Should parents be present during screening examinations for retinopathy of prematurity?

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Purpose: To investigate whether parents should be present during screening examinations for retinopathy of prematurity (ROP) by investigating the anxiety levels of parents using two different approaches.

Methods: This cross-sectional and two-center study was carried out with the parents at the time of the first ROP screening examination of their premature infants. At one center, the parents accompanied the infants during the ROP examination (Group 1), and in the other center, they did not (Group 2). Anxiety levels were assessed with the State-Trait Anxiety Inventory (STAI), which consists of the State Anxiety (STAI-S) and Trait Anxiety (STAI-T) subscales and a visual analog scale (VAS). Results: A total of 147 parents of 127 infants were included in the study. STAI-T and -S levels were 40.5 ± 8 and 37.9 ± 7.5, respectively, in Group 1 and 39.6 ± 8.1 and 39.4 ± 9.1 in Group 2 before the examination. There were no statistically significant differences in terms of these values between the two groups (P > 0.05). The state anxiety levels increased by an average of 1.7 ± 8 in Group 1 and reached 39.6 ± 10.1 after the examination. In Group 2, these levels decreased by an average of −2.7 ± 7.5 points to a score of 36.4 ± 10.3. This difference was found to be statistically significant (P = 0.001). A similar pattern was observed in the evaluation of the VAS data.

Conclusion: As a preliminary opinion, it may be more appropriate for parents to not participate in screening examinations, but single-center controlled studies are required to confirm the results.

Key words: Anxiety, examination, parents, retinopathy of prematurity, screening

Retinopathy of prematurity (ROP) is a vitreoretinal vascular disease that may lead to visual impairment or complete blindness in premature infants. Since ROP does not exist at the time of birth and shows sequential development, preterm infants in the risk group should be examined at regular intervals to identify infants who need treatment. Although blindness due to ROP is largely avoidable because of screening and treatment strategies, examinations can be stressful for both babies and their parents.

Recently, with family-centered approaches, parents have increasingly participated in their infant’s care. Additionally, parents have expressed a wish to be involved in the pain care of their preterm infants.

However, when this approach is evaluated in terms of ROP screenings in outpatient conditions, there is no consensus about the participation of parents in the screening examinations. When the parents are allowed to be in the examination room, witnessing their babies’ suffering could cause anxiety in the parents; when the parents remain outside the examination room, both their separation from their babies and their concern about the kind of intervention being made inside the room could cause anxiety. To our knowledge, this issue has never been investigated.

The purpose of this study is to obtain an opinion on whether parents should participate in ROP screening examinations by investigating the levels of anxiety of parents using two different approaches and to identify the possible factors that might be associated with the anxiety levels.

Methods

This cross-sectional and two-center study was conducted on parents during the first ROP screening visits in outpatient settings in two government hospitals, which were tertiary referral centers for ROP. The study was approved by the institutional review board (IRB) of one of the centers, and the IRB of other center also gave the approval for the study. Study procedures were in accordance with the principles outlined in the Declaration of Helsinki of 1964 and the following amendments. The study was approved primarily by the institutional review board of Etilk Zübeyde Hanım Women’s Health Education and Research Hospital (Date: 07.04.2017, Number: 2017/3).

At the first center, examiners preferred that the parents should be present with their babies during

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examinations (Group 1), and at the second center, the examiners believed that the parents staying outside the examination room could be a better approach for the parents and also for the examiners (Group 2).

Parents of babies under 32 weeks of gestational age and less than a birth weight of 1,500 g and parents of selected infants with a birth weight >1,500 g or gestational age of >32 weeks with an unstable clinical course who were identified to be at risk by the attending neonatologist were included in the study. All parents were informed about the study, and consent was obtained.

Parents who were diagnosed with a psychiatric disorder, were illiterate, came from a different country (refugee or migrant), had babies with a diagnosis or suspicion of any syndrome, or previously had premature babies were not included in the study.

The sample size was calculated as 64 for the detection of a difference of 5 with a 95% confidence interval and 80% power. Considering a 10% dropout rate, the study sample size was set at 70.

The evaluations in the study were made using the parent–infant information form prepared by the researchers, State and Trait Anxiety Inventory (STAI), and visual analog scale (VAS). The STAI was developed by Spielberger et al. and adapted to Turkish by Öner and Le Compte in 1985 was used to assess the anxiety levels. The STAI evaluates two types of anxiety: state anxiety and trait anxiety. The State Anxiety Scale (STAI-S) assesses the current state of anxiety, and the Trait Anxiety Scale (STAI-T) evaluates the general predisposition toward anxiety. The STAI consists of 40 items rated on a 4-point scale. Both scales consist of 20 items. The total score can range between 20 and 80, and higher scores indicate a greater degree of anxiety.

The second instrument used for anxiety assessment was VAS, which includes a 100-mm horizontal line anchored at each end by the statements “not anxious at all” and “the most anxious I have ever been.” The parents were asked to rate their current level of anxiety on the VAS. The distance in millimeters from the left edge of the line anchor to the mark placed by the parents was taken as the VAS score of the participant.

Before the examination, the parents were informed about the study, and if they were eligible and willing to participate in the study, they were asked to complete the parent–infant information form, STAI-T, STAI-S, and VAS forms in a separate room. No identifiers were recorded.

The examinations were carried out by all the authors experienced in ROP screening. Before the examinations, in both centers, the parents were informed about why and how the examination was performed. The parents in Group 1 were allowed to be in the room during the examination, and the parents in Group 2 were asked to wait outside and not be present for the examination (Group 2). The parents in Group 1 were not allowed to make any intervention regarding their infants during the examination.

Standard examination procedure was similar in both centers in terms of equipment used and methodology. The examinations were performed using a lid speculum and scleral depressor with an indirect binocular ophthalmoscope (Omega 2C, Heine, Germany) with a 20- or 28-diopter lens under topical anesthesia obtained with proparacaine HCl drops following pupil dilatation achieved by instilling tropicamide 0.5% and phenylephrine 2.5% twice at a 5-minute interval, 45 minutes before the examination. The infants were held by nurses during the examination to achieve immobilization. The average examination time was between 4 and 5 minutes at both the centers.

After the examination, the parents were informed about the examination results and were then asked to complete the STAI-S and VAS forms again.

For the statistical analysis, categorical data were expressed as numbers and percentages, and quantitative data were expressed as means ± standard deviations (minimum–maximum). Normality was evaluated by using the one-sample Kolmogorov–Smirnov test and the Shapiro–Wilk test. Chi-square tests were used to evaluate categorical data. Covariance analysis was used to compare the anxiety levels and VAS scores before and after the examination between the groups. In this model, the level of anxiety before the examination was taken into the model as a covariate. Multiple linear regression was used to analyze associations between anxiety levels and demographic features. P values <.05 were considered statistically significant.

Results
A total of 147 parents of 127 babies were included in the study. Of these parents, 101 (68.7%) were mothers, and 46 (31.3%) were fathers. Group 1 consisted of 79 parents, 51 (64.6%) of whom were mothers and 28 (35.4%) were fathers. Group 2 consisted of 68 parents, 50 (73.5%) of whom were mothers and 18 (26.5%) were fathers. The mean age of the mothers and fathers was 28.3 ± 5.6 (18.0–46.0) and 31.6 ± 5.2 (20.0–49.0) years, respectively. The demographic characteristics of the parents are summarized in Table 1.

Sixty-seven (52.8%) infants were females, and 60 (47.2%) were males. The mean gestational age was 30.3 ± 1.9 (24–35) weeks, and the mean birth weight was 1,439 ± 437 (600–2,470) g. Of the screened infants, 84 (66.1%) were born as a result of a planned pregnancy, and eight (6.3%) were born after infertility treatment. Additional health problems were detected in 17 (13.4%) infants. The demographic features of the infants are shown in Table 2.

The mean STAI-T scores before the examination were 40.1 ± 8 (22.0–56.0) in the whole study population, 40.5 ± 8 (24.0–54.0) in Group 1, and 39.6 ± 8.1 (22.0–56.0) in Group 2. The mean STAI-S scores were 38.6±8.3 (20–56) in the whole study population, 37.9 ± 7.5 (25.0–53.0) in Group 1, and 39.4 ± 9.1 (20.0–56.0) in Group 2. There were no significant differences between the two groups and between the parents (P > 0.05).

After the examination, the state anxiety levels increased by an average of 1.7 ± 8 (~13 to 19) in Group 1 and reached 39.6 ± 10.1 (20.0–61.0), and these levels decreased by an average of −2.7 ± 7.5 (~21.0 to 15.0) in Group 2 and dropped to 36.4 ± 10.3 (20.0–62.0). This difference was found to be statistically significant between the groups (P = 0.001), the mothers (P = 0.009), and the fathers (P = 0.034). A similar
situation was observed in the evaluation of VAS scores. The anxiety levels of the study groups are summarized in Table 3, and a graphical representation of state anxiety level changes is shown in Figs. 1 and 2.

When each group was separately evaluated, it was found that the increase in anxiety level after the examination in Group 1 was not significant ($P = 0.06$). In terms of the sex of the parents, the increase in anxiety levels of the mothers...
after the examination was found to be higher than that of the fathers, but the difference between them was also not significant. In Group 2, the decrease in anxiety levels after the examination was found to be significant overall ($P = 0.005$). When this situation was evaluated in terms of the mothers and the fathers, the anxiety decrease in the mothers was not significant ($P = 0.06$), whereas the anxiety decrease in the fathers was found to be significant ($P = 0.02$).

Table 2: Demographic features of infants

| Characteristics                                   | Overall (n=127) | Group 1 (n=60) | Group 2 (n=67) | $P$  |
|--------------------------------------------------|-----------------|----------------|----------------|------|
| Gestational age (weeks)                          | Mean±SD (range) | 30.3±1.9 (24‑35) | 30.4±2.1 (26‑35) | 30.2±1.8 (24‑35) | 0.679* |
| Birth weight (g)                                 | Mean±SD (range) | 1,439±437 (600‑2,470) | 1,427±419 (685‑2,420) | 1,450±455 (600‑2,470) | 0.860* |
| Gender (n, %)                                     |                 |                |                |      |
| Female                                           | 67 (52.8%)      | 32 (53.3%)     | 35 (52.2%)     | 0.902** |
| Male                                             | 60 (47.2%)      | 28 (46.7%)     | 32 (47.8%)     |      |
| Pregnancy (n, %)                                 |                 |                |                |      |
| Planned                                          | 84 (66.1%)      | 39 (65.0%)     | 45 (67.2%)     | 0.632** |
| Unplanned                                        | 32 (25.2%)      | 14 (23.3%)     | 18 (27.3%)     |      |
| After fertility treatment                        | 8 (6.3%)        | 5 (8.3%)       | 3 (4.5%)       |      |
| Birth type (n, %)                                |                 |                |                |      |
| Single                                           | 103 (81.1%)     | 49 (81.7%)     | 54 (80.6%)     | 0.878** |
| Multiple                                         | 24 (18.9%)      | 11 (18.3%)     | 13 (19.4%)     |      |
| Breastfeeding status (n, %)                      |                 |                |                |      |
| Yes                                              | 110 (86.6%)     | 55 (91.7%)     | 55 (82.1%)     | 0.226** |
| No                                               | 15 (11.8%)      | 5 (8.3%)       | 10 (14.9%)     |      |
| Not reported                                      | 2 (1.6%)        | -              | 2 (3.0%)       |      |
| Length of hospitalization (days)                 | Mean±SD (range) | 39.6±28.4 (8‑140) | 40.1±30.3 (9‑140) | 37.6±27.6 (8‑120) | 0.786** |
| ROP status (n, %)                                |                 |                |                |      |
| Absent                                           | 90 (70.9%)      | 46 (76.7%)     | 44 (65.7%)     | 0.173** |
| Present                                          | 37 (29.1%)      | 14 (23.3%)     | 23 (34.3%)     |      |
| Additional health problem (n, %)                 |                 |                |                |      |
| Absent                                           | 110 (86.6%)     | 51 (85.0%)     | 59 (88.1%)     | 0.613** |
| Present                                          | 17 (13.4%)      | 9 (15.0%)      | 8 (11.9%)      |      |

*Mann-Whitney $U$ test, **Chi-square test

When the relationships between the STAI-T and demographic data were evaluated, a negative correlation was found with the mean income of the families in all groups ($P = 0.01$, $r = -0.23$). When this situation was evaluated in terms of the parents, no relationship was found between the general anxiety levels of the mothers and the average income of the family ($P = 0.41$), but there was a relationship observed in the fathers ($P = 0.01$, $r = -0.40$).

In both the groups, although there was a positive relationship between unplanned pregnancy and STAI-T scores ($P = 0.002$, $r = 0.25$), a negative relationship was present between planned pregnancy and STAI-T scores ($P = 0.001$, $r = -0.28$). There was no significant association between pregnancy because of fertility treatment and STAI-T scores ($P = 0.32$). When this relationship was evaluated in terms of the mothers and the fathers, a statistically significant relationship was found between the mothers and the planned pregnancy ($P = 0.06$, $r = -0.28$) but not between the fathers and planned pregnancy ($P > 0.05$), and a statistically significant relationship was found between the fathers and unplanned pregnancy ($P = 0.02$, $r = 0.25$).
Table 3: Comparison of anxiety levels of between groups

|                      | Overall (n=147) | Group 1 (n=68) | Group 2 (n=79) | P     |
|----------------------|-----------------|----------------|----------------|-------|
|                      | Before examination | After examination | Before examination | After examination | Difference | P (Before vs. After) |     |
| STAI-Trait Score     |                 |                 |                 |       |
| Overall              | 40.1±8 (22-56)  | 40.5±8 (24-54)  | 39.8±8.1 (22-56) | 0.438 |
| Mothers              | 39.5±7.9 (22-56) | 40.8±8 (25-54)  | 38.9±7.8 (22-56) | 0.227 |
| Fathers              | 40.5±8.4 (24-56) | 40.8±8 (24-53)  | 41.4±9.3 (26-56) | 0.647 |
| P (Mothers vs. Fathers) | 0.732          | 0.672           | 0.344           |       |
| STAI-State Score      |                 |                 |                 |       |
| Overall              | 38.6±8.3 (20-56) | 37.9±7.5 (25-55) | 39.4±9.1 (20-56) | 0.291 |
| After examination     | 38.2±10.2 (20-62) | 39.6±10.1 (20-61) | 36.4±10.3 (20-62) | 0.078 |
| Difference            | 0.3±7.8 (-21-19) | 1.7±8 (-13-19)  | -2.7±7.5 (-21-15) | 0.001 |
| P (Before vs. After) | 0.656           | 0.062           | 0.005           |       |
| Mothers              | 38.7±8.2 (20-56) | 38.7±7.2 (25-55) | 38.8±9.2 (20-56) | 0.974 |
| After examination     | 38.9±10.3 (20-62) | 41±9.9 (22-61)  | 36.9±10.4 (21-62) | 0.049 |
| Difference            | 0.3±7.9 (-21-19) | 2.3±8.4 (-13-19) | -1.7±6.8 (-21-15) | 0.009 |
| P (Before vs. After) | 0.624           | 0.058           | 0.064           |       |
| Fathers              | 38.2±8.6 (23-54) | 36.4±8.1 (25-53) | 41.1±8.7 (23-54) | 0.082 |
| After examination     | 36.6±9.9 (20-57) | 37.1±9.9 (20-61) | 35.8±10.1 (20-56) | 0.699 |
| Difference            | -1.6±8.2 (-18-16) | 0.6±7.1 (-10 to16) | -5.6±8.7 (-18-12) | 0.034 |
| P (Before vs. After) | 0.189           | 0.637           | 0.020           |       |
| Visual Analogue Scale (cm) |         |                 |                 |       |
| Overall              | 2.8±2.5 (0-10)  | 3±2.3 (0-8.9)   | 2.5±2.7 (0-10)  | 0.048 |
| After examination     | 2.8±2.8 (0-9.6) | 3.5±3.1 (0-9.6) | 1.9±2.2 (0-7.8) | <0.001 |
| Difference            | 0.2±2.8 (-9-9.8) | 0.5±3 (-7-8.6)  | -0.6±2.3 (-9-9.4) | 0.004 |
| P (Before vs. After) | 0.507           | 0.142           | 0.007           |       |
| Mothers              | 2.9±2.6 (0-10)  | 3.2±2.4 (0-8.9) | 2.4±2.8 (0-10)  | 0.044 |
| After examination     | 3±3 (0-9.6)     | 3.7±3.1 (0-9.6) | 1.9±2.4 (0-7.8) | 0.011 |
| Difference            | 0.1±2.8 (-9-9.8) | 0.5±3.1 (-7-8.4) | -0.5±2.2 (-9-9.4) | 0.010 |
| P (Before vs. After) | 0.792           | 0.245           | 0.084           |       |
| Fathers              | 2.6±2.4 (0-10)  | 2.6±2.1 (0-7.1) | 2.5±3 (0-10)   | 0.411 |
| After examination     | 2.7±2.8 (0-9)   | 2.8±2.8 (0-9)   | 1.8±2.1 (0-5.5) | 0.100 |
| Difference            | 0.1±3 (−8-8.5)  | 0.3±2.6 (−6-8.6) | -0.7±2.7 (−5.6-4.4) | 0.665 |
| P (Before vs. After) | 0.163           | 0.539           | 0.024           |       |

STAI: State and Trait Anxiety Inventory

relationship was found between the fathers and unplanned pregnancy ($P = 0.06, r = 0.41$) but not between the mothers and unplanned pregnancy ($P > 0.05$).

There was no significant difference in the education levels between the groups ($P = 1.00$, Chi-squared test). No relationship was found between the education levels and the anxiety levels in both the groups ($P > 0.05$).

In the analysis of the relationship between the STAI-S scores obtained after the examination and demographic data, no relationships were found with the fathers’ anxiety levels. There was a positive relationship between postexamination STAI-S levels for the mothers and multiple pregnancy status ($P = 0.01, r = 0.14$). Additionally, a positive correlation was found between postexamination VAS levels of the mothers and breastfeeding status ($P = 0.04, r = 0.17$).

Thirty-seven infants (29.1%) in total suffered from ROP in both the study groups, but none of them had ROP severe enough to merit treatment. The groups displayed no significant differences in ROP status ($P = 0.17$, Chi-squared test). With respect to the ROP status and the anxiety levels of parents, it was observed that the ROP status did not significantly affect the anxiety levels of the parents in both the groups and also between the parents ($P > 0.05$).

Discussion

In this study, a slight increase in the anxiety levels of the parents present in the ROP screening examination was observed, especially in the mothers, but this increase was not significant. In the other group, the parents were not included in the examination, but there was a decrease in the anxiety levels, which was more pronounced in the fathers. The change in anxiety levels between the two groups was significant.

Parents of the infants admitted to the NICU (neonatal intensive care unit) have been shown to experience much more anxiety, depression, and stress symptoms than the parents of healthy infants.[6] The main reason for these findings has been attributed to the inability to fulfill parental roles because of both physical and emotional isolation from their infants. Another important stress factor for parents is that their babies suffer pain. This situation seems to be one of the most important stress

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factors compared with the other personal and environmental stress factors. The effect of this anxiety on parents continues even in the long term. During interviews, mothers of 3-year-old infants born preterm and hospitalized in intensive care units reported that their infants’ suffering was one of the most stressful situations in this process.[7]

From this point of view, for the parents who participated in the screenings, the feelings of an inability to protect their infant from the harmful effects of pain during the screening examination may explain the increase in anxiety in the first group. Studies have supported the positive relationship between the infants’ pain and the parents’ anxiety levels. Furthermore, the reason for the increase in anxiety in the mothers may be due to the emotional connections that they establish with the babies during pregnancy and having feelings instinctively to comfort their offspring.[8] It was also reported that the mothers are more concerned than the fathers during painful procedures applied to children.[9]

Interestingly, contrary to expectations, ROP status showed no impact on the anxiety levels of parents in the study. Similarly, Özürt et al.[10] found that having a baby with ROP does not appear to significantly affect the mothers’ anxiety levels. However, Duman et al.[11] discovered that anxiety symptoms in mothers of infants diagnosed with ROP are higher. A possible explanation for the contradictory observations of this study is that no patients suffered from severe ROP requiring treatment or that parents were not fully aware of the negative consequences of ROP.

In fact, 85% of parents in this study were not aware of ROP. Similarly, in a study from our country, Ekinci and Celik[12] found that 63.5% of parents were ignorant of what ROP means. These findings emphasize the need for more parent education on ROP during the intensive care period.

It was shown that mothers with planned pregnancies have more positive feelings about their pregnancy and bond with their child more easily than mothers with unplanned pregnancies.[13] In contrast, mothers of unintended children reported weak mother-to-child bonding and increased negative feelings compared with mothers of children whose birth was intended.[14] In this study, the negative association between trait anxiety levels and planned pregnancy observed in the mothers might be related to the situations mentioned above.

Multiple pregnancies can be stressful for mothers. In a study from Japan, mothers with multiple pregnancies were reported to have higher state anxiety levels than mothers with single pregnancies. Hay et al.[15] reported that, in the early postpartum period, twin mothers had more anxiety symptoms than singleton mothers. Vilska et al.[16] reported greater anxiety in twin mothers at 2 months postpartum than in singleton mothers, and this disparity persisted until 24 months. A positive relationship between postexamination state anxiety levels and multiple pregnancies was found in this study, which may have been caused by the predisposition of these mothers to increase in anxiety.[17]

In addition to maternal stress-reducing effects, breastfeeding also has a maternal bond-increasing effect.[18-20] In this study, a positive association between breastfeeding and postexamination anxiety levels determined in VAS evaluation was observed. This finding might have been caused by the maternal bond-enhancing effect of breastfeeding rather than a maternal stress-reducing effect.

The decrease in anxiety levels in the group of parents not included in the examination is interesting. Normally, although parents are expected to experience more anxiety as a result of being separated from their babies, this situation did not occur; on the contrary, a decrease in anxiety was observed. This may have been caused by the reuniting of the parents with their babies as healthy after the examination. In addition, the anxiety reduction in fathers of babies may have resulted from the traditional role of the father in the family. Fathers play a role in the livelihood and protection of the family.[21] The feeling that they will return to their routine work and life after the examination may have yielded this situation. The relationship between the STAI-T levels of fathers and family income and unplanned pregnancy presented in this study may also be a reflection of this situation. In the literature, it has been shown that the anxiety levels of fathers increased as family incomes decreased.[22]

From the clinician’s perspective, including the parents in the examinations may negatively affect clinicians with the concern that the infant’s pain is too much for the parents to see and manage. This concern could prevent an optimal examination, especially in clinicians with less experience and with longer examination times. In this regard, although many nurses reported that parents play an important role and can be effective in the management of infant pain, most of them were not very willing to involve the parents in pain management because it may add to the parents’ stress or the parents may express a desire to maintain authority over infant care.[23]

This study has certain limitations. First, the study was planned as an observational study at two centers to compare the two different approaches rather than as a randomized study to compare these approaches at a single center. This situation also causes a major limitation to the study. There may be different uncontrolled environmental factors that affect the parents’ anxiety levels in each center rather than being or not being present in the examination room. Second, although parents completed the surveys in a comfortable setting, the difference in how people understand the survey questions depends on their level of education, and this might have provided less standardization than face-to-face interviews. In addition, the less number of fathers in the parent population might be a factor reducing the strength of the results.

Conclusion

In conclusion, the results of this study might be considered as a preliminary opinion that keeping the parents outside the examination room during ROP screening might be a more reliable approach. However, single-center comparative controlled studies with interventions such as making parents hold the baby during screening are required to confirm these results, construe them as clinical recommendations, and determine how to make this experience more pleasant for the parents. Additionally, evaluation of the anxiety states in the parents who remain outside the examination room during a second examination, after being previously included in the screening examination may be helpful.

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Conflicts of interest
There are no conflicts of interest.
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