

# Do not resuscitate orders in a Saudi pediatric intensive care unit

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## ABSTRACT

**الأهداف:** معرفة نسبة وفيات الأطفال الذين لم يستخدم لهم الإنعاش قبل الوفاة ومقارنتها بالخبرات العالمية.

**الطريقة:** أجريت دراسة استيعادية لملفات جميع الأطفال الموتى في العناية المركزة للأطفال والذين تقل أعمارهم عن 14 سنة وعددهم 154 طفلاً في الفترة من يناير 2007م إلى يونيو 2009م.

**النتائج:** أغلب حالات الوفاة كانت نتيجة لعدم الإنعاش حيث بلغت 79 حالة بنسبة 51%. بينما 60 حالة (39%) لم تنجح محاولات الإنعاش. كما بلغت حالات الوفاة الدماغية 15 حالة بنسبة 10% من جميع الوفيات. من 79 حالة ميؤوسه تم سحب الأدوية القلبية المنشطة والأجهزة عن 46 حالة بنسبة 58%.

**الخلاصة:** عدم عمل الإنعاش القلبي الرئوي في الحالات الميؤوسه هو أغلب أسباب الوفاة في إحدى العنانيات المركزة الإسلامية للأطفال. لتخفيف الألم على الطفل الذي لا يرجى برؤه يجب أخذ بالاعتبار عدم عمل إنعاش قلبي رئوي للحالات الميؤوس منها والتي تكون الوفاة فيه شبه أكيدة.

**Objectives:** To determine the percentage of deaths in the pediatric intensive care unit (PICU) attributed to do not resuscitate (DNR) orders, and to compare our DNR practice with the international experience.

**Methods:** Retrospective chart review of all children less than 14 years of age who died in the PICU at King Faisal Specialist Hospital and Research Center, Riyadh, Saudi Arabia from January 2007 to June 2009 (n=154).

**Results:** The main mode of death was attributed to DNR orders in 79 cases (51%), failed cardiopulmonary resuscitation in 60 cases (39%), and brain death in 15 cases (10%). Of the 79 DNR orders, 46 (58%) were related to withdrawal of life support measures.

**Conclusion:** The DNR is the most common cause of death in the PICU in tertiary hospitals in Saudi

Arabia. To minimize the suffering of the dying child, life support limitation should be considered for children with terminal or untreatable diseases with low chances of survival.

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Mortality rates differ from one intensive care area to another. At present, the practice of do not resuscitate (DNR) orders, withdrawal of treatment, and life support limitation (LSL) in children are medically, ethically, and religiously acceptable, under certain circumstances. In pediatric intensive care units (PICU), the moment of death, in many cases, is determined by the decision to limit or withdraw the support that is keeping the patient alive since it will not alter the outcome and will just prolong the process of death.<sup>1-4</sup> Among adults, the incidence of DNR varies from 40-90%, with the frequency in the PICU being lower.<sup>3,4</sup> A DNR order is a binding, legal document that states that resuscitation should not be attempted if a person suffers cardiac or respiratory arrest in a known terminal or untreatable disease with confirmed low chances of survival. Do not resuscitate documents are widespread in some countries, but unavailable in others. Do not resuscitate orders were first described in the literature in 1976.<sup>5</sup> The worldwide incidence of DNR is variable and multifactorial, and has exhibited a dramatic increase over the last 20 years. Previous studies<sup>6,7</sup> demonstrated that currently, more patients in the ICU die from DNR

than after a failed cardiopulmonary resuscitation (CPR). It was only at the beginning of the 1990s that the first studies regarding end-of-life in pediatric intensive care were published in the USA, which reported that more than 30% of deaths were preceded by some form of DNR.<sup>4,8</sup> There is a greater incidence of DNR in North American PICUs (60%) than in European or Latin American PICUs (30-40%). The difference appears to be related to cultural, legal, and economic factors.<sup>9</sup> In Salt Lake City, Utah, USA, the most common mode of death was DNR, where 58% of children who died in the PICU underwent either active withdrawal or limitation of supportive care.<sup>4</sup> In Europe, DNR is more common in the northern countries (47%) than in the southern parts. Moreover, the families from the northern parts have greater participation with the decision-making process.<sup>10</sup> Moreover, DNR orders were written for 30% of pediatric patients in Argentina.<sup>11</sup> In India, DNR orders vary from 20-50% in private hospitals; but, in the ICUs of deprived areas and poor cities, DNR practices are completely unacceptable.<sup>12</sup> A recent study in an Australian PICU showed 74% of their deaths were related to DNR.<sup>13</sup> The objective of this study is to determine the percentage of deaths in the PICU that is attributed to DNR orders, and compare our results with the international experience. The rationale for this study is to raise awareness among healthcare providers regarding the limitations of aggressive life support measures, and reduce unnecessary patient suffering and medical care costs as cardiopulmonary resuscitation should only be performed for patients who are likely to benefit from it. Moreover, this will result in better utilization of pediatric intensive care beds for patients with favorable outcome. As it is important for the healthcare provider to recognize when to provide therapy, it is of the same importance to recognize when to withhold therapy such as cardiopulmonary resuscitation in children with dismal prognosis and very poor outcome.

**Methods.** The PICU at King Faisal Specialist Hospital and Research Centre (KFSHRC), Riyadh, Saudi Arabia is an 18-bed, combined medical and surgical ICU, excluding cardiac surgery, which is staffed by well-trained pediatric intensivists. The files of all patients less than 14 years of age who died in the PICU from January 2007 to June 2009 were retrospectively

reviewed and analyzed to determine the percentage of deaths that were attributed to DNR orders. The PICU has a computerized log system that keeps track of all admissions, deaths, and other relevant data for the unit. This system served as our data source for the deaths in the PICU during our specified study period. Patient information was presented as descriptive data only. The modes of death were categorized into 3 groups DNR or no code, failed cardiopulmonary resuscitation (failed CPR), brain death (BD) was defined according to the diagnosis of death by brain function criteria, council of Saudi Health Services, 2009.<sup>14</sup> The confidentiality of the collected data was taken in full consideration by the authors and all data were kept private and classified. The collected data were used solely for this retrospective chart review. Moreover, all data collected for this study was a result of routine medical practice and all the charts were reviewed by the principal investigators only. Furthermore, the Research Advisory Council, which is the institutional review body of KFSHRC, reviewed and approved this manuscript and has waived the need of informed consent.

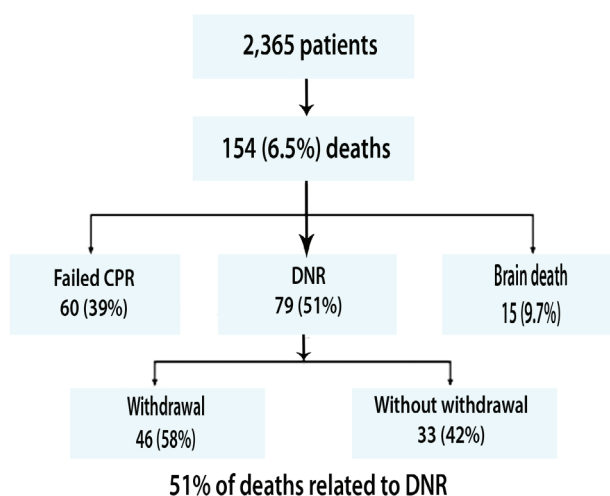
**Results.** There were 2,365 admissions to the PICU with 154 deaths identified from January 2007 to June 2009. The overall mortality rate was 6.5% (Figure 1), which is similar or even better compared with other international PICUs. All patients initially received aggressive therapy. The total number of no code was 51%, failed CPR was 39%, and brain death was 9.7%.

As shown in Table 1, the vast majority of deaths were in hematology/oncology patients. Of these 50 cases, DNR was ordered in 32 cases (64%), and 19 (38%) cases had bone marrow transplant. Followed by cardiology patients, most of these cases were inoperable because of very complex congenital heart disease or associated with severe dysmorphology that made their life expectancy very short. And the third common are the immune-deficient patients (13.6). Ten out of 15 patients (43%) had bone marrow transplantation.

**Discussion.** Brain death was diagnosed in 15 cases (9.7%); only 4 of them were medically suitable for organ donation, and consent was obtained in one case. A DNR order was placed for all of these patients who were brain dead before confirmation of brain death and withdrawal of life support was carried out for all of them after confirmation of brain death.

Recently, with enormous medical advances, there is an increase in human life expectancy. However, this also brings new ethical, moral, and economic issues as a consequence of the exaggerated use of technological

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**Figure 1** - Pediatric intensive care unit admissions at King Faisal Specialist Hospital & Research Centre, Riyadh, Kingdom of Saudi Arabia. DNR - do not resuscitate

**Table 1** - Number of deaths per service among the pediatric intensive care unit admissions of King Faisal Specialist Hospital & Research Centre, Riyadh, Kingdom of Saudi Arabia from January 2007 to June 2009 (N=154).

Service	n	(%)
Hematology/oncology	50	(32.5)
Cardiology	38	(25.0)
Immunology	21	(13.6)
Metabolic	15	(9.7)
Gastroenterology	11	(7.0)
Neuroscience	7	(4.5)
Nephrology	2	(1.3)
Others	10	(6.4)

resources in patients with terminal illnesses, making the process of death slow and painful. Withholding therapy at the end-of-life has been widely accepted in many countries including Saudi Arabia.<sup>6,13</sup> The local Saudi Islamic religious concepts regarding DNR decisions have been clarified by the Residency of the Administration of Islamic Research and IFTA in Riyadh, Saudi Arabia.<sup>15</sup> In Fatwa No. 12086 issued on 6 February 1989 stating that if a patient's condition is hopeless, the life support machines can be withheld or withdrawn provided that 3 knowledgeable and trustworthy physicians agreed.<sup>15</sup> Some of the Saudi pediatric hospitals are applying the DNR policy, but most of them have no DNR policy yet in the hospital. Also, the Islamic Medical Assembly of North America (IMAN) incorporated the status of law from North America, and the right of the competent patient to decide for himself the status of DNR, despite the local and worldwide experiences of

other medical institutions worldwide. The practice of DNR is underutilized in most pediatric hospitals in the Gulf Region and the Middle East, and most of these hospitals have no DNR policy. In our institution, as per hospital's policy, all DNR orders must be written by a primary physician, attending pediatric intensivist, and a certified-board physician after further discussion with the patient's family. Since euthanasia is prohibited by law in the Kingdom of Saudi Arabia, no child was given the option for euthanasia or assisted suicides. All decisions for DNR were initiated by the medical care provider with the approval of the patient's family, as they have an important role in the decision-making process.

Little is known on the practice of DNR in children in the Middle East and the Gulf Region. The only pediatric study published in the Middle East was by Chehab<sup>15</sup> from the Pediatric Intensive Care, Prince Sultan Military Medical City, which is an 18-bed medical and surgical unit for children <14 years of age, similar to our units. In this study deaths secondary to DNR orders accounted for 31% while our study showed that deaths secondary to DNR orders accounted for 51%. The parents were involved in the decision-making in all cases.<sup>16</sup>

In Saudi Arabia, the practice of DNR is variable only for hospitals that has existing DNR protocols. The great variability in DNR practices between different countries raises the question on the globalization of bioethics; therefore, further study and research is highly needed to standardize the cure of suffering children with very poor prognosis. Over our study period of 30 months, there were 2,365 admissions to the PICU with 154 deaths, leading to a mortality rate of 6.5% (Figure 1). Deaths attributed to DNR state in our center were better than Europe and South America (36-41%) and comparable to North America (49-58%). Some European and South American countries published their data as shown in Table 2.

In our study, the DNR deaths (46/79, 58%) were related to withdrawal of life support, which included weaning from mechanical ventilation or inotropic support, or withholding renal replacement therapy. Extubation was carried out in brain dead patients only. The DNR deaths without withdrawal of life support were 33/79 (42%). Parents from North America, Australia, Middle East, and Asia seem to be more involved in the end-of-life decision-making process compared with those from Europe and South America.<sup>19</sup> The practice of discussing the issue of end-of-life support differs from country to country. Approximately 28% of Israeli physicians discuss this issue with parents,

**Table 2** - Comparison of do not resuscitate (DNR) studies with European and South American countries.

Area	Percentage of DNR	Number of deaths	Duration of study (years)
King Faisal Specialist Hospital, Riyadh, KSA	51	154	2.5
Australia <sup>7</sup>	74	27	1
Pittsburgh, USA <sup>21</sup>	40	125	5
Argentina <sup>11</sup>	36	457	5
Riyadh Armed Forces Hospital, Riyadh, KSA <sup>15</sup>	34	154	5
Portugal <sup>22</sup>	41	44	1
Lille, France <sup>18</sup>	28	259	5
Edmonton, Canada <sup>18</sup>	49	73	1
Salt Lake City, USA <sup>4</sup>	58	300	4.5

KSA - Kingdom of Saudi Arabia, USA - United States of America

while 95% of USA physicians will discuss this issue with the parents.<sup>20</sup> In our study, all DNR orders were discussed with the families. Despite an overwhelming reluctance to address the decision of end-of-life care, parents of children who are diagnosed with a potentially life-limiting illness face current and future decisions on available treatments. They might choose to pursue or forego these treatments for their children. Failure to address end-of-life decision making with the families early in the course of the child's illness can result in a delay in providing effective palliative care for the child and increase the stress on the parents who struggle with making these difficult decisions. Comfort care were ensured during and after the process of decision of DNR in the form of sedation and analgesia for comfort and care, and any potential painful intervention. Recognition and open communication on the potential death of a child is required to begin addressing these difficult decisions regarding the appropriate treatment choice. There has been a small but noticeable trend towards the acceptance of DNR orders over the years by an increasing awareness through global communication and literature and because of increasing experience both locally and internationally.

Children were unable to participate in the decision-making process as they were conscious or still very young are one of the limitation of the study.

In conclusion, end-of-life support is not well-utilized in Middle Eastern countries, as the concept of DNR is not clearly recognized and there is a lack of DNR policy in most Arabic and Islamic countries. In addition, is the confusion with religious and legal positions on DNR and poor communication between the healthcare provider and the family. Efforts should be made in the developing countries to improve and optimize end-of-life care by training medical staff, and addressed

the urgent need for the development of palliative care. Do not resuscitate was the most common cause of death in a tertiary hospital in Saudi Arabia, and limiting life support should be considered in children with terminal or untreatable diseases with a low chance of survival to minimize the suffering of the dying child.

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