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From the Department of Health Sciences, Medical Faculty,
Lund University, Sweden 2010

DECISION-MAKING IN CRITICAL SITUATIONS DURING PREGNANCY AND BIRTH

av

Margaretha Danerek
Leg. sjuksköterska och barnmorska

AKADEMISK AVHANDLING

som med vederbörligt tillstånd av Medicinska Fakulteten vid Lunds universitet för avläggande av
doktorsexamen i medicinsk vetenskap kommer att offentligen försvaras i Hörsal 1,
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Abstract <p>The overall aim of this thesis was to describe the experiences of obstetricians and parents and the attitudes of midwives in relation to critical situations during pregnancy and birth. The data collection (Paper I and II) started in year 2000 with interviews with obstetricians (n=14) concerning the meaning of being in ethically difficult situations. During 2002 to 2004 interviews with parents (n=23) about handling preterm labour and birth were performed. The quantitative studies had a cross-sectional method and a descriptive (Paper III and IV) and comparative (Paper III) design. The data collection was performed during 2007 to 2008, using a structured, anonymous and self-reported questionnaire for midwives (n=259). The midwives' attitudes about very/extremely preterm labour and birth (Paper III) and towards a woman's refusal of emergency cesarean section (CS) or request of CS without any medical indication (Paper IV) were investigated. The tape-recorded interviews with obstetricians were analysed using the hermeneutic-phenomenological method and with the parents the Grounded theory method was used. Descriptive and analytic statistics was used to analyse the data of the quantitative studies.</p> <p>The overriding theme in Paper I was "Sympathetic responsibility in decisions of critical importance for the mother and her baby" (Paper I). Together with the five subthemes this illuminated the decision-making process, which the obstetricians went through during the situations. The parents' main concern is shown through the core category "Inter-adapting" followed by three categories; Interacting, Reorganizing and Caring. "Inter-adapting" is a new concept and was interpreted as a mutual adaptation between the actors involved in the situation (Paper II). The midwives' attitudes in relation to very/extremely preterm labour and birth, was that midwives at university hospitals were more likely to agree on to start interventions at an earlier gestational age than midwives at general hospitals. Obstetricians seemed to be more active in management than midwives, though midwives seemed to be more willing to disclose information to the parents (Paper III). In a conflict of interest concerning a woman's refusal of an emergency CS for fetal distress, the midwives thought that the obstetrician should try to persuade the woman to accept the recommended CS. If a woman requests a CS without medical indication, the midwives thought that the obstetrician should comply with the woman's request if she had had previous maternal or fetal complications. The reason for supporting the woman's choice was mostly out of respect for the woman's autonomy, although midwives at university hospitals were significant less willing to do so (Paper IV). In conclusion this thesis revealed that the obstetricians respected the autonomy of the woman during the decision-making process (Paper I). Inter-adapting strategies were used to achieve the best possible outcome for the fetus/infant (Paper II). Midwives and obstetricians with experience of handling preterm births at 21 – 28 GW develop a positive attitude to interventions at an earlier gestational age as compared to midwives without such experience (Paper III). The main focus of midwives seems to be the baby's health and a positive birth experience for the woman and therefore they do not always agree to the woman's</p>		
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Department of Health Sciences, Faculty of Medicine,
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DECISION-MAKING IN CRITICAL SITUATIONS DURING PREGNANCY AND BIRTH

Margaretha Danerek



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ABSTRACT

The overall aim of this thesis was to describe the experiences of obstetricians and parents and the attitudes of midwives in relation to critical situations during pregnancy and birth. The data collection (Paper I and II) started in year 2000 with interviews with obstetricians (n=14) concerning the meaning of being in ethically difficult situations. During 2002 to 2004 interviews with parents (n=23) about handling preterm labour and birth were performed. The quantitative studies had a cross-sectional method and a descriptive (Paper III and IV) and comparative (Paper III) design. The data collection was performed during 2007 to 2008, using a structured, anonymous and self-reported questionnaire for midwives (n=259). The midwives' attitudes about very/extremely preterm labour and birth (Paper III) and towards a woman's refusal of emergency cesarean section (CS) or request of CS without any medical indication (Paper IV) were investigated. The tape-recorded interviews with obstetricians were analysed using the hermeneutic-phenomenological method and with the parents the Grounded theory method was used. Descriptive and analytic statistics was used to analyse the data of the quantitative studies.

The overriding theme in Paper I was "Sympathetic responsibility in decisions of critical importance for the mother and her baby" (Paper I). Together with the five subthemes this illuminated the decision-making process, which the obstetricians went through during the situations. The parents' main concern is shown through the core category "Inter-adapting" followed by three categories; Interacting, Reorganizing and Caring. "Inter-adapting" is a new concept and was interpreted as a mutual adaptation between the actors involved in the situation (Paper II). The midwives' attitudes in relation to very/extremely preterm labour and birth, was that midwives at university hospitals were more likely to agree on to start interventions at an earlier gestational age than midwives at general hospitals. Obstetricians seemed to be more active in management than midwives, though midwives seemed to be more willing to disclose information to the parents (Paper III). In a conflict of interest concerning a woman's refusal of an emergency CS for fetal distress, the midwives thought that the obstetrician should try to persuade the woman to accept the recommended CS. If a woman requests a CS without medical indication, the midwives thought that the obstetrician should comply with the woman's request if she had had previous maternal or fetal complications. The reason for supporting the woman's choice was mostly out of respect for the woman's autonomy, although midwives at university hospitals were significant less willing to do so (Paper IV). In conclusion this thesis revealed that the obstetricians respected the autonomy of the woman during the decision-making process (Paper I). Inter-adapting strategies were used to achieve the best possible outcome for the fetus/infant (Paper II). Midwives and obstetricians with experience of handling preterm births at 21 – 28 GW develop a positive attitude to interventions at an earlier gestational age as compared to midwives without such experience (Paper III). The main focus of midwives seems to be the baby's health and a positive birth experience for the woman and therefore they do not always agree to the woman's refusal or request of cesarean section (Paper IV).

ABBREVIATIONS

ACC	Antenatal Care Clinic
CS	Cesarean Section
EUROBS	Development of Perinatal Technology and Ethical Decision-making during Pregnancy and Birth; the attitudes of obstetricians from eight European countries
GA	Gestational age
GH	General Hospital
GT	Grounded Theory
GW	Gestational Week
NICU	Neonatal Intensive Care Unit
NICU Level III	Neonatal Intensive Care Unit associated with a university hospital
NICU Level II	Neonatal Intensive Care Unit associated with a general hospital
SWEMID	Ethical decision-making during pregnancy and birth: midwives' perspective in Sweden
UH	University Hospital
WHO	World Health Organisation

ORIGINAL PAPERS

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

- I Danerek M, Udén G, Dykes A-K. Sympathetic Responsibility in Ethically Difficult Situations. *Acta Obstetrica et Gynecologica Scandinavica* 2005; 84: 1164-1171.
- II Danerek M, Dykes, A-K. A theoretical model of parents' experiences of threat of preterm birth in Sweden. *Midwifery* 2008; 24:416-424.
- III Danerek M, Maršál K, Cuttini M, Lingman G, Nilstun T, Dykes A-K. Attitudes of Swedish midwives towards management of extremely preterm labour and birth. In manuscript.
- IV Danerek M, Maršál K, Cuttini M, Lingman G, Nilstun T, Dykes A-K. Attitudes of midwives in Sweden to a woman's refusal of an emergency cesarean section or to cesarean section on request. Submitted

Paper I and II have been reprinted with kind permission of *Acta Obstetrica et Gynecologica Scandinavica* and *Midwifery*.

INTRODUCTION

In decision-making during pregnancy and birth the obstetricians have both a medical and moral responsibility to the fetus and the woman [1]. An ethically difficult obstetric situation involves two important issues; the autonomy of the woman and the possible outcomes for the fetus. When ethical issues arise there is a need to balance the autonomy of the woman against the health of the fetus during the decision-making process [2, 3]. The woman must be adequately informed about the risks and benefits of the available alternatives, to be able to exercise the ethical principle of autonomy [4]. Autonomy gives the woman the responsibility for her fetus but also the right to refuse intervention for her own part [5-9]. A woman can also refuse an intervention that is recommended for fetal reasons and this might conflict with her moral obligation to her baby. The situation can also lead to a conflict of interest between the woman and the obstetrician or the midwife. The woman's right to request an intervention is more circumscribed and according to Kingdon et al. [10], the women felt that there were circumstances beyond their control in the choice of mode of delivery. To make this decision was not always desirable for the women, as it is based on assessment of risks and benefits concerning herself and her baby. The obstetrician and the midwife may increase the parents' participation in decision-making by applying the process of informed choice [4].

Becoming a parent is a challenge and a life changing event for the woman and her partner [11-14]. When a new member joins the family, it has an impact on the whole constellation and when the threat of preterm birth occurs it is a critical situation for the fetus, the parents and the professionals. The life of the fetus is at risk, which can cause the parents excessive worry. During preterm labour and birth, when the woman is hospitalized, the separation from the family is a strain. The parents feel worried about their fetus and, later their preterm infant. Some women experience depression [15] and this requires the support of people around them. The woman can experience a loss of control during hospitalization.

Active management of extremely preterm labour and birth means to utilise modalities as fetal monitoring, ultrasound, cesarean section (CS), delivery at a clinic with a neonatal intensive care unit (NICU) and administer tocolytics and steroids [16]. If there is a very high probability that the baby will not survive, will have severe morbidity or if it is the wish of the parents, non-active management could be recommended. For parents to be able to make an informed choice, information must be given to them by the professionals [17]. It is not easy for the woman to make an informed choice and therefore she needs guidance, which is one of the midwife's tasks [18]. Generally women agree to follow the advice of their obstetrician and in most situations the obstetricians and the woman have no conflicting interests as they are sharing the common goal of a healthy neonate. It is also important for the obstetrician and the midwife to be able to have an open communication, to co-operate within the team and that they have the same objectives; the best for the woman and her baby [19].

BACKGROUND

Ethically difficult situations during pregnancy and birth

A conflict of interest

The ethical principle respect of autonomy gives the woman the right to accept or refuse treatment [4]. If a conflict of interest occurs between the woman and the obstetrician or the midwife, there might be a dilemma, in so much as that the ethically difficult situation has two (or more) solutions, but irrespective of the decision the result is not optimal. Adequate information from the caregivers is a primary necessity for the woman to make decisions about which treatment and interventions are acceptable for both her and her baby. Through participation, the parents' identity and self-esteem are strengthened [20]. The parents should, as far as possible, participate in the choice of treatment or any other care [21, 22]. Decision-making are decisions made in the meaning of resolution after consideration. The obstetrician has a medical responsibility and moral obligation in the process of informed consent [23].

In a situation with fetal distress emergency cesarean section (CS) is indicated to save the life of the fetus [24]. The CS rates in Sweden was in 1991 10.9% of all deliveries and in 2008 it has increased to 17.2%. Of all CS 4% were acute in 1991, compared to 7.8%, 2008 [25]. WHO recommended in 1985 a CS rate not > 10-15% [26]. A refusal of emergency CS is extremely rare and there is no law in Sweden to enforce the recommendations from the caregivers [5]. Consequently, the majority of Swedish obstetricians would keep trying to persuade the woman to accept CS in cases of imminent risk to the fetus [27]. The obstetricians would also tell the woman that if the recommended CS was not performed, the baby might survive with disability. In a case report a fully informed and competent woman refused the recommended CS for fetal distress due to religious reasons [24]. In spite attempts to persuade her, the woman refused, and the obstetricians found themselves in an ethical difficult situation, although in this case the woman later delivered a healthy baby vaginally. It has been argued how to solve this delicate dilemma in perinatal care [2, 6, 7, 16, 28, 29].

A contrary issue is when a woman requests a CS for non-medical reasons. Of all CS 4% were planned (elective) CS in 1991, compared to 2008, 7.8% [25]. According to Stjernholm et al. [30] the main indication for planned CS was psychosocial, 10.5% in 1992 and 38.5% in 2005, and one might presume that this includes the rate of CS on request without medical indication. Maternal outcomes in relation to CS for non-medical reasons have shown that re-hospitalizations for wound complications and infection during the first month postpartum were significantly more common among women who had a planned CS than among those who had a vaginal delivery [31]. It has been shown that neonatal mortality rates are higher for infants born with CS with no indicated risks (1.77 per 1000 live births), than for infants born vaginally (0.62 per 1000 live births) [32]. Maternal request is often given as the reason in the discussion concerning the increasing CS rates. In a national survey from Sweden, on the mode of delivery, only 8.2% of 3013 of the women preferred to have a CS [33]. In a longitudinal cohort study in the UK 3% of 397 women preferred a planned CS and

72% would prefer to give birth vaginally [10]. Of those women expressing a wish for planned CS, some change their mind later in pregnancy. The women's preferences seem not to be congruent with the attitudes of obstetricians and midwives, according to Karlstrom et al. [34]. In focus group interviews with 16 midwives and nine obstetricians they found that the professionals described the woman giving birth as wanting to plan, control and demand. The women were well-informed and prepared and argued for their right to have a CS if it was their wish. They were also less confident concerning their ability to give birth vaginally. The professionals also thought that media has an influence in the attitudes towards CS. According to Wiklund, Edman and Andolf [35] the women's reason for request of a cesarean section was that they experienced their health as less good, were more often planning for one child only, they were worried for lack of support during labour, for loss of control and they were concerned for fetal injury/death more often than those who were planning for vaginal birth. A way to decrease the rate of CS on maternal request is according to Halvorsen et al. [36], a coping attitude of counselling. Significantly more women changed their request for CS after counselling.

In the USA, Bettes et al. [37] examined 699 obstetricians' attitudes towards elective primary CS and found that beliefs regarding the right to CS on maternal request were strongly related to the likelihood of performing one. American male obstetricians were more positive than their female colleagues towards women's right to request and obtain CS. When a woman had had previous delivery complications, no differences were found. Similar results were found in a study in Europe ("Development of Perinatal Technology and Ethical Decision-making during Pregnancy and Birth; the attitudes of obstetricians from eight European countries" [EUROBS]). The obstetricians in Sweden were more willing to comply with the woman's request for a CS, if the woman had a previous maternal or fetal complication [38]. If the woman had a fear of vaginal delivery and had a previous CS they would comply to a lesser degree. Danish obstetricians' attitudes towards a woman's request for CS without any medical indication, was according to Bergholt et al. [39], that 37.6% of 364 obstetricians would accept the woman's request. The obstetricians' own personal preferences for mode of delivery in an uncomplicated pregnancy, was to await spontaneous labour. Gunnervik et al. [40] showed that those obstetricians that would accept a woman's request for CS were older and more experienced.

Midwives' and obstetricians' attitudes towards the benefit of elective CS showed that midwives thought that elective CS should reduce the chance of stress and faecal incontinence more rarely than did the obstetricians [41]. Midwives would agree to offer an elective CS less frequently than obstetricians concerning advice given to a woman with a previous CS. Complications of elective CS which were discussed with the woman differed between the midwives and the obstetricians. Midwives discussed more frequently about fetal distress, emotional stress and risk of anaesthesia. Obstetricians discussed more frequently about systemic infections. Midwives at antenatal care clinics (ACC) agreed more often to a woman's right to have an elective CS and thought it was the best choice for a woman with fear of birth, than midwives on labour wards [42]. Midwives at ACC thought that obstetrician were more restrictive

about use of CS than midwives on the labour wards. The older, more experienced and longer they had worked at an ACC the higher the agreement was that the elective CS is as safe as vaginal birth for the mother.

Another major issue in delivery units is to make decisions in cases of preterm labour and birth.

Preterm labour and birth

Definition and prevalence

Spontaneous (idiopathic) preterm birth is when labour starts where no known fetal or maternal complications are present. Most preterm births fall into this category. The definition for preterm birth, according to World Health Organisation (WHO) is when a child is born before 37 gestational week (GW). According to WHO and the Swedish law, the recommendation for the definition limit, as a child, is > 22 GW or > 500g [43, 44]. The definition of very preterm birth is < 32 GW and of extremely preterm birth < 28 GW [45]. In Sweden, the prevalence of preterm births < 33 GW was in 2007 1.1% and of preterm births < 37 GW 5.4% [25]. The very preterm (< 32 GW) birth rate in 10 European countries, was on average 9.9 per 1000 total live births and ranged from 7.7 to 13.1 per 1000 [46]. The preterm birth rate (< 37 GW) in the USA was in 2006 12.8% and for very preterm birth (< 32 GW) 2.04% [47].

The short-term outcome after active management for infants born at 23-25 GW was investigated at two university hospitals in Sweden [48, 49]. Of 224 infants 213 were born alive and 140 survived to discharge home. The cause of morbidity for the extremely premature infant who survived, were retinopathy of prematurity (15%), severe cerebral lesion (6%) and bronchopulmonary dysplasia (36%). Of all survivors there were 81% who were discharged at home without major morbidity as severe cerebral lesion and retinopathy. The long-term effects for children that survive, with or without any physical handicap, can be lower intelligence, poor school performance and behavioural disturbances [50]. A national study in Sweden [51] investigated one-year survival of infants born < 27 GW after active perinatal care, during April 2004 to March 2007. During the period 1011 infants were born and 70% born alive. The incidence of extreme preterm birth was 3.3 per 1000 infants. Perinatal mortality was ranged from 93% at 22 GW to 24% at 26 GW and occurred early in the neonatal period. The one-year survival was 9.8% for infants born at 22 GW; 53% at 23 GW; 67% at 24 GW; 82% at 25 GW and 85% at 26 GW. Infants who survived had intraventricular haemorrhage (10%), retinopathy of prematurity (34%) and bronchopulmonary dysplasia (25%). Discharged from the hospital without major morbidity were possible for 45% of the 497 survivals.

Active management

The policy in Sweden since the early 1990s is to centralize extremely preterm deliveries to regional hospitals with level III NICU, i.e. to the seven university

hospitals (UH). This could indicate transferral from a general hospital (GH) to a UH for the woman and the infant, preferable in-uteri. The policy has also been to perform active perinatal management [51-54]. Active management include delivery at hospitals with level III NICU and to be able to give steroids to the woman before birth, tocolytics are administered to prolong the pregnancy and allow steroids to have an effect. To reduce respiratory distress syndrome in the infant born very prematurely, steroids are administered from 23 GW. CS is usually not performed for fetal reasons before 24 GW and fetal electronic monitoring is indicated at 25 GW. Fifteen guidelines for extreme preterm labour and birth were investigated and illuminated the fact that 22 GW seemed to be a “cut-off” point for viability [55]. Interventions were mainly indicated at 25 GW, but at 23–24 GW, interventions were recommended on individual basis as these weeks were considered to be a “grey zone”. In the EXPRESS study [51] 70% of the infants were born at level III hospitals, tocolytics and antenatal steroids were used more frequently later in the pregnancy and 50% were born by CS. Active management has been shown to be a benefit for infants born extremely preterm [51-54]. In a prospective questionnaire survey in the UK concerning management of extreme preterm labour and birth, midwives felt that electronic fetal monitoring should start at 25 GW, CS for fetal reasons was indicated in 26 GW, administering steroids should start at 24-26 GW and in-uteri hospital transfer was accepted at 24-26 GW [56]. Regarding the survival of extreme preterm infants and neurosensory impairments, 98 neonatologists in Canada had a more optimistic view than the 99 neonatal nurse who participated in the study by Streiner et al. [57]. The doctors in neonatal units would recommend all life-saving interventions at an earlier GW than the nurses. In a cross-sectional survey in Sweden, the participating neonatologists would resuscitate in the delivery room at 23 GW [58].

When non active management is recommended a decision is made not to intervene in the pregnancy and all interventions are therefore indicated only for maternal reasons. [16].

Hospitalization during preterm labour

The treatment of preterm labour is often ante-partum bed-rest at home or in hospital and tocolytic therapy [12, 13]. Goulet et al. [59] examined, in a controlled clinical trial, differences in neonatal outcomes between home care and hospital care in 250 pregnant women experiencing preterm labour. They found no significant difference with regard to antenatal stress and the family function, except in social support where women in home care were more satisfied with the social support from their male partner. When women were hospitalized for preterm rupture of the membranes, Mu [60] found in a phenomenological study, that the women felt safe with the care received in the hospital and this enabled them to rest easier, although the restriction of physical activity could also lead to a feeling of powerlessness. They had to wait until the fetus was mature enough for delivery. Katz [14] found that women who are hospitalized with placenta previa experience stressors while in hospital. Psychological consequences for the women from preterm labour and birth were found by Holditch-Davis et al. [15] who showed, that posttraumatic stress symptoms were seen in

mothers with preterm birth and who had infants in hospital neonatal care. In a study of preterm labour and preterm premature rupture of the membranes at 26 GW, 71% of the 814 obstetricians recommended bed-rest for women with preterm labour, although they thought there was minimal benefit with it [61]. Bed-rest could have impact on the family and cause a social and economic burden for all concerned. After the pregnant women came home from hospital, when they experienced threat of preterm labour, they felt that it was their responsibility to “keep the baby in” [62]. To do this they had to make arrangements for work and childcare. They were also dependent on support from others at home. Fifty women’s experiences of stress and support during the threat of preterm birth, while the woman was hospitalized, were a feeling of isolation and frustration because of fear for the infant’s outcome [11]. Emotional reactions as fear, depression, anger and guilt could occur.

Studies about women’s experiences of threat of preterm birth have shown that the women related the prematurity to life events [63-66]. They also described experiences like an uncertainty to recognise the preterm labour symptoms, concern for their baby and how to find a balance in the crisis. Women’s experiences of what causes the onset of preterm labour have been reviewed by Mackey and Coster-Schultz [67] and they found that the women thought it was hard physical work, work outside the home, a hectic life, medical causes and emotional stress. Though, in a population-based follow-up study, leisure time physical activity was shown to be associated with a reduced risk of preterm delivery [68]. The emotional stress was mostly worry about the outcome for their baby and the side-effects of eventual medical treatment for the infant [67].

The affect on the family

The whole family is affected if the woman is diagnosed with threat of preterm birth and has to be hospitalized during pregnancy. According to May [13] the women experienced that they and their families did as best as they could to try to balance the woman’s restrictions with the family’s needs. The mother’s restrictions gave an increased feeling of stress and, in some cases, disruption within the family. Barlow et al. [69] described the women’s experiences of hospital admission during preterm labour and found that the women needed more information to understand their condition as the onset of labour happened suddenly and unexpectedly. After a preterm delivery, the main problem for the women was separation from their baby and concern of the baby’s health [70]. Mothers with preterm babies had more negative emotions than those with full-term babies. Erlandsson and Fagerberg [71] explored women’s experiences of co-care and part-care when their baby was in the neonatal ward. The women had a strong desire to be close to their baby. Co-care gave the women confidence and a feeling of control in the situation. Part-care, was difficult for the women, involving separation from the baby, as the women spent the night at home. Bonding that was prolonged, affected the women’s feeling of being a mother and also their state of health. Muller-Nix et al. [72] observed the mother-infant interaction (47 preterm infants born at < 34 GW) at six and 18 months of infant’s age. Mothers, in this situation, had lower interaction with the infant than parents with a term infant had. Interviews with seven parents of preterm infants, < 34 GW, showed that mothers

experienced having more responsibility for and control of the care and the need to be endorsed as a mother [73].

Lundqvist and Jakobsson [74] found that fathers of preterm infants felt worried and distressed related to their responsibility for child care, household management and being supportive for their partners. Information given by the caregivers and support from significant others was important for the fathers. The first meeting and contact with their newborn infant gave a feeling of happiness. Fathers were confident to leave the care of the infant to the staff and wanted to find a balance between work and family. Both of the parents felt concern for their baby. Lindberg et al. [75] found that fathers to preterm infants felt that the professionals helped and educated them to take care of their preterm baby. They felt that they had a strong bond to their infant, they had changed as a person and the stressful event had strengthened their relationship with their partner, as they had experienced this together.

In critical situations the woman and her partner sometime have to make difficult decisions. The midwife, together with the obstetrician, should take the woman's experiences and wishes seriously and listen and guide her through the decision-making process [18].

The role of the midwife

In Sweden, the midwife has independent responsibility for normal pregnancy, delivery and postpartum care [76]. The midwife should have the ability to identify and evaluate deviations from the normal course, and when caring for the woman, co-operate within and between the professional groups. The midwife's ideological points are that childbirth is a natural process, to strive for continuity, maintain safe care and to prevent unnecessary interventions. Furthermore the midwife must establish a good relationship with the woman and her family. The midwife supports the woman in her right to autonomy, to make informed choices and to take part in the decision-making concerning the planning of care. The midwife follows the Ethical code for midwives in Sweden and the International Code of Ethics for Midwifery [76, 77]. The midwife in Sweden has an autonomy which she has retained through history. In other countries it has not always been the same, as e.g. in Ireland, where Keating and Fleming, [78], explored midwives' experiences of working in a unit using a medical model of birth approach. This did not enable the midwives to use their midwifery skills. They had to "stand up" for the normal birth process and they needed extensive professional experience to do so. Younger midwives were influenced by colleagues who were more midwifery oriented. Night duty, on the other hand, could make it easier to promote normal birth as there were fewer doctors around and the midwives could make their own decisions. The midwives on night duty seemed to be more autonomous. In *complicated pregnancy and birth*, the midwife tries to promote the natural process as much as possible [79]. Behruzi et al. [80] investigated midwives perceptions of humanised birth in high-risk pregnancies. They found that the midwives tried to balance between medical intervention and the normal birth process. Larsson and

Aldegarmann [81] explored with focus groups how the role of the Swedish midwife had changed over the last 20-25 years. They found that the midwives experienced some improvements such as communication with the doctors and that midwifery research was a strength for the profession. Other changes included that some tasks had been taken over by other professions e.g. assistant nurses.

Ethical standpoints

Several articles exist concerning analysis of cases in relation to fetal-maternal conflicts by applying the principle-based approach, especially the principles of respect of autonomy, beneficence and non-maleficence [2, 6, 7]. The moral responsibility of the obstetrician and midwife implies helping and doing the best for the woman and the fetus/infant. The decision-making requires an interaction and relationship between the parents-to-be and the professionals. Therefore the principle of ethics and theoretical analysis is not always enough when reflecting on decision-making in the health care practice of everyday life. Relational ethics, with focus on the meeting and the relationship with other human beings, could be a “bridge” between theory of ethics and health care practice [82-85].

A central part in relational ethics is the meeting/interaction between people [82]. In the meeting between people, the ethical demand appears. There is inter-dependence, a mutual obligation to each other and there is a changeable relationship of vulnerability and power in the encounter. One can choose to use the power for one's own advantage or take care of the other's life. The ethical demand is also silent; it is not voiced by the other person. What is good for the other, one has to find out for one's self. The power in this inter-dependence does not mean that one could take over the responsibility for the other. Each one of us has a responsibility for one's own life. In an encounter with other human beings a trust that we show each other also appears. If the trust is met by an attitude of not being received, the trust is changed to mistrust. As relational ethics is based on that ethical practice is placed in relationship, it is in the relationship that the caregivers determine how to be and how to act [85]. Acting ethically is not only to make the right decision in critical situations; it is also in practice how we relate to the person we care for and a commitment to this person. Gilligan [86] brought to light the discussion of a new structure to ethics (compared to the principle of ethics) and the essence of care, connection and respect were aspects that were acknowledged. In the study by Bergum and Dossetor [85] of ethics in health care practice, four essential themes emerged; mutual respect, engagement, embodiment and environment.

In an observational study, Hallgren et al., [87] investigated how four couples and nine midwives related during the childbirth process and one hour after the baby was born. It was found that trust was a component that was expressed by the midwife and the woman as important. It enabled the woman to manage on her own and the couple to co-operate. Information, given by the midwife in an everyday language and the shared decision-making, promoted trust. These midwives, managing to promote trust, were able to combine their professional knowledge within a caring relationship. Other

midwives could neglect the caring relationship with the woman and her partner, which could be experienced as disturbing the childbirth process. Being commanding and telling the couple what had to be done made the woman lose energy and the couples' ability to manage the childbirth process and co-operation decreased.

Midwives can experience a conflict between hospital workplace/service providers and values of the individual midwives [88]. The principle of ethics could be adequate for the midwives if the context, individual rights, values of personal characteristics and relationship were also considered. Midwives placed the mothers in the centre of decision-making regarding her baby. Midwives maintain a continuity of relationship from birth through to the postnatal period "being with the woman- approach". This corresponds to the relational ethics and its four components for ethical practice according to Bergum and Dossetor [85]. In critical situations during pregnancy and birth, the meeting with the woman, her partner and their significant others is important. This means, for the obstetricians and the midwives, they should meet the parents with respect, have a genuine dialogue and take their wishes and values into account. Furthermore it is important to understand their situation of being in a vulnerable position and in a context not familiar to them. It is the role of midwives and obstetricians to act in a way that the parents can feel secure and have a sense of control, which can increase by inviting the parents to take part in the decision-making process.

Critical situations during pregnancy and birth are difficult issues for the obstetricians and midwives as well as for the parents, and it is therefore important to gain deeper and explicit understanding of their experiences and attitudes, in the meaning of their way of thinking.

AIMS

The overall aim of this thesis was to describe the experience of obstetricians and parents and the attitudes of midwives in relation to critical situations during pregnancy and birth.

Specific aims:

- to highlight the experiences and meaning of being in ethically difficult obstetric situations as narrated by obstetricians (Paper I)
- to gain a deeper understanding of both parents' experiences and handling of their situation, while the mother was hospitalized, for the threat of early delivery and preterm birth (Paper II)
- primarily to ascertain the attitudes of Swedish midwives towards management of extremely preterm labour and birth (SWEMID study), and, secondarily, to compare the attitudes of midwives with those of Swedish obstetricians (EUROBS study) (Paper III)
- to describe the attitudes of midwives in Sweden towards the decision-making by obstetricians in relation to a woman's refusal of an emergency cesarean section but also to a woman's request of cesarean section without a medical indication (Paper IV).

STUDY POPULATION AND METHODS

Design

The studies in the thesis have both a qualitative (Paper I and II) and a quantitative approach (Paper III and IV). Paper I has a descriptive design and a hermeneutic phenomenological method was used [89] and Paper II has an explanatory design and a Grounded Theory method [90, 91]. Paper III has a descriptive and comparative design and Paper IV has a descriptive design, both from the same cross-sectional multicenter study. Paper I and II were performed at a university hospital in southern Sweden and Paper III and IV at 13 hospitals, both university and general hospitals in Sweden. The methods are illustrated in Table 1.

Table 1. Description of the methods and participants

	Paper I	Paper II	Paper III-IV
Design	Qualitative, descriptive	Qualitative, explanatory	Quantitative, descriptive, comparative
Method	Hermeneutic phenomenology	Grounded Theory (GT)	Cross-sectional, multicenter
Participants (n)			
Female	9 obstetricians	17 mothers	256 midwives
Male	5 obstetricians	6 fathers	3 midwives
Total	14 obstetricians	23 parents	259 midwives
Data collection	Tape-recording, conversational interviews	Tape-recording, interviews	Anonymous self-administrated questionnaire
Data analysis	Hermeneutic-phenomenological analysis	Constant comparative method (GT)	Descriptive and analytic statistics, Chi2 - test, Mann-Whitney test, Percentages and 95% confidence intervals (95% CI), Q1 - Q3

Study population and data collection

Participants

Inclusion criteria for Paper I was to have been actively working as an obstetrician for at least two years at the department when the study took place. Twenty obstetricians were asked to participate and 14 accepted the invitation. Reasons for not participating were; being on parental leave, temporarily working elsewhere or an excessive workload. Inclusion criteria for Paper II were a singleton pregnancy, with threatened spontaneous preterm birth starting with contractions, preterm rupture of the membranes or bleeding. Thirty-one parents were asked to participate and 23 parents were interviewed. Four mothers were also interviewed a second time postpartum, a total of 27 interviews. This included 15 mothers during pregnancy, six mothers postpartum and six fathers postpartum. The participants had to be able to understand and speak Swedish. Inclusion criteria for Paper III and IV were working as a midwife at a maternity unit associated with NICU in Sweden. Sixteen maternity units were invited to participate and 13 units accepted. In total 513 questionnaires were distributed and 259 returned.

Data collection

The interviews were performed during January through May in the year 2000 (Paper I). The sample was purposeful. Socio-demographic data about the obstetricians was collected after the interviews. This included age and years of professional experiences as obstetricians. The interviews with the parents were performed from spring 2002 to spring 2004 (Paper II). The sample was, according to Glaser, open, selective and theoretical [90-92]. Socio-demographic data from the parents was

collected to gain variance, such as parity, gestational week, age, civil status and profession. Data collection for Paper III and IV took place at the same units as from previous studies of ethical issues concerning obstetricians [27, 38]. The units consisted of both university hospitals i.e. level III hospitals and general hospitals i.e. level II hospitals. The data collection took place from March 2007 to June 2008. An anonymous, structured and standardised, self-administrated questionnaire was distributed to the units which had accepted to participate. The local study coordinator returned the sealed envelopes, containing the questionnaires, to the project coordinator (MD). Gender, age, married/co-habitant, own children, religious affiliation, importance of religion, professional position, hospital appointment and years of routine delivery room practice were collected for socio-demographic data and professional characteristics of the participants. Answers to corresponding questions were earlier obtained from 278 obstetricians from 17 maternity units with NICU in Sweden. Two units had amalgamated since the EUROBS questionnaire was distributed. Datacollection is illustrated in a flow-chart (Figure 1).

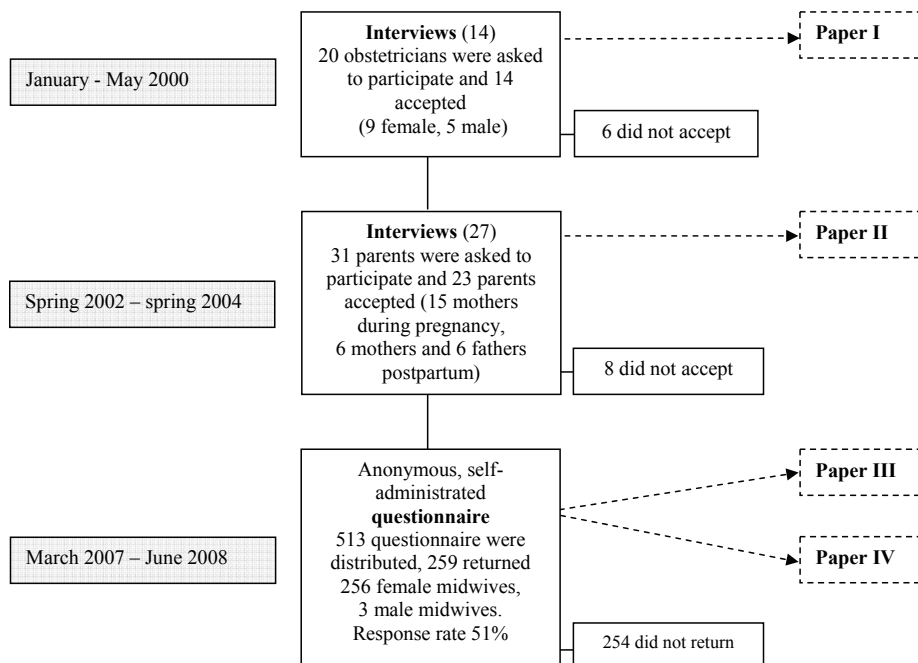


Figure 1. Datacollection for Paper I - IV

Qualitative methodology

Hermeneutic-phenomenology

The hermeneutic-phenomenological method is not aimed to generalize [89]. To understand the lived experience, in a deeper meaning, it is useful to turn to the life world, which is the context where we exist and reflect on the experience. It is essential to reflect upon a situation from one's own experience as phenomenological reflection is retrospective. This makes it possible to get to the structure of the meaning of the lived experience. Pure phenomenology according to Husserl [(93 p 79-92] describes the phenomenon as it "shows itself in the world". Through the process of reduction pre-understanding is put aside to describe the phenomenon as a "pure description". Hermeneutic is an interpretation of experiences via text. Ricouer is at present one of the most important representatives of hermeneutic and has developed his theory of text. Today his method is explicitly hermeneutic, but has its roots in phenomenology [94]. In the views of Ricouer's predecessors such as Heidegger in the "Being and Time" from 1927, the question of the meaning of being has been deepened. In hermeneutic-phenomenology van Manen [89] implies that we cannot neglect our pre-understanding but we use it when we reflect, interpret and describe a lived experience to understand the life world. In hermeneutic-phenomenology it is possible to use pre-understanding to find the meaning of being in the phenomenon under study.

To understand the meaning of the ethically difficult situations the obstetrician's experience, it is important to turn to the obstetricians themselves and let them portray the situations they have participated in during their daily work. By letting them choose a situation to narrate it made it possible to come closer to the experience and thereby gain a deeper understanding.

Grounded Theory

Grounded theory was 'discovered' by Glaser and Strauss in the mid of 1960's [95]. Glaser and Strauss were sociologists, but had different theoretical backgrounds which they used and combined in their research work together. They 'discovered' Grounded Theory during their work with "Awareness of Dying" in 1967. Grounded Theory's main point is the constant comparative method; concepts emerge from the data generating a new theory. Grounded Theory aims to conceptualize what is happening and what we do to handle the situation. In the late 1990's Glaser and Strauss started to differ in opinion about what Grounded Theory really is. According to Glaser, Grounded Theory includes open phase; data collection, to find categories and the core category, selective phase; to choose the categories which relate to the core category and theoretical phase; to describe the relation between the core category and the other categories [90, 91]. Strauss felt that Grounded Theory includes an open phase; to find categories, axial phase; to describe the relation between the categories and selective phase; to find the core category and describe it [96]. In the axial phase Strauss uses a paradigm to find the relationship between the categories and subcategories. The basic components of the paradigm are conditions, action/interaction and consequences. In this thesis Grounded Theory according to Glaser was applied. When the parents

experience a threat of preterm birth and the woman is hospitalized, they have to handle the situation. How they experience it and what they do to resolve it could be explained with the Grounded Theory method.

Preunderstanding

To interpret a phenomenon according to hermeneutic-phenomenology a specific knowledge in the research area is important. One's own experience makes it possible to be interested in a phenomenon in the life-world. The experience makes it possible to reflect on the situation and to interpret the phenomenon [89]. The author has 26 years clinical experience in midwifery, including antenatal and delivery care and this made it possible to meet the participants during the interviews in a relevant way. The author has not the obstetricians' perspective of ethically difficult obstetric situations, which can have been a benefit during the analysis, as it was possible to focus on their personal experience (Paper I).

In Grounded Theory, it is an advantage to be not so knowledgeable about the research question so as to be able to discover the research area with an open mind, so it was a benefit that the author had no personal experience of the threat of preterm birth. The constant comparative data analysis leads one as to where to collect new data, although one has to know the research area to be able to identify something interesting to explore (Paper II) [90, 91].

Quantitative methodology

In Papers III and IV a cross-sectional multicenter design was used, collecting information about midwives' attitudes through a self-reported, self-administrated questionnaire. The midwives answered statements in nominal and ordinal-scales and some questions were preceded by a brief description of a situation which the respondents were asked to react to. The cross-sectional design was considered appropriate in this study as, according to Altman [97] and Polit and Beck [98], the aim was to describe the attitudes of the midwives at only one point in time.

The questionnaire

The questionnaire in the SWEMID-project ("Ethical decision-making during pregnancy and birth: midwives' perspectives in Sweden") was based on the questionnaire used in the EUROBS- project. The questionnaire in the EUROBS-project was developed in English, translated into Swedish, back-translated into English, and used in a study of Swedish obstetricians [27, 38]. The EUROBS questionnaire consisted of six parts and included 54 questions. The parts were; background and working situation, value of life, management of preterm delivery, conflicts of interest, legal issues and socio-demographic data. The questionnaire used in the SWEMID-project included the same original parts with a reduced number of questions, in total 32 and was adapted to the midwifery context. In 2006 the content validity was evaluated by two obstetricians, two midwives and one ethicist. Using face

validity the questionnaire was examined by six midwives and this evaluation led to a few minor changes to clarify some questions [97, 98]. Paper III describes the attitudes of midwives towards management of preterm labour and birth at 21– 28 GW. The attitudes were investigated by giving a short case report about preterm birth at 21–28 GW, when the parents wished for either active or non-active management: “Pregnant woman with spontaneous preterm labour, singleton pregnancy, the fetus in cephalic presentation, normal fetal growth and absence of malformations. What is the lowest GA (in completed GW) at which you think the following should be performed (Table 2). Furthermore, questions about what information should be given to the parents when the threat of very/extremely preterm birth occurred and questions regarding the involvement of the neonatologists were also included (Paper III).

Paper IV describes the attitudes of midwives regarding decision-making, by the obstetricians, concerning a woman’s refusal of emergency CS and a woman’s requests for CS without a medical indication. The attitudes of the midwives were investigated through fictive cases and the midwives were asked what they thought the obstetrician should do when a woman refuses an emergency CS recommended for fetal reasons: The answers were reported on a nominal scale (Yes, Maybe or No). If a woman requests a CS without any medical indications, the midwives were asked what they thought the obstetrician should do; reported on a nominal scale - comply or refuse to comply (Table 2). If the answer was “comply” another question was to be answered; “Why would you support the woman’s choice?” The alternatives were: 1) out of respect for the woman’s autonomy; 2) to avoid possible problems of non-compliance during delivery; 3) to avoid possible legal consequences if something goes wrong. The answers were reported on a nominal scale (Yes or No).

Table 2. Items from the questionnaire SWEMID (Paper III and IV)

Paper III	Paper IV	
Management of very/extremely preterm labour and birth	Refusal of cesarean section	Request for cesarean section
Steroid prophylaxis to stimulate lung maturation	Accept the woman’s decision and assist vaginal delivery	This is her choice
Cardiotocography (CTG) monitoring	Keep trying to persuade the woman to accept cesarean section	Fear of vaginal delivery
Cesarean section for preterm labour only	Tell the woman that the baby may survive with disability	Previous cesarean section
Cesarean section in case of acute fetal distress	Tell the woman that her life may be in danger too	Previous traumatic vaginal delivery
Alert neonatologist / pediatrician before delivery	Proceed with cesarean section	Previous intrapartum death
Suggest admission to neonatal intensive care unit		Her first child is disabled This patient is a colleague

DATA ANALYSIS

Qualitative analysis

Hermeneutic-phenomenology (Paper I) strives to make a reflection on the lived experience and make the structure of meaning in this lived experience explicit [89]. To reach the meaning of the structure it is helpful to reflect on the phenomenon which is described in the text, in terms of meaning units, meaning structure and themes. The text analysis was circled from the parts to the whole and from the whole to the parts, to keep close to the narratives and the context.

The analysis procedure started with reading the text as a whole to get an overall impression of the data and then line by line. Meaning units appeared and were transformed, step by step, to capture the essential themes of the phenomenon. The analysis proceeded with asking “what does it mean to the obstetricians to be in this ‘lived experience’, the ethically difficult obstetric situation?” Through hermeneutic conversation the analysis deepened and themes appeared. These were then clustered into five themes and further on, an overriding theme could be identified. The overriding theme was the structure of the meaning of being in an ethically difficult obstetric situation, which was “Sympathetic responsibility in decisions of critical importance for the mother and her infant”. The structure of the meaning was discussed in seminars to deepen insight and understanding [89]. The description was woven around the themes and the ethically difficult obstetric situation was described thematically.

In the Grounded Theory method (Paper II) the focus is on conceptualizing the main concern of the participants and how they try to solve it. During the analysis questions were asked. “What is going on”? “What is the main problem for the participants”? “How do they try to solve it”? The method generates concepts which explain how people handle their problems in situations they have found themselves in. This will be explained by the core category, categories and sub categories in the generated theory [90, 91]. In Grounded Theory, data collection and analysis is performed at the same time - constant comparative analysis. The data from the previous interview is analysed and guides further research questions.

In the open phase, variations of codes emerged and two possible core categories appeared. The core category “Inter-adapting” was selected as the final core category. In the selective phase, the codes were reduced by selective coding and only those relating to the core category were included. Twelve categories were reduced to seven with related subcategories. Later these categories were reduced to three categories with their six, linked, subcategories. In the theoretical phase, the relation between the categories was clarified through theoretical coding. The core-category “Inter-adapting” showed how the participants handle their situation and how they used different strategies to resolve their problems. Therefore the code-family “Strategy” was chosen. Memos were constantly written, in the shape of text and figures, during the whole process to clarify the codes. The memos were analysed and sorted to find a pattern

which emerged, building the theoretical model. While sorting the memos to write the theoretical model it is, according to Glaser, appropriate to test the theory on some of the participants or colleagues [99]. It then is possible to discover how understandable the findings are and what needs further clarification. The findings were read by three colleagues and discussed at a seminar. After this the author could revise and clarify the theoretical model for the final version. Literature review was performed after the theoretical model had emerged and was related to the findings.

Statistical analysis

Descriptive and analytic statistics was performed. Socio-demographic data are given as frequencies. To identify differences between the two sub-groups (UH and GH) Chi²-test was used except for the variable “own children” which were tested with the Mann-Whitney U-test. The p-values <0.05 were considered statistically significant (Paper III and IV). Median value and quartile was calculated for comparison with unpublished results for obstetricians of Sweden (Paper III). Percentages and 95% confidence intervals (95% CI) were calculated for comparisons with the published EUROBS results for obstetricians from Sweden and UK, respectively (Paper IV).

ETHICAL CONSIDERATIONS

Permission to conduct the studies for Paper I and II was obtained from the head of the Department of Obstetric and Gynaecology at the hospital, as well as permission from the Research Ethics Committee, Lund (LU-599-99; LU-511-02). According to Swedish law anonymous questionnaires are excluded from being assessed by a Research Ethics Committee, so no permission was necessary concerning Paper III and IV [100, 101]. Permission from the head of the units of the different hospitals was obtained.

The first contact with the obstetricians, who fulfilled the inclusion criteria, was through written information delivered to their mailbox at the hospital. In accordance with this information, the first author telephoned the participants a week later and at this time oral information was given. If the obstetrician was willing to participate, a time for the interview was set (Paper I). The first contact with the mothers and fathers was written information, given to them by the midwives working on the prenatal ward. When the first author visited the ward, both oral and written information was given and if the mother wanted to participate, a time for the interview was arranged (Paper II). There was time to consider participation before the interview took place and both obstetricians and parents gave their written informed consent beforehand. They were told that they could withdraw at any time and that their participation was voluntary, according to the principle of autonomy (Paper I, II, III and IV). A withdrawal would not make any difference in the care given (Paper II). In Paper III and IV the questionnaires were anonymous. Considering the principles of non-maleficence and beneficence, all data was handled confidentially and information

given to the researcher about staff and parents during the interview was stored in a locked document cupboard. Furthermore the obstetricians chose the place for the interview themselves and all choose their work room at the hospital. This gave them privacy (Paper I). Respect for privacy was given to the parents as they were in a vulnerable situation. The interviews took place in the participants' room at the hospital, if they were alone, in a room chosen by the staff or in the participants' home (Paper II). Both women and men were invited to take part in the studies (principle of justice) (Paper I-IV). The author had no connection with any of the hospitals in the studies, and had never worked in any of them. This made the researcher an "out-sider" who was not involved, either as a colleague or a care-giver (Paper I-IV) [4, 102].

RESULTS

Socio-demographic data of the participants

Among the participants in Paper I (n=14) there were nine female and five male obstetricians. The median age was 41 years old, range from 30 to 59. The years of their professional experiences was 10 years (median) and range from 2.5 to 30.

Of the parents (n=23) in Paper II there were 17 mothers and six fathers. Nine of the mothers- to-be were nullipara and eight were multipara. The GW varied from 24 GW to 35 GW. The median age for the mothers was 29 years old, range from 21 to 42. The median age of the fathers was 29.5 ranged from 25 to 32. All of the mothers were married or cohabiting. The participants' professional carried from academic to blue collar.

Thirteen of 16 approached units (81%) accepted to participate and there were seven GHs and six UHs. The response rate for the returned questionnaires was 51%. The midwives (n=259) in Paper III and IV, were working at university affiliated hospitals, UH, (n=123) and at hospitals without such affiliation, general hospitals, GH, (n=136). There were 256 female midwives and three male. The majority of midwives were older than 40 years. Most of them were married or co-habitant and had two or three biological children. Religious affiliation was mostly protestant. Religion was, to various degrees, important in the life of many midwives; though for 73(29.2%) religion was not at all important. Many midwives had more than 6 years (up to 40) of professional experience at a delivery ward. For the variable "biological children" it was shown that midwives at GHs had more children (p=0.004) and for the variable post: full-time/part-time that more midwives at GHs were working full-time (p=<0.001). Socio demographic and characteristics data of the obstetricians are described elsewhere [27, 38]

Findings

The obstetricians' stories were diverse, but nine of 17 dealt with the threat of preterm birth (Paper I). Eight of the cases were extremely preterm, (gestational weeks < 25+6), and one preterm. Six cases were at term, (37+0 – 41+6), and one post-term. One dealt with a difficult situation at mid-term.

The obstetricians' lived experience of being in ethically difficult obstetric situations

The overriding theme in the findings of Paper I was "Sympathetic responsibility in decisions of importance for the mother and her infant". Five themes illuminated the decision-making process that the obstetricians went through during the situation they recounted. The themes are presented below in bold letters.

Sympathetic responsibility in decisions of critical importance for the mother and her infant

In the encounter with the woman, sympathetic responsibility ensures that the obstetrician tries to do the best for the mother and her infant. **To proceed with a moral reasoning that leads to the choice of a solution** was the first theme. The moral reasoning that guided the trains of thought was the principles of beneficence and non-maleficence. The moral reasoning was balancing between the health of the mother and the risks to the child's future health. During the decision-making process, good communication and genuine co-operation with the staff, especially with the midwife, was important to obtain views about the woman's situation. Otherwise it could disrupt the process.

"And there I think the ethical question is how far we can risk the mother's health. It was almost so that she was close to dying...should we risk her life for that of the infant?" (Int. G).

The obstetrician was aware of his or her professional knowledge and moral obligations, but did not take over the parents' responsibility. **To balance one's own medical knowledge and moral insight with the needs and requests of the parents** was the second theme. The parents' desires and requests were considered and, through information and participation in the decision-making process, the parents made an informed choice. They reached a decision about treatment that was acceptable for all parties. Any choice taken here could lead to long term consequences for the mother and the child. The moral reasoning was between the health of the mother and her autonomy versus the health of her child.

"as a general principle one had this discussion with her in an attempt to get her to understand the risk to her own life compared with the risk of continuing the pregnancy" (Int. L).

The third theme was **To know one's medical and moral responsibility in relation to the decision made**. This implied that the parents should participate in the decision-making process and be able to speak their minds. The parents should not make the medical decisions. The obstetrician's responsibility here was to help the parents to make these difficult decisions.

"Yes and then I don't think that one can expect a patient to make a medical decision. We have the knowledge. Naturally, they should be able to make their voice heard and do this in collaboration with the doctor. They shall not have to make the decision on their own. It is we that have been trained and are paid to help the patient to make decisions of critical importance." (Int. G).

To experience the ability to take action and to make and carry out difficult and important decisions for the health of the mother and infant was the fourth theme. Once the decision was made there was a resolution to carry it out, although it could also be felt to be difficult, which could result in a state of uncertainty. The obstetricians wanted and hoped to make a decision with the optimal choice with the best outcome for both the mother and her child. At this moment they did not know if it was the optimal choice. They could only know this afterwards. They could feel uncertain as they could make other choices with a greater risk for the mother or her child.

"... in my naivism, I believed that it would be a rather simple procedure, but it was unbelievably difficult... yes, for me it wasn't so easy but at the same time I felt that I was quite decisive." (Int. V).

As the obstetrician did not know what the optimal choice for the best outcome was for the mother and her infant, a state of uncertainty could occur. The last theme was **To reflect on a given situation, in a manner leading to a rational acceptance of one's own conduct**. Feelings of guilt, doubt, dissatisfaction, tiredness and loneliness could be the result, even though the obstetrician made a professional effort. Therefore he or she went through the event, predominantly in their thoughts, many times to achieve an acceptable standpoint to be able to move on to the next situation.

"...for a doctor then, when one feels that one has done one's absolute best and the outcome has been good, it is naturally a drawback to be reported and be questioned.. It is a difficult situation... Emotionally it hasn't felt so good, no it hasn't..." (Int. F).

The parents' experiences and handling of the threat of preterm birth

In Paper II, where parents had experienced a threat of preterm birth and the woman was hospitalized, there were three women with a threat of extreme preterm and 14 preterm births, although two mothers were included postpartum. The reasons for admission for eight mothers was contractions, for two mothers preterm rupture of the membranes and seven mothers were admitted for due to bleeding.

The core category was “*Inter-adapting*”, and three categories with six related subcategories emerged from the data (Paper II). *Interacting* (‘Communicating with the professional caregivers’, ‘Keeping the family together through a stressful situation’, ‘Seeking empowerment during labour and birth’), *Reorganizing* (‘Arranging for a new family situation’) and *Caring* (‘Accepting restrictions for the sake of the health of the fetus’, ‘Reaching out to the infant and taking part in the care’). The categories are explaining the parents’ main concern and the strategies used to resolve the situation they had found themselves in. During the analysis of the memos, a pattern emerged and the theoretical model was developed; “Inter-adapting to Threat of Preterm Birth (Figure 2).

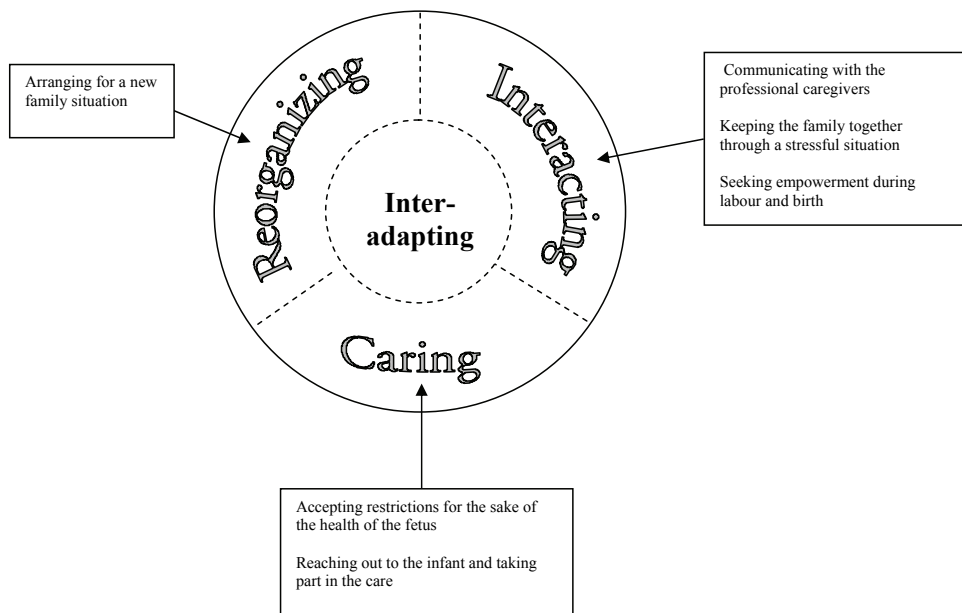


Figure 2. The theoretical model - “Inter-adapting to Threat of Preterm Birth” – the strategies to handle the situation. (Danerek & Dykes, 2005).

Inter-adapting

When the mother is hospitalized due to a threat of preterm birth, both parents have to adapt to the care routines and to each other. During the hospitalization the parents are separated as a couple (if living together) and the mother is separated from the family. To keep the family together there has to be an interaction within the parents’ relationship and between the parents and the caregivers. By accepting the mother’s restrictions during pregnancy and hospitalization the parents’ concern is to achieve the best outcome for the fetus/infant. Hospitalization requires reorganization of home responsibilities and work situation and is achieved by different actors adapting to the

situation. After birth, the interaction with the infant was of the utmost importance and the adaptation to the parental role started. To manage this situation both parents tried to adapt both to each other and also to the caregivers and the treatment, for the best of the fetus/fetus. Mutual understanding and support developed and “Inter-adapting” took place. The subcategories are presented in the text in italics.

Interacting

The parents used interacting strategies to handle the threat of preterm birth and to adapt to the unexpected family life-situation. When the mothers became aware of the first shocking threat of preterm birth they, as well as the fathers, felt frightened, worried and stressed. Initially they handled the acute situation by seeking advice from friends and caregivers and then the hospital where their needs could be met and taken care of. In the encounter with *the professional caregivers* the mothers *interacted* and the mothers felt safe with the professional care and monitoring. The mothers experienced a responsibility of their own and used the strategy of partaking in the decision-making process, concerning the care of themselves and their fetus. The fathers appreciated when the caregivers communicated in an honest manner and they trusted the caregivers as their needs were met. The mothers wanted to know about the current situation although the shock, at first, could make it hard for them to understand the information imparted. If the mother felt that the family was functioning she felt calm. If there were problems in the relationship these became more obvious and caused more stress and worry for the mother. The strategies they used were to *keep the family together* and achieve affinity. The fathers supported the mothers and made the family function. The mothers were longing for home and the fathers tried to support and be with the mothers as much as possible. To handle premature *labour and birth* the mothers were *seeking empowerment* through the midwives, as they did not want a preterm birth to take place at this time. Although the fathers were present during labour and birth they felt slighted and needed more attention than the caregivers could give in the situation (Figure 3).

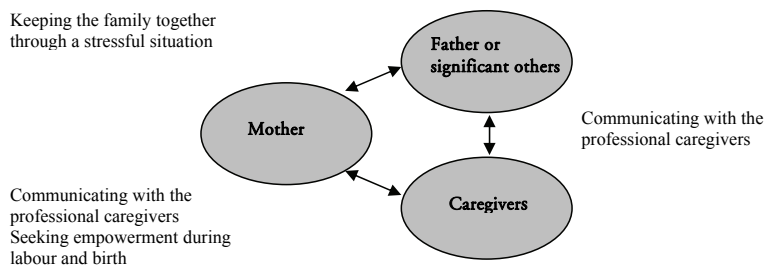


Figure 3. The interacting strategy between the mother, father (or significant others) and the caregivers, illustrating their “Inter-adapting”.

Reorganizing

The reorganizing strategy was used during the mothers' hospitalization when the parents had to *arrange for a new family situation*. This had an impact on their roles as parents, wives and husbands and employees. The roles changed during the mother's stay in hospital. As parents they had to reorganize home responsibilities and as most parents were working they had to reappraise work conditions. To do this they utilized significant others and the fathers used the strategy of taking full responsibility for organizing the family, so the home, work, school and day-care functioned. If the mothers were able to go home before birth the parents had to prepare for homecoming with eventual restrictions for the mother. There was a lot of "Inter-adapting" taking place in order to manage the situation (Figure 4).

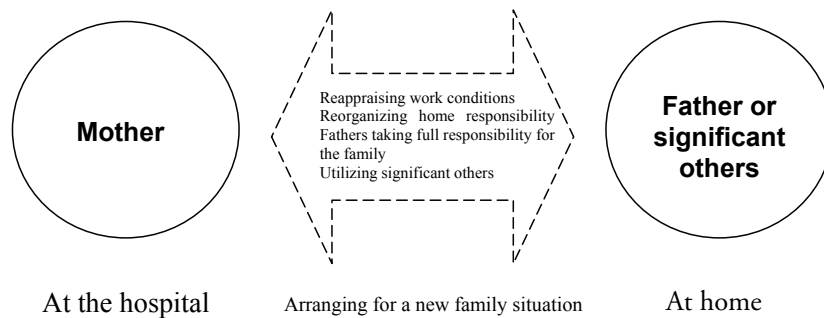


Figure 4. Reorganizing strategy arranging for the new family situation, illustrating the "Inter-adapting" between the mother, father, their work, home, family members and significant others.

Caring

The caring strategy was used for the benefit of the fetus/infant. The mothers felt lonely, forgotten and unseen as they often had bed-restriction during pregnancy. This inactivity gave a feeling of restlessness and combined with the long wait it created nervousness. The mothers *accepted the restrictions for the sake of the health of the fetus*, and they adapted to the situation by using investigations and things like reading, writing and watching television as entertainment strategies. The mothers' and fathers' concern about the fetus made them agree to the necessary restrictions. The fathers' strategies were to think in a positive manner during the mothers' hospitalization and restrictions. The fathers felt it was very important to be as physically near the mothers as possible. Both parents needed to get immediate nearness and contact with their infant, after birth and were *reaching out* to it. Often the fathers got physical contact direct and the mothers as soon as possible after birth. The mothers found it difficult to be separated from their infant, when this was necessary. The strategy *part-taking actively in the care* helped them to interact with the infant. The caregivers could have opinions that differed from the mothers about how to take care of the infant and the mothers questioned who was the one to decide. As the fathers were taking care of the

infant they felt like “being a father”, although they needed support from the caregivers concerning this (Figure 5).

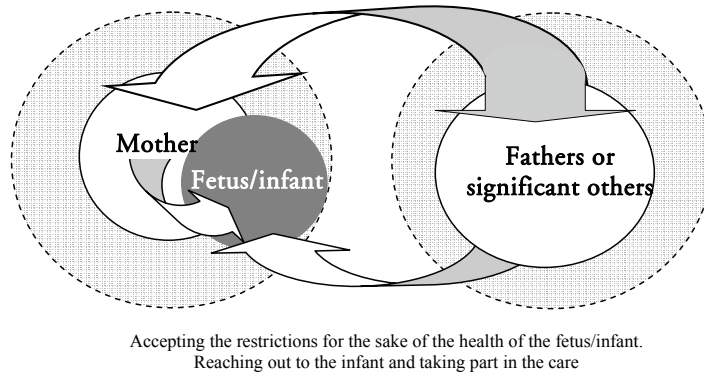


Figure 5. Caring strategy for the fetus/infant makes the parents accept the mother’s restrictions during the hospitalization by adapting to the situation. The figure illustrates “Inter-adapting” between the mother and father (or significant others) and their caring for the fetus/infant.

Attitudes of midwives towards very/extremely preterm labour and birth

The gestational week at which the midwives would consider starting treatment/-procedures or giving information, varied. In the following, the most frequently proposed GA is presented.

Midwives would agree to start *steroid prophylaxis* at 23 GW in active management (Paper III). When comparing the sub-groups, a significant difference was found in active management ($p=0.025$) and non-active management ($p=0.007$); midwives at UHs seem more willing to agree to start steroid prophylaxis at an earlier GA (Figure 6 and 7). Midwives would agree to start *CTG monitoring* at 25 GW. There were a significant difference between the sub-groups; more midwives at GHs seemed to agree to start at a later GA, active management ($p=0.001$), and non-active management ($p<0.001$) (Figure 8 and 9). A cumulative illustration of CTG monitoring for all midwives ($n=251$) when active management was the wish of the parents, is shown in Figure 10. The midwives felt that *CS due to fetal distress* was indicated at 25 GW. *CS due to preterm labour only* was indicated at 25 GW if active management was presented and at 28 GW if there was non-active management. *Transfer to NICU* should according to the midwives’ attitudes be carried out at 23 GW and *information to the neonatologists* before birth should be given at the same week. Concerning transfer to NICU, midwives in GHs were significantly more willing to wait until a later GA if non-active management was presented ($p=0.011$). Midwives at GHs were also significantly more willing to wait until a later GA concerning when information to the neonatologist before birth should be given, when active management was presented ($p=0.040$).

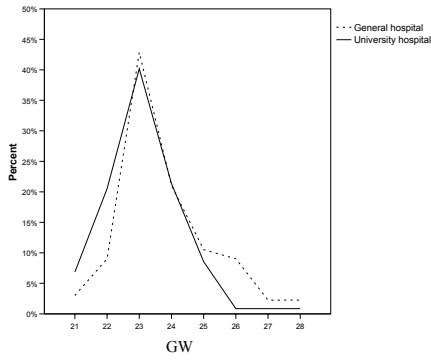


Figure 6. Attitudes of 250 midwives towards lowest GA to agree to start steroid-prophylaxis (active management)

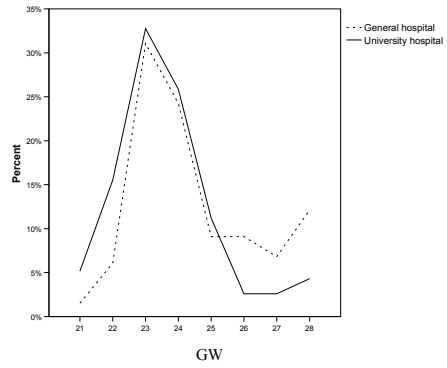


Figure 7. Attitudes of 248 midwives towards lowest GA to agree to start steroid-prophylaxis (non-active management)

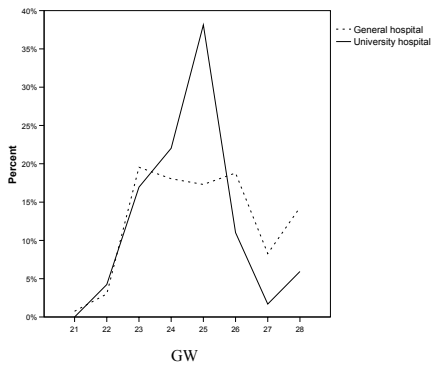


Figure 8. Attitudes of 251 midwives towards lowest GA to agree to start CTG-monitoring (active management)

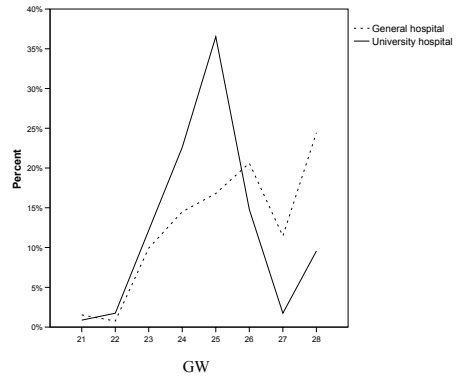


Figure 9. Attitudes of 246 midwives towards lowest GA to agree to start CTG-monitoring (non-active management)

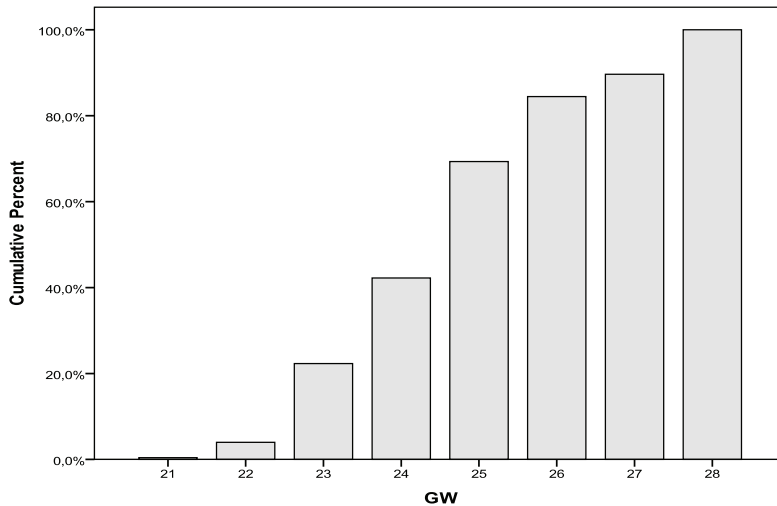


Figure 10. Attitudes of 251 midwives towards when to start CTG monitoring – active management – cumulative presentation (GW)

The most important information that the midwives thought should be given, on a regular basis, to the parents concerning their baby was the baby’s well-being, prognosis and the treatment the baby would receive at birth. The information should also include planned mode of delivery and transfer to NICU. Information that should be given to a lesser extent or only when the parents asked for it, was estimated birth weight, estimated possibility of survival in percent and the possibility to refrain from resuscitation if the fetus is < 25 GW. The midwives’ attitudes of the lowest GA for the statements “To tell the parents that the possibility for the baby to survive is 50%” and “the risk for serious disability among those who survive is approximately 10%”, was at 24 GW. The midwives thought that the obstetricians involved the neonatologists on a regular basis at their hospital and felt the neonatologists were as active as they wished them to be.

There was a significant difference between the sub-groups. Midwives at GHs seemed to be more likely to inform the parents, only when they inquired, about the type of treatment the baby would receive at birth ($p=0.008$). A significant difference ($p=0.001$) was also found between the sub-groups, for the variable “estimated risk for disability (in percent)” there midwives at UHs seemed to be more willing to disclose handicap in percent than midwives at GHs, who would do so mostly on request. Midwives at GHs seemed to feel that the neonatologists were less involved compared to those at UHs ($p=0.013$).

Comparison with the attitudes of the obstetricians

The analysis showed that, in cases of parents wishing active management, the obstetricians ($n=278$) would most often initiate steroid prophylaxis at 23 GW, CTG

monitoring at 24 GW, CS for preterm labour only at 25 GW, CS for fetal distress at 24 GW, give information to the neonatologists before preterm birth at 23 GW, and suggest admission to NICU at 23 GW. In active management, the attitudes of midwives in our study differed from those of obstetricians concerning the start of CTG monitoring and CS for fetal distress. Obstetricians were more likely to monitor and intervene at an earlier GA than midwives were.

When non-active management was the wish of the parents, the attitudes of midwives and obstetricians differed regarding the initiation of steroid prophylaxis, start of CTG monitoring, and CS for preterm labour only. Obstetricians would initiate these at an earlier GA than midwives. The obstetricians (95%) involved the neonatologists routinely in the discussion of the prognosis of the infant with the parents and the midwives were agreed with the obstetricians (91.8%). Midwives (75%) and obstetricians (84%) thought that the neonatologists at their hospital were as active as they wished them to be.

Information that should be given routinely to the parents before very/extremely preterm birth, according to the attitudes of obstetricians: on the current condition and wellbeing of the fetus – 98% of obstetricians, estimated birth weight – 68%, mode of delivery – 100%, prognosis of the baby in general terms - 89%, transfer to NICU – 93%, and type of assistance baby will receive at birth – 74%. Information that should be given to a lesser extent: on the estimated survival probability in percent – 22%, estimated probability of handicap in percent – 13%; and possibility of withholding resuscitation if GA is < 25 GW – 23%.

Midwives were significantly more willing to disclose information on following issues than the obstetricians were: information on the planned mode of delivery ($p=0.001$), estimated survival probability in percent ($p<0.001$), estimated probability of handicap in percent ($p<0.001$), type of treatment the baby will receive after birth ($p<0.001$), and possibility of withholding resuscitation if GA < 25 GW ($p<0.001$).

Midwives' attitudes on refusal of or request for cesarean section

When a woman refuses an emergency CS the midwives felt that the obstetrician should try to persuade the woman otherwise (Paper IV). The information that the baby might survive with disabilities should be given, but not the information that her own life could also be in danger. The attitudes of the midwives towards “to proceed with a CS” were mostly negative. When a woman requests a CS for a non-medical reason, the midwives felt that the obstetrician should comply if there was a previous maternal or fetal complication. If the woman had an intense fear of childbirth 50% of the midwives felt that the obstetrician should comply. If the only reason for the woman was “her choice” or if the woman was a colleague, the midwives felt that the obstetrician should not agree to the woman’s request. Midwives at UHs were significantly less willing to comply in these statements. The answers “comply” are presented in Table 3. If the midwives wanted to support the woman’s choice for a CS, it was out of respect for the

woman's autonomy. Midwives at UHs were significantly less willing to accept the woman's choice in this respect. The answers "yes" are presented in Table 4.

Table 3. Attitudes of midwives towards a woman's request of cesarean section with no medical reason.*.

The obstetrician should: Comply with the woman's request for a cesarean section for each of the following reasons	General hospital subgroup n =136 n (%)	University hospital subgroup n =123 n (%)	P-value**
This is her choice			0.010
Comply	36 (30.0)	16 (15.4)	
Fear of vaginal delivery			0.523
Comply	62 (51.2)	45 (46.9)	
Previous cesarean section			0.405
Comply	83 (66.9)	66 (61.7)	
Previous traumatic vaginal delivery			0.244
Comply	100 (82.6)	81 (76.4)	
Previous intrapartum death			0.656
Comply	90 (75.0)	76 (72.4)	
Her first child is disabled			0.151
Comply	93 (75.0)	69 (66.3)	
This patient is a colleague			0.032
Comply	33 (28.4)	15 (16.0)	

* Case: A 25-year-old woman started labour at 39 completed weeks after uneventful pregnancy. The fetus was apparently normally formed, healthy and in cephalic presentation. Despite being informed that vaginal delivery is indicated, and that there is a higher morbidity and mortality associated with cesarean delivery, the woman insists on a cesarean section.

**Pearson Chi-Square-test, significance of difference between the subgroups.

Table 4. Reasons for supporting the woman's choice.

Midwives' reasons for supporting the woman's choice for a cesarean section:	General hospital subgroup n =136 n (%)	University hospital subgroup n =123 n (%)	P-value*
Out of respect for the woman's autonomy			0.044
Yes	83 (82.2)	65 (69.9)	
To avoid possible problems of non-compliance during delivery			0.331
Yes	40 (42.1)	32 (35.2)	
To avoid possible legal consequences if something goes wrong			0.196
Yes	27 (28.4)	18 (20.2)	

*Pearson Chi-Square-test, significance of difference between the subgroups

DISCUSSION

Methodological considerations

Design and method

To assess rigour in qualitative studies the term “trustworthiness” is used and can be discussed by applying the aspects true value, applicability, consistency and neutrality [103, 104] (Paper I). According to Glaser, rigour of a generated theory is established with the criteria fit, workability, relevance and modifiability [92, 95] (Paper II). The concepts validity and reliability are discussed concerning the quantitative studies (97, 98, 105) (Paper III and IV).

Trustworthiness

Paper I

True value is evaluated against the criteria credibility and is achieved when the participants and other individuals with the same lived experience, recognize the researcher’s description of the lived experience as their own. Credibility could be demonstrated through “member-checks”. As the participants in a conversational interview get more involved in the research [89] it is trustworthy to let the structure of the meaning go back to the participant and let them reflect on the themes. Two participants in this study read the findings and found it relevant to their experience. The participants were suitable for the purpose of the study as both male (n=5) and female (n=9) obstetricians were included, they were all actively working as obstetricians and had more than two years of professional experience.

Applicability is evaluated against the criteria fittingness. It means the findings could be understood outside the research area and are applicable to other similar situations. Qualitative research is not aiming at generalizability as the situation is about the researcher’s interaction with a subject in a specific context. It is aiming at the variation and the uniqueness in the situation. The findings should also be well anchored in the lived experience under research. The findings in this study emerged from the obstetricians’ own narratives, the subject of which was their own choice. By quotations connected to the themes, relationship is shown between the interviews and the findings in this study. This shows that the author’s interpretation is connected with the obstetricians’ narratives.

Consistency is evaluated against the criteria auditability and is understood as how another researcher is able to follow every stage of the study and to be able to reach comparable findings by using the same research process. It is important to describe what has been done and why [89]. All the steps during the analysis are described in the method part in Paper I.

Neutrality is evaluated against the criteria confirmability and is reached when the three other aspects are achieved. The findings should be grounded in the data. The limitation

in Paper I could be that some informants have narrated situations that took place some time ago and do not remember everything clearly, but rather what they have reflected on and learnt from the situation. Difficult situations often remain clearly in the minds of those who have lived through them. Women's long-term memories of their first birth experiences were found to be generally accurate and vivid many years later [106]. The author's difficulty has been to use the pre-understanding to reach proximity to the text and at the same time keep a distance so as to be able to interpret the text in a meaningful way. It was beneficial that the interviewer was an "out-side" person and had never worked at the department, which made it possible to focus on the obstetricians' perspective.

Paper II

Fit has to do with how closely concepts fit with the incidents they represent. During the analysis the authors went back to the already coded data several times trying to stay close to it. Quotations from this, incidents, are linked to the concepts in the findings to show that the concepts represent the incidents. The informants were suitable for the purpose of the study as they had all experienced a threat of preterm birth, there was a variation of gestational weeks and of the age of mothers and fathers. As the focus was on the threat of preterm birth, when the women were hospitalized, more women than men were represented, although saturation was achieved with the last two men interviewed.

Workability means that the theory works when it explains how the problem is being solved. During the analysis in this study, questions were asked as "what is going on here" and "how do the participants handle the situation"? This is done to try to really show what the parents went through during the threat of preterm birth and how they resolved the situation in which they found themselves. The theoretical model shows how the parents handled the threat of preterm birth.

The theory is *relevant* when it describes what is most important for the participants. This is achieved by letting relevant concepts emerge from the data and not to force any previous theory on it. By letting the participants and the theoretical sampling guide the process during the interviews, it was possible to get closer to the parents main problem. By going back to four informants after preterm birth had occurred, the interviewer was able to deepen the interviews around the parents' main problem. The author and the co-author of the study have analyzed the transcripts separately and together discussed the findings during the comparative analysis.

Modifiability means that the theory must be able to change if new data appear and in comparison to the "old" data. The theory should adapt to the changing world. The theoretical model shows a pattern of "Inter-adapting" and might change with different care contexts and individuals, if new research is performed. Through modifiability the theory can stay relevant and work as a model for line of thought for caregivers who are working with mothers experiencing a threat of preterm birth. The limitation in Paper II could be that there are fewer fathers than mothers that participated in the interviews, but the fathers should not be seen as a separate group in the analysis. The fathers'

interviews are a part of the whole data material of 27 interviews and appeared in the end of the analysis.

Validity

Paper III and IV

Validity is when an instrument measures what it is supposed to be measuring [98 p 328]. Face and content validity is assessed by experts and grounded in their judgements according to Polit and Beck [98] and is carried out before data collection. *Content validity* means that the scale had enough items and covers the domain under investigation. *Face validity* could increase the acceptance of the questionnaire by those who will use it [105]. Content validity was carried out by a group of experts to evaluate if the questions were representative for the area under study. Face validity was carried out by midwives to see if the questionnaire appeared to measure what it was constructed to measure, if they understood the purpose of the statements. A few changes were made to clarify some questions.

External factors, which could affect the outcomes, could be that the midwives in our study filled out the questionnaire at their department or in their homes. To complete the questionnaire at the department could have disturbed them if it was a stressful time. In this case it should not be a problem as their working place was familiar to them. The time delay for two units due to reorganisation, could affect the outcome as the midwives completed the questionnaire at different times, but as there were no major changes in the clinical practice during this timespan it was not considered to be a problem. When the results from the midwives from these two hospitals were compared with the results from midwives at the other 11 hospitals, no major differences could be seen. Concerning communication to the respondents, all midwives had been given the same written information and the specific information to all local co-ordinators, regarding distribution of the questionnaire. Mail and 'phone contact was available for the local co-ordinators if necessary.

Statistical power can be achieved if a sufficiently large sample is used. The response rate for some unit was low but in total 259 questionnaires were returned (51%), the latter at the lower limit which is acceptable in a study with a cross-sectional design, according to Altman [97]. As the respondents were anonymous no reminders was possible, which could have decreased the sample size. Although, a significant difference appeared between the sub-groups, which indicate a sufficient sample, and should therefore be acceptable for this cross-sectional study [97, 98].

Some respondents might not choose from the alternatives given in the questionnaire because it does not reflect their opinions. This could be seen in the proportion of missing answers. For the questions about "managing preterm labour and birth" the statement "perform CS due to preterm labour" had a higher proportion of missing answers, 15.1%–16.2% (Paper III). Missing answers for the questions about "information", two statements concerning, "possibility for the baby's survival" and the

“risk of disability” had a higher proportion of missing answers, 28.6% and 32% (Paper III). In the open comments by the midwives, they expressed the opinion that, in these two statements, it was the responsibility of the neonatologists to inform the woman.

In Paper IV a higher proportion of missing answers were found concerning four statements; “tell the woman that her life may be in danger too” (16.2%), “proceed with CS” (17.4%) [refusal of emergency CS], “fear of vaginal delivery” (16.2%) and “the patient is a colleague” (18.9%) [request for CS] (Paper IV).

Reliability

Paper III and IV

Reliability is the consistency with which an instrument measures the attribute [98 p 324]. The less variation an instrument produces the higher is its reliability. One approach is the aspect of *stability*. It means to what extent the same results could be produced if it is used with the same persons but on another occasion. This could be made by test-retest reliability. Test-retest was not performed in this study, as parts of the questionnaire had been used successfully in previous studies [27, 38]. Test-retest could have a limitation especially when the questionnaire is measuring attitudes. The changes that might appear could be changes over time and do not have to depend on the questionnaire’s stability. Another approach to test is internal consistency and can be used if all categories and items in the questionnaire are measuring the same aspects. This is often done with Chron-Bach’s alpha [97, 98, 105]. Chron-Bach’s Alpha is not suitable for this questionnaire as not all the categories are measuring the same aspects. The questionnaire consisted of different parts. Internal consistency was tested for the different parts separately. For the items in Paper III Chron-Bach’s alpha was for questions about “Preterm labour and birth”, 0.94 and for the questions about “Information to the parents”, 0.56. For the items analysed in Paper IV Chron-Bach’s alpha was for the question “Refusal of CS”, 0.40 and for questions concerning “request for CS”, 0.85. Chron-bach’s Alpha has a range of values between 0.00 – 1.00, the higher reliability coefficient the higher internal consistent [97, 98, 105].

The findings might not be representatvie for all midwives in Sweden, but the findings reflect the attitudes of midwives at both UHs and GHs and from different parts of the country at the time for the data collection. When comparing the attitudes of the midwives with those of the obstetricians in relation to extreme preterm birth, it is important to consider the time span between the two data collections. As there were no major changes in the units or perinatal care during the time for the data collection this should not be a major problem. Though, it is always difficult to know if differences that appear are related to change of attitudes over time, or a difference in the attitudes themselves [97, 98]. Those important issues that could be considered to have an impact on the attitudes of midwives and obstetricians, the study of the EXPRESS group [51] concerning extreme preterm birth and the change of limit for a child (22 GW) [44], both appeared after the data collection of Paper III and IV.

General discussion

Decision-making and the autonomy of the woman

To avoid maternal-fetal conflict, the obstetrician (Paper I) invited the mother/parents to participate in the decision-making process, concerning the treatment for both mother and fetus. The obstetricians felt that they, and the women, were in agreement most of the time. This was also revealed in the study of preterm birth (Paper II), where the mothers agreed with the obstetrician as long as it did not go against their own desires about the care given to them or their baby. With respect to the woman's autonomy, the obstetricians (Paper I) wanted the parents' informed consent and the way to achieve this was to have an ongoing dialogue with the mother and her partner. They hoped to achieve a satisfactory outcome for both the mother and her infant. The obstetricians had points of view concerning their moral obligations to the fetus, especially when the mother refused intervention. To avoid maternal-fetal conflict the obstetricians needed to balance the best for the fetus and the mother's autonomy. Chervenak & McCollough [28] support this and point out that, to prevent conflict between the obstetrician's recommendation and the woman's decision in critical situations, an open dialogue throughout the pregnancy is an advantage. A sense of moral obligation both to the mother and her baby is important [1].

When the mother refused intervention, the obstetrician (Paper I) felt frustrated by not being able to carry out the treatment required for the fetus. In these cases, as Gyamfi et al. [107] recommended, it is of the outmost importance that the woman is well informed and has fully understood the matter of refusal and eventual consequences for both herself and for her baby. According to Harrison et al. [20] the mothers could, during the decision-making process, be active, be passively trusting or be satisfied if the care is congruent with their own values and wishes. The fathers (Paper II) trusted the caregivers and often left the decision-making to the doctors and the mother. Both parents felt that participating in decision-making decreased their fear and increased their feelings of control and trust, according to Jackson et al. [73]. The fathers appreciated communication in an honest manner and both parents felt that they were given sufficient information (Paper II). When maternal/fetal conflicts existed, it was a hard time for the obstetricians to make such difficult decisions and it created an emotional strain (Paper I).

When a woman refuses an emergency CS for fetal distress, the findings revealed that the midwives (Paper IV) felt that the obstetricians should try to persuade the woman to undergo CS. The obstetricians in Sweden would accept the woman's wish [27] to a greater extent than midwives. The reason to support the woman's wish was mostly out of respect of the woman's autonomy for both midwives (Paper IV) and obstetricians [27]. This could be an ethical dilemma for the midwives and obstetricians. As there is no law to enforce CS [5] obstetricians would try to persuade the woman to undergo CS [27] for the sake of the health of her baby. It has been argued if forced CS could be indicated when the lack of treatment would harm the fetus [2, 6, 7, 16, 24, 28, 29]. Informal opinions could be that some physicians do support this possibility. Those who believed in sanctity of life supported forced CS but those who believed in patient

autonomy did not, according to Wieneger [24]. These informal opinions do not have legal basis. The frustration of the obstetricians in these ethically difficult situations, not being able to perform an intervention to save the life of the fetus, could evoke the discussion of forced CS.

This is also argued by Draper [6] and Lyng et al., [29] in case reports about women who refused the recommended emergency CS for fetal reasons. In two cases by Lyng et al. [29] the women refused and their babies were still born. In a third case the woman was persuaded to undergo CS and the baby was born healthy. A fourth case illustrated another situation; the woman refused and the baby was healthy born anyway. Draper [6] argued that when the woman has agreed to take her baby to term she also has obligation to the unborn baby and to consent to interventions which make it possible to carry the baby to term and to be born healthy. As the baby is contained within the woman's body, no interventions can be done without the woman's consent [6]. The woman's right to decide what happens to her body is against the argument of forced CS for the benefit of her unborn baby. The woman might decide that the risks to her own well-being are not worth taking even if the intervention should be of benefit for her baby [2]. To preserve fetal life, in case of fetal distress, it might be justified to over ride maternal autonomy. Though in such cases the obstetrician is required, together with the midwife, to persuade the woman (Paper IV) and inform her about the necessity of the CS and its benefit for her baby [2]. The concept of the fetus as a patient has been argued by Chervenak & McCullough [28] and Pinkerton & Finnerty [7]. The fetus is a patient when the fetus is presented to the obstetrician and when the interventions are expected to do more good than harm for the fetus in the future. Viability and the woman's autonomy are important when presenting the fetus as a patient. The pregnant woman can withhold or consent the status of the fetus of being a patient according to her own values and beliefs. These conflicts might be prevented through informed consent and an ongoing dialogue throughout the pregnancy and with respectful /sympathetic persuasion (Paper I, IV). One solution might be to let two obstetricians take part in the decision of CS as suggested by Lyng et al. [29].

When a woman requests a CS (Paper IV) without medical reasons, the attitudes of midwives were that the obstetricians should comply with the request if any previous maternal or fetal complications existed. This is supported by Bettes et al. [37] and Habiba et al. [38]. In this situation the midwives and obstetricians respect the autonomy of the woman and expect the outcome to be of benefit for both the woman and her baby. If the only reason was "her choice" or if the woman was a colleague, the attitudes of the midwives were that obstetricians should not accept the woman's request at the same extent. A healthy woman and baby might not benefit of the intervention of a CS as both maternal and fetal complications might occur as shown by Declercq et al. [31] and MacDoman et al. [32]. It has been argued that the woman's choice of mode of delivery has increased the rate of CS and that professionals' attitudes are that the women often are very well-prepared and argue for their right to CS [34]. The attitudes of midwives and obstetricians and as well as their own personal preferences, influence the willingness to accept a woman's request for CS, according

to studies from Denmark, Sweden and the USA [30, 34, 37, 39, 40]. The most frequent reason for accepting the woman's wish is out of respect for her autonomy [38].

Women are not always willing to use their autonomy, when it comes to deciding mode of delivery. According to Hildingsson et al. [33], only a minority of the women preferred a planned CS. In a recently conducted longitudinal cohort study by Kingdon et al. [10] in the UK, women's views towards decision-making concerning the choice of vaginal or cesarean delivery were explored. This study use both quantitative and qualitative approaches. Of 397 women only 3% preferred to give birth with planned CS. The preference for planned CS did decline later in the pregnancy to 2%. The safety of their baby as well as their own safety and recovery were important to the women. Many of the women believed that their right to choose mode of delivery should be overridden by professionals if necessary. In the interviews the women talked about how they got to know about vaginal and cesarean birth during the pregnancy. Information from different sources, including friends and family as well as professional, influenced them to varying degrees and during different points in time. This highlights the importance of informed choice to reach an informed decision, stated by Chervenak & McCullough, [2, 16, 28]. It has also been shown by Halvorsen et al. [36], that a coping attitude in counselling women with fear of birth could decrease the request for planned CS to favour for vaginal birth. Even if the women preferred a vaginal birth they were aware of that CS would be more preferable in certain circumstances [10]. In interviews none of the women thought that they could request a CS and personal preferences were secondary. Decision-making regarding mode of delivery should be entrusted to midwives and obstetricians. To express a preference for mode of delivery was seen to be difficult and not desirable. The attitudes of the women are supported by midwives who try to maintain the natural process of birth even when complications occur [42, 78-80].

Concern for the fetus/infant

The obstetricians' concern for the fetus/infant made them balance their moral obligation to the fetus against the autonomy of the woman (Paper I, IV) also described in Chervenak & McCullough [2, 16, 28], Draper, [6] Pinkerton & Finnerty [7] and Lyng et al. (29). They were feeling decisive, though uncertain, about taking action after a difficult decision had been made (Paper I). When midwives thought that the obstetrician should persuade the woman to undergo CS they do this probably for the sake of the baby's health. For the same reason they do not comply with the request for CS without a medical indication (Paper IV). Concern for the fetus, as well as for the mother, created emotional feelings such as guilt, loneliness and dissatisfaction (Paper I). The obstetricians tried, through reflecting over the situation, to reach rational acceptance. As the obstetricians could not know beforehand the consequences of their actions they hoped, they had made the right decision. This was the predominant ethical dilemma (Paper I). The concern about the fetus/infant was an issue they shared with the mothers and fathers in the study of threat of preterm birth (Paper II). Parents concern about their infant has also been described by Padden & Glenn, [63], Erlandsson et al. [71], Jackson et al. [73] and Lindberg et al. [75].

The parents' concern for the fetus was very obvious and it was this that made the women accept and adapt to hospitalization. "Inter-adapting" between the actors made them re-organize home responsibilities and together they could make the situation manageable. The social network woven around the mother was important while dealing with the threat of preterm birth. This finding is supported by Mu [60] who found that the women accepted restrictions to protect their fetus. According to Sittner [108] the family used a great deal of strength to manage the stress and the critical situation. There was a sense of commitment to the fetus and the family. The caregivers should be aware of these strengths to enable them to help the family to function and to empower them. After the preterm birth, the parents, (Paper II) needed contact with the infant as soon as possible. Mostly it was the fathers that got the first physical contact and the mothers had to wait until the birth process was completed, irrespective of mode of delivery. The separation from the infant in these cases was experienced as a strain by the woman. Both parents felt it important to have the infant close, outside the incubator, when possible. It has been shown that mothers of preterm infants are more controlling than mothers of full term infants and that the interaction with the infant can be delayed over time. Therefore it is important to encourage interaction as soon as possible [63, 71-73].

Active management of very/extremely preterm labour and birth

In some cases, the obstetricians' narratives were about a threat of extreme preterm birth and the obstetrician experienced this as a very difficult predicament e.g. to let the pregnancy proceed (disadvantage for the mother) or to bring it to an end (with the risk that the fetus would not survive) (Paper I). The fear of harming the fetus/infant was obvious and as each situation was unique there were no guidelines to follow. Garel et al. [109] found that decisions are often made individually, from case to case, although criteria existed for determining management. To take care of "infants on the border of viability" gave the caregivers a feeling of moral stress; as shown by Hefferman and Heilig [110].

The findings revealed that midwives at UHs seem to be more willing to agree to start interventions at an earlier GA than midwives at GHs and obstetricians agreed to take action at an earlier GA than midwives in general (Paper III).

For active management to be successful, access to NICU at a level III hospital e.g. UHs is necessary [3, 16]. This indicates that the woman and the fetus/infant will be transferred to a UH if their home hospital is a GH. This is preferable before birth, and midwives thought this to be indicated at 23 GW (Paper III). This was congruent with obstetricians from Sweden, but in the study from the UK by Chan et al. [56] obstetricians and midwives were more likely to agree to transfer in utero out of their hospital at a later GA, 24-26 GW. According to Pignotti and Donzelli [55], obstetricians would agree to maternal transfer at 24-25 GW. It has been shown that care at hospitals with NICU is a benefit for the infant's survival and morbidity [49, 51, 54]. The fetal benefit from maternal hospitalization which could include bed-rest, CTG monitoring, tocolytics, steroid prophylaxis and at delivery, CS could be required.

To achieve optimal outcome for the baby it is necessary that the woman participates in the plan of obstetric care [2, 49, 51, 54].

It might be difficult for the parents to change environment in this critical situation if they have to be transferred to another hospital (Paper II and III). As the father-to-be wants to be close to his woman and after birth, to his baby, a hospital far away from their home could be a strain and an economical burden (Paper II). The parents wanted to feel affinity in the family during this stressful situation. Separation from the family was one of the most stressful issues for the mothers, especially if younger children were at home. If the mothers felt that the family was functioning as usual, they also felt calmer. If the family did not function, e.g. had problems with the relationship, the mothers felt more stressed. In spite of the crisis, the parents tried to have some enjoyable time together as shown by Mu [60]. Coster-Schultz & Mackey [64] showed that the women in their study tried to balance their life, while hospitalized for preterm labour. This equation consisted of the best for the fetus/infant versus the needs of the family. They also appreciated the concern offered by their partner and significant others. The fathers (Paper II) often had a heavy workload as they had to divide their energy between the hospital and the children (if any) at home. After reorganizing the family they had to take full responsibility for this and continue their work for financial reasons. Similar results have been revealed in studies from other countries like Canada and USA [12-14, 64] especially concerning the need for support from significant others for both the parents but also the mothers need for support from her partner.

As it is important to prolonge the time the fetus is in uteri, tocolytics are given when preterm labour occurs [3, 51]. This gives an opportunity to administrate steroid prophylaxis for maturation of the fetal lungs. Midwives (and obstetricians) (Paper III) would agree to administrate steroids at 23 GW. According to Chan et al. [56] obstetricians and midwives would agree to administrate steroids at a later GA, 24-26 GW. Pignotti and Donzelli [55] found that steroid prophylaxis was mostly administrated at 24-26 GW. Steroids were rarely administrated at 22 GW but more frequently at 23- 26 GW, according to EXPRESS group [51]. CS for fetal distress as reported by the midwives (Paper III) would be indicated at 25 GW and while the obstetricians stated at 24 GW. Chan et al. [56] and Pignottii and Donzelli [55] suggest CS for fetal reasons at 25-26 GW. Express group found that obstetricians would perform CS from 24 GW [51]. Midwives and obstetricians in Sweden were more likely to start interventions at an earlier GA. The differences between the countries might be due to cultural factors and the organisation of perinatal care in the different countries [38].

According to Garel et al. [109] when caring for women experiencing extreme preterm labour and birth the midwives worried about the long-term outcome for the children. They pointed out that the consequences for the whole family not always was taken in enough consideration. Criteria for determining active mangement varied from 24–27 GW, but even if criteria existed in their unit, decisions were often made case-by-case. In order to take part in the decsion-making the parents need to be adequatly informed but midwives thought that the parents were not given enough information

and not sufficiently listen to [109]. It is important for caregivers to know about new evidence concerning long-term consequences for extremely preterm infants

A prospective long-term follow-up study of a cohort, of very low birth weight children when they were 20 years old, has been conducted. They were investigated regarding self-perceived health, quality of life, educational level and occupation [111]. It was found that the young adults considered their health and way of living to be similar to that of the control group and they had similar educational levels and occupations, although a subgroup that were handicapped thought that this influenced their physical function [111]. Being aware of this might help when informing and making decisions together with the parents.

Information and co-operation

Communication between colleagues, midwives and the parents was of utmost importance to the obstetricians (Paper I). Co-operation with the midwife, who was caring for the woman, was a desirable necessity. Interaction was needed between the professional groups involved, as well as between the obstetrician and the parents. If the staff, who were not involved in the actual case, had different opinions about the treatment, it could disturb the decision-making process. With the aid of good communication a consensus about the treatment could be reached. The obstetricians did not always have the support they wished for from colleagues or midwives during and after the situation. They wished for the support that well functioning teamwork could give. A previous study has shown that when midwives were handling acute obstetric situations, team work was the most important aspect when striving towards the same goal, the best for the mother and fetus/ infant [19]. If the obstetricians did not listen to or trust the midwife and her judgement, it created a feeling of great frustration for her.

The parents' dialogue with the caregivers about the treatment concerning the mother or their baby, decreased the fear and anxiety felt by the parents (Paper II). Information that was given to the mother, when she was admitted to the perinatal ward, could sometimes be experienced as too much and it could take a few days before the mother understood the information. Zupancic et al. [112] found that the concordance between the parents' and the doctors' recall of discussions concerning complications during pregnancy and neonatal outcomes, showed that the agreement was higher for obstetricians and parents than neonatologists and parents. Mothers, who had a high level of anxiety, were less likely to agree with the doctors' recall of what information had been given, as were the parents with previous experience of preterm birth. The women felt that the information should be consistent and that the professionals should give the same information according to Barlow et al. [69]. They could also have a feeling of not being believed or listened to. When seeking an understanding and a cause for the preterm labour, the women connected the labour with e.g. high level of daily stress. In this situation the women appreciated support from significant others and information from other women who had experienced the same situation. The women did not feel prepared for labour and birth. This might be due to lack of information during pregnancy.

The findings (Paper III) highlight that the information that should be given to a lesser extent according to the attitudes of midwives and obstetricians, was the information about; estimated survival probability (in percent); estimated probability of handicap (in percent); type of assistance baby will receive at birth and if gestational age is < 25 weeks: possibility of withholding resuscitation. Obstetricians were significantly less willing to disclose information of these issues. This could be due to concern about the parents, not wanting to worry them. Midwives' willingness to disclose this information that could be a heavy burden for the parents might be for their concern to invite the parents into the decision-making process. To make decisions the parents have to be well informed as stated by several authors [2–4, 16].

Behruzi [80], has highlighted the importance of the information flow in high risk pregnancies. Of utmost importance was how the woman was prepared for the interventions. It is important to listen to the woman and her family to find out what is the best for them. High-risk pregnancy creates stress for the professionals, which could lead to an increase in the number of interventions, negative feelings in the situation and increase the woman's anxiety. The woman is less involved in the decision-making process in high-risk pregnancy because of lack of time. Often decisions are made quickly. There is a fear of litigation and this could lead to unnecessary tests and procedures and also too much information to the woman. The midwife's lack of responsibility during high-risk pregnancy was the main barrier to implement humanised birth. The midwife should help the woman to make an informed choice, not influence her decision. The midwife must understand the woman's feelings and beliefs and respond appropriately to them. Caring and listening are two important concepts in this process. To create a relaxing environment during labour and birth, in the delivery room, could decrease anxiety.

Co-operation and communication between the obstetrician and midwife might facilitate the management and decision-making concerning extreme preterm labour and birth or when cases about conflict of interest occur (Paper III – IV). The role of the midwife in critical situations is to gather the team and it is a benefit for the woman and her baby that team-work functions [19]. In complicated pregnancy and birth the midwife tries to maintain the normal process of childbirth and integrate the medical care [78–80]. In these situations the midwife uses her theoretical knowledge, intuition gained by experience and available resources (both staff and material) [79].

According to Larsson et al. [81] midwifery has changed during the last 20-25 years. During interviews, midwives expressed that communication with doctors had improved and that they often reached a decision that was acceptable for both of them. A great deal of medical technology (e.g. ultrasound/Doppler) has replaced the sole judgement of the midwife and has changed the midwife's responsibility, decision-making and power. There are also more female obstetricians now and more obstetricians that increasingly take part in the care of the woman. The midwives felt that they did not consult each other as much as they used to as there were other professionals around to turn to. Some tasks that used to be the task of midwives had been taken over by other professionals. Auxiliary nurses collaborate closely with the

midwives and have often taken over the initial care of the newborn baby. The neonatologist now does the examination of the newborn. The midwives felt that the midwifery research had given them better tools in discussions with obstetricians. Research was felt to be of strength for the profession and increased the self-esteem of the midwives. The midwives felt that it was important to impart their knowledge and skills to the new generation of colleagues.

Relational ethics and reflections on the findings

It has been argued that ethical issues in perinatal care often are discussed in the term of principles of ethics [2-4, 6, 7, 16, 24, 28, 29]. Relational ethics could facilitate the ongoing dialogue between the woman and the professionals involved in her care. I will reflect upon the findings of this thesis in the terms of relational ethics and its four components inspired by Bergum and Dossester [85], Austin, [83, 84] and the philosophy of Lögstrup [82].

The obstetrician had a feeling of sympathetic responsibility in the encounter with the woman (Paper I). This implies that the obstetrician took the needs and requests of the woman into account and tried to make a choice for the best outcome for the woman and her baby; the ethical demand of caring. Although the obstetricians had power with their medical and obstetric knowledge, they made a decision with respect for the women's autonomy. The woman was vulnerable and her ethical demand was unspoken and silent as her needs and requests were interpreted by the obstetrician. There was change in the relationship when the woman refused intervention and the obstetrician could not give suitable treatment (Paper IV). Then the woman had the power and the obstetrician was vulnerable, in the meaning that he/she could not perform the treatment his/her medical knowledge and moral responsibility required [82, 85].

When a woman refuses an emergency CS, the midwife felt that obstetrician should persuade her to accept the recommended intervention, for the wellbeing of her baby (Paper IV). In this way the caregivers can get the power back and if the woman accepts the trust the caregivers offer, they can perform an emergency CS and do what they think is best for the woman and her baby. When a woman requests a CS without any medical indications, she has voiced a demand and wish. The obstetricians and midwives do not find this to be the best for her or her baby, unless she had previous maternal or fetal complications. In these situations the woman does not accept the trust that the obstetricians and the midwives are showing, thus leading to mistrust. The mistrust makes a disturbance in the encounter and an ethical difficult situation might occur. Management of very/extremely preterm labour and birth make the woman vulnerable as she often is in shock and has a fear for her baby's health (Paper II). She needs help and guidance as well as consistent information to make an informed choice. There is a need for the woman to trust the obstetricians and midwives, but the woman also wants to be involved in the care and treatment [82, 85].

The four components in relational ethics

Mutual respect is to be respectful to self and to others. The midwife has to respect the woman and the woman has to respect the midwife during the process of childbirth. There is an inter-dependence in the relationship. In the midwives' and obstetricians' relation to parents, colleagues and neonatologists, mutual respect, communication and a genuine dialogue are very important (Paper I, II). As the actors (mother, father, caregivers and significant others), are dependent on each other in a situation of threat of preterm birth, they have to show mutual respect to one another. Inter-adapting was interpreted as a mutual adaption between the actors involved in the situation. to be able to handle it. Within the team mutual respect is of utmost importance. Often it is the midwife who co-ordinates the team. This involves conducting and assisting all members in the team to work in collaboration. The team work has to function to achieve the best outcome for the woman and her baby (Paper I, II). In a conflict of interests it is again of utmost importance that the obstetrician and midwife have the same goal for the care of the woman and her baby, although, sometimes they could have different opinion about the care (Paper IV). They have to accept each other and co-operate while at the same time they have to respect the woman's wishes. Experiencing preterm labour and birth include a trust in the caregiver on behalf of the parents (Paper II, III). The midwife and obstetrician are taking actions for the baby in the case of active management, if that is the parents' wish (Paper III). The same applies if there is a conflict of interest (Paper IV). With theoretical knowledge and practical experience the midwife can use her power in emergency cases for the health of the mother and her baby in e.g. being very firm and determine in her acting [83–85].

The component *engagement* is shown in practical actions as when the midwives thought of the best for the woman and her baby and also wished that the obstetrician should try to persuade the woman to accept the recommended CS, as this might save her baby's life (Paper IV). For the same reason they do not comply for the woman's request for CS for non medical reasons, as an operation should have a clear medical indication and is always a risk in itself. When threat of preterm birth occurred, the father-to-be wanted to be close to his woman (Paper II). There was a genuine relationship and they were engaged in the situation. It was important for the woman to feel that the caregivers and her partner were there for her, present in an authentic way, here and now. Engagement for the midwife means to be with the woman, listen to her and have time for her. Engagement might give meaningfulness to a tragic experience in a way each one could only find out for themselves. To care for the "whole" woman the caregivers have to think about the woman's wellbeing and consider her needs and requests. When caring for women with threat of extreme perterm labour and birth (Paper II, III) and for extreme preterm infants, technology could disturbe in that way, that the caregivers focus to much on the equipments and loss focus on the parents. The dialogue might be more between the caregivers trying to solve problems instead of a genuine dialogue with the parents [83-85].

Embodiment requires that the whole person-model should be represented. Body/action means, the midwives and obstetricians want to take action for the sake of the baby's well-being (Paper III, IV). Mind/reason means that the midwife/obstetrician wants a

dialogue and discussion with the woman about the different options available and does not accept the woman's autonomy without reasoning with her (Paper I, IV). Heart/feeling means that the caregivers try to take the woman's wishes in account and let her take part in the decision-making (Paper I, II) that might increase her feeling of control in the situation. If the woman has a strong fear of giving birth this should be acknowledged and respected (Paper IV). Spirit/vision implies that religious aspects should be respected if they occur. Even values that are important for the woman should be taken into account [83-85].

The *environment* is changeable and as we are the environment it is changing all the time. It is in the environment the ethical reflections take place. It is important in the environment of healthcare practice that this aspect is supported and valued. If the woman is hospitalized she experiences routines which are unknown to her and she must accept (Paper II). This might influence her wellbeing in that way that she might for example, feel lonely. Although the environment is familiar to the caregivers, the environment must be a place for moral action so they do not feel moral distress (Paper I). The woman is vulnerable in the hospital and is dependant on the caregivers, the routines, the organisation and possible guidelines at the unit (Paper II). These should allow an open atmosphere for ethical discussions within the own professional group and between other professions. The parents have to change their environment as they suddenly have to go from their home and /or work to the hospital when the woman is hospitalized. The environment must allow flexibility for the family to be together as the father felt the he had a moral obligation to the woman and their infant. As we are the environment it is we who create it and can make it function to the best for the parents. The units have often guidelines for management of very/extremely preterm birth, which might be a help for both parents and professionals in the decision-making process, although most decisions are made on an individual basis. For some women this can mean transfer to a UH as the care of infants < 28 gestational weeks are centralised to UH (Paper III). This could be an emotional strain for the parents, create inconvenience for the family, although it is the best for the baby [83-85].

CONCLUSIONS

The thesis revealed that, sympathetic responsibility in the encounter with the parents was the overall theme of the obstetricians' experience of being in an ethical predicament (Paper I). The obstetricians were able to see the unique in each situation and often reach a solution acceptable for all parties. Concern for the best outcome for the fetus/infant and respect for the woman's autonomy was important to the obstetrician during the decision-making process. Good communication with colleagues, midwives and the parents was important for the obstetricians to get information about the case so as be able to reach a solution. Due to the parents' concern for the fetus/infant they accepted hospitalization and the restrictions this involved for the mother (Paper II). The parents interacted and communicated with the caregivers, family members and significant others in order to handle the situation and to enable the family to function. Partaking in decision-making of the treatment for the

mother and the care of the infant made the parents feel they had some control over the situation. Information was given from the caregivers and made it possible for the parents to make an informed choice about care. It was very important for the parents to reach out, touch and interact with the infant as soon as possible after the preterm birth. The concept “Inter-adapting” emerged and the theoretical model was developed.

Midwives’ experiences of handling preterm birth at 21-28 GW, leads to a positive attitude to start interventions at an earlier gestational age compared to midwives without such experience (Paper III). Information that midwives regularly want to give the parents was about the baby’s well-being, prognosis, treatment and transfer to NICU as well as the mode of delivery. The difference between midwives at UHs and GHs in relation to the experience of management of very/extremely preterm labour and birth is probably due to the fact that the handling of preterm birth (< 28 GW) is centralised to university hospitals in Sweden. Obstetricians seemed to be more willing to take action at an earlier GA than midwives. Though, midwives would disclose information about severe outcomes (in percent) to a greater extent than obstetricians. The midwives thought (Paper IV) that the obstetrician should try to persuade the woman to comply with the obstetrician’s decision if she refused an emergency CS; this for her beneficence obligation to the baby. If the woman’s request for a CS was “her own choice” with no medical indications, the midwives thought that the obstetrician should not comply. On the contrary, if the woman had previous complications during childbirth they thought the obstetrician should agree with the woman’s wish. The midwives’ obligation to the health of baby and to the woman’s autonomy and their wish to steer the labour and birth towards a process as natural as possible, requires good communication and a trustful relationship between the woman and her midwife.

Implications for practice

Formal inter-professional meetings, to discuss cases and the feelings which could occur in work with ethically difficult obstetric predicaments, could support and empower the caregivers. This could lead to a deeper understanding between colleagues and different professions and could, in a larger perspective, benefit future care. To decrease the feeling of separation and to strengthen the family during the critical situation of preterm labour and birth, good co-operation and organization between the relevant wards involved, is of importance. A family nursing focus on the care during the threat of preterm birth is preferable and could be achieved by mapping out the woman’s network. To know her social possibilities and to give the fathers and significant others social and psychological support, could help the family to function. This could facilitate the family’s wellbeing during the hospital stay. Good forms of communication between the parents and the caregivers and co-operation between the professionals can lead to optimal care for mother and fetus/infant. If “Inter-adapting” occurs between the actors involved, it could enable the family to function and to manage the situation with less stress and strain. More communication and exchange of knowledge between general and university hospitals might benefit the management of very/extremely preterm labour and birth. Guidelines for management of this situation

could be a help in the decision-making process for professionals. Inter- professional courses concerning ethical issues related to authentic cases and relational ethics and its four components (mutual respect, engagement, embodiment and environment) might increase the understanding of ethics in the daily work of perinatal care.

FUTURE PERSPECTIVES

The findings in this thesis awaken interest to:

- Investigate midwives experiences of ethically difficult situations through interviews and compare these with the findings in Paper I.
- Through interviews, gain more insight and knowledge about fathers' experiences of complicated pregnancy and birth.
- Capture a larger perspective of parents' experiences of threat of preterm birth by developing a specific questionnaire from the theoretical model. This could later be tested on parents in a pilot study and further on, in a larger population.
- With an intervention program, test the value of inter-professional meetings concerning the ethically difficult obstetric situations they encounter.
- To interview midwives and obstetricians together in focus groups. Using authentic cases, their ethical decision-making could be discussed, which would deepen understanding of ethically difficult situations in perinatal care.

SUMMARY IN SWEDISH

(Decision-making in critical situations during pregnancy and birth)

Beslutsfattande i kritiska situationer under graviditet och förlossning

Etiska frågor uppstår ofta inom obstetrikern och kräver konstant övervägande av läkaren som är involverad i fallet. Det krävs att kunna balansera fostrets välbefinnande med kvinnans autonomi, för att göra det bästa för båda. Med information, stöd och råd från läkaren, kan kvinnan göra ett realistiskt val som är acceptabelt för både henne själv, barnmorskan och läkaren. I en del fall kan kvinnan och läkaren ha olika uppfattningar, om vilken vård och behandling kvinnan och hennes barn, bör få. Under och efter förlossningen litar föräldrarna ofta på vårdgivarna och vill att de gör allt för att rädda deras barn. Att fatta beslut angående förtidig förlossning är en av de större frågorna inom en förlossningsklinik. Förtidig förlossning (före graviditets vecka 37) är den största orsaken till dödlighet och sjuklighet på både kort och lång sikt för barnet. Det beskrivs i litteraturen att kvinnor kopplar ihop olika händelser i livet med förtidigt värkarbete. Kvinnor som har fött förtidigt har större känsla av oro, ångslan och depression. Vid vård på sjukhus kan kvinnan få en känsla av frustration på grund av rädsla för hur det ska gå med graviditeten och över sin förmåga att fungera som moder, hustru och yrkesarbetande kvinna. Tillgång till ett välfungerande socialt stöd och att ha en partner som stöd minskar risken att föda för tidigt. Fäder är mycket oroliga när deras partner under graviditeten får förtidiga värkar. Efter en förtidig förlossning kan fäder känna sig stressade inför ansvaret för barnet, hemmet och för att vara ett stöd för kvinnan. Det är viktigt att kvinnan och hennes partner får en god information och är med i beslut om behandling och vård. Genom att vara delaktiga stärks kvinnans och hennes partners identitet och självkänsla.

Vid mycket/extremt förtidig förlossning (< 28 graviditetsveckor) har det visat sig att aktivt handläggande har en positiv inverkan på barnets överlevnad och sjuklighet. Aktivt handläggande innebär att kvinnan vårdas på ett universitetssjukhus med möjligheter till neonatal intensiv vård. I Sverige är vård av nyfödda barn i graviditets vecka < 28 centraliserad till sju universitetssjukhus. Detta kan innebära för kvinnan att bli förflyttad från sitt "hemsjukhus" till ett universitets sjukhus. Aktivt handläggande innebär också att värkämmande medel ges för att förlänga graviditeten, i syfte att kunna ge steroider för barnets lungmognad. Vidare är övervakning av fostrets hjärtljud och kejsarsnitt också en del av vården. Inaktiva handläggande kan rekommenderas om prognosen för barnet är mycket dålig, svåra komplikationer förväntas i framtiden samt om det är föräldrarnas önskan.

Ibland kan intressekonflikter uppstå mellan kvinnan och obstetrikern och barnmorskan. I de flesta fall är kvinnan och vårdgivarna överens om vården som rekommenderas. Kvinnan kan, genom att använda sin autonomi, tillstå eller vägra en behandling eller intervention. Hon kan vägra för sin egen del, men också för interventioner som måste göras för barnets skull. Problemet inom obstetrikern är att varje intervention som måste göras för barnets skull måste gå via kvinnans kropp. Det

är mycket ovanligt att kvinnan vägrar ett akut kejsarsnitt och det finns ingen lag i Sverige som säger att man kan påtvinga en rekommenderad intervention, så därför försöker de flesta obstetrikern övertala kvinnan till att acceptera kejsarsnitt om det finns en omedelbar risk för barnet.

En motsatt situation är när kvinnan begär kejsarsnitt utan att det finns någon medicinsk orsak. Det har framkommit att det var vanligare med sårkomplikationer och infektioner för kvinnan den första månaden efter förlossningen, hos kvinnor som genomgått kejsarsnitt utan medicinsk orsak, än för kvinnor som fött vaginalt. Det har också visat sig att den neontala sjukligheten var större hos nyfödda som fötts med kejsarsnitt utan medicinsk orsak än för nyfödda som fötts vaginalt. Den ökade frekvensen av kejsarsnitt (17%) anses bero på att kvinnan begär kejsarsnitt i större utsträckning idag. Dock visar litteraturen att endast ett fåtal kvinnor önskar föda med kejsarsnitt utan föredrar att föda vaginalt. Barnmorskors och obstetrikerns attityder är av betydelse för om man accepterar kvinnans beslut eller inte.

Barnmorskans roll i Sverige är att ansvara för den normala graviditeten och förlossningen. När avvikelser uppstår ska barnmorskan tillkalla expertis, vilket i de flesta fall är obstetrikern. I dessa situationer samarbetar barnmorskan och obstetrikern angående vården av kvinnan. Det medicinska ansvaret och beslutsfattandet vilar på obstetrikern. I de flesta fall är barnmorskan och obstetrikern överens om vården, men i ibland kan de ha olika åsikter. Barnmorskan strävar efter att födandet ska vara en naturlig process och etablerar en god kontakt med kvinnan och hennes partner. Barnmorskan stöder kvinnans rätt till autonomi och uppmuntrar henne att delta i beslutsfattande i vården. Beslutsfattande inom obstetrikern kräver en interaktion och relation mellan föräldrarna och de professionella. Relationsetik som har fokus på mötet och relationen mellan människor kan användas i beslutsfattandet i verksamheten.

Kritiska situationer under graviditet och förlossning är svåra områden såväl för obstetrikern och barnmorskor som för föräldrarna. Det är därför viktigt att få en djupare förståelse av deras upplevelser och attityder.

Det övergripande syftet för avhandlingen var att beskriva obstetrikerns och föräldrarnas upplevelse samt barnmorskors attityder i samband med kritiska situationer under graviditet och förlossning. De specifika syftena för studierna var att belysa obstetrikerns upplevelse och innebörden av att vara i en etiskt svår obstetrisk situation (Delstudie I); Att få en djupare förståelse av båda föräldrarnas upplevelse och hantering av deras situation, när kvinnan vårdas på sjukhus, för hot om förtidig förlossning (Delstudie II); Att i första hand beskriva barnmorskors attityder till handläggandet av mycket/extremt förtidig förlossning (SWEMID) och i andra hand jämföra barnmorskornas attityder med obstetrikerns attityder (EUROBS) (Delstudie III) och Att beskriva barnmorskors attityder till obstetrikerns beslut i samband med en kvinnas vägran till akut kejsarsnitt och även en kvinnas begäran om kejsarsnitt utan medicinsk indikation (Delstudie IV).

Delstudie 1 hade en kvalitativ ansats och en deskriptiv design. Intervjuer genomfördes med 14 obstetiker. Hermeneutisk-fenomenologisk metod enligt van Manen valdes för att fånga innebörden av att vara i en etiskt svår situation. Delstudie II har en explanatorisk design med Grounded Theory metod. Intervjuer med 23 föräldrar genomfördes. Datainsamling och analys genomfördes samtidigt för att begreppsliggöra föräldrarnas viktigaste problem och hur de hanterade sin situation. Paper III och IV har en kvantitativ ansats och är genomförd som en tvärsnittsstudie, med en deskriptiv design (Delstudie III och IV) och en komparativ design (Delstudie IV). Ett strukturerat och anonymt frågeformulär (SWEMID) distribuerades till 513 barnmorskor på 16 kliniker i Sverige. Klinikcheferna från 13 sjukhus accepterade att delta i studien och 259 barnmorskor besvarade frågeformuläret. En tidigare, liknade studie har utförts med obstetiker i Sverige och sju andra länder i Europa (EUROBS). Data om obstetikererna i Sverige från denna studie användes för att jämföra barnmorskors och obstetikers attityder. Deskriptiv och analytisk statistik har använts för att analysera det kvantitativa materialet.

Den etiskt svåra situationen som obstetikererna berättade om bestod i 9 fall av 17 av hot om förtidig förlossning i v 23-28, ett fall om en svår situation i andra trimestern, sex fall var om förlossning i fullgången tid och ett fall om överburenhet (Delstudie I). Resultatet utmynnande i ett övergripande tema; Medkännande ansvar i livsavgörande beslut för modern och hennes barn samt fem relaterade teman. De fem temana speglar den beslutsprocess som obstetikererna genomgick; "Att föra ett moraliskt resonemang som leder till en möjlig lösning", "Att balansera sin medicinska kunskap och moraliska insikt med kvinnans behov och önsningar", "Att känna sitt medicinska och moraliska ansvar inför beslutet", "Att erfarit handlingskraft i att fatta och genomföra det svåra beslutet för modern och barnets bästa" samt "Att reflektera över situationen vilket leder till förnuftsmässig acceptans av sitt handlande".

Begreppen som framkom om föräldrarnas upplevelse av hotande förtidig förlossning (Delstudie II) var kärnkategorin "Inter-adapting" med följande tre kategorier med sex relaterade underkategorier; "Interagering" ('Kommunicera med de professionella vårdgivarna', 'Hålla ihop familjen under en stressad situation', 'Söka sin inre kraft under förlossningsarbetet'), "Omhulda" ('Acceptera restriktionerna för barnets skull' 'Nå fram till barnet och vara delaktig i vården') och "Omorganisering" ('Arrangera för en ny familjesituation'). Ett nytt begrepp framkom - "Inter-adapting"- och tolkades som en ömsesidig anpassning till varandra, av de aktörer som var involverade i situationen. Den teoretiska modellen "Inter-adapting Till hot om Prematur Börd" ("Inter-adapting to Threat of Preterm Birth") utvecklades.

Barnmorskor på universitetssjukhus var mer benägna att börja med en intervention i tidigare graviditetsveckor än barnmorskor på länsjukhus (Delstudie III). Det fanns en signifikant skillnad vid aktiv handläggande mellan de två undergrupperna, när det gällde att påbörja steroid profylax, fosterljudsövervakning och när man skulle informera neonatologerna. Den viktigaste informationen som barnmorskorna tyckte skulle ges till föräldrarna regelbundet före förlossning var framför allt om barnets välmående och prognos, den behandling barnet skulle få vid födelsen, planerat

förlossningssätt och om överföring till neonatal intensiv vård. Information som inte skulle ges så ofta eller endast om föräldrarna efterfrågade det, var uppskattad födelsevikt, överlevnad (i procent), möjligheten att avstå från återupplivning om barnet var < 25 graviditetsveckor. Barnmorskorna tyckte att obstetrikerna involverade neonatologerna regelbundet och att neonatologerna var så aktiva som de önskade att de skulle vara.

I jämförelsen mellan barnmorskors och obstetrikernas attityder, framkom att obstetrikerna var mer benägna att påbörja en intervention i tidigare gestationsålder än barnmorskor. Detta gällde vid aktivt handläggande angående fosterövervakning och kejsarsnitt då barnet visade på syrebrist. Obstetrikern var mindre benägna än barnmorskorna att delge information om förlossningssätt, uppskattad överlevnad (i procent), uppskattad risk för handikapp (i procent), vilken behandling barnet skulle få vid födelsen och möjligheten att avstå från återupplivning om barnet var < 25 graviditetsveckor.

När en kvinna vägrar ett akut kejsarsnitt tyckte barnmorskorna att obstetrikern skulle övertala kvinnan att acceptera den rekommenderade interventionen (Delstudie IV). Information att barnet kan bli handikappat var viktig att ge. När en kvinna begärde kejsarsnitt utan medicinsk anledning, tyckte barnmorskorna att obstetrikern skulle gå med på kvinnans beslut om det fanns tidigare komplikationer. Om kvinnan hade förlossningsrädsla ansåg hälften av barnmorskorna att obstetrikern skulle följa kvinnans önskan. Om kvinnans enda anledning var hennes eget val, tyckte inte barnmorskorna att obstetrikern skulle acceptera hennes beslut. Om barnmorskorna ville stödja kvinnans beslut så var det av respekt för hennes autonomi. Barnmorskorna på universitetets sjukhus var mindre benägna att acceptera detta.

Slutsatsen från Delstudie I är, att medkännande ansvar var ett genomgående tema för obstetrikerna i deras beslutsfattande i situationen. Kommunikation mellan läkare och föräldrar samt mellan obstetrikern, deras kolleger och annan vårdpersonal är viktig för att nå det bästa för mor och barn. Obstetrikerna kunde erfara emotionell påfrestning före, under men framför allt efter beslutsfattandet och genomförandet av beslutet. Osäkerheten av att inte veta om beslutet var det optimala för mor och barn, kunde ge en känsla av skuld, otillfredsställelse, ensamhet och trötthet. Ett av föräldrarnas problem var deras oro för barnet, vilket gjorde att de accepterade moderns restriktioner och anpassade sig till hennes sjukhusvistelse (Delstudie II). För föräldrarna var det viktigt att hålla samman familjen under sjukhusvistelsen, att få snabb kontakt med det nyfödda barnet, att ha ett fungerande nätverk, att ha god kommunikation med vårdgivarna och att delta i beslut angående vården av modern och barnet. ”Interadaptering” är ett nytt begrepp som vuxit fram i analysen och det innebär att de olika aktörerna anpassar sig till situationen och till varandra.

Barnmorskors erfarenhet av att handlägga förtidig förlossning i graviditetsvecka 21-28 leder till en positiv attityd att påbörja interventioner i tidigare gestationsålder än barnmorskorna som inte har denna erfarenhet (Delstudie III). Skillnaden ligger förmodligen i det faktum att vården av de förtidigt födda barnen (v 21-28) i Sverige är

centraliserad till universitetens sjukhus. Vid jämförelsen med obstetrikernas attityder framkom att obstetrikerna är mer benägna att agera i en tidigare gestationsålder än barnmorskorna. Däremot var barnmorskorna mer benägna att delge information om dåligt utfall (i procent) än vad obstetrikerna var. Barnmorskans fokus verkar vara barnets hälsa och en positiv förlossningsupplevelse för kvinnan och därför accepterar de inte alltid en kvinnas vägran eller önskan av kejsarsnitt (Delstudie IV).

Implikationer för vården kan vara att initiera formella möten med olika professioner för att diskutera fall och de känslor som väcks i arbetet med etiskt svåra obstetriska situationer (Delstudie I). Dessa möten kan fungera som ett stöd för vårdgivarna. Det kan också leda till djupare förståelse mellan kollegor och olika professioner och i ett längre perspektiv en bättre vård för mor och barn. Genom att stärka och stödja kvinnan och hennes partner och ha ett nära samarbete mellan den perinatale vårdkedjan, kan känslan av separation minska för familjen (Delstudie II). Om en ömsesidig anpassning uppstår mellan aktörerna i situationen, kan det innebära att familjen klarar av sin påfrestande situation på ett bättre sätt. Utökad kommunikation och utbyte mellan universitetssjukhus och länssjukhus skulle kunna vara av godo för handläggandet av mycket/extremt förtidig förlossning. Riktlinjer för handläggandet av dessa situationer kan vara en hjälp för vårdgivarna under beslutsfattandet. Inter-professionella kurser med autentiska fall och tillämpning av relationsetik skulle kunna öka förståelsen för etik och beslutsfattande i det vardagliga arbetet inom perinatal vård och omvårdnad.

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