Family Support Groups: An Essential Contribution to Follow-up Care

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Oesophageal atresia (OA) is a rare medical condition and patients with OA must cope with issues that are common with all such conditions including, amongst others, a lack of medical protocols for care and follow-up, limited research, and limited information available both to patients with OA and to medical professionals. To address these issues, the first family support group was established in the United Kingdom (TOFS—Tracheo-Oesophageal Fistula Support) in the 1980s and more have appeared during the past 20 years.

Groups from Australia, Austria, France, Germany, the Netherlands, Switzerland, and the United Kingdom contributed to the presentation at this workshop and there is now an embryonic international association referred to as ''EAT'' (Esophageal Atresia and Tracheo-esophageal Fistula Support Groups).

Although the emphasis in each individual group's activities is slightly different, there is a predominant set of objectives common to all of them. These aims include the following:

1. Provide communications between families affected by tracheo-oesophageal fistula (TOF)/OA
2. Enable sharing experiences and disseminating information
3. Provide help and guidance
4. Raise awareness of the TOF/OA conditions and the support groups themselves
5. Encourage and promote research

Establishing links with the medical profession and appointing medical patrons has been a feature of most support groups from their inception, and much of the information and publication disseminated by the support groups originates from the medical profession. In a number of instances the support groups have specifically commissioned leaflets and articles from their medical patrons.

Family support groups also play a key role by collecting the experiences of patients with OA that give the support groups a unique perspective on OA issues. As an example, TOFS has supported some 2000 families since it was established.

The support groups' Web sites and online forums provide a topical and interactive means of communication, and in addition, each group publishes regular newsletters and/or magazines. Conferences and/or workshops are also organised, but given that these are voluntary charitable organisations, all of these activities are, of course, only possible by meeting the challenge of raising funds from members and through sponsorship.

Their major challenges remain those of developing the awareness of the TOF/OA conditions and of their existence as support groups, lobbying for ongoing research, and improving aftercare.

THE KEKS AFTER-CARE CONCEPT

In Germany only a few hospitals perform OA surgery more than 1 to 3 times per year. Therefore, substantial practical experience cannot easily be gained within each hospital, in particular with regards to the problems that typically arise after the initial surgery.

As in many other medical conditions, the quality of patients' medical care depends on the specific practice of the hospital and paediatrician. The time that is needed to be aware that a complication is occurring and to find the correct diagnosis and treatment depends on experience; if symptoms are misdiagnosed, then there is a high risk of secondary damage.

Studies that consistently observe patients with OA from infancy to adulthood are not yet available. There are no evaluated data about the development of problems in relation to the different available treatments. Defined and approved standards of aftercare are also lacking.

Recent medical articles have recognised the importance of aftercare; however, there is controversy about how often, how long, and to what extent aftercare should be performed.

Kinder und Erwachsene mit kranker Speiseroehre (KEKS) aims to improve and standardise the postsurgical aftercare of OA by means of its aftercare concept (''Nachsorge Konzept''). The key aims of this concept, which has been accepted by many German hospitals and also by the German Association of Paediatric Surgeons, are as follows:

1. To enable the affected children to eat age-appropriate meals (in consistency as well as in a personally and socially acceptable time needed for a meal)
2. To prevent the oesophagus and lungs from being damaged further
3. To provide the best possible development and quality of life for all patients with OA

These aims are supported by 3 key activities:

1. The establishment of consistent and structured aftercare. KEKS and its scientific advisory board have developed a guideline for regular and consistent aftercare. The aftercare folder contains questionnaires covering all possible symptoms, whether they occur earlier or later.
2. Making documentation and communication easier by offering patients and doctors a summary medical record covering the specific medical history relating to a particular malformation

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3. Building a register to record developments after the repair of OA

The frequency of aftercare and of invasive examinations, as defined in our aftercare folder, represents the consensus of members of KEKS and of its scientific advisory board. It aims to support the early detection of complications and minimise patients' inconvenience.

The aim of the register is to observe the development of symptoms and complications and the physical and social development of the patients. This will be correlated to the initial findings and different treatments, and should contribute significantly to the improvement of patient aftercare.

VOKS: PATIENT EMPOWERMENT

In the Netherlands, Vereniging voor Ouderen en Kinderen met een Slokdarmafsluiting (VOKS) discovered, by examining the experiences of parents and young adults, that there was a serious lack of recorded personal health data and information from pregnancy through birth to 18 years of age. When making the step to adult care, serious continuity problems and health care can be compromised because of the lack of exchanging data between different medical professionals and among the medical profession, parents, and young adults.

In 2000, VOKS decided to encourage more active input from patients in their own personal health by building an effective and efficient data management system for self-care and follow-up between them and their TOF/OA care professionals. The VOKS Web site (*www.voks.nl*) contains information about TOF/OA, including guidance on arranging good follow-up care from 0 to 18 years and from 18 years of age onwards. Originally the Web site (Web 1.0) offered limited information to the public; today its Web site (Web 2.0) publishes a range of information on the Internet, whether in the form of text, the spoken word, photographs, or videos. One particular aspect of information provided by VOKS comes from a short film it produced entitled *Empower Your Transition*, which focuses on the transition to adult care. An abridged version is accessible from the VOKS Web site.

The exchange of data and information, cooperation, and community building on the WEB OA Community (*http://voks.hyves.nl/*) enhance the performance of the individual patients, parents, and professionals in the TOF/OA health care system.

These 2 Internet solutions have already proved that the aimed ''J3'' information goals (just in time, just enough, and just for me) narrowed the gap between the professionals and parents of a child/young adult with TOF/OA. The defining characteristic of Health 2.0 is active participation, with direct communication between patients, between professionals, and between patients and professionals.

In 2007, VOKS started writing a handbook entitled *My TOF/OA Self-Management*. The handbook supports the collation of necessary data from pregnancy to 18 years of age on matters ranging from feeding problems, airway and breathing problems, and preventive checks and treatments through to personal development and the social aspects of life as, or with, a patient with TOF/OA.

Since 2008, VOKS has participated in a project with the Dutch Organization of Child Surgeons, Good Care Support and Careweb, which aims to build a TAS3 (*www.tas3.eu*)-compliant patient health record (PHR). Several pilots will be running during 2010 and 2011 in 2 or 3 hospital settings, and it is also hoped to exchange data from the PHR to the electronic medical record (EMD). The outcomes of the pilots are expected at the end of 2011.

SUPPORTING RESEARCH

The Oesophageal Atresia Research Auxiliary (OARA) was formed in 1980 at the Royal Children's Hospital (RCH) in Melbourne, Australia. OARA is a unique support group in that it operates within the scope of the RCH, and therefore has direct links and established relationships with the medical and nursing teams that care for children born with OA and TOF. OARA's primary purposes are to provide parental/family support and to raise money for research into TOF/OA.

The most recent major contributions OARA has made to research have been through its financial assistance in helping set up the Nate Myers Database. There are more than 930 patients entered into the database who were treated for OA/TOF at the RCH, dating back to 1948. Information entered relates to each patient's initial diagnosis, type of repair, subsequent recovery, and further admissions and/or surgeries. The database is continuously updated, and entries of all of the newborns with the condition admitted to the RCH neonatal unit for repair are also entered.

OARA also assisted financially in the establishment of the adult clinic at St Vincent's Hospital Melbourne, Australia, for patients born with TOF/OA. Surgeons from the RCH teamed up with gastroenterologists from St Vincent's Hospital to set up the clinic for patients once they turn 18 years old. This ongoing clinic enables adult patients to have continued management and surveillance of their health into adulthood. As a result of its formation, a paper was jointly produced by the doctors involved in the establishment of the clinic entitled ''Gastro-oesophageal Reflux and Related Pathology in Adults Who Were Born With Esophageal Atresia: A Long-Term Follow-up Study.''

Association Francaise de l'Atresie de l'Oesophage partially funded in 2007 and in 2009 2 research programs on oesophageal tissue engineering. The aims of this research were to create substitutes that restore, maintain, or improve oesophageal function.

Managing long-gap oesophageal atresia remains a challenging problem. Oesophageal reconstruction by interposition or transposition carries high morbidity and mortality rates and—even where successful—often has disappointing functional results. Tissue engineering could eventually prove to be an alternative to more traditional approaches to oesophageal reconstruction.

CONCLUSIONS

Family support groups have their own OA expertise and, jointly with medical and scientific boards, they can contribute to improve follow-up and aftercare. They often play a key role in initiating, promoting, and encouraging new therapeutic strategies and new aftercare management.

Acknowledgments: The support groups express their gratitude to the workshop organisers for providing the opportunity to present their aims and objectives, and to discuss some of the projects being undertaken. It is their wish to emphasise the need—and desire—to work cooperatively (and not competitively) with the medical profession and to share information.

EAT welcomes interest in our international association from other existing support groups and, because EAT's objective is encouraging the establishment of support groups in additional countries, it also welcomes those interested in establishing such groups.