

Clinical Profile and Outcome of Newborns Discharged Against Medical Advice From a Tertiary Care Centre

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Objective: To determine the clinical profile and outcome of neonates discharged against medical advice (DAMA) from the neonatal intensive care unit (NICU) of a tertiary care public hospital. **Methods:** We retrieved information from hospital records of infants who had been discharged against medical advice from the NICU between January, 2016 and December, 2020. This was followed by a telephonic interview to document the infant's outcome. **Results:** Out of the 187 (7.7%) neonates that had left DAMA, 165 case records were available, and 65 (39%) families could be contacted telephonically. Congenital malformations accounted for 96 (58%) of the cases; cardiac malformations accounting for 42 (43.7%). 52 (80%) out of the 65 infants had died after median (IQR) 11 (5-35) days of DAMA, and 13 (20%) were alive at a median (IQR) age of 31 (18.5-31.5) months. Post-DAMA medical care was continued at another health facility in 12 (18%). **Conclusions:** One out of every five infants was alive for a median age of 31 months after having left DAMA. Mechanisms to ensure continuation of care after DAMA need to be explored.

Key words: Comorbidity, Management, Outcome, Survival

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The Ministry of Health and Family Welfare (MoHFW), reports the rate of discharge against medical advice (DAMA) to be 4% among inborn and 7% among out born neonates [1]. Previous studies on neonates with DAMA have focused on patient profiles and causes [2,3]. However, no study from India has sought to find out the outcome of neonates who left after DAMA. Post-DAMA continuation of care is another aspect that remains unexplored. Suffering from life-limiting conditions, many of these infants deserve palliative care, a practice that is not widely followed in our country [4]. Assessing the burden of post-discharge mortality and morbidity in these neonates is necessary for ensuring continuity of medical care for these neonates, and might also serve as a stepping stone in scaling up neonatal palliative care services in our country.

METHODS

This cross-sectional study was conducted in the newborn follow up clinic of a public sector tertiary care hospital between July and December, 2020 after obtaining institutional ethics committee clearance. A list of all infants discharged against medical advice from our NICU between January, 2016 and December, 2020 was prepared. The case records of these infants were traced from the medical records department, and contact numbers of families retrieved. All these newborns were eligible for inclusion in

the study. There were no exclusion criteria. Their clinical details were noted in the study form.

Major congenital malformations were defined as congenital anomalies that have medical, surgical, or cosmetic consequences [5]. As many of the infants had involvement of multiple systems, the authors decided by consensus to determine the predominant morbidity or the primary illness during the NICU stay.

Two research nurses called up these families. A family was labeled as 'not attended' if two phone calls made 24 hours apart went unanswered. If the family responded, verbal consent for participation was obtained, structured interview was carried out based on the study questionnaire. The questionnaire consisted of open-ended questions on the cause of DAMA, the infant's outcome, age of death in case the child had died, and if medical care was sought elsewhere after leaving the hospital. The calls were not recorded. A call log book was maintained and the replies were noted down in the study form.

Statistical analysis: Descriptive statistics were employed to present the results, after analysis using Microsoft Excel 2013. Gestational age and birth weight had a non-normal distribution, and were expressed as median with IQR. All categorical variables were expressed as percentages.

RESULTS

During the study period, 2407 newborns were admitted to the NICU, of which, 187 (7.7%) had been discharged against medical advice. During these 5 years, a falling trend in the number of DAMAs was noted from 10.9% in 2016, to 6.7% in 2020. Contact details and case records of only 165 neonates [median (IQR) birthweight, 2425 (1665–2910); $n=160$] could be retrieved. All of these 165 phone numbers were called of which 97 calls were unsuccessful (wrong number or not attended) and three families refused consent. Finally, 65 families (39.3%) participated in the telephonic interview.

More than 60% (102 out of 165) of DAMA infants were

Table I Clinical Characteristics and Outcome of Neonates Discharged Against Medical Advice ($N=165$)

Characteristics	Value
Gestational age, wk ($n=163$) ^a	37 (34,39)
<i>Gestational age categories ($n=163$)</i>	
Extremely preterm (<28 wk)	7 (4.3)
Very preterm (28–31 wk)	15 (9.2)
Moderate preterm (32–33 wk)	12 (7.3)
Late preterm (34–36 wk)	27 (16.5)
Term (≥ 37 wk)	102 (62.5)
Inborn neonate	142 (89)
Day of life at DAMA ^a	5 (2,10)
Ventilated during the hospital stay	53 (32)
Infants eligible for comfort care	33 (20)
Soon after birth	14
During course of treatment	19
DAMA after few days of decision for comfort care	23
DAMA immediately after decision for comfort care	10
<i>Primary diagnosis associated with DAMA</i>	
Congenital malformations ^c	96 (58)
Cardiac	42 (43.7)
Neurological	27 (28)
Syndromic /multiple anomalies ^b	15 (15.6)
Gastrointestinal	6 (6.2)
Hypoxic ischemic encephalopathy	23 (13.9)
Complications of prematurity	18 (10.9)
Neonatal sepsis	10 (6)
Miscellaneous ^d	7 (4.2)
Inborn errors of metabolism	3 (1.8)
Diagnosis unclear ^e	8 (4.8)

Data presented as no. (%) or ^amedian (IQR). DAMA-discharged against medical advice. ^bincludes 5 neonates who had heart disease as part of their syndrome/multiple anomalies; ^ctwo babies each had congenital renal anomalies, congenital diaphragmatic hernia, and miscellaneous condition; ^dincluded epidermolysis bullosa, Neonatal lupus, congenital nephrotic syndrome, term newborn with neonatal jaundice, term newborn with hypoglycemia, term newborn with meconium aspiration syndrome; ^eNeonatal illness leading to DAMA could not be determined from the case record.

term, 100 (60%) were females, median gestational age at birth being 37 weeks (IQR 34–39 weeks). The median age at DAMA was 5 days. The commonest morbidities in these infants were major congenital malformations in 96 (58%), followed by perinatal asphyxia in 23 (14%) (**Table I**). Complications of prematurity like extreme prematurity, respiratory distress syndrome, necrotizing enterocolitis, intraventricular hemorrhage and post-hemorrhagic hydrocephalus accounted for 18 (11%) of the cases and sepsis for another 10 (6%). Among congenital malformations, cardiac diseases followed by disorders of the central nervous system accounted for 42 (43.7%) and 27 (28%) of the cases, respectively. Among those in whom congenital heart disease was the major morbidity, 37 were isolated and 5 were associated with syndromes/anomalies. There were 11 cases of hypoplastic left heart syndrome (HLHS), 22 cases of other cyanotic heart diseases, and three infants with acyanotic conditions. In six neonates, a clinical diagnosis of complex congenital heart disease was made as the child had been taken DAMA even before echocardiographic confirmation could be done. Among neonates who were primarily syndromic or with multiple anomalies, five had heart disease- four acyanotic and one unconfirmed. In 5% the primary illness leading to DAMA was not evident from the case record. Eligibility for comfort care was found in 33 (20%) of the infants. In 14 of them, the decision for comfort care was taken soon after

Table II Characteristics of Infants Followed-up Telephonically After Discharge Against Medical Advice ($N=65$)

Characteristics	Value
Maternal age ^a , y	27 (24,29)
Paternal age ^a , y	31 (30,35)
<i>Primary diagnosis</i>	
Congenital malformations	40 (61.5)
Cardiac	21
Neurological	7
Others	12
Hypoxic ischemic encephalopathy	9 (13.8)
Complications of prematurity	4 (6)
Miscellaneous conditions	9 (13.8)
Diagnosis unclear ^b	3 (4.6)
<i>Reason for DAMA</i>	
Poor prognosis	48 (73.8)
Wanted better care	16 (24.6)
Social reasons	1 (1.5)
Sought medical care elsewhere after DAMA	12 (18.4)
Alive	13 (20)
Age at death ^a	11 (5, 35)
Age at follow-up ^a , mo	31 (18.5, 35.5)

Data presented as no (%) or ^amedian (IQR). ^bNeonatal illness leading to DAMA could not be determined from the case record. DAMA-discharged against medical advice.

birth. These included 11 cases of hypoplastic left heart syndrome (HLHS), 2 cases of anen-cephaly, and 1 case of suspected Edward's syndrome. In the remaining 19, the decision was taken during the course of treatment (**Table I**). In these 33 infants, the treating team was convinced about the cessation of aggressive medical care and redirection to comfort care as the best option. In all other cases required treatment was offered.

The details of neonates, whose parents participated in the telephonic follow-up, are provided in **Table II**. The telephonic interview with 65 families revealed poor long-term prognosis as the commonest reason cited for DAMA by parents in 48 (74%). Fifty-two infants (80%) had died after median (IQR) 11 (5-35) days of DAMA. Thirteen (20%) were alive at a median (IQR) age of 31 (18.5-31.5) months. Only 12 (18.4%) had sought medical care elsewhere after DAMA, of which, 5 survived (38.4% of all survivors) and 7 did not survive (13.4% of all non-survivors).

DISCUSSION

Between 2016 and 2020, the rate of DAMA in our unit was 7.7%. Congenital malformations, especially cardiac conditions, were the commonest morbidity associated with DAMA. After DAMA, 13 (20%) infants were alive at a median age of 31 months. Only 12 (18%) were given the benefit of continued medical care.

Although the MoHFW has reported the rate of DAMA to be 4% among inborn and 7% among outborn neonates [1], neonatal units from India have published DAMA rates ranging from 10% to 25% [2,3,6]. As inborns account for more than 90% of our NICU admissions, most of the infants discharged against medical advice were inborn (89%). Gender bias in medical care of children is a well-known phenomenon [7], reflected in our study by the higher proportion of female infants being taken DAMA. Term neonates had been taken DAMA more commonly than preterm ones because congenital malformations, the single largest contributing cause were more common among newborns with term gestation. Most studies report DAMA to be commonest within the first week of admission [2,8,9], similar to the median of 5 days in this study.

Sepsis, birth asphyxia and low birth weight (LBW) have been reported as the commonest morbidities associated with DAMA [2,3,8,9]. In our study congenital malformations followed by sepsis, perinatal asphyxia and prematurity related conditions were the main neonatal illnesses associated with DAMA. Being a tertiary level hospital we receive referrals of antenatally detected congenital anomalies. With outcomes of common neonatal morbidities being reasonably good, congenital malfor-

mations became the leading morbidity in DAMA. Majority of the malformations were cardiac in nature. Intervention for HLHS, of which we had 11 babies, is not offered in most centers in India, including ours. For duct dependent pulmonary circulation situations, our center performed Blalock-Taussig (BT) shunt until 2019, after which ductal stenting was also offered. All these conditions require definitive surgery at a later age. Despite advances in cardiac care, congenital heart diseases in our country remain largely untreated [10]. We found poor prognosis to be the commonest cause of DAMA. Apart from an obviously poor chance of survival, prolonged hospital stay, food and lodging expenses even if treatment is free, need for multiple surgeries and overall compromised quality of the child's life were factors that were most probably perceived as 'poor prognosis' by parents. Poor outcome has been universally identified as a cause of DAMA [2,3,9,11,12].

Post-DAMA continuation of medical care was sought in 18% of the children. Garten, et al. [13] reported 1.5% of newborns to have been subjected to comfort care in their NICU, of which 8.7% had been discharged home or into a hospice. Jiang, et al. [14] estimated a 7% absolute reduction of mortality among very preterm infants, assuming neo-nates who had been discharged against medical advice had not done so and had actually completed medical care. Continued provision of care after DAMA might be a way to reduce mortality in these neonates. Parents should be encouraged to bring the child for follow-up and physicians to be ready to readmit the child, if necessary, even after DAMA.

The study is limited by its retrospective single center nature, in addition to a large proportion of missing data. In cases of multi-system involvement, retrospectively determining the primary illness associated with DAMA is fallacious. A prospectively conducted study with preferably a qualitative arm and live rather than telephonic interviewing may more conclusively document the reasons for DAMA. The study; however, has brought to light a previously unaddressed area viz., of outcomes following DAMA. Studies involving follow-up of NICU DAMA infants would help understand the course and outcomes of these infants.

In our tertiary level NICU, congenital heart diseases were the single largest contributor to neonatal DAMA. Medical care was available to only a small number of these children. Continued provision of medical care after DAMA, whether with curative or palliative intent, is an area that deserves more attention from both policymakers and public health experts.

Ethics clearance: IEC, JIPMER; No. JIP/IEC/2019/355 dated Oct 18, 2019.

WHAT THIS STUDY ADDS?

- Congenital malformations, especially congenital heart diseases, were the commonest diagnosis in neonates discharged against medical advice.
- Only one-fifth of newborns discharged against medical advice from the neonatal intensive care unit were alive at a median age of 31 months.

Contributors: NM: conceived the study, collected data and drafted the manuscript; SS: designed the study protocol, performed the analysis and critically revised the manuscript. Both authors approved the final manuscript. NM should be approached for access to raw data.

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