

### Institutionen för kvinnor och barns hälsa

# Stillbirth – a loss for the whole family

#### AKADEMISK AVHANDLING

som för avläggande av medicine doktorsexamen vid Karolinska Institutet offentligen försvaras i Samuelssonsalen, Tomtebodavägen 6, Karolinska Institutet, Solna.

# Torsdagen den 13 juni 2013 kl. 10.00

av

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#### **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