

# Discharge against medical advice in pediatrics: a 10-year retrospective analysis in a tertiary care center

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**BACKGROUND:** There is still limited data on Discharge Against Medical Advice (DAMA) in the pediatric population. Most research comes from low—and middle-income countries, where the financial burden associated with medical care is often an important reason to leave a healthcare facility prematurely. Discharge against medical advice in the children's population is considered a significant issue that may lead to an increased risk of morbidity and mortality.

**OBJECTIVES:** Describe the characteristics and predictors of DAMA in children over ten years in in Riyadh, Saudi Arabia.

**DESIGN:** Retrospective

**SETTING:** Tertiary care center.

**PATIENTS AND METHODS:** This study included all patients aged <14 years who had DAMA during all admissions between 1 January 2012, and 31 December 2022.

**MAIN OUTCOME MEASURES:** Data was retrieved from medical records and included 1) sociodemographic data, 2) medical history and clinical characteristics, 3) utilization of services during the admission leading to DAMA, and 4) interventions provided to prevent departure.

**SAMPLE SIZE:** 355 DAMA episodes.

**RESULTS:** Males accounted for 45.4%, and the average age was 4.4 years. The overall DAMA prevalence of was 0.4%. At baseline, 277 children (78%) had at least a chronic illness or severe baseline condition; 59% had a potential life-limiting or life-threatening condition. Reasons for DAMA included disagreement about the treatment plan (14.9%), social reasons (12.6%), and perception that the child's condition improved (5.6%). An increased risk of DAMA recurrence was associated with pre-existing severe or chronic medical conditions (OR: 8.2,  $P=.004$ ) and a discharge during the treatment phase (OR: 1.9,  $P=.040$ ).

**CONCLUSIONS:** Despite inconsistent documentation, preventive measures included the involvement of healthcare providers, social services, and patient relations. The study highlights the need for standardized protocols and improved documentation practices to effectively address discharge against medical advice.

**LIMITATIONS:** Needs to moderate documentation quality of DAMA episodes. The study was limited to a single center, which may affect the generalizability. Children might also have presented to receive care in another facility post-DAMA.

**CONFLICT OF INTERESTS:** None.

**D**ischarge against medical advice (DAMA) is when a patient leaves a healthcare facility while the medical team recommends that further stay is needed. However, there are no established criteria for the classification of DAMA. DAMA is subjective and depends on the discretion of the discharging physician, leading to varying interpretations among healthcare providers.<sup>1</sup> A competent adult may refuse treatment, and the medical team must respect this choice, even when they view their choice as irrational and they anticipate that harm exists.<sup>2</sup> However, in pediatrics, a higher level of complexity exists as we deal with proxy decision-makers. We start with the assumption that parents want the best for their children, but we must remember that their rights over their children are not unlimited.<sup>3</sup> In some situations, a parent's request for a DAMA warrants the involvement of Child Protective Services.

There is still limited data on DAMA in the pediatric population.<sup>4,5</sup> Most research comes from low- and middle-income countries, where DAMA rates range from 1.5% to over 6%.<sup>6</sup> In these countries, the financial burden associated with medical care is often an important reason to leave a healthcare facility prematurely. Specific factors have been associated with DAMA, like the child's age (<2 years old, adolescent group), male gender, a hospital stay of 48 hours or less, parental financial constraints, lack of health insurance, and lower socioeconomic status.<sup>7</sup> The parental perception that the child's condition has improved sufficiently for discharge, unsatisfactory care, and inconvenience linked to the hospitalization have also been reported as reasons to leave the hospital.<sup>8-10</sup> DAMA is worrisome for healthcare teams due to its possible repercussions on the child's health. Children are at increased risk of readmission and increased morbidity due to deterioration of their medical condition.<sup>11</sup>

Regionally, a study from Oman showed that the wish to get a second opinion and dissatisfaction with the care were the most cited reasons.<sup>8</sup> However, the majority of cases needed to be better documented.<sup>8</sup> In Saudi Arabia, Al-Turkistani examined all cases of DAMA in a Neonatal Intensive Care Unit over ten years (n=51) and found that parents often had erroneous perceptions of the risks involved, thinking a baby with a proper weight that 'looks' well was necessarily healthy. The most prevalent admitting diagnoses were transient tachypnea of the newborn and possible sepsis, both conditions with potential life-threatening outcomes.<sup>12</sup> Al-Mohammadi identified that parents' false assumption that their child's condition had improved, dissatisfaction with the treating team, and difficulties arranging care for other children at home were essential factors.<sup>13</sup> Alwallan re-

ported that 63.2% of children who were DAMA in a center in Saudi Arabia were less than five years of age and that females were 4.4 times more likely to have a DAMA than male children.<sup>14</sup> Due to Saudi Arabia's unique economic, environmental, social, and cultural context and their potential influence on the phenomenon of DAMA, extrapolation from studies conducted abroad is insufficient; the phenomenon warrants further studies to understand better the reasons leading to these premature and potential harmful discharges in the pediatric population.

This study aimed to assess the prevalence of DAMA and describe the characteristics of children discharged against medical advice over ten years in a tertiary center.

## PATIENTS AND METHODS

This retrospective study was conducted at a large tertiary care and research center in Riyadh, Saudi Arabia. The pediatric care resources include a Children's Cancer Center, specialized cardiovascular services, four intensive care units, a Level-III neonatal intensive care unit, and a pediatric emergency room. The pediatric population included children from birth to the age of 14 years. Children whom DAMA between 1 January 2012, and 31 December 2022, were included. Data were retrieved from medical records and included 1) sociodemographic data, 2) medical history and clinical characteristics, and 2) utilization of services during the admission leading to DAMA. Each episode was treated separately if a patient had more than one DAMA. The data was kept confidential and managed using REDCap electronic data capture tools (<https://projectredcap.org/>) hosted in the organization. This study received approval from the institution's review board (Reference #2231161). A waiver for informed consent was granted.

Data analysis was done using STATA version 18 StataCorp LLC, College Station, TX, USA. Categorical data were presented as percentages. Continuous data were summarized as medians and interquartile ranges (IQR) (**Table 3** for delay in seeing the physician, LOS) and **Table 4** (LOS). Univariate logistic regression was done to investigate predictors of multiple DAMA. A *P* value less than .05 was considered significant. Figures were generated using Microsoft PowerPoint and Excel 2016.

## RESULTS

### Sociodemographics

A total of 767 cases were initially coded as DAMA in medical records. After an initial screening, 412 cases

were excluded as wrongly coded, bringing the sample to 355 DAMA cases for the studied period. Males accounted for 54.4% (n=193). The median age at admission was 4.4 years [IQR: 1.2, 9.4], with half under the age of five years (n=195; 54.9%). Most were Saudis (n=346; 97.5%) (**Table 1**).

The yearly distribution of cases from 2012 to 2022 indicates a slight decrease in DAMA cases. In 2012, there was a prevalence of 0.6% (48 DAMA/7462 total admissions). This number slightly decreased over the years, with prevalences of 0.3% (23 DAMA/7676 total admissions) and 0.2% (17 DAMA/8021 total admissions) observed in 2021 and 2022, respectively (**Figure 1**).

### Medical history and clinical characteristics

At baseline, 277 children (78%) had at least a chronic illness or severe baseline condition (**Table 2**); 210 (59%) had a potential life-limiting or life-threatening condition (**Figure 2**). The most common diagnoses were malignancy (33.9%), severe neurological disorders (13%), and genetic disorders (9.7%) (**Table 2**). Eight children (2.3%) had a Do-Not-Attempt-Resuscitation status, and based on available records, (8.7%) were potentially in their last year of life. Twenty-four children had died (6.8%), but it seemed unrelated to the DAMA as the median (IQR) number of days between the DAMA and their death was 214 (98353).

### Admission and hospitalization processes

The most frequent reasons for admission were for investigation, treatment, surgery, or transplant (elective admissions) (46.2%), fever (17.7%), and gastrointestinal symptoms (11%) (**Table 3**). The Emergency Department was the entry point for (38.3%), and the Emergency Tracking Acuity mainly consisted of 2-Emergent (36%) and 3-Urgent (50%) (**Table 3**). The median length of stay was 3.8 days [1.5, 8.3]. Interestingly, the most frequent weekday for discharge was Thursday, which corresponds to the day preceding the weekend in Saudi Arabia. Patients mostly left when receiving treatments (55.2%). Half of those left, while the primary ongoing intervention was intravenous antibiotics (54%) (**Table 2**). Seventeen (4.8%) absconded. Twenty (5.6%) returned to the Emergency Department, and 36 (10.1%) had to be re-hospitalized within five days with a similar complaint.

### DAMA reasons and interventions to prevent DAMA for all cases

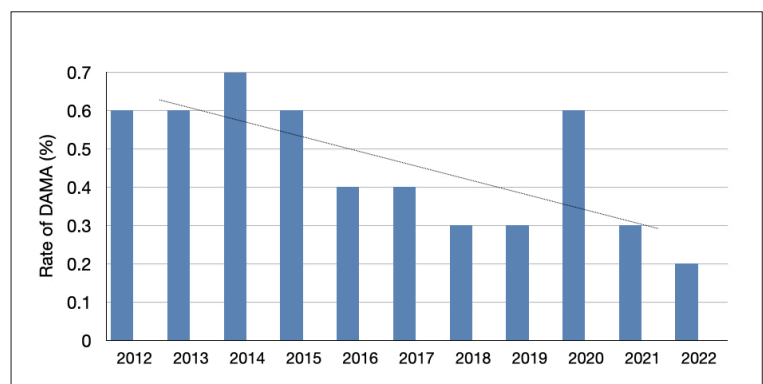
In an attempt to prevent DAMA, in 232 (65.4%) of instances, the best treatment options were explained, and 151 (42.5%) had follow-up and safety instructions

provided (outside of regular planned follow-up) (**Table 3**). Reasons given by parents for their premature departure included disagreement with the care plan (14.9%), social reasons (12.6%), and the impression that their child was doing well (5.6%) (**Figure 3**). Of parents who disagreed with the treatment plan, 20.8% wanted to

**Table 1.** Sociodemographic characteristics (n=355).

Sex		
Female	162	45.6
Male	193	54.4
Nationality		
Saudi	346	97.5
Non-Saudi	9	2.5
Place of residence in Saudi Arabia		
Central	167	47.0
North	68	19.2
South	43	12.1
West	37	10.4
East	35	9.9
Outside of Saudi Arabia	5	1.4
Age group <sup>a</sup>		
Neonates (<28 days)	28	7.9
Infants (<1 year)	56	15.8
Children (1-4 years)	111	31.3
Children/adolescents (5-14 years)	160	45.1

Data are median (interquartile range [IQR]) for age (median: 4.4 years, interquartile range: 1.2, 9.4 years) and number (percentage) for categorical data. <sup>a</sup>Median = 4.4 years [interquartile range: 1.2, 9.4]



**Figure 1.** Rate of discharge against medical advice in recent years.

**Table 2.** Medical history and clinical characteristics (n=355).

	n (%)
Baseline health status	
Medically free	78 (22.0)
Chronic conditions	277 (78.0) <sup>a</sup>
Malignancy	94 (33.9)
Severe neurological conditions	36 (13.0)
Genetic disorders	27 (9.7)
Allergy and immunology conditions	22 (7.9)
Non-malignant blood disorders	21 (7.6)
Chronic kidney diseases	20 (7.2)
Congenital heart diseases	16 (5.8)
Liver diseases	15 (5.4)
Lung diseases	5 (1.8)
Gastrointestinal diseases	5 (1.8)
Other	16 (5.9)
Frequency of DAMA	
Once	304 (85.6)
Twice	38 (10.7)
Three	9 (2.5)
Four	4 (1.1)
Timing of DAMA	
During Investigation	96 (27.0)
During treatment	196 (55.2)
During observation	63 (17.7)
Do-Not-Attempt-Resuscitation	8 (2.3)
End-of-life <sup>b</sup>	
Likely	31 (8.7)
Not Likely	268 (75.5)
Insufficient information to judge	56 (15.8)
Death <sup>c</sup>	24 (6.8)

<sup>a</sup>277 (Children with at least a severe or chronic medical condition). <sup>b</sup>Would answer "Yes" to the question: "I would not be surprised if the child died within the following year". <sup>c</sup>Period between DAMA and death (median, range=214 days [98353]).

**Table 3.** Admission and hospitalization characteristics (n=355).

	n (%)
Admission type	
Newborn delivery	25 (7.0)
Elective or direct admission	194 (54.7)
Emergency visit	136 (38.3)
Tracking acuity	
1-Resuscitation	3 (2.2)
2-Emergent	49 (36.0)
3-Urgent	68 (50.0)
4-Less urgent	14 (10.3)
5-Non urgent	2 (1.5)
Delay to see a physician (minutes)	44 [26,114]
Reasons for admission <sup>a</sup>	
Investigations and treatment	164 (46.2)
Fever	63 (17.7)
Gastrointestinal symptoms	39 (11.0)
Respiratory symptoms	35 (9.9)
Neurological symptoms	30 (8.4)
Newborn delivery	25 (7.0)
Pain	16 (4.5)
Bleeding	8 (2.3)
Medical device issue	7 (2.0)
Other reason	13 (3.6)
Medical service	
Hematology-Oncology and Allergy & Immunology	132 (37.5)
Pediatrics specialties	98 (27.3)
Surgical	52 (14.7)
General pediatrics	31 (8.7)
Neonatology/Perinatology	25 (7.0)
Cardiovascular	16 (4.6)
Interventions to prevent DAMA	
Primary physician contacted to convince the parents	185 (52.1)
Social worker consultation	43 (12.1)
Patient relations consultation	47 (13.2)
Follow-up/safety instructions provided	151 (42.5)

**Table 3 (cont.).** Admission and hospitalization characteristics (n=355).

	n (%)
Consequences explained	127 (35.8)
Alternatives explored	95 (26.8)
Length of stay (days)	3.8 [1.5, 8.3]
Absconded from the hospital	17 (4.8)
Revisit Emergency within 5 days <sup>b</sup>	20 (5.6)
Rehospitalization within 5 days <sup>b</sup>	36 (10.1)

Data are median (IQR; 25th-75th percentile). <sup>a</sup>Some children had more than one reason recorded. <sup>b</sup>For the same complaint.

travel abroad for a second opinion, 5.7% to use traditional medicine instead, and 7.5% to bring their child home for end-of-life. Surprisingly, only six cases were referred to the organization's Child Protective Team (available 24/7).

#### Predictors of multiple DAMA for the same patient

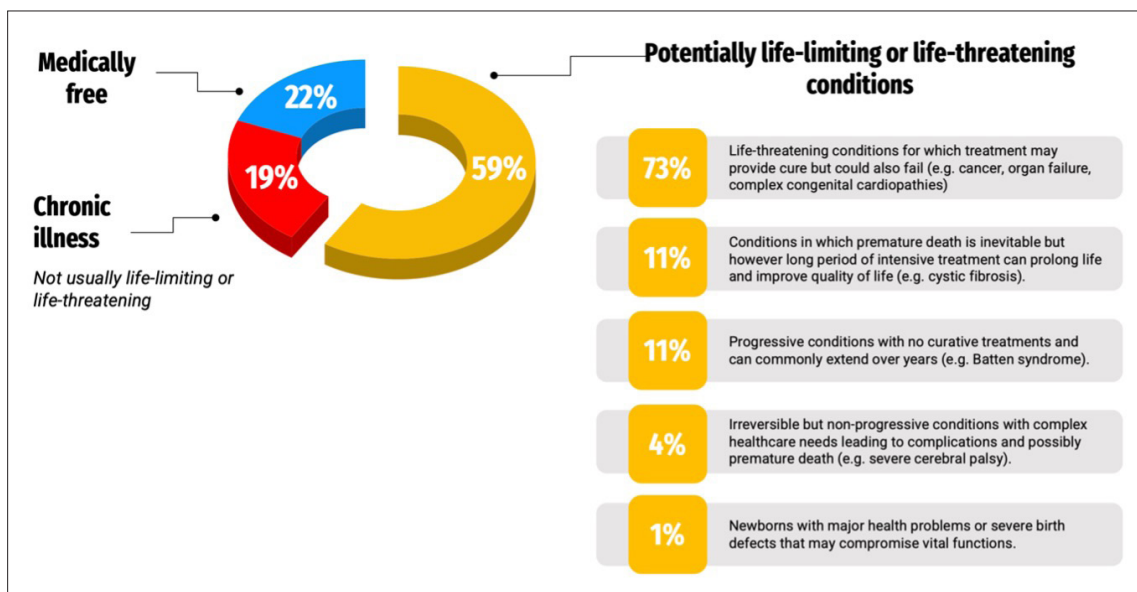
Recurrence of DAMA in the same patient was significantly associated with the presence of a chronic illness or severe baseline condition (OR: 8.2,  $P=.004$ ) and discharge during treatment (OR: 1.9,  $P=.040$ ). Neonates and infants exhibited a negative association with multiple DAMA (OR: 0.2,  $P=.008$ ) (Table 4).

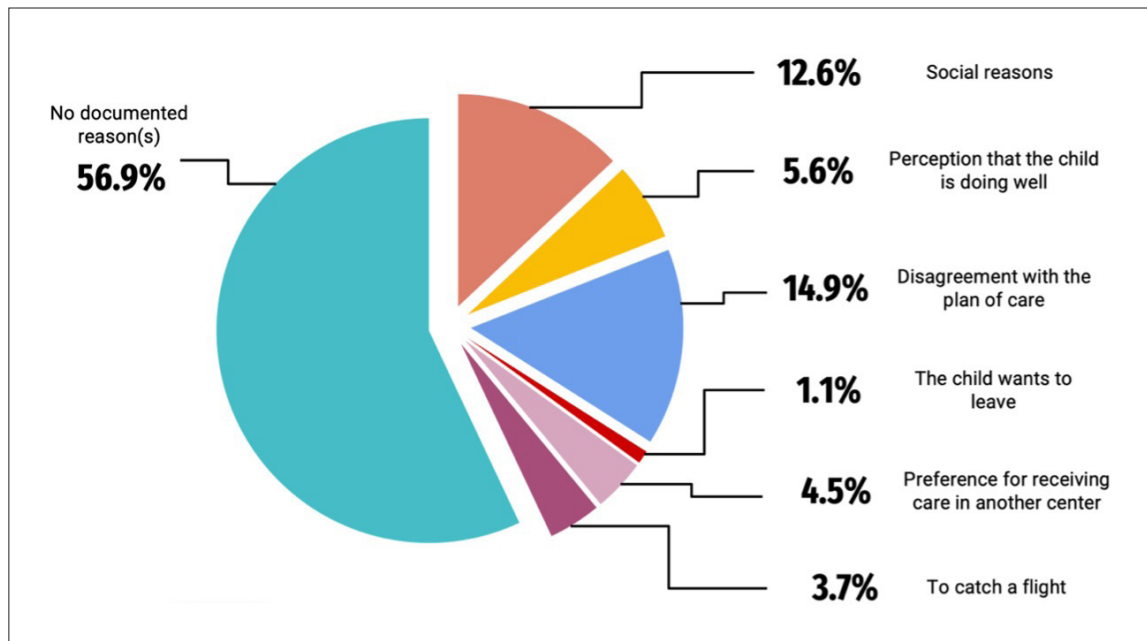
Twenty-five neonates (aged less than 28 days) were DAMA with a median (IQR) age of 2.8 days (2, 4.6).

Regarding timing, 12% left during treatment, 36% during investigation, and 52% during observation. Multiple cases left during an antibiotic course or with neonatal jaundice. For 52%, another physician was contacted to convince parents to stay. Social workers, patient relations representatives, and the Child Protection Team should have been consulted. Seventy-two percent had no documented reasons for DAMA. Only one revisited the emergency department within five days, and none were re-hospitalized. No deaths were recorded.

## DISCUSSION

Over ten years, our study identified a mean DAMA prevalence among pediatric patients of 0.4%. In addition, there is a decreased trend over time, with prevalences of 0.3% and 0.2% recorded in 2021 and 2022, respectively. These rates represent a relatively low prevalence compared to other regions. For instance, studies led outside the Middle East reported a prevalence rate ranging from 1.2% to 7.5% among the pediatric population.<sup>10,15</sup> Locally, our study showed a lower prevalence than other reported studies in Saudi Arabia, where prevalence rates ranged from 0.6% to 1.6%.<sup>12,14</sup> The variations can be attributed to different underlying conditions, departments, levels of the healthcare institute, socioeconomic conditions, and cultural factors influencing parental decisions.<sup>10</sup> In addition, studies outside most likely include adolescents from 14 to 18 years who are known to be more prone to non-adherence. Our study showed a slight male predominance (54.4%) with

**Figure 2.** Baseline health conditions.



**Figure 3.** Parental reasons for the discharge against medical advice.

**Table 4.** Predictors of multiple discharges against medical advice (n=355).

Predictors	Multiple DAMA (n=51) n (%)	Single DAMA (n=304) n (%)	OR [95% CI]	P
Male gender	24 (47.1)	169 (55.6)	0.7 [0.3, 1.2]	.259
Age ≤1 year	4 (7.8)	80 (26.3)	0.2 [0.1, 0.6]	<b>.008</b>
Residence (Central region) <sup>a</sup>	22 (43.1)	145 (47.7)	0.8 [0.4, 1.5]	.546
Admission through the Emergency	18 (35.3)	118 (38.8)	0.8 [0.4, 1.5]	.632
Presence of significant illness	49 (96.1)	228 (75.0)	8.2 [1.9, 34.3]	<b>.004</b>
End of life (prognosis ≤1 year)	2 (3.9)	29 (9.5)	0.4 [0.1, 1.6]	.204
Redflag for potential neglect <sup>b</sup>	28 (54.9)	127 (41.8)	1.7 [0.9, 3.0]	.083
DAMA during treatment	35 (68.6)	161 (53.0)	1.9 [1.0, 3.6]	<b>.040</b>
Discharged on Thursday <sup>c</sup>	9 (17.6)	62 (20.4)	0.8 [0.3, 1.8]	.650
Length of stay (in days), median (IQR)	3.9 (1.1, 9.1)	3.8 (1.6, 8.2)	1.0 [0.9, 1.0]	.958
Mortality	2 (3.9)	22 (7.2)	0.5 [0.1, 2.2]	.391

Data are median (IQR; 25th-75th percentile) for continuous data and number (percentage) for categorical data. P-values were reported using univariate logistic regression. <sup>a</sup>The hospital is located in the Central region of Saudi Arabia. <sup>b</sup>The red flags for potential medical neglect encompassed one or more of the following indicators: vital or clinical instability, refusal of potentially life-saving interventions, signs of abuse or neglect, and anticipation of long-term consequences.

<sup>c</sup>Thursday corresponds to the day before the weekend in Saudi Arabia.



most children younger than five years, which aligns with findings from other studies.<sup>16</sup> Our study's median length of stay before DAMA was 3.8 days, comparable to other studies reported in pediatric patients.<sup>8,17</sup> Children who were medically free before were found to have shorter lengths of stay before DAMA when compared to children with chronic illness ( $P=.003$ ). This reflects the complexity and severity of their health conditions, necessitating prolonged and more intensive medical care.

Most DAMA cases were children with severe or chronic baseline conditions ( $n=277$  [78%]). Two hundred and ten (59%) of children whose DAMA had what is considered a 'potentially life-limiting or life-threatening condition' (**Figure 2**). These were conditions eligible to receive palliative care services. Among these children, 73% ( $n=152$ ) had potentially life-threatening conditions for treatment might bring a cure but could also fail. These included children with malignancy and those awaiting a bone marrow or an organ transplant. It is somewhat surprising to witness parents who opt to DAMA children with these types of severe conditions. These children often seem to receive their 'mainstream' oncological treatment (e.g., chemotherapy, bone marrow transplant), but there seems to be a misunderstanding by parents regarding the importance of supportive treatments (e.g., antibiotherapy, hydration following oncological treatments, observation while recovering blood count).

Parents often feel that, when looking at the child, he/she is looking 'well enough' and that these supportive treatments are not as necessary. In addition, we found that children with severe or chronic medical conditions had an odds ratio (OR) of 8.2 for having recurrent DAMA episodes. Such conditions usually require prolonged and recurrent hospitalizations, which makes it difficult for patients and families. The most frequent underlying conditions included malignancy (33.9%), severe neurological disorders (13%), and genetic disorders (9.7%). Most cases of DAMA were seen under pediatric hematology-oncology and allergy-immunology services. These findings are consistent with other studies indicating that children suffering severe medical conditions have an increased likelihood of DAMA.<sup>9</sup>

Newborns represented another particular group in our cohort. We found that most DAMA cases occurred during the investigational or treatment phase and involved the refusal of phototherapy or intravenous antibiotics. This is consistent with other studies in the neonatal age group and points to the need for particular interventions that may include parenteral education, engagement, and a more supportive care system.<sup>17,18</sup> What is more surprising is that in contrast with other

studies where parents leave prematurely with their newborns due to the cost of care, in Saudi Arabia, all the cost of healthcare is covered for its citizens.

Admissions were categorized into three main types: elective or direct admissions, emergency visits, and newborn deliveries. Elective admissions were associated with most DAMA cases; this was unexpected, considering that planned hospitalizations indicate that parents have pre-existing expectations about the hospital stay. Emergency admissions were also categorized based on acuity; most DAMA cases were classified as urgent. This contradicts data from another study, which showed urgent acuity was a negative predictive factor for DAMA.<sup>5</sup> Our findings underscore the critical need to prevent DAMA in high-acuity scenarios where children may leave without immediate attention.

Looking at the timing of DAMA, an interesting finding was that DAMA cases increased on Thursday, the beginning of weekends in Saudi Arabia. This trend shows the familial and social influence of the DAMA decision as families desire to have the child at home during weekends. Many families living in remote areas have to take flights back home that are only sometimes available daily, influencing their decisions. Understanding these patterns can help healthcare providers develop strategies to anticipate and address DAMA cases. Evaluation of which phase of admission the DAMA takes place is also critical. We found that most discharges occurred during the treatment phase of the admission, especially when the primary treatment was intravenous antibiotics. After several days, the child will likely be afebrile and 'looking better'; thus, parents might not grasp the importance of completing the antibiotic course. Furthermore, we identified that DAMA during the treatment phase was a significant predictor of DAMA recurrence in the same patients (OR of 1.9), indicating that active medical intervention phases are critical periods. Perceived improvement, financial constraints, or dissatisfaction with care may drive DAMA decisions during this phase.

As reported by parents, the primary reasons for DAMA were disagreements with the care plan, social reasons, and the perception that the child was doing well, which also aligns with other studies. Such findings showcase the importance of effective communication and shared decision-making between healthcare providers and families.<sup>8,9</sup>

DAMA is a well-known risk for readmission and mortality.<sup>19</sup> Our study found that 5.6% of DAMA cases resulted in visits to the emergency department within five days, and 10.1% required rehospitalization for similar complaints. These rates are comparable to those

reported in the literature, indicating that DAMA significantly increases the risk of adverse health outcomes.<sup>20,21</sup>

It was also surprising to find that only six cases had been brought to the attention of the Child Protection Team, which is available 24/7 in the organization. Some of these DAMA cases have the characteristics of potential medical neglect situations. Recognizing medical neglect is tricky. Besides frank situations of neglect, grey areas exist, especially when dealing with children with chronic medical conditions and complex treatment choices. However, more awareness of red flags associated with potential medical neglect seems warranted: 1) neonate and infant age group, 2) vitally or clinically unstable, 3) refusal of potentially life-saving treatments, 4) signs of physical, sexual, emotional abuse, or neglect, and 5) foreseeable long-term consequences to forgo treatments.

Reported efforts to prevent DAMA included involving another physician well-known to the family and consulting social workers or patient relations representatives. However, the relatively low engagement of such resources indicates an area for improvement. Enhancing multidisciplinary approaches and ensuring consistent involvement of such services could mitigate DAMA risks.

A significant limitation noted in our study is the need for better documentation of the DAMA episodes. The documentation of the DAMA episode and interventions were of weak to moderate quality. There was no documentation of the parental reason in 56.9% of cases. Such limitation hinders a comprehensive understanding of the factors driving DAMA decisions. Additionally, our study was retrospective and limited to a single center,

which may affect the generalizability of the findings to other regions or healthcare settings and limit the ability to establish causality of DAMA events. Children might also have presented to receive care in another facility post-DAMA. The main strengths lie in the extended review period and sample size.

In conclusion, future research should aim to develop and study implemented standardized protocols for dealing with DAMA cases. Multicenter studies across different healthcare settings can provide a better understanding of the perspective and generalizability of findings. A valuable model of a standardized process to improve safety and ethics in managing DAMA cases was developed by the Hospital for Sick Children in Toronto. Their approach includes shared decision-making and the involvement of institution resources, underscoring the importance of standardized protocols and multidisciplinary engagement.<sup>22</sup> Additionally, there is a need to expand options for patients needing care and families presenting specific challenges with prolonged hospitalization. Expanding services provided by Medical Day Units or Home Care services and establishing better partnerships with local hospitals could enable some children to pursue essential treatments (e.g., intravenous antibiotics) without being hospitalized for the whole duration. Expanding virtual care follow-up could provide a better safety net. Engaging health education for patients and families may also provide benefits (e.g., pre-natal education about common health issues with neonates). Prospective studies could offer deeper insights into the motivations and circumstances leading to DAMA, helping to identify effective interventions.



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