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Important differences in management policies for children with end-stage renal disease in the Netherlands and Belgium—report from the RICH-Q study

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Abstract

Background. The low prevalence of childhood end-stage renal disease and the small centre sizes have been a barrier for clinical studies and the development of evidence-based guidelines for chronic renal replacement therapy (cRRT) in children. Few data exist on the quality of care for these patients and the applicability of existing guidelines. The aim of this study is to quantify variation in treatment policies and actually delivered care in nine centres that deliver cRRT for children.

Methods. We surveyed treatment policies in all nine centres in the Netherlands and Belgium and compared them with the actually provided therapies and with recommendations from available guidelines. Data on treatment policies were gathered by questionnaires; actually provided care and outcomes were registered prospectively from 2007 to 2010.

Results. Data on policies and actual patient care were obtained from all nine centres. We found relevant differences between centres in treatment policies on various topics, e.g. estimated glomerular filtration rate threshold as an indication for initiation of cRRT, preferred initial mode of cRRT, peritoneal dialysis catheter care, haemodialysis frequency and vascular access. Discrepancies were seen between stated treatment policies and actual performed therapies. For the majority of policies, no evidence-based guidelines are available.

Conclusions. Health care disparities exist due to large and unwanted variation in treatment policies between hospitals providing cRRT for children. Delivered care does not live up to stated policies, for which clear and internationally accepted guidelines are lacking.

Keywords: children; end-stage renal disease; guidelines; management policies; renal replacement therapy

Introduction

End-stage renal disease (ESRD) in children is a rare but serious disorder [1, 2]. In the Western world, the yearly

incidence rate of ESRD in patients <19 years of age is ~6–8 per million age-related population [3]. On an age-related population of 3.9 million people in the Netherlands [4] and 2.5 million in Belgium [5], this implies that there are ~30 new patients/year in the Netherlands and 20 patients in Belgium. In order to maintain acceptable travel distances to the dialysis centre, patients can choose between several, and consequently all very small, dialysis centres, of which there are four in The Netherlands and five in Belgium. The low prevalence of childhood ESRD and the overall small centre sizes have both been a barrier for large clinical studies and the development of evidence-based guidelines for treatment of children with ESRD worldwide. The RICH-Q study (Renal Insufficiency in Children-Quality assessment and improvement) [6] started in 2007 as a collaborative initiative of all Dutch and Belgian centres for paediatric chronic renal replacement therapy (cRRT). It aims to improve the quality of care for children with ESRD by peer review and plenary discussion of prospectively recorded data on treatment characteristics and physical and psychosocial health outcomes applying the latest scientific evidence and guidelines on cRRT in children.

In this paper, we describe treatment policies for children with ESRD on dialysis in all treatment centres in the Netherlands and Belgium at the onset of RICH-Q and we compare stated treatment policies with currently available guidelines and with the actually performed care between 2007 and 2010.

Materials and methods

In this study, information was obtained from three sources. A survey was conducted on management policies, a literature search was performed to identify guidelines and clinical data were collected prospectively as part of the RICH-Q project. Each of the three methods of data collection are described in detail below.

Survey on treatment policies

At the start of the RICH-Q study in 2007, we asked one paediatric nephrologist per participating centre to complete a questionnaire on treatment policies. The questionnaire was developed with input from all participating paediatric nephrologists, to ensure content validity. The questionnaire included 30 questions on 16 topics (Table 1) divided in to four main sections, i.e. initiation of cRRT and peritoneal dialysis (PD) policies and haemodialysis (HD) policies and paramedical care.

Literature search

Existing guidelines were identified by a comprehensive search in PubMed and websites of organizations known to produce guidelines for patients with ESRD (KDIGO [7], KDOQI [8], CARI [9], UK Renal Association [10], CSN Canada [11], Renal Physicians Association [12], ISPD [13] and EBPG [14]).

Clinical data collection in the RICH-Q project

In the RICH-Q project, anonymous data on treatment characteristics and physical and psychosocial health outcomes are registered prospectively concerning all children with ESRD treated in one of the nine hospitals in the Netherlands and Belgium that provide cRRT for children. In the RICH-Q registry, we included (i) all prevalent Dutch and Belgian patients aged <19 years on chronic dialysis on 1 September 2007 and (ii) all Dutch and Belgian patients aged <19 years who started cRRT or were transplanted from 1 September 2007 to date. We obtained ethical approval from the ethical boards of all participating hospitals and written Informed Consent from all participants or their parents. Online data extraction forms (DEFs) are filled in for each included patient four times a year. An independent research institute (the Hans Mak Institute [15]) checks these data for missing values and irregularities and assures the quality of the data by monitoring 20% of all completed DEFs.

The clinical data from the RICH-Q database that we used in this paper were data concerning initiation of cRRT, PD catheter management and HD frequency. For the initiation of cRRT, the following variables were used: date, age, treatment modality, height and creatinine at initiation of cRRT and reason for initiation of cRRT (indicated by the health care professional). For the calculation of the estimated glomerular filtration rate (eGFR) at initiation of cRRT, we used the original Schwartz equation: GFR (mL/min/1.73m^2) = k (height in cm)/(serum creatinine in mg/dL), with k being an age-dependent variable [16]. For the section on PD catheter management, we used data on type of PD catheter, number of cuffs, exit-site

Table 1. Overview of topics and items of the questionnaire on treatment policies

Topics	Items
Initiation of cRRT	
eGFR at start cRRT	eGFR at which cRRT initiation should be considered, in the absence of signs of uraemia and/or growth failure and/or malnutrition
Reasons to start cRRT	Reasons to start cRRT
Choice of cRRT modality	Preferred type of cRRT to start with Preferred second choice of cRRT if first choice is not available
PD	
PD types	Types of PD used (continuous cyclic PD/continuous ambulatory PD)
Adequacy tests	Calculation of kt/V for PD patients Performance of peritoneum equilibrium-/standard permeability tests Intra-abdominal pressure measurements
Consultation	Frequency of consultation in the outpatient clinic
PD catheter care	Mupirocin prophylaxis yes/no Swimming yes/no Bath or shower
HD	
Home HD	Possibility yes/no Number of children treated with home HD
Overnight HD (in centre)	Possibility yes/no Number of children treated with overnight centre HD
Adequacy measurements	Calculation of kt/V for HD patients
Frequency of HD	Frequency and duration of HD sessions at start cRRT in children <3 years Frequency and duration of HD sessions at start cRRT in children 3–12 years
Policy for preservation of vasculature upper extremity for future vascular access	Policy present or not
AVF	Time between AVF creation and (scheduled) start HD Type of surgeon who creates AVF Minimum age for AVF creation Monitoring of AVF function
Central venous catheters	Type of surgeon who performs surgery Preferred type of catheter Preferred catheter lock solution
Paramedical care	
Medical personnel in the dialysis centre	Paediatric nephrologist or adult nephrologist Type of nurses: specialized (paediatric) dialysis nurses
Composition of paramedical team	Social worker, dietician, psychologist, hospital teachers

direction, use of mupirocin prophylaxis and number of peritonitis. For the section on HD frequency, we used data on HD prescription and number and duration of dialysis sessions per week.

Descriptive statistics are used to report the results.

Results

We received completed questionnaires from all participating centres. In Table A1, all existing guidelines with recommendations on the topics chosen by the paediatric nephrologists on initiation of cRRT are presented [17–20]. Guidelines with recommendations on topics concerning PD [19–21] and concerning HD [22, 23] are presented in Tables A2 and A3, respectively.

Table A4 shows the guidelines with recommendations on topics concerning paramedical care [18, 20, 22, 24]. Between 1 September 2007 and 1 December 2010, 201 children with ESRD were included of whom 59% were boys. The first mode of cRRT at initiation of therapy was HD in 38%, PD in 38% and pre-emptive transplantation (pTx) in 24%. Median (range) age at inclusion of the study was 10 (0–18) years and median (range)] duration of renal replacement therapy (cRRT) 11 (0–209) months; 107 patients (53%) were prevalent patients on dialysis at the start of RICH-Q.

Initiation of cRRT

Both the stated policies of the participating centres and the available guidelines showed variations with respect to the recommended lower limit of the eGFR at which cRRT should be initiated. Table 2 shows the stated policies with respect to the lower limit of eGFR for initiation of cRRT in comparison with the actual median eGFR at onset of cRRT. Centre policies varied between a recommended lower eGFR limit of 15 and 10 mL/min/1.73m^2. In contrast, the median eGFR levels at which patients actually started with cRRT were almost equal for all centres. Both policies and guidelines agreed to start cRRT at an eGFR <15 mL/min/1.73m^2. However, in 22% (37/166) of patients, cRRT was started at an eGFR >15 mL/min/1.73m^2 and in 11% (18/166) of patients, cRRT was started even at an eGFR >20 mL/min/1.73m^2. Pre-emptive transplantations were performed at a median (range) eGFR of 14.0 (0–28.5) mL/min/1.73m^2 compared to a median (range) of 10.6 (0–29.9) mL/min/1.73m^2 for starting dialysis (P = 0.011).

Reasons for initiation of cRRT in these specific cases are presented in Table 3. All centres reported pre-emptive transplantation (pTx) as the preferred mode of cRRT at initiation of cRRT in a child >3 years old, but this could only be realized in 23% (32/138) of the patients. No clear recommendation on this choice was found in the guidelines. If pTx was impossible, stated policies of hospitals varied between PD and HD as a second choice. The actually performed first mode of CRRT, if pTx was impossible, differed from these stated policies in 27% (29/106) of patients (Table 4).

Peritoneal dialysis

All centres preferred continuous cyclic peritoneal dialysis over continuous ambulatory peritoneal dialysis in children. Intra-abdominal pressure measurements were routinely performed in seven of nine centres and adequacy measurement, by calculating *Kt*/*V* in six of nine centres. Topics that did not vary between centres were frequency of consultation (once per month, which is also the recommended frequency in the KDOQI guideline) and performances of peritoneum equilibrium tests or standard permeability analysis tests (performed in all centres, conform to the KDOQI guidelines, once or twice per year). We found differences in treatment policies and actual performed therapies concerning PD catheter care and prevention of peritonitis (Table 5). In summary, mupirocin prophylaxis, applied at the exit site, was included in standard treatment

Table 2. eGFR at start of cRRT

	Reported policy	Registry data	
Centre	eGFR at start cRRT (mL/min/1.73m^2)	eGFR at start cRRT Median (range) (n = 166)[a]	Patients that met reported policy/all patients that started cRRT (%)
1	<10	10.4 (7.2–25.1)	10/25 (40)
2	<10	9.4 (2.6–28.5)	15/27 (56)
3	<10	11.8 (5.16–24.2)	10/31 (32)
4	<10	12.9 (5.1–32.0)	7/16 (44)
5	<15	11.0 (8.5–25.1)	5/6 (83)
6	<15	11.8 (2.8–21.3)	23/28 (82)
7	<15	10.2 (9.1–26.3)	4/6 (67)
8	<15	12.3 (5.7–21.9)	11/15 (73)
9	Never starts solely based on eGFR	11.8 (5.2–23.7)	8/12 (67)

[a]Data to calculate eGFR (age, height and serum creatinine at start cRRT) were available for 166 patients that started cRRT between January 2007 and 1 December 2010.

Table 3. Reasons to start cRRT at eGFR >20 mL/min/1.73m^2, by modality

First cRRT modality	Reasons[a] eGFR (20.3–32.0) mL/min/1.73m^2 (n = 18)
Transplantation (n = 6)	eGFR High potassium High phosphate Poor condition Next year final exam for school Anorexia Increasing inability to focus at school
HD (n = 6)	eGFR High potassium High phosphate Hyponatraemia Poor condition Hypervolaemia with severe arterial hypertension ESRD
PD (n = 6)	eGFR High potassium High phosphate Acidosis HUS Uraemia Non-compliance (medication and diet)

[a]In some children, more than one reason was reported to start cRRT.

in three of nine centres only and double-cuff catheters were used in 69% (66/95) of all PD patients >3 kg. The direction of the exit site of catheters points downwards in 27% (26/95) of all catheters. The peritonitis incidence rate varied from 0 to 2.26 per patient year per centre, but the numbers were too small to detect meaningful differences between centres.

Haemodialysis

HD was offered in all centres in the Netherlands and Belgium; but in two centres, it was only performed if PD was absolutely contraindicated or impossible. Three Dutch centres offered home HD and one Belgian centre overnight centre haemodialysis.

Between 2007 and 2010, 93% of HD patients were treated in the dialysis unit during daytime (66 of 71 HD patients at baseline), 3 patients (4%) were treated overnight in the dialysis unit and 2 patients (3%) were treated with home HD. The policies with respect to recommended frequency of dialysis varied per centre and ranged from 3 to 7 sessions per week. Actually applied frequencies of dialysis varied from two to seven dialysis sessions per week (Table 6). In six of nine centres, there was an explicit policy to preserve the vasculature of the upper extremity for future vascular access. There was variation in the minimum age for arterio-venous fistula (AVF) creation. In six centres, this surgery was performed in children from 6 years on; in three centres, AVF were created at a younger age (from 1 to 2 years). AVF function was monitored by regular physical examination and flow measurements in five centres, by physical examination only in two centres and in two centres regular check-ups were not routinely performed. If central venous catheters were used, all centres stated the right internal jugular vein as preferred site. These catheters were inserted by paediatric surgeons in five centres and by a paediatric nephrologist, an adult nephrologist and a vascular surgeon in one centre each. In one centre, central lines were inserted by a paediatric or adult nephrologist, whereas tunnelled catheters were inserted by a paediatric surgeon. Various types of catheters were used: single-lumen Hickman or Broviac catheters in four centres, double-lumen Hickman or Broviac in three centres and two centres used two single Tesio catheters. Preferences on catheter lock solutions also varied: five centres preferred heparin, three centres preferred citrate and one centres preferred heparin or urokinase. *Kt/V* calculation as an indicator of dialysis adequacy was routinely performed in six of nine centres.

According to the RICH-Q data, 35 of 73 HD patients who started HD between 2007 and 2010 had AVF; 38 patients had central lines. Of these 38 patients, 26 patients were placed in the right jugular vein, 4 patients in the left jugular vein, 5 patients in the right subclavian vein, 2 patients in the left subclavian vein and 1 patients in the left femoral vein. Of the 38 patients who received HD through a central line, heparin was used as catheter lock solution in 23 patients, urokinase in 6 patients, citrate in 5 patients, danaparoid

Table 4. First mode of RRT (cRRT) in children of ≥3 years that started cRRT between January 2007 and 1 December 2010

	Reported policy		Patient registry ($n = 138$)				
			First mode of cRRT			Adherence to own policy (%)	
Centre	Mode of first choice	If Tx is not possible	Tx[a]	HD	PD	First mode	If Tx is not possible
1	Tx	PD	7	5	12	7/24 (29)	12/17 (71)
2	Tx	HD	4	4	11	4/19 (21)	4/15 (27)
3	Tx	HD	7	13	6	7/26 (27)	13/19 (68)
4	Tx	HD	2	10	2	2/14 (14)	10/12 (83)
5	Tx	PD	1	1	3	1/5 (20)	3/4 (75)
6	Tx	PD/HD	6	10	8	6/24 (25)	18/18 (100)
7	Tx	PD	0	2	2	0/4 (0)	2/4 (50)
8	Tx	HD	2	8	2	2/12 (17)	8/10 (80)
9	Tx	PD	3	0	7	3/10 (30)	7/7 (100)
Total			32	53	53	32/138 (23)	77/106 (73)

[a]Only transplanted patients that are included in the RICH-Q study are reported. Transplanted patients were included in the study only when they were transplanted after September 2007. Tx, transplantation.

Table 5. PD policies and policy-related patient information ($n = 95$)

Source	Policy			Patient data	Patient data	Policy	Patient data	Patient data
	Lifestyle guidelines			Double-cuff catheters in patients >3 kg/all PD catheters (%)	Exit site pointing downwards/all exit sites (%)	Mupirocin prophylaxis		Peritonitis incidence rate (95% CI) (per patient year on PD)
Topic Centre	Shower	Bath	Swimming			Stated policy	Adherence to own policy (%)	
1	Yes	Yes	Yes	13/17 (76)	1/17 (6)	No	12/17 (71)	0.87 (0.46–1.48)
2	Yes	No	Yes (with stoma bag)	4/14 (29)	5/14 (36)	Yes	13/14 (93)	0.63 (0.20–1.46)
3	Yes	Yes	Yes (with stoma bag)	3/14 (21)	0/14 (0)	Yes	11/14 (79)	0.36 (0.10–0.93)
4	Yes	No	Yes (in private swimming pool)	6/6 (100)	6/6 (100)	No	3/6 (50)	0 (0–0.82)
5	Yes	No	Yes (with special 'swimming belt')	5/5 (100)	4/5 (80)	No	5/5 (100)	1.35 (0.58–2.66)
6	Yes	Yes	Yes	15/17 (88)	1/17 (6)	Yes	15/17 (88)	0.46 (0.17–1.01)
7	Yes	No	No	2/3 (67)	2/3 (67)	No	3/3 (100)	2.26 (0.47–6.59)
8	Yes	No	Yes (in private swimming pool)	5/6 (83)	4/6 (67)	No	6/6 (100)	0 (0–1.14)
9	Yes	No	No	13/13 (100)	3/13 (23)	No	13/13 (100)	0.76 (0.33–1.49)

Table 6. Policies and policy-related patient information on frequency and duration of dialysis sessions for patients on HD treatment ($n = 73$)

	Children <3 years ($n = 7$)			Children 3–18 years ($n = 66$)		
	Policy	Registry		Policy	Registry	
Centre	Sessions/week	Sessions/week (*n*)	Hours/week	Frequency	Sessions/week	Hours/week
1	4	3 (2)	9[a]	3	3 (1) 2 (1)	12 6[a]
2	4	0	0	3	6 (1) 4 (1) 3 (12)	18 16[a] 12[b]
3	4	6 (1)	18[a]	3–4	3–4 (14) 2 (2)	9[c], 12[d], 14, 15[a] 6[a]
4	4	4 (1)	12	3–4	3–4 (6) 2 (1)	12[d] 6[a]
5	HD <3 years not provided	0	0	4	3 (2)	12
6	5–7	7 (1)	14	5–7	5–7 (4) 4 (6) 3 (2) 2 (1)	12[a], 14, 15 8[a], 11, 12[e] 9[a] 6[a]
7	3	0	0	3	3 (3) 4 (1)	24[f] 20
8	4	4 (2)	16	4	3 (6) 2 (1)	12[d] 6[a]
9	4	0	0	3	0	0

[a]Patient(s) had residual renal function.
[b]Nine of the patients had residual renal function.
[c]Two of the patients had residual renal function.
[d]Three of the patients had residual renal function.
[e]One of the patients had residual renal function.
[f]Nocturnal dialysis.

sodium in 2 patients, Actilyse® and Taurolock® in one patient each.

Paramedical care

In-line with the guidelines, all children on dialysis in all treatment centres were not only treated by paediatric nephrologists but also surrounded by a team of paramedical experts. The composition of this team varied between the different centres: in seven of nine centres, a social worker was included in standard care for the patient, in eight of nine centres a dietician, in six of nine centres a psychologist and in six of nine centres hospital teachers were present on the dialysis ward.

Discussion

In this paper, we demonstrate important differences in treatment policies across the nine hospitals providing cRRT for children in the Netherlands and Belgium. We also found that the physicians often do not follow their own reported policies for the management of children with ESRD. Here, we will discuss some of the most important policy variations.

Indication of initiation of cRRT

Stated policies on initiation of cRRT varied from a threshold eGFR of 10–15 mL/min/1.73m^2 at which cRRT initiation should be considered, in the absence of signs of uraemia and/or growth failure and/or malnutrition.

A considerable proportion of patients (22%), however, started cRRT at an eGFR >15 mL/min. This is not in accordance with any stated policies or international recommendations. pTxs are performed at a significantly higher eGFR than onset of dialysis. The wish to avoid dialysis for patients that are candidate for pTx and planning logistics may motivate physicians to choose for a 'safe' eGFR level at the time of transplantation. Clinical factors are presumably considered at least as important as eGFR level in the decision to start renal replacement therapy (RRT). One additional reason to start RRT even at a relatively high eGFR level may be the lack of the patient's compliance to diet and therapy prescription.

Part of the discrepancy between eGFR recommendations, policies and actually applied therapy could be explained by the use of different formulas to calculate the eGFR, e.g. the updated or not-updated Schwartz formula [16, 25] or the Counahan formula [26]. In this analysis, eGFR calculation by original Schwartz formula was used, in concordance with all local policies. Recently, an updated version of this formula was published [27]. However, we used the original formula in this analysis since decisions to start dialysis in this population were made in the past and therefore based on the previous formula. Yet, the use of different formulas cannot explain discrepancies of >5 mL/min/1.73m^2. The findings of the present study are in-line with data from the European registry for paediatric nephrology (ESPN), concerning 938 patients

from 14 European countries [28]. In that survey, the percentage of children who started cRRT accordingly to the eGFR levels recommended by two sets of guidelines [17, 19] was also low; 22% started cRRT at an eGFR >15.

Pre-emptive transplantation as first cRRT

All centres reported that pre-emptive transplantation was their preferred first mode of cRRT in children of ≥3 years, but this could only be realized in 23% (32/138) of all patients who started cRRT during the study period. An explanation for this could be that some patients only presented shortly before onset or even at the time of ESRD, which made acute dialysis necessary. Also, the waiting list system of Eurotransplant favours dialysis patients to such an extent that pre-emptive post-mortem transplantation in children has been made virtually impossible. Nevertheless, these figures show that pre-emptive living donation is less easily achieved in the Netherlands and Belgium than desirable.

PD policies

Treatment policies for PD patients varied considerably between the nine treatment centres. Unfortunately, the follow-up time of this cohort is yet insufficient to determine associations with clinical outcomes, such as peritonitis incidence. We found considerable variation in lifestyle guidelines. These variations are important because extensive lifestyle-related restrictions result in lower quality of life. As far as we know, there are several studies that address exit-site care, but none of these studies investigated the association between lifestyle guidelines for bathing and swimming and peritonitis frequency [29–31]. Double-cuff catheters are used in 69% of all PD patients >3 kg, which is in-line with two guidelines that clearly recommend the use of double-cuff catheters in these patients. Apparently, due to anatomical or practical reasons (surgical impossibility, availability of double-cuff catheters), in 31% of these patients, PD catheters cannot be inserted according to current recommendations. For exit sites, the need for improvement is even more important because only 27% of all catheters are inserted according to the recommended direction (downwards). Surgical and anatomical reasons combined with practical reasons could be explanations why this guideline cannot always be followed. For example, if a child needs to wear a diaper, the exit-site direction will be upwards, as described previously by Rönnholm *et al.* [32], but this could only explain some of the cases and cannot be responsible for this low guideline adherence. The question is whether it is realistic to strive for more guideline adherence on all topics or whether the recommendations need adjustment because they are not feasible in all cases.

Current guidelines for local mupirocin prophylaxis to prevent exit-site infections and peritonitis in paediatric cRRT are contradictory. Both stated and performed policies in our study varied. Recently, large studies have proven the preventive effect of mupirocin [33–35]. Based on this new evidence, the guidelines need to be updated by recommending the use of mupirocin, which should be implemented in clinical practice.

HD policies

With respect to HD policy, we found remarkable differences between the centres. Some centres only offer a maximum of three sessions per week as standard policy, whereas others adapt to the patients' specific needs and offer up to six to seven sessions per week. Only three centres offer home HD and only one centre has facilities for overnight-HD. In two centres, HD is offered only when PD is not possible. All these differences in policy may have a great impact on the life of the patients and their families. In most centres, for financial and/or practical reasons, HD is only possible on particular and restricted days. Organizational and financial reasons are weighed differently against patient preferences in different centres. High-quality evidence needs to be generated to elicit the association of dialysis frequency and important outcomes, such as quality of life and survival.

The fact that there is only one paediatric guideline on vascular access and that this guideline does not deal with all topics requested by the paediatric nephrologists, may explain differences in vascular access policies. Also, vascular access policies might be influenced mainly by the paediatric or adult surgeons in the centres and to a lesser extent by the paediatric nephrologist. For example, the possibility of creation of an AVF in young children demands surgical expertise, which is not available in all centres. If consultation at the adult vascular access department will not help out, as recommended by the KDOQI guideline [21], collaboration with other paediatric dialysis centres should take place, and harmonization of patient care should make it possible that every small child on HD may obtain a functioning AVF.

Paramedical care

Four guidelines for management of children on dialysis [18, 20, 24, 36] emphasize that a team of paramedical experts is an important requirement for children on cRRT. In general, we found that in most centres, at least six paramedical health professionals are involved in the treatment of the patients with ESRD in the Netherlands and Belgium but also that not all recommended paramedical disciplines are accessible to all patients. This could be due to the small number of patients treated in some of the centres. Again, centralization of care could be helpful to guarantee quality of paramedical care.

Implications for practice

Our observations imply that, given the same clinical condition, management depends on in which centre a child with ESRD is treated, e.g. at what eGFR cRRT is initiated, what cRRT treatment modality is given to the patient and how strict the lifestyle recommendations are. It means that optimal and suboptimal management strategies may be applied in children with otherwise similar conditions and clinical problems. This is remarkable in two highly organized countries with a highly qualified medical care system and may jeopardize health outcomes for these children. If these disparities exist in these two countries, they may

also exist in other European countries and around the world. Suboptimal management strategies may well deteriorate the course of disease as well as the quality of life in these children. Obviously, many of the differences in patient care that we found, such as the significant differences in choice of dialysis modality and lifestyle recommendations, have various different important psychosocial implications for patient and caretakers. To what extent these differences also affect patient outcomes is more difficult to assess as empirical research relating management choices to health outcomes in this field is scarce, demonstrated by our finding that >95% of the existing guidelines for paediatric cRRT are opinion derived and not based on clinical evidence. The lack of a solid scientific ground for the existing guidelines may also be an explanation for the remarkable deviations of the local policies from the recommendations as stated in these guidelines and also for the deviations in daily practice in most units from their own stated treatment policies that we found.

ESRD in children is a rare disease. Its treatment is highly sophisticated, complicated and, unfortunately, as a consequence of its rarity generally offered only by very small treatment units. National and international collaboration of paediatric cRRT units, regular peer reviewing of treatments and outcomes and analyses of data of a comprehensive Good Clinical Practice database on treatment aspects and outcomes may offer a method to generate more evidence for treatment, develop more evidence-based guidelines and harmonize cRRT in children.

Conclusion

In conclusion, health care disparities exist due to large and unwanted variation in treatment policies between all hospitals providing cRRT for children in the Netherlands and Belgium. Delivered care does not live up to stated policies, for which clear and internationally accepted guidelines are lacking. Disparities may deteriorate the course of disease as well as the quality of life in these children.

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Appendix

Table A1. Guidelines about the initiation of RRT (cRRT)[a]

Guideline	eGFR[b] at which cRRT initiation should be considered	Exceptions GFR start	Choice of cRRT modality
NKF KDOQI HD [17]	<15	'. . . GFR >15 if clinical course is complicated by the presence of signs and symptoms listed in table as well as malnutrition or growth failure'	No clear recommendation, no discussion
NKF KDOQI PD [18]	<8 9–14 'consider'	'. . . or start earlier when malnutrition, fluid overload, hypertension, hyperkalaemia, hyperphosphataemia, acidosis, growth failure or neurological consequences of uraemia'	No clear recommendation 'Choice of cRRT depends on variety of factors, e.g. patient/family choice, size, medical co-morbidities, family support'
White *et al.* [19]	<10	'. . . and/or signs of uraemia and growth failure'	No clear recommendation, no discussion
Watson and Gartland [20]	10–15	'Unless the child remains asymptomatic and growth is well maintained'	No clear recommendation 'Patient and family should be involved in choice'

[a]GFR, glomerular filtration rate.
[b]eGFR, eGFR in mL/min/1.73m^2.

Table A2. Guidelines for PD

Guideline	Number of cuffs	Direction of exit site	Mupirocin prophylaxis	PD catheter care
White *et al.* [19]	'Double-cuff catheters can be used in children >3 kg where the external cuff can be placed 2–3 cm from the exit site'	'Downward or laterally'	No clear recommendation, no discussion	No clear recommendation, no discussion
Watson and Gartland [20]	'Double-cuffed curled catheters are preferred in most children (8–10) (paediatric size in patients 3–10 kg of bodyweight and adult catheter in patients >10 kg). A single-cuffed catheter may be needed in infants <3 kg.'	'In all but the smallest infants, the exit site should be downward facing'	'. . . no convincing data to suggest screening children or care givers for *Staphylococcus aureus* nasal carriage or on the use of mupirocin cream around the exit site on a regular basis'	'There is to be no swimming during the initial 6-week period' 'Due to danger of *Pseudomonas* infection, there should be no prolonged immersion of the exit site in the bath but showering before the exit-site change is suggested. Swimming is not encouraged, especially in public pools, lakes, rivers and whirlpools or hot tubs. It can take place with good supervision and with occlusive dressings covering the exit site and catheter after the 6-week healing period. An immediate dressing change should take place after swimming'
Warady *et al.* [21]	No clear recommendation, no discussion	No clear recommendation, no discussion	'Prophylactic antibiotics for *Staphylococcus aureus* nasal carriage is recommended'	No clear recommendation, no discussion

Table A3. Guidelines for HD

Guideline	Frequency and duration of dialysis sessions	Vascular access
Fischbach *et al.* [22]	'Dialysis session, prescription and monitoring: individual prescription is required: babies/infants/children and assessment and adjustment is needed regularly in small/growing children'	No clear recommendation, no discussion
NKF KDOQI Vascular access paediatric patients [23]	No clear recommendation, no discussion	'Permanent access in the form of a fistula or graft is the preferred form of vascular access for most paediatric patients on maintenance HD therapy' 'Circumstances in which a central venous catheter may be acceptable for paediatric long-term access include lack of surgical expertise to place permanent vascular access in small children, patient size too small to support a permanent vascular access, bridging HD for PD training or PD catheter removal for peritonitis and expectation of expeditious kidney transplantation' 'If surgical expertise to place permanent access does not exist in the patient's paediatric setting, efforts should be made to consult vascular access expertise among local adult-oriented surgeons to either supervise or place permanent vascular access in children' 'An AVG stenosis surveillance protocol should be established to detect venous anastomosis stenosis and direct patients for surgical revision or PTA'

Table A4. Guidelines for paramedical care

Guideline	Recommendation
NKF KDOQI PD adequacy 2006 [18]	'. . . all disciplines involved in the care for the paediatric PD patient, including physicians, nurses, social workers, dieticians, play therapists, psychologists and teachers.'
Watson and Gartland [20]	'The multidisciplinary team provides support for the child and family during training and should include a nephrologist, a renal nurse, a renal dietician and a renal social worker. Other staff that may be involved include play staff, school teachers, psychologists/psychiatrists and youth workers.'
Fischbach *et al.* [22]	'HD should be delivered in a "paediatric" dialysis centre with a multidisciplinary support team, which supports individualized and integrated therapy.'
Coleman *et al.* [24]	'As part of the overall nutritional assessment, it is essential for the dietician, as a key member of the multidisciplinary team, to become familiar with each child's psychosocial environment.'