

Föräldrars delaktighet i sitt barns vård vid neonatal intensivvård

Akademisk avhandling

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av

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Avhandlingen baseras på följande delarbeten:

- I Wigert, H., Johansson, R., Berg, M., & Hellström, A-L. (2006). Mothers' experiences of having their newborn child in a neonatal intensive care unit. *Scandinavian Journal of Caring Sciences* 20:35-41.
- II Wigert, H., Berg, M., & Hellström, A-L. (2007). Health care professionals' experiences of parental presence and participation in neonatal intensive care unit. *International Journal of Qualitative Studies on Health and Well-being* 2:45-54.
- III Wigert, H., Hellström, A-L., & Berg, M. (2008). Conditions for parents' participation in the care of their child in neonatal intensive care – a field study. *BioMed Central Pediatrics* 23:8:3.
- IV Wigert, H., Berg, M., & Hellström, A-L. Attendance and factors influencing parents to be with their child in neonatal intensive care. *Inskickad 2008*.



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ABSTRACT

Original titel: Föräldrars delaktighet i sitt barns vård vid neonatal intensivvård.

Title in English: Parents' participation in the care of their child in neonatal intensive care.

Language: Swedish with summary in English.

Keywords: health care professional, hermeneutics, lifeworld, mother-child, mothers' experience, neonatal intensive care unit, newborn caring, parental participation, parental presence, phenomenology.

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When a newborn baby is in need of care in a neonatal intensive care unit (NICU), the care is assumed to be carried out not only by personnel but also by parents. To promote parental participation in this care, the parents are welcome to stay with their child whenever they wish.

This thesis includes four papers and has the overall aim of contributing to the understanding of the significance of parental participation in the care of their child on the NICU, as well as the factors that influence, facilitate or obstruct that participation.

The thesis is based on participative observations and interviews with parents and personnel at two NICUs. Paper I used a phenomenological hermeneutic lifeworld approach, while Papers II and III used a hermeneutic lifeworld approach, and Paper IV had a descriptive quantitative design.

The results of this thesis show a general feeling of exclusion, with the mother experiencing a lack of interaction with the personnel and a sense of not belonging on the NICU. This has a negative impact on her maternal identity. However, when a continuous dialogue existed, and the mother was cared for as a unique person with unique needs, she experienced that she was participating, and this strengthened her maternal identity (I). The personnel on the NICU were ambivalent regarding the presence of parents, and set limits that included dictating conditions for parental participation. In the encounter with the parents they had difficulties in meeting worried parents and sometimes manifested an evasive attitude (II). Although the personnel had good ideals and intended to encourage parental participation, the care, including the terms of parental participation, was determined by the conditions set by the personnel, routines focusing on the care environment and medical technology, and budgetary constraints (III). The nature and extent of parental presence on the NICUs varied depending on the types of accommodations parents were offered. Those who stayed in parent rooms on the units showed more of presence with their children than did parents who stayed at a family hotel, at home or on the maternity ward. The main reason parents had for being with their child was a wish to take parental responsibility. Good treatment by the personnel was the primary factor facilitating parental presence, while parental ill health was the primary obstructing factor (IV).

The results show a need to develop a family-friendly environment and tangible strategies to provide optimal conditions for enabling parents to be present and involved in the care of their child on a NICU. In addition, the personnel must be given the resources needed to make this possible.