POSTER ABSTRACT

Parents experiences with integrated family obstetric and neonatal level 2 care to improve patient empowerment.

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Introduction: This study described the evaluation by parents who have experienced an integrated infrastructure for high risk obstetric and neonatal level 2 care, from the perspective of patient empowerment. This unique infrastructure facilitate 24 hours a day parental participation and closeness between parents and sick newborns in a general hospital. Co-care, rooming in facilities for partners, Family Integrated Care and medical visiting rounds within Single Family Rooms (SFR) were implemented. At the moment knowledge is lacking on how parents experience empowerment in these infrastructures. The aim of this study was to explore parents’ experiences regarding the new infrastructure’s contribution to parent empowerment.

Methods: A qualitative design with a contextual constructivist approach was chosen, using focus group discussions and in-depth interviews between December 2015 and January 2017 with parents of sick newborns who were admitted for more than 7 days. Data were analyzed by realistic evaluation to identify contexts, mechanisms and outcomes. A conceptual map was used to categorized outcomes for patient empowerment.

Results: Eight fathers and twenty-eight mothers participated. Parents have indicated that they have undergone an intensive practical learning process at their suite to independent parenthood through the support of health care providers 24 hours a day. They acquire self management tools, feelings of control and realistic insights about the health condition of their newborn. Parents experienced to be much involved as equal primary caregivers, especially in making shared decisions during medical rounds at the SFR. Some parents experienced a change of power, because healthcare providers visit them in their own suite, instead of parents visit their child at the neonatal ward. Parents were feeling respected as a whole family being able to have privacy, homeliness and closeness in their SFR. Finally parents made self-initiated discharges, due to feelings of self-efficacy.

Parents experienced challenges when their self-efficacy and self management did not match what caregivers expected from them, when they experienced sleep deprivation due to excessive involvement in taking care of their newborn, when they felt more skilled than the
staff, and when care was focused at mother OR newborn. Due to the SFR, some parents felt isolated from other parents to compare and share their situation with that of other parents and sick newborns.

**Discussion:** Parents views on integrated infrastructures are important to the discussion around patient empowerment.

**Conclusions:** The new integrated infrastructure seems to contribute to parent empowerment according to parents of sick newborns. Parents also face new challenges with the new infrastructure, such as power issues with staff, health care conflicts and feelings of isolation.

**Lessons Learned:** Guiding parents in an infrastructure where they can learn 24 hours a day, in addition to learning content, must be expanded to find a balance in parenting.

**Limitations:** This case is about level 2 neonatal care with post-IC facilities. Additional requirements will be necessary for level 3 NICU’s.

**Suggestions for further research:** We need to explore staff experiences regarding their role in the new infrastructure’s contribution to parent empowerment, in order to optimize the alignment between parents and staff.

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**Keywords:** patient evaluation; family integrated care; patient empowerment; obstetrics; neonatal care