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Original Article

Paediatrics Section

# Profile and Outcome of DAMA among Paediatric Patients from a Tertiary Care Centre of a Non Profit Private Teaching Institute at Gujarat, India

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## ABSTRACT

**Introduction:** The problem of Discharge Against Medical Advice (DAMA) has been reported globally, including in patients of the paediatric age group. Even the Indian subcontinent faces such problems, whether, it is the private sector or public sector. Terminal illness, low affordability, social reason are a few of the common reasons for this DAMA problem.

**Aim:** To know the outcome and demographic profile of DAMAs among paediatric patients at a tertiary care teaching institute.

**Materials and Methods:** This mix-method, prospective descriptive study was conducted in Department of Paediatrics, Pramukhswami Medical College and Shree Krishna Hospital, Karamsad, Gujarat, India, from March 2020 to February 2021. Contact details of patients, whose parents took DAMA from the hospital, were retrieved from the Electronic Health Record system. Interviews were recorded and the required information was gathered. Median (interquartile range), frequency, percentage and proportion of age, sex, diagnosis, and reasons of DAMAs derived.

**Results:** Out of a total of 1752 registered paediatric patients (1 month to 18 years), 74 patients were given DAMA, of which 42 consented to interview. The mean age was 70.36±67.9 months and 65% were males. Amongst these 42, 31(73.81%) were taken to home and 11 (26.19%) to another hospital; 20 (47.62%) patients died. Among the rest, 6 (14.28%) had morbidity. Total deaths were 20, out of which six died within one hour, another four died within 24 hours, two died within 7 days and rest eight were died any time after 7 days till contacted. Family or social reason was the top cause of DAMA, whereas, poor prognosis with or without affordability issues was next. Among all diagnoses, nearly half of the cases were infectious/inflammatory, 10% tumour/malignancy, and 6.14% trauma/head injuries.

**Conclusion:** DAMA rate was not high in this study. But this was not preventable in majority of the cases as poor prognosis as well as family or social reasons were the major causes of DAMA.


**Keywords:** Electronic health record, Discharges against medical advice, Morbidity, Poor prognosis, Terminal illness

## INTRODUCTION

Discharge Against Medical Advice (DAMA) refers to instances in which patients are discharged from a healthcare setting against the advice of their clinician. Patients who leave against medical advice are both a challenge and concern for physicians as these patients are lost to follow-up, and their outcomes remain unknown [1]. Incidence, reasons, and outcome of DAMA have not been adequately studied but can have a significant impact on the evaluation of quality of care [2]. The exclusion of these patients from analysis of research studies and quality audits such as calculation of standardized mortality ratio confounds results and reports. DAMA has also been shown to be associated with significantly higher risk of morbidity and mortality, hospital readmission, and higher costs for the subsequent care of an initially inadequately treated condition [3,4]. It implicitly assumes that it is an informed decision that can only be taken by a mentally sound adult. It exonerates the clinician in case of adverse events. For the clinician, it is, however, frustrating and often unexpected. DAMA reflects a failure to reach a consensus between the attending physician and patient regarding the need for continued inpatient care. This failure may reflect, in part, poor communication and lower trust between the physician and the patient.

However, for the paediatric population it may not be true as alcohol-related diseases and acute myocardial infarction are not the diseases of children. The present study was undertaken to evaluate DAMA among paediatric patients at the study institute, which is one of the private tertiary care teaching hospitals of western part of India. It is a 750-bedded multispeciality hospital with 90 paediatric beds with state of art paediatric and neonatal intensive care units. The primary aim of this study was to know the outcome of paediatric patients whose parents took DAMA from the hospital, and also to know their demographic and disease profile.

## MATERIALS AND METHODS

This mix-method, prospective descriptive study was conducted at Department of Paediatrics, Pramukhswami Medical College and Shree Krishna Hospital, Karamsad, Gujarat, India, during March 2020 to February 2021. The approval from Institutional Ethics Committee was obtained, (IEC/HMPCMCE/118/faculty16, 15/02/2020).

**Inclusion and Exclusion criteria:** All patients from 1 month to 18 years were included in the study whose parents took DAMA from Emergency Department or Paediatric Intensive Care Unit or Paediatric Ward. Paediatric patients seen by other department where Department of Paediatrics was not involved at any stage of evaluation or treatment were excluded from the study.

### Study Procedure

Contact details of parents or care taker were retrieved from computer record system within 24 hours to one week of DAMA, and the parents were contacted by the first author telephonically after one month of DAMA. After the initial introduction of self by the first author, interview was started and the mobile call was recorded, with their permission. Recorded calls were transcribed by first author and then useful information and interpretation of information were done collectively by all authors. Every attempt was made not to hurt their sentiments

and/or bad experiences, if any, while interviewing. Apart from the demographic details and subsequent outcome, the reasons of DAMA were also noted. The reasons of DAMA were there in system because on Duty Doctors and Hospital Counsellors were required to do so whenever any patient took DAMA, as per hospital policy. The reasons for DAMA were also verified from parents at the time of interview.

## STATISTICAL ANALYSIS

Analysis of the data was performed using STATA 14.2. Descriptive Statistics (Mean±SD), Median (interquartile range), frequency (%) were used to depict the baseline profile of the study participants.

## RESULTS

Out of total 1752 registered paediatric patients (except neonates), 74 patients were given DAMA, of which 42 consented for interview subsequently when contacted telephonically. The mean age of those 74 patients were 70.36±67.9 months and male:female ratio was 1.8:1 (65% were males). Other demographic characteristics were as per [Table/Fig-1]. Majority of patients were from upper lower or lower middle class, from joint family and from rural background. Most of parents' age-group was 21-35 years whereas in majority of cases mothers were housewives.

| Demographic characteristics | | n,% |
|---|---|---|
| Gender (n=74) | Male | 48 (65%) |
| | Female | 26 (35%) |
| Socio-economic status (n=42) | Upper lower | 24 (57.14%) |
| | Lower Middle | 17 (40.48%) |
| | Upper Middle | 1 (02.38%) |
| Family type (n=42) | Joint | 31 (73.81%) |
| | Nuclear | 11 (26.19%) |
| Residence (n=42) | Rural | 32 (76.19%) |
| | Urban | 10 (23.81%) |
| Mother's age (n=42) | 21-35 years | 33 (78.57%) |
| | >35 years | 9 (21.43%) |
| Father's age (n=42) | 21-35 years | 28 (66.67%) |
| | >35 years | 14 (33.35%) |
| Mother's education (n=42) | Illiterate | 13 (30.95%) |
| | Primary | 21 (50%) |
| | Secondary | 6 (14.29%) |
| | Higher secondary | 1 (2.38%) |
| | Graduation | 1 (2.38%) |
| Father's education (n=42) | Illiterate | 4 (9.52%) |
| | Primary | 7 (16.67%) |
| | Secondary | 16 (38.10%) |
| | Higher secondary | 10 (23.81%) |
| | Graduation | 5 (11.90%) |
| Child's education (n=42) | Not applicable/ Not studying | 27 (64.29%) |
| | Studying | 15 (35.71%) |
| Mother's occupation (n=42) | Housewife | 36 (85.71%) |
| | Working | 6 (14.29%) |
| Father's occupation (n=42) | Service/Job | 31 (73.81%) |
| | Business | 2 (04.76%) |
| | Farming | 9 (21.43%) |
| Department from where DAMA taken (n=74)? | Paediatric intensive care unit | 27 (37%) |
| | Paediatric ward | 24 (32%) |
| | Emergency department | 23 (31%) |

**[Table/Fig-1]:** Distribution of demographic characteristics of DAMAs.

Patients took DAMA from the Paediatric Intensive Care Unit (PICU), Paediatric Ward, and Emergency Department in almost equal proportion. However, in comparison to total 285 (PICU), 951 (Paediatric Ward) and 516 (Emergency Department) admission, DAMAs were sought by 27 (9.47%), 24 (2.52%) and 23 (4.5%) patients, respectively. The various reasons for taking DAMAs were primarily family or social issue, poor prognosis and poor affordability mainly. [Table/Fig-2,3] shows outcome of the DAMA patients, where almost half of the patients died. Majority of parents did not regret the decision of DAMA. The overall DAMA rate in the present study was 4.22%. Outcome of DAMA is presented in [Table/Fig-4].

| Reasons of DAMA | n,% |
|---|---|
| Poor prognosis but no affordability issue | 7 (16.67) |
| Poor prognosis and affordability issue | 8 (19.05) |
| Not satisfied with hospital staff | 4 (09.52) |
| Facility not available in hospital | 3 (07.14) |
| Family and social pressure to take child | 15 (35.71) |
| No recovery/ improvement | 5 (11.90) |

**[Table/Fig-2]:** Common reasons of DAMA (n=42).

| Variables | | n,% |
|---|---|---|
| Acute or chronic? | Acute | 35 (53.85%) |
| | Chronic | 5 (07.69%) |
| | Acute on chronic | 25 (38.46%) |
| Congenital or acquired? | Congenital | 22 (33.85%) |
| | Acquired | 43 (66.15%) |
| System involvement- Single or multisystem? | Single | 40 (61.54%) |
| | Multisystem | 25 (38.46%) |
| Predominant system involvement | Central nervous system | 24 (36.92%) |
| | Respiratory system | 12 (18.46%) |
| | Cardiovascular system | 8 (12.31%) |
| | Gastrointestinal system | 7 (10.77%) |
| | Hemato-oncological | 7 (10.77%) |
| | Endocrine system | 3 (4.62%) |
| | Renal system | 2 (3.08%) |
| | Circulatory | 1 (1.54%) |
| | Inborn errors of metabolism | 1 (1.54%) |
| Type/Nature of disease | Infection/ Inflammation | 29 (44.62%) |
| | Neoplasm | 7 (10.77%) |
| | Trauma/Head injury | 4 (6.15%) |
| | Other | 25 (38.46%) |

**[Table/Fig-3]:** Disease profile of DAMA as per provisional or confirmed diagnoses (n=65)*.
*Diagnosis details not found in few records

| Variables | | n,% |
|---|---|---|
| After DAMA where was child taken? (n=42) | Home | 31 (73.81%) |
| | Another hospital | 11 (26.19%) |
| Outcome (n=42) | Died | 20 (47.62%) |
| | Alive with morbidity | 6 (14.28%) |
| | Alive without morbidity | 16 (38.10%) |
| Interval between DAMA to death (n=20) | Within one hour | 6 (30%) |
| | Within 24 hours | 4 (20%) |
| | Within 7 days | 2 (10%) |
| | Any time after 7 days | 8 (40%) |
| Any regret for considering DAMA? (n=42) | No | 39 (92.86%) |
| | Yes | 3 (7.14%) |

**[Table/Fig-4]:** Outcome of DAMA.

| Variables | Present study | Vidya BU and Shetty A [6] | Awasthi S and Pandey N [7] | Datta D et al., [8] | Ibekwe RC et al., [9] | Al-Ghafri M et al., [10] |
|---|---|---|---|---|---|---|
| DAMA rate (%) | 4.22 | 2.9 | 5.6 | 6.12 | 3.1 | 1.6 |
| Male: Female | 2:1 | 1.2:1 | 2:1 | 1.25:1 | 1.1:1 | - |
| Mortality after DAMA | 47.62% within 24 hrs | - | - | - | - | - |
| System involvement | Central nervous system-37% | Newborn-61.6% (Photo-therapy or procedural refusal) | Central nervous system-33% | Central nervous system-22% | Neonatal conditions-36.7% | - |
| | Respiratory-18.46% | | Respiratory-28.6% | Respiratory-38% | Severe malaria-22% | - |
| | Cardiovascular-12.31% | | Cardiovascular-4% | Cardiovascular-12% | - | - |
| | Trauma cases- 10% | - | - | - | Road traffic accident-12.2% | - |

**[Table/Fig-5]:** Disease profile comparison of DAMAs to other studies [6-10].

## DISCUSSION

The present study aim was to know burden of DAMAs at the study institution, its subsequent outcome, and reasons for DAMA among the paediatric age group. DAMA among children also has clinical, ethical, and legal consequences. It was also linked to an increased risk of readmission and complications [5]. It is also linked to an increased risk of readmission and complications. The overall DAMA rate in the present study was 4.22 %.

Though the DAMA rate was comparable to other studies [6-8], it may or may not hold true as the current study was carried out during the Coronavirus Disease 2019 (COVID-19) pandemic, which caused widespread fear and panic. Variations in DAMA rate appears to have different study settings and, geographical or socio-economic factors. Ibekwe RC et al., [9] and Al-Ghafri M et al., [10] reported lower rates as compared to Indian studies [6-8] and even among Indian studies, northern parts reported more DAMAs though both are teaching hospitals similarities were that majority DAMAs were from lower socio-economic status. Variation in the DAMA rates appear to have different study settings, geographical or socio-economic factors.

In the present study, DAMAs in males were more than females. A similar higher proportion of DAMA rate is reported in other studies [7,11]. No gender bias was also reported in other studies [6,8,12] This can be taken as an extension of the societal behaviour for spending less for sickness in female child and they were not brought to hospital especially private sector. Likewise, a higher proportion of care providers of male terminally sick patients were DAMA, as they probably planned to spend money availing care in a higher paid centre.

In the present study, around 80% of the mother were either illiterate or educated up to the primary standard. In a study done by Awasthi S et al., found that paternal illiteracy can be the significant risk factor for DAMA cases [7]. In the present study, 76.19% of the patients were from rural area but Awasthi S et al., reported it to be 91.1% [7].

Awasthi S et al., and Datta D et al., also agreed that DAMA among paediatric patients was most commonly due to financial reasons [7,8]. Financial factors are more relevant in countries where health services are not free at point of care, as also highlighted in studies from Nigeria [12] and Iran [13], where financial constraints were cited as a common reason for DAMA.

In the present study, 38% DAMA occurred due to poor prognosis, irrespective of affordability issue. In the study done by Awasthi S et al., low-probability of survival or perceived terminal illness was the reason in majority (41.82%) [7]. In present study, 9.52% DAMA were due to dissatisfaction to hospital staff/policies which was little lower than reported in the Awasthi S et al., [7] (11.82%). In the present study 7.14% of the cases, DAMA occurred due to lack of some facilities especially for paediatric age group. In our study, family and social pressure as a reason for DAMA was seen among 35.71% while in a study done by Awasthi S et al., it was 18.18% [7]. This variation can be explained by different set up of trust versus public hospital.

In present study, 73.81% of the children were taken to the home after getting DAMA while 26.19% were taken to another hospital. In a study done by Al-Mohammadi E et al., 28% were readmitted to other hospitals [5]. These findings might indicate the caregiver's dissatisfaction, which led him or her to obtain DAMA from the initial hospital. In the present study, mortality rate after getting DAMA was 47.62% within 24 hours of DAMA. However, an important aspect is that around 38.1% survived without morbidity. An alarming point was that 93% of parents had no regret of DAMA, suggesting that whether a child died or survived, parents had a firm belief that their decision regarding DAMA was appropriate.

Disease or system-wise profile was also compared to other studies [Table/Fig-5]. The study institute had a significant proportion of patients with cardiac ailments as the hospital gets referrals due to its well-developed Paediatric Cardiac Centre. In the study done by Ndu IK et al., the most common condition contributing to DAMA was malaria (20.1%), followed by pneumonia (15.7%) and sepsis (12.3%) [14]. Whereas, Victor AM et al., reported respiratory (31%) system followed by gastro-intestinal cases (25%) [15].

### Limitation(s)

Because of the COVID-19 pandemic it is difficult to say that the findings derived represent the true scenario related to DAMA. Also, only around two-thirds of the total DAMA could be traced or contact and narratives recorded by telephonic conversation may have some limitations as compared to personal visit and personal interviews.

## CONCLUSION(S)

Nearly half of the DAMA patients died and rest were alive with majority of them having no morbidity. Overall, DAMA rate was not high. Poor prognosis with or without affordability issue was the leading cause of DAMA, followed by family/social reason, lack of facility and dissatisfaction to hospital and its staff among other reasons. Majority of the parents did not regret their decision of DAMA.

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