THE INTERDISCIPLINARY TREATMENT OF CASE OF A BOY WITH SYNDROME FLOATING – HARBOR WITHIN A DAY HOSPITAL FOR CHILDREN, ADOLESCENTS AND ADULTS

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Introduction

Day Hospital for children, adolescents and adults with psychiatric disorders in the prefecture of Fokida

The Day Hospital for children, adolescents and adults with psychiatric disorders who live in the community of Fokida's prefecture is part of the network services provided by the Society of Social Psychiatry and Mental Health in the prefecture of Fokida. It started to provide services in November 2012 under the Priority Action "15 - Consolidation of psychiatric reformation in the field of Mental Health, Development of Primary Health Care and Protection of the public health of the population in two regions" of the operational program "Human Resources Development". It was co – financed from the European Social Fund for 24 months. It is currently funded from the Government annual budget.

It's a model hospital that provides free services to children, adolescents and adults with a variety of difficulties related to learning, behaviour, emotions and communication.

Through the involvement of experts from both the General Hospital and the Society of Social Psychiatry and Mental Health, the interdisciplinary clinical team of the D.H. considers that co – operation not only within the team, but also with the immediate social environment such as institutional frameworks, parents associations, social organizations, local bodies, e.t.c. is essential in order to achieve the best results. Therefore it's an integral part of their therapeutic approach.

Clinical Case Study

The syndrome Floating Harbor, known as Pelletier – Leisti syndrome, is a rare genetic disorder with less than 50 cases described in the literature. Named by Hospitals Boston Floating Hospital and Harbor General Hospital in California as it was the first hospitals that greeted patients with this disorder in 1973 (Patton, Hurst, Donnai, McKeown, Cole & Goodship, 1991). Key features of the syndrome are low birth weight, the short stature, delayed bone growth, skeletal abnormalities, severe delay in the development of speech and mental retardation that can be mild or moderate. Accompanying symptoms may be hyperopia, strabismus, conductive hearing loss, seizures, gastroesophageal reflux disease, renal disorders and disorders of the genitals (*Nowaczyk, Nikkel & White, 2013)*. (pic. 1, www.floatingharborsyndromesupport.com).

pic. 1

Because of the complex disorders that the syndrome causes, it’s necessary to be adopted a multifaceted and complex approach that includes not only the person who has the syndrome but also the family and the institutional framework that will attend (Nowaczyk, Nikkel & White, 2013).

Purpose of the Present Case Study

This present case study refers to a boy, named A who is 8 years old and has been diagnosed with Floating – Harbor syndrome. It’s aimed not only to discuss development and progress of his developmental disabilities after 2 years of rehabilitation treatment but also to demonstrate the importance of interdisciplinary intervention and harmonic cooperation with the family, institutional framework, local community and organizations of the country.

Floating Harbor Syndrome Support Group

Welcome!

Prenatal – Developmental Background

- Twin pregnancy.
- Prematurity. He was put in an incubator for two months due to low weight.
- Infantile hypothyroidism: he follows pharmaceutical treatment until the present time.
- Genetic testing combined with clinical examination: diagnosis of developmental disorder – Floating Harbor Syndrome (in Unit of Developmental and Behavioral Pediatrics of General Children's Hospital "Agia Sophia").

Psychological and Locomotive Delay

- He walked at the age of 18 months.
- Insufficient control of sphincters.
- Delay in language expression and comprehension (Bilingualism).
- Difficult non – verbal communication.

Access and Adjustment to School

- At his early childhood he stayed at home.
- K.E.D.D.Y. (Centre of Differential Diagnosis and Support of Special Educational Needs) of Viotia recommended for attending the Special Nursery School in their area. Parents denied their recommendation at that time.
- At the present time he attends Special Elementary School in Amfissa since January, 2015.

Main Clinical Data

- Delay in self – care skills.
- Deficits in socialization.
- Deficits in speech.
- Disruptive behaviour.
- Peculiar phenotype consistent with a genetic disorder.

- Diagnosis: Comorbidity of Pervasive Developmental Disorder (F84 in ICD-10) and Unspecified Mental Retardation (F79 – in ICD – 10).

Case Management

- E.K. is receiving treatment in D.H for Children, Adolescents and Adults in the prefecture of Fokida since June, 2012 until now.
- The diagnostic procedure included the following steps: Medical History, Child Psychiatric Assessment, Speech – Language, and Occupational Evaluation by the interdisciplinary team of D.H.
- Deficiencies have been identified in all developmental sectors. Therefore he has been accordingly integrated into individual programs of Speech – Language Treatment, and Occupational Treatment.
- At the same time his parents joined in a counseling program in order to have realistic expectations for the overall development capacity of their child.

Speech – Language Treatment

Language Evaluation at presentation (age 8 years 8 months 15 days) of his language abilities after 2 years of speech – language treatment using a combination of verbal communication and a system of augmentative / alternative communication.

Let's first mention the targets that were selected:

A. Long – Term Targets for pre – linguistic skills, receptive and expressive language, and sound production

- To develop age – appropriate skills understanding.
- To develop conversation skills, imitation and joint attention skills.
- To understand and produce expressions that contain one to two words, as it's developmentally expected.

B. Short – Term Targets for pre – linguistic skills, receptive and expressive language, and sound production

Eye Contact

- To develop his ability to initiate and maintain a consistent level of stimulation and eye contact to indicate his desire to communicate.

Listening and Attending Skills

- To teach him to attend to the therapist's face and respond to visual and auditory cues.

Imitative Skills

- To teach him to watch others and increase the frequency imitating the gestures of others, the motivation and the voice.

Following Directions and Instructions

- To teach him to independently follow directions.

Greeting and Farewell Routines

- To teach him routines that acknowledges others and encourages social interaction.
- To increase the frequency of communication efforts with one to two words expressions.

Turn Taking

- To teach him to observe, listen and share with others.

Vocabulary

- To teach him the vocabulary to enhance his participation and learning.

Word Retrieval

- To teach him to respond to cues to recall learned vocabulary.

Feelings

- To teach him the words he needs to express emotions.

The monitoring was stable with no cancellations. There was a significant change to the selected targets. Specifically:

- He can greets and say his name either spontaneously or with small guidance from therapist's part.
- He can sit alone in the seat with less help from therapist's part.
- He can choose between two activities and indicate his pleasure or displeasure. He can show emotions such as joy, satisfaction, as well as anger, dissatisfaction for some activity.
- If he's tired or frustrated, he may throw various objects on the floor in a more sporadic frequency and / or he may be verbally / physically more active.
- He turns his head when sb calls him even though he deals with something else at the time.
- He learns to keep the eye contact for a longer period of time.
- He learns to wait in turn.
- He learns to identify similar objects, similar pictures of objects with similar images.
- He continues to enrich his vocabulary.
- He learns to use more appropriate the ball – he can hold it easier and can throw it to sb – he has more difficult to kick it as he has no lasting balance.
- He likes playing with skittles with ball – he gets excited when he manages to throw them either with the ball or with his hands.
- He likes playing also with Lego bricks, with cars, small wooden puzzles, and making bubbles.
- He can follow simple commands with / or without a visual aid.
- He likes reading to him small books with colour images - if he likes a book, he "tells" to the therapist to reread it to him.
- He can imitate sounds in a more stable frequency.

- He can imitate words with simple syllabic structure in a more stable frequency - in some cases he needs to repeat the first syllable of the word and / or partially the whole word.
- He loves singing to him simple songs and listening to music – he rhythmically wagges his body.

Occupational Treatment

The aim of the occupational therapy sessions was to improve A's ability to perform a wide range of play, self – care, social, and school – related activities to maximise his skills for living.

Occupational therapy sessions involved:

Long – Term Targets

- Promoting and maximising A. occupation performance, health, well – being, and participation.
- Assisting A. to develop new skills.
- Ensuring new skills are maintained and built upon.
- Modifying the environment or activity to ensure A. can participate in a meaningful way.

Short – Term Targets

- To develop play skills that include social interaction, sharing, and taking turns.
- To model and support for parents learning to interact and play with their child.
- To teach self-care activities like toileting, bathing, clothing and feeding.
- To engage in activities to improve A.'s fine and gross motor skills.
- Behaviour management such as learning to sit and wait.

At present A. is capable of:

- Having more constant eye contact.
- Be positively associated with the person of the therapist and the therapeutic material.
- To cooperate and get concentrated
- Running, catching and throwing ball.
- Playing in playground with seesaw, slide, swings with assistance from therapist's part.
- Interacting and imitating sounds and words with simple syllabic structure.
- Obeying simple orders with assistance from therapist's part.
- Showing emotions such as fun and satisfaction with laughs and mobility and/or dissatisfaction with crying, screaming and asking for his parents.

- Concentrating on an activity for a short time.
- Using both his hands so as to clap and carry toys.
- Doing palmar conception, tripod and bipolar handle.
- Asking for assistance.
- Capable of self-handling in dressing, though avoids toilet and food demonstrating challenging behavior.
- Adapted more easily to new environments.

Parental Counseling

At first the denial of the problem dominates, anger, guilt, fear of "the unknown” that parents have to cope with, anxiety about their child's future.
Parents used as a defense their silence. At the beginning of the intervention family was socially isolated. Relatives of the family and the local community were unaware of the child's difficulties.

Targets and Main Points of the Consultative Working

- Emotional support for parents so as to understand and work out their personal feelings. It is noticed a cycle of emotional reactions from parents: from sadness, anxiety and fear into calmness, from denial to acceptance of the situation.
- Deepening into the way in which their emotional difficulties in contact with their child affect his behaviour:
  The reaction of parents contributes to the maintenance of these dysfunctional behaviours.
- Appropriate training in order to enable them to operate as co – therapists, and be able to continue the intervention at home.
- Systematic and coordinated effort in order that A. can attend Special Elementary School of Amfissa in coordination with his treatment in D.H.: Proper networking with the principal of Primary Education, the principal of Social Welfare, the Special Elementary School of Amfissa and K.E.D.D.Y. of Viotia.
- Continuous support and guidance not only on the proper adjustment of their child to the educational environment but also to overcome any difficulties that arise due to the difficulty to use the Greek language from their part (e.g. applications, filling school questionnaire, e.t.c.)

Concluding Comments and Future Research

- Results of the present study indicate that the successful treatment of a child with multiple biological and psychiatric problems requires a multifaceted management by a team of professionals from various disciplines.
- The interdisciplinary approach offers the highest level of collaboration. Team members interact in assessment and service planning, with one assigned primary responsibility for providing intervention services within his/her professional scope of practice, based on the child and family's needs.
- It also indicates that interdisciplinary treatment helps the child in attainment of many developmental tasks and enhances functioning of the family unit.
- Our experience is in conformity with the international data that highlights as positive predictors for the therapeutic outcome of a child with neurodevelopmental disorder, the interdisciplinarity, the coordinated collaboration with the treating pediatricians, and the constant collaboration with the family, the school and the local community.
- More studies are required to understand the duration and frequency of interdisciplinary interventions in neurodevelopmental disorders.

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