

COMMITTEE REPORT

The future of primary paediatric care in Europe: reflections and Report of the EPA/UNEPSA Committee

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Abstract

Background: Changes in the scope of the field of paediatrics and the variability in primary paediatric care (PPC) and practice throughout Europe motivated the *European Paediatric Association and Union of National European Paediatric Societies and Associations* (EPA/UNEPSA) to establish a working group to discuss definitions of paediatric coverage in terms of age limits, find common denominators in the provision of PPC and examine the challenges and goals of 21st century paediatrics relevant to the continent. These issues were presented at the 2008 Europaediatrics in Istanbul, where a consensus declaration was drawn up and accepted by the EPA/UNEPSA Executive Committee.

Aim: To present an outline of the essential elements of the 2008 EPA/UNEPSA Executive Committee consensus declaration.

Conclusion: The definition of basic characteristics and the establishment of requirements for optimal PPC and practice are important steps in overcoming the differences among European countries and pave the way for an acceptable formulation of standardized high-quality paediatric medical care in Europe.

INTRODUCTION

Europe is undergoing transformations in which traditions, cultures and administrative systems are being forged into common denominators for mutual benefit throughout the continent. One of the issues involved is the organization of the health care systems, and the *European Paediatric Association and Union of National European Paediatric Societies and Associations* (EPA/UNEPSA) have been seeking ways to achieve an optimal standard of paediatric care (PC). To that end, a committee was established in 1997 with the mandate of gathering information on the demography of PC delivery, of training of the physicians responsible for the care of children, and of studying the variations between and within European countries regarding primary paediatric care (PPC) and community paediatrics. Their report (1) identified three types of healthcare delivery systems and two types of physicians practicing in community-based settings.

Formal training for both paediatricians and general practitioners (GPs) varied from established curricula to none at all. Economic and socio-political issues, professional manpower, geographical factors and income per capita emerged as being predictors and indicators of infant mortality and general health status of the paediatric populations.

A second working group, appointed in 2007, was charged with studying the lower and upper age limits of paediatric coverage, a goal similar to that of the AAP Council on Child and Adolescent Health (2,3), and defining the framework, challenges and goals of European paediatrics in the 21st century. The committee's recommendations were presented to the General Assembly of UNEPSA during the 2008 Europaediatrics held in Istanbul, Turkey, and a declaration was drafted and accepted. This study is a summary of the issues and the text of this declaration.

ISSUES TO BE DISCUSSED AND QUESTIONS TO BE ANSWERED

The definition of optimal PPC should take into consideration all relevant variables involved in the system and address the two main points of disagreement, i.e. the identity and training of the primary paediatric caretaker (PPCT) and the age limits of children who should receive PC.

Abbreviations

EPA/UNEPSA, European Paediatric Association and Union of National European Paediatric Societies and Associations; PC, primary care; PPC, paediatric primary care; CP, community paediatrics; PPCT, primary paediatric caretaker.

Identity and training of the PPCT

The uniqueness of the field of paediatrics

Children's diseases are specific and special and have been recognized as such since antiquity (4). The care of children differs in many aspects from that of adults and requires special knowledge, ethics, empathic behaviour and services. The practice of paediatrics involves distinct applications of basic sciences (e.g. anatomy, physiology, pathology, etc.) and is characterized by the relative prominence of topics less relevant to the adult medical practitioner (e.g. genetics, congenital defects, inborn errors of metabolism, inoculations, etc.). The paediatrician needs to be familiar with the wide spectrum of possible variations within the norm as a vast part of his/her practice involves monitoring healthy individuals. In addition, the paediatrician needs to deal with special sensitive legal and ethical considerations and issues of guardianship, privacy, legal responsibility and informed consent, given that most patients are minors. Being the primary and logical source of knowledge and advice for parents and surrogates in matters of physical health, developmental pace, behavioural characteristics, etc., the paediatricians' involvement in the raising of children becomes a kind of partnership. As such, and unlike practitioners of adult medicine, the paediatrician's knowledge and expertise inevitably extends past the fundamental responsibilities of medical diagnosis and treatment of disease to include all the disciplines at work in the world of a growing child, such as human relations, expected behaviour in a given cultural environment, academic progress and others.

The changing face of paediatrics in the 21st century

Nineteenth-century paediatricians could do little to cure their patients, but excelled in the description of clinical symptoms and focused in supportive care of the sick. Our teachers, 20th century paediatricians, profited greatly from the availability of vast information, better understanding of the mechanisms of sickness and health and the discovery of therapeutic panaceas, shifting the focus from 'diagnose and care' to 'find, treat and cure'. Today's paediatrician practices a new medicine, the result of major changes occurring in the spectrum, incidence and relative importance of diseases. The most outstanding among them are:

- A dramatic change in the aetiology of infant and childhood morbidity and mortality, with a decline in disease-related causes and a rise in accident- and violence-related causes.
- A drop in the absolute and relative incidence of certain infectious diseases (the effect of antibiotics and vaccines), with the 'disappearance' of the classic diseases of childhood and the emergence of 'new microbes' (e.g. HIV, MRSA).
- The development of the ability to pinpoint exact diagnoses to patients once assigned to highly generalized groups, such as 'congenital malformations', 'inborn

errors of metabolism', 'mental retardation', 'behavioural problems', etc.

- A dramatic improvement in diagnosing, treating and preventing conditions once considered 'lost battles' (e.g. childhood malignancies, congenital malformations, inborn errors of metabolism, extreme prematurity).
- Changes in the relative incidence of certain diseases that had affected small numbers in the past but have now become a matter of major concern (e.g. allergies and hyper-reactive airways disease) or medical situations that, fulfilling Barker's *thrifty phenotype hypothesis* (5,6), appear nowadays early in life and are precursors of life-shortening (diabetes, hypertension, obesity and ASCVD).
- The appalling explosion of substance addiction and sex-related medical conditions (including HIV and unwanted/teenage pregnancies) is becoming a substantial part of routine medical care of teenagers in developed countries.

All these changes have shifted professional attention from mere treatment of existing conditions to a 'prevent, survey and follow-up' approach. Monitoring of normal growth, development and health is the focus and the emphasis of today's paediatrics for the enhancement of the child's well-being, for the prevention of health hazardous factors and diseases and for laying the foundations of continuous lifetime care. Therefore, paediatricians play a major role in providing the proper framework for *preventive* medicine and healthcare. They do so by tracking deviations from normal patterns of growth and neuropsychological development and by implementing policies on proper nutrition and prevention of obesity. They monitor policies on vaccinations while maintaining healthy environments, minimizing accidents and curtailing substance use and addiction, the propagation of venereal diseases, unwanted adolescent pregnancy and more.

Identifying the PPCT

The vast scope of knowledge and expertise that characterizes modern medicine has inevitably led to specialization and to the establishment of a rather complex triple-level structure of health care: primary (ambulatory), secondary (specialist outpatient clinical- or hospital-centred care) and tertiary (high-level sub-specialty centres). Unlike some other specialties, paediatrics is practiced mostly at the primary care level, probably the only major discipline to do so. Almost all European countries have board-certified paediatricians at their secondary and tertiary levels, but PPC is delivered by either primary paediatricians or GPs. A qualified primary paediatrician has completed a minimal residency programme of 3–5 years. Those holding accreditations in one of the many paediatric sub-specialties have had a total of 6–8 years of training. In contrast, the average GP has undergone paediatric training lasting for as little as

a few months and usually held in a hospital setting in which healthy children or minor ailments were rarely seen (1). This is not likely to prepare GPs for dealing with aspects such as growth, development, mental health, immunizations and preventive measures of childhood diseases and, at best, trains them in the management of acute states. Many countries in which GPs are the principal deliverers of PPC admit as much and would prefer other arrangements, but have neither the funds nor the adequate infrastructures to achieve them. In the UK, for example, in response to a study on infant mortality by the Confidential Enquiry into Maternal and Child Health (CEMACH) (7), the RCPCH responded (8): *'...even though the deaths may not ultimately have been preventable, there is an unacceptable number of avoidable factors involved – and lessons must be learned. One important message is that children must be seen by healthcare personnel who have had the appropriate training to provide proper and timely care, or who will refer to a paediatrician who does have those skills. We do not currently have enough numbers of paediatricians to provide comprehensive safe services for children and the government must recognise that we need to be resourced to do so'*. This issue was discussed extensively in a meeting of the European Forum for Primary Care (EFPC) where Prof. Mykola Aryayev of The Ukraine presented the limited options for a common harmonious future between paediatrics and family medicine (FM) (9): *'Either FM partially or wholly withdraws from the care of children, or they could compete directly with paediatrics for the PPC, or FM and paediatrics could collaborate in providing PPC for all children and their families'*.

Finding a solution acceptable by all European nations is beyond the scope and mandate of this EPA/UNEPSA committee and should be the subject of serious discussions in all European paediatric forums. Our recommendations on the subject are presented below.

Age limits of paediatric coverage and practice

Definitions

Rigid age limits of paediatric practice are almost axiomatic, usually defined as 'birth to 18 years' (10,11), sometimes extending to 24 years of age (12). Exceptions are rare, the best known being the definition in Nelson's Textbook (13), where ages are not mentioned at all and paediatrics is described as *'...concerned with the health of infants, children, and adolescents; their growth and development; and their opportunity to achieve full potential as adults'*.

The 'lower range' of paediatric coverage – is conception too early?

Historically, the responsibility for the baby has passed at birth from the obstetrician to the paediatrician as if it were an Olympic torch. The evolution of fertility medicine and neonatology has caused dramatic changes in the definitions of viability, life and the care of foetuses. Prenatal medicine is still regarded as a branch of obstetrics, but in an era of *in vitro* fertilization, fertility clinics and multi-foetal pregnancies, a multidisciplinary

approach is often desirable and everybody should bear in mind that the foetus is, in principle, an unborn child. Advances in genetics, imaging and minimally invasive therapeutic techniques, as well as a better understanding of the natural history of foetal diseases have revolutionized the management of many conditions diagnosed *in utero* (14). It is the committee's considered opinion that the challenges that should be dealt with by obstetricians should mainly involve the *prevention of prematurity and maternal complications*, but that the *in utero* care of diagnosable and treatable foetal conditions should be the province of paediatric subspecialists (cardiologists, imaging experts, surgeons, etc.). Primary paediatricians should also participate in the management of pregnancies, both normal uneventful and those at risk. Antenatal screening programmes for identifying diseases provide the parents the option to either terminate the pregnancy or knowingly accept the birth of an affected child. The family's attending paediatrician is in the best position to serve as consultant and advisor in this dilemma. Many post-partum difficulties and problems can be prevented with adequate antenatal counselling, especially among primiparas [e.g. early breastfeeding failure (15,16) or post-partum depression (17)].

Extension of the upper age limit of paediatric coverage

The transition of care from paediatrician to 'grownups' physician should be carried out when adulthood is reached. The problem is agreeing on definitions. Everybody accepts that adolescence begins with puberty, but does it end when the individual reaches a specific chronological age (legal adulthood), or when he/she assumes an independent responsible role in society (social adulthood)? Alternatively, is it a gradual and individual process when physical and psychological maturity have been attained, chronological age notwithstanding?

Adolescents are concerned with unprecedented health issues for which they have neither knowledge nor means by which to contend (18). Without overshadowing their personal responsibility, society should offer them services specially geared to meet their needs, including the guidance of knowledgeable adults. This has been traditionally the role of the parent, but in many cases modern parents have lost their place and position as role models, advisors and friends, and so other adults, especially teachers and health providers, should step in and serve both as role models and providers of support.

The scale of the challenges confronting those dealing with 21st century adolescents is huge. For the first time in human history, the present generation of young adults is in danger of a substantial drop in their life expectancy, with the appearance of obesity and life-shortening diseases (e.g. diabetes, ASCVD) among youngsters. The present generation of adolescents represents the widest discrepancy ever between sexual and psychosocial maturity. They are exposed to great risks of contracting serious sexually transmitted diseases and, due to a continued lack of education and limited choices, they have become vulnerable (girls in

particular) by having to deal or live with either the consequences of unwanted pregnancies or face the risk of unsafe abortions, a leading cause of death in young women in developing countries. Drug, tobacco and alcohol misuse are widespread among young people, both in affluent societies and in the slums of developing countries and emerging economies. These trends are a menace to emerging economies and developing countries. Many countries fail to put sufficient emphasis on the special needs of adolescents and either treat them as children or require them to share facilities with older adults, particularly undesirable when it involves adolescent mental health care. The shortcomings of adolescent medicine within the UK health system (19) are echoed across almost all of Europe: inadequate access to primary health care, concerns about confidentiality, consent and privacy, insufficient education of health professionals and the absence of dedicated hospital wards. The task of mending this situation is daunting. Even internists have expressed the need for better training in congenital and childhood-onset conditions, for training more adult subspecialists, and for continued family involvement as well as for identifying concerns about patients' psychosocial issues and maturity and acquiring financial support to care for patients with complex conditions (20). Transition of care should be gradual and performed after compiling a fully updated medical history that includes non-medical issues warranting close follow-up (e.g. parental-sibling relationship, sexual habits, eating patterns, substance use and abuse, etc.).

In an era of global financial crisis, health budgets are particularly sensitive issues. We are all proud of the growing successes in neonatology and the increased rates of premature survival, but this is mainly the result of financial investment. In the USA, premature babies account for only 12% of births but they account for 47% of the costs for all infant hospitalizations and 27% for all paediatric hospital stays (21). Hospital bills may sometimes reach a staggering 1 million dollars per baby (22). In parallel, there is a pressing need to invest in the welfare of endangered teenagers and focus on saving them. Therefore, the committee considers that governments should weigh all the factors when establishing their adolescent healthcare budget. Rather than talking about existing gaps in services that need to be bridged, adolescent healthcare services should be perceived as the most important opportunity for early treatment of newly emerging problems and for the prevention of ill-health by educating the youth about what is meant by a healthy lifestyle and instilling the desirability of leading one. Only then will the full potential of future generations be met.

Transition of care for adults suffering from paediatric conditions

The problem of smooth transition is especially relevant when dealing with adults who suffer from so-called paediatric illnesses or chronic medical conditions requiring special health care. These patients belong to three main groups:

- Patients suffering from 'paediatric medical conditions' once thought to be incompatible with normal adult life (e.g. cystic fibrosis, malignancies, etc.) and for which paediatricians are the traditional sources of expertise.
- 'Mental minors living in adult bodies': patients with cognitive handicaps who, although having reached legal adulthood, are by other measures incapable of self care (mental retardation, autism, etc.), especially those not confined to institutions and who remain in their parental homes.
- Patients with mainly physical handicaps (e.g. cerebral palsy) whose medical problems are better understood and cared for by caretakers with a specific paediatric orientation (paediatric orthopaedics, physical therapists, etc.).

Patients in these categories should have access to uninterrupted, comprehensive and accessible care tailored to their needs. Optimal transfer should guarantee continuity of medical care, provide ongoing good quality of life and assure that they will not suddenly initially appear in the adult system at the time of a medical crisis. The transition should be carried out only after the patient and/or family have given full consent and when the patient's situation is stable. The new healthcare service should be adolescent-friendly and empathetic, attuned to smooth continuity of care, multidisciplinary, developmentally appropriate and have the appropriate technical facilities. Prior to the transition, a multidisciplinary meeting should be held in which the adolescents, their PPCT, the paediatric subspecialists and their parallel adult colleagues should discuss specific, relevant topics and details.

Definitions of the European paediatric framework

European Paediatric Association and Union of National European Pediatric Societies and Associations has the moral, ethical and professional responsibility of promoting and maintaining the health and well being of Europe's future generations, and of promising them the most appropriate care by the best and most highly dedicated professionals. The concept of PC should convey aspiration towards the ideal while allowing the members to implement such lofty ambitions according to the intricate professional systems in their own countries and to the boundaries of the medical care that can realistically be provided, given their human and economical resources. There are a number of main issues that need to be confronted by each country.

Demography

Europe is undergoing dramatic demographic changes, among them a decrease in birth rate, an increase in the number of persons aged 60 years and over, a wave of immigration from underprivileged areas of the world and an unchanged relatively high prematurity rate (23,24).

There has also been a radical change in the pattern of the family unit, with more single-parent families and an increase in mean parental age. In terms of PPC, the most important demographic factor is the ratio of paediatricians to children under the age of 18 years. The Netherlands, the UK and Ireland have insufficient numbers of paediatricians to maintain any reasonable form of PPC. Ireland has 4 million inhabitants of whom 25% of them are children, the highest birth rate in Europe, and only 120 paediatricians, yielding a ratio of one paediatrician for 8333 children (25). By contrast, Slovakia with a similar demography (5 million inhabitants, 20% of them children) but with 2500 paediatricians has a ratio of one paediatrician per 400 patients under the age of 18 years, leading the officials to extend the age limit for paediatric patients to 28 years or up to the end of university studies (data by the Slovakian Association of Primary Care Paediatricians presented in the EAP/EBP annual meeting, Brussels, 2007). Even Western European countries that accept in principle that paediatricians should deliver comprehensive care up to the end of adolescence (e.g. Spain) have, in fact, limited de facto the upper age limit for PC applicability to only 6 or 7 years of age and could not raise the age limit of care without overloading paediatric offices and leading to a lower standard of medical care (26).

Geography

It is impossible to compare the lifestyles of urban and rural communities or the medical services existing within them. Switzerland, for example, has paediatricians as primary caregivers in the concentrated urban setting (approximately 50% of children), while family physicians treat everybody, including young children, in rural areas where the population is dispersed.

Economy and sociology

The 'Value of Life' has two price tags, moral and economic. Morally, every child deserves the best care available but economically the training of a competent paediatric health care provider is expensive and, in an era of economic crisis, not always 'cost beneficial'. Training a paediatrician may not be more expensive than that of a family practitioner, but it is several-fold costlier than that of a GP. Another problem is the yield a country can expect from training a specialist paediatrician. The last decade witnessed an increase in the number of paediatricians working part-time or reduced hours [partly due to the growing number of female paediatricians (27,28)] and those that are not willing to do out-of-hours work or 'on-call duties'.

Political issues

In a near future, the free flow of professionals across their national borders may provide nation-members of the European Union the opportunity to reach an ideal ratio of paediatricians to patients (depending, to a great extent, on the academic and economic incentives and attractiveness for practice).

The EPA/UNEPSA Committee's recommendations

The Committee recommends that individual nation-members implement and address the question of PPC in their independent national programmes according to the following points:

- Ideally, paediatricians should be the deliverers of PPC from birth to late adolescence and play an important role both during pregnancy (including the education of prospective parents and availability if and when problems in the newborn are foreseen and expected) and early adulthood.
- The borders and limitations of PC should be set by the child's physical and developmental stages rather than by his/her chronological age alone.
- In countries in which GPs are responsible for PPC, their curriculum should include an adequate training programme in ambulatory paediatrics. The opportunity to obtain a second opinion should be accessible to the patient within a reasonable period of time.
- A framework of smooth transition of care should be developed for adults suffering from 'paediatric diseases'.
- Paediatricians should play a major role in outlining measures of preventive medicine and healthcare follow-up at the national level and in implementing policies, in particular the war against avoidable causes of morbidity and mortality.

Conclusion: The EPA/UNEPSA declaration

'The health and well-being of future generations in Europe will be achieved by providing proper environment and promising an ideal setup for the physical and psychosocial growth and development of infants, children, adolescents and young adults. This must include assuring continuous, competent and specialized medical surveillance from early in pregnancy to full healthy physical and psychological adulthood. Therefore, the responsibility of paediatrics in providing health care begins with the foetus and continues through young adulthood up to the age when the growth and developmental processes are generally completed. At both frontiers, in prenatal life and during the transition to adulthood, paediatricians should enjoy full co-operation and co-ordination with the relevant specialists (obstetricians, geneticists, adult medicine specialists, etc). In special circumstances (e.g. chronic disease and/or disability), when appropriate and mutually agreeable to the paediatrician, the patient, the patient's family (if applicable) and the legal system in the country of residence, the services of the paediatrician may continue to be the optimal source of medical care beyond the legal age of adulthood and until a smooth transition of the patient, and the patient's problem and needs is made to the hands of an adult professional colleague. The

recommendations in this statement do not indicate an exclusive course of treatment or procedure to be followed. Variations, taking into account the circumstances in the given countries, may be appropriate.'

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TAKE HOME MESSAGE

Optimal primary paediatric care and practice in Europe can and will be achieved by defining and adhering to basic characteristics and requirements of high-quality medical care.

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