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Parents' expectations, experiences and reactions to a routine ultrasound examination during pregnancy

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2008

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Citation for published version (APA):

Ekelin, M. (2008). *Parents' expectations, experiences and reactions to a routine ultrasound examination during pregnancy*. [Doctoral Thesis (compilation), Department of Health Sciences]. Lund University, Faculty of Medicine, Dept of Health Sciences.

Total number of authors:

1

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**PARENTS' EXPECTATIONS,
EXPERIENCES AND REACTIONS
TO A ROUTINE ULTRASOUND EXAMINATION
DURING PREGNANCY**

Maria Ekelin



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ISBN 978-91-86059-67-5
Printed in Sweden by
Media-Tryck

*To my mother,
Ingrid Thelin*

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ABSTRACT

The overall aim of this thesis was to describe parents' expectations, experiences and reactions to a routine ultrasound examination during the second trimester of pregnancy and to develop, test and use a questionnaire. The aim was also to conceptualize the parents' experiences and ways of handling the situation when the diagnosis was a non-viable fetus.

The data for this thesis was collected between 2001 and 2007. The work started qualitatively and inductively with interviews using the Grounded Theory method for data collection and analysis of 22 women's and 22 men's expectations experiences and reactions to routine ultrasound examination with normal findings. The results were used during the instrument development of the PEER-U questionnaire. The procedure included a pilot study where 126 parents answered both parts of the questionnaire. Factor analysis and statistical tests for validity and reliability were performed. The PEER-U questionnaire was then used for deductive testing of the results of the qualitative study with a one year cohort in which 2183 parents (1258 women and 925 men) answered both parts of a two-part (before and after ultrasound) questionnaire. The questionnaire included the PEER-U scale with an ultrasound specific state of mind index and the scales state and trait anxiety (STAI) and sense of coherence (SOC) as well as demographics. A follow-up Grounded Theory interview study was performed with 15 parents from the cohort who had been given a diagnosis of a non-viable fetus. The results from the qualitative parts showed that the parents expected to get a confirmation of a normal and apparently healthy child during the ultrasound. For parents with normal results, the ultrasound was experienced as very positive and they started to feel like a family. Afterwards these parents were left with a feeling of relief. Parents who received the diagnosis of a non-viable fetus experienced a collision between hopes and facts. They felt deceived by a false sense of security as the condition was unexpectedly discovered during a routine examination. These parents required clear information and focused on what would happen next. The need for a general and individual care plan was evident as was the need for a follow-up initiated by the care-givers.

The development of the PEER-U questionnaire resulted in 30 items to measure parents' expectations and 23 items to measure their experiences and reactions. Internal consistency, calculated by Cronbach's coefficient alpha, was 0.77 for the "before ultrasound" part of the PEER-U questionnaire and 0.75 for the "after ultrasound" part. The results from the cohort study showed that both parents' degree of worried state of mind decreased after the ultrasound but their sense of coherence remained stable. In a gender comparison the women's state anxiety decreased significantly while the men showed no significant change. Before the examination the women showed a significantly higher degree of worried state of mind in relation to ultrasound than the men while afterwards the situation was reversed.

The findings show that parents easily accept fetal diagnosis that gives them a visual evidence of the fetus. This should be remembered when new forms of fetal diagnosis are introduced in the future. Their state of mind in relation to ultrasound can be measured with the ultrasound specific state of mind index. Further research might improve the questionnaire and make it better adapted for use when the parents have experienced adverse findings during a routine ultrasound examination.

ABBREVIATIONS

FUB	Riksförbundet för barn, unga och vuxna med utvecklingsstörning/ The Swedish National Association for Persons with Intellectual Disability
GT	Grounded theory
NT	Nuchal translucency
PEER-U	Parents' Expectations, Experiences and Reactions to routine Ultrasound examinations during pregnancy (scale)
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
SOC	Sense of Coherence (scale)
STAI	State and Trait Anxiety Inventory (scale)
STAI-S	State Anxiety
STAI-T	Trait Anxiety

ORIGINAL PAPERS

This thesis for is based on the following papers referred to in the text by their Roman numerals:

- I Ekelin, M. Crang Svalenius, E. Dykes, A-K. (2004). A qualitative study of mothers' and fathers' experiences of routine ultrasound examination in Sweden. *Midwifery*. Dec;20(4):335-44
- II Ekelin, M. Crang Svalenius, E. Dykes, A-K. (2008). Developing the PEER-U scale to measure parents' expectations, experiences and reactions to routine ultrasound examinations during pregnancy. *Journal of Reproductive and Infant Psychology*. 26(3): 211-228.
- III Ekelin, M. Crang Svalenius, E. Larsson, A-K. Maršál, K. Dykes, A-K. Parental expectations, experiences and reactions, sense of coherence and grade of anxiety related to routine ultrasound examination during pregnancy. *Submitted*
- IV Ekelin, M. Crang Svalenius, E. Nordström, B. Dykes, A-K. (2008). Parents' Experiences, Reactions and Needs Regarding a Nonviable Fetus Diagnosed at a Second Trimester Routine Ultrasound. *Journal of Obstetric, Gynecologic, & Neonatal Nursing*. 37(4):446-454.

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INTRODUCTION

Since the introduction of ultrasound into obstetrics in the 1950's, there have been major developments in its use in fetal diagnosis. Nowadays much more can be seen and many parents look forward to getting the first visual evidence of their baby during the second trimester routine ultrasound examination. The other side of the coin is that ultrasound can now be used to identify prenatally about half of the severe fetal malformations. This might affect parents' psychological well-being. The development of ultrasound techniques is ongoing and new methods are being developed and introduced. To optimize the care, parents' needs have to be evaluated. The unique aspect of this thesis is that, throughout the whole study, the partners' views of ultrasound are sought, as well as the women's.

Fetal diagnosis gives rise to ethical debate. For decision makers, parents' need for care and their reactions to existing forms of ultrasound-based fetal diagnosis can serve as a foundation in planning the introduction of new techniques. No instrument that specifically measures the impact of ultrasound on parents' well-being was found during a review of the literature.

In Sweden, routine ultrasound examinations are mainly performed by specially trained midwives. The midwives at the antenatal clinics are the ones who inform the parents about routine ultrasound and who might meet parents' reactions after the examination.

My personal motivation as a midwife to carry out this research project can be compared to my motivation when I chose my profession; a longing to be close to the essence of life. I am amazed over our existence! The start of it is the reproduction, which is joy but can also be sorrow. Who should decide over the life itself? I know that the primary drive in many peoples' lives is to become a parent and for me, this project is a search, born of curiosity, about the process of becoming a parent. A holistic view forms an important component of the Caring Sciences. Therefore I believe that the issue of the impact of ultrasound on parents' well-being is an obvious topic for a midwife.

BACKGROUND

Routine ultrasound examinations

Ultrasound is a diagnostic tool used throughout the world. There are significant regional differences in its use in obstetrics, for example the extent to which ultrasound examinations are performed routinely and when it is used, with what frequency and in what context. It has also been stated that there are cultural differences in the impact of ultrasound, for both women and their partners, on the interlinked scale of perceiving it as a diagnostic test versus a way of elaborating the social identity of the fetus (Mitchell and Georges in Rudinow Saetnan et al. 2000).

In a recent Swedish study, women expected to get confirmation of the normality of their fetus (Georgsson Öhman & Waldenström 2008) but one of the health care's purposes of the examination is to exclude malformations (Nikkilä et al 2006). Thus there is a basic difference in what the actors are searching for. It has even been defined as a meaningful social ritual of seeing and meeting the baby, which for women dominates its medical purposes (Mitchell 2004). For these reasons women can be unprepared for adverse findings (Garcia et al. 2002). Recently, it has been argued that the medical message and prenatal attachment are inseparable for the women and their partners as those aspects are both parts of the process of becoming a parent in modern society (van Dijck 2005, Hellmark Lindgren 2006).

Past

The use of ultrasound in obstetrics in Sweden started when Associate professor Bertil Sundén at Lund University Hospital, who had studied the method in Scotland, bought a Disonograph (manufactured by Smith Industries, England). With this he made the world's first ultrasound identification of a twin pregnancy in 1962 (Nilsson & Westling 2004). In 1973 the hospital in Malmö was the first department in Sweden to introduce a routine screening programme available to all women for the detection of twins (Person et al 1979). Around 1980 it became common to also use ultrasound to date the pregnancy and the scanning for malformations was developing as the ultrasound technology improved (Weldner 1998). Randomized studies to determine whether a routine ultrasound examination before pregnancy week 24 was beneficial showed that it reduced the rates of induction of labour for post-term pregnancy (Waldenström et al. 1988). Twin pregnancy could be detected earlier (Waldenström et al. 1988, Bricker et al. 2000), which had also been shown by Persson et al (1979). No differences were found in perinatal outcome between study populations and control groups (Bricker et al. 2000). The number of terminations for fetal anomaly increased (Saari-Kemppainen et al.1990). In the Helsinki Ultrasound Trial (Saari-Kemppainen et al.1990) (performed in the late 80's) ultrasound was already a popular examination for the parents as 22 % in the intervention group had had an ultrasound before the time for the second trimester screening. In the control group 77% had an ultrasound examination at some time during pregnancy.

By 1993 all obstetrical units in Sweden offered routine ultrasound examinations and 79% of the ultrasound departments included screening for malformations. At that time 97% of the pregnant women underwent one or more routine ultrasound examinations during pregnancy (Hagenfeldt et al. 1998).

Present

In 2005, all "non-private" ultrasound units in Sweden offered at least one routine ultrasound examination, in all units but one it is carried out between pregnancy week 15 and 20. The nuchal translucency (NT) examination which is an ultrasound method, primarily for calculating the risk for Down syndrome in the first trimester (Nicolaidis et al. 1994) was at this time available at four units, but not as a routine (Nilsson et al.

2006). NT can not replace the second trimester routine ultrasound for the detection of structural malformations (Westin 2006). Presently, NT in combination with serum screening is offered to women aged 33 or over in the southern region of Sweden, where the studies in this dissertation were performed. Outside the Swedish health insurance system, it is possible for parents to have extra ultrasound examinations at a few private clinics.

The detection rate for malformations varies widely in published studies, due to differences in definition of the concept of malformation (Hagenfeldt et al. 1998, Nilsson et al 2006) and in the study design (Levi 2002). An overall detection rate of 55% for malformations has been shown in a large UK study with 0.005% risk for false positive results, mostly caused by soft markers, which are ultrasound appearances associated with increased risk for chromosome disorders (Boyd et al. 1998). Nikkilä et al. (2006) also found few false positive ultrasound diagnoses when she compared prenatal ultrasound diagnoses with the diagnosis of newborn and aborted fetus during the years 1984-1999 in the south of Sweden. The detection rates for different forms of malformations vary and are for example known to be higher for the central nervous system than for heart malformations (Hagenfeldt et al. 1998, Bricker et al. 2000). In a Swedish study performed in 1994, fetal malformations were detected in 0.5% of the second trimester routine ultrasound examinations (Eurenius et al 1996).

No incidence figures have been found from the second trimester for non-viable fetuses, but due to the increased number of NT examinations that result in earlier detection, it is low. The detection rate for a non-viable pregnancy is 2.8% in gestational week 10-13 (Pandya et al. 1996).

Future

Ultrasound techniques are being developed further as are new methods for fetal diagnosis. For example the three-dimensional scanner which sends sound waves at different angles, producing a lifelike 3-D picture. If further developed, it might be even better for examining fetal anatomy than real-time two-dimensional ultrasound (Michailidis et al. 2002).

NT is being introduced in Sweden in combination with maternal serum screening. Other methods for risk screening might be developed for use in combination or alone, such as the measurement of the nasal bone (Cicero et al. 2006). Methods for detection of chromosomal abnormalities through maternal blood test for fetal DNA are under development and some success has been presented (Dhallan et al. 2007). Medical equipment and techniques for second trimester ultrasound are also likely to continue to improve. It is possible that private clinics will expand, since ultrasound is a popular examination for parents. A brief search on Swedish web sites for parents indicated that an extra ultrasound examination to determine the sex of the baby is in popular demand.

Psychological aspects

The psychological impact of routine ultrasound examination has been reviewed by Bricker et al. (2000) and by Hagenfeldt et al. (1998) and both have found that it is very attractive for parents but that it can also cause anxiety. For parents with adverse findings, the reactions can be grief and sorrow and they may be less prepared because of the routine status of the examination (Garcia et al. 2002).

Anxiety and relief

Parents might feel anxious about the results of the examination and what it might lead to. A reduction of anxiety has been described among pregnant women with a normal scan, after the routine ultrasound examination (Brisch et al 2002). In a qualitative study of 30 pregnant women's anxiety about fetal health, almost all of the participants had experienced anxiety though they had looked forward to the ultrasound and to getting the confirmation of a healthy fetus (Harpel 2008). They were relieved after examinations with normal findings.

Parents might also be worried that the examination itself could be harmful. No serious risks with prenatal exposure to ultrasound in the second trimester have been found so far (ISUOG 2000, Nilsson et al. 2006, Glimskär Stålberg 2008). Two studies indicate that non right-handedness is more common among boys who have been exposed to ultrasound than among those who have not (Salvesen & Eik-Nes 1999, Kieler et al. 2001). As the energy level in modern ultrasound equipment is considerably higher than for the participants in the studies mentioned above, the possibility of risks being detected in future can not be excluded (Glimskär Stålberg 2008).

Little has been written about fathers' well-being in connection with ultrasound. Kowalcek et al. (2003) noted a significant reduction in stress reactions for both parents before and after ultrasound performed between weeks 12 and 20. Buist et al. (2003) concluded, following repeated measures of distress levels, that most men deal well with the transition to fatherhood but that their anxiety may be missed in the antenatal period as the focus is on the pregnant woman.

Attachment

Maternal-infant attachment has been described as the extent to which women engage in behaviours that represent an affiliation and interaction with their newborn baby (Cranley 1981). Attachment is a process that starts prenatally. A literature review by Alhusen (2008) shows that ultrasound examination during pregnancy increases maternal-fetal attachment when measured before and after the examination. Movement is especially important in the attachment process, both when seen at the ultrasound examination and when perceived as quickening (Colucciello 1998). Prenatal attachment is a predictor for the early mother-infant relationship (Siddiqui & Hägglöf 2000). Ultrasound examinations in early pregnancy and for women undergoing their first examination are known to have the largest impact on attachment,

but no differences between the impact of two or three dimensional techniques have been seen (Sedgemen et al. 2006). A literature review has not given data solely on the fathers' process of fetal attachment.

The partner – one of the parents

First time expectant fathers experiences of pregnancy has been described as a transition to fatherhood (Finnbogadóttir et al. 2003). In this context transition was described as psychological, social and/or physical change during the pregnancy. The fathers interviewed in that research thought it very important to take part in the pregnancy and to seek knowledge. The second trimester routine ultrasound examination was an opportunity to do so. No data has been found on exactly how many partners are present at the routine ultrasound examination, but it is usual in Sweden.

Since 2005, lesbian couples have had the right to insemination or in vitro fertilization in Sweden. Hence, in the future, female partners of pregnant women might become more common.

Measuring psychological aspects/well-being in relation to ultrasound

Several generic instruments have been used in studies on the impact of ultrasound on parents' psychological well-being. "Well-being" is a concept with several aspects. The STAI instrument has been used frequently to evaluate anxiety in connection with ultrasound examinations. For example Zlotogorski et al. (1995) measured anxiety before and after routine ultrasound on women with normal findings. Brisch et al. (2002) used it to evaluate differences in maternal anxiety for different high-risk subgroups in a longitudinal perspective. Georgsson Öhman et al. (2004) investigated differences in anxiety among women who had first or second trimester examinations but found none. The concept of state anxiety is described by Spielberger (1983) as an emotional state at a given moment with a subjective feeling of tension, apprehension, nervousness and worry that leads to an activation of the autonomic nervous system. He defined the concept of trait anxiety as a person's relatively stable individual tendency to perceive stressful situations and react with more or less state anxiety.

Other instruments that have been used in studies on the impact of ultrasound on parents' psychological well-being are for example the Cambridge Worry Scale and Edinburgh Postnatal Depression Scale (Georgsson Öhman et al. 2004) as well as other scales for stress and depressive reactions (Kowalcek et al. 2003).

The SOC instrument evaluates grade of health or specifically the ease with which an individual copes with stressors in life (Antonovsky 1987). During a literature research it was not found to have been used in a specific ultrasound context but it was used for the evaluation of SOC at different times during pregnancy (Sjöström et al 2004).

No specific instrument for measuring parents' well-being in connection with ultrasound examinations has been found during a literature research and therefore there was a need to develop one. To develop an instrument requires several steps. Both reliability and validity are important criteria for assessing the quality of the instrument (Polit & Beck 2006).

The roll of the midwife

In Sweden the midwife is the person who most often gives the parents the information about ultrasound before the examination. At the ultrasound department it is a midwife who performs the examination. Afterwards the parents meet a midwife again at the antenatal clinic. Parents who experience the diagnosis of a non-viable fetus and who need to terminate the pregnancy at the hospital also meet midwives or nurses there.

Information

In a Swedish study a major lack of pre-scan information was shown when one hundred women were interviewed immediately after their second trimester routine ultrasound (Crang-Svalenius et al. 1996). More than half of the women thought that the ultrasound was a compulsory part of maternity care and fewer than half could remember that they had been informed that screening for malformations was included in the routine examination.

At the antenatal clinics, connected to Lund University Hospital, where the research for this thesis was carried out during the period 2001 to 2006, information about the ultrasound examination was, and is, given both written and verbally at the booking visit. If the parents decide to have a routine ultrasound examination, the midwife refers the woman to the ultrasound department. SBU, The Swedish Council on Technology Assessment in Health Care together with the Vardal Foundation, has published a parental information pamphlet (Leander 1999) concerning routine ultrasound examinations, though it is not a routine procedure to give it to all parents. After the booking visit, during a normal pregnancy the next contact with caregivers is at the second trimester routine ultrasound examination. A Swedish study has shown that to a large extent (84%) women seek supplementary information on pregnancy related issues in general on the internet but unfortunately, do not discuss their findings with their midwives (Larsson 2007). According to Larsson's study, women seek more internet information in the first part of pregnancy which indicates that there are too few visits at the antenatal clinic during this period.

Further written information is given together with the appointment time. During the period when the research for this thesis was carried out, it included information on the purposes of the examination, preparations, security, how the examination is performed and the information that only one adult person may accompany the woman during the examination.

During the examination, parents are given information about what is shown on the screen. Cox et al. (1987) compared two different levels of feedback from the sonographer, during routine ultrasound. One group high feedback could see the screen while the other group, low feedback only had the results explained to them. They showed that the high feedback group had significantly less state anxiety and more positive emotional experience than the other group after the examination. This difference in state anxiety between groups was not significant in a similar study (Zlotogorski et al 1996) although an overall reduction of anxiety was shown.

Interaction with parents

During the ultrasound examination, the parents need to see the ultrasound picture to be reassured about the baby's normality. At the same time they are dependant on the midwife for interpretation; that she explains to them what they are seeing. It is important she does not show signs of hesitation as the parents easily "read" the midwife's body language (Jonsson 2004, Mitchell 2004). Mitchell (2004) states that some of the factors shaping the meaning of the ultrasound image to parents are the sonographers word choice and behaviour and the way in which an adverse finding is described. During the writing of Paper IV, two midwives working at the ultrasound department where the research for this thesis took place were interviewed about the routines that were followed when a non-viable fetus is diagnosed. No special preparation was made if it was a second trimester ultrasound. If it was a NT examination, when missed abortions are more common, they asked for the anamnesis if not given spontaneously, as a preparation for themselves for an adverse outcome of the examination, for example to be informed if the woman had been bleeding. After the verification of a non-viable fetus, these midwives told the parents that it was not looking good, showed them the uterus and the anatomy, and then explained to the parents that it was a non-viable fetus. When they had given the parents time to react, they showed them the fetus if visible, in order to demonstrate to the parents that, though the heart was not beating, it was still their fetus, a human being. The ultrasound midwives hoped that this might help the parents to cope with their loss. After this, a doctor was brought in as soon as possible.

Ethics in fetal diagnosis

The purpose of fetal diagnosis for the individual might be curiosity, mental preparation for the delivery of a baby with a handicap or to avoid a baby with a certain handicap (SMER 2006). From an ethical perspective, the right of the fetus and the principle of the equal value of all humans might stand against the woman's autonomy (ibid). In Sweden, the woman alone has the right to decide to have an abortion until the end of week 18 of the pregnancy.

The development of new screening methods for fetal malformations is ongoing, though there are contrary views, for example from The Swedish National Association for Persons with Intellectual Disability (FUB). They object to fetal diagnosis aimed at

finding certain handicap but sympathize with it if the purpose is to find conditions which might be medically treatable. FUB urges that prospective parents must be given information on what the discovered deviation is and how it will affect the family in everyday life, before they decide whether to continue the pregnancy. They wish that written information should be produced in co-operation with handicap organizations (FUB 2007). Together with the Swedish National Council on Medical-Ethics (SMER 2006) FUB believes that society must allocate resources to support families with handicapped children so that the alternative of continuing the pregnancy will be a possible choice.

Informed choice is a central issue in fetal diagnosis. The woman's well-being might be improved by fetal diagnosis but might also be damaged, especially if she receives information she did not request (SMER 2006). The Health Technology Assessment (Bricker et al. 2000) warns that rapid changes in care may leave both maternity staff and women behind and points out that better information is needed for both.

Nicole (2007) states that it is impossible for an expectant mother to make an informed choice about whether to have an ultrasound or not, due to the medical environment and culture of hospitals. A discussion between the midwife and the expectant couple before the first ultrasound might improve informed choice. According to Mitchell (2004) informed choice can lead to reflection, engaged thinking, empowerment and active participation in life's decisions.

It has been concluded that specific information about the second trimester scan is required, rather than general information on ultrasound during pregnancy, to make its purpose clear to parents (Lalor & Devane 2007). To offer information does not increase anxiety overall (Thornton et al. 1995). Garcia et al. (2002) conclude in a review of women's views of pregnancy ultrasound, that they often lack information about the purpose of the ultrasound examination and its technical limitations. In a Swedish context, parents in a large trial in 1999 and 2000 were generally satisfied with how and why the second trimester ultrasound examination was performed, but lacked information about possible risks (Georgsson Öhman & Waldenström 2008). SBU (Nilsson et al. 2006) points out that the time mostly given, during antenatal care, to imparting information to parents-to-be considering fetal diagnosis, is very short.

When new forms of fetal diagnosis are introduced, they are associated with practical difficulties such as reaching all midwives working with antenatal care, with teaching/information offers. Hospital resources to meet demand can also be underestimated. In a study including two hospital areas it was also discovered that one third of the midwives working in antenatal care were doubtful, from an ethical point of view, about the role of fetal diagnosis in general (Ekelin & Crang Svalenius 2004). SMER (2006) has presented an opinion that the woman's self-determination is limited by the framework established by society and that this framework should be based on an ethical analysis, continuing follow-up on fetal diagnosis and a debate within society.

Bashour et al. (2005) have warned about the use of ultrasound for profit. They have found a risk that doctors carry out multiple ultrasound examinations on uncritical mothers with insufficient information on its purposes and recommended frequencies. They also warn against the risk of unskilled performers in developing countries. This underlines that it is important to follow technical development with an exploration of parents' views.

AIMS

The overall aim of this thesis was to describe parents' expectations, experiences and reactions to routine ultrasound examination during the second trimester of pregnancy and to develop, test and use a questionnaire. The aim was also to conceptualize the parents' experiences and ways of handling the situation when a non-viable fetus diagnosed.

Specific aims:

- **Paper I:** The aim of this study was to conceptualise women's and their partners' thoughts and feelings before, during and after the routine ultrasound examination in the second trimester of pregnancy
- **Paper II:** The aim was to develop, test and analyse a questionnaire for measuring parents' expectations, experiences and reactions in connection with routine ultrasound examinations during pregnancy
- **Paper III:** The aim was to investigate parents' expectations, experiences and reactions (state of mind index), sense of coherence and degree of anxiety before and after a second trimester routine ultrasound examination with normal findings.
- **Paper IV:** The aim was to conceptualize women's and their partners' experiences and ways of handling the situation in connection with an ultrasound examination in the second trimester of pregnancy, when the diagnosis was a non-viable fetus.

METHODS

Design

The design of this thesis has been both qualitative and quantitative. Grounded theory was used in the qualitative parts (Papers I and IV). The items in the instrumental development paper (Paper II) arose from the qualitative study (Paper I) and the instrument was used in a pilot study (Paper II). The revised instrument was used for evaluation of a one year cohort of mothers' and fathers' expectations, experiences and reactions of a second trimester ultrasound examination with normal findings (Paper III). The parents who had been diagnosed with a non-viable fetus during the routine ultrasound were included in a follow-up study with qualitative design (Paper IV). The design and number of participants in these papers are described in Table 1.

Table I. Design and Participants

	Design and Method	Participants (n)	
		Before ultrasound	After ultrasound
Paper I	Qualitative interviews with Grounded theory		22 women and 22 men
Paper II	Instrument development, including factor analysis and statistical test for validity and reliability. Pilot study for test of a two-part questionnaire	156 parents (women n =88, men n=68)	126 parents (women n=71 men n= 55)
Paper III	One year Single-Group Cohort Design with questionnaires	2914 parents (women n =1671, partners n=1243 of whom 3 were female)	2183 parents (women n =1258 partners n=925 of whom 3 were female)
Paper IV	Qualitative interviews with Grounded theory		9 women and 6 men

Instruments (Papers II and III)

The scale Parents' Expectations, Experiences and Reactions to routine Ultrasound examination (PEER-U) is described in the results of Paper II; its development is described under the heading "Data analysis". The PEER-U scale includes the ultrasound specific state of mind index that was used in Paper III.

The generic instruments STAI, State and Trait Anxiety Inventory (Spielberger 1983) and SOC, Sense of Coherence (Antonovsky 1987) were both used in Papers II and III. In the former paper they were used as part of the validation of the instrument, while in the latter they were included as variables for comparisons with the outcome of the PEER-U scale.

The STAI instrument measures grade of anxiety both as a state and as a trait. Each part of the STAI questionnaire consists of 20 items. The items are statements with which the respondents are asked to agree or disagree using a Likert scale with four alternatives. The scores can vary from 20-80, the higher the score, the greater anxiety. In Paper III, a six-item short form of the STAI-S was used as developed by Marteau and Bekker (1992) while in Paper II the full scale was used. The internal consistency coefficient alpha has been calculated as a median value of 0.90 for the trait scale and 0.93 for the state scale (Spielberger 1983). For the six-item short form, the reliability coefficient has been calculated to be 0.82 (Marteau & Bekker 1992).

The SOC scale that measures Sense of Coherence (Antonovsky 1987) was used (Papers II and Paper III) in its 13 item short form with a reported Cronbach's alpha of 0.82. The items have seven alternatives for measuring the extent to which the respondents agree or disagree with a statement. The higher the score the greater is the individual's sense of coherence.

Data collection

The participants in all the studies have been recruited with the help of the Ultrasound Department, Lund University Hospital in Sweden. The data collection started with interviews in 2001 (Paper I). Following this, a questionnaire was constructed and tested in a pilot study performed in 2004 (Paper II). The one year cohort study (Paper III) finished in March 2006 and was continued by follow-up interviews (Paper IV) until early 2007.

Setting

Lund is a university city of 106 000 inhabitants with above average educational levels. The mean age for mothers at the time of the first delivery, in this area, is 30 years. The catchment area for the ultrasound department also includes surrounding towns and villages. About 3000 second trimester routine examinations are carried out annually. Specially trained midwives perform the ultrasound and inform the parents who can follow the examination on a separate screen. In the case of adverse findings, a doctor is contacted to make a diagnosis and inform the couple. Preferably, she is available at once though this is not always the case. If the diagnosis is a non-viable fetus, the parents are referred to the gynaecological emergency unit for further care planning.

Procedure and inclusion criteria

Paper I. The women, who met the inclusion criteria, were consecutively recruited with the help of the ultrasound department during a three-week period in 2001. To be included, the women should have had a normal scan, be able to understand and speak Swedish and have had their partner present at the examination, which should also have been their first routine ultrasound screening during the pregnancy. After sending written information, the researcher contacted the women by phone to ask if they and their partners were willing to participate. The participants chose the place for the interviews and all choose their own home. The parents were interviewed separately and the interviews were tape recorded and transcribed verbatim.

Paper II. Based on the results from Paper I and on a literature review, the two-part ultrasound specific questionnaire PEER-U was constructed. The participants for the testing procedure of the questionnaire were consecutively recruited during the summer of 2004. The PEER-U questionnaires for both parents, were sent to the women. The couples were asked to put the questionnaire in a designated locked post box at the Ultrasound Department. The second part of the questionnaire was sent only to those respondents who had answered the first part and the inclusion criteria were extended to include only those women who had a normal scan. They were sent an “after ultrasound” questionnaire, if necessary followed by two reminders.

Paper III. The PEER-U questionnaire developed in Paper II was used together with the State-Trait Anxiety Inventory STAI (Spielberger 1983) with the full form of the trait scale (20 items), a six-item version of the state-scale (Marteau & Bekker 1992) and

with the short form of the Sense of Coherence scale, SOC (13 items) (Antonovsky 1987) (Appendix, the scanning form of the total questionnaire in Swedish). The first part of the questionnaire was sent to all parents who had their second trimester ultrasound examination at Lund University Hospital during the period 10th February 2005 to 30th March 2006 inclusive. The ultrasound department sent two identical questionnaires, one each for the woman and her partner, together with the appointment time, about two weeks before the examination, to the women (n=2982x2) explaining that one was for her partner. Those who answered the first part of the questionnaire were sent the second part after the ultrasound examination, with the exclusion of those parents who, to our knowledge, had not had a normal scan result. Both parts of the questionnaire as well as the written information to the parents were written only in Swedish. If necessary, two reminders were sent.

Paper IV. Swedish speaking women who were diagnosed with a non-viable fetus were asked to participate in an interview study together with their partner. Following receipt of written information, they were contacted by phone, to request their verbal consent by the researcher. The interviews took place during 2005-2007, 1.5-9 months after the participants' ultrasound examination had been performed. The women and their partners were interviewed together. The participants chose the place for the interviews which lasted between 35 and 60 minutes. The interviews were tape recorded and transcribed verbatim.

DATA ANALYSIS

Grounded Theory (Papers I and IV)

The Grounded Theory (GT) method was originally discovered by the two American social scientists Glaser and Strauss during a research project with dying persons (1965). GT has its roots both in qualitative methods and in mathematics and both qualitative and quantitative data can be used. Glaser states that a statistical formula can be expressed qualitatively and that a qualitative hypothesis can have a mathematical model developed for it (Glaser 1998). They first described the method together (Glaser & Strauss 1967) but later diverged and developed the method in different directions. The purpose of the method is to generate a theory that explains the participants' main problem and how they solve it, in our study a basic social process. The theory should be modifiable so that it is flexible when new data arise in the future. There are no rules for what data must consist of, so all kinds of information can be used. Glaser states that it is the reader that should judge whether a story is valid (1998).

The GT components of validity are:

- if it fits (how well the concepts represent the incidents)
- if it is relevant (how interesting the readers find it)
- if the result works (how well the results explain the participants' problem and how they solve it)
- if it is modifiable so that new data can alter the model

The respondents were asked to speak freely about their expectations, experiences and reactions to routine ultrasound examinations. In Paper I the attendant questions focused on information, communication, thoughts, feelings, well-being and decision making. In Paper IV attendant questions focused on thoughts, feelings and the way the parents had handled the situation. The analysis process (Papers I and IV) began after the first interview with open coding and the writing of memos which is an inductive process. The open coding was the first conceptualization, close to the text. Each interview generated a number of codes which describe the properties of the categories. Writing memos is a way of making notes about the concepts and the way they are interlinked (Glaser 1998). The codes were compared to each other, in order to start to build the theory and new areas of interest were found. These areas were broached, by the researcher, in the subsequent interviews. This in order to get a better understanding of the areas of interest for the participants, as a GT researcher is free to vary questioning as she follows the emerging problem (Glaser 2001), as a deductive part of GT. Early in the process, a core category emerged and the coding began to be selective, i.e. only the codes that were relevant for the core category was noted, called theoretical sampling, a deductive aspect of GT (Glaser 1998). Finally, the relationships between the categories were determined by sorting memos and a model was built using this theoretical coding.

Instrument development (Paper II)

The questions in the PEER-U (parents' expectations, experiences and reactions to routine ultrasound examinations) questionnaire were constructed with the results from Paper I as a theoretical model. To establish content validity, the questions covered the different chronological categories from the results of Paper I.

The PEER-U questionnaire was constructed in two parts. The first was intended to be used before ultrasound examination, the second one after. Face validity (Streiner & Norman 2003) was assessed by a couple expecting their first baby, three midwives working with ultrasound, a group of health professional researchers and a statistician. Relevant adjustments were made. For further validation of the questions a short telephone interview was conducted with nine respondents (five women and four men). The respondents were asked if they found the questions understandable and if they had other comments.

The questionnaire was then tested for reliability and validity during the following procedure. The completed questionnaires were scanned into SPSS 11.5 and an

exploratory factor analysis, using a principal components analysis, was carried out, now with SPSS 14.0. The two parts of the questionnaire “before” and “after” were analysed separately. This was followed by rotation to orthogonal transformation by the Varimax method, performed to establish construct validity and assumed that the factors would be unrelated (Pett et al. 2003) as the questions concerned divergent aspects of the problem area. Development of the instrument was performed in a process comprising statistical evaluation and discussions about clinical relevance between the authors. Several different factor analyses were performed separately for the “before” and “after” ultrasound parts, until results with a clinical relevance and a acceptable amount of factors were reached. Finally a separate gender factor analysis was made in order to see if the result of the factor analysis was the same for both genders.

Concurrent validity (Streiner & Norman 2003) was evaluated using State-Trait Anxiety Inventory STAI-S (Spielberger 1983) and the short form of Sense of Coherence scale SOC (Antonovsky 1987) as variables for comparison with the outcome of the PEER-U scale. Internal consistency was established using Cronbach’s alpha.

Analysis of the questionnaire (Paper III)

The results of the different scales (PEER-U state of mind index, STAI and SOC) in the one year cohort study (Paper III) were analysed for the whole group, as well as separately by gender. The three female partners were included in the male gender analysis as their function in this connection was the same as the males – supportive partner and parent. The parts of the PEER-U questionnaire that were not included in the state of mind index are not analyzed in this thesis. The results of the state of mind index analyses and STAI-S were also related to age, number of children, experience of miscarriage and earlier experiences of ultrasound in the current pregnancy. The analyses were made according to the following inclusion criteria;

- 1. For all instruments:** respondents to both questionnaires with normal ultrasound findings.
- 2. Included in PEER-U analysis:** respondents who had replied to all questions in the scale.
- 3. Included in the STAI-T respectively the SOC analysis:** the respondents who had replied to all questions in those instruments and who were included in the analysis of the PEER-U scale.
- 4. Included in the STAI-S analysis:** the respondents who had replied to all questions in this scale within 10 weeks of the scan and who were included in the analysis of the PEER-U scale.

This limit was set in order to minimize biases as it was considered that STAI-S reflected the impact of the ultrasound to an extent which diminished with increasing

time after the ultrasound examination. STAI-S is a generic instrument and the results might be reflecting other influencers than the ultrasound examination.

As all scales were measured on an ordinal level, statistical analyses were performed using non-parametric methods (Mann-Whitney U-test, Wilcoxon's signed rank test). A p-value <0.05 was regarded as significant. Due to multiple comparisons a reduced p-value ($p < 0.0125$) was applied to determine significant differences between sub-groups. SPSS (Inc., Chicago, IL) was used for statistical analyses. Drop-out analysis was also carried out to obtain information about some of the characteristics of this group.

PRE-UNDERSTANDING

GT allows the use data even from the researchers own experiences; personal knowledge and knowledge from the literature, if it is clarified that this is only one part of the analysis, like other data (Glaser 1998).

I, the author of the thesis do not perform ultrasound examinations by myself. I have only made educational visits to the ultrasound department, apart from the experience of having routine ultrasound examinations performed when expecting our three children. My clinical experience is as a midwife at the labour delivery ward. Elizabeth Crang Svalenius is a midwife with extensive experience of ultrasound screening and has taken part in writing two reports on fetal diagnosis for the Swedish Council on Technology Assessment in Health Care (Hagenfelt et al. 1998, Nilsson et al. 2006). Anna-Karin Dykes is a midwife who has long experience of performing routine ultrasound examinations and has previous experience of GT research. The co-author of Paper IV, Berit Nordström is a specialist in clinical psychology with many years experience from maternal and child health care.

ETHICAL CONSIDERATIONS

Ethical approval and permission to undertake the study was obtained from the Research Ethics Committee of the Medical Faculty of the University of Lund. No. LU 453-00.

All of the participants in Papers I and II, had received normal results from the routine ultrasound examination and therefore no ethical problems were foreseen by the researchers except that the items in the questionnaire could make the parents aware of the possibility of adverse findings at the ultrasound examination. The participants were given written and oral information of the study that explained the purpose and stressed that participation was voluntary and that it was possible to drop out at any time, with no consequences.

Parents in the study reported in Paper III were given written information about it. In an attempt to minimize the time the parents had to spend on filling in the questionnaire, the short form of STAI-S and SOC was used. Parents that had not received normal results were excluded from this study and were not sent the after ultrasound part of the questionnaire. This was in order to not upset them without a person to support and verbally explain the purpose with the research and to underline the fact that it was voluntary to participate. Follow up with these parents is made in a separate ongoing study.

The parents in study IV had all experienced the diagnosis of a non-viable fetus and were more vulnerable than the participants in the other studies. These parents were given both written and oral information about the study that explained the purpose and informed that participation was voluntary. Because the researchers feared that the interviews might raise sad memories for the parents, this information was repeated and the right to end the interview at any moment they wished was stressed. In contrast to those in Paper I, these parents were interviewed together in order to be able to provide mutual support.

None of the researchers were working at the ultrasound department at the time for any of the data collection and were therefore not involved in the care of these parents.

FINDINGS

Parents' expectations, experiences and reactions to a routine second trimester ultrasound examination, with normal findings, have been explored in dept (Paper I). From the results, an instrument was developed and tested (Paper II) and used in a one year cohort study to investigate the psychological effects of ultrasound examinations on parents well-being (Paper III). From the cohort study, when a diagnosis of a non-viable fetus was found at the routine ultrasound examination, these women and their partners were recruited to a study of parents' reactions and needs in this situation (Paper IV).

Is there a life? - The ultrasound's importance to parents

The results from Papers I and IV are presented in an integrated form.

Expectations

The women and their partners' expectations of the second trimester ultrasound were much the same. The parents wanted to see that the woman was actually carrying a baby and that the baby looked healthy. To get this confirmation, the midwife had to interpret the scan and explain it to the parents.

Almost all of the parents had understood that ultrasound screening was a choice and not a compulsory part of antenatal care. Nevertheless, there was no hesitation to have the examination, by any of them – it was an obvious choice. The parents felt well informed about the examination and its purposes, but felt it would have been an advantage to have the information closer to the examination than the booking visit.

The parents' expectations were influenced by earlier experiences, either personal or those they had heard of from others. This was a stronger factor for predicting their expectations than gender or parity. Strong "protectors" or defence mechanisms were activated against eventual fear of adverse findings. Even if the women had experienced worrying signs like decreasing pregnancy symptoms, they managed to focus on positive expectations on the day of the ultrasound examination, keeping anxiety at the back of their minds (Papers I and IV). If any abnormal findings were to become apparent, the parents preferred to handle these when they occurred.

Parents who had a non-viable fetus diagnosed (Paper IV) thought that they had experienced a sense of security that turned out to be false. They felt that they had been deceived by the woman's own body, the literature and the caregivers, to believe that the pregnancy was proceeding normally. The woman's body had deceived them in those cases where no signals of decreasing pregnancy symptoms had occurred. The literature had deceived them as it was common knowledge that miscarriages very rarely occur after the 12th week of pregnancy. The caregivers had deceived them because the parents had learned that everything probably was normal if the woman still experienced the physical symptoms of pregnancy. If an ultrasound earlier in pregnancy had shown normal findings, this was also a part of the parents' experience of sense of security before the second trimester ultrasound examination.

Experiences

The parents who had normal findings at the ultrasound examination (Paper I) had their positive expectations fulfilled. They expressed the overwhelming feelings they had experienced when they saw their fetus for the first time. Seeing fetal movement was described as especially important.

The ultrasound examination made the pregnancy feel more real, but it was also an unreal experience for those women who could see but not yet feel the fetus move. If they could have had the opportunity, the parents would have liked more ultrasound examinations during pregnancy as they found it a valuable and exciting way to meet the baby. The staff could contribute to the positive experience by showing that they understood that it was a unique experience to the parents, and by giving the impression that they were in no hurry. If it was not the case, this negatively affected the overall experience, though the fact that the result of the examination was normal took precedence. The information given by the midwife during the examination was crucial for the parents to understand the scan. This was especially true for first time parents. This information also made the parents feel like participants during the examination, which they valued.

For the parents who had to face the diagnosis of a non-viable fetus (Paper IV), they had to confront a collision between their expectations and the reality. They could sometimes see and understand that something was wrong, before the midwife called for a physician to make the diagnosis. It was a shock; a real but also an unreal experience. The parents experienced it as a loss of control of the situation. They both felt anger, discomfort and foolishness. The men thought that their role should be supportive. The midwives were also supportive but as the parents were very sensitive, could also make the situation worse, by thoughtless comments, such as “are you sure you are pregnant?”.

Parents required straightforward clear information and they valued sympathetic staff and basic things being taken care of as, for example, when someone took care of further arrangements. Parents in the acute phase focused on what would happen next and requested to be given an appointment as soon as possible, though sometimes the delay was significant, due to administrative difficulties.

Reactions and needs

For parents with normal findings from the ultrasound examination, the reaction was relief. This sentiment was also experienced by those parents that stated that they had not been worried before the examination. They expressed confidence in the care they were receiving and in the diagnostic possibilities of ultrasound. The parents felt amazement and elation although to different degrees. This reaction lasted for a period of time, but later on the experiences of the developing fetus, like quickening eclipsed this. The ultrasound examination could be a milestone during the pregnancy and the signal for the parents to speak openly about it.

For the parents who had a non-viable fetus diagnosed, the reactions were grieving followed by a reorientation phase. The women and the men had all imagined the baby, her or his place in the family and how the future, with the baby, might have been. They could be grieving for the specific baby or for a planned future that was not to be. They felt lost, as they were used to be able to plan their lives. Those with previous children were particularly troubled by the fact that the difference in ages between siblings would now be greater than planned. Earlier problems with becoming pregnant, or if the couple did not plan to try to have more children, caused them additional grieving. The loss could become part of a life crisis, as well as the cause of difficulties in reorientation. Nevertheless, they appreciated to be given the diagnosis at the time of the routine ultrasound and not having to wait for the miscarriage to occur spontaneously.

All of these parents had a need for comforting support. If the termination had taken place at the hospital, all had positive memories of the care. Some valued the comfort given by relatives and friends, or were relieved by natural reactions from their older children. A memory, like an ultrasound photo from when the fetus was alive, was also valued but not pictures from the time of the diagnosis. All these parents had a need for information and some kind of explanation in order to reorientate and plan for the

future. The information not to blame themselves had been given and was essential. In the reorientation phase, the defence mechanism of rationalisation occurred – it could have been worse. The thought of planning a new pregnancy was discussed by the parents at an early stage. They imagined that they would be more anxious next time and request an earlier ultrasound, in order to see that the fetus was alive. Not all had been offered a follow-up but this was valued by those who had. It was important that this was initiated by the caregivers as the parents did not have the strength to ask for it. A simple phone call from a doctor was incomparably better than a note with contact information.

The measured impact of ultrasound on parents' psychological well-being

How to measure it?

As literature research found no specific instrument to measure the impact of ultrasound on parents' well-being, a questionnaire was constructed and tested for validity and reliability (Paper II). A factor analysis of the 38 “before ultrasound” questions led to a seven factor solution with a total explained variance of 59.2% and a reduction to 30 questions concerning the parents' expectations of the ultrasound examination. The factors were named after their contents and the first factor explained the largest amount of variance. They factors measured different dimensions of parents' expectations.

Factor 1 (6 items) was named “Anxiety about the baby's health” and contained items measuring concerns about the result of the ultrasound examination.

Factor 2 (6 items) “Expectations about interaction with staff” contained items measuring parents' expectations of information and the way they wished to be treated by the midwife during the examination.

Factor 3 (6 items) “Attachment” contained items measuring the degree of transition to parenthood.

Factor 4 (3 items) “Verification” contained items measuring the estimated importance of the ultrasound as a confirmer of pregnancy.

Factor 5 (4 items) “Reservation” contained items measuring hesitation about the pregnancy and the degree of repression of the results of the ultrasound examination.

Factor 6 (3 items) “Deciding” contained items measuring the decision to have an ultrasound examination

Factor 7 (2 items) “Interpretation” contained items measuring expectation of understanding the ultrasound image.

The factors 1 “Anxiety about the baby's health”, 2 “Expectations about interaction with staff” and 5 “Reservation” were calculated into an index for measuring state of mind for later use (Paper III).

The results of the separate gender analysis showed the same factors as for the whole group though the factors loaded differently for men and women. For women, the

anxiety factor gave a high explained variance but for men, the attachment factor loaded highest.

The “after ultrasound” questionnaire resulted in a five factor solution with 48% explained variance and reduced the number of questions from 33 to 23. These items measure the parents’ experiences and reactions to the ultrasound examination.

Factor 1 (9 items) was named “Information during examination” and contained items measuring satisfaction with the examination.

Factor 2 (4 items) “Attachment” contained items measuring attachment to the child.

Factor 3 (3 items) “Family affinity” contained items measuring the degree of transition to parenthood.

Factor 4 (4 items) “Anxiety about the results” contained items measuring anxiety caused by the ultrasound examination.

Factor 5 (3 items) “Sense of security” contained items measuring relief.

The factors 1 “Information during examination” and 4 “Anxiety about the results” were calculated into an index for state of mind for later use in Paper III. The relation between the factors (Paper II) and their origin in qualitative categories (Paper I) in the PEER-U questionnaire are shown in Table 2.

Table 2. The relation between the factors (Paper II) and their origin in qualitative categories (Paper I) in the PEER-U questionnaire.

Routine ultrasound	Paper I Categories	Paper II and III Factors/Dimensions
Before	Visualising - the evident option	1, 4, 5, 6
	Becoming a family	3
	Interaction with staff	2, 7
After	Overwhelming to see life	1 and open question
	Becoming a family	2,3
	Reassuring	4,5
	Interaction with staff	1

Internal consistency calculated by Cronbach’s coefficient alpha was 0.77 for the “before ultrasound” part of the PEER-U questionnaire and 0.75 for the “after ultrasound”. Factors measuring state of mind index in the before ultrasound part of the instrument were significantly correlated with STAI-S ($r_s = .543$, $p < 0.001$) and significantly but moderately with SOC ($r_s = -.293$, $p < 0.001$). For the after ultrasound part of the instrument the corresponding correlation coefficients were, for STAI-S $r_s = .374$ ($p < 0.001$) and for SOC $r_s = -.269$ ($p = .003$). The SOC and STAI instruments correlated with each other in the “before ultrasound” $r_s = -.606$, ($p < 0.001$) and in the “after ultrasound” $r_s = -.627$, ($p < 0.001$).

The investigation of a one-year cohort

In Paper III, three instruments were used to measure parents' state of mind, state and trait anxiety and sense of coherence.

State of mind

Measured by the PEER-U state of mind index, women were found to have a significantly higher degree of worried state of mind before the ultrasound examination than the men. Although both women and men had significantly lower scores in PEER-U after the examination, the men had significantly less reduction in scores of state of mind than the women afterwards. The Cronbach's alpha for state of mind index in this material was calculated to be 0.86 for the before ultrasound part and 0.74 for the after part.

State and trait anxiety

Women had a significantly higher level of state and trait anxiety, before the ultrasound examination, than did the men. Women had significantly lower scores in STAI-S after than before, but for men there was no significant change.

Sense of coherence

Before the ultrasound examination, the women had a significantly lower sense of coherence, than the men. There were no significant differences in SOC scores before and after the ultrasound for women or for men. The parents who had the lowest scores also had significantly higher PEER-U index scores than the others. The result of the PEER-U, STAI-S and SOC are graphically presented in Figure 1.

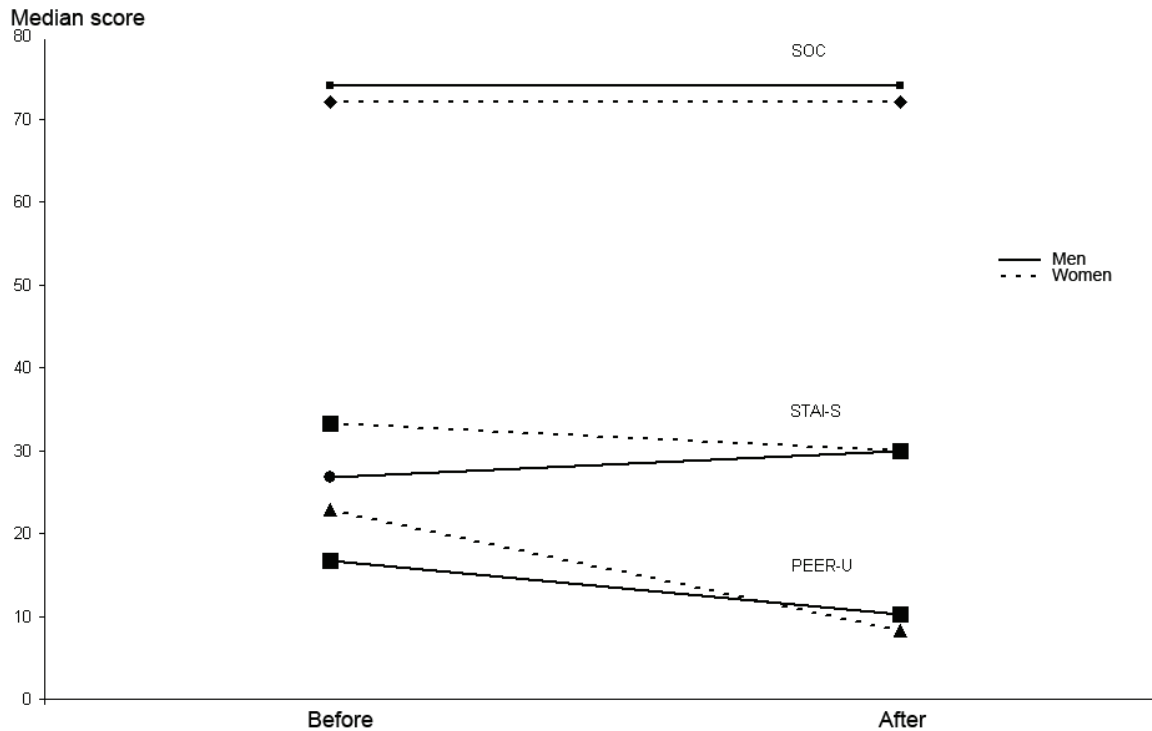


Figure 1. The results of the PEER-U, STAI-S and SOC instruments for women and for men. The higher scores in PEER-U and STAI-S, the higher degree of worried state of mind/anxiety.

State of mind and anxiety compared to other variables

The scores of the PEER-U state of mind scale and the STAI-S scores were compared with age, number of children, experience of miscarriage and earlier experience of ultrasound in the current pregnancy. The following significant correlations were seen:

- Parents who expected their first child had higher scores of PEER-U than those with previous children, before the ultrasound.
- Women with previous experience of miscarriage had significantly higher scores in PEER-U and STAI-S before the ultrasound, than did other women.
- Women under the age of 35 had higher scores in PEER-U and STAI-S than women 35 years or older before the ultrasound.

DISCUSSION

Methodological considerations

Design and method

The choice of having an ultrasound examination during pregnancy is so obvious to parents that the time has past for a randomised study – ultrasound or not ultrasound. Thus a study of the consequences of a second trimester routine ultrasound examination

on parents' psychological well-being has to have a different form. In this thesis it is explored in depth through interviews (Paper I) and the results were used in the instrumental development process (Paper II). Then, the instrument was used in a year long observational study with a single-group cohort design (Paper III); a special subgroup of parents given the diagnosis of a non-viable fetus was followed-up (Paper IV).

To use multiple paradigms in nursing research can be a profitable, as the methods can complement each other in strengths and limitations (Polit & Beck 2006). In this thesis, the positivistic and naturalistic paradigms are both used, chosen to fit the purpose of the different papers and also to unite in an effort to understand parents' expectations experiences and reactions to second trimester routine ultrasound examinations. The positivistic paradigm is represented in the quantitative studies (Paper II and III) and the naturalistic paradigm in the two interview studies (Papers I and IV). However, within Paper I and IV there are both deductive and inductive parts of the GT research process. It begins inductively and when the theory is emerging, the method starts to be deductive. Similar, in Paper II, the theoretical framework comes from the qualitative concepts in the results from Paper I and thus the two paradigms also complement each other in Paper II.

Sample and reply frequencies

To include the partners, and not just the pregnant woman, in all of the studies was natural as the partner is one of the parents. These results in particular widen the perspective of the psychological significance of second trimester routine ultrasound examinations. The decision to include partners can also perhaps mirror an attitude from researchers that welcomes the fathers as a part of the process of becoming a parent.

A sample in a GT study should be decided by an effort to widen the theory as much as possible; that is to include participants with diverse characteristics systematically and continuously, until saturation is reached and no more concepts evolve (Glaser 1998). As very little about the participants were known to the researchers before the interviews Paper I, except that they had undergone an ultrasound examination with normal results, they had to be recruited consecutively. The same applies to Paper IV. Nevertheless, a good mixture of first- and second- (or more) time parents were represented in these studies. The results showed that this factor was important, as expectations, experiences and reactions could vary because of this. For Paper I, only 22 of the 43 couples invited to participate accepted; however as the predominant reasons, spontaneously given, for declining was "lack of time", this might not have affected the result. For Paper IV, nine of the 15 couples declined to participate. The reason was not requested, but five women mentioned that they thought the experience was too difficult to talk about and one declined due to lack of time. This might have affected the result, but as women who reported both a high and a low level of grieving were included in the participants group, the difference between participants and non-participants might be due to different coping strategies. Those can be introvert or

extrovert, and therefore not necessarily represent differences in the experience between the groups.

During the studies leading to Papers II and III considerable problems were experienced with the inclusion of participants for the before ultrasound questionnaire, mainly due to two practical reasons. Firstly, there was a limited time for reminders to be sent out before the ultrasound examination and once the ultrasound was performed those who had not replied to the questionnaire had also to be excluded from the after ultrasound part. Secondly, the questionnaires for the partner had to be addressed to the woman, and sent to her address, as this was the only information available. Many partners might not have been given it.

Validity

According to Glaser (1998) validity in a GT study is to be judged by the readers in terms of how well it fits, is relevant and the result works, and the extent to which the theory is modifiable. The researchers tried to plan for a high degree of validity in Papers I and IV from the viewpoint of Lincoln and Guba (1985) who described validity in a qualitative study in terms of credibility, transferability, dependability and conformability. To establish credibility, theoretical saturation (Glaser & Strauss 1967) was sought and new angles and hypotheses, which emerged during the analysis, were tested during the following interviews. The transferability might be limited, as only those who had their partner present at the examination were included. For practical reasons only Swedish-speaking parents were interviewed which can also be a limitation. The dependability refers to the stability of data over time and conditions (Polit & Beck 2006). The analysis of the first interviews in both papers was done by all the authors in an effort to make the overall analysis more valid than individual analyses would have been if calculated together. The extent of conformability was investigated by all the authors analysing the material first separately and then comparatively and also by the fact that in Paper I a couple who read the transcript could recognise themselves.

External validity is defined as the extent to which the results can be generalized to persons, settings, times, measures, and characteristics other than those in this particular experimental design (Kazdin 2003). The results of Paper III include a one year cohort and thus many participants to ensure external validity. On one hand the research was performed at a single Swedish ultrasound department and routines can diverge, which might decrease the external validity, on the other hand it can possibly be increased by the fact that the aims of the routine ultrasound examination are similar at most Swedish departments (Hagenfelt et al. 1998). Thus the parental expectations, experiences and reactions might be more similar than diverse. Surprisingly the fact that the questionnaire was in Swedish only was not such a problem, as foreign born individuals were well represented in the sample for Paper III.

The construction of items in a scale is of great importance and there are several sources from which they can be evolved (Streiner & Norman 2003). The major source for the construction of the items in Paper II was the parents. Streiner and Norman (2003) classify patients as an excellent source for construction of items. Face validity was judged by key individuals and clinical relevance was sought during the factor analysis to find a logical factor solution. All of the original categories (Paper I) were represented in the factor solution.

Internal validity is defined as the extent to which the experimental manipulation (here the ultrasound examination), rather than extraneous influences, can account for the result, changes, or group differences (Kazdin 2003). In Paper III, the two instruments also used, SOC and STAI, are generic. The answers to the after ultrasound part of the questionnaires might have been influenced by several other factors in the respondents lives. Therefore, a time limit of ten weeks was set as an inclusion criterion for the STAI-S analysis as STAI-S is known to vary over time. Still, it is believed that the PEER-U state of mind index might be a better and more valid instrument as it is ultrasound specific.

The reliability of the PEER-U questionnaire as a whole was calculated with Cronbach's alpha to 0.77 for the before ultrasound part and 0.75 for the after part (Paper II). Correspondingly, the Cronbach's alpha for the state of mind index, when calculated on the material used in Paper III, was 0.86 for the before ultrasound part and 0.74 for the after ultrasound part. Burns and Grove (2001) states that a Cronbach's alpha over 0.70 is to be recommended for calculating the internal consistency of a new instrument. More in general, Streiner and Norman (2003) write that in general 0.75 is minimal for a useful instrument. This indicates that the PEER-U scale and state of mind index are reliable.

Discussion of results

Today, ultrasound is considered part of the process of becoming a parent, for both the woman and her partner. The longing and the desire for a child are so strong that any contact with the expected baby, or proof of its existence, is valuable. With ultrasound it is possible to visualise the fetus and to see its movements as evidence of life. To parents this is irresistible. The results of the studies in this thesis are in accordance with the description of ultrasound examinations that Sandelowski wrote in 1994, when she called it the "channel of desire". This fact places great responsibility on caregivers to be prudent when decisions about fetal diagnosis are to be made and to consider the parents psychological well-being among other factors. The issue of information about the fetal diagnostic aspect of ultrasound, prior to accepting the offer, is also central.

Parents' psychological well-being in relation to ultrasound

The purpose of this research, to illuminate parents' expectations, experiences and reactions and therefore also the impact of ultrasound on their psychological well-being, is a holistic way of looking at the parents needs. This approach is consistent with that recommended by several creators of nursing theories, starting with Florence Nightingale (Kim & Kollak 1999); that nurses/midwives should have a holistic view of patient' needs.

This thesis shows that the second trimester routine ultrasound examination is valued by parents. It has earlier been shown, in a systematic literature review, by Hagenfeldt et al. (1998) that women with normal findings from the routine ultrasound examination find it positive and reassuring. In this thesis it is shown that not only the parents with normal results from the scan (Paper I) but also those parents who were given the diagnosis of a non-viable fetus (Paper IV) valued the ultrasound. The first group set great store by it because it gave confirmation of a living fetus and the second because they appreciated being given the diagnosis as soon as possible.

The results described in Paper I show that the impact of the ultrasound on parents' psychological well-being is mainly short-term but during that time period it is of great importance. Pregnancy and the transition to parenthood are major developmental periods for women and men (Deave & Johnson 2008). The second trimester ultrasound might be especially important for the parents' psychological well-being those women who have still not felt the baby quickening and most women meet their midwife at the antenatal clinic on few occasions at the beginning of the pregnancy. In fact, in Sweden, healthy women, who have been assessed as low risk at the booking visit, do not meet their midwife again until around week 25 of the pregnancy. It has been shown (Papers I, III and IV) that during this period parents are anxious about the results of the ultrasound examination. This supports earlier research (Brisch et al 2002) that demonstrated a reduction of anxiety among pregnant women with a normal scan after the routine ultrasound examination. In the results of this thesis, anxiety is often successfully suppressed by parents, whose longing for a normal result and to see the baby, are greater than their anxiety (Papers I and IV). The suppression of anxiety might be a natural and healthy way of coping.

The differences in expectations between the genders were not dominant in the results of Paper I. Earlier personal experiences, or those of others, seemed to be of greater importance. Statistically, Paper III showed that there is a significant difference in state of mind, as men showed a less worried state of mind than women before the ultrasound examination. After the ultrasound, both women and men show a reduction, though women to a greater extent. These are the first unique results measured with the state of mind index from the PEER-U questionnaire (developed in Paper II). The differences measured between women and men might be partly due to the fact that the women become aware of the pregnancy earlier than the men and therefore are more worried at an early stage. Studies (Jordan 1990, Finnbogadóttir et al. 2003) have shown that after the ultrasound fathers feel that the pregnancy has become more real

and their worried state of mind might therefore be greater than the mother's after the ultrasound examination.

The comparisons between state of mind and other variables showed that women with earlier experience of miscarriage scored significantly higher on worried state of mind and anxiety, before the ultrasound, than did other women. For men there was no significant difference. A separate interview study could help to understand the reasons for this, but a part of the explanation might be that the prenatal attachment starts later for partners than for pregnant women. Jordan (1990) showed that men await the confirmation by health care providers, of their partners' pregnancy.

As the PEER-U and the state of mind index scales are newly developed (Paper II) they should be particularly questioned. As the two parts, the before and after questionnaires, measure different dimensions of the concept parents state of mind in relation to ultrasound (Paper III), it could be questioned whether the parts can be compared. In the before ultrasound part, the dimension of expectation is measured, while in the after part the dimensions of experiences and reactions are measured. As a correlation with STAI-S has been shown (Paper II) and the results of the cohort-study (Paper III) are not contradictory, the two parts of the PEER-U state of mind index might well be used for comparisons before and after ultrasound. In the before ultrasound part, the state of mind is mainly measured as degree of anxiety about the babies health (Factor 1 in the factor solution shown in Paper II). After the examination, the parents have had a confirmation, as far as could be seen, of a healthy fetus and the dimension of satisfaction with the information given during the examination gains more importance for the parents' experience and reactions (Factor 1 in the factor solution shown in Paper II) but the dimension of anxiety is still prominent.

The full PEER-U questionnaire consists of several dimensions that are not included in the state of mind index, the only part that has been analysed from a large sample (paper III). A number of other items and dimensions in the PEER-U scale have not yet been evaluated.

Interaction with staff

It is not surprising that the way the caregivers treat a couple with a non-viable fetus is of great importance (Paper IV). Even the experience of the parents with normal findings are reliant on the interaction with the midwife who performs the ultrasound, but it has been shown earlier that the importance of the interaction between the pregnant woman and the midwife can be great during the different parts of pregnancy, childbirth and in the early postpartum phase (Lundgren & Berg 2007). For example, in a questionnaire study of 1300 Dutch women's birth experiences, most women chose positive adjectives to describe the staff, but a negative description was a strong factor for negative recall of birth experience three years postpartum (Rijnders et al 2008). It is interesting to find that little can mean much for the parents. For example, that the impression that the midwife has a lot of time is important and requested by the parents, rather than a general increase in the time set for the routine ultrasound examination

(Paper I). Another example is that a simple phone call from the caregivers can be of great importance as a follow-up for parents who had had a non-viable fetus diagnosed (Paper IV). Thus potentials for improvement exist without demanding great resources.

Ethics and information

As earlier underlined, a key issue is the information about fetal diagnosis (Bricker et al. 2000). When and how the information should be given presents very complex issues. SMER (2006) recommends a two step model, where the parents are first asked if they want any information about fetal diagnosis at all and secondly are only given information about the aspects they ask for. One problem is that today's parents may not consider the routine ultrasound as a form of fetal diagnosis, as it has been shown (Paper I) to be an obvious choice and to be perceived as a natural part of pregnancy examinations. The status of ultrasound as a method for fetal diagnosis must be underlined by caregivers. A pregnant woman cannot make an informed choice unless she has been provided with correct information that she has also understood.

To improve the information given to pregnant women and their partners, Lalor and Devane (2007) suggest educational programmes for staff as well as the provision of resources to meet parents' individual needs. It has been suggested that such programmes should include the professionals in order to explore their own personal feelings towards fetal screening and hopefully enable them to impart neutral information (Ekelin & Crang Svalenius 2004, Lalor & Devane 2007).

In a country like Sweden with a well established National Health Service, the ideal situation would be that the form of fetal diagnosis offered is the same throughout the country. This would imply not only central allocation of resources, earmarked for the purpose, but also consensus as to which forms of fetal diagnosis should be available. This is especially important today when new methods are being rapidly developed. It is also extremely important that the opinions of all categories of health professionals as well as of people availing themselves of the service are considered. It has been said that technology and society mutually shape one another and that the individual should become directly involved in the shaping of technologies that affect their health and daily lives (Rudinow Saetnan et al. 2000).

CONCLUSIONS AND IMPLICATIONS

The expectations, experiences and reactions to routine ultrasound screening in pregnancy are much the same for the women and their partners when the result of the ultrasound is normal. A difference in their state of mind in relation to ultrasound has though been shown to be significant; women have a greater degree of worried state of mind than men before the examination. Though scores decrease significantly for both genders after the ultrasound examination, men have a more worried state of mind afterwards than women. This has been measured with the state of mind index, a part of the Parents' Expectations, Experiences and Reactions to routine Ultrasound

examination scale (PEER-U), developed in this project. The scale is in two parts one to be used before and one after the routine ultrasound examination. It has been tested for validity and reliability. Factor analysis has given a solution where the first part measures seven dimensions of expectations before the ultrasound examination and part two five dimensions of experiences and reactions. The dimensions that measured the parents' state of mind were used to calculate the state of mind index. Internal consistency was calculated by Cronbach's coefficient alpha which was 0.77 for the "before ultrasound" part of the PEER-U questionnaire and 0.75 for the "after ultrasound". Concurrent validity was established by correlating the state of mind index to two well known instruments, STAI and SOC and it correlated significantly to both, the former being strongest. The results also show that women's anxiety decreases after the ultrasound examination while there is no significant change for men. The SOC scores remain stable.

In-depth GT studies have shown that the choice of having an ultrasound examination was obvious to parents as their longing for confirmation of expecting a healthy baby was stronger than their fears for adverse findings, which they tried to suppress. To see the fetus during the examination was an overwhelming experience for the parents, making them feel like a family for the first time. Afterwards they felt relief and joy. The process was largely dependent on the way they were treated by the midwives performing the examination and the information given by them. Not only was professional treatment needed, but so was a calm and personal atmosphere with an obvious understanding of the uniqueness of the situation.

Parents who were given the diagnosis of a non-viable fetus were unprepared for this as it was a routine ultrasound examination. In addition to the crisis reaction, they realized that the sense of security they had experienced was false. The men took a supportive role during the time from the diagnosis to the termination and had a delayed grieving reaction. As different professionals were involved in the care of these parents, the need for a care plan was evident. Support from caregivers, or the lack of it, is a very important factor regarding how well parents can handle the acute situation and later move on.

When introducing new forms of fetal screening and diagnosis in the future, it must be considered that routine ultrasound examinations are easily accepted by parents who long for confirmation of a new life. The complete PEER-U questionnaire, or just the part concerning the state of mind index, can be used in different ultrasound settings to evaluate the impact an ultrasound examination has on parents' psychological well-being. Special issues must be considered concerning the parents who are given the diagnosis of a non-viable fetus. The parents themselves suggested that the pre-scan information includes the fact that one of the purposes is to see if there is a living fetus. They also would also like it to include the recommendation that the woman should take her partner, or another supportive person, with her to the ultrasound examination. Parents who have a non-viable fetus need a follow-up visit to be incorporated as a care routine. As several actors are involved in the care process there is a need for a general care plan, modifiable for the individual.

FURTHER RESEARCH

It is of further interest to illuminate the experiences, reactions and needs of parents who have adverse outcomes of the routine ultrasound examination and to see if the health care system's goals of informed choice and satisfaction with treatment are reached. This might include an adaptation of the after ultrasound part of the PEER-U questionnaire to encompass these parents experiences and reactions. A new factor analysis of this extended material could be carried out to test the questionnaire further and possibly shorten it. Further analysis will be necessary to explore if it is possible to calculate an index for the questionnaire as a whole. It would also be valuable to analyse the answers for the individual items with the purpose of developing the quality of care.

SUMMARY IN SWEDISH

Svensk sammanfattning

Ultraljudsundersökning erbjuds i dag rutinmässigt alla gravida kvinnor i Sverige. Även då undersökningen är frivillig, är det mycket få kvinnor som avstår från den (SBU-rapport 139, 1998). Undersökningsresultatet antas ha stor betydelse för hur föräldrapar kan påverkas i sitt psykologiska välbefinnande. Hur väl informerade anser sig föräldraren vara, hur upplever de vården och vilka tankar och känslor väcks i samband med rutinultraljudsundersökning? I konsensusuttalandet om fosterdiagnostik understryks vikten av forskning inom ämnesområdena information och fosterdiagnostikens inverkan på kvinnans och familjens psykosociala situation (Vetenskapsrådet 2001).

Det övergripande syftet med avhandlingen var att tydliggöra föräldrars upplevelser av den rutinmässiga ultraljudsundersökningen under graviditetens andra trimester samt att utveckla, testa och använda ett frågeformulär. Syftet var även att utveckla en modell för att beskriva föräldrars upplevelser, reaktioner och behov när diagnosen var icke-levande graviditet.

Doktorsavhandlingen omfattar fyra delarbeten som följer på varandra. Designen på samtliga delarbeten är prospektiv och både kvalitativa och kvantitativa forskningsmetoder har använts. Samtliga studier vänder sig till båda föräldrarna.

Delstudie 1. Syftet med studien var att tydliggöra blivande mödrars och fäders upplevelser både före, under och efter ultraljudsundersökningen i graviditetens andra trimester. Metoden var Grounded Theory (GT) (Glaser & Strauss 1967). Resultatet var att kärnkategorin var "bekräftelse av ett nytt liv". De fyra kategorierna, Att se – det självklara valet, Överväldigande att se liv, Att bli en familj och Lugnande, representerade alla en kronologisk process i kvinnans och mannens väg mot att bli föräldrar. Omvårdnaden och informationen var synnerligen betydelsefull för de blivande föräldrarna som önskade inte bara kunnig undersökare utan även ett personligt bemötande med förståelse för det unika i deras situation.

Delstudie 2. Syftet med studien var att utveckla samt att reliabilitets- och validitetstesta ett frågeformulär för att undersöka föräldrars förväntningar, erfarenheter och reaktioner före, under och efter rutinultraljudsundersökning. Metoden var instrumentutveckling i flera steg. Det specifika frågeformuläret, utvecklat med hjälp av resultaten i delstudie 1, validitetsgranskades med hjälp av face validity (Streiner and Norman 2003). En pilotstudie där formuläret sändes till 150 föräldrapar genomfördes. Construct validity (Streiner and Norman 2003) upprättades med explorativ faktoranalys (Pett et al. 2003). Frågeformuläret reliabilitetstestades med Cronbach's alpha och var i före ultraljudsdelen 0,77 och efter 0,75. Resultatet av faktoranalys av svaren på frågeformuläret gav en lösning där formulärets första del mäter sju dimensioner av förväntningar inför ultraljudsundersökningen och den andra delen fem dimensioner av upplevelser och reaktioner. De dimensioner som mäter

föräldrars sinnesstämning har sammanställts till ett index, som kan användas för att mäta ultraljudsundersökningens inverkan på föräldrarna genom att följa skillnaderna före och efter undersökningen. Index har också prövats relatera till validerade mätinstrument för oro (STAI, Spielberger 1983) och känsla av sammanhang (KASAM, Antonovsky 1987) och korrelerar signifikant med dessa.

Delstudie 3. Syftet med studien var att kartlägga en årskohort, ca 3000 föräldrars förväntningar, erfarenheter och reaktioner i samband med ultraljudsundersökningen samt att relatera detta till deras psykologiska välbefinnande och känsla av sammanhang före och efter undersökning i graviditetens andra trimester samt att studera eventuella skillnader mellan kvinnor och män. Metoden var en enkätstudie av en årskohort föräldrar där kvinnan genomgick rutinmässig ultraljudsundersökning kring den 18 graviditetsveckan. Index för sinnesstämning hämtat från frågeformuläret Parents' Expectations, Experiences and Reactions to routine Ultrasound examination during pregnancy (PEER-U) utvecklat i delstudie 2, användes tillsammans med kortversionerna av State Trait Anxiety Inventory (STAI) (Spielberger 1983) för att mäta välbefinnande och (KASAM) (Antonovsky 1987) för att mäta Känsla av sammanhang. Resultatet visade att både kvinnan och mannens grad av orolig sinnesstämning minskade signifikant efter ultraljudsundersökningen, men att mannen från att ha haft en mindre orolig sinnesstämning än kvinnan före undersökningen fick signifikant högre värden efter ultraljudsundersökningen. Med STAI-instrumentet uppmättes en minskning i oro för kvinnan efter ultraljudet, medan ingen signifikant skillnad hos mannen kunde påvisas. SOC-värdet var stabilt över tid. Reliabilitetstest beräknades med Cronbachs alpha för index för sinnesstämning till 0,86 i delen före ultraljudet och till 0,74 i efter delen.

Delstudie 4. Syftet med studien var att med intervjuer studera föräldrapar som fått icke-levande graviditet diagnostiserad vid rutinultraljudet i graviditetens andra trimester och att utveckla en modell för att beskriva deras upplevelser, reaktioner och behov över tid. Metoden var åter igen GT för datainsamling och analys. Diagnosen innebar en förändring i livet för föräldrarna. De upplevde sig ha haft en känsla av säkerhet som visat sig vara falsk. Därför blev det en kollision mellan förväntningar och diagnos. De sörjde både det väntade barnet och sina förlorade framtidsplaner, för att sedan nyorientera. Dessa föräldrar behöver särskilt stöd genom upprättandet av generell och individuell vårdplan inkluderande en av vården initierad uppföljning. Föräldrarna efterlyste vidare att informationen till dem före undersökningen skall inkludera att ett av syftena med rutinmässigt ultraljud är att se om det finns ett levande foster, samt rekommendationen att kvinnan inte går dit ensam.

ACKNOWLEDGEMENTS

The work described in this thesis was carried out at the Department of Nursing, Lund University. I wish to express my sincere gratitude to:

- All the women and men who kindly participated in the studies, especially to those who participated in the study of parents' reactions and needs after the diagnosis of a non-viable fetus (Paper IV). They were in a difficult situation yet were willing to try to help others in the same situation by sharing their experience.
- My supervisors Anna-Karin Dykes and Elizabeth Crang Svalenius who have made it possible for me to write this thesis and thereby given me a once in a lifetime chance for incredible and enjoyable work. I wish to thank you for excellent supervision always with a quick understanding of my needs.
- My co-authors Anna-Karin Larsson, Karel Maršál, Berit Nordström and Per Nyberg for all the commitment and knowledge you have brought into the project. Anna-Karin Larsson my doctoral student colleague, also for being willing to share success as well as misfortunes and for being a supportive friend.
- The staff at the ultrasound department. Without your help the work in this thesis would not have been possible.
- The members of the research group Health and Care of Women and Children for constructive criticism of my manuscripts.
- Gun Rinkmar Bengtsson who was my senior school teacher and has been my friend for decades since. Thank you for all the work with revising the language of the Papers I, II and IV.
- Kristina Arnell for being a supportive friend since nursing school and kindly revising the language of Paper III.
- Richard Shock for excellent editing of the English in the frame story of this book.
- My husband Anders for being there. To our beloved daughters Liv and Alva for helping me during the last intensive weeks of work to take care of your little sister. To Sigrid - the star that leads me home every day.

The study has obtained funding from the Vardal Foundation.

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