



Where Should the Transition of Newborns Who are Technology Dependent and in Need of Support to Home Care in Turkey?

Türkiye’de Teknoloji Bağımlı ve Destek İhtiyacı Olan Yenidoğanların Evde Bakıma Geçişi Neresi Olmalıdır?

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Abstract

Introduction: The discharge rates of newborns dependent on medical technology and in need of palliative care have increased. Specialized care units aimed to reduce patient load in neonatal intensive care units (NICU), and increase the quality of home care. In our country, there are few specialized care units for these patients. This study aimed to determine the characteristics of patients who were hospitalized in NICU and transferred to pediatric intensive care unit (PICU) due to continuing care.

Methods: The data of patients who were hospitalized in NICU between January 1, 2008 and July 31, 2022 and transferred to PICU were analyzed.

Results: Twenty (51%) of 39 patients were male, 46% had congenital anomaly(s), 33% had neurometabolic diseases. Forty-nine percent (n=19) of patients died during PICU stay, 2.6% (n=1) died after discharge. Demographic findings of died and survived patients were similar. Ninety percent of patients received invasive respiratory support (IRS) for a median of 43 days during NICU, 97% received IRS for a median of 31 days during PICU. Percutaneous endoscopic gastrostomy (PEG) and tracheostomy were performed 31%, and 51% of patients, respectively. The median length of stay in NICU and PICU were 55 days and 37 days, respectively. The discharged patients had a higher rate of PEG or tracheostomy (p<0.05).

Conclusion: Establishment of specialized care units is important to provide comprehensive, family-centered care to newborns who need palliative care, to reduce the burden on NICUs and PICUs. This study, which is first in our country, will lead to future studies for establishment of specialized care units.

Keywords: Pediatric intensive care, palliative care, neonatal intensive care

Öz

Giriş: Neonatoloji alanındaki gelişmelerle birlikte tıbbi teknolojiye bağımlı ve palyatif bakım ihtiyacı olan yenidoğanların sayısı ve bu hastaların taburculuk oranları artmaktadır. Taburculuğa hazırlık için kurulan donanımlı bakım ekipleriyle yenidoğan yoğun bakım ünitelerindeki (YYBÜ) hasta yükünün azaltılması, hasta ve ailelerine multidisipliner bakım hizmetleri verilerek evde bakım kalitesinin artırılması amaçlanmaktadır. Ülkemizde, bu hastalara yönelik özelleşmiş bakım birimlerinin sayısı çok azdır. Çalışmamızda, YYBÜ’ne yatırılmış, tıbbi teknoloji bağımlılığı veya palyatif bakım ihtiyacı devam ettiği için çocuk yoğun bakım ünitesine (ÇYBÜ) devredilen hastaların özelliklerinin belirlenmesi amaçlanmıştır.

Yöntemler: Çalışmamızda 1 Ocak 2008-31 Temmuz 2022 arasında YYBÜ’nde yatan ve tıbbi teknoloji bağımlılığı veya palyatif bakım ihtiyacı devam ettiği için ÇYBÜ’ne devredilen hastaların verileri, geriye dönük olarak incelenmiştir.

Bulgular: Otuz dokuz hastanın 20’si (%51) erkek olup, %46’sında doğuştan anomali(ler), %33’ünde nörometabolik hastalık tanıları mevcuttu. Hastaların %49’u (n=19) ÇYBÜ takibindeyken, %2,6’sı (n=1) taburculuk sonrasında kaybedilmişti. Kaybedilen ve taburcu olan hastaların demografik ve tanılal özellikleri benzerdi. Hastaların %90’ı YYBÜ yatış sürecinde ortalama 43 gün invaziv solunum desteği (İSD) almışken, ÇYBÜ yatış sürecinde %97’si ortalama 31 gün İSD almıştı. Hastaların %31’ine YYBÜ veya ÇYBÜ yatışı sürecinde perkütan endoskopik gastrostomi (PEG), %51’ine trakeostomi açılmıştı. YYBÜ ve sonrasında ÇYBÜ yatış süreleri ortalama sırasıyla 55 gün ve 37 gündü. PEG ya da trakeostomili olma durumu, taburcu olanlarda kaybedilenlere göre daha fazlaydı (p<0,05).

Sonuç: Tıbbi teknoloji bağımlılığı olan yenidoğanlara kapsamlı ve aile merkezli bakımın sağlanabilmesi, YYBÜ ve ÇYBÜ’ler üzerindeki yükün azaltılabilmesi için kompleks bakım birimlerinin kurulması önemlidir. Ülkemizde bu alanla ilgili bir ilk olan çalışmamızın gelecek çalışmalara ve kompleks tıbbi bakım ve palyatif birimlerinin kurulmasına öncülük edeceğini düşünmekteyiz.

Anahtar Kelimeler: Çocuk yoğun bakım, palyatif bakım, yenidoğan yoğun bakım

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Introduction

Globally, 2.4 million infants died in the first month of life in 2020, and neonatal mortality accounts for almost half (47%) of all deaths in children under 5 years of age. Most neonatal deaths (75%) occur in the first week of life and are most commonly caused by prematurity, birth-related complications (such as birth asphyxia) and congenital anomalies.¹ However, in recent years, with the developments in the field of neonatology, the number of extremely premature newborns and newborns with chronic diseases and the life expectancy for those having diseases such as hypoxic ischemic encephalopathy and severe congenital anomalies, who were previously lost in the early stages of life, have been gradually increasing.^{2,5}

These changes in the field have created the need for two important patient groups and associated definitions. Medical technology-dependent neonates are defined as infants who are dependent on a medical device such as invasive or non-invasive mechanical ventilation with tracheostomy, nasogastric catheter feeding, parenteral nutrition, cardiovascular monitoring, airway care and aspiration.^{6,7} Palliative care is defined as the organization of end-of-life care and refers to an active and holistic approach to meet the physical, emotional, social and spiritual needs of the patient and family.⁸ In newborns, almost all patients with life-limiting diseases who need palliative care are also dependent on medical technology.

In many centers around the world, equipped care teams and units are established to meet the care needs of these babies, and it is aimed to increase the quality of home care and reduce hospitalizations after discharge by providing more comprehensive, family-centered, specialized and multidisciplinary care services to patients and their families.⁹⁻¹¹ In a survey conducted in 2022 with pediatricians in four major cities in our country, it was found that 19.1% of the centers had a pediatric palliative care unit.¹²

Since the number of specialized teams and centers for both technology-dependent supportive patients and palliative care patients is insufficient in our country, these patients are transferred to pediatric intensive care units (PICUs) in many centers for the continuation of their treatment and follow-up after completing the neonatal period. This situation increases infections due to chronic patient follow-up in PICUs, leads to loss of workforce and motivation of the team, decreases bed turnover rate, causes bed occupancy and problems in the admission of real intensive care patients. In this study, we aimed to evaluate the characteristics of patients who were transferred to PICU after NICU follow-up in our hospital due to medical technology dependency and palliative care need and lack of palliative care unit.

Materials and Methods

Patients who were hospitalized in Ankara University Faculty of Medicine NICU between January 1, 2008 and July 31, 2022 and who were transferred to the PICU after completing the neonatal period due to medical technology dependence or continued need for palliative care were included in the study. Demographic data, hospitalization diagnosis, duration of invasive respiratory support (IRS), percutaneous endoscopic gastrostomy (PEG) and tracheostomy interventions, and survival status of the patients were retrospectively recorded from their files. Data of lost and discharged patients were compared. Tracheostomy opening on day ≥ 14 in a patient who received IRS was defined as late tracheostomy.¹³

Between January 2008 and February 2014, Ankara University Faculty of Medicine NICU served as a tertiary intensive care unit with 24 beds and PICU served as a secondary intensive care unit with 6 beds. As of February 2014, the NICU continues to serve as a tertiary intensive care unit with 30 beds and PICU continues to serve as a tertiary intensive care unit with 20 beds.

The study was approved by the Ankara University Faculty of Medicine Clinical Research Ethics Committee (103-126-23).

Statistical Analysis

Statistical analyses were performed using standard statistical software (IBM SPSS 22). Continuous variables were expressed as mean and standard deviation or median [interquartile range (IQR) (25-75%)]. Categorical variables were expressed as numbers and percentages. The chi-square test was used to compare nominal variables and the Mann-Whitney U test was used to compare means. In all analyses, $p < 0.05$ was used to indicate statistical significance.

Results

During the study period, 39 (0.4%) of a total of 9242 patients admitted to the NICU were transferred to the PICU. Of the 39 patients, 20 (51%) were male, the median gestational week was 37.6 weeks (IQR: 34.1-38.5 weeks) and the mean birth weight was 2422 ± 632 g. The comorbidities in the patients were congenital anomalies (46%) and neurometabolic disease (33%) in order of frequency. Table 1 shows the demographic and diagnostic characteristics of the patients.

Of the patients, 49% (n=19) died during PICU follow-up and 2.6% (n=1) died during post-discharge follow-up. Demographic and diagnostic characteristics of the discharged and deceased patients were similar (Table 1). Eight (42%) patients died due to cardiac arrest, 7 (37%) due to septic shock and 4 (21%) due to respiratory failure.

90% of the patients received IRS for a median of 43 days (IQR: 9-53 days) during NICU hospitalization and 97% of the patients received IRS for a median of 31 days (IQR: 11-47 days) during PICU hospitalization. PEG was opened in 23% of patients in the NICU and 8% in the PICU, while tracheostomy was opened in 15% of patients in the NICU and 36% in the PICU.

The median lengths of NICU and then PICU stay were 55 days (IQR: 43-77 days) and 37 days (IQR: 14-62 days), respectively. The rate of PEG or tracheostomy was higher in those who were discharged compared to those who were lost ($p < 0.05$) (Table 2).

When the calculation was made according to the bed capacity used during the study period, it was found that infants who were dependent on medical technology and needed palliative care used 3% of the NICU capacity and 3.9% of the PICU capacity.

Discussion

In recent years, medical technology dependency of extremely premature infants, whose survival and discharge rates have increased with advances in neonatology and medicine, has been increasing, and some of these infants can be discharged home with respiratory and nutritional support. Similarly, newborns with complex chronic diseases that limit life expectancy can be discharged home with medical devices. Education and preparation for discharge of these two vulnerable groups of patients and their families are a difficult and long process.³⁻⁵ This group of patients who are followed up in the NICU of our hospital are transferred to the PICU if the need for intensive care continues after completing the neonatal period, as in most of the centers in our country. In this study, in which the characteristics of patients who were transferred to the PICU after NICU follow-up due to medical technology dependence and palliative care need were

evaluated, it was found that 39 patients hospitalized in the NICU were transferred to the PICU in a 15-year period.

The majority of newborns who are dependent on medical technology are extremely premature infants and infants with congenital anomalies, neurometabolic diseases or genetic and chromosomal anomalies.⁹ In a study by Kieran et al.,⁹ it was found that 48% of the patients were diagnosed with genetic/chromosomal diseases, 26% with extremely premature, 12% with neurometabolic disease and 11% with congenital anomaly. In our study, 46% of the patients who were transferred to the PICU due to continued dependence on medical technology had a diagnosis of congenital anomaly and 33% had a diagnosis of neurometabolic disease.

In a study of neonates in need of complex care, it was reported that 58% of patients were discharged with tracheostomy and 69% with PEG,¹⁴ while another study showed that 40% had technology dependency (tracheostomy, PEG, cardiorespiratory monitoring, supplemental oxygen) at discharge.¹⁵ A study by Kieran et al.⁹ showed that 91% had technology dependency (tracheostomy, supplemental oxygen, PEG, nasogastric catheter, total parenteral nutrition, central venous catheter, ventriculoperitoneal shunt, cardiorespiratory monitoring) at discharge. In our patients, 90% received IRS during NICU hospitalization and 97% during PICU hospitalization; PEG was opened in 31% and tracheostomy in 51% of the patients during NICU or PICU hospitalization.

It has been reported that neonates in need of complex medical care should be given care by specialized multidisciplinary teams.^{16,17} These practices have been shown to improve care coordination and family education, facilitate the transition of newborns to home and/or community and shorten the duration of hospitalization.^{9,15} Identifying patients in need of complex medical care during their hospitalization allows the development of innovative complex care models that focus on the needs of patients and families. The transition from hospital to community care is a very difficult process,

Table 1. Demographic and diagnostic characteristics of patients

	Total number of patients (n=39)	Deceased patients (n=20)	Discharged patients (n=19)	p
Gestational age, <34 weeks, n (%)	7 (17.9)	5 (25)	2 (10.5)	0.239
≥34 weeks, n (%)	32 (82.1)	15 (75)	17 (89.5)	
Sex (male), n (%)	20 (51.3)	13 (65)	7 (37)	0.079
Delivery method (CS), n (%)	29 (74.4)	14 (70)	15 (78.9)	0.522
Distribution of diagnosis, n (%)				
Congenital anomaly(s)	18 (46.2)	11 (55)	7 (36.8)	0.170
Neurometabolic disease	13 (33.2)	5 (25)	8 (42.1)	
Acquired brain injury	5 (12.8)	1 (5)	4 (21.1)	
Multiple organ failure	1 (2.6)	1 (5)	0	
Genetic disease	2 (5.1)	2 (10)	0	
CS: Caesarean section				

Table 2. Duration of treatment and hospitalization length of discharged and deceased patients

	Total (n=39)	Deceased (n=20)	Discharged (n=19)	p
With PEG, n (%)	12 (30.8)	3 (15)	9 (47.4)	0.029*
With tracheostomy, n (%)	20 (51.3)	3 (15)	17 (89.5)	<0.001*
Duration of NICU hospitalization (day)*	55 (43-77)	49.5 (42.25-74.5)	66 (46-86)	0.411^
Duration of PICU hospitalization (day)*	37 (14-62)	36.5 (12.5-54)	41 (18-65)	0.461^
Total duration of MV (day)*	72 (31-115)	66.5 (26.5-102.25)	79 (43-147)	0.411^
Total hospitalization length	99 (72-142)	95 (67.5-125)	107 (79-181)	0.411^

*: Median (IQR), †: Chi-square test, ^: Mann-Whitney U test, PICU: Pediatric intensive care unit, MV: Mechanical ventilation, PEG: Percutaneous endoscopic gastrostomy, NICU: Neonatal intensive care unit, IQR: Interquartile range

especially for families of infants with chronic care needs. The most appropriate approach is to establish complex care units and teams to improve parenting skills and thus improve outcomes for infants and their families, and to involve families in the care of their infants as soon as possible in these care units.

In our country, infants continue to be hospitalized in NICUs or transferred to PICUs after completing the neonatal period due to the lack of specialized units and palliative care centers that play a role in the transition of newborns with complex medical care needs and ongoing technology dependency to home care. Similar to the hospitalization durations reported in the literature,⁹ the median durations of both NICU and PICU hospitalization were 55 days (IQR: 43-77 days) and 37 days (IQR: 14-62 days), respectively. When the bed capacity used during the study period was calculated, it was found that infants who were dependent on medical technology and needed palliative care used 3% of the NICU capacity and 3.9% of the PICU capacity. Considering that only 39 patients were followed up in our hospital for medical technology dependency and palliative care needs in the 15-year period covering the study period, it can be said that this patient group used a significant portion of the intensive care unit beds due to their long hospitalization periods. In our country with a high birth rate, very long hospitalization periods make it difficult to admit new patients to NICUs. PICUs accept patients between 0-18 years of age for many reasons, such as the need for advanced cardiorespiratory support, major traumas, poisonings, renal replacement therapies and complex postoperative care after major surgeries. In addition to the limited capacity of PICU beds to provide these services in our country, the

number of PICU specialists is far below the needs of our country. Although the critical intensive care process does not continue, the continued long-term hospitalization of infants in the PICU due to the need for complex care and technology dependency makes it difficult to admit patients who need advanced intensive care and specialized treatments, and prevents the use of the workforce of healthcare personnel such as physicians and nurses in necessary areas. Pediatric palliative care is a new field for our country and there are very few centers providing pediatric palliative care. On the other hand, while a child in need of palliative care should be handled with a family-centered, holistic approach in all aspects of physical, mental and spiritual life, these needs can only be partially met in dynamic NICUs and PICUs where the patient cycle is faster. The difficulties in the establishment of these care units include the need for the training of competent and experienced personnel, the need for team formation and the necessity to plan cost-effectiveness studies.^{9,18}

Study Limitations

The limitations of our study include the small number of patients, the lack of objective clinical scoring that can express the severity of the patients, its being a descriptive, single-center and retrospective study in which different practices were not compared, and the lack of cost-effectiveness analysis. We think that our study is important in terms of taking steps towards the establishment of complex medical care and palliative units, which we think is an important need in our country.

Under the conditions of our country, the patient density, which is quite high according to the limited bed capacity and insufficient number of specialist physicians, can only be overcome with the proper use of trained and experienced manpower. We believe that establishing complex medical care and palliative care centers in each province, taking into account the number of neonatal and intensive care patients, and using these centers as an intermediate step before discharge for patients dependent on medical technology can provide a more effective service without disrupting NICU and PICU services.

Conclusion

In conclusion, NICUs and PICUs are units where patient turnover is rapid and treatment and care services are provided to a large number of infants with limited bed capacity. Neonates with medical technology dependence constitute a significant proportion of total intensive care unit hospitalizations due to prolonged hospitalization. It is important to establish complex care units to provide comprehensive and family-centered care to this patient group after the neonatal period in order to

reduce the burden on both NICUs and PICUs. These units should aim to counsel parents, plan health care resources, shorten length of stay in intensive care units and plan post-discharge care coordination interventions.

Ethics

Ethics Committee Approval: The study was approved by the Ankara University Faculty of Medicine Clinical Research Ethics Committee (103-126-23).

Informed Consent: Retrospective study.

Authorship Contributions

Surgical and Medical Practices: F.D., M.H., Y.E.K., H.Ö., A.G., F.K., E.O., Ö.E., B.A., T.K., S.A., Concept: E.O., Ö.E., B.A., T.K., S.A., Design: M.H., A.G., E.O., Ö.E., B.A., T.K., S.A., Data Collection or Processing: F.D., M.H., Y.E.K., H.Ö., A.G., F.K., Analysis or Interpretation: F.D., M.H., Y.E.K., H.Ö., A.G., F.K., E.O., Ö.E., B.A., T.K., S.A., Literature Search: F.D., Y.E.K., H.Ö., F.K., Writing: F.D., E.O., Ö.E., T.K.

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