The grief of late pregnancy loss

A four year follow-up

Joke Hunfeld

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Rouwreacties bij laat zwangerschapsverlies. Een vervolgstudie over vier jaar.

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Theoretical and empirical background and research objectives

1.1 Introduction

In the Netherlands, approximately 200,000 infants are born each year of which 8,000 (4%) display some degree of structural pathology. In approximately 2000 - 2500 (25 - 30%) of those infants, the malformation will be either lethal or will lead to severe physical and/or mental handicaps. The largest category of malformations concerns anomalies as a result of a combination of environmental and hereditary factors, such as spina bifida and congenital heart problems.

In the Netherlands pregnant women with a known increased risk of a fetal abnormality, for instance advanced maternal age, a previously affected child, or being a known carrier of a genetic abnormality, are eligible for prenatal diagnosis. This is also the case when fetal problems are discovered during a basic ultrasound scan, such as severe growth retardation or polyhydramnion.

A considerable number of severe or lethal fetal malformations are diagnosed during the second half of pregnancy, sometimes at 24 weeks or later. In the Netherlands, the legal upper limit for pregnancy termination is 24 weeks. At this stage of pregnancy maternal-fetal bonding, the unexpected emotional trauma of carrying an infant with a severe anomaly and the fact that pregnancy termination beyond 24 weeks is generally illegal, might enhance the psychological burden of the bad news about the unborn baby.

This chapter deals with the present knowledge on prenatal diagnosis, particularly anomaly scanning, its psychological impact on women and specific problems related to late (threatened) pregnancy loss. Furthermore, perinatal grief and its theoretical framework which provides the background for this study, are introduced. A short review is given regarding the determinants of perinatal grief, views on normal versus abnormal grief, and methodological issues in perinatal grief research. Finally, a compilation of the research objectives that will be addressed, is presented.

1.2 Prenatal diagnosis

The tests used in prenatal diagnosis are designed to detect genetic diseases or defects in the unborn infant. The four most important prenatal procedures are: chorionic villus sampling, amniocentesis, cordocentesis, and tertiary centre ultrasonography. A specific test in prenatal diagnosis which is still very much under scrutiny is the maternal serum alpha-fetoprotein test (MSAFP-test).

Chorionic villus sampling (CVS) is used to detect genetic defects in the first trimester of pregnancy (9-12 weeks). Fetal cells are extracted from chorionic villi. These are protrusions of a membrane (the chorion) that surrounds the developing unborn infant. The procedure is carried out through a thin tube via the cervix or by a needle inserted into the maternal abdomen, under ultrasound guidance. The collected cells undergo chromosomal, DNA or biochemical analysis for the detection of specific ge-

netic diseases such as Down's syndrome. Results are available within 8-10 days. Experienced centres generally quote a one per cent fetal loss rate following CVS (De Crespigny and Dredge, 1991).

Amniocentesis is the most widely used technique in the second trimester of gestation (between 15-17 weeks). A needle is inserted under ultrasound guidance through the maternal abdomen into the amniotic sac that surrounds the unborn child. A small amount of amniotic fluid containing fetal cells is extracted and cultured. Cells and fluid are then analyzed for genetic abnormalities, such as Down's syndrome or neural tube defects, including anencephaly and spina bifida. Results are available after 2-3 weeks. The fetal loss rate is 0.3-0.5%.

Cordocentesis entails blood sampling from the umbilical vein. The procedure is similar to that for CVS and amniocentesis. Adequate fetal blood sampling is possible from 19-20 weeks of gestation. It is often used following the detection of fetal anomalies in late pregnancy, since chromosome results are available as soon as 72 hours.

In **ultrasonography** structural disorders such as neural tube defects, central nervous system anomalies, skeletal, kidney and urinary tract disorders can be assessed. The accuracy depends on the experience and skill of the investigator, the type of equipment and fetal age. The test is carried out in an Academic Centre with 1) a laboratory for advanced ultrasound equipment, 2) a clinical genetics centre for chromosomal, biochemical and DNA investigations and 3) a multidisciplinary team of pediatricians, neurosurgeons, pediatric surgeons, pediatric cardiologists, pediatric urologists for medical and surgical management when the infant is born.

Ultrasound energy is absorbed by tissue and produces heat, but as yet there is no evidence of resulting damage at the low intensities used (Galton Institute, 1990). Ultrasound, often used as an adjunct to amniocentesis, is also applied as a separate form of fetal diagnosis, not only for the detection of birth defects but also to establish gestational age, or to detect multiple pregnancy. This technique has been expanded to include real time scanning, which yields a moving picture of the fetus.

The **Maternal Serum Alpha-fetoprotein test** (MSAFP-test) is performed mainly to detect neural tube defects in the second trimester of the pregnancy (between 15-20 weeks) by maternal venous blood sampling. High MSAFP-levels might indicate neural tube defects and low values are indicative of Down's syndrome. However, the MSAFP-test is not a general test for birth defects. The test will identify some normal fetuses as abnormal and will miss a defect in others (Nightingale and Goodman, 1990).

The next section focuses on the ultrasound technique and the psychological impact of prenatal diagnosis with emphasis on ultrasound, since the present medical psychological study concerns the attitudes of women after the sonographic diagnosis of a severe or lethal fetal anomaly.

1.2.1 The ultrasound technique

Ultrasonography, or ultrasound imaging, makes use of high frequency sound waves (3-7 MHz) to visualize the infant while it is still in the womb. Pulsed sound waves are beamed into the uterus through a transducer placed on the maternal abdomen. The

reflected waves are then imaged on a computer screen and printed out (Nightingale and Goodman, 1990).

In the past twenty years a large number of innovations have been introduced in ultrasound equipment allowing considerable improvement in image quality. Up to 15 years ago only static B-mode equipment was used allowing static pictures of the unborn infant. Nowadays, 2-dimensional real-time equipment enables us to continually view the fetus in all its movements. This has greatly added to the accuracy of anomaly scanning (search for structural anomalies).

It has recently become possible to see the direction of fetal blood flow through the heart, its arteries and veins by means of colour-coded Doppler ultrasonography (Wladimiroff, 1985; Stewart and Wladimiroff, 1993).

1.2.2 The psychological impact of prenatal diagnosis

Central issues concerning the psychological impact of prenatal diagnosis are stress, attachment, and decision making. We will discuss these themes below.

Stress in normal pregnancies

Psychological studies on women's experiences of diagnostic ultrasound started appearing in the early 80s (Kohn et al., 1980; Milne and Rich, 1981; Reading and Cox, 1982). These studies reported that "tension was dramatically released by being able to recognise fetal movement or the pulsating fetal heart on the real time scan", although "women frequently needed help in interpreting these." About ten years later Tunis (1993) concludes from a review on the psychological impact of fetal diagnosis that the results of several studies do reveal "subclinical elevations in negative mood states in many women before the procedure (CVS or amniocentesis) and again before results are known".

Whereas invasive prenatal diagnostic procedures are potentially stressful, ultrasound is very different in that it is non-invasive and results are instantly available. Yet, like the other prenatal diagnostic procedures, ultrasound has the potential of directly provoking instead of alleviating anxiety. In this respect it was pointed out that "ultrasound operators are actually in a unique, and potentially difficult situation because the diagnostic procedure is taking place literally before the woman's eyes" (Galton Institute, 1990). As Furness (1987) observed: `patients having antenatal scans are actually sensitive to variations from the routine, and a doctor seeing a major lesion or fetal death cannot fob off the question "does the baby look normal?"'

Stress in high risk pregnancies

It is striking that psychological studies are mainly concerned with the anxiety of women of advanced maternal age[1] who had no particular reason to think that anything was wrong with their baby. These women represent the majority of women undergoing prenatal diagnosis and their experience is likely to be very different from that of women with

[1] The age from which women are eligible to make use of prenatal diagnosis varies between 35 and 38 years. In the Netherlands the age limit was reduced from 38 to 36 years in 1984 (Brandenburg, 1992). It is around this age that the probability of having a chromosomally abnormal baby is greater than that of a spontaneous abortion as a result of the procedure.

indications involving much greater genetic risk.

In addition to anxiety assessments, the psychological impact of the quality of the communication taking place during an ultrasound scan, such as the extent and the specificity of the information offered about the baby on the screen, was assessed. The findings indicate that "a lack of information and a high risk status are both associated with a - further not specified - 'poorer psychological state' of the mother" (Galton Institute, 1990).

As far as we know, no studies focus on the psychological effect of ultrasound scanning in women with a high risk pregnancy resulting from a previous lethal fetal anomaly detected by ultrasound. Therefore we carried out an explorative interview study on 20 high risk pregnant women with the following outcome (Hunfeld et al., submitted).

> *Tentatively four different anxiety patterns could be discerned. Pattern 1: the anxiety level gradually increased approaching the ultrasound scan. Pattern 2: the anxiety level was high from the beginning of the pregnancy and increased abruptly approaching the ultrasound scan. Pattern 3: the anxiety level remained at a base level (i.e. the woman's self-reported anxiety level in a previous normal pregnancy until the lethal fetal anomaly was detected) and increased abruptly approaching the ultrasound scan. Pattern 4: the anxiety level remained at a base level.*
>
> *Whatever the anxiety level, all the women reported relief immediately after the investigation, especially because "the previous anomaly was excluded" and "the investigation was carried out by an experienced and skilled specialist". Yet the majority of the women thought that they would only be reassured when the baby was born healthy.*

Since the majority of the women thought that they would only be reassured when the baby was born healthy, the individual differences in anxiety experiences seem more to reflect different coping styles, for example active approach (i.e. thinking about, talking about) versus avoidant/denial coping styles, than different anxiety levels.

Attachment

An aspect that is unique to ultrasound scanning is its assumed impact on attachment: seeing the image of the baby may have a positive effect on the parents. Lederman (1984) suggested that "having a mental image of one's infant is a precursor to attachment" and that it is "conceivable that the obstetric use of ultrasound provides that image, thus enhancing attachment and facilitating later parent-infant interaction". Particularly American studies have high hopes for ultrasound in this respect. Fletcher and Evans (1983), for example, claim that ultrasound scanning hastens maternal attachment, even before quickening (the commonly assumed start of attachment). They propose that "viewing the fetal form in the late first or early mid trimester of pregnancy, before movement is felt, may result in fewer abortions and more desired pregnancies".

However, the observation of Fletcher and Evans was based on the experiences of only two women. Other - empirical - research findings have been less clear cut. Sparling et al. (1987) found no long-term differential relationship between visualization of the unborn by ultrasound and early maternal attachment. Black (1992; 1993) observed no statistically significant association between mood (measured with the Profile of Mood

Scale) and frequency of ultrasound viewing prior to the loss, although she reports from her interview, that 60% of the women felt that seeing the ultrasound image had made them feel closer to the fetus. According to 44% of the women, seeing the unborn had made coping with the loss more difficult and only 9% reported that seeing the unborn had made coping any easier.

Decision making

The number of women undergoing prenatal diagnosis continues to increase (Rhoads et al., 1989). Since, in 1984, in the Netherlands the maternal age limit for invasive prenatal diagnosis was lowered from 38 years to 36 years and older, an overall increase was seen in the Division of Prenatal Diagnosis of the Department of Obstetrics and Gynecology in Rotterdam[2] from 1668 women in 1984 to 2264 women in 1989. Particularly the utilization of prenatal diagnosis by women of 36 and 37 years of age increased in this period (Brandenburg, 1992). Several Dutch studies observed that following the diagnosis of a fetal chromosome anomaly (≤ 24 weeks of gestation), almost every woman (99%) will decide to have her pregnancy terminated (Thomassen-Brepols, 1985; van de Meent-Nutma, 1990; Brandenburg, 1992).

A number of studies have tried to identify factors or motives for the - actual or hypothetical - decision whether or not to terminate the pregnancy in case of a serious fetal anomaly. These are presented in Table 1.1 and discussed below.

Table 1.1 Factors relating to the decision whether to terminate or to continue a pregnancy

Factors	Relationship	Authors
Education	+	Beeson et al., 1985; Breslau, 1987
Religion	-	Breslau, 1987; Faden et al., 1987
Perceived burden of having a handicapped child	+	Davies et al., 1982; Ekwo et al., 1987
Increased risk or presence of a serious fetal anomaly	+	Faden et al., 1987
Poor prognosis regarding a serious fetal anomaly	+	Beeson et al., 1985; Ekwo et al, 1987; Drugan et al., 1990; Pryde et al., 1992
Exposure to the disability in question	+	Beeson et al., 1985
	0	Breslau, 1987
Previous abortion	+	Faden et al., 1987

+: factor is positively correlated with termination
-: factor is negatively correlated with termination
0: factor is not related to termination or continuation

Breslau (1987) found that having a handicapped child (cystic fibrosis, cerebral palsy, myelodysplasia and multiple physical handicaps) was not related to the women's attitudes on abortion. However, religion and education were: Catholics and women with

[2] This division serves the southwest region of the Netherlands including Rotterdam and suburbs which together represents nearly a quarter of the Netherlands with approximately 45,000 deliveries a year (Brandenburg, 1992).

less education were less inclined to endorse legal abortion than non-Catholics and those with more education. In the study by Faden et al. (1987), 490 pregnant women who were recruited from obstetrical practices participating in a MSAFP screening programme for neural tube defects and Down's syndrome and who had normal (negative) test results, were asked their views on the justifiability of abortion under varying degrees of handicap and of certainty of the diagnosis. Regardless of whether they had participated in the screening programme, the majority of women considered abortion to be justified for both an abstract "other" and themselves. Nevertheless, there was a sharp increase in the number of screening programme participants who said they would have an abortion when the probability of the fetus being affected with a neural tube defect rose from 95 to 100%. These findings are in line with those of Pryde et al. (1992) who evaluated factors influencing the decision to abort after abnormalities were found in a chromosomally normal fetus. They reviewed all pregnancies that were complicated by sonographically-detected structural abnormalities (n=262 in one year). Cases diagnosed after the legal gestational age limit for abortion (≥ 24 weeks) were excluded. Prognostic severity of the abnormality appeared to be strongly correlated with the decision to abort ($p<.0001$) and not the patients' age, gravidity, parity, and the gestational age at diagnosis. About two-thirds of the parents opted for pregnancy termination when the prognosis was poor, which meant certainly a lethal or markedly disabling lesion for which either no adequate therapy was available or extensive surgery was required (i.e. anencephaly, encephalocele, hypoplastic left heart, non-immune fetal hydrops). This percentage decreased to 12% with an "uncertain" prognosis which included "abnormalities having variable natural histories and uncertain outcomes" (i.e. bilateral hydronephrosis without oligohydramnios, neural tube defects). The percentage decreased even to zero per cent with a "mild" prognosis which meant anatomical abnormalities with consequences considered neither disabling nor life-threatening to the future infant (i.e. isolated unilateral uretero-pelvic junction obstruction, unilateral choroid plexus cyst). Drugan et al. (1990) also found that the seriousness of the abnormality was decisive in the decision to terminate the pregnancy; they found that the length of the pregnancy (first or second trimester) was of no influence. In this respect, Faden et al. (1987) point out that counsellors should be sensitized to the fact that although 95% accuracy in diagnosis is very acceptable to many professionals, to parents the psychological difference between a high risk probability and a hundred per cent certainty may be tremendous and may make the difference between deciding to abort the fetus or to bear the child.

The studies by Davies and Doran (1982) and Ekwo et al. (1987) on 100 and 252 pregnant women who were gene carrier coding for a chronic disorder, demonstrated that the basic decision to terminate an affected pregnancy was not so much determined by the objective probability to deliver an infant with congenital anomalies as by the perceived burden of having a handicapped child. Beeson and Golbus (1985) conclude that actual decisions concerning prenatal diagnosis and selective abortion in case of X-linked disorders (hemophilia A and Duchenne muscular dystrophy) indicate that perceived psychosocial consequences are more important than biomedical data and abstract ethical values.

The weakness of several of the above-mentioned studies (Breslau, 1987; Faden et al., 1987; Ekwo et al., 1987) is that women answered to a hypothetical question: no actual fetal abnormality was detected. In addition, in the study of Pryde et al. (1992) the evaluation was done retrospectively by means of medical reports instead of by asking the patient how the decision was made. It is doubtful if the results attained by this methodology are valid for the real life situation in which the woman has to make a choice whether or not to terminate the pregnancy. With respect to the procedure, one may wonder if the woman's decision is different when made after a sonographic diagnosis with the possibility to see the image of the baby or when the diagnosis is made in another way with no image of the baby. We do not know of any empirical studies on the specific impact of the ultrasound procedure on the woman's choice to terminate pregnancy.

After prenatal diagnosis of a severe or lethal fetal anomaly no treatment is available for the unborn baby. The only possible action is "therapeutic abortion"[3] (Leschot et al., 1982). However, according to Dutch legal standards, abortion is generally out of the question late in pregnancy (≥ 24 weeks). Prenatal diagnosis at this stage of pregnancy has, therefore, its specific problems, which are discussed in the next section.

1.2.3 Specific problems of late - threatened - pregnancy loss

The sonographic diagnosis of a severe or lethal fetal anomaly which was established late in pregnancy (≥ 24 weeks) leads in most parents to uncertainty and sorrow. In this period the decision whether or not to terminate the pregnancy and coping with the threatened loss are the dominant features.

Decision making whether or not to terminate the pregnancy

We do not know of prospective psychological studies on the decision making of women late in pregnancy after the sonographic diagnosis of a severe or lethal fetal anomaly. The only study concerning the experiences of women after the diagnosis of a fetal malformation in the 32nd week of pregnancy, showed that three-quarters of these women would have had their pregnancy terminated if the malformation had been detected earlier (Jörgensen et al., 1985). However, although untreatable, the malformations were compatible with life.

What, then, are the benefits of knowing that the fetus has a severe malformation, if pregnancy termination is no longer an option because of advanced gestation? One of the benefits may be that arrangements of suitable medical and surgical care promptly after birth can be made. It is further hypothesized that advance knowledge of a severe or lethal fetal malformation shortens grieving. However, these potential benefits have not yet been subject to critical analysis (Galton Institute, 1990).

Coping with (threatened) pregnancy loss

Not only do we know little about the decision making process, we also have little insight into the reactions upon the - threatened - loss of an infant in a pregnancy of 24

[3] The term "therapeutic abortion" is not correct according to van de Meent-Nutma (1990), since "a therapy is something different from killing life to prevent suffering."

weeks or more. Here it is possible to quote again the study by Jörgensen et al. (1985) concerning how the diagnosis of a fetal malformation influenced the remainder of the pregnancy. All the women (n=14) described the remainder of the pregnancy as a dreadful strain and had great difficulty in forming a realistic picture of their infant. Some wanted to be delivered as soon as possible in order "to put it all to an end". Others wanted to postpone the delivery in order not to be confronted with the child.

Regardless of how prenatal diagnosis was established, knowing that one is pregnant with a malformed infant is an event with radical short term and long term psychological consequences. These consequences might be labelled as "perinatal grief". The remainder of this chapter deals with this issue and its theoretical background.

1.3 Perinatal grief[4]

For about the last 15 years, scientific literature has increasingly recognized that loss of a wanted pregnancy is a traumatic experience (Peppers and Knapp, 1980a; Leppert and Pahlka, 1984; Hohenbruck et al., 1985; Taner Leff, 1987; Theut et al., 1989; Toedter et al., 1988; Keirse, 1989; Timmers et al., 1990; van Spijker et al., 1992). The reactions of the parents after pregnancy loss are compared with those after the loss of an older beloved person and described in terms of a classic grief process. For instance, the grief model of Parkes (1972) and Bowlby (1980) is often cited in this field. From an empirical and a theoretical point of view they distinguish phases of bewilderment, yearning and searching for the lost one, disorganization and despair, followed by reorganization and recovery. Based on their ideas the American psychiatrist Horowitz (1976; 1986) introduced his theory on the Stress Response Syndrome (the SRS). Our study is based on Horowitz' theory concerning the general aspects of grief that follow bereavement. The SRS is discussed in section 1.5.1.

At the same time there is increasing insight into the specific circumstances of pregnancy loss that will lead to specific grief characteristics (Peppers and Knapp, 1980a; Lewis, 1983; Toedter et al., 1988; Leon, 1992; Iles and Gath, 1993) which might make the grieving process more difficult. For example, pregnancy loss takes place at a moment of somatic preparation for and anticipated joy over the arrival of the baby. Therefore, Leon (1990) calls the grief process after pregnancy loss "prospective mourning". He contrasts this to most mourning which is retrospective and based on memories of the deceased. Parents have no concrete image of the lost baby, therefore they have to give up all expectations, hopes and fantasies over a baby who should have lived. Lewis (1983) calls pregnancy loss a "double loss": The woman is left behind with an empty womb

[4] In the English language a differentiation is made between bereavement, grief and mourning. Bereavement is the objective situation of having lost someone significant and refers to the period of time during which mourning is largely unresolved. Grief refers to all painful affects associated with the loss, such as sadness, anger, guilt, shame, anxiety. Mourning refers to a complex interplay of all the psychological processes that are triggered by the loss (including biological reactions, behavioral reactions and cognitive and defensive operations related to the loss). It also denotes the actions and manner of expressing grief which often reflect the mourning practices of one's culture (Zeanah, 1989; Stroebe et al., 1993). We follow this terminology.

and without a child. In addition, pregnancy loss might mean loss of female gender identity which consists of being able to carry a baby to term and take good care of the baby, promoting health and growth (Gilbert and Smart, 1992). Mainly based on clinical observations, several authors argue that the doubts concerning one's adequacy as a marital or sexual partner (Adler and Kushnick, 1982), the feeling of being betrayed by one's own body and lowered self-esteem also render the grief process after pregnancy loss more difficult than that after the loss of an older person (Phipps, 1981). Iles and Gath (1993) observed in an interview the following features of perinatal grief: being upset by pregnant women and by seeing babies, avoiding items prepared for the baby, still feeling pregnant, experiencing emotional distress around the time of the estimated delivery date of the terminated pregnancy, and at anniversaries. Toedter et al. (1988) carried out a standardized study about specific perinatal grief reactions. They assume that the dimensions presented in Table 1.2 are important after perinatal loss.

Table 1.2 Twenty-one dimensions of perinatal grief with examples (Toedter et al., 1988)

Dimensions	Example
Positive overall functioning	I am now functioning as well as before the baby died
Depression (non-somatic)	The best part of me died with the baby
Depression (somatic)	I don't sleep well at night
Social withdrawal	I'd rather people would leave me alone
Shock/Disbelief	It's hard to believe that the baby died
Irritability	I get cross at my friends and relatives more than I should
Preoccupation with loss	I can't avoid thinking about the baby
Sadness	I cry inside for him/her
Fear/vulnerability	I am afraid to have another child
Resolution	I have accepted the baby's death
Self confidence	I now know I can work out problems that face me
Anger	I feel it's unfair that the baby died
Attempts to cope	I try to keep very busy
Fantasies about the baby	I feel that the baby is still with me
Feeling comforted	I don't know what I would do without relatives and friends to lean on
Guilt	I blame myself for the baby's death
Replacement	No one will ever take the baby's place in my life
Locus of control	I feel I don't have control over what happens to me
Loneliness	I feel somewhat apart and remote even among friends
Religion	I sometimes get angry with God for taking the baby away
Jealousy	I feel uncomfortable around pregnant women and small children

1.4 Theoretical background of perinatal grief

Over the years various concepts such as stress and trauma have been used to describe the consequences of extreme experiences. The unexpected event of a (threatened) pregnancy loss fulfils the criteria of a traumatic event as proposed by, among others, Freud (1920), namely complete helplessness, extreme discomfort and acute disruption of the course of daily existence. Grief might be viewed as a special form of coping with trauma. The next section will be devoted to grief theories, particularly Horowitz'

Stress Response Syndrome (the SRS) and Leon's (1992) multidimensional model on perinatal grief. Prior to this, the concepts of stress, trauma and coping are described in short as the general conceptual background against which the theoretical discussion of grief takes place.

1.4.1 The stress concept

Stress has been conceptualized in three different ways: in terms of responses of the organism (predominantly in terms of biological reactions), in terms of characteristics of the environment, and in terms of a lack of fit between characteristics of the organism and those of the environment. The latter approach of stress is now predominant in scientific research and is the most useful to our study. According to this interaction approach, stress arises when there is an imbalance between a perceived demand and a woman's perception of her capability to meet that demand (Cox, 1978). In this respect, several social and individual characteristics are mediating factors for the relationship between stressors (threatened pregnancy loss which initiates stress), stress (an inferred internal state: emotions, cognitions) and strains (consequences of stress: somatic or psychological disturbances) (see also section 1.6).

1.4.2 The trauma[5] concept

"Trauma" can be considered as a specific, intense, form of stress. An objection to the term "trauma" is that it suggests a separate entity that can be seen independently of its context. However, the way Freud originally described it favours an interaction approach. According to him "psychological trauma" takes place when an excessive amount of stimulation overwhelms the ego and evokes anxiety, pain, fright, shame, and feelings of uncontrollability (Freud, 1920). The moment at which this point is reached depends on 1) individual characteristics and personal life history, 2) the person's physical condition (fatigue, exhaustion, illness), and 3) the situational opportunities for action and defense that prevail just before and during the traumatic event (Freud, 1920). Although Freud recognized that some extreme events could have a traumatic effect on all human beings, he concentrated on these individual differences in reaction to stress. This means that mentally unstable persons might be traumatized by objectively less intense traumatic events.

1.4.3 Coping with a traumatic event

Coping is a general term for the conscious ways of dealing with extreme events. Lazarus and Folkman (1984) defined coping as: "...the process of managing demands (external or internal) that are appraised as taxing or exceeding the resources of the person". He distinguishes between two main forms of coping: problem-oriented coping which means changing the disturbed relationship between the individual and the environment. This might be done by direct action and by dealing with the source of the anxiety. An example

[5] The term "trauma" is used freely either for physical injury caused by some direct external force or for psychological injury caused by some external emotional assault (Reber, 1985).

is when a pregnant mother overhears a conversation between two doctors about a child which will be born severely handicapped, goes to the doctor and asks about which child they are talking. The other form is called emotion-regulating or palliative coping and refers to the regulation of the disturbed relationship without tackling the actual causes, mostly intra-psychic processes, such as defense strategies[6], for instance denial. An example of this way of coping is when the aforementioned mother says to herself "they are not talking about my child". The latter form of coping is viewed in terms of management as opposed to mastery and is the most appropriate for our study.[7]

1.5 Grief theories

Many investigators have proposed stages of normal grief after the loss of a loved one through which the bereaved must work in order to resolve grief successfully (Lindemann, 1944; Kübler-Ross, 1969; Parkes, 1972; Ramsay and Happée, 1977; Horowitz et al., 1979; Bowlby, 1980). Prior to the description of Horowitz' trauma theory and the multidimensional model on perinatal grief (Leon, 1992), we discuss briefly the ideas of Freud, Bowlby and Parkes, because Horowitz' and Leon's views are largely based on theirs.

Freud

Freud was one of the first researchers to address the issue of loss. In *Trauer und Melancholie* he outlined certain characteristics of the mourning process that are still considered essential in the most recent literature. According to Freud, the ego defends itself against a psychological trauma (or too many painful stimuli) by means of a stimulus barrier. In the case of perinatal bereavement, the mother tries to keep the thoughts about the loss outside her consciousness. Nevertheless, she often tends to think compulsively and involuntarily back to the moment of the loss and this elicits anxiety. When anxiety increases, the stimulus barrier is raised, thus decreasing the input of stimulation. This process, presented in Figure 1.1, is a kind of feedback cycle.

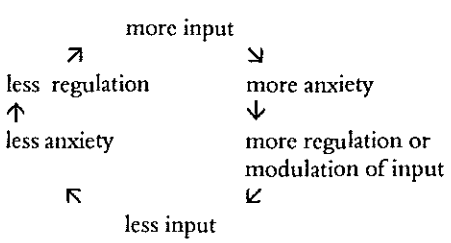


Figure 1.1 The dynamics of the grief process (Freud, 1920)

Freud hypothesized that mental representations of the distressing event were "belated attempts at mastery", motivated by painful feelings arising from the awareness of helplessness in the face of danger. In the case of pregnancy loss, preoccupation with painful

[6] Defense strategy is a general term for any number of strategies that people use to defend themselves from anxiety. Strictly speaking, defense strategies are unconscious mechanisms, while emotion-regulating coping might also be conscious.

[7] In our study the terms perinatal grief and coping with or working through pregnancy loss are used interchangeably.

reminiscences about this experience would help the woman to assimilate the experience which eventually results in a restoration of her emotional equilibrium. This process is also referred to as "coping with" or "working through" the trauma.

Parkes and Bowlby

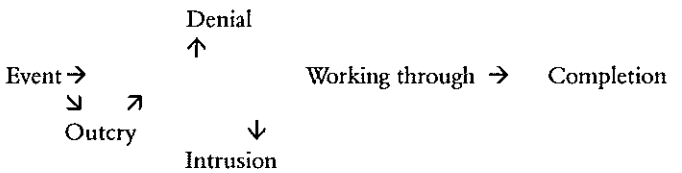
Parkes (1972) and Bowlby (1980) are often mentioned together, because they complement each other in their empirical and theoretical grief research.They state that the preoccupation of the bereaved with the loss indicates an attempt to re-establish the bond with the dead person. Bowlby observes similarities between a surviving partner searching for the deceased and a child's attempts to find his mother again, and its protest against the separation. From a rational point of view, this search is a hopeless matter, as the deceased will not return. Bowlby (1980) believes that the deceased partner is experienced as a comrade who accompanies the bereaved everywhere, or who exists in some familiar place. In Bowlby's view, this indicates that attachment remains, which is diametrically opposite to Freud (1917), who interpreted the grief process in terms of the withdrawal of the libido of the loved person. For Freud grief implied the severing of bonds with the other (Kleber and Brom, 1992).

1.5.1 The Stress Response Syndrome

The American psychiatrist Horowitz based his trauma theory both on the phases of grief as described by Parkes and Bowlby and upon his own research findings concerning war, disaster and grief. It can also be seen as an elaboration of Freud's trauma concept and a representative of the interaction approach of stress. The starting point of our study are Horowitz' ideas, because the coping with the news of the impending death and subsequent loss of the baby can well be understood from his theory and operationalization of coping with trauma. Our description is based on Horowitz' book *The Stress Response Syndromes* (1986) and on Kleber and Brom (1992) in their book *Coping with trauma, theory, prevention and treatment.*

Elaborating upon psychoanalysis, stress research and clinical studies, Horowitz introduced the term "stress response syndrome" (SRS)[8]. He described the SRS presented in Figure 1.2, as "all personal reactions when a sudden, traumatic life event triggers internal responses with characteristic symptomatic patterns".

[8] When one considers trauma as a specific form of stress, a more preferable term might have been "trauma response syndrome."



Phases	Symptoms
Outcry	Almost reflexive emotional outburst, feelings of bewilderment and disbelief, screaming
Denial	Emotional numbness, avoidance of thoughts and images of the extreme event
Intrusion	Nightmares, pangs of emotions concerning what has happened
Working through or integration	Fewer unbidden thoughts and uncontrolled pangs of emotions
Completion	Reality and schemas are adapted

Figure 1.2 The Stress Response Syndrome

It often begins with a feeling of bewilderment and disbelief ("it cannot be true!"), sometimes accompanied by crying or screaming. Intrusion and denial are labels for two extremes of responses to stressful life events. Intrusion means the surge of emotions and images that directly or indirectly imply the re-experiencing of the event. Denial refers to an intrapsychic process, in which the implications of the event are denied and which is expressed through emotional numbness, the avoidance of thoughts and images of the extreme event, the avoidance of activities reminiscent of what has happened, and a loss of sense of reality. Examples of intrusion include nightmares, startle responses triggered by situations similar to the original event, daydreams, pangs of emotions concerning what has happened and preoccupation with the event. A main characteristic of the SRS is that intrusion and denial alternate, Horowitz refers to this as "oscillation". He claims that precisely through this alternation the individual copes with the event and related implications which are gradually integrated into his or her awareness. In the working through or integration phase, fewer unbidden thoughts and uncontrolled pangs of emotion emerge and the intensity of denial diminishes. The sense of reality increases. Moods become more stable and the significance of the event is more readily accepted. Eventually the completion of this coping process takes place. Instead of "completion", Bowlby's terms "reorganization" or "recovery" might be better words, since completion wrongly suggests that sorrow stops.

Although Horowitz gave the label "syndrome" to this response pattern and thereby implied that these responses are symptoms of illness, no precise distinction is made between symptoms triggered by an extreme event and prior tendencies toward neurotic symptoms, which are manifested as a result of the event. It is a predictable reaction pattern with normal and pathological variations. The pathological SRS is a coping process that takes longer, becomes blocked or too intense (see also section 1.7).

Explaining the Stress Response Syndrome

Horowitz introduced the concept of "schema" to clarify the SRS. Schemas are the opinions and expectations which persons have built up about themselves and the world and which are rarely verbalized (for example, the faulty assumption that women give birth to healthy children and that babies do not die). Individuals continuously absorb new information that fits in with existing schemas. It is these schemas that fail after pregnancy loss. The result is a discrepancy between the implications of the loss and the existing schemas of the individual and, according to Horowitz, this discrepancy creates emotions.

To explain why the bereaved has to deal with the emotions after the traumatic event, Horowitz (1986) introduced the concept of "completion tendency". The completion tendency means a strong urge or compulsion to integrate new information about the event with the existent assumptive world and to establish consistency between old and new schemas. A simple representation of Horowitz' theory is presented in Figure 1.3.

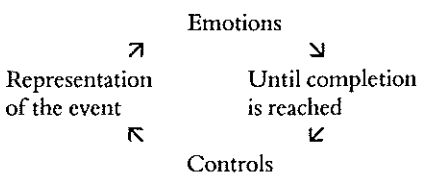


Figure 1.3 The origin of the SRS (Horowitz, 1986)

To establish integration of the pregnancy loss into daily life, the memories are presented repeatedly and the loss is re-experienced each time, until finally the reality and the schemas are adapted to each other. The degree to which the experience of the loss keeps returning in the individual's mind and to which emotions are reduced or activated, is regulated by "controls". Controls are processes that govern mental functioning, such as defense mechanisms formulated in psychoanalysis. These control processes work in such a way that the representation of the loss is inhibited or accelerated (in accordance with "the dynamics of the grief process" as shown in Figure 1.1). Optimal control delays the intrusion and yields tolerable dosages of the new information and the emotions. This leads to an optimal alternation between denial and intrusion. Too much control prevents the repeated representation and prevents further processing. Too little control gives way to excessive emotions and a continual return of the traumatic experience. An optimal control leads to both denial and intrusion. The intrusive experience leads to a revision of the expectations and ideas of the individual. Thus, completion can occur. Completion implies that the person is no longer, or hardly ever, overwhelmed by anxieties or memories and at the same time no longer tends to avoid the images of the loss.

Horowitz' ideas are criticized, for instance by Kleber and Brom (1992) who consider his description of the grief process as too cognitive (i.e. *appraisal* of the meaning of the loss and integration of old *information* with new *information*), ignoring emotions and the content of what has to be completed. The ideas of Leon (1992) form an important addition to Horowitz' SRS, particularly in the field of perinatal grief.

1.5.2 A multidimensional model of perinatal grief

According to Leon (1992), the impact of pregnancy loss cannot be understood as separate from the meaning of pregnancy to the woman. From a psychoanalytical point of view, he proposes a multidimensional model to understand pregnancy loss. He interprets pregnancy as 1) a developmental milestone, 2) a revival of earlier instinctually charged conflicts, 3) the creation of a new relationship, and 4) an enhancement of oneself. For this reason, pregnancy loss means not only the loss of the baby, but also a number of other frustrations, such as the development towards (parenthood) motherhood, meeting the instinctive need to care for and to receive, and the loss of the opportunity to increase one's self-worth through the pregnancy. According to Leon, "most researchers adhere to the prevailing model of infant loss, comfortably using measures of mourning designed for other bereavements such as the death of a spouse" (LaRoche et al., 1982; 1984; Nicol et al., 1986; Smith and Borgers, 1988-9; Friedman and Gath, 1989; Black, 1989; Prettyman et al., 1993; Iles and Gath, 1993) "and thereby disregarding important developmental, narcissistic, and conflict-related effects of perinatal death that would go undetected by these limited measures". In this respect, he welcomes the construction of measures specifically oriented to perinatal loss, such as the Perinatal Grief Scale (PGS) including items which index narcissistic damage (Leon, 1992).

1.6 Determinants of perinatal grief

The pregnancy loss does not take place in a void. Different factors interplay to determine the grief reactions to the loss. Figure 1.4 presents a model which consists of three general groups of determinants: 1) the obstetric context; 2) individual characteristics and 3) social environment. The latter two both function as moderating variables.

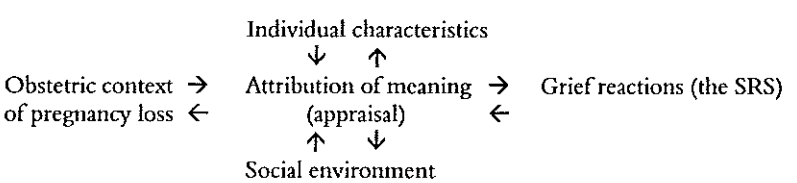


Figure 1.4 Determinants of perinatal grief

The following is a short review of the major findings with regard to the effect of these determinants on perinatal grief. A summary of these effects is presented in Table 1.3. This table only includes empirical studies (i.e. studies in which standardized measures and statistical analyses were applied).

Table 1.3 Determinants of perinatal grief

Determinants	Effect	Authors
Obstetric context of pregnancy loss		
Previous perinatal loss	0	Forrest et al., 1982; LaRoche et al., 1984; Nicol et al. 1986; Toedter et al., 1988; Smith et al., 1988-9; Black, 1989; Janssen et al., 1992
	+	Friedman et al., 1989; Beutel et al., 1992
Pregnancy planned	-	Prettyman et al., 1993
	0	Friedman et al., 1989; Beutel et al., 1992
Fertility problems	0	Forrest et al., 1982; Toedter et al., 1988
Period of gestation before loss (≤ 16 wks vs ≥ 16 wks)	+	Kirkley-Best, 1981; LaRoche et al., 1982; Toedter et al., 1988; Theut et al., 1989; Janssen et al., 1992; Black, 1993
	0	Smith et al., 1988-9; Iles et al., 1993
Seeing and holding the dead baby	-	Kirkley-Best et al., 1982; Theut et al., 1989
Seeing and *not* holding the dead baby	+	Nicol et al., 1986
	0	LaRoche et al., 1984; Tudehope et al., 1986
Type of malformation	#	
Unexpectedness of the loss	0	Tudehope et al., 1986; Janssen et al., 1992
Hospital care (i.e., usual vs special care)	-	Forrest et al., 1982; Harmon et al., 1984; Nicol et al., 1986; Murray et al., 1988; Mourik et al., 1994
	0	LaRoche et al., 1984; Tudehope et al., 1986; Janssen et al., 1992
Early subsequent pregnancy or birth of a viable child (6 months)	+	Forrest et al., 1982; Theut et al., 1988; 1990; 1992
	0	Rowe et al., 1978; LaRoche et al., 1984; Smith et al., 1988-9
Individual characteristics		
Age	-	Kirkley-Best et al, 1982
	0	LaRoche et al., 1984; Nicol et al., 1986; Tudehope et al., 1986; Toedteret al., 1988; Turner et al., 1991; Janssen et al. 1992; Prettyman et al., 1993
Religion	0	Nicol et al., 1986; Black, 1989; Toedter et al.,1988; Janssen et al., 1992
Pre-loss mental health	+	Toedter et al., 1988; Friedman et al., 1989; Janssen et al., 1992
	0	Forrest et al., 1982; Black, 1989
(Intensity of) early grief reaction	+	Tudehope et al., 1986; Black, 1989
	0	LaRoche et al., 1984
Social environment		
Quality of partner relationship	-	Forrest et al., 1982; LaRoche et al., 1984; Nicol et al., 1986; Toedter et al., 1988; Black, 1989; Janssen et al., 1992
	0	Prettyman et al., 1993
The presence of siblings	0	Forrest et al., 1982; Nicol et al., 1986; Tudehope et al., 1986; Toedter et al., 1988; Friedman et al., 1989; Black, 1989; Turner et al., 1991; Janssen et al., 1992; Prettyman et al., 1993
	+	LaRoche et al., 1984
	-	Kirkley-Best, 1981
Social support	-	Forrest et al., 1982; Nicol et al., 1986; Tudehope et al., 1986; Murray et al. 1988; Toedter et al., 1988; Janssen et al., 1992

+: determinant is positively correlated with intensity of grief or disordered mourning, other than grief intensity
-: determinant is negatively correlated with intensity of grief
0: determinant is not related to intensity of grief
#: determinant is not studied

1.6.1 The obstetric context

With respect to the obstetric context of pregnancy loss, the majority of research findings on the relevance of *having lost a baby in a previous pregnancy* show no effect on perinatal grief (Forrest et al., 1982; Nicol et al., 1986; Toedter et al., 1988; Black, 1989). However, according to Beutel et al. (1992) habitual abortion (three times or more) evoked more depression, operationalized with the perinatal grief scale (PGS) (Toedter et al., 1988), than not having experienced habitual abortion, but only in childless women.

With regard to *planned vs unplanned pregnancy*, Prettyman et al. (1993) found significantly more "anxiety cases", operationalized with the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983) at week 12 amongst those women whose pregnancy was unplanned. Most research findings on the effect of the *length of gestation at the time of the pregnancy loss* indicate more grief when the loss took place late in pregnancy (Kirkley-Best, 1981; La Roche et al., 1982; Lovell, 1983; Rosenblatt and Burns, 1986; Toedter et al., 1988; Theut et al., 1989; Janssen et al., 1992). Kirkley-Best (1981) claims that the length of gestation was even the most important predictor of grief: the later the loss, the greater the grief.

On the other hand, a number of studies suggest that for many women early pregnancy loss or miscarriage is an even more profoundly adverse life event (Lovell, 1983; Leppert and Pahlka, 1984; Hall et al., 1987; Stirtzinger and Robinson, 1989). For example, Hall et al. (1987) claim, from a psychoanalytical point of view, that pregnancy loss during the narcissistic stage of pregnancy which is assumed to last until the first quickening, entails more grief than neonatal loss. They attribute this to the fact that early pregnancy loss might be experienced more as a loss of a part of oneself which is harder to accept than the loss of an external object (which is in accordance with Leon's view (1992) on pregnancy loss as loss of self-esteem). Leppert and Pahlka (1984) propose that in many cases of early pregnancy loss, "when the size of the uterus is not yet visibly evident, friends and even family members may not be aware either of the pregnancy or of the loss of it, making the spontaneous abortion even more of a private and unshared burden for the couple to bear". Some authors found no difference between the length of gestation at the time of the loss and the intensity of perinatal grief (Peppers and Knapp, 1980a,b; Smith and Borgers, 1988-9). However, the latter studies are difficult to interpret, due to small or atypical samples, retrospective design or lack of standardized measures.

Most researchers agree that *seeing and holding the dead baby* facilitate grieving in the woman (Kirkley-Best and Kellner, 1982; Lovell, 1983; Rosenblatt and Burns, 1986; Nicol et al., 1986; Theut et al., 1989). In her descriptive study, Lovell (1983) states that women seemed more capable of making sense of their loss and of grieving when they had seen the infant, "even if the infant had been grossly disfigured". However, Kirkley-Best and Kellner (1982) note that more research is needed on the meaning of this effect. Are women who want to see the child more capable of experiencing the painful reality of the loss and therefore more advanced in the grieving process or do they cling more to the baby which might indicate more problematic grieving. And why is it as Nicol et al. (1986) report that having seen but not touched the infant was related to pathological

grief? Is depression more likely to occur in women who do not have this physical contact, as proposed by LaRoche et al. (1984)? Forrest et al. (1982) compared the effect of the *usual hospital care* with that of the *special hospital care* which meant that arrangements were made, such as to let the parents name, see, hold and bury their dead child; make photographs of it, inform them about normal grief reactions, and offer the opportunity to express their emotions about the loss. It was found that women who received special care were less depressed as operationalized by the General Health Questionnaire than women after usual care (i.e. the above-mentioned arrangements were not made). However, this effect disappeared after 14 months. Descriptive studies emphasize repeatedly that bereaved parents are exceptionally vulnerable to insensitive care, and callous or paternalistic staff attitudes may adversely affect the mourning process. Parents report more satisfaction when they feel they have been talked to openly and frankly by their physician and when they feel they were not avoided during or after delivery (Klaus and Kennell, 1982; Lovell, 1983; Estok and Lehman, 1983). According to Murray and Callan (1988) a consistent predictor of better adjustment was the parent's level of satisfaction with the comfort and support provided by doctors, nurses and other hospital staff. For instance, parents who were pleased with the level of support were less depressed (operationalized with the measure of global depression from the Health and Daily Living Form) and had higher levels of self-esteem (operationalized with the Rosenberg's Self-Esteem Scale) and psychological well-being (operationalized with a global rating of well-being or happiness). In addition, satisfaction with support from hospital staff was the single predictor of fewer depressive symptoms. In a study from our group (Mourik et al., 1994) parents were more satisfied when they received special attention from the hospital staff during the dying and after the death of their (newborn) child, while a minority of parents who expressed their dissatisfaction about this hospital care also showed more intense grief as measured by the Perinatal Grief Scale (PGS) (Potvin et al., 1989). However, the dissatisfaction and the intense grief might have been caused by another variable, associated with the history of the parents, since these parents were either divorced or had been drug addicts. Tudehope et al. (1986) and Janssen et al. (1992) found no effect of parental perception of overall hospital care on pathological grief measured with an interview and with Potvin's Perinatal Grief Scale. Further research is required in order to gain a better understanding of the methods of crisis support most likely to aid these parents (Kirkley-Best and Kellner, 1982).

1.6.2 Individual characteristics

Most authors found no relationship between the *age* of the woman and grief intensity (Laurell-Borulf, 1982; LaRoche et al., 1984; Nicol et al., 1986; Turner et al., 1991; Janssen et al., 1992; Prettyman et al., 1993). However, some authors observed a relatively low intensity of grief in women of advanced age: the younger the woman the more disbelief exists with regard to the loss (Kirkley-Best and Kellner, 1982; Toedter et al., 1988). This might be related to older women having more resources with which to cope with the loss and having older children (Toedter et al., 1988). Empirical studies did not show the *religion* of parents to correlate with adjustment to perinatal loss (Nicol et al., 1986; Janssen

et al., 1992), but in interview studies parents do mention that their religious belief helped them to accept the loss (Stringham et al., 1982).

A number of authors claim that *personality* is a key determinant of grief in general (Raphael and Middleton, 1990; Horowitz, 1990; Stroebe et al., 1992). Particularly neuroticism, which includes apprehensiveness, worrying, anxiety, ambivalence, and intrapsychic conflicts are supposed to make the person more vulnerable to depression (Stroebe and Stroebe, 1987). Horowitz (1988; 1990) points at the risk that both ambivalence and conflict might impede the ability to ask for mental support from others during mourning. Persons with an obsessive personality disorder (Hall et al., 1987) who are "grief-prone", expressed in terms of intense clinging and pining (Parkes and Weiss, 1983) or who, prior to their loss, tended to avoid confrontation and attempted to escape from difficult situations (Ramsay, 1979) are also associated with an increased incidence of grief reactions.

Friedman and Gath (1989) found, in one of the few standardized studies about personality on perinatal grief, that psychiatric history, operationalized with the Present State Examination (PSE), and neuroticism, measured with the neuroticism scale of the Eysenck Personality Questionnaire (EPQ) (Eysenck and Eysenck, 1975), predispose to psychological morbidity four weeks after early miscarriage, according to the general depression scales and the PSE. Toedter et al. (1988) found a positive relationship between pre-loss mental health, operationalized with the Symptom Checklist-90 (SCL-90), and more intense grieving. Black (1989), however, did not find significant associations between pre-loss mental health, operationalized as previous use of mental health treatment, and moods, one and six months after pregnancy loss, operationalized with the Profile of Mood Scale (POMS).

Some authors found the *early grief reaction* positively related to *later grief reactions* whether it was disordered or intense (Tudehope et al., 1986; Black, 1989). This was against the generally held belief that the initial acting out of grief saves the person from maladjustment to the loss (Bowlby, 1980; Brown and Stoudemire, 1983).

1.6.3 The social environment

Women who had *difficulty communicating with their husbands* before the pregnancy loss or were single (Kennell et al., 1970; Forrest et al., 1982; Toedter et al., 1988; Friedman and Gath, 1989) and who perceived their *social environment as unsupportive* (Nicol et al., 1986) are, not unexpectedly, at increased risk of a poor grief outcome. Kirkley-Best (1981) observed that *the presence of siblings* predicts less intense grief. Already having children might facilitate mourning after pregnancy loss, because the "parents know that they are capable of childbearing and other children might comfort and distract them" (Toedter et al., 1988; Friedman and Gath, 1989). In contrast, LaRoche et al. (1984) observed in women who already had children, more intense grief after pregnancy loss. They assume that these women lack time to grief which might lead to emotional problems later on. However, the majority of authors found no effect of having children on the intensity of grief (Nicol et al., 1986; Tudehope et al., 1986; Toedter et al., 1988; Black, 1989; Turner et al., 1991; Janssen et al., 1992; Prettyman et al., 1993).

1.7 Normal versus abnormal grief

Grief is a "normal" psychological reaction after a loss through death. Moreover, grief is not only considered a normal but even a necessary process. Freud (1917) already pointed out that grief is not a pathological condition but an adaptive process which, according to him, requires no intervention. The individual detaches himself from a loved one and this "grief work" - a term employed by Freud - is useful. Bowlby (1961) even regards the grief process as biologically functional. Some characteristics, for instance searching for the lost loved one, are relevant when a loss is not irreparable. Others, such as sadness and defense are functional because they evoke comforting behaviour in the social environment, or protect the individual from too much grief. Horowitz interprets the Stress Response Syndrome (SRS) both as reaction to the loss, and as attempt to take away sorrow, hence the SRS is functional and adaptive. In other words, grief might be a healthy process.

The duration of a normal grief process cannot be sharply defined. The most intense reactions may have disappeared after about six to twelve months (Gilbert and Smart, 1992), but many effects remain present in a less severe form for at least one or two years after the loss.They may also suddenly return years later (Peppers and Knapp, 1980a,b; Gilbert and Smart, 1992).

Although it is not easy to differentiate between normal and pathological grief, a disturbed grief process becomes manifest in impeded work, creativity and intimacy, because the person sticks in the avoidance phase or in the phase of intrusion (Horowitz et al., 1979). The complete absence or the persistence and the intensity of the symptoms over a long period of time differentiate pathological grief from normal grief. In Table 1.4 Horowitz' symptoms of normal and pathological grief are presented.

Table 1.4 Common experiences during grief and their pathological intensification (Horowitz et al., 1993)

Phase	Normal response	Pathological intensification
Dying	Emotional expression and immediate coping with the dying process	Avoidant; over-whelmed, dazed, confused; self-punitive; inappropriately hostile
Death and outcry	Outcry of emotions with news of the death and turning for help to others or isolating self with self-succouring	Panic, dissociative reactions; reactive psychosis
Warding off (denial)	Avoidance of reminders, social withdrawal, focusing elsewhere, emotional numbing, not thinking of implications to self or certain themes	Maladaptive avoidance of confronting the implications of the death. Drug or alcohol abuse, counterphobic frenzy, promiscuity, fugue states, phobic avoidance, feeling dead or unreal

Re-experience (intrusion)	Intrusive experiences including recollections of negative relationship experiences with the deceased, bad dreams, reduced concentration, compulsive enactments	Flooding with negative images and emotions, uncontrolled ideation, self-impairing compulsive reenactments, night terrors, recurrent nightmares, distraught from intrusion of anger, anxiety, despair, shame or guilt themes, physiological exhaustion from hyperarousal
Working through	Recollections of the deceased and contemplations of self with reduced intrusiveness of memories and fantasies,increased rational acceptance, reduced numbness and avoidance, more "dosing" of recollections and a sense of working it through	Sense that one cannot integrate the death with a sense of self and continued life.Persistent warded off themes may manifest as anxious depressed, en raged, shame-filled or guilty moods and psychophysiological syndromes
Completion	Reduction in emotional swings with a sense of self coherence and readiness for new relationships. Able to experience positive states of mind	Failure to complete mourning may be associated with inability to work, create, to feel emotion or associated positive states of mind

Like the transition from normal to abnormal grief, it is also difficult to determine the incidence of pathological grief. Various studies employing representative random samples estimate percentages of 10 to 20% for chronic mourning (Bowlby, 1980). According to Kleber and Brom (1989) 15 to 25% of persons in the general Dutch population suffer from pathology after a traumatic event.

With respect to perinatal grief Friedman and Gath (1989) observed that 48% of 67 women were found to be psychiatric cases (level 5+ on the PSE), exhibiting depressive features one month after early pregnancy loss (at first or early second trimester). (This rate was about four times higher than that found among women in the general population.) Iles and Gath (1993) found about the same percentage (41%) of psychiatric morbidity (operationalized with the same PSE Index) also one month after second trimester pregnancy loss for fetal abnormality. This number dropped to 15% six months later and twelve months later the level was similar to that found in non-puerperal women (10%) and women six months post-partum (9%). It can be questioned whether the findings concerning the first month after the loss do reflect normal grief reactions instead of chronic grief, considering the short lapse of time between assessment and pregnancy loss. Zeanah (1989) concludes, from a review, that perhaps 20 to 30% of those bereaved by perinatal loss (ranging between pregnancy loss at 20 weeks and newborn loss within 30 days after birth) experience significant psychiatric morbidity during the first year after the loss. Thomassen-Brepols (1985) labelled 43% of 30 Dutch women as having long-term coping problems six to 27 months after pregnancy loss (16-20 wks), according to self-report and lay-judge ratings. She describes these problems as not being capable of accepting the loss, having persistent intrusions concerning the loss; not having made up one's mind concerning reproduction because of fear or doubt as consequences of the loss.

1.8 Methodological issues in perinatal grief research

It is important to keep several things in mind with regard to the results on the determinants of perinatal grief. The first concerns the operationalization of grief. Grief reactions are sometimes described in terms of intensity and sometimes in terms of psychopathology. Further, based on the assumption that grief proceeds in stages, it is not always clear at what stage the measures of grief are taken. Another problem concerns the different statistical analyses which are used to test an association between predictors and grief. Until recently a number of studies were anecdotal. Often an interview was the only source of information and, not rarely, the interviewer also judged the interviews instead of independent judges (Silvestre and Fresco, 1980; Elder and Laurence, 1991; van Spijker et al., 1992). When questionnaires were used, these were often general depression scales, seldom was a specific instrument to measure perinatal grief applied, which makes comparison of findings from other studies difficult. Many studies are retrospective, the period of retrospection sometimes varies considerably even within the same study and might diverge from several weeks to some years after the pregnancy loss with an upper limit of 46 years (Kennell et al., 1970; Jörgensen et al., 1985; Rosenblatt and Burns, 1986; Timmers et al., 1990; Janssen et al., 1992). The research group often consists of a small number of women and is heterogenous with respect to the severity of the malformations and the gestational age at the time of the loss. In the above-mentioned study by Jörgensen et al. (1985) only 14 women participated and the fetal anomaly was either treatable or untreatable although not lethal. Prospective and longitudinal designs are lacking, therefore risk factors predicting disordered grieving are difficult to trace. It is also not known which parent is at risk for pathological mourning, because of a lack of personality assessments. Finally, it is unknown which measures might reduce psychological morbidity (Zeanah, 1989).

1.9 Conclusion

Prenatal diagnosis of a severe or lethal anomaly leads to a difficult situation in which coping with the (threatened) loss and the decision whether or not to terminate the pregnancy are central features. However, insight and knowledge are limited with regard to the effects of this situation in women in late pregnancy. According to the ideas of Horowitz, in the present study threatened pregnancy loss is described as a specific traumatic event which causes the balance between existing beliefs and expectations (schemas) and the new information to be severely disrupted. The loss is so divergent from these schemas that very painful emotions emerge. The perinatal grief process is considered a specific form of coping which is mediated by the obstetric context of the pregnancy loss, individual characteristics and social environment.

1.10 Research objectives

The present study tries to find evidence for the above-mentioned theoretical insights by making use of the resulting operationalizations and by avoiding some of the methodological flaws. The study differs from other studies in this field, in that it investigates Dutch women in late pregnancy ($\geq$ 24 weeks) in whom a fetal anomaly was detected

which was not compatible with extrauterine life or would at least result in severe mental and/or physical handicap(s), while in the Netherlands the legal upper limit for pregnancy termination is 24 weeks. In addition, these women were studied over a long period of time: from shortly after receiving the unfavourable diagnosis to three months and four years after pregnancy loss, with particular focus on their motives for pregnancy termination and their need for support. The following questions were addressed by means of interviews and standardized questionnaires specific for perinatal grief:

1 What is the course of the grief process from the sonographic diagnosis of a severe or lethal fetal anomaly to three months after delivery and four years after perinatal loss?
2 Which characteristics are predictive for the grief process?
3 What is the prevalence of severe psychological instability (measured with an interview) in women in the period immediately after being informed about the diagnosis of a severe or lethal fetal anomaly and three months after delivery.
4 What is the prevalence of severe psychological instability (measured with the General Health Questionnaire-28) in women four years after perinatal loss?
5 Which motives determine whether the woman wishes to terminate or to continue the pregnancy and what is the relationship between the way the request of pregnancy termination was presented and the intensity of grief (measured with the Perinatal Grief Scale)?
6 What is the need for assistance in women and what kind of assistance is expected?

The study is presented as follows. A grief scale which specifically focuses on perinatal grief (PGS) was translated from English into Dutch and was adapted for women who had received the diagnosis of a severe or lethal fetal anomaly and still carried a live fetus or had delivered a live infant. Its reliability and validity for women with late pregnancy problems were investigated. This investigation is presented in *chapter 2. Chapter 3* describes a study on women's emotional reactions and the severity of psychological instability shortly after the diagnosis of a severe or lethal fetal anomaly (≤ six wks) and three months after delivery. In this chapter also the relationship between emotional reactions and the obstetric context, the age of the woman and the family composition is described. In *chapter 4* the investigation on the disposition for feelings of inadequacy and psychological defense to the diagnosis as predictors of perinatal grief is discussed. *Chapter 5* reports on women's emotional reactions four years after perinatal loss and offers an answer to the question whether these reactions might be predicted on the basis of emotional reactions shortly after the diagnosis and three months after the delivery. In *chapter 6* the motives which determine whether the women wish to terminate or to continue pregnancy are described. In addition, the relationship between the way the woman presented the request to terminate the pregnancy and the intensity of perinatal grief is reported. *Chapter 7* describes the prevalence and kind of need for help. Finally, a general discussion, suggestions for possible intervention and further research are presented in *chapter 8.*

References

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2

Reliability and validity of the Perinatal Grief Scale for women in late pregnancy (24 weeks or longer) following the ultrasound diagnosis of a severe or lethal fetal anomaly[1]

2.1 Synopsis

The psychometric qualities of the Perinatal Grief Scale (the PGS) were evaluated in a sample of 46 Dutch women in late pregnancy (≥ 24 weeks), who were informed on the diagnosis of a severe or lethal fetal malformation. The validity of the Perinatal Grief Scale was assessed by comparing it to a general measure of traumatic impact and to a clinical diagnosis of psychological instability based on a semi-structured interview. The perinatal grief scores appeared to be strongly related to the general trauma measure and to psychological instability in particular. The Perinatal Grief Scale is therefore a valuable instrument for the psychological assessment of women who experience late pregnancy loss.

2.2 Introduction

The past ten years have witnessed increasing scientific interest in maternal reactions to perinatal death. The loss of a wanted pregnancy is a traumatic event, which evokes severe grief reactions from the mother. It has been emphasized that the mother feels "betrayed" for not being able to deliver a healthy infant and that she experiences feelings of failure and uncertainty regarding the cause of the pregnancy loss. These feelings could make it especially hard for her to accept the perinatal trauma (Peppers et al., 1980; Taner Leff, 1987; Toedter et al., 1988; Theut et al., 1989).

Unfortunately a number of methodological shortcomings are attached to research into perinatal grief. Many studies are anecdotal and employ questionnaires or an interview as the only source of information, without using independent rating methods (Cullberg, 1971; Silvestre and Fresco, 1980). The questionnaires often only measure general depression or grief instead of focussing on the perinatal loss situation (Forrest et al., 1982; LaRoche et al., 1984). Toedter et al. (1988) therefore conclude: "one of the major problems in perinatal loss research has been the lack of a comprehensive measure of perinatal grief that might facilitate comparison among findings in the field". To solve this problem, they developed the Perinatal Grief Scale. Their study on a sample of women of random gestational age, who mostly aborted before 16 weeks of gestation, and with different types of loss (spontaneous abortion, ectopic pregnancy, fetal and neonatal death), demonstrated that the Perinatal Grief Scale is a reliable instrument for the measurement of perinatal loss in relative *early* pregnancy. However, the concurrent validity with

[1] This chapter is a slightly revised version of a publication in British Journal of Medical Psychology, 1993, 66, 295-298: Reliability and validity of the PGS for women who experienced late pregnancy loss by Hunfeld, JAM, Wladimiroff, JW, Passchier, J, Uniken Venema-Van Uden, M, Frets, PG, Verhage F.

which scores on the Perinatal Grief Scale are compared to results obtained by other measurement methods for grief and to a clinical diagnosis of psychological instability, has so far never been investigated. In addition, no research has been conducted into the suitability of the Perinatal Grief Scale for measuring perinatal grief in *late* pregnancy.

The objective of the present study therefore was to evaluate the psychometric qualities of the Perinatal Grief Scale in women of advanced gestational age (≥ 24 weeks) in which a lethal or severe fetal anomaly had been diagnosed.

2.3 Method

Patients

Pregnant women who were referred to the Division of prenatal diagnosis for an anomally scan, were asked to participate (n=55). Inclusion criteria were: i) a pregnancy of 24 weeks or more and ii) the presence of a fetal malformation which was not compatible with extrauterine life or would at least result in severe mental and/or physical handicap(s). Excluded were women with a previously known risk for a congenital fetal structural malformation and who could not express their experience sufficiently in the Dutch language.

Nine of the women approached did not participate in the study: eight women because they did not wish to be confronted with the traumatic event or the loss and one woman because she and her partner were both deaf. The final sample consisted of 46 women who completed the questionnaires and from 44 women also interview data were available.

Procedure

A medical psychologist (JH) paid a home visit to carry out an audiotaped interview two to six weeks after the women had been informed of the presence and severity of the particular fetal malformation. After the interview questionnaires about perinatal grief were left behind for completion, together with a pre-stamped return envelope. The women were instructed to contact the interviewer if any problems arose regarding completion. A reminder was sent if the questionnaires had not been returned two weeks later.

Instruments

The interview was semi-structured and included both open-ended items and closed-ended questions, which covered the emotional reactions of the women immediately following the diagnosis. The following questionnaires were used: the Perinatal Grief Scale (the PGS) a translation into Dutch from the short version of the Perinatal Grief Scale (Potvin et al., 1989). The scale measures general and specific, perinatal grief, and consists of 33 items clustered around three factors or subscales derived from factor analysis: active grief; difficulty coping and despair. The items of the active grief subscale register normal or common emotional reactions following a traumatic event, such as sadness, crying for and missing the baby. More complicated emotional reactions are measured with the difficulty coping subscale and include, for example, social withdrawal and problems with day to day functioning. The items of the despair subscale, such as "the best part of me died with the baby", suggest the potential for serious and long-term

psychological problems following the loss. The PGS scores relate to grief symptoms in the preceding week. We labelled the total score as "perinatal grief"; it consists of the summation of each subscale. The Perinatal Grief Scale was adapted for women who had received the unfavourable diagnosis and still carried a live fetus or had delivered a live infant. The Perinatal Event List (the PEL) is an elaboration and a translation into Dutch of the Impact of Event Scale (Horowitz et al., 1979). The scale was developed to measure subjective stress after a traumatic event and consists of 15 items clustered around two factors: intrusion and avoidance. Intrusion is characterized by unbidden thoughts and images, troubled dreams, strong waves of feelings and repetitive behaviour (i.e. recurrent talking about the loss). Avoidance includes denial of meaning and consequences of the event, counterphobic activity, behavioural inhibition and emotional numbness. These processes are supposed to be important dimensions in grieving. In our study the items of the original scale were anchored to the traumatic event of perinatal loss, as was recommended by Horowitz et al. (1979). The total score consists of the summation of the subscale scores; we labelled the total score as "perinatal stress". The PEL score relates to stress symptoms in the preceding week. The reliability and validity of the original scale are good (Horowitz et al., 1979).

Data reduction and analysis

The content of the audiotaped interview was transcribed into a report. Firstly, the following reactions were scored, sadness, anger, fear, sleeping and eating disorders, feelings of failure and adaptive coping (i.e. talking with others about the event; trying to go on with daily activities). Secondly, based on the report, three clinical psychologists judged independently the emotional reactions of the women regarding the presence of severe psychological instability (SPI) following the ultrasound diagnosis.

Signs of SPI were extreme eating and/or sleeping disorders, panic or fear, neglecting household activities, medicine, drugs or alcohol abuse and social isolation. Interjudgement agreement was achieved by consensus diagnosis. This procedure was generally used by the clinical staff in screening for psychological guidance programmes.

The reliability of each Perinatal Grief subscale as defined by Potvin et al. (1989) and of the total test, was determined by i) Cronbach's alpha and ii) correlations between the separate items and the subscale scores. The concurrent validity of the Perinatal Grief Scale was analyzed in two ways. Firstly, by Pearson's product moment correlations between each subscale score of the Perinatal Grief Scale and the Perinatal Event subscales; secondly, by t-tests on the Perinatal Grief subscale scores as dependent variables and the clinical ratings of the psychologists regarding the presence of SPI as independent variable (on two levels: SPI present vs no signs of SPI).

2.4 Results

Sample characteristics

The maternal age in the sample (n=46) ranged between 19 - 44 years (median: 30) and the gestational age varied between 24 to 38 weeks (median: 31). At the time of the interview, 27 women from the sample had already given birth to an infant who had died, while the remainder still carried a live fetus (n=18) or had delivered a live infant (n=1).

Reliability and validity

In Table 2.1 the reliability and validity of the Perinatal Grief Scale is presented.

Table 2.1 Cronbach's alphas for the subscales and the total score of the PGS in the total Dutch and in Potvin's sample and in the subgroups

PGS subscales	Total group		Dutch subgroups	
	Dutch sample (n=46)	Potvin's sample (n=138)	BD* (n=27)	(U)BA** (n=19)
Active grief	.86	.92	.90	.85
Difficulty coping	.84	.91	.87	.84
Despair	.89	.86	.93	.80
Total PGS score	.95	.95	.96	.94

* BD: Born and Died
** U(BA): (Un)born and Alive

Although the reliability (internal consistency) of the subscales of active grief and difficulty coping of the Perinatal Grief Scale was slightly less for the Dutch sample of late pregnancy termination women than for the sample of Potvin et al. (1989) for women of relative early pregnancy termination, it was the same for the total Perinatal Grief score and even somewhat higher for the scores on the despair subscale. Further, there was only a small difference in the reliability of the Perinatal Grief subscales between the women whose infants were born and died (the BD = Born and Died group) and the women who still carried a live fetus or had delivered a live infant (the (U)BA = (Un)born Alive group). An exception was despair, which was somewhat lower, but still acceptable, in the (U)BA group. Because of these small differences, both subgroups were combined for the remaining analyses.

The interscale correlations, presented in Table 2.2 below, appeared to be high and similar for the women after late (Dutch sample) or early pregnancy termination (sample of Potvin et al., 1989), except for the correlation between the active grief subscale and the despair subscale, which was higher in the Dutch sample (.71 vs .56).

Table 2.2 Interscale correlations of the PGS subscales for both the Dutch sample (right upper rectangle) and Potvin's sample (left lower rectangle)

PGS subscales	Active grief	Difficulty coping	Despair
Active grief	-	.79	.71
Difficulty coping	.70	-	.82
Despair	.56	.80	-

In Table 2.3 the inter-item correlations are given.

Table 2.3 Correlations between each item with its own and the other subscales of the PGS (ordered from low to high with their own subscale)

PGS subscales	Active grief	Difficulty coping	Despair
Active grief			
[5] I feel a need to talk about the baby	.14	.02	-.04
[7] I am frightened	.51	.48	.50
[19] Time passes so slowly since the baby died	.57	.60	.66
[12] It is painful to recall memories of the loss	.60	.28	.26
[10] I very much miss the baby	.65	.40	.40
[3] I feel empty inside	.70	.56	.41
[1] I feel depressed	.71	.70	.44
[6] I am grieving for the baby	.71	.47	.43
[14] I cry when I think about him/her	.78	.55	.47
[27] I feel so lonely since he/she died	.79	.79	.76
[13] I get upset when I think about the baby	.83	.56	.54
Difficulty coping			
[8] I have considered suicide sine the loss	.23	.43	.45
[4] I can't keep up with my usual activities	.52	.57	.36
[24] I get cross at my friends and relatives more than I should	.42	.57	.47
[28] I feel somewhat remote even among friends	.46	.66	.45
[30] I find it difficult to make decisions since the baby died	.47	.69	.60
[34] It feels great to be alive	.47	.69	.67
[2] I find it hard to get along with certain people	.41	.70	.44
[25] Sometimes I feel like I need a professional counselor to help me get my life together again	.64	.72	.58
[21] I have let people down since the baby died	.60	.73	.68
[11] I feel I have adjusted well to the loss	.58	.78	.69
[26] I feel as though I am just existing and not really living since he/she died	.74	.79	.69
Despair			
[9] I take medicine for my nerves	.25	.30	.42
[29] It is safer not to love	.45	.55	.47
[32] I worry what the future will be like	.41	.49	.60
[16] I feel physically ill when I think about the baby	.43	.46	.63
[15] I feel guilty when I think about the baby	.42	.47	.74
[18] I try to laugh but nothing seems funny anymore	.58	.60	.77
[20] The best part of me died with the baby	.68	.73	.79
[22] I feel worthless since he/she died	.59	.64	.79
[33] Being a bereaved parent means being a second-class citizen	.53	.66	.79
[17] I feel unprotected in a dangerous world since he/she died	.56	.73	.79
[23] I blame myself for the baby's death	.53	.69	.81

Each item displayed a positive correlation with its own subscale of .40 or higher, except for item 5 ("I feel a need to talk about the baby"), for which the correlation was only .14. The median correlations were .70 for the active grief subscale; .69 for the difficulty coping subscale and .77 for the despair subscale. Further, the items showed the highest correlations with their own subscale, except for item 19 ("time passes slowly since the baby died" of the active grief subscale, item 8 ("I have considered suicide since the loss") of the difficulty coping subscale and item 29 ("it is safer not to love") of the despair

subscale. These three items displayed slightly higher positive correlations with one of the other subscales than with their own subscale.

The validation of the Perinatal Grief Scale against the Perinatal Event List showed that correlations between each subscale of the Perinatal Grief Scale and those of the Perinatal Event List were positive and .40 or higher (see Table 2.4).

Table 2.4 Correlations of the subscales of the Perinatal Grief Scale (PGS) and the Perinatal Event List (PEL)

PGS subscales	PEL subscales	
	Intrusion	Avoidance
Active grief	.68*	.43*
Difficulty coping	.64*	.52*
Despair	.58*	.49*

* $p<.001$

Particularly high correlations were observed between the Perinatal Grief subscales and the intrusion subscale of the Perinatal Event List.

Table 2.5 shows the mean scores on the Perinatal Grief Scale and the outcome of the t-tests as a function of the presence of severe psychological instability (SPI) as judged by the clinical psychologists.

Table 2.5 Mean scores on Perinatal Grief subscales as a function of severe psychological instability (SPI) and other reactions as expressed in the interview and p values of the differences

PGS subscales	SPI		Interview							
			Fear		Sadness		Failure		Active coping	
	yes	no	yes	no	yes	no	yes	no	yes	no
Active grief	42.9***	31.8	38.8	37.8	40.9	34.9'	42.5	44.3	28.4	40.3****
Difficulty coping	29.3***	17.6	27.6	22.5	25.3	21.8	29.4	26.3	16.2	25.4***
Despair	26.3***	15.3	25.3	21.1	22.9	21.0	26.9	27.0	15.8	23.5'
Total PGS score	98.6***	64.7	91.7	81.4	89.0	77.7	98.7	97.5	60.5	89.2****

* $p<.05$
** $p<.01$
*** $p<.005$
**** $p<.001$

In 45% of the women signs of severe psychological instability were judged to be present. These women appeared to have significantly higher scores on the Perinatal Grief Scale, which were 1.5 - 2.0 times higher than women in whom these signs were absent.

2.5 Discussion

The Perinatal Grief Scale was originally designed to measure grief in women following perinatal loss. In a heterogeneous sample regarding type of loss and gestational age, which

was low (mostly ≤ 16 weeks), the scale showed good psychometric qualities. In our sample of women who had been informed about the diagnosis of a severe or lethal fetal malformation late in pregnancy (≥ 24 weeks), the psychometric qualities of the Perinatal Grief Scale were also found to be good. Both the total perinatal grief score and its subscale scores showed satisfactory reliabilities (Cronbach's alpha >.80), which were comparable with those in the sample of Potvin et al. (1989). In addition, no statistically significant difference in reliability existed between the women who had already delivered an infant who subsequently died and the women who were still carrying a live fetus or had delivered a live infant which was severely mentally or physically handicapped.

Only one item (no. 5: inquiring about the need to talk about the baby) demonstrated a low correlation with the subscales. Either this item did not tap one of the Perinatal Grief Scale dimensions of grief or it had no discriminative ability for women with perinatal loss. The latter alternative was supported by the fact that most of the scores were in the high range and displayed only small variation, indicating a need to talk about the baby. It is also consistent with the finding that during the interview, almost each woman expressed the need to talk about the (loss of the) baby. As this item apparently reflects part of the grieving process which is generally present in the weeks following perinatal loss, and elimination would limit the comparability of test scores obtained by other researchers, we decided to retain it in the scale.

The validity of the Perinatal Grief Scale appeared to be good. This was reflected by high correlations between each Perinatal Grief subscale and the subscales of the Perinatal Event List (intrusion and avoidance) and was particularly supported by significantly higher overall Perinatal Grief Scale scores as well as Perinatal Grief subscale scores in women in whom severe psychological instability was judged to be present. In addition, there were high correlations between the subscales. The latter finding differs from the results of Potvin et al. on early pregnancy loss, because in that study the correlations between the Perinatal Grief subscales were only moderately high. The dissimilarity between the findings can be attributed to differences in gestational age and type of loss, which varied more in the sample of Potvin et al (1989). Perhaps the high correlations found in our study, especially between the active grief subscale and the despair subscale, were due to more advanced attachment to the infant in late pregnancy (Black, 1989; Goldbach et al., 1991).

Another explanation may be the time of grief assessment, which took place later in the study of Potvin et al. (8 weeks following the loss). It may be that extreme grief reactions, as measured by difficulty coping and despair, are part of a normal reaction pattern shortly after perinatal loss, while differentiation between the dimensions does not occur until later.

In summary, the Perinatal Grief Scale provides a standardized instrument which measures grief following perinatal loss in a reliable and valid way, not only for women with early pregnancy loss, but also for women who lost their infant in late pregnancy. Further, the scale appeared to be a valid predictor regarding the presence of severe psychological instability as independently diagnosed by clinical psychologists.

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3

Prevalence of psychological instability and course of perinatal stress (PEL) and perinatal grief (PGS) in women in late pregnancy (24 weeks or longer) following an unfavourable ultrasound diagnosis[1]

3.1 Synopsis

We studied the emotional reactions of 46 women in late pregnancy shortly after they had been informed of the diagnosis of a severe or lethal fetal malformation and three months after delivery. In addition, situational variables were explored as determinants of grieving. While grief did not diminish during the study period, psychological instability was less pronounced at three months after delivery. More grief reactions were evoked by self-reported easily versus self-reported not easily initiated pregnancy, gestational age between 24 and 34 weeks versus beyond 34 weeks, multiparity versus primiparity and viewing versus not viewing the baby.

3.2 Introduction

At present our knowledge on short and long-term emotional reactions in women following the late diagnosis of a severe or lethal fetal anomaly (≥ 24 weeks) is scarce. Jörgensen et al. (1985a,b) found that women were emotionally imbalanced during the remainder of their pregnancy (≥ 32 weeks). Almost half of these women reported that they would have requested pregnancy termination if they had been informed about the severe fetal malformation within the legal period for pregnancy termination.

Unfortunately studies on perinatal grief are often anecdotal or employ only one source of information, for example a questionnaire or an in-depth interview in which the interval until retrospective data collection varies widely within the same sample, sometimes even from six months to 36 years (White et al., 1984; Nicol et al., 1986). The questionnaire often only measure general depression or grief instead of focusing on circumstances concerning perinatal loss, such as uncertainty regarding the cause of the pregnancy loss. These studies generally suggest that emotional reactions are frequent after perinatal death (Silvestre and Fresco, 1980; Harmon et al., 1984; Firestein, 1989).

In the present study, we used both in-depth interviews and perinatal grief questionnaires to address 1) the short and long-term emotional reactions of women in late pregnancy (≥ 24 weeks); 2) the evolvement of perinatal grief in the period starting from shortly after being informed of the diagnosis of a severe or lethal fetal malformation up to three months after birth and 3) the relationship between situational factors, mainly pregnancy features, and perinatal grief.

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[1] This chapter is a slightly revised version of a publication in Prenatal Diagnosis, 1993, 13, 603-612: Emotional reactions in women in late pregnancy (24 weeks or longer) following the ultrasound diagnosis of a severe or lethal fetal anomaly by Hunfeld, JAM, Wladimiroff, JW, Passchier, J, Uniken Venema-van Uden, M, Frets, PG, Verhage, F.

3.3 Method

Patients

Fifty-five patients who were referred to the Division of prenatal diagnosis in the period between January 1990 - August 1991 for an anomaly scan, were approached. Inclusion criteria were: i) a pregnancy of 24 weeks or more and ii) the presence of a fetal malformation which was not compatible with extrauterine life or would at least result in severe mental and/or physical handicap(s). Women with a previously known risk for a congenital fetal structural malformation and women with insufficient knowledge of the Dutch language were excluded from the study. A total of 46 pregnant women consented to participate in the study. Nine of the women approached did not participate in the study: eight women because they did not wish to be confronted with the traumatic event or the loss and one woman because she and her partner were both deaf.

Procedure

After the diagnosis of a severe or lethal fetal anomaly had been made, the doctor who carried out the ultrasound investigation invited the woman to participate in the medical psychological study to assess her emotional reactions. The doctor introduced the study by stating that the aim of the investigation was to collect this information for the optimization of future care.

A medical psychologist (JH) paid a home visit to carry out an audiotaped interview two to six weeks after the women had been informed of the presence of a severe fetal malformation (first measurement). This time interval was chosen because in a pilot study several women were too distressed to be interviewed at an earlier stage.

To measure the long-term emotional reactions, a second interview took place three months following birth (second measurement). The rationale for the time interval between the first and second measurement was that according to the DSM-III-R description of uncomplicated bereavement, grief symptoms should occur within three months following the loss. If this was not the case, it might indicate delayed or pathological grieving.

At the first and second measurements, questionnaires were left behind for completion, including a stamped addressed return envelope. The women were instructed to contact the interviewer if they had any problems regarding the completion. The women received a reminder by telephone if the questionnaires had not been returned two weeks later.

Instruments

The interviews were semi-structured and included both open-ended items and closed-ended questions, which covered the emotional reactions of the women shortly after the diagnosis, the period following birth and the subsequent death of most of the infants.

Three questionnaires were completed. The Perinatal Grief Scale, a translation of the short verion of the Perinatal Grief Scale (Potvin et al., 1989), which measures general and specific perinatal grief. The scale consists of 33 items clustered around three factors or subscales derived from factor analysis: active grief, difficulty coping and despair. The 11 items of the active grief subscale register normal or common emotional reactions following a traumatic event, such as sadness, crying for and missing the baby. More

complicated emotional reactions are measured with the difficulty coping subscale, the 11 items include social isolation and problems with day to day functioning. The 11 items of the despair subscale, such as "the best part of me died with the baby", suggest the potential for serious and long-term effects of the loss. The total score consists of the summation of each subscale score; we labelled this score as "perinatal grief". The Perinatal Grief Scale was adapted for pregnant women. The reliability and validity of the scale are good for both the American and Dutch version (Toedter et al., 1988; see chapter 2 of the present study).

The Perinatal Event Scale was developed to measure subjective stress after a traumatic event and is an elaboration of the Impact of Event Scale (Horowitz et al., 1979). It consists of 15 items clustered around two factors which are considered to be important dimensions in grieving: intrusion and avoidance. Intrusion is characterized by unbidden thoughts and images, troubled dreams, strong waves of feelings and repetitive behaviour. Avoidance includes denial of meaning and consequences of the event, counterphobic activity, behavioural inhibition and emotional numbness. In our study the items of the original scale were anchored to the traumatic event of perinatal loss, as was recommended by Horowitz et al. (1979). The total score consists of the summation of the subscale scores; we labelled this score as "perinatal stress". The reliability and validity of the original scale are satisfactory.

The Self-report Health Scale is an original Dutch questionnaire and was used to measure psychosomatic complaints, such as heart palpitations, dizziness, chest pain, headaches, which indicate psychosomatic maladjustment. The scale consists of 13 items. The reliability and validity are good (Centraal Bureau voor de Statistiek (CBS), 1989). This scale was only administered at the second measurement, because pregnancy-related somatic complaints might influence the scores during the first measurement.

Data reduction and analysis

The content of the audiotaped interviews was first transcribed into a report. The following reactions were scored: sadness, anger, fear, sleeping and eating disorders, feelings of failure, adaptive coping. Based on the report, three clinical psychologists independently judged the emotional reactions regarding the presence of severe psychological instability (SPI) following the ultrasound diagnosis. Signs of SPI were extreme sleeping and eating disorders, panic or fear, neglecting household activities, alcohol, medicine or drugs abuse and social isolation. Interjudgment agreement was achieved by consensus diagnosis. This procedure was prefered above objective ratings, because the method is commonly used in screening for psychological guidance programmes.

The potential determinants investigated were derived from the interview with the mother and included: self-reported easily versus self-reported not easily initiated pregnancy, gestational age, induced versus spontaneous delivery, nature of the fetal malformation, viewing or not viewing the baby, first or subsequent pregnancy and maternal age.

The data analysis for each objective was as follows: 1) short and long-term emotional reactions were described by frequencies and means; 2) evolvement of grief was assessed by t tests for paired observations for the questionnaire outcome and by the McNemar

test or Friedman two-way ANOVA for the interview findings. The exploration of grief determinants was performed by t tests on the questionnaire scores and by chi-square tests and ANOVAs for the interview scores. As these analyses have an exploratory character with the purpose of generating hypotheses, p values of less then .10 (trends) are also reported.

3.4 Results

Sample characteristics

Maternal age in the sample (n=46) ranged between 19 - 44 years (median: 30 yrs) and gestational age varied between 24 and 38 weeks (median: 31 wks). Further characteristics of the sample are described in Table 3.1.

Table 3.1 Demographic characteristics of the women (n=46)

Characteristics	*Number*
Religious	19 (41%)
Not religious	27 (59%)
Married relationship	41 (89%)
Unmarried	5 (11%)
Secundary educational level	45 (98%)
University educational level	1 (2%)
Previous mental health support	10 (22%)

Table 3.2 shows the nature of the fetal malformations. Over half (59%) of the malformations were not compatible with extrauterine life. At the time of the first measurement, 31 women from the sample had delivered. Twenty-one of these infants had died before or during delivery and seven infants died afterwards. Three women had given birth to a live infant and fifteen women were still carrying a live fetus. At the time of the second measurement, five women withdrew from the study because they did not wish to be confronted with the loss. Therefore 41 women remained for further analysis. All the women had delivered at the time of the second measurement. From the total sample of delivered infants, 36 had died, 19 before or during delivery and ten infants shortly afterwards; six infants had died before 28 days and one infant after 28 days. A total of five infants were alive during the study period, but were suffering from severe physical and/or mental handicap(s).

Thirty-eight of the deliveries were induced, of which four following intrauterine death. There were eight spontaneous deliveries, one also following intrauterine death.

Table 3.2 Nature of the fetal malformations

Malformations	Lethal (n=27)	Non-lethal (n=19)*
Central nervous system anomalies	8	13**
Renal tract anomalies	2	--
Cardiovascular anomalies	4	3
Skeletal anomalies	3	--
Multiple anomalies	10***	2
Diaphragmatic hernia	--	1

* non-lethal, but expected to result in severe mental and/or physical handicap(s)
** ten cases of combined spina bifida and hydrocephaly, two cases of spina bifida only, and one case of hydrocephaly only
*** four cases of trisomy 13 or 18

3.4.1 Prevalence and course of psychological instability, perinatal stress and perinatal grief

Table 3.3 shows the frequencies and mean scores for emotional reactions during the first and second measurements, as derived from both the interviews and questionnaires. Shortly after the diagnosis of a severe or lethal fetal anomaly, more than half of the women expressed severe sadness and/or anger in the interview and were suffering from eating and sleeping disorders. Almost half of the women reported feelings of failure and some expressed feelings of fear. Severe psychological instability (SPI) was judged to be present in 45% of the women.

Three months following delivery and the subsequent death of most of the infants, there was a significant improvement in eating and sleeping disorders. The number of women who showed SPI was significantly reduced: only half of the number at the first measurement. However, more women reported anger at the pregnancy outcome.

Comparison of the scores on the questionnaires from the first and second measurements showed that during the second measurement the women displayed significantly more difficulty coping with the perinatal loss than during the first measurement.

Table 3.3 Emotional reactions derived from the interview and questionnaires at the first and second measurements and the p value of the difference

Emotional reactions	First measurement shortly after ultrasound diagnosis (n=46)	Second measurement three months after delivery (n=41)	p value of the difference*
Interview ratings			
Number with:			
Sleeping disorders	32 (69%)	2 (5%)	.001
Eating disorders	26 (56%)	7 (14%)	.001
Sadness	26 (56%)	7 (14%)	
Anger	21 (45%)	24 (49%)	ns
Feelings of failure	21 (45%)	17 (35%)	ns
Fear	10 (21%)	-	-
Active coping	9 (19%)	16 (33%)	ns
Clinical ratings			
Number with:			
Severe Psychological			
Instability (SPI):	21 (45%)	9 (22%)	.01
Somatic signs	15 (31%)	7 (14%)	-
Psychic signs	15 (31%)	7 (14%)	-
Social signs	3 (6%)	3 (6%)	-
Questionnaire ratings			
Means of:			
Perinatal Grief:			
Active grief	38.0 (sd 9.5)	35.6 (sd 10.3)	ns
Difficulty coping	23.6 (sd 8.3)	24.7 (sd 9.8)	.03
Despair	21.7 (sd 9.1)	22.0 (sd 10.9)	ns
Total score	83.2 (sd 24.8)	82.5 (sd 29.9)	ns
Impact of Perinatal Event:			
Intrusion	20.7 (sd 4.3)	19.6 (sd 5.8)	ns
Avoidance	13.6 (sd 4.6)	13.9 (sd 4.7)	ns
Total score	33.8 (sd 8.0)	33.5 (sd 9.5)	ns
Self-reported health	-	4.2 (sd 3.8)	-

* concerns the means scores of patients who participated in both the first and the second measurement (n=40)

3.4.2 Determinants of perinatal stress and perinatal grief

Significant determinants and trends of emotional reactions are presented in Table 3.4.

Table 3.4 Determinants of grief: trends and significant associations with situational variables (x = p ≤ .10)

Grief determinants	Number of women	Grief scores	1st measurement	2nd measurement
Pregnancy				
Easily initiated	8	Intrusion	x	x
versus		Avoidance	-	-
not easily initiated	33		-	-
Gestation				
< 34 weeks	32	Perinatal grief (Total)	x	-
		Difficulty coping	x	-
versus		Despair	x	-
		Perinatal stress (Total)	x	x*
		Intrusion	-	x*
≥ 34 weeks	9		-	-
Spina bifida (whether or not combined)	10	Perinatal stress (Total)	-	x
		Intrusion	-	x*
versus other malformations	30		-	-
Perinatal death	36	Self-reported health	-	x****
versus survival at three monts	5		-	-
Maternal age				
< 30 years	24	Self-reported health	-	x
versus				
≥ 30 years	17		-	-
Parity				
0	28	Self-reported health	-	x
versus				
≥ 1	13		-	-
Viewing of the infant				
+	35	Difficulty coping	-	x**
versus		Despair	-	x*
-	6		-	-

* p ≤.05
** p ≤.01
*** p ≤.005
**** p ≤.001

The analyses showed that unlike the women who had experienced problems with becoming pregnant, the women who had not experienced fertility problems displayed a

trend towards more subjective stress, in particular intrusion (unbidden thoughts and images and troubled dreams), at the first measurement and a trend towards more avoidance reactions (denial of meaning and consequences of the event, emotional numbness) at the second measurement. Further, women who delivered between 24 and 34 weeks instead of after 34 weeks, showed a trend towards more despair and difficulty coping on the Perinatal Grief Scale at the first measurement and significantly more subjective stress on the Perinatal Event List, in particular intrusion, during the second measurement. No relationship was found between the mode of delivery (induced versus spontaneous) and the intensity of grief at the first and second measurements. During the first measurement there was no difference between the grief scores of mothers who had already delivered and those who still carried a live fetus. At the time of the second measurement, however, perinatal death resulted significantly more often in psychosomatic complaints than the delivery of a live infant that was suffering from severe mental or physical handicap(s). Of the anomalies, only spina bifida evoked more perinatal stress, in particular intrusion, during the second measurement.

Further, there were trends towards more psychosomatic complaints in the multiparous than in the primiparous women and in the younger than in the older mothers. Finally, the mothers who had viewed the dying or dead infant shortly after birth, expressed significantly more despair and difficulty coping during the second measurement than the mothers who had not viewed the infant.

3.5 Discussion

The ultrasound diagnosis of severe or lethal fetal malformation evoked strong emotional reactions, such as eating and sleeping disorders, anger and sadness in women whose fetus was of advanced gestational age. In 45% of the women, the severity of the reactions was clinically judged as reflecting severe psychological instability (SPI). This percentage seems fairly high, but it should be kept in mind that in the general population, around 10% of the women who deliver a healthy infant become clinically depressed during the first year (Zeanah, 1989; Pop et al., 1991). Furthermore, in a study on psychiatric morbidity in the first month following pregnancy termination for a fetal abnormality, Iles (1989) found the same percentage which was four times higher than that found in the general population. This percentage declined to half of the women within three months after delivery.

The decrease in number of women displaying SPI as judged by the clinical psychologists, was not reflected in lower grief scores on the questionnaires. After three months, a clear-cut shift had occurred from active or normal grief reactions to despair and even to significantly more difficulty coping with the loss in women who were clinically judged as showing SPI. In contrast, the women who were not found to show SPI had considerably (1.5 to 2 times) lower grief scores and did not show an increase in grief scores from the first to the second measurement. Comparison of the scores on the Perinatal Grief Scale of our total sample to those of an American sample of pregnancy loss (mean gestational age 16.5 weeks) showed similar levels after three months and six to eight weeks, respectively (Goldbach et al., 1991).

Our findings on the determinants of the emotional reactions have to be considered as exploratory. In general, it is noteworthy that most of the associations between situational variables and emotional reactions occurred only during the second measurement. The turmoil of the diagnosis and the delivery on the one hand and the attention from the family, friends and hospital staff on the other at the time of the first measurement, probably attentuated an effect of the situational variables on grief in the period following the diagnosis.

Curiously, not all the associations between pregnancy features and emotional reactions were in line with previous research findings (see also Table 1.3 of the present study) or common sense expectations. For instance we expected to find more grief in the women who had (according to self-report) experienced difficulty with becoming pregnant, while there was actually more grief in the women without fertility problems. It might be that the problems with becoming pregnant led to less maternal-fetal bonding, because the women feared that something might still go wrong with the pregnancy or delivery. Our finding that multiparity evoked more instead of less intense grief reactions seems to support the assumption of LaRoche et al. (1984) that women who already have children "lack time to grief which might lead to emotional problems later on". The finding that viewing the dying or dead infant shortly after delivery provoked more grief than not viewing, also seems to be in contradiction with other studies (Kirkley-Best et al., 1982). Longitudinal studies will help to reveal whether not viewing the infant will lead to delayed grieving. Further, the finding that there was no difference between the grief reactions in the mothers of a dead infant and the mothers who still carried a live fetus during the first measurement might indicate that delivery and loss of the infant does not add to the strain which was already present at the time of the diagnosis, at least not during the first measurement.

Finally, post hoc regression analyses were carried out on the grief measures determined by more than one predictor, which was the case for self-reported health and intrusion. It appeared that perinatal death, parity and maternal age each had a significant, unique contribution to self-reported health after three months. Further, maternal age remained significantly associated with intrusion after correction for fetal malformation (spina bifida versus other malformations, but not vice versa).

3.6 Conclusion

The emotional reactions to infant loss from fetal malformations are still strong three months after delivery. However, the large majority of women with an afflicted infant who showed severe psychological instability at the first measurement were able to overcome the crisis stage without the need for professional help. The grieving process was intensified by easily initiated pregnancy, relatively early delivery, multiparity and viewing of the dead infant, and therefore deserve further investigation, over a longer period of time.

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4

Predictors of perinatal stress and perinatal grief three months after the delivery of an infant with severe or lethal anomalies. An exploratory study[1]

4.1 Synopsis

We evaluated whether the emotional reactions of women between two and six weeks after the prenatal diagnosis of a severe or lethal anomaly and at three months after delivery might be predicted by previous stress and acute psychological defense reactions. Previous stress was defined objectively as a history of major life event(s) and having received professional mental health treatment in the past, and subjectively as the disposition for feelings of inadequacy (hereafter referred to as "feelings of inadequacy") (i.e. feeling depressive, instabile, inhibited and shy). Forty-one women were interviewed and completed measures on their history of major life events, whether they had received professional mental health treatment in the past, inadequacy, acute psychological defense reactions and perinatal grief. Regression analyses showed that inadequacy was the most strongly positive predictor of perinatal stress and perinatal grief shortly after receiving the unfavourable diagnosis and three months after the delivery. In addition to inadequacy, having received professional mental health treatment in the past led to significantly more intense grief, but only shortly after receiving the unfavourable diagnosis. Previous life events intensified grief three months after the delivery. The grieving process was significantly moderated by the defense of "principalization" while it was significantly intensified by "turning aggression against oneself". These effects were not contaminated by relationships with pregnancy-related variables.

Our findings imply that psychological support for women with perinatal loss should particularly be offered to those who have been identified as having the disposition for feelings of inadequacy, who have reported previous major life events and have received professional mental health treatment in the past.

4.2 Introduction

Our previous study showed that the emotional reactions of 41 women to the stress of infant loss owing to severe fetal malformations, were still strong three months after delivery and for most women the subsequent death of the infant (see chapter 3 of the present study). In addition, we found more grief in women whose gestational age lay between 24 and 34 weeks (versus beyond 34 weeks), in women who had viewed the dead infant (versus not viewed the dead infant) and in women who had not experienced any difficulty with conceiving (versus difficulty with conceiving).

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[1] This chapter is a slightly revised version of a publication in Social Science and Medicine, 1995, 40, 829-835: Previous stress and acute psychological defence as predictors of perinatal grief - an exploratory study by Hunfeld, JAM, Wladimiroff, JW, Verhage, F, Passchier, J.

Apart from these factors which are directly related to pregnancy, previous stressful life events of the mother might also lead to disordered mourning: perinatal loss was at first seen as a "non event" (Lewis, 1983), previous perinatal loss is now considered to be an important factor in a troublesome grieving process (Bowlby, 1980; Nicol et al., 1986; Hall et al., 1987). Further, experiences of incest can lay the foundation for complicated mourning in adult life (Clark et al., 1990). It might be questioned whether previous life events in general (i.e. loss of parents or siblings) also lead to more intense grieving.

In addition, research findings generally suggest that stress-related personality characteristics, such as an obsessive personality or insecure, anxious-attached and fearful individuals, sometimes labelled as "neurotic", may be at higher risk for troublesome grieving than individuals without these features (Bowlby, 1980; Belitsky and Jacobs, 1986; Friedman and Gath, 1989; Rapee et al., 1990); see also recent reviews on bereavement (Hall et al., 1987; Middleton and Raphael, 1987; Raphael and Middleton, 1990; Iles, 1989). However, there is little systematic knowledge on the relationship between inadequacy and coping with perinatal loss, because these studies have assessed this relationship without using any specific standardized measure or statistical test.

Owing to the fact that previous use of professional mental health treatment generally indicates that the psychological burden of life outweighs the psychological carrying capacity of an individual (Auslander, 1987), it can further be hypothesized that women who have received professional mental health treatment at some time in the past, might suffer more distress after later perinatal loss than women who have not. Black (1989) had not found a significant association between previous use of professional mental health treatment and distress. However, the association was determined only at a second measurement six months after pregnancy loss and by means of the Profile of Moods Scale (POMS) which is a general mood scale. It might be questioned whether this relationship is also absent if assessed shortly after hearing the unfavourable diagnosis and by means of a specific perinatal grief scale.

Being informed of a diagnosis of a severe or lethal fetal anomaly is a heavy blow to the mother, so she will mobilize several psychological defenses against the situation to protect herself from being overwhelmed by painful emotions, such as fear, guilt, loss of self-esteem and anger (Freud, 1966). Particularly in the beginning, defenses against painful emotions are considered to be a useful part of coping, but they might also lead to delayed or disordered mourning, for example by continual suppression of the unpleasant feelings and thoughts related to perinatal loss (Lindstrom, 1989). In addition to the few studies on the relationship between feelings of inadequacy and perinatal grief, no studies are available on perinatal grief in relation to psychological defenses. Therefore the present study addressed two questions:

1. What is the relationship between previous stressful life events, feelings of inadequacy and having received professional mental health treatment in the past on the one hand and perinatal stress and perinatal grief on the other?
2. What is the relationship between psychological defenses, and perinatal stress and perinatal grief?

4.3 Method

Patients

We approached 55 women who were referred to the Division of prenatal diagnosis in the period between January 1990 and August 1991 for an anomaly scan. Inclusion criteria for the study were: i) a pregnancy of 24 weeks or more and ii) the presence of a fetal malformation which was not compatible with extrauterine life or would at least result in severe mental and/or physical handicap(s). Women with a previously known risk for congenital fetal structural malformations and women with insufficient knowledge of the Dutch language were excluded from the study. A total of 46 pregnant women consented to take part in the study. The remainig nine women did not participate in the study because they did not wish to be confronted with the traumatic event or the loss (n=8) or because the woman and her partner were both deaf (n=1).

Procedure

A medical psychologist (JH) paid a home visit to carry out an audiotaped interview two to six weeks (first measurement) after the women had been informed of the presence of a severe or lethal fetal malformation. To measure long-term emotional reactions, previous life events, feelings of inadequacy, whether the woman had received professional mental health treatment in the past and psychological defenses, a second interview took place three months following the birth of the infant (second measurement). We chose the three-months time interval between the first and second measurements because we expected that the women would be more able to provide biographical information by that time.

At the first and second measurements, questionnaires were left behind for completion. The women were instructed to contact the researcher (JH) if they had any problems regarding completion. The women received a reminder by telephone if the questionnaires had not been returned two weeks later.

Instruments

The interviews were semi-structured and included both open-ended items and closed-ended questions, which covered the history of life events and whether the woman had received professional mental health treatment in the past. The prevalence of major life events was determined by means of a semi-structured interview instead of a standard questionnaire, because the former method leads to better recall of the life events (Berden, 1992).

Perinatal grief reactions were measured with two questionnaires: the Perinatal Grief Scale and the Perinatal Event Scale. The perinatal Grief Scale (PGS) is a translation of the short version of the Perinatal Grief Scale (Potvin et al., 1989). The scale consists of three subscales: active grief, difficulty coping and despair. The total PGS score is a summation of each subscale score; we labelled this score as "perinatal grief". The reliability and validity of the scale are good for the American and Dutch versions (Toedter et al., 1988; chapter 2 of the present study). The Perinatal Event Scale, which was developed to measure stress after a traumatic event, is an elaboration of the Impact of Event Scale (Horowitz et al., 1979). We anchored the items to the traumatic event of perinatal loss, as was recommended by Horowitz et al. and labelled the outcome as "perinatal stress".

The scale consists of 15 items clustered around two subscales: intrusion and avoidance. The total score consists of the summation of the subscale scores. The reliability and validity of the original scale are satisfactory (Horowitz et al., 1979).

Acute psychological defenses were measured with an adapted version of the Defense Mechanism Inventory (DMI) (Ihilevich and Gleser, 1991) which registers reactions to threat or conflict. In this study, the description of and the reactions to the general threat or conflict situations of the DMI were elaborated into the event of hearing the ultrasound diagnosis of a severe or lethal fetal anomaly, in order to increase the clinical validity (Vaillant, 1992). This was followed by four questions about the woman's actual reactions, reactions in fantasy and reactions regarding thoughts and feelings upon hearing the unfavourable diagnosis (see appendix). From the reactions which reflected the five major defenses, the intensity of usage against the traumatic event was ranked: i) turning aggression against a real or presumed external frustrating object[2] (TAO); ii) projection, which means attributing negative intent or characteristics to an external object, without unequivocal evidence (PRO); iii) principalization (PRN) which refers to a mental process in which a person obscures, reinterprets or generalizes the affective meaning of a perceived threat; iv) turning aggression against oneself (TAS) expressed in excessive self-criticism or self-reproach; v) reversal (REV) which means a positive or neutral reaction to a traumatic event, while more negative reactions are expected. The defenses TAO and PRO can be considered to measure hostile impulses directed towards other persons, while the defenses PRN, TAS and REV can be considered to measure repression of the affect and self-directed aggression. The reliability and validity of the Dutch version are satisfactory for women (Passchier and Verhage, 1986).

Feelings of inadequacy were measured with the scales of social inadequacy (SI) and personal inadequacy (PI) which are subscales from the Dutch Personality Questionnaire (DPQ). High scores on social inadequacy indicate incompetence in social contacts. These persons feel inhibited and shy. "Personal inadequacy" items include questions about depressed mood, anxiety, feelings of insufficiency or low self-esteem. Both subscales can be considered to measure inadequacy. The scales have good test-retest reliability and validity research has confirmed the intented content of the subscales (Lutëijn et al., 1985).

Data reduction and analysis

A composite index for repression (REP) was calculated as the difference between (REV + PRN) and (TAO + PRO) as proposed by Juni and Yanishefsky (1983). The content of the audiotaped interview was first transcribed into a report from which the variables major life events and having received professional mental health treatment in the past were derived with two levels (present versus absent). Six major life events were registered; five of them had the highest rates of stressfulness in the life event scale of Paykel et al. (1971). These were: death of partner, offspring or parents; divorce and death of a good friend. Further, incest was added as a major life event.

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[2] The term "object" comprises anything from human beings to things in the outside world through which gratification can be achieved.

First, the relationships between life events, feelings of inadequacy, having received professional mental health treatment in the past and acute defense measures on the one hand and the perinatal stress and perinatal grief scores at the first and second measurements on the other, were assessed by Pearson's product moment correlations. Second, multiple regression analyses were carried out on the perinatal stress and perinatal grief measures as dependent variables. Measures which proved to be significantly associated with both the independent variables and the grief scores were chosen as independent variables (Cohen and Cohen, 1983).

4.4 Results

Sample characteristics

Maternal age in the sample (n=46) ranged between 19-44 years (median: 30 yrs) and the gestational age varied between 24-38 weeks (median: 31 wks).

Thirty-eight of the deliveries were induced, including four following intrauterine death. There were eight spontaneous deliveries. A total of five infants were alive during the study period, but were suffering from severe physical and/or mental handicap(s). A more detailed description of the sample is reported elsewhere (see chapter 3 of the present study). At the time of the second measurement, five women withdrew from the study because they did not wish to be confronted with the loss. Therefore 41 women remained for further analysis.

4.4.1 Prevalence of previous stress, acute psychological defenses, perinatal stress and perinatal grief

There was no significant reduction in perinatal stress and perinatal grief between the first and the second measurements (mean scores were 38.3 versus 33.5 and 83.2 versus 82.5). A more detailed description of the grief scores is reported in chapter 3 of the present study. Twenty-six women (63%) reported that they had experienced one or more major life events. Ten women (24%) mentioned that they had received professional mental health treatment in the past.

Table 4.1 shows the frequencies and mean scores for feelings of inadequacy and acute defenses as measured by the questionnaires. The defense "turning aggression against oneself" was most prominent in the reactions to hearing the diagnosis.

Table 4.1 Mean scores for feelings of inadequacy and acute psychological defenses (sd between parentheses) (n=41)

Psychological measures	Mean
Feelings of inadequacy	
social inadequacy	11.7 (8.1)
personal inadequacy	15.5 (10.8)
Defenses	
projection	2.9 (1.0)
repression	3.3 (2.5)
reversal	4.5 (1.4)
principalization	4.6 (1.2)
turning aggression against oneself	5.3 (1.1)
turning aggression against others	2.9 (1.1)

4.4.2 Relationship between previous stress, acute psychological defenses and perinatal stress and perinatal grief

Table 4.2 shows the relationship between major life events, feelings of inadequacy, having received professional mental health treatment in the past and defenses on the one hand and perinatal stress and perinatal grief on the other.

Table 4.2 **Pearson's correlations between life events, inadequacy, previous professional mental health treatment in the past, acute psychological defenses and perinatal stress and perinatal grief at the first (m1) and second measurements (m2)**

Independent variables	Dependent variables			
	Perinatal grief		Perinatal stress	
	m1	m2	m1	m2
Life events	ns	.31*	ns	ns
Feelings of inadequacy				
social inadequacy	.38**	.42**	48****	ns
personal inadequacy	.64****	.75****	.67****	.63****
Mental health treatment	.36**	ns	ns	ns
Defenses				
projection	.35**	ns	.34**	ns
turning aggression against others	ns	ns	ns	ns
turning aggression against oneself	.42**	.36*	.48****	ns
reversal	ns	ns	ns	ns
repression	-.43**	-.39*	-.44**	ns
principalization	-.41**	-.45**	-.52****	-.46***

* $p < .05$
** $p < .01$
*** $p < .005$
**** $p < .001$

Feelings of inadequacy, particularly personal inadequacy, showed a significant and positive relationship with perinatal stress and perinatal grief shortly after hearing the unfavourable diagnosis and three months after the delivery. The defense "turning aggression against oneself" had a positive and significant association with perinatal grief at both measurements and with perinatal stress only shortly after the unfavourable diagnosis. At both measurements, significant negative correlations were observed between the defense principalization and perinatal stress and perinatal grief. Having received professional mental health treatment in the past was significantly and positively related to perinatal grief shortly after hearing the unfavourable diagnosis, while major life events showed a significant positive relationship with perinatal grief three months after delivery. Both these variables showed no relationship with perinatal stress.

4.4.3 Prediction of perinatal stress and perinatal grief using previous stress and acute psychological defenses

The outcome of the multiple regression analyses is presented in Table 4.3. Personal inadequacy explained almost half of the variance in perinatal stress and perinatal grief scores shortly after hearing the unfavourable diagnosis. The women who displayed per-

sonal inadequacy showed significantly more perinatal grief than the women who did not. In addition, having received professional mental health treatment in the past made a unique and significant contribution to perinatal grief and accounted for 12% of the variance: the women who had received professional mental health treatment in the past showed more intense perinatal grief. In addition to personal inadequacy, the defenses "principalization" and "turning aggression against oneself" made unique and significant contributions to the variance in perinatal stress: the women who reacted to the unfavourable diagnosis with "principalization" showed less perinatal stress, while the women who "turned aggression against themselves" showed more perinatal stress. Both defenses did not predict perinatal grief.

Table 4.3 **Life events, inadequacy, previous professional mental health treatment and acute psychological defenses as predictors of perinatal stress and perinatal grief at the first and second measurements**

Psychological measures	R^2	R^2 change	F	P
First measurement (n=46)				
Perinatal Grief				
inadequacy	.37	.37	18.67	<.0001
mental health treatment	.60	.127	.01	<.01
Perinatal Stress				
inadequacy	.35	.35	17.90	<.0002
principalization	.51	.16	10.87	<.002
turning aggression against oneself	.58	.07	5.57	<.02
Second measurement (n=41)				
Perinatal Grief				
inadequacy	.54	.54	36.99	<.0001
life events	.61	.07	5.54	<.02
Perinatal Stress				
inadequacy	.39	.39	24.72	<.0001

R^2 = explained variance
R^2 change = increment in explained variance

Personal inadequacy also explained more than half of the variance in the perinatal grief scores three months after the delivery. In addition, major life event(s) made a unique and significant contribution to perinatal grief: the women who had experienced major life events showed more intense perinatal grief than the women without a history of major life events. Personal inadequacy also explained almost half of the variance in perinatal stress three months after the delivery, but none of the other variables made any significant contribution.

4.5 Discussion

Feelings of inadequacy, previous life events and having received professional mental health treatment in the past led to more intense perinatal stress and perinatal grief reac-

tions. Of these variables the disposition for feelings of inadequacy, particularly personal inadequacy, was the strongest predictor of the variance in perinatal stress and perinatal grief. In addition, a history of major life event(s) and having received professional mental health treatment in the past contributed to the variance in perinatal grief. Both variables were positively related to perinatal grief: having received professional mental health treatment in the past shortly after receiving the unfavourable diagnosis (first measurement) and previous life events three months after the delivery (second measurement). In agreement with the finding of Black (1989), the relationship between having received mental treatment in the past and perinatal grief had disappeared at the second measurement. The impact of having received mental treatment in the past might therefore be limited to crisis situations.

The finding that individuals with high scores on feelings of inadequacy showed more intense grief reactions is in agreement with research findings in other areas. These studies found more disordered mourning in neurotic women after an abortion and in neurotic soldiers after the Vietnam war (Friedman and Gath, 1989; Casella and Motta, 1990). It was found that trauma often leads to the intrusive re-experience of earlier traumatic events (Roy et al., 1987; Theut et al., 1988); our findings indicated that this only took place after the first turmoil of the event had subsided. Rapee et al. (1990) observed that anxious persons attributed a significantly more negative impact to life events than non-anxious persons. Unfortunately, our sample was too small to determine whether impact of life events, type of life event (loss by death, incest, divorce) or coming to terms with an event was influenced by the strongness of feelings of inadequacy of the mother and made any difference to the perinatal grief reactions.

Only "turning aggression against oneself" and "principalization" among the acute psychological defenses made a contribution to the variance in perinatal grief, in addition to personal inadequacy. "Turning aggression against oneself" led to more intense grieving and "principalization" to less intense grief reactions. As expected, this relationship was only found at the first measurement on a version of the Defense Mechanism Inventory which focused on the psychological state after hearing the unfavourable diagnosis. The finding that the defenses of "turning aggression against oneself" and "principalization" were related to more or less intense perinatal grief is consistent with the viewpoint of a hierarchy of defenses arranged according to their pathological significance. In this hierarchy, "turning aggression against oneself" is regarded as an immature defense which is negatively related to mental health. "Principalization" is considered to be a more mature defense and has no relationship with mental health according to Vaillant (1992). Longitudinal research is necessary to reveal whether the defenses reflect either a healthy coping process or delayed grieving.

Previous analyses on these women showed that several pregnancy-related variables, such as viewing the dead infant and no difficulty with conceiving, were positively and significantly related to the intensity of grief (see chapter 3 of the present study), therefore these variables may have confounded the relationships found in this study. However, entering these potential confounders into the analyses did not change the significant associations reported above. The outcome can therefore be considered to be inde-

pendent of these pregnancy-related variables.

A methodological weakness of this study is that the feelings of inadequacy scores were collected in the same period as the grief scores, instead of before the traumatic event. The psychological state of the women might therefore have influenced the scores on the predictive measures. However, the mean scores on feelings of inadequacy largely fell within the range of the norm scores for the general Dutch female population (12.3, sd 7.1 for social inadequacy and 13.9, sd 8.3 for inadequacy) (Luteijn et al., 1985) and were not increased. This indicates that the scores of the women three months after delivery were also representative for feelings of inadequacy before the diagnosis.

Another methodological aspect concerns our rather small number of patients. The relatively large number of variables tested implies that the findings have to be considered with caution. On the other hand, significant findings which are obtained in a small sample can indicate the presence of a large and probably clinical relevant effect.

4.6 Conclusion

The emotional reactions to infant loss owing to severe fetal malformations are most strongly determined by feelings of inadequacy. In addition, having received professional mental health treatment in the past led to more intense grief reactions shortly after receiving the unfavourable diagnosis, while previous life events intensified the grief reactions three months after the delivery. The grieving process was further intensified by the defense of "turning aggression against oneself" and moderated by "principalization" shortly after receiving the unfavourable diagnosis. Longitudinal research is necessary to reveal whether the defenses reflect either a healthy coping process or delayed grieving.

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5

The disposition for feelings of inadequacy predicts perinatal stress, perinatal grief and general psychological distress (GHQ-28) after perinatal loss. A four year follow-up study[1]

5.1 Synopsis

The emotional reactions of women (n=29) after perinatal loss were evaluated over a four year period by means of standardized questionnaires and a semi-structured interview to evaluate whether long-term reactions might be predicted by short-term emotional reactions and the disposition for feelings of inadequacy (hereafter referred to as "feelings for inadequacy").

Emotional reactions declined significantly during this period, except for difficulty coping and despair. Eleven women (38%) displayed general psychological distress which is probably of clinical significance (GHQ-28 score ≥ 5). This number is similar to that in a control group obtained from the general Dutch female population. However, the distribution of scores in the case group showed a relatively large proportion of women within the high range of general psychological distress (GHQ-28 score ≥ 10).

The feelings of inadequacy were strongly and positively related to the intensity of perinatal grief, perinatal stress and general psychological distress after four years. These relationships were not associated with pregnancy-related variables, such as contact with the dead infant or the type of malformation. Our findings emphasize the importance of psychosocial screening of those women identified as showing signs of inadequacy following the diagnosis of a lethal fetal anomaly with the objective to offer them mental support.

5.2 Introduction

Results from many investigations suggest that 20 to 30% of women experience significant psychiatric morbidity (i.e. depressive disorders and anxiety) during the first year after perinatal loss (Zeanah, 1989). However, few investigations have studied the course of grief after perinatal loss, particularly not in the long term. It has been found that symptoms of grief in the early months begin to decline after the first year of bereavement (Black, 1989; Iles, 1989; Iles and Gath, 1993). In contrast, another follow-up study (Laurell-Borulf, 1982) showed that 12 to 14 years after the death of their infant, about one-third of the women were not considered to have adequately overcome the psychological crisis of their infants' death.

In chapter 3 of the present study it was demonstrated that grief assessed between two and six weeks and three months following perinatal loss (i.e. between 24 weeks of gestation and 28 days after birth) did not diminish during this period. Difficulties with

[1] This chapter is a slightly revised version of a publication by Hunfeld, JAM, Wladimiroff, JW, Passchier, J (submitted).

coping with the loss, as measured by the Perinatal Grief Scale (PGS) were particularly persistent.

Frequently studied *determinants of grief* are social support and partner support. Disordered mourning seems to be positively related to a lack of social support, particularly from the partner (Forrest et al., 1982; Toedter et al., 1988; Black, 1989). Important factors related to characteristics of the mother, such as personality traits, have rarely been considered (see Zeanah, 1989).

Several methodological problems characterize the studies on perinatal grief, which precludes any firm conclusions about the course of grief over time and its determinants. The majority of investigations assessed grief at only one moment in time (Nicol et al., 1986; Friedman and Gath, 1989; Neugebauer et al., 1992) or studied grief retrospectively, which implies a risk of distortion of recall (Wilson et al., 1985). Furthermore, several studies made assessments within one or two months after the loss only, resulting in relatively short-term and probably normal, non-pathological, grief reactions (Friedman and Gath, 1989; Prettyman et al., 1993). Samples of women were often heterogeneous and comprised pregnancies with different gestational ages at the time of loss, which sometimes varied from seven to 27 weeks within the same sample (Black, 1989), probably indicating varying degrees of prenatal attachment. Many studies used general grief or psychopathology measures and did not standardize the measures specifically for the situation of perinatal loss (Friedman and Gath, 1989; Neugebauer et al., 1992). This makes identification of specific problems related to perinatal loss difficult (Theut et al., 1989; Leon, 1992). Furthermore, very few studies assessed the original sample at more than one point in time (see Zeanah, 1989). Some of the studies in which the original sample was used, applied different measures during early and later assessments, or had a very small number of participants due to high drop-out rates (Forrest et al., 1982; LaRoche et al., 1984).

In our study we solved several of the above-mentioned methodological problems by assessing grief in women with a comparable gestational age at the time of the loss, at relatively fixed moments in time and by means of standardized perinatal stress and perinatal grief questionnaires and interviews. The present study addressed three questions pertaining to women four years after perinatal loss.

1. What is the prevalence of general psychological distress and what are the characteristics of the perinatal grief process in these women?
2. What is the course of the perinatal stress and perinatal grief process following the unfavourable ultrasound diagnosis?
3. Which predictive value has the disposition for feelings of inadequacy for perinatal stress, perinatal grief and general psychological distress?

5.3 Method

Subjects

We approached 43 women who had been referred to the Division of prenatal diagnosis for an anomaly scan in the period between January 1990 and August 1991. Inclusion criteria for the study were: i) a gestational age of 24 weeks or longer and ii) the presence

of a fetal malformation which was not compatible with extrauterine life or would at least result in severe mental and/or physical handicap(s). Women with a previously known risk for congenital fetal structural malformations and women with insufficient knowledge of the Dutch language were excluded from the study. A total of 29 women (response rate 67%) consented to take part in the study. Five women had already declined to take part in the second measurement three months after the delivery, for fear of becoming upset. The remaining nine women declined because they did not wish to be confronted with the loss (n=6) or their (severely handicapped) child was still alive (n=3).

Control group

A control group was introduced to compare women with and without perinatal loss regarding general psychological distress. The control group was obtained from the general Dutch female population and consisted of 121 women matched for age and parity, without handicapped children or a previous perinatal loss due to lethal fetal anomalies.

Procedure

A medical psychologist (JH) paid a home visit to carry out an audiotaped interview between two and six weeks (first measurement) after the women had been informed of the presence of a severe or lethal fetal malformation. To measure long-term perinatal stress, perinatal grief and inadequacy, a second interview took place three months following the birth of the infant (second measurement). Both interviews took place face to face at the home of the participant. At the first and second measurements, the Perinatal Grief Scale (PGS) and the Perinatal Event List (PEL) were completed, while the Dutch Personality Questionnaire (DPQ) was administered at the second and third measurements only. A detailed description of the procedure and the results concerning the first and second measurements is reported elsewhere (see chapter 3 of the present study). To assess long-term perinatal stress and perinatal grief reactions and general psychological distress, a third audiotaped interview was held by telephone four years after perinatal loss (third measurement). In addition, the PGS, the PEL, the General Health Questionnaire (GHQ-28) and the DPQ, were completed by the women at home.

Instruments

In a semi-structured interview questions were asked about the respondents' present mental and physical health, adjustment to the loss and need for support with respect to the loss. If they subsequently had become pregnant, we enquired about any concerns during this pregnancy and maternal feelings towards the child.

Grief reactions were measured by the Perinatal Grief Scale and the Perinatal Event List. The Perinatal Grief Scale, a translation into Dutch of the short version of the Perinatal Grief Scale (Potvin et al., 1989), measures general and specific perinatal grief. The scale consists of 33 items clustered around three factors or subscales derived from factor analysis: active grief, difficulty coping and despair. The 11 items of the "active grief" subscale register normal or common emotional reactions following a traumatic event, such as sadness, crying for and missing the baby. More complicated emotional reactions are measured with the "difficulty coping" subscale, the 11 items include social isolation and problems with day to day functioning. The 11 items of the "despair" subscale about feelings of guilt, loss of self-esteem and items such as "the best part of me died with the

baby", suggest the potential for serious and long-term effects of the loss. The total score consists of the summation of each subscale score. We labelled the total score as "perinatal grief". The PGS score relates to grief symptoms in the preceding week. The reliability and validity of the scale are satisfactory for both the American and Dutch version (Toedter et al., 1988; chapter 2 of the present study). The Perinatal Event Scale was developed to measure subjective stress after a traumatic event and is an elaboration of the Impact of Event Scale (Horowitz et al., 1979). It consists of 15 items clustered around two factors which are considered to be important dimensions in grieving: intrusion and avoidance. Intrusion is characterized by unbidden thoughts and images, troubled dreams, strong waves of feelings and repetitive behaviour. Avoidance includes denial of meaning and consequences of the event, counterphobic activity, behavioural inhibition and emotional numbness. The total score consists of the summation of the subscale scores. In our study the items of the original scale were anchored to the traumatic event of perinatal loss, as was recommended by Horowitz et al. (1979). We labelled the total score as "perinatal stress". The PEL score relates to stress symptoms in the preceding week. The reliability and validity of the original scale are satisfactory (Horowitz et al., 1979).

General psychological distress consists of nonpsychotic mental disorders (anxiety and depression) and was measured with the 28-item General Health Questionnaire (GHQ-28). The questionnaire was designed to provide a short self-report instrument for use in the general population and among primary care patients to identify psychopathology likely to be of clinical significance (Goldberg and Hillier, 1979). The questionnaire consists of four subscales: somatic complaints, anxiety and insomnia, social dysfunctioning and severe depression. We labelled the total GHQ-28 score which consists of a summation of the subscale scores as "general psychological distress". The total GHQ-28 score relates to the symptoms of general psychological distress during the past few weeks. The validity and reliability are satisfactory (Koeter and Ormel, 1991). Inadequacy was measured with the scales of social inadequacy (SI) and personal inadequacy (PI) which are subscales from the Dutch Personality Questionnaire (DPQ). High scores on social inadequacy indicate incompetence in social contacts. These persons feel inhibited and shy. Personal inadequacy items include questions about depressed mood, anxiety, feelings of insufficiency or low self-esteem. Both subscales can be considered to measure inadequacy or the disposition of the women towards being anxious. The scales have good test-retest reliability, and validity research has confirmed the intended content of the subscales (Luteijn et al., 1985).

Data reduction and analysis

The standard cut-off score of 5 for general psychological distress was used for the GHQ-28 (Goldberg and Hillier, 1979; Koeter and Ormel, 1991) and to establish women in the high range of general psychological distress we used a cut-off score of 10. Manovas were carried out on the scores on the PGS and PEL to assess the overall course of perinatal stress and perinatal grief at the first, second and third measurements. This was followed by paired t-tests which were done on any measures which showed a significant effect of change over time (i.e. alpha $\leq .05$), to test the change between adjacent measurements. Pearson's product moment correlations were used to assess social and personal inad-

equacy in relation to the intensity of perinatal stress, perinatal grief and general psychological distress at the third measurement. Regression analyses were carried out on the PGS and PEL scores obtained four years later using the corresponding PGS and PEL scores and the inadequacy scores obtained at the second measurement as independent variables. This was done to test whether perinatal stress and perinatal grief at three months after the loss would predict perinatal stress and grief at four years, independent of the contribution of the personality trait inadequacy. T-tests were used to compare differences between inadequacy scores on the Dutch Personality Questionnaire obtained at the second and third measurements, to assess whether grief had influenced the inadequacy scores on this personality scale. Women with considerable general psychological distress (score 10-27) and with the lowest score (0) on general psychological distress were compared on the interview with respect to self-reported mental and physical health; adjustment to the loss; need for support with regard to the loss; concerns in the subsequent pregnancy and maternal feelings towards the subsequent child according to the qualitative method (Smaling and van Zuuren, 1992). T-tests and chi-square analysis were done to establish differences between women with a previous perinatal loss and the women from the control group regarding their mean scores and the distribution of scores on general psychological distress.

5.4 Results

Sample characteristics

Twenty-nine women had experienced perinatal loss between 24 weeks of gestation and 28 days after birth (median: 32 wks). Maternal age in the sample at the third measurement ranged between 27 and 47 years (median: 33 yrs).

A more detailed description of the sample is reported elsewhere (see chapter 3 of the present study). Twenty-five women (86%) had become pregnant between 0.5 and 3.3 years (median: 1.6 yrs) after perinatal loss. The subsequent pregnancy of five of these women had first ended in a miscarriage (≤ 16 weeks).

Three women (10%) had not become pregnant again and five women (17%) were pregnant at the third measurement, one woman for the first and four women for the second time after the loss.

5.4.1 General psychological distress and characteristics of the grief process four years after perinatal loss

The time lapse between perinatal loss and the third measurement varied from 2.6 years to 4.1 years (median: 3.3 yrs). Table 5.1 presents the mean scores on general psychological distress (General Health Questionnaire) at the third measurement for both women with previous perinatal loss and women from the control group. The total GHQ-28 score revealed that after four years, 11 out of the 29 women (38%) had a score of 5 or more, indicating general psychological distress which is probably of clinical significance. Seven of these women (24%) scored 10 or higher. No significant difference was found on general psychological distress and subscale scores between women with and without perinatal loss on general distress (Table 5.1).

Table 5.1 Emotional reactions derived from the questionnaires at the first, second and third measurements and the p values of the differences (sd between parentheses)

Psychological measures	1st measurement 2-6 weeks after ultrasound diagnosis	2nd measurement 3 months after delivery	3rd measurement 4 years after pregnancy loss		p value 1st versus 2nd measurement	p value 2nd versus 3rd measurement
Perinatal grief						
active grief	38.0 (9.5)	35.6 (10.3)	28.0 (8.4)		ns	.000
difficulty coping	23.6 (8.3)	24.7 (9.8)	22.1 (8.3)		.03	ns
despair	21.7 (9.1)	22.0 (10.9)	20.2 (7.6)		ns	ns
Total score	83.2 (24.8)	82.5 (29.9)	70.3 (22.8)		ns	.009
Perinatal stress						
intrusion	20.7 (4.3)	19.9 (5.8)	16.5 (5.5)		ns	.005
avoidance	13.6 (4.6)	13.9 (4.7)	12.3 (5.1)		ns	.026
Total score	33.8 (8.0)	33.5 (9.5)	28.8 (9.6)		ns	.006
General Health			Case	Control		
somatic complaints	--	--	2.5 (1.3)	2.1 (2.1)	--	--
social dysfunction	--	--	1.2 (2.1)	.91 (1.7)	--	--
anxiety/insomnia	--	--	1.6 (2.1)	1.5 (2.0)	--	--
severe depression	--	--	.69 (1.6)	.28 (.94)	--	--
Total score	--	--	5.7 (6.9)	4.6 (5.6)	--	--

To establish which perinatal grief experiences characterized high and low levels of general psychological distress, we compared women with high scores (i.e. n=7, 24%, score 10) to women with score 0 (i.e. n=9, 30%) on the GHQ-28 with respect to their responses to the themes discussed in the interview. The women with high scores had more often received professional mental support during the post-loss period (86% versus 33%) and less often succeeded in becoming pregnant again (75% versus 100%). They reported more somatic complaints, such as headaches, abdominal pain and insomnia (71% versus 22%) and more maladjustment to the loss (71% versus 44%), expressed in their regret about the way in which they had parted from the dead infant or because they were haunted by doubts about their child's malformation. Further, the content of the actual experiences of the women with considerably high or low scores on the GHQ-28 was similar, with both groups of women reporting troubled maternal feelings towards the subsequent infant. However, there were differences in the way the issues were presented. Women with low scores reported relatively more positive and active coping with the loss, such as "I am now helping fellow sufferers" or "I do not wish to get carried away by negative feelings" (78% versus 29%). Further, they were more satisfied with the support they received from their partner, health care workers and fellow sufferers (66% versus 43%).

5.4.2 Course of perinatal stress and perinatal grief four years after perinatal loss

Table 5.1 also shows the mean scores on the PGS and PEL at all measurements. The total scores of perinatal stress and perinatal grief showed a significant change from shortly after receiving the unfavourable diagnosis until four years after the loss ($p=.007$ and $p=.03$, respectively). The subscale scores for difficulty coping and despair did not show any significant decline.

The third measurement, which was taken four years after the loss, showed a significant decline in the total scores for perinatal stress ($p=.006$), subscale scores for intrusion ($p=.005$), avoidance ($p=.03$) and perinatal grief ($p=.009$) and subscale scores for active grief ($p=.001$) compared with the scores obtained at the second measurement. No significant decline was observed across the second and third measurements on subscale scores for difficulty coping and despair.

5.4.3 Prediction of perinatal stress, perinatal grief and general psychological distress four years later

Table 5.2 shows the feelings of inadequacy (second measurement) in correlation with perinatal stress, perinatal grief (second and third measurements) and general psychological distress (third measurement).

When we compared the inadequacy scores at the second measurement with those obtained four years after the loss, no significant differences were found regarding the influence of the traumatic event, therefore we used the inadequacy scores obtained at the second measurement, three months after perinatal loss.

The correlations between personal inadequacy and the other variables measured four years after perinatal loss were still significant, except for the subscale score for intrusion, although somewhat diminished. A significant positive relationship was also present between personal inadequacy and the total GHQ-28 score obtained four years after perinatal loss. Feelings of social inadequacy showed no relation with the total perinatal stress, perinatal grief or the total GHQ-28 score four years later, except for the subscale score for avoidance (Table 5.2). Regression analyses showed that the significant relationship between short term and long term perinatal stress and perinatal grief reactions ($p=.001$) disappeared when personal inadequacy entered the comparison.

Tabel 5.2 **Pearson's product moment correlations to assess inadequacy in relation to perinatal stress and perinatal grief at the second and third measurements and general psychological distress at the third measurement**

Psychological measures	Determinants			
	Second measurement		Third measurement	
	Social Inadequacy	Personal Inadequacy	Social Inadequacy	Personal Inadequacy
Perinatal grief (PGS)				
active grief	ns	.62****	ns	.33*
difficulty coping	.50****	.75****	ns	.49***
despair	.43***	.76****	ns	.41**
Total	.42	.75****	ns	.44**
Perinatal Stress (PEL)				
avoidance	ns	.61****	.32*	.44**
intrusion	ns	.54****	ns	ns
Total	ns	.63****	ns	.38*
Psychological distress (GHQ)	-	-	ns	.46**

* p = .05
** p = .01
*** p = .005
**** p = .001

5.5 Discussion

Four years after perinatal loss, 11 out of the 29 women (38%) displayed general psychological distress indicative of the need for mental health support (as defined by the manual of the General Health Questionnaire, GHQ-28). This percentage was similar to that in a control group. It indicates that generally perinatal loss does not interfere with general psychological well-being and that disturbances are limited to pregnancy-loss related problems, such as feeling guilt with regard to the loss or having intrusive memories about the loss. Zeanah (1989) reports a percentage of 20 to 30% of women experiencing significant psychiatric morbidity during the first year after perinatal loss. Our higher percentage might partly be due to the fact that the GHQ-28 is a screening instrument which means that false positives might also have been detected. The GHQ-28 does not replace clinical assessment: a high score only indicates the probability of general psychological distress which is of clinical significance. This should subsquently lead to diagnosis.

With respect to the presence of general psychological distress, the content of the actual experiences as discussed in the interview of the women with high or low scores on the GHQ-28 was similar. However, women with high scores seemed to have considerably less control over their feelings of distress, both related to the perinatal loss and to the subsequent pregnancy. Their wish to communicate about the traumatic event was not met by the available support in their own environment.

In addition to the obvious concerns in a subsequent pregnancy, in both women with low and high scores on general psychological distress sometimes ambivalent maternal feelings emerged towards the subsequent child. These feelings which can be character-

ized as overprotective and emotionally unresponsive were also observed by Forrest et al. (1982). However, our data suggest that becoming pregnant after a perinatal loss assisted most women in resolving the traumatic event, whereas for a minority it seemed to have represented a way of avoiding the loss and thereby impeded resolution of mourning (Lewis, 1979).

Concerning the course of grief, there was a significant decline in the total scores for perinatal stress and perinatal grief and for the subscale scores for active grief, avoidance and intrusion four years after the loss. This is in agreement with the findings of Black (1989) and Iles, (1989) and Iles and Gath (1993). The pattern of grief in our sample also closely resembled the Stress Response Model of Horowitz (1986) which shows that denial and intrusion gradually diminish in intensity over time. When compared with the criteria of psychological maladjustment for subscale scores (Horowitz et al., 1981), 26 out of 29 women (90%) were still at a medium (n=19, 66%) or high (n=7, 24%) level of distress for intrusion, and 19 out of 29 women (66%) scored at a medium (n=15, 52%) or high (n=4, 14%) level for avoidance four years after perinatal loss. According to Horowitz et al. (1981) a high level of intrusion or avoidance indicates the presence of psychopathology. In accordance with the latter finding, scores on the subscales difficulty coping and despair of the Perinatal Grief Scale did not diminish significantly. Toedter et al. (1988) consider these dimensions to be indicators of pathological grieving. However, considering our finding that the majority of women displayed a moderate level of general psychological distress, part of the high scores might be attributed to a longlasting grieving process specific for women after perinatal loss. Although most women do not suffer from general psychological distress, they do from pregnancy loss-related problems, such as "feeling less self-esteem than before the loss"; "feeling guilt concerning the loss" or the feeling of "being somewhat apart and remote even among friends".

With respect to the determinants of grief, the disposition for feelings of personal inadequacy was the strongest positive predictor of perinatal stress and perinatal grief three months after perinatal loss, followed by social inadequacy. Four years after perinatal loss, personal inadequacy still predicted perinatal stress and perinatal grief, except for the subscale score for intrusion, although the relationship had diminished somewhat. Social inadequacy as a predictor of perinatal stress and perinatal grief disappeared, with the exception of avoidance. The majority of women still wished to communicate about the loss even after four years, while the environment was often increasingly unwilling to do so. This might have been particularly daunting to the women with strong feelings of social inadequacy, who may have protected themselves against disappointment by completely avoiding the subject.

Our findings on personal inadequacy support those of Toedter et al. (1988) and Friedman and Gath (1989) who showed a significant positive relationship between psychopathology before the loss and the intensity of perinatal grief. The feelings of personal inadequacy were not only significantly and positively related to perinatal stress and perinatal grief, but also to general psychological distress. This suggests both a specific and a non-specific influence of this personality trait. The importance of personal inadequacy in the grieving process was also shown by regression analysis: the influence

of short term on long term perinatal stress and perinatal grief reactions disappeared when this trait entered the statistical model. This indicates that the latter is a moderator variable between the association of perinatal stress and perinatal grief reactions at three months and at four years after perinatal loss.

Our data emphasize the importance of psychosocial screening of women following the diagnosis of a severe or lethal fetal anomaly. Women who show signs of inadequacy and general psychological distress can subsequently be offered additional mental support.

With regard to methodological aspects, three issues should be discussed. Firstly, 29 out of the initial group of 43 women (67%) participated in the follow-up study four years after perinatal loss. Nearly all longitudinal studies with a time frame like ours showed equal or higher drop-out rates (Forrest et al., 1982; LaRoche et al. 1984). Nevertheless the question remains as to whether those who refused to participate were more distressed and had more trouble with coping than those who remained in the study. The fact that three clinical psychologists agreed on the judgement that six out of the nine non-participants (67%) were severely psychologically unstable at the two early measurements seems to provide an affirmative answer to this question.

Secondly, to assess long-term emotional reactions at the third measurement, we interviewed the women by telephone instead of face to face at home, which might have prevented gaining full insight into the women's psychological condition. However, this more distanced form of communicating did not impede an extensive exploration, which was revealed in the information the women imparted and in the considerable time they spent on the interview (about 45 minutes on average). This may have been due to the relationship the researcher (JH) had established with them earlier during the interviews at home and to their persisting need to talk about the loss.

Thirdly, the inadequacy scores were obtained three months after the loss, not three months before. Grief might therefore have influenced the scores on this personality scale, even if it is a trait measure. However, this is not very likely, because the mean scores for inadequacy largely fell within the range of the norm scores for the general Dutch female population. Furthermore, when we compared the inadequacy scores at the second measurement to those obtained four years later, no significant differences were found regarding the influence of the traumatic event; this also indicates its validity as a trait measure.

Final comments

The characteristics of the grief process of the women revealed in the interviews, indicate that counselling should make the loss tangible (i.e. encourage the parents to view and hold the infant, offer a medical report about the infant), and discuss potential ambivalent and overprotective maternal feelings towards subsequent infants and siblings. This anticipatory guidance might also help to prevent psychological problems in a subsequent pregnancy and enable the women to experience a new pregnancy as worthwhile in itself instead of as a continual series of memories of the lost infant.

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6

Decision-making concerning late pregnancy termination and perinatal grief. An exploratory study[1]

6.1 Synopsis

Shortly after hearing the diagnosis of a serious or lethal fetal anomaly, 46 women were interviewed on their motives for terminating or for continuing their pregnancy of ≥ 24 weeks. In the majority of cases (67%) the pregnancy was terminated two to six weeks following the diagnosis. The main reason for doing so was that the women considered the fact that they were carrying a baby which would die to be unbearable. A minority of the women (33%) wanted to continue with the pregnancy, the most important reason for this being "the strong tie with the baby". The 30 women whose delivery was induced and whose baby died within 28 days following birth were questioned as to whether they saw the way they arrived at a request to terminate the pregnancy as being their own choice. Whether or not they seemed to have had a choice appeared to have no effect on their grieving process, as measured by the Perinatal Grief Scale three months after the loss of the baby.

6.2 Introduction

From research and reviews of the literature on the emotional consequences of induced abortion, it appears, generally speaking, that no emotional trauma occurs in the majority of women who undergo an induced abortion. According to the American Psychiatric Association and the American Psychological Association, neither are there any indications of the existence of a "post abortion syndrome" that is characterised by anxiety, depression, anger and feelings of guilt and regret (Lemkau, 1991). Serious mental morbidity can be found in a few women following induced abortion, the percentages for which vary between 2% and 15% (Ashton, 1980; Turell et al., 1990; Armsworth, 1991; Lemkau, 1991; Major and Cozzarelli, 1992). The socio-cultural climate within which the decision is taken plays an important role in this. Women in an environment dominated by an anti-abortion attitude and women who lack the support of important others, such as partner or parents, have a greater risk of emotional problems following the intervention than women in an environment that is liberal towards abortion and who feel supported by their partner (Turell et al., 1990; Lemkau, 1991; Major and Cozarelli, 1992).

Furthermore, the literature also gives the following as being important predictors of an emotional trauma after abortion: the medical situation, such as the grounds for the abortion, the duration of pregnancy and the abortion procedure (Lemkau, 1991). An

[1] This chapter is an extensive version of a publication in Psychological Reports, 1994, 74, 217-218: Pregnancy termination, perceived control and perinatal grief by Hunfeld, JAM, Wladimiroff, JW, Passchier, J.

abortion that is carried out on genetic grounds and in the second trimester of the pregnancy when the woman has already felt the baby move, leads more often to her having emotional problems than does an elective abortion early in pregnancy (Turell et al., 1990; Adler et al., 1992). As far as the procedure is concerned, it appears that when the woman is prepared for the intervention, she has emotional problems less often than when this is not the case (Strassberg and Moore, 1985). In studies in which comparisons were made between second trimester patients undergoing a saline procedure and those undergoing dilation and evacuation, more favourable responses were shown by the latter (Osofsky et al., 1975; Kaltreider et al., 1979; Cates, 1980).

However, one of the most important risk factors for the occurrence of emotional problems following abortion was given as the way in which the decision was arrived at (Turell et al., 1990). Women who saw the decision to terminate as being their own choice, showed fewer emotional problems than women who, according to them, had taken the decision under pressure. Being aware of one's own choice is also referred to as "perceived control" as opposed to the experience of "had no choice". "Perceived control" means that "the woman perceived herself as agent, that is, a person who acts on major events in her life" (Turell et al., 1990). In other words, she perceives a causal relationship between her behaviour and reactions in the environment which does not necessarily correspond with the objective circumstances.

Most studies into the mental effects of abortion mainly involve women in an unwanted, first trimester pregnancy. This means that mother - child bonding has barely started, and that, from a legal viewpoint, all women are relatively free in their decision to have an abortion.

We are not aware of any studies into the emotional consequences of pregnancy termination due to lethal fetal anomalies late in pregnancy (≥ 24 weeks) where a wanted child is involved. Moreover, little research is done into the way a decision is arrived at with late pregnancy termination. The only research we are aware of was a study of women whose ultrasound scan in the 32nd week of pregnancy revealed serious anomalies in the baby (Jörgensen et al., 1985). The majority of women in this research had wanted to terminate the pregnancy if the anomaly had been established within the legal termination period (≤ 24 weeks). The research by Jörgensen et al. involved a pregnancy with non-lethal fetal anomalies. The study was retrospective, and the motives of the woman for wanting to terminate the pregnancy were not investigated.

Based on the specific characteristics of late pregnancy (≥ 24 weeks), it would be expected that women who wish to terminate a pregnancy because of lethal fetal anomalies, have an increased risk of emotional problems afterwards. This is the case because their request to terminate the pregnancy is more or less involuntary and carrying out the decision is legally punishable on the grounds of article 82a[2] of the Termination of Preg-

[2] Article 82a of the Penal Code reads: "By depriving another person, or a child of life, at or shortly after birth, is understood: the killing of an embryo which has a reasonable chance of survival outside the mother's body." The legislator is assuming a pregnancy of 24 weeks' duration as the limit between permissible termination of a pregnancy and punishable deprivation of life. In other words, killing an independently viable embryo can be equated with killing a child at or shortly after birth (Nota Late Zwangerschapsafbreking, 1994).

nancy Act. Moreover, the request for termination is made at a time that mother - child bonding will have significantly increased, and in a situation in which the social environment might be experienced more as a burden than as support in the decision (Major and Cozzarelli, 1992). This is the reason why we researched women whose severe or lethal fetal anomaly was diagnosed at an advanced stage (≥ 24 weeks) of pregnancy. In connection with this we had the following questions:

1. How many women wish to terminate their pregnancy or to continue with their pregnancy and what are their motives for doing so?
2. What is the relationship between "perceived control" and "had no choice" in the request to terminate the pregnancy and the intensity of grieving?

6.3 Method

Patients

Fifty-five patients who, in the period between January 1990 and August 1991, had been referred to the Division of prenatal diagnosis for an anomaly scan were approached in the AZR-Dijkzigt in Rotterdam. Inclusion criteria were (i) a gestational age of 24 weeks or more, and (ii) the presence of a fetal malformation which was not compatible with extrauterine life or would at least result in severe mental and/or physical handicap(s). Women with a previously known risk of a congenital fetal structural malformation and women with insufficient knowledge of the Dutch language were excluded from the study. A total of 46 pregnant women consented to participate in the study. Nine of the women approached did not participate in the study: eight women because they did not wish to be confronted with the traumatic event of the loss, and one woman because she and her partner were both deaf. Forty-six women participated in the investigation concerning the first research question. At the time of the second measurement, five women had withdrawn from the study because they did not wish to be confronted with the loss. Therefore, 41 women remained for further analysis. Of them, 30 women who had undergone induced delivery which resulted in perinatal death participated in the study with regard to the second research question. The last question is restricted to those whose pregnancy was ended, because the group of women who wished to continue their pregnancy was too small to make the same division as to how they arrived at a decision.

Procedure

A medical psychologist (JH) paid a home visit to carry out an audiotaped interview two to six weeks after the women had been informed of the presence of a severe fetal malformation (first measurement). This time interval was chosen because, in a pilot study, several women were too distressed to be interviewed at an earlier stage. To measure the long-term emotional reactions, a second interview took place three months following birth (second measurement). The rationale for the time interval between the first and second measurement was that, according to the DSM-III-R description of uncomplicated bereavement, grief symptoms should occur within three months following the loss. If this was not the case, it might indicate delayed or pathological grieving.

When, in the first measurement, the women reported that an induced delivery of the infant had taken place, the interviewer asked questions with respect to "perceived control" or "had no choice" regarding their decision. If the induced delivery was reported as occurring between the first and the second measurements, the woman's perception of the decision was explored in the second interview. At the first and second measurements, the Perinatal Grief Scale was left behind for completion, including a stamped addressed return envelope.

The women were instructed to contact the interviewer if they had any problems regarding the completion. The women received a reminder by telephone if the Perinatal Grief Scale had not been returned two weeks later.

Instruments

The interviews were semi-structured and included open-ended questions with regard to the motives of the women whether to continue or to terminate pregnancy following the diagnosis of a severe or lethal fetal anomaly and how they perceived the situation of pregnancy termination.

Grief reactions were measured with the Perinatal Grief Scale (PGS). This scale is a Dutch translation of Potvin's Perinatal Grief Scale (Potvin et al., 1989). The scale consists of three subscales: active grief, difficulty coping and despair. The total PGS score is a summation of each subscale score. The PGS score relates to grief symptoms in the preceding week. The reliability and validity of the scale are good for the American and Dutch versions (Toedter et al., 1988; chapter 2 of the present study).

Data reduction and analysis

The contents of the audiotaped interviews was first transcribed into a report, and included the women's literal description of their motives to terminate or to continue pregnancy and how they perceived the event of induced delivery. Two psychologists categorized the description into "did perceive control", indicated for instance by statements such as "I wished to have the pregnancy terminated, because it was useless to wait any longer" or "It is better for our family to terminate the pregnancy now". Or "did not perceive control" (i.e. "had no choice") regarding pregnancy termination, exemplified by statements such as "What were my motives? I did not have any choice!" or "I had so much pain, it had to be wrong". The difference in the scores on the Perinatal Grief Scale obtained at the second measurement (three months after the loss) between the women who "perceived control" versus the women who "had no choice" was assessed by a t-test.

6.4 Results

Sample characteristics

Maternal age in the sample (n=46) ranged between 19 - 44 years (median: 30 yrs) and gestational age varied between 24 - 38 weeks (median: 31 wks). Further characteristics of the sample are presented in chapter 3 (Tables 3.1 and 3.2). Over half (59%) of the malformations were not compatible with extrauterine life. At the time of the first measurement, 31 women from the sample had delivered. Twenty-one of these infants had died before or during delivery and seven infants died afterwards (six infants ≤ 28 days

and one infant ≥ 28 days). Three women had given birth to a live infant and fifteen women were still carrying a live fetus. All the women had delivered at the time of the second measurement. From the total sample of delivered infants, 36 had died, 19 before or during delivery and ten infants shortly afterwards; six infants had died within 28 days and one infant following 28 days after birth. A total of five infants were alive, but were suffering from severe physical and/or mental handicap(s). Thirty-eight of the deliveries were induced, four of which following intrauterine death. There were eight spontaneous deliveries, one also following intrauterine death.

6.4.1 Number and motives of women who wished to terminate or to continue pregnancy

Pregnancy termination

Shortly after the diagnosis of a severe or lethal fetal anomaly, 29 women (63%) wished to terminate the pregnancy. According to about half of them (n=14), the most important motive was that knowing they were carrying a baby that would die at or near birth was unbearable. Other motives that the women also mentioned as being most important were: the seriousness of the anomaly (n=8); the physical pain (n=5); fear of a confrontation with the environment (n=5); not being able to cope with the uncertainty about the state of the baby (n=5); not wanting the child to suffer any longer (n=3); the pointlessness of the pregnancy (n=3); the advice of the gynaecologist (n=3); wanting to increase (n=1) or decrease (n=1) the life expectancy of the baby.

Continuing the pregnancy

Shortly after the diagnosis, 17 women (37%) stated that they wished to continue the pregnancy. Nine of them wanted to do so for emotional reasons. They found "the bond with the baby too strong", they wanted "to fight for the baby", or held "the hope that everything would be all right". Four women "did not want to intervene in the life" for religious reasons and three women said that they dare not take onto themselves the responsibility for terminating the pregnancy. What was striking was that only one woman wishing to continue the pregnancy did actually carry to term.

6.4.2 The relationship between "perceived control" versus "had no choice" and the intensity of grief (on the Perinatal Grief Scale)

Of those women (n=30) who underwent induced delivery which resulted in perinatal death, eighteen women (60%) seemed to have perceived control over the event of induced delivery, for instance by stating: "I wished to have the pregnancy terminated, because it was useless to wait any longer". Twelve women (40%) expressed a lack of control as exemplified by the statement: "What were my motives? I did not have any choice!".

The perception of having no control did not lead to a more intense grieving process: there were no significant differences on the Perinatal Grief Scale between women who perceived control (median: 76, sd=31) versus women who said they "did not have any choice" (median: 85, sd=20, p=.17).

6.5 Discussion

Motives for terminating or continuing the pregnancy

The majority of women had wanted to terminate the pregnancy if a severe or lethal fetal anomaly were diagnosed. Their most important motive was the "unbearable prospect that the baby would die". Our findings are consistent with those of Jörgensen et al. (1985). They found that six of the eight mothers with a seriously handicapped child had wanted to terminate the pregnancy if the diagnosis had been made within the legal termination period.

Less than half the women in our investigation wanted to continue the pregnancy, mainly for emotional reasons. The number of women by their own account had wanted to terminate the pregnancy, was relatively greater among women who had already given birth than among women who were still pregnant (74% versus 40%). A possible explanation for this is the cognitive dissonance theory (Festinger, 1957). Cognitive dissonance is an emotional state that arises due to a conflict between belief and the deed as carried out. According to cognitive dissonance theory, persons are driven to reduce the dissonance by bringing the belief into harmony with the behaviour. This means that a number of women possibly adjusted their wish to continue pregnancy not only prior to the induced birth (i.e. wanting to continue - because it was otherwise punishable in law), but also afterwards (i.e. wishing to terminate - because the pregnancy had already ended). Another explanation is that in some women who initially wished to continue the pregnancy, there was a stronger denial of the seriousness of the situation than in women who, right from the outset, stated that they wished to terminate the pregnancy. The shift in the initial wish of those women to continue pregnancy may mean that the women gradually became aware of the reality of the seriousness of the anomaly of their child. During the interview it was noticeable how loaded the subject of "pregnancy termination" was for many women. This manifested itself in talking about the taking the decision not only non-verbally, through pauses and hesitations, but also verbally, in careful wording: "it was not a decision, it was simply the case". Not only were scruples noticeable with respect to pregnancy termination, but also when exploring the motives to take a decision did it appear that many women did not want to talk of a decision. Some women appeared rather to be "driven by powers from outside": according to them, the seriousness of the anomaly and the physical pain did not allow them any other choice but to terminate the pregnancy.

The way in which the decision to terminate the pregnancy was arrived at does not always appear to have taken a rational path. This conclusion conflicts with the common view that, when taking a decision, a person operates rationally, is aware of all options and is able to assess the outcome of the decision in advance with respect to the desired effect (Janis and Mann, 1976; Ashton, 1980). Apart from the coping phase, in which one is not always clearly aware of thoughts and feelings, the social context is also likely to have played a role here (generally speaking pregnancy termination at ≥ 24 weeks is not legally permissible). The results of our research are linked more closely to data from another investigation. Frets (1990) found that parents, one or both of whom were carriers of a gene for a congenital illness, were more often led in their decision to have a child by

their desire for a child than by the objectively established risks of carrying the gene, to a statistically significant degree.

The way of reaching a decision and the intensity of grief reactions according to the PGS

For the second research question we made a distinction between women whose description of how they arrived at a decision to terminate the pregnancy was characterised or not by "perceived control". The subsequent variable "perceived control" did not appear to have an effect on the intensity of the grieving. This seems to conflict with most other research data where it appears that not experiencing control over an illness (Breemhaar and van den Borne, 1991; Lepore et al., 1992; Sieber et al., 1992) or over abortion (Turell et al., 1990) has a negative effect on emotionally coping with it. Probably the turmoil of the entire situation on discovering a lethal fetal anomaly overruled the possible effect of perceived control concerning decision-making on grief. An alternative explanation is that the negative effect of having no control, as observed in many other research areas, might have counterbalanced the lack of feelings of guilt often associated with the decision to have an abortion.

A number of methodological problems in our research should be discussed. For most women (67%) the question on motives and on the way in which the pregnancy was terminated could only be asked retrospectively, because at the time of the first interview they had already given birth. This may have contributed to distortion in the description of the decision taking situation. It also remained unclear whether terminating the pregnancy in all cases meant an "abortus provocatus".

Due to the limited size of the sample, apart from the effect of the way the decision was arrived at, it is not possible to investigate the influence of the stage of pregnancy, the information from the gynaecologist and the abortion procedure. In a replication investigation with a prospective design, the connection between these variables with grieving should be investigated.

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7

Threatened late pregnancy loss and the need for assistance. What kind of assistance is desired? At what time?

7.1 Synopsis

The scale and kind of assistance required in cases of threatened perinatal loss due to congenital anomalies of the unborn child was investigated among 46 women whose pregnancy was ≥ 24 weeks. The need for assistance as we investigated it includes both the desire for assistance as expressed by the woman and the need for assistance as could be deduced from her behaviour (i.e. because the woman reported that she was consulting a psychiatrist or a psychologist). A distinction could be made between the need mainly for medical information or mainly for emotional support. The latter included more understanding and attention for her loss from her environment.

Shortly after the diagnosis and the delivery, the need for information was dominant, and concerned information on the nature and prognosis and on the risk of the anomaly of which the previous baby had died being repeated. In this period most women found emotional support in their own environment (i.e. from the partner, the family, and the general practitioner).

Three months following delivery more emotional support was sought, particularly from others who had undergone the same experiences, and there was a noticeable tendency of diminished attention from those in the environment for the loss. Four years after the loss of the baby, about one third of the women required both information and emotional support. Again, the need for information concerned the risk of repetition and extra medical examination in a new pregnancy. The need for emotional support was mainly sought as professional assistance (i.e. from a psychiatrist, psychologist or social worker), and this assistance was given to relatively more women than at three months following delivery. It appeared that it was mainly women with an above average to very high score on inadequacy (i.e. strong feelings of depression, instability, diminished self-worth, inhibition and shyness) on the Dutch Personality Questionnaire (score ≥ 18) who received this professional assistance. It is recommended that this group of women in particular be offered mental support, which may involve listening and putting into words the emotions that the woman expresses about her loss.

7.2 Introduction

Perinatal loss late in pregnancy (≥ 24 weeks) is a traumatic event. Since the eighties, attention for the support of persons following a traumatic event has increased. This support is both curative and preventive, i.e. an attempt is made to prevent serious mental abnormalities by recognising the risk factors at an early stage (Kleber and Brom, 1992).

In a recent review on hospital support as experienced by women after a serious or

lethal anomaly in the unborn child had been detected, Cuisinier et al. (1993) established that in the situation in the Netherlands it was particularly the hospital support *during the loss* that the parents regarded positively. The little amount of data on the care in Dutch hospitals given to parents *prior to the loss*, when a severe or lethal anomaly in the baby (hereafter referred to as "threatened perinatal loss") is suspected, show that this is something they are less satisfied about. Sometimes information is lacking on the nature and the prognosis of the anomaly and on "what parents can expect". Parents appear most dissatisfied about the *after care*, both the scope and the organisation of the care, where it comes to light that the coordination between first and second line care leaves something to be desired.

The guidelines for the hospital support surrounding (threatened) perinatal loss are often based on theoretical suppositions about grieving and about the needs of the parents (Worden, 1983; Condon, 1986; Lilford et al., 1994) or on the appreciation of the part of the parents for the hospital care received (Hohenbruck et al., 1985; Murray and Callan, 1988; Timmers et al., 1990; Cuisinier et al., 1990; van Spijker et al., 1992). Little research has been carried out into the effect on grieving of such special hospital support following perinatal loss, such as giving (taking) photographs of the deceased infant, seeing and holding the child, a follow-up discussion. As a result of the latter, Forrest et al. (1982) saw in women six months after perinatal loss (≥ 28 weeks) a statistically significant decrease in anxiety, depression and physical complaints as compared with a control group that had not received this support. Murray and Callan (1988) also established that hospital support that was intended to develop in the parents recollective images of the dead baby, was a significant factor in the adjustment of the woman to perinatal death.

In general this support is done by doctors and nursing staff and psychosocial aid workers that are not usually involved in these matters. Research by Keirse (1989) carried out in a number of Belgian hospitals showed that a social worker was present in almost all cases of perinatal death. A majority of the parents regarded this contact positively, whilst the behaviour of doctors and nursing staff was often considered to be "not very informative and too distant". Some authors consider that psychosocial assistance from a trained psychotherapist should be offered to *all* parents following perinatal loss (Robinson et al., 1984; Oglethorpe, 1989). Lilford et al. (1994) researched the effect of specialised psychological support following perinatal loss. They compared a control group with a group of women selected at random who underwent a number of psychotherapeutic discussions. The aim of the discussions was to support the woman in her grieving. In addition, the women from the therapy group had additional support in a subsequent pregnancy. The researchers found no effect of this special support: women in both the therapy group and the control group appeared on conclusion of the support not to differ significantly in anxiety, depression and grieving.

It is noticeable that little research has been carried out into the *self-reported needs* of parents for support in general in cases of (threatened) perinatal loss; most studies involve an evaluation of the support *received*. In particular there is a lack of data on parents for whom a severe or lethal anomaly in the baby was discovered late in pregnancy (≥ 24 weeks). It can be expected that parents in this situation have particular wishes with re-

spect to the support, because the mother - child bonding is at an advanced stage and because, from a legal standpoint, the parents no longer have a choice to have the pregnancy terminated. With this as background, we had the following questions for this group of women:

1. How great was their need for assistance?
2. What kind of assistance was required and when?

7.3 Method

Subjects

Fifty-five patients who, in the period between January 1990 and August 1991, had been referred to the Division of prenatal diagnosis for an anomaly scan were approached. Inclusion criteria were (i) a gestational age of 24 weeks or more, and (ii) the presence of a fetal malformation which was not compatible with extrauterine life or would at least result in severe mental and/or physical handicap(s). Women with a previously known risk of a congenital fetal structural malformation and women with insufficient knowledge of the Dutch language were excluded from the study. A total of 46 pregnant women consented to participate in the study. Nine of the women approached did not participate in the study: eight women because they did not wish to be confronted with the traumatic event of the loss, and one woman because she and her partner were both deaf. A total of 41 women consented to take part in the second measurement, and 29 women participated in the third measurement. Seventeen women withdrew from the second measurement (n=5) or third measurement (n=12), because they did not wish to be confronted with the loss (n-11), they did not respond to a reminder (n=3) or because the (severely mentally and/or physically handicapped) infant was still alive after 4 years (n=3).

Procedure and measurements

After the diagnosis of a severe or lethal fetal anomaly had been made, the doctor who carried out the ultrasound investigation invited the woman to participate in the medical psychological study to assess the need for assistance and the kind of assistance. The study was introduced by stating that the aim of the investigation was to collect this information for the optimization of future care.

A medical psychologist (JH) paid a home visit to carry out an audiotaped interview two to six weeks after the women had been informed of the presence of a severe fetal malformation (first measurement). This time interval was chosen because, in a pilot study, several women were too distressed to be interviewed at an earlier stage. A second interview took place three months following birth (second measurement). Four years after the loss, a third measurement (telephone interview) was carried out.

The semi-structured interview was used to explore the presence of a need for assistance, and the type of assistance required beyond the assistance received in her immediate social environment, such as from her partner, family or friends. The need for assistance was operationalized as the actually reported need and the behaviourally induced need, such as the woman's report that she consulted a psychiatrist, a psychologist or a fellow sufferer. In addition, whether the woman had in the past sought professional

psychological assistance was investigated.

The contents of the interviews were audiotaped and transcribed into a report. This was followed by a classification of the answers in the report into those that indicated the need for information and those that indicated the need for emotional support.

All the women completed the Dutch Personality Questionnaire (DPQ) in connection with other questions in our research (see chapters 4 and 5 of the present study).

7.4 Results

Sample characteristics

Maternal age in the sample (n=46) ranged between 19 - 44 years (median: 30 yrs) and gestational age varied between 24 - 38 weeks (median: 31 wks).[1] Over half (59%) of the malformations were not compatible with extrauterine life.[2] At the time of the first measurement, 31 women from the sample had delivered. Twenty-one of these infants had died before or during delivery and seven infants died afterwards (six infants ≤ 28 days and one infant ≥ 28 days). Three women had given birth to a live infant and fifteen women were still carrying a live fetus.

All the women had delivered at the time of the second measurement. From the total sample of infants delivered, 36 had died, 19 before or during delivery and ten infants shortly afterwards; six infants had died within 28 days and one infant following 28 days after birth. A total of five infants were alive during the study period, but were suffering from severe physical and/or mental handicap(s). Thirty-eight of the deliveries were induced, four of which following intrauterine death. There were eight spontaneous deliveries, one also following intrauterine death. Four years later, nine women declined to participate out of fear of becoming upset. In three cases (severely mentally or physically handicapped) the infant was still alive, and these women were excluded from further analyses. Therefore, the final sample consisted of 29 women.

Need for assistance

The mothers' need for assistance is categorised according to the period to which the interview question related: shortly after the diagnosis, shortly after the delivery, three months after the delivery and four years after the loss.

Table7.1 Numbers and percentages of women who needed assistance (information and emotional support) at all moments of measurement

Kind of assistance	Shortly after the diagnosis (n=46)	Shortly after the birth (n=44)	Three months after delivery (n=41)	Four years after the loss (n=29)
Medical information	7 (15%)	11 (25%)	1 (2%)	10 (34%)
Emotional support	2 (4%)	3 (7%)	10 (24%)	10 (34%)

[1] Further characteristics of the sample are presented in chapter 3 (Table 3.1).

[2] Further characteristics of the malformations are presented in chapter 3 (Table 3.2).

7.4.1 Medical information

As Table 7.1 shows, there is a need for information from the hospital shortly after the diagnosis and the delivery and this need has almost disappeared after three months. In the intervening period up to four years after the loss, the need for information has, however, returned.

Shortly after the diagnosis, information is needed mainly on the nature and the prognosis of the anomaly and on the time and method of delivery. Both shortly after delivery and after three months, the information required was on the cause of the anomaly. In the period three months after delivery to four years after losing the baby, about one third of the women required information on the risk of the anomaly being repeated or an additional medical examination (i.e. prenatal diagnostics) in a new pregnancy.

7.4.2 Emotional support

Table 7.1 shows that shortly after the diagnosis and the delivery a small number of women require support from the hospital, particularly in the form of more understanding for their emotions of shock and bewilderment. Most women say that in this period they received sufficient emotional support from their own social environment. Three months after the delivery there is greater need for support from outside one's own environment, particularly in the sense of exchanging experiences with fellow sufferers. Two women had actually sought contact with them. In this period, one woman was referred by her gynaecologist to a psychiatrist and one woman was put in contact with a social worker by the hospital where she had delivered.

In the period three months after delivery to four years after the loss of the baby, there was, in about one third of the women, a need for support. Four of them received professional assistance from a psychologist or psychiatrist and one woman from a social worker. For two of these women this involved the continuation of an already existing contact. Furthermore, two women had maintained contact with fellow-sufferers and one woman was considering such contact.

7.5 Discussion

Over the entire research period, from shortly after the diagnosis to four years after the loss, there was a need for information, but this need shifted over time from a wish for information to the need for support. Four years after the loss both information and support were required on an equal footing. As far as the information requirement was concerned in the period shortly after the diagnosis, it is consistent with other research data (Cuisinier et al., 1990; Timmers et al., 1990).

With respect to the support required it appeared that the majority of women in the period shortly after the diagnosis and delivery, has enough support by the partner and their own environment. Only a small number of women had missed emotional support from the hospital. This finding supports the general fact that about 80% of persons manage to cope with an intrusive event such as the loss of a baby on their own and with support from the immediate social environment (i.e. partner, family) (Kleber and Brom,

1992). Three months after the delivery more women need emotional support from outside. Our findings indicate that, in this period, the woman becomes increasingly aware of the loss of the baby and of the corresponding emotions (i.e. missing the baby and longing for the baby). This tendency is accompanied by diminished interest on the part of the environment for her loss. Evidently, the support in one's own circle is no longer so matter-of-course after a period of time. This may explain why more women seek support outside their own social environment, particularly contact with fellow-sufferers.

Four years after the loss the need in women for assistance is relatively great and involves both information and emotional support. It is noticeable that professional assistance from a psychiatrist, psychologist or social worker is greater (24%) than three months after the delivery (5%) when it was mainly contact with fellow-sufferers that was sought. Sharing a common experience of perinatal loss with fellow-suffers did not always meet with the mothers' expectations. One woman commenting on this contact stated "I now try to avoid (this person), because she wants to keep the memory of the loss alive all the time, and I think that's unhealthy".

It appears that professional support in particular is given to women with an above average to very high score on inadequacy. This was the case in 80% of them compared with 20% of the other women. It also appeared that about two thirds of the women with a score of ≥ 18 on the DPQ before perinatal loss were already receiving professional assistance for disturbed family relationships.

On the one hand, the relatively great need for assistance four years after the loss is striking. On the other hand, there is a good chance that in a period of four years many events take place that activate the memories of the traumatic event of the loss, such as a new child being born or the death of a loved one. Moreover, most women in the intervening period to four years after the loss had become pregnant or expressed the wish to become pregnant. From the interview it appeared that for almost all the women this was a tense period. The new pregnancy and the rekindling of memories of the traumatic event may bring with them the greater need for assistance.

Our expectation that there is special need for assistance in women with threatened perinatal loss late in pregnancy was confirmed by our research. For a minority of women this means setting out with her doctor the medical options, so that a well informed decision can be taken on whether or not to terminate the pregnancy. In the majority of women there is special need on matters surrounding a new pregnancy, particularly for information on the risk of the anomaly recurring and extra medical examination in a new pregnancy.

The fact that in the period shortly after the diagnosis and the delivery the need for assistance is only to be found in a minority of women, does not mean that in general in the rest of the women this need was not there, but that, in so far as our research group was involved, this need had already been met. It is not known whether this was done at the request of the woman herself or that it was suggested by the gynaecologist.

In answering the question on the need for assistance, we made a distinction between informative and emotional support. In fact these two forms of assistance cannot be strictly

separated, sometimes the need for information may arise from uncertainty. We did not research this any further, but based our distinction on whether the need for information or for emotional support dominated.

From our findings, the association between the disposition for feelings of inadequacy and grief was salient. Other researchers have indicated that there is an association between neuroticism (i.e. feelings of inadequacy) on the one hand and low social adjustment and not being able to provide structure and meaning to a traumatic event on the other (Friedman and Gath, 1989; Casella and Motta, 1990). Further, it has been found that empathic listening to the women and labelling the emotions that they express concerning perinatal loss, have a positive effect (Jörgensen et al., 1985; Zeanah, 1989). Our findings imply, therefore, that such opportunity should be offered, particularly to women who have been identified as showing the disposition for feelings of inadequacy and who have received professional mental health treatment in the past.

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8

General discussion

There has been a strong increase in the amount of attention paid to coping with pregnancy loss over the past 15 years. In this respect, a distinction has been made between reactions which occur after losing an older loved one and a baby. The latter is also referred to as perinatal grief and signifies a specific situation in which someone does not grieve for a consciously-known person, but for a fantasised child with whom a bond has been formed even before his or her birth. In addition, specific emotions are supposed to play a central role in coping with perinatal loss, such as guilt ("was it my fault") and loss of self-esteem ("other women have managed to bring healthy babies into the world"). These reactions are likely to become intensified because the introduction of contraceptives and women's liberation particularly in relation to employment, mean that the parents consciously choose to have a child and really want to have one.

If it is found that a fetus has lethal congenital malformations, not only emotions related to threatened pregnancy loss play a role, but also problems related to the decision process of whether or not to terminate the pregnancy. The latter is particularly applicable if the lethal anomaly is not detected within the legal termination period (≤ 24 weeks). Psychological knowledge and insight into this situation are scarce.

This study was performed on women in whom advanced ultrasound examination had revealed at a late stage (≥ 24 weeks) that their pregnancy was complicated by a severe or lethal fetal anomaly. We investigated how they coped with the (threatened) pregnancy loss, what problems were associated with the decision process and to what extent they needed help.

8.1 Theoretical background

In research into coping after perinatal loss, two theoretical approaches can be distinguished (Adler et al., 1992.) The "psychopathology approach" which aims at evaluating pathological reactions to pregnancy loss. This approach is chiefly based on clinical case studies on selected groups of women who sought psychological assistance for their pregnancy loss. Diagnostic criteria are used to detect symptoms of psychiatric illness. The other approach was introduced more recently and is represented by the Stress Response model (see also chapter 1 of the present study). In this model, pregnancy loss is considered to be a potentially stressful event which does not necessarily lead to psychopathology in the woman concerned. This means that there can be a wide variation in reactions, not only in the form of negative emotions and psychopathology, but also growth and maturation. Stress in this approach is defined as "emerging from an interaction of the individual and the environment in situations that the person appraises as taxing or exceeding her resources and endangering her well-being" (Lazarus and Folkman, 1984). On the basis of a continuum of reactions to stressful events, with normal and pathological reactions at opposite extremes, the stress approach relates to the whole scala of reac-

tions in the evaluation of the psychological state of the woman. According to this approach, the severity of the reactions is both determined by the duration and intensity of the reactions and whether or not they have been blocked (Kleber and Brom, 1992) and psychological morbidity. Our study was based on the Stress Response model in which pregnancy loss was regarded as a specific stressor which could lead to various levels of stress reactions in individual women. We chose this approach because our psychological study on pregnancy loss concerned a random sample of women who were representative of this population. In addition, this approach offers the opportunity of providing help at an early stage, instead of having to wait until serious psychological problems had developed.

8.2 Method

Psychological instability and coping with pregnancy loss were measured at three different times: two to six weeks after having heard the diagnosis, three months after delivery and at four years after perinatal loss. Data were obtained by means of interviews and questionnaires (Dutch versions of the Perinatal Event List and the Perinatal Grief Scale). This combination was chosen to gain insight into the duration, intensity and course of the reactions and also into the quality and background of the reactions. Psychological instability was evaluated on the basis of an interview two to six weeks after the diagnosis and three months after the infant had been delivered. For the clinical evaluation, three clinical psychologists based their diagnoses on symptoms of psychological instability which led to long-term disruption of various aspects of daily functioning, such as looking after the other children. These symptoms could be present on a physical, psychological and social level. Four years after the infant had been delivered, standardised measurements were performed, instead of a clinical evaluation, to detect psychological distress which formed an indication for the need of mental support. Data were obtained using the (Dutch version of the) General Health Questionnaire (GHQ-28).[1]

8.3 Psychological instability

Clinical evaluation showed serious psychological instability in 45% of the 46 women, two to six weeks after hearing the unfavourable diagnosis about the baby. Three months after the infant had been delivered, there was a significant decrease in the number of women showing instability (22%). Only one of these women had not been judged as severely psychologically unstable in the earlier part of the study. Our findings were consistent with research data from other countries in which percentages of 48% and 41% were reported within one month after the loss (Friedman and Gath, 1989; Iles and Gath, 1993); six and twelve months later the percentage had dropped to about 20% (Iles and Gath, 1993).

We presume that our percentage of instability after three months was an underestimation, because all five of the women who withdrew from further follow-up were diagnosed as seriously psychologically unstable shortly after receiving the unfavourable

[1] Our resources did not permit assessment by means of clinical interviews.

news about the baby. Moreover, their motive for withdrawing was fear of emotions related to the loss. According to the Stress Response model (Horowitz et al., 1993) this may have been an indication of a severe form of avoidance of the traumatic event (see chapter 1, Table 1.4 of the present study). When we corrected for this situation, the percentage of instability after three months was 27%. The severely psychologically unstable women distinguished themselves from the others in the interview by making more frequent reports of: a poor relationship with their partner or other people nearby, earlier unexpected loss because of the death, problems with terminating the pregnancy, feelings of failure and guilt about the loss of the baby and earlier consultation with professional psychological assistance in relation to the loss or before pregnancy loss owing to disrupted family relationships.

Four years later, 38% of the women showed general psychological distress, measured with the General Health Questionnaire. This appears to be a high percentage, but it is very similar to the percentage found in a comparable group of women from the general Dutch population (Sanderman and Stewart, 1989). This indicated that although the women in our study group had specific problems related to pregnancy loss, such as feelings of guilt and the feeling of "being somewhat apart and remote even among friends" (measured with the Perinatal Grief Scale), this did not hinder their general psychological functioning (measured with the General Health Questionnaire).

8.4 Perinatal stress and perinatal grief

The answers to the questionnaires showed that two to six weeks after hearing the unfavourable ultrasound diagnosis, the scores of the women with pregnancy loss were three to four times higher on the Perinatal Event List than those of women who gave birth to a healthy baby in a similar time period (Brom and Kleber, 1985). In other words, after a stressful event such as pregnancy loss, the women concerned had more difficulty letting go of the unpleasant images, emotions and thoughts about the baby, but at the same time, they were more liable to try to avoid the subject of the infant's delivery than (Dutch) women who had experienced a stressful event such as delivery. The scores on the Perinatal Grief Scale were significantly correlated with the clinical assessment of psychological instability: women who were labelled as severely psychologically unstable also displayed more intense grief reactions. Contrary to the significant decrease in the number of psychologically unstable women three months after delivery, the intensity of the emotional reactions measured with the questionnaires had not decreased in this period, while difficulty coping had even increased significantly. This is in agreement with the Stress Response model which describes that after the first reactions of shock and bewilderment, realisation of the reality of the loss and emotions associated with it come forward (expressed in our interviews in terms of: "I fell into a very deep hole" and "I keep on thinking about all the things that I would have been able to do with the baby").

It was striking that even after four years, difficulty coping and despair had not decreased significantly. In addition, intrusion and avoidance were still at the level of psychological distress in about one quarter of the women, which according to Horowitz (1981) indicates a need for further diagnostic tests and treatment.

In view of the normal level of general psychological distress, it is possible that the grief reactions in our study group were an expression of a "normal" long-term coping process which is typical for women with late pregnancy loss (≥ 24 weeks).

8.5 Predictors of perinatal stress (PEL), perinatal grief (PGS) and general psychological distress (GHQ-28)

The disposition for feelings of inadequacy (i.e. feeling labile, depressed, anxious and low self-esteem) proved to be a good predictor of difficulties related to coping with perinatal loss: women with a strong disposition displayed significantly more intense grief reactions. Our finding is consistent not only with data from other research into coping with pregnancy loss (Toedter et al., 1988; Friedman and Gath, 1989), but also with studies on coping after various forms of trauma (Hovens, 1994). This indicates that coping with loss is not only determined by specific problems, but also by the way in which a person - both genetically and through lessons in the past - copes with major life events.

Another important predictor of pathological grief reactions is the intensity of the emotional reactions early in the grief process. There are indications that there is a positive relationship with later emotional reactions. So far, very little research has been performed into the background of the phenomenon (Kleber and Brom, 1992). We found that an important intermediating factor in a positive relationship between early and late grief reactions was the disposition for feelings of inadequacy.

8.6 Motives to terminate or continue pregnancy

Our study group comprised women whose pregnancy was found to be complicated by a severe or lethal fetal anomaly at a late stage (≥ 24 weeks). For these women, terminating the pregnancy meant that they were aborting their baby during a viable period of his or her existence. Ethical and legal factors caused extra problems in the decision process and emphasized the major differences from a "usual" abortion (Nota Late Zwangerschapsafbreking 1994).

Despite this, the majority of women (67%) in our study group terminated their pregnancy within six weeks, chiefly because they found it unbearable to know that they were carrying a child that would probably not survive for long after delivery. The choice of pregnancy termination was not always made explicitly and many of the women did not feel that they had had much control over the decision. Our assumption that this may have influenced the intensity of the grief (stress) reactions could not be confirmed, contrary to the results of several other studies (Major and Cozzarelli, 1992; Collins et al., 1993). The scores on the Perinatal Grief Scale of the women who had felt that they had control over the decision did not differ from those of the women who had not. It is possible that experiencing control over the decision led to more feelings of guilt ("I was the one who took the initiative to abort the baby"), whereas experiencing a lack of control may have intensified feelings of helplessness and depression. However, in-depth psychological research would be necessary to bring such feelings of guilt to the surface. Such an interview fell outside the framework of this study.

8.7 Prevalence of a need for assistance and recommendations

In our study, the need for assistance was divided into a need for information and a need for emotional support. Shortly after hearing the diagnosis, a minority of the women felt the need for chiefly medical information about the nature, prognosis and cause of their baby's anomaly, and about when and how delivery would take place. For emotional support in relation to the decision to have the pregnancy terminated and coping with the (threatened) loss of the baby, the majority of women could turn to their partner and family in this period.

Three months after delivery, about three quarters of the women needed assistance. The need for assistance had shifted from medical information to emotional support, particularly in the form of understanding from family and close friends. Our study findings indicated that in this period, the women were becoming increasingly aware of the loss and the emotions associated with it, while the attention of family and close friends was diminishing. That is why some of the women felt deserted. In a proportion of them, this led to problems in the long-term, such as apathy, lethargy or avoidance of talking about the loss. This was particularly true of the women who displayed the personality trait "disposition for feelings of inadequacy". It appeared that more than three quarters of these women (80%) had sought professional psychological assistance in the period between pregnancy termination and the subsequent four year period, or even before the loss. Furthermore, almost three quarters of them showed general psychological distress on the General Health Questionnaire.

It is well-known that an extreme event, described in the DSM-III-R (1988-9) as an event that falls outside the range of usual human experience and is distressing to nearly everybody, brings about a process of intensive coping. Distinction is made between *man-made* traumatic events (bank robbery, hostage situations, acts of war) and *natural* disaster (volcanic eruptions, earthquakes, etc.). Nowadays for both types of traumatic event, direct aid for victims is a socially accepted phenomenon. The help is simple, supportive and well-structured, i.e. aimed at the direct need of many victims for practical information and emotional support (Kleber and Brom, 1992; Hovens, 1994). A traumatic event, such as the unexpected death of a loved one, is viewed more in the range of usual human experience, which means that direct help is not offered as a matter of course.

However, (threatened) pregnancy loss late in pregnancy as a result of congenital anomalies, is not a "usual human experience", either with regard to the decision about having the pregnancy terminated (i.e. the taking of life) or to the actual loss of the baby (usually, babies stay alive after they have been delivered). Consistent with the findings of Kleber and Brom (1992) after a traumatic event, we found that many of the women in our study group required informative and/or emotional support in the period around the diagnosis and delivery. Support for this specific group of women should fulfil these requirements. In the Nota Late Zwangerschapsafbreking (nota LZ, 1994), besides medical-technical, legal and ethical aspects of late pregnancy termination, the importance of - not further specified - emotional guidance is mentioned. Our study results confirmed both the importance of emotional support and the observation that initially, the treating

gynaecologist, in cooperation with the general practitioner, takes on the guidance and after-care. On the basis of recent research by others (Keirse, 1989; Timmers et al., 1990; Cuisinier et al., 1990, van Spijker et al., 1992) and the studies described in the previous chapters, the guidelines of the nota LZ 1994 can be supplemented as follows (see also Table 8.1).

Care before delivery in the case of threatened pregnancy loss. The gynaecologist responsible for informing the parents of the diagnosis of a severe or lethal fetal anomaly, will do this in a "bad news" consultation (Schouten, 1982). Characteristic for a bad-news consulation is that the doctor divulges the most important aspect of the bad news, the fact that the baby has a severe or lethal anomaly, at the beginning of the consultation and in language which the parents can understand. In addition, he does not answer the denial reactions of the parents ("you are wrong, it can't be true") with arguments in favour of the opposite. Instead, he should regard these as expressions of shock and bewilderment from the parents. At this stage, many of the parent's questions will represent a search to find out what the news will mean in their lives. It is better for the doctor to postpone giving more detailed information until the parents have had more time to come to terms with the news and similarly to postpone giving advice and suggesting solutions until the parents show that they have accepted what they have been told and are themselves ready to consider what should be done next. In this way, the doctor offers the parents the opportunity to bring up and review past information at a later stage or to ask new questions about the baby and/or delivery. It is a good idea for the doctor to examine whether support is available in the home environment with regard to the pregnancy and the decision of whether to terminate the pregnancy. If this is not the case, then if required, measures can be taken to provide support at home, for example by the general practitioner, the treating gynaecologist or a medical social worker.

The doctor should realise that a woman's decision regarding pregnancy termination or carrying the baby to term is not always a rational one and that it can shift as the pregnancy progresses. In many cases this decision shifts in the direction of termination; the most important motive is not being able to endure the pregnancy. On the other hand, the doctor should also realise that a pregnancy with a baby with a lethal anomaly which, from a medical standpoint, can be considered pointless, and experienced as such by many women, is not pointless by definition. A lethal anomaly having been established in her baby, one woman found that her pregnancy was "presented to obviously as being pointless". She found that "you should be careful that a decision you may later regret is not forced on you. I know that I want to continue this pregnancy; another woman may be less able to stand her ground."

It is only when the consultations with the doctor take place in the above-described manner that the assumption "at all times the parents have been properly informed with regard to the situation in which they find themselves" (nota LZ, p. 17) will have been fulfilled.

Care after delivery in the case of (late) pregnancy loss. The treating gynaecologist and/or the midwife who supervised the delivery or termination of pregnancy, offer the parents the opportunity to preserve evidence of the birth and brief life of the baby. In con-

crete terms this means that the parents are given plenty of time to see the baby and to hold it, to take photographs of their child, to give the baby a name (if necessary they can be encouraged to do so) and to make arrangements for the funeral. The parents can also be given the autopsy report to read.

If necessary, the general practitioner, who is informed of the situation as soon as possible after the pregnancy termination, can refer the parents to appropriate aid providers, such as a medical social worker, a medical psychologist or patient associations for fellow-sufferers. The general practitioner can also contribute to providing support for the parents by informing them about grief reactions that can be expected and by discussing their worries about a new pregnancy.

In addition, it is important that the doctor, the family, friends and acquaintances of the bereaved mother, and often also the father, realise that the desire to talk about the loss can continue for several years. We found that four years after perinatal loss, many of the women in our study group still felt the need to talk about the loss. The opportunity to do so could be offered in the form of, for example, a sympathetic gesture on the anniversary of the day the baby died. For it is as Shakespeare noted: *"The grief that does not speak, whispers the o'er-fraught heart and bids it break"* (from Macbeth).

Table 8.1 Recommendations for hospital care concerning (threatened) late pregnancy loss

Care before delivery	Care after delivery
Tell the parents the bad news almost directly, in simple terms	*Give* the parents *time* to look at the baby and hold him or her
Come back later with details, advice and suggestions	*Encourage* the parents to give the baby a name, to take photographs, say goodbye and arrange the funeral (cremation)
Inform the general practitioner and treating gynaecologist and if necessary arrange support via them or via a medical social worker	*Give* the parents a summary of the postmortem (formulated in simple terms)
	General practitioner can *provide information* about *coping with the loss* and *discuss any problems* related with a new pregnancy
	General practitioner can *refer* the parents to a medical social worker, psychologist or bring them in contact with fellow-sufferers

8.8 Future research directions

The most ardent wish of nearly all the women, but at the same time also their most dreaded fear, was to become pregnant again. This finding is of importance owing to a possible negative relationship between the level of stress experienced by the mother during pregnancy and the birth weight of the baby (Vingerhoets et al., 1991; Paarlberg et al., 1995). Stress manifests itself not only through reports of negative emotions, but also through increased physiological activity. Besides psychological complaints, this can also

lead to physical problems and deterioration in a person's state of health. Prenatal (ultrasound) examination often forms a considerable stressor in women with previous pregnancy loss due to fetal anomalies. So far, psychological tests have been limited to measuring anxiety one day before and one day after the prenatal ultrasound examination. Although women experience a favourable result as a great relief, there are indications that there is often an increase in stress about the actual outcome of the pregnancy (Hunter et al., 1987; Tsoi and Hunter, 1987). At this moment, a case-control study is underway using questionnaires and interviews to gain insight into the extent to which women with and without pregnancy loss differ. Anxiety, physical complaints and health-related quality of life are recorded over a fairly long period, two weeks before to three weeks after the ultrasound examination. More knowledge in this field is expected to clarify whether women with previous pregnancy loss due to fetal anomalies need support in relation to prenatal examination and, if so, provide information about the nature of the support required.

In our study, the personality characteristic "neuroticism" proved to be a strong predictor of the intensity of grief reactions. Furthermore, our interviews indicated the importance of other potential predictors, such as "problems with previous stressful events" and "social support". In the past, research concentrated particularly on the positive effects that social support can have on the coping process. However, more recent research has also demonstrated negative effects (Coyne and Delongis, 1986; Buunk et al., 1989; Collins et al., 1990), for example, in cases where a woman wishes to receive support regarding her decision to terminate her pregnancy from people who are against abortion (Cozzarelli and Major, 1990). The predictive value of "social support" and "the way in which a person has dealt with previous stressful events" in relation to coping with pregnancy loss should therefore be included in future studies.

In our study, 63% of the 46 women wanted to terminate their pregnancy. However, this study was clearly a first exploration, performed largely in retrospect, because the majority of participants had delivered their baby before they were contacted by the researcher. Moreover, the study was limited to the way in which the women described their situation and this may have been a distortion of reality. This study would need to have been broadened prospectively to gain more insight into issues such as the course of this decision process, the motives at the time the decision was made, the communication process between the pregnant woman and her doctor, the doctor's motives for acting in accordance with the woman's wishes and the nature of the fetal anomalies demonstrated at autopsy. More knowledge about what motivated the woman and the doctor to terminate the pregnancy or to carry the infant to term, would help to clarify whether there is a need for support before or after the pregnancy termination and provide information about the nature of the support required.

In many studies on coping with perinatal grief, attention has mainly been focused on the mother. However, studies are also required which focus on the next baby, siblings and the role of the father in the coping process. Such studies could answer questions such as: What consequences does pregnancy loss have on the social and emotional development of a new baby (Cummings and Davies, 1994)? What consequences does

perinatal loss have on the mother-child relationship? Does pregnancy loss affect the relationships within the rest of the family and between the parents?

Three of the infants of the women in our study were still alive at the four years follow-up, but they were severely physically or mentally handicapped. The scores of these women on the grief questionnaires were not found to be different from those of the mothers who had lost their baby. In the interviews with the women whose infant was still alive, the burden of caring for a handicapped child was clearly apparent, not only mentally but also physically ("I always have to carry him and he's getting heavier and heavier, of course. There have been times when we have stayed home just because of that"). Further research is necessary to examine the specific problems of these parents, also in the long-term.

Our study results showed that most of the parents considered that important sources of support not only included the partner and close family, but also the hospital, general practitioner and midwife, both at the time of (threatened) pregnancy loss and during a subsequent pregnancy. The combination of information and emotional support offered at the hospital can make it easier for the parents to integrate the pregnancy loss into their everyday lives. In this way, the danger of medicalising such a major life event (Leon, 1990; 1992) is counteracted by promoting the integration process.

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Summary

This thesis covers a four year period of longitudinal research into the grief reactions of women to the threatened or actual loss of a baby late in pregnancy or shortly after delivery. These reactions are referred to as perinatal grieving.

In **chapter 1**, a number of themes are discussed which form the framework of the study results presented in later chapters. These include knowledge about and the psychological meaning of prenatal diagnosis, particularly ultrasound scanning, and the specific problems related to threatened pregnancy loss late in pregnancy (≥ 24 weeks); the psychological concept "perinatal grieving" and the "Stress Response Model" developed by Horowitz on which the study was based; a short overview of the following: i) factors found by empirical research that influence perinatal grieving; ii) views on normal versus abnormal grief reactions and iii) methodological aspects of research into grieving after pregnancy loss. The chapter is concluded with the questions addressed in this study.

Chapter 2 reports on research into the reliability and the validity of the Perinatal Grief Scale (PGS). This questionnaire was adapted for use in the Netherlands and administered to a study group of 46 women with (threatened) pregnancy loss late in pregnancy, diagnosed by prenatal ultrasound examination. The construct validity of the PGS was tested in two ways: by means of comparison with the Perinatal Event List (PEL), a version of the Impact of Event Scale developed by Horowitz, adapted to the situation of late pregnancy loss, and by comparison with a clinical assessment of psychological instability, based on a semi-structured interview. The results showed that the scores on the PGS were, in particular, positively related to the level of psychological instability. It was concluded that the PGS is a useful instrument for measuring grieving after late pregnancy loss.

Chapter 3 describes the emotional reactions of the study group shortly after hearing the bad news about the unborn baby and at three months after delivery. Data were gathered using a semi-structured interview and questionnaires. On the basis of the interview, almost half of the women were assessed as being seriously psychologically unstable shortly after hearing the bad news; at three months after delivery, the number had halved. The intensity of the emotional reactions, measured with the PGS and the PEL, had not diminished between the two measurements, however. This was most highly applicable to "Difficulty coping" with the loss.

The women who had seen their dying or dead infant, showed stronger grief reactions three months after losing the baby than those who had not seen their infant. It was concluded that rather than a difference in intensity of the emotional reactions, this indicated a difference in coping. There were no differences in the intensity of the grief reactions between the women who delivered spontaneously and those who were induced.

Chapter 4 addresses the question of whether there were differences in intensity of perinatal stress and perinatal grief between the women who showed different forms of defense mechanisms during or shortly after the ultrasound diagnosis. In addition, it was

investigated whether the level of stress that the woman had experienced in the past, was a predictive factor for her later reactions to pregnancy loss. Indications for these stress experiences were: i) the disposition for feelings of inadequacy (depression, instability, inhibition and shyness), measured with the Dutch Personality Questionnaire (DPQ), ii) having earlier experienced a traumatic event (e.g. losing a parent, both parents, a brother or sister at a young age) and iii) earlier consultation with professional psychological assistance. The disposition for feelings of inadequacy was the strongest positive predictor of perinatal stress and perinatal grief reactions at both measurements (i.e. shortly after the ultrasound diagnosis and at three months after delivery). Grief reactions were significantly less strong in women who had used the defense mechanism "principalization" in reaction to the bad news about their baby, whereas significantly more intense grieving was found in women who reacted to the ultrasound diagnosis by "turning aggression against oneself".

Chapter 5 reports the findings of the study on the emotional reactions to late pregnancy loss four years after the event. More than one third of the women showed "general psychological distress which is indicative of the need for mental support", measured with the General Health Questionnaire (GHQ-28). Although this number does not differ significantly from that of a control group from the general Dutch population of women, they did have specific problems in relation to losing the baby. This could be seen from the fact that their scores for the dimensions Difficulty Coping and Despair on the Perinatal Grief Scale did not significantly diminish in this period. The intensity of the other emotional reactions, measured with the PEL and the PGS had decreased significantly in this period. Even after four years, feelings of inadequacy still showed a positive relationship with the level of general psychological distress and the intensity of the perinatal stress and perinatal grief reactions. In a semi-structured interview, it was found that these women were still reliving the ultrasound diagnosis and delivery in their thoughts and feelings, particularly when they became pregnant again. They also mentioned that the people in their environment were unwilling to accommodate their (still present) need to talk about the loss after four years.

Chapter 6 describes the women's motives for wishing to terminate the pregnancy following the unfavourable ultrasound diagnosis, or to carry the baby to term. The majority of women had had the pregnancy terminated within six weeks following the bad news. Their main motive was the unbearable knowledge of the threatened loss of the baby. A minority of the women wished to continue the pregnancy with "the strong tie with the unborn baby" being the most important motive for this.

In the women whose delivery was induced and whose baby died within 28 days (n=30), a distinction was made between those who felt that they had had control over the decision to terminate the pregnancy and those who did not. Three months after the loss no association was found between the feeling of having had control over the decision and the intensity of the emotional reactions, measured with the PGS.

Chapter 7 addresses the women's need for assistance. This need could be divided into a need *mainly* for medical information and a predominant need for emotional support (e.g. attention and understanding). Shortly after the diagnosis and the delivery, a

minority of the women had felt a need for medical information in particular, while finding an adequate level of emotional support in their own circle (from their partner, family and general practitioner). Three months after the birth, during which time the majority had lost the baby, a large proportion of the women felt a much stronger need for emotional support, especially from fellow-sufferers. This need coincided with a decreasing tendency of the people in their own social environment towards showing interest in the woman's loss. After a period of four years, about one third of the women expressed equal needs for medical and emotional support. The medical aspect was for information about the risk of recurrence and close medical supervision in a new pregnancy. According to these women, the need for emotional support was mainly due to a "standstill" in their coping with the loss. For example, by frequently wanting to talk about it, but not being able to find anyone prepared to listen; by being hampered with feelings and thoughts about the loss or a general feeling of apathy. In contrast to three months after the loss, it appeared that emotional support was now sought mainly from professionals (such as a psychiatrist or a psychologist). Among the women who sought this help the number with strong feelings of inadequacy was over-represented.

Chapter 8 comprises a general discussion of the study and recommendations for future research. Attention is focused on the choice of the Stress Response Model for clarifying the emotional reactions, the methodological problems associated with the study and the findings on psychological instability, perinatal stress and perinatal grief reactions.

Recommendations are made about optimal counselling for the woman after the diagnosis of a severe congenital abnormality late in pregnancy and after the infant has been delivered. Several suggestions are made for further research based on the results of this study: i) evaluation of the anxiety and general health status related to prenatal ultrasound examination in women with and without a history of late pregnancy loss as a result of congenital anomalies in the baby; ii) prospective research into the course of the decision-making process of the parents who wish to terminate a severely affected pregnancy and the factors that influence this decision; iii) research into the consequences of late pregnancy loss for the relationship between the mother and the child in a subsequent pregnancy and after delivery and iv) studies on the handicapped child: consequences for the family and care providers, and factors that influence the physical and mental burden of the parents.

Samenvatting

Dit proefschrift is het verslag van een longitudinaal onderzoek van de rouwreacties van de moeder op het dreigende en dikwijls reële verlies van een baby laat in de zwangerschap of kort na de geboorte. Deze reacties worden met perinatale rouwverwerking aangeduid.

In **hoofdstuk 1** wordt een aantal thema's besproken die het kader vormen van het in latere hoofdstukken gerapporteerde onderzoek. Beschreven worden de kennis over en de psychologische betekenis van prenatale diagnostiek in het bijzonder het echo-onderzoek, en de specifieke problemen bij dreigend zwangerschapsverlies laat in de zwangerschap (≥ 24 weken). Voorts worden besproken het psychologische concept "perinatale rouwverwerking" en het "Stress Response Model" van Horowitz waarop het gerapporteerde onderzoek is gebaseerd. Daarnaast wordt een kort overzicht gegeven van het volgende: i) de in empirisch onderzoek gevonden factoren die van invloed zijn op de perinatale rouwverwerking; ii) opvattingen over normale versus abnormale rouwverwerking en iii) methodologische kwesties in het onderzoek naar rouwverwerking bij zwangerschapsverlies. Het hoofdstuk wordt afgesloten met de vraagstellingen van het eigen onderzoek.

In **hoofdstuk 2** wordt een onderzoek gerapporteerd over de betrouwbaarheid en de validiteit van de Perinatal Grief Scale (PGS). Deze vragenlijst werd voor Nederland bewerkt en afgenomen bij een onderzoeksgroep van 46 vrouwen met (dreigend) zwangerschapsverlies laat in de zwangerschap zoals vastgesteld door prenataal echo-onderzoek. De construct validiteit van de PGS is op twee manieren onderzocht: door middel van een vergelijking met de Perinatal Event List (PEL), een aan de situatie van het zwangerschapsverlies aangepaste versie van de Impact of Event Scale van Horowitz, en door een vergelijking met een klinische beoordeling van de psychische instabiliteit, gebaseerd op een semi-gestructureerd interview. Het bleek dat de scores op de PGS in het bijzonder positief waren gerelateerd aan de maat voor psychische instabiliteit. Geconcludeerd werd dat de PGS een bruikbaar instrument is om rouwverwerking te meten na zwangerschapsverlies laat in de zwangerschap.

Hoofdstuk 3 handelt over de emotionele reacties van de onderzoeksgroep kort na het vernemen van het slechte nieuws over de ongeboren baby en drie maanden na de bevalling. In dit onderzoek werd zowel gebruik gemaakt van een semi-gestructureerd interview als van vragenlijsten. Bijna de helft van de vrouwen werd kort na het vernemen van de diagnose op basis van het interview beoordeeld als ernstig psychisch instabiel; drie maanden na de bevalling was dit aantal gehalveerd. De intensiteit van de emotionele reacties, zoals gemeten met de PGS en de PEL, was daarentegen niet verminderd. In het bijzonder was dit het geval voor "Difficulty coping" met het verlies.

Moeders die hun stervende of overleden baby hadden gezien, vertoonden drie maanden na het verlies van de baby sterkere rouwreacties dan moeders die de baby niet hadden gezien. Geconcludeerd wordt dat dit niet zozeer op een verschil in intensiteit van emotionele reacties wijst, maar op een verschil in de manier waarop met de gebeurtenis wordt omgegaan. Er bleek geen verschil in intensiteit van de rouwreacties tussen vrouwen met een spontane of met een opgewekte bevalling.

Hoofdstuk 4 gaat in op de vraag of vrouwen die verschillende vormen van afweer gebruikten tijdens of vlak na de echodiagnose, eveneens verschillen laten zien in de perinatale stress en perinatale rouw. Voorts werd nagegaan of de mate van stress die de vrouw in het verleden had ondervonden een voorspellende factor was voor haar latere reacties op het verlies van de baby. Indicaties voor deze stresservaringen waren: i) de neiging tot gevoelens van inadequatie (depressiviteit, labiliteit, geremdheid en verlegenheid), gemeten met de Nederlandse Persoonlijkheids Vragenlijst (NPV); ii) het hebben meegemaakt van een eerdere schokkende gebeurtenis (bv. het verlies op jonge leeftijd van ouders of een broertje of zusje), en iii) eerdere consultatie van de professionele psychologische hulpverlening. De geneigdheid tot gevoelens van inadequatie bleek de sterkste positieve voorspeller van perinatale stress en perinatale rouwreacties te zijn, zowel voor die kort na de echodiagnose als die welke drie maanden na de bevalling optraden. De rouwreacties waren significant minder sterk bij vrouwen die overwegend het afweermechanisme "principalization" gebruikten in reactie op het slechte nieuws over de baby, terwijl significant intensere rouwreacties voorkwamen bij vrouwen die op de echodiagnose reageerden met "turning aggression against oneself".

In **hoofdstuk 5** wordt verslag gedaan van het onderzoek naar de emotionele reacties op het verlies na vier jaar. Meer dan eenderde van de vrouwen vertoonde "algemene psychische distress die indicatief is voor de behoefte aan mentale steun", gemeten met de General Health Questionnaire (GHQ-28). Hoewel dit aantal niet significant verschilt van dat van een controlegroep uit de algemene Nederlandse populatie van vrouwen, bleek uit het feit dat hun scores op de dimensies Difficulty coping en Despair van de Perinatal Grief Scale in deze periode niet significant waren afgenomen, dat zij wel specifieke problemen hadden in verband met het verlies van de baby. De intensiteit van de overige emotionele reacties, zoals gemeten met de PEL en de PGS, was in deze periode wel significant afgenomen. Gevoelens van inadequatie bleken ook na vier jaar significant en positief samen te hangen met de mate van algemene psychische distress en de intensiteit van perinatale stress en perinatale rouwreacties. In een semi-gestructureerd interview werd gevonden dat deze vrouwen de echodiagnose en de bevalling in hun gevoelens en gedachten vaak opnieuw beleefden, vooral wanneer zij weer zwanger waren geworden. Tevens vermeldden zij - ook nog na vier jaar - dat de omgeving dikwijls te weinig aandacht had voor het verlies van hun kind.

In **hoofdstuk 6** worden de motieven van de vrouwen beschreven om de zwangerschap na de ongunstige echodiagnose af te willen laten breken of uit te dragen. De meerderheid van de vrouwen had de zwangerschap reeds binnen zes weken na het slechte nieuws beëindigd. Hun voornaamste motief was de onverdraaglijke wetenschap van het dreigende verlies van de baby rond de geboorte. Een minderheid van de vrouwen wilde de zwangerschap uitdragen met als belangrijkste motief "de sterke band met de ongeboren baby".

Bij vrouwen bij wie de bevalling was opgewekt en de baby binnen 28 dagen was overleden (n=30), werd een onderscheid gemaakt tussen vrouwen bij wie uit de beschrijving van hun verzoek om de zwangerschap te willen beëindigen een besef van controle bleek en vrouwen bij wie dit niet bleek. Drie maanden na het verlies van de

baby werd geen relatie gevonden tussen het gevoel controle te hebben over de beslissing en de intensiteit van de emotionele reacties, zoals gemeten met de PGS.

In **hoofdstuk 7** wordt ingegaan op de behoefte aan hulp van de vrouwen uit de onderzoeksgroep. Deze kon worden onderscheiden in *overwegend* behoefte aan medische informatie en *overwegend* behoefte aan emotionele steun (bv. aandacht en begrip). Kort na de diagnose en de bevalling wenste een minderheid van de vrouwen vooral medische informatie, terwijl emotionele steun in voldoende mate in de eigen kring werd gevonden (bij partner, familie en huisarts). Drie maanden na de geboorte, die in de meeste gevallen snel gevolgd werd door de dood van de baby, wenste een minderheid van de vrouwen juist meer emotionele steun, in het bijzonder van lotgenoten. Deze behoefte ging gepaard met een tendens tot verminderde aandacht vanuit de eigen sociale omgeving voor de vrouw en haar verlies. Over een periode van vier jaar na het verlies van de baby was er bij ongeveer eenderde van de vrouwen in gelijke mate behoefte aan zowel medische als emotionele steun. De medische vraag betrof informatie over het herhalingsrisico en nauwlettende medische begeleiding in een nieuwe zwangerschap. De behoefte aan emotionele steun kwam volgens eigen zeggen voort uit het "vastgelopen" zijn in de verwerking van het verlies. Dat wil zeggen zij hadden een grote behoefte om over het verlies te praten, maar voelden ook dat niemand bereid was hun gevoelens en gedachten over het verlies aan te horen. Of zij rapporteerden een algemeen gevoel van lusteloosheid. In tegenstelling tot drie maanden na het verlies, bleek de emotionele steun nu vooral te worden gezocht bij professionele hulpverleners (zoals bij een psychiater of een psycholoog). In deze categorie vrouwen was het aantal vrouwen met sterke gevoelens van inadequatie oververtegenwoordigd.

Hoofdstuk 8 bestaat uit een algemene discussie over het gerapporteerde onderzoek en een vooruitblik op toekomstig onderzoek. Besproken worden de keuze voor het Stress Response Model bij de beschrijving van de emotionele reacties; de methodologische problemen van het gerapporteerde onderzoek en de bevindingen over psychische instabiliteit, perinatale stress en perinatale rouwreacties.

Aanbevelingen worden gedaan hoe de arts bij het vaststellen van de letale afwijking en na de geboorte van de baby de moeder optimaal kan begeleiden. Tot slot worden suggesties gedaan voor onderzoek dat voortvloeit uit het gerapporteerde onderzoek. Genoemd worden i) onderzoek naar de angstbeleving en gezondheidsstatus rond het prenatale echo-onderzoek bij zwangere vrouwen met en zonder een voorgeschiedenis van zwangerschapsverlies als gevolg van congenitale afwijkingen bij de baby; ii) prospectief onderzoek naar het verloop van de besluitvorming van ouders bij het willen beëindigen van een zeer ernstig aangedane zwangerschap en factoren die daarop van invloed zijn; iii) onderzoek naar de gevolgen van zwangerschapsverlies voor de relatie tussen de moeder en het kind in een nieuwe zwangerschap en na de geboorte; iv) onderzoek naar het gehandicapte kind: de gevolgen voor gezin en hulpverlening en de factoren die van invloed zijn op de fysieke en mentale belasting van de ouders.

Appendix

Respondentnummer: .....
Datum: .....
Meting:

De PGS

Hoe moet u de lijst invullen? Hieronder treft u uitspraken aan over gedachten en gevoelens die sommige mensen hadden na een verlies zoals u is overkomen. Wilt u bij elke uitspraak nagaan hoe vaak deze de AFGELOPEN WEEK op u van toepassing was. U doet dat door een cirkel te zetten om het nummer dat het beste de mate aangeeft waarin u het er wel of niet mee eens bent.

Wanneer u niet zeker bent omcirkelt u dan het nummer onder 'eens noch oneens', maar doet u dat alstublieft alleen als u écht geen mening heeft. Er zijn geen goede of foute antwoorden.

1. Ik voel me depressief.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

2. Ik kan moeilijk met bepaalde mensen overweg.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

3. Ik voel me leeg.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

4. Ik kan mijn dagelijkse bezigheden niet naar behoren doen.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

5. Ik heb behoefte om over de baby te praten.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

6. Ik rouw over de baby.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

7. Ik ben bang.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

8. Sinds het verlies van mijn baby heb ik gedachten over zelfmoord.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

9. Ik gebruik kalmerende middelen.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

10. Ik mis de baby heel erg.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

11. Ik heb het gevoel dat ik mij goed heb aangepast aan het verlies van mijn baby.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

12. Het doet pijn om te denken aan het verlies van de baby.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

13. Ik raak van streek als ik aan mijn baby denk.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

14. Ik huil als ik aan de baby denk.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

15. Ik voel me schuldig als ik aan mijn baby denk.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

16. Ik voel me ziek als ik aan de baby denk.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

17. Ik voel me onbeschermd in een onveilige wereld sinds de dood van mijn baby.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

18. Ik probeer te lachen, maar voor mijn gevoel valt er niets meer te lachen.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

19. Sinds de baby is overleden gaan de dagen erg langzaam voorbij.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

20. Met hem/haar stierf ook het beste in mij.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

21. Ik heb het bij mensen af laten weten sinds de dood van mijn baby.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

22. Mijn gevoel van eigenwaarde is sterk verminderd sinds zijn/haar dood.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

23. Ik geef mijzelf de schuld van de dood van mijn baby.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

24. Ik vlieg mijn vrienden en kennissen vaker in de haren dan behoort.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

25. Soms heb ik het gevoel dat ik professionele hulp nodig heb om mijn oude ritme terug te vinden.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

26. Ik heb het gevoel of ik besta maar niet echt leef sinds de dood van mijn baby.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

27. Ik voel me zo eenzaam sinds zijn/haar dood.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

28. Ik voel me enigszins alleen staan en niet betrokken, zelfs bij mijn vrienden.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

29. Het is veiliger om van niemand te houden.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

30. Sinds de dood van hem/haar vind ik het moeilijk om beslissingen te nemen.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

31. Ik maak me zorgen over hoe mijn toekomst eruit zal zien.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

32. Als ouder van een overleden kind ben ik een tweederangs persoon.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

33. Ik ben heel blij dat ik leef.

Helemaal mee eens	Mee eens	Eens noch oneens	Niet mee eens	Helemaal niet mee eens
1	2	3	4	5

Respondentnummer: .....
Datum: .....
Meting: .....

De PEL

Hoe moet u de lijst invullen? Hieronder treft u een aantal uitspraken aan. De uitspraken zijn afkomstig van vrouwen die evenals u tijdens hun zwangerschap te horen kregen dat hun kindje een ernstige afwijking had. Wilt u van elke uitspraak nagaan hoe vaak deze op u van toepassing was IN DE AFGELOPEN WEEK. U doet dat door een kruisje te zetten in het rondje onder het gekozen antwoord.

Als een uitspraak de hele vorige week niet op u van toepassing was, zet u dan s.v.p. een kruisje onder 'helemaal niet'. Er zijn geen goede of foute antwoorden.

1. Ik dacht eraan, zelfs als ik niet wou.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

2. Ik liet me niet van mijn stuk brengen als ik eraan dacht of eraan werd herinnerd.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

3. Ik probeerde het uit mijn geheugen te wissen.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

4. Ik had inslaapproblemen of werd steeds wakker.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

5. Ik werd overspoeld door golven van sterke gevoelens.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

6. Ik droomde erover.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

7. Ik vermeed dingen die me eraan deden denken.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

8. Ik had het gevoel alsof het niet was gebeurd of dat het niet waar was.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

9. Ik probeerde er niet over te praten.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

10. Allerlei beelden erover kwamen plotseling in mij op.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

11. Andere dingen deden me er steeds aan denken.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

12. Ik was me ervan bewust dat ik nog veel onverwerkte gevoelens had, maar ik stopte ze weg.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

13. Ik probeerde er niet aan te denken.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

14. Bij elke herinnering kwamen die nare gevoelens weer naar boven.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

15. Mijn gevoelens erover waren als het ware bevroren.

Helemaal niet	Zelden	Soms	Vaak
0	0	0	0

ERASMUS UNIVERSITEIT ROTTERDAM

FACULTEIT DER
GENEESKUNDE EN
GEZONDHEIDS-
WETENSCHAPPEN
dr. Molewaterplein 50

Afdeling
verloskunde en vrouwenziekten
echoscopie
Prof.dr J.W. Wladimiroff

Uw Brief	Ons kenmerk	Datum
Onderwerp	Faxnummer	Doorkiesnummer
	010-436.3981	010-408.7812

Geachte mevrouw,

Ten tijde van uw zwangerschap bent u op .... (datum) echografisch onderzocht in ons ziekenhuis. U heeft destijds ingestemd deel te nemen aan een onderzoek van de Erasmus Universiteit Rotterdam, de afdeling Medische Psychologie en het Academisch Ziekenhuis Rotterdam-Dijkzigt, over uw ervaring met de opvang na de mededeling van een ongunstige echodiagnose.
Het is voor het slagen van het onderzoek van zeer groot belang te kunnen beschikken over enige gegevens over hoe het nù met u gaat.
Daarom wil ik u verzoeken om aan mw drs J.A.M. Hunfeld, medisch psychologisch onderzoekster, toestemming te verlenen om vanuit ons onderzoekscentrum u hierover te mogen bellen. Indien u géén toestemming wilt geven, kunt gebruik maken van het bijgesloten antwoordformulier en de antwoordenveloppe. Anders gaan wij er vanuit dat u bereid bent uw medewerking te verlenen en mw Hunfeld zal dan contact met u opnemen.
Indien u nog vragen heeft, kunt u zich wenden tot mw J.A.M. Hunfeld, op telefoonnummer 010-4087812 of 4087987.

Ik hoop te mogen rekenen op uw medewerking.

Hoogachtend,

Prof.dr J.W. Wladimiroff, gynaecoloog

The adapted version of the Defense Mechanism Inventory

Questions/answers	Defenses
How did you react at that time?	
I burst into tears and wondered why it had to happen to me.	*Turning aggression against self (TAS)*
I told the ultrasound doctor that what ever happened, I was pleased that it had been detected before the baby was born.	*Reversal (REV)*
I didn't show much reaction at the hospital, because the doctors have to be able to do their jobs, too.	*Principalization (PRN)*
I was horrible to anyone who came near me at that time.	*Turning aggression against others (TAO)*
I asked to see the senior doctor, because I did not trust the result.	*Projection (PROJ)*
What would you have liked to have done impulsively in your fantasy?	
I would like to have hit myself in the stomach.	*Turning aggression against others (TAO)*
I would like to have hit myself on the head.	*Turning aggression against self (TAS)*
I would like to have told the ultrasound doctor that I didn't trust him/her.	*Projection (PROJ)*
I would have liked to have run away, but I didn't dare.	*Principalization (PRN)*
I would have liked to have made it clear to the ultrasound doctor that it must be awful for him/her to have to tell somebody something like that.	*Reversal (REV)*
What sort of thoughts did you have?	
Why does something like this have to happen to me?	*Turning aggression against self (TAS)*
Why couldn't they have found out sooner?	*Turning aggression against others (TAO)*
The doctors are trying to do the best they can.	*Reversal (REV)*
Now it has happened to me, but it can happen to anyone.	*Principalization (PRN)*
The baby is suffering from pain; I feel very sorry for it.	*Projection (PROJ)*
What are your feelings, and why?	
Angry, because they think that it might be my fault.	*Projection (PROJ)*
Hopeless, because I can't do anything more.	*Turning aggression against self (TAS)*
Thankful because I found out in advance through the ultrasound scan that there is something wrong.	*Reversal (REV)*
Resigned, because that's just the way it is.	*Principalization (PRN)*
Angry about the way they told me the result.	*Turning aggression against others (TAO)*

Dankwoord

Een aantal mensen wil ik graag persoonlijk bedanken voor hun aandeel in het tot stand komen van dit proefschrift. Mijn promotor Professor dr J.W. Wladimiroff. U noemde het tweejarige project waar ik eind 1989 op werd aangesteld al snel promotie-onderzoek. Met uw heldere bijdragen stimuleerde u mij om het als zodanig te kunnen voortzetten. U las mijn manuscripten snel, zorgvuldig en met een speciaal oog voor eenvoudig en goed engels taalgebruik. Mijn tweede promotor, Professor dr F. Verhage. Frans, jij hebt een talent om complexe en lastige zaken zó eenvoudig voor te stellen dat ik twijfels over de uitvoerbaarheid van bepaalde aspecten van het onderzoek gemakkelijk opzij zette en aan de slag ging. Vooral door deze voortvarendheid is de klinische beoordeling van de interviews systematisch ter hand genomen. Daarnaast dwong je voortdurend om te zoeken naar de individuele betekenis achter scores op een psychologische vragenlijst.

Dr Petra Frets, via jou kwam ik terecht bij dit project waaraan jij met de beoordeling van de interviews een belangrijke klinische bijdrage leverde. Dr Monica Uniken Venema - van Uden, samen begonnen wij dit onderzoek. We bleken twee kapiteins op een schip en ook wij ontkwamen niet aan de eeuwenoude maritieme ervaring "dat dit niet werkt". Vanuit een andere positie bleef je gelukkig nauw betrokken bij de psychologische analyse van de interviews.

Drs Marco Koenders en drs René Verheij, jullie hulp bij de data-invoer en verwerking was een grote steun.

Drs Annelies Plekker, dankzij jouw bereidheid en betrokkenheid als simulatiepatiënte heb je mij en keuzestudenten behoed voor menige misstap op het gebied van de psychologische gespreksvoering.

De vrouwen die ten tijde van het (dreigende) verlies van hun baby bereid waren om aan dit onderzoek mee te doen. Hun verhaal vormde de leidraad voor dit en toekomstig onderzoek.

Lieve Jan, onze hechte en inspirerende samenwerking vind ik eigenlijk nog steeds vanzelfsprekend, al hebben anderen hebben mij duidelijk gemaakt hoe speciaal dat is.

Curriculum Vitae

Johanna Aurelia Maria Hunfeld werd op 9 juni 1950 geboren te Utrecht. Na een opleiding tot medisch secretaresse en doktersassistente aan de Cloese in Maarssen werkte zij vanaf 1972 tot 1986 als zodanig bij een aantal ziekenhuisafdelingen. In deze periode begon zij, in 1980, aan de Faculteit der Psychologische en Pedagogische Wetenschappen van de Vrije Universiteit te Amsterdam haar studie pedagogiek en behaalde in 1986 het doctoraalexamen, met de specialisatie theoretische en historische pedagogiek. Vanaf 1986 werkte zij freelance als bureauredacteur bij een wetenschappelijke uitgeverij. Daarnaast assisteerde zij van 1987 tot 1989 bij onderzoek naar alopecia androgenetica bij vrouwen, ten behoeve van het Centrum voor Psychomedisch en Psychotherapeutisch Onderzoek te Rotterdam. Vervolgens werd zij voor de periode van twee jaar aangesteld op het Ontwikkelings Geneeskunde project "besluitvorming, verwerking en hulpbehoefte van vrouwen bij echoscopisch vastgestelde letale foetale afwijkingen" bij de afdeling Obstetrie en Gynaecologie van het Academisch Ziekenhuis Dijkzigt te Rotterdam. Dit onderzoek werd verricht in samenwerking met het Instituut voor Medische Psychologie en Psychotherapie van de Erasmus Universiteit Rotterdam. Van 1991 tot 1994 werd vervolgonderzoek op het genoemde thema gefinancierd door het Universiteitsfonds van de Erasmus Universiteit en het Nationaal Fonds voor de Geestelijke Volksgezondheid.

Vanaf 1 mei 1995 heeft zij een deeltijd-aanstelling bij de afdeling Kinderheelkunde van het Sophia Kinderziekenhuis te Rotterdam en verricht zij onderzoek bij ouders met een gehandicapte kind.

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