

LONG-TERM IMPACT OF EXTREMELY PREMATURE CHILDBIRTH

Parents' experiences when the children reach
school age



PhD thesis
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2008

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Abstract

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The objectives of the present thesis were to describe how an extremely premature childbirth may influence child development and family life in a long-term perspective.

Extremely premature childbirth that is birth before 28 complete weeks of gestation is a disruption of child development in a critical period and a disturbance of the normal processes of parenthood. In addition to neonatal complications, adverse long-term impact of extremely premature childbirth on child development is well-documented. Parents' reactions in the postnatal period have been studied and a large percentage of the parents may show crisis reactions. The caregivers' psychological distress may attenuate during the first years, but reports of long-term negative impact on the families are prevalent.

The qualitative research interview was an obvious choice for an explorative study on human experiences starting with an important life event, the birth of a child. As most studies focus exclusively on the mothers, it was mandatory to include the fathers' experiences, emotions and attitudes. Thus 9 fathers and 11 mothers were interviewed when their children, born before 28 completed weeks of gestation, were between 7 and 10 years of age. The semistructured, qualitative research interviews were analysed according to the editing strategy described by Miller and Crabtree.

The thesis is a synopsis of three articles following the trajectories of health and development of the child paralleled by the trajectory of the development of parental competence. Two courses deeply interrelated through child-parent interactions.

In paper I development of parental competence starting in the neonatal intensive care unit was in focus. The complex concepts of being parents of an extremely premature infant were described as a process with interconnected elements. Possible barriers in this process were identified. Theoretical knowledge and instructions of special skills are important but cannot stand alone. According to the parents, it is support and encouragement which enable them to feel important in their babies' lives and build up a confidence in their own empathy through many hours contact with the baby.

Paper II follows the before mentioned trajectories of child development and development of parental competence. The daily life of the family after the discharge of the baby from hospital is described. The study demonstrates the parents' efforts to perceive their children's basal and special needs and act accordingly. Both parents seem to be involved trying to protect the child towards hyper stimulation, to adapt activities to the child's functional level and to promote motor and social development. Likewise, traits in the children's personalities that may facilitate catch-up of developmental delay are indicated. Thus, home environment and child characteristics are suggested to be possible moderators of more subtle sequelae of the premature birth.

Paper III: Whereas developmental delay, functional limitations, family burden and parental distress are commonly used outcome measures, complementary experiences are reported in the lives of survivors and their parents. Thus, in spite of periods of deep distress and fear, periods of concerns and anxiety and for some parents a workload far beyond average, their descriptions of their children's trajectories were also characterised by a perception of improvement and progress. Likewise, all parents reported much love and joy from childrearing.

In conclusion. Through the accounts of mothers and fathers from the child's birth to the time of the interviews this thesis is a supplement to existing literature because it contributes to a more comprehensive picture of family life with an extremely prematurely born child. It suggests that the Scandinavian tradition of parental involvement in care must be continued and further developed. Moreover, it shows that the parents participating in this study in spite of a difficult start all became involved and competent parents with great expertise in the care of their child.

Thus the value of this work and its untraditional approach may lie in the perspective it adds to the interpretation of current research on family outcome, the inspiration it may lend to future intervention studies, as well as the balance it may offer to the information provided to parents of premature children.

Paper III Questions Never Asked . Positive Family Outcomes of Extremely Premature Childbirth
Lou,H, Pedersen,BD,Hedegaard M Quality of Life Research. In press.