

Family-oriented first information at the birth of a handicapped child

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This study analyses parents' experiences of first information at the birth of a handicapped child. Here first information is primarily analysed from the perspective of the parent's experiences, which are reflected against the experience of workers (e.g. doctors, midwives and nurses). The experiences of parents have been examined from the perspective of family research employing the psychodynamic and psychosocial model (Ferguson & Ferguson, 1987). Previous research has not analysed first information in similar situations from the perspective of both parties simultaneously.

The goal of the study is to increase understanding of the experiences of parents in receiving first information and the experiences of workers as conveyors of information and knowledge on how the experiences of parents and workers encounter each others.

First information means the process whereby information concerning the child's handicap is conveyed to the parents. The focus is on first information during the time when it is not yet certain what type of handicap the newborn child has.

The definition of the first information is very difficult because the situations' contents are so different each time. In short first information consist of knowledge, feelings, support, hope, repetition and directing steps forward.

In this study two kind of analysis methods were used: narrative analysis and analysis of narratives. Narrative analysis considers interviews as narratives of preliminary information. In these, the conveyance of first information is examined through the different roles of the parents. A stage metaphor is adopted for interpreting the narratives with parents playing various roles in the different narratives. Parents are either in a subsidiary role, in a main role and as part of the audience.

Child's handicap was viewed from three angles: a handicap which is not clearly outwardly visible, a visible handicap and a handicap which threatens to lead to the child's death.

Family-oriented first information model views the encounter in a situation of first information on three levels. The first level comprises an interactive encounter between parents, baby and workers, where open dialogue is of importance. On the second level is the genuine presence of the workers important. The third level involves an encounter with the handicap, i.e. information relating to it, witch should also include mention of the positive features of the child. If all of these levels of encounter are present in the situation of first information, family-oriented first information arises from the interaction between parents and workers that corresponds with the needs of each family, which in turn enables them not only to process information but to deal with sorrow and hope.