



A profile of the medical conduct preceding child death at a tertiary hospital

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Abstract

Objective: To study the profile of care provided to pediatric patients suffering fatal outcomes at a university hospital, including: description of models, comparisons between units, associated factors, participants involved and records of decisions made.

Methods: Cross-sectional study. One of the investigators reviewed the medical and nursing records of deceased patients. Interviews were held and questionnaires filled out with the care team members over a period of 12 months (May 1, 2002 to April 30, 2003).

Results: The study included 106 cases. The most frequent treatment patterns at the hospital were: withholding advanced life support (51.9%) and unsuccessful cardiopulmonary resuscitation (44.3%). The decision to make a do-not-resuscitate order occurred later in the intensive care unit ($p < 0.05$). The restricted care category was more prevalent in the neonatal unit and among patients with chronic diseases that limit survival ($p < 0.05$). The professionals that most often participated in the decision-making process were the unit's treating physician and resident (52.8%) and the medical team (31.1%). Parents or guardians were observed to have been involved in 20.8% of cases. For the entire hospital, seven cases (6.6%) of ambiguous or discordant cardiopulmonary resuscitation procedures were found.

Conclusions: Procedures involving limitation of therapy are frequent, especially in the neonatal unit. Diagnosis of brain death and withdrawal of advanced life support are, nevertheless, rare. Decisions to grant do-not-resuscitate orders are generally made late, especially in the intensive care unit. In this sample procedures for full participation in decisions and for recording decisions were imperfect.

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Introduction

Over the last few decades important changes have taken place in hospital medical care that have resulted in a shortsighted process of "medicalization of death" and therapeutic obstinacy in hospitals.

In the context of the ethical and philosophical debate on the subject, certain positions have attained consensus

(at least relatively so): a rejection of therapeutic obstinacy, the equivalence of foregoing and withdrawing treatment, the possibility of withdrawing life support to alleviate suffering, the acceptance of shortening life as an unintentional effect of pain management or of appropriate life support withdrawal, the position that death provoked or assisted by physicians is ethically unacceptable and the equivalence of brain death and whole body death together with the legitimacy withdrawing life support in such cases.¹⁻⁴

In the field of research, certain significant findings have been observed: fears of lack of autonomy and suffering during a prolonged and impersonal end-of-life, the perception of death as professional failure among physicians together with the offer of exaggeratedly extensive treatment and a limited medical perspective on the possible interests of the patients themselves in decisions affecting them when critically ill.^{5,6}

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In the light of this debate and based on a case series, the current study describes the profile of care given to patients suffering fatal outcomes in the pediatric units of the *Hospital das Clínicas* (HC) of the *Universidade Federal de Minas Gerais* (UFMG). Further factors were also evaluated: the interval of time involved in decisions not to reanimate, comparisons between units, factors associated with the care model distribution (place of death, state of chronic disease and physiological instability), parties involved and which details of the decisions made were added to medical records.

Methods

This study was approved for the Committee for Ethics in Research with Human Beings at UFMG. As this was an observational study the requirement for free and informed consent was waived. The research was performed at the hospital's pediatric units – the emergency department (ED), the infirmary, the intensive care center (ICC) and the neonatal unit. Pediatric deaths taking place in the surgical services were also considered. This was a cross-sectional observation study with patients enrolled prospectively. The sample was chosen intentional, covering a 12-month period (01/05/2002 to 30/04/2003). One of the authors reviewed the medical records (patient records, death certificates) and nursing records of patients who died during this period. The same researcher performed a semi-structured interview and filled-out a structured questionnaire with members of the care team (both anonymously). In 93.5% of cases information sources were accessed within 24 hours of death.

The inclusion criteria specified the selection of all patients younger than 16 who progressed to death within the pediatric units with exclusions in the following circumstances: death in the delivery room, essential information missing and questionnaires/interviews two or more weeks after death.

Chronic disease status was classified using a scale that had been previously tested in a pilot study of 15 patients. Based on objective information in the literature (survival analyses) and the accompanying specialties, the following categories were defined: condition limiting survival (chance of survival < 5%) to childhood or adolescence; condition incapacitating patient for adult life (persistent vegetative state), condition not limiting survival to childhood or adolescence or incapacitating patient for adult life, condition with indefinable prognosis and, finally, not suffering from any chronic diseases.

Validated risk-of-death score protocols were used to evaluate the influence of physiological instability (data expressed as percentage): PRISM/DORA – for evaluating individual risk of death (over the whole length of the hospital stay or by 24-hour periods) for patients more than 28 days old⁷⁻⁸ – and SNAPPE-II – for assessing average risk of death by scoring bands (over the whole length of a hospital stay), for patients under 28 days old.⁹

Care modalities were split into four categories: brain death,¹⁰ unsuccessful cardiorespiratory resuscitation (CPR – positive pressure ventilation, chest compressions, drugs and/or cardioversion); withholding life support (CPR, ventilation via endotracheal tube, volemic expansion and/or pharmacological circulation support) and actively withdrawing life support (ventilation via endotracheal tube and/or pharmacological circulation support). A minimum period of 2 hours was required between the decision not to resuscitate and death for the decision to be defined as a do-not-resuscitate order. Decisions were classified by the researcher reviewing records and the method of grouping them had been previously tested in a pilot study.

The time passed before death under a do-not-resuscitate order was recorded and corrected for the total period the patient had remained in the ward where death occurred in order to attenuate the influence of different survival times on the analysis of decision-making speed.

In the evaluation of the involvement of professionals in care decisions, any type of participation in the discussion was accepted. When analyzing the involvement of parents and guardians, any spontaneous or induced manifestation of wishes or simple agreement with the medical team's decision, after full explanation, was accepted.

In function of the physical and operational separation of the neonatal unit and because of its restricted treatment scope (limited to neonates born at the hospital), comparative analyses were based on binary grouping (neonatal unit versus all other units).

In analyzing all data, categorical variables were based on frequency or proportion of occurrence. Quantitative variables were expressed as central tendency and variability. Proportions were compared using the chi-square test (Yates) and Fisher's exact test (when appropriate); when comparing quantitative variables the Kruskal-Wallis non-parametric test was employed. The cut-off point for statistical significance was set at $p = 0.05$. Data was computerized using Epi-Info (version 6.04d).

Results

The total patient sample was 112 deaths with six cases lost (one from the ED, two from the neonatal unit and three from the infirmary), making a total of 106 cases to be analyzed.

The female/male ratio for the global sample was 1.52. Excluding data from the neonatal unit, there was a predominance of deaths among those less than 24 months old (39 out of 65 or 60%).

The distribution of patients with respect of deaths per hospital sector is shown in Table 1.

Primary causes of death are detailed in Table 2.

Table 3 presents the classification of patients by chronic disease status.

With respect of risk of death estimate scores, the percentage of information lost due to carelessness was negligible (less than 0.5%). Losses were essentially due to

restrictions imposed by the protocols (exclusion criteria) or by the patients' conditions (e.g. terminal patient with limited chances of collecting samples for laboratory tests). The percentage of cases for which scores could be calculated was 81.3% in the pediatric ICC and 70.7% at the neonatal unit. The remaining units did not have enough data for risk to be described.

Table 4 shows the data on individual risk of death estimated by PRISM/DORA in the pediatric ICC.

The distribution of care models across the whole hospital are shown in Table 5.

Table 1 - Distribution of patients with respect of deaths per hospital sector and median hospital stay (in hours)

Sector	Frequency	%	Median (h)
Emergency room	3	2.8	41.05
Ward	10	9.4	530.40
Neonatal unit	41	38.7	45.84
Pediatric ICU	48	45.3	80.80
Surgical block	4	3.8	3.87
Total	106	100	

Table 2 - Primary causes of death: emergency department, infirmary, pediatric intensive care center and surgical unit

Cause	Frequency	%
Failure of multiple organs	17	26.2
Acute respiratory insufficiency or intensified	15	23.0
Septic shock *	13	20.0
Cardiogenic shock	9	13.8
Neurogenic shock	4	6.2
<i>Cor pulmonale</i>	5	7.7
Acute pulmonary edema	1	1.5
Unknown	1	1.5
Total	65	100

Neonatal unit

Cause	Frequency	%
Failure of multiple organs	12	29.3
Acute respiratory insufficiency or intensified	18	43.9
Septic shock *	5	12.2
Cardiogenic shock	5	12.2
Unknown	1	2.4
Total	41	100

* Here understood as any hemodynamic instability (bad tissues perfusion, with or without arterial hypotension) with infectious etiology - includes the concepts of severe sepsis and septic shock from the Society of Critical Care Medicine and from the American College of Chest Physicians (Chest, 1992; 101:1644-55).

Table 3 - Classification of patients by chronic disease status* during hospital stay before death

Status †	ED, pediatric infirmary and ICU		Neonatal unit	
	Frequency	%	Frequency	%
1 ‡	17	26.2	17	41.5
2	0	0	2	0
3	18	27.7	2	4.9
4	15	23.1	9	21.9
5	15	23.1	13	31.7
Total	65	100	41	100

* Irreversible condition or expected to last for more than 90 days.

ED = emergency department; ICU = intensive care unit.

† 1 = condition limiting survival to childhood or adolescence even with adequate treatment; 2 = condition incapacitating patient for adult life; 3 = condition not limiting survival to childhood or adolescence or incapacitating patient for adult life; 4 = condition with indefinable prognosis; 5 = not suffering from any chronic diseases.

‡ In grouped units: leukemias (six cases), imperfect twinning (two cases), metastatic neuroblastoma, bone marrow aplasia, myelodysplasia, metastatic sarcoma of clear cells, trisomy 18, Fanconi syndrome, posterior fossa brain tumour with metastasis, Pompe's disease, Dandy-Walker syndrome (one case of each). In the neonatal unit: hydranencephaly (five cases), Potter's syndrome - bilateral renal agenesis (four cases), imperfect twinning (two cases), thanatophoric dwarfism (two cases), trisomy 18 (one case), trisomy 22 (one case), left ventricle hypoplasia syndrome (one case).

Table 4 - Individual risk of death (percentage) estimated by PRISM/DORA in the pediatric Intensive Care Center

Parameter	Measures		
	n	Median	(IQ 25%-75%) *
General risk †	26	4.5	(2.7-27)
Risk 24 ‡	26	15.4	(7.1-41.3)
Risk DMR §	11	14	(3.3-37.2)

* Interquartile from 25% to 75%.

† General estimated risk in the entire unit.

‡ Estimated risk for the last 24 hours of life (starting from the last score recorded).

§ Estimated risk for the 24 hours after Definition (D) of the Restrictive (R) model (M): withholding or withdrawing of life support.

Table 5 - Care models across the hospital

Models*	Frequency	%
A	3	2.8
B	55	51.9
C	1	0.9
D	47	44.3
Total	106	100

* A = brain death (clinic inference).

B = withhold of life-support (cardiopulmonary resuscitation, ventilation via endotracheal tube, expansion and/or pharmacological circulation support).

C = withdrawal of life-support (expansion and/or pharmacological circulation support).

D = unsuccessful resuscitation (unconstrained use of therapies).

The most often employed model was to withhold life support (55 cases or 51.9%), including 53 cases (96.4%) of do-not-resuscitate orders, with 23 being isolated orders and 30 orders being associated with other care withholding methods. It was observed that just two of these decisions were entered onto medical records. Of the 53 cases in which a decision was made not to resuscitate, 30 children (56.6%) were already on mechanical pulmonary ventilation and 24 (45.3%) were receiving pharmacological circulation support when the order was fixed upon; eight patients (15.1%) had already received CPR at the place of death before progressing to the final outcome.

The second most common model was unsuccessful resuscitation (47 cases or 44.3%). A diagnosis of brain death was observed in just three cases (2.8%), none of which was confirmed by electroencephalogram. A single case of active withdrawal of life support was recorded for the sample and this involved the withdrawal of prostaglandin E1 from patient suffering from hypoplasia of the left ventricle.

Table 6 contains the comparison between the three principle units studied with respect of the distribution of the different end-of-life models.

The time intervals related to period of hospitalization and the decision not to resuscitate are presented in Table 7.

In 50.9% of cases ($n = 27$) the time passed between the decision not to resuscitate and death was greater than 12 hours. In the pediatric infirmary, the percentage was 83.3%, at the neonatal unit 60% and the ICC 23.5%.

With respect of the time passed under the do-not-resuscitate order and time spent in the unit, significant differences were observed when the following comparisons were made: ICC versus the neonatal unit ($p < 0.01$) and the pediatric infirmary ($p < 0.01$), with lower values for the ICC.

The univariate analysis of the factors possibly associated with care model distribution (categorized in a binary manner) is presented in Table 8.

The professional participation involved in the definition of the models are shown in Table 9.

When analyzed by sector, the greatest percentage of participation by the team was recorded in the infirmary (70% or seven cases in 10) and the lowest in the ICC (22.9% or 11 in 48) with intermediate values for the neonatal unit (36.6% or 15 in 41).

Parent involvement in the discussions was observed in 22 cases (20.8%).

The sudden nature of the event or rapid deterioration of the disease were indicated as the primary explanation for decision-making modalities that are either little participative – limited to the on-call doctor and the resident ($n = 56$) or excluding involvement of the physician or accompanying specialties ($n = 59$) – or that exclude parent involvement ($n = 84$). The percentages for these three types of case were, 82.1, 72.9 and 66.7%, respectively. Another common explanation was the lack of opportunity for any participation – for physician or accompanying specialties exclusion (23.7%) and for excluding parents (44%). In the case of the parents the primary justification was the obvious nature of the decision to be taken (the patient's best interest (43.2%).

Four cases of discrepancy between the model adopted in practice and that described on the medical record were observed, in which CPR was not performed in practice, but what was recorded was *did not respond to resuscitation maneuvers*, which conduct could be explained by fears of possible legal consequences of withholding treatment. Three cases of dubious or imprecise medical record entries were also highlighted, in which CPR was withheld, but the record stated *support maneuvers performed with no response* (the term support was considered here vague or dubious: life support or palliative support?) – which attitude could also be explained by fears of possible legal consequences of withholding treatment.

Table 6 - Comparison between the three principle units studied - pediatric infirmary, pediatric intensive care center and neonatal unit

Models*	Infirmary		Pediatric ICC		Neonatal unit	
	Frequency	%	Frequency	%	Frequency	%
A	0	0	2	4.2	1	2.4
B	6	60	19	39.6	30	73.2
C	0	0	0	0	1	2.4
D	4	40	27	56.3	9	22
Total	10	100	48	100	41	100

* A = brain death (clinic inference); B = withhold of life-support (cardiopulmonary resuscitation, ventilation via endotracheal tube, expansion and/or pharmacological circulation support); C = withdrawal of life support (ventilation via endotracheal tube, expansion and/or pharmacological circulation support); D = unsuccessful resuscitation (unconstrained use of therapies).

All patients recorded in the emergency department (three) and in the surgical unit (four) were submitted to unsuccessful resuscitation (D), closing the 106 cases of the sample.

Table 7 - The time intervals related to period of hospitalization and the decision not to resuscitate

Time passed (in hours) between the decision not to resuscitate and death			
Unit	n	Median	(IQ 25%-75%) *
Hospital	53	13	(4-27.4)
Infirmery	6	240	(192-504)
Pediatric ICC	17	6	(3-13)
Neonatal unit	30	15	(5-27.4)

Ratio between time passed between the decision not to resuscitate and total hospital stay before death			
Unit	n	Median	(IQ 25%-75%) *
Hospital	53	0.3	(0.1-0.9)
Infirmery	6	1	(0.7-1)
Pediatric ICC	17	0.1 †	(0.01-0.1)
Neonatal unit	30	0.6	(0.1-1)

ICC = intensive care center.

* Interquartile 25% to 75%.

† p < 0.01: neonatal unit *versus* pediatric ICC, with higher values in the neonatal unit; pediatric infirmery *versus* ICC, with higher values in the pediatric infirmery.**Table 8 -** Univariate analysis of the factors possibly associated with care model distribution (categorized in a binary manner)

Variables	Models			Statistics		
	Restrictive	Non- Restrictive	Total (N)	p	Test	
Chronic disease status after admission*	A	30	4	106	< 0.01	χ^2_C †
	B	29	43			
Place of death ‡	1	27	38	106	< 0.01	$^1\chi^2_C$ †
	2	32	9			
Place of death (among patients with the A state of chronic diseases)	1	13	4	34	0.10	Fisher
	2	17	0			
Place of death (among patients with the B state of chronic diseases)	1	14	34	72	0.01	$^1\chi^2_C$ †
	2	15	9			
PRISM/DORA (ICC) – median of general risk § (%) () = n of the group	6.1% (11)	3.8% (15)	26	0.64	Kruskal-Wallis	
PRISM/DORA (CTI) – median of risk 24 (%) () = n of the group	7.2% (11)	4.4% (15)	26	0.76	Kruskal-Wallis	
SNAPPE-II (ICC) – median of the general risk (%) () = n of the group	25.5 (6)	2.8 (7)	13	0.09	Kruskal-Wallis	
SNAPPE-II (neonatal unit) – median of the general risk (%) () = n of the group	6.5 (23)	1.3 (7)	30	0.22	Kruskal-Wallis	

ICC = intensive care center.

* A = chronic disease with limiting survival to childhood or adolescence or incapacitating patient to adult life; B = other diseases.

† Chi-square with Yates continuity correction (one degree of freedom).

‡ 1 = all units (except the neonatal unit); 2 = neonatal unit. In the direct comparison among different sectors (pediatric infirmery, pediatric ICC and neonatal unit), the only significant difference as for models distribution was recorded between the pediatric ICC and the neonatal unit ($p < 0.01 - ^1\chi^2_C$), with higher prevalence of the restrictive model in the neonatal unit.

§ Estimated general risk for the entire unit.

|| Estimated risks for the last 24 hours of life (starting from the last score recorded).

Table 9 - The professional participation involved in the definition of the models

Categories	%	n *
On-call doctor and resident	52.8	56
Coordinator/preceptor, on-call and resident doctors	12.3	13
Medical team †	31.1	33
Other	3.8	4
Total	100	106

* n = total number of participants.

† Defined by the simultaneous participation of the following members: coordinator/preceptor + on-call and resident doctors + accompanying specialties.

Discussion

A high chronic diseases prevalence rate was observed in this sample, many of which are survival-limiting, which is reflected in the complexity of the patients in this series.

The low medians of individual risk of death estimated by PRISM/DORA in the ICC reveal, for the subset in question, the poor relation between estimated risk and actual death. In addition to possible errors with relation to the records needed for the protocols, the prevalence of certain diseases – neoplasms in general, congenital heart diseases and genetic diseases – are recognized as resulting in these scores performing worse in terms of prognosis.⁷

The data from this series confirm the high prevalence of restrictive forms of care (withholding or withdrawing treatment) observed in the literature. However, limitation of therapy is much more established in the USA, Canada and Western Europe. In general, developing countries exhibit a more conservative profile.^{11,12} The only Brazilian study of this type (Carvalho *et al.*, 2001),¹¹ undertaken at a pediatric ICC, revealed how common limitation of therapy can be in our country (40.9% of the sample).

Excluding records from the neonatal units, the present study demonstrated lower observed proportions (n=65) of brain death and restrictive modalities (withholding and withdrawing life support), when compared with other published data:¹¹⁻²¹ 3% of brain death compared with 6.5 to 38%, 38.5% limitation of therapy against 28 to 76.7% (generally > 40%); 0% of withdrawing essential life support against 4.7 to 50.6% (generally > 15%). In contrast, in the current study a greater proportion of unsuccessful resuscitation was observed: 58.5% against 16.9 to 46.3% in other research.

Exclusively analyzing the neonatal units, the proportions of restrictive modalities observed (n = 41) are comparable with other research:²²⁻²⁶ 75.6% against 52 to 86.6%. Withdrawal of advanced life support is more frequent in other studies: 2.4% against 66.5 to 72.4%.

In the current series there were just two cases in which the decision to limit investments was registered formally. The habit of formally recording such decisions is much more established in other countries.^{17,26}

Possible reasons for the observed discrepancies that might be ventured are: temporal differences and sampling variations between the series, differences in professional training and the organization of healthcare teams and variations in the cultural, religious and legal backgrounds (legal implications).

When direct comparisons are made between the units (infirmary, ICC and neonatal unit), a greater proportion of unsuccessful resuscitations was observed at the ICC (56.3%) and of restrictive models (including brain death) at the neonatal unit (78%). Potential explanations of these differences are the selection of patients and greater pressure for resuscitation to be attempted at the ICC, in addition to greater facility for the neonatologists to effect restrictive actions (more tenuous links between parents and newborns).

The time intervals between the decision not to resuscitate and death, while being influenced by forms of disease progression (explanation of diagnosis and prognosis), indicate that in the ICC, non-resuscitation was decided upon after an aggressive initial investment, maintained until close to death. The search for near certainty in prognoses and the slow decision-making process may also have delayed the do-not-resuscitate decisions in this sector.

Survival-limiting chronic diseases and death at the neonatal unit were significantly associated with limitation of therapy. Other series have registered similar findings with respect of severe or debilitating chronic diseases.^{11,13} The place of death analysis stratified by chronic disease state confirms the tendency towards treatment limitation in the neonatal unit. With respect of physiological instability as measured by the scores, no significant difference was observed in risks (PRISM/DORA and SNAPPE-II) between the different care categories.

In the current series a worrying predominance was observed towards exclusive participation in the decision-making process by the on-call physician and resident (52.8%) and of decisions from which families were excluded (79.2%). Decisions involving the healthcare team and family members by means of formal meetings have been recorded in the literature with frequency.^{12-18,21,22,24-26} The lack of opportunity for manifestation of wishes was indicated as a significant cause of these findings, showing just how precarious the process of involving interested parties (family members and other professionals) in the decisions is.

The argument based on the patient's best interests for excluding parents reveals signs of paternalism in the relationship between doctors and family members. Despite, as Kipper points out,²⁷ the cultural difficulties observed in Brazil in stimulating a more autonomous family posture in decision-making, the passive attitude will not change unless the medical classes assume the initiative in the inclusion process, however uncomfortable and inopportune it may appear, and capacitate themselves for the task.

Equally worrying is the absence of professionals who are not doctors from the decision-making process. Published work suggests that nursing professionals would like greater participation in discussions about end-of-life care and that these professional' and doctors' conceptions about the best way to care for patients are relatively divergent.²⁸

The discrepancies between the model actually adopted and that entered onto the medical record or dubious records of the actions taken, although only observed in seven cases, does not fail to cause a certain concern because of the ethical significance of such procedures at a university hospital. Such initiatives without doubt constitute serious ethical violations in addition to contributing for a sense of distrust and disbelief within the care team. Similar findings were observed in Brazil by Torreão *et al.*,²⁹ with false CPR procedure records in 29 out of 40 patients who progressed to fatal outcomes without having been given resuscitation.

Fears of possible legal implications related to limiting investments become evident in inadequate medical records. The background of legal support against which Brazilian doctors work appears to contribute, palpably, to certain practices that bring their conduct close to therapeutic obstinacy. The conservative interpretation of the Penal Code distances medical professionals from orthothanasia (death with relief from suffering and at the appropriate time), impelling them towards "dysthanasia" (slow anxious death with great suffering) because of fears of accusations of failure to save. In the light of the scarce Brazilian jurisprudence that can be extracted from concrete cases, such fears do not appear to be justified. Reforming judicial movements nevertheless propose the reformation of the Penal Code (understanding orthothanasia as merely normal medical practice) or a modification of the form in which the current code is interpreted (accepting medical intervention limitation based on moral and ethical justification).³⁰

Despite the apparent lack of legal support, the development of protocols for limiting therapeutic efforts in hospitals has become an urgent necessity. Without intending

to establish rigid norms to control decisions, protocols would encourage wider discussion of the issues and at an opportune time, organization of the debate, formal records of duly founded decisions and the involvement of family members in the form of giving informed consent. In addition to the support of the hospital institutions, protocols could benefit from the backing of medical associations and medical councils. Their possible legal implications should be faced in a serene and courageous manner by all those who work within the principles of good medical practice.

In conclusion, limitation of therapy procedures are frequent with children who progress to fatal outcomes at the pediatric units of the HC-UFGM, approaching the proportions of restriction to be observed in similar studies in the literature. Frequency rates of brain death diagnosis and the active suspension of advanced life support, however, remain negligible. Within the ICC, in the majority of cases decisions not to resuscitate are accompanied by initial therapeutic investment attempts, habitually sustained until very close to death. Limitation of therapy is employed with greater frequency in the neonatal units and with carriers of chronic, survival limiting conditions. Ethical decisions resulting from wider participation of professionals and family members remain restricted. Fear of the possible legal implications of limitation of therapy appears to be a determining factor in the inappropriate recording of do-not-resuscitate orders. Analyses in depth, involving specific aspects of the process are needed to better understand the determinants involved.

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