## Linköping University Medical Dissertations No. 939

# **Miscarriage:**Women's Experience and its Cumulative Incidence

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Linköping 2006

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# **ABSTRACT**

Many women experience miscarriage every year. Every fourth woman who has given birth reports that she has previous experience of miscarriage. In a study of all women in the Swedish Medical Birth Register 1983-2003, we found that the number of cases of self reported miscarriage had increased in Sweden during this 21 year period. This increase can be explained by the introduction of sensitive pregnancy tests around 1990, as well as an increase in the mean age of the mothers, by approximately 3 years, during the observation period. The risk of miscarriage is 13% with the first child. With subsequent pregnancies, the risk of miscarriage is 8%, 6% and 4% with the second, third and fourth child, respectively.

Thirteen of these women who had suffered a recent miscarriage were interviewed four months later, and their feelings of guilt and emptiness were explored. Their experience was that they wanted their questions to be answered, and that they wanted others to treat them as the mothers to be that they felt themselves to be. They also experienced the need for time to grieve their loss.

Measurement of grief by means of the Perinatal Grief Scale (PGS) is used in research but has also been proposed for clinical use. We have translated this psychological instrument to Swedish, back-translated and tested it in a small pilot study. In a randomized controlled study, women with early miscarriage were allocated, either to a structured visit (study group) or a regular visit (control group) to a midwife. The structured visit was conducted according to the Swanson caring theory. We could conclude that the structured visit had no significant effect on grief compared to the regular visit, as measured using the PGS. However, women with the sub-diagnosis missed abortion have significantly more grief four months after early miscarriage, regardless of visit type.

We also performed a content analysis of the tape-recorded structured follow-up visit. The code-key used was Bonanno and Kaltman's general grief categorization. Women's expression of grief after miscarriage was found to be very similar to the grief experienced following the death of a relative. Furthermore, the grief was found to be independent of number of children, women's age, or earlier experience of miscarriage.

**Conclusions**: Every fourth woman who gives birth reports that she has also experienced early miscarriage. The experience of these women is that they have suffered a substantial loss and their reaction is grief similar to that experienced following the death of a relative.

*Keywords:* Miscarriage, Grief, Perinatal Grief Scale in Swedish, Follow-up visit to midwife, Medical Birth Register, Spontaneous abortion.

# List of original papers

This thesis is based on the original publication, which are referred to in the text by their Roman numerals I-V.

- Adolfsson A, Larsson P-G. Cumulative incidence of previous spontaneous abortion in Sweden 1983-2003: A register study. *Acta Obstet Gynecol Scand* 2006 In press.
- II. Adolfsson A, Larsson P-G, Wijma B, Berterö C. Guilt and emptiness: Women's experiences of miscarriage. *Health Care Women Int* 2004:25;(6):543-560.
- III. Adolfsson A, Larsson P-G. Translating of the short version of the PerinatalGrief Scale to Swedish. *Scand J Caring Sci.* 2006 In press.
- IV. Adolfsson A, Berterö C, Larsson P-G. Effect of a structured follow-up visit to a midwife on women with early miscarriage: A randomized study. *Acta Obstet Gynecol Scand.* 2006 In press.
- V. Adolfsson A, Larsson P-G. Applicability of general grief theory to Swedish women's experiences after early miscarriage, with factor analysis of Bonanno's taxonomy, using the Perinatal Grief Scale. Submitted.

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# **List of Abbreviations**

# **Abbreviation Definition in this thesis**

α	Alpha
β	Beta
BV	Bacterial Vaginosis
CES-D	Centre for Epidemiological Studies Scale
CI	Confidence interval
FSH	Follicle-stimulating hormone
HADS	Hospital and depression scale
hCG	Human chorionic gonadotrophin
LH	Luteinizing hormone
MVC	Antenatal health care centre (Mödravård-
	scentral)
OR	Odds ratio
PCO	Polycystic ovaries
PGS	The Perinatal Grief Scale
PSE	Present State Examination Scale
PTSD	Post Traumatic Stress Disorder
RR	Relative risk
TSH	Thyroid-stimulating hormone
WHO	World Health Organization

# 1 Background

Miscarriage is a common occurrence in the life cycle of the woman. Exactly how common this experience is, however, is not known exactly. In Sweden about 97,000 children are born every year. Spontaneous abortion (miscarriage) occurs in approximately 15-20% of all known pregnancies (Hemminki & Forssas, 1999; Smith, 1988), which gives a figure of approximately 15,000 each year in Sweden. Legal abortions are more than twice as common as miscarriage (The Swedish National Board of Health and Welfare).

#### 1.1 Definition

Spontaneous abortion and miscarriage are synonymous terms. In the medical literature, spontaneous abortion is most often used, while in clinical practice and among the general population, miscarriage is the preferred term. According to the criteria of the World Health Organization (WHO-1977), spontaneous abortion is defined as the expulsion of an embryo (blighted ova) or extraction of a fetus weighing 500g or less. This fetal weight will normally correspond to a gestational age of 20-22 weeks. An early miscarriage is one that occurs before 12 gestational weeks and a late one between 13 to 22 weeks. In a "complete miscarriage", the products of conception are expelled in their entirety. In "incomplete miscarriage", on the other hand, not all the products of conception are expelled. In a "missed abortion", a pregnancy demise takes place but nothing has yet been expelled, sometimes it is a blighted ovum. The definition of what should be counted as a missed miscarriage (missed abortion) can differ both geographically and historically. Previously, the term missed abortion was used when the mother did not feel any fetal movement, or when lack of growth of the fetus was identified by lack of increase of the symphys/fundus measurement for several weeks. This could mean a long, uncertain wait for the woman. In clinical practice today, a fetus without viability, as seen on the ultrasound examination, is usually diagnosed as being a missed abortion. The woman has often no or only small signs of vaginal bleeding, often with loss of nausea and breast tension (Brody & Frank, 1993; Hart, 2004). Recurrent spontaneous abortion is defined as three or more consecutive pregnancy losses prior to 22 weeks of gestation, usually occurring in approximately the same gestational week (Jablonowska, 2003).

# 1.2 Normal pregnancy

The normal menstrual cycle is 28 days long, with ovulation usually occurring on day fourteen. Implantation of the fertilized zygote occurs 7 days after conception, which is day 21 of the cycle. A normal pregnancy is 40 weeks long (plus or minus two weeks), counted from the date of the last menstruation, which is two weeks longer than the age of the fetus. Gestational age (in Sweden) is today defined from the ultrasonography in weeks and days. Normal time for delivery is from 37+0 to 41+6. The first symptoms of pregnancy are missed menstrual period, nausea and breast tension, upon which the woman usually performs a pregnancy test on the urine.

#### 1.2.1 Pregnancy test

Pregnancy tests are designed to demonstrate the presence of Human Chorionic Gonadotropin (hCG), which is a glycoprotein consisting of two non-covalently linked polypeptides, the alpha ( $\alpha$ ) and beta ( $\beta$ ) subunits. HCG has the same alpha subunit as other hormones, such as follicle stimulating hormone (FSH), Luteinzing hormone (LH) and thyroid stimulating hormone (TSH) (Ganrot et al., 2003; Khan et al., 1989). The  $\beta$ -unit is unique, therefore, the beta subunit of hCG is more specific for diagnosing pregnancy in urine or in blood than the alpha subunit (Khan et al., 1989). In pregnant women, circulation of  $\beta$ -hCG can be detected 21 days after the latest menstruation, i.e. 7 days post conception (Chard, 1992). During pregnancy, gonadotropin is produced from the trophoblast and released into the maternal circulation. hCG's main function is to support the cells in corpus luteum in the production of progesterone during the first weeks of pregnancy thus preventing menstruation (Brody & Frank, 1993; Ganrot et al., 2003).

 $\beta$ -hCG is detected in the pregnancy tests of today using a solid-phase, two-site flouro- immuno assay, in which two monoclonal antibodies are directed against two separate antigenic determinates on the hCG molecule (Chard, 1992), so called Perkin Elmer Delfia hCG (Unipath, 2005). Test stick is dipped into urine or a few drops of urine are dropped onto a membrane. After a few minutes, the answer is positive or negative detection of  $\beta$ -hCG in text or symbols. Often even a check of the test function is indicated on the stick. A positive test is a  $\beta$ -hCG level above a certain level determined by the manufacturer.

On the day of the missed menstrual period, the concentration of  $\beta$ -hCG is 100IU/l in serum. In order to detect pregnancy on this day, a pregnancy test requires a sensitivity of 20 mIU/mL (Cole et al., 2004). The maximum levels can be detected 60 to 80 days post conception (Ganrot et al., 2003) Fig. 1. In a normal pregnancy, hCG doubles every 48 to 72 hours between gestational weeks 4 and 8 (Scott, 2000), Table I.

Table I. β-hCG levels during pregnancy.

B-HCG level mIU/mL	Day	Week
100	23	3.3
250	28	4.0
1000	35	5.0
4000	42	6.0
15000	49	7.0

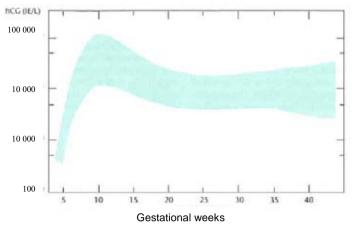


Fig. 1. Normal distribution of hCG during pregnancy.

Home pregnancy testing was introduced in 1975. The first brand analyzed both  $\alpha$  and  $\beta$  subunits, which gave false positive tests at ovulation, due to the LH-peak which has  $\alpha$ -hCG units too. Sensitivity of the first test was around 2000U. Subsequently, when more specific tests were introduced, the level dropped to 500U and it is down to 20U today. Now there are more than 20 brands of home pregnancy test available. These are capable of giving a positive test on the first day following a missed period (Cole et al., 2004).

In the pharmacies in Sweden, there are two brands of home pregnancy test available. The first, Clearblue, is capable of giving a positive test on the day of missed menstruation, the test time is one minute. If the day of last menstruation is not known, the test can be performed 19 days after the latest unprotected sexual intercourse. In the case of a negative test but when the woman has a feeling that she may be pregnant, the test can be repeated after three days, in which case a positive test indicates that the first test may have been carried out too early. The sensitivity is more than 99% (Unipath, 2005). The other brand available is Preg, which has a sensitivity of more than 99% on the day of missed menstruation. Test time is three minutes (Pharma, 2005). At the gynecology clinic at Skaraborg's hospital in Skövde, the urine pregnancy test, Analyz hCG Strip 20IU/l is used. The test time is five minutes and the sensitivity is more than 99% (ANL Produkter, 2004).

Urine Pregnancy tests can give false positive and false negative results. The normal value of  $\beta$ -HCG in non-pregnant women is less than 5 IU/l. For values during pregnancy, see figure 1.

#### 1.2.2 Manual examination

There are several different reasons why women are examined by a physician during early pregnancy, such as routine examination, women's anxiety or symptoms.

## 1.2.3 Ultrasonography

The ultrasound machine sends out high-frequency sound waves, which bounce off body structures and, by means of computer analysis, a picture is created on the screen (Hart, 2005).

Vaginal ultrasound has an internal ultrasonography transducer inserted into the vagina, thus getting closer to the woman's uterus than with the conventional transabdominal technique. The woman is examined while lying in the lithotomy position. The transducer is a long probe, covered with a condom and a lubricant before insertion into the vagina. The physician will move the probe within the vaginal cavity to scan the pelvic structure. The examination is carried out with the bladder empty. There may be mild discomfort from the pressure of the vaginal probe (Hart, 2005). Ultrasound pictures (Fig. 2, Fig. 3, and Fig. 4).



Fig. 2. Fetus CRL 15.9 mm gestational age 8 weeks 0 day.



Fig. 3. Fetus CRL 44 mm gestational age 11 weeks 1 day.



Fig.4 Missed abortion, expected weeks 9.

# 1.3 Miscarriage

# 1.3.1 Epidemiology

Women's experience of miscarriage is obvious and distressing, both psychologically and physiologically. The reported ratio of the number of clinically recognizable miscarriages to the number of known pregnancies in general population studies varies between 12 and 15% (Regan & Rai, 2000). In a Finnish study, a questionnaire was mailed to 3 000 women aged 18-44 years, randomly sampled from the population register. Seventy-three percent of questionnaires were returned completed. The frequency of miscarriage was 13% of recognized pregnancies (Hemminki & Forssas, 1999). A prospective population based register-linked study from Denmark, 1978-1992, included women (n=634 272) from the civil registration register, national discharge register, medical birth register and national register of induced abortion. Of the known pregnancies (n=1 221 546), 13.5% ended in miscarriage (Nybo Andersen et al., 2000). The only published data from Sweden concerning spontaneous abortion are from 1983. The study comprised 521 women and the incidence of miscarriage was 8.7% (Selbing, 1983). In a study by French, a frequency of 23.6% of known pregnancies ending in miscarriage was reported (French & Bierman, 1962; Smith, 1988). Kline reports that 50% of conceived ova will not result in a living child and that 22% of these early losses will occur before the pregnancy has been clinically recognized (Kline et al., 1989; Wilcox et al., 1988).

# 1.3.2 Etiology

The cause of a miscarriage is not usually known. Environmental causes are of different significance and no consensus has been found, despite several studies having been performed. Some risk factors have been identified (Cramer & Wise, 2000). The etiologies of spontaneous miscarriage, as well as of recurrent miscarriage are to some degree the same and to some degree different. Some of the medical causes have a higher incidence in cases of recurrent miscarriage (Hogström, 2002; Jablonowska, 2003). In individual cases, however, it is not possible to say anything about the cause with certainty. Even when all known causes are excluded, the cause in more than the half of cases remains unknown (Cramer & Wise, 2000; Regan & Rai, 2000).

#### Cytogenetic Abnormalities

Cytogenetic abnormalities are a possible cause of miscarriage, especially before nine weeks of gestation, according to Kajii et al. When all fetuses were karyotyped, cytogenetic abnormalities were found in 54%. The most common chromosomal abnormality was autosomal trisomies, followed by 45X and triploidy (Kajii et al., 1980). Karyotyping detected gross chromosomal abnormalities and other causes were lethal X-linked mutation or glucose 6-phosphate dehydrogenase deficiency (G6PD) (Cramer & Wise, 2000; Jablonowska, 2003; Kajii et al., 1980). In very early and not clinically recognized cases of miscarriage, failure of gene activation in the 4 to 8 cell stages karotype is often responsible (Cramer & Wise, 2000). In investi-

gations of recurrent spontaneous abortion, chromosome cultures of the parents are included. If either of them has a balanced translocation which is a chromosome abnormality without any stigmata, there is a higher risk of chromosome abnormalities in their fetuses (Hogström, 2002; Jablonowska, 2003) This risk was low, being only 3-5%, but higher than for the general population (Cramer & Wise, 2000).

#### Physical problems

Structural abnormalities in the uterus, such as bicornuate or septate uterus, which are congenital, can cause miscarriage (Cramer & Wise, 2000; Heinonen et al., 1982). Even submucosal or intramural myomata may cause early miscarriage (Cramer & Wise, 2000; Hogström, 2002).

#### **Endocrine or Metabolic Abnormalities**

A higher incidence of endocrine and autoimmune abnormalities has been identified in women with recurrent spontaneous abortion. Since there are several different causes, it is not possible to give any certain risk in studies that are small. Women with insulin-dependent diabetes mellitus who have poor control of their blood glucose and thereby a high HbA1c (glucosylated hemoglobin) have been shown to have an increased risk of miscarriage (Cramer & Wise, 2000; Mills et al., 1988). Women with hypothyroidism have an increased risk of miscarriage (Cramer & Wise, 2000; Grossman et al., 1996; Homburg et al., 1988). Women with Polycystic Ovarian Syndrome (PCO) have a higher risk of spontaneous abortion. Whether this risk has a connection with luteinizing hormone (LH) levels remains unclear (Cramer & Wise, 2000; Homburg et al., 1988; Regan & Rai, 2000).

#### Infection

Genital infections may cause miscarriage. Genital infection with *Chlamydia trachomatis* or *Mycoplasma hominis* has been found to lead to an increased risk to miscarriage (Cramer & Wise, 2000; Harrison et al., 1983). An increase risk of late miscarriage has been reported by Oakeshott in women with bacterial vaginosis (Oakeshott et al., 2002). Bacterial vaginosis occurs when lactobacilli are lacking and overgrowth of anaerobic bacteria, including gardnerella vaginalis and mycoplasma, occurs. The diagnosis of bacterial vaginosis can be made in the presence of a high pH (>4.5), the presence of "clue cells" and a positive "whiff test" (fish odor when potassium hydroxide is mixed into the smear sample) (Larsson et al., 2005). When primary genital herpes occurs in pregnancy, an increased risk of miscarriage exists (Cramer & Wise, 2000). Other infectious diseases, such as rubella, toxoplasmosis, cytomegalovirus and listeria have also been reported to be possible causes of miscarriage (Jablonowska, 2003).

#### Immune response

With regard to immune response, antiphospholipid antibodies, lupus anticoagulant and anticardiolipid antibodies have been the most studied potential causes of miscarriage but any causality remains unclear. The risk of miscarriage may be as high as 70% when these antibodies are identified in the mother (Clark et al., 2001; Cramer & Wise, 2000; Hogström, 2002; Kut-

teh et al., 1999b). The antibodies can be detected already at implantation and may possibly give rise to subsequent thrombosis in the placenta (Regan & Rai, 2000).

Thrombophilia in patients with factor V-Leiden, lack of protein C, protein S or antithrombin-III deficiency may cause late but not often early miscarriage. The most common is V-Leiden mutation, which exists in 5% of the population, this gives rise to increased activity of protein C-Resistance (APC-R) (Hogström, 2002; Kutteh et al., 1999a; Rai et al., 2001).

#### Age

The frequency of miscarriage increases with maternal age. In one study, the frequency increased from 12% before 25 years of age, to 18% after 39 years of age (Cramer & Wise, 2000). In the register-study from Denmark, spontaneous abortion increased, from a minimum of 11% for the age interval 20-24 years, to as much as 51% for the interval 40-44 (Nybo Andersen et al., 2000). The anembryonic pregnancies are usually more common at higher ages (Smith, 1988). Factors influencing maternal age at reproduction are complex and include menarche and menopause. Cultural and socio-economic circumstances also impact upon desired family size, birth order and interval between pregnancies. Thus, perhaps there are additional circumstances, over and above age, that impact upon the number of miscarriages a woman will suffer (Regan & Rai, 2000).

#### **Environmental Factors**

Factors in the women's environment were found to represent an increased risk of miscarriage, such as smoking and even maternal exposure to environmental tobacco smoke, so called passive smoking. Smokers have a higher risk than non smokers and this risk is in turn further increased in relation to the number of cigarettes smoked per day (Cramer & Wise, 2000; Mishra et al., 2000; Shiverick & Salafia, 1999). Alcohol intake gave an increased risk of miscarriage (Cramer & Wise, 2000; Kesmodel et al., 2002; Windham et al., 1997). Consumption of caffeine has been described as a weak and debatable risk factor of pregnancy loss (Cramer & Wise, 2000; Fenster et al., 1991; Leviton & Cowan, 2002). Other causes studied giving divergent results concerning their connection to miscarriage were drinking tap-water (Hertz-Picciotto et al., 1992; Waller et al., 1998), watching video films more than 20 hours/week (Schnorr et al., 1991), standing more than 8 hours/day at work (Florack et al., 1993), or working with anesthetic gases (Ahmad et al., 2001; Axelsson & Rylander, 1982; Boyles et al., 2000; Cramer & Wise, 2000). High levels of job related stress are related to spontaneous abortion (Brandt & Nielsen, 1992; Mulder et al., 2002). Fenster is of the opinion that it is not work related stress per se that leads to miscarriage but rather in combination with other factors, such as if the mother is above 32 years old, smokes or is primiparous (Fenster et al., 1995). Neugebauer has investigated extreme stress, such as the death of another child in the family during the first trimester of the current pregnancy. He found a correlation, sometimes even in conjunction with a chromosomal abnormality (Neugebauer et al., 1996). Hansen et al. indicate that congenital malformation, especially of the cranial neural crest, may be caused by

extreme stress during the first trimester, such as the death of partner or child, newly discovered physical disease, such as cancer or myocardial infarction (Hansen et al., 2000).

#### Previous miscarriage

The risk of a new miscarriage, after the first, is approximately 28% and after the third miscarriage the risk rises to 43% (Regan & Rai, 2000). However, after three consecutive spontaneous abortions of unknown cause, the risk of a new miscarriage is approximately 20% (Jablonowska, 2003).

# 1.3.3 Symptoms

The woman may have symptoms of miscarriage, such as low back pain or low abdominal pain, dull or sharp pain, or cramp. Vaginal bleeding may occur, with or without abdominal cramps, tissue or clot-like material that passes from the vagina. Diagnosis is made after pelvic examination, followed by transvaginal ultrasound.

#### 1.3.4 Treatment

Treatment of miscarriage varies, depending on the patient's subdiagnosis (Nielsen et al., 1999). At the gynecology clinic at Skaraborg's hospital, a miscarriage medical record form is used to facilitate documentation, because it is a routine medical condition. There are, however, always individual differences. All patients are given verbal and written information. Emotional experiences in connection with miscarriage are discussed. Even information about the pain that may remain during the coming days is given, perhaps the patient is also given analgesic pills, or she is told she can buy them at the pharmacy without a prescription. Women who have had three or more consecutive miscarriages are invited for follow-up and investigation. Contact with a social worker can be established, if the woman require it.

#### Complete miscarriage

Complete miscarriage has occurred if ultrasonographic examination identifies an empty uterus, and that the endometrium is less than 15 mm thick. No further treatment is required. Women have bleeding for a few days (Brody & Frank, 1993; Nielsen et al., 1999).

#### **Expectant treatment**

Incomplete miscarriage has occurred if the cervix is open and ongoing bleeding can be seen. Ultrasonic examination reveals an endometrial thickness of more than 15 mm, and/or non-visible pregnancy products, and the patient's general condition is good. Information is given to the patient about continuation of bleeding and pain for a few days. The woman is encouraged to take an analgesic and, in order to prevent infection, she is advised not to use tampons, bathe or have sexual intercourse while the bleeding continues. Second visits within 3-7 days will decide if it is complete miscarriage or if curettage needs to be performed (Brody & Frank, 1993; Nielsen et al., 1999).

#### Dilatation and curettage (D&C)

An incomplete miscarriage, with heavy bleeding or where the patient's general condition has been affected, emergency curettage is performed under anesthesia the same day. The following tests are done in preparation for the operation: Hemoglobin, blood grouping and perhaps blood transfusion test and blood pressure. Before anesthesia the patient should have had nothing peroral, for four to six hours. When the paperwork formalities, with filling in the medical records, as well as notification of anesthesia have been completed, the nurse goes with the patient to the operating room. The husband is not allowed onto the ward. The patient is given a patient's shirt and lies on a bed while waiting to be transported into the operating room; sometimes she is given a pre-anesthetic before she is taken into the operating room. In this room, there is an anesthetic nurse and her assistant, as well as an operation nurse with her assistant nurse. The patient is moved onto an operating table, which is equipped with leg supports. The anesthesia and operation are prepared. The anesthetist/nurses anaesthetize the patient and the physician performs the surgical operation, with the aim of emptying the uterus of pregnancy products. Operation times are five to ten minutes, after which the patient is awakened and returned to her bed, so that she can sleep off the anesthetic. When she wakes up she is given water to drink and then coffee. Pain relief is given according to each individual patient's needs. The patient has to go to the toilet before her husband or relatives collect her or she goes home by taxi. When the sub-diagnosis is missed abortion, the curettage is performed according to a planned operation time and the fasting patient thus arrives at the operation preparation ward from home.

# 1.4 Women's experience of miscarriage

Many women are happy during early pregnancy, while at the same time having ambivalent feelings about the pregnancy, even if it was planned and wanted. The woman is the protector of the pregnancy and the nurturer of the wanted child (Berry, 1999; Frost & Condon, 1996). A pregnancy may give a romantic social situation with motherhood a positive personally experience. There is no space for pain, loss, or death (Austin-Smith, 1998). The early pregnancy is a symbiotic relation between the fetus and the pregnant woman. By as early as twelve weeks of gestational age, one third of women have given the fetus a nick-name and have dreams about its future (Madden, 1994).

# 1.4.1 The care given to women at the time of the miscarriage

Women are given emotional support by different caregivers at the occasion of caring (Brier, 1999; Friedman, 1989; Lee et al., 1997; Madden, 1994). In a study from the United Kingdom, Friedman has described that patients with symptoms of miscarriage often arrived at hospital during unsocial working hours. They were cases at the emergency room but they have low priority there. They are usually seen by a physician who treats them as though they were routine cases, at the same time as they themselves are experiencing a great trauma (Friedman, 1989). The women often have to wait to the end of the operation schedule. The time from diagnosis to the D&C is stressful (Friedman, 1989). The support of the staff was important to

the women (Griffin, 1998). A great part of the women who had experienced miscarriage were angry with and uncomfortable over the care that was given to them. The biggest problem is the staff's lack of feeling and the lack of occasion to talk about the personal meaning of their loss (Brier, 1999). A group of 26 percent was dissatisfied with the information given to them. They lacked information about bleeding and possible complications (Friedman, 1989).

Miscarriage would seem to be an insignificant event for the professional care givers. They believe that the woman will quickly recover from the experience, with no lasting psychological effects (Friedman, 1989; Frost & Condon, 1996). The most satisfied patients were those who had a second-visit within a very short time, allowing them to receive answers to their general questions about why miscarriage occurs and the risk of being struck by a new miscarriage and with enough time directed toward their feelings (Brier, 1999). A check-up of the emotional experience will have a good effect on the women (Lee et al., 1996). A miscarriage can, for a woman, be compared with other losses in life, but perhaps needs to be considered in a special manner by the health care service (Mahan & Calica, 1997). Neugebauer has recommended that women ought to be given a second visit during the first week after their miscarriage, with prioritization of women at high risk, such as childless women and those with earlier episodes of depression or psychiatric morbidity (Neugebauer et al., 1997). This is not, however, feasible at most of the clinics in Sweden.

# 1.4.2 Women's feelings and response at the time of the miscarriage

Women have a lot of different conflicting feelings around their experience of miscarriage.

#### Physical pain and bleeding

The woman often experiences physical pain. The pain can be explained as ranging from light cramp to severe pain. The bleeding during a miscarriage is sometimes so heavy that the women fear for their lives. Some women undergo surgery. The D&C may be woman's first experience of surgery. Sometimes miscarriage causes rapid hospitalization (Lee & Slade, 1996).

#### Loss of something, child, dreams

A woman's first experience of a bigger loss in life is sometimes the miscarriage (Friedman, 1989). Some women think of the loss of the fetus as the loss of their first child (Bansen & Stevens, 1992). The woman can not create an identity for a lost baby, she didn't know the sex, she has not got a photograph, nothing to hold or to bury. She thus has no object to mourn. A miscarriage is the loss of a part of herself (Frost & Condon, 1996; Rosenfeld, 1991; Stack, 1980).

#### Self-accusation

Women feel responsible for their miscarriages and have feelings of guilt (Bansen & Stevens, 1992). More than two thirds of women have guilt reactions (Moulder, 1994). Miscarriage represents the loss of a pregnancy, of a baby or future child, of motherhood, of self-esteem and it may also engender doubts regarding ability to reproduce (Friedman, 1989; Lee & Slade, 1996; Moulder, 1994; Moulder, 1999). Feelings of emptiness, shame, helplessness and low self-esteem are commonly expressed after miscarriage (Frost & Condon, 1996; Rosenfeld, 1991; Stack, 1980).

#### **Depression**

Even desperation, anguish and listlessness have been identified in connection with the physically traumatic event of miscarriage (Alderman et al., 1998; Neugebauer et al., 1992; Prettyman et al., 1993). For many women, miscarriage is a life event, a crisis. Some women have symptoms of anxiety and sometimes depression for several months (Bansen & Stevens, 1992). The women do not have any occasion to show their feelings and their fear. They think about the miscarriage every day, they think they will never be normal again (Friedman & Gath, 1989). The majority of women have an intensive period of grieving, guilt, and anxiety after miscarriage. The greater part of reaction wanes within four to six weeks and ends after four months following the miscarriage (Brier, 1999). Grief is an explanation of feelings after miscarriage (Cecil & Leslie, 1993; Friedman & Gath, 1989; Hutti, 1992; Lee & Slade, 1996).

Several studies describe that women have symptoms of depression after miscarriage (Lee & Slade, 1996). The studies give differing incidences of Major depressive disorder after miscarriage. When the Hospital and Depression Scale (HADS) was used one week post miscarriage, depression was found in 22% of cases (Prettyman et al., 1993). After ten days, Broen reports 47.5% (Broen et al., 2004). This is four times higher than in the normal population, which has a frequency of 10-12% (Lee & Slade, 1996). In another study, depression was 3.4 times higher two weeks after miscarriage than it was in pregnant women (Neugebauer et al., 1992). In a British study, when the standardized instrument Present State Examination (PSE) was used four weeks after the miscarriage, 48% of women showed symptoms of depression, which was four times greater than the rate for the general population (Friedman & Gath, 1989). After six weeks, the frequency was 6% in Prettyman's study (Prettyman et al., 1993). Two months after miscarriage, 51% has depression, while the corresponding frequency in the general population is 6% (Judd et al., 1994). Even six months after miscarriage, the frequency of depression is 3-4 times higher than in the normal population (Neugebauer et al., 1992). Jacobs reported that 32% of cases showed depression after six months (Jacobs et al., 1989). Even anxiety was identified with different incidences, after one week 41%, six weeks 18% and three months 32% (Prettyman et al., 1993).

# 1.4.3 Feelings about a possible future pregnancy

In the midst of the emotional pain of miscarriage lies the cognizance of the woman's possibility of becoming pregnant again. Women asked how they would be able to feel confident upon

becoming pregnant again. Women sought knowledge before the next pregnancy about how to be good parents (Bansen & Stevens, 1992). Four weeks after miscarriage, women feared further miscarriage and were uncertain as to whether or not they would attempt to conceive again (Friedman & Gath, 1989; Lee & Slade, 1996). Women were dissatisfied with the information they received about when they could conceive again (Friedman, 1989).

# 1.4.4 Emotional support given to the women

#### Husband

Women receive support from their partners (Puddifoot & Johnson, 1997). Women are conscious about their feelings and are ready to show these to their partners (Alderman et al., 1998). Miscarriage can be a new and unfamiliar situation for the husband. Johnson gives an example of how the husband was paralyzed and did not know what to do, when his wife started bleeding heavily. The woman had to take control of the situation (Johnson & Puddifoot, 1996).

#### **Family**

The family would appear to be unaware of what has occurred. They believe that the woman will quickly recover, with no lasting psychological effects (Friedman, 1989; Frost & Condon, 1996).

#### Friends

There is a certain amount of criticism from the women that everything around miscarriage is kept so secret and that they thus receive insufficient support. The silence gives a feeling of isolation. When women speak about their experience of miscarriage they find that they are not alone in their experiences. Some women receive support from others (Bansen & Stevens, 1992).

# 2 Theory of grief and grieving

# 2.1 Grief and the grieving process

Grief is a painful and common experience. Individuals grieve for differing lengths of time and the intensity of their grief also varies. Some grieve intensively for a short time, others moderately for a longer period and others ignore their grief completely. This variation makes defining normal grief difficult, neither too much nor too little, as well as what represents complicated grief.

# 2.1.1 The definition of grief

Grief is a normal reaction to a permanent loss. Grieving is a normal phenomenon and has cultural forms of mourning and grief behavior (Bonanno & Kaltman, 2001). Bereavement covers the situation of losing somebody of importance. Everyone is exposed to death during their lifetime, such as the death of parents, brothers and sisters, friends or children. Reaction to bereavement is defined as grief, which implies emotional reactions, as well as cognitive, social-behavioral and physiological-somatic expression. The term mourning is sometimes used as being synonymous to grief, especially within the psychological sciences. Mourning is the expression of grief in the social and cultural context (Stroebe et al., 2001b). Cullberg defines a traumatic crisis, such as the loss of a close relative or friend, as an experience of such type and degree, that the person experiences his physical existence, social identity and security, or other aspects of life, as being seriously threatened (Cullberg & Bonnevie, 2001).

# 2.1.2 The scientific history of grief

Freud was one of the first to describe grief as a painful loss. All the griever's energy goes into thoughts, feelings and activities that are connected with the dead person. There is a risk that the griever gradually isolates him or herself and becomes stuck in the grieving process (Freud, 1957 (Original work published 1917)). Lindemann's classic study describes some characteristic signs of grief: Somatic distress; preoccupation with the image of the death; guilt; hostile reaction; loss of normal behavior patterns (Lindemann, 1944). Cullberg's description of the grief process has received great attention in Scandinavia and Sweden. He states that the grieving process has four necessary stages or phases. First, the shock phase, with shock, disbelief and denial of the occurrence. Then the griever progresses to the response phase, where he or she is conscious of the loss and feelings vary e.g. crying, anger, isolation, and denial. During the restitution phase, the person returns to daily living and gets on with the business of living. Finally, the reorientation phase is experienced, where the individual's life situation has changed after the loss. Some degree of adaptation and change is required, practically, emotionally and with regard to identity, in order for the griever to be able to work through the loss (Cullberg & Bonnevie, 2001). Worden explains the grief as a process involving four steps. Firstly the person has to accept the meaning of the loss and secondly to work through the pain of the grief. Then, adaptation to a life where the dead person is missing occurs and finally, emotional transfer of the deceased and return to daily living (Worden, 1999). Bowlby point out that that the loss must be understood in the light of the relationship between the person who has been lost and the person left behind who mourns that loss (Bowlby, 1980). Grief has been studied by others within different scientific disciplines and of the authors a few represent recurrent names in the literature: Bowlby (Bowlby, 1980), Cullberg (Cullberg & Bonnevie, 2001), Parkes (Parkes, 1970) Rando (Rando, 1992), Raphael (Raphael & Wilson, 2000), Stroebe (Stroebe et al., 2001a), Worden (Worden, 1999) and Wortman (Wortman & Silver, 2001). Bonanno and Kaltman (2001) have made a most appreciated summary of the scientific history of grief and its clinical application that is summarized in the Bonanno and Kaltman description of the grieving process.

# 2.1.3 Bonanno taxonomy of the grieving process

Bonanno and Kaltman generalize the grief theory described below, in order to allow it to be applied to other losses, such as the loss of work, or symbolic losses, such as loss of a child that moves from their home, psychiatric diseases, or mental retardation. Grief is a general process that exists in all cultures (Bonanno & Kaltman, 2001). Bonanno and Kaltman have 5 categories of grief in different situations.

Cognitive disorganization – During the first months, the griever has difficulty in accepting the reality of the loss combined with feelings of abandonment, disorganization and pre-occupation. Searching for the meaning of and the reason for the loss is usual. The world around is not so important anymore. They even ask themselves why just they have been struck by the loss. The bereavement continues, with the griever talking about the loss, working though it and emotionally picturing the deceased. The first month after the loss, a small group (20%) of grievers has problems with decision making, concentration, and makes more mistakes than usual. The grievers also experience problems with their identity and are uncertain about the future during the first months after the loss.

Dysphoria – lack of inclination - emotional illness and discomfort are very common during the first month of bereavement but are not experienced by everyone. The emotional stress is expressed as anger, irritation, grief, guilt, and hostility, followed by sadness and a state of enmity. Only rarely does the mourning involve anxiety, shame, guilt, antipathy, fear, and jealousy. Feelings of yearning and pining are also expressed. Feelings of loneliness are usual, even when together with others. Two forms of loneliness occur, i.e. social and emotional. The feeling of social loneliness is explained as general loneliness, lack of enthusiasm, social network and a feeling of being marginalized. Emotional loneliness is a feeling of absolute lack of friendship and someone to communicate feelings with.

*Health deficits* – The grief may be expressed as physical symptoms, such as shortness of breath, cardiac palpitations, digestive disorders, loss of appetite, restlessness and difficulty in falling asleep. Serious grief is linked to higher mortality during the first year of bereavement.

A link between bereavement and immune suppression has been studied and is suggested to be similar to that seen in connection with depression.

Disrupted social and occupational functioning – In half of the grievers, social function diminishes during the first months after the loss. Others, such as family members, friends and colleagues can hinder the bereavement through negative statements or treatment of the individuals, so that they are not allowed to express their grief. Even the grievers' emotional or verbal expression of their grief may lead to others avoiding them. They may experience problems in their working role and dissatisfaction with their work performance. Difficulty in role identification exists, especially in daily living, mainly for parents or caregivers of the dead person.

Positive aspects of bereavement - Passing through grief implies a change in personal identity. The person is given a new identity, a new view of life, a new zest for life and a new humbleness. Some experience a new sense of freedom after the loss. Positive thoughts about the future exist. Positive feelings and thoughts are important for the grieving process. The grief is reduced by smiling and laughter.

Between 50 and 85% of grievers express normal grief, (Fig. 5). Normal grief includes moderate disorder in cognitive, emotional, physical or interpersonal functioning during the first months after the loss. After one year, the majority of grievers have returned to normal function. Only 15% express complicated grief (chronic grief), which exhibits symptoms like major depressive disorder, anxiety or post traumatic stress disorder (PTSD). It is necessary to express grief, working through memories, thoughts and experiences as well as to express the pain of the loss (Bonanno & Kaltman, 2001).

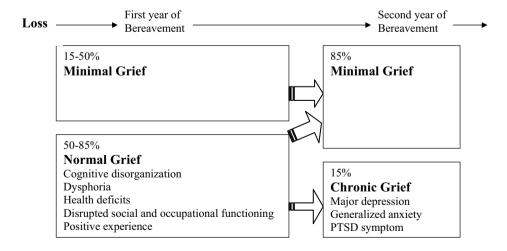


Fig. 5. Structure of Bonanno's taxonomy in the grieving process after loss.

#### 2.1.4 Complicated grief according to Bonanno and Kaltman

Complicated (chronic) grief is when the mourning continues for a longer time. Pathological grief is a synonym. The risk of pathological grief exists if the person has not passed through the grief process in a suitable and individual manner, if there was an unhealthy relation or ambivalent feelings between the deceased and the griever, if the griever has had health problems previously, or if there is no support available (Bonanno & Kaltman, 2001).

According to Bonanno and Kaltman, complicated grief can be expressed as depression, anxiety or post traumatic stress disorder (PTSD). Complicated grief includes forbidden thoughts about the deceased, fantasies about the relation to the deceased, emotional pain, destructive yearning for the deceased, and feelings of loneliness. The grievers avoid places, activities, or people having a strong connection with the deceased. People with complicated grief often experience insomnia, loss of interest in their work and social activity. Anxiety is a strong indication of complicated grief, both normal anxiety and panic (anxiety) disorder exist among grievers. Upon experiencing traumatic losses, grievers sometimes express PTSD, with flash back instead of depression, this is especially common among younger people. This group is at greater risk of chronic grief (Bonanno & Kaltman, 2001)

# 2.2 Measurement of grief

It is difficult to measure the intensity and magnitude of the grief because of the great variation in the grieving process. Several attempts have been made to measure grief. In a literature review, 42 instruments have been found from 1996-2001. The concepts studied were grief, depression, anxiety and stress.

# 2.2.1 Measurement of grief after miscarriage

The majority of women pass through a normal grieving process, with a plethora of thoughts and feelings (Bonanno & Kaltman, 2001; Cowles & Rodgers, 2000; Frost & Condon, 1996; Hutti et al., 1998; Toedter et al., 1988; Worden, 1999). Grief after miscarriage is different from that following other losses. The women do not have a physical object they can grieve and their sense of guilt is greater than with other losses (Frost & Condon, 1996). The authors of the handbook of bereavement have recommended the Perinatal grief scale, since it takes into consideration that which is specific to perinatal loss, as well as on the basis of its validity and reliability (Neimeyer & Hogan, 2001).

# 2.2.2 The Perinatal grief scale -PGS

The Perinatal grief scale - PGS was developed in Pennsylvania USA, starting in 1984. The participants were women with spontaneous abortion (n= 63 women); extra uterine pregnancy (n= 18); intrauterine fetal death (n= 39) and neonatal death (n= 18). Both married and unmarried women; with different social backgrounds; ethnicities and different ages were included, as well as 56 husbands. Each woman participating in the project was matched to a control

woman. Upon the construction of PGS, the women's reactions emotionally, psychologically, physiologically and socially have been taken into account. The PGS was tested against other instruments so that it covers, apart from general grief, marital relationship, religiousness and psychiatric health (Toedter et al., 1988).

#### PGS three factor structure

In the final PGS is comprised of 104 questions. These were condensed into a short version of PGS with 33 questions. PGS is divided into threes subscales: *Active grief* (normal grief) like missing and crying for the baby. The score can be high on this subscale without indicating a complicated grief reaction. *Difficulty coping* focuses on social function and daily living, and the symptoms are more similar to depression. A high score for difficulty coping gives a hint of problems in the daily living, the person has difficulty asking for help and this will increase the risk of complicated grief. *Despair* indicates that the loss has given persistent effect. The individual coping mechanism is reflected in this subscale. Another risk of complicated grief is when earlier losses are brought to the fore (Lasker & Toedter, 1991; Potvin et al., 1987; Toedter et al., 1988).

#### Translation of PGS

Cultural and linguistic adaptation of the PGS was necessary when the original English version was translated into Spanish (Capitulo et al., 2001). Several translations of the PGS have been performed to European languages, such as Dutch and German. The English version is used in the UK as well as the USA (Ohio, Illinois, California, Minnesota; Rhode Island, and Wisconism (Toedter et al., 2001). Even a letter form of the PGS exists (Kroth et al., 2004).

#### PGS today

PGS short version, with 33 questions, is answered on a Likert scale from one to five (Likert, 1932; Neimeyer & Hogan, 2001; Potvin et al., 1987; Toedter et al., 1988). Those who answer mark on the scale how they have been feeling during the most recent days. The answering time is less than five minutes (Paper IV). The normal score from 19 studies and 2,457 participants, most data collections were 1-2 months following the loss (Table II). For total score of PGS the 95% confidence interval was 78-91 (Toedter et al., 2001). A total score above 90.0 indicates psychiatric morbidity (Davies et al., 2005).

*Table II.* Score for PGS short version 5-point Likert scale (n=2 457).

Scale	М	SD	High score
Total	84.3	16.26	>90
Scale 1: Active grief	32.1	4.90	>34
Scale 2: Difficulty coping	26.5	6.75	>30
Scale 3: Despair	23.7	7.27	>27

# 2.3 Swanson caring process / Theories of Human science, nursing and caring

When caring for patients, there is a need for guidelines regarding how good care could be given and described. On of the most usually used method is Swanson's caring process. This process was derived from Swanson's studies of women with miscarriages.

#### 2.3.1 Swanson Caring Categories

Swanson has identified five therapeutic caring-categories from different studies in nursing. The first group was women with miscarriage, second group parents with children at a neonatal intensive care unit (NICU), and third group women with high risk pregnancies (Swanson, 1990; Swanson, 1991; Swanson, 1999a; Swanson, 1999b; Swanson-Kauffman, 1986).

Knowing – The caregiver should have medical knowledge of diagnosis, treatment and complications. Upon miscarriage, even knowledge of closely related fields, such as the menstrual cycle, infertility, recurrent spontaneous abortion and their investigation are desirable. Knowing involves identifying the women's wishes and longings, understanding the personal meaning of the loss in their lives.

Being with – Being emotionally present for the other person. It includes being there, listening attentively, giving reflective answers and if possible giving time to be physically present. Allowing the other person to show grief, without burdening her. Being with must occur in a manner so as not to burn out the caregivers.

*Doing for* – is doing for another person what she would have done for herself if it were possible. It includes physical and psychosocial caring such as comforting, anticipating and protecting the other person's need while preserving her dignity.

Enabling – Help the patient work through the new and unfamiliar experience like a miscarriage

*Maintaining belief* – is sustaining faith in the patient's capacity to get through the event and giving them in high esteem, maintaining a hopeful attitude. Standing by them no matter how the situation may unfold to give a meaning to the life event as part of one's life experience.

The five caring factors discussed above can be generalized to be applied to all other nursing occasions. Swanson's caring process is also applicable to others caregivers than nurses (Swanson, 1991; Swanson-Kauffman, 1986).

# 3 The Studies

# 3.1 Background to the studies

The presentation of patients with miscarriage is fairly common at gynecological wards. The frequency of miscarriage at the gynecological ward at Skaraborg hospital, Skövde is approximately 280 cases every year. From the literature, the frequency of symptoms of depression is high a few weeks after miscarriage. Reported frequencies vary between 40 and 55%, two to four weeks after miscarriage (Friedman & Gath, 1989). If no follow-up visit is conducted, the risk of anxiety increases (Lee & Slade, 1996; Peppers & Knapp, 1980). Some of the women's impressions of the routine basic treatment formed the basis for studying women's experience of early miscarriage.

#### 3.2 Aims

In order to answer the research question, each study had a specific aim.

**Paper I** The aim was to explore how common miscarriage is among women in Sweden and to examine if there has been any change in incidence over time.

**Paper II** The aim was to identify and describe women's experiences of miscarriage.

**Paper III** The aim was to translate the Perinatal Grief Scale into Swedish and to test the translated scale in a small pilot study. A further aim was to compare the 5-point scale with a 10-point Likert scale.

**Paper IV** The aim was to identify women's need for a follow-up visit to the midwife after miscarriage and whether a structured follow-up visit after miscarriage could reduce grief at 4 months after miscarriage.

**Paper V** The aim was firstly to investigate whether, after miscarriage, women experience grief, and reactions similar to those that accompany general grief, such as grief after death of a relative or dear friend. Secondly, the aim was to test, in a factor analysis, if the intensity of grief according to Bonanno's categories is correlated with maternal age, number of children, number of miscarriages, week of pregnancy or nature of miscarriage, and with the Perinatal Grief Scale (PGS).

#### 3.3 Materials & Methods

# 3.3.1 Analysis of data from the Medical Birth Registry

Data were extracted from the Swedish Medical Birth Register (MBR). The study period was from 1983 to 2003. The study basis was all women in Sweden who delivered a child. At the first visit to the antenatal care clinics, the midwives asked the women about previous miscarriages. This information is registered in their medical file Medical Birth Reports (Mödrahälsovård 1, MHV1) and after delivery, a copy of the medical file is sent to the MBR, together with information about the delivery and delivery outcome. This data is manually registered. From the register, the numbers of reported pregnancies and miscarriages were extracted, together with information on age and smoking. In the case of the woman's current pregnancy having ended in an early miscarriage, no information about the outcome is registered in the MBR.

The data from MBR are grouped by age and not on an individual level. Information on when the miscarriage occurred in relation to subsequent pregnancies which go on to delivery is not available. For multiparous women, the number of miscarriages can therefore be registered more than once. We have therefore studied primiparous and 2-parous women separately, since for primiparous women, the number of miscarriages can only be counted once. Almost all of the 2-parous women had their first delivery during the study period. Their abortion experience could, in the case of the miscarriage happening before the first delivery, be counted twice. The figures for each parity are therefore presented separately. Both the number of women who have experienced a miscarriage and the number of miscarriages per delivery have been calculated.

Odds ratio and linear regression analysis were performed using the SPSS program 11.5 (SPSS INC., Chicago IL), to investigate the increase in number of miscarriages. The test variables were: Women's mean age at delivery, the frequency of smoking and a new dummy variable. The dummy variable was created for two periods (Wackerly et al., 1996), the first for the years 1983-1990 and the second for the period 1994-2003. This was carried out in order to test if the increase in frequency between 1991 and 1993 could explain the total increase in miscarriage during the period 1983-2003.

#### 3.3.2 Interviews

In caring, different forms of conversation is frequent; sometimes being more similar to daily conversation and at other times being conducted as an interview where different techniques are used in different situations, for instance Balint vocational training to interview with the aim of obtaining information when searching for a diagnosis (Samuel et al., 2004) and therapeutic conversation according to a predetermined strategy, e.g. cognitive therapy (Jansson, 1986). In research interviews, one or two questions can be used (general interview guide) or

many questions (semi-structured) interview (Kvale, 1996; Malterud, 1996). With all the different forms of interview, a practical technique is to repeat the last sentence to give the conversation continuity.

The research interview always has a specific area of questioning and an aim. In Study II, a general interview guide was used with one introductory, one main and a final question. This is designated deep-interview or unstructured interview. This interview technique gives width and depth of data. The semi-structured interview was used in study V; it is more like a questionnaire. Several questions were posed and answered during the interview (Kvale, 1996; Patton, 2002).

Tape-record interviews are transcribed word by word. The interview text is divided into meaning-bearing units. After deleting unnecessary words i.e. and, or, what, etc. what remains can be designated as meaning-bearing units. There is, however, a slight difference between assigning meaning-bearing units in analysis of data from a general interview guide and analysis of data from semi-structured interviews. In the general interview, the meaning-bearing units are short phrases of words whereas in the semi-structured, 3-5 sentences make up the meaning-bearing units, with one or two key words. The analysis of the text depends on method used.

#### Analysis of data from general interview guide

All meaning-bearing units that mean the same, or have the same contents, are grouped together to create a new categorization. First, the contents of the meaning-bearing units are interpreted in their context (what does she or what does this mean) and aggregated into many different groups. Next, groups are put into clusters having more or less the same meaning. This is then repeated a third and a fourth time, until the clusters build up the categories. Categories are grouped together to identify the sub-theme. This will form the basis of the essence (Appendix 1). The essence is then a very brief description of all the interviewed women's experiences of early miscarriage (Kvale, 1996; Patton, 2002).

Meaning-bearing	Cluster	Categories	Sub-theme	Essence
units				

The general interview guide (Interpretive phenomenology based on the work of Heidegger, 1996) was used to address our aim in study II, namely to identify and describe women's experiences of miscarriage. Interpretations are made from the descriptions obtained from the women who have suffered miscarriages. By listening to and then interpreting the experiences of many people who have experienced the same event, the investigator can come to understand this event (Heidegger, 1996). An assumption central to phenomenology is that a basic

"essence" exists, that is shared by all those who experience the same phenomena (Berterö, 2000; Kvale, 1996).

#### Analysis of data from semi-structured interviews

Content analysis of a semi-structured interview differs from analysis of data from a general interview guide in that all meaning-bearing units are classified according to a known categorization. Bonanno and Kaltman's categorization of general grief was used in study V. Bonanno and Kaltman's categorization has five different categories *Cognitive disorganization; Dysphoria; Health deficits; Disrupted social and occupational functioning;* and *Positive experience of bereavement,* and each category is, in turn, divided into around ten different subcategories (Bonanno & Kaltman, 2001), (Table 1, Paper V). The meaning-bearing units are then placed into the appropriate sub-categories. Each code is described with text and by some examples (Flick, 2002; Weber, 1990). In each category, the frequency of meaning-bearing units was summarized to be a measure of their respective categories' importance to the individual woman concerned, and also of how much grief the woman had experienced.

#### Statistical analysis

Factor-reduction analyses were performed using the SPSS program 12.0 (SPSS Inc., Chicago IL), to investigate if Bonanno categories and PGS indicated the same level of grief; and if the length of the interview corresponding to Bonanno categories and the perinatal grief scale (PGS1).

Correlations were analyzed between the meaning-bearing units of grief, according to Bonanno' categories and women's age, number of earlier children, number of previous miscarriages, week of pregnancy, nature of miscarriage (missed abortion or other miscarriage diagnosis), and the score from Perinatal grief scale (PGS).

Two step-wise multiple regression analyses (Forward) were performed; as independent variables, were the total score on the perinatal grief scale, first measurement (PGS1) and the interview length measured in minutes (time). Dependent variables were the different categorizations from Bonanno and Kaltman's classification of general grief, as well as the woman's age, number of children, previous miscarriages and missed abortions.

#### 3.3.3 Translation and validation of the Perinatal Grief Scale

Of accessible methods of translation, we selected translation and back-translation (Brislin, 1970; Brislin et al., 1973). The original PGS short version published by Potvin (Potvin et al., 1987) was translated from English into Swedish.

In order to validate the scale, it was tested on twelve test persons, who answered the questions anonymously. The original PGS scale has a 5-point Likert scale, from one to five. In this validation, both a 5-point (from one to five) scale and a 10-point (from one to ten) scale were tested. The questions are the same. The twelve test persons answered the questionnaires twice on the same day, first thing in the morning and then again in the afternoon. Half of them were given the 10-point scaling first and the other half the 5-point scales first. The answers to the 10-point scale were translated onto a 5-point scale by grouping, 1-2 = one, 3-4 = two, 5-6 = consthree, 7-8 = four, 9-10 = five. For calculation of the scale's reproducibility, the Kappa coefficient was calculated. With Kappa calculation, a two by two table is usually used and a Kappa value of greater than 0.70 indicates good agreement. The weighted Kappa coefficient takes several categories into consideration, in a 3 by 3 table or more, where the categories are weighted differently depending on the discrepancy form the principal magnitude. Difference of only one magnitude is less serious than if there are several categories with discrepancies (Altman, 1995; Cohen, 1960; Haley & Osberg, 1989). A weight Kappa value of greater than 0.50 indicates good agreement (Haley & Osberg, 1989). We have calculated weight Kappa for all questions (n = 372) in a five by five table.

# 3.3.4 Intervention - Follow-up Visit to Midwife

All women who had experienced an early miscarriage were invited to participate in a prospective randomized study of the effect of a follow-up visit. Inclusion criteria were: Visit to the gynecological outpatient clinic for a miscarriage before 13 weeks of gestation, above 18 years of age and Swedish speaking. Exclusion criteria were: Pregnancy kept secret from the next of kin, e.g. husband, extra uterine pregnancy or suspicion of extra uterine pregnancy. The women included were randomized into two groups. Randomization was performed in blocks of ten, using sealed envelopes. The women were informed of the study by the physician and were offered a follow-up visit to a midwife 21-28 days later. A letter containing information about the study and a scheduled time for a follow-up visit were subsequently sent to all the included women.

In the first group, structured follow-up visit (group 1), a structured conversation with one midwife (AA) was conducted and the time allocated to each visit was 60 minutes. The second group, regular visit (group 2), met one of five different midwives during a 30 minute visit. The structured visit focused on the woman's own experience of her miscarriage, what she had lost and gained, and who she could share her losses with. The women were asked about their feelings "right now", how to go public, the risk of being reminded of their loss when they meet pregnant women etc. Women had to work through their emotions and their physical loss before they could be themselves again. The women would perhaps try to become pregnant again, facing the risk of a new miscarriage, or they might need some form of contraceptive. The midwife's attitude is influenced by Swanson caring process (Swanson, 1999b).

In the second group, attending a regular follow-up visit (group 2), the midwives asked the women about their general health and any complications after their miscarriages. At this visit, the midwife did not ask about the women's feelings and emotions and only if the woman took the initiative of asking further questions did the conversation continue.

Each woman in both groups answered the perinatal grief scale Swedish short version (PGS) at the follow-up visit to the midwife. Each question is answered on a visual analog scale/Likert from one to ten. Each subscale gives a sum ranging between 11 and 110 points. The total minimum sum is 33 and the maximum is 330.

Three months later (four months after the miscarriage), a new questionnaire were sent, by mail, to the women with the same perinatal grief scale and some additional questions. On a visual analog scale, the women answered a question about the importance of the follow-up visit to them. The other additional questions were whether the women had any other questions which had not been answered and if they had somebody who they could talk to and whether they had consulted other care-givers. There were open questions where women described what had been bad and what had been good in the assistance given to them.

Table III. Overview of the papers

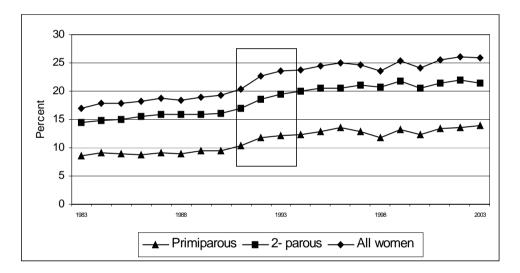
Paper	Design	n	Data collection	Outcome Measures	Data collection period
I	Register study	2 136 809	Extraction from the Medical Birth Registry	Frequency of self-reported miscarriage in women who give birth	1983 - 2003
II	Qualitative	13	Interview from general interview guide	Essence of women's experience miscarriage	January 2001 - April 2001
III	Method article	12	Translation of scale	Swedish version of short PGS	Not applicable
IV	Randomized Controlled Trial	88	Follow-up visit to a midwife 21-28 days after early miscarriage	The effect of a structured follow-up visit to a midwife on PGS	August 2002 - May 2003
V	Qualitative	25	Semi-structured interviews 21-28 days after early miscarriage	Content analysis from general grief theory according to Bonanno's taxonomy	August 2002 - May 2003

### 3.4 Results

## 3.4 1 Incidence of previous miscarriage in Sweden

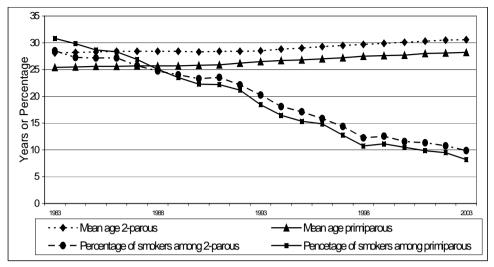
Between 1983 and 2003, a total of 2 136 809 deliveries were identified and 366 796 women experienced a miscarriage.

The numbers of women with early miscarriage among all women increased from 17.0% to 25.8%. For primiparous women, the reported experience of miscarriages per delivery increased, from 8.6% in 1983, to 13.9% in 2003. The corresponding figures for 2-parous women also showed an increase, from 14.5% to 21.3%, respectively (Fig. 6). Marked increases in the number of miscarriages were noticed in both primiparous and parous during the period 1991-1993.



*Fig.* 6. The percentage of women who reported previous experience of miscarriage, i.e. prior to the current birth, as well as the figures separated into primi-parous, and 2-paorus.

During the same period, the mean age among primiparous women rose, from 25.4 to 28.2 years and in women who had had two deliveries, the corresponding age increase was from 28.1 to 30.6 years of age (Fig. 7). Smoking declined from 29.8% to 9.5% in primiparous and from 28.6% to 10.7% in all parous women during this period (Fig. 7).



*Fig.* 7. Mean age at delivery for primipaous and 2-parous women. Percentage of pregnant women (primiparous and 2-parous) who are smokers.

The experience of miscarriage prior to the present delivery among primiparous women increased in the age group 20-24, from 7.9% to 13.7% during the period 1983-2003. In the age group 30-34, miscarriage increased from 15.3% to 19.0% during the same period (Fig. 8). Women in the age group 25-29 have been used as a reference and the odds ratios for the different age groups are shown in Table IV. The odds ratios increase with increasing age of the mother, from 0.81 among 20-24 year olds, to above 3 for women older than 40. The same figures for all multiparous women are shown in Fig. 9.

*Table IV.* The risk of spontaneous abortion among primiparous women in Sweden 1983-200.

Age group	n	OR*	95% CI
20-25	284 788	0.81	0.80 - 0.83
25-29	346 460	1.00	
30-34	173 327	1.43	1.40 – 1.45
35-39	48 586	2.13	2.08 - 2.17
40-	7 636	3.22	3.10 - 3.33

<sup>\*</sup> the age group 25-29 was selected as a reference

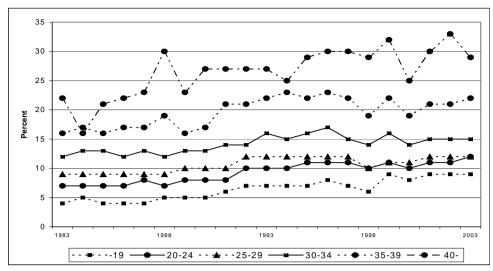


Fig. 8. Reported experiences of miscarriage per delivery for primiparous women in different age groups.

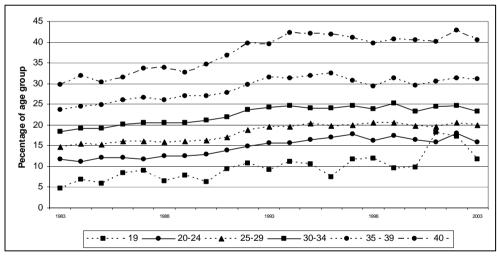


Fig. 9. Reported experiences of miscarriage for all multiparous women in different age groups.

When calculating the risk of miscarriage per new child, we used the number of reported miscarriages /deliveries instead of the number of women with experiences of miscarriage. In Fig. 10, the increase of miscarriages per new child is shown for the most recent years, around 13% miscarriage for primiparous and 8% for 2-parous, 6% for 3 p-parous and 4% for 4-parous.

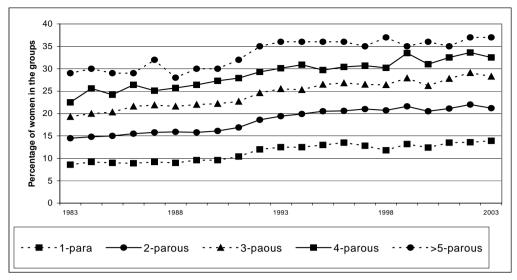


Fig. 10. Reported experiences of miscarriage per delivery, grouped by number of children for all women in Sweden, 1983-2003.

Women who smoke have a higher frequency of miscarriage than non-smokers Fig.11 The odds ratio (OR) of having a miscarriage is for women who smoke 1.14 (95% CI 1.12-1.15), if she, at her first visit to the antenatal care, reported that she smokes. The odds ratios differed over the observed time period, with OR 1.16 (95% CI 1.09-1.24) in 1984, rising to as much as 1.38 (95% CI 1.28-1.48) in 2003, which can be seen as a gap between the two curves which increases from 1993 onwards.

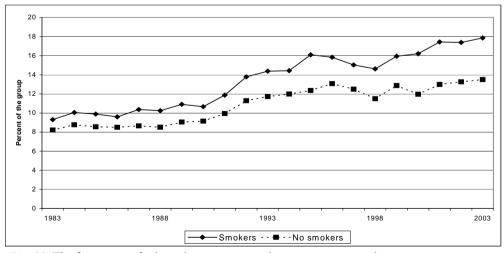


Fig. 11. The frequency of miscarriage among smokers versus non smokers.

The increases in frequencies of miscarriages were tested using linear regression analysis. In the linear regression analysis, the frequency of miscarriage per year was the dependent variable and predictors the dummy variable (increase 1991-1993), mean age and smoking. The linear regression analysis showed that the increase in frequency seen between 1991 and 1993 could explain most of the increase in miscarriage seen for the whole 21 year period, 1983-2003. The R<sup>2</sup> value was 0.939 (p<0.001) for the increase 1991-1993 and the R<sup>2</sup> value was 0.844 (p<0.001) for the increase in mean age. However in the stepwise linear regression analysis, the increase between 1991 and 1993 had a R<sup>2</sup> value of 0.939 and addition of mean age increased the R<sup>2</sup> value to 0.954, an increase of only 0.015 but this is still significant (p=0.043). In the stepwise linear regression among 2-parous, the increase between 1991 and 1993 had a R<sup>2</sup> value of 0.956 and addition of mean age increased the R<sup>2</sup> value to 0.977, an increase of only 0.011 but this is still significant (p<0.002).

## 3.4.2 Guilt and Emptiness

In the interview study the women (n=15) who were willing to participate were contacted by telephone and interviews were scheduled at a time and place that they found convenient. Five women were interviewed in their homes and ten in an undisturbed consultation room at the hospital. The general interview-guide approach was used (Patton, 2002). The guiding questions for the study, which were posed to each interviewee, were: "Tell me about what you felt when you knew that you were pregnant"; "Tell me about your feelings and what happened in connection with the miscarriage" and "Tell me about how things have been for you since you had the miscarriage". The audio taped interviews varied in length from 45 to 100 minutes. Before the interview, there was some small talk to establish a comfortable relationship between the interviewer and interviewee. After the interview, there was talk about and reflection on the interview (Berterö, 2001; Kvale, 1996). Thus, the total time required per interview was 85 - 150 minutes. Fifteen interviews were carried out; however the first two were classified as test interviews and are not included in the analysis. Thirteen interviews form the basis of the present results.

All sub-themes have to be identified in every woman as an example, see Appendix 1. In turn, the categories were interpreted and examined to identify sub-themes of the overall experience. In the analysis five sub-themes and one major theme were identified. The minor themes are the parts considered to make up the major theme. The major theme, guilt and emptiness, described the essence of the experience of women who have had miscarriages, figure 12.



Fig. 12. The Essence and sub-categories of women's experience of early miscarriage.

### The essence - Guilt and emptiness

Women's feelings after miscarriage are guilt and emptiness. The experience of miscarriage creates a great negative impact in the woman's mind. The women had gathered information from books, pamphlets and from the Internet about how the life inside them grows and develops into a new person. The losses described by the women often include an expected child, the child's future, including the maternity role/motherhood, which includes responsibility for a child for the rest of the woman's life. A great part of the early pregnancy is planning for the future. For example, the women makes plans for how the new family is going to live; perhaps moving to a new home suited to children. Plans are also made for a leave of absence for maternity. What will happen at her place of work, who will replace her there and when will she be replaced?

It is a pleasure for her to give her husband a child and the children she already has anticipate brothers or sisters. The Swedish ideal includes few children, expected after having bought a house and several years of marriage or after expectations from grandparents and friends.

The women wish to have their feelings confirmed, since nobody sees them as they are and how bad they feel inside themselves. They want to know and they want to regain their control. What they do no want to hear and feel is: "It's not important for you. It's only a miscarriage". The women search for obvious reasons for the miscarriage. As no reasons as to the possible causes of their miscarriages could be given, the women assigned reasons themselves, such as stress, anxiety, smoking, or food, or too much or too little physical exercise.

## Feeling emotionally split

When the pregnancy-test is positive, the women have a split emotional feeling. Soon after the conception, women may feel that they are pregnant. They start planning for the role of motherhood. Later they do the pregnancy test to confirm their feeling. If the pregnancy is not planned, the women wonder if they should, or should not continue with it. It takes a few days before the women are pleased to be pregnant. They continue their planning, including child and parental leave. At the same time, the woman who has had a previous miscarriage is anxious how things will work out with this pregnancy. These anxieties over-shadow her pleasure in being pregnant. The women who have had miscarriages before fear having a new miscarriage. All women feel split between happy anticipation and anxiety.

## **Bodily sensation**

Sensations in a woman's body give certain signals, and when the child is expelled they experience other signs. They can feel that something is wrong, but they don't know what it is; for example, the pregnancy signs seem to go away. Then the woman knows when the bleeding comes that it is a miscarriage. "I immediately felt that this was not right. Directly there was a small bleeding". The women are anxious, they phone the medical service. The answer that is

given is: "Don't worry, there is no danger". Inside her the woman knows that this is not true but she accepts the answers.

The women hope that their sensations are wrong and that their pregnancies will continue. They want examinations without having to wait. The women continued to hope that their sensations were wrong and that everything was all right when they waited for their first examination, until they were convinced by ultrasound examination. The women just thought: "It is not true that the fetus is not alive", even if they see it on the ultrasound picture. The women were in the examination-chairs when they were informed that their fetuses were dead. After the examination, when couples were informed and talked with the physician, they were shocked. They talked, but they did not know what to say or what was said to them. Some were in great despair. Others did not show their despair, because they would not have been able to control themselves.

#### Loss

All interviewees talk about their losses. Their losses consist not of an embryo or a fetus; but their child, which they have prepared themselves for, this child, not another child later. It is their identities and rights as mothers that have been lost. A feeling expressed as emptiness occurs, a longing for the little living creature who was there and who no longer exists.

Each woman had a lot of dreams in her heart when she felt the pregnancy. All dreams grow when they are given a positive pregnancy test. The women cannot be the masters of their bodies. They did not know why the miscarriage occurred. After the operation, they felt that they are deprived of something. The miscarriage is experienced as a loss that can be a feeling of loss or something physical, i.e. losing a body part.

#### Grief

The feelings that exist after a miscarriage are disappointment, loss, weakness and grief. Grief could be seen as a reaction to loss. The women's mental health is not good, they feel feeble and everything is heavy, they are listless, they take no walks, and they do little or nothing. They rest in their beds, and everyday chores are too difficult to perform. Their physical health is not good, for example, they have pain in the lower abdomen or in the back and they feel dizzy:

All women grieve over a miscarriage, but in different ways. Some women shut themselves off from their families and everyday life. They want to be alone with their thoughts and feelings. Others put off and repress their feelings until they are alone during the night. During the grieving period, the emotions of the women varied during the day between tears, mirth and anger. They have no control over their bodies. During the grieving period, some women realize that the feelings are those of grief; other women wish they had more time to grieve over the miscarriage, but they could not be absent from work:

Some of the women, who had held clots of blood/fetus in their hands, had looked at them and thought of everything that they had lost. A few women put their fetuses in beautiful little boxes and buried them in secret places, where they sometimes visit and place flowers. That the women's grief is taken seriously by others is important for them. They needed to talk with competent staff. Most importantly, they must be able to talk with someone who understands them and answers their questions. When the women tell fellow workers that a miscarriage has occurred, they find out that others have had the same experience. Each talk gives the women a new dimension and they proceed in their adaptation. A feeling of unification comes from other women who have had these bad feelings, too. Women do not forget miscarriages. The losses find a place inside them. The remembrance of the loss returns to the women when they see other pregnant women or babies. The loss of dreams and of hopes for the future seems unfair to the women, and their losses will always rest within them: "Even if it's only a fetus, as everybody tells me so, it's a human being. It's not only words, it's something very important which was there in my uterus".

#### Abandonment

### Abandonment as Professional Avoidance

During the pregnancy following a miscarriage, the women worried how that pregnancy would advance. They phoned the maternity centre (MVC), to ask how they could avoid having another miscarriage. The answers were that if the pregnancy test was positive, they could come back for registration after five or six weeks. Later, when they bled, they phoned again. When they were told, "Don't worry, it's not dangerous", the women felt betrayed, since they believed the pregnancy was not normal.

The women's thoughts were of the little creature inside, its future, if it was a boy or a girl. They worried that the little bleeding would end in a miscarriage. The uncertain waiting time makes the women feel self-absorbed and neglected, feelings that diminished when someone showed sympathy. The hospital staff includes diligent workers, but they do not understand the women's emotions. It is important that the women are noticed and treated professionally, humanly and with sympathy/empathy.

### Abandonment by husband, friends, and relatives

The husbands grieve at the time when the miscarriage occurs and then they want to move on. They do not understand when their wives continue to grieve for days and weeks. Women want to talk repeatedly about what has happened and to ponder about why. If the couple talks a lot and the husband was with his wife at the examination, they become closer. If the husband does not talk much, there can be conflicts and a distance in the relationship after the miscarriage. The men only see the next time when everything will go well. They are not able to talk about it over and over again, as their wives need to do. The women who talk of their miscarriage with friends and fellow workers find that they are not alone in their experiences. When they have had their own experience, they fully understand other women's feelings and

also their own feelings, which turn out to be the same for all women. Through talking about miscarriage, they can come to understand common aspects of what all women who miscarry experience.

A miscarriage is a personal failure. The women do no want to explain why they did not go to work because of the miscarriage. The custom is not to tell anyone about the pregnancy before twelve weeks have passed. Couples who have hoped for a pregnancy for a long time do not tell anyone that they have had a miscarriage, as it means they tell everyone that they hoped for a pregnancy. The fact that the women themselves ruminate is very common. Therefore, the women do not phone and ask questions. They feel they ought to know because they have children already or have had miscarriages before, too. They are not ill. They do not want to intrude on the staff: The women put on a strong appearance. On more than one occasion the women first thought of other patients, their husband or their children and not of themselves.

### Guilt

The women blame the miscarriage on themselves. The women accepted that the blame for the miscarriage should be put on them, as if it were their bodies that were guilty of not continuing their pregnancies. The causes were for example, high fever, that they did not want the baby enough, stress, or smoking:

The women were angry with themselves and of course they saw their miscarriages as a consequence of what they had done wrong in general, for example, smoking and drinking alcohol, taking too little physical activity, or having a full-time job involving lifting heavy things. They were angry that they did not know that these actions would result in miscarriage. For others, one specific occasion caused the miscarriage, for example, she had trouble with her car and inhaled the exhaust fumes on the way to service station. The glucose shock when she ate ten "snowball" biscuits at one time when she wanted sugar. Other women said that they were not in good condition emotionally, since at their places of work there was too much trouble and too much stress. So their bodies thrust away the pregnancy. Women view the miscarriages as a personal failure and an embarrassment. Some think the miscarriage is a result of their thoughts – that she did not want a child enough. The women hold themselves responsible for the miscarriage.

### 3.4.3 Translation and validation of the Perinatal Grief Scale

Each question from the English original of Perinatal grief scale (Potvin et al., 1987) was translated into Swedish by AA, this representing *version 1*. This translation was discussed and modified in collaboration with a gynecologist, Professor Barbro Wijma, working both in clinical practice and as a researcher. This gave rise to *version 2*, which was analyzed a further time by a gynecologist (PGL), giving rise to *version 3* of the PGS. A translator then reviewed and corrected this version to ensure that there were no remaining grammatical or linguistic errors which had occurred during translation from English to Swedish, this was *version 4*. The process of translation concerns translating individual words such as "guilty" to "skuld" or "skyldig". The word order and grammar are also relevant, such as "I get cross at my friends & relatives more than I should". This could have been translated to "Jag bli mer osams med vänner och släktingar än jag skulle gjort". However, the final translation was "Jag blir mer förtretlig mot vänner och släktingar än jag borde ha varit". "I become more annoyed with friends and relatives than I should do".

Cultural differences are highlighted by the question "I take medicine for my nerves", ("I take tranquillizers"), which could have been translated to: "Jag tar lugnande" but we chose to write "Jag tar mediciner för mina nerver", ("I take medicine for my nerves"). Finally the Swedish version 4 was translated back to English, version 5, by a professional translator who is a native of the United Kingdom and works as a professional translator of medical articles. Since this was in agreement with the English original, the translation in version 4 can be considered to be correct. The Swedish translation of each question from the English original is given in Appendix 2 (Toedter et al., 2001).

In the pilot study, there was one of the 12 test persons who did not answer all the questions. She has therefore been excluded from the analysis of the total sum but has been included in those questions that she answered. The average score from the pilot study shows that the 10-point Likert scale has a slightly higher score on average, even when the score was grouped into five groups. The mean score is 68.3 for the 5-point Likert scale, compared to 71.7 for the 10-point corrected scale, or a 4.8% difference (p>0.05). There was no difference in which order the different scales were answered. The weighted Kappa coefficient, all questions, is 0.58 (Table V).

*Table V.* Five-five table for the weighted Kappa coefficient for test persons' answers to identical questions in the 5-point Likert and the 10-point Likert. The weighted Kappa index for 372 answers was 0.58.

5-point	10-point Likert 5 grouped					
Likert	1-2	3-4	5-6	7-8	9-10	Total
1	138	12	6	2*	7*	165
2	35	23	16	7	0*	81
3	5	13	30	23	4	75
4	3*	2	9	21	11	46
5	0*	0*	0	1	4	5
Total	181	50	61	54	26	372

<sup>\*</sup> Divergent answers, see text for details.

Twelve test persons had divergent answers between the first and second occasions questions numbers 1, 2, 5, 13 and 29. In particular, question no. 16 "I have let people down since the baby died" had five divergent answers. Not all the test persons in the pilot study had personal experience of miscarriage, which could explain the divergent answers. The aim of using test persons was to see if the translation was easy to understand and to compare the 5-point and 10-point Likert.

## 3.4.4 Follow-up Visit to a Midwife

Letters of invitation giving details about the study were sent to 146 women. Of the women invited, 80% attended the follow-up visit and 88 answered both questionnaires. The women's median age was 31 (range 20-42) years and their mean length of formal school education was 13.2 years (range 10-17). The women's occupational statuses were employment (n=67), parental leave (n=4), student (n=2) unemployment (n=13) and other (n=2). There were no significant differences between the two study groups and the women who did not participate with regard to background variables, such as number of gestations, 2.9; mean gestation length at the time of the miscarriage, 9.7 weeks; and being primiparous, 36%. However, since data on education and occupation were not obtained for the women who did not participate in the study it is not known if they differ with regard to these variables. The pregnancy was planned for 75% of the women; four women were living as single and 14 were smokers.

#### Women's mental health estimated with PGS

The 88 women who participated were distributed as follows: 43 women with structured follow up visits (group 1) and 45 with regular visits (group 2). The difference between the first and second measurements shows a 30% greater reduction in total PGS score in-group 1 compared to group 2 (Table II Paper 4) (p=0.43). The reduction in the total PGS score was for structured follow-up visits 24 and for regular visits 18. The biggest differences were in the subscales active grief and difficulty coping. However, none of these differences was statistically significant.

### The women's own estimation of the follow-up visit

The women's own estimation of the importance of the structured follow-up visit, measured using a visual analog scale from one to ten, was for group 1 (n=43) 8.6 and in group 2, regular visit (n=45) 7.0 (p<0.05).

### Bad mental health four months after miscarriage, especially after missed abortion

Four months after the miscarriage (measurement two), 20 women had higher PGS scores than at the first measurement. Of these women, 18 (87%) had experienced missed abortion. The group of women with missed abortion (n=43) had significantly higher PGS scores for active grief and difficult coping than the women with other diagnoses and a higher total PGS score (85.2 versus 65.0), (p<0.05) independent of which kind of follow-up visit (structured visit or regular visit) the women had attended. In addition, women with missed abortion showed less improvement than women with other diagnoses, as the reduction in total PGS score was only 13.9 for missed abortion, versus 27.8 for all other diagnosis (p<0.05), i.e. between measurements one and two.

#### Childlessness has an influence on mental health

Women without any children had significantly higher PGS scores at the follow-up visit than women with children did (87.8 versus 68.7 p<0.01), regardless of the type of follow-up visit. The pregnancy was planned in 75% but there was no significant difference in the PGS scores between those with planned, and those with unplanned pregnancies.

### Physical influence of miscarriage

The number of days on which women had vaginal bleeding was 9.5 (0-30) days, with heavy vaginal bleeding on average for 2.3 (0-11) days. Twenty-five percent of the women returned to work after only one day, 34% were on sick-leave for less than one week, 31% needed one to four weeks' of sick-leave and only 3% needed more than four weeks. Contraceptives were given to 26% of the women and 12% were pregnant again four months after their miscarriage and one woman had had a new miscarriage. Five women were referred for further consultations.

#### **3.4.5** Grief

Twenty-five patients from the structured follow-up visit in study IV were included in the analysis. The follow-up visits took place four weeks after the miscarriage. At the visit, each woman had a semi-structured interview during which her experience and emotions in connection with the miscarriage were discussed. The women's feelings of grief were measured using the PGS questionnaire. The interviews, which were tape-recorded, lasted 20–100 minutes, with an average of 45 minutes.

Mean gestational age at the time of the miscarriage was nine weeks (range: 5-13), and the mean age of the women was 31 years (range: 20–40). Eight women were primiparous. Twelve had given birth previously, and six of the 25 women had prior experience of miscarriage.

#### Content analysis

In all of the 25 women, three of Bonanno and Kaltman's categories of grief are represented in the content analysis. These are cognitive disorganization, dysphoria, and health deficits. Disrupted social and occupational functioning, and positive experience of bereavement were each represented in 22 of 25 women, respectively.

Cognitive disorganization was found a median of 18 times (range 3-45). For example, all the women's energy and thoughts were focused on the prospective child, and they feared that they would never get pregnant again and that they had missed their chance of becoming a mother before becoming too old. They often blamed themselves for something they had done or eaten.

The code for *Dysphoria* was registered a median of 24 times (range 2-63), some examples being that the women were experiencing internal stress and fatigue and found it difficult to talk about their experience, so they felt lonely.

*Health deficits* were coded a median of 6 times (range 2-26), examples being bleeding, pain in the lower abdomen and back, and dizziness.

Disrupted social and occupational functioning was coded a median of 5 times (range 0-18); examples are that the women experienced fatigue and emotional instability for longer periods than members of the (woman's or man's) family regarded as normal. Remarks such as "Why is she so down? It's a whole week since the miscarriage" were made. Reminders of childbirth and pregnancy were ubiquitous in their immediate surroundings, in the community as well as the media. Their concentration at work was poor.

Positive experience of bereavement was registered a median of 4 times (range 0-22). One example was that the husband stood by his wife as her protector and supporter. Conversations with other women, too, showed that other women have also experienced miscarriage and similar feelings.

## **Factor-reduction analysis**

The descriptive statistics for the variables included in the factor analysis are shown in table VI.

Table VI. Descriptive Statistics of 25 women in the factor analysis.

	Mean	Std. Deviation	Analysis N
Cognitive	20.0	11.2	25
Dysphoria	22.8	14.4	25
Health def	6.7	5.3	25
Social	6.6	4.9	25
Positive	4.8	4.6	25
PGS1	96.3	50.2	25
Time	45.2	21.2	25

Commonalities the square and than sum of each factor (for every variable) before extraction, is even called principal axis factoring. Table VII.

Table VII. Commonalities of the variables placed in one factor.

	Initial	Extraction
Cognitive	1.0	0.8
Dysphoria	1.0	0.7
Health def.	1.0	0.7
Social	1.0	0.6
Positive	1.0	0.9
PGS1	1.0	0.7
Time	1.0	0.9

Extraction Method: Principal Component Analysis.

Table VIII. Total variance explained in the factor analysis.

Component	Initial Eigenvalues		Extraction Sums of ent Initial Eigenvalues Squared Loadings			Rotation Sums of Squared Loadings			
-		% of	Cumu-	% of Cumu-			% of	Cumu-	
	Total	Variance	lative %	Total	Variance	lative %	Total	Variance	lative %
1 Cognitive	3.1	44.7	44.7	3.1	44.7	44.7	3.1	44.5	44.5
2 Dysphoria	1.3	19.0	63.7	1.3	19.0	63.7	1.3	19.0	63.5
3 Health def.	1.1	15.1	78.8	1.1	15.1	78.8	1.1	15.4	78.8
4 Social	0.6	8.9	87.8						
5 Positive	0.5	7.1	94.9						
6 PGS 1	0.2	3.3	98.2						
7 Time	0.1	1.8	100.0						

Extraction Method: Principal Component Analysis.

From Table VIII the total variance can be explained. It can be seen that three factors will explain 79% of the total variation. In Table IX the rotation component matrix will show that time, dysphoria, cognitive, social function, and the Perinatal grief scale (PGS1) creates one factor that could be called "grief'. Health deficits and positive experience will create two separated factors. Therefore the three categories of Bonanno; dysphoria, cognitive, social function, are merge to one new category "Bonanno's grief" which measure the same as the Perinatal grief scale (PGS1) and the length of the interview (time).

Table IX. Rotated Component Matrix(a)

		Compone	nt
	"Grief"	Health	Positive
Time	0.9	-0.2	
Dysphoria	0.9		0.1
Cognitive	0.8	0.3	0.1
Social	0.7		-0.3
Health def.	0.2	0.8	-0.1
PGS1	0.5	-0.7	-0.2
Positive			0.9

Extraction Method: Principal Component Analysis, Rotation Method: Varimax with Kaiser Normalization. a Rotation converged in 4 iterations.

## Multiple regression

With a stepwise multiple regressions analyze the variables "Bonanno' grief", the Perinatal grief scale (PGS1), the length of interview (time) as well as women age, number of children, earlier miscarriage and the diagnosis missed abortion were used.

Model A. Dependent variable was time and the others independent variables were "Bonanno" grief', PGS1, women age, number of children, earlier miscarriage and the diagnosis missed abortion. In the stepwise (forward) regressions model the three significant variables were; "Bonanno grief", PGS1 and the diagnosis missed abortion. This three variables explain 83% (p<0.040) (Table X), excluded variables (Table XI).

Table X. Model A Summary<sup>d</sup>

Model	R	R Square	•	Std. Error of	Change S	Statistics
	Square 1	the Estimate	R Square Change	Sig. F Change		
1	0.79(a)	0.62	0.60	13.2	0.62	0.000
2	0.89(b)	0.79	0.78	9.9	0.17	0.000
3	0.91(c)	0.83	0.81	9.2	0.04	0.040

a Predictors: (Constant), "Bonanno grief"

b Predictors: (Constant), "Bonanno grief", PGS1 c Predictors: (Constant), "Bonanno grief", PGS1, Missed abortion

d Dependent Variable: Time

Table XI. Model A, Excluded Variables(d)

Mode	I	Beta In	t	Sig.	Partial Correla- tion	Collinearity Statistics Tolerance
1	PGS1	0.43(a)	4.3	0.00	0.77	0.92
	Missed abortion	0.11(a)	0.8	0.43	0.17	0.96
	Age	0.02(a)	0.2	0.86	0.04	0.96
	Children	0.00(a)	-0.0	0.99	-0.00	0.99
	Previous miscarriage	-0.14(a)	-1.9	0.29	-0.22	0.92
2	Missed abortion	0.20(b)	2.2	0.04	0.43	0.92
	Age	0.01(b)	0.1	0.9	0.03	0.96
	Children	-0.01(b)	-0.1	0.90	-0.03	0.99
	Previous miscarriage	-0.15(b)	-1.6	0.13	-0.32	0.92
3	Age	-0.080(c)	-0.8	0.43	-0.18	0.80
	Children	-0.013(c)	-0.1	0.89	-0.03	0.99
	Previous miscarriage	-0.154(c)	-1.7	0.09	-0.36	0.92

a Predictors in the Model: (Constant), "Bonanno grief"

Model B. Dependent variable was PGS 1 and the others independent variables were "Bonanno" grief", time, women age, number of children, earlier miscarriage and the diagnosis missed abortion. In the stepwise (forward) regressions model the three significant variable were; time, "Bonanno grief", and the diagnosis missed abortion. This three variables explain 60% (p=0.03) (Table XII), excluded variables (Table XIII).

Table XII. Model B Summary(d)

Model	Model R R Squ	R Square	•	Std. Error of	Change S	Statistics
Square t	the Estimate	R Square Change	Sig. F Change			
1	0.61(a)	0.38	0.351	40.4	0.38	0.001
2	0.70(b)	0.49	0.452	37.1	0.12	0.032
3	0.77(c)	0.59	0.539	34.1	0.10	0.034

a Predictors: (Constant), Time

b Predictors in the Model: (Constant), "Bonanno grief", PGS1 c Predictors in the Model: (Constant), "Bonanno grief", PGS1, Missed abortion

d Dependent Variable: Time

b Predictors: (Constant), Time, "Bonanno grief" c Predictors: (Constant), Time, "Bonanno grief" , Missed abortion

d Dependent Variable: PGS1

Table XIII. Model B, Excluded Variables(d)

Mode	ıl	Beta In	t	Sig.	Partial Correla- tion	Collinearity Statistics Tolerance
1	"Bonanno grief"	-0.56(a)	-2.2	0.03	-0.44	0.38
	Age	-0.03(a)	-0.2	0.84	-0.04	0.97
	Children	0.01(a)	0.0	0.94	0.02	0.99
	Previous miscarriage	0.04(a)	0.3	0.79	0.06	0.99
	Missed abortion	-0.22(a)	-1.4	0.19	-0.28	0.99
2	Age	-0.00(b)	-0.0	0.98	-0.00	0.96
	Children	0.03(b)	0.2	0.86	0.04	0.99
	Previous miscarriage	0.19(b)	1.2	0.26	0.25	0.87
	Missed abortion	-0.33(b)	-2.3	0.03	-0.44	0.94
3	Age	0.15(c)	0.9	0.35	0.21	0.81
	Children	0.03(c)	0.2	0.85	0.04	0.99
	Previous miscarriage	0.197(c)	1.4	0.19	0.29	0.87

a Predictors in the Model: (Constant), Time

The multiple regression analysis shows that the women's score on the perinatal grief scale (PGS1) has a strong correlation with how much grief they express in the semi-structured interview, measured by the number of meaning-bearing units from Bonanno and Kaltman's general grief (Bonanno grief). There is also a correlation between the length of the interview (time) and the score of the perinatal grief scale (PGS1) and the number of meaning-bearing units from Bonanno and Kaltman's general grief (Bonanno grief). From the analysis, there is no correlation between the intensity of grief measured by the perinatal grief scale (PGS1) or Bonanno and Kaltman's categorisation of general grief (Bonanno grief) and women's age, number of children, earlier miscarriages. However, women with the diagnosis of missed abortion have greater grief, both on the perinatal grief scale and as measured by Bonanno and Kaltman's categorisation of general grief.

b Predictors in the Model: (Constant), Time, "Bonanno grief"

c Predictors in the Model: (Constant), Time, "Bonanno grief", Missed abortion

d Dependent Variable: PGS1

## 4 Discussion

The frequency of miscarriage reported by primiparous women, in relation to the number of deliveries, has increased from 7.9% to nearly 13.7% during a 21 year period in Sweden. A marked increase in miscarriage was noted, during the period 1991-1993. During the last 10 years of the period studied, hardly any further increase in the number of miscarriages could be seen in the register data from the MBR.

The increase of miscarriage has been thought to be caused by an increase in mean age among primigravida (Hemminki & Forssas, 1999; Nybo Andersen et al., 2000; Odlind et al., 2003). The age of the women was found to have a significant impact on the frequency of miscarriage. Using the age group 25-29 as a reference, the odds ratio increased from 0.83 in women 20-25 years of age, to 3.22 (95% C.I. 3.10-3.33) in women 40 years or older. During the study, the mean age of primiparous women at delivery had increased by 3 years (Fig.7),(Odlind et al., 2003). This increase in mean age was not large enough to explain the whole increase in the frequency of miscarriage seen between 1983 and 2003. From our multiple stepwise regression models, we could show that the increase between 1991 and 1993 has a much stronger impact on the whole increase, seen between 1983 and 2003, than does the increase in mean age of the mothers.

There are several possible explanations for the marked increase between 1991 and 1993; a more sensitive urine pregnancy test was introduced into clinical practice around 1990. The detection level of  $\beta$ -hCG reduced from >2000 U/l to 20-40 U/l (Khan et.al, 1989). This would result in a detection of a larger number of very early miscarriages, as Sydsjö et al. had pointed out (Sydsjo et al., 1999). Women had confirmed their pregnancies earlier and could therefore report several miscarriages. Another possible explanation could be that routine vaginal ultrasound examination performed pre-operatively in induced abortions sometimes discovered missed abortions. These women, who had actually undergone an induced abortion, could, easily report their missed abortion as a miscarriage to their midwives, thus appeasing their conscience about the induced abortion.

Women who have a pregnancy that results in a miscarriage are not registered in the MBR and therefore not included in this study. The frequency of miscarriage can be reported, as in our study, in relation to deliveries, or in relation to known pregnancies. Nearly 30% of pregnancies in Sweden end as induced abortions and this will lower the incidence of miscarriage, from approximately 25% per delivery to 13% of known pregnancies. Data on all induced abortions in Sweden are available from the Swedish National Board of Health and Welfare (The Swedish National Board of Health and Welfare) and between 1983 and 2003, a total number of 697 832 induced abortions had been performed in Sweden. However, we were not able to use this data, as the self-reported experience of miscarriages does not include in which

year the miscarriage has occurred, nor can it be matched since personal identification numbers are not registered in the induced abortion register.

Smoking has been suggested to be a risk-factor for miscarriage (Cramer & Wise, 2000; Leviton & Cowan, 2002). During the study period, smoking decreased. The odds ratio of 1.14 for miscarriage among smokers is statistically significant (95% C.I. 1.12-1.15) but this increase is so small that it has very little clinical significance. However, at the end of the study period, the odds ratio increased to 1.38 (95% CI 1.28-1.48), which is astonishing and we do not have any possible explanation for this. An odds ratio of 1.38 is not only statistically significant but could also be of clinical significance.

The group of women who experience miscarriage is substantial, as around 25% of all women who have a delivery report that they also have experience of a previous miscarriage. This is somewhat higher than in the population study from Finland (Hemminki & Forssas, 1999) and the register study from Denmark (Nybo Andersen et al., 2000). The risk of a new miscarriage in our study was 13% before first delivery, 8% between first second child, 6% between third and fourth child and 4% between the fourth and fifth deliveries.

Thirteen of these women who had a recent miscarriage were interviewed four months later. The major theme was guilt and emptiness, for all thirteen women. This major theme was influenced by five minor themes and illustrates how women's experiences of miscarriage are described. The women felt that they should be the protectors of their fetuses. The women were happy about being pregnant soon after deciding to try to become pregnant. But if they had a miscarriage, they were fearful about having a second pregnancy, which may end in a new miscarriage. The feelings become emotionally split inside the women.

People experiencing sudden loss search for the meaning of the loss, even if the causes they find have nothing to do with medical reality. The women felt responsible for causing their miscarriages. To give a medical explanation of why miscarriage occurs is difficult, since the cause is, in most cases, unknown (Regan & Rai, 2000).

An indication of when the grieving process is finished is the ability to discuss the loss experiences without emotional reaction (Bonanno, 2001; Worden, 1999; Zeitlin, 2001). Grief is one important aspect of miscarriage and this is in concordance with other studies (Hutti, 1992; Lee & Slade, 1996; Prettyman et al., 1993). There are so many things the interviewed women loses with the miscarriage. In the grief-counseling handbook, it says that miscarriage is a perinatal loss, but there is no child, no memories or no life to grieve (Worden, 1999). Therefore, grief after a miscarriage is more problematic. At the hospital, the women were given adequate medical treatment but the women's feelings of loss ought to be met with sympathy at the hospital. The information was given, but the women were not capable of accepting the

information. They said that they were shocked after the first information that the fetus was dead, information which women were often given in the examination chair, where they feel very vulnerable. But as the ultrasound picture gives the physician the information that the woman has suffered a miscarriage, this situation is not favorable but inevitable. Even the woman needs to see the picture and to see that there is no viability of the fetus or blighted ovum. Another reason for feelings of abandonment on the part of the interviewed women is that they are neglected by those closest to them. Even this aspect has been discussed by other authors (Berry, 1999; Swanson, 1999b), i.e. that women and their husbands grieve in different manners that can cause conflict in their relationship. In conclusion, in the present study (II), women who have had miscarriages tell us that it is a loss of a pregnancy, an expected child, and the future with it and motherhood. The feelings are guilt and emptiness and they need time to grieve. The women wanted to be seen as the women they felt themselves to be. They wanted their questions to be answered. They came up with their own causes of the miscarriage and they felt guilty for what had happened.

The American Psychological Association has, from the perspective of the latest scientific knowledge on grief, coping and care, given out the "Handbook of bereavement research; consequences, coping, and care" (Stroebe et al., 2001a). Their aim is to combine the theoretical approach with research results, and to identify and create a debate around contrasting results. Leading researchers and clinicians from different parts of the world, such as Australia, Canada, Germany, Israel, the Netherlands, the United Kingdom and the United States, have contributed to the book and have created recommendations for researchers, practitioners and health care professionals. The book recommends the use of the short version of the perinatal grief scale (PGS) (Neimeyer, 2001).

Despite the instrument appearing, at first glance, to be easy to translate, it is however quite a time consuming process and not something that can be done easily. The aim of publishing this translation of the short version of PGS is to make a Swedish grief scale designed for perinatal loss available to others (Appendix 2).

A comparison between a 5-point and a 10-point Likert scale was carried out. A 5-point and a 10-point Likert scale give concordant answers, as confirmed by a weighted Kappa coefficient of 0.58, even though the 10-point has a slightly higher mean total score than the 5-point scale.

The results of a follow-up visit to midwife show that the effect of the structured visit, which was influenced by Swanson caring process (group 1), was not statistically significantly better than the regular visit (group 2). The difference between the first and second measurements showed, however, 30% greater reduction in grief in group 1 as compared with group 2. However the women's own estimation of the importance of the second visit was significantly greater in group 1, structured visit. However, this was not reflected by a greater reduction in

the PGS score, as was stated in our hypothesis. It could be explained that the grief working process has been completed after 3-4 months, as suggested by Lee et al. (1996). Earlier studies have shown that 30-50% of women are depressed after early miscarriage (Beutel et al., 1995; Broen et al., 2004; Geller et al., 2001; Lee & Slade, 1996; Nielsen et al., 1999). These studies have, however, used depression scales. In the PGS-scale, difficulty coping correlates with depression (Potvin et al., 1987). Our results show that the PGS-score of difficulty coping changed little during our observation time, indicating that the women are not depressed. As active grief is more reduced during the observation period, this would indicate that the normal grieving process is in place.

Women with the diagnosis of missed abortion had significantly higher active grief at measurement two than women with the other types of miscarriage. The effect of a structured visit was not different among this subgroup of women. Half of the women with missed abortion actually had a higher score at the second measurement. We therefore asked ourselves why missed abortion as a group had more grief than the other groups. In the open question of what was bad regarding the care the women had received, they answered that they had been in contact with the hospital many times before they had received an appointment. They had a suspicion that something was wrong with the pregnancy; no nausea, breast tension had gone away but they had only had one very scanty bleeding. Unfortunately they were often given the information that this is normal, nothing to worry about. This seems to create a credibility gap between the hospital and the patient. This may be one of the reasons for the high PGS-score.

The staff's knowledge and understanding should increase in accordance with the findings of this study. This will, in turn, increase their ability to give information and answer the women's questions. Women need confirmation of their suspicion that they have suffered a missed abortion. The structured visit is not of great importance for all women with early miscarriage but women who experience missed abortion might be in greater need and this will be further addressed in a new study.

By classifying grief according to Bonanno's taxonomy and measuring it according to numbers of meaning-bearing units, one can obtain a measure of grief, or its intensity and difficulties encountered in the experience of grief. This grief is then comparable among different groups and cultures. In Sweden, women who experience early miscarriage have been found to undergo a grief process in accordance to the general principles of grief, as laid down by Bonanno and Kaltman.

What distinguishes grief in women who have suffered miscarriages is that there are no memories, no object to grieve, and other people are unaware of the woman's loss, in contrast to the loss of a close relative (Brier, 1999). The grief process after miscarriage is more rapid than after other losses. Following early miscarriage, the most intensive grief lasts for a few days,

up to a week, and most of the grief process is over after four to six weeks. After four months, most women have emerged from the normal grieving process (Brier, 1999; Wolff et al., 1970). In a previous study, paper II, the women reported that they stayed in bed at home for a few days because they had abdominal or back pain and were tired. After that, life had to go on. In paper IV, a third of the women were absent from work because of the miscarriage for only one day.

In the factor analysis, three of Bonanno and Kaltman's categories are; cognitive disorganization, dysphoria and social, will make up to one factor, subsequently we summarize them to one new category, "Bonnano grief" as they more or less measure the same. Bonanno and Kaltmans's difficult and complicated taxonomy and the considerably easier and quicker PGS make up one factor. PGS measures a woman's grief in relation to her social network and functioning. Bonanno and Kaltman's taxonomy measures the manifestations of a woman's grief.

From the step wise (forward) multiple regression analysis there is a correlation between the intensity of the grief measured with the perinatal grief scale (PGS1) and Bonanno's grief, and the length of the interview. As PGS, is simpler to answer and to analyze it can be recommended for use in identifying women with insensitive grief (Toedter et al., 2001).

As a secondary outcome variable, multiple regression analysis was performed showing that the number of children, woman's age, and number of previous miscarriages are unconnected with the intensity of the grief, as expressed by the number of meaning-bearing units. Women who had never miscarried before experienced and described as much grief as those who had suffered more than one prior miscarriage.

From Bonanno and Kaltman's positive experience, it becomes obvious that traumatic experience such as miscarriage can have a positive effect. The women had good support from their husbands and this event binds them together more closely in the future.

The regression analysis also showed that women with the diagnosis of missed abortion had more intensive grief. Many women describe their sense of abandonment and loneliness in relation to the care services (Cognitive disorganization). The women called their local maternity center, emergency department and gynecological clinic repeatedly to set up an appointment for an investigation of their bleeding and had the subtle feeling that something was wrong with the pregnancy. They were told to wait and see, and to come back if their bleeding or abdominal pain worsened. These symptoms start immediately in connection with a complete or incomplete miscarriage, but in the case of missed abortion they are often delayed a few weeks. Sometimes the women found themselves in a long telephone-call queue, or were asked to return the next day. For women who suffer missed abortion, diagnosis takes longer and

they have believed that they were pregnant for several weeks. Instead, their pregnancy was no longer viable. Here, we in the healthcare sector can improve by listening and being more proactive in asking about the women's subtle symptoms and physical sensations.

In the interviews, women described feelings of being abandoned or marginalized and that they experienced loneliness during the consultation (Dysphoria). The encounter visit to the physician and staff is routine-based and devoid of empathy for the woman's loss of so much more than the tiny embryo or fetus. Others, have described gaps in the information provided and a lack of empathy toward women who have miscarriages (Brier, 1999; Prettyman et al., 1993). The reaction among health professionals is to think of a miscarriage during the first trimester as an extremely common occurrence. To them, it is an everyday event and nothing momentous.

If the staff bear in mind the fact that the woman's first visit to the physician is when she is told of her loss (i.e. the miscarriage is diagnosed) and by the same token, her grief process begins, their response should contain more empathy and confirmation of every woman's reactions. As Worden (Worden, 1999) expresses it, miscarriage is the loss of a person-to-be. This is why it is important for grief work to be done. This includes talking about the loss.

General grief involves moderate disruption in cognitive disorganization, dysphoria and social disruption, as described by Bonanno and Kaltman (2001). As women express normal grief it must be erroneous to use scales that measure depression, anxiety or PTSD. There will be an overlap between grief and depression and thus the women will score high on depression because of normal grief. The women must have the possibility, after their loss, of expressing and working through their grief before they can finish this pregnancy – their loss emotionally. The caregiver must facilitate this process and accept that the intensity of the grief is not dependent on the woman's age, or her number of earlier miscarriages.

## **5 Conclusions**

- Approximately 25% of all women who deliver report that they also have experience of a previous miscarriage.
- Between 1983 and 2003, the frequency of self reported experience of miscarriage increased.
- This increase of miscarriage can be explained both by the introduction of sensitive pregnancy tests around 1990 and the increasing mean age of mothers.
- The risk of miscarriage is 13% with the first child. With subsequent pregnancies, the risk of miscarriage is 8%, 6% and 4% with the second, third and fourth child, respectively.
- Women's feelings after miscarriages involve guilt and emptiness.
- Women with miscarriage came up with their own explanations concerning the cause of the miscarriage and they felt guilty about what had happened.
- The women wanted to be seen as the women they felt themselves to be mothers -to –be.
- Women should be taken care of, as they are as grieving women who in most cases have lost an expected child.
- Women with miscarriage wanted their questions to be answered and need time to grieve.
- A structured visit is not of great importance for all women with early miscarriage.
- Women with the diagnosis missed abortion have a higher Perinatal grief scale (PGS) score four months after their miscarriage.
- Women's experience of grief after miscarriage is similar to general grief experienced after the death of relatives.
- Experience of grief after miscarriage can be measured using the Perinatal Grief Scale, as this instrument contains all the expressions of grief described by Bonanno and Kaltman.
- The intensity of the grief was independent of number of children, women's age and earlier experience of miscarriage.
- As the miscarriage occurred so early, friends and relatives did not know about the miscarriage and could therefore neither discuss the experience nor understand the women's grieving reactions.

# **6 Clinical Implications**

Miscarriage has medical, psychological and social aspects in a woman's life cycle. Who is best suited to support women during early pregnancy?

Talking about early pregnancy could reduce the silence and loneliness surrounding women who experience miscarriage. If her pregnancy is known about, the woman has a greater chance of receiving support in her grieving process.

All pregnant women should receive information about whom to consult if suspicion of early miscarriage occurs. As the first consultation is often carried out over the telephone, the staff must be competent in asking questions, neither too many nor too few. Good listening skills are therefore desirable. Most women could wait for an examination at a scheduled time when the physician has the possibility of reducing waiting-times; give good treatment, valuable information and advice.

Women should be encouraged to grieve their miscarriage.

The first treatment occasion has a great impact on the woman's grieving process after her loss. Every woman should be given written information with telephone numbers of those to contact when questions arise. This is because she is in a state of shock when the information is given, even if miscarriage was what she suspected.

The 'confidence gap' towards the health care system, expressed by women with missed abortion, needs to be addressed, probably by changing routines.

Even young women, experiencing their first miscarriage, have to be met in their grief, not only multiparous women.

A few women will need extra support after their early miscarriage.

## 7 Future Research

Women with missed abortion need to be further investigated. Would better information from all persons involved in taking care of women with missed abortion lead to a reduction in their grief reaction? Careful questioning regarding medical history could possibly give them the inevitable diagnosis of missed abortion a few weeks earlier.

Could women at risk of suffering complicated grief in some way be identified?

Women's fear and anxiety during their next pregnancy after miscarriage needs to be investigated further. What is the medical need? What do the women feel they need and who can provide this?

Is the traditional care of early pregnancy optimal?

## Conclusion in Swedish

# Sammanfattning på svenska

Varje år är det många kvinnor som får ett missfall. Några av dessa kvinnors upplevelse ligger till grund för denna avhandling.

## **Syften**

För att besvara forskningsfrågorna har varje studie ett specifikt syfte:

**Studie 1** Hur vanligt är missfall bland svenska kvinnor och att undersöka om frekvensen av missfall förändras över tiden.

Studie 2 Att identifiera och beskriva kvinnors upplevelser av tidiga missfall.

**Studie 3** Att översätta kort versionen av Perinatal grief scale (PGS) till svenska samt att testa skalan i en lien pilot studie. Ett ytterliggare syfte var att jämföra 5-gradig och 10-gradig Likert skala.

**Studie 4** Att identifiera kvinnors behov av återbesök till barnmorska efter missfall och om strukturerat återbesök kan minska sorgen fyra månader efter missfallet.

**Studie 5** Är kvinnors upplevelser av sorg efter missfall lika sorgen efter förlust av nära anhörig samt att testa med faktors- och regressionsanalys om sorg intensiteten enligt Bonannos kategorisering samvarierar med kvinnans ålder, antal barn, tidigare missfall, typ av missfall och med PGS.

### Studie 1

Data från Medicinska födelseregistret 1983-2003, inkluderade 2 136 809 förlossningar i Sverige som studerades. Av de kvinnor som har fött barn rapporterar 25% att de före denna förlossning har upplevt minst ett missfall. Av kvinnorna som fött sitt första barn var 13,7% som hade upplevt minst ett missfall tidigare. Mellan första och andra barnet var det 8% som haft missfall, mellan andra och tredje 6% och för de med fyra förlossningar var det 4%. En ökning av antalet missfall har skett under studieperioden. Tänkbara orsaker är ökad medelålder bland förstföderskorna, men större betydelse har troligen införandet av känsligare graviditetstester omkring 1990.

### Studie 2

Genom intervjuer med tretton kvinnor framkommer det att de känner skuld och tomhet fyra månader efter missfall. De uppvisar olika symtom på sorg och känner sig övergivna både från maken och från vården. Dessa upplevelser influeras av kvinnornas tidigare upplevelser i livet. Tankarna på att bli mor ger dem en positiv identitet i samhället. Deras graviditet var ofta välplanerad, kanske efter flera års barnlöshet. Kvinnorna kan också ha oavslutade sorgprocesser efter tidigare dödsfall i familjen. Ett missfall upplevs ibland som ett straff för tidigare genom-

gångna aborter. Just när missfallet inträffar beskriver kvinnorna hur de saknar kontroll över vad som händer i kroppen. De kommer ihåg exakt var och när missfallet inträffar. När de kommer till akuten får deras besvär ibland låg prioritet och de får en lång osäker väntetid. Kvinnorna känner att det är något fel med deras graviditet samtidigt som de förnekar det tills de ser det på ultraljudsbilden. Kvinnorna tröstas, men de saknar en förståelse av deras upplevelser av att ha ett missfall. Inför framtiden innebär missfallet att kvinnorna förlorar möjligheten att bli mor nu. De är rädda för att bli gravida igen eftersom det var något fel i deras kropp som orsakade missfallet. De är också rädda för att de inte ska bli mödrar innan de är för gamla. Har kvinnorna barn tidigare så försvann kanske deras möjlighet att vara hemma med syskonen gemensamt under en längre tid. Missfallet innebär även svårigheter med ekonomin och därmed att planera för en ny graviditet. Kvinnorna har inte bara förlorat en tidig gravitet med ett några millimeter stort foster. De har förlorat sina drömmar, sin planerade framtid och sin identitet som gravid kvinna och blivande mor.

### Studie 3

Den rekommenderade sorgskalan från litteraturen är Perinatal grief scale (PGS) som är anpassad till perinatala förluster. Denna översattes till svenska, "Hur mår du?" Vid översättning måste även hänsyn tas till kulturella olikheter förknippade till språket. Det är ingen signifikant skillnad mellan att använda en 10-gradig eller en 5-gradig skala.

## Studie 4

Barnmorskebesöken var upplagda som en randomiserad interventionsstudie. Hälften av kvinnorna erbjöds ett strukturerat återbesök 4 veckor efter missfallet, utifrån Swansons omvårdnadsteori. Effekten av interventionen mättes med sorgskalan "Hur mår du?" (PGS). Kvinnorna besvarade även betydelsen av återbesöket på en visuell analog skala. Det var trettio procent större minskning av sorgen mätt med PGS efter det strukturerade återbesöket än det vanliga barnmorskebesöket. Men denna skillnad var inte signifikant. Det framkom att efter fyra månader mådde en del kvinnor (n=20) sämre än vad de gjorde fyra veckor efter missfallet. Av dessa hade 18 (87%) subdiagnosen missed abortion. Tänkbara förklaringar till varför kvinnor med missed abortion mår sämre är att deras symptom på missfall är mindre, otydligare och förväxlas i första skedet med ofarlig blödning under graviditeten. Vid den första kontakten med vården, bemöttes de inte i sin oro för symptom och känslan av att något var fel i kroppen.

## Studie 5

Av de strukturerade samtalen i studie 4 bandades 25 intervjuer. Dessa skrevs ut ordagrant och analyserades med innehållsanalys. Bonanno och Kaltman's kategorisering av sorg efter förlust av nära anhörig i fem grupper användes som kodningsmall. Kvinnor upplever sorg efter missfall på samma sätt som sorg efter förlust av nära anhörig. Faktoranalysen gav att det var ett starkt samband mellan "Hur mår du?" (PGS), tiden på samtalet och de negativa kategorierna från kodning, (känslomässig oordning, olustkänsla och hälsobrister) ifrån Bonanno och Kalt-

man fem kategorier av generell sorg. Det fanns i detta material inget samband mellan kvinnans ålder, antal barn eller, antal missfall.

# Sammanfattning

Av de kvinnor som föder barn rapporterar var fjärde att hon har upplevt minst ett missfall. En ökning av självrapporterade missfall har skett under åren 1983-2003. Detta förklaras av den ökade medelåldern hos barnafödande kvinnor och införandet av känsligare graviditetstester. Risken för missfall är 13% före första barnet, 8% mellan första och andra barnet, 6% till tredje barnet och 4% till fjärde barnets födelse. Kvinnors känsla efter missfall är skuld och tomhet. De söker orsakerna till missfallet hos dem själva. Kvinnorna vill ha svar på sina frågor och önskar bli sedda i sin känsla som var "en blivande mamma". De behöver tid att sörja sin förlust. Mycket påverkar kvinnornas sorg efter de tidiga missfallen, som bemötande och information. Strukturerat återbesök påverkar inte sorgen signifikant efter tidiga missfall. Kvinnorna behöver tid att bearbeta sin förlust och en del behöver stöd i detta. De kvinnor som har subdiagnosen missed abortion har mer sorg efter fyra månader än kvinnor med andra missfallsdiagnoser, mätt med PGS.

Kvinnornas sorg efter tidiga missfall är lika den sorg som finns efter förlust av nära anhörig. Sorgen är oberoende av kvinnas ålder, antal barn, samt tidigare erfarenhet av missfall. Eftersom missfallen är tidiga så är oftast inte graviditeten känd av släktingar och vänner. Därför kan det vara svårare att diskutera sin upplevelse med andra och få förståelse för sin sorgreaktion.

## Acknowledgments

The research presented in this thesis was carried out at the Department of Obstetrics and Gynecology, Skaraborg hospital, KSS. My affiliation to the department is gratefully acknowledged. I would like to express my sincere gratitude to the women who participated in the different studies. I would also like to thank all those named below.

My main supervisor and co-author **PG Larsson**, MD, Associate professor. Without his encouragement, I would never have completed this thesis. His enthusiasm, knowledge, guidance in clinical research, quick responses to my questions and his strength in always encouraging me has been invaluable.

Professor **Mats Hammar**, Prefect and professor at the Department of Obstetrics and Gynecology, IMK, Faculty of Health Sciences, Linköping University. Thanks for giving me the opportunity to be a PhD student and thanks for all your advice on how to navigate the academic administrative jungle.

Midwife **Ragna Renström**, Nursing head, Department of Obstetrics and Gynecology Skaraborgs sjukhus, Skövde for support and for making it possible for me to complete this thesis, remain employed at the department in Skövde and for arranging financial support.

**Karin Tullander**, MD, medical head at the consultation ward, Department of Obstetrics and Gynecology, Skaraborgs sjukhus, Skövde. Implementation of the new medical PM and miscarriage journal in the clinic, which facilitated me in finding patients, giving each women a correct diagnosis and providing some background variables.

Professor **Anders Selbing**, MD, PhD, my co-tutor for good advice and constructive criticism, and for support. You directed me in clarifying my conclusions scientifically

Associate professor **Carina Berterö**, RN, RNT, BScN, MScN, PhD, co-author of papers I and IV. Thank you for introducing me to qualitative method research in the science of nursing, guidelines and for all our interesting and stimulating discussions.

Professor **Barbro Wijma**, MD, PhD, department of Genus and Medicine, IMK, Faculty of Health Sciences Linköping, my co-author of paper I. Thank you for providing me with the basis of advanced research and stimulating my interest in qualitative methodology.

The Skaraborg Institute for Research and Development represented by the director, Professor **Ingela Krantz**, Professor **Beth Maina Ahlberg**, psychologist **Christina Lundqvist**, PhD, **Anneli Darheden** and the PhD-students. You have provided a very stimulating centre of scientific conversation, reflection and education.

**Karin Kullberg**, MD, statistician, for helping with all statistical issues.

Susan Barclay Öhman, PhD, for English language revision.

**Gerald Wallstersson,** MD and **Sonja Kvint**, MD, head of the Department of Obstetrics and Gynecology Skaraborgs Sjukhus, Skövde, who made it possible for me to complete this thesis.

Midwife **Marita Nilsson**, head of the Gynecological outpatient clinic, Department of Obstetrics and Gynecology, Skaraborg Sjukhus, Skövde for daily contact as my colleague and for facilitating me when I was absent from my work at the outpatient clinic while I completed this thesis.

To all the entire staff, midwives, nurses, physicians and secretaries at the Department of Obstetrics and Gynecology, Central Hospital Skövde, especially at the outpatient clinic, for supporting me and for your everlasting patience.

To the Research and Development unit, Skaraborg hospital, Skövde, especially to **Nomie Eriksson, Anna-Lena E-son-Loft, Lisbeth Jinneståhl-Ferrow and Hans Hedelin** for your support.

To the personnel at the library service, Skaraborg hospital, for all your help in tracing the relevant literature.

To **Ingela Bergström**, my friend, for all your support.

To **Birgitta Johansson** KSS, for help with the English language.

And last but not least, to my dear family; my husband **Kjell** and our two boys **Axel** and **Gustaf** for all your support.

Additional financial support was given by Department of Obstetrics and Gynecology Skaraborgs Sjukhus, Skövde, Research and Development unit Skaraborg hospital, Skövde and the Skaraborg Institute for Research and Development.

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Interview No, Line	Meaning –bearing units	Interpret meaning Cluster bearing units	Cluster	Categorizes	Sub-theme	Essence
3/242 3/243 3/244	Men det är så nytt allting Jag vet faktiskt inte hur länge det brukar ta att blöda Sån här sak	Blödningen	Allt är nytt Ingen att fråga	Missfallet Informations brist	Bodily sensation	
3/345 3/246 3/247	Jag har inget Jag har ingen att prata med Hur dom har gjort	Kvinnan har ingen att Frågor fråga hur lång tid det tar Ensamhet	Frågor Ensamhet	Allt är nytt Isolering	Abandonment	
4/117 4/118 4/119 4/120	Jag visste inte ens jag har varit där i alla fall åkt hem och Visste inte hur jag skulle tala om för min Men jag gjorde det Han trodde väl inte att det behövde betyda något	Kvinna fundera på hur hon skulle berätta för mannen. Han trodde inte att blödningen behövde betyda något.	Påverkar allt Mannen Tror ej	Kvinnan känner sig övergiven av mannen	Feeling emotionally split Abandonment Abandonment	]
4/121 4/122	Men jag kände att det är fel Så har det aldrig varit förut	Kvinnan kände att det var fel.	Känslan i kroppen Nya signaler i kvinnas kropp	Nya signaler i kvinnas kropp	Bodily sensation	Empti
4/301 4/302 4/303 4/304 4/305 4/306 4/306 4/308	Beskriva Med det kan ju ha att göra med hur jag mådde innan eller själv vid tillfället Vad jag hade runt omkring mej Det vet jag inte Sorgen detdet klartja det kanske ska jag säja Känner den Oerhörda tomheten även om det är så tidigt Man hinner ställa in sej så snabbt på att va gravid och det är juja Sorgen jag kan lägga mer men störst är nog den där tomheten	Mitt fel.  Totala situ  Tomheten efter det lilla livet som fanns och inte Förväntan finns längre.  Tomhet	ationen	Missfallet Sorg Känsla	Guilt Emptiness Grief Emptiness	iness
4/309 4/310 4/311	Det man hade ett litet liv dår som inte finns långre Det år omställningen och sorgen över det som försvann Sorgen över att inte få var lycklig	Sorgen över att inte få var lycklig	Känsla Förändring Ej lycklig	Tankar Förlust	Loss	

several different round. Clusters gave categorizes. From the categories was the sub-theme identified and this was concluded in the essence the meanings-bearing units were interpreted from their context. Then was the interpreted meaning-bearing units grouped together to cluster in Appendix 1. Some example of analyzes of text from general interview guide. From the text the meaning-bearing units was extracted. The major theme. All meaning-bearing units in this example ended in the emptiness.

## Hur mår du?

# Sätt en ring runt den siffra som bäst motsvarar hur du känner dig.

1. Jag känner mig nedstämd/deprimerad.	1         2         3         4         5         6         7         8         9         10           Inte alls nedstämd         Oerhört nedstämd
2. Jag känner mig tom inombords.	1 2 3 4 5 6 7 8 9 10 Inte alls Oerhört tom tom
3. Jag har behov att prata om fostret/barnet.	1         2         3         4         5         6         7         8         9         10           Inte alls behov av att prata         Oerhört behov av att prata
4. Jag sörjer fostret/barnet.	1 2 3 4 5 6 7 8 9 10 Sörjer inte Sörjer oerhört mycket
5. Jag är rädd.	1         2         3         4         5         6         7         8         9         10           Inte alls rädd         Oerhört rädd
6. Jag saknar fostret/barnet väldigt mycket.	1         2         3         4         5         6         7         8         9         10           Saknar inte alls barnet         Saknar barne väldigt mycket
<ol> <li>Det är smärtsamt att återkalla minnena av förlusten.</li> </ol>	1         2         3         4         5         6         7         8         9         10           Inte alls smärtsamt         Oerhört smärtsamt
8. Jag blir upprörd när jag tänker på fostret/barnet.	1 2 3 4 5 6 7 8 9 10 Inte alls Oerhört upprörd
9. Jag gråter när jag tänker på fostret/barnet.	1         2         3         4         5         6         7         8         9         10           Gråter inte inte alls         Gråter oerhört mycket
10. Tiden går så sakta sedan fostret/barnet dog.	1         2         3         4         5         6         7         8         9         10           Tiden går inte sakta         Tiden går oerhört sakta
11. Jag känner mig så ensam sedan fostret/barnet dog.	1         2         3         4         5         6         7         8         9         10           Inte alls ensam         Oerhört ensam

12. Jag tycker att det är svårt att komma överens/gå. ihop med vissa personer.	. 1 2 3 Inte alls svårt gå iho		5	6	7	8	9	10 Oerhört svårt gå ihop
13. Jag kan inte hålla på med mina vanliga aktiviteter.	1 2 3 Alla vanliga aktiviteter		5	6	7	8	9	10 Absolut inga vanliga aktiviteter
14. Jag har haft självmordstankar sedan förlusten.	1 2 3 Inte alls självmords- tankar		5	6	7	8	9	Oerhört mycket självmords tankar
15. Jag tycker jag har förlikat mig med förlusten.	1 2 3 Oerhört förlikad med förluste	3 4 en	5	6	7	8	9	10 Inte alls förlikad med förlusten
16. Jag har gjort andra besvikna på mig sedan fostret/barnet dog.	1 2 3 Inte alls besvikna	3 4	5	6	7	8	9	10 Oerhört besvikna
17. Jag blir mer förtretlig mot vänner och släktingar än jag borde ha varit.	1 2 3 Inte alls förtretlig	3 4	5	6	7	8	9	10 Oerhört förtretlig
18. Ibland känner jag att jag behöver en professionell kontakt för att få ihop mitt liv igen.	1 2 3 Inte alls behov av kontakt	3 4	5	6	7	8	9	10 Oerhört behov av kontakt
19. Jag känner som jag bara existerar och inte lever sedan fostret/barnet dog.	1 2 3 Lever	3 4	5	6	7	8	9	10 Existerar
20. Jag känner mig annorlunda och utanför också när jag är med vänner.	1 2 3 Inte alls utanför	3 4	5	6	7	8	9	10 Oerhört utanför
21. Jag tycker det är svårt att fatta beslut sedan fostret/barnet dog.	1 2 3 Inte alls svårt att fatta beslut		5	6	7	8	9	10 Oerhört svårt att fatta beslut
22. Det är härligt att leva/finnas till.	1 2 3 Härligt att leva	3 4	5	6	7	8	9	10 Inte alls härligt att leva

23. Jag tar medicin för mina nerver.	1 2 3 Inga mediciner	4	5	6	7	8	9	10 Mycket mediciner
24. Jag känner mig skyldig när jag tänker på fostret/barnet.	1 2 3 Inte alls skyldig	4	5	6	7_	8	9	10 Oerhört skyldig
25. Jag känner mig fysiskt sjuk när jag tänker på fostret/barnet.	1 2 3 Inte alls fysisk sjuk	4	5	6	7	8	9	10 Oerhört fysisk sjuk
26. Jag känner mig oskyddad i en farlig värld sedan fostret/barnet dog.	1 2 3 Inte alls oskyddad	4	5	6	7	8	9	10 Oerhört oskyddad
27. Jag försöker skratta men inget verkar roligt längre.	1 2 3 Skratt/roligt som förr	4	5	6	7	8	9	10 Absolut inget skratt/roligt
28. Den bästa delen av mig dog med fostret/barnet.	1 2 3 Inte alls att bästa delen av av mig dog	4	5	6	7	8	9	Oerhört mycket att bästa delen av mig dog
29. Jag anklagar mig själv för fostrets/barnets död.	1 2 3 Inga själva anklagelser	4	5	6	7	8	9	10 Mycket själv anklagelser
30. Jag känner mig värdelös sedan fostret/barnet dog.	1 2 3 Inte alls värdelös	4	5	6	7	8	9	10 Oerhört värdelös
31. Det är säkrare/bättre att inte älska.	1 2 3 Älska	4	5	6	7	8	9	10 Absolut inte älska
32. Jag oroar mig för hur min framtid ska bli.	1 2 3 Inte alls oro för framtid		5	6	7	8	9	10 Oerhört mycket oro för framtiden
33. Att vara en sörjande förälder är att vara en andra klassens medborgare.	1 2 3 Inte alls andra klassens medborgare		5	6	7	8	9	Oerhört andra klassens medborgare