

## **Cognitive and psychological deficits of children undergoing long-term medical treatment in hospitals**

It is my privilege to introduce the project “Caring school”. It was launched at the beginning of 2014. Its aim is to create a full-fledged school for children who have serious illnesses and who have to stay in hospitals undergoing long-term treatment.

The project is carried out in cooperation with four organizations: The Dmitry Rogachev Federal Research Center of Pediatric Hematology, Oncology and Immunology (Moscow); Russian children`s clinical hospital (Moscow); School 109 (Moscow) and The Moscow Education Ministry. The mission of project is to provide conditions for realization of the constitutionally established right to education of Russian children staying in hospitals for a long period of time by creating an integrated educational environment for children with health problems. This educational environment is created to realize unlimited opportunities of personality and medical-social rehabilitation of children with the illnesses together with their family members. The project involves psychologists and speech therapists to the exclusion of teachers. As a pedagogical psychologist, I represent the psychological group.

Children we work with stay in hospitals due to brain tumors or oncohematological conditions and have a high risk for a wide range of speech problems. caused by the tumor itself and its surgical removal, as well as subsequent treatment including chemotherapy and radiation therapy. Multiple studies have indicated that children with oncological diseases have dyslexia, dysphagia, dysarthria.

Radiation therapy, chemotherapy, and tumor resection are the reason for negative effects on cognitive development. These cognitive deficits are thought to be related to adverse effects on the development of white matter ( Mulhern et al. 2004; Moore 2005; Mabbott et al. 2006).

Children who received a dose of radiation ( low dose is about 25 Gy,

standard dose is 35 Gy) exhibited impairment of verbal and visuospatial intelligence (Grill et al. 1999), verbal fluency and fine motor skills of the dominant hand (Kieffer-Renaux et al. 2000). As the result, these children often have academic failure, and a need for special education services (Mitby et al. 2003). They need coaching with speech therapist and neuropsychologist. They could also demonstrate difficulties in continuing education, and deficits in reading and spelling skills (Mulhern et al. 2005; Reddick et al. 2003), math and exact sciences (Mabbott et al. 2005), foreign languages (Lahteenmaki et al. 2007).

Also they often have wide range of cognitive problems. During the treatment their cognitive conditions characterized by short-term memory, visual memory and working memory deficiency, they also have problems with attention, and information processing speed.

In teaching young long stay inpatients several factors are to be borne in mind. First, their physical condition as a result of receiving the prescribed treatment; second, their emotional state characterized by latent anxiety caused by the disease and treatment and the very fact that they are in a ward for a long time and miss school and are deprived of communication with peers. In short, they are in isolation from everyday life.

These effects determine how they feel and identify themselves, and their academic performance in hospital school. In this report I will explain how these problems are addressed by participants of the project "Caring school".

On arrival at the hospital school, every child undergoes examination by an educational psychologist and a speech therapist. This examination is aimed to ascertain whether a person is in a position to study.

Severe motor or speech impairments as a result of surgery or aggressive treatment can impede a prompt start of schooling and a young patient is given a time during which he/she is attended to by a psychologist and speech therapist only. This period of adaptation is aimed to help an inpatient to overcome difficulties that hamper learning.

During this period special attention is given to basic literacy skills such as

reading, writing, counting. Writing challenges are very often caused by constrained graphomotor skills.

A child's ability to write is quickly restored as a result of methodical and consistent teaching. A speech therapist begins by improving pronunciation and phonemic awareness. The hallmark of our approach is that at this phase a psychologist and speech therapist work jointly on a single pedagogical task, such as to restore a reading ability. Both specialists apply their specific methods and in regularly held debriefings share observations on what has worked and what has not and what the causes of the failure may be. Methods of intervention are individually chosen for every child. As a result of teamwork a skill may return fast.

Psychological intervention is very important throughout treatment. All psychologists obtain a qualification as counsellors and psychotherapists. No matter how a case develops, a child is given psychological support.

We apply what we call "a green-pen method" meaning that only a child's success is taken note of. This method helps a patient to deal with the feeling that he/she is able to do something. In the next step, a psychologist improves goal-oriented behavior of a young person. This is needed to involve a child in learning, to teach him/her to set goals autonomously (such as to improve reading or writing) and to be an active learner.

Focus on the product of activity and its purpose are very important. The purpose of activity is defined in the context of a given learning task. Consider a case when a child does not want to learn reading to read literature or text books (or this is what he says owing to his lack of confidence in his abilities), but this child may set the aim to learn reading to read text messages or browse the Internet. It is this aim that helps a child to become involved in studies.

Psychologists work jointly with disciplinary teachers and respond to their concerns. Cognitive functions of an inpatient may be affected depending on the kind of therapy received at a particular stage of treatment, with certain functions such as speaking impaired or motivation reduced. This is when a psychologist intervenes and the process unravels following the afore-mentioned stages. First, the

condition of a child is examined and his skills are tested.

Then in cooperation with a psychologist an immediate goal is set, a plan is devised and studies begin. A teacher and a psychologist closely interact. The psychologist with the teacher thoroughly analyze the learning material to understand what is accessible to a child and what is not at a given stage. This analysis provides basis for a plan of joint work. A distinctive feature of this approach is its flexibility: as a result of regularly held debriefings between a teacher and a psychologist (sometimes joined by a speech therapist if a speech deficit is observed) set a plan for a week or two. If a condition changes, the plan is updated.

A separate example in its own right is robotics instruction during which a psychologist works jointly with a teacher to help a child develop planning and motion control. A teacher and student both learn to build robots and program them while a psychologist selects a set of applications for a tablet computer that will help a student to improve the planning and memory retention processes.

Motivation is given special importance. We spare no effort to motivate a child. For instance, a psychologist gives classes to improve memory and attention, which are strenuous enough and are perceived by a child as self-sufficient. However, for homework a psychologist may give games to play on a tablet that target specific cognitive functions. The accomplishments are to be recorded (a form is filled). A child does not realize it is a serious home task and does it willingly and with pleasure.

Another important topic to mention is work with school-leavers. It should be noted that students that take exams in hospital form a risk group and are always supported by psychologists. These children can develop anxiety over an upcoming examination. A psychologist provides counselling aimed at giving support to help a student improve confidence, goal-oriented behavior and reduce anxiety.

In particular, this is done by staging a mock examination. Examination materials are brought to a ward, a camera is set and a task is assigned as though at a real examination.

Another theme is work with patients who are about to be dismissed from hospital, convalescents. They are about to return home, to their local school and patients as well as their parents become concerned about how this will happen, whether people will ask questions or worry about the contagiousness of their disease - it is superstitiously believed by some even in our days that cancer is contagious – and why they have to wear a mask. Some children are ashamed of scars and short hair. Therefore, at this stage we aim to re-integrate children in their original educational environment. A psychologist thoroughly discusses with a child their feeling and develops a program of actions that may help so that a return is as smooth as possible.

Another aspect of our work is with parents. During the process of treatment , parents stay at hospital with their children and act as the clients of a hospital school. Moreover, they are worried about their children, the effects of therapy and the quality of life their children will have afterwards. A counsellor provides a consultation or a series of consultations. We watch how parents adapt to the situation. Our main concern here is prevent induced anxiety – parents ’ feeling of worry passed over to a child.

Parents are invited to take part in after-class activities with their children to switch away from their worries and engage in creative activities and thereby to deal with anxiety.

In conclusion, the educational project “Caring school” fosters an educational environment for long-stay inpatients that profoundly integrates counselling, teaching and medical treatment . It is aimed to meet a combination of psychological, physiological and educational needs of children who have serious illnesses, such as oncology and who have to stay in hospital undergoing long-term treatment. During treatment (including chemotherapy, radiation, brain surgery) their cognitive and speech conditions are impaired. The solutions that have been attempted are to find opportunities for cooperative work of psychologists, speech therapists and teachers serving the purpose of development of the executive function (memory, attention) in parallel with speech therapy, to ensure the

psychological adaptation of convalescents and to provide support for school leaving students that prepare to take Russian State Exams. In effecting this a fully individual approach is emphasized with proper attention given to counselling parents of young long-stay inpatients.

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