



How to Train Families to Cope with Lifelong Health Problems?

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A significant proportion of children and adolescents in industrialized countries suffer from chronic health problems requiring special care. The diagnosis of a long-term disease brings about a dramatic change in the life of families with increased requirements for disease management. This often leads to more stress, anxiety, and depression, as well as reduced health-related quality of life (hrQoL) and impaired everyday life for the whole family. The quality of medical and psychosocial care after diagnosis is crucial for the future course of disease.

The main challenge of pediatric health education is transforming medical theory into daily practice. Standards of health care after the diagnosis of a long-term disease differs dramatically across Europe. Taking the example of children with type 1 diabetes, the time spent with a diabetes educator after the diagnosis during in-patient care varies widely.¹ After the onset of diabetes, German children and adolescents together with their parents receive 2 weeks of individualized education and psychological treatment from a multidisciplinary diabetes team affiliated with the hospital. In the United Kingdom, families go home after 2 days of in-patient care and education, equipped with a pile of brochures and a telephone number that they can call with diabetes management queries. Testimonials from patients and their parents collected within the European-Certified Diabetes Educator Course project show that parents of children with type 1 diabetes in the United Kingdom gain knowledge mostly from other parents and from online parent forums.¹ Both sources have great value for families. Whereas a multidisciplinary team provides a robust basis for diabetes management, there is no doubt that much can be learned from other parents. Recent comparison studies of national registries have shown clear differences in the quality of diabetes control across countries²; for example, the average hemoglobin A1c value for children and adolescence with type 1 diabetes was 7.9 in Germany, 8.5 in the US, and 9 in the United Kingdom. The prevalence of diabetes ketoacidosis was lowest in the German and Austrian registry. It is known from the Diabetes Control and Complications Trial that a lower hemoglobin A1c value substantially reduces the risk of late complications.³

Standard diabetes care in Germany incorporates ongoing long-term health education. All children and adolescents with

type 1 diabetes, as well as their parents, receive family-oriented education, often delivered in small group sessions, as an integral aspect of long-term care, with the goal of improving their self-management skills in dealing with the disease. Self-management means engaging in health-promoting activities, including medically managing the condition, maintaining and creating meaningful life roles, as well as dealing with the emotions entailed with a chronic condition.⁴

Self-management education guides parents and children in becoming experts in their disease.⁴ It imparts age-appropriate knowledge and skills on how to manage the disease. Furthermore, the family receives psychological support in dealing with stress and sorrows, resulting from living with a chronic condition. The sharing of personal experiences within the group of professionals and patients provides an opportunity to master coping. Such programs lead to better self-management and hrQoL, improve physical health (eg, lung function, hemoglobin A1c value), and reduce school absences and hospital admissions due to acute complications.⁵⁻⁹ Family-oriented patient education programs also improve long-term prognosis and promote age-appropriate psychosocial development in children. Effective health education aims to enable children with a chronic condition to have a lifestyle similar to their peers.

Patient health education is incorporated into the therapeutic guidelines in many countries. For example, the International Society for Pediatric and Adolescent Diabetes guidelines for type 1 diabetes recommend ongoing education as an integral aspect of long-term treatment. Some European countries, including Austria, Slovenia, Germany, and Sweden, have incorporated structured education in their guidelines; however, many other European countries could do more in this respect.¹⁰ Similarly, the Global Initiative for Asthma has published international evidence-based guidelines for asthma treatment. Although detailed instructions and structured procedures for medical care are available for children with more common disorders such as asthma, there is a paucity of resources for less common disorders, such as cystic fibrosis, phenylketonuria, and primary immunodeficiency. Patients

hrQoL	Health-related quality of life
ModuS	Modulares Schulungsprogramm fuer chronisch kranke Kinder und deren Familien

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with rare diseases must be treated by experts who practice far away from their homes. They may have limited contact with other patients, and evidence-based guidelines for treatment may be missing. Much effort has been expended to develop structures and programs for these patients, but in the majority of the rare diseases, they are lacking.

Learning from Others: Development of the ModuS Program

To close the gap between expert knowledge on one side and parents' health beliefs on the other side, multidisciplinary groups—including pediatricians, psychologists, patient trainers, dieticians, and sport therapists active in patient education for more common diseases—joined forces in 2008. To develop the cross-diagnosis education system known as *Modulares Schulungsprogramm fuer chronisch kranke Kinder und deren Familien* (Modular Education Program for Chronically Ill Children and Their Families; ModuS), these groups analyzed the existing training programs for asthma, diabetes, atopic eczema, and obesity to identify common content areas and effective methods.¹¹ Educational modules were developed for 7 topics, including 4 generic topics that can be applied across several diseases and 3 disease-specific topics that depend on specific indications (Table I; available at www.jpeds.com).

Disease-specific modules deliver knowledge and skills relevant to the basic therapy and management of acute complications of the particular disease. Generic modules deal with themes relevant for all group-based education programs (eg, team building, future planning) and for all chronic childhood diseases (eg, coping with anxiety and stress, questions of upbringing, therapy motivation, social integration). These aspects are nearly the same for all families with a chronically ill child regardless of the disease. For each generic module, detailed learning targets and teaching recommendations were formulated.¹¹

The disease-specific modules were designed and combined with the generic modules for 8 diseases (Table II; available at www.jpeds.com). The new programs underwent a quality assurance process, involving evaluation and auditing in different settings across Germany. A total of 1075 family members participated in these programs. The families rated the ModuS program positively, and parents and children demonstrated significant increases in disease-specific knowledge and hrQoL after training.¹²

Boundaries and Limitations of Qualified Patient Health Education

Traditional doctor–patient communication is a crucial barrier to effective health education. Health education supports patient autonomy and responsibility, guiding patients in becoming experts in their own disease; however, it can be successful only when promoted by health care professionals. Another barrier to adequate health competence of families arises from the small number of patients with rare diseases per health center. The majority of health centers do not have

the resources (eg, knowledge, budget) or sufficient numbers of affected patients to provide effective and rare-disease tailored education.

The ModuS Group sought new ways to deal with these challenges. In all centers, local health care professionals were supported by a traveling trainer team consisting of an experienced psychologist and a study nurse. Local centers were responsible for disease-specific modules, and the traveling team was responsible for the generic modules, psychosocial topics, and group dynamics. Due to the lack of sufficient numbers of patients suffering from primary immunodeficiency at single pediatric centers, multiple centers joined forces for a patient education course. In another case, the metabolic care unit for patients with phenylketonuria cooperated with the phenylketonuria patient support group. The patient education course was conducted at the support group's annual meeting.

The greatest obstacle to implementing educational programs into practice is funding. German health insurance reimburses only programs that are structured, quality assured, and evaluated. Therefore, ModuS defines cross-diagnosis quality standards and incorporates a modular trainer education curriculum. The basis for this is the existing standards for more common diseases (eg, diabetes, asthma). At present, health insurance coverage for outpatient education is still provided on a case-by-case basis. In contrast, for asthma and diabetes, funding for education is already in place. The aim of the ModuS group is to include the rare disease educational programs into the established funding structure of the German health system.

Initiating the Debate

Well-structured patient education can be offered for less common and rare diseases as well. It is possible to adapt the modules for respective indications and settings easily. Programs for further indications and cross-diagnosis themes (eg, transition of youth, supporting healthy siblings) are currently under development (Table II). The willingness to learn from others and to act across borders is a prerequisite for the success of these programs.

We are well aware that primary pediatric care has the first priority in countries with limited resources. Nonetheless, we believe that a modular structure for patient and trainer education can be successfully introduced in all countries if the health-care decision makers accept the role of patient-oriented health education. In the long term, effective patient education during childhood will improve the health status of adults and also reduce patient and health care service-driven costs.

Details of the program are available at www.kompetenznetz-patientenschulung.de. ■

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