Individual Behavior Therapy in a young lady with ASD: a 46 months evolution

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The Autistic Spectrum Disorder (ASD) is characterized by delays in the development of socialization and communication skills. Parents may notice symptoms as early as infancy, although the typical age of onset is before three years of age. Symptoms may include problems with using and understanding language, difficulties relating to people, objects and events, as well as difficulties in changing routine or familiar surroundings, repetitive body movements or behaviour disorders. The behaviour disorders (aggressive behaviour and self-injurious behaviour, also known as SIB) can occur and manifest with a large spectrum of clinical symptoms (Fombonne,1999, Holt et al2002, Rogé, B.,2003, Lord C et al, 1994 Miles et al, 2005.).

Even though the first residential treatment program designed specifically for adults with autism was developed in the 1970s and 1980s in the USA (Van Bourgondien et Elgar; Van Bourgondien et Reichle 2001; Van Bourgondien, Reichle et Schopler 2003, Van Bourgondien et Elgar, 2005) it is difficult for parents to find placements for adults with severe intellectual disabilities and autism or ASD fitting with the specific need of the person. It is now a well-known fact that individuals presenting ASD have specific characteristics that make their integration in homes particularly difficult. In their paper, Van Bourgondien et Elgar describe how the difficulties of clients with autism can affect their participation in traditional

community-based training programs. Moreover educational teams have significant difficulties in managing challenging disorders, which often result in exhaustion of teams, families and clients. These difficulties very often lead to more specific behavioural problems and assume the setting of very specific structures (Rojahn, Aman, Matson et Mayville 2003).

Therefore and in order to give them a good quality of life during adulthood, we provide residential programs in Geneva (Switzerland). Based on structured pedagogy, this program called PAMS (so called following the French abbreviation of "Structured Method Autism Program" - Programme Autiste Methode Structurée) seems to have good clinical effectiveness. Some studies performed in residences proposing this kind of program in an adult population with mild to severe intellectual disabilities and ASD have demonstrated a significant decrease of behavioural problems (Galli Carminati et al 2007,G. Galli Carminati et al, 2007a et b, Gerber et al, 2008)

PAMS (so called following the French abbreviation of "Structured Method Autism Program") is inspired by the Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH) by Schopler and Mesibov (Schopler et Mesibov, 1985, Schopler et al 1994, Schopler et al 2001, Mesibov et al 1997, Mesibov et al 1989 Eigisti et Shapiro T.2003). This program includes specialized education, work on communication, socialization and behaviour management. This work is based on partnership with families. PAMS uses space and time structuring systems as a means to create spatial boundaries as well as individual programs that use on visual aids. (G. Galli Carminati et al 2007 a, b)

The purpose of this work is to describe the evolution of a young lady 35 years old with ASD and intellectual disabilities (ID) living in residence with a structured program within the Public Socio-Educational Establishment in Geneva – EPSE (now Public Establishement for Insertion EPI) and benefiting of individual one-to-one therapy with a psychologist of the team of Psychiatry of Mental Development Unit (UPDM)

For the young lady considered in this observation the presence of challenging behaviours such as self-injury presented serious barriers to adaptive integration into the residence and originates hospitalisation for long periods. The family decided to support an individualised

care with a psychologist of our therapeutic team, working in partnership with the socio-educational team of EPI.

Our principle hypothesis is that behavioural disorders and SIB could be reduced when the environment is structured, constant and predictable. We also think that adding an individual behavioural coaching more focused on specific behavioural disorders as well as on non adapted social behaviours will improve the effectiveness of PAMS (characterised by a less individualised presence of the team because of practical institutional constraints).

For the observation of the behaviour disorders, we use the Aberrant Behaviour Checklist (ABC). Data were gathered on a weekly basis.

We remember that the ABC is a rating scale developed for persons with ID. Originally developed as a measure of treatment effects and as an instrument for assessing behavior problems, the ABC is made up of 58 items and has been shown to be valid. The ABC was derived by factor analysis, and its five subscales were labelled as follows: I Irritability, Agitation, Crying (15 items); II Lethargy, Social Withdrawal (16 items); III Stereotypic Behaviour (7 items); IV Hyperactivity, Non-compliance (16 items); and V Inappropriate Speech (4 items) (Aman et al 1985 a ,b, 1987,1995, Marshburn, et al 1993, Rojahn et Helsel 1991).
Considering our hypothesis, we predicted having a diminution of ABC results over the period of observation due to an improvement of behaviour troubles.

CASE REPORT

This study concerns a 35 year old lady presenting ASD and severe Intellectual Disability (ID), following the ICD10 definition (World Health Organization (1994).
With the collaboration of the parents we collected her personal history. She is the only child of a family without psychiatric history. After a normal pregnancy, the delivery at due term was without noticeable incidents. Autistic behaviour was remarked starting from the first months with eating disorders, sitting position at seven months and walking at 18 months. At the age of three she did not talk, did not perform symbolic games and had behaviour characterized by stereotypes and autistic regression, aggressiveness and sleeping disorders.

She underwent surgery in 1973 for a hernia and in 1976 for the removal of the amygdales. She was allergic to bees and wasp stings. She benefited from special schooling from 1986 to 1987. From 1987 she went to live in the Castalie Medico-Social Institution "La Castalie"-Valais (Switzerland). Starting from 1995 she was integrated to the Thônex Residence of EPSE (now EPI)-Geneva (Switzerland).

From 1990 to 2005, several hospitalizations were necessary in the Psychiatry of Mental Development Units (UPDM), due to serious behavioural troubles including hetero-aggressiveness, bulimia and SIB (Self Injurious Behavior) as typically head-banging.

In December 2004 the patient was admitted in a clinical applied research benefiting from the intervention between two to four hours three times a week with a psychologist experienced in PAMS administering an individual accompanying (one –to-one intervention). The observation of behaviour of the patient was collected with a proxy (the referent educator) using the ABC, weekly.

In 2005 she was hospitalized because of a severe impairment of her troubles, such as aggressiveness, bulimia, SIB, beating and scratching herself, and head-banging. At this moment, her treatment was clonazépam 5mg/j, de lorazepam 5mg/j, de zuclopenthixol depot 100mg/7js and de melanin 6mg/j. During July 2005 because of the severity of behaviour disorders (the patient was banging her head against the wall) and due to a dramatic impairment of equilibrium troubles with repetitive falls, we decided to perform a brain CT Scan to exclude a sub-dural hematoma. The CT Scan revealed an well delimited hypodensity of the first frontal right convolution, as well as the presence of a cerebellar ataxia linked to the classical antipsychotic treatment. Because of the presence of severe equilibrium troubles and important achatysia, we progressively reduced and stopped the treatment of clonazépam (Rivotril®), de lorazepam (Temesta®) and de zuclopenthixol depot (Clopixol®) in July 2005. Progressively a treatment of Clozapine(Leponex®) and of Gabapentine (Neurontin®) was introduced following the proposition of the neurologist .

The IRM in August 2005 confirmed the presence of a frontal glyoma of low malignancy. In September 2005 the patient suffered a generalised tonico-clonic epileptic crisis and we introduced a treatment with Lévétiracétam (Keppra®) starting from 500 mg/day obtaining the cessation of epileptic crisis (Olsson et al,1988 ,Volkmar et Nelson 1990,Masi, 2004; Tassinari et al., 2005 Lamusuo et al 2001, Rossi et al1995).

As in routine tests for developmental troubles patients, we performed a test for celiac disorders and the positive dosage of anti-boby anti-gliadine confirmed the diagnosis. A gluten free diet was introduced starting from August 2005 (Galli Carminati et al. 2006)

In September 2005 the patient was discharged with the following treatment: Clozapine (Leponex®) 125mg/j, de Gabapentine (Neurontin®) 300mg/j, de Lévétiracétam (Keppra®) 1000mg/j, de Melatonine 6mg/j and of Esomeprazolum (Nexium®) 20mg/j.

The clinical evolution of the patient was favourable with only a short re-hospitalisation of 2 weeks in August 2006 because of some hetero aggressive behaviour.

PSYCHO_EDUCATIONAL INTERVENTIONS FROM 1995 to 2008

During the period from 1995 to 2005, behavioural a psychologist specialized in the treatment of person with developmental troubles conducted psychotherapy. This therapy aimed to develop interpersonal social relationships and to place the patient in everyday, real-life situations. The psychotherapist met occasionally with the socio-educational team and the family to discuss and understand the needs of the patient.
From 1999 to 2006, the Mobile Team handled part of the care; this team also gave an informal supervision to the socio-educational team and provided a weekly walk-around session of a psycho-educational member of the Mobile Team.
Starting from the end of 2006 the intervention of Mobile team was reduced to the weekly walk around session of a psycho-educational member of the Mobile Team. The supervision was assured by an external psychotherapist specialized in the psychodynamic approach of autism.

DESCRIPTION OF THE BEHAVIORAL INTERVENTION FROM DECEMBER 2004 to SEPTEMBER 2008

In a first phase before beginning with the intervention on the patient, the therapist acted as observer in the patient's residence, and met several times with the educational team and the family in order to establish the objectives of the intervention and to progressively guide the educational team and the patient through the changes. The team filled in a chart to establish a therapeutic and educational intervention program, based on the hypothesis that a behavioural

disorder is a means of communication that needs to be decoded. The gathered elements consisted of the manifested type of behavioural disorder, the place, the time of day and the exact situation in which the behavioural disorder arose, the case history and consequences of this behaviour, as well as the reaction of the patient and her environment.

The therapist first intervened on the psycho-educational level, by bringing an external objective view to the caregiver process of the patient, allowing the educational staff to analyze their daily practice from a different point of view. The chart allowed the therapist and educational staff to organize and describe elements to be worked on, establishes a critical analysis of the selected strategies, and discusses alternate strategies. This deliberation process on the practice of the educational staff also enabled important elements of the therapy to be recalled, such as the primordial need of the patient for a stable and foreseeable program (aided by a simplified agenda illustrating her activities over the week), coherent and homogeneous educational strategies and feedback from the educational staff, and the importance of well-structured activities, each in their respective, well-delimited environment.

Starting at the end of 2006, the patient's weekly program was simplified, activities from waking up to going to sleep more structured, rest breaks were introduced and more adapted educational strategies were put in place. In addition, the patient's participation in activities of daily living was strongly stimulated, e.g. selecting clothes, getting dressed, etc.

In the context of this "new program" three weekly sessions with the therapist taking place outside the home of the patient were introduced. Initially the care-taking process focused essentially on the way the patient managed difficult situations hic et nunc. The therapist familiarized with the idiosyncratic vocabulary of the patient in order to establish a means of mutual communication. The formulation of a basic vocabulary adapted to the comprehensive level of the patient gave rise to a decreased level of anxiety and reduced manifestation of behavioural disorders. The therapist adapted and simplified traditional relaxation methods in order to make them applicable to the patient. These sessions were held in a room generally used for Snoezelen therapy (references), an environment that promotes relaxation.

The therapist gradually introduced activities once the state of the patient was stabilized. These activities were pleasant for the patient, yet required significant effort from her side: visiting a bistro. This activity allowed the patient to gradually develop and train several basic but essential social and group competences: to remain calmly seated in a public place, manage

various noises and the passing by of strangers in an unfamiliar environment, being able to patiently wait for service, drinks, her turn to go to the bathroom, the bill, for the accompanying person to finish her drink, learn to order her own drink, and to consume it calmly and in a mannerly way. Once these tasks were managed satisfactorily, a new activity consisting of looking through a magazine and naming each picture was introduced, allowing the patient to considerably increase her vocabulary and train her memory. Indeed, as sessions progressed the patient would ask for the magazine and search for pictures of a certain object or animal she had seen during the last session or over the past week. Additionally, the patient learned to recognize and name basic emotions based on their manifestation (a smile = being happy/amused, tears = being sad) from pictures in the magazine. As a consequence of the intervention, behavioural disorders of the patient are currently rare, and their cause is often if not always comprehensible (can always be verbalized by the patient).

On the period described in this study, the therapist held a weekly meeting with the complete educational staff as well as with the educators involved in the intervention of the patient. The frequency of these meetings was reduced gradually as the state of the patient improved.

Our observation covers the period from December 2004 to May 2007. The ABC was performed weekly with the observation on the previous week. The psychologist accompanying the patient interviewed the proxy. The observation of the proxy was on the period of the past week. We studied the results of ABC with a Fourier analysis and no frequencies appeared, but the weekly pic. All the ABC factors show a large irregularity nevertheless we can observe some general trend, we will consider each factor one by one. The trends of the five ABC factors are similar. The period of the second hospitalization, August 2006, corresponds to 81^{st}-83^{rd} weeks. The “new program” (see above) began at the end of 2006 corresponding to 90^{th} – 100^{th} weeks

Factor I: Irritability, Agitation, Crying. This Factor presents amelioration during the first hospitalization that is not so coherent but could be explained with the different, more structured environment in the psychiatric unit. Then it shows deterioration until amelioration concerning the period of 60 weeks and the impairment after the second hospitalization. It took all the following period of observation to come back to the level before the second hospitalization. Il the last part of the period of observation, around 115 weeks, the improvement is clearly present.

Factor II: Lethargy and Social Withdrawal stay almost at the same level throughout the observation.

Factor III: Stereotypic Behaviour shows, with fluctuation, a progressive impairment starting slightly before the second hospitalization. We have to note that in the last 60 weeks, starting from the worse level after the second hospitalization, the level is gradually diminishing without reaching the very low level at the beginning of 2005.

Factor IV: Hyperactivity and Non-Compliance is more or less similar to factor I, showing two different periods before and after the second hospitalization, but the differences between the two periods are less significant for Factor IV than for Factor I.

Factor V: Inappropriate Speech is constant throughout the observation.

DISCUSSION

This is a descriptive study based on a long-term observation of a patient benefiting from the individual accompanying between 2 to 4 hours 3 times a week with a psychologist.

The presence of an individual approach one-to-one produce a clear amelioration in the FactorI (Irritability, Agitation, Crying), this amelioration is clearly present after the introduction, at the end of 2006 of the new approach with a better separation in the spaces (inside versus outside of residence) and probably a better integration of the psychologist's "external" intervention in the educational team.

A more philosophical conclusion could be that, when a one-to-one psycho-educational intervention is organised inside a socio-educational team the different rules have to be clarified as soon and as clearly possible to assure a satisfactory coherence in the global care.

Another important point to underline is that this intervention is beginning to yield some results after more than one year. This is in accord with our observation in previous works on ADS population (Galli Carminati et al 2007,G. Galli Carminati et al, 2007a et b, Gerber et al, 2008).

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Figure 1 – ABC Factor 1

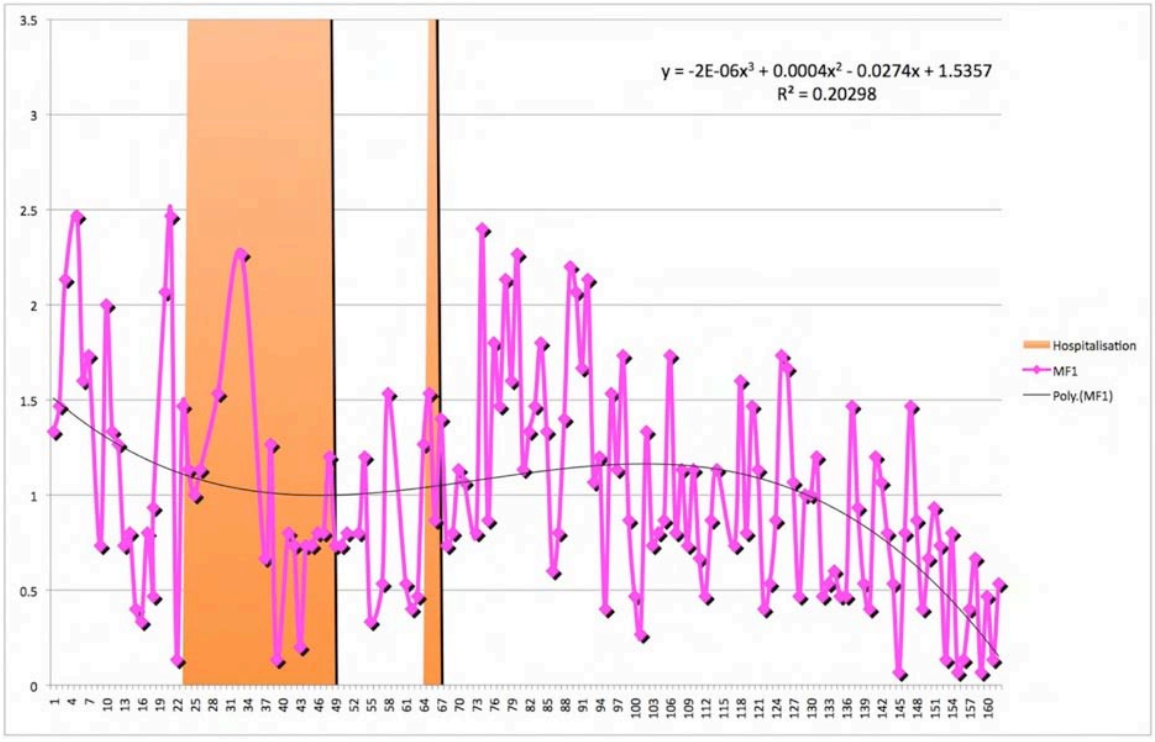

Figure 2– ABC Factor 2

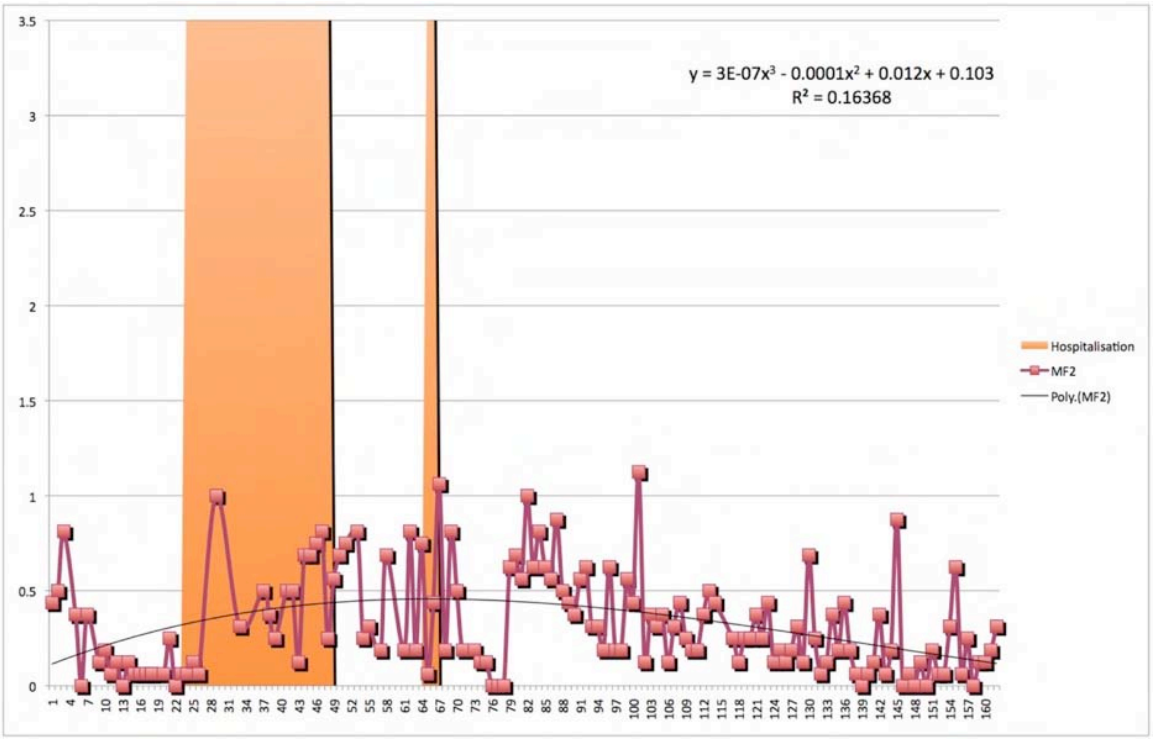

Figure 3 – ABC Factor 3

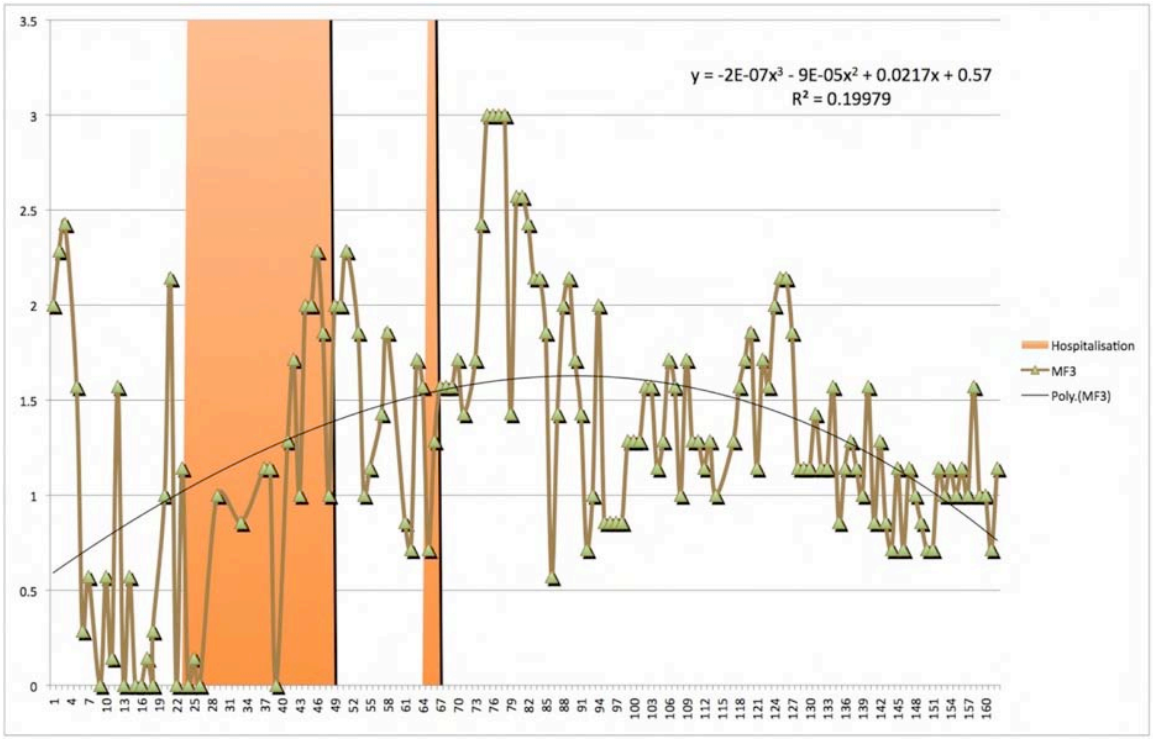

Figure 4 – ABC Factor 4

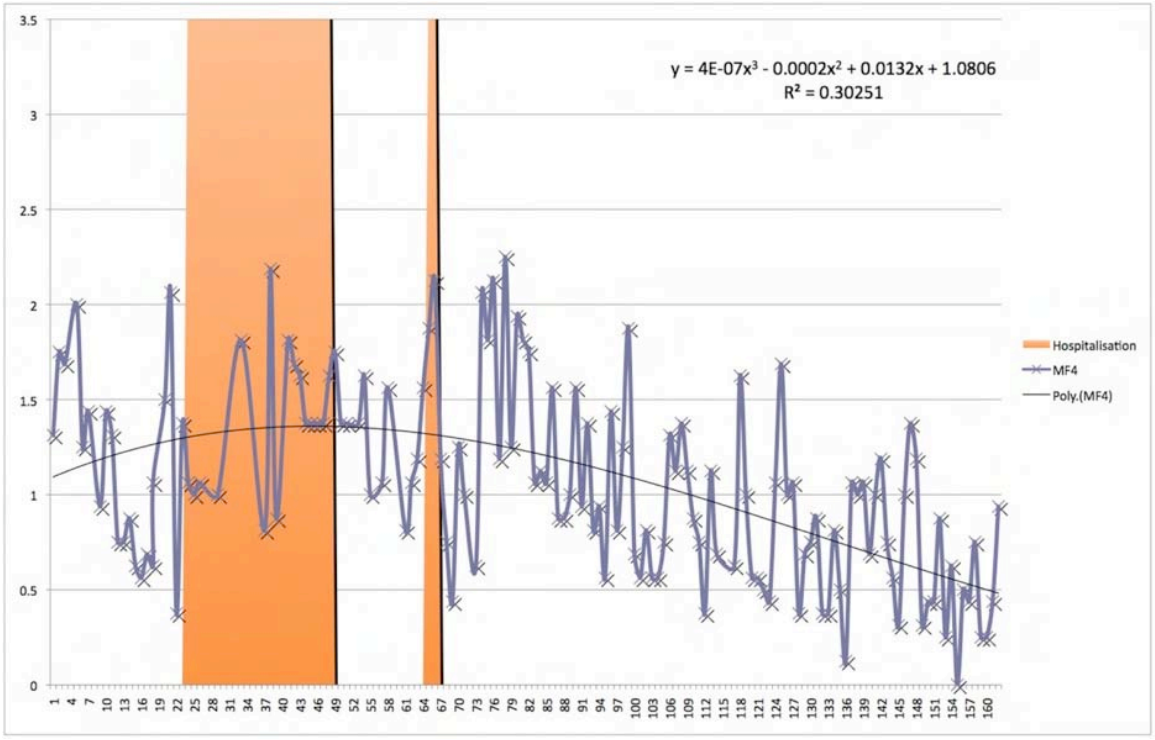

Figure 5 – ABC Factor 5

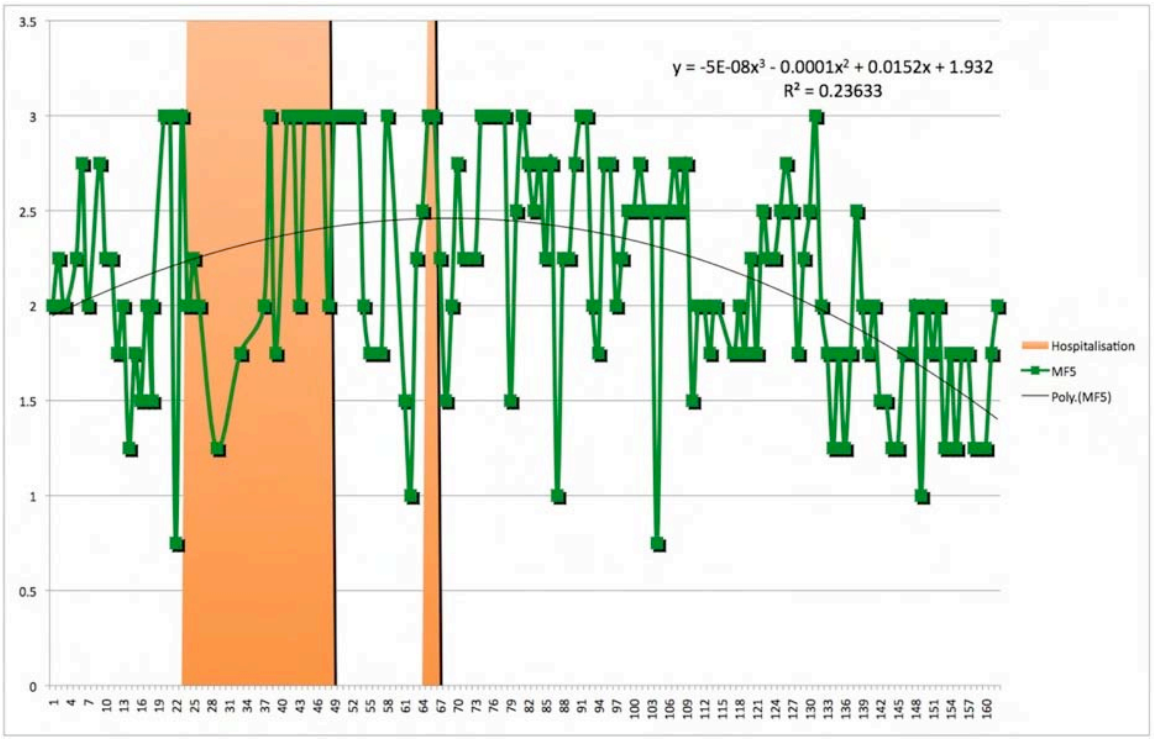

Figure 6 – ABC all the Factors