



EMpowerment of PArents in The Intensive Care

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EXECUTIVE SUMMARY

The aim of this thesis – the EMPATHIC studies – was to develop and implement validated parent satisfaction questionnaires for pediatric and neonatal intensive care units. **Part I** presents the general introduction, which justifies the construction, validation, and utilization of parent satisfaction instruments. **Part II** provides a review about the few existing parent and family satisfaction instruments. A theoretical framework incorporating family-centered care, parental needs and experiences, as well as parent satisfaction are described. **Part III** describes three explorative studies conducted to identify the parental and professionals' experiences related to intensive care services. First, an interview study among parents of 41 children revealed 63 sub-themes divided into six major themes. Second, a Delphi study among 364 healthcare professionals identified and prioritized 78 meaningful items of pediatric intensive care services. Third, a survey study among 559 parents identified the most important care items. **Part IV** presents the differences of perceptions between parents and healthcare professionals by comparing the results of the Delphi and the survey studies. Parents rated 31 items as more important than the professionals. Ten of these were related to communication. Caregivers rated 12 items as more important than the parents. A comparable method among parents and professionals of a neonatal intensive care unit revealed that parents rated 25 of 92 items as significantly more important than did the professionals. Two of these were related to medication administration. Caregivers rated seven items as more important. **Part V** considers two validation studies of the EMPATHIC and EMPATHIC-N questionnaires. The psychometric properties of both questionnaires were satisfactory. Several issues in pediatric intensive care were identified as being below acceptable standards, such as having daily talks with the physician, the physicians preparing the parents about the child's discharge, and the noise levels in the units. For the neonatal intensive care, low ratings were given to the physician's information about expected health outcomes, the distraction of receiving the same information from the physicians and the nurses, and the possibilities for parents to be actively involved in decision-making processes. **Part VI** discusses the overall results of the EMPATHIC studies. The measures, meanings, and memories of satisfaction are highlighted including the utilization of validated parental satisfaction questionnaires. Finally, future research directives are provided.