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# Ethics at the beginning of life

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## Parent's Decision Making Concerning Medical Care for their Children

**Context.** A paternalistic approach to medical decision-making concerning children has traditionally been taken in order to reduce burden on parents. The current trend is for greater patient autonomy. However, parental intention for active participation in decision-making has not been established.

**Objective.** To determine mothers' and fathers' preferences concerning medical decision-making. Preferences were related to sociodemographic, medical, and psychosocial factors.

**Design, Setting, and Participants.** Cross-sectional and longitudinal design in which 863 expectant parents (435 women and 428 men) were consecutively recruited at gestational week 19 in conjunction with routine ultrasound examination at 2 hospitals in Uppsala County, Sweden. A subsample of 123 women at gestational week 34 was followed-up.

**Results.** The majority of parents expect to be jointly and actively involved. Few parents preferred the final decision to be taken by the attending physician or to be "protected" from difficult decisions. The mean level of preferred participation differed significantly among parents so that men intended to be more involved and were more confident about their decisions than women at midpregnancy, but as pregnancy progressed the level of women's intentions increased significantly although their confidence did not. The need for information was consistently higher for women than for men. Results of multiple regression analyses showed that parents' need for information in the medical consultation was closely related to their intent to actively participate in decision making. Active decision making was also explained by parents' confidence in their ability to make a "good" decision, by perceived medical risk for complications, and knowledge of risk factors. Socioeconomic variables were not relevant predictors.

**Conclusions.** Parents intend to make informed decisions concerning medical care for their children. Increased perceived medical risk and knowledge about medical risk factors increased parents' intention to participate in decision making. Our results are of clinical relevance for neonatal medicine.