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ORIGINAL ARTICLE

Physicians' attitudes towards ethical issues and end-of-life decision-making for pediatric patients with unresponsive wakefulness syndrome: An international survey

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Abstract

Aim: We examined physicians' perspectives on the mental capabilities of pediatric patients with unresponsive wakefulness syndrome (UWS) and their attitudes towards limiting life-sustaining treatment (LST) in an international context.

Method: A questionnaire survey was conducted among 267 neuropediatricians, practicing in 65 countries. Comparisons were made according to the Human Development Index (HDI) of the countries. The Idler Index of Religiosity was applied to determine religiosity.

Results: Participants from countries with a very high HDI were generally more favorable to limiting LST ($p < 0.001$), specifically cardiopulmonary resuscitation ($p = 0.021$), intubation/ventilation ($p = 0.014$), hemodialysis/hemofiltration ($p < 0.001$), and antibiotic therapy ($p < 0.001$). Treatment costs that were too high had a weaker influence on their decisions ($p < 0.001$). Participants who found it never ethically justifiable to limit LST had a higher mean Idler Index of private ($p = 0.001$) and general ($p = 0.020$) religiosity and were less satisfied with treatment decisions ($p < 0.001$) and the communication during the process ($p = 0.016$).

Interpretation: The perspectives towards limiting LST for pediatric patients with UWS are markedly different between physicians from countries with very high and lower HDIs.

Disorders of consciousness including unresponsive wakefulness syndrome (UWS; also known as persistent vegetative state) pose particular ethical challenges to the field of pediatrics because of their high degree of uncertainty in diagnosis, prognosis, and treatment.[1] UWS results from severe neurological impairment and is characterized by the loss of purposeful responsiveness to external stimuli, suggesting an impaired consciousness, while brainstem and hypothalamic functions, including sleep–wake cycles, are usually preserved.[2]

The diagnosis of pediatric UWS is fraught with uncertainty.[3] A seminal study among members of the Child Neurology Society indicated that a diagnosis of UWS could only be made after the age of 2 years.[4] Furthermore, the prognosis of pediatric patients with UWS is notoriously difficult to determine with certainty and is mainly dependent on etiology, level of consciousness, and duration of observed critical parameters.[3,5] When UWS is caused by incurable metabolic or degenerative disorders, recovery cannot be expected, because their course is usually progressive or reaches a clinical plateau.[3] The lifespan of pediatric patients with UWS is generally limited.[6]

The uncertainty about diagnosis and prognosis significantly affects treatment decisions for patients with UWS.[7,8] The question of whether to limit the provision of life-sustaining treatment (LST) for pediatric patients with UWS is a core ethical challenge and often generates complex

This original article is commented on by Fins on pages 1549–1550 of this issue.

Abbreviations: ANH, artificial nutrition and hydration; HDI, Human Development Index; LST, life-sustaining treatment; non-VH-HDI, non-very-high Human Development Index; UWS, unresponsive wakefulness syndrome; VH-HDI, very high Human Development Index.

legal challenges and sparks public attention.[1,9] According to normative best-practice recommendations, treatment decisions for these patients should be in the best interest of the child and shared among caregivers with parental authority and with the treating healthcare team, depending on the applicable laws of the respective country.[10] However, it has been shown that the reality of decision-making can deviate in various ways.[11] Physicians play a crucial role in making the diagnosis and informing caregivers about prognosis and treatment options. They also determine the medical indication for interventions, including artificial nutrition and hydration (ANH).[12] Therefore, physicians' perspectives and attitudes, directly or indirectly, significantly influence treatment decisions for this population of patients.

Although physicians' attitudes towards diagnosis, prognosis, and treatment decisions for adult patients with UWS have been investigated, scant data exist about pediatric patients.[12–14] Cultural and religious differences as well as national laws can be expected to influence perspectives on limiting LST.[15,16] However, most studies on ethical challenges of UWS have been limited to affluent, mostly Western countries and rarely include an international perspective.

In this study, our aim was to investigate the perspectives of a broad international group of neuropediatric physicians on the presumed capabilities of pediatric patients with UWS and on the limitation of LST for this population of patients. Furthermore, we aimed to determine whether these perspectives differed between physicians with varying religiosity and working in countries with different levels of wealth and human development.

What this paper adds

- In lower developed countries, more physicians disapproved of limiting life-sustaining treatment for pediatric patients with unresponsive wakefulness syndrome.
- Hypothetical explanations include differences in cultural and religious background, and national law.
- Physicians disapproving of limiting life-sustaining treatment were less satisfied with the decision-making process and results.

METHOD

Study design

To be able to reach neuropediatricians/pediatric neurologists practicing in as many countries as possible, we performed a cross-sectional study using a self-administered online survey in a convenience sample, applying a snowball sampling strategy. An e-mail was sent to contact members of various international and national neuropediatric associations, which contained a link to the survey created on the platform SurveyMonkey, an invitation to share the e-mail with members of the respective associations, as well as a short description of the study and a note that adult patients were excluded. Although limiting LST is a multidisciplinary concern, the e-mail was targeted at physicians specializing in the care of pediatric patients with neurological disorders, because they were most likely to be familiar with the particularities of the diagnosis and prognosis of pediatric UWS, which has a crucial impact on decision-making. This also allowed us to have a professionally homogenous yet internationally diverse sample. A reminder e-mail was sent 1 month later. Before being asked for informed consent, participants were given a short description of the study and informed about the principal investigators, confidentiality, risks, benefits, funding, their rights, and the estimated time involvement of 10 minutes. All data were anonymized through an alphanumeric coding system and saved on keyword-protected computers in a secured building to which only authorized research team members had access.

Compliance with ethical standards

The study received ethics approval of the Research Ethics Board at LMU Munich (041–11). All procedures involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed written consent was obtained from all individual participants included in the study.

Participants and recruitment

The initial invitation to the survey was sent to 23 neuropediatric associations from different countries around the world and 28 national coordinators of the European Academy of Childhood Disability. Our choice of associations was based on a comprehensive Internet search but limited to sites that contained a valid e-mail address or functioning contact form. No incentives were offered for participation. The survey was open from October 2016 to February 2017. We received explicit responses from the International Child Neurology Association, which sent the questionnaire to its 4713 members; from the Canadian Neurological Society, which sent it to 150 pediatric neurologists and trainees in their country; and from the Danish neuropediatric society, which forwarded it to 156 members.

Questionnaire

We developed a semiquantitative questionnaire based on a previous German version validated in a local group of

neuropediatricians, itself based on previously developed surveys, literature review, and theoretical reflection among the authors (see Appendix S1 for more detailed information).[13,17,18] Thereby the survey was pre-tested with 196 German neuropediatricians participating in the former study.[18] The questionnaire was then translated by using a forward–backward translation protocol. The forward translation to English was done by a bilingual research associate and the backward translation to German by native German speakers, according to scientific standards. To increase validity, the questionnaire started with setting the thematic focus by describing the case of a pediatric patient in UWS. It was made explicit that the questionnaire related to patients under the age of 18 years. It contained 26 ordinally scaled questions, with subcategories and Likert scales for seven of them. Choosing multiple responses was possible for selected questions. There were questions about diagnosis, prognosis, treatment, and ethical considerations of UWS for pediatric patients. Questions about diagnosis included questions on diagnostic certainty, assessment tools, and presumed capabilities of pediatric patients with UWS. Participants were asked which LST they would limit and whether they considered ANH to be medical treatment or basic care. In addition, participants were asked which circumstances influenced these treatment decisions, how they were made, and how satisfied the participants were with these decisions and the communication associated with them. The demographic data contained information about the age group, sex, profession, and work experience, but also about the country of current practice and medical training and questions required to calculate the Idler Index of Religiosity and its subcategories of public and private religiosity.[19] The subcategory of private religiosity focuses on internal beliefs whereas public religiosity focuses on public religious practice. Both subcategories are summarized as 'general religiosity'. In a second step, we subcategorized countries according to their Human Development Index (HDI) as published by the Human Development Report 2016 of the United Nations Development Programme. This index measures the grade of development of a country by examining three national dimensions: health (measured by life expectancy at birth); education (measured by mean number of years of schooling for adults aged at least 25 years and expected years of schooling for children of school-entering age); and standard of living (measured by national income per head).[20,21] The usability and technical functionality of the electronic questionnaire was tested before distribution.

Statistical analysis

The data were analyzed using IBM SPSS 19 statistics software (IBM Corp., Armonk, NY, USA). Data from participants who did not give informed consent or who answered fewer than 25% of the questions were excluded. A χ^2 test for trend was performed on all ordinal data from Likert scales. To compare our participants' satisfaction with treatment decisions and their experience with who was involved or consulted in the decision-making process (Table 3), we dichotomized the data for satisfaction (Likert scale with the options very dissatisfied [1–4] and very satisfied [5]) into two groups (dissatisfied, 1–2; satisfied, 3–5) and used a multiple-response χ^2 test. As the questions about our participants' experience with who was involved or consulted in the decision-making process allowed multiple responses, this facilitated the analysis. For the central ethical question of whether in the participant's opinion it was ethically justifiable to limit LST measures in children with UWS, the possible responses 'never', 'always', and 'under certain circumstances' were compared in two groups, 'never' and 'always or under certain circumstances', using a Pearson's χ^2 test. We compared countries with a very high HDI (VH-HDI) with those with an HDI other than very high (non-VH-HDI), including a high, medium, and low HDI. A VH-HDI is defined as being above 0.800.[20,21] This clustering was chosen because the main countries where research on ethical challenges of pediatric UWS has been conducted and where the healthcare system and palliative care system is highly developed show a VH-HDI. Furthermore, the clustering enabled us to form comparable groups, as the number of responses was very unevenly distributed among countries and their HDI, with most responses coming from countries with a VH-HDI. The Idler Index of Religiosity of public, private, and general religiosity was calculated for each participant and then compared between different groups using a *t*-test for unpaired samples.[19] Normality was graphically tested. Results were considered significant if $p < 0.05$. The *p*-values were adjusted for multiple comparisons when required, using the Bonferroni method. Percentages presented in the results are related to the number of participants who responded to the respective question(s).

RESULTS

Sample

Our sample included 267 physicians practicing in 65 different countries, 86.1% practicing in the same country where they obtained their medical training (Table 1 and Appendix S2). Referring to North American terminology, most held the position of attending physician (having completed residency and being responsible for patient care; $n = 116$; 43.4%) or chief physician (heading a department as senior medical manager; $n = 88$; 33.0%). The work settings included inpatient care ($n = 210$; 78.7%), outpatient care ($n = 182$; 68.2%), acute care ($n = 123$; 46.1%), and rehabilitation care ($n = 78$; 29.2%). Participants practicing in countries with a VH-HDI had a significantly lower mean of public (0.9 vs 1.1; $p < 0.001$), private (1.1 vs 1.5; $p < 0.001$), and general (2.0 vs 2.6; $p < 0.001$) religiosity than physicians of countries with a non-VH-HDI.

Attribution of capabilities

We did not find any statistically significant difference in the capabilities attributed to pediatric patients with UWS

TABLE 1 Demographic and professional characteristics of participants ($n = 267$).

Variable	*n*	%
Sex ($n = 236$)		
Female	123	52.1
Male	113	47.9
Age cohort ($n = 236$)		
21–29 years	2	0.8
30–39 years	40	16.9
40–49 years	70	29.6
50–59 years	72	30.5
≥60 years	52	22.0
Number of patients with UWS taken care of so far ($n = 267$)		
0	19	7.1
1–20	172	64.4
21–40	45	16.9
41–60	13	4.9
>60	18	6.7
Duration of professional practice ($n = 234$)		
<2 years	4	1.7
2–5 years	25	10.7
6–9 years	23	9.8
>9 years	182	77.8
HDI of country physicians currently practicing in ($n = 232$)		
Very high	131	56.5
High	50	21.6
Middle	48	20.7
Low	3	1.3
Idler Index of Religiosity	Median	Range
Public religiosity (value 0–2)	1.00	1.58
Private religiosity (value 0–2)	1.25	1.42
General religiosity (value 0–4)	2.33	3.00

The percentages shown are the share of the absolute number of participants choosing the respective response of the overall number of participants who responded to the respective question.

Abbreviations: HDI, Human Development Index; UWS, unresponsive wakefulness syndrome.

depending on their demographic data, religiosity, or the HDI of the country in which the physicians practiced. See Figure 1 for the attribution of capabilities in VH-HDI and non-VH-HDI countries and in all participants.

Attitudes towards limiting LST

When asked about limiting LST for pediatric patients with UWS, 15.0% of the participants found this never to be ethically justifiable, 68.5% justifiable under certain circumstances, and 16.5% always justifiable (Table 2). Significantly more participants found limiting LST for pediatric patients with UWS never justifiable, when they worked in non-VH-HDI countries ($p < 0.001$). Those participants who found it never ethically acceptable to limit LST for pediatric patients with UWS had significantly higher degrees of general religiosity (mean 1.5 vs 1.2, $p = 0.001$) and private religiosity (mean 2.6 vs 2.2, $p = 0.020$). Overall, 66.0% of our participants regarded ANH as basic care and 34.0% as medical treatment. We did not find a statistically significant link between the participants' perception of ANH and their religiosity or the HDI.

We further asked for circumstances that might influence the decision-making on limiting LST of pediatric patients with UWS (Figure 2). The three circumstances that influenced most participants (>80% chose 3–5 on the Likert scale) were the presence of severe comorbidities (87.8%), an obvious intense suffering of the patient evident to the external observer (85.8%), and the certainty that consciousness could never be regained (83.4%). More than one-quarter (28.3%) of our participants considered treatment costs that were too high to influence their decisions (3–5 on the Likert scale), yet this possibility significantly influenced more participants from non-VH-HDI than VH-HDI countries (47.0% vs 14.9%, adjusted $p < 0.001$).

For specific measures of LST, more than two-thirds of our participants leant towards considering limiting cardiopulmonary resuscitation, intubation/mechanical ventilation, hemodialysis/hemofiltration, and surgery (3–5 on the Likert scale). However, only a clear minority would do so for antibiotic therapy and ANH. Physicians from countries with a non-VH-HDI were less favorable to considering limiting cardiopulmonary resuscitation (adjusted $p = 0.021$), intubation/ventilation (adjusted $p = 0.014$), hemodialysis/hemofiltration (adjusted $p < 0.001$), and antibiotic therapy (adjusted $p < 0.001$) (Figure 3).

Satisfaction with treatment decisions

Physicians who considered limiting LST for pediatric patients with UWS as never ethically justifiable were significantly more dissatisfied with the treatment decisions than those who perceived these decisions as justifiable under some circumstances or as always justifiable (38.7% vs 10.4%/12.0% Likert scale 1–2, $p < 0.001$). Similarly, the first group was more dissatisfied with communication than the last two (34.4% vs 11.0%/7.5% Likert scale 1–2, $p = 0.016$). We could not find a difference in trend for dissatisfaction between participants practicing in countries with different HDIs. Furthermore, we found a statistically significantly higher dissatisfaction among participants who had cared for more patients with UWS than for those with less experience about the communication process ($p = 0.040$) and the ultimate decision ($p = 0.048$). Satisfaction was further influenced by who was involved or consulted in the decision-making process (Table 3). No difference in terms of satisfaction could be established between the participants with various degrees of religiosity.

TABLE 2 Physicians' attitudes towards life-sustaining treatments for pediatric patients with UWS.

Limiting life-sustaining treatment measures for pediatric patients with UWS is …				
Variable	**Always ethically justifiable, *n* (%)**	**Ethically justifiable under certain circumstances, *n* (%)**	**Never ethically justifiable, *n* (%)**	**(Adjusted) *p***
Total ($n = 254$)	42 (16.5)	174 (68.5)	38 (15.0)	
Sex				
Female	15 (12.2)	88 (71.5)	20 (16.3)	0.519
Male	23 (20.4)	75 (66.4)	15 (13.3)	
Duration of professional practice				
≤9 years	6 (11.5)	41 (78.8)	5 (9.6)	0.221
>9 years	32 (17.6)	120 (65.9)	30 (16.5)	
Participants who consider patients with UWS being aware of themselves as …				
Not possible (0)	17 (25.4)	41 (61.2)	9 (13.4)	16.745[a]
Extremely unlikely (1)	15 (15.3)	70 (71.4)	13 (13.3)	
(2)	5 (12.8)	28 (71.8)	6 (15.4)	
(3)	3 (9.1)	25 (75.8)	5 (15.2)	
(4)	2 (18.2)	7 (63.6)	2 (18.2)	
Extremely likely (5)	0 (0.0)	3 (60.0)	2 (40.0)	
Participants who consider patients with UWS feeling pain as …				
Not possible (0)	4 (44.4)	5 (55.6)	0 (0.0)	15.164[a]
Extremely unlikely (1)	8 (23.5)	22 (64.7)	4 (11.8)	
(2)	9 (16.1)	39 (69.6)	8 (14.3)	
(3)	3 (5.9)	37 (72.5)	11 (21.6)	
(4)	8 (13.3)	43 (71.7)	9 (15.0)	
Extremely likely (5)	9 (21.4)	27 (64.3)	6 (14.3)	
Participants who consider patients with UWS feeling hunger as …				
Not possible (0)	9 (33.3)	16 (59.3)	2 (7.4)	12.835[a]
Extremely unlikely (1)	14 (21.5)	43 (66.2)	8 (12.3)	
(2)	5 (10.0)	43 (71.7)	9 (15.0)	
(3)	4 (12.9)	38 (76.0)	7 (14.0)	
(4)	1 (5.3)	21 (67.7)	6 (19.4)	
Extremely likely (5)	41 (16.3)	13 (68.4)	5 (26.3)	
Participants who consider patients with UWS having emotions as …				
Not possible (0)	11 (27.5)	26 (65.0)	3 (7.5)	4.556[a]
Extremely unlikely (1)	19 (24.7)	46 (59.7)	12 (15.6)	
(2)	5 (9.1)	30 (70.9)	11 (20.0)	
(3)	1 (2.8)	31 (86.1)	4 (11.1)	
(4)	3 (11.5)	19 (73.1)	4 (15.4)	
Extremely likely (5)	2 (12.5)	12 (75.0)	2 (12.5)	
Participants who regard artificial nutrition and hydration as …				
Medical treatment	20 (24.4)	55 (67.1)	7 (8.5)	0.074
Basic nursing care	21 (13.2)	111 (69.8)	27 (17.0)	
Participants currently practicing in countries with a …				
VH-HDI	32 (24.4)	90 (68.7)	9 (6.9)	<0.001
Non-VH-HDI	6 (5.9)	70 (69.3)	25 (24.8)	

The percentages shown are the row percentages. For analysis, the data were dichotomized into the two groups, 'never ethically justifiable' and 'always or under certain circumstances justifiable', and compared using a Pearson's χ^2 test, with a few exceptions as indicated.

Abbreviations: non-VH-HDI, non-very-high Human Development Index; VH-HDI, very high Human Development Index; UWS, unresponsive wakefulness syndrome.

[a] χ^2 test for trend was used and the *p*-value was adjusted for multiple comparisons (17 comparisons), using the *Bonferroni* method.

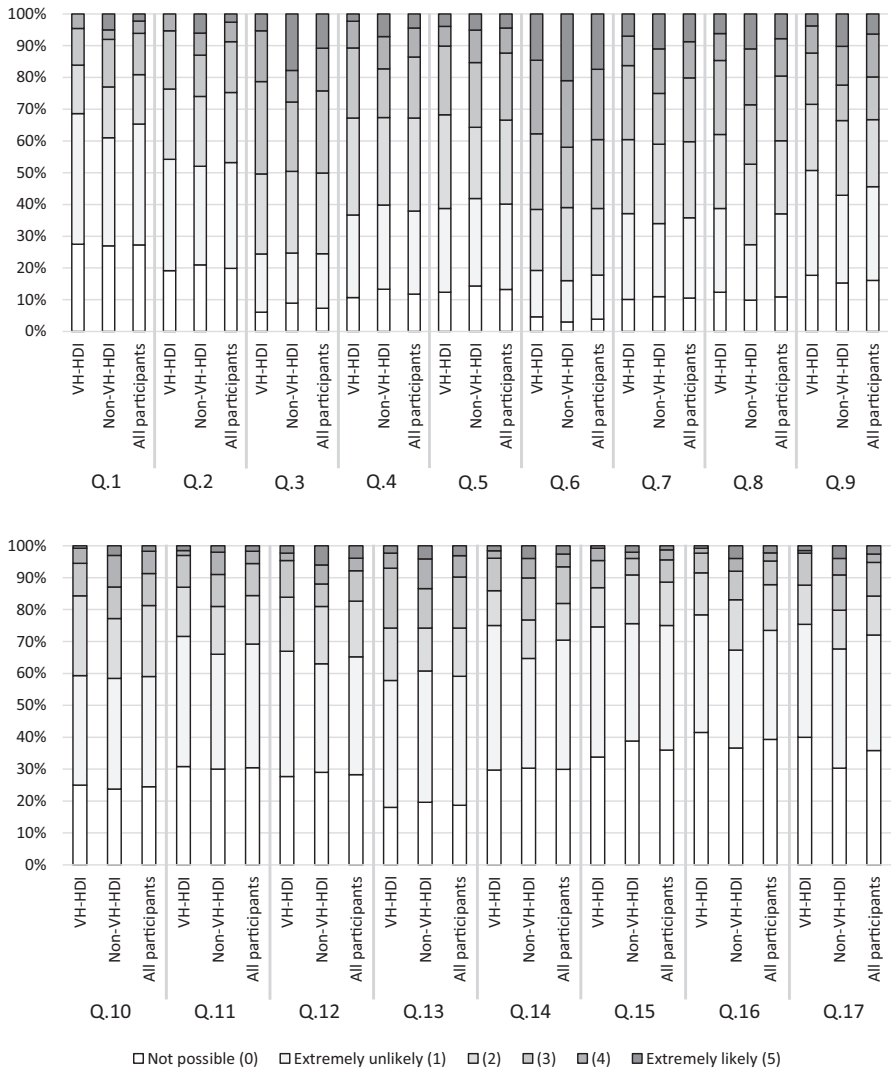

FIGURE 1 Mental processes that, in our participants' opinions, pediatric patients with unresponsive wakefulness syndrome were capable of (as percentage of the participants who responded to both questions). Q.1, Being aware of oneself ($p = 2.567^{a}$). Q.2, Being aware of surroundings ($p = 5.746^{a}$). Q.3, Feeling touch ($p = 7.208^{a}$). Q.4, Smelling ($p = 12.699^{a}$). Q.5, Tasting ($p = 12.886^{a}$). Q.6, Feeling pain ($p = 7.310^{a}$). Q.7, Feeling thirst ($p = 6.630^{a}$). Q.8, Feeling hunger ($p = 2.669^{a}$). Q.9, Having emotions ($p = 1.683^{a}$). Q.10, Recognizing people ($p = 4.369^{a}$). Q.11, Understanding what others say to them ($p = 4.131^{a}$). Q.12, Having thoughts ($p = 5.780^{a}$). Q.13, Experiencing dreams ($p = 14.314^{a}$). Q.14, Remembering past experiences ($p = 1.734^{a}$). Q.15, Storing new information ($p = 9.367^{a}$). Q.16, Expressing their will ($p = 0.595^{a}$). Q.17, Establishing contact with others ($p = 0.612^{a}$). [a]A χ^2 test for trend was used and the *p*-value was adjusted for multiple comparisons (17 comparisons), using the *Bonferroni* method. Abbreviations: non-VH-HDI, non-very-high Human Development Index; VH-HDI, very high Human Development Index.

DISCUSSION

This is the first study, to our knowledge, to give insight into international physicians' perspectives towards pediatric patients with UWS and to examine differences in these attitudes related to the degree of socioeconomic development of their country of practice.

Regional and cultural influences on physicians' attitudes towards LST have been shown with adult patients and have been suggested to play a greater role than other individual factors.[13,16,22] Although countries with a VH-HDI have better funded healthcare systems, including resources for neurorehabilitation and long-term care, physicians working in these countries were significantly more ready to limit LST. We suggest that the decisive factor may be the liberal, highly secular, and more utilitarian Western culture dominating in most VH-HDI countries. This is emphasized by the fact that, in our study, physicians practicing in countries with a VH-HDI showed significantly lower degrees of self-identified religiosity.

Although the role of financial costs in treatment decisions for patients with UWS is controversial, it might be assumed that limiting LST would be more accepted in non-VH-HDI countries owing to the associated financial burden.[23] A study of physicians from intensive care units in Asia showed that those from low- and middle-income countries were more likely to withdraw LST in a case where the family of an adult patient with a reasonable chance of recovery wanted

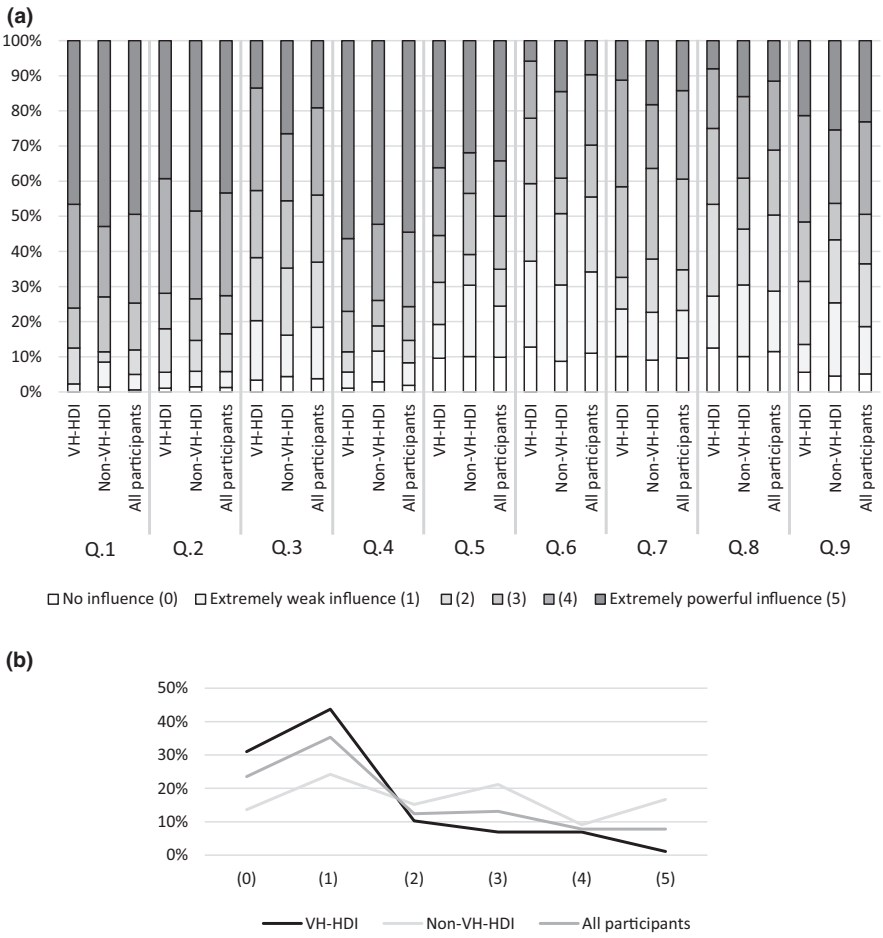

FIGURE 2 Circumstances that influence the participants' justification for limiting life-sustaining treatment for pediatric patients with unresponsive wakefulness syndrome (in percentage of the participants who responded to both questions). (a) Q.1, Severe comorbidities ($p = 8.470^{a}$). Q.2, If consciousness cannot be (re)gained ($p = 5.060^{a}$). Q.3, If (re)gaining the ability to communicate is unrealistic ($p = 3.550^{a}$). Q.4, If the patient obviously suffers intensely ($p = 3.040^{a}$). Q.5, If the patient expresses their will themself ($p = 2.130^{a}$). Q.6, If care cannot be guaranteed ($p = 0.690^{a}$). Q.7, If it is the wish of relatives ($p = 9.470^{a}$). Q.8, In case of extreme burden for relatives ($p = 2.530^{a}$). Q.9, If surrogate decision-makers (e.g. parents) do not consent to treatment ($p = 3.350^{a}$). (b) Q.10, If treatment costs are too high ($p < 0.001^{a}$). [a] A χ^2 test for trend was used and the p-value was adjusted for multiple comparisons (10 comparisons), using the *Bonferroni* method. Abbreviations: non-VH-HDI, non-very-high Human Development Index; VH-HDI, very high Human Development Index.

to avoid financial burden.[24] Although high treatment costs were found to have a significantly greater impact on treatment decisions in countries with a non-VH-HDI than in those with a VH-HDI, in this study physicians from countries with a non-VH-HDI were more likely never to consider limiting LST. A shift of the perceived ratio of suffering with or without limitation of LST could be discussed as one of the underlying reasons. As the pediatric palliative care system was shown to be less developed in low- and middle-income countries, medical staff might not feel well-enough prepared to treat symptoms and thereby prevent potential suffering when limiting LST.[25] Additional factors may be laws and policies that vary drastically between countries.[26] In fact, some of the options we presented in our survey may have been legally impossible in some jurisdictions, such as considering ANH as basic care rather than medical treatment.[27] The same Asian study as mentioned above showed a perceived greater exposure to legal risks when limiting life-support in low- and middle-income countries as a result of fewer written policies and ethics committees.[25] Furthermore, it is known that Asian culture tends to support a family-centered rather than a patient-centered model for decision-making.[28]

Consistent with previous studies, physicians with lower religiosity were more accepting of limiting LST.[16,24] Religions vary in their views on limiting LST, which can affect individual attitudes through affiliation and identification. Yet, national culture also plays a role because opposing trends were shown in groups of the same religion in different countries.[15]

Physicians' perspectives affect treatment decisions. As part of the patient's care team, physicians inform parents about their understanding of the diagnosis, prognosis, and treatment options. In conflicts with patients' parents, some physicians try to persuade family members of their own opinion.[29] Furthermore, physicians determine the indication for medical interventions including ANH, which is influenced by their own individual views and feelings.[12] We suggest that physicians' attitudes are a multivariable construct influenced by religiosity, cultural background, their

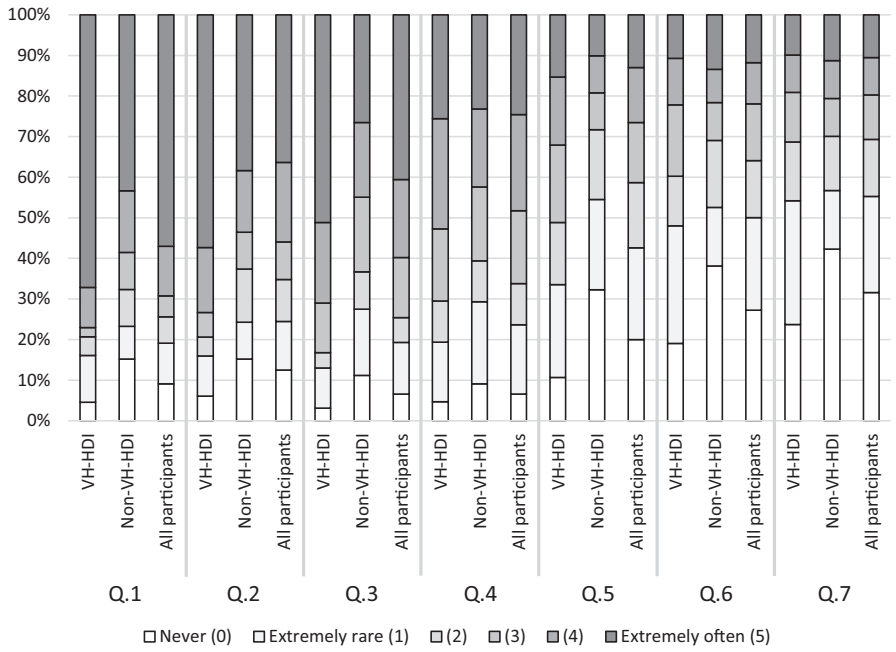

FIGURE 3 Life-sustaining measures the participants could imagine limiting for pediatric patients with unresponsive wakefulness syndrome (in percentage of the participants who responded to both questions). Q.1, Cardiopulmonary resuscitation ($p = 0.021$[a]). Q.2, Intubation/ventilation ($p = 0.014$[a]). Q.3, Hemodialysis/hemofiltration ($p < 0.001$[a]). Q.4, Surgery ($p = 0.609$[a]). Q.5, Antibiotic therapy ($p < 0.001$[a]). Q.6, Artificial nutrition ($p = 1.330$[a]). Q.7, Artificial hydration ($p = 2.723$[a]). [a]A χ^2 test for trend was used and the p-value was adjusted for multiple comparisons (seven comparisons), using the *Bonferroni* method. Abbreviations: non-VH-HDI, non-very-high Human Development Index; VH-HDI, very high Human Development Index.

TABLE 3 Physicians' experience and satisfaction with the decision-making process and results.

Variable	Satisfaction with the treatment decisions made ($p < 0.001$)		Satisfaction with the communication during the decision-making process ($p < 0.001$)		Total, ($n = 267$)
	Dissatisfied (1–2),[a] *n* (%)	Satisfied (3–5),[a] *n* (%)	Dissatisfied (1–2),[a] *n* (%)	Satisfied (3–5),[a] *n* (%)	
Total ($n = 235$)	34 (14.5)	201 (85.5)	32 (13.6)	203 (86.4)	
The attending physician makes the decision alone	3 (20.0)	12 (80.0)	1 (6.7)	14 (93.3)	15 (5.6)
The parents make the decision alone	3 (25.0)	9 (75.0)	4 (33.3)	8 (66.7)	12 (4.5)
The healthcare team and parents make the decision together	24 (11.2)	190 (88.8)	23 (10.7)	191 (89.3)	219 (82.0)
The nurses are involved in the decision-making process	4 (3.9)	99 (96.1)	4 (3.9)	98 (96.1)	104 (39.0)
The physical therapists/occupational therapists/speech therapists are involved in the decision-making process	8 (10.4)	69 (89.6)	3 (3.9)	74 (96.1)	78 (29.2)
A pastor/chaplain is consulted	4 (6.9)	54 (93.1)	4 (6.9)	54 (93.1)	58 (21.7)
An ethics committee or ethics support service is consulted	16 (11.4)	124 (88.6)	14 (10.0)	126 (90.0)	144 (53.9)
A psychological supervision is used	12 (17.4)	57 (82.6)	4 (25.0)	12 (75.0)	70 (26.2)

In the questionnaire, multiple answers were allowed for the question: 'In your experience, how are decisions about limiting life-sustaining treatments made?'. The percentages shown for 'total' are the share of the absolute number of participants choosing the respective response (n) of the overall number of participants who responded to the respective questions. The other percentages shown are the row percentages. A multiple-response χ^2 test was used for the analysis.

[a] Value on a Likert scale with the options very dissatisfied (1), (2), (3), (4), and very satisfied (5).

practicing country's laws, historical experiences, ethics culture, socioeconomical development, and possibly further factors. Physicians, patients, and professional caregivers may not share the same background about religiosity, culture, or nationality. This creates a potential for both interprofessional conflicts and conflicts between professionals and parents.[30]

Over 10% of our participants were dissatisfied with treatment decisions and decision-related communication. Physicians who found limiting LST never ethically justifiable were three times more dissatisfied. In particular, when conflicting views clash, the decision-making about the life of a child can cause significant moral distress leading to sadness, anxiety, and burnout.[29,31] Our data show that the decision-making process needs to be improved and better communication models for medical staff and relatives need to be developed. Regardless of their own opinion, a physician can be part of the team that implements the treatment decision made. Dissatisfaction with the treatment decision might accordingly increase their emotional burden. Further exploration and sensitivity towards different preconditions that influence decision-making is needed in both research and clinical practice to foster understanding and improve communication.

Owing to recruitment difficulties, we used snowball recruitment, which precludes any information about the exact response rate. We did not take specific measures to protect unauthorized access to the survey or multiple participation. Although we contacted many neuropediatric associations and coordinators, we were not able to include physicians from all countries around the world and thereby guarantee a balanced distribution of participants per country. The share of participants from countries with a low HDI (1.3%) is especially low. Furthermore, 71.5% of our participants had only cared for up to 20 patients with UWS. To measure the socioeconomic development of the physicians' countries of practice, we used the HDI, which does not take inequalities within countries and cultural backgrounds into account. We did not obtain data on the religion of our participants, nor did we assess the impact of different countries' laws on the physicians' decision-making; both of these are likely to influence treatment decisions. Our findings about satisfaction with the decision-making process were also limited by our lack of data about the participating physicians' exact involvement in the decision-making and the outcome of respective decisions.

CONCLUSION

We examined attitudes of pediatricians towards UWS for pediatric patients and compared them between very highly socioeconomically developed countries and those with a lower development status. Physicians practicing in countries with very high development were more likely to find limiting LST for pediatric patients with UWS ethically justifiable. Hypothetical explanations for these results include differences in cultural and religious backgrounds, and national laws. Further research is needed to identify such factors and their degree of impact. Physicians who found limiting LST never ethically justifiable were shown to be more dissatisfied with treatment decisions and the communication in the process. Underlying reasons for this dissatisfaction need to be explored.

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CONFLICT OF INTEREST STATEMENT

The authors have stated they had no interests that might be perceived as posing a conflict or bias.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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SUPPORTING INFORMATION

The following additional material may be found online:
Appendix S1: The full original questionnaire.
Appendix S2: Table of countries of practice and medical training of our participants with assigned Human Development Index.

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