

KAROLINSKA INSTITUTET DANDERYDS SJUKHUS  
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# **An Analysis of Parents' Experiences and the Caregivers' Role Following the Birth of a Stillborn Child**

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“The caring hand”  
*The baby in the caring hand  
is a figure in stone given to  
parents at the funeral ceremony  
of their child at the Danderyd  
Hospital Church, Stockholm.*

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# Abstract

The objective of this thesis was to describe and analyse parents' experiences of hospital care and to describe caregivers' role and attitudes to the management of stillbirth. To accomplish the overall aim, three studies were conducted. The prospective, quantitative study compared 22 couples' experiences of bonding with their stillborn child, and of hospital care and evaluated their well-being three months after the event. The retrospective qualitative study comprising 57 interviews and representing 31 stillborn children demonstrated the parents' experience of the caregivers support four to six years after the stillbirth. The physicians' roles, attitudes and advice were investigated in a nationwide study comprising 594 physicians.

The findings indicated that all but one couple in the prospective study and most of the parents in the retrospective study hold the baby. This was also in line with what 94% of the physicians with significantly more female physicians ( $p=.008$ ), considered to be important for the parents' grieving process. The prospective and retrospective studies showed that the parents need the support of the caregivers in both facing and separating from the baby. Most of the parents in the prospective study thought the amount of time they held the baby was too short. When holding the baby, the fathers in the prospective study stated that they had strong feelings of warmth, pride, tenderness and grief to the same extent as the mothers. Having mementos such as a photo of the baby and the need to look at the photo was reported more often by the mothers ( $p<.0001$ ) and was also considered by the physicians to be an urgent thing to encourage the parents to do (92%). If the labour had to be induced, most of the mothers wanted and 40% of the physicians agreed the induction to be started within 24 hours, while 30% of the physicians thought the issue lacked significance. The physicians (73%) considered the diagnosis important from a medical point of view in order to be able to give a correct explanation of why the child had died, and most of the parents also thought it was essential from a psychological point of view to better understand why the child was born dead. Significantly more male than female physicians prescribed tranquillisers for the mother ( $p=.001$ ). Most parents are sick-listed, but the female physicians extend the mothers' sick-leave to a greater extent than the males ( $p=.020$ ). Three months after the event, there were significant differences within the couples in the prospective study in that no father and all but five mothers were still on sickleave ( $p=.004$ ). The women also scored a significantly higher negative well-being ( $p<.0001$ ), a lower positive well-being ( $p=.010$ ) and a lower general well-being ( $p=.001$ ) than the fathers three months after the event.

The most frequent approach to a subsequent pregnancy expressed by the majority of the physicians was to support the couples (59%).

Six qualities summarising the transitional process of stillbirth were found in the interview study: 'Support in chaos', 'Support in the meeting with and separation from the baby', 'Support in bereavement', 'Explanation of the stillbirth', 'Organisation of the care' and 'Understanding the nature of grief'.

The results of the present thesis contribute to the understanding of the factors related to the transitional process following the birth of a stillborn child. Taking these factors into account when planning psychosocial guidance for the couples may improve the counselling for the bereaved parents.

Keywords: Stillbirth, parental grief, hospital management, staff support, physicians' advice.



# Original papers

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

## I

Säflund K, Sjögren B, Wredling R

Parents' bonding experiences with their stillborn child, encompassing their hospital care and well-being three months following the event

*Manuscript, submitted for publication*

## II

Säflund K, Sjögren B, Wredling R

The role of caregivers after birth of a stillborn baby: Views and experiences of parents

*Accepted for publication in Birth, 2003*

## III

Säflund K, Sjögren B, Wredling R

Physicians' role and gender differences in the management of parents of a stillborn child: a nationwide study

*Journal of Psychosomatic Obstetrics & Gynecology 2000;21:49-56*

## IV

Säflund K, Sjögren B, Wredling R

Physicians' attitudes and advice concerning pregnancy subsequent to the birth of a stillborn child

*Journal of Psychosomatic Obstetrics & Gynecology 2002;23:109-115*

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# Abbreviations

ENE	Energy
GWB	General well-being
ICD	International Statistical Classification of Diseases and Related Health Problems
IUFD	Intrauterine fetal death
NWB	Negative well-being
PWB	Positive well-being
PST	Psychosocial Transition
PTSD	Post traumatic Stress Syndrom
WBQ	Well-being questionnaire
WHO	World Health Organisation
QSR NUD*IST	Qualitative Solutions and Research. Non-numerical Unstructured Data Indexing, Searching and Theorizing





# Introduction

In the first millennium, the normal situation was that most deaths occurred in early childhood and it was sometimes said that you were not a woman until you had lost a child for the first time (Parkes, 2000).

In past times, it was not unusual that a crime was behind the death of a child. In an English statute of 1624, it was stated “any woman found to have concealed the death of a bastard child was to be found guilty of murder unless she could prove that the child had been born dead” (Jackson, 1994). If a woman said that she had a miscarriage or a stillborn child, she was accused specially if there was a presence of milk in her breasts, as the milk was taken to indicate that she had a full-term delivery. The demonstration of milk in the woman’s breasts was an issue for the courts (Jackson, 1994). Anne Green, an unmarried woman became pregnant in 1650 after being seduced by a young man. She delivered a stillborn child, which she buried in secret. She was arrested and ‘hanged by the neck’ for infanticide. Fortunately two physicians who examined her body, found her breathing, tickled her throat with a feather and Anne survived (Raju, 1999).

Women all over the world have suffered a great deal in their efforts to give birth to a child. One of two queens of England, Queen Jane Seymour, gave life to an heir but suffered with her own life. Her husband King Henry VIII ordered the physicians to save the child because a new wife could be found easily (Raju, 1999). The other, Queen Anne, had 17 pregnancies but did not produce an heir to the throne. Eleven of her total pregnancies were recorded as stillbirths. While she not was able to give life to an heir, the succession passed to George I of England, but Queen Anne managed to break the power of France and changed Europe’s history (Emson, 1992).

One of two short notices from Swedish medical journals stated that 27 of 1000 born children were registered as stillbirths in the years 1886–88. The majority of them were ‘bastards’. The explanation was that the syphilitic sickness was more prevalent amongst unmarried mothers. Generally, the unmarried mother had a stillbirth more often with her first child (Wretling, 1891). The other notice determined that the increasing rate of stillbirth was due to the fact that the labours occurred at ‘institutions’ instead of at home. In an argument in the same news item it was also stated that there was an increase in the stillbirth rate and a decrease in fertility and the decrease in fertility could be blamed on the increasing number of apartments with hot water (Quensel, 1946).

In this millennium, we think that it is normal both to die in old age and to grieve the person who died. In 1917 Sigmund Freud stated that grieving the dead was a ‘job of work’, as the bereaved has to withdraw emotional energy

(libido) from the loved person, because otherwise it could not be easily redirected elsewhere. Furthermore, he compared grief to clinical depression but stated that the roots of the depression were to be found in earlier traumatic experiences. Freud's paper was important for, and influenced, the psychoanalytic theory of depression but also became relevant to bereavement (Parkes, 2000). An important paper by the psychoanalyst Lindemann in 1944 gave a description of the reactions to bereavement and claimed that grieving could also be repressed, which was a confirmation of Freud's work. He also declared that it was a psychiatrist's task to share the patient's grief work and this could be done in eight to ten interviews if the grief was uncomplicated. He also stated that not all bereaved persons could have expert psychiatric help but could be supported by, for example, social workers (Lindemann, 1944).

# Background

Thirty years ago the conventional care of a woman with a stillborn child was to protect her from any contact with the child in order to help her in her grief (Leon, 1992). During the last few decades, hospital practices after stillbirth have begun to change and a discussion was started about the importance of seeing and holding the stillborn child. It was assumed that ignoring the event could result in failure to mourn and could give rise to anxiety and depression in the mother (Lewis, 1976; Lasker et al. 1994). For this reason, the psychosocial management then slowly changed to supporting the mother in seeing and holding the child, keeping mementos, taking photos, involving siblings and other family members and also formulating special guidelines for hospital staff (Kowalski, 1980; Hunfeld et al. 1996; Condon et al. 1997; Rådestad, 1998).

A disagreement among researchers has arisen concerning these sensitive issues, such as, for instance, the importance of seeing and holding the stillborn child (Hughes, 2002). The disagreement might be a result of wide differences in study design, periods of time from loss, measures used to assess the grief and definitions of gestational weeks when a fetus is classified as a child (Lang et al. 1996; Graafmans et al. 2000; Toedther et al. 2001).

## **Differences between countries in notification and registration of stillbirths**

There are differences between countries in the registration of a child's birth and death. The registration of births and deaths vary widely between countries ranging from 24 hours (Hungary) to 3 months (former USSR). The registration of births and deaths are usually fixed by law. As a result of long delays, there is under registration of very early neonatal deaths as neither the birth nor death is registered (Gourbin et al. 1995). Sweden register both births and deaths with no fixed delay at all.

## **Differences between countries in the use of gestational age and birth weight as a key criterion**

Despite attempts of the World Health Organisation (WHO) to introduce common definitions, there is still international variation in the measurement of perinatal mortality (Graafmans, 2000). Therefore, comparisons of *perinatal mortality* obtained from vital registration statistics can be made in different ways (Gourbin et al. 1995).

The term 'perinatal period' was introduced in 1936 by a German paediatrician. The period was defined as the time interval just prior to, during, and after birth (Bakketeig et al. 1984). In 1925, the League of Nations considered

that viability of 'the dead product of conception' would be set at a minimum gestational duration of 28 weeks or 35 cm body length. In 1950, WHO made use of gestational age to distinguish 'late fetal deaths'  $\geq 28$  weeks from total fetal losses. In 1975 ICD-9 (the Ninth International Classification of Diseases) stated birth weight to be a key criterion for the elaboration of national and international perinatal mortality statistics. In ICD-10, the definitions of fetal, perinatal, neonatal and infant mortality rates strengthened the use of birth weight as a criterion for producing statistics (ICD-10 1992). Almost every country in Europe uses the gestational duration as a criterion for fetal deaths, which is in disagreement with WHO, which recommends birth weight as the criterion (Gourbin et al. 1995). WHO recommends that birth weight (500 g), gestational duration (22 weeks) and body length (25 cm) should be the applied criteria to both live births and for *national perinatal mortality* statistics. And, for *international* comparisons, the standardised perinatal mortality statistics should be calculated from birth weight (1000 g), gestational duration (28 weeks) and body length (35 cm) (Gourbin et al. 1995; Graafmans et al. 2000).

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**Definitions in relation to fetal, perinatal and neonatal infant mortality, declared by the World Health Assembly under Article 23 of the Constitution of the World Health Organisation**

*Fetal death (deadborn fetus)*

Fetal death is death prior to the complete expulsion or extraction from its mother of a product of conception, irrespective of the duration of pregnancy, weighing 500 g. or more.

*Perinatal period*

The perinatal period commences at 22 completed weeks (154 days) of gestation (the time when birth weight is normally 500 g) and ends seven completed days after birth.

*Neonatal period*

The neonatal period commences at birth and ends 28 completed days after birth.

Early neonatal deaths occurring during the first seven days of life.

Late neonatal deaths occurring after the seventh day but before 28 completed days of life.

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**Differences between countries in criteria for including stillbirths**

The difference in the gestational age measurement regarding the definition of a stillborn child at different cut-off points does affect the comparability between countries (Graafmans et al. 2000). The cut-off points used between countries to define the notification of a stillborn child in e.g. 22, 24 or 28 weeks' gestation has consequences, as below the criteria of cut-off, the fetus is considered to be a miscarriage. That implies no existence and no funeral in some countries and, above the cut-off point, there are advantages from insurance systems in some countries, such as a birth allowances (Gourbin et al.

1995). In Sweden, for example, the mother of a stillborn child at the gestational age of  $\geq 28$  weeks is entitled to 29 days' maternity leave with economic benefits from the social insurance office. This entitlement does not apply to the father. Since 1997, Sweden approved the diagnosis intrauterine fetal death at the 22nd gestational week according to ICD 10 but the fetus is still not registered as a child if not delivered at  $\geq 28$  gestational weeks (ICD 10 1997).

### **Differences between countries regarding where birth is given**

The differences between countries in the gestational age cut-off regarding a stillborn child add another variation, concerning whether the mother-to-be gives birth on a gynaecological or labour ward. One disagreement in study designs might simply be as a result of these wide differences. In Sweden, generally a mother gives birth on the gynaecological ward before the 22nd gestational week and on a labour ward at  $\geq 22$  gestational weeks (Säflund et al. 2000). In Great Britain, the mother gives births on a labour ward in the  $\geq 18$ th gestational week and the loss is registered at  $\geq 24$  gestational weeks as a child (Bakketeig et al. 1984). The weeks between 18 and 22 in gestational age make a large difference, as the fetus in the 22nd gestational week is believed to have a weight of approximately 500 g. A loss in the 18th gestational week could be a fetus well below 500 g, i.e. small enough to hold in one's hand.

### **Definitions used in Sweden**

The Swedish National Board of Health and Welfare describes perinatal mortality as 'stillborns' and those 'dead within 7 days'. The general rule in Sweden is to define stillbirth in terms of the  $\geq 28$ th gestational week or, when there is uncertainty, of a body length of 35 cm (Statistics - Health and Diseases, 2003). The National Board of Health and Welfare publication registered 345 stillbirths out of a total of 90 527 births in 2001. Out of all live births that year, 293 were registered as births below the cut-off point of 28 gestational weeks. Out of the 293 births before the 27th gestational week, 13 were registered as stillbirths. Despite the general rule in Sweden to register a stillbirth from the  $\geq 28$ th gestational week, 13 fetuses born dead at  $\leq 27$  gestational weeks were still registered as stillbirths. This increases the rate of stillbirth cases in Sweden, with 13 extra cases, to 345 instead of 332 (Statistics - Health and Diseases, 2003).

The death of a child is, irrespective of gestational age, always traumatic and the birth of a stillborn child is psychologically stressful as it is not anticipated or prepared for (Parks, 1998). *Stress* is an effect of a psychological trauma and could be regarded as a signal and starting point for psychologically work through what has happened (Michel et al. 2001). The parents are grieving the dead child and are, for a longer or shorter period of time, in a state of mourning. Depending on their individual physical and psychological strength, the parents may have varied responses to the event and an individual way to *cope* with what has happened. To understand the psychological impact of loss, both

Parkes and Bowlby have developed systematic studies of bereavement in adults and *attachment theory*. The essence of attachment theory is “when I am close to a loved person I feel good and when I am far away I am anxious”. Attachment behaviour is triggered by separation (Holmes, 1994). *Grief*, psychological and social changes are two processes started up by a loss (Parks, 1998). The term *psychosocial transition* covers the process of learning, that then takes place. Hospital staff have to face parents in the process of their relearning for the new situation, that of being parents of a stillborn child and not being a mother and father of a live baby (Parks, 1998). *Stress, grief, coping, attachment theory* and *psychosocial transition* will be further described in the Theoretical Framework section.

# Theoretical framework

## Stress and Crises

The terms stress and crisis are often used synonymously. Crises can be said to be the psychological aspect of situations of stress. In daily usage, the designation 'stress' is often used rather carelessly in pressure situations (Cullberg, 1984). Experimental psychologists and physiologists have developed stress research (Parkes, 1971). Childbirth, bereavements, major physical illness, migration and disablement, have all been termed as 'stresses' or 'crises'. But according to Parkes, the terms are not altogether satisfactory. He stated that stresses and crises have too wide a meaning and the terms do not give a distinct indication of their limits. Crises can be said to be developmental or accidental (Erikson, 1959) but still there are problems, according to Parkes, in that an event that can be a crisis for one person can be an opportunity for somebody else. And as both terms have strongly negative connotations, this makes it difficult to achieve a positive outcome. Parkes suggests that there is an overlap between them as 'most losses can be construed as stressful and many stresses can be construed as losses'. Therefore, he advocates combining ideas from both fields in a more satisfactory conceptual field – the field of Psychosocial Transitions (PST) (Parkes, 1971). Psychosocial transition will be described further elsewhere.

## Physical Stress

The origin of the concept of stress is the physiological reaction in the body caused by strain. This stressor could be of both a physical and a physiological nature and the common feature between them is that the stressor is a strain on the psychological reserve capacity (Cullberg, 1984). The reaction to physical stress has been called a 'general adaptation syndrome' and has been described in three phases: alarm reaction, a phase of resistance and then fatigue. The phases can be explained as the organism's physical response to the strain and an effort to neutralise its effects. A phase of fatigue commences when the defence yields (Selye, 1956). As a rule, there are no effects on a person's health if the stress is of the normal kind and is temporary (Michel et al. 2001).

## Psychological Stress

The psychological stress is important for a human being's survival and also for the acquired ability to cope with stress and to be able to adjust to severe situations or to situations of strain. Stress is necessary for psychological growth and maturity (Michel et al. 2001). According to Lazarus, psychological stress is an interaction between an event and a human being and becomes evident when the person has been subjected to a dangerous situation, such as a threat

or loss (Lazarus, 1966). Traumatic stress is an effect of a psychological trauma. There are a lot of symptoms reflecting different aspects of the reactions to normal posttraumatic stress such as the agony of death, feelings of guilt and numbing. It is not unusual for there to be behavioural disorders such as increased aggressiveness, irritability, or feelings of unreality. There can also be psychophysical symptoms such as suffering from insomnia (Michel et al. 2001). These reactions occur in the immediate period after the event while post-traumatic reactions are the long-term reactions (Winje, 1997). Within Lazarus' framework, the global stressor is bereavement and bereavement in and of itself results in different stressors. The major one is the primary loss of the attachment to a person (Stroebe et al. 1999).

When a loss is unexpected, as a stillbirth usually is, there is a risk that the immediate grief could develop into a complicated reaction of grief (Michel et al. 2001). To be informed and to have to realise that the expected child is to be born dead is a stressful situation and could trigger both a crisis reaction and psychosomatic illness. Sometimes the parents' react in a way that is not anticipated. The parents' reaction to the event can be seen in the light of the fact that the stress reaction could be a result of accumulated stress as stress is additive (Michel et al. 2001). Normal reactions to a loss are sadness, anger, guilt and self-reproach, anxiety, loneliness, yearning, fatigue and helplessness (Worden, 1991). A traumatic event elicits feelings of extreme fear and the perception of absolute helplessness (March, 1993). If a pregnancy loss has been traumatic, e.g. if the woman's life was at risk or there has been an ectopic pregnancy, it is not unusual that a post-traumatic stress disorder can arise (Engelhard et al. 2001; Boyce et al. 2002). Posttraumatic stress symptoms (PTSD) are the long-term reactions after the occurrence with specific symptoms related to the event of three main symptom clusters: intrusion, avoidance or arousal. The PTSD diagnosis is defined in ICD-10 as an "exceptionally threatening event that is likely to cause pervasive distress in almost everyone" (Winje, 1997).

## **Bereavement**

A loss can be due to other causes than death, for example, to divorce or the loss of a limb. The effects of a loss can be both psychological and physical. Bereavement is mostly due to traumatic circumstances, such as the death of a spouse, child or parent, multiple deaths or murder (Parkes, 1988).

Lindemann was the first investigator to describe reactions to bereavement. He pointed out that acute grief is a definite syndrome with both psychological and somatic symptomatology. The syndrome could appear immediately, be delayed, be exaggerated or seem to be absent (Lindemann, 1944). Lindemann's work gave the world a model for short-term psychotherapy of grief (Lindemann, 1944). Moreover, the treatment of the problems could be carried out by other persons than a psychiatrist and, this could be said to have 'sowed the seeds of bereavement counselling' (Parkes, 2000). But there were limitations to his theory. Lindemann's paper described short-term psycho-



therapy for grief and asserted that the grief could be delayed or distorted. In 1949, Anderson published a paper on the psychiatric consequences of bereavement that Lindemann had not given weight to (Anderson, 1949). Anderson called this the chronic grief syndrome. Those with chronic grief do not show any sign of mastering their grief. Instead, they grieved intensely from the beginning and, although they were expected to stop grieving, they did not (Parkes, 2000). Parkes' research on people asking for the help of a psychiatrist showed that a minority suffered from pathological grief, which confirmed Anderson's assertion that chronic grief was more frequent than delayed grief. Furthermore, Parkes proclaimed that there were no systematic studies of normal or uncomplicated grief. And there were more questions to be answered: does grief have a range of normality, how long can it last, was there a pattern? These questions were answered in Bowlby's and Parkes' own research in the 1970 (Bowlby et al. 1970). Bowlby observed young children who had been separated from their mothers. The children showed a distinct pattern of grieving ranging from a phase of separation anxiety to a phase of despair and disorganisation and, finally, a phase of recovery (Holmes, 1994). Parkes found the same pattern in a study of young widows, but with an initial phase of numbness before the phase of crying and yearning. Both Bowlby and Parkes recognised that there were individual variations in response to bereavement in that everybody did not go through their grief in the same way or at the same speed (Worden, 1991). The phases of grief in Parkes' theory will be explained further in the 'Course of Grief' section.

For hospital staff, there has to be a balance between detecting the parents' at risk and understanding that reactions to stillbirth are usually normal. They should not classify the grief as pathological too soon after the stillbirth (Dyregrov et al. 1999).

### **Attachment Theory**

Attachment theory could be described as a major theoretical development in psychoanalysis by the psychiatrist John Bowlby and has a great impact in social work. Attachment can be explained in terms of understanding that an individual is linked emotionally with another one. Evidence for an existing attachment may be seen in a longing for that person, the phenomenon of a secure base and separation protest. According to Bowlby, there has to be a relationship of love and caring for someone to experience separation anxiety and grief (Holmes, 1994). Bowlby's research asserts that the psychological response to the separation in the earlier phase is an intense form of separation and the later phases are confusion and misery as the person the bereaved would turn to for comfort is no longer there. Bowlby's research on children and Parkes' research on bereavement in adults developed our understanding of the psychological impact of loss.

In 1980 Peppers and Knapp initiated a discussion asserting that there is not only a mother-infant attachment, but also a prenatal attachment (Peppers et al. 1980). Maternal-fetal attachment represents the earliest form of human in-

timacy and is also the most basic (Condon et al. 1997). According to Condon, this attachment has both theoretical and clinical significance (Condon et al. 1997). The attachment includes a desire for knowledge about the child-to-be, pleasure in interacting with the fetus in reality and fantasy and also a desire to protect the unborn baby (Condon et al. 1997). The results of his research indicated that depression can have an effect of detachment and that satisfaction with a partner relationship has a positive correlation with attachment (Condon et al. 1997). According to Peppers & Knapp, there is an attachment to the child long before birth. The mother's attachment to her child-to-be could be summarised in nine steps: planning, confirming and accepting the pregnancy, feeling fetal movement, accepting the fetus as an individual, giving birth and then seeing the baby, touching and providing care for the baby. These steps can be seen in the light of their impact on attachment. Peppers & Knapp stated that when the mother has physical contact with the child after its birth, the attachment that had begun before birth is now set or fixed (Peppers et al. 1980). In a Swedish study of women undergoing amniocentesis and chorionic villi biopsy, the aim of the author was to describe aspects of the emotional attachment of the mother-to-be and the fetus during the period when the women underwent the tests with normal results. Most of the women undergoing the tests had already reported emotional involvement with the fetus and this involvement grew during the observation period in both groups (Sjögren, 1989).

### **The Course of Grief Work**

At different times during the course of grief, three main elements influence the grieving process: the need to cry, to control crying and to change. According to Parkes, the course of grief covers denial, numbness, bitter pining, disorganisation, despair and reorganisation (Parkes, 1998).

The first phase of grief, *numbness and sometimes denial*, might last for hours' or days. The next phase follows with a period of *anxiety and intense feelings of pining for the lost person*, which may affect normal functions such as eating and sleeping, and the bereaved might become irritable and depressed. The third phase leads to *despair and disorganisation* and the bereaved usually goes through the event repeatedly. The final phase is *reorganisation*. As time passes, the intensity of grief tends to diminish, although the grief often returns with renewed intensity at anniversaries (Parkes, 1998). The phases of grief have sometimes been misunderstood and treated as if they were a fixed sequence through which every bereaved person must pass in order to recover from bereavement (Parkes, 1998). It is more likely that the bereaved person will pass back and forth between the phases before coming to reorganisation (Parkes, 1998). Grieving people may also need permission and encouragement to stop grieving and reassurance that nobody has to grieve all the time (Parkes, 1998).

Worden viewed the term grief as referring to the personal experience of grief and used the term mourning to indicate the process after a loss. He also suggested alternatives to 'phases of grief' as he thought that 'phases' implied

passivity and instead called it 'tasks' which implies that the mourner had to take action. He describes four tasks of mourning: to accept the reality of the loss, to work through the pain of grief, to adjust to an environment in which the deceased is missing and to emotionally relocate the deceased and move on with life. Worden thought that 'tasks' gives the mourner influence and hope and that the individual can actually do things. Using this approach, he further suggested that mourning could be influenced by intervention from the outside (Worden, 1991).

It could be regarded as help for the parents of stillborn children to be provided with information about a normal grieving process if they are masking their grief and perhaps do not believe it is legitimate to grieve (Boyce et al. 2002). Nevertheless, professionals who blandly recite the stages in the grieving process show an absence of any real concern for the parents (Leon, 1992).

## **Coping**

Coping can be viewed as context-specific emotional and behavioural processes as Lazarus and Folkman suggest (Miller, 1992). The individual has to estimate, encounter and recover from contact with a stressor. A strategy to resolve distressing feelings such as grief, anxiety and guilt is to cope with the same feelings. Coping can be regarded as having to deal with pain and grief. Grieving work implies an active and ongoing striving to handle the loss. The grieving person needs to bring the reality of loss into one's awareness as much as possible and be aware that suppression is a pathological phenomenon (Stroebe et al. 1999). On the basis on this definition Stroebe elaborated her grief work hypothesis that a person has to confront the experience of grief and has to come to terms with the loss in order to avoid harmful health consequences. The grief work model implies that the grieving person can work through the grief with the help of others (Stroebe et al. 1999).

A person's individual coping style can be regarded as the person's ability to meet challenges and stress. A first step in a coping process is to determine if what happened is to be judged as a threat and to ask, "Am I OK"? The second step is what a person can do about it if what happened is perceived as a threat. The results of a coping process may be resilience, mastery or crisis (Miller, 1992). Avoidance, approach and non-specific defence can be regarded as three categories of coping styles. Denial is one aspect of avoidance and could be helpful in an early stage of illness or during a traumatic event, but if denial continues to the extreme so that the person does not seek treatment, it is no longer effective (Roth et al. 1986).

It has been said that defensive behaviour such as denying the truth of the unpleasant and distressing event and forgetting the facts about it and in some way shutting out the mental pain could be destructive. But today irregular avoidance of loss is regarded as a normal part of grieving (Michel et al. 2001).

Caplan described a strategy of effective coping, namely to be able to express both negative and positive feelings and to have tolerance for frustration.

To be active in involving help from others, to get problems divided into manageable pieces and work through them one at a time, to realize that both fatigue and a tendency towards disorganisation could appear, to engage in solving problems and to master feelings and accept not having trust in others' as well as in oneself and to keep alive an optimism about the outcome (Caplan, 1963).

It is not only the bereaved who have to cope with what has happened. The involved caregivers have to cope with and understand how the loss affects a person, otherwise it is not possible to help and find ways of handling the bereaved. Parkes as well as Caplan state that if too much information is given, there is a risk the person will be overwhelmed. One way of coping for the caregivers in the first meeting is to tell the bad news a little piece at a time, or as much as they think the persons will be able to handle at that time (Caplan, 1963; Parkes, 1988). The caregivers can be agents of change. Effective coping with grief is to find the balance between confrontation and avoidance (Parkes, 1988).

### **Psychosocial Transition**

Psychosocial Transition theory is a model that has been found to be useful in explaining aspects of the reaction to loss. In an attempt to combine ideas from stress research, crisis studies and loss research, Parkes stated that the field of Psychosocial Transitions could be regarded as turning points for a better or worse psychosocial adjustment. PST is a model described by Parkes to understand bereavement in the sense that two main processes are started by major losses: *grief* and *psychological changes*. Grief, as already stated, is the normal emotional reaction to a loss. The term *Psychosocial Transition* covers the complex process of relearning which then takes place. The mourner's view of the world must change and his or her plans for the future have to be restructured. This process of transition has been termed a psychosocial transition.

According to Parkes, three criteria are characteristic in defining events that can be termed psychosocial transitions (Parkes, 1988):

- Require the grieving person to begin an important alteration of his or her assumptions about the world, i.e. the assumptive world includes our interpretation of the past and our expectations and plans for the future. In order to properly understand the effects of the loss of a child, spouse, or job, it is necessary to identify the areas of one's life space and assumptive world that will or should be changed in one's life.
- The effects of the loss are permanent rather than temporary.
- They take place over a relatively short period of time with little opportunity for preparation.

Excluded from the field of PST are, for instance, maturing and aging because of the gradual process of change. Frightening situations and transient illness are also excluded because they will have no lasting effect on the person.

Since the person in transition has no models for how to behave and how to meet the new situation, he or she will eventually feel helpless and in danger.

According to Parkes, the bereaved person needs (1) *emotional support*, (2) *protection throughout the period of helplessness* and (3) *assistance in discovering new models of the world appropriate to the emergent situation*. The first two of these actions may need to be provided before the person can feel safe enough to accept the third one (Parkes, 1988).

The parents of a stillborn child need support at times of transition. This support is given by particular medical social workers in close connection with the event. Parkes suggests that 'social workers are likely to find it less difficult than medical personnel to make use of a theory of transition, because much of their existing work is carried out from a similar viewpoint.' Furthermore Parkes indicates that social workers should take the lead in educating physicians, nurses and other staff. Important help in the transition could also come from parents who have their own experiences of stillbirth, although they themselves need to have come through successfully, as it should be the case that they solve their own problems before helping other parents (Parkes, 1988).

PST could also be used as a model when studying the parents of the stillborn child for explaining the psychological and social changes the parents will inevitably undergo. And there are ways in which the caregivers might facilitate the meeting with the stillborn child as well as the mourning process. The loss of a stillborn child can be defined as a psychosocial transition as follows (Parkes, 1988):

- The mother and father-to-be are changing and adjusting in the assumptive world in their moving from a childless state to parenthood (Andersen, 1984). When the mother and father are expecting the child, they organise their lives, home, and future and when they lose the child before birth they lose the future with that specific child (Andersen, 1984). Sometimes the parents experiences with their stillborn child is too limited and they have only a few memories. Instead, they must mourn the wishes and expectations that they had for that specific child (Grout et al. 2000).
- The dead child is someone who is forever missing and the loss of the child is ongoing despite other subsequent children (Grout et al. 2000).
- The stillbirth is often unexpected and happens quickly with little or no time for preparation (Rådestad, 1998).

Most people who experience a loss of a 'significant other' come through the loss without help from others than their own family. But the loss of a stillborn child is a specific loss, usually unexpected, and happens without the possibility of preparation by the parents. It is not unusual that the next-of-kins also need support from the hospital in their grief.

### ***Emotional support***

The caregivers' support is of great value in meeting with the dead child. It is important that the caregivers are warm and understanding in advising what to do. The parents need information, advice and support at every step of the way with the stillborn baby (Parkes, 1977). Caregivers, relatives, close friends and fellow-workers can all be helpful by recognising that support in bereavement

takes time and also that the parents sometimes need help with what might be called permission to grieve. Still, there is a lack of knowledge about the recovery process among both the caregivers and lay persons (Parkes, 1988).

### ***Protection throughout the period of helplessness***

As the parents have no models of thought and behaviour to deal with the situation of the loss of their child, they may feel helpless (Parkes, 1988). The mother and father are in a vulnerable situation, especially before and during the delivery. Most of the parents have no experience of death at all and they do not know what to do in this situation and what will be best for the future. The parents need support in both facing and separating from the child. It is an obligation of the caregivers to support them through this crucial transition (Parkes, 1988).

### ***Assistance in discovering new models of the world appropriate to the emergent situation***

A loss of a baby is a transition that bridges from the reality in losing the baby and the future with this specific baby, to a new reality consisting of how to manage without this specific baby. "The parents have to come to terms with grieving for a potential life with all its hopes and aspirations" (Boyce et al. 2002). In life-changing events, there are components of both loss and gain (Parkes, 1988). Most parents report that their values in life have changed for the better although they deny finding meaning in the baby's death (Kachoyanos et al. 1993). It is not unusual that parents report being more humble and more grateful towards life itself.

# Aims

The overall aim was to describe parents' experiences of hospital care following a stillbirth, as well as caregivers' role and attitudes concerning the management. Specific aims were as follows:

To compare mothers' and fathers' (the dyad's) experiences of bonding with their stillborn child and of hospital care and to evaluate parents' well-being three months after the event.

To explore parents' experiences of caregivers' assistance in the transitional process several years after the stillbirth.

To describe physicians' opinions about the management of parents to a stillborn child in relation to the physician's gender and age.

To describe the physicians' attitudes and opinions regarding a possible subsequent pregnancy.

# Methods

This thesis consists of four papers based on clinical studies. Two of the papers focus on the parents' experiences of the stillborn child and hospital staff management and in two papers the focus is on the caregivers' role, and especially the physician's role in the management.

## Paper I

The study comprising paper I is the first assessment in an ongoing study and has a descriptive and comparative design based on one questionnaire. During a period of two years from the event, three measurements will be done, at three months, one year and two years after the event. From the second assessment, a comparison group consisting of mothers and fathers of a living child will be added. In total, five questionnaires have been developed for the study. The first assessment after three months is included in this thesis. The study-specific questionnaire developed for paper I and the Well-being Questionnaire will be further described. The study was conducted in 2001. In total, 55 parents (33 mothers and 22 fathers) in 33 stillbirth cases were included in the study. Criteria for inclusion were parents with a stillborn child in the  $\geq 22$ nd gestational week. Criteria for exclusion were parents who did not understand the Swedish language or had a twin delivery with one living baby. The parents were recruited from the delivery wards of all five hospitals in the Stockholm area. Two fathers agreed to participate but did not answer the questionnaire and became non-responders. Paper I is based on the responses of 22 couples (44 parents).

## Paper II

This study is retrospective and has a descriptive design based on interviews and was conducted in 1992, four to six years after the parents had lost their child. A convenience sample of parents in 48 cases of stillbirth were asked to participate. Criteria for inclusion were parents with a stillborn child from  $\geq 28$  gestational weeks. The parents in 31 stillbirth cases agreed to participate in the study, a total of 55 parents. In the first interview, 24 couples and 7 mothers participated and, in the second interview, 16 couples and 10 mothers participated. The parents were recruited from two of the hospitals in the Stockholm area.

## Paper III

This study has a cross-sectional design and is descriptive and comparative and is based on one questionnaire; it was conducted in 1997. Gynaecologists from 58 out of 61 gynaecological departments in Sweden took part in the study. All



gynaecologists in service were invited to participate in the study (n=919). Forty-eight gynaecologists were no longer on duty at the department of gynaecology in question and were excluded. The questionnaire was answered by 761 gynaecologists, 167 gynaecologists were excluded when their demographic data revealed that they did not work within the field of intrauterine fetal death (IUFD). The attrition comprises of 110 gynaecologists who did not answer the questionnaire despite two reminders. The study comprised a total of 594 gynaecologists, a response rate of 87%. Of the 594 gynaecologists, 319 were women and 275 were men. 154 were under 40 years of age, 269 were between 40 and 49 and 171 were  $\geq$  50 years old. No significant difference concerning sex, age and type of hospital was noted between those who filled out the questionnaire and the non-responders.

#### **Paper IV**

Of the 594 gynaecologists included in the study 552, answered one specific open-ended question in the questionnaire of paper III. Forty-two did not answer the question, giving a response rate of 93%.

### **QUESTIONNAIRES**

The study-specific questionnaires were developed for the parents of a stillborn child (paper I) and for gynaecologists working in the field of IUFD (paper III). The well-being questionnaire was standardised and well established.

#### **Paper I**

##### ***Study-specific questionnaire 1***

Focus group discussions were used to identify appropriate issues for development of items included in the study-specific questionnaire as research on fathers of a stillborn baby is sparsely documented. For that reason, two focus group discussions were arranged involving fathers from two hospitals in the Stockholm area. The two meetings gave an opportunity to discuss sensitive topics and to identify activities of importance for the fathers (Sim et al. 1996). The questionnaire was then developed.

The study-specific questionnaire sent out three months after the event consisted of 113 items that covered ten areas: demographic data, self-rated psychological and physical health before the pregnancy (6 items), pregnancy (22 items), care before labour (6 items), labour (8 items), care during labour (5 items), the stillborn baby (30 items), sick-leave (7 items), tranquillisers (3 items), siblings (4 items), relationship to partner (4 items) and funeral ceremony (6 items). The items had either four response categories ranging from 'Very good' to 'Very bad' (10 items), 'Always' to 'Never' (3 items), 'To a high degree' to 'Not, at all' (10 items) or 'Yes' and 'No' (27 items) fixed (34 items) (e.g. normal labour, caesarean section) or open-ended alternatives (17 items).

The questionnaire was validated using face validity and was assessed by ten parents of stillborn children and an obstetrician with a special knowledge of these problems.

### ***The Well-being Questionnaire W-BQ12***

A well-being questionnaire (W-BQ12) was used in paper I to determine the parents' psychological condition three months after the event. The instrument was developed and tested by members of the Diabetes Research Group at Royal Holloway, University of London, (Bradlye, 2000). The W-BQ12 consists of selected items from the longer instrument, the 22-item Well-Being Questionnaire (W-BQ22) (Bradlye, 2000). The instrument has been translated into Swedish and validated in a Swedish population of diabetes patients (Wredling et al. 1995). The W-BQ12 has been shown to have adequate levels of reliability and validity in patients with diabetes (Pouwer, 1999). Cronbach's alpha coefficient was used to assess the internal consistency of the W-BQ12.

This generic instrument consists of three 4-item subscales: Negative Well-being (NWB), with all four items negatively worded, Energy (ENE), consisting of two positively and two negatively worded items, and Positive Well-being (PWB) with all four items positively worded. Based on these subscales, an overall scale, General Well-being (GWB), has been composed. All items were based on the parent's recall during the last weeks and scores were calculated according to the manual. The instrument consisted of 12 Likert-type items with answers ranging from 0 (not at all) to 3 (the whole time). Total scores of the NWB, ENE and PWB range from 0 to 12 and the GWB from 0 to 36. The higher the score, the more experience of negative well-being, energy and positive well-being. In this study, Cronbach's alpha coefficient was 0.70, 0.81 and 0.84 for NWB, PWB and ENE, respectively.

## **Papers III–IV**

### ***Study-specific questionnaire 2***

The questionnaire was developed especially for the study and concerns items about IUFD for gynaecologists. The 48 items comprised demographic data (7 items), management of the stillborn child (15 items), medical measures of psychological significance (11 items) and the respondent's own professional role (11 items). The answer alternatives were designed as ranking scales, e.g. 'always', 'often', 'seldom', 'never'. Nine items were formulated with fixed-response alternatives. Thirty-five items had fixed-response alternatives and space for the respondent's own comments. Four items regarding new pregnancy three were designed with open alternatives only, and one with fixed-response alternatives with space for the respondent's own comments.

In order to provide meaningful and useful questions, the questionnaire was validated using face-validity; i.e. it was assessed by ten obstetricians from different hospitals and of both genders with a special interest in these problems. The questionnaire was revised following their comments.

## **PROCEDURE**

### **Paper I**

The present author (KS) orally presented the study to the concerned hospital staff. Midwives in chief positions at the five hospitals introduced the study to

all midwives. Before leaving the hospital, the parents were given the introductory letter, an answer sheet and a paid reply envelope by the midwife. The answer sheet also contained information on how to contact the person responsible for the study (KS) if the parent wanted more information.

The first questionnaire was sent out three months after the event. The participating parents filled in separate questionnaires and three reminders were sent in all. The time interval of three months was chosen because of the fact that the parents are then in a period with intense feelings of pining and anxiety, as explained in grief theory.

## **Paper II**

The introductory letter was addressed to both parents of the stillborn child. A physician from each hospital signed the letter. The letter contained an introduction to the study and a request to consent. The letter guaranteed anonymity and mentioned the possibility of leaving the study at any time. Four assistant psychologists (none of which were involved in the actual stillborn child management work in question) conducted the interviews with the parents. The interviews took place in the parents' homes, except one that was conducted at the mother's office with both parents present. There was one week between the first and the second interview.

Each assistant psychologist also studied the material from all interviews. The interview was based on two working hypotheses: (1) The parents need to have an attachment to the child as a condition for the grieving process. (2) The caregivers at the hospital aim to give support to establish an attachment. The first interview was semistructured with questions about attachment to the stillborn child, the management at the clinic, the parents' own control of the situation and the grieving process. The average time for the first interview was 90 minutes. The aim of the second interview was to give attention to questions never fully addressed at the first meeting. All interviews were tape-recorded and transcribed verbatim.

## **Papers III and IV**

This cross-sectional study was conducted in 1997. The county hospitals with gynaecology departments, 61 in number, were identified. All heads of departments were mailed a questionnaire and an introductory letter with an answer sheet for written approval of the study and details on gynaecologists in service. Fifty-eight clinics consented to their inclusion in the investigation (95%) and supplied lists of the gynaecologists who were working in the department at the time.

The gynaecologists were then sent an introductory letter regarding the study and a questionnaire. To maintain anonymity, the questionnaire was returned in a separate reply-paid envelope. An answer sheet with details of the gynaecologist's name and hospital was returned in another reply-paid envelope. This procedure helped make the process of reminders easier. Two reminders were sent.

# DATA ANALYSES

## Statistical Procedures

### Paper I

Student's paired *t*-test was used for comparisons between the mothers and the fathers within the couples (dyads) on the mean scores of the subscales in the W-BQ12. Wilcoxon's signed rank test was used for analysing differences in scores between the mothers and the fathers within the couples (dyads) on the multiple-choice questions in the study-specific questionnaire. The relation between birth weight and time spent with the child was calculated using Spearman's rank correlation coefficient. Cronbach's alpha coefficient was used to assess the internal consistency in the W-BQ12 scale. For group-level comparisons, coefficients >0.70 are suggested to reflect good internal consistency of an instrument (Streiner et al. 1995).

### Paper III

Student's unpaired *t*-test was used for testing differences between two groups in the quoted scaled variables. To test differences in categorical data, chi-square statistics were performed. Multiple linear regression was performed on variables found to be statistically significant in the univariate tests. The independent variables were age, years as a registered physician, years as a specialist and the number of stillborns in the previous 3 years. To analyse differences according to age, the gynaecologists were divided into three age groups <40 years, 40-49 years and ≥50 years and one-way ANOVA was used.

### Paper IV

Chi-square statistics were performed to test for differences in the proportion between male and female gynaecologists included in the study. The unpaired *t*-test was used for comparisons between men and women concerning age, years as a registered physician, years as a specialist and number of stillborns in the previous 3 years.

P-values of <0.05 were considered statistically significant in all the studies. The statistical analysis was conducted using StatView 5.12.

**Table 1. Statistical Methods Used in Papers I, III and IV**

	Paper I	Paper III	Paper IV
Student's paired <i>t</i> -test	x		
Student's unpaired <i>t</i> -test		x	x
Wilcoxon's signed rank test	x		
Spearman's rank correlation coefficient	x		
Chi-square statistics		x	x
ANOVA one-way analyses		x	
Multiple linear regression analyses		x	
Cronbach's alpha coefficient	x		

## **QUALITATIVE ANALYSIS**

### **Paper II**

The transcribed interviews were analysed using a qualitative content analysis method (Berg, 2001). The statements were read for the purpose of getting an overall impression and understanding of different aspects of the participating parents' experiences. The first author subsequently analysed the statements stepwise. The first step was to read the text line by line to conceptualise the statements and divide them into text units of sentences.

As a second step, the text units were coded using terms close to the parents' sentences containing positive terms that facilitated the grieving process and negative terms that were devastating for the parents. The coding procedure was carried out using the QSR NUD\*IST computer program (Scolari, 1997). The coding list was read several times and then merged into categories. To establish inter-coder reliability, the co-authors read through the lists of categories independently to see if more categories could be found and to discuss the categorisation.

### **Paper IV**

This paper presents a content analysis (Krippendorff, 1980) of the responses to the item: 'Give a short summary of your advice to the women/parents about a possible subsequent pregnancy.'

The answers from the 552 gynaecologists were transcribed verbatim. All responses were carefully read through several times by the author (KS) to gain an overall picture of the content. Five themes and a pattern of ten subthemes were identified. The comments were coded according to age, gender, years of professional experience and the specific advice given. QSR NUD\*IST revision 4 for Apple Macintosh was used when categorising the answers.

# Ethical considerations

## Paper I

To ask parents to consent to a study in close connection with a stillbirth may put not only the parents, but also the person asking for consent, in an awkward situation. The authors elected the midwife to be the person to ask the parents to consent, as the midwife is a well-known person to them and usually someone they trust. It was important for the authors to obtain written consent and to let the consenting parents understand their right to withdraw from the study. In order to evaluate the parents' view on participating in the study, a concluding question was added to the questionnaires. It was phrased: 'How do you feel about answering the questions in this questionnaire?' Most parents answered that question. Sometimes a parent answered with just an OK. Mothers wrote more often than the fathers that the questions call up memories they want to forget. A lot of the parents thought the questions helped them to sort out their bereavement. There were also parents who thought it was a hard job to answer the questions, but also concluded that they were satisfied with the opportunity to share their impressions and to contribute to the development of care for other parents.

## Ethical Approval

The studies included in this thesis were approved by the Regional Ethics Committee of the Karolinska Institutet (Dnr 01-014 and 96-353) and the Local Ethics Committee of the Karolinska Hospital (Dnr 91:243).

# Results

According to the theory of psychosocial transition, there are three requisites the bereaved person needs: 'emotional support', 'protection throughout the period of helplessness' and 'assistance in discovering new models of the world appropriate to the emergent situation'. The three requisites are described in this thesis as the transitional process comprising six qualities identified by the authors: 'support in chaos', 'support in the meeting with and separation from the baby', 'support in bereavement', 'explanation of the stillbirth', 'organisation of the care' and 'understanding the nature of grief'.

## Support in chaos

The loss of a relative or significant other is usually preceded by a period of time to adapt to the situation. The loss of a stillborn child is almost never predictable and the information about the stillbirth can therefore be overpowering and choking and throws the parents into chaos. Twelve couples never thought that a stillbirth could happen, but eight mothers visited the antenatal clinic because they felt anxious about their pregnancy and six of the mothers also thought the staff at the antenatal clinic took their anxiety seriously (**paper I**). The mother and father of the stillborn child asked for information, advice and support at every step of the way in the process (**paper II**).

When ultrasound or an alternative examination indicated the stillbirth, 92% of the Swedish gynaecologists informed the women directly without waiting for the husband or another relative to be present (**paper III**). The female gynaecologists under 40 years of age significantly more frequently informed the women directly without waiting for the husband ( $p=.002$ ) (**paper III**). The male gynaecologists' reported that they had handled more cases of stillbirth than their female colleagues during the last three years ( $p=.003$ ) (**thesis**).

In their vulnerable and helpless situation, the parents are almost immediately forced to absorb a lot of information. If the information is given in a sensitive or insensitive way is often crucial to the parents. The moment itself and what is said is remembered by most parents verbatim (**paper I**). The physician or other person who gives the information also has the responsibility of dealing with the effects of the information on the parents. The message could be given in an inappropriate manner as stated by a mother in the retrospective study (**paper II**).

*"The physician answered abruptly and told me "to calm down" after I had mentioned the possibility of a caesarean section. I get angry every time I think of that stupid physician."*

When informed about the child's death the fathers thought the behaviour of the physician more insensitive than the mothers did ( $p=.021$ ) (**paper I**). The parents are informed about having a normal delivery but not a caesarean section. In the retrospective study, most of the parents thought it was a matter of course that the delivery would be by caesarean section (**paper II**). Nevertheless, they did understand and were satisfied with the experience of normal delivery and especially of not having a caesarean section retrospectively (**paper II**). A father expressed his opinion:

*"The delivery went well. I did not think a delivery by caesarean section was right. We felt that the last thing we could do for our child was to deliver her the "normal" way. This decision served as a comfort to us."*

The first reaction in the prospective study was to ask for a caesarean section among 13 out of 22 mothers and also 10 out of 22 fathers (**paper I**). Nineteen out of 20 women thought that they had got an explanation from staff for why a normal delivery was planned and were also satisfied with the explanation (**thesis**). If there are medical reasons for a caesarean section but the situation is not acute, 55% of the female gynaecologists and 45% of the male gynaecologists could consider a delivery of the woman in the awake state (**thesis**).

A labour ending with a stillbirth starts with induction if the labour is not spontaneous and does not seem to be approaching. The parents could then be given the suggestion to either go home for a couple of hours or a night or stay on the labour or gynecological ward as a free choice. Eighty-two per cent of the female gynaecologists and 75% of the male gynaecologists suggest that the women should go home and come back to the hospital the following day (**paper III**). In the retrospective study there were women who were already in labour and mothers who did not go home at all before the delivery. Most of the couples who followed the suggestion by the staff to go home thought that it was a good suggestion (**paper II**). A couple and a mother's statements:

*"It was terrible to go home knowing there was a dead child inside me. It was really awful. It think we had to go home because of a lack of places (mother)". "No, they did say it would be better for us to go home and think it all over (father)". "Afterwards I am very satisfied that we had the opportunity to go home (mother)."*

*"At first we thought it was horrible to go home, but at the same time it was very good to come home as we could talk to our other children about what had happened."*

Out of 11 couples who went home after information about the stillbirth in the prospective study, the immediate reaction to the suggestion was rather good in one couple and rather bad in two couples. Five fathers and two mothers



thought the immediate suggestion was better than their spouse did (one parent failed to answer and the couple is therefore considered a dropout). Three months later seven couples thought the suggestion to go home was quite/very good and two mothers and two fathers thought the suggestion was better than their spouse did (**paper I**).

In 14 mothers in the prospective study the mode of delivery was induction of labour. In 10 of the mothers, labour was induced within 24 hours, labour was induced in three mothers over 24 hours and in one, labour was induced immediately (**paper I**). When the gynaecologists were asked their opinion about when to start the labour, 40% considered within 24 hours, 26% over 24 hours, 4% did not know and the opinion of 30% was that the issue lacked significance. There were no differences between the sexes or age groups of the gynaecologists about labour induction (**paper III**). When the mothers in the prospective study were asked their opinion about when they wanted the induction of labour, 10 mothers wanted the induction within 24 hours, two in over 24 hours and two immediately (**paper I**).

### Support in the meeting with and separation from the baby

In the meeting with the dead baby, guidance is of great importance for the parents. In the prospective study, there were six couples that expressed a great need for discussion with the staff before labour and ten couples also thought they got sufficient information about spending time with the child (**paper I**). Regardless of parental reactions with tears or anger, all parents in the prospective study thought that the staff had treated them with understanding during the delivery (**paper I**). The fathers had the same strong feelings of warmth, pride, tenderness and grief as the mothers when they held the child (**paper I**).

The parents were asked to what degree the staff involved in the delivery supported them (**thesis**).

**Table 2. Parents' appraisal of support by staff involved in the delivery**

	Women Mean (SD)	Men Mean (SD)	Woman/Men Md
Midwife	3.7 (0.6)	3.7 (0.7)	4/4
Assistant nurse	3.1 (1.3)	3.0 (1.2)	4/3
Physician	1.6 (1.8)	2.5 (1.5)	1/2

The possible score was between 0 (no support at all) and 4 (very good support)

Most of the parents in the retrospective study were satisfied with the support from the midwife, half of the couples were not satisfied with the gynaecologist and medical social worker involved (**thesis**). Six couples had feelings of fear when they thought about seeing and touching the child. Despite their feelings, 42 parents held the child (**paper I**). One couple with a baby with a birth weight of 500 g did not hold the baby (**paper I**). In response to two questions,

20 mothers and 19 fathers recalled the time they held the child was long enough in connection with the delivery. Three months later 12 of the mothers and seven of the fathers thought that the time they held the child was too short (**paper I**). The length of time that the couples had the child with them in the delivery room ranged from less than ten minutes to more than ten hours. Eight couples had the child with them for more than ten hours. There was a relatively strong positive association between the time the father spent with the child and the child's birth weight. The higher the weight, the longer the time spent following the delivery ( $r=.53, p=.022$ ) (**paper I**). Six out of 31 parents in the retrospective study did not hold their child and three of them regret they did not (**thesis**). Regardless of how many hours the parents in the retrospective study spent with their child, they later thought that the time was too short (**paper II**). The majority of the gynaecologists considered that the parents should hold the child (94%), but there was a significant difference between the genders with the female gynaecologists showing a preference in encouraging the parents to hold the child ( $p=.008$ ) (**paper III**). All fathers and 20 mothers said that they decided themselves about the amount of time to be with the child without pressure from the staff involved. Nearly all parents thought the staff treated the stillborn child with respect (**paper I**). But there are sometimes moments when the staff can also worsen the despair. A mother in the retrospective study (**paper II**) gives an example of this:

*"The midwife talked about the funeral and feelings associated with the funeral before the delivery. I thought it was negative and too early."*

### **Support in bereavement**

It is important that hospital staff supports the parents in informing both next of kin and siblings as soon as possible and tell about the possibility of seeing the dead child. If the siblings are allowed to see the dead child they may also share in the family's grieving. In the prospective study eight women had had one or two children before the stillborn baby. Three of the siblings saw the dead baby and the mothers were also satisfied with the fact that the sibling had seen the baby. In three cases the mothers thought the sibling was too small and in two cases there was another reason for why the sibling did not see the baby (**thesis**). The gynaecologists did not consider it very important for siblings and next of kin to see the dead child (55%) (**paper III**). There were no significant gender differences between the female and male gynaecologists concerning the importance of the siblings seeing the dead baby. But significantly more female than male gynaecologists considered it important to have a lower age limit for siblings to see the baby. Most of the males thought the sibling should be 5–7 years old, with, at the extremes, one male gynaecologist stating that the sibling should be 18 years old. The female gynaecologists suggesting that the sibling should be 3–5 years old before seeing the baby (**thesis**). Evidence from the retrospective study of the siblings' reaction in the grief

process is mediated here through the voices of their parents (**thesis**):

*“Our daughter reacted strongly, she did not want to play with her doll any longer. We experienced that she processed what happened a long time. She kissed and hugged every baby she saw.”*

*“Our daughter had not really accepted that her subsequent sibling has become a sister. She has reacted strongly.”*

*“Our son looks very often at the photos.”*

*“Our children saw the baby after autopsy and I think that was something that helped them. Our daughter patted him on the cheek, and the other day she said, ‘it was the first and last time I saw him and he was so beautiful.’”*

Most parents think midwives and assistant nurses are the most important persons during the delivery. In the prospective study (**paper I**), most parents talk about them as being warm, most helpful and understanding with an empathic awareness of the situations. One mother’s comment:

*“Our child was placed on my chest straight after the delivery. Everybody present cried, the midwife, assistant nurse, my husband and I. This was a very touching moment.”*

The parents commented on the importance of being supported in their bereavement as they felt that appropriate support and counselling were helpful. To meet the physician and the midwife involved even after the stillbirth and to again have the opportunity to talk about the event seems to be beneficial for the grief process according to the parents. Many parents had meetings once a week with a medical social worker as long as they needed support in the grieving process (**paper II**). One mother stated:

*“I think the contact with the medical social worker was the most positive in the management. She made me understand my own behaviour more. She also helped us to listen to each other.”*

The most common reaction to the event of both the mothers and the fathers in the prospective study was tears; nine fathers also stated that they reacted with irritation, quietness and anger (**thesis**). Three months after the event the women scored a significantly higher negative well-being ( $p < .0001$ ), a lower positive well-being ( $p = .010$ ) and a lower general well-being ( $p = .001$ ) than the fathers, while energy did not differ between the parents (**paper I**).

## Explanation of the stillbirth

The majority of the gynaecologists considered it important to give a diagnosis and there was no significant difference between genders (**paper III**). Both male and female younger gynaecologists (under 40) considered to a significantly higher extent that it was important to be able to give a correct explanation of why the child had died, from a medical point of view ( $p=.044$ ) (**paper III**). Regarding the gynaecologists' attitudes to autopsy, the majority accepted the parents' refusal of autopsy without any deliberation. Only 28% went back to the parents to re-examine the question. Significantly more male than female gynaecologists accepted the parents' 'refusal' as final ( $p=.012$ ). There was no difference between the age groups (**paper III**). The female gynaecologists answered "do not know", to a greater extent than the males about their knowledge of whether the parents regret the decision of either having said yes or having said no to the autopsy i.e. 46% vs 34% and 68% vs 52%, respectively (**thesis**).

For most parents, it is important to have a diagnosis of why the child was stillborn. In the prospective study, the staff had asked 20 couples about an autopsy of the child. Eleven mothers and 14 fathers out of 22 responding couples thought the physician gave them sufficient information on the question about autopsy (**thesis**). Fifteen mothers and 14 fathers stated that the autopsy did not give an explanation of the stillbirth, and four couples said the autopsy did give explanation. Although most of the couples did not get an explanation from the autopsy, only one mother out of 40 regretted the procedure (**thesis**). There were two reasons for why the parents wanted the autopsy to be performed. The main reason was to know why the baby was stillborn and the second reason was to contribute to general knowledge (**thesis**). The retrospective study shows that, as comprehensive as possible an explanation of the stillbirth is an important issue for the parents (**paper II**). But it also shows that it is not unusual for parents to have feelings of guilt. Both mothers and fathers talked about possible incidents that could have influenced the outcome. Most parents in the prospective study did not blame anyone for the stillbirth, but three mothers considered the midwife at the antenatal clinic responsible (**paper I**). If the stillbirth was not investigated medically, the parents in the study felt that it might have a negative impact on any new pregnancy. One mother (**paper II**) commented:

*"We did not get a diagnosis of why our daughter was born dead. But I think a lot about whether it could have been the cigarettes or the fever or that I was stressed. I will never accept not getting a diagnosis of why she died."*

Twenty-seven per cent of the physicians, 69 women and 78 men, pointed out that their advice concerning a subsequent pregnancy would also depend on the diagnosis regarding the stillbirth (**paper IV**). A further 3%, 7 women and 10 men, considered that the new pregnancy entailed a risk of recurrence (**paper IV**).

## Organisation of the care

Many parents thought that the caregivers' help with understanding the grieving process, having as much sick leave as needed and the offer of special antenatal care for the next pregnancy had eased their despair. The mothers in the retrospective study were sick-listed between 0 and 12 months and the fathers were sick-listed between 0 and 4 months after the baby's death (**thesis**). Most of the parents in the prospective study were on sick leave after the event but three fathers were not sick-listed at all. Three months after the event, there was a significant difference within the couples in that no father and all but five mothers were still on full time or part-time sick-leave ( $p=.004$ ) (**thesis**). Six mothers and one father had wished that the periods of sick-listing would have been held together in longer periods (**thesis**). Female gynaecologists were more inclined to extend the sick-leave if the parents wished ( $p=.020$ ). A comparison between the various age groups for each gender showed that younger female gynaecologists (under 40) prolonged the woman's sick-leave significantly more frequently than the older physicians did ( $p=.038$ ) (**paper III**).

All the gynaecologists treated the women with suppressive drugs to inhibit milk production and 30% issued repeat prescriptions with no difference between genders or age groups (**paper III**).

In the prospective study, seven mothers and one father got a prescription for tranquillisers and ten parents got a few pills. Seven parents stated that they got the prescription on the initiative of their physicians. Three parents stated that they had often used the drug in connection with the event (**thesis**). Male gynaecologists showed a significantly greater inclination to prescribe tranquillisers ( $p=.001$ ). No differences were noted between the various age groups within each sex. One hundred randomly chosen questionnaires were checked through by hand to collect comments on the question regarding prescription of tranquillisers. Fifteen of 49 female gynaecologists reported a reluctance to issue prescriptions, as they did not wish to disturb the grieving process. Sixteen out of 51 male gynaecologists stated the same opinion. A few male gynaecologists stated that they prescribed tranquillisers as a matter of routine (**paper III**).

Over 90% of the gynaecologists followed the course of delivery by reading the medical record with the parents. There was no significant difference between either the sexes or the age groups (**paper III**). Most of the physicians often thought the conversations with the parents of a stillborn child are more serious than conversations with patients about other illnesses 83% (**thesis**). The gynaecologists cooperated to a great extent with other staff in these conversations (95%) (**thesis**).

A clear majority of the gynaecologists thought about the event some time after it had happened. A fairly large group (30%) was worried that it might become a disciplinary matter. A minority felt guilty about what had happened (**paper III**). A comparison between age groups for each sex showed that female gynaecologists under 40 significantly more frequently think over what happened ( $p=.013$ ) and worry more about possible disciplinary action

( $p=.004$ ) than older females. Among male gynaecologists, the 40–49 year old age group considered that departmental organisation was an obstacle to psychological management ( $p=.040$ ) (**paper III**). The majority of the gynaecologists expressed their need for guidance (90%) and stated that only a minority had received guidance (40%) (**paper III**).

The study of the gynaecologists answering the open-ended question about their attitudes to the subsequent pregnancy shows that the mothers get a lot of advice about when to become pregnant again. A supportive approach was advocated by 59% of the gynaecologists. Regarding gender differences, the female gynaecologists mentioned offering support significantly more often than their male colleagues ( $p=.005$ ) (**paper IV**). Advice to wait 0–12 months or just wait (time not specified) was given by 21% of the gynaecologists (**paper IV**). Fifty-one gynaecologists (9%) specifically mentioned that the women/parents themselves should decide when to have a new baby. No significant gender or age differences were found (**paper IV**).

### Understanding the nature of grief

It seems to be of great importance for most parents to have mementos of the child and most parents in the prospective study had a hand-footprint (81%) and ten also had a lock of hair (**thesis**). A wristband, which 19 parents had, is also a memento if it had been on the child's wrist (**thesis**). An important memento is the photos. A large majority of the gynaecologists considered that the child should be photographed and there were no significant differences between the genders (**paper III**). All but one child in the prospective study was photographed, and most of the parents (88%) stated that it was very important to have a photo of the baby. Significantly more mothers often looked at the photos ( $p<.0001$ ) and wished they had more photos ( $p=.0002$ ) (**thesis**). The parents in the retrospective study stated that seeing and holding the baby, having tokens of remembrance and a photo helped them to realise what really happened and to better understand what they were grieving for (**paper II**). One comment of a mother:

*“Since the time with the baby is too short anyway, you really need help with what to do with the baby. I think it is very important to have as many memories as possible so you can face the grief and be able to mourn properly.”*

The parents are often encouraged to name the baby and preferably the name they talked about earlier. All but two babies (**paper I**) and nearly all babies (**paper II**) were given a name and significantly more female gynaecologists considered it important to encourage the parents to give the baby a name ( $p=.035$ ) (**paper III**).

Eighteen couples had a funeral ceremony for the baby and 14 couples had a next of kin present. More fathers (14) than mothers (9) were very satisfied with having a next of kin present at the funeral ceremony (**paper I**). All siblings

but one were present at the funeral and the parents were satisfied with having them present (**paper I**).

The grief process is illustrated by statements of parents in the qualitative study (**paper II**).

The four phases emanate from Parkes' process of grief.

- **Numbness**

The period of numbness could be said to help the bereaved to try to forget what happened for a short moment. Below are the parents' recall of moments of distress and chaos when informed about the stillbirths.

*"I could not understand what they said, I wanted to crouch in a corner." (Mother)*

*"I was so chocked, all was in a state of flux." (Mother)*

*"I could not cry. I was totally numb." (Mother)*

*"I was totally cut off and I could not care about what would happen." (Father)*

*"The day after the delivery, when the baby was not there, my belly was empty, and I had nothing in my arms, I got really chocked." (Mother)*

- **Intense feelings of pining for the lost person**

There were intense feelings of pining for the baby. Anger plays an important part in the second phase.

*"I saw with an intensive feeling of pining that the baby was beautiful, I felt he was a part of myself." (Mother)*

*"When I visited the memorial grove, I felt I could talk to him and that we were together. When I left the place, I felt intense feelings of pining, but also a feeling of solidarity and the experience of having a little son". (Father)*

*"I have cried and smashed things to express my grief." (Father)*

- **Despair and disorganisation**

The memory of the dead child is never far away.

*"When we were at hospital we grieved intensively. I also grieved because my wife had to go through this. For six month my wife was*

*full of despair, she couldn't do anything, her world had been demolished". (Father)*

*"Thoughts about what had happened come with an intense presence sometimes." (Mother)*

- **Reorganisation**

Although time elapses and life gradually becomes normal again, the parents think a lot of their child. Anniversaries seem to revoke memories of the baby and what happened.

*"I will never get over this and will never forget. I often ride my bike to the grave after work and sit there thinking for a while." (Father)*

*"We think of him with more intensity at his anniversaries but the pain has slowly diminished." (Mother)*

*"The first two years were tough work when he had his anniversary and now I think of him a little extra that day." (Mother)*

In life-changing events with a worse outcome, values in life can change for the better anyway. Despite finding meaning in the death, the parents in the retrospective study stated that they had been more humble and more grateful toward life itself and they do not take anything for granted (**paper II**). In the prospective study, 18 couples thought the loss influenced their relationship by bringing them closer to each other (**paper I**). Seventeen mothers and 18 fathers did not think they were grieving the child in the same way as their spouse (**paper I**). More fathers than mothers added a comment on the question. Comments by four fathers (**paper I**):

*"The grief and the loss of the baby is more obvious for my wife as she physically carried the baby during the pregnancy."*

*"The mothers grief is probably longer and deeper."*

*"We both know that we grieve in different ways."*

*"I think we complement each other. She is sadder, I had shared in giving her a lot of warmth and perhaps comfort. I try to encourage us to look forward. However, we should not forget."*



# Discussion

## GENERAL DISCUSSION

### Support in chaos

It is a powerful and devastating moment when the parents are to be informed about the stillbirth. The baby, who just a short time earlier was kicking in the mother's uterus, will be born dead in a couple of hours or the following day. The information is in itself a tragedy, but it could be worse if it is told in an insensitive way and given to the mother when she is alone (Lasker, 1989).

Most women with a suspected stillbirth are examined with ultrasound or an alternative procedure. The present study shows that it is not unusual for the woman to be alone when she receives the information about the death of the baby in her womb (Säflund et al. 2000). If there are no medical reasons to hurry with the ultrasound in order to save the baby's life, it is preferable to wait until the husband or other relative arrives so that the information can be given jointly to both parents. It is important not to leave the mother or parents immediately after the information given (Parkes, 1998). Staying with the parents giving them a hand to hold and reassuring them of support during labour will make the situation easier for all involved.

In the first state of chaos, mothers initially want to have the delivery by caesarean section. The only valid reason for having a delivery by caesarean section is the mother's state of health or if there is a suspicion that the baby could be rescued with such a procedure.

Labour sometimes has to be induced and the parents may choose to go home for a couple of hours or for the night before the induction is started. The studies in this thesis show that most parents want to have the induction within 24 hours and, furthermore, that there are certain advantages in going home, when the parents will have the opportunity to inform siblings and next of kin. It is important to give the parents information about the free choice of going home or staying at the hospital and also to give structured information about what will happen the next day when they return. The structured information could include informing them that it is not dangerous for the mother to carry the dead child, information about the choice of analgesic, a possible course of the labour and reassurance of staff support in the meeting with the stillborn child.

Usually there is very short time for consideration and the parents seem to need sensitive help at every step during the course of events. Although the parents want to have structured information about what will happen, they sometimes receive more information than they are able to absorb, which could prove devastating. Too much information may overwhelm the parents, so it is

always better to give information in pieces (Parkes, 1998). The parents need to have moments of recovery before receiving additional information about the next step.

In this thesis, 'support of staff' is emphasised. The support given by a physician, a midwife, an assistant nurse, chaplain and medical social worker in the management of the parents of a stillborn child are not comparable. All staff have their own responsibilities that specify and characterise their profession. Katie Eriksson's theory attempts to describe the active part of the care (Eriksson, 1987). Her theory clarifies the act of caring; she suggests that all who devote themselves to the act of caring should build their profession on a joint base. There are three important concepts according to Eriksson: the human being, health and the care. According to Orem: "All helping situations have similar general designs or patterns. The design is engendered by the roles of the person involved – a person who is to give assistance – and by the expected behaviours of these persons" (Orem, 1985). Although the medical social worker could be said to be a listener with an understanding presence (van Kaam, 1966) and is presumably the person who provides the best psychosocial support, it is important to stress that assisting a parent in bereavement is not restricted to any special profession (Orem 1985). All parents cannot tolerate having close contact with hospital staff, and the parents of a stillborn child differ like other people in their tolerance of contact in accordance with their temperament and available energy (Orem, 1985). Nevertheless, Parkes felt that individuals who are undergoing psychosocial transitions are usually aware of their need for help and do want to have support (Parkes, 1988).

### **Support in the meeting with and separation from the baby**

Providing guidance for parents in their meeting with the dead baby and also separating from it is a cornerstone in crisis management. It can be regarded as a challenge and a difficult balancing act for the staff between encouraging and pushing the parents to see and hold the baby and not going beyond the boundary line and forcing them.

The studies show that parents need support by the staff in bonding to their baby. The parents may be in a helpless predicament, as they do not know what is best for the moment or for the future. For almost 25 years hospital practice after stillbirth has been to support the parents in seeing and holding the child, keeping mementoes and photos in order to help the woman in her grief (Condon, 1987; Rådestad, 1998). But the pendulum swings back and forth (Parks, 1998). A recent study stated that mothers who held the child were more depressed than those who only saw the child, and the least depressed were those who did not see the child at all (Huhges et al. 2001). It is important to note that 40 out of 65 women in that study lost their infant at 19-27 weeks (personal communication). According to WHO, a fetus in the 22nd gestational week has a weight of about 500 g, small enough to hold in one's hand. Early pregnancy losses are relatively straightforward medically, but they are more problematic psychologically with a complicated grieving process (Boyce et al.

2002). It is extremely important to know how to handle a loss at a gestational age of  $\leq 22$  weeks, as the parents way of dealing with the loss as a miscarriage or a stillbirth could be based on their own comprehension. However it could also be both a result of and caused by the caregivers' support (Lasker et al. 1991; Säflund et al. Accepted).

Attachment is mediated by looking, hearing and holding (Holmes, 1994). An essential difference between a mother and her newborn live baby and a mother with a stillborn baby is the attachment. A mother with a newborn baby does not normally need help with touching her child. In the prospective study both parents expressed a need to be emotionally supported in the meeting with their stillborn baby. A sensitive staff member will offer the options of seeing and holding the child in an atmosphere where the parents can feel free in their behaviour and have control of the situation. It should be the parents' own decision about how long they want to hold the baby and if they want to have the child in the labour room overnight. Regardless of how many hours the parents spent with their baby the studies showed the time was too short. This could be interpreted to mean that the amount of time seems to be more important in qualitative terms than in relative terms. It is also essential to realise that contact with the dead baby is not necessarily optimal for all parents.

The mothers' state of well-being after a stillborn child has been explained differs to a great extent. Hughes et al. (2001) explained the mothers' depression as an effect of holding their child, while Rådestad's (1998) explanation of anxiety among the mothers is due to not having seen the child as long as they wished.

This thesis will try to explain the mothers' lower general well-being in other terms than that of the cause and effect of holding the baby or not. Attachment is mostly explained as an emotional tie between a child and the mother (Condon, 1993). The attachment before birth is stronger in a mother-to-be than in the father (Robinson et al. 1999). Already in the 1950s, Winnicott made mention of a pregnant woman's internal preoccupation. The parent-fetal attachment could be said to comprise both reality and fantasy. The framework of antenatal attachment is of considerable importance in understanding many of the psychological problems of pregnancy and the postnatal period, including perinatal bereavement. In a study with an assessment of antenatal emotional attachment, the fathers scored significantly lower than the mothers. The instrument used in that study was focused on feelings, attitudes and behaviours towards the fetus (Condon, 1993). The mothers' lower well-being in our study could be interpreted in terms of the death of the fetus breaking off the attachment bond between the mother and child-to-be (Säflund et al. Manuscript). Another explanation could be that studies of grief work hypothesise that 'the female model of grieving' is not generalisable to a male sample (Stroebe et al. 1999).

## Support in bereavement

Many of the parents, and especially the mothers, thought the photos were very important mementos and also that one or two photos were not enough (Säflund et al. Manuscript). Some guidelines recommend that the hospital photographer should take photos as soon as possible after the baby is delivered, but after it has been cleaned or bathed. If the baby has hair, it is important to comb it. It is recommended to take one close-up photo of the baby's face and a full-length picture of the naked body. A photo with the parents holding the baby could also be appreciated. The staff should inform the parents that they can take as many photos as they want by themselves as this will be their only opportunity.

Hospital staff should support the parents in involving siblings. According to the study of the physicians, there seems to be too little knowledge about how siblings can participate in the grief (Säflund et al. 2000). A child's comprehension of death develops with the child's intellectual maturity (Dyregrov, 1990). For children younger than about five years old, death is reversible. They are not able to understand that the death of a sibling is irreversible (Dyregrov, 1990). It is also important that somebody can be there for the child, as a parent in bereavement may not really be there for their sibling (Dyregrov, 1990). It is to worsen the matter for the sibling by excluding him or her from the parents' grief and the baby's funeral. The best support parents can give the child is that they, the parents, take care of themselves (Dyregrov, 1999).

The parents of a stillborn baby are likely to be advised when it is the best time to parent again by friends, neighbours and counsellors, as well as their physician. Rather frequent advice given by physicians is to first work through the grief before parenting again (Säflund et al. 2002). But when is the grieving work finished and who is to say? Worden (1991) wrote: "Asking when mourning is finished is a little like asking how high is up?" According to the bereavement literature, the time required for grief work is four months, one year, two years or forever. It is most correct to say that it is impossible to set a definitive date. A criterion of completed grief is the point in time when the bereaved is able to think of the baby without pain (Worden, 1991). In 2001, the mean age of a woman giving birth for the first time was 27.9 years in Sweden (Statistics - Health and Diseases, 2003). It is not unusual for a woman to start to worrying about her age if the subsequent pregnancy is delayed because of advice she has been given. Consequently, when a couple wants to have another pregnancy, it is a personal decision and they only need to have specific advice if there are medical reasons for it.

## Explanation of the stillbirth

Although it is stated in the Swedish law on autopsy (3.3§11) that it is the obligation of the physician to discuss the issue with the parents, it is recommended that all staff involved should inform the parents of the better possibility of reaching diagnosis if an autopsy is done.

The majority of the physicians in our study considered it important to pro-

duce a diagnosis for the stillbirth. Although most of the couples in the prospective study did not receive an explanation from the autopsy, only one mother out of 40 parents regretted the autopsy. Parents seemed to think of two reasons why the autopsy should be performed. The main one was to acquire knowledge about their own particular child and the second reason was to contribute to general knowledge. The retrospective study also shows that a correct explanation of the stillbirth is an important issue for the parents. The autopsy may also contribute positive information that no deformity has been found.

A Swedish study using an Internet-based database for the purpose of collecting results from 188 cases of IUFD in five hospitals in the Stockholm area was made in 1998-99. The study showed that a presumptive explanation was established in 91% of the cases. The most common factor identified was infections (24%). The author of that study suggests that, in addition to an autopsy, a placental pathological examination should be included in the routine investigation of stillbirths (Pettersson, 2002).

Another Swedish study showed that low socio-economic status was associated with an increased risk of stillbirths but the results could not be further explained, as the underlying reasons remained unclear (Stephansson et al. 2001).

Most of the physicians in our study who considered that the advice about a subsequent pregnancy depended on the diagnosis gave no other information, indicating that a medical diagnosis was of the highest priority for them. Based on this knowledge, we recommend an informative discussion between the physician and the parents about the dead infant's diagnosis, i.e. the certainty or lack of certainty, and the importance, of the diagnosis.

### **Organisation of the care**

The parents should be given the opportunity to have repeated visits. Having the option to meet the caregivers who were with them during the stillbirth can ease the parents' despair. The parents should also have the opportunity to discuss dissatisfaction with the medical care (Boyce et al. 2001). To be able to meet the midwife again after the delivery and again have the opportunity to talk about the delivery seems to be very important. It is not unusual for misunderstandings and disagreements to be discussed and worked through in such meetings. For the professionals, this meeting could be regarded as a necessary intervention to secure working through a critical event (Dyregrov, 2003). Parents also seemed to feel abandoned when the staff did not offer their services in the grieving process. Having meetings with the medical social worker once a week is beneficial for the grieving process. Regular meetings are recommended for the first six months (Boyce et al. 2002).

Educating and informing hospital staff is important. The majority of the gynaecologists considered that they did not receive sufficient guidance when an IUFD occurred and that the need for such guidance was great (Säflund et al. 2000). When there have been exceptional circumstances during the deli-

very, such as when the baby dies during labour, a emergency meeting on the same day with all staff involved is recommended (Dyregrov, 2003). A group leader could give the staff the opportunity to put into words what happened (Dyregrov, 2003). This is not to be regarded as a debriefing meeting, which is usually held a couple of days after a tragic event (Dyregrov, 2003).

### **Understanding the nature of grief**

In the past parents accepted the loss of a child more readily than today. Today we have fewer children than in the past and the parents' feelings about a loss is that it is statistically rare, and they are not likely to be prepared for such tragedy. As there are usually only one or two children in a family of today, the tie between the parents and the children may be greater (Parkes, 1972).

In helping parents with coping strategies, it is necessary to confront them with the loss. It is important to go back to the pregnancy and the time of the stillbirth and let them focus on memories of the delivery and the time in hospital. To help the parents master said event, a carefully constructed meeting can be set up in order to facilitate the parents confronting of the event. This could lead to highly emotional and stressful moments. But the main goal of such an intervention is to help the parents to come to terms with their loss. (Caplan, 1967).

As all people are unique and it cannot be said beforehand who will be especially sensitive to bereavement, it is important for hospital staff to recognise the mothers and fathers at risk. Suffering may be said to comprise two behavioural states: enduring what has happened in that the emotions are suppressed in an emotionless state and a state of emotional suffering where the emotions are released. The bereaved move back and forth between these two states depending on their own needs and the support of others (Morse, 2001). It is important to ensure resources for support to the parents as well as to arrange opportunities for support to the caregivers (Parkes, 1988).

This thesis shows that parents have an essential need for the caregivers' support. The caregivers seem to have a strong ambition to support the parents in order to relieve their despair. It is obvious to say that every parent studied in this thesis had a different way of dealing with his or her grief. However, one aspect was constant throughout the study - that the loss of a child made the victims of such a tragedy more humble and more appreciative to life itself.

### **Methodological Considerations**

The dyad study (Paper I) was at first meant to be an investigation of fathers of a stillborn child. This soon turned out to be impossible to accomplish as the investigator first had to contact the mother to obtain her permission to contact the father. Therefore both parents were included in the study.

The items of the study-specific questionnaire were constructed with exactly the same questions for both the mother and the father. Therefore, it was important that the questionnaire should have important items and response options relevant also to a father (Murphy et al. 1992). For this reason, two fo-

cus group discussions were used. The fathers were able to talk about reactions and what they felt to be sensitive topics in the stillbirth process. Furthermore, the fathers were able to share important information about their experiences. A focus group could be used as a data collection method for the purpose of identifying appropriate domains of content for the development of more structured survey instruments (Fowler, 1993). A focus group discussion could also be regarded as an effective technique for exploring the attitudes and needs of staff (Kitzinger, 1995). The overall aim in using focus group discussions was that the analysed material from the discussions should generate data for the questionnaire.

One limitation in the study was to assign the responsibility of inviting the parents to participate in the study to the midwife who assisted the women during the birth. It is difficult to know how many of the 48 women not included were invited in all and how many were invited but did not want to participate or did not understand the Swedish language. Unfortunately it was not possible to calculate a response rate for that study. In an attempt to find out how many women had a stillbirth during the inclusion period, each department was contacted to reveal the total number of stillbirths during this specific period. There turned out to be 81 eligible cases of stillbirth during the inclusion period.

It cannot be stated that those included are a typical sample of the population, especially since most of the mothers and 50% of the fathers had a university degree. The results of the small sample size, with parents only from the Stockholm area, perhaps cannot be generalised for all parents in Sweden having experienced a stillbirth, but this is the first study in Sweden comparing results within the couples in close connection to the event. It is recommended that the results of the dyad study should be interpreted with caution.

Two of the studies (papers II and IV) are analysed by content analyses. The retrospective study (paper II) presented the 'Psychosocial Transition Theory', which established the overall framework throughout the study. One advantage of using content analysis for this study (paper II) was the ability to examine over a span of years (Berg, 2001).

In the retrospective study, a convenience sample of 48 out of 60 eligible cases was asked to participate from two hospitals in the Stockholm area (paper II). The psychologists invited the first 48 mothers of a stillborn child listed from both hospitals. It is not known if the sample of participating parents is representative of the whole population of parents to a stillborn baby. The interview technique for the retrospective study was validated with pilot interviews and supervised by a senior lecturer at Stockholm University, Department of Psychology. It may be argued that too long a time had passed after the event and since the material was gathered. However, the findings were consistent with the material from the prospective study in that the parents in the two studies showed the same need for support from the caregivers in meeting the child and also in their impression of the caregivers' handling of the event.

In paper IV, there were a large number of responses to the open-ended

question with 802 items of advice. By using more than one method of data collection to answer a research question the material could be said to address internal validity (Barbour, 2001). Counting is sometimes helpful in the analysis process to recognise patterns and therefore statistical measurements were used in this paper to give more meaning to the results (Sandelowski, 2001).



## Conclusions

The studies show that, despite the passage of ten years between the retrospective study and the prospective study, the parents have the same need for the caregivers' support at every step in the management of a stillbirth. This shows that the need for support is perpetual and has nothing to do with the amount of time elapsed. The prospective study also shows that, with warm and empathic support from the staff, the mothers and fathers will hold their baby despite their initial feelings of fear when they first confronted with such a proposition. This could be interpreted to mean that today the midwives are confident in their approach to managing their support.

The parents expressed their opinions about the caregivers' emotional attitudes. In several situations, the parents reported that the physician and other caregivers were either warm or understanding when advising what to do, or ice-cool, mechanical and cursory. To handle the consequences of loss in a sensitive way should be a topic of major interest and should receive more attention in medicine.

Nearly all gynaecologists stressed a great need for guidance and only a minority had access to such guidance. Against this background and the fact that one-third of the gynaecologists' were worried about a possible disciplinary action, it is important to create opportunities for guidance.

## Clinical implications

This study adds important information, not only about the mothers' but also about the fathers' impression of the caregivers' handling of the event. The study also contributes new insights showing that the fathers have the same strong feelings as the mothers when holding the child. It is important that the caregivers do not overlook the fathers in clinical care.

A uniform psychosocial guideline for the caregivers would be desirable in the management of parents to a stillborn child, at all departments in Sweden, in order to obtain a minimum quality of care for these parents.

Continuing education of all staff involved around stillbirths could both improve skills and yield a better understanding of the importance of sensitivity when confronting parents of a stillborn baby.

It is also important that all staff should take an active part in the continuing education and new science in this area. Beyond providing optimal care, the bereavement programme benefits quality assurance (Witter et al. 1990).

## Future research

The longitudinal study has to be further analysed, using data gathered one year and two years after the event. A control group of mothers and fathers with a living child has been added to the one year assessment. Matching of the subjects and controls are set to the same hospitals and day of birth. There are different opinions in grief theory regarding the duration of the normal grief process and how long the period of bereavement might last. It was therefore important to study the parent's self-rated well-being one year after the event and their impressions of the support of hospital staff in their bereavement. Two years after the event it was important to study the parents' attitude to a possible new pregnancy and subsequent baby and their self-rated well-being.

An important study to be made would be about the existing sibling's impression or understanding of the event. Very little research has been done on this subject. There have been far more studies about the subsequent child's vulnerability and psychological problems. The preferable way to approach the sibling issue would probably be to interview the parents, as most siblings are too small to be subjected to an investigation of this kind