The ECPCP Manifesto on Primary Paediatric Care

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Primary Paediatric Care (PPC) is an academic and scientific discipline with a unique and specific spectrum of educational content, research, evidence base and clinical activity combining knowledge and expertise intrinsic to paediatrics with the curriculum, methods and setup of primary care medicine. PPC deals comprehensively with the health and wellbeing of infants, children and adolescents in the context of their family, community and culture, respecting their autonomy and seeing in the child the prime subject of care whose personal wellbeing precedes all other considerations, while at the same time setting the frame for the involvement of parents/guardians/custodians as integral parts of the "unit of care".

The Primary Paediatric Caretaker (PPCT) is a personal paediatrician trained in the principles of this discipline. He is usually the first contact the child has with and within the medical profession and system and becomes the primary responsible for the provision of comprehensive and continuing care from birth and even before that in his capacity of pre-natal counselor and until a smooth transition of care has been established to an adult medical practitioner.
In his management, the PPCT integrates physical, psychological, social, spiritual, cultural and existential factors, utilizing the knowledge and trust engendered by repeated contacts with the patient. PPCT exercises his professional role by promoting health, preventing disease and providing cure, care or palliation, either directly or through the services of others and according to the health needs and resources available within the community they serve.

The PPCT should make efficient use of these resources to ensure his patients get the most appropriate care for their particular problem. This is done through co-ordination with other professionals and the use of high technology services based on secondary care. The PPCT should guide his/her patients through the complexities of the health care system and assist them in accessing these

services where and when necessary while protecting them from unnecessary screening, testing, and treatment.

The PPCT should also take an active role in the educational and social upbringing of the individual by managing the interface with parents, guardians and teachers and taking an advocacy role for the patient when needed. He/she should develop a person-centered approach, orientated to the individual, his/her family, and the community and deal with people and their problems in the context of their life circumstances.

The starting point of the process should be the patient and not an impersonal "pathology" or "case". It is as important to diagnose and deal with the disease itself as it is to understand how the patient and his family cope with and view the illness (their faith, beliefs, fears, expectations and needs).

The presentation of problems, the prevalence and incidence of illnesses and the percentage of serious cases in primary care and ambulatory settings is very different from that in hospital setting. This requires a specific probability based decision-making process which is informed by knowledge of patients and the community. The predictive value, positive or negative of a clinical sign or of a diagnostic test has a different weight in primary care compared to the hospital setting. To manage all these, the PPCT must take responsibility for developing and maintaining his skills, personal balance and values as a basis for effective, safe and cost effective patient care.

<u>The PPCT vs. the non paediatrician primary care physicians</u>

Due to intricate professional, human and economical limitations, many European countries have opted for General Practitioners (GPs) or Family Medical Doctors (FMD) as deliverers of PPC. These professionals have, as a rule, only a short and lacking training in paediatrics, lasting not more than months and held usually in settings in which healthy children or minor ailments are rarely seen, thus not likely to prepare them to deal with many aspects of child care. Even those accredited for General Primary Care and specifically trained for comprehensive

first contact and continuing care of adult persons with undiagnosed sign, symptom, or health concern have had an improper preparation for paediatric patients.

Paediatrics is not "Medicine of the very young or very small" and the care of children requires special knowledge, ethics, empathic behavior and services. Paediatrics involves distinct applications of basic sciences (e.g., anatomy, physiology, pathology, etc.), has a relative prominence of topics irrelevant to the adult medical practitioner (e.g., genetics, congenital defects, inborn errors of metabolism, vaccinations, etc.) and compels the practitioner to be familiar with the wide spectrum of possible variations within the normal since a vast part of his/her practice involves monitoring healthy individuals.

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.

Prof. Aryayev from the Ukraine has summarized the limited options for a common harmonious future between paediatrics and family medicine (FM) as follows: "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".

<u>PPCT as a special branch of the profession (vs. General Paediatricians)</u>

Changes in the scope of Medicine in the last decades have shifted professional attention from treatment of existing conditions to an approach of prevention, survey and follow-up, none more than in paediatrics. Most monitoring of growth, development and health is done in primary care settings and has become the focus and emphasis of today's primary paediatricians. In addition, these professionals are the primary and logical source of knowledge and advice for parents and surrogates in matters of physical health, developmental pace, behavioral characteristics, etc., thus their involvement in the raising of children has become a kind of partnership. Unlike other doctors, the knowledge and expertise required from PPCT extends inevitably beyond the fundamental responsibilities of medical diagnosis and treatment of disease to include all the

disciplines at work in the world of a growing child (e.g., human relations, expected behavior in a given cultural environment, academic progress, etc.).

Age limits of paediatric primary care coverage and practice

PPC is naturally limited by the age limits of the patients in care. Historically, the responsibility starts at birth but in an era of active prenatal medical involvement and taking in consideration that the fetus is, in principle, his unborn patient the PPCT should participate in decisions made during pregnancies relevant to postnatal care, especially when screening identifies diseases that confront the parents with options of either terminate the pregnancy or knowingly accept the birth of an affected child. In addition the PPCT is in the best position to serve as consultant and advisor dealing with preventable post-partum difficulties and problems (e.g., early breastfeeding failure or post-partum depression).

On the other edge, transition of care should be done when adulthood is reached, a cultural-sociological frontier open to debate and discussion among patients, doctors, policy makers, sociologist and legislators. In principle PPC should be available until the patient reaches legal adulthood at a specific chronological age but the line may be moved either way if and when the individual assumes an independent responsible role in society or if and when physical and psychological maturity have been delayed, chronological age notwithstanding.

In the matter of transition of care for adults suffering from paediatric conditions ("paediatric illnesses" like cystic fibrosis, malignancies, etc., cognitive handicaps like mental retardation, autism, etc or physical handicaps like cerebral palsy) patients 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 patients will not appear initially in the adult system abruptly, at the time of a medical crisis. The transition should be done only after the patient and/or family have given full consent and when the patient's situation is stable.

The Primary Paediatric Caretaker Core Competencies

There are six layers of expertise to be mastered by the competent PPCT:

1. Primary Care Management:

The PPCT should have the ability to

- **manage primary contact**
- **deal with unselected problems**
- **cover the full range of health conditions**
- **co-ordinate care with other professionals in primary care and with other specialists**
- **master effective and appropriate care provision and health service utilization**
- **make available to the patient the appropriate services within the health care system**
- **Act as advocate for the patient.**

2. Person-centered Care: The PPCT should have the ability to

- **adopt a person-centered approach in dealing with patients and problems in the context of patient's circumstances**
- **develop and apply the general practice consultation to bring about an effective doctor-patient relationship with respect for the patient's autonomy**
- **communicate**
- **set priorities and act in partnership**
- **provide longitudinal continuity of care as determined by the needs of the patient, referring to continuing and coordinated care management.**

3. Specific Problem Solving Skills: The PPCT should have the ability to

- **Relate specific decision making processes to the prevalence and incidence of illness in the community**

- **gather and interpret selectively information from history-taking, physical examination, and investigations and apply it to an appropriate management plan in collaboration with the patient.**
- **Adopt appropriate working principles (e.g. incremental investigation and the use of time as a tool), tolerate uncertainty, intervene urgently when necessary, manage conditions which may present early and in an undifferentiated way and make effective and efficient use of diagnostic and therapeutic interventions.**

4. Comprehensive Approach: The PPCT should have the ability to

- **manage simultaneously multiple complaints and pathologies in the individual, both acute and chronic**
- **Promote health and well being by applying health promotion and disease prevention strategies appropriately**
- **Manage and co-ordinate health promotion, prevention, cure, care and palliation and rehabilitation.**

5. Community Orientation: The PPCT should have the ability to

- **Reconcile the health needs of individual patients and the health needs of the community in which they live in balance with available resources.**

6. Adoption of the Holistic Approach: The PPCT should use a bio-psycho-social model that takes into account cultural, spiritual and existential dimensions.

Based on the issues above mentioned this is the six point declaration accepted by the founding members of ECPCP as the agreed goals and Credo of ECPCP

1. **CHILDREN'S RIGHT TO HEALTH CARE:**
   - 1.1. **Children have the unquestionable right to good health and wellbeing and to access the highest attainable standards of health care services and facilities.**
   - 1.2. **Any restriction in the deliverance of appropriate care, especially failing to develop a proper primary health care system, contradicts article 24 of the UN Convention on the Rights of the Child.**
   - 1.3. **Governments of Europe should ratify the Chart and ensure optimal paediatric care in the Continent.**
2. **PAEDIATRICIANS ROLE IN PRIMARY CARE**
   - 2.1. **ECPCP advocates the role of paediatricians as deliverers of primary care in the community from pre natal counseling prior to birth to the verge of adulthood in late adolescence, taking into account the patient, his/hers family and their social environment.**
   - 2.2. **Services should be formed according to the patients needs and their physical/developmental stages rather than their chronological age and should include besides medical diagnosis, treatment and cure also promotion of health education, guidance and preventive health measures.**
3. **PPC IN COUNTRIES LACKING PRIMARY PAEDIATRICIANS**
   - 3.1. **Countries having primary care delivered by non paediatricians should at least assure proper training of these caretakers by paediatricians with expertise in PPC and allow patients, when needed, easy access to paediatricians within reasonable time.**
4. **ACADEMIZATION OF PRIMARY PAEDIATRIC CARE**
   - 4.1. **Medical schools in Europe should promote PPC as a teaching topic, establish Academic departments of PPC at all Universities and take active steps towards the continuing development of research in the primary care office setting.**

4.2. The education in PPC should be done at all levels, from medical students to certified physicians, especially in countries in which primary caretakers are not paediatricians, where an adequate curriculum for the General Practitioner should be formulated and implemented by pediatricians with expertise in PPC.

5. CERTIFICATION AND CME OF PRIMARY PAEDIATRIC CARE

5.1. PPC should be delivered with transparent standards of good medical practice applying quality assurance and continuous medical education and possibly leading to certification of the primary paediatrician and his well equipped practice.

5.2. ECPCP will encourage and promote research, teaching, training and the formulation of guidelines for good clinical practice in PPC.

6. PROMOTION OF ECPCP IDEAS AND GOALS

6.1. ECPCP will foment contacts and cooperation among primary paediatricians practicing and teaching in Europe and collaborate with other European and International paediatric associations interested in the promotion of excellence in PPC.