

Commentary: Parental involvement in retinopathy of prematurity care: An individualized approach

The premature birth of a baby is accompanied by many medical problems that involve prolonged neonatal intensive care unit (NICU) stay and multiple interventions. The babies can develop many co-morbidities, one among them is retinopathy of prematurity (ROP). Parents of premature babies are subjected to increased parental stress in the course of dealing with these issues.^[1] In the study "Should Parents Be Present during Screening Examinations for Retinopathy of Prematurity?"^[2] the authors evaluated anxiety levels in parents pre and post ROP screening. In Group 1, the parents accompanied the baby during exam, but were not allowed to intervene. Mothers in this group had significantly increased anxiety, which the authors attribute to an inability to intervene or comfort a baby that appears to be in distress. In group 2 where the parents remained outside the exam room, anxiety levels were seen to decrease post exam, more significantly in fathers.

Of interest to note is that the parents in this cohort had very poor awareness about ROP (85% were not aware), and none of the screened babies required any form of intervention for ROP. A lack of awareness implies a lack of knowledge regarding the possible lifelong vision-threatening consequences of ROP. Screening for ROP involving the use of a speculum, globe manipulation, a bright light with a loudly crying baby can be difficult for parents to witness. On the other hand, the examining physician is reassured that a baby crying out loudly and making clear vocalization is breathing well and not going into apnea. For parents, witnessing the screening and seeing doctors apparently ignoring a crying baby lead to a sense of helplessness and an apparent failure to fulfill parental roles with increased state anxiety levels as a consequence. On the other hand, parents who do not witness the process and are reunited with a healthy baby post exam demonstrate reduced anxiety, especially in the absence of need for further interventions.

While the results of this study implicate that separating parents from the baby during ROP screening reduces anxiety, multiple factors can influence parental response and anxiety levels. Parents of premature babies who receive early theory-based interventions have demonstrated better understanding of preterm baby's developmental needs and show less anxiety.^[3] Similarly, parents who are made aware of ROP and its possible visual consequences would be more willing to subject their babies to screening sessions. Information posters, brochures as well as educational videos can be made available to parents. NICU staff can play a vital role in educating about ROP. A discussion with parents before screening describing the procedure and informing the parents that the baby will cry can help them cope with the situation better. The option to stay in the exam room or wait outside can be made available to parents at their own comfort. Parents who stay in the room with the baby may be allowed to stand near, hold and touch baby, as well as make comforting sounds. They can be requested to not disrupt the examination process. Presence of parents promotes participation in care and creates an emotionally stable environment that can alleviate irritability in baby. Parents develop confidence in treating doctor and this decreases apprehension regarding follow-up visits.

Contrary to this, training of novice examiners and screening by them may be affected by presence of parents. Parents who are uncomfortable witnessing any procedure may prefer to remain outside the exam room. Establishing peer support groups for parents can clarify their doubts and provide a safe environment to voice their concerns and fears. Communication between health care providers and parents can improve, with a better understanding of the risks involved.^[4] Early intervention in the form of psychological support can improve maternal-child bonding and prevent depression in mothers. Decision making about parental presence in the examination room can vary from individual to individual—both parents and doctors. A flexible individualized approach toward parents of premature babies, rather than laying down strict guidelines for examination would be most desirable.

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