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Highlights of the Meeting of the Psychosocial Working Group of the Association for European Paediatric Cardiology, Vienna, March 4–6, 2004

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On behalf of my colleagues, and all members of our interdisciplinary working group, it is my pleasure to report on the Meeting of the Psychosocial Working Group of the Association for European Paediatric Cardiology held in March 2004, in Vienna, Austria. I extend my apologies to all those colleagues who made interesting and significant contributions which could not be included in this report because of the limited space at our disposal.

The Psychosocial Working Group of the Association for European Paediatric Cardiology was founded by Anna Blanquaert, who realised very early that it was important to consider the psychosocial burdens on families with a child who suffers from congenital cardiac disease. The members of the working group include paediatric cardiologists, psychologists, nurses, social workers, and members of parent self-help groups. The group was also joined recently by members from associations supporting grown-ups with congenital heart disease. Traditionally, the biannual meetings are organized by the chairing paediatric cardiologist. The Vienna meeting was planned by the Division of Paediatric Cardiology from the Medical University of Vienna. We attracted nearly 80 participants from all over Europe, with all the disciplines mentioned above being represented.

Psychology

We started our meeting by discussing psychological topics. We learned from Nicola Doherty, Chris McKusker, Nichola Rooney, and Frank Casey, working at The Royal Belfast Hospital for Sick Children in the United Kingdom, that several factors predict psychological distress for parents of infants with severe congenital cardiac disease. These include parental appreciation of their own skills in coping, their understanding of the diagnosis, and the degree of cohesive family functioning. Furthermore, "sick" behaviour, and the behavioural adjustment of the child, are associated with maternal worry, mental health, and parenting skills. These findings have implications for new psycho-educational programmes for intervention.

Neurodevelopmental outcome, cognitive function

Rachal Van der Rijken, from Nijmegen in the Netherlands, and Ivan Malcic from Zagreb in Croatia, reported that a remarkably large proportion of schoolchildren with congenital cardiac disease experience problems at school after their operation. Hence, further prospective research on cognitive function after cardiopulmonary bypass was strongly recommended.

Cost of psychosocial care, roundtable of self-help groups

Elisabeth Sticker, from Köln, reported that current structures of psychosocial services in in-patient care in Germany do not meet the desired standards. Two-thirds of psychosocial employees are remunerated from mixed financial resources, frequently with the assistance of parents' associations. Comparative data concerning psychosocial care for congenital heart disease in Europe were presented by Benedicte Remmert, also from Köln. This was followed by a roundtable discussion between several parents' self-help groups on the delivery of psychosocial care. The main topics were the inclusion of psychosocial workers on the hospital staff, the funding of such jobs, greater transparency in the quality of service at paediatric cardiac centres for the general public to access, and the need for proper clinical drug studies in paediatric cardiology.

Multidisciplinary approach, prevention

For this session, we had contributions from Mila Markova from Sofia, Bulgaria, and Elisabeth Kober and Karin Hamann, who are based in Vienna, Austria. These presentations focused on the multidisciplinary approach in daily practice, and teamwork, such as the changing role of nursing in paediatric cardiology, and the role of in-hospital teachers and psychologists.

Jacqueline Blyth, from Birmingham Children's Hospital in the United Kingdom, reported on an in-hospital programme aimed at reducing procedural anxiety by the use of age-related techniques, such as distraction for younger children, and guided imagery and relaxation for older ones.

Suzie Hutchinson, from Little Hearts Matter, which is a self-help group based in Birmingham, told us about the "Enable Project", which was established to focus on the needs of children affected with functionally univentricular disorders. A multidisciplinary follow-up programme for children with complex congenital cardiac disease, offering regular and detailed out-patient consultations, was described by Mariette Edling, from Lund in Sweden.

Adolescents and adults with congenital cardiac disease

Tracy Sutherland, from Guy's Hospital in London, United Kingdom, explained that organising a stable transition of patients from a paediatric to an adult cardiology unit is a must for paediatric cardiologists. She and Sophie Zacherl-Wightman, from Vienna emphasised that only sound information and education will enable this population to take greater responsibility for self-care. Doctors must be aware that adolescents lack sufficient understanding of their illness. This may be because medical professionals do not provide enough information. It may also be because a child's comprehension of illness depends very much on his or her parents' knowledge of the disease. Parents, in turn, may lack information themselves, or may not have fully understood the information provided by the doctors. Even well-informed parents may be reluctant to explain fully the nature of the cardiac disease and its consequences for their child. Kristien Van Deyk, from Leuven in Belgium, suggested several topics to be included so as to educate patients as they transfer to adult clinics. These are the name of the disease, the anatomy of the lesion, explanation of surgical procedures, details about medication, past and current options for treatment, description of symptoms that indicate deterioration, the importance of follow-up, awareness of the risk of infective endocarditis, problems relating to sexuality and reproduction, how much their condition limits participation in sports, their employability and insurability, as well as traditional management of cardiovascular risk-factors.

The number of adults with congenital cardiac disease, many of them early survivors of modern paediatric cardiologic management, will have increased by one-quarter in 2010. Their specific medical needs and experiences were excellently portrayed by Ad Van Ruth from the Netherlands, who is personally affected by the problem of growing up with congenital heart disease. Elisabeth Utens, from Rotterdam in the Netherlands, using data from a long follow-up period of 20 to 33 years after surgery, identified a number of factors related to psychopathology. These were subjective restrictions secondary to the scar, low maximal exercise capacity, restrictions imposed by physicians, and the female gender. Helmut Baumgartner, from Vienna in Austria, emphasised that care must be provided by well-trained adult cardiologists, and should be aimed at the establishment of interdisciplinary medical as well as psychosocial networks for this specific population.

Current paediatric cardiology

During preparation of this conference, we agreed that the members of the Working Group should also exchange thoughts on three major phenomenons which have emerged in recent years. The first was the changing relationship between the patient/parent and the doctor, which has become more open, critical, and less hierarchical than it was earlier. The second to discuss was the dynamic information technology of today. Finally, we considered the greater public interest in monitoring of performance and outcome with regard to paediatric cardiological and surgical management for congenital cardiac disease. With these aspects in mind, we invited speakers to talk about the following topics.

Informed consent in adolescents

Marco Nademleinsky, a lawyer, and Renate Fuiko from Vienna, addressed the issues regarding informed consent. Adolescent patients have a right to be involved in the decision-making process for operations or interventions. Legal aspects in several European countries were outlined, as were the common denominators for decision-making on behalf of the child, with due regard to the patient's self-determinism, and the doctor's commitment to maximum professional care. Informed consent was defined as the ability to understand the reasons and purpose of the treatment and to decide accordingly. In order to make medical decisions it is important to know that a child's concept of illness undergoes predictable changes with advancing age, and is primarily determined by cognitive maturation.

Second opinion, role of the internet

Andreas Höher, from Vienna, considered the phenomenon of second opinion in modern medicine. Patients and parents want doctors to treat them as equal partners in a decent and friendly atmosphere. The art of communication is more important today than ever before.

Henri Verhaaren, from Ghent in Belgium, explained that the internet may aid in the counselling process, but it will never be able to replace it. The internet and cybermedicine are powerful tools for public learning and may assist in decision-making. Rather than opposing this trend, we should guide patients and parents through the websites and information systems. Paediatric cardiology is a small specialty, and we can do with every kind of external help.

Human errors

Antonio Corno, from Lausanne in Switzerland, now working in Liverpool, England, elaborated on human errors in medicine, their frequency, the role of organizational systems in causing errors, and the lessons learned from the Bristol affair. He concluded his talk with an urgent request for organized reporting of errors, effective management of issues relating to safety, and, most importantly, communication and teamwork.

Paediatric cardiology of tomorrow

The last part of the conference was devoted to paediatric cardiology for the future. It started with a lecture on scientific research and basic science given by John Hess, from Munich in Germany. The speakers in this session emphasised the need for prospective studies to weigh the risks and benefits of initial management, and draw comparisons with the long-term outcome. Ethical aspects, and the role of parents in the decision-making process, must also be addressed. The role of ethics committees in ensuring the safety of clinical trials in minors was presented by a local representative from Vienna, Christianne Drumyl. The core message was, "Studies in children must be viewed as studies *for* children."

Jacqueline Blyth informed us that the promising new Pediatric Cardiac Quality of Life Inventory, which was developed in the Children's Hospital of Philadelphia, will be converted from American to British English, and tested in three centres in the United Kingdom.

The conference concluded with a talk from Maria Shortis, representing Constructive Dialogue for Clinical Accountability, from the United Kingdom. She discussed the lessons learned from Bristol concerning the nature of communication between parents/patients and clinicians, the journey of the patient through our hospitals, and how to organise services focused on the needs of the patients

On behalf of the organizing team in Vienna, namely, Sophie Zacherl-Wightman, Doris Luckner, Talin Gulesserian, Anna Kieboom, and Monika Jungwirth, I would like to thank all speakers and participants for their input in the discussions. We were particularly honoured by the fact that the Secretary of the Association for European Paediatric Cardiology, Ingrid Oberhänsli participated in the conference.

The next meeting of the working group will take place in Belfast, and will be organized by Frank Casey.