has been shown to be rather low among clinical experts (Marsal 2005; Sheiner et al. 2007). Ultrasound operators are responsible for maintaining their skills through regular updates of their training. Postgraduate educational programs have been established in countries such as the United Kingdom (www.city.ac.uk) and Norway (<http://www.stolav.no>).

There are limited epidemiological data regarding the safety of obstetrical ultrasound (Duck 2003; Torloni et al. 2009). Current epidemiological data on childhood development show there no significant differences in deleterious effects of multiple ultrasound studies at any age as measured by standard tests of childhood speech, language, behavior, and neurological development (Newnham et al. 2004). Some studies indicate that prenatal ultrasound, may potentially have effects that could be regarded as adverse (though not classified as diseases), such as non-right handedness, left-handedness, delayed speech development, subnormal intellectual performance, and attention deficit disorders (Campbell et al. 1993; Kieler et al. 2001; Kieler et al. 2005; Salvesen thesis 1993; Salvesen 2002). Finally, current studies on the long-term effects (beyond childhood) of ultrasound scanning are limited (Salvesen et al. 1997) and do not reflect all possible effects.

Today's increased output level of B-mode ultrasound scans (Henderson et al. 1995) is challenged by our lack of knowledge about whether higher output effects increase actual risks of adverse fetal effects (Kieler 2007). The radiologic principle known as ALARA (as low as reasonably achievable) is generally supported and encourages balance between necessary medical information, minimal settings, and optimum examination time (ACOG 1997). The output display standard was developed to provide the ultrasound user an estimate of the examination's safety. It includes both thermal and mechanical parameters (Fowlkes 2008). The thermal index (TI) measures the development of heat as tissues or water absorb the ultrasound energy, which increases local temperature. The amount of energy absorbed depends upon the type of tissue, duration of exposure, and the ultrasound mode or route. Mechanical index (MI) include the formation of bubbles (cavitation) when dissolved gases

come out of solution because of the local heat caused by ultrasound (Barnett et al. 2000; Stratmeyer et al. 2008).

3.2 THE FETAL EXAMINATION AND DETECTION OF FETAL MALFORMATION

Ultrasound has given us the possibility to get detailed information about the fetus and the intrauterine environment. Routine fetal examination through ultrasound was primarily intended to estimate gestational age, localize the placenta, and screen for multiple pregnancies. It has gradually become used as a sensitive fetal screening for the detection of fetal abnormalities, leading to a reduction in inductions of labour for post-term pregnancies (Whitworth et al. 2010) and a reduced rate of fetuses that are small for gestational age (Waldenström et al. 1992).



Photo: Nina Asplin. 2D Fetal profile gw 18. Center for Fetal Medicine, Karolinska University Hospital Stockholm Solna.

All pregnant Swedish women are offered a second trimester ultrasound screening. The birth rate in Sweden is approximately 113 000 per year (MBR 2012) and the vast majority of pregnant women, 97%, accepts the opportunity of at least one ultrasound examination, usually in gestational week 17-18 (SBU 2006). According to a survey by the Swedish Council of Technology Assessment in Health Care women receive 5 to 10 minutes of information about the diagnostic aspects of prenatal ultrasound (SBU 2006).

Approximately 2% of all new-born babies have a serious malformation (SBU 1998). In a study by Chitty et al. (1991) it was shown that most malformations are detected in low-risk pregnancies. The sensitivity for detection of fetal malformations in the second trimester ultrasound examination varies between 13% and 88% in different studies (Eik-Nes 2010; Garne et al. 2005; Levi 2002; Nikkilä et al. 2006; Romosan et al. 2009; Saltvedt et al. 2006; SBU 2006).

In some cases the malformation is clear and can be diagnosed at the first examination, but in other cases the findings are vague. This means either further diagnostic tests, for example amniocentesis or chorionic villus biopsy, or further ultrasound examinations are required for a final diagnosis (Creasy & Reasnik 2003). All of this information should be communicated to the woman at the same time a fetal malformation is detected (Larsson et al. 2010).

The Swedish Birth Defect Registry (2012) recorded 1850 fetuses and babies with serious malformations in the year 2011 (17.2/1000). The number of terminated pregnancies as a result of a suspected or verified congenital fetal malformation or chromosomal aberration remains at 5.4 per 1000 births, representing 24% of all reports of malformations in fetuses and babies. The most common serious congenital disorders are heart defects, which occur more often than neural tube defects (e.g., spina bifida and anencephaly) and chromosomal aberrations (e.g., Down syndrome) (Hoffman 1995). Birth defects known as “orofacial clefts” (i.e. cleft lip, cleft palate) are also common (MBR 2011). The prenatal diagnosis of congenital heart anomalies is one of the most difficult in ultrasound screening and requires detailed examination of a low-risk population, since most cases occur in families with no known risk factors (Kleinert 1996).

Detection of a fetal malformation may lead to termination of the pregnancy. Of all reported cases 95% of pregnancies with anencephaly and 67% of those with spina bifida were terminated. In non-chromosomal bilateral kidney agenesis and isolated hypoplastic left heart syndrome, the percentage of terminations in 2007-2011 were 87% and 55%, respectively. This highlights the importance of a thorough registration of terminations due to suspected or verified congenital malformations.

3.2.1 Termination of pregnancy and Swedish law regarding abortion

Swedish law allows the termination of a pregnancy states up to gestational week 18+0 on request from the woman if the procedure does not threaten her life or health. After 18 weeks, the National Board of Health and Welfare must approve the termination through its Legal Advisory Council. Since 1995, 93% of pregnancy terminations in Sweden have been performed before gestational week 11, 6% between 12 and 17 gws, and 1% after the 17th gestational week (SOSFS 2004:4). Medical abortion is provided up until, but not after, 9 completed weeks of gestation through the administration of progesterone antagonists and prostaglandins with an interval of 1 to 2 days. Abortions performed between gestational weeks 9 and 12 are often performed surgically using vacuum aspiration with local or general anesthesia. After 12 completed gws, medical abortion is again the method of choice, and may sometimes be followed by surgical evacuation of the uterus if the abortion is incomplete (MBR 2011).

Termination of a pregnancy is an intense experience that raises existential questions about life and death. The woman may have mixed feelings: feel sorrow for her child, but also pride in her own fertility. When the reason for the termination is a malformation detected at the ultrasound examination, these feelings will be even more complicated, and the woman may question her fertility and future capacity to have a healthy child (Cote-Arsenault et al. 2001). Dommergues et al. (1999) showed that in 50% of the cases, a fetal malformation cannot be diagnosed earlier than in the third trimester, which can lead to late termination or to the woman having no other choice but to continue the pregnancy.

Redlinger-Grosse et al. (2002) showed that religious reasons, personal convictions, and values about life were the most important factors in making the decision whether or not to terminate. In other studies gestational age, the kind of malformation, viability, and expected quality of life for the child were cited as crucial factors in women’s decisions (Grevengood et al. 1994; Kramer et al. 1998; Schechtman et al. 2002).

3.2.2 Ethical issues connected to fetal diagnosis

It is important to determine how women who expect a child with a prenatally diagnosed malformation or anomaly experience their care and the decision-making process, and how well-equipped they feel emotionally to offer the best of care to their potential child. This determination is important both for women who terminate the pregnancy and those who continue their pregnancy. These women are vulnerable and in crisis especially those women who decide to terminate their pregnancy. All women should feel respected by their caregivers, and their suffering should be minimized, no matter what they decide (Benute et al. 2012).

Ethics is an understanding of the nature of conflicts arising from moral imperatives and how we best may deal with them. Ethics in medical research deals with conflicts of interest across various levels. The Helsinki Declaration (2010) expresses the ethical rules that should apply to research in human subjects, originally adopted by the World Medical Association in 1964 and periodically revised. Beauchamp and Childress' expression of four fundamental principles of ethics (autonomy, beneficence, non-maleficence, and justice) is one of the most widely used ethical frameworks and offers a broad consideration of medical ethics issues in general, not only for use in a clinical setting. The Four Principles are general guides and are further explained herein in accordance with Beauchamp & Childress (2001).

1. Respect for autonomy: respecting the decision-making capacities of autonomous persons; enabling individuals to make reasoned informed choices.
2. Beneficence: balancing the benefits of treatment against the risks and costs; the healthcare professional should act in a way that benefits the patient.
3. Non-maleficence: avoiding as much as possible any harm to the patient. All treatment involves some harm, even if minimal, but the harm should not be disproportionate to the benefits of treatment.
4. Justice: distributing benefits, risks, and costs fairly; patients in similar positions should be treated in a similar manner.

Respect for autonomy is a central principle in medical ethics and law. This ethical principle obliges the physician to elicit and implement the patient's preferences. As early diagnosis of fetal abnormality as possible and the option of early termination of pregnancy are important to many women and consequently the provision of high-quality screening significantly enhances the autonomy of pregnant women (Chasen et al. 2001). From another point of view, the right of the fetus and the principle of equal value of all human rights may stand against woman's autonomy (SMER 2006). Integrity is a central concept in fetal diagnostics and is close to the concept of autonomy (SBU 2006). Integrity and the worth of human being, is two of the fundamental values in life and fetal diagnostics thus be experienced as a threat. These values has to be protected. One way is to use the process of informed choice (i.e. that a person fully understands all the arguments before making a choice). This would then be a choice that is based on a full understanding of the costs and benefits of all available options (Dekker thesis 2009).

Rights to abortion differ worldwide and are a matter of continuous debate. One important questions is whether a male partner has an equal say in whether a woman can obtain an abortion or not. Another is if the state by law should take the responsibility of protecting the fetus. This would imply that none of the above mentioned can override that of the pregnant woman. The liberalization of abortion laws, as in Sweden (National Board of Health and

Welfare 2011) and many of the European countries (Guttmacher Institute 2011) is an important indicator of woman's human right to make decisions regarding her reproductive life-including her decision to either continue or terminate a pregnancy. Liberalizing restrictive abortion laws and legalizing medical procedures for abortion is essential to in a safe way enhancing women's fundamental rights, thus saving the lives of thousands of women every year. In countries where abortion is legal, maternal morbidity and mortality are generally lower because abortions are performed by trained professionals and are safer, more available, and more affordable (WHO 2011). To handle the situation of abortion with empathy and professional care is crucial. It may influence the women's total experience of the ultrasound examination and how to handle their crisis. An open dialog and an individual plan of care may contribute to increase women's satisfaction with care (Söderberg et al. 1998; White-van Maurik et al. 1992) which may be difficult to obtain in the light of less resources. To alleviate stress related to the abortion and to achieve awareness, understanding and acceptance, women would most likely benefit from being offered increased support from caregivers (Dyer 2005; Larsson et al. 2010; Leithner et al. 2004).

3.3 PSYCHOLOGICAL ASPECTS

3.3.1 Psychological aspects during pregnancy

During pregnancy the woman is bound to create a new identity and handle the process towards being a mother. Transition periods always comprise of changes with possibilities, loss, joy and sorrow and at the same time new thoughts and values are arising. How to prepare for this depends on the society, cultural structure, social network and previous experiences and pattern (Raphael-Leff 1992).

Worry is a state of mind during the entire life and important for activating our urge to survive. During pregnancy worries can depress the ability to enjoy life and create a negative influence due to feelings of guilt. At the end of pregnancy it is quite common that the the feeling of restlessness and worry increases (Alfvén & Hofsten 2005).

By offering an ultrasound screening of fetal malformations during pregnancy there is a risk that the feeling of worry has an advantages against the feeling of joy for the pregnancy (Georgsson Öhman & Waldenström 2008). Information about and realization of fetal screening by ultrasound has to be seen in the light of psychological aspects due to a normal pregnancy. The purpose of detecting structural fetal malformations and the theory that ultrasound has "psychological benefits" has been questioned. Though clinical experience has shown enhancing of attachment to the fetus (Siddiqui & Hägglöf 2000) recognition of the unborn baby and reassurance of fetal well-being, which reduces maternal anxiety in women at both low (Garcia et al. 2002) and high risk of fetal anomalies (Sklansky et al. 2002). One reason that "psychological benefits" are considered important is that if ultrasound increases a woman's awareness of the fetus (Dykes & Stjernqvist 2001) and that the awareness allow the woman to modify her behaviour (Campbell et al. 1982; Wiebe & Adams 2009) it may improve the physical health of the fetus (Field et al. 2001; Field et al. 2003).

3.3.2 Factors influencing maternal well-being

Mental health is often seen as a result of a stress, with both biological and psychological vulnerabilities. It is difficult to estimate individual risk factors (Wickberg et al. 2005), but a

woman's denial or acknowledgement of experience of an earlier crisis may give valuable information about her ability to handle this new situation.

There are several factors of influencing the prediction of being depressed. Mild depression is more common caused of psychosocial factors, for instance grief, than severe depression which is affected through biological and social factors (Ottosson 2000). With limited ways to influence a situation or lack of support or a weak social network there are also an increased possibility for depression both in early pregnancy as well as postnatal (Wasserman 2000; Rubertsson et al. 2005).

The level of anxiety is naturally increased due to the information about an ultrasound finding but if there is a continuity regarding the contact with the health care professionals the levels of anxiety decreases (Van der Zalm & Byrne 2006).

It is well known that prenatal examination has an impact on women's well-being. There are several studies exploring the state of worry before and after an ultrasound examination. Women's worry increases immediately before the ultrasound examination and decreases shortly thereafter if the results are positive (Andersson et al. 2006; Harpel 2008; Björklund et al. 2013). When there a fetal malformation is found, studies show an increased state of worry (Larsson et al. 2009). Some studies highlight factors such as information, test results, and the women's own experiences of the risk of something being wrong (Durand et al. 2010; Green 1990; Sahin & Gungor 2008). Information about fetal screening does not in itself lead to increased worry (SBU 2006), thus incorporating this information can be seen as a positive mental process in the preparation for undergoing the procedure.

3.3.3 Psychological aspects following a detected fetal malformation

Women normally attend the routine ultrasound screening to get a confirmation that everything is well. Because of that they are often not prepared for the detection of malformations or anomalies (Crang-Svalenius et al. 1996, Garcia et al. 2002, Georgsson Öhman & Waldenström 2008). Thus women who are unprepared when a serious fetal malformation is detected at a routine ultrasound examination may experience a more severe psychological trauma, dominated by feelings of shock and denial. Although they feel guilty about the prospect of abandoning the baby, few women express guilt about deciding to terminate the pregnancy (Dellaire et al. 1995).

The time between repeated ultrasound examinations with vague findings are correlated with a high level of stress (Statham et al. 2000). The assertion that detection of a malformation in early pregnancy would lead to less emotional stress than if the malformation is detected later during pregnancy cannot be confirmed but is independent of gestational length (Kowalcek et al. 2003). Kemp et al. (1998) show in a study that women who have received information that their fetus was affected by a surgical disease had significant higher levels of worry than women who received information that their fetuses seemed healthy. However, the levels of worry decrease to the same level as in the control group after talking to pediatric surgeon. Even if there is an available treatment to the malformation there are no guarantees that the treatment will be successful. This fact generates worry (Kemp et al. 1998, Madarikan et al. 1990).

In a review by Statham et al. (2000) it is established that there are few studies performed which illuminate the psychological affection to carry out a pregnancy when a fetal

malformation is diagnosed. The article describes that parents may feel ambivalence. The importance to prepare the parents on where and when the baby is going to be born, what it will look like and what is going to happen to the baby after the birth is pointed out. Communication and teamwork are essential as well as thinking about practical problems.

3.3.4 Psychological aspects after fetal loss

Psychological reactions after the termination of a pregnancy due to fetal malformation in the second trimester are comparable to the reactions (i.e. grief, post-traumatic stress, depression, anxiety and psychiatric disorders) of losing a baby at or before an intended birth (Avelin et al. 2013; Bennett et al. 2008; Kersting et al. 2007). Care, support and understanding are of the same great importance for these women (Erlandsson et al. 2013). The care may not be satisfactory and increased follow-up and counseling are required to decrease remaining harm when terminating the pregnancy due to fetal malformation (Lloyd & Laurence 1985).

3.4 COUNSELING, CARE AND TREATMENT

3.4.1 Information and communication

Information has two important aspects of communication. One is to communicate the medical status interpreted from the ultrasound investigation in such a way that it can be understood by the woman. The other one, which is of great psychological importance, is to see this new information as an introduction to the process of adapting to the new situation. This is more like a dialogue focused on upcoming difficulties and similar to a debriefing (Forneris et al. 2013), which allows for women's emotional reactions and better maternal understanding of their new situation. This way of communication allows professional caregivers to facilitate women's coping strategies in adapting to information that they are carrying a malformed fetus.

Information about fetal malformation may be traumatic to the parents-to-be, and the psychological aspects are particularly important as well as the medical and social follow-up (SBU 1998). The information to the expectant parents may be ambiguous. When receiving information about fetal malformations the parents have to make difficult decisions about further examinations and whether the pregnancy should go on or not. The prerequisite to make that decision is adequate, repeated and adapted information (Mitchell 2004; Redlinger-Grosse et al. 2002). Written information (Larsson et al. 2009) as well as visual illustration are also of great importance to facilitate the decision whether to let the pregnancy go on or to terminate the pregnancy when a malformation is detected (Aite et al. 2004). To use the same terminology and to give sufficient information without days of delay is of utmost importance for to minimize anxiety (Larsson et al. 2009). The challenge to understand information about fetal screening in general is well documented (Eurenius et al. 1997; Marteau 1995) and in particular when it includes difficult information about malformation or increased risk (Georgsson Öhman et al. 2006).

The possibility to detect malformations and that the expectant parents confront the choice of a selective termination of the pregnancy may be interpreted in different ways depending on the view of the human and the view on suffering, which makes the ultrasound controversial to some. To give adequate counseling before a decision to go on or to terminate a pregnancy requires special competence of the counsellor and possibility to get information from experts

(Pelly 2003; SOU 1989:51; Tännsjö 1999). Precise, updated, personal information and a possibility to see a pediatrician, as well as to have the opportunity to see other parents with equivalent experience are desirable and favorable for the woman to handle the situation in the best way (Detraux et al. 1998; Skotko 2005).

3.4.2 Supportive and professional dialogue

To face information that the parents-to-be expected child has a malformation is difficult and on top of that has to take a decision to continue or terminate the pregnancy can be tough and emotionally draining. The life becomes like a roller coaster, alternately hope and disappointment. It is also common to feel both powerless and helpless when faced with something you did not ask for and neither have much influence over. The future may seem uncertain and it is difficult to plan ahead. In these circumstances the support in form of a dialogue is crucial for these women and their future well-being and is also continued needed at different stages in the treatment process (Larsson et al. 2010; Gudde et al. 2013). In some cases, when disclosing deeper psychopathology, the long-term effects of a psychoanalysis is needed into the lasting consequences of decisions made in the context of prenatal diagnostics (Leuzinger-Bohleber & Teising 2012).

In ordinary conversation, participants made their important points armed with their own arguments. Dialogue between patients and caregivers, on the other hand, is a conversation in which participants build on each other's contributions, and caregivers may anger or hurt patients through lack of empathy or understanding. It is of utmost importance that caregivers pay serious attention to the patient's thoughts and feelings, take responsibility for the dialogue, and take the time to listen to the patient with empathy and compassion. It is time for us to recognize the power of a sensitive dialogue, in which the aim is to gain a new insight or understanding of an issue. Experience has shown that when parents are invited to participate as experts in their own life, it is advantageous to both the expectant mother and her child (Eriksson & Arnkil 2009).

Communication problems between health care professionals and patients due to language and cultural differences are widely recognized (Street 2002). This communication might be improved by specific training sessions about how to interact with patients from different cultural and religious backgrounds or/and that trained medical interpreters are to be used, in combination with extended time for consultation. A more understanding approach with compassion for patients with different cultural backgrounds who do not speak the same language are requested (Degni et al. 2012).

Little has been published regarding the experience of immigrant parents associated to ultrasound examination. However, a study by Ranji et al. (2012) showed that the immigrant parents were very pleased with the quality of communication. In addition, how this procedure was perceived by the parents turned out to be valuable.

3.5 MATERNAL-FETAL ATTACHMENT

When a woman learns that her fetus may not be entirely healthy, it may affect her attachment to the baby (Baillie et al. 2000; Georgsson Öhman et al. 2006). The terms "bonding" and "attachment" are both used in the literature. Bonding refers more to the parents' tie towards the fetus, whereas attachment refers to a bilateral relationship developed between mother and

child postpartum (Pretorius et al. 2006). When referring to questionnaires/studies we use the term attachment to mean the special emotional relationship that involves an exchange of comfort, care, and pleasure. The roots of research on attachment began with Freud's theories about love (Fonagy et al. 1999).

Bowlby, another researcher, is known as the father of attachment theory. He shared the psychoanalytic view that early experiences in childhood have an important influence on development and behavior later in life. Our early attachment styles are established in childhood through the infant/caregiver relationship. The concept of attachment is described as a "lasting psychological connectedness between human beings" (1969, p. 194). Interestingly, Bowlby here also touches upon what is known as basic trust – the fundamental platform for healthy human development according to Erikson (1959).

Bowlby (1969) believed that there are four distinguishing characteristics of attachment:

1. Proximity maintenance: the desire to be near the people we are attached to.
2. Safe haven: returning to the attachment figure for comfort and safety in the face of a fear or threat.
3. Secure base: the attachment figure acts as a base of security from which the child can explore the surrounding environment.
4. Separation distress: anxiety in the absence of the attachment figure.

These four aspects are fundamental to developing basic trust as an important and stable aspect of self-identity as a person.

3.5.1 Attachment process

Reviews by Erikson & Erikson 1997, Muller 1992, Canella 2005, has contributed to a more sound understanding of the theory of maternal-fetal attachment as follows.

Prenatal attachment refers to a process through which a pregnant woman experiences feelings and emotions for her fetus, interacts with her fetus and develops a maternal identity (i.e. begins to identify herself as a mother) during pregnancy. The bond between a woman and her fetus is often conceptualized by health professionals in terms of maternal-fetal attachment or prenatal attachment. The extent to which a woman attaches with her fetus during pregnancy is an important determinant of the extent to which she attaches with her newborn baby after childbirth. Women who attach more during pregnancy, also develop a greater attachment with their baby during infancy. The attachment between a mother and her newborn in turn influences the baby's future growth and development. A strong attachment between a mother and her baby is associated with the child's better developmental outcomes later in life (Alhusen et al. 2013).

3.5.2 Factors influencing maternal-fetal attachment

Ultrasound enables women to view the fetus growing in their womb. It has been argued that ultrasound is likely to allow a woman to bond with the fetus earlier in the pregnancy than she otherwise would (e.g. women may otherwise only begin to feel attachment once they feel the fetus moving) (Dykes & Stjernquist 2001). Greater maternal-fetal attachment has been reported among women who had ultrasound versus those who did not. The type of ultrasound (2-, 3- or 4 dimensional) does not affect the extent to which a woman bonds with her fetus

(Righetti et al. 2005; de Jong-Pleij et al. 2013). Levels of maternal-fetal attachment are reported to increase as the pregnancy progresses regardless of whether an ultrasound examination is performed (Yarcheski et al. 2009).

Difficulties with attachment to the fetus during pregnancy is thought to be more common among women from low socio-economic backgrounds who tend to have poorer health and are also less likely to access health care facilities than women with a higher socio-economic status. Maternal-fetal attachment and fetal growth can be affected by the maternal emotional state, including stress or depression (Alhusen et al. 2012). Scientists are still studying whether or not maternal-fetal attachment is associated with indicators of socio-economic status such as income and level of education. There is, however, evidence that women who have low educational, poor maternal health, and are dissatisfied with their marriage (Kwon & Bang 2011) or social and relationship support during pregnancy (Shieh et al. 2001), exhibit low maternal-fetal attachment.

There is some evidence that positive health-seeking behaviors such as receiving prenatal care, maintaining a healthy diet, and obtaining regular exercise are associated with increased maternal-fetal attachment (Lindgren 2001; Callister & Birkhead 2002).

According to a study by Yarcheski et al. (2009), maternal-fetal attachment is not associated with parity or high-risk pregnancy. A study by Hedrick (2005) further affirms that no differences were found in maternal-fetal attachment between women with high-risk pregnancies and those with normal pregnancies.

Depression and anxiety are highly prevalent during pregnancy and are correlated with an increased risk of postnatal depression after childbirth (Stowe et al. 2005). Women experiencing such mood disorders during pregnancy do not bond with their fetus as much as those who have stable moods (Murray et al. 1996). According to a study by Siddiqui & Hägglöf (2000), maternal-fetal attachment screening during the third trimester can serve as a diagnostic tool to identify women with a likely sub-optimal mother-child interaction.

4 RATIONALE

The studies in this thesis were conducted to assess women's experiences of learning that their fetus had a malformation, their reactions to the information and communication from their healthcare provider, and their general well-being to contribute to our understanding of the situation these vulnerable women face after a fetal malformation is detected following an ultrasound examination.

Prenatal diagnosis ought to allow the woman/parents to make informed decisions about their pregnancy, but is not always agree with the reality. A detected fetal malformation includes issues of termination as an option. These are complicated questions related to the potential conflict between the interest of the fetus and those of the woman in whose womb the fetus is carried. Ethical issues and management of fetal disorders have been a focus for debate for decades.

This thesis contains both quantitative but also qualitative research, thus partly of quotations. Along with these findings healthcare professionals should be able to optimize and develop the antenatal and postnatal care.

Using these data, the researcher working in this area are able to be pinpointing the women's resources and important factors to create a frame for best possible solution. In addition, this thesis could be used as a benchmark for improving the level of communication and women's well-being, thus should be regarded as a very important aspect of care and treatment.

5 AIMS

The overall aim of this thesis was to describe women's experiences and reactions when fetal malformation was detected by ultrasound examination.

Specific aims were to explore the experiences of both women who continued the pregnancy and those who chose to terminate the pregnancy:

Paper I: To explore pregnant women's experiences of received information in relation to fetal malformation detected on ultrasound.

Paper II: To explore factors influencing the decision to continue or terminate pregnancy due to detection of fetal malformation following ultrasound examination, to elucidate the need for more information or other routines to facilitate the decision-making process, and to assess satisfaction with the decision made.

Paper III: To explore what women who have had a pregnancy terminated due to a detected fetal malformation perceived as having been important in their encounters with caregivers for promoting their healthy adjustment and well-being.

Paper IV: To explore women's emotional wellbeing and attachment to the fetus among women informed during pregnancy of a fetal malformation.

6 METHODS

Table I. Overview of aims and methods in Paper I-IV.

Study	Paper 1	Paper II	Paper III	Paper IV
Aim	To explore pregnant women's experiences of received information in relation to fetal malformation detected on ultrasound.	To explore factors influencing the decision to continue or terminate the pregnancy due to detection of fetal malformation following ultrasound examination, to elucidate the need for more information or other routines to facilitate the decision-making process and to assess satisfaction with the decision.	To explore what women who have had a pregnancy terminated due to a detected fetal malformation perceived as having been important in their encounters with caregivers for promoting their healthy adjustment and well-being.	To explore women's emotional well-being and attachment to the fetus among women informed during pregnancy of a fetal malformation.
Design	Qualitative descriptive	Quantitative descriptive	Qualitative descriptive	Quantitative descriptive
Participants (n)	27 women continuing and terminating group	99 women continuing and terminating group	11 women terminating group	56 women continuing group
Data collection	Qualitative interviews	Questionnaire: study specific	Qualitative interviews	Questionnaire: EPDS, CWS, STAI, MFAS
Analyses	Qualitative content analysis	Descriptive, The Pearson Chi-square test and t-test	Qualitative content analysis	Descriptive, Chronbach's alpha
Status	Published	Published	Submitted	Submitted

By Nina Asplin unpublished

6.1 STUDY DESIGN (I-IV)

The designs used in this thesis were longitudinal and the four papers included in this thesis were based on descriptive, qualitative (I, III) and quantitative (II, VI) data.

Participants in all four studies were recruited from four fetal referral centers (units performing examinations during pregnancy and invasive prenatal tests) in Stockholm, Sweden: the Karolinska University Hospital in Solna and Huddinge, the South General Hospital, and the Ultragyn Odenplan/Danderyd Hospital.

6.2 SAMPLE AND PROCEDURE (I-IV)

6.2.1 Participants

A total of 99 women were the main data base for the main study conducted between September 2007 and June 2009. These women all had a detected fetal malformation or anomaly, although the difficulty of the malformation was not considered in the recruitment criteria. Women included in the studies were n=27 for Paper I; n=99 for Paper II; n=11 for Paper III, and n=56 for Paper IV.

Exclusion criteria

Women expecting a baby with an abnormality in their sex chromosome, which is on the border of what might be regarded as an anomaly, were excluded in order not to affect the woman's likelihood to see her baby as normal.

The selection of participants was consecutive due to the uncovering of the fetal malformation. A sample was then chosen for the in-depth interview in order to best possible represent all the malformations that had been accumulated for the study. Recruitment took place after the decision about continuing the pregnancy or not had been made. The women were informed verbally by the caregivers at the ultrasound units about the aim and the method of the study and they received written information as well. If they agreed to participate, the first author contacted them by telephone to confirm participation. The educational level of the respondents was high and most of the participants, 45 (80.4%) (continuing group) respectively 33 (76.7%) (terminating group), had Swedish as their native language (Paper II). Two (Paper I) to five (Paper II, IV) women who were not fluent in Swedish needed an interpreter in order to be able to participate. There were no differences regarding socio-demographic or obstetric history between the groups (Paper II).

Drop-outs

Ninety-nine women (73.9%) out of 134 returned their questionnaires, comprising 56 (71.8%) of the group who continued their pregnancy and 43 (76.8) of the group who decided to terminate their pregnancy (terminating group) included in the study (Paper II). In Paper IV, 56 women (83.6%) out of 67 returned their questionnaires and were included in the study.

Fifty-four (96.4%) completed EDPS and CWS in mid-pregnancy, as did 49 (87.5%) at two months postpartum and 41 (73.2%) at one year postpartum. In all 53 (94.6%; trait) and 54 (96.4%; state) women completed the STAI questionnaire in mid-pregnancy, 46 (82.1%; trait) and 47 (83.9%; state) two months postpartum and 40 (71.4%; trait and state) one year postpartum.

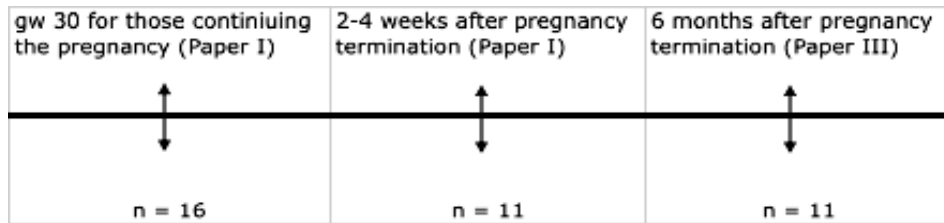
The reasons for declining participation were varied and included not having the strength to proceed with the study (continuing and terminating group), delivering the baby before the first meeting or intrauterine death of the baby (continuing group), and not understanding some of the statements in the questionnaire.

In Papers I and III none of the women declined to participate.

6.2.2 Data collection

In paper I and III the data were extracted verbatim from interviews with 16 women continuing and 11 terminating their pregnancy due to a detected fetal malformation. The interviews were performed in gestational week 30 or three weeks after diagnosis if the malformation was detected after week 30 and 2-4 weeks (Paper I) respectively 6 months (Paper III) for those terminating the pregnancy, a total of 38 interviews. All interviews were performed by the first author (NA) and a semi-structured interview guide ensured that the same basic questions were used in all interviews (Patton 2002).

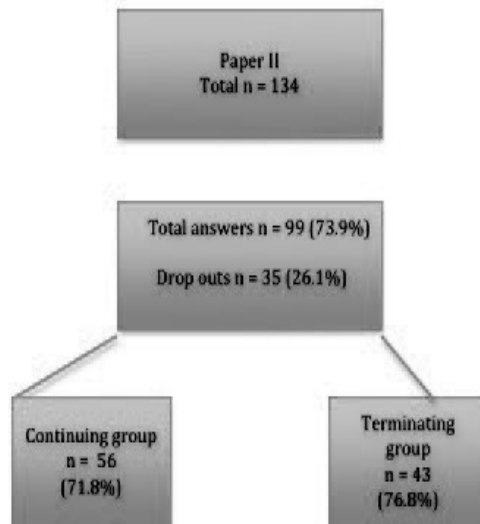
Figure III. Flowchart over the interviews.



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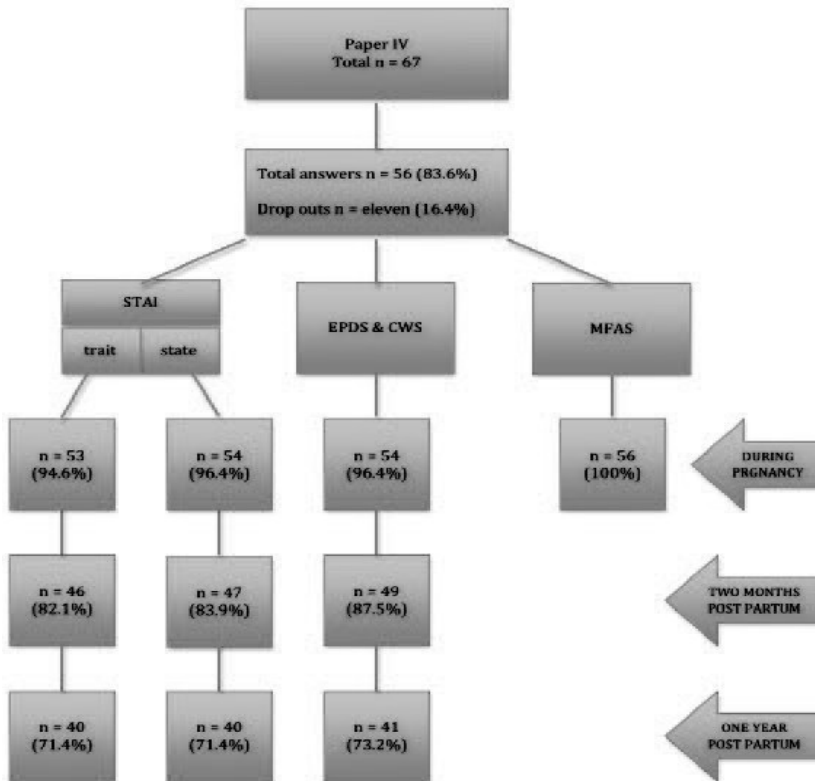
In Paper II, a study-specific questionnaire was developed to explore whether the woman was satisfied with her decision. Questions about medical and obstetric history and socio-demographics were also included in the questionnaire (as well as an open-ended question), with the possibility to add comments. In Paper IV data from common self-report instruments about prenatal depression symptoms, worries and anxiety, and maternal-fetal attachment were collected and considered within the context of pregnancy with an abnormal fetus. These data are compared with women those with a normal expected outcome of pregnancy in the Discussion. The questionnaires were distributed in gestational week 30 or three weeks after diagnosis if the malformation was detected later than gestational week 30 (Paper II, IV), or two months and one year after delivery (Paper IV).

Figure IV Flowchart of the questionnaires: participants and drop outs (Paper II).



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Figure V Flowchart of the questionnaires: participants and drop outs (Paper IV).



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6.2.3 Interviews (I, III)

Semi-structured interview with open ended questions

The purpose of doing qualitative interviews was to produce more in-depth, comprehensive information, and to seek women's interpretations of their entire situation. The interviewer is an integral part of the investigation. To obtain an immediate interpretation in order to enable the interviewer to pose further questions to gain understanding is important. The interview as a research method allows considerable flexibility in the conversation (Polit & Hungler 1999). It emphasizes the importance of looking at variables in the natural setting in which they are found. Interaction between variables is important. The systematic reflexive sort of interview has been used which means that reflections has been done throughout the interviews irrespective of using them or not (Thomsson 2002). Detailed data is gathered through open ended questions that provide direct quotations. This differs from quantitative research, which attempts to gather data by objective methods to provide information about relations, comparisons, and predictions (Smith 1983).

A pilot study was conducted testing the questions in the semi-structured interview guide before it was introduced in the first study. Before each interview the interviewer informed and

obtained written consent to ensure that the consenting women understood their right to withdraw from the study. In paper I the participants were first asked to describe their experience in receiving the information about the results of the ultrasound examination. Further clarifying questions were asked about care, treatment and support. When the questions from the interview guide had been asked and answered, the informants were invited to supplement the information with anything else they wanted to share. As it is very important to generate trust between the interviewer and the informant, the informants were asked to choose the time and setting for their individual interview. They were conducted at an ultrasound unit, at the office of the interviewer, or at the informant's home or workplace. All interviews were audio-taped and lasted between 35 and 113 minutes, transcribed verbatim by the first author (NA).

6.2.4 Questionnaires (II, IV)

The questionnaire (Papers I to IV) gathered characteristics of participants (i.e. sociodemographic data and obstetric backgrounds) as well as types of malformations in the fetus. Paper II included 22 questions about decision-making, e.g. the influence of relatives or healthcare personnel, the perceived difficulty of the decision, and whether the woman was satisfied with her decision. Also if the information received from healthcare personnel was sufficient and perceived as comprehensible, time aspects (duration and quantity of information). Most of the ultrasound questions were statements and the women were asked to mark how well they agreed on a Likert scale (Likert 1932) ranging from “strongly disagree” to “strongly agree” (Streiner & Norman 2003). Other questions had yes or no questions and one open-ended question was included, with the opportunity for respondents to volunteer other information and opinions. A pilot test was conducted and performed before it was introduced in the second study (Paper II).

Instruments

Edinburgh Postnatal Depression Scale (EPDS)

One of the most widely used screening tools for detection of pre- and postnatal depression is the Edinburgh Postnatal Depression Scale (EPDS). Developed by John Cox and colleagues in the 1980s to identify depression symptoms in women who had recently given birth (Cox et al. 1987), the Swedish validation of the instrument led to a recommended cut-off at 11/12 (Wickberg & Hwang 1996). The scale has been validated for antenatal use in UK, where the recommended cut-off was 14/15 (Murray & Cox 1990); and recently in Sweden, the cut-off of ≥ 13 (Rubertsson et al. 2011) has been recommended. It is a well-validated self-reported questionnaire easy to distribute, to answer, and to interpret (Rubertsson et al. 2005; Gibson et al. 2009; Eberhard-Gran et al. 2001; Massoudi et al. 2013).

EPDS was used for Paper IV and included 10 items, assessed on a four-point scale (0-3), specific to both prenatal and postpartum assessment of symptoms of depression, anxiety, and feelings of guilt (Cox et al. 1987). The total score range between 0-30 points and the cut-off of ≥ 13 was used for depressive symptoms in accord with the Swedish validation of Rubertsson, et al. (2011). If the respondent's score is more than 13, a psychological investigation is recommended. Because the scale does not distinguish the grade of depression or adequately measure anxiety (Jomeen & Martin 2005), it is extremely important that healthcare professionals use their clinical judgment as a complement to this or any other instrument (Karimova & Martin 2003; Rubertsson et al. 2003).

The Cambridge Worry Scale (CWS)

Green et al. (2003) developed the Cambridge Worry Scale (CWS) with the aim of assessing the content and extent of women's worries during pregnancy. It is a multidimensional measure that identifies worries in four domains: socio-economic, socio-medical, health, and relationship. It is a self-report questionnaire and includes 16 items on a Likert scale (0-5) (Likert 1932) and contains items concerning such issues as giving birth and baby's health. A fixed choice response format that ranges between the endpoint of "not a worry" (0) and "major worry" (5) are offered (Green et al. 2003). In the analysis, the responses for each item were dichotomized into 0-3 = "less than major worry" and 4-5 = "major worry" (Paper IV) in accordance with the Swedish validation (SCWS) performed by Öhman et al. (2003). The Swedish validation had a satisfying internal consistency, with a Chronbach's alpha of 0.81 in early pregnancy and 0.83 in mid-pregnancy. The reliability of the scale obtained has also been confirmed in other studies, with Cronbach's alphas of 0.79–0.86 (Jomeen & Martin 2005; Petersen et al. 2009; Carmona et al. 2012).

State-Trait Anxiety Inventory (STAI)

A widely used instrument for measuring anxiety is the Spielberger-State-Trait-Anxiety Inventory (STAI) (Spielberger et al. 1970). STAI is a well-validated scale for the evaluation of anxiety (Meades & Ayers 2011) and fairly short to fill in. STAI includes two scales measuring anxiety, describing two distinct anxiety concepts: trait anxiety (A-Trait) describing a general feeling, and state anxiety (A-State) describing feelings at a particular time (Spielberger et al. 1970). Each scale includes 20 statements assessed on a four-point scale (1-4: 1= not at all and 4= very much). The STAI-scores can vary from 20 to 80, where a low score stands for a low anxiety level. Spielberger (1983) classifies STAI scores as low anxiety (≤ 39), moderate anxiety (40-59), and severe anxiety (≥ 60). The mean scores are presented in Paper IV in accordance with a study by Georgsson Öhman et al. (2004). Internal consistency reliability was estimated by using Cronbach's alpha coefficient. The STAI has internal consistency ranging from 0.91 to 0.95 for the state sub-scale of the full version and 0.96 for trait scale of the full version (Grant et al. 2008).

Maternal-Fetal Attachment Scale (MFAS)

The MFAS has been used widely, and there is evidence for its reliability and validity. Content validity of the MFAS was based on review by experts and developed to measure the theoretical construct of maternal-fetal attachment during pregnancy (Cranley 1981). Maternal fetal attachment is defined as "the extent to which women engage in behaviors that represent an affiliation and interaction with their unborn child" (Cranley 1981, p. 282). MFAS is a self-report questionnaire and continues to be used in a high extent when it comes to prenatal studies (Van den Bergh & Simons 2009; Alhusen 2008). MFAS withhold 24 items measuring five dimensions of maternal-fetal relationship (MFR) behaviors: *Role taking* (R) four items, *Differentiation of self from fetus* (D) four items, *Giving of self* (G) five items, *Interaction with the fetus* (I) five items, and *Attributing characteristics and intentions to the fetus* (A) six items (45). The items are scored on a five-point Likert-scale (0 = definitely no to 5 = definitely yes) (Paper IV). Internal consistency reliability was estimated by using Cronbach's alpha coefficient. In previous studies, the Chronbach's alpha has shown satisfying consistency of 0.82 to 0.91 for the total scale and from 0.52 to 0.73 for the sub scales (Bloom 1995; Georgsson Öhman & Waldenström 2010; Lindgren 2001; Shieh et al 2001).

7 DATA ANALYSIS

7.1 QUALITATIVE CONTENT ANALYSIS

All interviews were transcribed verbatim by the first author (Paper I, III). The literature shows several approaches to content analysis. The qualitative one can be defined as an empirical method used in psycho-social fields primarily for analyzing recorded human communication, such as interviews, in a quantitative, systematic and inter-subjective way (Hsieh & Shannon 2005). Content analysis is a flexible method for analyzing text that focuses on the characteristics of language as communication, with attention to the relationship between smaller units in the text and the content or contextual meaning of the whole (Graneheim & Lundman 2004; Hsieh & Shannon 2005; Morse & Field 1995). The process of identifying categories and themes has been anchored in the evaluation theory that the review and reporting of evaluation should permeate all stages of the study and should encompass the steps of description and analysis interpretation, judgment and recommendations (Patton 2002). The analysis was performed in six steps; (1) the first author listened and read through the interviews several times to obtain an overall impression of the full material; (2) meaning units (words, sentences, or paragraphs related to each other through their content and context) were identified; (3) meaning units were condensed to preserve relevant core expressions; (4) units were coded and categorized into subcategories; (5) categories were built from the subcategories; (6) and categories were united in comprehensive themes.

Finally, an extensive latent analysis i.e. a coding of the underlying meaning and implied feelings was formulated into themes (Downe-Wamboldt 1992; Graneheim & Lundman 2004).

7.2 STATISTICAL ANALYSIS

In Paper II and IV, descriptive non-parametric and parametric statistical methods were used. Age is presented as means which were compared using the Student *t*-test. Categorical variables such as background characteristics are expressed as numbers and percentages. When differences were compared, the chi-squared test was applied and, *p*-values < 0.05 were considered statistically significant. In Paper IV, internal consistency reliability was estimated by using Cronbach's alpha coefficient.

The calculations were performed using the Statistical Package for the Social Sciences, version 18 in Paper II and version 21 in Paper IV (SPSS Inc., Chicago, Illinois, USA).

8 ETHICAL CONSIDERATIONS

To ask women to consent to a study in close connection with a detected fetal malformation put not only the woman, but also the person asking for consent, in an awkward situation. Endeavors were therefor made to avoid feelings of inconvenience or offense of the participants. A specialist at the ultrasound unit were chosen both to inform the women about the study, and ask for their consent to be contacted by the first author for further information. This doctor was also the one telling the women about the finding of the fetal malformation and discussing the choice of to continue or terminate their pregnancy.

There was also preparedness for to refer the woman to a welfare officer if she indicated she felt depressed, but none of the women had that need. Informed choice was important to obtain from all participants as well as written consent to ensure that the consenting women understood their right to withdraw from the study. To minimize the difficulty filling in the questionnaires both oral and written information about the study was given, as well as a covering letter on the first page in each of the questionnaire. The cover letter described the overall aim of the study and gave details how to contact the research team by phone or email. Written consent ensured that participating women understood their right to withdraw from the study. None of the researchers participated in the clinical work with the subjects. For some of the women it took several weeks to answer the questionnaire and a reminder was sent out twice at the most, in order to collect data, for those who had not notified the research team of their withdrawal from the study.

Most of the women thought of the opportunity to share their experiences as valuable and very important to contribute to the development of care and treatment for other women in the same situation. Many also expressed that it had some sort of therapeutic impact, mainly those who were interviewed but also among those who just filled in the questionnaires.

The Regional research and Ethical Committee at Karolinska Institutet approved the studies, Dnr: 2007/702-31/1.

9 MAIN FINDINGS

The papers in this thesis are numbered in the order in which they were carried out.

Papers I and II gave a deeper understanding of how women with a prenatally detected fetal malformation experience information given and manage the situation of how to deal with the situation occurred. In Paper III women who chose to terminate their pregnancies following a prenatal detected malformation expressed the importance of communication and compassion and also the significance of providing on-going care for them to feel assured of receiving good medical care and treatment. Paper IV about maternal-fetal well-being and maternal-fetal attachment, contributed to increased understanding of this vulnerable group both during pregnancy but also up to one year postpartum.

9.1 EXPERIENCES OF INFORMATION (I)

Paper I addressed women's experiences of given information in relation to the situation arise when a fetal malformation is detected by an ultrasound examination.

The information given was experienced as insufficient, often miss leading, conflicting or incoherent and sometimes negative. Negative information unrelated to the detected malformation led to feelings of guilt and confusion.

Important factors for interaction between women and caregivers were timing, duration and manner of the initial dialogue and ongoing support. Time to clarify and elaborate on the information was one of the most important aspects mentioned by the respondents. In addition the opportunity to obtain extra information also gave a chance for reflection. The dialogue felt like an important part of the information and increased the feeling of safety

Positive interactions such as feelings of coherence, improved the women's ability to understand information, fostered feelings of trust and safety which reduced their anxiety.

9.2 FACTORS INFLUENCING THE DECISION MAKING PROCESS (II)

Paper II addressed important factors to increase women's perceived possibilities to influence the decision whether to continue or terminate a pregnancy following detection of a fetal malformation.

Both women who continued and those who terminated pregnancy based their decision on the severity of the malformation. Other reasons for terminating the pregnancy were aspects including socio-economic considerations. None stated religious factors as important to their decision.

The doctor at the fetal care unit also had an influence on the decision-making. The timeframe receiving information was regarded as long enough in duration but not the number of occasions.

In both groups the women made the decision by themselves or together with their partners. The majority experienced that they had made the right decision.

Women who terminated their pregnancy had a significant higher rate (51.2%: $p \leq 0.004$) of previous abortions than those in the continuing group (23.2%).

9.3 EXPERIENCES OF IMPORTANCE AFTER A PREGNANCY TERMINATION DUE TO A FETAL MALFORMATION (III)

Paper III addresses a deeper understanding of the women's thoughts of what is important to achieve satisfaction with care as illustrated below (Figure VI). The findings are described as two categories: *Satisfaction with care*; *Management of feelings and reactions* and five subcategories: *Communication and how to feel acknowledged and thus experience support*; *Structure and information*; *In-depth understanding and compassion*; *Sadness and frustration as reactions and a part of adaptation*; and *Follow-up care*. Those categories together provided the basis for the main theme: state-dependent communication and in-depth understanding and compassion.

Figure VI Important factors in providing the feeling of support.



By Nina Asplin, unpublished.

Throughout all interviews, the concept of being seen and met individually was used as a platform to influence and provide support to enhance the best care. Being spoken to or treated with dignity and establishing some sort of communion were of great value in gaining the support needed to assimilate the loss of the pregnancy. The importance of having a plan for a next visit for follow-up about obstetrical issues was highlighted in some of the interviews. Also discussing the implications of the new information and the diagnosis and prognosis for a future pregnancy as soon as possible was important, especially for those with an advance age.

To be reassured by other people, to have the feeling of trust and safety and to receive attention from the health care providers was significant in adapting to the crisis. Sadness and frustration and a feeling of burdened of having abandon the child with the sorrow that follows was common reactions. As mourning was increasing instead of decreasing after a month and sometimes longer, it was tough to adapt to the crisis and there was a need for help to ease and manage feelings and reactions.

9.4 WOMEN'S EMOTIONAL WELL-BEING AND MATERNAL-FETAL ATTACHMENT (IV)

Paper IV addressed the effect of carrying a fetus with prenatal detected malformation and found that such knowledge did affect women's emotional well-being to a great extent.

Approximately 35.7% of women in mid-pregnancy, 23.2% at two months' gestations, and 16.1% of women one year postpartum were considered at high risk of depressive symptoms. Notably, 8.9% of women at mid-pregnancy scored high on item ten of the EPDS scale "the thought of harming myself has occurred to me,".

Table II. EPDS items over time period antenatal – postnatal

EPDS item	Antenatal mid-pregnancy (n=96,4%)		Postnatal 2 month (n=87,5%)		Postnatal 1 year (73,2%)	
	Scale 0=Pos	Scale 3= Neg	Scale 0=Pos	Scale 3=Neg	Scale 0=Pos	Scale 3=Neg
1. I have been able to laugh and see the funny side of things	37.5%	3.6%	44.6%	3.6%	35.7%	5.4%
2. I have looked forward with enjoyment to things	55.4%	14.3%	58.9%	1.8%	55.4%	3.6%
3. I have blamed myself unnecessarily when things went wrong	21.4%	8.9%	19.6%	10.7%	16.1%	8.9%
4. I have been anxious or worried for no good reason	30.4%	5.4%	32.1%	8.9%	26.8%	7.1%
5. I have felt scared or panicky for no very good reason	53.6%	1.8%	46.4%	1.8%	44.6%	1.8%
6. Things have been getting on top of me	21.4%	5.4%	23.2%	8.9%	21.4%	1.8%
7. I have been so unhappy that I have had difficulty sleeping	30.4%	12.5%	51.8%	5.4%	28.6%	1.8%
8. I have felt sad or miserable	16.1%	7.1%	14.3%	8.9%	10.7%	5.4%
9. I have been so unhappy that I HAVE BEEN CRYING	16.1%	5.4%	30.4%	7.1%	33.9%	3.6%
10. The thought of harming myself has occurred to me	87.5%	8.9%	80.4%	1.8%	58.9%	1.8%

By Nina Asplin, unpublished.

Major worries were identified on all CWS items during pregnancy especially item 9, "the possibility that something is wrong with the baby", and item 12, "giving birth". Item 4, "relationship with husband or partner," was rated as more of a worry both two months and one year postpartum. There was also an increased level in item four "relation with husband or partner" two months and one year postpartum. Women scored as a major worry item 2, "money problems," on all three occasions. During pregnancy state anxiety mean scores were higher at 43.41 than trait anxiety 39.17, but the levels were opposite two months postpartum at 38.77 and 39.74 respectively. One year postpartum the anxiety levels of state and trait were equal with a mean score of 40.03 and 40.33 respectively. The reliability measured by Chronbach's alpha was high and stable.

Mean score for maternal fetal attachment was 3.7 (SD 0.67), indicating a high level of attachment. The subscale, *role-taking*, scored high (0.71), but scores were lower on the items "It seems that my baby kicks and moves to tell me it is time to eat" (within the subscale *attributing characteristics to the fetus*) and "I feel my body is ugly" (within the subscale *giving of self*). Cronbach's alpha for attachment was 0.87. One sub-scale, *differentiation of self from fetus*, scored particularly low, 0.31, and item scores within that sub-scale were not consistent with each other. The reliability of the scale measured with Chronbach's alpha was 0.87.

10 DISCUSSION

10.1 REFLECTIONS ON THE FINDINGS

An abnormal ultrasound finding often comes unexpected to most women/parents (Lalor et al. 2006; Van der Zalm & Byrne 2006; Larsson et al. 2009) and creates a need for professional support i.e. sensitive communication of the information and strategies for mental preparation (Paper I). The challenge increases when difficult information about malformation or increased risk for chromosomal aberrations is included (Georgsson Öhman et al. 2006). Paper I and II shows that most of the women thought that the information received was an asset but could be improved. New knowledge to the area of women's experiences and interpretation of the information provided (Paper I) showed that the women were dissatisfied regarding the caregivers' methods of giving information, thus that can be improved. To meet a specialist providing proper and not confusing information about the finding both in written and visual illustration and with a positive approach may mediate complicated information (Paper I). In addition, manner and timing of providing the information were very important to achieve interaction and mutual understanding as shown by several studies (Bricker et al. 2000; Larsson et al. 2009). This knowledge might be useful in quality development as to how those improvements may help and learn women understand and make decisions about the diagnosis which sometimes leaves them with almost impossible choices. In some cases it could create a state of not being able to be aware of, and identify, what is happening around them (Paper III). This is supported by Baillie et al. (2000) and Larsson (thesis 2009).

In this study the decision to continue or terminate the pregnancy was in a great extent based on the severity of the malformation (Paper II) similar to previous findings (Grevengood et al. 1994; Menahem & Grimwade 2004; Schechtman et al. 2002). In general as well as by other researcher (Awwad et al. 2008; Redlinger-Grosse et al. 2002) it has been assumed that religious factors has an impact on the decision to continue or terminate the pregnancy. However, our study cannot confirm that. This may be due to small sample (n=5). Although it could also be seen as an opposite reaction where the religion strengthened the decision of the women (to continue the pregnancy) and thus even more feeling committed showing love and scare for her baby really needing that. Paper II showed that religious aspects were the least common factor which influenced the decision-making to terminate the pregnancy.

Termination for fetal abnormality is relatively uncommon and rarely discussed. Few parents will be prepared for facing the responsibility of their decision to end their pregnancy. This will sedate on the social network to be more open for discussions. Mc Coyd (2007) and France et al. (2013) discussed that if the decision is disclosed to their social network, this might encounter less disapproval than expected, thus be able to cope with any disapproval and be able to gain support. There is also suggested that selective disclosure, such as telling different stories to people, some are informed about the termination others are told that it was a miscarriage. This might lead to stress because of the struggle of managing two versions of events (Bryar 1997).

In Paper II the women stated their relation to the partner as very important to feel comfortable with the decision made. In addition very few women stated health care professionals to be of importance in the decision-making. This might be interpreted as if the women's judgement of health care professionals influence was a disappointment. Although the doctor at the ultrasound unit seemed to have some influence on the decision made which strengthens that it is important to provide explicit and pedagogically presented information to prevent

unnecessary anxiety or worry (Dimavicius 1998). However, personal values did not seem to have a substantial part in the decision made.

Notable in Paper II was that of those who had possibility to affect the decision-making, several had the experience of not being asked or had any discussion about the possibility to choose whether they wanted to terminate the pregnancy, thus the need to interact with the caregivers seems to be the most important part of information. Ambivalence is also an inherent part of any pregnancy and of any decision to terminate a pregnancy as shown by Zlotogorski et al. (1995). This is in line with the results in study II, in which many women expressed a need for information on additional occasions to be able to make a satisfying decision. However, the number of women who were satisfied with their decision exceeded 90%. This result should be viewed within the context of the need to be in harmony, maybe for the rest of your life with the hard decision made, particularly due to personal and ethical aspects of life. It could also be viewed in the context of that this may be due to coping strategies. Lafarge et al. (2013) has studied women's experiences of coping with the procedure of terminating and revealed that support was one of the main coping strategies used. Support both from their partner and health professionals were considered as essential for the experiences of the process in accordance with Paper II. The procedure to end the pregnancy is by Lafarge et al. (2013) described as one of the most difficult experiences the women ever had to go through. Therefore dissociating themselves from the procedure and attributing meaning to the birth experience was one way of coping. This was done by preparing and focusing on the task ahead which required factual information about the fetal condition and the termination procedure, in line with Paper I and III. Coping strategies also involved to acknowledge the baby which was seen as a way of accepting, thus coping with the loss Lafarge et al. (2013). Self-distraction or attempts to block the pain having an "out of body experience" or going on "autopilot" was another way to cope and in agreement with Paper III.

The results in Paper II indicates a need for changed routines in the maternal care. Guidance for health professionals on how to support parents is lacking. Protocols offering advise on supporting parents following termination for fetal abnormality should be developed.

Paper III indicate the importance of ensuring a high level of knowledge for pregnant women making choices about participation in prenatal screening. This is of great value in order to improve the psychological management of decision-making, as also reported by Dahl et al. (2011). Women who terminated their pregnancies, due to a fetal malformation, emphasized that state-dependent communication (i.e. at the level of the woman state) at the moment was important in their encounters with caregivers for promoting their healthy adjustment and well-being. In-depth understanding and compassion was also an important factor for realizing the feeling of support needed to be able to adapt to crisis (Paper III). A caregiver's ability to respond to feelings and thoughts related to the pregnancy termination differs and may be a disappointment for some women (Stålhandske et al. 2011).

To ensure adequate psychological support there may be a need of offering counseling services, as indicated in Paper III, assessing women for mental health outcomes and considering the effect of the loss for the woman and on the entire family. To have someone within healthcare to talk to seems to be of importance and as a first step in the process of coping with the bad news. Initially this can be made by spending sufficient time with the parents, mostly listening and answering questions (Larsson et al. 2010).

There should always be a second opinion in a tertiary center for best medical care, i.e. that before 22+0 of gestational week the attitude towards the mother and her views are critically important for the decision-making. Before terminating the pregnancy, all involved in the process should be participating in a written care plan. To achieve best of care there has to be a changed approach towards training program in obstetrical ultrasound (Asplin et al. 2013) as well as in counseling by offering postgraduate education for both midwives and doctors.

Standard care is often not sufficient for women with a diagnosis of fetal malformation (Statham et al. 2000). Well-organised follow-up care is essential after termination due to fetal malformation to ensure satisfaction (Söderberg et al. 1998; White-van Mauric et al. 1992). This is an area of care that women find lacking (Paper III). Good communication is essential for ensuring support. As a part of a more planned follow-up with primary care it is necessary to see to that the woman's maternity-care unit is informed about that the pregnancy is not continuing so that support can be offered to the woman, in line with Paper III. This could be done in form of a visit, either at the maternity-care unit or at home. It is also absolutely necessary that health professionals working in the area of prenatal diagnosis should have access to education on how to break bad news sensitively since there are well known that negative consequences are significant for all when there are unsupportive encounters (Lalor et al. 2007). Also to recognise when complex skills are needed (Larsson thesis) when some patients can benefit from being referred to a psychologist for further evaluation/treatment.

Ultrasound scanning, prenatal screening and diagnosis may increase women's anxiety and worry during pregnancy and difficult decision-making is distressing to most women (Ayers & Pickering, 1997; Dimavicius 1998; Eurenus et al. 1997; Öhman et al. 2003). This is confirmed in study IV which address that women's emotional well-being is affected due to a fetal malformation. In line with a recent study (Larsson et al. 2009) women with abnormal ultrasound findings were more worried and anxious than women with a normal result. Paper IV also address a higher amount of depressive symptoms among pregnant women carrying a fetus with a malformation than among women with a normal pregnancy. Psychological intervention, such as structured counseling has been shown to have an impact on relieving symptoms of anxiety and depression experienced by pregnant women with fetal malformation (Gorayeb et al. 2013). This is in line with the findings in Paper IV and supports the findings in Paper III about psychological support and follow-up care. When there is significantly higher levels of anxiety and depression (Paper IV) compared to a normal pregnancy (Rubertsson et al. 2005) the psychosocial distress caused by the diagnosis of a fetal malformation should be the main focus in the psychosocial consultation with the women and their partner (Paper III). The importance of this kind of psychological counseling is supported by Benute et al. (2012).

Prenatal attachment to the fetus has been described as the first important mother-child interaction (Hayes et al. 2001; Spinelli & Endicott 2003), and has been correlated with the development of the maternal-infant relationship (Muller 1996). How prenatal depression may affect a women's attachment to her unborn baby has been studied. One study found no correlation between depression and maternal-fetal attachment (Chazotte et al. 1995). Another study found that women with higher levels of depression had lower levels of maternal-fetal attachment (Condon & Corkindale 1997). However, there is suggested that depression and anxiety during pregnancy may increase the risk for behaviour disorders in the child and disrupt maternal-fetal attachment (Wickberg et al. 2005). In Paper IV the study group had slightly stronger attachment, a total mean score of 3.70, than women with a normal

pregnancy (intervention group 3.50; control group 3.44) (Georgsson Öhman & Waldenström 2010). This may be related to the opportunity offered by several ultrasound examinations to moderate some of their concerns about the fetus. Support from the woman's partner is one of the most important influences on prenatal attachment (Misri et al. 2000), but other social support has also been found crucial for the women's adaptation to pregnancy and their prenatal attachment to the fetus (Rubertsson et al. 2003).

The overall messages from this study indicate that quality of the information is essential to increase a woman's perceived possibilities to influence the decision-making. When caregivers provide adequate psychological support and organized follow-up care, women may find their situation more manageable. Finally, when caregivers base their communication on the specific needs of the woman, and also in a more profound way communicate with other care units, her journey of treatment may be positive. This will ensure mutual satisfaction with the information provided and facilitating good quality of treatment.

10.2 METHODOLOGICAL CONSIDERATIONS

Methodological strategies to achieve a more precise description of women's experiences and reactions due to a fetal malformation detected by ultrasound was used. The choice of using both qualitative/quantitative methods was based on the research problem. Strengths as well as limitations of paper I-IV included in this thesis are reflected upon in the text below.

The data collection through questionnaires and qualitative interviews provides an increased knowledge and understanding of the vulnerable situation occurred among women with a detected fetal malformation following an ultrasound examination. The study design and small sample size suggest that the results should be interpreted with caution. Data was collected from four fetal referral centers to make sure these samples made the best possible representation of the population. In this way the various catchment areas and differences of the socio-demographic can be captured, thus increase the generalizability of the study.

The long term follow-up of psychological effects was desirable but not possible within this study due to time limits. Some studies show that women may cope well initially, but may reappraise the event negatively months or even years later (Goodwin & Ogden 2007; Trybulski 2006). The main purpose of this study was to focus on women's experiences of a fetal malformation, thus the partners were not included.

This study was based upon interviews with 27 women, and questionnaires with 99 women, and it should not be generalized to depict all women with a prenatally diagnosed fetal malformation. The result should be viewed in a Swedish context and the individual situations for women who consented to participate may not be representative.

Study strengths include the wide range of information collected about women's experiences and reactions due to a detected fetal malformation, and the longitudinal approach. An additional strength was that the author who performed the interview did not contribute to the care of the recruited women, thus the women were not addicted to the author (Paper I-IV). Also that both Swedish speaking women and women who were not fluent in Swedish were offered an interpreter in order to be able to participate can be seen as a strength as it give a broader spectrum of understanding and through increasing the diversity of the sample (Paper I-IV).

The sample at the first point of time seems was representative regarding the fetal abnormalities. The art and the degree of the difficulty of the malformation or anomaly which is detected during pregnancy vary. It can be about a less serious malformation, rather easy to correct, such as talipes or cleft lip or about fetal heart defects or abdominal wall defects. Women with the following diagnoses were included in this thesis; cerebral malformation, neural tube defects, intra abdominal and gastrointestinal defects, thorax and lung defects, fetal heart defects, renal defects, skeletal defects, tumors, talipes, cleft lip, miscellaneous defects and chromosomal abnormalities. Women who were expecting a baby with sex chromosomal abnormalities, which is in the borderland of what can be regarded as an anomaly, were excluded not to affect the woman to see the baby as abnormal (Paper I-IV).

The reasons for choosing data collection in gestational week 30 was to catch difficulties after decision-making but also to reach the women before birth, which often becomes premature. For women who terminated their pregnancy the time point was decided to increase the possibilities to catch the women's experiences and feelings related to the termination but without interfering in a future pregnancy. The reason for choosing data collection one year postpartum was to follow women's well-being postnatally as well as prenatally.

PAPER I, III

In qualitative research the concepts credibility, dependability and transferability have been used to describe various aspects of trustworthiness (Polit & Hungler 1999; Graneheim & Lundman 2004). A coding framework method, as used in Paper I and II, is essential for establishing trustworthiness in analysis (Hsieh & Shannon 2005). The analysis is described carefully to make it possible for any researcher to replicate the study. The trustworthiness was strengthened by having two of the authors compare their findings from the analysis. Their analyses were similar but were discussed before reaching final agreement.

Validity and Credibility

Validity is seen as a strength of qualitative research. Being on the scene of the action, perhaps even participating in it, offers a greater depth of understanding than are possible via a few standardized questions on a questionnaire and enhance the internal validity (Creswell 2009). On the other hand, again in comparison with survey research, qualitative field research depends on subjective assessments that may undercut the reliability of measurements. The fact that me as the author who performed the interviews (Paper I, III) has a professional understanding as an ultra sonographer could be considered as a strength, thus also create opportunities for asking more detailed questions because of education in interview technique. On the other hand, the background might have resulted in influencing the interviews by using leading questions. To clarify the bias the researcher brings to the study is seen as a strength to the internal validity and may create an open discussion.

In Paper I and III the validation of all steps was considered carefully; the first and last author went through the analysis independently, and discussed their findings several times before reaching final agreement to enhance credibility (Graneheim & Lundman 2004). Data analysis was continued until so called theoretical saturation is achieved, i.e. when new data do not add anything substantially new. Appropriate and representative quotations from the text were

included which strengthens the studies. By coding the interview person and quotation we assured that the quotations were represented from all women included.

Asking women for their consent soon after they have been given information about a fetal malformation puts both the woman and the person asking for consent in an awkward situation. The ultrasound specialist, who had diagnosed the fetal anomaly, ask the woman for her consent to be contacted by the researcher. Although there could be a risk that the most positive and well informed person was chosen influencing the results in a more favourable distinction.

Dependability

The interview is used widely to supplement and extend our knowledge about individual(s) thoughts, feelings and behaviours, meanings, interpretations, etc. Large amounts of relevant information about the experiences of others may be collected by directly questioning or talking to people. Interviews, especially unstructured or semi-structured ones, offer considerable researcher flexibility (Patton 2002).

By using a semi-structured interview guide with open-ended questions we ensured that the specific topics of the study were covered (Kvale & Brinkmann 2009) and that the participants were asked similar questions throughout the course of the study (Patton 2002). A good qualitative interview question should be open-ended, neutral, sensitive and clear (Patton 2002). The interview guide comprised a few entry questions and follow-up questions were used if needed. The entry questions used were asked to describe the participants experience in receiving the information about the results of the ultrasound examination. Further clarifying questions were asked about care, treatment and support. The informants were then invited to supplement the information with anything else they wanted to share. It is recommended to avoid questions that require answers such as “yes” or “no” (Kvale & Brinkmann 2009).

A common question within the field of research is if there are any rules for sample size in qualitative studies. Patton (2002) states that there are no rules, which can be discussed. The importance of sample size in qualitative research must be understood. The Qualitative sample must be big enough to assure the likelihood of hearing most or all of the perceptions that might be important. Within a target group, different participants may have diverse perceptions. Therefore, the smaller the sample size, the narrower the range of perceptions. On the positive side, the larger the sample size, the less likely it is to fail to discover a perception that is desired to be aware of. The guiding principle should be the concept of saturation (Mason 2010). Saturation is a tool used for ensuring that adequate and quality data are collected to support the study. The concept of saturation can be argued to differ between qualitative methodologies. Such differences can lead to a significant variance in resulting sampling size. The premise of descriptive saturation is that the researcher finds that no new descriptive codes, categories or themes are emerging from the analysis of data (Rebar et al. 2011).

Before each interview informed consent was obtained from each informant. It is important to create confidence between the interviewer and the informant, thus contributing to a more un formal atmosphere to collect information. The informants chose the time and setting for their individual interview. Of the total 27 performed interviews, 13 were conducted at an ultrasound unit, 7 at the office of the interviewer, and 7 at the informant’s home or work. The

length of the interviews lasted between 35-113 minutes which was considered to be required to elucidate the topics of interest but also depending of the capacity of communication of the respondent. All the interviews were audio taped and transcribed verbatim by the first author (NA). The interviews were performed consecutive and numbered with 1P (interview participant).

Transferability

Transferability refers to the degree to which the results of qualitative research can be generalized or transferred to other contexts or settings. The findings provide a broader understanding of women experiencing a detected fetal malformation due to an ultrasound examination. This understanding might improve our understanding of women in similar vulnerable situations, where problems around loss and existential values of life and death is important. Transferability is a process performed by readers of research. The qualitative researcher can enhance transferability by doing a thorough job of describing the research context and the assumptions that were central to the research. The transferability (Paper I and II) was secured because the process of the analysis is described carefully to make it possible for any researcher to replicate the study (Creswell 2009; Polit & Hungler 1999). Providing quotations from the interviews contributed to supporting the relationship between the empirical data and the categories used to describe the variety of conceptions. To enhance transferability a rich presentation of results followed by appropriate quotations is required (Graneheim & Lundman 2004).

PAPER II, IV

Quantitative research strives to present valid and reliable research finding. Reliability and validity are ways of demonstrating and communicating the rigor of research processes and the trustworthiness of research findings. Trustworthiness depends on a number of research features: the initial research question, how data are collected including when and from whom, how they are analyzed, and what conclusions are drawn (Roberts et al. 2006).

The purpose of the sample technique (questionnaires) for Paper II and IV was to reach a wider range of women with a detected fetal malformation during pregnancy and postpartum.

Validity and Reliability

Validity describes the extent to which a measure accurately represents the concept it claims to measure (Punch 1998). There are two broad measures of validity – external and internal. External validity addresses the ability to apply with confidence the findings of the study to other people and other situations, and ensures that the conditions under which the study is carried out are representative of the situations and time to which the results are to apply (Black 1999). Internal validity addresses the reasons for the outcomes of the study, and helps to reduce other, often unanticipated, reasons for these outcomes. To achieve validity the questionnaires (Paper II) were conducted by the first, second and last author, all with a great extent of experiences about fetal screening and ethical issues but from different perspectives. All questionnaires (Paper II, IV) were pre tested on a convenience sample of pregnant women and a pilot study was performed among the target population to increase the measures validity.

The longitudinal design of this study made it possible to examine answers to an open ended question at the end of each questionnaire, where the participants were encouraged to write down areas of importance to them. Several women spontaneously remarked that they found most of the questions interesting, important and that filling in the questionnaire had provided a good opportunity to work through their feelings.

The reliability of a research instrument concerns the extent to which the instrument yields the same results on repeated trials. A reliability of 0.9 means 90% of the variability in the observed score is true and 10% is due to error. A reliability of 80 to 90% is recommended for most research purposes. Although unreliability is always present to a certain extent, there will generally be a good deal of consistency in the results of a quality instrument gathered at different times. The tendency toward consistency found in repeated measurements is referred to as reliability (Carmines & Zeller 1979).

Most of the questions used in this study (Paper II, IV) were adopted from previously used questionnaires. Well validated scales for measuring depressive symptoms, worry, anxiety and maternal-fetal attachment has been used in present study as well as in previous large studies (Georgsson Öhman et al. 2004; Georgsson Öhman & Waldenström 2010; Rubertsson et al. 2005) on women with a normal pregnancy. This has been useful in our discussion in comparison instead of a control group (Paper IV). STAI (Paper IV) is describing two distinct anxiety concepts; trait anxiety and state anxiety (Spielberger et al. 1970), in general, but gives us no information on what the pregnant woman is anxious about.

Internal consistency of scales

To evaluate the internal consistency (measure of reliability) of the scales, Cronbach's alpha (Cronbach 1951) was calculated. In paper IV Cronbach's alpha coefficient was high and stable, for MFAS 0.87 for the total score and for STAI during mid-pregnancy 0.93 (state)-0.93 (trait) 2 months postnatal 0.94 (state)-0.99 (trait) and 1 year postnatal 0.77 (state)-0.88 (trait). This means that the scale of Cronbach's alpha is reliable as a minimum of 0.71 is recommended (Kline 2000). The internal consistency of research tools needs to be assessed. Internal consistency is the relationship between all the results obtained from a single test or survey.

Generalizability

Generalizability and transferability are important elements of any research methodology, but they are not mutually exclusive: generalizability, to varying degrees, rests on the transferability of research findings (Creswell 2009). Statistically the small sample size (Paper II and IV) can inadequately affect mean value and inclusion of women only from the Stockholm area, limits the generalizability to represent the experience of all women with a prenatally diagnosed fetal malformation, and implicates that the results should be interpreted with caution.

11 CONCLUSIONS AND CLINICAL IMPLICATIONS

- Informing women of a fetal malformation detected at ultrasound scan remains a challenge for caregivers. Women expressed both a considerable lack of information and dissatisfaction with caregivers' ways of providing information (Paper I).
- Women require further information on several occasions to decide whether to continue or terminate a pregnancy following the detection of a fetal malformation (Paper II).
- Women who decide to terminate their pregnancy need better and more empathetic and compassionate support (Paper III).
- Women who continues their pregnancy despite a fetal malformation tend to have high levels of depressive symptoms during pregnancy and at two months and one year postpartum. A pregnancy with a fetal malformation also seems to greatly affect general levels of anxiety and worry (Paper IV).

This thesis contributes to the knowledge and understanding of how women with a fetus prenatally diagnosed with a malformation or anomaly experience their care, how they feel emotionally, how they make their decision, and how they understand the situation. Paper I and II show important implications for caregivers who are responsible for providing this sort of diagnosis and for helping women who are faced with such a decision.

The findings in Papers III and IV indicate that caregivers need to ensure women have adequate support, perhaps in form of complete follow-up routines and increased resources, but also through talk therapy with a counselor who specializes in prenatal or postnatal issues related to a prenatal diagnosis of malformation and concerns both during pregnancy and the postpartum period.

Targeted education for caregivers may help to ensure that they properly meet the needs of these patients.

12 FURTHER RESEARCH

Findings from this thesis highlight the need for further studies and evaluations of the care, information, and communications available to women with a prenatally detected fetal malformation.

Investigations into how health care professionals are prepared to deal with difficulties associated with fetal screening and fetal malformations would be important to increasing the prenatal and postnatal care of these vulnerable women.

It would be of great value to the care and treatment of these women if we could screen those who are sensitive for depressive symptoms. This could be achieved by creating an overall plan for women with pregnancies with or without fetal malformations, to provide for better postnatal outcomes.

It might also be of interest to investigate experiences of parenthood in this context.

A future study comparing partners' experiences of learning the diagnosis and of the decision-making process are also necessary, as are studies of men's attachment to their partners' fetus during pregnancy and after.

Different intervention studies need to be constructed to further investigate the benefit of care programs or strategies for support, especially for women who experience a crisis following a detected fetal malformation.

13 SUMMARY IN SWEDISH – SVENSK SAMMANFATTNING

Bakgrund: En ultraljudsundersökning i andra trimestern är idag en väl etablerad metod för att fastställa graviditetslängden, lokalisera placenta läge, upptäcka flerbörd men också till att diagnostisera strukturella missbildningar hos fostret. I Sverige genomgår nästan samtliga gravida kvinnor ultraljudsscreening i graviditetsvecka 18. Teknologins snabba utveckling har möjliggjort för erfarna ultraljudsspecialister att upptäcka allt fler avvikelser vilket medför nya dilemman då kvinnan ofta är dåligt förberedd på detta. Informationen till de blivande föräldrarna blir sällan självklar och vid besked om missbildningar hos fostret måste föräldrarna fatta svåra snabba beslut om vidare undersökningar och huruvida graviditeten ska fortgå eller inte. Svårigheter att ge bra information och stöd i samband med avbrytande av graviditeten kan ge negativa konsekvenser på hur kvinnan bearbetar förlusten av sitt foster.

Syfte: Avhandlingens övergripande syfte var att studera kvinnors upplevelser och reaktioner efter att en fosteravvikelse upptäckts via ultraljud.

Metod: Två semistrukturerade djupintervjustudier genomfördes. En med 27 kvinnor vid graviditetsvecka 30 eller tre veckor efter diagnos för de som fortsatte sin graviditet. För de som valde att avsluta graviditeten blev denna registrering utförd två till fyra veckor efter avslutad graviditet (Studie I). Den andra intervjustudien genomfördes med elva kvinnor (Studie III) sex månader efter avbrytande av graviditet. Två enkäter, en besvarad av 99 kvinnor (Studie II) utförd under graviditetsvecka 30 eller tre veckor efter diagnos för de som fortsatte graviditeten eller två till fyra veckor efter avslutad graviditet för de som valt detta. Kvinnorna fick också svara på 22 studiespecifika frågor. I enkäten ingick också skattningsskalor om emotionellt välbefinnande och socio-demografiska variabler, samt medicinsk- och obstetrisk bakgrund. Den andra enkäten som besvarades av 56 kvinnor genomfördes med självskattningsinstrument för emotionellt välbefinnande med datainsamling under graviditetsvecka 30, två respektive sex månader post partum (Studie IV). Kvalitativ data analyserades med innehållsanalys, och kvantitativ data med deskriptiva statistiska metoder..

Resultat: Tidpunkt, varaktighet, inledande kommunikation (skapa förtroende och bygga en dialog) samt stöd visade sig vara viktiga faktorer för samspelet mellan kvinnorna och vårdgivare. Ett positivt samspel med vårdgivaren underlättade kvinnornas förmåga att förstå information, skapade känsla av tillit och trygghet som kunde lindra ångest. De flesta kvinnor som väntade ett barn med fosteravvikelse uttryckte stort behov för information vid flera olika tillfällen, för att underlätta den svåra beslutsprocessen. Kvinnorna önskade också information och uppföljning från flera specialister, vilket framträdde ännu starkare hos gruppen som valde att avsluta graviditeten. Kvinnor som fortsatte graviditeten hade stor risk för att utveckla symptom på depression, oro och ångest under graviditeten samt två månader och ett år post partum. Trots detta visade mor-barn relationen en hög anknytningsnivå.

Slutsats och Kliniska implikationer:

För att kvinnorna ska kunna få adekvat stöd behöver kommunikationen förändras utifrån kvinnans behov av empati och information samt en förbättring av uppföljningsrutiner ske. Detta skulle öka möjligheten till en god vårdkvalitet. Avhandlingens resultat kan användas som ett stöd för hälso- och sjukvårdspersonal att förbättra sin kommunikation med kvinnor i situationer när information om avvikelser ska ges. Viktigt är också att vidareutbilda hälso- och sjukvårdspersonal för att kunna möta patienters behov på ett bra sätt.

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