



PSYCHOSOCIAL

ABSTRACT NO.: P-129

The organization of the social help to the families having a child with an oncological disease at the Medical and Rehabilitation Scientific Center "Russian Field"

M.Ye. Kokoreva, G.Ya. Tseitlin, A.F. Karelin, N.N. Volodin

Medical and Rehabilitation Scientific Centre "Russian Field" of the Federal Research Centre of Pediatric Hematology, Oncology and Immunology named after Dmitry Rogachev, Moscow, Russia

Key words: sibling, disabled child, medico-social work

Introduction. A child's grave disease, long-term treatment, a reluctant isolation, exclusion from the customary way of life, a change in the system of values, the uncertainty of the nearest and the distant future all constitute a severe stress for the whole family with a child suffering from an oncological disease. The life of the majority of such families in modern Russia is characterized by a number of serious social problems. A family finds itself in socio-psychological isolation, having no moral or financial support either from the close circle of friends or from the government. Siblings, i.e. brothers and sisters of an ill child, end up in a difficult situation since all moral and financial resources of a family are as a rule focused on the ill child. Our study showed that 20 % of parents get a divorce after their child goes down with a disease. The financial standing of the majority of such families is poor: 75.5 % spends 50–100 % of their cumulative income on food; 27.8 % cannot purchase durable goods; for 18.7 % of respondents buying clothes presents a financial difficulty; 17.7 % of respondents struggle from paycheck to paycheck. Their home is usually not suited for a disabled child or a family does not have their own accommodation at all. The situation is further aggravated by the complete ignorance of 90 % of parents in legal issues, especially in those concerning various aspects of social protection (privileges, welfare benefits, the registration of a disability status). A family is the main element in the system of a disabled child's socialization, education and professional orientation, which is why providing help to a family is a necessary condition for a disabled child's rehabilitation.

Aim. The aim of the medico-social efforts in Pediatric Oncology is to achieve a maximal standard of health and of a psychosocial adaptation of ill children as well as to provide a complex psycho-pedagogical and socio-legal help to a family.

Materials and methods. In the structure of the Medical and Rehabilitation Scientific Centre «Russian Field» there is a medico-social group organized for a social accompaniment of ill children and their family members. The primary objectives are the following: 1) diagnosing a family's social problems; 2) informing medical officers, psychologists and other members of a multidisciplinary team about a child's problems, the socio-psychological situation in the family etc; 3) taking measures for the social adaptation of a child and his/her family members; 4) providing legal and informational support to children and their family members as well as providing help with the registration of a disability status, the improvement of the living conditions etc; searching for additional financial resources, providing accommodation; 5) cooperating with health, social security, education authorities etc at place of residence in order to provide help to a family after a discharge from hospital.

Results. Thus, medico-social efforts are characterized not only by a rehabilitational but also by a preventive orientation. The leading role in medico-social measures organization is played by social service specialists with sufficient knowledge in such related fields as Social Security, Pedagogics, Psychology and Law. The functions of a social service specialist consist in providing legal, medical, psycho-pedagogical, financial and other help as well as prompting a family to achieve financial independence.

Conclusion. The experience of the Group for medico-social efforts showed its high efficacy in resolving families' social problems as well as in integrating a disabled child into society.

ABSTRACT NO.: OP-154

Testing of cognitive, emotional and behaviour disorders in children with acute lymphoblastic leukaemia

V.N. Kasatkin¹, R.B. Miroshkin¹, A.I. Karachunsky¹, Yu.V. Rummyantseva¹, E.V. Zhukovskaya¹,

S. Malykh², V. Ismatulina², I. Voronin²

¹Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitriy Rogachev, Moscow, Russia;

²Psychological Institute, Russian Academy of Education, Russia

Key words: cognitive functions, emotional and behaviour sphere, acute leukaemia

Introduction. The results of a number of studies suggest the potential negative impact of modern methods of cancer treatment (chemotherapy, radiotherapy) on cognitive functioning of children and adolescents, however, specific results of certain studies are rather contradictory, in particular due to the lack of comparability of the study groups.

Aim. To evaluate the effectiveness of protocol of diagnostics of neuropsychological disorders in patients with acute lymphoblastic leukaemia (ALL) within the randomized pilot study.

Materials and methods. 81 patients from the Rehabilitation Centre "Russian Field" of the FRC PHOI n.a. Dmitry Rogachev with ALL who had finished treatment took part in the pilot study of emotional and behaviour and cognitive functions.

According to the randomization within the protocol ALL-MB-2008 a part of the patients (37 children) received cranial irradiation with the 12 Gy total focal dose, the rest 24 boys and 20 girls received additional intrathecal injections of chemotherapeutic agents (methotrexat, cytosar, prednisolone). A set of neuropsychological tests of the hardware-software complex CANTABclipse (Cambridge Cognition, Great Britain) and a T. Achenbach checklist were used for the cognitive functions assessment. All methods have high retest reliability (from 0.73 to 0.95) (M. Luciana, 2003).

Results. The findings of visual-motor coordination test, understanding of instruction showed disorders in the visual-motor sphere in research subjects.

A spatial memory test suggesting memorization of stimulation pulses in space shows low degree of this function. Pediatric patients who had not received the course of radiotherapy have more efficient working memory abilities compared to the patients who had received irradiation. During investigation of emotional and behaviour sphere according to the results of the Achenbach checklist some problematic issues related to the patients' behaviour and emotional and behaviour sphere can be clearly outlined when compared with the norm. Almost all children show abnormalities concerning all studied behaviour patterns.

Conclusion. Combination of hardware-software complex CANTABclipse (Cambridge Cognition, Great Britain) tests and the T. Achenbach checklist in one protocol ensures effective diagnostics of neurocognitive and emotional and behavioural disorders in the patients who had ended ALL-therapy, helps to define guidelines for the development and implementation in practice of further targeted rehabilitation activities.

ABSTRACT NO.: P-173

Social isolation as a long-term psychological side effect of bone marrow transplantation in children

S. Oleshko, O. Chernenko, O. Ushakova, D. Bakun, Yu. Fedyukova, A. Borovkova,
P. Kozhokar, O. Paina, K. Ekushov, L. Zubarovskaya, B. Afanasyev

Raisa Gorbacheva Memorial Research Institute of Children Oncology,
Hematology and Transplantation, First Pavlov State Medical University of St. Petersburg, Russia

Key words: long-term psychological side effect, social isolation

Introduction. Hematopoietic-stem cell transplantation (HSCT) is one of the most advanced methods of treatment of the patients with blood and genetic disorders. However despite its proven effectiveness for the main condition, allogeneous transplantations have serious complications and side effects, which are accompanied by disturbance of physical, emotional and psychological condition of the patient.

Aim. To study the determinants of psychological adversity in children and adolescents post-HSCT.

To create a list of guidelines which are directly suited to those determinants for a rehabilitation of the patients.

To develop a system of a timely detection of psychological and psycho-social disorders of the patients during the period of post-transplant care.

Materials and methods. The study introduces us to the results of psychological examinations of children and adolescents that have undergone a HSCT ($n = 11$, age 7–13 years old, post-transplant care period 1–5 years) as well as their parents or guardians, that have accompanied them in the process of the treatment.

Different kinds of methods were used, such as, but not limited to:

- Projective "Pip Wilson Test"
- Projective test "Drawing of the Family"
- Projective test "Nonexistent Animal"
- Special questionnaire for parents or guardians, aimed at detecting the sphere of possible psychological disorder of the child or teenager
- Parents' questionnaire for assessing family functioning aimed to diagnose the style of the parenting and its' possible dysfunctions.

Results. All the children that were the subjects of the study were being homeschooled.

64 % of the children did not participate in any after-school activities and also did not interact with their peers.

27 % of the children were spending 4–10 hours on average in front of a television set or a personal computer.

Child loss phobia was diagnosed in only 18 % of the parents. Overprotection signs were more prominent (45 %) which shows that the responsibility for an adolescent's life planning was shifted towards their parents. This leads to the child's isolation, their inability to acquire social experience in any environment other than their parents' home, which, respectively, causes specific personality disorders.



Conclusion. Distinctive aspects of parenting of the children after HSCT often lead to a significant limitation of their social experience and to the specific personality disorders. It is vital to integrate psychological support in form of counseling about the importance of communication and interaction of a child or adolescents with their peers.

In order to form such "School for the Patient" one needs the help of certain specialists, such as

- experienced psychologists, who understand the importance of the issue and consequences of lack of action;
- doctors, who would help to define the amount of social contact for each patient;
- teachers from schools attended by our patients.

In order to inform the teachers of the special needs of post-HSCT children we have written the "Guideline for the Teachers" that informs school personnel about possible psychological and physical risks that need to be taken into account when a post-HSCT pupil is in class.

To sum it up, institution like this would provide a more complete personal, social and emotional development in the post-transplant period which will lead to improvement of the quality of life.

ABSTRACT NO.: OP-177

Clinical psychological rehabilitation program of the Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitry Rogachev for children with oncological diseases

R.B. Miroshkin, E.V. Fisun, V.N. Kasatkin, N.N. Volodin, A.F. Karelin

Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitry Rogachev, Moscow, Russia

Key words: rehabilitation, cognitive functions, clinical psychological diagnosis, neuropsychological correction, oncological disease

Introduction. Lack of proven rehabilitation clinical psychological programs for pediatric cancer survivors. In the process of the development of clinical psychological programs for pediatric cancer survivors, a question of the compatibility of medical measures universality with the specific character of disorders occurred during the course of disease and treatment constantly arises.

Aim. The creation and implementation of clinical psychological rehabilitation program with due regard to diagnostic data and based on neuropsychological correction of disturbed cognitive functions.

Materials and methods. Any corrective measures should be congruent with thorough preliminary diagnosis. Clinical psychological diagnosis performed at the Treatment and Rehabilitation Scientific Centre "Russkoe pole" of FSBI "FRC PHOI n.a. Dmitry Rogachev" of the Ministry of Health of Russia includes.

1. Clinical psychological pathopsychological examination.
2. Clinical psychological neuropsychological examination .
3. A complex of automated clinical psychological diagnostic examinations of cognitive functions.

Correctional clinical psychological programs are designed with due consideration of the obtained data. They present a complex of measures aimed at neuropsychological correction of certain dysfunctions. These include exercises improving interhemispheric connections, cortical and subcortical interactions. The correction is divided into 2 stages.

1. Correction of emotional impairments by the method of biofeedback.
2. Instrumental methods of the correction of cognitive functions. (FitLight, CogniSense, DynaVision).
3. Interactive correction of cognitive functions:
 - a. mechanical (Pertra®)
 - b. computer-based (iPad)
 - c. paper.

Results. The investigations of cognitive impairments in children with neurooncological diseases have revealed that the overall majority of patients (82 %) has the degradation of intelligence, educability and refocusing; 100 % of patients have visual, motor and conceptual difficulties of various degree; 63 % of patients have shown a decrease in visuospatial memory span. In addition, more than 80% of subjects experience various difficulties in the solution of spatial tasks and motor control. Those children who underwent treatment for hematological diseases have motor and visual impairments (60 %) as well as working and spatial memory dysfunctions, deficiencies in planning and control (75 %).

Conclusion. Thus, the combination of comprehensive diagnosis, standardized blocks of correctional exercises and their focused use depending on the nature of dysfunctions provide us with a flexible and effective tool for clinical psychological rehabilitation.

ABSTRACT NO.: P-181

To the justification of the investigational approach to factors of psychological adjustment to hematopoietic stem cell transplantation in pediatric oncology/hematology

A.Ye. Khain

Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitriy Rogachev, Moscow, Russia

Key words: psychological adjustment, coping, distress, resilience, hematopoietic stem cell transplantation, a complex approach

Introduction. The modern organization of therapeutic process in pediatric oncology/hematology enables the participation of specialists from psychosocial services at various stages of treatment. A preliminary psychological preparation as well as support during the treatment are especially needed in case of hematopoietic stem cell transplantation (HSCT) since this type of therapy is unavoidably accompanied by isolation and a large number of requirements and limitations, being one of the most psychologically challenging treatments both for the child and the family (C.M.J. Vrijmoet-Wiersma, 2009; A.F. Patenaude, 1990). However, due to the organizational and methodological issues of the conduct of psychological studies in this field, there is a certain deficiency of evidence-based standards and recommendations for psychological support of the HSCT process in Pediatrics (A.Ye. Khain, 2015).

Aim. The analysis of approaches, limitations and relevant problems in order to further investigations of psychological adjustment to hematopoietic stem cell transplantation factors in pediatric oncology/hematology in Russia.

Materials and methods. Data from publications covering the study of a child's adjustment and coping to stress situations associated with threats to health and wellbeing in pediatric oncology/hematology with the special attention to HSCT.

Results. Studies of the psychological distress of children undergoing treatment of oncological/hematological disease as well as their families have been actively developing in the recent decades. Due to large investigational projects, a great array of data regarding distress levels, quality of life and peculiarities of coping is being accumulated (S.L. Heather Jim, K.L. Syrjala et al., 2012; C.M.J. Vrijmoet-Wiersma, R.M. Egeler et al., 2009). At the same time, a number of authors point out a large amount of contradictions in the obtained data, the lack of a complex approach to the study of the interrelation between various adaptation factors, the necessity of an additional consideration of sociocultural and familial aspects of coping as well as of the perception of a disease and its treatment (S. Phipps, 2004; A.F. Patenaude, M.J. Kupst, 2005). This problem is associated both with the difficulties in controlling a large number of factors, the lack of existing assessment methods and with insufficiently clarified criteria of adaptation success not only in the personal but also in the familial perspective as well as in respect to various kinds and stages of treatment. The Russian medical psychology places great emphasis on the development of a complex approach to the consideration of factors of personal and familial stress adaptation (A.B. Kholmogorova, 2002; N.A. Sirota, 1994; E.V. Kyfytak, 2010). Still, there are relatively few investigations involving children undergoing treatment of oncological/hematological diseases in the Russian medical centers. There are no studies in Russia on peculiarities of psychological adjustment to such a modern and specific treatment as HSCT.

Conclusion. The necessity of the further development and implementation of psychological service standards in Pediatric Hematology/Oncology gives a new perspective on the issue of evidence-based approaches to psychological interventions and support (L. Wiener, A.E. Kazak et al., 2015). Despite the large amount of accumulated data, further efforts are needed in analyzing the interrelation between the factors of personal and familial adjustment to various kinds of treatment. The investigation not only of maladaptation risk factors but also of resilience (S. Phipps), the consideration of systemic factors (the familial system, sociocultural peculiarities of perception) are needed to understand criteria of successful psychological adaptation and to develop psychosocial care programs for children undergoing HSCT and their families.

ABSTRACT NO.: P-187

Needs for provision of information and communication in families with adolescents in pediatric oncohematology

N.S. Nikolskaya, A.Ye. Khain

Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitriy Rogachev, Moscow, Russia

Key words: adolescence, provision of information, information needs, communication style, adaptation

Introduction. A modern comprehensive approach to healthcare delivery implies addressing the issues of psychosocial adaptation of children to the disease and treatment. A child's adequate age-appropriate perceptions of a disease have a protective function toward the risk of distress development and compliance violation during the treatment. The practice of informing patients of the disease and treatment not only in pediatrics has been used rather recently within the traditions of national approach, so it raises an issue of communication styles that would allow to inform children about the features of the disease and therapy. In the Russian Federation adolescents aged 15 and older have a right to give a voluntary, informed consent. In spite of this, health care personnel often face parents' unwillingness and resistance to inform adolescents about specific character of their disease and let them take part in the discussion of the treatment process, its duration and the prospects. Communication approaches to providing information should take into account needs of the adolescents themselves, their individual capacity to integrate the received information. The approaches should also be adjusted to sociocultural aspects and traditions. The study of information needs of all the participants of treatment process appears to be of current interest and enables us to adjust existing foreign communication approaches to informing adolescent patients and their parents better.

Aim. To investigate information needs of parents and adolescent patients in respect of disease and its treatment.

Materials and methods. Questionnaires were designed to identify the desired style of informing, information needs (form, scope, content, sources of information). Versions for adolescents and their parents/legal guardians. Respondents: 1) parents of adolescents ($n = 54$, aged 32–63 years old; $M = 43.7$; $SD = 9.1$; 53 female and 1 – male); 2) adolescent patients ($n = 49$, aged 14–18 years old; $M = 16.4$; $SD = 2$; 23 – female and 26 – male).

Results. The study has demonstrated the need of adolescents in building direct communication with a doctor rather than indirect communication through their parents. Adolescents much prefer receiving information directly from a treating physician ($p \leq 0.05$), and this fact is underestimated by their parents. Readiness of adolescents for getting information about the severity of the disease and treatment is dependent on the quality of communication with a physician, the degree of the achieved trust ($p \leq 0.05$). Vice versa, unwillingness



to get information is significantly related ($p \leq 0.05$) to the main sources of information from Internet or directly from parents. Parents are more willing to let doctors inform adolescents about their diagnosis rather than discuss with them the severity of treatment, prognosis or side effects of therapy ($p \leq 0.05$), 37.5 % of them do not believe it possible at all to inform their children. Adolescents concern themselves about the causes of the disease and the issues of direct participation in the treatment process, e.g. guidelines for hygiene, nutrition, significantly more than parents ($p \leq 0.05$). Parents, however, are primarily concerned about future perspectives, the plan and prognosis of the therapy being administered ($p \leq 0.05$). **Conclusion.** The study demonstrates the importance of direct communication between adolescents and treating physicians while providing information for better adaptation rather than indirect communication through parents. Adolescents declare their readiness to deal with illness and treatment with the help of healthcare personnel and parental backing, whereas more than one third of parents do not consider it possible to inform their children.

ABSTRACT NO.: P-240

Level of psychological trauma in mothers of children with cancer

O. Chernenko, O. Ushakova, S. Oleshko, D. Bakun, Yu. Fedyukova, E. Morozova,
A. Gevorgyan, L. Zubarovskaya, B. Afanasyev

*Raisa Gorbacheva Memorial Research Institute of Children Oncology, Hematology and Transplantation,
First Pavlov State Medical University of St. Petersburg, Russia*

Key words: psychological state of the mother, oncological disease of a children

Introduction. Serious illness of a child is a difficult challenge for parents. Parents who are permanently supporting the child during his treatment at a cancer clinic are faced with strong emotional experiences. These experiences are associated not only with disease but also with the treatment process. Standard chemotherapy protocols are not always possible to achieve stable remission of the disease. Autologous transplantation improves the results of treatment substantially, but high risk of developing life-threatening complications has a negative impact on psycho-emotional state of the parents of the patients.

Aim. The goals of the study are as followed:

- to study of the psychological state of the mother of a seriously ill child;
- to analyse the impact of an oncological disease of a children the psychological state of the mother.

Materials and methods. During the research 32 mothers of children undergoing treatment at Raisa Gorbacheva Memorial Research Institute for Pediatric Oncology, Hematology and Transplantation and at the Cancer Research Institute by N.N. Petrov were studied. Different kinds of methods were used, such as, but not limited to:

- clinical psychological interview, aimed at identifying the characteristics of the personal response of mothers to child's illness;
- experimental psychological method: Impact of Event Scale – Revised (IES-R);
- the test of an assessment of self-actualization (POI);
- questionnaire for diagnostics of the mother's reaction to an illness of the child.

Results. Research of level of traumatic stress (IES-R) allowed to determine three groups of mothers: with low (31.2 %), high (34.4 %) and extremely high (34.4 %) level of a psychological trauma accordingly.

For mothers with extremely high levels of psychological trauma the sick child was significantly more often the only one in the family and was undergoing the relapse treatment. Most of the women in this group weren't residents of Saint Petersburg. Analysis of the results of the assessment of self-actualisation (IES-R) has shown that mothers with high levels of psychical trauma tend to express their feelings spontaneously and directly.

The higher the degree of a traumatic stress, the more expressive is behaviour. This could often be shown not only in interaction with the child or relatives, but also with the other people, first of all, the medical personnel.

The study of the relationship of mother towards the child's illness shows that mothers with high levels of trauma tend to feel powerless and unable to affect illness outcome. These feelings increase proportionally to the duration of the disease, especially in case of a relapse.

Correlation analysis of the results showed that parents' ability to cope with their psychological and emotional state is important for the successful and timely treatment of the child, as in many respects determines the behavior of the sick child, and his relationship to treatment, and to the doctor.

Conclusion. Oncological diseases in children are traumatic experiences for most mothers. The way the traumatic experience is perceived is influenced not only by the mother's personality, but also by external factors, such as the stage of the disease, the act of relocating to a different city with the purpose of getting access to the treatment, as well as the overall spirit of the relationship inside the family. Psychological support has been providing not only patients but also their relatives during the passage of the child's treatment in our clinic.

ABSTRACT NO.: OP-270

Evaluation of burnout syndrome in pediatric hematologists oncologists

T.V. Stepanova¹, G.V. Trubnikova², I.Yu. Balalaeva², N.B. Yudina²

¹Voronezh State Medical University named after N.N. Burdenko, Russia;

²Voronezh Regional Children's Clinical Hospital № 1, Russia

Key words: emotional burnout syndrome, pediatric oncologists, primary care physicians

Introduction. According to the International Classification of Diseases (ICD-X): Burnout is stress associated with difficulty maintaining a normal lifestyle (category Z73). Definitions of burnout syndrome are: Burnout is a prolonged response to chronic emotional and interpersonal stressors on the job, and is defined by the three dimensions of exhaustion, cynicism, and inefficacy (Maslach, 1976). Emotional burnout – is a psychological defense mechanism in the form of full or partial exclusion of emotion in response to the traumatic effects of stressors (Boyko, 1999). Prevalence of burnout among physicians is as follows: 27 % of residents demonstrates signs of burnout; primary care physicians has burnout in 46.3 %. Among cancer clinicians in Switzerland, 33 % expressed signs of emotional exhaustion. In Russia Pediatric Oncologists and Hematologist might be at higher risk of burnout.

Aim. To evaluate the level of burnout in Pediatric Hematologists Oncologists and to compare the level of burnout Pediatric Hematologists Oncologists with that in primary care physicians and Pediatric residents.

Materials and methods. Cross-sectional pilot study was performed in Voronezh N.N. Burdenko University Hospital in January 2010 – January 2013. There were three study groups under investigation: 1. Pediatric Hematologists Oncologists ($n = 13$); 2. Primary Care Pediatricians ($n = 17$); 3. Pediatric Residents ($n = 13$). We use the Questionnaire "Burnout syndrome" V.V. Boyko. The basis of the questionnaire is the assumption that the burnout phase includes the "tension", "resistance" and the "exhaustion". Score interpretation for phases: from 36 points to 60. Each of the phases includes a range of symptoms 1 – tension: Stressful circumstances; Dissatisfaction with oneself; "Drive into the cage"; Anxiety and depression. 2 – Resistance: Inadequate response; Emotional disorientation; Emotional economy; Professional reduction. 3 – Exhaustion: Emotional deficit; Emotional detachment; Personal detachment; Psychosomatic disorders. The severity of each symptom was assessed on a scale 0 to 30 points.

Results. The distribution of the total score in study groups was: in Pediatric Hematologist Oncologists – 143 points; in Primary care Pediatricians – 130; in Pediatric Residents – 83. Tension phase score in study groups was not different. The Resistance phase score was higher in Primary care Pediatricians. According to phase formation in Pediatric Hematologist Oncologists number of formed phases were: one – in 15.3 %; two – in 7.6 % and all – in 7.6%. In Primary care Pediatricians only one phase (Resistance) is formed in 47 %. In Pediatric Residents phases of burnout are not formed.

According to summary score and phase formation Burnout syndrome was diagnosed in 38.5 % of Pediatric Hematologists and in 11.7 % of Primary care physicians. Spearman rank correlation coefficient demonstrated expression of the tension (score) by profession $r = 0.5$, $P = 0.000$; expression of exhaustion (score) by profession $r = 0.6$, $P = 0.004$. Expression of the total score by profession was $r = 0.8$, $P = 0.000$.

Conclusion. Burnout syndrome was defined in 38.5 % of Pediatric Hematologists and in 11.7 % of Primary care physicians. Dominant symptoms of burnout for each phase were identified and the severity was assessed.

ABSTRACT NO.: O-280

Reproductive behavior of families with children-cancer survivors

M.A. Guseva¹, G.Ya. Tseitlin¹, A.I. Antonov²

¹Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitriy Rogachev, Moscow, Russia;

²M.V. Lomonosov Moscow State University, Russia

Key words: reproductive behavior, paediatric oncology, parents, family

Introduction. Childhood cancer and its treatment influence both individuals within the family and the family as a whole, in particular its reproductive strategy. This aspect of family functioning is poorly understood.

Aim. The purpose is to study reproductive behavior of families with children-cancer survivors.

Materials and methods. Data from the families were collected through individual interviews and questionnaires of 1085 mothers from 78 regions of the Russian Federation; mothers aged 25–49 (average 36.6), with a cancer child aged 5–17, in remission from 1–12 years (average 4.2). The results were compared with the data of the Russian state statistics agency's demographic research of the same period – 1118 female respondents of the same age range (the control group).

Results. The number of born children in our group considerably differed from the control: 1 child – 39.7 % vs 58.3 %; 2 children – 48.7 % vs 27.8 %; 3 – 9.6 % vs 3.8 %; 4 and more – 2.1 % vs 0.7 % respectively. The indices of reproductive attitudes in our group were higher than in control: average desired number of children – 2.59 vs 2.28; average expected number of children – 2.05 vs 1.72 respectively. Family values – family moorings and relationship, ties, household, possession of many children in our group took higher rank places than in control. Childhood cancer impacts on parents' relationship: 25.3 % – improved; 10.7 % – deteriorated; 9 % – divorced; 55 % – no change. Chronical emotional stress considerably impacts on reproductive health: 12.5 % had reproductive function's disorders.

Conclusion. It is suggested that childhood cancer changes the meanings and life priorities towards a pro-family orientation, considerably increasing the need in children. The families need psychological, social and medical support to overcome stress, improve their health and quality of life.



ABSTRACT NO.: 0-287

Psychological service development of PBHF of SO ODCH 1 Children's Oncology and Hematology Centre

T.A. Ziskelevich, I.S. Savran, S.V. Logvinenko, A.O. Kuznetsov
Regional Children's Clinical Hospital № 1, Yekaterinburg, Russia

Key words: psychological service, psychological aid, oncopsychology

Introduction. Initially psychological service (PS) creation project was planned not only in a narrow sense of aiding to oncology patients, but also as a structure, aimed at outreach and educative activities in the field of oncological problematic, both in the framework of professional environment and in the society.

Aim. Formation of aims was carried out in several directions: a psychological aid to children and parents, a rehabilitation course, integration issues of PS in medical sphere of healthcare centre, preparation and education of professionals.

Materials and methods. For 5 years of PS work there were defined groups of issues that were solved during work: issues in the field of dyadic mother-child intercourse, oncology subject adaptation at the social level, burnout, prevention of rehabilitation, acquisition of different social institutions for the coverage of oncology issue of the society, professional improvement. One of the main principles of PS work is individual and collective responsibility to society. A key aspect in service organization and functioning is a well-structured system formation which includes general principles of process organization, statistics, structuring of PS-addressed-requests, a psychological instrumentation set that is authentic to professionals, well-defined work strategy and concept, distinct requirements set to professionals. Such work process structure allows to support a predictable work space with well-defined lines, which is the foundation of stable and long PS functioning at high professional level. Along with this clear frames allow to detect problematic zones in PS work.

Results. Definition of PS work perspectives/opportunities is very important, because in our opinion absence of clear perspectives of PS development during work in this field leads to fast stagnation and burnout of the system itself in very short terms. This may be one of the obstacles in PS creation and functioning in the oncology field. Shortness and burnout prevent scientific site creation and experience exchange, i.e. the processes that are the basis of scientific oncopsychology school creation in Russia.

Conclusion. Nowadays we managed to integrate PC into Children's Oncology and Hematology Centre, to actualize needs of patients, their relatives and medical staff in psychological aid in oncological in-patient facility, to lay a rehabilitation basis for the period of inpatient stay till the moment of release.

ABSTRACT NO.: OP-316

The stigma of cancer in developing countries

Atish Narayanrao Bakane, Ramya S Uppuluri, Divya S Subburaj, Sreejith R Kurup, Revathi R Raj
Apollo Speciality Hospital, India

Key words: developing countries, diagnosis of childhood cancer, retrospective oral questionnaire, psychosocial aspects of cancer

Introduction. The diagnosis of cancer is seldom disclosed to children or discussed with them in developing countries after completion of chemotherapy. We present here data on the extent and patterns of social stigma associated with the diagnosis of childhood cancer in middle income families in India after completion of therapy.

Aim. Data on the extent and patterns of social stigma associated with the diagnosis of childhood cancer in middle income families in India after completion of therapy.

Materials and methods. This a retrospective oral questionnaire done on parents of children treated in a tertiary cancer centre in India over a ten year period between 2002 and 2012. The children who were less than 7 years old during therapy and were in remission over 3 years were chosen as our study population. The parents were questioned on 3 parameters – discussion of the treatment of cancer with the child, attitude towards follow up care and fear regarding long term side effects of the treatment.

Results. A total of 59 parents were interviewed for the study. The diagnosis was Acute Lymphoblastic leukaemia in 37 children, Hodgkins lymphoma in 5 and non Hodgkins lymphoma in 10 children. Only two parents had discussed the diagnosis of cancer with their child (3.4 %). Follow up was not offered for fear of sensitive questions from the children in 83 % of children and only 10 children have been coming for regular annual follow up since discharge. All parents – 100 % expressed fears about delayed side effects from the chemotherapy especially on pubertal growth and fertility but did not wish to discuss this issue with the child. Separate appointments were made to perform a chart review in 12 % patients by the parents to address this issue of late side effects.

Conclusion. The social stigma of cancer chemotherapy in our society has resulted in a huge loss of data on the psychosocial aspects of cancer and its impact on the family. More COPE programs – creating opportunities for parent empowerment are required to overcome these barriers and help support these families long term.

ABSTRACT NO.: P-335

Psychiatric issue of “medical stress” of parents in pediatric oncology/ hematology

S.N. Masikhina

Federal Research Center of Pediatric Hematology, Oncology and Immunology named after Dmitriy Rogachev, Moscow, Russia

Key words: adjustment disorder, stress-related disorders, anxiety, depression, parents, adherence, pediatric oncology

Introduction. A treatment success in pediatric oncology depends largely on the parents that are “intermediaries” between the child and the system of health care. Untimely treatment, violations of the drug therapy, treatment failures and defects in care are essential factors of poor prognosis of cancer. Among the factors of low adherence to treatment are the individual characteristics and psychopathological symptoms.

Aim. The clinical study of the role of mental disorders in the structure of “medical stress” in parents of children with cancer and impact on treatment adherence.

Materials and methods. There was conducted a screening study of 428 parents of children with cancer (solid tumors, leukemia and lymphomas) who have agreed to participate in the study. The study was conducted by using Hospital Anxiety and “Depression Scale” (HADS), Morisky Medication Adherence Scale (MMAS) and additional items to assess the quality of care. The mean age of parents was 34 ± 7.8 , length of hospital stay from 1 to 6 months. 82 parents (69 mothers, 13 fathers) were selected among the total sample that scored more than 11 points on HADS (HADS-A and HADS-D). There were excluded parents of children in terminal conditions, and parents with pre-existents conditions as chronic alcoholism, mental retardation or organic brain disease. The analysis focused on premorbid characteristics, clinical patterns and dynamics of “medical stress”-related disorders. The obtained data were correlated with the diagnostic criteria of ICD-10. Comparison of mean values and the proportion of paired values was conducted by using Student’s criterion (level of significance < 0.01).

Results. According to clinical analysis of “medical stress”-related disorders in parents were identified: adjustment disorders (AD) – 48.7 %; decompensation of personality disorders (DPD) – 34.1%; mood depressive disorders (MDD)- recurrent depression, dysthymia, moderate depressive episode – 10.9 %; exacerbation of schizophrenia spectrum disorders associated with stress (SSD) – 6 %. The main clinical and psychosocial characteristics of the groups shows the differences in terms of adherence to treatment. Comparative analysis of the MDD group showed: parents less likely to comply with hours of medication and ($M = 2$, $SD = 0.22$ and $M = 48$, $SD = 0.96$, $t = 8.3$ psychotic symptoms, cognitive disorganization significantly reduced rates of adherence to therapy.

Conclusion. Mental disorders in parents has a negative impact on the treatment of cancer in children. The impairment of therapeutic cooperation were the most significant in the groups DPD and SSD. In clinical practice, it is necessary to identify in advance psychiatric disorders in parents to improve the quality of medical care. Medical staff need to adhere to certain rules of psychosocial interaction with parents with mental disorders.

ABSTRACT NO.: PP-397

Subculture groups of children in medical institution in aspect of interaction with parents communities and public organizations

I. Ageeva-Podobed, G. Kireeva

Chelyabinsk Regional Children's Hospital, Russia

Key words: subculture, children, therapy

Introduction. Forming of subculture inside of children's groups in medical institution connected with children's adaptation and rehabilitation that have serious illness and needed in restoration to health, education and assigning educational values.

Aim. To confirm the effect of formation healthy lifestyle in subculture groups of children in medical institution.

Materials and methods. Researches of subculture children's groups were made in the unit of pediatric oncology and hematology of Pediatric Hospital of Chelyabinsk Oblast. Interconnections between public organizations, parent's communities and subculture groups of children were studied.

On the basis of the studied material plan of the creative associations in office of play therapy was built. Research was made in conjunction with specialist from unit of pediatric oncology and hematology of the Pediatric Hospital of Chelyabinsk Oblast. Most active among them were educational psychologists, educators, volunteers.

Results. The culture of relations in the hospital is sophisticated and dynamic phenomenon which depends on level of forming culture of communication relations children's group but also in medical institution, their focus on socio-cultural values.

Culture of relations in isolated social groups is a subculture. During hospitalization in the unit of oncology and hematology besides medical treatment patient require his or her everyday life. During medical treatment it is important to mobilize internal psychological, physical, intellectual reserves of the children and to form the orientation of the personality in socio-cultural values – healthy way of living.

Conclusion. Subculture as a kind of socialization is a social phenomenon which impacts on recover. It connected with the occurrence of the personality in educational space, with interaction with his or her values and assignment, i.e. including them into the structure of personality. This requires a cultural approach as methodological principle of socialization of children during medical treatment in hospital.