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KAROLINSKA INSTITUTE, STOCKHOLM, SWEDEN

STILLBIRTH – A LOSS FOR THE WHOLE FAMILY

Pernilla Avelin



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To
Alva and Emanuel
For reminding me of the great value of life

ABSTRACT

Background: Stillbirth loss is a profound experience affecting around 450 families every year in Sweden. **Method:** Two questionnaires, one postal with three measurements over a two-year period with 55 parents (I), and a web questionnaire answered by 411 parents (III), five focus groups with a total of 25 parents (II), and individual face-to-face interviews with 13 bereaved adolescent siblings of a stillborn baby (IV) constitute the data collection. The qualitative data were analysed with a content analysis, descriptive statistics were used for the quantitative data. The overall aim of the thesis was to study the loss of a stillborn baby from the perspective of parents and siblings. **Results:** The parents strived to create an environment in which siblings are confidently allowed and invited to participate in processes surrounding the stillbirth. They promoted an understanding of the new and unexpected family situation. Some parents expressed difficulty in focusing on the needs of siblings during the acute grief after the loss. Most of the siblings met their stillborn sister or brother. The meeting was described as natural, enriching and self-evident and as an important component to create understanding; it attributed identity and personality to the stillborn baby. When the siblings created memories the baby was acknowledged and took on a tangible form. Furthermore, parents and siblings expressed feelings of broken expectations of becoming a larger family. Additionally, being a sister or brother of a stillborn baby brought up thoughts about the sibling relationship, and whether they could still identify themselves as big sisters or brothers. Many parents reported the loss had strengthened their relationship. Some parents and adolescent siblings expressed that they were grieving alone as well as together with other members of the family. They developed an inner strength and a trust in each other. For others, expectations of their own and other family members' way of grieving could pose a threat to their close relationship; a lack of understanding for each other's way to express grief or their needs could create an emotional distance. Some adolescents expressed feelings of being part of a common grief in the family, but simultaneously being outside. The loss of their baby sibling implied a temporary loss of their parents' parenthood. **Conclusions:** This thesis gives new information on the thoughts and feelings in a family after they have experienced a stillbirth. Clinically the information can be used to help health-care professionals communicate with parents and siblings after this event. For parents seeking advice, it may help to know that the parents in this study, who actively involved the stillborn baby's siblings in the meeting and farewell afterwards, by and large reported encouraging experiences only.

Key words: adolescent, bereavement, content analysis, grief, parenthood, relationship, sibling, stillbirth

LIST OF PUBLICATIONS

This thesis is based on the following papers, referred to by the Roman numerals:

- I. Avelin, P., Rådestad, I., Säflund, K., Wredling, R. & Erlandsson, K. (2012). Parental grief and relationships after the loss of a stillborn baby. *Midwifery*, available online 2 August
- II. Avelin, P., Erlandsson, K., Hildingsson, I. & Rådestad, I. (2011). Swedish parents' experiences of parenthood and the need for support to siblings when a baby is stillborn. *Birth*, 38(2), 150-158.
- III. Avelin, P., Erlandsson, K., Hildingsson, I., Davidsson Bremborg, A. & Rådestad, I. (2012). Make the stillborn baby and the loss real for the siblings – parents' advice on how the siblings of a stillborn baby can be supported. *Journal of Perinatal Education*, 21(2), 1-9.
- IV. Avelin, P., Gyllenswärd, G., Erlandsson, K. & Rådestad, I. (2013). Adolescents' experiences of having a stillborn half-sibling. *Death Studies*, Accepted 2013-04-29

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1 INTRODUCTION

I was given the opportunity as a PhD student to become a participant in the project presented in this thesis. I have no clinical experiences in this specific field, but am nevertheless rich in experiences of caring for bereaved families as a registered nurse on an emergency ward for almost ten years before starting my academic career. Nor have I researched in the past. Nevertheless this was a project I considered to be relevant and important. I have thus gone into the field with an open and interested mind, and become committed to the field of stillbirth, grief, bereavement and the family situation after stillbirth loss.

In Sweden around 450 babies are stillborn each year [1], and the loss means that expectation and joy is replaced with despair and sadness. Furthermore the stillbirth often occurs without notice and the possibility of being prepared is limited. Over 30 years ago a stillbirth was considered as a non-event [2] and it was thought that parents could be protected from grief by preventing them from seeing their baby. Today, health care is different, and parents are invited to see and hold their baby [3, 4], mementoes are preserved and remembrance ceremonies are held [5, 6]. Meeting the parents and siblings, if any in grief and providing information, is identified as important after stillbirth. Recently, *the Lancet stillbirth series* emphasised the unique status of stillbirth and added that grief may be exacerbated by social stigma, marginalisation and by the standard of care provided for parents [7]. The importance of good-quality care is emphasised in international and national guidelines for the management of stillbirth [8].

2 BACKGROUND

2.1 LOSS, GRIEF AND BEREAVEMENT

Grief, mourning and bereavement are terms that apply to the reactions of those who experience a significant loss. *Loss* may be defined as being deprived of something valuable [9]. In tangible terms this includes the material loss experiences to the loss of someone significant. It could furthermore include the loss of respect or independence. *Grief* is the subjective feeling, the emotional distress associated with the loss and consists of physical changes as well as psychological feelings and can include emotional expression, crying, sleeplessness, anxiety and a wide range of symptoms, such as anorexia, restlessness, agitation and somatic disturbance [10]. Grief has been used synonymously with mourning, although, most often *mourning* is seen as the process by which grief is resolved [11], further mourning refers to the acts expressive of grief. These acts are shaped by the mourning practices of a given society or cultural group which serve as guidelines for how bereaved persons are expected to behave. Grief is more associated with the emotional aspects of losing someone to whom one is attached, which is then followed by a period of bereavement. *Bereavement* literally means the state of being deprived of someone by death and refers to the objective situation of an individual who has recently experienced the loss of someone significant. Bereavement is the cause of both grief and mourning; hence bereavement is influenced by the extent to which mourning, and the social cultural behaviour associated with death, occurs [10]. Bereavement may be seen as the social fact of loss, which obliges the observer to offer condolences and expressions of sympathy to the mourner. This may, however, be considered culture bound and varies according to the rules and norms adopted by the cultural context in which grief has taken place. Hence grief can be affected by many variables, including the type of loss, relationships and attachment to the deceased, the circumstances surrounding the loss, the personalities of the bereaved and the ability to cope, and social variables such as cultural expectations and personal variables [12, 13]. An understanding of grief and the behaviour associated with the loss can help to focus on what the bereaved is feeling, although how they express their emotions depends on the cultural context as well as the perspective taken by the person listening to them.

2.1.1 Perspectives on grief and bereavement

2.1.1.1 *Grief work hypothesis*

Approaches to grief and bereavement were traditionally expressed through a range of ideas, attitudes and values that can be traced to the early work of Freud [14]. These ideas, based on psychoanalytical outcomes from therapy, have been supported by further work from psychiatrists such as Lindemann [15], Bowlby [16], Kübler-Ross [17] and Parkes [18]. Collectively, their views have laid the foundations for what many refer to as the grieving process and represent a dominant part of what may be regarded as a culture of grief and bereavement. Freud [14] argued that those who experienced loss needed to work through this and eventually emotionally detach themselves from the deceased in order to achieve successful resolution. This view dominated understandings of bereavement, especially in psychoanalytical terms, for many decades

and became known as the grief work hypothesis [19]. Working through grief is seen as an ultimate goal, that mourners should acknowledge the permanent absence of the deceased by initial expression of emotion, focusing on past memories and by being encouraged not to suppress feelings. This approach to explaining emotional expressions after loss almost prescribes grief through recognition of the reality of the loss, working through feelings and never ‘moving on’, or, as Worden [20] points out, ‘emotionally relocating’. The latter is an important part of grief work and involves severing the emotional bond with the deceased. This involves letting go emotionally, moving on and relinquishing any future hopes of relationship. Freud believed that continuing to have any on-going emotional connection with the deceased was pathological [21, 22]. The work of Lindemann [15] closely aligned to, and following, a similar psychodynamic approach, supported Freud’s grief work hypothesis, expressing the view that grief may be seen as an acute episode of illness with clear symptoms and a pathological focus.

2.1.1.2 Traditional perspectives on grief and bereavement

Bowlby [16] outlined his early work on childhood attachment in the 1960s, which strengthens much of what Freud and others had been arguing for in terms of grief reactions. Further, Kübler-Ross [17] was a pioneer in conceptualising the five stages of grief as defined in her book, *On death and Dying*. Building on the work of Freud, Bowlby and Kübler-Ross, Parkes [18] unfolded his theory of bereavement. His work, together with Kübler-Ross’s, led to what has become known as stage-based theories or approaches to grief and bereavement. Parkes’ works indicate that grief was experienced by a series of phases, beginning with shock and anger, leading to pining and yearning behaviour. He also stressed its being seen as a process and that one could identify aspects of grief as normal or abnormal. His early writing held that retained emotional links with the deceased could be seen as pathological, although subsequent reprints modified this view. Parkes argued that many of the emotions experienced by the bereaved varied in intensity and were not constant, depending on a number of factors, such as the relationship of attachment between the mourner and the deceased [23].

This idea of experiencing grief and bereavement in stages or phases was further developed [20, 24], and according to Cullberg [24] a crisis, such as a death of someone significant, can be divided into four phases; *shock, reaction, adaptation* and *new-orientation*. These phases are there to create structure when a person experiences a crisis and each phase has a specific content. The four phases are not static; they can flow into one another and one phase may go unnoticed [24]. Worden [20], somewhat later, identified grief as occurring in stages, with the bereaved behaving as an active participant in their grief, undertaking four emotional stages and not becoming a passive recipient of grief as an illness. Worden identified the fact that in order to successfully resolve grief, mourners are required to 1) *face and accept the reality of the loss*; this stage involves both an intellectual and an emotional acceptance. 2) *Experience the pain of grief*, which can be of a physical, emotional and/or behavioural nature. 3) *Adjust to an environment where the deceased is missing*; in this Worden describes three areas of adjustments: the external adjustments - which means how daily life is affected by the death; the internal adjustments - how death affects the definition of the self; self-esteem and the sense of self-efficacy; and spiritual adjustments – one’s own sense of the world, life values and philosophical beliefs. Finally Worden describes what he calls 4) *emotional relocation*, which is achieved by developing continuing bonds with the

deceased instead of withdrawing bonding feelings. Worden [13] means, in line with Klass, Silverman, and Nickman [25] that the fourth stage of mourning will be to find a place for the dead which enables the mourner to be connected with the deceased but to do it in a way that allows them to go on living effectively in the world. This is hindered, says Worden [13] by previous bonds being kept fixed instead of forming new ones. The stages of mourning are not described as a linear process; stages can be revisited and worked through again and again over time. Different stages can also be processed at the same time; hence mourning is a fluid process.

2.1.1.3 Contemporary perspectives on grief and bereavement

Stroebe and Shut [26] in the 1990s constructed a model of bereavement based on research, which examined the ways that spouses coped with the loss after the death of their partner. Their *dual process model* has become applicable in describing coping in more diverse groups of mourners. Unlike other models, the dual process model identifies and includes stressors associated with bereavement, as well as how people cope with the loss using a variety of cognitive strategies. The key feature of the model is its focus on explaining the process by which mourners oscillate between *activity oriented loss* and *restorative behaviour*. The dual process model places the process of grieving in a more dynamic, interactive, and personal perspective than more traditional theories of phases and stages. The model is based on two types of stressors: the *loss*, the person who is dead, the death, the reality of the event and secondary consequences of the death/bereavement, especially the awareness that life goes on without the deceased person – *restoration oriented*. The model recognises that grief is a dynamic process, and the central argument is that mourners can be observed demonstrating various behaviours, dependent on individual and cultural idiosyncrasies, that can be considered as either restorative or loss-focused coping behaviour.

The model attempt to explain how everyday experiences of the mourner's time are necessarily focused on socialising with others, doing things and planning other activities not related to the deceased. The bereaved find themselves oscillating between activities that may be related to loss (loss-oriented), such as denial, letting go or relocating bonds, and other restoration-oriented activity, and establishing new roles and relationships. In this sense, the bereaved can be observed moving between behaviour which is loss-oriented and that focused on enabling them to adapt and restore order, integrity and harmony to their lives. That the bereaved oscillate between these two dimensions, confronting one and avoiding the other, and going back and forth results in that the model allows a dose of mourning for the bereaved.

2.1.1.4 Constructing emotional links between the deceased and the bereaved

Grief can be seen as it is socially constructed – that it is based on an understanding of grief as a 'state of being' as opposed to a process of goal-directed activities aimed at 'grief-resolution' with predefined notions of normality [27]. Remaining connected seemed to facilitate both adults' and children's ability to cope with the loss and the accompanying changes in their lives. These 'connections' provided solace, comfort and support, and eased the transition from the past to the future [25]. From this perspective, grief is defined by the individual person who is attempting to move forward through life with a new sense of meaning-making [28]. The loss is integrated, but not gone, and is given meaning through a narration of loss and creating continuing bonds [25, 29].

Loss and its subsequent grief compel one into an existential crisis, necessitating a new world view and meaning-making of life that can result in reconciliation of the loss.

According to Neimeyer's [30] model, *meaning reconstruction* in response to a loss is the central process in grieving. This model is another view of the process of loss and mourning. It places the grieving process in a dynamic, active and (inter-) personal perspective – more so than models of stages and phases. The reconstruction of meaning is an active process and is on three levels: *intrapersonal level* – by, with, within and of ourselves; *interpersonal level* – interacting with one's environment and *social level* – creating one's (sub-) culture. After a traumatic life event or loss it is up to oneself to adjust/reconstruct one's own narrative (life story). There is a clear distinction, however, between having and giving meaning: a loss in itself is meaningless; what matters is what one does with the loss, with the experience. In addition people always reconstruct their narratives in connection with others and their environment. The bereaved wish to retain memories of their past lives and relationships with their deceased, connecting with them in an emotional way, visiting the grave, talking to them, keeping mementoes and ensuring that their memory is kept alive. Rather than relinquishing their ties with the deceased or working through their grief, mourners wish to revisit their previous lives, retaining the things they hold dear in the knowledge that the previous relationships have changed. The significant memories and symbolic images of their relationships are retained, nurtured and held to be important in helping the bereaved to continue with their future lives [30].

2.1.2 Child and adolescent grief

Children's and adolescents' grief and their understanding of death are aligned to their intellectual development and both involve a gradual process [31, 32]. Children and adolescents relate to their experience of loss in nuanced ways, while trying to fully comprehend the death itself, regardless of the context of the death. Developing a concept of death is a lifelong, dynamic process [33], affected by the individual child's experiences of communicating feelings, their cognitive abilities and the presence of other supportive persons. Children may react in many different ways; they react primarily by maturation and age, although the child's personality and relationship to the deceased have an impact [34]. Children do not always show any appreciable reaction, but that does not mean they are unaffected by the loss. [34, 35]. Children grieve differently than adults; they often grieve in spurts and can re-grieve at new developmental stages as their understanding of death and their perceptions of the world change [34, 31]. Childhood grief may be expressed as behavioural changes and/or emotional expressions. Two predictive factors of a child's successful outcome after suffering a loss are the availability of one significant adult and the provision of a safe physical and emotional environment [34, 36, 37].

2.1.2.1 Age-appropriate grief reactions and apprehension of death

Children who are 0-2 years (infants) do not have the cognitive capability to understand an abstract concept like death. However, grief reactions are possible and separation anxiety is a concern. Behavioural and developmental regression can occur as children have difficulty in identifying and dealing with their loss; they may react in concert with the distress experienced by their caregiver [38, 39]. Because infants cannot verbally communicate their needs, fear is often expressed by crying. When their parents and

loved ones are sad, depressed, scared, or angry, she/he senses these emotions and becomes upset or afraid. There is a need to maintain routines and to avoid separation from significant others [34].

Preschool children, between 2-6 years of age, see death as temporary and reversible. They interpret their world in a concrete and literal manner and may ask questions reflecting their perspective [31, 34, 38]. They do not usually visualise death either as separate from life, or as something that can happen to them. They may believe that death can be caused by thoughts and provide magical explanations, often blaming themselves for the death. Children of this age may also connect occurrences that do not have anything to do with one another. If a child bought a certain toy the day that her/his sister died, she/he may attribute the toy to causing the sister's death, especially if the real cause of the death is not fully explained. Providing simple and straightforward explanations, avoiding euphemisms, correcting misperceptions, and reminding them that the deceased will not return are important strategies [34, 35]. At 6-9 years, children understand that death is final and irreversible but do not believe that it is universal or could happen to them. Death is often personalised and/or personified [34, 38]. Expressions of anger towards the deceased or towards those perceived to have been unable to save the deceased can occur [31]. Anxiety, depressive symptoms, and somatic complaints may be present. The child often has fears about death and concerns about their other loved ones' safety. In addition to giving clear, realistic information offer to include the child in for example funeral ceremonies. It is important that school staff understand the child's reactions and provide additional adult support [34].

Preadolescents, in the ages of 9-13, years begin to have an adult understanding of death – that it is final, irreversible, and universal. In understanding death, preadolescents attempt to understand both the biological and emotional processes [34, 37, 38]. They are, however, more able to understand the facts surrounding the death of someone than they are the feelings surrounding the death. Preadolescents tend to intellectualise death as many of them have not yet learned to identify and deal with feelings [34, 38]. They may be very curious about the physical process of death and what happens after a person dies, and they are often interested in religious and cultural traditions surrounding death. Preadolescents may believe that they can escape from death through their own efforts. They might also view death as a punishment [34, 35]. Preadolescents are in the process of establishing their own identity, increasing their independence from their parents and other adults and increasing their dependence on their peer group. Fear of the unknown, loss of control, and separation from family and friends can be the child's main sources of anxiety and fear related to death [37]. For adolescents aged 13-17 past experiences and emotional development influence their concept of death. Most adolescents understand that death is permanent, universal, and inevitable [38]. During adolescence the ability to think hypothetically develops, in a way that makes it possible to view many aspects of the loss. In this age they are more able to draw parallels and they can review inconsistencies in the information they receive about the loss more critically. Cognitively they are furthermore more capable of reflecting on deeper themes and more existential aspects of death. Adolescents, similar to adults, may want to have their religious or cultural rituals observed. Most adolescents are beginning to establish their identity, independence, and relationship to peer groups [34, 37]. A predominant theme in adolescence is feelings of immortality or being exempt from death. Their realisation of their own death threatens all of these objectives. Denial and defiant attitudes may suddenly change the personality of an adolescent

facing death. An adolescent may feel as if they no longer belong or fit in with their peers. In addition, they may feel as if they are unable to communicate with their parents. Another important concept among adolescents is self-image. The adolescent may feel alone in their struggle, scared, and angry [40].

2.1.3 Family bereavement associated to stillbirth

The grief that follows after the loss of a stillborn baby has been described as a complex and unique loss [41-43]. The social and cultural attitudes and values that surround stillbirth are associated with guilt, fear and failure [44], and grief reactions after stillbirth involve avoidance, confrontation and re-establishment. The loss of an adult who lived a life gave memories to cherish, while the loss of an unborn baby does not give the same sort of memories or history to gain consolation through. Although theories about grief are generally applicable, grief is complex and not every person within the family context goes through their grief in the same way [12, 45]. In addition, grief after stillbirth is described as unique because the stillborn baby is part of the parents' identity [46], in the form of hopes and fantasies that come with parenthood.

The forming of bonds [25, 47, 48] with the unborn baby has been argued as an important element of grief [49], and there are assertions that both mothers and fathers bond with their unborn baby even early in pregnancy [25, 50]. However, some studies suggest distinctions between maternal and paternal antenatal attachment. Some of those distinctions are explained by biological factors such as fetal movements [51] and that the women develop a more profound attachment when carrying the baby through pregnancy [52]. Grieving parents tend to look towards one another for comfort after the loss of their stillborn baby [53, 54]. Furthermore, bereaved mothers and fathers tend to have different grieving styles and roles, and their emotional expressions of loss differ [12, 51, 55, 56], which can lead to the parents finding themselves in conflict over coping with styles and other matters at an already stressful time [57].

2.1.3.1 Siblings' grief after stillbirth

While much of the research has focused on parents bereaved through stillbirth, the stillborn baby has a wider, continuing social presence within families. Hence sibling bereavement is a phenomenon with an impact upon the processes of grieving. Rowe [58] with Kempson and Murdock [59] found in both their studies that the absence of direct knowledge of the stillborn baby did not mean that the sibling was untouched by the families' grief. Although the memory of the baby may be experienced more as an absence than a presence, the role of siblings as memory keepers has been studied by Kempson and Murdock [59] and explored by others [58, 60, 61]. These researchers suggest that bereaved siblings develop and maintain a sense of connection to their deceased sibling, including those who never knew the deceased child. Furthermore, siblings' grief after stillbirth is not always the priority for grieving parents and they may unbalance the situation for siblings [62]. The consequence may be that siblings suffer from guilt, fear and anxiety and have difficulty resolving the situation themselves [63]. When a baby dies during pregnancy or at birth, siblings have only known their sister or brother through talks about the baby with their parents. As the word of the baby's anticipated arrival is shared, the siblings begin to construct what this news means to them and their family. Suddenly, these children become bereaved siblings before they have the chance to act as just siblings. This situation has been named *the*

invisible loss of siblings never known [59]. Parental reaction of the loss can further be different between parents and from one mother or father to another [51] and therefore, as the parents determine their responses to the stillbirth, they will subsequently choose what thoughts and feelings to pass along to other children in the family. Parents who do not acknowledge the sibling's personal loss and withdraw into their own grief may fail to help their children to understand that the baby was stillborn and this may complicate the sibling's grief [64-66] as well as the changed dynamic in the home [67].

2.1.3.2 *Stillbirth acknowledgement*

Stillbirth – like any death – is both a personal and a communal event. However, the opportunities for private and public acknowledgement of the stillborn baby have been hindered by past practices of the immediate removal of the stillborn babies from their mothers and their often anonymous interment. Whilst in Sweden and many other western societies this situation has vastly improved in the past few decades, such disenfranchised grief remains for some families [68]. The unacknowledged social presence of a deceased family member, combined with expected grief reactions, left mourning incomplete [69]. In what Klass [70] describes as a 'disconnect between inner and social reality', this disenfranchisement of grieving disallows validation of the deceased persons' identity, making the loss more ambiguous and immobilising normal reactions to grief [59, 65, 71]. It has been observed that family functionality promotes the resolution of family grief. Family functionality itself exists within a broader social context; the previous practices regarding the removal and interment of stillborn babies were pre-empted by an expectation that stillborn babies should not be acknowledged by the families or the wider community [72]. Contemporary practices, however, are much more likely to encourage the acknowledgement and memorialisation of the stillborn babies in more recent times; the babies are seen, held and named. These actions in some way mark the presence of the baby in the family and provide a path for validated grieving. Bleyen [72] describes this as transforming the stillborn baby from *something* to *someone*. This social permission to mourn a loss that was disenfranchised has seen generational changes to the personal and public acknowledgement of stillborn babies, including ritualised grief behaviours. The value of grief or mourning rituals in providing this acknowledgement and memorialisation has been established. In a study by Rowe [58], 'remembering' is equated to keeping the deceased person 'alive' in the story of the bereaved. Hence the memorialisation described plays a role in the ritualised grieving practices for stillborn babies. Ritualised grieving encompasses not only ceremonial conduct but other actions that make tangible the intangible losses, experienced by many of these bereaved as results of stillbirth. Ritualised grieving practices are universal [73], providing the means for the bereaved to privately and publicly express their grief. Whether religious or secular, grief and mourning rituals give voice to the social presence of the deceased within families and communities [74]. Such practices are acknowledged as having a healing quality [73] and may form a valuable element of grief recovery.

2.2 STILLBIRTH

2.2.1 Incidence and definitions

Stillbirth is a devastating pregnancy complication affecting near three million pregnancies worldwide per year. It is less common in developing countries but still occurs at an incidence of 3-7 per 1000 live births [75]. In early 1970s the incidence was about five per 1000 births and until 1985 it declined to about 3-4 per 1000 births. Since then the incidence of stillbirth has remained almost constant. In 2011, 443 babies were registered stillborn in Sweden according to the Swedish Medical Birth Register, which gives an incidence of 4.0 per 1000 live births, out of these, nearly 40 per cent, were born after gestational week 37 [1]. Stillbirth is in Sweden defined as fetal death from completed gestational week 22. Prior July 2008 stillbirth was defined as fetal death from gestational week 28. The definition was changed to concord with international praxis and are in line with WHO (World Health Organization), where stillbirth is defined as the birth of a baby after 22 completed weeks of gestation, or if the gestational week is uncertain with a birth weight of 500 gram or more, or a body length of 25 centimetres or more, who died before or during birth [7].

2.2.2 Causes and risk factors

Although several conditions have been linked to stillbirth, it is difficult to define the precise etiology in many cases. An important proportion of stillbirths are associated with complications related to the placenta and umbilical cord, such as placenta insufficient, abruption placenta and different umbilical cord accidents, and furthermore pregnancy-related disorders (such as preeclampsia and gestational diabetes). Other causes include prenatal infections (both virus and bacterial), intrauterine growth restriction, genetic abnormalities, isoimmunisation, and maternal chronic diseases (such as diabetes, thyroid disease, cardiovascular disease and systemic lupus erythematosus) [76, 77]. Knowledge about risk factors and the mechanism by which they are linked to stillbirth may facilitate the identification of high-risk pregnancies. High maternal age is one known factor that increases the risk for stillbirths; women over 35 years have a 40 to 50 percent increased risk compared with women aged 20-29. A possible explanation could be the increased incidence of multiple birth, gestational diabetes, hypertension, and preeclampsia among women over 35 years. This age-associated risk is more pronounced among primiparas than among multiparas [78, 79]. Maternal smoking also increases the risk of stillbirth. A possible causal relationship may be that smoking increases the risk of intrauterine growth restriction and placental complications [80]. Furthermore there are associations between maternal body-mass index (BMI) and stillbirth risk, with the highest risk among the overweight and obese (BMI > 25; > 30 respectively). The mechanism for the BMI-related increases in risk of stillbirth is not known in full; however, pregnancy complications such as gestational diabetes, preeclampsia and eclampsia, are more common among overweight and obese women [78, 81]. Social factors, such as the level of education and socioeconomic status also influence the risk [82]. In addition, if women have previously given birth to a stillborn baby, this recurrence tendency is most pronounced in women with diabetes and/or hypertensive disease [78]. Stress is furthermore a potential explanatory factor for stillbirth; hence it releases numerous bioactive mediators and hormones which contribute to complications during pregnancy [83]. In a recent study László et al. [84]

present data linking maternal stress and stillbirth: in their nationwide study including almost three million births taking place in Sweden during 1973-2006, they assess the association between bereavement during pregnancy and stillbirth. To achieve reduction in stillbirth rate all this risk factors has to be take into consideration and one of the most important is to find the growth restricted fetus, since stillbirth associated with restricted fetal growth, without any other direct causes is one of the major types of stillbirth [85].

2.2.3 Care

Health care professionals in the early 1970s first recognised stillbirth loss as a crisis that was not being addressed. Parents who lost their stillborn baby urged to forget the event and the baby, while the wider community denied the event and midwives who were responsible for the birth removed the baby to avoid parental distress at the sight of their dead baby. This act was the approach at that time: that an attachment between mother and baby did not exist before birth, and thus there was no reason for the mothers to grieve [86]. Contemporary practices, however, are much more likely to encourage the confirmation by the families and the wider community. Today the norm in Sweden is that parents should spend the time they wish with their stillborn baby. Additionally, Säflund, Sjögren and Wredling [87] argue that health care professionals' attitude and behaviour, for both the mother and her partner, are significant in relation to stillbirth. Parents need support, not only in meeting with the stillborn baby, but also to be able to separate from the baby. The time parents spend with their stillborn baby is often perceived as too short. Health care professionals facilitate the holding and seeing of the stillborn babies and provide evidence of their existence; the babies are named, photographed with their parents, siblings and others; plaster casts of feet and hands are taken and a certificate of stillbirth may be issued; the baby is memorialised. Such ways of creating memories of the babies have been found to facilitate grieving and improve the long-term emotional well-being of parents and siblings [88].

2.3 FAMILY

The family can be defined in various ways, and the definitions and perception of the family as a concept depends on the perspective used with their respective focus on: *Legal*: relationships through blood ties, adoption, guardianship, or marriage; *Biological*: genetic biological networks among people; *Sociological*: groups of people living together and; *Psychological*: groups with strong emotional ties [89]. Instead of focusing on the legal and biological aspects one can focus on the relationships between individuals within the family, and this relationship is highlighted by Meister [90] who speaks of the family as a social network with a special bond between its members. The personal bond is directed towards the most loved ones and welcomed with joy when they meet [91]. Stuart [92] defines a family as a social system or a unit with at least two people that is self-defined by its members and is not a constant. The members may or may not be related, may or may not live under one roof, and may contain children, but not necessarily. Commitment and bonds between the family members include future obligations, and the unit carries out the relevant functions of caregiving, consisting of the protection, nourishment, and socialisation of its members [92], and this is the perspective permeating this thesis when using the concept of the family. In many families there are children, and more children in one family become siblings, when to define siblings it is helpful to use criteria by Mahon and Robinson [93]. In their article,

which analyses previous studies on sibling bereavement, they use what they call ‘critical attributes’ in studying this topic. Family attributes include a shared experience or history. They, however, deem it not necessary to share biology. The important component is that they share the experience of belonging to the same family. Hence siblings are children in a family where the children feel they have a relationship to one another, either by sharing a biological background as full- or half-siblings, stepchildren, adopted, or sharing some degree of commitment or socialising with given standards of the sibling role. What is important, there is not a choice in the relationship; one does not pick one’s siblings. Because of this, there is no guarantee that your sibling is someone you like, or would like to be around given a choice. This is one of the reasons that sibling loss and sibling relationships can be so complicated [93].

2.4 RATIONALE

Stillbirth usually occurs within a family context, where the parents, but also siblings, are affected. One of the key actions of *The Lancet Stillbirths Series, Stillbirths: the vision for 2020* [94] is to provide bereavement support. This is a field in need of further research; in addition previous research in the field has focused on the experiences of mothers and fathers in losing a baby before birth. Few studies have described the loss of a stillborn baby from the perspective of the family: the parents’ relationship, parents’ support for the siblings of the baby and the siblings’ own perspectives of being a bereaved sibling in a nuanced situation as after stillbirth loss.

3 AIMS

The overall aim was to study the loss of a stillborn baby from the perspective of parents and siblings.

Specific aims for the four studies comprising this thesis were:

- I. To describe the grief of mothers and fathers, and its influence on their relationship after the loss of a stillborn baby.
- II. To describe parenthood and the needs of siblings after stillbirth from their parents' perspective.
- III. To investigate parents' advice to other parents on the basis of their own experiences of siblings' taking leave of a stillborn baby. A specific aim was to study whether the advice differs between parents who lost their child early or late in pregnancy.
- IV. To describe adolescents' experiences of being siblings to a stillborn sibling.

4 METHODS

4.1 DESIGN

This thesis embraces two different study designs and four different data collections. The studies have an inductive qualitative (I-IV) and descriptive quantitative (I, III) approach. Throughout all the studies, parents' and siblings' descriptions of their experiences and thoughts have been about the effects of loss. An overview of the studies is presented in Table 1.

Table 1 Overview of the studies

Design	Data collection	Participants	Analysis method
I. Descriptive quantitative and qualitative	Postal questionnaires	55 parents, 33 mothers and 22 fathers	Content analysis together with descriptive statistical test
II. Qualitative	Focus groups	25 parents, 20 mothers and 5 fathers	Content analysis
III. Descriptive quantitative and qualitative	Web questionnaires	411 parents, 360 mothers and 61 fathers	Content analysis together with descriptive statistical test
IV. Qualitative	Face-to-face interviews	13 adolescents, 11 girls and 2 boys	Content analysis

4.2 PARTICIPANTS AND PROCEDURE

The thesis includes parents' and siblings' experiences of intrauterine fetal death after 22 completed weeks of gestation, either before (antepartum) or during birth (intrapartum), regardless of cause. All the participating parents (I-III), or the participating adolescents' mothers/stepmothers (IV), were either diagnosed with an intrauterine fetal death before induction of birth or in the early stage of birth. Inclusion criteria for the studies were that mothers and fathers should have experienced a stillbirth (I-III) and before the loss has had children i.e. siblings to the stillborn baby (II, III). For study IV the inclusion criteria were an adolescent between 13 and 17 years of age, having experienced the loss of a stillborn sister or brother when they were preadolescents or adolescents. Exclusion criteria were twin births with one surviving child and participants who did not understand and speak the Swedish language (I-IV).

4.2.1 Study I

The participating mothers and fathers were recruited from five hospitals in the Stockholm region of Sweden. The mothers and fathers were recruited consecutively over a period of one year. The midwives working at the delivery wards, at the five hospitals included assisted the researcher in the recruitment phase. Thus when a mother had given birth to a stillborn baby and if the midwife had determined that the study criteria were fulfilled, the mother and the father were provided with information about the study orally and in writing before they left the hospital. Participating mothers and

fathers sent their signed consent form to the researcher after being discharged from the hospital.

The study-specific questionnaires were developed for mothers and fathers of a stillborn baby. During the two-year period from the stillbirth three measurements were made, thus three questionnaires [95] and part of the questions are used in study I. The questionnaires were developed based on a review of literature in the field, and two focus groups with fathers experienced a stillbirth. Understanding of the questions was pilot tested by ten parents of stillborn babies and one obstetrician [95]. The questionnaires contained a broad spectrum of questions, both multiple choice questions with space for comments, and open-ended questions. The questionnaires were sent out separately to the mothers and the fathers, during the two-year period from the stillbirth: after three months, one year and two years. A letter was sent out to remind the mothers and fathers in order not to lose participants if no response was received; in all three reminders were sent. The data collecting was conducted from 2001-2003.

The first questionnaire, sent out three months after the stillbirth, consisted of 113 items that covered eleven areas: demographic data and self-rated psychological and physical health before the pregnancy (6 items), the pregnancy (22 items), care before delivery (6 items), the delivery and care during delivery (13 items), the stillborn baby (30 items), sick-leave (7 items), tranquillisers (3 items), any siblings (4 items), influence of grief on partner relationship (4 items), funeral ceremony (6 items), and well-being (12 items). The second questionnaire, sent out one year after the stillbirth, consisted of 55 items that covered nine areas: the stillborn baby (1 item), sick-leave (3 items), care from hospital staff (10 items), siblings and close relatives (4 items), friends and colleagues (1 item), influence of grief on partner relationship (6 items), sexuality (9 items), if any new pregnancy (9 items), and well-being (12 items). The third and final questionnaire, sent out two years after the stillbirth, consisted of 54 items that covered eight areas: the stillborn baby (2 items), care from hospital staff (2 items), grief reactions (4 items), sexuality (6 items), subsequent pregnancy (3 items), on-going pregnancy (14 items), subsequent child (11 items), and well-being (12 items). In the final question, of all three questionnaires the parents were asked how they felt about answering the questionnaire. The mothers and fathers could choose among multiple choice alternatives; some questions could be answered yes/no other had closed alternatives or was open-ended.

From the questionnaires, questions covering demographic data about the parents and the stillborn baby, grief reactions, grieving process and influence of grief on partner relationship are included in study I; these questions were multiple choices, with closed response options and space for comments. The items had either four response options ranging from *yes, to a high degree* to *no, not at all*, two response categories *yes/no* or were fixed. In the questionnaire at the two-year follow-up there is also one open-ended question included: *If you believe that you and your partner have reacted differently in grief - please say in what way.*

During recruitment time, 20 426 children were born in the five hospitals included. During the same period 81 mothers gave birth to 86 stillborn babies; 24 of the 81 mothers were excluded because of not understanding and speaking the Swedish language [95]. Of the remaining 57 mothers, 33 agreed to participate in the study, and 24 of their partners, that is fathers of the stillborn baby. Participating parents were recruited from the delivery wards of all five hospitals in the Stockholm area with maternity wards. Two fathers who had agreed to participate did not answer the

questionnaire and became non-responders. In the measurement after three months 33 mothers and 22 fathers participated, after one year 31 mothers and 18 fathers, and after two years 26 mothers and 15 fathers. Thus seven mothers and seven fathers did not complete their participation in the study, and became dropouts. The mean age among the participating mothers as well as the fathers was 33 years (range 24-42 years and 27-44 years, respectively), all either married or cohabiting. The stillborn babies were born between gestation weeks 22-43 (median 38 weeks); there were one pair of twins, both stillborn. Thirty of the mothers (91 %) and 20 of the fathers (91 %) held the baby, and 32 out of 34 babies were photographed. A funeral was held for 27 (79 %). For 15 (45 %) of the mothers and 11 (50 %) of the fathers the stillborn baby was their first child.

4.2.2 Study II

Recruitment was accessed through the Swedish National Infant Foundation where written information about the study was given through newsletters and on their website. The foundation is a member organisation of the International Stillbirth Alliance, and supports parents who have lost a baby before or after birth. Potential participants were able to contact the research group by email. All those who contacted, and met the inclusion criteria, received an information letter and when at least four parents in one local area expressed an interest in participating, a time and place for a focus group was agreed on. Before the focus group took place, the participants received written information about the method for data collection and the issues that would be discussed; informed oral and written consent was obtained before the discussion started. The focus groups were conducted between 2008 and 2010. Twenty-five parents participated in five focus groups, with three to seven participants in each group; the groups were mixed, with 20 mothers and five fathers. The mean age of participating mothers (at the time of the stillbirth) was 33 years (range 22-42), and for the fathers 39 years (range 34-41). The stillborn babies were born between 1987 and 2009 (median 2006) and they were born between gestation weeks 22-42 (median 39 weeks). The 25 parents represented 22 families, and in total, the 22 stillborn babies had 39 siblings. The median age of the siblings at the time of the stillbirth was six years (range 1.5-19). All the parents had seen their baby and 28 out of 39 siblings (72 %) saw their sister or brother. All the babies were photographed, in most cases with their sibling/siblings. For all of the babies a funeral or a memorial ceremony was held.

The focus groups took place in conference rooms in different parts of Sweden. They were conducted by two members from the research group: one moderator and one observer [96, 97]. The first author was the observer in the first session and thereafter the moderator. The opening question was *Please tell us what happened when you lost your baby*. The parents related their experiences and the focus group continued with questions designed to elicit a description of parenthood after stillbirth with the focus on the siblings' situation. An interview guide was used to ensure that the same basic line of inquiry was followed in each focus group. The issues were: sibling meeting and farewell, supporting sibling farewell, memories of the stillborn, advice to other parents who lose a stillborn baby and having siblings, and advice to health care professionals in care of the family. The participants were encouraged to talk freely, and when necessary the moderator asked follow-up questions. Each focus group lasted for 90 to 120 minutes, was audio taped and transcribed verbatim by the first author, with marks for silence, hesitation, crying, and other forms of communication.

4.2.3 Study III

Recruitment was accessed through the Swedish National Infant Foundation where written information about the study was given through newsletters and on their website. In addition there were advertisements in nationwide covered newspapers and journals addressed to parents. The parents were recruited consecutively over a period of two years. Data collection was carried out with two web questionnaires that were available on the Swedish National Infant Foundation website between 27 March 2008 and 1 April 2010: one questionnaire for mothers and one for fathers. The web questionnaires were originally developed for parents whose children had died perinatally, aiming to study mementoes, memory-building actions and parental identity after this loss. In collaboration between the researchers the study was increased in extent. The questionnaires were developed based on the review of literature in the field, the researchers' expertise and clinical experience. Understanding of the questions was pilot tested among mothers and fathers who had experienced stillbirth and were active in the Swedish National Infant Foundation. The questionnaires contained a broad spectrum of questions, both multiple choice with space for comments, and open-ended. The questionnaire consisted of 94 items for mothers and 82 items for fathers, covering demographic information about the stillborn baby (9 items), the diagnosis (7 items), the delivery (8 items), seeing and holding the baby (17 items), photographs and memories (17 items), the funeral ceremony, burial-place and anniversary (14 items), continuing bonds (3 items), questioned about grief and/or parenthood (3 items), sick-leave (1 item), care and support from health care professionals after the stillbirth (2 items), subsequent pregnancy and or children (6 items), self-rated psychological and physical health during the previous month (5 items) and in the final questions, the parents were asked to add anything they wished to comment on in the questionnaire and how they felt about answering the questionnaire. The mothers and fathers could choose among multiple choice alternatives; 42 items could be answered yes/no, 37 items had closed alternatives and rest of the questions were open-ended.

In total 1193 parents, 1034 mothers and 159 fathers answered the questionnaires. Inclusion criteria for study III were that the mothers and fathers should have experienced a stillbirth, have older children i.e. siblings to the stillborn baby, and answered the open question: *Did you have older children, siblings to the stillborn baby at the time of the loss?; If yes, please describe what advice you would give to other parents about siblings' farewell to their sister or brother.* A total of 811 mothers and 85 fathers replied to the open question included. After further exclusion of the mothers and fathers who miscarried (i.e. up to gestational week 22) and those who did not have older siblings before the stillbirth, 350 mothers and 61 fathers were remaining, hence 411 parents were included.

From the questionnaires, background questions covering the year of birth of the participating parent, year of stillbirth, gestational week, weight of the stillborn baby, and the open-ended question are included in the study. The participating mothers were born between 1938 and 1988 (median 1971). The stillborn babies were born between 1961 and 2010 (median 2004). The fathers were born between 1949 and 1981 (median 1969). Fifty-eight fathers (95 %) were present at their child's birth. The stillborn babies were born between gestation weeks 22-42 (median 37 weeks), of the babies, 46 (11 %) were born before gestational week 28 was completed and 365 (89 %) after that week,

the median weight of the babies born before gestational week 28 was 650 grams, and for the babies born later 3050 grams. Parental experiences of seeing and holding the baby state that 328 (94 %) of the mothers and 60 (98 %) of the fathers saw their baby, and 266 (76 %) of the mothers and 52 (85 %) of the fathers held the baby. 310 of the mothers (87 %) and 58 (95 %) of the fathers had photographs of their child and 305 (87 %) mothers had a funeral ceremony for their child, and for fathers 59 out of 61 (97 %).

4.2.4 Study IV

Recruitment was accessed through the Swedish National Infant Foundation and prospective participants contacted the first author by email. All those who contacted, and met the inclusion criteria, received an information letter and those who subsequently agreed to participate were contacted to make an appointment for the interview. Before the interview, the participants received comprehensive information about the method of data collection and the issues. Adolescents, under the age of 15 years could only be asked to participate after their parents had been informed and gave permission. Adolescent were to give their assent before they become involved in the research after being informed of its meaning. Informed oral and written consent was obtained from the adolescents or their parents in case of them being under the age of 15 years, as well as the adolescents' assent. The interviews were conducted in 2011 and 2012 by the first author and the interview setting was chosen by the participating adolescents (in their home, their school or in a private place at a café). The opening question was *Please can you tell me about what it was like when you lost your stillborn sister or brother?* The interview continued with questions designed to elicit their experiences of being the sibling in a family after stillbirth loss. An interview guide was used to ensure that the same basic line of inquiry was followed in each interview. The interview guide included the following issues: knowledge about the stillbirth, meeting and farewell, reactions, memories and reminders, care from the family and care from the health care professionals.

Thirteen adolescents (11 girls and two boys) participated and they were between 13 and 17 years old at the time of the interview (median 14 years), and between 11 and 16 years old at the time of the stillbirth (median 13 years). The stillbirth took place between 2007 and 2010 (median 2009) and the stillborn babies were born between the gestational weeks 28-42 (median 40 weeks). The adolescents' experiences of seeing and holding the baby state that all of them saw their sister or brother and all but one held the baby. All of them had photographs of the baby, and they had a funeral or memorial ceremony. Furthermore, all of the siblings were half-siblings to the stillborn baby, and all but one lived alternately with their mother and stepfather (8 out of 13) or father and stepmother, with their parents divorced. The participating adolescents' mothers or stepmothers were either diagnosed with an intrauterine fetal death before induction of birth or during birth. The time of diagnosis and the time between diagnosis and induction varied, yet in all cases of diagnosis before birth, the participating adolescents were told about the stillbirth at the time of the diagnosis. All but one of the participating adolescents had other bereaved siblings in their families. Each interview lasted for 30 to 90 minutes; they were audio taped and transcribed verbatim by the interviewer, with marks for silence, hesitation, and other forms of communication.

4.3 DATA ANALYSIS

In the thesis different approaches of content analysis were used for the qualitative data to reach knowledge of the loss influence by relating the content of the text to the context. In the text from the questionnaire questions (I, III), transcribed focus groups (II) and interviews (IV), the participants' experiences, thoughts, feelings and reflections were analysed. The analysis involved a stepwise systematic categorisation process that was oriented towards summarising the content and to find valid conclusions on the basis of the texts describing the experience of the loss of a stillborn baby (I-III) or sibling (IV) and its influence on the couple's relationship (I), parenthood (II) and siblings (II-IV).

The analysis was based on a procedure in line with Graneheim and Lundman [98] (I, II), Elo and Kyngäs [99] (IV) and Malteruds [100] (III) step guidelines. The different approaches broadly follow the same procedure; however, there are differences in steps and the description of concepts, and the level of abstraction. In the preparation phase of the analysis the unit of analysis has to be chosen, that is what is to be analysed, and after that the analysis is carried out in several steps. Firstly the data for each study were read several times in order to get a sense of the whole and become familiar with their content. The second step in all approaches was searching for meaning units, where statements that contained descriptions corresponding to the aim were identified. This step was conducted simultaneously with the next step of condensation (I, II) or transformation (III), when data were reduced by only retaining the essential parts of longer answers, with perceived meaning. As the statements were of different lengths, the compilation and condensation steps were intertwined, because some of the meaning units did not require condensation. The next step was grouping the descriptions together after they were compared for similar content and labelled with codes (I-IV). The coding was the bridge between the meaning units' text and further analysis, and meant that meaning units were abstracted (I-III) and labelled (I-IV). In the transition to a more interpretive approach, the underlying meaning was sought and codes formed categories (I-IV), which included codes with similar content. In the further analysis process (I, II, IV) the descriptive content constituted the base of the interpretation, this being to seek understanding of the codes and the categories' underlying meaning. In this process, the content of subcategories and categories formed themes (I, II) or a main category (IV). Meanings that emerged in the interpretation of the themes or main category were verified both in condensed meaning units, codes, subcategories and categories. The analysis was done in an interaction between the text and the context. Furthermore the analysis process was repeated back and forth between the original text, categories and themes or main category, and thus the analysis is not a linear process. The analysis was pursued by a self-critical approach to see alternative descriptions and/or interpretations. During the analysis, there was an open and critical dialogue in the research group until the final terms were determined. The final step also included that different categories were illustrated by quotations that demonstrated the variation in conceptions. An example of the analysis process is presented in table 2.

4.3.1 Study I

The aim was to describe the grief of mothers and fathers, and its influence on their relationship after the loss of a stillborn baby. Data from the multiple choice questions about background characteristics, grief response, the effect on the relationship of the

loss and ability to talk about the loss with the partner, were analysed statistically and are described using number, mean, median range and percentage.

Regarding comments to multiple choice questions and answers to the open-ended question, ten pages of transcripts (4 400 words) were analysed qualitatively using inductive content analysis inspired by Graneheim and Lundman [98]. In the preparation phase the comments and descriptions as a whole were chosen as the unit of analysis. This analysis was performed in several steps and firstly the whole text was read through to get a sense of its content, thereafter meaning units were established, condensed, abstracted and labelled with codes. Through comparison of the codes similarities and differences and seeing the underlying meaning, the codes formed categories and in the analysis three categories emerged. In the final stage of the analysis process all three emergent categories with content were collated to reveal the underlying meaning, on a more interpretative level. This was done by analysing the three categories in the light of whether or not they were satisfied in the couple relationship forming two themes.

4.3.2 Study II

The aim was to describe parenthood and the needs of siblings after stillbirth from their parents' perspective. The transcribed text, in all 148 pages (71 000 words), from the focus groups was analysed using inductive content analysis, as described by Graneheim and Lundman [98]. Firstly all text was read several times to get a sense of whole and its content. The transcripts was chosen as the unit of analysis and analysed as a whole, thereafter meaning units were identified, condensed and abstracted close to the text and labelled with codes. Through comparison of the codes' similarities and differences and seeing the underlying meaning, the codes formed subcategories. During the analysis seven subcategories were sorted into three categories, and in the final step of analysis the underlying meaning of the categories emerged in a theme.

4.3.3 Study III

The aim was to investigate parents' advice to other parents on the basis of their own experiences of siblings' taking leave of a stillborn baby. One specific aim was to study whether the advice differs between parents who lost their child early or late in pregnancy. The answers to the open question included were analysed qualitatively inspired by the Malterud analysis [100]. The data have also been processed quantitatively. The comprehensive description before and after gestational week 28 were analysed statistically by using number (n), percentage (%), standard deviation (SD), and the Mann-Whitney U test (p). Statistical significance was set at 95%. The interval for comparison between before and after 28 weeks of gestation was chosen, since the definition of stillbirth prior to July 2008 in Sweden was the birth of a baby after 28 completed weeks. Additionally that the meeting with an extremely preterm stillborn baby (born before 28 weeks of gestation) may involve special circumstances possibly related to attachment process and the baby's height and weight.

All text from the parents' answers, 40 pages, (16 000 words), together with corresponding biographic data, was firstly categorized according to whether the stillbirth occurred before or after gestational week 28. Thereafter the text was read to get a general sense. Meaning units were then identified and after labelling transformed

and abstracted meaning units with one of the codes that emerged during the analytical process, the number of statements in each code was counted, inspired by other researchers [101, 102]. For counting the number of statements, the codes were entered into Microsoft Excel and marked 1 or 0, for the presence or absence of the individual parent (binary index). Thereafter the tables with statements were gone through statistically, searching for differences between before and after gestational week 28. After this comparative analysis, which is reported separately, all the material was put together. By continuously comparing the codes for similarities and differences and after further abstraction and analysing the essence of concepts, a final description in terms of categories and subcategories became possible. In total, two categories and six subcategories emerged.

4.3.4 Study IV

The aim was to describe adolescents' experiences of being siblings to a stillborn sibling. The transcribed text from the interviews, 60 pages of transcripts (30 000 words) were analysed as a whole, using content analysis inspired by Elo and Kyngäs [99]. To make sense of the data, all the written material was firstly read through several times, and after that the text was read again and an open coding phase began, where content related to the aim was noted. Thereafter codes were grouped in subcategories by collapsing those that were similar and as a result of further interpretation and abstraction two generic categories and an overall main category that combined the categories, emerged. The two generic categories include altogether seven subcategories.

Table 2 an Example of the analysis process (IV)

Meaning Unit	Code	Subcategory	Generic Category	Main Category
Everything became so different at home, so it was hard. We were supposed to be a larger family and I wanted to have a sibling, but instead I got a very sad mom ... Mom disappeared for a while, as a mother ... She was like a black hole, I feel like we lost that mother-daughter relationship	Relationships	Changing relationships and roles	Finding oneself in a grieving family	Inside yet outside

4.4 ETHICAL CONSIDERATIONS

The project was ethically revised and all four studies have received the approval of ethical review boards: *The Regional Ethics Committee, Karolinska Institute* approved study I (reg. no. 41 01-014), and the *Regional Ethical Review Board in Uppsala* study II (reg. no. 2009/157) and IV (reg. no. 2010/435), and approval for study III was obtained from *The Regional Ethics Committee, Lund* (reg. no. 467/2006). Furthermore ethical considerations were continuously discussed throughout the project in order to raise consciousness to the potential impact of the work. Participants received written (I-IV) and oral (I, II, IV) information about the studies from the midwife at the delivery ward (I) or the moderator/interviewer (II, IV). After informed consent from the participating mothers, fathers, and adolescents with their parents, where the former were under 15 years of age, they were reminded again that participation was entirely voluntary and that they were free to withdraw at any time. All materials were made anonymously, coded and stored locked up. The personal information contained in the project has been treated confidentially. No data are to be traced to the individual participant and the results are presented anonymously. The web questionnaires (III) were answered anonymously; the IP numbers of the computers used were not saved and can thus not be associated with individual responses.

In all the interviews and focus groups extra time was allocated before and after the interview or discussion, in case a parent or adolescent needed further talk. The opportunity was also offered to contact the interviewer by telephone or email, in connection with the interview. Participants (II-IV) were also informed that they could contact the Swedish National Infant Foundation, which has a nationwide network of support persons. Participants in study I were invited to contact the principal investigator if necessary. Preparations had been made to take care of parents and adolescents, but none of them expressed such a need. In order to evaluate the parents' view on participating in studies I and III, a concluding question was added to the questionnaires about how they felt about participating.

5 RESULTS

The result section consists of a description of the results of each study, followed by a summary.

5.1 STUDY I

The study on the grief of mothers and fathers and its influence on their relationship after the loss of a stillborn baby led to the formation of two themes: *A movement towards togetherness* and *A movement of withdrawal*. The themes were formed when analysing the three categories: *Expectations*, *Expression*, and *Needs* in the light of whether or not they were satisfied in the relationship. Grieving, and its influence on the relationship, revealed for the mothers and fathers, when grieving immediately and gradually as individuals, and together as a couple. In this immediate and gradual grieving process, expectations of their own and their partner's way of grieving could pose a threat to their closeness as a couple. However, most of them shared their grief with each other with an understanding and supportive attitude, they thought the loss had affected their relationship, most of them became closer after the loss and that feeling deepened over the course of the following year (table 3 and 4).

A movement towards togetherness

Having initially experienced the stillbirth together, the parents expressed that they felt their relationship physically and emotionally deepened. They had gone through the loss together and in this common grief their relationship was strengthened. They expressed a sense of experiencing a special unifying bond. As time passed the mothers and fathers relationship gradually changed as they shared experiences of their loss. They came closer to each other in communicating openness and respect for the uniqueness of them as individuals, giving each other freedom to grieve in their own way. They each had a desire and a willingness to understand their partner. In this movement towards togetherness they expressed admiration, valued each other highly and showed understanding for their partner's different expressions of grief or that they being in different phases in grieving. This was experienced as nurturing acceptance in the couple supporting each other.

A movement of withdrawal

Initially the couple might feel disconnected from each other, when there was a lack of understanding for each other's grieving process and/or way to express their grief. Unsatisfied needs, expectations and communication, as time passed, could for some of the mothers and fathers create distance and feelings of having grown further apart following the loss. Hence there were feelings of withdrawal and sometimes feelings of loneliness in the relationship. A different approach in the grieving process created frustration and a feeling of grieving alone and it was difficult to express feelings to each other for fear of additional strain in an already strained situation. According to the parents, expectations involved in the dissonance in the couple's relationship were derived from gender role expectations in which the father was expected to be the strong one to support his partner, not showing feelings or showing anger, whilst the mother could show her feelings more emotionally. The mother's grief reaction was also

expected to be stronger and of longer duration than the father's, as the mother carried the unborn baby and was thus expected to have a deeper attachment to the stillborn baby than the father.

Table 3 Data from the multiple choice questions about loss influence on relationship; the results are presented in numbers (n)

	Three months after stillbirth			One year after stillbirth		
	Total n=55	Women n=33	Men n=22	Total n=49	Women n=31	Men n=18
Has the loss of child affected the relationship with your partner? *						
Yes, to a high degree	18	13	5	12	8	4
Yes, to some extent	26	17	9	30	21	9
No, not particularly	4	1	3	4	1	3
Not at all	5	2	3	3	1	2
No response	2	0	2			
How has the loss of child affected the relationship? *						
We have come closer to each other	43	25	18	41	25	16
The same relationship as before	6	3	3	3	2	1
We have come further apart	5	5	0	3	3	0
No response	1	0	1	2	1	1

* The question were not at the two year follow up

Table 4 Data from the multiple choice questions about grief respond; the results are presented in numbers (n)

	Three months after stillbirth			One year after stillbirth			Two year after stillbirth		
	Total n=55	Women n=33	Men n=22	Total n =49	Women n=31	Men n=18	Total n=41	Women n=26	Men n=15
Do you think that you and your partner grieves the child the same way?									
Yes	10	6	4	10	6	4	3	2	1
No	45	27	18	39	25	14	37	23	14
Do not know							1	1	0

5.2 STUDY II

The findings in the study on parenthood and the needs of siblings after stillbirth from the parents' perspective are represented by the theme: *Parenthood in a balance between grief and everyday life*. The balance involved an oscillation between being physically present and psychologically absent in trying hard to be a satisfactory parent. In the analysis three categories emerged that described the construction of the theme: *Support in an acute situation*, *Sharing the experience within the family* and *Adjusting to the situation*. And there were seven subcategories: *caring and guidance as a basis*, *meeting with the stillborn*, *taking farewell - a single event and a process*, *memories as a concretisation of what is abstract*, *the parents' passage through insufficiency*, *in a process of understanding* and *find ways and strategies*.

Support in an acute situation

In the subcategory *caring and guidance as a basis*, the parents expressed the need of that health care professional supervised and taking the leading role in caring as a foundation to enable them to handle their loss and future parenthood. The parents wanted to do what was best from the siblings' perspective, and they felt a need, even before the birth, for information on how to involve siblings afterwards. Parents emphasised the importance of guidance on how siblings might react on meeting their stillborn sister or brother, and on how the baby should be presented to them.

Sharing the experience within the family

In the subcategory *meeting with the stillborn*, the parents described the importance of informing the siblings themselves about the stillbirth, so that they could take care of the siblings' reactions and questions before their meeting with their dead sister or brother. Siblings of all ages experienced the stillborn sister or brother as lifelike by seeing, holding and touching the baby, it was important for siblings to have a picture of the dead baby according to the parents. The parents initially hesitating as to whether the siblings should meet the baby after birth described the meeting as natural and self-evident. In some families extended family members and/or friends additionally meet the baby, in those cases the parents thought it as positive, thus it increased support and added understanding for them and their children. The parents described that for the siblings *taking farewell was a single event and a process*. This event might have been a memorial ceremony or a funeral. Taking farewell meant for some siblings putting something like a teddy bear or a drawing in the baby's coffin. The parents described that the process of taking farewell was for the siblings an on-going process of keeping the stillborn baby lifelike within the family. The parents invited the siblings to participate in order to create an understanding of the family situation. They emphasised the importance of honest information related to the siblings' age and frame of reference, responded to the siblings' feelings and were sensitive and ready to talk. The parents also invited the siblings to participate in preparations for the funeral. Together with their parents the siblings chose the music, made and decorated the coffin, dressed the stillborn and put her or him in the coffin. In the subcategory, *memories as a concretisation of what is abstract*, the parents expressed that creating memories was an important part of sharing the experience within the family and to make the loss concrete. When the siblings created memories the baby took on a tangible form. The parents suggested that memories such as photographs or the grave could enable the

stillborn to take on a concrete form after having been an abstract semblance for the sibling.

Adjusting to the situation

The subcategory, *the parents' passage through insufficiency* indicates that parents had temporary feelings of insufficiency in their parenthood during their grief. The insufficiency was described as having difficulty in focusing on and meeting the needs of siblings, as well as a lack of strength to support them. Taking a wider perspective, parents were also afraid that their potential long-lasting insufficiency would affect the siblings' future health. They went through their grief with the desire that the siblings would come through the passage of grief with their health intact. The subcategory, *in a process of understanding* involved realising that some other children also had sisters and brothers that were stillborn. In ordinary life the siblings often felt excluded from being big sister or brother, but when meeting these children with the same loss experience they felt included. Furthermore the parents perceived that the siblings showed their understanding through actions. For example, siblings in younger ages would stand beside the empty crib, just looking or wanting to read books they had read exclusively during the pregnancy. The parents interpreted these actions as the siblings' way of showing loss as the beginning of understanding. The parents tried to *find ways and strategies* to handle their new changed life. They tried not to focus on their own grief so that they could be present for the siblings. According to the parents, daily routines created a sense of security for the siblings, and after the stillbirth daily routines disappeared, which were not beneficial. The parents therefore forced themselves to keep up with daily routines for the siblings' sake. The parents stated that the more people outside the family were involved in the loss experience the better it was for the siblings, because the siblings received more understanding, acknowledgement and support. The parents described finding ways and strategies, involving balancing their need to have time to themselves and having time together with the sibling. The parents often gained strength from the siblings' presence, thus they suggested that sometimes the siblings needed to rest from their parents' grief.

5.3 STUDY III

The findings in the study investigating parents' advice to other parents on the basis on their own experiences of siblings' taking leave of a stillborn brother or sister led to six subcategories, in parentheses indicates the number of statements for each subcategory: *experience the stillborn baby* (n= 335), *get siblings involved* (n= 329), *respect the siblings' feelings* (n= 199) *inform and communicate* (n= 147), *adapt to the siblings' age* (n= 131) and *create memories* (n= 92). The six subcategories formed two categories: *Make the stillborn baby and the loss real for the siblings* and *Take the siblings' resources and prerequisites into account*. Parents' advice is that siblings should see and hold their stillborn sister or brother and thus be invited and included into the leave-taking process with respect to their feelings, resources and prerequisites.

The comparison of the parents' pieces of advice according to the gestational week when the stillborn baby was born indicate that it was more common for parents with a baby stillborn after 28 gestational weeks to give advice falling within the subcategories *experience the stillborn baby* (p value 0.02) and *get siblings involved* (p value 0.01) compared to parents whose baby died in weeks 22-28.

Make the stillborn baby and the loss real for the siblings

The subcategory *experiences the stillborn baby covers advice about letting siblings meet* their stillborn sister or brother. The advice went from giving siblings the opportunity to see the baby; to letting them hold and touch. The parents emphasised the importance of making a meeting possible that would render the loss real – as it would help the siblings to understand that their sister or brother was dead. The parents thought that having her or his own image of the baby would make it easier for the sibling to mourn. The meeting with the stillborn ought to be prepared, though, and it might have to be repeated in order for the siblings to really understand that their sister or brother is dead. The subcategory *get siblings involved* comprises comments about letting siblings participate in the processes surrounding the stillbirth. By letting siblings participate actively in the funeral and the preparations for it, the unreal could become real for the siblings, according to the parents. Later in life, it was argued, it can be of importance for the siblings to know that they were present at the funeral, even if they do not have first-hand memories. Siblings meeting with the baby and the funeral can be prepared by talking about what the baby looks like and what is going to happen. It was adjusted that the siblings should have an adult at their side to support them, a person who can answer questions and take care of them if their parents, due to their own grief, are incapable of giving support. In the subcategory *inform and communicate*, the parents expressed thoughts that it was best to tell siblings early on that their sister or brother was dead. Correct and honest information ought to be adapted to the siblings' frame of reference. Abstract explanations should be avoided and the word death be used instead of circumlocutions. In order to increase the siblings' understanding and provide an opportunity to ask questions, the information may have to be repeated. The parents reflected that one should let the siblings talk when they feel like it, but invite conversations where they can give expression to their thoughts, questions, and emotions. The subcategory, *create memories* gather statements about acknowledging the baby by letting siblings create, collect, and preserve memories. This can be a confirmation that the baby existed and a way for the siblings to retain the dead sister or brother in their memory as they grow older, according to the parents. Photographs were of special value, especially if the siblings and the stillborn baby were on them together.

Take the siblings' resources and prerequisites into account

The subcategory, *respect the siblings' feelings*, comprises statements about being aware of the siblings' prerequisites and about being encouraging, but never coercive, when it comes to them meeting their stillborn sister or brother. The parents thought that one should encourage the siblings to participate on their own terms, trust their ability to handle their grief, take them seriously, and respect their standpoint. Older siblings can give expression to their needs, according to the parents, and no feelings, thoughts, or expressions should be taboo. The parents' advice to other parents is to view death as a part of life. The parents stressed the importance of confirming siblings' grief and additionally show how they feel themselves. Parents can explain how they feel, but siblings do not have to mourn in the same way. Additionally, confirming sister- or brotherhood was pointed out as important, siblings must be allowed to feel proud – they have waited and got a beautiful, though stillborn, sister or brother. The subcategory *adapt to the siblings' age* is about the children's age, maturity, and internal resources determining the level of participation in processes surrounding a stillborn sibling and

the leave-taking from that sibling. Siblings will have to take their own time to say farewell and their age and level of maturity also determine how and to what extent the loss needs to be concretised, according to the parents. Furthermore the parents expressed that play is to be encouraged, since children express and model their grief through play, which allows them to process their experiences, thoughts, and feelings.

5.4 STUDY IV

The results in the study on adolescents' experiences of being siblings to a stillborn sibling were represented by the main category: *Inside yet outside* which combines the generic categories: *Being bereaved* and *Finding oneself in a grieving family*. There were seven subcategories forming the categories: *grief reactions, feelings about life and death, otherness and perceived loneliness, broken expectations, participation and creating memories, be the child of bereaved parents* and *changing relationships and roles*.

Being bereaved

In the subcategory *grief reactions* the siblings expressed that they were not prepared when the stillbirth occurred. They expressed an inability to take in the incident, the stillbirth seemed an unnatural event to them, and some of them found it difficult to understand their own reactions. All adolescents articulated loss in different ways; some described the stillbirth with some distance. The adolescents expressed feelings of sadness and despair, injustice, helplessness, aggressiveness, and anxiety. Anxiety included worry for their mother/stepmother's health and a concern over time about what the future would hold now. All of the adolescents expressed that the loss did not affect their daily lives with for example schoolwork, at least not in long-term, though some stated that they could feel inattention just after. In the subcategory *feelings about life and death* the siblings described that the loss brought increased existential thoughts, concerns and questions. The loss brought feelings of grief that they could not quite define; their sister or brother had been in their lives, but still not quite. Some of the adolescents were able, with some perspective to see the loss enriching in their lives, and thought that they bear this experience with them in their future.

The subcategory *otherness and perceived loneliness* contain siblings expressions of the stillbirth's impact on their relationships with their family; they stated feelings of loneliness and/or feelings of otherness. The perceived loneliness came from the fact that they felt alone with their feelings, thoughts and concerns. The experiences of being alone in their grief could be strengthening by the fact that their parents were overwhelmed by their own grief and unable to master its functional role as parents to the full. In such cases, this meant a double loss for the siblings, who both mourned their lost sibling and their parents, albeit temporary, emotional unavailability. The perceived loneliness was also in relation to other members in the family in cases of absence of cohesion between siblings or stepsiblings or other extended family members. The adolescents also experienced feelings of loneliness in that they experienced feelings of being an outsider, excluded from the nuclear family loss. They were not fully involved in the family grief as children in a reconstituted family. Also, the 12 of the 13 who lived alternately with their parents related that they could in some way rest from the grief when at the unaffected parent's. Several adolescents reported that their strategy in dealing with loneliness was to seek support from someone who experienced grief, and

thus had additional understanding. Some chose not to share their feelings with their parents because they did not want to burden them. All adolescents however, shared the experience with their closest friend/friends. Some felt that their friend understood other friends expressed incomprehension which led to some increased distance between them. In addition some experienced that they were treated differently by their friends and that was something they did not want. They wanted to be like everyone else, still have their position and identity. The adolescents expressed that losing their stillborn sibling aroused feelings of *broken expectations* regarding the future as a larger family. During pregnancy the siblings had thought about what life with their sister or brother would be like. Now it was not as planned, and for most of them this brought up questions and thoughts about how different life might have been if their sister or brother had been alive. Furthermore, having a stillborn sibling brought up ideas about sibling relationships and whether they could still identify themselves as older siblings. It also raised questions about whether it was legitimate to grieve a sibling that they in some way had not known.

Finding oneself in a grieving family

In the subcategory, *participation and creating memories* the siblings described that they had been invited to participate in rituals after the loss. They emphasised the importance of not being excluded in circumstances surrounding the stillbirth. Although it differed as to how much involvement they felt comfortable with, they expressed the importance of their parents being encouraging, but never coercive. All adolescents met their stillborn sibling, and they expressed the meeting as naturally and enriching. This and the fact that the baby was given a name attributed identity and memory to the sibling as a person. Furthermore, all adolescents talked about rituals surrounding the remembrance of their sister or brother and described it as something they and their family gathered around and shared. They captured the importance of rituals and their endurance over time, however, for most of them it lost its impact a year or so after the loss. Furthermore, the baby's death was described as an open topic in all the siblings' families. They reported their families preserving memorabilia; they had something they brought with them that they lost. The adolescents described what it was like to *be the child of bereaved parents*. When the adolescents did not express their own grief in the same way and in some cases not as much as their parents did, it gave rise to feelings that they did not meet their parents' expectations of them as being bereaved. Some of the siblings stated that they had difficulty in finding their identity as a child of bereaved parents. They experienced feelings of being inadequate; they should feel more involvement with the family in their grief. In an effort to take care of their parents some of the adolescents expressed that they withhold their own grief, out of loyalty to and protection of their grieving mother or father. Additionally, some felt that their loss was just as significant, but was not recognised as such.

The subcategory *changing relationships and roles* indicate that losing a baby changed all of the siblings and their families, more or less. The adolescents report changes in all the members of the family and more specifically in their parents, and in the relationship with their parents. Some described the family as one family before the stillbirth and a different family after, and how the family members separated, each into their own grief. However, some of the siblings described that support from the family eased their grief and some sibling's impressions were that the family had come closer to one another after the loss. But there were also examples, of when the relationship

with others in their family hindered their process of grief. In these cases, the siblings described the occurrence of fights and blame. The adolescents furthermore expressed how the loss of a sibling meant that some of their roles changed, while others were added, which in turn characterised their attitude towards the family. The prospects for the relationship to the stillborn sibling changed, and there was also a new role from that of a sibling: they become a young person in grief. Regarding sibling relationships the adolescents expressed how some were able to share thoughts and feelings with another sibling or stepsibling. Siblings, who could share the experience, felt that they were allowed to be honest with their sadness, without having to take anyone into account, they also developed an inner strength in each other, thus giving each other support. Among the adolescents, there was furthermore a desire for orderliness; that everyday life would be as it was before the loss. At the same time, this feeling could bring feelings of guilt and dual loyalties could lead to conflicts between the adolescents' own interests and being with their grieving family.

5.5 SUMMARY OF THE RESULTS

5.5.1.1 Sharing the experiences of loss in a family perspective

The parents invited the siblings to participate in the processes surrounding the stillborn baby in order to create an understanding of the family situation (II-IV). Additionally the adolescents stated the importance of not being excluded in circumstances surrounding the stillbirth. Although it differed as to how much involvement the adolescents felt comfortable with (IV), parents should be encouraging, but never coercive (III, IV). The child's age, maturity, and internal resources was determining the level of participation (II, III). By letting siblings participate actively in the funeral and the preparations for it, the unreal could become real for the siblings, according to the parents (II, III). It could later in life be of importance to the siblings knowing that they were present at the funeral, even if they do not have first-hand memories (III). Furthermore the parents expressed that it was best to tell siblings early on that their sister or brother were stillborn. Correct and honest information ought to be adapted to the siblings' frame of reference (II, III). Abstract explanations should be avoided and the word death be used instead of circumlocutions (II, III). In order to increase the siblings' understanding and provide an opportunity to ask questions, the information may have to be repeated. The parents responded to the siblings' feelings when they were sensitive and ready to talk, and they invited the siblings into conversations where they could cry and receive consolation (II-IV).

Siblings that met their stillborn sister or brother experienced the baby lifelike by seeing, holding and touching the baby (II-IV). Parents or siblings, who before was hesitating whether siblings should meet the baby, described the meeting as naturally, enriching and self-evident afterwards (II, IV), the meeting ought to be prepared though (II, III). The parents emphasised the importance of making a meeting possible that would render the loss real, for siblings to have a picture of the stillborn baby, thus provide a personal bond or connection and enabling the stillborn baby to be more concretised (II-IV). When the siblings created memories the baby was acknowledged, took on a tangible form, and this brought with them the baby that they lost (II-IV). Furthermore, parents and siblings expressed feelings of broken expectations regarding their expectations and thoughts of becoming a larger family, for themselves as parents and for the siblings not becoming big sisters or brothers (I, II, IV). Additionally being a

sister or brother to a stillborn baby brought up ideas about sibling relationships, and whether they could still identify themselves as big sisters or brothers (II-IV). It also raised questions about whether it was legitimate to mourn a sibling that they in some way had not known (IV). Confirming sister- or brotherhood was pointed out as essential (II-IV). Siblings must be allowed to feel proud – they have waited and got a beautiful, though dead, sister or brother (II, III).

5.5.1.2 The impact of loss on family relationship

All studies indicate that the loss of the stillborn baby had an impact on family relationship. The parents and siblings expressed that they were grieving both as individuals, alone, and together with other members of the family. They went through the loss together, developed an inner strength in each other, thus giving each other support and in the common grief the family relationship was strengthened (I-IV). Parents expressed that they got strength both from their partner and from the siblings' presence, together with partners and/or siblings the parents, children and adolescents were able to share feelings and they could together express grief. They came closer to each other and shared their grief with an understanding and supportive attitude (I, II, IV). However, expectations of their own and other family members way of grieving could pose a threat to their closeness as a couple (I) or family (IV) when there was a lack of understanding for each other's grieving process, way to express grief or their needs, thus creating a distance. Both mothers, fathers (I, II) and adolescents (IV) expressed feelings of sometimes being alone in grief and it was difficult to express feelings for fear of additional strain in an already strained situation. Further, parents expressed feelings of insufficiency in their parenthood (II). The insufficiency was described as having difficulty in focusing on and meeting the needs of siblings, as well as a lack of strength to support them. Thus parents were overwhelmed by their grief and unable to master its functional role as parents fully (II, IV). Additionally parents and adolescents described feelings of guilt not being there for their partner or affected parents and other siblings as much as they should (I, IV). Both mothers, fathers (I, II) and adolescents (IV) stated experiences of how to handle and in some cases withhold their own grief in relation to others in the family. Parents tried not to focus on their own grief so that they could be present for the siblings (II), the adolescents sometimes withhold their own grief not burdened their affected parents (IV), and in the couple relationship some parent kept their grief within themselves (I). However the parents stressed the importance of confirming siblings' grief and also being able to show how they felt themselves (II, III).

6 DISCUSSION

6.1 RESULT DISCUSSION

The overall aim of the thesis was to study the loss of a stillborn baby from the perspective of parents and siblings. Results from the studies indicate that parents strive to create an environment in which siblings are confidently allowed and invited to participate in processes surrounding the stillbirth in order to create understanding of the family situation.

6.1.1.1 Meeting a stillborn sister or brother

Most parents and all of the adolescents expressed good experiences of letting siblings/ themselves meet their stillborn sister or brother. Further, all of the adolescents expressed good experiences of meeting the stillborn baby. The meeting was described as natural, enriching and self-evident and an important component to create understanding, thus attributing identity and personality to the baby. The results support that by seeing and holding the baby, the siblings gain insight into the fact that their sister or brother was dead. It has previously been argued that understanding death is an important component when recovering from bereavement, and put into practice by being encouraged to meet the stillborn [4, 36, 103,], further confirmed by similar studies on the importance of parents meeting and holding their stillborn baby [3, 86, 104-106]. In addition parents emphasised the importance of guidance from health care professionals as to how siblings might react and how to present the baby.

A larger share of the parents with a stillborn baby lost after gestational week 28 gives the advice that siblings should see and hold the baby and participate in processes surrounding the stillbirth compared to those with losses in earlier gestational weeks. This can be related to the fact that an extremely preterm baby is smaller and that its sibling may not have grasped yet that she or he was expecting to be a big sister or brother, which is why the parents may be more restrictive with advice concerning meeting and participation [91, 107]. This is linked to another important issue, namely that of how the parents and their children acquired knowledge about the fact that the baby was to be stillborn. In the thesis there are differences in this; the parents and siblings acquired knowledge about the fact that the baby was dead either before (antepartum) or during birth (intrapartum); giving different time to be prepared.

6.1.1.2 Talking about the stillborn baby

The parents strove to create a place where the siblings were confidently allowed to grieve and the siblings were invited into conversations where they could cry and receive consolation and acknowledgement. This can be related to the importance of siblings talking to a caring, supportive person they trust [108]. In order to enhance the siblings' understanding of what has happened in the family their parents emphasised the importance of being honest and responsive when the siblings' were sensitive and ready to talk, further providing siblings with accurate and honest information in a way suitable for their frames of reference. Similarly, Dyregrov [34] emphasised the importance of giving the same information to all family members in order to improve the communicative climate between parents and children. Several researchers have

additionally pointed to the importance of communication between family members as a way of helping in bereavement [34, 103, 109, 110]. Furthermore some parents thought that participation in certain events should be repeated; a child may feel the need to see and hold the stillborn baby on several occasions. Information and communication may have to be repeated, and be adapted to the siblings' age, needs, and understanding. Stroebe and Schut's [26] approach to dealing with loss tallies with this. They describe the double approach of evading and confronting a loss. Such an approach gives the grieving child the possibility to measure out the grief over time [26], since children mourn according to their age-related level of development [31, 34, 111, 112].

6.1.1.3 Rituals surrounding the stillbirth

In the studies rituals concerning the stillbirth were important. Drawing on interviews with the parents of 19 deceased children, some of them stillborn, Cacciatore and Flint [113] argue that rituals after the death of a child enable parents to retain a link with the stillborn. In present studies one can see that rituals can be intentionally tailored to bring siblings into full participation with other family members, thus creating further opportunities for meaningful memories. Similarly, rituals and memories have previously been described as important for the grief [103, 109, 113, 114], and this is supported by the thesis' findings of the siblings' participation in sharing experiences within the family and together with others. This is confirmed by other researchers [73, 103, 109] indicating that rituals involve dimensions of meaning-making, intention and participation, and lead to the fact that the siblings have a story to relate. The present studies as well as previous research [114-116] further revealed that through rituals, children can give words to feelings, give sights and sounds to relationships and become a part of the family's experience. Both formalised rituals, such as naming- and memorial ceremonies and funerals, and informal rituals, such as reflecting or interacting, can be used, helping the parents, children and adolescents to connect with the stillborn baby in special ways. Additionally the results indicated that when the parents and siblings created these memories, the baby was acknowledged, took on a tangible form, and this retained the memory of the baby that they lost. Côté-Arsenault [114] describes these remembrances as the families' way to have their stillborn remain a visible part of their lives and Layne [117, 118] argues that the retention of material traces of the unborn child enables the family to legitimate their grief.

6.1.1.4 Continuous bonds, new sibling and parent identity

The stillborn baby was a natural part of the family lives, albeit not physical; there was a psychological presence of the baby. Cacciatore, DeFrain and Jones [119] reported results in their study of the ambiguity surrounding stillbirth for siblings, through a retrospective, anonymous compilation of group responses of a range of family members. The results of the present studies, and another [59], support their tentative conclusions that the death of a stillborn baby is in some way invisible and ambiguous, as there is no physical presence of a relationship, and are in line with the construct of ambiguous loss, a loss that in some way is unclear and does not have external validation [68, 71]. In addition the siblings and the mothers and fathers all struggle to define the enduring relationship with their stillborn, a relationship that in some cases is unnamed and unacknowledged. This can be understood as what Howarth [61] suggests

that in stillbirth losses it seems that bereaved parents need to construct a biography for their stillborn and, in doing this, retain the baby's place within the family.

Murphy and Thomas [120], in their interview study of parents of 22 stillborn babies, found expressions that referred to continuing bonds with the stillborn. The parents created a biography for the baby which was then shared with other family members. This led, in keeping with results in present thesis, to siblings considering their own lost role and relationship with their stillborn sister or brother. The stillborn was in some degree integrated into the family, and the siblings described something that can be seen as a kind of continuing bond. This is in line with other studies [58, 59, 119], in which the notion of continuing bonds with a sibling not physically known is described. Additionally, continuing a bond with the stillborn may, for bereaved parents, reinforce their sense of being a mother and father. This can also be related to arguments that in cases of stillbirth the dead baby does not leave behind a trail of existence; a stillborn baby lacks the material traces of social life [121]. However, as there is no physical presence of a relationship, the stillborn is in some way invisible. This is similar to recent findings in a focus group study with bereaved parents' experienced stillbirth, who reported that their loss was recognised but not as parents who had lost a child [122], and confirmed by Murphy and Thomas [120] who similarly found that especially parents who lose their first child in stillbirth have to struggle with their identity, and thus their identity as a parent is dependent on a relationship with a child. They feel they are parents, yet society does not view them as parents.

As the results of the present thesis further indicated, the changed, lost, and new roles are related to and relevant for how the family members experience their own identity and self-image. This, in accordance with what Goldblatt [123] in her thesis of adolescent sibling bereavement argues, could lead to parents and siblings experiencing uncertainty about their own identity; the new role as a bereaved person imposes a new identification. Mandell, McAnulty and Carlson [124] found similar results of new roles terminated on interviewing 26 families bereaved after their infants' death while having older children, siblings to the dead baby.

Additionally having a stillborn baby in the family could lead to the fact that siblings, especially those without other siblings, could feel excluded by not being able to be a big sister or brother. Hence, sharing their experience with other children who have experienced a similar loss and realising that those other children also had stillborn sisters and brothers gave them comfort and support, and they felt included, as previously discussed by Fanos, Little, Edwards [109] and Wilson [103]. This is in accordance with similar studies on the parents' need to share their experience of stillbirth with others who have experienced a similar loss [6, 125, 126]. Furthermore, having an invisible sibling never known makes them important as memory keepers of their unknown sibling [59]. Having the stillborn as a part of the family and memory is reflected in the thesis, but for most of the adolescents the continuing and strong personal connection with their stillborn sister or brother is most conspicuous during the first year after the stillbirth.

6.1.1.5 Continuous bonds and new family identity

The family changed with the loss and the results provide insight into how this change impacted into the family members' daily lives and shaped the way they related to one another. It is apparent that siblings in bereaved families are in a precarious position: not

only do they lose their expected sister or brother, but the results reveal how the loss of their baby sibling meant a temporary loss of their parent's parenthood as well, which is confirmed in other studies [64, 65, 127]. This was at a time when many of the parents were preoccupied with their own grief, not being able to attend to their needs. Similarly, Crehan [128] mentions this absence of parents for the siblings after the loss of a child. However, the results indicate that the parents in their parenthood tried to balance their own grief in order to ensure their children's emotional wellbeing; the parents needed to find this balance between grief and everyday life. This is in line with the perspectives on grief, meaning that everyday experiences of the mourner's time are necessarily focused on other activities not related to the deceased [26]. Additionally most parents were aware of their children's situation, being afraid that their temporary insufficiency would affect the siblings' future health. Thus the parents feel that they are left somewhat alone in their parenthood after the stillbirth and therefore need support and guidance. This is similar to recent findings in an interview study with 25 parents who reported loss of faith in their personal capacity to function effectively in their family lives [129]. In addition, the siblings are in some way forgotten when most of the attention is put on the parents. Or sometimes one partner in a couple, or the child, feels as though they have to deny their grief so that they do not become more of a burden to their already over-burdened partner or parents. In relation to the loss, some of the adolescents mentioned this kind of before and after scenario to their family. The families needed to redefine themselves after the loss; Roose and Blanford [67] describe this as a changed dynamic in the home. Furthermore it is also conceivable that as a result of the changed dynamic in the families, the mothers, fathers and children take on a more responsible role towards their partner/parents and an associated notion that they have to be as good as possible for others in the family, and the adolescents experiencing increased feelings of responsibility to be there for their parents and other siblings. This is in accordance with Rosen [130] who reports that children and adolescents are loyal to their parents in loss, them being the good child, the one who will never leave.

6.1.1.6 Grieving together and alone

The children and adolescents often looked to their parents for response and support in the loss experience, making the family environment important for them. Davies [131] suggests that one of the best ways to encourage cohesion in a family is to include all the members in the grief. In the present studies the parents and siblings expressed that they were grieving both as individuals, alone, and together with other members of the family. They went through the loss together, developed an inner strength in one another, thus giving one another support, and in the common grief the family relationship was strengthened. At the same time, the parents said that they sometimes needed to grieve alone as their experience was different from that of their partner. This is confirmed by the Toller and Braithwaite [132] description that bereaved parents need to grieve both together and apart. In addition, most adolescents described the difficult act of family members engaging in listening to one another after the loss. This can depend on the fact that within the family, various family members have different relationships to the stillborn baby; someone is grieving her child, another unborn sibling, which can lead to difficulties in understanding and supporting one another. Additionally results indicate that mothers, fathers and siblings could also have different grief processes leading to increased risks of conflicts between them. Everyone could

feel misunderstood, alone and excluded; this is a crucial element in the communication process. Gilbert [62] suggests supportive communication to facilitate the discussion of thoughts and emotions, making it easier for family members to disclose their beliefs about the loss and the meaning for each of them. Differences in grieving do not always have to be harmful to the relationship, and can enhance communication and the relationship itself [56].

However there is a lack of willingness sometimes to understand and face one another in the loss experience, and this can become a threat to their unity as a couple or family and lead to feelings of withdrawal. This experience is supported by other studies [57, 132, 133], and can create conflicts and lead to beliefs that the individual feel alone in their experience. Some researchers have argued that whether a relationship will be strengthened or negatively impacted following the death of a child depends on the climate of the relationship prior to the loss [12, 74]. This can also be related to the adolescents' description as if they were outside, not fully involved in the family grief. All but one lived alternately with their mother or father in a new family constellation. Hence, it is not their nuclear family loss; it is one of their parents who lost a baby along with a stepmother or stepfather, leading to this feeling of exclusion. Additionally, the adolescents expressed feelings of being alienated from the outset not being really included in the new family and having a foot in another family. Similarly, studies demonstrate the difficulties of creating good relationships in new family structures [134-136]. Families become more complex when expanding through remarriages, with the addition of stepparents, stepsiblings and half-siblings. Then, when the loss and grief appeared, this exclusion was extended for the participating siblings. Hence, support plans for grieving families might take into account how well connected a child feels to her or his family and how the family functions [49, 137].

Even though most of the bereaved parents expressed the fact that they grieved differently from their partner, most of them, however, were able to accept this and expressed a degree of tolerance and respect for the style of the other, which allowed them to become closer together in sharing their loss. Toller and Braithwaite [132] similarly found that couples who accepted their individual needs were more connected as a couple, making it easier for them to grieve together. Many parents, in the present thesis indicated feelings of renewed closeness, while a few others struggled to connect emotionally with their partner. This may have to do with the uniqueness of grieving styles [51, 55, 56, 62]. Additionally expectations, expressions and needs involved in the dissonance in the couple's relationship resided, according to the parents, among other things in gender role expectations. However, gender differences in bereavement have a likely and plausible source in a combination of causes [138, 139]. There are several possible explanations that may contribute to gender differences in grieving, for example differences between mothers and fathers in the bond of attachment, which was expressed by some parents and supported by other research studies [50, 56, 140, 141]. The difference may also be due to differences in gender-role socialisation, social norms and culture [52, 54, 62, 132, 142]. It is suggested that one should look beyond gender to understand different patterns or styles of grief. These patterns could be related to gender but are not determined by them. Martin and Doka [12] describe gender, culture, and initial temperament all interacting in producing patterns of grief, and they describe three basic patterns: *intuitive*, *instrumental*, and *dissonant* [12]. In one of the studies in this thesis one can assume that most mothers expressed their grief intuitively, while

most fathers fell into the instrumental group; hence gender may contribute to a particular grieving style due to socialisation and cultural influence.

6.2 METHODOLOGICAL CONSIDERATIONS

The aim of this thesis was to study the loss of a stillborn baby from the perspective of parents and siblings. Based on this objective, the qualitative approach was mainly chosen, giving an opportunity to highlight the participants' individual experiences, and thus trying to capture the complexity that exists in such an event. Furthermore qualitative approaches provide options for accomplishing a deeper knowledge of an issue and that level of detail can for example be established by either talking directly to the participants or asking them to write down their experiences. Hence, questionnaires (I, III), focus groups (II) and individual interviews (IV) have been conducted, where parents and siblings describe their experiences.

6.2.1 Data collection

6.2.1.1 Questionnaires (I, III)

In the thesis two questionnaires studies (I, III), parts of questionnaires, were used, and since they do not form an entirety, it is important to display both the questions used, and the subject areas that each questionnaire consisted of, to illuminate the questions in their context. Furthermore we have taken the questionnaire questions for the study from questionnaires previously designed [95], and therefore it was not possible to influence the framing of the questions used in study I. For example, the participants were not asked, at the two-year-follow up questionnaire, about the effect on their relationship of having a stillborn baby. Additionally, it is a weakness regarding the questionnaire used in study III that the parents' advice cannot be related to the siblings' age at the time of the stillbirth, since this information was not asked for; hence the questions used were not the main purpose of the questionnaires, i.e. the focus was on the care and mementoes of a baby who died perinatally.

The advantage of questionnaires is that they can give answers from a large number of respondents since there is an additional time-consuming element. The disadvantage may be that the issues are dominated by the researcher's pre-understanding the selection and design of the questions. The risk is also that respondents interpret the questions differently [143]. One way of minimising these problems was that before the main questionnaire pilot studies were made for both the questionnaire studies. Hence to improve validity and consistency of the questionnaires they were tested for face validity on parents who experienced a stillbirth (I, III) and on an obstetrician working with this issue (I). The questionnaires were well understood and easy to use. Furthermore, the inclusion criteria were specific, in order to minimise any bias in the studies. In the design of questionnaires, there are usually two main options; closed response questions with structured answers, giving participants the opportunity to grade their response, or open-ended questions in which participants freely formulate their answers. These responses often cause a significant complement to the questions with closed responses. Through open-ended questions important comments, explanations and valuable insights can be obtained when the participants in their own words describe their experiences and perceptions, which are otherwise difficult to capture using closed response questions only. Therefore it is also advisable

to have space for comments and open-ended questions in addition to other questions, as was the case in the questionnaires used (for the web questionnaire the space was almost endlessly), and upon which the qualitative findings are based.

The use of web questionnaires (III) does present challenges in terms of applying traditional questionnaire research methods [144]. The advantages of using web questionnaires include access to individuals in distant locations, the ability to reach participants who are difficult to contact, and the convenience of having automated data collection, which reduces researcher time and effort. The disadvantages of web questionnaire research include for example uncertainty over the validity of the data and sampling issues, and concerns surrounding the design, implementation, and evaluation of a web questionnaire [145]. Although many of these problems are also inherent in traditional questionnaire research, some are unique to the computer medium. When conducting online research, researchers can encounter problems as regards sampling. Thus the participants for study III were self-recruited; there are no guarantees that a participant did not answer the questionnaire twice. Furthermore, the fact that the web questionnaire was answered anonymously means not knowing whether the participants from studies I and II, and if so how many of them, also replied to study III. Non-response rate tracking can also be difficult to ascertain in online communities. Self-selection bias is another limitation, since in any given Internet community there are some individuals who are more likely than others to complete a web questionnaire [144, 145].

The strengths of study I were the population, the considerations of the needs of both parents following the birth of a stillborn baby, and the longitudinal approach with data gathered at three months, one and two years after the stillbirth. However, the fact that data collection took place some considerable time after the stillbirth could have had an impact on the parents' perceived grief and their relationship. Another disadvantage with studies extending over a longer period can be that many participants may drop out; in study I, 68% of the fathers and 78% of the mothers remained at the two-year follow-up. One can reflect as to which parents continued their participation; Stinson et al. [142] speculate in their study that the parents who continue to participate may be those who are most affected by the loss, but it could also be those who experienced their relationship as strengthened and therefore wish to communicate their experience. The strength of study III is the large amount of advice that has been collected and described. The advice comes from a large group of parents who have experienced a stillbirth while at the same time there are older siblings of the stillborn.

6.2.1.2 Focus groups (II)

The use of focus groups for the study seemed suitable, as it is an appropriate method when wanting to use group dynamics in order to obtain as many thoughts and experiences from the objective as possible and to facilitate open discussions among the participants [146]. Focus groups afford the opportunity for multiple interactions, not only between an interviewer and respondent, but among participants in the group, and unlike an individual interview, the group members influence one another by responding to ideas and comments, which can develop and clarify opinions [97, 147]. An alternative method that could have been considered was to conduct individual interviews. Thus, interviews might have given deeper knowledge about the phenomena which were studied i.e. some participant might have refrain to add information they

find very private could have produced different results. However, the interaction between the participating mothers and fathers discussing their loss experiences was dynamic, and agreements and disagreements emerged, which was deemed enriching. Advantages of focus groups are that they are focused and that the method can encourage people who otherwise would not feel that they had something to say about their experiences.

An interview guide was used and it was seen as essential in conducting the focus groups for keeping the interaction focused while allowing individual perspectives and experiences to emerge. In a study based on focus group discussions, Krueger [146] recommends that at least three focus groups are included, while Morgan [97] argues that a greater focus group project includes five groups. The recommended number of participants in each group also shows variation [96, 146, 148]. Very much indicates, however, that the group should not be too large; all participants must be involved in a conversation and everyone's attention should be retained. In addition it is easier to give and receive feedback in a small group, and time allows everyone to be able to express their opinion, ask questions and respond to other group members' comments. The number of participants per focus group in study II was found suitable; there was an interaction in which all the participants were involved, thus eliminating the risk of frustration resulting from participants not having enough time or opportunity to express themselves.

It is of importance that the participants in a focus group feel safe and comfortable to speak their minds. Given this it was considered a suitable way to have the participants recruited through the Swedish National Infant Foundation and thereby have the participants' confidence when the study was sanctioned by the Foundation. Furthermore how useful data generated from focus groups is largely dependent on how participants feel before sharing their thoughts and experiences in the group. Hence, the time before the focus group starts is important so that participants would feel at ease and prepared to begin, and in all the focus groups there was a relaxed atmosphere with small talk before the focus group began. Furthermore, several focus groups were conducted, which increased the credibility of the research. One disadvantage of focus groups could be that one individual may dominate the group [149]. A tendency of this was seen in one of the groups, but as the moderator was knowledgeable about the technique, the other members soon got involved.

6.2.1.3 Face to face interviews (IV)

In study IV qualitative face-to-face interviews with an interview guide were selected for data collection. A qualitative research interview is a structured conversation conducted in a specific aim and according to Kvale and Brinkmann [149] constructs knowledge just by the mutual interaction between the researcher and the person being interviewed. The purpose of interviewing is to enter another person's perspective, a perspective that is meaningful, knowable, and able to make explicit. Using an interview guide involves outlining a set of issues that are to be explored with each respondent before interviewing begins, and although structured it is flexible in its composition. There is a lack of consistency in the way research questions are posed because researchers can change the way to pose them. The interviewer is able to ask follow-up questions based on responses to pre-constructed questions. Building trust is a necessity when interviewing, and it requires respect, acceptance and understanding on the part of

the interviewer [149]. As an inexperienced interviewer of adolescents, albeit with the capacity to listen and encourage them to share their experiences, it was valuable to have a course in research methodology regarding children and adolescents prior to conducting the interviews in order to counteract the factual inexperience. In addition, there were discussions within the research group, and also individual conversations with one of the co-authors; an experienced psychologist clinical working with bereaved children and adolescents, to increase awareness about the role of the interviewer.

Conducting interviews in an area that arouses feelings is in addition not easy, so it is important to try to make participants feel at ease, understand the issues and have enough time for reflecting on their experiences [149]. One advantage of this approach meant that the researcher could read the communicative nuances in the participant's body language and tone of voice. However, this interview situation places higher demands on an awareness of the signals that the interviewer sends out to the participants, both in a verbal and non-verbal communication plan. For some of the adolescents, particularly the younger, it was important to have the opportunity to include small breaks in which they had the chance to reflect on their answers. The time before and after the interview was also important so that they would feel prepared to begin and to end. Furthermore there was a wide spread regarding how much the various participating adolescents told and shared. Most of them shared their experiences generously, but for others it was more difficult, thus leading the interviewer into giving more precise follow-up questions. Many previous studies that illustrate the siblings' situation after stillbirth are based on interviews of parents [103, 150, 151]. By the siblings in this study having to tell about their experiences in own words, their own experiences could become available and better understood. In research with children and adolescents the perspective has changed to involve them and get information directly from them. Previously there has been a tradition not to include children and adolescents in research, because they should be protected from any discomfort or because children were considered not to be able to express what they think and feel. Children and adolescents were later involved, more as informants in research, though research is no longer just doing research *on* children, but *with* them [152]. The importance's of using age-appropriate methods was considered but since the participating adolescents were 13 years and older, in addition to facilitating relationships and adapting linguistic concepts, no other age appropriate activities were needed.

6.2.2 Analysis

In this thesis data collection has been done in consistency with the qualitative approach, and the method of analysis has been based on the purpose of the study and in compliance with the analysing data allowed. The process of data gathering, analysis and reporting has been permeated by a striving towards openness to the research question and during the process there have been an awareness of and reflection on the circumstances studied. When analysing, the ambition has been to describe the content as well as to clearly describe the analysis process.

For study IV inductive content analysis was used supported by the reference method [99], to systematically describe and find meanings and summarise the contents of data [102, 153, 154]. A stepwise analysis was performed with the purpose of making sense of the data, identifying codes and categories, in relation to the study. The process

of content analysis described by Elo and Kyngäs [99] provides a description of how to practically conduct either an inductive or a deductive analysis. The decision concerning which approach to employ came after the transcribed text had been read several times to get a sense of the whole. In study IV the choice was that an inductive analysis should be used to arrange the data, hence the text seemed to offer more levels than could be reached with the deductive approach. The steps in the analysis process allowed the movement between the analysis of the material as a whole and focusing on particular sections of the transcribed text at all levels of abstraction. Thus the abstractions and eventually the findings were confirmed by constantly going back to the original data and listening to the audio tape-recording and reading the transcriptions. Elo and Kyngäs [99] state that the analysis process should continue as far as is reasonable or possible, which was the starting point when the analysis process was discussed within the research group.

In studies I and II, a more interpretive approach was used [98]. It was done with analysis where the aim was identified and presented as themes which formed the basis for reflection. The analysis method gave the opportunity to move back and forth between the material as a whole and specific parts of the material at different levels of abstraction. It was considered important to perform such an oscillation between the transcriptions in order not to lose the content of the text, and thereby confirming the analysis. Since answers to open-ended questionnaire questions, comments to multiple choice questions and focus groups represent a kind of data collection that does not generally give in-depth information [143], content analysis as described by Graneheim and Lundman [98] was considered to be a suitable method, because it can be applied to data with variable depths. However, it is the data that constitute the determining factor of how deep the analysis can go, and a more interpretive analysis was conducted in studies I and II in order to reach the full depth of the data. In study III Malterud [100] was selected as an inspiration for the analysis, when it seemed appropriate for the purpose of the study, by keeping the analysis descriptive, close to the text, and additionally that the collected material consisted of short statements from a large number of participants. For all studies in the thesis, the final interpretation is reasonable but not universal [143]; thus a text involves multiple meanings and when approaching a text there is always a degree of interpretation [98]. Furthermore content analysis is flexible in terms of design, and can be applicable in various depths [98]. Hence the analysis included was found to be congruent with the aim of the studies.

However, another qualitative method could have been used, presented descriptions that could have been differentiated if tied to their context or perspective than the content analysis description. Additionally, in retrospect Malterud [100] had probably not been the chosen approach for study III, and thus it seemed more appropriate to go to the original source for inspiration [155, 156]. In all the studies the analysis approaches used was carefully described to ensure that the process could be followed. It should be emphasised that although a different understanding may emerge in the light of alternative approaches, the possible interpretations of the text vary in terms of credibility. During the analysis process the findings and interpretations made were thoroughly scrutinised, and critically reflected upon, in conjunction with the existing literature as well as the knowledge held by the researchers within the research group.

6.2.3 Issues of trustworthiness

The trustworthiness of the studies has been considered through a description of the context, data collection and samples, and by describing the analysis process. Additional steps to enhance trustworthiness have been taken, resulting in a reflection as to whether the correct questions (I-IV) and interview techniques (II, IV) were used and compliance with what the text says. Trustworthiness includes concepts such as stability and credibility. The research group discussed the analysed data in order to ensure that the descriptive categories and themes are in accordance with the data material. The texts for each study were read a large number of times to achieve stability [102], and discussed by the co-authors and in research seminars proportionately to each study and its method, to strengthen their credibility [98]. When carrying out various forms of interviews, it is important to differentiate between therapeutic and research situations [149] and to maintain the research identity during the interviews (IV) and focus groups (II). The researchers had no established relationships with any of the included participants. While an established relationship could help participants to feel secure and comfortable, it may at the same time increase the likelihood of the interviews or focus groups becoming therapeutic or preventing the protection of the researcher's identity. What is important is that the quality of the analysis is dependent upon the quality of the interviews/focus groups. To ensure accuracy and increase the credibility of the data collected, the focus groups (II) and interviews (IV) were audio recorded and transcribed by the first author. The transcripts were double checked to make sure the written text reflected the situation, as were the non-verbal expressions.

Transparency of the research in the study's aim, samples, analysis and reporting of results gives the reader the opportunity to assess the trustworthiness [98, 143]. In the findings there are conclusions that answer the research question and that are validated by quotes from the meaning units to strengthen and vitalise the findings [157]. The methodological approaches used in the studies are forms of qualitative analysis [98-100]. These methods are well documented and used in several studies by various researchers. The analyses were discussed with members of the research group, as well as in research seminars, reducing the risk of unilateral descriptions and interpretations [98, 102]. Attitudes towards scientific openness, in both data collection and analysis, have been taken into consideration as well as a critical approach during the whole process. Therefore credibility is evaluated by the reader based on the fact that assessment of the application of the selected methods and data analysis has been carried out.

Since this thesis has a qualitative approach it does not claim to generalise its results but rather to gain an understanding of the experience of losing a stillborn baby. This is because the selection is limited and non-random, which severely limits the ability to generalise [143]. All of the participants' situations and experiences are unique and contextually marked, and therefore not appealing to everyone who has experienced the loss of a stillborn baby (I-III) or sibling (IV). Hence one should be cautious when considering transferability. Furthermore, it is important to highlight that the methodology on informants recruited through the Swedish National Infant Foundation (II-IV) has meant that any person who is not a member or has received the information given through newsletters or on their website, or has directly utilised the internet, but perhaps still wished to participate in the studies, has not been given the same access to information and participation. However, advertisements in nationwide newspapers and

journals addressed to parents (III) counterbalance this. Additionally, the thesis is limited in the sense that informants are only searched for through Swedish forums, which means that the participants in the studies are affected to varying degrees by the current Swedish social context, reflecting Swedish society's definition of family constellations and acceptance of the need to grieve a stillborn baby. Hence the findings in the present thesis should not be transferred to other contexts and settings without careful consideration.

Another issue that is to be illuminated is memory-related problems in relation to the time elapsing between the stillbirth and participation in studies II and III, which may have reduced the ability to identify phenomena that occurred. There is research, however, that indicates that memories of events around childbirth have been shown to be clear and to last up to 20 years afterwards. Memories related to information of significant importance have proven to be detailed many years afterwards [158]. Additionally, the parents participating in both studies II and III had experienced the stillbirth between 1987 and 2009 (II), and 1961 and 2010 (III) respectively, a long period during which attitudes and customs concerning the involvement of parents and siblings in stillbirths and children's grief have changed [159]; caring routines and culture within western society might also have changed during this period. This must be taken into account when thinking in terms of transferability. However, the median rate, year 2006 (II) and 2004 (III) respectively, shows that most of the experiences reflect the customs and attitudes of today.

Furthermore, the self-recruitment approach probably implies that it is mostly mothers, fathers and adolescents who are especially interested in the topic, in sharing their experiences or in need of communicating their loss experience, that have been the participating parents and adolescents in the studies. The samples also consist of mostly women or female adolescents, which may have influenced the results; i.e. the results should be interpreted with this perspective. It could also be the case that it is in particular those with good experiences who have chosen to participate. The self-recruitment approach also leads to limited understanding of the overall study base. Despite recruitment strategies for study IV, there were some difficulties in recruiting adolescents for participation. This may partly be due to the research topic and the fact that adolescence is a time in life focusing on development and identity formation, which can lead to uncertainty as to what the adolescent as an individual can contribute. Additionally, the employment of qualitative research automatically means that only the effects of stillbirth loss influence and the grief perspective from people who have been answering the questionnaires (I, III) or have been interviewed (II, IV) and expressed a willingness to participate, are studied in the thesis, which means the omission of many important perspectives from other people who, for various reasons, do not have the desire or ability to talk about or share their experiences.

The sample in study IV consists of half-siblings. Hence the findings, which show alienation from the nuclear family's loss, must be viewed with caution. However, there is strength in seeing the half-siblings' perspective, thus highlighting their nuanced situation. Furthermore, it is impossible to know whether the findings are due specifically to the death of a stillborn sibling, as adolescence is a time of development and identity formation, which must be seen in a wider context. Lastly there were significant differences for two of the subcategories in study III, concerning advice from parents with stillbirths before and after gestational week 28; however, these findings should be approached with care as they are a consequence of interpretations of the

answers to the open question studied. Hence the results from the studies cannot be transferred to all the mothers, fathers and/or adolescents who lose a stillborn baby/sibling. Nevertheless, the ability to transfer findings is strengthened by the fact that the results are in accordance with previous research in the field, which further increases the trustworthiness of this thesis [160]. So despite the limitations, the results of the present thesis can be a valuable contribution to see the impact of losing a stillborn baby from the perspective of parents and siblings.

7 CONCLUSIONS AND IMPLICATIONS

This thesis gives new information on the thoughts and feelings in a family after they have experienced a stillbirth. The baby was a natural part of the family lives, albeit not physical; there was a psychological presence. Stillborn loss from the perspective of parents and siblings further indicated the importance of sharing the experience within the family, of letting siblings experience their stillborn sister or brother and of inviting them to participate, to a degree that corresponds to their level of development and their own resources. Siblings' participation and involvement in the loss experience may help to acknowledge the significance of the loss for their parents and themselves. The family changed with the loss and the results provide insight into how this change affected the family members' daily lives and shaped the way they related to one another. Most of them went through the loss together, developed an inner strength in one another, thus giving one another support, and in the common grief the family relationship was strengthened.

Clinically the information can be used to help health care professionals communicate with parents and siblings after stillbirth loss. For parents seeking advice, it may help to know that the parents in this thesis, who actively involved the stillborn baby's siblings in the meeting and farewell afterwards, by and large reported encouraging experiences only.

8 FURTHER RESEARCH

This thesis is an initiative which can prepare future research for undertaking more extensive investigations into the perspective of siblings. For example with research methods adapted for different ages, exploring any possible gender differences, with both full siblings and half-siblings and in both nuclear and reconstituted families.

Also this thesis is an initiative, preparing the way for future researchers' to start with more extensive research that could take in the perspectives of extended family members, and to explore the perceptions from different cultural groups. Future studies could furthermore focus on the relationship of children's and adolescents' grief responses to families' grief responses.

9 SWEDISH SUMMARY

Bakgrund: Omkring 450 barn föds döda varje år i Sverige (efter 22 fullgånga graviditetsveckor). Ofta inträffar händelsen snabbt och oväntat, och möjligheten att förbereda sig är begränsad. Att mista ett barn redan innan det är fött eller under förlossningen innebär att förväntan och glädje byts mot förtvivlan och sorg och den känslomässiga belastningen blir stor för hela familjen; föräldrar och eventuella syskon. Efter förlossningen stöds föräldrarna att se och hålla sitt barn, minnen som hårlock, hand- och fotavtryck bevaras, fotografier tas och namngivnings- och minnesceremonier hålls. Ett barns död är omskakande och syskons sorg får inte alltid utrymme när föräldrarna sörjer. Barn- och ungdomars sorg och hur de visa sin sorg skiljer sig från vuxnas, förståelsen och bearbetningen av förlusten följer barnets intellektuella utveckling och tankemässiga mognad. Mammans och pappans upplevelser och erfarenheter av att mista ett barn före födseln har beskrivits i tidigare forskning men få studier fokuserar förlusten ur ett familjeperspektiv. Avhandlingens övergripande syfte var att studera förlusten av ett barn som dött före födelsen utifrån föräldrars och syskons perspektiv.

Metod: Studie I baseras på en datainsamling med frågeformulär till föräldrar som mist barn före födelsen, 55 föräldrar, 33 mammor och 22 pappor medverkade. Under två år efter förlusten utfördes tre mätningar med tre studiespecifika frågeformulär: tre månader, ett- respektive två år efter förlusten. Frågeformulären innehöll frågor gällande demografiska data samt studiespecifika frågor relaterade till sorg, sorgereaktioner och föräldrarnas relation. De flesta frågor hade slutna svarsalternativ med utrymme för kommentarer. I studien ingick även en öppen fråga om sorgereaktioner. För studie II genomfördes fem fokusgrupper med 25 föräldrar, 20 mammor och fem pappor, som mist barn före födelsen och som hade äldre barn, syskon till det döda barnet. En frågeguide användes med frågor som berörde föräldrars stöd till syskon och syskons möte, avsked och minnen av sin syster eller bror, samt råd till föräldrar som mist barn och till professionella vårdgivare. Datainsamling för studie III utgjordes av ett frågeformulär som fanns tillgängligt på internet under en period av två år, och som vände sig till föräldrar; mammor och pappor som mist ett barn före födelsen. I studien inkluderades de som innan förlusten hade barn, syskon till det dödfödda barnet. Det var 411 föräldrar, 350 mammor och 61 pappor som besvarade den öppna frågan i webbformuläret: *Om ditt barn som dog hade äldre syskon vilket råd skulle du då ge till andra föräldrar när det gäller hur syskonen skall få ta avsked av sin syster eller bror.* Individuella intervjuer med 13 ungdomar (13-17 år), med erfarenhet av att ett syskon dött före födelsen, utgjorde datainsamlingsmetod för studie IV. Frågeområden för intervjuerna var: beskedet, reaktioner, mötet, avskedet, minnen samt det stöd ungdomarna fått i samband med förlusten av syskonet. Data från de olika delstudierna analyserades med beskrivande statistik för slutna flervalsfrågor och med innehållsanalys vid kommentarer, öppna frågor och utskrifter från fokusgrupper och individuella intervjuer.

Resultat: Föräldraskapet för syskon till ett dödfött barn kännetecknas i det akuta skedet av föräldrar som balanserar sin egen sorg för att värna syskonen. Föräldrarna strävade efter att skapa en miljö där syskon på ett tryggt sätt inbjöds att delta i aktiviteter kring dödfödelsen; ritualer som skulle främja en förståelse för den nya och

oväntade familjesituationen. Vissa föräldrar uttryckte svårigheter att fokusera på behov hos syskonen när de själva sörjde som djupast. De flesta syskon mötte sin dödfödda syster eller bror. Mötet beskrevs som naturligt, berikande och självklart, det skapade förståelse för det som hänt och bidrog till att det döda barnet blev en verklig person för dem. Syskonen deltog också aktivt genom att skapa minnen vid avskedet av barnet. Information och samtal med syskon ska ta sin utgångspunkt i deras referensramar. Föräldrar och syskon uttryckte känslor av spruckna förväntningar då förlusten innebar att de inte blev den större familj som var planerat. Förlusten väckte också tankar om huruvida syskon kunde identifiera sig som storasyskon till ett barn som dött före födelsen. Många föräldrar menade att sorgen hade stärkt deras relation. Vissa föräldrar och några ungdomar uttryckte att de sörjde såväl ensamma som tillsammans med andra. De utvecklade en inre styrka och en tillit till varandra i familjen. För andra kunde en brist på förståelse för varandras sätt att uttrycka sorg skapa känslomässig distans. Några ungdomar uttryckte känslor av att vara en del av en gemensam sorg i familjen, men samtidigt vara utanför och förlusten av syskonet kunde innebära en tillfällig förlust av föräldrarnas föräldraskap då föräldrarna i den akuta sorgen kunde ha svårt att möta syskonens behov.

Slutsats: Denna avhandling ger ny information om tankar och känslor i en familj som mist ett barn före födelsen. Föräldrarna betonade vikten av att dela erfarenheten inom familjen och att syskon görs delaktiga utifrån sina egna känslor, resurser och förutsättningar. Familjen förändrades efter förlusten och resultaten ger insikt i hur det påverkat familjemedlemmarnas vardag och inbördes relationer. De flesta upplevde att de sörjde tillsammans och i den gemensamma sorgen stärktes familjebanden. Avhandlingens resultat kan användas som ett stöd för hälso- och sjukvårdspersonal att kommunicera med föräldrar och syskon i sorg. För föräldrar som söker råd, kan det vara en hjälp att veta att föräldrarna i denna avhandling, som aktivt uppmanat det dödfödda barnets syskon att möta och ta avsked av sin syster eller bror, hade goda erfarenheter av det.

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