

## Abstract

### A different parenthood?

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The overall aim of this thesis is to describe and analyse parents' perceptions and experiences of having a daughter with Turner syndrome (TS). Five empirical studies are included that are based on interviews with parents. Studies I, II and IV include 44 parents (33 mothers and 11 fathers), study III includes 54 (39 mothers and 15 fathers) and study V includes four couples (4 mothers and 4 fathers). Most of the parents included in **study I** (n=27) reported that professionals observed that their daughter should be referred for medical investigation, and the remainder (n=17) reported that they themselves perceived the need for investigation. The parents' experiences of who initiated the diagnosis were found to affect their descriptions of the diagnostic process. The parents who initiated the investigation themselves described the diagnosis in terms of a confirmation of their own suspicions. When professionals initiated the investigation the parents reported that they felt unprepared when they received the diagnosis. The results of the study indicate that the parents' experiences of receiving the diagnosis of TS appear to depend on the ability of the doctor to provide relevant information and to adequately manage the psychosocial aspects of the situation. In **study II** 26 parents reported that they sought further information about TS beyond that which was provided by the professionals. The motives for seeking information were related to the parents' experiences of the consultation held at the time of diagnosis. The parents' motive was to learn more about the condition. The mothers described different strategies for gaining information and the dissatisfied mothers used more and different strategies to find information as compared with all fathers and the satisfied mothers. **Study III** focused on parents' experiences of having an infant with TS. The parents reported late development in the areas of motor activity, fine motor control, speech and language. Feeding problems were common and screaming periods occurred very often. No differences were found between the parents whose daughters were diagnosed before two years of age and those diagnosed after two years of age. No differences between the genotypes were found in terms of development and/or problems. The problems affected the everyday life of the families, especially the problems related to feeding. Most of the parents in **study IV** (n=36) felt that their daughters had difficulties that were explained by TS, although there was great variation in how the difficulties were expressed and in how the parents perceived them. Most parents felt they were affected by their daughter's condition and had developed different strategies in their everyday life to help and stimulate their daughters. The parents believed that their own education, family economy, time and patience were important in handling their daughters' difficulties. The emotional and social difficulties appeared to have a considerable impact on the parents. In **study V** some couples focused on the normalisation of their daughters and others on raising their level of understanding. It is possible to explain their different perspectives as effects of the families' different cultures, thus showing that the couples are an illustration of how different kinds of family awareness affect the coping strategies of the parents and their descriptions of their daughters. Furthermore, the couples exhibited traditional family structures: the mothers took responsibility for family practices and the fathers assisted them in this. The fathers participated to different extents, however. In the families in which the fathers participated to a lesser extent, the mothers took greater responsibility and delegated fewer tasks to the fathers than in the other families. However, in those families, the fathers were responsible to a greater extent for economic support. This is interpreted as a more traditional family structure than in the other families, which showed elements of a more modern family structure.

**Key words:** Parents, Turner syndrome, diagnosis process, need of knowledge, infancy, teenage period, difficulties in everyday life

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