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Evaluating the effects of a structured program for adults with autism spectrum disorders and intellectual disabilities

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Abstract

This study observes the evolution of persons with pervasive developmental disorders (PDD) and profound intellectual disabilities living in residences with a Program for Residents with Autism Spectrum Disorders (ASD) characterised by a different educator's presence ratio and different logistic accommodations. This population is characterised by the need to live in a very structured and predictable environment and greatly benefits from specific programs in residential settings. We evaluated the evolution during 2.5 years of 2 groups of 10 residents using the Aberrant Behaviour Checklist (ABC) and the Children Autism Rating Scale (CARS). Evolution appears to be slow and irregular but we observed significant changes in social withdrawal along the study for one group. Possible implications of this study are discussed.
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1. Introduction

Autism Spectrum Disorders (ASD) is a life long disability. It therefore requires continuous treatment and education in residential settings. Autism is a syndrome encompassing several

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impairment features in three main areas: social interaction, communication and restricted interests, and repetitive and stereotypic activities. Among ASD, childhood autism, atypical autism, asperger's syndrome and unspecified pervasive developmental disorders are more frequently diagnosed disorders. The major difficulty of defining the aetiology of ASD is largely described in the literature (Holt & Bouras, 2002; Schopler, Yirmiya, Shulman, & Marcus, 2001; Rogé, 2003). Although progress will have to be made in understanding the aetiology of ASD, we actually know that multifactorial genetic and organic causes are sustaining thoses disorders. Multiple causes are affecting physiopathological and neuropsychological mechanisms (cognitive and information processing), affection, communication and social skills. Thus, the cognitive and behavioural features vary a lot from one individual to another. We know that prevalence has been evaluated worldwide to 7.2:10,000 (Fombonne, 1999) persons presenting a ''classical autism'' and 1:1000 (Association Internationale Autisme-Europe, 2000) considering the whole ASD. The sex ratio is about one female for four males.

Because of this great complexity of aetiology, prevention of ASD is impossible at this time. There are no antenatal, genetic or blood tests. Therefore, we have to concentrate our efforts on treatments and evaluation of these treatments in order to be more efficient.

Major literature is concerned with childhood and adolescent evaluations, treatments and education but actually the majority of persons with ASD are adults. The management of this population is a major social problem. 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 & Elgar 1990; Van Bourgondien, & Reichle, 2001; Van Bourgondien, Reichle, & Schopler, 2003), they still remain very rare in Switzerland. It is difficult for parents to find placement for adults with severe intellectual disabilities and autism or ASD, which are penalized by a lack of early intervention and stuck in much anchored behavioural disorders. 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 and Elgar (1990) describe how the difficulties of the clients with autism can affect their participation in traditional community-based training programs. These difficulties very often lead to more specific behavioural problems and assume the setting of very specific structures.

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 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., unpublished). The main difference in the two groups linked to the environment is the educator's presence ratio and environment accommodation. In cohort 1, workshops are outside the apartments, while in cohort 2, residents stay in their apartments; the leisure and working activities are punctual and situated in the same building.

To control for effectiveness and reflect clinical experience of proposed programs, we decided to observe behavioural disorders, which are usually the cause of hospitalisation in psychiatric unit. Educational teams have the biggest difficulties in managing challenging disorders, which often result in exhaustion of teams. The occurrence of challenging behaviours such as self-injury in the autistic population is very frequent and those behavioural problems ''present barriers to successful integration into the community and unrestricted access to

available educational, vocational and leisure opportunities'' (Rojahn, Aman, Matson, & Mayville, 2003).

The purpose of this work is to observe the evolution of adults with ASD and intellectual disabilities (ID) living in residences with a structured program within the Public Socio-Educational Establishment in Geneva. This special program is called PAMS, the French abbreviation of ''Structured Method Autism Program''.

PAMS program is inspired by the Treatment and Education of Autistic and related Communications Handicapped Children (TEACCH) by Schopler and Mesibov (1985). This adaptation of TEACCH includes specialised education, work on communication, socialisation, behaviour management, and work in partnership with families. Specific training has been provided to the socio-educational staff in order to increase their knowledge and understanding of the usual thinking and learning processes of autistic individuals. PAMS uses space and time structuring systems as a means to create spatial boundaries as well as individual programs which use on visual aids. PAMS is composed of several apartments for 6–8 residents, offering adapted and individual schedules for each person. These programs include domestic activities (e.g. having breakfast, bathing, walking or watching TV) and/or educational activities (e.g. basic constructions, categorization of objects). All these occupations' objective is autonomy. They are therefore performed based on individual programs represented by objects, pictures or pictograms depending on cognitive and developmental level.

The other goal of this program is to insure that the same socio-educational staff is in charge of the apartment's care and workshop activities. Staff intervene in both residential homes and workshops to permit continuity in environment and to enhance time management. The socio-educational team also had specific theoretical and practical training concerning ASD. We know now that a better understanding of the psychopathology of autism and ASD is a key to better management of behavioural disorders.

In a preliminary period, the residents were tested with the French version of the Psycho Educational Profile-Revised (PEP-R) (Schopler & Tréhin, 1994) or Adolescent and Adult Psycho Educational Profile (AAPEP) (Mesibov, Schopler, Schaffer, & Landrus, 1997) which determines the capabilities of each resident. Then an adapted program for activities, leisure and residential environment was implemented. It is important to note that we often see too much pressure on persons with ASD who are required to fit into a program. In contrast, PAMS' philosophy is that the structure has to adapt itself to the resident.

This study used a longitudinal prospective design. We started the evaluation after a organizing a PAMS residence, assessing the residents themselves and designing programs specifically tailored to each resident. We evaluated behaviour disorders every 3 months during several months with the Aberrant Behaviour Checklist (Aman, Singh, Stewart, & Field, 1985a); we also checked for the presence and importance of autistic features with the Childhood Autism Rating Scale (CARS) (Schopler, Mesibov, Reichler, & Renner, 1988). The purpose of this data was to assess the modifications that occurred after the introduction of a PAMS program and compare the two residences.

Our principal hypothesis was that behavioural disorders could be reduced when the environment is structured, constant and predictable. This is because these attributes should reduce the anxiety which usually comes with a lack of understanding of their surroundings. Considering this hypothesis, we predicted a diminution of ABC scores over the long term while ASD symptoms (CARS scores) would remain stable.

2. Method

2.1. Participants

We observed two groups of adults. In cohort 1, we had 10 residents and in cohort 2, 9 residents. Each group was composed of 8 or 7 males and 2 females and the two groups did not differ in term of age, sex ratio and CARS total score (see Table 1). The inclusion diagnostic was the presence of Pervasive Developmental Disorders (PDD) as described in World Health Organization's (WHO, 1994) diagnosis (ICD-10) and Intellectual Disabilities. ASD diagnosis are largely represented by autism and unspecified PDD. The residents live in a PAMS program. Residents for whom we could not obtain consent were excluded from the study. Autistic features were measured using the total CARS score as reported in Table 1.

2.2. Measures

For each data collection, the total number of socio-educational team hours were added. This number gives an indication of the degree of educator presence. We calculated a score ratio score by dividing the educator's presence index by the number of residents in each PAMS apartment.

We used the Aberrant Behaviour Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985b). It is a 58 items questionnaire graded on a 3 point scale (0: the behaviour is not at all a problem, 3: it is a very significant problem). Results can be grouped into five factors: F1, Irritability, Agitation, Crying (15 items); F2, Lethargy, Social withdrawal (16 items); F3, Stereotypic Behaviour (7 items); F4, Hyperactivity, Non-compliance (16 items); F5, Inappropriate Speech (4 items). Frequency of behavioural episodes is also recorded. The higher the score the greater the behaviour problem.

The Childhood Autism Rating Scale (Schopler et al., 1988) was completed as well. CARS's quotation is a mean evaluation resulting from psychologist and educational staff observation. It is a 15 items scale evaluated on a 0 (*normal behaviour*) to 4 points (*severe behaviour problems*) scale. The total score indicates three diagnostic categories: non-autistic (0–26), moderate autism (cut-off: 27) and severe autism (cut-off: 33.5): Cut-off references are based on a study of Mesibov, Schopler, Schaffer, and Michal (1989) using the CARS with adults. This scale is one of the most frequently used measures in ASD research.

2.3. Procedure

The ethics commission of the University Hospitals of Geneva approved this study. An explanation and clear oral information were given to the patient and their families during individual sessions.

Table 1
Sample characteristics: age, sex ratio and CARS scores at the beginning and end of the study

	Cohort 1 Mean (S.D.)	Cohort 2 Mean (S.D.)	Stat. tests	Sign.
Gender (female/male)	2/8	2/7	$X^2(3) = 3.78$	ns
Age (years)	38.3 (8.9)	39.7 (13.4)	$t(16) = 0.54$	ns
CARS total score[a] T1	45.8 (7.8)	41.5 (7.5)	$t(16) = 1.17$	ns
CARS total score[a] T11	43.1 (6.9)	40.6 (7.7)	$t(17) = 0.76$	ns

[a] Childhood Autism Rating Scale (Schopler et al., 1988).

Data collections for the ABC were retrieved at 3 months intervals. All the residents were observed by the socio-educational team during 1 week and the ABC was completed with a psychologist. The ABC was chosen since it has the advantage of a limited number of items in conjunction with a clearly established and validated factorial structure (Aman et al., 1985a, 1985b; Aman, Burrow, & Wolford, 1995; Aman, Turbot, & Singh, 1987; Marshburn & Aman, 1992; Rojahn & Helsel, 1991). The scale was designed for a population of individuals with medium to profound intellectual disabilities.

Two studies were done separately on separate cohorts. Each cohort lived in different places and was observed over different periods of time. Cohort 1 started in April 2000 and cohort 2 in December 2002. We compared the scores, 2 × 2, along 11 data collections for ABC scores and 3 for CARS.

To avoid missing values we used the Last Observation Carried Forward (LOCF) method for one participant in cohort 2 for whom the last data point was missing.

3. Results

In cohort 1, the mean scores of the ABC show a general tendency to decrease but this tendency is irregular (see Graph 1). A paired sample *T*-test shows that the diminution of aberrant behaviour between the first and the last data collection is significant only for social withdrawal (F2) ($t = 5.273$; $p = 0.001$) (see Table 2). Concerning CARS scores, no change during the study period was noted (see Graph 2).

In cohort 2 a descriptive analysis of the ABC scores (Graph 3) shows that after the PAMS re-organization of the services provided there was an increase in behavioural problems through T3. We computed a paired sample *T*-test between the first and last data collection for each factor (see Table 3). Those tests indicate no decrease between T1 and T11. With respect to autistic features, we compared the CARS' total score results with a Wilcoxon Signed Rank Test. No significant changes were noted over time (see Graph 4).

In order to better understand what can contribute to a favourable evolution in cohort 1, we compared cohorts 1 and 2. A rapid descriptive analysis shows that the residents in cohort 2 have
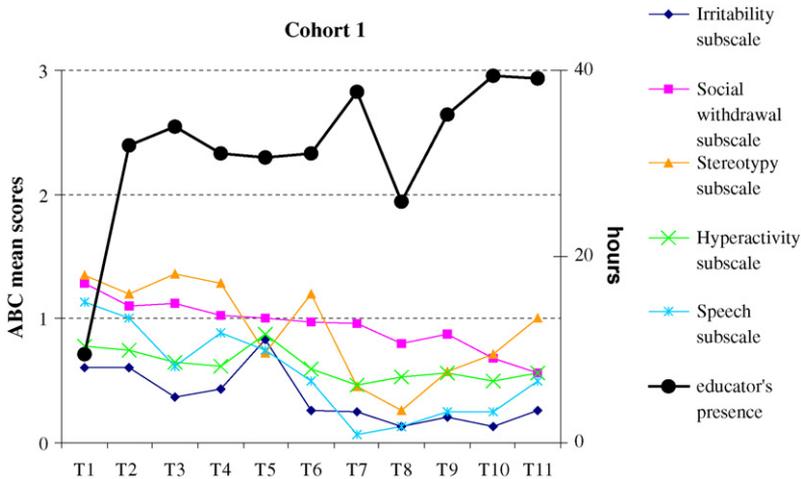
Graph 1. Mean scores of ABC's factors along time with hours ratio of educational staff presence in Cohort 1.
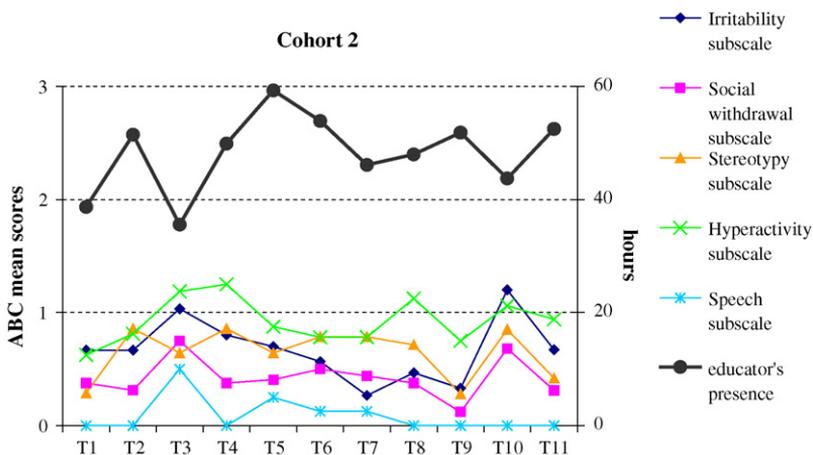
Table 2
ABC mean (standard deviation) scores at the beginning and the end of the Cohort 1

ABC Cohort 1	First data collection (T1)	Last data collection (T11)	T-test	
	Mean (S.D.)	Mean (S.D.)	t	P
Irritability subscale	11.4 (6.8)	7.9 (9.9)	0.997	0.348
Social withdrawal subscale	23.4 (10.4)	10.9 (8.2)	5.273	0.001
Stereotypy subscale	8.8 (5.7)	7.4 (5.7)	1.109	0.229
Hyperactivity subscale	15.0 (10.9)	11.8 (10.4)	1.058	0.321
Speech subscale	4.3 (4.6)	3 (3.2)	1.298	0.231
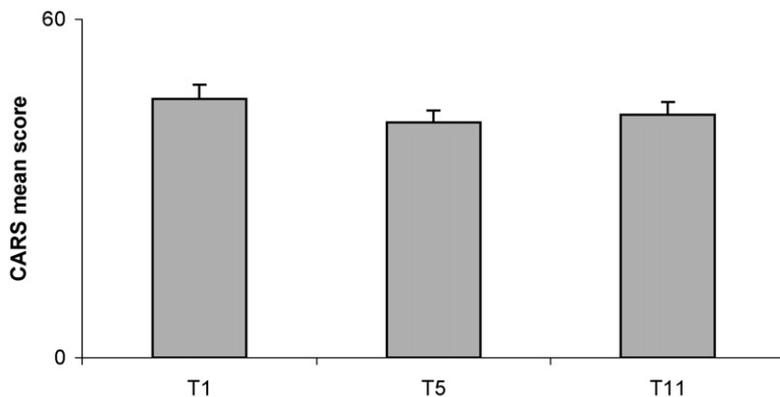
Graph 2. Mean scores (standard errors) of CARS's total score in Cohort 1.

less social withdrawal (F2) than in cohort 1. This finding is true for a majority of data collection points. We then ran a T-test and it shows differences between the two cohorts mostly for social withdrawal (F2) at T1, T4, T5, T6, T7, T8, and T10. At the end social withdrawal's problem of cohort 1 reduce statistically join the values of cohort 2. The other ABC factors do


Graph 3. Mean scores of ABC's factors along time with hours ratio of educational staff presence in Cohort 2.

Table 3
ABC mean (standard deviation) scores at the beginning and the end of the Cohort 2

ABC Cohort 2	First data collection (T1)	Last data collection (T11)	T-test	
	Mean (S.D.)	Mean (S.D.)	t	P
Irritability subscale	12.5 (10.0)	11.6 (6.3)	0.394	0.706
Social withdrawal subscale	7.6 (9.3)	5.6 (4.1)	0.812	0.444
Stereotypy subscale	3.4 (4.3)	6.0 (5.1)	−1.238	0.256
Hyperactivity subscale	13.6 (9.6)	13.3 (8.4)	0.118	0.910
Speech subscale	2.1 (3.4)	2.13 (3.3)	−0.424	0.685
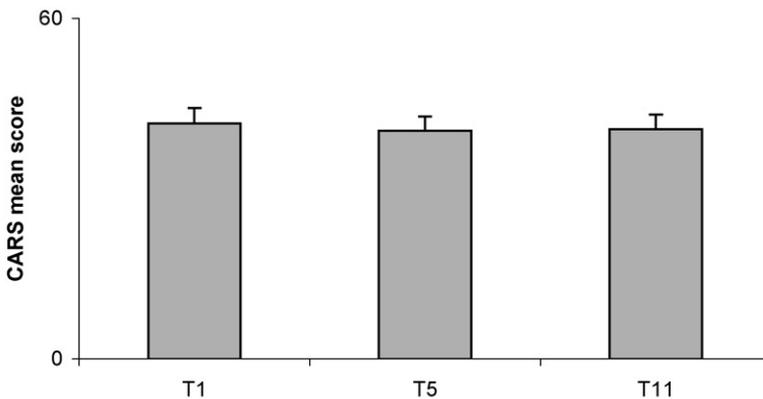
Graph 4. Mean scores (standard errors) of CARS's total score in Cohort 2.

not show statistical differences between the two groups, except punctually on irritability (F1) at T3 and T9.

To test and understand the importance of the educator's presence we chose to compare data points with a Wilcoxon Signed Rank Test where we found minimum educator's presence ratio values and maximum ratio values. Thus, in cohort 1 (see Graph 1), we compared T8 (ratio presence minimum = 25.8) and T10 (ratio presence maximum = 39.5) and found no differences for none factor. In cohort 2 (see Graph 3) we compared T3 (ratio presence minimum = 35.6) and T5 (ratio presence maximum = 59.3) in the same way and found no differences for any factor.

4. Discussion

Overall, we can say that there is a continued decrease of Social Withdrawal in cohort 1. Conversely, in cohort 2, we can say that most factor scores are stable except for Inappropriate Speech (F5). However, this factor was not appropriate for the sample since 2 participants of 9 could speak. Most factors decreased significantly between the third data collection (T3) and the ninth data collection (T9), while at T10 all factors increased. The increase observed at T3 might be explained by an integration of a new resident in one apartment. The increase could be a reaction to changes. As we know, persons with ASD react and have problems managing a new environment. Apparently, stress induced by the reorganization of their environment had a greater impact on almost all factors except stereotypic behaviour (F3). This could possibly indicate that residents had to acclimate themselves during 6 months before feeling less stressed. The increase

observed at T10 is due to a staff change which probably lead to an exacerbation of behavioural problems. We can say that some changes occurred during cohort 2 and various explanations can be formulated but behavioural problems are generally more stable than in cohort 1.

In order to better understand what can contribute to improvements observed in cohort 1, we compared cohorts 1 and 2. First of all, a descriptive and statistical analysis shows that the residents in cohort 2 have less problems of social withdrawal (F2) than in cohort 1. This is true for a majority of the data collection points. One of the differences between the two cohorts in environmental variables was educator's presence. When we look at Graphs 1 and 3, one of the important points is that the presence ratio (quantity of hours per resident) is not the same in cohort 1 (mean = 32.4, S.D. = 6.6) as it is in cohort 2 (mean = 47.8, S.D. = 5.9). It is interesting to note that a greater quantity of presence influences social withdrawal in a positive way. Another observation can be done when we look in Graph 3, at T3. All factors increase, except Factor 3, when presence decrease. We were wondering if in a global way, the presence of the educational staff could influence behavioural problems? A comparison showed us the same result for both studies: no differences when there is a minimum or maximum educator's presence. Even if we could not demonstrate the implication of presence, probably due to the small sample, it continues to be an interesting variable to explore. A second difference is the environment location: in cohort 1, workshops are outside the apartments in another building while in cohort 2 residents stay in their apartments or at least in the same building during work time. Cohort 1 might be more expose to social contacts than cohort 2 and therefore had more problems concerning social withdrawal at the beginning of the study and with time could reduce those problems.

Although we have a hypothesis for our results, the study's first limitation is the evaluation tool itself. We cannot prove that the ABC completes the full spectrum of behavioural disorders. It is possible that the scale is more sensitive to some behavioural components than others. Moreover, there are substantial irregularities over time, and a week of observation might be too short knowing that the correct observation time is one month. The small sample is another major limitation and decrease statistical significance.

Another important variable in our cohort was the psychotropic medication. Drug and dose varies considerably between residents and within a single resident over time. In cohort 1 (see Graph 5) over time the classical antipsychotic were replaced by atypical antipsychotic. Mood stabilizers, anxiolytics and anti-Parkinson treatments were reduced, while hypnotics were introduced. In cohort 2, classical and atypical antipsychotics were reduced while hypnotics were introduced. Antidepressants, anxiolytics, and anti-Parkinson stay quasi constant (Graph 6). Therefore, we could not ignore the impact of medication on behavioural problems.

The major strength of this study was the longitudinal and prospective design. Such a long observation has the major advantage of understanding the evolution of this challenging population. Such a design requires considerable energy and money, but allows us to think about adaptations of PAMS which would increase the clinical programs' effectiveness. As the socio-educational teams were blinded to the results, they were asked to do what they felt was good for their residents and were allowed to change programs and activities depending on resident need. Another major advantage of our experimental design is that no extra contacts were made with residents; this is less stressful for them.

For the next study, we should try to specify our sample in order to determine what is working for who. In order to increase effectiveness we would need to introduce a paired sample. So in further studies we obtained the collaboration of another Swiss institution and we decided to complete our evaluation with a control group. To increase efficiency we will evaluate quality of life with an adequate tool as a global evaluation, wishing to offer this population wellness and a better life.
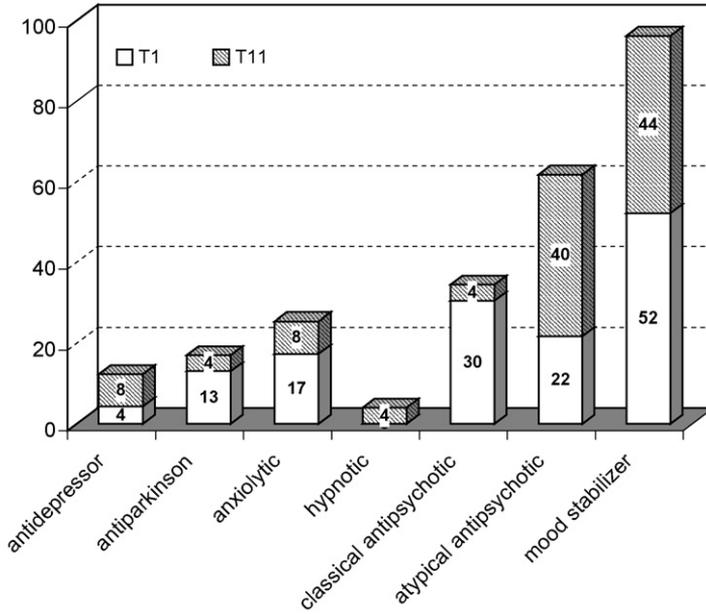
Graph 5. Repartition of psychotropic medication between beginning and end of Cohort 1.
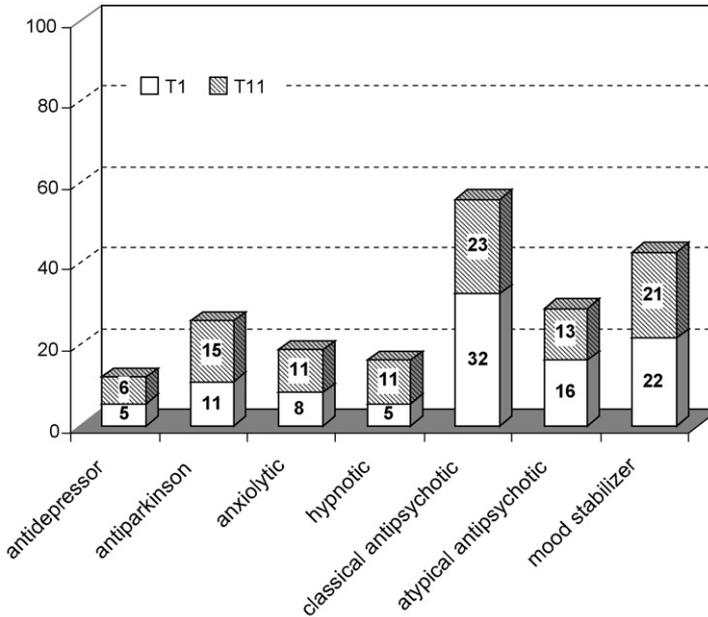
Graph 6. Repartition of psychotropic medication between beginning and end of Cohort 2.

Nevertheless, another perspective is that the collaboration between staff and families has been greatly increased. New programs and new organization of time and space was an opportunity to enhance collaboration with families and make an effort to continue this partnership.

Acknowledgement

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