International Journal of Contemporary Pediatrics
Meena R et al. Int J Contemp Pediatr. 2026 Aug;13(8):1460-1465
https://www.ijpediatrics.com
pISSN 2349-3283 | eISSN 2349-3291

DOI: https://dx.doi.org/10.18203/2349-3291.ijcp20262421

Original Research Article

Study of neonatal outcome during follow-up post neonatal intensive care unit discharge with or without parental observational checklist

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Received: 28 May 2026
Accepted: 03 July 2026

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ABSTRACT

Background: Checklist is a simple intervention tool which helps in early identification and treatment of new-borns. The aim is to study impact of parental observational checklists on neonatal outcomes during the early follow-up period post-NICU discharge.
Methods: An Observational prospective study was conducted in a tertiary institute wherein 135 neonates with weight of 1000 gms to 1500 gms were enrolled. A random sampling was used to form two groups. Parents in group A (n=64) received a structured pictorial checklist in addition to routine discharge advice, while those in group B (n=71) received routine discharge advice. During follow-up at 7th and 28th day checklist was analyzed and both groups were compared in terms of number of readmissions, mortality rates, weight gain, and the number of emergency visits to healthcare workers.
Results: The neonates in group A showed higher follow-up adherence (92.2% vs. 76.1%, p=0.011) and higher weight gain at 28th day with mean weight being 1.90±0.22 kg in checklist group compared to 1.79±0.19 kg in group B (p=0.043). Re-admissions and emergency room visits were higher in the checklist group, reflecting timely health-seeking behaviour. Mortality was lower in the checklist group (4.7% vs. 7.0%). Majority of deaths in group A occurred after hospital admission as compared to group B suggesting earlier recognition and timely referral by checklist group.
Conclusions: Health workers do use checklist but, educating parents with a simple pictorial checklist after NICU discharge significantly improves neonatal survival and follow-up adherence. By early recognition of danger signs, this tool reduces mortality and strengthens post-discharge care in preterm in low- resource setting.

Keywords: Checklist, Family integration, Preterm neonate, Postnatal care, Outcome

INTRODUCTION

Preterm birth remains a major issue worldwide, particularly in developing nations. It significantly contributes to neonatal mortality and morbidity, with associated health challenges often persisting into adulthood, which leads to substantial physical, emotional, as well as financial burdens.[1] According to the World Health Organization, the postnatal period is the time between one hour after the placenta is delivered and six weeks after the birth, during which, the mother and her child go through critical social, emotional, and physiological changes.[2] After delivery, a large number of preterm new-borns need care in the neonatal intensive care unit (NICU). Families and caregivers have particular difficulties while dealing with preterm new-borns which can be made worse if the child is admitted to a NICU. The high costs of delivery and NICU hospitalization sometimes cause parents of these new-borns to experience a great deal of stress once they are discharged

leading to both monetary and emotional consequences.[3,4] A lack of family-centred care, poor staff communication, and staff members unwillingness to modify their work schedules to suit parents can all contribute to emotional problems and decreased parental engagement. After being discharged, some parents experience stress because of their child's health problems, having to reschedule visits, or visiting doctors who are not familiar with their child's medical history and condition. Parents need tailored guidance and resources to ensure appropriate care of new-borns at home.[5] The time when a baby leaves the NICU and goes home is very important as parents becomes the main caretakers. However, taking care of a fragile baby can be very hard and stressful. To overcome this, doctors and nurses often give parents instructions on how to monitor their baby's health and growth at home.[6]

Home-based new-born care (HBNC) is a structured program in India where trained ASHAs provide scheduled home visits to ensure early detection of health issues, promote essential new-born care, and reduce neonatal mortality. However, the days of visit are fixed and limited due to which even when the new born is sick, parents are unable to pick the danger signs early which delays treatment. If we educate parents regarding danger signs and provide them with tools to monitor health issues at home, it can lead to early recognition of danger signs and timely health seeking.[7] In most of the studies checklists are filled by health care workers only, hence involving parents in health monitoring can be beneficial.

Parental observational checklists are one such tool that can empower parents to recognize signs of potential health issues and seek timely medical attention.[8] These checklists typically include guidance on monitoring vital signs, feeding patterns, weight gain, and developmental milestones. Many studies show that use of checklists has enhanced patient safety in intensive care units in developed nations but there are only a few studies which signifies role of checklist in routine follow up.[9] In India, follow-up of new-born's who are discharged from SNCU is done at fixed days, and parents comes for follow up on those days only. Many times, parents do not pick danger signs at home and visit hospital only on scheduled follow up, leading to delayed treatment. Involvement of parents and guardians can help in early identification of danger signs in new-borns. Checklist is a simple intervention tool in local language or pictorial format easy to understand and interpret which further helps in early identification and treatment of new-borns favouring better prognosis.

Although we know the potential benefits of parental observational checklists, there is limited research examining their impact on neonatal outcomes during the post-discharge period. Understanding the effectiveness of these checklists is crucial for optimizing neonatal care and improving long-term outcomes for NICU graduates. This study aims to fill this gap in understanding by looking into impacts of parental observational checklists on neonatal outcomes during the early follow-up period post-NICU discharge.

METHODS

This Observational prospective study was conducted at a tertiary care hospital over a period of 18 months after obtaining written permission from the Institutional Ethics Committee. Total 135 Neonates delivered during the study period with weight of 1000 gms to 1500 gms were enrolled in the study only after obtaining written informed consent from parents. Neonates with any major congenital malformation, Birth weight less than 1000 gms or more than 1500 gms and not willing to participate in study were excluded.

A random number approach was used to form two groups, group A (n=64), group B (n=71). Routine care and danger signs were explained to participants in both groups individually throughout their stay and at the time of discharge. In group A, checklist was filled out once in the ward/SNCU, and parents were asked to fill the checklist daily and bring it during follow-up visits which were scheduled at 7th day and 28th day post-discharge.

The checklist was formulated based on IMNCI principles and validated by two independent subject experts. It was prepared in local languages (Hindi and Marathi) and also included a pictorial format to improve parental understanding. The checklist was explained to the parents by the doctor along with nursing staff in their local language. Parents were instructed to tick the checklist daily or refer to it whenever they were unsure about their child's symptoms, and to contact a healthcare worker if any symptoms were present. During follow-up visits, the checklist was collected and analysed, and the babies' weights were checked. In group B also the follow up was done as scheduled. In both groups data was collected during each follow up visit and upon completion of the study, a comparison was made between the two groups based on the weight gain, follow-up adherence, number of readmissions, mortality rates, and the number of emergencies visits or calls to healthcare workers.

Sample size was calculated using the following formula with total 124 participants (each group having 62 participants).

$$\bar{p} = \frac{(p_1 + m \cdot p_0)}{(m + 1)}$$

$$n = \frac{\left[z_\alpha \cdot \sqrt{\left(1 + \frac{1}{m}\right) \cdot \bar{p}(1 - \bar{p})} + z_\beta \cdot \sqrt{\frac{p_{0(1-p_0)}}{m} + p_{1(1-p_1)}}\right]^2}{(p_0 - p_1)^2}$$

$$n_c = \frac{n}{4}\left(1 + \sqrt{1 + \frac{2(m + 1)}{(nm|p_0 - p_1|)}}\right)^2$$

p_0=proportion (or probability) of outcome in the control group,

p_1=proportion (or probability) of outcome in the intervention group,

$\bar{p}$=weighted/pooled average proportion,

n=the required sample size per group (before applying corrections,

n_c=the final corrected sample size per group (after continuity correction).

Statistical analysis

The statistical analysis was performed using SPSS 27. Descriptive measures, including mean and standard deviation (SD) for continuous data and frequencies with percentages for categorical data, were calculated. The association between categorical variables was assessed using the Chi-square test. To compare the means of quantitative variables across study groups, an unpaired t-test was applied. Visual representation of the analysed results was provided through bar graph. A significance level of 0.05 was considered for statistical tests.

RESULTS

Out of 135 neonates enrolled, total 64 were enrolled in group A and 71 neonates were enrolled in group B. The sex distribution was nearly identical between the two groups, with males comprising 46.9% in group A and 46.5% in group B, and females 53.1% and 53.5%, respectively. There was no statistically significant difference in gender distribution between the groups (χ^2 =0.0, p=0.963), indicating balanced gender representation.

Table 1: Comparison of follow up at 7th day between study groups (n=135).

Follow- up at 7th day	Group A (n=64) N (%)	Group B (n=71) N (%)
Done	60 (93.8)	62 (87.3)
Not done	4 (6.3)	9 (12.7)

Chi-square test, p value=0.206, not significant.

At the 7th day follow-up, completion rates were high in both groups—93.8% in group A and 87.3% in group B. The corresponding loss to follow-up rates were 6.3% and 12.7%, respectively.

At first follow-up (7th day), In group A, the mean weight increased from 1.40±0.10 kg at discharge to 1.56±0.15 kg showing a mean gain of 0.16±0.11 kg, whereas in group B, the mean weight increased from 1.40±0.11 kg at discharge to 1.53±0.15 kg showing a mean gain of 0.13±0.11 kg. This increase was significant statistically (p value=0.020), indicating a meaningful improvement in weight over the follow-up period after excluding cases with missing first follow-up data (Figure 1).

At second follow-up (28th day), In group A, the mean weight increased from 1.56±0.15 kg at the first follow-up to 1.90±0.22 kg with a mean gain of 0.34±0.15 kg, whereas In group B, the mean weight increased from 1.51±0.14 kg at the first follow-up to 1.79±0.19 kg with a mean gain of 0.28±0.15 kg This improvement was highly significant (p value=0.009) demonstrating substantial weight gain during this period after excluding cases with missing second follow-up data.

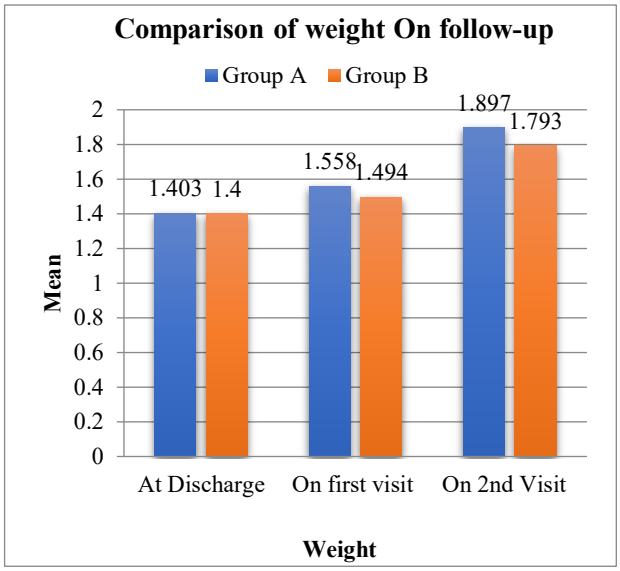

Figure 1: Comparison of weight on follow up visits.

At 7th day, the follow up were high in both groups with 93.8% and 87.3% in group A and group B respectively. The corresponding loss to follow-up rates were 6.3% and 12.7%, respectively. The difference between the groups was not statistically significant (p value=0.206) suggesting that checklist use does not have a notable impact on early follow up adherence, as both groups maintained a low loss to follow up rate during the first week (Table 1).

At 28th day, follow-up was completed by 92.2% of neonates in group A compared to 76.1% in group B. The loss to follow-up rate was notably lower in group A (7.8%) than in group B (23.9%). This difference was statistically significant (p value=0.011), indicating that the checklist was associated with better long-term follow-up adherence and reduced attrition by the end of the first month after discharge (Table 2).

Table 2: Comparison of follow up at 28th day between study groups (n=135).

Follow-up at 28th day	Group A (n=64) N (%)	Group B (n=71) N (%)
Done	59 (92.2)	54 (76.1)
Not done	5 (7.8)	17 (23.9)

Chi-square test, p value=0.011, significant.

Out of the total 64 participants in group A, 58 (90.6%) completed the checklist, whereas only 6 (9.4%) did not. This reflects a very high level of compliance with the checklist protocol, indicating that the majority of participants adhered to the intended follow-up process.

The most common documented reason for loss to follow-up was death after discharge (8 cases, 5.92%), occurring between the 2nd and 21st day post- discharge. The majority (84.44%) continued follow- up without any reported reason for discontinuation. These findings highlight that targeted interventions such as improved communication, financial support, and linkage with peripheral health facilities could help further reduce attrition or deaths (Table 3).

Table 3: Comparison of reason to lost to follow up between study groups.

Reasons	Group A (n=64) N (%)	Group B (n=71) N (%)
Call not received	-	1 (1.4)
Death	3 (4.7)	5 (7.0)
2 to 5 days of discharge	2 (3.1)	1 (1.4)
10 to 14 days discharge	-	3 (4.2)
>14 days discharge	1 (1.6)	1 (1.4)
Financial	1 (1.6)	2 (2.8)
Visit at near PHC	1 (1.6)	7 (9.9)
Child is healthy	-	1 (1.4)

Total 14 babies in group A visited ER out of which 5 babies got admitted with 3 deaths whereas in group B, 9 babies visited ER out of which 2 got readmitted and includes 5 deaths. This means that number of visits to ER and readmissions were higher in checklist group and lower deaths as compared to non-checklist group. Hence, we can conclude that parents were able to pick up danger signs at home and visited emergency room for further diagnosis and treatment (Table 4).

Table 4: Comparison of number of ER visits between study groups (n=135).

	Group A (n=64)	Group B (n=71)
No. of ER visit for hyperthermia	1	1
No. of ER visit for fast breathing	2	1
No. of ER visit for cyanosis	-	1
No. of ER visit for little movements	1	1
No. of ER visit for vomiting	5	3
No. of ER visit for eye discharge	2	2
No. of ER visit for refusal to feed	3	-
Total ER visits	14	9

The proportion of re-admissions was significantly higher in group A (7.8%) compared to group B (2.8%). The difference is statistically significant ($p<0.190$) by Chi-square test, indicating that infants in the checklist group had a higher likelihood of re-admission compared to those without the checklist. The odds ratio suggests that the odds of re- admission were about 2.8 times higher in group A than in group B (Figure 2).

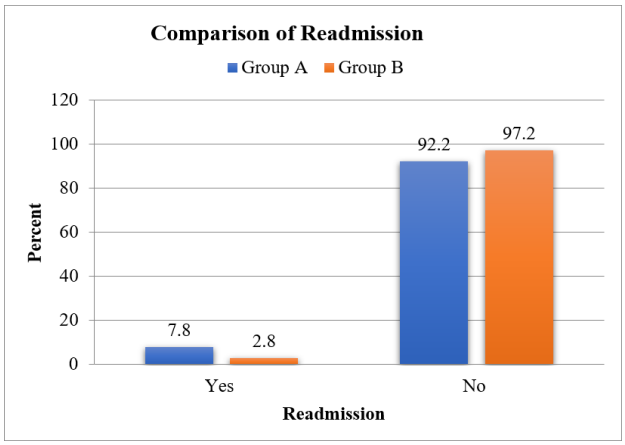

Figure 2: Comparison of readmission between study groups.

There were 3 deaths in group A and 5 deaths in group B. Group B had a higher proportion of deaths before hospital arrival (80%) compared to group A (33.3%).

DISCUSSION

This study found that neonates in a parental checklist monitored group achieved a significantly higher weight gain by their 28 days with the gain of 0.34±0.15 kg as compared to group B with a mean gain of 0.28±0.15 kg. These findings indicate that structured parental monitoring contributed to earlier recognition of feeding or health problems and better adherence to recommended practices. These results align with existing research suggesting that structured parental monitoring and family integrated care programs effectively improve growth outcome and caregiver awareness for preterm infants.[10-14]

The checklist promoted proactive feeding practices and timely recognition of feeding refusal, which was the most common indication for readmission in our study. These outcomes echo findings from O'Brien et al who highlighted that family participation in neonatal care directly improved infant feeding outcomes and weight trajectories.[13]

This study found that while initial follow-up adherence was high in all infants, the use of parental checklist significantly improved long term follow-up, with 92.2% follow up by group A as compared to 76.1% in group B. This finding resonates with prior literature emphasizing the role of structured parental education tools in enhancing continuity of care post-discharge.[13-16]

The checklist group experienced higher rate of hospital emergency room visits and re-admissions, which can be interpreted as a positive sign of early parent recognition of danger signs rather than delayed presentation. The concept of increased healthcare utilization through early parental recognition has been reported in other studies as well.[12-17]

While in group A, 3 deaths occurred and in group B, 5 deaths occurred, though there is difference of two deaths but it makes a very large difference in larger population. The place of death varied notably. In group B, 80% deaths occurred before hospital arrival. Conversely, 66.7% of deaths in group A occurred after reaching the hospital suggesting better recognition of danger signs by parents with checklist as compared to the non-checklist group. These results align with previous Indian research suggesting that caregiver education and structured follow-up can prevent avoidable neonatal deaths.[18,19]

The parental observational checklist provided a simple, pictorial, and easy-to-use tool that improved adherence to follow-up, enhanced recognition of neonatal danger signs, and timely healthcare-seeking. While digital follow-up program significantly improved maternal competence in caring for new-borns at home with fewer complications, this simple paper-based checklist is advantageous in rural and resource-limited settings, where internet connectivity and smartphone availability may be inconsistent.[20]

Research in rural India, such as the Gadchiroli field trial19 and SNCU+ initiatives proves that structured home visits and caregiver education, significantly reduce neonatal mortality. While community programs like HBNC have been successful, this study shows that providing parents with simple paper-based checklist after hospital discharge can yield similar benefits especially in areas with limited resources and technology.

The strengths of our study is that it is among the few prospective studies in India to directly assess the role of a structured parental checklist in neonatal follow-up after NICU discharge. The study used objective clinical outcomes which minimize recall bias. This checklist was used in addition to routine home-based new-born care. The high compliance with the checklist suggests good feasibility and acceptability among caregivers. The inclusion of both short-term (7-day) and longer-term (28-day) follow-ups allowed a nuanced understanding of how adherence patterns evolve over time.

The limitations of this study were premature discharge due to resource constraints, relatively small sample size, short follow-up duration and loss to follow-up.

CONCLUSION

Future studies should ensure balanced cohorts at baseline or adjust for confounders in analysis. Extend follow-up to 6-12 months to capture growth trajectories, morbidity, and mortality, as recommended in international guidelines. Explore digital adaptations of the checklist for scalability, consistent with emerging digital follow-up programs.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: The study was approved by the Institutional Ethics Committee

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Cite this article as: Meena R, Ahire NV, Ballaiya R, Shinde SS, Patil SV. Study of neonatal outcome during follow-up post neonatal intensive care unit discharge with or without parental observational checklist. Int J Contemp Pediatr 2026;13:1460-5.