



Opening the Debate on Pediatric Subspecialties and Specialist Centers: Opportunities for Better Care or Risks of Care Fragmentation?

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Expert specialist care is essential for the diagnosis of rare conditions and for children who require complex investigations and highly technical interventions, such as transplantation. This intensive specialist care often requires deep collaboration between a number of specialists to ensure optimal outcomes. Generally, how this specialist care is planned, organized, funded, and assured has not been fully researched, thus, the result is a huge diversity of provision across Europe.

Less well-resourced countries in Eastern Europe face the dilemma of how best to develop specialist care in the future, better resourced countries in Western Europe face the problem of how best to rationalize and co-locate interdependent specialist services to improve outcomes, and small countries must find ways of developing effective cross-border care.

Large centers with multiple specialists often are recommended as the best way forward, but this strategy also risks fragmentation and potentially undermines the competence within local hospitals, as well as being inconvenient for families living far away.

We describe the nature of specialist care, the training of specialists, and the interdependencies between specialist teams and propose networked solutions to overcome some of the concerns, such as the increasing gap between primary and tertiary care.^{1,2}

European Pediatric Subspecialties and Training

A questionnaire regarding the accredited pediatric subspecialties was mailed to all the presidents or leading experts in tertiary child healthcare of the 24 national pediatric societies within the European Union (n = 16) and to European non-European Union-member countries (n = 8). The results were then discussed with 35 presidents of national pediatric societies during a round table symposium of the Europaediatrics Congress 2015 in Florence, Italy. Twenty-four European countries reported a total of 38 different accredited pediatric subspecialties in 2014 (Table I; available at www.jpeds.com) compared with 22 in the US in 2012. The number of accredited pediatric subspecialties per European country ranged from 0-20. Six of 24 countries reported no accreditation of any pediatric subspecialty. The other 18 countries split equally (9 vs 9 countries, respectively) with either 1-7 or 11-20 subspecialties. Eighteen countries reported that

subspecialty training started during the postgraduate pediatric training program irrespective of whether the subspecialty was accredited or not. Six countries offered no subspecialty experience during the 4-5 years of basic pediatric training. More than one-half of the reporting European countries had no accredited subspecialty qualifications.³

It also should be analyzed if the career choices meet the needs of subspecialists,⁴ and if there are appropriate incentives to become a subspecialist. The training of pediatric scientists in basic, translational, clinical, and healthcare research in the centers must follow guidelines according to the recommendations of European pediatric subspecialty societies.⁵ Subspecialty training programs should be vigorously quality assured, and the competence of trainees should be regularly assessed.

More than 30 European pediatric subspecialty societies and associations now exist in Europe (Table II; available at www.jpeds.com). For example, a 1990 survey from the European Society for Paediatric Nephrology revealed in 1990 that there was an unacceptable variation in delivery of pediatric renal care within Europe.¹ This was related to factors such as size of the population, geography, politics, design of health systems, and financing. These inequities still persist, particularly with regard to access of renal replacement therapy for youngest patients.⁶

Highly Specialized Pediatric Centers

The concept of centralizing subspecialty care is based on the assumption that centralization will lead to improved quality of care and reduced costs; however, this hypothesis is as yet unproven for most subspecialties. There is some consensus on what needs to exist within specialist centers including a highly competent multidisciplinary team, co-location of interdependent specialists, high-tech diagnostics and therapeutic interventions, and appropriate

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research facilities. There is, however, a paucity of published data on how different pediatric subspecialties have developed^{3,7} or, indeed, how they work together. This poses a challenge for healthcare planning and policy makers to improve access to high-quality healthcare services across Europe.

A 2-day international seminar on the role of highly specialized pediatric centers was held in Salzburg, Austria, in 2014 to discuss future provision in Austria, Switzerland, The Netherlands, and Germany⁸ with specialist and general pediatricians, public healthcare experts, administrators, politicians, and representatives of a patients' organization for children with rare diseases. The seminar confirmed: (1) the significant differences in highly specialized care across European countries; (2) the absence of consistent definitions of either specialist care or specialist centers; (3) differences in training programs and assessment, both within and between specialists; (4) absent data on the numbers and qualifications of specialists; (5) lack of quality measures relating to competence and service provision; (6) largely no data on numbers in training or future workforce planning; and (7) the difficulties in achieving significant change or reorganization in provision.

The Salzburg seminar focused first on how best to plan an adequate number and the geographical distribution of specialist centers across neighboring regional and national borders,⁹ in order to avoid either underprovision or oversupply between centers. Second, it focused on how to develop a sustainable workforce to meet the medical needs of children. Many different factors must be taken into account in this process including geography, population distribution, transport links, relationships between centers, political appetite for change, and engagement with clinicians to name but a few. Critical to the discussion is the number of children requiring highly specialized interventions to maintain the competence of the specialist team within the center. Most families accept traveling long distances to receive specialist investigations or treatment but not for care that could be provided safely by their local health services.

The ideal system that combines the best of both worlds can be summarized with the words "centralized specialization and decision-making, but decentralized provision of treatment whenever possible." From a patient perspective, all the parts are in place and working well together with specialist advice easily accessible, but delivery is as close to home as is safe and sustainable. In this networked solution, all the teams actively collaborate and constantly strive to improve safety and experienced outcomes. The specialist centers should not be seen as "stand-alone" institutions but part of a well managed clinical network that promptly refers the most appropriate children and simultaneously receives children back into the local system for rehabilitation after specialist care. Clinical leadership for specialist care resides with the center, which organizes shared care with clear clinical care plans, with training and joint clinics for local teams. The local team organizes every day care, habilitation liaison with social care, and

education as appropriate or with good 2-way communication with the center. This has already been achieved in some cancer and neonatal networks.¹⁰

Further research is needed to determine either the optimal size of specialist centers based on the primary outcomes of effectiveness, equity, and efficiency, given different circumstances or the optimal size of population covered by specialist centers. Work has already been undertaken to determine the co-location of pediatric subspecialties (Figure; available at www.jpeds.com).

The consensus of the Salzburg symposium was that the process should be initiated by political representatives that all stakeholders should be involved with finding solutions, the best options being endorsed by policy or legislation and then change being led by senior clinicians.

Highly specialized pediatric subspecialty care may potentially lead to fragmented care if there is no general pediatrician to oversee the integration of care plans from the perspective of the child and family. As stated by Vohra et al¹¹, "pediatric integrative medicine should be the pediatricians' new subspecialty" to bring specialist care together.

Key Messages

1. Specialist care should focus on the diagnosis and treatment of children with rare and severe diseases to ensure that these children receive the right treatment from the right experts, at the right time and in the right place.
2. Highly specialized teams must collaborate closely with the pediatric teams who refer children and those who then rehabilitate children after complex interventions. There must be clarity over which teams provide what to guarantee comprehensive family friendly healthcare including other comorbidities in the child and the consequences for other family members.
3. Integrating specialist centers into the traditional organizational structures of primary, secondary, and tertiary pediatric care is of utmost importance to avoid fragmentation of pediatric care. A successful network would include centralized management and decision-making by specialized teams with decentralized provision of treatment whenever possible.
4. This networked approach requires good clinical leadership and governance, shared values, common protocols, competent clinicians throughout the network, and collaboration rather than competition between centers.
5. Smaller countries should collaborate with foreign centers. Workforce planning on a pan-European basis is a high priority to prevent either overprovision or underprovision of specialists. ■

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Subspecialty	H-O	CARD	NEPH	META	ENDO	HEPA	OTx	CHIR	PICU
Hemato-Oncology (H-O)	Black						Gray	Gray	Gray
Cardiology (CARD)		Black					Gray	Gray	Gray
Nephrology (NEPH)			Black	Gray			Gray	Gray	Gray
Metabolism (META)				Black			Gray		
Endocrinology (ENDO)					Black				
Hepatology (HEPA)						Black	Gray	Gray	Gray
Organ transplantation (OTx)	Gray	Gray	Gray	Gray			Black		Gray
Pediatric surgery (CHIR)						Gray		Black	Gray
Pediatric intensive care unit (PICU)		Gray	Gray					Gray	Black

Figure. Necessary co-location of pediatric subspecialties in centers of competence according to their selected competence (eg, a center for organ transplantation should have the following other subspecialties well developed: H-O, CARD, NEPH, META, CHIR, PICU [gray] whereas other subspecialties like ENDO [white] are not required).

Table I. Thirty-eight different subspecialties in child healthcare, reported as recognized subspecialties in 24 European countries

	Subspecialty	Number of countries
1	<i>Adolescent medicine</i>	1
2	<i>Allergology</i>	8
3	Anesthesiology	2
4	<i>Cardiology</i>	14
5	Community pediatrics	1
6	<i>Dermatology</i>	2
7	<i>Developmental pediatrics</i>	1
8	<i>Emergency pediatrics</i>	5
9	<i>Endocrinology</i>	13
10	<i>Gastroenterology</i>	13
11	<i>Genetics</i>	2
12	Gynecology	2
13	<i>Hematology</i>	8
14	<i>Hepatology</i>	2
15	<i>Immunology</i>	3
16	<i>Infectious diseases</i>	4
17	<i>Intensive care</i>	9
18	Mental health	1
19	Metabolic diseases	5
20	<i>Neonatology</i>	16
21	<i>Nephrology</i>	12
22	<i>Neurology</i>	14
23	Neurodisability	1
24	Neuropsychiatry	5
25	<i>Oncology</i>	12
26	Ophthalmology	3
27	Orthopedics	2
28	Oto-rhino-laryngology	3
29	Pharmacology	1
30	Palliative pediatrics	1
31	<i>Pneumology</i>	12
32	Primary care pediatrics	5
33	Radiology	3
34	Rehabilitation	3
35	<i>Rheumatology</i>	8
36	Stomatology (dentist)	2
37	Surgery	6
38	Urology	5

Not listed: *Child psychiatry and child abuse.*

In Italics: accredited subspecialties by the American Council of Pediatric Subspecialties. Pediatrics Volume 130, Number 2, August 2012.

Table II. Selection of European pediatric subspecialty societies and other pediatric societies that had been active in the last 25 years

1. European Society of Paediatric Infectious Diseases (ESPID)
2. European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN)
3. European Society for Cystic Fibrosis (ESCF)
4. European Paediatric Neurology Society (EPNS)
5. European Society for Paediatric Haematology and Immunology (ESPHI)
6. European Society for Paediatric Endocrinology (ESPE)
7. European Society for Paediatric Nephrology (ESPN)
8. European Society for Immunodeficiencies (ESID)
9. European Society of Paediatric Allergy and Clinical Immunology (ESPAI)
10. European Society of Cardiology
11. International Society of Paediatric Oncology (SIOP) European section
12. European Society for Paediatric Research (ESPR)
13. Society for the Study of Inborn Errors of Metabolism
14. Paediatric Rheumatology European Society (PRES)
15. European Society for Social Paediatrics (ESSOP)
16. Club International de Pédiatrie Sociale (CIPS)
17. European Society of Paediatric Intensive Care (ESPIC)
18. Unité multidisciplinaire de santé des adolescents (UMSA)
19. International Federation of Paediatric and Adolescent Gynaecology (FIGIJ)
20. Société Européenne de Pédiatrie Ambulatoire (SEPA)
21. European Association of Children in Hospital (EACH)
22. Association for European Paediatric Cardiology (AEPIC)
23. Association for Paediatric Education in Europe (APEE)
24. European Association of Paediatric Surgical Association (EUPSA)
25. European Society of Developmental Pharmacology
26. Pediatric section of European Society of Human Genetics
27. European Society for Paediatric Urology
28. Pediatric section of European Public Health Association (EUPHA)
29. European Paediatric Surgeons' Association
30. Society for Pediatric Pathology (SPP)
31. European Network of Paediatric Research at the European Medicines Agency (Enpr-EMA)
32. European Association for Palliative Care (EAPC)
33. European Paediatric Formulation Initiative (EUPFI)
34. Association of Paediatric Emergency Medicine (APEM)
35. European Society for Child and Adolescent Psychiatry (ESCAP)
36. Paediatric Nursing Associations of Europe (PNAE)
37. European Union for school and university health and medicine (EUSUHM)
38. European Union Committee of experts on rare diseases (EUCERD)
39. Hospital Organisation of Pedagogues in Europe (HOPE)